

"Nothing for Me without Me"
Why and How to Engage Clients in Co-Designing Models of Care

Stock Photo. Posed by Models







Session Objectives

- 1. Describe the value of client co-design to promote effective, equitable engagement and improve outcomes.
- 2. Identify who to include in co-design (clients, families, prospective clients, providers, leadership, neutral subject matter expert).
- 3. Develop strategies and techniques for co-facilitating inclusive, accessible, and equitable co-design and assessing the effectiveness of power-sharing in co-design.





Why Co-Design Is Essential

"When you do nothing you feel overwhelmed and powerless.

But when you get involved you feel the sense of hope and accomplishment that comes from knowing you are working to make things better"

Maya Angelou

Common Behavioral Health Disparities

- 58.2% of Black and African American young adults 18-25 and 50.1 percent of adults 26-49 with serious mental illness did NOT receive treatment in 2018.1
- 90% of Black and African American people over the age of 12 with a substance use disorder did NOT receive treatment.²
- 11.5% of Black and African Americans, versus 7.5 percent of white Americans were still uninsured in 2018, despite the ACA³
- > 50% of Latinx young adults ages 18-25 who have a serious mental illness may not receive treatment 4.

LGB adults are more than twice as likely as heterosexual adults to experience a mental health condition.

Transgender individuals are <u>nearly four times as likely</u> as cisgender individuals to experience a mental health condition. They are <u>twice as likely</u> to experience depressive symptoms, seriously consider suicide, and attempt suicide compared to cisgender lesbian, gay, bisexual, queer and questioning youths.

LGB youth are more than twice as likely to report experiencing persistent feelings of sadness or hopelessness than their heterosexual peers 6.

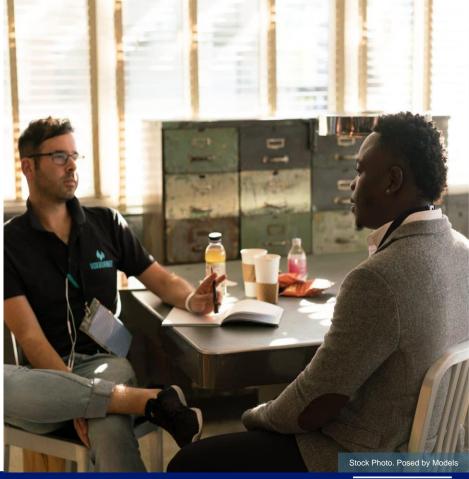






Traditional Care Planning Can (and Does) Perpetuate These Disparities

- Services developed in response to the clients who are accessing care
- Usual voices=usual approaches
- Fitting care into existing structure (e.g. standard "business hours", existing workforce)
- Assumptions about "what works"







Co-Design Opens the Door to Innovation

- Co-Design uses the expertise of those with lived experience, those receiving care, clinicians and other advisors/experts to understand a 'problem' and develop innovative strategies to address it.
- Co-Design "relies on the creation of a safe environment where power imbalances are acknowledged and mitigated, and decisions are made collaboratively" (Tindal et al 2021)
- Co-Design "centers an ethical relation of being-for that moves beyond unethical and transactional approaches of beingaside and being-with" (Palmer et al 2023)









Thought exercise

- Think about a time you either engaged clients in service or program planning.
- What word comes to mind when you reflect on that experience?
- What images are you reminded of?





Possible Stakeholders for Co-Designing Services or Programs

People receiving BH care

Family members of people receiving BH care

Local partners serving the targeted population

People not receiving BH care who represent underserved populations

Clinicians

Representatives from Peer or Family Run Organization(s) Subject matter expert with knowledge or experience in bestpractices in relevant behavioral health models









Mitigating Challenges to Co-design

- Common Challenges:
 - Same voices= same results
 - Power imbalance
 - Need for rushed decisions (e.g., grant deadline)
 - Distrust or cynicism based on prior history
- Mitigation Strategies
 - Creating formal, compensated roles for consumers of care
 - Allowing sufficient time to build trust among co-design collaborators

Source: Tindall RM, Ferris M, Townsend M, Boschert G, Moylan S. A first-hand experience of co-design in mental health service design: Opportunities, challenges, and lessons. Int J Ment Health Nurs. 2021 Dec;30(6):1693-1702. doi: 10.1111/j.mm.12925. Epub 2021 Aug 13. PMID: 34390117.







Principles, Techniques, and Methods for Co-Design

Core Principals









Equal power distribution

Building capacity among participants

Building relationships among participants

Promoting active participation





Co-Design Process



Resourcing and Planning

- Establish an organizational policy for compensating participants
- Intentionally plan outreach to ensure diversity and representation
- Provide accommodations (e.g. in-person and remote options, community-based gathering, interpreters, childcare, etc.)



Recruiting and Sensitizing

- Curate the right team
- Prepare all participants for power sharing and participation
- Provide advance orientation about the process and clarity about the goals



Facilitation

- Identify required elements for the service or program (e.g. regulatory/compliance limits, accessibility requirements, funder expectations)
- Use multiple methods to elicit input related to key components
- Empower a neutral subject matter expert to help



Evaluation

- Seek feedback about the process from all participants
- Adopt the feedback and plan to continually improve the process used, based on lessons learned













Planning Co-Design

- Consider a problem you would like to target for co-design
- Take a moment and write down who you want to include
- Take another moment to write down the barriers you are likely to face
- What are some strategies you can use to overcome each barrier?





Strategies to Facilitate Engagement



Authenticity



Active listening



Empathy



Methods/techniques for involving clients in decision-making and idea generation (e.g., journey mapping, world café, brainstorming)



Identifying and addressing barriers



Measuring Success and improving over time







Co-Design Case Study: Intensive Crisis Stabilization Center

The needs the model addressed:

• Program design for a one stop center for peer-led, clinically supported crisis stabilization for child and adult populations experiencing mental health or substance related BH crisis

The stakeholders involved in codesign:

- Adults, adolescents, and parents of children who received psychiatric and substance use emergency care in the emergency room and from mobile crisis
- Providers who responded to BH crisis
- •Subject matter expert able to bring in national models and best practices for discussion

Techniques and strategies used to engage clients in co-design:

- •Structured interviews with representatives from each group
- Discussion with current clients
- Interviews with local partners

How co-design success was measured

- Participant representation, inclusion of youth representative of LGBTQ community
- Responsive to necessary planning elements
- Winning the grant

The impact of the co-design process on the approach to care

• Emphasis on peer support, how waiting area is appointed, the lighting, noise control, client choice in decision making, family support









Survey Link

To better inform our future trainings and request topics for office hours, please complete this short survey. Use the QR code or short URL to access it. Your feedback is important. Thank you!



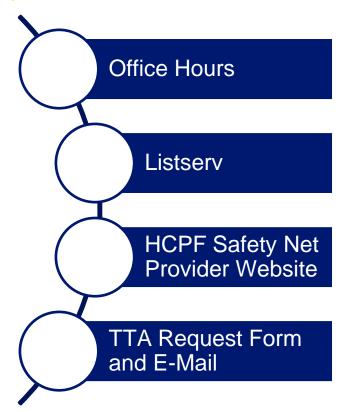
https://bit.ly/bhprovidertrainingsurvey







Appendix A: Additional Resources



Office Hours are often offered on the last Friday of every month (through September 2024) at noon!

Please visit the HCPF Saftey Net Provider webpage to register.

Join the Listserv to receive notifications of trainings, technical assistance, and other stakeholder engagement opportunities:

Register Here

Visit the website for details on upcoming training topics and announcements, training recordings and presentation decks, FAQs and more: https://hcpf.colorado.gov/safetynetproviders

Request TTA support or share your ideas, questions and concerns about this effort using the <u>TTA Request Form</u> or e-mail questions and comments to: <u>info@safetynetproviders.com</u>







Appendix B: References

- 1. Kaiser Family Foundation. (2020). Changes in Health Coverage by Race and Ethnicity since the ACA, 2010-2018. Retrieved from https://www.kff.org/disparities-policy/issue-brief/changes-in-health-coverage-by-race-and-ethnicity-since-the-aca-2010-2018/
- 2. CDC. (2019). Summary Health Statistics: National Health Interview Survey: 2017. Table A-7. Retrieved from https://www.cdc.gov/nchs/nhis/shs/tables.htm
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- 4. Agency for Healthcare Research and Quality. (2018). 2018 National Healthcare Quality and Disparities Report. Retrieved from https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/2018qdr.pdf
- 5. NAMI https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/Hispanic-Latinx#:~:text=Hispanic%2FLatinx%20communities%20show%20similar,illness%20may%20not%20receive%20treatment.
- **6.** National Association for Metal Illness https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/LGBTQI23. Mental Health America https://www.mhanational.org/racial-trauma
- 7. Tindall RM, Ferris M, Townsend M, Boschert G, Moylan S. A first-hand experience of co-design in mental health service design: Opportunities, challenges, and lessons. Int J Ment Health Nurs. 2021 Dec;30(6):1693-1702. doi: 10.1111/inm.12925. Epub 2021 Aug 13. PMID: 34390117.
- 8. Palmer VJ, Bibb J, Lewis M, Densley K, Kritharidis R, Dettmann E, Sheehan P, Daniell A, Harding B, Schipp T, Dost N, McDonald G. A co-design living labs philosophy of practice for end-to-end research design to translation with people with lived-experience of mental ill-health and carer/family and kinship groups. Front Public Health. 2023 Nov 30;11:1206620. doi: 10.3389/fpubh.2023.1206620. PMID: 38115850; PMCID: PMC10729814.
- **9.** Dietrich, T., Trischler, J., Schuster, L. and Rundle-Thiele, S. (2017), "Co-designing services with vulnerable consumers", Journal of Service Theory and Practice, Vol. 27 No. 3, pp. 663-688. https://doi.org/10.1108/JSTP-02-2016-0036





