

# AUTISM SPECTRUM DISORDER EMERGENCY PREPAREDNESS AND RESPONSE STRATEGIES

*For Minnesota Families and Public Safety  
Officials*

*June 2011*



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# ABOUT THIS PROGRAM AND OUR PARTNERS



In January 2011, The Minnesota Governor's Council on Developmental Disabilities (Governor's Council) in partnership with the Autism Society of Minnesota (AuSM) received a grant from the Minnesota Department of Human Services—Disability Division to assess needs and recommend solutions for improved emergency preparedness and response for persons with Autism Spectrum Disorder (ASD).

The original focus of the grant was on resources for persons with ASD and presumably that professional responders could leverage as well. Our research indicated a particularly pressing need for general awareness about ASD and the unique challenges for public safety officials—police, fire, EMS—when interacting with persons with ASD in emergency situations.

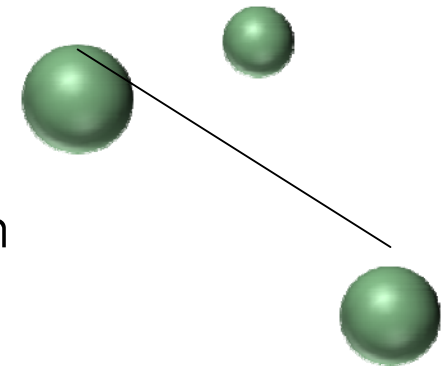
The purpose of this presentation is to begin to address that “awareness” gap and to provide an overview of the new resources now available to improve emergency preparedness and planning for persons with ASD and their families and to better inform our community support systems on how to better serve and respond to persons with ASD in emergency situations and emergency planning.

**Many thanks to DHS and the Governor's Council for their funding and support for this initiative.**

# AUTISM

## FASTEST GROWING DEVELOPMENTAL DISORDER

- 1 in 110
- less than 2 years ago it was 1 in 150
- 12,000 Minnesota families
- 13,000 children
- age 8 is the largest bubble of children diagnosed
- largest adult population of people with ASD in history



According to the Centers for Disease Control, Autism currently affects 1 in 110 children and many families have multiple children on the spectrum. According to the Autism Spectrum Disorder Foundation, more children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined.

# AUTISM AND EMERGENCY SITUATIONS

- Persons with ASD are **7 times more** likely than their neuro-typical peers to have an **emergency encounter**
- Professional responders (police, fire, EMS, ECC, emergency management and others) are **generally unprepared for the specific needs and challenges** that this group will present
- Under The Americans with Disabilities Act (ADA) people with disabilities must be provided with **an equally effective opportunity to participate** in, or benefit from, a public entity's aids, benefits, and services

7 Times  
more often



ADA &  
Emergencies

# OUTLINE

- About ASD and Emergency Preparedness and Response
- What is Autism Spectrum Disorder (ASD)?
- Why is this a challenge in emergency situations?
- Findings of recent study
- New resources now available
- What you can do to help

Please reference Notes Pages for additional detail within this presentation.

# WHO IS THE AUTISM SOCIETY OF MINNESOTA?

☐ be informed   ☐ be prepared   ☐ be involved

**Our mission:** as an agency of families, educators, caregivers and professionals, we are committed to supporting individuals with ASD and their families.

**Our vision:** to realize its mission through education, support, collaboration and advocacy.

Established in 1971 as the local presence of the autism community in MN we have provided over 40 years of services and programs that have enhanced the lives of individuals with ASD.

# WHY IS AuSM INTRODUCING THE EMERGENCY PREPAREDNESS PROGRAM

**Knowledge and awareness** are essential to ensure better Preparedness and Response in an emergency situation, especially for persons with ASD, Families, Public Safety Officials and the Community. Learn more about.....

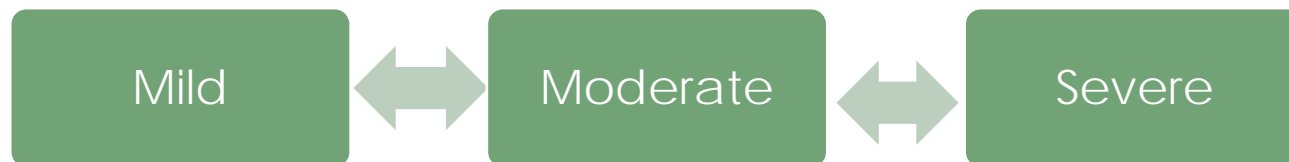
- What is Autism Spectrum Disorder
- Characteristics of Persons with ASD
- Common Emergency Scenarios
- The Challenge for Professional Responders

# WHY IS AuSM INTRODUCING THE EMERGENCY PREPAREDNESS PROGRAM

- Our intent today is not to provide extensive insight and training about ASD—there is a wealth of information and training generally available and some of you may even be certified as an educator, psychologist or other professional discipline to support persons with ASD.
- In fact it is unreasonable to demand or expect that level of understanding and competency from all members of our community or even public servants like public safety professionals. Rather our hope is to create enough awareness and skill through the new resources now available so that persons with ASD, their families and caregivers, and public safety professionals can promote safe outcomes and be more effective in preparing for, avoiding and responding to these situations.

# ABOUT AUTISM SPECTRUM DISORDER

- Complex Neurological disorder affecting how the brain processes information. **A lifelong disability.**
- Affects **essential human behaviors**—social interaction, communication, repetitive patterns of behavior and interests
- A “spectrum disorder” that **affects each person differently**. Symptoms can be mild, moderate or severe.
- Family income, lifestyle, education, race and ethnicity **are not dispositive.**
- Identify by behaviors, not physical characteristics. At first glance **a person with ASD looks just like you and me!**



# CHARACTERISTICS OF PERSONS WITH ASD

- Verbal direction, physical touch, strobe lights and sirens are likely to **cause fear and anxiety**.
- Very literal and need more time to process commands. Fear and anxiety further hinders effective communication. **May be difficult** to provide information during an emergency even for persons who communicate verbally.
- May not comprehend danger. Anxiety and sensory “overload” or discomfort may result in “**fight or flight**” response.
- Often unable to sense and thus greater tolerance of **heat, cold and pain**.

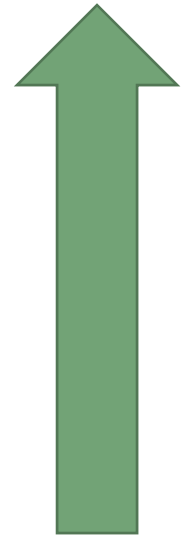
Fight

Flight

Fright

# CHARACTERISTICS OF PERSONS WITH ASD

- Attraction to water – **drowning is the number one cause of death** for persons with ASD.
- Repetitive, self stimulating behaviors and movement, and echolalia are common and **may be confused** with mental illness, aggression or someone high on drugs—may actually be calming to the individual.
- Poorly developed upper trunk creates **greater risk** of positional asphyxiation
- May be self destructive and wandering is common. Strategies employed by families and caregivers for safety or to teach life skills **may look odd or appear abusive.**



**RISK**

# COMMON EMERGENCY SCENARIOS



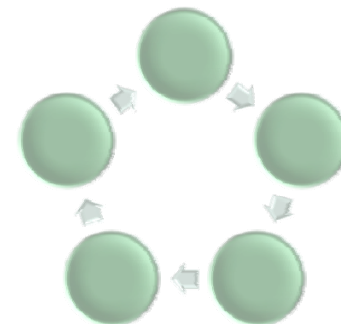
- Police
- Fire
- EMS
- Emergency Management
- Wandering Incidents

# THE CHALLENGE FOR PUBLIC SAFETY OFFICERS

- Professional responders may need to respond to a person with ASD in a manner different than how they respond to others.
  - **The most effective response may not be readily apparent or may be counter intuitive from customary response training and protocols.**
- Responders may find it unusually difficult, if not impossible to calm, direct or obtain basic information from a person with ASD who is in danger, injured or in pain.
  - **A lack of awareness, training and information on what to do when interacting with a person with ASD may hamper the responders' effectiveness, critically delay assistance or cause more harm.**
- A lack of awareness, training and information may be further exacerbated with the "hand off" of a vulnerable adult to emergency room personnel or the criminal justice system (especially without adequate briefing on the person's condition and unique circumstances).

# STRATEGIES FOR BETTER PREPAREDNESS AND RESPONSE

What strategies can we bring to bear to ensure safety and lower the risk for persons with ASD (children and adults) in emergency situations?

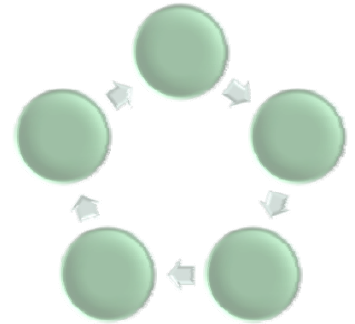


- For persons with ASD and their families
- For Public Safety Officials
- For Social Service Professionals, Educators and others supporting persons with ASD

# KEY FINDINGS

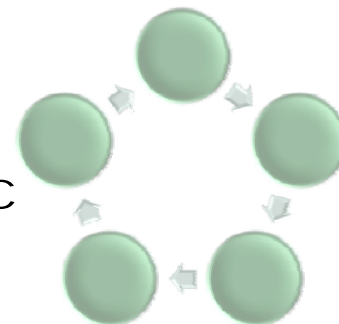
- The reaction to this topic has been Overwhelmingly positive.

Adults with ASD, families of children with ASD, public safety officials and other professional supporters are clamoring for greater awareness and practical guidance.



# KEY FINDINGS

- A wealth of information and resources already exist, but the community seeks help to navigate resources and plan their own actions.
  - Create **greater awareness** about the issue through basic training, most notably for public safety officials.
  - Create **roadmaps for persons with ASD** and public safety officials alike to help them navigate available resources and plan their own actions.
  - Particularly for people on the spectrum and families, identify a **range of solutions** from no tech-know how, to low tech, to high tech
  - Provide a **clearinghouse** to access information and resources.



# OTHER LEARNING—FROM PEOPLE WITH ASD

- **Understand personal responsibility**, need to “own” their situation and recognize need of responders to protect self and the safety of others.
- This is **a diverse population**. A one size fits all kit or package is not productive or useful.
- **Easily overwhelmed** by breadth of information and choices available.

**Families need supports** to help children be prepared. Low income families have limited access to supports.

- Make emergency preparedness, planning and training easily **accessible, simple and straightforward**.
- **Effective outcomes** can be achieved by using materials and tools to react appropriately and to facilitate an appropriate response in emergency situations

ie: ID, storing ICE information, planning, practice.

# OTHER LEARNING—FROM PUBLIC SAFETY OFFICIALS

- Among all responder disciplines, there is **a need for general awareness and strategies** in order to best support persons with ASD within their communities.
- Prefer messages **uniquely relevant** to their discipline.
- Responder community is **highly fragmented**--state, county, local and by discipline—each with their own jurisdiction and autonomy.
  - Nonetheless, major disciplines all have licensing and CE requirements, statewide associations and governing bodies that can be leveraged to create awareness and promote ASD specific training if we make some basic tools and resources available.
- Responders can only tailor their response **if they know the person has ASD** and if they have the awareness and skills to act differently than normal training and protocols might require.

# CONCLUSIONS

- Identify **Emergency Preparedness Essentials (EP Essentials)** for those affected by ASD and for professional responders.
- Suggest a range of **potential solutions** to facilitate better preparedness.

Example, Project Lifesaver is a great solution for wandering only if supported by someone's community and if they can wear and manage the device

- **Create a clearinghouse**, through AuSM, for resources, training, speaker's bureau and guidance on Emergency Preparedness and autism awareness education.
- DHS, Governor's Council, lead agencies and other community leaders can similarly **create awareness**, highlight the same resources and direct inquiries to AuSM and consult AuSM for assistance as needed.

# NEW RESOURCES NOW AVAILABLE



- **Turnkey Solutions for Training and Awareness**
  - General Awareness Presentation
  - Responder videos (for demonstration or loan)
  - Discipline specific responder training modules and handouts
    - Police, Fire, EMS
- **EP Essentials Overviews and Resource Lists**
  - For Persons with ASD/Families/Caregivers
  - For A Broad Array of Public Safety Officials
- **Suggestions and Guidance**
  - Specific materials and tools for Emergency Preparedness
  - 5pt scale and Video Modeling tools also help families plan and practice

Encourage families and community leaders to leverage educators and public safety officers who have children with ASD to educate others using the tools provided!

# EP ESSENTIALS FOR PERSONS WITH AUTISM SPECTRUM DISORDER

*Six Ways To Prepare BEFORE An Emergency Happens*

Assess the Risk

Identify Yourself

Educate Your Support Network

Make a Plan and Practice

Prepare for Wandering  
(if needed)

Be an Advocate

*Consult the one page overview and detailed resource list entitled "EP Essentials for Persons with Autism Spectrum Disorder" for further guidance*

# EP ESSENTIALS FOR PROFESSIONAL RESPONDERS

*Six Ways To Prepare BEFORE An Emergency Happens*

Be Aware

Learn More  
about ASD

Get to Know  
Persons  
w/ ASD

Tailor your  
Response

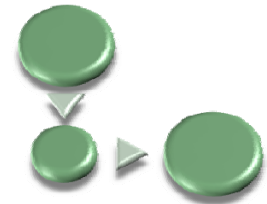
Prepare for  
Wandering

Communicate  
Effectively

Public safety officials also need to prepare before an emergency encounter. *Consult the one page overview and detailed resource list entitled "EP Essentials for Professional Responders" for further guidance.*

# WHAT CAN YOU DO?

- Create Awareness
- Utilize Resources and Training
- Act On Resources and Training
- Advocate and Encourage Others to Do the Same



## This Is A Beginning—By No Means the End!

- Invest in infrastructure for community outreach and training of public safety officials across all disciplines and in all communities

# HOW TO ACCESS RESOURCES



- Available on **AuSM website**: [www.ausm.org](http://www.ausm.org)
- **Minnesota Governor's Council on Developmental Disabilities website** [www.mnddc.org](http://www.mnddc.org)
- **PathLore** (for DHS and others with access)
- **Contact AuSM** for assistance, more information or speaker's bureau. [info@ausm.org](mailto:info@ausm.org) or 651-647-1083

# THANK YOU

