

Proud Aspy Mom Newsletter August 2023



We Had our LAST IEP- So What!

This month was fragile. We had our last Individual Education Plan Meeting. It was strange because truthfully our daughter is in a space where logistically the environment is supportive of her needs so the added services are hard to implement and measure. Our sole focus for the past year has been TRANSITION services. But here is the deal - there is no meaningful transition. You get the - you should consult these resources speech and by the way - your autistic person is responsible for their own education when they turn 18 and you get essentially - GOOD Luck!???

Now I mean no shade on the specific individuals who support my kiddo, because they are in fact rock stars. But the truth is they are dishing out bad news. I have been researching transition services for years and after your child becomes a legal adult it is a state-by-state battle reliant on the social service policies of the state you live in - because the STATE allocates how they plan to spend Medicaid dollars. Since my research nearly 8 years ago, there are practically no changes. In essence families like ours are directed to the Aging for Persons with Disabilities, (APD) which was created to provide social, medical, behavioral, residential and therapeutic services for individuals with developmental or invisible disabilities. But the key word is "May". There is a lot

to this application process and the waitlist in LONG!



Agency providing services for Florida Persons with Disabilities. Currently in Florida approximately 20,000 people on the waiting lists.

Learn More

What happens when all support resources end at the age of 21

Read The Story



The real issue is we do not take into account that Autistic persons like all of humanity have different skill sets. We do not know what they are until we support them.

"When the CDC estimates that 1 in 68 8-year-olds in this country have an autism spectrum diagnosis, we're talking about kids, some of them who are going to earn PhDs at Harvard, and some of them who are going to need 24/7 supports for the rest of their lives."

Sharon Lewis, Principal Deputy Administrator of the Administration for Community Living at the Department of Health and Human Services and the Senior Disability Policy Advisor to the HHS Secretary

We had our LAST IEP- so what now? The REAL work begins.

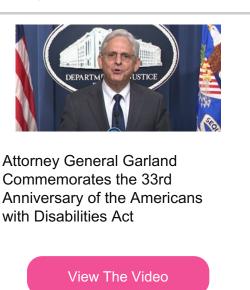
30 + Years of Service- So MUCH More to do.

The American with Disabilities Act, (ADA) was enacted over 30 years ago. The Act addressed equity in all areas. Hiring, Housing, Education and Access. The ADA improved and continues to improve the lives of those with disabilities. As a result of the hard work of so many in the Justice Department, community advocates, families and attorneys, we now have yet another tool to support families who just want to have a chance. While the ADA has much work to do to advance equity for those with invisible disabilities and behavioral needs - it remains an aspirational Act for many on what could be.

There are still so many issues to address in the disability community. Believe me, as our family progresses on this journey it is often difficult to process. What I have learned along the way is that if there is an egregious act you must report it. Even if it is too late to impact your family you may be responsible for saving someone else. So, what do you do?

I recently connected with a Civil Rights Attorney, with the U.S. Attorney's Office (USAO). It was refreshing speaking to someone who believes in the mission of protecting those who are vulnerable to patterns and practices of discriminatory actions in the federal trial courts.

"The USAO in coordination with the Department of Justice, is charged with enforcing federal civil rights laws throughout the Middle District of Florida. These laws prohibit discrimination, protect the constitutional rights of residents of this District, and ensure equal opportunity for all. The USAO's Civil Division enforces civil federal civil rights statutes, such as the...the Americans with Disabilities Act."





The U.S. Attorney's Office (USAO), in coordination with the Department of Justice, is charged with enforcing federal civil rights laws throughout the Middle District of Florida.

Read All About It

Now to be clear, these attorneys cannot address every unfortunate, deliberate or unconscionable act of malice, but they can address systemic wrongs. So again, how do your report? Just email or call! 30 + years of service and SO MUCH More to Do!

Contact

The District's main office is located in Tampa, Florida, with branch offices in Fort Myers, Jacksonville, Ocala, and Orlando.

Civil Rights Hotline: (813) 274-6095

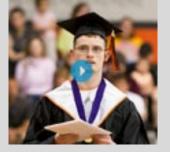
Email: USAFLM.Civil.Rights@usdoj.gov

Mailing Address: ☐ United States Attorney's Office, MDFL ☐ Attn: Civil Division ☐ 400 N. Tampa Street, Suite 3200 ☐ Tampa, Florida 33602

Say it LOUD- Autistic and Proud!

If you have the time, you should check out the story of DJ Savarese ("Deej"), a nonspeaking, unapologetic autistic person who does not hold back on his journey. His journey - which is too much to summarize - is beyond inspirational and expands your understanding of inclusivity.

"Once a 'profoundly disabled' kid, DEEJ is now a college student standing up for his peers."



Take off the Mask!

So our daughter is her authentic self and we absolutely LOVE it! I recently learned the term, "masking" which I did not know existed. Masking is the concept of accommodating others to hide who you are for their comfort. In sum it is asking someone to be less than who they are.

Autistic persons mask by either hiding their true behavior or compensating to feel included. Both actions deplete you. When you are anything leas than your authentic self you fail to thrive.





"How "unmasking" leads to freedom for autistic and other neurodivergent people"

Learn More

For those of us who want to support our friends with ASD - we should try to look at the world from a wider view. It is ok to be different.

Take off the Mask!

In case you missed it! July Newsletter

Check Our Resources Page

View Our Blog!



Visit Our Podcast!



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