

# International Disability Rights Affirmation Conference (IDRAC)

Friday November 18, 2016 - 8:00am- 3:00pm

Saturday, November 19, 2016 - 8:00am - 1:30pm

Sojourner Auditorium, Virtual Ability Island in Second Life®

[http://maps.secondlife.com/secondlife/Virtual Ability/54/170/23](http://maps.secondlife.com/secondlife/Virtual%20Ability/54/170/23)



Speaker: Pathfinder Lester

Title: "But you're not supposed to use it that way!"

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[11:00 AM] 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 Nearby Chat.  
Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:  
LoriVonne Lustre  
Carolyn Carillon

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

PL = Pathfinder Lester / John Lester

[11:01 AM] Vulcan Viper: Hi, I am Vulcan.

I live in The Netherlands, where I've been a member of a real life group that audits the accessibility of buildings.

I came to Second Life wanting to share a new approach that addresses this very issue where it actually begins: in the minds of the architects.

In the year...2013, I believe...I had the great pleasure of sharing my presentation, entitled "Accessibility In Mind".

Today, I stand before you, not to offer a presentation of my own, but to introduce someone else.

Our speaker today is John Lester, known in Second Life as Pathfinder Lester.

John has been working with virtual worlds and online communities since the 1990s, creating online patient support groups at Massachusetts General Hospital for people dealing with neurological disorders.

He worked at Linden Lab for 5 years where he founded Linden Lab's Boston Office and led the development of the education and healthcare markets in SL while evangelizing the innovative use of virtual worlds in research, art and immersive learning.

He now serves on the Board of Directors of Virtual Ability, Inc.

Virtual Ability, Inc. is a non-profit organization that enables people with a wide range of disabilities by providing a supporting environment for them to enter and thrive in online virtual worlds like Second Life.

At his day job, John works as a Product Manager at OpenText where he does R&D in unstructured data analytics and enterprise information management.

John joins us here today, from Toronto, Canada, to share his presentation, entitled: "“But you’re not supposed to use it that way!” - Exploring how people shape technologies to empower online communities.’

Today, John will tell his story of how a continuing quest for more emotional bandwidth and perceptual immersion was enlightened by communities of people who often used technologies in completely unexpected and breathtakingly beautiful ways.

Pathfinder, the stage is yours.

[11:05 AM] LV (lorivonne.lustre): PL: Thanks so much

and thank you for the opportunity

This topic is near and dear to my heart

The intersection of the people

Here is my bio that Vulcan used

I am interested in how technology brings people together

Not the databases or the programming, but how people can use the tools to connect with one another

I am very "old" in terms of virtual worlds, using dial up modems to connect to bulletin boards

When the web came out I was interested in how people connected -- especially chatrooms and discussion

Emotional bandwidth

How you express your feelings in virtual environment

Perceptual immersion -- you don't need VR or to completely recreate the physical world

The human mind can create using the tools in creative ways

Like the world we are in right now, it is not VR

but we are able to connect

VR is a part of the spectrum of choices

I am very interested in how people use technology in unexpected ways

Today I want to talk about 4 stories about how people used technology in interesting ways and what I learned

I am just telling the stories -- these are about the people who created it

### Story 1 -- The Club

When I first started setting up chat rooms in 1994 at Mass General

I had chatrooms for many different neurological conditions -- about 200 of them

People could also create their own chatrooms

One day I saw a chatroom called "The Club"

I heard that it was fantastic! But was unsure about what it was about

It was called Club Avonex -- a drug for MS that people self-inject. A lot of them do not like it and many had to do this alone

They met in the MS chatroom -- and decided to coordinate their self-injection schedules for the same time regardless of where in the world they were

They logged into the club and provided support before, during and after the injection

It was an example for me of how the online tools were being used to coordinate things in the physical world

Not what I expected. It was a beautiful thing

All user created.

Club Avonex (chuckles). Such a beautiful story.

### Story 2 -- The Guy from NYC

Still with the chatrooms... this guy from NYC was diagnosed with early onset Parkinson's Disease. He introduced himself as Mike from NYC.

He gave lots of support and received it as well

Other than his name and location, he did not share anything about himself

In 1998 -- he let the group in on who he was -- Michael J Fox

Yeah sure! No one believed him

He did not let the world know until after about 7 years after diagnosis. He was very young

He invited people to come to see a filming of Spin City. Sure enough...

He was Michael J Fox

The beauty of it was how he had a wonderful reputation for supporting others without sharing his real identity

Pseudonymity, not anonymity

Strong social ties that occurred

'Mike from NYC' allowed him to give and receive support that he would not have been able to as 'Michael J Fox'

### Story 3. The Faces.

In 1999 we set up the use of emoticons

In one of the chatrooms they were using more emoticons than any of the others

At the same time I was experimenting with a platform called The Palace

A flat 2D space. Avatars like paper dolls

This particular chatroom loved the Palace.

This room was for people with Mobius syndrome, where the individual is unable to have facial expressions

The participants loved emoticons and the Palace where they could "be" the emotional facial expression

### Story 4. The safe and the scary

The story of Brigadoon Island, before I worked at Linden Lab

I said, there is this platform called Second Life. I wanted to do something...

A safe and supportive environment for people with autism and Aspergers syndrome

It was the first non-profit island

I called up Robin Harper and inquired about the non-profit discount (and educators)

50% off -- sure!

What happened was I noticed people creating spaces that looked like real world places

I asked: what are you using this for?

I heard, this is a place where we can create safe places and scary places -- to practice for when you go to these in RL

An amazing combination of safe and scary

If the shopping mall is too much, teleport to your garden

The really special thing about Brigadoon Island, was that one member: The Sojourner

This auditorium was named for her

She wanted to create additional communities for people with many different types of disabilities

The Sojourner's legacy is amazing

The participants at Brigadoon Island went way beyond what I thought would happen

The beautiful lessons, the big ones I took from these stories

There is real magic in online communities is when there are real time malleable interactions

That is when people bend the tools

People need to be able to create completely new things

I have seen this everywhere -- from chat rooms to virtual worlds

The more malleable, the more you have unique creative content creation

People will squeeze emotional bandwidth out of the tools as much as they can

They will use the tools however they are able

People use these tools because they are fun, and may be challenging

Comfort and challenge, growing and developing

We grow by facing challenges

Pseudonymity is powerful -- we don't need to know your real name and where you live

Let the real person come out by projecting who you want others to know

[11:42 AM] Leondra Larsson: other facets of self:)

[11:42 AM] LV (lorivonne.lustre): PL: Perfect Leondra

Not a mask of anonymity, a mask of pseudonymity

I think this is critical

Lastly, cultivate communities. Cultivate the creation of new communities

The communities you think are needed are only a small part of what the users will create

Second Life is the perfect example of all 5 points

Creating new communities is the life blood of Second Life

You can see the potential of technologies when you let it loose with the group. It is only realized when the people are allowed to shape their own direction.

Questions?

[11:46 AM] Gentle Heron: Thanks Pathfinder. Your presentations are always thought-provoking.

QUESTION- Can you please say a little more about the distinction between pseudonymity and anonymity? Aren't the down sides the same for both, even if the upsides are different?

[11:47 AM] LV (lorivonne.lustre): PL: it is complicated Gentle. When I say anonymity I mean that there is nothing known

Look at how much anonymity has led to some of the nastiness of comments etc.

Although Google is cleaning this up

Masks as pseudonymity are about identity -- like MikeNYC

or possibly just Mike

About choices in sharing

[11:48 AM] Leandra Kohnke: Sometimes you need some anonymity. For example if you disagree with the majority opinion you can still express yourself.

This can be very important when it comes to politics or science.

[11:48 AM] Bridgette Rossini: or religion

[11:48 AM] Beth Ghostraven: does pseudonymity = "some anonymity"?

[11:49 AM] Gentle Heron: selective anonymity?

[11:49 AM] LV (lorivonne.lustre): PL: nom de plume perhaps

[11:49 AM] Gentle Heron: persistent selective anonymity

[11:49 AM] LV (lorivonne.lustre): PL: persistence of identity that is tied to an identifier -- name, picture, avatar

You can know who the person is due to the persistence of identity

[11:50 AM] Beth Ghostraven: Part of our need for some anonymity is for RL safety, to help protect us against RL stalkers

[11:50 AM] LV (lorivonne.lustre): PL: Agreed Beth

[11:50 AM] Gentle Heron: QUESTION for Robbie Koray: Why do you say that "SL is the safest place in the world"?

and asking Pathfinder: Do you agree with Robbie's statement?

[11:51 AM] LV (lorivonne.lustre): PL: What do you mean by safe Robbie?

[11:51 AM] Bridgette Rossini: I think physically safe

[11:51 AM] Robbie Koray: SL like you said.. if some place is too disturbing, you can TP out.

[11:51 AM] Leandra Kohnke: I think certain places are safe and others are very unsafe.

There are predators in here.

[11:51 AM] LV (lorivonne.lustre): PL: Physically safe -- yes. Mostly

[11:51 AM] MatildaMoontree: But you can be stalked, and harassed

[11:51 AM] Princess Claire (clairedear): Use a VPN lol  
Expect more lag  
[11:52 AM] LV (lorivonne.lustre): PL: There are ways to track IPs. There are shields you can put up  
[11:53 AM] Pathfinder Lester: <https://www.eff.org/privacybadger>  
Check out privacy badger to protect your ID online  
There are things you can do to protect your identity - like when surfing the web  
[11:53 AM] Pecos Kidd: "Increase the odds of protection"... there is never any "guarantee" of privacy.  
[11:54 AM] LV (lorivonne.lustre): PL: Yes, Pecos, there are no guarantees  
[11:53 AM] Vulcan Viper: If people find a location based on my IP address, they're going to be way off.  
...and I'm not even using a VPN.  
[11:57 AM] Vulcan Viper notices Privacy Badger doesn't support Safari.

[11:52 AM] Leandra Kohnke: I have met people who pretend to be counselors in RL and then use it to abuse people who are vulnerable.  
[11:53 AM] Bridgette Rossini: Leandra, someone who wants to take that type of position should apply with LL to be allowed to treat others  
They should prove it  
[11:54 AM] Leandra Kohnke: Predators are not interested in registering with LL.  
If they are real counselors with credentials they should be able to prove it in RL.  
[11:55 AM] Leandra Larsson: right, agreed Leandra. If they are saying they are counselors, they ought to be able to reveal accessing them in RL.  
[11:55 AM] Leandra Kohnke: I have also had people be very abusive in SL with me for holding differing political or religious opinions. This is why the Lindens invented the mute.

[11:53 AM] Robbie Koray: Inside SL, you can TP out of a situation if it's too much.  
[11:54 AM] Shyla the Super Gecko (krijon): I think the idea that SL is 'safe' is something we should be very careful about saying - it may cause people to put down their guard when most of us know it is not entirely safe, anywhere in SL. Be smart always.  
[11:55 AM] LV (lorivonne.lustre): PL: It comes down to identity, right? Think about persistence of identity and check out who they are.  
Good point Shyla. Some people are more vulnerable.  
Everyone is different.  
[11:55 AM] Pecos Kidd: But - Robbie is fundamentally right in one key aspect: you can always log out!  
[11:56 AM] Shyla the Super Gecko (krijon): I think it is thrown around sometimes because it is 'good for business' - having folks feel safe. But it is a disservice, we should teach folks to be safe, not tell them things are safe that may not be...  
[11:56 AM] iSkye Silverweb: I have frequently had to caution people about oversharing personal information in online settings, and not just in SL and other virtual worlds.  
[11:56 AM] LV (lorivonne.lustre): PL: Comes down to definitions of safe -- to be clear on. I remember the days before derender -- it is the most amazing thing  
[11:57 AM] Robbie Koray: Mute, block, Derender... YOU OUT OF MY UNIVERSE!  
[11:57 AM] Slatan Dryke: Mute/block is your best friend in SL

[11:55 AM] Mook (mook.wheeler): 'safety' is not only about the 'physical'. Safety also applies to the emotional, the mental, the psychological. It is like how the phrase 'sticks & stones can break my bones, but names will never hurt me' is total nonsense. Of course they can, and the damage goes far deeper and for far longer.

So SL, unless you only consider the physical, is no more safe than any other environment.

[11:56 AM] MatildaMoontree: I agree with Mook about words.

[11:56 AM] LV (lorivonne.lustre): PL: Yes Mook

[12:04 PM] Mook (mook.wheeler): I should clarify on the term 'safe'. There is a lot of 'safety' in SL, but most of it refers to some sort of 'escape' method. You can derender or mute. You can tp out. You can escape racism, but usually only by not using a coloured avatar (big story there). You can log out. If one decides to completely 'go real' in SL, then safety may possibly not exist. SL in this context is only safe IF you employ anonymity.

[12:05 PM] MatildaMoontree: Agreed, Mook, well put.

[12:24 PM] Mook (mook.wheeler): Can I add something to an earlier comment? I couldn't focus fast enough to say what I mean lol. I was trying to say that if 'safety' in SL only EVER involved methods of escape (derender, mute, logout, tp, etc), that means this form of 'safety' allows no personal empowerment. It means the only one empowered may be the troll/griever, because they get to make you leave or force you to mute them. And if there is no personal empowerment in one's daily issues/experiences, is it really 'safety' in the larger sense? I actually don't know -- it is a big question with no easy answers.

[11:57 AM] Shyla the Super Gecko (krijon): Still, people censor folks in SL, saying their creations are offensive or bothersome in some way - but the reality is we CAN derender things - I derender horses all the time...

[11:58 AM] Leandra Kohnke: horses?

[11:58 AM] Shyla the Super Gecko (krijon): indeed

[11:58 AM] Eme Capalini: I love derender when I go shopping. I can essentially have the sim to myself with no lag.

[11:58 AM] LV (lorivonne.lustre): PL: That tool was added when harassers tried to circumvent mute and block.

This all comes back to malleability -- using derender to go shopping.

It supports a malleable experience.

Something as simple as changing the sky -- maybe you want it to be daylight!

[11:59 AM] Shyla the Super Gecko (krijon): We can even control weather here - lol, no clouds, only sun only day on the beach all the time 24/7

[11:59 AM] Princess Claire (clairedear): You can go into debug and remove the sky lol.

[12:00 PM] LV (lorivonne.lustre): PL: Removing sky and water is very unique

All of my slides (except Brigadoon) are from OpenSim spaces.

Unless you spent time outside of virtual worlds like SL and OpenSim, you do not realize how lovely it is, so malleable.

Open it up and see what people will do.

[12:01 PM] Gentle Heron: Sometimes I forget where I am and try to modify RL.

[12:02 PM] Shyla the Super Gecko (krijon): I think it is natural to be malleable - we are generally that way as a society, and we bring it into our virtual worlds - we have to learn to be and use malleable tools.

[12:01 PM] Gentle Heron: QUESTION- How do you define "virtual world" and "virtual reality" to provide the most information about what distinguishes them? (I do NOT think they are the same, but the terms are often used interchangeably.)

[12:02 PM] LV (lorivonne.lustre): PL: Good one Gentle

[12:02 PM] Bridgette Rossini: I always thought of VR as limited..where as VWs are not  
However it would be great to have a VR head set to use on SL.

[12:02 PM] LV (lorivonne.lustre): PL: I define VR as the idea that you need stereoscopic field of view -- like goggles.

Virtual worlds are different. Look at the game Fall Out-- you are all alone. It does not have to be the full perceptual experience. Our brains are great at filling in the gaps.

That is what everyone is so excited about. Remember, the people that are most excited are those who are selling the tools.

Look at your screen. You can think of it as a window.

VR has compelling use cases, but does not give you the same sense of place.

Our tools become extensions of ourselves.

Our brain's capacity to fill in the gaps.

[12:05 PM] Pecos Kidd: Something you learn pretty quickly here: you find your self saying "I went dancing last night", not "I played the game Second Life and went dancing in it"

[12:06 PM] Gentle Heron: [12:03] Kyna Blackburn: But doesn't the lack of "real" danger do a disservice? Something we all need to do IRL on a daily basis is to cope with unpleasant situations we can't escape from. Do you see VR worlds as a "dry run" so that people can prepare themselves for various scenarios?

[12:07 PM] LV (lorivonne.lustre): PL: That is the value of simulations.

That is what the folks were doing at Brigadoon. Flight simulators for example, not just learning how to use the tools but also how well your brain can respond to stress and situations that are dangerous.

This applies to VWs and VRs.

[12:07 PM] Shyla the Super Gecko (krijon): But they can do so in the volume that works best for them, instead of raw full flood.

[12:09 PM] Gentle Heron: Thank you Pathfinder.

Lots of things to think about now.

[12:09 PM] Pathfinder Lester: <http://johnlester.me>

[12:09 PM] LV (lorivonne.lustre): PL: Feel free to contact me

Thank you for inviting me Gentle. And thank you to Golda for helping to keep the Sojourner's legacy alive.

[12:09 PM] Svea Morane: Great job Pathfinder.. thank you ;)

[12:09 PM] Fran Serenade: THANK YOU, VERY INTERESTING AND HELPFUL

[12:09 PM] Leondra Larsson: Thank you so much, Lester! Very thought provoking topics:)

[12:10 PM] iSkye Silverweb: Thank you for sharing that, it's awesome that you encourage people to discover how they can use technology to connect and do wonderful things.

[12:10 PM] LV (lorivonne.lustre): <transcription ends>