



THE PARTNERSHIP
FOR INCLUSIVE DISASTER STRATEGIES

Plain Language Edition

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



To Start

Extreme heat is when the weather gets hot enough to be dangerous for people. Extreme heat also gets called “heat emergencies.” Extreme heat is happening more often than it used to. But extreme heat does not get talked about as much as other kinds of weather emergencies. For example, hurricanes, tornados, or floods get talked about more than extreme heat.

But extreme heat kills more people in the U.S. than other kinds of weather emergencies. In most years, extreme heat kills more people than hurricanes, floods and tornadoes combined. Extreme heat hurts people with all kinds of disabilities. That means extreme heat hurts people with intellectual and developmental disabilities (IDD). Extreme heat hurts people with disabilities more than people who do not have disabilities. This is also true for other weather emergencies, like hurricanes, floods, and tornadoes.

This report is for disability advocates, disability rights lawyers, and people who make policies. Policies are rules and laws the government made. This report could also be helpful to people who work in public health. Public health means the health of large groups of people, like cities or countries. Public health is also about how the government helps people stay healthy.

We hope this report helps people with IDD understand how extreme heat could affect them. People with IDD should have as much control over their lives as people without disabilities. People with IDD should get the support they need from friends, family, and other helpers. But they should always be in charge of their lives. That means they should be in charge of planning for extreme heat.

People with disabilities, especially people with ID, should have the dignity of risk. Dignity of risk means the right to make choices that might not go well, even when others disagree with those choices. People with ID should learn about how to stay safer in extreme heat. But in the end, they should get to make their own choices for what to do when extreme heat happens. Letting people with IDD make their own choices will help save more lives during extreme heat.

Many people don't know a lot about extreme heat. How does that make extreme heat worse for people with IDD?

Extreme heat is the kind of weather that kills the most people. Extreme heat hurts the disability community, like people with IDD, more than it used to. Extreme heat will keep hurting people, and will not go away. This is because of climate change. Climate change is when things people do cause the weather and temperature to change all over the world. This makes the environment harder for everyone to live in.

The way extreme heat hurts people has not been taken as seriously as it should. This might be because:

- Extreme heat does not destroy buildings as much or as quickly as some other weather emergencies. For example, hurricanes, floods, and tornadoes.
- Extreme heat has happened in the past, but it did not happen as often as it does now
- It took a long time for extreme heat to happen as often as it does now. People often do not notice a difference when something changes over a long amount of time.

The media also does not do a good job of helping people understand that extreme heat is dangerous. When news channels tell people about extreme heat, they usually don't talk about how extreme heat hurts or kills people. Instead, the news talks about extreme heat like it is a fun time with lots of sunshine.

The media and public health workers might tell people to check on older adults and people with disabilities during extreme heat. But, they usually do not tell people how to know if someone is sick or dying from extreme heat. People are usually not told what to do if someone is sick or dying from extreme heat.

Some medications can make someone more likely to get hurt from extreme heat. Many disabled people take these kinds of medications. Public health workers

have started telling people that these medications could make extreme heat more dangerous. But public health workers usually do not say how people on these medications can protect themselves from extreme heat.

Public health workers do not usually tell disabled people that they are more likely to be hurt by extreme heat. They also do not usually tell disabled people how to protect themselves from extreme heat.

Disabled people are 2-4 times more likely to be hurt or die in weather emergencies than non-disabled people. But public health workers, disability rights lawyers, and policy-makers usually don't know this. Even many disability advocates don't know how dangerous extreme heat can be.

Because people don't know, people with IDD get left out of planning for weather emergencies like extreme heat. For example, public health workers share information about extreme heat. But that information might not be shared in a way people with IDD can understand.

Disability lawyers and advocates might not do as much work to make extreme heat less dangerous for disabled people. They might know a lot about some disability rights laws. For example, the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act. But they might not know as much about how different policies can hurt people with IDD in extreme heat.

Extreme heat hurts all people with IDD more than other groups. But extreme heat can be even more dangerous for people with IDD who live in congregate settings. Congregate settings are places where many disabled people live together. Some examples of congregate settings are nursing homes, institutions, group homes, jails, and prisons.

Congregate settings are supposed to have emergency plans for different weather emergencies. But these plans usually only talk about things like hurricanes and tornadoes. People with IDD might not be prepared for a heat emergency.

It is a big deal that people don't take extreme heat seriously enough. People with IDD get sick or die from extreme heat, and that shouldn't happen. Some

people act like it makes sense for people with disabilities to get more sick and die from extreme heat. But the biggest reasons disabled people get sick or die from extreme heat have nothing to do with being disabled. Instead, policies that leave out people with IDD lead to them getting stuck in extreme heat.

What makes extreme heat more dangerous for people with IDD?

There are a lot of reasons why extreme heat is more dangerous for people with IDD. One reason is that some people with I/DD have heat sensitivity. This means their bodies have a harder time dealing with heat.

Some people with ID also have mobility disabilities. For example, they might need to use a wheelchair, or get help moving around. That means they might not be able to move somewhere cooler if it gets too hot.

People with IDD might have trouble letting others know if it gets too hot. People with IDD who can't speak might not have a good way to let others know what they need. Or, someone with IDD might not know they are getting too hot.

People with IDD may not be taken seriously when they say or show they are hot. This can be dangerous if they don't get to make their own choices. They might not get the choice to move somewhere cooler or get help cooling off.

People with IDD sometimes take medications. These medications can make them have an even harder time in the heat. Many people with IDD also use medical devices that need electricity to run. For example, power chairs and ventilators. Extreme heat can make the power go out. That makes extreme heat even more dangerous for people with IDD.

Studies show that people with mental health disabilities are more likely to get sick or die in extreme heat. Around half of people with IDD also have mental health disabilities. That means many people with IDD are in even more danger from extreme heat.

Policies that leave out disabled people make extreme heat even more dangerous. Policies get made because people want to fix problems. That means people have to decide what problems are important enough to make policies about. Sometimes people forget that people with disabilities are just as important as people without disabilities.

Because of that, some policies get made that treat disabled people unfairly. Ableism is when someone gets treated unfairly because they are disabled. People who make policies might not think people with disabilities are important. So ableist policies get made that hurt people with disabilities. Some policies about weather emergencies, like extreme heat, are not fair to people with disabilities.

Sometimes the way something is built can make it hard for people with disabilities to get what they need. For example, sometimes the government opens up cooling centers during extreme heat. These are buildings with air conditioning that anyone can go to stay cool. But sometimes these cooling centers are built in ways that people with certain disabilities can't get inside. Or, the directions to the cooling center are too hard for people with IDD to understand. The people who made the cooling centers were not trying to leave disabled people out. But it happened anyway, because they did not think about disabled people. This is not fair.

Many people who work in the government don't know a lot about IDD. Even people who work in public health might not know a lot about IDD. They might not know that extreme heat is more dangerous for people with IDD. They don't get the training they need to help people with IDD in extreme heat. They don't try to teach people with IDD what to do in extreme heat. This leads to people with IDD getting put in more danger in extreme heat.

Some other things that make extreme heat more dangerous for people with IDD are:

- Not having a lot of money. People with IDD are more likely to not have a lot of money than people without IDD.
- Living in a congregate setting.
- Being a part of other groups that get treated unfairly by society. For

example, a Black person with ID could end up in more danger from extreme heat than a white person with ID.

- Information about extreme heat being too hard to understand. The government or public health workers might use words that are too big to explain extreme heat.
- Being homeless, or living in housing without air conditioning.
- Not getting a chance to learn about extreme heat in school.

What can people do to make extreme heat less dangerous for people with IDD?

There are a lot of problems that can make extreme heat more dangerous for people with IDD. But we think these problems can be solved. Disability advocates, lawyers, policy-makers, and public health workers need to work together. Here are some ideas we have for what needs to happen:

Information about extreme heat must be accessible to people with IDD and the people who help them

The government and public health workers give out information about extreme heat. Right now, a lot of information is written in ways that are hard to understand. That means people with IDD might not get the information they need to stay safe. Families and support people might not know how to explain heat emergencies to people with IDD.

Information about extreme heat should get written in plain language. The information should not just be in words, just in case someone with IDD can't read. There should be pictures and videos that explain extreme heat and what to do in an emergency. People with IDD should be able to look over this information on their own or with people that support them. Teachers that teach students with IDD should also help them learn about extreme heat.

It is also important to have information about extreme heat in many languages. Lots of people in the U.S. don't speak English. Having information in Spanish, ASL, and other languages helps more people understand extreme heat.

People who support people with IDD, like families and paid support people, also need to learn about extreme heat. They should know the warning signs that someone is in danger from heat. They need to know how to keep people with IDD safe in extreme heat.

Information about cooling centers also needs to be shared in ways people with IDD can understand. The cooling center should be a place that is easy to get to, and that people with disabilities can get in. There should be easy directions that people with IDD could follow to get to the cooling center.

People with IDD need homes and communities that protect them from extreme heat

Many people with IDD don't have housing, or live in housing without air conditioning. The government needs to help people who don't have a lot of money to stay safe in extreme heat. One way the government can do this is by setting up more cooling centers. Or, they could give people money to buy an air conditioner.

Another way the government can help is by putting more money into housing. Building more housing with air conditioning will help people stay cooler. The government could also work to change the way cities are laid out. This can help parts of a city stay cooler, like places that have housing without air conditioning.

People with disabilities in congregate settings need to be protected from extreme heat

Congregate settings must make sure they have ways to cool down. For example, all congregate settings should have air conditioning. It does not matter what kind of congregate setting someone lives in. They should have what they need to stay cool in extreme heat.

The government needs to make sure congregate settings keep people with IDD safe. That means making sure people with IDD are safe during extreme heat. The government should check congregate settings to make sure they have what they need for extreme heat. If someone in a congregate setting gets hurt by heat, the government needs to work with that congregate setting so it doesn't happen again.

People with IDD need to be a part of planning for extreme heat

Making new policies takes a lot of work. But people with IDD need to be a part of this work. If people with IDD get left out, new policies about extreme heat could hurt them without meaning to.

The government and public health workers need to talk to people with IDD. People with IDD can share their feedback about plans for extreme heat. They can make sure the plan is accessible and would actually help people with ID in their community.

Conclusion

Extreme heat is an emergency that kills people. As the Earth gets warmer because of climate change, extreme heat will keep becoming a bigger problem. Extreme heat affects people with IDD more than others. This is because policies about extreme heat left out people with IDD. When people with IDD get left out, they get more hurt by emergencies like extreme heat.

Lots of people need to work together to make extreme heat less dangerous for people with IDD. People with IDD need to have chances to learn more about extreme heat. Families, doctors, and support people need to know the signs when someone with IDD gets sick from heat. Everyone needs to know what to do when extreme heat happens.

Disability rights lawyers, disability advocates, and policy-makers have their own work to do. They must work together with people with IDD and public health workers. New laws should be made to make extreme heat safer for everyone.

Public health workers need to try new ways to handle extreme heat in their communities. Right now, a lot of public health work about extreme heat just tells people what to do in an emergency. But this information is not enough to really help people with IDD. People with IDD need to work together with public health workers. Together, they can come up with new ideas to keep people with IDD safer in extreme heat.

It will take a lot of time and work to change how things happen during extreme heat. The way things have been done for many years left out people with IDD. There are many other groups that need to work together to fix this:

- Government agencies
- Groups that give services to people with IDD
- Schools
- Congregate settings
- Groups that run housing for people with IDD
- Jails and prisons
- Community groups

It is very important for all these groups to work together. If not, more and more people with ID will get sick or die from extreme heat.

Dignity of risk says that people with disabilities should always get to make their own choices. But that doesn't mean other people should stop trying to keep people with IDD safe. When extreme heat happens, people with IDD cannot get left behind. When people in power plan for extreme heat, they need to make people with IDD a part of the plan.

The Earth will keep getting hotter. That means it is more and more important for people with disabilities to get what they need to survive extreme heat. New policies need to be made that show disabled people are important, and deserve to be safe in heat emergencies.

“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>