COCHLEAR IMPLANT INTERNATIONAL COMMUNITY OF ACTION. AISBL
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KENYA

Caregiver Name: Moses **Child: Samara**
Age at Implantation: 4 **Age Today: 6**

Samara's birth was a distressful process. She had been strangled by her umbilical cord, a situation which caused her to be deprived of her vital body functionalities. Even though she had attained her full gestation cycle of nine months, she was rushed into the Neonatal Intensive Care Unit. They provided essential support

during her substantial 2.2 kg weight loss, enabling her to breathe and feed successfully. She was subjected to strong antibiotics and other medications to keep her fully alive. She progressed well within the next 14 days and met all her growth milestones and goals. No hearing issues were detected within her three years of check ins at pediatric clinics.

Up until she was four and started school we had not realized she had a profound hearing loss. Several hearing loss concerns emerged from her first quarter of school, which led us to hire a speech therapist on the assumption that she was only delayed in speech development. However, several referrals to ENT doctors/audiologists emerged, which advanced to involving an auditory specialist. With a final referral to an audiology centre, Samara was diagnosed with profound hearing loss. A cochlear implant was immediately recommended, a term we had never heard before. This created many difficult experiences and challenges.

Families raising children with cochlear implants navigate a complex interplay of medical, educational, social, emotional, and financial challenges. Successful rehabilitation goes beyond the surgical procedure—it requires ongoing therapy, family involvement, supportive schools, and well-coordinated systems to foster listening, communication, and participation across the lifespan of the individual.

1. Medical and Pre-Implantation Challenges

Diagnosis and Decision Making:

- Timing of detection: Early diagnosis of profound hearing loss is ideal, but delays occur due to limited newborn screening or late referral. Samara's case is our example of this, and the screening should have been done in earlier stages.
- Complex decision process: Choosing whether to proceed with cochlear implantation involves weighing benefits (access to sound) against surgical risks and long-term commitment.
- Parental uncertainty: We experienced anxiety and guilt, asking: Will it help? Is it the right choice for our child?

Medical Access & Surgical Concerns.

- Access to specialists: The experts are few and not well known in the vast area of Kenya and Africa. Not all families can easily consult ENT surgeons, audiologists, or pediatric neurologists.
- Surgical risks: Concerns about anesthesia, device complications, and future surgeries (especially in very young children) made me almost cancel the whole process out of fear.
- Costs and insurance: Even when supported financially, we still have out-of-pocket expenses for the implant, mapping sessions, therapy, and equipment. We are still paying a loan taken in 2023 for the surgery which makes it difficult to support the rehabilitation required and hinders a second cochlear implantation in the right ear.

2. Major challenge: Financial and Practical Constraints

Direct Costs

- **Surgery, mapping, therapy sessions, accessories, and travel add up. Even with insurance, co-pays and non-covered services strain family budgets.**

Indirect Costs

- Time off work: Both parents had to alternately leave for appointments and parental home therapy, leaving for at least four hours per day. At school, she also had a daily professional speech therapist for two hours.
- Transport: Long travel to specialised centers increases expense and fatigue.

3. Post-Implantation Rehabilitation Challenges.

Auditory and Speech Development

- Relearning hearing: After activation, children must learn to interpret sound. This takes time and varies widely.
- Speech therapy needs: Most children require intensive, ongoing speech-language therapy to develop spoken communication.
- Progress variability: Some children progress rapidly, others show delayed or plateauing skill development which is often frustrating for families.

Access to Quality Rehabilitation Services

- Geographic limitations: Families living outside urban centers may have limited access to trained therapists.
- Service costs: Rehabilitation sessions (speech therapy, auditory training) can be expensive and are not always covered by insurance. Most of the insurance firms don't support the CI and the therapy. Creating proper awareness should be done to handle this problem.
- Coordination of care: Scheduling and maintaining consistent therapy across multiple providers can be overwhelming.

Device Maintenance & Technical Issues

- Equipment breakdown: External processors and accessories are fragile and repairing them causes stress.
- Battery management: Especially in young children, keeping batteries charged and functioning consistently is a daily challenge.
- Upgrades: New technology may outpace what families can afford or access. How compatible will the current implant support/adopt the changing technology?

4. Educational and Social Challenges.

School Environment

- Inclusion vs. support: Mainstream schools may lack accommodations like FM systems, quiet classrooms, or trained staff.
- Teacher awareness: Educators may not fully understand how to support children with hearing loss effectively.
- Academic gaps: Even with implants, children may lag in literacy, language complexity, or phonological awareness.

Peer Interaction and Social Identity

- Communication barriers: Difficulty in noisy environments like playgrounds can lead to withdrawal or misunderstandings.
- Bullying and stigma: Children with visible differences (e.g., wearing processors) may face teasing or exclusion.
- Cultural identity issues: Some families grapple with deaf identity, navigating between deaf culture and hearing world expectations.

5. Family Dynamics and Psychosocial Stressors.

Emotional & Psychological Impact

- Parental stress: Caring for a child with hearing loss and rehabilitation demands often leads to anxiety, fatigue, and emotional strain.
- Sibling concerns: Siblings may feel neglected or confused about the extra attention directed to the child with a CI.
- Hope and disappointment cycles: Progress can fluctuate, leading to emotional highs and lows for families.

Communication within the Family

- Language choice conflict: Families may disagree about spoken language vs. sign language or taking a bilingual approach.
- Consistency at home: Effective rehabilitation requires daily structured communication practice, which can be hard to maintain.

6. Samara Joy's Key Greatest Achievement to Date
   - **To hear and speak – OUR ALL TIME MIRACLE**
   - **Being able to associate and socialize well in a normal societal environment**
   - **The ability to attend and participate at home, school, church and other outdoor whereabouts with almost no support.**

7. Changes We Made to Achieve Better Access to Cochlear Implantation.
   - **Conducted research on the best ENT surgeon nationally**
   - **Adoption of the referral to the best audiologist and found an audiology centre. Listened and followed their guidelines to date and as the support center.**
   - **Selling the family valuables, taking loans and subscription to insurance to mitigate the high cost of the CI.**
   - **Emotional alignment to the new CI and rehabilitation journey - Acceptance and adoption.**

8. Recommendations To Families/Parent from Our Experience.
   - **Engage in early, consistent therapy. More so consistent parental, house manager and dedicated speech therapist to the child with CI.**
   - Building routines around auditory practice is fundamental.
   - Join parent support networks
   - Advocate in schools for accommodations. Involving class teachers and creating more awareness. More so, educating the teacher on how to handle the kid.