



International Autism Epidemiology Network (IAEN)

Recent epidemiological findings have shown the prevalence of children with autism has increased rather dramatically over the past decade. In the United States, the prevalence of autism spectrum disorders is now estimated at 1 in 150 children. This finding calls attention to many important, but unanswered, questions pertaining to autism epidemiology, etiology, and natural history. Specifically, what is the prevalence of autism in different communities and countries, how has prevalence changed over time, and if prevalence has increased, what is causing this trend.

In an effort to answer these important questions, in 2004 Autism Speaks and the Centers for Disease Control and Prevention (CDC) co-developed the International Autism Epidemiology Network (IAEN). The objectives of this project are to:

1. Develop a network for exchange and collaboration of epidemiology activities across countries
2. Examine successful international collaborative models applied to other health conditions and identify common features that might facilitate autism surveillance and research
3. Identify the unique role that epidemiology can play in understanding the causes of autism; particularly in comparisons across diverse genetic and cultural settings.

By working to standardize epidemiologic methodology internationally, autism prevalence can be compared across territories, stimulating the design of new research projects to interpret the results of those comparisons. This initiative and the resulting findings have the potential to significantly enhance our understanding of autism etiology and natural history, specifically by examining similarities and differences in genetic and environmental factors around the world.

The network is tackling its objectives from three different perspectives, each representing a workgroup:

1. The registry systems approach involves territories with large, population based health registries which may be used in establishing a large multi-national database for ambitious, previously unfeasible research projects
2. The records or services-based approach looks to collect and systematically review medical, school, and service records in territories that maintain information on autism diagnoses and services, allowing for estimates of prevalence using a multiple-source, population-based methodology
3. The developing/low-resource countries approach is designed to examine autism prevalence using population-based screening strategies in territories lacking well-organized public health surveillance infrastructure.

Currently, network members include nearly 80 research professionals from 30 countries around the world. For more information, please visit www.autismepidemiology.net



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Autism Speaks Epidemiology Information Guide Frequently Asked Questions

Epidemiology

1. What is epidemiology?

Epidemiology is a sub-specialty of public health that simply stated, looks to determine where and how often disease occurs and why. It is more formally defined as the study of distributions (patterns) and determinants (causes) of disease in populations, and the application of this study to managing health problems.

2. What is the purpose of epidemiology?

Epidemiology has many purposes, including to: (1) study the course, or natural history, of disease, (2) determine the frequency of disease in populations, (3) identify the patterns of disease occurrence, (4) identify risk factors for and potential causes of disease, and (5) evaluate the effectiveness of preventative and treatment measures. The ultimate goal of epidemiology is to apply this knowledge to the control of disease through prevention and treatment, resulting in the preservation of public health.

3. What are the measures used in epidemiology?

Epidemiology often focuses on measuring the occurrence of disease in populations. The basic measures of disease frequency in epidemiology are incidence and prevalence. *Incidence*¹ is the number of new cases of disease in a population occurring over a defined period of time. *Prevalence*, on the other hand, measures the number of existing cases, both new cases and cases that have been diagnosed in the past, in a population at any given point in time. By using these measures, epidemiologists can determine the frequency of disease within populations, and compare differences in disease risk among populations.

¹ The term incidence used above denotes *cumulative incidence* - the total number of new cases in a population occurring over a given period of time. Another important measure of disease incidence is *incidence rate*, which gauges how fast disease occurs in the population by measuring the number of new cases emerging as a function of time. The term incidence alone is often incorrectly used to denote incidence rate.

4. What are some sources of epidemiologic data?

One of the most important considerations in conducting epidemiologic research is the source of data, as this will often determine the ability to conduct a study and the quality of the results. When epidemiologists look to determine population-level estimates of

disease frequency, the ideal data source would include everyone in the population. This, however, is almost always impossible to achieve in large populations. To address this, epidemiologists aim to use “population-based” samples that are representative of the population as a whole. As a general rule, the larger the sample, the more accurate the results, since a larger sample is less likely to, by chance, generate an estimate different from the truth in the full population. All samples, large and small, need to be chosen using methods that minimize bias - a tendency to choose a sample with different characteristics than those of the whole population. With this in mind, some important and useful sources of epidemiologic data include population-based health registries, medical records, regular national health surveys, and other public health surveillance systems that collect data on large numbers of individuals using careful strategies to minimize bias.

It is often the case, particularly in low-resource countries with limited public health infrastructure and research capacity, that these expansive data sources are not available. In situations such as these, epidemiologic techniques for collecting data often involve special data collection approaches. In order to do this feasibly with available resources these approaches often will rely on screening. Screening is a first step in identifying individuals with a disorder, intended to sort out those likely to have the disorder from those unlikely to have it using affordable, easy-to-implement approaches. After a positive screen, individuals will then be seen by the research team to determine if they meet criteria for a formal diagnosis.

5. How does epidemiology lead to policy change?

Epidemiologic findings have the potential to influence governments, public health agencies, and medical organizations policies and practices. It can also create greater public awareness and galvanize the community. For instance, based on recent epidemiologic findings in the United States suggesting that the prevalence of autism has risen dramatically from approximately 2-3/10,000 children in the 1980's to a stunning 1/150 children today, Congress passed the Combating Autism Act of 2006, which, over the next five years, will allocate approximately one billion dollars to combating autism spectrum disorders through increased education, service, and research. This was a historical policy change, particularly for autism research funding, as prior to the passing of this act, less than 1% of total NIH funding went towards autism research.

Autism Epidemiology

6. What questions aimed at understanding autism can epidemiology help answer?

Below are some of the questions that epidemiology can help answer:

1. How common is autism? Is the prevalence similar around the world and across different geographic areas within countries? Are certain subgroups more affected than others?
2. Has autism prevalence changed over time, and if so, then why?
3. What are the causes of or risk factors associated with autism?
4. How do genetic and environmental factors interact in autism?
5. How does the course of autism change over the lifetime?
6. How common are co-morbid disorders (e.g., GI disorders, immune deficiencies, etc.) among children with ASD?
7. Which therapies are effective and what are the implications for prognosis?

7. What is the importance of International autism epidemiology?

Just as understanding the prevalence of autism in the United States was critical to its emergence as a public health priority here, children in nations around the world will benefit when their governments come to understand how common this condition is. In addition, epidemiologists can sometimes make comparisons of autism prevalence across nations as a means of generating clues about the involvement of susceptibility genes or environmental exposures that occur with different frequency in different countries. To be fruitful, however, these comparisons have to be based on data from prevalence studies that are free from bias or that have similar biases among countries being compared. International studies also creates opportunities to study autism in different ethnic groups, in special populations (e.g., those that are genetically isolated), and among populations with environmental conditions (e.g., exposure to certain pollutants) not found when research is based in one territory alone. Additionally, some nations have special resources, such as large health registries and public health surveillance systems, that can generate large, especially rich datasets. These data sets might even be combined into more comprehensive, international population-based data sources that could allow for ambitious, previously impossible studies on autism etiology and natural history.

8. What are the major challenges to conducting international autism epidemiology research?

Many of the challenges to international autism epidemiology stem from the fact that presently autism is diagnosed behaviorally based primarily on deficits in social interaction and communication. Since social and communication norms are influenced by and intertwined with culture, how autism is diagnosed could potentially vary from one country to another. For example, limited or absence of eye contact, an autism “red-flag” in some western cultures, may be seen as a sign of respect rather than deficit in some Asian cultures. As such, much time and effort needs to be devoted to translating screening and diagnostic instruments, both for language and cultural sensitivity, to ensure accurate and reliable identification of individuals with autism in international territories.

Because of these possible differences in autism diagnosis across cultures, it becomes difficult to compare epidemiologic measures cross-culturally. On the other hand, there are aspects of human behavior that have been found to be universal, especially in young children. Several of these aspects, such as the ability to respond to one’s name or the motivation to relate socially to other people, show up very early in life and are present throughout all cultures. Therefore, we are optimistic that autism can be readily recognized in all cultures, especially in very young children.

An additional challenge to conducting autism epidemiology in some countries is a general lack of research expertise and capacity. Insufficient numbers of qualified research professionals limit the ability to conduct sound epidemiologic studies. Furthermore, shortfalls in the autism diagnostic or treatment infrastructure compromise care and service delivery, and subsequently hamper research.

The Current Landscape of International Autism Epidemiology

9. What have been the recent findings in international autism epidemiology in terms of prevalence around the world?

More than forty years ago, the first survey of autism was done in the United Kingdom and suggested the prevalence of autism in young children to occur at a rate of 4 per 10,000 (or 1/2,500). More recent studies have estimated prevalence to be approximately 6.6 per 1,000 (or 1/150) children in the United States, and as many as 12 in 1,000 (or 1/80) children with an ASD in Europe and Scandinavia. Most studies have taken place in select areas of relatively developed nations and communities and have used strikingly different methods to estimate prevalence. Further, very little is known to date about the occurrence of ASDs in low-resource territories with limited to no public health infrastructure (see *Table and Map* below).

For additional information, please refer to:

1. Fombonne, E. Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. *Journal of Autism and Developmental Disorders* 2003;33(4):365-82.
2. Newschaffer *et al.* The Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health* 2007;28:235-258.
3. Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. *MMWR* 2007; 56(SS-1).

10. How is Autism Speaks contributing to international autism epidemiology research?

In 2004, Autism Speaks working in collaboration with the CDC launched the International Autism Epidemiology Network (IAEN, see above). The IAEN promotes collaboration between epidemiologists internationally and presents a forum for the sharing of research methods and expertise. By working to standardize epidemiologic methodology internationally, autism prevalence can be estimated and compared worldwide, elevating the global attention devoted to autism and stimulating the design of new research projects to interpret the results of those comparisons.

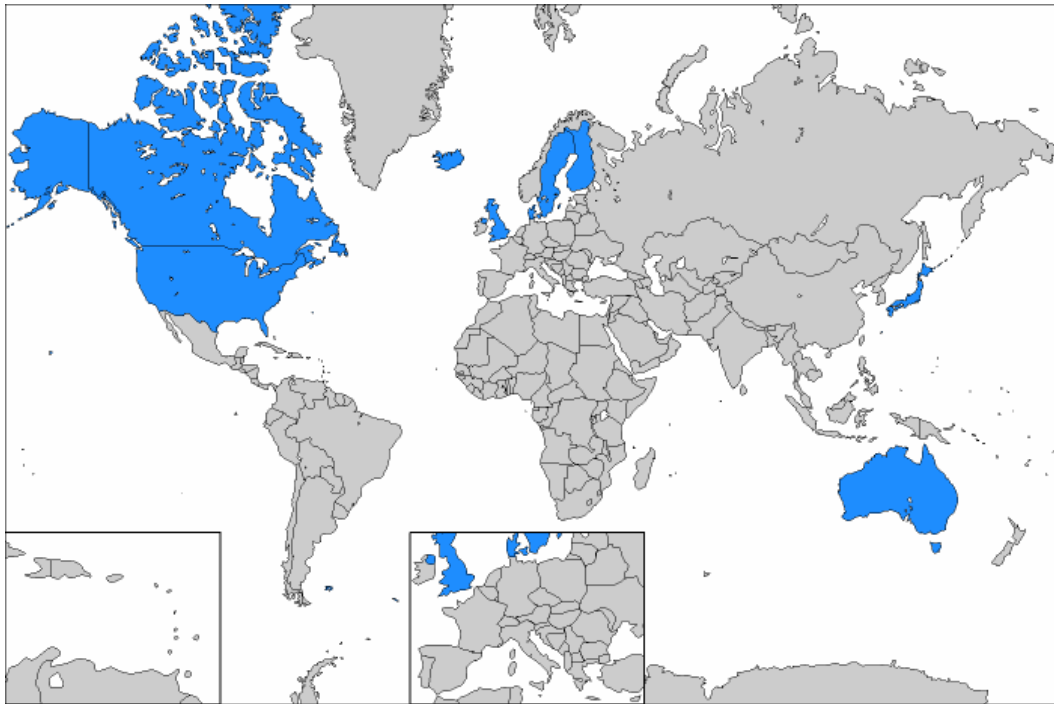
Since 2005, Autism Speaks has funded more than \$1M in epidemiology research internationally. Among the projects Autism Speaks is supporting are first ever autism prevalence studies in Korea, India, and Bangladesh (see *International Epidemiology Research Portfolio* below). We are also exploring epidemiology research opportunities in the Middle East, Latin America, China/Taiwan, and in Eastern Europe. Additionally, Autism Speaks recently launched new international epidemiology targeted funding mechanisms that may result in a commitment of up to \$725K in additional epidemiology research funding in 2008. One of the mechanisms focuses specifically on building research capacity in low and middle income countries by asking researchers to translate screening and diagnostic instruments and to utilize those tools in a pilot epidemiology study.

Autism Prevalence around the World (2000-2008)

Continent/Region	Country	Prevalence	Reference
North America	United States	~66/10,000 = 1/152	CDC, MMWR 2007
	Canada	~65/10,000 = 1/154	Fombonne <i>et al.</i> 2006
Caribbean	Dominican Republic, Aruba, other	Insufficient Data	
Central America	Mexico, Costa Rica, Panama, other	Insufficient Data	
South America	Venezuela, Brazil, Chile, other	Insufficient Data	
Europe	UK	~116/10,000 = 1/86	Baird <i>et al.</i> 2006
	Sweden	~53/10,000 = 1/188	Gillberg <i>et al.</i> 2006
	Finland	~12/10,000 = 1/833	Kielinen <i>et al.</i> 2000
	Denmark	~12/10,000 = 1/833	Laurtisen <i>et al.</i> 2004
	Iceland	~13/10,000 = 1/769	Magnusson & Saemundsen 2001
	France, Spain, Italy, Greece, other	Insufficient Data	
Eastern Europe	Russia, Poland, others	Insufficient Data	
Middle East	Israel, Qatar, Saudi Arabia, other	Insufficient Data	
Africa	All regions	Insufficient Data	
South-central Asia	India, Bangladesh, others	Insufficient Data	
Eastern Asia	Japan	~89/10,000 = 1/112	Honda <i>et al.</i> 2005
	China	Insufficient Data	
	Korea	Insufficient Data	
South-east Asia	Taiwan, Singapore, Thailand, other	Insufficient Data	
Oceania	Australia	~39/10,000 = 1/256	Icasiano <i>et al.</i> 2004
	New Zealand	Insufficient Data	

¹ Table based on data published 2000 or later.

² Please be aware that some findings may not be comparable across sites due to differences in study design, case ascertainment techniques, and among sample populations.



Autism Speaks International Epidemiology Research Portfolio (by Country)

Australia, Denmark, Finland, Israel, Norway, Sweden, United States (Columbia University and CDC)

Helen Leonard, MBChB, MPH, Telethon Institute for Child Health Research, University of Western Australia | **Glenys Dixon, MA**, Telethon Institute for Child Health Research, University of Western Australia | **Poul Thorsen, MD, PhD**, University of Aarhus, Denmark and Emory University, USA | **Erik Parner, PhD**, University of Aarhus, Denmark | **Andre Sourander, MD, Dr Med Sci**, Turku University, Finland and Columbia University, USA | **Mika Gissler, M Soc Sci, PhD**, STAKES National Research and Development Centre for Welfare and Health, Finland and University of Oulu, Finland | **Raz Gross, MD, MPH**, The Gertner Institute for Epidemiology and Health Policy Research, Israel and Columbia University, USA | **Abraham Reichenberg, PhD**, Institute of Psychiatry, King's College, London, England | **Camilla Stoltenberg, MD, PhD**, Norwegian Institute of Public Health | **Cathrine Dahl, MD**, Norwegian Institute of Public Health | **Pål Surén, MD, MPH**, Norwegian Institute of Public Health | **Christina Hultman, PhD** – Karolinska Institutet | **Micheline Bresnahan, PhD**, Columbia University | **Mady Hornig, MD**, Columbia University | **Ezra Susser, MD/MPH, Dr. PH**, Columbia University | **Diana Schendel, PhD**, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Total: \$1,014,900 for 3 years

International Collaboration for Autism Registry Epidemiology (iCARE)

Population-based disease registry systems are invaluable research resources due to their non-biased coverage, prospective data collection, large size, and length of follow up. The relative rarity of autism, as well as many perinatal conditions, makes use of large multi-national registry-based samples an ideal approach for filling important gaps in our understanding of the relation between perinatal factors and autism. This proposal builds on the Autism Speaks-CDC International Autism Epidemiology Network Registry Workgroup. The Workgroup established the International Collaboration for Autism Registry Epidemiology (iCARE) and identified relevant registry systems for the proposed investigation in Scandinavia (Denmark, Sweden, Finland and Norway), Australia and Israel. The goals of the investigation are 1) to establish the necessary infrastructure for multi-registry autism research, including establishing a multi-registry virtual data set approach to analysis and establishing written guidelines for multi-national registry-based research collaboration, and 2) demonstrate the capabilities of the multi-registry approach to elucidate etiological pathways to autism by thoroughly investigating candidate factors for perinatal adversity in relation to autism, beginning with gestational length and fetal growth. The study will consider variation in diagnostic criteria and trends over time, and based on heretofore unrivaled sample sizes that will permit examination of risk across more finely defined birth weight and gestational age categories; consider effects on risk of fetal size at a given gestational age; control for confounding; and conduct robust stratified analyses considering other important risk factors, such as gender, parental age, and birth multiplicity, and features of autism, such as diagnostic subtype. The proposed project presets a new scope in epidemiological investigation into risk factors for autism, and will provide the foundation and guidelines for future investigations.

Australia and Denmark

Glenys Dixon, B Psych | Telethon Institute for Child Health Research
2008 Autism Speaks Research Award: Basic & Clinical | \$128,045 over 2 years

International trends in diagnoses and incidence of autism spectrum disorders

Although there have been numerous studies investigating the increased prevalence or "epidemic" or autism spectrum disorders (ASDs), it is still not clear whether this relates to a true increase in ASDs. Factors such as increased awareness by parents and clinicians, methods of reporting, and changing diagnostic criteria may account for this apparent increase. Examining the impact of these factors on the rate of ASD diagnoses will help to untangle whether ASDs are truly on the rise, or whether only the rate of diagnosis has increased. To attempt to provide the most accurate estimate of trends in the incidence of ASD, this study will analyze population-based records of ASD diagnoses which used diagnostic criteria that remained constant over time. Two datasets of ASD diagnoses will be analyzed: one from Denmark, and one from Western Australia. These datasets used different diagnostic criteria consistently (DSM for Western Australia, and ICD for Denmark). This study will determine whether the criteria used affected the age at which ASD is first diagnosed, and thus affected the perceived incidence.

Bangladesh

Naila Khan, M.D. | Bangladesh Protibondhi Foundation
2008 Autism Speaks Research Award: Pilot Study | \$59,966 for 1 year

Scales, procedures, and intervention programs for estimating the prevalence of childhood disability and autism in Bangladesh

The diagnosis of autism spectrum disorders (ASDs) has increased six-fold over the past decade in Bangladesh. However, this resource-poor country has no comprehensive early screening system for neurodevelopmental disorders. Studies in western countries have suggested that estimates of the prevalence of ASDs may underestimate unless children with a range of neurodevelopmental problems are assessed, as the early signs of autism are so variable. The purpose of this study is to standardize tools for the identification of neurodevelopmental problems, including ASDs, in 0 to 5-year-old children in Bangladesh. This will include a modified version of the Ten Question (TQ) checklist as a first-stage screening tool, a General Developmental Assessment (GDA) for second-stage screening, and a DSM-IV based clinical diagnostic instrument. These tools will be designed for use by community workers in both rural and urban communities and will be linked with facilitated access to services and early intervention for families. The procedures developed in this study will be a starting point for a full-scale study of the prevalence of ASD in Bangladesh, and may be applicable for use in other developing countries.

Finland

Andre Sourander, M.D. | Turku University, Turku, Finland
2007 Autism Speaks Research Award: Pilot Study | \$119,075 over two years

Early Developmental Risk Factors for Autism in a National Birth Cohort

This pilot study will establish a new project called the Finnish Prenatal Study of Autism and Autism Spectrum Disorders and is based on the Finnish Maternity Cohort (FMC), which consists of virtually all births in Finland (N=1.1 million) from 1987- 2005. The investigators will use maternal medical and exposure history collected during pregnancy to examine if infection, hormonal abnormalities and smoking are related to an increased risk of autism, and will aim to identify potential early risk factors including improper growth and development to assess whether these parameters can be included in early signs of autism. In addition to medical data, this project has the ability to analyze blood samples that were drawn during pregnancy in random samples of cases and controls. This project has the potential to become one of the largest epidemiological studies to investigate prenatal and perinatal risk factors in autism, including a large biomarker repository to isolate possible early prenatal risk factors.

India

Vikram Patel, PhD
London School of Hygiene and Tropical Medicine, London, UK; and
The Sangath Center, Goa India
Total: \$179,542 for 3 years

ARTI: The Autism Research and Training Initiative in India

The goals of the ARTI project are: 1) to develop and evaluate a case-detection methodology for the identification of autism spectrum disorders (ASD) for use with children aged 4 to 7 years; 2) to use this method to estimate the prevalence, determinants and needs of families affected by ASD; and 3) based on these findings to generate a model for a community based intervention for ASD which can be tested in future research. These goals will be achieved in two phases over three years. Phase 1 will take place during the first year will include translation and adaptation of the Ten Questions (TQ), Social Communications Questionnaire (SCQ), and Autism Diagnostic Observation Schedule (ADOS) screening and diagnostic instruments. The instruments will be translated into the local languages of Konkani and Marathi and will be validated to ensure cultural sensitivity. Phase 2, which will take place

over years 2 and 3, will focus on using these instruments in conducting a pilot epidemiology study to estimate the prevalence of ASD. The project will be conducted in the state of Goa, on the west coast of India, and will be implemented by Sangath, one of India's leading child development and mental health research NGOs. Sangath and the Goan investigators will utilize its strong collaborations with the Ministry of Education and the Ministry of Health, as well as work in partnership with a team of national and international collaborators, drawn from a range of disciplines and sectors including academics, child development practitioners, policy makers and parent groups. Not only will the current study lead to a better understanding of the scale of the autism problem in India, which can inform government and lead to policy reform, it will help establish the necessary research capacity to develop future epidemiology studies in this region. Additionally, using standardized epidemiologic methods may allow for cross-country comparisons of autism prevalence; an approach that is not currently possible. The study findings will also be used to advocate for "scaling up" community based intervention for children with ASD in India, which may serve as a model for building service capacity in other low and middle income countries around the world.

Shaneel Mukerji, MSc, DSE (ASD)
Action for Autism, New Delhi, India
Total: \$60,000 for 1 year

A large scale, two phase study to estimate prevalence, and raise awareness, about Autism Spectrum Disorders in India

Despite being the second most populous country in the world, there is a serious dearth of epidemiological research on Autism Spectrum Disorders (ASD) in India. While estimates suggest that India could have more than 2 million people with ASD, this has never been directly tested. The current project represents a large-scale attempt to estimate the prevalence of ASD in India, by focusing on three major cities of India. In Year 1, the group proposes to create a central secure online database with phenotypic details and clinical notes of patients between 4-7 years of age, from pediatric outpatient departments of multiple government/charitable and private hospitals in each city. The members of the online database would then be contacted to take part in a screening study using translated versions of the Social Communications Questionnaire (SCQ) and Autism Spectrum Quotient (AQ) in Hindi, Bengali, or Marathi depending on the local language of the city. Those children who meet the cut-off scores for ASD will then be approached in years 2 and 3 for in-person testing using translated versions of the Autism Diagnostic Observation Schedule (ADOS) and measurement of further socio-cultural variables. This case ascertainment methodology will be used to conduct a pilot epidemiology study that will result in a multi-city prevalence estimate of ASD in India. In parallel, a structured program to raise autism awareness in the country will be carried out, which will include: a) organizing yearly workshops for medical professionals, teachers, and parents of children with ASD, b) making a documentary film, c) translating existing awareness material into regional languages, and d) assessing awareness about ASD in the general population, both at the beginning and at the end of our program. As the first major epidemiological study of autism coupled with a structured autism awareness drive in three major cities of India, as well as being driven by the leading autism advocacy organization in India, Action for Autism, this project has the potential to hugely improve the state of autism research and awareness in India.

MKC Nair, MD, PhD | Child Development Center, Thiruvananthapuram, India
Special Project: Co-Funders: Autism Speaks (\$100,000/2 years), the Indian National Trust/ Ministry of Social Justice and Empowerment (\$200,000/2 years) and International Clinical Epidemiology Network (INCLIN) (\$201,962/2 years)

Neurodevelopmental Disabilities among children in India

Given current epidemiologic estimates, there are approximately 1.7 million individuals with autism in India. The primary objective of this research project is to assess the screening and diagnostic prevalence of neurodevelopmental disorders, including autism, in children between the ages of 2-9 in India and gain information on risk factors in these children. The investigators will develop a novel neurodevelopmental disability screening tool and consensus clinical criteria, and validate these instruments so that they can be used in as a diagnostic instrument for further evaluation of the prevalence of autism in this country. In addition to studying the prevalence of autism in India, the investigators will also identify the full clinical spectrum of autism using their test instruments. Furthermore, potential risk factors for autism, including infections, nutritional deficiencies and

genetic factors will be identified through open ended interviews with health personnel. Not only does this study have the potential yield the first national estimate of autism prevalence in India, but also to lay the foundation for future autism research in that territory and serve as a model for international epidemiology research.

This study is currently in a piloting phase after which the screening and consensus clinical criteria will be modified accordingly, in preparation for the full scale epidemiological study. In September of 2007, this group received supplementary funding from the NIH in the form of an RO1 grant.

South Africa

Shuaib Kauchali, PhD

**University of KwaZulu-Natal, Nelson R Mandela School of Medicine, South Africa; and
Columbia University, Mailman School of Public Health, New York, NY**

Total: \$120,000 for 2 years

KwaZulu-Natal (KZN) Autism Study

Little is known about how frequently Autism Spectrum Disorder (ASD) occurs in children in developing countries. The primary aim of the KZN Autism Study is to find out how best to identify children who are suffering from ASD in South Africa. Without understanding how autism occurs in South Africa, researchers and service providers cannot plan on how to help those children and families suffering with the burden of autism. This is particularly true of indigenous African children with ASD, who often do not have access to services. In addition to the limited information about autism epidemiology and the lack of service availability, South Africa is a region of the world with a very high prevalence of HIV infection. This presents a unique opportunity to study autism in the context of HIV infection and explore the possible link between the two. The committed health personnel from Inkosi Albert Luthuli Central Hospital (IALCH), Phoenix Assessment and Therapy Center (PATC), and the ASENZE Study, along with personnel from Columbia University and support from the KZN Department of Health, will design and carry out a study that will test how best to identify and assess children with ASD in the Zulu language and culture, explore the prevalence of autism in South Africa, and further explore the hypothesized relationship between autism and HIV infection. The team will adapt and translate the Ten Questions (TQ), Social Communications Questionnaire (SCQ), and Autism Diagnostic Observation Schedule (ADOS), and use those tools to conduct a pilot epidemiology study that will identify a population of children with autism in South Africa. In addition, this group will work conduct important ethnographic analyses which will explore awareness and understanding of autism and how autism is perceived by the community. Ultimately, this study will develop the necessary research infrastructure to allow for the identification of children with autism in South Africa, will shed light on the awareness of and service availability for autism in the region, and will provide the groundwork to investigate the possible connection between HIV infection and autism.

South Korea

**Roy Richard Grinker, Ph.D. | The George Washington University
2005 NAAR Research Award: Biomedical | \$120,000 over 2 years**

The Prevalence of Autistic Spectrum Disorder (ASD) in Korean School-aged Children

Dr. Grinker and his associates have conducted the first epidemiological study of autism in South Korea and will reporting their results later this year. The investigators took a two stage screening and diagnosis approach to estimating the prevalence of ASD. All school-aged children in the region of Jinju, approximately 26,000, were screened and all screen-positive children were then diagnosed using the gold-standard assessment tools, the ADI-R and ADOS, adapted and translated to ensure cultural sensitivity in South Korea. The investigators also collected data on public perception and attitudes about ASD, as well as investigated the service utilization patterns among Korean children with ASD. Aside from ascertaining an estimate of ASD prevalence in South Korea, the study also serves to establish a population-based cohort of children with ASD and their families for future etiologic studies of genetic and environmental risk factors.

Furthermore, the study and the activities of these investigators have helped raise awareness of ASD among the South Korean community and within the government.

Young Shin Kim, M.D., Ph.D., MPH | Yale University
2007 Autism Speaks Research Award: Pilot Study | \$114,545 over two years

Prospective Examination of 6-year Cumulative Incidence of ASDs: A Total Population Study

The prevalence of autism has increased dramatically over the past 10 years, however, reported measures of prevalence do not accurately assess the role of the environment over better diagnostic techniques and service availability. This is better evaluated by measuring the incidence of autism over time – that is, the number of new cases diagnosed with autism on a yearly basis using rigorous screening, standard diagnostic assessments and valid case ascertainment in a specific age category over successive years. Korea presents an ideal situation to examine the changes in incidence and prevalence over time. As investigators in Korea and in the US have already developed methods to identify, screen and diagnose children with autism thanks to a 2005 Autism Speaks grant. This project will allow Dr. Kim and her colleagues to analyze incidence rates over time in 6 year olds with autism in Korea. This and other ongoing international research is potentially modeled for state-of-the-art epidemiological research on ASDs which will allow for cross-cultural comparisons. Along with the ongoing prevalence study, this pilot study will pave the way to answering critical questions about the cause of the increase in autism over the past decade.

Taiwan

Li-Ching Lee, Ph.D., Sc.M. | Johns Hopkins Bloomberg School of Public Health
2007 Autism Speaks Research Award: Basic & Clinical | \$450,000 over three years

The Development of Chinese Versions of the ADOS and ADI-R

The ADOS and ADI-R are considered the gold-standard diagnostic assessments for ASD and are the most commonly used tools for identifying cases in epidemiologic research. While both tools are available in numerous languages it is not available in Chinese Mandarin, a language spoken by 1.2 billion people worldwide. The unavailability of proper diagnostic tools in Chinese has been one of the major barriers for autism researchers who conduct research in Chinese speaking populations. To fill the gap and facilitate future autism research in Chinese speaking populations, this project aims to translate and adapt the ADOS and ADI-R into Chinese mandarin and train Chinese-speaking clinicians to become research reliable. This will lay the groundwork for future epidemiological studies of prevalence in Chinese-speaking territories and will allow multi-national and multi-cultural comparisons in variations and similarities of ASDs using standardized assessment procedures. Standardized assessment techniques will further allow researchers to examine different genetic and environmental risk factors on better understanding the causes of autism.

Recently, in working with Western Psychological Services, the publisher of the ADI-R and ADOS, Autism Speaks has brought together 5 research teams, including Dr. Lee's team in Taiwan, and researchers in Hong Kong, China and Singapore, to finalize a consensus version of the diagnostic instruments with broad utility across the Chinese-speaking territories.