March 2021

Do Black Girls Receive Later Developmental Disability Diagnoses?: Results from a National Study of Children in the United States

Danequa Forrest

DO BLACK GIRLS RECEIVE LATER DEVELOPMENTAL DISABILITY DIAGNOSES?: RESULTS FROM A NATIONAL STUDY OF CHILDREN IN THE UNITED STATES

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

In

The Department of Sociology

by
Danequa Forrest
B.A., University of Texas at San Antonio, 2015
M.A., Louisiana State University, 2018
May 2021

This dissertation is dedicated to all of the wonderful people who supported and inspired me to complete this work. Austin Forrest, Cookie & Ronell McCray, Brei Noel, Annie Robertson, Sabrina Williamson, Cliff Straughn, Kiana Williamson, Tamia Johnson, Royal & Shirley Noel, Roosevelt Norris Jr. & Viola Norris, Carolyn McCray, Kelsey & Robert Perkins, Kayla & Corie Abadie, Aranisha Longoria, Lori Martin, Ifeyinwa Davis, Maretta McDonald, Alana Peck, John Aggrey, Mahalia Crawford, Caitlin Charles, Dominique Dillard, and Kami Rutherford.

And of course, to the two who sparked my research interests: G.M. and J.D.

Thank you all for making this a beautiful journey.

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Abstract

This study sought to analyze if age at diagnosis of autism spectrum disorder, intellectual disability, and developmental delay varies by race and sex for children between ages 6 and 17 years old. I used data from the 2011 Survey of Pathways to Diagnosis and Services ("Pathways"), a follow-up survey to the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). With this nationally representative dataset, I was able to perform ordinary least squares linear regression in Stata 13. Results determined that Black girls were diagnosed with autism spectrum disorder about two years later than White girls, nearly three years later than Hispanic girls, and a little over two years later than Other-race girls. Black girls with intellectual disability were diagnosed over two years later than White girls. Implications and theories are discussed.

Introduction

Age at diagnosis of developmental disabilities, which include autism spectrum disorder, intellectual disability, and developmental delay, is important for receiving early treatment intervention and better life outcomes (Landa, 2008; Rogers & Vismara, 2008). Recent paradigms for understanding disability have veered away from the purely medical model. Rather, a socioecological model has redefined the experiences of disability as a function of social and structural impairments (Nagi, 1991; Pledger, 2003; Pope & Brandt Jr, 1997). Applying this model has led scholars to uncover cultural narratives of disability, such as that people with disabilities are frequently viewed as deficient, irrational, and that there is something *wrong* with them. This matters for age at diagnosis because recognizing and breaking these harmful cultural narratives starts with early diagnosis. Understanding a person's disability or disorder helps therapists and others provide those diagnosed with the tools they need to socially function, avoid or stop discrimination, and live a fulfilled life. While these cultural scripts are predominately applied to people with physical disabilities, people with developmental disabilities also suffer from negative narratives, as well as the burden of having to prove the legitimacy of their disability due to it being non-physical and, for some people, invisible. For children, this burden primarily falls to their parents who have the responsibility of advocating on behalf of their child. Parents of children with developmental disabilities have come to realize the negative scripts that will be used against their children. For example, people with developmental disabilities are often accused of using their condition to avoid working hard and are judged as being less intelligent (Beilke & Yssel, 1999; Kruse, Elacqua, & Rapaport, 1998). However, similar to light-skinned Black people (Hooks, 2000), or non-open LGBTQ people (Harper, 2005; Sherry, 2004), people with developmental disabilities could potentially "pass" and evade some discrimination. Overall,

research has indicated the following factors to be associated with higher age at diagnosis of developmental disabilities: being a Black child (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012), being a girl (Giarelli et al., 2010), having low SES (Fountain, King, & Bearman, 2011; Mandell et al., 2010; Mandell, Novak, & Zubritsky, 2005; Mazurek et al., 2014), living in rural areas (Mandell et al., 2005; Ouellette-Kuntz et al., 2009), being older (Mazurek et al., 2014), having less noticeable symptoms, such as oversensitivity to pain (Mandell et al., 2005; Mazurek et al., 2014), having multiple primary care doctors as opposed to one specialist (Mandell et al., 2005), and having a higher I.Q. (Mazurek et al., 2014).

The present research involves the relationship between age at diagnosis of developmental disabilities and race by sex differences, which depend on socioeconomic resources and the role of power and oppression within cultural narratives. The cultural narratives of developmental disabilities are exacerbated by race and vary across identities (Charlton, 2000; Fine & Asch, 2009; Stuart, 1992; Vernon, 1999). For example, having a disability can isolate people from their racial group, and being a racial minority can isolate people from others with disabilities (Stuart, 1992; Vernon, 1999). Racial minorities with disabilities face discrimination from multiple sources and find it difficult to overcome negative stereotypes associated with either identity (Block, Balcazar, & Keys, 2001). This may be less severe for people with developmental disabilities because it is often not a "visible" disability. However, parents of children with developmental disabilities may feel forced to choose between social support for racial discrimination or social support for their child's disability, similar to how Black queer people feel as though they must choose between these two sources of social support (Harper, 2005).

Being a racial minority with dual identities is not new. Parents' perceptions of their child's dual identities might make them particularly aware of the difficulties their child will face as they age. As Hooks (2000) explained, Black women have dealt with the frustration of being both a sex minority and a racial minority, particularly during the civil rights movement. This sociological use of "minority" refers to having relative disadvantage compared to the dominant social group (Healey, Stepnick, & O'Brien, 2018). McDonald, Keys, and Balcazar (2007) found developmental disabilities come with the assumption of low intelligence, as well as illegitimacy and worthlessness. Furthermore, racial narratives are relevant for people with developmental disabilities, and they are filled with stories of people needing to remove themselves from oppressive environments and reframe dominant cultural narratives to turn discouragement into motivation (McDonald, Keys, & Balcazar, 2007). Black exceptionalism is a phenomenon in which other racial groups assimilate into the White majority more easily than Black people (Kroeger & Williams, 2011). According to Black exceptionalism, these racial narratives are expected to vary not just between Black people and White people, but generally between Black people and non-Black people (Gans, 2005; Lee, 2008; Lee & Bean, 2007). This is because as non-Black people assimilate into mainstream White America, Black people and White people continue maintaining social distance. Therefore, the present study expects to find differences between Black people and both Whites and those of other-racial/ethnic identities.

Age at diagnosis of developmental disabilities varies by sex and race, both individually and intersectionally. A Scottish study on 150 children with autism spectrum disorder found girls had delayed diagnosis compared to boys (Rutherford et al., 2016). A similar study performed in the Netherlands with 2,275 children confirmed the same results (Begeer et al., 2013). In Australia, 152 girls and boys with ASD were surveyed, and the authors found that girls were

diagnosed later than boys, and girls presented symptoms differently (Hiller, Young, & Weber, 2016). Furthermore, Kreiser and White (2014) argued ASD diagnosis may be under identified in females due to sociocultural differences in symptom manifestation. Sociocultural differences for girls include less displays of stereotyped and repetitive behaviors as well as more internalization of symptoms (Kreiser & White, 2014), which could also explain delayed diagnosis in females. While there is less research on sex differences in age at diagnosis of intellectual disability and developmental delay, studying sex disparities for all developmental disabilities is important for early age at diagnosis and developing sex-specific indicators and interventions (Thompson, Caruso, & Ellerbeck, 2003). When applying a feminist intersectional paradigm to health disparities (Schulz & Mullings, 2006), I expect race variations in age at diagnosis of developmental disabilities to differ by sex. Race, when viewed on its own in health puts Black and Hispanic children at a disadvantage, as they are diagnosed with ASD later than White children (Fountain et al., 2011). Examining race by sex through the lens of Black feminism, as detailed by Patricia Hill Collins, reveals the experiences of Black women and girls are exacerbated by both racism and sexism in an intersectional way (Collins, 2002).

Research Aims

This research considers whether age at diagnosis of developmental disabilities varies across racial groups and by sex. Three questions guided this investigation:

1) Are there racial differences in age at diagnosis of autism spectrum disorder (ASD), intellectual disability (ID), and developmental delay (DD)?
2) Are there racial differences in age at diagnosis of ASD, ID, and DD among girls?
3) Are there racial differences in age at diagnosis of ASD, ID, and DD among boys?

Literature Review

The three developmental disabilities examined in this dissertation are autism spectrum disorder (ASD), intellectual disability (ID), and developmental delay (DD). They were selected because ASD and ID are the two most common non-physical developmental disabilities, and DD is the most common diagnosis that children with non-physical developmental disabilities receive until they get older and can be more accurately diagnosed with ASD or ID. While they are all equally important to the analyses, there has been far more research related to ASD than ID or DD, and this is reflected in the literature. While reading through this general review, bear in mind the present research will contribute to expanding the literature on diagnosis of ASD, as well as the underrepresented research on ID and DD.

Autism spectrum disorders include autism, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. PDD-NOS and Asperger syndrome are older designations from the Diagnostic and Statistical Manual of Mental Disorders, or DSM-4 for short. Under the DSM-5, these designations are all under the umbrella term of autism spectrum disorder (ASD), but professionals may still use these older terms when speaking of a child diagnosed prior to 2013. All of the children in the present study were diagnosed before 2013. ASD encompasses neurodevelopmental disorders defined by difficulties in social functioning and communication, often paired by repetitive and stereotyped behaviors (APA, 2013). The age at diagnosis of ASD averages between 3 to 6 years, but observational research shows early diagnosis and treatment of ASD leads to better outcomes than those who receive later diagnosis and treatment (Rogers & Vismara, 2008), such as greater likelihood of behavioral therapy retention and improved quality of life. While much about ASD remains unknown, what we do know is that it is not linked to the measles, mumps, or rubella vaccine (Taylor et al.,

1999). Some of the key findings of current research are: 1) Early signs of ASD include limited social skills and engagement, small range of gestures and forms of communication, and repetitive behaviors; 2) Siblings of children with ASD should be followed closely for signs of ASD, especially because ASD is known to have genetic links; 3) Diagnosis of ASD can be possible soon after 1 year of age, but the diagnosis can be unstable for up to 1/3 of those diagnosed before 30 months; and 4) Early intervention can lead to improved social skills, communication, language, play, and cognitive functioning (Landa, 2008). The fourth finding is particularly relevant to my research because early age at diagnosis can lead to earlier intensive interventions that are developmentally appropriate.

Because early diagnosis of autism spectrum disorder (ASD) is critical for early intervention and successful behavioral therapies, Mandell, Novak, and Zubritsky (2005) attempted to identify factors associated with age at diagnosis of ASD. Using a sample of 969 guardians of children with ASD in Pennsylvania, they performed linear regression to identify significant characteristics and demographics. They found the average age of diagnosis was 3.1 years for children with autism, 3.9 years for pervasive developmental disorder not otherwise specified, and 7.2 years for Asperger's syndrome. As stated earlier, all three of these developmental disabilities are now categorized under the same umbrella term of autism spectrum disorder, but during Mandell, Novak, and Zubritsky's (2005) study they were separate. Low SES children, and children with an oversensitivity to pain had a higher age at diagnosis of ASD than their counterparts. Also, children in rural areas received a later diagnosis, a finding supported by Ouellette-Kuntz and colleagues (2009) during their study on 769 Canadian children diagnosed with autism between 1997 and 2005. Their results suggest geography influences age at diagnosis, giving reason for special controls to be incorporated in age at diagnosis research (Ouellette-

Kuntz et al., 2009). Alternatively, children with severe language deficits or overtly visual symptoms, such as hand flapping, toe walking, and sustained odd play, were associated with an earlier age at diagnosis (Mandell et al., 2005). More recent research supports the claim of lower levels of noticeable ASD symptoms being associated with delayed diagnosis of ASD, along with lower SES, higher I.Q., and older current age (Mazurek et al., 2014). Additionally, children who had multiple primary care doctors received a later diagnosis compared to children who were referred to a specialist (Mandell et al., 2005). The present research will add to these existing findings by focusing ASD diagnosis timing differences by race and sex, using nationally representative data while controlling for a variety of background characteristics.

Geography is also important because while the age at diagnosis of ASD has not decreased overall in the UK (Brett, Warnell, McConachie, & Parr, 2016), it did in California (Hertz-Picciotto & Delwiche, 2009). Hertz-Picciotto and Delwiche (2009) sought to ascertain whether the rise of autism in California throughout the 1990's was due to the decrease in age at diagnosis or inclusion of milder cases. Using the California Department of Developmental Services, they identified autism cases from 1990 to 2006 and found earlier age at diagnosis explained a 12% increase in the prevalence of autism, and inclusion of milder cases explained a 56% increase. While earlier ages at diagnosis, inclusion of milder cases, and changes in diagnostic criteria do not fully explain the increase in autism prevalence, the authors identified another reason for age at diagnosis to be further researched. Similar to Hertz-Picciotto and Delwiche (2009), Fountain, King, and Bearman (2011) used a California sample to identify characteristics associated with age at diagnosis of autism. They analyzed 17,185 children enrolled with the California Department of Developmental Services between 1992 and 2001 using a multilevel strategy to examine both individual and community-level factors across 10 birth cohorts. Age at diagnosis

was earlier for children with highly educated parents, and there was a persistent gap between high and low SES children (Fountain et al., 2011). Fountain and Colleagues (2011) also found the age at diagnosis of ASD was later for Black and Hispanic children.

Intellectual disability (previously termed "mental retardation") is defined by cognitive deficits, usually measured with an IQ score of less than 70, which is two standard deviations below the mean of 100 in a population. It is also characterized by limitations in functional and adaptive skills to carry out age-appropriate daily activities. The DSM-5 diagnosed intellectual disability based on three criteria: 1) Limitations in intellectual apprehension, such as reasoning, problem solving, academic learning, abstract thinking, or ability to judge a situation and learn from experience; 2) Lack of social conformity, independence, and ability to meet sociocultural standards. And 3) The presence of these deficits during childhood (APA, 2013). Later diagnosis of intellectual disability leads to later intervention and support, thus reducing the benefits that intervention and support can offer.

Developmental delay (previously known as "Mental Retardation, Severity Unspecified") is defined in the DSM-5 as a neurodevelopmental disorder that is usually accompanied by delays in milestones like speech and language, motor functions, cognition, and social understanding (APA, 2013). Often, developmental delay is a temporary diagnosis for children who are unable to take IQ tests. Once they are old enough to undergo evaluation, many children diagnosed with developmental delay later meet the criteria for intellectual disability (APA, 2013).

Age at diagnosis of intellectual disability and developmental delay is influenced by similar factors as ASD, but they have different percentages of prevalence. While there is not as much research on factors related specifically to age at diagnosis of intellectual disability or developmental delay, I expect them to be influenced by similar factors as one another along with

ASD because of the common co-occurrence of ASD with ID and DD, as well as the fact that DD is often a temporary diagnosis until the child is old enough to be diagnosed with ID (APA, 2013). Zablotsky and colleagues (2017) found from 2014 – 2016, the prevalence of children between 3 and 17 years old diagnosed with a developmental disability increased from 5.76% to 6.99%. However, during the same time period, the number of children diagnosed with ASD and intellectual disability did not significantly change (Zablotsky, Black, & Blumberg, 2017). As for comorbidities, anxiety and depression have been linked to diagnosis of ASD (Strang et al., 2012), intellectual disability (Holden & Gitlesen, 2004), and developmental delay (Gotham, Brunwasser, & Lord, 2015), and early diagnosis is important for obtaining treatment of both, which improves developmental potential (Kim & Sung, 2007).

Race

Previously, Mandell and colleagues (2002) also found race to have significant implications for age at diagnosis of ASD. The authors used linear regression to study the association between race, age at diagnosis of autistic disorder, time in mental health treatment, and number of visits until the diagnosis was made among 406 Medicaid-eligible Philadelphia children with claims from 1993-1999. The sample being Medicaid-eligible is important because later, Mandell and colleagues (2010) find that children who were eligible for Medicaid through the disability category are diagnosed later than other children (Mandell et al., 2010). Within the Medicaid-eligible sample, White children received an autistic disorder diagnosis at an average of 6.3 years of age, compared to 7.9 years for Black children (Mandell et al., 2002). Black children also required more time in treatment before receiving their diagnosis. Racial disparities in early detection and treatment of autism could be due to differences in help-seeking, physician behaviors, and advocacy and support from social institutions (Mandell et al., 2002), such as the

government, education system, and economy. These findings are particularly relevant to the current research because I also expect race to play a role in the age at diagnosis of ASD in children at the national level, not just Philadelphia. Additional research confirmed these trends. Using logistic regression with random effects for site on a sample of 2,568 children aged 8 years, Mandell (2009) also found Black, Hispanic, and Other-Race children were less likely than White children to have a documented ASD diagnosis. This stratification existed for Black children, regardless of IQ, and was concentrated for Other-Race children who met the criteria for intellectual disability (Mandell et al., 2009). Furthermore, Valicenti-McDermott and colleagues' (2012) more recent research supports the earlier work of Mandell et al. (2002). Black, Hispanic, foreign-born, and children born to foreign mothers were more likely to be diagnosed with autism later than their White counterparts (Valicenti-McDermott et al., 2012).

Intellectual disability and developmental delay intersect with race in a multitude of ways. One such intersection is the ability, or lack thereof, to "pass." Passing usually refers to one's ability to appear or "pass" as White. However, it is also related to developmental disabilities and the ability to pass as neurotypical depending on the severity of the symptoms. Being a passing individual, whether by race, neurotypicality, or both, affects identity and social categorization (Reid & Student, 2013), thus influencing the social factors associated with age at diagnosis of intellectual disability and developmental delay. For instance, early age at diagnosis of intellectual disability or developmental delay can help people pass as nondisabled, which lessens discrimination from within racial and ethnic groups (McDonald et al., 2007). The most powerful acts of resistance against internalizing oppressive cultural narratives around race and developmental disabilities include removing one's self from oppressive environments and reframing the dominant cultural narratives (McDonald et al., 2007). This can mean removing

validation from negative narratives, using those negative narratives to motivate, and promoting positive self-talk. Negative narratives also vary based on the developmental disability. In adults, Black individuals with intellectual disability are more likely to be described as displaying "challenging behaviors," as compared to their White counterparts (Horovitz, Matson, Hattier, Tureck, & Bamburg, 2013).

Sex

My research examines both race and sex as having significant influences over age at diagnosis of developmental disabilities. Within autism spectrum disorder, boys are frequently studied because they are more likely to be diagnosed with ASD (CDC, 2014). Giarelli and colleagues (2010) used a sample of 2,568 children born in 1994 who were identified as having ASD by the Autism and Developmental Disabilities Monitoring Network for ASD surveillance. Their findings reinforced prior research indicating boys being more likely to be diagnosed with ASD. However, they also found that girls had a higher age at diagnosis than boys, especially if the girls did not have a cognitive impairment. While girls were more likely to have seizure-like behavior, boys were more likely to be identified as having hyperactivity, a short attention span, and aggression (Giarelli et al., 2010).

Intellectual disability and developmental delay intersect with sex through their dominant cultural narratives. Having a developmental disability minimizes positive sex expectations and amplifies negatives ones (McDonald et al., 2007). This is due to the negative cultural narratives surrounding intellectual disability and developmental delay – that they are perceived as having an illegitimate impairment and being socially unworthy with lower intellectual abilities (McDonald et al., 2007). Typically, in studies of intellectual disability or developmental delay and sex, boys are focused on because they have a higher prevalence of both (Zablotsky et al.,

2017). However, I felt this was all the more reason to examine factors related to girls and developmental disabilities. Furthermore, girls with developmental delay and girls with ASD were predicted to have greater increases over time in anxiety and depressive symptoms than their male counterparts (Gotham et al., 2015).

Both racial and sex narratives are important for individuals with developmental disabilities (McDonald et al., 2007). Autism spectrum disorder, intellectual disability, developmental delay, race, and sex are not monolithic constructs that can be interrogated on their own. Rather, they are intersectional and complex entities which need to be examined in conjunctions and with consideration of one another (Ben-Moshe & Magaña, 2014).

Intersections of Race and Sex

I am examining age at diagnosis of developmental disabilities across race by sex because prior research has indicated health outcomes vary by this intersection (Schulz & Mullings, 2006). Across health, opportunities are stratified by race and sex due to an unequal distribution of wealth, power, and privilege – which creates multiple dimensions of disadvantage, particularly for Black women (Zamani-Gallaher & Polite, 2013). Due to barriers of race, sex, and socioeconomic status, Black women suffer more on particular health outcomes compared to other groups (Zamani-Gallaher & Polite, 2013). Black people experience higher rates of most physical health morbidities than White people (Brown, O'Rand, & Adkins, 2012; Williams & Mohammed, 2013), and women have more nonfatal health problems than men, despite having lower mortality rates (Bird & Rieker, 2008; Read & Gorman, 2010). Specifically, Black women's experience of simultaneous racism and sexism – or gendered racism (Essed, 1991) – is related to negative mental health, such as greater psychological distress (Lewis & Neville, 2015; Thomas, Witherspoon, & Speight, 2008; Woods, Buchanan, & Settles, 2009) and negative

physical health, such as shorter telomere length, which is a biomarker of premature morbidity and mortality related to stress (Lu et al., 2019). Brown and Colleagues (2016) used panel data from the Health and Retirement Study (N=12,976) to examine racial-ethnic health outcomes by gender and socioeconomic status. Supporting an intersectional perspective, they found self-rated health differences between racial-ethnic groups were greatest among women, and Black and Mexican-American women experienced fewer health returns to SES resources (Brown, Richardson, Hargrove, & Thomas, 2016) than their White counterparts. The present research applies the perspective of intersectionality, which is informed by Black feminism (Collins, 2002), and critical feminist theories (Few, 2007). The perspective of intersectionality posits that Black women are especially disadvantaged due to dimensions of inequality being multiplicative, not additive (Choo & Ferree, 2010; Collins, 2002; Hinze, Lin, & Andersson, 2012). Being both Black and a woman multiplies inequality, and the health impacts of this dual identity must take into consideration both race and sex. Intersectionality of race and sex is simultaneous, interactive, and interlocking (Ailshire & House, 2011; Brown & Hargrove, 2013; Dill & Zambrana, 2009; Landry, 2007). Consistent with the intersectional perspective, many studies found the racial inequality in non-life-threatening physical health outcomes was worse with women than men, indicating a multiplicative interaction (Brown & Hargrove, 2013; Hayward, Miles, Crimmins, & Yang, 2000; Umberson, Williams, Thomas, Liu, & Thomeer, 2014).

While there is much research on intersectionality and health outcomes for Black women, there is less for Black girls – especially for Black girls with developmental disabilities. Unfamiliarity with Black culture has led to misinterpretations and misunderstandings between Black women and healthcare providers (Sims, 2010). I am expecting similar mechanisms to be at work between Black girls with developmental disabilities and healthcare providers, as well as

between the Black parents of girls with developmental disabilities and healthcare providers, thereby influencing age at diagnosis of developmental disabilities. There are fewer Black children being diagnosed with developmental disabilities, and Bobb (2019) hypothesizes two reasons: 1) Black families do not get involved in the data collection process and reject labels of disability as shameful or a sign of weakness. 2) Black children with developmental disabilities integrate into the communities successfully, despite being as severely affected as their White peers. Then, as fewer Black children are diagnosed, healthcare professionals believe fewer Black children are affected by developmental disabilities. Those responsible for referring children for diagnosis expect to find less Black children, so they do – completing a self-fulfilling expectation. This diagnostic circularity is influenced by Black children having fewer externalized symptoms of developmental disability (Bobb, 2019). In the case of ASD, this can lead to not meeting the diagnostic threshold, or perhaps meeting it later in age (Bobb, 2019). Support and information for families about developmental disabilities is usually presented from a White cultural perspective. Differences in culture, language, and traditions can influence perceptions of what developmental disability looks like on a Black child, as well as health-seeking behaviors of Black parents on behalf of their children (Bobb, 2019). I do not expect these factors to affect Black girls and boys equally. Using logistic regression with random effects on a sample of 2,568 8-year-old children with ASD (some with co-occurring ID or DD) from 14 states, prior research has found Black children have lower likelihood of ASD recognition, and boys were more likely to have a documented diagnosis than girls (Mandell et al., 2009). While their sample may not be generalizable to all states, the results suggest both sex and race appear to play significant roles in developmental disability diagnosis.

Parental and Practitioner Bias

Diagnostic differences for Black girls could be partially due to racial and gender bias on the part of practitioners and parents, especially because some of the diagnostic process is based on subjective judgements. For example, racial differences in parental reports of child development to healthcare providers may contribute to delayed diagnosis of autism spectrum disorder in Black children. As noted earlier, having a disability can isolate people from their racial group, and being a racial minority can isolate people from others with disabilities (Stuart, 1992; Vernon, 1999). Black parents of girl children with developmental disabilities are socially isolated and may not have the social capital to help them with rating their children's development compared to other children with disabilities. Donohue and colleagues (2019) performed a study on 174 toddlers from 18 to 40 months old with autism spectrum disorder and their parents. The parents answered free-response questions about their child's development. Black parents were more likely than White parents to misinterpret ASD-related behaviors as disruptive. As a result, Black parents reported significantly fewer ASD concerns for their children, which may impact providers' lower diagnoses of ASD in Black children (Donohue, Childs, Richards, & Robins, 2019). Their results support previous research, like Mandell and colleagues (2007) who conducted a similar study with 406 Medicaid-eligible children. Black children were found to be 2.6 times less likely than White children to be diagnosed with ASD on their first specialty care visit. Furthermore, while ADHD was the most common diagnosis for children not diagnosed with ASD, Black children without ASD were 5.1 times more likely to be diagnosed with adjustment disorder than ADHD, and they were 2.4 times more likely to be diagnosed with conduct disorder than ADHD (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Again, research has established a pattern of Black children's symptoms being interpreted as

"problem behavior" rather than as signs of developmental disability – by both parents and practitioners. These differences in diagnostic patterns point to racial bias in parents' descriptions of children's symptoms, practitioners' interpretations and expectations, and presentation of symptoms.

Even "objective" diagnosis measures can be biased. For example, the Autism Diagnostic Observation Schedule (ADOS) is widely used to assess symptoms of autism spectrum disorder. Harrison and colleagues (2017) examined a subset of ten ADOS items among 2,458 participants. They found significant bias for race and ethnicity on three of the ADOS items. Their results supported their theory of social behaviors across cultures not being accounted for across sociodemographic groups (Harrison, Long, Tommet, & Jones, 2017). They highlighted the need to not apply a one-size-fits-all approach to diagnostic accuracy among culturally-diverse groups. Practitioner training and diagnostic criteria were created with predominately White males in mind, as they are the largest group diagnosed with developmental disabilities. This is how diagnosis becomes cyclical in nature. Practitioners are trained to recognize symptoms presented from White male children because they are the largest group diagnosed. Because they are the largest group diagnosed, they continue to be the prototype for recognizing symptoms.

Not all research leads to the direct conclusion that Black children are diagnosed with developmental disability later than White children. With data from the 2011-2012 National Survey of Children's Health, Emerson, Morrell, and Neece (2016) used multiple linear regression to examine age at diagnosis of ASD, as predicted by race, ASD severity, and having a consistent source of care. They found that Black children were diagnosed earlier than White children. However, the relationship was moderated by ASD severity and having a consistent source of care. Having a consistent source of care predicted earlier diagnosis for White children,

but not for Black children. They also concluded that both parental and practitioner bias may contribute to diagnostic delays for Black children (Emerson, Morrell, & Neece, 2016).

Data and Analytic Strategy

Data

This analysis uses data from the 2011 Survey of Pathways to Diagnosis and Services ("Pathways"), a follow-up survey to the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Pathways is nationally representative and includes children ages 6-17 years old with autism spectrum disorder, developmental delay, and/or intellectual disability. Children's guardians were re-contacted by telephone for the Pathways interview if their child was randomly selected from the NS-CSHCN. The interview asked parents or guardians about diagnoses, symptoms, providers, clinical treatments and interventions, educational resources, and other parental concerns. At this point, guardians completed a self-administered questionnaire (SAQ) on the phone (n = 4,032). Of those who completed the phone questionnaire, some also completed the mailed version of the SAQ (n = 2,988). The questionnaire asked parents or guardians about their child's strengths, difficulties, and behaviors. Since the Pathways survey followed the NS-CSHCN, it shared the complex survey design of the NS-CSHCN. This includes the clustering of children within households, the stratification by state and sample type (landline or cell phone), and how the random selection of Pathways-eligible children for follow-up were stratified by conditions reported in the NS-CSHCN.

Variables and Descriptive Statistics

Dependent Variables

The first dependent variable analyzed in this study was the age at diagnosis of autism spectrum disorder. I used questions which asked "sex of the child" and "To the best of your knowledge does [child] currently have ASD" to create subsamples of children with ASD, girl children with ASD, and boy children with ASD to analyze. Parents were asked "How old was [child] when you were first told [he/she] had autism or ASD?" to construct the variable that

indicated the age at diagnosis of ASD. The average age at diagnosis of ASD for children with ASD was 5.71, for girl children with ASD was 5.50 years, and for boy children with ASD was 5.74 years, with a range of 6 to 17 years old.

The second dependent variable was the age at diagnosis of intellectual disability. I used the questions which asked "sex of the child" and "To the best of your knowledge does [child] currently have intellectual disability" to create subsamples of children with intellectual disability, girl children with intellectual disability, and boy children with intellectual disability to analyze. Parents were asked "How old was [child] when you were first told [he/she] had intellectual disability?" to construct the variable that indicated the age at diagnosis of ID. The average age at diagnosis of intellectual disability for all children diagnosed was 5.44 years, for girl children it was 5.88 years, and for boy children it was 5.16 years, with a range of 6 to 17 years old.

The third dependent variable was the age at diagnosis of developmental delay. I used the questions which asked "sex of the child" and "To the best of your knowledge does [child] currently have developmental delay" to create subsamples of children with developmental delay, girl children with developmental delay, and boy children with developmental delay for the analysis. Parents were asked "How old was [child] when you were first told [he/she] had developmental delay?" to construct the variable that indicated the age at diagnosis of DD. The average age at diagnosis of developmental delay for all children diagnosed was 5.17 years, for girl children it was 5.27 years, and for boy children it was 5.12 years old, with a range of 6 to 17 years old.

Independent Variables

The sex variable was constructed from the question which asked the "sex of the child." Of the children with autism spectrum disorder, 17.54% of them were girls and 82.46% boys. Of

the children with intellectual disability, 39.21% of them were girls and 60.79% boys. And of the children with developmental delay, 34.98% of them were girls and 65.02% boys.

The race variable was constructed from a question which asked the "race/ethnicity of the child." For all children with ASD in the analytic sample, 67.42% of them were non-Hispanic White, 10.14% non-Hispanic Black, 11.60% Hispanic, and 10.85% Other-race. For all children with ID in the analytic sample, 57.19% were non-Hispanic White, 19.49% non-Hispanic Black, 13.20% Hispanic, and 10.12% Other-race. For all children with DD in the analytic sample, 59.97% were non-Hispanic White, 18.30% non-Hispanic Black, 13.17% Hispanic, and 8.55% Other-race.

In examining age at diagnosis among children with ASD, ID, or DD, a variety of covariates were controlled: age, number of comorbidities, parent's education, whether the child was inconsistently insured in the past year, region, parent's marital status, total number of adults in the household, total number of other children in the household, and the federal poverty threshold of the guardian's household, where higher values indicated less poverty (derived from the poverty guidelines of the Department of Health and Human Services).

The interviewers asked the "current age of [child] in years at the time of Pathways interview," and the average age at time of interview for the analytic subsamples were 11.46 years old for children with ASD, 12.69 years for children with ID, and 11.47 years for children with DD.

I created the comorbidities variable based on questions which asked if the child "ever had/currently has attention deficit disorder or attention deficit hyperactivity disorder," "ever had/currently has depression," "ever had/currently has anxiety problems," or "ever had/currently has behavior/conduct problems." It is a dichotomous variable which indicated if the child had

any of the aforementioned comorbidities, and 76.34% of children with ASD did, compared to 65.74% of children with ID and 67.60% of children with DD.

The "highest education level of parents in the household" was divided into less than high school (7.47% ASD parents; 10.46% ID parents; 12.92% DD parents), high school (17.27% ASD parents; 24.39% ID parents; 22.64% DD parents), and greater than high school (75.26% ASD parents; 65.15% ID parents; 64.44% DD parents).

The indicator variable for being inconsistently insured comes from a question on the 2009/10 National Survey of Children with Special Health Care Needs which asked parents if the child was "without insurance at some point during the past year," including health insurance prepaid plans such as HMOs, or government plans such as Medicaid. The inconsistently insured group represented 5% of ASD children, 4% of ID children, and 6% of DD children.

Parents were asked their "region of residence", which was categorized based on Census standards: Northeast (20.53% ASD parents; 20.54% ID parents; 17.85% DD parents), Midwest (24.60% ASD parents; 20.17% ID parents; 23.84% DD parents), South (33.25% ASD parents; 39.44% ID parents; 38.84% DD parents), and West (21.63% ASD parents;19.85% ID parents; 19.47% DD parents).

In addition, parents were asked the "marital/cohabitation status of parents in the household," and I categorized the analytic subsamples as married (65.93% ASD parents; 59.60% ID parents; 59.22% DD parents) and unmarried (1 = married).

The "total number of adults in household" had an average of 3.22 for children with ASD, 3.28 for children with ID, and 3.23 for children with DD. The "total number of children in household 0-17" averaged 1.26 for children with ASD, 1.21 for children with ID, and 1.25 for children with DD.

When parents were asked the "poverty level of this household based on DHHS guidelines," they had nine options which started at below 50% poverty level and capped at above 400% poverty level, with lower percentages indicating lower income. In keeping with prior research (Issa & Zedlewski, 2011; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008), I dichotomized this variable into households with a federal poverty level of 199% or less - to encompass those in poverty and near poverty - and households with a federal poverty level of 200% or more. For households of children with ASD, 36.96% of them had a federal poverty level of 199% or less, compared to 47.63% of ID households and 50.21% of DD households. Tables 1, 2, and 3 summarize the descriptive statistics for all variables.

Table 1. Descriptive Statistics

	ASD		ID		DD		Range	
	Mean/ Proportion	Std. Err	Mean/ Proportion	Std. Err	Mean/ Proportion	Std. Err	L	U
Female (child)	18%	0.02	39%	0.04	35%	0.02	0	1
Non-Hispanic Black (child)	10%	0.02	19%	0.04	18%	0.02	0	1
Non-Hispanic White (child)	67%	0.03	57%	0.04	60%	0.02	0	1
Hispanic (child)	12%	0.02	13%	0.03	13%	0.02	0	1
Other-race (child)	11%	0.02	10%	0.02	9%	0.01	0	1
Age at Diagnosis (child)	5.70	0.16	5.44	0.32	5.17	0.15	2	17
Any Comorbidities (child)	76%	0.02	66%	0.03	68%	0.02	0	1
Age (child)	11.46	0.17	12.69	0.24	11.47	0.14	6	17
Federal Poverty Level 199% or less	37%	0.03	48%	0.04	50%	0.02	0	1
Inconsistently Insured	5%	0.01	4%	0.01	6%	0.01	0	1
High School or Less than High School	25%	0.03	35%	0.04	36%	0.03	0	1
South	33%	0.03	39%	0.03	39%	0.02	0	1
North East	21%	0.02	21%	0.02	18%	0.02	0	1
Midwest	25%	0.02	20%	0.02	24%	0.02	0	1
West	22%	0.02	20%	0.02	19%	0.01	0	1
Married	66%	0.03	60%	0.04	59%	0.02	0	1
Number of Adults in Household	3.22	0.08	3.28	0.08	3.23	0.07	1	9
Number of Other Kids in the Household	1.26	0.06	1.21	0.06	1.25	0.06	0	5
	n=974		n=606		n=1602			

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; L = Lower Limit; U = Upper Limit; Variables are for parent characteristics unless otherwise indicated

Table 2. Mean Age at Diagnosis Across Independent Variables

		Mean Age at ASD Diagnosis		Mean Age at ID Diagnosis		Mean Age at DD Diagnosis	
		Mean	St. Error	Mean	St. Error	Mean	St. Error
Sex (child)	Male	5.74	0.18	5.16	0.36	5.12	0.18
	Female	5.50	0.37	5.88	0.57	5.27	0.28
Race (child)	Hispanic	5.53	0.56	5.46	1.06	5.17	0.65
	Non-Hispanic Black	5.62	0.56	7.05	0.91	5.09	0.44
	Non-Hispanic White	5.82	0.19	5.01	0.31	5.19	0.15
	Other-race	5.17	0.53	4.77	0.61	5.22	0.39
Age at Time of Interview (child)	6 -- 9	4.32	0.35	4.47	1.15	4.59	0.50
	10 -- 13	5.56	0.50	4.90	0.61	4.90	0.37
	14 -- 17	6.90	0.67	6.05	0.93	5.91	0.65
Comorbidities (child)	None	4.60	0.23	4.60	0.61	4.47	0.32
	One or More	6.04	0.20	5.88	0.35	5.51	0.17
Federal Poverty Level	200% or more	5.78	0.22	4.83	0.35	5.14	0.21
	199% or less	5.55	0.24	6.11	0.51	5.20	0.22
Parent's Education	Greater Than High School	5.78	0.19	4.93	0.32	5.22	0.19
	High School or Less Than High School	5.45	0.33	6.39	0.63	5.09	0.27
Inconsistently Insured	Consistently Insured	5.68	0.17	5.39	0.33	5.21	0.16
	Inconsistently Insured	5.94	0.77	6.69	0.86	4.74	0.46
Region	Northeast	5.83	0.43	4.27	0.50	4.53	0.29
	Midwest	5.57	0.24	5.31	0.61	5.31	0.25
	South	5.73	0.28	6.28	0.57	5.32	0.29
	West	5.68	0.39	5.13	0.60	5.31	0.33
Parent's Marital Status	Unmarried	5.86	0.33	6.49	0.54	5.19	0.25
	Married	5.62	0.18	4.73	0.34	5.16	0.19
Number of Adults in Household	1 -- 4	5.79	0.44	5.40	0.69	5.40	0.34
	5 -- 8	5.27	0.61	4.40	1.05	4.62	0.71
	9			3.00	.	1.80	1.70
Number of Other Kids in Household	0 -- 2	5.59	0.29	5.48	0.52	5.31	0.30
	3 -- 5	5.25	0.52	3.66	0.65	3.86	0.61
		n=974		n=606		n=1602	

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; Variables are for parent characteristics unless otherwise indicated

Table 3. Mean Age at Diagnosis Across Independent Variables – Stratified by Sex

		Mean Age at ASD Diagnosis by Sex				Mean Age at ID Diagnosis by Sex				Mean Age at DD Diagnosis by Sex			
		Girls		Boys		Girls		Boys		Girls		Boys	
		Mean	St. Error	Mean	St. Error	Mean	St. Error	Mean	St. Error	Mean	St. Error	Mean	St. Error
Race (child)	Hispanic	4.25	1.22	5.77	0.59	5.14	0.75	5.75	1.86	5.36	0.88	5.08	0.87
	Non-Hispanic Black	6.87	0.71	5.11	0.55	7.92	1.24	5.98	1.15	5.58	0.87	4.74	0.42
	Non-Hispanic White	5.44	0.34	5.90	0.22	4.86	0.64	5.08	0.34	5.22	0.28	5.17	0.18
	Other	4.72	0.47	5.23	0.60	6.56	1.43	3.99	0.43	4.67	0.40	5.47	0.55
Age at Time of Interview (child)	6 -- 9	4.06	0.52	4.50	0.34	3.30	0.60	4.70	1.37	4.03	0.48	4.85	0.66
	10 -- 13	5.50	0.70	5.53	0.55	5.39	1.01	4.70	0.74	5.17	0.60	4.91	0.43
	14 -- 17	6.56	0.96	7.02	0.78	6.78	1.64	5.42	0.85	6.43	1.06	5.44	0.61
Comorbidities (child)	None	3.99	0.52	4.78	0.24	4.13	0.64	5.00	0.95	4.01	0.40	4.78	0.44
	One or More	6.17	0.36	6.01	0.22	7.03	0.71	5.23	0.31	6.03	0.33	5.26	0.18
Federal Poverty Level	200% or More	5.31	0.43	5.87	0.24	5.28	0.55	4.64	0.45	5.28	0.36	5.09	0.26
	199% or Less	5.72	0.57	5.51	0.26	6.27	0.85	5.95	0.57	5.27	0.39	5.15	0.26
Parent's Education	Greater Than High School	5.57	0.36	5.82	0.22	5.29	0.47	4.71	0.43	5.31	0.32	5.17	0.23
	High School or Less Than High School	5.31	1.03	5.48	0.34	6.89	1.19	6.04	0.63	5.22	0.48	4.99	0.30
Inconsistenly Insured	Consistenly Insured	5.48	0.38	5.73	0.19	5.85	0.58	5.09	0.37	5.36	0.30	5.13	0.19
	Inconsistenly Insured	6.02	0.22	5.93	0.88	6.91	2.08	6.62	0.91	4.41	0.58	5.09	0.75
Region	Northeast	4.11	0.39	6.16	0.49	4.73	1.09	3.94	0.34	4.19	0.49	4.71	0.36
	Midwest	6.11	0.57	5.47	0.26	6.40	1.20	4.60	0.53	5.79	0.43	5.04	0.29
	South	5.67	0.79	5.74	0.30	6.28	0.97	6.27	0.69	5.33	0.53	5.31	0.34
	West	5.81	0.52	5.65	0.45	5.77	0.96	4.81	0.75	5.54	0.53	5.20	0.41
Parent's Marital Status	Unmarried	5.83	0.61	5.86	0.38	7.79	0.88	5.67	0.58	5.45	0.46	5.03	0.29
	Married	5.29	0.41	5.68	0.20	4.61	0.51	4.81	0.45	5.14	0.33	5.17	0.24
Number of Adults in Household	1 -- 4	5.24	0.65	5.87	0.49	5.92	1.02	4.93	0.83	5.42	0.52	5.39	0.42
	5 -- 8	5.52	0.89	5.41	0.70	4.19	1.50	4.80	1.19	3.93	0.94	4.54	0.69
	9							3.00	.			1.80	1.70
Number of Other Kids in Household	0 -- 2	5.15	0.53	5.66	0.32	6.03	0.97	5.10	0.55	5.33	0.54	5.28	0.34
	3 -- 5	4.86	0.78	5.35	0.57	2.94	1.05	3.94	0.96	3.87	0.83	3.80	0.73
		n=190		n=784		n=262		n=344		n=574		n=1028	

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; Variables are for parent characteristics unless otherwise indicated

In Appendix A. Supplemental Tables, Table A.1 provides wording for the variable questions, and Table A.2 shows a correlation matrix of all variables. In Appendix B. Supplemental Figures, Figures B.1, B.2, and B.3 are histograms of frequencies of ages at diagnosis of ASD, ID, and DD. Figures B.4 – B.12 are bar charts of the average age at diagnosis of ASD, ID, and DD by race, by sex, and by race and sex together.

Analytic Strategy

I used Stata 13 for all analyses, and due to the complex survey design and sample weights of Pathways data, I used the svy command. I used ordinary least squares linear regression to complete the analyses. All analytic samples were attained through listwise deletion, which omits subjects from the sample if they have missing data on any of the variables analyzed. The first sample was comprised of 1,080 children with autism spectrum disorder, but due to missing data, 104 were omitted, leaving an analytic sample of 976 children. The second sample began with 689 children with intellectual disability, but due to missing data, 83 were omitted, leaving an analytic sample of 606 children. The last sample began with 1,820 children with developmental delay, and 215 were omitted due to missing data, leaving 1,605 children in the analytic sample.

The analysis examines racial differences in the age at diagnosis of three developmental disabilities: autism spectrum disorder (ASD), intellectual disability (ID), and developmental delay (DD). The analysis also examines racial differences in these outcomes separately for girls and boys. The analysis proceeds as follows. First, I present descriptive statistics for the whole sample (girls and boys combined). Second, I show mean values for outcomes across independent variables. For ease of display, I collapse some continuous independent variables into categories. Third, I show mean values for outcomes by independent variable separately for girls, and then

for boys. Fourth, in a multivariate OLS regression I analyze outcomes for the whole sample. Fifth, I conduct regressions separately for girls and boys.

Results

Table 4 shows the regressions of age at diagnosis of ASD, ID, and DD for girls and boys combined. For every additional year of age at the time of interview, age at diagnosis of ASD increased by 0.27 years ($p<0.001$***). Also, having comorbidities increased the age at diagnosis of ASD by 1.14 years ($p<0.001$***). Living in the Northeast, compared to the South, decreased the age at diagnosis of ID by 1.84 years ($p<0.01$**). For every additional year of age at the time of interview, the age at diagnosis of developmental delay increased by 0.14 years ($p<0.01$**). Similar to children with ASD, having comorbidities increased the age at diagnosis of DD by 0.90 years ($p<0.01$**).

Table 4. Regressions of Age at Diagnosis of ASD, ID, and DD for All Children Diagnosed

	Autism Spectrum Disorder			Intellectual Disability			Developmental Delay		
	Coefficient	St. Error		Coefficient	St. Error		Coefficient	St. Error	
Female (child)	-0.057	0.347		0.708	0.557		0.132	0.305	
Race (Compared to Black)									
Non-Hispanic White (child)	0.202	0.648		-1.122	0.763		0.028	0.438	
Hispanic (child)	0.381	0.781		-0.778	1.267		0.315	0.797	
Other-race (child)	-0.676	0.789		-1.361	0.954		0.189	0.576	
Age (child)	0.272	0.046	***	0.102	0.076		0.135	0.050	**
Comorbidities (child)	1.142	0.296	***	0.868	0.634		0.899	0.340	**
Federal Poverty Level of 199% or Less	-0.044	0.323		-0.152	0.611		0.246	0.303	
High School or Less Than High School	-0.241	0.396		0.778	0.546		-0.196	0.315	
Inconsistenly Insured	0.395	0.650		1.691	0.956		-0.461	0.450	
Region (Compared to South)									
Northeast	-0.175	0.481		-1.839	0.667	**	-0.759	0.433	
Midwest	-0.231	0.349		-0.928	0.647		-0.082	0.348	
West	-0.345	0.442		-0.752	0.863		-0.103	0.475	
Married	-0.118	0.428		-0.974	0.608		0.453	0.318	
Number of Adults in Household	-0.225	0.259		-0.028	0.358		-0.322	0.214	
Number of Other Kids in Household	0.222	0.284		0.555	0.463		0.166	0.276	
Constant	2.364	0.919	**	4.640	1.742	**	3.616	0.896	***
	n=974			n=606			n=1602		

p<0.05*; p<0.01**; p<0.001***

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; Variables are for parent characteristics unless otherwise indicated

Table 5 shows the regressions of age at diagnosis of ASD, ID, and DD for girls only. Compared to non-Hispanic Black girls with ASD, non-Hispanic White girls were diagnosed 1.95 years earlier ($p<0.05$*), Hispanic girls were diagnosed 2.76 years earlier ($p<0.01$**), and Other-race girls were diagnosed 2.23 years earlier ($p<0.05$*). Having any comorbidities increased the age at diagnosis of girls with ASD by 1.49 years ($p<0.05$*). Compared to non-Hispanic Black girls with ID, non-Hispanic White girls were diagnosed 2.18 years earlier ($p<0.05$*). Also, having any comorbidities increased the age at diagnosis of girls with ID by 1.77 years ($p<0.05$*). For every additional year of age at the time of interview, the age at diagnosis of girls with DD increased by 0.24 years ($p<0.05$*). Similar to girls with ASD and ID, having any comorbidities increased the age at diagnosis of girls with DD by 1.58 years ($p<0.01$**).

Table 5. Regressions of Age at Diagnosis of ASD, ID, and DD for Girls

	Autism Spectrum Disorder			Intellectual Disability			Developmental Delay		
	Coefficient	St. Error		Coefficient	St. Error		Coefficient	St. Error	
Race (Compared to Black)									
Non-Hispanic White (child)	-1.952	0.829	*	-2.177	0.992	*	-0.283	0.739	
Hispanic (child)	-2.759	0.923	**	-1.835	1.259		-0.037	1.071	
Other-race (child)	-2.230	1.118	*	-0.899	1.708		-0.621	0.847	
Age (child)	0.138	0.074		0.244	0.133		0.237	0.098	*
Comorbidities (child)	1.491	0.682	*	1.771	0.795	*	1.577	0.503	**
Federal Poverty Level of 199% or Less	0.368	0.484		-1.108	1.085		0.015	0.497	
High School or Less Than High School	-0.092	0.681		0.120	0.966		0.109	0.522	
Inconsistenly Insured	-0.122	0.789		1.560	2.597		-0.818	0.554	
Region (Compared to South)									
Northeast	-0.806	0.813		-0.047	1.049		-0.385	0.658	
Midwest	0.896	0.757		0.306	1.018		0.757	0.555	
West	0.636	0.739		0.846	1.321		0.444	0.622	
Married	0.185	0.596		-1.623	1.152		0.297	0.535	
Number of Adults in Household	0.500	0.324		-0.459	0.554		0.066	0.400	
Number of Other Kids in Household	-0.502	0.373		0.823	0.641		-0.268	0.543	
Constant	3.275	1.273	*	4.986	2.570		1.481	1.467	
	n=190			n=262			n=574		

$p<0.05$*; $p<0.01$**; $p<0.001$***

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; Variables are for parent characteristics unless otherwise indicated

Table 6 shows the regressions of age at diagnosis of ASD, ID, and DD for boys only. For every additional year of age at time of interview, the age at diagnosis of boys with ASD increased by 0.28 years ($p<0.001$***). Also, having any comorbidities increased the age at diagnosis of boys with ASD by 0.94 years ($p<0.01$**). Compared to the South, living in the Northeast decreased the age at diagnosis of boys with ID by 2.25 years ($p<0.01$**), and living in the Midwest decreased the age at diagnosis of boys with ID by 1.77 years ($p<0.05$*). For every additional adult in the household, the age at diagnosis for boys with DD decreased by 0.47 years ($p<0.05$*).

Table 6. Regressions of Age at Diagnosis of ASD, ID, and DD for Boys

	Autism Spectrum Disorder			Intellectual Disability			Developmental Delay		
	Coefficient	St. Error		Coefficient	St. Error		Coefficient	St. Error	
Race (Compared to Black)									
Non-Hispanic White (child)	0.775	0.706		-0.322	0.969		0.303	0.499	
Hispanic (child)	0.976	0.857		0.195	1.958		0.480	1.005	
Other-race (child)	-0.182	0.860		-1.093	0.934		0.711	0.735	
Age (child)	0.283	0.053	***	0.064	0.085		0.075	0.049	
Comorbidities (child)	0.939	0.335	**	0.125	0.814		0.388	0.442	
Federal Poverty Level 199% or Less	-0.182	0.370		0.362	0.661		0.376	0.359	
High School or Less Than High School	-0.196	0.447		0.563	0.650		-0.237	0.387	
Inconsistenly Insured	0.482	0.698		1.351	1.002		-0.119	0.716	
Region (Compared to South)									
Northeast	-0.043	0.546		-2.252	0.694	**	-0.766	0.539	
Midwest	-0.320	0.375		-1.770	0.723	*	-0.414	0.406	
West	-0.446	0.506		-1.283	1.010		-0.280	0.574	
Married	-0.113	0.497		-0.965	0.745		0.507	0.413	
Number of Adults in Household	-0.302	0.288		0.294	0.388		-0.474	0.237	*
Number of Other Kids in Household	0.303	0.316		0.296	0.521		0.369	0.300	
Constant	2.065	0.997	*	4.494	1.714	**	4.674	1.005	***
	n=784			n=344			n=1028		

p<0.05*; p<0.01**; p<0.001***

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Std. Err = Standard Error; Variables are for parent characteristics unless otherwise indicated

Discussion

This study examined age at diagnosis of autism spectrum disorder (ASD), intellectual disability (ID), and developmental delay (DD) by both race and sex for children between 6 and 17 years old. This age range allowed me to study children who were young enough for parents to answer questions about their past, such as health insurance coverage around the time of diagnosis, yet old enough to have received their diagnosis. Using nationally representative data from the 2011 Survey of Pathways to Diagnosis and Services (Pathways), I implemented ordinary least squares linear regression on three subsets (children with ASD, children with intellectual disability, and children with developmental delay) and six more subsets with each of the previous three subsets divided into girls and boys. The analyses yielded significant race and sex effects on age at diagnosis.

Black girls were diagnosed with ASD about two years later than White girls, nearly three years later than Hispanic girls, and a little over two years later than Other-race girls. Black girls with ID were diagnosed over two years later than White girls. The non-significant race and sex effects are also interesting. While there were significant racial effects on age at diagnosis for girls with autism spectrum disorder and girls with intellectual disability, there were not any for other groups. Results found there was a later diagnosis for Black girls with ASD and Black girls with ID, but not for Black girls with DD. One possible explanation for this is that developmental delay is used somewhat like a “catchall” developmental disability diagnosis until children are older and can be more accurately diagnosed with ASD or ID. While symptoms of ASD can present in children a little under one year old, it may take practitioners more time to confirm less overt symptoms. Intellectual disability is confirmed based on an IQ test result that’s two standard deviations below the average. With the average IQ being 100, and the standard deviation being

15, a child would have to score at or below 70 to confirm intellectual disability. Children who are too young to have this diagnosis confirmed may be diagnosed with developmental delay until further notice. This aligns with the results of the current study and how no children received late diagnosis of developmental delay compared to one another (based on sex or race). This may be because developmental delay is diagnosed early as a net to catch those who may need further assessment in the future.

Other significant results involved age at the time of interview, regional effects, and comorbidity effects. For every additional year of age at time of interview, age at diagnosis increased by 0.27 years for children with ASD and 0.14 years for children with developmental delay. This was even more for girls with developmental delay who saw an increase of 0.24 years for every additional year at time of interview. Additionally, boys with ASD had an increase of 0.28 years for every additional year at time of interview. Notice that while overall children diagnosed with ASD and developmental delay saw an increase in age at diagnosis for every additional year of age at time of interview, when examined by sex, it was *girls* with developmental delay and *boys* with ASD who saw the greatest increase. This supports previous research of boys with ASD being diagnosed earlier and more frequently, yet it also illuminates new conclusions of girls with developmental delay being particularly susceptible to later diagnoses for every additional year of age. Results also suggest there is not a significant main effect of age at time of interview and sex on age at diagnosis of intellectual disability.

As for regional effects, the South generally had a higher age at diagnosis of ID compared to the other regions. Living in the Northeast, compared to the South, decreased the age at diagnosis of ID by almost two years. For boys, living in the Northeast decreased the age at diagnosis of ID by 2.25 years, and living in the Midwest decreased the age at diagnosis of ID by

1.77 years, compared to the South. Speculatively, this trend could follow health insurance trends. The South generally has a higher percentage of uninsured people, although this can depend on each specific state's Medicaid expansion. However, this does not explain why the same regional trend was not found for ASD and DD. Perhaps ASD and DD can be more easily recognizable, while ID diagnosis relies on an IQ test, which cannot be administered until a certain age.

Comorbidities included attention deficit disorder, depression, anxiety, and behavior/conduct problems. Having any of these comorbidities generally resulted in a higher age at diagnosis. Having comorbidities increased the age at diagnosis of ASD by 1.14 years and DD by 0.90 years. For girls, having comorbidities increased the age at diagnosis of ASD by 1.49 years, ID by 1.77 years, and DD by 1.58 years. For boys, having any comorbidities increased the age at diagnosis of ASD by 0.94 years. This trend was not found for ID. It is possible that having comorbidities could conflate the symptoms of ASD and DD, but not ID because ID can be confirmed with an IQ test, thus more easily identifying ID.

Lastly, the age at diagnosis for boys with DD decreased by 0.47 years, for every additional adult in the household. This was not the case for any other sample or subsample. Having additional adults in the household seems to help children with DD get diagnosed earlier, possibly because there are more people to notice symptoms and delayed developmental milestones. The same effect did not hold for children with ASD and ID. Since intellectual disability is confirmed with an IQ test administered at a certain age, having more adults notice symptoms would not increase the speed of diagnosis for ID. While having more adults notice behavioral and mental patterns might theoretically help children with ASD receive an earlier diagnosis, it appears the diagnoses of ASD is not aided by more household adults.

An important limitation of the present study is that analyses only apply to children already diagnosed with ASD, intellectual disability, or developmental delay. Because of this, I cannot make inferences to the general population of undiagnosed children. Results indicate factors associated with age at diagnosis among those already diagnosed. Future research could include an event history analysis to determine risk factors for late diagnosis for all children, not just those already diagnosed. Another important limitation is that the present research did not take into consideration the co-occurrence of ASD, ID, and/or DD. For Black children, diagnosis of ID can affect practitioners' diagnosis of other developmental disabilities, which could lead to Black children not being fully evaluated for ASD (Mandell et al., 2009). The data measurement tools are a limitation as well. Many of the questions are worded in terms of "when did a health care profession tell you that child had [diagnosis]" which limits the answers to people who have more access to health care professionals. Parents may notice their children have anxiety, depression, ADHD, ADD, conduct/behavioral problems, or other diagnoses before they have the opportunity to obtain an official diagnosis from a health care professional. There is also a language barrier, so the race results are not generalizable to all Hispanic/Latino children with special healthcare needs, primarily households who do not speak English. While Pathways is a useful, generalizable dataset, future data measurement tools could improve upon it by expanding their question wording and offering more languages.

Beyond the limitations of this study, there are other contributions future research could make. The measurement of race and ethnicity has been long debated and could be elaborated upon. The racial indicators in this research do not capture the complexities within "Other-Race" individuals. This category could include Asian-Americans, Native-Americans, and mixed-race people. The cultural nuances between these groups could affect narratives around developmental

disabilities and practitioners' perceptions for diagnosis. Further complicating matters are the contextual complexities of individuals' environments. Socioeconomic status could moderate the relationship between race and age at diagnosis of developmental disability. Lastly, individual identities of the parents may also play a role in the diagnostic status of their children. Gender identity, sexuality, nativity, and religion all have their own intersections with health and cultural scripts. There are many directions future research could take to expand upon age at diagnosis of developmental disabilities. As mentioned earlier, autism spectrum disorder has received relatively greater attention, so incorporating the less-researched developmental disabilities like intellectual disability and developmental delay – as I have – would be beneficial.

Current diagnostic tools were not created to address how selected disabilities present for different racial groups and sexes. We know that Black and Hispanic children are less likely than White children to have a documented ASD diagnosis (Mandell et al., 2009), and we know that ASD symptomology can present differently by sex, thus leading to boys being diagnosed more often than girls (Rivet & Matson, 2011). However, my research examines not only autism spectrum disorder, but also intellectual disability and developmental delay. Although age at diagnosis of intellectual disability and developmental delay is less researched than autism spectrum disorder, ID is the second most common non-physical developmental disability diagnosis (right after ASD), and DD is a common pre-diagnosis for both ASD and ID. Further, this research is also unique in that it examines the nuances of age at diagnosis by both race and sex, exposing the intersection of the two. While diagnostic research may take into consideration race and sex as individual demographics, my research suggests they should be studied together in an effort to identify groups with delayed diagnoses, such as Black girls.

Appendix A. Supplemental Tables

Table A.1 Variable Question Wording

Variable	Question Wording	Answer Choices
Age at Diagnosis (child)	How old was [S.C.] when you were first told that [he/she] had autism or ASD?	Age 0 - Age 17
	How old was [S.C.] when you were first told that [he/she] had intellectual disability?	Age 0 - Age 17
	How old was [S.C.] when you were first told that [he/she] had developmental delay?	Age 0 - Age 17
Race (child)	(Derived) Race of target child	White Only; Black Only; Other
	(Derived) Indicates whether child is of Hispanic origin/ethnicity	No; Yes; Don't Know; Refused
Age (child)	Current age of [S.C.] in years at the time of Pathways Interview	Age 6 - Age 17
Comorbidities (child)	Has a doctor or other health care provider every told you that [S.C.] had Attention Deficity Disorder or Attention Deficit Hyperactivity Disorder, that is, ADD or ADHD?	No; Yes; Don't Know
	Has a doctor or other health care provider ever told you that [S.C.] had depression?	No; Yes; Don't Know; Refused
	Has a doctor or other health care provider ever told you that [S.C.] had anxiety problems?	No; Yes; Don't Know; Refused
	Has a doctor other other health care provider ever told you that [S.C.] had behavioral or conduct problems, such as oppositional defiant disorder or conduct disorder?	No; Yes; Don't Know; Refused

Note: Variables are for parent characteristics unless otherwise indicated

(Table cont'd.)

Variable	Question Wording	Answer Choices
Federal Poverty Level of 199% or Less	(Derived) Poverty level of this household based on DHHS guidelines	At or Below 50% poverty level; Above 50% to at or Below 100% Poverty Level; Above 100% to at or Below 133% Poverty Level;
High School or Less Than High School	(Derived) Highest education level of parents in household	Less Than High School; High School Graduate; More Than High School; Don't Know; Refused
Inconsistently Insured	(Derived) Was [S.C.] without health insurance at some point during the past year, including health insurance prepaid plans such as HMOs, or government plans such as Medicaid?	No; Yes; Don't Know; Refused
Region	Region of Residence	Northeast; Midwest; South; West
Married	(Derived) What is the marital/cohabitation status of parents in the household?	Married; Divorced; Separated; Never Married
Number of Adults in Household	(Derived) Total number of adults in household	1 Adult - 9 Adults
Number of Other Kids in Household	(Derived) Total number of children in household ages 0-17	0 Kids - 5 Kids
Note: Variables are for parent characteristics unless otherwise indicated		

(Table cont'd.)

Table A.2 Correlations of All Variables

	Age ASD Diagnosis (child)	Age ID Diagnosis (child)	Age DD Diagnosis (child)	Black (child)	Hispanic (child)	Other-Race (child)	Age (child)	Federal Poverty Level 199% or Less	Federal Poverty Level 200% or More	High School or Less Than High School
Age ASD Diagnosis (child)	1									
Age ID Diagnosis (child)	0.5987	1								
Age DD Diagnosis (child)	0.5678	0.7182	1							
Black (child)	-0.0243	0.0374	-0.0408	1						
Hispanic (child)	-0.0279	-0.0463	-0.0284	-0.1012	1					
Other-Race (child)	-0.1067	0.0045	0.0433	-0.1144	-0.1333	1				
Age (child)	0.1839	0.1191	0.0459	-0.0624	-0.1523	-0.0357	1			
Federal Poverty Level 199% or Less	0.0095	0.0771	0.0277	0.197	0.0097	0.0352	-0.0727	1		
Federal Poverty Level 200% or More	-0.0095	-0.0771	-0.0277	-0.197	-0.0097	-0.0352	0.0727	-1	1	
High School or Less Than High School	-0.0305	0.0329	0.0339	0.1192	0.0365	0.0571	-0.006	0.3103	-0.3103	1
Greater Than High School	0.0305	-0.0329	-0.0339	-0.1192	-0.0365	-0.0571	0.006	-0.3103	0.3103	-1
Inconsistently Insured	0.073	0.1533	0.0122	0.0537	0.0821	0.0572	-0.0376	0.081	-0.081	-0.0152
North East	0.0348	-0.0049	0.0044	0.0115	-0.0587	-0.0295	0.0933	-0.008	0.008	0.0341
Midwest	0.0515	-0.028	-0.004	-0.0584	-0.0954	-0.0745	0.1453	0.018	-0.018	0.0463
West	-0.0214	-0.0615	-0.0342	-0.1872	0.1483	0.1586	-0.106	-0.0427	0.0427	-0.1123
South	-0.0524	0.0879	0.033	0.2228	-0.0124	-0.0639	-0.0999	0.0316	-0.0316	0.0404
Unmarried	0.0412	0.1058	0.0432	0.4119	0.0266	0.1137	-0.0021	0.4979	-0.4979	0.2484
Married	-0.0412	-0.1058	-0.0432	-0.4119	-0.0266	-0.1137	0.0021	-0.4979	0.4979	-0.2484
Number of Adults in Household	0.0095	0.0336	0.0446	-0.2189	0.0607	-0.0196	-0.1124	0.0718	-0.0718	-0.0139
Number of Other Kids in Household	-0.0667	0.0101	0.0134	-0.1092	0.0212	0.0754	-0.2159	0.1195	-0.1195	-0.0032
Comorbidities	0.1826	0.0597	0.151	-0.0039	-0.0732	-0.0782	0.0779	-0.0107	0.0107	-0.0656

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Variables are for parent characteristics unless otherwise indicated

(Table cont'd.)

	Greater Than High School	Inconsistently Insured	North East	Midwest	West	South	Unmarried	Married	Number of Adults in Household	Number of Other Kids in Household	Comorbidities
Greater Than High School	1										
Inconsistently Insured	0.0152	1									
North East	-0.0341	-0.0152	1								
Midwest	-0.0463	-0.0022	-0.2368	1							
West	0.1123	0.1089	-0.2845	-0.3354	1						
South	-0.0404	-0.091	-0.3126	-0.3685	-0.4428	1					
Unmarried	-0.2484	0.0599	0.1008	-0.1057	-0.129	0.1372	1				
Married	0.2484	-0.0599	-0.1008	0.1057	0.129	-0.1372	-1	1			
Number of Adults in Household	0.0139	-0.0011	-0.0289	0.0612	0.0754	-0.1036	-0.2819	0.2819	1		
Number of Other Kids in Household	0.0032	-0.0316	-0.0493	0.0303	0.0628	-0.048	-0.1132	0.1132	0.8459	1	
Comorbidities	0.0656	-0.1153	-0.089	0.0913	-0.0479	0.0366	0.0351	-0.0351	0.0006	-0.0047	1

Note: ASD = Autism Spectrum Disorder; ID = Intellectual Disability; DD = Developmental Delay; Variables are for parent characteristics unless otherwise indicated

(Table cont'd)

Appendix B. Supplemental Figures

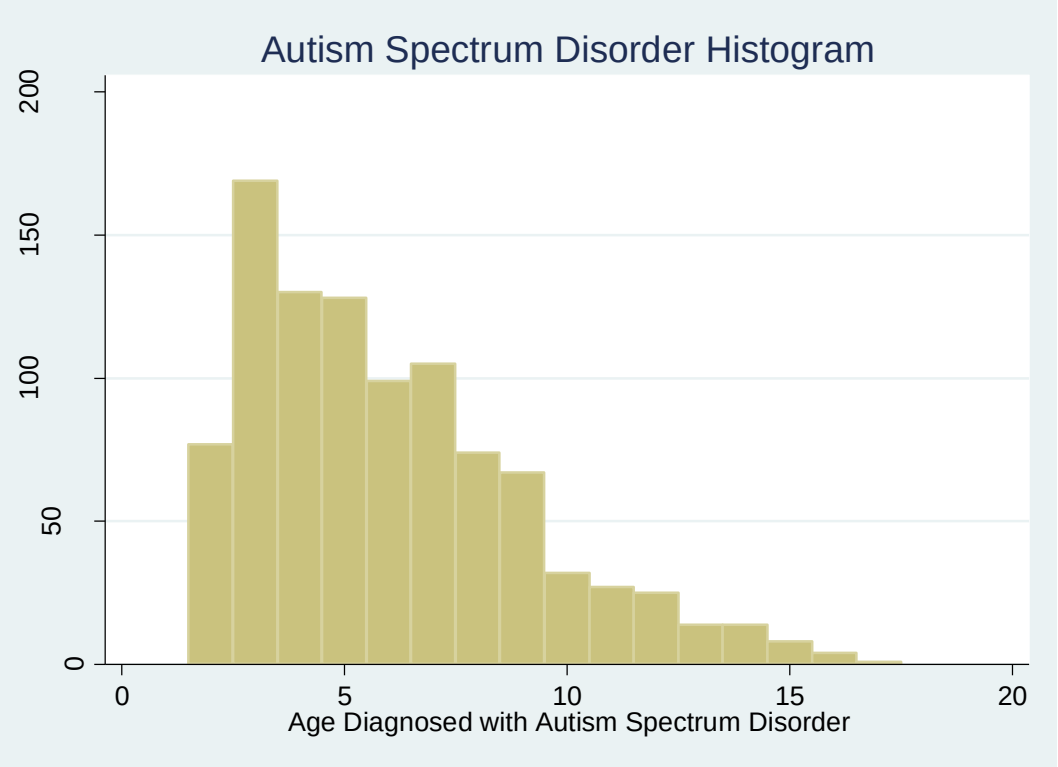

Figure B.1 Autism Spectrum Disorder Histogram

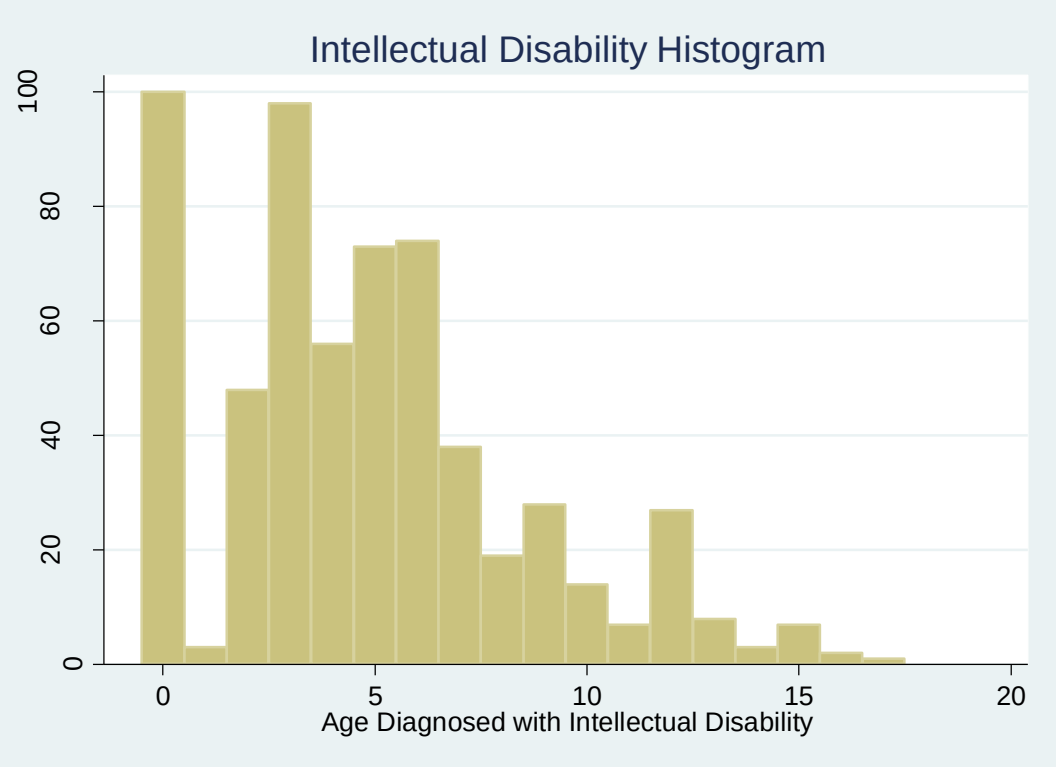

Figure B.2 Intellectual Disability Histogram

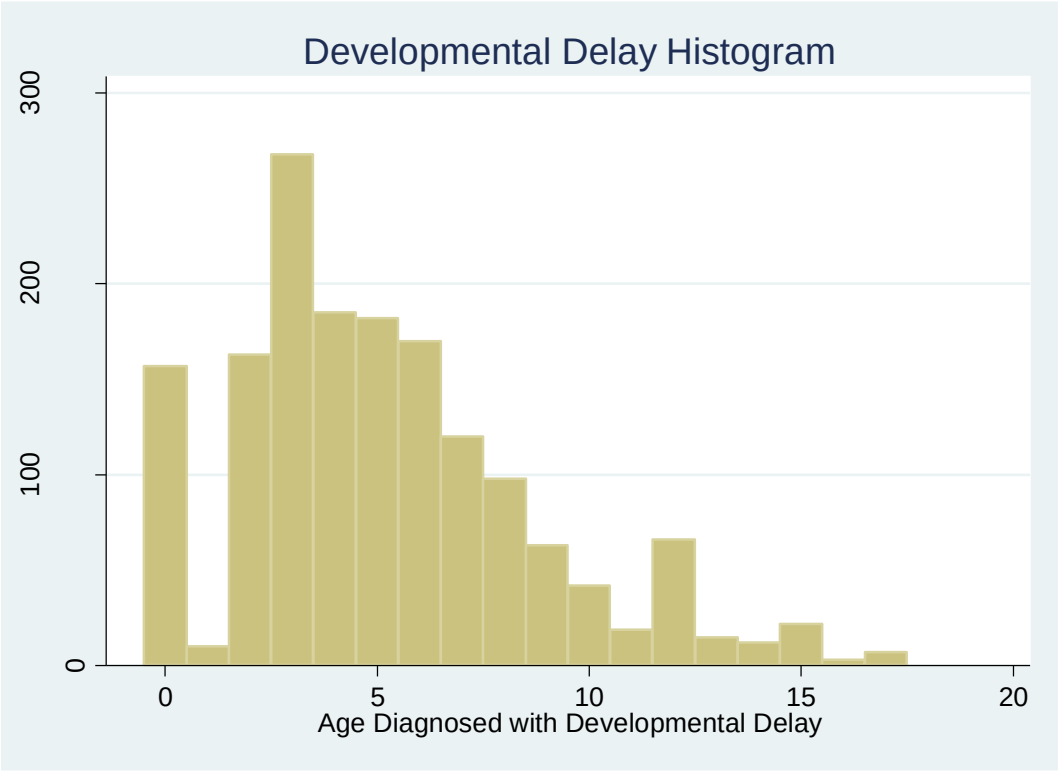

Figure B.3 Developmental Delay Histogram

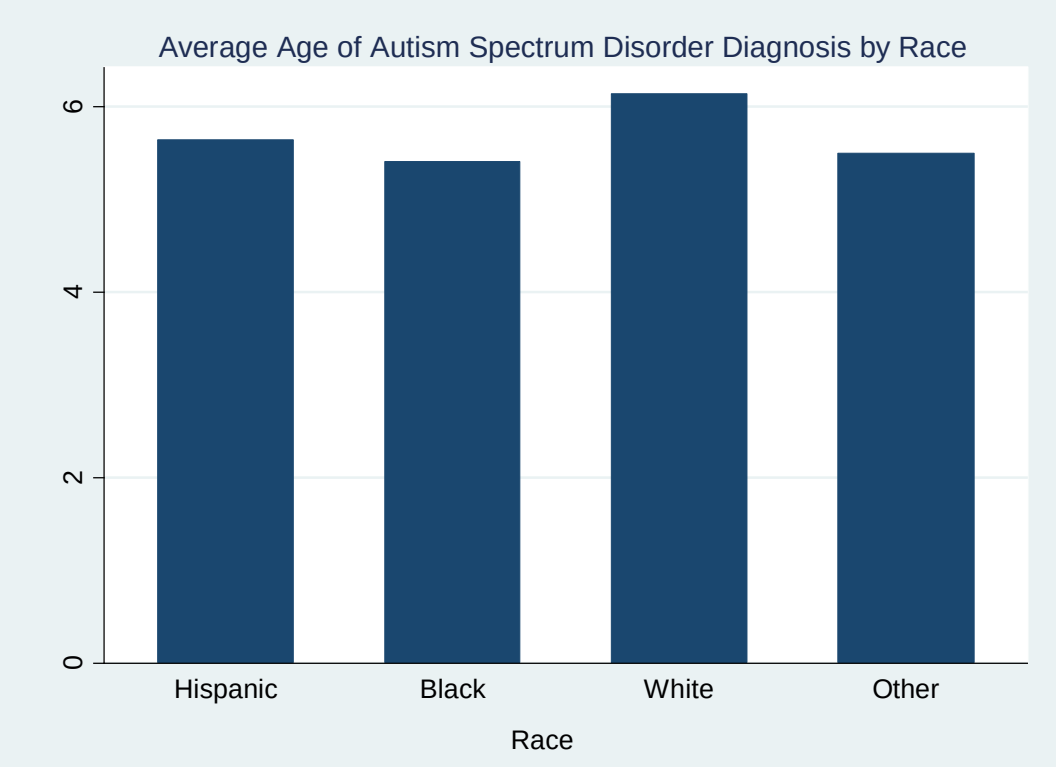

Figure B.4 Average Age of Autism Spectrum Disorder Diagnosis by Race Bar Chart

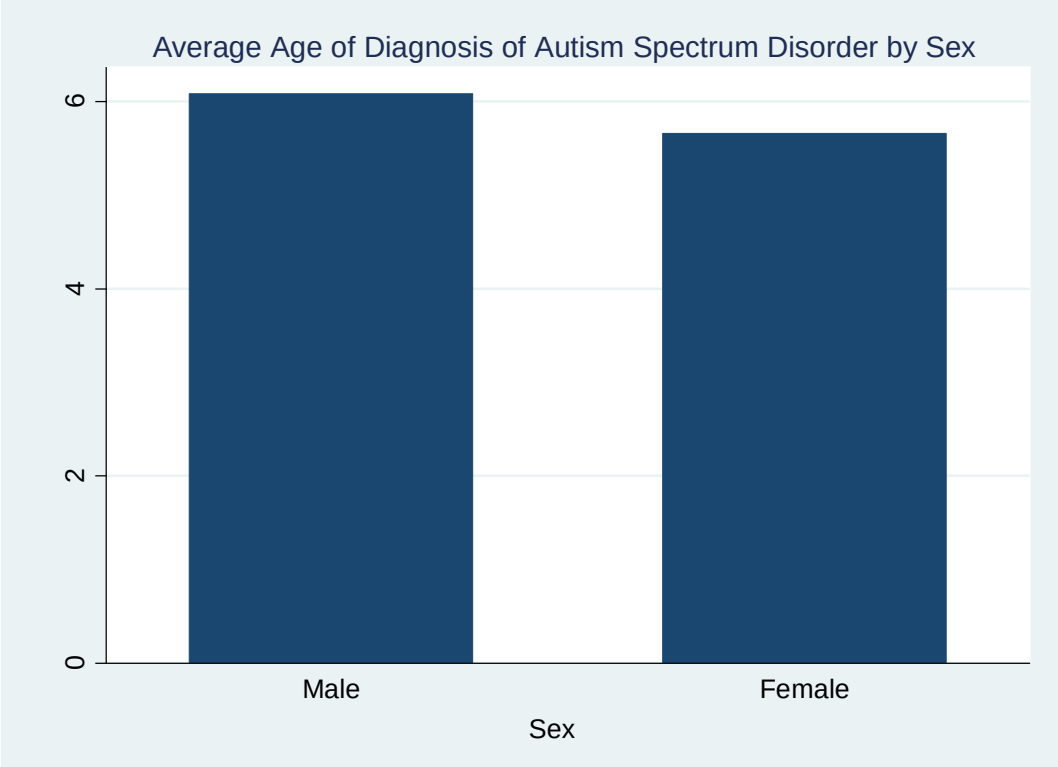

Figure B.5 Average Age of Diagnosis of Autism Spectrum Disorder by Sex Bar Chart

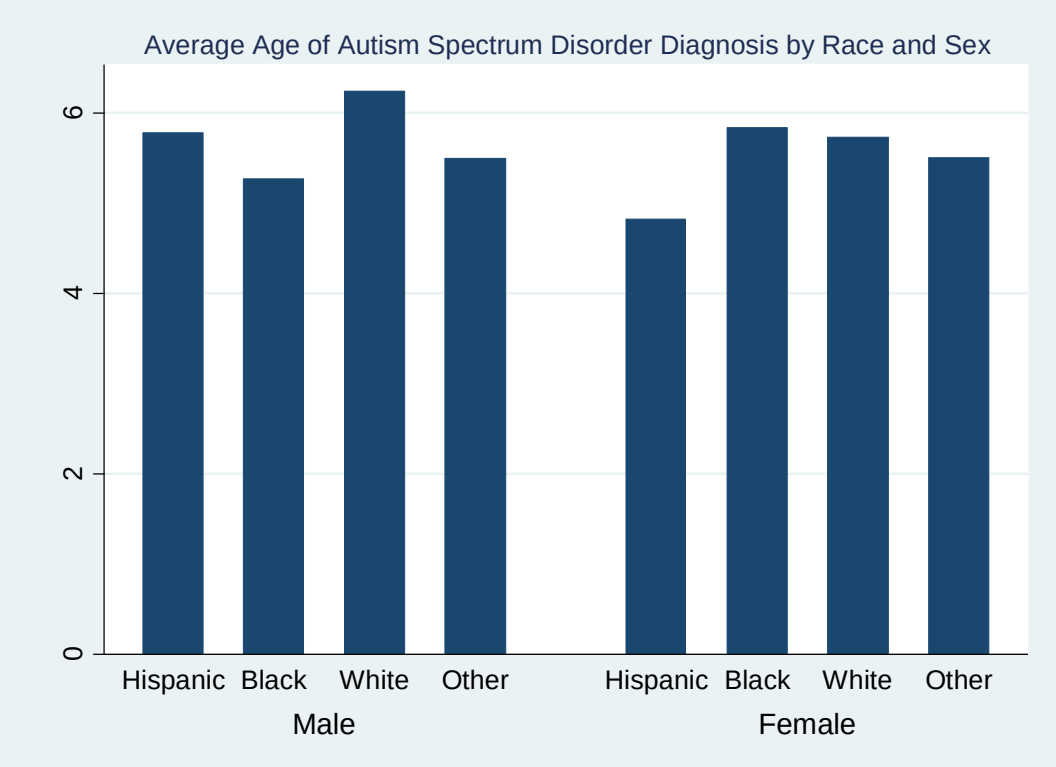

Figure B.6 Average Age of Autism Spectrum Disorder Diagnosis by Race and Sex Bar Chart

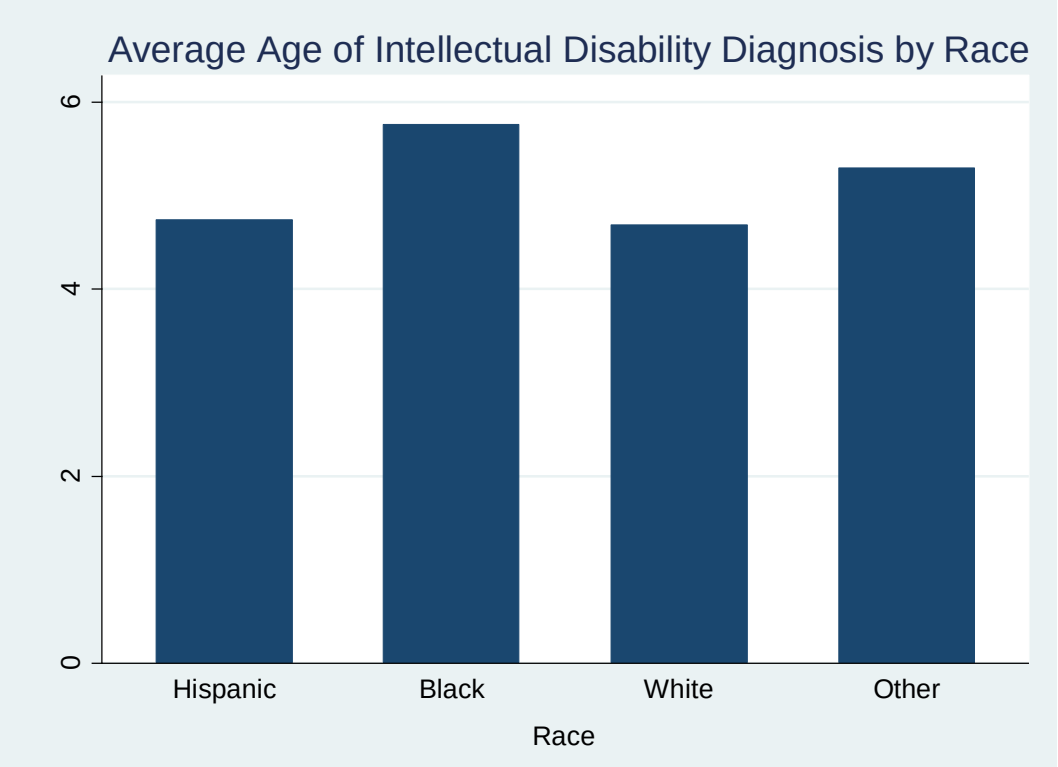

Figure B.7 Average Age of Intellectual Disability Diagnosis by Race Bar Chart

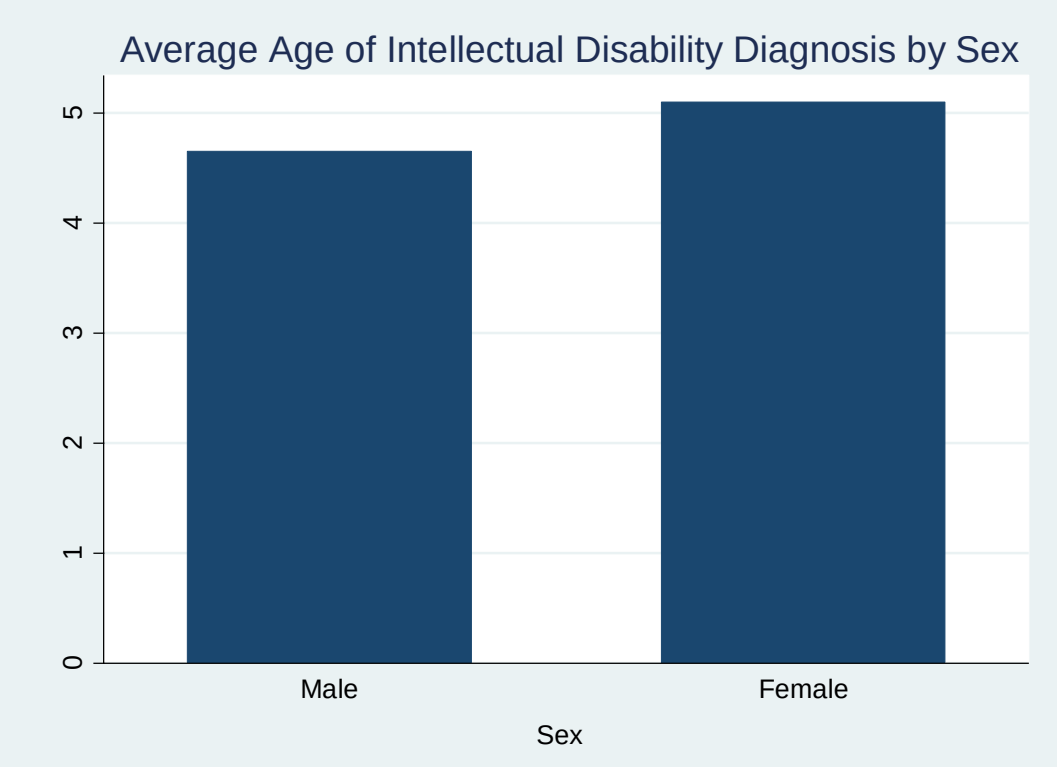

Figure B.8 Average Age of Intellectual Disability Diagnosis by Sex Bar Chart

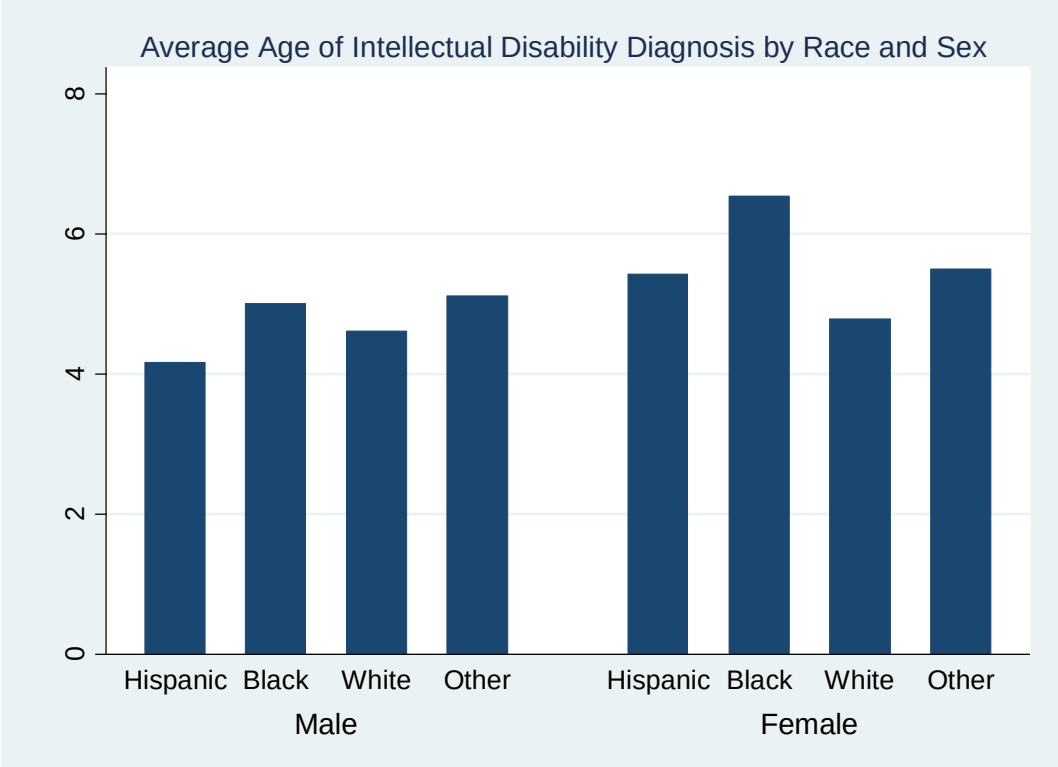

Figure B.9 Average Age of Intellectual Disability Diagnosis by Race and Sex Bar Chart

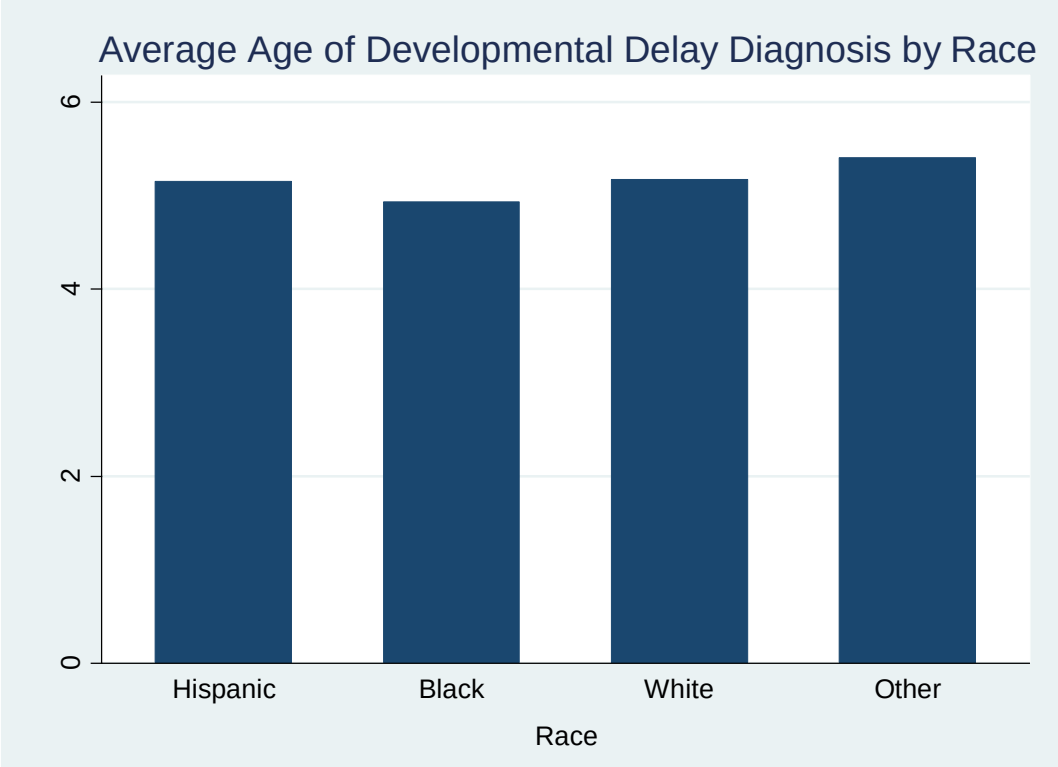

Figure B.10 Average Age of Developmental Delay Diagnosis by Race Bar Chart

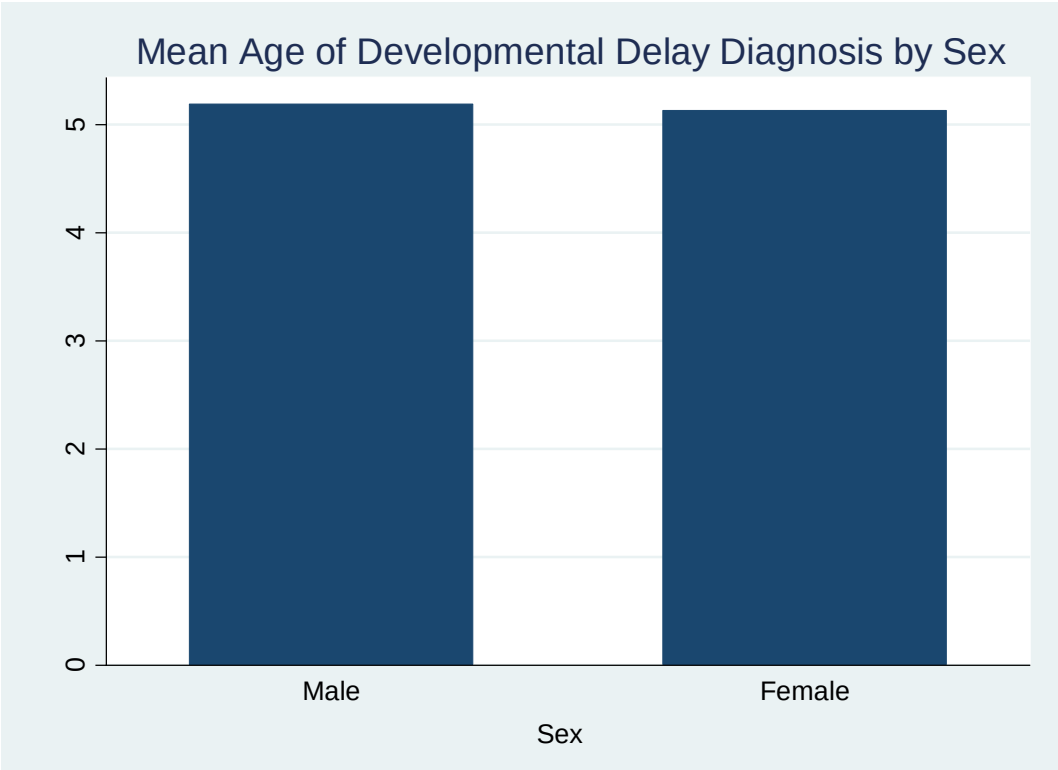

Figure B.11 Average Age of Developmental Delay Diagnosis by Sex Bar Chart

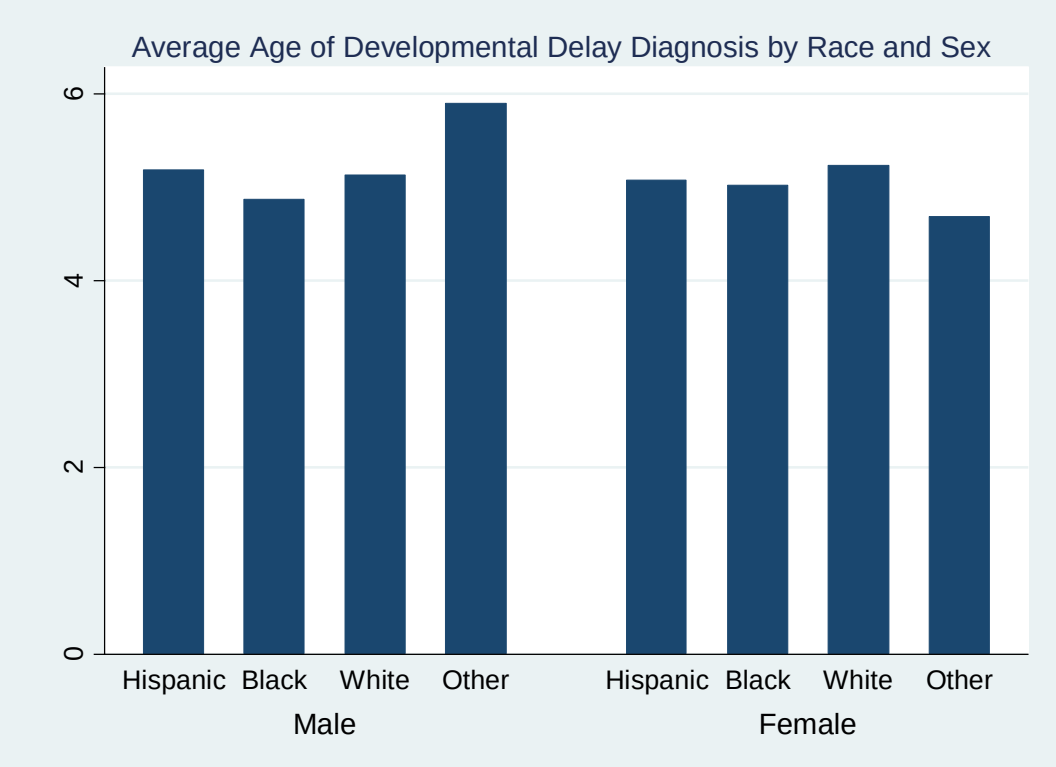

Figure B.12 Average Age of Developmental Delay Diagnosis by Race and Sex Bar Chart

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Vita

Danequa Forrest works at the University of Texas Health Science Center as a Research Coordinator with Community Information: Now. With a double major in psychology and sociology, she graduated with a Bachelor of Arts degree from the University of Texas at San Antonio with Honors, in three and a half years. Then, she was awarded a full graduate assistantship at Louisiana State University where she earned her Master of Arts degree in sociology. In the Spring of 2021, she anticipates graduating with a PhD in sociology with double minors in Applied Statistics and African and African-American Studies. She is a mixed methods researcher with experience in quantitative and qualitative data analysis. Her many research interests include health, race, and diverse methodologies.