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)

[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] 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?
Des (myown.des): Your roles change. Guilt, because family members are so busy, and caring for someone takes a lot of time.

Gentle Heron: Em, what are the negatives of receiving care from a family caregiver?
Em Warrior: - they forget I am not them
- infringe on my personal identity

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?
Des (myown.destiny): word of mouth, family discussion

Gentle Heron: Aunty, what do you think are the positives of providing care to someone who is paying you for that job?
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.

Gentle Heron: Em, what are the positives of paying a non-family member to provide your care?
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

Gentle Heron: Destiny, what are the positives of paying a non-family member to provide your care?
Des (myown.destiny): they are not involved emotionally.. it gives a family member a break

Gentle Heron: Aunty, what are the negatives of being a paid caregiver for a person with a disability?
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

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

Gentle Heron: Em, what are the negatives of receiving care from a paid caregiver?
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

LV (lorivonne.lustre): GH: We are getting a lot of insights here

Gentle Heron: Aunty, what have you learned from the family member you provided care for?
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: 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] 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.
Gentle Heron: Em, what did you learn from your family caregiver?
Em Warrior: trust and respect are hard to earn and easy to lose
That's about it ...

Gentle Heron: Destiny, what did you learn from your family caregiver?
Des (myown.destiny): How frustrating it must be to take care of someone whose needs change daily
Done

Gentle Heron: Aunty, what did the persons with disabilities who hired you learn from you?
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.

Gentle Heron: Destiny, what did you learn from your paid caregiver?
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.

Gentle Heron: Em, what did you learn from your paid caregiver?
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

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?
LV (lorivonne.lustre): GG: Patience. Tolerance. They are the same as everyone else and have feelings and intellect. Autonomy and choices are important.

Gentle Heron: Destiny, what else should our audience know about caring for a person with a disability?
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

Youri Ashton: Very true Destiny
Des (myown.destiny): 😊 Thank you! 😊

Gentle Heron: Em, what else should our audience know about caring for a person with a disability?
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

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.

Des (myown.destiny): very good

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

Des (myown.destiny): changes....better caregiver choices, better skill, more appropriate placements

LV (lorivonne.lustre): GH: that is a lot of questions! You can pick a few to respond. Aunty? Could you go first?

G.G. (aunty.lockjaw): just too overwhelmed

LV (lorivonne.lustre): GH: I think we have had a little bit of an answer from Des on that

Youri Ashton: sorry, I feared it would be a little too much already.

LV (lorivonne.lustre): GH: Lets take it one at a time. what changes were made that you see as being positive?

G.G. (aunty.lockjaw): monthly training classes improved over the 8 years I worked in paid caregiving

Des (myown.destiny): positive is that there are caregiver programs

Em Warrior: acceptance that family values and norms have changed

Gentle Heron: I think that was too many questions at once, Youri, sorry. What still needs to be improved about caregiving?

G.G. (aunty.lockjaw): #1 funding

Em Warrior: filling of quotas in employment

Gentle Heron: Are those 2 related?

LV (lorivonne.lustre): GH: do you think those 2 things are related? Funding and filling quotas?

Em Warrior: for me yes

G.G. (aunty.lockjaw): in our state the funding moves around among government agencies meaning no consistency

Des (myown.destiny): somethings are going worse: cut hours

Gentle Heron: who cuts the hours Des?
Des (myown.destiny): the SW who interviews q yr has the ability to set your hours
Em Warrior: same here Des
Des (myown.destiny): every year:
LV (lorivonne.lustre): q yr = every year
Youri Ashton: thank you for your answers ladies

Des (myown.destiny): Burn out: trying to meet patients needs, and they are resistant due to their own problems
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
LV (lorivonne.lustre): Thank you. :)

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
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
G.G. (aunty.lockjaw): I had to learn to go more slowly than even I do naturally when talking to them and teaching them
Em Warrior: especially if language is a barrier right aunty
G.G. (aunty.lockjaw): right
Des (myown.destiny): yes!
Des (myown.destiny): stop treating me like I am dumb.

LV (lorivonne.lustre): GH: All 3 agree on the language barrier.
Gentle Heron: Why is language a barrier?
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
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
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
Gentle Heron: Thank you for participating in this session Aunty, Des and Em and Dorie for voicing, and thank you audience.

Des (myown.destiny): Thank you! For inviting us, and allowing us to share

G.G. (aunty.lockjaw): thank you listeners and readers for your patience

Em Warrior: you're welcome and please feel free to ask questions .. Prefers a notecard

LV (lorivonne.lustre): GH: Please take the folder in the notecard giver on the stage. There is some good information on caregiving there

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!

Des (myown.destiny): waves to all
Willow (whispering.portal): thank you all
Mook Wheeler: Thank you, Em, Destiny, GG, Gentle
Lorin Tone: Thanks everyone for great content, great discussions!
Gentle Heron: Thank you everyone

LV (lorivonne.lustre): <<Transcription ends>>