

**Reclaiming Africa's Intellectual Futures** 

## My journey from an autistic adult to a Postdoctoral Fellow

Dr. Emile Gouws EASA Conference 17 January 2024





Define tomorrow.

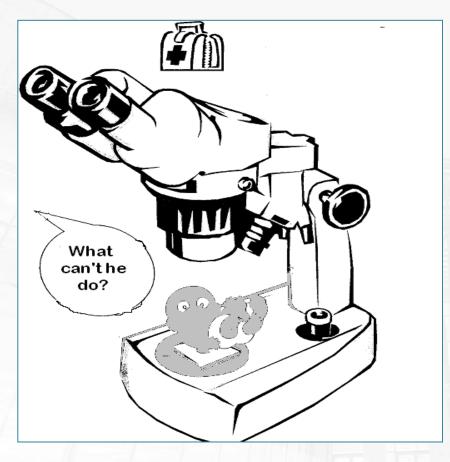
## Where do we find ourselves?

- Global north vs Global South.
- Existing research primarily focuses on early childhood development.
- Lack of first-hand accounts in published research.
- Statistics from the World Bank.
- Why is it important to conduct autism research in Southern Africa?
- Who might benefit from our research and what is the possible contribution?

## **Background and Context**

- Medical model
- Socio-Ecological model
- Constitution adapted
- Statistics of disabled students who are enrolled in Higher Education Institutions (HEIs)
- Limited support for students on the (ASD) spectrum
- Insider's perspective
- Assess the operation of a HEI
- Inclusive policy to include neurodiverse students

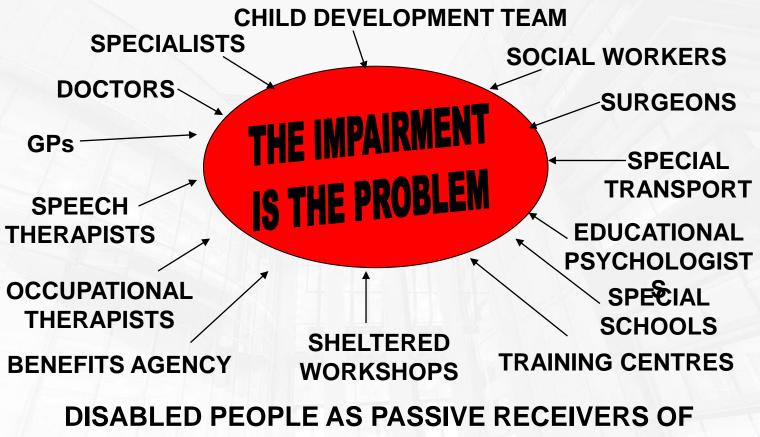
## The medical model views disabled people from a 'deficiency' lens



Consequently, the emphasis is placed on:

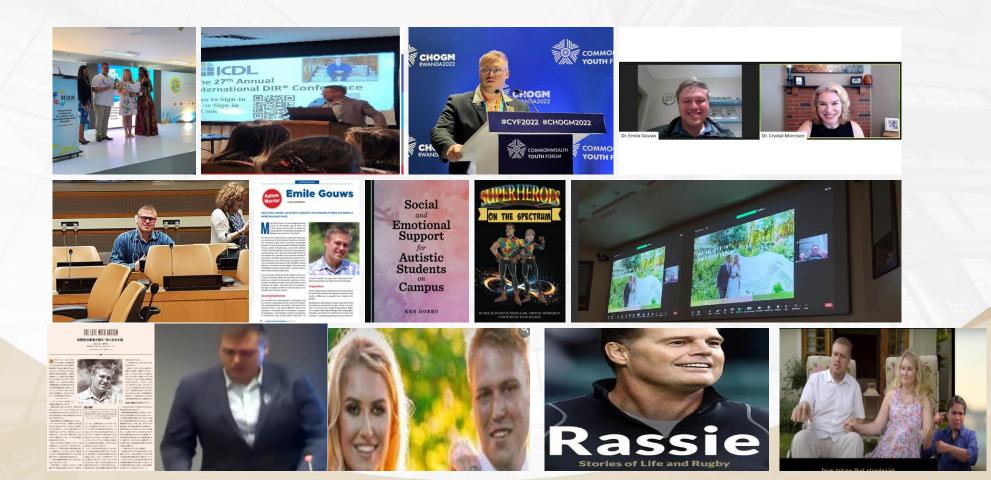
- Treatment and Cure
- Make as normal as possible
- If not possible, then segregate and institutionalise
- Or isolate at home
- Unwilling to accept people as they are

#### The dominant view is the Medical Model.



SERVICES AIMED AT CURE OR MANAGEMENT

#### Experiencing university life as an autistic student : a critical autoethnography Gouws, Emile



## How do I want to contribute?

- Publish articles on ASD and Higher Education.
- Present papers and research at conferences
- Co-supervising and supervising masters and PhD candidates
- Autism self-advocacy and research are affiliated.

#### **Theoretical Framing**

#### 1. THE DOUBLE LENS: SELF-AWARENESS THEORY

Erickson's and Chickering's theory on identity development.

#### 2. SELF-AWARENESS THEORY

Circles to evaluate the progress, feelings and learning experiences.

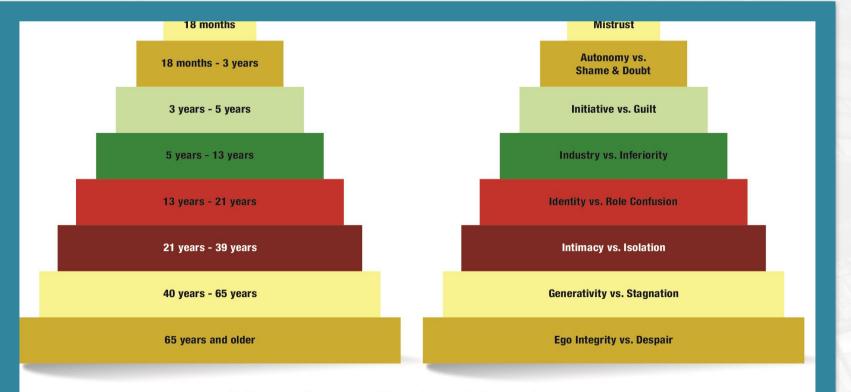
#### 3. ENVIRONMENTAL STIMULI

The principles of the Gestalt theory.

#### 4. INDIVIDUALS ON THE AUTISM SPECTRUM'S SELF-CONCEPT AND AWARENESS

The brain development of students on the autism spectrum.

#### Erickson epigenetic diagram (E)



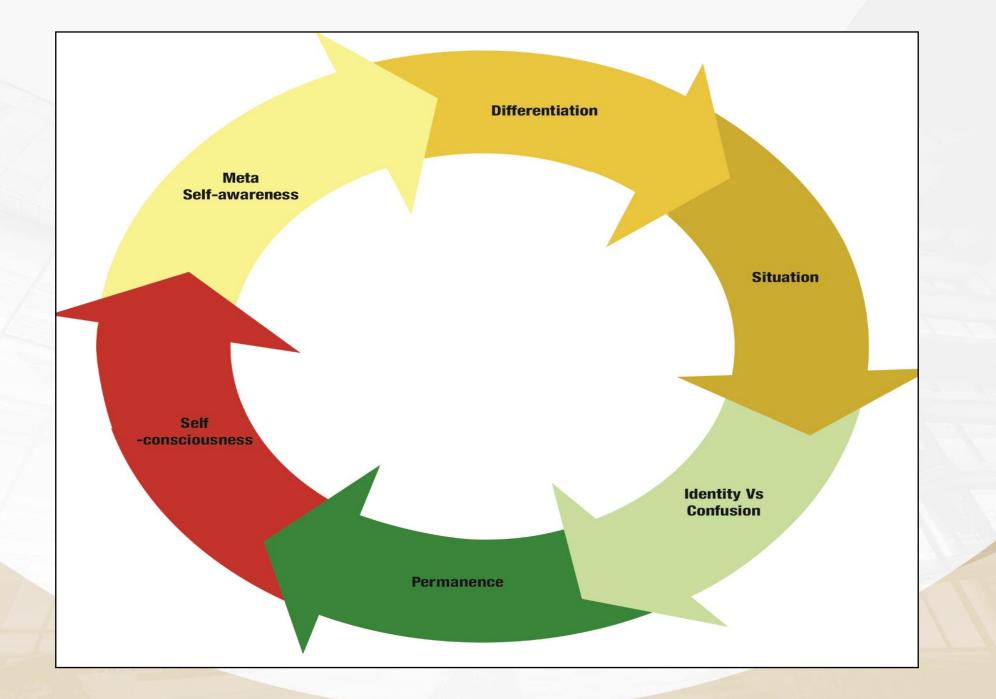
#### Erikson's Stages of Psychosocial Development

#### 1. Identity vs. role confusion

- Search for identity
- Unsure about their future
- Beliefs, ideals and values.

#### 2. Intimacy vs. isolation

- Insecure and requires support
- Adapt to the circumstances
- Development of self-concept and general awareness
- Works daily on identity formation



## Cognitively

- Goal orientated
- Hyper-focused
- Focused on completing my PhD
- Online teaching

#### **Emotionally**

- Stimmed
- Expressive outbursts
- Self harm
- Implemented different defensive mechanisms
- Support system

#### As a PhD student...

- To provide an insider's perspective.
- To create awareness of how students on the autism spectrum experience university.
- To explain my experiences through the use of autoethnography as methodology.
- To reveal the lack of understanding and acceptance by society in general.

#### Literature review

- Vulnerable groups face increasing isolation through their physical, neurodevelopmental and psycho-social conditions.
- Significant challenges.
- Persons with autism require varying levels of individualised support
- International universities embrace inclusivity.
- Heightened levels of frustration and anxiety.
- Sensory processing differences.
- Different levels of support ranges.

	PLAN THE ESEARCHER USES	Research paradigm Approach ontological Epistemological assumptions
2. 01	NTOLOGY	Structure of university Suited for a particular "target group" students Risk for failure The origins of knowledge are based on my personal experiences
	RITICAL PARADIGM CLUSIVE EDUCATION	Aim of this study: share my personal account Change the public institutions perceptions Critical paradigm: formulate ideas to promote change within our HEIs

#### **Research Methodology**



#### **QUALITATIVE APPROACH**

**1. INTERVIEWS**Interviews were conducted with key<br/>members of the university community.Belief that neurodiverse students are<br/>competent to be successful.

# **2. A PARTICIPANT**<br/>MYSELFAs the researcher, I became a participant.<br/>Objective position.<br/>Form a perception of a specific culture.<br/>Personal observations and experiences.

3. QUALITATIVE APPROACHES

Variety of research methods employed. I was subjectively involved.

## **Emotional Domain**

- I portrayed non-verbal behavior during my primary school career.
- I portrayed my emotions by making use of non-verbal hand gestures to express myself.
- Fellow learners noticed my non-verbal behavior and I became a victim of emotional abuse.
- I was not invited into social groups and was isolated.
- This affected my self-confidence levels negatively and I did not compete in any sports.

## **Social Domain**

- Sensory overstimulation was one of the reasons why I was nonverbal, especially in unfamiliar environments.
- My social skills were limited. I struggled to start and end a conversation.
- My parents exposed me to different social situations and motivated me to not portray avoidance.
- In high school my social skills developed more, and I participated in cultural activities such as the revue.
- I've learned defense mechanisms to deal with sensory overstimulation challenges.

## **Remedial Senior School**



### I believe in neuroplasticity.

- The ability of the brain to change by forming new connections among neurons in response to environmental inputs.
- The ability to quickly establish new neural networks would increase processing speed and efficiency.
- The brain's capability of greater plasticity would therefore develop stronger intellectual skills.

## Support for autistic students in HEIs

- If the environment is more accommodating of autistic people, they will enrol at university with less pain and won't experience social trauma.
- With appropriate support, autistic students will excel and gain control over their own behaviour.
- Environmental modification must take place so that autistic students can strive and reach their goals.
- Autistic students need to study in an environment that accommodates their needs.

## Support for autistic students in HEIs

So far, I have adapted to environments and self-actualised. I believe that I survived because of my phenotype, because I have learned to adapt to any changing environment, and my learning experiences were rewarding because I have learned that I can modify my behaviour in social environments.

I had to learn through experience that I can self-actualise in a neurotypical environment.

I believe the environment at university shaped my behaviour and that I am pre-wired to learn.

## Conclusion

Through retelling my personal experiences as an undergraduate student on the autism spectrum, my study revealed that stigmatisation persists in all aspects of university life and prohibits students who proclaim to be different, from enjoying the full university experience.

#### My Postdoc will focus on...

I am now poised to extend my self-advocacy to representing the broader neurodiverse community within HEIs, as my research will focus on "Support for neurodiverse staff and students within higher education".

Together with my current mentor, Prof Clasquin-Johnson, I will be editing *African Perspectives on Autism, Volume 2*.

I will be co-supervising postgraduate students across the globe on various topics related to autism.

My international disability rights activism will continue.

## **Contact details**

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