

Scientists crowdsource autism data to learn where resource gaps exist

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Stanford researchers want families and caregivers of people with autism to help populate GapMap, which will show the communities where people with autism live and the services available in their area. Credit: JMIR Public Health & Surveillance

Many areas across the globe have few autism experts, leading to delayed care for kids who live there. Stanford scientists have launched a crowdsourcing project to pinpoint such geographic gaps, and find ways to fill them.

A new crowdsourcing tool aims to map all the locations in the world, beginning with the United States, where individuals with [autism](#) live to determine which communities need more resources for diagnosis and treatment of the condition.

The tool, called [GapMap](#), was developed at the Stanford University School of Medicine and is described in a study published online May 4 in *JMIR Public Health & Surveillance*.

Data from an early version of GapMap show that people living near autism diagnostic centers are more likely than those who live far away to have been diagnosed with autism, indicating likely inequities in who gets diagnosed.

The data also show that there are far fewer U.S. autism treatment centers than needed. Across the country, the average demand for treatment is 18 times larger than the available supply of caregivers, the research showed. Prior studies have indicated that the number of children affected by the developmental disorder is still rising.

"There is a growing imbalance between the number of people who need autism care and the number of places that can provide care," said the study's senior author, Dennis Wall, PhD, associate professor of pediatrics and of biomedical data science at Stanford. "It's a geographic distance problem. We need to quantify, in real numbers, the geographic disconnect between people and treatment options so that we can see where the gaps are."

Children who are diagnosed quickly and receive early, intensive autism therapies fare better than those who do not, but parents who suspect that their child has autism often face months-long waits to see caregivers who can make the diagnosis, prior research has found. And current estimates of autism prevalence do not identify geographic gaps in autism resources; the U.S. Centers for Disease Control and Prevention says 1 in 68 children nationwide have autism, but this estimate relies on data from only 11 states. Incidence elsewhere across the globe has not been rigorously established.

Pilot study

The first iteration of GapMap, described in the paper, used data that the researchers collected by programming a web spider to gather information from the websites of 840 autism treatment centers in the United States and 135 centers in the United Kingdom. These were placed onto geographic heat maps of the two countries. Autism prevalence in each part of the United States was estimated by assuming a rate of 1 case of autism per 50 people, and then using U.S. census data to generate a map estimating where people with autism live. Data on people in the United Kingdom with autism was also used to confirm that GapMap works as expected. (Comprehensive data on people in the United Kingdom with autism is already publicly available.)

Across the United States, 70 percent of people live within 30 miles of a diagnostic center, the study found. The average distance from an individual in the United States to the nearest diagnostic center is 50 miles, whereas people who have been diagnosed with autism live on average 20 miles from the nearest diagnostic center. Although the gap may partly reflect that people move closer to diagnostic centers after diagnosis, the researchers also think it reflects lower diagnosis rates among people in rural locations.

The latest version of GapMap functions as an interactive site accessible on any internet-connected device. It will help connect families to autism-based resources. In the future, Wall's team will add more functionalities, such as layering the map with environmental factors to understand their impact on autism prevalence. GapMap also aims to create one of the largest databases that will enable families to connect to and participate in current autism research.

'An important unmet need'

"Our findings highlight that there is an important unmet need with respect to individuals in resource-poor areas, where there is a significant lack of autism services," Wall said. "As a consequence, we think they are getting diagnosed later and not reaching the care they need during the time when it matters most."

Now, the researchers are asking families and caregivers to contribute to the database. Individuals with autism and their families can enter basic data about themselves into GapMap, such as their state, ZIP code, gender, birth date and [autism diagnosis](#). They are also asked to answer a short list of questions about the degree to which the person with autism shows traits associated with the disorder. The data are stored in a secure, Health Insurance Portability and Accountability Act-compliant database. Participants have the option to receive notifications inviting them to take part in future research, and can see where other people with autism live. Autism experts can also contribute information about the services they provide.

Wall hopes the database will help build global online communities of families affected by autism, will inform them about resources in their areas and will clarify where more autism treatment centers should be located or where technology-based solutions can be invented to fill the void.

"We really need to see where the imbalances are and how big they are as the first step to creating change in the health care system," he said.

More information: Nikhila Albert et al. GapMap: Enabling Comprehensive Autism Resource Epidemiology, *JMIR Public Health and Surveillance* (2017). [DOI: 10.2196/publichealth.7150](https://doi.org/10.2196/publichealth.7150)

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