

Parenting and Caregiving for Neurodivergent Children: Building Resilience



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Agenda

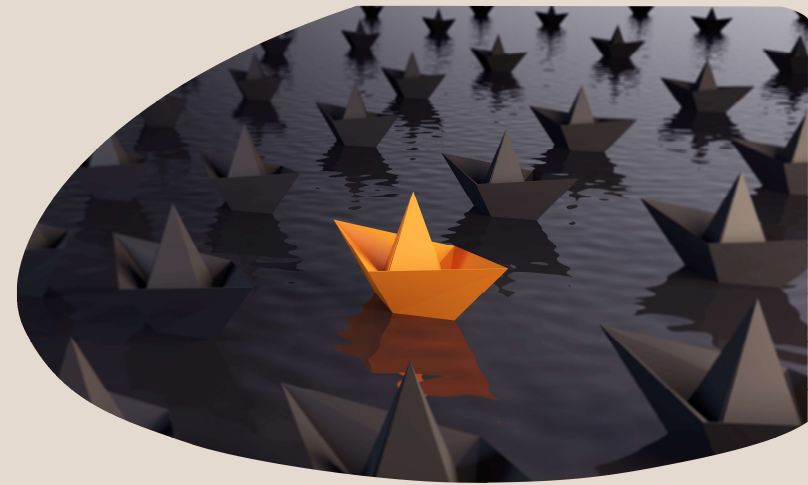
What is Neurodivergence?

Impact on caregiving

What is resilience, and why does it matter?

How do we build resilience?

Discussion



What is Neurodivergence?

Commonly recognized:

- autism
- ADHD
- intellectual disabilities
- speech and language disabilities
- learning disabilities
- movement and tic disorders

developmental pathways that differ and result in divergent neurological functioning.

(Black et. al., 2024)



Medical model historically focused on the risks, impairments and challenges faced by caregivers and their children

Not inherently negative, but reflective of natural human variance. (Dwyer, 2022)

Disability a mismatch between individual and the environment.



Social Emotional Impacts

Research

Being neurodivergent puts an individual at risk for lower school participation and educational attainment, greater levels of unemployment and underemployment, poorer physical and mental health outcomes (Baraskewich & McMorris, 2019; Jonsson et al., 2017; Steinhausen et al., 2016)

Families who have a child diagnosed with autism are dealing with a number of stressors within the family, as well as outside pressures when trying to establish systems of support for their child (Tway, Connolly, & Novak 2006).

Children with autism are significantly less likely to attend regular community activities, school or spiritual services. Parents are also more likely to have a host of concerns around bullying, challenges with learning, and overall achievement (Tway, Connolly, & Novak 2006).

Belief about the origins and nature of a child's neurodivergence can impact a mother's mental health. Mothers who believed that they were responsible for their child's autism had the worst outcomes. (Goin-Kochel et al., 2020; Hebert & Koulouglioti, 2010)

Those mothers who had the most hope for their child's progress and future had the best mental health outcomes, and that was regardless of severity of symptoms (Costa et al., 2017; Hebert & Koulouglioti, 2010).





Economic Impacts

HOW DOES CAREGIVING IMPACT
FAMILY FINANCES?

Breaking Down the Cost

- Lit review of 33 studies from 10 countries found that parents of autistic children were susceptible to adverse employment impacts and increased financial burdens, especially mothers (Liao, Li, 2020)
- Often the loss of one parent's income, specialty schools, specialty activities and equipment, therapies, insurance, copays. Lifetime cost for supporting autistic individuals ranges from is 1.4 million. (Autism Spectrum Disorder Foundation 2022).
- These financial challenges also put the family members at risk for increased stress, mental health challenges (Estes et al. 2009), anxiety and depression (Benson 2010), and decreased well-being (Benson 2012).



What Does This Look Like?

IN OUR LIVES?

We experience a range of challenges

These experiences lead to different types of stress:

- Emotional- worry not doing enough, guilt about child's differences, anxiety, sadness, frustration over behavior challenges
- Social- feeling judged, lack of community
- Advocacy- constant need to advocate in complex systems of care- worry, guilt, shame, overwhelm
- Burn Out- Feeling physical/emotional exhaustion, lack of self-care



Diagnostics gone wild...

	Baby A	Baby B	Baby C
2 years old	Hypotonia/ Global delays	speech delay/Motor delays	PDD-NOS
		Motor delay	
3 years old	Autism		Autism
4 Years old		Autism	
9 years old	ADHD	ADHD	Tourette's
	Anxiety	Anxiety	OCD ADHD
15 years old		Gender dysphoria/ Eating disorder	

Intervention Snapshot

OT/PT	Speech	Discrete Trial-ABA	PRT-ABA	Verbal Mapping-ABA
PECS	Denver Model	LEAP	Hanen Language Program	Sensory Integration Therapy
Facing Your Fears	SCERTS	PEERS	RDI	Social Skills Groups
Habit Reversal Training	CBT/DBT	GFCF Diet	Supplements	Acupuncture
		Essential oils		

Coyne and Associates

ACE

PUC San Diego Medical Center

Creative Perspectives (now Spectra)

Chatterpillars

JFK Partners

Developmental FX

Firefly

Rocky Mountain Autism Center

5 different SpEd school teams

Ascendigo

Kaiser psychologists and psychiatrists

Rocky Mountain Human Services

Laurie Sperry, PhD, BCBA

Naturopathetic providers

Rocky Mountain Development Center

Westside Behavioral Health

SWAP Coordinators

Vocational Rehab Case Manager

Developmental Pathways

Medicaid

Dirt Coffee

First Ascent Career Planning

Contributing Factors

- Level of child functional ability and behavior
- Co-existing health challenges
- Limited social supports
- Lack of socio-economic resources
- Poor family functioning
- Psychological and physical health
- Current interventions limited to respite care and parent support groups.

We **need** interventions for caregiving demands and social supports, that specifically target the development of **psychological coping skills** that can build resilience to current and future stress.





These challenges make us feel

Tired

Irritable

Detached

Trouble sleeping

Sick more often

Loss of interest

Low energy



Building Resilience

WHY IT MATTERS

What is Resilience?



The ability to bounce back from adversity

Protective factors outweigh the risk factors



Risk and Protective Factors

Identifying Risk and Protective Factors

- Vital to mitigate negative mental health outcomes

Risk Factors- Negative Coping Strategies

- **Emotion-coping strategies** (withdrawal, denial, venting) associated with more negative mental health outcomes (Abbeduto et al., 2004; Vernhet, et al, 2018).
- **Reliving** past traumas or fearing future events

Positive Coping Strategies

Health Focus- Are you eating, sleeping, moving your body?

Optimism- instead of why, what can we do?

Acceptance- accept child uniqueness instead of comparing

Cognitive Reframing- difficult event rather than a difficult child)

Attitudes, beliefs, and perceptions about a child's neurodivergence can affect how we adjust and cope, and ultimately impacts our mental health. This is true regardless of child's symptom severity.





Social Support

Social support was one of the most influential predictors of well-being and adjustment among parents raising a child with autism (Benson 2012). Mediates stress of raising a child with autism (Paynter et al, 2013)

Mindfulness Meditation



- Focus on breathing
- Notice your thoughts- let them pass by like river water or clouds
- If thoughts overwhelm you, return your focus to breathing
- Noticing your thoughts, not trying to stop them, being curious about them as an observer
- Non-judgmental about your own thoughts

Seriously...It works

- Study found that all participants experienced a significant decrease in perceived stress
- Significantly increased mindfulness, self-compassion, and well-being
- Parents engaging in these community-based mindfulness practices report feeling less depressed
- Studies have found that meditating three to four times per week can have big benefits—and, regularly meditating for eight weeks will alter the brain, according to neuroimaging studies

Bazzano, A., Wolfe, C., Zylowska, L., Wang, S., Schuster, E., Barrett, C., & Lehrer, D., 2015)

Zeng X, Chio FH, Oei TP, Leung FY, Liu X., 2017

Best Meditation Apps 2024

Best overall: Headspace

Best for Beginners: Ten Percent Happier Meditation

Best for Sleep: Calm

Best Budget: Insight Timer

Best Guided: Buddhify

Best For Focus: Unplug

Best Selection: Simple Habit

Best for Learning Breathing Techniques: Breathwrk

Best for Kids: Smiling Mind

Best for BIPOC: Shine



Thank You!

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Podcast

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