

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."

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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