Addressing the Adolescent Mental Health Emergency

Part 4: Measuring the Mental Health and Well-Being of Adolescents

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Why Measuring the Mental Health and Well-Being of Adolescents Is Important

Understanding the mental health and well-being of adolescents is an important first step in delivering effective and high-quality care. From a clinical perspective, this is typically achieved through standardized assessments, survey instruments, and clinical interviews. However, since these tools are often designed to measure and serve adult populations, there is a lack of well-researched measures to evaluate the mental health of youth, particularly diverse youth. As a result, culturally relevant assessment approaches that capture an expansive notion of wellness have varied widely, have had little opportunity for reliability and validity research, and are difficult to measure quantitatively. This gap exists for two reasons: youth of color are underrepresented in mental health research samples and there is a lack of funding for mental health research projects specifically focused on diverse youth populations.

Once a thorough assessment of strengths and needs is conducted, clinical interventions, support tools, and treatment plans can be put into action. However, there is also a lack of culturally relevant outcomes research to determine what interventions and strategies are truly effective in supporting youth of color and LGBTQ+ youth. Following an intervention, appropriate measurement of outcomes and mental health improvement is necessary to develop a broad evidence-base for what works and what doesn’t in serving wellness needs.

It is important to note that a majority of Upswing grant recipients are providing care outside of clinical settings and using a wide range of tools and treatment interventions designed to best meet youth where they are. In the section that follows, we share the challenges in measuring mental health and well-being experienced by a handful of Upswing grant recipients and offer ways funders, researchers, and policymakers can help to alleviate them.
MEASURING THE MENTAL HEALTH AND WELL-BEING OF ADOLESCENTS

Insights from Upwing Advisor, Dr. Kimberlyn Leary

Although psychological research provides the basis for development of mental health assessment measures, outcomes, and support tools, few research publications tackle issues related to race. Youth of color and LGBTQ+ youth experience different risk and strengths factors that impact their mental health and they use different, culturally relevant language to describe these experiences. Upwing Advisor Dr. Kimberlyn Leary, associate professor of psychology at Harvard Medical School and health policy and management at the Harvard T.H. Chan School of Public Health, has conducted research on mental health and girls of color. She notes, “We don’t yet know [...] how to design school-based mental health care so that programs may be maximally responsive to the needs of girls of color.” In order to improve mental health care for our target population, we need to take a hard look at the cultural relevancy of the assessment and support tools currently available to mental health professionals.
Recommendations

For Funders

Allow applicants and grant recipients to define and share progress using their own measures of impact. This requires funders to broaden understanding and acceptance of different qualitative measures of impact. Almost all grant recipients interviewed shared that they knew their programs and approaches were working because youth overcame the first barrier: they showed up. With broad need for programs, and greater barriers to care faced by youth, one of the biggest challenges can be finding the place in which they are comfortable letting their guard down and engaging in mental health programs.

What we’re hearing:

"Whenever we use traditional, non-Westernized methods, those aren’t accepted... these things that we as Indigenous people have been using for thousands of years, but because it doesn’t fall into this Westernized idea, it doesn’t count for some reason and that’s kind of frustrating to be faced with... those barriers [that] exist being an Indigenous person."

“There’s those moments where you see these [LGBTQ+] youth be able to put on garments or personal items that reflect their identity, and you can just see them stand up straighter and come to life. And if you’re paying attention, you can see those differences. So that’s really the subjective aspect that comes in.”

Be mindful of the challenges of collecting impact data overall, particularly amid pressing operational concerns.

What we’re hearing:

"Some of the data collection challenges are the barriers that exist in asking for certain information. Sometimes, we have to ask questions a couple different times in a couple different ways to actually get to the core information that we need to connect them with the services they really need."

"We have struggled with outcomes. We’ve gotten pulled away from working on measurement in order to deal with the day-to-day struggles of responding to COVID changes and needs. We have a partnership with [a university] which has been really great, but creating the reports is just taking so much longer than anyone anticipated."
Support staff training and targeted measurement, learning, and evaluation capacity building.
Organizations serving this population often need to customize or create assessment tools from scratch so that they are culturally-relevant. Unrestricted funds and/or targeted training opportunities to support capacity building in this area can enable organizations to develop tools that better reflect the needs of the young people they serve.

What we're hearing:
"We really want to know what areas in our work we can improve...there’s been powerfullness behind evaluations we’ve created but having someone who has already went through that—it would be helpful to ask, ‘how have you done it?’ and how to present that to people that are outside of your community as well."

"Our [evaluation model] is founded on strong relationships with youth. Our staff are often the best window into understanding what’s going on with a young person’s mental health needs. The best methods of access are always changing with the changing needs of the community. We need to be trained and have the tools to stay relevant in diverse and adapting communities."

For Funders, Researchers, and Policymakers
Adapt clinical measurements, tools, assessments, and process to be culturally responsive.

What we're hearing:
"A lot of these trainings, therapies, and measures were not designed or created with our diverse populations in mind or based on their needs."

"The documentation that EHR (Electronic Health Record) systems require is governed by Medicare regulations designed for medical visits, resulting in irrelevant, time-consuming, and unnecessary documentation. Our telehealth platform is directly embedded in our EHR; it features our clients’ legal names, and we are not able to customize that name during telehealth visits. For our transgender clients, this means that each time they have a virtual visit with their therapist, their ‘dead’ name is front and center."

"There needs to be not only a closer examination of how surveys and assessment tools can be more inclusive, but also to create space and opportunities for organizations that stand for youth of color to utilize the assessment methods and survey tools that are best for our work and populations."
Use language and methods that resonates with youth and parents/caregivers.

What we’re hearing:

“Organizations serving youth of color want to use existing survey methods to ensure we are in alignment with donor, stakeholder, and reporting best practices, but a lot of the most relevant and common survey questions that speak to our work and help measure impact and feedback are confusing to our demographic, offensive, or not culturally appropriate for the groups we work with. For example, internally we use ‘mental health difficulties’ instead of ‘mental illness.’ Youth don’t want to say they or someone in their family is ill.”

“We do pre- and post-workshop surveys and we can really see a great reduction in anxiety. But I don’t think we’ve found effective methods or language that stays true to our values. We don’t want our participants to feel exhausted by long surveys or feel like lab experiments, yet we still want their feedback and insights.”

Invest in clinical and participatory research models which prioritize the development of equitable, culturally relevant data tools with, and for, communities of color.

What we’re hearing:

“... if a consortium of researchers were to develop or modify a few baseline measurement tools and then make those tools available across, for example, [Upswing] grantees, this would be groundbreaking.”

“A lot of communities, they know what they need. I want to see our field move toward not just the biophysical and biopsychosocial markers (those are important), and I also want to see us lean into ‘What are the strengths of these communities? What are the social factors? What are the factors that we never talk about like race and ethnicity?’”

Provide access to population-level data and research to support benchmarking and collective impact tracking by community-based organizations.

What we’re hearing:

“Market data that allows larger providers to demonstrate outcomes is available by expensive subscription only and is inaccessible to organizations like us. Access to population health data is critical to prove outcomes and resultant cost savings in healthcare. In order to do that, we need assistance to be able to access expensive population health data, and/or work-arounds like tracking our own client outcomes using Fitbits or other wearable technology.”

“On the measurement, learning, and evaluation side of things, we would love to do more of that. I would love to be able to do a statewide needs assessment—not only for our own data and understanding needs so that we can make the case for greater funding, but also so that we can contribute to the field and contribute to the long term impactful preventative work.”
Endnotes


