Autism and Gastrointestinal Problems (Part 1)

Science Brief 3


Study Purpose
(What questions are the researchers trying to answer?)

Since 1995, there have been many articles published on (1) gastrointestinal (GI) problems in people with Autism Spectrum Disorders (ASD), (2) what might cause GI problems, (3) and how diet might be useful in treating GI problems and possibly autism. Not all of the articles published report the same findings so there is confusion about what is really known about GI problems and ASD.

This article describes the work of a large group of scientists and experts worldwide who reviewed many scientific articles on GI and autism.

The scientists and experts met for two days and tried to answer 3 questions. (1) Do we have good research on the GI problems people with autism have? (2) What is the best way to evaluate GI problems in people with Autism? (3) Do we have good research on whether special diets and other treatments can help people with autism? Because this article covers a lot of information, we broke it up into two Science Briefs. This is Part 1: Autism and Gastrointestinal Problems.

Research Design
(What did the researchers do?)

This is a “review” article which is an important part of the research process. When a lot of articles have been published about a topic, or when articles don’t agree on the results, experts will do a “review of the literature.” Then they can figure out what we really know, why there is confusion, and what needs to be studied more. Twenty-eight (28) experts in autism and/or diagnosing and treating GI problems reviewed many scientific articles on GI problems and treatments for people with autism. The experts were medical doctors, other health care professionals,
and researchers. They were chosen because they had special training in GI problems, child
development and behavior, neurology, pain in children, child psychiatry, allergy, immunology,
genetics, and molecular/cell biology. They met for two days in Boston, Massachusetts, in
2008, to talk about what they found. They wanted to see if they could agree on what we
know about GI problems in children with autism and how to treat them.

**Results**
*(What did the researchers find?)*

I. GI problems in people with autism (Statements 1 & 2)
There are many types of GI problems, so it will help if we start with a description of the
GI system in the body. The purpose of the GI system is to get food into the body and break
it down so nutrients can be absorbed and used by the body. The GI system also gets rid
of food that is not used by the body. The GI system has many organs and each one has an
important function. See Figure 1 for a picture of all of these organs. The main organs are the (1)
mouth, oral cavity, and throat (where food comes into the body, is broken down by chewing
and saliva, and swallowed), (2) esophagus (a tube which connects the oral cavity to
the stomach), (3) stomach (where food is broken down more using chemicals), (4)
intestines or bowel (a very long tube where nutrients and water are absorbed into the
bloodstream so cells can use them) and (5) rectum and anus [where food which is not
digested (feces) is stored and then leaves the body].

The expert panel stated that the GI problems described in articles about people with autism were not different than what we
know about GI problems in people without autism. Common GI problems in people
with autism included (1) abdominal pain with or without diarrhea, (2) chronic
constipation, or (3) encopresis (leaking of stool in the underwear of children who are
already potty-trained). Other GI problems, which were not as common, included (4)
gastro esophageal reflux (GER or GERD),
(5) inflammatory disease of the intestines,
(6) abdominal bloating and flatulence (gas).
The experts agreed that if a person with autism has a possible GI problem, medical doctors should use the same procedures or tests to diagnose the problem that they would use for any patient. Most doctors usually start with a physical exam. For example, a doctor may use his hands to feel the child’s abdomen (see picture), the stomach, liver and other organs. He would check if any organs are bigger than they should be and whether there is bloating (gas) or pain. The doctor might order blood tests or check to see if there is blood in the stool. If the doctor thinks the patient might have food allergies or problems with digestion, s/he may suggest the parent give or not give certain foods and see if the symptoms get better.

If there are more serious problems, such as blood in the stool, the patient is losing weight or has a fever, pain, or other symptoms that are not getting better, the expert panel stated that it is appropriate for doctors to do more complicated tests. Some of these tests are called “invasive” because the medical procedure either breaks the skin (as in surgery) or there is contact with an organ or body part that is considered inside the body. An example of an “invasive” procedure is when a specialist puts a tube with a magnifying glass and light down a child’s throat (called an “endoscopy”) to see if there is anything unusual in the esophagus or stomach. The child is put to sleep when this procedure is done.

As a general rule, the expert panel felt invasive procedures should be used only after non-invasive procedures have been tried. They agreed that we need better guidelines for doctors so they know when to refer children with ASD for more comprehensive and invasive medical procedures for possible GI problems.

II. Do we know how many people with ASD have GI problems and do they have “special” GI problems which are related to their autism? (Statements 3, 4 & 5)

One common research question is “How many people (or what percentage) have a certain problem?” For example, how many people have autism? How many people have allergies? How many people have skin disease or cancer? This is an important type of research question (called “prevalence” or “incidence”) because it helps us to know if something is rare or very common. If GI problems in people with ASD are very common, then doctors will pay more attention to diagnosing and treating the problem. If it is rare, then doctors may miss something or want to refer to a specialist early.

The panel stated that we do not know how many people with ASD are likely to have GI problems. Different studies reported that 9%-70% of people with Autism have GI problems - this is a big difference. When scientists use good research methods, it is unusual
to have such a big difference. One reason the panel gave for the big difference is that many of the studies did not use good research methods. The expert panel said it is very important to do better research so we can answer this important question.

The expert panel also reviewed articles which suggested people with autism might have “special” GI problems, which are different from people without autism or might cause symptoms of autism. For example, some studies found inflammation in the intestines of children with ASD. These researchers “hypothesized” this might be a reason why children with ASD regress in their development. The expert panel stated we do not have enough evidence that “special” GI problems might cause ASD.

III. Recognizing GI problems in people with ASD can be complicated (Statements 6, 7 & 8)
Most patients can talk about what they are feeling and point to it on their body. They also might be able to tell the doctor how often they feel this way and when these symptoms happen during the day (for example, before or after eating). We know that people with autism might have a hard time telling a doctor about GI symptoms. This can make diagnosing GI problems in ASD hard for some doctors. The expert panel stated this may be why we do not have good research on how many people with ASD have GI problems.

The expert panel also reviewed research that found people with ASD with GI problems are more at-risk for having behavior problems. See Table 1 at the end of this Science Brief for some of these behaviors. As you can see, people with ASD may not sleep well. They may be more irritable or they may hit themselves. They may also be aggressive towards others. These behaviors may be caused by GI problems. The expert panel agreed this was important research because doctors and other professionals need education about how to recognize and diagnose GI problems in people with ASD.

The expert panel agreed several strategies would be helpful. First, a multi-disciplinary approach is critical. Doctors should work closely with psychiatrists, psychologists, gastroenterologists and nutritionists to evaluate and treat people with ASD with GI problems. Second, when a child with autism is referred for treatment of a problem behavior, doctors and other professionals should consider if stomach pain or GI problem might be causing these behaviors. For those who have had a long-history of behavior problems, a sudden change in behavior should not be a substitute for medical evaluation and treatment. Both should begin when needed. If problem behaviors are cause by GI problems, then the behaviors will decrease or go away as the GI problems are successfully treated. At the same time, behavior treatment can focus on teaching the child to identify and communicate pain or discomfort using non-verbal as well as verbal cues. The behavior plan also focus on teaching the child other ways to cope with pain and discomfort, instead of hurting themselves or others. Fourth, some medications for behavior management can have side-effects which may cause GI pain and discomfort. Doctors should always review medication side-effects.
What does this mean for my child and my family?

If your child with ASD has nausea, diarrhea, constipation, gas, or any other GI problems that do not go away, ask your doctor if other tests might be needed. If your child’s behavior problems change suddenly or s/he is more irritable or sleeping poorly, talk to your doctor about this Science Brief. Your doctor may want to read the original article. You may also want to share this Science Brief with your child’s behavior specialist.

The second half of this article is in Science Brief 4—GI and Autism Consensus Report (Part 2).

Table 1. Behaviors that may indicate abdominal pain or discomfort in individuals with ASD

<table>
<thead>
<tr>
<th>Vocal Behaviors</th>
<th>Motor Behaviors</th>
<th>Changes in overall state</th>
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<tbody>
<tr>
<td>• Clears throat, swallowing a lot, may have tics, etc.</td>
<td>• Makes faces that look like something hurts or is uncomfortable</td>
<td>• Trouble getting to sleep or staying asleep</td>
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<td>• Screaming</td>
<td>• Gritting teeth</td>
<td>• More irritable than usual—may have changes in response to touch, food, noise, etc.</td>
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<td>• Crying “for no reason at all”, sighing, whining, moaning, groaning</td>
<td>• Wincing (shrink back from pain)</td>
<td>• Oppositional: Does not listen or follow instructions which the child used to do earlier.</td>
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<td>• Repeats words the child has heard before but later. For example, Child says “does your tummy hurt?”</td>
<td>• Constant eating/drinking/swallowing</td>
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<td>• Child directly says “tummy hurts” or says “ouch”, “ow”, “hurts”, or “bad”—may point to stomach or not.</td>
<td>• Chewing on clothes like sleeves, neck of shirt etc., or eating things that aren’t food</td>
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<td>• Pressing on or rubbing abdomen with hands or may lean abdomen against or over furniture, or kitchen sink</td>
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<td></td>
<td>• Tapping finger on throat</td>
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<td></td>
<td>• Unusual body positions, like sticking their jaw out, turning head, arching back, odd arm positions, turning and twisting upper body</td>
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<td></td>
<td>• Jumps or reacts if someone touches their abdomen, flinching</td>
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<td></td>
<td>• Agitation—moving a lot, pacing, jumping up and down, hitting objects</td>
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<td></td>
<td>• Increase in repetitive behaviors without cause</td>
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<td></td>
<td>• Hitting, biting, slapping face, banging head, sudden increase in these behaviors</td>
<td></td>
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<tr>
<td></td>
<td>• Pushing, hitting, others—all of a sudden or worse than usual</td>
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Glossary

Gastrointestinal – Refers to the major organs and functions of the body responsible for getting food into the body, breaking it down and absorbing the nutrients and providing the cells with “energy,” and getting rid of waste that is left over after going through the system. GI problems can affect any part of this process.

Gastroenterologist – A medical doctor who specializes in diagnosis and treatment of GI disorders.

Pediatrician – A medical doctor who specializes in health and disease in children.

Neurologist – A medical doctor who specializes in the nervous system and diseases of the brain, spinal cord, nerves.

Registered Dietitian or Nutritionist – A person who is trained in nutrition, with a special focus on diet and physical growth and development.

Review Article – A paper in which the authors summarize a number of key studies, and often draw conclusions on a specific topic. In this study, the authors looked at multiple studies on genetics and autism.

Psychiatrist – A medical doctor trained in evaluating and treating psychiatric disorders. This includes prescribing medication.

Psychologist – A licensed professional who is trained in evaluating human behavior and development, assessing and treating behavioral and mental health disorders.

Chronic – Something that lasts a long time. May refer to a disease or medical condition.

Diarrhea – Loose, watery, stools. If chronic, can affect absorption of nutrients.

Constipation – Hard stools that are difficult to expel.

Encopresis – The voluntary or involuntary passage of stool in a child who has been toilet trained (typically over age 4), which causes the soiling of underwear.

Gastroesophageal reflux disease (GERD) – A medical condition in which stomach contents (food or liquid) goes back into the esophagus (the tube from the back of the throat to the stomach). Stomach contents are very acidic and can irritate the lining of the esophagus and cause pain, nausea and other symptoms.

Inflammatory Disease of the Intestines – Inflammation is a natural way the body reacts to infection, irritation or other injury. Symptoms of inflammation are redness, warmth, swelling and sometimes pain. Sometimes, inflammation can happen when there is no infection, irritation or injury. Inflammation of the bowel can cause abdominal pain, abnormal bowel movements, and weight loss.

Abdomen – The abdomen is the area between the bottom of the chest cavity and the pelvis. The human abdomen is where the organs responsible for digestion and absorption of food are located. Other vital organs inside the abdomen include the liver, the kidneys, the pancreas, and the spleen.
Bloating – A swelling. Abdominal bloating is when the abdomen feels full and tight. May be caused by organs which are enlarged, gas, or fluid in the abdominal cavity.

Flatulence – Refers to the mixture of gases caused by the digestive tract—usually leaves the body through the anus. Can cause abdominal bloating if the gases collect and are not released.

Invasive procedure – A medical procedure that cuts the skin or inserts instruments inside the body.

Endoscopy – Medical procedure that uses a thin scope with a light and camera at its tip to look inside the esophagus, stomach, and first part of the small intestine.

Multi-disciplinary approach – Experts from different disciplines come together to solve a problem together.

To read the original scientific journal article please use the following web address link: http://pediatrics.aappublications.org/cgi/reprint/125/Supplement_1/S1

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