

**Panel discussion of caregiving issues with caregivers and care recipients (Day Two)**  
**International Disability Rights Affirmation Conference 2018**  
**October 5 - 6**

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Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription. Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

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Transcription is provided by Virtual Ability, Inc. The transcriptionists are:  
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(NOTE: The above did not appear in this particular presentation's transcript, but is attached as an explanation about the transcription process)

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[2018/10/06 15:30] Gentle Heron: Good afternoon. Welcome to the last session of Virtual Ability's 2018 International Disability Rights Affirmation Conference. The theme for this year's conference is "Taking Care of Us," so I think it is appropriate to end with a panel of caregivers and care recipients.

Rosalyn Carter made a wise statement that we should all keep in mind, no matter what role we have been or are in regarding personal care.

She said, "There are only four kinds of people in the world: those who have been caregivers, those who are caregivers, those who will be caregivers, and those who need caregivers."

I'd like to begin by asking our panelists to introduce themselves.

Dorie, please introduce yourself to the audience.

[2018/10/06 15:31] Dorie Bernstein: On the other side of this hairy mug, I am disabled and caring for my disabled son. I have an orphan syndrome that has created a complicated health profile, along with being on the high-functioning end of the autism spectrum. My son is quite healthy, thankfully, but is significantly disabled by his autism and ADHD. He is 20 and 8, all at the same time, it seems.

Within Second Life, I help manage the Dreams estate and related groups of Dream Travelers, Dream Builders, ShockProof, and Brigadoon Explorers. Our group was founded by The Sojourner, of blessed memory, in order to offer a safe zone for those dealing with strokes and other brain injuries as well as folks on the autism

spectrum. When I'm not focused on "work", I enjoy building. It is really the side of SL that has kept me here so many years. I am still old-school, working with "traditional" prims for most things I do.

Dorie Bernstein ends

[2018/10/06 15:32] Rhiannon Chatnoir: ♥ on memory of The Sojourner

[2018/10/06 15:33] Dorie Bernstein: ♥

[2018/10/06 15:33] Gentle Heron: Shyla, your turn to introduce yourself.

[2018/10/06 15:33] Shyla the Super Gecko (krijon): My name is Shyla the Super Gecko. I'm a prolific writer, focusing mostly on poetry.

I live with chronic pain and chronic illnesses. In the last years of my mom's life, my mother and I shared a symbiotic relationship caring for each other. Near her death I hired help for her, and now that she is gone, I hire help for myself.

I do not yet qualify for assistance.

My preference, on a good day is to focus on what I can do, to stay involved in being, as best I can, part of the solution.

In Second Life I have a parcel called Accessibility Park, and I enjoy building and participating in the various open mics throughout the world.

Thank you. I'm done.

[2018/10/06 15:35] Gentle Heron: Keira, please tell us a little about yourself.

[2018/10/06 15:35] Keira Wellesley: My name is Keira Wellesley. I have Cerebral Palsy since birth and use a power wheelchair. I currently live with my sister.

At first my mother was my caregiver. Starting when I went to college I used paid caregivers that I interviewed and hired myself.

My aides were paid by Vocational Rehabilitation. After college I was on Medicaid and they require me to use a Medicaid approved agency to pay for my caregivers.

[2018/10/06 15:35] Gentle Heron: Thank you panelists. As you can tell, our panel definitely has impressive credentials to speak about the caregiving relationship.

Now I'm going to ask several questions, and I will direct them to individual panelists. After we are done with this set of prepared questions, we will open the discussion up to the audience to ask questions of either the entire panel or of individual panelists.

Shyla, you are a care recipient. What sorts of care do you receive from your caregivers?

[2018/10/06 15:37] Shyla the Super Gecko (krijon): Well I have three caregivers. 1 takes care of my pets twice a day, cleaning, feeding and providing them with medication.

Then I have a cleaning person, who comes every two weeks.

My third assistant is a personal aide, who handles the rest. She comes two days a week for about six hours and does laundry changes and makes the bed, cooks, shops, transports me and much much more just about anything that needs doing.

For me I was unable to find one aide to meet all my needs.

Done

[2018/10/06 15:38] Gentle Heron: Keira, you hire your caregivers. What sorts of care do those caregivers need to provide?

[2018/10/06 15:38] Keira Wellesley: My caregivers provide for my total care. I have no ability to stand. They need to lift me for all transfers.

They also need to provide for my bathing and dressing. They need to provide meal preparation and drive me to all appointments. Since I am home alone during the day they need to provide for my safety and security.

[2018/10/06 15:38] Gentle Heron: Dorie, you are in the unique position of being both a caregiver and a care recipient. Please tell us the kinds of care you provide to your family member, and what kinds of care you receive.

[2018/10/06 15:39] Dorie Bernstein: I am the forever-parent, as my son's autism is significant enough that he is both man and boy in one body. He has the hormones and related drives of a man, but the understandings and behaviors of a child still in elementary school. I help my son with navigating school situations, relationship situations with his girlfriend, plus the usual day-to-day activities of life. I am his legal guardian, since he is no longer a minor.

Yes, a girlfriend. I had never dreamed he would find someone who so completely makes him happy and fulfilled. And especially for that to be a two-way street. Once I got him to stop chasing fantasies with the "normals" in high school, he looked to the kids he actually spent time with. He has now developed true friendships and found the love of his life. Her mother and I agree that the two seem to have been made for each other. Now we're both learning how to guide them through this stage of their lives.

On my own side of things, my mom and dad help with the practical side of dealing with a chronic permanent condition. I'm unable to drive, so my dad helps with that. Mom has power of attorney so she can step in as needed with finances and other boring things. My son and I live with them, and they are integral to raising him.  
Dorie Bernstein ends

[2018/10/06 15:40] Gentle Heron: Dorie, did you receive any training on how to provide appropriate care for your son?

[2018/10/06 15:41] Dorie Bernstein: Much of the training I've received is from how I was raised. My mom had to get creative with teaching me how to navigate social situations without knowing about autism spectrum disorders. My college coursework focused on elementary school education at the beginning before I completed my bachelor's in speech/language pathology. I was never able to start a Master's program due to worsening health. Thanks to the internet, I have been able to learn more as new situations crop up.

A lot of this is just trial and error

[2018/10/06 15:42] Youri Ashton: couldn't agree more with that Dorie, trial and error indeed

[2018/10/06 15:41] Gentle Heron: trial and error indeed!

Michael J. Fox, advocate in the Parkinson's community, said, "Family is not an important thing. It's everything."

Dorie, what do you think are the positives and negatives of providing care for a family member with a disability?

[2018/10/06 15:42] Dorie Bernstein: Positives... I get to see my son grow into himself. He has grown so much over the years. And not just in height. He's figured out who he is and what he needs to be happy, and is only seeking the simple things in life. Love, happiness, and a purpose.

[2018/10/06 15:42] Gentle Heron: And Dorie, what are the positives and negatives of receiving care from a family member?

[2018/10/06 15:42] Dorie Bernstein: Negatives... I often feel too close to see what may be going on with him. I also struggle to deal with him on an even keel, because I am having to deal with my own disabling condition.

Positives... My family has seen me at my best and worst. And I don't have to worry that they'll use it against me. My mom has been here from the beginning, and that helps with advocating with doctors.

Negatives... I'm a grown woman living with my mom. While raising my son. That brings its own crazy dynamic. Sometimes it feels like Mom forgets how old I really am. I know, I know. Forever her baby and all that. There is always a struggle when emotions get into the decision-making mix.

Dorie Bernstein ends

[2018/10/06 15:43] Gentle Heron: Receiving care from a paid, non-family caregiver brings with it a complex set of issues.

Shyla, what are the positives and negatives of receiving care from a paid caregiver?

[2018/10/06 15:44] Shyla the Super Gecko (krijon): I'm going to start with the negatives for me

a big one for me because I must pay for it is that I'm living in the red and my resources will eventually run out, and there are some questions of what happens to me at that point.

Hopefully in a year and 1/2 hour qualify to be provided with a caregiver and maybe even Meals on Wheels, so I'm hoping my funds last at least that long.

Also a negative is just finding one in today's environment. There is a shortage, so I worked to keep mine as happy as possible. My current one likes to keep busy, so it's important I provide a long list of things to do, so it fills the six hours and she is not board. This is my responsibility, to guide and direct and be an effective communicator as to my needs.

Also, it is been my experience especially with the dirge of caregivers that many come very inexperienced.

I must train them, and then they can quit at any time, if they decide they don't like the duties they may quit in as little as two weeks. And then I must muster up the energy to train them again, a new person, meaning if I can find one.

The positives come when everything is working in sync. Right now everything is in sync and working well and what needs to get done is getting done and I don't feel that anyone is going to disappear soon.

The three aids that I have make a good team and my needs are met. And just for the record my cats are emotional service animals for me, there are an important part of my care I just can't take care of them. So I have a cat caregiver that does that I just want to clarify that.

So one of the big positives when it's all working well is I have less stress and I feel more secure. Done.

[2018/10/06 15:48] Gentle Heron: Keira, what are the positives and negatives of receiving care from a paid caregiver?

[2018/10/06 15:48] Keira Wellesley: The positives of using paid caregivers rather than just my family are potential friendships, reliability and someone else to talk to.

If my caregiver is hired thru an agency and the aide cannot come for a day, the agency is responsible to send an aide immediately. If the aide quits the agency must find a replacement.

The negatives of using paid caregivers is lack of privacy, high turnover, reliability.

If the aide is self-hired and they do not show up I had to start over and do without an aide until I found a new one.

If the aide was supplied from an agency there is limited pool of caregivers. There is not a real interview process. I have the right to say no and they try to find another aide. There may be a time gap before they can find someone and the aide can start.

[2018/10/06 15:49] Gentle Heron: Paid caregivers can be hired through an agency or independently. Sometimes the care recipient has a choice in who their paid caregiver is; other times there is no choice.

Shyla, how do you find your paid caregivers?

[2018/10/06 15:50] Shyla the Super Gecko (krijon): I really don't go through agencies anymore because the number of caregivers available is simply so low that I have not had success finding competent caregivers in this area where I live. I have been known to use sites like care.com, which tries to match caregivers to people needing care and also provides a lot of instructions on how to do this under the auspices of legalities.

All that said, my current caregiver was a friend who was watching me go through such difficulties trying to find a caregiver that she offered to become mine. This is a temporary relationship, as at some point she has other things she wishes to do with her life, but it is working very well for me right now.

I want to say that it's very hard to find a caregiver even just a cleaning person. I went to three cleaning people before I found one that I felt was a good fit. And my current aid was really worried about her ability to cook, but she is turned out to be a great cook. So it is finally worked out and things are smooth right now.

Done

[2018/10/06 15:52] Gentle Heron: Keira, how do you find paid caregivers?

[2018/10/06 15:52] Keira Wellesley: When I was self-hiring I found several thru word of mouth in a local nursing school. Otherwise I put an ad in the newspaper. Since I have been on Medicaid I pick an agency that takes Medicaid and they find the caregiver.

[2018/10/06 15:53] Gentle Heron: Shyla, what characteristics would a good paid caregiver have?

[2018/10/06 15:53] Shyla the Super Gecko (krijon): This is a hard question to answer because each person's needs are different. I recommend, when searching for an aide, it's best to make a list of what you need them to do.

Then write short interview questions around those needs. Then interview. I interviewed my current aid, even though I knew her. Then interview them in a comfortable setting for you.

Make sure they meet your needs. A privately paid caregiver can often do more things than an agency provided caregivers, but be prepared to pay a fair wage. For example when I had agency caregivers they were not allowed to iron my clothes, however when I have hired privately paid caregivers they have been willing to do ironing for me.

Done

[2018/10/06 15:54] Gentle Heron: Keira, what characteristics would a good paid caregiver have?

[2018/10/06 15:55] Keira Wellesley: A good caregiver needs to treat me as an adult. The caregiver needs to have patience, honor my privacy and we should have some shared interests.

[2018/10/06 15:55] Gentle Heron: Shyla, how easy or difficult is it to find and retain a good paid caregiver?

[2018/10/06 15:56] Shyla the Super Gecko (krijon): I think finding one is very hard and I've worried in the past that I might have to go to assisted living when it took months to find one. By dividing up responsibility amongst three people, if one leaves, there is a smaller gap in services for me, so that is an advantage.

I also work to be very flexible with my aides, so they are happy working for me and want to stay. We sort out how they can take vacation and I can get by for a week or so without them. I find it serves me to be flexible and be the kind of employee sorry to be the kind of employer that they want to work for. They seem to stay longer.

Done

[2018/10/06 15:57] Gentle Heron: Keira, how easy or difficult is it to find and retain a good paid caregiver?

[2018/10/06 15:57] Keira Wellesley: It is very difficult. I am subject to the pool the agency has. The caregivers are not paid well and therefore there is a lot of turnover. Medicaid pays less than a private agency.

[2018/10/06 15:57] Gentle Heron: Those who receive care from a family member instead of from a paid caregiver have different types of concerns.

As our first speaker today pointed out, both care provider and care recipient have gifts to offer in the caregiving relationship.

Dorie, what does your son learn from you when you provide care? What do you learn from him?

[2018/10/06 15:59] Dorie Bernstein: He's learned how to be compassionate to others dealing with health problems because of having a mom who is dealing with a chronic condition. He's learned about worry, the possibility of death, and how plans can change in a moment.

He's learned humor, finding it in rather unexpected situations. To the supposed experts who claim autistics don't have any sense of humor: you need to get out of the lab more.

He also has learned that it is indeed possible to push too far and get yelled at. I've learned from him about expectations, limitations. He knows and proves that happiness isn't tied to having a career that has high social or monetary value. He's shown me that there are some coping mechanisms that don't need to be taught when your spouse or significant other is doing something that bugs you or is just ignoring you.

My son taught me to never count out humor as a reason for trying new grooming techniques. After at least 4 years of avoiding shaving his beard at home, my dear son tried out his electric razor. And in the process shaved off half of one eyebrow. He did it solely because it amused him. He evened it out the next day with the idea of eventually shaving them off completely. Again, solely for the humor in it.

Sometimes I really don't want to know where he gets his ideas.

Dorie Bernstein ends

[2018/10/06 16:01] Gentle Heron: Dorie, in your other role, what do you learn from your family caregiver? What does your family caregiver learn from you?

[2018/10/06 16:01] Dorie Bernstein: I've learned that one is always a kid to their mom. I have learned when I can talk about things and when it is best to just crochet through it.

Mom says I've taught her that it is okay to wear clothing items because you wish to and not worry so much about the little rules we were always taught about time, location, reason for activity, etc etc etc. My clothing choices are often dictated by how my body is feeling, and what I feel like wearing to make myself happier. Also, Mom has had to learn how to flush IV lines.

Dorie Bernstein ends

[2018/10/06 16:02] Gentle Heron: Shyla, what do your paid caregivers learn from you? What do you learn from them?

[2018/10/06 16:03] Shyla the Super Gecko (krijon): My current one learned to cook for me and she's fantastic at it and really enjoys it.

I am learning to be more flexible, these are all things I used to do for myself and I used to do them a certain way and I used to separate the lights and the darks before I did laundry and reds were always washed on their own, but it turns out there's a lot of ways to do laundry and the result seems to be about the same.

So I'm learning to be flexible where appropriate, instead of my old controlling self.  
Done

[2018/10/06 16:04] Gentle Heron: Keira, did I accidentally erase your question from my notes or did I forget to ask you, what do your paid caregivers learn from you? What do you learn from them?

[2018/10/06 16:05] Gentle Heron: KW: She learned how to express her needs. She learned patience.

[2018/10/06 16:07] Mook Wheeler: KW: I learned how to be patient, and they learned how to communicate with me if they have problems with the job.

[2018/10/06 16:06] Gentle Heron: Social worker and author Nancy L. Kriseman reminds us, "One goal of the mindful caregiver is to find ways to not feel 'dis-eased' in the caregiving process."

Dorie, how do you deal with the stresses of caring for your son?

[2018/10/06 16:06] Dorie Bernstein: I crochet a lot. I have also learned the art of the blank stare when he's going through another repeat of a script. Chocolate and special treats can do a lot to improve mood after a long day.

Dorie Bernstein ends

[2018/10/06 16:07] Gentle Heron: Shyla, how do you deal with the feeling of being dependent on your caregiver?

[2018/10/06 16:07] Shyla the Super Gecko (krijon): I didn't like it at first. And that's how I dealt with it. But my first caregiver was very experienced and also very helpful. So she help me see that I was actually in less pain when I let her do the things she was hired to do. Over time I simply came to accept that I am dependent on the help of others right now at least today, and I have to say that is a huge stress reliever  
There's time to tell a short story, I used to always try to make sure the dishes were in the dishwasher and that the laundry was sorted and that the house was pretty clean before my aide came defeated the whole purpose, I just wasn't used to needing help

and I couldn't actually do those things so I didn't succeed anyway in any of them but I did manage to really frustrate myself  
So now I'm just good with it, and that works better. Done.

[2018/10/06 16:09] Gentle Heron: Dorie, how do you deal with the feeling of being dependent on your caregiver?

[2018/10/06 16:09] Dorie Bernstein: Crochet. Tears. Complaining to a helpful friend when I feel safe to. My internal conversations about it can get a bit dark, but I manage to climb out of it.

Dorie Bernstein ends

[2018/10/06 16:10] Gentle Heron: Keira, how do you deal with the feeling of being dependent on your caregiver?

[2018/10/06 16:10] Elektra Panthar: KW: Internal frustration, but I've been dependent from others since birth so you learn to internalize it

[2018/10/06 16:11] Mook Wheeler: KW: A lot of internal frustration but I've always been dependent on people in one way or another so you learn to internalise it

[2018/10/06 16:11] Gentle Heron: One final question for everyone on the panel. Shyla, what else should our audience know about caring for a person with a disability?

[2018/10/06 16:11] Shyla the Super Gecko (krijon): When I cared for my mom it helped to read the help that was out there for her condition, to use the agencies available and to remember I was doing the best I could, because there was just no way I could feel in that moment that I was doing enough.

If you're caring for me, get to know me, as an extension of me to empower me so I can do more with the energy I have.  
done

[2018/10/06 16:12] Gentle Heron: Keira, what else should our audience know about caring for a person with a disability?

[2018/10/06 16:12] Keira Wellesley: I am lucky because my state took advantage of the Medicaid expansion program and developed a Community First Choice waiver. This pays for caregivers for people with a disability who need a nursing home level of care but who live at home. The results for me is 70 hours of weekly care and I do not have to live in a nursing home.

[2018/10/06 16:13] Gentle Heron: Dorie, what else should our audience know about caring for a person with a disability?

[2018/10/06 16:13] Dorie Bernstein: Things rarely go as expected. People don't judge you as much as you think they are. Everyone is fighting their own battles and rarely have the energy to get too involved in yours. Obviously, there are exceptions. But on the whole, most people just don't notice all the things that you do about your situation. Extend yourself the courtesy of not judging yourself for failures or perceived failures. Yes, that is easier said than done. I tend to fall down on that regularly.

Dorie Bernstein ends

[2018/10/06 16:13] Gentle Heron: Thank you to all our panelists this afternoon. They have given us quite a bit to consider about the caregiving relationship.

We are over time, but I think our panelists will stay for a little time for just a few questions from the audience. Please type your questions and direct them either to the whole panel or a particular panelist. Thank you in advance to Elektra!

[2018/10/06 16:14] Marcus Llewellyn: QUESTION: Do those of you who have cared for and/or been assisted by a family member feel that it has strengthened or tested your bond to that person?

[2018/10/06 16:14] Dorie Bernstein: Both, strengthen and test

[2018/10/06 16:15] Elektra Panthar: KW: Completely agree with that

[2018/10/06 16:16] Elektra Panthar: Shyla: Both in my case because my mom had Alzheimer's, she didn't recognize she had that condition

[2018/10/06 16:16] Elektra Panthar: DW: I had fights with my mom. She forgot I had agency and could take care of myself

But we also know more about each other and are more comfortable with each other

[2018/10/06 16:17] Gentle Heron: [16:14] Mook Wheeler: COMMENT: I totally relate to Shyla's description of the caregiving "symbiosis". I am the caregiver for my physically-disabled husband, and he is an even bigger caregiver for me and my autism. Neither of us are trained to do this. Just love and willpower. I was very interested in hearing what other simultaneous caregiver/care-recipient relationships were like. One positive is that we don't need to worry about anyone else's schedules, just our own. And I don't need to stress about having strangers invade my space. I would not be able to handle that. Thank you Shyla, Dorie and Keira for sharing.

[2018/10/06 16:19] Shyla the Super Gecko (krijon): I would just say for my mom and I before the dementia was real bad, it really invigorated our relationship because both of us were feeling less than do our disabilities. The ability to help each other gave us purpose and I think that was a real plus. As her dementia worsened and as she came towards the end of her life it changed a little bit, it was harder, but I wouldn't trade my experience caring for my mom for anything in the world. I'm so glad I did it.

[2018/10/06 16:19] Mook Wheeler: ((( Shyla ))) I totally understand and agree.

[2018/10/06 16:19] Gentle Heron: (((Shyla)))

[2018/10/06 16:19] Gentle Heron: [16:14] laysfarbonelima Resident (Q-Translator b:pt->en): Both caregivers should treat them with love, care and attention, so don't feel inconvenience, we are spiritual beings living a human experience, any normal person, may become deficiente the important thing is to love and accept yourself independent. disability..

[2018/10/06 16:20] Elektra Panthar: DW: You're right, it's hard to remember when the voices in your head tell you how much of a burden you are and look at what the other person is able to do...

[2018/10/06 16:20] Gentle Heron: Last chance for questions!  
Let's thank the panelists before I conclude

[2018/10/06 16:21] iSkye Silverweb: Thank you so much

[2018/10/06 16:21] Willow (whispering.portal): Thank you all for sharing

[2018/10/06 16:21] Miss Suzanne Super Sweet (supersuz): thank you very much.  
Very informative

[2018/10/06 16:21] Des (myown.destiny): thank you all so very much for sharing your experiences in order to help each other

[2018/10/06 16:21] iSkye Silverweb: while I don't have a caregiver and am not one, it really helps to understand more about the situations of our friends in this community and to be supportive and more understanding

[2018/10/06 16:22] Rhiannon Chatnoir: thank you so much, this was a great discussion, and I think relevant to many of us here who either are helping with care, needing care, or needs to come. Thank you!

[2018/10/06 16:21] Gentle Heron: Thank all those who worked for the conference. First and foremost, the conference team of iSkye Silverweb, Mook Wheeler, Shyla the Super Gecko, and Eme Capalini.

The fabulous transcriptionists who work so hard to make the conference accessible: LoriVonne Lustre and Elektra Panthar.

The important greeters who are the first persons our audience guests meet when they arrive: Slatan Dryke, Carla Broek, Lorin Tone, Vulcan Viper, Zip Zlatkis, Fran Gustav, and Gemma Cleanslate.

And our community members who introduced our presenters: Gaia Maria, Slatan, Zinnia, Serenity, Lorin, Haubi, OperativePhoenix, Shyla, and Cassandra.

[2018/10/06 16:22] Gentle Heron: I also want to recognize our audience for the quality of their questions and comments, and for overall highly professional behavior and admirable patience. Thank you all!

[2018/10/06 16:23] Gentle Heron: We will archive the sessions from this conference in both text and video format within the next couple of weeks.

And a reminder that this is an annual conference, and we have another annual conference in the spring, our Mental Health Symposium.

[2018/10/06 16:23] Gentle Heron: Be sure to check out the exhibits and displays over on Healthinfo Island. They are on topics related to our IDRAC conference.

There's a notecard with SLURLs in the blue VAI sign to the left side of the stage.

And now one final quotation to carry home from the conference:

Harold Kushner, Rabbi and author, reminds us that, "Caring about others, running the risk of feeling, and leaving an impact on people, brings happiness."