

Proud Aspy Mom Newsletter

July 2024

Siblings Love



Year of Jordan!

Our older daughter, Jordan "Chloë" Jackson, turned 25 this year. We simply cannot believe our energetic, outspoken, vivacious and beyond intelligent child is now a true adult! If you have ever had the opportunity to meet Chloë, you know what a force she is. However recently we had the opportunity to view her through the eyes of our daughter Emersen.

At Emersen's graduation celebration she expressed how much Chloë meant to her and the impact she had on her. I am paraphrasing now but in essence she said,



I wanted to do everything my sister did. When Chloë joined Girl Scouts, I joined Girl Scouts. When Chloë became a thespian, I became a thespian. I wanted to do **EVERYTHING** Chloë did.

And She Did

Dance

- Spelling Bees
- Swimming

- Cheerleading
- Girl Scouts

- Acting
- Away Camp





According to research, our daughters followed best practices for supporting persons on the spectrum. Turns out that children with ASD with older neurotypical siblings tend to do better. They have someone to look up to and emulate their achievements.

We are beyond proud of Chloë's accomplishments and are grateful that she set the standard for success for Emersen. Keep going Chloë, we have more mountains to climb!

Sibling Support

Just because you are a sibling of a person on the spectrum does not mean you are a natural fit to support them. There are so many factors to consider:

- What is the age difference?
- Do the siblings get along?
- Do they live in the same geographic area?
- Are there fiscal resources to support the transition?
- Is the older sibling alone or is there a broader level of support?
- Most importantly- does the sibling want to take on this life changing role?





We often do not talk about the impact of those around the person on the spectrum, but it is definitely challenging to say the least. So much of the household planning and energy, particularly during younger years is directed to the person with needs. This often leads to little room for other routine events and often puts a strain on the activities of daily living. Like many parents, those with children on the spectrum and other neurotypical children want balance. It is quite frankly hard to achieve this. A recent

Harvard Study reflects this conundrum. The article focuses on what sibling relationships with persons with intellectual developmental disabilities ("IDD") look like and why there are so many layers to these relationships.



Sibling Relationships Autistic Adults

Read All About It



Services for Sibling Support

Find Programs



Starting the Conversation: Future Planning and Siblings of People with IDD

Read Article

Never too late to plan

So even though most parents of persons with Intellectual Disabilities often feel that they are "catching" up, it is never too late to plan. If you do not know how to navigate resources, ask someone and keep asking until you find someone who will speak to you and not at you. Everyone has a different scenario but if you have to explore any of them, start with the big "4".

Social Security Disability Insurance (SSDI) - income based for most families, but assists families with persons statutorily defined with disabilities.

Supplemental Security Income (SSI) - for adults with disabilities with financial needs.

Medicaid - state based support for low-income persons with disabilities.

Medicare - provides coverage with persons with statutorily defined disabilities.

Each of these programs have eligibility requirements. You should check with an attorney and accountant to determine eligibility. If you cannot afford either consider going to your local Bar Association. These organizations generally have resources that will direct you to pro bono services.

There are also Special Needs Trusts and ABLE Accounts. I will not delve into Special Needs Trusts at this time as they are quite complex, but an ABLE account gives family members the opportunity to pour funds into an account for the benefit of the person with the disability without penalty to that person or their incoming benefits. It is never too late to plan. The hardest part of any plan is to start. Setbacks are setups for success. Never stop seeking assistance. It is out there!



Tax-free savings accounts that could be used to pay for disability-related expenses

Get More Info

Say Cheese

On a lighter note, my husband and I were going down memory lane and found a video of Emersen in her directorial debut. Her muse- Chloë. Big suprise! Enjoy





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