www.medscape.com

Autism "Epidemic?": A Newsmaker Interview With Morton Ann Gernsbacher, PhD, And Craig J. Newschaffer, PhD

Laurie Barclay, MD

Jul 15, 2005

July 15, 2005 — *Editor's Note: Despite heightened media attention on the autism "epidemic," a report published in the July issue of* Current Directions in Psychological Science *offers three arguments against a true increase in autism prevalence. These include changes in diagnostic criteria for autism, with current criteria being more inclusive than when the diagnosis was first defined in the 1940s; methodological flaws in an unpublished California study widely cited as showing dramatically increased prevalence; and problems in using the U.S. Department of Education's annual "child count" data.*

To find out more about this issue and its clinical implications, Medscape's Laurie Barclay interviewed lead author Morton Ann Gernsbacher, PhD, a Vilas Research Professor, the Sir Frederic Bartlett Professor at the University of Wisconsin-Madison, and President-Elect of the American Psychological Society.

For an alternate viewpoint, Dr. Barclay also interviewed Craig J. Newschaffer, PhD, an associate professor of epidemiology at the Center for Autism and Developmental Disabilities, Johns Hopkins Bloomberg School of Public Health in Baltimore, Maryland. Dr. Newschaffer is lead author of a study using cohort curves to suggest that autism prevalence has been increasing with time, as reported in the March issue of Pediatrics.

Medscape: What is the evidence supporting an autism "epidemic?"

Dr. Gernsbacher: The evidence that is often used to support the notion of an "autism epidemic" is the changing prevalence rates across time, according to epidemiological data, and the increasing number of individuals being served; for example, the increasing number of children being served by the public schools under the Individuals with Disabilities Education Act.

Dr. Newschaffer: There is no doubt that numbers of children with an autism diagnosis or special education label has increased tremendously over the past two decades. These numbers are clearly beyond what we would have anticipated using historical estimates of autism prevalence. The real question is what proportion of this increase is attributable to a real change in the risk of autism and what proportion is attributable to changes in diagnosis/labeling tendencies.

Medscape: Why should we be cautious about this label, given changes in diagnostic criteria and in heightened awareness and recognition of this condition?

Dr. Gernsbacher: One thing that some people fail to realize is there were no standard diagnostic criteria for autism in the Diagnostic and Statistical Manual (of the American Psychiatric Association), the DSM, until 1980, and the criteria in the DSM have undergone purposeful change during the past 25 years. Therefore, any estimates of the prevalence of autism prior to 1980 would have been based on individual clinicians' or specific researchers' definitions, and would have fluctuated because of factors that continue to introduce variation into current-day estimates, such as variation in the size of the population sampled and the manner of identification. Estimates since 1980 would have been based on changing versions of the DSM criteria.

Another thing that some people fail to realize is that increases in the usage of services is not always a good metric for prevalence. There can be a myriad of reasons why more individuals are using services at one point in time than another, independent of how many individuals qualify for those services.

Dr. Newschaffer: The formal definition of the term "epidemic" is surprisingly loose. However, this term should be

reserved for situations where a higher-than-anticipated increase in case number is believed to be attributed to a shift in the real risk of the disease occurring.

For autism, unfortunately, this is difficult to determine.There are, on one hand, serious challenges to developing good quality scientific evidence supporting a hypothesis of "real risk increase" and also serious challenges to developing an evidence base supporting a "diagnostic/labeling practice change" hypothesis. It is hard to test the hypothesis of real risk because specific risk factors for autism are largely unknown. It is also difficult to develop good studies testing hypotheses related to diagnostic/labeling changes because the autism diagnosis is behaviorally based – for example, studies of diffusion of hard diagnostic technology are not relevant here.

I believe that there currently is little strong evidence supporting either hypothesis (real risk versus diagnostic bias) and that proponents of one versus another hypothesis seem to hold their view based mainly on the basis of beliefs that are fallacious – either that the increase has been so large [that] some of it has to be real, or that the heritable component of autism is so large [that] the increase over time must be due to diagnostic changes.

Medscape: What are the significant changes in diagnostic criteria for autism between 1980 and 1994?

Dr. Gernsbacher: Whereas the 1980 DSM-III entry required satisfying six mandatory criteria, the more recent 1994 DSM-IV offers 16 optional criteria, only half of which need to be met. Moreover, the severe phrasing of the 1980 mandatory criteria contrasts with the more inclusive phrasing of the 1994 optional criteria. For instance, to qualify for a diagnosis according to the 1980 criteria, an individual needed to exhibit "a pervasive lack of responsiveness to other people." In contrast, according to 1994 criteria, an individual must demonstrate only "a lack of spontaneous seeking to share.... achievements with other people" and peer relationships less sophisticated than would be predicted by the individual's developmental level. The 1980 mandatory criteria of "gross deficits in language development" and "if speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal" were replaced by the 1994 options of difficulty "sustain[ing] a conversation" or "lack of varied ...social imitative play." "Bizarre responses to various aspects of the environment" became "persistent preoccupation with parts of objects."

Furthermore, whereas the earlier 1980 (DSM-III) entry comprised only two diagnostic categories (infantile autism and childhood onset pervasive developmental disorder), the more recent 1994 (DSM-IV) entry comprises five. Three of those five categories connote what is commonly called autism: Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS), and Asperger's Disorder. Autistic Disorder requires meeting half of the 16 criteria, but Asperger's Disorder, which did not enter the DSM until 1994, involves only two thirds of that half, and PDDNOS, which entered the DSM in 1987, is defined by subthreshold symptoms. Therefore, Asperger's Disorder and PDDNOS are often considered "milder variants." These milder variants can account for nearly three fourths of current autism diagnoses, as shown by Chakrabarti and Fombonne in 2001.

Dr. Newschaffer: Formal changes in diagnostic criteria over this time period include the shift from the DSM-III criteria introduced in 1980 to the DSM-III-R criteria, introduced in 1987, and then the move to the DSM-IV in 1994. The DSM-III-R was seen as perhaps too broad an expansion of diagnostic criteria for what was referred to as "infantile autism" in the DSM-III (referred to as "autistic disorder" in DSM-III-R and beyond). The DSM-IV included a conscious effort to rein back on the DSM-III criteria but also added new categories (Asperger's syndrome, and PDDNOS) for other pervasive developmental disabilities phenotypes similar to but not meeting criteria for autistic disorder.

Medscape: What do you believe was the impetus behind making the diagnostic criteria less restrictive?

Dr. Gernsbacher: I believe the effort was to better identify individuals who truly needed services and support but were not receiving them before.

Dr. Newschaffer: The recognition that the autism phenotype was in fact broader than it was believed to be in 1980.

Medscape: What is the significance of the unpublished California study claiming to show that these new criteria did not contribute to the increased number of California cases diagnosed from the 1980s to the 1990s, and, Dr. Newschaffer, of your study in the March issue of *Pediatrics*?

Dr. Gernsbacher: A strength of the [California] study is the effort to understand the changing prevalence rates.

Dr. Newschaffer: The California study provides little reliable evidence. Our study offers weak to moderate evidence against a fairly restricted hypothesis – that there has been a major increase in the tendency to use the autism category for kids who formally would have been classified under other special education categories.

Medscape: What, if any, are the limitations of the California study and of its authors' conclusions?

Dr. Gernsbacher: A great limitation is that the study used only current-day and putatively broader diagnostic criteria to assess whether there had been any changes in diagnostic criteria from the 1980s to the 1990s. As I mentioned before, the standard diagnostic criteria changed quite dramatically from the 1980s to the 1990s, so it would have been odd if the criteria used to qualify Californians for services did not also change during that time. A better design for the California study would have been if they had used two sets of criteria: those used in the current day and those that were used previously. If they then would have applied both sets of criteria to both groups of children (those served in the 1980s and those served in the 1990s), they would have had a more authentic way of discerning whether the criteria have changed or not.

Dr. Newschaffer: Both studies [the California study and our *Pediatrics* study] illustrate how difficult it is to acquire good data to support or refute a hypothesis that diagnostic/labeling phenomenon explain the increases witnessed over recent years. The California study was retrospective in design and thus vulnerable to recall biases – mothers of children diagnosed 10 years previously needed to recall behaviors at time of diagnosis. It also suffered from poor participation rate, less than 20%, making it also very vulnerable to selection bias. Our *Pediatrics* paper presented an analysis of administrative data – always a data source [that] must be viewed cautiously when trying to learn something about real risk. Our analysis suggested that children previously classified in other special education categories were not being shifted wholesale into the autism category. However, our analysis was a group level, not an individual level, comparison and had no ability to see whether there are children who formerly would not have received a special education classification at all that are now receiving an autism classification.

Medscape: Please comment on whether or not the U.S. Department of Education's annual "child count" data can be used as supportive evidence of an autism epidemic.

Dr. Gernsbacher: Three serious drawbacks to using the U.S. Department of Education's annual "child count" data as support for a so-called "autism epidemic" are first, that the data are a count of only the children served, not of all the children who meet diagnostic criteria. If a child does not need special education services, he will not be represented in the child count. Second, the criteria for which children will receive services vary from state to state and across time. Third, and perhaps most overlooked, the child count data for autism only began to be collected after the school year 1991-92.

Many states report in their annual report to Congress that they are still revising their identification and reporting policies. For example, from 1992 to 2001, the state of Massachusetts reported the lowest percentage of children with autism of any state. Then, in 2002, Massachusetts reported a 400% increase in just one year! Why? Because that is when Massachusetts began actually counting the students with autism that were served rather than simply applying a ratio to the total population – a ratio that had been calculated way back in 1992. In their 2002 IDEA report to Congress, Massachusetts state officials warned that the increase will continue for several years as "[school] districts better understand how to submit their data at the student level" (IDEA, 2002, p. 4) and as "all districts comply completely with the new reporting methods" (IDEA, 2002, p. 4).

Dr. Newschaffer: Administrative data like this can never be a definitive source on real risk changes. However, these

data can be used to explore certain questions related to classification tendencies.

Medscape: Independent of loosened diagnostic criteria and heightened public awareness, are there any biological reasons to suspect the true incidence of autism could be increasing, and if so, what are they?

Dr. Gernsbacher: Because we do not have validated biological markers for autism, there is nothing to track for an increase other than the behaviorally based diagnostic formulations.

Dr. Newschaffer: If the true risk of a condition increases over a short time period, that implies that there have been changes in nonheritable risk factors, because shifts in genetic risk factors take generations to have perceptible impacts on risk trends. So, if real risk changes are driving all or a substantive part of the recent secular trend in [autism spectrum disorder] ASD, there must be important nonheritable determinants, also known as environmental determinants, of ASD, and these determinants must have changed drastically over time. Because we know so little about the etiologic mechanism underlying ASD, we have no solid leads as to what these determinants might be. I do think that even if there had not been the increases in reported rates of ASD, the fact that all of the genetic research on ASD has suggested very complex mechanisms, this, in itself, increases the likelihood that environmental factors are involved. Also, please remember that in this context the term "environmental" refers to anything other than genes – this, of course, includes chemicals, but also includes things like diet and stress.

Medscape: What, in your opinion, are the benefits and potential harms of the new criteria?

Dr. Gernsbacher: The benefits are identifying individuals who are in need of services and support and supplying those necessary services and support. A potential harm is if other persons – for example, parents or other members of the community – become very worried that their children are "doomed" because they have been identified or diagnosed. I believe that the earlier a parent realizes that his or her child might be developing atypically, the earlier that parent can meet the child's needs and structure the child's environment to capitalize on the child's unique strengths.

Autism intervention research is still in its early stages. We simply do not know with any scientific certainty what types of interventions, in what combinations or sequences, are useful, necessary, or even possibly contraindicated, or how to fit particular services and support to different individuals.

Dr. Newschaffer: The heightened awareness of ASDs, in part related to shifts in perception of the phenotype, is what is really driving the push for early detection. There is clear evidencesupporting the effectiveness of early, behaviorally based interventions, but there is much need for continued work in order to determine, for example, best intervention practices for different ASD subtypes. If you were to compare the depth and richness of the evidence already accumulated for ASD intervention compared to that for, say, hypertension, the contrast would be striking.

I think that experienced clinicians make very effective use of recent criteria. However, as we push for more and broader screening for ASDs, there are increasing chances that more children without ASDs will, at least, be flagged for follow-up assessments. It is imperative that resources be available to allow these screen-positive children to receive thorough diagnostic follow-up. There has been some research suggesting that children identified as potentially having ASDs (through brief parental interview tools that can be used in screening efforts) who are not confirmed as ASD cases still could potentially benefit from more intensive follow-up services. However, I think we need to monitor this very carefully as ASD screening initiatives gain ground.

Medscape: What suggestions do you have for future research in this area?

Dr. Gernsbacher: We clearly need a better understanding of how many adults with autism there are in our communities. It is possible that many of these individuals were not identified when they were younger, and it is possible that their needs are still not being met sufficiently.

Dr. Newschaffer: Part of the initial strategy in the start of the "War on Cancer" several decades ago was to put in place a national monitoring system that could accurately track trends in cancer incidence. This was accomplished with the establishment of state cancer registries and the Surveillance Epidemiology and End Results (SEER) program at [the National Cancer Institute] NCI. The data generated by these efforts have been invaluable in helping us to understand the forces behind changes in trends of various cancers (ranging from pediatric brain cancer to prostate cancer). A similar effort needs to be established for ASDs (and other developmental disorders). The CDC has begun this with its creation of the Autism and Developmental Disorders Monitoring (ADDM) network.

However, there are a number of special challenges faced by this, or other similar initiatives, focusing on ASDs. First, concerns of privacy protection have made it increasingly difficult for public health projects focusing on monitoring disease occurence in full population samples to gain ground. We in public health have to redouble our efforts explaining why these programs are crucial. Second, because of the behavioral nature of the ASD diagnosis, in addition to monitoring prevalence using standard case definitions, we need to do more: either concurrently validate disgnoses in samples of subjects through direct observation, and/or find a way to monitor diagnostic tendencies among clinical and educational practitioners. All of these efforts are nontrivial in terms of resources needed and methodological and logistical challenges to be surmounted.

Medscape: Is there anything you would like to add?

Dr. Gernsbacher: I want to stress that the conclusion to our article stated strongly the following: "Realizing that the increasing prevalence rates are most likely due to noncatastrophic mechanisms, such as purposely broader diagnostic criteria and greater public awareness, should not, however, diminish societal responsibility to support the increasing numbers of individuals being diagnosed with autism. Neither should enthusiasm for scientific inquiry into the variety and extent of human behavioral, neuroanatomical, and genotypic diversity in our population be dampened."

Disclosures: Dr. Gernsbacher has throughout her career received funding from the National Institutes of Health, the National Science Foundation, the Army Research Institute, and the Air Force Office of Sponsored Research. She is also currently an investigator on a grant titled "Wisconsin Autism and Other Developmental Disability Surveillance," sponsored by the Centers for Disease Control.

Dr. Newschaffer's Center receives support from NIH, CDC, and NAAR (National Alliance for Autism Research) and participates in the ADDM network.

Curr Dir Psychol Sci. 2005;14:55-58

Pediatrics. 2005;115:e277-e282

Reviewed by Gary D. Vogin, MD

Cite this article: Laurie Barclay. Autism "Epidemic?": A Newsmaker Interview With Morton Ann Gernsbacher, PhD, And Craig J. Newschaffer, PhD. *Medscape*. Jul 15, 2005.