Disability and Aging with Senior Vice President of AARP, Susan Reinhard

Becca Howell:

Welcome to The Heumann Perspective with internationally recognized badass disability activist, Judy Heumann.

This week, Judy is chatting with Susan Reinhard, who is the senior vice president at AARP directing its public policy institute. She leads the family caregiving initiatives and also serves as the chief strategist for the Center to Champion Nursing in America, a national resource center created to ensure that America has the highly skilled nurses it needs to provide support for the future. Judy and Susan chat about how vital it is to include disability in conversations around aging and include aging in conversations around disability as disability is a natural part of life and that people's disabilities evolve over time and change as they age and so will their needs.

The Heumann Perspective is produced by me, Becca Howell, and Judy Heumann. Be sure to rate, review and subscribe to The Heumann Perspective. So let's roll up, lay down, dance around, get some snacks ready, whatever makes you feel best and let's meet our guest today.

Judy Heumann:

Hello, everyone. Welcome back to The Heumann Perspective. Today our guest is Susan Reinhard, who is the senior vice president of the American Association of Retired Persons otherwise known as AARP, in charge of their institute on public policy. Welcome to our program, Susan.

Susan Reinhard:

Thanks, Judy. I'm really looking forward to this.

Judy Heumann:

Well, our intention today is to help our audience learn more about issues around aging and disability, and work going on between the younger and older disability communities and common issues. So what made you decide to go into nursing in the first place?

Susan Reinhard:

Oh, that's an interesting question. Well, I come from a family that has nurses and actually several nurses. I really like the idea of working with people directly so rather than become a physician, which you don't get as much interaction on a regular basis, and I particularly wanted community health nursing. Many nurses want to be in the ICU, in the emergency room where all the movies show nurse. I really like talking with people and being in their homes. So that's why I'm so deeply rooted in home and community-based services because that's really... My very first job as a nurse was in the Veterans Administration Hospital in East Orange. Because in order to be a nurse at that time, it was like you have to put at least six months' time into a hospital. So I chose, but basically it was a MASH unit, if people have ever watched MASH. It's really great. At least six months, and then I went into a visiting nurse role.

Judy Heumann:

What did you like about that? What did you learn from it?

Susan Reinhard:

Well, the biggest thing I learned, although I learned some of this in nursing school itself because we did do home visiting, but not as much, is that once you ring that doorbell or knock on the door and somebody opens it and you cross that threshold, they are in charge. This is their home. You are a guest, you are a consultant. I thought at myself a consultant to the care that is going on, and then you're going to leave and they're still there. So their health and wellness and disability and everything is where people live, and that came through really, really very early in my nursing career. So what could I do in the relatively brief time I had with people to support what they needed, what their goals are, what they really want it and what resources could I bring to the table, because really it's not me. It's really after I leave, what's going to help them. So I learned that very early.

Judy Heumann:

Well, I think what you've just stated is going to be important throughout our discussion. You wouldn't have gotten that same set of knowledge if you had just been in the hospital.

Susan Reinhard:

It's very true, because people in hospitals of all sorts tend to that they're in those four walls, I'll just say, right? So it's hard for them because they are focused on really critical things at the moment and we'd want them to be, right, we really want them to do that. They don't think what happens when you leave. They rarely even think about what happens when you go down the elevator and try to get in a car, just as happened to my brother-in-law and sister. So it's very hard to think beyond where you are, right, in your life.

Judy Heumann:

Yeah, I think you're raising amazing points right now. So how long did you work in the field?

Susan Reinhard:

So I worked as a visiting nurse for a baby about three years, and then I got a master's degree so I could teach. One of the most interesting times was when I would teach nurses. They're already nurses who were going back to get a baccalaureate degree. Many of them were in intensive care or pediatrics or something like that. I have to tell you, they were like a little alarmed about going into homes. Some of them were like, "Well, what am I going to do?" They're used to equipment. They're used to like important things, no doubt. But what am I going to talk about? How do I do this? So it was very interesting to see that this is a different environment like it should be in every nurses' head. Every healthcare and social care professionals should be very centered on the person and the person's family and where they live. That's so hard to get across though.

Judy Heumann:

Unless you're living in. I think the perspective that you come into this work is that people live a life-

Susan Reinhard:

That's right.

Judy Heumann:

... and that you're really there to help them piece together different things. So you have to have a different relationship, which is why when I got my degree in public health it was so exciting. So when did you stop doing nursing in people's homes?

Susan Reinhard:

I've always been active in the American Nurses Association. Being a visiting nurse, I started understanding that you can get care one or support care one at a time, but that you're really going to help policy is one route to do it.

Susan Reinhard:

This is a true story. I was a pretty new visiting nurse. I went to one patient's home and I was able to order orthopedic shoes and I was excited. So the next, maybe it was a month or two later, I was in a similar situation and I call my nursing supervisor and I said, "I think this person needs orthopedic shoes, too." She said, "Hmm, look at the bottom of the chart and look where it says payment and look at the boxes," and the boxes could be Medicare, Medicaid, Veterans, Blue Cross, Blue Shield, private pay, some other insurance, et cetera.

Susan Reinhard:

She said, "This one doesn't have the right box checked." That was life-changing for me. Life-changing because it really sunk in that my practice and my ability to support people was affected by payment and that could only be changed through policy. I couldn't like call somebody up and fix it. It had to be changed. So that led me into going. I got my doctorate degree and worked on policy and I then worked for the New Jersey State Nurses Association while I was also teaching. So advocacy was really new to me. How do you get more people on board and formed coalitions and work with legislators? So I was doing that for quite a while and then eventually was recruited to work for a governor. I became deputy commissioner of Health and Senior Services in New Jersey.

Judy Heumann:

I think the way you're explaining your background is very similar to myself and many other people. You learn a little bit about how to make a law. But when you actually really get down to doing it, there's so many complex issues. One of which is really being able to put something together where many organizations or individuals are in agreement or support, and then to get people convinced. So when you think about the legislative process, both in the past and today, what changes do you think have or have not gone on within legislators' thinking about issues, for example, around the importance of home and community-based services.

Susan Reinhard:

That's a really important one. I think part of it is over time. So I've been doing this for a while. I co-lead the Center for State Health Policy in New Jersey and then I was recruited to AARP, so various lenses, as you say, looking at this thing. Over time, more people have experienced it themselves either because they have a family member or an older, maybe their parent who really something happened. In many cases, it's something sudden, right? It's like a stroke or something, a fracture or something, but it leads to a longer term disability that then is a wake-up call. So more and more legislators, you don't have to tell them this because they have this experience. At least they have that much, right? They don't know what to do about it, which is what we need to do. So what do we do about this?

Susan Reinhard:

So gradually, I mean, we've seen the Medicaid world. People spend down or they were low income and they're eligible for Medicaid. We still have a nursing home entitlement. That's what you get, the nursing home. You don't want to medically get access to home and community-based services. But we've shifted it and that's been since the '80s. It's like about a 1% change over time and we track this and we can get into details, but you'll see that change. A lot of it has to occur at the state level. They're really for long-term services and supports. It's been generally state initiatives.

Susan Reinhard:

Now the current administration and Congress, we hope will take on more that they're going to invest more in home and community-based. We will see. But that took a long time in coming, people to really get this. So we're excited, very. This is like such an exciting time. It really is.

Judy Heumann:

Beyond the personal experiences that people have had, what do you think is the motivating really driving force in this? Because as you're saying, there have been gradual changes so that homeland community-based services as an option is something which is becoming more possible and that has been driven at the state level. I think this is another important issue that many pieces of federal legislation really emanate from multiple states, seeing an issue as important and begin to work on it and test it. Then when it rises to the national level in a large part is being driven by local experiences, positive and negative.

Susan Reinhard:

That's very true, absolutely. But I think also financial, I think there is a growing awareness that institutional care is more expensive and that also comes from state budgets again. So you'll see legislators they work in states and then they're elected to Congress and they joined different caucuses and so you're learning more and more. But again, most of that funding is directed at the states. But in Medicaid, there's the federal match. So there are these policy levers we'd like to call on. There are ways to increase the match. That's what's happening now that, oh goodness, if we could do more increase, we have a 10% increase right now as an incentive for states to increase the homie community-based services.

Susan Reinhard:

I have to say COVID has also had a remarkable, remarkable impact. Yesterday, as state officials in Connecticut were presenting at the National Academy for State Health Policy, all virtual of course, and this presentation was pretty profound. They have been estimating through data how many people will be needing home and community-based care over time. They've been doing this for, I don't know, 15 years and they've been going into the future so that they could prepare. It's been about for them about 2% change a year, which is double what the national average is, so that's really good. This official, who I think is fantastic, said that within months, they went from where they were to 2029. That's such a shift from institutional care to home care, jumped them eight years in their projections that meant they were short 10,000 home care workers. That's what they would need for 2029. These were all their projections like on top of that where they were losing workers, right?

Susan Reinhard:

So workforce has become, not that it shouldn't have been before, but such a huge priority. I think Congress and state legislators are getting that we are beyond crisis in terms of what you need to be able to stay at home.

Judy Heumann:

Yeah. I mean, as one who uses personal assistants in the home and have many friends who also use personal assistance, it's a crisis everywhere. Part of it is salary, but I think it goes way beyond that, which maybe leads us a little bit into another part of this discussion. Most people hope to become older and statistically we understand that disability increases as we get older. Yet it's been difficult to have meaningful discussions with people in their 40s, 50s, 60s, 70s to look at disability as something which is normal and to be preparing for it so that they're not falling off a cliff if like you said something happens. Yes, it may be a stroke, but it also may be a gradual change in whatever. What changes have you seen in being able to have this type of a discussion? Do you feel that it's important for a larger number of people who may not yet have disabilities as well as those who have acquired disabilities to be engaged in this discussion?

Susan Reinhard:

Absolutely do. I've been thinking a lot of this since we talked earlier about it. First of all, people don't want to think about anything difficult happening to them in the future. I think that's human nature. You want to be positive. You're focused on what you're doing that day and very busy with your life. So thinking ahead is not a great thing. We don't do that in general very well. They don't financially plan for the future. Sort of as humans I guess, we just don't do much of that. But that is also reinforced by what we see in movies, for example. It used to be. I think it's changing. It's starting to change, but everybody movies was like beautiful and always young. All of this idealized version of living, you're starting to see that change and I think that's good. You're seeing more diversity in general in race, ethnicity, disabilities, ages. We see romantic leads in their 60s. They're kissing and what have you in their 70s. Like that was like, "Oh ,my God, that never happens," right?

Susan Reinhard:

So I feel good about that, that that's changing some of the myths, I think. But nonetheless, people are generally in denial. They believe they're going to be fine. Those statistics belong to other people. I'm going to be the survivor. I'm going to be the one that does this doesn't happen to. So it does take more thinking about this. I see articles in the press more often in the popular press, in the New York Times, in the Wall Street and where local newspapers getting more into it. So it's a little bit harder to deny it and I think we need much more of that, and they are paid. We often use the lens of a family caregiver and it is something. Since I was a visiting nurse, it was a family member very often there and that family member needed help to be able to help and needed some attention to their own needs as well .

Susan Reinhard:

So we have this document and we call it Prepare to Care. It is online and it's downloadable and I know it's in at least Spanish. We have different versions of this, too. But it gets to exactly your question like how do you have this conversation about what you're going to need in the future? How do you create a plan? Have you started thinking about it? There's very concrete advice. It talks about is this something you've read in the newspaper that you could bring up a conversation with like, "Oh, did you see that? Have you thought about this," and da-di-da-di-da or a movie that you just saw or it could be the holidays. People coming together, let's say Thanksgiving, and you notice that your mother or someone in your

family is not quite themselves, is maybe a little more forgetful or not walking as strongly as they did that might open the conversation about let's just talk about what you might need.

Susan Reinhard:

The most important thing is to really go from what the person's goals are, not we need to get you into another place. We need to move you here. We need to do this for you, right? It's more let's talk about how you're doing, and we could go more into some of those aspects of it because it's very good. They have tools for goals and needs assessments. It's really pretty simple and pretty good. But it's also, as you're doing this, let's say I'm the daughter and I'm talking to my mother, it is making me aware, too. The more you do that, the more it goes down through the ages, right, as, "Ooh, I shouldn't be thinking about this, too."

Susan Reinhard:

One of the things that just amazes me that people don't think about it is where you live, how accessible visit. By the way, it's not just if you have a disability or you're aging, people have accidents. They fall. Our homes have to be more universally designed and any chance you can to do that or if you're going to be moving in any way to look at that and people don't do it. They just don't do it. I'm just so surprised. Because even if you want to have someone visit you, you want to make it possible for someone to visit you that might have a disability, even if it's temporary, you're going to have to make sure they can get in the house and they can use the bathroom and they can get in. So that's something that I really hope we do more work on as a society. We've done better with the curb cuts that came from the disability community. That was ADAPT, ADAPT to made that happen.

Judy Heumann:

And the veterans.

Susan Reinhard:

Right, the veterans and ADAPT. It was like-

Judy Heumann:

The first piece of legislation that came out on curb cuts was initiated by a disabled guy who lived, worked for a US Senator in Alaska. In 1968, the law came through that curbs that were being repaired or constructed with federal money would have to have curb cuts. I think the discussion that we're just having is very important and a guide to preparing to be a caregiver. I look at it from the independent living perspective and saying a guide to preparing-

Susan Reinhard:

Yourself.

Judy Heumann:

Exactly. I think many of the points that you're raising around housing as an example are so very critical. We talked to people who are older, who weren't doing any planning and their homes are not accessible and they can't necessarily make the home accessible or get the money to make it accessible. So this area to me is how do we get our people living in the community today to look at the issue of accessibility so that when cities and counties and states are putting money into housing and into design that this issue

of accessibility becomes built in. It really relates to the discussion that you and I have been having right now. I agree with you. We look at the immediate. What do we need to get done today? It's difficult to look to the future, I would say particularly in areas like accessibility of housing, because people haven't thought about it. They haven't seen it.

Judy Heumann:

How is AARP working to try to get people to live the vision that you're discussing, getting people to be proactive instead of reactive when we know that being reactive frequently means it's not going to benefit the person, maybe the future, but not now?

Susan Reinhard:

So we've created what we call; it's a big name, right, Long-Term Services and Support State Scorecard. It's www.longtermscorecard.org. We started this more than 10 years ago. I think it was like 2009 with a vision like what is the vision of a high-performing state system. We'll just say long-term care for short, long-term term services and supports. We have an advisory committee. In fact, I really want to expand that advisory committee to have more people with disabilities. We have some, but I think we really need more. Anyway, what is the vision and we have five dimensions. So we've just been talking about access. It's not accessibility it's more of financial access. Like, how do you get in? What are the options? What are the choices that you have? What do we have to support family caregivers? What about quality?

Susan Reinhard:

Then we have the transitions, how would states do in helping people leave nursing homes, for example. We have like 26 data points that we've been tracking over time. We just issued our last one just about a year ago today, just about, and we will do another one in another two or three years, generally better every three years. But we use it with our state offices, really used this a lot and they use it with volunteers. So it's aimed a lot to policymakers by consumers and volunteers. Advocates can use this. We do a lot around home and community-based services, a lot, how our state spending the money, what is the availability of assisted living, for example, what is the supply of home health aides? It's hard if you don't have data for everything. That's the real issue. So you have to have all the states collect, et cetera. So that's the limiting factor.

Susan Reinhard:

But we have employment. This came from the disability community from the very beginning that we wanted to look at employment within quality that that's part of quality of life. So we've been tracking this from the beginning and we look at the ratio of employment of persons with an ADL disability.

Judy Heumann:

What is ADL?

Susan Reinhard:

Thank you, activity of daily living. As a form of disability, these are data that we can get.

Judy Heumann:

Could you give us an example of what ADL is?

Susan Reinhard:

So it's bathing, dressing, mobility, walking, toileting. These are ADL disabilities. So we're tracking the ratio of employment of working age adults who have an ADL disability over those that don't. So the highest percent that we have found is 30% and that's in Minnesota and Nevada. Now we know in the last time that like North Dakota, Vermont, Virginia, Idaho are improving. They went up about another 20% for them. Well, we don't know why.

Judy Heumann:

Maybe you could explain that a little bit more.

Susan Reinhard:

So in other words, we're looking what are the employment opportunities for people with disabilities in states?

Judy Heumann:

Mm-hmm (affirmative).

Susan Reinhard:

How did that vary? I mean, look, we rank states and various things, so Minnesota and Nevada top ranked in that area. So you are more likely if you, and you're looking for a job, more likely to get a job if you're having this, a physical disability we're talking about, in Minnesota and Nevada than you do in any other state. Why we don't know though?

Susan Reinhard:

So there's an example of, okay, we're going to give you the data. Now could advocates in that state, those states, in any state, determine why are there policies that are helping with this? Is there a better use of the ADA against discrimination of people with disabilities? Is that governor or legislature taking that more positively as far as their private industry that is doing? I don't really know. I would like to know though, but it is something that we should be advocating for.

Judy Heumann:

It's very interesting. Because when you think about states that are doing more around personal assistance and not making people drop off the cliff so early, you look at Massachusetts, New York and Washington state. So yeah, it'd be interesting to look at the scorecard for those three states. So do you ever go in like with this issue and can you do further research?

Susan Reinhard:

Yes, we do that and that's why I'm saying we should do that. We call them promising practices or some other spotlight. Like, what's going on here? How does this state do this? Self-direction is another one. So self-direction is a term that really comes from the disability community. Your paper years ago, Judy, I read it and understand it. You were making the point that older people can have self-direction, too. It's not only younger people with disabilities. That really affected AARP, I think, years ago, like, "Oh, maybe we should pay attention to this. What is that all about?"

Susan Reinhard:

So we do track that, what states have more programs that allow people to hire their own worker and choose what services they want, as opposed to certainly a nursing home. But even home care agencies that it's a little bit more prescriptive I'll say, a little bit more like here's what we have, this is the worker you're going to get, right? So self-determination is something we're tracking in the scorecard, too, and that varies. California is number one because they've been doing it for, I don't know, 30 plus years.

Judy Heumann:

Well, In-Home Supportive Services in California I think started in the '50s. You know it started I believe because there were a group of post polios who had been at Rancho Los Amigos in LA and they wanted to move out and they weren't able to. So I think that's where the IHS as program came about and it was certainly in the beginning very much impacted by the disability community. So there were some people who were able to be self-directing in their services in a way that I think has been very important and you've seen that in other states. I think it also leads partly to this next part of our discussion, which is what we've been discussing right now or kind of learning moments. I think from the aging community perspective, looking at how to help others prepare for someone becoming older, as opposed to either preparing the person themselves who's going to become older, or I think as you were implying, doing something in a more collaborative way between the individual who's getting older and a family member or a friend. Do you think that form of a discussion is gaining more ground?

Susan Reinhard:

Well, it's hard to know because we don't have data on that. We can have stories. We do collect stories at AARP. I'd have to look and see if that's something that anyone is tracking. Just talking to friends and colleagues, it seems more likely that people are going to talk, but it may be just certain things like it might be finances. Let's make sure you're going to have the money that you need to go forward. Or it could be maybe advanced directives because there's been more and more attention to living wills or what do you want should you become very ill and need to have decisions, have your decisions made rather than somebody else's decision. So there's certain areas that I think are being done. As you point out, I don't think accessibility is one at all. It blows me away.

Susan Reinhard:

I mentioned my sister and brother-in-law a moment ago about little more than a week ago. My brother-in-law who is an attorney had no financial issues. My sister, his wife is a nurse. She was my role model, right? They live in a beautiful home, not far from me that is completely inaccessible, completely, to even get in their house either in the front or the back. Because this is an area that easily floods so that's why it's up, right? But there's no ramps. There's no way you can get up there. He fell off the back steps and he completely, his tendon; this is the part that attaches the muscle to your bone, basically exploded. So he's going to be in this, it's not even a cast, a brace. He's probably got at least a six months recovery and he needs an enormous amount of help. He didn't hit his head so he's very lucky. So they can amend. But how's he going to get upstairs? That's where his bedroom is. They don't even have a couch that opens up downstairs.

Judy Heumann:

I bet they do now.

Susan Reinhard:

It's like, "Oh my, God. We've never thought about this. Now, me as a visiting nurse, we have a couch that opens up downstairs. This is also interesting. We are going to redo our kitchen. There's only a little step in, so that's good. But I wanted to make sure the doorway that goes into the kitchen, I think it's 36 inches, I forget what it is.

Judy Heumann:

Yeah.

Susan Reinhard:

Yeah. I want to make sure that they had a strip off to get like to kind of 36 inches. We called in this thing, the Lowe's. Lowe's was doing this work and I said, "What if we knocked out this closet?" In the little bathroom we had, we made a shower. We did all this. He was like amazed. We didn't do it right now, but we have a plan for doing it. He was like, "What a good idea. This is like the major person from Lowe's. He never even thought of that and I live in a community where it's not an age friendly. It's not an age community, but this area in general it has many older people. By the way, they have resources to do this. The 50 plus communities, many of them are completely off. They're inaccessible.

Judy Heumann:

Yeah. My aunt and uncle moved into one of those and the unit that they got was up two steps. Then when my aunt got sick, she couldn't get up and down the two steps. So how do you think we can move more collaboratively together between the disability community, which has older people in it obviously, and the younger generation of disabled people and AARP and others? How do we really launch a campaign, which allows people to look at planning for your future in a way which really enables you to be more in charge of your future? By the way, I would say on finances, I actually do not believe that most people are really looking at their finances.

Susan Reinhard:

You're right. You're right.

Judy Heumann:

So have you thought at all about and/or can you give examples of how greater collaboration is going on between the aging and disability communities to allow these kinds of discussions to become more front and center?

Susan Reinhard:

So when I was at the Center for State Health Policy, I was awarded a grant from the Centers for Medicare and Medicaid Services. This was like 2001. Remember there was the ADA had been passed, Olmsted with Supreme Court decision, all this was active. Congress, actually it was President Bush I think, Junior I think it was, and Congress put together this package of dollars that could go to states that the Centers for Medicare Medicaid Services was overseeing to help get more home and community-based services, right? Within that, there was a real push to bring aging and disability advocates together, and I was awarded a grant along with ILRU it's called in Texas.

Judy Heumann:

ILRU, the Independent Living Resource Utilization project at Baylor College in Texas.

Susan Reinhard:

So we both were awarded grants to collaborate on how we could do this. Oh, and at the state levels, we have ADRCs, Aging and Disability Resource Centers. These were very intentional to bring the groups together. So I think there's more progress, more people. I always feel the disability community has infused your independent living philosophies, tenets, principles into the aging world. People didn't say person-centered care very much. It just wasn't for self-determination and not just the words, but the meanings behind the words. So the disability community in my mind has influenced the aging community profoundly, at least the advocacy world.

Susan Reinhard:

Now are we doing enough together? No, I can tell you that AARP is going to be doing more together, not just me and modern world of policy, but throughout our organization. Looking at equity, health and financial equity, there's a real passion I would say, for looking at multicultural populations and including disability like we should be doing more. So that's just starting. I don't want to say starting. We have a lot, we have an ARP litigation group that does a lot of work on discrimination based on disabilities, Olmsted work, big case in DC, lots of things. We have a policy book that talks about access to Social Security, disability benefits, and certainly home and community-based services. Our advocacy is very much focused on aging and disability in home and community-based services.

Susan Reinhard:

Sounds like AARP isn't doing anything, I don't mean that. But I do see a big push to do even more. So in the next years, I'll just say years, I think we'll be doing important things and that's going to require conversations, big conversations.

Judy Heumann:

What do you hope as it pertains to the American Rescue Plan, the maximum and the minimum?

Susan Reinhard:

Yeah. So I work with someone, Brian Burwell, his name is. We've been doing this for many years and Brian and I did a blog together on this. He said this is the most money he's ever seen in his entire career that is possible, right? I agree with him, it is. Unfortunately, it's money. That particular pot of money is only available for three years. You have to keep making plans. But still it's a lot of money and you can address it for infrastructure, as they say, for things that can be fixed. There's a lot of things that that could go for it. I mean, you can certainly give bonuses to workers. You can do things. States are worried about getting over committed and will they have the funding later, but there's things you can do now that would have long-lasting effects.

Susan Reinhard:

So we are watching this. We're not the only ones watching it, but we are studying this. When I mentioned Connecticut, that was what they were talking about, where they're going to put their money in. By the way, they are going to do things in accessibility. So it's very, very exciting. This is the most

exciting time. To see if Congress passes any of that money into infrastructure, soft infrastructure they call it, will be incredible. We are working very hard. You can imagine our advocacy at both the national and state levels is completely dedicated to this.

Judy Heumann:

So as our program is winding down, what are some messages that you'd like to give to our audience?

Susan Reinhard:

Well, first of all, I want to thank them and thank you for having me on and to encourage people to keep speaking up. We have to keep saying what is needed. This is a very important time to weigh in, talk to your Congress people, your legislators about what is possible and what is needed and how it affects your lives. Legislators in general, they do like stories. We give data, that's my job, lots of data, right? But we need the stories to humanize the data or the data to back up your stories. They got to go together. So don't be shy about speaking up.

Judy Heumann:

Yeah, and I completely agree. It's one of the reasons we started. Doing the Heumann Perspective is to get people's stories forward because I completely agree with you stories in regards to what we're discussing today, like common community-based services. For people who've lived in institutions or who've been at the threat of living in institutions, being able to talk about how their lives are different, by being able either to move out of institutions and live in the community, or stay out of institutions and using data that you're discussing through the long-term scorecard, these are all very promising approaches.

Judy Heumann:

So Susan, thank you so much for giving us this time. I've learned a lot and I look forward to working with you more in the future.

Susan Reinhard:

Thanks, Judy, and I've learned a lot, too. Thank you. I have no idea some of what you've mentioned, so thank you.

Judy Heumann:

Thank you.

Becca Howell:

You've been tuning into The Heumann Perspective with Judy Heumann. This week, our guest was Susan Reinhard. Be sure to stay up to date with the work AARP is doing surrounding disability and beyond by going to their website and following them on social media.

Becca Howell:

The intro music for the Heumann Perspective is Dragon, which was produced and performed by Lachi, Yonterro and Juarren, and the outro music is I Wait by Gaelynn Lea. Please be sure to rate, review and subscribe to The Heumann Perspective and follow Judy on twitter @judithheumann and on Instagram and Facebook @theheumannperspective.