

**'Building an empathetic, conscious and sensitive society that embraces difference' – a speech by Ms Thembelihle Ngcai at the Eastern Cape Inclusive Education Indaba, 14 March 2019.**

With all protocol observed, good afternoon everyone.

My name is Thembelihle Ngcai.

Nearly twenty years ago, I was diagnosed with a neuromuscular disease called Spinal Muscular Atrophy. SMA is characterised by a wasting away or weakening of all the muscles in my body. While I was able to walk for most of my life, as per the prognosis, I've since lost that ability. Apart from a loss of lower limb mobility, standing and sitting, walking, climbing stairs, holding heavy objects independently were daily activities I struggled and still struggle with.

A few years ago, during my first year at Rhodes, I was coming back from a lecture with other students who I had met. Naturally, as was the case in most of my interactions with fellow students that year, they were curious about my disability.

Anyone who knows me knows that I'm incredibly open about the trials and triumphs of being a Black woman who is disabled; so I welcome and encourage questions. Upon hearing about the challenges I had to endure as a disabled person, one student I was walking with said; "Well, congrats for making it to University.

I contemplated this strange congratulations as I walked back to my residence, asking myself "Kanti what do people **do** after high school?" Nakhona, if you took disability out of the picture, what was it that I was doing that could be considered an achievement?

But when I looked around for people who had visible disabilities, I found none in my residence, I knew two in all the courses I took and on campus, I could probably count them all on one hand.

But that comment has stayed with me for all these years because it perhaps encapsulates why inclusive education, matters.

Finding that comment strange was natural. I had grown up in a family that, very soon after diagnosis, affirmed me as someone who equally had something to contribute to the world. **Education** was not a question. **Pursuing and achieving my dreams** was not a question. I had physical limitations but my ambitions need not have any. And this was a recurring theme that people around me, including teachers, instilled.

When I was diagnosed, I was actually living in a village, emaMpondweni ngapha kweMthatha. I lived with my grandparents who'd had a limited education. They didn't know the intricacies of this rare disease, but they were unwavering in their determination to give me a great future. So I moved to East London to be close to my medical practitioners and in the process, gained access to opportunities. I often wonder how differently my life would look, today, if not for their determination all those years ago.

A lot of people who know me won't know that, upon my relocation to East London, my incredible paediatrician at the time, the late Dr Norman Cooper, wrote a letter to Clarendon Primary, recommending that I be admitted. He shared with the SGB the concern that my full potential would not be realised if I went to a special school. And I was welcomed by both staff and students at Clarendon with this ethos and culture – that I was there to realise my potential, in the same way other children were.

Clarendon was great – when I arrived to start grade 6, all the children in my class had been sensitised that they would be welcoming a “special” girl to their class and they were to give me the “Clarendon welcome”. I even had a chaperone, which ensured that I fit into the school seamlessly.

The thing is though, I never did fit in.

Sure, teachers and students knew I was disabled and they were sensitive in all our interactions. Sure, all my classes were moved downstairs so I could access them. But I never fit in.

During a physical education class or swimming gala or athletics days – I would sit on periphery and watch other children make and concretise friendships through their mutual interest.

When it was a 5km school walk for charity, I was alone in the bus that chaperoned the girls to and from their destination.

When all the other children sat cross-legged in class rows on the floor during assembly, I sat alone, in a chair, at the back of the hall.

In the classes that couldn't be moved to accessible floors, it would take me longer to arrive in class and by the time I did, the teacher had already started the lesson.

The alternative? To be carried by a fellow student. And because mine was a desperation to not miss anything, I **allowed myself to be** carried up several flights of stairs. On one occasion, I wound up in hospital with injuries.

As I turn 25 soon, what I've realised about being born disabled is that I grew up acutely aware that I was disabled. I was acutely aware of where I was versus where everyone my age was. And this awareness turned into a debilitating fear of being left out that seeped into my adult life.

In the absence of people who looked like or had similar challenges to me in primary, high school and even University, I tried to shrink myself instead of embracing who I was. I was seen and labelled as “special” which further alienated me and made it daunting for other children to approach me or even relate to me.

It's easy to dismiss these experiences of not being included outside of the classroom as minor in relation to the reality that I went to one of the best, most well-resourced schools in the province. But these things **do** matter. They set the tone for how we, as disabled children and later adults, resign ourselves to the fact that we just, **will never be** part of our communities and society.

But more importantly, children who grow up without seeing disability and diversity valued in the settings like school grow up to be adults who congratulate us for normal adult milestones. These children grow up to ask us, “So what’s wrong with you?” before they even know our names.

Inclusive education is not **just** placing a child in a mainstream school.

It’s not **just** sensitising staff and learners about an **individual**.

It’s not **just** accessible infrastructure through universal design or accessible learning materials or even a differentiated curriculum.

It’s not **just** about what happens in the classroom alone.

It’s also not **just** about having an affirming and reassuring support at home.

To echo what Mr Putter said, inclusion is not forcing children with diverse needs to conform to the accepted norm.

What characterised my experience was either feeling like I had to shout, wave or scream to be included, assimilate **or** leave my disability at home. And this is not a unique experience; too often, the burden to be included falls on the disabled person. And when they can’t morph themselves, when they can’t chisel parts of themselves and their disability in order to fit a system not designed for them, they are rendered “too disabled” to be a part of their community and society.

And these “too disabled” children are the same 500 000 children who still languish out of the school system today.

They are the same children who are exhausting themselves navigating systems that are designed to say that the inadequacies lie within them, and not the absolute fact that we as leaders have not made a focused effort with appropriate investments to create an authentically inclusive system.

I want to live in a world where disabled children can better relate to their disabled or non-disabled peers because they have been given the tools and support to participate equitably in all things.

I want to live in a world where disabled children are better able to assert their sexual rights because sexual health education in schools is not non-disabled person-centered.

I want to live in a world where my boyfriend isn’t considered an extraordinary person because he “endures” all the challenges that come with a disabled partner.

I want to live in a world where we don’t lower the expectations for disabled people but where we value genuine achievement.

I want to live in a world where disability is not exceptionalised, but normalised.

I want to live in a world where capacity, ability and potential outweigh limitations.

And we **can** build that world, for **all** our children.

We can longer relegate the responsibility to do so solely to teachers and principals.

It is all of our jobs, in whatever capacity we're in; to build an empathetic, conscious, sensitive society that embraces difference. But we can only do this if we look at inclusive education as an opportunity, not a burden.

So, to quote former United States President Bush, "***Let the shameful walls of exclusion finally come tumbling down.***"

***My name is Thembelihle Ngcai. Thank you.***