

Q&A: The Autism GI Link • July 31, 2009

A recent study published in *Pediatrics* claims that kids on the autism spectrum don't have GI problems more often than is typical. Age of Autism's Anne Dachel asked Judy to respond...here's the interview:

Age of Autism (A of A): Hearing about the recent research that shows that autistic children don't have more GI problems than typical kids seems to contradict the experience of so many parents I know personally. What has been your experience dealing with affected children?

Judy: My experience is that overwhelmingly, children with autism do have GI problems that are entrenched and severe enough to impact nutrition status, learning, growth, and development; that these are treatable; and when you treat them, these kids feel better, function better, eat better, grow better, and their nutrition status improves. Identifying and treating GI or nutrition problems can afford a child life-changing progress, whether they have autism or not. This is no surprise - children must absorb food normally to have good nutrition status - and we have known for decades that nutrition is crucial for growth, learning, and development. It doesn't make sense to suggest that there should be no screening and treatment for these problems in a child with autism. The child with autism needs to optimize this piece, for the best possible long term developmental status, just as you would do for a child with Down's syndrome, Crohn's disease, celiac, or what have you.

A of A: Dr. Nancy Snyderman on NBC's Today Show seemed adamant about the conclusions of this study. Did the findings indicate to you that all the science is settled?

Judy: It's simplistic to view this as a conclusive study. Most the doctors I work with are better critical thinkers than this and are likely to recognize that this was not a robust enough study to answer all their questions. These authors found GI problems in just about everybody, because of low specificity in the study design. Every kid has a GI problem sometime or other - we already knew that. More work to do for sure.

A of A: Do you know of research that does find gut problems in autistic children?

Judy: A report was published in 2002 in a peer-reviewed journal called *Current Gastroenterology Reports* by a team from University of Maryland. The findings published there are consistent with my experience in practice. About 40% of the children with autism in this study had four or more GI symptoms, while only 5% of their healthy siblings showed this degree of GI impairment. There is a lot of detail in this study about types of symptoms and behaviors that accompanied GI symptoms. Histologic findings - that is, actually looking at condition of gut tissue - was reported also. Anywhere from 70-90% of children with autism reviewed in this report showed changes to gut tissue away from what is normal, meaning they may have been experiencing pain, malabsorption, or inflammation on a chronic basis. This was a more robust, thorough study design that gave us more actionable data.

A of A: Medpage Today seemed to say that more research is needed. What are some of the defects in this study?

Judy: A retrospective design can be a good starting point for new research questions, so it is never a final answer or a place to close the case. But even from that forgiving standpoint, this study is not very useful. Just as the authors acknowledge, it is weakened by its retrospective design - because there is no real-time data to look at. But that isn't its biggest problem. The real problem here is that it only looked at one parameter of a typical nutrition assessment or GI work up; and, it used a potentially unreliable source for that parameter. In a nutrition assessment, there are five parameters to collect data on and review, and these can overlap with GI findings: anthropometrics (this is weight, height, body mass index, and growth trends over time), food intake assessment, clinical signs and symptoms, medical history, and biochemistry (this is lab tests). The retrospective approach used here excluded most of this information. And, whether they looked at medical records or interviewed families or both, I would not consider that terribly reliable - because in my own practice, children usually come in with nutrition and GI problems that their MD providers have missed. I am often in the position of finding GI concerns before the child's doctor does, or asking for lab tests the doctor never thought to run, and there we find an active GI or nutrition concern. So, the reality is, these problems are missed by doctors all the time. Looking to a medical record for this could be a flawed predictor of what was really going on five or six or ten years ago. This could lead to under-reporting of GI issues for kids with autism, something I have witnessed often in practice. No mention of GI symptoms in a medical record would not surprise me; in fact, if it is present in a child's record, my experience is that it usually has to be a pretty profound GI problem, because doctors tend to minimize these. They may tell families it is a behavior problem or that it is of no consequence. A final problem with the design was the controls. Since 1 in 6 kids now has some type of learning or developmental disability, seizure disorder, or neurological issue, we can expect that children in the general population will very frequently have some GI or nutrition co-morbidity. The study did not control for this.

A of A: Did it seem unusual to you that 72% of the children in the non-autistic group had GI symptoms?

Judy: Yes and no. When I trained in the 1980s, I would say this was not the norm. As an example, many parents say they've been told their child has "toddler diarrhea" - but phrases like this are dangerous - because it suggests this is normal, and it makes it okay to do nothing. It isn't normal. Toddlers who have persisting diarrhea or constipation are not absorbing their diets and nutrients normally. If this persists long enough, it impacts nutrition status, and that impacts development, growth, and learning. Like the researchers from Maryland, I see behaviors that go with these as well. The behaviors go away when the GI problems are treated. At the same time, it doesn't seem unusual that the control group here showed a high frequency of GI symptoms. The way the study defined this parameter, it was broad and weak. Both mild and severe GI symptoms could fall into that. There was no differentiating between inconsequential versus persisting GI problems. Lastly, many kids I see do not have an autism diagnosis but they also have myriad developmental problems, like speech delays, processing disorders, learning disability, seizure disorder, global developmental delay, and so on. These kids often have GI symptoms that are quite daunting. So - back to the control group. With one in six kids now affected by some type of neurological or developmental or learning problem, one can argue that this makes the general population an invalid control group. Between the control group, the retrospective design, the weakness of the parameter used - there are lots of problems with this study, and it doesn't tell us much about autism.

A of A: Regardless of the findings presented in the study, do you think it's important to continue to focus on an autism and GI problem link?

Judy: I don't think this particular study gives us much to work with as clinicians, so yes, we have to continue. Better research here could help hundreds of thousands of children. We already know how important nutrition is for children. Any child with a developmental delay should be monitored and treated to sustain strong nutrition status, an adequate diet, and a normal ability to absorb that diet without pain, inflammation, or chronic bowel problems. It's simply ethically correct to approach it this way, as well as clinically logical.