

CASD CHAT E-Newsletter

Let's Talk about Gluten and Casein

Let's talk about food! It nourishes us, it sustains us, for many, it has cultural and spiritual significance, but unfortunately, for many Autistic folks and their families, it's become a source of tension, misinformation, and disagreement. And with the holidays around the corner it's a topic on many of our minds!

When we talk about food, I think it's important to be mindful of the lens through which we look at this conversation- I'm a young, cis-gender, white-presenting woman with a Cuban-American mother and an Irish-American father. In my family growing up, good food was emblematic of both love (Cuba) and wealth (Ireland), so I am biased by being raised with the mentality that restricting or limiting food is unthinkable. But as a young, white-presenting, cis-woman, I also make my own hair gel out of flax seeds so I can understand the arguments of those who want to take a naturalistic approach to caring for their own or their children's bodies. Finally, above all, in this newsletter, I'm a clinical psychologist who is responsible for respecting your viewpoint and culture while doing my utmost to make sure you have the facts you need to make the best decisions for yourselves and your children.

With all that in mind, let's dive into the information on arguably the most popular dietary program pursued by parents for their Autistic children and review the pros and cons.

Before we dive in here, I cannot emphasize enough, **ALWAYS** talk to your child's pediatrician or your primary care provider before making radical dietary changes! Food is powerful, and not having appropriate nutrients can do very real damage!

Gluten-Free/Casein Free (GFCF) Diet

This diet is one of the most popular diets trialed by families of Autistic folks. A few recent review articles summarize what we know about this diet so far

including how it theoretically works, the potential benefits, and the potential dangers.

Theoretically- how does this work?

- **Known fact:** We all have little chemicals, proteins, etc. that float around in our bodies and are supposed to connect up to specific places in our bodies to help our bodies do things. Kind of like little boats docking at piers. Once a chemical docks, it tells your body to do things. For example, a chemical or protein might dock on the adrenal glands near the kidneys to tell your body to make epinephrine (the hormone that gives you the rush of energy when you're in danger). They can also tell your body to do other things like make other proteins, release other hormones, or release more chemicals to dock other places.
- **Known fact:** Gluten and casein make little chemicals called "opioid-like peptides" when our body breaks down wheat and dairy. (Don't let the word opioid throw you off, this isn't a pain reliever like Morphine- same word, slightly different thing.)
- **Known fact:** We all have something called the "blood-brain barrier", a kind of wall that surrounds our brain, that stops most of these little chemicals (including opioid-like peptides) from getting into our brain when they're not supposed to be there.
- **Only a theory:** Autistic folks have gastrointestinal problems that allow opioid-like peptides from wheat and dairy to leave the digestive tract, enter the bloodstream, and eventually cross the blood-brain barrier. Once they're in the brain area they dock at places that they're not supposed to be. (This is called the "leaky-gut theory.")
- **Only a theory:** When the opioid-like peptides dock at places they aren't supposed to be, the body does things it isn't supposed to do, and this creates things like social skills deficits, behavioral problems, and repetitive behaviors.
- **Only a theory:** By limiting the intake of Gluten and Casein by Autistic folks, they'll be better able to engage socially, participate in things more flexibly, and be better able to regulate emotions.

So, does it actually work? (Pros)

I know it's not the most helpful answer, but really, we don't know. Three review articles have tried to round up all the research on this diet and have come to different conclusions.

- Article 1 (written in 2020) says that some studies have reported benefits from this diet (increased attention, and social engagement, for example) but all the studies done have been with small groups of people. This matters because when you have only a small group of people in a study you run a higher risk of getting results that don't apply to most other people, and a higher risk of your results just kind of being a "fluke" or coincidence.
 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7651765/>
- Article 2 (written in 2021) was the most favorable to this diet and says that overall, this diet seemed to result in improvement in difficult behaviors related to ASD without any significant safety side effects. One

thing important to note with this article is that this diet seemed to be more helpful in reducing difficult behaviors in kids with already diagnosed stomach problems or allergies, so we need to consider that they just felt better and more comfortable in their bodies on this diet, and this is what improved behavior.

- <https://academic.oup.com/nutritionreviews/article/80/5/1237/6382508>
- Article 3 (written in 2022) was the least favorable. This article basically shared that there's not enough good evidence to say one way or the other if this diet is helpful because researchers haven't been using good measurements in their studies. For example, they've relied on parents just saying whether or not they feel like their child is doing better instead of observing the child themselves before and after the diet.
- <https://link.springer.com/article/10.1007/s41252-022-00268-4>

What could go wrong? (Cons)

- The biggest risk with these kinds of elimination diets is the risk that kids won't get the nutrients they need for their growing and developing bodies. Articles 1 and 2 mentions that the biggest concern with this diet is that a calcium deficiency from cutting out dairy will impact the strength of growing kids' bones. Article 2 reported that there was no evidence suggesting that this diet would result in calcium deficiency, but Article 1 was less optimistic and reported that this could be a significant safety risk. Article 1 also points out that many Autistic people have a lot of sensory-based food aversion and there are only so many things that many Autistic kids are willing to eat. This leaves families in the bad spot of trying to decide whether to cut out some of the only things their child will eat reliably.
- This is only my opinion, but I believe that in that situation- fed is best! The first priority is making sure kids don't starve, everything else comes after. A full belly is better than "hangry".

The bottom line is that at the end of the day people have many ways they choose to prepare food for themselves and their families. The priority is making sure no one starves and that everyone has all the nutrients they need so that their bodies function properly. This is why it's so important to have a doctor or registered dietician on board and sign off on any dietary changes. We also need to keep in mind that many families who might want to try an alternative diet don't have the means to do so (one of the articles above mentions that the GFCF diet is many times more expensive than doing a non-specialized grocery run).

The holidays reflect a time of celebration, but also some challenges. We at CASD hope this article was helpful in understanding why some folks might choose or not choose to pursue a specialized diet, and that there's not necessarily only one 'right' way to feed yourself or your family. As the holidays approach we all may find ourselves around the table with folks who are choosing to eat or not eat in a way different than what we would choose for

ourselves (or for them!) We at CASD also want this article to be a reminder that decisions around food can be complex, and loaded with cultural and medical significance. We hope that, as long as everyone has access to adequate food and nutrition, this makes it a little easier to let go, shrug, and just say “pass the peas” this holiday season. (This article was developed by Ashley Muskett, Ph.D., CASD Clinical Psychologist with the assistance of Andrea Lopez, B.S., CASD research assistant)

Happy holidays!!

Profiles Celebrating Neurodiversity



We’re featuring Ivelisse Housman this month as a late celebration of a Latinx woman in honor of National Hispanic Heritage Month in October as well as to highlight this wonderful Autistic author who has a book coming out in January featuring an Autistic teen if you’re looking for a book to curl up with this winter! Housman describes herself in her own words on her website.

<https://www.ivelissehousman.com/>

“Ivelisse Housman has been writing stories her whole life.

At all seven schools she attended throughout her childhood, she was infamously “that kid who gets in trouble for reading during class, but stubbornly refuses to stop.” Raised in a Puerto Rican-American home, she’s always been fascinated by stories about standing between two worlds. She was diagnosed with autism when she was 15, which made everything before and after that make a lot more sense.

After switching majors way too many times, she remembered that writing was actually a career that people can have, and wrote her first novel while finishing her degree in graphic design. She lives in the Blue Ridge Mountains with her high school sweetheart/archnemesis and their two beloved rescue dogs.”

2022 Calendar of Events

Free Parent Support Group

Where: Virtual

When: Every Monday at 1 PM EST

Dr. Dan Shapiro, friend of CASD, will be offering a free parent support group, every Monday at 1 PM EST. To register, [click here](#).

Dr. Shapiro is offering new courses for parents of different age groups. To learn more about these courses, please visit his website:

<http://www.parentchildjourney.com/>

Dr. Shapiro also offers [parent-child excursions](#): stand-alone courses on common topics in developmental and behavioral pediatrics: ADHD, anxiety, autism, social success, sibling relationships, eating, sleeping, violence, adolescence, gender, sexuality, and more. These in-depth seminars are for parents of children with challenging temperaments or developmental differences. Each Excursion starts with a review of background concepts then dives deep into specific strategies. As with all Parent Child Journey courses, the emphasis here is on individualizing the approach for each child. Choose the topics that interest you. Real-life challenges. Real-life solutions.

ECHO Autism Diagnostic and Treatment Clinic

Join the **ECHO Autism Diagnostic and Treatment Clinic, November 4 and 18, noon-1:30 PM!**

The ECHO Autism program is a virtual telementoring program, which utilizes a hub and spoke model to connect community practitioners (“spokes”) with a multidisciplinary team of autism specialists (“hub”). The format involves 90 minutes of case presentation with feedback and group discussion, along with a structured didactic on specific content. We hold clinics twice a month over the course of a 6-month session. Free Continuing Education credits are available to several disciplines (medical, speech-language pathology, psychology, and social work).

If you’d like to register, please e-mail

Chelsea Armour: aarmour@childrensnational.org.

Participate in Research

RDoC Executive Function Research Project

Georgetown University Developmental Cognitive Neuroscience Laboratory and Children’s National Hospital are studying executive function skills like attention, memory, and learning using magnetic resonance imaging (MRI). Using MRI

technology, we expect to pinpoint the parts of the brain that are responsible for these cognitive functions and hope to determine the potential of using MRI as a tool to help clinicians personalize treatment.

We are recruiting 8-13 year olds with a clinical psychological diagnosis (of any kind), no genetic conditions, no metal in their bodies, and no neurological conditions.

If you are interested, please contact
Laura Campos:

- Phone: 301-765-5478
- Email: lcampos@cnmc.org



ASD Research Study

George Washington University and George Mason University are studying brain development in autism. As part of the study, participants play child-friendly computer games while we track their gaze and brain function. Families can earn up to \$90 for participating.



We are recruiting 5-17 year olds with an autism diagnosis.

If you are interested in participating, please contact Chelsea Armour:

- Email: aarmour@childrensnational.org
or andilab@email.gwu.edu

Unstuck & On Target Resources



A resource for **TEACHERS!**

- Free, asynchronous, online educator training
- First 600 to finish get 3.5 free CE credits!

Unstuck Elementary is a Tier 2 executive functioning curriculum

- Planning
- Transitioning
- Following directions

[Click here](#)

"One student had three meltdowns per day, and Unstuck reduced her outbursts to two a quarter."



A resource for **PARENTS!**

Free, online supports for preventing overload, compromising and staying motivated

Created by parents, educators, and experts

- 15 3-5 min videos
- 5 also in Spanish
- Tip sheets

[Click here](#)

"The videos made me feel less alone...and hopeful that there are more things I can try to help [my child]."



¡Feliz Mes de la Herencia Hispana!

Explora nuestros recursos en Español:

- Videos en Español
- Manual para padres en Español

Haga clic aquí

Unstuck Elementary es un plan de estudios de la función ejecutiva de Tier 2 para estudiantes neurodivergentes

A continuación:
Todos los videos traducidos al Español
Grabación de seminarios web en Español para implementadores

"Un estudiante tuvo tres crisis por día y Unstuck redujo sus arrebatos a dos por trimestre."



Un recurso para **PADRES**

- Apoyos gratuitos en línea para padres de niños con dificultades para manejar las emociones, concentrarse, hacer planes y más

Creado por padres, educadores y expertos.

- 5 videos de 3-5 minutos en español
- Hojas de consejos

Haga clic aquí

"Los videos me hicieron sentir menos solo... y con la esperanza de que hay más cosas que puedo intentar para ayudar [a mi hijo]."

The *Unstuck* author team has created short videos to help parents of children with executive functioning difficulties. Please click the playlists below to view the videos in both English and Spanish! **We have added new videos to address feedback from parents. Please click on our playlist to view our new 3-part video series on "troubleshooting."**

Playlist of all videos



Recursos para padres



Click here for the
video

Male: One Family's Experience

We would like to share an interview with a family of a college-bound autistic young adult and an accompanying reflection by Tawara Goode, Director of the National Center for Cultural Competence and Director of the Georgetown University Center for Excellence in Developmental Disabilities.

Featured New Resources

DC Autism Collaborative

The [DC Autism Collaborative](#) (DC-AC) has developed several resources for parents of young children and professionals (including health providers, early childhood educators, and community leaders) on topics related to autism spectrum disorder (ASD). All materials have been, or are in the processes of being, translated into both Spanish and Amharic. These resources can be downloaded as PDFs, though we encourage you to [visit the website here](#) as we plan to update these regularly.

Additional Resources

Ivymount School Resources

We want to highlight *Ivymount School Resource Guide* which provides information on a wide range of resources in the community:

www.ivymount.org/resourceguide2022

Pathfinders for Autism

Pathfinders provides a list of programs for all ages including video group for spouses/partners of adults with Asperger's; Transitioning services and Job skills; Baby and Family Navigator programs, and new this month, Autism from the Autistic Perspective and free Pediatric Occupational Therapy Screening and more! <https://pathfindersforautism.org/calendar/>

20+ free resources available to view anytime, anywhere!

Enjoy these [information-packed free webinars](#) on your own or make them a powerful group learning event with your colleagues, friends, and family members. Topics include:

- Working/learning in groups
- Face-to-face communication
- Social anxiety
- Executive functions
- Children's stress
- Self-regulation
- Individual webinars on 10 core Social Thinking Vocabulary

Hosted by Social Thinking

Supporting Mental Well-being

Yetta Myrick, Executive Director/President of DC Autism Parents (DCAP) and CDC's Act Early Ambassador to the District of Columbia has multiple resources to share with families to support mental well-being.

Yoga Tranquilo: *Para familias que hablen español*

https://drive.google.com/file/d/1uY6kdp3trF2liwON9KAf4I1GtPuY9DC_/view?usp=sharing [drive.google.com]

<https://drive.google.com/file/d/1c6hjvrnfb17gHvI90hMxCK7zQwwEeaCC/view?usp=sharing> [drive.google.com]

Rest and Restore:

https://drive.google.com/file/d/1O9VgOISEtUw5Ed0TYINfuU3kNWQb5G_K/view?usp=sharing [drive.google.com]

<https://drive.google.com/file/d/1qq7KhCRh-igwZ-DpD6JonYxydjp5kp55/view?usp=sharing> [drive.google.com]

Tips to Help Parents Keep Calm Every Day:

https://drive.google.com/file/d/1NDflt9y7HA8nrHICILWpO2_6P78DOBZI/view?usp=sharing [drive.google.com]

Additional Resources

Advocacy Resources

[Autistic Self Advocacy Network-Navigating College: A Handbook on Self Advocacy](#)

Resources on Anti-Racism

[Spectrum Support's Social Stories on Racism](#)

[ASAN's What is Police Violence?: A Plain Language Booklet](#)

[@TheMorganCruise Worksheets for Black Children](#)

COVID-19 Safety Resources

[Behavioral Directions LLC's Safety Teaching Protocol](#)

COVID-19 National and Local Government Resources

[Centers for Disease Control and Prevention](#)

[World Health Organization](#)

[DC Department of Health](#)

[Maryland Department of Health](#)

[Virginia Department of Health](#)

[U.S Department of Education's Individuals with Disabilities Education Act \(IDEA\) Part C Dispute Resolution Procedures](#)

[U.S Department of Education's Individuals with Disabilities Education Act \(IDEA\) Part B Dispute Resolution Procedures](#)

[**Visit Children's National Hospital COVID-19 Resources**](#)



**If you have feedback or suggestions, please scan the QR code and complete the survey!
Thank you!**