

My son's hearing journey (Kenyan perspective)

Steve Kittur shares his heartfelt personal account as a father of a deaf child in Kenya

I am very pleased for the opportunity to write the story of our son's hearing loss journey.

I graduated from college as a trained high school teacher, and though I loved teaching, I didn't do it for long. I went from teaching to farming, to consultancy and finally settling into doing what most Kenyans do: sitting strategically with some cash to buy anything low and sell high. It's a strange concept to the western minds but this 'profession' has a 'prestigious' name in Kenya – a hustler!

In 2009, I was picked as a board member of a Deaf School in my hometown, Eldoret. I knew nothing about deafness and did not interact much with the kids beyond the

occasional engagements with the school administration during their formal functions. My tenure lasted 2 years and ended in 2011 before I learned anything about children with hearing loss. At the time we had one daughter aged 4 and had never known or heard any such disability on both sides of the family.

In mid-2012 a doctor surprised us with the exciting news that we were expecting our second born. As a young family we were thrilled and adjusted our lives accordingly in preparation for the big day. Estimated delivery time was then projected to be some seven months away. Everything was fine and as my wife approached her last trimester, we



With Dad



With Mom

Are you out there?

Do you work with deaf learners in a sixth form, in an FE college, with apprentices or do you have several Post 16s on your case list?

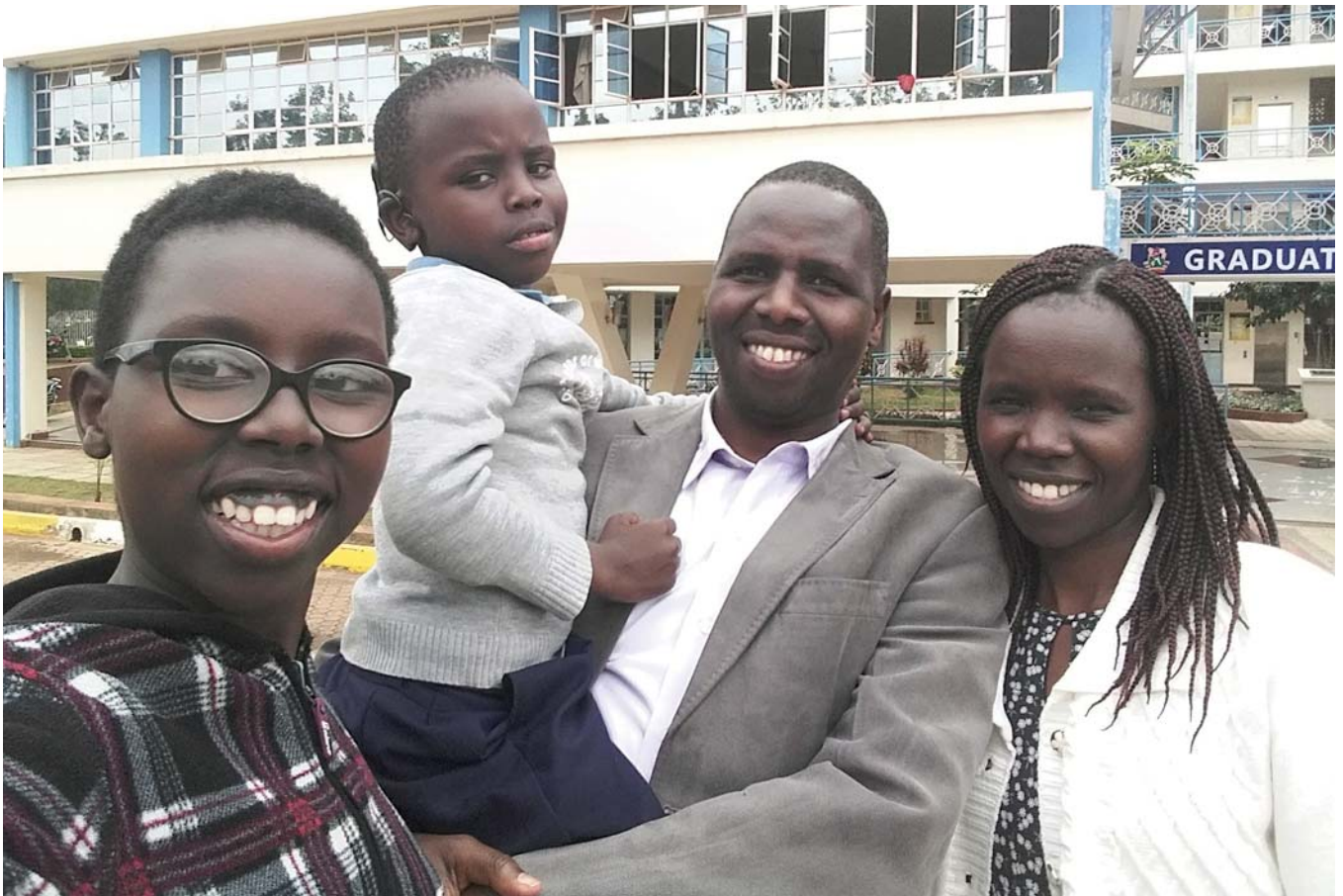
How many ToDs are working with this age group?

There is almost no data about ToDs working with this age group, such as employment status, types of learners, working patterns, etc.

So will you please respond so that we can start collecting information?

Please contact me, Jill Bussien (member of the BATOD National Executive Council), on JillBussien@gmail.com





Daddy holding Wieland between his mom and sister

were informed that it was a boy and the news couldn't be more exciting for an African father! My wife consulted widely and read every book under the sun on prenatal care for boys. Within months, we were set and waited with baited breath for little man's entry into the family.

The situation, however, quickly changed around her 24th Week. While I was away on a business trip, my wife called me and dropped a bomb-shell: her waters had broken!! We didn't know what to do but tried to get a friend to rush her through our not-so-smooth roads to some emergency room. Her gynecologist referred her to a specific facility for complete bed rest. We were hoping against hope that she'd last another eight or so weeks. She lasted only four and on Thursday 1st Nov. 2012, our son, Kibet (named after the time of birth, midday) was born! At only 28 weeks, he weighed 1200g and even looked a lot smaller! Our lives were on edge! Living one minute at a time. The pediatricians did everything they could in the Newborn Unit to battle his prematurity and low birth weight. The young man also didn't disappoint and after seven weeks he was discharged.

All was well until around the 9th month when his mom noticed that Kibet was not startled by any environmental sounds however loud. Initially, I was a little skeptical, almost dismissive of her observations, but after a month we decided to visit an ENT specialist. He also didn't carry out any formal tests but instead merely observed the baby's behavioral responses to sounds. Finally, he concluded the baby was fine, insisting that premature

babies come with delayed milestones. He advised us 'to relax' and give the baby a chance to catch up at his own pace. As a senior specialist in town, we had to believe him though our gut feeling indicated otherwise. This, unfortunately, is the situation for most parents in Africa. They quickly sense something's not fine with their children but are told (almost reprimanded) to 'wait' by the specialists (the doctor, counselor, teacher, social worker, nurse or family members). Early intervention training should target these first responders.

After six months, we sneaked in to another junior specialist who equally believed in waiting a little longer but gave us several test options that were hundreds of kilometers away. We waited a little then went in for the test. The boy was almost turning two. He was not uttering a word or speech sound. Anxiety was setting in. It was another 3 months, 3 test centers, and 300km from home before we finally got the news: the boy was congenitally deaf! Our worst fears were confirmed! It was devastating! We didn't know what to do next. Before we even processed the reality of our child's diagnosis, the testing center offered us the option of buying their hearing aids at US\$3000. We didn't even know how hearing aids looked or worked.

We quietly took our results and started the lonely long drive back home, both of us trying to process the news without saying a word as our son slept in the back seat. We had no counselors, no support group, nobody to go to for advice.



Wieland with little brother

After a few days, we began to collect our thoughts. The local specialists had no more options beyond the special school and sign language. We were on our own. We remembered the tests were not conclusive on the extent of the loss since the instruments only measured up to 70 dB. We explored the possibility of going to India to determine exactly what was wrong with the child's ears. Because we had no referrals, we blindly searched online for possible hospitals and emailed them our hearing test results. We received several responses each with an attachment of their ENT's opinion. We settled on one Dr. Shomeshwar Singh through sheer gut feeling, and partly because his opinion seemed to capture the exact condition of the young man.

At the age of 2.5 we settled for New Delhi for our first formal hearing test. The decision came with huge financial implications for tickets, testing and probably treatment. Many friends were in support of us establishing his true diagnosis.

In New Delhi we got the full picture of our child's condition – profound bilateral sensorineural hearing loss. We were taken through the only realistic option available to us, cochlear implants, which sounded promising but for the shocker cost, \$40,000! We didn't have any insurance and most local donors generally considered cochlear implant a non-emergency 'elective cosmetic surgery'! We returned home a bit optimistic but unsure of our ability to raise the funds. Most friends and relatives, for lack of precedent, questioned our intentions and game plan.

The child, they reasoned, looked perfectly normal and was still too young to require surgical interventions. Besides, they whispered among themselves, if indeed he was deaf then all he needed was nothing but love and sign language training 'when he attains school-going age'.

Some doctors were also unsure of the effectiveness of a cochlear implant with many wondering if our 'gamble' was worth the cost. Religious leaders prayed and pleaded to have us go slow. In fact our own parents wanted us to give the young man time, suggesting (strangely!) the boy might outgrow his deafness! Luckily, as a family we both were convinced that the time was right and the procedure was safe. And so, while we listened and sympathized with their feelings, we quietly sold off whatever little assets we had.

Finally, after a month or so we had the cash. We flew back to Delhi for the implant. A few hours into the surgery, however, the doctors noticed the boy's blood levels were low. Mercifully, further tests revealed no underlying causes. The doctors discouraged infusion as it wasn't an emergency and recommended he be put on a good diet for another two months to build his own blood. We figured out it was cheaper to fly home than stay in a hotel. So we flew back home and his grandma got him some traditional African food that boosted his hemoglobin to the required levels in just a month! And immediately we were back in Delhi for the third time to implant.

So, on Friday 30th October 2015, I stood at the changing room preparing to carry him to the operating table. I remember the boy clinging on to me as the anesthetist worked on him. Suddenly he went limp as they quickly took him from my hands and uttered the words, "Steve, you may leave the room now". I reluctantly stepped out and walked back up a long, lonely corridor, almost in tears, wondering if I'd see my son again. It was the lowest moment in my life.

All went well, though, and the boy recovered, got switched on and stayed in India for another 3 months for speech therapy services. After we returned to Kenya, we began a journey of trying to convince the skeptics that hearing loss is correctable. That's the journey I am now on. Speech development has not been easy. Schooling options were tough. He enrolled in a regular pre-school against all the advice to choose a special school. His teachers were great but didn't have the skills to support his newfound hearing skill or handle his processor. We struggled to find a therapist and would drive a grueling 700km return trip every week for therapy. This was our solemn call and duty for two and a half years. It was exhausting, disruptive to family life and expensive. The sacrifice began to pay off. I am happy to record that though his language is not where he ought to be, my son is now on his way to leading an independent hearing life. Other families heard of our 'success' story and came out to seek help. It was, however, not easy to encourage a parent to follow my path. We set up a support group and a community-based organization to smoothen the path for others in need. Most parents needed advice, counseling, treatment options, equipment and financial support to



Listening to a story

walk their children through the hearing journey.

As part of an effort to meet those needs, I decided to drop other personal pursuits and go back to school to become a speech therapist. I was hoping to find a local therapy solution to my family situation and benefit others in the process. I joined a local university for a Masters in Speech and Language Pathology. I am very glad I did but the needs are overwhelming. I have met very wonderful people in the process: my brother Eddie from Uganda who inspires me, my son's surgeon in India and my mentor therapist, Rosie Gardner, who volunteers monthly to offer free teletherapy AVT training to our family.

As a parent and a therapist, I am in a very good position to understand the frustrations of both sides when helping deaf children. Many parents are not endowed with resources or information to support their kids. They need regular information and training sessions on the available technology options for their children's hearing loss. They also need knowledge on how to access, handle or manage them when provided. The governments and other stakeholders are not sure of the solutions to the growing problem of hearing loss. The society needs to have early screening, immediate intervention, and access to (re)habilitation services. These are non-existent elements in most of Africa.

With advancing technology, many children are getting diagnosed with hearing loss every day. Informed parents are attracted by the promise of hearing technology and listening/spoken language. Sadly, after much sacrifice of time and resources, they come to realize that speech rehabilitation services are not available. In Kenya and much of Africa, these services are only offered in clinical settings in high-end hospitals or facilities.

In Kenya, for example, about 200 families have ventured to adopt this technology for their deaf children. Thousands of others have hearing aids. Their decision to implant

comes at a tremendous cost – emotionally and financially – as they fly out to far-flung destinations or import highly specialized surgeons to perform the operations locally. All these commitments are done without considering the requisite policy and technical support systems in which this hearing technology is ideally designed to operate. Once implanted, the families return home to start their hearing and spoken language communication journey. Their stories from diagnosis, implantation through to rehabilitation and schooling are as unique as mine. There's an immense knowledge gap of the pre- and post-implantation parental experience, without which our policy-makers and other professionals are limited in their capacity to provide any meaningful family-centered therapy practices.

Through our organization, we have come across children in deaf schools who need very minimal support to enable them to go back to mainstream schools. Some kids with ear discharge, ear wax or mild hearing loss need routine treatments and basic hearing aids to realize their potential. Unfortunately, hearing aids are still out of reach for the majority and lack of information at the family level denies children the opportunities available to their peers in the developed world. At this rate, and if left unattended, there will be more deaf schools housing children who are not necessarily deaf. It is a hopeless situation that requires coordinated efforts between parents, specialists, governments and non-government actors. We desire to use our unique skills and backgrounds to partner with like-minded individuals to offer hearing/speech training services to families and communities across Africa. We need to take this message to the community through community-based rehabilitation and advocacy campaigns. My little research reveals that if we had clear referral and hearing screening/treatment systems, parents would come out to seek help. But for now they prefer to hide their children until it's too late to help.

An understanding of parental views and perspectives is very critical to improving services and outcomes. There's a need to gather and document parental experiences – struggles, frustrations, challenges and personal reflections – in their quest for spoken language development of their deaf children.

They say it's easier for a father to have a child than for a child to have a father. And so we have had children with hearing loss. I hope in my small way to do what I can so that these children will know that they also had fathers in their life. Ensuring that every child everywhere receives the wonderful gift of sound is my dream, and I hope that my son and his peers will pick up from where we leave. Thank you. ■



Steve Kittur is a father of a child with a cochlear implant, a speech therapist, teacher and an early intervention advocate.