

Crisis Supports

Autism with IDD

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Disclosures

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

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Objectives

- Learn about the needs of parents and families of children and youth with IDD when there is a crisis.
- Understand types of assistance that would be beneficial to parents and families during times of crisis.
- Learn about resources to prevent crisis.



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



Population defined: High-needs or severe autism

- Intellectual and Developmental Disability (IDD)
- Limited language proficiency
- Significant challenging behaviors in the form of aggression, self-harm, property damage, and bolting
- Low adaptive life skills

High Functioning Autism or Low Support Needs

Placement at in-patient facility

Lack accommodations

Sensory overload

Inappropriate treatment

Lack of expertise

Returned home unsafe

Cycle repeats

Traumatizing

Rate of suicide 3 times higher for HF autistic people

Published in [JAMA Network Open](#), the study analyzed whether people with ASD had higher rates of suicide attempt and suicide when compared to people with no ASD using national register data from 1995-2016 and risk factors of suicidal behaviors in those with ASD.

Current Situation

Parents are told to call 911 or take to the ED

- Most EDs are not equipped to handle IDD population
- Services up and down stream are limited/barriers
- If in-patient placement is deemed necessary:

Severe Autism/IDD:

- No placement available
- Inappropriate hospital/medical stay
- Physical or pharmaceutical restraints used
- Return home unsafe
- Cycle repeats
- Traumatizing, impact individual and family

**Report by WA
Developmental Disabilities
Ombuds:**

Stuck in the Hospital:

<https://ddombuds.org/wpcontent/uploads/2019/10/DD-Ombuds-Hospital-Report-12.10.18-Final.pdf>

What do Patients and Families Need?

Understand their unique crisis situation

Identify resources available

Candid and upfront about the realities of limited services

What we think they need vs. reality, family situation, and readiness

Why aren't they accepting the services offered?

Understand the Barriers

Long wait times for services

Access to services

Family circumstance

Readiness level

Loss of income/strain

Language barrier

Cultural considerations

Fear, overwhelmed, isolation

Crisis Services: In Active Crisis

Limited for IDD population

- **Call 911**
- **Emergency Dept**
- **Crisis Line:** limited knowledge of IDD population and often tell parents to contact DDA
- **In-patient psychiatric facilities:** Do not serve IDD population
- **PBMU** at Children's: Short term and cut off at age 17
- **Medicaid and DDA:** Involve case managers
- **PCP or Pediatrician:** Notify
- **King County Only:** Children's Crisis Outreach Response System (CCORS/ISS)
CNP in King County

What is Helpful?

Prioritize Recommendations

Parent as Quarterback

On-going care planning with autism provider

DDA and Medicaid Case Manager

Connection to other parents and advocacy

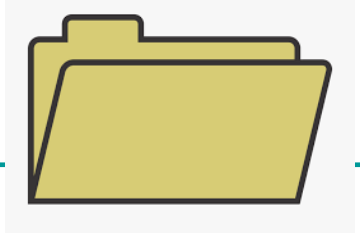
Resilience, confidence and competency

Mindfulness-based approach

Honest/upfront realities of limited services

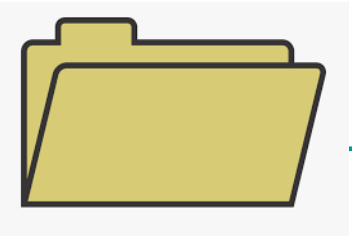
Witness

Resources to Prevent Crisis



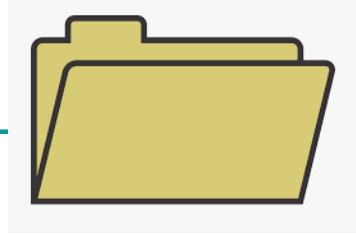
- ABA
 - Difficult to obtain. Long wait times. Agencies closed COVID. On-line alternative not working for many. Be pleasantly persistent.
- Seattle Children's Bio Behavior and RUBI clinics
 - <https://www.seattlechildrens.org/clinics/autism-center/services/therapies-for-challenging-behaviors/>
 - Long wait lists. Short term, goal focuses. Center-based.
- DDA: Maximize what is available
 - Respite, Assistive Technology, Caregiver hours, Community Guide, Specialized Habilitation and Intensive Habilitation Services (NEW). Positive Behavior Supports have been dropped from all waivers. DDA can no longer provide this service. Ask for Staff and Family Counseling instead.
 - Enhanced Respite limited offerings and long wait times
 - RHCs (Fircrest, Yakima School) closed to children
 - Still very important to notify and involve DDA if family in crisis
- WISe: Wrap Around with Intensive Services
 - Medicaid-eligible children, youth, and their families with intensive mental health care needs. Emerging Autism and IDD expertise

Resources to Prevent Crisis - Continued



- Medicaid
 - Medication management: Difficult to find autism expertise
 - Mental health therapy: CBT, DBT, Trauma-focused
 - Case Manager
- Private insurance
 - if enrolled in DDA, might have private plan as primary insurance
- WA State Mental Health Referral Line: Outpatient MH Providers
www.seattlechildrens.org/clinics/washington-mental-health-referral-service/
- Children's Crisis Response Outreach System (CCORS)
 - **King County only**
 - Short-term, goal-focused, in-home
- BeST Team/DDA
 - **King County only**
 - Short-term, goal-focused, in-home

Resources to Prevent Crisis - *Continued*



- Other Recommended Therapies for the Child
 - Speech, AAC, OT, Social skills, community participation
- Education/School/IEP
 - On-line learning due to COVID, difficult for IDD population
<https://www.seattletimes.com/author/rachel-nemhauser/>
 - Conduct Functional Behavior Assessment with corresponding Behavior Plan
 - PAVE.org
 - WA State Education Ombuds
 - The Arc of King County
- CPS Home Builders: mixed reviews from parents
- Out-of-home placement
 - Medicaid will pay but long wait times, limited choice, limited accountability
 - Private insurance might pay (WAAA)

Connecting Parents to Parents

On-line Autism parent support groups

Autism Family Group – Washington State (Facebook)

Raising Autistic Kids Washington (Facebook)

Moms of Autistic Teens and Young Adults Washington (Facebook)

Autism Moms of nonverbal kids (Facebook)

Autism Moms of Seattle KWCB kids with challenging behaviors (Facebook)

National Council of Severe Autism

Severely Autistic Children with LD (Facebook)

Families of Color (WA) www.focseattle.org

Somali Parent Health Board Parent Support Group somalihealthboard@gmail.com

Spanish groups available through Arc chapters or counties

Open Doors for Multicultural Families (Somali, Amharic, Spanish, Russian, Arabic, and Mandarin)

Into Adulthood for parents raising teens and adults (Google Group)

Exceptional Families of Washington

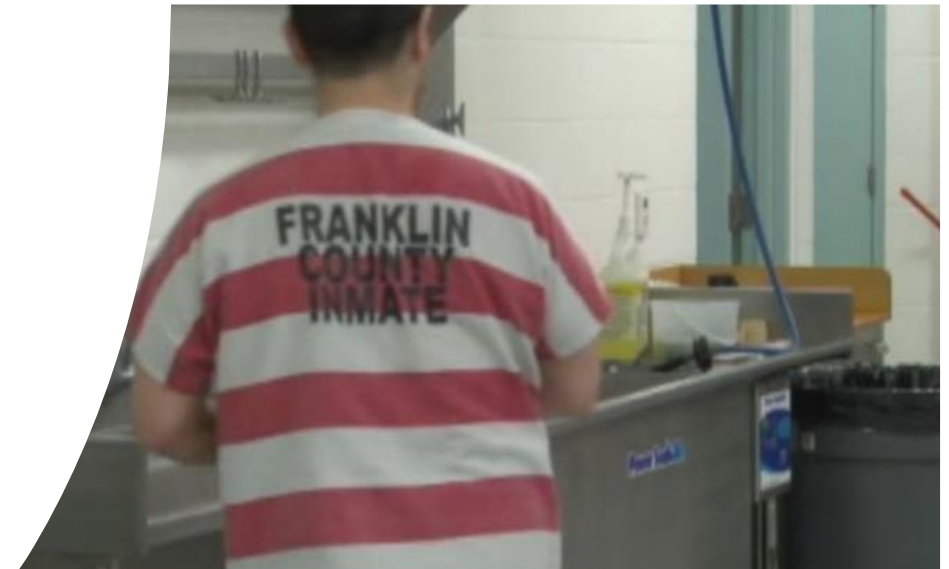
More information can be found at:

www.seattlechildrens.org/clinics/autism-center/patient-family-resources/

Crisis Driven

Non-Verbal Man with Severe Autism Jailed as Last Resort

- <https://wgxa.tv/news/nation-world/nonverbal-man-with-severe-autism-jailed-as-last-resort-02-13-2020>



What is being done about it?

Known concern/on advocacy radars: House Bill 1394 (SSHB 1394)

- In 2019 Jay Inslee signed into Law, **House Bill 1394** (SSHB 1394)
 - Requires the HCA, DDA, DCYS, Behavioral Health Providers, Developmental Disability Advocates, and Stake Holders
 - Create recommendations regarding Behavioral Health Treatment for individuals with IDD before, during and after mental or behavioral health crisis.
 - Final report completed and will be submitted to Governor's office this legislative cycle. A copy of recommendations will be in Crisis Folder in Google Docs Resource section when available.

[WA State Developmental Disabilities Ombuds](#)

[WA State Developmental Disabilities Council](#)

Advocacy

WA State Developmental Disability Ombuds www.ddombuds.org

WA State Developmental Disabilities Council www.ddc.wa.gov

NW Justice Project www.nwjusticeproject.org

Washington Autism Advocacy www.washingtonautismadvocacy.org

Your Local Arc by County or Region www.thearc.org/chapter/the-arc-of-washington-state/

Basic Needs for IDD Population

2.1.1 Community Resource Line: www.wa211.org

Developmental Disabilities Administration (DDA)

The Arc of (your county or chapter)

Open Doors for Multicultural Families

Thank You

**‘THE TRUE MEASURE OF ANY SOCIETY
CAN BE FOUND IN HOW IT TREATS ITS
MOST VULNERABLE MEMBERS’**

-Mahatma Gandhi



Questions



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