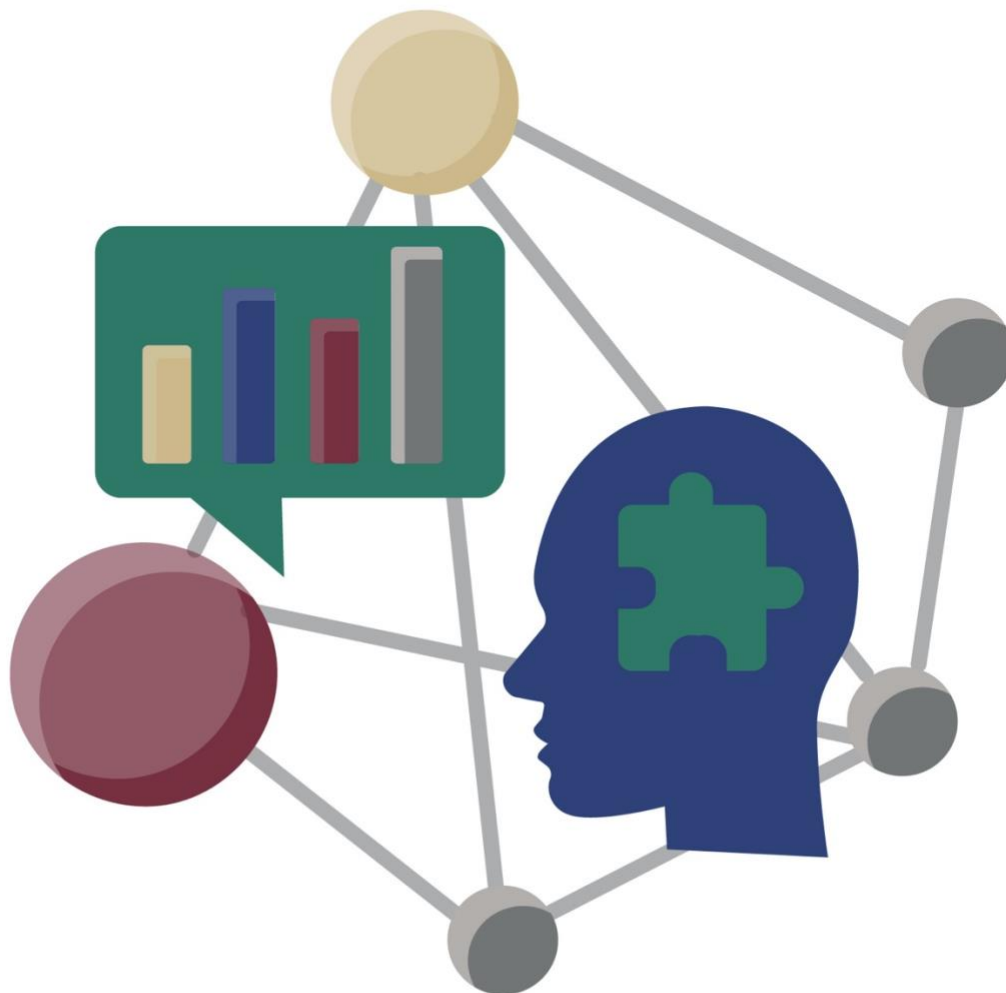




# Behavioral Health Literacy

## A NEW CONSTRUCT TO IMPROVE OUTCOMES AMONG JAIL RESIDENTS

Carrie Pettus, PhD, MSW | Stephanie Kennedy, PhD, MSW  
Tanya Renn, PhD, MSSW, MPH | Stephen Tripodi, PhD, MSSW  
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## **Behavioral Health Literacy**

### **A New Construct to Improve Outcomes Among Jail Residents**

Millions of people cycle into and out of local jails each year with significant negative public health consequences across the US. Jail residents have disproportionate rates of behavioral health disorders (BHDs); untreated BHD symptoms bring people into jail settings and are associated with re-arrest after release. Although lack of motivation to seek out and engage in BHD treatment is often used to explain these outcomes, individuals may have limited knowledge about BHDs and their symptoms, when and why treatment is warranted, and how to access treatment. We propose a new construct called behavioral health literacy to facilitate linkage between individuals with BHDs and appropriate treatment options. In this paper, we define behavioral health literacy, review extant literature, describe why behavioral health literacy is needed, and explore how behavioral health literacy interventions may be developed to expand research knowledge and guide both policy and practice in the field.

***Keywords:*** Behavioral Health Literacy, Jail Residents, Incarceration, Reentry

Millions of people cycle into and out of local jails each year with significant negative public health consequences across the United States.<sup>1</sup> Individuals who come into contact with the jail system have disproportionate rates of mental health and substance use disorders, otherwise known as behavioral health disorders (BHDs).<sup>2</sup> Symptoms of BHDs increase risk for individuals to come into the jail system, incarceration often worsens individuals' symptoms during custody, and untreated BHD symptoms are associated with increased rates of re-arrest after release.<sup>3</sup> Further, because incarceration disproportionately affects individuals of color, incarceration both creates and exacerbates the documented BHD racial health disparities.<sup>4</sup> These racial health disparities extend beyond individual jail residents to negatively affect their intimate partners and children, which shapes community health and fuels generations of health disparities.<sup>5</sup>

Although the total prison population has declined somewhat since 2008, the overall jail population has remained relatively stable.<sup>1</sup> Stark geographic variation in the use and growth of jails is also noted, with jail populations decreasing in urban jurisdictions and skyrocketing in rural communities over the past decade.<sup>6</sup> Few jails provide screening or treatment for BHDs to their residents, citing challenges with capacity and logistics.<sup>7-9</sup> However, as incarceration is one causal factor in the United States' widening health inequalities, activating jails as a leverage point for screening and intervention represents a profound missed opportunity.<sup>5</sup> Jails could be leveraged to prevent the worsening of BHD symptoms for millions of individuals and reduce behavioral health disparities by providing services during jail custody, connecting individuals to treatment after release, or providing self-management skills to enhance coping when no treatment is available. The churn of incarceration, release, and reincarceration will not be disrupted without addressing many common BHD symptoms, which often bring people into contact with the criminal justice system.

One common misperception about individuals with BHDs who make contact with the criminal justice system is that they lack motivation to seek out and engage in BHD treatment in both jail<sup>10</sup> and community settings.<sup>11</sup> This notion is often used to explain low rates of treatment access and engagement in the community among justice-involved populations.<sup>12</sup> However, low BHD help-seeking and treatment engagement among this population may be better explained by individuals' limited understanding of BHDs and when and how to access appropriate treatments. For example, instead of having an established system for assessing and treating BHDs in jails, jail residents are often responsible for recognizing their own BHD symptoms, understanding their own treatment needs, and then identifying and accessing existing community resources after their release. Thus, even a highly motivated individual simply might not be capable of searching out, accessing, and engaging in treatment.

To bridge this gap, we propose a new construct called behavioral health literacy to guide intervention development and facilitate linkage between individuals with BHDs and appropriate treatment options. Behavioral health disorders include both mental health and substance use disorders. We define behavioral health literacy as an individual's capacity to obtain, process, and understand basic behavioral health information and to become aware of supports, symptom

management, services, and treatment options for helping to redress potential negative impacts of BHDs. The purpose of the construct is to guide the development, implementation, and testing of interventions to increase knowledge about BHDs and their symptoms, facilitate linkage to treatment when appropriate, and ultimately improve both behavioral health outcomes and reduce criminal justice system involvement among this population. This definition builds upon the health and mental health literacy literature and fills substantive gaps in both constructs. In this paper, we provide a review of extant literature on mental health and health literacy, describe why behavioral health literacy is needed, and explore how behavioral health literacy can expand research knowledge and guide both policy and practice in the field. We end by proposing a staged behavioral health intervention research agenda for building out behavioral health literacy scholarship and interventions in jail settings.

## **BACKGROUND**

### **BHDs among jail residents**

More than 11 million individuals cycle through local jails every year, nearly 7 million of whom have BHDs.<sup>8</sup> Just under 65% of jail residents have been identified as having a mental health disorder, compared to just 19% of individuals in the general public.<sup>8,13</sup> Substance use disorders are also reported at epidemic rates among jail residents with national prevalence data indicating that 63% percent of jail residents meet criteria for substance use disorders.<sup>14,15</sup> In contrast, the prevalence of substance use disorders among members of the general public are estimated at 12%.<sup>9</sup> Comorbid BHDs are also extremely common, with 41-68% of incarcerated samples being identified as having both a mental health and substance use disorder,<sup>16,17</sup> which is significantly higher than non-incarcerated individuals.<sup>8</sup>

Individuals with BHDs are more likely to be incarcerated for crimes associated with public nuisances, homelessness, and being under the influence of drugs and alcohol; these individuals are also more likely reincarcerated for violating the terms of their probation.<sup>12,18-20</sup> When compared to individuals charged with similar crimes who do not have BHDs, those with BHDs also tend to be held pre-trial (versus releasing to the community to await a future court date) and to receive longer sentences.<sup>21</sup> After release from incarceration, individuals with BHDs are reincarcerated more quickly when compared to those without BHDs.<sup>22,23</sup> Women with BHDs are 16% more likely to be reincarcerated after release when compared to their peers without BHDs.<sup>22</sup> Further, individuals with substance use disorders are increasingly likely to make multiple contacts with jails and prisons. For example, more than half (52%) of incarcerated adults with substance use disorders have at least one prior incarceration compared to fewer than a third (31%) of those without substance use disorders.<sup>22,23</sup> Individuals with substance use disorders are reincarcerated more quickly after release from incarceration; 20-25% of those with substance use disorders are reincarcerated within the first year after release<sup>19</sup> compared to 9-12% of those without substance use disorders.<sup>24</sup> Approximately 68% of individuals released from county jail who have co-morbid mental health and substance use disorders end up being reincarcerated within four years, a much higher rate when compared to individuals with either a

mental health disorder or a substance use disorder and compared to those without a BHD.<sup>3</sup> Simply put, untreated BHD symptoms fuel the churn of incarceration and reincarceration for many individuals who make contact with jails.

The presence and impact of BHDs have serious consequences beyond criminal justice system-involvement for jail residents. Suicide is the leading cause of death for incarcerated individuals,<sup>25-28</sup> with estimates suggesting that suicide comprises between 34-50% of all deaths which occur in custodial settings.<sup>29</sup> The highest reported rates of suicide are among jail residents.<sup>28</sup> Further, the days and weeks following release from incarceration also carry extraordinarily high risk for death. Individuals leaving incarceration are 12.7 times more likely to die in the two weeks following their release when compared to other state residents.<sup>30</sup> These deaths are driven by drug overdose fatalities, with estimates suggesting that individuals leaving incarceration are 1290% more likely to have a drug overdose fatality in the two weeks after release when compared to other members of the community.<sup>30</sup> Physical illness, homicide, suicide, and motor vehicle accidents are additional drivers of death after release from incarceration<sup>31</sup>; the relative risk for death is highest among women (RR=5.5), younger individuals (those aged 25-34 at the time of release; RR=4.8), and those identified as White (RR=3.8).<sup>30</sup>

### **Screening and treatment for bhds in jails**

Despite high prevalence of BHDs among jail residents, only a third of jails provide any screening for BHDs at any point during custody.<sup>7</sup> While jails may offer some mental health and substance use programming in the form of 12-step self-help groups or educational programming, 66% of jails offer no professional services.<sup>7-9</sup> Additionally, behavioral health treatment access during jail custody varies by county size; although 35% of jails in urban jurisdictions and 24% of suburban jails offer any professional BHD treatment, these services are available in only 18% of rural jails - the location where the jail population has increased dramatically over the past decade.<sup>32</sup>

Further, jails do not typically have BHD treatment programs where individuals can access services outside of confinement through community-based supervision programs. In a recent study, 13% of small counties (fewer than 50k residents) offered BHD treatment out of confinement.<sup>32</sup> Treatment access for individuals incarcerated in jails is thus restricted by the jails' treatment capacity, the inability of jails to seek insurance reimbursement for services provided during custody, and limited quality of community approaches.<sup>9</sup> Although jail residents are sometimes mandated to receive community-based BHD treatment after release (e.g., they release to probation or other forms of community supervision), in general, the system relies on the majority of individuals to recognize their own BHD symptoms, identify suitable community-based treatment options, and pursue treatment on their own. Although the absence of accessible community-based BHD treatment providers in many areas is well-documented, it remains unclear whether individuals leaving incarceration are able to recognize any symptoms they might be experiencing as symptoms of a BHD, thus complicating their ability to seek appropriate treatment in the community.

## WHAT IS BEHAVIORAL HEALTH LITERACY?

We define behavioral health literacy as an individual's capacity to obtain, process, and understand basic behavioral health information and to become aware of supports, symptom management, services, and treatment that are options for helping to redress potential negative impacts of BHDs. The purpose of the behavioral health literacy construct is to guide intervention development that are designed to help individuals recognize their own symptoms of BHDs and to seek out potential avenues to decrease their symptoms and optimize their well-being. We developed this definition after a comprehensive examination of existing literature on both health literacy and mental health literacy. Below, we examine the state of the literature and identify the critical gaps to which the proposed definition of behavioral health literacy responds.

### Health literacy

Health literacy intervenes on an individual's capacity to obtain, process, and understand basic health information and what services are needed to make appropriate health decisions.<sup>33,34</sup> The health literacy construct was developed in the 1970s and was initially understood as a function of literacy. Health literacy was developed to gauge an individual's ability to recognize physical health conditions, seek out and comprehend information about those conditions, and understand and adhere to medical professional's treatment recommendations.<sup>33,35,36</sup> In 1992, the American Medical Association defined health literacy as the "ability to read and comprehend prescription bottles, appointment slips and other essential health-related information required to successfully function as a patient." This definition was expanded by the World Health Organization in 1998 to include the "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health."

More recently, the health literacy construct has been expanded to include individuals within the context of the health systems with which they interact.<sup>34,37</sup> Health literacy is now understood as a mechanism for not only improving individual health outcomes, but also for decreasing population-level health inequities, developing health policy, and improving health systems to maximize accessibility. The World Health Organization (2013) further identifies health literacy as possibly the most potent predictor of many social determinants of health, noting how health literacy is "a stronger predictor of an individuals' health status than income, employment status, education and racial or ethnic group" (p. 7). By including systems-level factors, health literacy has transformed into an asset that can be developed and enhanced through education, rather than a simple risk factor for poor health outcomes based on an individual's failure to adhere to treatment recommendations.<sup>36</sup>

Low health literacy is a significant problem in the United States, affecting an estimated 36% of adults in the general population.<sup>38</sup> Low health literacy is linked to poorer management of chronic disease symptoms, lower preventive care access, and higher rates of hospitalizations.<sup>39-41</sup> Health literacy among incarcerated populations is exceptionally low, with estimates suggesting that 60% of those incarcerated have low health literacy. However, systematic reviews find that

health literacy interventions are promising and lead to positive outcomes such as increased preventive care access, medication adherence, and lower rates of emergency department use for a variety of at-risk or marginalized populations.<sup>42,43</sup> Thus, research on improved outcomes related to health literacy interventions underscores the potential positive impact that behavioral health literacy interventions could have for people with BHDs. literacy.<sup>44</sup> Health literacy is also suggested as a mediator to explain existing racial health disparities in many common physical health outcomes, underscoring the need to increase health literacy among those at highest risk.<sup>40</sup>

### **Mental health literacy**

Mental health literacy<sup>45</sup> is mostly focused on helping those without BHDs to recognize the signs and symptoms of mental health disorders in other people and helping to guide others to community supports or treatment.<sup>36</sup> When mental health literacy interventions are implemented, findings suggest that improving symptom recognition among individuals without BHDs does increase help-seeking in the community by their loved ones, coworkers, and peers with BHDs.<sup>46</sup> Jorm and colleagues<sup>46</sup> proposed the mental health literacy construct in 1997, and, like health literacy, the definition of mental health literacy has been refined somewhat since that time. Jorm<sup>46</sup> coined the term mental health literacy and defined the construct as the public's "knowledge and beliefs about mental disorders which aid their recognition, management or prevention" in other individuals (p. 182). Further, Jorm and colleagues<sup>46</sup> suggested that mental health literacy "includes the ability to recognize specific disorders; knowing how to seek mental health information; knowledge of risk factors and causes, of self-treatments, and of professional help available; and attitudes that promote recognition and appropriate help-seeking" (p. 182).

Jorm<sup>46</sup> later expanded this foundational definition to include knowledge about specific mental health conditions to aid prevention, early recognition, self-help strategies for mild-to-moderate symptoms, and how to provide help to aid others, especially those approaching a crisis state. Other dimensions of the mental health literacy construct include a consideration of those skills, capacity, and cognitions which might promote positive mental health for individuals in the community and enacting health policies designed to promote population-level well-being.<sup>36</sup> More recently scholars have proposed another dimension of mental health literacy to include addressing stigma because they hypothesize that stigma drives prejudiced attitudes and discriminatory behavior towards those experiencing acute or chronic symptoms.<sup>47,48</sup>

Although the mental health literacy construct has significantly advanced knowledge and interventions for using social support to help those with mental health disorders identify their symptoms and seek treatment, we believe this approach is limited because it does not usually intervene with the individual themselves experiencing the mental health disorder. Furthermore, despite high levels of comorbidity, substance use disorders are given cursory attention in both health literacy and mental health literacy research.<sup>46</sup> This represents a clear gap as substance use disorder symptoms are associated with criminal justice system contact.

## **WHY BEHAVIORAL HEALTH LITERACY IS NEEDED**

The World Health Organization examined data from 28 developed and developing countries and found that only a minority of individuals received treatment within the first year of BHD symptom onset.<sup>49</sup> Ample evidence underscoring the significant role that BHDs play in an individual's trajectory toward incarceration in jail and re-incarceration in jails after release. Limited screening, assessment, and treatment of BHDs in jail settings are likely only one contributor to the intersection of BHDs and incarceration. It is likely that even when individuals are screened, assessed, and referred to treatment for BHDs - in jails or in communities - they may lack a fundamental understanding of how BHD symptoms impact their lives and may not know how to manage their BHD symptoms or communicate to others that they have a BHD. Health literacy interventions, and to a lesser degree, mental health literacy interventions, have made positive impacts on vulnerable and marginalized populations. Yet, health and mental health literacy interventions are limited by their relative silence on substance use disorders - a key component of BHDs. Although some scholars may include substance use disorders under the mental health construct umbrella, mental health literacy interventions give no more than cursory attention to the experience of substance use disorders and their symptoms. Given that substance use disorders are present in the majority of jail residents and that substance use disorders are highly intertwined with crime, silence on this topic from a literacy training perspective cannot be sustained. Moreover, unlike the approach used for mental health literacy, literacy for BHDs must be focused on helping the individual experiencing the BHD to recognize, understand, and take action to address their own BHD symptoms. That is because jail residents are isolated from their loved ones, other social supports, and formal systems of care while incarcerated. But this isolation does not end when individuals are released from jail. Once individuals are released from jail isolation continues because of the disruption incarceration has caused, stigma that may lead to fissures in social ties, closed doors to treatment options due to criminal convictions or other factors in their criminal justice history, and the numerous court and corrections systems obligations they may have to fulfill, leaving little time and energy to seek out information or treatment options. Former jail residents must be able to understand and manage symptoms of BHDs and communicate to others what they are experiencing to navigate complicated life circumstances as best as possible. It is not enough for all of those around them to understand BHDs if the individuals themselves are not deeply knowledgeable about a condition that could make or break their success after an incarceration experience.

Of course, not all jail residents will need behavioral health literacy. Some jail residents may have extensive experience with treatment and high levels of knowledge about BHDs. Therefore, behavioral health literacy assessments are also needed to determine whether an individual has a need for a behavioral health literacy intervention. We were not able to find research on assessment tools for self-understanding and management of one's BHD. Therefore, the behavioral health literacy constructs provide a starting point for the development of behavioral health literacy measurement tools. Like the health literacy and mental health literacy constructs, the overarching goal of behavioral health literacy is to shorten the time to help-seeking and help people to manage their symptoms most effectively.



Behavioral health literacy may be a key mechanism to reduce morbidity and mortality rates as health literacy interventions conducted with incarcerated individuals have shown positive impacts on chronic disease management.<sup>44,50,51</sup> Intervening with this population is critical as jail residents are disproportionately low income, undereducated, drawn from highly marginalized and disadvantaged communities, and report high rates of trauma.<sup>12,52,53</sup> Behavioral health literacy may improve coping with both life stressors and the stress of the incarceration experience, as incarceration exacerbates BHD symptoms.<sup>54</sup> Although BHD symptoms play a critical role in the future health and success of individuals, few incarcerated individuals or their loved ones can identify BHD symptoms and initiate the process for connecting to community-based behavioral health treatment services. Addressing this syndemic of issues requires the design, implementation, and testing of responsive interventions to increase behavioral health literacy among individuals in jail-based settings and their loved ones at home to increase service utilization and disrupt the churn of incarceration, release, and reincarceration among individuals with BHDs.

## **DISCUSSION**

Identifying new supports for incarcerated adults with BHDs is urgently needed and may reduce disease burden and allow individuals to thrive in the community after release. Although the prevalence and impact of BHDs for this population are well documented, it is less clear whether lack of behavioral health literacy - rather than low motivation - are complicating individuals' ability to access community-based BHD treatment providers or other necessary supports for their success. The behavioral health literacy construct was designed to guide assessment and intervention development as a potential mechanism for increasing an individual's capacity to recognize their own symptoms of BHDs and seek out needed community and social supports.

We propose a staged behavioral health literacy intervention agenda using the ORBIT model, suggested by the Office of Behavioral and Social Science as a guide for developing behavioral and social systems interventions to improve health outcomes.<sup>55</sup> Although the model was designed to guide obesity interventions, the fundamental principles of the ORBIT model easily translate to other facets of behavioral and social sciences research. ORBIT is a rigorous translational process which increases the likelihood that carefully defined, refined, community-engaged, and scalable interventions, programs and policies, developed from a strong foundation of basic behavioral and social science research, are successful in full scale trials.<sup>56</sup> In order to advance knowledge on behavioral health literacy and to develop behavioral health literacy interventions, we suggest the following steps are needed. First, a descriptive study of jail residents' current knowledge of BHDs – their origin, symptoms, consequences, strategies for management, and options for support is needed. Second, development of a behavioral health literacy measurement tool is needed. Third, building on the evidence base from health literacy and mental health literacy, behavioral health literacy intervention manuals should be developed.

Then, pilot feasibility and acceptability studies can be conducted to further refine the intervention manuals. Once the manuals are refined, efficacy trials can be conducted to see if effectiveness trials are warranted. During experimental trial stages key intervention ingredients should be identified as well as subpopulation analysis to determine whether behavioral health literacy interventions needed to be tailored by race, gender, age, or region of the country. Using this systematic and staged approach to intervention development, we will be able to understand the extent to which behavioral health literacy may be contributing to the revolving door of incarceration for those with BHDs as well as what intervention approaches may have the most potent impact on disrupting that cycle.

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