

PROJECT SUMMARY

Overview:

One of the puzzling dynamics of the autism epidemic is the emergence of divergent and contradictory interest groups with different definitions of the illness. The existing literature on health social movements cannot make sense of this heterogeneity because it assumes that people who share common illness experiences develop unified movements to challenge mainstream science. Further, there are no studies which address how racial minorities make sense of their experiences with autism. This project will examine how a delimited population group (Somali refugees) in two different national locations (Minneapolis, MN and Toronto, Canada), contending with the same empirical puzzle (high rates of autism), have forged distinct, yet coherent epistemic groups around a definition of illness, its causal pathway, and possible courses of treatment. The forging of 'epistemic communities' impacts health behavior, including vaccine uptake and treatment choices.

There is growing statistical evidence that Somali refugee populations have higher prevalence rates of autism spectrum disorder (ASD) than all other ethnic/racial groups. Somali parents refer to autism as the 'Western' disease because they are convinced that autism does not exist in Somalia. Yet, Somali parents have widely divergent explanations for the epidemic, which has introduced schisms within Somali refugee communities. In Minneapolis, the controversy is about whether vaccines are a causal factor for the development of autism. In Toronto, there is also a vaccine-skeptic movement, but another parent group has joined scientists researching the possibility that gut bacteria is a key to autism causation and severity. This project fills a gap in the extant literature by tracking the following processes: 1) the ways in which social position informs perceptions of vulnerability; 2) the 'illness narratives' people construct in order to make sense of their children's disorder; 3) the broader structural and cultural frames, as well as institutional conditions, which facilitate or constrain different pathways to action.

Intellectual Merit :

This project seeks to understand how people interpret being part of an autism cluster and how these interpretations affect their health behavior. Drawing on three sets of sociological literature [risk perception, health social movements (HSMs), and race and health], the PI hypothesizes that race, class and nationality are missing variables in explaining how people come together to forge epistemic communities. The PI develops the concept of 'epistemic communities' through a cross-national comparison, which has both theoretical and practical implications. This project has 4 specific aims: 1) to describe and explain the causal theories Somali parents have about the development of autism; 2) to describe the health experiences of parents of Somali children with autism (from discovery of the disorder, through securing diagnosis, accessing benefits and resources, and seeking treatment) in Toronto and Minneapolis; 3) to explain when/if Somali parents get involved in or forge an HSM; and 4) to examine the causal links between these three previous dynamics. The PI will accomplish these aims through two years of qualitative research in Minneapolis and Toronto.

Broader Impacts :

This research into the formation of epistemic communities on autism has profound implications for understanding health behavior and the interaction of laypeople with scientific expertise. Such information could lead to more accurate policy initiatives on health care and support for those with autism, not to mention better information on vaccine skepticism and refusal. In addition, unlike most analyses of autism, the PI explores this topic from a global perspective and asks about the relevance of race, class, and nationality to peoples' experiences with and explanations of disability. Racial minorities have been underrepresented in the research on autism, and this project seeks to address this bias.

The project will actively engage Somali refugee populations in the research design. Through their participation in subject recruitment and focus group discussions, parents will meet other parents affected by autism and learn about resources and benefits for their children.

The PI will also conduct workshops with the communities to share research findings. The project will employ two full-time RAs for two years, contributing to graduate student training and publishing. The PI will employ students from underrepresented backgrounds.