



What does it ALL mean?

So, this is NOT an easy topic for me BUT it is overdue. I have touched on aspects of "aging out of the system" before, however, now that our family is at this stage - it feels well - like we are starting ALL OVER AGAIN! Families like ours struggle for whatever normalcy is. We literally plan our day to day lives 24-7- on how to support our loved one with ASD. While you never feel truly settled, seen or heard, you do experience a beautiful rhythm of life. AND THEN you begin again and ponder What does it ALL mean?

We are blessed to have people who genuinely care about our family unit. Even those who know and love us may not understand the magnitude of what it feels like to contemplate future housing, educational and career opportunities and socialization which is, to many, the meaning of life. My brain works overtime so unfortunately, I am always thinking about how our family will support our young teenager as she ages into adulthood.

I went back through my research recently and discovered this article by Noah Remnick of the Atlantic.



for Autistic Adults? - The Atlantic

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The story resonated with me because so many of the families I advocate for have these very concerns. Families worry and experience significant anxiety over day-to-day challenges and supportive services. It has been my experience that families either KNOW or have NO IDEA how to navigate bureaucratic systems. As a result, families rely on the good will of others and their personal network to survive. Professor Julie Taylor, of Vanderbilt University said it best in the Atlantic Article.

“It’s profoundly difficult for families to get the resources they need, especially middle- and lower-income families who need the funding the most,”... “So a lot of the time, parents end up essentially devoting their entire lives to fighting on behalf of their children.”

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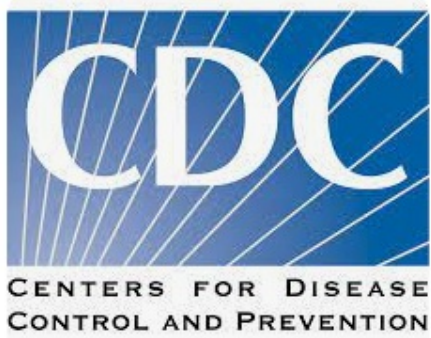
Again I come back to the question of What does it ALL mean?

- Quality of Life is not the same as Quantity of Life.
- Quality of life requires each of us to acknowledge our gifts and how we are designed to use them. Quality of life requires us see each other and respect our strengths and limitations.
- Quality of life requires each of us to dig deep about our footprint and what we do to make our community better.
- Quality of life requires us to acknowledge that everyone MAY NOT agree with how we value life.

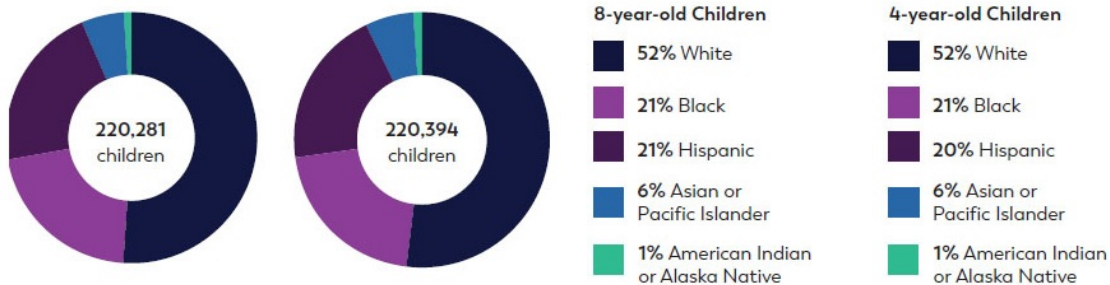
STILL, numbers do not lie. Persons diagnosed with ASD is on the rise. Here are the facts:

Facts About CDC’s Autism and
Developmental Disabilities Monitoring
(ADDM) Network

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POPULATION BY RACE/ETHNICITY IN 2018



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I am still on the journey of what does it ALL mean? While I continue down this path, it is my hope that I inspire young families like ours to continue dreaming.

MORE Services!

I mentioned in the last article that many families have no choice but to rely on services as their children age into adulthood. FULL ADMISSION! I have spent some time advocating in this area and it is STILL TOO MUCH to absorb. During my deep dive I was pleasantly surprised to see the plethora of resources available in one place to help Floridians search for the best form or support for their loved one. Generally, it is not the lack of resources that challenge families, rather it is access and understanding how to navigate systems and resources. It is also the fatigue of asking for support. The documentation required to obtain the support and the time required to follow up on what you are seeking.

Unfortunately, there is no solution I am aware of that resolves these challenges. However, there are an army of families who are doing the work each day to make it easier for the next families who follow in our footsteps. For now know there are **MORE services** and it is our job to ask for help EVEN when it seems difficult and overwhelming.

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**APD - Agency for
Persons with Disabilities
- State of Florida**

Vocational Rehabilitation

**APD - Information
Document**

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Creative Spirits

Our daughter loves Music, specifically CLASSICAL music. This past weekend we had the privilege to attend the concert, Classic Black at the Palladium. The performance was a collaboration with the St. Petersburg Opera Company and the ladies of the St. Petersburg Alumnae Chapter of Delta Sigma Theta Sorority, Inc., of which I am a proud member of. It was beautiful to listen to an ensemble of All Black Classical performers and particularly inspiring to my daughter. She was so giddy! It was like me seeing Prince for the first time. Role models matter. How we present and share our creative spirits matter! Special thanks to my dear friend and colleague, Terri Lipsey Scott of the Dr. Carter G. Woodson African American Museum for creating this special forum to celebrate our voices.

In that spirit, follow this young creative, Michael Fuller who proves that genius is present in each of us.

The autistic musician who makes music with his mind

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