

VIEW OF AUTISM AND NEURODIVERSITY AS A PARENT AND PHYSICIAN

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William Carey University College of Osteopathic Medicine

My Story...

Medical School:

University of Missouri – Kansas City

1992-1998



My Story...

Residency Training:

University of Kansas Medical Center

Department of Family Medicine

1998-2001



My Story...

Family Physician in Rural Community

National Health Service Corp (NHSC)

Licensed Adoptive/Foster Parent



WILLIAM CAREY UNIVERSITY COLLEGE OF OSTEOPATHIC MEDICINE

The Traditional Medical Model

“Most of us have been trained to think about autism using a deficit model. Such a model, which focuses almost exclusively on impairments and limitations, ultimately leads us to see Autistic individuals as broken people who are ill and, as my child’s first psychologist explained, need to be fixed.”

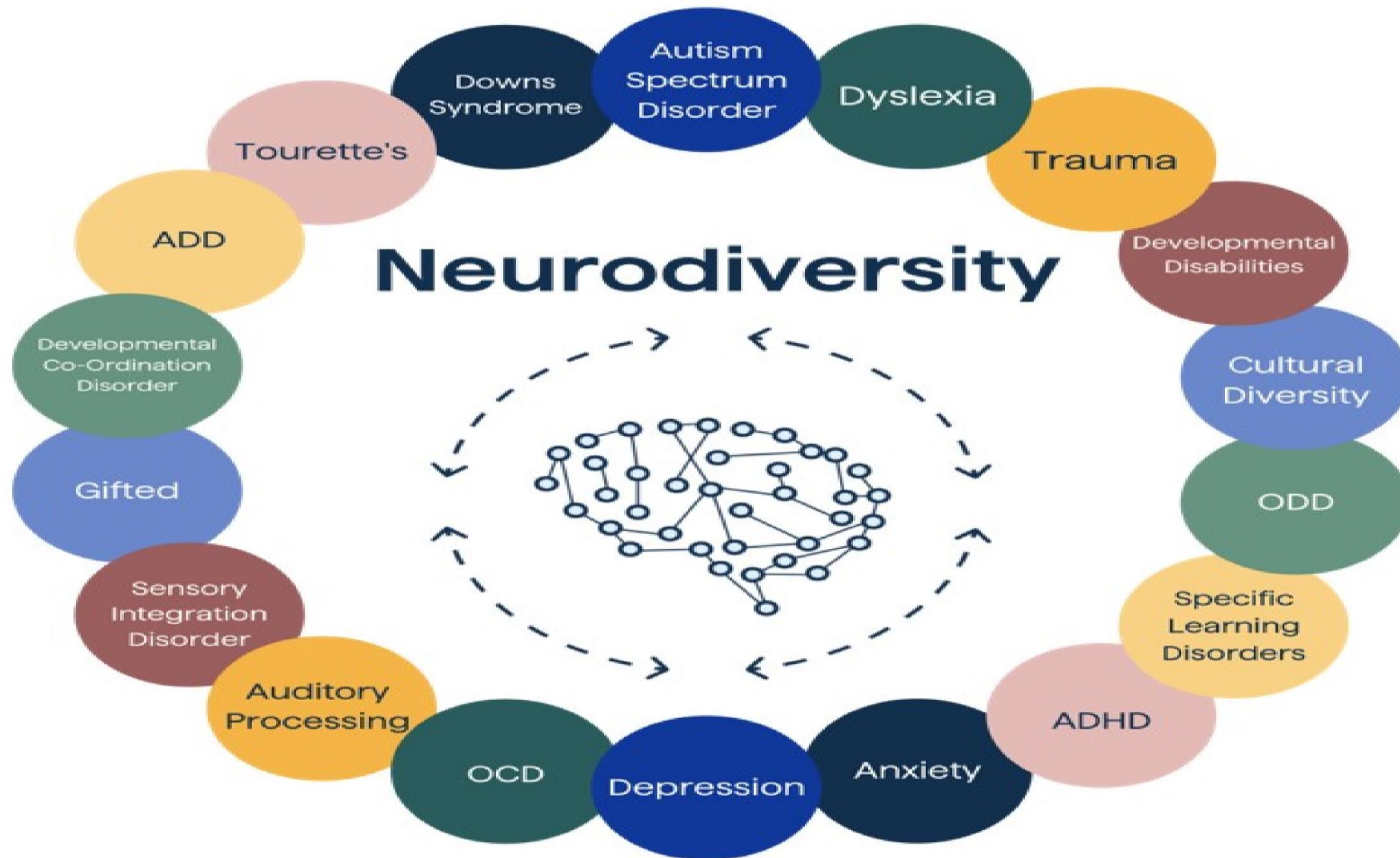
Christina Nicolaidis, MD, MPH, parent

Nicolaidis, C. (June 2012). What Can Physicians Learn from the Neurodiversity Movement? AMA Journal of Ethics.
<https://journalofethics.ama-assn.org/article/what-can-physicians-learn-neurodiversity-movement/2012-06>

What is Neurodiversity?

Neurodiversity reflects the idea of the variation in human brains as being biologically normal and adaptive, with no one brain being prized as ideal.





Shifting Our Frame of Thought

“The neurodiversity movement challenges us to rethink autism through the lens of human diversity. It asks us to value diversity in neurobiologic development as we would value diversity in gender, race, ethnicity, religion, or sexual orientation. As opposed to only focusing on impairments, the neurodiversity model sees autistic individuals as possessing a complex combination of cognitive strengths and challenges.”

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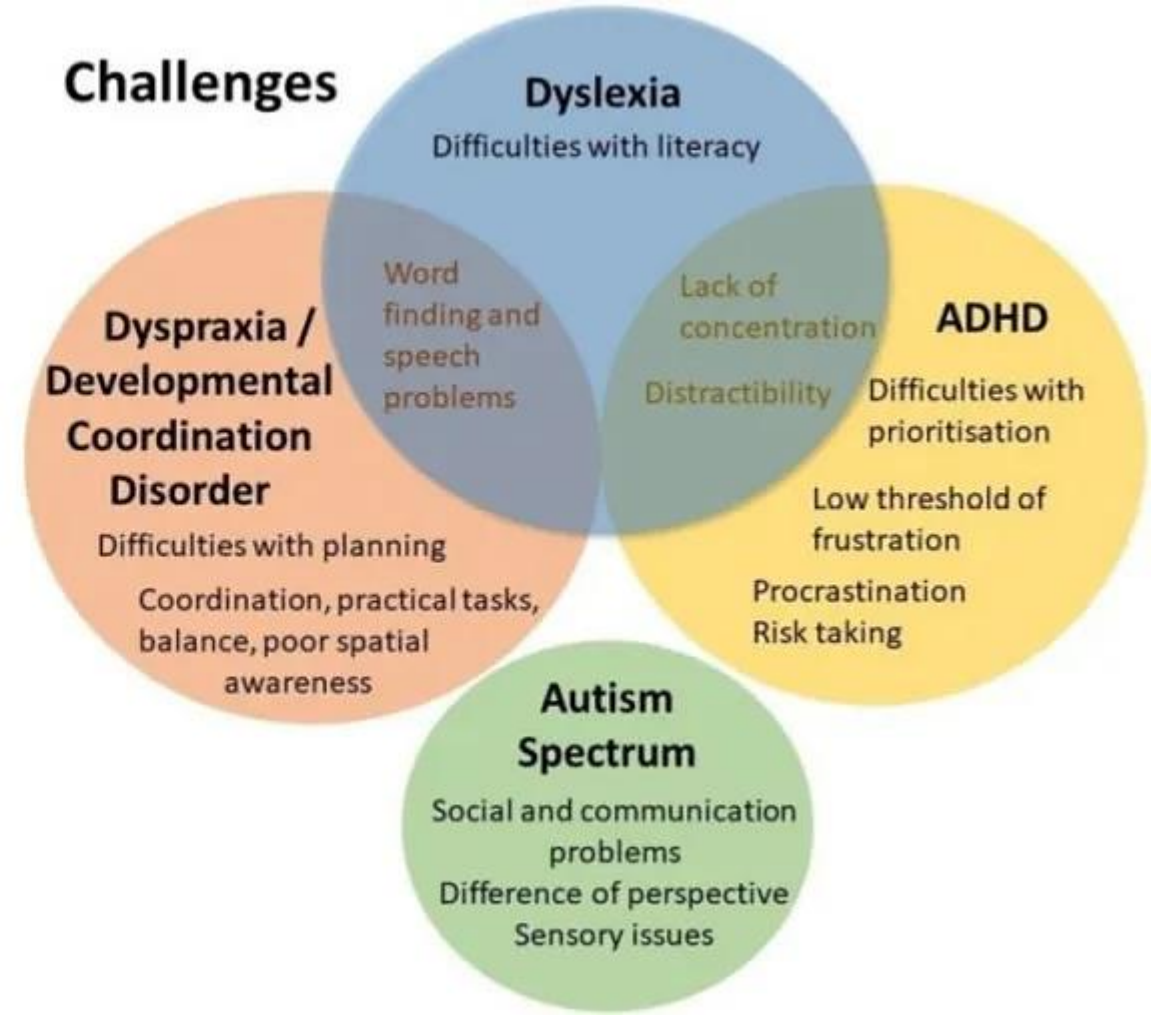
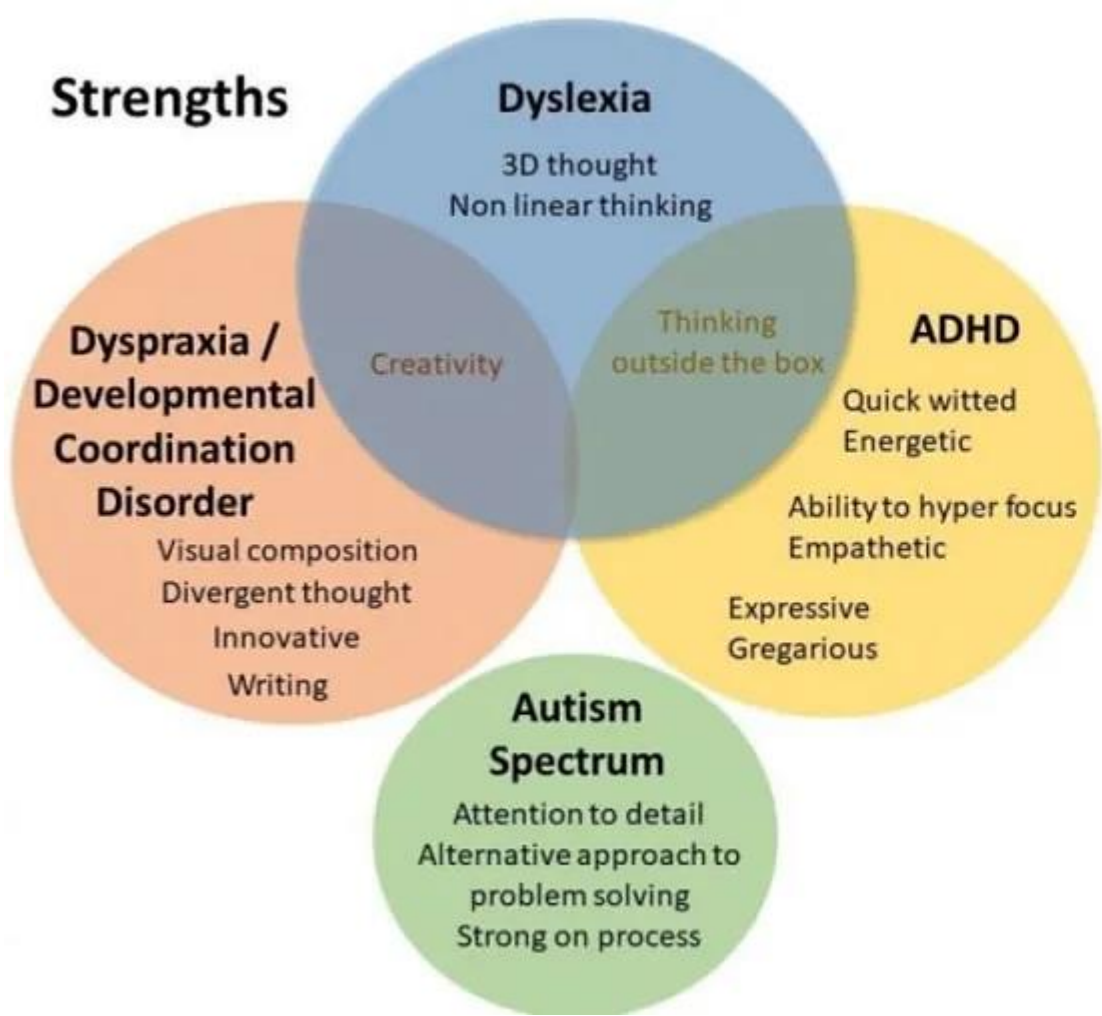
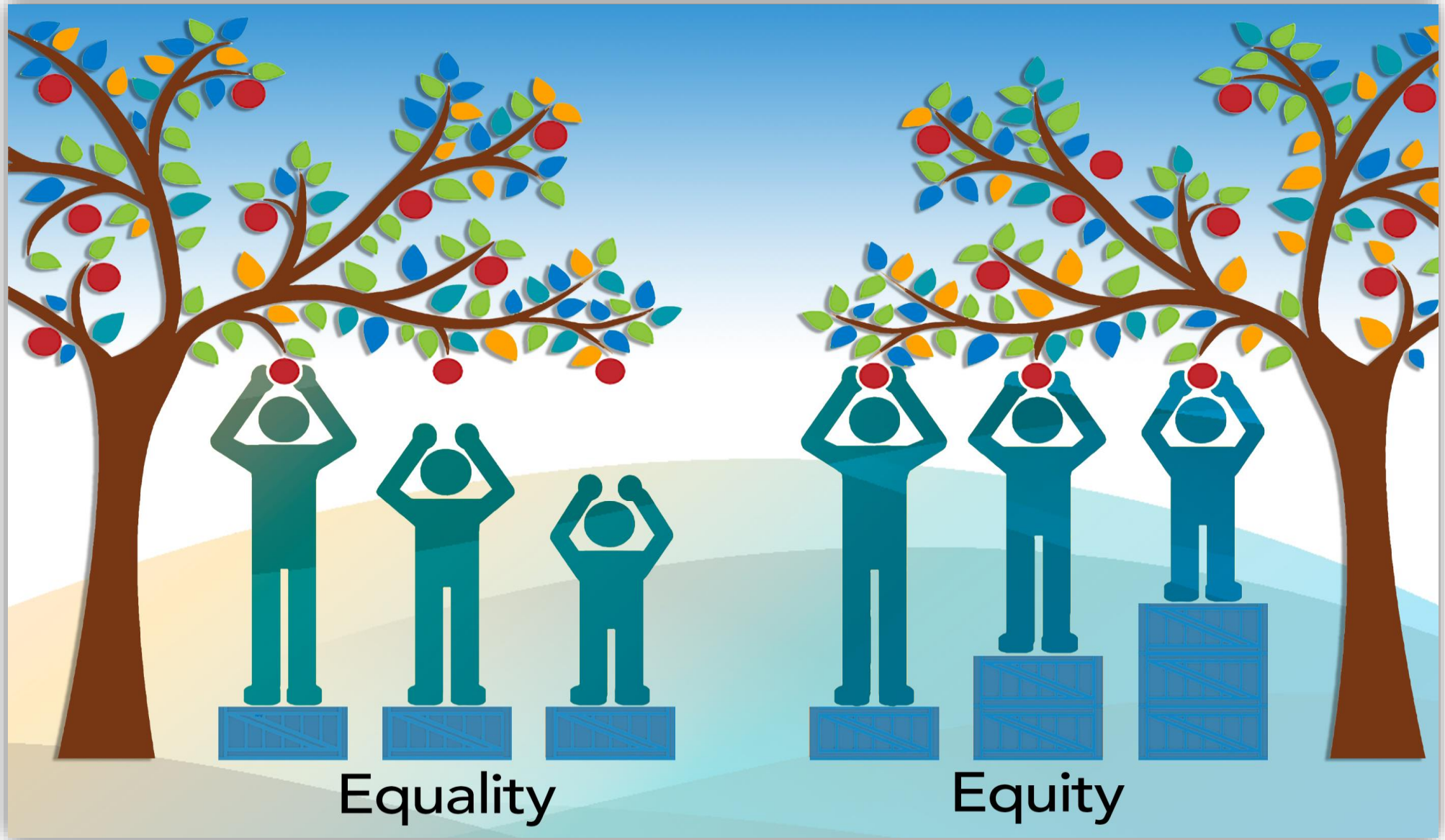


Image Credit: Sarah Rankin, National Heart Lung Institute, Imperial College of London

Support, Services, and Therapies

I work with a team of physicians and other professionals to coordinate accommodations, medications, and other therapies that help my child communicate better, improve his ability to function, regulate his emotions, lessen his anxiety and sensory discomfort, allow him to obtain a good education, and promote positive interactions with all his peers (neurotypical and neurodivergent).

I am not trying to change who my son is—I just want to give him every possible opportunity to enjoy the same quality of life as all my children.



Not everyone that comes to the table sits. Some lie on the floor underneath, some stim and flap nearby, some run around the table, some twirl and dance at the side.

Everyone is valuable.
Even if you don't sit, you still deserve space at the table.

STALEN'S WAY

Words Matter

Communicating a strengths-based approach to autism and other neurodiversity may not only afford these individuals the respect and dignity that they deserve, but may also help their family members (and other caregivers) better understand and support their loved ones.

Building a Bridge Over the Autism Cliff

Sudden reduction or loss of services after age 18-21

Special considerations before age 18:

- Legal guardianship
- Financial power of attorney
- Power of health

Autistic individuals may have a higher risk of exploitation and victimization from others due to social difficulties. Because of this, they could experience fraud or other financial abuse without essential legal safeguards in place.

Drake, K. (April 25, 2022). Through My Eyes: Empowering my son to negotiate the 'autism cliff,' enter adult life. Medical News Today. <https://www.medicalnewstoday.com/articles/through-my-eyes-empowering-my-son-to-negotiate-the-autism-cliff-enter-adult-life>

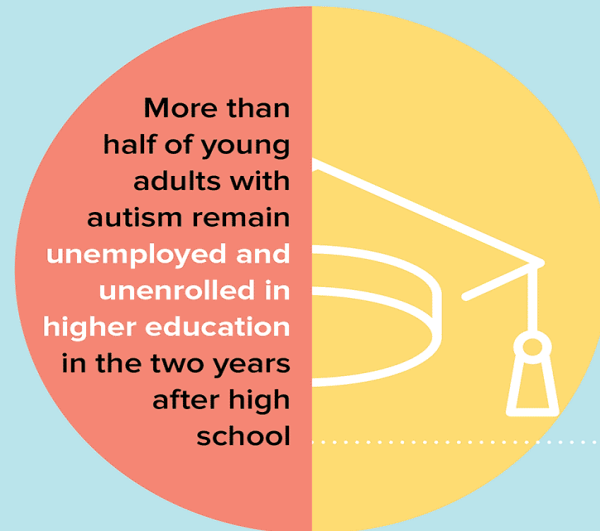
adults with autism

Adult life — with its bosses, coworkers, roommates and romantic partners — can be tough enough. Then add the hallmark social and executive-function challenges of autism spectrum disorder.



An estimated 5 percent of adults with autism have ever been married

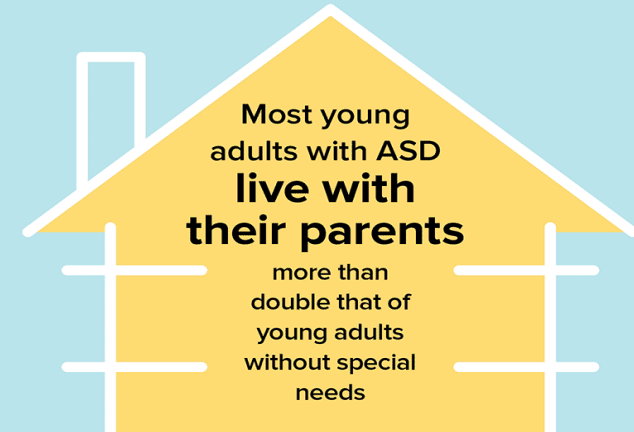
Depression affects an estimated 26 percent of adults with autism **3 times the U.S. average**



Many young adults with autism don't receive any health care for years after they stop seeing a pediatrician

An estimated one in four to one in five is unemployed

As many as **one-third** have epilepsy



UC Health Davis. (Summer 2019). Helping Adults with ASD to Live Better Lives.

<https://health.ucdavis.edu/health-magazine/issues/summer2019/features/autism/helping-adults-with-ASD-live-better-lives.html>

Meet John.

He's a wizard at data analytics.

“And although corporate programs have so far focused primarily on autistic people, it should be possible to extend them to people affected by dyspraxia (a neurologically based physical disorder), dyslexia, ADHD, social anxiety disorders, and other conditions.

Many people with these disorders have higher-than-average abilities; research shows that some conditions, including autism and dyslexia, can bestow special skills in pattern recognition, memory, or mathematics.

Yet those affected often struggle to fit the profiles sought by prospective employers.”

Pisano, G. (May-June 2017). “Neurodiversity as a Competitive Advantage.” Harvard Business Review.
<https://hbr.org/2017/05/neurodiversity-as-a-competitive-advantage>



Parents of newly diagnosed kids

It is going to be okay. Your child is still the same child. Your love for them won't ever change.

There will be days that are hard. Heartbreaking even. It's okay to not be okay. Just don't get stuck there. Your child needs you to be strong.

When you think you have it hard, remember, it's harder for your child.

FB/PIECEOFKALEY

Find your tribe. Find those who support you and understand the path you're walking.

Channel your emotions towards the fight. The fight for services, quality education, and quality of life.

Never give up.

ALWAYS have hope. Your child is going to teach you SO MUCH!

Common Struggles Faced by Parents

Chronic exhaustion

Feelings of guilt

Long waitlists

Lack of available resources

Feeling socially isolated

Receiving unsolicited advice from others

Not enough time to focus on other children

Worrying about the future

Tips for Overwhelmed Parents

Stop feeling guilty

Make self-care a priority

Prioritize (essential, important, unimportant)

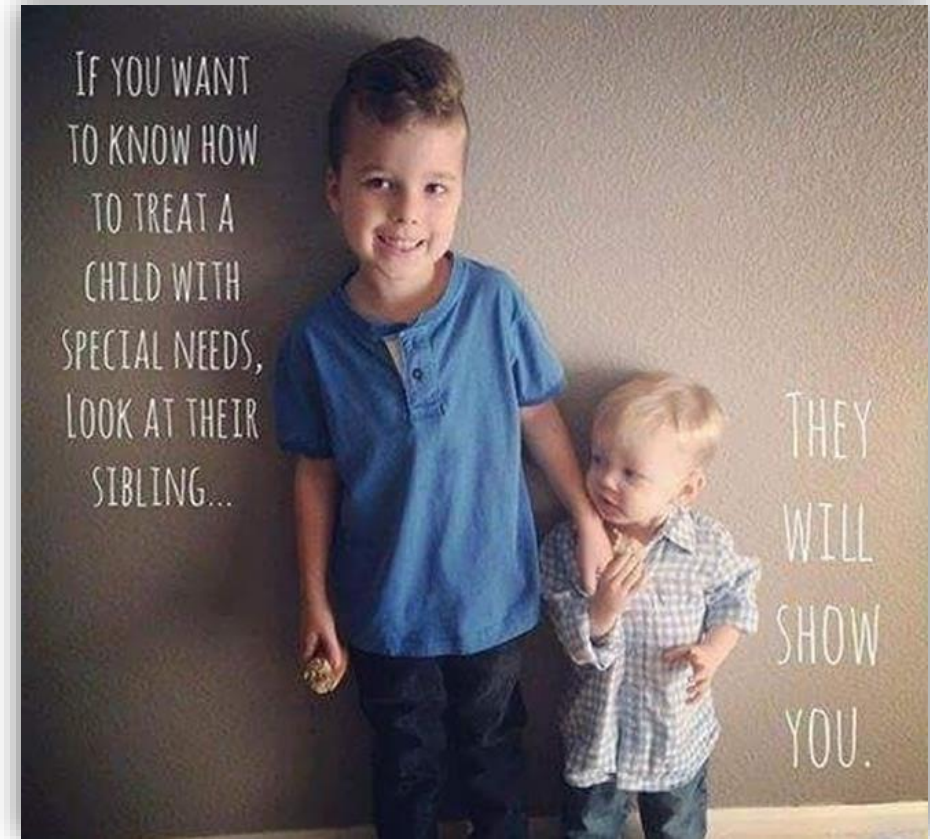
Organize help (learn to let go)

Connect with other parents

“Find your tribe”

Siblings of Children with Special Needs

Siblings are too important to ignore because no one spends more time with special needs children than their brothers and sisters, with the exception of their parents.



Caring for Special Needs Siblings

Medical crises and public meltdowns take a toll; be aware of signs of emotional trauma.

Don't expect children to help with their sibling's needs, but don't discourage it either.

Be honest when explaining their sibling's condition or treatment (in age-appropriate way).

Carve out one-one-one time whenever you can; give each kid time to shine in their own way.

Arnold, J. (June 28, 2021). Supporting the Siblings of Children with Special Needs. North State Parent Magazine.
<https://northstateparent.com/article/siblings-of-children-with-special-needs/>



FRED ROGERS
— INSTITUTE —
Saint Vincent College

“ANYONE

WHO DOES ANYTHING
TO HELP A CHILD

IS A HERO”

— FRED ROGERS

