

Advancing Research on and Treatment of Dissociative Identity Disorder With People With Lived Experience

Matthew A. Robinson, Ph.D., Juliann B. Purcell, Ph.D., Laura Ward, M.B.A., M.P.H., Sherry Winternitz, M.D., Milissa L. Kaufman, M.D., Ph.D., Kim A. Baranowski, Ph.D., Lauren A.M. Lebois, Ph.D., Lived Experience Advisory Panel

Dissociative identity disorder is a posttraumatic, psychobiological syndrome that develops over time during childhood. Despite empirical evidence supporting the validity of this diagnosis and its relation to trauma, the disorder remains a misunderstood and stigmatized condition. This article highlights expert consensus guidelines and current empirical research on the treatment of dissociative identity disorder. In addition, the authors describe the Lived Experience Advisory Panel (LEAP), which was designed to leverage the expertise of individuals with dissociative identity disorder to combat

stigma and improve research, clinical programming, professional education, and public outreach related to the disorder. This article also describes how LEAP members have partnered with other researchers to create new knowledge through participatory action research in order to advance equitable service provision and effect positive change.

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It feels like an ethical endeavor, where people are participants rather than subjects. It is a framework that was far too long overlooked in human subject[s] research.

—Lived Experience Advisory Panel member

Dissociative identity disorder is a treatable mental health condition that remains highly stigmatized (1). Skepticism, misunderstanding, and lack of professional education about the disorder contribute to underdiagnosis, underrepresentation in treatment research, and worse health outcomes for people with this disorder compared with those with other trauma-related disorders (2). One powerful way to improve health outcomes is to include people with lived experience in the research process. For instance, including the voices of people with lived experience can ensure that research is measuring and targeting relevant outcomes and that treatments are aligned with the needs of the community of people experiencing a given condition. Including the voices of people with lived experience can also facilitate a positive research experience for participants, improve retention of participants in clinical studies, and enhance effective communication and dissemination of research results. We believe that prioritizing and valuing the input of individuals diagnosed as having dissociative identity disorder are essential in research on and development of treatments for this disorder.

McLean Hospital, an affiliate of Harvard Medical School, is dedicated to destigmatizing psychiatric illness. In 2016, an

advisory board, consisting of individuals diagnosed as having dissociative identity disorder, was established as part of this mission. This board, referred to as the Lived Experience Advisory Panel (LEAP), provides the opportunity for people with dissociative identity disorder to use their lived experience to help guide the hospital's clinical and research programs on this condition. The LEAP is an essential stakeholder in a broader initiative to destigmatize the disorder and to improve research, professional education, clinical programming, and public outreach. Below, we briefly outline the current understanding of dissociative identity disorder, its treatment, and the inclusion of the voices of individuals with lived experience of the disorder in the research process.

UNDERSTANDING THE DISORDER AND ITS TREATMENT

Dissociative Identity Disorder

A wealth of empirical evidence (e.g., epidemiological, experimental, case histories, and neurobiological) consistently supports the validity of the dissociative identity disorder diagnosis and its relation to trauma (3, 4). Historical misunderstanding about the disorder is rooted in a reluctance to acknowledge the prevalence of childhood abuse and its psychological impact—at both individual and societal levels (2, 5).

Dissociative identity disorder is a posttraumatic, psychobiological syndrome that develops over time during childhood (6). As with other psychiatric conditions, dissociative identity disorder emerges from an interaction between one's genetic profile (e.g., the innate capacity to dissociate) and environmental experience. Paradoxically, dissociative identity disorder is both a disorder and an effective adaptation to childhood maltreatment—helping a child to survive, learn, and grow into adulthood despite traumatic experiences and confounding attachment dilemmas (6).

The core subjective experience of individuals with dissociative identity disorder is a loss of agency and ownership over trauma-related thoughts, emotions, actions, and body image (7). This experience manifests over time as a disruption in one's sense of self-cohesion (7). People with the disorder experience shifts in their sense of agency—particularly when stressed or highly conflicted—such that they can feel as though they are observing an aspect of self, or another “self-state,” that is taking control of the “wheel” and driving (R. Oxnam, personal communication, February 2016).

Developmentally, children who possess high capacity to dissociate may cope with ongoing trauma by generating multiple “not-me” self-states. This dissociative process is theorized to occur through pseudo-externalized displacement and personification (8). Each self-state serves to distance a child from painful, and often frightening, life experiences and highly conflicted feelings. For example, for young children being abused by a caregiver, it may be too overwhelming to feel such fear (e.g., “That’s not me, that is someone else”), too dangerous to feel such anger toward the caregiver, and too overwhelming to know what is happening to their body. This coping mechanism allows the child to maintain attachment to their abusive caregiver by compartmentalizing awareness of conflict (8, 9). As a predominant mode of coping during long-standing maltreatment, the dissociative defense continues to operate into adulthood, even after the original traumatic circumstances have ended.

People with dissociative identity disorder also experience amnesia and detachment from their sense of self and surroundings (i.e., depersonalization, derealization) (7). In addition, despite having intact reality testing (in contrast to those with psychosis), people with dissociative identity disorder are often painfully puzzled by their symptoms (10). Furthermore, individuals with the disorder universally experience co-occurring symptoms of posttraumatic stress disorder (PTSD) and often experience depression, anxiety, disordered eating, problematic substance use, suicidal ideation, self-harm, and shame (7).

Treatment According to Expert Consensus Guidelines

According to the expert consensus guidelines from the International Society for the Study of Trauma and Dissociation

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(11), the main goal of dissociative identity disorder treatment is to gradually foster individuals’ capacity to experience trauma-related thoughts, emotions, actions, and body image as their own. To do this effectively, the guidelines advocate for a long-term

relational approach to psychotherapy that centers on the strength of the therapeutic relationship and maintenance of firm boundaries.

Within this relational framework, treatment occurs in phases (11). In brief, phase 1 focuses on gradually building trust and a shared language between patient and therapist, while working to reduce posttraumatic and mood symptoms, suicidality, and self-harm behaviors. This phase can take years because of the intensity of traumatic transference-countertransference patterns (12) and numerous other factors, including the presence of multiple comorbid issues as described above, interfering trauma-related beliefs, and patients’ overwhelming fear of emotion and feeling connected to their bodies. However, with this foundation, phase 2 focuses on confronting, working through, and processing trauma-related memories while maintaining stability and safety. Finally, phase 3 focuses on managing daily living and relationships with less reliance on dissociation, given gains in agency or ownership over trauma-related thoughts, feelings, memories, and actions. During this last stage, individuals with dissociative identity disorder may no longer experience not-me senses of self but instead believe and understand that “it was me, after all, all along” (8).

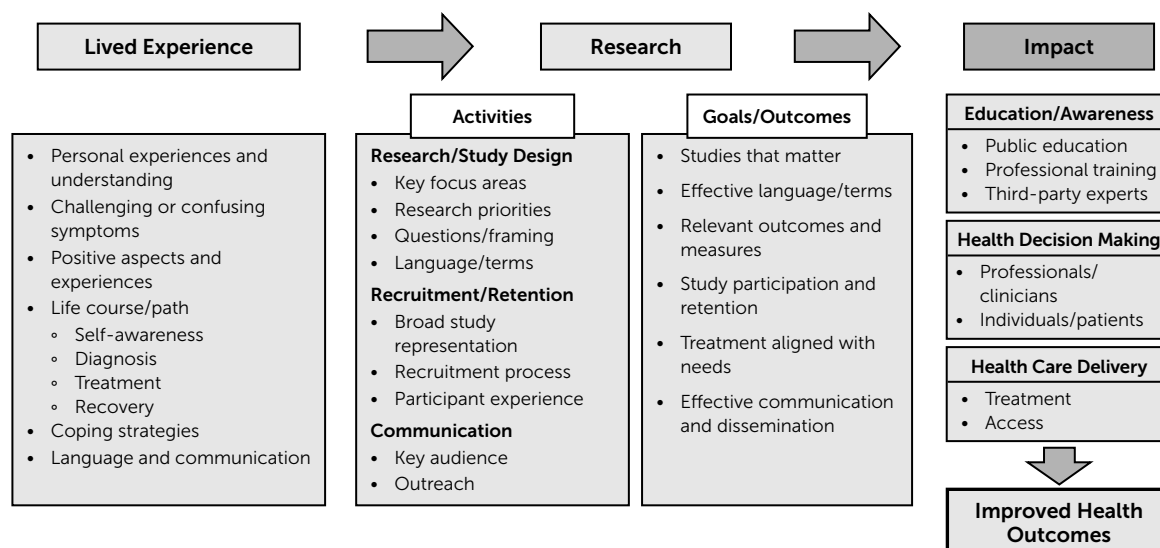
Importantly, progress throughout treatment is not necessarily linear, and frequent movement between phases can occur. In conjunction with this phased treatment, medication is often part of an individual’s treatment regimen and is typically targeted to reduce depression, anxiety, and sleep disturbances. However, to date and to our knowledge, there are no evidence-based pharmacological treatments specifically for the core dissociative symptomatology of dissociative identity disorder (11).

Empirical Research on Treatment for Dissociative Identity Disorder

Individuals with dissociative identity disorder historically have been excluded from trauma treatment outcomes research, because of their co-occurring conditions and elevated risk for suicidal ideation and self-harm. Therefore, the scientific literature on treatment consists primarily of case studies, clinical observations, and naturalistic studies. However, a robust, systematic line of research on phase 1 of treatment has confirmed the treatment’s effectiveness in improving global functioning, reducing psychiatric symptoms, and promoting stabilization (13, 14).

On the basis of this body of work, Brand et al. (3) recently developed a phase 1 psychoeducational intervention for dissociative identity disorder (as well as for other

FIGURE 1. Participatory action research process



trauma-related and dissociative disorders). Of note, they sought feedback from individuals with lived experience of dissociative identity disorder early in the development of the intervention and again after updating the intervention (15). To reach a broader audience, Brand et al. disseminated their work as the Finding Solid Ground program, which includes a workbook comprising educational modules and homework assignments covering relevant topics, such as psychoeducation about PTSD and complex PTSD, maintaining safety, and how dissociation can interfere with healthy emotion regulation (3, 15). Although other phase 1 trauma treatments exist, this program (3) is novel and innovative in its inclusion of content specifically targeting symptoms of dissociation, an approach that is absent from most other trauma-related disorder treatment approaches.

Pioneering studies of this approach have demonstrated robust reductions in symptoms of depression, PTSD, and dissociation; reductions in nonsuicidal self-harm; and improvements in emotion regulation and adaptive capacities (15). Moreover, individuals in the later stages of treatment have demonstrated a trend toward fewer hospitalizations and suicide attempts. Participants who initially reported having the most dissociation were the ones who benefited the most from the treatment, suggesting that this intervention may serve those with the greatest need (15). Altogether, the body of research on treatment for dissociative identity disorder and recent advances with the Brand et al. (3) psychoeducational intervention are serving to support one of the first randomized controlled trials of a phase 1 dissociative identity disorder treatment. The invaluable input and feedback provided by individuals with lived experience of the disorder have undoubtedly contributed to this intervention's initial success.

DESTIGMATIZATION—THE VOICE OF LIVED EXPERIENCE IN ADVANCING RESEARCH AND TREATMENT

Despite noteworthy advances in research on treatment for dissociative identity disorder, the disorder remains understudied, and the knowledge and experiences of people living with dissociative identity disorder need to be centered in this research. Participatory action research (PAR) is an established framework for centering the voices of people with lived experience to advance research on and treatment of general medical and psychiatric conditions (Figure 1). PAR engages people with lived experience as coresearchers to promote social justice, foster inclusion, and meet the needs of diverse community members. See Box 1 for recommendations on advancing research on and treatment of dissociative identity disorder.

Specifically, PAR supports the creation of new knowledge that grants privilege to the expertise of individuals with lived experience. It “radically challenges who is an expert, what counts as knowledge and, therefore, by who[m] research questions and designs should be crafted” (16). Including individuals with lived experience in each step of the research process subverts traditional hierarchies reflected in scientific study and the powers contributing to stigmatization and exclusion (17).

In addition, the Substance Abuse and Mental Health Services Administration (SAMHSA) recommends incorporating trauma-informed principles into research and treatment (18), especially when participants are from highly stigmatized, historically underrepresented or underserved groups. Trauma-informed principles include establishing safety; demonstrating trustworthiness and transparency; nurturing peer support; fostering collaboration and mutuality; supporting empowerment, voice, and choice; and giving attention to cultural, historical, and gender issues (18).

BOX 1. Recommendations for advancing research on and treatment of dissociative identity disorder

- Further research is needed to better understand dissociative identity disorder and to destigmatize this condition.
- Integration of the voices of those with lived experience of various conditions has been shown to advance the research on and treatment of those conditions and should be continued.
- Participatory action research (PAR) provides an effective framework for centering the experiences of individuals with lived experience and their communities in designing research and creating new knowledge.
- Inclusion of the voices of individuals with lived experience throughout the PAR process can serve to support advances in scientific knowledge and responsive clinical care.
- Partnerships with people with lived experience can enhance and enrich the development of professional training, public education, and community outreach.

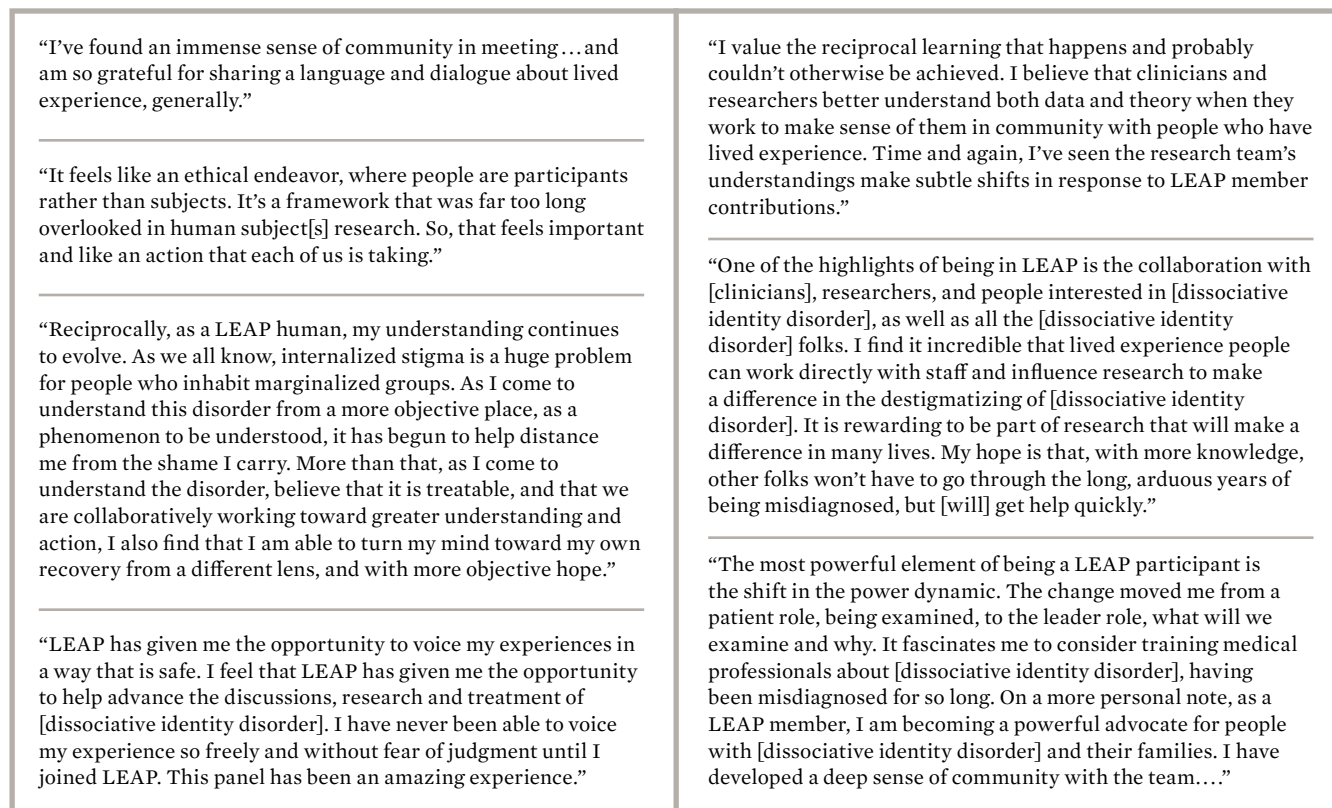
Combining these principles with PAR provides a powerful paradigm for accelerating progress in research and for improving treatment outcomes among people with dissociative identity disorder.

The development and formalization of the LEAP is one way our group is working to implement SAMHSA’s recommendations. The LEAP meets monthly, in partnership with our Dissociative Disorders and Trauma Research Program, which is composed of researchers with clinical and neuroscientific expertise in trauma and dissociation. As coresearchers, we leverage PAR principles and SAMHSA’s trauma-informed guidelines in our efforts to contribute to the transformation of our field.

This partnership has enabled our team to better understand barriers to dissociative identity disorder diagnosis and

treatment, as well as the impact of stigma on health care decisions. For example, LEAP members have described their experiences with general medical and mental health professionals who were unequipped to assess patients for dissociation or to understand the language of dissociative identity disorder, resulting in LEAP members’ avoidance of care seeking or receipt of suboptimal care at times. Our clinical and research teams met with the panel and gathered feedback regarding language and terminology that reflect their experiences, enhancing our understanding of phenomenology of the disorder. We then incorporated that language into clinical and research practices. Our collaboration has also helped to shape our research priorities and procedures. LEAP members have participated in research and provided feedback that resulted in adjustments to

FIGURE 2. Quotations from the LEAP about the participatory action research experience^a



^a LEAP, Lived Experience Advisory Panel.

methods, suggestions for new questions to explore and data to analyze, and considerations for LEAP members' participation in writing manuscripts and disseminating results.

LEAP members have also contributed to real-time changes to clinical unit programming at McLean Hospital. The panel's guidance has led to improved clinical services through expanded professional education and training efforts within our inpatient, partial hospitalization, and outpatient services, including the hiring of expert consultants on dissociative identity disorder treatment. Of note, the LEAP has been integral in broader professional and public education efforts by encouraging incorporation of individuals with lived experience into McLean Hospital's monthly Perspectives on Trauma speaker series, as well as participation of individuals with dissociative identity disorder in the Deconstructing Stigma campaign (<https://deconstructingstigma.org>).

LEAP members have found meaning through their involvement in this process, noting that participation has strengthened their community, empowerment, and agency (Figure 2). As a next step, the LEAP members, our research team, and other stakeholders will develop a research agenda, led by individuals with lived experience, to address the often protracted process of arriving at a correct dissociative identity disorder diagnosis—by using methods similar to those of recent efforts for other mental health conditions (19).

CONCLUSIONS

Historically, individuals with dissociative identity disorder have been prevented from participating in evaluation of treatment outcomes and from contributing to research design, interpretation, and dissemination. Our hope is that the research by the LEAP may represent a promising reversal of these exclusionary practices, by ensuring that the expertise of people with lived experience is incorporated at each stage of the research and treatment development process. The voices of these individuals are imperative for the equitable delivery of a range of goals, including the successful advancement of scientific knowledge, responsive clinical care, robust professional education, and effective public education and community outreach. Considering both historical stigmatization and exclusion, research that centers the perspectives of people with dissociative identity disorder is vital to advance research on and treatment of the disorder as well as to prevent additional exploitation and harm.

AUTHOR AND ARTICLE INFORMATION

Trauma Continuum, Division of Depression and Anxiety, McLean Hospital, Belmont, Massachusetts (all authors); Department of Psychiatry, Harvard Medical School, Boston (Robinson, Purcell, Winternitz, Kaufman, Lebois).

Send correspondence to Dr. Robinson (mrobinson@mclean.harvard.edu).

Dr. Robinson, Dr. Purcell, and Ms. Ward contributed equally to this study as first authors. Drs. Kaufman, Baranowski, and Lebois contributed equally to this study as last authors.

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