FACE OF CARE:

What are the priorities and challenges of frontline providers in the Paediatric-Adolescent HIV response?

Visual report of findings from research with 801 frontline providers in twelve African Countries

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This visual report was developed based on the experiences and perspectives shared by 801 frontline providers in the paediatric-adolescent HIV response at the Paediatric-Adolescent Treatment Africa (PATA) Summit in November 2022. In this research, participants ranked and discussed their priorities and challenges in delivery of paediatric-adolescent HIV and sexual and reproductive health (SRH) services, alongside their priorities for improving their contextual realities. Participants included nurses (n=192), doctors (n=103), peer supporters (n=129), community health workers (n=36), those providing psychosocial support (n=109), and community partners, ministry of health officials and programme implementers (n=232). Sites included Eswatini (Ezulwini), Kenya (Homa Bay; Nairobi), Malawi (Lilongwe; Blantyre), Mozambique (Maxixe City; Inhambane), South Africa (Johannesburg; East London), Tanzania (Dar es Salam; Kagera; Tari mel), Uganda (Kampala; Soroti), Zambia (Lusaka; Kapiri), Cameroon (Yaounde), Ethiopia (Bahir Dar City), Nigeria (Lagos; Abu (Port Harcourt); and Zimbabwe (Harare; Bulawayo).

The impetus for this research is clear. Frontline providers in the paediatric-adolescent HIV response deliver services that are crucial to the health and well-being of children and adolescents living with HIV. While they are often tasked with creating safe and enabling spaces for children, youth and caregivers, less focus has been provided to creating such spaces for frontline providers themselves. Further evidence is required to bring frontline health problem voices to the fore, improve their wellbeing and create supportive service delivery environments.

This research addresses a critical knowledge gap on the challenges, priorities and needs of frontline providers, who are the face of paediatric-adolescent HIV care in Sub-Saharan Africa. Findings offer a unique perspective of multi-occupational healthcare providers after the crises days of the COVID-19 pandemic. This report presents — in writing and visually — the work-related priorities and challenges of nurses, clinicians, psychosocial support providers, peer supporters and community health workers, who form the backbone of the paediatric-adolescent HIV response. We aim to support frontline providers to feel seen and heard, and to offer key programmatic and policy insights into the multi-level factors that influence and inhibit conducive service provision environments for frontline providers and those they serve.

Thank you to the frontline providers who so generously shared their time and expertise.
Participant Quotes

"I just wanted to say to our managers… Sit down with your team members, what can we do the following year? Where did we fail, you see? Those are the conversations, are going to help us to ensure that we continue to try on an annual basis… "
(South Africa)

"We need encouragement and appreciation."
(Nigeria)

"Supportive supervision is really going to add value to... to clinical care, the services that we provide, one, it makes the clinicians know that they are not alone, they are not left alone, they are not just asking them, give, give, give and nobody is telling them or giving a pat on their back... "
(Cameroon)

"When you work as a team then you’re able to identify quite a variety of things. You are able to move in the same direction, you are able to achieve more and where you make losses or where you fail, you fail together. Where you make achievements, you achieve together, other than doing it alone. So when you work as a team, we are sure that we will be able to, you know, reach out to many of these young adolescents, reach out to these other families and be able to, you know, discover a lot that can be able to really improve on the uptake of HIV/AIDS services among the young people."
(Uganda)

"Teamwork empowers us. When you do it alone you may struggle..."
(Uganda)

"...But teamwork, team work help us to cope up... right there from a cleaner, to support staff, to what, values. So for us to see these adolescents and HIV services, sexual reproduction services go on well, we actually need to consider everyone very important in the clinic... you want things, you want results, incorporate everyone into the system... teamwork is the best we can do." 
(Uganda)

"And one of those things would be finding rest, sometimes there’s a lot of burnouts doing counselling... under supervision, you are provided, at least some little rest that will boost your morale to be more productive and more performant with the services that you're providing."
(Cameroon)

"…honestly, it is a challenge... supervision is not very, very common, mentorship, is not very, very practised even though... it is very core and pivotal to ensure that the quality of care is maintained... the mentorship, supportive supervision is not regular. If it is available, it’s once in a while... I am saying that mentorship is very, very, very valuable because it helps the younger ones, the new nurses or clinicians to be empowered on the job and it also help them to know that they are right, if you now check, if what you’re doing is not verified, you can never really know whether you’re on the right track..."
(Cameroon)

In this research, frontline providers expressed that they want improved work environments. Many shared that they do not feel appreciated in their work, and they wish for more acknowledgement and appreciation from colleagues and clients. They also say that supervision and mentorship are important, and that they wish for more performance assessment and monitoring to support their professional growth, and a safe space to ask questions and trouble-shoot with supervisors and mentors. They also requested spaces at their workplaces where they can debrief, discuss the emotional impacts of work-related challenges and seek support when they are feeling overwhelmed or struggling with vicarious trauma. Unfortunately, participants described limited opportunities for supportive supervision and mentorship, within contexts of strained human resources, training and high client loads. Participants also described wishing to feel connected with their colleagues and as part of a team. They desire multi-disciplinary teamwork environments to share knowledge, build capacity and share workload. By contrast, many participants described environments lacking in collaboration and teamwork, where information and workload are not shared, with teams fragmented and under strain.
MENTAL HEALTH AND WELLBEING

Mental health of frontline providers was a theme across many sites and all occupational categories. Providers spoke about two challenges in relation to mental health.

First, they spoke about burnout from heavy workloads. Second, they described vicarious emotional challenges related to hearing difficult stories from children and adolescents. Frontline providers shared that they need more support for their mental health and wellbeing within and outside of the health facility. Empowering and supportive interventions suggested by participants included self-care, debriefing, and workplace mechanisms for ongoing psychosocial support for peer supporters, healthcare providers and psychosocial service providers. For burnout-related challenges, supportive factors included teamwork and addressing human resource shortages by hiring and training more healthcare providers.

Participant Quotes

“As a counsellor and a social worker... Honestly you listen to people’s cases and you’re really broken, you’re broken, and you need somebody to come on site to be able to counsel you the same as a counsellor needs a counsellor. So at times we need that supervision to be counselled and be encouraged.”

(Cameroon)

“...you will see people who are expected to execute a lot of things and it becomes like too heavy at times, we suffer from that burnout because one person has to perform a lot of activities. For example, you’re, like, the case of... I may have technical activities... For example, I may have disclosure sessions with the children, or... educational sessions with the volunteers. And then... sessions that need to be offered to the children like mental health, mental health activities or sexual reproductive activities... we have some forms that we need to fill in to track information maybe on a monthly basis. So I am engaged in technical activities that I have to carry out with the children and you absolutely need another strong person who can give that support...”

(Cameroon)

“And I think the debrief sessions with professional counsellors are very key for mental health as we implement the project... after you attend a particular case then you get home and you cry yourself to sleep which is not healthy. I think we should have some kind of system where we will be able to talk to someone. So I was kind of thinking that maybe if we can have something that's going to be a 24 hour number that people can text or call, I'll have someone to talk to...”

(Eswatini)

“...we all need the counselling. We all face the psychosocial problems. It’s not only our young people. Because even we health workers sometimes, alongside with these young people who are, who need to take their treatment and also who are facing problems at home. I think every facility should have a psychologist or a psycho nurse, it should be in place so that we are also helped as health workers, yeah...”

(Eswatini)
Participants were concerned that peer supporters are not well integrated into health facility teams and do not have adequate transport or supplies to do their work. Peer supporters discussed feeling stigmatised and stigmatised as young people living with HIV, and described emotional challenges with supporting their peers while at the same time experiencing the same challenges themselves. They discussed not being well-integrated or acknowledged in health facility teams, and sometimes inadequate or non-existent pay. Transport and funds to visit clients was discussed by peer supporters as an important priority.

Patient Quotes

“When you talk about little transport, you are going to visit like 10 families or 10 young people in a week and at the end of the week they are going to combine all the home visits... the extra money you used to visit these people, it is on your own. And yet we are not economically empowered, we don't have other businesses or other sources of income since we spend Monday to Friday on a hospital.”

(Uganda)

“We are also disclosing ourselves to the world out there. We are standing out for the world to see that we are HIV positive and in as much as we are proud of ourselves, but there's still stigma, there's discrimination. So right now as I am sitting here, if we are not gonna go out that I was talking on behalf of the HIV positive youth and people are still going to stigmatize me, I'm still going to face discrimination. And on top of all these traumas that I am going through I’ve said nothing. So yeah, we felt like we kind of need support on that...”

(Eswatini)

“I want to draw a picture of us peer supporters... we do voluntary work. And whatever kind of work we do, we do it out of passion to help in the community, out of passion to create a change. We come up with all these amazing ideas, we come up with a lot of things. You can even imagine that most of the projects that happen in our facilities, we are the brains behind everything. But it’s a bit unfortunate that even the little stipends we get as peer supporters come in late... This is our knowledge, this is our power, this is what we can put out there, but it is not appreciated in the way it is supposed to be appreciated. So in that way we are being demotivated. That’s why we put a point of poor motivation when it comes to what is the most difficult thing we face.”

(Uganda)
Remuneration was discussed as one of the biggest priorities for what would make participants feel motivated, empowered and supported in their work, and was also described as a challenge facing frontline providers. Different cadres of frontline providers spoke about different needs and challenges. Peer supporters, counsellors and community health workers described working for free, or receiving inadequate stipends. Participants described needing payment to meet their basic needs, and also to feel recognized and incentivized to produce results. For healthcare providers such as nurses and doctors, remuneration was discussed in relation to an (inadequate) amount. Further, the timing of payment was often discussed, with participants describing late and/or skipped payments.

**Participant Quotes**

“What would make me feel empowered and supported in my workplace to provide HIV and SRH services? The shouting one is salary increment. This comes in strongly... the counselors... we carry the clients... We are few... we do home visits regardless of distance... we need value if you recognize us.”

(Kenya)

“What would make me feel empowered and supported in my work place to provide HIV and SRHR services?... Allowances... Like I love my work. I would be a care support worker for this with my life. But when you look at how much allowances we’re given, we love this work... But allowances they make - they give us energy... Motivation... It becomes very easy for us to do it... Like in terms of the movement... and other...”

(Zambia)

“Most cases the health workers don’t get adequate support in terms of finances. Our money is very little, we have children to take care of, we have bills to pay and even when it’s coming, it comes... It doesn’t even come on time and yet you expect us to actually go to our rooms to treat and take care of people. I won’t give them that much attention because even me as a person, I’m having issues I’m solving...”

(Uganda)

“...they (doctors and nurses) cannot meet up with their basic needs; they are not psychologically stable to give good care to this uh... client that comes to the facility... And when you come to the doctors, they have spent over seven years in school but how do they earn over a thousand dollars per month, and because of that... they come to the facility, they don’t concentrate, and all of that so I think there is need to improve on the salary of clinicians.”

(Cameroon)
Stockouts of essential medicines and supplies was described as a significant resource-related challenge across sites and amongst different occupational groups. Commonly discussed stocked out supplies included condoms; birth control; ART, PrEP and test kits. Stock-outs were discussed in relation to material resources at the facility and/or national level, due to supply chain issues. Service providers shared that this impacted heavily on their ability to provide effective services and stock-outs breaks down a trusting relationship with clients.

Participant Quotes

“Okay, like some of the materials needed for the sexual and reproductive health, we talk of condoms, family planning methods, education materials, we need money to provide those commodities and make them available to the target audience.”
(Cameroon)

“… stock out of testing kits and refills plus condoms. You find that when someone, maybe you talk to them very well, you want to cover test, someone wants to know that he or she is not suffering from anything before you find out that there is no testing kit. Someone might need a protective gear like a condom, you find out that this is also out of stock. So which will cause a lot of challenge in providing this health issue.”
(Uganda)

“I’ll talk about medication – it’s still a problem. I think most clinicians or most sisters who are working with these, they are aware that we don’t have… syrup and we’ve been asking or listening to distribute, when it’s a clinic day it’s like, it’s a problem. That’s one thing, the treatment eh?”
(South Africa)
CONFIDENTIAL SPACES TO PROVIDE ADOLESCENT-FRIENDLY SERVICES

Participants described inadequate facility space to see clients privately, which they said is especially important given concerns of HIV-related stigma and confidentiality. Frontline providers described that space may be officially set aside – for example, for a youth-friendly corner – but in practice is often repurposed or converted into spaces for other clients and services. Participants highlighted the importance of providing adolescents with confidential space to speak freely, and suggested that not having such spaces deters adolescents from coming to the health facility for HIV and SRH services.

Participant Quotes

…you need space for those adolescents, because that is the critical age. So if you don’t have space for them, then you lose them. So even on this one, really we need – even if we try to improvise, but we need to identify the space that will be away from the adults where they will be comfortable, you know, to be served. (South Africa)

…if you don’t have a conducive place for that counselling and one to one encounter you cannot get what is true about the client… So space is very important when it comes to managing adolescents. (Nigeria)

…we are not going to discuss or counsel this youth in an open space uh? Can we have privacy even if we are doing HIV testing? There are a lot, you cannot do an HIV testing without privacy… (Kenya)
HUMAN RESOURCES

Issues of staffing and adequate human resources emerged strongly from priority setting and group discussions. Participants across cadres, including clinicians, nurses, counsellors and peer supporters, described insufficient numbers of trained frontline providers to meet caseloads and the demands of their jobs due to issues of turnover and limited resources for hiring new staff. They described feeling stressed and stretched, unable to execute their job requirements and feeling like they need support and additional staff who are capacitated to provide HIV and SRH services to children, adolescents and young people. The services they felt under-resourced to provide ranged from community information sessions to client case finding, clinical consultations, viral monitoring, the provision of psychosocial support, and even recruiting more staff to do this work. Participants described how inadequate human resources results in sub-optimal care and support for the children and adolescents they serve.

Participant Quotes

In our clinic we are on a red flag or with a shortage of nurses, and it’s like you don’t want to involve yourself, but you do. I believe on my youth, on my youth -... (South Africa)

First challenge is the human resource shortage… most of the trained staff who have received some training on management of children and young adults... they have gone for greener pastures. So high attrition rate is now leading to us having untrained nurses in such issues caring for these, taking care of these children and young adults... So human resources is a problem...so we need to maybe to skill up training of these new guiders... and new nurses so that we can provide uhm a quality care... (Zimbabwe)

I think that insufficient human resources is truly and really a challenge in the field... HIV is not really in the curriculum of training here in Cameroon. So you may have nurses that are in the facility who... do not have much information about HIV even the medications and so the ratio of the number of children to the nurses are really high. And you can find facility with just one nurse with maybe over two hundred children or three hundred children they don’t have time to take care of... so the number of clinicians are insufficient in the clinic, given that, they double the function of doing clinical care, providing psycho-social support, they do holistic care and we have seen that, for us to do it right, we need to have the right nurses, they need to be empowered, and they need to have sufficient, that they can have enough time to do the clinic assessment, do the psycho-social assessment and provide the care... they become overwhelmed with their functions... we see that there is also movement of staff... you may train about five health personnel from a particular health facility, you go back there and find that they have transferred,... I think if the facilities can allocate more staff... to carry on these functions, I think it’s very important so that we have people actually there to provide the services. (Cameroon)
Training and information were frequently discussed as priorities across occupational groups and countries. A variety of types of training were requested, including counselling, the provision of adolescent-friendly services, confidentiality, new guidelines and service provision for key populations. Different occupational groups described different training needs. Nurses spoke about how seeking clinical training often fell upon the individual provider, and counsellors and peer supporters described needing more information about counselling, family planning and SRH. In order to ensure that everyone has access to the information they need, frontline providers suggested making training attendance merit-based, training the trainer models for information to be shared within facilities and dedicated time from work to attend training.

Many participants described not having adequate information to provide children, adolescents and young people the HIV and SRH services that they need. This included not having readily available information (e.g., guidelines, tools) available in health facilities. They further described the rapidly changing HIV and SRH environment, reflected in guidelines and new biomedical technologies. These were considered hard to understand and implement.

Participant Quotes

“...Capacity building trainings, this simply means that when you are equipped with knowledge, we get motivated like to train more. And after - if we train more than means we are passing out the information, right. Yeah, so that makes - that makes us to be motivated because we are passing out the information. And that information is being used by the young people in the adolescents.”

(Zambia)

“...what would make me feel more empowered and supported in my workplace to provide HIV and SRHR services to children and young people?... Capacity building. Why we say capacity building is because the kind of work that we do we need more information. We need to be empowered with knowledge so that we can impart it to our clients. This will help in them trusting us and even taking up the services that we'll be giving them. And it would also help in trying to phase the... Trying to help them with the challenges that they will be facing.”

(Zimbabwe)

“...You find a situation whereby while you are doing a particular program or project then somebody... someone somewhere will go and design a project... then you see somebody coming up with another policy, with another program and that will completely change the whole thing. Not minding the fact that whether you have the resources to carry forward what he or she is bringing us a new project or not.”

(Nigeria)

“For example, there are new innovations that are happening in sense of care and treatment for adolescents... And also we are having, also the key population aspect yesterday we also had a session on our side and also... It is really a gap in our working system, we don't have enough of knowledge or capacity to support the key populations...”

(Zimbabwe)
“So the fact that we’re living in an evolving world, so many issues are coming up. Way back we’re not talking about mental health. Way back we’re not talking about GBV. These are issues that are now coming in. So we need this training so that we keep updated. We need to continue being relevant to our clients... adequate training on HIV national guidelines. We need to know the do’s and the don’ts... even how HIV is evolving. Things are changing. So we need to be well informed. And these guidelines also need to be available even in our facilities.” (Zambia)

“I’m a nurse... what would make us feel better when we’re working, is the training... you can be ten people working in a single room but then, if you’re not adequately trained, you cannot provide quality care because you’re not trained in that particular thing, and you know nothing. For example, I used to work in the STI department... I work there because I was allocated there but then I wasn’t trained in STI but because I love my work, I went to somebody else, who knows the stuff being the coordinator and she explained a lot of things... if you have adequately trained staff, it’s a plus and you enjoy doing the work, you can see a lot of people without complaining because everything is in you, it flows automatically, so that’s good... If you don’t have a lot of information, you wouldn’t answer (client questions), so that particular person, will not trust you that you’ll provide care to him or her. She will say, ‘ok, she’s not trained, I will never go there again’.” (Malawi)

“I feel like as peer supporters, we’re not given enough training especially because we are at the ground level. So I feel like we are more like neglected. Say for example, when an adolescent comes to you and needs more psycho-social support, I’m not trained or equipped enough to help them on that situation. So at that time the person I need to refer them to is not available. So they need to come back another day. So the only thing I can offer them is just a friendly advice or just a mere support.” (South Africa)

“...we need to be capacitated more on the, whatever is happening – like the trends. Because as we perform or as we grow, implements HIV prevention programmes we need to keep up with the times. So I think constant capacity building for the programmers or the implementers, who will then assist the cadre to also be capacitated and constantly be kept up with the trends or the current terms. Like for instance what - who or which group at least be inclusive or included at that particular time, what - or how we can include or how we can contribute towards the inclusion of that particular group or that particular beneficiary - type of beneficiary - in that particular time...” (Eswatini)

“...we find that we are missing a lot on the facilities or trainings... We need to be empowered on the same so that even when you give, we give the package... to provide HIV and SRH services to children also... So we need more empowerment sessions, more training sessions (enhanced agenda of ending AIDS)...” (Nairobi)

“...community health workers are not really capacitated. There is that capacity gap in the community health work force...” (Nairobi)

“Yes. I want to add something in the cadre of pharmacies, doctors and nurses... providing HIV services to children, adolescents and young people. Most of us health workers have difficulties accessing information about HIV and treatment, such as the national treatment guidelines and data. For instance, in my facility we only have one national guideline and one, a quick base of reference which cannot be accessed by my colleagues...” (Nigeria)

Frontline providers described an ideal scenario with up-to-date information and adequate training to provide paediatric and adolescent HIV services.
STAKEHOLDER RELATIONSHIPS AND COLLABORATION

Positive stakeholder relationships and collaboration, between clinics and community organisations, and other governmental and non-governmental social actors was described as conducive to providing holistic support to children and adolescents and their communities. Institutions discussed included HIV education organisations, social services, police, orphan and vulnerable children services, and community-based services to meet the holistic needs of children and adolescents living with HIV.

Participant Quotes

“…the different stakeholders… a nurse… is trained to provide health services, but now when it comes to a patient who needs psychosocial support, she cannot be able to wear different hats at the same time… Now that is where the other stakeholders come in so that they can be able to provide psychosocial support where it is needed. They can be able to do follow-ups and home visits and everything that she cannot be able to do, because now when she has to do a home visit that means she will leave her office vacant because she needs to fill the different hats.”

(South Africa)

“It is important – even ourselves as healthcare workers to really engage even in our policy work, when we hear that certain policies are in place or there’s conversations to put in place certain policies... Sometimes this data is there, but our national policy workers it either they either do not understand, they need someone to interpret that data for them, or we even need peer supporters to come and the voice of this adolescent who cannot access that policies first... So please when we hear about these policy conversations, let us find ways in which we can present our opinion…”

(Kenya)

“…you find that like for instance in one district, we in VCN, there’s quite a number of partners working, you know, with HIV care related programs – or HIV care related programs, but work it silos... but we don’t sit on the table and say ’Okay, what are you guys doing?’... you find that there can be referral linkages. Because for instance, why are the community partner, we can trace for you. Most facilities know this, some of them don’t know that we can trace for them... But there’s no collaboration between these partners that I’m supposed to be working with this person, with this community of people living with HIV. We are chasing numbers.”

(South Africa)

“And the systems are the ones that are failing the children. It’s not that, you know, there are no people there to assist. But we don’t know who to reach out to because we are working in silos. Everybody is pushing their own mandate and not realising that the problem of Social Development is the same as the Department of Health, as the Department of Justice; we can actually all work together to solve our problems... and realise that our objective is the same. We want our children to be healthy, we want our children to be taken care of. We need to be sure of the referral system and make sure that we’ve maintained those relationships with the other departments and know who exactly to call.”

(South Africa)
Participants in some sites described discriminatory policies including those with a high age of consent, limitations to termination of pregnancy, and homophobic legislation that criminalizes same-gender sex were discussed in some sites. These were described as a major barrier to service delivery, including HIV testing, termination of pregnancy and family planning services.

**Participant Quotes**

“Most of the policies around SRHR are very unfavourable and us dealing with adolescents and young people, we need to have favourable policies. For instance, you cannot give a young person - let’s say a 9-year-old - a condom because the policy does not provide for that, but in real sense you find that children in this age groups they’ve already started experimenting on sex, they know what sex is.”

(Kenya)

“There is a mismanagement of policies here in Zimbabwe, for instance the constitution its states that a child is (unable to consent to sex) under the age of 18... So when you are trying to sit down and offer services to that child (you cannot offer) contraceptives...”

(Zimbabwe)

“We’ve been given guidelines and we know what we’re supposed to do. They need to work with us, not enforcing these things, because at the end of the day it will not work. So government first, they need to consult if they’re working with these bylaws. They need to consult us first, not inform us that they just passed the bylaw. And then next, they need to work with us as well.”

(Uganda)