

Participation, Expertise And Science

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Some background questions

How should social researchers be spending their time in contexts where resources are scarce?

In divided societies, how do researchers gain credibility?

What does community participation in research mean, and what makes it a 'good thing'?

The context

Need to produce knowledge in poorer country contexts

Imbalance between knowledge produced in wealthier countries and need for knowledge in poorer countries (90-10 gap)

Increasing demand internationally for 'evidence' as precursor for policy and implementation changes, and especially for funding

Challenges in research (I)

Infrastructure and resources

Power relationships – internationally and within countries

Ethical questions

- informed consent

- research burden on the poor

- third world 'guinea pigs'

Challenges in research (II)

Ignoring context – e.g. Saving the children for the tobacco industry

Design issues – especially contamination

Cultural differences in ways that research is seen, understood and experienced

Promise of research as a 'way out'

The time frame problem

The burden on data collectors

(Nama & Swartz, 2001)

Assessing versus intervening

Insiders & outsiders

Cultural beliefs & witchcraft

Ubuntu & the imperative to help – identity politics

Some implications

Research ethics versus local responsibility

Dilemmas broader than individual or isolated questions of ethical/cultural problems

Need broader debate about design, ethics, and what research means in different contexts

Two areas of interest

Disability research in South Africa: the interface between science and the politics of participation

Participation and empowerment in Aids vaccine research

Disability research

Two stories

Medical and social model

South African disability politics

Social security research

Two stories

Medical model

Locates disability in the body of the 'sufferer' and role of science to alleviate suffering

Seen as:

Welfarist

Patronising

Controlled by able bodied

Excluding disabled people from power

Contributing to human rights abuses

Social model

Move from bodily impairment to disability

Contextual: environmental facilitators and barriers

Human rights, participation, inclusion

Locates disablement in societal barriers to the extent that 'Society is disabled'

Implies different processes in decision-making – e.g. 'nothing about us without us'

Consultation models wrest expertise from professionals to disabled people – foregrounding of 'insider knowledge'

Legitimacy issues for professionals

Disability policy in SA

Office on Status of Disabled Persons in the Presidency

Integrated National Disability Strategy (INDS)

Africa Decade on Disability (NEPAD context)

SA Human Rights Commission focus on disability

The INDS

Human rights approach

Participation

Part of broader moves towards social inclusion

Emphasises the interactional nature of disability

Defining disability: the SAHRC

Disability is a social construct and most of its effects are inflicted on people by the social environment (*emphasis added*)

Most of the day-to-day problems that people with disabilities face are caused by the fact that they live in a hostile, disabling world which is largely designed to suit able-bodied people (*emphasis added*)

Defining disability: the SAHRC (2)

Classification... should be made in a social and not an individual context

No one should be 'forced' to belong to the group of citizens known as 'people with disabilities'

'Prejudice remains the greatest disability'

How do we assess accurately for disability benefits?

Challenge to determine social security provision when disability is seen as:

Experience or situation that person faces as a result of an interaction between a health condition or an impairment and the context of the person (including personal and societal factors)

Not static feature of the individual

Social security (2): the problem of boundaries

Decision-making about grants requires two things:

A focus on the individual (*Does this person qualify for a grant?*)

A clear boundary between disability and nondisability (*Is this person ineligible for a grant, on the grounds of not being disabled?*)

We have to force people to belong to the category of people *without* disabilities (cf SAHRC approach)

Social security (3): technical questions of assessment

Disability as a *relational concept* as opposed to a *static attribute*

Difficulties throughout the process in meeting both the technical needs and the broader social needs, including those of participation and communication with public

Social security (4)

Policy/legislation/practice divides

Implementation and capacity challenges

Dealing with corruption but not allowing this to dictate all policies

Problem of lack of other poverty relief measures

Ethics of fair distribution as opposed to ethics of the individual assessor

SA Aids Vaccine Initiative

Established in 1999 by the MRC

Aim: to co-ordinate the research, development and testing of HIV/AIDS vaccines in South Africa

Of necessity: focus on at-risk communities (racial and social skews)

Key sociobehavioural questions

How best do we attract participants into the study and make sure that they remain in the study for the necessary duration?

How do we make sure that being in the study does not cause them harm?

Community education and preparation

ensure the ethical and scientific quality of proposed research

ensure relevance to the affected community

evaluate acceptance by the affected community

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(Source: HVTN)

Community preparation (contd)

involve community representatives in the design, development and implementation of trials and distribution of trial results

establish a process for arriving at standards and best practices at international, national, and local levels.

(source: HVTN)

Community preparedness

SAAVI has a Community Involvement Programme that disseminates information, raises awareness and promotes human rights in relation to the development of HIV vaccines within South African communities.

Masikhulisane ('Let us grow together')

Vision

A South African society working in a mutually beneficial and meaningful partnership with AIDS vaccine researchers within a vibrant human and legal rights environment.

Mission

A sustainable, accountable, learning organisation, founded on a human rights ethos to ensure an informed and educated South African society with active and sustained community involvement in the AIDS vaccine development process.

Mission and vision go far broader than Aids Vaccine research

Emphasis on human rights context in South Africa

Research as an opportunity to contribute to a better society

Research providing a *responsibility* to contribute to a better society – can we deliver?

The empowerment/WTP matrix

What is participation?

Differing meanings in different contexts

Sometimes an end in itself, independent to a degree from research design and outputs

Sometimes a pragmatic necessity rather than a social good in itself

Danger of confusing the two

Is participation only (or especially) for the poor and vulnerable?

What is participation?

Who participates on whose behalf?

Who speaks for whom and who may speak for whom (even within oppressed groups)?

Need for 'docile'/'collusive' representatives?

Need to address the linked issues of participation and expertise explicitly and recursively