Diagnosing Autism in Africa

Sierra Leone

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Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by deficits in communication and social skills, and the presence of restrictive, repetitive behaviors and interests (American Psychiatric Association, 2013). Considered a global health concern, ASD has no cure nor known cause. Although diagnostic instruments have been developed to identify individuals with ASD, many of them were validated for use in the United States and pose challenges when used in other settings. Cost, restrictions on who can purchase and score the assessments, and cultural differences that invalidate items (Smith et al., 2017), result in available assessments being inaccessible to low- and middle-income countries. This is particularly problematic for areas of sub-Saharan Africa, where very little is known about ASD (i.e., only 120 studies have been published on ASD; Franz et al., 2017). Without a validated, culturally appropriate method for identifying people with ASD, prevalence data cannot be generated. Globally, this leads to an incomplete, and possibly biased, understanding of ASD. Locally, it leads to an inaccurate understanding of the causes and characteristics of ASD. For example, in Sierra Leone, many people believe the typical characteristics of ASD have supernatural causes (Ruparelia et al., 2016). As such, families of children with ASD are often shunned and lack access to necessary services. Moreover, in some countries, such as Sierra Leone, infanticide and violence against children with disabilities are common (Rohwerder, 2018). Prevalence data are crucial for being able to identify and plan for educational, social, and medical service needs (Myers et al., 2019). Being able to accurately plan for these needs is even more important in low- and middle-income countries due to their limited access to additional resources.

The initial objective of this project is to develop a culturally appropriate, freely available screening tool for ASD for implementation in Sierra Leone. Once the screening tool is validated, we will work to create and validate a culturally appropriate diagnostic tool. Our long-term goal is to disseminate the tool throughout other countries in sub-Saharan Africa, making cultural adaptations as needed to meet the needs of other countries. Additionally, we aim to disseminate information about ASD throughout each of the countries we are working in, to bring awareness and acceptance of ASD to these communities. Through the development and administration of our screener, we aim to dispel commonly-held beliefs that people exhibiting characteristics of ASD are demon-possessed by educating the community about ASD. In doing so, we hope to improve the standard of living for individuals with ASD in those countries by promoting inclusion and the provision of necessary supports and services.

To address the need for a culturally appropriate and feasible screener, this project is currently in the concept phase of designing an ASD screening tool for use in Sierra Leone. In order to develop our screening tool, we first conducted a thorough review of Western screeners to determine feasibility in low- and middle-income countries (Bauer et al, in review). We reviewed readability, materials required, verbal ability measured, training required, and the startup and continued costs of use. The information obtained in this review will be used to develop the items for the Multicultural Autism Screening Tool (MCAST), to ensure that the screener will be feasible for use in low- and middle-income countries. Additionally, we have developed partnerships with the University of Makeni, World Hope International, Sierra Leone Autistic Society, and the Centre

for Autism Research in Africa. These partners will provide feedback on the cultural appropriateness of the items, ensure the items represent the daily lived experiences of individuals in Sierra Leone, connect our team with individuals in the community to gather pilot data, and will be crucial resources for implementation.

The six members of our team are divided between three sub-groups, respectively focused on the development of the screening tool, qualitative research, and the development of awareness and acceptance training materials. The five students above are advised by principal investigator Dr. Kristi Morin, an Assistant Professor in Special Education at Lehigh University.

Our team plans to travel to Sierra Leone in August of 2021 to gather pilot data for our screener. These data will be used to examine the reliability and validity of the MCAST and revisions will be made as needed to support sensitivity and specificity. Additionally while in Sierra Leone, our team will conduct interviews and focus groups with parents of children with disabilities as well as community members in order to gain a better understanding of how people view individuals with disabilities, the lived experiences of family members of those with disabilities, and the supports that are available to or may be needed for families with disabilities. Lastly, our team will conduct trainings about the signs and symptoms of autism at the University of Makeni, in local schools and healthcare facilities, and in the community to raise awareness about this disability.

Once the MCAST has been validated, we will train three healthcare workers at each healthcare facility and three teachers at each school in Sierra Leone to administer our screener. To ensure the screener is being administered as intended and that we are reaching all children in Sierra Leone, we will conduct trainings and introduce implementation of the screener in 2-4 districts each year, reaching approximately 20% of children each year. As a result, our goal is to have all 16 districts in Sierra Leone implementing the MCAST to screen for ASD within five years.

Three years from now, our team will have developed a validated screener for ASD for use in Sierra Leone. Ten years from now, our team hopes to expand its use to Western Africa and eventually, sub-Saharan Africa. Our goal is to have a minimum of 20% of children screened by 2022 and 100% of children living in Sierra Leone screened by the year 2026. We will have trained and certified community members to travel to the healthcare facilities and schools in the Bombali, Port Loko, and Kambia districts by 2022 and have training completed in all 16 districts of Sierra Leone by 2026. Other long-term impacts our solution will have include a greater understanding of disabilities, increased inclusion for people with ASD, improved quality of life for people with ASD and their families, and increased community knowledge about the potential causes, consequences, and effects of ASD.

Our venture's success will not be measured by monetary value, but by the number of children that are screened for autism as well as the number of healthcare facilities and schools that have trained professionals qualified to administer the screener in Sierra Leone. To measure our venture’s impact, an important member of our team, the measurement and evaluation consultant, will evaluate our systems within schools and healthcare facilities annually to ensure that our screeners continue to be administered with fidelity and integrity.

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