911 for Families Raising Children with Disabilities: Preparing for Interactions with First Responders

Presented by:
Eric Ringgenberg; M.A., B.S.
Kaylie Schmidt; Family Advocate
Session Outline

- Presenter Introductions
- Planning and Practice
- Systems of Disclosure
- Visual Supports
- De-escalation Strategies
- Community Resources

- Disability and Intersectionality
- Prevent, Teach, Respond
- Community Resources
Presenter Introductions

• Eric Ringgenberg
  – Education Program Director, AuSM

• Kaylie Schmidt
  – Parent, Family Advocate
Disability and Intersectionality

- Disability impacts all communities, locally and globally.

- While consistent across communities, access to diagnosis and support services differs across demographics and identities.
  - Race/ethnicity
  - Socioeconomic status
  - Sexuality/gender
  - Geography
  - Age
Intersectional Stigma

• Different stigmas are often correlated and interrelated, and their combined effects can be additive but may often be more complex.

• Many people experience intersecting forms of stigma, which have complex effects on health behaviors, physical health, and mental health.

(Mccauley, 2017)
ADA and Police: Training as a Reasonable Accommodation

- “dealing with this specific disability at the moment of a police encounter is simply too late… If police conduct is excused because of exigent circumstances, or if officers can simply assert that they were unaware that someone had ASD, then some of the protections that Title II is supposed to provide are essentially eliminated… It leads to a self-fulfilling, cyclical problem.”

  (Shonebarger, 2019)

Positive Behavior Support

Prevent

Teach

Respond
• Families are the main providers of support for their autistic family members, and yet their role is not recognized or supported as it should be.

• Families of color and those with lower incomes face additional difficulty and stressors when trying to access services and supports and locate quality care.
Anxiety Curve

1. This is the foundation of your plan. This is where positive and valuing relationships are built and where you teach skills needed to function successfully in challenging situations. Examples might include the 5-point scale, Social Stories, Power Cards, a calming sequence, yoga, or social skills.

2. Now is the time to leave the anxiety producing event if possible.

3. Use encouraging, supportive words here. If possible, don’t discuss the incident.

4. This is peak anxiety. It is not a time to talk, direct or problem solve. Redirection here can result in a ripped assignment. The person should be encouraged to relax rather than make any decisions.

5. This is not a time to ask the person to make choices. Model calming strategies.
Distressed Behavior: Iceberg Metaphor

Observable Behaviors
- Refusal
- Yelling, Threats
- Aggression/Self-injury
- Shutdown
- Elopement

Underlying Needs
- Physical Health
- Communication
- Cognitive Flexibility
- Sensory Perception
- Emotional Regulation
- Mental Health
- Adaptive Behavior
Competing Behavior Pathway

Setting Event: 

Antecedent: 

Problem Behavior 

Desired Behavior 

Consequence: 

Consequence: 

Functions: 

Alternate Behavior
Preparing for Emergencies

• Natural Disasters
  – Tornado
  – Flood
  – Winter Storm

• Emergencies
  – Fire
  – Power Outage
  – Illness/Injury
  – Car Accident
Most emergencies can result in one of two plans of action:

- **GO**: leave immediately and evacuate
- **STAY**: shelter-in-place, don’t go out

Important to think about home, but also work, school, and/or other common locations you spend time.

Individuals with specific and/or severe needs can benefit most from proactive planning.


Four Elements of Evacuation Information

1. Notification (What is the emergency? How will I be notified?)
2. Way finding (Where is the way out?)
3. Use of the way (Can I get out by myself, or do I need assistance?)
4. Assistance (What kind of assistance might I need?)
Tips For Emergency Planning

• You should communicate with others, such as family members, friends, co-workers, and neighbors.

• Plan and practice how to escape from your home in an emergency.

• Keep a “Go Bag” with emergency supplies.

• Practice telling people about your personal needs.
Safety Planning at Home

• **Items to Have Available:**
  – Smoke and Carbon Monoxide Detectors
  – Fire Extinguisher
  – First-Aid Kit
  – Flashlight/Candles
  – Matches/Lighter
  – Weather Radio
  – Supply of Food, Water, Medication

Don’t Forget About Pets!
Systems of Disclosure

• Verbal Disclosure
• Medical Alert
• Wallet Card
• VITALS
• Project Lifesaver
What is Disclosure?

• Sharing personal information about your disability with someone for the purpose of receiving accommodations, support, or understanding.

  – **Types of Disclosure:**
    • Formal Disclosure
    • Informal (Soft) Disclosure
    • Non-Disclosure
What Information to Share?

• Disclosure is a personal decision. Whether to share, when to share, and what to share depends on the situation and your preferences.
  – Label:
    • “I have autism/am autistic”, “I have a disability”
  – Need:
    • “I have trouble focusing when it is noisy”
    • “I need to be able to move my body to stay in control”
Medical Alert

• Wearing a medical ID can help prevent misdiagnosis, unwanted drug interaction, and treatments that can pose risk to a patient’s medical condition.

• EMS personnel are trained to look around the neck or wrist which gives wearers a choice between a medical alert bracelet or necklace.

• Health insurance plans may reimburse you for the purchase of your medical ID.
Free Wallet Card

• [https://www.americanmedical-id.com/free-wallet-card](https://www.americanmedical-id.com/free-wallet-card)

• **Code:** MYFREEWC
VITALS

• The only digital medical ID shared with first responders in real-time. Reduce the risk of misunderstandings during medical or mental health emergencies.

• Vitals™ Profile911 gives you the ability to share critical information such as disabilities and conditions, allergies, behavior triggers, de-escalation techniques, medications, emergency contact info and more!

• https://thevitalsapp.com/communities-where-we-are
VITALS

Allen ("Big Al") Bernard

Early Stage Dementia
Diabetes

<table>
<thead>
<tr>
<th>ALERT</th>
<th>COVID-19 At-Risk</th>
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| Gender:     | Male             |
| Age:        | 78               |
| Height:     | 6'2"             |
| Weight:     | 250              |

Critical Information
I am overall a pretty healthy person aside from my Diabetes. Due to my age and my diabetes, I am at greater risk for getting the COVID-19 virus. I currently live by myself and have been experiencing stages of memory loss. My daughter stops by occasionally and helps me buy groceries, but due to the virus, and for my safety and hers, she is not going to come around as often.

De-Escalation Techniques
If I were to be in an emergency situation or am confused, know I am at risk for COVID-19, and call my daughter 763.212.3045.

Vitals™ Standard Bluetooth Device $20.00
Vitals™ Bluetooth Device - Tag $25.00
Vitals™ Bluetooth Waterproof Band $40.00
Project Lifesaver

- Uses radio technology and specially trained search and rescue teams.

- Individuals enrolled in Project Lifesaver wear a small transmitter on the wrist or ankle that emits an individualized frequency signal. If an enrolled individual goes missing, a trained emergency team responds to the area.

- First responders will then use the individualized frequency to locate the position of the individual.
Project Lifesaver
Communication Strategies

• Use language that is simple, clear, and literal
• Allow for additional processing time
• Break directives down into specific steps
• Offer choices
• Use written or visual communication
### 5-Point Scale

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<tr>
<th>5 Point Scale</th>
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- What does it look like?
- What does it feel like?
- What strategies can I use?
Zones of Regulation

The ZONES of Regulation®

BLUE ZONE
- Sad
- Sick
- Calm
- Tired
- Bored
- Moving Slowly

GREEN ZONE
- Happy
- Calm
- Feeling Okay
- Focused
- Ready to Learn

YELLOW ZONE
- Frustrated
- Worried
- Silly/Wiggly
- Excited
- Loss of Some Control

RED ZONE
- Mad/Angry
- Terrified
- Yelling/Hitting
- Elated
- Out of Control

The ZONES of Regulation Visual

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Relationship Circles

Interpersonal boundaries:

• Physical contact
• Information sharing
This is the foundation of your plan. This is where positive and valuing relationships are built and where you teach skills needed to function successfully in challenging situations. Examples might include the 5-point scale, Social Stories, Power Cards, a calming sequence, yoga, or social skills.

1. This is the staff or parent curve. You need to control your own anxiety during a crisis in order to help to diffuse the person’s anxiety. Your instincts tell you to engage in fight or flight, you can do neither. Use silence and your own calming sequence.

2. Now is the time to leave the anxiety producing event if possible.

3. Use encouraging, supportive words here. If possible, don’t discuss the incident.

4. This is not a time to ask the person to make choices. Model calming strategies.

5. Redirection here can result in a ripped assignment. The person should be encouraged to relax rather than make any decisions.

This could include hitting, throwing, biting, swearing and crying.
Calming Strategies

• Dim lights and lower sounds, reduce sensory input
• Remove individuals and limit number of people interacting
• Reduce verbal language, give simple directives
• Limit touch, give advanced notice before doing so
• Give space, allow movement/stimming
• Take a break to regulate
Meltdowns: S.C.A.R.E.D. Method

- Safe - Move to or create a safe space
- Calm - Simple instructions
- Affirmations - Positive statements
- Routine - Strategies to recover
- Empathy - Trauma-informed approach
  - “what happened to you” not “what’s wrong with you”
- Develop - Safety plan
• **Instructions to use Text-to-911:**
  
  – In the “To” part of the text message, enter the numbers 911.
  – In the text message, describe your location or provide an address and describe the emergency.
  – Press send.
  – Dispatch will ask if they can voice call you so that they can gather information more quickly and gather your exact location. If you are not able, let them know.
  – Wait for a response with instructions and respond promptly.
  – Do not use emojis, slang, abbreviated text, or photos in Text-to-911.
ICE- In Case of Emergency

• Store emergency numbers in your cell phones under “ICE” (“In Case of Emergency”), so someone else can call your emergency numbers if you’re not able.

• Use more than one entry (“ICE-1,” “ICE-2,” etc.) if you have more than one emergency number.
Community Resources

• County Crisis Response Teams
  – https://namimn.org/support/resources/crisis-resources/

• Waivered Services
  – MNChoices Assessment

• Respite
Emergency Preparedness Resources

- https://www.ready.gov/
- https://thevitalsapp.com/
- https://projectlifesaver.org/
- https://www.americanmedical-id.com/free-wallet-card
- https://www.justdigit.org/wallet-cards/
- https://ausm.org/ausm-services/training/emergency-preparedness.html
- http://www.temple.edu/instituteondisabilities/aacvocabulary/e4all/EprepPictureAid.pdf
Resources

- https://namimn.org/support/resources/crisis-resources/
- http://www.lifecoursetools.com/
- https://drexel.edu/~media/Files/autismoutcomes/publications/NAIR%20Family%202021%20Final.ashx