

Ethical issues arising from assistive technology: navigation devices & video remote sign language interpreting (VRI)

Minerva Rivas Velarde, PhD

Team Leader Disability and Global Health

Director of the Europe and Central Asia of the Disability Data Initiative Hub

Department of Radiology and Medical Informatics & iEH2 - Institute for Ethics, History, and the Humanities

Faculty of Medicine, University of Geneva

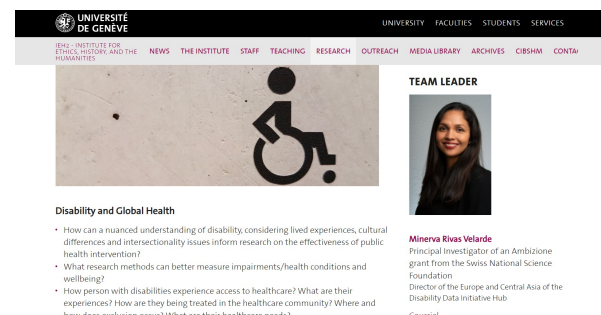
18-20 January 2023

Disability and Global Health

How can a nuanced understanding of disability, considering lived experiences, cultural differences and intersectionality issues, inform research on the effectiveness of public health intervention?

How do persons with disabilities experience access to healthcare? What are their experiences? How are they being treated in the healthcare community? Where and how does exclusion occur? What are their healthcare needs?

How can assistive devices and ICT technology enhance each person's capability? How can use technology to bridge the gaps in access to healthcare?



The screenshot shows a website header for the University of Geneva, Faculty of Sciences, Institute for Ethics, History, and the Humanities. The main content area features a large image of a wheelchair icon on a textured background. Below the image is the title 'Disability and Global Health' and a list of research questions. To the right is a 'TEAM LEADER' section with a portrait of Minerva Rivas Velarde and her credentials.

UNIVERSITÉ DE GENEVE
UNIVERSITY FACULTIES STUDENTS SERVICES
IHH - INSTITUTE FOR ETHICS, HISTORY, AND THE HUMANITIES NEWS THE INSTITUTE STAFF TEACHING RESEARCH OUTREACH MEDIA LIBRARY ARCHIVES CISHM CONTACT

Disability and Global Health

- How can a nuanced understanding of disability, considering lived experiences, cultural differences and intersectionality issues inform research on the effectiveness of public health intervention?
- What research methods can better measure impairments/health conditions and wellbeing?
- How person with disabilities experience access to healthcare? What are their experiences? How are they being treated in the healthcare community? Where and how does exclusion occur? What are their healthcare needs?

TEAM LEADER

Minerva Rivas Velarde
Principal Investigator of an Ambizione grant from the Swiss National Science Foundation
Director of the Europe and Central Asia of the Disability Data Initiative Hub


The Europe and Central Asia of the Disability Data Initiative Hub

- The Disability Data Initiative provides analyses of disability data to help advance the rights of persons with disabilities and sustainable human development for all.

The 2022 Disability Data Report

Find out about our 2022 report: it reviews disability questions in national censuses and household surveys and disaggregates wellbeing indicators between women with and without functional difficulties in 35 countries.


[Main Text ▶](#) [Results Tables ▶](#) [Country Briefs ▶](#) [Method Briefs ▶](#)



The 2021 Disability Data Report

Explore our report that provides an analysis of disability questions in national censuses and household surveys as well as indicators disaggregated by disability status for 41 countries.

[Main Text ▶](#) [Results Tables ▶](#) [Country Briefs ▶](#) [Method Briefs ▶](#)



Team



Douglas Teodoro,
Assistant Professor



Racha Gouareb,
post doctoral fellow



David Vicente Alvarez,
Research Assistant

<https://disabilitydata.ace.fordham.edu/>

FNS

To link disability theory with the empirical challenges of public health research. By gathering empirical evidence on the health needs of Deaf persons and testing an intervention that responds to the structural and societal factors that are in tune with impairments to determine how an individual experiences health and disability.



Dr. Angela Martinez Gonzalez



Jyoti Dalal,
Data Scientist



Dr. Danna Cruz Reyes



Juliana Reyes Daza, Inter



Laura Izquiero Martinez,
Research Assistant

Populations trends

As of 2021, approximately 1.3 billion people – about 16% of the global population – have disability [1].



Persons with disabilities continue to be left behind in every dimension of the universal health coverage framework

[1]. Global report on health equity for persons with disabilities. Geneva: World Health Organization; 2022. License: CC BY-NC-SA 3.0 IGO.

Digital Divide

The Global Report on Assistive Technology states that children and adults with disabilities lack access to AT, particularly in low and middle-income countries where access was reported to be as low as 3% [2].

The current lack of access to AT reflects not only an economic gap but a severe malfunction of social provision and coverage schemes as well as in AT design and development [3].

Accessibility tends to be understood as technical features of devices, systems or environments. These features may be hiding or even deepening a profound structural divide.

2. World Health Organization (WHO) and the United Nations Children's Fund (UNICEF). Global report on assistive technology. Geneva.

3. Stein M, Lazar J. Accessible Technology and the Developing World. Stein M, Lazar J, editores. Oxford: Oxford University Press; 2021.

Assistive technology

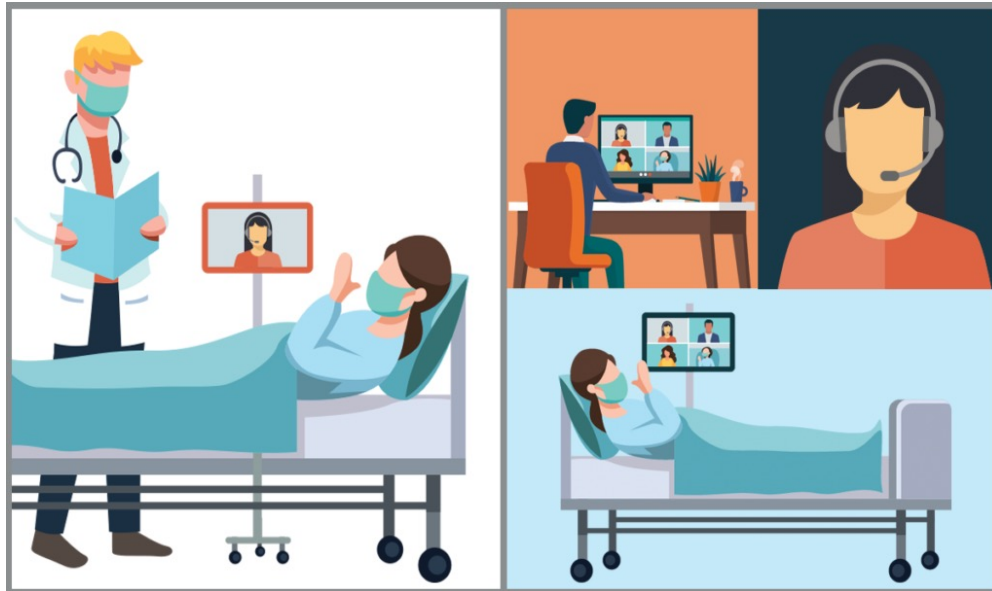
Assistive technology is an umbrella term covering the systems and services related to the delivery of assistive products and services [4].

Assistive products maintain or improve an individual's functioning and independence, thereby promoting their well-being.

Hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organisers and memory aids are all examples of assistive products.

[4] <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>

AT is not a quick fix for accessibility



VRI refers to a video camera on an electronic device, either a computer or tablet, that is used to connect patients and health providers with a sign language interpreter via video call.

Its use has rapidly expanded due to its flexibility and advantageous cost compared with in-person sign language interpretation [5].

[5] Masland, M.C., C. Lou, and L. Snowden, *Use of communication technologies to cost-effectively increase the availability of interpretation services in healthcare settings*. *Telemedicine and e-Health*, 2010. 16(6): p. 739-745.

Access to Translator (AT&T) project: Interpreter on Wheels during the COVID-19 pandemic

Matthew Mo Kin Kwok,^{1,2,3} Richard K Chan,^{1,3} Cindy Hansen,³ Kris Thibault,³
Hing Yi Wong³

'A deaf gentleman presented with hip pain. He had his note pad and pen ready to write notes to the staff. He was pleasantly surprised that we were able to access an American Sign Language video interpreter within seconds. We were able to take an accurate history, guide him through focused physical exam, provide discharge instructions and answer his questions. It was very easy and efficient, and we were confident that we were able to help address his medical concerns'. (p.3) [6]

[6] Kwok MM, Chan RK, Hansen C, Thibault K, Wong HY. Access to Translator (AT&T) project: Interpreter on Wheels during the COVID-19 pandemic. BMJ Open Quality. 2021 Feb 1;10(1):e001062.

VRI

- **Easy to use**
- **Cost-effective**
- **Efficient**



Good communication is the basis of diagnosis and treatment



Copyright © 2012 Wellcome Library, London

- Does the existing literature provide enough evidence on how VRI can enable deaf users to **overcome interpretation barriers** and improve communication outcomes between them and healthcare personnel within healthcare settings?

Published on 9.6.2022 in Vol 24 , No 6 (2022) :June

📄 Preprints (earlier versions) of this paper are available at <https://preprints.jmir.org/preprint/32439>, first published July 28, 2021.



Video Relay Interpretation and Overcoming Barriers in Health Care for Deaf Users: Scoping Review

Minerva Rivas Velarde ¹ ; Caroline Jagoe ² ; Jessica Cuculick ³ 

[Article](#) [Authors](#) [Cited by](#) [Tweetations \(8\)](#) [Metrics](#)

- [Abstract](#)
- Introduction
- Methods
- Results
- Discussion

Abstract

Background:

Persons who are deaf are more likely to avoid health care providers than those who can hear, partially because of the lack of means of communication with these providers and the dearth of available interpreters. The use of video remote interpretation, namely the video camera on an electronic device. to connect deaf patients and health providers has rapidly expanded owing to its

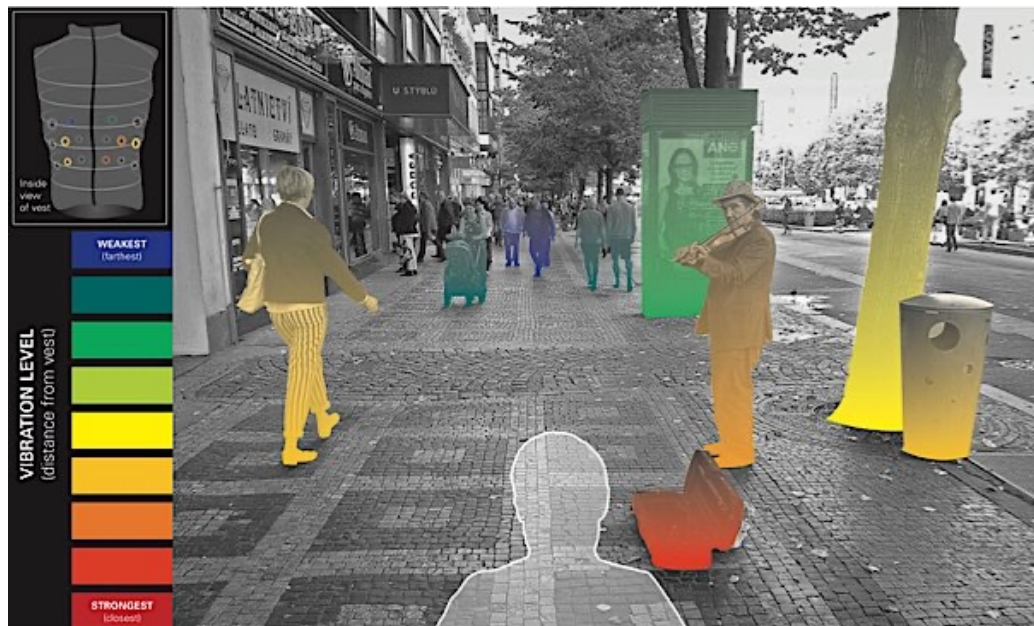
Precondition

- Literacy
- Health literacy
- Standardised Interpreter training
- Check and balances on professional ethics for interpreters
- Technical infrastructure (internet, devices, software, electricity)
- Data protection
- Adapted consultation times
- Disability awareness health personnel



Not trying to 'fix' disabled bodies

Navigation devices



<https://tactilenavigationtools.com/>

Barriers

 <p>OrCam</p>	<p>Traffic light, text & object recognition; For visually impaired; Cost \$3500</p>
 <p>AuxDeco</p>	<p>Tactile image; Few weeks for training; Cost \$15000;</p>



TARIFAS MENSUALES POSPAGO DE PLANES MÓVILES

	15GB	25GB	40GB	Ilimitado
Movistar	\$ 34.900	\$ 44.990	\$ 59.900	\$ 75.000 - \$ 99.900 <small>Ilimitados</small>
tigo	\$ 35.000	\$ 45.000	\$ 60.000	75GB \$ 75.000 \$ 100.000



Navigation devices



User Centred Design

The following 6 principles guide UCD:

- a) the design is based upon an explicit understanding of users, tasks and environments;
- b) users are involved throughout design and development;
- c) the design is driven and refined by user-centred evaluation;
- d) the process is iterative;
- e) the design addresses the whole user experience; and
- f) the design team includes multidisciplinary skills and perspectives.

The information on the system architecture reported in state-of-the-art was prioritised over the participants' needs with respect to AT.

Users' involvement was reported mainly in usability assessment at the end of the process.

Feedback from users, when present, took the form of “**informal**”, “**casual**” or “**anecdotal**” data.

focus on the public utilitarian function of AT

Digital divide

AT is not a quick fix for accessibility

The design of AT should focus on enhancing the user's agency, bodily integrity, and capabilities and not trying to 'fix' disabled bodies.

This divide is also present in digital technologies in general. (big data regulation tends to be heavily focused on privacy)

New technology-related vulnerabilities.

Thanks

Mineva.rivas@unige.ch