

# ‘Feeling Freedom’<sup>1</sup>: an anthropological perspective from Cape Town on the right of access to health care for Deaf people who use SASL

Hanne Jensen Haricharan

Marion Heap

May 2009

<sup>1</sup>Malakheke Jezile describing his first ever  
experience of a signed language interpreter

# Outline

- Aim of SASLIP.
- Framework: Health as a human right.
- Case study: Neliswa's narrative.
- Inefficient communication between Deaf patients and health professionals.
- Rights violations in Neliswa's story.
- Operationalising health as a human right for Deaf patients through SASL interpretation.
- Advancing human rights through qualitative research.

# Aim of SASL IP

- Aim of SASLIP: Operationalise health care as a human right for Deaf people.
- a) Implementation: Pilot project implementing sign language interpretation in health care.
- b) Research the impact of SASL interpretation on Deaf people's 'access' to health care and right to health.
  - analysing communication between patient and health care professionals.
  - comparing patients' experiences of health care with/without an interpreter.
  - comparing health care professionals' experience with/without interpreter.
- c) Advocacy: Use research to advocate for the use of SASL interpreters in order to operationalise Deaf people's access to health care as human rights.



# Framework: Health as Human Right

- The Universal Declaration of Human Rights: Right to health and a standard of living adequate for health and wellbeing.
- The South African Constitution, Bill of Rights:
- Everyone has the right to have access to:
- Health care services, including reproductive health care.
- Sufficient food and water.
- Social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.

# Framework cont.

- National Health Act (Act No 61, 2003)
- The health care provider must inform the users of the services, where possible, in a language and in a manner that the user understands.
- Right to information about services and treatment.
- Informed consent.
- Participate in decision making about your care.
- Confidentiality.



# Convention the rights of people with disabilities

- RSA has ratified this Convention (2007).
- Accessibility (Article 9 (2) (e))
- State parties will also take appropriate measures ...
- To provide forms of live assistance and intermediaries including guides, readers and professional sign language interpreters to facilitate access to buildings and other facilities open to the public

# Inefficient communication between deaf patients-health care professionals

- SASL is a unique language with own syntax/grammar. No written equivalent.
- Written communication insufficient (poor education level of many deaf, too lengthy to be efficient, time constraints, complex questions not asked or answered)
- Lip-reading is of limited use: many Deaf people do not lip-read. Only 30 percent of spoken communication understood from lip-reading.
- Use pf family member/friend as interpreter problematic (may not 'speak' SASL, messages may not be translated properly, confidentiality/privacy compromised).



# Rights violations - definition

- ‘Failure/omission to respect, protect or fulfill rights’  
(drawing on Chapman, 2000)



# Rights violated - rape

## Rights violated

- Right to information in language of choice.
- Right to participate in decision re. health care.
- Right to health.
- Access to health care?

## Consequences

- Discarded post-exposure prophylaxis.
- HIV-positive status?

# Rights violated – VCT

## Rights violated

- Right to information.
- Right to confidentiality.

## Consequences

- Involuntary disclosure.



# Rights violated – blood tests

## Rights violated

- Right to information.
- Consent.
- Right to dignity?

## Consequences

- Anxiety and uncertainty.

# ARV counselling and treatment

## Rights violated

- Right to information.
- Right to participate in decision re. health care.
- Right to health..
- Access to health care?

## Consequences

- Lack of understanding of ARVs, side-effects and importance of adherence.
- Insufficient knowledge about where to get medicine.
- Compromised immune system?
- Potential resistance to ARVs.



# Rights violated - accident and hospitalisation

## Rights violated

- Right to information.
- Right to participate in decisions re. health care.
- Right to health.
- Right to dignity.
- Access to health care?

## Consequences

- Risk of misdiagnosis.
- Standards of care not applied with regard to scanning.
- Unchecked low haemoglobin level.
- Fear and anxiety re. treatment.

# Rights violated - PMCTC

## Rights violated

- Right to information.
- Right to participate in decision-making.
- Right to health.
- Access to health care?

## Consequences

- Not given ARV or info. About ARVs at antenatal clinic (Cape Town).
- Risk of transmitting HIV to her child.
- Choice of breastfeeding/formula feeding unclear (current pregnancy).



# HIV information/counselling

## Rights violated

- Right to information.
- Right to health.
- Right to dignity.
- Access to health care?

## Consequences

- Couple not practising safe sex.
- Risk of re-infection.
- Risk of infecting partner.

# Access to health care?

- Neliswa has access to health care, as enshrined in the Bill of Rights.
- Accessibility according to General Comment 14:  
Informational accessibility - the right to seek, receive, and impart information and ideas concerning health issues. Core obligation.
- Access = informational accessibility → Neliswa's access to health care violated.



# Possible consequences of lack of SASL Interpreter

- Misdiagnosis/late diagnosis.
- Incorrect/insufficient treatment.
- Problems with adherence/treatment.
- Deaf patients missing appointments, follow up appointments, referrals, etc.
- Deaf people refrain from seeking health care.
- Chronic patients refrain from follow-up appointments.
- Misunderstanding, uncertainty and anxiety.
- Deaf patients refraining from seeking information/knowledge ('nod their head').
- Lack of information/understanding of health seeking behaviour.

# Operationalising health as a human right through SASL interpretation

- Neliswa achieved ‘full communication’ and ‘understood everything 100 percent’.
- Understood ARV adherence, side-effects and PMTCT.
- Analysis of communication between doctors and health care professional suggests that communication improves significantly.
- Interviews with health care professionals suggest that SASL interpreter service is a cost-effective intervention.



# Additional barriers to access

- Neliswa's rights to health continues to be violated by her socio-economic situation.
- ARV adherence problematic due to insufficient food.
- Access to health care compromised by poverty (choice between food and money for transport).
- SASL interpretation puts deaf people un par with hearing.

# Addressing human rights through qualitative research

- Demonstrates and documents rights violations and consequences for a marginalised group.
- Examples of how qualitative research ‘uncover’ consequences:
  - A) Neliswa’s discarding of ARVs after rape.
  - B) Neliswa’s anaemia.
- Demonstrates how these can be redressed.
- Next steps:
  - A) Use research for advocacy/policy change
  - B) Training





Thank you