BHTIMPACT

Youth and Family Design Toolkit

THE WORK BEFORE THE WORK

How to Build an Organization That's ***Actually*** Ready for Youth and Family Engagement



Letter from Dominique and Amber





You're here because you're down for the revolution in youth mental health. The one working to ensure that youth and family voices, perspectives and lived experience expertise intentionally shapes the path forward. We love that for you and for us!

Given that you're aligned on the why, the next step is to grapple with the real nuts and bolts of how to meaningfully partner with youth and families to ensure we integrate what they have to offer in mutually beneficial ways. In other words, what happens next, and how can we make sure that whatever we're doing is safe, non-extractive, sustainable, puts its money where its mouth is, and ultimately helps move the needle in youth behavioral health. Not to mention, for all of this to go well it relies on taking place within an organization that is committed and ready to do the internal work to prepare for youth and family engagement.

We know from experience, and from the many conversations that we have with innovators in the space, that there are seemingly countless factors that must be considered in order to do the real (non-performative! Too much? Actually, it has to be said, and we stand by it) work that youth and family inclusion requires.



And that's where we come in! This piece is part of a collection of resources that are forthcoming to help you do just that. Before we start throwing out a strategy for the broader strategy and recommended actions you'll need to take in your work, it's our custom to begin with laying a framework to help you orient your thinking around what matters most. In other words, before we even lay out the bigger picture for youth and family engagement, we want to make sure we're aligned on some of the necessary precursors. So, in this specific piece, we're bringing you critical considerations about:

- **Who** is in the room of your initiative (and who isn't)
- **An organizational gut check** to evaluate readiness core factors are in place to make the most effective and beneficial use of youth and family expertise
- **What to do** with youth and families once they're on board (e.g., engagement, co-design, etc).



Context Corner

Engagement and Co-Design

First things first, let's level set on a few key terms so we're on the same page. Engagement and co-design are used interchangeably, but they can mean different things. So here's how we are defining them.

Engagement Any role or activity that enables families to have direct and meaningful input into and influence on systems, policies, programs, or practices affecting services for children and families[1]

Co-Design An approach to designing with, not for, people and communities. This approach amplifies the voices and experiences of the people closest to the needs addressed through an engagement or initiative (e.g., youth advisory committee; focus groups; youth-led research, etc.) It also prioritizes relationships, increases trust across all stakeholders, and uses participatory approaches to ensure the work is guided by those most affected.[2]

When both practices are implemented effectively, the results have been impactful and transformative. The field is still beginning to document that services may become more accessible, institutional trust is increasing, and engagement and retention in the solutions themselves are rising. In research-based engagement, the 2024 study "Engaging youth voice and family partnerships to improve children's mental health outcomes" found that the collaborative effort between youth and families "respects the diverse expertise and knowledge of each group while improving mental health systems, services, and outcomes.

"There is obvious demand for youth voices, yet not enough youth participation to create the lasting cultural and organizational change necessary."

AIM Ambassador ZW

THE ROADMAP

A note before we dive in: the way we've organized this guide, its sections, and considerations might suggest a neat, linear sequence. In reality, these processes happen simultaneously and cyclically. They overlap, influence each other, and loop back in unpredictable, unscripted ways. What we have outlined is presented for clarity and isn't meant to be followed step by step. Since the engagement and co-design process will be constantly evolving, more dynamic and lively, our guide is an attempt to reflect that.

Each section includes:

THE AUDIT

Questions to ask yourself as you go through each step



Resource Call Out

There's no need to go it alone; here are more resources to dig into!

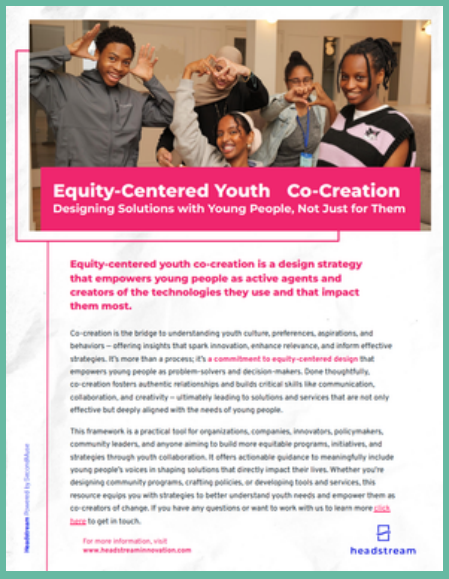
Section 1: Who's Actually in the Room

Picture the ideal participant. How did you create them? Who is missing from your imagination? Are you picturing an ideal participant, and who did you leave out to create them?

Who is missing, and who do we find easily? In some ways, we've been conditioned to seek out youth who fit the mold of a professionalised lived-experience expert. This is not because we're bad, but because we have some practical realities we're trying to meet. Often, we trend toward the young person or caregiver who is most accessible to reach, has flexible time, and the financial and social support to show up consistently. In other words, someone who can navigate comfortably in the structures we have already built. Slowly and surely, and without realizing it, we are limiting representation. We're gathering data and generating feedback that only reflects a subset of the population. The result? We build solutions that don't work for our broader communities. This is where we pause and acknowledge the role of implicit bias. Our design choices are rarely ever neutral; in fact, they are shaped by assumptions unaware we're making.

Resource Call Out

Headstream Equity Centered Youth Co-Creation Framework



Link

THE AUDIT

Are you currently collecting, or do you plan to collect, information on race, language, geography, and other identity markers for your outreach efforts? And how will you evaluate and use the data?

What community organizations, trusted messengers, or grassroots groups are you currently in relationship with? What relationships do you still need to build?

Are your engagement opportunities designed to reflect the barriers communities face, such as transportation challenges, housing instability, language barriers, and immigration status?

What do the data tell us about the missing voices?

The reason we're missing voices isn't just that we need to diversify our outreach strategies (we do). A few things here: first, there is a major trust issue. Namely, research shows that youth with marginalized identities, including Black, Indigenous, and 2SLGBTQIA+ youth, often face discrimination in healthcare. Overwhelmingly, the literature suggests that this contributes to mistrust of research institutions, researchers, and healthcare systems based on these experiences. Second, there is an SDoH issue. Currently, the research is limited where considering and addressing the impact of SDoH on youth engagement and co-design, is concerned. Skipping SDoH is like planning a youth and caregiver engagement party without making sure all the guests have the directions (and a ride!) to get there.

Resource Call Out

Measuring What Matters: Social Determinants of Health



Link

THE AUDIT

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Who from your team is showing up, and what are they bringing to the table?

Keeping it real for a minute: meaningful youth engagement is not just about the participants, it's also about us. To make movement here, we need to self-evaluate. Who from our internal team is showing up, and what beliefs are they carrying? Are they coming in as the expert ready to fix the identified problem, or as partners ready to listen and learn? We have to take the time to evaluate whether our staff has the cultural humility and the capacity to hold space for the unpolished, sometimes critical, and raw feedback that inclusive engagement and co-design require.

This is the organizational readiness gut check: the moment we shift from "are youth and families ready to work with us?" to "are our organizational culture and systems designed for (and ready to work with) them?"

Resource Call Out

City of Alexandria's "The Racial Equity Tool"


AT A GLANCE:

THE RACIAL EQUITY TOOL

What is the Racial Equity Tool? The Racial Equity Tool is a step-by-step guide to help you and your team apply a racial equity lens to your work. The longer toolkit provides definitions of racial equity and related terms, a self-assessment, and practical case study.

Groundwork

Do your research before connecting with BIPOC communities and starting Stage 1.

Assess: What are you working on? What are the root causes of racial inequities in this topic?
Discuss: What is the racial makeup of your internal team?
Consider: How does this project align with Cityorganizational priorities?
Research: What information do you have about who is impacted?
Evaluate: How did your team promote racial equity in this stage using the racial equity rubric?

1 Align & Co-Design

Connect with BIPOC communities, hear their expertise, and make sure you both agree on the path forward.

Discuss: How do members of the community want to engage with you and your organization?
Co-Align: Do we agree that this is the right topic?
Co-Design: Agree on the process for future stages.
Co-Evaluate: How did your team promote racial equity during this stage using the racial equity rubric?

2 Co-Strategize

Work with BIPOC communities to co-develop a racially equitable strategy.

Research: What are the disaggregated data outcomes by racial and ethnic group?
Co-Strategize: Brainstorm strategies and existing best practices within impacted BIPOC communities and the benefits and burdens of the proposed strategies.
Co-Evaluate: How did your team promote racial equity during this stage using the racial equity rubric?

3 Co-Implement

Work with BIPOC communities to implement the project in a way that shares power.

Co-Assign: Who is responsible for all actions and deliverables?
Co-Reflect: How is each step within the implementation process promoting power sharing with BIPOC who are directly impacted?
Co-Implement: Put plan into action.
Co-Evaluate: How did your team promote racial equity, empowerment, and engagement using the racial equity rubric and BIPOC Stakeholder Engagement Spectrum?

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Link

THE AUDIT

Who is on your team, and do their identities, languages, and lived experiences reflect the communities you're trying to engage?

What emotional, financial, and training support structures are in place for staff who will be leading this work?

What does your team and organization currently believe about the expertise that youth and families bring, and does the way you currently work reflect that belief? Where is there room to do better?

Section 2: The Gut Check

Now you have carefully thought through who you're inviting in and how you'll partner with them. Naturally, you're thinking about strategies and recommended actions, but by now you know we're coming with the step before that. The gut check, the organizational look in the mirror moment, where you ask, "Can our systems and culture support, empower, and hold youth and family engagement?

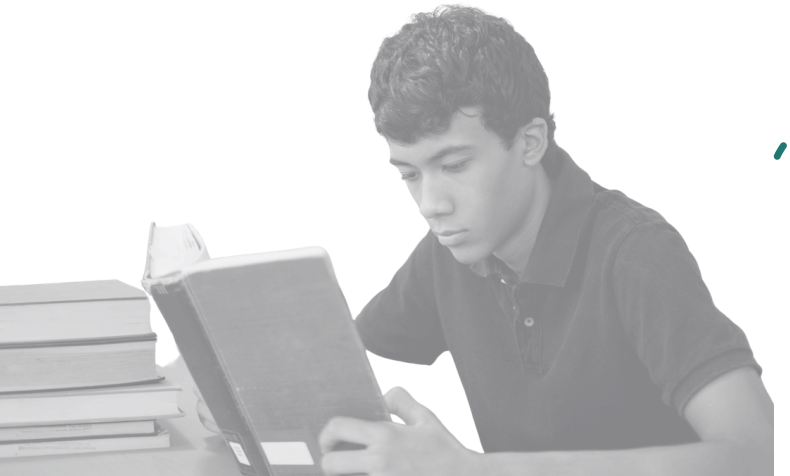
For more on how to actually track innovative shifts in youth behavioral health impact and measurement, check our Measurement and Impact pillar.

THE AUDIT

Are we ready to accept when we're wrong?

Co-design is messy. The organizations and people who do this well are the ones that welcome disruption as part of their culture. Authentic partnership requires valuing lived experience as much as clinical or professional credentials, and that shows up in pivoting, changing course, or stopping in response to feedback from youth and families.

For your co-design process to become a practice, it requires a cultural shift from focusing on improving what you have already identified as the solution instead of wanting to protect it, to having the desire to reveal gaps in understanding, rather than protecting the production timeline, and to prioritizing the people you're designing for.



THE AUDIT (cont.)

Does the funding match our values?

Engaging and co-designing with youth and families takes real investment. True partnership will require capital across three areas to plan for:

- **Financial capital:** We know that compensating youth and families for their expertise is a standard best practice, and there's an opportunity to go further. Beyond monthly/hourly stipends, explore the full cost of participation and budget to remove barriers such as childcare, transportation, cellphone plans, and the equipment needed to participate.
  - Some of the most innovative practices we've seen have funds for milestones, which include gifts for graduations, birthdays, etc., and emergency support for participants navigating crises.
  - Pro tip: And don't forget your staff. It's important to compensate your staff for the extra time and energy required to establish, build, and maintain true partnerships. Preventing burnout and staff turnover starts here.

- **Time capital:** Building trust takes longer than most engagement budgets do not allow for. You are investing in informal check-ins, peer mentoring, and social get-to-know-you interactions. People show up because of passion, but they stay because they are doing the work alongside others who care as much as they do. Investing here is a reminder that the work is human.

- **Relational capital:** This is the reputation organizations build among youth and families, and within the broader community. It's earned through consistency, transparency, and showing up even when you don't need anything. Actions such as attending events, social gatherings, or volunteering your time, reporting back, and being a reliable resource. These are the acts that make your invitation mean something when it arrives.

THE AUDIT (cont.)

Have we baked in safety?

Safety in engagement design is both structural and psychological. And, granted, there are some things you are only going to learn from being in the thick of it. Execution will always teach you things planning cannot, and there's beauty in that! But there are areas you can get ahead of, and these three are worth exploring:

- **Privacy and confidentiality:** These are the legal considerations that lead to process outlines that define knowing what participation information and feedback will be shared, with whom, and in what form. Thoughtful planning of how contributions are attributed, ensuring structures for anonymity, parental consent, and sensitive disclosures, is key. Privacy and confidentiality considerations are regular, ongoing conversations that should absolutely be part of your onboarding checklist, but should be assessed regularly as participation evolves.

- **Online safety:** Most engagement and co-design opportunities occur in digital spaces, and protecting participants in those spaces requires thoughtful consideration of the environment. This means understanding how to use secure, protected platforms to access and store information, establishing community agreements on how people interact, and carefully protecting the digital footprints of the youth and families you are working with so their participation does not create unintended consequences, exposure, or risk.

- **Trauma-informed care:** Intentional staff and organizational capacity building is essential, given that sharing lived experience is heavy work. This means training that defines the concepts of trauma-informed care and demonstrates how to apply them in practice. Having protocols for emotional support, having a culture that encourages and respects boundaries, and most importantly, remembering that youth and families are not always reflecting on their experiences from a safe distance away, they are showing up in the middle, actually, sometimes despite it, and that requires your organization to be on the journey with them.

THE AUDIT (cont.)

Are we closing the loop?

This is the part of engagement and co-design that often feels like the "end," so it rarely gets the upfront attention it deserves. But closing the loop is where trust is either solidified or broken. It's about being transparent about how youth and family input is implemented, what gets changed, and, most importantly, the process for deciding what doesn't.

- **Communicate what's possible upfront:** before your engagement begins, be clear with participants about possibilities and limitations for their influence. Communicate what decisions have already been made, and what's still open for discussion. And remember to allow space for them to identify where the gaps are present

- **Create a two-way feedback mechanism:** Closing the loop will not be just an end-of-the-year report or a thank-you email. It's an ongoing practice of letting participants who have dedicated time, emotion, and passion know what their contributions have led to and changed. Practices such as "you said, we did" summaries, standing follow-up sessions, and regularly updated shared documents all communicate what keeps engagement going: we heard you, and here's what happened next.

- **Evaluate the process, not just the outcomes:** Turning engagement into a sustaining, evolving co-design process within a culture means evaluating both the impact of what you built and how it felt to those who experienced it. Honest and continuous evaluation practices (surveys, focus groups, listening sessions, etc) alongside your youth and families will allow you to move beyond fancy grant reporting to impactful data on authentic partnership improvements and measurable outcomes.



Section 3: The What: Understanding Your Level of Partnership

You've done the reflection, asked the hard questions, and built an accountable process. Now you are thinking it's time for youth and family participants to arrive. This is the moment we have been preparing for, and how you show up in the co-design process will look different depending on where you are. Co-design exists on a spectrum; it's not a one-size-fits-all approach. Choosing your level of participation with youth and families will depend less on ambition and more on your organizational culture, readiness, funding, and capacity. The goal is to decide which level you're genuinely prepared for, because that will have the most impact without causing harm. Here's how we break down the levels



CONSULTATION

This is often the entry point into youth and family engagement. So there is nothing wrong with starting here. You already have a plan or program model drafted or in place, and you want to know how to improve, expand, and align it with the realities of youth and families. You're asking whether this resonates with you? Or what are we missing? The organization has set the direction, still holds the power, but is at a critical moment where lived experience can sharpen, redirect, and strengthen what's already been built

When this works: This level works best for organizations early in their lived experience and community engagement, high-output organizations with tight deadlines, or those with highly regulated projects where the bones can't change much and the time is structured and focused.

Just the Beginning: consultation is a great place to start, but you should always aim to grow from here. Staying at this level indefinitely without moving towards shared decision-making power will become extractive over time. The goal is progress, not perfection.

COLLABORATION

At this level, you're working on a specific piece of the puzzle together. You've defined the goal, and are inviting youth and families to help you figure out the how. Their expertise will directly shape the product's final outcome, shifting it from a service to a shared initiative.

When this works: This level works best for organizations with strong internal alignment, a clear enough scope that participants know what they're contributing to, and enough runway to build out the process. Your team is ready to be challenged and genuinely open to changing directions based on what's discovered in the engagement.

CO-DESIGN

This is the high-intensity, all-in level. There's no draft already developed, just a blank canvas and seats at the head of the table for all your participants. Problems and solutions are identified together from the very beginning.

When this works: This level works best for organizations with a real innovation mindset and a lot of bravery, because, well, that's the point. Your organization should have done the internal work, established relationships with the communities you're inviting in, and leadership is genuinely prepared to share decision-making power. This level also requires dedicated staffing, financial resources, and time built into the process.

Resource Call Out

Hart's Ladder of Youth Participation
Developed by Dr. Roger Hart, is an eight-rung model used to conceptualize the degree of youth involvement in projects, ranging from non-participation to genuine empowerment. (Link)

IAP2's Spectrum of Public Participation
Assists with selecting the level of participation that defines the public's role in any community engagement program. (Link)



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Section 4: Whew, that was a lot!

Hopefully, we've set the stage for a broader set of conversations and resources that we're cooking up for meaningful youth and family inclusion in behavioral health innovation, strategy and design. Building on the themes we've laid here, we'll start to provide tactical guidance and strategy on the logistics of this work, including everything from confidentiality, to compensation, to psychological safety in the co-design process and more. We'll focus our work on helping you make sure that the goals of your work are matched with best practices to help you build a sustainable and ethical process.

We started with an invitation to think out loud, but know that we're also learning and building out loud as well! Part of our upcoming work will include drawing back the curtain on our own process of building a Writers Program. We'll step you through how we're working to align that program with the processes and considerations we've outlined here and will be serving up in upcoming resources. We'll also share the challenges we encounter along the way and the strategies we use to solve them.

Want to hear what youth think right now about the mental health crisis that is headlining their generation until then?

Head on over to bhtimpact.org/youthandfamily, where you can hear youth perspectives, including an interview with AIM Youth Ambassadors.

TLDR (WE GET IT)

Meaningful youth and family engagement requires preparation in your organization: are you considering safety? Accountability? Updating your solutions based on feedback? Closing the loop on feedback? Bringing in youth and family voice is not just about listening, it is about ensuring your organization is ready to act on the feedback.

There are voices that are consistently overlooked and excluded from youth and family engagement opportunities, a problem that can be addressed through honest reflection on assumptions, barriers, and design of the engagement processes.

Understanding the difference between consultation, collaboration, co-design, and participation levels, and selecting the level your organization is truly prepared for, determines whether your engagement efforts foster genuine partnership or inadvertently cause harm.

Building an organization capable of effective youth and family engagement and co-design is not a one-time effort. It is an ongoing practice that should be continually evaluated and improved.



RESOURCES AND REFERENCES

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