



Autism 200 Series

Autism 208:

Crisis Support for Individuals with Complex Behavioral and Mental Health Needs

Eric Boelter, PhD, BCBA-D

Clinical Supervisor, Biobehavioral Program Seattle Children's

Katrina Davis, Family Advocate
James Mancini MS, CCC-SLP



Target Group--*Who are we talking about?*

- Individuals with intellectual and developmental disabilities (IDD) with or without Autism who are experiencing a mental and/or behavioral health crisis
- Individuals who meet criteria for DDA
- Individuals experiencing crisis in the form of mental or behavioral health crisis (aggression, property damage, self-harm, psychosis, etc) requiring a high level of care

Agenda:

- Brief introduction about current services for individuals with IDD with severe behavioral and/or mental health issues
- Brief introduction of the problem—*what are the barriers, gaps, and deficits?*
- Panel discussion to discuss the state of crisis services and how to improve these services moving forward
- **Call to Action:** *How to get involved/advocacy*



Our Panel

David O'Neal

IDD Services Director, Behavioral Health Agency
Sound Health

Arzu Forough

President, Chief Executive Officer
Washington Autism Alliance and Advocacy

Elizabeth Landry

Staff Attorney
NW Justice Project

Beth Leonard

Legal Counsel to the DD Ombuds
Office of the Developmental Disabilities Ombuds

Stacy Dym

Executive Director
Arc of King County

Beth Krehbiel

Acting Chief of Medicaid and Eligibility
Department of Social and Health Services
Developmental Disabilities Administration

Gail Kreiger, BSN

Section Manager, Medicaid Compliance Review and
Analytics, Medicaid Program Operations and Integrity

Gary Stobbe, MD

Clinical Associate Professor
Medical Director, UW Medicine Adult Autism Clinic

Current Crisis Services for IDD/ASD Population

Medicaid offers:

- Community-based behavioral health outpatient agencies
- Community Network Program in King County offers crisis stabilization supports.
- Out of State In-Patient Placement: Because there are no inpatient facilities who serve those with severe IDD experiencing a mental or behavior health crisis

DDA offers:

- Community Crisis Stabilization Services, 3 beds in Lakewood
- Enhanced Respite Services, 3 locations in WA
- Behavior Support and Consultation depending on waiver

Current Crisis Services for IDD/ASD Population -continued

- **Individuals with IDD in crisis are directed to call 911 or take to the Emergency Department, call their DDA case manager to access other supports, or contact their behavioral healthcare provider:**

This may lead to:

- Children's Long-Term MH Inpatient Program (CLIP): State-run Inpatient Psychiatric Facility
- Private Inpatient Hospital (typically meant to be short-term)
- Prolonged boarding in Emergency Room or Hospitals

- The individual in crisis is taken home, medicated, isolated, and unsafe to self and family members

Overview of the problem

- Crisis services in *all systems* are very limited compared to the need resulting in individuals stuck in hospitals or returning to parents home unstable and unsafe.
- Scope of problem not well understood – not enough data collected on hospital admissions etc.
- Placement in settings with no or limited staff trained to work with IDD, mental health and ASD (e.g., inpatient settings).
- Lack of preventative services to head off crisis (e.g., community, in-home, out-patient clinic, IOP, or partial hospitalization programs focused on treatment of severe behavior in IDD population)
- Lack of specialized, interdisciplinary, intensive settings an individual can be placed once in crisis (e.g., specialized inpatient units)
- The lack of interdisciplinary and coordinated crisis supports places pressure on other systems of support. **One example: Psychiatrists and other medication prescribers. *Meds should not be the sole intervention, unfair to individual and places undue burden on providers.***

Overview of the problem

- 2011 Survey
- 9 specialized Inpatient Units in US
- 6 States
- Now 1 in Colorado

Siegel et al., 2011

*Specialized Inpatient Psychiatry
Units for Children with Autism and
Developmental Disorders: A U.S.
Survey*



Overview of the Problem--continued

- Lack of residential options and high levels of staff turnover in residential placement
- Overall Shortage of specialized providers to do the work
- Lack of coordinated continuum of step-down or step-up of intensity of services
- Lack of supports to family members who also experience the crisis
- Care is fragmented and unevenly distribution of services throughout the state.



Our Panel

David O'Neal

IDD Services Director, Behavioral Health Agency
Sound Health

Arzu Forough

President, Chief Executive Officer
Washington Autism Alliance and Advocacy

Elizabeth Landry

Staff Attorney
NW Justice Project

Beth Leonard

Legal Counsel to the DD Ombuds
Office of the Developmental Disabilities Ombuds

Stacy Dym

Executive Director
Arc of King County

Beth Krehbiel

Acting Chief of Medicaid and Eligibility
Department of Social and Health Services
Developmental Disabilities Administration

Gail Kreiger, BSN

Section Manager, Medicaid Compliance Review and
Analytics, Medicaid Program Operations and Integrity

Gary Stobbe, MD

Clinical Associate Professor
Medical Director, UW Medicine Adult Autism Clinic

Questions



David O'Neal

IDD Services Director, Behavioral Health Agency
Sound Health

What is the nature of crisis, why does it arise, and common factors that create crisis situations?

Questions

Arzu Forough

President, Chief Executive Officer
Washington Autism Alliance and Advocacy



Individuals with IDD and Mental Health issues often do not currently have a medical home. What do you see as the outcomes when these individuals don't have a medical home? Can this lead to crisis?

- *Please explain what a medical home is and why it is important in terms of this issue?*

Questions

Elizabeth Landry

Staff Attorney

Northwest Justice Project



Can you tell us a few examples of individuals and families who experienced a behavioral or mental health crisis and who were served by the Northwest Justice Project?

Questions



Beth Leonard

Legal Counsel to the DD Ombuds
Office of the Developmental Disabilities Ombuds

Can you describe how the DD Ombuds became aware of the lack of crisis services issue and how the DD Ombuds responded?

Questions



Stacy Dym

Executive Director
The Arc of King County

Many of the topics discussed so far focus on the child in crisis. However, a child in crisis impacts the entire family. What are the current supports in place for parents and care providers and how can those be improved?

Questions



Beth Krehbiel

Acting Chief of Medicaid and Eligibility

Department of Social and Health Services Developmental Disabilities Administration.

How can DDA help families who are in crisis now and what can families expect from DDA and their case manager when in crisis?

Questions

Washington State
Health Care Authority

Gail Kreiger, BSN

Section Manager, Medicaid Compliance Review and Analytics

Medicaid Program Operations and Integrity

What are current services available by HCA to help severe behavior in the IDD population?

Questions



Gary Stobbe, MD

Clinical Associate Professor

Medical Director, UW Medicine Adult Autism Clinic

How do we scale up services to address the great need in the State? What type of data do we need to gather to get a better picture of the crisis problem?

Questions



David O'Neal

IDD Services Director, Behavioral Health Agency
Sound Health

How can we address the lack of preventive care so that individuals do not get to crisis phase---which is most expensive and has the least number of resources available?

Questions



Beth Leonard

Legal Counsel to the DD Ombuds
Office of the Developmental Disabilities Ombuds

What are some possible systemic solutions that could improve the crisis response system for people with Autism and IDD?

Questions

Arzu Forough

President, Chief Executive Officer
Washington Autism Alliance and Advocacy



Knowing what the current state of crisis services are what do you see as possible solutions to improve these services?

- *Why are these proposed solutions the right ones?*
- *How should they be implemented?*

Questions



Gary Stobbe, MD

Clinical Associate Professor

Medical Director, UW Medicine Adult Autism Clinic

Tell us about the recently funded Echo Model for training and how it might impact crisis and scaling up services in State?

Questions

Washington State
Health Care Authority

Gail Kreiger, BSN

Section Manager, Medicaid Compliance Review and Analytics

Medicaid Program Operations and Integrity

What work is HCA doing now to address the barriers to getting appropriate preventative and crisis care for individuals with IDD and severe behavior?

Questions

Beth Krehbiel

Acting Chief of Medicaid and Eligibility

Department of Social and Health Services Developmental Disabilities Administration.



Can we expect DDA to expand crisis services? If yes, what can we do to help make this happen? If no, in your opinion, why and where should parents and advocates put their focus?

Questions

Elizabeth Landry
Staff Attorney
Northwest Justice Project



Can you discuss the legal rights these families have to services and placement?

Questions

Stacy Dym

Executive Director

The Arc of King County



Call to Action:

What can parents, advocates, providers, and concerned members of society do to get involved to affect change in the system?

Information:



NPR Radio: Hundreds of people who are stuck in Washington hospitals without medical need because of a lack of community placements. Families, advocates sound alarm: <https://www.kuow.org/stories/families-advocates-sound-alarm-over-patients-stuck-in-the-hospital-without-a-medical-need>



In this report, the **DD Ombuds** describes its findings that individuals with developmental disabilities are dropped off and left at hospitals by service providers, after which their services are terminated. This has left many individuals at the hospital with no place to go for long periods. This is a preventable problem. View the report here:

<https://ddombuds.org/wp-content/uploads/2018/12/DD-Ombuds-Hospital-Report-12.10.18-Final.pdf>

Advocacy—A Call to Action



Contact your elected officials.

This is a legislative issue—and will require policy changes and funding.

- **The Arc of King County** offers advocacy training, civic engagement, leadership, and annual an informative legislative forum in November.
- **Arc of Washington** www.arcwa.org to find your local Arc
- **Office of Developmental Disabilities Ombuds:** <https://ddombuds.org/>
- **Washington Autism Advocacy and Alliance** www.washingtonautismadvocacy.org

Special Thanks to...



Individuals living in crisis and those who love them.



Our panel members for their dedication and commitment to improving crisis services, systems, and quality of life for individuals with IDD and Autism who are currently in need of crisis stabilization.



All of you who join the call to action!