O'NEILL INSTITUTE
CENTER FOR ADDICTION & PUBLIC POLICY

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SAMHSA Reports Clearance Officer
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RE: Agency Information Collection Activities: Proposed Collection; Comment Request (89 FR 66429)

The Center on Addiction and Public Policy at Georgetown Law's O'Neill Institute works to advance a public health approach to substance use disorder and the overdose epidemic through legal and policy strategies that promote evidence-based treatment and support recovery.

We would like to thank SAMHSA for the opportunity to provide input on the proposed Unified Client-level Performance Reporting Tool (SUPRT). We applaud SAMHSA's efforts to improve the consistency of data collected and streamline existing tools into a new tool that will reduce the burden of questions on clients and grantee reporting, and also incorporate new measures that will better capture the breadth of client experiences.

Measuring the diverse experiences of millions of people in recovery is challenging, however, these data are necessary to respond to the needs of community members in or seeking recovery. Performance reporting tools must capture the breadth of an individual's recovery capital, as well as the resources and capacities that enable growth and human flourishing.

To further this goal, we offer the following comments:

1. Ensure the voices of lived and living experience are centered in the development process from the beginning.

This proposed tool will be the lens through which SAMHSA-funded services are delivered. It will shape the goals set by service providers and recipients. It also furthers the foundation for nationally recognized and validated measures of recovery that will spur innovation in service delivery and payment models. A wide and diverse range of experience must, therefore, be involved at every stage as outcomes measures, recovery metrics, and related tools are developed. This input is critical to capturing the full range of experiences of people who use substances and/or who have a substance use disorder and their families.

If SAMHSA's process for developing this tool did not involve meaningful and sustained engagement of a wide range of people with lived and living experience from the beginning, we strongly urge SAMHSA to restart the process and include those perspectives at every stage. Alternatively, we urge SAMHSA to consider adopting an existing, validated tool that measures recovery capital, such as the Brief Assessment of Recovery Capital (BARC-10).

2. SAMHSA's Office of Recovery must lead the development of any new tool seeking to measure recovery capital and outcomes, and SAMHSA's Office of Behavioral Health Equity must be strongly involved.

The role of SAMHSA's Office of Recovery is to "advance recovery across the nation, forging partnerships to support all people, families and communities impacted by mental health and/or substance use conditions to pursue recovery, build resilience, and achieve wellness."[1] This tool is one initiative of many that reflects a larger shift towards a recovery-oriented system of care. The Office of Recovery is leading that effort, and this tool must be part of that strategy. As such, we believe that SAMHSA's Office of Recovery must lead the development of any new tool seeking to measure recovery capital and outcomes.

It is equally important that SAMHSA's Office of Behavioral Health Equity advises the process of developing recovery measures and related tools, as this work must be approached through a health equity lens. American Indians, Alaska Natives, and Black people are among the demographics experiencing disproportionately higher rates of overdose mortality, and have long experienced barriers to care due to historical trauma and lack of culturally responsive services.[2] In addition, demographic groups such as older Americans, pregnant and parenting persons, veterans, and others have unique challenges and perspectives that should be considered in the development of metrics. To properly measure recovery outcomes, SAMHSA should ensure the perspectives of a wide range of communities help shape the development of this tool. SAMHSA's Office of Behavioral Health Equity is central to this role.

The response to our nation's addiction crisis has not reflected the diversity of our Nation, thereby exacerbating existing barriers to recovery experienced by people of color. Research, data collection, and initiatives must be intentionally inclusive for all people. Representation matters in recovery. When someone enters a space and doesn't see people who look like them, or when they experience an assessment or treatment modality that was clearly not built for them, they might turn around and in many cases not come back. Being intentional about creating inclusive recovery measures will show people that recovery is possible for everyone and not just a few.

3. The tool should measure recovery, not just social determinants. Established and tested recovery capital scales should be used as a guiding resource when developing recovery outcomes.

SAMHSA should consider modifying or reframing the statements outlined in the proposed tool to better reflect recovery, not simply account for the presence of social determinants of health. Recovery and social determinants are not necessarily the same thing. For example, in the section on "Client-Reported Core Outcomes of Recovery," statement #4 "I have stable housing" can be closed-ended with no room for understanding a person's recovery. Sure, they may have stable housing, but are they living in a supportive and loving household? It could be an abusive and unsafe environment, albeit "stable." To better understand whether someone's housing is conducive to their recovery, the statement might be amended to: "My housing situation supports my recovery" or, as stated on the BARC-10, "My living space has helped to drive my recovery journey."[3] This recovery-oriented framing would better capture whether someone has achieved this important outcome and, most importantly, whether it supports their recovery. All measures in this section should be revisited with a recovery lens that looks beyond mere presence of social determinants of health.

Resources which share the priorities of people with lived and living experience should be consulted in the development of recovery measures and related tools. Research findings from a national examination of treatment outcomes prioritized by people with substance use disorders show individuals with substance use disorder care most about survival, improving their quality of life and mental health, reducing harmful substance use, meeting their basic needs, increasing their self-confidence, and increasing their connection to ongoing services.[4] The measures developed to be included in this tool must be able to shed light on these important outcomes.

There are a wide range of existing validated recovery readiness and measurement tools that can be adapted to fit the needs of the SUPRT. Examples include the Recovery Capital for Adolescents Model (RCAM), Multidimensional Inventory of Recovery Capital (MIRC), Brief Assessment of Recovery Capital (BARC-10), and the Recovery Capital Index. These scales are cognitively tested and there are years of data to evaluate whether the language of the measures is accessible and useful.[5,6,7] SAMHSA should consider incorporating and attributing the measures found in existing tools into this one.

SAMHSA should also consider incorporating findings from research developed by the NIDA-funded Consortium on Addiction Recovery Science (CoARS), which aligns research and programming by including goals to increase infrastructure and harmonize data measures to advance research on addiction recovery services.[8]

4. Language in this tool should be accessible and easily understood.

Any tool developed for collecting information from people should use language that is simple and easily understood. This can help make this tool accessible to more people. When a person is able to understand the questions being asked of them, they are able to provide a more accurate account of the information this tool seeks to collect.

It is also important that questions being asked are able to obtain insights about issues that people with substance use disorder care most about as it relates to their recovery experience. For example, in the question, “Which goals do you have for participating in this program? Check all that apply.” One of the listed choices in the adult section is “be a better parent or caregiver.” This question may not ask what is precisely relevant to respondents. While gaining parenting skills may be one narrow goal of parents who have substance use disorders, four in 10 out-of-home placements have parental substance use listed as a factor.[9] This indicates that many parents experiencing substance use may not have current custody of their children. Therefore, a more representative and pressing goal to include is “get my kids back” or “custody of my children.” To adopt questions which are accessible and relevant, it is essential to use validated tools and partner with diverse advisory committees, which include people with lived and living experience.

5. Outcomes and goals need to recognize that cessation of use, not just reduction, is the goal and desired outcome for many people.

We appreciate SAMHSA’s efforts towards creating a culture of belonging that includes the lived and living experiences of all pathways of recovery, including people for whom complete abstinence or

cessation of alcohol and drug use is not the ultimate goal. However, it is equally critical to capture the goals and experiences of those who desire to cease use of drugs and/or alcohol entirely. Question #14 under Client-Reported Core Outcomes of Recovery, for example, provides a checklist for the client's goals of receiving services. It only lists reduction of use as a possible goal. This should be modified as follows: "Reduce or cease my drug and/or alcohol use" This modification will better capture the goals of a broader range of people, including those who wish to cease their substance use entirely.

Additionally, under Client-Reported Core Outcomes of Recovery, statement #3 states "I am in control of my substance use" and uses a Likert scale to obtain client or patient responses. Studies have suggested that substance use is underreported in primary care and research settings, therefore, reports of "I am in control of my substance use" may result in underreporting.[10] The impact of screening is life altering for some as it provides an avenue for brief intervention and referral to treatment. While the statement may seek to understand the severity of one's substance use, the statement used as a measure of recovery may be flawed in that many people who believe they are in control of their substance use may actually not be. It also presumes that the goal of services or treatment should be to control one's substance use. For many people, the goal is cessation of substance use.

This statement could be more inclusive by reframing in a similar way as statement #6 from the Brief Assessment of Recovery Capital (BARC-10) that states "I regard my life as challenging and fulfilling without the need for using drugs or alcohol," which may be a more useful Likert measure on a scale from strongly disagree to strongly agree.

6. The youth social drivers of health included in this tool are not unique to youth.

The "Social Drivers of Health" section in the proposed SUPRT Client Level Tool's youth section currently asks all the same questions being asked of adults. Many of these questions are not applicable to youth and should be modified to reflect the specific drivers that youth experiencing substance use disorders face. For example, in question #3 "What is the highest level of education you have finished?" There is a response, "4-year degree or higher." Because this section is for 12-17 year olds, this response does not apply to that population. We recommend removing this answer, and, more generally, we suggest tailoring questions to youth both in content and adapting the reading level to be accessible to 12 year olds would yield responses that more appropriately represent the population targeted in this section. Adolescents may experience substance use differently than adults. One example is the estimation of rates of substance use for unhoused adolescents compared to all ages of unhoused people. The estimation for the general population of unhoused people is 16 percent, while the estimation for unhoused teens is somewhere between 39 and 70 percent.[11,12] The tool should be modified to reflect youth-specific social drivers of health.

7. This tool should provide youth-specific Client-Reported Core Outcomes of Recovery.

SAMHSA should consider developing and including youth-specific recovery outcomes. As proposed, there are no metrics for youth in this tool. Such outcomes should be designed and developed with the input of youth and young adults throughout the process.

Existing recovery capital scales such as Recovery Capital for Adolescents Model (RCAM), adapted the adult-focused Recovery Capital model to the adolescent experience, and SAMHSA should consider doing the same. When adapting the RCAM, specific components of recovery capital were modified to be more relevant to youth.[5] For example, instead of focusing on education generally, the tool focuses on high school engagement, for financial capital components it is about their caregiver's financial capital, for social capital, having supportive friends was a special focus for adolescents, and for community capital, having special recovery meetings and recovery supportive school environments were especially relevant to youth. It is important that youth outcomes are captured as it reflects a critical time of development and an opportunity to evaluate key interventions.

8. This tool underscores the need for programming in SAMHSA-funded services to shift beyond a focus on just delivering treatment to one that prioritizes and incorporates recovery-oriented services and supports

Our systems are primarily organized and funded to deliver treatment, not to deliver the long-term support needed to sustain recovery. Research has recognized that "screening for circumstances without the capacity to ensure referral and linkage to appropriate treatment is ineffective and, arguably, unethical," and that, when social factors are included in screening, they must be accompanied by a strategy that is patient centered and strengths oriented and include linkages to services beyond the medical home.[13]

If we are measuring recovery, our systems must shift to support recovery. Recovery is about healing the whole person, and treatment is just one part of that. Treatment is not a person's ultimate goal, it is a mechanism for achieving broader outcomes like family reunification, social and economic mobility, emotional and financial stability, and a whole array of big and small dreams that bring someone a sense of purpose and belonging. Cycling people with mental health and substance use disorders through a treatment-oriented system of care without a plan or ability to address the broader frame of health, home, community and purpose isn't a model that supports recovery. Measuring these elements isn't enough - the system has to be re-imagined for the goal to be *recovery*, not simply treatment completion or adherence. The goal should be a system of care that recognizes the humanity of people, restores the dignity they deserve, and creates an opportunity for people to live full and meaningful, self-directed lives in their communities.

Thank you for the opportunity to comment. Please contact Shelly Weizman at shelly.weizman@georgetown.edu with any questions about our comments.

Sincerely,

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