



HOUSE OF COMMONS

# International Development Committee

Oral evidence: FCDO's approach to sexual and reproductive health, HC 1216

Tuesday 4 July 2023

Ordered by the House of Commons to be published on 4 July 2023.

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Members present: Mrs Pauline Latham (Chair); Chris Law; Mr Virendra Sharma.

Questions 72 - 91

## Witnesses

**I:** Kirsty Smith, CEO, CBM UK; Dr Tsitsi Chataika, CBM Zimbabwe Country Advisory Panel (non-exec role), CBM UK; Alessandra Aresu PhD, Director, Global Inclusive Health, Humanity & Inclusion; and Saskia Perriard-Abdoh, Head of Policy and Public Affairs, Kaleidoscope Trust.

**II:** Alice Welbourn, Funding Director, Salamander Trust; Dr Camilla Ducker, Senior Adviser, Global NTD Programme, WHO HQ, Representative for the FGS Integration Group (FIG); and Fionnuala Murphy, Head of Global Advocacy, Frontline AIDS.



## Examination of witnesses

Witnesses: Kirsty Smith, Dr Tsitsi Chataika, Alessandra Aresu and Saskia Perriard-Abdoh.

Q72 **Chair:** Welcome to our second evidence session on the FCDO's approach to sexual and reproductive health. I am Pauline Latham. I am not the normal Chair of this Committee. Our normal Chair is on a Bill Committee and cannot be with us today, so I am taking over from her.

Before we start, I just want to draw everyone's attention to the fact that I am currently the vice-chair of the All-Party Parliamentary Group On Malaria And Neglected Tropical Diseases, and I have recently resigned from the All-Party Parliamentary Group on Population, Development and Reproductive Health, so everybody knows I have had that involvement.

Kirsty, I wonder if you could tell us what challenges people with disabilities face in accessing sexual and reproductive healthcare in lower-income countries? Could you perhaps introduce yourself, too?

**Kirsty Smith:** I am Kirsty Smith. I am the CEO of CBM UK and part of the CBM Global Disability Inclusion federation. The barriers that women with disabilities face are multiple. They can be in terms of accessing any healthcare service. That might be because the information provided is not accessible. It is often shared in community spaces in ways that people who are blind, or particularly people who are deaf, are not able to follow.

That is particularly true when you are talking about sexual and reproductive health, because it is often very sensitive. You are not allowed to mention body parts specifically. When you have a spoken word, you can use euphemisms and get around the subject. However, if people do not have any sign language interpretation or any kind of accessible information, they are not getting the messages that might allow them to access the services.

They also face economic barriers. They are often completely dependent on male members of the family who may control their finances. We have heard of community members whose husbands lock their wheelchairs away when the husband travels away from the house. It is, therefore, very difficult for a woman to be independent in that situation, and it is particularly sensitive if she is trying to access sexual and reproductive health services, particularly if that is contraception. She may not be able to travel freely to a village health worker who may be providing that service, and she may not be able to speak easily about it. That is particularly true for people who have mental health conditions or learning disabilities.

We also find that, when women do access health services, they are not accessible, so they may go to hospitals where there are no ramps, where the doorways are too narrow or where the signs are too small. They also face quite severe attitudinal barriers from the staff themselves, who view women with disabilities as non-sexual beings. They are surprised that they are there. Women with disabilities may have had very little contact



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with figures of authority and may lack the confidence to speak freely, so they may not be able to vocalise what they need, and the staff may stigmatise them and turn them away.

The extreme end is that we have had members of our communities speaking about the fact that, when they have gone as pregnant women to access antenatal services, the police have been informed. The assumption is that the women must have been raped because no man would choose to have sexual relations with a woman with a disability. The barriers are multiple. The barriers that women in marginalised communities face are exacerbated still further for women with disabilities.

**Chair:** Alessandra, could you introduce yourself as well, please?

**Alessandra Aresu:** Good afternoon. I am Alessandra Aresu. I am director for global inclusive health at Humanity & Inclusion.

**Chair:** Could you answer the same question about the challenges that particularly women with disabilities have in accessing sexual and reproductive healthcare in lower-income countries?

**Alessandra Aresu:** Thank you for the opportunity to add to what Kirsty has just said. Just as a reminder, an estimated 16% of the global population has one or multiple disabilities, and 18% of women around the world have disabilities. Many of them live in low-income countries.

The context in which the majority of women with disabilities live also represents an additional element to be considered when it comes to accessing sexual and reproductive health information and services. The additional element to be kept in mind is that this rate varies in humanitarian settings, particularly as violence and natural disasters increase the number of women and young persons with disabilities around the world.

I would also like to add that, in addition to what Kirsty has just mentioned, the barriers that she has clearly identified are present, despite the fact that women and girls, and persons in general, with disabilities have the same sexual and reproductive health needs and rights as any other person, any other adolescent girl or any other woman without disabilities.

When it comes to the factors that prevent women and girls from accessing sexual and reproductive health information and services, the intersectionality perspective is essential to keep in mind, in that women with disabilities are, first of all, women. They face all the same barriers that other women without disabilities face, in addition to those that are typical for women who have one or multiple disabilities. When it comes to multiple disabilities, it is important to keep them in mind, because this also brings complexity to the picture.

The other element that I would like to highlight is the importance that women with disabilities have the same right of informed consent as any other woman, but that is often violated when it comes to accessing and choosing services that they would like to access. This often results in



reproductive coercion, which means forced sterilisation, forced abortion, forced contraception or forced pregnancy, on the assumption that women and girls with disabilities do not have the capacity to take decisions for or by themselves and that caregivers or health workers are in a better position to take decisions about their sexual and reproductive health.

This is a form of violence against women and girls with disabilities. In addition to this form of violence, it is also important to highlight that women and girls with disabilities are at higher risk of violence overall, including sexual violence. Between 40% and 68% of young women with disabilities will experience sexual violence before the age of 18. According to the information we have today, the most exposed are women with intellectual disabilities or with multiple disabilities.

Vulnerable factors that intersect will, overall, bring to women with disabilities an additional risk of experiencing violence, but the same factors also prevent women and girls with disabilities from freely accessing information and services related to sexual and reproductive health.

**Chair:** Thank you very much. I would also like to welcome Dr Tsitsi Chataika, who has joined us now. Thank you for joining us.

**Q73 Chris Law:** Saskia, welcome. I wanted to ask you a few questions—and please introduce yourself—about the work you do at the Kaleidoscope Trust. What challenges do LGBT+ people face in accessing sexual and reproductive healthcare in lower-income countries and, in particular, in countries where same-sex relationships are criminalised or where people face social stigma?

**Saskia Perriard-Abdoh:** I would be very happy to. I have a double-barrelled name, so I will stick to one last name to make it easier. I am Saskia Abdoh. I am the head of policy and public affairs at Kaleidoscope Trust. We are a UK-based international-facing charity that focuses on upholding and capacity-building the rights of lesbian, gay, bisexual and transgender people across the world. We work very closely with Government institutions, partners and, of course, organisations on the ground. I will go more into the case studies for your secondary question in a second.

When it comes to the overall challenges faced by LGBTI+ people when it comes to accessing sexual and reproductive services, a lot of the issues have already been covered. There is an intersectional approach to a lot of the work we do, and it is really important to note that a lot of members of the LGBTI+ community are also members of the disabled community or often have concurrent disabilities. We often have very clear but also very complex cases that emerge within the people we work with.

A lot of what I am going to say now, in terms of a cursory overview, has already been covered, but the point about stigma and discrimination is especially salient when it comes to members of the LGBTI+ community. The reason for that is because they often face a double stigma, both for the type of service they are seeking and for individual characteristics that might be visible or they may be forced to disclose as they seek those



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services.

In many countries, you run the double issue of saying that you need help or that you need a service, but seeking that help and service may lead to your having to out yourself and your sexual status or gender identity to members of your community or to professional services that are not necessarily equipped to serve you.

On top of that, I am afraid that we have recently had a lot of emerging reports—I am not going to go too far into those, but I am happy to follow up later—of cases like Uganda and Ghana, where there is an increase in anti-LGBTI+ sentiment. The choice and the right to go for health and sexual reproductive services is very difficult, and it almost has an opportunity cost where you may end up putting your life at risk and being in a situation where medical professionals report that you have asked for help. You then get outed and get into a situation where your name becomes known to the local community and authorities, which might not have your best interests in mind.

We are talking about health, but if you take a look at it through an intersectional lens, which a lot of members have already spoken about, a very complex social dynamic starts emerging from the evidence.

On top of that, there is a lack of awareness and education when it comes to the specific needs of members of the LGBT+ community. There are also very clear barriers to healthcare access. We have already spoken about the urban/rural divide, but I would also note that a lot of members of the community are often pushed into more precarious work, such as sex work, when it comes to finding a route to economic survival. To be clear, all these factors are not directly linked to sexual or gender orientation or expression, but these are complicating factors that mean that, again, makes the ability to seek and secure health services much more complicated.

I do not want to underestimate the importance of mental health here. You often have a situation where, especially with children and young people, and also certain population segments like older members of the community, the ability to come to terms with your gender identity or your sexual orientation, while not necessarily being in the safest social landscapes, whether it is at home or outside the home, let alone having to try to navigate a very fragmented, underfunded and not necessarily systematic or comprehensive healthcare system, turns a challenge that an average person would already find quite complicated and difficult into something that borders on being unsurmountable in many cases.

I close by saying there is a bit of bright light here. It is not all negatives. We have also seen, especially post pandemic, a lot of access to supportive networks, especially peer-to-peer, local communities or different initiatives, coming in to fill that gap. We still have support. We still have help. We still have places where people can get the support they need. It is just a bit unfortunate that it is not as comprehensive or systematically funded as it should be, if we really want to make the system fit for purpose.



**Q74 Chris Law:** I will come back to that in just a minute. How do you manage to deliver programmes on the ground when you could be in really hostile environments that are anti-LGBT and where, in fact, there are cases of people being criminalised for coming out? How do you deal with that?

**Saskia Perriard-Abdoh:** That is a great question. I will speak specifically from the Kaleidoscope Trust perspective, but I note there are a lot of other organisations that operate in this space on a bigger scale and that would have different stories to share.

At the Kaleidoscope Trust, we do a lot of work with partner organisations on the ground. Some of them have had to go into hiding, so I will not go too much into the details on that front. The big thing here is that members of the community know their community really well, and also know how best to get services where they are most needed, and most urgently needed, in those types of rather difficult economic, financial, social and legal circumstances, if we can put it that way.

From our perspective at Kaleidoscope Trust, our job is not to get involved on the ground. Our job is to support those who support others and to make sure they are as equipped as they possibly can be to do the work they need to do. We have a lot of case studies on that front. Some of them are on health, some are on mental health and others are more on the provision of safe houses, for example, or safe harbour, especially when there is an intersectionality with the domestic violence component, as you can imagine. We have case studies, but I do not want Kaleidoscope Trust as an organisation to take credit for the work that our partners on the ground do, other than to say that it is very precarious.

I am glad that I have a chance to bring up this point, because I was not planning on it. The funding of those grassroots organisations really needs to be made explicit here. In our surveys during the pandemic—and we are going to be doing a secondary survey next year—we asked the organisations we work with across our networks how big their reserves were. About 50% of the organisations surveyed did not have enough to surpass three months of operation if the funding stopped.

I am very happy to send the stats separately, because I am conscious that is not exactly the point of this evidence session, but it is really important to remember that a lot of the organisations that provide much-needed help and support—and especially the peer-to-peer aspect—are tiny. We are talking about one-man bands. We are talking about organisations of three to four people. We are talking about organisations that rely heavily on volunteers who are putting their lives at risk and providing services when they themselves need help.

Again, I cannot overstate the importance of volunteering here. You are talking about individuals who are putting their life at risk to serve members of their community and who themselves are in need of help. Burnout is really important. Staff safety is a huge issue. When something happens—and the recent example is Uganda, of course—the very fragile





ecosystem that has emerged in the absence of something systematic is at risk of being completely dismantled and lost within weeks, if not days, so funding, support and security are really important.

**Q75 Chris Law:** How can the UK mitigate the risk of inadvertently funding anti-LGBT+ organisations in low-income countries?

**Saskia Perriard-Abdoh:** This is why we always have to be really careful in terms of intent and outcome. Funding pots are sometimes fragmented. Funding can often be disbursed through an ecosystem and end up in hands where it was not necessarily expected to end up. There is a difference, I would say, between an intention and an unfortunate outcome.

The first thing I would say is that it is really important to have transparency and accountability, especially when it comes to intermediary organisations. As an example, Kaleidoscope Trust is an intermediary organisation. We run our own programmes, but a lot of the work we do is about disbursing funding, including from Government Departments like the FCDO and from the Commonwealth, to charities on the ground.

Those checks and balances and that accountability, and making sure that we do not end up inadvertently providing resource and funding to the wrong organisations, are an internal check and balance. More upskilling could happen across civil society, to be frank, because a lot of intermediary organisations may not know that they are doing this. It may just happen by accident—again, I have to say that mistakes do happen—but you need to have those transparency and accountability components.

What I would like to see from the FCDO—and I am sure we are getting there; I am very hopeful—is that, as these questions come to light and these isolated incidents happen, there are remedies to make sure it does not happen again. That is the important thing, because you also do not want to do the opposite, where you create a threshold to access support and funding that is so high that tiny organisations that really need help and support are not able to apply for that funding because they do not meet the threshold. There is sometimes a very clear capability gap.

I am sorry, because we are slightly going around the topic of the evidence session, but the one example I will bring up is that digital upskilling is a huge issue that has emerged through the pandemic. A lot of organisations and individuals had to learn about using social media, about grant proposals that happened virtually and about evidence sessions and meetings that had to happen through Zoom. You also have that very clear tech aspect, which requires support and help.

Going back to your question, if you make the situation overly complex, you run the risk of having very valid organisations turn away from the system, because they are better off trying to find resources elsewhere. My conclusion here is, yes, have your checks and balances, and, yes, have your accountability protocols, but it is much more important that, when a moment happens where you realise that an organisation has been funded that should not have been, there is a remedy rather than stopping



the disbursement of funding throughout the system.

**Q76 Chris Law:** To what extent do FCDO's strategies, including the international development strategy and the international women and girls strategy, take account of the needs of marginalised groups, including persons with disabilities and LGBT+ people? On the back of that, how well does the FCDO disability inclusion and rights strategy take account of the needs of persons with disabilities?

**Kirsty Smith:** What we find is that the international development strategy and the women and girls strategy make reference to women with disabilities and people with disabilities, but the disability inclusion and rights strategy is not integral to them. Despite the fact that the international development strategy came out only three months after the disability inclusion and rights strategy, it was almost invisible.

There are three references in the international development strategy—one reference to barriers to girls' education, one to ending gender-based violence and one listing people with disabilities as one of the most at-risk groups in need of protection at times of crisis or conflict. The commitments that are made in the very ambitious disability inclusion and rights strategy about hearing the voices of people with disabilities, or about, as Saskia said, enabling representative groups like organisations or people with disabilities to have a place at the table, to influence decision-making or to have any kind of control over resources just was not there.

Similarly, with the women and girls strategy, there are two or three mentions of women with disabilities. There is a recognition that there is an increased risk of violence, that there are additional barriers to accessing and remaining in education, and that there is a need for disaggregated data, but the ambition of the disability inclusion and rights strategy and the very strong emphasis on including the voice of those who are traditionally marginalised is absent.

That is particularly disappointing for the women and girls strategy because, if we want that strategy to reach the most marginalised, it is going to fail if women with disabilities are not seen as a really fundamental part of that consideration. That has to be from the needs assessment and planning stage. We sometimes find that this is added on later—"Oh, yes, we will make sure that a certain number of the people we reach in our programmes will be women with disabilities"—but that is completely impossible. It just does not work, because women with disabilities do not tend to access mainstream programmes. They will not have identified them in the first place. They will not have found them in their homes—I mentioned inaccessible communications—or they will find that they are not welcome in a group or that the programme is unsuited to their needs.

At the moment, it feels as if this very ambitious and exciting disability inclusion and rights strategy sits slightly apart from, rather than being an integral foundation of, both the international development strategy and the women and girls strategy.





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**Chair:** If we have such long answers, we are going to run out of time, so could we perhaps abbreviate them slightly, please?

**Saskia Perriard-Abdoh:** I will keep mine short and not duplicate what has already been said. It is very difficult to have an integrated strategy if the underlying data is not necessarily combined. By that, I mean that sources of LGBT+ specific funding, for example, are often held separately from overarching funding targeted towards inclusion or the women and girls strategy. While it does not undermine the stated aim of the strategies, you end up with the risk that really valuable programmatic aims fall through the cracks when those funding streams are sometimes disconnected or when there is fragmentation of objectives and goals. That is an inadvertent result as opposed to a stated objective of the system.

I would just add two things. The first is that an inclusive women and girls strategy means that it is, by necessity, an LGBTI+ inclusive strategy, even if it is not a stated, overt objective. The second is that, while I know it is very much part of the programmes on which we work with the FCDO, a bit more explicit commitment and outreach towards marginalised groups would be welcome, because we often find that the communities we work with are not necessarily confident that this is a space in which they are welcome.

You need to go above and beyond to make sure you have the right people in the room, that the invitations have been sent out and that you have done the outreach. You cannot just go on the basis of saying, "We have done a call for action and a consultation. Here are the people who have shown up. Out of the people who have shown up, we have tried to be as inclusive as possible." You need to go beyond that and make sure that, when you do these strategies and this work, you take a very clear and critical look at yourself and say, "Have we brought in everybody who should be here?"

Q77 **Mr Virendra Sharma:** Alessandra, what impact has the UK's recent reduction in ODA spending had on marginalised groups, including people with disabilities and LGBT+ people, in sexual and reproductive health programming?

**Alessandra Aresu:** The recent spending cuts have caused heavy disruption and damage to programmes. I appreciate the opportunity to share the consequences of these spending cuts, hoping this will support the discussion about FCDO's future allocation and management of funds, including for the forthcoming WISH dividend, about which we are already concerned due to the reduction in budget that has already been announced.

In our experience, the way that budget allocations and contract extensions have been managed, with annual stops and starts, has negatively impacted the implementation and sustainability of the programmes, and has made it very hard for programmes to plan for meaningful medium-term change, which is essential for the delivery of value for money, and is so badly needed to achieve sustainable visibility



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and inclusive SRHR.

High-impact activities have had to be ended very rapidly and, as a result, local organisations and individuals supported by the programmes have lost precious support and access to information and services, which has proportionally affected persons with disabilities, and especially women and girls with disabilities, and their representative organisations.

Specifically as a partner of the WISH programme—the Women’s Integrated Sexual Health (Lot 2) programme—funded by FCDO, we have observed a lot of disruptions. For example, we experienced a sudden stop in inclusive SRHR activities in key countries like Madagascar, where, thanks to the WISH programme, great progress was made with the Minister to create a more enabling environment for inclusive SRHR, and the sudden and drastic budget cut resulted in stopping activities 12 months before the planned date, with only two months’ notice. This did not allow for a proper transition and exit strategy to be put in place.

South Sudan has a very fragile context, where we work with the support of FCDO. It is a country where really entrenched social norms around the reproductive rights of women, but even more so for women with disabilities, are present. Community mobilisation activities have had to be scaled back and reduced to a minimum.

In addition, the scope of technical support to SRHR stakeholders and inclusive SRHR has reduced by half in recent times. It is essential to make sure mainstream SRHR stakeholders can really be inclusive and make sure they reach the most vulnerable, including women with disabilities. In particular, remote technical support was reduced from four countries with five partners to two countries with two partners. This means the number of supporting sessions were cut by half only recently, and this happened when, after a lot of investment of funds from FCDO and of energy by many of us, remote technical support was finally starting to build momentum and bring positive effects.

WISH is one of the few disability-inclusive SRHR programmes at present globally, and FCDO has been a leader and a champion in this sector, but, to continue doing so, significant longer-term investment is essential in order to have a long-term and meaningful impact on policy and services within the communities, such that all persons with disabilities, and specifically women and girls, can access SRHR.

**Kirsty Smith:** It has been absolutely devastating. Every single FCDO-funded project that CBM was running was cut in the aid cuts, apart from the aid match. To give you some examples of how that impacted on communities, we had a direct aid grant in Ghana, which was providing safe birth, child health and psychoeducation for pregnant women and mothers through building new maternal health self-help groups and outreach clinics. That had a 25% cut. We had a health project for the most marginalised communities in Bangladesh. There was a £1.1 million cut to a £2 million project, two years into a three-year project, with no notice.

It has had a devastating impact on some of the most marginalised



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communities and the most needed projects, without any consideration of the vulnerability of the communities affected. The suddenness destroyed the relationships we had with our local partners, many of whom, as Saskia mentioned, are often very small, extremely grassroots and do not have very much experience.

The whole aid infrastructure is extremely challenging for them to access in the first place, and it came at a period during Covid when many of our organisations of people with disabilities—OPD—partners had had to pivot from what was normally an advocacy approach in their community, in terms of trying to influence the Government and change policy, to providing emergency food for many of their community members. They were already at crisis point and then had their community projects completely slashed at extremely short notice.

**Q78 Mr Virendra Sharma:** To what extent are UK aid programmes on sexual and reproductive health sufficiently focused on persons with disabilities? Can I ask Dr Tsitsi to comment on that?

**Dr Tsitsi Chataika:** Assistance will never be enough. Of course, we appreciate what is being done, but the challenge we normally find is that, at times, most of these programmes do not reach the hard-to-reach communities where the assistance is greatly needed. That means the people who are at the back of beyond are neglected, and yet they have the needs that really need to be covered.

Most of them go into cities and towns, as well as rural areas that are already developed, rather than those that are hard to reach, which makes it very difficult. That is an area that needs to be highlighted and identified, such that, when you come up with funding, you say, "What indicators will show us that we have money to get out to hard-to-reach communities so that they can also benefit?"

Marginalisation is there, because of our cultural and religious beliefs that impact on the lives of women and girls with disabilities. Maybe I can give an example to show that it is very difficult to get to the hard to reach. For instance, in 2019 in Zimbabwe, there was a case of a nine-year-old child who was pregnant. She died on a religious shrine, where she could not get assistance to give birth. She was given to an elderly man. These are the issues that can normally happen in the back of beyond. If we do not address those issues, girls will continue to suffer.

**Kirsty Smith:** If we look at the DAC marker, about 25% of FCDO funding is marked as disability inclusion, which means that 75% is not inclusive. If we consider the marginalisation of people with disabilities, and particularly women with disabilities, we can see that that means that 75% of programmes are missing a very important contingent of marginalised people.

Having said that, the UK is fourth on the list of disability inclusion in the DAC marker, which is to be celebrated and encouraged, but it would be, from our point of view, extremely valuable to see a very much higher preponderance of those projects, recognising that, if they do not reach people with disabilities, they are failing to reach the most marginalised.



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The style of funding that we are all pushed into competing for moves you away from trying to find the most marginalised, because they tend to be more expensive and more difficult, and it takes more time. We are pushed into providing proposals that reach bigger numbers rather than those that reach the most difficult to reach and, in this way, they are left behind.

**Alessandra Aresu:** To add to what the other speakers have just mentioned, in order to make sure the FCDO can further support the inclusion of persons with disabilities in the programmes, the indicators to measure disability inclusion are essential, yet these are often not part of the mandatory requirements of programmes. The support of FCDO in promoting the initiative of having disability inclusion indicators will really move forward this effort to further support persons with disabilities through FCDO programmes.

Disaggregated data by disability was mentioned before as an important aspect. At the moment, disaggregated data by disability is not mandatory under FCDO-supported programmes. Again, this is an essential element, because, if you are not counted within the project, you do not count in the end.

Among the other important elements is the aspect of supporting organisations of persons with disabilities. Today, FCDO, being a leader in inclusive sexual and reproductive health and rights, has identified organisations of persons with disabilities as key partners in projects. The example of its women's integrated sexual health programme is before our eyes.

However, as some colleagues have mentioned, a lot of the structural challenges that organisations of persons with disabilities are facing require our additional attention, especially when it comes to access to direct funds from FCDO. Adjusting and becoming more flexible in the offer of funds to make sure they are more inclusive of persons with disabilities could be an extra step forward in continuing to assist persons with disabilities.

Q79 **Chris Law:** What effect do FCDO performance targets have on the reach of sexual and reproductive health aid programming? What would you like to see change?

**Kirsty Smith:** I mentioned before that the pressure to demonstrate you are reaching a lot of people often pushes you away from reaching the most marginalised, which would include women with disabilities, in sexual and reproductive health programmes, particularly because of the barriers that I mentioned at the start.

What I would really like to see is that disability inclusion is an expectation in every sexual and reproductive health programme that the FCDO funds, because, if it is disability-inclusive, it is good for everybody, not just for women with disabilities. If that were a fundamental requirement of all funding, women with disabilities would have a better chance of being served.



Q80 **Chris Law:** Saskia, I see that you are nodding. I take it that you agree.

**Saskia Perriard-Abdoh:** I do. I would just add one minor comment, which is that engaging marginalised communities requires a long-term commitment. By that, I mean that, as well as adequate levels of funding, you also need multi-year funding that is stable and secure and builds trust within communities that something that has been given will not be inadvertently taken away the next day.

**Chris Law:** We hear that repeatedly. We get the message.

**Saskia Perriard-Abdoh:** On top of what has already been said, it is not just the right level of funding, but also the commitment to multi-year funding that is needed.

**Chair:** Because of our time constraints, we are going to have to finish the first panel. I would like to thank everybody who came and joined us. I know there is lots that we have missed, so if you want to send any more written information to us on anything you think we have missed, or if you would like to add to anything you have already said, please do. We would be very grateful to receive that. If any of you want to stay and listen to the next panel, you are very welcome to do so. Thank you very much.

## Examination of witnesses

Witnesses: Alice Welbourn, Dr Camilla Ducker and Fionnuala Murphy.

Q81 **Chair:** If there is anything that you want to follow up with in writing that you do not cover today, please do so. Unfortunately, we have to cut short the session due to lack of members and the fact that Virendra has to rush off at 3.45, so we have only 35 minutes. Please feel free to add any more that you would like to add in writing afterwards.

I would like to start with Alice. What challenges do people face when living with HIV and AIDS in lower-income countries? Could you also introduce yourselves and your organisations, too?

**Alice Welbourn:** Thank you very much for inviting me today. My name is Alice Welbourn and I am the founding director of the Salamander Trust. I am a researcher, a trainer and an activist. I was diagnosed with HIV in 1992, when I was expecting a baby boy. The 31st anniversary of losing that boy—because I was advised to have a medical termination—was yesterday. I have been incredibly lucky, because that was in England and I have had the NHS holding my back throughout all these years, but the tentacles of SRHR in the context of HIV are very long.

By contrast, there are, of course, immense challenges around the world for so many women, including here. I would rather turn it around and perhaps talk instead about what the opportunities are and what women want and desire. We talk so often about challenges, and yet, if we talk to women and learn from them, just as you have been hearing from our



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colleagues on the previous panel, we can learn so much about what women want and need in order to achieve our SRHR.

Back in 2014, we were commissioned by the World Health Organisation to conduct a global values and preferences study. We reached over 1,000 women across 94 countries in multiple languages, and they were able to share with us what they felt were the most important issues of SRHR affecting their lives—not just the challenges but what constitutes our sexual and reproductive health and rights, and what we want. This was fed into the WHO guideline on this topic, which was published in 2017.

We love images and we created the image of a safe house. It was called *Building a safe house on firm ground*, and the foundations of this house were, first and foremost, safety at home, in healthcare and in our communities. The second layer was support for us all across our lifespans, from conception—or contraception—until old age. The third layer was respect for all of us in all of our diversities. Maybe my colleagues might like to add something.

**Q82 Chair:** Thank you very much for sharing that story with us. It is very good of you to do so. Fionnuala Murphy, would you like to add to that?

**Fionnuala Murphy:** Alongside access to HIV treatment, which I think you mentioned at the beginning, I will say a word or two about HIV prevention. We had a global target to get new HIV infections below 500,000 a year by 2020, and we are three years past that target. We are sitting at about 1.5 million, so we are 1 million over our target. When you look at where those infections are happening and who is most affected, it is adolescent girls and young women in Africa. In the time we spend together in this room, 36 young women in Africa will contract HIV; it is 3,000 every week. What we call key populations, which can be a very depersonalising term—people who use drugs, sex workers and the LGBT community—are really disproportionately affected.

It is worth saying that, from the perspective of the UK's investments, the UK invests in the Global Fund, which delivers really important results for those populations and is working really hard to get access to prevention and get the numbers down. UK bilateral investments in SRHR look in that direction, and some of the programmes that were funded pre the cuts did that pretty well, but we lost a number of programmes. Frontline AIDS lost three.

If you are doing SRHR programming in high-prevalence settings in Africa, where one in 10 people has HIV, it is unacceptable that you have young women coming in and getting family planning, but not getting a conversation about their HIV risk, not getting support with condom negotiation skills, and also, now that we have a growing number of innovative HIV prevention technologies coming along, not getting offered those technologies. It is not just a missed opportunity. It is really a derogation of duty in that high-prevalence setting for the young women who are most at risk.

Hopefully we will talk a bit more about that in the session, but I would





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really like us to think about how we can make sure that, with upcoming calls like the WISH call, the investments that are made explicitly cover the different issues that need to be covered, and HIV, alongside STIs, is definitely one of them.

Q83 **Chair:** Dr Ducker, can you explain to us what female genital schistosomiasis is and what impact it has on women and girls? Is it being sufficiently addressed by aid donors, including the UK?

**Dr Camilla Ducker:** Female genital schistosomiasis is a complication of schistosomiasis, also known as bilharzia, which is contracted from snails through water. It is a complication of untreated schistosomiasis and happens in women and men—but, in this case, we are talking about women’s genital tracts—causing inflammation and chronic symptoms of pain and bleeding. It increases a woman’s chances of contracting HIV by about three times. Although we do not know the figures around it, it increases a woman’s chances of contracting other infections and, therefore, also having a greater risk of cervical cancer secondary to HPV. It exposes women to a huge amount of further complications and disease.

Many women do not know they have it. It very often goes misdiagnosed, because even healthcare workers are not taught about it within their curriculum, whether that be through medical school, nursing or whatever education they have. Even communities are not aware of it, so it is very misdiagnosed and often leads to mental health issues and stigma.

One of the great reasons that I am here today to talk about this condition is because, as Alice and Fionnuala have said, there is such opportunity for cross-collaboration. We are not looking for more vertical funding or programming. What we are looking for is an increased mandate.

I was listening to my colleagues in the first session talking so passionately about disability in marginalised communities, and all of the women we are all talking about are marginalised through various conditions. We do not want to create a shopping list, but we want to make sure everybody is under the same umbrella that we are, in the end, through resources and providing essential and comprehensive healthcare for all, because that, in effect, is a human right.

We have to be intentional in that inclusivity. We heard that about disability. We cannot assume that equity is a given. We know that. Whether we are talking about women who are suffering from FGS and get misdiagnosed, get stigmatised within their communities, cannot reach their potential, cannot work and cannot get married, or whether we are talking about women suffering from HIV or a disability, or all of these chronic conditions, we are talking about accessible healthcare. That is the most important thing for us to talk about, as Fionnuala and Alice said, as well as really thinking about it from a patient or a person-centred approach.

I used to be a GP in the NHS, working in west London. Women do not often come in and say, “I think I have this disease.” They say, “I am suffering. I am scared. I am anxious. I think I may need some help.” How



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can we, all together, create a system that can support those women through that journey to make sure they get the right treatment?

Ironically, with FGS, we have a drug that is donated for free. We just need to get it to the right people. Praziquantel is donated by a pharmaceutical company and is given to children yearly in endemic areas, but girls often drop out of school. There are often reasons why people in these marginalised communities drop out of the system. If we can have that mandate to work more closely together and to be intentional in our inclusivity, we really can make a difference to these women.

**Q84 Chris Law:** Fionnuala, many lower-income countries lack the capabilities necessary to diagnose, prevent and treat STIs, including HIV and AIDS. Is UK aid helping lower-income countries to strengthen the capacity of their own healthcare systems to tackle STIs?

**Fionnuala Murphy:** It is, for sure. That is the short answer. The mechanism that I am most familiar with is the Global Fund, which is a global fund for AIDS, TB and malaria, but it does invest in health systems, in STI-related care and in lots of other areas that are essential to delivery in that area—things like trained staff, models for working, for integration and for task shifting, laboratory testing, which is essential for STI care, infrastructure, supply chains, and information management. The Global Fund does all those things and, critically, it also does community systems.

Camilla was telling me over lunch about a lovely example of women providing antenatal care for one another through these community systems and groups. It is often in remote areas or in communities that are marginalised. Saskia talked in the last session about LGBT people for whom it is unsafe to turn up in the mainstream health system, so they rely on community organisations and community systems.

The UK invests in all those things through the Global Fund, which provides person-centred services and supports the goal of leaving no one behind. There are also a lot of examples of those types of investment in other areas of SRH.

**Q85 Chris Law:** Something that I am particularly interested in is how countries like the UK could help to strengthen the ability of lower-income countries to manufacture their own medicines, such as those preventing HIV and AIDS, at a lower cost. I visited a place called Afrigen in Cape Town last year, which was specifically looking at Covid vaccinations. The big issue was the global north pharma. That was a unique contract for a unique situation. In terms of HIV and AIDS, it is still very expensive. What can the UK do to change that?

**Fionnuala Murphy:** I will keep this really brief, because it is not my area of current expertise, although I did write my dissertation on it 20 years ago. First of all, the UK needs to support countries to be able to use things like the TRIPS flexibilities. It also needs to support tech transfer. It has not been very supportive of either of those things over the last couple of years, and it is important to acknowledge that.



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One of the things the UK has done over time is support Unitaid. I am not going to use very techy terms here, but it is a body that manages the farming out of patents. When a company has invented something and it is still on patent, no one else can produce it for 20 years without permission. Unitaid creates a patent pool and offers licences to other companies that can produce it more cheaply in the global south.

Right now, Unitaid is doing that for a new, injectable form of HIV treatment, so it is great for people in settings where it can be difficult to store your medicines. You might not have a fridge. You may not have access to quality food all the time, and HIV medicine can be very harsh on your stomach. It can also be used as HIV prevention, so you can use it pre-emptively as a form of injectable PrEP. This medicine is called CAB-LA. It can reduce a person's risk of HIV infection by 98%, so it is an absolute game changer. It is not out there yet and it needs to be. Unitaid has a patent pool that, eventually, will make this medicine available for young women like those I talked about earlier. The UK really needs to retain its support for Unitaid.

**Q86 Chris Law:** It is chronically underfunded, if I am not mistaken. Is that right?

**Fionnuala Murphy:** That is right. There is plenty of written information on that in the STOPAIDS submission, so do look there for a more expert perspective and the right terminology.

**Q87 Chris Law:** What role is antimicrobial resistance playing in limiting the ability to treat sexually transmitted infections? Is the UK engaged enough in countering the threat of this resistance globally?

**Fionnuala Murphy:** We discussed this as a group and it is not an area of expertise for any of us, but we could get some written information from somebody more expert.

**Chris Law:** That would be great. Thank you very much.

**Q88 Mr Virendra Sharma:** Do UK aid strategies, such as the international women and girls strategy, give sufficient priority to tackling STIs and FGS?

**Fionnuala Murphy:** I have spoken quite a lot, so I will try to keep this brief. I want to frame my response with a couple of stats. AIDS is still the leading cause of death for women in Africa, yet it is not mentioned in the FCDO's women and girls strategy. It gets one mention in our ending preventable deaths strategy. While the intentions are there, and there is UK support to the Global Fund, that says quite a lot about how well addressed or how well integrated it is. I have talked already about missed opportunities. We really need to see the UK make HIV an explicit, essential component of its work on SRHR and of its women and girls strategy in its WISH funding and in other areas of funding.

Doing that is not just about the funding that goes into health systems and health service delivery. It is also about things like social norms and legal barriers, which mean that, in many countries, teenage girls cannot



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go and get any of these services without their parents' consent, and their parents may not want to give it.

Decades into the HIV crisis in Africa, many girls still do not get accurate information in school in the form of comprehensive sexuality education. Those things need to be addressed as well, and they can be best addressed through the activism of women, including young women, through the activism of other populations such as LGBT communities, and through work on social norms and violence against women in all those areas. It goes beyond the health system and is really about investing in social change.

**Dr Camilla Ducker:** My other colleagues have said that the women and girls strategy nods to integration, but there needs to be more explicit articulation of what that means in terms of the programming and implementation. As I said earlier, it is really important that we think about the journey from a girl or a woman-centred point of view, rather than thinking about it from a disease point of view. We treat patients; we do not treat diseases. That is critical to ensuring that we are fully inclusive and are thinking about a fully accessible and comprehensive health system, so that we have quality diagnostics in place, as well as access to treatment, care and support. We need to be much more intentional and explicit.

Q89 **Mr Virendra Sharma:** Alice, is UK aid programming on STIs and FGS doing enough to reach the most marginalised groups? What more could it do?

**Alice Welbourn:** Just to echo what my colleagues have been saying, all of this needs to be an integrated approach, a woman-centred approach and a survivor-centred approach, as the What Works 2 programme was talking about specifically in relation to violence against women. We cannot look at STIs, FGS or any of these issues in a vacuum.

I go back to the work I have done with my colleagues from GNP+ and ICW, who have also sent in submissions. You will soon receive a submission from the Global Network of Young People Living with HIV. When we think about defining our sex and reproductive rights, think about a beautiful tree in the forest, with a lovely, thick trunk and wonderful branches. Each branch can represent a different dimension of our sex and reproductive health and rights. It can represent physical wellbeing, sexual wellbeing, reproductive wellbeing, mental health, which you have heard about, physical safety as well as sexual safety, which is absolutely critical, spiritual and social safety, as well as material wellbeing, financial wellbeing and legal safety, and having those protective laws in place.

As you know, a huge, beautiful tree gives so much life to birds, bees, other insects, animals grazing and to children playing. If you think about that as our sex and reproductive health and rights, just think, when you cut one branch off, the whole of the tree is diminished. Not only that tree,



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but we now also know about the wood wide web and how other trees in the forest are also affected.

So much of the focus from top-down, western donors is disease-focused, biomedical and siloed, and only addresses what you can see down a medical microscope, whereas what is going on within our communities, from colleagues like those whom I have mentioned around the world, is incredible peer support, supporting one another, one-to-one, across communities, but also across countries and continents.

There is also fantastic gender transformative social norms training. For example, we have one colleague in Kenya, Lucy Wanjiku Njenga, who is an extraordinary young woman who has recently written her memoirs. She was sexually abused when she was eight, growing up in an informal settlement in Nairobi. By the time of 15 or so, she had an unplanned pregnancy. Her baby and she were both diagnosed with HIV, and she sadly lost that baby from an AIDS-related illness. All of this happened before she was 18. She has now developed the most fantastic organisation, called Positive Young Women Voices, in this same settlement, specifically to make use of her lived experience to ensure that girls and young women growing up in her own community do not experience what she did.

There are women like Lucy around the world with whom I am in touch, who are desperately marginalised and are also doing extraordinary things. They are experiencing post-traumatic growth because they are learning from their own trauma, and they are turning it around for good for the world in relation to STIs, FGS and all these different things—grief, violence and so on. They are missing the political will, advocacy and funding of the global north, which can enable them to realise their sexual and reproductive rights in all their diversity.

We have the knowledge. We know what works. The science is incredible. Here I am incredibly fit and well, thanks to the ARVs I take every day. We have the technology. We have Unitaid and mRNA hubs. We have that technology at our fingertips. We have the phenomenal resources of all these amazing women doing incredible things, often with no funding. The missing pin is what you have to offer. It is that gift and power of advocacy and funding.

Q90 **Mr Virendra Sharma:** Fionnuala, would you like to add something?

**Fionnuala Murphy:** It is really hard to add when Alice speaks, because she speaks so laterally and holistically. I will just reiterate the point that the Global Fund is doing its best, and the UK can help that by making sure it fully funds the Global Fund. The Global Fund had a replenishment, and the UK was not able to contribute the amount that was requested. Almost all other countries did, including some of the world's poorest countries. I would encourage the UK to think about whether it can make a supplementary allocation.



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Alongside that, I would also encourage the UK to think about what it can do with its bilateral funding for SRHR, so that it is targeted at the most marginalised people and communities, and also so that it is taking that person-centred approach. We also know that marginalised people often miss out on healthcare. They lose their day's wages, and they have to pay travel costs. They may have to pay user fees. They cannot keep making different visits to different parts of the health system to have their multiple needs met when, actually, there is no reason why they could not get things like contraception, HIV prevention, STI testing and FGS testing all in one place at the same time. That integrated approach can address some of the drivers of marginalisation in the first place.

**Q91 Chris Law:** Alice and Camilla, is UK aid funding to tackle STIs and FGS aligned with its commitment to sexual and reproductive health?

**Dr Camilla Ducker:** FGS, at the moment, is not included as an STI. It is not included in SRHR commitments. We have spoken to the Global Fund about incorporating FGS. It would make sense, but there needs to be a political shift for that to happen.

If we can look at this programming, as we have all been saying, in terms of what a woman needs, we can get our programming right and make efficient use of resources. We know we now live in a different funding landscape, but we want to be efficient while ensuring the resources are centred around the people who need it most and not around targets and pushing resources to where is not needed.

I will let Alice finish but, from an FGS point of view, we want to be able to work and co-ordinate with our colleagues to ensure that women do not suffer from people treating and programming for disease and not for women.

**Alice Welbourn:** I would really encourage the UK Government to follow the Gutmacher–Lancet Commission report. They have a really inclusive, holistic, 360° definition of sexual and reproductive health and rights, which includes all the different arms of the tree I was talking about. FGS may not be there yet, but it certainly would be in that vision and principle of it being women-centred, survivor-centred and survivor-focused.

This is basically about equity, inclusion and systems-wide thinking. We also need to be talking about other things, like climate change and international financing structures. All of these have massive implications on what is happening in terms of women's exposure to violence and experience of violence. They have implications for all the STIs and all the consequences of climate change and its effects on poverty and women's violence, which directly connect to an increase in women's vulnerabilities to HIV and to STIs by a factor of 1.5.

Similarly, once women have HIV, they are exposed to further violence, mental health issues and STIs. These are all intimately connected. There are adverse childhood experiences, like the sexual abuse of Lucy that I described, or transactional sex. Young women and girls, basically child-





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headed households because they have lost their parents to Covid, are having to have cross-generational transactional sex just to buy fish and to get clean water for their younger siblings. Organisations like the Global Fund are supporting the HER Voice Fund, which is organised by Y+ and talks about these kinds of experiences. That funding can make such a difference to those young girls' lives.

**Chair:** We will draw this session to an end. We have not exhausted the questions we have for you but, because Virendra has to go, we will not be quorate so we cannot take any more answers. We will write and ask you questions and give you the opportunity to respond to those that we have missed. Thank you very much for coming.