

NEWS

# Researchers track down autism rates across the globe

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In urban areas of South Korea, some families of children with developmental delays will go to great lengths to avoid a diagnosis of *chapaee*, or autism. They think of it as a genetic mark of shame on the entire family, and a major obstacle to all of their children's chances of finding suitable spouses.

The stigma is so intense that many Korean clinicians intentionally misdiagnose these children with *aechak changae*, or reactive detachment disorder — social withdrawal that is caused by extreme parental abuse or neglect.

"The parents prefer this [diagnosis] because the mother can take the bullet and protect everybody else," says **Roy Richard Grinker**, professor of anthropology at George Washington University in Washington, D.C., who has screened some 38,000 children in South Korea for the country's first study of autism prevalence.

Because of stigma, lack of awareness about mental health and poor medical infrastructure, few autism prevalence studies exist outside of the U.S., Canada and the U.K. "Even though it seems like anybody and everybody has heard of autism, in many places in the world it's still sort of a new topic," says **Charles Zaroff**, assistant professor of psychology at the University of Macau in China.

Zaroff and Grinker are part of a small but growing group of researchers charting autism in new territories. Rigorous autism screening studies are underway not only in South Korea, but in Mexico, India and South Africa. In the past year, prevalence estimates from Brazil<sup>1</sup>, Oman<sup>2</sup> and Western Australia<sup>3</sup> have been published in mainstream journals for the first time.

Calculating prevalence is often the first step toward launching government and nonprofit mental health services in these countries. Numbers can also lead to scientific insights on the genetic, environmental and cultural underpinnings of autism.

"It's been a big question for years to ask: Is there any difference across countries and across cultures in the rates of autism?" notes **Eric Fombonne**, professor of psychiatry at McGill University in Montreal, who has led autism epidemiological studies in a half-dozen countries.

## Misleading methods:

The first prevalence studies in any region typically find low numbers. For instance, the new study in Brazil found 27.2 cases of autism per 10,000 people, and last year's report from Oman found 1.4, compared with the oft-quoted U.S. average of 66. Similarly small numbers have come out of studies in China (16.1), Indonesia (11.7) and Israel (10).

These low rates are likely to be the result of the methods used, experts say. Most first-pass epidemiological studies are based on a review of medical records, which are often incomplete or non-existent, depending on the state of a country's healthcare system and the number of clinics with experts qualified to diagnose childhood disorders. "A records-based approach can only count the cases that you can see," Grinker says.

This is also a problem in the U.S. Data collected by the Centers for Disease Control and Prevention shows the **highest autism prevalence** in states with the best autism health and support services, such as Arizona (121 cases per 10,000 people), Missouri (121) and New Jersey (106). In contrast, areas with fewer services have lower rates, such as Alabama (60), Arkansas (69) and Florida (42).

Over time, however, as more parents and clinicians become familiar with autism, prevalence goes up. In many parts of the world, including the U.S., U.K., Canada, Japan and Scandinavia, "The rates were flat through the late '80s, and then suddenly a massive rise happened at same time," Fombonne says. The rise is probably not due to a mysterious global environmental exposure, he says. "It's more likely to reflect new concepts of autism worldwide."

Low autism prevalence is not confined to poor countries. A handful of small studies in France, for example, have found rates around 5 cases per 10,000 people. One study in Germany calculated it to be 1.9, and another in Portugal 16.7.

Differences in scientific approach among these countries may affect the results, notes **Mayada Elsabbagh**, research associate at Birkbeck University of London.

"In some European countries, they have very psychodynamic views about autism," she says. "If you don't think this disorder is driven by biological causes, then you wouldn't think there was any use in doing epidemiological studies or trying to understand causal pathways."

Elsabbagh is working with 11 international researchers on a systematic review sponsored by the **World Health Organization**, including articles published in languages other than English.

"Some of us started with the bias that there's nothing out there, but it turns out there's a lot, they just don't tend to be in mainstream journals," she says. The report is expected to be published later this year.

## Counter-culture:

Language and culture may also affect the way this research is carried out. For instance, the Korean language uses an extensive array of suffixes that denote the relationship between the speaker and the subject. South Korean children with autism have trouble using these social markers, but the Western-based standard tests of autism, such as the Autism Diagnostic Observation Schedule (ADOS), don't test for this.

Similarly, Grinker points out, healthy children from non-Western cultures may display a trait that ADOS counts as a symptom of autism. In South Korea, for example, making eye contact with an adult is not socially appropriate.

"This is why it's pretty useful to have [anthropologists] who can translate diagnostic instruments that were designed in one culture and used in another," Grinker says.

It's also possible that the nature of social development in children who grow up in the West is not the same as that for children who grow up elsewhere. Take, for instance, the theory of mind, the ability to infer what other people are thinking, which is **impaired in people with autism**.

Unlike in English, verbs such as 'think' and 'believe' have different forms in Chinese, depending on the speaker's perception of the statement's accuracy<sup>4</sup>. This linguistic reinforcement could mean that Chinese children develop theory of mind differently than do children in the West, Zaroff notes.

Most experts agree that methodological and cultural factors explain the bulk of differences in autism prevalence around the world, but they don't rule out the possibility of genetic differences among populations.

For example, U.S. prevalence studies show that autism rates in Hispanic communities are lower than in non-Hispanic communities, even when adjusted for socioeconomic factors<sup>5</sup>. In contrast, the highest recorded autism prevalence is from a 2008 study in Japan, which calculated a whopping 181 cases per 10,000 people.

One provocative, though unstudied, explanation is that in Hispanic cultures, where gregariousness is highly valued, having features of autism could affect one's reproductive opportunities more than in Asian cultures, which value solitude and seriousness, especially in men.

"This is just a hypothesis, but we just don't know," says Cristiane Silvestre de Paula, an investigator on the new Brazil study.

To explore the genetic contribution, **Young-Shin Kim**, one of Grinker's collaborators on the South Korea prevalence study, is screening blood samples from South Korean children with autism. Because of geographic and cultural isolation, Koreans are ethnically similar, which helps

researchers find autism-related hotspots, says Kim, assistant professor at the Yale University Child Study Center.

Because of the stigma against autism in South Korea, Kim says about half of the families declined to participate in the genetic study. Still, the situation is gradually improving, she says.

"Once they are diagnosed," she says, "that's when we have a chance to develop a rapport with them and talk them through with autism really means."

## References:

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