

CAIRN REVIEW

of Evidence-based Diagnosis and Treatment in Autism

Canadian Autism Intervention Research Network

Volume 4, No. 1 MAY 2008

The food war: Turning mealtimes from “horrible” to “happy”

It's not unusual for kids to be picky about what they eat, but mealtimes can be especially challenging for families of children with autism spectrum disorders (ASD).

Children with ASD can be as restricted in the foods they eat as they are in the toys they play with or the games they enjoy, says Dr. Jane Summers, a psychologist and clinical supervisor with the Niagara Regional Autism Intervention Program.

“Some parents have told me that their child will eat only French fries, or macaroni and cheese. Some will refuse to eat anything unless it's pureed. Others will eat only cold foods, or foods of a particular color.”

Staying seated can also be a problem. The child may grab a piece of food and head to the TV, throwing a tantrum if forced to return to the table.

Some say a heightened sensitivity to flavors and textures among children with ASD is to blame. But this may not be the case, says Dr. Summers.

“Lack of flexibility and resistance to change are hallmarks of ASD. These kids can be really rigid, and will refuse to try new foods. They tend to have more extreme reactions to things, and can become very upset. Parents often give in to keep the peace, but they end up inadvertently reinforcing the behavior and the whole pattern repeats itself at the next mealtime.”

With time and patience, parents can start to break the cycle. Dr. Summers suggests making small changes gradually and systematically. “Start with a food the child really likes and add a new twist – if they like crackers, for instance, try spreading a little processed cheese on top. If they love applesauce, try mashing up a little banana and adding it in, increasing the amount gradually over time until it's almost all banana.”

There are tried and true strategies that work for most children. They just take longer for children with ASD.

If the problem is staying at the table, tell the child you expect everyone to sit together as a family. Start by keeping the child's portion small to make it easier for him or her to finish a meal before being allowed to leave the table.

Make snacks and meals a positive experience and build in rewards, such as the opportunity for the child to play a favorite game or watch a favorite TV program after he or she has finished eating. And don't give up.

“These are tried and true strategies that work for most children,” says Dr. Summers. “They just may take longer for children with ASD.”

Checklist for dealing with a difficult eater

- Take your child for a professional evaluation first. A child who is lactose intolerant or suffering from gastrointestinal problems may avoid certain foods because they cause discomfort. Other children could have oral motor problems that make it difficult for them to chew certain foods.
- Examine the child's learning history and behavioral patterns for clues to the problem. Some children have never learned to sit and eat a meal with their parents.
- Introduce change gradually. Try a new food that's similar to something the child already enjoys, or add a new topping to a favorite food.
- Establish a meal schedule the whole family must abide by. Tell the child you expect him to finish his meal before he gets up from the table. Reduce portions, if necessary, to make it easier for the child to finish eating.
- Be patient. Changing the eating habits of a child with ASD will require repeated efforts over a long period of time.
- Avoid restricted diets unless recommended by a doctor. A gluten- or casein-free diet may work for some kids, but for others it further restricts what they eat.
- Build in rewards and make mealtime a positive experience for both child and parent.
- Don't give up. If at first you don't succeed, try, try again.



What is epidemiology and what can it tell us about ASDs?

by Eric Fombonne, MD, FRCPsych

Epidemiology is the study of the distribution of disease (how, when and where it occurs) and of the factors that influence that distribution. Some of these factors may contribute to the disease, and we call them risk factors. Others may protect people from getting the disease (protective factors).

As an epidemiologist specializing in autism, I study both the incidence (how many new cases are occurring) and the prevalence (how many people have it at any given time) of autism spectrum disorders (ASD). This information is important for many reasons. It aids in the implementation of public health policies and helps us monitor their effectiveness. It helps us target resources to people who are most at risk. And it helps us develop interventions that may prevent the condition.

Conducting regular surveys and maintaining registries of affected individuals are key tools in gathering information about incidence and prevalence of a particular condition. We can find out how who is affected (their age, sex, etc.), where they live, and at what age they were diagnosed. Without epidemiological data, health policies and service planning cannot be guided rationally.

What does the data tell us?

Most of what we know about autism comes from surveys conducted in different studies at different points in time. A few of these studies have consistently shown increased rates of incidence. However, it is difficult for investigators to interpret trends because case definitions and diagnostic concepts change over time as our understanding of ASD grows.

Prevalence surveys suffer from the same limitations but there are a larger number of studies to draw from to evaluate the magnitude of the health problems due to autism spectrum disorders in young children. In total, over 50 prevalence studies have now been conducted in different countries since the mid-60s.

More recent studies done in the UK, Canada, and the US indicate that the prevalence of all autism spectrum disorders is at least 0.6% to 0.7%, translating into roughly 1 child affected for 150 children in our population. These results have been available for eight years but it is only now that public health authorities are measuring the impact on individuals, families, and societies of this not-so-rare condition and are developing policies to address the needs in terms of screening, early diagnosis and support services.

The prevalence of autism spectrum disorders has increased over the last 30 to 40 years but, to a large extent, this upward trend in prevalence reflects a broadening of the concept of autism, changes in diagnostic criteria, improvements in our ability to identify new cases, and better awareness and services in many countries.

Zeroing in on risk factors

Still, the possibility remains that the upward trend in prevalence that we are seeing is partly due to a higher incidence of the disorder. If this is true – that the number of individuals with ASD is increasing – it may mean that environment is also a risk factor.

There are few clues at this time as to what these environmental risk mechanisms might be, or if they are indeed accounting for some part of the increase in prevalence. This is why monitoring systems are so important. By using consistent methods to determine the number and nature of ASD

cases, we can begin to track over time the prevalence of autism in a systematic fashion.

Not only will we know whether the incidence of ASD is increasing, these monitoring systems are likely to provide very useful information about the true magnitude of this spectrum of disease in young children and about factors which must be considered when planning screening programs and intervention services, especially among young children.

Eric Fombonne holds a Canada Research Chair in Child Psychiatry at McGill University and heads the McGill University Division of Child Psychiatry at the Montreal Children's Hospital.

Public health surveillance and ASDs

Public health surveillance is the tracking and predicting of diseases and health conditions and what causes them. It involves collecting, analyzing and interpreting information from many sources – doctors and service providers, patient health records (confidentially, of course), and national surveys, for example. It looks for trends and patterns that may shed light on how and when the condition arises and where it is occurring most often.

Surveillance usually measures:

- the number of people with a disease or health condition,
- the number of newly diagnosed cases,
- whether certain interventions are effective or not,
- what resources people are using to maintain or improve their health or quality of life,
- people's knowledge and attitudes about what causes disease and how to prevent or treat it, and
- people's health behaviors, such as smoking, exercise and health diets.

Surveillance in ASD

Monitoring the rates and trends of ASD across Canada could improve the ability of community agencies, health practitioners and governments at every level to respond to the needs of individuals and families affected by ASD.

This information could be used to plan and evaluate services, policies and programs for individuals with ASD locally, regionally and nationally. It could also help identify new research questions that could be considered in a university or other setting.

There is currently limited surveillance of ASDs in Canada. Most of it is focused on establishing the number of cases of ASDs in a variety of populations (in other words, how prevalent the condition is). It tells us things like how many boys have ASD compared to girls, or the number of individuals affected by ASD in a given province. The National Epidemiologic Database for the Study of Autism in Canada produces updates on prevalence¹. A recent study using this database found that the prevalence of pervasive developmental disorders among children 1-14 years of age was 28.4 per 10,000 in Manitoba and 35.2 per 10,000 in PEI².

ASD surveillance is new around the world and may be technically challenging³. The fact that no biological marker currently exists for ASD

See Public health surveillance and ASDs, p. 4

Research shows signs of autism can be detected even at 18 months

by Jessica Brian, PhD, CPsych

For eight years now, we have been following the development of babies who have an older sibling with an autism spectrum disorder (ASD).

Our goal was to identify behaviors at 18 months that predict a diagnosis of ASD at 3 years of age. Two groups of babies were followed (baby siblings and babies with no family history of ASD), and all children received a gold standard diagnostic assessment at 3 years of age.

In this study, we used two different assessment tools to help us identify early signs of ASD in 18-month-olds: the Autism Diagnostic Observation Schedule (ADOS), and the Autism Observation Scale for Infants (AOSI).

Parents may be familiar with the ADOS because it might have been used as part of the diagnostic assessment with their older child with ASD. The ADOS can be used as early as 18 months, but can be too challenging for some toddlers with delayed language development.

The AOSI is a play-based task that was developed as part of our ongoing sibling research for use with infants between 6 and 18 months of age. The AOSI will be familiar to parents in our study. We would have asked you to sit across from an examiner, with your baby on your lap, while we showed him or her toys and played games such as peek-a-boo.

Not surprisingly, behaviors from each of the three core domains of ASD came out as important signs at 18 months. The signs include:

Social behaviors

- reduced facial expressiveness
- lack of reciprocal smiling
- inconsistent response to name

Communication behaviors

- lack of pointing
- few gestures

Other behavioral signs

- repetitive interests
- repetitive hand or finger movements
- intense examination of visual patterns, sniffing objects or other sensory-related behaviors
- extreme reactivity
- marked problems with transitions
- limited motor control

One sign occurring alone does not predict ASD, but rather a stable pattern over time consisting of several signs occurring together

These findings have provided us with some important insights into the specific behaviors that may be most concerning at 18 months. However, it is important to emphasize that none of these signs, when occurring alone, means that the child will go on to receive a diagnosis of ASD. Rather, what tends to identify children who go on to receive a diagnosis is the presence of a stable pattern over time, consisting of several signs occurring together.

In some cases, a baby will show signs at one point in time, but these may not persist and thus the child does not go on to receive a diagnosis. In

some other cases (especially in children who are high functioning and/or receive a later diagnosis of Asperger syndrome), we may see relatively few concerning signs at 18 months.

We hope these findings will help professionals identify signs of autism at an earlier stage and avoid delays in referral for diagnostic assessment.

Earlier identification may also increase opportunities for earlier intervention targeted at the child's specific needs. We have recently begun a pilot study in Halifax and Toronto (funded by *Autism Speaks*), to implement and evaluate a very early intervention program for infants who show some of the early signs described above.

These findings may help professionals identify autism earlier and avoid delays in referral for diagnosis.

In future research (funded by the *Ontario Mental Health Foundation*), we will examine a broader sample of infants who are at risk for developmental delays other than ASD to see the extent to which these signs differentiate infants with ASD from those with other developmental difficulties.

We would like to take this opportunity to thank all of the participating families for their incredible dedication to our research. None of this would be possible without you!

*Jessica Brian is Co-director of the Autism Research Unit at The Hospital for Sick Children and a Clinician-Investigator at Bloorview Kids Rehab. Findings from this study will be published this summer in the journal *Autism* under the title [Clinical assessment of autism in high-risk 18 month olds](#) authored by Brian JA, Bryson SE, Garon N, Roberts W, Smith I, Szatmari P, & Zwaigenbaum L. This project was funded by Autism Speaks and the Canadian Institutes of Health Research.*

References

- Bryson SE, Zwaigenbaum L, Brian JA, Roberts W, Szatmari P, Rombough V, McDermott C. **A prospective case series of high-risk infants who developed autism.** *Journal of Autism and Developmental Disorders* 2007; 37(1):12-24.
- Bryson SE, McDermott C, Rombough V, Brian J, Zwaigenbaum L. **The Autism Observation Scale for Infants (AOSI): Scale development and reliability data.** *Journal of Autism and Developmental Disorders* 2008; 38:731-738.
- Gotham K, Risi S, Pickles A, Lord C. **The Autism Observation Schedule: Revised Algorithms for Improved Diagnostic Validity.** *Journal of Autism and Developmental Disorders* 2007; 37:613-627.
- Lord C, Risi S, Lambrecht L, Cook EH, Jr, Leventhal BL, Dilavore PC, Pickles A, Rutter M. **The Autism Diagnostic Observation Schedule-Generic: A Standard Measure of Social and Communicative Deficits Associated with the Spectrum of Autism.** *Journal of Autism and Developmental Disorders* 2000; 30:205-223.
- Zwaigenbaum L, Bryson SE, Rogers T, Roberts W, Brian J, Szatmari P. **Behavioural manifestations of autism in the first year of life.** *International Journal of Developmental Neuroscience* 2005; 23:143-152.

Brain plasticity and the case for early intervention



Can the right experience at the right time improve functioning for kids with autism spectrum disorders (ASD)? Proponents of early intervention believe so, and researchers are beginning to discover why.

The key is something neurodevelopmental experts have known about for a long time – brain plasticity.

Brain plasticity refers to the brain's ability to develop new connections and functions as a result of new experiences. Sure, we all have a network of neurons that is set down in our brains before birth as a result of our genes. But our brains change and grow as a result of environmental factors, as well, specifically, the experiences we have as we interact with the world around us.

Brain plasticity helps us understand how new or programmed experiences can help these children change and grow.

Public health surveillance and ASDs, con't from p. 2

means that diagnosis is based on an assessment of an individual's social interaction, communication and stereotyped behaviors. Many different tools are used to make a diagnosis and many different kinds of professionals are involved in diagnosing ASD, including pediatricians, psychologists and psychiatrists.

Getting good data also poses a challenge. To get an accurate picture of ASD in Canada, it is important to have access to multiple data sources. Depending on how the information is collected, it may be difficult to compare data accurately between different regions, somewhat like comparing apples to oranges. Other concerns, including privacy concerns, also complicate the situation.

Approaches to consider

Several approaches to developing ASD surveillance in Canada could be considered. Options include:

- accessing the billing records of family doctors, pediatricians and other professionals who diagnose ASDs,
- obtaining information from health insurance databases,
- tapping into registries and databases run by towns and cities, justice departments, schools and prisons,
- studying clinical record summaries from which personal information has been removed,
- conducting regular surveys of individuals and families affected by ASDs.

Each approach would offer different pieces of the surveillance puzzle, and a combination of these options would provide a more complete picture.

1 National Epidemiologic Database for the Study of Autism in Canada: Update. Autism Spectrum Disorders Canadian-American Research Consortium. June 2005. www.autismresearch.ca

2 Ouellette-Kuntz H et al. Prevalence of Pervasive Developmental Disorders in Two Canadian Provinces. *Journal of Policy and Practice in Intellectual Disabilities* 2006; 3(3):164-72.

3 Coo H et al. Trends in Autism Prevalence: Diagnostic Substitution Revisited. *Journal of Autism Developmental Disorders* 2007.

According to Dr. Geoffrey Hall, a neuroimaging expert with McMaster University's Brain-Body Institute, a child's brain undergoes a "bloom" in the first years of life, during which there is an overproduction of nerve growth and synapse formation.

This early bloom is followed by a pruning process – a literally "use it or lose it" scenario that continues through adolescence, in which neural circuits in the brain become faster and more refined according to how much use they get.

What does this mean for kids with ASD? For one thing, it helps us understand how new experiences or programmed experiences (like early interventions) can help these children change and grow.

He points to recent experiments with typically developed adults that show changes in focal brain activity resulting from practice and expertise. As for children with ASD, "we are seeing kids who have gone through early intervention now functioning very well," says Hall. "If the way we interact with the world right now shapes our brain, then we can expect these children to continue to do well into the future."

The challenge now, says Hall, is to find out which interventions will have the most impact at any given time. "By understanding the developmental sequence by which changes in the brain occur, we can ensure that kids get the right intervention at the right time for a better outcome."

CAIRN

Canadian Autism Intervention Research Network

The CAIRN Review of Evidence-based Diagnosis and Treatment in Autism is published by the Canadian Autism Intervention Research Network for the benefit of front-line therapists, educators and other professionals working with autism. Additional copies may be ordered free of charge.

Editor: Sherry Cecil

Design and layout: Graphic Ideas

Research Coordinator: Patricia Colton

We'd like to hear from you.

Send your comments to info@cairn-site.com or write to:

The Editor

CAIRN Review, Offord Centre for Child Studies

Chedoke Site, Patterson Building

1200 Main Street West, Hamilton, ON L8N 3Z5

The Canadian Autism Intervention Research Network is a project of the Offord Centre for Child Studies, a research institute affiliated with McMaster University and McMaster Children's Hospital.

No part of this publication may be reprinted without written permission from the publisher.