

Office of Developmental Programs Acknowledgements

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The EPCWG brought together voices from across the Commonwealth of Pennsylvania to ensure that preparedness for individuals with intellectual disabilities and/or autism (ID/A) is not only technically sound but also person-centered, practical, and sustainable. Their commitment reflects the shared belief that safety and continuity are essential to preserving dignity, health, and everyday lives.

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Each member contributed unique insights—ranging from clinical expertise and operational knowledge to family-centered perspectives and frontline experience. Together, they shaped a process that is both rigorous and adaptable, ensuring it can be applied across diverse service settings.

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EPCWG offer a special note of appreciation to **Kristin Ahrens, Deputy Secretary of the Office of Developmental Programs (ODP)**. Her vision and leadership, grounded in the principles of *Everyday Lives*, have been instrumental in guiding this work. By championing preparedness as a cornerstone of dignity and inclusion, Kristin has inspired a framework that protects not only health and safety but also the continuity of daily life for individuals with intellectual disabilities and/or autism (ID/A).

Sincerely, Dan Miller, EPCWG Workgroup Coordinator, ODP Continuity Manager

Safety for Individuals with Intellectual Disabilities and/or Autism

**How ongoing preparedness with a Hazard
Vulnerability Assessment protects
everyday lives in residential habilitation and
day services.**

Executive Summary

People with intellectual disabilities and/or autism (ID/A) face unique risks during emergencies such as: communication barriers, sensory overload, disruption of routines, elopement risks, and dependence on medications, equipment, and known caregivers.¹ A living Hazard Vulnerability Assessment (HVA) makes preparedness person-centered and continuous.² By identifying top hazards, quantifying impact on people, places, and operations, and closing gaps³ through targeted mitigation, providers can safeguard health, dignity, and everyday lives across residential habilitation and day services.⁴

“We want to make this Hazard Vulnerability Assessment tool available to community providers... foremost for individual health and safety, and beyond that— protection from risk of financial and reputational loss that may impact service delivery to people with intellectual disabilities and autism.” — Kristin Ahrens, ODP Deputy Secretary

This white paper outlines:

- Why ID/A-specific safety needs must anchor preparedness
- How an HVA cycle translates risks into concrete protections
- Practical strategies, tools, and metrics for continuous improvement
- An implementation roadmap providers can adopt now

1. The Safety Imperative For ID/A

Emergency events intensify everyday barriers for individuals with ID/A⁵:

- **Communication differences:** reliance on Augmentative and Alternative Communication (AAC)⁶ such as speech generating devices, picture boards, or objects, limited speech skills, and difficulty with rapid or abstract instructions.⁷
- **Sensory sensitivities:** alarms, sirens, crowds, flashing lights, and confined spaces can trigger distress or cause an individual to shut down.⁸
- **Predictability/routine:** sudden changes increase anxiety, behavioral escalation, or elopement.⁹

- **Health continuity:** seizure disorders, diabetes, dysphagia, special diets, psychotropic/behavioral meds, and airway or mobility supports.¹⁰
- **Trust and familiarity:** transitions are safer with known staff, peers, and predictable scripts.¹¹
- **Transportation and navigation:** novel routes, vehicles, and wait times can pose risks.¹²

Preparedness that is not adapted to these realities may unintentionally increase harm. Preparedness that is individualized and practiced can turn moments of crisis into manageable disruptions.¹³

2. Ongoing Preparedness Through An HVA

A Hazard Vulnerability Assessment is the backbone of a living preparedness program. In ODP-funded service settings, an HVA should:

- Identify and score hazards by probability and impact.
- Consider effects on people (health/safety, behavior, communication), places (sites, utilities), and things (medications, equipment, records).
- Assess internal/external response readiness (staffing, partner support, communications).
- Incorporate an incident log to ground decisions in real experience.
- Drive annual priorities for mitigation, training, and exercises.
- Update after incidents, drills, and changes in population or sites.



This cycle ensures preparedness evolves with the people and environments you support.¹⁴

3. Person-Centered Preparedness: Integrate HVA With Individual Support Plans (ISPs) and the CMIST Framework¹⁵

Link HVA insights into individual plans and team practices¹⁶. The CMIST stands for:

- **Communication:** document expressive and receptive preferred modes (AAC, visuals, gestures), comprehension level, any hearing or vision supplies, and emergency scripts.¹⁷



- **Maintaining health:** medication continuity, cold-chain needs, seizure or airway protocols, dietary textures, and backup supplies.
- **Independence:** what individuals can do with prompts, what supports reduce distress, sensory kits, and coping strategies.
- **Support and safety:** elopement risks, door alarms, buddy systems, de-escalation plans, and personal identification/reunification cards.^{18,19}
- **Transportation:** accessible vehicles, car seat/restraint needs, familiar drivers, quiet routes, and timed transitions.²⁰

Use the **CMIST** lens (Communication, Maintaining health, Independence, Support & Safety, Transportation) to translate hazards into person-centered supports.²¹

4. Hazard Profiles And ID/A-Focused Options/Strategies

Each hazard profile below is supported by best practice guidance from the Federal Emergency Management Agency (FEMA), the Centers for Disease Control and Prevention (CDC), the National Fire Protection Association (NFPA), and disability advocacy organizations.^{22,23,24,25,26,27,28,29,30}

Hazard	ID/A-specific risks	Practical options/strategies
Flooding (riverine/flash)	Rapid transitions; sensory overload; lost routines; medication/equipment loss	Pre-identify dry relocation sites; "go-bags" with medications/AAC/ID card; visual social stories for evacuation; waterproof device cases; staff buddy assignments; memoranda of understanding (MOUs) with hotels/partners
Power outage	Loss of AAC charging; refrigeration; lifts/beds; increased anxiety after dark	Generators with tested load; generator quick connects with MOUs; battery banks/solar for AAC; cold-chain coolers; headlamps and blackout curtains; quiet spaces; backup paper communication boards
Severe winter weather	Shelter-in-place for 48–72 hours; staffing shortages; snow/ice injuries	3–7 days of food and water; staff sleep kits; medication reserves; indoor activity kits; snow/ice removal priority; telehealth backup

Hazard	ID/A-specific risks	Practical options/strategies
Extreme heat/poor air quality	Heat intolerance; seizure threshold; respiratory issues; outdoor program disruption	Cooling centers; portable air conditioning (AC)/filters; hydration schedules; indoor programming plan; real-time air-quality triggers; heat illness protocol
Water disruption/internal pipe break	Hygiene and hydration barriers; infection risk; routine disruption	Potable water storage; hygiene kits; disposable supplies; temporary restroom access; visual schedules for altered routines
Information Technology/network outage	Documentation and communication loss; telehealth disruption	Offline Individual Support Plans (ISPs); paper Medication Administration Records (MARs); radio/single mobility systems (SMS) trees; redundant contact lists; cache of printed visual supports
Public health emergency (infectious disease)	Personal protection equipment (PPE) desensitization; testing tolerance; isolation distress; communication barriers	Gradual PPE desensitization; behavior supports; cohort plans; family video check-ins; alternate activity menus; communication support tools

Hazard	ID/A-specific risks	Practical options/strategies
Nearby violence/active threat	Sirens/crowds may trigger flight; communication overload or not receiving effective communication	Lockdown scripts and role-play; silent alarms; layered door security; calm kits; reunification cards; Local Law Enforcement pre-planning/floor plans
Transportation incident	Novel responders; sensory triggers; separation from staff	Clear vehicle egress plans; ID cards and medical info pouches; co-travel buddy system; staff ride-along policy; emergency communication cards
Wildfire smoke and environmental events	Respiratory irritation; outdoor exclusion	High-Efficiency Particulate Air (HEPA) units; N95 alternatives with desensitization; indoor activity and sensory plans; sealed rooms

This is not an exhaustive hazards list and should not replace all hazards planning for your organization.

Tip: For each high-priority hazard, prepare short visual stories, step-by-step schedules, and “first-then” boards and social stories tailored to your population.³¹

5. From HVA To Action: Mitigation, Training, And Exercises

- Mitigation (permanent risk reduction)³²
 - Raise or relocate generators; protect basements against flood intrusions
 - Door/window alarms and fencing for elopement risk as outlined within ISPs and restrictive procedure plans; shaded waiting areas for heat
 - Redundant power for AAC; secure medication refrigerators

- Preparedness (capability building)³³
 - Sensory-friendly drills: short, scaffolded, with predictable scripts; increase realism gradually
 - Crosstrain staff on AAC³⁴ use, seizure response, de-escalation, and transfers
 - Stock standardized kits: go-bags, calm kits, hygiene, chargers, and documentation
 - Agreements with hotels, transportation vendors, and pharmacies
- Response³⁵
 - Plain-language, multi-modal communications (text, visuals, phone trees)
 - Family updates cadence; reunification plans; continuity for ISPs and MARs
- Recovery³⁶
 - After-action reviews that include individuals and families; adjust plans and HVAs
 - Psychological first aid for staff and individuals; return-to-routine pathways



6. Incident logging and metrics that matter

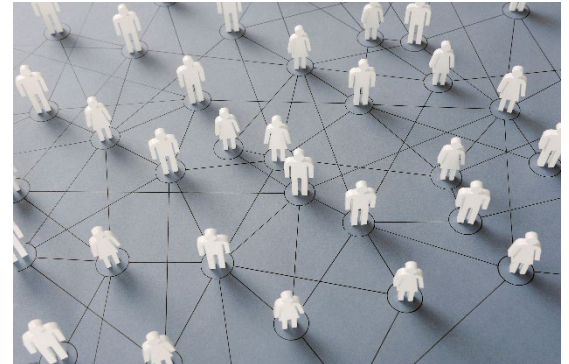
Embed data or Key Performance Indicators (KPI) into decision-making^{37,38,39}:

- **Incident log fields:** hazard/alert type, staffing level, person impacts (behavioral events, injuries, elopements), service hours disrupted, medications missed, equipment failure, communication barriers, relocation time, family notifications
- **Leading indicators:** percent of individuals with completed emergency support plans and visual supports; days of critical supplies on hand; generator test pass rate; percentage of staff trained in AAC/seizure protocol; MOU coverage

- **Lagging indicators:** injuries; elopement incidents; missed medication doses; time-to-relocation; duration of service interruption
- **Quarterly dashboards:** trend analysis to update HVA probabilities and prioritize improvements

7. Governance, roles, and partnerships⁴⁰

- **Program leadership:** own the HVA/Continuity Plan cycle; align budgets and workplans with top risks
- **Safety/quality committees:** track metrics, run drills, and share monthly learning briefs
- **Clinical leads:** individual risk flagging; health continuity plans; staff coaching, ISP
- **Direct support professionals:** co-create realistic procedures; report front-line barriers
- **Families and advocates:** validate communication scripts; plan reunification details
- **External partners:** local emergency management agency (EMA), fire/emergency medical services (EMS), law enforcement, hospitals, pharmacies, transportation vendors—share floor plans, contact lists, and special considerations in advance⁴¹

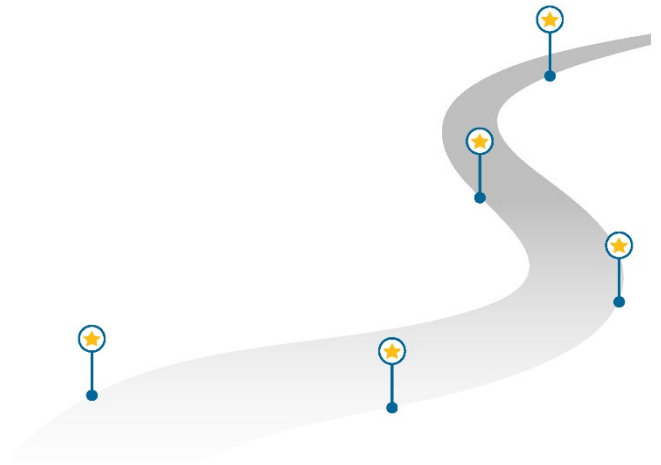


8. Equity and context: rural and urban realities

- **Rural:** plan for longer response times, and language access needs; extended shelter-in-place, and limited hotels; pre-position supplies and battery power; develop neighbor-to-neighbor mutual aid
- **Urban:** intense heat islands, evacuation congestion, and language access needs; pre-identify multiple safe sites; prioritize air filtration and indoor activity plans
- **Language and culture:** accessible formats, interpreters, culturally aligned scripts; and ensure AAC and visuals reflect language preferences

9. Provider Best Practice Implementation roadmap⁴²

- **Months 0–2:** Form a preparedness workgroup; compile incident history; draft regional HVA(s)
- **Months 2–4:** Select top 3 hazards per region/site; implement quick wins (go-bags, communication trees, generators/battery banks)
- **Months 4–6:** Sensory-friendly drills for top hazards; finalize MOUs (transport, lodging, pharmacy); staff training on AAC, seizure, and behavior supports
- **Months 6–9:** Site-specific mitigations (floodproofing, alarms); stock 3–7 day supplies; test relocation to dry sites
- **Months 9–12:** Full HVA review; publish dashboard; plan next-year training and mitigation projects



10. Practical Best Practice tools and templates^{43,44}

- Individual emergency support plan (communication, triggers, coping, medical, contacts)
- Crisis communication planning to prevent information deprivation trauma, visual social stories for evacuation, shelter-in-place, PPE, and transport
- Calm kits: headphones, preferred items, weighted lap pads, and cue cards⁴⁵
- Go-bags: 72-hour meds, Medication Administration Record (MAR) copy, AAC, ID/reunification card, snacks, hygiene, and chargers
- Paper backups: ISP highlights, contact lists, communication tools, route maps, and floor plans
- Service Location readiness checklists: generator load test, water/food stock, door alarms, lighting, and filters
- Reach out to local Healthcare Coalitions, Emergency Management Coordinators, and the Business Emergency Operations Center for planning and resources.

Conclusion

Prepared People Save Lives - Safety for individuals with intellectual disabilities and autism is built before the storm. A living HVA, grounded in person-centered practice, data from real incidents, and partnerships with local responders—turns preparedness into everyday protection. When hazards are known, plans are individualized, teams are trained and equipped, and residential habilitation and day services can preserve health, dignity, and continuity—no matter what the day brings.

Appendix A: ID/A-aware HVA scoring prompts

- **Probability:** Has this hazard occurred at this site in the last 5 years? Does local data show increasing trend?
- **People impact:** Communication barriers? Sensory overload risk? Elopement potential? Health continuity complexity?
- **Property impact:** Utility fragility (power, water, IT)? Flood susceptibility? Accessible egress constraints?
- **Operations:** Staffing surge/shelter-in-place capacity? Transportation availability? Partner response time?
- **Preparedness:** Percentage of individuals with emergency support plans/visuals? Generator capacity? Drills completed? MOUs in place?

Appendix B: Sample sensory-friendly drill steps

1. Preview day-before with visuals and a short video.
2. Provide noise-reduced alarm option where permissible.
3. Use buddies, first-then boards, social stories, and quiet exits.
4. Debrief immediately with choices and reinforcers.
5. Log outcomes; adjust scripts and supports accordingly.

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