

Proud Aspy Mom Newsletter | 2021

Peace and Blessings



It Is Not All Reindeer Games



It's December-and we survived another year! For many it's been a challenging year. So many of us have experienced significant loss. And while that loss may not include loved ones it does include a sense of normalcy and we thought we would regain by this time.



My grandmother would say to me as a child that, "life is not all reindeer games". It was always a strange statement to me because I was quite a serious person even as a little person and I truly did not understand her

analogy BUT her statement resonates with me now. In sum she was saying that Hummanity sustains significant trauma at times.

Now I don't want to be all doom and gloom because it is 'tis the season and all BUT AGAIN I do want to be real about mental health. At this time of the year loneliness engulfs some of us. Many people who care for loved ones on the spectrum experience this tenfold during the holidays or in general when there are special occasions where people naturally gather. Why? Well it's really quite simple, because the autistic immunity is isolated during normal or "non-celebratory times". Consequently finding spaces for ASD loved ones during "gathering times" or where life has no structure not only impacts them but also challenges the caregiver. Families in this circumstance feel a compelling need to make holiday traditions seamless and extra special in ALL ways. It's not always a practical formula but it's real.

A simple Google search provides a plethora of tips to help autistic families. AND the advice is good- great even but it doesn't scratch the surface of the reality.



For what it's worth here is my additional advice.

- 1. Listen to your body
- 2. Try to be transparent with your family and friends about how the change in routine impacts your family
- 3. Rest when you can
- 4. Force yourself to be in the moment when the opportunity arises
- 5. Locate safe spaces around your town to enjoy holiday traditions
- 6. Ask for help and accept it
- 7. Let yourself experience any emotion you need to process during this period
- 8. Be selfish. If you can get some "me" time do it!
- 9. Count your blessings. Life can ALWAYS get worse
- 10. Find Joy in the smallest of everything

As I was opening my heart to write this my pastor sent me a scripture. It is apropos for this moment.

Psalm 102:17 KJV

He will regard the prayer of the destitute, and not despise their prayer.

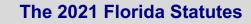
How Much Is Too Much

Like every American we worry about money. Oh every household has a budget and every family member in the household argues about that budget. Can you imagine if you had to add an additional \$60-\$70,000 in the budget for general care? That is what most families with children on the spectrum have to face. Whether they receive the funds in subsidies, by getting extra jobs, by sacrificing, by asking loved ones and finally by petitioning the state - this IS the cost! Of course no one believes us. When people ask you how much does it cost to take care of your loved one and you say these exorbitant amounts your peers literally look at you like you have horns on your head. It is not a stretch, it's not fictional or an exaggeration. The hard truth is that money matters and you have to make decisions that aren't always easy. Do you go on a family trip or do you pay for your child's therapy? Do you go out to dinner or do you take your child to special-needs camp? Do you make much-needed home improvements or do you pay for college education to place your child in the least restrictive environment?



Autism and Insurance Coverage State Laws

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The landscape is always changing as well. Our states have individual personalities and individual laws which makes it that much more difficult to navigate. Daily families make a choice about whether to place their child in a loving group home, leave their child in a state with additional accessibility or move to a state where they might find balance.

I have a personal stake in this particular argument so I won't go any further about saying what is right and what is wrong about our moral space. Instead I hope you review these brief CBS news articles that truly provide a window into the cost analysis and care of some of our most vulnerable spirits.

How much is TOO much!



