



**Proud Aspy Mom Newsletter**  
**January 2025**

## Oops! Did I Miss an ENTIRE Month?



## It is NOT Complicated! Persons with Disabilities have RIGHTS!

So, I know I am overly involved in this space for obvious reasons, but I am continually asked what rights do persons with disabilities receive and WHY? Well, it is simply NOT complicated. The United Nations, which consists of nation-states or in general terms countries around the world-agreed that persons with disabilities have universal rights. AND the rights are truly not different than the general population.



**Convention on the Rights of  
Persons with Disabilities**

As an advocate, both personally for my daughter and for many other families, I take that seriously. If you have ever spent any time with a family who cares for a loved one you know they are simply exhausted! That is because they spend countless hours navigating complex education and healthcare systems and advocating for their children's rights and needs to make sure they can attend school and learn and acclimate into the community at large. There are countless studies on the deficits families who support loved one's experience, but a study does not quantify, the excessive money, time, stress and overall stress associated with protecting your family and helping them navigate life.



[Families of children with disabilities experiences with being an inclusive family, navigating school, and participating in community engagement](#)

[Find Out More!](#)

According to Christina Cipriano, [an educational researcher and parent of children with disabilities], “The barriers that families of children with disabilities face are a constant reminder that the systems they operate in were not designed to include their children. Positioning families as partners in their child’s education is essential to ensuring their needs and rights are upheld.”

It is not the perfect example but here is a modest attempt. When you have children, you generally expect to support them extensively until around third grade. Then, magically you spend less time as a caregiver and more time enjoying the growth and development of your child as they navigate life through senior year. That is not always the case of course but I hope you get the gist. Conversely, if you are a family member advocating for your child, regardless of your income, ethnicity, education, or life circumstances you are thrust into the role of being everything for your child on a much larger level and for a longer period of time.

Scholar Joyce Epstein explains the significant levels of care families are required to provide to loved ones. The levels include Caregiving, Building Community, Decision Making and Leadership, Volunteering Time and Resources, Communicating and Learning at Home. I could go on and on about what families do DAILY within these categories, but that would turn this small discussion into a research paper. In sum, persons with disabilities need community buy-in. If you are a business leader, active in the community, work for a healthcare system or educational structure it will help the disability to ask Why Not, instead of Why? Communities across the world are stronger when the least of them are served.



COPAA stands for the Council of Parent Attorneys and Advocates. I have been a member for some time now and wanted to share more about the organization and why it matters. When our daughter was first diagnosed, I had NO idea what I was doing. Although many people sent love and prayers- that I took to heart- I personally needed an action plan. It was strange to think with all the many organizations dedicated to this-that-and the other- that there was not a specific place for families to learn how to care for their loved one and to simply not feel alone. COPAA did that for me. Full disclosure, I sit on the board of COPAA, but that is because a very kind man, Mark Kamleiter, (a fierce advocate and attorney) empowered me to seek knowledge with people sharing similar experiences.

There are so many ways to benefit from COPAA. For me, although I am an attorney, I stay on the board because I am a parent. When other parents reach out to me, I want to share resources, guide them in the right direction and let them know they are not alone. COPAA provides training for parents, guidance for attorneys and supports advocates. We meet annually however these resources are available all year.



Council of Parent Attorneys and Advocates

**Supporting educational  
advocacy for students  
with learning differences**

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Your copy should address 3 key questions: Who am I writing for (audience)? Why should they care (benefit)? What do I want them to do (call-to-action)?

Create a great offer by adding words like "free," "personalized," "complimentary," or "customized." A sense of urgency often helps readers take action, so consider inserting phrases like "for a limited time only" or "only 7 remaining!"

## Superman

I grew up at a time when Christopher Reeve was a pretty BIG DEAL. Superman was and still is an aspirational person who cares about the overall health of the world. When Christopher Reeve's life changed, he remained an inspiration - even amid controversy. While many did not agree with his aggressive effort to support research or his approach, I think we can agree that he changed the way we look at persons with disabilities. Politics aside-here is a look back at one of his most moving pleas.



From the archives: Christopher Reeve addresses 1996 DNC in Chicago

[Watch Video](#)

## Still Smiling

Lastly, I want to say how resilient our daughter is. Going off to college, living on her own, navigating relationships, engaging with professors, keeping up with her schedule, being present with executive functioning is quite ALOT for many of us. She is still smiling. That is what matters.



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