



**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: "On Speaking and Not Speaking: Autism, Friendship, Interdependency"
Speaker: Dr. Sonya Freeman-Loftis, Morehouse College

[2017/12/02 11:04] 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.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

Elektra Panthar

Carolyn Carillon

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

SFL: Sonya Freeman-Loftis

[2017/12/02 11:05] Carolyn Carillon: <<transcription begins>>

[2017/12/02 11:05] Topper Brenham: Good morning everyone. Welcome to the International Disability Rights Affirmation Conference. My name is Topper Brenham. I'm a member of Virtual Ability and a long-time user of Second Life.

Due to a permanent spinal injury, I use Second Life to do things I can't do in the physical world, such as run or dance, or hang out with mates and chat. Second Life is a form of therapy for me.

It is my pleasure to introduce to you Dr Sonya Freeman-Loftis. Her avatar in Second Life is called Miranda Shaw.

Sonya is an associate professor at Morehouse College and the author of two books, Shakespeare's Surrogates, deriving from her passion for Shakespeare, and Imagining Autism, which is influenced by her personal experiences as an autistic.

Chapter Three of Imagining Autism received honourable mention from the Society for Disability Studies Irving K. Zola Award for "best emerging scholar in the field of disability studies".

She currently serves on the editorial review boards for the peer-reviewed journals Disability Studies Quarterly and Review of Disability Studies: An International Journal, two of only a handful of Disability Studies journals in the world.

Sonya is also a wife and mother.

Sonya's presentation today is called 'On Speaking and Not Speaking: Autism, Friendship, Interdependency'.

Sonya explores the subject of autistic voice with a collection of autobiographical fragments, and compares moments when autistic communication is recognised and understood, and when it is not.

The presentation also looks at ideological tensions between independence and interdependency, the liminality between friendship and support, and problems that may arise when one person speaks for another, or when social systems and authority figures fail to recognise autistic voices.

I would like to ask the audience to refrain from typing in Local Chat during the presentation, to reduce distraction. Please leave questions and comments to the end of the talk, thank you.

Please help me welcome Dr Sonya Freeman-Loftis!

[2017/12/02 11:08] MirandaShaw Resident: Abstract: This collection of autobiographical fragments

explores the subject of autistic voice.

Juxtaposing moments when autistic communication is recognized and understood with moments in which it isn't,

this work of creative nonfiction examines ideological tensions between independence and interdependency,

the potential lines (or lack of lines) separating friendship and support,

and some of the inevitable problems that are created when one person speaks for another.

The piece also explores the dangers that may arise when social systems and authority figures fail to recognize autistic voices.

Title: On Speaking and Not Speaking: Autism, Friendship, Interdependency

1

I am 12 years old, riding the school bus. "Where are you from?" the girl sitting next to me asks.

When I tell her that "I have lived here in town all of my life," she is amazed.

Although we have been in the same class all year, she has never heard me speak before.

She had assumed that I could not speak English.

2

I am 16 years old, having a meltdown.

All I know is that I can't communicate, that I have become chaos and entropy.

I lie on the floor of my bedroom and scream for hours.

I cover my ears so that I won't hear the sound of my own screaming.

3

I am 22 years old, working on a Ph.D. at the University of Georgia.

I can't navigate the crowded, noisy streets downtown by myself, but my friends often take me.

"Do you want sour cream?"

The restaurant is even more crowded and noisy than the perfectly unnavigable street,

the line behind me steadily building.

My friend, Jess, chews at her bottom lip, uncertain of what to do.

The majority of the time, I speak just fine.

Except when I don't.

So my friend is having a dilemma. Should she order for me?

Should she give me more time?

She would never dare to speak for another—to trample on someone else's subjectivity.

But the problem we are having is practical as well as philosophical: I do want sour cream, even if I can't ask for it.

I wish Jess would speak for me. The crowd at my back builds precariously. The silence lengthens.

4

I am 27 years old, a professor of English on my way to a professional conference. The senior shouting officer of the TSA (my friend Lisa says that the TSA in Atlanta have officers employed explicitly for shouting) is doing his best work at maximum volume.

He can't tell that I'm autistic, and he can't figure out why yelling "move to the left" isn't helping me move to the left.

Actually, I'm not moving at all: I'm standing helplessly still in a sea of moving people. I can't understand why this man is yelling at me nor understand what he is yelling about.

Lisa, hesitant to touch me, is also trying to get me to move to the left. But my body isn't doing what it's told.

"You can't separate us." Lisa is trying to stay calm in the chaos that is airport security.

"I'm her assistant. You won't be able to communicate with her without me."

"What number are you?" she asks later as we get on the plane.

No response. Long pause. "What number are you?" she types on her phone.

The ability to type, unlike the fleeting ability to speak, rarely leaves me: I type "9."

Lisa breathes deeply and calmly, while I sit beside her, my face in my hands.

On our 1-10 scale, a 10 is a full-blown meltdown.

You can't have a meltdown on a plane, I think to myself. You can't have a meltdown on a plane.

THERE IS NO PLACE TO HAVE A MELTDOWN ON A PLANE.

"Security thought you were deaf," Lisa says later, when it has passed.

5

I am pregnant, six months along.

"It won't hurt you," the doctor says in an attempt to be reassuring. I can't say anything in response.

I have yet to realize that the most complicated part of my very complicated pregnancy will be my inability to communicate with my doctors. I want to say, "I feel like I'm dying."

Later, the doctors discover that I am, in fact, dying.

So is the baby. They need to do an emergency C-section.

I can't answer basic questions—can't make any noise at all. When they cut me open, my husband says anxiously, "Shouldn't you check to see if she can feel that?"

My whole body trembles. "If she could feel that, she would be screaming right now," the doctor says confidently.

6

I am never singular, never alone. This duality confuses people.

Who is this person with her? What is this person's role?

At the Comparative Drama Conference, my friend Steph is mistaken for my lover. (“You make an adorable couple,” a conference-goer says to her during my presentation, “You must be so proud—she’s so articulate!”)

At the Modern Language Association, Lisa is mistaken for my graduate student. When Lisa explains that she is my support person, the chair of my disability studies panel asks, “So you are helping her travel? How does that work?”

At the Society for Disability Studies conference, people aren’t quite sure how to work conversationally with my support person. I am glad that people are talking to me, but I am sorry that they are ignoring my friend.

Even in disability circles, independence remains an alluring ideology. We want to regard independence as the end goal—the sign of adulthood, the mark of arrival. We want to believe that independence is possible for everyone.

I recognize the dilemma: to engage my support person in conversation may seem to overlook me in my autistic silence, may seem in some way to fail to acknowledge my disabled humanity.

But Steph is a brilliant gal. Like all of my friends who help me travel, she doesn’t get paid for her work.

My autism specialist is surprised to hear that my friends travel with me to conferences, that they have made my career possible.

She is surprised to find that they take me to doctor’s appointments and help me to get my hair cut.

She fails to recognize that our relationships are complex and symbiotic, that I also give. This makes Lisa and Steph angry.

“You have good friends,” Lisa says, “because you are a good friend.”

My autism specialist seems to assume that I am a burden rather than a friend. Sometimes I worry that she is right.

7

I am 31 years old, having a meltdown. I lie on the bathroom floor and scream. My husband lies down on the floor beside me, just far enough away so that I know he isn’t trying to touch me.

He lies there without speaking, a silent solidarity in the lines of his body. He waits. He smiles. He is patient.

In our 11 years of marriage, it is the most romantic thing that he has ever done for me.

8

I am 33 years old, and I need to have surgery. The hospital cannot decide whether to treat me as a child or as an adult.

Angry conversations are held in front of me about my legal status.

“She is an adult, and she can speak,” the ultrasound technician says, “Legally, she must speak for herself.”

But I can’t speak for myself at the moment, so I cover my ears with my hands and scream.

The hospital says that they cannot allow a support person in the recovery room.

“If she has a meltdown, I can’t guarantee that they won’t use restraints,” the hospital administrator says.

In the weeks leading up to the surgery, I lie awake in bed at night and imagine the restraints. I know that I may not be able to communicate with the nurses and that they may not look closely at my medical records.

"We should write the word AUTISM on your arm with a Sharpie," my friend Allison says.

I imagine inscribing my body with my disability label as the ultimate act of both acceptance and defiance.

The doctors give me so many anxiety drugs that I don't remember the surgery at all. In the weeks that follow, I'm so grateful that I can't remember.

But my friend Alice is angry. "There shouldn't be things you don't want to remember," she says.

I understand Alice but do not agree with her. Alice imagines a world in which the medical system accommodates and cares for people like me.

Such a world is a theoretical possibility, I know, but it isn't the one I have lived in. For my part, I am glad that the drugs have erased the sound of my screaming.

9

"What kind of ice cream do you want?"

The man behind the counter can tell that there is something "wrong" with me. My friend Ann, whom I met on the floor during circle time in Kindergarten, is sizing me up with her knowing eye: after twenty-eight years of friendship, she knows intimately what an incipient meltdown looks like.

It is too crowded in here. Much too crowded. "She wants strawberry," Ann says with false confidence.

She slams the palm of her hand down on the wooden bar in front of us. "Definitely the strawberry."

And I am glad to have the strawberry ice cream, glad that Ann hustles me into a quiet seat in a hurry, so very grateful to have had Ann to speak for me all of these years.

It is dangerous and beautiful and bittersweet, this speaking for me.

After all, if someone doesn't speak for you, you don't get any ice cream at all—but I wish I could tell her that I wanted cookies and cream.

[2017/12/02 11:20] Treasure Ballinger: APPLAUSE!!!!

So moving

[2017/12/02 11:20] James Heartsong (peacefuljames) blinks the mist in my eyes

[2017/12/02 11:20] Gloriejoy (joycie.string): Wonderful

[2017/12/02 11:19] Gentle Heron: Oh my Sonya! Your testimonies are so so moving. You have wonderful friends. Are they mostly friends you've had for a long time or are any newer relationships? If newer, can you tell us a bit about how those newer friendships developed? PS- I doubt you are a burden to your friends.

[2017/12/02 11:20] Carolyn Carillon: SFL: Ann is the oldest relationship dating back to elementary school

My mom helped cultivate that friendship

My other friends are from graduate school

It was easier because I had things in common with those students
In some ways, in grad school, I could trade academic capital for social capital
I could help people with their paper
[2017/12/02 11:21] Carolyn Carillon: GH: I found the same
And I am neurotypical
I found in grad school that it was the commonality of interests that made it possible
to make friends
[2017/12/02 11:22] Carolyn Carillon: SFL: Shared interests are important at any
stage
The problem with autistic kids is that they rarely have shared interests with their
peers

[2017/12/02 11:23] Carolyn Carillon: GH: what advice would you give people who
are neurotypical?
How can they help people who don't have neurotypical tendencies
[2017/12/02 11:23] Carolyn Carillon: SFL: Some say that invisible disabilities aren't
invisible
We're just taught not to look for them
My colleagues when I first taught noticed that I wasn't typical
Patience is important
[2017/12/02 11:24] Gloriejoy (joycie.string): and understanding
[2017/12/02 11:24] Carolyn Carillon: SFL: As my colleagues got used to my
communication style, it helped
Don't jump to conclusions

[2017/12/02 11:24] Suellen Heartsong (suln.mahogany): sometimes the sound
overload is far too much for me, even though I am not neurotypical, basing if we stay
at a location due to noise has become something that is more common.
[2017/12/02 11:25] Treasure Ballinger: Mine either
[2017/12/02 11:26] 01 (01.hifeng): I won't say hello because I don't see well so
sometimes I don't notice people -_-
[2017/12/02 11:26] Treasure Ballinger: Happens all the time. People think I am rude,
stuck up, whatever
[2017/12/02 11:26] Elektra Panthar: SFL. Yes, the problem is that the noise is too
much and by the time I'm ready to say hi the person is already gone
It puts up obstacles that shouldn't be there in connecting with others
It's hard to accommodate in the workplace
I often don't need physical ones but social ones

[2017/12/02 11:27] Carolyn Carillon: GH: Morehouse is an interesting institution
Could you tell us about what Morehouse is like?
<http://www.morehouse.edu/>
[2017/12/02 11:28] Elektra Panthar: SFL: Morehouse is a fascinating institution
The focus is on social justice for everyone, they are very active
It's a great community

[2017/12/02 11:28] James Heartsong (peacefuljames): not sure if I am "neurotypical" or not, since I have MS. But I can relate to much of these things. Sensory overload, and being unable to understand what is being said to me, since the part of my brain that understands language has been dinged by the MS lesions. But I have to say, I am .. well, deeply touched by all you have shared with us today. Thank you!

[2017/12/02 11:29] Elektra Panthar: SFL: It's been a great pleasure seeing people responding to this

[2017/12/02 11:30] Carolyn Carillon: GH: what do you find interesting about Shakespeare?

That's your thing isn't it?

[2017/12/02 11:30] Elektra Panthar: SFL : Shakespeare IS my thing!

I latched onto Shakespeare in late HS/ early college. It's so fulfilling. My students latch onto my passion for the subject matter

My hyperfocus is supposedly a disadvantage but it actually helps in this case

[2017/12/02 11:31] Carolyn Carillon: GH: What would Shakespeare say about seeing passion as a disadvantage?

[2017/12/02 11:32] Elektra Panthar: SFL: Shakespeare would disagree that it's a disadvantage because all his characters are deeply passionate

[2017/12/02 11:31] Mook Wheeler: COMMENT: hi Sonya, I have ASD and I relate to much of what you described, except for having people speak for me. I didn't have anyone to do that for me, and I didn't even know, when growing up, that that was even an option. I had to speak, in a manner, but I believe that others who heard me speak, both in a sensory and ideological context, perhaps did not hear me, or understand me, or accept what or how I said it. Much of that 'speaking' and 'voicing' therefore ended in meltdowns and screaming events. I may have 'voiced' or 'spoken', but it certainly did not get 'heard' or 'understood'. The one sure way I found to avoid this problem was to avoid speaking whenever I could, and retreat to text. Just like this. :)

[2017/12/02 11:33] Elektra Panthar: SFL: I sympathize with that experience. At one point I thought it was futile to talk , especially in HS where there's a lot of pressure to socialize

[2017/12/02 11:34] Elektra Panthar: SFL: Any other questions?

[2017/12/02 11:35] Carolyn Carillon: GH: I feel like I'm monopolizing the questions Do others have questions?

[2017/12/02 11:36] James Heartsong (peacefuljames): Do you (like me) find it any easier to watch people's lips when they speak? Somehow, that helps to get around my audio sorting issues.

[2017/12/02 11:37] Elektra Panthar: SFL: Yes, especially when there's background noise

[2017/12/02 11:38] Zombie doggie (tarquin.evermore): Peace, the hard of hearing find it better to understand people if we can watch lips and hear at the same time Or read along and listen

[2017/12/02 11:39] Suellen Heartsong (suln.mahogany): Sometimes not facing James in RL makes it difficult for us as if he is having overload at that time, he has to ask me to repeat, which is not always easy for me, but we work on that

[2017/12/02 11:34] Jadyn Firehawk: Can you say why possibly it is so much easier to communicate in text vs voice for a lot of us? it's certainly true for me
This is one reason SL has been so fantastic for me as a socializing medium

[2017/12/02 11:37] 01 (01.hifeng): no, I like socializing everywhere

[2017/12/02 11:37] Teresa (teresaprairie): Yes I socialize mostly in SL

[2017/12/02 11:36] Elektra Panthar: SFL: I'm not a neuroscientist, but the part of the brain that uses vocal speech is separated from the one that handles writing, and it makes sense to me. Not sure if this article has been disproven but it rings true to me I can see why socialising in SL can be easier, there are fewer 'interferences'

[2017/12/02 11:38] Mook Wheeler: I cannot imagine if I had been born in an age where I could not communicate through a keyboard and screen. Pen and paper, then handing the paper to someone in person, is NOT the same.

[2017/12/02 11:39] Elektra Panthar: SFL: I agree with Mook, I can't imagine how I could have completed my studies and did my job without e-mails etc

[2017/12/02 11:39] James Heartsong (peacefuljames): SL is (usually) less overloading for me. And it is much easier to get here, since I don't have to use the car.

[2017/12/02 11:40] Elektra Panthar: SFL: I have the pleasure of attending this conference without a support person. It's a wonderful and very different thing

[2017/12/02 11:39] Jadyn Firehawk: wow

[2017/12/02 11:39] Suellen Heartsong (suln.mahogany): awesome

[2017/12/02 11:40] Treasure Ballinger: Great job.

[2017/12/02 11:40] James Heartsong (peacefuljames): :)

[2017/12/02 11:40] 01 (01.hifeng): great :)

[2017/12/02 11:40] Jeff (jefferr): We are honored

[2017/12/02 11:40] James Heartsong (peacefuljames): yes

[2017/12/02 11:40] Elektra Panthar: SFL: I'm very glad Gentle asked me to come and speak

[2017/12/02 11:40] Carolyn Carillon: GH: We're glad you came to speak to us

It's a wonderful opportunity for us

Many of will never attend a professional conference

Without or with support

This is a real gift

[2017/12/02 11:41] Moose Maine: In real life the hustle and bustle tends to make everyone speaking and ability 25% more. I come from a stroke, aphasia, and epilepsy disability, I feel that Second Life makes everybody talk of 25% lessHim.

[2017/12/02 11:43] Elektra Panthar: SFL: My first experience in SL was instantly appealing because of the texting option

[2017/12/02 11:41] Elektra Panthar: SFL: This is the first conference with a waterfall in the auditorium which is awesome!

