

S Korean study finds higher rate of autism

HEALTH

The New York Times

An ambitious six-year effort to gauge the rate of childhood autism in a middle-class South Korean city has yielded a figure that stunned experts and is likely to influence the way the disorder's prevalence is measured around the world, scientists say.

The result, that 1 in 38 (2.6 per cent) of all children aged 7 to 12 in the Ilsan district of the city of Goyang were autistic, is far higher than the generally accepted estimate of 1 in 100 in the developed world.

But experts said yesterday the findings did not mean that the actual numbers of children with autism were rising, simply that the study was more comprehensive than previous ones.

"This is a very impressive study," said Dr Lisa Croen, director of the autism research programme at Kaiser-Permanente Northern California, who was not connected with the new report. "They did a careful job and in a part of the world where autism has not been well documented in the past."

For the study, which is being published in *The American Journal of Psychiatry*, researchers from the Yale Child Study Centre, George Washington University and other leading institutions sought to screen every child aged 7 to 12 in Ilsan, a community of 488,590.

By contrast, the Centres for Disease Control and Prevention in the United States and most other research groups measure autism prevalence by examining and verifying records of existing cases kept by health care and special education agencies. That approach may leave out many children whose parents and schools have never sought a diagnosis.

In recent years, scientists have come to see autism as a spectrum of disorders that can include profound social disconnection and mental retardation, but also milder forms, like Asperger's syndrome, that are pervasive and potentially disabling but that often go undiagnosed.

"From the get-go we had the feeling that we would find a higher prevalence than other studies because we

were looking at an understudied population: children in regular schools," said the lead researcher, Dr Kim Young-shin, a child psychiatrist and epidemiologist at the Yale Child Study Centre.

South Korea was chosen not only because autism prevalence had not been measured there, but also because its national health-care system, universal education and homogeneous population made it a promising region for a planned series of studies that will also look at genetic and environmental factors in autism.

The study, which was largely financed by the research and advocacy group Autism Speaks, raises the question of whether a similarly high prevalence would be found elsewhere if all children were screened.

Dr Marshalyne Yeargin-Allsopp, chief of developmental disabilities at the US National Centre on Birth Defects and Developmental Disabilities, said her agency's records-based approach probably missed some autistic children – especially among the poor, among racial minorities and "potentially among girls" – and said the agency was interested in taking part in a population-based approach like the Korean study.

"We believe this will be a way to get as complete an estimate of ASD prevalence as possible," she said, using the abbreviation for autism spectrum disorder.

Most cases of autism spectrum disorder in the Korean study, the researchers said, turned up among children in regular schools who had no record of receiving special education or mental health services. A third were found among a "high-probability group" of 294 children who were attending special-education schools or were listed on a registry of disabled children.

Researchers used a two-step process to identify autism among ordinary schoolchildren: parents and teachers completed a 27-item questionnaire on each child, and children who scored in the autistic range on that questionnaire were individually evaluated.

"If we had only looked at the high-probability group, we would have come up with about 0.7 per cent, which is in line with CDC statistics for the US," said the study's senior author, Roy Richard Grinker, a professor of anthropology and international affairs at George Washington University.

Professor Craig Newschaffer, chairman of epidemiology and biostatistics at the Drexel School of Public Health in Philadelphia, praised the new report, calling it "quite a strong study", but he added that the results were based on information about 63 per cent of the schoolchildren, a good response rate but not ideal.

"It is just one area of Korea," he said, "and we know that there's random variation in how diseases are distributed."

Startling study

A district of Goyang in South Korea was the focus of autism research

The finding that 1 in 38 of children aged 7 to 12 were autistic translates to a percentage figure of

2.6%

Korea study hints autism often goes undiagnosed

Finding surprises experts and could change how syndrome is studied

BY CLAUDIA WALLIS

An ambitious six-year effort to gauge the rate of childhood autism in a middle-class South Korean city has yielded a figure that stunned experts and is likely to influence the way the disorder's prevalence is measured around the world, scientists reported Monday.

The figure, 2.6 percent of all children aged 7 to 12 in the Ilsan district of the city of Goyang, is more than twice the rate usually reported in the developed world. Even that rate, about 1 percent, has been climbing rapidly in recent years — from 0.6 percent in the United States in 2007, for example.

But experts said the findings did not mean that the actual numbers of children with autism were rising, simply that the study was more comprehensive than previous ones.

"This is a very impressive study," said Lisa Croen, director of the autism research program at Kaiser-Permanente Northern California, who was not connected with the new report. "They did a careful job and in a part of the world where autism has not been well documented in the past."

For the study, which is being published in *The American Journal of Psychiatry*, researchers from the Yale Child Study Center, George Washington University and other leading institutions sought to screen every child aged 7 to 12 in Ilsan, a community of about 500,000.

By contrast, the Centers for Disease Control and Prevention in the United States and most other research groups measure autism prevalence by examining and verifying records of existing cases kept by health care and special-education agencies. That approach may leave out many children whose parents and schools never sought a diagnosis.

In recent years, scientists have come to see autism as a spectrum of disorders that can include profound social disconnection and mental retardation, but also milder forms, like Asperger's syndrome, that are pervasive and potentially disabling but that often go undiagnosed.

"From the get-go we had the feeling that we would find a higher prevalence than other studies because we were looking at an understudied population: children in regular schools," said the lead researcher, Dr. Young-Shin Kim, a child psychiatrist and epidemiologist at the Yale Child Study Center in New Haven, Connecticut.

South Korea was chosen not only because autism prevalence had not been measured there, but also because its national health care system, universal education and homogeneous population made it a promising region for a planned series of studies that will also look at genetic and environmental factors in autism.

The study, which was largely financed by the research and advocacy group Autism Speaks, raises the question of whether a similarly high prevalence would be found in other countries if all

Study hints that autism often goes undiagnosed

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children were screened.

Dr. Marshalyn Yeargin-Allsopp, chief of developmental disabilities at the National Center on Birth Defects and Developmental Disabilities of the C.D.C., acknowledged that her agency's records-based approach probably missed some autistic children in the United States — especially among the poor, among racial minorities and “potentially among girls” — and said the agency was interested in taking part in a population-based approach like the Korean study.

“We believe this will be a way to get as complete an estimate of A.S.D. prevalence as possible,” she said in an e-mail, using the abbreviation for autism spectrum disorder.

Most cases of autism spectrum disorder in the Korean study, the researchers said, turned up among children in regular schools who had no record of receiving special education or mental health services. A third were found among a “high-probability group” of 294 children who were attending special-education schools or were listed on a registry of disabled children.

The children in that high-probability group were similar in many ways to children with autism in the United States and elsewhere. Fifty-nine percent were intellectually disabled, or mentally retarded; more than two-thirds had full-blown autism, as opposed to milder forms like Asperger's; and boys outnumbered girls 5 to 1.

Among the children with autism spectrum disorder in regular schools, only 16 percent were intellectually disabled, more than two-thirds had a milder form of autism, and the ratio of boys to girls was unusually low: 2.5 to 1.

In addition, 12 percent of these children had a superior I.Q. — a higher proportion than found in the general population.

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“If we had only looked at the high-probability group, we would have come up with about 0.7 percent, which is in line with C.D.C. statistics for the U.S.,” said the study's senior author, Roy Richard Grinker, a professor of anthropology and international affairs at George Washington University in Washington.

The surprisingly large proportion of cases uncovered in ordinary schools, he noted, may in part reflect the low level of awareness and high degree of stigma attached to autism in South Korea. In addition, children with autism spectrum disorders may stand out less in South Korean schools, which follow highly structured and predictable routines and emphasize rote learning.

Other experts said that more “population-based” studies, though costly, could help determine how broadly the Korean findings could be generalized to other societies.

Craig J. Newschaffer, chairman of epidemiology and biostatistics at the Drexel School of Public Health in Philadelphia, praised the new report, calling it “quite a strong study,” but he added that the results were based on information about 63 percent of the schoolchildren, a good response rate but not ideal.

“It is just one area of Korea,” he said, “and we know that there's random variation in how diseases are distributed.”