Title: "Who's Responsible for Inclusion?"
Speaker: Dr. David Wasserman, Department of Bioethics, National Institutes of Health

[2017/12/01 10:56] Carolyn Carillon: Hello everyone. 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.
LoriVonne Lustre: Hello Virtual Ability colleagues, presenters, and International Disability Rights Affirmation Conference (IDRAC) attendees. My name is Lorraine Mockford, known as LoriVonne (LV) Lustre across the metaverse. I am a retired instructional designer from Nova Scotia, Canada. In-world, I work with the outstanding voice-to-text transcription team for Virtual Ability. I am also one of the organizers with the Virtual Worlds Best Practices in Education conference.

We ask that the audience refrain from typing in local chat during the presentation as many of our speakers are new to Second Life. You may want to make note of your questions so you can ask them during the Q&A time.

It is my pleasure today to introduce our next speaker, Dr. David Wasserman. Dr. Wasserman is with the Department of Bioethics, National Institutions of Health. Previously, he was Director of Research at the Center for Ethics, Yeshiva University (New York City, NY).

He has written extensively on ethical issues in biotechnology, neuroscience, disability, reproduction, genetics, and health care. He is the co-author of the book, Disability, Difference, Discrimination.

Dr. Wasserman’s presentation today is "Who’s Responsible for Inclusion". He will discuss the importance of universal social welfare reforms to achieve full inclusion for people with disabilities, and how individuals and society efforts can make this

Dr. Wasserman says "I argue that both individual and collective efforts are necessary for meaningful accommodation. But I conclude that full inclusion is only possible through universal social welfare reforms that must be collective undertakings."

I am truly looking forward to hearing more about this topic. Please join me in welcoming Dr. David Wasserman.
[2017/12/01 11:03] Elektra Panthar: DW: Let me start with saying that these are my views, they don't represent anyone else's
I want to distinguish two senses of responsibility
1. Backward-looking sense: who's to blame or praise for the situation?
2 What we try to do here is forward looking
It's not helpful to say we are all responsible
ADA right now classifies people into categories of disability and who qualifies. We should focus on including people, not excluding the and separating them in many categories
Employers and tertiary sector for example are required to provide accommodations

The ADA has been criticised, because they argue the State should be the one responsible to provide these accommodations primarily, and not the private sector
State and large institutions have also more resources to make sure the practices of universal design could be implemented
Some of the work of inclusion has to be individualized because of the large variety of differences. The complains of accommodation come from employers who think they have property rights and arrange their space as they see fit
Reasonable accommodation is a vague mandate
Regulations provide guidelines that can be more or less applicable depending on circumstance

If one is conscientious one can see the potential of the guidelines, the adjustment is seen as a process that aims to include people AND help the business
Some say disability discrimination is different from racial or religious discrimination - we don't have to spend as much money to accommodate these 'categories'
But this is a misconception
To make an example, different religions have different places of prayer, different vacation days, etc
You're not trying to distribute extra wealth to them, you're trying to accommodate them, not a redistribution exercise
As illustrated, equality is providing everyone with the same resources - equity is giving them resources to achieve the same goal
Individual accommodations require exercises in ingenuity and empathy, but still are not enough
When you provide specific accommodation you are highlighting the disability and provide the false idea that they are being granted handouts
It's preferable to provide accommodations that benefit a wider range of population
The idea is to make the environment more accessible to everyone in general, accounting for the wide variety of needs

Of course this requires a collective action, not just individual initiative
To break the hold of certain kind of perception of what is 'normal' and required, for example in the workplace, requires also a collective change, which would ultimately even benefit the employers
Collective responsibility is also making sure people with disabilities can participate in society by removing obstacles, providing healthcare support, so that they can
participate in the workforce as well and be more able to contribute to the economy and benefit from it

Good social insurance in a broader sense

The point of this talk is to provide an overview, provide suggestions

Thank you for having me and for your attention

Any questions?

[2017/12/01 11:32] iSkye Silverweb: Thought-inspiring about the collective approach, this is where universal design comes in

[2017/12/01 11:33] Gentle Heron: You've given us quite a lot to think about, David! Meeting personal needs for ANYONE with a need (rather than just for those who pass qualification exams) sounds like the idealism of Universal Design. Does it meet your concept of "reasonableness" though? Is it too idealistic to aspire to? Or should reasonableness even factor into our future visioning?

[2017/12/01 11:34] Elektra Panthar: DW: I haven't talked about limits but for example a lot of people living in older homes have to find other places to socialise with friends with disabilities

The idea is to some extent for example providing incentives to help individuals to make these accommodations if they want to

[2017/12/01 11:37] ShylatheSuperGecko: Here in Illinois our state has shut down all services with the exclusion of 'live-saving' services. Should there be some Federal oversight that prevents disabled people from the constant instability of the structure of our democratic govt, which, by its nature, seems to change its mind on a regular basis. Do we need Federal oversight to ensure states do not terminate benefits due to party squabbles?

[2017/12/01 11:38] Elektra Panthar: DW: Relying on the fed govt NOW may be going from the pot into the fire

There ought to be a course that is more attractive than it is now

[2017/12/01 11:38] ShylatheSuperGecko: which is precisely my point, I guess - it's hard to re-assimilate when positions keep changing.

[2017/12/01 11:35] iSkye Silverweb: I have a question, I've heard complaints that universal design is a "lowest common denominator" approach rather than a 'design once, usable for all' philosophy. Your thoughts on that?

[2017/12/01 11:38] Elektra Panthar: DW: I have heard those complaints about assistive tech

For me it can be made in such a way that can be used by a large variety of people with different needs

If you manage to attract a wide marketplace it can be easier to be implemented, as are environment changes that can benefit a large part of the population, rather than being disability specific

Assistive technology can take several forms, even those one wouldn't think as assistive tech

[2017/12/01 11:40] Pecos Kidd: My reading glasses are Assistive Technology. I can't read the screen without them......
Elektra Panthar: DW: All sorts of devices that help people in their daily lives, like eyeglasses, should be seen as assistive technology.

RachelPfieffer: I have a question too. It seems to me that in the U.S. a lot has to be done with infrastructure to bring universal access about. Would you say we are more like a third world country as compared to Europe which is continually modernizing?

Elektra Panthar: DW: Right now there need to be significant changes to the infrastructure, which in the current situation is unlikely to happen for now.

Carolyn Carillon: Dhira Giha: I'd like to ask your opinion about how MIH is contributing toward the goals you mentioned?

Elektra Panthar: DW: For better or worse most of the work they do is going to be oriented toward individuals and not the environment. I know very little about the Inst. for environmental health and what they are working on now.

Public health is not as funded and appreciated as it should be. The advances in life expectancy is not primarily about scientific breakthroughs, but about quality of life. Modern tech advancements are attractive to everyone, which means there is a bigger possibility to be developed and available on a larger scale which can also be beneficial to people with disability. I think it's a very important question.

Are there any other questions? If you have any other questions you can contact me via e-mail dtwasser@gmail.com

Gentle Heron: What is the title of Martha Russell’s book?

Elektra Panthar: DW: "Beyond Ramps"

VAIPresenter2: Thanks, David. I am especially interested in psych disabilities, reasonable accommodations, etc, partly with my own exp in academic world.

In my experience, tons of the work involves finding out what accommodation would be helpful to me, but workplace expects easy answers there.

Elektra Panthar: DW: I have a paper in drafts about that to share with you if you’re interested.

VAIPresenter2: Yes please.

Elektra Panthar: DW: A lot of employers would like to make it as mechanical as possible, I think.

Progressive ones understand that it's a process of learning in both senses.

It has to be a conversation.

It's about trying to make people as comfortable as possible.

Gentle Heron: Carol, contact Job Accommodation Network. JAN = https://askjan.org/
Carolyn Carillon: Shyla: I feel one of the inhibitors to the quality is the constantly changing environment
I might be able to get back in the workplace
And then things change again
And I can't stay in that position
Then I have to go through the entire bureaucracy again to requalify
Requalify
That makes full assimilation hard
The turf keeps moving
I don't know where the question is

Mook Wheeler: very good point, Shyla. So many conditions are progressive.

Elektra Panthar: DW: A good workplace that values their employees takes the effort to make sure tech upgrades don't leave a chunk of workplace behind if they want to try to adapt
Both parts need to be reasonable in their expectations

iSkye Silverweb: In a past job I had trouble with "re-organisations" every few months which meant I was getting a new manager and department head and I would have to re-educate them on my accommodations and skills THEN I could get back to being productive as a 'team member'
People assume things about what I can and can't do, so I was in a cycle of having to re-educate people just so I could be allowed to keep doing my job

Elektra Panthar: DW: I was fortunate to be in a job where management was fairly stable. I can imagine having to re-educate people can be tremendously hard

Gentle Heron: Isn't it our basic responsibility to respect others and their needs, and to be able to expect others to respect us and our needs?

ShylatheSuperGecko: Yes, I had the same issue, my employer decided I could work from home as opposed to their providing special equipment for me to work on-site. With each change in manager or staff member, I had to educate them that I cannot hear "over-the-cubical" conversations and decisions.

Elektra Panthar: DW: That's one of the challenges of being in a 'minority', they currently have the burden of education
The relentless reorganization treats respect as luxury, that fast moving organization don't feel they can afford

iSkye Silverweb: I wish I had perceived that at the time and gotten out

Elektra Panthar: DW: I think flexibility is paramount, there's value in a physically accessible workplace
Part of my concern is that doing away with physical proximity thanks to technology is not a positive solution

ShylatheSuperGecko: I agree-- working from home is NOT a solution.

YasminEliora: For some working at home is the only solution
I can only work from home as a caregiver of my severely autistic son
[2017/12/01 12:10] Mook Wheeler: different courses for different horses is not being disputed here...

[2017/12/01 12:09] Carolyn Carillon: Shyla: I feel the decision to remove me from the workplace was responsible for my downfall
It's important to have compromise
[2017/12/01 12:10] iSkye Silverweb: @Shyla: I think that's because you were not a part of that decision that your employer made, they made it for you, am I right?
[2017/12/01 12:10] ShylatheSuperGecko: Yes iSkye
They made the decision
[2017/12/01 12:10] Elektra Panthar: DW: Being flexible is the key, there can be times where one can work only from home, but a conscientious employer needs to understand also face to face interaction is important
[2017/12/01 12:12] Carolyn Carillon: Shyla: I believe what you're saying is that there should be a balance
[2017/12/01 12:12] Elektra Panthar: DW: Yes, I meant that those willing to work at the workplace should be able to
[2017/12/01 12:12] Carolyn Carillon: Shyla: But I'm hearing that's not always there
I'm not sure how we get there
The points you made are valid
A lot is how we're perceived
My company did what was required
But I became a nuisance to them because I was disabled
That makes it hard for everyone to participate
But I thank you
You made a lot of great points
[2017/12/01 12:14] Elektra Panthar: DW: Yes, broader social reforms are necessary to avoid this mentality to continue, bargaining power needs to be more equal between employer and employees

[2017/12/01 12:14] Gentle Heron: Thank you David. I’d like to remind the audience as they take a break to visit Healthinfo Island to our west. We’ve got exhibits and displays on a wide variety of topics related to our conference. Pick up a notecard with additional info by clicking the blue poster on the left side of the stage.
[2017/12/01 12:14] YasminEliora: thank you :-)
[2017/12/01 12:14] Mook Wheeler: Thank you very much, David, that was great :)
[2017/12/01 12:15] LV (lorivonne.lustre): Thank you David. You have given us much to think about. I work within a Universal Design for Learning paradigm, and I will be viewing my work through a different lens now. These conversations are so important. I hope you will come back and share your work with us again.
[2017/12/01 12:15] Slatan Dryke: great talk David, thank you !
[2017/12/01 12:15] Elektra Panthar: DW: Thank you for the very thoughtful questions and to the organizers that made this virtual world accessible to me
Suellen Heartsong (suln.mahogany): well done, you should come back again
Elektra Panthar: Thank you David!
Carolyn Carillon: <<transcription ends>>