Breakout Session 1: Health and access to healthcare during COVID-19

16th March 2022

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International Centre
for Evidence in Disability

PENDA
PEOPLE | KNOWLEDGE | TOOLS

covid collective

Breakout Session 1: Socioeconomic impact of COVID-19

Chair: Hannah Kuper	
Jill Hanass-Hancock	**Young Women with and without Disabilities' Sexual and Reproductive Health and Rights during COVID-19 in South Africa: Experiences from the Field**
Tracey Smythe	**Toward disability-inclusive health in Zimbabwe: A qualitative study on the national response to Covid-19**
Atul Jaiswal	**Is Patient-centred communication a promising solution for equitable healthcare for older adults with dual sensory loss during the COVID-19 pandemic?**
Niluka Gunawardena	**The Impact of COVID-19 on the Sexual and Reproductive Health Rights of Women and Girls with Disabilities in South Asia**
	Q&A

Jill Hanass-Hancock
South African Medical Research Council

Young Women with and without Disabilities' Sexual and Reproductive Health and Rights during COVID-19 in South Africa: Experiences from the Field

Forgotten Agenda

YOUNG WOMEN WITH AND WITHOUT DISABILITIES' SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS DURING COVID-19 IN SOUTH AFRICA: EXPERIENCES FROM THE FIELD

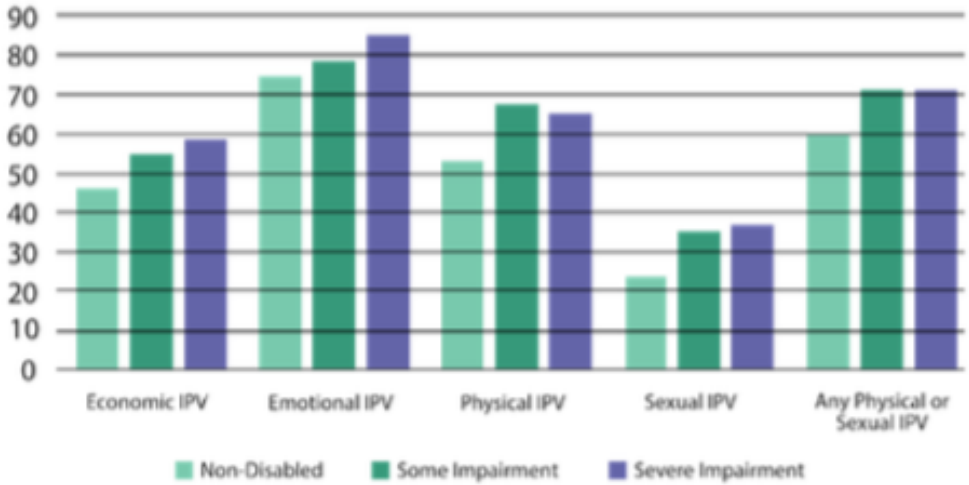
16 March 2022

Jill Hanass-Hancock,
Ayanda Nzuza,
Amanda Clyde,
Samantha Willan,
Kirstin Dunkle,
Mercilene Machisa,
Susie Hoffman,
Thesandree Padayachee,
Bradley Carpenter

BACKGROUND

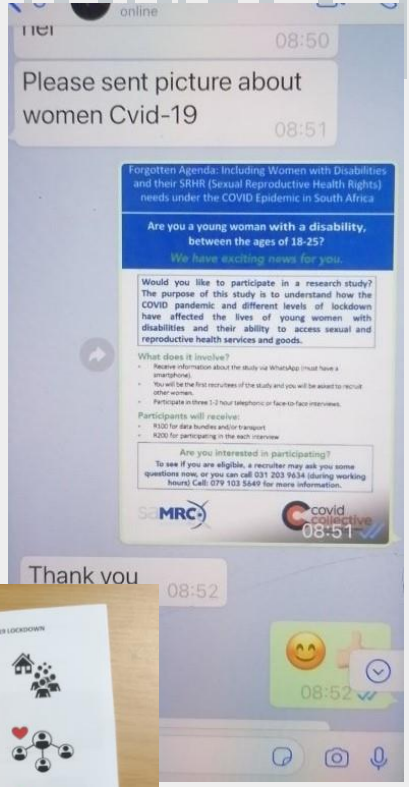
- New HIV infections in South Africa were highest among the youths aged 15–24 years (1% annual incidence), with females having three times higher annual incidence than males (1.5% versus 0.5%) with 1 in 3 young women being infected (Simbayi, 2017).
- HIV prevalence is higher among people with disabilities than national average (Shisana, 2012) and 2 times higher among women with disabilities then their peers (de Beauderap, 2014, 2020)
- Women with disabilities are two times more likely to experience intimate partner violence (IPV) then their peers without disability. The risk increases with severity of disability. (Dunkle, 2018)
- Research indicates that people with disabilities lack access to SRHR services and young people lack access to Comprehensive Sexuality Education and SRHR (Hanass-Hancock, 2018; UNFPA, 2018; UNESCO, 2021)

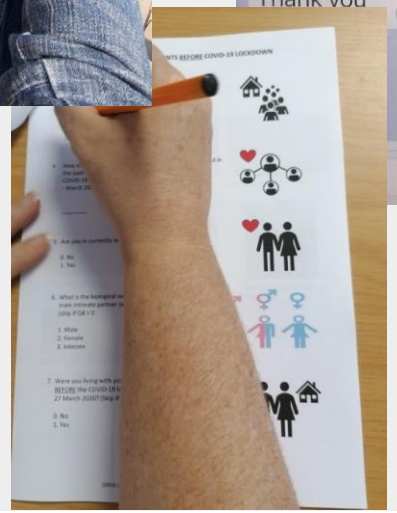
Figure 4: Experience of IPV in the past 12m among disabled and nondisabled women participating in the What Works Stepping Stones Creating Futures Project in South Africa



METHODS

- Conducted longitudinal cohort study with young women with (n=35) and without (n=37) disabilities aged 18-26 during, who had completed grade 12
- Data collected during COVID pandemic (2020-2022)
- Recruited in city of Durban through Universities, Colleges, FET centers and peer-to peer recruitment
- Conducted a series of telephonic or face-to-face interviews using validated scales, set of questions, open-ended questions and photovoice
- Explored experience with COVID-19, demographic, socio-economic and relationship status, food security and living conditions, mental health and coping, access to SRHR services/products, and exposure to and management of violence.





SAMPLE DEMOGRAPHICS AT INTERVIEW 1

	Women without Disabilities N=37 (%)		Women with Disabilities N=35 (%)	
	Pre-lockdown	At interview 1	Pre-lockdown	At interview 1
Average age in 2020	21.4 years		22.0 years	
Studying in 2020	83.8%		94%	
Having intimate partner		75.7%		51.4
CES-D10 over 10 (depressive symptoms the four weeks before interview one)		83.8%		80%
Average number of people living in household before and during hard lock down in 2020	3.35	5.97	6.69	6.26

Women with disabilities included women with physical, hearing, visual and mild/moderate intellectual disabilities

CONTRACEPTIVE USE AT INTERVIEW 1

	Women without Disabilities N=37 (%)		Women with Disabilities N=35 (%)	
	Pre-lockdown	At interview 1	Pre-lockdown	At interview 1
Implants = Yes (%)	2.7%	2.7%	0%	0%
Pill = Yes (%)	27.0%	5.4%	31.4%	5.7%
Male condom = Yes (%)	13.5%	54.1%	2.9%	34.3%
Female condom = Yes (%)	8.1%	0%	2.9%	0%
Emergency contraception = Yes (%)	8.1%	10.8%	11.4%	2.9%
Periodic abstinence= Yes (%)	81.1%	32.4%	62.9%	17.1%
Early withdrawal= Yes (%)	0%	27.0%	2.9%	28.6%
No contraceptive method= Yes (%)	0%	29.7%	25.7%	51.4%

Women with disabilities included women with physical, hearing, visual and mild/moderate intellectual disabilities

VIOLENCE AT INTERVIEW 1

	Women without Disabilities N=37 (%)		Women with Disabilities N=35 (%)	
Physical non-partner violence = Yes (%)	5.6%	2.7%	11.4%	11.4%
Sexual non-partner violence = Yes (%)	2.7%	0%	2.9%	2.9%
Emotional intimate partner violence = Yes (%)	16.2%	14.3%	20.7%	16.7%
Physical intimate partner violence = Yes (%)	8.1%	3.6%	20.7%	11.1%
Sexual intimate partner violence = Yes (%)	0%	0%	17.2%	5.6%

Women with disabilities included women with physical, hearing, visual and mild/moderate intellectual disabilities

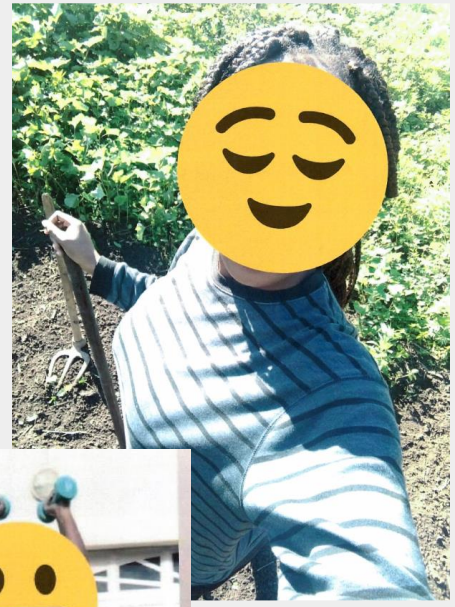
FIELDWORK EXPERIENCE

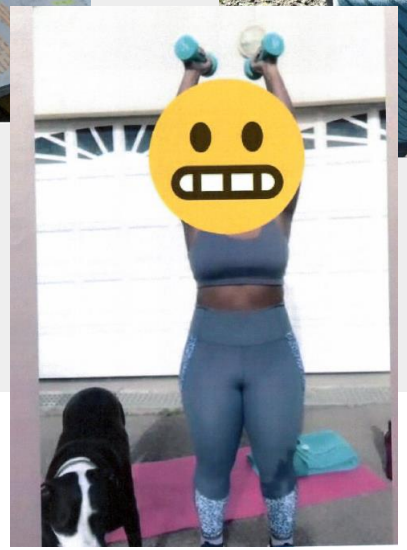
- All women had phones but needed internet data to participate in study
- Informed consent, interviews, and reimbursement were conducted via the phone and WhatsApp
- Data collection tools had to be adapted to retrieve SRHR data safely without disclosing participation in study (confidentiality)
- Survey questionnaire was collected verbally, with some questions requiring only yes or no answers
- Open ended questions provided more insight into lived experience
- Very few experiences of violence were reported over the phone

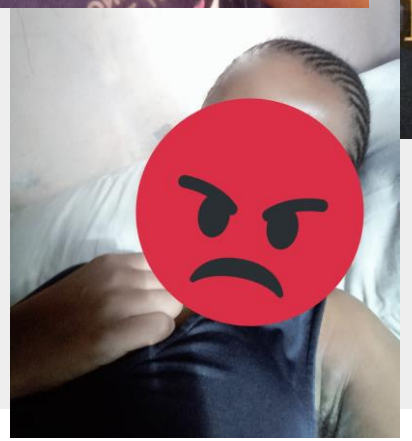
FIELDWORK EXPERIENCE CONT.

- Interviews conducted via phones or face to face, depending on communication support needs
- Building trust and sharing information about study needed more support
- Survey questionnaire and open-ended questions had to be accessible (including the use of pictures)
- Fieldwork staff had to balance protective measures and communication needs
- Fieldwork staff had to educate about technology and explanation of SRHR terms and questions
- SRHR questions had to be supported with picture material and additional information as not all women with disabilities were familiar with the SRHR vocabulary, products, and services.
- Online recruitment and reimbursement processes were new for some women with disabilities.

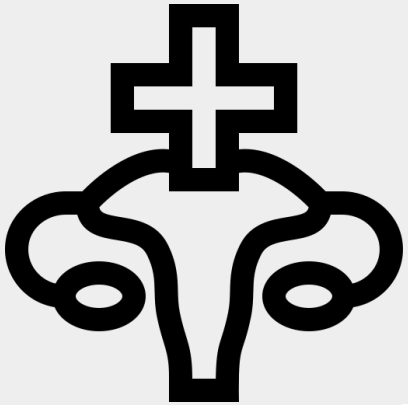
DIFFERENCE IN LOCKDOWN EXPERIENCE

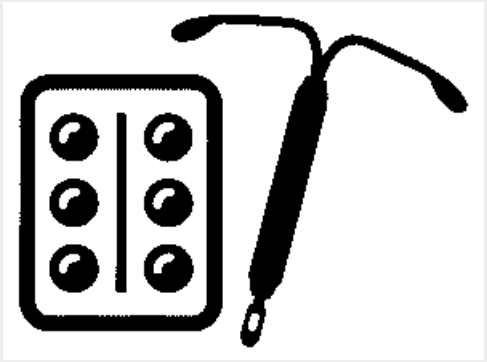






FIELDWORK





Thank you

Forgotten Agenda Study – SRHR and Women with and without disabilities under COVID-19 project: https://www.samrc.ac.za/intramural-research-units/covid-and-srhr-project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covid
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SOCIAL SCIENCE RESEARCH
FOR COVID-19 ACTION

Tracey Smythe
LSHTM

Toward disability-inclusive health in Zimbabwe: A qualitative study on the national response to COVID-19

Toward disability-inclusive health in Zimbabwe

A qualitative study on the national response to Covid-19

Smythe T, Mabhena T, Murahwi S, Kujinga T, Kuper H, Rusakaniko S

Aim

Explore the perspectives and experiences of people with disabilities in accessing health services

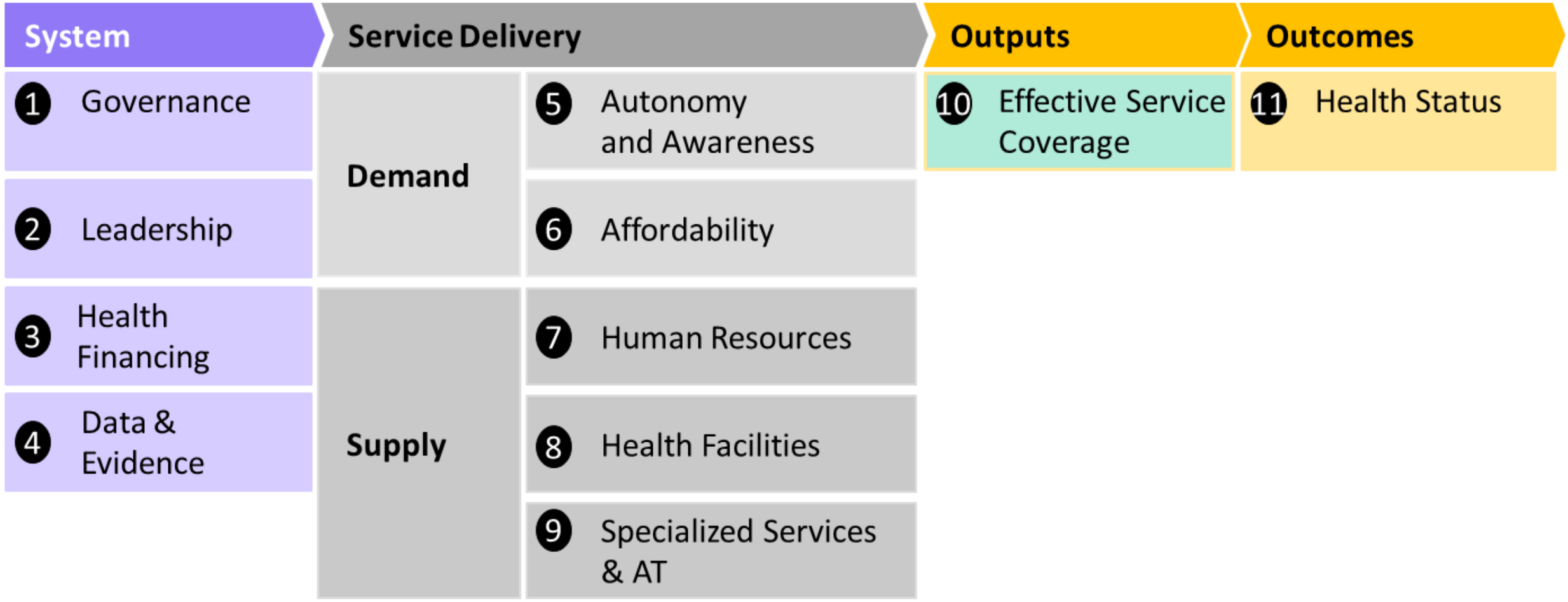
Identify perceived challenges to inclusive-health, and key actions to improve accessibility.

Methods

In-depth interviews:

- 24 people with disabilities
- 10 key informants
- Transcribed, coded, and thematically analysed the interviews
- Used the “Missing Billion” framework to map and inform barriers

Methods – Missing Billion Framework (1)



Methods – Missing Billion Framework (2)

Demand – autonomy and awareness before COVID-19

“If government excludes me from their health and education planning, then I will continue to depend on them and it will cost them”

“I was just very ignorant”

“I have never told anyone; I do not know how to talk about this

Demand – autonomy and awareness during Covid-19 (1)

- Good awareness
- Radio
- Rumours
- Adherence limited by function and finance

Demand – autonomy and awareness during Covid-19 (2)

“Washing hands after every contact is impossible. Social distancing is another challenge, if I’m in a wheelchair and social distance is not possible”

“The sanitisers that I have used have burnt my skin. It usually stings when I use sanitiser”

“If I give her a mask to wear, she usually tears it off”

Demand - affordability

“The challenge was for me to go to the clinic and see for sure that the clinic didn’t have any of the medication. They usually don’t have it.”

“There is no money, my medication for my eyes needs US$3 at the pharmacy, there is no way I will ask for a sanitiser whilst I have problems with my eyes. I would rather be fighting for my eyesight so that I will not be blind forever”

Supply – human resources

“As a person with a disability, you cannot do some of the activities and health workers have no patience for that”

“Sometimes they don’t even take time to address you because you have a disability”

“I think it’s because of my condition, that is why I’m served quickly”

Supply – health facility availability

“There is a big challenge because there are no ramps, they have steps only…in clinics there are no disability friendly toilets”

“We were scared but travelling during that time was even scarier. Other people informed us that it was pointless to go to the hospital because nurses were said to be reluctant to serve people and consulted people from a distance”

Supply – specialised services and assistive technology

“Rehabilitation centres were not available because they involve a lot of physical contact, so the government dissuaded people from running operations during the pandemic”

“Community rehabilitation is not being practiced these days because of lack of resources”

“We feel like the government is not interested in addressing the needs of people with disabilities. NGOs come here and they don’t include us either”

Outcomes and impact on functioning

“When the seizures come again because of not taking pills, the seizures are more powerful. There are times when I would spend more than a week not knowing where I was or what I was doing, or times when I went for two or three days without eating because of powerful seizures”

“When I don't have pills I fear going to the garden or doing other tasks by myself. An epileptic episode can occur anytime and I may collapse. Fetching water or cooking on fire is daunting for me”

Recommendations to building a disability inclusive health system (1)

- Twin-track approach
- Meaningfully engage
- Accessible formats
- Identify & remove barriers to prevention measures for Covid-19
- Ring-fencing financial allocations

Recommendations to building a disability inclusive health system (2)

- Identify & remove access barriers to social support & social protection
- Collect and analyse disability-disaggregated data
- Invest in OPDs
- Identify and remove barriers to routine medical care

Thank you! Tatenda! Mazvita!

Atul Jaiswal
University of Montreal

Is Patient-centred communication a promising solution for equitable healthcare for older adults with dual sensory loss during the COVID-19 pandemic?

Is Patient-centred communication a promising solution for equitable healthcare for older adults with dual sensory loss during the COVID-19 pandemic?

École d'optométrie
Université de Montréal et du monde.

Presented by:

Atul Jaiswal[1,2], PhD, MSW (Disability Studies), BSc. OT
FRQS Post-doctoral fellow in Vision Science, University of Montreal, Canada

Co-authors:

Peter Holzhey[1], Shreya Budhiraja[1], Abinethaa Paramasivam[1], Sangeetha Santhakumaran[3], Samuel Côté[1], Norman Robert Boie[1], Marie Savundranayagam[4], Claude Vincent[5], Edeltraut Kröger[6, 7], Walter Wittich[1,2,8]

Affiliations:

1. Wittich Vision Impairment Research Laboratory, École d'optométrie, Université de Montréal, Montreal, QC, Canada
2. CRIR/Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre, Longueuil, QC, Canada
3. Faculty of Medicine, McGill University, Quebec, QC, Canada.
4. Sam Katz Community Health and Aging Research Unit, Faculty of Health Sciences, Western University, London, ON, Canada.
5. CIRRIS/Department of Rehabilitation, Université Laval, Quebec, QC, Canada.
6. Faculty of Pharmacy, Université Laval, Quebec, QC, Canada.
7. Centre d'excellence sur le vieillissement de Québec, CIUSSSCN
8. CRIR/Centre de réadaptation Lethbridge-Layton-Mackay du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal, Montreal, QC, Canada

Land Acknowledgement

I acknowledge that I live, work and raise my family on the traditional homeland of the Anishinaabe, Haudenosaunee and the Huron-Wendat.

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Cirris

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COVID-DSL Research Citizen Engagement Panel members

Research partners

CNIB DEAFBLIND COMMUNITY SERVICES

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Canadian Helen Keller Centre
Centre canadien Helen Keller

CANADIAN HEARING SERVICES

The Prince Edward County Community Care for Seniors Association

Centre intégré de santé et de services sociaux de la Montérégie-Centre

inlb Institut Nazareth & Louis-Braille

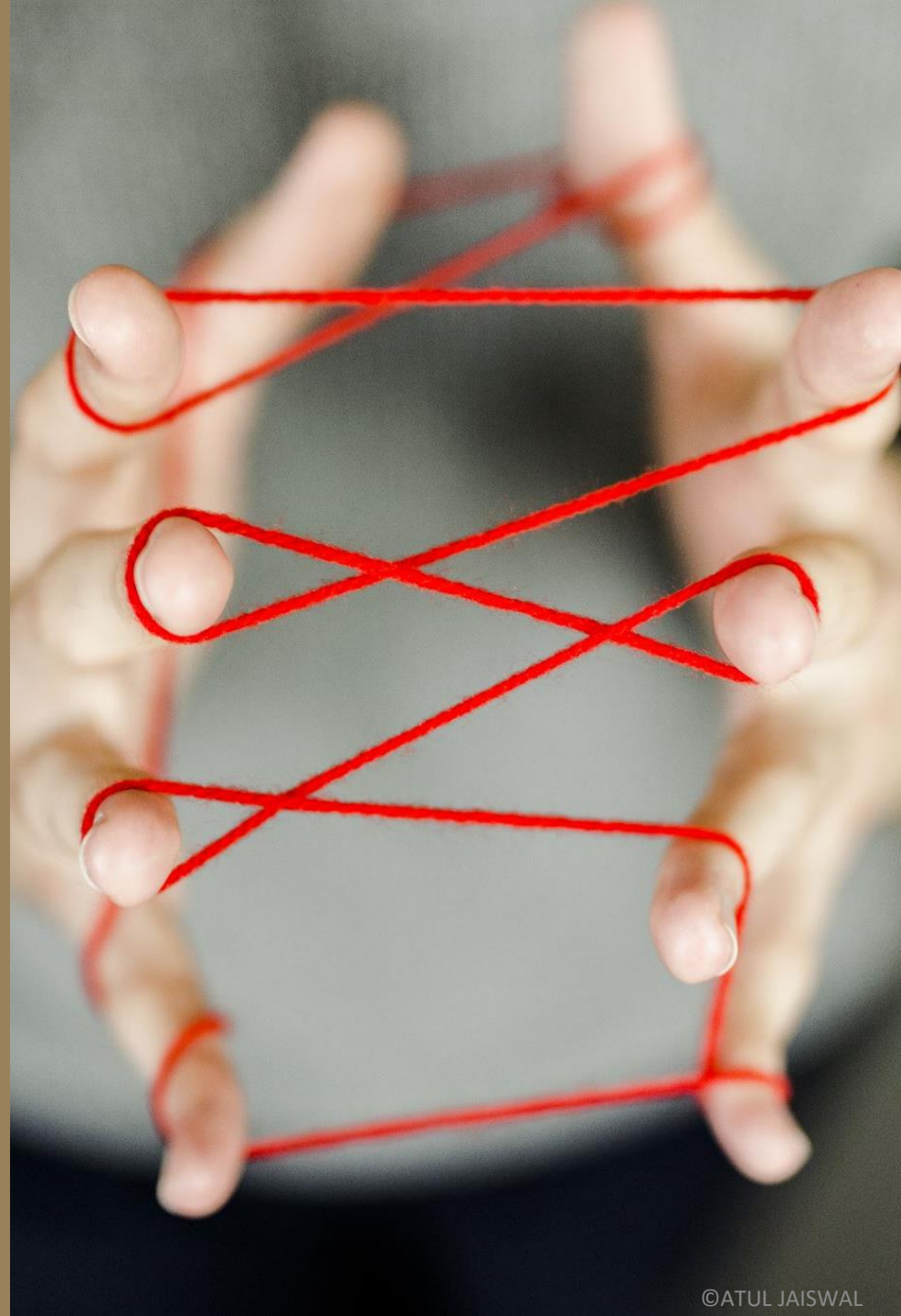
Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal

Centre de réadaptation LETHBRIDGE-LAYTON-MACKAY Rehabilitation Centre

Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal

IRD Institut Raymond-Dewar
Centre de réadaptation spécialisé en surdité et en communication

DOES SENSORY IMPAIRMENT REALLY MATTER??



World Health Organization

WORLD REPORT ON HEARING

World report on vision

©ATUL JAISWAL

GLOBAL FACTS

Globally,
1.5 billion had hearing impairment,
2.2 billion had vision impairment, and
150 million had combination of both.

(WFD, 2018; WHO, 2019; 2021)

A 2015 report on the Global Burden of Disease estimated that hearing and vision impairment, respectively, ranked second and third of all impairments contributing to the number of years lived with disability.

(Vos et al., 2020)

Hearing loss, Vision loss, and Dual sensory loss (DSL)

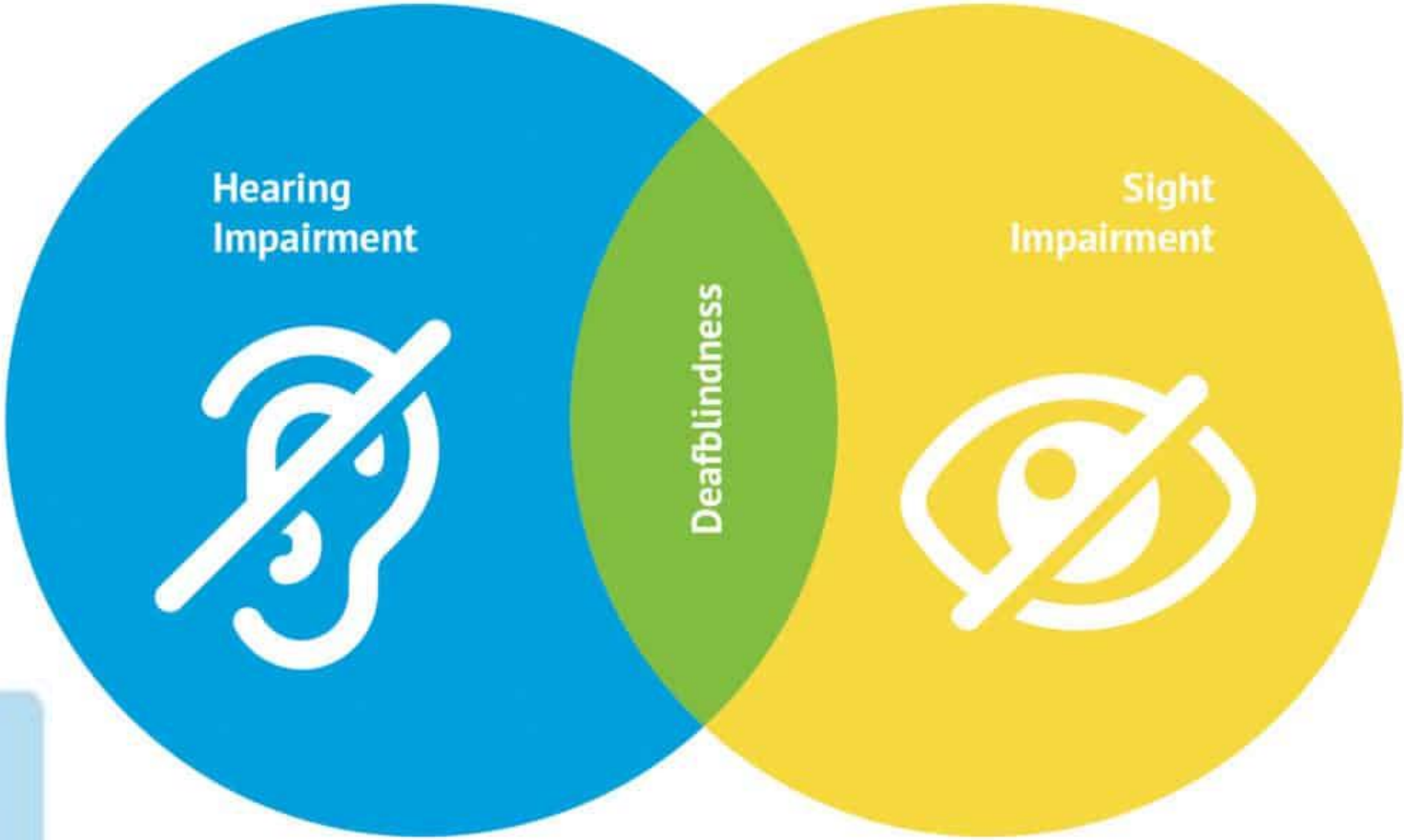


Image Source - Deafblind UK

"Blindness cuts us off from things, but deafness cuts us off from people."

~Helen Keller

Unique challenges of this population

DUAL SENSORY LOSS

Difficulty in engagement of person in the environment

Hinder many aspects of functioning

Moving around from one place to another

Communication with the world

Establishing and maintaining interpersonal relationships

Experience restriction in participation in society

Extreme social isolation

All theses challenges make deafblindness - one of the **most isolating disabilities**

(Aitken et al., 2013; Hersh, 2013; Moller, 2003)

Current estimates suggest that up to **2% of the world's population** have this impairment.

(World Federation for the Deafblind, 2018)

- Approx. **150 million in the world**

- Approx. **14.5 million in the North America by 2036**

(Swenor et al, 2017)

- Up to **1.1 million in Canada**

(Mick et al, 2020)

The Prevalence of Hearing, Vision, and Dual Sensory Loss in Older Canadians: An Analysis of Data from the Canadian Longitudinal Study on Aging

Published online by Cambridge University Press: **17 June 2020**

Paul Thomas Mick, Anni Hämäläinen, Lebo Kolisang, M. Kathleen Pichora-Fuller, Natalie Phillips, Dawn Guthrie and Walter Wittich

Show author details

Older adults with DSL and Healthcare

Older adults with DSL

- are at a **high risk** of cognitive impairment, functional decline, social isolation, falls, depression, and mortality,
- often have **poor access** to health care,
- are experiencing distinct set of challenges in access to healthcare during the current pandemic.

However, there is a **lack of sufficient scientific evidence** to inform clinical practice during the pandemic.

Study objective: To explore the healthcare experiences for older adults with DSL in Canada during the pandemic.

Research studies

Study 1: Qualitative study with older adults with DSL and their caregivers/support providers

Study 2: Qualitative study with healthcare providers

STUDY 1: Qualitative study with older adults with DSL and their caregivers/support providers

Methods

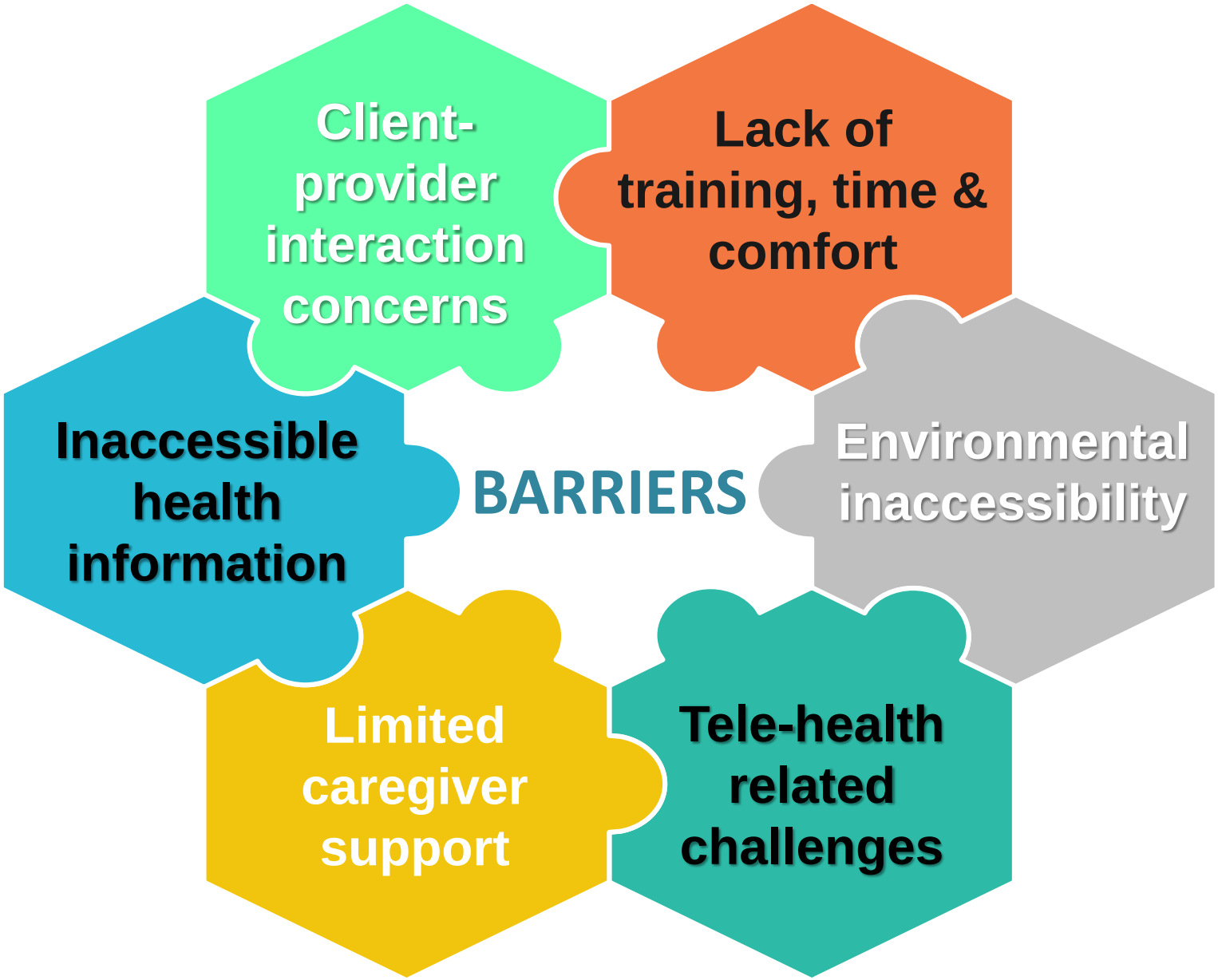
Data Collection

- Semi-structured qualitative interviews with 32 community-dwelling older adults with DSL in Quebec and Ontario
- Diverse remote communication modes and accessible formats were used to obtain consent and interview older adults.
- Online focus group discussions with 30 caregivers or support providers in Quebec and Ontario.
- Interviews and FGDs were audio-recorded and transcribed verbatim.

Data Analysis

- Data were managed using NVivo software and analyzed using a thematic analysis approach.

Key findings



STUDY 2: Qualitative interviews with healthcare providers

Methods cont.

Data Collection

- Online survey with 228 healthcare professionals working in various setting in Canada.
- In-depth interviews with 24 healthcare providers working in various setting in Canada.

Data Analysis

- Thematic analysis was used to analyze qualitative data.

Challenges experienced by Healthcare providers

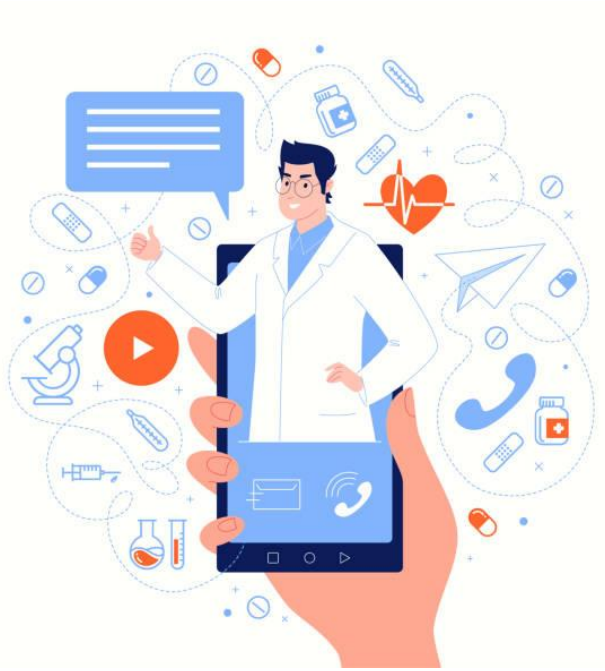
- Identification of DSL
- Health-related communication
- Technological challenges
- Limited resources/staff

HELPFUL STRATEGIES

- Environmental accessibility
- Preferred modes of communication
- Training on DSL-specific care
- **STRATEGIES**
- Reliable accompaniment support
- Use and maintenance of aids
- Cross-disciplinary care approach

Conclusions

- Healthcare inequities exist for older Canadians with DSL as they face significant barriers in accessing healthcare and health-related information.
- The pandemic heightened the risk and challenges for older adults with DSL.
- Tele-healthcare model has inherent challenges in delivering care to older adults with DSL.
- Dire need for training of healthcare providers to accommodate the communication and accessibility needs of older adults with DSL.
- Healthcare administrators and policymakers should consider the distinct accessibility and communication needs of this population in order to help them age well.



Take Home Messages

- Every time you are working or researching with older adult, ask yourself whether they have sensory impairment. If yes, ask them their preferred mode of communication and what you can do to have an effective communication.
- Recognize and refer to vision and hearing care professionals. Work in collaboration with sensory rehabilitation specific service professionals or organizations.
- Take training on DSL to develop your own knowledge and skills.
- Optimize the use of residual senses to conduct assessments and deliver interventions. Focus on life domains that are valuable to them.
- Make sure information, letters and care plans are in accessible formats (e.g., large print, Braille, online modes). Assistive technology could be beneficial but how it is introduced will determine its acceptance and uptake.

TAKE THAT EXTRA STEP TO MAKE THE WORLD MORE INCLUSIVE

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THANKS

Please join us to generate and use research to bring real change

Atul Jaiswal, ***PhD, MSW (Disability Studies), BSc. OT***
Post-doctoral Fellow in Vision Science,
Wittich Vision Impairment Research Laboratory,
School of Optometry, Université de Montréal,
3744, rue Jean-Brillant, Bureau 6442,
Montréal, Québec, H3T 1P1

Email: atul.jaiswal@umontreal.ca

twitter
Twitter: @atuljais111

ResearchGate

Google Scholar

Niluka Gunawardena
University of Kelaniya and the University of Colombo, Sri Lanka

The Impact of COVID-19 on the Sexual and Reproductive Health Rights of Women and Girls with Disabilities in South Asia

Health and access to healthcare during COVID-19

ICED Disability and COVID-19 Conference

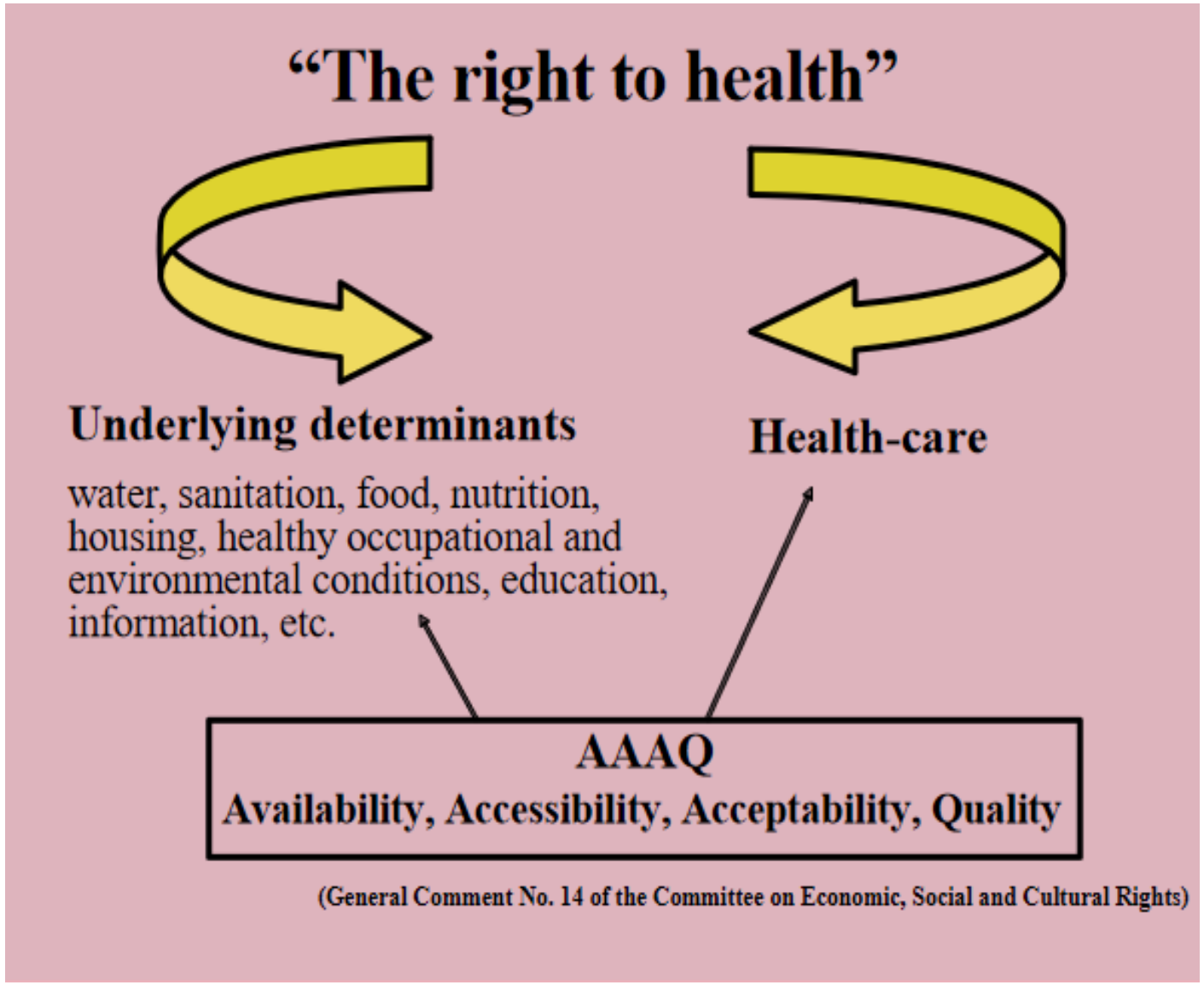
16th March 2022

The Impact of COVID-19 on the Sexual and Reproductive Health Rights of Women and Girls with Disabilities in South Asia

Niluka Gunawardena
(nilukag@gmail.com)

South Asia Segment

- 5 national consultations – India, Sri Lanka, Nepal, Bangladesh, Pakistan
- 1 regional experts' consultation


"The right to health"
Underlying determinants
water, sanitation, food, nutrition, housing, healthy occupational and environmental conditions, education, information, etc.
Health-care
AAAQ
Availability, Accessibility, Acceptability, Quality
(General Comment No. 14 of the Committee on Economic, Social and Cultural Rights)

Basic Needs

- Lack of food security - Limitations to availability on the supply side was compounded and amplified by reduced income, unemployment and lack of income security on the demand side.
- “Disabled women, especially in the rural areas are in suffering to a great extent. They're almost reduced to begging during this pandemic situation because there is hardly any way in which they are able to fulfill their basic needs, especially access to food. When their husbands have lost jobs and there are problems in accessing food” (Participant, Bangladesh)
- “95% of people complained that they were not able to get food and medication they needed on a daily basis”. (DPO, Sri Lanka)
- “Because of the loss of jobs and income and food being scarce, disabled people were given the food at the end. The disabled woman receive food only at the end and that means she received what was leftover after everybody had eaten… (Participant, Nepal)
- “Sometimes persons with psychosocial disabilities in rural communities relied on neighbors for food and care. However, concerns regarding sanitation and hygiene had disrupted such informal community level arrangements. Given that everyone was facing COVID related hardships local arrangements like community microloan mechanisms were also non-operational” (participant, Sri Lanka)

Basic Needs Contd.

- Lack of information and awareness regarding food distribution
- Inaccessibility of food trucks, limited coverage of rural communities
- Lack of access to menstrual products – stock ‘running out’, not considered ‘essential’
- Lack of access during temporary curfew suspensions – face masks obstructing communication for Deaf persons, difficulties with standing in line, barriers to social distancing
- Disruption to communal support systems – fear of contagion and transmission, COVID stigma
- Rs 5000.00 living allowance provided by the Government of Sri Lanka (GOSL) for vulnerable populations – Women entrepreneurs with disabilities not eligible for small business concessions.

Adequate and Safe Housing

- “The closure of hostels which meant that disabled women who came back to the families became a burden on the families. Or interpreted as burden on the families. This resulted in different forms of violence and situations. Family, there is one girl she talked about that returned from the hostel. When the family realized she was going to stay for a longer period of time, they started to take away privileges that were given to her.” (Participant, Sri Lanka)
- Threat of homelessness, eviction, threat of sexual violence
- ‘Burden’rhetoric - “And then it's happening to a woman who has a disability that we had cases where people actually were thrown out of the house at this COVID period, women were thrown out of the house, but they were not allowed in any short-stay home or any kind of services because usually it is not there in the pandemic… so this is something that made things difficult for women who have psychosocial disabilities” (Participant, India)
- “Schools are closed, colleges are closed. Everyone was a home, so there a lot of intolerance. Already, our disabled community is facing a lot of trouble by being a burden on their families” (Participant, Bangladesh)
- Fear of contagion - “Everyone says you are mad so you must be prone to covid-19”(participant, Nepal)

Access to Healthcare

- Safety guidelines may not be applicable to persons with disabilities
- 1990 emergency ambulance service – transport to nearest hospital, no means of getting back home – ‘access gaps’
- Rise in incidence of psychosocial disabilities – disruption to community support services, isolation, containment to homes and restricted environments – inadequate medical/ social support
- Lack of COVID related counselling
- Lack of access to clinics, rehabilitation facilities and essential items like catheters
- Emergency services – Mental health related crises not regarded as medical emergencies , National Institution of Mental Health ceased admitting new patients
- Harder to obtain healthcare for those without pre-existing conditions
- Shortage of essential medication – esp. for those on long term medication –led to a reliance on traditional medicine
- Suspension of home-based services

Access to Healthcare Contd.

- Deprioritization of those with long-term health needs , Deprioritization of SRH including pre/post natal care, Deprioritization of MH
- Lack of access to assistive devices and services
- Inaccessible testing and quarantine facilities – cost, access
- High cost of private healthcare
- Difficulties with isolating, socially distancing

Access to Information

- COVID Specific information – Sign Language interpretation for standard news but not breaking news/ emergency information, no standard sign language in Sri Lanka – local variants
- 1919 – Government information centre hotline – no emergency health information for persons with psychosocial disabilities
- Limited access to information on status of PWDs in institutional settings (lack of accountability), isolation of specific populations
- Civil Society – try to make information more accessible, especially in militarized areas

Access to Education

- significantly lower level of literacy and exposure to any form of sex education for women and girls with disabilities. The dropout of girls from education during the pandemic has exacerbated these issues of ‘being left behind’ in the long run Link to WHO study
- Online learning inaccessible – exacerbates existing inequities

Digital divide, especially inaccessible for students with visual impairments

- De-prioritize needs of learners with disabilities due to resource limitations
- Inability of Deaf students to communicate with members of their household/ community – isolation, alienation

GBV

- Escalation in GBV – restriction to home based environments, breakdown of community supports
- The scarcity of resources and the restrictions to social determinants of health including food security, safe and adequate housing, freedom of mobility, adequate disability supports and access to income and education have led to the heightened vulnerability of women with disabilities.
- Rise in alcoholism and related violence (participants, Sri Lanka)
- Reduced opportunities for safety and recourse – lack of privacy, containment to homes, overcrowding, gendered roles and expectations
- Microviolence – deprivation of electricity, data, medication etc. – impact on support networks
- Vulnerability to sexual abuse, sexual bargaining
- Lack of accessible domestic violence shelters
- Blaming and ‘scapegoating

<u>Not covered in consultation</u>

- Reports of sexual assault and police harassment (persons with intellectual/ learning disabilities)
- Rise in general prevalence of GBV/ domestic violence – no disaggregated data

SRHR

- Cultural taboo relating to the sexuality of women with disabilities
- Curtailment of SRH related services during lockdown, limited information available
- Lack of privacy – especially for Deaf/ hearing impaired women who must rely on interpreters for communicating with SRH service providers
- Negative stereotypes – asexual, hypersexual, deprived of gendered, socially sanctioned roles of wife, mother etc.
- Viewed as burdens – when in fact they do much of the housework – kept in the shadows – shame/ stigma

Ecology of Access

- The lack of accessible, affordable transportation options during the pandemic was a major obstacle to seeking necessary healthcare during the pandemic for persons with disabilities and their families
- “There are very few hospitals that are non-COVID and many women with disabilities because of many co-morbidities, they need safer environments. So access to health has been challenging in rural areas. Access to a woman doctor, so more maternal health, pregnancy care has been super challenging and yet not available. And there is not enough affordable accessible public transport to get to places” (Participant, India)
- The lack of access to assistive devices and technologies including their maintenance and repair was a major obstacle for persons with disabilities. The inability to get new batteries for hearing aids and replacement parts for prosthetic limbs were cited as major barriers by participants
- ‘’Essential goods”- sanitary products, adult diapers, catheters, regular medication, contraceptives
- Lack of care and respite related supports – care dynamics
- “A lot of mothers called up [our helpline] and they said that they are feeling very restless. They don't know how to handle the situation. They cannot explain to their child or who is probably adult in age who has got intellectual disabilities, why certainly this change is happening.” (Participant, India)
- Access to information - SL interpretation, access to telemedicine, hotlines, public health alerts, special assistance schemes
- Need for disaggregated data and targeted responses