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Awareness of Autism in Black and Brown Communities in South Florida

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Undergraduate Honors Thesis of

Varun Kota

Awareness of Autism in Black and Brown
Communities in South Florida

Nova Southeastern University
Farquhar Honors College

January 2023

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**Awareness of Autism in Black and Brown Communities in South
Florida**

Honors Thesis

March 2023

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PREFACE

The inspiration behind this Honors Thesis emerged during my Junior year when I was taking Honors 2020A Autism Today Seminar with Dr. Susan Kabot. Through the seminar, I enriched myself with knowledge about Autism, its signs and significance, how the disorder impacts families, and most importantly delayed diagnosis. At the same time, I was also working with Dr. Mark Jaffe to create a Health Literacy Project in BIOL 4960 Practicum I in Biology. Through this process, I was able to reach out to my community partner UM-NSU CARD to focus on what caused a delayed diagnosis of Autism in Black and Brown populations in Broward County. Due to the duality of these two courses, I was able to gain further knowledge of delayed diagnosis and steps to rectify the issue. Thanks to Dr. Kabot, I was able to identify a problem within the community concerning Autism as well as the natural resources to tackle the issue. Similarly, thanks to Dr. Jaffe I was able to dive into the problem head first and work with community partners to create a timeline for success. Furthermore, thanks to Dr. Carole Zangari and Mx. Shantigra from UM-NSU CARD who aided largely as community partners to develop resources in support of the Autism Multicultural Initiative. I was driven by a desire to see and cause change given that I was in a unique position to do so.

Despite, my eager and overambitious plans I encountered some setbacks that prevented me from properly carrying out the project. The foremost was the timeline of the Health Literacy project occurring within a single semester. It did not offer me enough time to handle unforeseen elements like the IRB process for survey materials or a longer time to research the overarching issue. Learning from my failures and mistakes, I aimed to expand the scope of the project from one staging area to three as well as incorporate

more stakeholders to reach out to a variety of individuals. I was excited to do so through the Honors Thesis and the backing of the Honors College. I am grateful to Dr. Jaffe for working alongside me to propel the future forward and resolve the existing issues of delayed diagnosis.

Dr. Jaffe has greatly supported my academic research every step along the way and has provided me with knowledgeable critiques. However, UM-NSU CARD took a step back due to shifting responsibilities. As a result, I reached out to Dr. Jacqueline Hinckley from the NSU Speech Language and Pathology department to work alongside me as my community partner. Furthermore, learning from my past mistakes and experiences I reached out to more community partners in various areas. These collaborative efforts allowed me to greater understand the resources in the given area and create unique and culturally appropriate interventions in the form of infographics.

My research into this field and respectively the thesis project would not have been possible without professors, educators, doctors, academic fellows, teachers, and professionals. I thank every one of them for their impactful assistance throughout the thesis as I would not have done it without their guidance. I especially appreciate the support and reassurance shown by Dr. Jaffe and Dr. Hinckley. I was able to tackle an ambitious project due to their assistance and I will never forget that. This experience has strengthened my perspective on a multicultural approach to research. I am glad that I have had this impactful opportunity to help many people through a serious issue.

ABSTRACT

Autism Spectrum Disorder (ASD) affects a multitude of races and ethnicities as its impact varies from person to person. ASD is typically diagnosed around the age of two to three years old since signs and symptoms of Autism become clinically apparent at that time. Increased reporting of Autism in local communities has surged from diagnostic tools and criteria. However, even with these advancements, the African American community suffers a delayed diagnosis of ASD. This issue poses problems for both the parents and children with Autism and has broader implications for the South Florida community; opportunities are limited for developmental services by a delayed diagnosis. This project is an ongoing Honors thesis, and a thorough literature review was conducted to identify this issue in South Florida. The research presented useful information at the state and regional level, not specific to local south Florida communities. Based on this lack of information critical to the problem, research was conducted using a survey instrument to collect and analyze the data. Initial analysis reveals two specific themes: lack of identifiable local resources and understanding of Autism. The results of this study will be disseminated to community partners in the following communities using an infographic to be shared with the at-risk population. The thesis has focused on building connections with local community partners in Broward, Miami, and Monroe County. Overall, the project identified criteria that caused a delayed diagnosis of autism, understood current community resources, and is developing an intervention to showcase a pathway for care.

ACKNOWLEDGEMENTS

This Honors Thesis Project was able to be carried out due to the guidance of my faculty advisors, Dr. Mark Jaffe and Dr. Jacqueline Hinckley. They have given me support and encouragement throughout the entire process. Thank you for improving my skills as a researcher and I am proud to be under your tutelage. I cannot aptly describe how grateful I am to have both of you as my mentors and advisors.

I would also like to thank and appreciate the support of the NSU Farquhar Honors College. This project would have never been possible without their approval, funding, and support every step along the way. I can present this thesis at conferences and proudly explain how my project helps those that need it by shining a light on the issue. Furthermore, I especially would like to thank Dean Nevins for believing in me and my project to greenlight my thesis.

Furthermore, I significantly thank Dr. Kabot, Dr. Zangria, and Mx. Shantigra for welcoming me into the field of autism and educating me. I was able to properly understand the many nuances in this project in large part due to their guidance. It was due to their efforts that I was inspired and driven to carry out the thesis and address key issues.

Additionally, I thank all the community organizations in Broward, Miami-Dade, and Monroe County that aided in distributing the survey and served as wonderful sources of information. These include UM-NSU CARD, FIU CARD, School Boards from Broward, Miami-Dade, and Monroe counties, their respective ESE departments, Autism-related organizations, City Strategy Managers, and Faith-based organizations.

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**Awareness of Autism in Black and Brown Communities in South
Florida**

I. Introduction

Autism Spectrum Disorder (ASD) affects a multitude of races and ethnicities, and its impact varies from person to person. Given the name spectrum disorder, the symptoms of Autism differ from one person to the next. Typically, ASD is diagnosed around the age of two to four years old since the signs and symptoms of Autism become apparent at that time.

a. Delayed Diagnosis

Increased reporting of Autism in local communities has surged primarily because of better diagnostic tools and criteria as well as greater public awareness. However, even with these improvements, delayed diagnosis remains an issue for the African American community. Delaying the diagnosis affects the families of children with Autism; the delayed diagnosis limits the opportunities for developmental services. Parents lose out on the critical time to create an Individualized Education Program (IEP) for the child that is beneficial in charting out what school and government services to apply for (Kabot., 2021).

b. Purpose of Thesis

The purpose of this Honors Thesis is to first identify the significant factors that contribute to the delayed diagnosis of Autism in African American children. Secondly, to create a list of available healthcare resources to develop a better community response to reduce the incidence of delayed diagnosis.

c. Staging and Stakeholders

The staging area for this Honors Thesis will be the South Florida locations of Miami-Dade, Broward, and Monroe County. The Honors Thesis aims to tackle this issue with the aid of the Department of Speech-Language Pathology. The department will offer its myriad of connections to facilitate sending out surveys as well as distributing the intervention. Furthermore, the department will provide advice on upcoming steps as well as the goals of the Honors Thesis. Additionally, stakeholders in the Honors Thesis will be collaborative organizations found in the three staging areas. These will include Autism Organizations, CARD, Community Managers, City Planners, School Boards, and Superintendents.

II. Review of Literature

In support of this Honors Thesis, a literature review was conducted on the subject matter of Autism and its relation to African Americans and the problem of delayed diagnosis. The review crafted a perspective on the issue through multiple research databases provided by the school.

The databases used were as follows: Biomedical Reference Collection: Comprehensive – EBSCO Host, CINAHL Complete – EBSCO Host, MEDLINE – ProQuest, and PubMed Central – PMC. Each database was configured to a full text, peer-reviewed, and a search restriction of articles within a ten year range from 2012 to 2023. Articles were found using a combination of search terms like ASD, Minority, African American, Diagnosis, Intervention, Review, and Delayed. Primarily used search terms include ASD, African American, Diagnosis, and Delayed. For more expansive results Minority, Intervention, and Review were utilized to find similar case studies. These criteria resulted in several papers for review and visualization of the situation. The inclusion criteria for research articles focused on articles that discussed ASD concerning African American families, while the exclusion criteria were articles that discussed ASD without relation to African American families. Moreover, the research articles added nuance to the problem and proposed methods of reducing the issue. This literature review utilizes six peer-reviewed articles to illustrate the problem of delayed diagnosis of Autism amongst African Americans. This literature review supports the need for a health literacy project specific to the south Florida African American community. It should be noted that these studies either were data collected on a statewide basis or in specific areas. While the information is important, it is not pertinent to the South Florida area. As such, the

information conducted through a literature review is applied with location-specific surveys relevant to the staging areas.

The preliminary literature review found a factor behind the delayed diagnosis of Autism was parents missing specialty clinic appointments. The article, *Child and Family Characteristics that Predict Autism Spectrum Disorder Specialty Clinic Appointment Attendance and Alignment with Providers*, found these missing appointments were due to the distance of the household from the clinic or other detractors like socioeconomic status, health insurance, and the child's age. The study goes into further detail about how parents often hope that their child outgrows their current behaviors and how that also plays a factor in them missing critical appointments. The study presents valuable information and data on how to improve care for ASD in a clinical setting. The research paper concludes that there needs to be a reexamination of parent-to-provider communication and interaction. By forming a proper provider-to-parent relationship through means of empathetic wordage, intercultural awareness, and a sense of understanding providers are more likely to encourage parents to take more steps in the care of their child with ASD (Azad et al., 2019).

The research article *Timing of the diagnosis of autism in African American children* was able to identify any specific barriers to obtaining a diagnosis or services attributed to autism. The study had 584 African American children as participants while personal interviews were utilized for data collection. The article presented the following issues as problems that arose in the diagnosis process: repeat visits to a professional, a lack of healthcare professionals in the area, time, and cost expenses in the form of travel and insurance. The purpose of the study was to review data published by the CDC and

determine what barriers African American children with Autism face when accessing services for them. The results of the interview found the average age of diagnosis in those children and the reasons behind the delayed diagnosis. Leveraging this information, the researchers concluded with a call to action to remedy the overall situation and draft ideas on how to improve diagnosis rates (Constantino et al., 2020).

Concerning location-based surveys, an ethnographic study would review how urban African American families care for their child with Autism as well as the understandings of ASD researchers on the level of care. The research article, *African American Families on Autism Diagnosis and Treatment: The Influence of Culture*, assesses a study that reviewed the effect of culture on African American parents and how they interact with caring for their child with autism and health care professionals. To determine the effect that culture played, the researchers took field observations of 24 family members and analysis from 28 ASD professionals. This data was reviewed through Leininger's phases of ethnonursing analysis to generate two universal themes an African American family goes through after an Autism Diagnosis and treatment. These two themes respectively are: Protecting by pushing for independence or acting for the child, family, and community. These two actions take place after the child had been diagnosed with Autism or when the parents suspect the child has Autism (Burkett et al., 2015).

Following this information, it was imperative to review how parents, in general, handle finding services before and after diagnosis and if this contributed to a delayed diagnosis. The research article, *Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders* followed the experiences of 23 parents in how they found information about ASD after diagnosis. To

do so, the researchers interviewed the parents and reviewed verbal transcripts of the interviews. These interviews consisted of the parent's experience from diagnosis to researching ASD interventions. Like Leininger's phases of ethnonursing analysis, the researchers found themes common in all the experiences. These themes represented the types of sources that parents used in information gathering, why parents trusted certain sources, and how that information influenced the decision-making process. A common trait was parents were overwhelmed by the multitude of information as well as the quality. Many parents had to go through an arduous review process to find useful information. The research paper concludes by outlining the process parents had to take in finding appropriate treatment methods (Grant et al., 2016).

Another study, *Racial and ethnic differences in subspecialty service use by children with autism*, used statistical techniques and tests to determine differences in subspecialty service in terms of ethnicity. The study focused on χ^2 statistics and mean values by using the t-test. These statistical tests were compared in differences in proportions between children after the results of the M-CHAT and ASQ-II. Both the M-CHAT and ASQ-II were used to determine the sensitivity and specificity of Autism in children as well as any potential delays in development. By using statistical tests, the researchers were able to generate models based on the results of the questionnaires. Moreover, χ^2 statistics are utilized to compare model data against observed data, whereas a t-test is used to compare the mean of two groups and determine parameters of difference. The main difference between groups was the age when the child with Autism was referred to early intervention (EI) amongst developmental goals. Additionally, the researchers considered race, gender, age, ethnicity, mean income, and maternal education which might have

played a part in the differences. The outcomes of M-CHAT and ASQ-II were compared to developmental milestones to determine EI referral, EI referral completion, and EI eligibility (Broder-Fingert et al., 2013).

Furthermore, an article, *Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership*, discussed healthcare experiences between adults and adults with Autism. The article located and interviewed participants via the Gateway project and participants were found from the Academic Autistic Spectrum Partnership in Research and Education. These researchers were focused on comparing the healthcare experiences of Autistic and non-Autistic individuals. The overall survey used a variety of sources to construct an airtight questionnaire. The researchers did not need to go through the process of a nontraditional setting since their main method of obtaining data was through the Gateway project. Moreover, since the researchers worked primarily online, they were unable to build a relationship with the community or engage the participants. However, their data analysis went quite in-depth into age, sex, race/ethnicity, income, and parental education. The researchers partnered with a local organization to build up the participant pool since there were no collaborative activities. The content of the study and its findings were disseminated through the NIH for clinicians to review and reflect upon (Nicolaidis et al., 2013).

III. Methods

This Honors Thesis will employ the following methods for data collection: a combination of surveys and interview experiences. Participants involved in the study will review an NSU IRB Short Form Consent before taking part in the research study. Furthermore, a participant letter for anonymous surveys will be provided for participants to highlight the key aspects of this research project. Interviews will serve as an in-depth view of the survey results. Interviews are optional for the survey participants through the option to submit an email for further questioning. These interviews allow for survey participants to elaborate on their survey results as well as offer suggestions regarding the intervention. These interviews will occur over a private video conferencing call. These data points will serve as indicators of the level of care in communities regarding ASD and its diagnosis. Moreover, they will present information on how parents recognize signs of Autism and the diagnosis process.

Honors Thesis Survey

Page 1

Disclaimer: This survey is strictly confidential and anonymous, the intended use of the survey is educational. The distribution of the survey will occur through the NSU Speech Language and Pathology Department, please answer to the best of your abilities as this will provide information on community resources and potentially help other families.

Please complete the survey below.

Thank you!

Disclaimer: This survey is strictly confidential and anonymous, the intended use of the survey is educational. The distribution of the survey will occur through the NSU Speech Language and Pathology Department, please answer to the best of your abilities as this will provide information on community resources and potentially help other families.

[Attachment: "Participant_Letter_for_Anonymous_Surveys - Varun Kota - Honors Thesis.docx"]

After reading the participant letter attached above do you consent and agree to participate in the survey? I agree
 I do not agree

What ethnicity do you identify as? _____

What county are you apart of? Miami-Dade
 Broward
 Monroe
 Other

Figure 1: Honors Thesis Survey Section 1. This figure highlights section 1 the Honors Thesis Survey. The section focuses on obtaining the participant's consent, ethnicity, and county.

If you chose other, what county are you apart of? _____

How many children in your family are diagnosed with Autism? _____

At what age was your child(s) diagnosed with Autism _____

How easy was it for you to get a diagnosis for your child(s)? On a scale of 1-10, with 1 being very easy and 10 being very difficult

(Place a mark on the scale above)

How did you achieve your ASD diagnosis? _____

Did you face any barriers in the diagnostic process? Yes No

What were the barrier and how did your family overcome them? _____

On a scale of 1-10, with 1 being very easy and 10 being very difficult, how was your home and school life impacted

(Place a mark on the scale above)

Figure 2: Honors Thesis Survey Section 2. This figure displays section 2 the Honors Thesis Survey. The section focuses on understanding the age the child(s) was diagnosed and how many. Furthermore, the section aims to understand how the ASD diagnosis was achieved as well as any roadblocks.

What services have you reached out to after the diagnosis?

a. How did your family find appropriate services for your child? _____

b. What sources of information were most helpful _____

On a scale of 1-10, with 1 being very easy and 10 being very difficult, how would you rate the services provided to your child so far?

(Place a mark on the scale above)

Who provided you with information about Autism interventions?

a. How did you learn about autism? _____

In what format/s do you think information should be provided to parents newly diagnosed with autism? _____

If you are interested in a follow-up interview to elaborate on some of your responses please submit your email _____

Additionally, we hope to contact you via this email at a later date on spreading the intervention

Figure 3: Honors Thesis Survey Section 3. This figure showcases section 2 the Honors Thesis Survey. The section focuses on identifying what services the parent reached out to and which ones helped provide a diagnosis. Moreover, it offers parents an opportunity for a follow-up interview.

The data gained by the surveys will gauge how healthcare workers involve themselves with individuals with Autism and identify areas where parents can reach out for support. The overall goal of the surveys is to examine the problem on two fronts: Parental and Healthcare. The project will begin a process of statistical analysis once all data is collected. Leininger's phases of ethnonursing analysis will identify common themes found in each data collection. Utilizing the information provided by data analysis an infographic will be created to address these issues. The proposed intervention plans to distribute the infographic through the Department of Speech-Language Pathology, local clinics, hospitals, and school centers.

Moreover, the infographic will serve to guide new parents of African American children with Autism to community resources for their use. Furthermore, it will list out services that would aid in early diagnosis and potential interventions down the line for use. The stakeholders in this health literacy project are the Department of Speech-Language Pathology, parents of children with Autism, and health care professionals. Lastly, it is imperative to analyze the impact of the intervention through surveys and local reporting on ASD diagnosis. Success is measured by adding a QR code to the infographic that parents could scan which will then lead to a questionnaire that requests feedback on the health literacy intervention implementation. Resources for the health literacy intervention will be either found through prior research or the following questionnaire which will be sent out to the public.

IV. Results

The data obtained from the local surveys and corresponding interviews with parents leveraged Leininger's phases of ethnonursing analysis to identify common themes.

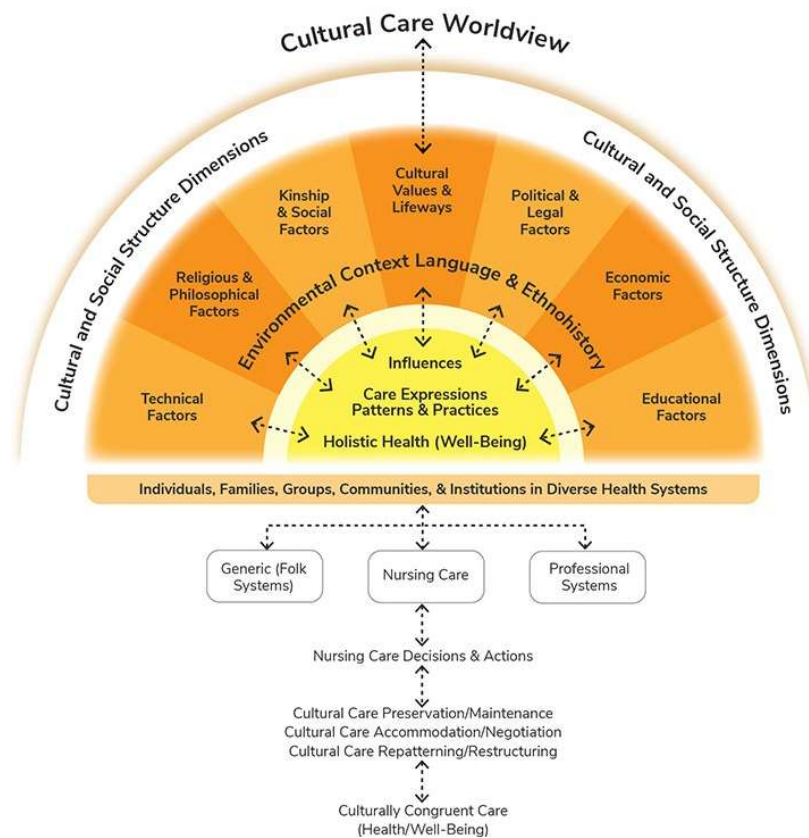


Figure 4: Leininger's Phases of Ethnonursing Analysis. The figure is a visual representation of how the analysis is meant to proceed. Furthermore, it represents how different environmental factors impact diverse health systems.

Leininger's phase of ethnonursing analysis is a statistical test. The process of this statistical test is to collect observations, data, and interviews that are assigned codes based on the content. These codes then are used to identify patterns of family values, beliefs, and practices that generate a universal theme for that population. This statistical test was appropriate for the honors thesis since it created universal themes based on the data collected. Resulting in core ideas for the infographic to build off of and address.

Furthermore, these themes were prevalent in the literature review and represent a confirmation of previously established theories. The themes found include a lack of identifiable local resources for parents and a lack of understanding of autism from parents. For the first theme, parents expressed that local resources were not easily accessible nor clear on services provided. Primarily due to numerous country and state-wide resources found rather than local resources. Moreover, the abundance of programs and community organizations posed an issue through decision-making paralysis. The other theme focused on the fact that in some communities' signs and symptoms of Autism are masked by myths or social stigmas. With mental health being a nebulous topic it can be hard to identify. Moreover for individuals who have had no prior experience with autism. Signs and symptoms could be masked by the terrible twos as disobedient behavior. Furthermore, other misconceptions like "they will grow out of it" pose a reason for delayed diagnosis.

The subjects contacted for an interview were reached out via email initially to confirm their availability. Once a meeting time and date were established, subjects were contacted via a zoom meeting session to further discuss areas not covered by the survey. Information gathered during this section was left to the parent's discretion regarding their experiences in obtaining a diagnosis. Guiding questions like, "talk about your experiences, what would you do differently, what do you recommend for new parents, etc." were utilized to gather additional information. The interview information alongside the survey data was processed through statistical analysis to generate the two established themes. Furthermore, a common response for new parents was indicated through what is referred to as the steps to success.

New parents of children with autism should focus on these steps to success

1. Child Milestones
2. Parental Support Groups
3. Pediatrician/Behavioralist
4. Call the school to arrange an IEP
5. Be an advocate

These steps would provide a streamlined process for new parents aiming to care for their child with autism through diagnosis and afterward. These steps were created through discussions with parents and data analysis to combat the two themes found. The first step, child milestones were used to sidestep local myths regarding autism since a child should meet these milestones. If a child were not meeting the milestones, then the parent would be urged to refer to their physician. Furthermore, the inclusion of parent support groups enables new parents to feel welcome by those who have gone through a similar experience. These support groups would aid in presenting local resources as well as pediatricians and behavioralists. As mentioned earlier, establishing an IEP is essential to a child's overall education and upbringing. Furthermore, a parent must be an advocate for their child and overcome hurdles.

V. Discussion and Conclusion

The Honors Thesis aimed to expand upon the initial research and work I had conducted for Practicum 1 in Biology course. During that course, I focused on understanding and learning the reasons behind a delayed diagnosis of autism for the African American population. It was through this process I was able to develop an intervention that I believed would resolve the issue, however, during the implementation phase I understood that obtaining patient experiences would take much longer. Upon my reflection, I understood that I would need to establish more time to conduct a proper study into the field. As a result, I was able to carry out an extended version of my initial study in Practicum 1 in Biology through the Honors Thesis. The additional time enabled me to reach out to a wider range of participants as well as conduct interviews with the participants. Furthermore, the title of an Honors Thesis encouraged more participation from both parents and local collaborators.

The Thesis would occur over three semesters providing me enough time to conduct further research into the field. The initial semester focused on researching the library databases using keywords like ASD, African American, diagnosis, and intervention to form a rationale behind the delayed diagnosis. Cumulating a literature review covering the scope of the project as well as areas that the project could apply itself to. Through writing out the literature review and reading additional articles on the subject, I could see other improvements that could be applied to the thesis. These came in the form of updating the initial survey sent out to local organizations and clinics as well as forms of data analysis.

Once that process is complete, the South Florida area was divided into communities that featured African American residents. During the project, I was able to identify local resources that parents could use both before and after the diagnosis of Autism. Noting these services, I sent out surveys tailored to each region to determine the effectiveness of each resource. In addition, I utilized patient interviews to expand data collection. These experiences would recount the parents' journey to receive a diagnosis for their child. Throughout the interview process, I had a set number of questions to ask however at times I would take a step back and listen to the parent's story. The interview process shed light on sections of a parent's story that the survey was not able to cover. Through this process, I have learned what has worked and what hasn't worked. This stage was most impactful for me since I could apply many of the lessons I learned from the initial trial to a long-term plan. One of the items that I put into action was working with local organizations to disseminate the survey. These organizations in addition to my community partners would be able to reach out to a greater number of African American families. Moreover, they also offered additional resources that I was able to keep note of.

Through additional literature and conversations with trusted professionals in the field, I realized that I should reach out to faith-based organizations as well. This was an unexpected discovery and it broadened my perspective on the local areas I could reach out to. Striking while the iron was hot, I reached out to city resource managers in each county who then connected me to more local communities. Furthermore, I also reached out to the public school boards and superintendents to have the survey disseminated. Additionally, I contacted each county's Exceptional Student Education (ESE) director for further assistance.

Through reaching out, I realized the difficulties of reaching out to other counties aside from Broward county. Many of these counties like Miami and Monroe operate independently from Broward. Resulting in fewer shared resources and different organizations in each area; this was the biggest shortcoming in the project so far. Despite my reaching out to these communities through various methods, I was unable to successfully pursue a connection that would bridge each of these services. Though I am still fervent in aiding the African American populations in the three counties: Broward, Miami, and Monroe to reduce any skepticism about healthcare. I now understand that my work will not fully solve the overall issue of delayed diagnosis, but I intend to document and record all everything. The success, failures, shortcomings, and surprises to aid those who follow my tracks. This would save those in the future time that they can utilize to improve the overall plan. Like what I initially had done for my reflection in Practicum 1 in Biology.

With this notion in mind and the data from both the survey and interviews, the information presented areas for the concurrent infographic to focus on. The infographic will provide information regarding available resources to assist families coping with Autism. Reviewing the previous infographic, it is clear that while the information provided is educational the layout and amount of information are dense. Rather it seemed appropriate to present the information in a clear and easy-to-read manner. Moreover, the over-addition of links to local resources greatly hindered a parent's ability to identify critical resources due to information overload. Thus, a streamlined and revised version of the infographic was created to not only address the issues posed. It also featured local

resources specific to each county in the form of parental support groups. As well as culturally sensitive language and tools recommended by local autism organizations.

Reflecting on the overall process of the Honors Thesis, I am glad that I was able to participate in such a momentous opportunity. Furthermore, I appreciate that I was able to use this platform to create a change for good and shine a light on a burgeoning issue. This thesis was able to execute the intended mission of identifying significant factors contributing to a delayed diagnosis of Autism in African American Children. As well as creating a local list of available healthcare resources to develop a better community response to reduce the incidence of delayed diagnosis. Lastly, with any project, there are avenues for future growth. Items like translating the surveys into multiple languages to reach a broader audience, testing out methods of local transport to arrive at appointments, and local diagnosis drives in communities.

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APPENDICES

Appendix A: Original Infographic

GUIDE TO AUTISM BEFORE AND AFTER DIAGNOSIS

This infographic serves to guide caregivers through Autism in the family



AUTISTIC PRIDE

Autism Spectrum Disorder is a developmental brain disorder present during early childhood. It may affect an individual's communication, behavioral, sensory tolerance, and social abilities. Can be diagnosed as young as 15 to 18 months old.

SIGNS

(may occur)



MYTHS

- "Autism does not happen to Black children."
- "They are just being a boy..."
- "They will grow out of it."
- "People with Autism cannot have fulfilling lives."
- "Every person with Autism is the same."

DIAGNOSIS OF AUTISM

Providers who may help:

- UM-NSU CARD
 - Case Manager
- Developmental Pediatrician
- Pediatric Neurologist
- Early Steps < 3 years old child
- FDLRS > 3 years old child



SERVICES AFTER DIAGNOSIS



- UM-NSU CARD
- 211 Broward
- Broward Children's Center
- Autism Society of Florida
- Autism Navigator

IMPORTANT NOTICE

Early diagnosis of Autism allows parents to create a developmental plan for their child. The diagnosis of Autism Spectrum Disorder can help families access resources. It is of greatest importance to access diagnosis as early as possible. This will empower your family to understand what supports are needed to support your child through their development.



USEFUL LINKS:

- <https://www.cdc.gov/ncbddd/autism/signs.html>
- <https://www.cdc.gov/ncbddd/early/milestones/index.html>
- <https://www.card.miami.edu/>
- <https://www.resourcehouse.com/211FirstCallForHelp/>
- <https://bckids.org/>
- <http://www.floridahealth.gov/programs-and-services/childrens-health/early-steps/index.html>

UM-NSU CARD registration page:



Submit feedback on infographic to CARD@nova.edu

USEFUL PHONE NUMBERS:

UM-NSU CARD
Miami-Dade & Broward: (305) 284-6563
Broward: (954) 292-7711
2-1-1
Florida Health Department:
850-245-4465

Appendix B: Broward Revised Infographic

Guide to Autism

BEFORE AND AFTER DIAGNOSIS

A clear and concise pathway through Autism Spectrum Disorder (ASD)



01 WHAT IS AUTISM?

ASD is a developmental brain disorder present during early childhood. It may affect an individual's communication, sensory tolerance, and social abilities.

02 MYTHS CONCERNING AUTISM

- "Autism does not happen to Black children."
- "They are just being a boy..."
- "They will grow out of it."
- "Every person with Autism is the same."



CDC's Developmental Milestones



03 PARENTAL SUPPORT

- Special Needs Advisory Coalition (SNAC)
- Black Parents of Children with Autism and other Disabilities Support Group

04 DIAGNOSIS OF AUTISM

- Developmental Pediatrician/Neurologist
- Early Steps < 3 years old child
- FDLRS > 3 years old child



05 POST DIAGNOSIS

- Create an Individualized Education Plan (IEP)
- Center for Autism & Related Disabilities (CARD)
- 211 Broward



06 BE AN ADVOCATE

Early diagnosis of Autism allows parents to create a developmental plan for their child. It is of the greatest importance to be an advocate.



Appendix C: Miami-Dade Revised Infographic

Guide to Autism

BEFORE AND AFTER DIAGNOSIS

A clear and concise pathway through Autism Spectrum Disorder (ASD)

01 WHAT IS AUTISM?

ASD is a developmental brain disorder present during early childhood. It may affect an individual's communication, sensory tolerance, and social abilities.



02 MYTHS CONCERNING AUTISM

- "Autism does not happen to Black children."
- "They are just being a boy..."
- "They will grow out of it."
- "Every person with Autism is the same."



CDC's Developmental Milestones



03 PARENTAL SUPPORT

- The Color of Autism Foundation
- NAMI Black Community Mental Wellness Support Group

04 DIAGNOSIS OF AUTISM

- Developmental Pediatrician/Neurologist
- Early Steps < 3 years old child
- FDLRS > 3 years old child



05 POST DIAGNOSIS

- Create an Individualized Education Plan (IEP)
- Center for Autism & Related Disabilities (CARD)
- 211 Miami-Dade



06 BE AN ADVOCATE

Early diagnosis of Autism allows parents to create a developmental plan for their child. It is of the greatest importance to be an *advocate*.



Appendix D: Monroe Revised Infographic

Guide to Autism

BEFORE AND AFTER DIAGNOSIS

A clear and concise pathway through Autism Spectrum Disorder (ASD)

01 WHAT IS AUTISM?

ASD is a developmental brain disorder present during early childhood. It may affect an individual's communication, sensory tolerance, and social abilities.



02 MYTHS CONCERNING AUTISM

- "Autism does not happen to Black children."
- "They are just being a boy..."
- "They will grow out of it."
- "Every person with Autism is the same."



CDC's Developmental Milestones



03 PARENTAL SUPPORT

- Autism Society of the Keys
- Autism Navigator



04 DIAGNOSIS OF AUTISM

- Developmental Pediatrician/Neurologist
- Early Steps < 3 years old child
- FDLRS > 3 years old child



05 POST DIAGNOSIS

- Create an Individualized Education Plan (IEP)
- Center for Autism & Related Disabilities (CARD)
- 211 Monroe



06 BE AN ADVOCATE

Early diagnosis of Autism allows parents to create a developmental plan for their child. It is of the greatest importance to be an *advocate*.

