

Identifying Autism in Jamaica: Program Design and Outcomes

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NASP Practice Model



Domain 8: Equitable Practices for Diverse Student Populations

Domain 9: Research and Evidence-Based Practice

Learning Objectives

- Discuss a training curriculum for graduate trainees to conduct culturally sound evaluations for autism in Jamaica
- Review culturally relevant considerations for evaluating and diagnosing autism in Jamaica
- Examine the obstacles encountered throughout the program
- Discuss future directions to promote autism identification practices in the Caribbean

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Outcomes

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Introduction



Background Information

- We are graduate students from Nova Southeastern University located in Fort Lauderdale, Florida
- South Florida is a melting pot of many ethnicities and cultures
- We work with diverse populations, especially from the Caribbean islands
- Connection with Caribbean Autism Supports and Education (CASE) Foundation which links us to Mico CARE Centre

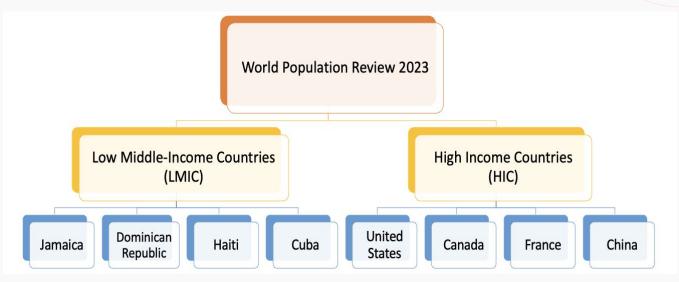




Autism is a neurodevelopmental disorder which is characterized by differences in social interactions. Symptoms include but are not limited to differences in social communication, repetitive behaviors, and restricted interests.

- 1 in 36 children in the U.S. have autism
- 1 in every 100 children in the world is diagnosed with ASD
 - 1% of the world's population is diagnosed with autism
- Large discrepancy in numbers globally
- The global prevalence of autism diagnosis have been rapidly increasing

The LMIC and HIC Classification



The Supports for Autism in High-Income Countries (HIC)

- Most HICs have the financial resources and health care to tend to neurological disorders along with the professions in the health-care system
- Trained professionals to recognize signs of autism
- Financial resources for families to receive early interventions
- HIC advocates for detecting children with autism early on and providing the resources needed for them to succeed in the future
- HIC include screening for autism starting in infancy/toddlerhood

The Challenges of Autism in Low Middle-Income Countries (LMIC)

- Limited knowledge about autism
- Limited healthcare professionals with expertise in autism
- Limited access to diagnostic tools
- Lack of awareness in warning signs and symptoms
- Low government and private resources
- Lack of standard screening process



Common Themes for LMIC

Awareness

- Lack of public awareness & professional knowledge
- · Lack of early detection
- · Poorly promoted

Professionals and Clinics

- · Lack of trained professionals
- · Lack of resources and clinics

Assessments and Instruments

- · High costs of instruments
- Few trained clinicians to administer assessments

Diagnosis

- Misdiagnosed
- Not trained in detecting autistic behaviors
- Delayed diagnosis

Stigma

- Negative societal attitudes
- Social stress
- Label of autism

Cultural Considerations

- Spiritual beliefs
- Insensitive assessments
- Cultural appropriateness



Research in Jamaica

- There is a lot of stigma attached to the autism label
- Jamaica has limited mental health services and neurodevelopmental support
- With the lack of awareness of the symptomatology of autism, parents are often unaware of the behavioral concerns reflective of autism and subsequently few children are identified



Common Themes Specific to Jamaica

| Lack of Awareness in the Community | Fewer Professionals and Clinicians | Limited Assessments and Tools available | Stigma |
|--|--|--|---|
| Few Clinics | Cultural Beliefs | Costly Evaluations | Limited Access to Special Education |





What can we do about it?







Project





Main goal of the Project is to collaborate and consult with clinicians in Jamaica about autism.



Collaborators

Caribbean Autism Support for Education (CASE) Foundation https://caribbeanautismsupport.com

Mico CARE Centre in Kingston, Jamaica







Spreading Awareness

- Web-based seminars focused on providing psychoeducation to parents, teachers, and clinicians in Jamaica
 - Social/Emotional Considerations
 - Q&A
- Meetings with CASE and Mico CARE to provide the Project Team with a deeper understanding of the specific needs of the island

The Project Team

- The Project Team consisted of 3 Graduate Students in a Doctoral School Psychology Program and 1 Licensed Psychologist
- The Project Team participated in a series of trainings to:
 - Learned measures such as the: ADOS-2, MIGDAS-2, & CARS-2
 - Practice Observing/Debriefing
 - Meeting with Mico CARE centre to solidify program design and to review institutional and legal requirements
- ADOS-2 Trained

The Jamaica Team

- There were 10 psychologists and clinicians who work at Mico CARE Centre and participated in the project
- Trained in the ADOS-2 (official training)
- This was all of their first (or second) time administering the ADOS-2
- 2 Locations: St. Anns and Kingston

The Original Project Design

- Scheduled for May 2023: Travel to Mico CARE Clinic in Kingston, Jamaica with faculty and students
- The project team planned to engage in observations of the test administrations of the ADOS-2 and the MIGDAS-2
- Team was supposed to engage in a debriefing session with the evaluators in order to review the administration and scoring and to discuss salient observations of the child and differential diagnosis
- Team was going to provide feedback to the families present for the evaluation
- For training purposes, the psychology trainees was going to also complete a Connors Autism Rating Scale, 2nd edition (CARS-2), following each evaluation session and share results with the team

Original Design Complications...

Jamaica Travel Advisory

Travel Advisory January 23, 2024 Jamaica - Level 3: Reconsider Travel





Last Update: Reissued with updates to crime and health information

Reconsider travel to Jamaica due to crime and medical services. U.S. government personnel under Chief of Mission (COM) security responsibility are prohibited from traveling to many areas due to increased risk. Please read the entire Travel Advisory.

Country Summary: Violent crimes, such as home invasions, armed robberies, sexual assaults, and homicides, are common. Sexual assaults occur frequently, including at all-inclusive resorts.

Local police often do not respond effectively to serious criminal incidents. When arrests are made, cases are infrequently prosecuted to a conclusive sentence. Families of U.S. citizens killed in accidents or homicides frequently wait a year or more for final death certificates to be issued by Jamaican authorities. The homicide rate reported by the Government of Jamaica has for several years been among the highest in the Western Hemisphere. U.S. government personnel under COM security responsibility are prohibited from traveling to the areas listed below, from using public buses, and from driving outside of prescribed areas of Kingston at night.

Emergency services and hospital care vary throughout the island, and response times and quality of care may vary from U.S. standards. Public hospitals are under-resourced and cannot always provide high level or specialized care. Private hospitals require payment up front before admitting patients and may not have the ability to provide specialized care. Ambulance services are not always readily available, especially in rural areas, and are not always staffed by trained personnel.









Design



The Layout

- The week prior, the Project Team met with the Jamaica Team via Zoom to review the ADOS-2 Module 3 and to answer any questions in preparation for the next week
- The following week, the Project Team joined testing sessions via Zoom with the Jamaica Team occurring in the clinic so that the administration of the ADOS-2, could be observed
 - After every administration, a debriefing session with the team was conducted to review the administration and scoring and to discuss salient observations of the child and differential coding
 - After this debriefing, the Jamaica Team then provided feedback to the families present for the evaluation

Recruitment and Evaluation Process

- Jamaica Team selected 5 boys; ages 7-14
- IQ, Achievement, Social, and Behavioral assessments were administered prior to the ADOS-2 administrations (to ensure validity of the diagnosis)
- ASRS was another autism assessment used for determination

Schedule of the Sessions

| Team | Day | Time | Details |
|---------------|-----------|---------|------------------|
| S. Miller & | Monday | 8:45 - | ADOS-2 |
| C. Myers | | 9:45 | Administration |
| - W. | | 9:45 - | ADOS-2 Debrief & |
| | | 10:30 | Scoring |
| J. Scott & T. | Tuesday | 8:45 – | ADOS-2 |
| Aarons | 70-E | 9:45 | Administration |
| | | 9:45 – | ADOS-2 Debrief & |
| | | 10:30 | Scoring |
| S. Westcarr | Tuesday | 10:45 – | ADOS-2 |
| & C. | Tuesuay | 11:45 | Administration |
| Douglas | | 11.45 | Administration |
| | | 11:45 - | ADOS-2 Debrief & |
| | | 12:30 | Scoring |
| S. Bell & G. | Wednesday | 8:45 - | ADOS-2 |
| Johnson- | | 9:45 | Administration |
| Grant | | | |
| | | | |
| | | 9:45 – | ADOS-2 Debrief & |
| | | 10:30 | Scoring |
| T. Ewen- | Thursday | 8:45 – | ADOS-2 |
| Smith & S. | | 9:45 | Administration |
| Matthews | | | |
| | | 9:45 – | ADOS-2 Debrief & |
| | | 10:30 | Scoring |
| | | | |

| The Format for Each Session | | |
|-----------------------------|--|--|
| 1. | 1 hour observation and notetaking of the clinician administering the ADOS-2 Module 3 | |
| 2. | Provide feedback to clinicians about their administration | |
| 3. | 10-15 minutes of independent coding | |
| 4. | Share coding scores for each section | |
| 5. | 15-30 minutes of discussing where codings differ from each other | |
| 6. | Come to an agreement for coding scores | |
| 7. | Convert and add up scores to get the results | |













Pictures from the Project

Design Limitations

- Limited research
- Norms for autism assessments are not based globally
- Flexibility
 - Travel restrictions
 - Arrival of assessment measures
 - Zoom platform (connection, ability to hear, camera placement)
- Cultural diversity

Administration Strengths

- The clinicians were well prepared for the administration
- The clinician demonstrates strong observational skills, effectively assessing the client's behavior and responses
- Clinicians exhibited calmness, organization, engagement, and a positive attitude throughout
- They established a secure environment, fostering comfort and openness for clients to interact with them

Administration Areas for Growth

- Children's awareness of observation/camera
- Distractions within the testing environment
 - The clinic is also a school, therefore, background noise would have been difficult to avoid
 - *Clients appeared to be unaffected by background noise*





Outcomes





With the collaboration of coding for each session, all children fell within the moderate to severe symptomatology ranges of autism on the ADOS-2.

Reminder, this was not used at the determining factor of whether the client met the criteria of autism.



Common Themes We Addressed



Limited Lack of Lack of Assessments Professionals Awareness in and Tools and Chnicians the Community available Inadequate Costly Cultural Beliefs Special **Evaluations**



Cultural Learning Opportunities

Things we learned during this experience was...

- The mannerisms and etiquette, such as "Yes, Miss."
 - Idiosyncratic/repetitive language or the culture of respect
- The cultural norms of marriage, such as living with mother and future wife in a house
 - Insight of social relationships or the cultural norms of the household
- The Patois language
 - Grammatical errors or dialect

Cultural Learning Opportunities

- Findings of what the Jamaican Team needed
 - Guidance and support on coding the ADOS-2
 - Gain a sense of comfortability of why codings were coded this way
- Findings of what the parents/family needed
 - Managing non-compliance and behavior
 - OT Services:
 - Eating
 - Toilet Training

Future Considerations

- Attend in person
 - In Jamaica, the clinic would need permission from the Government
- Clear audio to hear examinees during administration
- Expansion to other LMIC
- Country wide norms
- Understanding "female presentations" of autism
- "Grey-area" kids

Our Next Steps

- To continue collaborating with CASE Foundation to provide resources to families
- Debrief and consult with psychologists about autism evaluations
- Host more informative webinars (social skills, emotion regulation, behavioral supports)
- Attend Mico CARE Centre in person



We encourage graduate students and school psychologists to get involved in outreach projects and communities that are disadvantaged and provide a helping hand to support all children globally.



Questions?



Thanks!

Do you have any questions?

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