



Autism Spectrum Disorders

EDITED BY

David G. Amaral, PhD
Geraldine Dawson, PhD
Daniel H. Geschwind, MD, PhD

OXFORD
UNIVERSITY PRESS

OXFORD
UNIVERSITY PRESS

Oxford University Press, Inc., publishes works that further
Oxford University's objective of excellence
in research, scholarship, and education.

Oxford New York
Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in
Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Copyright © 2011 by Oxford University Press, Inc.

Chapters 51, 76, and 78 are works of the United States Government
and are not subject to copyright protection in the United States

Published by Oxford University Press, Inc.
198 Madison Avenue, New York, New York 10016
www.oup.com

Oxford is a registered trademark of Oxford University Press

All rights reserved. No part of this publication may be reproduced,
stored in a retrieval system, or transmitted, in any form or by any means,
electronic, mechanical, photocopying, recording, or otherwise,
without the prior permission of Oxford University Press.

Library of Congress Cataloging-in-Publication Data

Autism spectrum disorders / edited by David G. Amaral, Geraldine Dawson,
Daniel H. Geschwind.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-0-19-537182-6 (hardcover : alk. paper)
I. Autism spectrum disorders. I. Amaral, David, 1950- II. Dawson, Geraldine.
III. Geschwind, Daniel H.
[DNLM: 1. Autistic Disorder. WS 350.6]
RC553.A88A8743 2011
616.85'882—dc22 2010030248

ISBN: 978-0-19-5371826

9 8 7 6 5 4 3 2 1

Printed in the United States of America
on acid-free paper



Culture and Autism Spectrum Disorders: The Impact on Prevalence and Recognition



Points of Interest

- Autism exists throughout the world, even in societies that have no name for it.
- Understanding how culture influences the recognition, definition, and treatment of autism may lead to better prevalence estimates.
- Public and private funding agencies now support epidemiological research in low and middle-income countries to explore how autism varies internationally in terms of its clinical manifestation and the extent of disability associated with the disorder.
- Autism spectrum disorders and *explanations* of developmental disorders (scientific or otherwise) are products of the interplay between biological, psychological, and cultural phenomena.
- Local factors affecting “administrative” prevalence estimates include poverty, access to services, racial discrimination, stigma, cultural beliefs about what kinds of behavior are “normal” and “abnormal,” and a nation’s health and public health infrastructure.

Awareness of the prevalence and phenotypes of autism spectrum disorders (ASD) has increased significantly over the past decade, especially in North America and the United Kingdom. Knowledge about ASD has also begun to spread internationally to countries such as India, South Korea, and Kenya, where the fields of developmental psychology, developmental pediatrics, and child psychiatry are less robust and where clinicians and educators do not generally distinguish ASD from other neurodevelopmental disorders, such as intellectual disability or learning disorders.

A search of published ASD research activities across the globe, however, might suggest that there is little knowledge about ASD outside of North America and Western Europe. Indeed, there are insufficient data to estimate the prevalence of

autism in the Caribbean, Central and South America, Eastern Europe, the Middle East, South and Southeast Asia, and the entire continent of Africa (see Table 7-1; Figures 7-1 and 7-2). Mapping the prevalence of autism, as seen in Figure 7-2, can be misleading, as it does not reflect the history of autism research or the recent growth around the world in awareness and expertise. For example, Hans Asperger, whose studies of ASD were foundational to the field today and whose descriptions are, for the most part, still relevant today, was Austrian. Leo Kanner, the psychiatrist who first described autism, was Austrian-American and was deeply influenced by an Italian scientist, de Sanctis, who in 1906 published case reports on early onset “dementia praecox” (probably autism) in a group of children with intellectual disability.

In addition, despite the absence of international epidemiological studies, awareness, advocacy, and opportunities for treatment and education of children and adults with ASD are advancing rapidly throughout the world. Today, national autism societies exist in more than 100 different countries, and scientific research on ASD is underway in eastern and southern Africa, India, several Middle Eastern countries, Mexico, Venezuela, and a host of other nations.

For a number of reasons, continued growth of international research on ASDs, and neurodevelopmental disorders in general, should be expected. First, the number of child mental health professionals in non-Western countries is rising. Second, recent large-scale collaborations between UNICEF, WHO, the World Bank, and university-based scientists, have led to improved recognition of developmental and intellectual disabilities among children living in poverty in the developing world, as evidenced by a high-profile series of articles on child development in *The Lancet* in 2007. In war-torn countries, some United Nations peacekeepers are now trained to provide services to individuals with autism.

Third, as low and middle-income countries advance economically, and infectious diseases and child mortality

Table 7-1.
Autism prevalence around the world (2000–2009)

Continent/Region	Country	Prevalence	Reference
North America	United States	~90/10,000 = 1/110	ADDM 2009
	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	Lauritsen et al., 2004
	Iceland	~13/10,000 = 1/769	Magnusson & Saemundsen, 2001
Eastern Europe	France, Spain, Italy, Greece, other	Insufficient Data	
	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	
Southeast Asia	Taiwan, Singapore, Thailand, other	Insufficient Data	
Oceania	Australia	~39/10,000 = 1/256	Icasiano et al., 2004
	New Zealand	Insufficient Data	

¹Table based on data published 2000 or later.

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

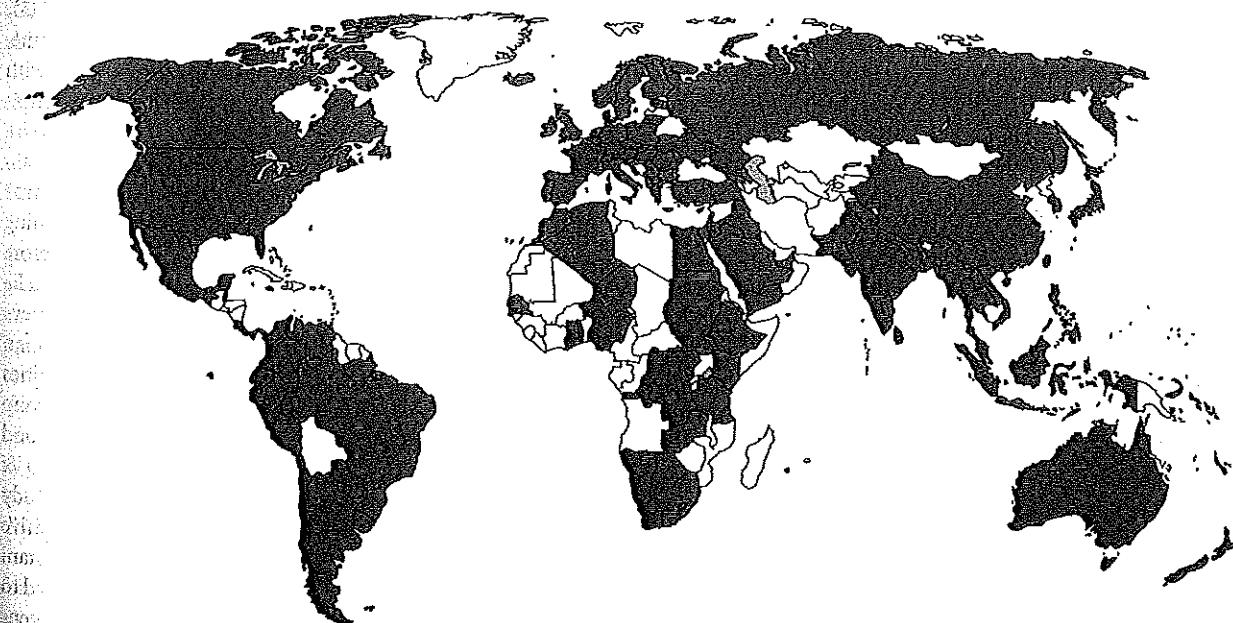


Figure 7-1. Map of autism societies around the world as of 2008 (Map courtesy of Tamara Daley).

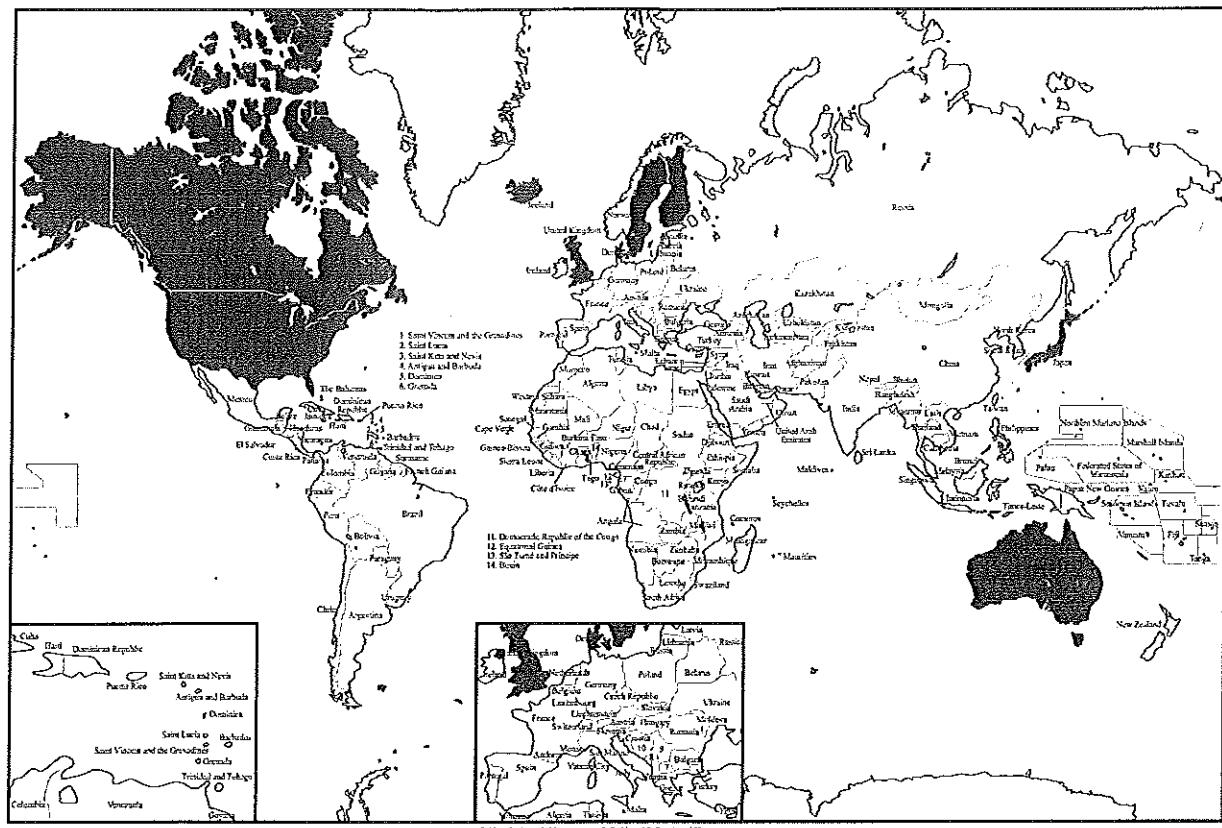


Figure 7–2. Map of autism prevalence studies around the world (2000–2008).

become less of a concern, disability and child development become more prominent as public health issues.

Nonetheless, researchers are just beginning to study the extent to which ASD varies across cultures. Although most researchers expect that the onset and core symptoms of ASD are consistent across cultures, this remains an assumption. ASD experts to date know little about how genetic heterogeneity and cultural differences interact to influence the kind and range of impairments that are essential to or associated with ASD, its prevalence, course, or familial patterns.

The most robust body of literature on autism as a global phenomenon is in the field of psychiatric epidemiology. Over the past 40 years, prevalence studies of autism have been conducted in numerous countries, with one major review citing English-language studies in 13 different countries, including France, Japan, Norway, Iceland, and Finland (Fombonne, 2003, 2009). Epidemiological findings are forthcoming from East Asia and South America (Montiel-Navia & Peña, 2008) and ASD screening tools have been tested in a wide range of locations (see, for example, Lung et al., 2010 on Taiwan, and Eldin et al., 2008 on the Middle East). However, the vast majority of prevalence studies have been conducted in the United Kingdom and North America.

A few case reports and screenings have been published for other countries, such as Malaysia (Kasmini & Zasmani, 1995), Taiwan (Chang et al., 2003), Zimbabwe (Khan & Hombarume, 1996), and the United Arab Emirates (Sartawi, 1999), with some studies reporting associated medical conditions such as mitochondrial respiratory chain disorders in Portugal (Oliveira et al., 2007) and Möbius sequence in Brazil (Bandim et al., 2002). Research on possible clusters of autism among Europeans and Americans of Somali origin is in the beginning stages (Barnevik-Olsson, Gillberg, & Fernald, 2008; Minnesota Department of Public Health, 2009). Some studies, such as La Malfa's epidemiological work in Italy, have examined the prevalence of pervasive developmental disorders (PDD) in an already identified pool of children with intellectual disabilities (La Malfa et al., 2004). Others examine ASD as one of a group of conditions in large-scale projects on challenging childhood behaviors or developmental disorders in general (Holden & Gitleson, 2006; Morton et al., 2002). At least one British study noted significantly higher prevalence of childhood cognitive disabilities, including autism, among citizens of Pakistani origin, whose high rate of consanguineal marriage is believed to be related to a rate of birth defects that is higher than the general population in the United Kingdom (Morton et al., 2002).

DSM criteria for ASD have been tested in multiple countries, and genetic research involves samples from populations throughout Western Europe. However, with the exception of Lotter's brief, anecdotal survey of autism prevalence in six African countries (1978) and Probst's exploratory survey of the stresses and demands of parents of children with autism in Brazil, Germany, Greece, and Italy (1998), there are, to our knowledge, no published cross-national studies that address the impact of culture on ASD. There is also very little information about how the genetics, biology, risk factors, treatment, and course of ASD differ across continents, countries, or ethnic groups. This chapter focuses on the international prevalence and diagnosis of autism because these are the areas in which international scientific publications exist. We consider the effect of culture on the conceptualization and identification of ASD, with special attention to the question of how studies of the sociocultural contexts of ASD, and neuropsychiatric disorders in general, can help us frame future international ASD research.

Given the fact that the majority of research on ASD has been carried out within the mental health field, we situate the research within the larger framework of psychiatric and psychological studies. However, we recognize that as research on ASD progresses, a greater number of studies will consider ASD from alternative, nonpsychiatric perspectives, such as within the context of a neurodevelopmental disorders framework.

Recognition and Epidemiology

Research to date has highlighted cross-national differences in the symptoms and course of psychiatric disorders. For example, although the age of onset and prevalence of both schizophrenia and obsessive-compulsive disorder are remarkably consistent across the globe, sex ratios, comorbid conditions, symptom expression, severity, and prognosis vary significantly (Hopper et al., 2007; Horwath & Weissman, 2000; Lemelson, 2003). Moreover, although researchers may use standardized assessments and criteria (at the very least, DSM and ICD criteria) to determine whether an individual constitutes a "case" of autism, clinicians who are not integrated into a research community—physicians and psychologists who see patients in private or clinic settings—may conform to folk categories of illness or rely on past training and personal clinical experience. Even with standardized criteria, considerable subjectivity and differences in clinical assessments exist, since the diagnosis depends on patient or caretaker narrative and behavioral observation rather than laboratory tests. Indeed, variations in diagnosis within and between societies can sometimes be explained in terms of the differences between research and clinical practice.

Cross-cultural variations in psychiatric diagnoses can be found, even between communities whose scientific traditions are often assumed to be similar, such as the United States and the United Kingdom. In a landmark study of the differences

between British and American psychiatrists (whose scientific cultures are not dramatically different), R. E. Kendell (1971) and his colleagues showed a video of a socially awkward man, described as a 30-year-old bachelor, and asked British and American psychiatrists to give a diagnosis based only on the video. Sixty-nine percent of the American psychiatrists diagnosed the man with schizophrenia; only 2% of British psychiatrists gave that diagnosis (a large number of the British clinicians gave a diagnosis of manic-depressive illness). Shifts in classification occur for many reasons—such as the need to screen and treat soldiers in military conflicts, shifts in the way the insurance industry conceptualizes appropriate reimbursements, and public attitudes about the stigma of mental illness—that have little to do with advances in science and much to do with social and historical context (Grinker, 2010a). The classifications of the most empirically verifiable disorders, such as bacterial or viral infections, evolve and are formed by consensus. A disorder, even one with a clear cause or biomarker, is only a disorder when a society construes it as such. Thus, although Asperger's disorder is scheduled for elimination from the proposed DSM-5, this does not mean that Asperger's once existed as a real disease and now has disappeared. Asperger's was useful when a non-stigmatizing term was needed for people with the disorder, but clinicians now question it for both cultural and scientific reasons. From the perspective of culture, Asperger's is fast becoming obsolete as a scientific category as the stigma of autism declines. Societies throughout the world are beginning to appreciate the strengths and capabilities of people with autism, and people with autism increasingly feel less self-stigma and may advocate for their needs in public forums. From the perspective of science, clinicians recognize that almost everyone with Asperger's also fits the profile of the more classic autistic disorder. Indeed, in the current diagnostic manual, the DSM-IV, a child who has good language acquisition and intelligence qualifies as autistic if, in addition to having restricted interests and problems with social interactions, he has just one of the following symptoms, which are common among children with Asperger's: difficulty conversing, an inability to engage in make-believe play or repetitive or unusual use of language. Even the best available diagnostic instruments, such as the ADOS and ADI-R, cannot clearly identify distinct subtypes on the autism spectrum (Grinker, 2010b).

The social construction of psychiatric classification can be illustrated by the differences between ASD diagnostic classification and research in the United States and France. In the United States, the American Psychiatric Association removed autism from the category of "psychosis" in 1980, but the French child psychiatric establishment, which uses its own indigenous manual of mental disorders, the *Classification Française des Troubles Mentaux de l'Enfant et de l'Adolescent* (CFTMEA), classified autism as a psychosis until November 2004. French health professionals also conceptualize the etiology of autism in a manner that is different from other European countries and consider the American classification of PDDs to be a product of Anglo-American culture.

Since French health professionals generally view autism as a problem that lies within family social relationships and with the mother-child relationship in particular, there are only a few psychiatric or medical centers with expertise on autism as a genetic or brain disorder.

In recent years, a battle has erupted between French parents, armed with scientific studies and classifications from the United States and the United Kingdom, and French child psychiatrists. French health professionals generally retain a more restricted concept of autism and are openly hostile to behavioral interventions, such as the Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) program or Applied Behavioral Analysis, and to parent and parent association efforts to shift the locus of autism treatment from the hospital to the school (Chamak, 2008). Despite the efforts of parents, autism research and treatment in France continues to be guided largely by psychoanalytic thought, in particular the idea that autism is a disorder of object relations. Research on treatment emphasizes play therapy and interactive techniques to facilitate the growth of autonomy and a sense of self.

A clinical trial is underway in Lille, France, on the controversial therapy called "packing," in which a child is wrapped tightly in wet, refrigerated sheets, for approximately sixty minutes while clinicians attempt to talk with them about their feelings. The therapy is based on an argument that a child's ability to establish a proper relationship between his internal world and his external, social reality depends on his ability to merge his body and his body image (Spinney, 2007).

One reason for the absence of a large number of cross-national studies in mental health is that, in addition to being expensive and difficult to coordinate, the standardized assessments and classifications needed for such studies are of somewhat recent origin. American psychiatrists and psychologists have become keenly interested in diagnostic classification only in the last 3 decades. As one result, psychiatric epidemiological studies using comparable methods did not begin in earnest until the 1970s, and there were few cross-national studies conducted until the 1990s. The World Health Organization (WHO) international studies of schizophrenia began in 1968 and eventually included thirty research sites in nineteen countries and involved a 26-year follow-up period. These studies represent the most ambitious and lengthy cross-cultural explorations of the manifestations, course, and outcomes of a mental illness. Yet, as recently as 2004, only two prevalence studies of mental disorders among European adults had used comparable methods of ascertainment at the same time in more than one country (ESEMeD/MHEDEA, 2004). However, if we accept Cohen and Volkmar's assertion about autism, in relation to the DSM-IV and ICD-9 criteria that "There is no other developmental or psychiatric disorder of children (or perhaps of any age) for which such well-grounded and internationally accepted diagnostic criteria exist," cross-national studies should be feasible (Cohen & Volkmar, 1997).

Although there is a rapidly growing literature on international studies of neurodevelopmental disorders, and ASD in

particular, there are few estimates of the prevalence of physical disabilities among children in low and middle-income countries and even fewer of behavioral disorders (Yeargin-Allsopp & Boyle, 2002). Researchers have made significant progress internationally, studying some disorders in childhood that have a neurodevelopmental component, such as cerebral palsy and epilepsy. Among psychiatric disorders, ADHD and conduct disorder have been studied extensively across the globe (Faraone et al., 2003; Polanczyk et al., 2007). However, epidemiological research on childhood onset disorders lags behind the epidemiology of such disorders in adults. Even within the area of the epidemiology of child mental disorders, more is known about psychiatric disorders in older children and adolescents than in younger children.

One area of progress in the diagnosis and epidemiology of autism across cultures has been at the level of screening, in particular the development of brief screening tools that can be validated in numerous languages and dialects and administered with minimal training. For example, the Childhood Autism Rating Scale (CARS) (Schopler et al., 1988), a 15-item, behavioral rating scale has been shown to be both sensitive and specific for ASD; the Autism Behavior Checklist (ABC) (Krug et al., 1980) includes 57 items but nonetheless takes less than 20 minutes to complete; and the Autism Spectrum Screening Questionnaire (ASSQ) (Ehlers et al., 1999), a 10-minute, 25-item rating scale appears to be particularly good at screening for high-functioning autism and Asperger's disorder. These scales have been used successfully in international research, have proved both reliable and specific, and are thus valuable in clinical and community-based settings. A broader approach, especially applicable in low and middle-income countries, is to screen children initially for an array of neurodevelopmental disabilities and then administer a condition-specific assessment for children who screen positive. This model was initially developed by Durkin et al. (1992) using a short questionnaire that includes only ten questions (known as the "ten questions screen"). More recently, the ten questions screen has been adapted by Indian researchers as part of the International Clinical Epidemiology Network (INCLEN) in India for a community-based screening study of autism and other developmental disorders among children ages 2–9 years.

In research settings in which scientists trained in the diagnosis of developmental disabilities are available, screenings are useful as a first-stage diagnostic tool. More lengthy and substantial diagnostic assessments are then performed with tools such as the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 1999) and the Autism Diagnostic Interview (ADI) (Rutter et al., 2003), both of which have been translated, validated, and are available for purchase in twelve European languages and Korean. Numerous other translations are underway, but more are needed. As one researcher in Thailand noted (where no translations of these tools have been validated), even when researchers and clinicians can characterize ASD as conforming to DSM-IV criteria, they cannot confirm the diagnoses in the absence of Thai-translated,

standardized investigator-based instruments and structured observational schedules (Chuthapisith et al., 2007).

Conducting Prevalence Studies in International Settings

In the United States and United Kingdom, investigators now ideally use a two-stage approach to estimate autism prevalence, and this approach is capable of detecting more cases than ever before. In general, the approach involves a screening phase to identify a pool of children who may have an ASD, followed by a diagnostic confirmation stage. The methods for both phases vary widely, and their validity is dependent on the clinical and educational infrastructure in the country or setting. The screening stage can range from a general population screen in a primary care setting, as done by Honda et al. (2005), to a screening of children identified in high-risk settings, such as special education schools. High-risk screening can be based on canvassing records in schools or health care settings that target children with developmental delays or administering an autism screening instrument to a knowledgeable informant, such as a parent, guardian or teacher, or a combination of these two.

The targeted approach to case screening has become easier in many countries in recent years due to better awareness of autism and, presumably, a combination of more accurate clinical diagnosis and critical policy level changes that promote identification. For example, in the United States, beginning in the 1991–1992 school year, autism became a separate area of “exceptionality,” meaning that children with autism could receive special education services specifically designated for children with autism. The U.S. Department of Education required schools to report, as part of an annual “child count,” the number of children receiving these services under the autism classification. The child count made it significantly easier to locate potential case children from school records. To add even more cases, the CDC studies examined records of children with educational classifications beyond autism, such as behavior disorders and intellectual disabilities, since all children with autism are not necessarily classified by schools as autistic. In low and middle-income countries, a records-based screening approach may not be feasible, because of the absence of records or because the diagnosis of autism is either unknown or rarely used. In such situations, researchers will have to screen individuals rather than records.

In the best of circumstances, a researcher can combine a record review with individual screening. During the individual screening, parents and teachers fill out standardized third-party questionnaires such as the Autism Screening Questionnaire (ASQ) or the Autism Spectrum Syndrome Screening Questionnaire (ASSQ). These questionnaires, which have been studied extensively for their reliability—i.e., to make sure that independent researchers using them with the same case would come to the same conclusion—help

epidemiologists identify potential cases, especially when two or more instruments with different sensitivities are used together. However, in some countries, it may be impractical to use parent self-administered screening tools for a variety of reasons. For example, many parents in low and middle income countries may have low literacy, especially mothers (since women often have more limited access to education than men), and may thus be unable to complete the surveys. Also, for political reasons, parents in some countries may be afraid of having their child’s health condition codified in writing.

In the second stage—diagnostic confirmation—epidemiologists ideally use trained diagnosticians to confirm case status among those who screen positive. If the screening phase was based on a record review, a standardized review process is established to determine case status (for examples, see Barbaresi et al., 2005; Honda et al., 2005; Williams et al., 2005; Powell et al., 2000; Lauritsen et al., 2004; and Autism and Developmental Disabilities Monitoring Network [ADDM], 2009). Because the study population is much smaller at the confirmation stage, assessments can be done in person with each child, preferably with more than one structured, reliable diagnostic assessment, such as the combination of the ADOS (a *synchronic* observation schedule over one 2- to 3-hour period of time) and the ADI (an extended parent/guardian interview that provides a detailed history, or *diachronic* perspective, on the child). Ideally, for both methods (record-based and in-person assessments) the confirmatory diagnoses are then validated by outside consultants using a group of randomly selected cases (some with and some without an autism diagnosis). This second stage is especially important for validating the less clear-cut cases, such as the ones on the border between two different diagnoses or between a diagnosis and none at all.

We have entered a period in history in which autism awareness is at an all-time high and in which the diagnosis of autism has broadened to include a range of different people along a wide spectrum. This is largely due to the current use of the two-stage case-finding approach, which yields many more cases of autism than the older studies. In addition, researchers ideally employ quality control measures, such as blinded reviewers, to establish interrater reliability. However, it must be stressed that it is exceedingly difficult and expensive to use such thorough and rigorous methods. Implementation of the gold standard assessments for autism is particularly challenging in low-income countries. Extensive training is necessary to obtain test reliability. Considerable participant burden is associated with the length of time, often several hours, to administer the assessments. Furthermore, in countries in which little research has been conducted on child development, the validity of results from such protocols will be hampered by the absence of established, documented norms of child development for a given population. Epidemiological studies in the low and middle-income country setting will therefore benefit from the development of more efficient and affordable diagnostic assessments.

Challenges to ASD Surveillance

The epidemiology of ASD should be understood in the context of the many challenges inherent in applying diagnostic criteria to growing and developing children in different cultural contexts. It is not feasible to produce a list of criteria for a disability that will be relevant at all developmental levels, and what counts as normal or abnormal development will vary from culture to culture. There is the obvious problem that researchers who study school-age children face the difficult task of reliably defining cases on the basis of information presented in teacher reports (which can be heavily influenced by a multitude of factors, such as class size, teacher training, and the local, cultural attitudes toward discipline and about what kinds of behaviors are age appropriate) and parent reports (which are influenced by the particularities of the parent who completes the report). For some childhood onset psychiatric disorders, estimates may appear higher in a country with great awareness among parents, educators, and clinicians; access to services; or in which the national government mandates the use of "autism" as a diagnostic term. In contrast, estimates may be lower in a country with little awareness, few services, and lack of research studies, especially of administrative prevalence. For example, school and clinic records of "autism" and "traumatic brain injury" grew tremendously following the 1991–1992 school year, when the U.S. Department of Education first introduced these terms to the American public school system (Newschaffer et al., 2005).

Previous studies confirm significant variations among locations, even within the same country, as the Centers for Disease Control and Prevention showed from their multisite surveillance network. Recent prevalence estimates for Arizona and Missouri (12.1 per 1000) were higher than those from Florida (ADDM, 2009). Research in Australia has demonstrated considerable variability in diagnostic rates across states and between state and national records. In Queensland, the number of diagnoses of ASD exceeds that of other states, since Queensland requires a DSM-IV diagnosis for eligibility for services but other Australian states do not (Skellern et al., 2005).

Moreover, clinicians will not make or record a particular diagnosis, and parents will not seek it, unless the diagnostic term is meaningful and in current use. Thus, for example, the Navajo Indians of the American Southwest tend to classify autism as "perpetual childhood" (Conners & Donnellan, 1995), and throughout most of India, clinicians call autism *paagol*, the Hindi word for "madness" (Daley, 2002, 2003). School and clinic records for a child with ASD, if there are any records kept, will not list the word "autism." In rural South Korea, the catch-all "brain disorder" can be used for children with disorders including traumatic brain injury, autism, epilepsy, speech and language disorders, Down syndrome, and other clearly genetic disorders. In this setting, record reviews will yield few cases of autism.

Researchers should expect to encounter additional obstacles when attempting to do public health screening in general and ascertain and classify neurodevelopmental disorders in

societies with low access to services. Illness categories are beneficial only if there is something one can do with them. Thus, for many American adults with ASD who require public assistance, it makes little sense to carry an autism diagnosis in states where services for adults with autism are provided only under the category of intellectual disability, or formerly "mental retardation." In urban India, where there are few autism-related services, a clinician is unlikely to give a diagnosis of autism since the clinician may believe that it would only confuse the family, the school system, and potential service providers (Daley & Sigman, 2002; Daley, 2003). Indian pediatricians interviewed by Daley (2003) and Grinker (2007) use a much more well-known category—mental retardation, popularly glossed as "madness"—even if it is sometimes inaccurate, and they will justify it by arguing that the treatments and educational services in India for someone with mental retardation are identical to those for someone with autism. For this reason, records-based approaches to the epidemiology of autism in societies where "autism" is uncommonly used as a diagnostic term are not feasible. Even in societies where the concept of autism does exist, people may not seek care from the experts who are familiar with the term. Indeed, epidemiologists should not assume that the population being studied shares the researchers' understanding about the relationship between the symptoms being studied and the name of the disease. In Korea, for example, despite dramatic changes in autism awareness, the word for autism (*chap'ae*) has quite negative connotations because many people mistakenly believe that all individuals with the diagnosis are profoundly intellectually disabled and nonverbal. The Korean research team in the first author's prevalence study of ASD worked hard to explain to teachers and parents the concept of an autism spectrum (Grinker, 2007). Toward this goal, researchers asked the child psychiatrists who led the information sessions at the "mainstream" elementary schools to remove from their presentations a film about autism because it depicted a quite impaired young man with autistic disorder.

Furthermore, in some developing countries there may be opposition to research on disorders that are not life threatening. It has been suggested that research on developmental disabilities in general is a low priority in many low-income countries where there are more pressing issues such as diseases that cause infant and child mortality (Durkin, 2002, p. 206). Consequently, in many countries, due to the lack of administrative records on child health, researchers need to be referred to potential cases by a wide range of individuals, such as priests and ministers, pediatricians, community leaders, and teachers. Researchers may need to conduct door-to-door household surveys and individual screenings of all children in a community (see, for example, Islam et al., 1993; Thorburn et al., 1992; Durkin, Hasan, & Hasan, 1998). Even then, parents and health officials may strongly oppose the introduction of a diagnostic category that is new and thus confusing.

Social stigma influences diagnosis. In South Korea, children that American clinicians might diagnose with autism are often diagnosed with reactive attachment disorder (RAD),

is are them. public osis in l only merly e few diag- would l serv- ndian 2007) ation, s inac- ments nental utism. emiol- monly cieties ot seek indeed, being e rela- name changes s quite akenly boudly search worked of an search- nation remove use it order. may be reatenn- mental income iiseases o. 206). imin- referred s priests teachers. household ommu- l., 1992; d health agnostic ea, chil- tism are (RAD),

pejoratively referred to as "lack of love" (*aejöng kyölpip*), a term that parallels the older American concept of the "refrigerator mother." In Korea, RAD is thought to be a condition mimicking autism, caused by a mother's absence of attachment to her child (Shin et al., 1999). Many parents prefer a RAD diagnosis to autism.

First, unlike autism, RAD or lack of love can be ameliorated by giving love and thus is not a permanent condition. Koreans widely consider autism to be untreatable (Grinker, 2007). Second, RAD, unlike autism, is not a genetic condition. Thus, while RAD may stigmatize the mother, autism would stigmatize the whole family—past, present, and future. This fear of autism as a genetic disorder is found in many other countries as well, where parents fear that a child's diagnosis of autism will marginalize the family from the social networks to which they feel they are entitled, and harm other family members' marriage prospects (such as the autistic child's siblings). Third, and perhaps most importantly, the diagnosis makes sense. Korea has been undergoing dramatic social change for the last 50 years, emerging from the total devastation of the Korean War to becoming the twelfth largest economy in the world, ahead of countries like Australia, Switzerland, and Sweden. Noting the increase in working mothers and nuclear, as opposed to extended, households, Korean sociologists and child health experts argue that children left with nannies or in daycare cannot form appropriate or lasting attachments with their mothers, and that the failure of attachment leads to RAD.

Such attitudes are not unique to Korea. Hypotheses about the causative role of environmental factors, such as poor parenting and social stressors, in ASD, attachment disorders, and other childhood onset problems, have considerable traction in impoverished or rapidly changing societies. In South Africa, for example, child psychiatrists argue that the role of such stressors have been grossly underrepresented in research on child development: young children are exposed to many forms of violence, parental substance abuse is common, and many children are orphaned or raised by multiple caretakers and with little continuity of care (Hugo et al., 2003).

Despite such obstacles at the clinical level, improvements in diagnostic specification with screening tools and "gold standard" assessments have opened the possibility for rigorous and comparable studies of ASD across cultures. Regardless of whether a society has a word for autism or maintains that autism is a rare condition, epidemiologists can ascertain cases. Children with ASD in a range of different countries have been identified in prevalence studies and can thus form cohorts for studies of etiology and intervention (Vogel & Holford, 1999).

As more diagnoses are made and recorded in school and clinic records, there will be greater opportunities for records-based epidemiological studies. In addition, advances in disability legislation and the growth of advocacy organizations in a number of countries, such as Brazil, China, India, Malawi, South Africa, and Uganda (Braddock & Parish, 2001) as well as at the transnational level (for example, the United Nations, UNICEF, PAHO, WHO, and the World Bank) have made it

possible for children with autism to obtain appropriate educational placements and have their diagnoses recorded in school records. As just one example, the well-known TEACCH program has been studied and subsequently adopted in numerous countries and is currently under development in China, India, Mexico, Morocco, Nigeria, and the Philippines, among other places.

Despite the progress in the epidemiology of ASD, there are only a handful of studies that examined the incidence of autism: the rate of occurrence of new cases in a population over a specified period of time (Fombonne, 2007; Rothman and Greenland, 1998; Kleinbaum et al., 1982). This absence is understandable due to the fact that the emergence of ASD in early childhood is insidious, and it is thus often difficult to determine disease onset, which is necessary to examine incidence. Of the studies that have examined incidence, the date of first diagnosis is usually used as a proxy for onset of the disorder. Incidence studies are particularly challenging in a low or middle-income country setting where autism is not routinely diagnosed and symptom onset is not well documented (Figure 7-3).

Despite all of these challenges, there are ongoing efforts to facilitate and standardize the epidemiologic approach to autism research from an international perspective. However, the approaches to autism epidemiology have to be based on local capacity and other attributes in a country. A large-scale initiative sponsored by the parent advocacy organization Autism Speaks distinguishes three separate approaches: one exclusively using records for those settings where most children with an ASD can be identified in schools and health care settings; another utilizing disease registry systems established in some countries as a mechanism to track the health of the population; and a third approach, for those countries with an undeveloped service system, which requires community canvassing or more generalized screening. The intent is to facilitate research within each of these settings and to explore how autism varies in terms of its clinical manifestation and the extent of disability associated with the disorder.

Effect of Social Organization, Culture, and Language on Prevalence Studies and Services

Social Organization and Culture

The WHO studies of schizophrenia constituted the first large-scale effort to explore the role of social organization and culture in influencing the prevalence and outcomes of a mental illness. However, the concept of "culture," broadly defined as the system of meanings through which people organize and make sense of their lives, has long been a central feature of psychiatric description and should not be used only in reference to non-Western societies. For example, researchers have considered how poverty, occupation, social class, and marriage systems affect mental illness in the United States. Epidemiological studies of schizophrenia as early as the 1930s (Faris & Dunham, 1939) noted differences in the prevalence of schizophrenia in urban and rural areas in the United States.



Figure 7-3. Hindi poster. Autism experts in India are promoting autism awareness through educational programs and posters, such as this one, in Hindi, that depict and describe a range of symptoms. For example, the poster describes the symptom at the top left as "Aloof in Manner"; the caption at the bottom right is "Unusual behavior of body movement such as flapping hands, rocking, or jumping." Courtesy of Merry Barua, Action for Autism (India).

Numerous studies highlight racial disparities in the diagnosis of schizophrenia (Mishler, 1965; Ruiz, 1982), with most researchers agreeing that the disparities are the result not of true differences in prevalence but rather racism, cultural misunderstandings, misdiagnosis, and mismanagement (Whaley, 2001). Among the mentally ill, poor people are also overrepresented, perhaps a legacy to the day when insane asylums also served as poorhouses.

As recently as 1984, Sanua, echoing Lotter (1978), argued that autism was not a universal phenomenon, but a culture-bound disorder, "an illness of Western Civilization"

(Sanua, 1984). And for decades following Kanner's original description of the parents of children with autistic disorder as highly educated, upper-middle-class workers, researchers focused on social class as a possible risk factor for autism, one result of which was the concept of the refrigerator mother (usually the educated, working, professional mother). Even today, some scientists continue to argue that ASD occurs more often in the offspring of scientists, engineers, mathematicians, and computer experts, and those with a sociobiological perspective have hypothesized that the increase in the prevalence of higher-functioning autism and Asperger's

disorder in the United States and the United Kingdom is the result of intermarriage between highly educated parents (Baron-Cohen, 2004). The development of computer technologies, they argue, makes it possible for autistic adults to find gainful employment, marry, and reproduce. The delay in finding a suitable mate may lead to an increase in parental age, which has been shown in some studies, but not all, to be a risk factor for ASD (Durkin et al., 2008; Croen et al., 2007; Shelton et al., 2010; Grether et al., 2009).

The hypothesis of an association between autism and high socioeconomic status (SES) stands in stark contrast to the large body of research consistently showing that low socioeconomic status is the strongest predictor of childhood disabilities (Durkin, 2002). It is important to point out that none of the claims associating autism or changing prevalence rates to computer technology or to higher SES has been proven. One research team (Cuccaro et al., 1996) did find that school-based clinicians, pediatricians, and psychiatrists were biased in favor of giving autism diagnoses to children of parents of high SES. In a survey of pediatricians, Stone (1987) found that a majority believed there was a true association between autism and SES. It is possible that such a bias explains, at least in part, the fact that African American children subsequently diagnosed with autism are at least 2.5 times less likely to receive a diagnosis at their first specialty visit than a white child with autism (Mandell et al., 2002). With respect to diagnosis, Bearman and colleagues (Liu, King and Bearman 2009; Fountain, King, and Bearman 2010) correlate lower age of diagnosis and increased diagnosis with higher socio-economic status, and social networks. All of these studies indicate that cultural attitudes about SES influence diagnostic practice, but SES does not appear to determine whether or not someone actually has autism.

Nevertheless, poverty, racial discrimination, and marginalization have real effects on outcomes among children with mental illnesses and disabilities (Brown & Rogers, 2003). Researchers have paid special attention to the differences in prevalence and course of mental illnesses between rural and urban environments. Rutter's comparison of the prevalence of psychiatric disorders among 10-year-olds showed significantly higher prevalence of disorders (25.4%) in London than in the Isle of Wight (12%). Rutter et al. (1975) concluded that higher rates of family conflicts, parental psychopathology, and poverty in London were positively associated with higher rates of psychiatric disorders in the children (Rutter et al., 1975). Similarly, in the Ontario Child Health Study, Offord et al. found higher rates of all psychiatric disorders in 4- to 16-year-olds in urban areas (Offord et al., 1987).

The World Health Organization studies on schizophrenia, conducted in the 1970s, showed that prevalence was consistent across rural and urban areas but that outcomes differed significantly depending on geographic location. Although schizophrenia occurs with similar frequency all over the world, people with schizophrenia in the sites in developing countries, such as Agra, India, do better over time than those in industrialized countries. They need less care, fewer medicines, and have fewer traumatic, psychotic episodes. For example, as

Hopper (2003) documents, psychiatrists in Madras, India, note that individuals with schizophrenia have had surprising success finding spouses. Thara, Padmavati, and Srinivasan (2004) attribute this success to the importance of one aspect of *dharma*, the duty to marry for the sake of the extended family and the continuity of the lineage. The institution of marriage "adapts and endures, accommodating even those whose nuptial capital would seem to be seriously devalued, given the persistent stigma attached to mental illness in India" (Hopper, 2003, p. 78). Hopper associates marriage of disabled persons with a measure of "social recovery" (2007). We need similar information about ASD to know if certain cultural conditions help people with ASD improve their ability to learn, communicate, and participate in social and economic life. Comparisons to schizophrenia may be useful. For example, in comparison to ASD, is there less stigma attached to the person with schizophrenia in some cultures because the onset of the disorder is in late adolescence, after a family and a community have had nearly two decades to form an attachment to the person? Is there greater stigma attached to a person with autism because the onset is so early?

Both developmental disorders and *explanations* of developmental disorders (scientific or otherwise) are products of the interplay between biological, psychological, and cultural phenomena. In part, as the result of the WHO studies, public health officials increasingly see disabilities as simultaneously both neurologically and culturally constructed. By including culture as a variable in medical research, scientists understand that an illness motivates behaviors in multiple areas of social life. A diagnosis of autism, for example, mobilizes kin groups toward common action or conflict and influences financial planning, choices about residence, reproduction, and employment. In the research community, changes in epidemiological methods produce different rates that can directly influence government policies and educational practices. Changes in educational practices also influence scientific research. Thus, in Italy, mandatory inclusion of children with disabilities, following national inclusion legislation in the 1970s, facilitated lively scholarly work on the course of ASD among children who are educated alongside unimpaired peers, as well as research on early diagnosis of autism (Levi & Bernabei, 2005).

Health services research is one area in which mental health professionals have shown that cultural differences within a single population, like the United States, can lead to disparities in recognition, diagnosis, and care. Availability of clinical services, access to and utilization of services, and cultural appropriateness of services vary considerably among ethnic minorities in the United States. As a result of centuries of racism and discrimination, many African Americans, for example, do not trust government health care institutions and so may not seek care. (Indeed, there is a long history of psychiatric misdiagnosis in African American patients.) Native Americans, a largely rural population, not only live in areas with low access to services, but often utilize traditional healers rather than doctors in clinic settings; some do not see ASD as pathological and may not seek any care at all (Conners &

Donnellan, 1995). Asian Americans underutilize the mental health care system in the United States because of the shame and stigma associated with mental illness. Latinos underutilize the mental health care system because of language barriers (USDHHS, 1999), and Latino parents of autistic children are more likely than the general population to use "nontraditional" treatments (Levy & Hyman, 2003).

For ASD, David Mandell showed that, on average, white children in the United States receive an autism diagnosis approximately 18 months earlier than African American children (Mandell et al., 2002). In the United States, rural children with autism received a diagnosis approximately 5 months later than urban children, and near-poor children received a diagnosis approximately 1 year later than children whose families had an income >100% above the poverty level (Mandell, Novak, & Zubritsky, 2005). Mandell and Novak (2005) urge researchers to conduct research on "the complex relationship between culture and treatment, focusing on cultural differences in the behavioral phenotype of ASD, recognition of symptoms, interpretation of symptoms, families' decisions regarding medical and educational interventions, and interactions between families and the healthcare system" (2005, p. 114). One implication of this recommendation is that even as researchers begin to study autism in other cultures, Americans have not yet resolved the questions that exist in our own society about when and how race, ethnicity, and class, among other cultural factors, influence diagnosis.

In most low and middle-income countries, where there are few or no services for children with special needs, family management and treatment of children with developmental disabilities are influenced directly by socioeconomic and demographic changes. As societies rapidly urbanize (today, for example, one fourth of the population of South Korea lives in Seoul) nuclear families replace extended ones. Parents thus lose the primary source of social support for disabled persons and are compelled to seek help elsewhere, from charitable organizations and other associational communities (such as churches and newly formed autism societies) and from local and national governments. The demands become even greater in households with two working parents.

Taken together, the impact of sociocultural factors on autism recognition, epidemiology, and services reveals an additional and important aspect of our contemporary understandings of autism: the degree to which autism can be conceptualized as a disability as well as a disorder. Disability is fundamentally about a person's interaction with an environment of discrimination, exclusion, and barriers to functioning. The concept of "environment" comprises attitudes, natural or built physical barriers, and policies or systems that may limit an individual's potential. Toward the goal of providing a common language for defining and comparing disabilities across cultures, the WHO developed the International Classification of Functioning, Disability, and Health (ICF). The ICF (which classifies health status), together with the ICD

(which classifies disease status), can help experts predict functional outcomes, the need for services, work potential, and possibilities for successful integration into community life (WHO, 2001).

Language

Researchers conducting international studies of developmental disabilities should remain vigilant about preconceived notions of culture. First, at a time of unprecedeted population movements across national borders, "culture" is no longer synonymous with place. The rich person in India and the rich person in England may be more culturally similar in terms of values associated with health and disease than the rich and the poor person in either one of those countries (Gupta & Ferguson, 1992). Thus, "culture" should not necessarily be equated with race, class, ethnicity, or nationality only. Second, culture cannot be easily measured and perhaps should not be. Each location demands different methods and types of description. An ethnographic study of help-seeking for ASD in the United States would likely focus primarily on the relationship between parents and health care providers, while the same study in Kenya would likely focus on an extended-family disease management group and how the family negotiates a plurality of coexisting medical and religious systems. Recognizing the particularities of each location leads to a third point: autism may be universal, but the contexts in which it occurs are distinctive. This claim can be illustrated with reference to children's acquisition of language and use of language in social situations.

Language delay and the ability to use language for social interaction are central features of the diagnostic criteria for ASD, and the two are inextricably related. Indeed, though language acquisition is universal, the process and speed of language acquisition varies across cultures, in large part because of differences in socialization. Samoan children, for example, learn certain forms of language much later than one would expect them to, not because they are developmentally delayed but because they are restricted from doing so (Duranti & Ochs, 1996). In Samoa, some syntactic operations are restricted to highly formalized occasions in Samoan society from which children are excluded, and so they do not learn them until adulthood. However, Samoan children learn how to use emotion-marked particles (words, prefixes, or suffixes, that index internal states, such as "oops!" or "wow!") very early in childhood—earlier than American children do—because emotion-marked particles are considered part of "baby language." This Samoan example highlights the fact that language is not a single entity. Children learn different aspects of language at different times in different societies, depending on the way a society organizes its verbal resources and exposes children to them.

Another way of approaching the relationship between language and social behavior is to study how children are both socialized through language and socialized to use language

(Ochs & Schieffelin, 1984; Ochs, 1998). Caregivers not only communicate to their children about the kinds of social behaviors that are acceptable, but they give children explicit instructions about how and when to speak in different social situations. For example, the Kaluli of Papua New Guinea do not consider babbling or any form of vocalization other than speech to be a mode of communication, and a Kaluli child who does not use words is not expected to respond to the vocal communication of others (Schieffelin, 2005). In this area of Papua New Guinea, a parent or teacher report on communicative skills in early childhood would no doubt be influenced by these perspectives.

Similarly, to return to the Samoan example, Samoan children interact with caregivers in a way that restricts direct, dyadic exchanges of meaning. Samoan society is highly stratified, with social interaction organized according to rank. A child who wants something will make the request only of someone who is of higher rank, perhaps an adult. But this adult will not respond directly to the child. Instead he will pass on the request to a third person, someone of lower rank. It is not known what impact such triadic patterns of communication might have on screening for abnormalities in social behavior using measures of social responsiveness designed in the United States, but the mere existence of such variations suggests that researchers should pay close attention to how communication can be shaped by society and culture.

In developing screening tools for autism, for example, items can be tailored to language impairment in particular languages and cultures. It is well known, for example, that English speakers with autism exhibit features such as echolalia, delayed echolalia, and monotonic speech. In addition, a commonly reported impairment is pronominal reversal; in fact, it was one of the diagnostic criteria for autism in the DSM-III. But pronominal reversal would seldom be observed in Korea, since pronouns are rarely used. In Korea one would find other abnormalities. In Korea, as one example, people on the autism spectrum commonly exhibit a particular language impairment: they generally cannot use language to distinguish social rank. The Korean language employs suffixes as honorifics that denote levels of politeness and respect and which are used in nearly every sentence a person speaks. However, a young person with autism may, for example, thank an elderly man with the equivalent of "Thanks, Dude," and thank his younger sister as if she is an elderly woman, "Thank you, Madame." In Korea, and most likely in other societies that employ grammatical forms to convey respect or mark one's place in a hierarchy, abnormalities in language and communication suggestive of an ASD can be identified in a screening instrument that includes a question about the appropriate or inappropriate use of honorifics.

Apart from screening, researchers face the problem of validating assessments in the native language of the community being studied. Unfortunately, researchers all too often use an assessment in a non-native language, such as English in India,

or a lingua franca in sub-Saharan Africa (e.g., Swahili in East Africa). There are other related issues. In communities that are ethnically and linguistically heterogeneous, what language does one use to conduct the research, and in particular, the assessments? When studying the role of culture, where does one draw the line between cultural groups? In India, for example, a single community or school system may consist of families from more than a dozen cultural and language groups. In that setting, what language should be chosen for the assessments?

Even when a translation has been validated, it is useful to do focus groups with parents and teachers prior to the beginning of the study to discuss language issues. For example, prior to beginning a prevalence study of elementary school-aged children in Korea, the first author conducted a focus group in which several mothers objected to some of the vocabulary used by the Korean child psychiatrists who translated and validated the protocols. The most objectionable word was *isanghan*, a word the Korean survey translators used to screen for odd behaviors because it means "unusual" but which parents interpreted to mean "bizarre" or "freakish." Thus, even native health care practitioners may not be able to anticipate problems with translation, since the meaning of a concept in the medical community may differ significantly from that in the general public (the classic American example being "hypertension," which Americans have long defined as excessive strain or nervousness, but which the medical community has defined as high blood pressure).

Interventions from a Global Perspective

Numerous interventions have been developed for the treatment of ASD in North America and Western Europe—behavioral/educational, medical, nutritional, and pharmacologic—although many are untested. However, there have been several reviews of the benefits of behavioral/educational interventions in children with ASD, and the results are encouraging (NRC, 2001; Dawson & Osterling, 1997; Evans et al., 2003; Rogers and Vismara, 1998, 2008). Although the specifics of these educational interventions vary, there is general consensus that the core components of a "successful" program include at least the following: entry into intervention as soon as an ASD diagnosis is seriously considered; active engagement of the child in intensive, daily instructional programs for a minimum of the equivalent of a full school day throughout the year; low, adequate student-to-teacher ratios; and promotion of opportunities for interaction with typically developing peers. A recent report of a randomized, controlled trial in the United States of an intervention with toddlers, the Early Start Denver Model, shows tremendous promise (Dawson, 2010). Nonetheless, some interventions in Western Europe, and South America, continue to focus on the treatment of maternal psychopathology, since the refrigerator mother hypothesis persists in those

areas where psychoanalytic theory still dominates child psychology and psychiatry.

In the Netherlands and in several Scandinavian countries, there is extensive government support for both children and adults with ASD, providing both groups with behavioral treatment programs, even for mildly autistic individuals. In the Netherlands, the government provides a residence ("Work Home") for adults who are unable to live independently. Multidisciplinary teams located in the Regional Institutions for Outpatient Mental Health Care (RIAGG) provide diagnostic and treatment services, including in-home training, daycare programs, placement in special educational centers, and residential placement. However, despite these services, the waiting lists for assessment by the RIAGGs are long, and educational programs are lacking. Moreover, as in many countries, autism services in the Netherlands are technically available under the Dutch disability laws only for people with a diagnosis of autistic disorder and not the other PDDs (van Engeland, 2005). In Sweden, the government has focused largely on the establishment of treatment homes, in the tradition of Rudolph Steiner's concept of curative education (or Heilpedagogie) (Rydelius, 2005), some of them arranged into villages. A similar model has been adopted by organizations in other countries, such as the Camphill communities in the United Kingdom, Ireland, Scotland, the United States, and Canada.

However, while progress has been made in increasing the number and availability of treatments for ASD throughout the world, a search of the English language literature (Pub Med, 2000 to the present) yielded little information on interventions for neurodevelopmental disorders (including autism) in low-income countries. Three articles discussed behavioral modification, early intervention, and medication for children with autism in India (Daley, 2002, 2003; Kalra, 2005; Karande, 2006). Kalra (2005), in an evaluation of behavior modification and early intervention, found improvement in core symptoms of autism in some children. Karande (2006) recommended the use of psychotropic drugs and counseling for parents and teachers in the treatment of autism in India. Daley (2002) emphasized that the responsibility for interventions lies primarily with the parents since there are few special education services for autism and few psychologists and speech/language pathologists available for treating autism.

Because information on interventions for autism in non-Western countries is scarce, we can use other neurodevelopmental disorders as a model for how a successful intervention plan can be implemented. Olusanya (2007) described a program in Nigeria to detect hearing loss in infants. A pilot program for neonatal screening for hearing loss was developed with financial support from a local nongovernmental organization (NGO). In the first year, more than 3,000 children were screened and fitted with hearing aids at no cost to the parents. This public-private partnership for screening and intervention was noted as a model for other low and middle-income countries. While not focusing on autism per se, in

South Africa there was an audit of referrals from primary care facilities (mostly managed by nurses) for a range of mental health services, many of which were for intellectual disability and scholastic problems in children under 19 years old. Following the audit, a recommendation was made that a professional "counselor" be responsible for providing psychological assessment and intervention services at the primary care level (Petersen, 2004). One would imagine that these "counselors" would be the first professionals to identify and diagnose children with autism as well as other developmental disabilities.

There are few estimates of the prevalence of autism in China, although one recent study in Hong Kong suggests a comparatively low rate of 16.1 per 10,000 among children less than 15 years old (Wong & Hui, 2008). Given the Chinese government's March 2009 census, showing 251,660,000 persons ages 0–14 (approximately 19% of the total population), even such a low rate would mean there are at least 402,656 children in that age group with autism in China (National Population and Family Planning Commission, 2009). Unfortunately, although the Ministry of Education in China has recently become concerned about services for children with disabilities overall, there are not enough programs and trained personnel to provide for children with disabilities, including autism.

There are few child psychiatrists in China, and these practice in the largest cities. Common diagnoses for Chinese children with autism include intellectual disability, hyperactive syndrome, childhood schizophrenia, and sporadic encephalitis (Tao & Yang, 2005). There is, nonetheless, a Chinese classification of mental disorders adopted from the ICD-9 but which uses the term "childhood autism" instead of autistic disorder.

Autism services in China, when available, include a mix of traditional treatments (i.e., herbs and acupuncture, which are increasingly popular as treatments for autism in China, although there are no studies of their effectiveness) and more contemporary treatments (i.e., sensory integration and Applied Behavioral Analysis/ABA) (Clark & Zhou, 2005). Part of the reason for the paucity of services for autism lies in the fact that it was not until the 1980s that special education of any type began in China, and when services are available, most of the resources have been put into services for children with physical disabilities. There is one exemplary private program, the "Stars and Rain" Education Institute for Children with Autism in Beijing. It is reported to have served nearly 500 children (ages 3–6) across China since 1993. The program uses an ABA approach to treatment along with a parent training model. However, at a cost of approximately \$36 per week, it is not feasible for most Chinese families. There are also limited programs in psychiatric facilities and no public school programs designed specifically for children with autism. There may, however, be some children who receive special services because they have an accompanying intellectual disability in addition to autism.

Future Growth in Global Research

Greater global awareness of both the characteristic features and prevalence of ASD has led to a range of new research activities on ASD supported by public institutions in both the United States (i.e., the Centers for Disease Control and Prevention [CDC], the National Institute of Mental Health [NIMH], and the National Institute for Child Health and Development [NICHD]) and in other countries (i.e., the National Institute of Mental Health and Neurosciences in India [NIMHANS], the National Institute for Health and Medical Research [INSERM] in France, and the National Health Research Institutes [NHRI] in Taiwan). Biological and genetic research on autism is expanding in Europe. In France, for example, the Paris Autism Research International Sibpair genome study has been analyzing samples from Italy, Sweden, France, Norway, the United States, Austria, and Belgium (Phillipe et al., 1999).

As reported prevalence estimates increased, funding increased. Between 1997 and 2008, when government funding for most medical research was unchanged, annual funding for autism studies at the National Institutes of Health increased from \$22 million to \$118 million (<http://www.iacc.hhs.gov/portfolio-analysis/2008/index.shtml>). Progress has also been made through new laws: the Combating Autism Act (signed into law by President Bush in February 2007) was designed to support autism research, and the French Chossy Act (December 1996) reclassified autism as a handicap rather than solely a psychiatric illness and thus ensured disability rights for autistic individuals.

Even more noticeable than these forms of public participation, philanthropists and the families of autistic individuals have founded private foundations to support basic scientific research on ASD and improve the availability and quality of services. Donors are contributing millions of dollars to parent advocacy organizations, private schools, and foundations in the United States (e.g., for example, the Autism Science Foundation, Autism Speaks, and the Simons Foundation) and in the United Kingdom (e.g., the National Autistic Society or NAS). The NAS, founded in 1962, has grown considerably over the past decade to include more than 17,000 members. It has launched a telephone helpline that, according to their website, took 38,000 telephone calls in 2007. As a result, even scientists who never before had an interest in autism, but worked in a related area such as neuroscience or genetics, are joining an increasingly long parade of autism researchers who are able to secure funding through these private foundations. Between 2003 and 2004 the number of grant applications to the National Alliance for Autism Research, then the leading private foundation for autism research (before its merger with Autism Speaks), doubled. In 2009 alone, the Simons Foundation and Autism Speaks awarded \$51,526,058 and \$23,416,615 respectively for autism research projects (<http://iacc.hhs.gov/events/2010/102210/materials.shtml>). Much of

the force behind the growth of research and advocacy has come from funding through the telecommunications or entertainment field: for example, Bob Wright, former president and CEO of NBC Universal, founder of Autism Speaks; the Fondation France Télécom in France, which supports Autisme France; and Carlos Slim, the magnate who controls the Mexican telecommunications company Telefónos de México.

Conclusions

This chapter described a significant number of obstacles to conducting international research on ASD but also highlighted opportunities for advancing knowledge about how autism varies across different settings. Even a preliminary cross-cultural exploration of the epidemiology of autism and the role that culture plays in diagnosis and treatment shows that ASD exists throughout the world, even in societies that have no name for it. The study of the cultural variations in ASD is therefore not so much a matter of whether ASD exists, but rather the *contexts* in which it takes shape. The increased funding for research by private and public institutions constitutes just one important step to meet the challenges of epidemiological research on autism across cultures. This chapter also argued that ASD should be conceptualized as a cultural phenomenon and as a disability—not just as a phenomenon of Western civilization, and not just a disease. Understanding how culture influences the recognition and definition of autism spectrum disorders will facilitate cross-cultural adaptations of screening and diagnostic tools, and generate knowledge that can one day be translated into a better understanding of its etiology and improved treatments, services, education, and community integration of people on the autism spectrum.

Challenges and Future Directions

- Provide support to low and middle-income countries for community education and awareness.
- Develop more efficient and affordable diagnostic assessments that are reliable and valid in multiple languages and societies.
- In addition to ascertaining prevalence, epidemiological studies should develop low cost, appropriate services for children identified through screening, surveillance, and research efforts.
- In order to develop culturally appropriate services, including educational programs, future epidemiological studies should study the impact of autism on the child as well as his/her family.

SUGGESTED READINGS

- Daley, T. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry*, 39(4), 531–550.
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, 65(6): 591–598.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. New York: Basic Books.

- Ochs, E., Kremer-Sadlik, T., Gainer Sirota, K., & Solomon, O. (2004). Autism and the social world: An anthropological perspective. *Discourse Studies*, 6(2), 147–183.
- Trostle, J. A. (2005). *Epidemiology and culture*. Cambridge: Cambridge University Press.

APPENDIX

Table 7-2.
Appendix: Selected epidemiological studies

Europe					
Gillian Baird, F. R.C. Paed Guy's and St Thomas' Hospital London, UK Tony Charman, PhD Behavioural & Brain Sciences Unit Institute of Child Health University College London, UK	The South Thames Special Needs and Autism Project (SNAP)	UK (South Thames)	Birth cohort study of the prevalence of ASD from 12 districts in the South Thames area.	56,946 children (18 month birth cohort July 1990–Dec 1991) screened at age 9 years; in-depth assessment age 9 to 14 years.	ASD subgroup(s): All ASD subgroups Diagnostic criteria: ICD-10 Source of cases: ongoing assessments
Jean Golding, PhD Institute of Child Health University of Bristol, St Michael's Hill, BS2 8BJ Bristol, UK	Avon Longitudinal Study of Parents and Children (ALSPAC)	UK (Avon)	Prospective cohort starting in pregnancy to identify the environmental and genetic antecedents of the autistic spectrum disorders, and of the traits that make up the autistic spectrum.	Children born in 1991–1992	ASD subgroup(s): All ASDs Diagnostic criteria: ICD-10 Source of cases: Service provider records for ascertainment of ASD; traits identified from maternal completion of sets of questions completed at different ages
Eric Fombonne, MD, FRCPsych(UK) McGill University and Montreal Children's Hospital Montreal, Quebec	Staffordshire Surveys	UK (Staffordshire)	Successive prevalence studies of PDDs among preschoolers, to examine temporal trends and changes in risk factors overtime.	160 case children identified from children born from 1992 to 1998	ASD subgroup(s): All ASD subgroups Diagnostic criteria: DSM-IV, ICD-10 Source(s) of cases: repeated screening of the general population
Camilla Stoltenberg, MD, PhD, Norwegian Institute of Public Health (NIPH), Oslo, Norway Nydalen, 0403 Oslo, Norway	The ASD Healthcare and Registry Project	Norway	Pilot study to monitor the prevalence of ASD in Norway, and possibly providing the foundations for a permanent national ASD registry.	Children born in Norway 1999 or later who have been given an ASD diagnosis in the Norwegian health care system	ASD subgroup(s): All ASD subgroups Diagnostic criteria: All ICD-10; F84.0–F84.9 will be included. Expected sample size: 1000–2000 cases.

(Continued)

Table 7-2. (Contd.)

(2004). spective. mbridge	Christopher Gillberg, MD, PhD Gothenburg University Gothenburg, Sweden	Bergen Child Study: the Autism Spectrum Study	Norway (Bergen)	Cross-sectional study to determine prevalence rates of ASD, test the ASSQ as a screening device for ASD, assess ASD risk factors using screening devices and neuropsychological/ neuroimaging.	Case children identified from 7- to 9-year olds in 2003 in Bergen, Norway.	ASD subgroup(s): All ASD subgroups Diagnostic criteria: DSM-IV (plus Gillberg criteria for Asperger's syndrome) Source of cases: general population screen- and clinic-referred cases
ASD	W. Ian Lipkin, MD Center for Infection and Immunity Mailman School of Public Health Columbia University New York, NY 10032	Gene- Environment Interactions in an Autism Birth Cohort (ABC)	Norway	Nested case-control study focused on the role of gene- environment interactions in the etiology of ASD. The ABC study builds on the Norwegian Mother and Child Cohort Study (MoBa).	Children born in 1999 through May 2008 and screened at 36 months for ASD.	ASD subgroups: All ASD subgroups Diagnostic criteria: DSM-IV Source of cases; Screening of the MoBa cohort of children at 36 months; referrals (parents or provider- based); search of health registries
DS-10 18	Christopher Gillberg, MD, PhD Gothenburg University Gothenburg, Sweden	Göteborg Prevalence studies of Autism Spectrum Disorders.	Sweden (Göteborg)	Cross-sectional prevalence study of ASD.	Case children identified from clinic and population screening of 7- to 9-year-olds in Goteborg, Sweden.	ASD subgroup(s): All ASD subgroups included Diagnostic criteria: DSM-IV criteria (plus Gillberg criteria for Asperger's syndrome) Source of cases: general population screen- and clinic-referred cases
ASDs DS-10 dis for traits cal	Paul Lichtenstein, PhD Department of Medical Epidemiology, Karolinska Institute, Stockholm, Sweden	Child and Adolescent Twin Study in Sweden (CATSS)	Sweden	Cohort study of liveborn twins to examine genetic and environmental influences for ASD and comorbid conditions (e.g., ADHD).	All twins (n = 24,000) born in Sweden during 1994–2001. (Expected number of twin pairs with ASD = 800.)	ASD Subgroup(s): All ASD subgroups Diagnostic criteria: DSM-IV (plus Gillberg criteria for Asperger's syndrome). Source of cases: general population screening with A-TAC and clinical testing
ASD DSM-IV, the ASD 4.9 will	Christopher Gillberg, MD, PhD Gothenburg University Gothenburg, Sweden	Faroe Islands ASD Genetic Epidemiology Study	Faroe Islands, Denmark	Cross-sectional prevalence study to estimate the prevalence of ASD and examine the genetic and environmental (mercury) risk factors for ASD in a genetically homogeneous population.	All children in the Faroe Islands, aged 7–15 years (n = 44 ASD cases).	ASD subgroup(s): All ASD subgroups included Diagnostic criteria: DSM-IV criteria (plus Gillberg criteria for Asperger's syndrome) Source of cases: school-based screening and clinic-referred cases

(Continued)

continued)

Table 7-2. (Contd.)

Paul Thorsen, MD, PhD, Institute of Public Health, NANEA at Department of Epidemiology, University of Aarhus Aarhus, Denmark	Danish national case-control study on infantile autism	Denmark	Case-control study to examine the association between genetic factors and the development of infantile autism, and to develop the methodological expertise for studying genetic markers for autism.	473 case children born in Denmark from 01/01/1990 to 12/31/1999 and diagnosed before age 10 years.	ASD subgroup(s): Infantile autism diagnosed before age 10 years Diagnostic criteria: ICD-8 and ICD-10 Source(s) of cases: Danish Psychiatric Central Registry and Danish National Patient Registry
Marko Kielinen, PhD and Marja-Leena Mattila, MD Department of Paediatrics Clinic of Child Psychiatry University of Oulu Oulu, Finland	Autism in Northern Finland	Finland (Oulu and Lapland)	Retrospective cohort study to estimate the prevalence of autism in Oulu and Lapland, and to examine secular changes in incidence.	152,732 children born between 1979–1994 and age 3–18 in 1996–1997 (time period for case ascertainment)	ADS subgroup(s): Autistic disorder and Asperger's disorder Diagnostic criteria: DSM-IV, ICD-10 (Gillberg & Szatmari, et al. criteria) Sources of Cases: Hospital records and the records of the central institutions of the intellectually disabled
Marko Kielinen, PhD and Marja-Leena Mattila, MD Department of Paediatrics Clinic of Child Psychiatry University of Oulu Oulu, Finland	An Epidemiological and Diagnostic Study of Asperger's disorder	Finland (Oulu and Lapland)	Retrospective cohort study to evaluate the diagnostic process and prevalence rates of Asperger's disorder.	5484 children born in year 1992 and screened in 2000–2001; 125 screened positive and 110 examined; 19 Asperger case children and 13 children with autistic disorder	ADS subgroup(s): Autistic disorder and Asperger's disorder Diagnostic criteria: DSM-IV, ICD-10 (Gillberg and Szatmari et al. criteria) Sources of Cases: Population screening followed by semistructured observation and testing
Evald Sæmundsen, PhD State Diagnostic and Counseling Center Kopavogur, Iceland	Prevalence of autism spectrum disorders in Iceland in children born in 1994–1998.	Iceland	Cross-sectional survey to examine the prevalence of ASD in Iceland and to identify risk factors associated with ASD.	Children born 1994–1998 identified through medical and other service system records through January 2008	ASD subgroup(s): All ASD subgroups listed in the ICD-10 Diagnostic Criteria: ICD-10 Source of cases: Service records of the referral center for autism and other developmental disabilities
Manuel Posada, PhD, MD, Research Institute for Rare Diseases, Health Institute Carlos III 28029, Madrid, Spain,	Spanish Autistic Spectrum Disorders Register (TEAR in Spanish and SASDR in English)	Spain (four regions)	Population-based registry and a nested case-control study to study the feasibility and costs of a population screening program using the M-CHAT and analyze risk factors for incident cases.	Children 18–36 months of age in 2006	ASD subgroup(s): All ASD subgroups Diagnostic Criteria: DSM-IV-TR Source of cases: population-based screening in the following venues: Public Health Care System-Well Child Care visits (WCC) and Compulsory Vaccination Program Parent's organizations, ASD settlements and educational and social services

(Continued)

Table 7-2. (Contd.)

	Astrid Moura Vicente, PhD Instituto Nacional de Saúde Av. Padre Cruz 1649-016 Lisboa, Portugal	Epidemiology of Autism in Portugal	Portugal	Cross-sectional study to estimate the prevalence of autism and to describe its clinical characterization and associated medical conditions.	Children born in 1990, 1991, and 1992, living in mainland Portugal or the Azores and attending elementary school in the school year of 1999/2000	ASD subgroup(s): Autistic disorder Diagnostic criteria: DSM-IV Source(s) of cases: School-based screening followed by clinical assessment
The Americas						
	Eric Fombonne, MD, FRCPsych(UK)	Prevalence of Pervasive Developmental Disorders in Montreal, Quebec	Canada (Quebec)	Retrospective cohort study to evaluate time trends in relation to use of thimerosal- containing vaccines and MMR.	180 case children identified from children born between 1997 and 1998 and ascertained in 2003	ASD subgroup(s): All ASDs Diagnostic criteria: DSM-IV Sources of Cases: special educational registers
	CDC: Diana Schendel, PhD National Center on Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention Atlanta, GA 30333 California: Lisa Croen, PhD Colorado: Lisa Miller, MD, MSPH Maryland: Craig Newschaffer, PhD North Carolina: Julie Daniels, PhD Pennsylvania: Jennifer Pinto-Martin, PhD, MPH,	The CADDRE Study: Child Development and Autism	USA (6 sites: California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania)	Population-based case-cohort study to investigate risk factors for ASD and phenotypic subgroups of ASD.	Children born from September 2003 through August 2005; Eligible children must be 30–60 months of age during data collection. Expected sample size is 650 children with ASD across 6 sites.	ASD subgroup(s): All ASDs subgroups Diagnostic criteria: DSM IV Source of cases: intensive screening and case finding in clinics and special programs for young children with developmental delays
	Catherine Rice, PhD National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention 1600 Clifton Road, MS-E-86 Atlanta, GA 30333	Autism and Developmental Disabilities Monitoring Network (ADDM)	USA (Alabama, Arizona, Colorado, Florida, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, South Carolina, Wisconsin)	Ongoing population- based surveillance of ASD in 8-year-old children in 11 sites in the United States to determine prevalence and trends.	Children who are 8 years old (selected states) beginning in 2000 and monitored biannually	ASD subgroups included: All ASDs Diagnostic criteria: Systematic review of service provider records—education (selected sites) and medical— by expert clinicians using DSM-IV criteria Sources of case: school, medical, and other service provider records
	Lisa Croen, PhD Kaiser Permanente Northern California Division of Research Oakland, CA 94612	Childhood Autism Perinatal Study (CHAPS)	USA (Northern California)	Case-control study to investigate prenatal and perinatal risk factors for autism spectrum disorders.	Children born 1995– 1999 in a Kaiser Permanente hospital in northern CA	ASD subgroup(s): All ASD subgroups Diagnostic criteria: DSM-IV Source of cases: Kaiser Permanente electronic medical records

(Continued)

(Continued)

Table 7-2. (Contd.)

Lisa Croen, PhD Kaiser Permanente Northern California Division of Research Oakland, CA 94612	Early Autism Risks Longitudinal Investigations (EARLI)	USA (multisite study—Northern California, Pennsylvania, and Maryland)	Prospective, longitudinal, cohort study to identify early autism risk factors and biomarkers based on an enriched-risk pregnancy cohort.	Women who have at least one ASD- affected child who have a subsequent pregnancy. Women will be followed through their pregnancies and the infants will be followed through age 3.	ASD subgroup(s): All ASD subgroups Diagnostic criteria: DSM-IV Source of cases (proband child) clinical care providers, service providers, educational system, self-referrals.
Lisa Croen, PhD Kaiser Permanente Northern California Division of Research Oakland, CA 94612	Early Markers for Autism Study (EMA)	USA (Northern California)	Case-control study to identify early (prenatal and neonatal) biomarkers for autism spectrum disorders.	Children born July 2000–Sept. 2001	ASD: All ASD subgroups Diagnostic criteria: DSM-IV Source of cases: Regional Center of Orange County (review of service provider records)
Michaeline Bresnahan, PhD Columbia University School of Public Health New York City	Aruba Autism Project	Aruba	Retrospective birth cohort study to examine prevalence and cumulative incidence of ASD in Aruba.	All children born in Aruba in 1990–1999 and followed through 2003.	ASD subgroup(s) included: Autistic Disorder, PDD-NOS, Asperger, Rett, disintegrative Diagnostic Criteria: DSM-IV Source of Cases: clinical/medical records
Cecilia Montiel-Nava, PhD School of Education La Universidad del Zulia. Maracaibo, Estado Zulia, Venezuela	Epidemiological Findings of Autism Spectrum Disorders in Maracaibo County	Venezuela (Maracaibo County)	Cross-sectional survey to estimate the prevalence of autism spectrum disorders (ASD) among children between 3 and 7 years of age in Maracaibo County.	Children aged 3 to 7 years, and children born in the 2003 (5 years old).	ASD subgroup(s): All ASDs Diagnostic criteria: DSM-IV criteria Source of cases: School-based screening and clinic-referred cases
Cristiane Silvestre de Paula Pervasive Developmental Disorders Program; Mackenzie Presbyterian University, Brazil São Paulo, Brazil.	Prevalence of pervasive developmental disorders in southeast Brazil: A pilot study	Brazil (Atibaia)	Cross-sectional survey to estimate the prevalence of pervasive developmental disorders in southeast Brazil.	7- to 12-year-old children	ASD subgroup(s): All ASDs combined Diagnostic Criteria: DSM IV criteria Source of cases: population based screening study
Middle East, Africa, Asia, and Australia					
Shlomo (Sol) Eaglstein, PhD Department of Research, Planning and Training State of Israel Ministry of Social Affairs Jerusalem 93,420 Israel.	The Israeli Ministry of Social Affairs (MOSA) Autism Registry.	Israel (Jerusalem)	Population-based registry to estimate the prevalence of autism/ASD in Israel, by means of detecting the number and age of people diagnosed who apply for services and to track placement (home, special education, assisted living, etc.).	Expected sample size 4,000 case children (12/07)	ASD subgroup(s) included: Autism, Asperger's syndrome, and PDD-NOS. Diagnostic criteria: DSM-IV Source of cases: children applying for services.

(Continued)

Table 7-2. (Contd.)

I-IV d service	Hideo Honda, M.D. Ph.D. Yokohama Rehabilitation Centre Yokohama, Japan	Cumulative incidence and prevalence of childhood autism in children in Japan Japan (Yokohama)	Japan (Yokohama City)	Cumulative incidence study of "childhood autism." Attempt to replicate earlier epidemiological study using identical methods in a large population with screening beginning at 18 months.	Cumulative incidence up to age 5 years was calculated for childhood autism among a birth cohort from four successive years (1988 to 1991).	"Childhood Autism:" (ICD-10) Source of cases: Yokohama City Routine Health Checkup (18 months).
DS VI-IV range ice ded: -NOS, grative SM-IV	MKC Nair, MD, PhD Professor of Pediatrics & Director, Child Development Centre, Medical College Campus, Thiruvananthapuram, Kerala, India 695,011 Dr. Narendra K. Arora Executive Director- INCLEN	Neuro-developmental Disabilities among Children In India: An INCLEN Study	India (5 regions)	Cross-sectional study to examine the prevalence of 10 neurodevelopmental disabilities, including ASDs, in children aged 2-9 years in India and gather information on potentially modifiable risk factors.	9,000 children aged 2-9 years old will be screened with a neurodevelopmental disability screening tool. Children with autism will be determined based on a clinical examination applying agreed on study criteria for ASDs	ASD subgroup(s): All subgroups of ASD Diagnostic criteria: DSM-IV Source of cases: Community based household screening
As ASDs M-IV	The INCLEN Trust International New Delhi, India 110,049					
ASDs SM IV ending	Richard Grinker, PhD George Washington University, Washington, DC 20052 Young Shin Kim, MD, MS, MPH, PhD Yale Child Study Center New Haven, CT 06520	Study 1: The Prevalence of Autistic Spectrum Disorder (ASD) in Korean School-age Children Study 2: Prospective Examination of 6-year Cumulative Incidence of ASDs: A Total Population Study	South Korea (Ilsan)	Study 1: Birth cohort study to examine the prevalence of ASD; to establish a population-based cohort of children with ASD for future genetic and environmental studies, to investigate public attitudes about ASD; and to examine patterns of service utilization in Korean children with ASD. Study 2: Prospective birth cohort study to examine the incidence proportion of ASD in children followed from birth to age 6 years.	Study 1: 36, 592 cases screened 9/2005-8/2006, confirmative diagnoses completed 2/2006-7/2009, among children born 1995-2000. Study 2: 2001-2002 birth cohort; screened at age 6 years in 2007-2008	ASD subgroups: All ASD subtypes Diagnostic criteria DSM IV using ADOS and ADI-R Source of cases: Study; community based screening; family referrals; and disability registry

(Continued)

Continued)

Table 7-2. (Contd.)

Craig J. Newschaffer, PhD Associate Professor of Epidemiology Center for Autism and Developmental Disabilities Epidemiology Department of Epidemiology	Epidemiologic Research on Autism in China	China (Shandong Province)	Pilot study to examine methods for population-based screening to estimate prevalence estimation toward capacity-building for conducting epidemiologic research on ASD in China.	3- to 5-year-old children residing in the Weicheng district of Weifang Prefecture of Shandong Province.	ASD subgroup(s) included: ADI-defined autism. Diagnostic criteria: ADI-R.
Joe Cubells, MD, PhD Department of Human Genetics Emory University School of Medicine Atlanta, GA 30322 USA	Genetic Epidemiology of Autism in China: Phase 1	China (Wujiang County near Beijing)	Pilot study to develop, validate, and field test culturally appropriate screening methods for identifying potential ASD cases in the offspring of mothers who were enrolled prior to pregnancy in a large longitudinal cohort study assembled in 1994–1996.	Children born in 1994–1996 and assessed in late 2008–2009	ASD subgroup(s): All ASD subtypes Diagnostic criteria: DSM-IV Source of cases: Local health centers where original study participants receive their health care.
Virginia C. N. Wong, MD Division of Child Neurology, Developmental Paediatrics, and Neurorehabilitation Department of Pediatrics & Adolescent Medicine, The University of Hong Kong, Hong Kong, China	Epidemiological Study of Autism Spectrum Disorder in Hong Kong	China (Hong Kong)	Retrospective cohort study to investigate the epidemiological pattern of ASD in Chinese children.	Children aged under 15 years who had a diagnosis of ASD in 1986 to 2005	ASD subgroup(s): All cases Diagnostic Criteria: DSM-III-R or DSM-IV Source of cases: Autism Spectrum Disorder Registry for Children in Hong Kong
Li-Ching Lee, PhD, ScM Department of Epidemiology Bloomberg School of Public Health Johns Hopkins University Baltimore MD 21205	Population-based prevalence study of autism spectrum disorders in Taiwan	Taiwan	Pilot activities to support development of epidemiology and clinical capacity for a population-based prevalence study.	Children in first and second grades, aged 6–7, to be ascertained in 2009.	ASD subgroup(s): All ASD subgroups Diagnostic Criteria: DSM-IV Source of cases: Screening of children in first and second grades.
Glenys Dixon, PhD Telethon Institute for Child Health Research Centre for Child Health Research University of Western Australia Perth, Australia	The West Australian Autism Register	Western Australia (WA)	Ongoing population-based registry of ASD for WA to describe the pattern of autism diagnoses and prevalence rates of ASD in WA.	1500 case children ongoing starting in 1999	ASD subgroup(s): All ASD subtypes Diagnostic criteria: DSM-IV Source of Cases: case reporting by diagnosing clinicians and WA service system records

REFERENCES

- Autism and Developmental Disabilities Monitoring Network 2006 Principal Investigators (ADDM). (2009, December 18). Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, United States, (2006), Surveillance summaries. *Morbidity and Mortality Weekly Report*, 58(No. SS#10).
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet*, 368, 210–215.
- Bandim, J. M., Ventura, L. O., Miller, M. T., Almeida, H. C., & Santos Costa, A. E. (2002). Autism and Möbius sequence: An exploratory study of children in Northeastern Brazil. *Arquivos de Neuro-Psiquiatria*, 61(2-A), 181–185.
- Barbaresi, W., Katusic, S., Colligan, R., Weaver, A., & Jacobsen, S. (2005). The incidence of autism in Olmsted County, Minnesota, 1976–1997: Results from a population-based study. *Archives of Pediatric and Adolescent Medicine*, 159, 37–44.
- Barnevik-Olsson, M., Gillberg, C., & Fornell, E. (2008). Prevalence of autism in children born to Somali parents living in Sweden: A brief report. *Developmental Medicine and Child Neurology*, 50(8), 598–601.
- Baron-Cohen, S. (2004). *The essential difference: Male and female brains and the truth about autism*. New York: Basic Books.
- Braddock, D. L., & Parish, S. L. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of disability studies* (pp. 11–68). Thousand Oaks, CA: Sage.
- Brown, J. R., & Rogers, S. J. (2003). Cultural issues in autism. In S. Ozonoff, S. J. Rogers, & R. L. Hendren (Eds.), *Autism spectrum disorders: A research review for practitioners*. Washington, DC: American Psychiatric Publishing.
- Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organizations. *Sociology of Health and Illness*, 30(1), 76–96.
- Chang, H.-L., Juang, Y.-Y., Wang, W.-T., Huang, C.-I., Chen, C.-Y., & Hwang, Y.-S. (2003). Screening for autism spectrum disorder in adult psychiatric outpatients in a clinic in Taiwan. *General Hospital Psychiatry*, 25, 284–288.
- Chuthapipith, J., Ruangdaraganon, N., Sombuntham, T., & Roongpraiwan, R. (2007). Language development among the siblings of children with autism spectrum disorder. *Autism*, 11(2), 153–164.
- Clark, E., & Zhou, Z. (2005). Autism in China: From acupuncture to applied behavioral analysis. *Psychology in the Schools*, 42(3), 285–295.
- Cohen, D. J., & Volkmar, F. R. (1997). Conceptualizations of autism and intervention practices: international perspectives. In D. J. Cohen & F.R. Volkmar, (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 947–950). New York: Wiley.
- Connors, J. L., & Donnellan, A. M. (1995). Walk in beauty: Western perspectives on disability and Navajo family/cultural resilience. In H. McCubbin, E. Thomson., A. Thompson, & J. Fromer (Eds.), *Resiliency in ethnic minority families: Native and immigrant American families* (Vol. 1, pp. 159–182). New York: Sage.
- Croen, L. A., Najjar, D. V., Fireman, B., & Grether, J. K. (2007). Maternal and paternal age and risk of autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine*, 161(4), 334–340.
- Cuccaro, M. L., Wright, H. H., Rownd, C. V., & Abramson, R. K. (1996). Brief report: Professional perceptions of children with developmental difficulties: The influence of race and socioeconomic status. *Journal of Autism and Developmental Disorders*, 26(4), 461–469.
- Daley, T. (2002). The need for cross-cultural research on the pervasive developmental disorders. *Transcultural Psychiatry*, 39(4), 531–550.
- Daley, T. (2003). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science and Medicine*, 58, 1323–1335.
- Daley, T., & Sigman, M. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *Journal of Autism and Developmental Disorders*, 32(1), 13–23.
- Dawson, G., Ringers, S., Munson, J., Smith, M., Winter, J., Greenson, J., & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, 125(1), e17–23.
- Dawson, G., & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In M. J. Guralnick (Ed.), *The effectiveness of early intervention: Second generation research* (pp. 307–326) Baltimore: Brookes.
- Duranti, A., & Ochs, E. (1996). Use and acquisition of genitive constructions in Samoan. In D. Slobin, J. Gerhardt, A. Kyrtzis, & G. Jiasheng (Eds.), *Social interaction, social context, and language: Essays in honor of Susan Ervin-Tripp* (pp. 175–190). Mahwah, NJ: Erlbaum.
- Durkin, M. S. (2002). The epidemiology of developmental disabilities in low-income countries. *Mental Retardation and Developmental Disabilities Research Reviews*, 8, 206–211.
- Durkin, M. S., Davidson, L. L., Hasan, Z. M., Hasan, Z., Hauser, W. A., Khan, N., et al. (1992). Estimates of the prevalence of childhood seizure disorders in communities where professional resources are scarce: Results from Bangladesh, Jamaica, and Pakistan. *Pediatric and Perinatal Epidemiology*, 6, 166–180.
- Durkin, M. S., Hasan, Z. M., & Hasan, K. Z. (1998). Prevalence and correlates of mental retardation among children in Karachi, Pakistan. *American Journal of Epidemiology*, 147, 281–288.
- Durkin, M. S., Maenner, M. J., Newschaffer, C. J., Lee, L.-C., Cunniff, C. M., Daniels, J. L., et al. (2008, October 21). Advanced paternal age and the risk of autism spectrum disorders. *American Journal of Epidemiology*, 168(11), 1268–1276. Epub.
- Durkin, M. S., Maenner, MJ, Meaney, F. J., Levy, S.E., DiGuiseppe C., Nicholas, J. S., et al. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a US cross-sectional study. *PLoS One*, 5: e11551.
- Ehlers, S., Gillberg, C., & Wing, L. (1999). A screening questionnaire for Asperger's syndrome and other high-functioning autism spectrum disorders in school age children. *Journal of Autism and Developmental Disorders*, 29, 129–140.
- Eldin, A. S., Habib, D., Noufal, A., Farrag, S., Bazaid, K., Al-Sharabi, M., & Gaddour, N. (2008). Use of M-CHAT for a multinational screening of young children with autism in the Arab countries. *International Review of Psychiatry*, 20(3), 281–289.

- ESEMeD/MHEDEA (2004). Prevalence of mental disorders in Europe: Results from the European Study of the Epidemiology of Mental Disorders (ESEMeD) project. *Acta Psychiatrica Scandinavica*, 109(suppl. 420), 21–27.
- Evans, J., Harden, A., Thomas, J., & Benefield, P. (2003). *Support for pupils with emotional and behavioural difficulties (EBD) in mainstream primary school classrooms: A systematic review of the effectiveness of interventions* [online]. NFER (National Foundation for Education Research). eppi.ioe.ac.uk/EPPWebContent/reel/review.../EBD/EBD1.pdf
- Faraone, S. V., Sergeant, J., Gillberg, C., & Biederman, J. (2003). The worldwide prevalence of ADHD: Is it an American condition? *World Psychiatry*, 2(2), 104–113.
- Faris, R. E. L., & Dunham, H. W. (1939). *Mental disorders in urban areas: An ecological study of schizophrenia and other psychoses*. New York: Hafner.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*, 33(4), 365–382.
- Fombonne, E., Zakarian, R., Bennet, A., Meng, L., & McLean-Heywood, D. (2006). Pervasive developmental disorders in Montreal, Quebec, Canada: Prevalence and links with immunizations. *Pediatrics*, 118(1), 139–150.
- Fombonne, E. (2007). Epidemiology and child psychiatry. In A. Martin, F. Volkmar, M. Lewis (Eds.), *Lewis's child and adolescent psychiatry: A comprehensive textbook* (pp. 149–170). Lippincott, Williams, & Wilkins.
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, 65(6), 591–598.
- Fountain, C., King, M.D., & Bearman, P.S. (2010). Age of diagnosis for autism: individual and community factors among 10 birth cohorts. *Journal of Epidemiology and Community Health*, Epub, October 25.
- Gillberg, C., Lamberg, K., & Zeijlon, L. (2006). The autism epidemic: the registered prevalence of autism in a Swedish urban area. *Journal of Autism and Development Disorders*, 36(3), 429–435.
- Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. New York: Basic Books.
- Grinker, R.R. (2010a). "In Retrospect: The Five Lives of the Psychiatry Manual." *Nature* (November 11), 468: 168–170.
- Grinker, R.R. (2010b). "Disorder Out of Chaos." *New York Times*, February 10, A23.
- Grether, J. K., Anderson, M. C., Croen, L. A., Smith, D., Windham, G. C. (2009) Risk of autism and increasing maternal and paternal age in a large North American population. *American Journal of Epidemiology*, 170: 1118–1126.
- Gupta, A., & Ferguson, J. (1992). Beyond culture: space, identity, and the politics of difference. *Cultural Anthropology*, 7(1), 6–23.
- Holden, B., & Gitleson, J. P. (2006). A total population study of challenging behavior in the county of Hedmark, Norway: prevalence and risk markers. *Research in Developmental Disabilities*, 27(4), 456–465.
- Honda, H., Yasuo Shimizu, Miho Imai, & Yukari Nitto. (2005). Cumulative incidence of childhood autism: a total population study of better accuracy and precision. *Developmental Medicine and Child Neurology*, 47, 10–18.
- Hopper, K. (2003). Interrogating the meaning of culture in the WHO international studies of schizophrenia. In J. Jenkins (Ed.), *Schizophrenia, culture, and subjectivity: The edge of experience* (pp. 62–86). Cambridge: Cambridge University Press.
- Hopper, K., Harrison, G., Janca, A., & Sartorius, N. (Eds.). (2007). *Recovery from schizophrenia: an international perspective: A report from the WHO collaborative project, the international study of schizophrenia*. Oxford: Oxford University Press.
- Horwath, E., & Weissman, M. M. (2000). The epidemiology and cross-national presentation of obsessive-compulsive disorder. *Psychiatric Clinics of North America*, 23(3), 493–507.
- Hugo, C. J., Boshoff, D. E. L., Traut, A., Zungu-Dirwayi, N., & Stein, D. J. (2003). Community attitudes toward and knowledge of mental illness in South Africa. *Social Psychiatry and Psychiatric Epidemiology*, 38, 715–719.
- Icasiano, F., Hewson, P., Machet, P., Cooper, C., & Marshall, A. (2004). Childhood autism spectrum disorder in the Barwon region: a community based study. *Journal of Paediatrics and Child Health*, 40(12), 696–701.
- Islam, S., Durkin, M. S., & Zaman, S. (1993). Socioeconomic status and the prevalence of mental retardation in Bangladesh. *Mental Retardation*, 31, 412–417.
- Kalra, V., Seth, R., & Sapra, S. (2005). Autism: experiences in a tertiary hospital. *Indian Journal of Pediatrics*, 72(3), 227–230.
- Karande, S. (2006). Autism: a review for family physicians. *Indian Journal of Medical Sciences (Practitioner's Section)*, 60(5), 205–215.
- Kasmini, K., & Zasmani, S. (1995). Asperger's syndrome: a report of two cases from Malaysia. *Singapore Medical Journal*, 36, 641–643.
- Kendell, R. E., Cooper, J. E., Gourlay, A. J., Copeland, J. R. M., Sharpe, L., & Gurland, B. J. (1971). Diagnostic criteria of American and British psychiatrists. *Archives of General Psychiatry*, 25(2), 123–130.
- Khan, N., & Hombarume, J. (1996). Levels of autistic behavior among the mentally handicapped children in Zimbabwe. *Central African Journal of Medicine*, 42(2), 39.
- Kielenin, M., Linna, S. L., & Moilanen, I. (2000). Autism in northern Finland. *European Child and Adolescent Psychiatry*, 9(3), 162–167.
- King, M. & Bearman, P. (2010). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology*, 38, 1224–1234.
- Kleinbaum, D. G., Kupper, L. K., & Morgenstern, H. (1982). Measures of disease frequency: Incidence. *Epidemiology and research: Principles and quantitative measures* (pp. 97–115). New York: Wiley.
- Krug, D. A., Arick, J. R., & Almond, P. J. (1980). Behavior checklist for identifying severely handicapped individuals with high levels of autism behavior. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 21(3), 221–229.
- La Malfa, G., Lassi, S., Bertelli, M., Salvini, R., & Placidi, G. F. (2004). Autism and intellectual disability: a study of prevalence on a sample of the Italian population. *Journal of Intellectual Disability Research*, 48(3), 262–267.
- Lauritsen, M. B., Pedersen, C. B., & Mortensen, P. B. (2004). The incidence and prevalence of pervasive developmental disorders: a Danish population-based study. *Psychological Medicine*, 34, 1339–1346.
- Lemelson, R. (2003). Obsessive-compulsive disorder in Bali: the cultural shaping of a neuropsychiatric disorder. *Transcultural Psychiatry*, 40(3), 377–408.
- Levi, G., & Bernadbe, P. (2005). Italy. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 1221–1223). New York: Wiley.

- Levy, S., & Hyman, S. (2003). Use of complementary and alternative treatments for children with autistic spectrum disorders is increasing. *Pediatric Annals*, 32, 685–691.
- Liu, K., King, M., & Bearman, P. (2009). Social influence and the autism epidemic. *American Journal of Sociology*, 115(5), 1387–1434.
- Lord, C., Rutter, M. L., DiLavore, P. C., & Risi, S. (1999). *Autism Diagnostic Observation Schedule—WPS*. Los Angeles: Western Psychological Services.
- Lotter, V. (1978). Childhood autism in Africa. *Journal of Child Psychology and Psychiatry*, 19, 231–244.
- Lung, F., Shu, B., Chiang, T., & Lin, S. (2010). Parental concerns based general developmental screening tool and autism risk: the Taiwan national birth cohort study. *Pediatric Research*, 67(2), 226–231.
- Maenner, M. J., & Durkin, M. S. (2010). Trends in the prevalence of autism on the basis of special education data. *Pediatrics*, 126(5): 1018–1025.
- Magnusson, P., & Saemundsen, E. (2001). Prevalence of autism in Iceland. *Journal of Autism and Developmental Disorders*, 31(2), 153–163.
- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41(12), 1447–1453.
- Mandell, D. S., & Novak, M. M. (2005). The role of culture in family's treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11(2), 110–115.
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480–1486.
- Minnesota Department of Public Health. (2009). *Autism spectrum disorders among preschool children participating in the Minneapolis public schools early childhood special education programs*. St. Paul, MN. Available at www.health.state.mn.us/ommh/projects/autism/index.cfm.
- Mishler, E. G., & Scotch, N. A. (1965, April). Sociocultural factors in the epidemiology of schizophrenia: a review. *International Journal of Psychiatry*, 1, 258–305.
- Montiel-Nava, C., & Peña, J. A. (2008). Epidemiological findings of pervasive developmental disorders in a Venezuelan study. *Autism*, 12(2), 191–202.
- Morton, R., Sharma, V., Nicholson, J., Broderick, M., & Poyser, J. (2002). Disability in children from different ethnic populations. *Child: Care, Health, and Development*, 28(1), 87–93.
- National Population and Family Planning Commission of the People's Republic of China. (2009, March 9). Available at http://www.chinapop.gov.cn/wxzl/rkgk/200903/t20090309_166730.htm Accessed March 16, 2009 (In Chinese).
- National Research Council (Committee on Educational Interventions for Children with Autism). (2001). *Educating children with autism*. Washington, DC: National Academies Press.
- Newschaffer, C. J., Falb, M. D., & Gurney, J. G. (2005). National autism prevalence trends from United States special education data. *Pediatrics*, 115, 277–282.
- Ochs, E. (1998). *Culture and language development: Language acquisition and language socialization in a Samoan village*. Cambridge: Cambridge University Press.
- Ochs, E., & Schieffelin, B. (1984). Language acquisition and socialization: Three developmental stories. In R. Shweder & R. LeVine, (Eds.), *Culture theory: Mind, self, and emotion* (pp. 263–301). Cambridge: Cambridge University Press.
- Offord, D. R., Boyle, M. H., Szatmari, P., Rae-Grant, N. I., Links, P. S., Cadman, D. T., et al. (1987). Ontario Child Health Study: I. Six-month prevalence of disorder and rates of service utilization. *Archives of General Psychiatry*, 44, 832–836.
- Olivera, G., Assunção, A., Marques, C., Miguel, T. S., Coutinho, A. M., Mota-Vieira, L., & Vicente, A. M. (2007). Epidemiology of autism spectrum disorder in Portugal: prevalence, clinical characterization, and medical conditions. *Developmental Medicine and Child Neurology*, 49(10), 726–733.
- Olusanya, B. O. (2007). Promoting effective interventions for neglected health conditions in developing countries. *Disability and Rehabilitation*, 29(11–12), 973–976.
- Petersen, I. (2004). Primary level psychological services in South Africa: can a new psychological professional fill the gap? *Health, Policy, and Planning*, 19(1), 33–40.
- Philippe, A., Martinez, M., Guilloud-Bataille, M., Gillberg, C., Råstam, M., Sponheim, E., & Leboyer, M. (1999). Genome-wide scan for autism susceptibility genes. Paris Autism Research International Sibpair Study. *Human Molecular Genetics*, 8(5), 805–812.
- Polanczyk, G., de Lima, M., Horta, B., Biederman, J., & Rohde, L. (2007). The worldwide prevalence of ADHD: a systematic review and metaregression analysis. *American Journal of Psychiatry*, 16(6), 942–948.
- Powell, J. E., Edwards, A., Edwards, M., Pandit, B. S., Sungum-Paliwal, S. R., & Whitehouse, W. (2000). Changes in the incidence of childhood autism and other autism spectrum disorders in preschool children from two areas of the West Midlands, UK. *Developmental Medicine and Child Neurology*, 42, 624–628.
- Probst, P. (1998). Child health-related cognitions of parents with autistic children: A cross-national exploratory study. In U. P. Gielen and A. L. Comunian (Eds.), *The family and family therapy in international perspective* (pp. 461–483). Trieste: Lint.
- Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child and Adolescent Psychology*, 27, 167–178.
- Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child and Adolescent Psychology*, 37(1), 8–38.
- Rothman, K. J., & Greenland, S. (1998). Measures of disease frequency. In K. J. Rothman & S. Greenland (Eds.), *Modern epidemiology* (pp. 29–64). Philadelphia: Lippincott-Raven.
- Ruiz, D. S. (1982). Epidemiology of schizophrenia: some diagnostic and sociocultural considerations. *Phylon*, 43(4), 315–326.
- Rutter, M., Cox, A., Tupling, C., Berger, M., & Yule, M. (1975). Attainment and adjustment in two geographical areas: I. The prevalence of psychiatric disorder. *British Journal of Psychiatry*, 126, 493–509.
- Rutter, M., Le Couteur, A., & Lord, C. (2003). *Manual for the ADI-WPS version*. Los Angeles: Western Psychological Services.
- Rydelius, P.-A. (2005). Sweden and other Nordic nations. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 1238–1243). New York: Wiley.
- Sanua, V. D. (1984). Is infantile autism a universal phenomenon? An open question. *International Journal of Social Psychiatry*, 30(3), 163–174.
- Sartawi, A. M. (1999). Educational and behavioural characteristics of autistic children in the United Arab Emirates. *International Journal of Rehabilitation Research*, 22(1), 337–339.

- Schieffelin, B. B. (2005). *The give and take of everyday life: Language socialization of Kaluli children*. Tucson: Fenestra.
- Schopler, E., Reichler, R. J., & Brenner, B. R. (1988). *The Childhood Autism Rating Scale (CARS)*. Los Angeles: Western Psychological Services.
- Shelton, J. F., Tancredi, D. J., & Hertz-Pannier, I. (2010). Independent and dependent contributions of advanced maternal and paternal ages to autism risk. *Autism Research*, 3, 30–39.
- Shin, Y., Lee, K., Min, S., & Emde, R. N. (1999). A Korean syndrome of attachment disturbance mimicking symptoms of pervasive developmental disorder. *Infant Mental Health Journal*, 20(1), 60–76.
- Skellern, C. M., McDowell, M., & Schluter, P. (2005). Diagnosis of autism spectrum disorders in Queensland: variations in practice. *Journal of Pediatrics and Child Health*, 41, 407–412.
- Spinney, L. (2007). Therapy for autistic children causes outcry in France. *Nature*, 370, 645–646.
- Stone, W. L. (1987). Cross-disciplinary perspectives on autism. *Journal of Pediatric Psychology*, 12, 615–630.
- Tao, K., & Yang, X. (2005). China. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 1203–1206). New York: Wiley.
- Thara, R., Padmavati, R., & Srinivasan, T. N. (2004). Focus on psychiatry in India. *British Journal of Psychiatry*, 184, 366–373.
- Thorburn, M. J., Desai, P., Paul, T. J., Malcolm, L., Durkin, M., & Davidson, L. (1992). Identification of childhood disability in Jamaica: the ten question screen. *International Journal of Rehabilitation Research*, 15, 115–127.
- U.S. Department of Health and Human Services (USDHHS). (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
- van Engeland, H. (2005). The Netherlands. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 1233–1235). New York: Wiley.
- Vogel, W., & Holford, L. (1999). Child psychiatry in Johannesburg, South Africa: a descriptive account of cases presenting at two clinics in 1997. *European Child and Adolescent Psychiatry*, 8, 181–188.
- Whaley, A. L. (2001). Cultural mistrust and the clinical diagnosis of paranoid schizophrenia in African American patients. *Journal of Psychopathology and Behavioral Assessment*, 23(2), 93–100.
- Williams, K., Glasson, E. J., Wray, J., Tuck, M., Helmer, M., Bower, C. I., et al. (2005). Incidence of autism spectrum disorders in children in two Australian states. *Medical Journal of Australia*, 182(3), 108–111.
- Wong, V. C. N., & Hui, S. L. H. (2008). Epidemiological study of autism spectrum disorder in China. *Journal of Child Neurology*, 23(1), 67–72.
- World Health Organization. (2001). *International classification of functioning, disability, and health*. Geneva: WHO.
- Yeargin-Alsopp, M., & Boyle, C. (2002). Overview: the epidemiology of neurodevelopmental disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 8, 113–116.