

Time to be seen and heard: Including children's and adolescents' voices in the South African TB response

C Goslett,¹ ; K du Preez,¹ ; G Hendricks,¹ ; A Best,² BSocSci (Hons), MPH 

¹ Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Faculty of Medicine and Health Sciences, Stellenbosch University, Cape Town, South Africa

² TB HIV Care, Cape Town, South Africa

Corresponding author: Alison Best (alison@tbhivcare.org)

Ciara Goslett's account of childhood tuberculosis (TB) sheds light on the challenges faced by children diagnosed with TB in South Africa (SA). Children are particularly vulnerable to TB infection and to dangerous forms of disseminated TB such as TB meningitis, which can cause death or major lifelong disability. They have distinct challenges with diagnosis, and TB treatment for adults is not necessarily child-friendly. In the absence of a child-friendly formulation, adult tablets are broken into the correct dosage and used to treat children. Crushed and dissolved in water, the pieces are not very palatable for children. There are therefore issues that may be neglected if the voices of children are not included in the TB response in SA. These include delays in the development and accessibility of child-friendly medication, vaccine shortages and a lack of educational support for hospitalised children under school-going age. Some positive progress has been made through the establishment of the paediatric working group in the TB Think Tank, and SA's contribution to pivotal childhood TB research studies. Additional steps could be the inclusion of children's feedback in community-led monitoring efforts and engagement between child TB activists and the SA TB Caucus, a collective of parliamentarians.

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Ciara: 'My name is Ciara Goslett. Seven years ago, when I was only 11 years old, I was diagnosed with MDR-TB [multidrug-resistant tuberculosis]. My experience with the TB medication was hard. I had to take over 17 tablets a day plus an injection. I can physically remember all the tablets that I took. The moxifloxacin was a peach capsule-like tablet on the outside with a horrible green on the inside. When I would take this tablet, it would leave a stain on my tongue. It was so bad that I had to eat chocolate to remove the ugly taste (I still get flashbacks today of how the tablet tasted).'

Children and adolescents have become leading voices in activism around the globe on climate change, gun violence, menstrual health and rights for women and people with disabilities.^[1] South Africa (SA) has ratified the United Nations Convention on the Rights of the Child, which affords children the right to express their views in matters that affect them.^[2] Ciara Goslett, a survivor of childhood TB, helps us explore how the needs and voices of children can be included better in the SA TB response.

Why do we need to consider the needs of children with TB separately from those of adults? TB does not affect children in the same way it affects adults. Children are particularly vulnerable to TB infection and to especially dangerous forms of disseminated TB such as TB meningitis, which can cause death or major lifelong disability.^[3] Globally, 1.25 million children developed TB in 2022, including 214 000 child TB deaths (the majority <5 years of age), but less than half were diagnosed and reported.^[4,5] In SA in 2022, it is estimated that 27 000 children developed TB, but only 16 534 were diagnosed and reported.^[5] The 2023 United Nations High-Level Meeting on TB recognised the importance of TB in childhood by assigning specific targets to diagnose and treat 4.5 million children with TB by 2027.^[6] SA was allocated 95 500 of the previous global target of children

diagnosed and treated for TB by 2023, but the country fell short by about 20%.^[7]

Since TB affects children differently to adults, there are particular issues that may be neglected if the voices of children are not heard.

For example, prior to 2015, children around the world would take TB drugs created for adults, split or broken to adjust the dose to their weight, and crushed up and mixed with food by their parents or caregivers so that the treatment could be ingested. This made the dosing challenging and potentially less precise.^[8] The experience of taking bitter-tasting medication adds to the psychological burden of the disease, and can have an ongoing effect on the experience of taking medication in future. Caregiver and child can both experience anxiety about how to navigate 6 months of daily, unpleasant treatment.

Ciara: 'Taking tablets at home could last up to 6 hours of struggling to swallow all. As a result, I sometimes used to have to stay up until 2 am at night just to finish taking my medication, one tablet at a time. This drained all my energy and I felt so demotivated. I still struggle to take medication today also, so it has had a lot of impact on me and my life.'

However, in 2015, a child-friendly TB treatment, or a dispersible paediatric formulation for TB, was launched at a global conference, the 46th Union World Conference on Lung Health, in Cape Town, SA.^[9] This medication was specifically formulated for children, could be dissolved in water, and tasted good. By 2019, a million courses had been procured and 93 countries had rolled out the treatment.^[10] SA was not one of them. Although the new drug formulations had been announced in SA, it took from 2015 until 2018, 3 years, for the formulation to pass the SA Health Products Regulatory Authority,^[11] and until July 2021, a further 3 years, to be available from the National Department of Health.^[12] We should all

work together to speed up regulatory processes and procurement when new child-friendly formulations become available to reduce timelines to access for SA children.

TB vaccine shortages have similarly mainly affected children. Children in countries with a high TB burden are routinely vaccinated against TB with the Bacille Calmette-Guérin (BCG) vaccine. While it is not very effective at preventing TB developing in adulthood, it is effective in preventing some of the more dangerous forms of TB in children, such as TB meningitis or miliary TB.^[13] In 2013, countries around the world started to experience a shortage of BCG vaccines due to supplier production issues. A mathematical model predicted that for each year of vaccine shortage, 100 000 deaths of children might be experienced globally over the first 15 years of life, for each year the shortage continued.^[14] By 2015, the shortages had reached SA. Researchers have noted that despite efforts to minimise the impact of the BCG shortages, data from the Western Cape Province showed that the rate of hospital admissions for TB meningitis in 2017 shot up to around double that seen before the shortages.^[14]

Ciara: 'My late paternal grandmother who was my primary caregiver was working full-time. She was forced to have me admitted to Brooklyn Chest Hospital in Cape Town. This hospital is dedicated to TB patients and TB treatment for children as well as adults.'

As well as having different biomedical needs, children are also different from adults in that they have specific educational needs. Children below school-going age are frequently hospitalised with TB for several months, or even beyond a year. This might be because of drug-resistant disease, because of the complexities of treating disseminated TB such as TB meningitis, or because their home circumstances might mean additional support is needed to facilitate adequate treatment. While the Department of Basic Education funds hospital schools for children of school-going age, those <5 years old are not catered for. Nurses in paediatric wards have a full workload caring for the clinical needs of their patients, and parents are often financially unable to visit frequently, if at all. Hospitalised children under 5 are therefore not likely to receive adequate mental, physical and social stimulation during a critical part of their development. Social workers who work in TB hospitals have reported that some children have to relearn their home language by the time they return home. Ciara recommends that psychosocial support for adolescents should be offered in addition to existing hospital schooling, and include support activities such as computing, sporting and exercise facilities.

Ciara: 'A huge challenge for me was dealing with stigma. It was especially hurtful and lonely when family members refused to let my cousins play with me or even come near me. Education and awareness are very important to remove the stigma associated with TB.'

The clofazamine TB medication had extremely bad side-effects, like the fact that my skin tone got darker and that I would get red in the sun. Because of this, when I went to high school, people would make fun of me because of how red my skin got in the sun, and this is the horrible bullying I faced as a young child that stemmed from the TB medication.'

While there are challenges in the TB response that are specific to children, there are also currently excellent opportunities to explore, including the voices of children in the SA TB response, and some important progress has been made.'

In October 2022, a Child, Adolescent and Maternal TB working

group was established within the TB Think Tank to ensure that the specific needs of children and adolescents are met, especially when guidelines and policies are developed.^[15] The TB Think Tank is a collective of TB experts convened by the National Department of Health to advise on TB control and policy in order to achieve the TB targets set out in the National Strategic Plan for HIV, TB and STIs (sexually transmitted infections) and at the World Health Assembly. It is critically important that advocacy is addressed at this high level, and the working group ensures that the voices of children and adolescents are heard. Following new recommendations from the World Health Organization (WHO), the group focused on updating the SA TB guidelines for children and adolescents, which will soon be released. SA researchers are leading pivotal studies on TB in children and adolescents, contributing significantly to global knowledge and providing evidence to inform WHO guidelines on TB in children and adolescents. The working group also creates a platform to bring different stakeholders together into one conversation. Ciara also emphasises the importance of adolescents and children talking to each other in groups. This can lessen stigma, reduce feelings of isolation and help refine issues requiring advocacy.

An additional arena where the needs of children should be included is in community-led monitoring (CLM). CLM initiatives are attracting increasing attention from funders and civil society groups.^[16] These initiatives are led by communities who are directly affected by the disease being monitored, and who are recipients of the health services being monitored. Communities report on the quality, acceptability and accessibility of services. In this way they are able to gather data on where and when health services fall short or where they are succeeding. The power of this activity is that it provides direct accountability to communities, and that where it is undertaken systematically and collaboratively, it can provide nuanced, context-specific information that is more likely to lead to local solutions. It is critical that as our country rolls out these potentially game-changing solutions, the needs and voices of children are also considered. CLM tools usually record the ages of participants, but specific tools may need to be developed to seek out the input of those <18, particularly those <12 years old. Child-friendly treatments need to be added to the list of medication monitored for stock-outs, and the training of facility clinicians on child health and specific child-friendly medication recorded. For TB hospitals, where a lengthy stay is possible, the activities undertaken to meet the educational and developmental needs of children should also be monitored.

Lastly, the SA TB Caucus, a collective of parliamentarians dedicated to championing the TB response in SA and launched in 2018, is being introduced at provincial level. These provincial caucuses have the power to influence budgets not only within the health arena, but also within that of social development and education. We would strongly urge that the SA TB Caucus parliamentarians consider meeting with children and adolescents with TB, particularly those hospitalised with TB. Provincial parliamentarians are in an excellent position to motivate for the Department of Basic Education to include the cost of educare centres in their budget submissions in every TB hospital where children <5 years old are routinely hospitalised. This is a relatively minor cost (estimated at around ZAR140 000 per hospital per year) that could have a massive impact on the development of children who would otherwise find themselves without adequate, or any daily age-appropriate stimulation.

While children cannot vote, section 28 of the Bill of Rights in our Constitution states that 'every child has the right to basic nutrition, shelter, health care and social services, as well

as the right to be protected from maltreatment, neglect, abuse or degradation.^[17] It is time for children's voices to be heard in the response to TB, and their needs seen. Without that, we risk losing thousands of children to death, lifelong disability or developmental disadvantage, and to violating section 28 by denying them healthcare and not protecting them from our own systemic neglect.

Ciara: 'Today, I am grateful to be fully healed and that the TB experience is behind me, but millions of children need our help. This is why I decided to be a champion for change.'

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