

VIEWPOINT

A global vision for autism with community solutions

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World view: Communities worldwide may need to tailor diagnosis and treatment of autism to their unique cultural sensitivities.

Many of us who are fortunate enough to cross geographic, cultural and political boundaries come to perceive people across these divides as more similar than they are different. When it comes to research and discovery, it is only natural that we want to ask questions relevant to humanity as a whole and achieve goals without boundaries.

A major barrier to this vision is that the overwhelming majority of research is centralized in a handful of countries. So it comes as no surprise that the mainstream agenda reflects the goals and priorities of those who set them rather than a more representative slice of the world.

Fortunately, an alternative world vision is increasingly making its way to the forefront of autism research. Although we clearly have a long way to go — with tensions and conflicting strategies that have yet to be reconciled — eventually we will recognize that a global approach is not a choice, but

a necessity.

Traditionally, autism experts working in underserved and low-resource countries have fallen into known traps of global development. One of these traps is the umbrella of charity, under which researchers play consultancy roles within communities that they believe are in need of their intellectual capital. This approach is built on the assumption that knowledge and research capacity flow only one way.

Another motivation to conduct research in 'exotic lands' is the prospect of scientific opportunities in parts of the world where there are unique genetic pools: for example, those resulting from a high prevalence of **marriages between first cousins**¹, or environmental exposures to substances such as toxins.

A wider range of what are perhaps well-intentioned attempts to help people in low-resource countries have mistakenly assumed that models developed for a narrow segment of the world's population can simply be 'exported' to other areas.

These attempts have inadvertently created a lucrative market for consultants, **instrument translators** and pseudo-researchers, who often turn a blind eye to local needs and capacity, ethical challenges and the potential for community innovation.

Lost in translation:

Some of the efforts to export knowledge or transplant research capacity may succeed, but they are not sustainable and reflect dependency rather than true collaboration. Everyone is to blame in these situations, including local professionals and researchers who often personally gain from the process, but deliver little sustainable impact to their community.

Autism researchers need to abandon the assumption that research and evidence-based care are transportable. In the same way that we reject a one-size-fits-all definition of autism, we should acknowledge that every community needs to set its own agenda and find its own best solutions.

Universality of knowledge is relevant to our understanding of biology, development and those principles underlying clinical care, but not in the blind application of context-specific models and standards. A world vision requires researchers to find a common ground, identify convergence across diverse contexts and feed this information back into the research agenda².

A key illustration of rising tensions in this area is the **debate around the utility of translation of diagnostic instruments** such as the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised. These instruments were originally developed to support standardization in research and reduce reliance on subjective clinical judgment, but have become increasingly used in community practice settings.

We focused on this issue during a special interest group meeting entitled ‘Lost in translation’ at the **International Meeting for Autism Research 2013** in San Sebastián, Spain. Expert panelists, who have either developed or translated such instruments, called for constructive discussion around successful models of care, without *a priori* assumptions about their utility in diverse contexts.

In other words, the role of researchers is to assemble and prioritize the evidence, and allow different communities to select or craft their own options.

The simple conclusion from the meeting was that the question should not be whether we should translate these instruments. This question lacks understanding of the broader purpose of translation and how it will yield immediate or long-term benefits for different communities. There is no one-size-fits-all formula for how to develop research or clinical capacity in diverse communities, but there is great value in learning from the experiences of others.

These conclusions echoed sentiments expressed last year in the special issue of *Autism Research*, “Global Perspectives on Autism,” which assembled views, evidence and models from 60 researchers in 20 countries³. An emerging theme across these perspectives was that translation of knowledge generated from research is often a complex process relying on active engagement of the community.

The special issue included a systematic review of the **global prevalence of autism**, which highlighted evidence gaps — for example, the absence of reliable **prevalence** data from many parts of the world and extremely limited evidence of the cultural and economic impact of autism⁴. The researchers called for concerted efforts to address further questions relevant to the world community.

The article is now the most frequently downloaded on the journal’s website, demonstrating that challenging flawed assumptions, promoting dialogue and working constructively toward a global research agenda is feasible and beneficial for the field as a whole.

Like many emerging ideas, a global vision for autism research is likely to struggle with definitions, boundaries and utility. It’s yet to be determined whether a subspecialty in autism research dedicated to global approaches will eventually emerge, or if championing the perspective is sufficient.

In any case, we need to learn from inspirational work being done in so many communities and collaborate with other fields, **such as global mental health**.

What is clear is that we need this global vision in research to hold up to standards of scientific rigor and quality. In other words, thinking and working globally is not an excuse for dilution or for creating a second-tier research agenda.

Instead, whether our research is at the bench or on the community frontline, a global vision encourages us to think outside of the box and to hold our field to higher standards. Without a doubt, this is the best contribution we can make to humanity.

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References:

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