

[Rachel]

All right. So, thank you so much. Thank you for being here for our webinar, the New Year's Resolution: Get Ready Now! webinar on emergency preparedness for people with disabilities. The webinar is brought to you by the University Center for Excellence in Developmental Disabilities, called the UCEDD, at Oregon Health and Science University and from the Institute on Development and Disability at OHSU.

Here's an overview of today's agenda. We're going to do welcome and introduction and instructions. And then we're going to go on and do emergency preparedness work at the UCEDD, a little overview. We'll have a Zoom poll for everyone to participate in, we'll review the Emergency Preparedness Resource Hub and the Ready Now Toolkit. We'll have some questions, and then wrap up. And I just want to mention too, there's no break today during our hour-long webinar, but please take a break if you need one. So I'm going to do some introductions here. First off, my name is Rachel Benson, I'm a senior community research liaison at the UCEDD. I use she/her pronouns. I am sitting in my home office in Portland, Oregon. I am a white woman in my mid-30s with shoulder length brown hair. I'm wearing a blue polka dot shirt. There is a tapestry of a forest and mountain scene in my background, and I will be moderating this evening's timely and important discussion. Larissa?

[Larissa]

Yeah, hi, I'm Larissa Yoshino. I use she/her pronouns. I'm the data and communication lead here at the UCEDD. I'm a white woman in my 30s with hair pulled back into a bun and glasses on and I'm wearing a black polka dot shirt and I'm sitting in my living room with windows and the fireplace in the background.

[Rachel]

Thanks, Larissa.

And we're waiting on Jan to pop on so I'll do a little introduction so you know Jan when you see her. She uses she/her pronouns, she has salt and pepper hair. Today, she'll be wearing pink and brown pattern glasses, a royal blue top with

silver rhinestones around the neck. She works for the UCEDD and is a self-advocate, a writer, and a public speaker.

All right, so we have live closed captioning available for this webinar. In Zoom, you can see the closed captioning if you click the CC icon at the bottom of your screen. And in Zoom chat, click the chat icon at the bottom of your screen. The chat box will open on the right of your screen, and you can type your questions there. To change the view of who you are seeing on the screen, click the view button that should be at the top right of your screen. If you choose speaker view, you'll only see the person who is speaking. We have pinned the ASL interpreter so you can see them and the speaker at the same time. Please let us know if you have any technical issues and we'll help out as best we can.

And before we review what we're chatting about today, let's go over a few more details about the webinar. So, this webinar is also being live streamed on our Community Partners Council Facebook page. The recording of this webinar will also be available on the UCEDD past events website, and I'll follow up in an email to everyone who registered with a link to this website. And I mentioned at the beginning, but we're having some issues with getting Spanish translation, so we'll also make sure that this webinar is translated into Spanish and that will be posted as well. We apologize for that inconvenience. And live American sign language interpretation is also today available today. Thank you so much McKay for being here this evening.

So, in Zoom please keep your audio and video off during the presentation so during the webinar your video and name can be included, or sorry, won't be included in the recording. And we will have time for questions at the end and you can type your questions in that chat box on the right of your screen. I'll be monitoring the chat in a little bit, and we'll make sure we get your questions answered. We will talk about emergencies today and we understand that this might be a difficult conversation for some people, and if the discussion makes you feel upset, please feel free to take a break or leave the webinar if needed. Your well-being is important to us, and we want to make sure that you feel okay during this time.

I know Jan is having some issues going on so we'll get Jan on and follow up with her story here in a little bit. So, we'll just move on to this slide.

Okay. So, why do this work? We started our work in emergency preparedness when we heard from people in our advisory board and the Oregon Self-Advocacy Coalition or OSAC about how important this work is to the disability community and the need for it. So, we decided to build a resource hub as part of our work because there are not many emergency preparedness resource specifically designed for people with disabilities, and those resources can be hard to find. Our current team at the UCEDD are not emergency preparedness experts, but we do have experience in building accessible online resource hubs, so we felt like this was a good place to start.

To start, we contacted our partners in the disability community around the state, and we also talked to disability community and wanted to form a workgroup to select the best resources to share on the website. The workgroup included members from the Disability Emergency Management Advisory Committee, or DMAC, the Central Oregon Disability Support Network called CODSN, self-advocates from the Oregon Self-Advocacy Coalition Group, the UCEDD Advisory Board, and UCEDD staff. So, we had nine people total who met twice a month over a six-month period, and we paid community members for their time and expertise. We used a rubric to score for accessibility and relevancy of resources, and then we selected resources to share on the website that Larissa will show you here in a few minutes.

All right, so now we're going to do a Zoom poll and then we'll go to our live demonstration of the Emergency Preparedness Hub. Let me get that going for you. All right, so a poll may have just popped up on your screen, well, hopefully. And our question is: "How prepared do you feel today?", and you can answer "very prepared", "prepared", "a little prepared", "not very prepared", "not at all prepared", or "I'm not sure". And feel free also to put your option in the chat if that works better for you. I'll just give a few more moments for you all.

All right. I'm not seeing a button where I can share this with you all, but it seems like about 8% feel very prepared, 30% feel prepared, 52% a little prepared, 6% not

very prepared, and 2% not at all, and 2% are not sure. So it seems like most people fall in the little prepared category, but there's nothing wrong with not feeling prepared. It can feel like a lot to get prepared and that's why we're here today too.

All right, so we have one more question that I'm going to pop up. I'm gonna just read in the chat--

[Rhonda]

This is Rhonda Eppelsheimer--we had one participant say: "We have been without power for 11 days now. We are finding out exactly how prepared we are!!"

[Rachel]

Thanks for sharing that. Yeah. We're--It's an interesting time to have this webinar. As we know, a lot of Oregon got hit with an ice storm and snow and, it may feel like you're prepared, but then something happens it kind of shows you that. Thanks for sharing.

All right, so I'm going to go to the second poll here. One second. Okay, here we go. Second poll. So: "What do you want to work on this year for emergency preparedness?" We have, "make a plan", "create a kit", "get to know my neighbors who might help me in emergency", "figure out what resources are offered in my community", "learn about different disasters that could happen", and "get my service animal or pet ready". And then we also have "talk to my support people about emergency preparedness", and "I'm not sure". I'll just give you all a moment to fill that one out. Oh, and if you did put "other", or if you have something other thing that you wanted to add just feel free to put it in the chat or you can also come off mute and let us know as well.

Right. Just going to share results here now that I figured out how to do that. So it looks like most people kind of are wanting to create a kit or make a plan and you can see the other answers here. Let's scroll down. So we have 16% that also want to figure out about resources. Sure.

[Larissa]

I noticed some comments in the chat--this is Larissa.

[Rachel]

So, let's see, we have "adding to my emergency kit". For sure. "To beef up my current kit." We have another one: "My grandma just moved in with us so we need to update our kit to include her needed items." And, "Help my kids get a bit more prepared." Great, well, thank you so much. I hope this will help us, kind of as we dive into the resources out there. Kind of flag ideas for you and kind of what you want to prepare for. And I know Jan is not able to get on so I'm hoping we can move back to Jan's story. If...

[Larissa]

Jan's still not able to join, so we can maybe circle back after the next section and...

[Rachel]

I see Jan in here.

[Larissa]

Do you?

[Rachel]

Well, yeah, how about we circle back at the end, Larissa, and do that.

[Larissa]

Oh yeah, I do see her name in the participant list, but I don't know why... hm, okay. Jan, maybe you can turn your video on or chat us, let us know if you're ready. Let's give it a minute here.

[Jan's Support Person]

We're just trying to get everything back in order so she can turn her camera on and start with you guys.

[Rachel]

Okay, great.

[Larissa]

Okay, let's move to the next section and we'll circle back to Jan then if that sounds okay.

Okay, all right, so now I'm going to share the Emergency Preparedness Resource Hub and tell you all a little bit more about the product of that workgroup that Rachel spoke about.

So, this is actually our UCEDD homepage, and I just wanted to start here to show you that to get to the Resource Hub, you can go to our Resources tab and then click Emergency Preparedness. And so this is our main page here that has three sections highlighted in the middle, and then there's also some information on the right column if you need to get help right now. So who to call or where to go. And we'll circle back to this part here at the top about the Ready Now Toolkit, but for now, we're going to go through the three sections of this website hub. The first one being Key Information. And so you can click on the text or the photo or image here. And I'm going to try to slow down for the ASL interpreter.

This page, Key Information, tells you about the Resource Hub and has a place to sign up for alerts. Some helpful definitions on the right here, the difference between a disaster and an emergency, the main Ready.gov website for people with disabilities, and also, at the bottom, some webinars that we hosted previously around emergency preparedness. And this is where you will find the future recording of today's webinar. And then a little bit about the workgroup itself, just acknowledging their help in this project.

I'm going to go back up to the top to note here on the right, we have links to those other two main pages. So, of the three main pages, we're on one of them and here's the other two so we're going to go to Types of Disasters.

And so here you'll see a grid of icons representing different emergencies and disasters and you can click on any of these, and it'll jump you down the page. So you'll be on the same page, just scrolling down, about specific resources for that kind of disaster. We're going to check out Power Outage, since that is something that people have been struggling or are still struggling with today, unfortunately.

So, every section here for the different types of disasters has a resource, a link, an image of what that looks like when you go there, and also a description of what the resource is. So this one, for example, is a web page about power outages including how to plan ahead and what to do during and after. And it also has two videos as well as a Spanish version, linked here. And you'll see throughout the resource hub that we have noted and linked where possible when materials are available in languages other than English.

So going back up to the top of the page, you can scroll, or you can click every so often there is [Return to Top of Page] link and then you can choose a new type of disaster to check out if you would like.

So now we're going to go to the third page of the three main pages, Get Prepared. So, clicking here. This page offers a lot of different kinds of resources to help you get prepared for an emergency in lots of different kinds of formats, and it all just depends on what is most helpful to you. A lot of them have some the same overlapping information and it's just delivered in a different way. So, for example, to start with here we have a video, and this is a short 4-minute video on how to prepare for a disaster. And we have some notes here on the right about YouTube accessibility.

Then we have three featured resources. One of these, the first one is a poster, so it's a visual of how to build an emergency kit for people who are more visual learners. In the middle, there's a flyer with specifically how to get supplies on a budget, so very helpful. And then the third one here on the right is a website called Emergency Planning for People with Additional Needs. And to visit any one of these resources, you can click on the linked text or the button here.

And we'll just check this one out. So, this is the PublicAlerts.org website for additional needs. It talks about who might have additional needs, and then what else to consider, and specifically for different needs. So, for people who rely on electricity for medical equipment, you could open this one and learn more about what to think about and plan for and check out some additional resources related to that. And there's lots of different categories here that could be helpful to many people.

To go back to our website, you can hit the back button on the browser. Then, to the right you'll see there's an ASL resource and a Spanish resource that we've highlighted here. Below, we have how to build an emergency kit. So, there's a web page from FEMA and a flyer that talks about how to store your emergency supplies. There's a couple of tools that might be particularly helpful including a health profile, which is a document to record all of your health information in one place, and communication aids that have downloadable PDFs that have picture aids and other communication resources. And then to the bottom, we have entire complete guides for planning. So, a sort of all-in-one approach. Here's two here, we're going to go to the second one briefly. So this one is the Feeling Safe Being Safe resource, including a video and a workbook.

And then the one above is the Ready Now Toolkit, and this toolkit is in its second edition as we have just updated it last year. It was originally created in 2014 by our Office on Disability and Health, the Oregon Office on Disability and Health. And it's linked here on another page, and we'll go check it out. So, you can click the visual or the text, and it's also in Spanish if you click here.

The Ready Now Emergency Preparedness Toolkit is quite a large toolkit and that's why we have it broken down by sections. So, you could open the whole thing if you wanted to say maybe print it or just look at it in its entirety, but you can go section by section depending on the topics that seem most relevant to you. Or, if you just want to do a really step-by-step approach and take it one thing at a time.

And then the far-right column is the fillable form version of some of these sections. It's the same document, it just has the ability for you to type into the form instead of just printing it out and then writing it in by hand. So, this kind of opened to the middle of the page for some reason. I think I was here earlier. But this is Tab 3: Personal Ability Self-Assessment, and its purpose is to help you get ready by thinking about what help you might need during emergency versus what you can do on your own. So, there's different sections and you can actually type into these fields and then download it and save it on your computer, or print it out and put it somewhere where you can access it later.

So, I'm going to show you just that these different tabs of the Ready Now Toolkit are variable in their length. Some are very short, and some are a little more in-depth. For example, the Tab 4 here on Emergency Support Groups--again this opens in a weird place--but so this is Tab 4 and it's only four pages long, including that page that's blank because of printing. So, this is talking about building an emergency support group and thinking about who you might want to talk to, what you might want to talk to them about, and other things to make a plan with your support group members.

And so that is Tab 4, versus for example, maybe Tab 8, which is a little bit longer. So this one: "Should I stay or should I go?" helps you figure out if you should leave during the emergency or if you should shelter in place, meaning stay at home inside. So how to decide, what things to think about, steps to shelter in place, building an emergency supply kit including a go bag. And this is a visual of what you might put in your go bag, which is a bag that you can grab and go if you're ready to leave your home without time.

And then there's a list of all of the things to put together, and it's quite comprehensive and you can go through step-by-step, one thing at a time. Maybe dividing this up over days or weeks or months depending on how long it feels reasonable to you to gather all the things and put it all together. So, this one just is a very comprehensive list, including space for you to add other items that you think you might need. So that's Tab 8.

That's briefly about the Emergency Preparedness Toolkit, available in Spanish by clicking here, and we'll send out all the relevant links after the webinar. I'm just going to go back to our landing page and note that to get to the Ready Now Toolkit, you can jump there or go there directly from up here at the top right as well, and it was on the Get Prepared page that we also had that linked.

So that's our Emergency Preparedness Resource Hub. We're open to any feedback, and we would like to get suggestions of other resources to maybe include or things that could be better than some of the ones that we have on here. We are definitely going to have this as an evolving project, so that's all I have to share for now.

[Rachel]

Thanks, Larissa. Jan, do you feel ready to do your part of the presentation. Sorry you're having a tough time getting in.

[Jan]

Yeah, let's go.

[Rachel]

Right, I think Larissa will pull back up your slides.

[Larissa]

Yeah, let me open that.

All right, it's being a little slow loading here. Getting there.

[Jan]

I am sorry I am late.

[Rachel]

That's okay.

[Jan]

I had trouble getting on.

[Rachel]

There were some tech issues today. It happens to the best of us. I'm glad you're able to make it, Jan.

[Larissa]

Here we go.

[Jan]

I am Jan. I use she/her pronouns. I have salt and pepper hair. I am wearing pink and brown pattern glasses. I am wearing a royal blue top with silver rhinestones

around the neck. I work for the UCEDD. I am a self-advocate, a writer, and a public speaker.

The wildfires of 2020 placed my group home in an evacuation zone. The sky was an orange color for days. It felt like we were on a different planet. It was so smoky that I couldn't go outside for, well, it felt like forever.

We didn't have a vehicle at that time, so we had to borrow a van from another group home that wasn't in the evacuation zone. The van was loaded with all our go bags and sat waiting to go. We had no idea if all three of our power chairs would fit into the van. I think it was possible that one of us would have had to leave their power chair behind.

When we were raised to level two "be prepared to leave" status, I thought, "Why don't we just leave right now?"

However, the real question hanging in the air was if we were evacuated and had to spend multiple nights somewhere, where would we sleep? One of my housemates has to sleep on a specialized air mattress. I don't know how easily that bed could have been moved.

Fortunately, my housemates and I did not need to be evacuated and remained safe. I learned a couple things through this experience. I learned that when I felt myself getting overwhelmed with the situation I had no control of, breathing in through my nose and sighing out through my mouth really calmed me.

And secondly, my experience made me aware that more thought needs to go into my house's emergency planning.

Thank you!

[Rachel]

Thanks so much, Jan. I am going to put Jan's blog link in the chat, and you can also use this QR code to get there. If you want to learn more about Jan's experience, and also Jan just has a great blog. It's great to look around at. Thank you.

Great. Well now we'll just open it up for questions. I saw a question in the chat from John just asking if our team is willing to make presentations, and I did respond, but just wanted to say that we are open to presentations. I'll add our contact information. If you want us to come speak to your group, feel free to reach out and we can figure it out from there.

And, yeah, if anyone has any chat or any questions feel free to come off chat--come off mute--and also put in the chat any questions that you have.

[Participant]

Hello, my name is Ainsley. Do you guys have any tangibles--any things that you guys can offer to individuals? Perhaps those of us who assist people who have, you know, different disabilities, or perhaps people who don't have access to a printer for copies of those actual packets that you were showing us? Do you have those available?

[Rachel]

That's a great question. I know we're talking about how we can print them, so stay tuned for that. I know it was something that we want to do at some point so I'm hoping that we will soon. Did you have anything to add, Larissa?

[Larissa]

No, I think that covers it. At first I thought we were going to be talking about emergency kit supplies and I was going to mention that there's some funding that's recently been distributed through the service provider agencies to help individuals get emergency supplies, but that is the extent of the details I know about that.

[Rhonda]

Hi, this is Rhonda, and I do have a quick question. Planning for emergencies can be really overwhelming, and I'm wondering if you have a recommendation on where people can get started.

[Larissa]

Yes, it is a lot of information that I have just shared on our resource hub as well. The Ready Now Toolkit that I showed that has the different tab sections--if you start with Tab 1, there's 10 basic steps to emergency preparedness. So that might be a good place to start, step by step, and go through one at a time. And just go piece by piece as far as learning about all the different things there is to emergency preparedness.

It's a very big topic and there is a lot to learn. As far as using our website, and all the resources we have linked on the website, it might be helpful to just take a look at one of those a day, or a week, however much information is at your maximum ability to process at one time. And know that it's a process and you'll get there.

[Rachel]

Thanks, Larissa. I also was thinking as well, something that's been helpful for me is that there's also a resource that Larissa previewed quickly about, on creating a kit on a budget and I think that can be a really good one, because it goes over week by week of what you could buy. Small amount of things each week to create your kit, and I think that can be really helpful. Because for me I know it can be overwhelming of, "I'm going to go out and buy all this stuff? Right now? What do I need?", and so that kind of walks you through it or goes through it step by step.

And I see in the chat, just said, not a question, but "Something we have learned in the last week without power we felt prepared but had never actually done a lot of actual work of getting up and running. We hadn't actually connected our generators to the house or figured out where we could cook. Make some dry runs on getting things set up. Do it when there isn't a disaster going on."

Yeah, thank you so much for sharing that, and if anyone has any other tips, any tricks that they have, feel free to pop it in the chat. I love this kind of group learning as well because there's a lot of people who've gone through some things and can share some helpful hints.

Any other questions out there? Or thoughts as well. Let's give a few more moments here and if not, we'll--Oh, "What is the..."

[Participant]

Rachel?

[Rachel]

Oh, yeah.

[Participant]

I have one, but I'll wait. Go take the one that you have.

[Rachel]

Oh, no worries, I see Janette: "What is the recommendation for getting medications ready in emergency kit? Should you ask your doctor for an extra supply?" Yeah, that is actually one of the things that we recommend in the kit that Larissa shared with you. Did you wanna, did you have anything to add, Larissa? Saw you came off mute.

[Larissa]

Yeah, just in the Ready Now Toolkit, and I think in other resources as well, it mentions trying to have up to at least a week, if not a month, depending on your medication and how you can get those prescriptions pre-filled, or filling them ahead of when you're going to run out, and kind of keeping that backup supply is definitely a good idea.

[Rachel]

Yeah.

[Participant]

Hi. I was just wondering if anyone on the call, or you all, have good advice for working with services coordinators, case managers, and other support folks to help do some of this planning because it's really an awful lot for one family to take on their own, and we like to talk about, you know, getting some help, not only thinking it through, but talking it through with support. So, has anybody had any good experiences with that and getting help from say Developmental Disability Services, the CCOs, etc.?

[Rachel]

That's a great question, thanks for asking that. I'll see if anyone has any wisdom to share or thoughts.

[Rhonda]

This is Rhonda. I'll just, I think this is just echoing kind of what we've heard in the chat too. It's never too early to start planning and so one of the things is making sure that you're bringing that up if you have a planning meeting, because often times when you're working with a service coordinator or an agency, you develop a service plan. And so, making sure that you bring up that emergency preparedness and being prepared is really important, and how do you work that into your support and planning as a place to start. And then making sure that you're kind of doing with whatever you set up in a plan. Whether that's just getting prepared that you're doing those activities. That might be a place to start, is making sure it's even on the radar.

[Rachel]

Yeah. Thanks, Rhonda. Yeah, I was thinking as well as starting the conversation, it's great if your service provider can start the conversation, but that's not always going to happen. And so, you know, having the conversation of what's the plan, do you all have a plan? And really just starting that conversation and seeing where they can help support and being clear about your needs as well.

[Rhonda]

There are some other questions in the chat.

[Rachel]

Yeah.

[Rhonda]

One about controlled substances, when doctors don't allow those ahead of time. I don't know the answer to that. I think that's something we'd probably have to do a little research on, and I don't know if there's anything in our resources that

would do that. So, Jamie, I think we'll have to check on that and see what information we might be able to find out about that.

[Larissa]

Tammy Bakewell also responded to that a bit, just that getting additional medications when they're controlled substances is difficult and will take advocacy with OHP, OHP being Oregon Health Plan. So, I guess, yeah, being clear on your needs and advocating for yourself, and there's probably more to it, but we'll have to look into it.

[Rachel]

I also see in the chat that Lindsay said, "Emergency planning is also part of the ISP process, so individuals should be having at least yearly conversations during planning with their service coordinator, personal agent." Yeah, thank you for that, Lindsay. And Stephanie also said, "I'm with Clackamas County Social Services and our DD department has emergency preparedness workgroup. Great department that is working on preparedness with their clients." That's great.

And I see Tammy also put, "We are happy to coach people on that through the Oregon Family to Family Health Information Center." And is that for, Tammy, for the controlled substance that you're responding to there?

[Tammy]

Yeah, yeah on advocacy, advocating--it's a well-known problem and I think it can be done, but it it's difficult. It's a lift.

[Rachel]

And I can follow up in the email I'll send out afterwards with some more information on the Family to Family Health Information Center for people who want to reach out. Thank you for that.

Oh, looks like Lindsay said, "For any anyone in the Yamhill Polk Marion area creating opportunities also has regular resources for training and support with kits." Great. Yeah, it's wonderful--I think this is becoming more of an issue and

hopefully more services and supports are going to start being created for this need, for sure.

All right. I know we just have a few minutes left, any last questions or thoughts before we wrap it up? We really appreciate everyone's, the great discussion tonight.

Well, I'm just going to put our contact information here in the chat, and I'll also include it in the email too in case you're not able to catch it this time around. But please reach out to us if you have any questions and if you want us to discuss anything that we talked about today with any of your groups.

And then, before we end, we do want to get some feedback from everyone about the webinar and we also want to really understand what more needs are around emergency preparedness to help us in our next steps here for emergency preparedness. So, I'm going to put this link in the chat for--it's an anonymous survey, and I'll also follow up with this in an email too. If you'd like to give feedback, that would be wonderful.

Yeah, thank you everyone for being a part of our webinar today. Thank you for McKay for being our great ASL interpreter.