Epidemiology Information Packet
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 minimizes 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 thorough 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 it's 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?

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. 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 and clinical capacity. Insufficient numbers of qualified clinical and 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**).

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. Seeking to establish accurate estimates of autism prevalence worldwide by encouraging international research collaborations, the network currently involves researches from over 20 countries including those with large population-based health registries to those low-resource countries without well-established public health infrastructure. As such, the network looks to enhance epidemiologic research on autism worldwide through three strategic initiatives. First, it is facilitating exchange of information and development of common protocols among the large, population based health registries systems across the world. Second, it is bringing together researchers from countries without formal registries but with existing autism service systems that generate medical, social service and education records from upon which epidemiologic research can be based. These researchers can compare common and disparate features across the service systems in their countries and work to find ways to standardize the review of records.

Finally, the Network is working to facilitate the development of new -approaches that can be implemented in developing/low-resource countries lacking any well-organized public health surveillance infrastructure. Here the initial focus has been on exploring ways to create short screening tools that are easy to administer and are valid and reliable in a range of cultural contexts.

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. 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 relevant genetic and environmental factors around the world.

In addition to the International Autism Epidemiology Network, Autism Speaks is currently funding independent epidemiology studies in Australia, Canada, Denmark, England, Finland, Ireland, India, Israel, South Korea, and Taiwan, and has interests in the Middle East (Qatar), China, Central America (Mexico), South America, and the Caribbean. We are also co-sponsors of the annual International Meeting for Autism Research (IMFAR 2006, 2007).

For more information on the International Autism Epidemiology Network, please visit our website at: www.autismepidemiology.net

To learn more about the international research Autism Speaks is currently funding, please see the "Research We Have Funded" section of our website.

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 *et al.* 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 *et al.* 2006
	Sweden	~53/10,000 = 1/188	Gillberg *et al.* 2006
	Finland	~12/10,000 = 1/833	Kielinen *et al.* 2000
	Denmark	~12/10,000 = 1/833	Laurtisen *et al.* 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 *et al.* 2005
	China	**Insufficient Data**	
	Korea	**Insufficient Data**	
South-east Asia	Taiwan, Singapore, Thailand, other	**Insufficient Data**	
Oceania	Australia	~39/10,000 = 1/256	Icasiano *et al.* 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.