



**Virtual Ability, Inc.® presents the 6th Annual
International Disability Rights Affirmation Conference
December 1 and 2, 2017
in Second Life at
<http://maps.secondlife.com/secondlife/Virtual%20Ability/54/170/23>**

Title: "Access to Health Care and the Liberation of People with Disabilities"
Speaker: Dr. Margaret Nosek, Baylor College of Medicine

[2017/12/01 09:26] LV (lorivonne.lustre): 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.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Elektra Panthar

LoriVonne Lustre

The following initials in the transcription record will identify the speakers:

MN: Margaret Nosek / Dhira Giha

[2017/12/01 09:29] Suln Mahogany: Good Morning

It is my extreme pleasure to introduce our next speaker

Margaret (Peg) Nosek, PhD, is a Professor

in the Department of Physical Medicine and Rehabilitation

at Baylor College of Medicine

and Senior Scientist at TIRR Memorial Hermann (Houston, TX, US).

She is the Executive Director of the Center

for Research on Women with Disabilities (CROWD).

She holds an additional position as Adjunct Professor

in the College of Nursing at Texas Woman's University, Houston.

Her doctorate is in rehabilitation research from the University of Texas at Austin.

Peg is on the Board of Directors for Virtual Ability, Inc.

Dr. Nosek's main research interest is on improving

the health of women with physical disabilities,

especially developing interventions disparities in reproductive health

and access to healthcare services.

She has conducted many large funded studies,

several of which have taken place in Second Life.

She is the author of numerous publications

and the recipient of several prestigious awards,

from organizations such as the American College of Physical Medicine

and the Rehabilitation Psychology Division of the American Psychological

Association.

Dr. Nosek lives with spinal muscular atrophy,

a severe congenital physical disability,

and is a disability rights activist.

"Access to Health Care and the Liberation of People with Disabilities"

Current debate in the US about health care reform

has not covered issues related to the well-being

of people with disabilities.

This presentation compares healthcare financing

under the current US system versus a

single-payer national health program

from the perspective of people with disabilities

and factors affecting their life options.

[2017/12/01 09:32] LV (lorivonne.lustre): <<transcription begins>>
Please remember to hold your comments and questions to the end

[2017/12/01 09:32] LV (lorivonne.lustre): MN: Thank you so much everyone.
Let me begin by saying what we are not.
This is my opinion and we have not been funded in any way for this work.
I would like to thank my colleagues with this work -- our blood, sweat, and tears
I would like to talk to you about the liberation of persons with disabilities -- in particular in the area of participation
When I talk about liberation -- it means freedom to participate in society to the extent that you want and the freedom to meet your life goals
If you are from a country outside the US, please type in chat

[2017/12/01 09:36] Buffy Beale: Canada
[2017/12/01 09:36] Tizzy Bright: me - England
[2017/12/01 09:36] Mook Wheeler: UK
[2017/12/01 09:36] Elektra Panthar: Italy
[2017/12/01 09:36] 01 (01.hifeng): *waves* Poland
[2017/12/01 09:36] Pecos Kidd: Texas... :)

[2017/12/01 09:36] LV (lorivonne.lustre): MN: Anywhere else?
Funny Pecos!
I have a proposition! People with disabilities have reduced levels of participation due to reduced access to quality healthcare
Higher levels of participation would be possible under a single-payer health insurance system
What is participation?
From the point of view of researchers and WHO: There is a list of variables -- self-care, mobility, domestic life, interpersonal interactions, major life areas (like employment and sexuality), "democracy" and civil life
Lack of participation characterizes persons with disabilities
We can also look at the environmental factors -- how we interact with the built and natural environment
How we interact with these is so important
There is also a transactional model -- individual, community, societal
Measure of participation include frequency, importance, choice, satisfaction, use of AT, use of personal assistance, and most importantly -- health care related
Healthcare and participation factors
Information and advice, medications (good and not so great)

I have lived to the ripe age of 65 due to the use of antibiotics
Supplies - I use a ventilator and am dependent upon clean supplies
Therapies

Assistive devices -- I would not be able to function without my wheelchair, although some participate from their bed

Chronic care services

Acute care services -- when we need help, we need help right away

We all need an MD, NP or other medical practitioner to sign off for access to the services

We will talk about the US situation first, then open it for the audience members from other countries

Facts: The US rations healthcare based on ability to pay

If you cannot access this (pay) you are shut out

Other industrial nations have some form of basic healthcare for everyone

Define single payer

A single public or quasi-public agency that organized health care financing

Delivery of care remains largely in private hands

All residents of the US would be covered with a basic set of necessary services

This would include immigrants (documents and non-documented)

General health care, emergency services, preventative

Long term care? This is a question and quite controversial

I would love to hear how other countries handle this

Mental and behavioural health

Reproductive health care

Rehabilitation services, I work at a rehab hospital however they would not accept my insurance coverage for the ventilator services and rehab I needed

Those of you from other countries... What is your national healthcare services? Do you receive the services on the screen?

[2017/12/01 09:52] 01 (01.hifeng): We have basic health care here but it's extremely low quality

So I choose to not use it anyway

Because I would be sicker if I did

heh

[2017/12/01 09:54] Sheila Yoshikawa: All of those in the UK, although some aspects better than others

As far as I'm concerned it is invaluable to have this - so for example my husband has had various health problems, and he e.g. has had several heart operations and takes expensive medication, and it is such a relief that we don't have to worry about payment on top of that

[2017/12/01 09:56] Dorie Bernstein: If it's put as a way of controlling costs, it would help greatly. The US pays exorbitant rates for medicines and care

[2017/12/01 09:56] iSkye Silverweb: A popular phrase in VAI is "currently able bodied" emphasis on "currently"

[2017/12/01 09:56] Elektra Panthar: TB: I'm from England, it's paid from taxation. I get the feeling that if you're going to ask the 'able bodied' to pay more taxes to pay for health care, I don't think you'd get a positive reaction

The mental care here is awful, the other basic physical needs are usually available

[2017/12/01 09:56] LV (lorivonne.lustre): MN: Thank you Tizzy. Can I ask about long term care?

[2017/12/01 09:56] Elektra Panthar: TB: There's no limitation on long term care

[2017/12/01 09:57] LV (lorivonne.lustre): MN: Amazing. You guys have your priorities in order

[2017/12/01 09:57] Sheila Yoshikawa: yes in the UK you get taken care of ongoing, also after you are of pensionable age you get free drugs on prescription from the doctor, free eye tests

[2017/12/01 09:59] LV (lorivonne.lustre): MN: One other thing that differentiates the UK and the US is that providers are paid by the government in the US. We are advocating for the provision of service paid by a single payer, not directly the government. However the govt sets the rate

Any other questions? Comments?

There is one service in the US that is similar to that in the UK, and that is Veterans services

[2017/12/01 09:59] Zombie doggie (tarquin.evermore): Any mention of taxes and raising them is going to make people complain.

I do like the idea of single payer, but I don't like the idea of dismal mental health, or being in a worse state than the US already are.

[2017/12/01 10:00] LV (lorivonne.lustre): MN: In the US we need to reframe the argument that we will all pay less for healthcare through the power of the group
This is why the VA can negotiate for better costs

Everyone benefits

There are currently insurance costs, co-pay costs, services that are not covered
You may not have any health care costs NOW, but you sure might in the future

[2017/12/01 10:00] Dorie Bernstein: And the government says "we will pay this much, like it or leave it" to the pharmaceutical companies, hospitals

[2017/12/01 10:00] Buffy Beale: In Canada it varies by Province, some like Ontario are free, but here in British Columbia I pay \$75 a month for standard and an extra \$40 for enhanced coverage and dental. I've not had to use it much but I know when I go to the doctor for a checkup or hospital for a broken bone I didn't have to pay anything. Some but not all prescriptions are covered and things like a percentage of extra like rehab or massage sessions.

[2017/12/01 10:01] Zombie doggie (tarquin.evermore): DORIE! Exactly! the US is the only country where the pharma can get away with price gouging. Looking at you Shkreli and EpiPen

It's sad when you have to choose between paying for medical or food on the table

[2017/12/01 10:02] ShylatheSuperGecko: that is true of many corporate plans today too, \$7.5K out of pocket

[2017/12/01 10:03] LV (lorivonne.lustre): MN: In a single payer system, everyone would pay a tax for the service, and it would be a lower rate than what they pay now, without the fear of bankruptcy if you become ill

[2017/12/01 10:05] 01 (01.hifeng): I've been actually going out of my way to hire myself in my org in a way that I wouldn't have to pay monthly fee/tax for basic health care.

I don't use it anyway, so...

In Poland a lot of businesspeople try to not pay that monthly tax and don't want to be covered by our basic healthcare
If something happens you can just pay out of pocket and it's better quality

[2017/12/01 10:03] LV (lorivonne.lustre): MN: Let's define disability
Government healthcare funding defines disability as not being able to work.
Private insurance is usually available for people who are able to work
There are also some people who work and receive medicaid / medicare.
There are some who have no coverage at all, especially if they are undocumented
This is Ralph. He works part-time at Walmart, which does not provide health insurance for part-time workers. He needs to remain poor to get the health care services he needs

This is Ashley. She has fibromyalgia. When she had to move to part-time employment, she lost her health care coverage for herself and her son
She got private insurer funding for her son and herself, but cannot earn very much money

She could not keep up the payments and now has no coverage

This is Teresa. Has post-polio. Uses a manual wheelchair. She is able to work and so was not considered a disabled person. She developed carpal tunnel -- a new disabling condition.

This gave her access to coverage through her employer and secondary coverage through government

Insurance type X disability

This is people in the community - not veterans

Folks like Ralph - 42%; like Teresa - 11% and 32%, like Ashley - 15% have no coverage
Graphs of private insurance coverage comparing people without and with disabilities
10% of the working age population have disabilities

Putting it all together... All US civilians aged 18-64 living in the community -- 2% have no coverage

Persons with disabilities are struggling to get their voices heard. There are just too few of us

We are often the first to be tossed under the insurance industries stretch hummer
We are ignored

What do we want from Health Insurance

Ralph want to live on his own and get married, but he can't afford it

Ashley wants to know why disability and insurance are tied to employment

During times when salaries could not be raised during WWII, health coverage was offered as an incentive

Ashley also wants coverage for her son that does not depend upon her

Teresa does not want her services to be limited by how much she earns. She also want quick access to service her wheelchair and type of wheelchair

These are the categories

Timely access to services

Quality and affordable services

Society wants lowest possible cost with the highest possible outcomes for everyone.

US current (fragmented non-) system v single payer

Single payer -- everyone in, cradle to grave
ACA -- there are still 30 million still uninsured
in 2022
Tens of millions under-insured
MNL limitations based on income and employment status
Full range of services
Yes to single payer
Under ACA -- limitations, rarely includes vision, dental, women's health,
contraception
Unbelievable violations of rights
Costs for individuals
Single payer - 95% would pay less than currently
Everyone would be covered
Long-term care options subsidized
ACA -- sky-rocketing costs
Choice of doctor and hospital
Single payer -- free choice
ACA -- severely restricted
Costs for society
Single payer: no net cost increase
Redirects 400 billion in administrative waste to care
ACA: increases, uncontrollable price increases
Block grants / high risk pool debate
You lower risk by spreading it out! Don't put all the high risk people in a single pool
In conclusion: For-profit private insurance must be eliminated
Until there is access to healthcare people with disabilities cannot make their dreams
real
Higher levels of participation are available for persons with disabilities
Resources list of organizations advocating
If you would like this information, let me know
Vote for single payer
Any questions?

[2017/12/01 10:35] Gentle Heron: Peg, I'm going to play the devil's advocate. What do you see as the limitations or barriers to progress created by Healthcare-Now's approach to insurance advocacy? I'll post their URL for folks to look at:
<https://www.healthcare-now.org/>

[2017/12/01 10:36] LV (lorivonne.lustre): MN: Attitude! That is the biggest barrier!

[2017/12/01 10:37] Zombie doggie (tarquin.evermore): There seems to be a lot of weaknesses to single payer, such as demonstrated by our overseas commentors. Such as lacking mental health insurance.

Or it being poor in general

How would we keep from making these serious downfalls?

[2017/12/01 10:38] LV (lorivonne.lustre): MN: you may get very good service, however as a whole people with disabilities have much lower outcomes

[2017/12/01 10:38] 01 (01.hifeng): Maybe health care cost just are too high?
Do something with these companies and doctors, etc
Instead of thinking how to pay for it force it to cost less
[2017/12/01 10:39] Zombie doggie (tarquin.evermore): Perhaps combine single
payer strengths with insurance company strengths, somehow? Kind of like a middle
road?

[2017/12/01 10:38] LV (lorivonne.lustre): GH: what is the reaction from people who
oppose?

[2017/12/01 10:39] LV (lorivonne.lustre): MN: It is the attitudes of those who are
making the laws that think that people with disabilities are included. This will
diminish the service or have to pay

[2017/12/01 10:39] Mook Wheeler: nods at Dhira. The medical model permeates
politics.

[2017/12/01 10:40] LV (lorivonne.lustre): MN: there are discrimination and stigma --
racism and ableism

Did I answer your question Gentle?

[2017/12/01 10:40] LV (lorivonne.lustre): GH: what is it about these facts you
presented that is unacceptable? It is more than attitude

[2017/12/01 10:41] LV (lorivonne.lustre): MN: It is resistance to change

[2017/12/01 10:39] α Techie Gent Ω (prymahl): And what Party will this be
associated with? And how do the powers that be look at this possible solution?
OMG Racism is rampant in TX

[2017/12/01 10:40] Zombie doggie (tarquin.evermore): Yeah the politicians don't
think about the disabled, they just think about themselves as in "Can I buy this new
condo?"

[2017/12/01 10:40] ShylatheSuperGecko: The policy makers are owned by Park Ave

[2017/12/01 10:40] Pecos Kidd: Profit. For the Insurance Companies.

[2017/12/01 10:41] Rhiannon Chatnoir: Also never underestimate the power of drug
and health care lobbying in effecting health care debate

[2017/12/01 10:41] ShylatheSuperGecko: When California figures out how to do it,
it will flow east

[2017/12/01 10:41] Suellen Heartsong (suln.mahogany) agrees with Shyla

[2017/12/01 10:41] LV (lorivonne.lustre): MN: Look at Canada. When their health
care system was first introduced in Saskatchewan, the doctors went on strike!

[2017/12/01 10:41] ShylatheSuperGecko: But even Gov Brown says he doesn't know
how to pay for it - so I think we should mail this presentation to Gov. Brown

[2017/12/01 10:41] Zombie doggie (tarquin.evermore): Not so much Shyla. Kansas
will dig their heels in and go "No no no! no change!" and plug their ears with wheat
stalks.

[2017/12/01 10:42] ShylatheSuperGecko: Eventually they will concede, it just takes
time Tarq, but you are right, Kansas will hold out as long as possible

[2017/12/01 10:43] Zombie doggie (tarquin.evermore): Yeah I happen to be from KS
so I know the KS attitudes XD

[2017/12/01 10:42] Conan (wyrmfœ): Or for certain people there's the concept of
personal responsibility. "You can pay for it yourself so why should I? I'm not using it?"

And who are you to me? No one." That's more than just racism or being a greedy business.

[2017/12/01 10:42] LV (lorivonne.lustre): MN: It is fear. Conservatives do not want to change

[2017/12/01 10:42] Gentle Heron: So it's cultural, not economic

[2017/12/01 10:42] Conan (wyrmfœ): Bit of both

[2017/12/01 10:42] ShylatheSuperGecko: they are the fear mongers

[2017/12/01 10:43] LV (lorivonne.lustre): Rhiannon Chatnoir: There are also strong lobbies for profit from healthcare insurance providers

[2017/12/01 10:43] Rhiannon Chatnoir: In my former 'day gig' I worked as an in-house designer for an insurance administrator

[2017/12/01 10:42] α Techie Gent Ω (prymahl): May I ask a dumb question? Single payer system - 1 insurance company for a population set?

[2017/12/01 10:43] LV (lorivonne.lustre): MN: Yes, we will force some to lose their stretch hummers or yachts. I don't want your yacht to be paid by my illness

[2017/12/01 10:43] α Techie Gent Ω (prymahl): Socialism is not bad when it deals with common decency

[2017/12/01 10:44] ShylatheSuperGecko: What do you think of starting a campaign like the TRUTH campaign was for cigarettes, where we say it that clearly?

[2017/12/01 10:44] Zombie doggie (tarquin.evermore): Exactly. But at the same coin, that's how the rich get rich if they aren't born into it. By screwing over others.

[2017/12/01 10:44] LV (lorivonne.lustre): GH: This is amazing Peg. It is great! Our audience is stirred up!

Thank you Peg. This was wonderful

[2017/12/01 10:44] LV (lorivonne.lustre): MN: Thank you.

[2017/12/01 10:44] Suellen Heartsong (suln.mahogany): Thank you Peg

[2017/12/01 10:44] Pecos Kidd: Awesome, Peg! Well done!

[2017/12/01 10:44] Eme Capalini: Great job Peg!

[2017/12/01 10:44] Eme Capalini: Thank you!

[2017/12/01 10:44] Treasure Ballinger: APPLAUSE!!!!

[2017/12/01 10:44] ThomasM Torok: Thank you Margaret!!!!

[2017/12/01 10:44] LV (lorivonne.lustre): <<transcription ends>>