Dr. Oswald's Corner

Comments on recent autism-related research reports

“Has a Doctor ever told you . . .”

A report in the Washington Post dated November 13, 2015 had the headline “Autism cases in U.S. jump to 1 in 45.” The story opened with the paragraph:

The number of autism cases in the United States appeared to jump dramatically in 2014 according to new estimates released Friday, but researchers said that changes in the format of the questionnaire likely affected the numbers.

The apparent incongruity between the headline and the end of the first sentence raises concerns about how science is too often reported; there is clearly a need to look at the data a bit more closely.

The source for the Post story is a National Health Statistics Report from the Centers for Disease Control and Prevention and the National Center for Health Statistics (Zablotsky et al., 2015). The report summarizes data from several iterations of the National Health Interview Survey (NHIS), a nationally representative household survey that is conducted with 10,000 - 11,000 households each year.

The survey details are important. In 2011 through 2013, parents were given a list of ten conditions including “Down syndrome,” “Muscular dystrophy,” and “Autism/autism spectrum disorder” and asked: “Looking at this list, has a doctor or health professional ever told you that [child’s name] had any of these conditions?” This question yielded a mean “prevalence” figure for “Autism/autism spectrum disorder” of 1.25% (1 child in 80), meaning that 1.25% of parents looked at the list and said, “Yes, a doctor or health professional has told me that my child had Autism/autism spectrum disorder.”

However, in 2014 the autism question was separated out from the list and asked as a stand-alone question, namely: “Did a doctor or health professional ever tell you that [child’s name] had autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder?” That question yielded a “prevalence” figure of 2.24% (1 child in 45), the number reported in the Post article.
The interpretation of the “dramatically increased prevalence rate” that was offered by the CDC and alluded to in the popular press, is that it is, in part, an artifact resulting from slight alterations in the survey (i.e., asking about autism as a stand-alone question rather than as one of a list of 10 disability conditions). In addition, the autism question was moved in the survey so that it came before a question about other developmental conditions (“Has a doctor or health professional ever told you that [child’s name] had any other developmental delay?”). The CDC concluded that “the significant increase in ASD prevalence and decrease in other DD prevalence seen from 2011–2013 to 2014 suggests that these changes [to the survey] did produce a measurement effect.” In other words, the “increased prevalence” is at least in part a function of changes in the survey rather than changes in the actual rate of ASD.

A further qualification is alluded to in the CDC report but not mentioned in the popular press. The same stand-alone autism question (“Did a doctor or health professional ever tell you that [child’s name] had autism, Asperger’s disorder, pervasive developmental disorder, or autism spectrum disorder?”) was asked in another recent national survey, the 2011 National Survey of Children’s Health (NSCH). However, in that survey it was followed by a second question: “Does [your child] currently have autism or autism spectrum disorder?”

In the 2011 NSCH, 2,041 parents reported that a health professional had told them that their child had autism . . . 2.1% of the sample or 1 in 48. However, of these, only 1,624 (or 1.7% of the sample) then said that the child did currently have autism, approximately 1 child in 60. Thus, these data suggest that among children whose parents report that a health professional told them that their child had autism, in some cases the diagnosis is later judged to have been incorrect, and parents will subsequently deny that the child “currently has autism.” In the 2011 NSCH sample, that was true for about one-fourth of children originally given an ASD diagnosis.

The extent to which a similar reduction would have occurred in the 2014 NHIS data if the follow-up question had been asked cannot be calculated with confidence. However, if one assumes a similar percentage of parents would indicate that the child does not currently have autism, the reported prevalence rate of 2.24% (1 in 45) would be adjusted downward to about 1.8% (or about 1 in 55).

So, one might reasonably ask, what is the correct number for the prevalence of ASD? National surveys offer samples that are roughly representative of the country as a whole; but they rely exclusively on parent report and the accuracy of parents’ reports about a child’s diagnosis is dependent not only on clinicians accurately diagnosing children, but also on parents’ understanding and memory of what clinicians actually said. The ADDM network on the other hand (the source for the most widely-cited CDC prevalence figures for ASD), employs on more comprehensive methodology but it is limited in coverage to a dozen or so geographic areas around the country, and significant prevalence differences across sites suggest that their case-finding method is also not perfect.

The ideal prevalence assessment has never been implemented, and sadly, probably never will be. An estimate of between 1% and 2% for the prevalence of ASD is consistent with the bulk of the data available and that range may be as close as one can come to the actual number.

The take-home message from the NHIS survey is that how one asks the question matters. While it is impossible to dispute the substantial increase over the past two decades
in individuals diagnosed with ASD, it is counterproductive to focus on headlines which always fail to tell the whole story.

References
