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Narrative Enhancement and Cognitive Therapy: A New Group-Based Treatment for Internalized Stigma among Persons with Severe Mental Illness, by Philip T. Yanos, Ph.D., David Roe, Ph.D., and Paul H. Lysaker, Ph.D.

Estimated Time to Complete this Activity: 90 minutes

Learning Objectives:

The reader will be able to:

1. Recognize the importance of internalized stigma in impacting outcomes for severe mental illness.
2. Identify the main elements of narrative enhancement and cognitive therapy.
3. Describe how narrative development can be a key process in psychotherapy for persons with severe mental illness.

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Narrative Enhancement and Cognitive Therapy: A New Group-Based Treatment for Internalized Stigma Among Persons with Severe Mental Illness

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ABSTRACT

Internalized stigma has been suggested to play a major role in negative changes in identity in severe mental illness. Evidence suggests that roughly one-third of people with severe mental illness show elevated internalized stigma and that it is linked to compromised outcomes in both subjective and objective aspects of recovery. Despite substantial evidence for the impact of internalized stigma, few efforts have been made to develop professionally led treatment to address this issue. In this article, we discuss our development of a new group-based approach to the treatment of internalized stigma which we have termed “narrative enhancement and cognitive therapy” (NECT). We describe the treatment approach and offer an illustration of it by way of a case vignette.

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While it has been long recognized that the experience of mental illness, along with its label and social consequences, influences identity (Estroff, 1989; Goffman, 1961), only recently have research efforts begun to identify the specific mechanisms involved in this process. One factor which has been suggested to play a major role in negative changes in identity in severe mental illness is internalized stigma. Internalized stigma, or self-stigma, refers to the process by which a person with severe mental illness adopts stigmatizing views (e.g., dangerousness, incompetence) widely held by the general public. Consequently, self-stigma restricts and limits previously held or hoped for identities (e.g., self as student, self as worker, self as parent). Evidence suggests that roughly one-third of people with severe mental illness show elevated internalized stigma (Lysaker, Roe, & Yanos, 2007; Ritsher & Phelan, 2004) and that internalized stigma is linked to both subjective and objective aspects of recovery, including hopelessness (Lysaker, Roe, & Yanos, 2007; McCay & Seeman, 1998; Yanos et al., 2008), diminished self-esteem (Corrigan, Watson, & Barr, 2006; Watson, Corrigan, Larson, & Sells, 2007; Yanos et al., 2008), and impoverished social relationships (Lysaker, Roe, & Yanos, 2007).

Previously, we argued that ignoring internalized stigma in comprehensive treatment programs for people with severe mental illness may leave difficult roadblocks to recovery untouched (Yanos, Roe, & Lysaker, 2010). However, despite substantial evidence for the impact of internalized stigma on recovery outcomes in this population, few efforts have been made to develop professionally led treatment to address this issue. In this article, we will review the strengths and weaknesses of previous attempts to address self-stigma and discuss our development of a new group-based approach to its treatment, which we have termed “narrative enhancement and cognitive therapy” (NECT).

PREVIOUS TREATMENTS FOR SELF-STIGMA

To date, we are aware of only four different programs that have sought to address self-stigma among persons with severe mental illness. Wiczyński (2000) developed and carried out a psychoeducational stigma management group in an inpatient setting at-

tended by 27 participants. While the participants reported the group was helpful, there were no significant increases in participant self-efficacy or knowledge, perhaps because of the brief number of sessions. Concurrently, Link and colleagues (Link et al., 2001; Link et al., 2002) developed a primarily educational intervention which sought to provide information sufficient to reduce agreement with views endorsing the community's devaluation and discrimination against people with mental illness. The approach helped share important information about stigma but offered little room for persons to support one another in the change process. Participation in this program was not found to be linked with changes in perceptions of stigma, stigma management strategies, or related outcomes such as self-esteem. Findings from these two studies suggest that purely educational interventions are not likely to be successful in altering self-stigma.

More recently, two more therapeutic interventions were developed and discussed. A study of a group-based intervention for young adults with first episode schizophrenia focusing on teaching skills to reduce "engulfment," a process of acceptance of the patient role as the primary definition of self, found promising findings with regard to improving self-conceptions at 3-month follow-up (McCay et al., 2006). Although the study used a small sample, brief follow-up period, and did not employ random assignment, it supports the view that interventions can have an impact on internalized stigma. Finally, Knight, Wykes, & Hayward (2006) developed and implemented a more comprehensive group treatment for perceived stigma, geared to help people with severe mental illness be more informed and educated about their illness and better cope with it. This seven-session intervention relied on cognitive behavioral techniques, emphasizing an empowering and supportive discussion of stigma-related issues. Findings based on 21 participants revealed an increase in levels of self-esteem and a decrease in depression, positive and negative symptoms, and general psychopathology.

Findings from the above studies suggest the limitations of education interventions to combat stigma, but support the potential promise of group-based interventions that move beyond education and focus on changes in how persons actively think about themselves and their lives.

THEORETICAL BACKGROUND FOR THE PRESENT INTERVENTION

In light of the strengths and weaknesses of the above, we sought to develop an intervention that would include not only educational materials about stigma, but also techniques aimed at enhancing the cognitive skills necessary for changing one's identity. We sought to help persons not only recognize and discard stigma but also be better able to recognize and correct dysfunctional cognitions which might impede the development of a new sense of self and positive identity. To that end, we turned to two major theoretical areas and related literatures: cognitive restructuring and narrative models of the processes involved in positive identity development.

First, *cognitive restructuring* (Beck, 1970) refers to the process of learning to challenge one's own inaccurate and/or maladaptive beliefs and then to replace them with more accurate and adaptive ones. Cognitive restructuring is a core element of most cognitive behavioral therapies (CBT) and specifically is accomplished by persons becoming aware of their sometimes most automatic thoughts and then learning to challenge them by examining the evidence that supports and does not support them.

Cognitive restructuring is relevant to reducing internalized stigma for several reasons. First, self-stigma can be conceptualized as involving a person's coming to develop and hold onto inaccurate and maladaptive belief, such as "I am incompetent to manage my own life," "I am a danger to others," or "my emotions are not to be trusted." Second, CBT has been successfully modified by a range of researchers and clinicians to address maladaptive cognitions among persons with severe mental illness. Controlled studies have further shown that persons with severe mental illness will accept CBT and that CBT leads to reduction in symptoms and improvements in function relative to treatments as usual (Drury et al., 1996; Haddock et al., 1998; Sensky et al., 2000). We reasoned that a group intervention could be developed which would help persons recognize self-stigma as a matter involving the acceptance of dysfunction beliefs which could be challenged and replaced. Indeed, this is consistent with a range

of theoretical discussions (Corrigan & Calabrese, 2005) and case studies (Holmes & River, 1998).

The second literature we drew upon in designing our intervention study concerns *narrative* and positive identity both among persons with and without severe mental illness. There is a considerable amount of work that suggests that a person's experience of his or her identity is not merely a matter of a set of particular beliefs about oneself, but is fundamentally experienced as a series of meaningful events arranged in a storied manner (Gallagher, 2000; Lysaker, Clements et al., 2002; Polkinghorne, 1995). Personal identity is inextricably bound within the stories we tell about ourselves to others and those we cherish and review with ourselves in private moments (Bruner, 1987). For example, one set of particular beliefs (e.g., "I am a talented musician with a devotion to certain humanitarian ideals but also someone who struggles to be assertive and who lacks personal discipline") could have totally different meanings depending on its storied context (McAdams, 2001).

Literature on narrative and identity is relevant for an intervention targeting self-stigma for several reasons. To begin, self-stigma is not merely a matter of inaccurate beliefs but also infects the stories one tells about oneself. To accept, for instance, that one is dangerous would seem necessarily to have an enormous range of consequences for how one might tell or not tell one's life narrative. Consistent with observations by Davidson (2003) and others (Lysaker, Lysaker, & Lysaker, 2001), accepting that us was incompetent or dangerous might lead one to conclude that there was no real future to our story, that our story was one of failure, or even that one was not worthy of being told. As a corollary of this, to decrease self-stigma and construct a positive identity, a person may need to come to tell a new story about his or her life. In other words, in addition to corrected beliefs, a new narrative may have to be evolved.

The perspective that overcoming internalized stigma may require a transformation in one's personal narrative may be a crucial point, as phenomenological observations suggest that severe mental illness often involves a profound diminishment in a person's ability to narrate his or her own life's evolving story (Gallagher, 2003; Lysaker, Wickett, Wilke, & Lysaker, 2003). Many with

severe mental illness may have stopped telling stories of their lives in which they are a protagonist meaningfully connected to others (Holma & Aaltonen, 1998; Young & Ensign, 1999). They may describe their lives and trials without sufficient temporal organization and have difficulty differentiating themselves from their disorder (Roe & Ben Yishai, 1999). Constructing or developing a meaningful story of one's disorder and life that promotes recovery may be particularly difficult for persons with schizophrenia and other forms of severe mental illness.

The view that interventions geared toward narrative transformation would be an important feature in the treatment of internalized stigma is consistent with other research suggesting that addressing narrative (or storytelling) in psychotherapy is beneficial (Lysaker, Davis, Eckert et al., 2005; Lysaker, Davis, Jones et al., 2007; Lysaker et al., 2001). It has been suggested that such a psychotherapy may help clients tell stories about what is wrong, not wrong, about hopes, losses, and what could be done (Lysaker et al., 2001; Lysaker & Buck, 2006). To help draw out stories, therapists inquire with curiosity and respect about what is wrong and not wrong in the lives of the clients. As they begin to tell their stories, the therapists actively offer reflections about the clients' presence or absence as protagonists in the stories they are telling. Therapists also reflect on how clients experience them as an audience for their stories. Finally, therapists offer a reflection about issues not mentioned. By listening carefully to what was being said, therapists also often recognize and note what has not been said, and encourage clients to elaborate on these important dimensions of their stories.

Based on these findings, we reasoned that disempowered narratives in which themes dominated by internalized stigma prevail can be gradually reframed and revised using similar techniques in a group setting so that themes of agency and potential come to be experienced, shared with others, and internalized as part of a more integrative experience of self.

THE PRESENT INTERVENTION

In developing the present intervention, we drew on our collective expertise in CBT, coping, and narrative enhancement to develop

a structured, group-based treatment. The intervention, which we called Narrative Enhancement/Cognitive Therapy (NECT), combines three central therapeutic approaches: psychoeducation, to help replace stigmatizing views about mental illness and recovery with empirical findings; cognitive restructuring geared toward teaching skills to challenge negative beliefs about the self; and elements of psychotherapy focused on enhancing one's ability to narrate one's life story. NECT is a group-based intervention, as we believed that a group orientation has several notable advantages for participants to gain feedback and support from peers (Yalom, 1995) and, within this context, to provide opportunities for interactions with an audience for their storytelling (Lysaker et al., 2007). We designed a manual that is geared to be user-friendly and could be easily implemented with reasonable fidelity by master's-level clinicians.

Treatment Manual

The treatment manual features a guide for the practitioner to help explain the rationale, tone, and technique of each section, plus handouts that can be used to guide group discussions. In addition, it includes worksheets to help group members learn and practice skills for coping with internalized stigma by identifying cognitive distortions or dysfunctional attitudes related to having a mental illness, and for telling stories and providing constructive feedback to the stories of others. Below is an outline of the main sections of the manual:

Introduction. The purpose of this section of the intervention is to begin the process of assessing where the person is with regard to his or her experience of self and, in particular, to the relation of self to illness (that is, their degree of internalized stigma). In order to do so, each participant engages in exercises designed to elicit a description of him/herself and a description of the problem for which he or she is seeking help (to avoid naming it for the person). These self-conceptualizations are elicited through written group exercises (although participants have the opportunity to dictate responses in the event that they are unable to write). The expected length of the introduction segment is 1 group meeting.

Psychoeducation. The purpose of this segment of the intervention is to provide participants with the current empirical knowledge about the prognosis of severe mental illness and the inaccuracy of stigmatizing views about it. Educational handouts summarizing information on the rates of recovery for severe mental illness are reviewed and discussed, as are handouts about stigma and how self-stigma develops. Common myths about mental illness are also presented and debunked using research-based findings. For example, the notion that “people never recover from mental illness” is presented as a myth and countered with the assertion that “research shows that many people fully recover from mental illness and stop either experiencing symptoms completely or experience symptoms that are so mild that they do not interfere with going about daily life.” The material is presented in a manner geared toward fostering discussion and consideration between the group leader and group members, and not in a manner that positions the group leader as an expert whose opinion is to be categorically accepted. The goal is to help “replace” stigmatizing and inaccurate myths but not a person’s experience or personal understanding of it. Discussion of material follows some of the principles discussed by Roe and Yanos (2006) in using psychoeducation to “inspire” persons with severe mental illness. The expected length of the psychoeducation portion of the group is 3 group meetings.

Cognitive Restructuring. This section introduces the first “active ingredient” of the treatment that we expect to impact self-conceptualizations. This section starts out by teaching the basic principles of cognitive restructuring, including: the connection between thoughts and feelings, how thoughts and feelings influence behavior, what an irrational belief is, types of irrational beliefs, how to monitor thoughts, and how to challenge, irrational beliefs. The participants then engage in exercises where they attempt to identify, challenge and consider replacing inaccurate beliefs and/or dysfunctional cognitions about self, illness, and self in relation to illness. For example, the negative thought, “I have a mental illness and can never recover and live a productive life in society,” is presented, and participants engage in the use of cognitive restructuring skills (e.g., considering the evidence for the thought and/or examining the advantages and disadvantages

of the thought) to challenge it. There is also information on common misconceptions related to stigmatizing views of mental illness and thinking errors related to these misconceptions. Group members engage in discussions of thinking errors, as well as complete exercises designed to stimulate the use of cognitive restructuring techniques outside of the group context. Participants are encouraged to monitor situations in which cognitions about the self, illness, and self in relation to illness are elicited, and then discuss these situations in the group. The expected length of the cognitive restructuring portion of the group is 8 group meetings

Narrative Enhancement. After the participants have completed the psychoeducation and cognitive restructuring portions of the group and have had the opportunity to develop significant group cohesiveness (Yalom, 1995), the group transitions into the narrative enhancement portion. The rationale for placing this segment last is that it is believed that participants will be more comfortable with the group and the group facilitators and therefore more prepared to take on the task of sharing personal stories in the group. The last section focuses on the process of constructing personally useful narratives of self, illness, and self in relation to illness. Participants are encouraged to write (or tell) and share stories within the group. The stories can be about past or recent events. The intervention focuses on trying to bring together previously fragmented and isolated aspects of the self by being an audience to the story, exploring the way (content and process) one tells his or her story, responding to the participants' difficulties thinking of themselves (and being center or/and an active agent), recognizing the participants' right to have and create their own stories, and reflecting about the participants as protagonists in the stories that they tell. A further focus during this section is to discuss how the types of stories may be influenced by cognitive distortions which can in turn be inspired by popular (and erroneous) beliefs about mental illness. This component therefore attempts to integrate aspects of psychoeducation and CBT to help participants internalize change and impact not only cognitions, but also the subjective experience that accompanies (and interacts with) cognitions. Thus, the ultimate goal is to enable participants to learn and practice skills which offer opportunities

to negotiate and rewrite their personal stories and experience as well as internalize the empowering role of the narrator and protagonist of these stories. The expected length of this section of the intervention is 8 weeks.

Recommended Structure of the Intervention. It is recommended that the group be conducted by 2 facilitators, which helps provide more personal attention when needed, strengthens continuity, and gives the facilitators the opportunity to discuss and process the group together and provide mutual support. The ideal size of the group is 4-8 members, not including facilitators. Each group meeting should last an hour. While reading and writing are major means by which the group teaches skills, literacy is not required, as group members can listen to what others read and facilitators can support group members by writing down their responses to exercises and stories. Each group meeting begins with a 5-10 minute structured section in which participants are welcomed and allowed to add to the day's agenda. This "check-in" time also allows participants to give a brief report of their experiences that week and call to mind any questions or concerns they may have. During this time, homework may also be "turned in" to the group. Following check-in is the didactic section which lasts roughly 40 minutes. During this period, group members together review and complete roughly 2-3 pages of manual worksheets. Group members are encouraged, but not required, to read from worksheets in order to facilitate participation in the group. Following the didactic session, participants have time to process what they learned, give their comments about the usefulness of the group, and offer one another support. This "processing section" lasts 10-15 minutes. During this time, each group member will identify a goal (or home assignment) they would like to accomplish during the upcoming week.

Recommended Techniques for Group Facilitation. In addition to the general structure outlined above, it is recommended that group facilitation approaches be used to encourage group cohesiveness, interpersonal learning, and supportive interactions and to limit disruptive behaviors such as one group member dominating the group. Specific techniques that are recommended include: 1) outlining and discussing the group norms (which include proscriptions against unsupportive comments and domi-

nance of group discussions) at the outset of the group and reiterating them where appropriate throughout the group meetings; 2) encouraging group members to speak with and provide feedback to each other rather than only to the group facilitator throughout the group, but especially during the narrative enhancement phase, where guidelines for providing feedback to each other are outlined; and 3) outlining facilitation techniques that are listed in a “fidelity rating scale.” Techniques outlined in this scale include: “reinforcement of small steps (e.g., reflecting relevant statements that might be embedded in irrelevant or disorganized statements),” “getting help from group members to facilitate learning,” “tactful limiting of peripheral and unproductive discussion (e.g., redirection combined with support),” and “identifies and responds to client distress (e.g., acknowledging affect in presentation even when it is not communicated directly and letting participants know that it is okay to feel upset by some of what is discussed).”

PILOT IMPLEMENTATION

The manual was developed during 2008 and separately piloted by the three authors (together with co-facilitators) between late 2008 and early 2009 at three different settings: an Assertive Community Treatment program in New York City, a day treatment program in Indianapolis, and a university clinic in Israel. A total of 17 individuals diagnosed with severe mental illness (with a variety of diagnoses, including schizophrenia, schizoaffective disorder, and bipolar disorder) participated in these three pilot groups. Participants volunteered to participate in the pilot intervention and were recruited through announcements and referrals from clinical staff in the three settings. Institutional Review Board approval was received for the pilot groups in all three locations.

Group Process

A focus of the pilot implementation was to help refine the manual but also to determine the “tolerability” of the group. In all three locations, we found the individuals who participated to be thoroughly engaged in the group. Attendance was generally

good, and although in some instances participants found that the group material elicited strong emotions, they showed no signs of being unduly upset by the group material. In terms of the key processes that unfolded in our initial groups, we observed essentially three related phenomena. First, the groups developed a shared curiosity in how each member's story could be deepened. Group members not only reflected the elements of the stories participants shared (e.g., that they performed a certain action in a certain place) but also asked about things they wanted to know more about (e.g., what happened in the participant's life in the years before that certain action). Following this was a related process in which members seemed to support one another in establishing a greater sense of themselves as people who were not really known by others but who could choose aspects of themselves which could be safely revealed and understood by the fellow group members. Here we observed members not only realizing things about other members but then applying that knowledge to themselves. They thus appeared to first discover that something was unknown about a particular (e.g., what preceded a certain event in his or her life) but then realized the same was true about them (e.g., something important may have preceded a certain event). Finally, we observed that group members began to help one another synthesize larger narrative understanding regarding identity. Metaphorically, it was as if individual members offered details to the group, or pieces of a puzzle, with the larger group then helped to assemble into a larger coherent and consensually valid of that individual which situated him or her as a meaningful agent in their own life story.

Group participants in all three settings reported being helped by the group, and some appeared to have made important changes as a result. The below case vignette illustrates some of the types of changes we observed in group participants. The vignette is a composite of several group participants, created to illustrate some of the central components of NECT.

Case Vignette

Peter is a 33-year-old male who lives alone and works part-time in a supportive employment program. He began experiencing

serious psychiatric symptoms in his early twenties, for which he was hospitalized three times, and he has been treated through outpatient and rehabilitation services for the last 10 years. He reported being diagnosed over the years by different psychiatrists as having schizoaffective and bipolar disorder. He heard about the pilot intervention from his case manager and was interested in participating.

At first Peter appeared quiet and cautious. He said he felt both drawn and threatened by the topic of self-stigma because he believed that part of his problem is that he thinks too much. During the first few sessions he said very little but followed the group with an intense look. He participated only when referred to directly, and he appeared quite anxious. When reviewing the psychoeducational material, he seemed notably drawn to the tone and information but was also hesitant, as though concerned that he might annoy someone. Gradually, however, he began to share personal stories which generated feelings of injustice and pain. He told the group that his brother wouldn't allow his kids to visit him alone since he first "got sick." On another occasion, he shared an incident of volunteering to give blood but being rejected by a nurse when she learned he used psychiatric medication, claiming his "blood was no good." As the group proceeded, Peter appeared less and less concerned about others' opinions, which manifested itself both in the group and in events outside the group that he shared with the group members. For example, he expressed his disapproval towards a mental health provider who spoke disrespectfully to a person who was receiving treatment at the same outpatient clinic. He appeared a little less shy and slightly more assertive, and he shared with the group his fear of feeling anger which he was afraid would lead to his losing control and getting into trouble. The cognitive restructuring section was a helpful opportunity for him to practice strategies to identify thoughts that accompanied these feelings. This helped him distinguish between situations in which he concluded that his anger was justified and resulted from an annoying or insulting incident, and situations in which he was overly "reading into" a situation. These tools helped him feel a little less threatened by his feelings, and he frequently negotiated this topic in group, moving towards a conscious decision that he chose to avoid confrontation. For

example, he came to the group one day and reported having a frustrating experience that same morning but proud that it did not get him “set off.”

During the last sessions, as part of the narration exercises, Peter shared stories about his post-hospitalization period, emphasizing his passivity and attributing any forms of activity to “miracles.” Hesitantly, he listened to his peers reflect the active role he played which must have at least “helped” make these miracles happen. This appeared to have an impact on him, and he gradually began to tell stories with elements of greater agency. A few weeks before the group ended, he shared how he had applied for and successfully obtained competitive employment. He related that he did this by saying that he realized that “having a mental illness does not limit you from pursuing your goals.” The accomplishment of obtaining competitive employment appeared to significantly improve his self-esteem.

At the last session, he described himself as “being in physical and spiritual struggle for survival and that he hopes for the best.” He gave the reason for seeking services as the result of “a struggle which required help and attention.” When one of the group participants commented that this is “a fate he has to accept,” Peter rejected this, saying “this is not fate but something that requires faith in myself.”

We believe that the case of Peter demonstrates how involvement in the group helped engage participants’ self-conceptualizations, provide them with skills for changing them, and ultimately impact outcomes outside of the treatment context.

INDICATIONS AND POSSIBLE CONTRAINDICATIONS

As previously discussed, internalized stigma is common among people with severe mental illness and constitutes a serious barrier to recovery by diminishing hope, self-esteem, and social relationships. Nevertheless, a majority of people with severe mental illness do not show elevated levels of internalized stigma and may either be indifferent to stigma or respond to it with “righteous anger,” rather than the sense of disempowerment that characterizes self-stigma (Corrigan & Watson, 2002). NECT should therefore

be offered primarily to those experiencing high levels of internalized stigma who are most likely to benefit from an intervention developed primarily for that purpose. Since participating in NECT requires interacting, learning, and practicing skills as well as self-reflection, it might be less effective for those people with severe mental illness with serious cognitive impairment or very disorganized symptoms. Persons who are actively psychotic and manic may also be a challenge to engage. Intervention is thus intended for persons who are in a “stable” phase of their disorder.

It is our hope that NECT will be made available to routine public-sector treatment and rehabilitation settings that offer services to persons with severe mental illness. We envision NECT as complementary to evidence-based practices, in that for many, overcoming internalized stigma amplifies their sense of agency which helps benefit from effective interventions such as supportive employment and illness management and recovery.

DISCUSSION AND FUTURE PLANS

In this article we described a new intervention we developed to reduce internalized stigma, our pilot efforts to implement it, and a brief vignette to help illustrate the process by which it might effect change. This pilot implementation in three sites was suggestive of its potential benefit. Providing a group of individuals with the opportunity to discuss and explore the often emotionally charged and personally relevant topic of “who am I?” appeared to be a meaningful and welcome task. A safe environment which enabled support, sharing, and tools while encouraging a genuine dialogue and the development of personal exploratory models appeared to be a good context for helping participants develop their sense of agency.

Given the demonstrated tolerability of the NECT intervention, our plans are to assess the effectiveness of the intervention in a randomized controlled trial study and ultimately to attempt to disseminate the intervention in routine treatment settings where it can benefit a large number of persons with severe mental illness.

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