BHTIMPACT

MEASUREMENT GUIDE

Power—Yours, Mine, & *Ours*:

How measurement lays the foundation for shared decision-making power with young people



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Letter from Dr. Amber W. Childs

Sharing doesn't come built into our factory settings as humans. In fact, you can probably remember some early and likely frustrating lessons of your own around sharing. Spoiler alert: sharing doesn't stop at toys. It includes sharing of choices and decisions.

We have to learn how to share and, largely through experience, be shown evidence of the benefits of sharing. We also find out what it can cost us when we don't share. We miss out on better ideas, more resources, strategies to avoid pitfalls or solve challenges, and the buy-in and commitment from others that are vital to moving important work forward.

And even though the benefits of these principles for sharing in youth mental health care are obvious from outer space, sharing hasn't always been in the room with us. Even though we know that collaboration helps to improve the effectiveness of youth-focused solutions, from design to engagement to outcomes, we still need to be taught how to go about sharing key decisions with youth. Just like when we were young.

Fortunately, measurement can play a helpful role in putting shared-decision making (SDM) frameworks into practice in youth-focused mental health solutions and interventions. This article gives you a primer on the case for shared-decision making in youth-focused care, with a focus on the role that measurement has to play in facilitating these collaborations practically. While I'll focus primarily on interventive solutions, and even throw out a few ideas about how an SDM framework to measurement can benefit us in other ways in youth innovation, you should know about the broader body of work at BHT Impact and many others around intentional inclusion of youth and family voices in solution development and design.

Note: This article is intended for educational and informational purposes only. It does not constitute medical, clinical, or legal advice. Organizations developing youth mental health programs should consult appropriate professionals and applicable regulations.

The (ultra fast) 411 on Shared Decision Making (SDM) and Youth Behavioral Health Interventions

SDM has its roots in general medical practice and long story short, moves away from patients just giving consent to a recommendation, to actively being involved in choice making. But SDM doesn't just live in medical care: it totally applies to youth behavioral health services. SDM by nature is flexible in how it is applied, but the formula in youth behavioral health includes the following elements:

- Youth (and families) actively collaborate with providers to make decisions about care, including the type (i.e., what specific interventions), format (e.g., individual, group-based, community-based), sequence, frequency and duration of those services
- Information is shared (see, sharing is everywhere) as a two-way street between youth and providers
- Youth and families decide what to do next, during each phase of care, by weighing the options, discussing challenges and opportunities, and agreeing on a course of action

If you're developing mental health solutions in the youth space, especially clinical or service delivery oriented innovations, the soundtrack for SDM conversations with youth and families who engage with those solutions might sound something like this:

- What are the challenges that we're here to navigate?
- What are the strengths we can bring to bear?
- How does your family typically make decisions about important issues?
- Of the available and recommended care options, which are the best fit, in what order and for how long?
- How can we decide when our work together is helping? When it is not?
- How do we decide when the work should change or end?

I'm convinced, aren't you? If only this were so straightforward and evenly applied. Before we discuss some of the challenges, let's spotlight how measurement can help to smooth the path for incorporating SDM principles into youth behavioral health interventions, design and priority setting.

Measurement Practices that support SDM in Service Delivery Solutions

First stop: Measurement Based Care

Honestly, it would be strange if MBC (or measurement-informed care if you're so inclined. Literally, same diff.) didn't come up in this conversation. Especially as it relates to SDM in downstream youth-focused intervention. Very handily, the "collect, share, act" process of MBC aligns almost exactly with the formula for SDM and offers a scaffold for the soundtrack of conversation described above within treatment. Since you're likely an expert on MBC at this point, you'll know that MBC is a crucial kickoff to SDM, beginning with deciding what is most important for the young person to measure and track, how that measurement is related to their specific treatment goals, and what to do if and when those goals or the areas of focus change and shift over time. Measurement is especially helpful as it highlights areas where youth, caregiver and/or provider perspectives align and where they diverge, and can help pinpoint where certain decisions and choice points lie.

The service doesn't have to be clinical to benefit from SDM

Measurement in other non-clinical solutions is still a strategy to support SDM and does not require that your solution provide clinical intervention. For instance, using screening tools to assess dimensions of SDoH may place a young person at risk for poorer mental health and can be used to initiate a collaborative discussion about challenges and/or strengths. The discussion might include exploring that young person's knowledge and awareness of resources available to them (e.g., educational workshops, after-school programs, in-school peer support, etc.) can guide decisions about which of these options to pursue. As a reminder, not all measurement efforts need to include numbers! Qualitative data and information can absolutely support SDM processes.

Resource Alert

For a deeper dive into the what, when and where of using brief screeners along the care continuum, check out this 11-page guide we've developed on this very topic as well as our curated menu of suggested measurement tools to get you started.

SDM Beyond Clinical Delivery Solutions

Dear Innovators,

Measurement doesn't need to be limited to clinical service delivery solutions to support some of the principles around SDM. Though we wouldn't pass a dissertation defense using this same terminology, we certainly encourage youth-focused innovators to explore the opportunities for measurement to help facilitate collaboration on what will help address the mental health needs of youth, sharing information bi-directionally, and deciding what path to take.

Survey data as a pathway to SDM

To state the obvious, survey data about youth mental health is critical for identifying priority areas of focus for prevention, intervention and solution-design, research, system innovation, and policy efforts. We see this especially in large scale survey data efforts. There are significant opportunities for SDM in youth innovation here, that move beyond youth simply providing the responses to these surveys. Instead, supporting SDM pathways with survey data can look like:

- Youth actively participating in survey development, identifying the themes and topics to be evaluated, the kinds of questions to ask, and how best to engage youth who will ultimately complete these surveys
- Sharing data back with youth, and engaging youth actively in the data interpretation process, including how to best contextualize and understand unexpected trends and findings
- Collaborating with youth to design recommendations about how to use survey data insights to shape intervention efforts

And just really quickly, if you're worried that SDM requires you to do large scale survey data, fear not. Innovators at every stage of the game can apply these same principles to any data that they're looking to collect. For example, you may want to do a series of listening sessions within your organization, or within a group of youth you've identified. You could have youth participate in crafting the listening session prompts including identifying how best to ask for the information you need, develop a plan to share the information you've gathered from the listening sessions back to the youth who participated (think presentation, video, infographic, the possibilities are endless), and then invite youth to collaborate on designing next steps based on what you learned. By now, you may be clocking that this process feels like a first cousin to co-design. And you'd be right! Here, the measurement is holding our hands through the process and giving us some of the structure we need for intentional youth inclusion.

AAP Case Study

When the AAP gave us a mini-master class and roadmap for SDM in digital engagement

As I hope is clear, the strategies for using measurement to facilitate aspects of SDM described above are not limited to quantitative survey data. The idea is to ensure that youth are participating in decisions around care (and solutions designed to support their wellbeing), that data are bidirectionally shared, and that youth are collaborating with different stakeholders to make decisions about how to move forward.

For example, involving youth in measurement design, collection and interpretation can and should be used to facilitate these broader SDM principles in other scenarios. Take for example, the American Academy of Pediatrics Center of Excellence on Social Media and Youth Mental Health, who recently engaged youth in a multi-pronged effort to define metrics that might be useful in understanding wellbeing for digitally engaged youth.

- Youth were actively engaged in problem identification (i.e., wellbeing in digital spaces requires a creative approach to measurement) and weighed in on the expert voices to draw perspective from (e.g., non-profits, social media and AI researchers, digital wellbeing organizations, youth engagement groups, etc.)
- Data was shared back to youth, who then participated in distilling themes from qualitative interview data
- And finally, youth participated in defining recommendations for wellbeing metrics (e.g., platform usage data metrics such as speed of return to an app following a nudge, reporting behaviors, etc.)

In turn, data from these wellbeing metrics can be used to support recommendations to guide a variety of next steps including development of digital media safeguards, future youth-focused solutions or interventions to support digital wellbeing, and more.



SHARING IS HARD: A FEW CHALLENGES TO KNOW BEFORE YOU GO

Hopefully, you've been nodding your head along in emphatic agreement, as you've reviewed this brief appeal to SDM. You'll recall however that sharing is hard. Here is a non-exhaustive summary to give you the heads up on some factors that can get in the way of SDM going as smoothly as we might imagine.

- Shocking no one, youth and adults (caregivers and providers) do not always agree and aligning perspectives can be challenging (again, measurement data are so helpful here!)
- SDM does not mean that youth and family preference is the only consideration or that these preferences outweigh evidence-based recommendations
- The grown-ups (caregivers and providers alike) may struggle to toe the line between adult-driven approaches to 'final decisions' and truly incorporating youth input
- Youth need transparency about where their input holds sway and factors that might lead to an alternate decision or arrangement, especially within treatment and intervention settings
- Be prepared to address any organizational or practical limitations about what kinds of decisions are actually on the table for youth
- Youth are not a monolith, their needs are fluid, and getting broad representation about those needs is challenging
- Many of the things that we know are important from the youth perspective to measure are not included in decisions about what gets funded and what does not

Measurement cannot solve all of the potential challenges to implementing SDM in youth behavioral health interventions and innovation. But it does offer objective and concrete strategies to put these core principles into practice. We can use measurement as a compass to kickstart our ability to really share decisions, which if you think about it, helps to move measurement past a conversation about outcomes and effectiveness, to one about collaboration, strategic and intentional design, and shared power. And, we really like that thought.

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