Review

HSRC researchers who live with disabilities pg 4 - 9

Deaf and hard-of-hearing learners: Looking at a bilingual model of education pg 16

Frontier technology and big science: The need to be inclusive pg 22

Living with disability

HSRC
Human Sciences
Research Council

Contents

Editor's note

The recent arbitration hearings into the Life Esidimeni tragedy brought to light a string of events that experts and veteran South African human rights activists predicted for months but were unable to prevent.

In 2016, at least 143 patients died after being transferred to NGOs that were not equipped to care for them.

In a recent policy brief, the South African Human Rights Commission (SAHRC) says this tragedy serves as a stark reminder of the untenable obstacles that people with disabilities still face in South Africa. The commission writes that merely defining the term 'disability' is contentious. The Convention on the Rights of People with Disabilities describes it as an 'evolving concept' defined more by the lack of an enabling environment than by individual capacity.

Disability can be caused by physical and intellectual impairments as well as mental health conditions. In the Life Esidimeni case, we saw that some of the most vulnerable patients had a combination of these impairments.

Every year, South Africa observes National Disability Rights Awareness Month (November) and Mental Health Awareness month (October) and in this edition of the *HSRC Review,* we profile three of our researchers who live with hearing and sight impairments. We do this recognising that among us, there are many more living with perhaps more silent types of disability that they are not yet ready to be open about as they fear stigma.

In his article about disability, Tim Hart writes about moving perceptions away from medical and welfare models to social and human rights understandings of disability, employment equity issues and the need for inclusive design of buildings and infrastructure to be the norm rather than the exception. In another article, Hart writes about the difficulty people with mental health conditions experience around disclosure. In an interview about his own hearing disability, he emphasises the diverse needs of people with disabilities,

which require individual rather than universal solutions.

At a recent HSRC seminar, experts in education for learners who are deaf and hard of hearing shared their insights about the poor education outcomes in this group. They also propose and are already testing some successful interventions.

In this edition, Leana Meiring writes about her experience of a social support intervention for people with severe mental illness. Recognising the dangers of social isolation, a group of students supported mental health patients in a primary healthcare setting to establish meaningful connections with others.

As seen in the Life Esidimeni case, government officials averted legal action by activists, assuring them that the patients would be moved in a properly controlled process. This did not happen, despite the Promotion of Equality and Prevention of Unfair Discrimination Act prohibiting the removal of supporting or enabling facilities that people with disabilities need to function in society. The SAHRC writes in its policy brief that this provision was "severely violated".

This raises the question of adherence and implementation of court decisions and agreements that relate to the socio-economic rights of our most vulnerable. In another article Prof. Narnia Bohler-Muller, Adv Gary Pienaar, Dr Michael Cosser and Dr Gerard Hagg write about the extent to which decisions of the Constitutional Court and Supreme Court of Appeal contributed to the realisation of socio-economic rights and promotion of equality.

Along with Hart, Bohler-Muller and HSRC researcher Lungelo Mlangeni, who both live with visual disabilities, are also profiled in this edition.

Cover Photo:
Polite Maporisa (25) from Salvokop in Pretoria obtained a bicycle that was used to convert his wheelchair into a handcycle. Before the conversion, his arms used to tire quickly while he commuted. A simple action like mounting a curb, was a challenge in areas that are not wheelchair-friendly. These days, he rapidly covers kilometres in an around the City of Tshwane without needing assistance.

News roundup

HSRC forms partnership to improve cities

Prof. Ivan Turok

South Africa, through the HSRC, is a founding member of a recently formed global knowledge partnership on the dynamics of cities. It is called the Centre for Sustainable, Healthy and Learning Cities and Neighbourhoods (SHLC).

This major new research programme is funded by the UK Government's Global Challenges Research Fund and administered by the University of Glasgow in Scotland.

In November, Prof. Ivan Turok, the executive director of the HSRC's Economic Performance and Development programme, attended and spoke at the SHLC's inaugural meeting in Glasgow.

Turok said the emphasis on international collaboration was particularly important in this new era of rising global tensions, when there is a tendency for countries to become more insular.

The new world order is also characterised by a preoccupation with national interests. This risks demoting sub-national agendas, including the development of regions, cities and neighbourhoods, where people live their everyday lives. Many of these are disabling, hazardous environments that limit people's chances in life and undermine their well-being.

An important feature of the research programme is the emphasis on useful knowledge for the public good. We need to identify ways of improving urban conditions through concerted efforts by government and communities themselves.

The SHLC aims to strengthen research skills among urban researchers, government officials and policy makers in developing countries and the UK to assess best practice in building inclusive cities. It will conduct comparative studies of urban neighbourhoods to address the challenges caused by large-scale rural to urban migration.

China, Tanzania, Rwanda, India, Bangladesh and the Philippines are other partners of the SHLC. The project will start by studying urban transformation in large and small cities in these countries, including Cape Town and Johannesburg. The HSRC and the University of the Witwatersrand are the consortium partners in South Africa.

Turok stressed that this is a partnership of equals, characterised by mutual respect and reciprocity among members, rather than an old-style imbalanced relationship between researchers in the North and South.

The commitment to capacity strengthening is also extremely important to develop the next generation of urban researchers in the social sciences.

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News roundup

Dr Firdous Khan

Young HSRC leader joins prestigious Ship for World Youth programme

The HSRC's Dr Firdous Khan has been selected to be part of the Ship for World Youth programme, a mostly ship-based international youth exchange program sponsored by the Cabinet Office of the Japanese Government.

Khan is one of 12 talented young South African leaders joining more than 200 participants of 11 countries, first in Tokyo and then on board the Japanese Nippon Maru ship between 16 January and 4 March 2018.

"We will attend seminars in Tokyo and then board the ship in Yokohama. For four weeks, the ship will be our venue for meetings and seminars," says Khan, a post-doctoral fellow and research specialist in the HSRC's Centre for Science, Technology and Innovation Indicators.

"The youth will be involved in running workshops and discussions on topics such as economic development, disease, inclusion and sustainability. The participants will be challenged to deepen their mutual understanding, broaden global perspectives, and strengthen their spirit of international cooperation."

Khan says the programme aims to develop the ability to deal with different cultures and to improve leadership and management skills through discussions and cultural exchange.

"It will broaden our global views and strengthen our spirit of international cooperation and, as a result, cultivate youth who are capable of contributing to society by exercising their leadership skills in various fields in our globalising and diversifying societies. We hope to establish a strong human network beyond national borders."

The ship will dock at ports in India and Sri Lanka where participants will meet government officials and attend meetings.

Khan says the 12 South African delegates were selected from around the country based on the contributions they have made in their respective fields. She holds a PhD in biotechnology and an MSc in bioinformatics from the University of the Western Cape.

"I was selected by South Africa's National Youth Development Agency and Japanese consulate for this programme after being named as one of the 2017 *Mail & Guardian* 200 Young South Africans in the Health Category.

"During the programme, I will be one of the main contributors in the health and social innovation seminars. I will also be the presentation coordinator for the South African delegation and the PR and communications representative."

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Japanese Nippon Maru ship

News roundup

HSRC attends Science Forum South Africa 2017

The 2017 Science Forum South Africa (SFSA 2017) took place at the International Convention Centre of the Council for Scientific and Industrial Research in Pretoria, in December.

More than 260 speakers covered themes such as "Preparing people for the knowledge economy", "Open science and open innovation for Africa's development", "Science transforming society" and "Innovation shaping the industry of tomorrow".

Started by the Department of Science and Technology in 2015, the SFSA brings together thought leaders, scientists, government representatives, industry leaders, civil society organisations and policy-makers.

The 2017 forum was opened by Deputy President Cyril Ramaphosa, who highlighted the fact that South Africa's National Development Plan and the United Nation's Sustainable Development Goals identify science as a crucial instrument for growth and development. Ramaphosa said that "in a rapidly changing global economy, our continent must invest in the development of young scientists to reap the economic and social benefits of the Fourth Industrial Revolution".

The Fourth Industrial Revolution was a major topic of discussion at SFSA 2017. We are currently in the midst of this revolution, which is characterised by new ways in which technology becomes embedded within societies and even the human body.

At one of the panel discussions titled "Transformative Innovation Policy and the Fourth Industrial Revolution", the HSRC's Dr Hester du Plessis, pointed out that "social innovation is an important part of technological innovation". Instead of society following technological trends, technological innovators need to consult with society in order

Delegates interact at the HSRC booth at the 2017 Science Forum South Africa.

to maintain a healthy balance. (See article on page 22.)

The SFSA 2017 showcased African science and also ignited conversations on topics such as open science, science diplomacy, science communication, the enabling environment for science, technology and innovation, the fundamental role of academies of science, human capital development, and investing in global research infrastructure within the context of a world in transition. Many of the sessions reflected on the importance of increased investments in African science and innovation.

At the closing ceremony, several scientists from the African continent received Science Diplomacy Awards. Prof. Phuti Ngoepe of the University of Limpopo received the Human Capital Development Award for his efforts to leverage international cooperation to support the career development of young scientists in Africa. Prof. Arun Kulshreshtha, the outgoing director-general of the Non-Aligned Movement Centre for Science and Technology, received the International Peace Understanding and Solidarity Award for successfully

ensuring the centre succeeds despite limited resources.

The former CEO of the HSRC, Dr Olive Shisana, received the Science Diplomacy Award for putting science at service for fostering international friendship and for her contribution to advancing South Africa's position in the global science arena.

Robert-Jan Smits, the European Commission's director-general for research, innovation and science, received the Excellence in Global Science Award for his contributions to the strategic South Africa-EU science partnership. Dr Heide Hackmann of the International Council of Science received the award for harnessing scientific advice for multilateral decision-making for demonstrating exceptional leadership in facilitating the merger of the International Council of Science and the International Social Sciences Council.

In closing, Minister for Science and Technology, Naledi Pandor, emphasised that "international collaboration is imperative for the advancement of not only African, but global science." – report by *Ithuteng Sekaledi.*

The impact of hearing loss:
Dealing with silence and noise

Hearing loss is not simply a medical matter, but more a communication impairment with social ramifications that have a significant impact on your personal life and career. Tim Hart, a senior research project manager at the HSRC, spoke to the *HSRC Review* about the sacrifices and positive choices that he has made to live with profound hearing disability.

He is completely deaf in his right ear and has very limited hearing in his left where he wears a hearing aid. Therefore, Tim Hart tries to place colleagues on his left side when they talk.

"However, when some see the hearing device, an entertaining shuffle ensues. I try to get them to talk into my left ear, but they only want to talk into the ear without the hearing aid, wrongly assuming that it is the functioning ear," he describes the interaction.

The clumsy response of some colleagues is most probably the consequence of their ignorance about his disability, rather than intended disregard. Most peers are supportive but occasional encounters have been downright rude.

"An executive director got so frustrated with my inability to follow a teleconference that this individual told me to get my ears cleaned and my hearing aid serviced. I received an apology later, but this is why I can empathise with people who feel too intimidated to disclose their disabilities," says Hart.

Launching a career

Diagnosed as totally deaf in his right ear at the age of four, Hart also lost 75% of the hearing in his left ear at the end of his second year at university. He still completed his degree the following year, then an honours degree in social anthropology at the University of Cape Town in 1991 and a master's degree (*cum laude*) in sociology at Stellenbosch University in 2003.

Hart read various social science subjects, initially choosing psychology, but his interest soon shifted toward anthropology.

"Its approach provides the most robust way of understanding human behaviour in transition. My honours year introduced me to the complex world of development and I was hooked.

> Many people still think that hearing impairment is a medical disability and do not accept the significance of the social and physical environment.

"In 2004, I started as a senior research manager at the HSRC doing lots of fieldwork-based research and regularly presenting at seminars and conferences. As an ethnographer, planning and conducting interviews are some of my most important skills. By 2010, I had lost another 10% of my hearing and spent five years trying to get my role changed toward more desktop research," says Hart.

Adapting

As a senior research project manager with 25 years' experience in managing project teams, he is acutely aware of the sacrifices and compensation that his disability requires of him.

"I have had to reduce my presence at conferences and seminars, which is career limiting and decreases networking opportunities. Large groups of people convene in large venues without the necessary technology to assist people with profound hearing impairment. This absence means that I miss most of the presentations and sometimes misunderstand questions. The surprise on people's faces can be quite embarrassing.

"Most delegates can digest recent scientific ideas from the presentations. I cannot and must do a lot more reading to remain abreast. I organise that I only attend very small meetings in small rooms and position myself so that I can hear as much as possible."

Misconceptions

Many people do not realise that every impairment is different, says Hart. They do not know how to respond or they make clumsy suggestions to solve the problem from their limited perspective.

"Some years ago, when I lost more hearing, the employer's response was that I should get a cochlear implant, simply because they had heard it was a technological breakthrough. Without knowing my situation, they thought this would solve everybody's problems, including my progressive hearing loss. Despite the progress in hearing aids, they simply serve to amplify sound and this includes background noise, such as air conditioners, people talking or the clattering of crockery. In an increasingly cosmopolitan world, hearing aids do not assist with clearly

Tim Hart doing fieldwork on indigenous knowledge with rural residents in eastern Limpopo

understanding accents that different people have. This is where subtitles and voice to text technologies (very much in its infancy) can help."

Social isolation versus integration

Hart says living with hearing loss has social ramifications that can lead to significant frustration and isolation.

"Many people still think that hearing impairment is a medical disability and do not accept the significance of the social and physical environment. Some show sympathy, which is not want we want. Hearing impairment can socially exclude you if you let it. I still have to remind my family that I cannot hear them when they talk to me without looking at me."

Modern society has embraced open-plan spaces in offices, banks and other public areas, but they frustrate people who are hearing impaired, says Hart.

"There is so much background noise in these open areas that it makes hearing virtually impossible. While normal telephone communication is a challenge, the noise from call centres is transmitted and impedes communication. Where I can and people are willing, I try to communicate with individuals in closed office spaces or via email.

I do not go to the cinema, but watch DVDs and channels such as Netflix where they use subtitles. I often ask my partner to repeat the news to me when I miss something. When I go to a restaurant, I try to find the quietest corner to sit in and let my partner do the ordering if I cannot hear the waitron."

Workplace challenges

According to Hart, organisations need to respect the diverse needs of people with disabilities, which require individual rather than universal solutions.

"When it comes to reasonable accommodation and access, public and private sector organisations focus mainly on those who are confined to wheelchairs. In all my years of employment for different organisations, not one has had the facilities for hearing or visually impaired people. Only one university had a lecture room with facilities for the hearing impaired, whereas NGOs in the disability sector make sure they have all the facilities for people with disabilities and ensure that these are made available at their conferences and seminars.

"Employers also need to prioritise programmes and career paths for people with disabilities, particularly

when these are progressive, and must include disability rights awareness programmes for staff. People within organisations who have impairments should consider forming peer support networks."

Staying positive

Acceptance and tapping into support networks are crucial to living with a disability, says Hart.

"New technologies that assist people have increased, but these are limited for those with hearing impairment and are costly. You need to adjust your environment as best as you can to ensure that you can function optimally. A portion of these expenses may be tax deductible, so explore that.

"Also, try to understand your disability as best you can. Never let it get you down to the point where you cannot accept it as part of your life. Be aware of how your disability affects you and make positive choices to ensure that you do not succumb to the emotional aspects of it. Where possible, try to avoid events that trigger feelings of helplessness."

Adapting to a visual disability: It develops grit

Some disabilities are not that apparent, such as poor eyesight. Prof. Narnia Bohler-Muller, an executive director in the HSRC, has a visual impairment caused by a genetic condition, but learning to cope with it contributed to her success in life.

'If I do not greet you from a distance, please don't be upset, my eyesight is poor.'

This line at the end of her emails is the only obvious indication that the HSRC's Prof. Narnia Bohler-Muller lives with a visual impairment.

"I have partial sight. Many people do not know and tend to take great offence if I do not greet them, but when they are more than 20 metres away, I struggle to recognise them. It also makes me clumsy so I am constantly walking into things and tripping on stairs. I included this line in my email messages to create more awareness and to prevent offence taken," says Bohler-Muller, who is the executive director of the HSRC's Democracy, Governance and Service Delivery research programme (DGSD).

Living with a neural condition

Her eyesight is affected by a rare genetic condition, a pale optic nerve (optic atrophy).

"The light entering my eyes is not able to travel to the visual center of my brain the way that it should. People typically respond with questions about better glasses or an operation. The reality is that, even with glasses, my eyesight is at 60% of what it should be, meaning I am partially sighted. It is a neural condition and not yet treatable. Until stem cell research in this area is improved, I must live with the condition. It was diagnosed when I was six years old, so I have had it for the last 40 years."

Bohler-Muller was brought up to believe she could do anything she put her mind to.

"My parents never let me believe that I was 'less'. I never felt like a victim, just that I needed to work harder, focus more and find ways of coping. When I could not read the blackboard, I would listen and write copious notes. An ophthalmologist once told me that I was probably often successful because I had to adapt to new situations all the time and was forced to cope because I didn't want to feel embarrassed."

Career success

She studied law and spent several years as a professor of law at the Nelson Mandela Metropolitan University before joining the Africa Institute of South Africa, which was later fully integrated into the HSRC. "Research is a passion and I wanted to bring my talents to bear in an environment where I could contribute more concretely to evidence-based policy-making."

> Research is a passion and I wanted to bring my talents to bear in an environment where I could contribute to evidence-based policy-making

In the last years, the DGSD consolidated an impressive body of work on policy issues pressing to South Africans. "We have developed a solid reputation in areas such as social justice, socio-economic rights, social cohesion, developmental local government, institutions supporting government, and the separation of powers. Our flagship projects include the *State of the Nation* book, the South African Social Attitudes Survey and we are coordinating an HSRC priority project on developing a Transformative Governance Index."

Challenges in the workplace

Bohler-Muller has tried to sensitise her colleagues to her condition.

"Some get it and others don't. If you cannot see a disability, it is probably considered less serious. I find it quite embarrassing to have to explain and re-explain it. Once the human resources department was informed, I received certain concessions. I am allowed to have a printer on my desk.

"This is because computer work tends to hurt my eyes if I spend too many hours staring at the screen and paper causes less strain. I have also been provided with a large monitor. I have tried a few software programmes that make reading less of a strain, but it feels like working in a fishbowl."

Most work documents are created with a font size of 10 to 11 point. "The most challenging situations are reading documents with fonts smaller than 14 to 16 point, seeing PowerPoint presentations, reading in bad light and other sight-related challenges.

"I have also not been able to renew my driver's license as my condition has deteriorated with time."

Getting around

One of the biggest obstacles is getting lost when she travels. "I've had to get used to it, so I don't panic anymore. On one trip, I got lost in the Paris underground and could not read the signs. I must say the people were not very helpful as they went along their busy ways, but eventually I ran into a stranger who guided me to where I needed to be.

"I don't want pity; I want to be understood as I am. Therefore, I have a driver. Of course, this may be seen as 'elitist', but I really have no choice, despite the expense and financial strain.

> Justice Zak Yacoob told me that I should be open and honest about my challenges and not be afraid that people will think I am 'weak' because of it.

"Even public transport is difficult as I struggle to read signs and have many meetings in all areas of Pretoria and Johannesburg."

Good advice from a veteran

Bohler-Muller recalls interviewing retired Justice Zak Yacoob for a research project.

"He was 90% blind by the time he sat on the Constitutional Court bench and was my hero. He told me that I should be open and honest about my challenges and not be afraid that people will think I am 'weak' because of it.

"I am also an admirer of Justice Minister Mike Masutha, who is visually impaired and learned to read in braille in his 40s. Both men worked tirelessly in their youth defending and protecting human rights and they persevered, making a difference despite their own challenges."

Prof. Narnia Bohler-Muller

Moving closer to the screen

It would have been nice to drive a car, but he gets around with Uber taxis. It is all about patience and clear communication with those close to you, says Lungelo Mlangeni, an HSRC researcher who lives with a serious visual impairment.

Lungelo Mlangeni

It was not always like that. Lungelo Mlangeni was about 12 years old when his parents noticed that he was pressing his face close to his books.

"Both my parents wore glasses, so the obvious plan was to get me a pair. They took me to an optometrist and that was when it was discovered that it was not a regular eyesight problem, but a serious and progressive medical condition called keratoconus," says Mlangeni who is a master's intern in the HSRC's HIV/AIDS, STIs and TB research unit.

The Pretoria Eye Institute describes keratoconus as a disease in which the eye's cornea (the clear window in front of the eye) bulges forward into a cone-like shape. The cornea helps the eye to focus; therefore, the shape change causes blurred and distorted vision.

"Initially, I could wear contact lenses, but later the condition worsened to the extent that the lenses could

> I got used to not being able to see properly and rather worked to improve my listening skills.

damage my eyes and that was when I started to struggle. It took me quite some time to adjust to the condition."

Learning to listen

"In primary school, I was one of the smartest kids in my class, but in high school I struggled to see the board. It was a good school with small classes and I could still take notes, but at university, I stopped taking notes altogether. I got used to not being able to see properly and rather worked to improve my listening skills," says Mlangeni.

His initial plan was to study geography, but he soon became more

interested in psychology, one of his elective subjects.

"I dropped geography and completed a degree in political science and psychology at the University of KwaZulu-Natal, followed by my honours and master's degrees in research psychology. After that, I wanted to get into the real-world research environment and the HSRC was the obvious choice."

Finding independence

Mlangeni helps to collect and analyse data for the South African National HIV Prevalence, Incidence and Behaviour Survey and he also works on the HSRC's first national TB survey.

He takes pride in his independence, but laments the fact that some people still assume that people with visual impairments are slow or unable to do their jobs properly.

"I think they look at the way I have to read, coming so close to the screens and make assumptions about how competent I am. I see myself as smart and this just motivates me to work twice as hard.

"Most of the things I need to do, I can do, like walking and doing groceries. Probably the only thing that I find a bit cumbersome is that I can't drive. Uber helps, but it makes it difficult to get around. It would have been nice to have my own car.

"My advice to people in my position, who lose their sight, is to be patient with the transition towards doing things in a different way. Communicate with those close to you. It can be difficult for them to understand that you need space to grow, and they tend to worry and be over-protective."

> Communicate with those close to you. It can be difficult for them to understand that you need space to grow, and they tend to worry and be over-protective.

ENABLING THE ABLE-BODIED

Globally, more than a billion people live with disability. They do not need anyone's pity or sympathy, but rather the removal of barriers that prevent them from exercising their right to live and work in an equal society, writes *Tim Hart.*

Do you ever stop for a moment to think of those who have never heard the sounds of children laughing or the jazz ensembles of Hugh Masekela, or of those who have never seen a rainbow after a Highveld thundershower?

What do you really know about the young woman in the supermarket struggling to reach products from the confines of her wheelchair?

Or the old man in the rural village in a dilapidated wheelchair who relies on others to move him around, as there are no sidewalks or paved roads?

Have you ever considered the constant fear of your senior colleague who is concerned that they might suddenly suffer a severe epileptic episode while chairing a meeting?

Impairment that results in a disability may be present from birth, a consequence of a serious injury or illness, or related to a person's life stage. As people age, they become more susceptible to certain impairments and the impact is often exacerbated by poverty and inequality. In 2011, more than a billion people or 15% of the global population lived with some form of disability.

Disability in South Africa

Last year's Community Survey indicates that approximately 7.7% of the South African population are people with one or more disabilities. This means that they are affected by at least one permanent, recurring or progressively worsening impairment. Statistics South Africa has pointed out that this figure is probably slightly higher than 12%, because many don't acknowledge their impairment. To do so may feel humiliating, is viewed a sign of weakness or they fear discrimination.

South Africa's increased association with international organisations has led us to broader and more accurate definitions of what constitutes a disability. As a result, our national surveys have improved. They are more sensitive and ask appropriate and dignified questions to obtain an accurate indication of people with disabilities in South Africa.

> Commemoration days for people with disabilities have nothing to do with the need for pity, sympathy or welfare support.

While disability is generally equated with a physical impairment, such as confinement to a wheelchair, the loss of limbs or their usage, it also includes sensory, cognitive, mental, developmental and emotional impairments, or some combination thereof. Recent statistics from the 2016 Community Survey indicate the diversity of disabilities encountered by South Africans. More than 10% are visually impaired and just under 4% are hearing impaired. Almost 2% have a communication impairment and close to 3% have difficulty with self-care. Slightly less than 4.5% have difficulty remembering and almost 5.5% have a walking or mobility impairment.

These figures confirm that an individual can have more than one impairment that results in a disability. Similarly, the presence of one impairment may increase the chance of the occurrence of another. For example, a person with autism is more likely to suffer epileptic episodes than a person without autism. Disabilities may cause other medical conditions, such as pressure sores, gradual organ deterioration, bad posture or poor physical growth, poor development and a reduced life span.

Celebrating achievements

Being a person with a disability does not and should not prevent one from participating completely in society – culturally, socially, politically and economically. Every year, South Africa observes National Disability Rights Awareness Month from 3 November to 3 December, which is the International Day of Persons with Disabilities and National Disability Rights Awareness Day.

This commemoration of people with disabilities has nothing to do with the need for pity, sympathy or welfare support. It is a period in which South Africans celebrate the gains and the continued obligation to address challenges faced by this sector. Gains include the promotion, entrenchment and protection of human and socio-economic rights of people with disabilities and other marginalised groups in South Africa. It also includes recognition of diversity within the sector. If anything is sought by people with disabilities; it is simply dignity, respect and recognition, as equal members of and contributors to South African society.

Changing mindsets

The people with disabilities movement has spent several decades promoting their inclusion into all spheres of society and in ensuring their rights. The movement has been committed to changing perceptions about disability in South Africa away from medical and welfare models to social and human rights understandings. The medical model emphasises the impairment (e.g. physical, sensory, neurological or cognitive functioning)

Year	2002	2004	2006	2008	2012	2014	2016
PWD as a share of the workforce in SA	1%	0.6%	0.7%	0.8%	1.4%	1.5%	0.9%

Source: Author's adaptions using CEE Annual Report 2016-2017 (2017) and DSD National Development Plan 2030: Persons with disabilities (PWD) as equal citizens (2015).

and this is considered the cause of inequality. The solution from the medical model point of view is to view people with disabilities as patients and to prescribe or even impose medical treatment. The welfare model considers people as passive objects who must be cared for through the provision of welfare and support, as they are viewed as incapable of caring for themselves or having much say in their wellbeing. While some aspects of these models may have merit in that some medical intervention or some welfare support is needed, on their own they are patronising, offensive and disrespectful of individual human rights and the entrenchment of inequality created by society through ignorance.

Social and rights-based models

The social model proposes that the barriers that create inequality and enhance their experience of disability, are a result of society and its limited understanding of impairment. This situation results in the inability or unwillingness of society to accommodate for the differences between people with disabilities and those without, and an inability to grasp diversity within the group. The rights-based approach to disability wants people with disabilities to be empowered and capable individuals. Their rights to meaningful participation in social,

> The social model proposes that the barriers that create inequality are a result of society and its limited understanding of impairment.

cultural, economic and political life in society and their own development must be recognised, entrenched and protected. Socially created barriers must be removed and the right to protection, accommodation and freedom from discrimination must be embedded in policies, legislation and strategies.

Transcending barriers

With the powerful slogan of 'nothing about us without us' the movement has transcended stereotypical barriers such as gender, age, race, religion and culture to ensure that

the government of South Africa has enshrined rights into the Constitution and other Acts of Parliament since 1994. It has also moved the government to become party to several international and continental conventions and strategies, including the United Nations Convention on the Rights of Persons with Disabilities and the first and second Continental Plan of Action for the African Decade of Persons with Disabilities. Affiliation to these conventions, plans of action and other human rights protocols have strengthened the activities of the movement and given proponents

a foundation in international practices and law. This has enabled the movement to improve the awareness about disability, the diversity and the experience of disability and in particular the role that socially created barriers play in transforming an impairment into a disability. Consequently, it has been able to ensure that mainstreaming of and sensitisation to people with disabilities and their challenges are recognised in terms of employment and procurement policies and procedures in some public and private sector enterprises.

Future prospects

A review of recent reports on progress by individual researchers, research organisations and the Commission for Employment Equity suggests that there is still a long road ahead to achieving targets for the employment of people with disabilities, improving on reasonable accommodation in the workplace and access and full utilisation of all facilities open to the public, including cinemas, airports, shopping centres and shops.

The National Development Programme (NDP) aims to ensure that by 2020 and 2030, 7% and 10% respectively of people with disabilities are employed. However, this seems highly unlikely if attempts to reach the existing target of 2% are considered using biennial data from 2002 until 2016. Nationally, the employment of people with disabilities has never reached the 2% level. More disconcerting is the fact that their present share in the workplace is below that of 2002. In 2015, the share was 1.1% indicating a downward trend. If this is so, a lot of energy will be required to meet the proposed NDP targets.

Many organisations claim that they cannot find people with disabilities within their sectors to meet the 2% target. They argue that there are no people with disabilities with the necessary skills, experience or qualifications. Such an argument is perhaps a reflection of organisational unwillingness to adopt, finance, implement and commit to policies relating to reasonable accommodation and skills development – especially when so few people with disabilities are in senior positions. There also seems to be a lack of foresight in aligning job opportunities with their needs. On the other hand, some people do not realise that they have impairments and others choose not to disclose.

Universal design as the norm

In the late 1990s, there was an upsurge in the building of ramps and refurbishment of cloakrooms to accommodate wheelchair users and legislation was passed to ensure universal design of public buildings and facilities. However, the implementation of minimum standards in this regard seems to be an overly drawn-out process and regulations unenforced. Universal design should not be considered a challenge or an inconvenience. Gradually sloping ramps could replace stairs, gates or booms could replace turnstiles, better lighting would enable the use of sign language interpreters and assist those with specific mild to moderate visual impairment. Tele-coil or loop induction systems, compatible with virtually all hearing aids, should be the norm in any large room, be it a classroom, lecture theatre, airport lounge, banking hall, community hall, cinema or waiting room. Closed captioning and subtitling should be

mandatory for all television services, cinemas and other video displays. None of these features would impose on people without disabilities and may in fact be beneficial to them but they would increase the social inclusion and interaction of those with disabilities.

A parting shot

I have often wondered how many supermarkets, restaurants, transport facilities and recreation venues lose potential customers and revenue because they do not concern themselves with the needs of people with disabilities. How often have you avoided going to a shop because it appears dirty, or going to one that is small and the aisles are narrowly spaced or even eating at a restaurant where the tables are close together or staff and management seem rude or unhelpful? You avoid such places because they make you feel uncomfortable or unwelcome. Social barriers that reinforce disability have the same effect on people with disabilities and must be removed for them to fully contribute to and enjoy the benefits of society.

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Universal design of public buildings and facilities should not be considered a challenge or an inconvenience.

Mental health awareness:

Not simply adherence to Acts, but about dignity

More than a fifth of South Africans will suffer from depression at some stage during their life but two-thirds of them will not get the support they need. According to the South African Depression and Anxiety Group (SADAG), approximately 23 people commit suicide every day and for each complete suicide another 10 people attempt it. *Tim Hart* reports.

Worldwide, an estimated 400 million people suffer from some form of mental health disorder. In South Africa, an estimated one third of the population has or will experience a mental health disorder, but only 20% of those will seek support.

Much of this has to do with the stigma attached to acknowledging feelings of depression, as well as awareness of what constitutes a mental health problem. However, if recognised and acknowledged most mental health disorders can be treated.

October was Mental Health Awareness Month and from 10 September to 10 October (World Mental Health Day), numerous organisations representing government and civil society reached out to increase mental health awareness and education. They pushed for advocacy to reduce the social stigma associated with mental, neurological or psychological disorders.

Defining mental health impairment

Definitions of mental health impairments in South Africa are based on the American Psychiatric Association's 2013 *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Like physical impairments, mental, neurological and psychological impairments vary in severity. Some are transient or temporary, like acute stress disorder, characterised by the onset of severe anxiety and dissociation about a month after exposure to an extremely traumatic event (e.g. violence of any form). Others are periodic, such as the periods of exaggerated elation followed by periods of extreme depression as in the case of people with a bipolar mood disorder. There are also permanent and progressive mental impairments, such as Alzheimer's disease, a form of dementia.

Causes vary and can relate to lifestyle practices and behaviour, lived experiences and traumatic episodes during one's lifecycle and lifecycle stage, with susceptibility becoming increasingly probable, as one gets older.

> Research shows the content and context of the workplace can contribute to the growth of work-related mental health challenges

The workplace

Because mental health problems stem from the complex interaction of social, psychological, biological and environmental factors, research has increasingly produced evidence that the content and context of the workplace can contribute to the growth of work-related mental health challenges. According to the Department of Health, key factors include an excessive or insufficient workload, lack of participation and control in the workplace, monotonous or unpleasant tasks, role ambiguity or conflict, lack of recognition at work, and inequity. Poor interpersonal relationships, poor working conditions, poor leadership and communication, and conflicting home and work demands also play a role.

Recognising the challenges of the modern workplace and the effects it can have on individuals, the government emphasises that employers must ensure programmes are in place to promote the mental health of workers and to ensure that mental health matters are recognised early and people afflicted with mental health challenges are treated effectively and with dignity.

Furthermore, the Employment Equity Act 55 of 1998 (EEA) includes people with a long-term or recurring mental impairment as people with a disability. This ensures that they are protected in terms of this act and also the Promotion of Equality and Preventions of Unfair Discrimination Act 4 of 2000. It also suggests that government recognises that while physical disability can result in mental health challenges (e.g. depression), physical impairments are not any more significant than mental impairments, despite the latter often being less visible.

Disclosing

One of the challenges that remains for people suffering from mental health impairment, as with those suffering from physical impairment, is to feel comfortable to inform their employers of this situation. It is difficult enough sharing this emotional information with family members. The purpose of acknowledging the presence of any disability should not only be to address the targets of

either the EEA or the Broad-Based Black Economic Empowerment practices. It should be to make people feel secure, comfortable, respected and treated with dignity by their co-workers, including management, and despite possibly experiencing episodic bouts of the debilitating effects of mental health impairments in the workplace. In fact, it makes sense that colleagues be aware of why a person is behaving in a specific way. Awareness and education are vital in this respect.

In a country such as South Africa with its history of racism and increasing criminal and structural violence in both rural and urban areas, alongside the gross intolerance of difference,

we must acknowledge the mental health impacts of both past and present acts of violence, intimidation, discrimination and the daily stressors of contemporary South African society. None of us can claim to be free of these events and their lasting effects. More than acknowledgement, we must be in a position to deal with the severely afflicted with the dignity and respect they deserve.

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> We must acknowledge the mental health impacts of both past and present acts of violence, intimidation, discrimination and the daily stressors of contemporary South African society.

For more information or advice on mental health issues, please contact:

The South African Federation for Mental Health
011 781 1852

The South African Depression and Anxiety Group
011 234 4837

SA is failing deaf and hard-of-hearing learners:

Can a bilingual model of education be the solution to acquiring literacy?

Deaf and hard-of -hearing learners comprise 5% of the school population, but their school attendance drops significantly between their early and late school years. Challenges in the acquisition of literacy may be at the root of their limited progress in the education system. Two experts in the field of Deaf education shared their insights at a recent HSRC seminar. *Antoinette Oosthuizen* reports.

When acquiring language, children who are deaf and hard of hearing follow roughly the same steps as those who can hear, but late identification of hearing loss, limits in the South African Deaf education system, and other environmental challenges prevent many deaf and hard-of-hearing children from reaching their full potential.

This is partly because many of these children don't become fully literate in a written language, said Prof. Claudine Storbeck, director of the Centre for Deaf Studies at the University of the Witwatersrand, and Lynette Diederichs, head teacher of the Quest Model School near Durban. They believe that bilingual models of teaching, for example, one that combines good quality South African Sign Language and English, which becomes fully accessible to the deaf or hard-of-hearing child through the support of Cued Speech, might be a solution.

Not enough done

"If we have 12 years of schooling for deaf children and they are still not learning the basics, we need to ask ourselves if it is ethical," Storbeck said at the seminar.

She said that there are 43 schools for deaf and hard-of-hearing learners in the country, the majority with excellent school facilities. However, there are currently no minimum qualifications

or requirements in order to become a teacher of the Deaf. Internationally, teachers of the Deaf are required to have a master's degree in Deaf education.

"In fact, to work in Deaf education, you should actually be a specialist in language development, the brain and literacy," she said, adding that mere access to Sign Language is also not enough.

The early bonds

Storbeck emphasised that children typically do not learn language, but acquire it almost effortlessly.

"I believe that all children are born with the equal neural capacity to learn, unless a child has additional cognitive challenges or delays. All brains are hard-wired for language, an innate knowledge of grammar that serves as the basis for language acquisition," said Storbeck.

She believes the first six months is a crucial time for children to acquire the building blocks of language, especially for deaf children, but that their environment often hampers the process long before a child reaches the education system, for example, when there are attachment problems with the main caregiver.

"We think and bond emotionally with our families through language, so when there is a language access problem, these bonds may not

> If we have 12 years of schooling for deaf children and they are still not learning the basics, we need to ask ourselves if it is ethical.

develop, and that is one of the reasons why some deaf adults feel that they don't have a bond with their families. It is not only because the family did not use Sign Language or did not get support, but rather because crucial shared early communication was disrupted."

Early language acquisition

Storbeck said that the foundations of acquiring language and learning to communicate with the world start in the first month of a child's life.

Children acquire language through their earliest relationships in the home, for example, when the father or mother and baby copy each other's cooing and babbling, the infant learns about turn-taking, which later becomes conversational turn-taking through which we experience every-day life. Babies also soon learn that we do not use sounds or words simply to make noises but with the intent of getting attention, sharing how they feel or what they need.

> To work in Deaf education, you should actually be a specialist in language development, the brain and literacy.

Late identification of hearing loss

Internationally, children are screened for hearing loss at birth or no later than one month of age. Hearing loss is identified by three months and by six months they get their first hearing aids and early intervention such as home-based family support. In South Africa, current statistics show that children are diagnosed on average by 18 months and many only receive 'early' intervention after the age of two years.

The importance of literacy

Dr Cas Prinsloo from the HSRC's Education and Skills Development programme, said becoming literate is more challenging for deaf and hard-of-hearing children, because they start learning language in a pictographic way, using symbols for words, which they then need to link to the alphabet in order to read and write English.

Diederichs, who has been deaf since the age of nine, shared her experience of working with a group of deaf and hard-of-hearing children at the Kwa Thintwa School for the Deaf at Inchanga in KwaZulu-Natal over five years.

The children started with her when they were 8-10 years old in Grade 0, but many were severely language-delayed with minimal Sign Language or grasp of their home language.

She said exposing children to consistent and complete Sign Language enabled them to think, reason, express and share their feelings, and to develop good cognition. Initially, this happened with her class, but acquiring English literacy was a bigger challenge.

"Sign Language does not have its own written language. Therefore, to develop literacy skills, the deaf children had to be exposed to a language (in this case English) that is traditionally spoken, but because of their deafness, they were not able to access English easily."

Developing a solution

Diederichs said it was difficult to teach using a blackboard, because many children were not ready to read or had no internalised English to understand what they were reading. Relying on lip-reading was also unreliable because many sounds look the same on our lips.

"Lip readers can use the context of the sentence to fill the gaps, but it is a catch-22. To get that context, they need a strong language base and for them to get a strong language base, they need to be able to lip-read."

Fingerspelling was another option, but it also means little until they can associate it with words, which comes at a later stage of development.

She then came across ground-breaking research into how the brain activates when people use Sign Language exclusively, or when they only speak.

"The findings rocked the audiology word. Regardless of whether Sign Language or voice was used, the same area in the brain was activated, the auditory cortex. It is not so much about whether we are using voice, or sign, but about the pattern in the language that the brain reads."

Based on this finding, Diederichs realised that a deaf child does not have to hear or speak; they need access to a system that provides the pattern of the spoken language. It is therefore crucial that any language that they are exposed to must be in its full intact form, not mixed.

Progress

Diederichs then decided to add Cued Speech and a UK phonics programme called THRASS to her teaching methods.

Cued Speech is a visual system of communication that uses eight hand shapes in four positions near the mouth to clarify the lip patterns of normal speech. With the structure of spoken language made visible, deaf children see all sound units of speech as clearly as hearing people can hear them, even without hearing aids. This eliminates the confusion of lip reading.

Moving away from the traditional alphabet where one letter is associated with a single sound to teach phonics, the THRASS system teaches 44 speech sounds (24 consonants and 20 vowels) and their related 120 key spellings in written English. Children learn that the same letters can make different sounds depending on where they are used in a word.

The Kwa Thintwa School for the Deaf was the first school in South Africa to use Cued Speech in its Foundation Phase as an educational tool to provide full access to English in conjunction with the THRASS phonics literacy programme in 2006.

Research with Quest

The establishment of the Quest Model School was initiated by a group of parents who were frustrated by the lack of government support when raising concerns regarding the education of their deaf and hard-of-hearing children. Some of these parents had received home-based early intervention support from HI HOPES and knew that their deaf children had the right to equal education opportunities. At Quest, Diederichs uses South African Sign Language and English, which is provided through Cued Speech in order to boost English literacy. Additionally there is a deaf teacher who teaches South African Sign Language as a first language and they are supported by a hearing teacher assistant.

The teachers will complete scholastic, neuropsychological and socio-emotional assessments to evaluate the model.

What needs to happen in SA?

Storbeck believes that the South African Deaf education community should question the status quo and that something drastic needs to be done to increase levels of education. "Also, the fact that something was written in the US or said by a researcher does not mean it is right. We need to find local solutions by tapping into research on language and literacy development and how this can be implemented in the Deaf education context."

She said that researchers need to look into new approaches to Deaf education and literacy acquisition; and teachers need formal training as specialists in the field of Deaf education.

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Researchers need to look into new approaches to Deaf education and literacy acquisition; and teachers need formal training as specialists.

Living with chronic and severe mental illness:
The value of social support

Humans are social beings whom by nature have a fundamental desire to establish meaningful connections with others and belong somewhere. People living with severe mental illness often struggle to maintain these interactions and may benefit from social support interventions in the primary healthcare setting, writes *Leana Meiring*.

Social interaction is such a normal part of life that we can easily take it for granted. This became strikingly apparent to me when I had the opportunity to facilitate a community-based social support group for people living with chronic and severe mental illness.

In this article, I share some of my personal experiences with the group members, some of their stories, and the lessons learned from the research project based on this initiative. The study aimed to highlight the value of the support group and the use of postgraduate psychology students as group facilitators to supplement overburdened mental healthcare service providers in South Africa's primary healthcare system.

Rehabilitation and support

It is generally accepted that medication alone is not enough to treat mental illness holistically. Whether one is feeling depressed or anxious or experiences more severe symptoms such as hallucinations (seeing or hearing things others do not) or delusions (false beliefs about reality), taking a pill might ease the symptoms, but does not help people deal with the underlying social or emotional problems that cause or result from the symptoms.

In severe forms, mental illness is incapacitating, preventing one from doing or taking part in normal everyday activities such as attending to personal hygiene, socialising, or earning an income. Apart from that, many people with mental illness experience stigmatisation and in cases where they display more obvious symptoms and behaviours, social rejection and isolation.

Providing supportive resources to people with mental illness is a vital part of treatment and rehabilitation. South African mental health policy and legislation advocate for and prescribe that support services are available to service users in primary healthcare settings as part of their treatment and rehabilitation plans.

However, due to understaffing and high patient loads the mental healthcare nurses often do not have the time or capacity to provide these services and resort to only giving medication. This calls for exploring alternative ways to offer cost-effective support services to these patients to help relieve the suffering caused by their mental illness.

Support group intervention

In response to the need to offer support services to service users in primary healthcare settings, the Tshwane District Department of Health in partnership with a local university psychology department entered into a collaborative partnership. Postgraduate psychology students were placed at clinics and community health centres around Tshwane to assist mental healthcare nurses with the facilitation of support groups.

Students received skills training and weekly supervision from the study leader at the university. The groups catered to the specific needs of the different sites. Groups targeted either the information or social support needs of service users. In this case, we initiated a social support group to offer socially isolated service users an opportunity to socialise. We established an open group in 2010 that allowed for new members to join and existing members to leave if they wished.

Group members changed over the years. Each year, there were roughly 10 to 12 members involved and the group size fluctuated between 6 to 8 members at a time. The group was open to any service user at the mental healthcare centre and included members of varying ages and diagnoses including schizophrenia, major depression, bipolar, and panic disorder. Group

activities entailed informational talks and discussions, singing songs, playing games, sharing problems and personal experiences, offering emotional support and advice based on their lived experiences with mental illness, as well as a fundraising project (selling second hand clothes). The money raised was used to go on annual outings such as to the movies and the zoo.

Intervention outcomes

During the initial stages of the group's establishment, the members were reserved and shy and the interaction between them limited. Group members shared their experiences of how their lives were affected because of their mental illness. Many shared that they were unable to work and experienced social rejection which led to isolation and inactivity. Their stories revealed the stigmatisation and social isolation they experienced:

"Because I'm mentally disturbed nobody wants me and I'm always alone ... I'm unable to communicate with others because others say we don't want to speak to this one, he is sick. So, when I greet them, they just keep quiet." - Participant 5

"There is nothing I am doing at home. All I do is sleep ... just sitting, alone ... I wake up, maybe sometimes I wash, sometimes I don't wash ... I don't have a friend anymore … when you sit alone, you won't think of nice things, you will only stay sleeping." - Participant 3

Their interaction patterns showed that they had severe difficulty with communication and social interaction. Most of them lost their friends and spent their days sitting around at home. The stories revealed how they lost their 'humanness' as their social rejection left them completely isolated to the point that their socialisation skills were very much deteriorated.

However, after some time the members who attended regularly showed remarkable improvement in their social skills and their outlooks on their lives and their capabilities. Members reported that the group helped them to deal better with their problems and gave them something to look forward to each week. These changes sparked my interest to do research to find out what the group members gained from attending the group.

The findings revealed that the group offered the members a sense of belonging and a means of emotional and social support. The group also offered opportunity for learning, encouraged mental and physical mobilisation and stimulation, and served as an additional link to professional services. Although the study findings cannot be generalised due to the small sample size, the stories told by the participants showed how the group helped them to feel more socially included, cope better with their symptoms and engage in meaningful activates as part of rehabilitative services.

"When we are in the group, we can give each other strength and advice... and when someone has a problem, we can talk about our problems... the hospital helps us with medication and the group members with advice... " - Participant 5

Concluding remarks

The findings suggest that student-facilitated support groups could offer a viable supplement for offering support to service users in primary healthcare settings. It offers valuable learning and practical experience for students and support for the overburdened mental healthcare nurses. Future research could explore the initiative on a larger scale to determine to what extent the groups assist members to heal and recover from mental illness.

Everyone has a need to fit in and belong somewhere. Support groups are important resources that should be made available to services users in the primary healthcare setting to assist with their recovery in addition to the medication they receive for their physical symptoms. It is part of their constitutional right and healthcare professionals are obligated to make these services available.

About the author:

Leana Meiring is a PhD research intern in the Education and Skills Development programme of the HSRC. This article is based in parts on the article by L Meiring, M Visser, and N Themistocleous, "A student-facilitated community-based support group initiative for Mental Health Care users in a Primary Health Care setting" published in *Health SA Gesondheid - Journal of Interdisciplinary Health Sciences*, 2017, Vol. 22: 307-315.

> Many shared that they were unable to work and experienced social rejection which led to isolation and inactivity.

Frontier technology and big science: The need to be inclusive

The Fourth Industrial Revolution is characterised by technological advances becoming more embedded in society than ever before, further supporting globalisation that also allows South African scientists to compete internationally. Is this bringing about development and transformation or further exclusion in our marginalised communities? HSRC researchers spoke about this at the annual Science Forum South Africa (SFSA) in Pretoria. *Antoinette Oosthuizen* reports.

The 4th Industrial Revolution is driven by technological advancements such as artificial intelligence, expanded broadband connectivity and the Internet of Things, a network of devices that will connect via the internet in almost every sphere of modern life. Elite scientists are also making breakthroughs in fields like quantum computing, nanotechnology and robotics, striving to be globally competitive. The change is rapid and analysts are already attempting to predict the impact.

A social revolution

Dr Hester du Plessis, a chief research specialist in the HSRC's Research Use and Impact Assessment unit, warned that this is not only an industrial revolution that is taking place, but also a social revolution that is generating a new global class structure.

Instead of the traditional three-class system, we now see a tiny plutocracy who own most of the money and property on the planet. They are atop a much bigger elite, called the salariat, who are in relatively secure salaried jobs. The proficians are the freelance professionals, the precariat are working class and the lumpen-precariat are an under-class characterised by severe poverty.

"The social uprisings are the first indication that the precariat is currently grouping and identifying their socio-political power in the market-place," Du Plessis said. "For many years, the precariat has been internally divided and scarcely conscious of its commodity. However, this is rapidly changing and more of those in or close to being in the precariat realise that their situation is structural rather than a reflection of personal inadequacy, and that together they have the ability and energy to force transformative changes."

New, but 'inferior' jobs

Du Plessis said it is a misconception that technology displaces jobs. It generates new labour, but this labour is still considered to be 'unprofessional' and often falls outside the regulations of minimum and living wages.

"An example is what is known as microwork. This involves breaking down complex, data-driven activities such as categorising images for search engines, transcribing audio or video clips, or updating databases, activities that machines are not good at. This is low-skill and low-pay work, with little possibility for professional development and job progression. As a result of such work, we see increasing resistance to the inadequate labour laws."

Intellectual property rights and tax

Du Plessis also said that highly contested and outdated intellectual property rights (IPR) laws do not meet the needs of the precariat, because of their duration and the way they make technology inaccessible to the public. "An example is a mobile phone, which might have over 3 000 patents. When you buy the phone, you pay against these patents to keep yourself from breaking the law. This leads to a very costly economy that does not depend on real labour.

"The precariat is also exposing the dirty underworld of tax. This includes the growth of politically manipulated think tanks that are changing thinking in the world to suit specific intentions, and there are all kinds of private structures that maximise tax obligations that do not suit the precariat in the work space. So, very often we find that they'll revert to cash payments to avoid tax."

Knowledge in uncontrolled spaces

"The knowledge that the precariat share is in uncontrolled spaces, which makes dissent and revelations of truth, previously tightly controlled by institutions, possible outside of the manipulative spaces of the ideologies, politics, religion and the academy. In other words, there are no peer reviewers anymore and the public has now become the peer reviewer. And that is a very unstable situation that governments can't control," Du Plessis said.

She said mental emotional and behavioural changes are taking place that are consistent with the spread of precariatisation.

"There is no respect in the digitised world for contemplation and reflection. It delivers instant stimulation and gratification and it is forcing our brains to give most of our attention to short-term decisions and actions. Although this has certain advantages and we talk about the multitasking aspects of our lives, a casualty is the literate

mind and the idea of intellectual individuality. There's a move away from a society made up of individuals with distinctive combinations of knowledge, experience and learning to one in which most people have socially constructed, rapidly acquired views that are superficial and geared towards group approval rather than originality and creativity."

Anger and anxiety

Du Plessis said the precariat has a weakened sense of social memory, because everything is instant, fast and superficial. They experience a mix of rising anger, anomie, anxiety and alienation "the flip side of a society that has made 'flexibility' and 'insecurity' the cornerstones of the economic system".

She says the precariat is much bigger than people think. In some countries, it takes up 40% of the work force. "You might already be part of the precariat or moving into that space. I think that in the end most people move into that space. It is not because you do not have knowledge and you are not a professional, it is just because the conventional labour market does not make space for you."

Balancing mandates in science

Dr Glenda Kruss, the deputy executive director of the HSRC's Centre for Science, Technology and Innovation Indicators, took delegates through the history of South Africa's science councils in another session. She said that HSRC research showed that many of the researchers at these councils are still motivated by individual scientific interests, the need to publish and developing their own careers rather than addressing a development mandate. "If we want to orient our science system towards the public good and towards developmental challenges, we need to have more interactive mechanisms between scientists, industry, communities and the government," Kruss said.

SKA's interventions

Dr Michael Gastrow, a chief research specialist in the HSRC's Education and Skills Development programme, spoke about the human development aspects of the Square Kilometre Array (SKA), which is set be become the largest radio telescope on Earth and the largest science project in Africa. He said that big science has improved the lives of people by laying the foundation for technology that supports a modern economy, such as the internet, devices and genetic medicine. "However, frontier technology and big science are seen to be very far apart from inclusive development and in a sense exclusive, because these projects harness the best skills and capabilities, often from the ranks of the privileged."

Although it was not a formal SKA's mandate, the project launched several interventions to develop communities in the Karoo.

"It is a bit of a juxtaposition. The SKA took advantage of the apex of the unequal system drawing from and competing on the global stage, but then it hits the ground in the Karoo, which is a very marginalised part of South Africa. There is a low population; it is mostly rural with high unemployment and alcohol abuse.

So the situation demanded that the project became more inclusive."

Significant investments were made in local communities through supplier development programmes and education interventions in local schools. Gastrow believes the development mandate of such projects need to be reconsidered. See a review of his book *The Stars in our Eyes* on page 40.

Harnessing knowledge from the marginalised

Dr Alexis Habiyaremye, an African research fellow at the HSRC, emphasised the need to tap into the creativity and knowledge of local communities. He spoke about the value of the Living Labs concept where the knowledge of would-be users of technology in communities are included in the development and testing phases of new technology. This empowers them and facilitates absorption of technologies. He also shared the story of the Nelson Mandela Metropolitan University's engagement with the local community to optimise a healthcare programme that monitors new cases in the healthcare system and improves delivery with the help and input from the local community. In a project in North West, researchers engaged with rural women to learn more about the nutritional characteristics of traditional foods, work that may benefit food security in the region.

Dr Peter Jacobs, a research director at the HSRC shared the success of the Rural Innovation Assessment Toolbox that promote science and innovation in local municipalities and networking with universities.

The gender issue

Prof. Heidi van Rooyen, the executive director in the HSD unit said that recent data show that men are twice more likely to have access to the internet than women. "We need to challenge the stereotype that technology is for boys. One of the fundamental differences between girls and boys in technology is the way in which we socially produce girls to think about themselves. A big challenge (in learning to code) is that girls are scared to take risks and to make mistakes, but if you are dealing with code you need to take risks…. boys make mistakes so they crack the codes."

Furthering development in education: Are we clawing back?

Should government become more directive and once again prescribe how schools should be managed or should we treasure the autonomy and democratic system of our school governing bodies? Or, is it time to redesign the entire system? Experts raised these questions at a recent HSRC seminar about South Africa's education legislation and policy. *Antoinette Oosthuizen* reports.

The proposed Basic Education Laws Amendment Bill that aims to limit the powers of school governing bodies, caused some recent controversy.

The seminar that spoke to this issue was based on the HSRC's macro report, "Furthering the Developmental Imperative? An assessment of the past 20 years of education legislation and policy in South Africa" prepared for the National Education Collaboration Trust.

Presenting the findings, HSRC CEO Prof. Crain Soudien said the dramatic overhaul of the South African education system since 1994 included at least 172 policy interventions establishing a "social justice apparatus with such a heavy agenda that experts are still struggling with it".

The introduction of school governing bodies was one of the most important interventions.

Democratic governance

The South African Schools Act of 1996 dissolved multiple departments of education to concentrate on a single national education system, managed with the principle of cooperative governance.

"The establishment of school governing bodies was a major opportunity to build democracy. It became a practice space for people to learn the craft of taking control over their own lives and managing the state of the people by controlling decisions of admissions, curriculum and language of instruction," said Soudien.

"But there are issues. We have seen our school governing bodies use their powers to keep people out by restricting admissions in to schools. They have also been able to determine the language of instruction in problematic ways."

> The establishment of school governing bodies was a major opportunity to build democracy

HSRC research specialist, Dr Andrea Juan, said the main points of contention in the proposed amendment bill are that schools and school governing bodies will need to submit their admission and language policies to the head of department for approval. It will also attempt to limit the powers of a school governing bodies to recommend candidates for appointment into certain promotion posts.

"Naturally, school governing bodies are opposed to these amendments, because they severely limit their autonomy. In the apartheid system, we had a traditional bureaucratic system of government that relied on force. Then we moved to a system of governance based on inclusion and participation. Are we moving back into a system of big government which relies on direct state intervention to ensure effective policy implementation?" Juan asked.

Intangible resources

Soudien said the differences between white and black schools during apartheid were seen in the ratios of teachers to learners (1:18 in white schools and 1:39 in black schools), an issue that the government is still trying to address.

The quintile system was established. In time, quintile 1, 2 and 3 schools became no-fee schools and quintile 4 and 5 schools were able to supplement their finances with school fees and fundraising.

Soudien questioned whether this system effectively dealt with the apartheid legacy. "We no longer have white and black schools, but rich and poor schools. The issue is complicated, because in relative terms, even our poor schools are better resourced than many countries in the world, but we are still struggling."

He said that school resources include not only material things like infrastructure, books and money, but also intangible cultural and intellectual resources, such as language, and that the struggle has a lot to do with the latter.

Language and executive function

PhD intern Jaqueline Harvey described why the difference between children's home and instructional languages hampers

Are we moving back into a system of big government which relies on direct state intervention to ensure effective policy implementation?

their development throughout their academic career, an issue not properly addressed in language policy.

"Many learners attend schools where they learn in a second or third language, which impacts on their executive function, a mental skill-set that we use to manage our thoughts, actions and emotions in order to get tasks done. When a child reads in grade one, a single word can take long to master, because they have to individually focus on and understand it letter by letter.

"Initially, they use all their mental capacity to read and not to understand what they are reading. When this process becomes automatic, they shift from learning to read to reading to learn. However, this process can take longer for learners who are second language speakers. If they don't make this

shift, they struggle to engage with content. All of their executive function goes into trying to read rather than actually learning. Later, they enter a complex environment where each field, such as science and information technology, has a language of its own." (See article on page 27)

Teachers and curriculum

Soudien also discussed issues around the repeated attempts to redesign the apartheid-era curriculum, the unique challenges of rural schools and teacher training. He said that it is wrong to assume that a common curriculum and equal treatment of teachers mean equal quality teaching. He said some teachers continue to reproduce the cultures and habits of their pre-1994 environments and we need to consider the contextual differences between communities.

> Many learners attend schools where they learn in a second or third language, which impacts on their executive function

Duncan Hindle, education expert and former director-general of the Department of Basic Education, responded to the debate around the closure of teacher training colleges in the 1990s. He pointed out that the most recent data from Trends in International Mathematics and Science Studies and the Southern and Eastern African Consortium for Monitoring Educational Quality show that the best performing learners were taught by teachers under the age of 30.

"These teachers have been trained by universities, so there seems to be some empirical evidence that university training is working in terms of learner outcome."

Schools as silos

Tina Singh, chief director for exams and assessment in the Western Cape Education Department, questioned the assumption that all poor learners should attend quintile 1-3 schools (no fee schools). "It is a huge debate in terms of separation and wanting again for the poor to attend poorer schools and secure 4 and 5 schools for a certain category of learners."

Soudien conceded that it is a difficult policy issue. "We need to understand the issue of schools as silos inside a school district. Should teachers be appointed to districts rather than schools? Should the reproduction of a particular school and its character coming out of 1994 be allowed to persist or should we intervene? We

> Do we keep tinkering or is it time to go back and ask if the fundamental architecture was right in the first place?

have not had the courage to deal with the political aspect."

Clawing back or redesign?

Hindle described the proposed new bill as part of a "clawing back process". "The 1996 South African Schools Act set up a very liberal decentralised framework and every bit of legislation since then has tried to tackle a particular aspect, pulling back some of the powers bit by bit. We did the same thing with the curriculum by setting up a liberating outcomes-based model in 2005 and then pulling back to the tightly controlled CAPS.

"Do we keep tinkering in that way or is it time to go back and ask if the fundamental architecture was right in the first place?" he asked.

According to Soudien, the education system is still in transition. "Is the scale of what came out of 1994 such what we need much more directive big government interventions? Opposed to that, is the question of how we build people's confidence in this country so that they feel sufficiently capacitated to make their own decisions."

Soudien also referred to the Cuba example of 1959. When the country became a democracy, schools were closed and the education system completely redesigned. "There was a managed discussion about what people wanted. We did not do that and still need to go to our communities. The school governing bodies can play an important role to hear from people what they want."
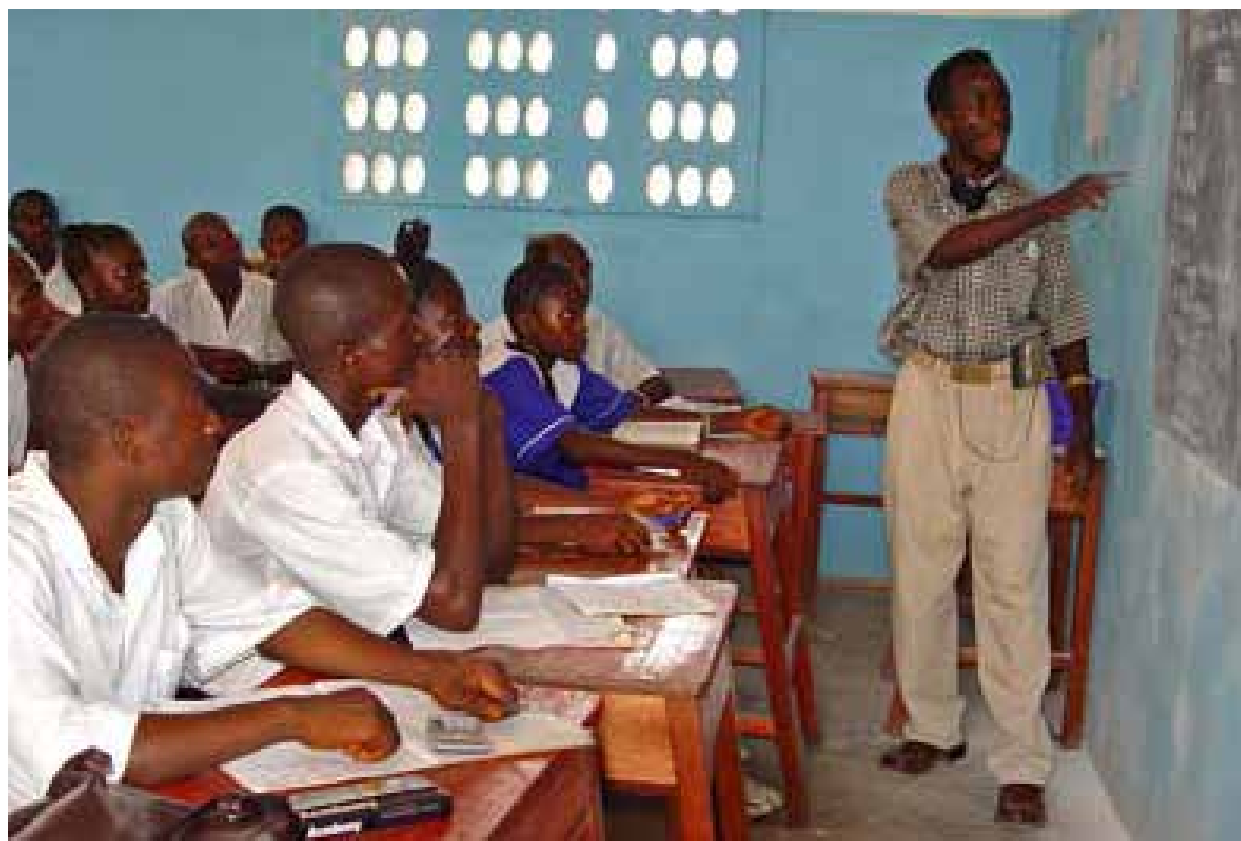
When it comes to school science, language can determine success

Learners who have access to tangible educational resources, such as books and computers at home, tend to perform better in science than those who do not. This has been proved by a great deal of international research. It is also true in South Africa, but our research has found that intangible factors also play a role in learners' science achievement. These factors include parental education levels, parental involvement in homework – and, crucially, home language, write *Dr Andrea Juan* and *Mariette Visser*.

Successive apartheid governments used language as a tool to create socio-economic and educational division in South Africa. This history means that language as a home resource cannot be overlooked when it comes to understanding learners' performance in science at school.

Today still, the language of teaching and learning in our schools often differs from the language spoken in a learner's home. Only 26% of learners who participated in the 2011 Trends in International Mathematics and Science Study (TIMSS) spoke the language of the test at home.

For our research, we studied data from 11 969 Grade 9 learners – who were, on average, 16 years old – who were part of that study. Our results proved just how important language is: the language most often spoken in a learner's home was the most important predictor for science performance. We therefore believe tackling language policy can improve learners' performance in this subject.

> Our findings suggest that by the time learners are in Grade 9, they have not mastered the language of instruction.

Poor science achievement

In developing countries such as South Africa, science, technology and innovation have become forces that drive economic growth and competitiveness and have the potential to improve quality of life. The number of skilled people (such as scientists, engineers and other technically skilled personnel) in a country is associated with its economic growth and ability to compete in the global economy.

The development of these skilled people begins at the school level. Therefore, it is cause for concern that the 2011 TIMSS found the average science achievement of Grade 9 South African students is well below the international centre point of 500 points.

The resource problem

Historically, the state provided educational resources in an unbalanced way. Schools designated for white learners were well resourced, while those for black learners were under-resourced. Today, these imbalances persist. There are vast differences in physical resources at poor schools compared to affluent schools.

The school resources we included in our study were the condition of the school building; the use of workbooks or worksheets as the basis of instruction and class size. We also explored the capacity of the school to provide instruction based on the availability of resources such as textbooks, science equipment and computer software.

For home resources, we asked the learners to report on how often the language of the test was spoken in the home, the number of books at home, and the number of home assets, parental education levels, and parental involvement in school homework.

The findings

Language emerged strongly as a success factor. Learners who used the language most frequently spoken at home in the TIMSS test, scored on average 62 points higher than those who seldom spoke the language of the test.

The number of home assets present in a learner's home had the second strongest positive association with science achievement. We found that for each additional asset (such as a fridge, television, computer etc.) in a learner's home, they scored an average of 11 points higher in science than their peers.

The third most important predictor of science achievement was the condition of the school building. Learners who attended schools with minor problems with the building performed 24 points higher, on average, than those who attended schools that reported moderate to serious problems with the buildings.

Implications

Language development is recognised as crucial for all other learning to take place. Our findings suggest that by the time learners are in Grade 9, they have not mastered the language of instruction (and of testing). In essence, most of the learners who were tested using the TIMSS were learning science through a foreign language.

This means that learners are likely to be at a disadvantage because their knowledge of the language of instruction is below the expected level for their age and grade. The implication is that education policies must seek to improve the manner in which the language of instruction is taught to students who do not speak that language at home, and concurrently, the policies that promote instruction in the home language must be strengthened.

It is important that we understand the determinants of science achievement for South African learners. This has far-reaching implications for the country's broader growth and development. This is because successful interventions at school level may contribute to increasing the pool of matriculants who are eligible to study science-related subjects at a tertiary level and who will later join the skilled workforce.

Disregarding these environmental factors may hinder the success of policies designed to improve achievement and further economic growth.

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Improving reading and literacy in the early school years:

The value of onsite teacher coaching

Most South Africans see basic education in the South African school system as a crucial foundation of their children's journey toward rapid life improvement - a life of employment and personal wellness. However, many children still don't acquire adequate literacy to reach this goal. *Dr Cas Prinsloo* and *Nompumelelo Mohohlwane* write about this challenge and the value of teacher coaching in schools in North West.

The factors that influence the success of any education system are multiple and complex, evident when one simply tries to list the key role players and stakeholders. They include, among others, learners, parents, teachers, teacher trainers, academics, researchers, and government officials. The latter, within the Department of Basic Education, include subject advisors, school principals, district and circuit managers, and all other national and provincial education managers.

A crucial chain of events

Education economists repeatedly point to pivotal factors that enable or hinder acceptable school achievement. Although potentially an oversimplification, the subsequent chain of events may be helpful. Learners should start school at the appropriate age, free of malnutrition, stunted growth, parasitic infections and other learning obstacles.

They should have the support of language-rich homes and communities. Within six months in Grade 1 they should master decoding at the letter-sound level. By the end of Grade 3, word and sentence reading should be fluent and with comprehension. Over the next five years, they should hone their foundational language proficiencies into academic and conceptual proficiency. Everyone who will have to switch to an official language of learning and teaching that differs from the initial home language should first be made proficient in both these languages.

Tackling poor performance

Regular systemic and comparative assessments, including the Progress in International Reading Literacy Study, show that almost 60% of South African learners are unable to read properly by Grade 4. This is important, because literacy and language underachievement in the early grades explains why so many learners leave school by Grade 9.

In trying to find and implement a strong solution, the Department of Basic Education (DBE) convened funders, implementation service providers, academics and an evaluation partner onto a single collaboration platform.

> Research shows 60% of South African learners are unable to read properly by Grade 4.

They focused on Setswana reading proficiency among early-grade learners. Teachers were trained to deliver two sets of interventions aligned fully with the national curriculum. They were implemented along with a parent-support intervention, over the course of two years. These teachers and learners were from Grade 1 in 2015, and Grade 2 in 2016; a cohort, therefore. To attribute any observed achievement changes to an intervention, a robust randomised control trial design was selected. It was complemented by qualitative data from two classroom-based

observation studies. The three interventions were each delivered in 50 schools, randomly selected from two districts from the North-West Province, and entailed:

- A structured learning programme using scripted lesson plans, graded readers, and related teaching materials, presented to teachers through centralised training workshops over two days at the start of each semester.

- The same structured learning programme contents and materials as above, presented to teachers through specialist on-site coaching and small cluster training workshops.

- Weekly meetings between parents and recruited community reading facilitators to discuss the importance of learning to read in the foundation phase and help parents with techniques for assisting their children.

Evaluating impact

For the impact evaluation, the HSRC developed individual oral learner assessment instruments in Setswana with the aid of linguistic specialists and officials from the DBE. Contextual questionnaires were also designed. These were administered in three waves: at the beginning and end of Grade 1, and the end of Grade 2. Data collection involved the three sets of 50 intervention schools, and 80 control schools. At the outset, 20 learners were randomly selected and assessed in each school. The assessment instruments covered vocabulary, decoding fluency at letter,

word and sentence level, phonological awareness, comprehension, and some proficiencies across other subjects (English and Numeracy). Some existing Early Grade Reading Assessment subtests were included in the process.

The teacher pedagogy intervention through coaching proved most successful (Figure 1). The effect size of 0,33 of a standard deviation was found equivalent to 40% of a year's learning by the end of Grade 2. Should such a change continue, learners would be a full year ahead of their peers during Grade 5. Even more telling, the gap could be two years just after completing Grade 9.

Following up

The initial two-year Setswana study was extended to Grade 3 in 2017. Another evaluation wave will follow early in 2018, as well as follow-up tracking after more years to evaluate the sustainability of impact. The parent intervention was discontinued after two years of implementation.

Cost-effectiveness calculations revealed that the coaching model carried the best cost-benefit ratio. It achieved more than double the impact of conventional training using less than double the cost. Although the parent intervention is much cheaper, the size of the impact does not warrant pursuing such small gains, without statistical certainty, and, in addition, in the face of too many challenges related to parental involvement.

Furthermore, a similar second study was started in 2017 in Mpumalanga to assess intervention impact for English First Additional Language and siSwati (an Nguni-group language). Scoping a Mathematics intervention has also commenced.

Conclusions

A number of conclusions and recommendations arose from the study. A pedagogy-based, structured programme with teachers, and materials, within the existing curriculum, proved to be strongest, and most cost-effective. The delivery mode of frequent coaching outperformed that of periodic direct central training.

Figure 1: Estimated intervention impact* (excluding repeaters)
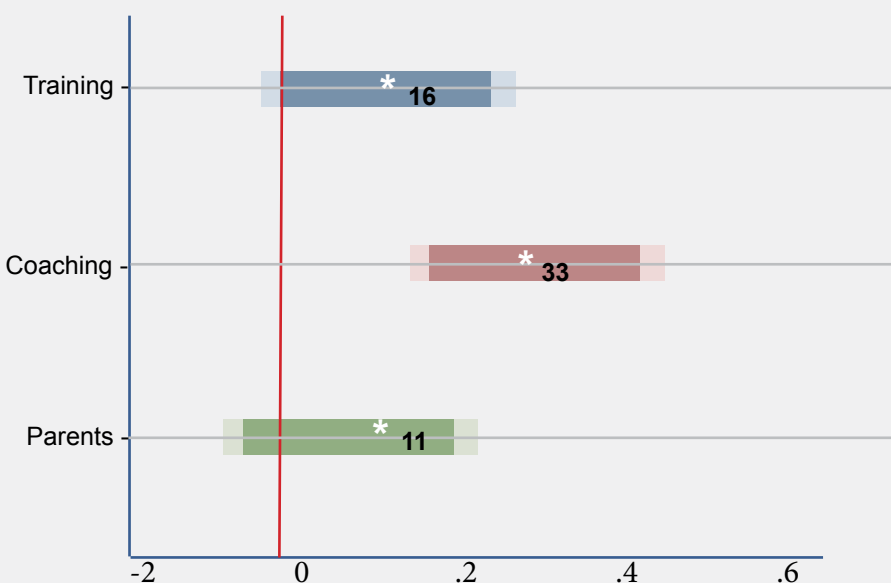
* With 90% and 95% confidence intervals.

(Source: DBE. (2017). Summary Report - Results of Year 2 impact evaluation: Early Grade Reading Study (EGRS). Pretoria: Department of Basic Education (also see DBE website).

The implications of this argument also argue against cascading versions of central training, most likely to have less impact. Observations related to the identity and role of coaches argue against considering existing subject advisors for this task. There are too few subject advisors in the system, and the current structures focus on accountability, not on support and professional development. Because the intervention and evaluation study were implemented in 230 schools, and involved coverage of almost all the schools in two provincial districts, upscaling is feasible, as long as around 100 to 500 schools per province are prioritised at a time, according to need.

Such intervention work should also straddle the full foundation phase to ensure optimal retention and transfer of reading and literacy teaching skills. Costs are estimated at approximately R6 million per 100 schools.

The study strongly emphasised the gap caused by the non-existence of reading norms in African languages. Such norms have to be developed authentically and reported as a matter of urgency. Although cost requirements for parent-based models

may be favourable, and potentially cost-effective, it will only make sense once the conundrum of sustainably involving parents has been solved.

Similarly, further attention and solutions relevant to remote rural settings are required. Tracking these initial cohorts further into their school lives is important for evaluating the long-term benefits and other sustainability issues related to the intervention.

References

More details about the study can be found here. https://www.education.gov.za

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Moving to cities uplifts hundreds of thousands, even in difficult times

Many people who migrate to cities from the countryside have managed to lift themselves out of extreme poverty, despite the poor economic performance of the South African economy over the last decade. However, many also refrain from committing fully to urban lifestyles. This dual existence may add to their cost of living and could perpetuate the psychological divide between town and country, write *Prof. Ivan Turok* and *Dr Justin Visagie*.

A new study reveals that migration to cities has helped many people to escape extreme poverty, despite unfavourable economic circumstances. The analysis is based on the National Income Dynamics Study, which tracks the progress of a representative sample of 30,000 South Africans every two years.

Scaling up from the sample, we estimate that around 385,000 citizens were lifted above the poverty line between 2008 and 2014 by migrating from rural to urban areas and entering the job market.

Worth taking the gamble

This important finding is even more surprising considering the anaemic performance of the national economy over the last decade, as indicated by a recent Statistics South Africa report about poverty trends in South Africa between 2006 and 2015. In addition, upward social mobility is known to be generally very low in SA compared with other countries. This reflects entrenched social and spatial inequalities, combined with a sluggish labour market and persistent failures in the education system.

What's more, poor households face major hurdles in relocating from the countryside to access urban opportunities. The cost of long-distance travel is one. Identifying somewhere to live that is safe, secure and affordable is another. The long queue for jobs facing people with low skills is daunting, coupled with the intense competition from city residents with established contacts.

Nevertheless, our results show that most of those who took the gamble succeeded in getting their foot in the door. Some of their jobs were casual and low paid, but better than being unemployed and destitute. Another recent study by Simone Schotter, Rocco Zizzamia and Prof. Murray Leibbrandt from the University of Cape Town found that migration is the biggest trigger to upliftment of all the events they examined.

> There is growing international recognition that urbanisation boosts productivity, spurs creativity and strengthens economic development.

Benefiting rural communities

Migration also benefits vulnerable rural communities through the flow of income from family remittances, although this is offset by the loss of an income generator. Mobility is generally beneficial for the economy because it concentrates productive capacity, which creates efficiencies for public service delivery and stimulates business investment. There is growing international recognition that urbanisation boosts productivity, spurs creativity and strengthens economic development.

These positive effects need to be properly comprehended across society. Current attitudes to migration within many communities and in government circles are ambivalent. Established city residents tend to resist the emergence of new settlements because they fear the costs of congestion and various hazards associated with burgeoning informality. The government is not doing what it could to smooth the process and reduce the risks.

Split households

As a result, it appears that many migrants refrain from committing fully to urban lifestyles. They seem to retain a dual existence – a kind of double life in the city and countryside. They remain attached to their rural

origins and identities by investing whatever spare resources they have in rural homes and livestock. Many also leave their children and elderly relatives in the rural areas, resulting in split households and disruption to family life.

It may be that people build houses in the rural areas because it is easier than in the cities to get hold of a plot of land without the threat of eviction and without having to abide by burdensome building regulations and other bureaucratic procedures. Rural homes are also insurance policies in case things go awry in the city − places of refuge if people fall ill or when they retire.

These behaviour patterns can presumably also be traced back to the forced migrant labour system and the tradition of temporary movement restricted to men. Nowadays cities are relatively high cost, complicated environments where people pay more to rent accommodation and for transport than elsewhere.

City dangers

They are also inhospitable places where migrants can be forced to live in precarious, overcrowded conditions without essential services. This means a fraught existence exposed to fire, flooding, disease, violent crime and other risks to personal safety. It is hardly surprising that people's hope of a better future lies elsewhere.

The dual toehold in urban and rural areas appears to be an unsatisfactory situation in many ways, although more research is required to analyse the costs and benefits. It seems to add to people's cost of living and perpetuates the psychological divide between town and country. Repatriating resources that would otherwise have been invested in urban settlements could also hamper the creation of local jobs, small-scale enterprises and thriving communities.

In principle, greater alignment between the spending decisions of households, businesses and government would promote prosperity and social progress. Coordinated investments would reinforce each other, generate greater value for families and firms, and attract other resources to build more productive and sustainable communities.

Concerted effort needed

The government should endeavour to create more conducive conditions for migrant households to settle, work and invest in cities. A more concerted effort across state entities is required to accommodate and integrate new arrivals so that there are steady improvements in well-being and life chances over time.

Different sectors need to work together more effectively to plan ahead and prepare for urban growth. They should make public land available for human settlement, and invest in the appropriate infrastructure and amenities to create more liveable, inclusive and enterprising places. This will also require streamlining a range of regulatory procedures and other red tape to accelerate the upgrading of informal settlements and backyard shacks.

A pro-active urban policy is a practical and uncontroversial way of reducing poverty and inequality in South Africa. It means recognising and responding to the reality and real achievements of people's spontaneous efforts to get ahead by uprooting themselves and moving to cities.

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Dealing with minority stress:
Male couples and HIV in Southern Africa

Along with many other marginalised groups, men in same sex relationships are at increased risk of contracting HIV. A study conducted by the HSRC and partner organisations, showed the extreme stress of living in an intolerant society contributes to poor mental health, risky sexual behaviour and reluctance to access healthcare services among male couples.

The HIV prevalence among men who have sex with men (MSM) in South Africa and Namibia is disproportionately high relative to other men. However, in African contexts there is a lack of information regarding primary MSM partnerships, including their sexual agreements regarding sex with outside partners, and their engagement in HIV prevention.

For this reason, researchers in the Together Tomorrow study conducted focus group discussions, in-depth interviews and surveys with over 600 males in same-sex partnerships in South Africa and Namibia. The aim was to learn more about their relationship functioning, sexual behaviour, the stress they experience as a minority group, as well as their HIV prevention and treatment needs and services uptake.

The HSRC collaborated with investigators from the University of California and the University of Michigan and worked with local community support organisations, the Gay and Lesbian Network in South Africa and Positive Vibes in Namibia to conduct the study. They presented the findings of the study to the media and stakeholders at the Aids Impact Conference in Cape Town in November 2017.

The research was carried out in phases. In the first phase, partner organisations conducted community engagement and mobilisation activities. A key component was gender sensitisation training of communities, including tribal authorities in KwaZulu-Natal. Individual interviews were conducted with key informants, including service providers and civil society. Focus group discussions were conducted with 64 partnered MSM in South Africa and 45 partnered MSM in Namibia. In addition, 27 couples in-depth interviews were conducted. In the second phase, the researchers used mobile technology to conduct interviews with 220 MSM couples who were recruited from communities in Pietermaritzburg and outlying areas of KwaZulu-Natal, as well as Keetmanshoop, Swakopmund, Walvis Bay and Windhoek in Namibia.

> Some developed defence mechanisms such as denial that people's negativity towards homosexuality caused them distress.

"We wanted to explore the dynamics of relationships such as love, trust and commitment. We also wanted to find out about risk-taking behaviour and the uptake of HIV prevention and treatment options, and to understand how these are impacted by relationships and how they influence minority stress," says Dr Zaynab Essack, a senior research specialist in the HSRC's Human and Social Development (HSD) research programme, who managed the study.

Coping with minority stress

Minority stress refers to the chronic stress experienced by a stigmatised minority group. Members of the MSM community often live in hostile and homophobic social environments and this can be linked to adverse mental health outcomes. Poor mental health among MSM in other countries has been associated with risk behaviours, including unprotected sex, multiple sex partners and substance abuse. This may increase their HIV vulnerability. A significant proportion of participants (59%) reported having sex while high on substances and 17.6% reported symptoms of depression.

The researchers found that the participants in this study use several coping mechanisms in attempts to reduce this stress. Some developed defence mechanisms such as denial that people's negativity towards homosexuality caused them distress.

Others learned to conform by acting straight or maintaining a concurrent heterosexual relationship. Some MSM have children in an effort to feel safe in a society where heterosexual relationships are seen as the norm. Several men reported using alcohol and drugs to lessen their inhibitions while exploring their sexuality.

Creating sexual agreements

A sexual agreement refers to an explicit and mutually agreed understanding between partners on what sexual behaviours they agree to engage in and with whom. Most participants described having sexual agreements in place, and most were monogamous. Only 15% of participants described having open relationships. The in-depth interviews revealed that when relationships were open, these were restricted to female outside partners. Some men reported that the more dominant partner was more likely to seek outside partners. In a few cases, the researchers detected discrepancies where one partner assumed monogamy and the other believed there was an explicit agreement in place.

The formation of and adherence to sexual agreements have been reported to establish higher levels of trust, communication and commitment in relationships, which may reduce HIV risk behaviours. Many participants found it difficult to communicate about these agreements. Therefore researchers recommend that couples should be supported with skills to discuss and create sexual agreements.

Relying on their partners

The researchers found that MSM couples experience many of the same challenges as opposite sex couples, including communication difficulties, infidelity and abuse. However, the anxiety and experiences of being discriminated against by family, friends and others mean that they are often socially isolated and tend to rely heavily on their partners for emotional support.

Most of the men in the survey identified as gay and reported high levels of both experienced and anticipated stigma around HIV and their sexuality. The researchers found low levels of uptake of HIV prevention interventions and high levels of risk behaviour. For example, almost 60%

reported having sex while drunk in the previous month. Only 21% of men had tested for HIV in the previous year and 12% self-reported that they were HIV positive. Couples in which both members reported high levels of stigma, frequent substance use, and poor communication skills displayed significantly lower knowledge of HIV prevention and were less likely to use condoms with each other or outside partners.

The researchers identified a need for MSM-focused couples services to support men who have sex with men in their relationships and stressed the importance of identifying safe spaces in society where they can express themselves freely, and demonstrate their love for one another, without fear of discrimination or aggression.

Queering public healthcare spaces

Many participants reported experiencing several forms of homophobic stigma and discrimination when accessing public healthcare, including healthcare workers' negative attitudes toward same-sex desire and behaviour. Some participants perceived public health facilities as "straight spaces" and felt that it was necessary for them to "act straight" through the ways they dressed and presented themselves when entering these facilities. They are reluctant to disclose their sexuality to healthcare workers and many preferred to access services at NGOs that provided targeted MSM-friendly services.

The researchers recommend that public healthcare services need to be more gender inclusive. A reluctance to disclose same sex practices to healthcare workers, limits access to HIV-related prevention options, such as pre-exposure prophylaxis (taking medication to avoid HIV-infection), and screening for other sexually transmitted infections.

This research was the first with male-male couples in southern Africa and provides important insights into the relationship dynamics of these couples. The researchers hope to leverage this understanding of couple dynamics to develop dyadic interventions for male-male couples that address their mental health, social and HIV prevention needs.

> Many participants found it difficult to communicate about sexual agreements.

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How the past can make the present tense:

Intergenerational trauma and implications for social cohesion in contemporary South Africa

The race-based injustices of colonialism and apartheid have brutalised generations of black South Africans. *Dr Cyril Adonis* writes about the importance of dealing with this trauma to improve social cohesion in contemporary South Africa.

It is vital to deal with the long-term traumatic impact of historical injustices in contemporary South Africa. We also need to bear in mind that traumatic memories of the past are seldom forgotten, they come to affect not only those who have personally experienced the injustices and its resultant trauma, but also future generations.

This process is known as the transgenerational transmission of trauma, which refers to the way in which unresolved traumas of the past can be subliminally transmitted from one generation to another. While this phenomenon is fraught with complexities, some scholars have insisted on the universal existence of the phenomenon and its effects, arguing that that it seems almost common sense that massive trauma would have a debilitating effect on the victim, and that this would have an impact on the nature of the victim's personal relationships, including parenting.

Despite this, few scholars have written on the subject in post-1994 South Africa. Discussions about the roots of contemporary social challenges often give cursory attention to the role that our traumatic past plays in these. The appeal is often that we should forget about the past, and focus on the present and the future. It has, however, been demonstrated that in previously divided societies, it is only through dealing with the past that forging a cohesive society becomes possible.

Talking about intergenerational trauma

In 2017, the HSRC in partnership with the Department of Science and Technology and Freedom Park hosted a seminar entitled: Intergenerational trauma and memory: implications for social cohesion in contemporary South Africa.

> It is only through dealing with the past that forging a cohesive society becomes possible.

The seminar resonated with the HSRC's commitment towards better understanding the cognitive and social structures that create and define change; as well as Freedom Park's mandate of fostering reconciliation, social cohesion and nation building in the country. Among the 108 delegates who attended the seminar were representatives from national and provincial government departments, academic institutions, the media, the HSRC, the Salvokop Youth Development Forum, the Voortrekker Monument, SA Women in Dialogue, Johannesburg Holocaust and Genocide Centre, the Consul-General of Bolivia, representatives of the Netherlands embassy, military veterans, and learners from the Pretoria Technical High School.

The Calata family

A notable presentation was that of Prof. Pumla Gobodo-Madikizela, who holds a Research Chair for Historical Trauma and Transformation at Stellenbosch University. Gobodo-Madikizela's presentation focused on the case of Nomonde Calata and her son Lukhanyo. Her husband, Fort Calata and three others were brutally murdered by the apartheid government and police in the 1980s and became known as The Cradock Four. The history of the Calata family illustrates various dimensions of transgenerational trauma, and provides insights on the traumatic experiences of Lukhanyo, who was only five years old when his father was murdered.

As a young man, he worked for the SABC and was recently among the eight SABC employees that were dismissed for speaking against government's silencing of broadcasts on violent protests. The Calata case provides a vivid picture of how trauma passes from one generation to another. Gobodo-Madikizela believes that what we are currently dealing

with in South Africa is both a past and a contemporary issue. The Truth and Reconciliation Commission (TRC) presented a way of liberating South Africans from their past in order to transcend it. This is not to say 'forget the past', but rather to recognise and name the apartheid violations, because when trauma is not healed, it keeps returning to haunt subsequent generations. She argues that young people face an abyss of violence in black residential areas, even in instances where no one has tortured them – it is a kind of economic torture, a form of violence that must be recognised as such.

Aggression transmission

Another noteworthy presentation was that of Prof. Maurice Apprey, who is a professor of psychiatry and neurobehavioural sciences, and the dean of African American Affairs at the University of Virginia in the United States.

Healing became possible after taking into account the family history across generations and then reconfiguring the history.

Apprey has written extensively on intergenerational transmission of trauma in the African-American community in the US and focused his presentation on the transgenerational transmission of destructive aggression.

He pointed out that transgenerational transmission of destructive aggression forces us to do things differently. In the context of transgenerational transmission, it is essential to obtain a thorough history, starting with the parents, and going back to the parents' parents. He cited three case studies that illustrated how phantoms from the past resurfaced to haunt later generations.

Healing became possible after taking into account the family history across generations and then reconfiguring the history. When patients seek help after abuse, trauma and apartheid, psychiatrists want to get the events of history translated into a sense of history. The emphasis falls on the

translation of sedimented (or forgotten events of) history to a reactivated sense of history. Apprey noted that transgenerational trauma involves a story of return – we are constantly returning home and discovering that home is not what it was before, we have changed and the home has changed too. Transgenerational haunting forces us to ditch the linearity between past present and future, and rather see time as being circular. Overall, the seminar highlighted the debilitating effect that the past, if not dealt with adequately, can have on the social fabric of a society.

Effect of grim daily trauma

One of the shortcomings of local research on intergenerational trauma has been the almost exclusive focus on cases of extreme victimisation such as those that the TRC has defined as gross human rights violations.

The TRC has conceded that the victims of apartheid were not only the approximately 21,300 who filed gross human rights petitions with the Commission, 'but the millions of Black South Africans for whom collective expulsions, forced migration, bulldozing, gutting or seizure of homes, the mandatory carrying of passes, forced removals into rural ghettos, unemployment, and increased poverty and desperation, were grim daily realities'. In addition to this, it would be important to engage with issues of collective shame and guilt, which, can also be transmitted across generations.

For example, it has been noted that the more the acknowledgment of shame was silenced in the public debates of post-war Germany, the more they migrated into the psyche and the cultural unconscious. Given the superficial manner in which the difficult legacy of apartheid and colonialism has been engaged, it would be relevant to focus on how this affects young white South Africans, particularly in relation to issues of shame, guilt and silencing.

This could help us understand how all of us continue to suffer from what can be referred to as psychic deformations of our violent past. We are also reminded of the fact that the silencing of guilt and shame damages the political culture

Young people face an abyss of violence in black residential areas, even in instances where no one has tortured them – it is a kind of economic torture, a form of violence.

of a democracy. This, according to German politician and political science professor, Gesine Schwan, is because it hinders the realisation of a vivid and motivating consensus on the common values of a polity; and it interrupts the psyches of perpetrators as well as their children, so that it becomes difficult for them to develop the strength of personal identity necessary for good citizenship.

Furthering the research agenda

As a follow-up to the seminar, the HSRC's Research Use and Impact Assessment Unit intends to pursue a number of collaborations to further the research agenda on intergenerational trauma. The researchers plan to work with Apprey, Gobodo-Madikizela, Prof. Tholene Sodi and his colleagues at the University of Limpopo, Prof. Ian Liebenberg from the Centre for Military Studies at Stellenbosch University, the Centre for the Study of Violence and Reconciliation, the Khulumani Support Group, the Voortrekker Monument, and Freedom Park.

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Eliminating poverty and inequality by realising socio-economic rights: The role of the courts

South Africa's Constitution is one of the most progressive in the world and HSRC research shows that our court decisions genuinely promote the realisation of socio-economic rights. Unfortunately, these decisions are not always implemented, write *Prof. Narnia Bohler-Muller, Adv Gary Pienaar, Dr Michael Cosser* and *Dr Gerard Hagg.*

Twenty-three years after South Africa's political transition, general public opinion reflects a downturn as people have grown increasingly discontented with continuing deep socio-economic inequality. Despite a Constitution that is hailed as one of the most progressive globally and the implementation of numerous policy programmes and initiatives, many feel that not enough has been achieved to realise the promise of fundamental human rights and to reduce income inequality, poverty, human underdevelopment, and uneven access to services. At the same time, the country's democratic institutions appear increasingly fragile and disrespected.

The key role-players in South Africa's project to achieve the Constitution's vision of transformation are the three arms of the state – the executive, the legislature, and the judiciary. We also need to consider the role of other critical actors, such as ordinary citizens, communities, civil society, organised labour, academia, and the private sector.

The role of the courts

In 2013, the Department of Justice and Constitutional Development commissioned the HSRC and the University of Fort Hare to investigate the extent to which decisions of the Constitutional Court and Supreme Court of Appeal contributed to the realisation of socio-economic rights and promotion of equality.

The research, which included 43 court cases, found that in general court decisions genuinely promote the realisation of socio-economic rights. However, the implementation of these decisions varied widely. Even years after the conclusion of the cases, litigants in several instances did not find recourse. The research revealed several reasons for non-implementation. In many cases, state departments do not have, or claim not to have, the resources to fully implement court decisions.

The state's ability to get away with minimum implementation is strengthened by the fact that the courts have repeatedly declared themselves reluctant to define the minimum core content of socio-economic rights. They do not want to be perceived as breaching the boundaries of the separation of powers doctrine and stray too far into what they view as exclusively executive or legislative policymaking and budget allocation terrain.

Remedies for socio-economic rights litigation have avoided conferring individual rights on demand as a result of the pressures of limited state resources. Instead, they have defined the rights as collective and to be realised in a progressive manner through a government programme assessed by the courts as being reasonable.

Based on our research, we submit that the three arms of the state need to collaborate more deliberately to achieve the transformative objectives of the Constitution.

Wary of dialogue

Within the context of separation of powers, some interesting ideas emerged during the research about the need for a more deliberate, concerted, inclusive and sustained "constitutional dialogue". Although there is wariness about whether this might interfere with the independence of the judiciary and compromise the doctrine of separation of powers, Chief Justice Mutunga of Kenya has illustrated how Kenyan constitutional development has benefited from such a process that is transparent and inclusive, thanks to political will:

"… *our [Kenyan] Constitution provides very clearly that the three arms are robustly independent, they have independent mandates. But there is a provision for consultation, for dialogue, for interdependence under collaboration…"*

Former justices interviewed for the Constitutional Justice Project support the idea of such a constitutional dialogue. One former Constitutional judge highlighted the need for engagement also to effectively implement and enforce court orders, noting that: "…in my view, courts are not in opposition to the executive and the legislature. I think [that] … sometimes that dialogue creates a coordinated role for all of them to ensure [that], in that particular case, … rights are implemented."

A redesigned constitutional dialogue would reduce the need for extensive and time-consuming litigation.
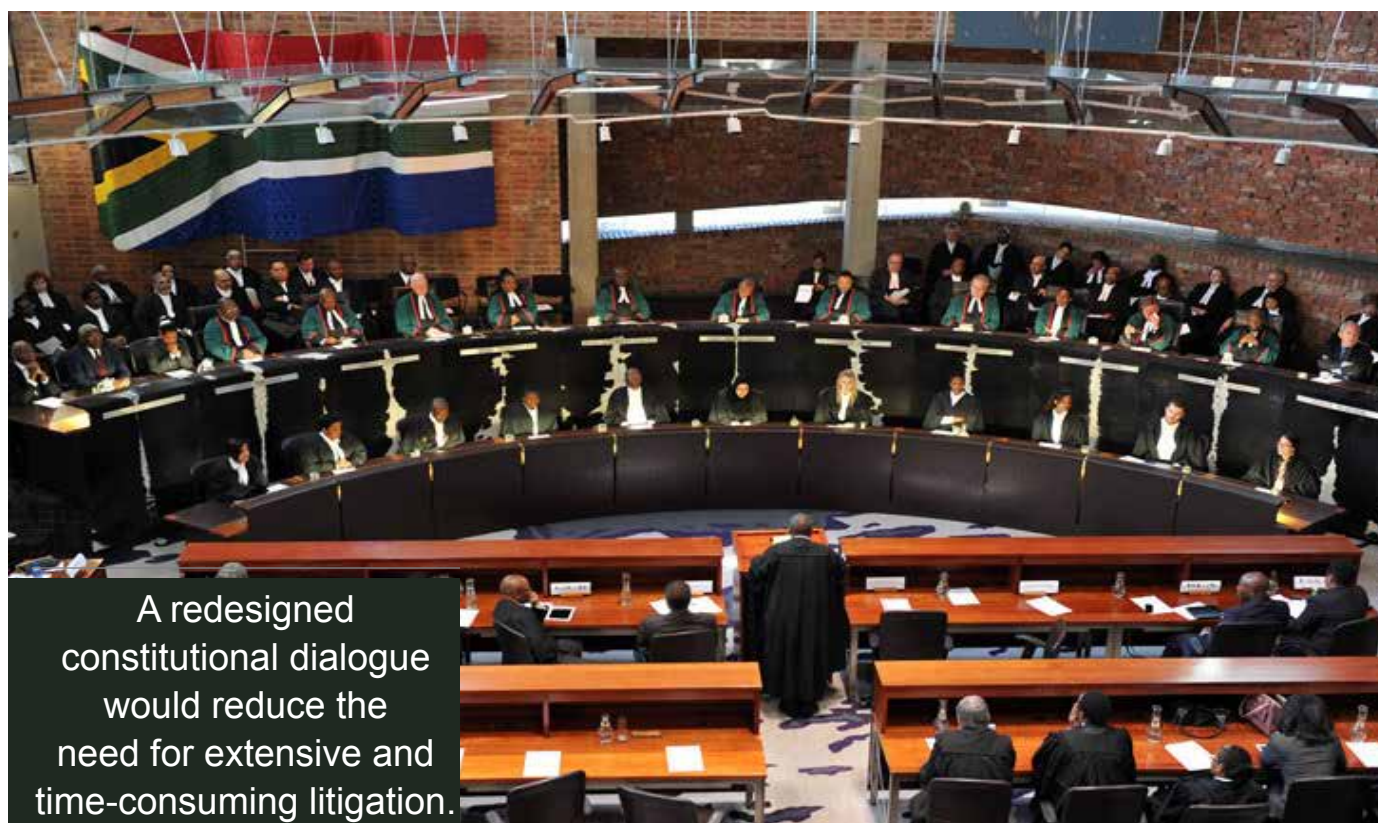
The TAC example

Two former justices of the Constitutional Court, Albie Sachs and Johann Kriegler echoed insights by Justice Zak Yacoob and others regarding a possible model that might be derived from the civil society campaign, litigation, and decision of the Constitutional Court in the Treatment Action Campaign (TAC) matter. Brought on by the absence of an effective policy response to the socio-economic devastation and human tragedy caused by the HIV/AIDS pandemic, a broad coalition emerged to develop the necessary state response.

Civil society, led by the TAC, undertook a nationwide education, awareness and advocacy campaign. It harnessed medical research that established the efficacy of anti-retroviral medication, medical professional support for a treatment rollout campaign including counselling and dispensing, as well as an offer by a pharmaceutical company to make available affordable antiretroviral drugs.

In addition, court evidence clearly spelled out the budgetary impact of the proposed course of action. This coalition thus ensured the provision of adequate evidence and information to the Court, enabling it to take a decision to clearly direct government to implement a particular course of action. In this instance, the Court was able to identify the 'minimum core' content of the right to access to adequate healthcare. In this way, the Court was able to overcome its institutional limitations and its ordinarily deferential stance towards the executive and take an otherwise 'polycentric' decision. The ongoing beneficial socio-economic impact of this landmark decision is now a matter of public record.

Dialogues and recommendations

A redesigned constitutional dialogue would clarify the entire state's shared responsibility to act with determination to realise South Africa's full democratic dividend. Ideally, such a dialogue would reduce the need for extensive and time-consuming litigation that further delays meeting the desperate and pressing needs of the poor and vulnerable.

This kind of dialogue needs to be complemented by a broader dialogue involving the public, private and volunteer sectors, as well as academia.

Against the backdrop of the criticism levelled at the government for its apparent inability to effect substantial socio-economic change and at the private sector for failing to be more inclusive, create employment and reduce poverty, the HSRC in 2016 initiated a project to create a Transformative Governance Index. This project seeks to assemble a body of evidence to support the development of a multi-year index that can help spur social accountability and responsiveness. One of the key objectives of the project is to enable stakeholders to collectively track efforts to address the overarching challenges of poverty, inequality and exclusion in South Africa.

Authors:

Adv Gary Pienaar, a senior research manager, Prof. Narnia Bohler-Muller, the executive director, and Dr Michael Cosser and Dr Gerard Hagg, chief research specialists, in the HSRC's Democracy, Governance and Service Delivery research programme.
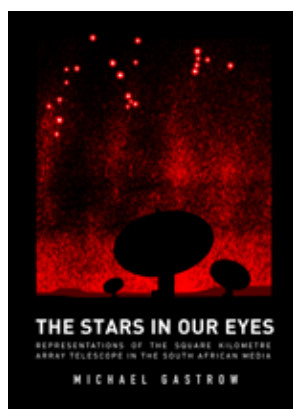
The stars in our eyes

Representations of the Square Kilometre Array telescope in the South African media

Author:	Michael Gastrow
Pub month and year:	November 2017
ISBN soft cover:	978-0-7969-2547-3
Format:	235 x 168 mm
Extent:	256 pages
Rights:	World Rights

Price **R250,00**

About the book

The Square Kilometre Array (SKA) radio telescope is set to become the largest telescope on Earth, and also the largest science project in Africa. From September 2011 to August 2012, the SKA featured regularly in the South African media. In *The stars in our eyes*, author Michael Gastrow dissects the representation of the SKA in the South African media in the period under discussion. Who were the main actors in this unfolding narrative? Who held the stage and who were marginalised? Where did gatekeeping occur and why? What was the relationship between journalists and scientists? How did the story unfold in the social media as opposed to the print media? Drawing on mass communication theory and science communication theory, *The stars in our eyes*: *Representations of the Square Kilometre Array telescope in the South African media* addresses critical gaps in the literature on science communication, particularly with respect to science communication in an African context.

Development, social policy and community action

Lessons from below

Edited by:	Leila Patel and Marianne S. Ulriksen
Pub month and year:	December 2017
ISBN soft cover:	978-0-7969-2551-0
Format:	240 x 168 mm
Extent:	256 pages
Rights:	World Rights

Price **R230,00**

About the book

Development, social policy and community action: *Lessons from below* explores how government assistance, through social grants and services, as well as community support mechanisms provide solutions to citizens in poor communities and the ways in which the citizens perceive and make use of such interventions. Solutions to poverty and inequality are often designed, implemented and evaluated in a top-down manner, thereby disregarding the views and agency of the poor citizens themselves - this book addresses that gap.

Based on research conducted in the urban area of Doornkop, Soweto, this insightful study broadens our understanding of citizen-community-state interactions in disadvantaged, urban communities in South Africa by using a range of different methodological approaches and theoretical perspectives. It points to the need for more nuanced policy strategies and interventions, pertinent to local challenges which also resonate with the global search for solutions in similar contexts. This book also provides a case for conducting community-based research that could support communities in their efforts to effect positive change.

Books that make a difference

Divided Country
The History of South African Cricket Retold - 1914-1950

Author:	André Odendaal, Krish Reddy, Andrew Samson
Pub month and year:	February 2018
ISBN soft cover:	978-1-928246-16-9
Publisher:	BestRed
Format:	235 x 168 mm
Extent:	512 pages
Rights:	Southern African rights [Zed Books]

About the book

Divided Country explains how segregation and apartheid became entrenched in a unique way in cricket in South Africa between 1915 and the 1950s. While the rest of the cricket world increasingly rubbed out old dividing lines, South Africa reinforced them until seven different South Africas existed at the same time in cricket. Each of them claimed the title 'South Africa' and 'national'. Each ran leagues and provincial competitions and chose national teams.

This book continues the task started by *Cricket and Conquest* (2017), which re-wrote the foundational narratives of cricket in southern Africa between 1795 and 1914. One reviewer noted it was 'simply the finest book ever written about sport in South Africa'. Another that it had the effect of 'bowling over prevailing histories, de-colonising existing narratives of the game … *and* throwing all that came before into a spin' so that 'what was will never be the same'. *Divided Country* similarly attempts to paint an entirely new picture of cricket in South Africa during a crucial and complex period. It completely inverts previous whites-only general histories of cricket, showing that the game has an infinitely richer history than has been recorded to date.

Without knowing how apartheid in cricket unfolded, one cannot even begin to understand the journey the country has travelled since the 1950s, and how, slowly, painstakingly, the cricket unity we take for granted today was struggled for and constructed. This will be the explosive theme of Volume 3 of this series.

Price **R295,00**
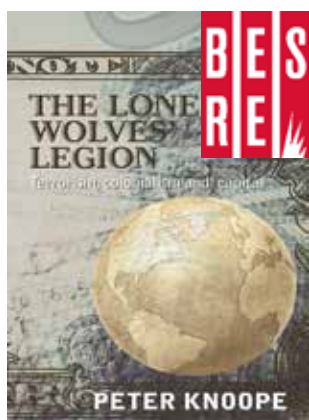
The Lone Wolves Legion
Terrorism, colonialism and capital

Author:	Peter Knoope
Pub month and year:	March 2018
ISBN soft cover:	978-1-928246-28-2
Publisher:	BestRed
Format:	210 x 148 mm
Extent:	160 pages
Rights:	Southern African rights [Zed Books]

About the book

Since 2011, attacks that sow terror in the hearts of people all over the world have increased significantly, both in their frequency and intensity. Victims of these attacks have also increased, in the West and, more specifically, elsewhere in the world. Is there indeed a war of terror, as many political leaders would have the world believe?

Endorsement 1

'In his examination of the relationship between the West and the rest of the world, the author turns many dearly held Western assumptions on their heads. Peter Knoope convincingly shows the fundamental differences over key concepts such as existence, time, development and violence.' - Prof. Bob de Graaf, senior lecturer in Intelligence and Security Studies at Utrecht University

Endorsement 2

'Highly recommended for anyone wanting to explore the notion of security." - Fulco van Deventer, founding member of the Human Security Collective