

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

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.

You will see the transcription in local chat.

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)

[2018/10/05 14:31] LV (lorivonne.lustre): For transcription as required: GH = Gentle Heron
Em = Em Warrior
Des = Myown Destiny
GG = Aunty Lockjaw

[2018/10/05 14:31] Gentle Heron: This is a panel of caregivers and care recipients. Suellen is not with us today. I'm a substitute moderator, and I'll do my best. Our panelists today are: Aunty, Des and Em.

Aunty, you are the caregiver on this panel. Please tell us the kinds of care you provided, both as a family caregiver and as a paid caregiver.

Introduce yourself Aunty

[2018/10/05 14:32] LV (lorivonne.lustre): GH: You should introduce yourselves first. I'm sorry

[2018/10/05 14:32] LV (lorivonne.lustre): GG: I have been in SL for 11 years, I am a very mature woman in the midwest
What I like most about SL is socializing with people from around the world

[2018/10/05 14:33] Gentle Heron: Destiny please introduce yourself?

[2018/10/05 14:33] Des (myown.destiny): Hi, I am Myown Destiny. I was a candystriper, a CNA then a nurse.

I volunteered in high school

☺ Thank you! ☺

[2018/10/05 14:33] Orange Planer: What's a candystriper?

[2018/10/05 14:34] Youri Ashton: candy striper according to wiktionary: "1944 US, due to red and white-striped jumpers worn by hospital volunteers, which resembled stick candy, originally a group of high school girls who volunteered as hospital workers at East Orange General Hospital."

[2018/10/05 14:35] Gentle Heron: Em your intro?

[2018/10/05 14:35] Em Warrior: I am Canadian, senior female with experience in all kinds of attendant care providers. I came into SL as a means to find ppl to talk with I also train individuals on some skills that they need to be an attendant for ppl with disabilities

[2018/10/05 14:36] LV (lorivonne.lustre): GH: Please let me know when you are done please folks.

[2018/10/05 14:36] Em Warrior: done

[2018/10/05 14:36] Gentle Heron: Aunty, you are the caregiver on this panel. Please tell us the kinds of care you provided, both as a family caregiver and as a paid caregiver.

[2018/10/05 14:37] G.G. (aunty.lockjaw): When I worked in supported living I followed a daily duty roster.

When I worked in supported living I followed a daily duty roster.

[2018/10/05 14:38] LV (lorivonne.lustre): GG: I supported 4 developmentally disabled adults

[2018/10/05 14:38] G.G. (aunty.lockjaw): Examples included helping them make weekly menus, shop, prepare meals and clean up after themselves and each other, including laundry.

I also passed out their medicines and took them to appointments. I was required to take notes and write detailed reports of what the doctors said and did.

We planned weekly outings together. I was required to load them all into the car and take them out.

I was required to keep daily records of how well each of them followed their individual service plans.

As a paid caregiver for a family member, my duties and daily schedule are also written.

He takes his own medicines and supplements but needs prompting to get up in the morning and take them.

I also assist him with home physical therapy exercises as well and take him to appointments.

[2018/10/05 14:44] LV (lorivonne.lustre): GG: That is all I will speak about for now

[2018/10/05 14:43] Gentle Heron: Aunty, did you receive any training on how to provide appropriate care for persons with disability?

[2018/10/05 14:44] G.G. (aunty.lockjaw): After being hired to work in supported living, I went through an extensive week long training courses that included such

things as personal safety, driving a passenger van, CPR, and proper procedures for giving medicines.

[2018/10/05 14:44] Orange Planer: A week doesn't seem like a long time to train.

[2018/10/05 14:45] G.G. (aunty.lockjaw): My family considers me trained by experience.

[2018/10/05 14:45] LV (lorivonne.lustre): GH: that makes sense

[2018/10/05 14:45] Gentle Heron: Both of our care recipients have used both family and paid caregivers.

Destiny, what kinds of care have your caregivers provided for you?

[2018/10/05 14:45] Des (myown.destiny): Financial management, emotional support, preparing meals, doctor appointments, advising me on many aspects of life, shopping

done

[2018/10/05 14:45] Gentle Heron: Em, what kinds of care have your caregivers provided for you?

[2018/10/05 14:46] Em Warrior: First off I don't use term 'caregivers' as that sounds medical. My home is exactly that MY HOME. The term used by the company/organization that provides them use the word - ATTENDANT.

Family helping me ended when I moved away from home at 18.

Almost anything legal ... from going on outings with me to wiping my butt. Also includes picking up after support animals when we out on a walk.

next

[2018/10/05 14:46] Gentle Heron: Aunty, what do you think are the positives of providing care to a family member with a disability?

[2018/10/05 14:47] G.G. (aunty.lockjaw): On the positive side I get to spend more time with him. I enjoy being a direct part of his successes as well.

[2018/10/05 14:47] Gentle Heron: Em, what are the positives of receiving care from a family member?

[2018/10/05 14:47] Em Warrior: In all honesty I can't say I have found any..

They did it their way and didn't care how I wanted it done or when.

k

[2018/10/05 14:48] Gentle Heron: Destiny, what are the positives of receiving care from a family member?

[2018/10/05 14:48] Des (myown.destiny): They are aware of your needs. They respect your privacy. They love you.

done

[2018/10/05 14:48] Gentle Heron: Aunty, what are the negatives of providing care to a family member with a disability?

[2018/10/05 14:49] LV (lorivonne.lustre): GG: I had to learn to take his cues and he had to learn I was not another parent.

[2018/10/05 14:49] Gentle Heron: Destiny, what are the negatives of receiving care from a family caregiver?

[2018/10/05 14:49] Des (myown.destiny): Your roles change. Guilt, because family members are so busy, and caring for someone takes a lot of time.
done

[2018/10/05 14:50] Gentle Heron: Em, what are the negatives of receiving care from a family caregiver?

[2018/10/05 14:50] Em Warrior: - they forget I am not them
- infringe on my personal identity
k

[2018/10/05 14:50] 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.
Let's find out how our care recipients found their paid caregivers.
Destiny?

[2018/10/05 14:51] Des (myown.destiny): word of mouth, family discussion

[2018/10/05 14:51] Gentle Heron: Em?

[2018/10/05 14:51] Em Warrior: thru my social worker and doctor's office

[2018/10/05 14:52] Gentle Heron: What characteristics would make for a good paid caregiver, Em?

[2018/10/05 14:52] Em Warrior: - accept ppl for who they are
- respectful and willing to learn
- should know the laws in the country of where they are working
- workplace safety
- first aid is a bonus
- as is flexibility in schedule

[2018/10/05 14:52] Gentle Heron: What characteristics would make for a good paid caregiver, Des?

[2018/10/05 14:52] Des (myown.destiny): A good caregiver, needs to be knowledgeable about various diseases, especially in the elderly who do IHSS. They need to not make clients feel rushed, even though their schedules are probably way too full. Caregivers need to listen to what the clients want, and not just try to make a client fit into what the caregiver thinks that they need.
This is not a family caregiver though, just additional caregivers

[2018/10/05 14:53] Gentle Heron: Aunty, what do you think are the positives of providing care to someone who is paying you for that job?

[2018/10/05 14:54] G.G. (aunty.lockjaw): it was easier to maintain some emotional detachment with non family members. Part of my training included ways to do that. Progress was easier to measure because expectations were more detailed and kept on file at the location.

My case notes helped me stay abreast of whether or not I was helping them meet stated goals.
end

[2018/10/05 14:55] Gentle Heron: Em, what are the positives of paying a non-family member to provide your care?

[2018/10/05 14:55] Em Warrior: - self autonomy is greater
- currently I get some say in who I want .. ex. a non-smoker and ok with animals
- its my way not theirs
- if they are abusive in anyway I can charge them and have the company back me...
This is physical, emotional, or sexual abuse.
- I can /will/ and have fired them from working with me
Keep in mind I would still charge a family member if need arose but wouldn't have all the emotional stuff from other family members

[2018/10/05 14:56] Gentle Heron: Destiny, what are the positives of paying a non-family member to provide your care?
[2018/10/05 14:58] Des (myown.destiny): they are not involved emotionally.. it gives a family member a break
done

[2018/10/05 14:58] Gentle Heron: Aunty, what are the negatives of being a paid caregiver for a person with a disability?
[2018/10/05 14:59] G.G. (aunty.lockjaw): Difficulties might include finding common ground and developing a rapport with each of them.
That might involved letting them know a bit more about me than is always comfortable.
Being scrutinized and evaluated by others such as supervisors and their family members could be nerve-wracking due to my perfectionist tendencies.
end

[2018/10/05 15:01] Gentle Heron: Destiny, what are the negatives of receiving care from a paid caregiver?
[2018/10/05 15:01] Des (myown.destiny): Privacy issues, not trained well enough, language barriers, in too much hurry to get to the next client.
done

[2018/10/05 15:01] Gentle Heron: Em, what are the negatives of receiving care from a paid caregiver?
[2018/10/05 15:01] Em Warrior: you may lose the ability of having someone who knows the values within your culture.
- right now I don't get to screen them like I would if I was running my schedule like a company.
- many don't have the communication skills I need to make my appointments and stuff for me
- some times I don't get to have the times I want on weekends especially as few ppl want to work 15 min shifts..
done

[2018/10/05 15:02] LV (lorivonne.lustre): GH: We are getting a lot of insights here

[2018/10/05 15:02] Gentle Heron: Aunty, what have you learned from the family member you provided care for?
[2018/10/05 15:02] G.G. (aunty.lockjaw): I learned a lot about the ways he and I are very similar.
And I have to relearn daily that he is an individual who may not have been raised to be the way I am about getting things done.

end

[2018/10/05 15:03] LV (lorivonne.lustre): GG: He is very tolerant of my imperfections, which is gratifying

[2018/10/05 15:03] Gentle Heron: Destiny, what has your family caregiver learned from you?

[2018/10/05 15:03] Des (myown.destiny): My caregiver has learned that because of my many ups/downs in life how to adjust how things are done for me, on a daily basis.
done

[2018/10/05 15:04] Gentle Heron: Em, what has your family caregiver learned from you?

[2018/10/05 15:04] Em Warrior: k I have to be honest here. - I haven't had one since I left home at age 18. When on vacation it's still their way ..
- family is family not a person to do personal care in my opinion
And I take an attendant with me on vacation even though I am married
done

[2018/10/05 15:05] Gentle Heron: Aunty, what have you learned from the persons with disabilities you have been paid to provide care for?

[2018/10/05 15:07] LV (lorivonne.lustre): GG: I did not know that much about persons with downs syndrome. They helped me to understand more about their needs

[2018/10/05 15:06] G.G. (aunty.lockjaw): end

[2018/10/05 15:06] Gentle Heron: Destiny, what has your paid caregiver learned from you?

[2018/10/05 15:06] Des (myown.destiny): My caregiver has learned that because of my many ups/downs in life how to adjust how things are done for me, on a daily basis.
done

[2018/10/05 15:07] Gentle Heron: Em, what has your paid caregiver learned from you?

[2018/10/05 15:07] Em Warrior: This was written by my full-time staff member who has been with me 8 years.

" - To be patient, respectful and accepts her as who she is.

- Help her to be more independence for herself.

- Her day to day challenge will change. "

[2018/10/05 15:08] LV (lorivonne.lustre): GH: That is neat Em, that you got your attendant to write that.

[2018/10/05 15:09] Em Warrior: thanks she is watching with me now

[2018/10/05 15:09] Orange Planer: No pressure!

[2018/10/05 15:08] Gentle Heron: Aunty, what did the family member you provided care for learn from you?

[2018/10/05 15:09] LV (lorivonne.lustre): GG: I hope he has learned a can-do attitude from me.

[2018/10/05 15:09] Gentle Heron: Em, what did you learn from your family caregiver?

[2018/10/05 15:09] Em Warrior: trust and respect are hard to earn and easy to lose
That's about it ...

[2018/10/05 15:09] Gentle Heron: Destiny, what did you learn from your family caregiver?

[2018/10/05 15:09] Des (myown.destiny): How frustrating it must be to take care of someone whose needs change daily
done

[2018/10/05 15:10] Gentle Heron: Aunty, what did the persons with disabilities who hired you learn from you?

[2018/10/05 15:11] LV (lorivonne.lustre): GG: they learned to be more independent. I taught one to read cursive and write her own checks. Another learned to sign her own checks. All learned to cook and make simple meals for themselves.

[2018/10/05 15:10] G.G. (aunty.lockjaw): end

[2018/10/05 15:11] Gentle Heron: Destiny, what did you learn from your paid caregiver?

[2018/10/05 15:11] Des (myown.destiny): How frustrating it must be to take care of someone whose needs change daily
Won't use one any more, unless I know them already.

[2018/10/05 15:12] Gentle Heron: Em, what did you learn from your paid caregiver?

[2018/10/05 15:12] Em Warrior: they have a right to be safe when working with me
- they have a right to their opinions AS LONG AS they don't push them on me.
- their personal life is none of my business just as my private life and thoughts are not theirs
- bit of geography and culture
done

[2018/10/05 15:13] Gentle Heron: One final question for everyone on the panel. Aunty, what else should our audience know about caring for a person with a disability?

[2018/10/05 15:14] LV (lorivonne.lustre): GG: Patience. Tolerance. They are the same as everyone else and have feelings and intellect. Autonomy and choices are important

[2018/10/05 15:13] G.G. (aunty.lockjaw): end

[2018/10/05 15:14] Gentle Heron: Destiny, what else should our audience know about caring for a person with a disability?

[2018/10/05 15:14] Des (myown.destiny): Slow down, Listen, and respect your client. If you feel you can not care for them by meeting their needs, do not accept or stay in the position

[2018/10/05 15:14] Youri Ashton: Very true Destiny

[2018/10/05 15:14] Des (myown.destiny): 😊 Thank you! 😊

[2018/10/05 15:15] Gentle Heron: Em, what else should our audience know about caring for a person with a disability?

[2018/10/05 15:15] Em Warrior: we are no less human than them..
- the laws of the country/company apply to us both KNOW THEM
- ask for criminal and abuse registry checks AND/OR make sure company gets them. EVEN IF FAMILY MEMBERS OR FRIENDS
- being safe is a right for both parties and it is YOUR BUSINESS AND RESPONSIBILITY to keep yourself safe.
That's it

[2018/10/05 15:15] Gentle Heron: Now we will take questions from the audience. Please use QUESTION, followed by the information you are asking about and allow the panel to respond.

[2018/10/05 15:15] Des (myown.destiny): very good

[2018/10/05 15:15] Youri Ashton: Question: To all 3 ladies, could you tell what changes were made that you see as being positive? Could you give us a few examples? And could you name something that you like to see improved, changed or added to care as soon as possible? Or seen something going worse then before? Sorry for the long list, was saving up

[2018/10/05 15:17] Des (myown.destiny): changes....better caregiver choices, better skill, more appropriate placements

[2018/10/05 15:17] LV (lorivonne.lustre): GH: that is a lot of questions! You can pick a few to respond. Aunty? Could you go first?

[2018/10/05 15:16] G.G. (aunty.lockjaw): just too overwhelmed

[2018/10/05 15:20] LV (lorivonne.lustre): GH: I think we have had a little bit of an answer from Des on that

[2018/10/05 15:20] Youri Ashton: sorry, I feared it would be a little too much already.

[2018/10/05 15:17] LV (lorivonne.lustre): GH: Lets take it one at a time. what changes were made that you see as being positive?

[2018/10/05 15:18] G.G. (aunty.lockjaw): monthly training classes improved over the 8 years I worked in paid caregiving

[2018/10/05 15:18] Des (myown.destiny): positive is that there are caregiver programs

[2018/10/05 15:18] Em Warrior: acceptance that family values and norms have changed

[2018/10/05 15:19] Gentle Heron: I think that was too many questions at once, Youri, sorry. What still needs to be improved about caregiving?

[2018/10/05 15:19] G.G. (aunty.lockjaw): #1 funding

[2018/10/05 15:20] Em Warrior: filling of quotas in employment

[2018/10/05 15:20] Gentle Heron: Are those 2 related?

[2018/10/05 15:20] LV (lorivonne.lustre): GH: do you think those 2 things are related? Funding and filling quotas?

[2018/10/05 15:20] Em Warrior: for me yes

[2018/10/05 15:21] G.G. (aunty.lockjaw): in our state the funding moves around among government agencies meaning no consistency

[2018/10/05 15:20] Des (myown.destiny): somethings are going worse: cut hours

[2018/10/05 15:21] Gentle Heron: who cuts the hours Des?

[2018/10/05 15:21] Des (myown.destiny): the SW who interviews q yr has the ability to set your hours

[2018/10/05 15:21] Em Warrior: same here Des

[2018/10/05 15:21] Des (myown.destiny): every year:)

[2018/10/05 15:22] LV (lorivonne.lustre): q yr = every year

[2018/10/05 15:22] Youri Ashton: thank you for your answers ladies

[2018/10/05 15:22] LV (lorivonne.lustre): [15:21] Marcus Llewellyn: QUESTION: I would like to hear about experiences regarding burnout in those assisting people.

[2018/10/05 15:22] Des (myown.destiny): Burn out: trying to meet patients needs, and they are resistant due to their own problems

[2018/10/05 15:23] G.G. (aunty.lockjaw): turnover was very high in the company I worked for as well as in the agencies we dealt with

Most due to burnout

[2018/10/05 15:24] Marcus Llewellyn: Thank you. :)

[2018/10/05 15:23] LV (lorivonne.lustre): (Gentle is voicing for Aunty)

[2018/10/05 15:24] Gentle Heron: [15:21] Willow (whispering.portal): Question: Em and Des: Is there anything that you have had done by caregivers that you didn't like and had to teach them? Aunty: Or things as a caregiver had to learn differently for different clients?

[2018/10/05 15:24] LV (lorivonne.lustre): GH: One last question from Willow.

[2018/10/05 15:24] Em Warrior: I have had to accept getting peri-care from them And I teach them this in a classroom but some don't get it

[2018/10/05 15:25] Gentle Heron: peri = perineal

[2018/10/05 15:25] Des (myown.destiny): yes. Different caregivers I hired previously.....not letting me say what I want, as I talk slowly

Also

Trying to do things for me all the time.. let me tell you my needs

[2018/10/05 15:26] G.G. (aunty.lockjaw): I had to learn to go more slowly than even I do naturally when talking to them and teaching them

[2018/10/05 15:26] Em Warrior: especially if language is a barrier right aunty

[2018/10/05 15:26] G.G. (aunty.lockjaw): right

[2018/10/05 15:26] Des (myown.destiny): yes!

[2018/10/05 15:26] Des (myown.destiny): stop treating me like I am dumb.

[2018/10/05 15:27] LV (lorivonne.lustre): GH: All 3 agree on the language barrier.

[2018/10/05 15:27] Gentle Heron: Why is language a barrier?

[2018/10/05 15:27] Em Warrior: a lot of multicultural employees

And companies have to hire so many and can at a lower cost

And those within same country don't want the jobs then

[2018/10/05 15:27] Des (myown.destiny): foreign speakers. broken English. very loud speaking is hard for some disabled people

It is hard enough to be disabled

And to not be able to explain yourself well, and add to that speak to someone and have them understand when they

have a different language

[2018/10/05 15:29] Youri Ashton: I can verify that Des, as having Asperger

Syndrome myself I can say it is a bad idea to speak louder to someone with autism.

Having a disability doesn't mean you are hard hearing or stupid

[2018/10/05 15:28] Gentle Heron: Thank you for participating in this session Aunty, Des and Em and Dorie for voicing, and thank you audience.

[2018/10/05 15:29] Des (myown.destiny): 😊 Thank you! 😊

For inviting us, and allowing us to share

[2018/10/05 15:29] G.G. (aunty.lockjaw): thank you listeners and readers for your patience

[2018/10/05 15:30] Em Warrior: you're welcome and please feel free to ask questions .. Prefers a notecard

[2018/10/05 15:30] LV (lorivonne.lustre): GH: Please take the folder in the notecard giver on the stage. There is some good information on caregiving there

[2018/10/05 15:30] Gentle Heron: Tomorrow's sessions of IDRAC begins at 8am SLT

at this same location.

The schedule is here: <http://virtualability.org/idrac-2018/>

See you tomorrow!

[2018/10/05 15:30] Des (myown.destiny): waves to all

[2018/10/05 15:30] Willow (whispering.portal): thank you all

[2018/10/05 15:30] Mook Wheeler: Thank you, Em, Destiny, GG, Gentle

[2018/10/05 15:30] Lorin Tone: Thanks everyone for great content, great discussions!

[2018/10/05 15:30] Gentle Heron: Thank you everyone

[2018/10/05 15:31] LV (lorivonne.lustre): <<Transcription ends>>