

# Black\*-African American ASD Identification Research Expansion Project



## Comprehensive Report Year 2



CENTER FOR AUTISM AND  
RELATED DISABILITIES  
Florida Atlantic University



## **Black\*-African American ASD Identification**

### **Research Expansion Project**

#### **Comprehensive Report**

**2022-2023**

**Florida Developmental Disabilities Council, Inc.  
Florida Atlantic University Center for Autism and Related Disabilities**

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## **I. FDDC Researcher Team**

### **Jack Scott, Ph.D., BCBA-D, Primary Investigator**

Jack Scott is the executive director of the Florida Atlantic University Center for Autism and Related Disabilities. He is an associate professor in the Department of Special Education and teaches courses on autism, inclusion, and behavior analysis. Dr. Scott received his doctoral degree from the University of Florida. His most recent book, *Safeguarding your child with autism*, is published by Woodbine and provides a toolkit for parents to reduce risks their child with autism will face. Dr. Scott has research interests in individualized instruction, suicide prevention for autistic people, police training and elopement prevention. He also has several grants examining the rates of participation by African American children in school autism programs and for educating parents of newly identified children with autism. As a behavior analyst, he is active in linking behavioral analysts with emerging issues in safety and autism. He serves on the boards of several charter schools and as chair of the Panel of Professional Advisors and as a board member for the Autism Society of America.

### **Torica Exume, Ph.D., Program Coordinator**

Torica Exume received her doctorate at The Chicago School of Professional Psychology and completed her internships/residencies with children and adults ranging from 1 to 60 years old with various mental health disorders and brain injuries. She is now coordinating the new Florida Developmental Disabilities Grant awarded to FAU CARD to research the under-representation of Black children in autism. Dr. Exume is an advocate for parents needing guidance and support for treatment for their special needs children. She continues to reach out to the community with various programs (i.e., parent training, school staff training, social skills group, mentoring) and behavior analytic research findings through pending journal articles. Dr. Exume continues to strive to make improvements in autistic children's lives. With extensive educational and hands-on training, she specializes in communication, social interactions, analysis and treatment of repetitive behavior disorders, safety skills, and more.

### **Gabriela Nunes, B.A., Research Assistant**

Gabriela Maluf Nunes provides support to the FAU CARD FDDC research grant, assisting the research team in meeting grant deliverables. She came to the U.S after finishing high school in Sao Paulo, Brazil. She earned a bachelor's degree in Psychology with a minor in Criminal Justice from Florida Atlantic University, and she is currently working towards her master's degree in Rehabilitation and Mental Health Counseling at FAU.

### **Jamie Mayersohn, J.D., FDDC Director, Program and Contracts**

We would like to extend our gratitude to Dr. David Mandell, Dr. Brian Boyd, and Dr. Sarah Dababnah for their engaged discussions, valuable guidance, and unwavering support throughout the course of this study.



## **II. Overview of Study**

**Purpose of Study:** The purpose of this study was to gain a deeper understanding of the process by which Black\* children are diagnosed with autism spectrum disorder. The insights gained from this study were used by FAU CARD staff to provide better support to parents, ensure accurate and timely identification, and develop training programs for parents, educators, and healthcare providers to enhance the identification process. The study aimed to achieve its objective by conducting a series of activities, including focus groups, one-on-one interviews conducted via Zoom, and online surveys involving parents of Black\* children diagnosed with autism spectrum disorder, early intervention staff, school psychologists, community psychologists, ASD Black\* educators, pre-k staff, Black\* special needs educators, exceptional student educators (ESE) staff and direct, healthcare providers, CARD staff, and university faculty residing in the following counties: Citrus, Flager, Gasden, Gulf, Hillsborough, Lake, Lee, Marion, Monroe, Orange, and St. Johns.

**Background and Rationale:** The Florida Atlantic University Center for Autism and Related Disabilities (FAU CARD) is a state discretionary grant funded by the Florida legislature and administered by the Florida Department of Education. Its purpose is to provide services to individuals with autism spectrum disorder (ASD) or related disabilities and their families in Palm Beach County and the Treasure Coast. However, upon reviewing its registration data, FAU CARD noticed a lack of representation of Black\* children and adults with autism among their registrants. To address this issue, FAU CARD initiated a research study to investigate the factors influencing the identification of Black\* children with ASD and the reasons behind their under-representation.

The study employed various methods, including focus groups, interviews, and surveys, to gather insights from parents of Black\* autism spectrum disorder (ASD) educators, Black\* special needs educators, pre-kindergarten staff, early intervention (EI) staff, university faculty, healthcare providers, Center for Autism and Related Disabilities (CARD) staff, school psychologists, and community psychologists. By exploring the beliefs, attitudes, and experiences of parents throughout the ASD identification process, the study aimed to contribute to the existing knowledge and practices in the field. The findings would help inform autism providers, educators, and practitioners in developing culturally sensitive and effective approaches to support Black\* parents during the ASD identification process.

The study also aimed to identify the barriers and facilitators perceived by Black\* parents in the ASD identification process for their children. The information gathered would assist FAU CARD in providing better education and support to parents during the ASD identification process. Additionally, it would enable educators and healthcare providers to receive professional development focused on effectively identifying Black\* children with autism and supporting their parents throughout the identification process.

Overall, the study sought to enhance the understanding of how Black\* children are identified in the ASD identification process and to pinpoint the factors influencing their success. The insights gained would assist FAU CARD in educating and supporting Black\* parents, as well as facilitating professional development opportunities for educators and healthcare providers, ultimately improving the identification and support of Black\* children with autism.

**Data Collection:** A qualitative and quantitative research design was utilized to provide the depth and breadth of the participants' experience. Data was collected via focus groups, interviews, and online surveys. Focus group and interview transcriptions and online surveys were analyzed to gain understanding and meaning (Corbin & Strauss, 2008; see also Rapley, 2007). Transcriptions of focus groups and interviews data were coded individually and multiple times by categories across responses to identify themes within the feedback. The online surveys consisted of questions requiring the use of a quantitative research design to analyze number-based data for the responses on participants' experience.

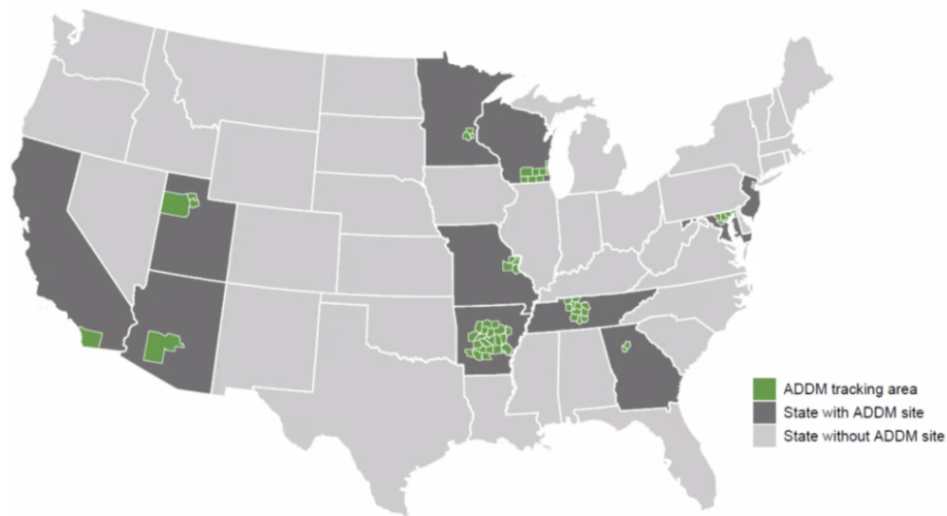
### **Current CDC Prevalence of Autism Spectrum Disorder**

Data gathered from 11 communities in the United States reveals that approximately 1 in 36 8-year-old children were diagnosed with Autism Spectrum Disorder (ASD). The report found that boys were nearly four times more likely than girls to be identified with ASD. Moreover, the percentages of ASD were higher among Black, Hispanic, and Asian or Pacific Islander children compared to White children. Additionally, among 8-year-olds, Black children had a high rate of both ASD and Intellectual Disability (ID), with a prevalence of 50.8%. However, it is important to approach these findings with caution as the data was collected from only 11 clinical sites, each with varying racial populations, which may lead to potential inaccuracies or limited generalizability.

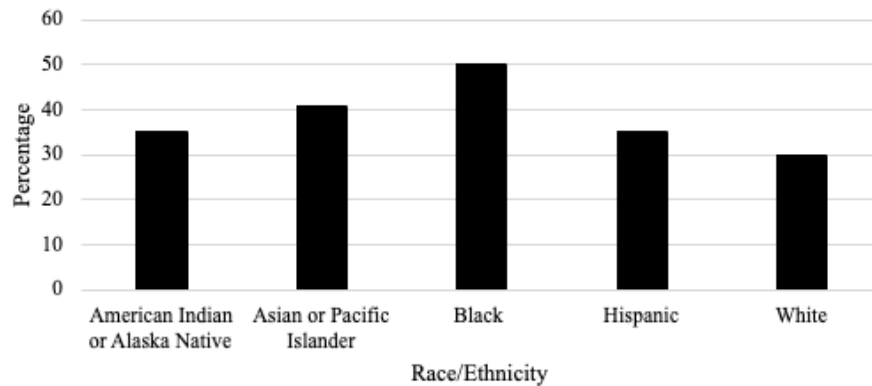
Notably, the progress in early identification of ASD was hindered by the impact of COVID-19. Nonetheless, the primary focus of the project, ADDM Network, remains on early

identification. Despite the limitations, these findings hold significance in terms of raising awareness about the prevalence of ASD, informing future research on ASD, promoting early identification practices, identifying appropriate lifespan services for individuals with ASD, addressing barriers to access, advocating for equitable and accessible screening and services for all, improving healthcare and educational outcomes for individuals with ASD, and empowering parents to advocate for their children's needs.

### **ADDM Network Sites, Surveillance Years 2018 and 2020**

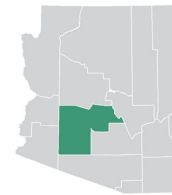


## ADDM Network: Percentage of 8-Year-Old Autistic Children with IQ ≤ 70 by Race/Ethnicity in 2020



## Arizona

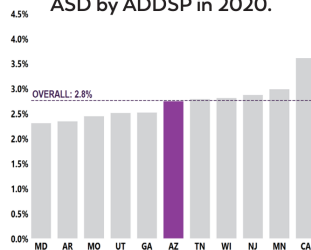
Findings from the Arizona Developmental Disabilities Surveillance Program (ADDSP) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**■ SITE TRACKING AREA**

### 1 in 36

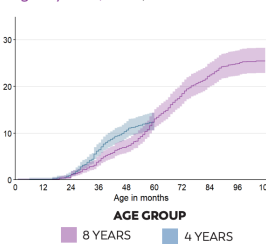
Or **2.7%** of 8-year-old children were identified with ASD by ADDSP in 2020.



This percentage is similar to the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

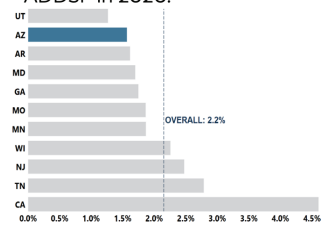
### By 48 months

Children who were age 4 years (1.1%) were **1.5 times as likely** to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children who were age 8 years (0.72%).



### 1 in 64

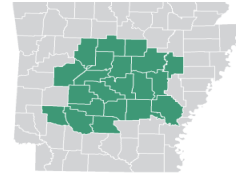
Or 1.6% of 4-year-old children were identified with ASD by ADDSP in 2020.



This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities where CDC tracked ASD among 4-year-olds in 2020.

# Arkansas

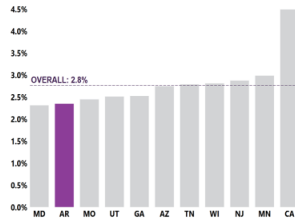
Findings from the Arkansas Autism and Developmental Disabilities Monitoring (AR-ADDM) Program help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



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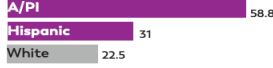
## 1 in 43

Or 2.4% of 8-year-old children identified with ASD by AR-ADDM in 2020.



This percentage is slightly lower than the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

Among 8-year-old children, children of Asian/Pacific Islander race were 1.5 times as likely to be identified with ASD as White children.

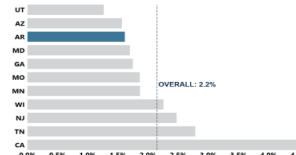


Values indicate prevalence per 1,000 children. No significant differences in ASD prevalence were found between White and Black 8-year-olds.

Among 4-year-olds, Black children were 1.6 times as likely to be identified with ASD as White children.



About 1 in 62 or 1.6% of 4-year-old children were identified with ASD by AR-ADDM in 2020.



This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities where CDC tracked ASD among 4-year-olds in 2020.

# California

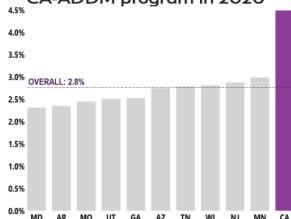
Findings from the California Autism and Developmental Disabilities Monitoring (CA-ADDM) program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



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## 1 in 22

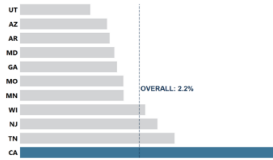
Or 4.5% of 8-year-old children were identified with ASD by the CA-ADDM program in 2020



This percentage is higher than the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

From 2016 through the beginning of 2020, 4-year-old children had more evaluations and identifications than the cohort aged 8 years had from 2012 through 2016. The pandemic onset in March 2020 coincided with a stark drop-off in evaluations and identifications. California experienced sustained drops in both evaluation and identification through the end of 2020.

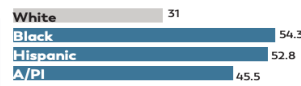
About 1 in 22 or 4.6% of 4-year-old children were identified with ASD by the CA-ADDM program in 2020.



Asian/Pacific Islander 8-year-old children were 1.5 times as likely to be identified with ASD as White children.

Values indicate prevalence per 1,000 children. There were no other significant differences in identification between other races and/or ethnicities.

White 4-year-old children were less likely to be identified with ASD than other races and/or ethnicities.



Values indicate prevalence per 1000.

The median age of diagnosis for 8-year-old children in California was 36 months. The median age of diagnosis was younger in CA-ADDM than the average median age of diagnosis in all communities in the US where CDC tracked ASD in 2020 (49 months).

# Georgia

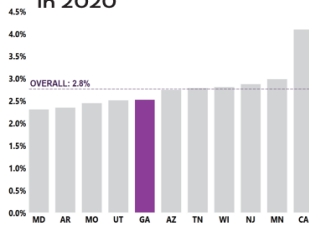
Findings from the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

## 1 in 40

Or 2.5% of 8-year-old children were identified with ASD by MADDSP in 2020



This percentage is similar to the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

Among 8-year-olds, Black children were 1.5 times more likely to be identified with ASD as White children.

Black 28.6

White 19

Values indicate prevalence per 1000. There were no significant differences in identification between other races or ethnicities.

Children in other racial/ethnic groups were 2 or more times as likely to be identified with ASD compared to White children at age 4 years.

White 8.1

Black 21.9

Hispanic 16.1

A/PI 17.4

Multiple races 20.8

Values indicate prevalence per 1000

47% of 8-year-old children identified with ASD received a comprehensive developmental evaluation by 3 years of age.



Children who were age 8 years with both ASD and ID were identified earlier

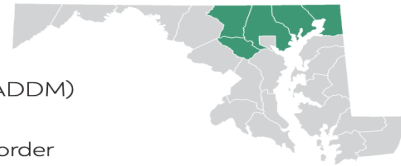
36 months

than children with ASD who didn't have ID.

40 months

# Maryland

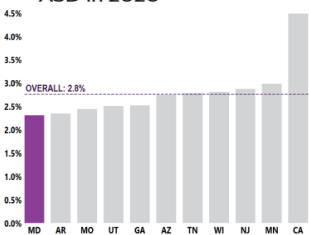
Findings from the Maryland Autism and Developmental Disabilities Monitoring (MD-ADDM) program help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



SITE TRACKING AREA

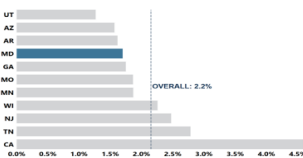
## 1 in 43

Or 2.3% of 8-year-old children were identified with ASD in 2020



This percentage is lower than the overall percentage identified with ASD (2.8%) in all communities tracked by the CDC.

About 1 in 59 or 1.7% of 4-year-old children were identified with ASD in 2020.



This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities tracked by the CDC.

About 83% of 4-year-old children identified with ASD received a comprehensive developmental evaluation by 3 years of age.



Among 8 year-olds, Asian/Pacific Islander (A/PI) and Black children were twice as likely to be identified with ASD as Hispanic and White children.

A/PI 36.5

Black 33.6

Hispanic 17.2

White 16.8

Values indicate prevalence per 1000.

Among 4-year-olds, Black children were 2.3 times as likely and Asian/Pacific Islander (A/PI) children were 1.9 times as likely to be identified with ASD as White children.

Black 27.6

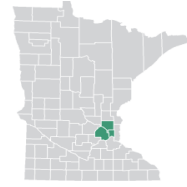
A/PI 22.3

White 11.9

Values indicate prevalence per 1000. There were no significant differences in identification between Hispanic children and White children.

# Minnesota

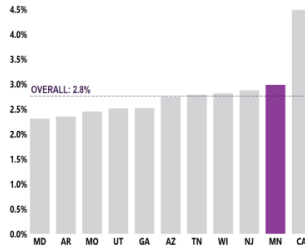
Findings from the Minnesota Autism and Developmental Disabilities Monitoring Network (MN-ADDM) help us understand more about autism in Minnesota, including number of children with autism spectrum disorder (ASD), their characteristics, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 34

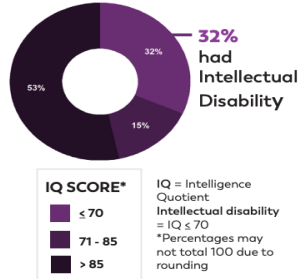
Or **3.0%** of 8-year-old children were identified with ASD by MN-ADDM in 2020.



This rate is similar to the average percentage identified with ASD in 2020, which was 2.8% of 8-year-olds across all ADDM sites.

**More children in Minnesota are being identified with ASD at an early age.** Children who were age 4 years were 1.5 times as likely to be identified with ASD by 48 months of age as children who were age 8 years.

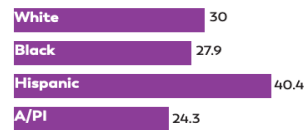
**IQ data available for 86%** of children identified with ASD by MN-ADDM.



**Half of 8 year-old children** were diagnosed by a community provider by 59 months of age.



**Among 8-year-olds,** Black children were about equally likely to be identified with ASD as White children; Hispanic children were 1.3 times more likely to be identified with ASD than White, 1.4 times more likely than Black children, and 1.7 times as likely compared to Asian/Pacific Islander (A/PI) of the same age.



Values indicate prevalence per 1000.

**8-year-old Boys were 4.3 times** as likely to be identified with ASD as girls.



# Missouri

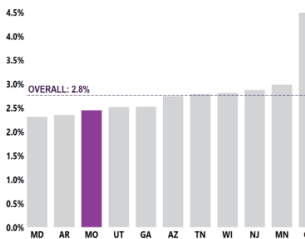
Findings from the Missouri Autism and Developmental Disabilities Monitoring (MO-ADDM) Project help increase understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 41

Or **2.5%** of 8-year-old children were identified with ASD by the MO-ADDM Project in 2020.



This percentage is lower than the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

**Children who were born in 2016 (16%)** were almost 1.8 times as likely to receive an ASD diagnosis or ASD special education classification by 48 months of age compared to children born in 2012.

**Among 8-year-olds,** Black children were 1.2 times as likely and Asian/Pacific Islander (A/PI) children were 1.5 times as likely to be identified with ASD as White children. Children with two or more races were less likely to be identified with ASD compared with all other races except Hispanic children.

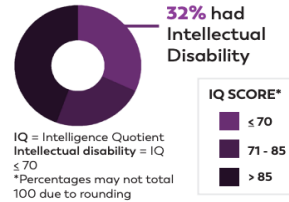


**40% of 8-year-old children & 75% of 4-year-old children** identified with ASD received a Comprehensive Developmental Evaluation by age 3 years

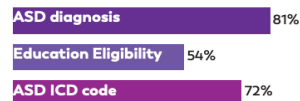
**4-year-old boys** were 2.6x as likely to be identified with ASD than girls



**IQ data available for 61%** of children identified with ASD by MO-ADDM



**Overall, 81% of 8-year-olds** who met the ADDM case definition had an ASD diagnosis by a health care provider; 54% had autism special education eligibility; and 72% had an ASD International Classification of Disease (ICD) code.





# New Jersey

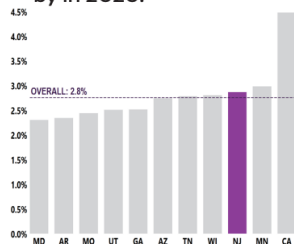
Findings from the New Jersey Autism Study (NJAS) help us to understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 35

Or 2.9% of 8-year-old children in New Jersey were identified with ASD by in 2020.

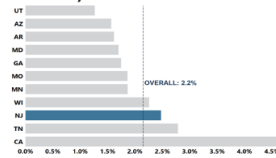


This is higher than the average identified with ASD (2.8%) across US communities where the ADDM Network tracked ASD among school-age children.

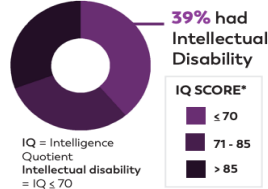
Children aged 4 years were 1.3 times as likely to receive an ASD diagnosis by 48 months of age compared to children aged 8 years in NJAS.

## 1 in 40

Or 2.5% of 4-year-old children were identified with ASD by NJAS.



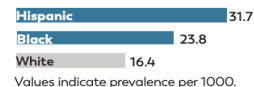
**IQ data available for 63%**  
Of children identified with ASD by NJAS



## 58% of 8-year-old children

were identified with ASD received a Comprehensive Developmental Evaluation by age 3 years

Among NJAS 4-year-olds, Hispanic children were 1.9 times as likely to be identified with ASD and Black children were 1.4 times as likely to be identified with ASD compared to White children.

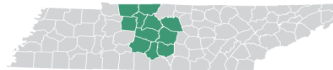


Among 8 year olds, Hispanic, and Black children were 1.7 times as likely to be identified with ASD as White children.



# Tennessee

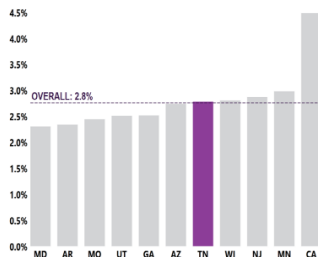
Findings from the Tennessee Autism and Developmental Disabilities Monitoring Network (TN-ADDM) help us understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 36

Or 2.8% were identified with ASD by TN-ADDM in 2020



This percentage is the same as the overall percentage identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

Black children were 1.5 times as likely and Hispanic children were 1.3 times as likely to be identified with ASD by age 4-years as White children.

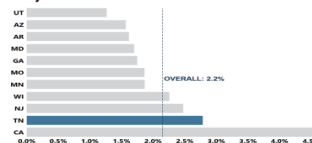


In TN-ADDM, 4-year-olds who met the ADDM case definition:  
71% diagnosed by a healthcare provider  
33% had Autism special education eligibility

93% had an ASD ICD\* code

\*International classification of disease code

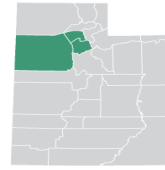
Among 4-year-old children, 1 in 36 or 2.8% were identified with ASD by TN-ADDM in 2020.



44% of 8-year-old children and 67% of 4-year-old children identified with ASD received a comprehensive developmental evaluation by age 3 years.

# Utah

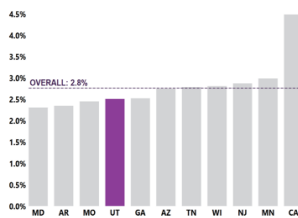
Findings from the Utah Autism and Developmental Disabilities Monitoring (UT-ADDM) Program help understand more about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are first evaluated and diagnosed.



**SITE TRACKING AREA**

## 1 in 40

Or 2.5% of 8-year-old children were identified with ASD in a three-county area in Utah by UT-ADDM in 2020.



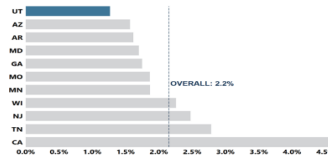
This percentage is similar to the average percentage identified with ASD (2.8%) in all communities in the United States where CDC tracked ASD among 8-year-olds in 2020.

**8-year-old** children living in lower-income neighborhoods had a higher rate of ASD identification compared to children living in higher-income neighborhoods.



For every 2 children identified with ASD who were age 4 there was 1 child who was suspected but not confirmed to have ASD.

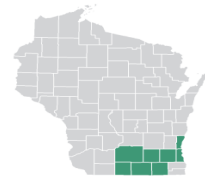
About 1 in 79 or 1.3% of 4-year-old children were identified with ASD in a three-county area in Utah by UT-ADDM in 2020.



This percentage is lower than the overall percentage identified with ASD (2.2%) in all communities tracked by the CDC.

# Wisconsin

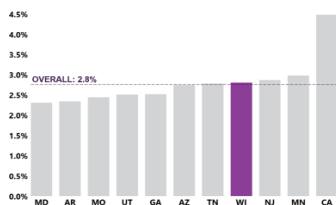
Findings from the Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDs) help understanding about the number of children with autism spectrum disorder (ASD), the characteristics of those children, and the age at which they are evaluated and diagnosed.



**SITE TRACKING AREA**

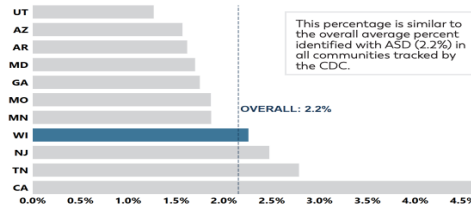
## 1 in 36

Or 2.8% of 8-year-old children were identified with ASD in WISADDs in 2020.



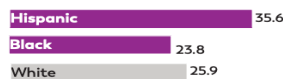
This percentage is higher than it was in 2018 (1.9%) and similar to the overall average percent identified with ASD (2.8%) in all communities where CDC tracked ASD among 8-year-olds in 2020.

About 1 in 44 or 2.3% of 4-year-old children were identified with ASD in WISADDs in 2020.

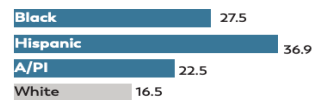


This percentage is similar to the overall average percent identified with ASD (2.2%) in all communities tracked by the CDC.

Among 8-year-old children, Hispanic children were 1.4 times as likely to be identified with ASD as White children. Hispanic 8-year-old children were also 1.4 times as likely to be identified with ASD as Black children.



Among 4-year-olds, Black, Hispanic, and Asian Pacific Islander (A/PI) children were respectively 1.7 times, 2.2 times, and 1.4 times as likely to be identified with ASD as White children.



### **III. Participant Data**

The study included a total of 148 participants, comprising parents of Black\* children with autism spectrum disorder across different age groups, Black\* ASD educators, Black\* special needs educators, pre-k staff, early intervention staff, university faculty, healthcare providers, CARD staff, school psychologists, and community psychologists. From June to December 2022, parents had the opportunity to participate in focus groups, engage in a one-to-one interview, or complete an online survey using the SurveyMonkey platform. Similarly, from January to March 2023, parents of Black\* children with autism spectrum disorder across various age groups, along with Black\* ASD educators, Black\* special needs educators, pre-k staff, early intervention staff, university faculty, healthcare providers, CARD staff, school psychologists, and community psychologists, had the chance to participate once in one of four focus groups, partake in a one-to-one interview, or respond to an online survey sent through SurveyMonkey.

Recruitment for the focus group participants was carried out using various methods, including the FAU CARD Registry, community outreach efforts, phone calls, postal mail, social media, and email. Flyers were designed and disseminated to FAU CARD constituents, local school districts in Gulf, Gadsden, Citrus, Marion, Flagler, St. Johns, Lake, Orange, Hillsborough, Lee, and Monroe counties, as well as county agencies. Additionally, the flyers were posted on FAU CARD's social media platforms. Invitations to participate were sent directly to parents of Black\* children registered with FAU CARD via email and traditional mail using the US Postal Service. The focus groups and interviews were conducted online through the Zoom platform, while the surveys were completed online using the SurveyMonkey platform.

**Participants:**

***Black\* parents:*** parents with origins in any of the Black racial groups of Africa, including

persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

***Black\* special needs educators:*** staff members assigned the professional activity of instructing students in courses in classroom situations, including exceptional student education, with origins in any of the Black racial groups of Africa, including persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

***Black\* autism spectrum disorder educators:*** staff members assigned the professional activity of instructing students in courses in classroom situations, specifically for children identified with autism spectrum disorder, with origins in any of the Black racial groups of Africa, including persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

***Center for autism and related disabilities staff:*** professionals working at the Center for Autism and Related Disabilities.

***Community psychologists:*** professionals licensed according to s. 490.005(1), s. 490.006, or the provision identified as s. 490.013(2) in s. 1, chapter 81-235, Laws of Florida. (Florida Board of Psychology, 2021).

***Early intervention staff:*** professionals specialized in providing support and services to young

children who have a disability or developmental delay and to their families (Florida Department of Education [FDOE], 2022).

***Exceptional student education staff and directors:*** professionals who support a child in the school setting with services designed to meet the child's unique needs and help the child progress in school and prepare for life after school (Florida Department of Education, 2022).

***Health care providers:*** professionals, e.g., neurologists, pediatricians, who are authorized to practice medicine within the scope of their practice as defined by State law (Family and Medical Leave Act of Advisor, 2017).

***Pre-kindergarten staff:*** personnel responsible for care, protection, and supervision of a child, for a period of less than 24 hours a day on a regular basis.

***School psychologists:*** professionals responsible for advising students regarding their abilities and aptitudes, educational and occupational opportunities, personal and social adjustments, for providing placement services, and for performing educational evaluations and similar functions (Florida Department of Education, 2020).

***University faculty:*** full-time equivalent teaching faculty member at a university according to Florida Statutes, chapter 1012, section 945 (Florida Senate, 2023)

Participant Data by County										
Districts	Black* Parents	Black* ASD Educators	Black* Special Needs Educators	Pre-K Staff	Early Intervention Staff	University Faculty	Health Care Providers	CARD Staff	School Psychologists	Community Psychologists
Citrus	3	0	1	0	2	1	0	0	2	0
Flagler	0	0	0	0	0	0	0	0	1	0
Gadsden	1	0	0	0	1	1	0	0	0	0
Gulf	1	0	0	0	0	0	0	0	0	0
Hillsborough	12	1	4	6	1	0	1	3	0	0
Lake	6	2	0	0	1	0	0	2	0	0
Lee	2	0	0	0	0	1	0	1	0	0
Marion	2	0	1	0	1	1	1	1	0	1
Monroe	3	0	0	0	0	0	0	4	0	0
Orange	51	3	3	1	1	0	3	4	1	1
St. Johns	3	0	0	0	1	1	1	0	2	0
<b>Total (n=148)</b>	<b>84</b>	<b>6</b>	<b>9</b>	<b>7</b>	<b>8</b>	<b>5</b>	<b>6</b>	<b>15</b>	<b>6</b>	<b>2</b>

Participant Data by Race (Count/Percentage)											
Race	Black* Parents	Black* ASD Educators	Black* Special Needs Educators	Pre-K Staff	Early Intervention Staff	University Faculty	Health Care Providers	CARD Staff	School Psychologists	Community Psychologists	%
Black*	84	6	9	2	1	4	3	4	2	1	78.38%
White	0	0	0	3	7	1	3	9	4	1	18.92%
Latinx	0	0	0	1	0	0	0	1	0	0	1.35%
Asian	0	0	0	0	0	0	0	0	0	0	0%
Two or More Races	0	0	0	0	0	0	0	0	0	0	0%
Other	0	0	0	1	0	0	0	1	0	0	1.35%

#### **IV. Lessons Learned from the Focus Groups of Black\* Family Members**

The parents were completely open and transparent, willingly sharing their personal stories through interviews and narratives, and actively engaging in a concise focus group. By gaining a comprehensive understanding of their experiences, we were able to develop a deep awareness of their perspectives and unearth valuable information that might have otherwise remained confined to the participants. Our research findings from the focus groups with Black\* parents shed light on the following key insights:

- Black\* parents faced barriers in obtaining ASD identification and the start of treatment services for their children. Black\* parents remain motivated and eager to receive the ASD diagnosis for their child and pick up on the start of the appropriate intervention to meet the therapeutic needs their child desperately requires. The results indicate strongly that it is necessary for Black\* parents to be heard and understood and be comfortable and welcomed during the ASD identification process.
- Lack in support groups - many Black families do not believe in the notion of a disability or show delayed acceptance; many Black families are more insistent on prayer and discipline as cures and treatments for any disorder. The help of support groups will appropriately guide parents in the right direction for help and care for their child. More importantly – acceptance.
- Black\* parents are more likely to mistrust health care professionals and other aiding professionals during the ASD identification process due to poor or failed client-patient relationships and the lack of cultural perspective.
- Until they had been in the identification process for an extended period or received their initial misdiagnosis, Black\* parents were unaware of the delays in identifying and initiating treatment for their child's condition.
- In addition, Black\* parents expressed that their communities lacked acceptance of ASD identification and had limited knowledge about ASD, creating significant

barriers that hindered them from obtaining an ASD diagnosis and accessing appropriate treatment for their children.

- Black parents have challenges with third party payers and reoccurring insurance denials.
- Black\* parents consistently voiced that they have been discriminated against due to their race. Black\* parents had their concerns brushed off, told to "wait and see," or denied resources. Many Black\* parents were frustrated and had no hope in accurately identifying their child with ASD.
- Black\* parents perceived a sense of bias from health care providers and school staff, believing that they would have received more assistance if these professionals had belonged to their own racial background. They also observed that White parents were provided with greater resources and more screenings for ASD, which further reinforced their feelings of unequal treatment.
- Black\* parents expressed a strong sense of dedication in their efforts to provide suitable care for their children and to acquire culturally relevant tools and strategies that could benefit their child's development.
- Black\* parents seek additional information that would enable them to identify their child with ASD accurately and promptly. By doing so, they aim to enhance their ability to support their child's progress and facilitate their overall improvement effectively.



## V. Qualitative results from focus groups, targeted interviews, and surveys

### Response Statements from Participants

"Oh, he'll be okay. It's just a phase that most kids go through. If it doesn't get better, then you let us know."  
- Black\* Parent

"It was difficult. I was pointed in a lot of different directions, but I took the time to actually start learning because I didn't even understand the whole autism diagnosis."  
- Black Parent - Black\* Parent

"Every step to get services for him was a complete fight. Even after he was diagnosed my family was resistance. I still have family members on his dad's side and also on my side, that will say "Well, he doesn't look autistic, I just think you got him misdiagnosed."  
Black\* Parent

"I was being brushed off, and I made it a point to constantly tell them [professionals], "My son needs to be checked out. If it wasn't for the daycare, we probably would just be getting a diagnosis."  
- Black\* Parent

"I could tell they were coming into my home with preconceived notions. The [professionals] were like, "Oh, you're doing this," and, "Oh, she eats that". I don't know how it would happen in a White home or a different home. But I could tell they were trying to see what my lifestyle was."  
Black\* Parent

"Well, maybe we should wait." That's when I pushed and said I don't want to wait and they [professional] said, "Well, you know, she's not quite far behind. You know, she'll catch up." I was like, "No, I don't want to wait. I want to start now." They said, "Well, we don't really see any other signs that could indicate that she may be."  
Black\* Parent

"I'm more outspoken than anything because I know that minority children are the ones that get services later. I know the prognosis without early intervention so I speak up and let them know they need to get services."  
- Community Psychologist

"I kept saying to her, "These are my concerns. This is what's been brought to my attention." She [professional] kept passing me over and saying that's too large of a diagnosis to place on him. It wasn't until an appointment where he was banging his head against the wall and banging his head against the floor and spinning around in circles screaming at the top of his lungs when finally, she saw it with her own eyes."  
Black\* Parent

"Oh, just keep waiting. Just keep waiting"  
Black\* Parent

"I really didn't have that many clients that would come to me by parents noticing it themselves first initially.... they will brush it out into something else."  
- Community Psychologist

"When they knew I was Haitian and, and I'm speaking Creole with them, they were more open to sharing diagnosis the symptoms. And they were more receptive regarding the treatment."  
- Community Psychologist

"I moved to central Florida two years ago. Due to me having private practice and self-pay, unfortunately, my clients have been more predominantly white."  
- Community Psychologist

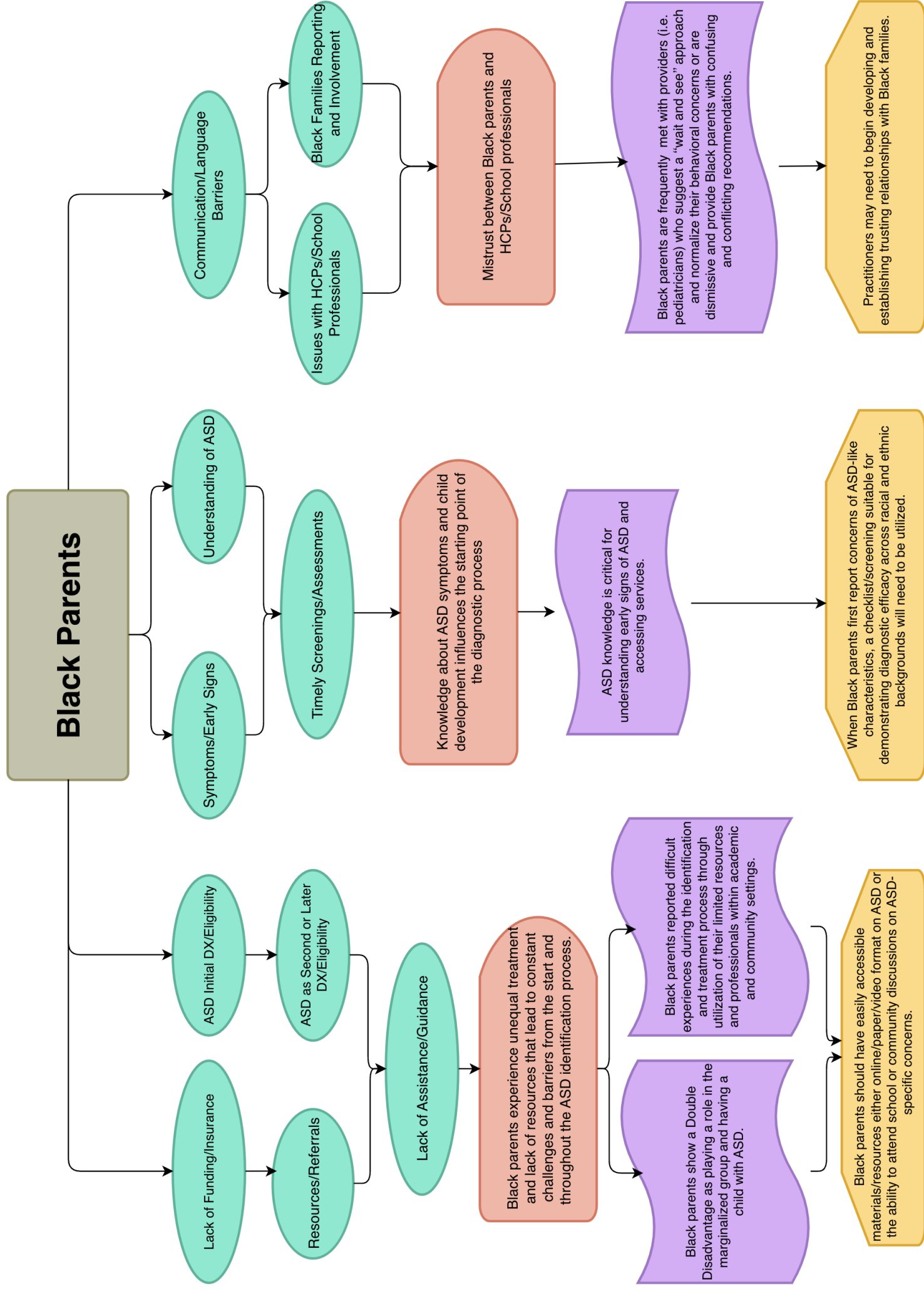
"So I refer them [Black parents] to all these resources that's within the community to get them started on there and then we'll push for these interventions. So I try to connect them with community agencies, the schools and making sure they get these healthcare services put into place"  
- Community Psychologist

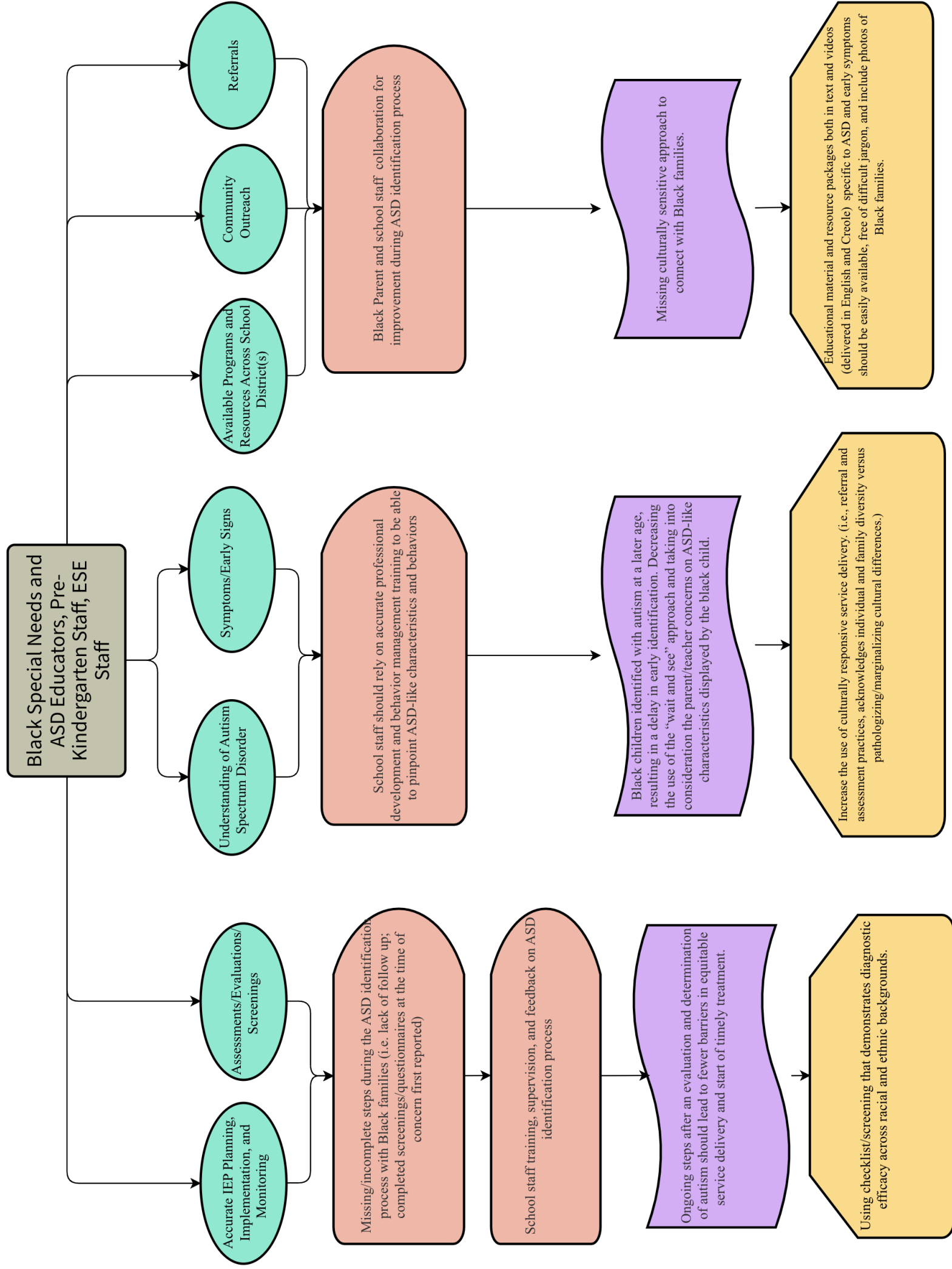
"I think once they are once they are aware and they have all these services, they are more receptive to followthrough."  
- Community Psychologist

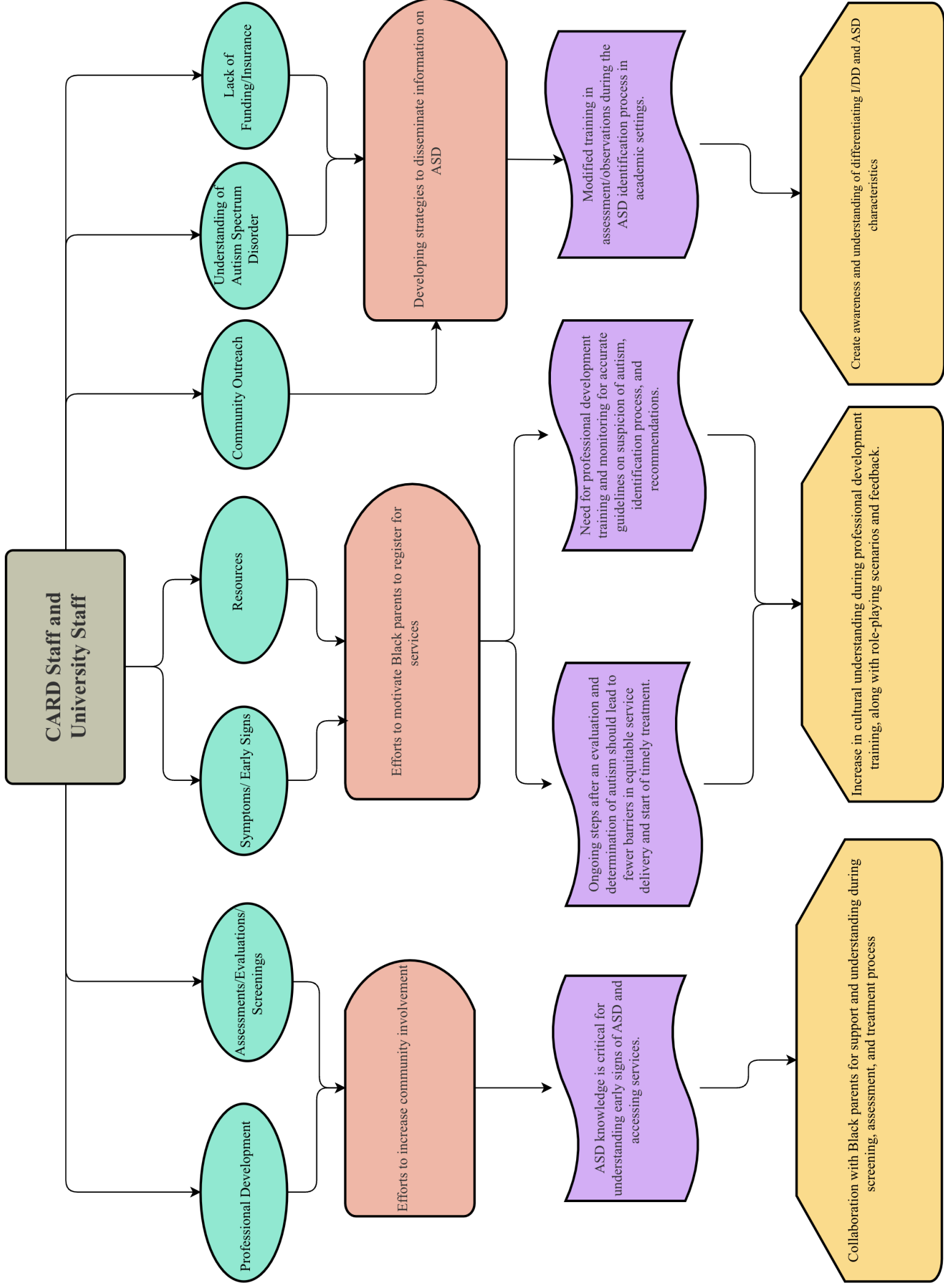
"A lot of times the videos of people that they're watching don't look like them [Black families]. So we need to make them feel included and find ways to include them"  
- University Staff

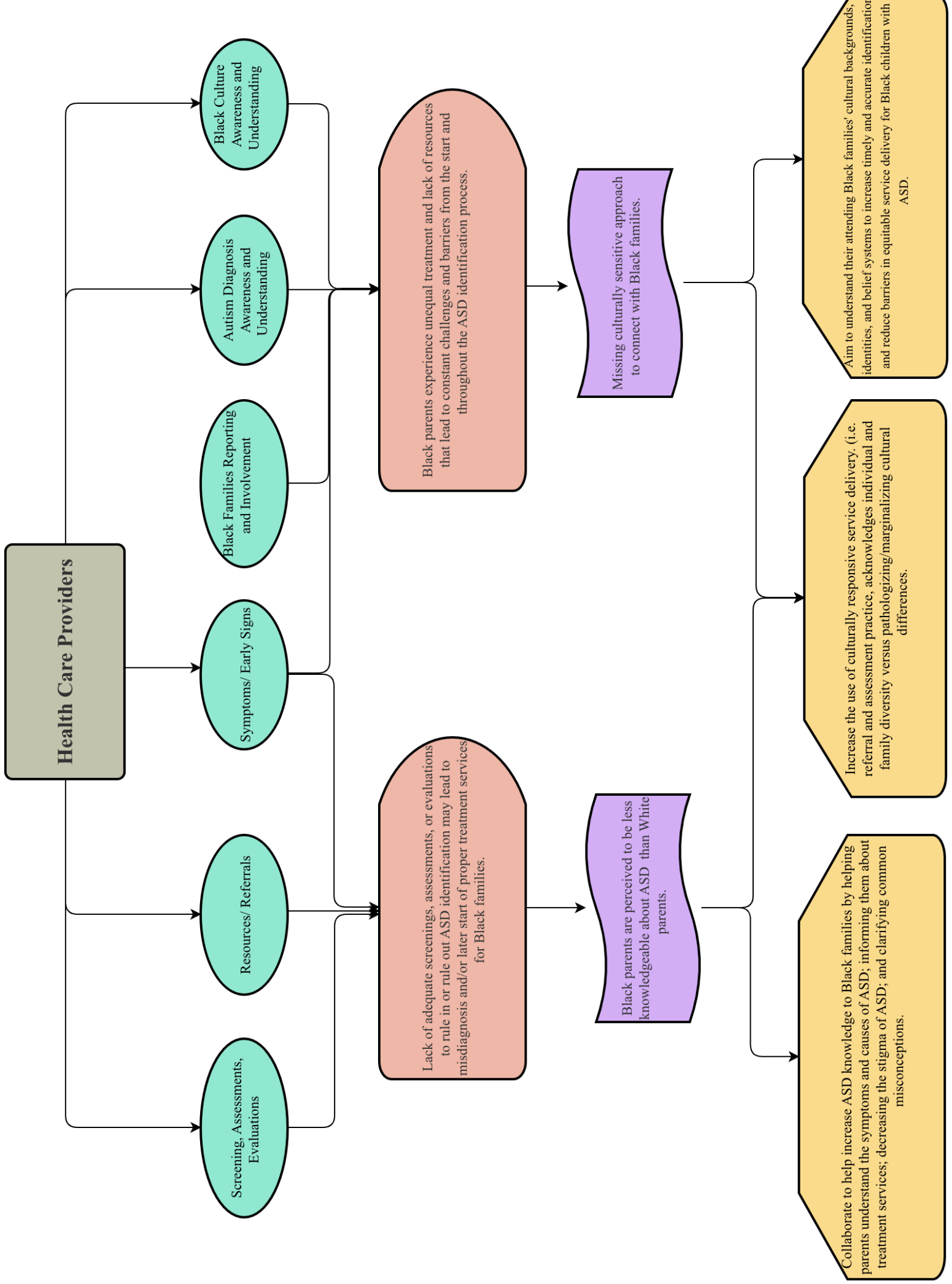
"I talked to [Black] parents who maybe their child was showing signs when they were preschoolers, but they were seen as, "Oh, they have a behavior problem or something else is going on."  
- University Faculty

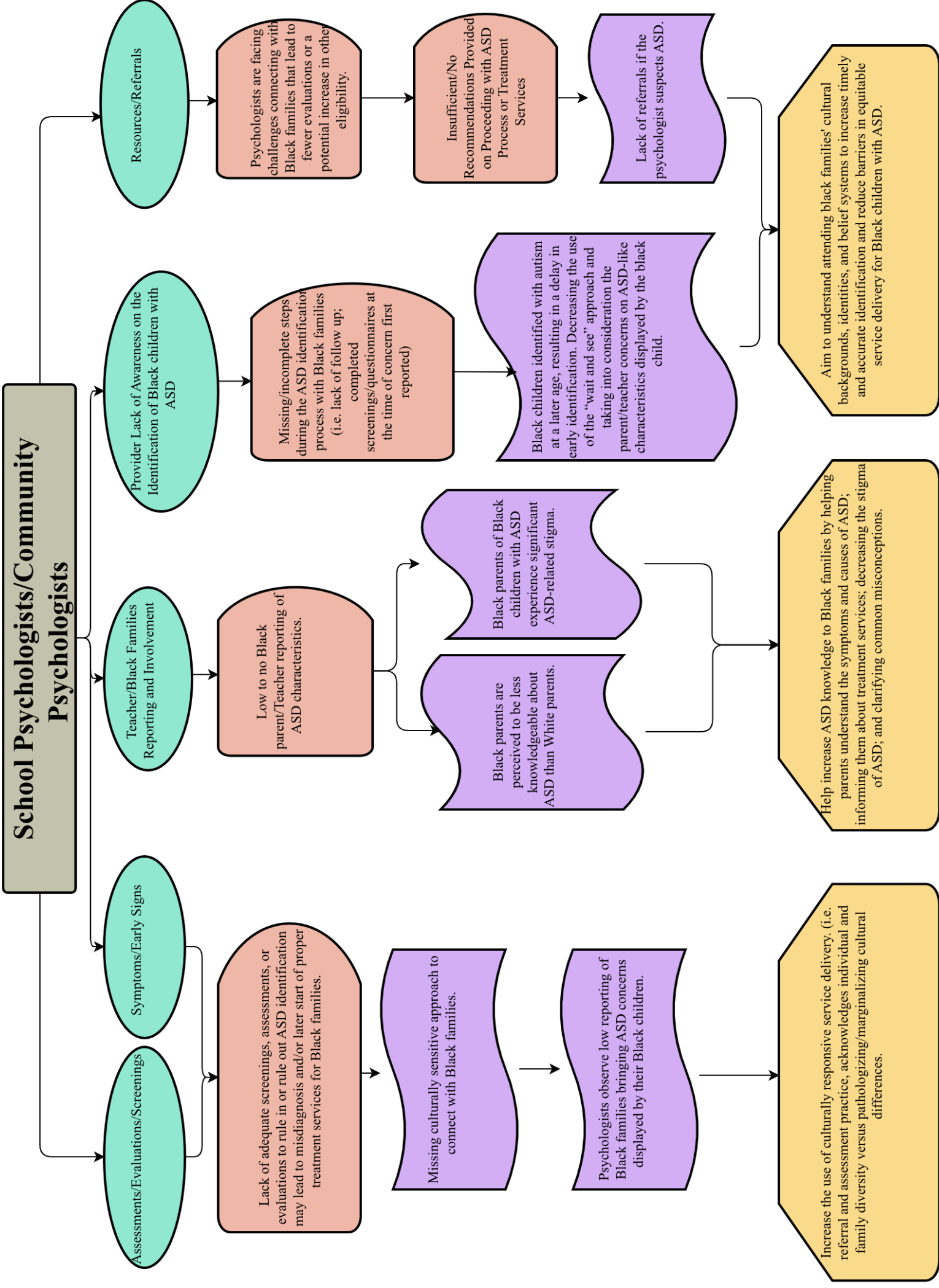
"I've learnt about how Black parents can be very skeptical of our labels. They're sceptical of our medical professionals and our professionals that are doing these diagnoses"  
- University Faculty













## VI. Quantitative Results from Surveys

### Key Quantitative Findings

<b>School Psychologists</b>  (n= 6 Participants)	<b>Community Psychologists</b>  (n= 1 Participant)
<p>According to our data, 50% of school psychologists reported that they are very comfortable in identifying the red flags of autism with Black parents. Only 33% of school psychologists provided resources to Black parents to collect information on developmental milestones.</p> <p>Results show that 67% of school psychologists never referred Black parents to a developmental pediatrician or pediatric neurologist to rule autism in or out autism.</p> <p>Based on our data, 50% of school psychologists reported that they do not see autism manifesting differently in White and Black children.</p>	<p>Based on our survey data from one community psychologist participant, sometimes Black parents report concerns of their child exhibiting ASD symptoms. The community psychologist was uncomfortable in identifying the red flags of autism with Black parents and sometimes referred Black parents to a developmental pediatrician or pediatric neurologist to rule out autism. It was reported that the community psychologist does not see autism manifesting differently in White and Black children.</p>

<p><b>Early Intervention Staff</b></p>	<p><b>Pre-K Staff</b></p>
<p>(n= 8 Participants)</p> <p>Based on our results, 50% of early intervention staff reported that they are not sure of any professional development training provided for staff working with children, parents, and families of culturally and linguistically diverse family.</p> <p>Our results show that 62% of early intervention staff do not have training in their work setting that explains the red flags of autism.</p> <p>It was reported that 37% of early intervention staff are not able to differentiate the difference between autism and DD for a Black child.</p> <p>Last, 37% of early intervention staff are able to differentiate the difference between autism and EBD for a Black child.</p>	<p>(n= 7 Participants)</p> <p>Our data shows that 57% (n= 4) of pre-k staff had training in their work setting that explains the red flags of autism.</p> <p>It was reported that 57% of pre-k staff are able to differentiate the difference between autism, DD, and EBD for a Black child.</p> <p>According to our survey results, 43% of pre-k staff reported that Black children are very frequently referred for ASD and DD.</p> <p>Based on the data, 29% of pre-k staff reported that Black children are very frequently referred for EBD.</p>



Results show that 75% of early intervention staff reported that Black children are occasionally referred for ASD.	The results show that 71% of pre-k staff have not observed that DD/EBD eligibility is being used more with Black students than others.
According to our results, 50% of early intervention staff reported that Black children are frequently referred for DD.	According to our results, 43% of pre-k staff reported that Black parents are frequently involved in the process and they are not hesitant to identify their child with ASD.
It was reported that 50% of early intervention staff reported that Black children are occasionally referred for EBD.	Based on the data, 57% of pre-k staff reported that they frequently ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed.
The data reported that 50% of early intervention staff do not observed that DD/EBD eligibility is being used more with Black students than others.	The data reported that 86% of pre-k staff meet the observation requirements during the assessment process when a child is under five.
Early intervention staff reported that Black parents are occasionally involved in the	Our report shows 71% of pre-k staff do not see autism manifesting differently in White and Black children.

process.

The data shows that 62% of early intervention staff felt Black parents are hesitant to identify their child with ASD.

Based on the survey results, 75% of early intervention staff reported that they very frequently ensure that the Black parent's concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed.

50% of early intervention staff reported that they met the observation requirements for the assessment process for children under five.

<b>Black* ASD Educators</b>	<b>Black* Special Needs Educators</b>
(n= 6 Participants)	(n= 9 Participants)
Based on the results, 67% of Black* ASD educators report that they have had training in their work setting that explains the red flags of autism.	According to our survey results, 56% of Black* special needs educators reported that they may have received training in their work setting that explains the red flags of autism.
According to our data, 83% of Black* ASD educators are able to differentiate the difference between autism and DD for a Black child.	Our data shows that 33% of Black* special needs educators can differentiate the difference between autism and DD for a Black child; while 44% of Black* special needs educators reported that they may be able to differentiate the difference between autism and EBD for a Black child.
100% of Black* ASD educators were able to differentiate the difference between autism and EBD for a Black child.	Results show that 67% of Black* special needs educators reported that Black children are occasionally referred for ASD, while 78% reported that Black children are frequently referred for DD and very frequently referred for EBD.

<p>Our results show that 33% of Black* ASD educators reported that Black children are frequently referred for ASD.</p>	<p>Based on the survey results, 56% of Black* special needs educators have observed that DD/EBD eligibility is being used more with Black students than others.</p>
<p>Based on the survey results 50% of Black* ASD educators reported that Black children are frequently referred for DD.</p>	<p>According to our data, 56% of Black* special needs educators reported that Black parents are occasionally involved in the process, and 67% of Black* special needs educators feel like Black parents are hesitant to identify their child with ASD.</p>
<p>According to our result, 67% of Black* ASD educators reported that Black children are very frequently referred for EBD.</p>	<p>Our data reported that 44% of Black* special needs educators said they may meet the observation requirements during the assessment process when a child is under five.</p>
<p>50% of Black* ASD educators reported that they have observed that DD/EBD eligibility was being used more with Black students than others.</p>	<p>It was reported that 67% of Black* special needs educators frequently ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed.</p>

Results of the survey show that 33% of Black\* ASD educators reported that Black parents are frequently or occasionally involved in the process.

Based on the survey, 83% of Black\* ASD educators felt Black parents are hesitant to identify their child with ASD.

The result shows that 50% of Black\* ASD educators very frequently ensure that the Black parent's concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed.

The data reported that 83% of Black\* ASD educators meet the observation requirements during the assessment process when a child is under five.

<p><b>University Faculty</b></p> <p>(n= 4 Participants)</p>	<p><b>CARD Staff</b></p> <p>(n= 7 Participants)</p>
<p>Based on our data, 50% of university faculty reported that they often gather up-to-date information and latest research findings on autism. According to our research results, 100% of university faculty reported that they think there are barriers for Black parents trying to receive an ASD identification for their child. Our report shows that 50% of university faculty did not see autism manifesting differently in White and Black children.</p>	<p>Based on the results, 71% of CARD staff report that they never screen for autism or autism for Black children.</p> <p>According to the data, 57% of CARD staff said that they are very comfortable in identifying the red flags of autism.</p> <p>43% of CARD staff are either neutral or very comfortable in identifying the red flags of autism with Black parents.</p> <p>Per the data, 57% of CARD staff reported that they sometimes have Black parents reporting concerns of their child exhibiting ASD symptoms.</p> <p>Following the survey results, 43% of CARD staff said that they never provide resources to Black parents to collect information on</p>

	<p>developmental milestones.</p> <p>According to the results, 100% of CARD staff reported that they do not have designated support groups for Black parents.</p> <p>Our results show that 71% of CARD staff reported that having a Black parent support group or outreach program for the Black community may be successful in gathering Black individuals.</p> <p>The data indicate that 57% of CARD staff reported a moderate retention rate for Black parents to attend and stay within the program.</p> <p>Results from the survey show that 71% of CARD staff have a strategy plan to increase the number of Black CARD constituents.</p> <p>According to the results, 43% of CARD staff reported that either autism does not manifest</p>
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	differently in White and Black children or it may manifest differently.
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## **Healthcare Providers**

(n= 6 Participants)

According to our data, 50% of healthcare providers reported that they may take action steps to guide parents through the ASD identification process.

33% of healthcare providers reported that they rarely screen for autism and 50% of healthcare providers rarely screen for autism for Black children.

Based on our survey results, 50% of healthcare providers were very comfortable in identifying the red flags of autism.

Our results show that 50% of healthcare providers were very comfortable in identifying the red flags of autism with Black parents.

According to the survey, 50% of healthcare providers reported that sometimes Black parents report concerns of their child exhibiting ASD symptoms.

It was reported that 33% of healthcare providers report that they rarely conduct follow ups with your Black parents after their ASD or other identification.

50% of healthcare providers reported that they often provide information, resources, or referrals to Black parents when they first report signs of ASD.

Our survey results show that 50% of healthcare providers sometimes provide resources to Black parents to collect information on developmental milestones.

According to the survey results, 50% of healthcare providers always refer Black parents to a developmental pediatrician or pediatric neurologist to rule out autism when they suspect a child has autism.

The data shows that 50% of healthcare providers do not see autism manifesting differently in White and Black children.

## **Black\* Parents**

(n= 78 Participants)

According to the survey results, 69% of Black\* parents said that they had difficulties during the process of receiving an ASD identification for their child.

Based on the survey data, 90% of Black\* parents reported that they had concerns and suspicious of autism since their child's early years.

Our results show that 22% of Black\* parents reported that their pediatrician sometimes agreed with their concerns and suspicion of autism.

According to the data, 28% of Black\* parents reported that their pediatrician never instructed them on how to proceed forward with autism diagnosis and treatment.

Our results indicate that 37% of Black\* parents reported that the information that was provided by the pediatrician was never enough to learn about autism to support their concerns for their child.

Based on the results, 36% of Black\* parents reported that sometimes family members or school members share the same concerns.

The results show that 28% of Black\* parents reported they sensed that the individuals

assessing/observing their child never knew what autism looks like for Black children.

72% of Black\* parents said that their child was not identified with autism within the school setting.

The survey results show that 92% of Black\* parents reported that their child was identified with autism by a medical provider (i.e, neurologist, clinical psychologist, or developmental pediatrician).

The data indicates that 76% of Black\* parents reported that their child was eligible for other disability categories such as Developmental Delay, Intellectual Disability, or Emotional Behavioral Disability, in the school setting.

According to the data, 63% of Black\* parents reported that autism is their child's first diagnosis/eligibility.

Results from the survey indicate that 51% of Black\* parents did not seek a second opinion from another school or medical provider to receive another eligibility or diagnosis.

84% of Black\* parents report that they are not trying to obtain a medical diagnosis of autism.

Following the survey results, 62% of Black\* parents reported that someone or something guided them through the process of obtaining autism resources and treatment services.

Per the results, 62% of Black\* parents report that they saw a better progress during the time of treatment.

According to the data, 33% of Black\* parents reported that they sometimes faced barriers to obtaining resources and treatment.

Based on the survey, 45% of Black\* parents reported that the identification of autism led them to the right treatment.

Per the survey data, 65% of Black\* parents reported that their child enrolled in the Early Steps or the Child Find program.

66% of Black\* parents report that their child could have been identified earlier.

According to the data, 36% of Black\* parents report that their child's treatment maybe was impacted by being Black.

Based on the survey, 37% of Black\* parents agreed that their journey was more or less difficult because of their race.

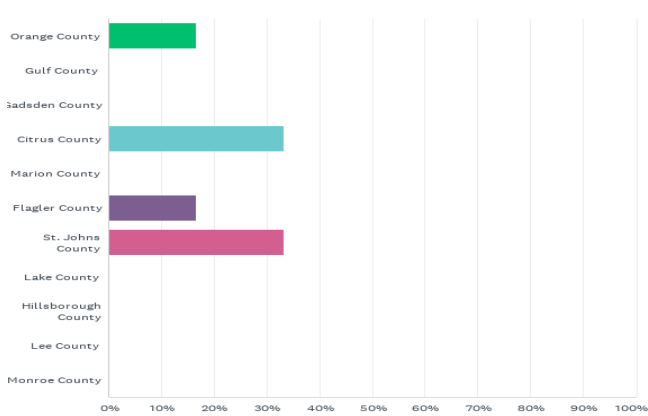
The data reported that 76% of Black\* parents reported that knowing the information they now know, they would do the process differently.

Results indicated that 94% of Black\* parents report that further training on the autism identification process for Black children should be provided to school professionals and pediatricians.

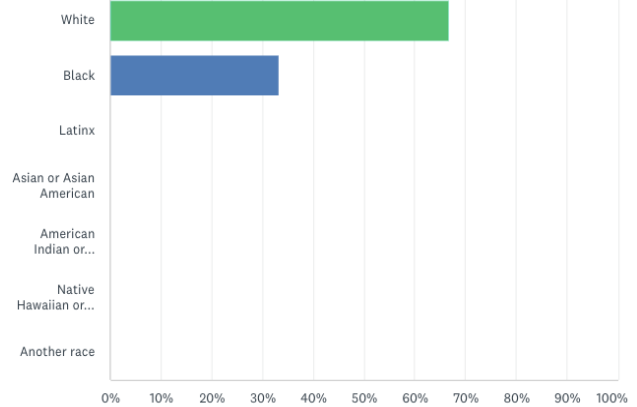
Following the data, 63% of Black\* parents reported that delayed identification of autism impacted their child.

## School Psychologists Survey Results

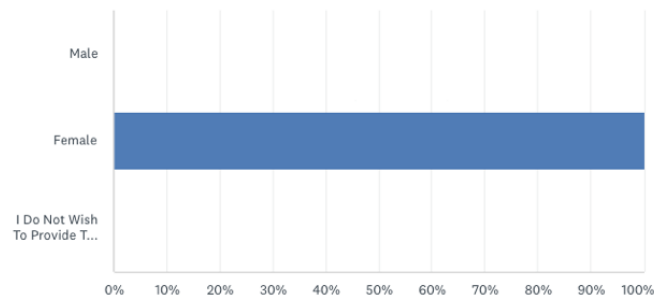
### Q1: Where are you located:



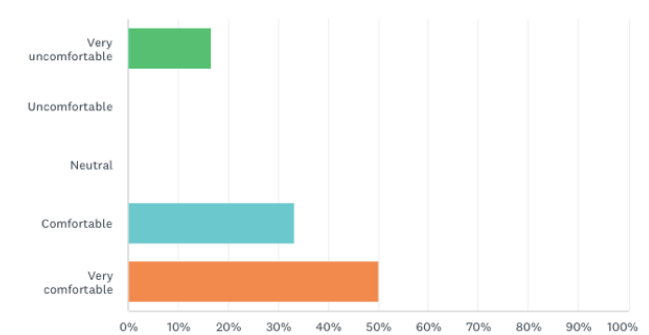
### Q2: Race:



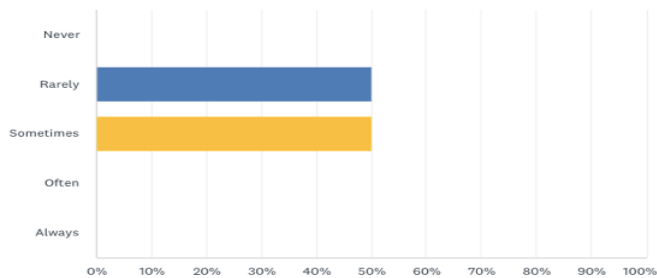
### Q3: Gender:



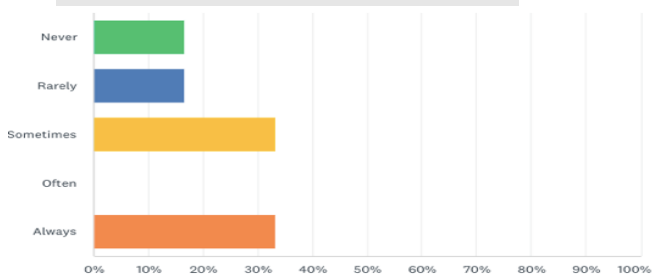
### Q4: How comfortable are you in identifying the red flags of autism with Black parents?



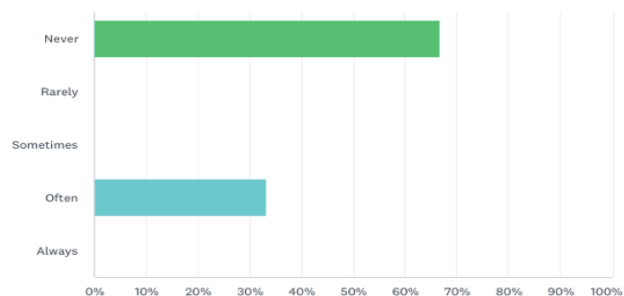
### Q5: Based on your experience, how often do you have Black parents reporting concerns of their child exhibiting ASD symptoms?



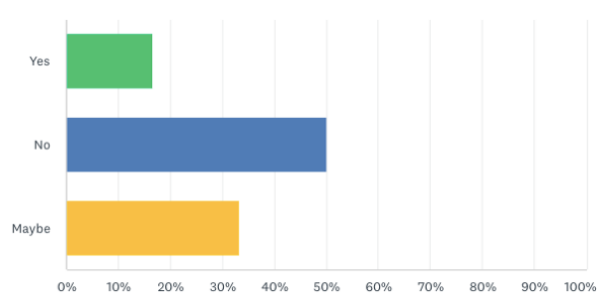
### Q6: Do you provide resources to Black parents to collect information on developmental milestones?



**Q7: When you suspect a child has autism do you refer Black parents to a developmental pediatrician or pediatric neurologist to rule out autism?**



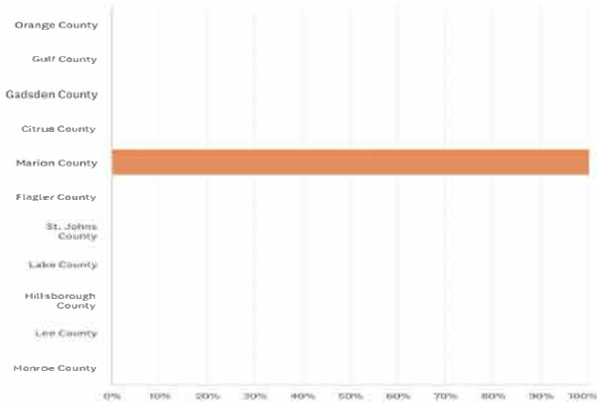
**Q8: Do you see autism manifesting differently in White and Black children?**



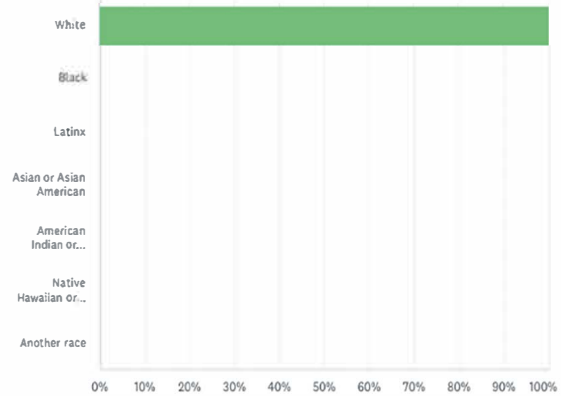


# Community Psychologists

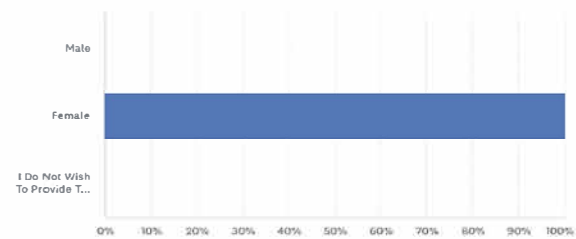
**Q1: Where are you located:**



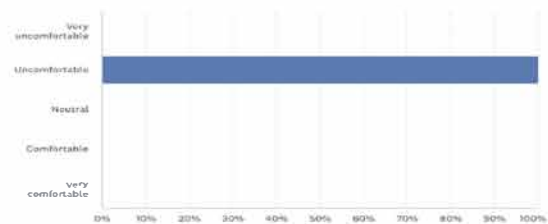
**Q2: Race:**



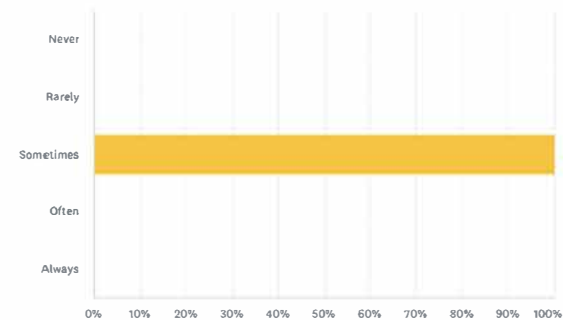
**Q3: Gender:**



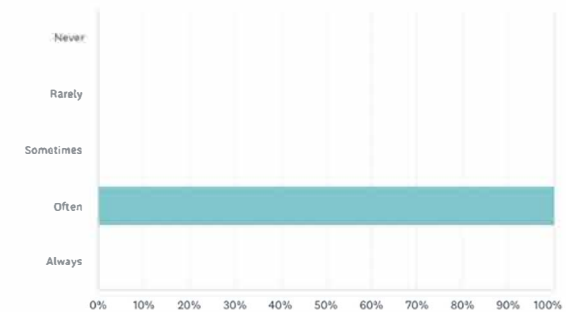
**Q4: How comfortable are you in identifying the red flags of autism with Black parents?**



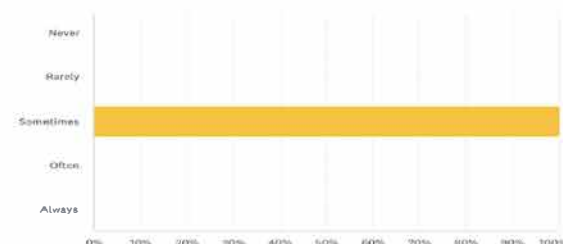
**Q5: Based on your experience, how often do you have Black parents reporting concerns of their child exhibiting ASD symptoms?**



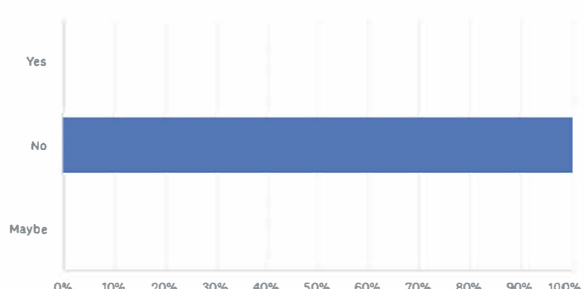
**Q6: Do you provide resources to Black parents to collect information on developmental milestones?**



**Q7: When you suspect a child has autism do you refer Black parents to a developmental pediatrician or pediatric neurologist to rule out autism?**

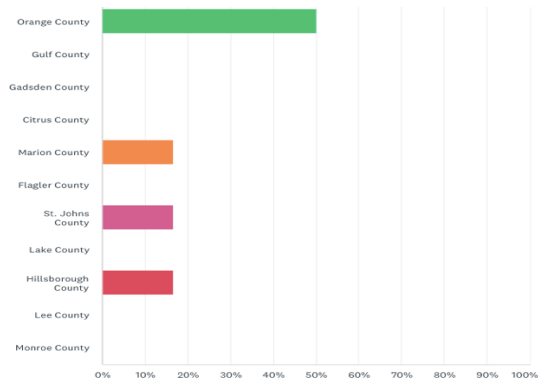


**Q8: Do you see autism manifesting differently in White and Black children?**

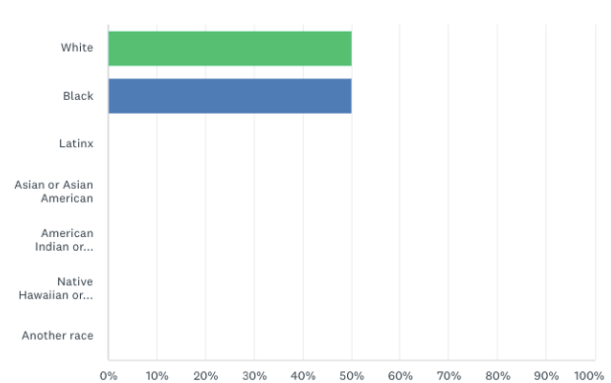


## Health Care Providers

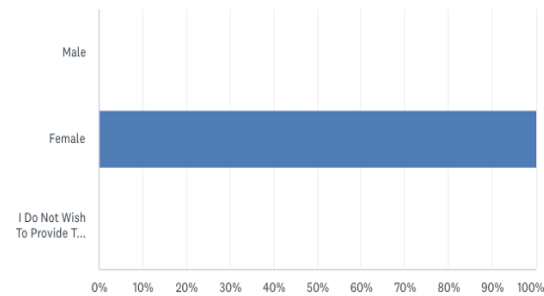
**Q1: Where are you located:**



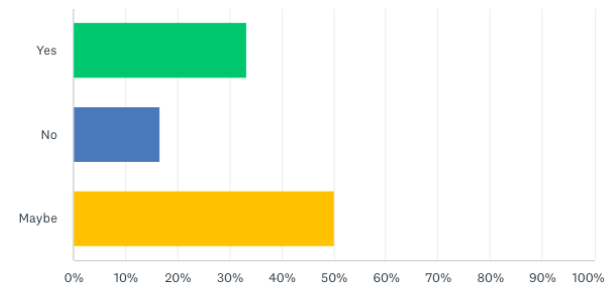
**Q2: Race:**



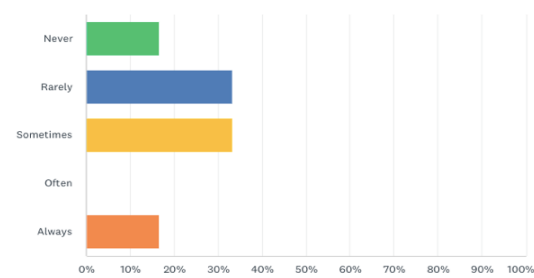
**Q3: Gender:**



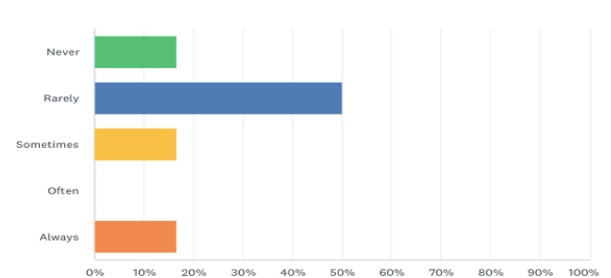
**Q4: Do you take action steps to guide parents through the ASD identification process?**



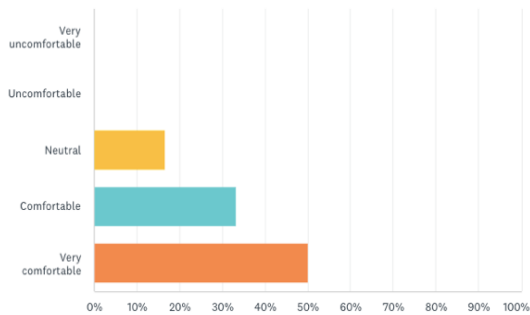
**Q5: How often do you screen for autism?**



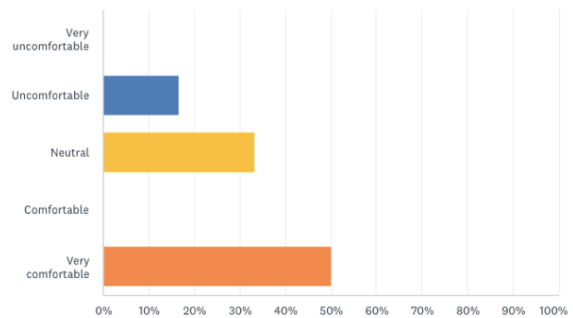
**Q6: How often do you screen for autism for Black children?**



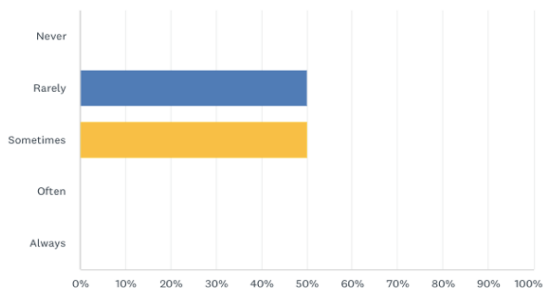
**Q7: How comfortable are you in identifying the red flags of autism?**



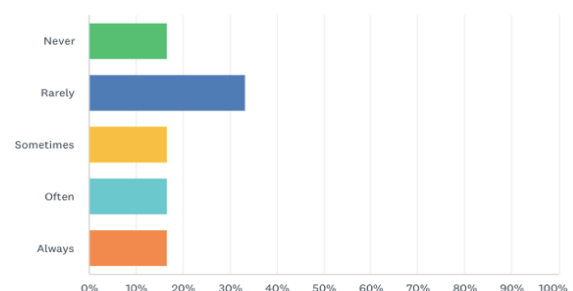
**Q8: How comfortable are you in identifying the red flags of autism with Black parents?**



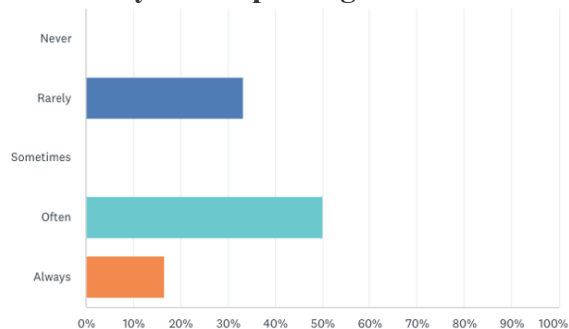
**Q13: Based on your experience, how often do you have Black parents reporting concerns of their child exhibiting ASD symptoms?**



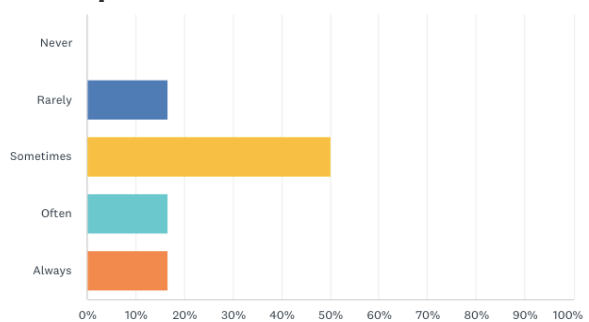
**Q14: Do you conduct follow ups with your Black parents after their ASD or other identification?**



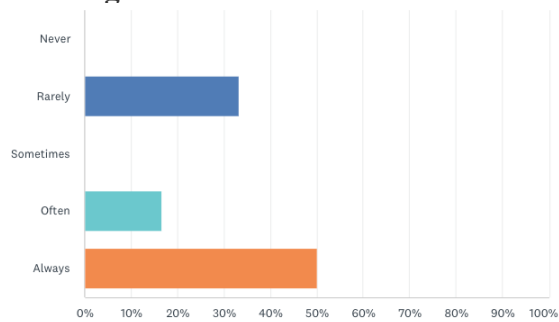
**Q15: Do you provide information, resources, or referrals to Black parents when they first report signs of ASD?**



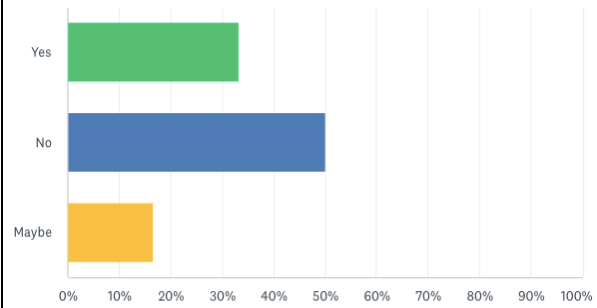
**Q16: Do you provide resources to Black parents to collect information on developmental milestones?**



**Q17: When you suspect a child has autism do you refer Black parents to a developmental pediatrician or pediatric neurologist to rule out autism?**

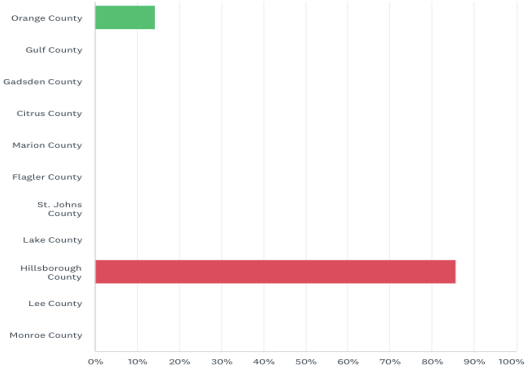


**Q18: Do you see autism manifesting differently in White and Black children?**

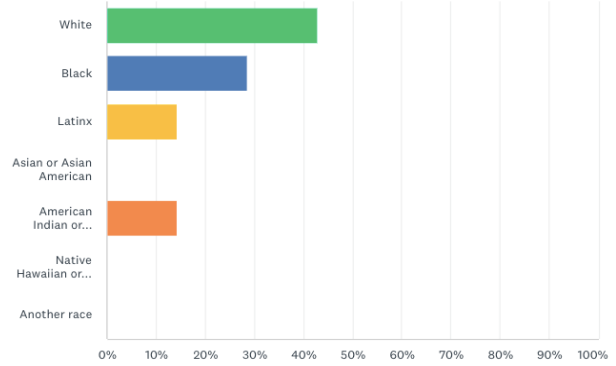


## Pre-K Staff

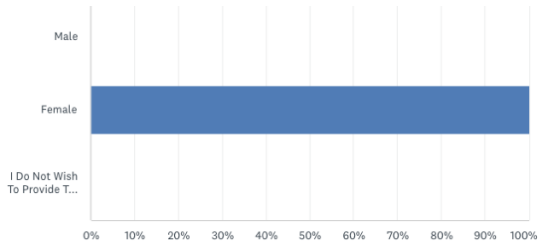
**Q1: Where are you located:**



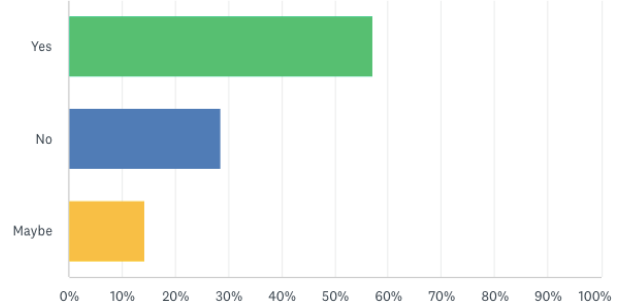
**Q2: Race:**



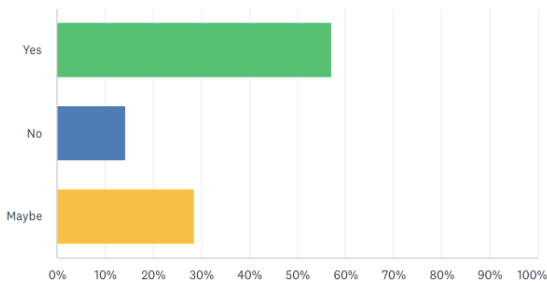
**Q3: Gender:**



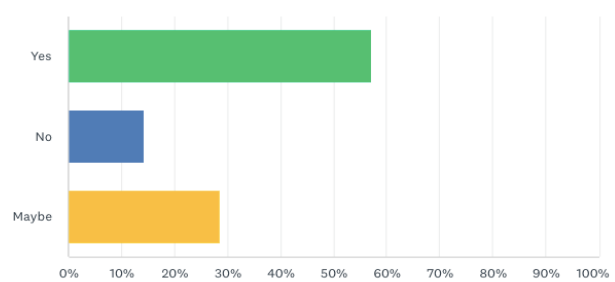
**Q4: Do you have training in your work setting that explains the red flags of autism?**



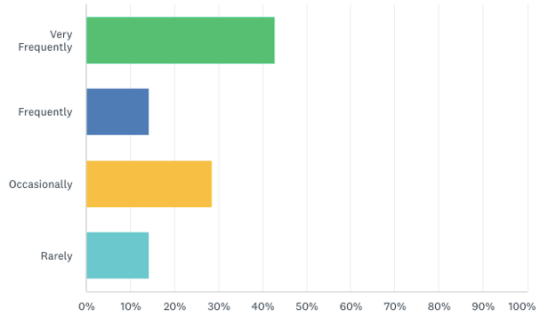
**Q5: Are you able to differentiate the difference between autism and DD for a Black child?**



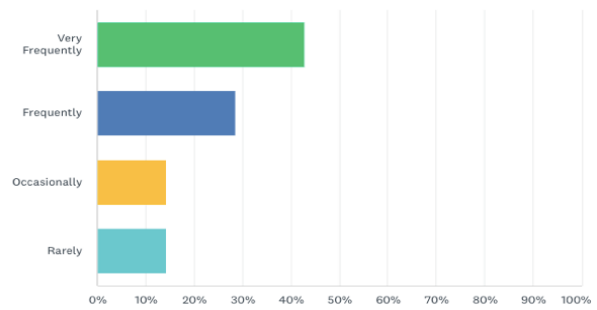
**Q6: Are you able to differentiate the difference between autism and EBD for a Black child?**



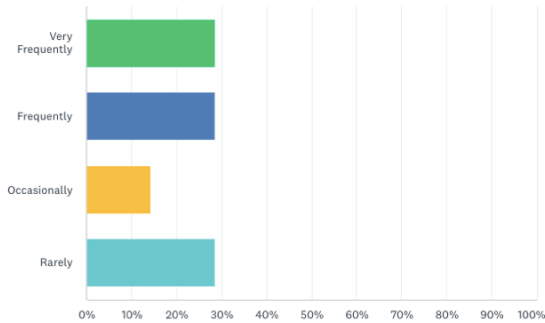
**Q7: Based on your experience, how frequently are Black children referred for ASD?**



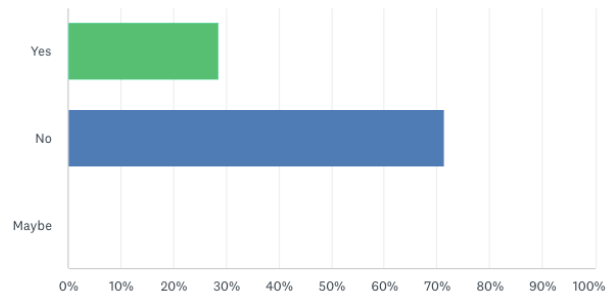
**Q8: How frequently are Black children referred for DD?**



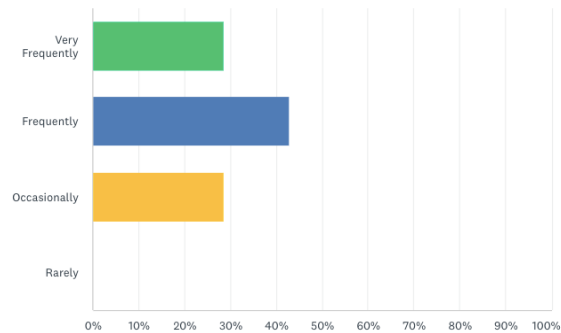
**Q9: How frequently are Black children referred for EBD?**



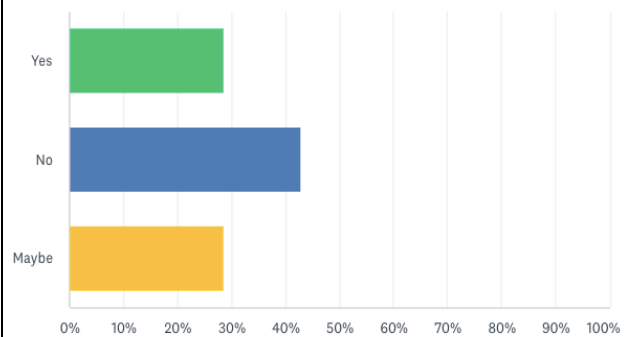
**Q10: Have you observed that DD/EBD eligibility is being used more with Black students than others?**



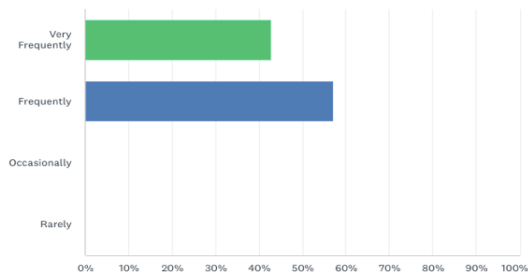
**Q11: How often are Black parents involved in the process?**



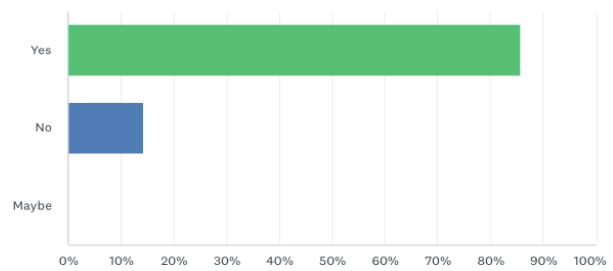
**Q12: Do you feel like Black parents are hesitant to identify their child with ASD?**



**Q13: You ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed?**

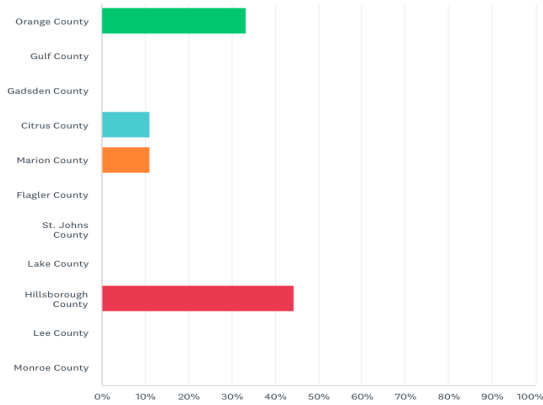


**Q14: Do you meet the observation requirements during the assessment process when a child is under five?**

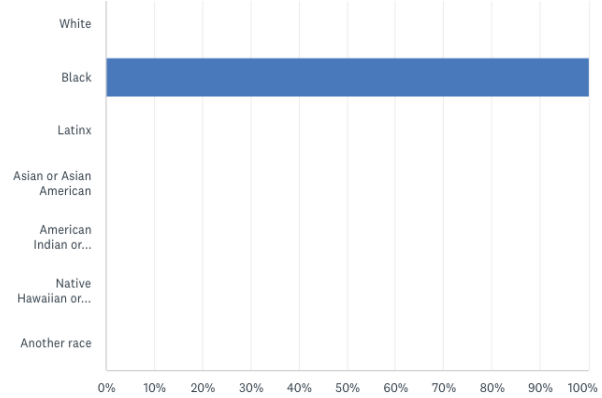


## Black\* Special Needs Educators

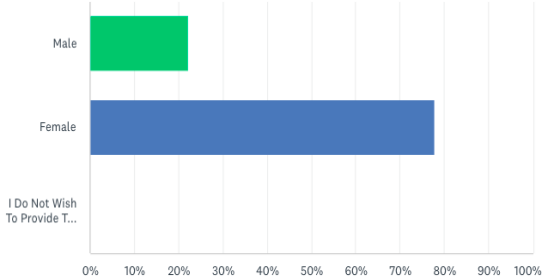
**Q1: Where are you located:**



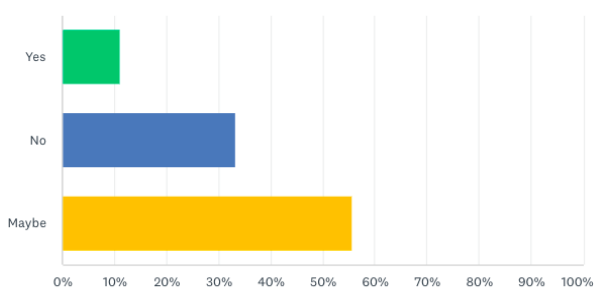
**Q2: Race:**



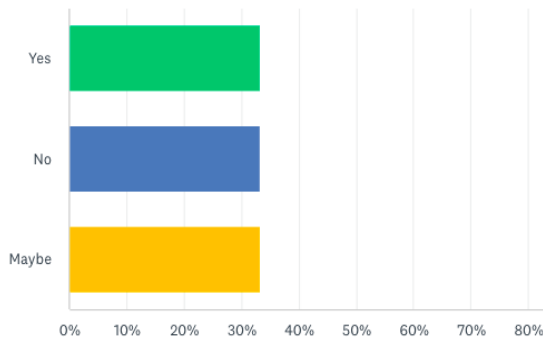
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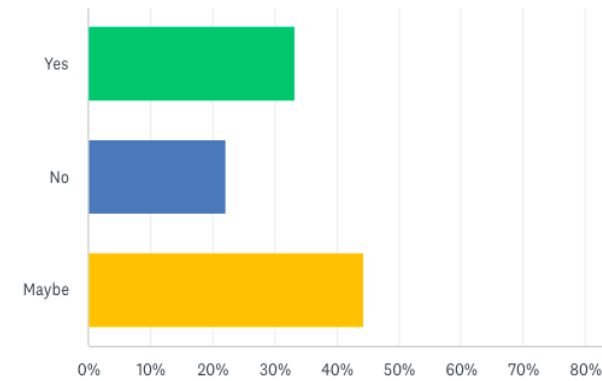
**Q4: Do you have training in your work setting that explains the red flags of autism?**



**Q5: Are you able to differentiate the difference between autism and DD for a Black child?**

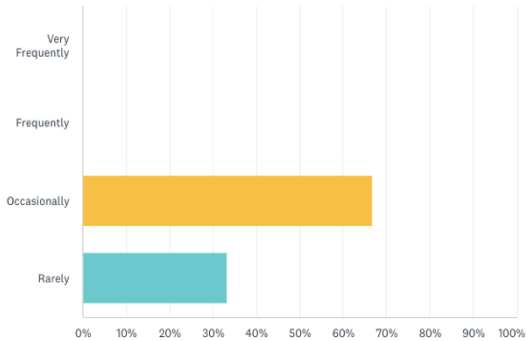


**Q6: Are you able to differentiate the difference between autism and EBD for a Black child?**

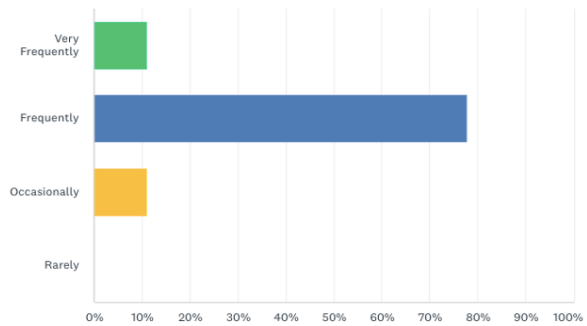




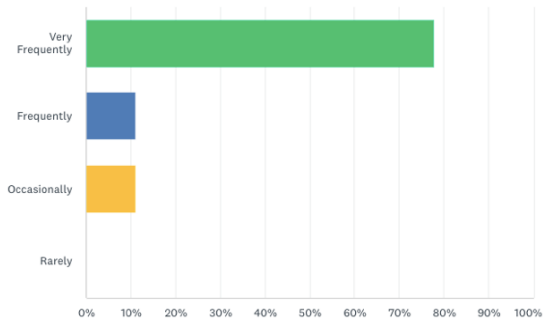
**Q7: Based on your experience, how frequently are Black children referred for ASD?**



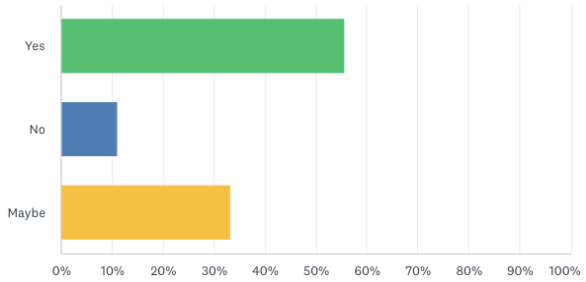
**Q8: How frequently are Black children referred for DD?**



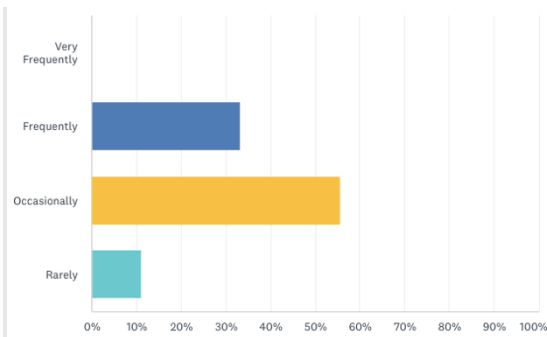
**Q9: How frequently are Black children referred for EBD?**



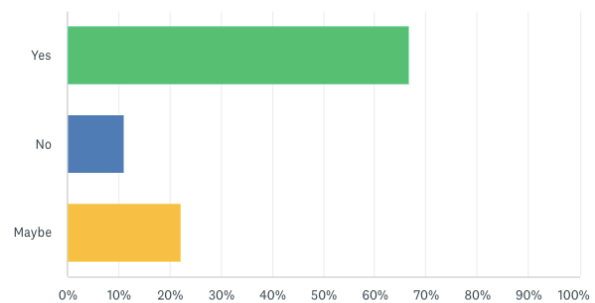
**Q10: Have you observed that DD/EBD eligibility is being used more with Black students than others?**



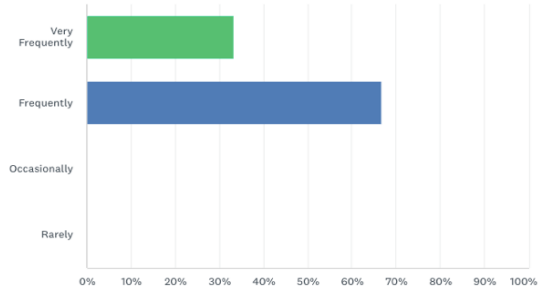
**Q11: How often are Black parents involved in the process?**



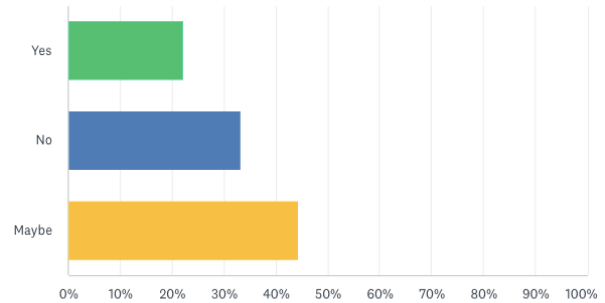
**Q12: Do you feel like Black parents are hesitant to identify their child with ASD?**



**Q13: You ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed?**

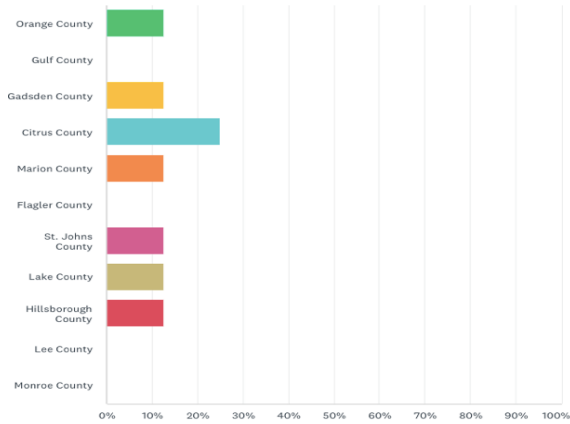


**Q14: Do you meet the observation requirements during the assessment process when a child is under five?**

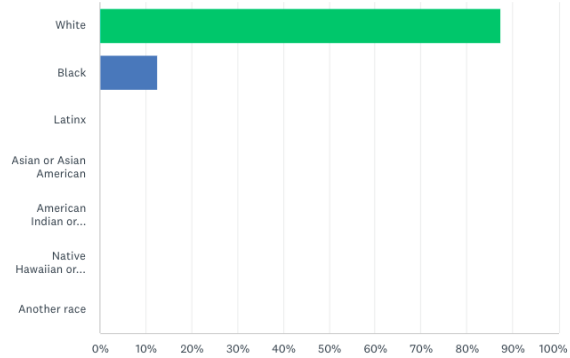


## Early Intervention Staff

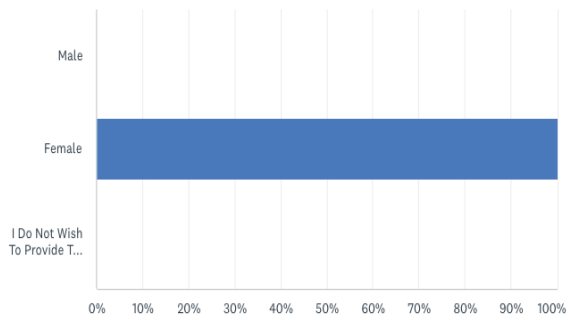
**Q1: Where are you located:**



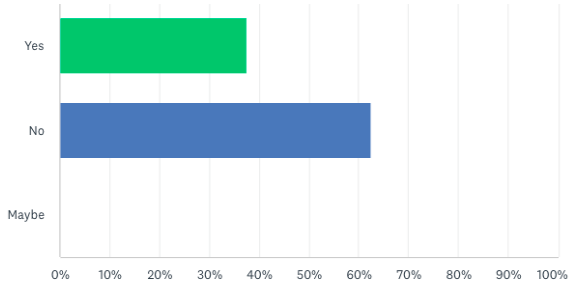
**Q2: Race:**



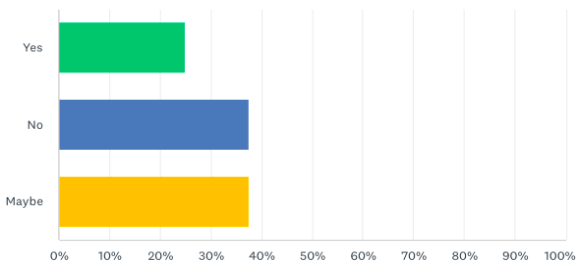
**Q3: Gender:**



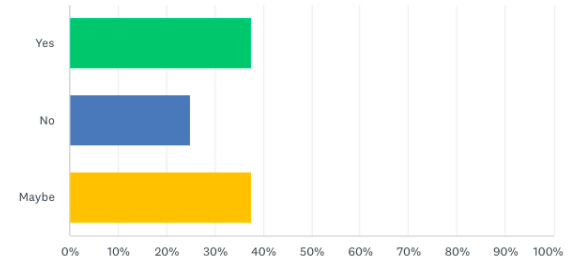
**Q4: Do you have training in your work setting that explains the red flags of autism?**



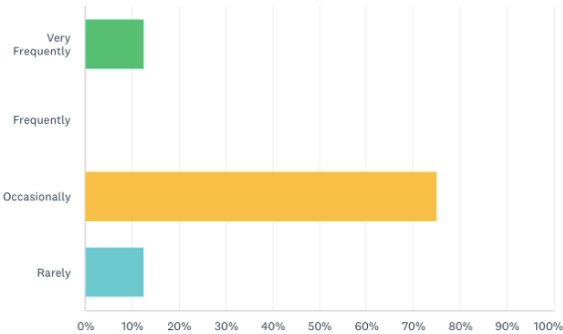
**Q5: Are you able to differentiate the difference between autism and DD for a Black child?**



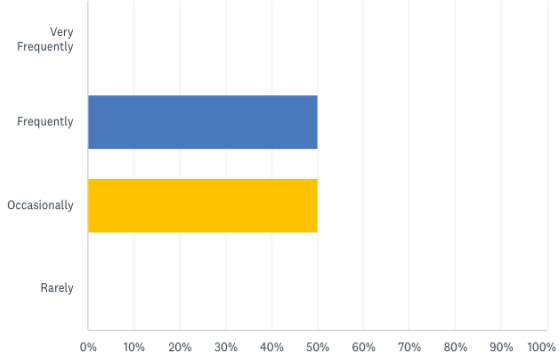
**Q6: Are you able to differentiate the difference between autism and EBD for a Black child?**



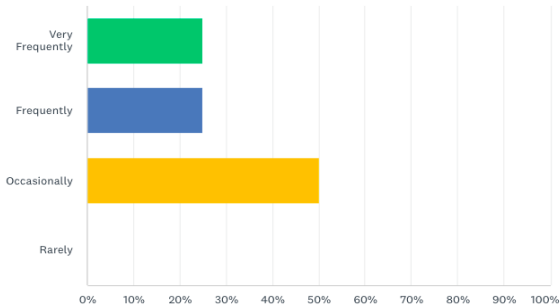
**Q7: Based on your experience, how frequently are Black children referred for ASD?**



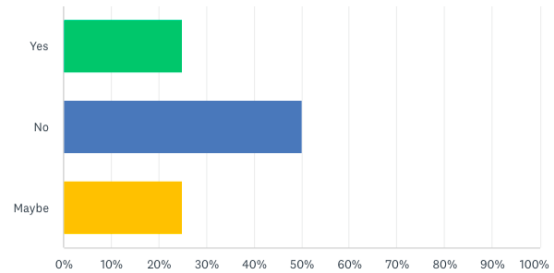
**Q8: How frequently are Black children referred for DD?**



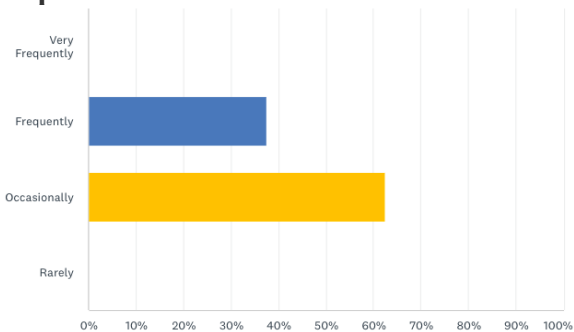
**Q9: How frequently are Black children referred for EBD?**



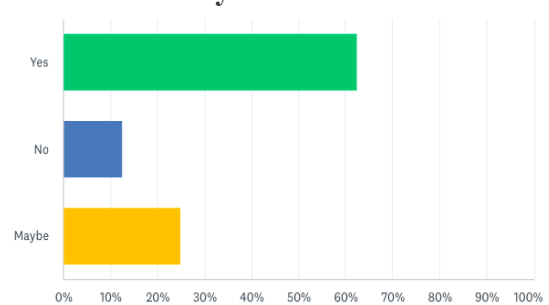
**Q10: Have you observed that DD/EBD eligibility is being used more with Black students than others?**



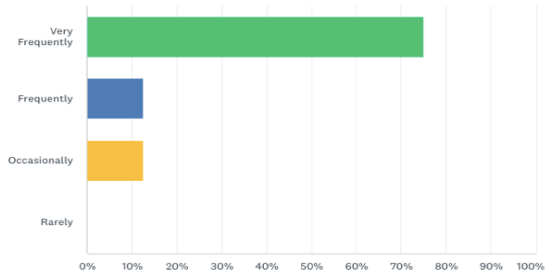
**Q11: How often are Black parents involved in the process?**



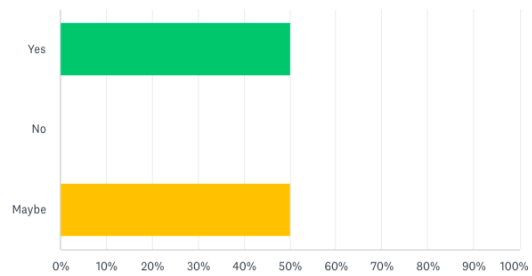
**Q12: Do you feel like Black parents are hesitant to identify their child with ASD?**



**Q13: You ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed?**

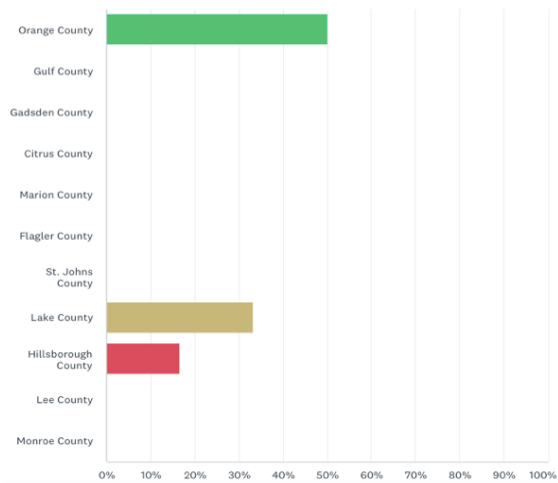


**Q14: Do you meet the observation requirements during the assessment process when a child is under five?**

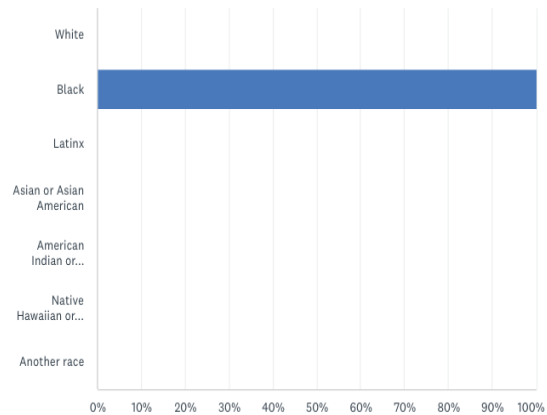


## Black\* ASD Educators

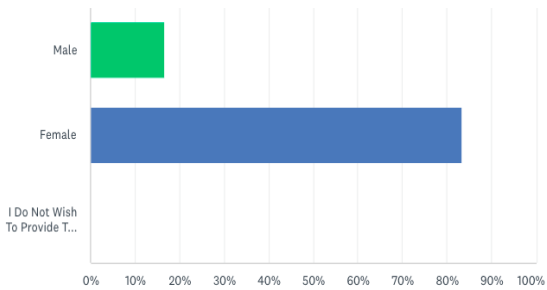
**Q1: Where are you located:**



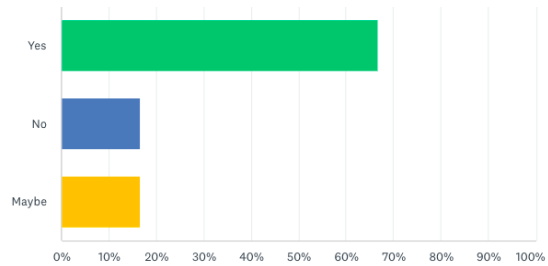
**Q2: Race:**



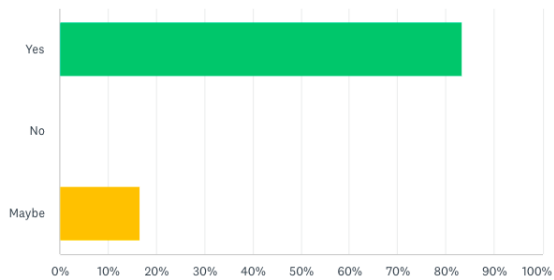
**Q3: Gender:**



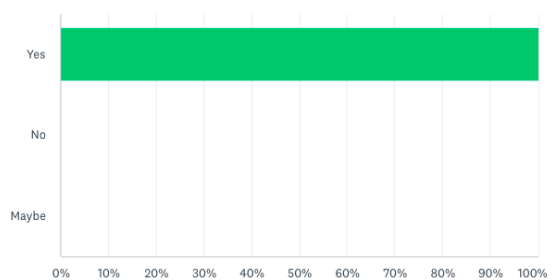
**Q4: Do you have training in your work setting that explains the red flags of autism?**



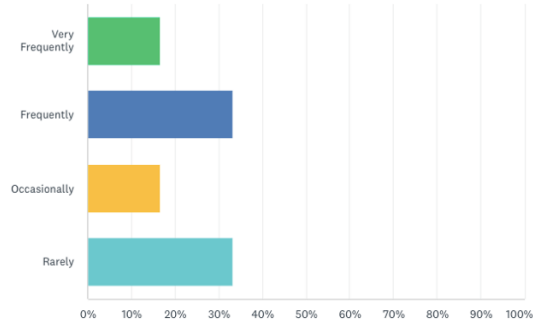
**Q5: Are you able to differentiate the difference between autism and DD for a Black child?**



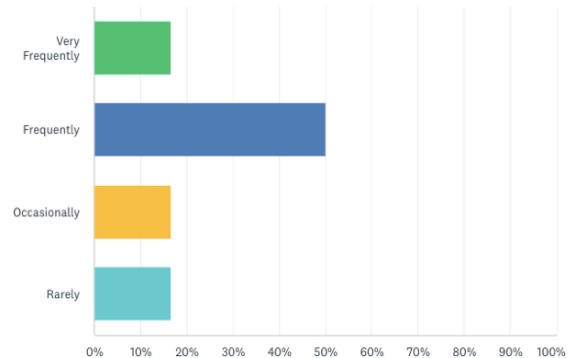
**Q6: Are you able to differentiate the difference between autism and EBD for a Black child?**



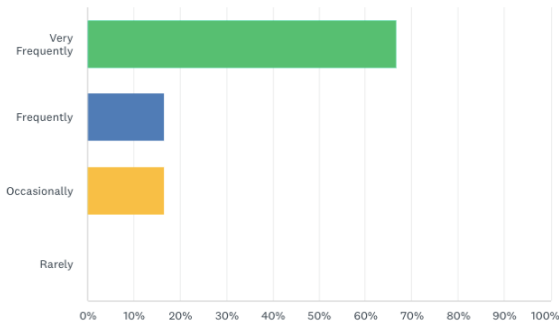
**Q7: Based on your experience, how frequently are Black children referred for ASD?**



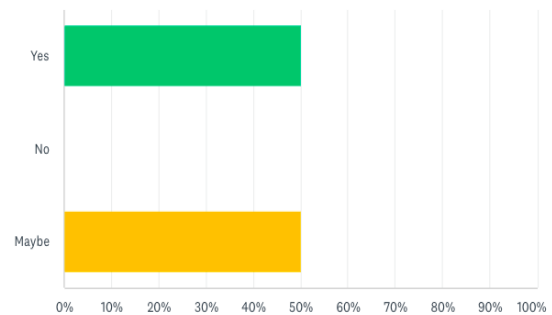
**Q8: How frequently are Black children referred for DD?**



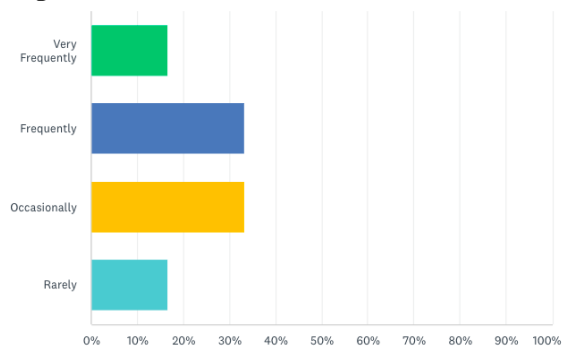
**Q9: How frequently are Black children referred for EBD?**



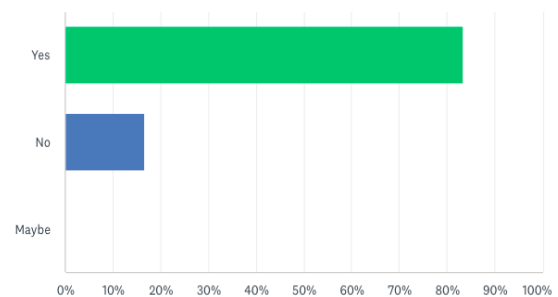
**Q10: Have you observed that DD/EBD eligibility is being used more with Black students than others?**



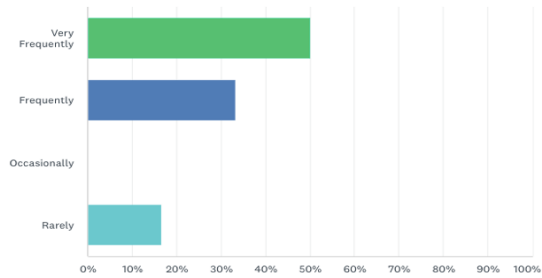
**Q11: How often are Black parents involved in the process?**



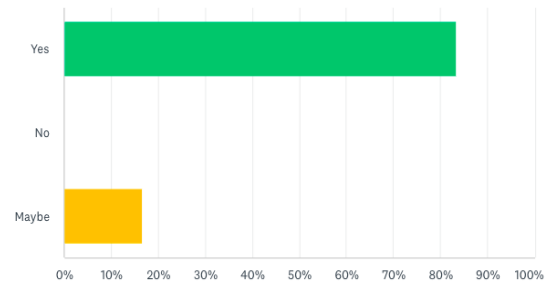
**Q12: Do you feel like Black parents are hesitant to identify their child with ASD?**



**Q13: You ensure that the Black parents' concerns about their child's behavior, language, and other characteristics showing problem areas are being addressed?**



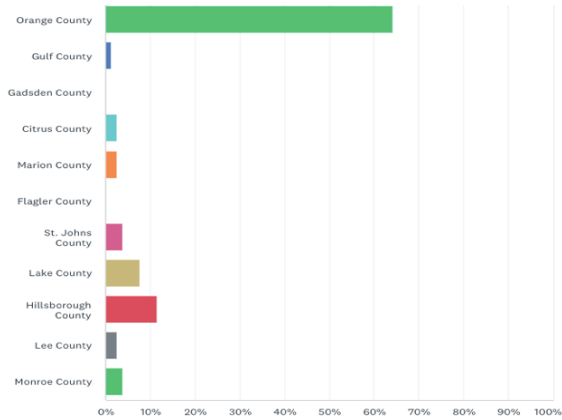
**Q14: Do you meet the observation requirements during the assessment process when a child is under five?**



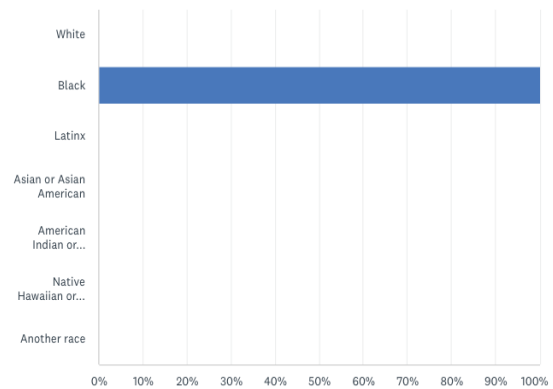


## Black\* Parents

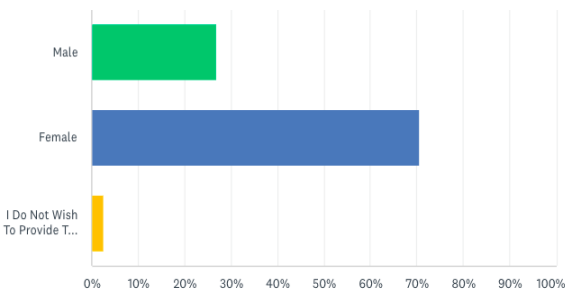
**Q1: Where are you located:**



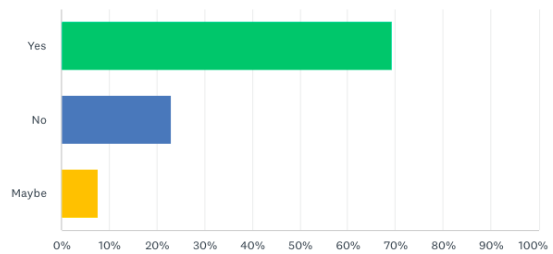
**Q2: Race:**



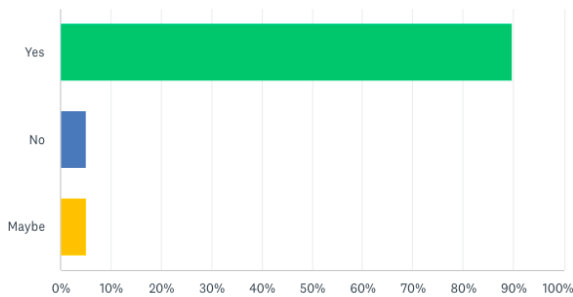
**Q3: Gender:**



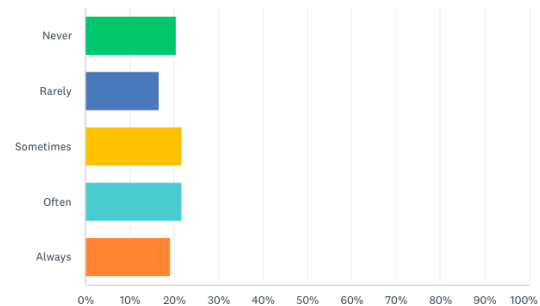
**Q5: You had difficulties during the process of receiving an ASD identification for your child**



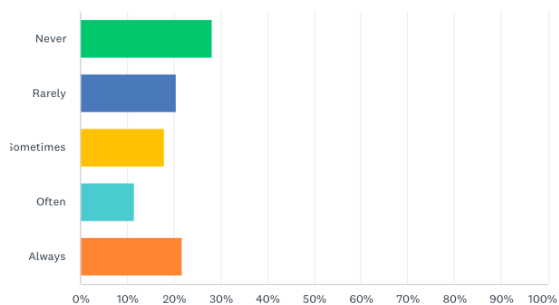
**Q6: You had concerns and suspicion of autism since your child's early years**



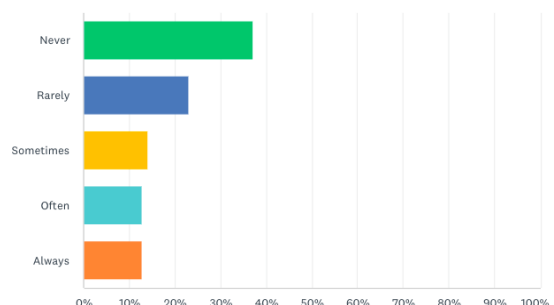
**Q7: Your pediatrician agreed with your concerns and suspicion of autism**



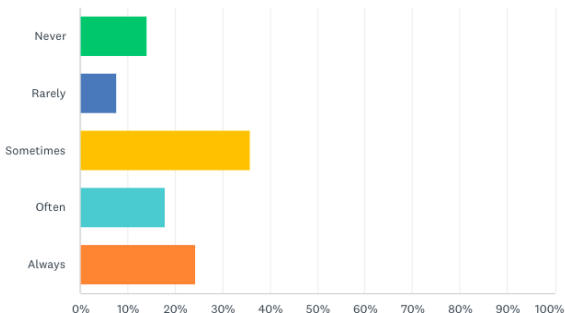
**Q8: Your pediatrician instructed you on how to proceed forward with autism diagnosis and treatment**



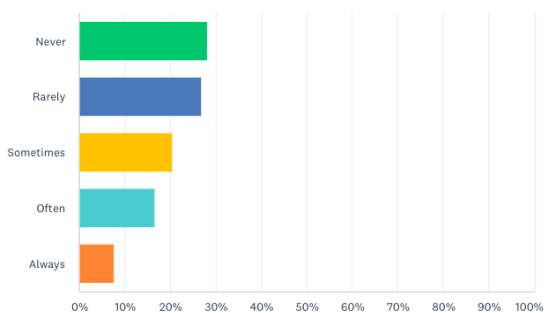
**Q9: The information that was provided by the pediatrician was enough to learn about autism to support your concerns for your child**



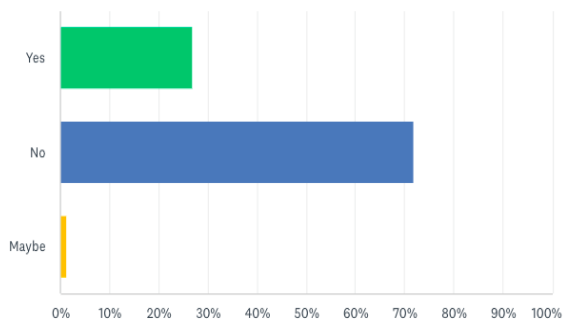
**Q10: Family members or school members share these same concerns with you**



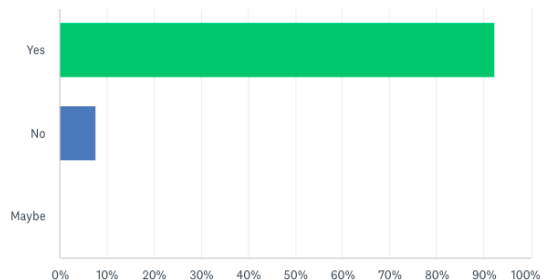
**Q11: You sensed that the people assessing/observing your child knew what autism looks like for Black\* children**



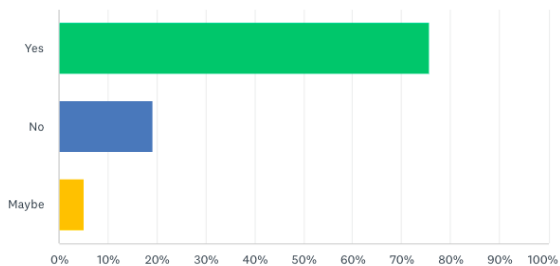
**Q12: Your child was identified with autism within the school setting**



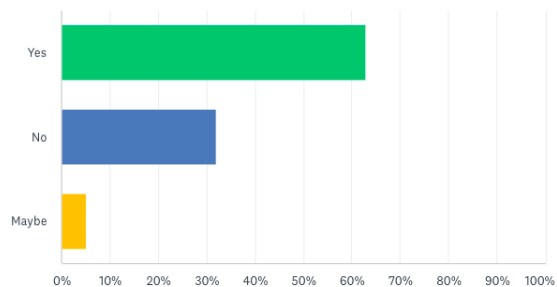
**Q13: Your child was identified with autism by a medical provider, e.g., neurologist, clinical psychologist, or developmental pediatrician**



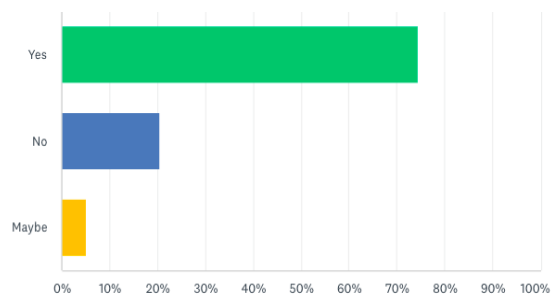
**Q14: Your child was eligible for other disability categories such as Developmental Delay, Intellectual Disability, or Emotional Behavioral Disability, in the school setting**



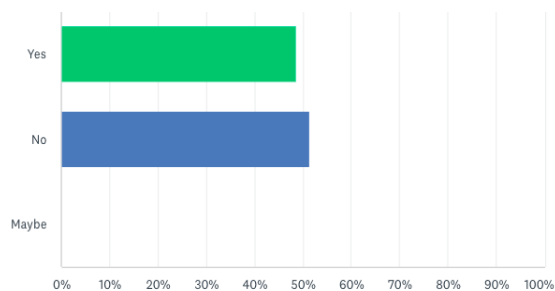
**Q15: Autism is your child's first diagnosis/eligibility**



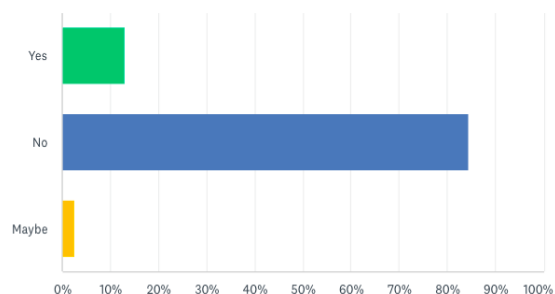
**Q16: You agreed with the eligibility or diagnosis given to your child the first time**



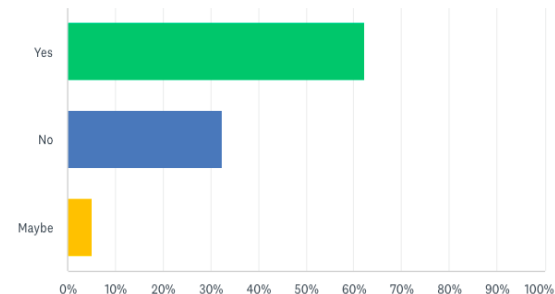
**Q17: You sought a second opinion from another school or medical provider to receive another eligibility or diagnosis**



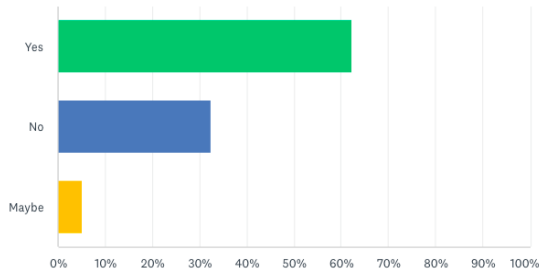
**Q20: You are still trying to obtain a medical diagnosis of autism**



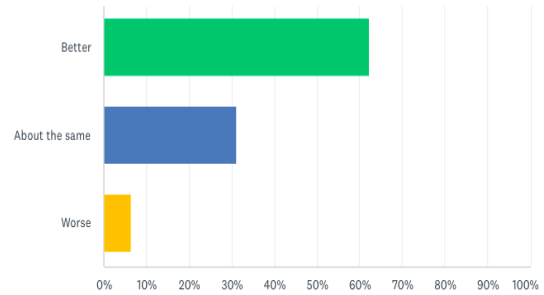
**Q22: Someone or something guided you through the process of obtaining autism resources**



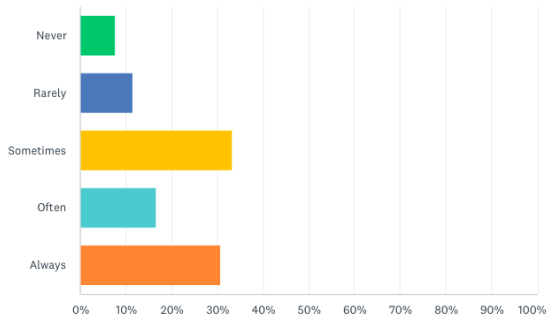
**Q23: Someone or something guided you through the process of obtaining autism treatment services**



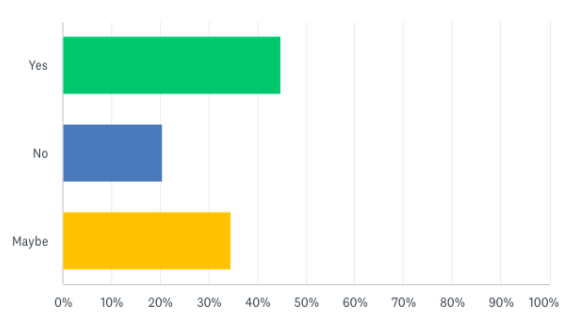
**Q25: What progress, if any, did you see during this time of treatment?**



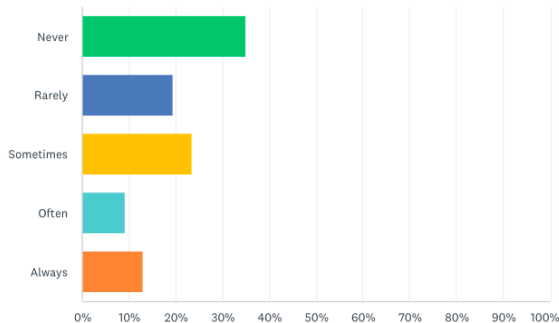
**Q26: You faced barriers to obtaining resources and treatment**



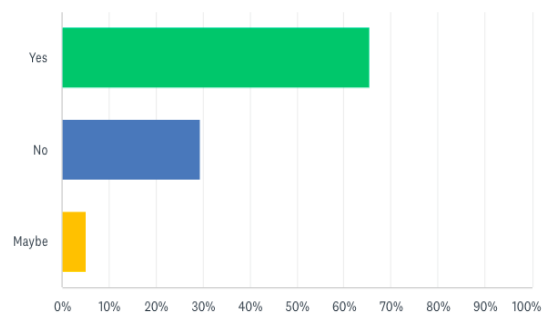
**Q27: The identification of autism has led you to the right treatments**



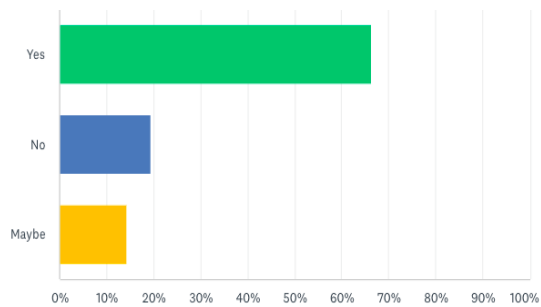
**Q28: There were barriers to obtaining treatment due to your child being Black\***



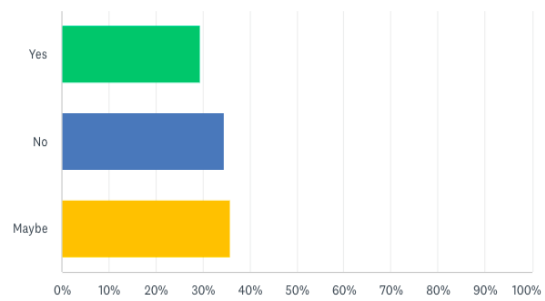
**Q29: Your child was enrolled in the Early Steps or the Child Find program**



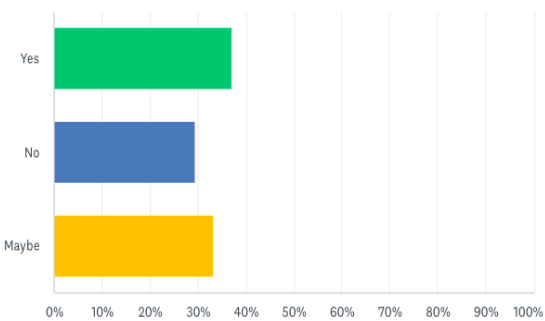
**Q30: Your child could have been identified earlier**



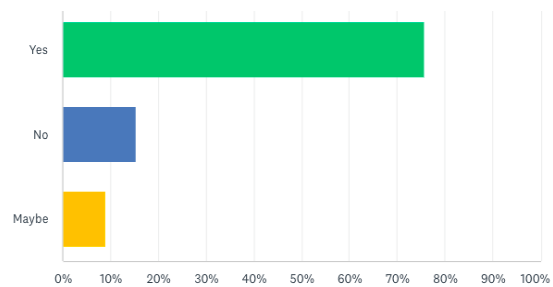
**Q31: Your child's treatment was impacted by being Black\***



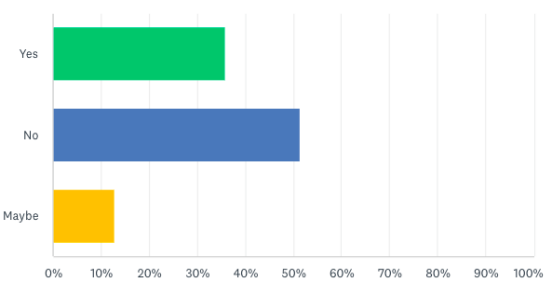
**Q32: Your journey was more or less difficult because of your race**



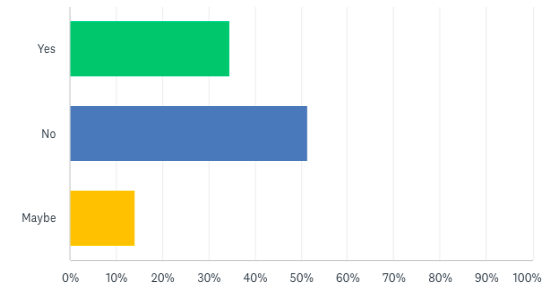
**Q33: Knowing the information you now know, you would complete the process differently**



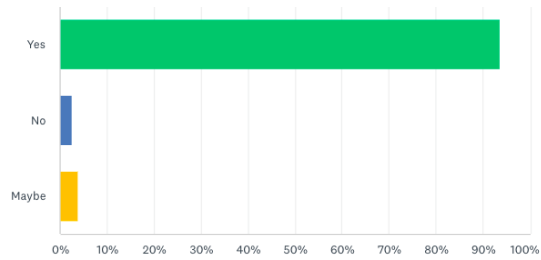
**Q34: School professionals negatively influenced your child's identification or treatment**



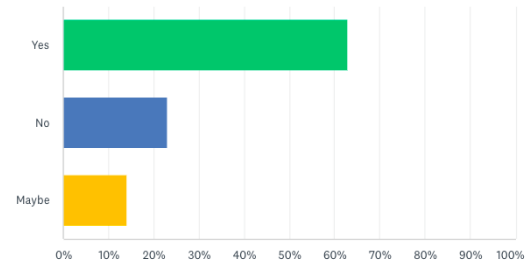
**Q35: Pediatricians negatively influenced your child's identification or treatment**



**Q36: Further training on the autism identification process for Black\* children should be provided to school professionals and pediatricians**

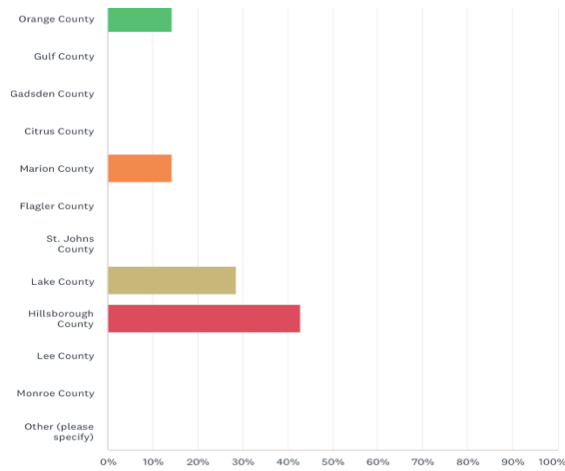


**Q37: Delayed identification of autism impacted your child**

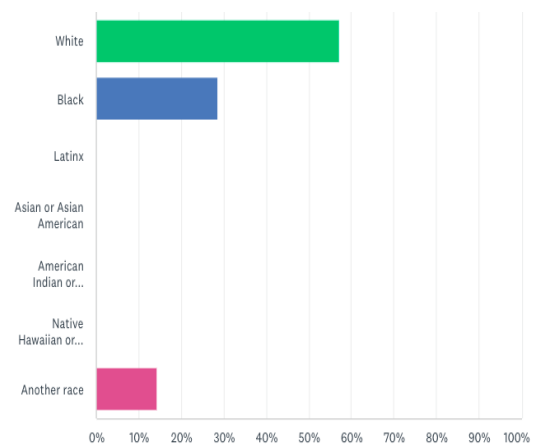


## CARD Staff

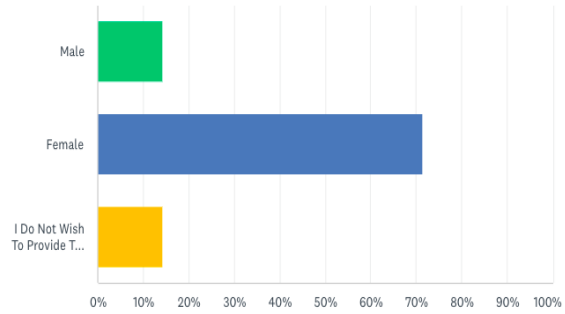
### Q1: Where are you located:



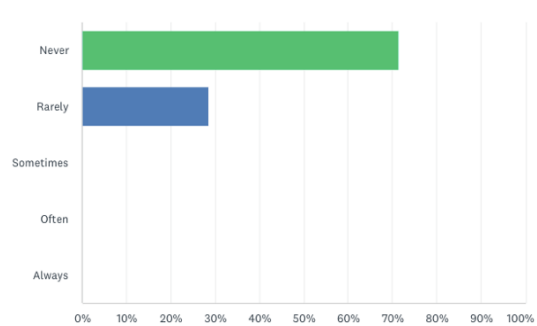
### Q2: Race:



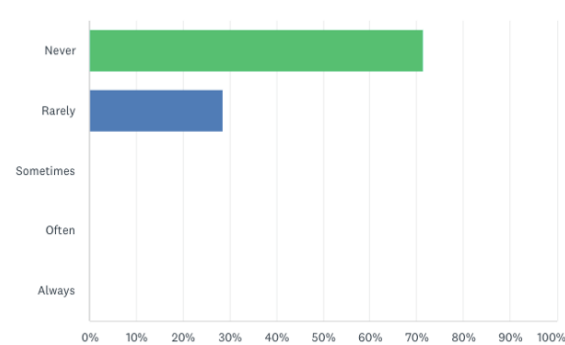
### Q3: Gender:



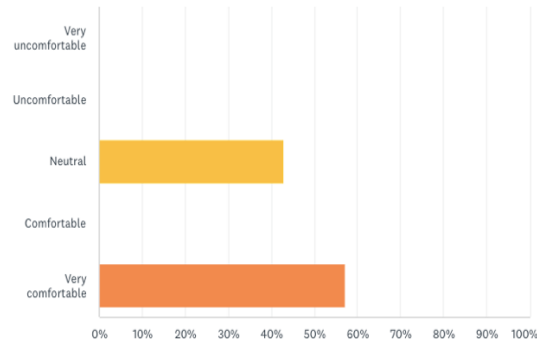
### Q8: How often do you screen for autism?



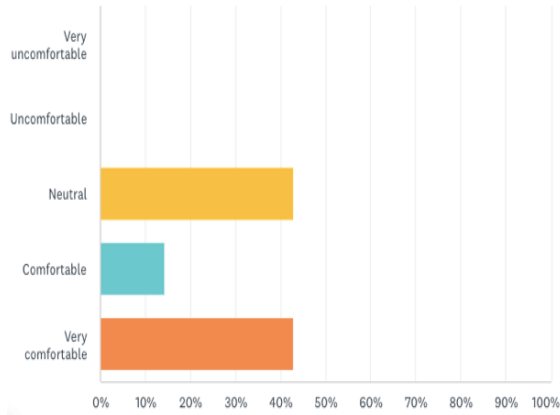
### Q9: How often do you screen for autism for Black children?



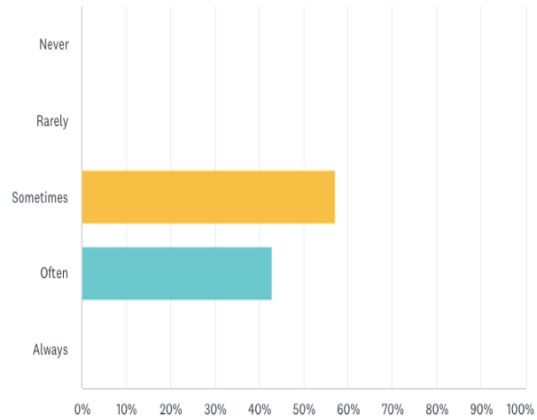
### Q11: How comfortable are you in identifying the red flags of autism?



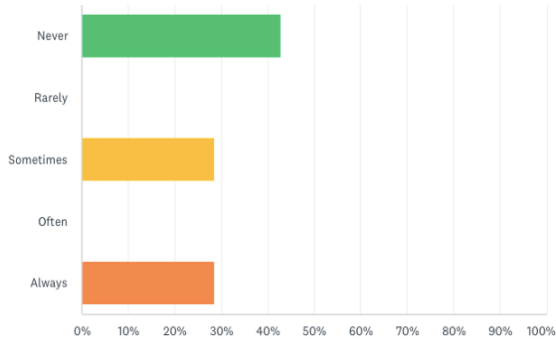
**Q12: How comfortable are you in identifying the red flags of autism with Black parents?**



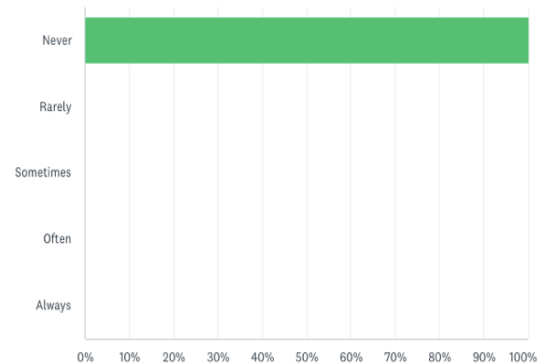
**Q13: Based on your experience, how often do you have Black parents reporting concerns of their child exhibiting ASD symptoms?**



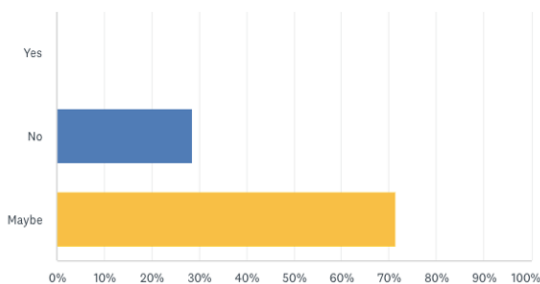
**Q19: Do you provide resources to Black parents to collect information on developmental milestones?**



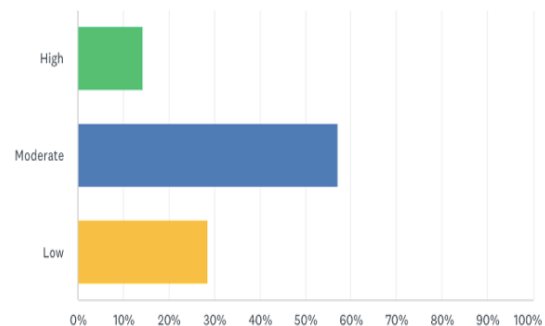
**Q23: Do you have designated support groups for Black parents?**



**Q24: If you have a Black parent support group or outreach program for the Black community, do you find it successful in gathering Black individuals?**

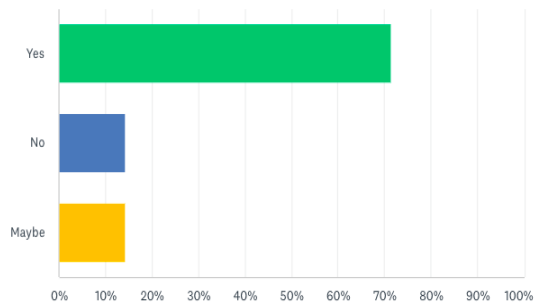


**Q25: What is your retention rate for Black parents to attend and stay within the program?**

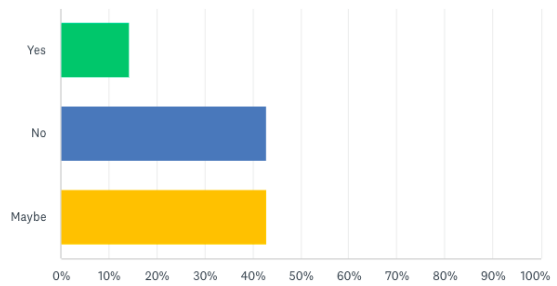




**Q30: Do you have a strategy plan to increase the number of Black CARD constituents?**

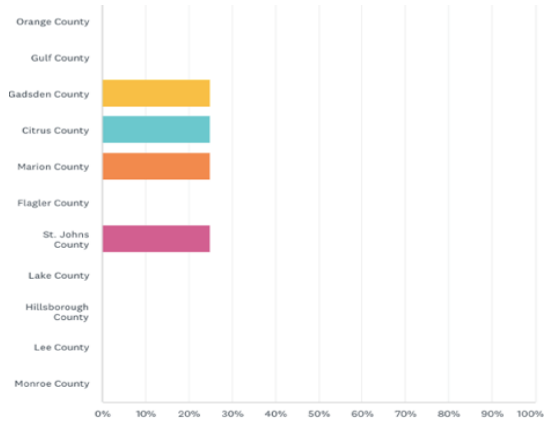


**Q31: Do you see autism manifesting differently in White and Black children?**

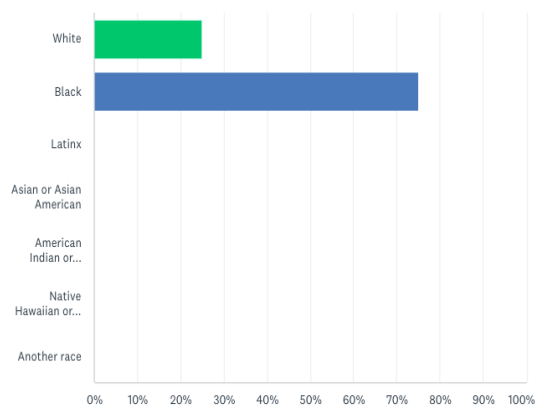


## University Faculty

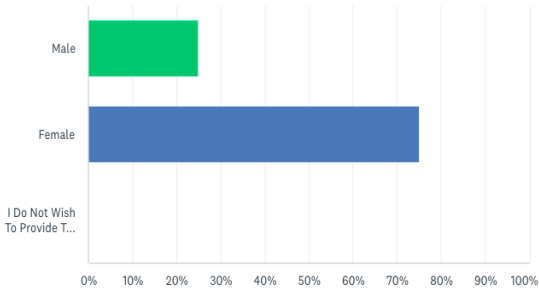
**Q1: Where are you located:**



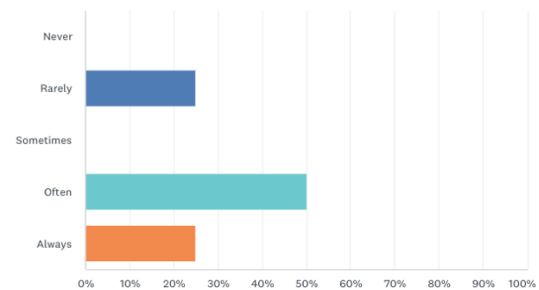
**Q2: Race:**



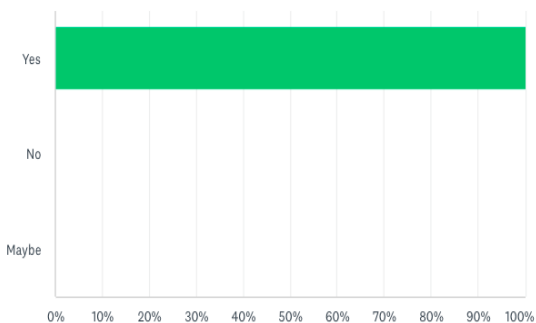
**Q3: Gender:**



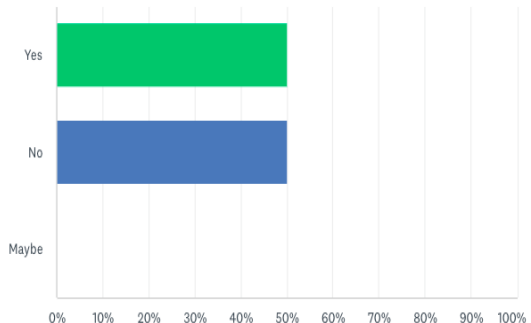
**Q6: Do you gather up to date information and latest research findings on autism?**



**Q9: Do you think there are barriers for Black parents trying to receive an ASD identification for their child?**



**Q14: Do you see autism manifesting differently in White and Black children?**



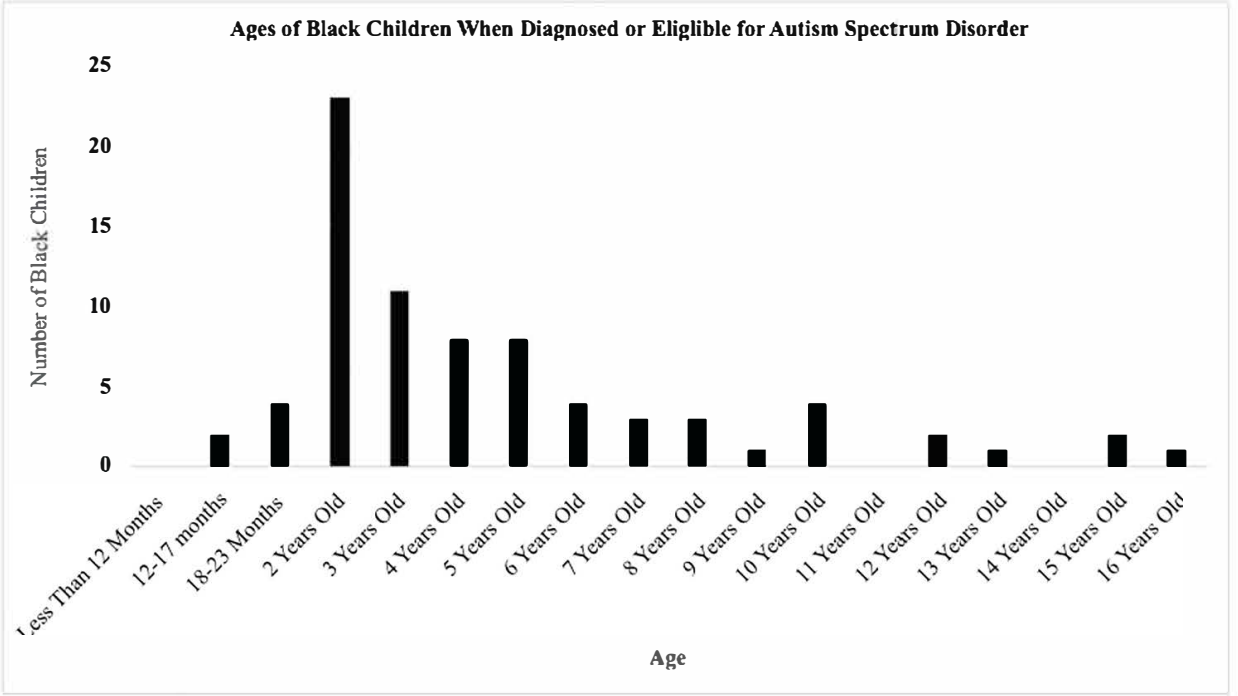
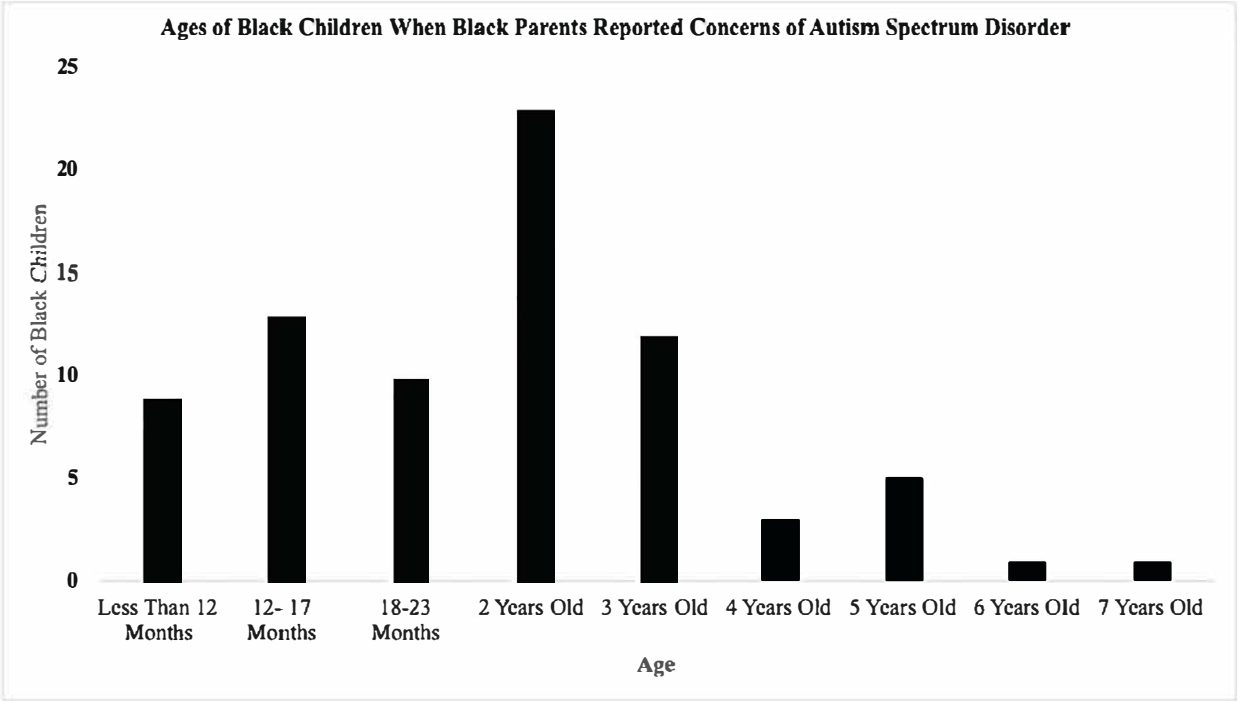
## **VII. Additional data summaries taken from Black\* parents focus groups, interviews, and survey responses**

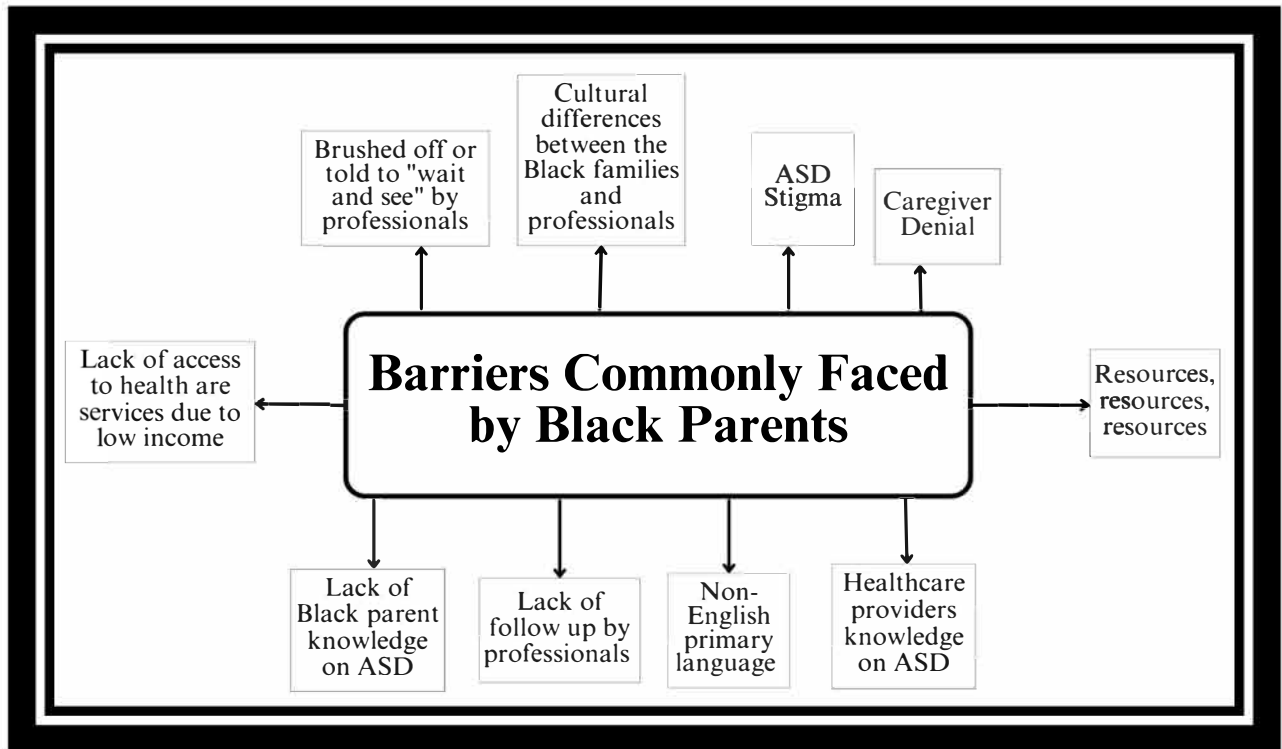
### **Important Lessons Learned About Interventions**

- Engaging community liaisons to tailor intervention and recruitment to local context.
- Training parents and non-specialist workers to deliver interventions.
- Offering optional modules and different formats (e.g., hybrid: group+ one-on-one; virtual) to accommodate diverse needs and schedules.
- Incorporating content on both trauma and stigma.
- Targeting multiple systems + policies.

### **Final Thoughts: Building community and clinical partnerships to better serve Black\* children and families**

- We are missing opportunities to truly engage with Black\* children, parents, other family members, teachers and community advocates in autism interventions.
- Reduce burdens on Black\* individuals, families and communities. For example, systems should examine:
  - o Location and hours of clinics (i.e., offer extended hours)
  - o Diversity (including neurodiversity) of service providers
  - o Inclusivity of forms and procedures; When forms and procedures become more inclusive, parents experience a heightened sense of respect, value, and understanding.





## **VIII. Recommendations that will be used to assist key stakeholders and decision makers in understanding the issues and effectively planning strategies and policies for addressing the identified issues**

### *Summary:*

Current research findings in Gulf, Gadsden, Citrus, Marion, Flagler, St. Johns, Lake, Orange, Hillsborough, Lee, and Monroe are consistent with national research and indicate that there is a disparity in the number of Black\* children being identified as ASD in the early years. When these children are identified as having needs, they are often misidentified and served in the category of developmental delay (DD) in Florida, which later may increase the probability of a determination of eligibility for services as a child with intellectual disabilities (InD) or emotional behavioral disabilities (EBD).

Additional preliminary data from 2021-23 research conducted through the FDDC grant to FAU CARD indicates the following:

- a. Black\* parents encounter cultural barriers when seeking ASD identification and treatment for their children, both within the healthcare and educational communities.
- b. Pediatricians demonstrate a lack of understanding regarding the red flags of ASD, neglect developmental screenings, and dismiss parents' concerns by not referring Black\* parents to community clinical providers for ASD assessment or to Early Steps or Child Find for further evaluation.
- c. Educators exhibit a lack of understanding regarding the red flags of ASD, particularly in Level 1 and 2 Black\* children with ASD, and often exhibit confusion regarding eligibility, misdiagnosing as developmentally delayed (DD), emotional behavioral disorders (EBD), or other health impaired (OHI)- attention deficit disorder instead of ASD, even when there is an ASD diagnosis from a community clinical provider. This study underscores the importance of reducing disparities in the diagnosis of Black\* children with ASD characteristics and promoting appropriate interventions across school districts.

*Recommendations and strategies based on our findings for school psychologists/community psychologists:*

- Psychologists must prioritize understanding the cultural backgrounds, identities, and belief systems of the attending Black\* families to enhance the timely and accurate identification of ASD and to break down barriers in providing equitable services for Black\* children with ASD.
- To achieve this, psychologists should adopt culturally responsive service delivery practices, such as utilizing referral and assessment approaches that recognize and respect individual and family diversity, rather than pathologizing or marginalizing cultural differences.
- Collaboration among ESE/EI staff and school psychologists is crucial to increase ASD knowledge in Black\* families. They should assist parents in comprehending ASD symptoms and causes, provide information about available treatment services, reduce the stigma associated with ASD, and clarify common misconceptions.
- To facilitate early identification, frequent screenings should be readily available across all areas of the county and provided in multiple languages, including Creole.
- Psychologists should continually undergo updated professional development training on the autism identification process and guidelines, including feedback and monitoring, to stay informed about best practices.
- Educational materials and resource packages specific to ASD and early symptoms should be easily accessible, available in both text and video formats, and offered in English and Creole. These materials should be user-friendly, free of complicated jargon, and include representation of Black\* families through photos.
- When determining ASD identification for Black\* children, the guiding practitioner should be the one who can offer reliable and valid intervention resources. This may involve referring the family to organizations such as FAU CARD or suggesting applied behavior analysis intervention through local agencies like Autism Speaks or Autism Navigator.
- Establishing a trusting relationship with Black\* families is of utmost importance. Psychologists should actively encourage parental involvement and maintain mutual respect throughout the diagnostic and treatment process.

*Recommendations and strategies based on our findings for health care providers:*

- Health care providers must prioritize understanding the cultural backgrounds, identities, and belief systems of attending Black\* families. This understanding is vital to improve the timely and accurate identification of ASD and breaking down barriers in providing equitable services for Black\* children with ASD.
- To achieve this, health care providers should embrace culturally responsive service delivery practices. This includes utilizing referral and assessment methods that recognize and respect individual and family diversity, rather than pathologizing or marginalizing cultural differences.
- Collaboration among health care providers and other practitioners is essential to enhance Black\* families' knowledge about ASD. They should assist parents in comprehending ASD symptoms and causes, providing information about available treatment services, reducing the stigma associated with ASD, and addressing common misconceptions.
- To facilitate early identification, there should be readily available and frequent screenings offered across all areas of the county and provided in multiple languages, such as Creole.
- Educational materials and resource packages specific to ASD and early symptoms should be easily accessible, presented in both text and video formats, and offered in English and Creole. These materials should be user-friendly, free of complicated jargon, and include representation of Black\* families through photos.
- Establishing a trusting relationship with Black\* families is of utmost importance. Health care providers should actively encourage parental involvement and maintain mutual respect throughout the diagnostic and treatment process.

*Recommendations and strategies based on our findings for autism/exceptional student educators, pre-k staff, and early intervention staff and directors:*

- Utilize a checklist/screening that demonstrates diagnostic effectiveness across diverse racial and ethnic backgrounds.
- Encourage collaboration between ESE/EI professionals to enhance ASD knowledge among Black\* families. Help parents comprehend ASD symptoms and causes, provide information about available services, minimize ASD stigma, and clarify misconceptions (e.g., debunking beliefs linking vaccines, bad parenting, or trauma to ASD).
- Ensure the availability of educational materials and resource packages tailored to ASD and early symptoms, delivered in both English and Creole. These materials should be



easily accessible, free of complex jargon, and include representation of Black\* families through photos.

- Foster collaboration with Black\* parents, offering support and understanding throughout the screening, assessment, and treatment process.
- Enhance cultural understanding during professional development training, incorporating role-playing scenarios and feedback to promote cultural competence.
- Encourage ESE staff and directors to gain insights into the cultural backgrounds, identities, and belief systems of Black\* families. This approach facilitates timely and accurate identification of ASD and reduces barriers to equitable service delivery for Black\* children with ASD.
- Promote awareness of the distinctions between developmental disabilities (DD) and ASD characteristics.
- Increase the utilization of culturally responsive service delivery practices, including referral and assessment approaches that acknowledge individual and family diversity instead of pathologizing or marginalizing cultural differences.

*Recommendations and strategies based on our findings for Black\* parents:*

- When Black\* parents express concerns about ASD-like characteristics in their children, it is essential to use a checklist/screening that demonstrates diagnostic effectiveness across various racial and ethnic backgrounds. These screenings should be widely available in all areas of the county and offered in multiple languages, such as Creole.
- To support Black\* parents, easily accessible materials/resources on ASD should be provided in various formats, including online, paper, and video. Additionally, opportunities for attending school or community discussions specifically addressing ASD-related concerns should be made available.
- The practitioner leading the process of determining ASD identification for the Black\* child should be the one who can offer reliable and valid intervention resources. This may involve referring the family to organizations like FAU CARD or suggesting applied behavior analysis intervention through a local agency, such as Autism Speaks or Autism Navigator.

- It is crucial for practitioners to actively build and nurture trusting relationships with Black\* families from the outset to ensure effective communication and understanding throughout the diagnostic and intervention journey.

## **IX. Conclusion**

Improving the identification of Black\* children with ASD requires accurate screening and effective systems to ensure that Black\* children at risk are appropriately assessed, diagnosed, and treated. We took an intense look at the six counties in Florida meeting with Black\* families and professionals to gain insight and understanding of these issues. By conducting interviews, focus groups, and web surveys with both Black\* families and professionals we were able to obtain confirmation that the identification process for these children remains problematic. In addition, we found that the representation of Black\* children with ASD is not equitable, nor were we able to identify any current developments that would result in significant progress in rectifying these inequities. The under-identification dilemma hinders Black\* children from accessing ABA services. As a result, in most but not all counties, inequities in identification and treatment services for Black\* children with ASD persist. As a result, Black\* children are half as likely to receive an ASD eligibility or diagnosis in some counties. Some hopeful steps would include acknowledging the lack of equity for Black\* children, a thoughtful revision of professional training, reviewing of current county data and policies for ASD eligibility provided by their state's Department of Education, utilizing culturally sensitive screenings, and sharing or developing a variety of ASD resources specifically for Black\* parents.

## X. Additional Resources

### Recommended Culturally- Sensitive Screenings

Name of Screening (with APA citation)	Screening Setting	Access Link
<p>Ages &amp; Stages Questionnaires®: Social-Emotional, Second Edition (ASQ®:SE-2)</p> <p>Squires, J., Bricker, D., &amp; Twombly, E. (2015). <i>Ages &amp; Stages Questionnaires®: Social-Emotional, Second Edition (ASQ®:SE-2): A Parent-Completed Child Monitoring System for Social-Emotional Behaviors</i>. Baltimore: Paul H. Brookes Publishing Co., Inc.</p>	Clinical Setting	<a href="https://agesandstages.com/products-pricing/asqse-2/">https://agesandstages.com/products-pricing/asqse-2/</a>
<p>Cultural Formulation Interview</p> <p>American Psychiatric Association. Cultural formulation. In: <i>Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition</i>. Washington, DC: American Psychiatric Association; 2013:749-759.</p>	<p>Research Setting</p> <p>Clinical Setting</p>	<a href="https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM5_Cultural-Formulation-Interview.pdf">https://www.psychiatry.org/File%20Library/Psychiatrists/Practice/DSM/APA_DSM5_Cultural-Formulation-Interview.pdf</a>
<p>Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)</p> <p>Robins DL, Fein D, Barton M. <i>The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)</i>. Self-published; 2009</p>	<p>Research Setting</p> <p>Clinical Setting</p>	<a href="https://mchatscreen.com/mchat-rf/">https://mchatscreen.com/mchat-rf/</a>
<p>Pictorial Autism Assessment Schedule (PAAS)</p> <p>Perera, H., Jeewandara, K. C., Seneviratne, S., &amp; Guruge, C. (2017). Culturally adapted pictorial screening tool for autism spectrum disorder: A new approach. <i>World Journal of Clinical Pediatrics</i>, 6(1), 45. <a href="https://doi.org/10.5409/wjcp.v6.i1.45">https://doi.org/10.5409/wjcp.v6.i1.45</a></p>	<p>Research Setting</p> <p>Clinical Setting</p>	<a href="http://csaat.sliit.lk/paas.html">http://csaat.sliit.lk/paas.html</a>
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# Autism Spectrum Disorder Identification for Black Children Parents Roadmap

## Checking Developmental Milestones of Child

The Center for Disease and Control Prevention (CDC) offers a full checklist of developmental milestones for children ages 2 months to 5 years (CDC, 2022). It is recommended by the CDC for autism screenings to be done between the ages of 18 and 24 months. All children should receive a developmental screening by 36 months of age.



## Parent's Concerns

If your child is not reaching development milestones for their current age or displaying red flags for autism, report your concerns to your health care provider for advice and the next steps to follow.



## Be aware of Autism Spectrum Disorder Red Flags

Some red flags are limited use of gestures, delayed speech, does not respond to their names, repetitive behaviors, excessive interest in a particular object, and lack of eye-contact (Autism Navigator, 2021)



## Referral to Developmental Pediatrician

If your child is not reaching development milestones for their current age or displaying red flags for autism, report your concerns to your health care provider for advice and next steps to follow.



## Get Services

According to the CDC, if your child is under 3 years old, free services can be provided by calling local early intervention programs. If your child is over 3 years of age, call your local public elementary school.



## Early Steps

Early Steps offers early intervention services to eligible infants and toddlers, ages birth to 36 months, who have or are at-risk for developmental disabilities or delays.



## Child Find

Child Find connects young children who have or are at risk of developing disabilities with services and programs available for them.



## Stay Consistent

Follow up with your doctors, early interventionists, school professionals, and therapists to ensure your child is receiving the appropriate treatment.



## Continue with Therapies

Look for your local Applied Behavior Analysis (ABA) agencies, speech and occupational therapy centers, to ensure your child gets service as soon as possible.



## You are not alone!

Contact your local Center for Autism and Related Disabilities (CARD). CARD offers support groups, resources, and community events all for FREE.



# Autism Spectrum Disorder Identification for Black Children Professionals Roadmap

## Become Familiar with Autism Spectrum Disorder Data Prevalence

1 in 44 children are diagnosed with ASD. ASD occurs in all races, ethnicities, and socioeconomic groups. Black children often receive a late diagnosis, approximately 3-4 years after the parents initial reported concerns (CDC, 2021).

## Listen to Parent's Concerns

A trusting relationship between parents and professionals is essential. This way, parents will feel more comfortable in sharing their concerns.

## Use Culturally Sensitive Autism Screening

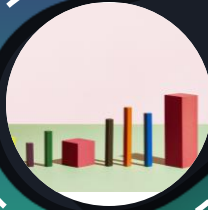
Some culturally sensitive screenings are M-CHAT, ASQ, and PEDS. Offered in multiple languages; consider using additional illustrations and examples to reflect item changes or to improve caregiver understanding.

## Follow-up

Pre-schedule follow-ups to keep Black families on the right path of care and in a timely manner. Make referrals for early intervention such as Applied Behavior Analysis, Speech Therapy, and Occupational Therapy.

## Keep up with the work!

You are one of the main pieces of the puzzle. Black families will report to you first. Therefore, they need your understanding and trust to proceed with a referral for assessment and start of early intervention.



## Developmental Milestones

Stay up to date with developmental milestones. The CDC offers a full checklist of developmental milestones for children ages 2 months to 5 years. An ASD screening should be administered between 18 and 24 months (CDC, 2022).

## Make a Referral

Do not wait to make a referral, if a parent mentions a concern regarding their child's development, it is recommended to refer him/her for further testing and screenings.

## Autism Spectrum Disorder Evaluation

If the screening is positive, make a referral for a neurologist or psychologist to complete a comprehensive ASD evaluation.

## Connect Families with Services

Suggest to Black families to contact CARD services, Early Steps, and support groups. Also, provide a list of resources (including video and available in multiple languages) that are up to date.

## Connect with CARD

The Center for Autism and Related Disabilities (CARD) offers various year-round free training for professionals to understand better the characteristics of ASD.



**Funding Statement:** This project is provided by the Florida Developmental Disabilities Council, Inc. and supported in part by grant numbers 1901FLSCDD-01 and 2001FLSCDD-01 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. Grant funding total amount at the time of initial project: \$155,188.00.

(Center for Disease Control and Prevention [CDC], 2022)



# Idantifikasyon Twoub Spectrum Otis pou Pwofesyonèl Timoun Nwa yo

## Tcheke transfòmasyon devlopman timoun nan

Sant pou Prevansyon Maladi ak Kontwòl (CDC) ofri yon lis konplè etap enpòtan nan devlopman pou timoun ki gen laj 2 mw a jiska 5 an (CDC, 2022). Li rekòmande pa CDC pou tès depistaj otis yo dwè fè ant laj 18 ak 24 mw a. Tout timoun ta dwè resevwa yon tès depistaj devlopman anvan 36 mw a.

## Enkyetid paran yo

Si pitit ou a pa rive nan etap enpòtan nan devlopman pou laj li ye kounye a oswa si li pa montre siy w ouj pou otis, rapòte enkyetid ou bay founisè swen sante w la pou w jwenn konsèy ak pwochen etap ou dwè swiv..

## Jwenn Sèvis

Dapre CDC, si pitit ou a gen mwens pase 3 zan, yo ka bay sèvis gratis lè w rele pwogram entèvansyon bonè lokal yo. Si pitit ou a gen plis pase 3 an, rele lekòl primè piblik lokal ou a.

## Child Find

Child Find konekte timoun piti ki gen oswa ki riske devlope andikap ak sèvis ak pwogramki disponib pou yo.

## Kontinye ak Terapi

Chèche ajans ABA (Applied Behavior Analysis), sant terapi lapawòl ak okipasyonèl lokal ou yo, pou asire pitit ou a jwenn sèvis pi vit posib.

## Pran konsyans de siy Otis Spectrum Twoub

Gen kèk siy ki limite itilizasyon jès yo, pale reta, pa reponn a non yo, konpòtman repete, enterè twòp nan yon objè patikilye, ak mank de kontak zye (Autism Navigator, 2021)

## Referans bay Pedyat Devlopman

Si pitit ou a pa rive nan etap enpòtan devlopman yo pou laj li ye kounye a oswa si li pa montre drapo w ouj pou otis, rapòte enkyetid ou bay doktè ou pou konsèy ak pwochen etap yo dwè swiv.

## Early Steps

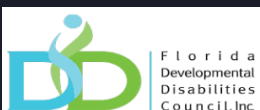
Early Steps ofri sèvis entèvansyon bonè pou tibebe ak timoun piti ki elijib, ki gen laj nesans jiska 36 mw a, ki gen oswa ki riske genyen andikap devlopman oswa a reta.

## Rete konsistan

Swiv ak doktè ou yo, entèvansyon bonè, pwofesyonèl lekòl yo, ak terapi pou asire pitit ou a ap resevwa tretman apwopriye..

## Ou pa pou kont ou!

Kontakte sant lokal ou a pou otis ak andikap ki gen rapò (CARD). CARD ofri gwoup sipò, resous, ak evènman kominite yo tout GRATIS.



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(Center for Disease Control and Prevention [CDC], 2022)  
Red Flags of Autism (2021). Autism Navigator. <https://autismnavigator.com/red-flags-of-autism/>

# Idantifikasyon Twoub Spectrum Otis pou Pwofesyonèl Timoun Nwa yo

## Vin abitye ak Prevalans Done Twoub Spectrum Otis

1 sou 44 timoun yo dyagnostike ak ASD. ASD rive nan tout ras, etnik, ak gwoup sosyoekonomik. Timoun nwa yo souvan resewwa yon dyagnostik an reta, apeprè 3-4 ane apre paran yo te rapòte premye enkyetid CDC, 2021).

## Koute enkyetid paran yo

Yon relasyon konfyans ant paran ak pwofesyonèl li esansyèl. Konsa, paran yo pral santi yo pi alèz lè yo pataje enkyetid yo.

## Sèvi ak tès depistaj otis ki sansib pou kiltirèl

Gen kèk tès depistaj kiltirèl ki sansib yo se M-CHAT, ASQ, ak PEDS. Yo ofri nan plizyè lang; konsidere sèvi ak lòt ilistrasyon ak egzann pou reflekte chanjman atik oswa pou pi byen konprann moun kap bay swen yo.

## Suivi

Pre-orè swivi pou kenbe fanmi Nwa yo sou bon chemen swen yo ak nan yon fason apwopriye. Fè referans pou entèvansyon bonè tankou Analiz Konpòtman Aplike, Terapi Lapawòl, ak Terapi Okipasyonèl.

## Kontinye ak travay la!

Ou se youn nan moso prensipal yo nan devinèt la. Fanmi Nwa yo pral rapòte ou an premye. Se poutèt sa, yo bezwen konpreyansyon w ak konfyans ou kontinye ak yon referans pou evalye ak kòmanse entèvansyon bonè.

## Etap devlopman yo

Rete ajou ak etap enpòtan nan devlopman yo. CDC ofri yon lis konplè sou etap enpòtan nan devlopman pou timoun ki gen laj 2 mw a jiska 5 an. Yo ta dwè fè yon tès depistaj ASD ant 18 ak 24 mw a (CDC, 2022).

## Fè yon referans

Pa tann pou w fè yon referans, si yon paran di yon enkyetid konsènan devlopman pitit yo, li rekòmande pou refere li pou plis tès ak tès depistaj..

## Evalyasyon Twoub Spectrum Otis

Si tès depistaj la pozitif, fè yon referans pou yon new lòg oswa sikolog pou konplete yon evalyasyon konplè ASD..

## Konekte Fanmi ak Sèvis

Sijere fanmi Nwa yo pou yo kontakte sèvis CARD, Early Steps, ak gwoup sipò yo. Epitou, bay yon lis resous (ki gen ladan videyo ak ki disponib nan plizyè lang) ki ajou.

## Konekte ak CARD

Center for Autism and Related Disabilities (CARD) ofri plizyè fòmasyon gratis pandan tout ane a pou pwofesyonèl yo konprann pi byen karakteristik ASD yo.



**Funding Statement:** This project is provided by the Florida Developmental Disabilities Council, Inc. and supported in part by grant numbers 1901FLSCDD-01and 2001FLSCDD-01 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. Grant funding total amount at the time of initial project: \$155,188.00.

(Center for Disease Control and Prevention [CDC], 2022)



## **XI. Glossary**

### *Glossary*

Term	Definition
Attention deficit hyperactivity disorder	The diagnostic term used to describe people who have excessive difficulty in concentrating and focusing, extreme distractibility or over activity, sometimes including disruptive behavior or aggression.
Autism spectrum disorders	A developmental disability caused by differences in the brain.
Black* autism spectrum disorder educators	Staff members assigned the professional activity of instructing students in courses in classroom situations, specifically for children identified with autism spectrum disorder, with origins in any of the Black racial groups of Africa, including persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

Black\* parents

Parents with origins in any of the Black racial groups of Africa, including persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

Black\* special needs educators

Staff members assigned the professional activity of instructing students in courses in classroom situations, including exceptional student education, with origins in any of the Black racial groups of Africa, including persons who indicate their race as “Black or African American” or report themselves as African American, Kenyan, Nigerian, or Haitian.

Center for Autism and Related Disabilities staff

Professionals working at the Center for Autism and Related Disabilities.

Community psychologists

Professionals licensed according to s. 490.005(1), s. 490.006, or the provision identified as s. 490.013(2) in s. 1, chapter 81-235, Laws of Florida. (Florida Board of Psychology, 2021).

Developmental delay

Delay in the age at which developmental milestones are achieved by a child or delay in the development of communication, social, and daily living skills.

Early intervention staff

Professionals specialized in providing support and services to young children who have a disability or developmental delay and to their families (Florida Department of Education [FDOE], 2022).

Exceptional student education staff and directors

Professionals who support a child in the school setting with services designed to meet the child's unique needs and help the child progress in school and prepare for life after school (Florida Department of Education, 2022).

Health care providers

Professionals, e.g., neurologists, pediatricians, who are authorized to practice medicine within the scope of their practice as defined by State

law (Family and Medical Leave Act of Advisor, 2017).

## Intellectual Disability

A developmental disability characterized by mild to profound limitations in cognitive function (e.g., learning, problem solving, reasoning, planning) and in adaptive behavior, impairing one's ability to acquire skills typical for one's age group as a child or necessary for one's later independent functioning as an adult.

## Pre-kindergarten staff

Personnel responsible for care, protection, and supervision of a child, for a period of less than 24 hours a day on a regular basis.

## School psychologists

Professionals responsible for advising students regarding their abilities and aptitudes, educational and occupational opportunities, personal and social adjustments, for providing placement services, and for performing educational evaluations and similar functions (Florida Department of Education, 2020).

University faculty

Full-time equivalent teaching faculty member at a university according to Florida Statutes, chapter 1012, section 945 (Florida Senate, 2023).

## **XII. Acronyms**

### *Acronyms*

Acronym	Term
ABA	Applied Behavior Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ADOS-2	Autism Diagnostic Observation Schedule, Second Edition
ASD	Autism Spectrum Disorder
ASQ-SE-2	Ages & Stages Questionnaires: Social-Emotional, Second Edition
BCBA	Board Certified Behavior Analyst
CARS	Childhood Autism Rating Scale
DD	Developmental Delay
DSM-5 TR	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition Text Revision
EBD	Emotional Behavior Disorder
EI	Early Intervention
ESE	Exceptional Student Education
FDLRS	Florida Diagnostic & Learning Resources System
FDOE	Florida Department of Education
ID	Intellectual Disability
IDD	Intellectual or Developmental Disability
IEP	Individualized Education Program

M-CHAT-R

Modified Checklist for Autism in Toddlers,  
Revised

SORF

Systematic Observation of Red Flags

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