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Disability-Inclusive HIV Service Delivery: A Participatory Mixed-Methods Study of Stakeholder-Identified Barriers and Solutions

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Abstract

Background

People with disabilities may experience barriers to HIV prevention, testing, treatment, and related services. However, evidence on stakeholder-identified barriers, priorities, and solutions for disability-inclusive HIV service delivery remains limited. This study explored stakeholder perspectives on disability-inclusive HIV services, with particular attention to women and girls with disabilities.

Methods

A participatory mixed-methods design was used during a four-day stakeholder-engagement programme at the AIDS 2026 Conference in Rio de Janeiro, Brazil. Participants engaged in five activities: SEE HER, HEAR WITH HER, DESIGN WITH HER, STAND WITH HER, and WHO IS MISSING IN HIV CARE. Structured responses were analysed descriptively using frequencies and percentages, while open-ended responses were analysed thematically. Quantitative and qualitative findings were integrated using a convergence approach.

Results

In STAND WITH HER, stigma and discrimination were the most frequently identified barrier (14/20, 70.0%), followed by lack of disability-inclusive HIV information (10/20, 50.0%) and limited availability of disability-inclusive services (9/20, 45.0%). In HEAR WITH HER, 50/51 (98.0%) classified disability inclusion across the HIV care continuum as reality, while 49/49 (100.0%) recognised that inequalities may remain unnoticed without disability-disaggregated data. In WHO IS MISSING IN HIV CARE, women and girls were the most frequently identified underrepresented population (38/118, 32.2%), followed by LGBTQI + and transgender populations and children, adolescents and young people (30/118, 25.4% each). Government was the most frequently identified actor responsible for addressing barriers (7/20, 35.0%). Qualitative and co-design findings highlighted accessible communication, provider preparedness, physical and digital accessibility, inclusive programme design, autonomy, privacy, and meaningful participation.

Conclusion

Stakeholders characterised disability-inclusive HIV service delivery as a multilevel issue involving stigma, accessibility, provider practices, programme design, data systems, participation, and intersecting vulnerabilities. The findings support embedding accessible communication, disability-responsive monitoring, inclusive service design, provider preparedness, and meaningful involvement of people with disabilities within routine HIV programming.

Introduction

Human immunodeficiency virus (HIV) remains an important public health challenge, with an estimated 41.0 million people living with HIV globally at the end of 2025. In 2025, an estimated 1.2 million people acquired HIV and 570,000 people died from HIV-related causes [1]. Although effective HIV prevention, diagnosis, treatment, and care are available, access to these services is not experienced equally across population groups [1]. People with disabilities may experience disparities in HIV-related knowledge, access to information, HIV testing, and health services, highlighting the importance of disability inclusion within HIV responses [2–4].

Evidence from multiple low- and middle-income countries demonstrates disparities in HIV-related knowledge and testing among people with disabilities. Rotenberg et al. analysed data from 37 Multiple Indicator Cluster Surveys involving 513,252 individuals, including 24,695 people with disabilities [2]. Men and women with disabilities were less likely to have comprehensive knowledge about HIV prevention and to know where HIV testing was available than their counterparts without disabilities. Women with disabilities were also less likely to know how to prevent mother-to-child transmission and to have ever been tested for HIV [2]. Similarly, a national population-based survey in South Africa examined HIV status, knowledge, attitudes, and behaviours among people with and without disabilities, providing evidence of differences in HIV-related knowledge and testing according to disability status [3].

The barriers to HIV services extend beyond knowledge and testing. A qualitative systematic review of the experiences of people with disabilities living with HIV in Africa identified intersections between disability, HIV, gender, stigma, and poverty in relation to access to HIV services [4]. The review identified three themes concerning the intersection of gender, HIV, and disability; stigma, HIV, and disability; and poverty, HIV, and disability [4]. The authors recommended that national HIV strategies address the needs of people with disabilities and involve people with disabilities living with HIV in the development of relevant policies and programmes [4]. UNAIDS similarly identifies disability as an important consideration within the HIV response and calls for a person-centred, disability-inclusive response that allows for increased participation of people with disabilities [8].

Accessibility encompasses more than the physical characteristics of health facilities. A 2025 systematic review of sexual and reproductive health services among women with motor disabilities in low- and middle-income African countries identified five broad categories of barriers: physical and logistical constraints, social and attitudinal barriers, institutional limitations, economic hardship, and information and communication barriers [5]. The review also identified healthcare-provider training, infrastructure adaptation, community mobilisation, and inclusive public-health policies as facilitating factors [5]. Although the review examined sexual and reproductive health services rather than HIV services specifically, these dimensions are relevant to disability-inclusive HIV programming because HIV prevention, testing, treatment, and related sexual and reproductive health services similarly require accessible information, appropriate communication, and responsive healthcare environments [5].

UNAIDS has also identified barriers to HIV services for people with disabilities and emphasised the need for accessible and adapted HIV information and services [8].

Disability inclusion also varies at the policy and health-system level. A review of National Strategic Plans for HIV/AIDS in 13 West African countries found that 30% recognised disability as an issue of concern and 38.5% recognised people with disabilities as vulnerable to HIV, while only 7.6% included specific support, monitoring, or surveillance related to people with disabilities [6]. These findings indicate that disability is not consistently incorporated into national HIV strategic planning and monitoring in the countries examined [6]. In Nigeria, a recent qualitative study involving 13 HIV service providers from six states identified persistent sociocultural beliefs about people with disabilities living with HIV, stigma, prejudicial provider attitudes, limited disability-disaggregated data, and insufficient targeted programming and HIV funding as concerns affecting antiretroviral therapy adherence and the delivery of HIV services [7]. The study further highlighted the need for targeted programming, disability-disaggregated data, and greater recognition of people with disabilities within the HIV response [7].

The available evidence therefore provides important information on HIV-related knowledge and testing, lived experiences, accessibility, policy inclusion, and provider perspectives [2–7]. These studies examine different populations, settings, and dimensions of disability and HIV. Bringing stakeholder perspectives together may provide complementary information on how barriers are prioritised, how their implications for service delivery are understood, what solutions are considered feasible, and which actors are perceived as responsible for implementation. Participatory approaches provide a mechanism for incorporating stakeholder perspectives into the identification of service-delivery problems and the generation of potential solutions. This approach is consistent with the UNAIDS emphasis on increased participation of people with disabilities within a person-centred, disability-inclusive HIV response [8].

In response to these considerations, this study adopted a participatory mixed-methods approach to explore stakeholder perspectives on disability-inclusive HIV service delivery, with particular attention to women and girls with disabilities. The study examined stakeholder knowledge and perceptions, identified barriers to accessing and delivering HIV services, explored stakeholder-generated solutions for improving accessibility, equity, and inclusion, identified populations and intersecting vulnerabilities perceived to require greater attention within HIV programming, and examined stakeholder perspectives on responsibility and priorities for advancing disability-inclusive HIV services.

Methods

Study Design

This study employed a participatory mixed-methods design to explore stakeholder perspectives on disability-inclusive HIV service delivery. The study combined structured quantitative responses with qualitative and participatory data generated through five stakeholder-engagement activities: SEE HER: Voices Wall, HEAR WITH HER: Myth or Reality, DESIGN WITH HER: Real-World Scenarios and Co-Design, STAND WITH HER: Regional Challenges and Recommendations, and WHO IS MISSING IN HIV CARE: The

IAS Hunt. Quantitative and qualitative data were analysed separately and integrated during interpretation to identify areas of convergence, complementarity, and divergence [9,12–14].

Study Setting and Participants

The study was conducted during a four-day stakeholder-engagement programme at the AIDS 2026 Conference in Rio de Janeiro, Brazil, held from 26 to 31 July 2026. Activities were conducted at the Global Village booth (G-AIDS-2026-11753; Booth 184) as part of a stakeholder-engagement programme focused on disability-inclusive HIV services. Participants were conference attendees and other stakeholders who voluntarily participated in one or more of the engagement activities. Participants included healthcare professionals, researchers, civil-society and non-governmental organisations, policymakers, community and advocacy organisations, and organisations representing people with disabilities. Participation across activities was not mutually exclusive. Therefore, activity-specific denominators were retained throughout the analysis, and the number of valid responses varied across activities and individual items.

Recruitment and Sampling

Participants were recruited through voluntary participation at the conference engagement space. A non-probability, self-selected sampling approach was used because individuals independently decided whether to participate in the stakeholder-engagement activities. No formal probability-based sampling or population-representative sampling was undertaken. The study therefore aimed to capture a range of stakeholder perspectives rather than generate population-level estimates.

Sample Size and Response Denominators

No formal sample-size calculation was performed because participation was voluntary and the activities were designed as stakeholder-engagement and participatory exercises rather than as a population-based survey. The number of responses was determined by participation in each activity. SEE HER generated 146 responses, HEAR WITH HER was completed by 52 participants, DESIGN WITH HER generated 19 recorded scenario responses, STAND WITH HER generated 20 responses, and WHO IS MISSING IN HIV CARE generated 118 responses. Because participants could contribute to more than one activity and some individual items had missing responses, activity-specific and item-specific valid-response denominators were used rather than assuming a common sample size across the study.

Data Collection

Data were collected through five sequential stakeholder-engagement activities: SEE HER, HEAR WITH HER, DESIGN WITH HER, STAND WITH HER, and WHO IS MISSING IN HIV CARE.

SEE HER: Voices Wall

SEE HER: Voices Wall presented four lived-experience stories concerning women and girls with disabilities and HIV-related services. Participants were invited to respond to the experiences presented and provide written reflections, including whether the situations were surprising, had been observed, could be changed, or had been personally experienced. The activity also provided an opportunity for participants to identify practical recommendations related to visibility, inclusion, accessibility, empowerment, solidarity, and dignified care. Responses generated through the Voices Wall therefore comprised both structured responses and open-ended qualitative reflections (Appendix I).

HEAR WITH HER: Myth or Reality

HEAR HER: Myth or Reality? was an interactive Evidence-to-Action activity developed to explore and challenge common misconceptions surrounding disability inclusion across the HIV care continuum. The activity was informed by findings from the Evidence Gap Review and was designed to facilitate participant reflection on how HIV programmes, policies, and health systems can become more accessible, equitable, and responsive to the needs of women and girls with disabilities (Appendix II). The activity consisted of structured statements addressing key dimensions of disability inclusion in HIV programming, including the HIV care continuum, HIV policy implementation, disability-disaggregated data, communication accessibility, health-system barriers, evidence gaps, the experiences and needs of women and girls with disabilities, and responsibility for advancing disability inclusion (Appendix III). Participants were asked to classify each statement as **"Myth," "Reality," or "Both,"**where applicable, and were given the opportunity to provide an explanation or justification for their response. To support evidence-informed reflection, participants also received an **evidence pamphlet** presenting relevant findings and key messages from the Evidence Gap Review. This allowed participants to compare their initial perceptions with available evidence and identify areas where assumptions, knowledge gaps, or systemic barriers may influence disability inclusion within HIV services. A total of **52 participants** completed the HEAR HER activity. Because participants were not required to respond to every statement, the denominator varied across individual items. Responses were therefore analysed at the statement level using the number of participants who responded to each item as the denominator.

DESIGN WITH HER: Real-World Scenarios and Co-Design

DESIGN WITH HER used 16 balloted real-world scenarios to explore practical changes that could improve disability-inclusive HIV service delivery. The scenarios addressed communication, physical and digital accessibility, autonomy, privacy, provider responsiveness, continuity of care, and inclusive service design. Participants selected scenarios through a balloting process and provided design changes or recommendations for the selected scenarios (Appendix IV). Nineteen recorded scenario responses were available for analysis. Responses were examined to identify practical recommendations and the design changes proposed by stakeholders. Because the number of responses varied between scenarios, scenario-specific response frequencies were retained.

STAND WITH HER: Regional Challenges and Recommendations

STAND WITH HER invited participants to identify regional and system-level barriers to disability-inclusive HIV service delivery and to identify stakeholders considered responsible for addressing those barriers (Appendix V). Participants could identify multiple barriers and responsible actors. Responses included barriers related to stigma and discrimination, disability-inclusive HIV information, service availability, gender inequality, transportation, communication, cost, physical accessibility, provider attitudes, policy or legal barriers, and childcare. Participants also identified stakeholders and actors responsible for addressing these barriers, including government, multisectoral actors, people with lived experience, researchers and academia, organisations of persons with disabilities, international organisations, donors, community leaders, and healthcare facilities.

WHO IS MISSING IN HIV CARE: The IAS Hunt

As part of the IAS Hunt, we invited participants to identify populations perceived to be missing, underrepresented, excluded, or overlooked within HIV prevention, testing, treatment, and care (Appendix VI). Participants could identify more than one population. Responses were subsequently categorised according to the populations identified, including women and girls, LGBTQI+ and transgender populations, children and young people, persons with disabilities, people living with HIV or affected by vertical transmission, Black people and people of colour, people living with HTLV, sex workers, Indigenous populations, people experiencing poverty or vulnerability, older people, people experiencing homelessness, people in prison or deprived of liberty, and migrants or mobile populations. Responses were also examined for intersecting vulnerabilities where participants identified overlapping population characteristics.

Data Management

All completed responses were compiled into a structured analytical dataset using Microsoft Excel for Microsoft 365. The dataset was reviewed for completeness, duplicate entries, invalid responses, and inconsistencies before analysis. Because participants could participate in more than one activity, responses were not treated as representing mutually exclusive participant groups. Each activity was analysed using its activity-specific valid-response denominator. For individual quantitative items, unanswered or invalid responses were excluded from the denominator for that item. Percentages were calculated using the number of valid responses for the relevant question or category as the denominator. Multiple-response questions allowed participants to select more than one category. Consequently, percentages for these questions were not expected to sum to 100%.

Analysis

Structured responses were analysed using descriptive statistics. Categorical responses were summarised using frequencies (n) and percentages (%). For HEAR WITH HER, frequencies and percentages were calculated separately for each statement using the number of valid responses to that statement as the denominator. For STAND WITH HER, frequencies and percentages were calculated for identified barriers and responsible stakeholders. Because participants could select multiple responses,

categories were not mutually exclusive. For WHO IS MISSING IN HIV CARE, population categories were summarised using frequencies and percentages based on the 118 recorded responses. Multiple population categories could be identified within a response; therefore, percentages did not sum to 100%. For DESIGN WITH HER, the number of recorded responses to each balloted scenario was summarised descriptively. The three scenarios receiving the highest number of recorded responses were described in greater detail in the main manuscript, while the complete scenario-level responses were retained in the Supplementary File. Quantitative analysis was conducted using Microsoft Excel for Microsoft 365. Open-ended responses generated through SEE HER, HEAR WITH HER explanations, DESIGN WITH HER, STAND WITH HER, and WHO IS MISSING IN HIV CARE were analysed using thematic analysis informed by the six-phase approach described by Braun and Clarke [11]. The analysis involved familiarisation with the responses, identification of meaningful concepts, generation of initial codes, grouping of related codes, development and review of candidate themes, definition and naming of themes, and production of the final qualitative findings. Coding was conducted by AIO, a physiotherapist and researcher. KEF reviewed the coding framework and candidate themes and contributed to interpretation of the qualitative findings. Differences in interpretation were discussed and resolved through consensus. Qualitative data were managed using Microsoft Excel for Microsoft 365, which was used for data organisation, coding, retrieval, and development of analytical matrices. Interpretation and theme development remained the responsibility of the research team.

Formal participant member checking was not undertaken because participants were engaged during a time-limited conference-based stakeholder programme and the data were collected anonymously.

Analysis of Stakeholder-Identified Barriers and Solutions

Responses concerning barriers were coded into conceptually related categories and summarised according to their frequency of identification.

Stakeholder-generated solutions from SEE HER and DESIGN WITH HER were coded according to the issue addressed and the proposed design or service change. Particular attention was given to recommendations concerning accessible information and communication, physical and digital accessibility, provider responsiveness, autonomy, privacy, participation, peer support, and inclusive service design. Responses concerning responsible actors were categorised according to the stakeholder or system level identified by participants. Responses from WHO IS MISSING IN HIV CARE were coded according to the population groups explicitly identified by participants. Where responses contained more than one population or intersecting vulnerability, the response was coded across the relevant categories.

Mixed-Methods Integration and Triangulation

Quantitative and qualitative findings were analysed separately and subsequently integrated during interpretation. Integration involved comparing structured responses with qualitative explanations, identified barriers, stakeholder-generated solutions, regional perspectives, perceived responsibilities, and identified priority or underrepresented populations. A convergence matrix was used to compare

quantitative findings with corresponding qualitative themes and stakeholder-generated recommendations [13]. Findings were considered in terms of convergence, complementarity, expansion, or divergence across the different sources of evidence. Where findings converged, the qualitative data were used to provide context and explanation for the structured responses. Where qualitative findings expanded on quantitative responses, the additional perspectives were retained as complementary findings. Divergent responses were retained rather than resolved solely in favour of the quantitative or qualitative findings [12,14].

Reflexivity and Researcher Role

The research team considered the potential influence of researchers' professional backgrounds, involvement in the stakeholder-engagement programme, and interactions with participants on data collection and interpretation. The qualitative analysis reviewed the coding framework and candidate themes and contributed to interpretation. Reflexive discussions were undertaken during the analytical process to consider alternative interpretations and minimise the influence of researcher assumptions.

Ethical Considerations

Ethical approval was obtained from the University of Nigeria Teaching Hospital Health Research Ethics Committee (UNTH HREC). Participants were informed about the purpose of the study, the voluntary nature of participation, confidentiality, and the intended use of the data. Verbal informed consent was obtained before participation. No participant identifiers were collected. Qualitative quotations were reported using non-identifying participant codes. Participants providing qualitative responses were informed that anonymised quotations could be used for research dissemination and publication.

Reporting Standards

The mixed-methods component was reported with reference to the Good Reporting of a Mixed Methods Study (GRAMMS) recommendations [9]. The qualitative component was reported with reference to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [10]. Thematic analysis was informed by Braun and Clarke [11], while mixed-methods integration and convergence were informed by established approaches to integration and joint displays [12–14].

Results

Participant Engagement and Characteristics

Stakeholder engagement was conducted over four days through five participatory activities: SEE HER: Voices Wall, HEAR WITH HER: Myth or Reality, DESIGN WITH HER: Real-World Scenarios and Co-Design, STAND WITH HER: Regional Challenges and Recommendations, and WHO IS MISSING IN HIV CARE: The IAS Hunt. Participants could contribute to one or more activities; consequently, the number of valid responses varied across activities and activity-specific denominators were retained for analysis. The STAND WITH HER activity included responses representing four geographic regions: Africa, Latin

America and the Caribbean, North America, and Asia. Africa and Latin America and the Caribbean each accounted for 8 of 19 responses (42.1%), followed by North America (2/19, 10.5%) and Asia (1/19, 5.3%). Locations represented included Malawi, Kenya, Brazil, Haiti, South Africa, Liberia, the United States, and other locations identified by participants. These figures describe the geographic distribution of responses within STAND WITH HER and should not be interpreted as the overall demographic distribution of study participants.

Quantitative Findings

HEAR WITH HER: Myth or Reality

The HEAR WITH HER activity assessed stakeholder perceptions of disability-inclusive HIV service delivery as shown in Table 1. Fifty-two participants completed the activity, although the number of valid responses varied across individual statements. Fifty of 51 respondents (98.0%) classified the statement that disability inclusion should extend across the entire HIV care continuum as reality. Similarly, all respondents classified the statements concerning HIV policy automatically leading to disability-inclusive services (50/50, 100.0%) and the potential for inequalities to remain unnoticed without disability-disaggregated data (49/49, 100.0%) as reality. Responses were more varied regarding communication accessibility. Thirty-two of 50 respondents (64.0%) classified the statement that communication accessibility was only a small part of disability inclusion as reality, 15 (30.0%) classified it as myth, and 3 (6.0%) selected both. The accompanying explanations indicated that communication was considered important, particularly in settings where other inclusive practices may be limited, but that it should not overshadow other dimensions of inclusion. One respondent explained that

“communication is very important in [a] setting without any inclusive care practice but it still doesn't overshadow [the] other aspect[s] of inclusivity.”

For the statement concerning the source of barriers, 51 of 56 respondents (91.1%) classified health systems as the predominant source, while 5 (8.9%) selected both. The accompanying explanations indicated that some participants also perceived barriers arising from interactions between people with disabilities and healthcare workers. These included difficulties with communication, cooperation, and treatment engagement, as well as situations in which people with disabilities might become distressed or frustrated during care. One respondent noted that

“sometimes the barriers originate from people living with disability because they can become aggressive during [the] course due to low self-esteem, self-pity, [or] wrong perception of the caregiver[’s] intention,” while also acknowledging that “health workers also find it difficult to communicate with them.”

Fifty-two of 53 respondents (98.1%) classified as myth the statement that evidence was evenly distributed across the HIV care continuum. Similarly, 52 of 53 respondents (98.1%) classified as myth the statement that services designed for everyone automatically meet the needs of women and girls with disabilities. One respondent, however, noted that this may vary by context, stating that

“this is regional based because US has made a lot of progress.”

Another suggested that implementing inclusion within the design of HIV services could potentially reduce the need for separate services, stating that

“if we implement the inclusivity agenda in designing HIV services this automatically suits everyone without creating separate services.”

All respondents (52/52, 100.0%) classified as reality the statement that responsibility for inclusion should be built into HIV services rather than placed on women and girls with disabilities. Finally, 28 of 30 respondents (93.3%) classified as myth the statement that current evidence was sufficient to guide disability-inclusive HIV programmes; one (3.3%) classified it as reality and one (3.3%) selected both. The accompanying explanation for the latter responses suggested that some existing guidance could potentially be implemented, with one participant noting that

“there are some already in existence guidance we can implement.”

STAND WITH HER: Regional Challenges and Recommendations

Twenty responses were analysed to identify perceived barriers to disability-inclusive HIV service delivery, their effects on women and girls with disabilities, and stakeholders considered responsible for addressing them. Participants could identify multiple barriers; therefore, response categories were not mutually exclusive and percentages do not sum to 100%. Stigma and discrimination were the most frequently identified barriers (14/20, 70.0%), followed by lack of disability-inclusive HIV information (10/20, 50.0%) and limited availability of disability-inclusive services (9/20, 45.0%). Gender inequality was identified in 7 responses (35.0%), transportation challenges in 6 (30.0%), and communication barriers and cost of accessing services in 5 responses each (25.0%). Physical accessibility of health facilities and negative attitudes of healthcare workers were each identified in 4 responses (20.0%). Policy or legal barriers were identified in 2 responses (10.0%), while childcare barriers were identified in 1 (5.0%). Participants also described how these barriers affected women and girls with disabilities. Responses included inadequate knowledge and skills among healthcare providers, limited access to services and information, treatment disengagement, stigma and discrimination, and difficulties communicating with providers. One participant described communication barriers as resulting in women either not receiving HIV information or not fully understanding it. Another noted that although legal protections may exist, women with disabilities may still experience barriers to accessing facilities and programmes (See Table 2).

Government was the most frequently identified responsible actor (7/20, 35.0%), followed by multiple or multisectoral stakeholders (3/20, 15.0%) and people with lived experience (2/20, 10.0%). Researchers/academia, organisations of persons with disabilities, international organisations, donors, community leaders, and healthcare facilities were each identified in one response (5.0%) (See Table 3).

WHO IS MISSING IN HIV CARE: The IAS Hunt

The WHO IS MISSING IN HIV CARE activity generated 118 responses identifying populations perceived to be underrepresented, excluded, or overlooked within HIV prevention, testing, treatment, and care. Responses were coded into population categories, and individual responses could identify more than one population. Women and girls were identified most frequently (38, 32.2%), followed by LGBTQI+ and transgender populations (30, 25.4%) and children, adolescents and young people (30, 25.4%). Persons with disabilities were identified in 15 responses (12.7%), while people living with HIV or affected by vertical transmission were also identified in 15 (12.7%). Black people and people of colour were identified in 12 responses (10.2%), and people living with HTLV in 10 (8.5%). Sex workers and Indigenous populations were each identified in 5 responses (4.2%). Other identified populations included people experiencing poverty or vulnerability (4, 3.4%), older people (3, 2.5%), people experiencing homelessness or street-connected populations (3, 2.5%), people in prison or deprived of liberty (3, 2.5%), and migrants/mobile/cross-border populations (2, 1.7%). Qualitative coding also identified intersecting vulnerabilities, including adolescent girls and young women with disabilities, women living with HIV and disability, Indigenous women, LGBTQI+ people with disabilities, rural women who were also LGBTQI+, and young people experiencing multiple forms of marginalization (Table 4).

Qualitative and Participatory Findings

SEE HER: Voices Wall

The SEE HER activity presented four lived-experience stories concerning women and girls with disabilities and HIV-related services. Participants' written reflections highlighted visibility, inclusion, accessibility, empowerment, solidarity, and dignified care. Participants emphasised the importance of recognising lived experience and increasing the visibility of women with disabilities. One participant stated:

“I believe experience is expertise.”

Participants also generated practical recommendations for improving service delivery, including peer-led information, greater investment in accessibility, stronger coordination with civil society, and more accessible pathways to care. One participant recommended:

“Have peer ambassadors that are also living with disability to give information.”

Another stated:

“We need to invest in accessibility.”

Participants also recognised that communication challenges may affect interactions between people with disabilities and healthcare workers. One participant explained:

“The healthcare workers don’t also have it easy because as people with disability try to communicate with us, we also find it hard to reciprocate and most time they do not make the job easy for us, especially in my

own setting they get easily agitated and difficult to understand.”

The importance of respectful and dignified care was also emphasised:

“Everyone deserves dignified & non-judgemental care.”

Overall, the Voices Wall responses included recognition of exclusion and practical suggestions relating to accessible information, peer support, service accessibility, provider preparedness, collaboration, and respectful care.

DESIGN WITH HER: Real-World Scenarios and Co-Design

The DESIGN WITH HER activity comprised 16 balloted real-world scenarios addressing communication, physical and digital accessibility, autonomy, privacy, provider responsiveness, continuity of care, and inclusive service design. Based on the recorded responses, Scenario 16 received the highest number of responses (4/19, 21.1%), followed by Scenario 3 (3/19, 15.8%) and Scenario 11 (2/19, 10.5%). The complete responses and recommendations for all scenarios are provided in Supplementary File.

Scenario 16, which focused on redesigning HIV services to be more inclusive for women and girls with disabilities, generated recommendations centred on information access, inclusion, advocacy, accountability, and inclusive reception services. Participants proposed:

“INCLUSION, ENGAGEMENT, ADVOCACY & ACCOUNTABILITY”

and:

“CAMPAIGNS TO COMBAT INFORMATION ON HIV IN WOMEN SHOULD INCLUDE WOMEN & WOMEN WITH DISABILITIES, INFORMATION IN LIBRAS (BRAZILIAN SIGN LANGUAGE)”

Another participant prioritised:

“DEVELOP INCLUSIVE RECEPTION”

Scenario 3, concerning a woman who was blind and received printed medication instructions that she could not independently access, generated recommendations focused on accessible information and independent medication management. Participants proposed:

“VIDEOS & AUDIOS OF INFORMATION”

“PROVISION OF PILL BOX FOR HER, SO SHE CAN INDEPENDENTLY KNOW WHERE, WHEN & HOW TO TAKE HER MEDICATION”

and:

“USE OF BRILLE MATERIALS SO THAT SHE CAN BE ABLE TO RECALL”

Scenario 11, concerning an online appointment system incompatible with screen-reading software, generated recommendations focused on inclusive digital design and meaningful community participation. One participant stated:

"FIRST OF ALL, MEMBERS OF THE COMMUNITY NEED TO BE INVOLVED IN EVERYTHING FROM THE DESIGN OF THE PROJECT. BY LISTENING TO THE VOICES OF WOMEN, THE DESIGN OF EVEN THE DIGITAL HEALTH PLATFORM CAN BE TAILORED, & IMPROVED BEFORE IT IS RELEASED. NOT ONLY SHOULD THE PROGRAM/SOFTWARE INCLUDE SCREEN-READING SOFTWARE, HEADPHONES OR EARPHONES SHOULD HAVE BEEN INCLUDED TO ENSURE PRIVACY AT THE END OF THE DAY, THE VOICE OF COMMUNITY MUST BE LISTENED TO."

Another participant recommended:

"PUT IT IN MORE LANGUAGES WITH IMAGES"

Across these three highest-response scenarios, stakeholder-generated design changes focused on inclusive service environments, accessible HIV information, independent medication management, accessible digital platforms, privacy, and meaningful involvement of people with disabilities in service design. The full scenario-level responses, including scenarios with fewer or no recorded responses, are provided in Supplementary File.

Integration of Quantitative and Qualitative Findings

Across activities, quantitative and qualitative findings converged around several domains of disability-inclusive HIV service delivery. Structured responses indicated recognition of disability inclusion across the HIV care continuum, the importance of disability-disaggregated data, health-system responsiveness, and embedding inclusion within HIV services. Qualitative responses complemented these findings by describing practical concerns related to communication, physical accessibility, provider responsiveness, autonomy, privacy, and participation.

Barriers identified through stakeholder-engagement activities were reflected in the solutions generated through co-design. Communication and information accessibility, provider attitudes and stigma, and physical accessibility were accompanied by proposed solutions including peer-led information, accessible communication formats, provider training, reasonable accommodation, inclusive service design, and stronger community participation.

The WHO IS MISSING IN HIV CARE activity further demonstrated that responses identified exclusion across diverse and intersecting populations, including women and girls, children and young people, LGBTQI+ and transgender populations, persons with disabilities, Black and Indigenous populations, people living with HTLV, sex workers, and people experiencing homelessness or incarceration.

Across the four-day stakeholder-engagement activities, disability-inclusive HIV service delivery was characterised as a multilevel issue involving communication, physical accessibility, provider practices,

programme design, data systems, policy implementation, meaningful participation, autonomy, and dignity. Co-design responses translated these identified concerns into practical actions, including accessible information, peer support, provider preparedness, inclusive physical and digital environments, meaningful participation of people with disabilities, and shared responsibility across stakeholders.

Discussion

This study explored stakeholder perspectives on disability-inclusive HIV service delivery through four days of participatory engagement. Across five activities, stakeholders identified disability inclusion as a multidimensional issue involving stigma and discrimination, accessible information and communication, service availability, physical and digital accessibility, provider practices, data systems, participation, and programme design. Stigma and discrimination were the most frequently identified barrier in STAND WITH HER (14/20, 70.0%), followed by lack of disability-inclusive HIV information (10/20, 50.0%) and limited availability of disability-inclusive services (9/20, 45.0%). Women and girls were the most frequently identified population perceived to be missing or underrepresented in HIV care, while persons with disabilities were identified in 12.7% of responses. Government was the most frequently identified actor responsible for addressing barriers (7/20, 35.0%). The qualitative and co-design findings complemented these structured responses by illustrating how stakeholders translated identified barriers into practical recommendations concerning accessible information, peer support, inclusive service environments, provider responsiveness, autonomy, privacy, and meaningful participation.

Communication, Stigma and Accessibility

Communication and information accessibility were prominent concerns across the activities, although stigma and discrimination were the most frequently identified barrier in the regional responses. In STAND WITH HER, lack of disability-inclusive HIV information was identified by 50.0% of respondents, while communication barriers were identified by 25.0%. This is consistent with evidence from 37 low- and middle-income countries showing that people with disabilities had lower comprehensive HIV prevention knowledge and were less likely to know where HIV testing was available than people without disabilities [2]. Women with disabilities were also less likely to have ever been tested for HIV [2]. These findings suggest that disability-inclusive HIV programming needs to consider not only whether information and services are available, but whether they can be accessed and understood by people with different disabilities. The qualitative responses provide further context. Participants described communication accessibility in relation to the ability to hear, read, understand, and use HIV information. This is consistent with evidence from African low- and middle-income countries identifying information and communication barriers alongside physical, institutional, social, and economic barriers affecting women with disabilities [5]. Although that review was not specific to HIV services, it supports the broader relevance of accessible communication within disability-inclusive health services. Stigma and discrimination were the most frequently reported barrier in the present study. This finding is consistent with the qualitative systematic review by Philip et al., which identified stigma, gender, poverty, and disability as intersecting influences on access to HIV services among people with disabilities in Africa

[4]. Evidence from Nigeria has also highlighted stigma, provider attitudes, disability-disaggregated data, and limited disability-responsive programming as concerns within HIV services for people with disabilities [7]. The present findings add a stakeholder-generated perspective by linking these concerns with proposed responses, including provider preparedness, respectful care, accessible communication, and more responsive service design. Physical accessibility was another important dimension. Participants identified physical accessibility of health facilities, transportation challenges, and limited service availability as barriers. The qualitative and co-design responses further demonstrated that accessibility extends beyond entry into a facility to include navigating services, receiving information, maintaining privacy, and using digital platforms. Together, these findings indicate that disability-inclusive HIV services require attention to the information provided, the physical and digital service environment, and interactions between service users and healthcare providers.

Policy, Data and Programme Implementation

Disability-disaggregated data were strongly prioritised by participants. In HEAR WITH HER, all valid respondents (49/49, 100.0%) classified as reality the statement that inequalities in HIV services may go unnoticed without disability-disaggregated data. Participants also identified limited disability-disaggregated data as a barrier in the broader engagement activities. This concern is consistent with evidence from Nigeria identifying limited disability-disaggregated data and inadequate disability-responsive programming as challenges within HIV services [7]. The findings also demonstrate the importance stakeholders placed on embedding disability inclusion within HIV services. All valid respondents (52/52, 100.0%) classified as reality the statement that responsibility for inclusion should be built into HIV services rather than placed on women and girls with disabilities. At the same time, 98.1% classified as myth the statement that services designed for everyone automatically meet the needs of women and girls with disabilities. Together, these responses suggest that stakeholders recognised inclusion as a responsibility of the health system rather than something that should depend primarily on individual women adapting to existing services. This interpretation is relevant to evidence from West Africa showing inconsistent incorporation of disability within national HIV strategic plans [6]. It also supports broader calls for policy and programme reforms to address accessibility, infrastructure, provider capacity, and meaningful participation of people with disabilities in HIV services [15]. However, the present study captures stakeholder perceptions and does not independently assess the completeness of HIV policies, data systems, or programme implementation. The evidence-gap findings further support this concern. More than 98% of respondents classified as myth the statement that evidence on disability-inclusive HIV services was evenly distributed across the HIV care continuum, while 93.3% considered current evidence insufficient to guide disability-inclusive HIV programmes. These findings indicate a perceived need for stronger evidence to inform disability-responsive planning and monitoring.

Women, Girls and Intersecting Vulnerabilities

Women and girls were the most frequently identified population perceived to be missing or underrepresented in HIV care (38/118, 32.2%). Other frequently identified groups included LGBTQI + and transgender populations (25.4%) and children, adolescents and young people (25.4%). Persons with disabilities were identified in 15 responses (12.7%). Qualitative coding further demonstrated intersecting vulnerabilities, including adolescent girls and young women with disabilities, women living with HIV and disability, Indigenous women, LGBTQI+ people with disabilities, and rural women who were also LGBTQI+. These findings are consistent with evidence describing the intersection of disability, gender, HIV, stigma, and socioeconomic disadvantage in access to HIV services [4, 5]. The findings also suggest that disability inclusion should not be approached as an isolated issue. People may experience overlapping forms of disadvantage related to disability, gender, age, sexuality, poverty, geography, or other social circumstances. An important aspect of the present findings is the emphasis on meaningful participation. The DESIGN WITH HER activity generated recommendations for involving people with disabilities in the design of HIV and digital services. One participant stated that community members should be involved “in everything from the design of the project.” This supports calls for meaningful involvement of people with disabilities in HIV policy and programme development [6, 15]. Such participation may help ensure that programme priorities reflect lived experiences rather than relying solely on assumptions by programme planners or providers.

From Barriers to Stakeholder-Generated Solutions

A key contribution of the participatory approach was the connection between identified barriers and stakeholder-generated solutions. Communication and information barriers were accompanied by recommendations for peer ambassadors, accessible information formats, audio and video resources, Braille materials, and multilingual communication. Physical and service-access barriers were accompanied by recommendations for inclusive reception services and more accessible service pathways. Provider-related concerns were linked to recommendations for greater preparedness, patience, respectful communication, and dignified care. The DESIGN WITH HER activity provided particularly concrete examples of this process. Participants proposed accessible medication information and pill-management support for a woman with visual impairment, screen-reader-compatible digital services and community involvement in digital design, and inclusive reception and information strategies for women and girls with disabilities. These recommendations are consistent with broader calls for trained healthcare workers, accessible infrastructure, and meaningful involvement of people with disabilities in HIV programming [15]. The value of the present study is therefore primarily practical. Rather than only documenting barriers, the participatory activities allowed stakeholders to connect identified problems with potential design changes, priority populations, and actors perceived as responsible for action. The qualitative findings also helped explain the structured responses, demonstrating complementarity between the quantitative and qualitative strands.

Policy Responsibility and Shared Action

Government was the most frequently identified actor responsible for addressing barriers (7/20, 35.0%), although stakeholders also identified multisectoral actors, people with lived experience, researchers and academia, organisations of persons with disabilities, international organisations, donors, community leaders, and healthcare facilities. This distribution suggests that responsibility for disability-inclusive HIV services was understood as shared across policy, health-system, community, and civil-society levels rather than as the responsibility of a single actor. The prominence of government is consistent with evidence of gaps in disability inclusion within HIV strategic planning across West Africa [6]. However, the identification of people with lived experience and organisations of persons with disabilities also highlights the importance of participation beyond formal policy structures. Policy commitments therefore need to be accompanied by mechanisms through which people with disabilities can influence service design, implementation, monitoring, and accountability.

Implications for HIV Service Delivery

Taken together, the findings support a multilevel approach to disability-inclusive HIV programming. At the service level, priorities include accessible communication, physical and digital accessibility, respectful provider interactions, privacy, and reasonable accommodation. At the programme level, disability-responsive information, disability-disaggregated monitoring, inclusive programme design, and meaningful participation should be incorporated into routine HIV planning and evaluation. At the policy level, government and other responsible actors need to support implementation, coordination, resources, and accountability. The findings also suggest that disability inclusion should be integrated into mainstream HIV services rather than addressed only through separate disability-specific initiatives. This approach is consistent with the stakeholder emphasis on building inclusion into HIV services and involving people with disabilities in the design of those services.

Strengths and Limitations

A major strength of this study was its participatory design, which enabled stakeholders to move from identifying barriers to generating practical solutions and identifying responsible actors. The use of multiple engagement activities also allowed structured responses to be complemented by qualitative reflections and co-design data. Several limitations should be considered. Participants were recruited through voluntary participation at an international conference and therefore represented a self-selected, non-probability sample. The findings should consequently be interpreted as stakeholder perspectives rather than population estimates. Participants could contribute to multiple activities, and activity-specific denominators varied; therefore, the results should not be interpreted as representing a single cohort of participants. The study also did not independently measure HIV service accessibility, policy implementation, or the completeness of disability-disaggregated data systems. In addition, the conference setting and explicit focus on disability inclusion may have influenced responses towards greater endorsement of inclusive approaches. Finally, the qualitative findings reflect participants' written

perspectives within structured engagement activities and should not be interpreted as equivalent to in-depth individual interviews or community-based ethnographic accounts.

Conclusion

This participatory mixed-methods study identified disability-inclusive HIV service delivery as a multilevel issue involving stigma and discrimination, accessible information and communication, service availability, physical and digital accessibility, provider practices, data systems, participation, and intersecting vulnerabilities. Stakeholders identified practical responses including accessible information, peer support, inclusive service environments, provider preparedness, disability-responsive monitoring, and meaningful involvement of people with disabilities in programme design. The findings support a shift from recognising exclusion towards embedding disability inclusion within routine HIV policy, service delivery, monitoring, and programme development.

Abbreviations

HIV: Human Immunodeficiency Virus

AIDS: Acquired Immunodeficiency Syndrome

UNAIDS: Joint United Nations Programme on HIV/AIDS

WHO: World Health Organization

LMICs: Low- and Middle-Income Countries

Declarations

Competing Interests

The authors declare that they have no competing interests.

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Author Contributions

AIO conceived and designed the study, coordinated the stakeholder-engagement activities, contributed to data collection and analysis, conducted the qualitative analysis, and drafted the manuscript. KEF contributed to the study design and data collection, reviewed the qualitative coding framework and candidate themes, contributed to interpretation of the findings, and critically revised the manuscript. UCI

contributed to the study and manuscript development and critically reviewed the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Ethics Approval and Consent to Participate

Ethical approval for the study was obtained from the University of Nigeria Teaching Hospital Health Research Ethics Committee (UNTH HREC; NHREC/05/22/210005B-FWA00008721-1RB00009427). The involvement of UNTH HREC was informed by the SEE HER phase of the study, which included obtaining responses through the hospital's Antiretroviral Therapy department. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki.

Patient and Public Involvement

Members of the public were involved in the design, conduct, reporting, or dissemination of this research.

Consent for Publication

Not Applicable.

Data Availability Statement

All data generated or analyzed during this study are included within the published article and its supplementary materials.

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Tables

Tables 1 to 4 are available in the Supplementary Files section.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- PopulationsidentifiedasmissingorunderrepresentedinHIVcare.docx

- StakeholderresponsestoHEARWITHHERMythorReality.docx
- Stakeholdersidentifiedasresponsibleforaddressingbarriers.docx
- BarrierstodisabilityinclusiveHIVservicedeliveryidentifiedthroughSTANDWITHHER.docx
- ALLAPPENDIX.docx