

Developmental Disabilities: The Benefit of Local Training and Storytelling



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PerformCare/AmeriHealth Caritas

New Jersey

Agenda

Understanding

Understanding developmental disabilities and their impact

Reviewing

Reviewing community preparedness and response initiatives

Highlighting

Highlighting health and mental health disparities

Exploring

Exploring challenges during extreme weather events

Showcasing

Showcasing training programs and volunteer involvement

**Academic and
Government
Data**

**Our
Professional
Experiences**

**Our Lived-
Experiences**



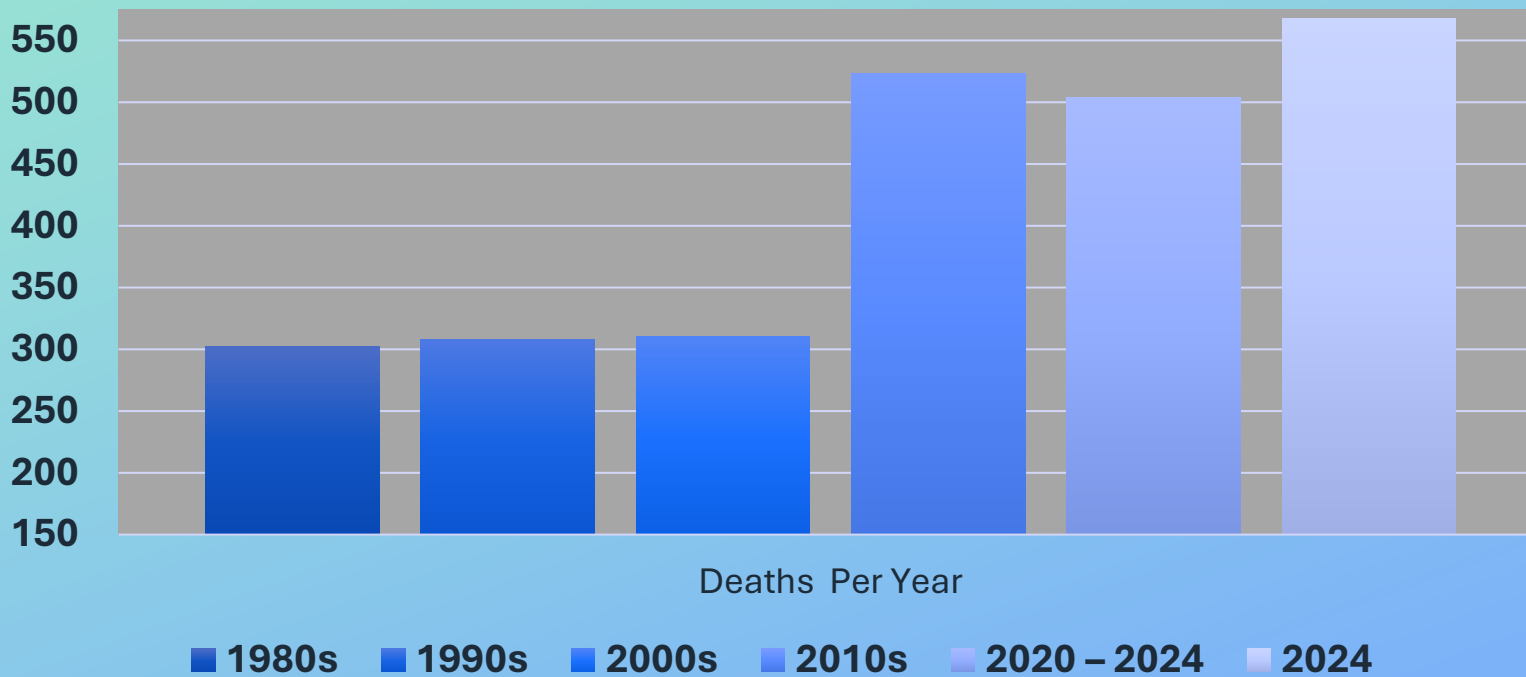
**The Monmouth
Method**

- **Jason**
- Licensed therapist
- Co-Chair, Monmouth County Board of Wellness and Support Services.
- Board Member, National Association on the Dually Diagnosed
- MRC Volunteer

- **Lauren**
- County of Monmouth, NJ - MRC Coordinator
- Manalapan Township, NJ – MRC/CERT Leadership Team
- Sponsor Manalapan TEEN CERT
- Previous NJEPA speaker

Growing Concerns

Annual Deaths Due to Natural Disaster



	Events Per Year (\$1 Billion)
1980s	33
1990s	57
2000s	67
2010s	131
2020 – 2024	115
2024	27

“The Impacts of Extreme Weather Events on People with Disabilities,” National Council on Disability, May 4, 2023, <https://www.ncd.gov/assets/uploads/reports/2023/ncd-extreme-weather-2023.pdf> “Billion-Dollar Weather and Climate Disasters,” National Centers for Environmental Information, 2025, <http://www.ncei.noaa.gov/access/billions/>

Report on Extreme Weather Events



“People with disabilities are 2 to 4 times to be injured/killed in natural disaster.”³



40% adults 65+ have a disability.³



2050 — 20% of the population will be 65+ (16% in 2020, U.S. Census).³



24% of IDD population had caregivers who were age 60 and older.³



Olmstead v. L.C. (1999) & Section 504 of the Rehabilitation

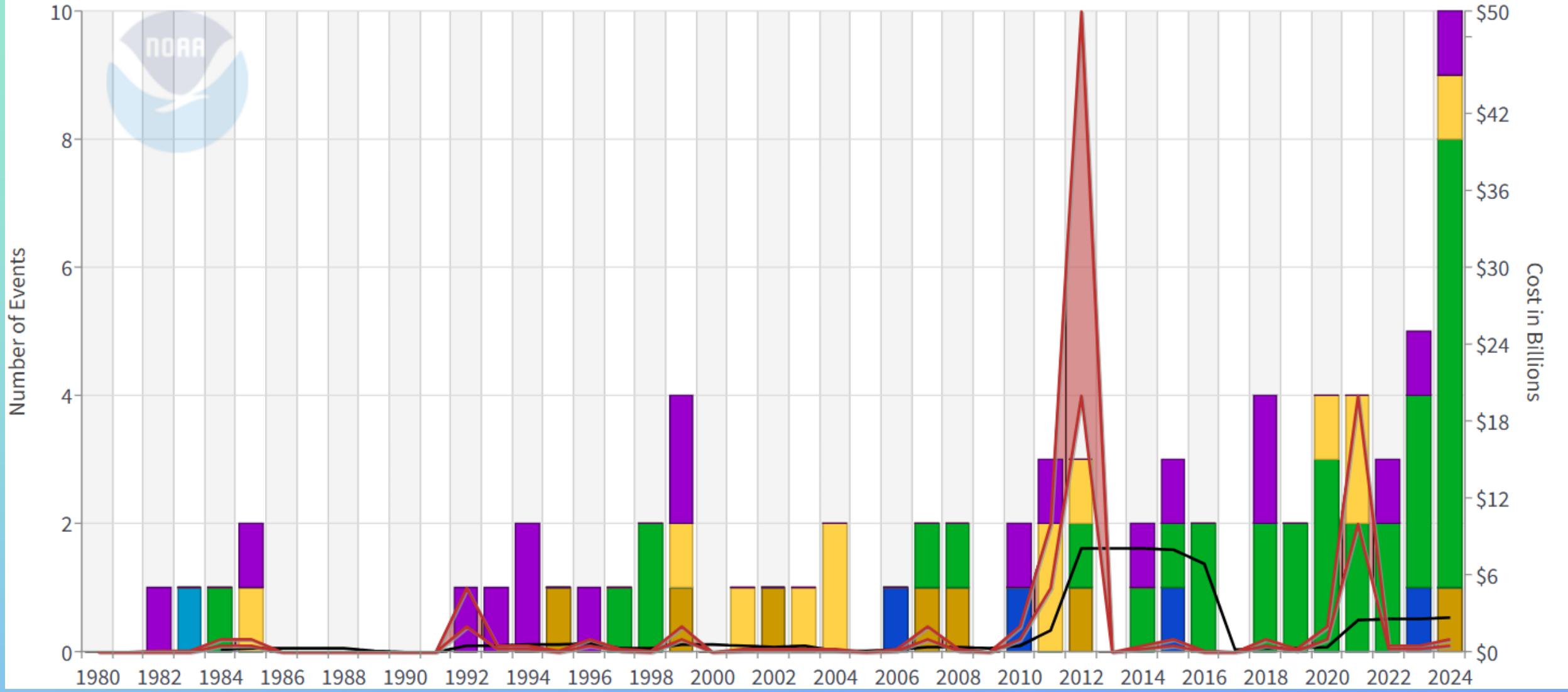


“The Impacts of Extreme Weather Events on People with Disabilities,” National Council on Disability, May 4, 2023, <https://www.ncd.gov/assets/uploads/reports/2023/ncd-extreme-weather-2023.pdf>

Zoe Caplan and Megan Rabe, “The Older Population: 2020,” United States Census Bureau, May 2023, <https://www2.census.gov/library/publications/decennial/2020/census-briefs/c2020br-07.pdf>

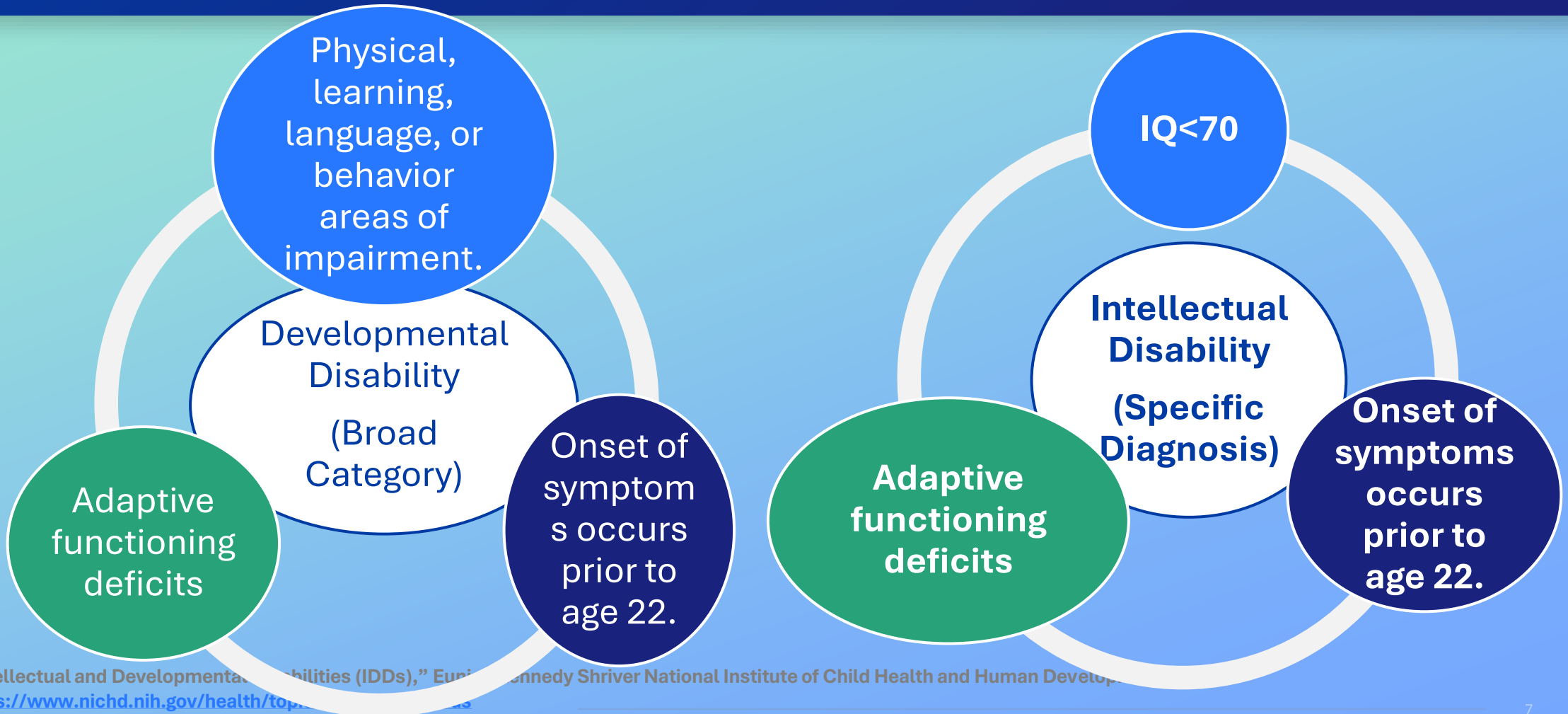
New Jersey Billion-Dollar Disaster Events 1980-2024 (CPI-Adjusted)

- Drought Count
- Flooding Count
- Freeze Count
- Severe Storm Count
- Tropical Cyclone Count
- Wildfire Count
- Winter Storm Count
- Combined Disaster Cost
- 5-Year Avg Costs



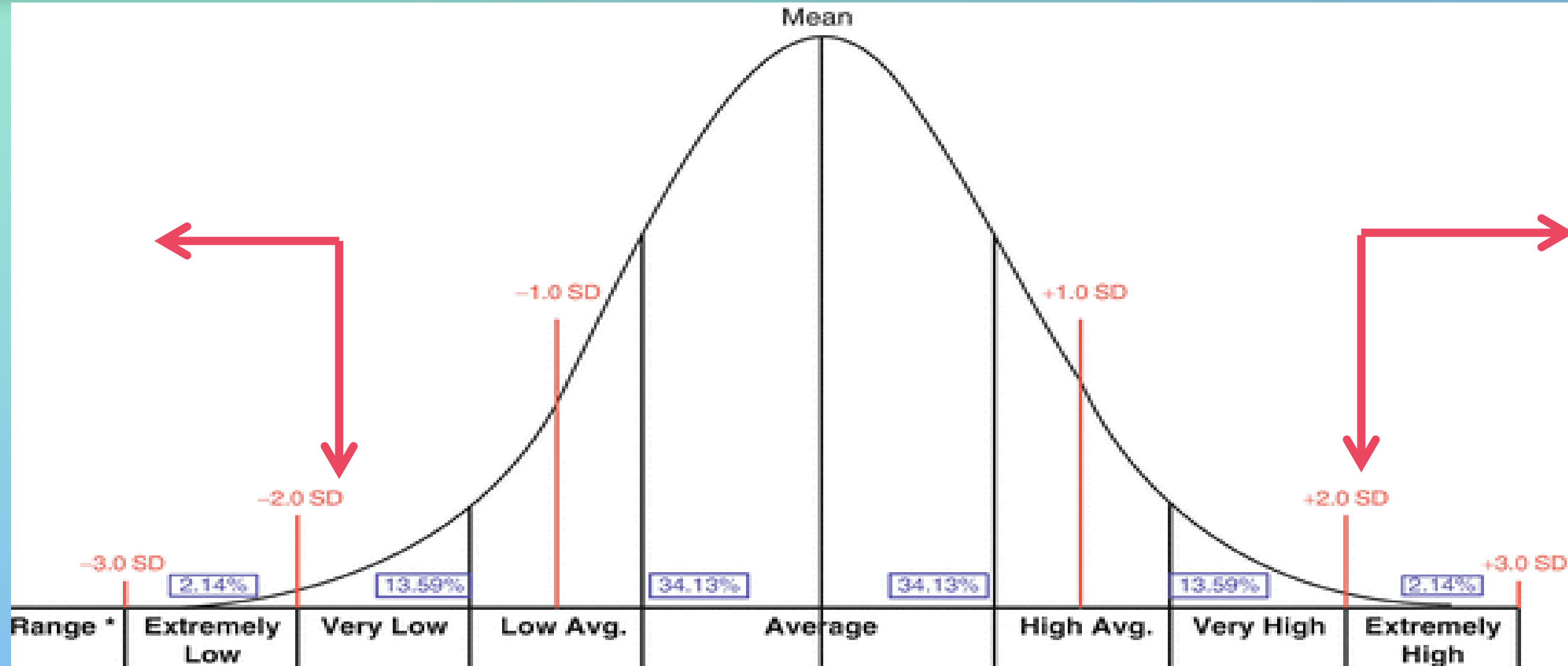
NOAA National Centers for Environmental Information (NCEI) U.S. Billion-Dollar Weather and Climate Disasters (2025). <https://www.ncei.noaa.gov/access/billions/>, DOI: 10.25921/stkw-7w73

Intellectual Disabilities and Developmental Disabilities (IDD)



Defining the Population

Koziol, L.F., Beljan, P., Bree, K., Mather, J., Barker, L. (2016). The Normal Distribution of the Bell-Shaped Curve. In: Large-Scale Brain Systems and Neuropsychological Testing. Springer, Cham. https://doi.org/10.1007/978-3-319-28222-0_3



Prevalent Developmental Disabilities

Autism (ASD)
1/29 (NJ)

Down Syndrome
1/775

**Fetal Alcohol
Syndrome**
1 – 5%

Cerebral Palsy
1 – 4/1000

Intellectual Disability
1.65%

Fragile X
M-1/7000
F-1/11,000

ADHD/Neurodiversity*
1/6

[A Snapshot of Autism Spectrum Disorder in New Jersey | CDC Archive](#)

Kelly Shaw et al., "Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years — Autism and Developmental Disabilities Monitoring Network, 16 Sites, United States, 2022," *MMWR. Surveillance Summaries*,

Vol. 74, No. 2, April 17, 2025, <https://doi.org/10.15585/mmwr.ss7402a1>

Gert De Graaf et al., "People Living With Down Syndrome in the USA: Births and Population," May 3, 2024, <https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-usa-factsheet.pdf>

IDD Health Disparities

• (Krahn & Fox, 2014)



People with DD make up roughly 15% of the population.

- About 1% have intellectual disability.



They are twice as likely to die prematurely.



Adults w/IDD's obesity rate is 14% higher.



As many as 60% may have a mental health condition.



Mental Health

Mental Health Diagnosis	IDD with DS (Charlot, 2021)	No DS with IDD (Charlot, 2021)	United States (NAMI, 2024)
Anxiety Disorders	18.8%	15.1%	19.1%
ADHD	11.9%	27.5%	Dev. Disability
Autism Spectrum Disorder	18.8%	39.7%	Dev. Disability
Bipolar/Related Disorders	6.9%	16.4%	2.8%
Depressive Disorders	26.7%	21.6%	8.3%
Disruptive Impulse Control Disorder	10.9%	19.8%	N/A
Trauma and Stressor Disorder	5.9%	10.6%	3.6%
Schizophrenia Disorders	5.9%	14.8%	<1%

<https://www.nami.org/about-mental-illness/mental-health-conditions/>

Charlot, L., Weigle, K & Calliope B. Holingue. (2021) Mental and Physical Health Conditions of Individuals with Intellectual and Developmental Disabilities (IDD) with and without Down Syndrome (DS), Journal of Mental Health Research in Intellectual Disabilities, 14:1, 122-134, DOI: [10.1080/19315864.2020.1864687](https://doi.org/10.1080/19315864.2020.1864687)

Diagnostic Overshadowing

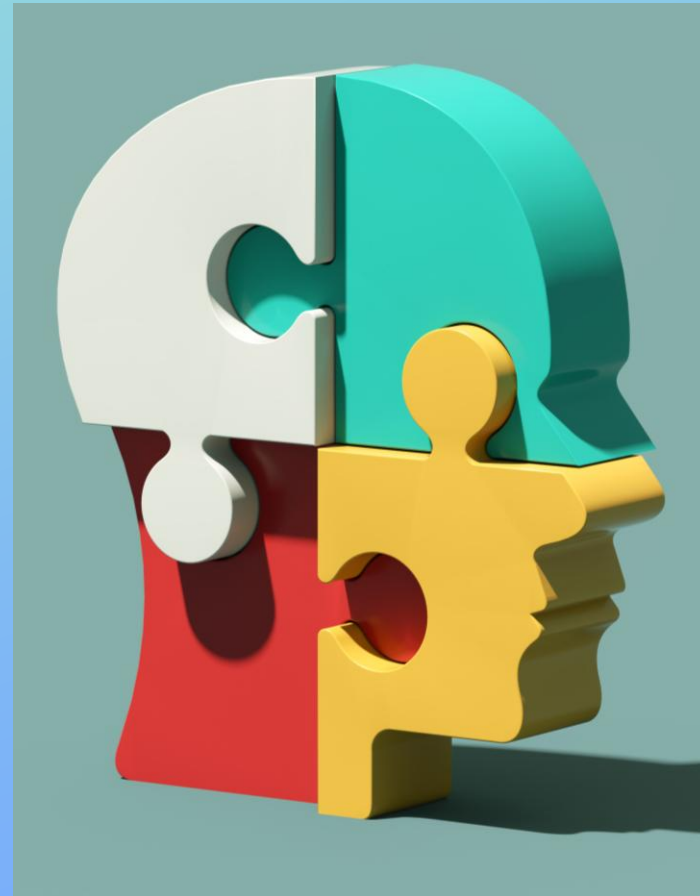


Common example- mistaking psychosis/intoxication for diabetes related issues.

Rossetti, P. (2020, May 29). *How "Diagnostic Overshadowing" Endangers People With Intellectual Disabilities*. The Mighty. <https://themighty.com/topic/intellectual-disability/psychosis-intoxication-for-diabetes-related-issues/>

“Nothing About Us, Without Us”

“If you’ve met one person with autism,
you’ve met one person with autism.”



Pandemic and All Hazards Preparedness Act (2019), ADA (1990 et al), ADAAA (2008)

- Requires considering the public health and medical needs of at-risk individuals in emergencies.
- "At-risk individuals" include children, pregnant women, older adults, people with disabilities
- **ADA Title II** mandates that state and local governments provide communication that is as clear for people with disabilities as for those without.
- The **ADA Amendments Act of 2008** expands the definition of disability and makes it easier for those with access and functional needs to be protected under the law.
- **ADAAA** requires that people with access and functional needs be included in all community disaster plans under **Title II**.
 - This means we are now meeting minimum criteria by pursuing trainings

Achieving Efficiency Through State and Local Preparedness (2025)

“...enable State and local governments to better understand, plan for, and ultimately address the needs of their citizens.”

“Achieving Efficiency Through State and Local Preparedness,” White House, March 19, 2025,
<https://www.whitehouse.gov/presidential-actions/2025/03/achieving-efficiency-through-state-and-local-preparedness/>



PerformCARE[®]

“Triage” – Why Storytelling Matters

- Empathic storytelling
- Allows for meaningful discussion
 - Personification
- Lived experience and disclosure
- MRC Leadership Committee
- Knowing your audience
- Political discourse



Lauren's Story

Allotted 10 minutes of cry-time on my steering wheel per day...



MRC Core Capabilities

- Emergency preparedness and response trainings and exercises
- Emergency shelter operations and medical care
- Disaster medical and behavioral health support
- Medical facility surge support
- Mass dispensing efforts (e.g., medication, water, other supplies)
- Disease testing and surveillance
- Community vaccination clinics
- Veterinary care
- Community education and outreach
- Emergency preparedness and response planning, logistical, and administrative support
- Support services to disaster call centers, family assistance centers, and reception/evacuation centers
- Emergency operations center and communications support
- Patient movement support
- Search and rescue operations
- Disaster clean-up and recovery support
- First aid and medical support during large public gatherings

New Jersey MRC Activities Reported

- MRC Unit by County data

New Jersey MRC Activities Reported

- January 2024-March 2026

Monmouth MRC is the 2nd most active unit

County MRC Unit	Number of Activities
Cape May	30
Warren	32
Morris	35
Cumberland	40
Newark	42
Ocean	42
Essex	43
Bergen	48
Manalapan Twp	50
Camden	56
Union	67
Gloucester	74
Sussex	75
Mercer	78
Hunterdon	106
Passaic	129
Salem	129
Middlesex	145
Hudson Reg	154
Burlington	179
Somerset	185
Monmouth	192
Atlantic	230

Monmouth Method: Medical Reserve Corps



Mental health

Autism

Neurodiversity

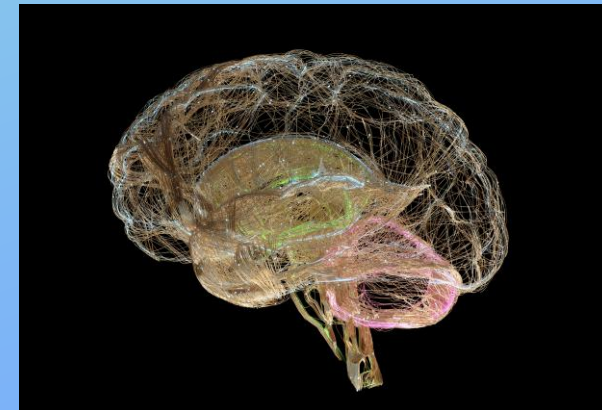
Down syndrome

Physical health

Dual diagnosis

Types of disabilities

Disasters and community safety



Kelly Shaw et al., "Prevalence and Early Identification of Autism Spectrum Disorder Among Children Aged 4 and 8 Years — Autism and Developmental Disabilities Monitoring Network, 16 Sites, United States, 2022," *MMWR. Surveillance Summaries*,

Vol. 74, No. 2, April 17, 2025, <https://doi.org/10.15585/mmwr.ss7402a1>

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[factsheet.pdf](https://docs.downsyndromepopulation.org/factsheets/down-syndrome-population-usa-factsheet.pdf)

PERFORM CARE | PROPRIETARY AND CONFIDENTIAL

Philadelphia Medical Reserve Corps Pilot



Survey Results

Attendee professional backgrounds:

- **75% of attendees — clinical professionals**
- **16% of attendees — non-clinical professionals**
- **8.33% of attendees — public health professionals**

How would you describe your overall training experience?

- **75% of attendees — very satisfactory**
- **25% of attendees — satisfactory**

Do you feel you know more about the subject matter after having attended the training(s) than you did before?

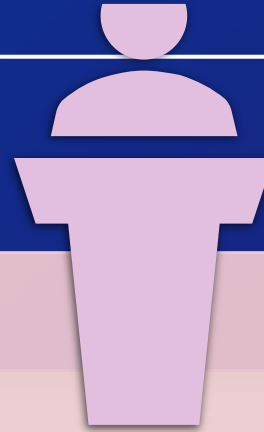
- **100% of attendees — Yes**

Would you register for a training series like this again in the future?

- **100% of attendees — Yes**

YouTube views and engagement:

Over 300 individuals have watched one or more of the uploaded trainings after the live-trainings were provided. .



Message

Clear, Concise,
Consistent
Short phrases
Avoid jargon

Format

Simple/logical
Avoid long
text/paragraphs
Use Repetition

Delivery

Use Multiple
formats
Audio/Visual/Written

Pace

Use pauses, ask
about questions,
ensure
understanding

Hypersensitivity/Sensory Processing

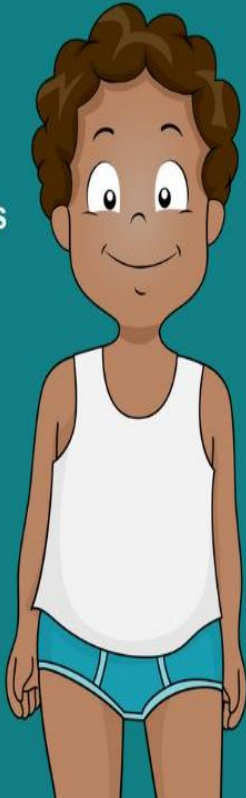
I love movement

I crave salty and crunchy foods

I like to crash into the walls

I enjoy running and jumping

I like to touch everything



I chew non-food items

I take risks while playing

I enjoy messy sensory play

I am often fidgeting

I frequently fall

I don't like to brush my teeth

I cover my ears from noises

I don't like messy sensory play

I avoid swinging and sliding

I don't like to have baths



I don't like bright lights

I avoid hugs and kisses

I struggle with food textures

I dislike clothing tags

I am sensitive to smells

<https://sensoryprocessingdisorderparentsupport.com/sensory-processing-disorder-symptoms-checklist/>

Blue Envelope Program



Learn more:

<https://www.gtpd.org/index.php/community-programs/blue-envelope-1>

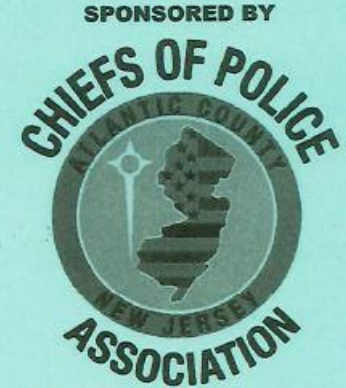
THIS DRIVER IS ON THE AUTISM SPECTRUM

DRIVER IS VOCAL DRIVER IS NON-VOCAL DRIVER MAY BECOME NON-VOCAL

THIS ENVELOPE CONTAINS IMPORTANT VEHICLE DOCUMENTS

- When the officer gets to your car, tell them that you have a blue envelope. The officer will tell you what to do next.
- Keep your hands on the steering wheel and let the officer know if you need to move any part of your body.
- The officer may shine a flashlight in your car, may have a radio, and may have flashing lights on their car.
- Ask the officer to call your emergency contact if you start to feel overwhelmed or scared.

POLICE OFFICER AUTISM SPECTRUM AWARENESS GUIDE ON BACK OF ENVELOPE



IMPORTANT INFORMATION FOR POLICE OFFICER:

- Driver may exhibit signs of anxiety due to bright lights/ radio noises.
- Driver may make repetitive body movements/ fidgeting ("stimming") may not be able to make eye contact, and/or may exhibit what seem like unusual facial expressions or noises (vocal tics).
- Remain calm, speak slowly and clearly, and use the most simplistic explanations possible. Allow the driver extra time to respond as they may need more time than usual. Clearly tell the driver when they are free to leave.
- If the driver becomes upset, reassure the driver and consider calling the emergency contact.
- Do not touch the driver unless absolutely necessary as this could have an unintended reaction.

IMPORTANT PAPERS

- Driver's License
- Vehicle Registration
- Current Insurance Card
- Emergency Contact

Special Needs Registries



“The information will be programmed to appear on the 9-1-1 Operator’s screen when an emergency call is made from your home.

This will allow dispatchers to alert emergency responders that there may be a unique situation in your home involving a person with special needs. It will also be used for the purpose of emergency planning.”

**1st responders
for 911
emergencies**

**Disaster and
public health
emergencies**

CAD System

**Mosaic/
non-standardized**

**Easily confused
populus**

Now political




- 10
- 9
- 8
- 7
- 6
- 5
- 4
- 3
- 2
- 1
- 0



no



need time



help



I / me



when?



yes



police




don't want



too loud



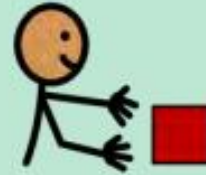
bathroom



lost



where?



want



firefighter



hurt



too bright



drink




family



what?




good




EMT



stop



move around




food



scared



who?



go



nurse

Traffic Stop Simulations

Practice Traffic Stop - Delaware Network for Excellence in Autism. (2025, June 25).
Delaware Network for Excellence in Autism.
<https://www.delawareautismnetwork.org/practice-traffic-stop/>



Fantastic opportunity for drivers and passengers. Real life experience makes learning possible and makes the experience easier for both the driver and police officer.

- Parent of an autistic individual



DNEA

**Delaware Network for
Excellence in Autism**

Hidden Disabilities and the Sunflower



For more information,
check out this website:
<https://hdsunflower.com/us/>

"Sunflowers Shine Bright for Travelers with Special Needs," *Blue Sky News*, April 3, 2023, <https://blueskypit.com/sunflowers-shine-bright-for-travelers-with-special-needs/>

Initiatives, Interventions, and Tools

Talk to and include people with IDD in your planning, in your committees, in your execution of plans and drills.



Simulated traffic stops



Simulated evacuations



Smart phone = communication device



Virtual and augmented reality



Government ID notations



Train the trainer



Shared services



Talk to your disabled population



**Arc of New Jersey
Autism New Jersey**

What Comes Next?



- **America #250/FIFA World Cup**
 - Expanding with your help
- **Include in your planning, thinking, and execution in blue sky times.**
- **Be creative with communication.**
- **Coordinate and collaborate with community-based organizations (CBOs).**
- **Take stock of what is needed in shelters/cars/trucks that is replicable.**



Questions

- **Email to Join Us:**
- **Jason Rechtman, MA, LPC, NADD-DDS, MBA**
- **Strategic Development Director, IDD Services, PerformCare/AmeriHealth Caritas**
 - **jrechtman@performcare.org**
- **Lauren Freda, MA**
- **Monmouth County Medical Reserve Corps Coordinator**
- **Lauren.Freda@co.monmouth.nj.us**
- **Division of Health OPRA Coordinator**
- **Division of Health Vehicle Pool Coordinator**
- **50 East Main Street**
- **Freehold, NJ 07728**

