Cooling the Crisis:
A Policy Brief on Protecting People with Intellectual and Developmental Disabilities from Heat Emergencies

Created By

The Autistic Self Advocacy Network *and*

The Partnership for Inclusive Disaster Strategies

With Support From

The WITH Foundation

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Introduction

This resource was developed by the Autistic Self Advocacy Network (ASAN) and The Partnership for Inclusive Disaster Strategies (The Partnership).

ABOUT THE AUTISTIC SELF ADVOCACY NETWORK (ASAN): ASAN is a disability rights organization run by and for autistic people. We believe that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us! Learn more at: **https://autisticadvocacy.org**.

ABOUT THE PARTNERSHIP FOR INCLUSIVE DISASTER STRATEGIES (THE PARTNERSHIP): The Partnership is the only U.S. disability-led organization with a focused mission of equity for people with disabilities and people with access and functional needs throughout all planning, programs, services and procedures before, during and after disasters and emergencies. To learn more, visit **www.disasterstrategies.org**.

Overview

It is well understood that extreme heat is increasing in intensity and duration.[1] However, the topic of extreme heat often does not carry the gravitas of other weather emergencies such as hurricanes, tornadoes, or floods. Yet extreme heat "is the number-one weather-related cause of death in the United States, and it kills more people most years than hurricanes, floods and tornadoes combined."[2] People with disabilities, including people with intellectual and developmental disabilities (I/DD), are disproportionately affected by heat,[3] just as they are disproportionately impacted by other weather disasters including hurricanes, floods, and tornadoes.[4]

This Policy Brief is intended for disability advocates, disability rights attorneys, policymakers, and public health officials, and provides immediate and long-term heat mitigation strategies for people with I/DD. Of course, everyone is welcome to read and share it.

People with I/DD should have as much control over their lives as people without disabilities. While people with I/DD might draw upon support from families, friends, and professionals, they ultimately should be in charge of their lives, including when planning for heat emergencies. People with disabilities, especially people with I/DD, should have the dignity of risk, or the right to make choices that have risks, even when others might disagree with those choices.[5] Prioritizing the right to dignity of risk when incorporating the mitigation strategies below is vital to saving the lives of people with I/DD.

Section I: Definitions and Terms

Intellectual Disability

There are many different definitions of I/DD. This Policy Brief uses the American Association on I/DD (AAI/DD) definition of intellectual disability, and the Developmental Disabilities Act definition of developmental disability.

"Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22... Intellectual functioning — also called intelligence — refers to general mental capacity, such as learning, reasoning, problem solving, and so on. One way to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a significant limitation in intellectual functioning."[6]

Developmental Disability

There are also many definitions of "developmental disability." The Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines a developmental disability as "a severe, chronic disability of an individual that:

(1) Is attributable to a mental or physical impairment or combination of mental and physical impairments;

(2) Is manifested before the individual attains age 22;

(3) Is likely to continue indefinitely;

(4) Results in substantial functional limitations in three or more of the following areas of major life activity:

(i) Self-care;

(ii) Receptive and expressive language;

(iii) Learning;

(iv) Mobility;

(v) Self-direction;

(vi) Capacity for independent living; and

(vii) Economic self-sufficiency.

(5) Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

(6) An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in paragraphs (1) through (5) of this definition, if the individual, without services and supports, has a high probability of meeting those criteria later in life."[7]

Exercises

Exercises provide a low-risk, cost-effective environment to: (1) Test and validate plans, policies, procedures, and capabilities; and (2) Identify resource requirements, capability gaps, strengths, areas for improvement, and potential best practices.[8]

Extreme Heat

Extreme heat is also a term where there is not a general consensus of its definition. Heat.gov defines it as a period of high heat and humidity with temperatures above 90º Fahrenheit for at least two to three days.[9] Context should be taken into consideration when defining extreme heat. For example, a three-day period of 95ºF temperatures may not be out of the ordinary in Phoenix, Arizona, in July, but in Augusta, Maine those temperatures would be unusual and likely categorized as extreme heat. Humidity should also be taken into consideration when determining if weather conditions constitute extreme heat.

Intersectionality

Intersectionality is a framework to analyze the interlocking effects of oppression people with multiple marginalized identities experience.[10] This "framework… examines how these identities [disability, race, gender, socioeconomic status, etc.] intersect to shape unique experiences of privilege or oppression. While identity is about the individual aspects of who we are, intersectionality looks at how these aspects combine within larger systems of power and inequality."[11] Multiply marginalized people with I/DD experience specific effects of ableism and other oppression. When extreme heat planning, response, and mitigation strategies ignore the unique and specific ways these systems of oppression interact, they reinforce structural inequities that predictably result in preventable illness, institutionalization, and death.

Public Policy

Again, there is not a consensus on the definition of public policy. For the purpose of this Policy Brief, "[public] policy is the framework of laws, regulations, and actions governments implement to achieve social and economic goals."[12] It is important to note which social and economic goals government officials choose to emphasize and follow through on, and which goals are pushed to the side. These choices determine who is prioritized and protected, and who is considered expendable. They also reveal the structural policy failures that result in preventable inequities for people with disabilities.

Section II: Lack of Awareness of the Disproportionate Impact of Heat on People with I/DD

Heat is the number one cause of weather-related death.[13] Due to climate change, extreme heat and its negative impact on the disability community, including people with I/DD, is increasing and will continue to do so.[14] Perhaps because heat does not suddenly destroy property, has increased somewhat gradually, or has always occurred but has gotten more dangerous, the effect of heat on people with and without disabilities has not been taken as seriously as is warranted. Although extreme heat has been recognized as a factor that causes fatalities, it is just beginning to be recognized as a threat that is particularly lethal for people with I/DD.

The media simultaneously sensationalizes and understates heat waves and their deadly consequences. News channels frequently warn of a heat wave but the tone often borders on celebratory. Phrases such as "It's going to be a hot one!" coupled

with anthropomorphic images of the sun wearing sunglasses conjure nostalgic images of childhood summers past, as opposed to an imminent and potentially deadly weather event.

Even when the media and public health suggest that we check on older adults and "vulnerable" people to ensure they are safe, it often does not provide adequate information about how to tell if someone has been affected by heat. People are rarely informed what the symptoms of heat-related illnesses are, or what to do when they recognize them. Public health has begun warning that certain prescription medications can increase the risk of heat-related illness. Yet, it often does not include adequate information about how to protect oneself from heat, or specific information about the increased heat risk. Public health also seldom specifically warns disabled people that they might be more sensitive to heat because of their disability or how to mitigate its effects.

The failure to take heat as seriously as other dangerous weather events results in preventable deaths and injuries of people with I/DD. It is not inevitable that heat has a disproportionate impact on disabled people to the degree that it does today. Much of the reason for this impact lies in policy that discriminates against, excludes, ignores, or does not take into account people with I/DD.

Although disabled people are 2-4 times more likely to be injured or die in disasters than nondisabled people,[15] public health officials, disability rights attorneys, policymakers, and advocates are often not aware of the threat disasters pose to people with I/DD. This lack of awareness causes people with I/DD to be left out of planning for disasters, including extreme heat. It also leads to allies and advocates to respond inadequately. For example, public health may fail to make its messaging about extreme heat accessible to and actionable by people with I/DD. Attorneys and advocates may not recognize the disproportionate impact of extreme heat on disabled people[16] and this may cause them to respond less vigorously.

While extreme heat disproportionately impacts people with I/DD in the community, it has an even greater impact on people with I/DD who live in congregate settings, including institutions such as "training schools" for people with intellectual disabilities, group homes, and carceral facilities.

Given that extreme heat is often not perceived as a life-threatening emergency, personal preparedness plans frequently do not include heat preparedness measures. Heat preparedness measures are not emphasized near the level as preparation for an imminent hurricane.

Just as the media and public health do not consistently and proportionately represent the significance of heat as a public health hazard; disability rights

attorneys, policymakers, and advocates may not be vigilant about legal ramifications of heat emergencies for people with I/DD. While they may recognize the rights of people with I/DD during other weather-related disasters under the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, as well as state and local disability rights law; they may not be as aware of inequities in heat mitigation programs and services.

Section III: Reasons Heat Is More Deadly for People with I/DD

Certain intellectual and developmental disabilities cause heat sensitivity. This includes inability to regulate body temperature, limited mobility, and difficulty communicating about heat.[17] Communication issues can manifest as not being able to identify heat as a source of discomfort and/or not having adequate ways to express this. At other times, people with I/DD may not be taken seriously when they identify being hot. This can be dangerous when persons with I/DD do not have the agency or the ability to mitigate heat independently.

Side effects of commonly taken psychiatric and other medications often contribute to heat sensitivity.[18] In addition, people with I/DD frequently rely on life saving or life sustaining devices that require power, including ventilators and power wheelchairs. Because of this, and the many specific situations that arise, power outages that often occur during heat emergencies are more dangerous for people with I/DD.

"Increases in average and extreme temperatures and heat waves are expected to lead to more heat illnesses and deaths among at-risk groups, including people with disabilities. Some people with disabilities are particularly at risk for heat-related illness and death."[19] This includes people with mental health conditions.[20] "Between 39 and 52% of people "with intellectual and disabilities have a co-occurring mental health condition."[21]

Section IV: Policies, Structural Factors, and Social Dynamics that Increase Heat Danger for People with I/DD

Policy:

- Is a law, regulation, procedure, or administrative action
- Helps implement public health law, regulations, or voluntary practices
- Decisions are frequently reflected in resource allocations[22]

Policies reflect conscious and unconscious societal values. Some of the policies discussed below reflect social dynamics such as systemic ableism: bias of a system,

such as emergency management or public health, against people with disabilities, including people with I/DD. Structural factors, such as physically inaccessible cooling systems, also reflect unconscious bias against people with disabilities, including people with I/DD.

Numerous policy, social dynamic, and structural factors contribute to increased heat-related illness and death of people with I/DD. Public health, emergency management and other government agencies, as well as service providers' failure to recognize that people with I/DD are at higher risk of heat-related illness and death creates a gap that heightens disparities. This results in a lack of adequate training and support for people with I/DD to recognize that heat is dangerous, and ways to lessen the impact of heat.

Dynamics that contribute to preventable heat-related deaths of people with I/DD include: intersectional oppression; pervasive poverty; messaging that is not accessible to people with I/DD; living in congregate settings, including nursing facilities, institutions, and carceral facilities; widespread homelessness and the lack of affordable, accessible, integrated housing; systemic inequity; and the failure to implement heat mitigation strategies in schools. Each risk factor will be examined, and strategies for advocates, attorneys, policymakers, and public health officials to reduce heat-related illness and death among people with I/DD will be suggested.

Universal Strategies

This Policy Brief addresses each risk factor by outlining immediate and long-term strategies to address heat mitigation for people with I/DD, which are further delineated for Lawyers, Advocates, and Policymakers and for Public Health. However, many strategies should be applied regardless of risk factor or audience. To be truly effective, heat mitigation strategies must embed disability leadership, intersectional frameworks, and shared decision-making into planning and implementation into each step. Refer back to this section when reflecting how to incorporate the strategies stated throughout this brief.

Immediate Mitigation Strategies

- Ensure multiply marginalized people with disabilities, especially people with I/DD, are part of and lead the discussion. Identify who is not "at the table" and make sure they are welcomed.
- Listen to and uplift the experiences and leadership of disaster-impacted multiply marginalized people with disabilities, especially people with I/DD.

- Start partnerships between trusted organizations and government agencies that work directly with marginalized communities.
    - Prioritize organizations led by marginalized people and are representative of the communities they serve, including people with I/DD.
- Ensure the planning process is accessible to disabled people. Refer to ASAN's Inclusive Meetings: The Autistic Self Advocacy Network's Community Living Summit and The Partnership for Inclusive Disaster Strategies' Making Virtual Meetings and Events Accessible.

Long-term Mitigation Strategies

- Establish compensated, decision-making roles for people with I/DD who hold multiple marginalized identities
- Establish coalitions that include trusted organizations and government agencies, such as public health and emergency management.
    - Some key trusted organizations include disability-led organizations, such as organizations led by people with I/DD and Centers for Independent Living (CILs); community-based organizations that serve communities experiencing poverty, houselessness, food insecurity; Councils on Developmental Disabilities; Protection and Advocacy Agencies (P&As); nonprofits that support the community and are led by multiply marginalized people; libraries; houses of worship, etc.
- Use these coalitions to create a heat emergency plan that is responsive to the needs of people with I/DD with multiple marginal identities
- Require that heat plans and policies explicitly address the compounded risks created by disability, race, poverty, housing instability, gender identity, and other intersecting forms of oppression.
- Standardize accessible communication (e.g., plain language, Easy Read, multiple formats, multiple languages) for all heat communications and materials. Require vendors and partners to meet those standards.
- Develop a data-informed heat outreach plan that identifies and prioritizes at-risk communities, including people with I/DD. Regularly share accessible materials in accordance with this plan.

Risk Factor: Intersectionality

Intersectionality should always be taken into account when considering the impact of a failed or poorly executed policy. For example, while poverty or the carceral system has a negative impact on anyone regardless of identity, they have a disproportionate impact on multiply marginalized people. People with I/DD, people of color with I/DD, and Lesbian, Gay, Bisexual, Trans, Queer, plus (LGBTQ+) people of color with I/DD all face specific and disproportionate impacts due to the ways systems of oppression interact with each other and individuals. It is critical to view policy that does not equitably and effectively serve people with I/DD through the lens of intersectionality.

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Ensure multiply marginalized people with disabilities, especially people with I/DD, are part of and lead the discussion. Identify who is not "at the table" and make sure they are invited and welcomed.
- Listen to and uplift the experiences and leadership of disaster-impacted multiply marginalized people with disabilities, especially people with I/DD.
- Begin to educate the advocacy community about intersectionality and how intersectional oppression can contribute to heat-related illness and death of people with I/DD.
- Ensure publication should reflect that having multiple marginalized identities increases all risk factors.

Public Health:

- Begin creating or revising informational text and electronic material for people with I/DD to address heat mitigation through the lens of intersectionality. Ensure it:
  - Is produced in ASL and other sign languages used locally, as well as in spoken languages used locally.
  - Contains images of people from a variety of class backgrounds, a variety of races and ethnicities, and with a variety of disabilities.
  - Reflect that having multiple marginalized identities increases all risk factors.
- Assess the inclusivity of your outreach to people with multiple marginalized identities. Make sure to note and address current barriers in outreach.

- Develop measurable strategies to broaden your outreach to people with multiple marginalized identities, including people that are unhoused.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Advocates, including people with I/DD, attorneys, and policymakers should educate themselves and the community at large about intersectional oppression during extreme/excessive heat events.
- Establish intersectional leadership in heat planning by establishing compensated, decision-making roles for multiply marginalized people with I/DD.
- Require that heat policies explicitly address the compounded risks created by disability, race, poverty, housing instability, gender identity, and other intersecting forms of oppression.
- Collaborate with people with multiple marginalized identities and emergency managers and public health to produce a heat emergency plan that is responsive to the needs of people with I/DD with multiple marginal identities.
    - Exercise this plan.

Public Health:

- Include extreme heat as a standing priority in Health Equity Plans, Climate Adaptation Plans, and Community Health Needs Assessments, requiring disaggregated data by disability and meaningful engagement of disability-led organizations.
- Create teams within public health departments responsible for coordinating disability, homelessness, and racial equity responses during extreme heat events.
- Develop year-round, community-based heat resilience programming that supports peer-led heat safety education, cooling equipment distribution, and preparedness planning within communities experiencing compounded marginalization.

Risk Factor: Disability Exclusion in Heat Planning

Heat-related illness and death among people with I/DD are not inevitable of disability, but the result of policy choices that marginalize and fail to protect disabled people. The survivability of extreme heat often is contingent upon

coordinated action by the public health sector, in collaboration with the disability community, to ensure that heat mitigation information and resources are accessible, understandable, and actionable for people with I/DD.

Existing heat mitigation programs are both inadequate and inequitable for people with I/DD. For example, when heat.gov was launched, while it included pets, it ignored disabled people as being at risk. After protest from across the disability community, "people with disabilities" was included in the groups that are disproportionately impacted by heat. Other examples include public health heat mitigation electronic and print material that is not accessible, notifications that are not interpreted, and cooling centers that are structurally inaccessible or not on a bus route. Even when cooling centers are on accessible public transit routes, the stops must have canopies and have short wait times when out doors between stops to reduce the likelihood of heat-related illness and death.

It is vital that the planning process is accessible to and for disabled people, especially people with I/DD.

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Ensure that people with I/DD are not only included but also hold key leadership positions in the heat emergency planning process.
- Educate people with I/DD about:
  - Their rights to equitable treatment under disability rights law under the ADA and Section 504 of the Rehabilitation Act, and state and local statute.
  - Recognizing signs of heat stress and exercising autonomy in mitigation decisions.
  - How to find resources that can support them in heat emergencies.
  - How to lessen the impacts of extreme heat.
- Advocate for training for caregivers, direct support professionals, and support networks to recognize and mitigate heat stress, and establish oversight and enforcement processes to ensure protective measures are consistently implemented.
- Advocate for enforcement of rights under the ADA, Section 504 of the Rehabilitation Act, and state and local disability rights laws and ordinances.

Public Health:

- Build relationships with the disability community by connecting and collaborating with disability-led cross-disability organizations, including CILs and disability-led and disability-focused organizations such as intellectual and developmental disability e.g. Autistic Self Advocacy Network (ASAN), Self Advocates Becoming Empowered (SABE), and People First.
- Prioritize meaningful representation from multiply marginalized communities, including people with I/DD, throughout the heat emergency planning process.
- In collaboration with disability-led organizations, educate people with I/DD about:
  - Their rights to equitable treatment under disability rights law under the ADA and Section 504 of the Rehabilitation Act, and state and local statute.
  - Recognizing signs of heat stress and exercising autonomy in mitigation decisions.
  - How to find resources that can support them in heat emergencies.
  - How to lessen the impacts of extreme heat.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Challenge exclusion of people with I/DD from heat mitigation programs and services, through advocacy, statutory change, or litigation.
- Advocate for the adoption of cooling equity standards in state and municipal law that require every heat response plan to explicitly demonstrate how the access and functional needs of people with disabilities, including people with I/DD, will be met, with compliance tied to licensing and funding.
- Establish a Medicaid-funded Heat and Energy Resilience benefit, including through Home and Community Based Services (HCBS) waivers, to cover accessible cooling equipment and backup power solutions for energy-dependent individuals.
- Mandate “Disability Equity Review” for every new climate or emergency management rule. Similar to an environmental impact statement, agencies must show how proposed rules will reduce heat disparities for people with I/DD.

- Negotiate multi-year Memorandums of Understanding (MOU) with disability-led organizations (CILs, statewide self-advocacy networks) that guarantee seat and vote in all hazard mitigation committees.

Public Health:

- Create permanent, compensated advisory and decision-making roles for people with I/DD and disability-led organizations in heat planning, implementation, and evaluation.
- Prioritize representation from multiply marginalized communities, including people with I/DD are part of the heat emergency planning process.
- Implement routine, accessibility reviews by appropriate partners of cooling centers, public messaging, digital alerts, and outreach strategies, with corrective action timelines.
- Establish grant programs that resource disability-led organizations to design and implement culturally-informed, accessible heat mitigation and preparedness strategies.
- Require ongoing anti-bias and accessibility training for public health staff responsible for climate, emergency preparedness, communications, and community outreach.

Risk Factor: Poverty

Poverty is a social dynamic that is the result of the culmination of many failed policies.[23] Disabled people are disproportionately poor. "Working-age adults with disabilities are almost twice as likely to have income below 200% Federal Poverty Level (FPL) compared with adults without disabilities." [24]

People experiencing poverty generally face greatly higher death rates from heat. One factor that contributes to this is the urban heat island effect. This occurs in redlined areas of cities with a high population density, where there are disproportionate paved surfaces such as streets and parking lots and limited green space. "A review of research studies and data found that in the United States, the heat island effect results in daytime temperatures in urban areas about 1–7°F higher than temperatures in outlying areas and nighttime temperatures about 2–5°F higher. Areas experiencing heat islands further contribute to higher daytime temperatures and reduced nighttime cooling. Heat is of greatest concern for groups such as older adults, young children, populations with low-income, people who work outdoors, and people with chronic health conditions, disabilities, mobility constraints, or taking certain medications."[25] "Urban and rural poor [people] are often disproportionately exposed to overheating due to low

quality housing and lack of access to cooling. Due to building materials, informal settlements are often hotter than other urban areas in some cities."[26]

Some of the barriers to heat mitigation that people experiencing poverty encounter are lack of affordable housing, lack of housing that is adequately cooled, lack of clean water, and lack of money to purchase fans, portable and box air conditioners, and drinks with high levels of electrolytes. In addition to barriers people experiencing poverty encounter, disabled people experience barriers to cooling that result from disability inequity and structural ableism. This includes lack of accessible transportation to accessible cooling centers; services, such as day programs, that do not provide adequate air conditioning; and lack of accessible, actionable information about the need for heat mitigation and how to implement it.

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Partner with public health and emergency management officials to design and implement heat plans that include the needs of the whole community.
- Ensure that all cooling centers meet or exceed ADA standards.
- Ensure that cooling centers are on accessible public transit routes, where there is public transportation.
- Partner with local emergency management and public health to develop transportation plans, like utilizing vans from senior centers, etc.
- Fund air conditioning units for people with disabilities experiencing poverty.
- Allow Medicaid managed care programs to pay for portable air conditioners where medically indicated.
- Ensure that there is potable water where it is lacking, and litigate where appropriate and feasible.
- Create or continue peer-led programs that support disabled people in recognizing the impacts of heat and mitigation strategies.
- Develop and present trainings on the rights of people with I/DD during extreme heat that have a focus on self advocacy.
- Provide free/low cost sports drinks and electrolyte supplements with education on how to use them. Make them available for disabled people experiencing poverty through disability-led organizations, including CILs.

Public Health:

- Collaborate with disability-led groups to provide training to people with I/DD about the potential danger of extreme heat and ways they can mitigate it.
- Provide resources and communications in accessible and inclusive formats, such as ASL, plain language, Easy Read, multiple formats, and multiple languages. Require vendors and partners to meet those standards.
- Disseminate materials via disability community peer-led trusted sources such as Centers for Independent Living and peer-led disability groups.
- Disseminate materials through state Councils on Developmental Disabilities and other intellectual and developmental disability focused groups.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Advocate for codification of disability- and poverty-inclusive heat planning requirements into state and municipal law, requiring that all heat response plans explicitly address the compounded risks faced by low-income disabled people.
- Advocate for the expansion or creation of accessible greenspaces in low income urban areas and heat islands. These are:

  "Structures such as buildings, roads, and other infrastructure absorb and re-emit the sun's heat more than natural landscapes such as forests and water bodies. Urban areas, where these structures are highly concentrated and greenery is limited, become "islands" of higher temperatures relative to outlying areas. These pockets of heat are referred to as "heat islands." Heat islands can form under a variety of conditions, including during the day or night, in small or large cities, in suburban areas, in northern or southern climates, and in any season."[27]
- Advocate for equity in employment of disabled people.
- Advocate to eliminate subminimum wage for people with I/DD.
- Advocate for development of affordable, accessible, integrated housing that is adequately air conditioned and designed to reduce exposure to urban heat island effect within communities where people already live.

Public Health:

- Partner with trusted organizations (CILs and other CBOs, libraries, houses of worship) year-round to act as hubs and support them with backup power systems, charging stations, quiet rooms, sensory-friendly signage, etc.
- Ensure hubs are within a short distance of accessible public transit stops. and publish wayfinding in multiple formats (Braille, pictograms, tactile maps, ASL videos).
- Partner with trusted organizations to develop annual "Heat Equity Scorecards" that break down emergency department visits, mortality by disability, poverty status during extreme heat events and other key indicators important to the community partners. Use the scorecards to trigger corrective action plans in under performing jurisdictions.
- Establish a disability-poverty council, composed of government decision-makers and trusted community partners, tasked to review spending plans and recommend reallocations when equity goals are not met.

Risk Factor: Being Unhoused

Policies that fail to prioritize affordable, accessible, integrated housing and require impoverishment as a condition of receiving public benefits has produced widespread and preventable homelessness across the United States. Such policies include not prioritizing creating affordable, accessible, integrated housing; gentrification of neighborhoods; and requiring impoverishment of people that receive Medicaid and other benefits. "People with disabilities are disproportionately likely to experience homelessness. Point-in-time counts (i.e., counts of the people in a community experiencing homelessness on a single night) suggest that nearly one quarter of individuals experiencing homelessness have a disability, including physical, intellectual, and developmental disabilities, as well as mental health and/or substance abuse disorders."[28]

It should be emphasized that people with I/DD require permanent affordable, accessible, integrated housing. Shelters for unhoused people and transitional housing are not an adequate solution. Shelters are often less accessible to and available for people with I/DD. In heat emergencies, they become more dangerous for people with I/DD as they have high heat risk factors, including a lack of adequate air conditioning.

"Extreme heat is especially a problem for homeless populations—up to 91% of homeless people in this country live in urban or suburban areas prone to the heat island effect, making heat waves more frequent and intense. Many cities have chronicled tragic mass fatalities of their homeless populations as a direct result of such heat events. Homeless people already lack regular access to clean water, which is further exacerbated by periods of drought and polluted water access."[29]

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Advocate that homeless shelters and cooling centers are structurally accessible, provide sign language interpreters and video remote captioning (VRI), and provide print and electronic materials in alternate accessible formats consistent with the law.
    - Advocate that more public spaces, such as libraries and other government-operated buildings, be designated as cooling centers if they are structurally accessible and provide communication access.
- Publicize the need for accessible, affordable, integrated housing that is adequately air conditioned and heated to government officials, including state, territorial, and local legislators.
- Collaborate with public health to host in person and virtual education campaigns to inform people with I/DD who are experiencing homelessness about dangers of heat, what they can do to reduce its impacts, and neighborhood locations where they can go to cool down and get hydrated.
- Collaboratively, create accessible messaging for people with I/DD experiencing homelessness.

Public Health:

- Collaborate with the disability community to host in person and virtual education campaigns to inform people with I/DD who are experiencing homelessness about the dangers of heat, what they can do to reduce its impacts, and neighborhood places they can go to cool down and get hydrated.
- In collaboration with the disability community, create accessible messaging for people with I/DD who are experiencing homelessness.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Advocate to create ample affordable, accessible, integrated housing stock that has adequate air conditioning and heating.
- Advocate for policy changes that allow people who receive Medicaid, Social Security and other benefits are able to maintain savings, so they are less likely to be unhoused if they are evicted, their rent is raised, or other unforeseen circumstances arise.
- Advocate for policies that integrate more green spaces to combat heat island effects in urban areas.

Public Health:

- Establish permanent, funded collaborative bodies between public health, disability-led organizations, and homelessness response entities to coordinate accessible heat education, outreach, and messaging for people with I/DD experiencing homelessness.
- Create formal agreements between public health, homeless services/ Continuum of Care, disability agencies to coordinate outreach, cooling access, transport, and follow-up services.
- Establish ongoing syndromic surveillance and public reporting of heat-related illness and death, including indicators tied to homelessness and disability.
- Invest in neighborhood-level cooling infrastructure as a long-term public health intervention prioritizing areas with high rates of homelessness and heat-island exposure.

Risk Factor: Schools with Inadequate Cooling Systems

Schools are usually under air conditioned or have none at all. This is a threat to students, staff, and visiting members of the public. It is a greater threat to students with I/DD. The trend of opening schools in August, the hottest time of the year, exacerbates the threat of extreme heat for all. Heat is not only intensifying, but the high heat season is lengthening.[30] More and more schools are canceling school or dismissing school early on extremely hot days.

Practices like these that have emerged to mitigate heat in under airconditioned or unairconditioned schools have unintended consequences that disproportionately impact students with I/DD. Starting the school year later is only an adequate policy decision when students have air conditioned homes or can participate in air

conditioned programs. Canceling school also has consequences. The most obvious is education loss. While this can be serious, the consequences for students with I/DD can have a greater impact. Students with I/DD often receive essential health services such as physical therapy, occupational therapy, speech and language therapy, counseling and other services at school through their Individualized Education Program (IEP). The disruption of these services due to extreme heat can have far reaching consequences. Further, schools may be able to serve as cooling centers after schools close for the day or during summer vacation.

Heat mitigation measures that target students with I/DD, including keeping disabled students indoors when peers go outdoors, moving only disabled students to air-conditioned areas, or dismissing only disabled students early during hot temperatures, carries the unintended consequence of promoting segregation.

Schools are legally obligated to keep disabled students safe, and an effective way to ensure their safety is through an IEP or 504 Plan that requires heat mitigation measures. However, there are measures that should be implemented that preserves integration.

Just as research demonstrates that the best way to mitigate bullying in schools is to improve school-climate for all students,[31] the best way to protect disabled students from heat is to mitigate heat for every student. This may include regulating school temperatures in school buildings by adding or improving air conditioning, reducing the amount of asphalt used as play areas, and replacing metal or plastic play equipment that become excessively hot.

As the impacts of climate change worsen, schools that previously experienced high heat infrequently or for short periods are now facing higher and more prolonged heat temperatures for a greater portion of the school year. The summer season is literally getting hotter and longer.[32] More schools are beginning to take heat mitigation measures such as dismissing or canceling school during periods of high heat.[33] This is inadequate for all students, especially for students with I/DD, as it leads to learning loss and presumes that students have air-conditioned homes. Some schools start the school year later in August or even September as an interim solution to providing air conditioning. [34]

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Educate parents to utilize the IEP or 504 Plan as a method of mitigating heat for students with I/DD.

    - Include mitigation strategies in IEP goals, such as recognizing and communicating about heat discomfort, responding to heat by removing outer layers of clothing such as a sweatshirt, requesting water, or taking other protective measures.
    - Include in IEP or 504 Plan having outdoor activities such as recess and physical education be moved indoors when temperatures are excessively high for your geographic location. Moving students with disabilities to air conditioned areas may have the unintended consequence of segregation. The IEP should stress that students should not be removed from their class, including during recess, if this results in unnecessary segregation, and that non-segregated options, such as having the entire class have indoor recess, must be considered.
    - Move students to air condition portions of the building or dismiss early during periods of high heat. This is not a long-term solution and should only be done when no other options are available.
- The best way to mitigate heat impact for students, staff, and visitors with I/DD is to mitigate it for the entire school community. Begin to advocate for air conditioning in all schools. Schools in lower income school districts with the highest poverty/lowest home air conditioning rates should be prioritized.
- Begin to advocate for schools to re-open in September as opposed to August. This type of advocacy must be cognizant that not all students live in air conditioned homes. It should be part of an advocacy campaign to operate cooling centers, incentivize landlords to provide air conditioning, and fund air conditioning for homeowners who cannot afford it.

Public Health:

- Collaborate with schools, parents, and students with I/DD to develop and disseminate age appropriate materials for all students, including students with disabilities on dangers associated with heat and heat mitigation strategies they can use to lessen the impacts of heat at school and at home.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Continue to educate parents to utilize the IEP or 504 Plan as a method of mitigating heat for students with I/DD when needed.

    - Ensure that when heat mitigation is incorporated into IEP and 504 Plans that students with I/DD are protected from extreme heat without being segregated from their peers. Schools must prioritize inclusive, school-wide cooling strategies over segregated approaches that remove students with disabilities from integrated educational settings.
- Advocate that segregated heat mitigation is not a long-term solution and does not constitute the least restrictive environment.
- Ensure that funding for air conditioning and resulting higher electricity costs is provided in all schools, prioritizing schools in low income areas where students' homes are less likely to be air conditioned.
- As needed, continue to advocate that school does not begin in August, and advocate that students have accessible places to go with transportation and support services provided when students live in unairconditioned homes.

Public Health:

- Continue to disseminate age appropriate materials for all students, including students with disabilities on dangers associated with heat and heat mitigation strategies they can use to lessen the effects of heat at school and at home
- Develop evidence-based locally-focused guidance defining safe indoor temperature and heat index thresholds for schools, and collaborate with departments of education and school boards to incorporate these standards into school health and safety policies.

Risk Factor: Segregated Congregate Settings

Around a quarter of people with I/DD live in congregate settings.[35] These settings include nursing facilities, segregated "training schools," intermediate care facilities for people with I/DD, and other congregate facilities such as group homes. Many of these settings typically are not air conditioned. Before the recent climate change surge,[36] heat mitigation devices such as air conditioning were viewed as a luxury. It is not acknowledged as a necessity in congregate settings. The benefits of living in the community as opposed to a congregate setting are numerous.[37] Congregate settings are generally more dangerous settings to live in. This is also true in heat emergencies. The COVID-19 public health emergency demonstrated congregate care settings are dangerous, deadly places to reside in during emergencies. The safest place to be is in one's own home with appropriate supports and services.[38]

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- If abuse, neglect, or exploitation is occurring, report to appropriate authorities if it is safe to do so.
- As applicable, review existing consent decrees or settlement agreements to ensure compliance with the consent decree or settle agreement.
- Educate people with I/DD who live in congregate settings, and their guardians, about the dangers of living in congregate settings during heat emergencies.
- Utilize supported decision-making and is the preference of the person with an intellectual and developmental disability.
- Support funding for CIL's fifth core service to assist people who want to transition from nursing facilities into the community, and to divert them from going to nursing facilities if they do not wish to go there in the first place. Although CILs are required to provide this as one of their core services, they have never received dedicated federal funding.
- Engage Developmental Disabilities Councils to develop education for people with I/DD on heat mitigation and community based options instead of institutional settings.
    - Develop an outreach plan to distribute this education with people with I/DD in non-congregate and congregate settings.
- Engage Developmental Disabilities Councils to add extreme heat and congregate setting safety to their State Plan priorities, including education for self-advocates and projects that support transition to community based housing.

Public Health:

- Create and disseminate accessible materials that address heat danger awareness and heat mitigation strategies to state and private agencies that fund and administer congregate and non-congregate settings.
- Require congregate settings to implement heat illness prevention plans, including hydration protocols, cooling measures, wellness checks, and documentation during heat emergencies.
- Conduct inspections of congregate settings during heat events to assess indoor temperatures, ventilation, air conditioning, and access to potable water. Order corrective actions when settings fail to maintain safe conditions, including requiring immediate or temporary heat mitigation measures.

- Coordinate with licensing and certification bodies to conduct enforcement steps when congregate settings pose an imminent public health risk due to heat.
- Advocate for comprehensive home- and community-based services so that people with I/DD live in the community, not institutions, by default.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Advocate for the creation of affordable, accessible, integrated, adequately insulated and cooled housing through education, increased budget allocation, statutory change, and litigation, including class action litigation, as necessary.
- Establish adequately funded resources that support people with I/DD in making plans to move out of institutions into the community, when this is their preference.
- Advocate for and adopt policies that reallocate funding away from segregated congregate care settings and toward community-based services.

Public Health:

- Establish communication partnerships with agencies and community-based organizations serving people with I/DD in congregate settings.
- Ensure that every person living in a congregate setting has access to individualized transition planning that includes climate and heat resilience considerations.
- Support people with I/DD in moving out of congregate settings by providing information and services to people as they move into community settings.

Risk Factor: Prisons and Jails

The United States policy surrounding incarceration and prisons is dangerous. According to the Prison Policy Initiative, mass incarceration has shortened the overall U.S. life expectancy by 5 years.[39] And as is the case with destructive policies, the negative impact of our prison system disproportionately affects disabled people. ”Compared to 15% of the United States general population, 40% of people in state prisons have a disability. While cognitive disabilities such as autism, Down syndrome, and learning disorders impact about 1/4 of incarcerated people, visual, hearing, and ambulatory disabilities are not uncommon…”[40]

Heat is particularly deadly in prisons and jails. “Over the past two decades, extreme heat coupled with inadequate ventilation and outdated infrastructure have amplified already-grim conditions for the over one million Americans in correctional facilities. One study found that approximately 13 percent of deaths behind bars in Texas during warm months may be attributable to extreme heat. Another reported that an unsafe heat index …can increase violent interactions in prison by 20 percent. High temperatures also correlate with a 30 percent increase in daily suicide-watch incidents, scholars say. Even states known for cooler weather in the Midwest and Pacific Northwest are contending with stifling heat in prisons, as facilities there frequently do not have appropriate infrastructure to manage extreme heat.”[41]

“Extreme heat poses a distinct risk to the 2.1 million incarcerated people in the United States, who have disparately high rates of behavioral health conditions. Few jails and prisons have been constructed to endure rising temperatures. Carceral structures are mostly built with materials, such as stone, metal, and concrete, that retain heat and have small or closed windows that impede air circulation, which create conditions for indoor temperatures that exceed those outdoors. Overcrowding is rampant in the U.S. carceral system, with hundreds or thousands of people cramped into poorly ventilated dormitories or small cells (single or double-bunked), which can intensify the physiological and psychological stress of heat exposures. The flip side of extreme overcrowding is extreme isolation (known as solitary confinement), generally defined as being confined in a cell for approximately 22 hours per day, which is defined by international bodies as torture and recognized as a public health and human rights crisis.

As recounted in litigation and commentaries, people in solitary confinement are especially susceptible to the hazards of extreme heat because they are less able to avoid or mitigate heat-related stress than those in general population units of prisons or in community settings. A growing body of research has explored associations between extreme heat and health among incarcerated persons, though the literature remains limited relative to intersectional identities. A study in Texas prisons found that an extreme heat day was associated with a 15.1% increased all-cause mortality risk and estimated that approximately 13% of deaths may be attributable to extreme heat in the state’s non–air-conditioned prisons. Another study in Mississippi found that ‘intensely hot days’ were associated with a 20% increased risk of severe violent incidents, and that ‘unmitigated exposure to heat generates an additional 44 cases of intense violence per year.

Research has long demonstrated that suicides tend to increase in hotter seasons. In the wake of the climate crisis, recent studies have reported positive associations between higher ambient temperatures and incidence of suicide. At a biophysical

level, heat stress may worsen mental health symptoms by altering the body's ability to thermoregulate and regulate emotions. This may trigger or exacerbate feelings of lethargy, irritability, and sadness, especially for people with existing mental health [disabilities]. Additionally, studies have linked heat waves and rising temperatures to escalations in community hospitalization rates for behavioral health symptoms, including substance use; mood disorders; schizophrenia and delusional disorders; and nonsuicidal self-harm."[42]

Immediate Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Develop a clear understanding of legal obligations of prisons to incarcerated individuals with I/DD under the Eighth Amendment, as well as under the ADA and Section 504 of the Rehabilitation Act and state, territorial, and local statute.
- Reach out to administrators of prisons and jails to notify them that failure to mitigate extreme heat may constitute deliberate indifference under the Eighth Amendment.[43]
- Report suspected violations of constitutional rights, disability rights laws, or unsafe heat conditions to appropriate oversight and enforcement authorities, including protection and advocacy agencies, departments of justice, licensing bodies, or other regulatory entities, when it is safe to do so.

Public Health:

- In collaboration with the disability community, provide accessible information to carceral facility administrators about the impacts of extreme heat and actionable mitigation strategies for incarcerated individuals with and without I/DD.
- Support prison administration in developing heat mitigation protocols for incarcerated individuals, including individuals with I/DD, and staff.
- Issue formal extreme heat health advisories to correctional facilities that outline minimum health-protective actions during heat events, including unrestricted access to potable water, modified schedules, wellness checks, and medical monitoring for individuals in high risk.
- Conduct real-time surveillance of heat-related emergency department visits, hospitalizations, and deaths associated with correctional facilities during extreme heat events, and share findings with relevant oversight bodies.

Long-Term Mitigation Strategies

Lawyers, Advocates, and Policymakers:

- Establish an independent oversight body with authority to conduct heat inspections, ensuring representation from the disability community and public health experts.
- Develop litigation strategy where warranted and as feasible.
- Advocate to abolish solitary confinement through policy change, statutory change, or litigation.
- Advocate that all carceral facilities be required to be energy efficient and facilitate heat mitigation, such as utilizing adequate air conditioning throughout facilities. Ensure funding for electricity costs incurred are included.
- Advocate that adequate space for incarcerated individuals is mandated.

Public Health:

- Collaborate with disability advocates to develop information to educate staff and incarcerated people about heat-related illness and death, and mitigation strategies. Ensure that all materials are in accessible formats, written in plain language and Easy Read, and available in the primary languages of incarcerated people.
- Integrate correctional facilities into state climate adaptation and heat action plans by formally designating prisons and jails as high-risk heat infrastructure requiring targeted surveillance and intervention.

Conclusion

Extreme heat is a deadly emergency that is accelerating with climate change, and disproportionately affects people with I/DD. These impacts are the predictable result of policy choices that exclude disabled people from planning and treat accessibility as optional. With systems designed to leave disabled people behind, heat illness, institutionalization, and death are anticipated conclusions. Mitigation begins with education of people with I/DD, family members, direct support professionals, and service providers about recognizing the signals of heat stress and understanding how and when to act.

In parallel, disability rights lawyers, disability advocates, and policymakers must work with individuals with disabilities and government agencies, including public health departments and emergency managers, to ensure that heat mitigation is integrated into law, policy, and daily practice. Simultaneously, public health must

move beyond awareness campaigns and into sustained, accountable action that integrates disability leadership in planning, implementation, and oversight. It will take a whole community approach to redesign systems that have historically excluded disabled people from emergency preparedness and climate response. Government agencies, service providers, schools, congregate care and penal facilities, housing authorities, and community organizations all have a role to play. Our communities and our lives are at stake, and the risks posed by extreme heat are intensifying each year.

The right to dignity of risk does not mean the right to be exposed to preventable harm. People with I/DD cannot be left behind in extreme heat mitigation efforts. Their safety, independence, and autonomy must be prioritized throughout all planning efforts. As climate change intensifies, the question is not whether extreme heat will continue, but rather whether our policies will continue to exclude disabled people, or whether we will choose to design systems that protect, include, and value their lives.

"Disabled people are experts at surviving and thriving in environments that weren't built for us. We really know how to adapt in the face of climate change, and can really lead the way."

- Abby Bresler

To learn more about this topic, go to https://www.disabilitydebrief.org/climate-understanding-justice/

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