

# 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®

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Speaker: Professor Theresa Lorenzo and Siphokazi Sompeta

Title: "Creating Inclusive Communities: The Role of Community Disability Practitioners in Africa"

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[09:28 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:

Carolyn Carillon

LoriVonne Lustre

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

TL = Theresa Lorenzo / Fish Eagle

SS = Siphokazi Sompeta / Vulithongo

[09:30 AM] Franja Russell: Hello, I'm Franja Russell in SL, Frances Jaekle in RL.

I'm a retired Elementary School Teacher--38 years experience.

My life-long love of Science Fiction brought me to Second Life's Portal to Sci-fi & Fantasy. A year later I became the Portal Leader.

We held monthly discussions on written, audio, and filmed Sci-fi and Fantasy.

Every month, real life authors came to talk about their writing.

Inside The Portal you found two floors of interactive information and displays.

I retired from the Portal about 5 years ago. Now I enjoy various SL events and places.

It's a delight to be with you today to introduce Theresa Lorenzo and Siphokazi Sompeta.

Professor Theresa Lorenzo is an occupational therapist and PhD Programme Convenor in the Division of Disability Studies, Dept. of Health and Rehabilitation Sciences, Faculty of Health Sciences at the University of Cape Town, South Africa.

She has extensive experience in developing a transdisciplinary community-based workforce to implement and monitor disability-inclusive development.

The focus is on youth and women.

Her Second Life name is Fish Eagle.

Siphokazi Sompeta is an occupational therapist in the Division of Disability Studies, Dept. of Health Sciences at the University of Cape Town.

She's the former Chairperson of the Community-based Rehabilitation Africa Network advocating for inclusive development programs, focusing on rural communities.

Her research explores chronic poverty of disabled persons in rural areas and training of community rehabilitation workers.

Her Second Life name is Vulithongo, which means Dream Opener.

Theresa and Siphokazi will speak about people with disabilities, their families, the stigma and social exclusion they experience, especially in poorly serviced rural communities.

Addressing their needs requires community-based disability workers (CDWs) highly trained in all phases of improving the lives of disabled people there.

Their academic paper develops three main themes---Integrated management of health and impairments within families. Negotiating for disability-inclusive community development.

Coordinated and efficient intersectoral management systems.

Please welcome Professor Theresa Lorenzo and Siphokazi Sompeta.

[09:35 AM] LV (lorivonne.lustre): <transcription begins>

TL = Theresa Lorenzo / Fish Eagle

SS = Siphokazi Sompeta / Vulithongo

[09:35 AM] Carolyn Carillon: TL: Thanks

It's great to be speaking to you from Cape Town

[09:35 AM] LV (lorivonne.lustre): SS: Good day everyone

It is good to be here. Thanks for the opportunity

[09:35 AM] Carolyn Carillon: TL: I want to thank Gentle for finding the paper we presented in Malaysia in September this year

[09:36 AM] LV (lorivonne.lustre): SS: Community Disability Workers - CDWs

[09:36 AM] Carolyn Carillon: TL: Our paper looks at how the community disability workers in 3 countries within southern Africa addressed the needs of disabled person & how they work across the traditional professions

This paper explores the activities and strategies that improve the lives and inclusion of people with disabilities

Within their own communities

These competencies should be strengthened

We were fortunate to have post grad students from the 3 countries

We used a qualitative interpretative approach

They interviewed the community workers in their countries

To explore their experiences

Each spoke to 4 workers

who had 5 - 20 yrs experience working in rural communities

The analysis was done as a group

We looked at main themes

Starting on the first slide

We looked at the barriers that stopped people from participating in everyday life

CBR is not an alternative system separate from primary health care but is envisioned as an integral component of the Alma Ata Declaration that ensures the particular needs of persons with disabilities are addressed through capacitating community based workers with competencies in alleviating consequences of impairments

We sought to break silos in service delivery

And address the needs of disabled persons holistically

[09:40 AM] LV (lorivonne.lustre): SS: Theme 1 focused on language

3. Language for social interactions

A major barrier is inadequate access to information about available services and activities (DYESL and DYRA)

When information is available, it is often not accessible to those with sensory impairments related to vision and hearing, or those with intellectual disability.

This slide shows an example of how a CDW helped to connect with a boy who used sign language

Once he became more proficient his condition improved

4. Mental well-being through building relationship

CDW intervention also involves the ability to build and restore relationships through informing neighbours and family about conditions.

Another success story involved a mother who had a psycho-social impairment. She was not taking her medication and was argumentative with neighbours who intended to report the matter to the police. The CDW managed the tensions as she brokered relationships and provided support for compliance in accessing treatment:

Those examples show how social interactions can be improved through interventions

#### 5. Mobilising village networks

A CDW facilitated interaction between a village headman and mothers of disabled children to form a supportive network:

Why were people hiding? Because they felt discriminated against, supportive networks helped to overcome this

#### 6. Connecting sectors

The CDWs felt they fulfilled a critical role in intersectoral referrals and the provision of assistive devices:

In many instances they themselves made devices from appropriate paper technology or ensured that individuals accessed their medication.

If a child wants to go to school, they need to have the supports they need -- assistive technologies, wheelchairs, etc

Theme 2 looks at economic activity

#### 7. Generating economic activity

Fostering disability-inclusive community development also necessitates competencies in negotiating transitions through the educational system and inclusion in livelihood opportunities.

As part of efforts to promote participation in the economy, the CDWs work involves organising people to work together, to write proposals for funding, seed money or equipment needed for a business venture, to write adverts for local newspapers and to market to potential customers.

A CDW felt the effort put into mobilising these resources was worthwhile as the persons with disabilities became economically independent:

Community connections help people to find meaningful and dignified work

They do not need to beg, they can work for themselves

[09:49 AM] Carolyn Carillon: TL: This showed how people help each other and how the development worker can bring in economic activity to support the productivity of disabled persons

Advocating for local public transportation

Advocacy requires practical skills to facilitate a change in attitudes that enables greater access for participation. CDWs demonstrated the competence to do simulation activities such as getting taxi drivers to be passengers so as to raise their awareness of disability:

Community workers advocate for local transportation

Taxi drivers were trained

to change their attitudes

They did simulation activities

So the community worker said we made sure that taxi drivers

If they wanted to stop in the streets

We'd stop for a distance

So they'd feel the pain

And helped them see what it does to not stop where someone expected  
It raised awareness  
And helped them know the role they played  
In South Africa, the students studying various therapies have service learning placements in rural hospitals  
It's an ideal time to expose students to life in a rural area  
The community workers raise awareness  
And create opportunities for the students to learn about service delivery in resource Poor communities  
The community worker learned a lot about the different therapies  
They could go into school & did recruitment drives  
To help people learn how to apply and get bursaries for higher education  
Another critical area is the collaboration that happens across sectors  
To look at environmental sustainability  
Community workers feel they're multiskilled  
They're often the people who connect different govt departments  
Before persons with disabilities couldn't stand up for their rights  
But now they do

[09:54 AM] LV (lorivonne.lustre): SS: The key issue was related to collective leadership and management

Because of others

11. Collective leadership and management

The sentiment that inclusive development “is not a one-man operation” requires deep consideration by many resource managers and planners

Leaders and managers need to recognise the meaningful contribution CDWs make to the families of persons with disabilities and the communities in which they live, not just the individual.

Collectiveness is so important

Competence in project management is critical as fundraising and proposal writing were identified as essential skills for sustainability of projects and initiatives at a community level  
CDWs may work where there is not professional support, so the community support is so important

Families are key -- they are the first point of call for service

Sometimes we forget that

Fund raising and advocacy are important

12. Career pathways for inclusive development

Human managers need to consider how career pathways are developed across the different sectors for such specialised practitioners to gain the necessary professional recognition.

Information systems development as to how to include the social and environmental aspects of disability.

Disability Information, Management and Communication Systems course at NQF 5 and monitoring disability in society at NQF 8

CDWs are specialized practitioners and deserve professional recognition

[10:01 AM] Carolyn Carillon: TL: I want to explain that the community workers only have short term training  
They don't have a degree  
So it's important to engage universities that have degree programs  
Because the workers' competencies influence the curriculum of these programs  
The workers don't replace therapists but enhance  
The approach is aligned with the goals and principles of the UN Convention on Rights of Persons with Disabilities (UNCRPD) so it will contribute to the achievement of disability inclusion in the UN SDGs  
So if the strategies are followed, we'll achieve inclusion  
We hope these stories have conveyed that disabled persons are able to contribute equally if they have the opportunity, if they have the resources  
This is done through raising awareness  
And in recognizing the community development worker as a critical part  
I'd like to say thanks to the post grad students who collected the data  
And the workers in the 3 countries who shared their experiences  
We had staff  
and funding to enable the research  
Questions?

[10:04 AM] Gentle Heron: Thank you both!  
QUESTION: What a great idea to do simulations to raise awareness, like with the taxi drivers.  
What other ideas have worked, similar to that one?

[10:04 AM] Carolyn Carillon: TL: They work on covering all the impairment groups  
shop keepers as well  
They simulate communication impairments

They have something in their mouths like marshmallows

[10:05 AM] LV (lorivonne.lustre): SS: We did simulations with students too, for example,  
how do you wipe a tear with dignity

[10:06 AM] Carolyn Carillon: TL: They are also taught to put on headphones  
& try to have interactions with others  
To simulate what it's like to have schizophrenia

Still needing to interact & how that feels

[10:07 AM] LV (lorivonne.lustre): SS: Also, wearing shoes that do not fit and see what that is  
like for mobility impairments and the discomfort of wearing shoes that are not yours  
UC Irvine simulation

[10:06 AM] Vulcan Viper remembers an experience in SL where we also heard voices.

[10:07 AM] Gentle Heron: NOTE: There is a schizophrenia simulation scene in Second Life.  
It's quite scary! (what Vulcan said)

[10:07 AM] Carolyn Carillon: TL: That would be good for us to use with students  
because it's hard to simulate those impairments

[10:08 AM] Gentle Heron: QUESTION: I was surprised that you are both occupational therapists. I would have expected such an integrated approach from social workers. Perhaps this is different in South Africa. At the professional level, do you work mainly with other

professional occupational therapists, or do you find colleagues from other medical professions like nurses or social workers?

[10:09 AM] LV (lorivonne.lustre): SS: Department of Health and Sciences so we work across disciplines with colleagues to promote health, disability, and inclusion goals

Not just 1 person

[10:10 AM] Carolyn Carillon: TL: Within the rural communities the need for a community worker who has integrated skills to address mobility, mental health & sensory impairments was critical

Because there aren't enough therapists

Until recently, the therapists were mostly white

If they were working in rural communities, they didn't know the local languages

That's changed

But there's still a shortage of therapists with the 4 year training, masters & PhDs

Someone to address the screening, etc.

There needed to be a good referral system

So there'd be a continuity of care

If someone needed additional services, the community worker could refer

Those pathways have strengthened

[10:13 AM] LV (lorivonne.lustre): SS: It is very difficult to work in a rural area. Timely continuity of care is a problem. There may not even be a telephone if someone has a health crisis, even cell phones do not have full coverage.

The development of consciousness and awareness as illustrated by this project has been very important

[10:13 AM] iSkye Silverweb: QUESTION: A lot of Deaf people are isolated because their primary language is Sign Language, and others around them do not know that language - there is a lot of pressure here to get deaf people wearing cochlear implants (very expensive) or hearing aids (also expensive) and get them talking, so they can be 'included' but this approach often fails. I was pleased to see that someone reached out to that Deaf boy in HIS language, to communicate with him. That opens floodgates of connection for Deaf people. I am curious how large the population of Deaf and hard of hearing people is in South Africa and how available are supports for them in the areas of communication and education, employment opportunities? Are they even aware of each other and working with each other to become successful and independent, also active in their communities? (sorry, big question, I know)

[10:15 AM] Carolyn Carillon: TL: That's a great question

There are even fewer speech therapists and audiologists

So it's a situation we needed to address

At first the deaf community didn't want to identify themselves as disabled

But since 1994, people have realized they gain access to resources if they self identify

Because of implants and hearing aids that are not accessible to most people

They'd gain by being part of the disability rights movement

Community workers built relationships

By helping people in the family communicate with each other

[10:17 AM] iSkye Silverweb: (we don't like to identify ourselves as 'disabled' here, either - it's a label put on us and we just live with it in order to get the language access we need)

[10:17 AM] Carolyn Carillon: TL: A lot has been done to help those communities.

Sign language is being advocated to being identified as a language  
There's a push to have sign language interpreters available at conferences  
We're training interpreters at university  
And getting people qualified  
It's a challenge for occupational therapists  
Because our training does not include sign language  
One of the audiologists in our dept has made us aware  
That if a child has disabilities, the occupational therapist is limited in what they can do  
It needs to come into our curriculum  
Because it's so key

[10:19 AM] iSkye Silverweb: Yes! I agree!

[10:19 AM] Carolyn Carillon: TL: We're challenged in that area

And we need to recognize that

Because people are marginalized

[10:20 AM] LV (lorivonne.lustre): SS: It has been an area that we can improve upon  
Deaf people have been isolated

[10:20 AM] iSkye Silverweb: It is so heartening to see you say this and recognise it

[10:20 AM] LV (lorivonne.lustre): SS: Cultural stereotypes are being challenged

[10:21 AM] iSkye Silverweb: Here in the US the Deaf community say that we are a 'linguistic minority'

[10:21 AM] Carolyn Carillon: TL: In terms of the prevalence  
of the hard of hearing

It's about 4% of the population

Who continue to post secondary education

Apps have improved the ability of the hearing world to interact with them

[10:22 AM] Gentle Heron: [10:14] Franja Russell: Is there a widely-available system of computers that connect to medical sites, medical institutions, schools, Doctors, Nurses, Community Centers, Schools, any place close enough for rural people to get to? Internet connections, through computers and cell phones could be a huge help.

[10:23 AM] Carolyn Carillon: TL: I think we're taking baby steps

In terms of medical doctors

Connected to rural areas

It is far better than the rehabilitation services

It's something that the National Institute for the Deaf

They've started a virtual interpretation centre

To train people to sit in a call center

Who have video cameras

So if the person goes to a doctor

If they have a smart phone or iPad

They could phone in to the center at the institute

And the person could interpret for them

A few years ago, anthropologists picked up that doctors were not able to interact

So they started training interpreters who could be employed within clinics

Just making medical students aware of the need

Of patients

Who sometimes get lost



Because of people not realizing they can't hear  
They miss out on the queue  
It's an area that can be exploited a lot more  
We just need the resources

[10:25 AM] iSkye Silverweb: This is so great to know, there is progress being made

[10:25 AM] Franja Russell: Thank you Theresa and Siphokazi, you've accomplished SO much!

[10:25 AM] Gentle Heron: QUESTION: How are the CDWs paid? It sounds like such a critical role in so many ways!

[10:26 AM] LV (lorivonne.lustre): SS: Now that's a good question.

[10:25 AM] Carolyn Carillon: TL: We started training community workers in rural areas  
Who were paid through the university

She had negotiated with the Dept of Health to employ them

Fortunately because the skills were integrated

People who were trained were mainly funded by NGOs

There's a pilot for a one-year training program

Subsequent training has been paid by the individual themselves or the organization they work for

[10:28 AM] LV (lorivonne.lustre): SS: It varies... if you are in an urban area you are paid better. In rural areas you may not even get transportation costs.

It is not fair

They do not get the remuneration they deserve

In the rural areas there may be no formal training. This needs to be improved

[10:29 AM] Carolyn Carillon: TL: I could add that it's been interesting in the last year with the 2nd intake

Private hospitals have employed the community workers

There's been a recognition to have the community workers trained

We are working on the Dept of Health to have the people integrated into the public health system as well

[10:29 AM] Gentle Heron: What is the push back?

[10:30 AM] Carolyn Carillon: TL: There's a huge worry that they will be seen as cheaper and more cost effective

Therapists worry they'll lose their jobs

The same is experienced by home based caretakers

They often have to take money out of their own pockets to pay for a family's food or simple things like soap

There's a huge emotional cost

Even if you have professionals working in rural areas, we don't stay there 24/7

We have some reprieve

from those constant needs

Community workers are seen as being available all the time

Because they're able to connect people to different resources

And there's potential exploitation

Because most of the workers are women

Their transport is limited

People are walking

Sometimes long distances

[10:32 AM] LV (lorivonne.lustre): SS: In rural communities women have great transportation problems

There is a physical and emotional cost - very heavy for the women

[10:34 AM] Carolyn Carillon: TL: Thanks for giving us the opportunity to share our experiences in this new format

We were really well supported

We're looking at sports, recreation & culture can be used for children to develop skills & become more part of their communities

We'll be able to share more in a few months

[10:34 AM] Gentle Heron: We have art therapy here in SL

[10:35 AM] LV (lorivonne.lustre): SS: Thank you for providing us with this opportunity It has been hard to just sit.. I want to run and play and fly here

[10:36 AM] iSkye Silverweb: Come and run, play and fly with us in VAI!

[10:35 AM] iSkye Silverweb: Thank you so much Fish Eagle and Vulithongo, for coming and sharing about your communities. I hope we can have you back to visit and talk further about your work.

[10:36 AM] Svea Morane: Thank you very much for sharing your passion, for providing services for so many people, and telling us about your work.

[10:37 AM] Franja Russell: So very much heartfelt thanks to both of you for your efforts and accomplishments. May you experience so much good luck in your work. To you personally--- good health and happiness with family and friends.

[10:34 AM] Gentle Heron: Thank you both so much for being willing to present in a virtual world. What a wonderful program! It sounds like it could work in my rural area of the US too. So glad we can learn about these ideas from you across the ocean. It would be nice for the audience to tell where we are all from.

[10:36 AM] Gloriejoy (joycie.string): US

[10:36 AM] Sage (sageclearwick): Los Angeles area, CA

[10:36 AM] Gentle Heron: I'm from the US

[10:36 AM] Mook (mook.wheeler): living in Liverpool, UK

[10:36 AM] Eme Capalini: Austin, Tx

[10:36 AM] Ruby Vandyke: Vancouver BC

[10:36 AM] Vulcan Viper: I'm from The Netherlands.

[10:36 AM] Leandra Kohnke: Alonsa Manitoba central Canada

[10:36 AM] iSkye Silverweb: I am near Green Bay, Wisconsin, USA

[10:36 AM] Pianoman (p1an0man): Louisville, KY

[10:36 AM] Franja Russell: Franja--San Francisco, California, USA

[10:36 AM] WCD1002: Blackpool England

[10:36 AM] Carolyn Carillon: me as Carolyn .... Wolfville, NS in Canada

[10:36 AM] Svea Morane: Midwest USA

[10:36 AM] LV (lorivonne.lustre): LoriVonne -- Nova Scotia Canada

[10:37 AM] Gentle Heron: Did you feel "with" us?

[10:37 AM] Carolyn Carillon: TL: Yes I did feel that

[10:37 AM] LV (lorivonne.lustre): SS: Initially I was uncertain, but now I feel that I am here with you

[10:38 AM] Carolyn Carillon: TL: Thank you very much & we'll pick up on the virtual world around schizophrenia with you.

Take care everybody

[10:38 AM] LV (lorivonne.lustre): <transcription ends>