

The GFCF Diet, FASD, and Adoption: Food for Thought

by Kari Fletcher

Kari Fletcher is NACAC's southern Minnesota parent support specialist through the state's Adoption Support Network. Kari and her husband, Mike, have six children: four "home-made" and two adopted from foster care who have FASD. Kari is passionate about helping others to better understand FASD, and has presented at local and national conferences.

A few years after adopting three children with FASD from Russia, Diane Black and her husband were exhausted from supervising a hyperactive and destructive son, a son with autistic traits, and a daughter who was sweet but disconnected. Three years later, after removing casein and gluten from the children's diet, Diane wrote about "the slowly unfolding miracle of watching our children develop into happy successful human beings." Seen as an effective treatment for children with atypical neurology, most notably autism, the Gluten Free and Casein Free (GFCF) diet may also help some children with FASD.

Shortly before we finalized our daughter's adoption in 2004 (we adopted her half brother a few years earlier), my husband and I learned that close relatives on her paternal side had celiac and Crohn's—diseases characterized by gastrointestinal problems. The best treatment for celiac disease: a gluten free diet.

Seven years later, my family has completely eliminated gluten (the protein in wheat, rye, and barley) from our diet, as well as the dairy protein casein. The decision to make the change and the change itself was not easy, but in our experience, it was well worth the effort. That said, adoptive families who are interested in this nutritional intervention must focus on attachment and their children's unique needs *before* making any diet changes.

Adoption-Related Food Issues

Food is a powerful ingredient in the attachment process. When a hungry baby cries, trust and attachment strengthens when a responsive and attuned caregiver quickly provides sustenance. When a hungry baby cries and his needs are chronically or even sporadically neglected by an absent or inattentive caregiver or series of caregivers, attachment and trust have little chance to develop. Weakened or broken attachments become a child's template for a life in which he cannot trust others to care for him or make sure he is adequately fed.

An elimination diet that takes away certain foods from a child with severe attachment difficulties is almost sure to fail and could even hurt the child's ability to attach to his adoptive family. Families should only work toward diet changes as they address more primary family concerns. Fortunately, positive sensory experiences can promote attachment, so parents could work with the child to make naturally appealing gluten and casein free foods like fresh salsa with fragrant cilantro, onions, and peppers.

Early neglect and trauma may cause some children to display survival behavior such as hoarding or stealing food. Until these children can learn that they will always have enough food in their adoptive home, and no longer need to steal or hoard food, an elimination diet could trigger an even stronger impulse to engage in survival behaviors.

When my family was about to implement a GFCF diet, I used a strategy we learned during our years as foster parents. I left an unlimited supply of foods the children could eat in plain sight, many in clear containers, and made a big deal about all of our choices. That first week we even made our own amazing homemade potato chips.

Adopted children who have experienced a lack of control early in life may have strong control issues about food. Do not start a GFCF intervention (and spark another control battle) if the child has unresolved food control problems. Focus on relationship and healing first, or your child may look for opportunities to thwart your efforts—perhaps by arranging clandestine Pop-Tart deals with neighborhood "suppliers" at the school playground.

Other food-related adoption issues may be tied to the role food played in the child's life. Did previous caregivers use food as a reward or punishment? Were some foods a source of comfort for the child? If your child was adopted internationally, what foods from their culture

provide a sense of comfort? To what orphanage food was the child accustomed? As with so many avenues of parenting, the adopted child's needs must be understood and respected before parents introduce a significant lifestyle change.

The Complexity of FASD

Little has been written about the way in which prenatal exposure to alcohol affects developing digestive and immune systems. The most prevalent and frustrating aspects of FASD tend to be cognitive and behavioral, so parents and professionals have focused primarily on the brain and central nervous system. There is evidence, though, that all developing body systems are vulnerable to the teratogenic effects of alcohol and anecdotal evidence suggests that some children with FASD are more susceptible to illnesses such as pneumonia and upper respiratory infections as well as chronic constipation and other digestive disorders.

Our two adopted children, now ages 13 and 9, have FASD. Like many individuals with FASD, they also have complex physical and mental health needs. One of their more frustrating co-occurring disorders is a neuropsychiatric reaction to strep infections known as PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections).

Our son had his first PANDAS episode at age six. Out of the blue, he began to display serious obsessive and compulsive behaviors but had no strep-like symptoms. Our pediatrician, who had encountered PANDAS before, had the insight to run a strep culture. It was positive.

After that, we watched for escalating behaviors and immediately tested for strep. As antibiotics cleared the infections, the behaviors gradually became more manageable, but in the spring of 2010, our son's behaviors during a period of chronic strep infections became so aggressive that school staff had to call the police to intervene. Our daughter had her first PANDAS episode soon after that and the summer of 2010 was very challenging—so challenging that I started researching nutritional interventions.

We still have much to learn about food and FASD, but it is clear that children with FASD need excellent nutrition to function at their best. Between sensory processing disorders, however, and a tendency to reject any food that fails to meet specific texture, taste, temperature, or smell requirements, children with FASD

are often picky eaters. Many will actually crave bread and milk-based foods and eat only items from those food groups.

Our son was one such child, and we worried that he would starve to death on a GFCF diet. Happily, he has not starved. It took him a few weeks to “detox,” but his sensory defensiveness has lessened considerably, and he is now eating foods he would *never* have tried before.

The GFCF Diet and FASD

Diane Black, Ph.D., mentioned at the start of this article, is chair of the European FASD Alliance and a biochemist. In a 2004 article, “Nutritional Interventions Can Help Your Child with FASD,” Dr. Black states:

Children with FASD have damaged intestines, kidneys and livers, which impairs their ability to digest food, absorb nutrients, and eliminate toxins. Gluten and milk are common culprits in intestinal irritation, leading to diarrhea or constipation, nausea and stomachaches. Both gluten and milk can lead to spacey or wild, unpredictable behavior. Gluten...as well as casein...have been implicated in the mental disturbances of autism, schizophrenia, and elderly dementia.

It is a medical fact that gluten and casein are difficult proteins to digest. Dairy is the first food group most parents drop when their children have stomach flu, precisely because it is hard to digest. Celiac disease is an abnormal immune response to gluten and people with this condition must avoid gluten entirely, but many people without the disease are also sensitive to or intolerant of gluten. Gluten intolerance may manifest itself in behavioral symptoms.

The prevailing theory is that some people have digestive systems that cannot fully break down gluten and casein. The resulting peptides leak from the intestines into the blood stream, and when they cross the blood brain barrier, they affect the brain like an opiate drug. Possible causes of the “leaky gut” condition include high sugar intake, stress, poor liver function, medications, caffeine, overeating refined foods like white bread and pastas, and antibiotics. Peptides have been found in the urine of some children with autism, lending credibility to the theory, but it is currently just that...a theory.

Research on food intolerance and behaviors, however, is not new. In the 1960s, research linked some schizophrenic symptoms to gluten intolerance—a con-

dition referred to then as “bread madness.” In 2009, a study in the *Journal of Pediatric Gastroenterology & Nutrition* found that one in five schizophrenic patients would likely benefit from a gluten-free diet. Current research into the increasing incidence of autism has also caused some physicians to consider a possible Neuro-Immune Dysfunction Syndrome (learn more at www.nids.net) and recommend that parents whose children have autistic symptoms try eliminating gluten and casein from the children’s diet.

While there is some controversy about the GFCF diet, and there is no guarantee that it will work for all children, anecdotal evidence of the diet’s benefit is considerable. My family has been on the GFCF diet for eight months now, and the results are better than I ever imagined.

Our daughter no longer needs her two digestive medicines and is much more regulated in her behavior. Exposure to gluten or casein results in a rash and heightened behavior problems. Our son’s sensory issues and his processing difficulties have diminished significantly. Neither child has developed a strep infection even though we were exposed to strep at least two times, and behavioral issues now tend to be more situational than chronic.

Parents whose adopted children have FASD and are considering a GFCF trial should remember the following:

- This diet should not be the first and will certainly not be the last intervention used, and it is *not* an FASD cure. Attachment strategies must be primary.

- Consult with a physician, nutritionist, or therapist *before* making any significant dietary adjustments.
- Put the entire family on the diet, not just the child. Food preparation is easier, and the whole family approach promotes a sense of team and togetherness.
- Strictly avoid gluten and casein for at least 3 to 6 months to see its benefits.
- Milk alternatives, like rice milk, often contain calcium and vitamin D, but supplements may be useful.
- Gluten and casein free does not mean healthy. Pre-made GFCF foods may contain added sugar and fats. Home-made options are less expensive, healthier, and more family friendly. Visit www.gfcfdiet.com and celiac disease sites to learn about the foods to avoid and options for making GFCF foods. Dr. Black also facilitates an online group about nutritional interventions for FASD at http://health.groups.yahoo.com/group/Nutrition_for_FASD/.
- Children with FASD may have other food sensitivities, so keep a food diary. Jodee Kulp, an FASD and adoption professional, discovered that her daughter is adversely affected by gluten and casein as well as chocolate, soy, MSG, eggs, corn, citrus fruits, and other foods.

Adoptive families who launch any new diet must first consider food issues related to prenatal alcohol exposure, early trauma, neglect, and multiple disruptions. The potential benefits to the child with FASD, however, make the GFCF diet worth investigating in conjunction with other treatments and therapies. ♦

Born June 1999, 12-year-old Allen is an intelligent and inquisitive youth who has a wonderful imagination. When asked recently how he envisioned the future, Allen predicted that, in 20 years, cars will run on glue, pets will have pets, and “a kid named Allen will be President.” In the present, he enjoys playing video games (typically war and racing games); riding his bike; reading adventure, mystery, and fantasy books; and playing with his LEGOs. Allen also likes to take things apart to see how they work; he aspires to become a machinist or inventor and one day create a real Iron Man suit that fights crime 24/7. Currently in 6th grade, Allen enjoys his reading class the best. Away from school, he likes to go out to McDonald’s and Chucky Cheese. His favorite pizza is sausage, pepperoni, and extra cheese. To make the most of his imagination and talents, Allen needs a family who is active and fun, can offer structure and consistent boundaries, and will facilitate contact with his older sister. His dream family includes a mom, dad, and two younger siblings, and he says he will do household chores to earn some extra money. Learn more from Amanda Dixon in Arizona: 602-930-4465; adixon@aask-az.org. ♦



Allen