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## Proud Aspy Mom Newsletter | October 2020

### My Truth



For many years I have struggled to define the challenges of caring for a child with Asperger's Syndrome. It is a sensitive subject for me and for many parents. My family, friends and colleagues often do not know how to support me and although they try, I often shut the door on their efforts because quite frankly it is hard to educate them on appropriate care. Asperger's Syndrome, Autism Spectrum Disorder ("ASD"), is a multi-faceted intellectual disability that impacts my daughter's mode of communication. My daughter is incredibly bright and extremely functional. However, the way she interacts with others is often "perceived" as odd. If you wrote a letter or text to her you would truly never know she has a disability. And thankfully, because of the efforts of many occupational therapists, speech therapists, behavioral therapists, physical therapists, aides, and caregivers, she enters several spaces a day which are not sensory friendly with more ease. While these spaces still have the disproportionate impact of giving her incredible anxiety, she has the skill set to navigate life.



My daughter has an intellectual disability or what some may call a cognitive challenge or an invisible disability. As an attorney, I appreciate the laws that protect her, but like any law there are opportunities for interpretation about implementation. Title II of the Americans with Disabilities Act protects individuals with "physical or mental impairment that substantially limits one or more major life activities", [Read More](#). The law further requires that the individual demonstrate that he or she (1) has a disability (2) has a record of disability or (3) is regarded as having a disability. The Individuals with Disabilities Act, ("IDEA") requires school systems to

identify and evaluate students with disabilities to provide them with a Free and Appropriate Education, (FAPE), [Read More](#). If a child meets the requirements of having a disability and needing services because of the disability, the school system has an obligation to provide special education and related services based on the student's identified needs. Autism falls under the IDEA, [Read More](#).



### [IDEA Disability Categories - Understood](#)

The Individuals with Disabilities Education Act (IDEA) requires public schools to provide special education and related services to eligible students. But not every child who struggles in school qualifies. To be covered, a child's school performance must be "adversely affected" by a disability in one of the 13 categories below.

[www.understood.org](http://www.understood.org)



### [Sec. 300.101 Free appropriate public education \(FAPE\) - Individuals with Disabilities Education Act](#)

Statute/Regs Main » Regulations » Part B » Subpart B » Section 300.101 300.101 Free appropriate public education (FAPE). (a) General. A free appropriate public education must be available to all children residing in the State between the ages of 3 and 21, inclusive, including children with disabilities who have been suspended or expelled from Continue Reading [sites.ed.gov](http://sites.ed.gov)

## [Nondiscrimination on the Basis of Disability in State and Local Government Services - ADA](#)

The ADA Home Page provides access to Americans with Disabilities Act (ADA) regulations for businesses and State and local governments, technical assistance materials, ADA Standards for Accessible Design, links to Federal agencies with ADA responsibilities and information, updates on new ADA requirements, streaming video, information about Department of Justice ADA settlement agreements ...

[www.ada.gov](http://www.ada.gov)

If your child has a disability that falls under IDEA, you then must determine what protection is appropriate for you. Under Section 504 of the Rehabilitation Act of 1973 a child who meets these requirements can request "reasonable accommodations" in the schools setting. Section 504 covers both physical and mental disabilities. [Read More](#) However, a 504 plan does not have the same strength as an Individual Education Program/Plan (IEP). An IEP places legal obligations on the school system. It requires the school to create a specialized plan to help your child in all educational settings. The difference is key as an IEP provides federal protections and a 504 plan focuses on discrimination. Also, an IEP has itemized disabilities and a 504 covers all disabilities. The Department of Education, Office of Civil Rights (OCR), enforces and provides guidance on these laws. [Read More](#)

### Protecting Students With Disabilities

Frequently Asked Questions About Section 504 and the Education of Children with Disabilities. Introduction | Interrelationship of IDEA and Section 504 | Protected Students | Evaluation | Placement | Procedural Safeguards | Terminology. This document is a revised version of a document originally developed by the Chicago Office of the Office for Civil Rights (OCR) in the U.S. Department of ...

[www2.ed.gov](http://www2.ed.gov)



### Section 504 and ADA: Protecting Children with Disabilities from Discrimination - Wrightslaw

Section 504 is a civil rights law that prohibits discrimination against individuals with disabilities. Section 504 ensures that the child with a disability has equal access to an education. The child may receive accommodations and modifications.

[www.wrightslaw.com](http://www.wrightslaw.com)



What is the real impact of all of this under COVID? No real protection. Since the beginning of 2020, most parents in some form have had to deal with our new normal of distance learning. Admittedly, the impact on every child, parent and educator is overwhelming. For families with special needs it can be

devastating. The many laws outlined above are challenging at best to

implement under COVID conditions. Many school districts have argued that they should not have to serve children with special needs in the same manner amid a pandemic. Educators indicate it is nearly impossible to meet the needs of children with Special Needs under the IDEA. They argue that their lack of resources and significant fatigue should excuse the requirement to serve children with Special Needs. Earlier I noted how challenging it is to explain to our family, friends, and colleagues why it is hard to care for a child on the Autism Spectrum. Prior to COVID there was already a lack of services including: Applied Behavioral Analysis, ("ABA") respite care, occupational, speech and physical therapy and most importantly, respite! Since COVID there are no words to describe the impact of lack of educational services, technological support, mental health fatigue and respite in the home. This is an equitable challenge.

Every day I start my day creating a sensory friendly environment for my daughter to learn. This means cleaning her desk space, checking every email, organizing each class by color, making a daily check list of everything she needs to do for each class, placing a kitchen timer on her desk to keep her organized. And THEN I stay next to her during her classes-if necessary, to ensure she does not have technical challenges in the zoom classroom setting. Of course, I am still working full time, hosting zoom meetings of my own, networking, completing community work and hosting live and virtual non-profit programs.

Being at home presents the additional challenge of isolation and for children with special needs, regression. My daughter is fortunate to have a team of committed artists who are vested in her growth. She has weekly virtual and occupational and speech lessons, with follow up work, she has virtual acting and singing lessons and we recently went back to ballet. The only analogy I can provide is that our life mirrors a chaotic but balanced opera. Where you know the challenges and pitfalls, yet you dutifully wait for it all to work out. This is life during COVID. For many families like mine this is life pre-COVID as well. I am grateful that I have the resources to balance and juggle the many roles I must play for our daughter. I am also extremely cognizant that many people who share my same life do not have the necessary resources that would allow them to give them respite. There is no easy answer- this I know. While our community balances equitable resources, we should continue to hold our system accountable.



## ARTISTS CHANGE LIVES

The Arts make life more colorful for everyone. My family believes in artists and their sustainability. Most importantly we care about the impact they have on our children. Since my daughter's diagnosis, there have been countless, musicians, singers, dancers and thespians in her life. I would like to personally take time to thank American Stage, the Academy Ballet of Art, Bring Music and a host of independent artists who took the time to enrich my daughter's life

through alternative communication. My daughter has a broader world view because she learned to tap into her creativity and express her thoughts without judgment.

Our community is an arts community and our children benefit from arts programs in education. As an advocate of many equity issues I realize the challenges our congressional leaders face as they attempt to balance appropriate funding for various communities. However, statistically we know the arts change lives.

This election cycle there is a referendum on the ballot to retain and recruit educators. As you consider how you will vote and what matters most to you, consider reviewing the following links on how the arts impact our future leaders. Your voice and your vote count!

### Learning from The Florida Orchestra's pros



Since 2017, The Florida Orchestra and Pinellas County Schools have teamed up for a program that places professional Teaching Artists into schools. The Teachi...

### Citizens for Pinellas Schools - Home



In 2004, Pinellas voters approved a property tax to directly enhance Pinellas County schools. Voters have renewed it every four years since. In 2019, it cost the average single family homeowner in Pinellas \$85.85 for the year or \$7.15 a month, producing approximately \$44.5 million.

### Referendum / Referendum - Pinellas County Schools

Helps recruit and retain quality teachers: Eighty percent of the Referendum revenue supplements teacher salaries. This year, each teacher receives a salary supplement of \$5,231 as part of their base salary.

[www.pcsb.org](http://www.pcsb.org)

We are blessed in our City to be a destination for the arts. If you have someone you love who is vulnerable and cannot go out into the world, please let them know that artists continue to bring the world to us.

A good friend routinely shares links with me and several others as a mental break. Little does he know how much it does for my mental space. Please receive the links below with the same spirit. They are well worth the watch! COVID teaches us that time truly matters. Enjoy!



## Creativity goes on

We have always believed deeply in the power of creativity. Now, more than ever, we

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