# CLAIRE PENN

### **TOP THREE AWARDS**

- Winner: Science & Technology Category, Shoprite/Checkers SABC2 Woman of the Year Award, 2008
- National Order of Mapungubwe (Silver), 2007
- Joint winner: Department of Science and Technology Distinguished Woman Scientist award (Academic Excellence in Social Sciences or Humanities), 2010.

# **DEFINING MOMENT**

Working on the South African dictionary of sign language, which introduced Penn to the notion of culture and language, eventually leading to her interest in better communication within health settings, particularly for the marginalised and voiceless.

### WHAT PEOPLE DO NOT KNOW

"I had a birthday once where I invited my hiking friends and my academic friends, and they must have thought, 'how can this be the same person?' - I'm leading two separate lives as a hiker and as an academic, Penn has climbed Mount Kenya and has recently taken up botanical art. "Botanical water colours go against my very nature because it takes a week to paint one flower. But my artsy side is coming out now – it's been supressed my whole academic career." Her sons share her two sides, though individually – one is an artist, the other a scientist.



### IT IS IN THE MESSAGE

"When I'm out of Africa for too long I feel terrible," asserts a well-travelled, Kenyan-born hiker, activist, therapist, mentor and mother.

Professor Claire Penn is all these things, and she's the Director of the Health Communication Research Unit at the University of the Witwatersrand (Wits). There, she's carved out a unique groove into which streams from both the 'hard' and 'soft' sciences flow.

To understand Penn's professional groove and mission, imagine you didn't have the confidence to say "no" when it really mattered, or that you could not find the words to convey a life-threatening emergency to a medical professional.

Picture suffering with a complex chronic disease and being expected to follow treatment instructions given to you in your third or fourth language. And consider the effect on the family of a career poet or novelist who suddenly loses the ability to compose the words their livelihoods depend on.

Whether because of stroke, language and cultural barriers, time constraints or deafness, thousands of South Africans are unable to aet their message across effectively. This fact is becoming more and more evident, says Penn, whose team of researchers study communication within many different health-related contexts.

Penn's research unit occupies a niche that brings many disciplines within health and the humanities together. She is trained as both a speech therapist and an audiologist. "One has to do with speech and language problems, and the other has to do with ears. I don't think you can separate the two when talking about communication in the South African context - because of our history and the problems we see in the communities we work in, we need people with the skills to do everything those communities require."

# SOCIAL ACTIVIST

It's no secret that Penn is a self-proclaimed social activist. This fuels her fervent insistence on a multi-disciplinary approach to research, and a reliance on qualitative methods, which she says is often the only way to study the complexities of health communication.

"What I'm most proud of is that instead of just sitting in some office, I'm actually doing things on the ground, working with people. For instance, I sat under a tree in Uganda teaching young girls how to say 'no' to transactional sex [a relationship in which money or gifts are exchanged for sex]. I love seeing the resources of people and their incredible resilience; both health care workers and patients, and seeing how we can help deploy them to make things better."

With such clarity in her calling today, it is strange to think that in her early years at university, Penn only chose speech pathology and audiology because she wasn't sure which direction she wanted her career to take.

"I saw it as something that would give me a lot of choices. It seemed a frivolous way to make a career decision, but I've always loved maths, biology, English and people," she says. "I used to count verbs and now I'm looking at narratives."

Though she enjoys every aspect of her career today – especially teaching, training communities, and writing - her work is far from merely collecting stories, and not at all fun and games.

Her journey into this niche really began during her PhD, when she studied patients suffering from aphasia, a lifelong condition of language impairment following brain damage.

"There is nothing more special than a person who has aphasia as a result of a severe life event such as stroke or head injury – the ability of these people to adapt and get on with life is incredible. They may have been a poet or a lecturer, but can never again express themselves as they did before."

She still runs an aphasia group at the institute, and treating them remains her first love. "I learn so much more from them than I'll ever be able to teach," says Penn. "These are just remarkable, wonderful people."

Her therapeutic approach is all about adaptation, compensation, attuning to the needs of the environment, and focusing on ideas rather than just words. "I get very cross with other therapists when they say, for example, 'Oh no, we don't do Tswana'. Make a plan! Meet the human being even if you don't have the vocabulary."

This idea of a human connection and an individual approach rather than relying on textbook methods underscores much of Penn's work following her PhD.

For instance, when she was seconded to the Human Sciences Research Council to produce the South African dictionary of sign language around the time South Africa was transitioning into democracy, she discovered colloquialisms as diverse as the country itself.

"The project was this common cohesive force bringing together black and white deaf people; Afrikaans ladies from Pretoria and Zulu people from rural areas came together to celebrate the diversity of sign language, but also to assert the rights and language of deaf people," she says. "It was just a microcosm of what was happening on a broader scale in South Africa."

This experience was one of the first to really introduce Penn to the notion of culture and language. "Working with the deaf taught me that deafness can be a disability with a small 'd', but Deafness is also a culture with a big 'D'."

#### NEED FOR COMMUNICATION

At the same time, her work as a therapist in the health sector began to make her aware of the need for better communication in a health context; communication that would take individual needs, such as language barriers, cultural differences and disabilities, into account.

"I then started looking at how better health communication could help us deal with the HIV/AIDS epidemic," says Penn. She completed an ethics qualification and has served on the Wits ethics committee for over 20 years, where she's been particularly engaged with language issues around informed consent. "This involves, for instance, helping those conducting drug trials get the language right so that participants would understand. And we look at how interpreting should take place in the health care sector."

Concerningly, Penn's research has consistently shown that understanding among patients in various health settings is very poor. But because every human being - health care practitioners and patients alike - is an individual, finding a broad solution is incredibly tricky, and, contrary to the textbooks, there is no one-size-fits-all approach.

"What you need to do is go into a site and use research methods that will uncover the specific dynamics of that site." These methods are often qualitative, including conducting interviews, recording interactions and ethnographies (observing people and cultures to understand their point of view).

"It is wrong to say, 'This is how we should explain diabetes to patients', or 'That is how a white doctor should talk to a black patient in a rural clinic'," she says, adding that this approach simply won't work. Penn explains that if a health worker merely asks, "Do you understand Ma?" the patient is likely to say "Yes" because they want to go home, not because they actually grasp the information.

In one study, Penn and her team divided mothers into two groups. "In the first group we took details about their babies in the standard form: 'aae!?'; 'when born!?'; 'how big!?' In the second we group we said, 'tell us your story'."

Doctors had initially protested that they didn't have enough time for that approach, but the study showed that it took the same time to collect patient information, and that in fact the most pressing concerns of the mother came out in the foreground. In other words, the patients communicated the reason for their visit to the doctor much more effectively, which simplifies diagnosis and hence treatment.

Penn has received much criticism for her approach to research. For example, although her work falls into the humanities, many insist the research belongs in the health sector. And those in the health sector ask questions such as, "Why did you only interview 15 people, rather than analysing 3 000 responses?"

But Penn believes her unit's methods make a tangible difference in communities, rather than being purely academic. The study she considers most impactful in this regard was conducted by Prof Jennifer Watermeyer during her PhD under Penn seven years ago. Watermeyer, who is an Associate Professor and an NRF-rated researcher like Penn herself, looked at communication in pharmacies in the North-West Province.

"Even though the pharmacists were Afrikaans-speaking, and the patients were Tswana-speaking, this community was able to achieve an excellent level of adherence to antiretroviral (ARV) drugs through a range of strategies," explains Penn. The pharmacists used props, various non-verbal techniques and repetition to convey their messages.

Despite being a single case study, Watermeyer's findings hint at interventions that may be trialled elsewhere and for other diseases like tuberculosis or diabetes. "Single case studies should be published [in peer-reviewed journals], especially if they are outliers," says Penn, in response to further criticism of this approach by academic peers.

"In that study we found fabulous evidence of mutual efforts towards understanding the complicated dosage of ARVs, which at that time depended on factors like whether the patient is ill, pregnant or overweight."

Another study revealed that informal structures within health care settings, such as patient support groups where mothers sit knitting and chatting, yield insights into barriers to care. In work as yet unpublished, Penn and her students aim to extract what works in some of those informal structures and feed it into formal structures.

A further example of how Penn's approach leads to concrete interventions can be found within a particular emergency call centre in the Western Cape that had been experiencing slow response times. When Penn first interviewed staff, the call takers, dispatchers, administrators and ambulance team all pointed the finger at each other as the root of the problem. Penn analysed recorded emergency calls and put the entire staff together in one room to identify communication problems – a simple intervention no one else at the centre had implemented before.

"We found all that was needed was an understanding of each other's communication needs," says Penn. In the end, her interventions improved response times per call by an average of four seconds, "just by changing the way people picked up the phone".

"I got so excited by this result I thought I might resign from Wits to go run the call centre!"

Fortunately for the many other communities she has impacted since, Penn did not resign from Wits, and now regularly conducts training on such 'team communications'.

"I go to Bara and they'll ask me to train the nurses. I say, 'No, everybody must be in one room together - cleaners, nurses, doctors and everyone will learn together how to make things easier for patients'."

She's also conducted training as part of her involvement with the Paediatric Aids Treatment in Africa (PATA) network, and has worked with Drama for Life to communicate with diabetes patients through theatre.

Penn has been told by some that she does too much – too many things, too much diversity. "I work hard, maybe too hard, but I will carry on forever if I can. This is what I really love to do – raising and solving issues."