ALAN J FLISHER MEMORIAL LECTURE 2024

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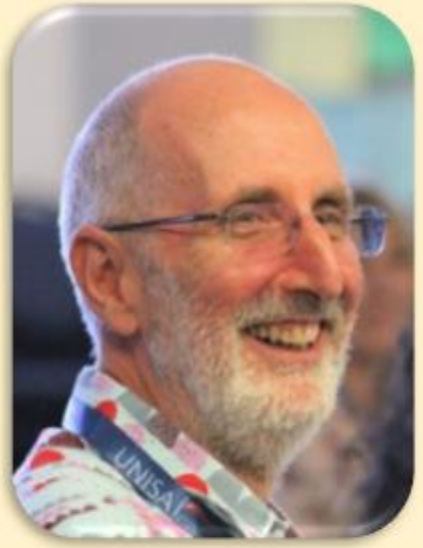

Professor Leslie Swartz

"All over the place: an undisciplined look at global mental health"

Stellenbosch UNIVERSITY
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Alan J Flisher Memorial Lecture 2024

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ALAN J FLISHER CENTRE FOR PUBLIC MENTAL HEALTH

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SPES BONA

Remembering Alan J Flisher

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Prof. Alan J. Flisher was a pioneer in the field of public mental health in South Africa and a world renowned scientist, academic, mentor and mental health professional. At the time of his untimely passing in April 2010, he held the position of the Sue Struengmann Professor of Child & Adolescent Psychiatry & Mental Health at the University of Cape Town and was Director of the Mental Health and Poverty Project.

Alan's remarkable achievements in the area of public mental health; his networks in African psychiatry and mental health; and his mentorship and leadership of many who are now involved in the work of the Centre motivates and inspires the work of the Centre.
(SOURCE: https://cpmh.org.za/about/alan-j-flisher/)

IACAPAP STUDY GROUP

Held at Kenya School of Monetary Studies, Nairobi

17th - 20th March, 2007

Seated L - R Dr. Oluwayemi Ogun (Nigeria), Dr. Birke Anbesse (Ethiopia), Dr. Monique Mucheru (Kenya), Dr. Ntone Felicien - (Cameroon), Dr. Ruth Kizza (Uganda), Dr. Puleng Mokoena - Molepo (South Africa).

1st Standing L - R Dr. Keith Kirimi (RSA), Dr. Rachel Kang'ethe (Kenya), Dr. Dolores G. Moreno (USA), Prof. Alan Flisher (RSA), Dr. Olayinka Omigbodun (Nigeria), Dr. Tolulope Bella (Nigeria), Dr. Yonas Baheretibeb (Ethiopia).

2nd Standing L - R Prof. Brian Robertson (South Africa), Dr. Patricia Ibeziako (Nigeria), Dr. Okello James (Uganda), Dr. Myron Belfer - (USA), Mr. Preston Garrison (USA), Dr. Naoufel Gaddour (Tunisia).

All over the place: an undisciplined look at global mental health

A (highly selective) origin story

- The colonial encounter with the ‘other’
- The excitement of difference:
  - Culture bound syndromes
- The pathologization of revolt/resistance
  - Drapetomania

Royal Academy for Overseas Sciences

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Renamed as the "Royal Academy of Colonial Sciences" in 1954, our Institution changed its name to the present "Royal Academy for Overseas Sciences" in 1959.

A South African story

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- Colonial conquest
- Asylums
- Racism and race science (but also a sincere wish to understand)
- Social work and miscegenation
- The abuse of cultural relativism
- “Acculturative stress”
- Critique and rebellion
- Adapting to a new democracy
- Progressive policy, innovation
- The challenge of ‘delivery’

The centrality of ideas about disability to colonial projects

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"In the broadest sense, colonialism demanded able bodyminds from subordinated subjects. Colonial projects imposed impossible regimes and expectations of self-regulation its subjects would not be able to perform. Thus, the colonized were ***always already figured and constituted as disabled***, whether because of their perceived unproductivity as laborers; embodied racial-sexual differences; "unchaste" proclivities of their women; susceptibility to moral contagion and infectious diseases; or inability to learn. In the undulating colonial hall of mirrors, the inversion of these qualities — too much learnedness and the adoption of European manners, for example — could mean colonized people had failed to maintain the vigor of their "race." Thus, we begin to see how disability operated as a flexible and capacious concept and a very useful weapon during the incarceration, elimination, and removal of unfit colonial Others."
(Imada, 2017)

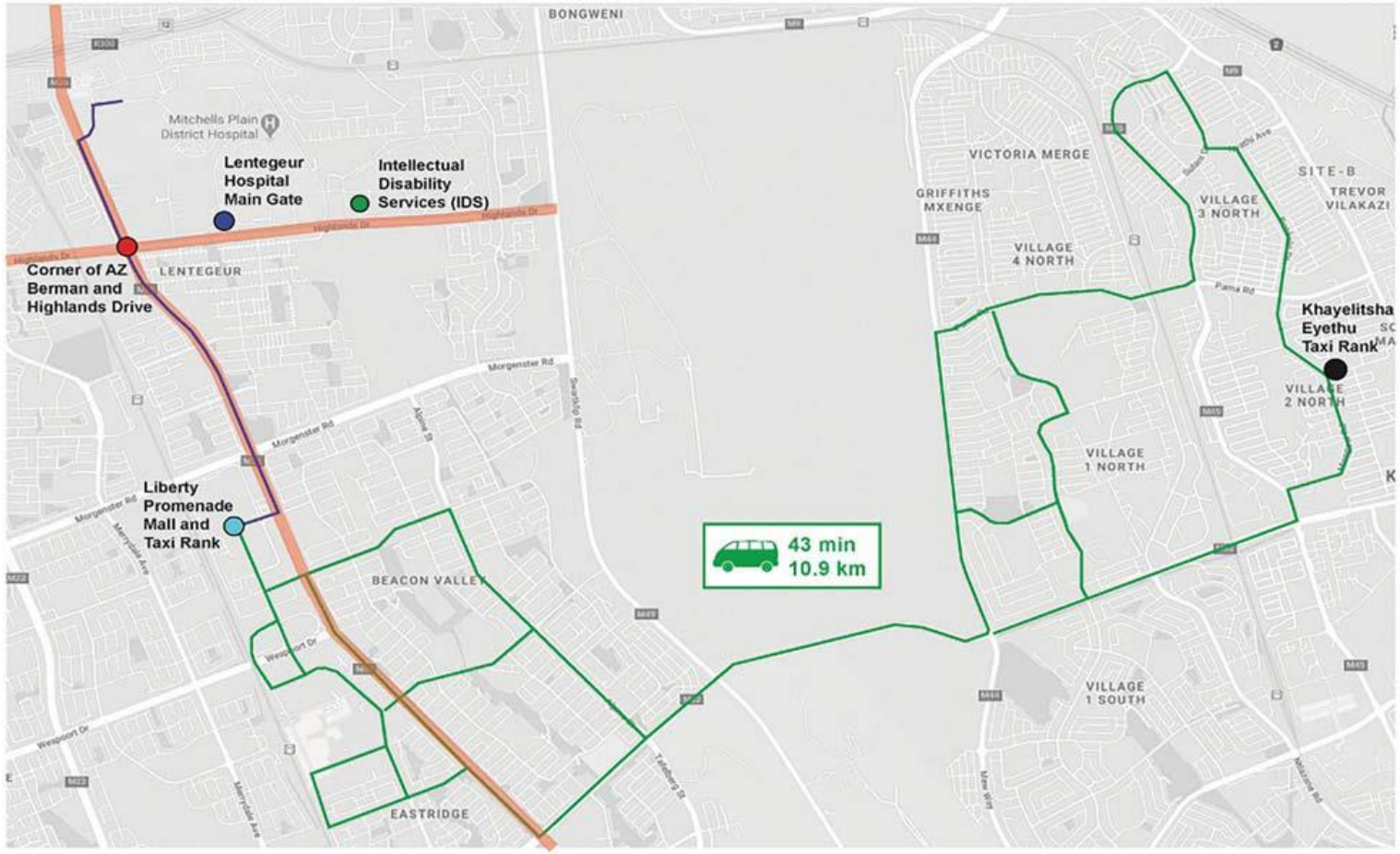
The United Nations Convention on the Rights of Persons with Disabilities

- Article 1 - Purpose
- The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
- Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

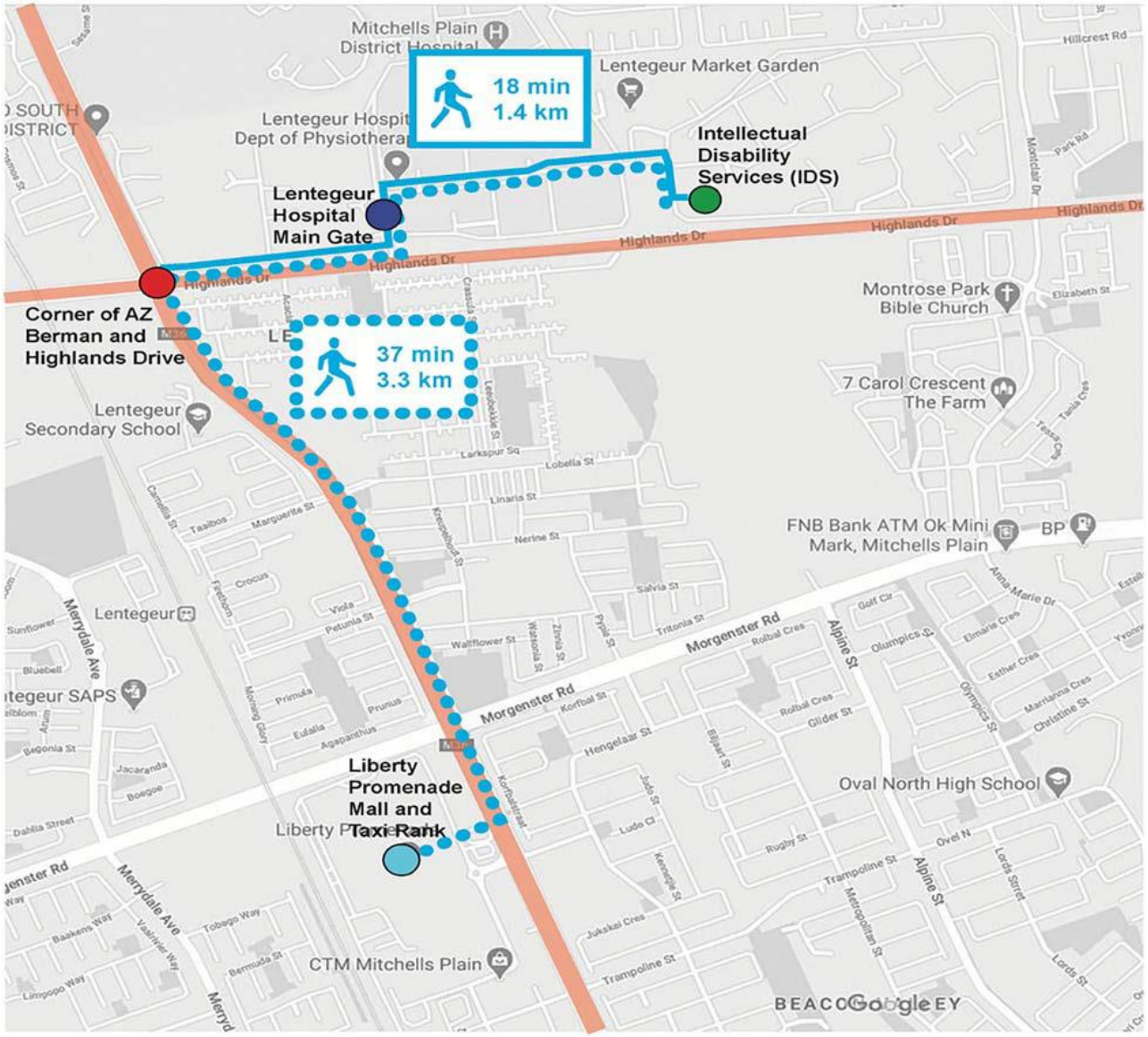
Some key contributions of disability studies thinking to global mental health

- Disability is a *relational construct (*Jette)
- Disability does not exist within people but in the relationship between people and the environment (physical, social, attitudinal, etc)
- Emphasis on participation
- ‘Nothing about us without us’
- Context matters, and context needs to be carefully looked at

An example (Mkabile & Swartz, 2022)



A hazardous walk



The three ‘T’s of disability in health service provision in low resource contexts

- Transport (as we have seen; Daily Dispatch article)
- Toilets (see Coulson, Napier & Matsebe, 2006)
- Time (Munthali et al., 2019)

EASTERN CAPE AMBULANCE: Mxolisi Sigaqa of Willowvale is pulled by his sister, Ntombencinci Sigaqa, in a wheelbarrow while his brother, Sikhwenkweni Sigaqa, helps to push. The 61-year-old man was on his way to Tafalofefe Hospital in Centane earlier this year when the Dispatch met him on the road. Read about Sigaqa in our special investigation into rural healthcare starting tomorrow Picture: SINO MAJANGAZA

Picture: SINO MAJANGAZA

DISABILITY AND REHABILITATION
2019, VOL. 41, NO. 6, 683–690
https://doi.org/10.1080/09638288.2017.1404148

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RESEARCH PAPER

Check for updates

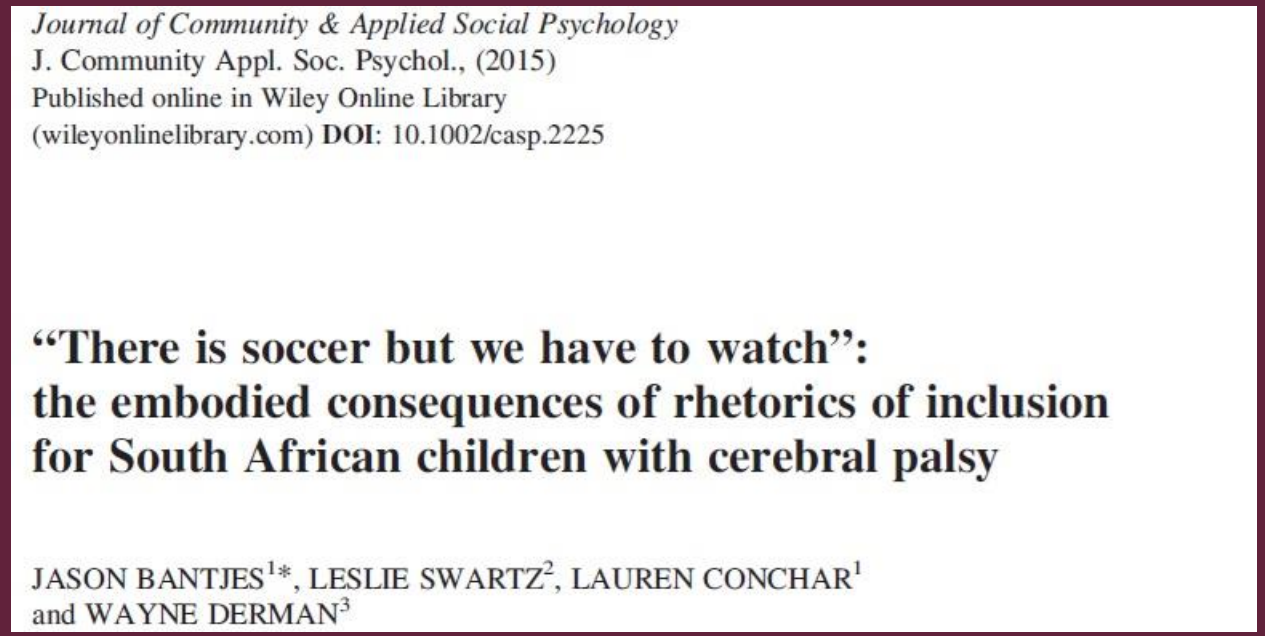
“This one will delay us”: barriers to accessing health care services among persons with disabilities in Malawi

Alister C. Munthali[a], Leslie Swartz[b], Hasheem Mannan[c], Malcolm MacLachlan[d,e,f], Charles Chilimampunga[g] and Cecilia Makupe[h]

[a]Centre for Social Research, University of Malawi, Zomba, Malawi; [b]Department of Psychology, Alan J Flisher Centre for Public Mental Health, Stellenbosch University, Stellenbosch, South Africa; [c]School of Nursing, Midwifery and Health, University College Dublin, Dublin, Ireland; [d]Maynooth ALL (Assisting Living & Learning) Institute and Department of Psychology, Maynooth University, Ireland; [e]Centre for Rehabilitation Studies, Stellenbosch University, Tygerberg, South Africa; [f]Olomouc University Social Health Institute, Palacky University, Olomouc, Czech Republic; [g]Department of Sociology, Chancellor College, University of Malawi, Zomba, Malawi; [h]Chancellor College, University of Malawi, Zomba, Malawi

Contextual realities and resource realities: the 'integration' question

- Equality and integration



Journal of Community & Applied Social Psychology
J. Community Appl. Soc. Psychol., (2015)
Published online in Wiley Online Library
(wileyonlinelibrary.com) **DOI**: 10.1002/casp.2225

"There is soccer but we have to watch": the embodied consequences of rhetorics of inclusion for South African children with cerebral palsy

JASON BANTJES[1]*, LESLIE SWARTZ[2], LAUREN CONCHAR[1] and WAYNE DERMAN[3]

Integration of mental health into primary health care

- Resource efficiency
- De-institutionalization
- Convenience and accessibility
- Many excellent studies on task sharing, role of nurses, CHWs, others
- Assumptions about destigmatization (intergroup contact)
- Contact hypothesis – more than just contact

Primary health care and the reality of waiting

- What happens in the queue?
  - Dangers of queueing
  - Difficulties of waiting in the context of mental disorder

  (Swartz & MacGregor, 2002)

- Staff dissatisfaction
  (Rall & Swartz, 2023)

Because I have been at the facility for 16 years now and when I came here, it was – but at that time it was not yet integrated. Then there was a, a, a dedicated nurse who did it and it went very well. And those dedicated nurses also went to the different villages. She also had her special people there who she went to visit. Like now everything has just disintegrated with the, collapsed because of the integration. (Mrs X, facility manager; translated)

Creative ‘re-segregation’ (Rall & Swartz, 2023)

I understand we have to fall in the same line every month to get our pills but then to go through all the questions about why are you here? Then you have to tell her, no I’m here to get my pills, and then she asks, what’s the pills? And then you have to say, my pills for bipolar, in front of everyone. So I say every month I tell everyone there I’m bipolar – everyone who can hear. And I don’t care – people can know. Because I don’t see it as a, as a sin or whatever, it’s not – I didn’t choose it. It chose me. And I have learned to live with it, but if it can be made easier to just be able to get my stuff every month that I can cope with, that would be much better. It will really, it will help just so much, help so much more . . .

Interviewer: *What happens if you have to stand here and wait? (translated)*

Gavi: *That’s something funny, sir . . .* (translated)

Interviewer: *Yes?* (translated)

Gavi: *It works on me, sir, because it’s my date, the waiting doesn’t make right with me, sir. Everywhere I go I have to wait. There, when I almost stand behind, I get sicker and then I have to take pills now I have to take pills at home, then I get those eye problems again. (Gavi, MHCU; translated)*

Interviewer: *And when you have come here recently, do they help you quickly?* (translated)

Gavi: *Yes, sir, they help me, they no longer make me wait for other people who come here. I get a date that I come here, then I don’t wait so long for other people. I said once [I] come in the afternoons then there are not so many people.* (Gavi, MHCU; translated)

Language barriers, waiting, care, and task-shifting in Africa (see Swartz et al, 2014)

- Waiting: Refugees and migrants in PHC (cf: ‘This one will delay us’ in Malawi)
- Unplanned (and sometimes invisible) task-shifting in the context of language differences
- Smith et al (2013):
  - Interpreting by cleaners as hidden care work
  - The hidden ‘ward round’
  - The importance of the researcher who is not a clinician
- Hanft-Robert et al (2024a&b)
  - Security guards’ multiple hidden roles
  - Pride and pleasure of informal interpreting
  - Ethical concerns (cf Hlongwani, 2021)

Clinician practices in light of language discordance

GLOBAL HEALTH ACTION
2020, VOL. 13, 1684072
https://doi.org/10.1080/16549716.2019.1684072

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ORIGINAL ARTICLE

OPEN ACCESS Check for updates

Ad hoc interpreters in South African psychiatric services: service provider perspectives

Sybrand Hagan[a], Xanthe Hunt [a], Sanja Kilian[b], Bonginkosi Chiliza [c] and Leslie Swartz [a,d]

[a]Department of Psychology, Stellenbosch University, Stellenbosch, South Africa; [b]Department of Psychiatry, Stellenbosch University, Tygerberg Hospital, Stellenbosch, South Africa; [c]Department of Psychiatry, University of KwaZulu Natal, King Edward Hospital, Durban, South Africa; [d]Alan J Flisher Centre for Public Mental Health, Cape Town, South Africa

ORIGINAL ARTICLE

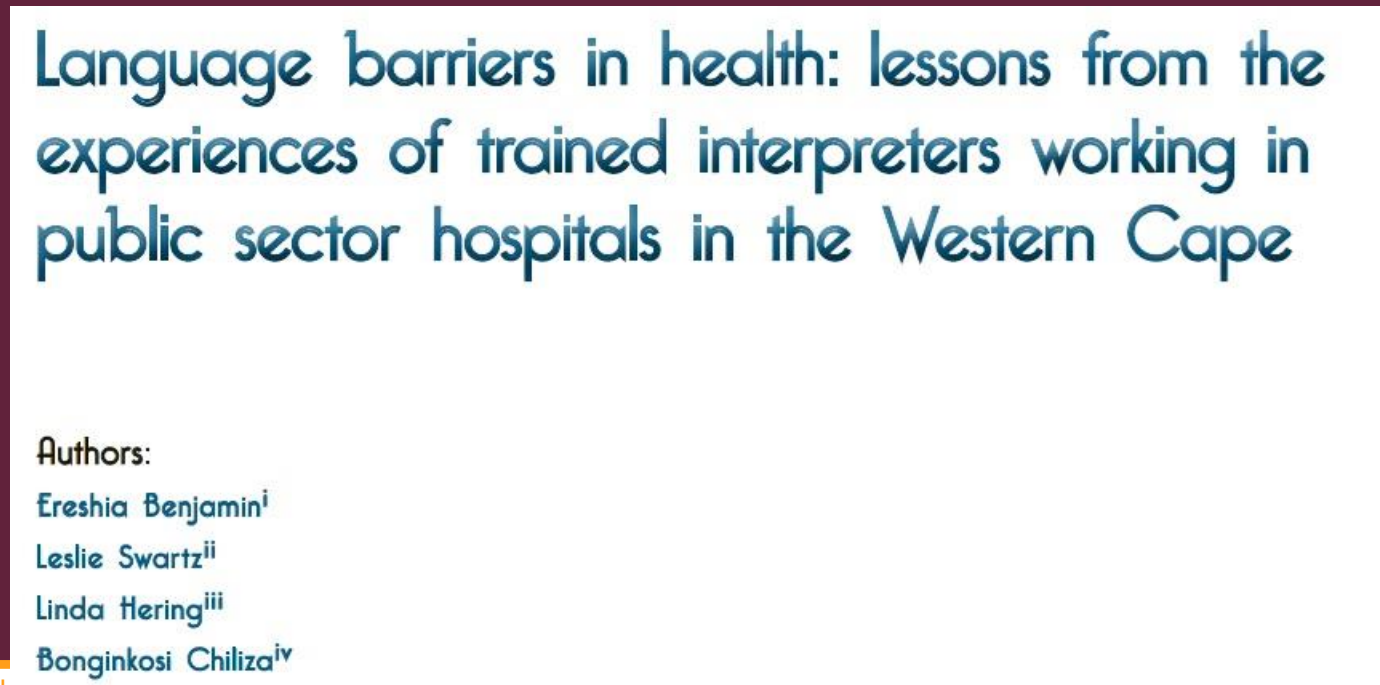
Doing their best: strategies used by South African clinicians in working with psychiatric inpatients across a language barrier

Sanja Kilian[1,2]*, Leslie Swartz[1] and Bonginkosi Chiliza[2]

[1]Alan J Flisher Centre for Public Mental Health, Department of Psychology, Stellenbosch University, Stellenbosch, South Africa; [2]Department of Psychiatry, Stellenbosch University, Tygerberg, South Africa

Interventions on addressing language issues (1)

- Benjamin et al (2016) pilot project:
  - Success stories in increasing access
  - Uneasy fit with services as they are (supervision issue)
  - Administration as ‘real work’
  - Time and waiting
  - Lack of career pathing
  - Sustainability (lack of economic evaluation)


Language barriers in health: lessons from the experiences of trained interpreters working in public sector hospitals in the Western Cape

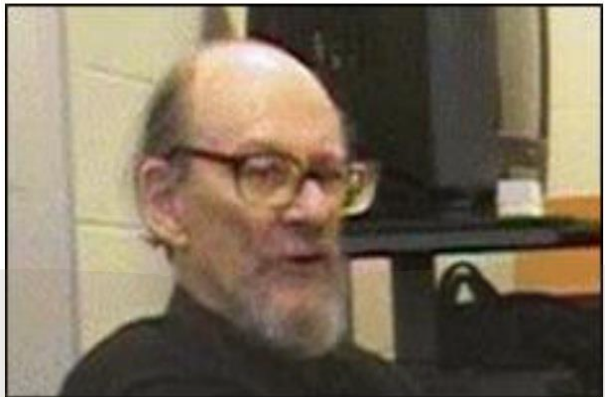
Authors:
Ereshia Benjamin[i]
Leslie Swartz[ii]
Linda Hering[iii]
Bonginkosi Chiliza[iv]

Interventions on addressing language issues (2)

- Current project planned (Anthonissen, Krishnamani, Madzamba, Mösko, Seedat, Setswe,Swartz):
  - Offshoot of MiM2M project
  - Pilot phase 2025
  - ‘Uber’ type platform for availability
  - Much larger evaluation project planned
  - Importance for trainee clinicians to receive training (mid-2025)

Disability ideologies: sometimes a poor fit with global mental health?

- The disability rights movement of the 1970s and beyond spearheaded by people with physical disabilities
- Similarities and links to anti-apartheid struggles
- Key role of Vic Finkelstein:
- *For many of us, the single factor that unites us together in our struggles is that it is our society that discriminates against us. Our society disables people with different **physical impairments**. The cause, then, of disability is the social relationships which take little or no account of people who have physical impairments. If this definition is correct, then it should be possible to prove that other social groups can become disabled, in an imaginary society which took no account of their **physical status**. In such an imaginary society it would be possible for physically impaired people to be able-bodied!* (Finkelstein, 1975, emphases added)
- 'I may be disabled but I am not mad/stupid' (cf racism, sexism)
- Psycho-emotional disability only later (feminist influence; Watermeyer)



‘Capacity’ in the UN Convention on the Rights of Persons with Disabilities (https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd)

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From *Article 12 - Equal recognition before the law*

States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

From General Comment 1:

17. Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making....“Support” is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication.... For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory.

HHR Health and Human Rights Journal
Drexel University Dornsife School of Public Health
FXB Center for Health & Human Rights at Harvard University

We need to know more about involuntary care and how people experience it


"They Had to Catch Me Like an Animal": Exploring Experiences of Involuntary Care for People with Psychosocial Conditions in South Africa

ALEX FREEMAN AND LESLIE SWARTZ

- The work of Alex Freeman suggests that
  - People with psychosocial conditions
  - Their families
  - Psychiatrists involved in their hospitalization and care
- ALL find involuntary care stressful, difficult, challenging ethically
- May not always easily be in a position to act fully in concert with GC1 provisions especially in low-resourced, multilingual contexts


Original research

Psychiatrists' experiences of involuntary care in South Africa: dilemmas for practice in challenging contexts

Alex Morung Freeman [1], Laila Asmal,[2] Leslie Swartz [1]

The importance of advocacy and aspiration (Kumar, van Rensburg and Petersen, 2023)

Panel: **Opportunities to create a better world via a liberatory global mental health field**

1 Social media and international development agencies are making the connection between peace, health, the environment, and happiness. Yet the current openness and embracing of a "mental health responsive" world must be equity-driven.

2 Southern partners need to develop global mental health training programmes that provide guidance, training, and frames of reference for HIC researchers and students, with the active support of funders.

3 With improved recognition of the voices and perspectives of individuals with lived experience and individuals living with adversities, the lived experience of practice and advocacy of researchers and clinicians in LMICs need to be similarly valued.

4 There is an increased recognition that mental health is a human right and a global good which needs strengthening across the world and within countries in all sectors of programming.[9] The recognition of integrated programming can help in formulating questions that target mental debilities that emanate due to poor social conditions.[10] In-country mental health researchers are the leaders here and point to persistent and understudied mechanisms.

5 Funders are willing to invest in mental health more than ever before and governments are talking about self care and behavioural risks in addressing population-level health and development. In taking advantage of these changes, we need to draw contextual lessons from system leaders and grassroot workers. We do not need more global think tanks or advisers from the Global North.

6 Political mobilisation cannot become a new arena of interest for global health actors without participation of local actors studying the contextual local burden of mental disorders and regional cross-sectoral actors.[10]

Taking up the challenge

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- Who may speak on behalf of whom?
- How do we preserve an understanding of diversity and intersectionality within different marginalized groups?
- How do we take epistemic exclusion and epistemic violence seriously and still reap the benefits of esoteric, professional knowledge?
- If our understanding of global mental health is broad and contextual, how do we maintain respect for, and focus on, specific forms of experience and what many of us would call illness?
- Three key areas to think about (not an exhaustive list):
  1. Medicalization
  2. Populism
  3. Professionalism

Medicalization

- Medicalization of social issues/nonconformity is clearly a problem
- But even amongst those who are critics of medicalization, it has proved useful politically, for example:
  - The establishment of PTSD as a disorder (Lifton)
  - Activism against the state during apartheid
- Anti-medicalism is **not** demedicalization:

  *Having a biological driver of a condition does not discount the social and psychological drivers of that condition, as even a passing understanding of epidemiology shows, even when considering medical conditions such as hypertension or cancer. **Healthcare personnel are trained to hold multiple drivers in mind simultaneously**. We use this understanding to develop the best management plans within the context of the resources available.* (Hoare & Vythilingum, 2023: 1355, emphasis added)

Category drifts as a challenge

- Mental illness
- Mental disorder
- Psychosocial disability
- Psycho-emotional disability
- Mental health
- Wellness….etc

- What is the particular contribution of global mental health?

Populism (Jami 2023)

Elites	The people
Powerful	Oppressed
Corrupt	Virtuous
Homogeneous	Homogeneous

Key (potential) consequences of this split

- Representatives of oppressed groups inevitably express the wishes of those groups accurately
- People from elite backgrounds/professions cannot have the interests of oppressed groups at heart
- There can be no oppression within oppressed groups/oppression within oppressed groups must be tolerated or excused
- Members of elites must disavow any expertise and knowledge that they have
- The ‘people’ always know better

Populism and its discontents

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- Rise of right-wing populism:
  - Trumpism
  - Climate change denialism
  - Anti-vax
  - Fauci as serial killer
  - Prospect of RFK as in charge of health
- Two South African tragedies
  - HIV denialism and over 300000 deaths
  - Esidimeni and moralist ideologies of community care (anti-psychiatry)
- But – what about the populist threads in our own work in global mental health?

Professionals and professionalism

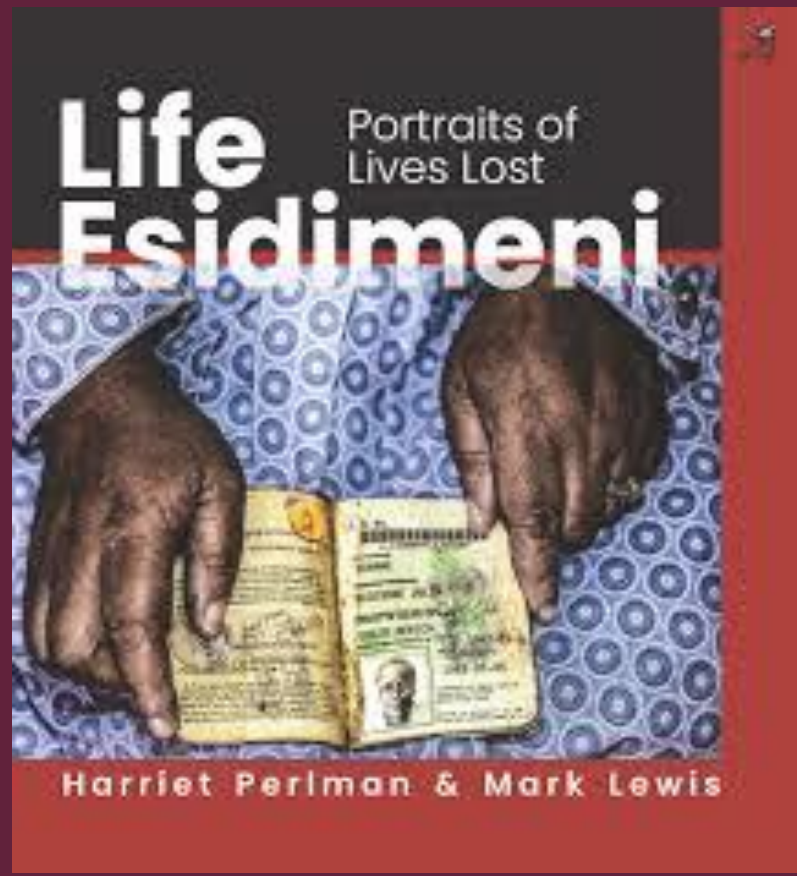
- It is abundantly clear that professionals don't know everything
- Epistemic exclusion is real – on the basis of race, class, gender, coloniality, disability, etc
- From "giving psychology away" to reinscription of psy-power post 1994
- Professional categorization and balkanization of knowledges (eg the importance of occupation)
- Even categories within professions like psychology are at odds with the epidemiological and global mental health evidence

Breaking professional boundaries while re-inscribing them (Swartz, 2022)

The psychological work that needs to be done by these families is to integrate the Life Esidimeni tragedy as part of their history and identity and to be able to live with that which cannot be forgotten.

...It will not be possible for these families to do this psychological work without professional assistance. The individuals in the families need to be assessed to determine the nature of the psychological intervention required. The indication from these consultations is that the individuals affected by this trauma need long-term psychotherapy. This needs to be done by any persons who are able to work psychoanalytically and who have had experience of trauma intervention. In addition, families may need family therapy so that the family units can heal.

(Trotter et al., 2017, p. 27).



Concluding remarks

- Among the best testaments to Alan's legacy is the work of people here today – thank you all.
- The more we build the future, the more we reproduce the past – this is inevitable (cf Posel, 2001)
- We need to keep a balance between the particular we have to offer and the general we need to know more about
- Over to the next generation….