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Debra A. Hope

Nathan Woodruff

Richard MocarSKI

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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

*Correspondence* — Debra A. Hope, Ph.D., Department of Psychology,  
University of Nebraska-Lincoln, Lincoln, NE 68588-0308 dhope1@unl.edu

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.

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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 have a direct “product” for the TGD community. As the local community board has developed, they have initiated the three advocacy projects described above.

Camp BOLD requires full engagement from the local community board. The board members at camp embody the diversity of TGD people for the youth, siblings, and parents. They are present and available as needed but camp counselors lead many of the activities. Board members avoid giving advice, seeing their role as providing opportunities to engage in camp activities and be together. At the parents’ request, the second year we had a medical provider who works with the TGD community join via teleconference, so parents could ask questions from an appropriate source rather than the TGD board members. Camp counselors are a mix of individuals who identify as cisgender and TGD, many of whom are graduate students on the research team.

### ***Mutual Respect and Good Communication***

Trans Collaborations includes the local community board as well as academic members from various disciplines (psychology, health communications, marriage and family, forensics, etc.), ranging from graduate students to fully promoted professors. Good communication has been essential to develop trust and mutual respect. The academic members have learned to monitor their use of acronyms and technical language, balancing communicating what is needed with the

board and avoiding bogging them down in details better discussed later in the research team meeting. 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.

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