Virtual Ability, Inc.® presents the 6th Annual
International Disability Rights Affirmation Conference
December 1 and 2, 2017
in Second Life at
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Title: "Stories from young women with intellectual disability: Meanings of gender and disability"
Speaker: Dr. Amie O'Shea, Deakin University, Australia

[2017/12/01 13:59] 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:
AO: Amie O'Shea

[2017/12/01 14:02] P1an0man Resident: Hello, first of all, welcome to the annual International Disability Rights Affirmation Conference.
I am glad to be here today as an introducer of our next honored guest and presenter.
To share a little bit about myself. Here in Second Life, I go by the name of Pianoman. I have been in Second Life for 5 years.
I am a builder, sailing and boating enthusiast and the resident trivia host at Cape Heron where I host trivia for our members the first Monday of each month at The Nest at Cape Heron, VAI's residential sim.
In real life, I am from Kentucky, and am a pianist of over 35 years and work in marketing as a freelance graphic designer. I am proud to be a member of this wonderful group here at Virtual Ability.
It is my privilege to introduce our next speaker, Dr. Amie O'Shea.
Dr. O'Shea holds a PhD in Disability Studies from La Trobe University Melbourne, Australia and is currently a Research Fellow at Deakin University in Burwood.
She also holds a certification as an Auslan-English Interpreter from the National Accreditation Authority for Translators and Interpreters.
Dr. O'Shea's presentation is titled "Stories from young women with intellectual disability: Meanings of gender and disability". This was the focus of her doctoral thesis published in October, 2016.
As a reminder, please refrain from typing in nearby chat during the presentation. Please save all messages and questions until the Q&A period at the end.
And with that, please give a warm welcome to Dr. Amie O'Shea.
Thank you.

[2017/12/01 14:05] LV (lorivonne.lustre): <<transcription begins>>

[2017/12/01 14:05] LV (lorivonne.lustre): AO: Can you hear me?
This is my first time in Second Life.
Thank you for finding out about me. I am pleased to be here
I am a researcher. My interests in particular are in sexuality and relationships. And intellectual disability. People who have a cognitive impairment.
I am also interested in methods for meaningful participation

What does this mean for people with intellectual disabilities or other marginalized groups
Breaking the tradition of not having a voice
I am at my house on a Saturday morning. I have 2 children who may put in an appearance
Let me tell you about my research
I worked with young women from 18-30 with an intellectual disability. They did not necessarily agree with the definition,
The women took images of their lives to help tell their stories

I used Foucault. Underpinning what I mean about social story
This richness has not been present for people with intellectual disabilities before
Using Foucault to move towards a more textured understanding of women's lives. It allows for the possibility that there can be multiple truths, multiple meanings and that these can be transformed and negotiated.
Foucault: power is relational, situated and available to all. Where there is power there is resistance – this prompted me to look for ways of gathering and identifying both power and resistance in the women's stories of their lives.
I looked at this with relationship to disability and gender

[2017/12/01 14:15] Gentle Heron: Information on Foucault's ideas on power-
https://www.cla.purdue.edu/english/theory/newhistoricism/modules/foucaultpower.html

[2017/12/01 14:15] LV (lorivonne.lustre): AO: Let's think about what we know about disability
There is the idea that medicine is not only true, but a greater truth
Very few of the things about intellectual disability are positive. It is defined by lack
An inherently 'bad' thing
Medicine, psychology, education --- these work together in very strong ways to define someone who is intellectually disabled.
Think about this... have you ever heard of someone becoming not intellectually disabled?
I wanted to hear what the women had to say

Biomedicine (Foucault) : the field in which biopower operates. Biopower is literally power over the body, the processes and means of management of a population including its illnesses, which he described as "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations"

Can we imagine being cured of Down Syndrome or un-cerebral palsied? Can you?

Mandy Stewart spoke about having Cerebral Palsy. She described some of what it meant for her, using medical terms and descriptions, with a story she clearly knows well. She focused on the physical aspects and did not speak about intellectual disability – this is also reported frequently in similar literature, I would suggest because discourses of physical disability may be seen as less stigmatising than intellectual disability, which if there was a hierarchy of disability, would be closer to the bottom. The result was that her status as a disabled subject is made visible, embodied and unquestionable, and she cannot 'pass' as 'normal'.

These are the first things Mandy said.
On slide: “I was born in the [local] hospital. Everything was fine through my Mum’s pregnancy, until the day of my birth. Because they knew that I was a twin sister, the youngest. But at that stage they found out my sister was stillborn. And I was perfectly fine until she was born because I was deprived of my oxygen after I was born for at least 22 minutes which is what caused my CP.
And to make it even worse, my hand and arm, my right and left arm were caught up in my back so it was causing more drama trying to find out where the body parts are. It was actually in my skin, so they had to cut the skin out. Which is what caused the CP and the scoliosis because the pressure on my hand and taking it out of my back has made it twist around all the body parts. ...
So I spent at least two years in the hospital. Didn’t come home, the whole time. Third day of my birth they moved me up to the [tertiary hospital] and ever since I was born I’ve been going up there.”

You can see how Mandy has situated her story within the hospital and medicalized terms
"the body parts" "the skin"
So what? I say this demonstrates how discursively strong these truths are.
If you have disability, you cannot go to non-disability
Mandy found a way. "there might be nothing wrong with you now, but there might be later on"
Mandy says she was perfectly fine until she was born.
"There but for the grace of God go I"
Mandy's resistance unsettles the idea that YOUR non-disability state is fragile. The space between disability and non-disability is decreased

How did the women talk about Gender, Relationships, Sexuality, Appearance, Motherhood?
I am going to talk about motherhood. You noticed that my motherhood status was one of the first things I told you about me
This is very fragile for these women. It is very common for the children of women with intellectual disabilities to be frequently removed.
Here is Bimbo's story (she chose the nickname)
“Me and my husband were both going to court, we had a solicitor each. I was breastfeeding, and if I didn’t express I got sore breasts and then I got mastitis. We were trying to fight and fight, but we never won it. They won it and they put her into a foster home. She was only about four weeks old. It was very hard for me, very upsetting. It was so bad.
I could’ve kept her. I would’ve had to live apart [from my husband Chris], and I could’ve kept her. Like: “leave your husband and keep your daughter”, is very hard. I knew if I kept Chris, I knew she would go.”
She was told that she could not both keep her child and remain with her husband.
It could be that she did not want to raise her daughter alone, or that she did not understand the courts.
More from Bimbo: … a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity (Foucault, 1980, p81)

“She calls us ‘Mum’ and ‘Dad’ and she calls them that too. One day she’ll have to stop calling them ‘Mum’ and ‘Dad’ though ‘cos really that’s our names”
“I am really trying again for another one. I’m trying to work out things to get my body to work properly. ... [Child Protection Services] will be involved, I know that. But they should be happy at the moment; I haven’t had one for a good seven years.”

Using Foucault allows the exploration of such ways of knowing, rather than their dismissal as ‘denial’, ‘misunderstanding’ or ‘confusion’ – commonly and easily associated with intellectual disability.
It is really easy to read Mandy's story and say she is in denial. It is also easy to say Bimbo must be a bad mother if her child was taken away.
I met with Bimbo 7 times, and she always called Suzie's foster parents "the carers". She was Mum.
She maintained multiple truths and kept open the idea of being a future mother.

Contact information: Amie O’Shea
Research Fellow, Disability & Inclusion
Deakin University, Melbourne, Australia
amie.oshea@deakin.edu.au

I am happy for you to contact me and continue the discussion
Many elements of the women’s stories may be familiar to you from your own experience or work alongside women with disability. What the analysis opened up for me was a powerful paradigm shift around how stories can be heard, understood and responded to, on important matters of gender and disability.
Does anyone have any comments? Questions?

[2017/12/01 14:38] Gentle Heron: Wow Amie, we definitely need to invite you back to tell us more about your research. The previous speaker got us thinking about empowerment. You certainly see Mandy and the others as empowered, and you showed us how you saw that in the stories they told you. How much do you think that your paying attention to their thoughts, that you “heard” them and respected them, how much did that add to their empowerment?
[2017/12/01 14:40] Carolyn Carillon: AO: How powerful is it to sit down with someone who will listen to what we have to say?
It's rare in disability practice and research
That was an important part of my research
I met with each woman 7 times
I didn't take notes
There were no set questions
I just facilitated a conversation
I had to value all their stories
Whether that was about a football team or the more powerful stories about their experience
What attracted me in speaking to you today

Is that this is a democratic space
You're empowering me to share these stories
[2017/12/01 14:43] LV (lorivonne.lustre): GH: that is very powerful. You have empowered our audience to listen and think about what you have said. And you are empowered to share with us

[2017/12/01 14:43] LV (lorivonne.lustre): [14:42] Aℓυмηια Aυтυмη (alumnia): May I ask, were you using any specific listening skills? (like active listening - counselors)
[2017/12/01 14:43] Carolyn Carillon: AO: great question
When I met with the women, I tried to make it as un-interview-like as possible
I didn't have questions or technology
But we did have the cameras that the women had been given
One of the comments I got is
Why would you give the women a camera?
They'll just forget to bring it to the interview
Only once did that happen
We'd often sit beside each other & look at the photos
Other times, interviews happened in cafes
One woman wanted to do the interview at her house
Another time, we sat in my car
Sometimes it was about eye contact
Sometimes it was about looking at the screen of the camera
That's supposed to be good advice
For parents
If you talk to them in the car
It takes the pressure off
Because you don't have to look at each other
[2017/12/01 14:46] LV (lorivonne.lustre): [14:45] Aℓυмηια Aυтυмη (alumnia): Oh so you give them a tool to define their own narrative?
I meant with the camera
[2017/12/01 14:46] Carolyn Carillon: AO: Absolutely
In my example, photographs were the beginning of that tool
I didn't come in with any particular agenda or interests
I'm interested in sexuality and relationships
but I didn't drive the conversation in that direction
That dictates a narrative
I had to sit back and just listen
The other thing was the physical production in those stories
People came away with something
We think people with intellectual disabilities have all the time in the world
Not true
Our work together was structured around the production of these stories
We spent time looking at the layout of the stories on my computer
The women would put stories beside the pictures they'd taken

Or they'd search for photos online
Another girl spent ages looking at the font
She chose a font that was bright pink and bold
Every word was double underlined
It was incredibly powerful to produce something and double underline the whole thing
So that was an important way to capture the narrative
[2017/12/01 14:49] iSkye Silverweb: She was given the ability to express in her own words and own way
[2017/12/01 14:50] Carolyn Carillon: AO: That's what I was going for
[2017/12/01 14:50] Aℓυмηια Aυтυмη (alumnia): #InclusivityAtBest
[2017/12/01 14:51] Gentle Heron: If you are still in touch with the women, please thank them from us as well
[2017/12/01 14:52] iSkye Silverweb: Yes, please thank them for letting you share their stories with us

[2017/12/01 14:50] Mook Wheeler: COMMENT: Your presentation correlates directly with Peg's talk on empowerment. Foucault's idea about where there's power, there's resistance, is all about adapting the situation so that you can 'profit' or 'gain' from it, so for instance when the historical French peasants were told that they could not speak in church, they got around that problem by singing instead. Sometimes this resistance does not appear as resistance. All power and resistance comes from context. What works in one context may not in another. Your presence with your 6 subjects actually encouraged them to acquire a sense of resistance, because they were encouraged to talk and discuss and re-situate their memories and what they *thought* about those memories -- re-curate them, as it were. Their voices were noted and captured. You made it possible for them to create a NEW space, a new memory, to look at their future trajectory. You had a direct hand in any expression of their resistance. :)
[2017/12/01 14:52] Carolyn Carillon: AO: what a great example about not speaking in church
[2017/12/01 14:52] iSkye Silverweb: hehheh when told not to talk in church... a friend and I resorted to signing to each other
I think there is still a very long way to go, but Amie what you did was give these women their voices
[2017/12/01 14:52] Carolyn Carillon: AO: I don't think it's about me discovering stories
There can be multiple truths
We don't have to set up stories as competing truths
[2017/12/01 14:56] Mook Wheeler: sometimes as researchers, we have to be careful about 'selecting' the type of 'truth' amongst the multiple truths you pointed out.... it's very much the anthropologist in the field affecting the outcome, in one way
[2017/12/01 14:56] Carolyn Carillon: AO: yes Mook
My work isn't meant to be objective
We can never pretend an objectivity
It's about the people who are there in the relationship that ensues
We acknowledge it
I wrote my thesis in the first person
I didn't situate myself within anthropology

But the ability of a researcher to reflect on themselves is essential
[2017/12/01 14:57] Aℓυмηια Aυтυмη (alumnia): It can as well be an issue of the anthropologist themselves having a form of disability
It can be challenging 1. getting the task of doing the research 2. then the judgment of the collected data

[2017/12/01 14:46] Pianoman (p1an0man): There's a viewpoint also, and let's use folks with Downs Syndrome as an example. That just having Downs is viewed as that person as intellectually disabled and automatically not able understand the world around them, without taking into consideration that there are high functioning people with Downs who are capable as leading a normal productive live just as those without disability, even parenthood.
[2017/12/01 14:52] Carolyn Carillon: AO: There were things that happened to people with disabilities that happened a hundred years ago
That horrify us
We don't leave babies on mountaintops
But have we really moved that far away?
People's ability to exercise their reproductive rights is still managed
I wonder how far we are from eugenics
There was a case in maybe NY
Of a deaf lesbian couple who wanted to use a donor who was also deaf
And the IVF clinics refused to treat them
Because they'd produce a baby that may be deaf
And the couple said "Well, YEAH!"
Maybe we're not far beyond those ideas
[2017/12/01 14:53] Aℓυмηια Aυтυмη (alumnia): I just learned today in history of clinical psychology of sterilisation and "wiping out" the disabled population in 2nd WW Germany
And now you said what is happening with forcing sterilization- I yelled irl
l[2017/12/01 14:54] Cora Heslop: When talking about sterilizing the disabled....yes, that's a bad thing. When using 'reproductive rights" to make sure disabled and nondisabled alike are never born....it is different
[2017/12/01 14:54] iSkye Silverweb: Eugenics, that's a four letter word among the Deaf community as well
So I guess you are right, Amie, we're not that far advanced in our view of full rights for individuals
I know about that case
Who really has the right or authority to decide what 'normal' is

[2017/12/01 14:57] Carolyn Carillon: AO: My thesis is available for download
If you're having trouble falling asleep, I can give you a recommendation!
[2017/12/01 14:58] Aℓυмηια Aυтυмη (alumnia): I am sure it is fascinating, not sleep story material :D
[2017/12/01 14:58] iSkye Silverweb: agree with alumnia on that one!
[2017/12/01 14:58] LV (lorivonne.lustre): GH: could you post the URL please
[2017/12/01 14:58] Carolyn Carillon: AO: I'll go find the link & post it for you

Feel free to send me an email
I don't want to go over time
[2017/12/01 14:58] Gentle Heron: Thank you again Amie for putting in the effort to come into our brave new world to chat with us today.
[2017/12/01 14:59] Carolyn Carillon: AO: I'm proud of myself!
I've learned something new today
Thank you so much everyone!
[2017/12/01 14:58] Slatan Dryke: brilliant Amie !!!!
[2017/12/01 14:58] Mook Wheeler: thank you very much, Amie :))
[2017/12/01 14:59] James Heartsong (peacefuljames): ☆Applause☆
[2017/12/01 14:59] Aℓυмηια Aυтυмη (alumnia) applauds
[2017/12/01 14:59] iSkye Silverweb: Thank you soooo much for coming, Amie!
[2017/12/01 14:59] Eme Capalini: Great job Amie!
[2017/12/01 14:59] LV (lorivonne.lustre): <<transcription ends>>