

## Autism and the Grand Challenges in Global Mental Health

There is increasing recognition of the global burden related to mental and neurological conditions greatly surpassing many health conditions such as cardiovascular disease and cancer. Recently, partnership among leading funders and academics has given rise to the grand challenges in global mental health initiative, aiming to reduce the global burden associated with mental and neurological conditions [Collins et al., 2011]. Among the actions of this initiative was a priority-setting exercise to articulate the most pressing challenges research in this area needs to address. Representing a diverse group of researchers and practitioners, we collectively considered progress and barriers in these priorities as they apply to autism research. In this editorial, we describe, based on our knowledge of and direct experience with autism in low- and middle-income countries (LMICs), the state of the science corresponding to the grand challenges and offer suggestions for how a truly global approach to autism research can bridge knowledge gaps leading to substantive improvements in quality of life for those affected wherever they may be.

### Identify Root Causes, and Risk and Protective Factors

Our knowledge of the phenotypes and aetiology of autism is almost entirely limited to a small proportion of the world's population [Elsabbagh et al., 2012]. To understand the nature of this complex disorder, a global approach offers opportunities to examine the impact of a much wider range of biological and social risk factors directly related to autism. For example, a growing number of genetic and genomic studies are exploiting the large population size of China [Xu et al., 2012]. Other studies from LMICs have informed the search for inherited risk factors through tracing shared ancestry in consanguineous families [Morrow et al., 2008]. Moreover, links between autism and a range of environmental risk factors have been proposed in diverse geographical settings [reviewed in Elsabbagh et al., 2012].

A major barrier to this line of investigation is that it relies on expensive infrastructure unfit with research capacity in most LMICs. Furthermore, when such projects are led by researchers in high-income countries, people affected may be reluctant to participate because of mistrust

resulting from negative experiences with research and/or lack of awareness of research benefits. This suggests that while research in LMICs can accelerate modelling of causal pathways underlying autism, this approach must go hand in hand with capacity building and public engagement in the target communities [see relevant discussion in Grinker et al., 2012].

### Advance Prevention of Disabling Consequences and Implementation of Early Interventions

It is widely acknowledged that early identification and intervention for a range of neurodevelopmental disorders including autism is critical in reducing the long-term negative impact of the condition. In view of this, a number of autism screening instruments have been translated for use across different cultural settings [see Elsabbagh et al., 2012, for a review]. An alternative approach has been to validate screeners such as the "Ten Questions Plus," previously used for childhood disabilities in LMICs [Durkin et al., 1994] to screen for a wider range of developmental conditions [Wu et al., 2011]. In a similar vein, translation of diagnostic tools commonly used in autism research and often described as the "gold standard" has been pursued [Wallace et al., 2012], but Progress in this area has been slow. Although such tools rely on the best available evidence and focus on comprehensive evaluation, they tend to be highly resource-intensive and reliant on specialist training. Overall, there is a demand to critically review the use of resource-intensive diagnostic instruments, as these may be barrier to research progress and capacity building in most low-resource settings.

In the complementary area of early intervention, there is a striking lack of studies emerging from LMICs [Hastings et al., 2012]. It is commonly thought that effectiveness of early intervention in autism is limited to costly, highly intensive programs delivered by specialized professionals [Myers, Johnson, & American Academy of Pediatrics Council on Children With Disabilities, 2007], limiting generalizability to most real-world settings, including LMICs. However, this landscape is beginning to change, with growing excitement around a wider range of innovative early intervention strategies. These include parent-mediated approaches that have demonstrated a positive impact in reducing disabling consequences and

improving cognitive function [Warren et al., 2011]. Such interventions are currently being tested across a range of settings including in LMIC.

It is critical to note that the landscape of supportive interventions in LMIC has not been void of alternative approaches to those developed in high-income countries, and these approaches provide equally viable targets for research. There is a need for these culturally sensitive and community-based models to become integrated into the range of approaches being evaluated internationally. This may inspire more diverse and creative approaches in meeting current challenges facing intervention research in autism, including its generalizability to low-resource settings.

### **Improve Treatments and Expand Access to Care**

Expanding the knowledge base in complementary areas of screening, diagnosis, and implementation of community-based services to support early identification and intervention is thought to yield benefits for those affected across the life-span. Common barriers currently hinder access to evidence-based treatments for those affected in childhood and adulthood. The state of science in relation to autism intervention coupled with little formal consideration of the generalizability of existing approaches to real-world settings clearly illustrates both knowledge and resource gaps even within high-income countries. In some communities, intervention remains limited to practices such as the use of medications and excludes the family and the wider community. In several countries, approaches already dismissed by research such as psychoanalytic treatments still thrive. Private, unregulated, and usually expensive services for autism are abundant. Such services often employ or directly apply “packaged” models used in high-income countries, with little consideration of cultural or contextual validity.

Rather than adopting a “one-size-fits-all” approach, research in this area should be motivated by the needs of diverse and especially under-resourced communities. Cross-cutting questions include the effectiveness of more efficient screening, diagnostic, and intervention procedures as well as the delivery of evidence-based care by nonspecialized community health workers, an approach known as “task-shifting” [Patel, Singh Goel, & Desai, 2009]. Research specifically targeting use of affordable technology to support implementation of evidence-based care will undoubtedly enhance positive impact.

### **Raise Awareness of the Global Burden**

Communities who combat stigma and misconceptions against disabled people benefit from their skills and

competencies instead of marginalizing them as a burden to society. It is acknowledged that advocacy and awareness efforts in North America, and some parts of Europe have had a global impact welcomed by those affected around the world and reinforced by local action. Today, there is a flourishing number of autism advocacy and awareness groups around the world.

In parallel, there is increasing focus in autism research on estimating the economic burden of the condition to support evidence-based policy. Adopting this approach across a wider range of communities around the world will broaden the impact of these findings from national to global policy. A critical move forward will be to produce cross-national evidence or standardized global data systems for collecting surveillance data on the prevalence, treatment patterns, and availability of human resources and services of autism.

### **Build Human Resource Capacity**

Our experience across several LMIC suggests improvements in the availability of training among researchers, specialist practitioners, community health workers, and parents. However, none of these training efforts are at an adequate scale to address the needs of their wider populations. In some countries, there has been a focus in recent years on training professionals on standardized instruments (delivered in high-income countries or by regional providers). This is a costly and challenging approach because it is detached from the specific research or practice context [see discussion in Wallace et al., 2012].

Effectiveness of training approaches on capacity building and service development has rarely been considered in autism research, and a global perspective can enrich and support this area. There is a need for innovative models to increase the number of culturally and ethnically diverse specialist and nonspecialist providers to deliver evidence-based services.

### **Transform Health-System and Policy Responses**

In most communities where policy change has taken place, it was the families of those affected who spearheaded changes through tireless activism, fundraising, and lobbying. Individuals with a wide range of neurodevelopmental challenges including autism have benefited from policy responses ensuring the inclusion of individuals with autism in health, social, and educational systems. Nevertheless, these policies are yet to have a wide and far-reaching impact on the lived experience of those affected. There is now growing momentum for leveraging these global community efforts towards substantive transformations in health systems and in policy.

Autism research can support policy transformation by systematically creating and prioritizing policy-relevant evidence in health services, education, vocational training, and family support both nationally and globally.

## Conclusion

Although the majority of autism research remains concentrated in a handful of high-income countries, advances in our understanding of this condition have no geographical boundaries. A number of principles cutting across the challenges considered earlier initially developed for a wide range of neurodevelopmental and mental health conditions resonate very clearly in autism research today. First, while some of the recommendations for future research may target specific age groups, it is necessary to adopt a life-course approach in considering the impact of autism on an individual. Second, autism does not only affect individuals but affects entire communities, and therefore, system-wide perspectives are crucial. Finally, an evidence-based approach is necessary for a wide range of knowledge users including families, practitioners, and policymakers to support informed decisions.

To meet the global challenges, autism research will need to characterize genotypes, phenotypes, and risk factors in autism across diverse geographical settings; develop culturally appropriate, valid, and comparable diagnostic instruments; and design affordable care packages for use by community health workers applicable to a range of neurodevelopmental disabilities. A recent rise in national, regional, and global research and practice networks has given new impetus to this area and created promising opportunities for research. It will be critical for these autism initiatives to forge alliance with global networks already achieving these goals for a wider range of disabilities. In view of the increased awareness of autism worldwide and the growing interest from a wide range of stakeholders, research in this relatively narrow field may be viewed as a potential vehicle for improvements in evidence and practice standards not only in autism but more generally in child mental health.

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