Race, Place, And Access To Early Intensive Behavioral Intervention Among Children With Autism Spectrum Disorder In South Carolina

Marissa E. Yingling

University of South Carolina

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RACE, PLACE, AND ACCESS TO EARLY INTENSIVE BEHAVIORAL INTERVENTION AMONG CHILDREN WITH AUTISM SPECTRUM DISORDER IN SOUTH CAROLINA

by

Marissa E. Yingling

Bachelor of Science
Marshall University, 2008

Master of Social Work
University of Georgia, 2011

Submitted in Partial Fulfillment of the Requirements For the Degree of Doctor of Philosophy in Social Work

College of Social Work
University of South Carolina

2016

Accepted by:

Robert M. Hock, Major Professor
Co-Chair, Examining Committee

Bethany A. Bell, Co-Chair, Examining Committee

Christina M. Andrews, Committee Member

Katie Wolfe, Committee Member

Paul Allen Miller, Vice Provost and Interim Dean of Graduate Studies
DEDICATION

To

My Gran
For your unconditional love, and for fostering my life-long love of reading, assuming that come what may, higher education was in my future, and encouraging me to “fly”

My Husband
For your unwavering devotion and confidence in me throughout our challenging, yet unique and enriching journey

My Mother
For teaching me to appreciate differences in abilities, and for supporting my early ambitions to write

My Father
For teaching me to follow my dreams and to cherish helping others
ACKNOWLEDGEMENTS

As my pursuit of higher education formally – if not technically – comes to an end, I find myself in a period of reflection. Most of all, I am humbled by the number and quality of people who gave their precious time and energy to help me realize my goal. It is with pleasure that I write to express my deep gratitude for their investment in my development prior to and throughout my student career.

First, I can never adequately express appreciation for my primary mentor, Rob Hock. You provided me with rich experiences, numerous opportunities, and treasured advice that exceeded my expectations. You are a selfless and generous teacher and an outstanding human being. I feel fortunate to know you and privileged to have learned from you. Thank you for taking a chance on me. I look forward to many years of collaboration and friendship.

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To the countless children, adults, and family members with whom I have interacted in the field, it is a privilege to have met and collaborated with you. Your
perseverance, strength, and exceptionality make my life more colorful and the working
day worthwhile. Your stories and accomplishments fuel my efforts, however miniscule,
to make the world a little better. If at the end of my career I have honored you, my life’s
work will have meant something.

Most importantly, I am forever grateful for the support I continue to receive from
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embarked on our journey, you have always provided care, compassion, and guidance, and
you have shared in disappointment and success. Your support is unparalleled. To my
sister, Kaity, I am thrilled about your newfound interest in the field, and I look forward to
sharing our mutual interest and passion in the future. To my irreplaceable dog, Oscar, you
bestowed an endless supply of unconditional love, and your light is a reliable beacon of
happiness that made numerous obstacles more bearable.

Chaz, you continue to be a tremendous source of strength, inspiration, and love.
Truly, I could not have succeeded without you. When the road seemed never-ending and
the mountain to climb too steep, you offered unwavering encouragement, kindness, and
reassurance, even on those days when I did not deserve it. These past several years have
been precious and unforgettable. As we write the conclusion to this chapter, I am eager to
turn the page and to experience many more pleasant surprises, memorable moments, and
thousands of sunsets together.
ABSTRACT

Public funding of early intensive behavioral intervention (EIBI) for the 1 in 68 children who meet criteria for autism spectrum disorder (ASD) is rapidly expanding. Evidence indicates that children with ASD experience racial, socioeconomic, and geographic disparities in access to health care services. However, the Interagency Autism Coordinating Committee and the World Health Organization cite disparities in access to early intervention among the most pressing yet understudied areas of research. Currently, ASD service research is dominated by inquiries into the age of diagnosis and enrollment in EIBI. We know little about disparities in the time-lag between diagnosis and treatment onset or treatment utilization trajectories. The aims of this dissertation, which are grounded in the Behavioral Model of Health Services Use, include: 1) to examine the relationship between time to treatment onset and child race and time to treatment onset and neighborhood racial composition, poverty, affluence, and urbanicity; 2) to examine the relationship between treatment utilization trajectories and child race and treatment utilization trajectories and neighborhood characteristics during the first year of treatment; and 3) to identify and describe the type and prevalence of treatment utilization trajectories and the association of child race and neighborhood characteristics with these trajectories during the first year of treatment. To complete this study, paper case records, excel spreadsheets, and electronic records provided by the South Carolina Department of Disabilities and Special Needs, as well as Medicaid claims data and Census data provided by the South Carolina Revenue and Fiscal Affairs Office, were integrated. This unique
dataset includes all children with ASD who enrolled in South Carolina’s Pervasive Developmental Disorder (PDD) Program (N=2,338) between its inception (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). The sample for Aim 1 (N=473) includes only those children who were diagnosed after the waitlist was established (August, 2007), placed on a waitlist, and had dates of diagnosis, placement on waitlist, enrollment, assessment, and initial therapy session. Aims 2 and 3 (N=807) include children who received at least one therapy session during a minimum of 26 weeks over the first year of treatment. Statistical analyses include ordinary least squares regression (Aim 1), two-level growth curve models (Aim 2), and latent class growth analysis (Aim 3). The results of Aim 1 indicate that there are not disparities in the time-lag between diagnosis and treatment onset. In Aim 2, although findings point to disparities in the percent of allotted treatment hours children use during their first week of treatment, there is no evidence of disparities in children’s treatment utilization trajectories. However, the results of Aim 3 reveal that there are four treatment utilization trajectory types, and that there are racial and neighborhood disparities in children’s assignment to these trajectory types. Collectively, these findings highlight critical areas for future research, underscore the importance of investigating multiple indicators of access to EIBI, offer theoretical contributions to research on access to EIBI, and provide insight into implications for the provision of publicly-funded EIBI and for social work practice.
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CHAPTER 1
INTRODUCTION

To meet the needs of the 1 in every 68 children who meet the criteria for autism spectrum disorder (ASD) (Baio, 2014), health coverage of early intensive behavioral intervention (EIBI) is rapidly expanding. It is unclear whether there is equitable access to this specialized service. Indeed, the Interagency Autism Coordinating Committee and the World Health Organization cite disparities in access to early intervention and challenges to implementing large scale early intervention among the most pressing, yet understudied areas of ASD research (Interagency Autism Coordinating Committee (IACC), 2014; World Health Organization, 2013).

Presently, three critical developments in the provision of EIBI are underway. First, 44 states, the District of Columbia, and the U.S. Virgin Islands each have health insurance mandates requiring coverage of EIBI, and there are ongoing efforts to establish mandates in remaining states (Autism Speaks, 2016). Second, the handful of states who adopted EIBI via 1915(c) Home and Community-Based Services (HCBS) Medicaid waivers within the last decade are required by the Centers for Medicaid and Medicare Services to transition the service to Medicaid state plans (Autism Feasibility Study Workgroup, 2013; Centers for Medicare and Medicaid Services, 2014; Michigan Department of Community Health, 2013; South Carolina Department of Disabilities and Special Needs, 2007; Utah Department of Health, 2013). Finally, effective January 2015, 29 states and the District of Columbia require individual and small business health plans
to cover behavioral intervention based on the principles of applied behavior analysis under their 10 “essential health benefits” (Autism Speaks, 2014). States are implementing EIBI in the context of mounting evidence that children with ASD experience racial, socioeconomic, and geographic disparities in access to diagnostic services, to primary and specialized health care, and to other services used by children with ASD (Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Murphy & Ruble, 2012; Parish, Magaña, Rose, Timberlake, & Swaine, 2012; Siller, Reyes, Hotez, Hutman, & Sigman, 2014; Tregnago & Cheak-Zamora, 2012). Combined with evidence that children who begin EIBI at a younger age (Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009; Makrygianni & Reed, 2010; Perry et al., 2011; Virués-Ortega, García, & Yu, 2013) and children who use more treatment (i.e., more weekly hours) achieve superior outcomes (Granpeesheh et al., 2009; Makrygianni & Reed, 2010, 2010; Reichow, Barton, Boyd, & Hume, 2014; Virués-Ortega, 2010), existing ASD service research warrants investigation into disparities in access to EIBI. Yet the exponential increase in the number of children eligible to receive EIBI is outpacing research that can inform policy and practice. To date, ASD service research has been dominated by inquiries into the age at which a child is diagnosed, the predictors of age of diagnosis, and predictors of access to health care. Much less attention has been given to access to EIBI.

This three-manuscript dissertation is informed by Andersen’s well-established Behavioral Model of Health Services Use (BMHSU), which emphasizes the importance of accounting for both individual and contextual characteristics in health services research, as well as health care disparities literature. The three studies that comprise this dissertation include an examination of the contribution of child race and neighborhood
racial composition, poverty, affluence, and urbanicity on time to treatment onset (Aim 1) and treatment utilization trajectories (Aim 2), and the identification of the type and prevalence of treatment utilization trajectories as well as the influence of child race and neighborhood characteristics on children’s trajectories (Aim 3) among participants of South Carolina’s Pervasive Developmental Disorder (SC PDD) Program.

To complete this dissertation, paper case records, excel spreadsheets, and electronic records provided by the Department of Disabilities and Special Needs, as well as Medicaid claims data and Census data provided by the South Carolina Revenue and Fiscal Affairs Office (RFA), were integrated. This unique dataset includes all children with ASD who enrolled in South Carolina’s Pervasive Developmental Disorder (PDD) Program (N=2,338) between its inception (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). Statistical analyses include ordinary least squares regression analysis (Aim 1), two-level growth curve models (Aim 2), and latent class growth analysis (Aim 3).

**Study Aims**

Using secondary data analysis of a sample of children with ASD enrolled in South Carolina’s, publicly-funded EIBI program, the aims of the proposed research are:

**Aim 1.** To examine the relationship between time to treatment onset and child race and time to treatment onset and neighborhood racial composition, poverty, affluence, and urbanicity.

**Aim 2.** To examine the relationship between treatment utilization trajectories and child race and treatment utilization trajectories and neighborhood racial composition, poverty, affluence, and urbanicity during the first year of treatment.
**Aim 3.1.** To identify and describe the type and prevalence of treatment utilization trajectories during the first year of treatment.

**Aim 3.2.** To examine the relationship between child race and treatment utilization trajectory types and neighborhood racial composition, poverty, affluence, and urbanicity and treatment utilization trajectory types, during the first year of treatment.

**Behavioral Model of Health Services Use**

Andersen’s Behavioral Model of Health Services Use (BMHSU) (Andersen, Davidson, & Baumeister, 2013) is a well-established and widely used model in research on access to health services. Originally published in 1968, this model has been periodically revised to reflect advancements in health services research. The goals inherent in the model include the prediction of service use, promotion of social justice, and enhancement of the effectiveness and efficiency of service provision. In addition to these goals, the model is appropriate for this dissertation because of its multiple dimensions of access, its flexible application to a range of health services, the inclusion of both individual and contextual factors, the bidirectional relationship between the four domains of the model (e.g., individual and contextual factors, health beliefs, and outcomes) to guide future research, and literature on the BMHSU that provides insight into explanations for and solutions to disparities.

Broadly, the authors define access as “actual use of personal health services and everything that facilitates or impedes their use” and “the link” between health services and people who receive the “right services at the right time to promote health outcomes” (2013, pp. 33–34). Access is conceptualized as individual and contextual predisposing, enabling and need characteristics. Although there are six dimensions of access, two are
used in this dissertation, or realized access (i.e., utilization) and inequitable access (i.e., access due to social structure and enabling variables) (Andersen et al., 2013). In particular, the impact of a child’s race and neighborhood racial composition, poverty, affluence, and urbanicity on the timely onset of EIBI (Aim 1), high utilization (Aim 2), and assignment to a treatment utilization trajectory type characterized by high utilization (Aim 3) is investigated to determine if there is inequitable access to EIBI. The sixth and most recent version of the model is presented in Figure 1.1.

Figure 1.1 Behavioral Model of Health Services Use, 6th Revision. Reprinted from Changing the U.S. health care system: Key issues in health services policy and management, by Andersen, R.M., Davidson, P.L., & Baumeister, 2013, p. 34. San Francisco, CA: John Wiley & Sons.

**Individual characteristics.** Individual predisposing characteristics include demographic factors (e.g., age), social factors (i.e., education, occupation, ethnicity, and social networks), and health beliefs. Demographic factors predispose utilization when social structure is not responsible for the predisposition, whereas social factors, which can be traditional demographics, predispose utilization due to social structure. For
example, sex is a predisposing demographic factor in the utilization of breast cancer screenings because breast cancer is more prevalent in women than in men. However, if sex predisposes health insurance coverage because coverage is more expensive for women than for men, sex is a predisposing social factor. Typically, individual enabling characteristics include factors such as income and wealth to pay for health services, cost of health services, social support, and organization of health services, including transportation, distance to travel, and wait time. Finally, there are two types of individual need characteristics, or need as perceived by an individual and need as evaluated by a professional.

**Contextual characteristics.** Contextual characteristics are defined as “the circumstances and environment of health care access” and are measured at the aggregate level (Andersen et al., 2013, p. 35). Contextual predisposing characteristics include community demographics, community social factors, and fundamental community or organizational beliefs and politics that inform the delivery of a health care service. Contextual enabling characteristics include public policies, financing, and amount and delivery of health service facilities and personnel. Finally, contextual need characteristics include population health measures that may or may not be impacted by factors in the physical environment. In this dissertation, the social factors of a child’s neighborhood are examined as contextual predisposing characteristics. Like individual characteristics, predisposing demographic and social characteristics at the contextual level depend on the outcome of interest. In this dissertation, the selection of contextual characteristics is informed by substantial evidence that neighborhood characteristics impact access to health care. Research points to poorer health care access in particular geographic areas,
including racially/ethnically segregated neighborhoods and neighborhoods with high concentrations of poverty, as well as differences in health care access between urban, suburban, and rural areas (Acevedo-Garcia, Osypuk, McArdle, & Williams, 2008; Florence, Pack, Southerland, & Wykoff, 2012; Kirby & Kaneda, 2005; White, Haas, & Williams, 2012; David R. Williams & Collins, 2001).

**Health behaviors and outcomes.** As illustrated in Figure 1.1, in addition to individual and contextual characteristics, health behaviors and outcomes are the third and fourth domains in the model. Health behaviors are defined as “personal practices performed by the individual that influence health status” (Andersen et al., 2013, p. 40). This domain includes the process of medical care, which comprises provider behavior (e.g., patient counseling and education), as well as personal health practices and use of personal health services. Thus, this domain includes “realized access” to a health service, the definition of which varies between studies comprises this domain. The outcomes domain includes perceived health status, evaluated health status, consumer satisfaction, and quality of life. Notably, the bidirectional relationships between individual and contextual characteristics, health behaviors, and outcomes are depicted by the arrow of the model.

**Significance of Study**

**Research.** This dissertation makes a substantial contribution to ASD service research by providing the first detailed account of children’s time-lag between diagnosis and treatment onset and the impact of a child’s race and neighborhood racial composition, poverty, affluence, and urbanicity on time-lag. Presently, research on disparities in access to services among children with ASD is dominated by inquiries into
the age at which children are diagnosed and the predictors of age of diagnosis. In recent years, evidence of delays and disparities in diagnosis prompted state- and nation-wide initiatives to screen and evaluate children earlier, and there are ongoing developments to improve and expand these efforts (Peacock & Lin, 2012). This line of research is critical and well-justified; the sooner children are diagnosed the sooner they can enter treatment. Yet the underlying assumption of this position is that after receiving a diagnosis, children immediately access treatment. To the contrary, parents report that after their child is diagnosed, they are unsure of who to turn to or what actions to take next. In a study that highlighted parents’ experiences after diagnosis, parents reported feeling “abandoned by the community… like trying to run through a maze blind folded” (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014, p. 355). Post-diagnosis, parents enter an unknown and complex reality. In addition to uncertainty, married parents report experiencing significant pressure on their relationship (Hock, Timm, & Ramisch, 2012), and parents may face years-long wait lists (L & M Policy Research, LLC, 2014), a shortage of providers (Wise, Little, Holliman, Wise, & Wang, 2010), and other factors that contribute to delays in treatment onset post-diagnosis, such as competing time demands of school (Yingling, Hock, Cohen, & McCaslin, forthcoming). Given the importance of enrolling children in treatment as early as possible, this dissertation provides critical insight into children’s timely onset of publicly-funded EIBI and lays the foundation for future research in this area.

This dissertation advances the operationalization of access to publicly-funded EIBI while using administrative data from one of the longest running EIBI programs in the country. Currently, the majority of existing literature on access to EIBI is limited by
cross-sectional survey data, in which EIBI is included in a category with other treatment approaches. Most research also includes dichotomous measures of access (e.g., enrollment) that cannot capture children’s time-lag between diagnosis and treatment onset or children’s treatment utilization post-enrollment. For example, using a community sample of families in North Carolina (N=383), Thomas, Ellis, McLaurin, Daniels, & Morrissey (2007) operationalized access to a major treatment approach (including several EIBI models) dichotomously, in which children did or did not receive treatment. Ruble and McGrew (2007) employed a similar design to investigate service utilization and parent-reported effectiveness among a small sample of families in Kentucky (N=113). In the first of two studies on access to EIBI, Shattuck et. al (2009) examined children’s enrollment using administrative data (N=1822) for Wisconsin’s statewide program. However, researchers did not examine disparities pre- or post-enrollment. In the second study (N=104), researchers sent a mailed survey to white and Latino parents in Wisconsin and asked whether or not their child ever received (i.e., yes/no) the state’s EIBI program (Magaña, Lopez, Aguinaga, & Morton, 2013). Notably, in studies on the effectiveness of EIBI, researchers tend to report the number of treatment hours children use. Despite calls for enhanced documentation and analysis of treatment utilization (Matson & Smith, 2008), this body of work lacks specificity. For instance, most researchers report a minimum number of hours per week or a range of hours per week children typically receive. Therefore, this dissertation makes a significant contribution to the literature by using longitudinal data to examine more precise and multiple indicators of access to treatment pre- and post- enrollment (i.e., time-lag, treatment utilization trajectories, treatment utilization trajectory types), and by
conducting the first analyses that examine the relative impact of child and neighborhood characteristics on access to publicly-funded EIBI.

Through the application of the Behavioral Model of Health Services Use and the analysis of multiple indicators of access, this dissertation stands to advance the conceptualization of access to publicly-funded EIBI. Collectively, the three studies included in this dissertation highlight that access to EIBI is complex and multifaceted. Indeed, by nature of the inclusion criteria for all three analyses, all children realized access to EIBI. However, although the definitions of access used in this dissertation are a starting point, whether or not they are optimal is unclear. For example, in the first study realized access is defined as the timely onset of EIBI post-diagnosis. Beyond the evidence-based yet ambiguous assertion that children need to begin treatment as early as possible, what is the best definition of “timely onset”? If time-lag is inevitable, what is the maximum time-lag for which states should strive? Is timely onset of EIBI restricted to after children are diagnosed, or is timely onset when children receive treatment after a positive screening for ASD? In the second and third studies, access is defined as high utilization during the first year of treatment and membership in a treatment utilization trajectory type characterized by high utilization during the first year of treatment, respectively. In both cases, what is “high” treatment utilization? Is it the use of a certain percentage of recommended hours during all weeks of the year, or the use of a certain percentage of recommended hours for 48 of 52 weeks out of the year? Currently, there is no theoretical framework to guide research efforts in this growing field. For future research to be effective, it is imperative that researchers engage in dialogue about how
best to conceptualize realized access to publicly-funded EIBI. Only then can disparities in access be detected and reduced. The findings of this dissertation can aid this effort.

**Policies and Programs.** The results of this dissertation have immediate implications for the provision of publicly-funded EIBI. Descriptive accounts of time-lag between diagnosis and treatment onset, treatment utilization trajectories, and treatment utilization trajectory types provide administrators and policy makers with insight into children’s experiences with publicly-funded EIBI across several years. The knowledge gleaned from the three analyses provides new and important questions about how to improve children’s access to EIBI overall. For example, study results that identify children who are at risk of experiencing disparities in access can inform targeted outreach efforts. Evidence of inequitable access can encourage meaningful dialogue regarding how to reduce disparities. As South Carolina and other states begin to provide EIBI at a rapid rate, findings are time-sensitive and offer an opportunity to inform ongoing decision-making at the levels of policy and practice.

**Research Questions**

I will achieve the aims proposed for this dissertation research by answering the following research questions.

**Aim 1 research questions.**

1. What is the relationship between time to treatment onset and a) child race and , and b) neighborhood poverty, affluence, racial composition, and urbanicity?

   1.1. Does the time between ASD diagnosis and when a child’s name is placed on the waitlist (Time 1) differ by a) child race
and/or b) neighborhood racial composition, poverty, affluence, and urbanicity?

1.2. Does the time between date of enrollment and date of assessment (Time 2) differ by a) child race and/or b) neighborhood racial composition, poverty, affluence, and urbanicity?

1.3. Does the time between assessment and initial therapy session (Time 3) differ by a) child race and/or b) neighborhood racial composition, poverty, affluence, and urbanicity?

1.4. Does the time between ASD diagnosis and initial therapy session (Time 4) differ by a) child race and/or b) neighborhood racial composition, poverty, affluence, racial composition, and urbanicity?

1.5. Does the relationship between each time point (Time 1, 2, 3 and 4) and child race vary by neighborhood racial composition?

1.6. Does the relationship between each time point (Time 1, 2, 3 and 4) and child race vary by neighborhood poverty?

1.7. Does the relationship between each time point (Time 1, 2, 3 and 4) and child race vary by neighborhood affluence?

1.8. Does the relationship between each time point (Time 1, 2, 3 and 4) and child race vary by neighborhood urbanicity?
Aim 2 research questions.

2.1 What is the relationship between treatment utilization trajectories and a) child race and b) neighborhood racial composition, poverty, affluence, racial composition, and urbanicity?

2.a. Does the relationship between treatment utilization trajectories and child race vary by neighborhood racial composition?

2.b. Does the relationship between treatment utilization trajectories and by child race vary by neighborhood poverty?

2.c. Does the relationship between treatment utilization trajectories and child race vary by neighborhood affluence?

2.d. Does the relationship between treatment utilization trajectories and child race vary by neighborhood urbanicity?

Aim 3 research questions.

3.1. What are the types of treatment utilization trajectories? What is the prevalence of treatment utilization trajectory types?

3.2. What is the relationship between children’s treatment utilization trajectory types and a) child race and b) neighborhood racial composition, poverty, affluence, and urbanicity?

Overall Research Design and Methodological Approach

The overall research design of this dissertation is longitudinal and nonexperimental, and it includes secondary data analysis. The dataset used includes children enrolled in the SC PDD Program. The program provides three years of EIBI to children between the ages of 3 and 10 who received an ASD diagnosis by age eight.
Based on need, each child may receive up to $50,000 per year and as many as 40 hours of direct line therapy per week, of which at least 50% must be in-home (South Carolina Department of Disabilities and Special Needs, 2013). To complete this study, paper case records, excel spreadsheets, and electronic records provided by the Department of Disabilities and Special Needs, as well as Medicaid claims data and Census data provided by the South Carolina Revenue and Fiscal Affairs Office, were integrated. This unique dataset includes all children with ASD who enrolled in the SC PDD Program (N=2,338) between its inception (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). The sample for Aim 1 (N=473) includes only those children who were diagnosed after the wait list was established (August, 2007), placed on a wait list, and had dates of diagnosis, placement on waitlist, enrollment, assessment, and initial therapy session. Aims 2 and 3 (N=807) include children who received at least one therapy session in a minimum of 26 weeks during the first year of treatment.

**Measures.** Table 1.1 includes the measures used in this dissertation.

Table 1.1
*List of Operationalized Variables and Data Sources*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Aim, Level</th>
<th>Operational Definition</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive Behavior</td>
<td>A1; A2: L2; A3</td>
<td>Continuous measure of the child’s Adaptive Behavior Composite standard score on the Vineland-II. Grand mean centered in Aims 1 and 2.</td>
<td>SC DDSN: Autism Division</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>A1; A2: L2; A3</td>
<td>A continuous measure of age by months in which the child was diagnosed with ASD. Grand mean centered in Aims 1 and 2.</td>
<td>RFA: Medicaid</td>
</tr>
<tr>
<td>Age at Enrollment</td>
<td>A1; A2: L2; A3</td>
<td>A continuous measure of age by months in which the child enrolled in the program. Grand mean centered in Aims 1 and 2.</td>
<td>SC DDSN: CDSS*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>RFA: Medicaid</td>
</tr>
<tr>
<td>Variable</td>
<td>Coding</td>
<td>Description</td>
<td>Source</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Assessment Date</td>
<td>NA</td>
<td>Date the child was assessed by a provider in the PDD Program</td>
<td>SC DDSN: CDSS</td>
</tr>
<tr>
<td>Children</td>
<td>A1; A2; L2; A3</td>
<td>Binary variable of the number of children in the household (1 = &gt;=3 children; 0 = &lt;=2 children).</td>
<td>SC DDSN: Autism Division</td>
</tr>
<tr>
<td>Enrollment Date</td>
<td>NA</td>
<td>Date the child officially enrolled in the program</td>
<td>SC DDSN: CDSS</td>
</tr>
<tr>
<td>Family SES</td>
<td>A1; A2; L2; A3</td>
<td>Dummy code of eligible category under which the child qualified for Medicaid categories (SSI, TEFRA, and other).</td>
<td>RFA: Medicaid</td>
</tr>
<tr>
<td>Initial Therapy Session</td>
<td>NA</td>
<td>Date the child received initial EIBI therapy session</td>
<td>SC DDSN: CDSS</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>A1: L1; A2: L2; A3</td>
<td>Binary measure of intellectual disability (1=Yes, 0=No).</td>
<td>RFA: Medicaid</td>
</tr>
<tr>
<td>Neighborhood Affluence</td>
<td>A1; A2: L2; A3</td>
<td>A composite variable calculated as a standardized (z-score) measure computed from the average (percent of single parent female headed households, of people in poverty, of residents who receive cash assistance, of residents enrolled in SNAP, of residents who receive SSI, and of people who are unemployed) by census tract.</td>
<td>RFA: Census</td>
</tr>
<tr>
<td>Neighborhood Poverty</td>
<td>A1; A2: L2; A3</td>
<td>A composite variable calculated as a standardized (z-score) measure computed from the average (median household income, percent of residents with professional/managerial employment, and percent of residents with a Bachelor’s degree or higher) by census tract.</td>
<td>RFA: Census</td>
</tr>
<tr>
<td>Neighborhood Racial</td>
<td>A1; A2: L2; A3</td>
<td>Percentage of white residents in neighborhood. Grand-mean centered in Aims 1 and 2.</td>
<td>RFA: Census</td>
</tr>
<tr>
<td>Composition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>A1: L1; A2: L2; A3</td>
<td>The child’s race as measured by two dummy variables (Black and Hispanic), with White/Asian as the reference group.</td>
<td>RFA: Medicaid</td>
</tr>
<tr>
<td>Sex</td>
<td>A1: L1; A2: L2; A3</td>
<td>Binary measure of the biological sex of the child (1=Female, 0=Male).</td>
<td>SC DDSN: CDSS</td>
</tr>
</tbody>
</table>
Notes.
Originally, in Aims 1 and 2, census-tract levels were intended to be the third level of multilevel models. However, there were too many census tracts with singletons. Therefore, they are used at the second level in analyses and I adjusted analyses accordingly.

**The Consumer Data Support System (CDSS) is an agency-wide electronic data system.**

**This variable would not estimate in the third manuscript when estimating a regression model in Latent Gold 5.1. Therefore, I conducted a sensitivity analysis in Aims 1 and 2 to determine if results changed when this variable was removed. Because they did not, I removed this variable from all analyses.
Analyses. Missing data analyses as well as univariate and bivariate analyses are completed for all three studies. Univariate analyses include descriptive statistics to gain an understanding of the data distribution, including statistics on density in multilevel models, and bivariate analyses include zero-order correlation analyses to better understand how the variables of interest are interrelated. Advanced statistical approaches include ordinary least squares regression models (Aim 1), two-level growth curve models (Aims 2), and latent class growth analysis (Aim 3). Multivariate analyses are conducted using PROC REG (Aim 1) and PROC MIXED (Aim 2) in SAS® 9.4, and Cluster Analysis and Step3 in Latent GOLD® 5.1 (Aim 3). Data is examined for violations of assumptions as appropriate.

Ethical Issues and Human Subjects Protection

The University of South Carolina granted IRB approval for this dissertation in February 2015. SC DDSN confidentiality agreements were signed in May 2015. Data entry on key variables not in SC DDSN’s electronic database began in June 2015 and ended in October 2015. RFA provided the final datasets to be integrated in January 2016. RFA removed all identifiable information (e.g., name, date of birth, address, and Social Security Number), and encrypted census-tract codes and patient identification numbers. For the duration of the study, the dataset was securely stored in a locked office on a password protected desktop computer.

Limitations of the Study

This dissertation provides the first descriptive account of the time-lag between diagnosis and treatment onset, treatment utilization trajectories, and the type of treatment utilization trajectories among children with ASD enrolled in publicly-funded EIBI.
Findings provide a detailed examination of the impact of race and neighborhood characteristics on these important outcomes using one of the most comprehensive datasets of its kind. Indeed, analyses have the potential to inform ongoing decision making in a rapidly developing field to lay a foundation of research on which to build future scholarship on access to EIBI. Despite the strengths of this study, however, there are a number of limitations.

At the broadest level, SC DDSN data only includes information for South Carolina’s EIBI Medicaid waiver, which limits generalizability to other states and to the provision of EIBI through Medicaid state plans. Still, because it is one of the longest running, largest programs of its kind and is located in a racially diverse and rural state characterized by a high poverty rate, South Carolina offers an exceptional opportunity to inform provision in other states. Despite South Carolina’s racial diversity, the study is also limited by the number of children in the sample whose race/ethnicity is “unknown.” Furthermore, only treatment utilization during the first year of treatment rather than in years one, two, and three is examined. While this approach aligns with current research that suggests children make the most significant gains during this first year of treatment (Howlin, Magiati, & Charman, 2009) and significantly increases the sample size of Aims 2 and 3, findings cannot be generalized to the second and third years of treatment.

Missing data is often a limitation in research that uses administrative data, and this is true for the current study. Missing data for all three analyses was less than 10%. However, although routine intake data is required for client participation and a record of the number of treatment hours used is required for provider reimbursement, it was
apparent during data entry that missing data was especially prominent in the case records provided by SC DDSN’s Autism Division.

An additional limitation is that it is unknown if a child who received publicly-funded EIBI also received private insurance coverage before and/or during their participation in the program. This could influence children’s time-lag between diagnosis and treatment onset and treatment utilization trajectories. For example, children who have private insurance coverage before their name is removed from the wait list and enrolled in the SC PDD Program may already be established with a provider that they can continue using. This prior relationship might prevent a delay in treatment provision and subsequently have an impact on treatment utilization trajectories due to never being able to find a provider or due to a good working relationship with their current provider. It is also unknown what percent of hours children received were home- or center-based.

While the program requires that children use a minimum of 50% of hours at home, the remaining 50% can either be in the home or in a treatment center. For example, if providers will only serve children in their center instead of traveling to the child’s home, children may only receive 50% of their allotted treatment hours. This difference complicates the conclusions that can be drawn from study findings. For example, if children who live in rural neighborhoods use less treatment than children who live in urban neighborhoods, is the ideal target to increase utilization a parents’ transportation or expansion of the geographic areas providers choose to serve?

The Current Study

Four sections follow this introduction, including the three manuscripts and the conclusion. In the first manuscript, the relationships between time to treatment onset and
child race and time to treatment onset and neighborhood racial composition, poverty, affluence, and urbanicity are investigated. In the second manuscript, relationships between treatment utilization trajectories and child race and treatment utilization trajectories and neighborhood racial composition, poverty, affluence, and urbanicity in the first year of treatment are examined. Finally, in the third manuscript the types of EIBI treatment utilization trajectories during the first year of treatment are identified and described, and the relationship between children’s treatment utilization trajectory type and child race and treatment utilization trajectory type and neighborhood racial composition, poverty, affluence, and urbanicity is analyzed. In the conclusion, an overall summary of study findings, recommendations for future research, and recommendations for the provision of EIBI are provided.
CHAPTER 2

THE INTERSECTION OF RACE AND PLACE IN THE TIME-LAG BETWEEN DIAGNOSIS OF AUTISM SPECTRUM DISORDER AND ONSET OF PUBLICLY-FUNDED EIBI

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1 Yingling, M. E., Hock, R. M., and Bell, B. A. To be submitted to the *Journal of Autism and Developmental Disorders*. 
Abstract

Public funding of early intensive behavioral intervention (EIBI) for the 1 in 68 children who meet criteria for autism spectrum disorder (ASD) is rapidly expanding. Evidence indicates that children with ASD experience racial, socioeconomic, and geographic disparities in access to health care services, and the Interagency Autism Coordinating Committee cites disparities in access to early intervention among the most pressing yet understudied areas of research. Currently, ASD service research is dominated by inquiries into the age of diagnosis. We know little about disparities in an important indicator of service access, or the time-lag between ASD diagnosis and treatment onset. To examine disparities in this time-lag, we examined: 1) the relationship between child race and time-lag; 2) the relationship between children’s neighborhood racial composition, poverty, affluence, and urbanicity and time-lag; and 3) whether the relationship between child race and time-lag varies by neighborhood characteristics. The current sample includes 473 children who enrolled in South Carolina’s EIBI program. We estimated 20 contextual OLS regression models using PROC REG in SAS® 9.4. Contrary to prior research, the number of days between diagnosis and treatment onset was not related to child race or neighborhood characteristics. Average overall time-lag was 1041 days, and average time-lag between diagnosis and placement on a wait list was 333 days. Findings provide insight into the high number of days between diagnosis and treatment onset, underscore the need for future research, provide theoretical contributions to future research, and offer lessons on the collection and use of administrative data in research on EIBI.
Introduction

The Interagency Autism Coordinating Committee (n.d.) cites disparities in access to early intervention services among the most pressing yet understudied areas of research on autism spectrum disorder (ASD). The World Health Organization (WHO, 2013) points to the need for research that focuses on the challenges of implementing large scale, community-based early intervention and inequitable access to ASD services. While the provision of early intensive behavioral intervention (EIBI) is being established in the United States, however, research in these areas is significantly lacking. States are delivering EIBI on a large scale in the context of mounting evidence that children with ASD experience racial, socioeconomic, and geographic disparities in access to diagnostic services, to primary and specialized health care, and to ASD-specific services (Liptak et al., 2008; Magaña et al., 2012; Murphy & Ruble, 2012; Parish et al., 2012; Shattuck et al., 2009; Siller et al., 2014; Tregnago & Cheak-Zamora, 2012). Indeed, the swell in the number of children eligible to receive EIBI is outpacing research that could inform policy and practice.

To address the needs of the 1 in every 68 children who meet criteria for ASD (Baio, 2014), health coverage of EIBI is rapidly expanding. Presently, three critical developments are underway. First, 44 states, the District of Columbia, and the U.S. Virgin Islands each have health insurance mandates requiring coverage of EIBI, and there are ongoing efforts to pass mandates in remaining states (Autism Speaks, 2016). Second, the handful of states who adopted EIBI via 1915(c) Home and Community-Based Services (HCBS) Medicaid waivers within the last decade are required by the Centers for Medicaid and Medicare Services to transition the service to Medicaid state plans (Autism
Feasibility Study Workgroup, 2013; Centers for Medicare and Medicaid Services, 2014; Michigan Department of Community Health, 2013; South Carolina Department of Disabilities and Special Needs, 2007; Utah Department of Health, 2013). Finally, effective January 2015, 29 states and the District of Columbia require individual and small business health plans to cover behavioral intervention based on the principles of applied behavior analysis under their 10 “essential health benefits” (Autism Speaks, 2014). These ongoing developments in the provision of EIBI for children with ASD underscore the urgent need to conduct research on access to this service.

**Importance of Early Diagnosis and Treatment Onset**

Although families use a variety of services to treat ASD (Green et al., 2006; Thomas, Morrissey, & McLaurin, 2006), EIBI based on the principles of Applied Behavior Analysis (ABA) is a well-established, evidence-based treatment (Howlin et al., 2009; Lovaas, 1987; National Autism Center, 2015; Reichow et al., 2014) and is the most preferred and frequently used among families (Stahmer, Collings, & Palinkas, 2005; Thomas et al., 2006). EIBI involves the application of ABA procedures in one-on-one instruction of adaptive and functional skills (e.g., communication, cognitive skills) in young children (Klintwall & Eikeseth, 2014). Meta-analyses indicate that children make significant improvements in intellectual ability, language, social communication, and daily living skills (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Virués-Ortega, 2010).

Researchers emphasize the importance of delivering treatment for ASD as early as possible. This emphasis is informed by evidence that the younger children are when they enter treatment the more likely they are to improve on key outcomes (Granpeesheh
et al., 2009; Makrygianni & Reed, 2010; Perry et al., 2011; Virués-Ortega et al., 2013). Especially relevant to the current study, unprecedented research conducted on Ontario’s province-wide program (N=332) revealed that compared to children who began EIBI when they were four years old or older, children who began EIBI when they were younger than four years old completed the program with better outcomes on most measures (Perry et al., 2011).

To date, however, research on access to services among children with ASD is dominated by inquiries into the age at which children are diagnosed and the predictors of age of diagnosis. In recent years, evidence of delays and disparities in diagnosis prompted state- and nation-wide initiatives to screen and evaluate children earlier, and there are ongoing developments to improve and expand these efforts (Peacock & Lin, 2012). This line of research is critical and well-justified; the sooner children are diagnosed the sooner they can enter treatment. Yet the underlying assumption of this position is that after receiving a diagnosis, children immediately access treatment. To the contrary, parents report that after their child is diagnosed, they are unsure of who to turn to or what actions to take next. In a study that highlighted parents’ experiences after diagnosis, parents reported feeling “abandoned by the community… like trying to run through a maze blind folded” (Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014, p. 355). Post-diagnosis, parents enter an unknown and complex reality. In addition to uncertainty, they face years-long wait lists (L & M Policy Research, LLC, 2014), a shortage of providers (Wise, Little, Holliman, Wise, & Wang, 2010), and other factors that contribute to delays in treatment onset post-diagnosis, such as competing time demands of school (Yingling, Hock, Cohen, & McCaslin, forthcoming). Given the
importance of enrolling children in treatment as early as possible, developing an understanding of how children proceed from diagnosis to treatment onset, as well as factors associated with this time-lag, is imperative.

**Race and Time to Treatment Onset**

Research on the time-lag between diagnosis and treatment onset, predictors of time-lag generally, and the relationship between race and time-lag in particular, is essentially nonexistent. In what appears to be the only study in which the impact of race on time-lag is examined, researchers conducted a qualitative investigation of how African American culture influences ASD diagnosis and treatment. When asked to explain delays in diagnosis and treatment initiation among African American children, family members (N=24) of children with ASD cited distrust of health care providers as well as a lack of information about ASD and the resources available to them (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015). In an examination of enrollment in Wisconsin’s publicly-funded EIBI program, Magaña, Lopez, Aguinaga, & Morton (2013) documented that despite reporting more unmet needs, parents of Latino children with ASD (N=104) were less likely to enroll.

Although research on access to EIBI is limited, literature on children’s mental health treatment is instructive. In a sample of Head Start programs in three southern states (i.e., Texas, Louisiana, and Mississippi), African American parents reported more negative help-seeking attitudes (i.e., acknowledgement of the existence of psychological problems and propensity to seek assistance from a professional) and greater mental health stigma than European Americans or Hispanic Americans (Turner, 2009). In a study on barriers to detection, help-seeking, and service use among parents of children with
ADHD symptoms, African American parents reported more negative expectations of treatment outcomes than Caucasian parents (Bussing, Zima, Gary, & Garvan, 2003). Similarly, in a mixed-method study on perceptions of mental health care and help-seeking among African American families living in rural areas, Murry, Heflinger, Suiter, & Brody (2011) found that while African American mothers were confident that mental health professionals could help their children, they preferred to seek support from family, church, and schools. These mothers also cited community stigma and cultural distrust as barriers.

Literature on early intervention (EI) services also suggests that some parents may be more likely to navigate the system of ASD treatment more easily than others. In a study that investigated differences in parents’ experiences with the pediatric referral process to EI services, parents with lower health literacy experienced greater difficulty contacting EI providers and were confused about the referral process, including written materials provided to them by pediatricians (Jimenez, Barg, Guevara, Gerdes, & Fiks, 2013). Limited health literacy, particularly in the twenty-first century when the internet is a primary source of information for ASD services, disproportionately impacts parents who identify with a minority race and who report limited English proficiency and lower educational attainment (Knapp, Madden, Wang, Sloyer, & Shenkman, 2011). Further, in a study on predictors of EI evaluation and enrollment, children with mothers who identified as black and reported higher poverty levels were less likely to receive an evaluation and to enroll in services (Clements, Barfield, Kotelchuck, & Wilber, 2007).
Neighborhood Context and Time to Treatment Onset

There is substantial, longstanding evidence that where people live impacts their access to health care. Research points to poorer health care access in particular geographic areas, including racially/ethnically segregated neighborhoods and neighborhoods with high concentrations of poverty. In a seminal article published at the turn of the twenty-first century, Williams and Collins (2001) argued that racial residential segregation is a fundamental cause of health care disparities. Although additional research is needed to target specific underlying causes of health care disparities within racially/ethnically segregated neighborhoods, literature published in the past 15 years underscores their argument (White et al., 2012). Additionally, racially/ethnically segregated neighborhoods are often characterized by concentrated poverty, a characteristic associated with poor access to health care. Neighborhoods marked by socioeconomic disadvantage may experience challenges such as recruiting providers to serve the area (Auchincloss, Van Nostrand, & Ronsaville, 2001; Kim, Disare, Pfeiffer, Kerker, & McVeigh, 2009). Indeed, research points to an association between neighborhoods with socioeconomic disadvantage and poor access to health care generally, a relationship that persists after controlling for individual-level characteristics (Kirby & Kaneda, 2005). Notably, minorities are more likely to live in neighborhoods with high poverty rates. On average, white children live in neighborhoods with a poverty rate of 7%, whereas black children live in neighborhoods with a poverty rate of 21% and Latinos live in neighborhoods with a poverty rate of 19%. Furthermore, “The worst-off white children are better off than the majority of black and Hispanic children, and these disparities are not accounted for by differences in family poverty” (Acevedo-Garcia et al.,
Double jeopardy, in which children live in both poor families and poor neighborhoods, is rarely experienced by white children.

Shattuck et al. (2009) provides the only study on the relationship between neighborhood characteristics and access to EIBI. Using administrative data of Wisconsin’s publicly-funded EIBI program to examine disparities in enrollment, researchers found that children (N=1822) who lived in neighborhoods with a higher percentage of families with incomes ≤200% of the federal poverty level, a higher percentage of women 25 and older with a high school degree or more education, and a lower percentage of people who were white were less likely to enroll. These results are similar to those in related fields of research. In a study on timeliness of provider designation in New York City’s EI program, children who lived in low-income neighborhoods and neighborhoods with large Spanish-speaking populations experienced delays (Kim et al., 2009). Researchers cited the shortage of providers in the state, both monolingual and bilingual, as well as providers who perceive low income neighborhoods as less desirable work environments as potential reasons for observed delays. Similarly, in a study on very low birth weight eligible 2-year olds in Wisconsin’s EI program, children who lived in socially disadvantaged neighborhoods were at increased risk of never receiving services (McManus, Robert, Albanese, Sadek-Badawi, & Palta, 2013).

Historically, individuals who reside in rural areas experience numerous barriers to health care, including provider shortages, higher health care costs, and geographic isolation, which translates to increased travel time and transportation costs (Florence et al., 2012). Additionally, although rural populations are overwhelmingly white, the number of racial and ethnic minorities who live in rural areas grew 21.3% between 2000
and 2010 (Johnson, 2012). This trend suggests that it is more important than ever to examine whether the relationship between race and access to treatment varies by neighborhood urbanicity.

**Behavioral Model of Health Services Use**

In response to a lack of research on access to EIBI, it is of paramount importance that researchers focus their attention on the labyrinthine system parents navigate to access treatment for their children. Central to this effort is the recognition that “access,” a term commonly plagued by ambiguity and used differently from study to study, is a multidimensional construct. To make progress, it is imperative that researchers move beyond the dichotomization of access (e.g., yes/no), and instead identify and more precisely measure multiple indicators of access over time. Andersen’s Behavioral Model of Health Services Use (BMHSU) (Andersen et al., 2013), a well-established and widely used model of health services research, offers a solid foundation on which to launch this effort. Originally published in 1968, six subsequent revisions reflect decades of advancements in health services literature. Broadly, the authors define access as “actual use of personal health services and everything that facilitates or impedes their use” and “the link” between health services and people who receive the “right services at the right time to promote health outcomes” (2013, pp. 33–34). The goals inherent in the model include the prediction of service use, promotion of social justice, and enhancement of the effectiveness and efficiency of service provision. In addition to these goals, we selected this model because of its multiple dimensions of access, its flexible application to a range of health services, the inclusion of both individual and contextual factors, the bidirectional relationship between four domains (i.e., individual characteristics,
contextual characteristics, health behaviors, and outcomes) to guide future research, and literature on the BMHSU that provides insight into explanations for and solutions to disparities in access.

The BMHSU includes individual and contextual predisposing, enabling, and need characteristics. In the current study, we focus on child race and neighborhood characteristics (i.e., individual and contextual predisposing social characteristics, respectively), and two of the model’s six dimensions of access, or realized access (i.e., utilization) and inequitable access (i.e., access due to social structure). We identify factors that contribute to the timely onset of EIBI (i.e., utilization of initial therapy session). In particular, we examine the impact of a child’s race and neighborhood racial composition, poverty, affluence, and urbanicity to determine if there is inequitable access to EIBI. For the purpose of this study, realized access is defined as the timely onset of EIBI post-diagnosis. Because all children in the study participated in an initial therapy session, all children realized access. Yet realized access is more nuanced than whether or not a child participated in an initial therapy session. More specifically, given the emphasis placed on age of treatment onset, we focus on the time-lag (i.e., number of days) between diagnosis and realized access to an initial therapy session. If results suggest that child race and/or neighborhood characteristics are related to time-lag, then there is evidence of inequitable access.

The Current Study

In 2007, South Carolina became one of the first states in the country to offer a Home and Community Based Services (HCBS) Medicaid waiver specifically for the statewide provision of EIBI, or the South Carolina Pervasive Developmental Disorder
(SC PDD) Program. The SC PDD Program, among the most generous of its kind, provides three years of EIBI to children between the ages of 3 and 10 who receive a diagnosis of ASD made by a professional psychologist by age eight. Professional psychologists diagnosed children. Prior to enrollment, SC DDSN reviews each child’s diagnostic report and either approves the diagnosis or requires the child to complete a second diagnostic assessment. Based on need, each child receives a maximum of $50,000 per year and up to 40 hours of direct line therapy per week, of which at least 50% must take place inside the child’s home (South Carolina Department of Disabilities and Special Needs, 2013). The purpose of this study is to examine the relative impact of child race and neighborhood racial composition, poverty, affluence, and urbanicity on the time-lag between a child’s ASD diagnosis and a child’s participation in an initial therapy session. Figure 2.1 depicts the relationships examined.

Methods

Data and Sample

As part of a larger research effort, we partnered with SC DDSN to create a comprehensive dataset (N=2,338) of all children with ASD who enrolled in the SC PDD Program between the date that the first child enrolled (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). First, we combined paper case records, excel spreadsheets, and electronic records at SC DDSN to build a base dataset. We then sent the dataset to the South Carolina Revenue and Fiscal Affairs Office (RFA) to obtain Medicaid claims data and Census data. The RFA returned the base dataset with all identifiers removed, a dataset that included census-tract data, and a dataset that included Medicaid claims data. We integrated all datasets. We included children in the
study sample if they were diagnosed after SC DDSN established a wait list to meet the growing demand for the program (August, 2007), placed on a waitlist, and had dates of diagnosis, placement on wait list, enrollment, assessment, and initial therapy session (N=473). For families that had two siblings with ASD in the program, we randomly selected one of the siblings. This reduced the dataset by 50 children. Details on missing data are below. We received institutional review board approval from the University of South Carolina.

Figure 2.1. Empirical model of study aims

Measures

**Time-lag.** A child proceeds through several distinct stages to begin participating in the SC PDD Program. After receiving a diagnosis, a child is referred by a parent or service coordinator, who request that the child’s name be placed on the program wait list. When a slot in the program is available and the child is at the top of the wait list, the child is removed from the list and officially enrolled. Parents select a provider from a list of
providers that serve their residential area, and then schedule an intake assessment. After an assessment, the parent and provider schedule the first therapy session, and the child begins therapy on a mutually agreeable date. The intake assessment and the first therapy session can take place either inside the home or in a treatment center. In the current study, time-lag is calculated as the number of days between these distinct stages. As illustrated in Figure 2.2., we use four measures of time-lag. These include Date of Diagnosis to Date on Waitlist (Time 1), Date of Enrollment to Date of Assessment (Time 2), Date of Assessment to Date of Initial Therapy Session (Time 3), and Date of Diagnosis to Date of Initial Therapy Session (Time 4). The RFA provided children’s date of diagnosis, and DDSN provided children’s wait list, enrollment, assessment, and initial therapy dates. The time-lag between placement on wait list and enrollment is not included because this time-lag is entirely administrative in nature.

**Primary independent variables.** We combined data from SC DDSN and the FRA to create the primary variable child race (white, black/African American, Hispanic, other non-Hispanic, and unknown). Both sources provided the category unknown, and we derived other non-Hispanic from a range of categories in the original data. We obtained neighborhood variables through the RFA, whereby personnel assigned a census tract ID to children based on the residential address recorded in SC DDSN’s organization-wide electronic database. Racial composition is measured by the percent of white residents in the census tract (centered). Poverty is a composite variable calculated as the z-score computed from the average percent of single parent female headed households, of people in poverty, of residents who receive cash assistance, of residents enrolled in SNAP, of residents who receive SSI, and of people who are unemployed. Also a composite
measure, affluence is the z-score computed from the average of median household income, percent of residents with professional/managerial employment, and percent of residents with a Bachelor’s degree or higher. We used Rural-Urban Commuting Areas to create dummy variables for urban, suburban, and rural census tracts.

![Process model of time-lag in the SC PDD Program](image)

**Figure 2.2.** Process model of time-lag in the SC PDD Program

**Covariates.** Covariates collected from SC DDSN include *adaptive behavior* (Adaptive Behavior Composite [ABC] standard score on the Vineland-II; grand mean centered), *sex* (1 = female, 0 = male), *single parent household* (1 = yes, 0 = no), *children in household* (1 = 3 or more children, 0 = 2 or fewer children), and *sibling with ASD* (1 = yes, 0 = no). Covariates collected from the RFA included *Asperger’s* (1 = yes, 0 = no), *Intellectual Disability* (1 = yes, 0 = no), and *age of diagnosis* (measured in months, grand mean centered). *Family socioeconomic status* is measured by the payment category billed by SC PDD program providers. Sources included payment under the Tax Equity and Fiscal Responsibility Act (*TEFRA*), which provides assistance to families with incomes too high to qualify for Medicaid, Supplemental Security Income (*SSI*), or *other* payment source (e.g., inpatient psychiatric facility). We used data from both SC DDSN and RFA to create the variable *age of enrollment* (measured in months, grand mean centered).
**Missing Data**

Of the 802 children who met inclusion criteria, 486 children had no missing data. On average, children were missing 1.99 items. There was no missing data on child race. Although children with a census tract ID were not missing on any neighborhood variables, 37 children did not have a census tract ID. Variables with strong correlations included Asperger’s, Intellectual Disability, age of diagnosis, age of enrollment, adaptive behavior, single parent, children in household, and sibling with ASD. These correlations indicate that missingness is not missing completely at random, and that results that involve these variables should be interpreted with caution. However, missing data across all children and all variables was 8.3%. When missing data is less than 10%, listwise deletion does not cause any more bias than imputation (Basilevsky, Sabourin, Hum, & Anderson, 1985; Roth, 1994). Therefore, we chose to listwise delete. The remaining 486 children included children (n=13) with negative outcome values. Because these values were impossible and most likely attributable to data error, we excluded them from the study for a final sample size of 473.

**Statistical Analyses**

We conducted all analyses using SAS® 9.4. We initially used two-level organizational models to answer our research questions. However, due to the number of singletons among census tracts (n=258), the models did not converge. Therefore, we estimated a total of 20 ordinary least squares contextual regression models using PROC REG, an appropriate approach when the interest is in the context of the neighborhood rather than differences between neighborhoods (Diez Roux, 2002). Because the outcome did not include zeroes and the means were large numbers, we did not use a Poisson
regression. Specifically, we estimated one main effects model and four interaction models for each outcome, for a total of five models per outcome. Because we estimated multiple models, we followed guidelines of the Bonferroni correction and used an adjusted alpha ($\alpha = .025$). To examine model fit, we compared changes in $R^2$. This process revealed that for all four outcomes, the main effects models were the best fitting models. We examined assumptions associated with OLS. All models did not appear to be normally distributed ($\text{Shapiro-Wilk} = p > .05$); kurtosis values of the residuals for two models exceeded three. However, given that regression is robust to violations of normality, that skewness values did not violate normality, and that we used an adjusted alpha, we determined that there is little concern for a Type I error. Additionally, using studentized residuals and Cook’s D, we identified no influential outliers. Although there were four instances of strong zero-order correlations (range of -0.548 to 0.790), all tolerance values of the best fitting models exceeded .20, providing no evidence of issues with multicollinearity.

**Results**

Descriptive statistics for the 473 children included in the sample are presented in Table 2.1. The sample includes more males (82.2%) than females (17.8%), most children are diagnosed with an Intellectual Disability (68.9%), and a minority of children were diagnosed with Asperger’s (17.1%). The average age of diagnosis is approximately three and a half years, the average age of enrollment is six years, and the average ABC score is 65.69. One-third of children identify as white (34%) and more than two-thirds live in an urban neighborhood (70%).
Table 2.1.
Univariate Descriptive Statistics for Time-Lag (4 measures), Child Race, Neighborhood Characteristics, and Covariates (N=473)

<table>
<thead>
<tr>
<th>Variable</th>
<th>% (M)</th>
<th>SD</th>
<th>Sk</th>
<th>Ku</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dependent Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis to Waitlist</td>
<td>332.67</td>
<td>324.01</td>
<td>1.20</td>
<td>0.43</td>
</tr>
<tr>
<td>Enrollment to Assessment</td>
<td>67.53</td>
<td>59.95</td>
<td>1.29</td>
<td>0.45</td>
</tr>
<tr>
<td>Assessment to Treatment</td>
<td>53.57</td>
<td>35.60</td>
<td>1.12</td>
<td>1.04</td>
</tr>
<tr>
<td>Diagnosis to Treatment</td>
<td>1040.89</td>
<td>357.04</td>
<td>0.93</td>
<td>0.08</td>
</tr>
<tr>
<td><strong>Child/Family Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>17.55</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7.61</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other Non-Hispanic</td>
<td>4.02</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Unknown</td>
<td>36.79</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Payment Category</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSI</td>
<td>51.37</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>7.82</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Female</td>
<td>17.76</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Age Diagnosed</td>
<td>-0.52</td>
<td>15.99</td>
<td>1.16</td>
<td>1.25</td>
</tr>
<tr>
<td>Age Enrolled</td>
<td>-0.52</td>
<td>18.54</td>
<td>0.70</td>
<td>-0.06</td>
</tr>
<tr>
<td>ABC Score</td>
<td>0.15</td>
<td>13.13</td>
<td>0.45</td>
<td>0.20</td>
</tr>
<tr>
<td>Asperger’s</td>
<td>17.12</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>68.92</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Single Parent</td>
<td>25.37</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Sibling with ASD</td>
<td>5.50</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>&gt;2 Children in Household</td>
<td>33.19</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td><strong>Neighborhood Variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% White</td>
<td>-1.40</td>
<td>21.53</td>
<td>-1.04</td>
<td>0.57</td>
</tr>
<tr>
<td>Poverty</td>
<td>0</td>
<td>0.74</td>
<td>1.05</td>
<td>1.34</td>
</tr>
<tr>
<td>Affluence</td>
<td>0</td>
<td>0.94</td>
<td>0.55</td>
<td>-0.53</td>
</tr>
<tr>
<td>Suburban</td>
<td>25.16</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Rural</td>
<td>4.86</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

Note: Table reports mean of centered continuous variables. Uncentered averages include 41.59 months (age diagnosed), 72.96 months (age enrolled), ABC score (65.69), and % white residents (67.87).

Two of the four main effects models were significant. Because none of the interaction models were significant, we only present results of the main effects models (Table 2.2). The first main effects model (Model 1a) accounted for 77% of the variability in the number of days at Time 1 (Date of Diagnosis to Date on Waitlist) \[F(20,452) = p < .025, \text{adj R}^2 = 0.76]\]. No primary independent variables were associated with a higher number of days. The variables with the strongest relationship with number of days were two covariates, or age of diagnosis \((\beta = -21.57, p < .025)\) and age of enrollment \((\beta = 21.09, p < .025)\), with magnitudes of -1.06 and 1.21, respectively. The second main
effects model (Model 2a), or Time 2 (Date of Enrollment to Date of Assessment), was not significant \(F(20,452) = p > .0025, \text{adj} R^2 = 0.01\), and the third main effects model (Model 3a), or Time 3 (Date of Assessment to Date of Initial Therapy Session), was not significant \(F(20,452) = p > .025, \text{adj} R^2 = 0.02\)). Finally, the fourth main effects model (Model 4a) accounted for 87% of variability \(F(20,452) = p < .0251, \text{adj} R^2 = 0.87\]) in the number of days at Time 4 (Date of Diagnosis to Date of Initial Therapy Session).

Child race and neighborhood variables were not significant. As in the first model, the covariates age of diagnosis \((\beta = -25.72, p < .025)\) and age of enrollment \((\beta = 25.84, p < .025)\) had the strongest relationship with number of days, with magnitudes of -1.15 and 1.34, respectively.
<table>
<thead>
<tr>
<th>Parameter Estimates for Best Fitting Models Across Outcomes (N = 473)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome</strong></td>
</tr>
<tr>
<td><strong>Model</strong></td>
</tr>
<tr>
<td><strong>Main Effects</strong></td>
</tr>
<tr>
<td>Intercept</td>
</tr>
<tr>
<td><strong>Child/Family Variables</strong></td>
</tr>
<tr>
<td>Race</td>
</tr>
<tr>
<td>Black</td>
</tr>
<tr>
<td>Hispanic</td>
</tr>
<tr>
<td>Other Non-Hispanic</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Payment Category</td>
</tr>
<tr>
<td>SSI</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Age Diagnosed</td>
</tr>
<tr>
<td>Age Enrolled</td>
</tr>
<tr>
<td>ABC Score</td>
</tr>
<tr>
<td>Asperger’s</td>
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<tr>
<td>Intellectual Disability</td>
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<tr>
<td>Single Parent</td>
</tr>
<tr>
<td>Sibling with ASD</td>
</tr>
<tr>
<td>&gt;2 Children in Hsld</td>
</tr>
<tr>
<td>Neighborhood Variables</td>
</tr>
<tr>
<td>% White</td>
</tr>
<tr>
<td>Poverty</td>
</tr>
<tr>
<td>Affluence</td>
</tr>
<tr>
<td>Rural</td>
</tr>
<tr>
<td>Suburban</td>
</tr>
<tr>
<td><strong>Model Fit</strong></td>
</tr>
<tr>
<td>R²</td>
</tr>
<tr>
<td>adj R²</td>
</tr>
</tbody>
</table>

Note: *p < .025

Due to extreme values in the outcome most likely due to errors in administrative data entry, we winsorized the dependent variable at the 95th percentile.

### Discussion

Contrary to prior research suggesting that children experience disparities in access to publicly-funded EIBI, our findings provide no evidence of inequitable access in South Carolina during the time period examined. Specifically, child race and neighborhood racial composition, poverty, affluence, and urbanicity are not predisposing social characteristics of the time-lag between diagnosis and treatment onset. However, as the
first study to examine time-lag between a child’s diagnosis and treatment onset in
publicly-funded EIBI, findings provide necessary insight into and underscore the need for
additional research on delays in treatment onset, provide theoretical contributions to
future research, and offer lessons on the collection and use of administrative data in this
rapidly expanding field.

Results indicate that there are no racial or neighborhood disparities in the time-lag
between diagnosis and treatment onset in South Carolina. These findings are in
opposition to existing literature on access to publicly-funded EIBI. Yet a detailed review
of the differences between current and prior findings provides a likely explanation for
why we did not detect evidence of disparities. Shattuck et al. (2009) compared the
census-tract level demographics of children who enrolled in Wisconsin’s EIBI program
to the state’s demographics, and Magaña, Lopez, Aguinaga, and Morton (2013) used
parent-reported enrollment as an indicator of access in the same program. In both studies,
researchers detected disparities by comparing children who did and did not enroll in the
program, whereas in the current sample all children had enrolled in South Carolina’s
program. It is possible, therefore, that disparities exist among children who do and do not
enroll in publicly-funded EIBI, but disparities do not exist in the time-lag between
diagnosis and treatment onset between children who do enroll. Clearly, enrollment and
time-lag are very different indicators of access. In the current study, data for children
whose parents never placed them on a wait list, and children whose parents placed them
on a wait list but never enrolled, were unavailable. There is no way to know how many
children in South Carolina were eligible to enroll but never did. It is possible that an
analysis that replicated the study by Shattuck et al. (2009) in South Carolina’s EIBI program would produce similar findings.

Importantly, Model 1a explains a substantial amount of variability (76.9%) in the average time-lag (333 days) between diagnosis and placement on a wait list. It is unlikely that the significant variability explained by the model is attributable to multicollinearity, as residual statistics revealed tolerance values greater than .20. More likely is the contribution of covariates that demonstrated strong relationships with time-lag, particularly age of diagnosis and age of enrollment. Certainly, the strength of these relationships points to the necessity of including these covariates in future research on time-lag. It also suggests that other potential factors play a role in time-lag. For example, given that children who are diagnosed at a later age experience a shorter time-lag, it is possible that parents of older children are more likely to be aware of available resources and/or experience a greater sense of urgency to seek treatment. Moreover, that it takes the average parent nearly one year to contact a publicly-funded EIBI program and request that their child’s name be placed on a wait list is concerning and points to the need to explore reasons for this extensive time-lag. The only other significant model, or Model 4a, is the combination of the first three models. The relationships between covariates and time-lag evident in Model 1a are also present in Model 4a (i.e., age of diagnosis, age of enrollment), but child race and neighborhood characteristics are not significant.

Limitations

Several study limitations are important to consider. First, the current study is an examination of children who enrolled in South Carolina’s EIBI program, limiting generalizability to other states. Also, the sample did not include children who were
placed on a wait list but never enrolled in the program because SC DDSN maintained no records on these children other than their name and social security number. There is no way to determine if the children who never enrolled are qualitatively different from children who did, and prior research suggests that this is a possibility. Finally, limitations of administrative data are evident, including apparent data entry errors that required the use of winsorizing outcome variables and the high number of children in the unknown racial category (36%). Compared to the racial distribution in South Carolina, black and white children are underrepresented in the sample. It is likely that most of the children in this category are one or the other, and it is possible that the high percentage of children in this category impacted findings.

**Future Research and Practice Recommendations**

This study lays the groundwork for future research on the time-lag between diagnosis and treatment onset, and it adds to a nascent body of literature on access to publicly-funded EIBI. Results demonstrate the importance of conducting research beyond the age of a child’s diagnosis to the time-lag between diagnosis and treatment onset. In this study, an average of 1041 days – or nearly three years – lapsed between a child’s diagnosis and initial therapy session. Importantly, nearly one year lapsed before children were placed on the SC PDD Program wait list. This time-lag is counterintuitive to the urgency placed on providing EIBI to children as early as possible. Recognizing this, in 2012 SC DDSN spearheaded a unique strategy, in which children who were diagnosed before their third birthday and who received EIBI at least 30 days before their third birthday bypassed the PDD Program wait list. Thus, in addition to conducting research
that explains this long time-lag, there is a need to research the effectiveness of current efforts to reduce the time-lag between diagnosis and treatment onset.

To build on these results, it is necessary to examine time-lag between diagnosis and treatment onset in other states and to investigate factors beyond predisposing social characteristics that might contribute to this time-lag (e.g., parent perceived need, provider availability), and to move beyond children’s initial treatment session to investigate treatment utilization over time. Given the long time-lag detected, it is also critical to examine if children receive other therapies while waiting to begin EIBI, and if so, the type and amount of therapy. Although EIBI has the strongest evidence for treating ASD, one-on-one therapy such as speech-language, occupational, and physical therapy are also recommended. Exploring whether or not children receive these services as a bridge between diagnosis and EIBI treatment onset is worthwhile, especially because an overwhelming majority of states have reported shortages of speech-language pathologists (82%) and occupational therapists (79%) (Wise et al., 2010).

Our findings illustrate the importance of constructing a theoretical framework to guide future research. Although the BMHSU is a good starting point for examining disparities in access, realized access is more complex in the context of EIBI compared to more common measures in health services research (e.g., health insurance coverage, having a primary care provider). There is work to do in the conceptualization of access to EIBI within the BMHSU. To this point, beyond the evidence-based yet ambiguous assertion that children need to begin treatment as early as possible, what is the best definition of “timely onset”? If time-lag is inevitable, what is the maximum time-lag for which states should strive? Is timely onset of EIBI restricted to after children are
diagnosed, or is timely onset when children receive treatment after a positive screening for ASD? The development of a theoretical framework that captures the nuances of access to publicly-funded EIBI will help to ensure that disparities in access (i.e., inequitable access) are detected and reduced.

Finally, there are at least three takeaways regarding data collection for future research and the provision of EIBI. First, there is a need to enhance the collection of demographic data, especially race and ethnicity. This is not a new challenge in health services research. In a study that surveyed hospital patients on this issue, although 93% of respondents reported that it is critical to conduct studies that ensure equitable care irrespective of race or ethnicity, and 80% of respondents reported that it is important to track race and ethnicity, 31% expressed concern that the information could be used to discriminate against patients (Baker et al., 2005). Results of a study by Hasnain-Wynia, Taylor-Clark, and Anise (2010) indicate that a solution to this perception is to clearly communicate through various mediums the reason for requesting patients’ race and ethnicity. In particular, a majority of study participants were most receptive to the statement, “race/ethnicity information is being collected to ensure that everyone gets high-quality care” (2010, p. 378). Adopting this approach when case managers collect information on children and parents could prove useful to future data collection efforts in publicly-funded EIBI. Second, in 2015 South Carolina began eradicating the PDD Program wait list because the state is in the process of transferring the delivery of EIBI from its HCBS Medicaid waiver to its Medicaid state plan. As South Carolina and dozens of other states begin providing EIBI through Medicaid, it is important to determine how to capture and record children’s initial contact with the EIBI service system. Lastly, as
EIBI expands to more states, it is worth discussing the potential benefits and feasibility of a coordinated effort by state administrators to collect similar data across the country. Ideally, this data would not only include child information, but family, provider, and organizational information. A nationally coordinated effort could promote quality research to monitor and reduce disparities.
CHAPTER 3

RACE, PLACE, AND TREATMENT UTILIZATION TRAJECTORIES AMONG CHILDREN WITH AUTISM SPECTRUM DISORDER ENROLLED IN PUBLICLY-FUNDED EIBI

Abstract

Public funding of early intensive behavioral intervention (EIBI) for the 1 in 68 children who meet criteria for autism spectrum disorder (ASD) is rapidly expanding. Evidence suggests that children with ASD experience racial, socioeconomic, and geographic disparities in access to health care services. The Interagency Autism Coordinating Committee cites disparities in access to early intervention among the most pressing yet understudied areas of research. However, current research heavily focuses on disparities in age of diagnosis, and we know little about whether disparities exist in children’s utilization of ASD treatments. The purpose of this paper is to examine the relationship between treatment utilization trajectories and a) child race and b) neighborhood racial composition, poverty, affluence, and urbanicity. We also determine whether the relationship between child race and treatment utilization trajectories varies by neighborhood characteristics. Using a sample of children who participated in publicly-funded EIBI (N=807), we estimated a total of 10 two-level growth curve models. Results reveal that children use an average of 41% of allotted hours per week. During the first week of therapy, compared to white children, black children use an average of 8.2% less hours, for every 1 standard deviation increase in neighborhood affluence a child uses 2.8% more hours, and compared to children in urban areas, children in suburban areas use 3.4% less hours. There is no evidence of racial or neighborhood differences in treatment utilization trajectories. Findings provide insight into children’s average utilization during the first year of treatment, underscore the need for research that examines different measures of utilization (e.g., by month or year) and utilization beyond
the first year of treatment, make contributions to the conceptualization of access to EIBI, and offer lessons on the collection and use of administrative data in research on EIBI.

**Introduction**

Although research on disparities in access to early intervention services among children with autism spectrum disorder (ASD) as well as the challenges of implementing large scale, community-based early intervention and inequitable access to ASD services are considered urgent areas of research (Interagency Autism Coordinating Committee (IACC), 2014; World Health Organization, 2013), work on these subjects is significantly lacking. In the context of mounting evidence that children with ASD experience racial, socioeconomic, and geographic disparities in access to diagnostic services, to routine and specialized health care, and to ASD-specific services (Liptak et al., 2008; Magaña et al., 2012; Murphy & Ruble, 2012; Parish et al., 2012; Shattuck et al., 2009; Siller et al., 2014; Tregnago & Cheak-Zamora, 2012), states are rapidly expanding the provision of EIBI. Yet there is no research that examines disparities in treatment utilization trajectories in publicly-funded EIBI. Indeed, the exponential increase in the number of children eligible to receive EIBI is outpacing research that can inform service delivery.

Currently, there are three developments in motion to provide health coverage of EIBI to the 1 in every 68 children who meet criteria for ASD (Baio, 2014). First, 44 states, the District of Columbia, and the U.S. Virgin Islands each have health insurance mandates requiring coverage of EIBI, and there are ongoing efforts to pass mandates in remaining states (Autism Speaks, 2016). Second, states who implemented EIBI via 1915(c) Home and Community-Based Services (HCBS) Medicaid waivers are transitioning the service to Medicaid state plans (Autism Feasibility Study Workgroup,
Finally, effective January 2015, 29 states and the District of Columbia require individual and small business health plans to cover behavioral intervention based on the principles of applied behavior analysis under their 10 “essential health benefits” (Autism Speaks, 2014). These ongoing developments in treatment provision underscore the urgent need to examine children’s treatment utilization.

**Treatment Utilization**

Professionals recommend that children receive between 20 and 40 hours per week of EIBI for as many as one to four years (Reichow et al., 2014). Most research demonstrates that greater treatment utilization (i.e., more weekly hours) results in better outcomes (Granpeesheh et al., 2009; Makrygianni & Reed, 2010; Reed & Osborne, 2012; Reichow & Wolery, 2008; Virués-Ortega, 2010), and that children make the most significant gains during their first year of treatment (Howlin et al., 2009). Despite calls for enhanced documentation and analysis of treatment utilization among children with ASD (Matson & Smith, 2008), however, extant literature lacks specificity, and there are no studies on treatment utilization trajectories in publicly-funded EIBI.

In a systematic review of case-control comparison studies (N=11) on the effectiveness of EIBI, Howlin, Magiati, and Charman (2009) reported that although a handful of researchers provided parent or therapist-reported hours per week (Magiati, Charman, & Howlin, 2007; Remington et al., 2007; Smith, Groen, & Wynn, 2000), most did not include the number of hours a child used. Instead, many provided ambiguous
measures, such as the minimum number of hours per week or a range of hours per week. When researchers noted a decline in utilization after a certain time period, they did not provide the number of hours by which utilization reduced. In all but one study included in the review, researchers reported that children used between 25 and 40 hours per week. In an updated review that only included randomized control trials, quasi-randomized control trials, or clinical control trials, all studies (N=5) were also included in the 2009 review (Reichow et al., 2014). Other researchers report treatment hours by month. For instance, Granpeesheh Dixon, Tarbox, Kaplan, & Wilke (2009) provided average treatment hours across four months. Furthermore, in the only published evaluation of a publicly-funded EIBI program, researchers reported that a government mandate required participants (N=332) to receive between 20 and 40 hours of treatment per week unless they were just beginning the program or transitioning out of the program into school (Perry et al., 2008).

Yet a range of 20 hours per week is significant, and program evaluators did not track weekly treatment utilization to determine if families adhered to the mandate.

**Race, Place, and Treatment Utilization**

Although there is no research on the relationship between child race and treatment utilization trajectories in publicly-funded EIBI, two studies provide insight into disparities in access in this context. In a study on disparities in time-lag between diagnosis and treatment onset in South Carolina’s program, Yingling, Hock, and Bell (forthcominga) found no evidence of racial disparities. However, Magaña, Lopez, Aguina, & Morton (2013) examined ethnic disparities in enrollment in Wisconsin’s EIBI program and revealed that compared to white children, Hispanic children were less likely to enroll. A small study (N=70) on longitudinal change in the number of hours
children used individual services outside of school, including behavioral intervention, suggests that race and ethnicity are related to the utilization of fewer weekly hours of individual services. Specifically, white and Asian children were more likely to utilize a higher number of weekly hours than black or Hispanic children (Siller et al., 2014). Moreover, children who lived in households with higher annual incomes and whose birthfather lived in the household used a higher number of weekly hours compared to children who lived in households with lower annual incomes and without a birthfather living in the home. Sample demographics in literature on the effectiveness of EIBI reveal important trends of treatment utilization. For example, there are more children whose parents identify with a race other than white, report lower SES, and report being single in comparison groups, which are characterized by fewer hours of treatment per week (Cohen, Amerine-Dickens, & Smith, 2006; Lovaas, 1987; Magiati et al., 2007). Although weak, there is evidence to suggest that these parents opt out of intensive treatment groups (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005).

There is substantial, longstanding evidence that where people live impacts their access to health care. Research points to poorer health care access in particular geographic areas, including racially/ethnically segregated neighborhoods and neighborhoods with high concentrations of poverty (Acevedo-Garcia et al., 2008; Kirby & Kaneda, 2005; White et al., 2012; David R. Williams & Collins, 2001). Historically, individuals who live in rural areas experience numerous barriers to health care, including provider shortages, higher health care costs, and geographic isolation, which translates to increased travel time and transportation costs (Florence et al., 2012). The only two studies that examine neighborhood disparities in access to publicly-funded EIBI offer
mixed results. In their study on the time-lag between diagnosis and treatment onset, Yingling, Hock, and Bell (forthcominga) found no evidence of disparities in neighborhood racial composition, poverty, affluence, and urbanicity, and the relationship between child race and time-lag did not vary by neighborhood disparities. To the contrary, in a study on the relationship between neighborhood characteristics (i.e., the percent of families at ≥200% of the federal poverty level, the percent of women 25 and older with a high school degree or more education, and the percent of people who were white) and enrollment, Shattuck et al. (2009) recorded disparities. This study adds to a small body of work on neighborhood disparities in access to other ASD services. For example, in a study on timeliness of provider designation in New York City’s EI program, children who lived in low-income neighborhoods and neighborhoods with large Spanish-speaking populations experienced delays (Kim et al., 2009). Researchers cited a shortage of providers in the state, both monolingual and bilingual, as well as providers who perceive low income neighborhoods as less desirable work environments, as potential reasons for observed delays. Similarly, in a study on very low birth weight eligible 2-year olds in Wisconsin’s EI program, children who lived in socially disadvantaged neighborhoods were at greater risk of never receiving services (McManus et al., 2013). Murphy and Ruble (2012) found that compared to parents who lived in metropolitan counties, parents who lived in non-metropolitan counties were more likely to report difficulties accessing professionals trained in the treatment of ASD. Importantly, although rural populations are overwhelmingly white, the number of racial and ethnic minorities who live in rural areas increased by 21.3% between 2000 and 2010 (Johnson, 2012), highlighting the need to examine racial differences in rural areas.
Behavioral Model of Health Services Use

In response to scarce research, it is imperative that researchers begin to examine treatment utilization in publicly-funded EIBI. As described elsewhere, central to this undertaking is to more precisely define and measure access to EIBI, and Andersen’s Behavioral Model of Health Services Use (BMHSU) (Andersen et al., 2013) provides a good framework for doing so (Yingling, Hock, & Bell, forthcominga). In the current study, we focus on child race and neighborhood characteristics (i.e., individual and contextual predisposing social characteristics, respectively), and two of the model’s six dimensions of access, or realized access (i.e., utilization) and inequitable access (i.e., access due to social structure). We estimate children’s treatment utilization trajectories and determine if race and neighborhood characteristics are related to trajectories. In particular, we examine the impact of child race and neighborhood racial composition, poverty, affluence, and urbanicity on treatment utilization trajectories to determine if there is inequitable access to EIBI. Because all children received at least one therapy session in a minimum of 26 weeks during their first year of treatment, all children realized access. However, realized access is more complex than utilization of one therapy session per week. More specifically, given the emphasis placed on high treatment utilization (i.e., more hours per week), we focus on the number of treatment hours a child utilized each week. We define realized access as high utilization during the first year of treatment. In other words, if results suggest that children’s treatment utilization trajectories are related to race and neighborhood characteristics, then there is evidence of inequitable access.
Current Study

In 2007, South Carolina became one of the first states in the country to offer a HCBS Medicaid waiver specifically for the statewide provision of EIBI, or the South Carolina Pervasive Developmental Disorder (SC PDD) Program. The SC PDD Program, among the most generous of its kind, provides three years of EIBI to children between the ages of 3 and 10 who receive a diagnosis of ASD by age eight. Professional psychologists diagnose children, and prior to enrollment, DDSN reviews each child’s diagnostic report. The agency either approves the diagnosis or requires the child to complete a second diagnostic assessment. Based on need, each child receives a maximum of $50,000 per year and up to 40 hours of direct line therapy per week, of which at least 50% must take place inside the child’s home (South Carolina Department of Disabilities and Special Needs, 2013).

The aims of this study are three-fold. First, to describe treatment utilization trajectories during the first year of treatment among children with ASD in a publicly-funded EIBI program. Second, to examine the relationship between treatment utilization trajectories and a) child race and b) neighborhood racial composition, poverty, affluence, and urbanicity. Third, to examine if the relationship between race and treatment utilization trajectories vary by neighborhood racial composition, poverty, affluence, and urbanicity. Figure 3.1 depicts the relationships examined.
Figure 3.1. Empirical model of study aims

Method

Data and Sample

As part of a larger research effort, we partnered with SC DDSN to create a comprehensive dataset (N=2,338) of all children with ASD placed on a wait list and/or enrolled in the SC PDD Program between the date that the first child enrolled (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). First, we compiled paper case records, excel spreadsheets, and electronic records at SC DDSN to build a base dataset. We then sent this base dataset to the South Carolina Revenue and Fiscal Affairs Office (RFA) to integrate Medicaid claims data and Census data. We included children in the study (N=807) if they received at least one therapy session in a minimum of 26 weeks during the first year (52 weeks) of treatment. We applied this inclusion criterion because of our focus on trajectories of treatment utilization. If children did not receive between 26 and 52 weeks of treatment, they arguably did not have a trajectory in the first year to analyze and could have significantly biased the models. In
addition, for families that had two siblings with ASD in the program, we randomly selected one of the siblings. This reduced the dataset by 50 children. Details on missing data are below. We received institutional review board approval from the University of South Carolina.

Measures

**Treatment utilization.** Treatment utilization is measured as the percent of allotted treatment hours used per week. Based on a thorough assessment, SC DDSN annually allots the number of hours children may receive per week. To calculate percent of hours used, we first divided the total year budget by 52 weeks to determine the number of allotted hours per week. For example, the quotient of a budget of 1560 hours divided by 52 weeks is 30 hours per week. Next, we calculated the quotient of the number of hours a child used each week divided by the number of allotted hours per week. For instance, if a child used 15 of 30 allotted hours in the first week of treatment, a child’s treatment utilization in the first week is 50%. If a child used zero hours in the first week of treatment, a child’s treatment utilization in the first week is 0%. We calculated this quotient for all 52 weeks.

**Level-2 independent variables.** We combined data from SC DDSN and the RFA to create five dummy variables for the level-2 variable *child race* (i.e., white, black, Hispanic, other non-Hispanic, and unknown). Both DDSN and RFA maintained an unknown category, and we derived other non-Hispanic from a range of categories in the original data. The RFA provided neighborhood variables, whereby personnel assigned an encrypted census tract ID to children based on the residential address recorded in SC DDSN’s organization-wide electronic database. *Racial composition* is measured as the
percent of white residents in the census tract (centered). *Poverty* is a composite variable calculated as the z-score computed from the average percent of single parent female headed households, people in poverty, residents who receive cash assistance, of residents enrolled in SNAP, residents who receive SSI, and people who are unemployed. Also a composite measure, *affluence* is the z-score computed from the average of median household income, percent of residents with professional/managerial employment, and percent of residents with a Bachelor’s degree or higher. Finally, we used Rural-Urban Commuting Areas to create dummy variables for *urban*, *suburban*, and *rural* census tracts.

**Time-invariant covariates.** Time-invariant covariates collected from SC DDSN included *adaptive behavior* (Adaptive Behavior Composite [ABC] standard score on the Vineland-II; grand mean centered), *sex* (1 = female, 0 = male), *single parent household* (1 = yes, 0 = no), *children in household* (1 = 3 or more children, 0 = 2 or fewer children), and sibling with ASD (1 = yes, 0 = no). Covariates collected from the RFA included *Asperger’s* (1 = yes, 0 = no), *Intellectual Disability* (1 = yes, 0 = no), and *age of diagnosis* (measured in months, grand mean centered). *Family socioeconomic status* is measured by the payment category billed by SC PDD program providers. Sources included payment under the Tax Equity and Fiscal Responsibility Act (*TEFRA*), which provides assistance to families with incomes too high to qualify for Medicaid, Supplemental Security Income (*SSI*), or *other* payment source (e.g., inpatient psychiatric facility). We used data from both SC DDSN and RFA to create the variable *age of enrollment* (measured in months, grand mean centered).
Missing Data

Of the 1334 children who met inclusion criteria, 813 children had no missing data. On average, children were missing 1.47 items. No children had missing data on the primary independent variable, or child race. Although children with a census tract ID were not missing on any contextual variables, 89 children did not have a census tract ID. Variables with strong correlations included Asperger’s, Intellectual Disability, age of diagnosis, age of enrollment, ABC score, single parent, children in household, and sibling with ASD. These correlations indicate that missingness is not missing completely at random, and that results that involve these variables should be interpreted with caution. However, missing data across all children and all variables was 7.3%. When the sample size is large and missing data is less than 10%, listwise deletion does not cause any more bias than imputation (Basilevsky et al., 1985; Roth, 1994). Therefore, we chose to listwise delete. Finally, of the remaining 813 children, three children had no budgeted hours and three children had extremely low budgeted hours. Because these values were impossible and appeared to be due to data error, we excluded them from the study for a final sample size of 807.

Statistical Analyses

To examine the relationship between child race and treatment utilization trajectories and neighborhood characteristics and treatment utilization trajectories, we first estimated three-level growth curve models. Due to the number of singletons among census tracts (n=299), however, the models did not converge. Therefore, we used two-level growth curve, contextual models, an appropriate approach when the interest is in the context of the neighborhood rather than differences between neighborhoods (Diez, 2002).
This approach allowed the estimation of mean trajectories of children’s treatment utilization from a child’s initial therapy session (Week 1) to the end of the first year of treatment (Week 52) by specifying an independent variable for time, as well as child differences in change in treatment utilization over time. In these models, observations of treatment utilization are at level-1 and child and neighborhood characteristics are at level-2, with observations of time nested within children. Both fixed and random growth parameters are specified. The fixed parameters include the intercept and the slope, and the random parameters capture the variation in within-child and between-child differences in treatment utilization trajectories and the variation in their change over time.

To determine the best fitting model, we used PROC MIXED in SAS® 9.4 with maximum likelihood (ML) estimation and Satterthwaite degrees of freedom. We estimated a total of 10 models. We first estimated an unconditional model with no predictors (Model 1). The intraclass correlation coefficient (ICC) revealed a 40% between-child variation in average treatment utilization at Week 1. After estimating the unconditional model, we plotted average treatment utilization for all 52 weeks. Because this plot revealed a slight curvature in the average treatment utilization trajectory (Figure 2), we assessed the form of change in treatment utilization by estimating one level-1 model with time as the only level-1 predictor and random slope and a second level-1 model with both time and time² (i.e., quadratic term) as level-1 predictors and random slopes (Model 2b).

The second model (Model 2) was the better fitting model, so we estimated all subsequent models as random intercept and slope models with time and time² as random slopes using standard variance components. We then estimated a main effect model.
(Model 3) with level-1 time and time\(^2\), level-2 child race and time invariant covariates, and a model with level-1 time and time\(^2\), level-2 child race and time-invariant covariates, and level-2 neighborhood characteristics (Model 4). Finally, we ran four cross-level interaction models to determine if the relationship between race and treatment utilization trajectories varied by each of the four neighborhood characteristics. To examine model fit, we compared differences in -2 Log likelihood. This process revealed that Model 4 was the best fitting model. To test model assumptions, we ran the MIXED_DX macro to examine residuals for violations of distributional assumptions at both level-1 and level-2 and to examine the data for influential outliers. No violations were detected.

Figure 3.2. Average linear change in percent of weekly treatment utilization.

Results

Descriptive Statistics

Descriptive statistics for the 807 children included in the sample are presented in Table 3.1. The sample includes more males (82.3%) than females (17.7%), most children were diagnosed with an Intellectual Disability (65.9%), and a minority of children were diagnosed with Asperger’s (15.5%). The average age of diagnosis is just under four years, the average age of enrollment is nearly six years, and the average ABC score is
Most children identified as white (44.6%) and lived in an urban neighborhood (70.5%). Average weekly percent of treatment for the first year of treatment is 41.3%.

Table 3.1
**Univariate Descriptive Statistics for Treatment Utilization, Child Race, Neighborhood Characteristics, and Covariates (N=807)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>% (M)</th>
<th>SD</th>
<th>Sk</th>
<th>Ku</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly Treatment Utilization</td>
<td>(41.33)</td>
<td>18.39</td>
<td>0.48</td>
<td>-0.15</td>
</tr>
<tr>
<td>Child/Family Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>18.46</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Hispanic</td>
<td>6.20</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other Non-Hispanic</td>
<td>4.09</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Unknown</td>
<td>26.64</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Payment Category</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>SSI</td>
<td>41.76</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Other</td>
<td>11.15</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Female</td>
<td>17.72</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Age Diagnosed</td>
<td>(-4.68)</td>
<td>18.35</td>
<td>1.22</td>
<td>1.59</td>
</tr>
<tr>
<td>Age Enrolled</td>
<td>(4.09)</td>
<td>18.69</td>
<td>0.59</td>
<td>-0.35</td>
</tr>
<tr>
<td>ABC Score</td>
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<td>13.29</td>
<td>0.27</td>
<td>0.31</td>
</tr>
<tr>
<td>Asperger’s</td>
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<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>65.92</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Single Parent</td>
<td>23.17</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Sibling with ASD</td>
<td>5.45</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>&gt;2 Children in Household</td>
<td>28.50</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Neighborhood Variables</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>(-3.48)</td>
<td>20.74</td>
<td>-0.97</td>
<td>0.39</td>
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<tr>
<td>Poverty</td>
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<td>0.73</td>
<td>1.15</td>
<td>1.70</td>
</tr>
<tr>
<td>Affluence</td>
<td>0.02</td>
<td>0.95</td>
<td>1.15</td>
<td>-0.34</td>
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<td>Suburban</td>
<td>24.78</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Rural</td>
<td>4.71</td>
<td>--</td>
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</tr>
</tbody>
</table>

Note: Table reports mean of centered continuous variables. Uncentered averages include 45.29 months (age diagnosed), 71.53 months (age enrolled), ABC score (66.13), and % white residents (69.32).

**Two-level growth curve models**

Parameter estimates and fit statistics for the best fitting models are presented in Table 3.2. Model 1 indicates that children vary in their percent of treatment utilization at Week 1 (b=328.77; p < .000), with a 40% between-child variation to be explained by subsequent models. Model 2 shows that children vary in their linear change in percent of treatment utilization (b = 0.89; p < .000). Model 3 contains the level-2 primary time-invariant variable child race and time invariant covariates. Results show that compared to white children, black children use an average of 9.65% less treatment at Week 1 (b = -
9.65; p < .000) and Hispanic children use an average of 6.72% less treatment at Week 1 (b = -6.72; p < .05).

Table 3.2.
Parameter Estimates for Main Effects Models, Including Best Fitting Model (N=807)

<table>
<thead>
<tr>
<th>Fixed Effect (SE)</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>Model 4a</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fixed Effects</td>
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<td></td>
<td></td>
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<tr>
<td>Intercept</td>
<td>41.33* (0.65)</td>
<td>31.46* (0.75)</td>
<td>41.49* (2.09)</td>
<td>40.93* (2.17)</td>
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<tr>
<td>Time</td>
<td>0.89* (0.04)</td>
<td>0.89* (0.04)</td>
<td>0.89* (0.04)</td>
<td></td>
</tr>
<tr>
<td>Time²</td>
<td>-0.01* (0.00)</td>
<td>-0.01* (0.00)</td>
<td>-0.01* (0.00)</td>
<td></td>
</tr>
<tr>
<td>Child/Family Variables</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td>-9.65* (2.02)</td>
<td>-8.63* (2.12)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
<td>-6.72* (2.99)</td>
<td>-5.96* (0.04)</td>
<td></td>
</tr>
<tr>
<td>Other Non-Hispanic</td>
<td>5.29 (3.60)</td>
<td>5.63 (3.57)</td>
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<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>-3.37 (1.73)</td>
<td>-2.85 (1.71)</td>
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<tr>
<td>Payment Category</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>SSI</td>
<td>-6.63* (1.70)</td>
<td>-4.86* (1.74)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>-2.13 (2.34)</td>
<td>-1.16 (2.34)</td>
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</tr>
<tr>
<td>Female</td>
<td>0.27 (1.82)</td>
<td>0.24 (1.79)</td>
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<tr>
<td>Age Diagnosed</td>
<td>0.06 (0.05)</td>
<td>0.05 (0.05)</td>
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<tr>
<td>ABC Score</td>
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<tr>
<td>Asperger’s</td>
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<td>-0.07 (0.05)</td>
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<tr>
<td>Intellectual Disability</td>
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<td>3.46 (3.03)</td>
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<td>&gt;2 Children in</td>
<td>1.52 (1.56)</td>
<td>1.51 (1.54)</td>
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<tr>
<td>Household</td>
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<tr>
<td>Neighborhood Variables</td>
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<tr>
<td>% White</td>
<td>0.07 (0.04)</td>
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<tr>
<td>Poverty</td>
<td>1.94 (1.70)</td>
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<tr>
<td>Affluence</td>
<td>2.91* (1.17)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Suburban</td>
<td>-3.34* (1.63)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>-5.08 (3.35)</td>
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<tr>
<td>Model Fit</td>
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<tr>
<td>-2 Log likelihood</td>
<td>381996.0</td>
<td>375598.0</td>
<td>375508.9</td>
<td>375487.4</td>
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<tr>
<td>Level-1</td>
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<td>381.28*</td>
<td>381.43*</td>
<td>381.58*</td>
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<td></td>
<td>(3.42)</td>
<td>(2.82)</td>
<td>(2.82)</td>
<td>(2.82)</td>
</tr>
<tr>
<td>Level-2</td>
<td>328.77*</td>
<td>381.94*</td>
<td>336.90*</td>
<td>326.38*</td>
</tr>
<tr>
<td>(Int)</td>
<td>(16.84)</td>
<td>(21.46)</td>
<td>(19.21)</td>
<td>(18.68)</td>
</tr>
</tbody>
</table>

Note: *p<.05; ICC = .460
a Best fitting model
Estimation Method = ML. Satterthwaite degrees of freedom. Entries show parameter estimates with standard errors in parentheses. Due to administrative data errors, some children had treatment hours greater than the maximum of 40 hrs./wk. Treatment hours were capped at 40 hrs./wk. In 14 weeks 99% of hours were <=40 hrs./wk, in 30 weeks 99% of hours ranged between 40.25 and 45 hrs./wk, and in the remaining 8 weeks, hours ranged between 45.5 and 49.25 hrs./week.
Finally, Model 4 includes level-2 neighborhood characteristics. For every one standard deviation increase in the affluence of a child’s neighborhood, a child’s percent of treatment utilization at Week 1 increases by 2.91 standard deviations (2.91; p < .05), and compared to children who live in urban neighborhoods, children who live in suburban neighborhoods use 3.39% less treatment at Week 1 (-3.39; p < .05). None of the interaction models were significant, suggesting that treatment utilization trajectories do not differ by race or neighborhood characteristics, and that the relationship between race and treatment utilization trajectories do not vary by neighborhood characteristics.

**Discussion**

Contrary to prior research, results indicate that in South Carolina during the time period examined there is no relationship between child race and treatment utilization trajectories, that neighborhood racial composition, poverty, affluence, and urbanicity are not related to treatment utilization trajectories, and that the relationship between child race and treatment utilization trajectories does not vary by these neighborhood characteristics. Nevertheless, this study is the first to examine treatment utilizations trajectories in publicly-funded EIBI. Findings provide necessary insight into children’s EIBI treatment utilization trajectories, underscore the need for additional research in this area, make theoretical contributions to future research on access to EIBI, and offer practice recommendations.

Results indicate that there is inequitable access to EIBI during the first week of treatment, and future research to determine why these disparities exist is important. However, there is no evidence of racial or neighborhood disparities in treatment utilization trajectories. These findings complicate existing research. Although two studies
provide evidence of disparities in enrollment (Magaña et al., 2013; Shattuck et al., 2009), the current results align with the recent finding that there are not racial or neighborhood disparities in the time-lag between diagnosis and treatment onset (Yingling, Hock, & Bell, forthcominga). They are also contrary to research that detected disparities in weekly utilization of individual services outside of school among children with ASD (Siller et al., 2014). It is possible that these nonsignificant findings are explained by our use of weekly treatment utilization rather than biweekly or monthly utilization. That is, it is unlikely that children participate in therapy at least once every week during the first year of treatment. In any given week, children in the current sample use zero hours of treatment. There are countless reasons for this, including holidays, family illnesses, emergencies or vacations, provider cancellations, or other events throughout the year. Measuring treatment utilization by weekly use, therefore, may not be the best approach.

In addition to the measurement of utilization, there may not be racial and neighborhood differences in treatment utilization trajectories due to the nature of the sample. Children excluded from the study because they used fewer than 26 weeks of treatment may be qualitatively different from those children who used a minimum of 26 weeks of treatment. Future research that examines treatment utilization of all children who participate in EIBI, including those who used less than 26 weeks of treatment during the first year, is warranted. Additionally, it is desirable that future research include investigations of treatment utilization measured as the total number of monthly or yearly hours

Despite a lack of evidence of racial and neighborhood disparities, this study provides essential insight into treatment utilization trajectories among children with ASD
enrolled in publicly-funded EIBI. On average, children use 24.6% of their allotted hours during their first week of treatment. Despite a rapid acceleration of treatment utilization during the initial 10 weeks of treatment, children plateau and use between 37% and 44% of allotted treatment hours for the remainder of the year. Certainly, reasons for low treatment utilization require immediate exploration. One possible explanation is children’s attendance at school, as parents have reported that time demands of school are a barrier to EIBI utilization (Yingling, Hock, Cohen, et al., forthcoming). This is likely a challenge in the current sample, where the average age of enrollment is nearly six years, and there was a negative relationship between age of enrollment and utilization during the first week of treatment. Given the emphasis on high treatment utilization (i.e., more weekly hours results in better child outcomes), it is also critical that researchers determine if trajectories predict short- and/or long-term child outcomes. Results also suggest that children vary in their treatment utilization over time. A next step for research is to identify the type and prevalence of treatment utilization trajectories in EIBI, and to determine if predisposing social characteristics are related to types of trajectories.

With the addition of this study, the current body of work on disparities in access to EIBI suggests that the relationships between predisposing social characteristics and realized access depends on the point at which children are participating in the EIBI service system (e.g., enrollment, utilization of treatment at Week 1, utilization of treatment during the first year). This suggests that there are different points in the system at which to intervene as well as different predisposing social characteristics to focus on depending upon the point of intervention. Perhaps it is desirable, therefore, that any
theoretical model of access to EIBI also captures the multiple systems through which children chronologically and simultaneously proceed.

**Limitations**

At the broadest level, this study is an analysis of treatment utilization trajectories in South Carolina’s EIBI program, and generalizability to other states is limited. Limitations of administrative data are also evident, including apparent data entry errors that required the use of winsorizing outcome variables and the number of children in the unknown racial category. It is also unclear what percent of hours children received were home- versus center-based. While the program requires a minimum of 50% of hours to be home-based, the remaining 50% could be either. Additionally, it is unknown if children received EIBI through private health insurance before and/or during their participation in the program. Children who receive EIBI through private insurance coverage while on the SC PDD wait list may enjoy an established relationship with a provider that facilitates high utilization. Finally, a child’s time on the wait list was not included as a variable because too few children were placed on a wait list. This would have reduced the sample enough to make it impossible to achieve the study aims.

**Practice Recommendations**

The current study highlights the need for administrators to determine why average treatment utilization is so low during the first year of treatment and to engage in efforts to increase utilization. It is also worthwhile for administrators to explore reasons why children who are black or Hispanic, qualify for SSI, and live in suburban neighborhoods use less treatment at Week 1 on average, while children who live in neighborhoods with higher affluence use more treatment. Furthermore, as suggested by Yingling, Hock, and
Bell (forthcominga) better data collection efforts are imperative to effectively monitor and evaluate children’s access to publicly-funded EIBI.
CHAPTER 4

RACIAL AND NEIGHBORHOOD DISPARITIES IN
TREATMENT UTILIZATION TRAJECTORY TYPES AMONG CHILDREN WITH
AUTISM SPECTRUM DISORDER ENROLLED IN PUBLICLY-FUNDED EIBI³

³ Yingling, M. E., Bell, B. A., and Hock, R. M. To be submitted to Administration and
Policy in Mental Health and Mental Health Services Research.
Abstract

Public funding of early intensive behavioral intervention (EIBI) for the 1 in 68 children who meet criteria for autism spectrum disorder (ASD) is rapidly expanding. Evidence indicates that children with ASD experience racial, socioeconomic, and geographic disparities in access to health care services. Yet the Interagency Autism Coordinating Committee and the World Health Organization cite disparities in access to early intervention among the most pressing yet understudied areas of research. We know little about disparities in treatment utilization trajectories. The aims of this study, which are grounded in the Behavioral Model of Health Services Use, are to identify and describe the type and prevalence of treatment utilization trajectories during the first year of EIBI, and the association of child race and neighborhood characteristics with these trajectory types. To complete this study, paper case records, excel spreadsheets, and electronic records provided by the South Carolina Department of Disabilities and Special Needs, as well as Medicaid claims data and Census data provided by the South Carolina Revenue and Fiscal Affairs Office, were integrated. This unique dataset includes all children with ASD who enrolled in South Carolina’s Pervasive Developmental Disorder (PDD) Program (N=2,338) between its inception (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). The sample for the current study (N=807) includes children who received at least one therapy session during a minimum of 26 weeks during the first year of treatment. We used latent class growth analysis. Results reveal that there are four types of treatment utilization trajectories, and contrary to prior research, that there are racial and neighborhood disparities in children’s trajectory types. Findings provide necessary insight into distinct types of and disparities in
treatment utilization trajectories, highlight the benefit of using person-centered analyses, suggest that an investigation into why these disparities exist is imperative, and provide theoretical contributions to future research.

**Introduction**

Research on disparities in access to early intervention services and the challenges of implementing large scale, community-based early intervention for children with autism spectrum disorder (ASD) are among the most urgent yet understudied areas of research on ASD (Interagency Autism Coordinating Committee (IACC), 2014; World Health Organization, 2013). There is evidence that children with ASD experience racial, socioeconomic, and geographic disparities in access to diagnostic services, to routine and specialized health care, and to other services for children with ASD (Liptak et al., 2008; Magaña et al., 2012; Murphy & Ruble, 2012; Parish et al., 2012; Shattuck et al., 2009; Siller et al., 2014; Tregnago & Cheak-Zamora, 2012). Despite an exponential increase in the provision of early intensive behavioral intervention (EIBI) to meet the needs of the 1 in 68 children who meet criteria for ASD in the United States, however, there is little research on disparities in children’s treatment utilization trajectories. Indeed, the large number of children eligible to receive EIBI is outpacing research that can inform service delivery.

Forty-four states, the District of Columbia, and the U.S. Virgin Islands each have health insurance mandates requiring coverage of EIBI, and there are ongoing efforts to pass mandates in remaining states (Autism Speaks, 2016). There is also a handful of states who adopted EIBI via 1915(c) Home and Community-Based Services (HCBS) Medicaid waivers within the last decade that are required by the Centers for Medicaid
and Medicare Services to transition the service to Medicaid state plans (Autism Feasibility Study Workgroup, 2013; Centers for Medicare and Medicaid Services, 2014; Michigan Department of Community Health, 2013; South Carolina Department of Disabilities and Special Needs, 2007; Utah Department of Health, 2013). Furthermore, effective January 2015, 29 states and the District of Columbia require individual and small business health plans to cover behavioral intervention based on the principles of applied behavior analysis under their 10 “essential health benefits” (Autism Speaks, 2014). These ongoing developments in treatment provision underscore the urgency of examining children’s treatment utilization trajectories in EIBI.

**Treatment Utilization**

Current recommendations for children’s treatment utilization in EIBI are between 20 and 40 hours per week for one to four years (Reichow et al., 2014). Evidence suggests that greater treatment utilization (i.e., more weekly hours) results in better outcomes (Granpeesheh et al., 2009; Makrygianni & Reed, 2010; Reed & Osborne, 2012; Reichow & Wolery, 2008; Virués-Ortega, 2010), and that children make the most gains after their first year of treatment (Howlin et al., 2009). Yet research that investigates children’s treatment utilization in publicly-funded EIBI is scarce. In the only study on treatment utilization trajectories in publicly-funded EIBI, Yingling, Hock, and Bell (forthcomingb) examined the impact of child race and neighborhood racial composition, poverty, affluence, and urbanicity on trajectories during the first year of treatment. On average, children used 24.6% of their allotted hours during their first week of treatment. Despite an acceleration of treatment utilization during the first 10 weeks of treatment, children plateaued and used between 37% and 44% of allotted treatment hours for the remainder
of the year. Although this study provides the only detailed account of treatment utilization trajectories in publicly-funded EIBI, a small body of literature offers additional insight. In a systematic review of case-control comparison studies (N=11) on the effectiveness of EIBI, all but one study reported that children used between 25 and 40 hours of treatment per week. However, Howlin, Magiati, and Charman (2009) documented that most researchers did not include the precise number of hours children used, and instead only provided ambiguous measures (e.g., the minimum number of hours per week). When researchers noted a decline in utilization after a certain time period, they did not provide the number of hours by which utilization reduced. This lack of specificity exists in the only published evaluation of a publicly-funded EIBI program. Researchers evaluating the effectiveness of a province-wide EIBI program in Ontario reported that a government mandate required participants (N=332) to receive between 20 and 40 hours of treatment utilization unless they were just beginning the program or transitioning out of the program into school (Perry et al., 2008). However, a range of 20 hours per week represents a potentially significant variation between children, and program evaluators did not track weekly treatment utilization to ensure families met the requirement.

**Race, Place, and Treatment Utilization Trajectories**

There is substantial, longstanding evidence that an individual’s race and where an individual lives impacts access to health care. Research points to poorer health care access in particular geographic areas, including racially/ethnically segregated neighborhoods and neighborhoods with high concentrations of poverty, as well as differences in health care access between urban, suburban, and rural areas (Acevedo-
Garcia et al., 2008; Florence et al., 2012; Kirby & Kaneda, 2005; White et al., 2012; David R. Williams & Collins, 2001). In the only study on treatment utilization trajectories in publicly-funded EIBI, although evidence of racial and neighborhood disparities existed in the percent of treatment hours children used during their first week of treatment, child race and neighborhood racial composition, poverty, affluence, and urbanicity were not related to treatment utilization trajectories (Yingling, Hock, & Bell, forthcomingb). Importantly, however, researchers used conventional growth modeling. This variable-centered approach assumes that individuals come from a single population and that a single (i.e., the average) growth trajectory can effectively estimate an entire population, whereas a person-centered approach would have allowed children to be placed into unique trajectories (Jung & Wickrama, 2008). The authors cite this as a limitation and reason for further research.

The only two additional studies that examine neighborhood disparities in access to publicly-funded EIBI offer mixed results. In their study on the time-lag between diagnosis and treatment onset, Yingling, Hock, and Bell (forthcominga) found no evidence of disparities in neighborhood racial composition, poverty, affluence, and urbanicity, and the relationship between child race and time-lag did not vary by neighborhood disparities. To the contrary, in a study on the relationship between neighborhood characteristics (i.e., the percent of families at ≥200% of the federal poverty level, the percent of women 25 and older with a high school degree or more education, and the percent of people who were white) and enrollment, Shattuck et al. (2009) recorded disparities.
Additional research among children with ASD suggests that disparities in treatment utilization do exist. For example, a small study (N=70) on longitudinal change in the number of hours of individual services children used outside of school, which included behavioral intervention, suggests that race and ethnicity are related to the utilization of fewer weekly hours of individual services. Specifically, white and Asian children were more likely to utilize a higher number of weekly hours than black or Hispanic children (Siller et al., 2014), and children who lived in households with higher annual incomes and whose birthfather lived in the household used a higher number of weekly hours compared to children who lived in households with lower annual incomes and without a birthfather living in the home. Literature on the effectiveness of EIBI that points to trends in treatment utilization is also noteworthy, in which there are more children whose parents identify with a race other than white, report lower SES, and report being single that participate in comparison groups characterized by fewer hours of weekly treatment (Cohen et al., 2006; Lovaas, 1987; Magiati et al., 2007). Although weak, there is evidence to suggest that these parents opt out of treatment groups that require the utilization of more weekly hours (Howard et al., 2005). Given the dearth of research on children’s access to EIBI in general, the lack of work on treatment utilization trajectories in particular, and the limitations of the only study to date on treatment utilization trajectories, further examination is necessary.

**Behavioral Model of Health Services Use**

Central to addressing limited research on access to publicly-funded EIBI is to identify, define, and accurately measure indicators of access, and as described in detail elsewhere (Yingling, Hock, & Bell, forthcomingb), Andersen’s Behavioral Model of
Health Services Use (BMHSU) provides a valuable framework (Andersen et al., 2013). In the current study, we focus on child race and neighborhood characteristics (i.e., individual and contextual predisposing social characteristics, respectively), and two of the BMHSU’s six dimensions of access, or realized access (i.e., utilization) and inequitable access (i.e., access due to social structure). We identify factors that contribute to children’s assignment to different treatment utilization trajectories. In particular, we examine the impact of race and neighborhood racial composition, poverty, affluence, and urbanicity to determine if there is inequitable access to EIBI. Because all children in the study participated in at least one therapy session for a minimum of 26 weeks, all children realized access to some degree. Yet realized access is more nuanced than utilization of at least one therapy session per week. More specifically, given the emphasis placed on high treatment utilization (i.e., more hours per week), we focus on the number of hours a child utilized treatment each week. We define realized access as membership in a treatment utilization trajectory type characterized by high treatment utilization. Thus, by this definition, if the proportion of membership in a trajectory type is different based on race and place, there is evidence of inequitable access, or disparities in access to EIBI.

Current Study

In 2007, South Carolina became one of the first states in the country to offer a HCBS Medicaid waiver. Also known as the South Carolina Pervasive Developmental Disorder (SC PDD) Program, the program is administered by the South Carolina Department of Disabilities and Special Needs (SC DDSN) specifically for the statewide provision of EIBI. The SC PDD Program, among the most generous of its kind, provides three years of EIBI to children between the ages of 3 and 10 who receive a diagnosis of
ASD by age eight. Professional psychologists diagnose children, and prior to enrollment, SC DDSN reviews each child’s diagnostic report. The agency either approves the diagnosis or requires the child to complete a second diagnostic assessment. Based on need, each child receives a maximum of $50,000 per year and up to 40 hours of direct line therapy per week, of which at least 50% must take place inside the child’s home (South Carolina Department of Disabilities and Special Needs, 2013).

The aims of this study are two-fold. First, to identify the type and prevalence of treatment utilization trajectories during the first year of treatment among children with ASD in a publicly-funded program. Second, to examine the relationship between treatment utilization trajectory types and child race, and treatment utilization trajectory types and neighborhood racial composition, poverty, affluence, and urbanicity. Figure 4.1 depicts the relationships examined.

Figure 4.1. Empirical model of study aims

**Method**

**Data and Sample**

As part of a larger research effort, we partnered with SC DDSN to create a comprehensive dataset (N=2,338) of all children with ASD who enrolled in the SC PDD
Program between the date that the first child enrolled (February 6, 2007) and the end of the first quarter of calendar year 2015 (March 31, 2015). First, we combined paper case records, excel spreadsheets, and electronic records at SC DDSN to build a base dataset. We then sent the dataset to the South Carolina Revenue and Fiscal Affairs Office (RFA) to obtain Medicaid claims data and Census data. The RFA returned the base dataset with all identifiers removed, a dataset that included census-tract data, and a dataset that included Medicaid claims data. We integrated all datasets. We included children in the study (N=807) if they received at least one therapy session in a minimum of 26 weeks during the first year (52 weeks) of treatment. We applied this inclusion criterion because if children did not receive between 26 and 52 weeks of treatment, they had a limited trajectory in the first year to analyze and could have significantly biased results. In addition, for families that had two children with ASD in the program, we randomly selected one for inclusion in the study. This reduced the dataset by 50 children. Details on missing data are below.

Measures

Treatment utilization. We measured treatment utilization as the percent of allotted treatment hours children used per week. SC DDSN budgets children’s allotted hours on an annual basis. To calculate percent of hours used, we divided the number of hours children used each week by the number of children’s allotted hours per week. For instance, a child that used 15 of 30 allotted hours during the first week of treatment would have a treatment utilization value of 50% for week 1. If a child used zero hours in the first week of treatment, a child used 0% of allotted hours. We then calculated the average percent of treatment utilization per month and created a categorical variable for
treatment utilization (1 = 0 to <25%; 2 = 25 to <50%; 3 = 50 to <75%; 4 = 75 to 100%). (We first estimated the models with 52 weeks, but resorted to collapsing the data to 12 months because the models would not run with greater than 50 nominal levels of time.)

**Child variable.** We combined data from SC DDSN and the RFA to create five dummy variables for the variable *child race* (white, black, Hispanic, other non-Hispanic, and unknown). Both DDSN and RFA maintained an *unknown* category, and we derived *other non-Hispanic* from a range of categories in the original data.

**Neighborhood variables.** We obtained neighborhood variables through the RFA, whereby personnel assigned a census tract ID to children based on the residential address recorded in SC DDSN’s organization-wide electronic database. *Racial composition* is the percent of white residents in the census tract. *Poverty* is a composite variable calculated as the z-score computed from the average percent of single parent female headed households, of people in poverty, of residents who receive cash assistance, of residents enrolled in SNAP, of residents who receive SSI, and of people who are unemployed. Also a composite measure, *affluence* is the z-score computed from the average of median household income, percent of residents with professional/managerial employment, and percent of residents with a Bachelor’s degree or higher. We used Rural-Urban Commuting Areas to create dummy variables for *urban*, *suburban*, and *rural* census tracts.

**Covariates.** Covariates collected from SC DDSN included *adaptive behavior* (Adaptive Behavior Composite [ABC] standard score on the Vineland-II; grand mean centered), *sex* (1 = female, 0 = male), *single parent household* (1 = yes, 0 = no), *children in household* (1 = 3 or more children, 0 = 2 or fewer children), and *sibling with ASD* (1 =
yes, 0 = no). Covariates collected from the RFA included Asperger’s (1 = yes, 0 = no), Intellectual Disability (1 = yes, 0 = no), and age of diagnosis (measured in months).

Family socioeconomic status is measured by the payment category billed by SC PDD program providers. Sources included payment under the Tax Equity and Fiscal Responsibility Act (TEFRA), which provides assistance to families with incomes too high to qualify for Medicaid, Supplemental Security Income (SSI), or other payment source (e.g., inpatient psychiatric facility). We used data from both SC DDSN and RFA to create the variable age of enrollment (measured in months).

Missing Data

Of the 1334 children who met inclusion criteria, 813 children had no missing data. On average, children were missing 1.47 items. No children had missing data on the primary independent variable, or child race. Although children with a census tract ID were not missing on any contextual variables, 89 children did not have a census tract ID. Variables with strong correlations included Asperger’s, Intellectual Disability, age of diagnosis, age of enrollment, adaptive behavior, single parent, children in household, and sibling with ASD. These correlations indicate that missingness is not missing completely at random, and that results that involve these variables should be interpreted with caution. However, percent of missing data across all children and all variables was 7.3%. When the sample size is large and missing data is less than 10%, listwise deletion does not cause any more bias than imputation (Basilevsky et al., 1985; Roth, 1994). Therefore, we chose to listwise delete. Finally, of the remaining 813 children, there were children with no budgeted hours (n=3) and children with extremely low budgeted hours (n=3). These values were programmatically impossible, and after examining the data, they appeared to
be due to data error. Therefore, we excluded them from the study for a final sample size of 807.

**Statistical Analyses**

To identify the type and prevalence of treatment utilization trajectories, and to identify child race and neighborhood characteristics related to treatment utilization trajectory type, we used a three-step approach in Latent GOLD® 5.1. First, we constructed a latent class growth model using the Cluster Analysis option for our indicator variable (i.e., categorical variable of percent of allotted treatment hours used per month). (Initially, we estimated the models by week. However, because the models did not estimate with greater than 50 nominal levels of time, we collapsed the data to 12 months.) Using $L^2$ and BIC statistics, we determined that a four-cluster model best fit the data, assigned each child to one of the four identified latent classes (i.e., trajectory types), and saved this classification information to a new dataset. In the third step, we estimated a bivariate regression model using the Step3 option and the new dataset to determine by proportional assignment which characteristics are related to trajectory types, while correcting for the classification error to prevent bias. Importantly, the regression model includes bivariate analyses. We employed a conservative approach to interpreting the six pairwise comparisons for each covariate by adjusting the alpha to 0.0083.

**Results**

We identified four distinctive types of treatment utilization trajectories (Table 4.1). One type of users, or the “Low” users (23.58%), demonstrated a trajectory of low utilization in which the highest proportion of children who used between 0% and <25% of allotted hours (Figure 4.2). A second type (38.12%) showed a “Low-Moderate”
trajectory in which the highest proportion of children who used between 25% and <50% of allotted hours across the entire period (Figure 4.3). A third type (27.39%), or the “Moderate” users, demonstrated a trajectory that included the highest proportion of children who used between 50% and <75% of their allotted hours (Figure 4.4). Finally, a fourth type (10.9%) showed a “High” trajectory with the highest proportion of children who used between 75% and 100% of allotted hours (Figure 4.5).

Table 4.1.  
*Cluster Analysis Model Fit Statistics (N=807)*

<table>
<thead>
<tr>
<th></th>
<th>Low Users</th>
<th>Low-Moderate Users</th>
<th>Moderate Users</th>
<th>High Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>LL</td>
<td>-10188.64</td>
<td>-12440.94</td>
<td>-10796.42</td>
<td>-9895.27</td>
</tr>
<tr>
<td>BIC(LL)</td>
<td>21113.54</td>
<td>25122.85</td>
<td>22081.46</td>
<td>20774.46</td>
</tr>
<tr>
<td>Npar</td>
<td>110</td>
<td>36</td>
<td>73</td>
<td>147</td>
</tr>
<tr>
<td>L²</td>
<td>9814.94</td>
<td>14319.55</td>
<td>11030.50</td>
<td>9228.20</td>
</tr>
<tr>
<td>df</td>
<td>697</td>
<td>771</td>
<td>734</td>
<td>660</td>
</tr>
<tr>
<td>Class.Err.</td>
<td>0.05</td>
<td>0</td>
<td>0.03</td>
<td>0.06</td>
</tr>
</tbody>
</table>
Figure 4.2. Proportion of children that use 0% to <25% of average monthly treatment hours by trajectory type

Figure 4.3. Proportion of children that use 25% to <50% of average monthly treatment hours by trajectory type

Figure 4.4. Proportion of children that use 50% to <75% of average monthly treatment hours by trajectory type

Figure 4.5. Proportion of children that use 75% to 100% of average monthly treatment hours by trajectory type
Figure 4.6 depicts average treatment utilization trajectories by type of trajectory using weekly percent of allotted hours. The average overall trajectory increased during the first seven weeks of treatment, with utilization among High users rapidly accelerating from 40.2% at Week 1 to 74.5% at Week 10, and later peaking at Week 26 (84.5%). The average percent of treatment utilization for Low users, however, began at 16.2% and remains and between 19% and 24% for the entire time period. The distributions of each covariate within each type is presented in Table 4.2.

![Figure 4.6. Average percent of weekly treatment utilization by trajectory type](image-url)
The regression model revealed characteristics significantly related to children’s treatment utilization trajectory types. Characteristics included identifying as black (p=0.006) and living in a suburban neighborhood (p=0.031), as well as neighborhood affluence (p=0.000) and poverty (p=0.033). The conditional proportions of trajectory type by child and neighborhood characteristics are presented in Table 4.3, and the significant
paired comparisons by these characteristics are presented in Table 4.4. The lowest proportion of black children are High users (3.8%), whereas the highest proportion of black children are Low users (37%). Paired comparisons demonstrate significant differences between Moderate users and Low users (p=0.003) and Low users and High users (p=0.006). Regarding neighborhood characteristics, the highest proportion of children who live in suburban neighborhoods are Low-Moderate users (34.4%) while the lowest proportion are High users (9.5%), average neighborhood poverty among High users is .15 standard deviations below the sample mean, and average neighborhood affluence among High users is .27 standard deviations above the sample mean. Based on paired comparisons, differences between any two trajectory types are not significant based on suburban neighborhoods or poverty in neighborhoods. However, there are significant differences in neighborhood affluence between Low-Moderate and Low users (p=0.006), Moderate and Low users (p=0.000), and Low and High users (p=0.000).
Table 4.3.
*Conditional Proportions of Membership by Trajectory Type (N=807)*

<table>
<thead>
<tr>
<th>Assigned label</th>
<th>Latent Class</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Users</td>
</tr>
<tr>
<td><strong>Class size</strong></td>
<td>0.235</td>
</tr>
<tr>
<td></td>
<td><strong>Conditional proportion</strong></td>
</tr>
<tr>
<td><strong>Child/Family Variables</strong></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Black*</td>
<td>0.370</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0.219</td>
</tr>
<tr>
<td>Other Non-Hispanic</td>
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</tr>
<tr>
<td>Unknown</td>
<td>0.259</td>
</tr>
<tr>
<td>Payment Category</td>
<td></td>
</tr>
<tr>
<td>SSI*</td>
<td>0.318</td>
</tr>
<tr>
<td>Other</td>
<td>0.205</td>
</tr>
<tr>
<td>Female</td>
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</tr>
<tr>
<td>Age Diagnosed</td>
<td>(45.52)</td>
</tr>
<tr>
<td>Age Enrolled</td>
<td>(72.40)</td>
</tr>
<tr>
<td>ABC Score*</td>
<td>(65.48)</td>
</tr>
<tr>
<td>Asperger’s</td>
<td>0.223</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>0.241</td>
</tr>
<tr>
<td>Single Parent</td>
<td>0.290</td>
</tr>
<tr>
<td>Sibling with ASD</td>
<td>0.165</td>
</tr>
<tr>
<td>&gt;2 Children in Hsld</td>
<td>0.251</td>
</tr>
<tr>
<td><strong>Neighborhood Variables</strong></td>
<td></td>
</tr>
<tr>
<td>% White</td>
<td>(64.49)</td>
</tr>
<tr>
<td>Poverty*</td>
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</tr>
<tr>
<td>Affluence*</td>
<td>-0.339</td>
</tr>
<tr>
<td>Rural</td>
<td>0.394</td>
</tr>
<tr>
<td>Suburban*</td>
<td>0.330</td>
</tr>
</tbody>
</table>

*Note:* $p<.05$

Values based on Latent GOLD® 5.1 Step 3 using ML estimation. All rows add to 1 except for continuous variables, which are presented as means. Due to administrative data errors, some children had treatment hours greater than the maximum of 40 hrs./wk. Treatment hours were capped at 40 hrs./wk. In 14 weeks 99% of hours were <=40 hrs./wk, in 30 weeks 99% of hours ranged between 40.25 and 45 hrs./wk, and in the remaining 8 weeks, hours ranged between 45.5 and 49.25 hrs./week.
Table 4.4.  
*Paired Comparisons for Significant Differences Between Trajectory Types (N=807)*

<table>
<thead>
<tr>
<th>Class</th>
<th>Class</th>
<th>Wald</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child/Family Variables</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>Moderate</td>
<td>Low</td>
<td>8.8798</td>
</tr>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
<td>7.6093</td>
</tr>
<tr>
<td>SSI</td>
<td>Low-Moderate</td>
<td>High</td>
<td>8.0365</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>Low</td>
<td>9.4734</td>
</tr>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
<td>9.6556</td>
</tr>
<tr>
<td>ABC Score</td>
<td>Low-Moderate</td>
<td>Moderate</td>
<td>13.6063</td>
</tr>
<tr>
<td></td>
<td>Low-Moderate</td>
<td>High</td>
<td>14.0244</td>
</tr>
<tr>
<td><strong>Neighborhood Variable</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affluence</td>
<td>Low-Moderate</td>
<td>Low</td>
<td>7.4711</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>Low</td>
<td>13.2199</td>
</tr>
<tr>
<td></td>
<td>Low</td>
<td>High</td>
<td>13.4328</td>
</tr>
</tbody>
</table>

Note: *p<.0083  
Values based on Latent GOLD® 5.1 Step 3.

**Discussion**

The current study adds to a modest yet growing body of literature on treatment utilization trajectories in publicly-funded EIBI. Results reveal four treatment utilization trajectory types, and evidence of inequitable access to treatment in South Carolina during the time period examined. Specifically, child race and neighborhood poverty, affluence, and urbanicity are related to children’s assignment to one of four treatment utilization trajectory types. Findings provide necessary insight into distinct types of and disparities in treatment utilization trajectories, highlight the benefit of using person-centered analyses, suggest that an investigation into why these disparities exist is imperative, and provide theoretical contributions to future research.

Overall, our findings provide the first account of distinct types of treatment utilization trajectories in publicly-funded EIBI, as well as document evidence of racial and neighborhood disparities in children’s type of trajectories. These results build on
previous findings in which researchers detected racial and neighborhood disparities in enrollment (Magaña et al., 2013; Shattuck et al., 2009), and racial disparities in the number of weekly hours children with ASD use a range of individual services, including behavioral intervention (Siller et al., 2014). Importantly, however, our findings diverge from the only prior study on treatment utilization trajectories in publicly-funded EIBI. Using the same sample as the current study, Yingling, Hock, and Bell (forthcomingb) estimated conventional growth curve models to examine average treatment utilization trajectories during the first year of treatment. They found no evidence of racial or neighborhood disparities. These contradictory results demonstrate the importance of investigating treatment utilization trajectories using person-centered analyses instead of, or in addition to, variable-centered analyses (Jung & Wickrama, 2008). Because we allowed children to be placed into unique trajectories instead of forcing them to be deviations from the average, we were able to determine the characteristics associated with children’s trajectories. What is more, we examined treatment utilization by month rather than by week. This may also contribute to the difference between the current findings and Yingling, Hock, and Bell’s (forthcomingb) results. It is unlikely that children participate in therapy at least once every week across the first year of treatment. In any given week, children in the current sample use zero hours of treatment. There are countless reasons for this, including holidays, family illnesses, emergencies or vacations, provider cancellations, or other events throughout the year. Thus, examining treatment utilization trajectories by week may not be the ideal approach. It may be more beneficial to measure trajectories by employing a more aggregate measure, such as biweekly or monthly treatment hours used.
Results indicate that the lowest proportion of black children are High users and the highest proportion of black children are Low users. Research on disparities in health care supports this finding and provides potential reasons for why this disparity exists. In a study on the quality of patient-providers interaction among children with ASD and other developmental disabilities, parents’ perceived quality of their interaction with health care providers mediated the relationship between ethnicity and health care utilization (Parish, 2012). Research also indicates that patient-provider racial concordance influences health care utilization (Cooper, Powe, & Fund, 2004; LaVeist, Nuru-Jeter, & Jones, 2003; Stevens, 2003), and it is widely considered to be a root cause of disparities (Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2005; Williams & Mohammed, 2009), whereby racial discrimination “adversely affects patterns of health care utilization and adherence behaviors” (Williams & Sternthal, 2010, p. S21). Notably, African American children are 2.6 times less likely than White children to be diagnosed with ASD on their first visit to a specialist, and when they are not diagnosed on their first visit, they are most often diagnosed with ADHD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2006). Such evidence of bias and discrimination in clinical decision-making raises questions about the presence of racial discrimination in other areas of the ASD service system, including EIBI.

Evidence that the proportion of children who live in affluent neighborhoods is highest among High users while the proportion of children who live in neighborhoods with higher poverty rates is highest among Low users aligns with a handful of studies that examine neighborhood factors rather than the more common focus on individual factors. Research suggests that neighborhoods characterized by socioeconomic disadvantage
experience challenges such as recruiting providers to serve the area (Auchincloss et al., 2001). Kirby and Kaneda (2005) found that even after controlling for individual factors and the supply of providers, neighborhood socioeconomic disadvantage is related to a reduced chance of having a usual source of care and accessing preventive services, as well as an increased likelihood of reporting unmet health needs. In a study on timeliness of provider designation to early intervention in Wisconsin, researchers found that children who lived in low-income neighborhoods and neighborhoods with large Spanish-speaking populations experienced delays. They hypothesized that providers who perceive low income neighborhoods as less desirable work environments contribute to delays (Kim et al., 2009). Similarly, the results of a study on low birth weight eligible 2-year olds in Wisconsin’s EI program indicated that children who lived in socioeconomic disadvantaged neighborhoods were at increased risk of never receiving services (McManus et al., 2013). Yet our findings also complicate the results of other studies. For example, Yingling, Hock, and Bell (forthcomingb) reported no evidence of neighborhood disparities in children’s average treatment utilization trajectories. Likewise, in their examination of early intervention services in Kentucky, Hallam, Rous, Grove, and LoBianco (2009) did not detect a main effect between county poverty and service use. Although the latter did not examine publicly-funded EIBI, the difference in outcome is perhaps due to a difference in measurement. In the present study, we measured poverty as a composite variable at the census-tract level, allowing for significant variability in poverty, whereas Hallam, Rous, Grove, and LoBianco (2009) measured poverty as the poverty rate at the county level.
Surprisingly, the proportion of children who live in suburban (not rural) neighborhoods is less among High users. This relationship is similar to the finding that compared to children who live in urban neighborhoods children who live in suburban (not rural) neighborhoods use 3.34% less of their allotted treatment hours during their first week of publicly-funded EIBI (Yingling, Hock, & Bell, forthcomingb). Conversely, it is in opposition to the finding of the same study that urbanicity does not impact children’s treatment utilization trajectories. As with the relationship between child race and trajectories, the relationships detected in the current study suggest that latent class growth analysis is superior to conventional growth curve modeling. This finding raises questions about the results of prior research on the role of urbanicity in access to services among children with ASD, which is largely characterized by dichotomous measures of urbanicity (e.g., metropolitan versus non-metropolitan, urban versus rural) at the county level. For example, Murphy and Ruble (2012) found that compared to parents who lived in metropolitan counties, parents who lived in non-metropolitan counties were more likely to report difficulties accessing professionals trained in the treatment of ASD. Although the current study investigated a different type of service and defined access differently, results indicate that the application of a more precise measure of urbanicity at the census-tract level (i.e., urban, suburban, and rural) may be more desirable than a dichotomous measure at the county level for detecting relationships. Furthermore, it is possible that a relationship between rural census tracts and treatment utilization trajectory types was not evident because too few children in the current sample live in rural neighborhoods.
Limitations

DDSN data only includes information for South Carolina’s EIBI program. This limits generalizability to other states. Still, as one of the first and largest programs of its kind in one of the most racially diverse, impoverished, and rural states in the nation, research conducted in South Carolina offers an excellent opportunity to inform current and future developments in the provision of EIBI. It is also unknown what percent of hours children received were home- or center-based. While the program requires a minimum of 50% of hours to be home-based, the remaining 50% could be either. Additionally, it is unknown if children received EIBI through private health insurance and/or during their participation in the program. Children who receive EIBI through private insurance coverage while on the PDD wait list may enjoy an established relationship with a provider that facilitates high utilization. The availability of line therapists in a given area is also unclear. Also, latent class growth analysis includes bivariate rather than multivariate analyses, in which there is no ability to control for other variables. Finally, although racial differences in perception of disability and help-seeking patterns are well-documented and could be important factors in treatment utilization, it was not possible to measure them in this study.

Future Research and Policy Recommendations

Study results suggest that even after children are enrolled in treatment, they experience disparities in their utilization of treatment over time. As the provision of EIBI expands exponentially across the United States, future research to identify the underlying causal mechanisms for the presence of racial and neighborhood disparities in treatment utilization is of utmost importance. Such efforts may include investigations into the role
of patient-provider racial concordance, perceived quality of parent-provider and/or child-provider interaction, and racial discrimination, as well as the role of the supply of providers and provider and organizational factors that contribute to less treatment utilization among children who live in neighborhoods with high poverty rates and in suburban neighborhoods. Future work will also need to be expanded to other states to determine if treatment utilization trajectory types are similar to those identified in South Carolina and if racial and neighborhood disparities exist elsewhere. Furthermore, the emphasis on ensuring that children’s treatment utilization is high is the result of evidence that the more hours children use of recommended treatment, the greater their improvement on outcomes will be. It is worthwhile, therefore, to determine if children’s treatment utilization trajectories in publicly-funded EIBI predict short- and long-term outcomes. The fact that the average treatment hours children used in each trajectory type remained relatively stable also suggests that the first several weeks of treatment provide a preview of children’s later treatment utilization. When children’s utilization begins low, this may serve as an early warning system for providers and case managers to deliver additional support.

Findings also suggest that it may be prudent for administrators who oversee the delivery of EIBI to begin a conversation with families and providers about racial and neighborhood differences in treatment utilization. Williams (2005) suggests that one way to reduce health disparities is to improve medical care by taking inventory of patient-provider racial concordance and acting on a need to reduce any underrepresentation of minorities among providers. Other approaches should be explored, implemented, and evaluated.
This study also provides theoretical contributions to research on access to EIBI. We defined realized access as assignment to a treatment utilization trajectory type characterized by high utilization (i.e., 75% to 100% utilization) during the first year of treatment. This is more specific than a prior study on treatment utilization trajectories (Yingling, Hock, & Bell, forthcomingb), which was limited by estimating a single average trajectory. Collectively, these studies demonstrate that there exist different measures of “high” treatment utilization. Dialogue concerning the optimal definition of high treatment utilization is essential. Is it the use of a certain percentage of recommended hours during all weeks of the year? Is it the use of a certain percentage of recommended hours for 48 of 52 weeks out of the year? Answers to these questions are central to future efforts to identify and reduce disparities.
CHAPTER 5
CONCLUSION

The results of this dissertation offer the first in-depth account of access to publicly-funded EIBI among children with ASD in the United States. Specifically, findings suggest that the impact of race and place on access to EIBI varies depending upon the conceptualization and operationalization of access. Evidence indicates that there are not disparities in the time-lag between diagnosis and treatment onset, and although findings point to disparities in the percent of allotted treatment hours children use during their first week of treatment, that there are not disparities in children’s treatment utilization trajectories. On the other hand, results demonstrate that there are four types of treatment utilization trajectories, and that there are racial and neighborhood disparities in children’s assignment to trajectory types. Collectively, these findings highlight critical areas for future research, underscore the importance of investigating multiple indicators of access, offer theoretical contributions to research in this field, and provide insight into implications for the provision of publicly-funded EIBI for children with ASD, as well as for social work practice.

Results of the first study suggest that time-lag is not related to child race, that neighborhood racial composition, poverty, affluence, and urbanicity are not related to time-lag, and that the relationship between child race and time-lag does not vary by these neighborhood characteristics. These findings are contrary to previous literature on access to publicly-funded EIBI, in which researchers investigated disparities in enrollment
(Magaña et al., 2013; Shattuck et al., 2009). Clearly, enrollment and time-lag are very different indicators of access. It is possible, therefore, that children experience disparities in enrollment but not in time-lag, suggesting the need to broaden the research agenda on access to publicly-funded EIBI by examining indicators of access that capture the complex, longitudinal nature of access before, during, and after enrollment. Importantly, findings also indicate that an average of 1041 days – or nearly three years – lapse between a child’s diagnosis and initial therapy session, and that it takes the average parent nearly one year (i.e., 333 days) to contact a publicly-funded EIBI program to request that their child’s name be placed on a wait list. This time-lag is counterintuitive to the urgency placed on providing EIBI to children as early as possible and justifies future research that explores the underlying causal mechanisms for this extensive time-lag.

The findings of the second and third studies are contradictory, yet highly informative and complimentary. Although results of the second study provide evidence of disparities in treatment utilization during the first week of treatment, they indicate that there is no relationship between child race and treatment utilization trajectories, that neighborhood racial composition, poverty, affluence, and urbanicity are not related to treatment utilization trajectories, and that the relationship between child race and treatment utilization trajectories does not vary by these neighborhood characteristics. Interestingly, the third study does provide evidence of disparities in treatment utilization trajectories, in which child race and neighborhood poverty, affluence, and urbanicity are characteristics related to children’s assignment to one of four treatment utilization trajectory types. Not only do these mixed findings further support the necessity of examining multiple indicators of access to publicly-funded EIBI, they also demonstrate
the benefit of using person-centered analyses (e.g., latent class growth analysis) instead of, or in addition to, variable-centered analyses (e.g., conventional growth modeling) in future research.

Together, studies two and three demonstrate that a majority of children use a low to moderate percent of their allotted treatment hours. Study two reveals that on average, children use 24.6% of their allotted hours during their first week of treatment. Despite an acceleration in treatment utilization during the first 10 weeks of treatment, children plateau and use between 37% and 44% of treatment hours for the remainder of the year. In study three, the smallest proportion of children (10.9%) were High users characterized by 75% to 100% of treatment hours used, and the highest proportion of children were Low-Moderate users characterized by 25% to <50% of treatment hours used. Low treatment utilization among a majority of children in the sample, as well as lower treatment utilization among black children, children who live in suburban neighborhoods, and children who live in neighborhoods with higher poverty rates is concerning. Indeed, low treatment utilization among these sub-groups and in general requires immediate exploration. Furthermore, given the current evidence-based recommendation of high treatment utilization (i.e., more weekly hours), it is important for researchers to determine if children’s treatment utilization trajectories in publicly-funded EIBI predict short- and/or long-term child outcomes. It is also necessary to examine treatment utilization trajectories beyond the first year of treatment.

**Conceptualization and Operationalization of Access**

As demonstrated by the findings of this dissertation, the conceptualization and operationalization of access to publicly-funded EIBI yields varying results. These results
have significant implications for how access is defined and measured in future research. Collectively, results of the three studies offer insight into the application of the BMHSU in research on access to EIBI and provide an overall contribution to the BMHSU.

Applying the strict definition of realized access within the BMHSU, in all three studies, all children realized access to some degree. However, realized access to EIBI is more complex than common measures of health care access (e.g., health insurance coverage, having a regular primary care provider). An investigation into disparities within the BMHSU framework, therefore, required the development of distinct definitions of realized access grounded in EIBI literature. What remains unclear is the optimal definitions of realized access in this context.

In addition to defining realized access in EIBI, this dissertation provides insight into predisposing social characteristics of realized access. Results of the first study suggest that there are not racial or neighborhood disparities in time-lag between diagnosis and treatment onset. Evidence that child race and neighborhood racial composition, poverty, affluence, and urbanicity are not predisposing social characteristics to EIBI is in conflict with the underlying assumptions of the BMHSU. It is possible that evidence was not found because disparities simply do not exist. However, there are at least two additional explanations to consider. First, once diagnosed, predisposing social characteristics that influence children’s time-lag but were not included in this dissertation (e.g., provider shortages in particular areas not captured by measures of urbanicity, parental health literacy, parental employment), and which would require different research methods to examine, may be more important than racial and neighborhood characteristics. Second, the SC PDD Program does not exist in a vacuum. It is connected

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to other services for children with ASD in the state, such as the statewide early intervention program and a state network of ASD diagnosticians. Considering evidence that indicates the presence of disparities in children’s age of diagnosis, it is possible that disparities in access to EIBI are frontloaded prior to diagnosis. A key question to ask, therefore, is whether the predisposing social characteristics of access to a diagnosis are subsequently subsumed by a child’s age of diagnosis. If so, instead of social characteristics predisposing time-lag between diagnosis and treatment onset, they would have a lasting, cumulative effect that originated pre-diagnosis and their impact experienced through a child’s age of diagnosis. This latter possibility connects directly with the justification for the first study in this dissertation. That is, there is a consensus that age of diagnosis is important because the earlier children are diagnosed, the earlier they can enter treatment, and research indicates that children make more gains the earlier they enter treatment. Thus, do the results of the first study, which show that age of diagnosis explains the largest percentage of variability in time-lag between diagnosis and treatment onset, add urgency to the need to reduce disparities pre-diagnosis so that children have equitable access to their “ticket” (i.e., diagnosis) to EIBI? In other words, is age of diagnosis currently a predisposing social characteristic of the timely onset of EIBI?

To complicate the proposition that age of diagnosis is a predisposing social characteristic, in the second study age of enrollment, not age of diagnosis, was a significant predictor of treatment utilization at Week 1, and in the third study neither age of diagnosis nor age of enrollment were associated with trajectory type (although the average age of diagnosis in months for the High users was approximately 3 months less
than the other three types). Contrary to the first and second studies, although age of diagnosis was not significant, child race and neighborhood poverty, affluence, and urbanicity were related to trajectory type. It is possible, then, that age of diagnosis is a predisposing social characteristic that impacts time to treatment onset but not treatment utilization. Moreover, because the third study includes bivariate regression rather than multivariate regression, the difference in significant relationships between age of diagnosis and access between studies is noteworthy and worth exploring further.

Overall, the results of this dissertation suggest that the predisposing social characteristics of children’s realized access depend on the point at which children are participating in the service system (e.g., pre-diagnosis, post-diagnosis, between diagnosis and treatment onset, treatment enrollment, utilization of treatment at Week 1, utilization of treatment during a certain time period). This suggests that there are different points in the system at which to intervene as well as different predisposing social characteristics to focus on depending upon the point of intervention. It is desirable, therefore, that any model of access to EIBI also capture the multiple dimensions of access and the multiple systems through which children chronologically and simultaneously proceed. Currently, the BMHSU depicts access as the “use of health services” under the “health behaviors” domain. This makes more sense when researching more traditional health services use, such as emergency room visits. However, in the case of EIBI, in which multiple systems and definitions of access are interconnected, the conceptualization is more complex. There is a benefit to capturing how access at one point (e.g., diagnosis) impacts access at a simultaneous or subsequent point (e.g., time-lag to EIBI). Accordingly, there might be value in integrating other theoretical frameworks, such as the life-course perspective,
with the BMHSU. Furthermore, particularly given social work’s dedication to social justice, which is a goal of the BMHSU, the profession’s focus on multiple levels of predisposing social factors (i.e., individual and contextual), and its long history with facilitating the coordination of health services, these conceptual challenges are pertinent to social work, and social work theorists are well-suited to tackle them.

In a systematic review of empirical studies that use the BMHSU as a guiding framework, Babitsch, Gohl, and von Lengerke (2012) determined that although the model is multilevel and complex in nature, most researchers that employ the model do not use advanced statistical methods. This dissertation adds to the BMHSU literature by using complex research methods in the second and third studies, or two-level growth curve models and latent class growth analysis, respectively. The reviewers also advocate for researchers to include a broader range of factors that impact health services use, rather than or in addition to those most commonly used (i.e., age, gender/sex, education, and ethnicity). By using a variety of child, family, and neighborhood variables, and by testing individual and contextual variables concurrently, this dissertation answered this call.

However, this dissertation includes at least two limitations relevant to the BMHSU. First, similar to existing research in which the BMHSU is applied, this dissertation was limited by the variables available in administrative data. Therefore, it was not possible to examine how other factors, such as those in the health behavior domain (e.g., provider quality or provider-child relationship) impact access. Second, the original intent of this dissertation was to use two-level organizational models in the first study (i.e., children nested in neighborhoods) and three-level growth curve models in the second study (i.e., time nested in children nested in neighborhoods), thereby conducting a true multilevel
study as promoted by the BMHSU. However, the high number of census tracts populated by singletons required the use of ordinary least squares regression and two-level growth curve models. Despite the importance of using multilevel models, the optimal geographic measure for this line of inquiry is a serious consideration for future research on a relatively small population, or children with ASD. I selected census tracts instead of block groups because I was confident there would be too many singletons at the block group level, and I selected census tracts instead of counties to more precisely measure racial composition, poverty, affluence, and urbanicity. Given the constraints of low density experienced in while conducting this dissertation, and considering that block groups are a more precise measure of a child’s neighborhood, it might be more beneficial to use block groups in contextual models in future research that includes examining
neighborhood disparities among children with ASD.

**Implications for Social Work Practice**

The findings of this dissertation have important implications for social workers involved in the provision of publicly-funded EIBI for children with ASD. For example, there are several key takeaways regarding data collection. First, that treatment utilization trajectories in study three remained relatively stable suggests that the first several weeks of treatment provide a preview of children’s later treatment utilization. Therefore, when children’s utilization begins low, this may serve as an early warning system for social workers to deliver additional support. In South Carolina’s program, case managers provide one hour of case management per month. This is a time in which they can assess the need for and provide assistance. Also, as demonstrated in this dissertation, there is a need to enhance the collection of demographic data, especially race and ethnicity. Current
research provides guidance in this area. In a study on hospital patients, although 93% of respondents reported that it is critical to conduct studies that ensure equitable care irrespective of race or ethnicity, and 80% of respondents reported that it is important to track race and ethnicity, 31% expressed concern that the information could be used to discriminate against patients (Baker et al., 2005). Results of a study by Hasnain-Wynia, Taylor-Clark, and Anise (2010) indicate that a solution to this perception is to clearly communicate through various mediums the reason for requesting patients’ race and ethnicity. In particular, a majority of study participants were most receptive the statement, “race/ethnicity information is being collected to ensure that everyone gets high-quality care” (2010, p. 378). Adopting this approach when case managers collect information on children and parents could prove useful to future data collection efforts in publicly-funded EIBI. Also related to data collection, in 2015 South Carolina eradicated the PDD Program wait list because the state is in the process of transferring the delivery of EIBI from its HCBS Medicaid waiver to its Medicaid state plan. As South Carolina and dozens of other states provide EIBI through Medicaid, it is important to designate how to capture when children first make contact with the EIBI service system. As the service expands to more states, it is worth discussing the potential benefits and feasibility of a coordinated effort by state administrators to collect similar data across states. Ideally, this data would not only include child data, but family, provider, and organizational data as well. Social workers have an obligation to ensure that data collection maximizes children’s treatment utilization, and that parents fully understand why data is collected, for only when data is collected and analyzed can disparities be detected and social justice be realized.
Results suggest that on average, children experience a time-lag between diagnosis and treatment onset of nearly three years (i.e., 1041 days), including a time-lag between diagnosis and being placed on a wait list of nearly one year (i.e., 333 days). Recognizing the need for a solution to reduce this time-lag, in 2012 SC DDSN implemented a strategy for children to bypass the PDD Program wait list if they were diagnosed before their third birthday and received EIBI at least 30 days prior to their third birthday. There is a need for social workers to promote such efforts to reduce this time-lag and to evaluate the effectiveness of these efforts. Also highly relevant to social work practice is that most children use a low to moderate percent of their allotted treatment hours during the first year, and that there is evidence of disparities in treatment utilization trajectory types. These findings highlight an opportunity for social workers to lead an effort in communicating with families and providers about why children use so few treatment hours and why racial and neighborhood disparities were detected. Through conversations with families and providers, social workers can determine how to improve treatment utilization, and ultimately, child outcomes. Regarding racial disparities, for example, Williams (2006) suggests that one way to reduce health care disparities is to improve care by ensuring patient-provider racial concordance. Social workers can play a key role in identifying and implementing such improvements.

Limitations

Several key limitations should be considered when interpreting significant findings and undetected relationships. At the broadest level, DDSN data only includes information for South Carolina’s EIBI program, which limits generalizability to other states. In the first study, the sample did not include children who were placed on a wait
list but never enrolled in the program. There is no way to determine if the children who never enrolled are qualitatively different from children who did. Limitations of administrative data are also evident, especially apparent data entry errors that required the use of winsorizing outcome variables and the high number of children in the *unknown* racial category. Compared to the racial distribution in South Carolina, black and white children are underrepresented in the sample. It is likely that many of the children in the *unknown* category are one or the other. It is also unknown what percent of hours children received were home- or center-based. While the program requires a minimum of 50% of hours to be home-based, the remaining 50% could be either. Additionally, it is unknown if children received EIBI through private health insurance before and/or during their participation in the program. Children with private insurance coverage on the SC PDD wait list and at the time of enrollment in the program may enjoy an established relationship with a provider that facilitates high utilization. The availability of line therapists in a given area is also unclear. In the third study, although latent class growth analysis is a stronger, more policy-relevant method, the downside to bivariate associations is the inability to control for other variables. Furthermore, although racial differences in perception of disability and help-seeking patterns are well-documented and could be important factors in treatment utilization, it was not possible to measure them in this study
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