

Managing Parent and Caregiver Stress

Supporting families of children with Intellectual and Developmental Disability

Katrina Davis

Family Advocate | Case Manager

Seattle Children's Autism Center

Disclosures

- Katrina Davis has no financial relationships relevant to this presentation to disclose.
- All planners have no relevant financial relationships to disclose.

UW Medicine
UW SCHOOL
OF MEDICINE

Objectives

- Offer insight: Parenting a child with Intellectual and Developmental Disability
- Provide strategies to:
 - Reduce parent and caregiver stress
 - Increase parent and caregiver resilience, confidence, and competence
 - Become an effective partner with the IDD population

Parenting a child with Intellectual and Developmental Disability



Parenting a child with Intellectual and Developmental Disability

Autism Parents Have Stress Similar To Combat Soldiers www.disabilitycoop.com/autism-moms-stress/6121/

Don't assume we want to cure or fix our kids

Barriers and lack of vital services

Isolating

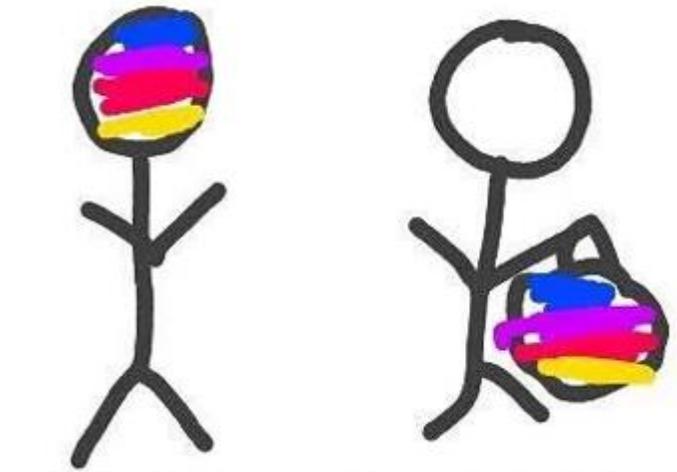
Great pride and joy

Effective Advocates

We want the world to seek to understand and include our children

Dignity and respect they deserve: Disability is part of the human condition

Redefine what it means to be "normal"



Understanding the barriers

Lack of or long wait times for services

Lack of crisis stabilization services

Family circumstance

Readiness level

Loss of income

Language barrier

Cultural considerations

Walking on eggshells

Fear, overwhelmed, isolation



Transition and Adulthood

- Legal Resources
- Developmental Disabilities Admin
- Supplemental Security Admin
- Medicaid
- Guardianship
- Finances
- ABA
- Education
- Housing
- Employment
- Relationships/Sexuality
- Advocacy
- Meaningful life

Strategies to reduce stress: What helps?

Don't Google Autism

Prioritize Recommendations

Information and support

On-going care planning with autism provider

Case management | Quarterback

Team Approach: Medicaid, DDA, School, natural supports

Connection to other parents and advocacy

Connection to other autistics and self-advocacy

Resilience, confidence and competency

Mindfulness-based approach

IDD and Autism Pride

Autism and IDD Pride



Autism: the positives



Understanding, embracing and celebrating different ways of thinking and doing can release the true power of the autistic mind. Here we look at the positive features of autism.



Attention to detail

- Thoroughness
- Accuracy



Methodical approach

- Analytical
- Spotting patterns, repetition



Deep focus

- Concentration
- Freedom from distraction



Novel approaches

- Unique thought processes
- Innovative solutions



Observational skills

- Listen, look, learn approach
- Fact finding



Creativity

- Distinctive imagination
- Expression of ideas



Absorb and retain facts

- Excellent long term memory
- Superior recall



Tenacity and resilience

- Determination
- Challenge opinions



Visual skills

- Visual learning and recall
- Detail-focussed



Accepting of difference

- Less likely to judge others
- May question norms



Expertise

- In-depth knowledge
- High level of skills



Integrity

- Honesty, loyalty
- Commitment

Remember

Every experience of autism is **unique**. No one person will identify with every positive feature of autism. We all have **individual** skills, attributes and characteristics that are as unique as our personalities – this is the **power of neurodiversity**.

Harriet Cannon
Disability Services, February 2018

Icons designed by Freepik from www.flaticon.com



Words We Use

Bad

Violent

Crazy

Naughty

Spoiled

Lazy

Weird

Good

Overloaded

Dysregulated and became aggressive

Behavioral health crisis

Had a difficult day

Not being Accommodated

Overwhelmed

Processing the world differently

He/She had a good day



Mindfulness based stress reduction

More research showing **mindfulness**-based programs for the **parents** of children with ASD were found to reduce parenting stress, anxiety, and depression, as well as to improve sleep, global health, well-being, and life-satisfaction.

The mechanism of mindfulness is: Non-judgmental awareness of the present moment

- Psychological flexibility
- Resilience
- Coping
- Good enough parenting
- Self-compassion
- Breathing and meditation
- Acceptance of self and situation
- Importance of caring for mind, body, and spirit

Mindfulness-based autism parent coaching on-line programs. Will post in Resource Folder.

Resilience Confidence Competence

Mindfulness

Understanding systems: DDA, ABA, Medicaid, School, etc.

Help navigating these complex systems

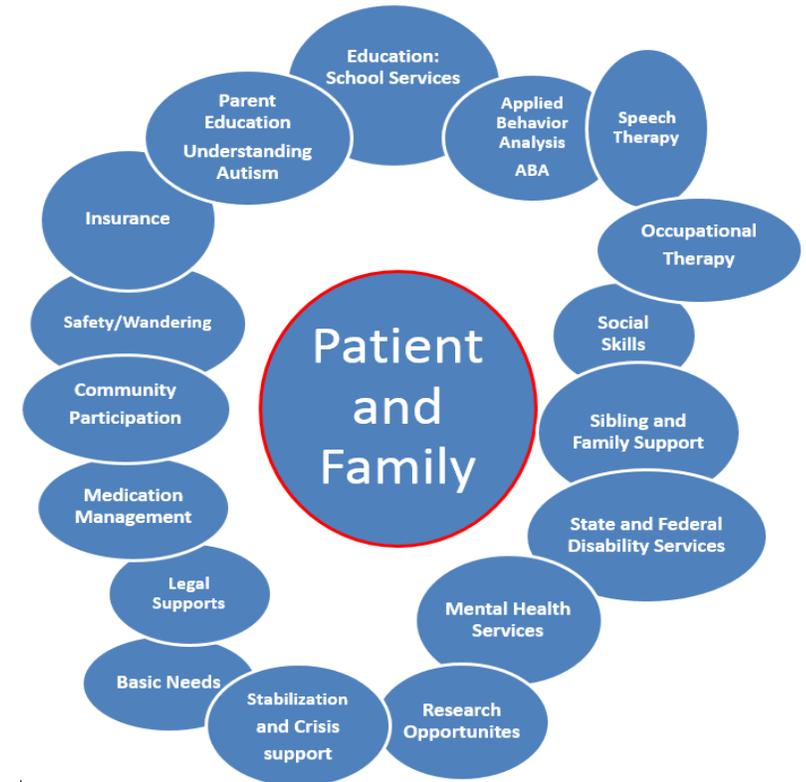
Increase your knowledge and understanding of services

Angry, unreasonable, difficult to help, despondent

- A part of the body's natural defense system
- And a natural reaction to dire circumstances

Witness

Deepest compassion, patience, and persistence



1

Siblings



Multicultural Children's Books about **AUTISM**



www.coloursofus.com



Questions

THANK YOU!

Katrina Davis

Katrina.Davis@seattlechildrens.org

Autism Resource Folder (link in chat)

New Resource Section: Seattle Children's Autism Center:

<https://www.seattlechildrens.org/clinics/autism-center/patient-family-resources/>