

Resilience

BY RAY POLO

It has been two decades since a widow desperately carried her son to a disability assessment centre, hoping he would be treated, walk back home and play football as he used to do. The son has never walked to date!

Duncan Onyango was born healthy and grew up as a bright and active boy.

Just as he turned seven, a "mysterious" illness struck, confining him to a chair indoors. Onyango became feeble and clumsy. He could not even stand. And with that came murmurs. Tongues wagged, spewing derogatory words on Onyango's family.

"Some people said I had been bewitched. Even my elder brother was not spared. He got into fights as he protected me from bullies," he recalls.

Onyango's sole sibling, Alfred Ouma, had made it his business to carry him to playgrounds, even if just to watch others jump and skip.

"It was puzzling. My strong and chubby brother could no longer walk or play. For long, we thought it was polio," Ouma says.

To survive, the boys had to be creative. They used simple homemade toys to woo peers to accommodate Onyango in their games and help move him around.

"There are times mother prohibited us from playing outside. That is when I realised that my life had changed. I was disabled. I began to hate everything and everyone," Onyango says.

His mother always ensured the boys had toys at home. It brought happiness back to Onyango. Gradually, he won back the hearts of many children in the village, many attracted to his toys.

Unfortunately, his physical situation deteriorated. He could not stand, sit or do ordinary things.

A worried mother carried him to Nyabondo Mission Primary School, a centre for disability assessment in Kisumu.

"Boy, get over here and shake my hands," an assessor told him. "I cannot get up," a tearful Onyango answered.

His mother had hoped for some miracle cure that would make him walk again.

The assessment dimmed the family's optimism. The assessors could not tell exactly what his condition was. Later, they discovered Onyango had muscular dystrophy.

The US Centres for Disease Control and Prevention, (CDC), says muscular dystrophies are a group of genetic disorders that result in muscle weakness.

Every type of muscular dystrophy is different from the others. The condition has no known cure, but an early diagnosis may help an individual adapt to the changes.

The CDC adds that muscular dystrophy can run in families, or a person can be the first in their family to have it and at any age.

Muscular dystrophies are rare, with little data on how many

people are affected. Survivors' tales reveal misdiagnosis and wrong treatment before the condition is established.

A woman who was diagnosed with the condition once said that the doctors she was seeing withheld the results from her "because there was no use". She got the news 13 years after the symptoms began to manifest.

She and Onyango were case studies who had joined weekly office learning sessions dedicated to creating awareness on muscular dystrophy.

A caregiver who joined the session said open communication, awareness, resilience and adaptations help survivors cope with the condition.

Muscular dystrophy causes progressive weakness and degeneration of skeletal muscles. Over time, muscle weakness decreases mobility, making daily tasks difficult or even impossible.

This changes one's interactions with family members, transport, accommodation, school work, and during notable transitions in life like school or job.

At the disability assessment centre, Onyango heard of surgery, foot callipers, crutches, and even the possibility of a permanent life in a wheelchair.

It was too much to bear for his young brain and even confusing for his distraught mother.

As the school first term of 2002 academic calendar fast approached, Onyango's mother was torn between surrendering him to a "special" boarding school and remaining with him at home.

Who would tend to his special needs? Who would settle his fees? How would Onyango cope in a new environment?

The questions swelled without answers. The poor widow took the decision to have Onyango home-schooled by his cousin Charles Anda.

The cousin-teacher noticed that Onyango was a quick learner and advised that he be enrolled in an ordinary primary school.

Coincidentally, Anda had enrolled for courses at the Kenya Institute of Special Education (KISE).

"Onyango was brilliant and had high self-esteem. He was also disciplined," Anda says.

"Teaching him helped me appreciate my studies as a special needs education (SNE) tutor. I was alive to the fact that some families hid their disabled children, never giving them a schooling opportunity. Onyango grabbed the chance and I was happy to nurture and counsel him."

Onyango's body condition grew worse at a time his mother began ailing. Onyango and Ouma were devastated when their mother died weeks later. Relatives said she had severe heartburns.

"I still recall that dark and lonely night. We lost her, dashing any hopes of us remaining in school. Painfully, we watched our mother's body for three days before burial as there was no money to

Muscular dystrophy did not stop me from scaling academic heights

He was born healthy but a debilitating condition set in when he was just seven, almost scuttling his schooling. Then his mother suddenly died, complicating matters for Onyango and his elder brother

Duncan Onyango poses as an intern at Zizi Afrique Foundation. PHOTO: IPOOL

I often woke up early to prepare for the lectures and help Onyango get ready too. I cooked and washed our clothes and ran errands for him. I often woke up to help him turn at night. I had never encountered anyone in such a state

Paul Murimi, Duncan Onyango's roommate at Kenyatta University



take her to the mortuary," Ouma says.

It was a new world for Onyango who had to contend with his frail health, disability and orphan status. A dark world had grown darker.

His stepmother stepped in to help, albeit briefly as she had to take care of eight children to take care of.

Onyango and Ouma pushed the number of children under the stepmother's care to 10 - too many mouths to feed for an unemployed widow.

After weeks of struggle and uncertainty, Onyango landed a chance at Nyaburi Integrated Primary School in Homa Bay County.

He found it difficult to make new friends, believing he would walk again and return home.

Later, Onyango realised he had to accept the situation and move on. A good teacher helped him focus on academic work.

Onyango read hard, now dreaming of flying out of the country for treatment some day as he had been told during the disability assessment.

He channelled all his energy to books and classwork, performing exceptionally well.

The friends Onyango had made pushed him along, even to the toilet and back.

While in Standard Seven, he got a fracture on the left hand as a boy attempted to lift him to the wheelchair.

He had to endure a cast through

the examination period to make it to the list of Kenya Certificate of Primary Education (KCPE) examination candidates the following year.

"I was teaching at the school Onyango was. After the wheelchair incident, he put up with me until the new term began. To be honest, I marvelled Onyango's love for education," Anda says.

Onyango's hard work and resilience paid off when he passed the KCPE test.

He received a letter to join Oriwo Boys High School in Homa Bay.

Unfortunately, Onyango could not join the school due to health complications, mobility problems and lack of fee.

He refused to sit and watch his future fade away. If he had to approach all well-wishers in the world, he would as he wanted to pursue his education.

Then the Adventist Relief Agency came to his rescue. The organisation paid Onyango's fees and supported his upkeep at Joyland Special Secondary School in Kisumu County from Form One to Form Four.

His cash-strapped family members also chipped in from time to time.

Life at secondary school was tough. Onyango had to depend on his peers for almost everything, including mobility, bathing and toileting.

While in Form Two, Onyango heard of a boy who had suc-

cumbed to muscular dystrophy. His heart sank.

A year later, he got a chest infection that lasted a whole term. A nurse at the hospital told Onyango that he was sick because of his "abnormal" chest, a sick statement in itself.

The hospital and home stay hit his studies hard, with stigma boiling over. Onyango endured long periods in bed, sometimes spending nights in the wheelchair and suffering fatigue, numbness and bedsores. He very much relied on willing friends to help him around.

Some friends and relatives loudly wondered why a young man "is suffering so much just to get an education".

Fortunately, a friend called Ken urged Onyango on: "Duncan, you can join the pity party, neglect your studies, fail and desperately cry 'serikali saidia' on the streets. You can also choose to fight right, excel, join the university and become a professor."

Onyango chose the latter. A timely talk by an old boy of his school who was a university student also motivated him to go on with his studies.

"I was thrilled and encouraged by his speech. He said it was not about disability at the university. It was all about brains," Onyango recounts.

With that, he was rejuvenated. Onyango worked hard, became a prefect and even took part in different academic symposia up to

Higher Education

22



the national level. Onyango was admitted to Kenyatta University (KU) in 2018. His hard work had paid.

Yet this was just another transition to a new world. A politician and relatives helped him get to KU, where he was admitted for a degree course in English Literature with a bias on SNE.

As he settled, he still had mobility and upkeep issues.

The cold made his fingers numb and often caged his chest so much so that he could not be up and writing in the morning. As if that was not enough, the young man deferred his studies for an academic year due to financial constraints.

A chance phone call broke his stay-at-home silence, as a group of scholars offered to fund his upkeep at university.

The institution had also improved the learning environment through the KU Directorate of Disability Services.

"Facilities are disability-friendly. There are scribes coming to the aid of students who cannot write or those who cannot do so fast, like Onyango's case. The scribes are facilitated by the university," says Dr Joyce Ogogo, a lecturer.

She and other dons helped Onyango secure funding through KU scholarship schemes.

Onyango returned to college with a distant relative who assumed the chaperon job until the day he vanished without notice or trail. Onyango was left to



Duncan Onyango on his graduation day at Kenyatta University in July last year. PHOTO IPOOL

his devices, but a student named Paul Murimi came to the rescue.

Murimi literally adopted Onyango, even abandoning his side hustles to take care of a friend.

"I met Onyango on the alleys by chance. I thought he had come to look for help as many people living with disability do. I later met him in the lecture theatre, and

we bonded," says Murimi, who took care of Onyango from their second to fourth year on campus.

"I often woke up early to prepare for the lectures and help Onyango get ready too. I cooked and washed our clothes and ran errands for him. I often woke up to help him turn at night. I had never encountered anyone in such a

state," Murimi says.

"I knew that could happen to anyone, even me. I was moved, knowing that service to humanity is service to God."

Murimi even had to adjust his weekend schedules, missing out on a lot of catch-up time with comrades.

"Saturdays were church days for Dun. I could wake up early to prepare and wheel him to church, then return to the hostel to wash our clothes, clean the room and other duties. When he came back - wheeled in by church mates - we spent time in the library studying, joined discussion groups or watched movies," Murimi says.

Onyango remains grateful to Murimi. He was lucky to have had an electric wheelchair, easing his mobility. Lecturers and course mates gave him notes that he photocopied or recorded.

The administration also allowed Onyango to have a transcriber during exams as he could not keep up with the required speed, especially on cold days.

"I believe there is an important assignment I need to fulfil. For as long as I am breathing, I will push myself towards achieving it. That keeps me going," Onyango says.

Studies became therapeutic. As he learned how to handle disabled students, so did he learn to handle his being a more empowered version of himself.

"Onyango is a brain and extraordinary. Even in his situation, he offered free tuition to children in the village during holidays," Ouma says.

Back in KU, Onyango studied hard. He was the vice-chairman of Kenyatta University Disabled Students Association, where he had previously served in the finance committee.

Onyango was a member of the KU Debating Society and served as an assistant coordinator of the Seventh Day Adventist Students Special Needs Unit.

To deal with stigma, he openly used humour to talk about his condition.

"I admire his resilience and dignity. As we were heading to the barber one day, someone stopped us and offered Onyango cash," Murimi says.

"He politely refused to take the money and made the man understand that people with disabilities do not need handouts. He has always approached life with an open mind."

Ouma says Onyango is humorous and friendly.

"We nicknamed him 'Deep State' and 'System', given his web of friends," he says.

Onyango returned to Joyland Special Secondary School for teaching practice. However, it seemed like success attracted new challenges. The wheelchair battery failed, and he resorted to a manual one that was locally fabricated. He also survived Covid-19, which disrupted his studies.

"There was a time I had gone out for shopping and someone came in to help Onyango to the washroom. The person took his phone," Murimi says.

"I was also worried when he fell so sick that he had to defer studies for a semester."

A hopeful Onyango resumed studies for an extra semester. He earned his degree in July 2023, setting another record as the first graduate in a family of 10 children, and perhaps one of the few in the sub-clan to secure direct university entry.

"It was an achievement, the happiest moment in my academic journey. I was overjoyed. My family and friends came to celebrate and I loved it. I could see a bright future. I could smell endless possibilities," he says.

Ouma and other family members were elated too.

"Seeing my brother in the graduation gown was a sight to behold. His star was shining. Reaching this far is a miracle, considering what Onyango and I went through as children. God did it. I am proud of his achievement," Ouma says.

Those close to him say Onyango's story is a stream of miracles. His determination, attitude towards life and team spirit are also praised.

"We are proud of Onyango and cannot wait to see him begin his master's programme. He will excel," says Dr Ogogo.

Two months after graduating, Onyango landed an internship at Zizi Afrique Foundation, where he joined the Directorate of Research and supported the Policy Learning for Universal Secondary Education (PLUS) project.

The aim of PLUS is to understand the barriers and enablers of the 100 per cent transition from primary to secondary school policy as well as test interventions that drive successful transitions in the education system.

"Onyango has a long story of resilience. I received a call one time, notifying me that a KU student with disability was about to drop out. The Association of East Africa Scholars, which I am a member of, offered him a scholarship," says Dr John Mugo, the Zizi Afrique Foundation Executive Director.

"On completing studies, Onyango knocked on my door: 'Daktari, now that I am through, where do I go?' Our Directorate of Research offered him an internship. We are glad the Zizi internship also opened for him another door at KISE."

Onyango's colleagues say he is focused, always in high spirits and has zeal to learn new things. One is Delphine Otieno, a Programme Officer at Zizi Afrique Foundation.

"I admire his writing skills. He is so talented and so patient with himself that he keeps writing, however little, daily. I also like

his open approach to communication. He has taught me how to handle him as a colleague. He corrects anyone who appears a little pitiful," she says.

Resilience has become Onyango's trademark.

"I have a dream to create a brand known as 'Onyango', a brand of inclusion. I want to be a policy influencer in education so that we actualise disability inclusivity. I am not comfortable with the plastic gloss and PR schemes that often shroud the concept of inclusivity," Onyango says.

He is grateful for having access at facilities during his internship at Zizi. The work schedule only required him to be at the office once every week.

The organisation also made arrangements for Onyango's taxi rides. He confesses a dread for public transport, especially matatus. He would rather do long-distance trips, as uncomfortable as they may be.

"There is much stigma towards people with disabilities in the matatu industry. Conductors are impatient with passengers who show up in wheelchairs. You get to the bus stop, but you hear every other tout shouting 'mmoja wa haraka' (one quick one to go), while you are there pleading to board," he says.

The challenges follow him to public spaces whose infrastructure is not designed with disability in mind.

"I seldom think much about my disability until I encounter a barrier. When I go for a meeting or event, it hits me hard when friends start offering to carry me upstairs. That is when I am reminded that I am disabled and must depend on others," he says.

He at times faces discrimination when looking for a house.

"I understand and forgive them. Life is too precious to be holding everyone in my heart," he says.

He adds that people living with disability need to accept themselves and help those around them know how best to offer support.

"I don't like too much attention and pity. I like it when the other person lets me ask for their help rather than treating me like I'm always needy. It is healthy to speak for yourself," Onyango says.

He is an intern tutor at KISE in Nairobi. Onyango is in the department of physical and multiple disability, where he teaches a diploma course in functional assessment.

He is pushed on a wheelchair to school but hopes to buy an electric one soon.

"As an SNE teacher, I no longer seek knowledge to acquire treatment abroad or seek education as an equaliser. I see education as an instrument for social transformation," he says.

Onyango commits to working hard enough to build his financial muscle and lead a comfortable and life. He rides on a quote by Stephen Hawking: "Concentrate on the abilities. Your disability doesn't hinder, and don't dwell on the things it interferes with. Be disabled physically, not in spirit."

2020

The year Covid-19 struck Kenya. Duncan Onyango had to defer his studies