Diagnosing Autism in Africa

Sierra Leone

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The initial goal of this project was to develop a culturally appropriate, freely available screening tool for autism spectrum disorder (ASD) for use in Sierra Leone. Once our screening tool was validated, our goal was to 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 the screener, we aim to dispel commonly held beliefs about individuals exhibiting characteristics of ASD, such as that they are demon-possessed. In doing so, we aim to improve the standard of living for individuals with ASD by promoting inclusion and the provision of necessary support and services.

This project was initially proposed due to the nature of ASD as a global health concern. Furthermore, while 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, where an ASD diagnostic tool doesn't exist, 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 limited access to additional resources.

In order to begin achieving the goals of our project, we utilized our Autism screener expert partners in-country to gain feedback for our initial rough draft of our MCAST screener. In Sierra Leone, we partnered with nonprofit organizations World Hope International and Sierra Leone Autistic Society, as well as the University of Makeni, due to their commitments towards empowering and educating the individuals of Sierra Leone. We also utilized two Makeni-based community members as our translators and local guides during fieldwork. We continue to further our partnerships with these groups and individuals in order to continue to receive feedback on the cultural appropriateness of our screener, ensure that items in our screener represent the daily lived experiences of individuals in Sierra Leone, and connect our team with individuals in the community to continue to gather pilot data. In terms of funding support beyond the Davis Projects for Peace, we have also received support from the Office of Creative Inquiry and the College of Education at Lehigh University.

Our original proposal included plans to travel to Sierra Leone in August of 2021, but due to the COVID-19 pandemic we had to delay our fieldwork research to July 31-August 19, 2022. We returned from fieldwork after gathering pilot data from interviews and focus groups on the perspectives of disabilities in Sierra Leone. We had a goal of conducting 180 interviews but due to delayed IRB approval and street uprisings against the government, resulting in mandatory curfews and lockdowns, our schedules for focus

groups and interviews were pushed back. We ended up collecting interview data from 50 educators, 23 parents, 26 community members and 38 healthcare workers, totaling 140 interviews including eight focus groups with educators and healthcare workers. This data will be used to help 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 of persons with disabilities.

In addition, we were able to receive in-country feedback for our screener from World Hope International partners who regularly work with children with disabilities and their families using behavioral therapy. They gave us cultural advice on how to format and word our screener taking into consideration local vocabulary. We will use this data to examine the reliability and validity of the MCAST to make revisions as needed to support sensitivity and specificity.

Lastly, our team created training materials for educators, health care workers, and parents to be able to administer them in future training 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. Unfortunately, we were not able to administer them on this trip due to the delays stated before, but we are confident we will be able to edit our current training templates after collecting the interview data to have a better influence on Sierra Leoneans when it comes to understanding how to care for people with disabilities in medical, educational and home settings.

Our first fieldwork trip was monumental in finally gaining insight on the perspectives of Sierra Leoneans. However, we need to continue our plans for future visits to ultimately implement our screener and training programs. We were able to understand first-hand how lackluster the clinics and schools are in their resources for disabilities. A screener like ours will allow us to identify the correct students and direct them to the right resources for support, like the Sierra Leone Autistic Society. In addition, our reformatted training materials will increase overall awareness and knowledge on disabilities to the individuals who can provide the most support to children with ASD. Healthcare workers and teachers expressed intense eagerness to learn more on how to assist those with disabilities that they are in contact with on a daily basis and are hopeful for reform in their job training.

For future fieldwork trips (in summer 2023 and beyond), 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 training 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, all of sub-Saharan Africa. Our goal is to have a minimum of 20% of children screened by 2025 and 100% of children living in Sierra Leone screened by 2029. 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 2025 and have training completed in all 16 districts of Sierra Leone by 2030. 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 causes 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 the screeners continue to be administered with fidelity. Another way in which we measure success would be through the way in which the government will acknowledge ASD as a problem and devote time and resources to set up necessary supports and services for those with ASD and their families.

We define peace as building capacity for empathy, addressing conflicts with justice and equity, celebrating differences, and ensuring that there is a space for people with disabilities to be heard. With our mission, we will create this space by advancing awareness and knowledge on ASD in Sierra Leone,

thus decreasing the stigma and negative connotations that carry throughout communities due to the lack of education. By administering training we are contributing to the resources in clinics and schools to help those socially separated by their intellectual and neurological disabilities.

By being a part of our project, we've been able to gain an immense appreciation for the way in which those from stigmatized communities - in our case, the neurologically disabled - fight to be heard, seen, and receive equitable treatment from others. This has inspired us to continue partnering directly with disabled communities, since true, positive impact can only be created when the voices and experiences of those we are trying to assist are amplified.