**PRESIDENT’S MESSAGE**

**Planning for ABCT’s Future**

Martin M. Antony, Ryerson University

Next month, ABCT will hold its 54th Annual Convention, which, for the first time, will occur virtually. The November convention will mark the end of my term as ABCT president and the beginning of David Tolin’s term. So, this will be my last column as ABCT president. I want to take a moment to thank everyone who helped to move ABCT’s work forward over the past year, including the numerous volunteers who serve the association (e.g., board members, coordinators, committee members, committee chairs, editors, reviewers, and SIG leaders), those who contribute content for our convention (i.e., presenters) and publications, our dedicated staff, and all of our members who work hard every day to advance the alleviation of human suffering. I am proud and honored to have had the opportunity to serve ABCT as president.

This column focuses on ABCT’s new strategic direction. Every 3 years, ABCT’s Board of Directors, coordinators, and senior staff meet for a strategic retreat. This year’s retreat occurred virtually over 2 days in June. The meeting was facilitated by Jeff De Cagna of Foresight First LLC. Initially, some of us wondered whether turbulent 2020 was the right time to begin a strategic planning process. However, it quickly became clear that this was exactly the right time to consider where we are at, where we want to be in the coming years, and...
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INSTRUCTIONS for AUTHORS

The Association for Behavioral and Cognitive Therapies publishes the Behavior Therapist as a service to its membership. Eight issues are published annually. The purpose is to provide a vehicle for the rapid dissemination of news, recent advances, and innovative applications in behavior therapy.

- Feature articles that are approximately 16 double-spaced manuscript pages may be submitted.
- Brief articles, approximately 6 to 12 double-spaced manuscript pages, are preferred.
- Feature articles and brief articles should be accompanied by a 75- to 100-word abstract.
- Letters to the Editor may be used to respond to articles published in the Behavior Therapist or to voice a professional opinion. Letters should be limited to approximately 3 double-spaced manuscript pages.

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how we can get there, given this uncertain environment in which we find ourselves.

Our process began with an “environmental scan” in which a group of stakeholders (e.g., ABCT leaders, staff, members, external contributors) answered questions about both ABCT and environmental trends and shifts. Through this process, we identified a range of orthodox beliefs held about ABCT. An orthodox belief is similar to what many of us might refer to as a “core belief” or “underlying assumption.” These are beliefs that we typically assume to be true, and that may hold us back from making meaningful change. Like any type of belief, orthodox beliefs may be true, untrue, or partially true. Examples of the more than 30 orthodox beliefs that were identified through our scan include:

“CBT is superior to other treatments”
“ABCT is primarily the ABCT convention”
“ABCT values diversity of perspectives”
“ABCT represents and values researchers over clinicians”
“ABCT focuses too much on anxiety disorders”

Another important purpose of our environmental scan was to identify anticipated external shifts that might impact us, both over the short term (2020 through 2022) and longer term (2023 through 2029), including general societal shifts (e.g., antiracism, antisience, aging population), shifts in health, technology, and well-being (e.g., focus on global mental health, shift toward telehealth, precision and personalized medicine), and shifts in behavioral health (e.g., mobile applications, expansion of BA- and MA-level providers, increased emphasis on social determinants of health, movement toward tiered care).

We are now in the process of learning from the information collected so we can prepare ABCT for the future. We are exploring and challenging our orthodox beliefs and fine tuning our strategic direction. We are still working out the details, but I expect our new direction to be grounded in a more accessible and inclusive approach to creating value for both current and emerging stakeholders who share our passion for using behavioral science to understand and treat a wide range of human problems. ABCT’s future will be guided by a number of core principles, which are likely to touch on themes such as:

- Building diversity, equity, inclusion, accessibility, and an antiracist stance in our association, and in the field of behavioral health, more generally;
- Fostering innovation to create and enhance evidence-based approaches to behavioral health;
- Promoting dissemination and implementation of evidence-based behavioral health, in part through promoting stakeholder engagement.

Importantly, we are carefully considering our purpose, who we see as key stakeholders, how to carry out our work, and how to measure whether our goals have been met. ABCT’s ongoing strategic process will continue through the end of my term and well into the future. Creating strategy is a dynamic process, necessary to meet the demands of an ever-changing world. We will have more to share in the coming months, and of course, stakeholder input (including from members) will be invited and encouraged before any important decisions are made.

Before I sign off, there are a couple of other things I want to mention. First, a word about the convention. By now, you probably know that ABCT’s Annual Convention will occur virtually. Months of deliberation went into our decision to cancel our in-person meeting, taking into account the impact on our members, as well as the impact on the association. More than 2,000 of you completed our online survey regarding your plans for November, and the message was clear—traveling to Philadelphia was simply not an option for most of us.

Although we’ll miss connecting with friends and colleagues in person, the virtual format will provide opportunities to do things differently this year. Many presentations will be recorded, with ongoing access for a period after the convention. So, anyone registered for the convention will be able to attend some events that are scheduled at the same time—something that usually isn’t possible. The online format will also allow for more flexibility in when you attend presentations (your participation won’t need to be limited to the 4 days of the convention). Also, without the need for travel, we hope that we’ll be able to reach a broader audience than might be the case for our more traditional convention format.

Finally, I want to highlight that this issue of the Behavior Therapist is a special issue, entitled “Advocacy in Action: Psychologists’ Role in Advocacy to Improve the Health of Marginalized Populations.” Thank you to Brian Feinstein and Jae Puckett for helping ABCT to address this important topic through their role as guest editors.

I look forward to joining you at our virtual convention next month!

...
From Your Executive Director:
What Your Leadership and Staff Are Working on to Serve You Better

Mary Jane Eimer, Executive Director

Once the decision was made to hold our November convention virtually, your staff focused its attention on all the details that need to be addressed to ensure a successful convention. I would like to formally acknowledge and thank the Philadelphia Marriott Downtown Hotel for their partnership in working with us to resolve an amicable cancellation of the space we reserved for our November convention. They understood our need to cancel based on the feedback from our convention survey. We have a long history with the Marriott Corporation and the Philadelphia Downtown Marriott Hotel in particular. If your travels take you to Philadelphia, perhaps you would consider staying at this hotel. FYI, we will be holding our 2024 convention at the Philadelphia Marriott.

As I write this column, we are working with the Finance Committee and the Board regarding convention registration fees. We are very much aware that COVID-19 has impacted your funding. Staff is working to offer the lowest rates possible for the convention registration fees while being mindful of our overhead expenses. We will be able to continue to offer reduced rates for our 2021 webinars and archived webinars to help members continue to earn continuing education credits. Please continue to support ABCT by renewing your dues and remaining active in the services and benefits we provide. We continue to produce 8 issues of tBT and offer 6 issues of Behavior Therapy and 4 issues of Cognitive and Behavioral Practice. ABCT has 41 Special Interest Groups that are active; you need to be a member of ABCT to be a member of one of our SIGs. We are updating our website constantly with resources for all stages of your professional development and interests. In 2021 we will migrate to a more user-friendly database and a new website platform. Then we will tackle better alternatives for the list serve.

We moved the annual election process to November, thinking more members would vote if we held it the same month as our Annual Convention. The election has been held online for over a decade and we hope you will participate. We have a strong lineup of candidates for your consideration. Their bios and position statements will be available on our website in mid-October. The 2021 candidates are:

**President-Elect**
- Jill Ehrenreich-May, Ph.D.
- Alec Miller, Psy.D.

**Representative-at-Large and Liaison to Convention and Education Issues**
- Katherine J.W. Baucom, Ph.D.
- Ana J. Bridges, Ph.D.

**Secretary Treasurer**
- Barbara W. Kamholz, Ph.D.
- Erin Ward-Giesielski, Ph.D.

It is my sincere pleasure to inform you the ABCT Board of Directors approved a new award, the Francis C. Sumner Excellence Award. The award is named in honor of Dr. Sumner, the first African American to receive a Ph.D. in psychology, in 1920. Commonly referred to as the “Father of Black Psychology,” he is recognized as an American leader in education reform. The award is intended to acknowledge and promote the excellence in research, clinical work, teaching, or service by an ABCT member who is a doctoral student or early career professional within 10 years of earning a PhD/PsyD/EdD/ScD/MD and who identifies as Black or Indigenous. The award is given to recognize Black and Indigenous practitioners and scholars making important contributions to our field. The Francis C. Sumner Excellence Award is meant to reflect the overarching goal of ABCT supporting its members of color. Please take a look at the 2021 Call for Award Nominations and nominate a colleague or yourself! Don’t overlook the opportunity to nominate colleagues outside of ABCT for our Champions Award.

As President Antony mentioned in his column, the leadership of ABCT is actively engaged in addressing our stakeholders and considering shifting from strategic planning to strategic intent. I would like to thank Dr. Antony for his commitment to ABCT over the past year. We all had no idea of all the “extra” time and attention that would be required due to the pandemic, social injustice, and switching to a virtual convention. Thank you, Marty, for your openness to new ideas, inclusion of many perspectives, and generosity of spirit.

Members, please continue to be active in ABCT by renewing your membership and registering for the convention. Participate in our list serve or in one of Special Interest Groups. This is your organization and your opinion and participation matter. The Board listens, as does the staff. We are counting on you.

You are always welcome to contact me directly at mjeimer@abct.org Thank you.

Stay safe and positive, everyone.

Until next time!

Correspondence to Mary Jane Eimer, CAE, Executive Director, ABCT, 305 Seventh Ave., Suite 1601, New York, NY 10001; mjeimer@abct.org

Congratulations

to David Antonuccio, Ph.D.,
who was recently presented with the National Register’s Alfred M. Wellner Lifetime Achievement Award in Research Excellence
Become an author with the Advances in Psychotherapy book series

About Advances in Psychotherapy – Evidence-based Practice
Developed and edited with the support of the Society of Clinical Psychology (APA Division 12), the Advances in Psychotherapy series provides therapists and students with practical, evidence-based guidance on the diagnosis and treatment of the most common disorders seen in clinical practice – and does so in a uniquely reader-friendly manner. A new strand is dealing with methods and approaches rather than specific disorders.

Each book is a “how-to” reference on a particular disorder. The books all have a similar structure, and each title is a compact and easy-to-follow guide covering all aspects of practice that are relevant in real life. Tables, boxed clinical “pearls,” and marginal notes assist orientation, while checklists for copying and summary boxes provide tools for use in daily practice.

The editors

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Linda Carter Sobell, PhD, ABPP
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Drop Editor in Chief Danny Wedding an email to discuss your ideas danny.wedding@gmail.com.

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Group Therapy for Depressive Disorders
Affirmative Counseling for Transgender and Gender Diverse Clients
Collaboration With Schools
Culturally Sensitive Psychotherapy
Supporting Children After Mass Disaster
Introduction to the Special Issue: Psychologists’ Role in Advocacy to Support the Health of Marginalized Populations

Brian A. Feinstein, Institute for Sexual and Gender Minority Health and Wellbeing, Northwestern University
Jae A. Puckett, Michigan State University

In 2019, along with several of our colleagues, we organized a panel for ABCT’s Annual Convention focused on psychologists’ role in advocacy to support the health of marginalized populations. We knew that advocacy could be a powerful tool for collaborating with marginalized communities to reduce health disparities, and that it could play an important role in science (e.g., by generating hypotheses based on the experiences of community members). However, we also knew that psychologists were rarely trained to engage in advocacy, and that there was a divide in the field wherein some viewed advocacy as part of their professional responsibilities and others did not. The potential for psychologists to engage in advocacy has long been acknowledged (e.g., King, 1968; Pettigrew, 2018), and there has been excellent scholarship on the topic of integrating a social justice perspective into psychology (e.g., Hargons et al.; Nadal, 2017). Still, advocacy continues to be treated as a niche topic in psychology (particularly in clinical psychology) rather than as a core value of the field. We believe that advocacy is critical to the work of psychologists—even an ethical imperative (Vasquez, 2012)—and that a commitment to advocacy and social justice should be embedded in clinical practice (e.g., Glassgold, 2007; Puckett, 2019; Russell & Bohan, 2007), research (e.g., Prilleltensky, 2001, 2003), teaching, and all of the other responsibilities of psychologists (e.g., Hargons et al., 2017; Kozan & Blustein, 2018). As such, we organized the aforementioned panel to share examples of how psychologists could use advocacy as a tool for disseminating scientific knowledge, for increasing the impact of psychological science, and ultimately for supporting the health of marginalized populations.

As we organized the panel, we were hopeful and cautiously optimistic that convention attendees would be interested in the topic of advocacy. Fast forward to minutes before the beginning of the panel and we were sitting in front of a packed room with 88 attendees, many of whom had to stand for the duration of the session because there were not enough seats to accommodate such a large audience. During the panel, as we shared our experiences engaging in advocacy and responded to attendees’ questions, it became even more apparent to us that psychologists were eager to learn how to incorporate advocacy into their own professional work. This special issue of *The Behavior Therapist* is the next step in our efforts to raise awareness of the importance of engaging in advocacy as psychologists. We have curated a collection of articles that address a range of topics related to advocacy, such as responding to the needs of community partners, adapting evidence-based interventions, teaching self-advocacy skills, and preventing burnout (a common consequence of engaging in advocacy, especially for people who are members of marginalized communities themselves). The collection of articles addresses the experiences of various marginalized populations (e.g., people of color, sexual and gender minorities, people living with HIV) and describes work being conducted in a number of unique settings (e.g., community-based organizations, clinics, camps, national and international contexts). The special issue concludes with a commentary written by Dr. Kevin Nadal, a leader in the movement for psychologists to combat systemic oppression through activism.

In closing, we are extremely grateful to the Editor of the *Behavior Therapist*, Dr. Richard LeBeau, for supporting this special issue, and to all of the contributing authors for sharing their expertise, research findings, and personal experiences. We hope that the articles included in this special issue will inspire readers and serve as useful examples of how researchers, clinicians, educators, and trainees can use their knowledge and skills to incorporate advocacy into their own professional work. We believe that psychologists need to do more than just repair the damage of our unjust world. Instead, psychologists must embrace advocacy as a professional responsibility and work to create true change by dismantling the power structures that give rise to health inequities to begin with. We hope the examples of psychologists engaging in advocacy included in this special issue will spark creative ideas for your own vision of your responsibilities as a psychologist.

References

Improving Clinical Research to Inform Advocacy Initiatives With Underserved Individuals

Claire Burgess, VA Boston Healthcare System and Harvard Medical School

Abigail Batchelder, Harvard Medical School, Massachusetts General Hospital, and The Fenway Institute, Fenway Health

ADVOCACY IS DEFINED by Webster’s Dictionary as “the act or process of supporting a cause or proposal” (Merriam-Webster, 2020). Health advocacy has been defined as “activities related to ensuring access to care, navigating the system, mobilizing resources, addressing health inequities, influencing health policy and creating system change” (Hubinette et al., 2017, p. 128). A substantial amount of clinical research has focused on addressing inequities to reduce disparities and improve quality of health care among underserved individuals, consistent with both definitions of advocacy. Therefore, in many cases, particularly when research is aimed at improving the health and well-being of underserved people, it can be considered a form of advocacy, or at least be thought of as informing and contributing to advocacy efforts.

However, to effectively advocate for underserved individuals, researchers and providers—including clinical psychologist researchers—must involve members of the populations with whom they work to accurately identify critical problems facing their communities, identify effective strategies to address those problems, and accurately interpret the results of the clinical assessments used in research. Problematically, the collaborative aspect of advocacy has not always been followed in clinical research. Health care settings have unknowingly contributed to minority stress for members of marginalized communities due to stigma and discrimination in both clinical and research contexts (Gessner et al., 2019; Gomez, 2013; Lambda Legal, 2014; National Coalition of Anti-Violence Programs, 2017). The historical legacy of minority health care consumers being mistreated and underserved in medical and research settings has exacerbated existing structural barriers to health care access, resulting in poor engagement in care for many that must be addressed to improve the health and well-being of underserved communities and to foster advocacy (Marmot, 2005; Rivenbark & Ichou, 2020).

In the present paper we briefly describe experiences in health care and research settings, and discuss how these settings can implement collaborative, inclusive practices aimed at alleviating chronic and systemic stressors of underserved populations through advocacy.

Addressing Health Inequities: Underserved Populations’ Experiences in Health Care and Research Settings

Marginalized and underserved people have consistently faced structural or systemic inequity and discrimination, which may be particularly felt by those with intersecting stigmatized identities (Robinson & Ross, 2013). For example, African American or Black sexual minority men are substantially more likely to acquire HIV and face barriers in accessing or initiating pre-exposure prophylaxis (PrEP medication) compared to White sexual minority men (Batchelder et al., 2017). These disparities are related to layers of socioecological inequalities rooted in systemic racism (Hanks et al., 2018), homonegativity (negative attitudes toward sexual minority individuals), and stigma related to HIV/AIDS.

For some clinical researchers and providers, understanding the history behind underserved populations’ interactions in health care and research settings may require additional effort and education. Without an understanding of minority stress (King et al., 2008; Meyer, 2003), health disparities outcomes and minority health engagement and adherence may not make sense. An understanding of the current and historical stressors and inequities experienced in health care and research settings is needed for researchers to appreciate what is needed to develop, refine, and...
implement effective interventions for underserved people.

Relatively, quality of provider education on minority health topics directly impacts the availability of competent, culturally sensitive care. This education has been notably lacking in many medical educational settings (Denboba et al., 2013; Gamble Blakey & Treharne, 2019; Like, 2011), despite its absence having deleterious consequences for quality of care as well as health engagement outcomes (Awosoga et al., 2013; McGuire & Miranda, 2014). Additionally, providers' perceptions of their competence related to one component of an underserved individual's identity may not be sufficient for effectively treating a person with interlocking underserved and stigmatized identities. For example, White et al. (2015) found that while providers may feel competent discussing HIV prevention with their patients, they may not feel prepared or comfortable with topics related to gender identity, which is problematic given increased risk for HIV in patients who identify as transgender or gender diverse. While topics related to minority health have not been routinely included in medical or mental health curricula (Beach et al., 2004; van Ryn, 2004), recent efforts seek to address this gap (e.g., Boroughs et al., 2015; Truong et al., 2014). Despite these efforts, inconsistencies in trainings focused on effectively addressing underserved population health raises concern about sufficient assessment competency, as some providers may feel uncomfortable inquiring about minority-health topics (Moll et al., 2014; White et al., 2015). Further, the lack of comfort and training addressing these topics can result in important topics not being brought up or inquired about awkwardly or unfamiliarly, leaving patients feeling stigmatized. Systematic efforts are needed to implement training to ensure competence and comfort among providers and clinical researchers working with underserved individuals, including those with interlocking stigmatized identities.

In addition to incompetent care and care settings marked by systemic inequities, underserved individuals may also experience discrimination or violence during treatment. For example, one underserved population disproportionately impacted by mistreatment in health care settings are transgender and gender diverse (TGD) individuals. Guiding our knowledge of these outcomes, the 2015 United States Transgender Survey (USTS; 2015) revealed that a high rate of TGD respondents endorsed mistreatment and discrimination in health care settings. Specifically, one-third of TGD individuals surveyed in USTS reported having a negative experience in a health care setting, including experiences of verbal harassment, physical, or sexual assault in the past year. Of those sampled, individuals who identified as racial minorities or as disabled reported higher rates of negative health care experiences compared to those without these interlocking identities, evidencing the need to be aware of interlocking stigmatized identities when considering chance of experiencing discrimination. Underserved individuals who experience discrimination, including gender minority individuals, may avoid health care settings altogether due to fear of mistreatment (National Transgender Discrimination Survey, 2010; USTS, 2015), perpetuating continued expectations of stigma and invalidation within care settings (Sloan et al., 2017). This population exemplifies a stark look at direct experiences of violence that may lead to a negative association with health care settings, which can be extrapolated to other marginalized and underserved populations, as many underserved patients carry mistrust of the very medical system intended to serve them. In order to reduce medical and research mistrust, efforts are needed to prevent discrimination in health care and clinical research settings and implement trauma-informed care practices.

Medical and research mistrust are common barriers to producing research that informs and supports advocacy efforts. Marginalized underserved communities, particularly people of color, have long faced exploitation and discrimination in the context of medical treatment and research (e.g., Tuskegee; Darcell et al., 2010). Evidence indicates that many African American health care consumers remain aware of past violations of rights in the Tuskegee Syphilis Study, yielding a demonstrable negative effect on attitudes toward medical care (Freimuth et al., 2001). Further, lack of trust in research is an influential barrier to participation in research (Brown et al., 2014; George et al., 2014; Limkakeng et al., 2014; Schomter, 2012). In addition to the historical context, insufficient provider training resulting in culturally incompetent or even discriminatory behaviors continue to perpetuate medical and research mistrust and, thereby, perpetuate inequities in health care more broadly.

Relatedly, the concept of cultural mistrust, the adaptive attitudinal stance in which a person of color is suspicious or guarded toward a White person (Terrell et al., 1981), may influence the acceptance of medical and psychiatric diagnoses and psychological interventions (Whaley, 2001). For example, the messages patients tell themselves about potential side effects and medical treatments, informed by the historical context of exploitative experiments and procedures, can reduce treatment engagement and adherence. Myers et al. (2018) examined urban African American women and found that age, uncertainty (measured via the Need for Closure Scale), and conspiracy beliefs predicted medical mistrust towards HIV treatment. The study authors acknowledge that conspiracy beliefs have been a strong historical predictor of medical mistrust, and also have a protective and social role, permitting the passage of information as it pertains to protecting a minority group. Thus, clinical interventionists are challenged to develop and implement effective strategies to address the impact of limited inclusion of underserved individuals who may not be trusting of medical systems. In pivoting to a collaborative model (discussed in the following paragraphs), informed by an understanding of minority stress and the historical context of exploitation, insufficient training related to working with underserved individuals, and continued discrimination, providers have the opportunity to strategically improve the quality of care and health and mental health outcomes through collaborations with community members.

Discussion/Specific Practice Recommendations: Improving Access to Care and Navigating the Health care System

While there are challenges related to merging advocacy and psychological research, including potentially competing goals and outcomes as well as differing conceptualizations of how to achieve psychological well-being, there are several strategies that may be useful. Community-based participatory research (CBPR), as described by Israel (2010) and others (e.g., Collins et al., 2018; Uerth et al., 2016), emphasizes a methodology based on a lateral, partnered approach in which both partners are egalitarian. Its methodology focuses on equitably counting all participants' expertise (community members, academic researchers, and other stakeholder team
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members) into decision making, resulting in shared ownership of the project. CBPR has been described as a way to increase the odds an intervention is effective by ensuring underserved community partners are empowered to voice their perspectives and contribute throughout the research process (Wallerstein & Duran, 2010). By involving members of an underserved community in every stage of the research, including identification of critical questions, the development of intervention strategies to be tested, as well as interpretation of results, research can best identify areas in need of advocacy and, ultimately, identify effective intervention strategies. As many challenges faced by underserved individuals are influenced and exacerbated by socio-political historical contexts, systemic inequity, and sociocultural layers of bias and discrimination, the research questions identified by members of underserved communities often indicate areas of needed advocacy that are often underestimated by “the ivory tower” (e.g., Chung et al., 2008; Williams et al., 2018). Further, by equitably fostering lateral collaborations between members of an underserved community and researchers, as well as other key stakeholders, questions that may isolate the underlying challenges, or root causes, of problems as well as effective solutions can be identified, tested, and accurately interpreted. For problems that are rooted in historical discrimination, economic inequity, and systemic oppression, these collaborations can result in the identification of community and research-based advocacy strategies. The end goal may be ensuring access to care, navigating research or medical settings, mobilizing resources, which are ultimately needed to improve the psychological and physical health of underserved individuals, consistent with Hubinette’s definition of health advocacy (Hubinette et al., 2017).

However, effectively implementing CBPR is difficult, time-consuming, and often expensive, which precludes its use in many contexts. Therefore, when conducting full CBPR is not possible, we propose that clinical researchers consider using components of this strategy, often referred to as community-informed strategies. These practices can be thoughtfully and systematically implemented in a range of research methodologies, with the goal of involving empowered community members at various stages across the research process. While the strategies we describe do not strictly adhere to CBPR methodologies, we suggest infusing these strategies into more traditional research methods, including intervention design and testing.

One example of using community-informed strategies is exemplified through Batchelder et al. (2015) and Batchelder et al.’s (2013) studies. Batchelder developed a psychological intervention strategy to reduce internalized stigma and shame among people living with HIV and substance use disorders based on previously conducted qualitative and quantitative analyses which solicited open-ended feedback from individuals living with HIV and substance use disorders about the root causes of suboptimal engagement in HIV self-care behaviors. Through this work, community members identified internalized stigma and shame as psychological barriers to engagement in HIV self-care. Batchelder then iteratively developed an intervention to improve HIV self-care behaviors (Batchelder et al., 2020) based on additional qualitative interviews with individuals living with HIV and substance use disorders and providers who work with this population, such as infectious disease and addiction medicine physicians, psychologists with expertise in HIV and substance use, and case managers who work with this population to identify key components. These interviews started with Dr. Batchelder presenting evidence-based content to the individuals living with HIV and substance use disorder, and next their providers, iteratively refining the content and presenting the updated content in subsequent interviews. Through this process, Batchelder updated language, including reading level and word choice; examples used in exercises; figures in worksheets (e.g., changing cartoons, perceived by individuals living with HIV and substance use disorders as child-oriented and condescending, to emojis, which were perceived as more adult-oriented); the number of sessions; and added a text platform to meet the needs of the marginally housed individuals who had government subsidized cellphones without smartphone capabilities (Batchelder et al., 2020). She then tested the refined intervention content in a proof-of-concept study, after which she conducted exit interviews with participants to obtain additional insight for interpretation of the results. To then adapt the intervention for men who have sex with men living with HIV and substance use disorders who were suboptimally engaged in HIV care in a different city, Batchelder et al. (2020) then conducted another set of qualitative and quantitative interviews to confirm the need for the intervention and refine the intervention content and materials in culturally relevant ways. The results from this work were then presented to local community advisory boards and community-based organizations that serve people living with HIV to obtain additional feedback. This later iterative refinement involved adding some new content identified in the interviews, including examples related to interlocking stigmatized identities described in the interviews (e.g., femmephobia) as well as additional content related to the role of stigmatizing language (using the “Addictionary”; Kelly, 2004). This trajectory of work exemplifies how clinical psychology researchers can involve empowered members of underserved groups at varying stages of clinical research to iteratively identify the problem or area of focus, inform the development and refinement of interventions, and to interpret the results, even when full CBPR methods are not feasible.

In addition to working collaboratively with members of underserved communities to identify areas in need of focus, specific research questions, and the development and iterative refinement of interventions, collaborations are imperative for accurately interpreting the results of research projects and ways that research results can inform advocacy initiatives. Involving community members and key stakeholders, via community advisory boards or peer advisors, in the interpretation of results often facilitates accurate and meaningful interpretation of research findings and the identification of areas in need of clarification. Further, as those who have lived experiences relevant to the questions being asked frequently have critical insights regarding the interpretation of research results and ways in which research findings can meaningfully inform advocacy strategies in the very communities they are geared to aid. For example, in a qualitative study of people with substance use disorders enrolled in group-based Hepatitis C treatment in the Bronx, participants identified ways in which their group treatment impacted their views of themselves, such as through reducing internalized stigma (Batchelder et al., 2015). Further, group members noted that the camaraderie they fostered in group treatment generated advocacy initiatives, including lobbying for increased access to Hepatitis C treatment for others.

When working with underserved individuals, it is imperative to foster trust through empowerment and gratitude for their contribution. In research contexts,
advocacy includes ensuring research participants have a clear understanding of what is involved in the research in which they are being asked to consider participating. In both clinical and clinical research contexts, practices of informed consent at appropriate reading levels at the outset of treatment can be useful to guide treatment, confirm participants understand the procedures taking place, and illustrate how their contribution will be used. Informed consent optimally allows patients to weigh the risks against perceived benefits and make an unbiased choice towards participating (or withdrawing) in any treatment or outcomes research. Working to ensure potential research participants feel comfortable and empowered to ask questions and voice disagreement is imperative in medical and research contexts.

Being aware of any barriers to informed consent is helpful for ensuring underserved individuals feel empowered in clinical and clinical research contexts. For example, when working with individuals with variable reading levels, consistently offering to read the consent form to participants, and normalizing this practice, can increase the likelihood that individuals who may be reluctant to disclose literacy challenges will engage in informed consent. Food insecurity can also be a barrier to informed consent; Batchelder and colleagues routinely offer impoverished, marginally housed individuals with substance use disorders a snack and beverage prior to completing the informed consent process to ensure individuals are comfortable prior to the informed consent process and subsequent study visits. Working to foster trust and empowerment when working with underserved individuals requires facilitating active participation in informed consent, which often includes being cognizant of potential barriers, including literacy level and unmet immediate needs, when necessary (e.g., providing food).

One issue that may occur within hidden or low base rate populations is the issue of scarcity, which may require plans in place for thoughtfully addressing insufficient representation of a population’s feedback on a protocol. Either by using a formal method, such as CBPR, or by thoughtfully incorporating members of the population with whom clinical researchers are focused, lateral opportunities for offering insights, guidance, and interpretations will improve the quality of clinical research, the effectiveness of interventions, and the utility of research in advocacy endeavors, even if the feedback comes from a small corps of community members.

For clinical research to effectively contribute to advocacy efforts, we propose that research questions, methods, and clinical interventions should be developed with the perspective of the target population in mind. When possible, clinical research should strive to equitably involve members of the target population and stakeholders at each phase. Efforts should be made to ensure all perspectives influence the formation of research questions, intervention development and refinement, and final interpretation. When it is not possible to involve members of the target population at each stage, involving individuals at selected stages can increase the likelihood that clinical research can inform advocacy. For example, involving target population members in the piloting of studies, giving feedback on the instruments being used, as well as the mode of delivery have been successfully implemented in Batchelder’s recent work.
Conclusion

In the present paper we defined health advocacy using Hubinette et al.’s (2017) definition: that which helps to ensure access, proper navigation, resources, policy and systems in place resulting in a decrease of health inequities. Based on this definition, we propose that clinical psychology research aimed at identifying and addressing the health and well-being of underserved individuals has the potential to serve as a tool in informing advocacy as well as be a form of advocacy in itself. Further, we examined how clinicians and clinical researchers can achieve research that informs and contributes to advocacy, by involving tenets and strategies of CBPR even when full CBPR is not feasible, with a focus on the barriers often faced by underserved individuals accessing and navigating health care systems.

There is a long history of underserved health care consumers receiving suboptimal treatment in medical, clinical psychology, and clinical research settings. This discriminatory historical context has directly contributed to poor access, undue barriers, and poor engagement in care—hurdles that must be addressed in order to improve the quality of care and its effectiveness. In the present paper we reviewed several ways that underserved individuals have been marginalized in health care and research settings, and discussed how the implementation of collaborative, inclusive practices might inform strategies for alleviating the chronic and systemic barriers to effective and accessible care for these historically underserved populations. Clinical psychologists must involve members of the communities with whom they work to accurately identify critical questions and problems facing communities, develop effective strategies to address those identified problems, collaborate with community members to accurately interpret the results of the research assessments, and work together to use the results in advocacy initiatives to improve the health and well-being of the communities.

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Advocacy initiatives with underserved individuals

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Address correspondence to Claire Burgess, Ph.D., 940 Belmont Street, Brockton MA 02130; claireburgess10@gmail.com
Supporting Transgender/Gender Diverse Youth Across Settings and Systems of Care: Experiences From a Pediatric Interdisciplinary Clinic

Melissa A. Cyperski, Mary E. Romano, and Cassandra C. Brady, Vanderbilt University Medical Center

ONE OF THE GUIDING PRINCIPLES of working as a mental health provider is to recognize and respond to various psychosocial needs in order to promote health and well-being. Supporting and advocating for the needs of our clients/patients is particularly important when working with diverse or marginalized populations such as sexual and gender minorities (SGM; e.g., lesbian, gay, bisexual, transgender individuals) who may experience greater physical and mental health needs subsequent to experiences of minority stress and frequent harassment or discrimination (e.g., Wagner et al., 2019). Transgender and gender diverse individuals (TGD) are at particular risk. A recent study found that 40% of TGD adults in the United States reported attempting suicide in their lifetime, which is approximately nine times higher than the national average (James et al., 2016). TGD children and adolescents exhibit similar mental health outcomes, with 44% of TGD youth endorsing that they have considered suicide as compared to 11% of their cisgender peers (Johns et al., 2019). Unfortunately, many TGD children and adolescents often experience violence, rejection, and other adverse experiences within the various contexts in which they live and interact, including, but not limited to, experiences in their families, intimate relationships, and schools (e.g., Kann et al., 2018; Kosciw et al., 2018; Ryan, 2009). Health care professionals and mental health counselors, in particular, are in a unique position to recognize, respond to, and advocate for the multifarious and complex needs of TGD youth. However, professionals may hesitate to step into the role of patient advocate for a variety of reasons, including a lack of awareness about appropriate resources for SGM patients and fear of overstepping their boundaries as a provider or operating outside the bounds of their competence—even if they feel strongly about the cause.

Therefore, the purpose of this paper is to outline several possible opportunities for mental health providers or other health care professionals to advocate for TGD patients in order to address their psychosocial needs, enhance health outcomes, and promote resiliency across settings. We hope to highlight various strategies or actions providers can take as needed to support patients and their families on an individual, community, or systemic scale. Additionally, although health care providers can be of service and benefit by acting on behalf of their TGD patients, professionals are ultimately encouraged to work alongside their patients and empower them to advocate for themselves. We have provided case examples from our own work throughout this manuscript to expand upon how to implement advocacy efforts.

Advocacy Examples and Recommendations

Individual Level

At an individual level, TGD youth may feel disempowered after experiencing rejection, bullying, discrimination, marginalization, and/or disenfranchisement. Mental health providers or allied health professionals have the opportunity to collaborate with TGD youth to regulate emotions and then co-construct an action plan that honors the patient’s wishes or needs. The provider might offer to intervene on the patient’s behalf or work to support the youth as they advocate for themselves. Supporting and empowering the individual to advocate for themselves may be partially accomplished through the provision of nonspecific therapeutic factors (e.g., active listening, validation, willingness to collaborate) that offer a corrective emotional experience for the TGD youth and help them believe that change is possible. Additionally, empowerment may be achieved through the application of therapeutic interventions that enhance self-esteem, promote effective interpersonal communication, or facilitate skill development.

For example, imagine you are working with a student who identifies as nonbinary and is repeatedly misgendered with consistent incorrect pronoun usage by one of their teachers. As the provider, you offer to reach out to their teacher to express your concerns and request they change their classroom behavior to become more affirming, but the patient declines and indicates they would like to talk with their teacher independently first. To help the youth prepare for the conversation effectively, the provider can practice role-playing various scenarios and possible outcomes with the youth. You may wish to practice what it might be like to receive a variety of responses from affirming to dismissive and develop a plan for how the youth will cope in the moment accordingly. During follow-up sessions, providers can review the consequences of the conversation with the teacher and assess for ongoing needs. If the youth encountered resistance or did not experience the intended outcome, collaborate with the patient on the development of a plan to escalate concerns such as involving the provider in a follow-up discussion or sharing concerns with the school principal and guidance counselor for additional support.

Community Level

• School. TGD youth may require consistent support as they navigate a variety of challenges at school or in the community. Adversity may be pervasive in the educational setting as acts of discrimination are perpetrated by peers or adults alike (Kosciw et al., 2018). Domínguez-Martínez and Robles (2019) reported that 9 out of 10 TGD students experienced acts of physical abuse, verbal abuse, and cyber-bullying. As a direct result of their experiences, many TGD adolescents feel unsafe at school; subsequently, they have higher rates of school absences, truancy, and premature dropout, which places them at greater risk for adverse outcomes in the future (Wagner et al., 2019). For this reason, it is important that health care providers frequently screen for academic and school safety concerns in their TGD patients.

Multiple national and international organizations have called for increased research productivity to evaluate best practices, curriculum, and programs that support SGM students. GLSEN (2019a) is one such organization that works to create safe
and inclusive schools. They offer a variety of materials that students and families can use to advocate for SGM youth, as well as resources educators and administrators may utilize to implement inclusive curriculum or programming like gender and sexuality alliances (GSAs) in their schools.

For example, consider the case of a transgender adolescent male who was forbidden by his high school to participate in extracurricular activities in his affirmed gender. Historically, this youth exhibited increased gender dysphoria and suicidal ideation after experiencing such injustice, but even with increased suffering he felt hopeless about changing his circumstances and believed speaking up or speaking out would only make the situation worse. Therefore, upon obtaining consent from the patient, his health care provider advocated directly on his behalf by expressing concern to school administrators in a letter of support. Primary goals when drafting the letter included raising awareness about the patient’s needs and making a request for a change in the district’s policies to allow this student to participate. Specifically, the letter presented psychoeducation and research findings about gender dysphoria, described risks associated with noninclusive practices, and offered evidence-based recommendations for more affirming practices or policies. Materials provided by GLSEN, such as On the Team: Equal Opportunity for Transgender Student Athletes (Griffin & Carroll, 2010) and the Transgender Inclusion in High School Athletics: Policy Brief (GLSEN, 2019b), were also attached to the letter to provide precedence and support for the argument.

As is to be expected, sociopolitical factors often dictate the extent to which the school system may be able to accommodate requests and adapt their policies; however, it has been our experience that educational staff members will hear and respond to individual requests to the extent possible. Providers may wish to be prepared to offer compromises and solutions that are agreeable to the patients they serve. For instance, even if amending the school’s athletic policy is still a work in progress, the school district may agree that an individual youth can be offered the opportunity to participate in extracurricular activities in their affirmed gender if the parents of other team members agree and offer a statement of support. However, such an action bears its own set of ethical considerations and must be made in careful partnership with the youth in order to represent their voice, wishes, and needs effectively. The importance of collaborating with and involving TGD youth in decision making that impacts them cannot be overstated. Providers who advocate for TGD youth at school or another public forum may play an important role in promoting access and equal opportunity for TGD youth, but it is not without risk. For instance, a public display of support requires that a student has come out about their identity, which may place them at risk for discrimination or violence. It may also increase feelings of gender dysphoria, even if temporarily, by highlighting differences and disparities between TGD youth and their cisgender peers.

In addition to collaborative problem solving, health care professionals are also advised to be proactive in engaging TGD patients about their needs and offering their support. Although some patients may make specific requests of their providers,
others may not be aware of the ways their health care team can be utilized to advocate or address concerns outside the medical setting. For example, providers may offer to document the medical necessity and their support of students gaining access to bathrooms or locker rooms consistent with their affirmed gender. In our experience, letters of support are best received when they include a specific request for change, an evidence-based rationale for the request, and when the provider offers to be available for additional consultation or dialogue. An invitation for ongoing communication fosters a strong working alliance with the school system and leaves the door open for future collaboration should the patient’s needs evolve or change over time.

Consider the case of a TGD adolescent who experienced bullying when using the restroom associated with their affirmed gender at school. Experiences resulted in fear, bathroom avoidance, and subsequent medical concerns via frequent urinary tract infections. In time, the patient was able to successfully advocate for themselves and asked for an alternative solution at school. Initially they felt supported by their administrators who permitted use of the facilities in the faculty lounge and nursing station. However, after trying the school’s proposed solution for several weeks, the student realized the faculty lounge was too far from their classes and they did not have enough time to use the restroom without receiving sanctions for being late to class. However, they were nervous about raising the issue again as they were worried they might appear ungrateful and because they did not believe another solution was possible. Upon hearing the concern, the provider was able to reach out to education or escalated to the governor’s office (as an extreme example) and, instead, can be addressed ethically and effectively one-on-one.

- **Family context.** It is important to evaluate and enhance experiences of TGD youth in educational settings whenever possible since many SGM youth receive critical support at school, particularly when their home life is challenging or unstable. Although many caregivers are highly supportive of their TGD youth, there is a wide spectrum of caregiving behaviors present in this population, ranging from fierce advocacy to disengaged and even harmful. A survey of SGM youth found higher rates of abuse perpetrated by caregivers as well as lower levels of parental closeness and decreased sense of parental attachment when compared with reports from their cisgender peers (Katz-Wise et al., 2016). Subsequently, familial rejection contributes to high rates of homelessness and involvement in the child welfare system among SGM youth, which further increases risk for trauma exposure, substance use, and health concerns such as sexually transmitted infections (Wagner et al., 2019).

Although family members of TGD adolescents can serve as perpetrators of violence and emotional abuse, caregivers can also enhance resilience. For instance, by using the name their child has chosen in affirmation of their gender identity, caregivers can significantly decrease their child’s suicidal ideation and self-harming behavior (Russell et al., 2018). TGD adolescents who report receiving parental support and acceptance also experience fewer symptoms of depression or anxiety and greater life satisfaction overall when compared to TGD adolescents who encounter parental rejection or those who do not feel comfortable coming out to their caregivers (Ryan, 2009; Wagner et al., 2019).

Data are lacking, but anecdotally parental responses to their SGM youth are often affected by factors such as culture, socioeconomic status, and religious beliefs. Therefore, to assess and address the needs of TGD youth effectively, health care providers are encouraged to do a comprehensive assessment of various values, strengths, and needs within the child/family system and advocate for change as indicated. By identifying sources of both strength and strain in relationships between TGD youth and their parents, providers can use a positive framework that capitalizes on parents’ identified strengths (e.g., protective spirit, willingness to try, interest in learning more) while also intervening and addressing specific concerns such as parents’ sense of stigma or fears of danger befalling their child (Ryan, 2009).

Although there may be a significant overlap with family therapy in the identified goals of improving the health and functioning of the family system, assessing and addressing the family context is also an important form of advocacy in which health care providers can align with and intervene on behalf of the patient. For example, imagine a nonbinary adolescent is seeking affirmative surgical intervention and their caregivers are ambivalent about the need for the procedure given their child’s nonbinary identity. In traditional family therapy, the mental health provider may strive to enhance communication and facilitate a process by which each party contributes to the shared vision and solution within the family context; whereas in an advocacy-focused intervention, the provider will first collaborate with the youth around their hopes and intentions,
then steer the family through psychoeducation and processing toward the particular solution that is consistent with the youth’s goal (e.g., surgery).

**Systemic Level**

- **Health care.** In addition to unsafe or uncomfortable conditions at home or school, TGD youth may experience challenges in other settings as well, including the health care system. Diverse patients have encountered a longstanding history of implicit bias, discrimination, and disparities in medical and mental health care settings (e.g., Boroughs et al., 2017; FitzGerald & Hurst, 2017; Harless et al., 2019). As a field, health care researchers and providers should strive to advance their understanding and approach to factors such as race, ethnicity, gender, sexuality, socioeconomic status, and intersectional identities (Harless et al.). We must continue to consider ways to promote evidence-based, culturally competent best practices and strategies for enhancing the patient experience so all may feel welcome and supported in their health-related needs.

  Particular consideration should be given to patients who have had previous adverse experiences in health care as each interaction with the system—from scheduling an appointment to meeting a new provider and revealing personal information—can be anxiety provoking. Given the negative personal or collectivist experiences TGD patients have encountered in the health care setting in the past, it is important for providers and their staff to be fully committed to offering culturally competent care by demonstrating inclusive and affirmative practices at every point of contact, including on the telephone and in the waiting room. To facilitate the provision of comprehensive affirmative care, professionals may need to step outside their traditional patient care roles to provide education about affirmative best practices to their administrative staff, care teams, medical students or other adult learners to increase access to quality services. Outside the office environment, health care professionals have also conducted trainings and provided consultation with managed care organizations or other systems of care (e.g., child welfare) in the past in which professionals played a critical role in increasing awareness about important TGD health concerns and used the available evidence base to inform best practice recommendations.

  One additional health care resource worth highlighting is the Trans Buddy program (Reilly, 2020). As part of the Program for Lesbian, Gay, Bisexual, Transgender, and Queer (LGBTQ) Health at Vanderbilt University Medical Center (VUMC), a Trans Buddy is a trained volunteer patient

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advocate who is available upon request to help TGD patients navigate the complexities of the health care system. As requested by the patient, a Trans Buddy can visit with or accompany TGD individuals to their medical appointments and serve as a liaison to improve access to affirmative care and enhance clinical outcomes. The advocate will collaborate with the patient around their unique needs and tailor their service accordingly. This may include being a friendly, supportive presence during procedures; advocating for preferred name and pronouns to be used throughout the visit as well as in the medical record; speaking up if patient’s needs, concerns, or requests are overlooked by the provider; or making referrals to affirmative providers. Mental health and affiliated care professionals can serve as volunteers, ensure patients are aware of the service, and collaborate with a patient advocate when available.

Additionally, in an effort to work and learn alongside patient advocates, a Trans Buddy attends visits in our interdisciplinary clinic for TGD pediatric patients to offer an introduction to the service and assist with any needs as requested by the patient or family. As with other aspects of medicine, patients are expected to have better outcomes when the care is provided in an interdisciplinary setting (e.g., Epstein, 2014) and a team of health care professionals can communicate or collaborate seamlessly under one roof. However, establishing and maintaining an interdisciplinary clinic requires a significant amount of advocacy and personal investment. Specifically, health care providers may need to communicate to organizational leadership a clear need for the interdisciplinary service and develop a plan for reallocation of resources as significant effort may be required to designate space, establish provider schedules, or create new billing structures. As with all advocacy efforts, providers are encouraged to have a clear “why” and mission statement around the identified cause.

Sociopolitical and Policy Implications

Providers who are interested in offering high-quality care to TGD youth are encouraged to be aware that they will be called to go above and beyond for their patients by promoting wellness and supporting collaboration, coordination, or continuity of care outside the standard appointment time. Although this process is facilitated by working in an interdisciplinary team as previously identified, health care professionals may also be asked to serve in arenas outside the health care setting. In particular, we would be remiss if we did not acknowledge that TGD youth and their families are influenced by the sociopolitical landscape. Therefore, providers can play a significant role in advocating at the state and federal level for legislation that honors, protects, and serves the SGM community.

For instance, health care professionals may be called to increase public awareness about important TGD health issues such as when a number of discriminatory policies were proposed by the Tennessee state legislature in 2020. Several bills were introduced that proposed to restrict access to affirmative care for TGD children and adolescents. Health care professionals collaborated with community agencies, legal experts, and lobbyists to draft expert testimony to be presented to legislators. In particular, providers engaged in advocacy efforts by using their expertise and social privilege for good to present case examples and synthesize the evidence base in a way that could be easily understood by a lay audience with the goal of influencing informed decision making. In addition to providing expert testimony to policymakers, health care professionals also wrote to their local congress members, signed petitions, penned op-ed pieces in local news sources, and posted commentaries on social media. However, social activism and public displays of social justice may not be for everyone; therefore, health care providers can also engage the discourse and advocate effectively by sharing their concerns among listservs, colleagues, and friends to raise awareness and generate a public presence regarding the issue of affirmative health care and equal rights for TGD people.

Conclusion

In conclusion, it has become clear while working with TGD youth that psychologists and other allied health professionals have an important role to play in advocating for their patients’ rights and needs. Each provider will need to decide what level of intervention is right for them personally and for their patient(s). Upon discussion and assessment of the patient’s unique needs, the provider may determine that promoting change across various systems and settings. At a systemic level, providers can serve as advocates and community leaders by presenting testimony regarding best practice recommendations to legislators and those who are making TGD-related policy decisions. However, there are many other opportunities for providers to engage on a smaller scale and in day-to-day operations that can also support and address the psychosocial needs of TGD patients and families. In the community and settings where youth interact frequently, health care professionals can work with educational personnel to establish affirmative schools and spaces that provide a safe place for TGD patients. At the individual level, providers can offer to be of support to youth as needs arise in treatment and continue to engage in patient-centered practices that communicate genuine care and concern for the well-being of their TGD patients.

For mental health care workers and other allied health professionals who work with TGD youth, we hope that this paper has provided examples of ways in which professionals can get involved and advocate effectively within the scope of their current practices. Ultimately, however, professionals are advised to balance their own call to action and desire to help with empowering their TGD patients to serve as their own advocates and agents of change. In our practice, we believe this is feasible and that children, adolescents, and families are best served by a collaborative relationship with their team of health care professionals who provide ongoing assessment and support for their biopsychosocial needs.

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Advocacy Opportunities From Academic-Community Partnerships: Three Examples From Trans Collaborations

Debra A. Hope, University of Nebraska-Lincoln
Nathan Woodruff, Trans Collaborations Local Community Board
Richard Mocarski, University of Nebraska at Kearney

For a number of years, much of what we know about marginalized communities from psychological research, even most social science work, came from the perspective of “research on” a particular marginalized group, with the majority group as the “healthy” reference sample (Awad et al., 2016). In part, this occurred because very few researchers are themselves members of these communities. In addition, researchers would come into a community, collect their data, and leave, with little ongoing benefit to the community itself. Over time, this exploitation led to communities becoming more suspicious of researchers (e.g., Christopher et al., 2008). Recognizing the problem, sometimes researchers tried to include a benefit to the communities in the research plan.

Community-based participatory research (CBPR) takes a different approach, partnering with marginalized communities in the research process. As described by Wallerstein and colleagues (2018), “CBPR embraces collaborative efforts among community, academic, and other stakeholders who gather and use research and data to build on the strengths and priorities of the community for multilevel strategies to improve health and social equity” (p. 3). The essential aspect of CBPR is the partnership across the research process at all stages, including which questions to ask, selection of research methods, and interpretation and dissemination of results.
Trans Collaborations

Founded in late 2014, Trans Collaborations is a CBPR collaboration between transgender and gender diverse (TGD) communities in Nebraska and academic researchers at two of the University of Nebraska system campuses, Lincoln and Kearney. From the very beginning, the academic researchers, Debra Hope and Richard Mocarski (first and third authors) and local community leader Nathan Woodruff (second author), were fully involved in building the organization. A local community board of six TGD adults, representing a range of ages and gender identities, guides Trans Collaborations. A national advisory board of academic scholars and three additional sites at University of Alabama, Michigan State University, and Louisiana State University round out the organizational structure. All research projects are developed in collaboration with the local community board, including project aims, recruitment strategies, and methodology. The local community board gives feedback on all questionnaire and interview items before deployment, recommends participant payment amounts, and helps recruit participants for research. For example, the local board recently served as an informal focus group to develop content for a new online study of the psychosocial assessment process for obtaining gender-affirming medical procedures. The academic team took the board’s information and developed specific survey items, with ongoing consultation. The board will help interpret the meaning of the results. Woodruff represents the entire board as a co-author on all papers, reviewing them before submission. Although this is our process overall, three Trans Collaborations projects have moved beyond the typical CBPR research collaboration. We would like to describe these examples of advocacy in more detail.

Self-Advocacy Workshops

During a local community board meeting, board members noted that our efforts to help providers be more TGD-affirming would be a long-term project. In the meantime, TGD people would still need to seek medical and mental health treatment, negotiating the often treacherous terrain of interactions with providers and health care staff with the likelihood of being marginalized in the process (James et al., 2016). Out of this conversation was born the idea to develop a self-advocacy workshop for TGD adults and an entirely new line of research for the academic team.

Once the local community board had identified the need, the academic team, led by Mocarski, gathered expertise and funding to develop self-advocacy workshops. Sim Butler, a nationally recognized forensics specialist, came on board and Woodruff, Mocarski, and Butler developed the first workshop plan and piloted it with one small group of six participants. Based on feedback from the pilot group, the self-advocacy workshop grew from a 4- to 6-hour format, built around narrative medicine, behavioral rehearsal of common health care interactions, and development of advocacy skills. Our national advisory board, especially medical providers, contributed to the selection of key interactions in the health care process—for example, making an appointment—a challenge for TGD people who have avoided seeking health care. Local foundation funding supported delivery of the workshop to 36 TGD adults. Butler and Woodruff ran the self-advocacy workshops. Led by Mocarski, the rest of the academic team collected efficacy, acceptability, and satisfaction data. Full pilot data are being published elsewhere but workshop participants were positive about their experience. For example, on a modified version of the Borkovec and Nau (1972) credibility measure, mean ratings were above 8 on the 0–9 scales (9 being the most positive) for whether the workshop would prepare them to share their gender journey with their provider and whether they would recommend the workshops to a friend in the TGD community. We are currently seeking federal funding to develop the model further, including online modules that would aid dissemination.

How do the self-advocacy workshops reflect our community-academic partnership? First, the initial idea of the workshops came from a member of the local community board. Second, the community board, and especially the board chair, were fully involved in every phase of workshop development, refinement, and delivery. Third, the workshop participants themselves helped guide development of the workshops by conveying their desire to take more ownership of their interactions with health care providers and sharing their lived experience in small groups. Fourth, the academic researchers gathered the needed expertise to develop a high-quality, evidence-based product, in collaboration with the community to ensure it was also culturally sensitive. Fifth, by gathering data about the workshop experience and outcomes, the academic researchers set the stage to seek federal funding and eventually enlarge the impact of the workshops, magnifying the impact of the local community board.

Camp BOLD

The second project that illustrates our community-academic collaboration is Camp BOLD, our camp for TGD children aged 5–15 and their families. Camp BOLD is a project of the local community board, not a research or clinical endeavor. Camp BOLD addresses the needs of TGD children who cannot safely participate in most overnight camp experiences without fear of marginalization. Camp BOLD is a weekend-long camp at a retreat center with all the traditional camp activities, including bonfires, swimming, arts and crafts, paddle boating, etc. Five families were enrolled the first year, growing to 7 families the second year and 10 families planned for 2020. Given the growing evidence that strong family support, affirming spaces, and positive peer interactions are associated with positive mental health and well-being of TGD youth (e.g., Austin et al., 2020), the goal is to create a safe space where the children and their families can be themselves and meet other families like their own. Many of the parents have never met a TGD adult, so interacting with the local board members is very helpful to them. The primary contributions of the academic members of Trans Collaborations are help with logistics, fundraising, and collecting participants’ feedback. The local community board has determined that all costs for Camp BOLD should be covered for the families. In the past 2 years, funds have come from national foundations, local churches, and individual donations, with the feedback data helping support funding applications. Feedback from families has been positive, describing the transformative experience of being in an affirming space that celebrates their children, decreases their sense of isolation and fear, and starts a support network that has continued among the families after camp is over.

COVID 19 Virtual Support Groups

Most recently, the Trans Collaborations Community Board has started a third advocacy initiative, online support groups for TGD adults in Nebraska during the COVID-19 pandemic. Social support can help buffer the effects of marginalization stress (e.g., Hendricks & Testa, 2012; Pflum
et al., 2015) and the local board sensed that many community members would be especially isolated during the stay-at-home orders. For these groups, the only role for the academic researchers has been to help publicize the support groups. However, the overall structure and organization of Trans Collaborations was important in several ways. The local community board met online to discuss the need and format for the groups with the project manager providing some logistical support. The Trans Collaborations brand is well known in our community and many mental health providers and local organizations were willing to share information about the support groups because we have built trust over time.

Lessons Learned

Despite the success of these three illustrations of our community-academic collaboration for advocacy, the development of Trans Collaborations has not been without its challenges. Below we will describe some of the lessons we have learned along the way.

Process and Development of the Local Community Board

It took about 2 years for the Local Community Board to develop into a cohesive working group. Many members had been on advisory boards in which they functioned as a rubber stamp or for whom it was more an opportunity to socialize. Over time, board members have engaged more fully in Trans Collaborations, excited by the positive impact they can have on TGD communities. Having an experienced chair for the local board has been important as he conducts the meetings, not the academic researchers. In fact, there is very little hierarchy on display in the meetings—everyone has their roles and takes turns speaking and listening. The local board took the lead on development of the Trans Collaborations mission statement and developed a policy that every research project had to go through the local community board as well as university bureaucracy. Managing the local community board as well as the university bureaucracy can be slowed down by the limited time available from the academic partners as well as university bureaucracy. Managing the local board members speak from their own lived experience as well as their sense of the broader TGD communities.

Extra Time and Effort Needed for Research

The CBPR approach means it takes longer to get research done but the partnership has made the science stronger. We ask better questions in a way that is a more accurate assessment of constructs of interest. The advocacy work benefits from the academic partnership in terms of accessing resources (e.g., a financial structure to seek and receive community foundation grants) but can be slowed down by the limited time available from the academic partners as well as university bureaucracy. Managing this requires patience and organization to keep activities moving ahead. Shared project lists reviewed at weekly team meetings attended by the local board chairperson and academic research team members and the addition of a paid project manager have been helpful to productivity.

Conclusion

In the 5 years since its founding, Trans Collaborations has grown from two informal conversations to a productive and impactful community-based participatory research partnership that has spawned important advocacy work. A shared sense of social justice, a commitment that TGD communities deserve the best evidence-based, culturally sensitive health and mental health care, and a sense of trust with each other have been essential to our success. Although there have been challenges along the way, the shared community and academic leadership keeps everyone focused on the mission. The advocacy projects described above were not in anyone’s mind when we started, but have been an important and valued outgrowth of the research.

References


The Role of Advocacy in Community-Partnered Research With Lay Health Workers in Latinx Communities (Promotoras de Salud)

Corinna Klein, Erika Luis Sanchez, Juan Carlos Gonzalez, Iliana Flores, Yessica Green Rosas, and Miya Barnett, University of California, Santa Barbara

Lay health workers (LHWs) have been recommended as a potential workforce solution to decrease disparities in access to both medical and mental health care globally and within the United States (Barnett et al., 2018; Lehmann et al., 2009; Sharma et al., 2019). LHWs include many different types of paraprofessionals, including community health workers, patient navigators, parent partners, peer support specialists, and promotoras de salud. Promotoras de salud are a specific type of LHW that has helped improve equitable access to services for Latinx communities1 (Ayala et al., 2010). LHWs are often members of the communities they serve or share some significant characteristic with the clients they help support. Research has demonstrated that LHWs can increase access to evidence-based practices (EBPs), such as cognitive-behavioral therapy and parent training programs, in a variety of roles from conducting outreach to serving as the primary treatment providers (Barnett, Gonzalez, et al., 2018). Though LHWs have successfully delivered EBPs in studies conducted in low- and middle-income countries, licensure and certification requirements in the United States frequently restrict EBPs delivery to professionals in mental health settings. Therefore, LHW roles may need to be distinct in regards to addressing service disparities domesticaly (Barnett, Lau, et al., 2018). For example, in this project the role of LHWs was to provide auxiliary support to professional providers to increase engagement in the EBP, Parent-Child Interaction Therapy (PCIT; Barnett et al., 2019).

LHWs address disparities in services by supporting linguistically and culturally competent services, helping community members navigate services, providing education, bridging gaps in access to services, and disseminating information about service availability to their communities (Sharma et al., 2019). LHWs use their social proximity, or membership in and familiarity with the diverse communities they serve, in order to engage clients and build trust (Gustafson et al., 2018). Although the social proximity and shared cultural and linguistic attributes of LHWs, such as promotoras, are critical for their effectiveness in supporting service delivery, engaging families, building trust, and providing interventions, their shared attributes also mean that promotoras face many of the same challenges as the communities they serve. Promotoras may face similar discrimination, poverty, linguistic barriers, and immigration concerns as the individuals they work with. While promotoras may contribute to health equity for Latinx communities, they also run the risk of exploitation by health care services and research institutions.

The risk of exploitation of LHWs is a pressing issue, particularly as health care systems increasingly rely on LHWs to decrease inequities. Task shifting, in which certain tasks that require minimal qualifications are shifted from highly trained workers, who are in shorter supply, to LHWs, has been recommended as a potential remedy for inequities in health care access (Orkin et al., 2019). Interventions focused on task shifting demand increased reliance on LHWs, whose positions are not governed by licensing boards, training requirements, or established systems of remuneration. Without established policies and regulatory frameworks, LHWs are

1The terms promotor/promotores and promotoras/promotoras reflect the gender of LHW(s) based on grammatical rules in Spanish. In this paper, we predominantly use promotoras as all participants were female identified, which is common in this workforce.
exposed to the arbitrary decisions of individual projects and agencies. It has been recommended that task shifting be accompanied by significant policy and infrastructure developments in order to ensure that LHWs are receiving adequate support, training, and funding (Lehman et al., 2009). Currently, although promotoras have developed robust organizations and systems within their communities and have successfully partnered with health care systems nationally, the infrastructure to support their work is often lacking (Schneider & Lehmann, 2016).

This paper will discuss how community-partnered research and advocacy can be leveraged to mitigate the potential exploitation of promotoras, a vital but undersupported workforce within health care systems who are increasingly playing a critical role in promoting health equity in Latinx communities. A community-academic partnered research project with university researchers and a promotora network will serve as an example to demonstrate steps researchers can take to learn about advocacy from promotoras, serve as advocates for promotoras, and to ensure that their advocacy is directly responsive to the promotoras’ expressed needs.

The LEEP Project

Lay Health Workers Enhancing Engagement for Parents (LEEP) is an NIMH-funded research study to develop, implement, and evaluate a LHW-delivered intervention aimed at increasing Latinx parent engagement in PCIT (Barnett et al., 2019). In this intervention, LHWs conduct home visits to promote entry into and engage in PCIT, which is delivered by professional providers in community mental health agencies. LEEP is a community-partnered study with university researchers, community mental health agencies, and a local promotora network. The LEEP intervention was developed collaboratively with promotoras and agency leaders. The intervention was informed by promotora knowledge of their community needs and strategies they use to enhance engagement into services, as well as agency awareness of mental health service provision within the community, and existing intervention materials from a pilot trial (Barnett et al., 2016).

The Santa Barbara County Promotores Network is a county-wide organization providing services to the community since 2002 (SBC Promotores Network; n.d.). The network provides training in being a promotora and coordinates projects with other service sectors. With approximately 200 members, promotores, who are a predominantly volunteer workforce, can provide services in English, Spanish, and some also speak Mixteco and Nahuatl (the latter two are native languages within Mexico). Promotores serve families in the community to provide education and connection to resources in a variety of mental health (i.e., alcoholism, drug abuse) and physical health topics (i.e., diabetes, cancer, and family violence prevention, emergency preparedness, low-cost health insurance). Through hands-on experience, this network’s mission is to “empower families and individuals with respect, dignity, and compassion by enhancing the quality of all aspects of their lives through education and the promotion of healthy behaviors” (Santa Barbara County Promotores Network, n.d., para. 1). Given the range of health and social issues addressed, promotores become involved in specific projects based on their interests. For the current project, promotores with a history and interest in working with parents were approached by the region’s lead promotora to participate.

The Quality Implementation Framework (QIF) informed the study aims and design (Meyers et al., 2012). The QIF outlines four phases for implementing new interventions and programs, the first of which is conducting a thorough assessment of needs, fit, and readiness for a new intervention (Meyers et al., 2012). The framework recommends assessing the needs and resources of the organization and community in which a new intervention will be implemented, as well as evaluating whether the intervention fits these needs and aligns with the organization and community’s preferences and values (Meyers et al.). This paper outlines the steps the LEEP team took to understand the promotoras’ needs and preferences, beginning with qualitative interviews, and to provide advocacy shaped and informed by and directly responsive to their expressed requests.

Qualitative Interviews

As part of the first phase of the QIF, qualitative interviews were conducted with LHWs to understand the local context and their training needs. Semistructured qualitative interviews were conducted by two bilingual, bicultural graduate students in Spanish with 15 Latina, Spanish-speaking promotoras, who each had 1 to 20 years of experience serving in their promotora role (\( M = 4.29, SD = 4.78 \)). Questions inquired about the work promotoras had done, their role as promotoras, and culminated in a question about how LEEP might best support the work promotoras were already doing with families. All interviews were then transcribed and coded in Spanish by a coding team of bilingual, bicultural graduate students. Initial coding took place using a priori codes based on interview questions (e.g., engagement strategies) and also allowed for the development of emergent codes (e.g., advocacy). An iterative consensus process was utilized in which coding team members met regularly to establish a final code book, discuss emergent codes, and resolve any coding discrepancies through dialogue until consensus had been reached. Upon completion of coding, thematic analysis of co-occurring codes was conducted using NVivo software. The analysis involved a process of analyzing the quotes that emerged within specific co-occurrences of codes (e.g., Advocacy + Community) to produce themes. Textual analysis provided further insight into themes such as advocacy. Advocacy emerged as a multifaceted theme, referring either to promotoras advocating for their community or as a request that the research team advocate for promotoras in order to support their work.

- Promotoras advocating for their community. Promotoras discussed serving as advocates for their community, by hearing the concerns of the individuals they serve and either helping individuals voice their needs or serving as an advocate for the individual. They discussed how helping members of their community find their voices was a gratifying part of their role as promotoras:

  This was a success for me because she could not raise her voice on her own. So I helped her, I advised her a bit, and this boosted her confidence in herself and gave her the courage to report [domestic violence].

They also narrated stories about families who were unable to navigate educational and other systems independently due to the many barriers they face, including language, time constraints, and working multiple jobs. Promotoras described how they were able to support families in navigating these systems, often serving as a voice in order to pave the way so that the families they served would then have a platform on which to speak and be heard. A promotora described helping a single mother who was unable to attend parent-
teacher meetings at school because of her work schedule, and her inability to communicate with the teachers about her need for a different meeting time due to language barriers and uncertainty about approaching a school authority. The promotoras accompanied the mother to meet with the principal and help advocate for modified scheduling:

I was only a translator for [the mother], [she] wouldn’t speak and tell them her needs, [she] was afraid because they had told [her] this principal is very strict and that you can’t speak with her….but now you see what we achieved.

All of the advocacy activities the promotoras described were based in the expressed needs of the families they served. The promotoras frequently mentioned the trust that they were able to establish, and the communication they were privy to as a result. Because community members trust the promotoras, due, in part, to their shared lived experiences, promotoras were granted further insight into the advocacy needs of these community members.

- Promotoras requesting advocacy. Promotoras identified several areas of their own need during the qualitative interviews. They spoke at length about the personal benefits they derive in their role as promotoras, emphasizing their work as a component of their identity and the primary compensation being gratification at serving their community. However, promotoras also voiced financial need, emphasizing their desire to receive monetary compensation for their labor:

I think we have to validate all the work the promotora does, and also, we have to pay the promotora who does that job. Why? Because the fact of being a promotora does not mean we don’t have needs.

In addition to highlighting the importance of receiving financial compensation for their work, promotoras discussed the need for legitimacy as a professional identity and recognition:

I believe they should prepare us better as promotoras because as promotoras we have a lot of reach in the community and many times the promotora is not recognized and I believe the promotora should also get recognized because now that I am a promotora, I see that we have a lot of reach in the community.

In addition to their frequent mention of the need for funding and public recognition and legitimacy, promotoras stressed their desire for additional training. Promotoras described dedicating their personal time to obtaining training in the community on a variety of topics that may be pertinent to their communities, including diabetes education, Alzheimer’s education, parenting, and more. However, due to their status as paraprofessionals, they reflected on limited educational opportunities available to them, particularly at no cost. They repeatedly articulated the need for more trainings as demonstrated by the two quotes below:

[You can support us by] giving us a little more training to know how to give the people what they want.

Another promotora described the need for more training in the following way:

You, as a school [could help us] have more access to your projects, … like how parents and children enrich each other, you and [the promotoras] can enrich each other…. There are many things that we can learn, and there are many professional people in many fields who we can learn from, and do many programs together. Because I think that you have the means to do it, and this would benefit both the promotoras and the community, no?

The promotoras expressed eagerness to develop and maintain partnerships that will ultimately benefit their communities and the families they serve. This quote also highlights the multiple levels of supportive collaboration and advocacy that permeate the work of promotoras. Promotoras enable parents to support children and emphasized the expertise they have in reaching families, while simultaneously expressing a desire to benefit from the resources and training available from the university researchers to enable them to support these parents.

Community-Partnered Activities

Following the qualitative interview and thematic analysis, the LEEP research team presented its preliminary results to the interview participants in a community meeting. The meeting was held at the promotoras’ primary meeting site in order to ensure accessibility, and feedback was elicited from the promotoras on the qualitative analyses, which included the themes presented in this paper and additional themes related to engaging parents, and the promotoras’ training needs, in order to ensure that their voices were being accurately represented in each theme. Their feedback was incorporated into the results and additional thoughts and concerns emerged in dialogue between the promotora network and the research team. During this meeting, the importance of advocacy was further highlighted as the promotora network requested that university researchers use their privileged academic positions to advocate for increased integration of promotoras within health equity projects and to support promotoras in receiving the funding, training, support, and recognition that they need in order to continue their work. They specifically requested that LEEP’s lead researcher present the study findings to system leaders (e.g., health care directors) on integrating promotoras into new projects and initiatives in an equitable way.

Advocacy with the promotoras included fully integrating them into the research project to make sure their voices and expertise shaped the LEEP intervention and their roles. Promotoras who expressed interest in participating at a higher level in the project were invited into an Advisory Group, which met quarterly to collaboratively discuss the needs that had been identified through the qualitative interviews and to develop the promotora-delivered intervention. In accordance with the promotoras’ expressed wishes for additional training, a training sequence was developed by the research team using a previous model for training LHWs and incorporating promotoras’ requests (Barrett et al., 2016). Promotoras were trained in providing LEEP care extension services for PCIT, as well as in conducting informed consent for parents. Training was aimed at enhancing promotora knowledge of PCIT, addressing practical barriers to engagement, motivating parents for treatment, modeling parenting skills taught in the program, and promoting homework adherence. Advisory Group meetings ensured that promotoras’ knowledge of their community’s needs, their own capacities, and their aspirations for the project were being regularly considered and incorporated into LEEP. Furthermore, the promotoras and research team co-presented at an annual conference for promotoras, led by Vision y Compromiso, a statewide agency providing training and support to promotoras. At the conference, university research team members presented along-
side promotoras, who are members of LEEP’s advisory group, allowing both promotoras and researchers to present and to bolster one another’s voices. Promotoras gave direct input on their experiences collaborating with researchers and participating in the LEEP project.

**Advocacy With Health Care Leaders**

In response to the promotoras’ request that qualitative results be shared with other system leaders, research team members presented at a local event that was intended to help researchers and other system leaders (e.g., hospital administration) learn about how to integrate promotoras into research and service projects with a lens on equity. The need for training, supervision, and compensation were all discussed in a panel that included researchers, promotoras, and other system leaders, who had successfully worked with promotoras.

**Advocacy to State Legislators**

In order to continue responding to the needs voiced by the promotoras and to their requests for advocacy by their university partners, LEEP’s lead researcher presented at The California Initiative for Health Equity and Action (Cal-IHEA)’s Workforce Innovation Briefing, an evidence-briefing for legislative staff and advocacy organizations focused on informing policy to strengthen health care in California by supporting front-line workers such as LHWs. Communicating research to policymakers is a critical component of the advocacy work psychologists can participate in (Emmons & Gandelman, 2019; Purrtle et al., 2017). LEEP’s lead researcher communicated the study’s findings to policymakers after discussing them with promotoras in order to ensure accuracy of representation. The findings focused on the need for financing, certification, and training in order to support the promotoras’ ongoing service to their community. Policy recommendations in the presentation included establishing infrastructure to support this vital workforce and ensure that they can continue to promote health equity.

**Conclusion**

Promotoras are uniquely situated to facilitate engagement and access to health, mental health, educational, and parenting services for Latinx families, in part due to the trust they engender in their communities. The factors that enable them to build trust and effectively support Latinx communities are frequently vulnerabilities that they share. Disparities in access to services have led to increased focus on task sharing and collaborating with promotoras and other LHWs who can address these disparities. Because infrastructure and systems of support for the work of LHWs are frequently limited, especially within formal systems of care, it is pertinent that researchers, agencies, and academic institutions who work with LHWs work to develop such supports by both providing them and advocating for policies to enhance their work. This advocacy has the potential to improve training, supervision, recognition, and compensation for promotoras, which may help address the potential for exploitation and burnout within their efforts to address mental health needs in their communities.

Advocacy efforts must be informed by the expressed desires of promotoras and should be directly responsive to their requests, particularly since university researchers may not be members of the group they are advocating on behalf of. Within their interviews, promotoras highlighted the core components of the advocacy they partake in on behalf of their community, with an emphasis on establishing trust, listening to the voices of the families they serve, and either supporting their community in voicing their own needs or serving as a voice only when the individuals they serve were unable to do so on their own. LEEP attempted to follow these guidelines, developing partnerships with promotoras, ensuring that their needs were being understood through ongoing dialogue and feedback, presenting at their request, and presenting alongside them so that both sides of the academic-promotora partnership were being voiced and heard in tandem.

Many of the requests for advocacy that the promotoras voiced in their qualitative interviews align with recommended steps in the QIF, including a desire for additional training, support, funding, and certification (Meyers et al., 2012). These concerns raised by the promotoras are not only vital to their work and ability to serve their community, but are critical within multiple phases of the QIF, which emphasizes building capacity for the implemented intervention by maintaining and training staff, fostering a supportive climate, providing assistance and supervision, and ensuring ongoing support. In order to make LEEP responsive to the community and sustainable over time, advocacy efforts emerged as a critical component of the project.

The promotoras’ descriptions of their advocacy efforts and their direct requests shaped advocacy efforts that emerged from LEEP. Promotoras described their role to the research team as a bridge (“mi rol es un Puente”) between their community and the services they need. Just as the promotoras described acting as a bridge between their communities and medical and mental health services, they requested that the research team serve as a bridge between their network and the larger legislative systems that impact the policy landscape.

**References**


Mobilizing Mental Health Training Efforts to Align With Advocacy for Disenfranchised Groups in Global Contexts: Trauma-Related Training in the Caribbean as an Example

Anu Asnaani, University of Utah
Su-Anne R. Charley White, HERStoire Collective, Castries, Saint Lucia
Tammi-Marie Phillip, Butler Hospital, Providence, RI

THE CARIBBEAN, a region comprised of 13 sovereign states, 17 dependent territories, and approximately 43 million persons, represents an area rich in diversity of all forms. While this region has made significant strides in a number of health care sectors, mental health progress has fallen behind. Historically, the Caribbean region followed the British model of mental health delivery, initially focusing on institutionalization and then later de-institutionalization once more effective psychotherapeutic and psychopharmacologic interventions became available (Hickling & Gibson, 2005). This model, however, remained highly centralized to mental health hospitals and major cities within the region, with limited outreach and community-based mental health resources, a pattern that continues to exist today. A report published by the World Health Organization (WHO) found that although roughly one quarter of the total disease burden in Latin America and the Caribbean is due to mental or neurological disorders, countries within these regions, on average, only spend about 4.3% of their health budget on mental health (World Health Organization, 2011). More recent studies have actually put this number closer to 2%, only the minority of which is allocated to outpatient, community mental health centers (Phillip, 2017).

As a result of this limited budgetary allocation for mental health care systems, the treatment infrastructure across the Caribbean remains deficient. Specifically, there is a lack of governmental funding to support a greater network of providers (who are, as a result, very overloaded in these settings; WHO, 2011), and relatedly, a lack of funding to provide essential training in effective treatments and crisis management to these overburdened providers (Caldas de Almeida & Horvitz-Lennon, 2010; Jarero et al., 2014). Another barrier to more widespread dissemination of evidence-based practices (EBPs) in particular has been a glaring lack of resources related to conducting high-quality research on factors impacting EBP utilization or implementation in this region (Razzouk et al., 2008; Sharan et al., 2009), which further impedes systematic roll-outs of EBPs in the region. This, coupled with the low numbers of providers (psychiatrists/psychologists, psychiatric nurses, and social workers), has led to limited access to effective treatments in the area (Caldas de Almeida & Horvitz-Lennon, 2010).

The current lack of legislation and national oversight to provide services and to protect the rights of those with mental health disorders in the Caribbean further compounds these issues. For instance, Saint Lucia, an independent island nation in this region (and one of the main countries of focus in this article), has none of the following: mental health policies outlining triage of services, strategic plans that outline national mental health education or awareness campaigns, legislation that protects the rights and safety of individuals seeking mental health treatment, or an overarching national mental health authority/council. These deficits exist even though several documents to address some of these deficiencies have been drafted (but not enacted) in the past decade (Francis et al., 2018). Current governmental budgets for mental health cater primarily to emergency or disaster situations, with little provisions for the daily mental health care of the citizens (WHO, 2009), similar to the majority of other countries in this region.

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Correspondence to Corinna Klein, Gevirtz School, University of California, Santa Barbara, CA 93106; cklein@ucsb.edu
(WHO, 2011). Of most concern, these reports highlight the fact that the vast majority of the countries in the Caribbean last updated their mental health legislation prior to the 1960s, which predated the current conventions for human rights.

This legislative weakness in ensuring the protection of human rights is particularly worrisome given that there still exist, quite prominently, laws that criminalize whole subsections of the population—specifically, those who identify as being part of the LGBTQ+ (lesbian, gay, bisexual, transgender, queer and related sexual or gender minorities) community across the region (Government of Saint Lucia, 2005; Human Rights Watch, 2018a; Jackman, 2017). This ongoing criminalization of LGBTQ+ citizens (specifically, with current legal codes outlining 5- to 10-year imprisonment terms for actual or even intended consensual sexual activity between two members of the same sex) has led to a notable number of individuals fleeing the region to seek asylum in the United States and Europe where there are human rights in place to protect members of this community (Alessi, 2016; Phillip & Williams, 2013). Governing bodies have argued that while these laws are technically in place, they are not enforced. However, the fact that no antidiscrimination laws exist to protect these individuals or to buffer ongoing stigma towards individuals identifying as LGBTQ+ means this group is still at constant risk for real threats to their safety by Caribbean societies at large (Human Rights Watch, 2018a, 2018b).

Needless to say, the lack of legislation protecting human rights violations towards the LGBTQ+ population (and others, specifically women and youth; United Nations Development Programme, 2012), combined with the lack of mental health legislation, creates significant concern for those individuals with mental health disorders in such vulnerable communities in the Caribbean.

Other complicating factors underlying these deficient mental health laws include ongoing stigma about mental health more broadly (i.e., that expressing mental health concerns is a sign of weakness or other moral failing) in this region (Dudley-Grant, 2016; Yorke et al., 2016), low treatment-seeking rates for mental health (Pan American Health Organization & Caribbean Community [CARICOM] Secretariat, 2006), and disparate access to mental health care in various parts of this island archipelago (Sharpe & Shafe, 2015). Thus, given these various factors impacting the current state of the poor mental health legislation and treatment infrastructure in this global setting, we believed that it was of paramount importance to establish a partnership between research scientists (who have psychological science expertise on implementation of EBPs) and regional advocates (who have public health and policy expertise) to make implementation efforts in the region maximally effective and culturally responsive.

Establishing Advocacy Partnerships

Given a number of priority areas in mental health, it is important to discuss here briefly why trauma-related psychopathology and training were chosen for the partnership we established with advocates for mental health reform in the region (the specifics of which will be discussed in detail below). First, given very high trauma exposure rates across the Caribbean and world (Benjet et al., 2016), coupled with a fairly significant proportion of trauma-exposed individuals going on to develop posttraumatic stress disorder (PTSD) or a number of other mental health problems (e.g., generalized anxiety, specific phobias, depression, substance use; Asnaani et al., 2010; Himle et al., 2009; Kessler et al., 2012; Pilgrim & Blum, 2012; Sabri et al., 2013), this area was regarded by public health advocates and providers on the ground as an important area for collaboration for the Caribbean region. Notably, there exists robust evidence for psychological treatments for trauma-related symptoms, with significant support for cognitive behavioral treatments (CBT) for PTSD symptoms in particular (one of the most common psychological sequelae following trauma exposure; American Psychiatric Association, 2013). Finally, given the well-documented higher rates of trauma and subsequent mental health burden in the youth, women, and LGBTQ+ individuals in the Caribbean specifically (Asnaani et al.; Himle et al.; Pilgrim & Blum), this area was deemed to be an important focus of mental health advocacy and education.

It is also important to acknowledge that the current partnership described in this paper came from a growing call from colleagues in the public health domain for direct social justice and advocacy activities (Horne et al., 2019). In order to more appreciably address the inordinate and well-documented mental health disparities in underresourced and underrepresented communities, this type of engagement is crucial (Desai et al., 2019; Kirmayer & Pedersen, 2014). Several advocacy frameworks have emerged to guide psychologists to conduct such work, such as one by Hodges and Ferreira (2013) that identified three levels of policy work (provider-, system-, and funder-levels) along with five action domains (Intervention Intent, Communication, Administrative Leadership, Staff Development and Support, and Evaluation) at which advocacy efforts can be most successful.

As a result of this call, the first author (A.A.), a clinical researcher working in outpatient- and community-based settings, started to follow the work of public health advocates and educators to better understand how their expertise could be integrated into such advocacy frameworks to broaden the impact of treatment-oriented research studies in mental health. In the summer of 2018, the work of a Saint Lucian public health advocacy group dedicated to improving the sexual and reproductive health (SRH) of women in the region, the HERSToire Collective (www.herstoirecollective.com), was very visible on social media. Specifically, the founder and Executive Director of this organization (second author S.R.C.W.) was effectively utilizing social media platforms to provide education about important SRH issues, publicizing efforts to change legislation and services for SRH in the region, and had made a request for those interested in various related fields to provide more expertise and support of these efforts. Thus, the authors of this paper started a dialogue about collaborating on ongoing projects.

At this time, the organization was engaged in piloting the Sister2Sister (S2S) Virtual Safe Space Program as a digital platform to address the significant gaps existing in SRH resources and service delivery in Saint Lucia (and the wider Caribbean), particularly for marginalized young women who identified as victims of abuse/violence, LGBTQ+, as engaging in transactional sexual activities, or belonging to other vulnerable groups. S2S was jointly funded by the Caribbean Vulnerable Communities Coalition (CVC) and the Organization of Eastern Caribbean States (OECS), under the Global Fund’s Safe Space and Service Access Grant for Marginalized Youth in the OECS. The pilot initiative, delivered over the span of 9 months, provided an integrated educational program that consisted of 14 virtual psychosocial support group sessions covering a range of pertinent SRH and associated mental health topics. These safe space virtual chats
were moderated by trained experts in these content areas (such as authors S.R.C.W. and A.A.), who would also provide helpful external resources during the virtual support sessions, archived on HERStoire website for later reference by attendees.

The program primarily targeted young women aged 16–24 years old in Saint Lucia, who possess limited access to SRH and related mental health services. Importantly, this intervention utilized and bolstered existing mental health infrastructure by partnering with existing organizations such as PROSAF, a registered support service provider for survivors of abuse and trauma in St. Lucia. Relevant funding agencies, local and regional body stakeholders, as well as the beneficiaries of the program considered the pilot to be highly successful in meeting both the SRH and associated mental health needs of young women, by providing those who accessed the virtual safe space with credible and sound SRH related information, resources and referral systems, as well as confidential and responsive psychosocial support. Consequently, the OECS has deemed this pilot program to be a Best Practice for the region, and the HERStoire Collective has since received commitments from local and regional partnerships to expand the reach of the program to several other Caribbean nations, via integrated mobile technology innovation.

Project Implementation

Content Determination

Given HERStoire’s success with the S2S program and with working with other providers/advocates such as PROSAF and governmental bodies in the region (including the Bureau of Health Education at the Ministry of Health and Wellness in St. Lucia), we decided to leverage these connections to assess specific mental health training needs across a range of stakeholders involved in mental health support in the region. Leaders of these groups noted the need for more training around trauma-related issues, and further highlighted the utility of providing practical tips for supporting trauma survivors in crisis. In addition, PROSAF was forthcoming about high rates of burnout in those providing support for survivors in various capacities, and thus requested that the team ensure provision of training in self-care.

An important feature of effective collaborative public health initiatives is the inclusion of community partners (such as these advocacy groups) as equal contributors to the knowledge exchange (Campbell et al., 2004). As a result, HERStoire (specifically, author S.R.C.W., as a seasoned public health educator) and the speakers (authors A.A., a licensed psychologist, and T.M.P., an attending psychiatrist) devised a 1-day workshop program that took in this advise ment to determine the final topics: psychoeducation on types of trauma and typical posttrauma reactions, informational session on evidence-based PTSD treatments (specifically, Prolonged Exposure, PE; Foa et al., 2007), hands-on skills training for short-term strategies to handle immediate trauma crisis (e.g., breathing retraining, distress tolerance skills), and a final session dedicated to self-care practices with small group break-out discussions on ways to engage in regular self-care to reduce burnout. Provision of such an educational session to a range of stakeholders was deemed consistent with recommended advocacy work at the provider level, targeting the intervention intent and staff development domains (Hodges & Ferreira, 2013). Such a training also closely followed work highlighting the significant utility of educational interventions as an advocacy tool to effect meaningful change in community mental health settings (Ponce et al., 2019).

Recruitment

The first scheduled workshop (held in March, 2019) was advertised a month before the workshop via an emailed flyer to the leadership of various relevant associations/organizations (e.g., medical nurses, psychiatric providers, school counselors, advocacy groups, and governmental health educators in Saint Lucia; for more detailed information on methods, see Asnaani et al., 2020). Despite some 100 requests to attend within the first 2 weeks of recruitment, we could only offer 45 participants a spot to attend due to funding constraints, but we prioritized attendance from a maximal range of stakeholders representing some 19 different organizations/associations on the island. We then offered a second workshop in February 2020 to those who had not been given an opportunity to attend the first one, and were able to increase our capacity to 60 in-person attendees. Furthermore, to expand the reach of this training and mobilize other partners in the broader region, we were able to offer this second workshop as concurrent remote training (via the online platform Zoom) to an additional 12 participants who identified as advocacy group leaders, clinical researchers, therapists, and medical association leaders from 6 other countries (Saint Vincent, Grenada, Antigua, Jamaica, Barbados, and Trinidad). The HERStoire Collective was instrumental in tapping into its professional regional network to broaden the reach of this second workshop.

Funding

It is important here to briefly mention the role of funding, given its relevance to establishing and maintaining partnerships with advocacy groups, particularly in low-resourced settings or non-federally-funded research areas. This first workshop was partially funded by a local corporate financial institution and hotel venue willing to donate space and technical equipment to us, and all remaining costs were covered by the first author’s general research funds so that there was absolutely no cost to attendees of the workshop, along with meals for the day free of charge. However, this limited funding in the first workshop, given the no-cost model for attendees, greatly hindered our ability to accept the majority of interested providers.

The HERStoire Collective was vocal in sharing the success of this first workshop and strongly advocated for a second workshop to be part of a regionally funded project provided by the Equality and Justice Alliance (EJA), in order to obtain financial support to provide this training to those who had been wait-listed for the first training, among others. EJA is a coalition project across several human rights organizations based in the United Kingdom that is dedicated to supporting civil societies and legislative reform that ensure more expansive antidiscrimination laws (specifically towards women and LGBTQ+ individuals) in specific Commonwealth countries. To this end, this coalition launched a funded initiative across multiple countries in the Caribbean region in the spring of 2019 to specifically encourage the development of a unified advocacy strategy across the region to support national-level activities that could inform legislative reform efforts, with mental health reform recognized as one of the three key areas in need of improvement in this region. Our team prepared a joint proposal to apply for this seed funding (another advocacy action recommendation; Ponce et al., 2019), for which we received the funds to hold the second workshop. Importantly, to better meet the objectives of this seed grant and the funding body (EJA), we added some pre- and postworkshop questions to assess change in stigma towards women and LGBTQ+ individuals, and incorporated a brief
formal presentation with testimonials by two invited LGBTQ+ activists from a local advocacy group (United and Strong), who provided education on key terms and issues surrounding mental health for this community, which proved to be a very powerful addition to the original content.

Outcomes

All participants completed pre- and postworkshop questionnaires generated by our team assessing changes in knowledge about trauma and effective treatments for PTSD, stigma towards survivors, and self-care knowledge/practice. Of the 95 individuals who attended both workshops, 93 of these individuals provided informed consent for these data to be examined, and the analytic approach and specific results of the first workshop have been discussed in detail elsewhere (Asnaani et al., 2020). Briefly here, the data revealed that participants from both workshops found the trainings to be overwhelmingly helpful in adding to their knowledge on effective and evidence-based treatments for trauma. In addition, participants reported significantly improved understanding around definitions of trauma, and lower stigma towards trauma survivors, all of which were promising indicators of the utility of such a training endeavor in this global context. Participants also found the self-care module particularly helpful in addressing burnout.

Advocacy-Related Deliverables

An important aspect of broadening the impact of training and research public health efforts in such global settings is to have concrete and well-defined deliverables to provide to the community, providers, and legislators/policymakers looking to make a change in their service/approach (e.g., Valdez et al., 2019). As a result, there were several key deliverables, some previously defined and some that emerged as potentially useful. For instance, during the first workshop with so many different stakeholders in the room, it was clear from group discussions that there were many more resources available to trauma survivors and their providers than each individual group/organization was aware of. Thus, one deliverable that was not initially conceived in the first workshop, but came about organically, was the creation of a group-think resource guide of local mental health treatment and support services provided by each of the stakeholder groups, which our team collated and distributed to all attendees.

Another major deliverable from these trainings was the provision of widely used (in the U.S., at least) psychometrically sound self-report questionnaires for PTSD in adults (namely, the Posttraumatic Diagnostic Scale for DSM-5; Foa et al., 2016) and children (namely, the Child PTSD Symptom Scale for DSM-5; Foa et al., 2018), to equip providers with better ways to assess for PTSD in those they supported. In addition, slide copies, handouts for skills taught and self-care, and some publicly available psychoeducation handouts were provided to all attendees for use as needed with their clients (or for themselves).

Finally, a major deliverable from the second workshop in particular, given its primary funding by the EJA and their mandate to advocate for mental health reform in the region, was the presentation of the preliminary results of the second workshop by second author S.R.C.W. within days of it occurring to a regional body plenary session held in the first week of March, 2020. During this session, it was made clear that to address existing intersectionality in vulnerable populations such as women, girls, and members of the LGBTQ+ community, it would be beneficial to capitalize on the involvement and organic creation of working groups in the mental health realm with members representing the diverse mental health needs of key populations. It was strongly suggested by the regional public health advocates and legal representatives attending this plenary session that intra- and inter-country working groups be established in order to yield significant improvements in mental health legislation. Specifically, this would entail having advocates in these workgroups use the results from this project, and others that were concurrently occurring across the region over the course of the 1-year EJA initiative, to inform strategies that advance mental health legislation at local and regional levels. These strategies include identification of key mental health training targets, stakeholder groups to partner with in each country, availability and accessibility of currently offered services, and ongoing situations where the rights of those seeking mental health services are threatened. These workgroups’ efforts in synthesizing these data and engaging in ongoing dialogue on mental health are intended to result in the ability to provide stronger, documented, and evidence-supported arguments for these teams to present to governing bodies to advocate for significant (and tangible) improvements in mental health legislation.

Challenges to Advocacy-Partnered Work

As the process described above for this advocacy partnership demonstrates, there is a potential for greater impact of our work as clinical trainers and researchers as a result of systematic partnership with advocates and engagement in social justice activities. That said, this work is certainly not without its significant challenges. By sharing these here, it is our hope that they serve as considerations (and not deterring) to colleagues engaging in similar work.

Limited Funding

As mentioned already, inadequate funding from legislative bodies continues to be a major challenge to doing such work. While obtaining research funds from federal or private foundations is itself no easy undertaking, looking for financial support for mental health efforts related to policy or legislation change can feel like an even taller order. It was because our team could fund the first workshop with some combination of corporate sponsorship and general research funds (greatly limiting the number of attendees as a result) that we had enough data to justify inclusion in the funding initiative offered by the EJA, allowing us to hold a second workshop. Indeed, with each passing success and impact on policy/legislation, the likelihood of additional funding increases. However, to initially build this momentum, it requires monetary infusion from somewhere outside of traditional outlets. Even in the second workshop, additional corporate sponsorship and engagement with local vendors to increase awareness and on-the-ground support were key, but this endeavor can feel foreign to those of us based in the U.S., where such corporate sponsorship is not always the norm for our work as psychologists.

Credibility and Media Exposure

Another obstacle faced during this project was creating buy-in from leaders of various health care systems in the region, several of whom were reticent to engage with a researcher who actually originates from the region (as first author A.A. does). That is, we surprisingly learned that there is actually more inherent trust and belief of credibility in foreigners wishing to provide support to the region. In addition, this
spilled over into the media exposure for this event (another feature we do not typically prioritize when doing community-based work stateside, but that is important in such settings: building awareness through TV and print media about such trainings to support advocacy efforts). Specifically, the trainers were purposely presented as “International doctors” by some media outlets and then proudly hailed as “Saint Lucians returning home” by others, creating interesting, sometimes opposing, optics around the expertise of the speakers.

Technical Limitations and Resources

While the second workshop expanded the reach of the material to providers in the region via the Zoom remote platform, there were certainly associated challenges with this addition. For instance, there was no ethernet wired connection in the hotel venue where the workshop was being held, and internet connectivity was quite inconsistent as a result, with frequent disconnections and loss of sound/video feeds. In addition, while the utilization of webinar-style trainings is quite commonplace and growing in popularity elsewhere in the world (Cummings, 2011; Matza et al., 2015), this is a modality that individuals are still learning to adopt more readily in the Caribbean region. That said, the participants who did join on remotely were very actively engaged in discussions about the topics with the online moderator for the entire duration of the workshop.

Other Cultural Nuances and Lessons

Finally, several other cultural nuances to doing such work in this specific region included conforming to the preferred mode of communication (i.e., use of the mobile application WhatsApp, and not email, as a primary mode of communication with most contacts on the ground), only providing information that is relevant to each sponsoring or partnering body (versus giving the whole picture of the project), and understanding the value of important elements such as free training and free provision of fully catered meals (another feature taken for granted in countries such as the U.S., where providers often self-pay).

Future Directions

This paper presented a detailed account of the logistics, implementation, challenges, and benefits of engaging in a research-advocacy partnership, with trauma-related training in a global context as an example of how such a partnership can work well. However, this project is still ongoing, and as it continues to grow, it is important to continually assess the impact of such a partnership. Thus, future directions are framed more readily as questions around how to effectively continue engaging in this fairly unchartered territory.

First, given the significant current controversy in our own training programs as psychologists and clinical researchers on how (and whether) to integrate advocacy and social justice issues into our profession (Ali & Sichel, 2019), what are some of the changes we need to systematically make across our traditional training models to encourage our current trainees to more widely engage in such efforts? Surveys of clinical psychology doctoral candidates increasingly highlight a desire for greater integration of diversity-focused issues across the clinical and research training curriculum (Gregus et al., 2019), with growing guidance that we should explicitly include direct instruction on working with advocates and other stakeholders to build such competencies (Chu et al., 2012).

Second, many global researchers and implementation experts have recognized that simply rolling out mass training in EBPs in low-resource settings is not going to suffice in terms of appreciably reducing health disparities globally. That is, if the overall legislation, policy, and services infrastructure do not support such training efforts, they are more likely to fail (Yorke et al., 2016). As a result, the onus is both on those of us who assess efficacy and effectiveness of EBPs, and for those of us who push for the dissemination and implementation of EBPs, to make the engagement with local or national legislative or policy-making bodies a major objective of what we aim to do (Hodges & Ferreira, 2013; Horne et al., 2019). Working with advocates to reach those top-down decision makers is an effective and sometimes less intimidating way to reach such a goal. Indeed, this project closely partnered with the Ministry of Health and Wellness in St. Lucia, with the hope that continued partnership with such leadership (who oversee the larger health care system in the country) could be an effective way to take such a top-down approach.

This point is clearly related to the ultimate consideration as we move forward, which is to ask ourselves, “Is it even our responsibility as psychologists and as clinical researchers to engage in such social justice activities and advocacy efforts to broaden the impact of our work to populations in need?” It should come as no surprise that the answer is a resounding “Yes!” For too long, our field has relegated such efforts to those few who are “the ones who like to get involved in social justice issues in the community” and “are known for doing minority population work” while the rest of us get to sit on the mainstream side of things, testing, innovating and, to put it bluntly—having our work miss the mark of actually making an impact where it counts and where it is needed.

Every single one of us dedicated to evidence-based practices should be thinking about maximizing our impact in the mental health realm by mobilizing our efforts with these broader societal issues in mind (Chu et al., 2012). Otherwise, to use a popular CBT metaphor, we are simply putting a band-aid over a gushing wound of mental health disparities, considerably unequal human rights, and a limited bottom-up approach to dissemination that has already been failing and will continue to do so. Some of our greatest strengths as mental health researchers and practitioners have been the ability to be flexible, thoughtful, and effective in our improvement of psychological science. Making the commitment to integrate this dimension of advocacy-partnered work would be wonderfully in line with these ideals and has the potential to appreciably broaden the impact of what we do.

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me/discriminatory-laws-against-lgbt-people-eastern-caribbean


First, our deepest appreciation to the Equality and Justice Alliance (EJA; www.equalityjusticealliance.org) for investing their financial and technical support resources into the Caribbean region (and consequently, our second workshop) in order to try to effect legislative change and improvement of the rights of women and LGBTQ community members in this geographical location. In addition, the regional organization Eastern Caribbean Alliance for Diversity and Equality (ECADE; www.ecequality.org) provided significant financial support in the second workshop to cover some of the other costs (such as snacks and some technical equipment), and negotiated the price of services with local vendors on our behalf, for which we are very grateful. In addition, we were able to provide meals for the day for all attendees in this second workshop, thanks to the generous financial, catering, and staff contributions by a company based in Saint Lucia called JTC Store (www.jtcstore.com), which is an online distributor of ethnic foods servicing several islands in the Eastern Caribbean. In addition, the Bank of Saint Lucia provided financial support for both workshops, for which we are thankful.

In terms of individuals from the community who made this partnership possible and for whom we are deeply indebted: Jessica St. Rose and Milly Moses, from the St. Lucian advocacy group United and Strong, who were brave enough to present in our second workshop to both educate the providers on issues pertinent to the LGBTQ community and share their own stories; Natasha Lloyd-Felix, Director of the Bureau of Health Education in the Ministry of Health and Wellness (Government of Saint Lucia); Joycelyn Eugene, Coordinator of the Guidance and Counselling Division within the Ministry of Education (Government of Saint Lucia), and Souyenne Dathorne, Founder of the Positive Reactions Over Secrets and Fear (PROSAF), for all of their support and guidance throughout the project so far.

Further, the authors would like to thank the HERStoire Collective program volunteers who assisted with registration and other administrative tasks on the day of the workshops to make sure they each ran smoothly. We are also very thankful for Ifrah Majeed, the Research Coordinator at the Treatment Mechanisms, Community Empowerment, and Technology Innovations (TCT) Lab at the University of Utah (PI: Asnaani) who spearheaded efforts related to administrative, data, and remote implementation of the project (and preparation of subsequent manuscripts from this project), and who oversaw the immense efforts of a number of dedicated undergraduate research assistants in the lab, particularly Ally Askew, Tracey Tacana, and Rachel Cole. Last, but certainly not least, we would like to deeply thank all of the stakeholders and workshop attendees who were open to sharing their feedback about the workshop, so that we can continue to improve and expand our advocacy efforts to improve the mental health of vulnerable populations in this region.

None of the authors of this study have any conflicts of interest to declare in this study.

**Correspondence to** Anu Asnaani, Ph.D., Department of Psychology, University of Utah, 380 S. 1530 E BEH S 502, Salt Lake City, UT 84112; anu.asnaani@psych.utah.edu
The Role of Advocacy in Adapting the Diabetes Prevention Program for Couple-Based Delivery That Reaches Marginalized Groups

Monique C. Aguirre, University of Utah
Heather Brown, Community Collaboration & Engagement Team, Center for Clinical and Translational Science, University of Utah
Dana Gershenoff, Park Nicollet International Diabetes Center
Kristie L. Hinton, Urban Indian Center of Salt Lake
Olivia M. Huntzinger, University of Utah
Natalie Klein, Lifestyle Coach and Master Trainer Select
Carmen Ramos, Office of Wellness and Integrative Health, University of Utah
O. Fahina Tavake-Pasi, National Tongan American Society
Brieanne Witte, Community Collaboration & Engagement Team Center for Clinical and Translational Science, University of Utah
Marc Wolfsfeld, Calvary Baptist Church
Tamara Sher, The Family Institute, Northwestern University
Debra L. Simmons, University of Utah and Salt Lake City VA
Timothy W. Smith, University of Utah
Lauren Clark, School of Nursing, UCLA
Katherine J.W. Baucom, University of Utah

Numerous studies have explored the relationship between close relationships and physical health. In the context of chronic physical illnesses (e.g., T2D, HIV), involving romantic partners and other family members in psychosocial interventions appears to lead to greater improvements in adjustment than interventions delivered individually (Martire & Helgeson, 2017). Despite this, few programs have utilized close relationships in the prevention of chronic diseases through health promotion programs (see Arden-Close & McGrath, 2017, for a review). Incorporating close others into the DPP has the potential to increase its effectiveness and extend its reach. Consistent with this, a recent study demonstrated that those who signed up for the DPP with another member of their household were more likely to start, complete, and stay in the program longer than those who signed up individually (Ritchie et al., 2020). As the DPP does not directly focus on relationships, and relationship functioning is closely linked with health (Kiecolt-Glaser & Wilson, 2017; Robles et al., 2014), an explicit focus on relationships is crucial for maximizing the impact of the DPP when delivered to couples.

The prevalence rate of T2D is higher among underrepresented racial and ethnic groups compared with non-Hispanic Whites (Cheng et al., 2019). However, non-Hispanic Whites are more likely to attend four or more sessions of the DPP and lose more weight on average than those from other racial and ethnic groups (Ely et al., 2017). These health disparities reflect social and economic disadvantage rather than essential differences based on race and ethnicity (Braveman, 2014). To reduce health disparities among underrepresented racial and ethnic groups, it is important to carefully consider social determinants of health in collaboration with members of disadvantaged groups. We particularly want to reach those from underrepresented racial and ethnic groups who are at higher risk for T2D (Cheng et al.), yet are less likely to remain in—or benefit from—the DPP relative to non-Hispanic Whites (Ely et al.).

Diabetes prevention efforts that are applicable to a wider range of individuals, particularly those from underrepresented racial and ethnic populations at heightened risk of developing T2D, are critical to increasing the effectiveness and reach of the DPP.

Given well-documented health disparities in T2D among underrepresented racial and ethnic groups, we are in the process of designing an adaptation of the DPP that

MORE THAN 30 MILLION people in the United States suffer from Type 2 diabetes (T2D), the seventh leading cause of death nationwide (Centers for Disease Control [CDC], 2017). To address this significant public health concern, the CDC has implemented the National Diabetes Prevention Program (DPP) Lifestyle Change Program. The DPP aims to facilitate weight loss and reduce the risk for T2D through increased physical activity and improved nutrition. The year-long program includes 22 group sessions focused on methods for tracking and increasing physical activity, methods for tracking and improving nutrition, navigating challenges related to physical activity and nutrition (e.g., maintaining activity and healthy eating away from home), and stress and coping more broadly (CDC, 2018). During the first 4 years of its implementation (2012–2016), more than 35,000 people at risk for T2D participated in the DPP (Ely et al., 2017). Despite the strong evidence base for the program, completion rates remain relatively low in health care and community settings, with only 1 in 10 participants who began the program completing the full 22-session intervention (Ely et al.). Social factors, particularly close family relationships, play a key role in the health behavior of individuals. The goal of this article is to describe and evaluate the use of a Community Advisory Board to adapt the DPP for delivery to a wide range of couples.
will be applicable to a wide range of couples at risk for T2D. The World Health Organization identifies advocacy as a key strategy for achieving health promotion goals to reduce health disparities (Carlisle, 2000). The current project utilizes advocacy in health promotion by ensuring broad participation of stakeholders in planning (Carlisle, 2000). We created a partnership between community members and clinical researchers using Community-Based Participatory Research (Wallerstein et al., 2017) methods. These methods were designed to reduce health disparities related to chronic disease through community engagement. Community Advisory Boards (CABs) (Newman et al., 2011) are a specific Community-Based Participatory Research tool for collaboration between community members and researchers to promote processes that are maximally beneficial and appropriate for members of the community. Within health promotion, CABs allow for the incorporation of a community’s voice in advocating for and shaping the development of an intervention (Carlisle; Newman et al.). In doing so, community members have a significant role in the process of developing a more appropriate and effective intervention for their community. In the current paper, we describe and evaluate the NIH-funded, Couple-Based Diabetes Prevention CAB.

Couple-Based Diabetes Prevention CAB

The Couple-Based Diabetes Prevention CAB was formed in January 2019 with grant support from the National Institutes of Health (K23DK115820; UL1TR002538). The CAB was established in collaboration with the University of Utah Center for Clinical and Translational Science Community Collaboration and Engagement Team. This team contacted community leaders from five organizations within the Salt Lake Valley to identify potential CAB members: Best of Africa, Calvary Baptist Church, the Hispanic Health Care Task Force, the National Tongan American Society of Utah, and the Urban Indian Center of Salt Lake. Relationships between the Community Collaboration and Engagement Team and these community leaders have existed for a decade as part of Community Faces of Utah, a community, university, and health department partnership (Drits-Esser et al., 2019). For the CAB to be maximally effective, we sought to identify additional CAB members with extensive professional expertise in the DPP. Towards this end, the principal investigator contacted colleagues at organizations recognized by the CDC to deliver the DPP. Members of the CAB include lifestyle coaches delivering the DPP, master trainers with extensive lifestyle coach experience who train facilitators to deliver the DPP, and community health workers who have been professionally involved with T2D prevention and management in their community. The master trainers and lifestyle coaches have experience delivering the DPP in a family context (e.g., teaching classes that include multiple family members) and to members of underrepresented racial and ethnic groups. Four CAB members are known to have prediabetes or T2D. Last, two members of the CAB are a couple coping with one partner’s T2D. The mean age of the 12 CAB members is 50.3 years old (SD = 13.1 years). The ethnic/racial identities of CAB members include Latinx/Hispanic (n = 4), Hawaiian Native/Pacific Islander (n = 3), White (n = 3), and Black/African American (n = 2).

The CAB meets on a monthly basis to discuss potential modifications to the CDC’s “Prevent T2” DPP curriculum. Prevent T2 is an updated version of the original curriculum tested in a large RCT demonstrating the efficacy of lifestyle intervention in T2D prevention (Diabetes Prevention Program Research Group, 2002), and thus is the curriculum we chose to adapt in the current study. Organizations recognized by the CDC to deliver the DPP may develop alternative curricula provided they meet CDC standards (of length, dose, content, focus) and have been approved by CDC (CDC, 2018).

A member of the Community Collaboration and Engagement Team with extensive group facilitation training facilitates each meeting, although the principal investigator of the project has taken a more active role in co-facilitation over time. The current adaptation of the DPP is based on Resnicow et al.’s (1999) model of cultural sensitivity in public health. A “surface structure” approach to cultural sensitivity refers to the broad analysis of surface-level concerns regarding racial, social, and cultural differences in order to expand the structure and delivery of a given program to a wider range of individuals (e.g., updating pictures, stories, and examples) (Resnicow et al.). A “deep structure” approach involves a more in-depth consideration of the factors that influence health behavior in a specific population (Resnicow et al.). As our goal was not to target any one group, we utilize a surface structure approach to cultural sensitivity in our adaptation of the Prevent T2 curriculum to couples across race, ethnicity, and culture.

The goal of each CAB meeting is to collect feedback on changes to the DPP that would extend its reach to a wide range of couples. The week prior to each meeting, CAB members receive the meeting agenda and materials for review, along with the minutes from the previous meeting. As Table 1 illustrates, meetings alternate between review of Prevent T2 modules and review of edits made by the research team based on feedback from previous CAB meetings. CAB members come to each
meeting prepared to provide feedback centered around two overarching questions: (1) Are there additions needed to increase the relevance/appropriateness for couples across communities? and (2) Are there potential issues discussing material with a partner present and/or relationship processes that need to be addressed? All CAB members are compensated for their time, and dinner is provided at each meeting.

CAB Evaluation

Regular evaluation is a critical component of CAB maintenance (Newman et al., 2011). As such, we regularly evaluate member perspectives on CAB functioning. For the first 6 months of the CAB, informal feedback was elicited from many CAB members at the end of each meeting and between meetings. We formalized the evaluation process with written evaluations at the end of the seventh monthly meeting, then at the end of each of the seven meetings thereafter. CAB members were informed their responses were voluntary and anonymous, and designed to help the facilitators improve CAB functioning. The evaluation includes 10 Likert-type items and 4 open-ended items. The focus of this study is on 4 Likert-type items we believe best capture whether advocacy via the CAB is thus far successful (i.e., whether CAB members are effectively included in the adaptation process), as well as 2 open-ended items that capture perspectives on contributions to the larger research project and the CAB process. Other items on the evaluation, excluded from the current manuscript, focused on meeting logistics and facilitator organization (meeting length, communication from and preparation by facilitation team) as well as the personal value of the meeting (e.g., if beneficial connections were made with others, what made participation worthwhile).

The four Likert-type items examined in the current study assessed participation and collaboration among CAB members ("The CAB facilitator allowed everyone’s voice to be heard" and "I learned from other participants"), whether members perceive the CAB to meet its overarching goal of broadening the applicability of the DPP to a wide range of couples ("The input provided by the CAB is having a positive impact on the research project"), and general satisfaction with the CAB meetings ("I was satisfied with the CAB meeting") on a scale from 1 (strongly agree) to 4 (strongly disagree). The two open-ended items examined in the current study assessed member perspectives on the most important contributions to the larger research project ("What do you believe are the most important contributions the CAB has made to the research project?") and the most important factors related to CAB functioning ("What has been most important in helping the CAB function well?").

CAB members completed the evaluation by hand at the end of each meeting. All data were then entered into a Qualtrics survey by members of the research team. Descriptive statistics for the four Likert-type items were computed in SPSS after the data were exported from Qualtrics. In order to categorize the topics of responses to the open-ended items, the first author manually coded responses to each item across participants and meetings using an inductive descriptive approach (Saldaña, 2016). The coding was reviewed and discussed with the last author, and final topics and topic labels were determined through consensus. The University of Utah IRB reviewed this project and determined it did not meet the definition of Human Subjects Research.

Results

CAB Evaluation

Table 2 presents average ratings across participants on the four Likert-type items at each meeting. Across the eight evaluations, CAB members generally perceived advocacy to be successful, as indicated by average ratings between "agree" and "strongly agree" for the Likert-type items focused on the inclusion of CAB members in the adaptation process. In addition to these quantitative ratings, many CAB members provided additional feedback in response to open-ended items about how the CAB helped the larger project and what helped the CAB function well. Responses regarding the most important contributions of the CAB to the larger research project included four topics: cultural competence ("Cultural outlook to make this program more understandable for this community."

<table>
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<th>Table 2. CAB Member Evaluations</th>
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<tr>
<td><strong>Meeting Number</strong></td>
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<td>The CAB facilitator allowed everyone’s voice to be heard.</td>
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<tr>
<td>I learned from other participants.</td>
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<tr>
<td>I was satisfied with the CAB meeting.</td>
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<tr>
<td>The input provided by the CAB is having a positive impact on the research project.</td>
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Note. M (SD). n = number of CAB members completing evaluation. Items were rated on scale from 1 (strongly agree) to 4 (strongly disagree). Data presented are from all members who completed evaluation forms following each meeting.

*In the first evaluation, which occurred following meeting 7, CAB members were asked to report on their experiences across meetings 1-7.
to come up with ideas and strategies to improve the curriculum,” “CAB team effort”). Responses regarding the most important factors for CAB functioning included two topics: facilitator characteristics (“The facilitators are amazing at making sure everyone has a voice,” “Great facilitators that are aware of the group dynamic”) and member characteristics (“The openness of everyone in hearing others’ comments,” “Group communication – everyone’s voice is valued”).

**Suggested Adaptations to the DPP**

The perspectives of CAB members from a variety of racial and ethnic backgrounds facilitated review of the DPP through a cultural and contextual lens that considered primary health concerns across communities. Suggestions from members included updating the language, pictures, and stories to include more racial and ethnic diversity and to focus more explicitly on couples. For example, based on member feedback, we updated one of the stories by highlighting an interracial couple with one partner with diabetes, culturally diverse eating patterns, varying preferences in physical activities, and differences in fitness and weight goals. Members also identified ways in which examples in the curriculum could be more broadly applicable. For instance, members suggested that examples of types of food focus on those consumed across cultures. Members also noted that some of the examples of ways to be active made assumptions about the participants’ environment (e.g., that they lived in a safe neighborhood). Importantly, the changes suggested did not alter the content of the intervention curriculum, but rather its presentation and delivery. Throughout discussions, CAB members were highly engaged and collaborative.

With regard to a focus on couples, CAB members raised key considerations for screening couples before enrolling them in the program. There was consensus among CAB members that both partners in participating couples need to be willing to consider certain lifestyle changes and feel comfortable participating in the program together with their partner. There was extensive discussion about differences between couples, including potential cultural differences, in how they may approach a couple-based lifestyle intervention, and the need to facilitate partners’ support of one another regardless of its form. For example, whereas some couples may prefer to engage in physical activity together, shared physical activity may not be feasible or of interest to other couples.

**Discussion**

This article illustrates the potential utility of Community Based Participatory Research methods, and CABs specifically, as a means for advocacy in the context of health promotion. A central feature within CABs is the collective participation among all members (Newman et al., 2011), which demonstrates an active role and voice of community members that facilitates advocacy on behalf of their respective communities based on their experiences and knowledge (Lating et al., 2009; Shilton, 2006). Consistent with this, CAB members perceived meetings to be collaborative and informative, believed the input provided by CAB members was useful to the couple-based adaptation of the DPP, and reported general satisfaction with the meetings. Consistent with advocacy as a means to reduce health disparities in health promotion (Carlisle, 2000), CAB members from communities at high risk of T2D had critical insights on how the interest in, and benefits of, an adapted program could be maximized. Members identified cultural competence, applicability to couples, diverse perspectives among members, and collaboration as key contributions of the CAB to the research project. CAB members raised suggestions in response to the two overarching questions. Thus, the common concern that CAB members may rely on the researchers to find solutions or alternatives to the issues at hand (Cramer et al., 2018) did not appear to be an issue for this CAB.

Several factors likely facilitated the success of the CAB. The research team’s collaboration with the Community Collaboration and Engagement Team allowed existing partnerships to be leveraged, and the researchers to learn from the extensive experience of facilitators. We believe the facilitators’ existing relationships with many of the CAB members helped create a balanced and equal partnership between community members and the research team that ensured all members’ thoughts and opinions were voiced. Consistent with this, CAB members described facilitator characteristics as a key factor for CAB functioning. We also followed applicable processes for the formation, operation, and maintenance of CABs (Newman et al., 2011). Having clear and open communication among CAB members and between members and the research team created a group environment centered on respect, trust, and cohesion. CAB members appeared to feel comfortable providing feedback to the research team and other members on possible adaptations to the DPP curriculum, which helped maintain engagement and create positive relationships within the CAB.

It is important to recognize several limitations to the current project. First, although evaluations were anonymous, it is possible member responses were biased or that CAB members who were less satisfied chose not to complete the evaluations in their entirety. On average, one or two CAB members declined to complete the evaluation at each meeting. Members who did complete the evaluations occasionally skipped items. Finally, CAB members were occasionally absent from the meetings. These factors may have led to collection of data from only the most satisfied and engaged members. Additional assessment of the CAB process by an objective observer would reduce the likelihood of demand characteristics.

Another limitation is the composition of the CAB, which will likely lead to a couple-based adaptation that is not inclusive, culturally competent, or comprehensive in addressing T2D-related health concerns of all possible participants. The primary goal of the diverse CAB membership is to ensure the concerns of a wide range of communities are considered in the couple-based adaptation of the DPP. However, there is substantial variability in T2D prevalence among racial and ethnic subgroups (Cheng et al., 2019), and the CAB does not include members from all subgroups at high risk. Further, the approach to recruitment of CAB members included identification of representatives from a range of communities, but the degree to which any one person can truly “speak for” a given community ignores the substantial variability within communities. Thus, the voices of individuals from a number of racial and ethnic subgroups are not represented (Ross et al., 2010). The CAB also includes only one (heterosexual, married) couple. It would benefit from the perspectives of additional couples including those from the LGBTQIA+ community. Including perspectives of LGBTQIA+ CAB members would increase the likelihood that the couple-based adaptation of the DPP appropriately addresses potential health concerns of individuals and couples within the LGBTQIA+ community (Cahill et al., 2016).
Despite these limitations, this project highlights the potential for Community Based Participatory Research to facilitate advocacy in health promotion by including members of marginalized communities in the process of developing an intervention with the goals of increasing its acceptability and efficacy. Upon completion of the adaptation, our team will test the feasibility, acceptability, and preliminary efficacy of the couple-based DPP. The CAB will provide feedback on all aspects of the pilot study design—from recruitment strategies to assessment methods—to ensure appropriateness across communities. We will use these pilot data to seek funding for a larger trial to evaluate the effects of the couple-based program on both engagement (enrollment, attendance, completion) and health outcomes (physical activity, weight loss, incident type 2 diabetes) among individuals from marginalized communities.

References

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Correspondence to Monique C. Aguirre, Department of Psychology, 380 S 1530 E BEH $ 502, Salt Lake City, UT 84112; ut0959118@utah.edu
Refill Your Well: An Online Acceptance-Based Behavioral Burnout Management Guide for Activists of Color Resisting Racism

Lorraine U. Alire, Kaitlyn R. Gorman, Anna M. Ying, and Karen L. Suyemoto, University of Massachusetts Boston

Multiple psychologists have called attention to the inherent relationship between psychological well-being and social justice (e.g., Martin-Baró et al., 1994; Prilleltensky, 2012; Vera & Speight, 2003). Given this relationship, it is important to consider how therapists can support the promotion of social justice. One way that we might do so is through providing psychological skills and support to activists who are seeking to make positive change for social justice. Working to make positive change in the world is a noble yet taxing endeavor. The cost of activism is greater still when an individual is personally connected to the cause they are defending (Gorski & Erakat, 2019). Although activism exacts a cost on individuals, therapists are uniquely situated to offer skills development needed to understand and ameliorate the burdensome psychological costs of engaging in and sustaining activism. Based on our understanding of the negative psychological effects of racism and discrimination (see APA Guidelines on Race and Ethnicity in Psychology), more specifically, experiences of racism have been associated with lower life-satisfaction and well-being, anxiety, depression, race-based traumatic stress, cardiovascular disease, chronic pain, and various other negative health consequences (e.g., Broman et al., 2000; Carter, 2007; Carter et al., 2017; Chou et al., 2012; Deitch et al., 2003; Franklin et al., 2012; Harrell et al., 2003; Liu & Suyemoto, 2016; Nadal et al., 2014; Scrufield et al., 2014). Some evidence indicates that coping strategies enacted by People of Color, such as social support seeking and developing racial and ethnic identity pride, can offset the distress associated with racism (Barnes & Lightsey, 2005; Brondolo et al., 2009; Sanders Thompson, 2006). These coping strategies have been associated with participating in racial activism (Suyemoto et al., in press); however, there is a growing need to develop psychological-based resources that may empower and protect People of Color, allowing them to sustain resistance against racism.

One unique contribution that psychologists could make is in the area of empowering and supporting the mental health and well-being of activists of color, fighting against racial injustice. Activists of color, particularly those who are advocating in areas in which they are themselves oppressed, are at risk of activist burnout (Gorski, 2018). Activist burnout is a condition characterized by feelings of amotivation, depletion, and irritability that not only leads to the deterioration of the well-being of individual activists (Gorski & Chen, 2015), but also undermines the sustainability of social justice movements (Gorski, 2015). More specifically, for activists of color who target racial injustice in their work, activist burnout may be especially high, given research suggesting that a barrier to activism can be unreasonably high self-expectations (Bobel, 2007); activists of color may feel particular pressure to constantly engage in difficult actions and conversations to eradicate racial injustice related to the marginalization of their identities as People of Color (Gorski, 2018).

Given this nuanced understanding of the unique psychological and physical costs of racism and particularly engaging in activism against racism among People of Color, therapists can use their skills to support activists of color, both directly or through the development and dissemination of resources. A growing body of research indicates that mindfulness-based strategies may foster more positive mental health and sustainability for People of Color addressing racism (Harrell, 2018; Zapolski et al., 2018). These strategies could also be effective in supporting activists of color, so that they might plan for and engage in effective activism (Gorski, 2015). In order to address this need, we developed Refill Your Well (https://sites.google.com/view/refillyourwell), an online burnout management website to promote self-care and burnout prevention for activists of color. This resource integrates understandings of racism related stress and activist burnout and connects these understandings to strategies based on acceptance-based behavioral and mindfulness principles (Orsillo & Roemer, 2016).

In this article, we briefly describe the three components of Refill Your Well. We present relevant psychologically based skills from each module from the online resource, which may aid activists of color and/or their therapists to identify signs of burnout, interrupt burnout, and sustain their action. We hope that providing therapists and activists of color with such a website and toolset may encourage both clinicians and activists to continue to fight against systemic racial injustice, and to further disseminate and sustain their important work within their communities.

Positionality of Authors

We would like to acknowledge our relevant positionalities to the readers, recognizing that these positionalities may affect biases that may have influenced the development and dissemination of Refill Your Well. Lorraine U. Alire (first author) identifies as a multiracial, Asian American and Latinx activist of color, who notices and feels the emotional and physical costs of challenging systemic racism and oppression. Kaitlyn R. Gorman (second author) identifies as a White, Jewish cisgender-woman and White ally. Anna M. Ying (third author) identifies as a biracial...
Refill Your Well: A Guide to Managing Burnout for Activists of Color

Refill Your Well consists of three modules: What Is Burnout, Interrupt Burnout, and Sustaining Activism. What Is Burnout provides an introduction to the signs and symptoms of activist burnout and the higher risks posed to activists of color resisting racism. Interrupt Burnout provides acceptance-based behavioral and mindfulness skills specifically adapted for activists of color resisting racism to challenge the cognitive, physical, and emotional costs of burnout. Sustaining Activism focuses on preventing burnout, to support activists’ well-being and sustain their activism. The three modules were developed upon the scholarship foundation presented above. Here, we present an introduction to the content of each module below, generally using a more colloquial voice with minimal citations.

Module One: What Is Burnout?

The first module of Refill Your Well provides an overview of the signs and symptoms activists of color may endorse when they experience burnout.

- Activists of color resisting racism face a higher risk. Activism involves giving of yourself in the effort to create change. It is an evolving and continual process of resistance against the inequities maintained by systems of oppression, power, and privilege. The “wells” of activists of color consist of the energy and time they are able to give. Although these resources are not tangible like water, at any given time, they are finite. Activists of color can give of themselves and their resources towards multiple goals and directions, including activism. However, like a literal well, this process of sharing cannot be endless. Activists of color become depleted if they are constantly giving of themselves without taking time to restore. Burnout is the experience of “the well running dry.” As a psychological experience, it is akin to emotional exhaustion (Maslach et al., 1996) or battle fatigue (Gorski, 2019). Individuals may experience physical symptoms (e.g., fatigue and gastrointestinal distress), cognitive symptoms (e.g., difficulty concentrating), and emotional symptoms (e.g., powerlessness or sadness; Arman et al., 2011). For activists of color, burnout often manifests with feeling hopeless, disengaged, and discouraged (Kovan & Dirkx, 2003).

Moreover, activism may be particularly challenging for activists of color resisting racism, for whom advocating for racial justice often means encountering discrimination and paying attention to what is painful, both for the individual and for the communities of color they serve. For activists of color, feeling the pain of oppressive systems is personal. It is understandable and natural to experience the physical, emotional, and cognitive symptoms of burnout as that pain builds up and can be heavy to carry. Remember, burnout is not a sign of weakness. Noticing the signs of burnout, as described here, is the first step towards preventing or addressing it.

Module Two: Interrupting Activist Color Burnout

The second module of Refill Your Well, called Interrupting Activist of Color Burnout, offers acceptance, behavioral, and mindfulness-based skills adapted for activists of color to notice and challenge perfectionism and self-critical thinking, find emotional acceptance, and engage in values-based social support seeking and community building to interrupt the emotional and physical costs of activist of color burnout. It is our hope that these skills may help activists of color refill their wells and sustain the marathon against racism.

- Challenging perfectionism and the perfect standard in activism. Activists of color often experience extra pressures to resist racism and systems of oppression that they have faced with their communities throughout their lives. They may feel the need to be self-sacrificing, or even to be a “martyr,” in order to be a “real” advocate for social justice (Bobel, 2007). This sets the bar impossibly high to achieve the “perfect standard” of effective activism for social justice for People of Color. The goal for activism often needs to be a step forward, in collaboration with others. Taking on personal accountability for major social change is impossible; recognizing this is central to preventing burnout. In Refill Your Well, we encourage activists of color who feel themselves striving for perfection to challenge these perfectionistic standards perpetuated by the “perfect standard” by asking, “Who is really setting the bar that I’m trying to reach?” Our goal is to remind activists of color that the ideal activist they may be striving for is not obtainable by anyone (and often, we are our own worst critics). We also encourage activists of color to ask themselves, “Is there a way I can find some kindness for myself when this bar feels especially high in this moment?” One way to go deeper in this practice is to ask the activist of color to think about someone they love and want to take care of (a child, friend, or parent, etc.) and ask themselves, “What would you want for them when they feel like they can’t reach these standards?” Often activists of color can find kindness for others they cannot muster for themselves.

Given the often impossible standards set on the meaning of effective activism and action, activists of color are vulnerable to falling into mind traps of self-critical or self-defeating thoughts, as they may be prone to criticize themselves for not learning or doing enough in their work against racial injustice and inequality. Self-critical thoughts may arise, such as, “If I can’t even advocate for justice for my family, how am I supposed to engage in this work for the public and society as a whole?” or “I’m not doing enough since I can’t get people to see that we are operating under systems of White supremacy.” One tool an activist of color might practice is thought decentering. Thought decentering is one of the first prerequisites underlying both cognitive and mindfulness-based skills (Sauer & Baer, 2010). Often activists of color find their identity and thoughts deeply fused, for example, an activist of color might have the thought, “I will never make any difference,” and in the moment, having that thought feels like evidence that the thought is true. In practice, thought decentering...
allows activists of color to notice the thought as just a thought. One way to practice thought decentering is to use language to distance oneself from one’s thoughts. In the same example, when the thought “I will never make any difference” comes to mind, activists of color may practice observing the thought. For example: “I notice the thought that I will never make any difference.” This small change may allow activists of color to take a figurative step back from these impossible standards and see them as thoughts and expectations shaped by systems of power in our sociocultural world. We encourage activists of color to interrupt the inner critic by viewing these self-critical thoughts as thoughts, rather than definitive truths.

- Harnessing power through emotional acceptance. It is natural and understandable for activists of color to experience increased levels of both positive and negative emotions surrounding their activism for racial justice. Positive emotions, like happiness or satisfaction, may arise when they experience a sense of pride or reward towards their work. On the other hand, negative emotions, such as anger, guilt, and shame, may arise as they experience challenges or obstacles in their work. For example, activists of color resisting racism may especially feel a sense of silent rage (Rodriguez, 2011) as they struggle to manage emotional experiences related to experiencing oppression (whether implicit or explicit racism) as they advocate for racial justice for their own communities. Refill Your Well encourages activists of color to practice strategies of emotional acceptance (Hayes et al., 2009). Through emotional acceptance, activists of color may learn to accept and experience, rather than criticize and reject both their negative and positive emotions. For example, activists of color may feel guilt for not doing more to resist racism and consequential anger that internalized oppressive systems contribute to these negative emotions. Accepting that negative emotions are natural and part of the process of activist work can mitigate the potential paralyzing effects of these emotions and highlight the importance of sustaining activism to dismantle the systems that produced these emotions. Although negative emotions may feel pesky and be perceived as getting in the way of the work, emotions are also a powerful tool to fuel activism. Finding ways to balance and connect their pain and rage with self-love and appreciation may help activists of color sustain and empower action to combat racism and systemic oppression.

- Building a community of change. Effective activism for social justice is the meeting of the heart and mind (Ruiz Junco, 2013). Refill Your Well highlights the importance of finding and building a community of activists of color and allies who share values and lived experiences—this may allow room for growth and greater meaningful change for social justice against racism (Polletta & Jasper, 2001). Working across differences is hard and may sometimes seem impossible. Nevertheless, finding allies who are open to communicating and understanding these differences may foster an even greater community to thrive with (Suyemoto et al., 2019). For activists of color, even making small steps to challenge racism is often very hard work. Proactively seeking social support and building a community of both activists of color and allies will cultivate bigger waves of change. Remember, everyone should do their part navigating systems of oppression and activism. Activists of color do not have to do all the work. Let others help activists of color carry the burden and heal this pain. We encourage activists of color to surround themselves with people who make them feel safe and communicate their genuine intentions to grow together with them. Safety, honesty, and genuineness contribute to building trusting, authentic relationships.

- Self-care. Activists often feel that they must always be selfless (Bobel, 2007), especially activists of color who are resisting racism and systems of oppression (Gorski, 2015). They may think that “time that I’m using for self-care is time that I’m not resisting these oppressive systems.” These thoughts are valid and natural. However, self-care is a helpful strategy to sustain activism (Gorski, 2015). It may be helpful for activists of color to understand self-care as a burnout management skill to use before their well is “dry,” and consider how self-care may fit within their activist values, to prevent the negative view of selfless sacrifice. Self-care can be a way to promote well-being and fuel activism, as well as provide a foundation for the importance of the prevention strategies that follow. Some self-care activities include, but are not limited to, healthy sleep and eating, exercise, hobbies, and music.

- Notice early signs. Sometimes activists of color go into autopilot to advance action and forget to notice how they are doing. They may not even realize they are burned out until the impact forces them to notice. Refill Your Well aims to help activists of color to notice the early warning signs before they are burned out. Practice noticing thoughts, emotions, physical sensations, and behaviors. “How do they relate, and do daily activities affect them?” Activists of color are encouraged to notice when activities push their limits. Everyone has different levels of water in their well based on their personal settings, resources, responsibilities, and experiences.

- Refill your well. In addition to noticing early signs, we suggest that it may be helpful to try strategies to preemptively “refill your well,” or prefill, to prevent burnout. Self-compassion is one strategy to prefill your well (Gorski, 2015). The act of self-compassion can be thought of as sitting with one’s own pain—not judging it, not fixing it, but sitting and allowing it space. Given the nature of oppressive systems, it is natural for activists of color to feel pressure for their work to be “everything” or be “perfect.” Refill Your Well encourages activists of color to try to notice thoughts of perfectionism before they become overwhelming, offer themselves self-compassion as an act of resistance. Activists of color may consider asking themselves, “Can the small steps matter?” “Can your activist work be good enough?” “Can you allow yourself to be human?” Activists of color may ask themselves these questions before or during situations that may evoke thoughts, feelings, and behaviors related to perfectionism or self-criticism and intentionally replace these responses with more adaptive behaviors (e.g., developing a more manageable task of activism in a reasonable time frame). Additionally, activists of color may want to consider the importance of community building and allyship in prefilling their wells (Vacarro & Mena, 2011). We encourage activists of color to surround themselves with people they can trust and who affirm their identity and values, including people who share their primary oppressed identi-
ties and those who do not share them but work as allies.

- Intentional and plausible goal setting. Finally, activists of color may try to set themselves up for sustainable activist work by making intentional, plausible, and actionable goals. Given the limited “water in their wells,” activists of color may ask themselves, “What is reasonable and sustainable?” They may consider what areas of activism energize them, where activism can be easily integrated into life, areas that need boundary-setting, initiatives that could wait for a later time, and the resources available considering their personal settings and experiences. Similarly, consider specific, attainable goals based on currently available internal and external resources. With the same intentionality given to their work, intentionally give space away from work for nourishing and meaningful activities.

Summary and Final Words of Encouragement

In summary, we hope that these skills presented from Refill Your Well will empower and support activists of color in their work resisting systemic racism and oppression. And we hope that therapists and psychologists will use this resource to support themselves (if they are activists of color) and their clients, students, peers, and colleagues who are activists of color. We recognize that the skills discussed may not be entirely accessible and doable for all, given the limited nature of resources, which may include time, finances, and emotional and cognitive capacities, activists of color have in their existing wells. Rather, we encourage activists of color to pick and choose one or two of them to practice and spread the word by modeling to others what it looks like to “refill your well.” And we encourage therapists and psychologists to emphasize this flexible and person-centered approach when disseminating this resource of fostering these skills. When activists of color can practice ways to notice and interrupt burnout and sustain their activism against racism with a community of activists of color and allies, we all win! Sustain your activism. Address burnout. Take good care of yourself.

References


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The Art and Science of Ethical Practice in Native Communities: A Native Psychologist’s Perspective

— William H. Shunkamolah, Ph.D.

This webinar provides clinicians with an introductory examination of factors that influence ethical decision making in the treatment of American Indian clients utilizing examples and vignettes based on the experiences of a Native psychologist. An overview of the Society of Indian Psychologist commentary on the APA Ethical Principles of Psychologists will also be utilized to assist clinicians with self-assessment and considerations when initiating services with an individual client or in a Native community.
From Revelations to Revolutions: Integrating Social Justice Principles Into Behavioral and Cognitive Science

Kevin L. Nadal, City University of New York

In 2020, the murders of George Floyd, Breonna Taylor, Ahmad Arbery, Tony McDade, and many other Black Americans inspired a new revolution for racial justice. While unarmed Black people have been killed for centuries by both law enforcement and White supremacist vigilantes (Hargons et al., 2017), in the summer of 2020, multiple protests, demonstrations, and uprisings emerged throughout the entire country, resulting in what has been labeled the most populous movement in American history (Buchanan et al., 2020). Perhaps, the advocacy for racial justice was influenced by the growing awareness of the #BlackLivesMatter movement, which began in 2014, after George Zimmerman was acquitted for murdering 17-year-old Trayvon Martin (Garza, 2014). Perhaps the COVID-19 pandemic and the shutdown of the entire nation led to increased reflections and revelations about race relations in the U.S. Regardless of the impetus, many institutions, groups, and individuals had begun to consider the ways that they should advocate for social justice in their work. Psychologists and mental health practitioners, specifically, created ways to participate in activism; for instance, Dr. Della V. Moseley and psychology doctoral student Pearis Bellamy co-founded Academics for Black Lives (www.academics4blacklives.com), a campaign that initiated a series of online curricula and dialogues promoting Black survival and wellness in academia and everyday life.

Over the years, many other social justice movements involving other identity groups had emerged as well. Following the presidential election of 2016, advocacy issues involving women’s rights became more public and mainstream, with the Women’s March gathering millions of participants in January 2017 (Nadal, 2017a) and the #MeToo and #TimesUp movements encouraging people, particularly women, to speak out about their experiences with sexual harassment and sexual assault (Strauss Swanson & Szymanski, 2020). LGBTQ rights have also become more visible, with many people publicly advocating against queer and trans injustices in law, government, and the criminal justice system (Nadal, 2020). Relatedly, while disability rights activists have been vocal about systemic ableism for decades (Dirth & Branscombe, 2019), societal awareness about ableism had grown exponentially, albeit in still limited ways, in recent years. Further, among all of these movements, there have been calls for intersectionality, or the ability to examine the impact of systemic oppression on people with multiple marginalized identities (Crenshaw, 2017). For example, women of color and transgender women have described feeling marginalized from feminist movements (Nadal, 2017a), while queer and trans people of color have been vocal about exclusion from both mainstream LGBTQ movements and racial justice movements (Nadal, 2020).

The purpose of this commentary is twofold: first, I will review the articles in this special issue of the Behavior Therapist (Feinstein & Puckett, 2020), all of which highlight the many ways that psychologists have integrated their advocacy work into practice—namely, through schools, clinical work, community-based organizations, and other institutions and collaborations. Second, I will provide recommendations that will assist psychologists in integrating social justice principles into all aspects of behavioral and cognitive science. While I have advocated for the need for psychologist-activists in past writings (see Nadal, 2017b), the goal of this paper is to offer additional tangible and accessible recommendations for practitioners with a range of experiences of activism engagement and who work across a variety of sectors.

Review of the Special Issue

In this special issue of the Behavioral Therapist, it is clear that the editors were intentional in representing an array of historically marginalized groups. In reviewing the titles alone, one will notice articles on different racial and ethnic groups, transgender and gender diverse (TGD) people, and other specific identity groups. Given that social justice issues are often an afterthought, or that many journals tend to only highlight one or two marginalized groups in an entire issue, it was refreshing to see the editors’ intentionality in their inclusivity. Being intentional about inclusivity is a crucial aspect to living as a psychologist-activist; one must be aware of the multiple intersectional dynamics that operate across various identity groups—accounting for which identity groups are included versus excluded, as well as which groups hold power and which groups do not. While it would be difficult (or even impossible) to represent every single identity group in any setting (e.g., a journal issue, a conference panel, a course syllabus, etc.), it is important to make an overt attempt; when shortcomings exist, it is necessary to make note of the exclusion and to acknowledge why the exclusion may exist. As an example, when voices of Indigenous Peoples are unheard or unrepresented in certain spaces, one must acknowledge how issues like genocide and systemic racism may result in the group’s lack of representation in specific fields and situations, while also committing to more representations in future programs. Similarly, when LGBTQ people are invisible in specific settings, one may question if some environments are safe enough for individuals to disclose their sexual orientations or gender identities, as well as identify the factors that impede them from doing so.

Nonetheless, the special issue begins with Burgess and Batchelder (2020), who introduce the ways that clinical researchers can integrate advocacy into their practice. After listing the many ways that people of historically marginalized groups have been unfairly treated by clinical research, they offer the need for community-based participatory research (CBPR) and community-informed practices. Underrepresented communities is indeed essential in conducting ethical and effective research, as it allows opportunities for people of such communities to share their own perspectives and to contextualize cultural components that are often misunderstood or misinterpreted by researchers who are outsiders to those communities. For instance, when White people conduct research or provide psychotherapy with people of color and pathologize their participants’ or clients’ values and behaviors, those diagnoses are influenced by their own Western biases and lack of knowledge.
and awareness of other groups (Sue et al., 2007). Similarly, when heterosexual or cisgender researchers or clinicians pathologize LGBTQ people for behaviors that are considered normalized within LGBTQ communities, it is more reflective of societal heterosexism, as well individuals’ heterosexist and transphobic biases (Nadal, 2013, 2020). While CBPR is especially critical for researchers who work with communities they are not members of, researchers must also question why there aren’t people from those communities who are engaged in academic research. In these circumstances, it becomes a personal responsibility for researchers to not just collect data from these communities, but to also create or offer programs and services for community members, particularly those from younger generations, who may not have access to such opportunities.

Two articles in this issue focus on experiences of transgender and gender diverse (TGD) people, highlighting the many disparities faced by TGD people, particularly TGD youth. Cyperski and colleagues (2020) provide recommendations based on their experiences with TGD youth in a holistic pediatric clinic, and Hope and colleagues (2020) impart a CBPR model called Trans Collaborations, which demonstrates ways academics can work in conjunction with a local community board. Both papers examine practical approaches that can be useful on individual, institutional, and systemic levels. For instance, Hope and colleagues describe various projects such as workshops, online support groups, and even a weekend-long camp for TGD youth and children. Cyperski and colleagues share advocacy strategies for individuals (e.g., practicing role-plays with TGD youth clients on how to talk to their teachers about being misgendered) and systems (e.g., starting a petition for a school or the state legislature to change transphobic policies). Given the many health disparities involving TGD people (e.g., poverty, homelessness, overrepresentation in the criminal justice system, etc.)—which have been found to be especially detrimental for TGD people of color (Nadal, 2013, 2020)—it is imperative for government and community organizations to provide programming and support services for TGD youth. If such programs or services do not exist, psychologists and other practitioners must jumpstart such initiatives in order to disrupt the status quo and assist TGD people (particularly TGD people with other marginalized identities) to thrive.

Relatively, using community-based methods, three articles focus on advocacy efforts for myriad groups—namely Latinx people, Caribbean people, and people at risk for diabetes. First, Klein and colleagues (2020) discuss research with promotoras de salud (or lay health workers) who are able to utilize culturally appropriate strategies to promote healthy behaviors and health care access among underserved, Latinx communities. Second, Asnaani and colleagues (2020) describe the ways that trauma-related training can be used effectively among Caribbeanans. Third, Aguierre and colleagues (2020) introduce a diabetes prevention program that has been used to target people of historically marginalized groups. Central to each of these articles is the notion of cultural humility, or the idea that psychologists (a) recognize their own limitations in working with diverse groups and (b) consider the worldviews and lived experiences of others, instead of centralizing one’s own biases and perspectives (Hook et al., 2017). Cultural humility is essential in serving and interacting with diverse communities, because what works well with some communities may not be effective with others. Further, making conscious efforts to be culturally humble across various situations keeps psychologists and other practitioners vigilantly focused on ensuring that culture is considered in all of their conceptualizations, decision-making processes, and interventions.

Finally, Alire and colleagues (2020) propose an online guide called “Refill Your Well” as a way to assist activists of color in navigating and coping with racism in their everyday lives. Presenting several modules, including (a) interrupting burnout among activists of color and (b) sustaining activism, the authors propose ways for building community and engaging in self-care. Given that burnout is a common and detrimental reason that prevents and/or deters the development or persistence of psychologist-activists (Nadal, 2017b), these practical recommendations are helpful in both normalizing the typical psychological stressors of activists of color, while also encouraging health and sustainability for these individuals who often take care of so many other people that they forget to take care of themselves.

Integrating Social Justice Into Behavioral and Cognitive Sciences

Considering these concrete examples of how psychologists have been able to integrate activism into their work, I will comment on some of the many ways that psychologists can integrate social justice principles into the field of behavioral and cognitive sciences. First, I acknowledge two theories that inform the ways that I present my perspectives: Queer Theory (see Ghaziani & Brim, 2019, for a review) and Intersectionality Theory (see Crenshaw, 2017). Queer theorists argue that historical definitions and conceptualizations of gender and sexuality are based on privileged and dominant worldviews; they offer the notion of “queering” the status quo, by disrupting and challenging all things that have been socialized as normal and standard. Meanwhile, as aforementioned, intersectionality considers the multiple ways that people of historically marginalized groups are harmed by multiple forms of oppression. In her original conceptualizations, Kimberlé Crenshaw describes how Black women live at the intersection of racism and sexism; metaphorically, if they ever get into a car accident, they would experience more damage because of their location at that intersection. These two foundational theories provide two integral arguments that will be embedded into all of my recommendations: (1) to “queer” or disrupt the status quo, and (2) to always consider multiple marginalized oppressions.

My first major recommendation is for people to question and reconsider all that people have ever learned about psychology. For decades, it has been argued that modern psychology has been based on White, Western, heteronormative, cisgender male perspectives and it has been common for cultural considerations to be dismissed or overlooked (Sue et al., 2019). In this way, psychologists must reflect on how their training has been embedded in systemic oppression and the erasure or pathologizing of historically marginalized groups. Further, psychologists and other practitioners must “unlearn” the ways that they have been taught to view or evaluate concepts or people. As an example, many psychologists may be hesitant to become social justice advocates because they are afraid of violating boundaries—a practice that is considered an ethical breach in the profession (Nadal, 2017b). While there is certainly a utility to setting boundaries in various aspects of one’s life, one must question how such a rule came to be, as well as whose values this rule was based on. If we know that collectivism and community involvement is integral for Indigenous people and other people of color, perhaps the profession should focus more on train-
ing future psychologists to successfully manage and navigate boundaries, instead of punishing or shaming people with less rigid boundaries.

Relatively, many people may be hesitant in becoming activists because they fear that they will not appear to be “professional” and therefore will lose credibility or esteem. Again, one must question who has set such standards that have now become normalized across the profession; perhaps one can challenge who sets standards of professional dress, professional hairstyles, professional language or communication style, professional behavior, etc. One can also hypothesize who will have a more difficult time maintaining these standards, as well as who will be more successful as a result of their proximity to these standards. For example, if Black women are criticized or questioned for their hairstyles not being professional (Sue et al., 2008) or if queer and trans people are punished or microaggressed for dressing in gender nonconforming ways (Nadal, 2013), they are already at a disadvantage for not abiding to White, male, heterosexual, or cisgender standards. When people hold multiple marginalized identities (e.g., a Black, lesbian, cisgender woman), they will face more obstacles than their privileged counterparts (e.g., a White, heterosexual, cisgender man).

Another major recommendation is to explore all of the current ways that psychology is taught and to critically analyze how social justice is integrated into psychology training. In scrutinizing curricula in psychology doctoral programs, training directors and professors must review when and how social justice is taught and discussed. While many programs offer a sole multicultural psychology course (which typically fulfills accreditation requirements), other classes fail to cover issues of race, class, gender, sexual orientation, ability, religion, age, or other identities at all. Such omissions are not just careless; they are also both unethical and illogical. Ignoring cultural factors is an ethical concern because it negates the American Psychological Association’s (2017) multicultural guidelines, which have been integrated into the organization’s Code of Ethics. If the governing board of the profession determines that culture must be considered in all forms of practice, then practitioners who refuse or ignore such standards would be considered in ethical violation.

Ignoring cultural factors is also illogical because culture is related to every single aspect of psychology. For instance, it would seem nonsensical to teach a Developmental Psychology course without examining how issues like gender and race influence children’s and adolescents’ development, as it would be odd to teach a course on Personality Theories and ignore the cultural factors that influence personality development. Thus, I recommend that all programs “decolonize” their curricula by discussing the history of oppression at the onset of each course and by centering the experiences of historically marginalized people. As an example, in teaching a Developmental Psychology or a Personality Theories course, I encourage professors to start the course by naming how the subfield in psychology had been historically oppressive to Black people, Indigenous people, and other people of color—perhaps sharing how psychologists have ignored race altogether or have pathologized people who did not fit White standards. I also encourage professors to present models that center marginalized people’s experiences first, before (or ever) teaching about models that are considered standard. For instance, instead of presenting Freud’s or Erickson’s theories as “normal” stage models of development, present Carol Gilligan’s models on girls’ development, Janet Helms’ models on identity development, or Derald Wing Sue’s models on personality development. Introducing these models first changes the ways that students learn about norms and standards; concurrently, educators also provide opportunities to acknowledge and correct past wrongdoings of the profession, while empowering people who have been silenced to feel included in the field.

A third major recommendation for advocating for historically marginalized groups is for individuals to take a personal responsibility and commit to social justice in all aspects of their lives. While I had previously written about psychologist-activists integrating social justice into work and even their personal lives (Nadal, 2017b), I take it a step further by challenging all psychologists to take responsibility and participate in this social justice activism every moment of their lives. No longer is it acceptable for people to merely have revelations about injustice and then ignore such truths when they become inconveniences; instead, it is imperative for people to join the revolution. For some, the revolution may be participating in protests or actions that advocate for Black lives, for Indigenous People’s rights, or for LGBTQ equity and justice. For others, the revolution may be vocalizing concern or anger for any and every injustice they may observe in the workplace—from everyday microaggressions to systemic issues like inequities in hiring and promotions. For others, the revolution may consist of creating new programs and organizations, advocating for changes in systemic policies, conducting community-based and culturally empowering research and scholarship, or engaging in local or state government. For others, the revolution may involve teaching the next generation with different language and values—disrupting all gender role norms; encouraging children to recognize and talk about race, sexual orientation, and difference; vocalizing disdain about societal standards of beauty; and empowering all children to find their voice and purpose. For some people, the revolution will consist of all or some of these things; and for others, the revolution will look completely different and unique. Considering each individual’s circumstances and personal capacity, it is my hope that everyone finds the revolutionary path that fits best for them.

Finally, I am sincerely optimistic that this current generation of psychologists recognizes that we must go beyond doing no harm and instead do everything we possibly can to ensure that the people we serve can thrive and live their best lives. I hope that all psychologists realize that the revolution is indeed happening; this is not just a moment, but a movement towards change. Thus, we all have to decide whether we want to assist in helping the revolution progress forward, or if we will choose to serve as a hindrance to justice and equity for all.

References
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