JOURNAL OF COMMUNITY HEALTH IN AFRICA

Volume I, Issue I, 2025, Pages 27-37

Youth Perspectives on Lived Experience Integration in Mental Health System Design in Kenya

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Citation: Njoroge, J. W. (2025). Youth Perspectives on Lived Experience Integration in Mental Health System Design in Kenya. *Journal of Community Health in Africa*, 1(1), 27–37.

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Abstract

This study examined the extent to which systems such as schools, hospitals, workplaces, and community programs in Kenya integrate young people's lived experiences to enhance their sense of safety. It was based on the assumption that exposure to mental health interventions by NGOs improves youths' awareness of how systems accommodate lived experiences. Using a survey design grounded in opportunity mapping, data were collected from 63 respondents selected from a calculated sample threshold of 69 using Cochran's formula. Cross-sectional qualitative data were analysed through descriptive statistics and thematic analysis. Respondents included 46.0% female, 49.2% male, and 4.8% non-binary participants. Most were mental health advocates (41.3%), followed by community organizers (15.9%) and student researchers (17.5%). Overall, 88.9% considered inclusion of lived experiences important or highly important. About 74.4% reported that lived experiences are at least sometimes incorporated into system design, while 73.1% felt systems moderately reflect community realities. A strong or somewhat strong sense of belonging was reported by 63.5%, mainly linked to feeling heard, valued, and included. Key barriers included limited decision-making access and power imbalances, prompting calls for co-creation frameworks and inclusive participation.

Keywords: Mental health, youth intervention, personal narratives, lived experiences, systemic inclusion.

1. Introduction

Youth mental health is an urgent global public health priority (Benton et al., 2021). Low- and middle-income countries shoulder a disproportionate share of the burden, driven by chronic resource constraints, systemic underinvestment, stigma, and discrimination toward individuals living with mental health conditions (Javed et al., 2021). Concerning this, young people face multiple and intersecting psychosocial stressors that heighten vulnerability to adverse outcomes, including substance misuse, alcoholism, and suicide in Kenya (Kumar et al., 2024). While the magnitude of these challenges is widely acknowledged, access to responsive, equitable, and youth-centered mental health systems remains inconsistent across the country (Onyiko et al., 2024). To address these gaps, a range of stakeholders—particularly non-governmental organizations (NGOs)—are devising, overhauling and implementing structured, youth-focused mental wellness programs aimed at strengthening prevention, awareness, and support services countrywide (Benton et al., 2021). These initiatives not only target individual coping and resilience outcomes but also seek to reshape youths' understanding of how inclusive mental health systems are conceptualized, designed, and experienced (Memiah et al., 2022).

Ideally, most of the mental wellness programs are grounded in Social Determination Theory (SDT), the Social Ecological Model(SEM), and Empowerment Theory. The Social Ecological Model conceptualizes youth mental health as a function of dynamic interactions across individual, interpersonal, community, and structural domains (Robins et al., 2024). SDT posits that psychological well-being is strengthened when individuals experience belonging, recognition, autonomy, and meaningful participation (Krausse et al., 2019). Accordingly, multi-level interventions delivered through schools, peer networks, workplaces, and community platforms are designed to enhance youths' awareness of both systemic strengths and service gaps (Mthiyane et al., 2023). Complementing this perspective, Empowerment Theory asserts that access to knowledge and authentic participation fosters a sense of agency and the capacity to influence systems that shape one's life (Grealish et al., 2017). Thus, integrating lived-experience narratives into mental wellness initiatives is deepens a population's critical engagement with issues of accessibility, stigma, and service responsiveness.

This study examined how exposure to NGO-led mental health programs interventions have influenced Kenyan youths' awareness and perceptions of integration of lived experiences into system design, governance, and decision-making processes to ensure they are inclusive and safe for youths.

2. Methods

2.1. Introduction

Perceptions of inclusion, sense of belonging, and the enablers and barriers to incorporating lived experience into system design were examined. Particular emphasis was placed on participants' post–mental health program exposure perspectives regarding the systemic inclusion of their lived experiences to promote a more inclusive and responsive mental health system within their communities.

2.2. Research Design

A qualitative research design was employed, utilizing an opportunity mapping survey approach (Gonera et al., 2024). Primary qualitative data were collected from youth in counties with ongoing NGO-led mental health and well-being programs and analyzed descriptively. This design enabled an in-depth exploration of participants' perspectives, experiences, and conceptualizations of existing systems, particularly regarding the inclusivity of personal lived experiences. The survey incorporated both closed- and open-ended questions. According to Semyonov-Tal and Lewin-Epstein (2021), this approach facilitates the capture of rich qualitative insights into barriers, enablers, and guiding principles for systemic improvement in the field.

2.3. Population and Sample

The study population consisted young people who had been exposed to community mental health and wellness events and interventions by various NGOs over the last two years. The sample size was calculated u Cochran's sample calculation formula at 90% confidence interval. According to Ahmed (2024), this formula is used when the population is large and infinite and is presented as follows;

$$n_0 = \frac{Z^2 p(1-p)}{e^2}$$

Where:

N_0=Sample Size

Z=Z-score based on the confidence level

P=Estimated population proportion

e=margin of error.

A 90 % confidence level was used. The Z-score associated with this confidence level is 1.645. Since the researcher had no clear knowledge of the actual population proportion that had been taken through the mental awareness program, this study used a margin of error of 10% and p=0.5 to compute the sample size. Using this criterion, the sample size for the study was computed as follows;

$$\text{Actual Sample size } (n_{0)} = \frac{1.65^2 0.5(0.5)}{0.1^2}$$

$$= 67.6504$$

Therefore, using Cochran's sample calculation formula, the threshold sample was set at n=68. The sample was drawn from 12 counties by opportunity mapping.

2.4. Data Collection Instrument

Data were collected through a semi-structured online questionnaire. The instrument was pretested to ensure it could effectively capture participants' experiences of the current system's inclusion of lived experiences, reflections of community values, sense of belonging, and perspectives on systemic change (Willis, 2016). The pretest was conducted with five members of the Integrative Wellbeing staff to assess question clarity and relevance prior to full distribution.

2.5. Data Collection Method

Snowball sampling was employed to facilitate data collection and ensure the target sample size was reached. All individuals who had participated in community mental health and wellness programs were invited to take part in the survey (Marcus et al., 2017). The questionnaire was converted into an online data collection form and initially distributed to 10 conveniently selected respondents, who were encouraged to share the survey link with their peers. Of the target sample of 69 participants, 63 provided consent and completed the survey in full, resulting in a response rate of 91.3%.

2.6. Data Analysis Procedure

Structured qualitative responses were analysed using descriptive statistics to determine frequencies and percentages, while qualitative data from open-ended questions were thematically coded (Rose et al., 2023). Themes were developed iteratively to capture patterns regarding enablers, barriers, and guiding principles for integrating lived experience into system design. The frequencies and percentages of theme appearance were computed and presented in tables too.

2.7. Ethical Considerations

This study adhered to established ethical standards, including informed consent, voluntary participation, non-maleficence, anonymity, and transparency (Dooly et al., 2017). Prior to participation, respondents were informed about the purpose of the study, their right to withdraw at any time without penalty, and the nature of the survey. Confidentiality and anonymity were maintained throughout the research process by ensuring that no identifying information was linked to participants' responses in the final dataset. Participants were also informed that the study was not conducted for monetary gain and that the reporting of findings would be transparent and free from bias. Ethical approval was obtained from the NGO's internal review board, ensuring adherence to the principles of respect for persons, beneficence, and the protection of participants' rights.

3. Findings

Table 1. Respondent gender

Respondent Gender	Frequency	Percent
Female	29	46.0
Male	31	49.2
Non-binary/ Gender- diverse	3	4.8
Total	63	100.0

Table 1 indicates gender parity between male and female participants, with a modest representation of gender-diverse individuals. Respondents identifying as males constituted the largest percentage of the sample with 31 participants (49.2%), closely followed by females at 29 participants (46.0%). The smallest proportion identified as non-binary**,** comprising 3 respondents (4.8%).

Table 2. Respondent distribution by county of residence

County of Respondent	Frequency	Percentage
Busia	1	1.6
Kajiado	6	9.5
Kiambu	4	6.3
Kilifi	18	28.6
Kirinyaga	1	1.6
Kisumu	1	1.6
Kwale	1	1.6
Machakos	3	4.8
Mombasa	3	4.8
Nairobi	22	34.9
Nakuru	2	3.2
Narok	1	1.6
Total	63	100.0

The distribution of the 63 respondents by county of residency showed diversity, though concentrated in a few counties. Nairobi accounted for the largest share 22(34.9%), followed by Kilifi 18 (28.6%).

Kajiado contributed 6 (9.5%) while Kiambu had 4 (6.3%). Smaller percentages came from Machakos and Mombasa Counties 3 (4.8%). Each of the remaining counties contributed between 1(1.6%) and 3(3.2%) respondents.

Table 4. Identity of respondents in Mental Wellbeing Discipline

Mental Wellbeing Role	Frequency	Percentage
Community Organizer	10	15.9
Creative/ Storyteller/Artist	6	9.5
Data or Technology Practitioner	3	4.8
Environmentalist	3	3.8
Mental Health or Wellbeing Advocate	26	41.3
Policy / Program Lead	4	6.3
Student or Researcher	11	17.5
Total	63	100.0

Table 4 results show that the largest group was Mental Health or Wellbeing Advocates 26(41.3%), followed by Students or researchers 11 (17.5%) and Community organizers 10(15.9%) respectively. Creative/Storytellers/Artists were 6 (9.5%), while Policy or Program Leads were 4(6.3%) in the sample. Smaller proportions comprised data or technology practitioners 3(4.8%) and environmentalists (3.8%), signaling multidisciplinary participation in the survey.

Table 5: Importance of including personal narratives and lived experience alongside other system design statistics

How important is it for system design data and evidence to include personal narratives and lived experience alongside statistics	Frequency (n)	Percent (%)
Very important	26	41.3%
Important	26	41.3%
Somewhat important	4	6.3%
Neutral	5	7.9%
Not important	2	3.2%
Total	63	100.0%

Table 5 results show that most respondents viewed integrating personal narratives with system design statistics as very important and important (41.3% each). A smaller percentage 4(6.3%) considered it somewhat important, while about 5(8%) were neutral. Only 3.2% felt inclusion of personal narratives and lived experience alongside statistics was not important.

Table 6. Feeling that personal lived experiences are considered during design or improvement of systems like schools, mental health programs, workplaces, or community projects

Are personal lived experiences are considered during design or improvement of systems	Frequency	Percent
Always	5	8
Never	6	9.5
Often	11	17.5
Rarely	10	15.9
Sometimes	31	49.2
Total	63	100.0

Table 6 results indicate that nearly 31(49.2%) of the respondents perceived that their personal lived experiences were sometimes considered during the design or improvement of systems. A smaller proportion, 11(17.5%) felt that their experiences are often considered while 5 (8%) held they were

always considered. Conversely, 10(15.9%) participants indicated that their experiences were rarely taken into account in the design, and 6 (9.5%) indicated they were never considered, suggesting that while some respondents felt like there is inclusion, a significant percentage perceive the systems as lacking consistent and meaningful integration of lived experiences into system design.

Table 7. Current system's reflection of community's values, stories and realities

How well do the current systems that you interact with reflect your community's values, stories and realities?	Frequency	Percent
Completely	3	4.8
Moderately	33	52.4
Mostly	10	15.9
Not at all	2	3.2
Slightly	15	23.8
Total	63	100.0

Table 7 shows that the highest proportion, 33(52.4%) of the respondents rated the current systems moderate in terms of reflecting their community's values, stories, and realities. A further 10 (15.9%) felt systems reflected them mostly**,** while 3 (4.8%) reported that the design illuminates a complete reflection. Conversely, 15(23.8%) perceived them as a slight reflection, and 2 (3.2%) felt systems did not reflect them at all**.**

Table 8. Respondents sense of belonging in mental health discussion spaces

I feel a sense of belonging in spaces where mental health and wellbeing are discussed or shaped	Frequency	Percent
Neutral	18	28.6
Not at all	1	1.6
Somewhat strongly agree	17	27.0
Disagree	2	3.2
Strongly Disagree	2	3.2
Strongly agree	23	36.5
Total	63	100.0

Table 8 results show that the largest proportion 23 (36.5%) comprised respondents who reported feeling a strong sense of belonging in spaces where mental health and wellbeing were discussed or shaped while 17 (27.0%) felt somewhat strongly. That said, 18 respondents (28.6%) expressed a neutral about it. Only small proportions felt excluded, with 2 (3.2%) strongly disagreeing, 2 (3.2%) strongly disagreeing and 1 (1.6%) indicating that they do not experience a sense of belonging at all, suggesting generally positive perceptions of belonging in spaces where mental wellbeing subject is discussed.

Table 9. Reasons why the respondent feels a sense of belonging in mental health and wellness discussion spaces.

What helps you feel a sense of belonging and safety in such spaces?	Frequency (n)	Percent of Respondents (%)
Being heard and valued	54	85.7%
Seeing others with shared experiences	44	69.8%
Emotional support and empathy	42	66.7%
Leadership that is inclusive and transparent	30	47.6%
Cultural or contextual understanding	20	31.7%
Seeing others benefit from my lived experience	1	1.6%

Table 9 results shows that being heard and valued the strongest source of feeling part of and safe in spaces where mental health and wellbeing are discussed 54(85.7%). A significant percentage 44(69.8%)

also held that seeing others with shared experiences and receiving emotional support and empathy 44(66.7%) are major triggers of a sense of belonging and safety in those spaces. Nearly half of the responses highlighted inclusive and transparent leadership 30(47.6%) as important, while only 20(31.7%)cited cultural or contextual understanding. The least frequent 1(1.6%) highlighted seeing others benefit from self-lived experience as a meaningful reason.

Note. The questions from table 9 onwards required the respondents to choose more than one barrier. The frequencies reflect the actual response distribution population rather than proportion of the respondents whose responses contained the theme. Thus, the sum of the percentages could exceed or be less than 100%.

Table 10. The main barriers that prevent lived experiences from influencing system design based on personal experience

Theme	Frequency (n)	Percent (%)
Lack of access to decision-making spaces	40	63.5%
Power imbalance between professionals and lived-experience contributions	31	49.2%
Limited funding or participatory processes	29	46.0%
Tokenism or lack of follow-up after participation	28	44.4%
Stigma or discrimination	26	41.3%
Limited data or evidence to back lived experience	16	25.4%
Cultural imperialism / Western norm dominance	1	1.6%

Table 10 findings highlight structural and cultural barriers that limit the influence of lived experience in system design. The most appearing challenge was restricted access to decision-making spaces 40(63.5%). This was closely followed by the subject of power imbalance between professionals and lived-experience contributors 31(49.2%). Resource constraints, including limited funding or participatory processes ranked third with 29 appearances (46.0%) while tokenism ranked fourth with 28 appearances (44.4%) in the responses. Stigma and discrimination was fifth with 26 appearances (41.3%), signaling the weight of marginalizing some voices. Meanwhile, the theme of limited data or formal evidence was second last with 16 responses (25.4%) reflects tensions between qualitative insight and evidence-based systems. Although infrequently cited, cultural imperialism was least appearing with only one appearance (1.6%) illuminating how dominant Western norms are insignificant in suppressing alternative ways of knowing and designing systems.

Table 11. Identify moments when lived experience shaped (or could have shaped) a system, policy, or service

Theme	Frequency (n)	Percent (%)
During mental health advocacy & suicide prevention	14	18.2%
During youth leadership & youth-centered programming	12	15.6%
During creation of safe spaces & peer support initiatives	11	14.3%
During policy advocacy & governance reform	9	11.7%
During mentorship, training & capacity building	8	10.4%
During community outreach & awareness creation	7	9.1%
During education system improvement (schools/campus support)	6	7.8%
During health system reform (SRHR, consent, referral systems)	6	7.8%
During gender equity & inclusion (women, single mothers, albinism, boy child)	5	6.5%
During economic empowerment & livelihood support	5	6.5%

Table 11 shows that mental health advocacy and suicide prevention as the most dominant time with 14 appearances (18.2%), followed by youth leadership and youth-centered programming with 12 appearances (15.6%). Times for creating safe spaces and peer support initiatives were third with 11 appearances (14.3%), while policy advocacy and governance reform period was fourth with a frequency of 9 (11.7%). Periods of mentorship, training, and capacity building took the fifth position with a frequency of 8 (10.4%) while community outreach took the 6th rank with 7 appearances (9.1%). The least popular moments were education and health system reforms 6 (7.8% each) and gender equity and economic empowerment 5(6.5% each).

Table 12. The kind of system change that feels most urgent in personal context

System Area	Frequency (n)	Percent (%)
Mental Health and Wellbeing systems	28	44.4%
Employment and Livelihoods	19	30.2%
Education and Learning	5	7.9%
Justice or Governance systems	5	7.9%
Across all the systems mentioned above	3	4.8%
Environmental and Climate Systems	3	4.8%
Total	63	100.0%

From table 12, it is evident that the respondents identified mental health and wellbeing systems as the most urgent area for change 28(44.4%). Change in employment and livelihoods followed 19(30.2%). Education and justice or governance systems each received a score of 5 (7.9%) in terms of frequency. Smaller proportions pointed to cross-cutting reform across all systems (4.8%) and environmental or climate systems (4.8%), suggesting broader systemic and sustainability concerns.

Table 13. Supports or structures that would help people turn lived experience into systems change

Theme	Frequency (n)	Percent (%)
Training and mentorship	50	64.9%
Funding or microgrants	30	39.0%
Platforms for storytelling and advocacy	29	37.7%
Partnerships with institutions	25	32.5%
Access to data and policy spaces	25	32.5%

The respondents emphasized capacity-building as the strongest enabler of turning lived experience into systems change, with 64.9% highlighting training and mentorship as essential for transforming lived experience into effective action. Funding or microgrants had a weight of 39.0%, suggesting the supports are seen as critical to resource grassroots ideas and sustain initiatives. Platforms for storytelling and advocacy had a score of 37.7%, indicating how structures for amplifying voices and influencing public discourse are valued. Partnerships with institutions and access to data and policy spaces had the same weight (32.5%), reflecting high regard for collaboration, legitimacy, and entry points into decision-making arenas to translate personal insight into structural reform.

Table 14. The first guiding principle if the respondent were to design a system built on lived experience and belonging

Theme	Frequency (n)	Percent (%)
1. Voice, participation & co-creation ("Nothing for us without us")	24	31.2%
2. Inclusivity, equity & fairness	18	23.4%
3. Safe spaces & psychological safety	11	14.3%
4. Empathy, compassion & human-centeredness	9	11.7%
5. Transparency & accountability	5	6.5%
6. Training, mentorship & capacity-building	5	6.5%
7. Data-driven & impact-oriented systems	4	5.2%

Table 14 findings highlight that voice, participation, and co-creation 24(31.2%) were the most prominent principles, underscoring the significance of meaningful involvement in decision-making. Inclusivity, equity, and fairness followed closely at 18 appearances (23.4%), illuminating regard for just and representative systems. The third most significant guiding principle was creating safe spaces and guaranteeing psychological safety 11(14.3%). Further, empathy and human-centeredness had a weight of 9 (11.7%) highlighting low weight of relational approaches as guiding principles. The low weight of transparency and accountability and training and capacity-building 5(6.5% each) pointed to low consideration for responsible and empowering structures. The low weight of data-driven, impact-oriented systems theme 4 (5.2%) reinforced the value of evidence-informed action.

Table 15. What would "a system where you feel like you belong" mean in your community or context?

Theme	Frequency (n)	Percent (%)
1. Being heard, valued & having voice in decisions	21	27.3%
2. Inclusion, equity & non-discrimination	17	22.1%
3. Safe spaces & psychological safety	14	18.2%
4. Mental health awareness & accessible support	9	11.7%
5. Youth empowerment & participation	8	10.4%
6. Community connection & shared identity	7	9.1%
7. Opportunities for growth & livelihoods	6	7.8%
8. Good leadership, accountability & responsiveness	5	6.5%
9. Hope, dignity & emotional wellbeing	5	6.5%

Table 15 indicates that the respondents interpreted the system as primarily being heard, valued, and having a voice in decisions 21(27.3%), emphasizing meaningful participation. Inclusion, equity, and non-discrimination 17(22.1%) were also central, reflecting the need for fairness and equal treatment. Safe spaces and psychological safety 14(18.2%) highlighted trust and freedom from harm. Mental health awareness and accessible support 9(11.7%) reinforced wellbeing as foundational. Youth empowerment 8(10.4%) and community connection 7(9.1%) pointed to shared identity and engagement. Opportunities for growth and livelihoods 6(7.8%), alongside accountable leadership 5(6.5%) and hope, dignity, and emotional wellbeing 5(6.5%), completed this vision.

4. Discussion

The findings present a nuanced assessment of how lived experience is incorporated into mental health system design and how such inclusion shapes youths' sense of belonging. Although 64.6% of respondents reported that their lived experiences are sometimes or always considered, this pattern suggests inconsistency rather than systematic integration. Similarly, while over half perceived existing systems as moderately reflective of community values and realities, the findings indicate uneven alignment between institutional frameworks and the lived realities of Kenyan youth.

Despite these structural gaps, perceptions of belonging within mental health discussion spaces were generally positive. In total, more than 60% of respondents reported a somewhat strong or very strong sense of belonging to mental health discussion spaces, with only a small proportion feeling excluded. Key contributors to belonging included being heard and valued, engaging with peers who shared similar experiences, and receiving emotional support and empathy. Inclusive leadership and cultural sensitivity further enhanced feelings of safety. The belongingness findings align with Self-Determination Theory (SDT), particularly the psychological need for relatedness and autonomy (Krause et al., 2019). When youth emphasize voice, shared identity, and empathy, they highlight the relational and participatory conditions necessary for psychological well-being.

At the same time, significant structural barriers were observed among these youngsters. Key barriers like restricted access to decision-making spaces (63.5%), power imbalances privileging professional expertise (49.2%), tokenistic engagement (44.4%), and stigma (41.3%) reflect systemic constraints on meaningful participation. These patterns resonate with Empowerment Theory, which underscores the importance of shared power and participatory governance in mental health systems (Grealish et al., 2017). The findings suggest that when lived experience is confined to symbolic consultation rather than embedded in governance and design processes, empowerment remains superficial. Youths' emphasis on training and mentorship (64.9%), sustainable funding, storytelling platforms, and access to policy spaces signals a desire to transition from consultation to genuine co-creation within their spaces.

More importantly, 82.6% of respondents viewed the integration of personal narratives with statistical evidence as essential or important, illuminating an emerging challenge to dominant evidence-based paradigms that often marginalize experiential knowledge perceived to be inconsequential. Concerns about limited recognition of lived experience and cultural misalignment point to unrecognized forms of epistemic exclusion within youth mental health discourse. The youths stand for legitimizing lived experience as valid evidence promotes more democratic and inclusive systems, consistently with empowerment framework.

Overall, the findings shed light on the need for cautious progress alongside persistent structural inequities. Sustainable transformation requires institutionalized co-creation, equitable power redistribution, and governance models grounded in lived experience, dignity, and shared authority.

5. Conclusion

The findings of this study are interesting. Youths' sense of belonging is clearly tied to being heard, valued, and included in co-creation processes. Because of this, they strongly support the integration of personal narratives with statistical evidence to enhance a shift toward more holistic, human-centered systems. The study reveals that system design views and attitudes are in a dynamic state of transition, with openness to lived experience alongside inconsistent structures for meaningfully embedding those experiences. Youth report a significantly positive sense of belonging in mental health discussion spaces; however, a significant number perceive that their experiences are excluded from the design of these systems and subsequent decision-making processes, with tokenism and limited decision-making power identified as the main barriers. Structural barriers, including power imbalances, restricted access to policy spaces, stigma, and resource limitations undermine the transformative potential of incorporating lived experience into system design and decision-making. The prioritization of mental health and livelihood, when given the opportunity to reform existing systems, further underscores the perceived interconnectedness between mental well-being and socioeconomic stability. Taken together, these

findings highlight both progress and persistent inequities in youth mental health discourse. Sustainable systems change requires the institutionalization of youth participation, the redistribution of power to address structural bureaucracies, and the resourcing of lived-experience leadership to ensure that belonging is not symbolic but structurally embedded in governance, design, and evaluation processes.

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