

Strategies for Staying in Care

Enhancing Engagement and Improving Treatment Retention in Mental Health Services



2026
*MENTAL HEALTH
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Strategies for Staying in Care: Enhancing Engagement and Improving Treatment Retention for Adults with Serious Mental Illness

Strategies for Staying in Care: Enhancing Engagement and Improving Treatment Retention for Adults with Serious Mental Illness was prepared for the Substance Abuse and Mental Health Services Administration (SAMHSA) under Task 2.2 of NASMHPD's Technical Assistance Coalition contract/task order HHSS283201700024I/75S20321F42001. Asha Stanly served as contracting officer representative.

Recommended Citation

Substance Abuse and Mental Health Services Administration: *Strategies for Staying in Care: Enhancing Engagement and Improving Treatment Retention for Adults with Serious Mental Illness*. Publication No. PEP26-01-002, Substance Abuse and Mental Health Services Administration, 2026.

Originating Office

Substance Abuse and Mental Health Services Administration, 5600 Fishers Lane, Rockville, MD 20857, SAMHSA.

Electronic Access

This publication may be downloaded from <https://library.samhsa.gov>.

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Publication No. PEP26-01-002

Released 2026

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ABSTRACT

Sustained treatment engagement is one of the biggest challenges in mental health and substance use services. All too commonly, treatment disengagement rates are the norm rather than the exception in serving individuals with serious mental illness (SMI), with high rates of appointment no-shows, inconsistent medication adherence, lack of response to the treatments received, and fragmented care delivery systems negatively impacting clinical, social, and system outcomes. Treatment engagement and retention in care are not just individual-level responsibilities; rather, services, systems, and policies can shape how an individual accesses and sustains treatment. Without sufficient resources or effort, these systems can sometimes result in what have been called person-resistant services. This paper will discuss intrinsic and extrinsic motivators of treatment, as well as patient nonadherence and disengagement from services, including the effects of perceived coercion, insight, and the therapeutic alliance. Models for maximizing treatment adherence will be discussed, with a spotlight on recovery-oriented cognitive therapy.

HIGHLIGHTS

- Treatment dropout rates for individuals with SMI after one year can range from 20 to 50 percent, with even higher rates of initial no-shows, depending on the treatment type or definition, as well as on the individual's personal characteristics.
- Insight is used to describe an individual's understanding of their illness, as well as how it affects an individual's interactions in the world.
- Treatment engagement is just as critical for individuals in voluntary services as in involuntary services, as well as for people with a variety of conditions, including psychotic disorders, substance use disorders, and others.
- Perceived coercion (i.e., the perception that treatment was forced upon an individual, whether they were treated voluntarily or under a court order) can impact an individual's sense of whether their treatment was fair.
- A positive bond between the provider and the individual served can be built through trustworthiness or broken right from the beginning of care.
- Recovery-oriented cognitive therapy is one model to support engagement and retention in care.



POLICY CONSIDERATIONS

1. Improving the appeal of treatment will result in more people engaging and sticking with it. Establish warm, welcoming environments that utilize peer support and maximize adaptability and flexibility to clients' needs.
2. Foster a culture that expects retention in services to be part of what drives outcomes, and ensure that this outcome is based on bidirectional effort between the provider and the individual served.
3. When evaluating treatment nonadherence, take inventory of what is meant by nonadherence, and break down barriers into small pieces in order to work with the individual to overcome them.
4. When insight is lacking, consider strategies to maximize external motivators, which can include family involvement, peer support, or court-ordered treatment as potential interventions.
5. A whole-person, theory-driven, recovery-oriented approach to care provides a pathway for providers to connect and make progress with clients who are not treatment-seeking, reluctant to participate, or mandated to care, sustaining long-term treatment retention that drives personally meaningful positive outcomes.
6. Focusing on a person's identity and life goals beyond symptoms, diagnosis, or legal requirements can strengthen intrinsic motivation by connecting treatment to what the person values and wants most for their life, which may enhance engagement and retention.
7. When individuals are lacking in decision-making capacity, such as when they may be experiencing psychosis that causes impaired reasoning, utilizing a variety of means to help ensure they are able to receive treatment can be lifesaving.



INTRODUCTION

Sustained treatment engagement is one of the biggest challenges in mental health and substance use disorder services. Treatment dropout rates can be the norm rather than the exception in serving individuals with serious mental illness (SMI), with high rates of appointment no-shows, inconsistent medication adherence, lack of response to the treatments received, and fragmented care delivery systems all negatively impacting clinical, social, and system outcomes.¹ Individuals who are homeless, living with active symptoms of mental illness, possibly using substances, and who have complex, co-occurring medical and other health risks and cycle between hospitals, emergency departments, jails, and the streets may decline treatment and services, leaving systems and communities frustrated and often at a loss as to how to help them. Despite these individuals' stated choices, it is important to build resources that understand that some of the population will be extremely challenging to engage in care. Yet, treatment engagement and care retention are not just individual-level responsibilities. Rather, services, systems, and policies can shape how an individual accesses and sustains treatment, and are sometimes known as person-resistant services.

Substance Abuse and Mental Health Services Administration's definition of serious mental illness (SMI)

SMI occurs when an individual over 18 years of age has (within the past year) a diagnosable mental, behavioral, or emotional disorder that substantially interferes with the person's life and ability to function. SMIs include conditions like bipolar disorder, major depressive disorder, and schizophrenia.

Treatment dropout rates after 1 year can range from 20 to 50 percent, depending on the treatment type or definition, as well as on the individual's characteristics, with even higher no-show rates after the first couple of appointments.^{2,3} One study noted at least one-third of those with SMIs who start treatment ultimately disengage from it.⁴ Individuals who disengage from services, sometimes because of "person-resistant" services (i.e., services that prioritize the needs of the system rather than the needs of the individual), often end up cycling in and out of high-cost services, including justice involvement. In a seminal review published nearly 20 years ago, it was reported that nearly 60 percent of individuals given a diagnosis of schizophrenia do not show up for the first appointment following hospitalization.⁵

Individuals who are no longer in treatment are at increased risk of homelessness and housing instability, incarceration or other criminal justice involvement, as well as increased use of inpatient psychiatric services.⁶ They often find themselves lacking resources to meet their basic human needs, which can leave them caught in the revolving door of the mental health or justice system.⁷ As a result, this instability and lack of resources for meeting their basic human needs leave individuals faced with



uncertainty and often feeling out of control over their everyday lives. This effect can exacerbate the negative impact of already-poor treatment outcomes.^{8,9}

Across the country, community partners are working to enhance their capacity to retain individuals in services—both on the individual as well as on the population level. Miami-Dade County has taken steps to create new services focused on the needs of individuals who use a disproportionately large percentage of public services but have poor outcomes in care.¹⁰ However, making more care available and readily accessible does not guarantee that individuals will show up or continue participating in services that could empower them.

It can be helpful to consider the terminology that is often used for this phenomenon and its implications (**Table 1**). Noncompliance as a term places the obligation of “complying” with treatment on the person in care, such that when there are gaps, it is the person served who is seen as noncooperative or difficult. This is one reason why shifting language to adherence creates a more neutral, less critical tone, which then helps tease out the factors that may be contributing to the low rates of individuals remaining in care. When there is a court order in place, however, noncompliance can be the more useful phrase, as a court order does legitimately shift the power differential.

Table 1: Definition of Terms

Term	Definition
Engagement	Active and collaborative participation in treatment. The person intentionally and collaboratively takes part in the activities of the treatment protocol, including follow-ups. Also can be seen as an ongoing, healing connection that supports their recovery.
Nonengagement	Minimal or no active participation, intentionally or unintentionally, in treatment. This includes missed or skipped appointments, lack of follow-through with care, attendance without participation, and periods of isolation from care team or providers.
Noncompliance	A term best used when there are power dynamics of relevance such as not following a court’s lawful order, implying negative tone that an order was not followed.
Nonadherence	A term that states factually and without judgment that an individual is not adhering to treatment recommendations.
Disengagement	Complete withdrawal of active participation in care (includes attendance without participation).
Adherence	Follow-through and consistent participation in identified treatment goals and treatment plans.
Retention	Ongoing participation in care across a period of time.

Source: Definitions developed by the authors based on peer-reviewed literature and government reports



Since some individuals choose not to engage or to disengage because they do not see enough benefit to participating in treatment,^{11,12} Lisa Dixon and colleagues propose that both the content and manner of service delivery must change: Treatment should meet each person's needs; be collaborative, recovery-oriented, and person-centered; and include peer support.¹³

Further support for changing the focus of treatment comes from interviews conducted with 50 people who self-identify as having fully recovered from schizophrenia.¹⁴ Three factors best account for what supported their success: (1) growing meaningful connections with others, (2) experiencing purposeful activity daily, and (3) developing effective ways to handle day-to-day stress. They sought out and stuck with care that featured these person-centered, recovery-oriented qualities and strongly advocated for similar treatment for everyone given a diagnosis of schizophrenia.

Connection, purpose, and empowerment are social determinants of wellness for all people, regardless of diagnosis.^{15,16} Not sufficiently integrating these social factors in the lives of people with schizophrenia, according to the best current theorizing and research, predicts a reduction in life expectancy of two to three decades.¹⁷ Furthermore, the genes that are thought to cause the premature aging observed in those diagnosed with schizophrenia can be turned "on" and "off" by environmental factors.¹⁸ Thus, treatment approaches that focus on these social determinants of wellness show much promise because (1) they are what individuals say they want from treatment,¹⁹ which should increase their uptake and retention; and (2) they seem to take great strides in closing the mortality gap²⁰ by helping the highest utilizers of services, as well as others, get the lives they have always wanted. The success of such treatments will be further illustrated below with one such treatment, recovery-oriented cognitive therapy (CT-R).²¹

INSIGHT AND MOTIVATION

Lack of treatment adherence, as well as difficulties in staying in care, in sticking to prescribed medications, or attending clinical appointments are challenges seen in everyday patient care and are not unique to psychiatric services or substance use treatment. However, there are larger factors at play that contribute to adherence and retention in psychiatric services, including insight, motivation, and logistics, as well as factors of the service system itself. It is important to understand these underlying factors in order to design services and systems to promote engagement and treatment retention.

Intrinsic and extrinsic motivators

Motivation is part of being human and drives our exploration with the outside world. Impairments in motivation can be seen in individuals with SMI, which can then impact treatment adherence and retention.²² Intrinsic motivators are those that come from within the individual and involve internal, goal-directed behaviors.



Extrinsic motivators, like external rewards, on the other hand, come from outside the individual and trigger behaviors to obtain these external rewards or to avoid punishment or negative consequences.²³

Both intrinsic and extrinsic motivation are diminished in individuals with SMI and are linked to amotivation and anhedonia, two of the negative symptoms often seen in schizophrenia and sometimes in mood disorders.²⁴ Intrinsic motivators to treatment engagement often involve aligning treatment with one's goals, such as wanting to feel better or achieve certain milestones. Extrinsic motivators include external incentives or pressures, such as avoiding hospitalization, preventing family criticism or rejection, complying with court mandates, or receiving financial rewards. Techniques that foster positive self-views and setting goals, including CT-R (discussed below), focus on intrinsic motivation as a method for increasing treatment engagement. Extrinsic motivation, however, is often also a factor in real-world treatment settings.²⁵

Insight and treatment engagement

Insight describes an individual's understanding of their illness as well as how it affects their interactions in the world. Insight is not bi-directional but rather exists on a continuum, as it is affected by numerous internal and external variables.²⁶ The conceptualization of insight has evolved over the past 30 years, including its effect on treatment adherence.²⁷ The 1990 landmark paper published by Anthony David, a British psychiatrist, proposes understanding insight in three dimensions: First is the recognition that one has a mental illness, second is adherence with treatment, and third is the ability to recognize unusual mental events, such as delusions and hallucinations, as pathological.²⁸ Further work by the psychologist Xavier Amador about a decade later classified insight among individuals with psychotic disorders as awareness of both illness and various symptoms, as well as an understanding of the need for treatment.²⁹ The work of psychiatrist Aaron Beck, recognized as the father of cognitive therapy, later conceptualized cognitive insight, including self-reflection and self-certainty, as an important facet of insight.³⁰ Later, the clinical psychologist Paul Lysaker introduced the concept of narrative insight to describe how individuals make meaning of their experiences, independent of clinical considerations. Lysaker has found that increased insight can actually lead to greater mental health challenges, with increased depression or demoralization in some individuals: Known as the insight paradox, this phenomenon suggests that insight alone cannot drive treatment engagement.³¹

There have been multiple research studies connecting levels of insight and treatment adherence.³² For example, by combining two large clinical trial datasets (The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) and the European First Episode Schizophrenia Trial (EUFEIST)) including in total almost 1,200 patients with schizophrenia, it was found that impaired insight correlated with reduced adherence to pharmacological treatment.³³ In a study of treatment adherence in Veterans with bipolar disorder, greater insight correlated with better



treatment adherence to psychotherapy and pharmacological treatment.³⁴ Further research has elucidated which aspects of insight may impact treatment adherence. A study of 90 patients with schizophrenia found that cognitive insight complements clinical insight and positively affects medication adherence;³⁵ insight, then, is not one-dimensional. Other research suggests that cognitive insight has no impact on treatment outcomes for cognitive training, so impaired cognitive insight should not be a barrier to participating in treatment.³⁶ CT-R (discussed in detail below) also shows successful outcomes without insight.³⁷

Anosognosia is often used synonymously with insight; however, it is not the same construct. Anosognosia refers to an underlying neurological deficit thought to be caused by changes or differences in brain structure or circuits.^{38,39} Anosognosia is more commonly associated with patients who have experienced a stroke or a traumatic brain injury, after which the individual is unable to recognize changes in their functional ability. For example, a person who no longer can move one side of their body after experiencing a stroke but who is totally unaware of their deficit could have anosognosia. Anosognosia, when used in the context of SMI, refers to a lack of knowledge or cognitive insight about mental illness.⁴⁰ Some studies have shown neuroanatomical changes associated with lower insight.⁴¹ However, there can be many factors that contribute to a lack of awareness in various domains of insight, to the denial of particular symptoms, or to other difficulties, such as deficits in neurocognition, social cognition, or metacognition, and even increased self-stigma.⁴² More work and research are needed to understand insight and how it does or does not relate to anosognosia with its particular brain changes.⁴³

In addition to insight, comorbid substance use, side effects of medications, inadequate efficacy of treatment, and negative symptoms also impact treatment adherence.

This distinction is especially important because insight is not the only driver of adherence: Research suggests that comorbid substance use,⁴⁴ side effects of medications, inadequate efficacy of treatment, and negative symptoms also significantly impact treatment adherence.⁴⁵ Lack of access to care and barriers to receiving care make it even more difficult to remain in care, especially if the individual is psychologically ambivalent as to whether they need care or not. Further commentary on the subject suggests that the relationship between insight and adherence is complex and that the complexity of mental illness as well as each individual's personal experience should be embraced.⁴⁶

PERCEIVED COERCION

There has been much discussion on court-ordered care in recent years, with many states shifting paradigms related to court-ordered care.⁴⁷ Court-ordered care is one literal way of putting forth a mandate- yet the questions of whether the individual actually feels coerced, and how that perception impacts adherence, are also quite complex. Perceived coercion, as opposed to formal and informal coercion, describes



the individual's subjective experience of being coerced. Estimates of the prevalence of perceived coercion in psychiatric care vary widely, from 16 to up to 90 percent, depending on the population studied, the legal status of the individual, and the location of services received.⁴⁸

Research suggests that an individual's perceived coercion regarding psychiatric services can influence the outcomes associated with that treatment, with the assumption that greater perceived coercion would more negatively impact psychosocial functioning and the therapeutic relationship, and even the willingness to remain in care.^{49,50} However, in studies of inpatient hospitalization, perceptions of coercion were influenced more by the experience of procedural justice rather than legal status alone.⁵¹ In other words, an individual who is involuntarily hospitalized may have less feelings of coercion if they felt fairness in the process and voice, neutrality, respect, and trustworthiness. In a study examining perceived coercion and procedural justice among individuals in outpatient treatment court programs, it was found that the judges and case managers involved in the programs can influence an individual's perceptions of the program by the degree to which they demonstrate procedural justice.⁵² The authors suggest this influence can affect long-term effects of the programs on individuals. Another systematic review that included 34 studies regarding factors that may influence a person's subjective experience of seclusion, restraint, or involuntary medication found that the staff and environmental conditions play an important role in improving the subjective experience of these coercive measures.⁵³

CLINICAL CONSIDERATIONS FOR MEDICATION AND OTHER TREATMENT NONADHERENCE

Nonadherence to treatment can take many forms, yet it is often referred to as one global descriptor of the behavior of a person served. Moreover, it is often attributed to anosognosia, so the solution offered is often a move toward commitment and a court order. Some individuals may lack decision-making abilities and warrant an alternative decision-maker, such as a guardian. Although these legal interventions may be necessary and can be helpful in particular circumstances, medication nonadherence, like insight, is more complex and warrants a deeper analysis—especially because, apart from injectable medications, many medications and therapies can still be declined even if mandated by a substitute decision-maker or judge. Furthermore, labeling an individual nonadherent entails particular negative biases—namely, that the individual will place an undue burden on the provider system. However, it is critical not to generalize nonadherence as a categorical issue as opposed to a single factor in care that occurs in a variety of ways and contexts on a continuum. In addition, although disorders that involve psychotic processes require a specialized approach, nonadherence is not unique to psychiatric

conditions. Many studies have examined adherence to treatment in other medical contexts, such as diabetes care and outcomes,⁵⁴ or in the medical management of hypertension,⁵⁵ to name a few. Adherence to treatment is complicated in any medical context. For example, one study described how adherence to treatment for schizophrenia is linked to the severity of symptoms and side effects, insight, and the individual's beliefs and attitudes, as well as support and relationships.⁵⁶

All of these elements can interact with each other and positively or negatively impact adherence depending on the context. For example, one study examined perceived coercion in outpatient commitment and found that individuals who felt stronger coercion also self-reported greater adherence to injectable medications.⁵⁷ This finding was replicated in another study, but the second paper also described that satisfaction with treatment was lower with higher perceptions of coercion, even if medication adherence was stronger. Therefore, the relationship between beliefs and attitudes is complex and can change over time: For example, if an individual feels coerced in one setting (e.g., while under court-ordered care) and dissatisfied overall with their care, when the court-order is removed, they may be nonadherent to treatment, leading to extended periods of court orders. Rather, it can be helpful to foster individual intrinsic motivation for treatment, as well as positive and meaningful relationships with treatment providers, which could lead to more satisfactory care and long-term adherence even without a court order.

Figure 1: Continuums of Adherence

(1) Partial→ Total Missing a single dose or appointment differs from missing nearly all of them. Clarify what “clinically meaningful adherence” means for that person.	(2) Temporary→ Long-term A missed day differs from years away from care. Treatment history matters, especially for restarting medications like clozapine safely.	(3) Deliberate, Accidental, or Unavoidable Side effects, stigma, lack of insight, or religious objections (deliberate); disorganization (accidental); lost prescriptions, incarceration, transportation (unavoidable).
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Treatment adherence exists on a spectrum and consists of multiple factors (**Figure 1**). In a case of nonadherence, it is assumed that the treatment recommendations are clear and feasible, and that the individual is simply not following the treatment as recommended. If, however, instructions are vague, confusing, or unclear, or even infeasible (e.g., prescribing a dose of medication that does not exist, or sending someone to a clinic that has closed), then there can be no expectation of adherence. As such, clinicians must give very clear recommendations at the end of careful discussions with clients. After this first step, then treatment providers can investigate whether the individual is adhering to the

recommendations. As a clinician, it is important to consider the following factors across their entire spectrum when working with an individual patient:

1. ***Partial to total nonadherence***: An individual in care may miss appointments with therapists or medication doses, or both. In addition, they may miss all of the prescribed appointments and medications or only some of them. They may take some medications but not others; they may take intermittent doses or come to appointments intermittently. An individual who misses one dose of medication or one therapy appointment may still be adhering to the majority of their recommended treatment. When a clinician is working in settings where adherence is “required,” clear definitions of what adherence means in these contexts are often missing; therefore, it is important to examine what clinically meaningful adherence is in each individual case.
2. ***Temporary to long-term nonadherence***: An individual may miss doses of medication for a day, a week, or a month, or disappear entirely and miss treatment for years. Treatment history is important in order to understand any patterns of nonadherence. It is also important because restarting medications can be critical to the individual’s stability, and some medications, such as clozapine or injectable medications, require an understanding of the timing of the last doses taken in order to develop a plan for restarting the medication safely.
3. ***Deliberate, accidental, to unavoidable nonadherence***: Almost every person prescribed medication has inadvertently missed at least one dose of that medication. Generally, there is no judgment attached to this kind of lapse. Yet in psychiatric care, missing a dose can be a significant issue for an individual who is mandated to be “compliant,” or for an individual in a fragile condition who is at risk for returning to symptoms without full adherence to a treatment regimen. Nevertheless, in taking a history of medication and other treatment adherence, it is important to look at whether the nonadherence is deliberate, and if so, why it is occurring. For example, intolerance of side effects is often given as a reason for deliberate nonadherence.⁵⁸ For some individuals with psychotic disorders, even the color of the pill can be given as a reason (e.g., when a person may have paranoia about the particular medication). In one review, religious objections to medications that contained pig products were also cited.⁵⁹ Furthermore, the lack of a positive relationship with a therapist can also be a reason for an individual not to show up for appointments.

Stigma associated with having a mental illness, or even the heavy psychological burden of the self-admission of having a mental illness, can be another reason for medication nonadherence.⁶⁰ Many patient-centered educational efforts attempt to help patients understand why medication can be an important component of treatment, but as providers, helping patients be willing to begin medication requires patience and an informed approach.⁶¹



A lack of insight into one's mental illness, as well as the resulting need for medication because of this lack of awareness, is yet another reason for deliberately choosing not to take medication.⁶² Xavier Amador and colleagues have developed the [LEAP \("Listen-Empathize-Agree-Partner"\) method](#) to help build rapport with and support individuals who deny that they are ill in adhering to their medication regimen.⁶³ They emphasize that medication or therapy nonadherence is often not due to deliberate choice.

Accidental nonadherence refers to mistakes, such as missing therapy appointments due to difficulty recalling dates, not keeping a calendar, or the like. Similarly, missing doses of medication can easily occur when an individual is distracted or disorganized, or miscounts pills. Case managers or peer support services in these contexts can be very useful, but support strategies must take the individual's circumstances into account in order to be effective. For example, if an individual keeps their belongings in different locations, or is illiterate or cognitively limited, a physical calendar may not be helpful. Technologies are available to help set reminders, but these tools also require that an individual have technology available.

Inadvertent and unavoidable nonadherence can occur for practical reasons: For example, an individual may have lost their prescriptions. They may have missed their bus, and therefore their appointment. They may have had their belongings, along with their prescriptions or appointment cards, stolen. They may be held in jail and so unable to access their medications or attend their appointments. Similarly, an individual may receive a "failure to appear" in court because they are psychiatrically hospitalized. Once a failure to appear is on a court record, they may be more likely to be denied bail to be released if arraigned on future cases.⁶⁴ In addition, difficulty in accessing treatment providers that are geographically distant or difficult to reach, as in rural areas, can be another factor that leads to nonadherence.⁶⁵

In sum, it is important to determine whether the individual actively chose not to take a particular medication or attend a therapeutic program, or whether other circumstances arose that led to accidental, inadvertent, or even unavoidable nonadherence.

By analyzing the various ways an individual might be "nonadherent," the practitioner can discuss with the patient what happened and work on a strategy to improve the likelihood of adherence moving forward. In having these discussions, the opportunity to engage in meaningful and less "critical" dialogue can arise, which can also increase treatment satisfaction to further support adherence.

THERAPEUTIC ALLIANCE

In 1936, Rosenzweig published a theory describing the "Common Factors" that make a therapeutic relationship effective.⁶⁶ Further work has examined the



ingredients common in psychotherapies: In a 2015 review, Wampold described what he called the contextual model.⁶⁷ Wampold detailed the importance of the initial therapeutic relationship, in which a bond between the therapist and patient is created, and a sense of trustworthiness in this relationship can be established or broken right from the beginning. After this initial encounter, there are three pathways for further building this “therapeutic alliance,” including 1) establishing a more genuine relationship, in which the treatment provider and recipient each experience the other as beneficial and trustworthy; 2) setting expectations that help shape treatment experience even in the face of prior disappointing treatments; and 3) adding “specific ingredients” that involve an actual treatment approach.

Within the common factors originally described by Rosenzweig, Wampold suggests that the therapeutic alliance is a key factor, which can be correlated with the treatment outcome. He describes the alliance as tripartite: the bond, the agreement about the goals of treatment, and the tasks associated with the treatment.⁶⁸ Although a full review of treatment alliance and the associated research in the psychotherapy literature is beyond the scope of this paper, the principles associated with these subjects are critical in supporting treatment adherence and ongoing care.

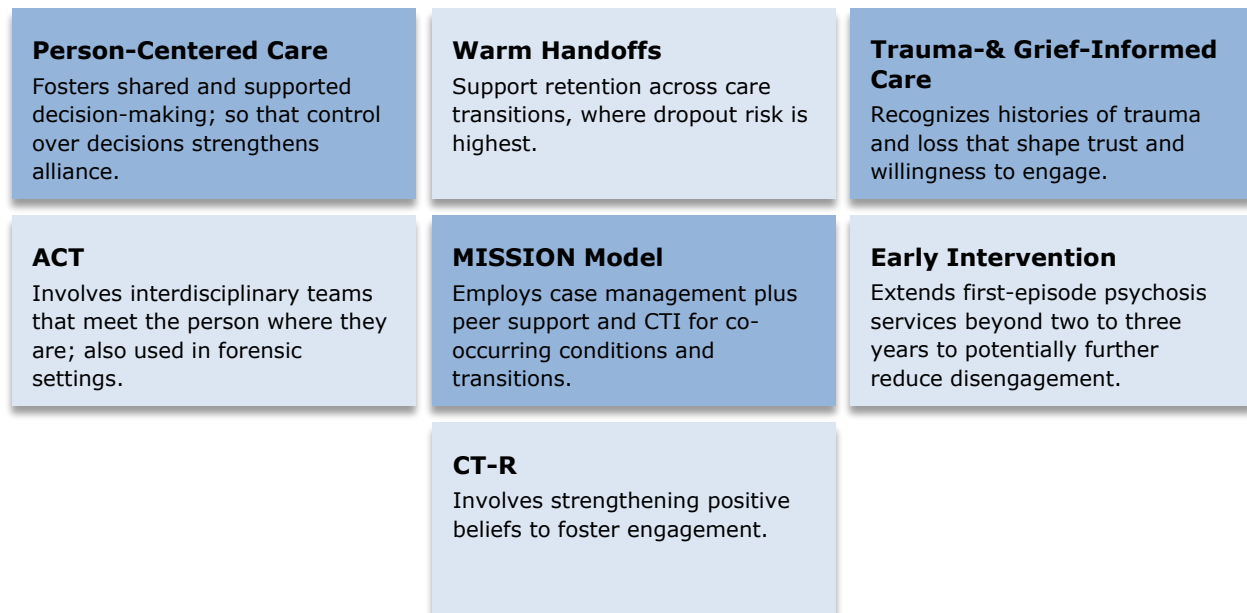
Research suggests that the therapeutic alliance is important in fostering treatment adherence. In one study of outpatients with schizophrenia, it was found that the therapeutic alliance significantly predicted medication adherence, even after controlling for insight and symptom severity.⁶⁹ In another study examining the role of insight, therapeutic alliance, and perceived trauma in psychiatric care, it was found that greater adherence was correlated with higher insight, a stronger therapeutic alliance, and lower rates of perceived trauma. Mental health providers’ recognition that a patient may potentially have a traumatic experience with psychiatric treatment, and the role this acknowledgement plays in building the therapeutic alliance, particularly fostered engagement.⁷⁰

MODELS FOR FOSTERING ENGAGEMENT

One of the challenges of working with individuals with SMI—many of whom have histories of trauma and involvement in juvenile and adult justice systems, possible foster care involvement, homelessness or transitional lifestyles, have had periods of institutionalization, and/or have undergone turnover in treatment providers and other disruptions in their relationships—is that attachment and trust can be challenging. Reactive attachment disorder is well-described for youth.⁷¹ It is considered a diagnosis of development in childhood and adolescence and therefore never seen in adulthood. Still, many of its characteristics persist in adults, with certain behaviors generally contributing to how personalities are formed. Identity disturbances, as well as difficulty in expressing empathy, in following instructions, or in forming lasting or meaningful connections, can appear. For treatment providers, working with individuals who are not eager to work with them can be very challenging and can even lead to burnout. Repeated “treatment failures” or

treatment nonadherence increase frustration and can even sometimes result in feelings of anger toward the individuals being served. Therefore, supporting staff who are doing the hard work of engagement are critical for leaders.

Figure 2: Models to Foster Engagement



Furthermore, services can become “person-resistant”: that is, can place blame on the individual for being “treatment-resistant,” without considering that the service structure or system may be inaccessible and therefore set up individuals to fail. In these contexts, it is important that providers consider their own reactions to the person being served and ensure that, despite the challenges a person may present, the provider community can continue to support them the best they can. Many states have included “no eject, no reject” policies in their service contracts to help decrease the tendency to ask uncooperative individuals to leave services—the very services they need to improve their ability to function.⁷²

It is also important to recognize that individuals in care are highly likely to have experienced trauma, which may make it harder to trust, to feel in control, and even to seek help. Thus, trauma-informed care is critical to supporting the therapeutic alliance.⁷³ In addition, individuals in care may be struggling with other social issues, including experiencing grief and loss over any number of things; therefore, grief-informed services can also be important.⁷⁴

One key method of fostering the therapeutic alliance and trust is the person-centered care approach, which has been codified in many laws, policies, and regulations. Person-centered care has been linked to stronger therapeutic alliances between provider and service recipient, with each influencing the other.⁷⁵ Similar to work in psychotherapy research from decades ago, research has found that the connection, continuity, and calibration of the therapeutic relationship, as well as

person-centered care itself as a modality, help foster engagement.⁷⁶ Shared as well as supported decision-making also support person-centered care, but their proper execution requires education and concentrated effort that could benefit from multidisciplinary approaches.^{77,78}

It should not be assumed that executing person-centered care is intuitive. For example, although Medicaid Home and Community Based Services require person-centered planning, some research has indicated that certain factors facilitate this type of planning, while others pose barriers. One study described the circumstances that can facilitate person-centered planning: when the individual realizes that they have freedom of choice and control over their decisions, when personal goals and strengths are truly part of the planning, and when there can be mutual, active, and honest communication with the staff regarding the client's wishes. In contrast, persons served have identified care plans oriented solely toward medical needs rather than individual persons, administrative and systemic barriers, and a lack of competence in care managers as barriers to person-centered planning.

Interestingly, care managers themselves also identified several administrative and systemic barriers to facilitating person-centered plans.⁷⁹ It is clear that training, monitoring, and quality improvement control can help staff who are working toward a person-centered approach,⁸⁰ while mental health and substance use treatment leaders can monitor and optimize activities in order to help improve therapeutic alliances with individuals who may be difficult to engage.

"Recognize that the mental health, community, justice, and public service systems are interconnected, and adopt and refine policies to identify and close gaps between them. Practices should include providing "warm hand-offs" and other necessary supports to help individuals navigate between the systems in which they are engaged."

—NASMHPD *Beyond Beds*

Another person-centered strategy for fostering engagement is to examine retention practices across care transitions. During times of change, such as upon discharge from inpatient hospitalization⁸¹ or the transition from the child to adult care system, dropout rates can be especially high. "Warm handoff" is not only a common buzzword, but also a critical strategy for improving retention across care systems; however, it can vary across settings and in practice.⁸² One of the recommendations in the original 2017 paper *Beyond Beds* by the Technical Assistance Coalition included linkages across transitions as a key issue to address. These retention strategies can be lifesaving: Research suggests that follow-up emergency department visits can reduce suicides,⁸³ and reentry services for individuals coming out of incarceration can reduce the risk of adverse reactions from high-level opioid exposure.⁸⁴

Motivational interviewing as a tool in the person-centered toolbox began in the 1980s and has grown into an evidence-based approach that relies on questions and



response styles that can be utilized to shift a client's thinking and motivation toward behavioral change. If done right, it involves training followed by practice coaching and feedback sessions.⁸⁵ Research has shown its promise, at least in the short to medium term for substance use disorders.^{86,87} Whether the same technique works with individuals with SMI with or without co-occurring disorders as a means of maximizing engagement and adherence is less clear. For example, one pilot study looking at the use of motivational interviewing with individuals with first-episode psychosis showed promise,⁸⁸ though a meta-analysis examining its use with co-occurring conditions resulted in modest effects at best.⁸⁹ Newer research also suggests that motivational interviewing may be best used in concert with other evidence-based approaches. For example, a study using cognitive behavioral therapy (CBT) alongside motivational interviewing for anxiety showed a positive impact on treatment outcomes.⁹⁰ Another recent study showed improvement in negative symptoms among individuals with schizophrenia when motivational interviewing was used alongside CBT.⁹¹ Recovery-oriented cognitive therapy (CT-R) also improves negative symptoms in those with SMI and has the advantage of focusing on action rather than conversation, a feature that increases the number of people who can benefit from it over traditional CBT.⁹² These findings are truly exciting, as negative symptoms can sometimes drive individuals to disengage from treatment.

To help develop their therapeutic skills and truly foster engagement, staff must be trained—and inspired—to do the work of everyday. Peers can also be incredibly helpful in fostering engagement given their credibility: They've been where the individuals being served have been and can therefore relate to them.⁹³ In addition, models of continuous outreach and intensive supervision, such as in work with high-risk youth, can serve as an inspiration for fostering engagement with complex individuals.⁹⁴ For example, Roca, Inc., an agency in several cities including Chelsea and Springfield, MA as well as Baltimore, MD, has developed an intensive supervision model for its staff, who were assigned to carry out a CBT strategy for high-risk youth. The model involves several components, including: sideways mentorship, in which supervisors show the same empathy and persistent relationship-building with clients expected of the direct care staff; field shadowing and coaching; and the integration of CBT in all staff training. Staff supervision is structured with goals and not just vague dialogue, fidelity to the approach is monitored, benchmarks and data tracking are used to help keep staff up to date on their work product, and there is an emphasis on continuous training and skill-building.⁹⁵ Although the model was not designed for individuals with SMI, its principles have merit and could be further studied in regards to difficult-to-engage populations more generally.

First-episode psychosis is another area of focus where developing strategies to help keep people in care can be lifesaving. In a Cochrane review of several studies, researchers found that extending specialized early intervention to support individuals with first-episode psychosis may be able to reduce the risk of disengagement.⁹⁶ These teams are designed to provide a more comprehensive



array of interventions, including therapies, medication, psychoeducation, and even support for employment and education. The study found that normally teams work with people for two to three years, but that extending these services beyond this time period may yield additional benefits. These findings show that it is key to understand how tenacious SMI can be and highlight the importance of retention in services, as establishing stable supports can help people sustain progress.

There are other well-studied therapeutic models with a strong evidence base for reducing repeated hospitalizations and keeping individuals with SMI in their community settings. Assertive community treatment as well as forensic assertive community treatment, both used across the country, provide an interdisciplinary team approach that meets patients where they are.⁹⁷ The MISSION model (MISSIONmodel.org) uses a case manager and peer support team to foster sustained community tenure for individuals with co-occurring conditions: It was first studied to address homelessness in Veterans, and later studied in the context of mental health courts and reentry services.⁹⁸ It utilizes the Critical Time Intervention (CTI) model, which was developed to help foster treatment retention as individuals face transitions.⁹⁹ The CTI model has gained traction, with at least one state, New Hampshire, adopting it to plan discharges from inpatient settings and at other transition points.¹⁰⁰ Furthermore, one study identified that initial trust in providers can be key in affecting outcomes even for people receiving intensive services such as assertive community treatment.¹⁰¹

SPOTLIGHT ON CT-R

How recovery-oriented cognitive therapy addresses treatment retention

Recovery-oriented cognitive therapy (CT-R) was originally developed in the urban areas of Philadelphia more than 20 years ago.^{102,103,104} It focused on individuals given a diagnosis of schizophrenia who were not seeking treatment and who appeared to have disengaged due to a lack of trust in mental health condition and substance use disorder services. Thus, from the outset, CT-R was designed for individuals with SMI and offered effective ways to promote initial engagement in treatment and sustain that participation in the long term. Providers can achieve both these objectives through the guidance of CT-R's powerful theory,¹⁰⁵ which combines Aaron Beck's cognitive model^{106,107} and his theory of modes.^{108,109} A key component of CT-R involves strengthening an individual's positive beliefs about themselves, others, and their future while simultaneously fostering a trusting and caring relationship with providers.

Initial engagement

According to the CT-R theory that providers use in practice, individuals who do not engage in treatment are considered to be in a *disconnected mode*, a state



dominated by negative beliefs about the self (“I am incapable”), others (“I can’t trust them”), and the future (“It is hopeless”). This disconnection causes the person’s lack of participation in activities with others, leaving them isolated and far more likely to experience ongoing challenges (e.g., hallucinations, delusions, low energy) that can reaffirm these negative beliefs, such as “I am a failure,” “This is as good as it gets,” or “I can’t trust other people.”

The key to initially engaging each person involves recognizing and tapping into their *adaptive mode*, or best self. This side of the person comes out when they are participating in or talking about activities that reflect their interests and passions. Positive beliefs about the self (“I have something to offer”), others (“They appreciate me”), and the future (“I can make a difference”) become more accessible during these activities.

Negative beliefs stem from adverse events, trauma, stigma, and previous experiences with care. These lived experiences shape the way a person sees themselves in the world and affirm their negative expectations about future providers and systems of care. Rather than initially focusing solely on challenges or symptoms—an approach that may unintentionally affirm these negative expectations—a provider can flip this script, offering opportunities to connect through the person’s interests via activities that bring out the person’s best self. Sometimes this approach requires keeping interactions shorter in the beginning until the provider discovers the individual’s interests and the best way to connect with them. This strategy offers an opportunity for the provider to connect with the person on a human level, outside of what brought them to care, which can jumpstart and streamline the process of trust and connection needed for treatment retention. This CT-R approach to engagement promotes retention in care: The person served begins to find the interaction appealing because it does not feel like treatment, and, at the same time, because it involves human connection outside of their symptoms, challenges, or negative beliefs. Success in this care-based relationship-building can lead naturally to pursuing connection in their everyday life.

Sustaining participation in treatment

Once CT-R providers have discovered activities that bring out a person’s best self, the next step is to make these activities a regular part of their daily experience. This *energizing* of their adaptive mode continues to be appealing because it focuses upon their interests, positive feelings, and repeated experience of success. The person feels it is worth showing up and participating to feel more like themselves, to find that they have more capability than they thought, and to see that others appreciate what they have to offer. In CT-R, as in many treatment approaches, nothing succeeds like success, and nothing is more successful and predictive of long-term success than these early positive encounters, as the person experiences a personally valuable connection and derives their own meaning from it (i.e., this connection strengthens positive beliefs such as “It’s better to do things with other people,” “Others appreciate me,” and “I have something to offer”). In CT-R, the first

goal lies in building the framework of trust in an engagement or relationship that can then help shape positive individual choices in the direction of recovery. So, if the person is giving advice, the provider might ask, “Seems like you are a really helpful person, don’t you think?” Or, “people seem to appreciate what you have to offer, have you noticed that?” Such questioning serves as a counterweight that can help the person stop dwelling in their disconnected states—and it offers another reason to keep coming to care, as they come to discover, believe in, and realize the possibilities of their best self.

Personal agency

Another appealing aspect of CT-R is helping persons served discover and accomplish their personal aspirations—that is, long-term goals that help a person attain their desired life. By energizing the person’s adaptive mode, the CT-R provider or team creates a trusting relationship and strengthens positive beliefs, which allows the person to think about a personally meaningful future. Eliciting an image (either a mental image or a physical image such as a vision board) of this future taps into positive emotions that can increase energy and motivation, which also elevates the person’s hope and confidence that they can achieve it. Uncovering the “best part” of each aspiration makes it possible for anyone to achieve what is personally meaningful or valuable about it each day, which can be especially important if they are in a very restrictive setting, a long way from realizing their long-term goal, or both. For example, if a person says their aspiration is “to become a care professional,” and they identify the best part as helping others, they can engage day-to-day in prosocial actions that allow them to help others. Along with engaging them in a helping role, the CT-R provider or team can guide them to notice how helpful they are being and how they are living up to their personal aspirations in their day-to-day life. This approach offers providers a unique opportunity to meet the person where they are, regardless of their circumstances, and to develop action plans that are person-centered, meaningful, and feasible.

In CT-R, the person’s aspirations become a roadmap for the active pursuit of the life of their choosing, a personally meaningful effort that they carry out. This method fulfills their need for personal agency, or running their own life, and helps them experience purpose every day.

Empowerment

Conversations and relationships that spark aspirations also provide a framework for addressing the various challenges that led to hospital admissions or incarceration in the first place. Aspirations become the driving force, or the “why” it’s worth overcoming challenges or carrying out treatment-related tasks that may otherwise feel undesirable or avoidable, like taking unwanted medications. Discovering a sense of inner strength can counter feelings of being incapable of follow-through, which may have led to treatment disengagement in the past. It is not that the person expects everything to go well now that they are pursuing their life aspirations; rather,

individuals come to recognize that though things do not always work out, they can handle it, it is not a disaster, and there is a possibility that things could work out differently than they once expected—that is, they develop resilience.

What is CT-R's evidence base? Theory, intervention, and implementation

There is substantial evidence supporting CT-R's conceptual model and key mechanism of change (strengthening positive beliefs). Multiple studies have highlighted the role of negative beliefs as predictors of social withdrawal and nonengagement.^{110,111,112,113,114,115,116} In contrast, positive beliefs have been shown to improve task performance and overall mood,¹¹⁷ in addition to predicting greater community participation, reduced negative symptoms, and decreased positive symptoms in the future.¹¹⁸ One community-based clinical trial supports CT-R as an approach that improves community participation while also reducing negative and positive symptoms of psychosis.^{119,120} Importantly, increased endorsement of positive beliefs correlates with increases in community participation in individuals who have undergone CT-R treatment.¹²¹ CT-R has been implemented widely across systems of care, spanning multiple levels and a range of provider types, to increase engagement in treatment and support individuals' return to their communities and pursuit of their desired lives.¹²² Thus, while CT-R has therapy in its name and lends itself well to individual and group therapy, it is also a multidisciplinary approach that can be implemented across a wide range of settings, disciplines, challenges, and diagnoses.

What does CT-R look like in practice?

CT-R has been implemented in settings across the care continuum that disproportionately serve individuals who typically do not engage in or stick with treatment. These individuals are often high utilizers of care and find themselves caught in the revolving door of the mental health and/or justice systems. In this section, we describe CT-R implementation in state hospitals, community teams, and problem-solving courts.

CT-R practice is guided by the Recovery Map (Figure 3),¹²³ a case formulation tool that organizes information about individuals' adaptive modes (interests, passions), aspirations, and challenges in a framework that can help providers understand underlying beliefs, how individuals may have difficulties, and how they can thrive. This tool provides a brainstorming space for providers to formulate an action plan within their respective roles in care to best engage, retain, and empower the individuals in their care.

Figure 3: A CT-R Recovery Map

Recovery Map	
ACCESSING & ENERGIZING THE ADAPTIVE MODE	
Interests/Ways to Engage: •	Beliefs Activated while in Adaptive Mode: •
ASPIRATIONS	
Goals: •	Meaning of Accomplishing Identified Goal: •
CHALLENGES	
Current Behaviors/Challenges: •	Beliefs in Underlying Challenges: •
POSTIVE ACTION & EMPOWERMENT	
Current Strategies and Interventions: 1. a.	Belief/Aspiration/Meaning/Challenge Targeted: 1. a.

State hospitals

CT-R can help address several challenges unique to state hospitals or other long-term, secure inpatient settings. High acuity symptoms of SMI (e.g., delusions, hallucinations, negative symptoms, self-injury, and aggression) are more commonly encountered at this level of care. Individuals may also be hesitant to trust and engage with providers due to a combination of early adverse experiences, traumas, and experiences of stigma, which have taught them that they cannot trust other people, that people are out to get them, or that others are unsafe. State hospitals that have implemented CT-R attempt to activate the individual's adaptive mode, getting to know them outside of their "patient" identity and encouraging them to share their experiences with their interests and passions. This systematic, active process builds trust with the treatment team members and fosters a genuine connection, which in turn increases treatment engagement because the person served perceives the treatment interactions as safe, trust develops, and progress can begin.

CT-R also includes specific, actionable strategies to foster empowerment in individuals striving to manage acute psychiatric challenges. For example, treatment staff can encourage de-escalation through a refocusing activity that both activates the senses and is personally meaningful (such as looking at fashion or playing basketball) when an individual is angry and at risk for acting aggressively. This approach provides not only an opportunity to successfully manage acute challenges but also space for the individual to have a positive connection with a provider during a moment that otherwise may further isolate and disengage them from care.

CT-R's strategies can be employed by any staff member on a care team in the state hospital setting. By training multidisciplinary staff and encouraging them to promote positive action together (guided by the Recovery Map) in a collaborative, consistent way, state hospitals can promote a positive environment no matter the circumstances. CT-R strategies can also work in tandem with medical interventions, helping, for example, to bridge the gap while medication is taking effect or when individuals do not agree to take medication.

Patients in a state hospital often experience longer stays than in community hospitals. Sometimes, the length of stay is extended due to difficulties in discharging the patient to a lower level of care or to a community setting. For an individual who may feel that discharge entails unmanageable, overwhelming risk, enriching their aspirations through imagery (either mental, a physical picture, or both) helps them develop positive emotions (motivation), hope ("My dreams are possible"), and a reason to risk returning to the community. Uncovering the underlying meaning of their aspiration—for example, helping people—provides focus for the activity while the person is still in the hospital and helps build up their momentum for discharge. All this future-oriented information, along with the challenges they need to build up the skills to face, live in the Recovery Map and help guide the staff's work with individuals who are initially reluctant to discharge.

When individuals move back into the community from a higher level of care, CT-R can serve as a common language facilitating these transitions and uniting multiple teams or systems. In addition to the Recovery Map, teams can use the CT-R Transitions Form (**Figure 4**). Completed in collaboration with the individual transitioning between levels of care, this empowering document allows the individual to reflect on their progress and success and to highlight what they want future providers to know about them as a person, along with their interests and desires for the future, and how they wish to be treated. This document provides the team at the next level of care with valuable information, while giving the individual autonomy and a voice in the process—which can be especially valuable in circumstances in which the next step in a person's treatment is one they are hesitant about or may not fully agree with (e.g., mandated care).

Figure 4: CT-R Transitions Form

TRANSITIONS PREPARATION HANDOUT	
Benefits of Moving	
1. What would be the best part about it (e.g., activities, feeling safe/in control, meeting new people)?	
2. What am I most looking forward to?	
3. Are there specific interests of mine that I want to engage in or new things I want to try?	
Getting to Know Me	
1. What do I want people to know about me at my best?	
2. When do I most feel like myself?	
3. What do I enjoy?	
4. What makes me feel most energized?	
My Hopes for Moving	
1. What do I hope to accomplish with a move?	
2. What am I hoping for while at a new place?	
Collaborating with Me	
1. What do I want people to know about how to best collaborate with me?	
2. What have been some of my favorite activities or events with staff or people I live with?	
3. When I'm feeling stressed or having a hard time, what would be helpful for others to do?	
4. How can people let me know that they understand where I'm coming from?	
Other Ideas that I Have	

A significant number of individuals in state hospitals are admitted for forensic services, including pretrial individuals who are committed for competency restoration services. For competency restoration protocols, CT-R's procedures can foster engagement and retention in medication-related or legal-education programming, keeping the focus on future aspirations beyond just "resolving legal matters."¹²⁴ CT-R can also be used by behavioral health and justice-related stakeholders: Once again, it provides a common language that fosters better collaboration across systems. For state hospitals that serve individuals committed to treatment under Not Guilty by Reason of Insanity or related statutes, CT-R can help individuals consider the meaning and values underlying their aspirations and shape hospital time as something meaningful rather than a long pause from living their desired lives.

Residential and community-based programming

CT-R has been applied across a broad range of community teams, including ACT, mobile crisis, forensic community treatment, and specialty care first-episode psychosis teams. CT-R is particularly useful as a common language across disciplines and as an approach that can be adapted and effectively employed by a variety of provider types, including clinical and paraprofessional providers. CT-R's specific focus on increasing engagement and finding an individual's "best self" is also helpful for community treatment teams, particularly when nonadherence is an issue and individuals have been assigned to services rather than voluntarily seeking them. For example, individuals mandated to care by the courts may feel like they are defined by their role in the justice system, or individuals in a first-episode psychosis or ultra high-risk treatment program may feel defined by a new set of symptoms or challenges. But with CT-R, treatment may look different than what the individual originally expected, in that it involves engaging in activities that they enjoy or are passionate about, which guide both their treatment interactions and their actions between points of contact. This process helps a person discover or rediscover their identity outside of their challenges (both mental health- and justice-related), which is especially important for individuals who have long been defined by adversity or are in a precarious or formative phase of identity development. Such meaningful support in identity development strongly encourages these individuals to stick with the team's collaborative care.

Problem-solving courts

Drug courts, mental health courts, and similar institutions are alternatives to standard prosecution for individuals with treatment needs. Within these settings, nontreatment providers (e.g., case managers, court staff, lawyers, judges, and supervision officers) have the opportunity to make a significant impact. A judge, for example, could use CT-R and the Recovery Map to organize status hearings and check-ins around the person's interests and activities that are personally meaningful to them. Rather than asking "How are you doing?" or "How are things going?" the judge could ask questions like, "How is your volunteer job at the animal shelter going?" or "I wanted to ask your advice on something." Such an approach not only creates an environment where the staff clearly appear to care about the individual, which can reduce tension in an often-stressful situation, but it can also help increase the likelihood that the person is able to celebrate wins at court, rather than discussing only challenges or things they "did wrong."

When the court knows what is most important to a person, they can help structure court mandates and requirements around what a person wants for their future. This approach not only helps tap into intrinsic motivation (e.g., "I should go to therapy because it helps me feel less angry and that lets me be a better father" rather than "I have to go to therapy because my probation officer says I do"), but also can help give context as to *why* the court is making certain recommendations. All stakeholders can also use CT-R strategies to help participants notice their progress



and success as they graduate through phases of court involvement, or to be mindful of their resilience as they navigate challenges in trying to build a life in their community.¹²⁵

CONCLUSION

Retention in care is a critical variable in the success of treatment. No one wants to be ill or need care, and yet people with SMI and co-occurring conditions must deal with these illnesses, and the stigma that comes with them, daily. Thus, no matter how accessible treatment is at the first appointment, if the care is not useful to the client and is therefore not pursued, dropout rates will be high. There is no simple answer as to how best to retain people in care, but there are lessons to be learned from the literature to date. First, retention must be a collaborative goal in care, and dropping out of care cannot be seen as a negative mark against the individual being served. For mental health care professionals, each case is unique, and therefore an analysis of why treatment was dismissed or declined is important to help the individual being served and to work with them toward adherence. Person-centered services are designed with this goal in mind, and yet this approach can entail nuanced methods when a person may not fully realize why they should want care. In some instances, external motivators, or even court orders, may be helpful; nevertheless, even court-ordered individuals may opt out of care, and thus mental health condition and substance use disorder systems should not solely rely upon court systems to solve the challenges of treatment adherence. Approaches such as CT-R and others can help inspire treatment adherence using an evidence-based approach that can be taught and administered with positive outcomes. System leaders can benefit from understanding these care strategies and supporting their implementation across settings and jurisdictions.



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