



**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: "Disability Identity Development"
Speaker: D. Anjali Forber-Pratt, Vanderbilt University

[2017/12/02 13:58] 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:

Carolyn Carillon

LoriVonne Lustre

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

AF: Anjali Forber-Pratt

[2017/12/02 14:01] LV (lorivonne.lustre): <<transcription begins>>

[2017/12/02 14:00] >: (Taps mic)

Testing one, two three?

Testing one, two three?

Hello, everyone. My name is Sister Abeyante, a long time member of the Virtual Ability community in Second Life.

In my physical life, I am Sister Patrice Colletti, SDS

and I am joining you from the depths of winter here on the Lake Traverse Indian Reservation in South Dakota.

I'm an educator, non-profit leader, scholar, change agent, techie, member of the disability community, and RL nun.

Today, I am pleased to introduce our next speaker, Dr. Anjali Forber-Pratt.

Dr. Forber-Pratt is an Assistant Professor at the Department of Human and Organizational Development at Vanderbilt University.

She is a scholar whose research explores issues surrounding identity development, school safety,

social-emotional learning, the impact of gang presence and school climate particularly for individuals who are different in some way, with a large focus on disability.

Dr. Forber-Pratt has presented at numerous state, national and international conferences and has published widely.

She has also been honored by the US White House, and has received prestigious awards from numerous organizations,

including the American Association of People with Disabilities (AAPD).

Dr. Forber-Pratt is also a track Paralympian, has competed in downhill skiing, and has shared her insights and gifts in venues as important as both doing a TED Talk and being on Sesame Street!

(I am particularly jealous about her being on Sesame Street!! LOL)

She has so much to share with us today, as we close our conference!

As we examine the term "disability identity" and explore some current and ongoing research,

I know we are going to find a lot to think about.

As we welcome Dr. Forber-Pratt to our stage, I'd ask you to please avoid typing into Local Chat until it's time for Q&A.

If you are using Voice, please MUTE your mic at this time, too.
This will really help presenters who are new to Second Life.

Dr. Forber-Pratt, on behalf of our community here in Second Life, and of all of us here, welcome!

Your topic today looks fascinating! We really look forward to learning from you.

Please come on up to the podium and begin whenever you are ready.

Slatan, on behalf of all of us, as well- thank you for voicing for me today!

[2017/12/02 14:06] LV (lorivonne.lustre): AF: Thank you so much everyone
This is my first presentation in a virtual world
I look forward to talking about a topic near and dear to my heart
As you heard about me in the intro... I am also an agent of change
Using a wheelchair is who I am. It has its perks as well -- parking, getting to the front of the line
This is our plan for today
Where does this desire to make a mark on the world come from? My Motto: Dream Drive Do
Mentors have helped me along the way, nurturing me
I believe we can all become change agents and researchers.
We need to push ourselves outside the norm. To ask "Who I am"
We can change the world by changing ourselves
Every dream starts with a dreamer
I was adopted at 2 months from India. When I was a baby I acquired transverse myelitis, in the US. I believe this was part of my deck of cards
I was fortunate to acquire this after coming to the US (4 months old).
I knew I was different from my siblings, or other children
As I was so young, I assumed having a disability was something I would outgrow -- a phase
Every adult I knew could walk. It made sense that I could some day too
My assumption was that in order to be a successful adult I needed to outgrow my disability
Have any of you ever felt that way about your disability? This is the burden I put upon my self
One day in preschool I was watching my classmates. I was crying in the bushes. I realized my disability was here to stay.
My preschool teacher found me.
Kudos to my Mom for fighting to get me into that preschool
The teacher explained that I could stay the rest of my life crying in the bushes OR I could learn to live my life, disability and all
The teacher met me at my level and said she would help me

Here is a picture of young me in a racing wheelchair, and a drawing of me at the Boston Marathon -- I am from Mass.

Isn't Marathon Monday a holiday everywhere? (smile)
Shortly after the incident at preschool our family was at Marathon Monday. I was bored until the wheelchairs raced by!
I discovered that racing could be my dream, and going to college!
For years my Halloween costume was as the Boston Marathon winner
I begged my parents to allow me to try wheelchair sports
This introduced me to a career in athletics and amazing opportunities
It also introduced me to the disabled community
This slide shows me at the Para-Olympics representing the US.
I finished the race at least 2 lengths ahead of my competitors
On the podium I wondered what did it take for me to get there

DRIVE -- Obstacles are opportunities in disguise
Naysayers and barriers were an aspect of my life.
A gym teacher in Grade 5 said I was a danger to the other children
My English teacher said what are you doing in an honours level class, you are never going to college
These experiences led me to sue my school district and has shaped my research

Dream Drive Do

I felt there was a responsibility as part of Team USA to encourage education and increase awareness
There is always a team behind the team
I could not do my work without the students in my lab.
And the research support I receive
In addition to the disability identity work, I also look at inclusion and inequalities
Much of my work looks at cross-cultural aspects of disability identity
I have worked with folks around the globe as collaborators and would like to work with more
Identity - the quality or beliefs that are shared and individual. Historically and culturally constructed

Disability identity -- on slide

A sense of self that includes one's disability and feelings of connection to, or in solidarity with, the disability community. A coherent disability identity is believed to help individuals adapt to disability, including navigating related social stresses and daily hassles.
If you have a circle on a page, where would you put your disability?
Is it age, how long, type? Would you answer these questions differently in-world rather than IRL?

THINK

How much is disability a part of YOUR identity?
My goal has been to ground my work solidly in disability identity
Qualitative study with 17 college students with disabilities
The model highlights four developmental statuses: acceptance, relationship, adoption and engagement

Why college students with disabilities? This group have been the first to have been covered by ADA all their lives. The ADA generation
When I looked at the early work, it was mainly done around the grassroots groups and movements that preceded ADA
Systematic literature review – 41 empirical studies on disability identity
Majority were qualitative; only 9 >100 participants
There is a great need for more rigorous large-scale studies as well as better measurement tools to assess disability identity development
Very few researchers take a broad framework
I am so thankful for the researchers who completed this work. Those with an * are empirical studies

Gill (1997): Disability Identity Development Model

Coming to feel we belong, coming home, coming together and coming out.

Gibson's (2006): Disability Identity Model

passive awareness, realization and acceptance.

*Hahn & Belt (2004): Disability Identity & Attitudes in Activists

Affirmation of disability identity, Communal attachments

*Darling & Heckert (2010): Questionnaire on Disability Identity & Opportunity

Participation and orientation. Orientation was most closely related to identity and included three dimensions: identity (pride vs. shame), model (social vs. personal) and role (activism vs. passivity)

Dunn & Burcaw (2013): Narrative Accounts of Disability

affirmation of disability, communal attachment, self-worth, pride, discrimination and personal meaning

Putnam (2005): Domains and subdomains of political disability identity

Self-worth, Common Cause, Pride, Discrimination, Policy Alternatives, Engagement in Political Action

*Forber-Pratt & Zape (2017): Model of Social & Psychosocial Disability Identity Development

Acceptance, Relationship, Adoption. Engagement

I wanted to know if my work stood up. I was not really intending to develop measurement scales of disability identity

Is there one disability culture to identity?

I believe not, however there are core values that are shared

There may be cultural and indeed in-world /IRL differences

Developed a measure: Disability Identity Development Scale (DIDS)

103 items on a Likert-type scale, ranging from 1 (Not At All Like Me) to 5 (Very Much Like Me)

Following our preliminary analyses, 31 items were kept

Example items:

- I believe there is a disability community.
- There are some days that I wish I did not have a disability.
- I seek out friends who have the same disability as me.
- If I see a stranger with ANY disability, I could care less.

- If I meet someone who discloses they have MY hidden disability, I engage with them (i.e., smile, wave, say hello).
- I give advice to parents/caregivers/spouses about disability.
- I serve on disability-related panels, boards or committees.

There are 103 items, these are a sample

The analyses are ongoing

How do these map with other models?

I believe there are 4 statuses - not stages.

Model of social & psychosocial disability identity development. Blue boxes with four status and descriptions under each with cyclical arrows.

Acceptance Status

- Become disabled and/or born with disability
- Person accepts own disability
- Close friends and family are accepting of the disability

Includes aspects of frustration (internal and emotionally); Not all individuals with disabilities exhibit positive acceptance of or embodiment of one's disability identity at all times

Relationship Status

- Person meets others like herself/himself
- Engages in conversation with these individuals
- Learns about the ways of the group

Adoption Status

- Adopts the shared values of the group
- Feeling a strong connection to the disability community

Engagement Status

- Become a role model for others
- Help those who may be in other statuses
- Give back to the disability community

Acceptance status includes frustration (both internal and emotional)

The acceptance may not always be positive and may change over time and situation

556 adults with disabilities across the US. This diagram show the gender breakdown

Snowball sampling was used

Type of disability breakdown

Visible, hidden, both

This work was validated using people across many disability communities

THINK

How has your concept of "disability identity" been shaped?

What conversations have you experienced in your life journey from when you started school as a young child to now that are related to disability?

These questions are fundamental in moving this work forward

What did other people say or do about disability?

What do YOU think about disability?

We cannot let people with disabilities fall through the cracks

They may not have a role model or someone in their family to look up to.

They need to find others and communities, IRL or in virtual worlds

Here is my contact information

Contact Info

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Image logo for Twitter handle and text @anjalfp Image logo for facebook and text: www.facebook.com/anjalfp

[2017/12/02 14:46] Gentle Heron: I recognized the name Anjali from the Mudras I do as part of my daily exercises. It is a Sanskrit (Hindi) word meaning "benediction." We certainly have been blessed by your presentation today for us, Anjali. Thank you for sharing these facets of your life and your research with us. Our community members have quite a bit of experience as both research subjects and trained research assistants. How can we convince you to think of doing research within our virtual world setting?

[2017/12/02 14:46] LV (lorivonne.lustre): AF: I look forward to more conversations with you

I would love to do that Gentle

Once we have a valid tool, we can look here in virtual worlds to see if there are differences or things we need to rethink. Perhaps focus groups

[2017/12/02 14:48] Carolyn Carillon: GH: I'd like to suggest we take a poll

Do you think there's a difference between RL & virtual world disability identity?

Type Y for yes

N for no

[2017/12/02 14:48] Frida Muircastle: yes

[2017/12/02 14:48] Stepin (stepinwolf.darkstone): Y

[2017/12/02 14:49] Jeff (jefferr): Y

[2017/12/02 14:49] Mook Wheeler: both Y and N

[2017/12/02 14:49] Pianoman (p1an0man): Y

[2017/12/02 14:49] iSkye Silverweb: N

[2017/12/02 14:49] Sister (sister.abeyante): Y

[2017/12/02 14:49] Sigsig Spot: Y

[2017/12/02 14:49] Gloriejoy (joycie.string): both

[2017/12/02 14:49] Princess Claire (clairedear): Y

[2017/12/02 14:49] Treasure Ballinger: N

[2017/12/02 14:49] Mary Bikcin (mary.peel): Y

[2017/12/02 14:49] Marloo Redd (marloored): N

[2017/12/02 14:49] JJ Drinkwater: It's complicated

[2017/12/02 14:49] LV (lorivonne.lustre): AF: I would love to investigate that further.

It would be amazing to investigate this

[2017/12/02 14:48] iSkye Silverweb: Anjali you had an interesting perspective. I am deaf and growing up I never saw any deaf adults so I just assumed that by the age of 18 I would be dead. I didn't see any point to preparing for graduating high school or going to university so I wasn't thinking about any future for myself until my dad asked me "where do you want to go for university?" and I thought, huh? What's the point?

It dawned on my parents that I was thinking this but only too late

[2017/12/02 14:50] Carolyn Carillon: GH: iSkye - I believe you've met her
She's deaf

She didn't meet any other deaf adults

So she thought by age 18 she'd be dead

So she wasn't thinking of a future for herself

Her dad asked her what university she'd like to go to

And she thought huh?

So she thought of this later in her life

[2017/12/02 14:51] iSkye Silverweb: My parents did not realise I was thinking this until later

They were horrified

But as a kid you internalise this

You don't know how to tell them

[2017/12/02 14:57] LV (lorivonne.lustre): AF: It is true (iSkye's story). There is a disability development process that parents and siblings go through that is different from Joe on the street. Parallel but not the same as the person with a disability

[2017/12/02 14:58] iSkye Silverweb: Maybe this is for deaf kids but I think it also applies to other kids with disabilities, they should not grow up isolated from other kids with disabilities

[2017/12/02 14:50] Sister (sister.abeyante): QUESTION: I am particularly interested in whether you've seen a link between cultural community and disability identity. In other words, some cultural communities see disability in different ways.

[2017/12/02 14:52] LV (lorivonne.lustre): AF: Yes Sister. We have started to look at this qualitatively

Listening to the stories

We can't make assumptions that all cultures are the same.

What are the other nuances?

In Ghana for example, disability is seen as contagious, or connected with witchcraft. Families are seen as cursed.

Personal acceptance is much harder to achieve.

The individual need education and awareness, as well as his / her culture

Acceptance started with other disabled people before the support of family and friends

We are working to include the diverse voices

Even in our work in the US

[2017/12/02 14:55] Mook Wheeler: how some cultures 'legitimise' disability as a negative thing... yeah

[2017/12/02 15:00] LV (lorivonne.lustre): AF: Yes Mook.

[2017/12/02 14:54] Gloriejoy (joycie.string): Stigma is a huge issue with many

[2017/12/02 14:56] Gentle Heron: Glorie, there is discrimination between different types of disabilities. I believe that has to stop!

[2017/12/02 14:57] Carolyn Carillon: [14:55] Jady Firehawk: I think maybe the "disability identity" has layers within it because there can be issues with the things (career, parenthood, a relationship, etc) you may construct parts of your identity around, as you lose certain "levels" of ability, in the cases where medical conditions are progressive. Or change. Any thoughts on this?

[2017/12/02 14:57] LV (lorivonne.lustre): AF: Yes, Jady. That is why there are only 41 empirical studies in this area

What we need are longitudinal studies as individuals develop over time so we can get a better picture

But we need to start somewhere

Disability in and of itself is not static. All of those pieces you mention are aspects.

When we did the THINK activity based on the circle, they may have asked to do it for each disability

[2017/12/02 15:00] Carolyn Carillon: [14:55] Sister (sister.abeyante): Nods. Thanks!
ANOTHER QUESTION: Have you had a chance to explore connections between mental health and status of disability identity?

[2017/12/02 15:00] LV (lorivonne.lustre): AF: Sister. Yes

One of the things that makes my work exciting is that I am trying to use a very inclusive model of disability

I worked closely with a broad spectrum of disabilities groups

We first of all need to know what we mean by disability, then we will look within disability groups and between groups

We can only do this if we include groups to start with

[2017/12/02 15:02] Jady Firehawk: I love that it doesn't force people into Y / N answers

[2017/12/02 15:03] LV (lorivonne.lustre): AF: Yes Jady, no one likes Y/N answers

[2017/12/02 15:06] Jady Firehawk: yes we have to start somewhere!

[2017/12/02 15:03] Carolyn Carillon: [14:57] Soy15: does it exist - a real support for these handicaps by member's family or just for persons suffers by handicap? what's most developed plz ?

[2017/12/02 15:04] LV (lorivonne.lustre): AF: It depends @Soy15. How is the person and their family defining disability. The questions used for a person with a disability are of necessity different from those use with family members

[2017/12/02 15:10] Soy15: thx for answer there

[2017/12/02 15:05] Carolyn Carillon: [14:59] iSkye Silverweb: Is a factor of the lack of these types of studies, funding?
(longitudinal ones for example)

[2017/12/02 15:05] LV (lorivonne.lustre): AF: @iSkye. Great question. I could always use more funding!

It is a hard sell. It is ironic when you look at the work with other groups
We do need more research dollars, however the research is messy. Funding agencies shy away from this
I try and explain the complexities and then say this is where we are going to focus in order to look at the broader picture

[2017/12/02 15:06] Bixyl Shuftan: A few decades ago, the pastor in my neighborhood church had a daughter whom was blind and mentally retarded. I was told he met a couple people over the years whom thought he had committed some sin and would have nothing to do with him. But most everyone he met was supportive.

[2017/12/02 15:06] Frida Muircastle: Anjali, I hope you move forward with your interest in conducting research in SL. I collaborate on research in SL with women with disabilities. The women provided very favorable feedback on participating in SL. You may want to read one of our articles: Nosek, M A, Robinson-Whelen, S, Hughes, R. B., & Nosek, TM. (2016). An internet-based virtual reality intervention for enhancing self-esteem in women with disabilities: Results of a feasibility study. *Rehabilitation Psychology*, 61(4):358-370..

I'll send you a copy!

[2017/12/02 15:09] LV (lorivonne.lustre): AF: Thank you Frida. I will definitely look it up.

I appreciate it

[2017/12/02 15:07] Carolyn Carillon: [14:59] Mook Wheeler: some Asian cultures still connect disability with religious beliefs -- ie disability is the result/effect of sin or previous generation sin/crime, and so on. This 'legitimises' the disability as something sent by natural and irresistible forces (such as God), and it legitimises a lot of cultural discrimination against the PWD

[2017/12/02 15:08] LV (lorivonne.lustre): AF: Absolutely Mook. I ask how does this affect the individual? How do you reconcile religious beliefs with how you are living your life?

[2017/12/02 15:09] Slatan Dryke: not only in the Asian culture Mook, think about the Spartans and how they were doing with disabled babies

[2017/12/02 15:10] Mook Wheeler: nods at Slatan. The Spartan culture was obsessed with 'physical' and physiological perfection in many ways, esp. within the context of warriorhood

[2017/12/02 15:10] LV (lorivonne.lustre): AF: Yes, there is a lot of history about how people with disabilities have been treated. Underlying impacts for identity

[2017/12/02 15:10] Gentle Heron: From all the kindly greeters who welcomed us into the auditorium to the introducers (and their voice assistants), the incredibly talented transcribers, our tech support, the audience who asks cogent questions, the people who will be creating the archives and posting them to our website, and of course our fabulous presenters, we've had a simply incredible conference. Lots of people work a long time behind the scenes, and I want to honor them all.

I know I'm the one who initially invites the presenters, but I am always pleasantly surprised at how well their talks fit together within the conference theme. This conference, despite tech issues, exceeded all my expectations. Thank you all for making these two days such a fantastic learning experience.

[2017/12/02 15:11] Dr. Anjali Forber-Pratt (vaipresenter8): thank you to you all!!!!
I look forward to doing more work with you too!

[2017/12/02 15:11] Slatan Dryke: transcribers rule !!! thank you LV Carolyn and Elektra for your great work !

[2017/12/02 15:11] Gloriejoy (joycie.string): this conference was a VACATION!!

[2017/12/02 15:11] Carolyn Carillon: :)

[2017/12/02 15:11] Sister (sister.abeyante): Indeed- thanks- this was terrific!

[2017/12/02 15:12] Jeff (jefferr): Thank you

[2017/12/02 15:12] Suellen Heartsong (suln.mahogany): well said Gentle

[2017/12/02 15:12] Treasure Ballinger: APPLAUSE!!!!

[2017/12/02 15:12] LV (lorivonne.lustre): <<transcription ends>>