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Project REACH

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Project REACH (Raising Exposure Awareness for Caregiver Help-Seeking) is a study that aims to improve access to exposure therapy for youth with anxiety and OCD by equipping family caregivers with the knowledge, skills, and motivation to seek evidence-based treatment. This project is led by Dr. Hannah Frank who is the Program Director of the Brown Research on Implementation and Dissemination Guide to Evidence Use (BRIDGE) program in the Department of Psychiatry and Human Behavior. Dr. Hannah Frank is a clinical psychologist and implementation scientist, her clinical work focused on adolescents and young adults with anxiety and OCD. The BRIDGE program bridges the gap between research and practice through implementation science training, consultation, methods development, and collaborative partnerships with community partners.

Implementation science is the study of understanding what helps evidence-based innovations be adopted, implemented, and sustained in real-world settings. The implementation scientists on the BRIDGE team, such as Dr. Hannah Frank, help people understand barriers and facilitators to implementation, develop strategies to support use, and maximize the real-world impact of evidence-based innovations. None of this is possible without deep-rooted, meaningful community engaged practices. The very core of the field of implementation science is making sure that the people who an evidence-based intervention (EBI) is meant to target actually use that EBI; this requires meaningful collaboration with those very people and the implementation scientists.

In terms of this project, we already know that anxiety and related disorders are the most common youth mental health problems (Racine et al., 2021). We also already know that exposure therapy is effective for treating anxiety (Bilek et al., 2021). The issue we are trying to tackle is that, despite all of this, exposure therapy is rarely used in routine care. Clinicians appear to underutilize exposure techniques when compared to other cognitive-behavioral methods due to negative beliefs about exposure therapy and less training in exposure (Reid et al., 2018). In order to increase parent and caregiver help-seeking of exposure therapy, it was imperative to work with parents, caregivers, and other stakeholders in order to overcome barriers. These are the people that directly experience these barriers and the people whose behavior we are hoping to change, so the work can only be credible in close partnership with them.

Parents and caregivers report limited awareness of exposure, which serves as a launching point for our research (Frank et al., 2023) and dissemination of science principles (Kwan et al., 2022) represent a promising approach to improve access to information about exposure. The focus of our work this past summer was the project's aim to co-develop and refine the dissemination campaign for exposure therapy using community advisory board (CAB) input and caregiver focus groups. We convened a community advisory board of physicians, parents of children with anxiety and OCD, and community health workers. Specifically, our CAB consisted of a director of a doctoral program in counseling and school psychology, a child clinical psychologist, a director of student services, a facilitator in mental health, trauma, and recovery, a certified community health worker, a LCSW therapist, and a clinical associate professor of health services, policy and practice. Each of these people bring an expertise in the relationship between child mental health and parent involvement that are crucial to the research we hope to conduct and implement.

We began by asking CAB members to identify barriers to exposure therapy related to attitudes, norms, and self-efficacy guided by the Theory of Planned Behavior. The Theory of Planned Behavior (TPB) posits that for one to engage in mental health care, one first must be motivated to do so. Motivation is predicated on having sufficient knowledge and awareness of how to act; this informs one's attitudes, norms, and self-efficacy, which predict intentions, which in turn predict behavior (Ajzen, 1991). Applied to caregivers, these categories include knowledge and awareness of exposure, attitudes toward exposure, perceived norms related to treatment-seeking behavior, and self-efficacy in how to seek exposure for their children.

We discussed the TPB with the CAB members, and then we identified relevant barriers to accessing exposure therapy as a group. We then asked about the CAB's preferred dissemination channels and materials. After generating these barriers, we prioritized them together on an axis from low impact to high impact and low feasibility to high feasibility. Barrier prioritization is a systematic ranking of barriers that functions tremendously in working with a community advisory board as it is designed to facilitate conversations to come to a consensus. We then grouped the high priority barriers (high impact and high feasibility) into larger barrier "buckets." We then identified strategies and matched them to barrier buckets. In our CAB, we worked to create a safe environment to ensure that everyone was comfortable asking any questions they had and expressing every opinion.

The next step of this project involved a partnership with the Rhode Island School of Design (RISD). Students in a digital design course were tasked with creating a brand identity and explainer materials for exposure therapy. In order to ensure that each student designer had the same baseline understanding of exposure therapy, Dr. Hannah Frank presented on the treatment and why we believe a rebrand would be helpful. This assignment was the final project

for this course, so the students had sufficient time and motivation to dedicate themselves to the designs.

We presented the RISD students with the CAB members' preferred channels of dissemination and types of materials. With their expertise in digital design and user experience, each group was able to create a welcoming and thoughtful brand for exposure therapy. We did see that the students with lived experience with anxiety and/or OCD did create designs that were more poignant and relevant, but each student was extremely proud of their work.

We brought these different designs to our community advisory board members and each member was able to give meaningful feedback based on their areas of expertise. The CAB was able to come to a consensus on their favorite design, but as we were having these conversations, we realized it important that we also speak to the group of people who these materials were aimed to support.

We then convened a youth advisory board (YAB) of young adults (ages 17-25) with anxiety and/or OCD. We were overwhelmed with interest for this YAB opportunity, receiving over 100 applications. Our YAB consisted of 13 young adults each with their own individual experiences of anxiety and or OCD, knowledge or experience with exposure, and new ideas for this community. We were then able to present the YAB with the RISD designs and they agreed with the CAB on the most applicable, desired design.

From conversations with our YAB, we identified other missing systems of support for this community of young and emerging adults with anxiety and/or OCD. The YAB expressed a desire and a need for spaces where young adults with anxiety and/or OCD could find others with similar experiences to them and feel comfortable to share those experiences. Members of the YAB articulated shortcomings from traditional mental health services such as therapy and a

desire for more community. They expressed a need for third spaces in the community of young adults with anxiety/OCD.

With this in mind, we brainstormed what a support group for emerging adults with anxiety and/or OCD might look like at Brown. YAB members emphasized a focus on community building and space to share with people with similar life experiences to one another. We discussed having a clinician facilitate the support group to answer questions and be ready to provide support if necessary. Others suggested peer leaders with shared experience instead of a clinician as a facilitator. YAB members also suggested that the support group begin on Zoom to make joining more approachable, and then transition into in person meetings. Additionally, these support group meetings would center around an activity such as yoga, games, or crafts to foster conversation and comfortable relationship building.

Another important step in our partnership with the RISD students was that we were then able to work with the chosen group to make any changes that the YAB/CAB felt were important to make their designs more inclusive and relevant. After hiring the RISD students, my team and I met with them to discuss modifying their designs. For one, we had decided in conversation with the CAB that the words “exposure therapy” themselves do not carry a bad connotation, so we decided to continue with that language. The CAB asked that the visuals depicting a face do not start out as sad and instead start as neutral to reflect that anxiety/OCD does not equate with sadness. Additional modifications included adding more gender neutral characters and language.

For additional input on the RISD designs for exposure therapy explainer materials, we wanted to conduct focus groups with parents and caregivers of children with anxiety and/or OCD. In order to recruit people for these focus groups, Dr. Hannah Frank spoke with her contacts in the OCD and anxiety space. In a well-intentioned attempt to gain interest, one of her

contacts had posted our recruitment flier to their organization's social media. We were flooded with interest in our focus groups for parents and caregivers and began scheduling nine 90 minute focus groups on Zoom.

As soon as our first focus group began, we were able to tell that all six of the participants were fraudulent. We were hoping to hear from parents and caregivers of children with anxiety and/or OCD about their experiences and impressions of exposure, but it was clear from their responses that these individuals did not have children with anxiety/OCD and perhaps participated in our focus groups for the monetary reward. We were disappointed that so many fraudulent participants would join our focus groups but in response, we updated our focus group eligibility protocol and began to re-recruit with pre-focus group screening calls. We will conduct focus groups and continue to learn about parent/caregiver impressions of exposure as we embark on the next part of this project which entails actually disseminating our materials and comparing their impact on help-seeking behaviors with a control.

Our YAB, CAB and focus group participants were fairly compensated for their time and effort via Amazon gift cards. We respected confidentiality for these participants. We clearly explained what was expected of them and our plans and intentions with the information that we learned and the materials we created. We collaborated with YAB and CAB members to create the dissemination plan. These individuals raised questions every step of the way.

Community advisory boards “serve as a source of leadership in the partnerships of community-based participatory research (CBPR) and provide structure to guide the partnership's activities.” CABs allow community members to voice concerns and priorities that researchers otherwise may not focus on. CAB members advise research practices that are respectful and

acceptable to the community. CABs as a research method function to build mutually beneficial relationships between the researchers and the members of the community (Newman et al., 2011).

Community advisory boards are not always successful as explored by Newman et al. (2011) in a study of the Center for Community Health Partnerships at the Medical University of South Carolina (MUSC), a group of community partners, researchers, clinicians, and educators with the purpose of engaging academic–community partnerships focused on chronic illness. Members of the MUSC describe that CAB members are often given advisory roles when ideally members function as partners with researchers. Our CAB and YAB members in Project REACH held partnering roles, bringing issues and concerns from the community to our discussions.

Another challenging aspect of community advisory boards discussed in this study is balancing power. Each member of a CAB should and likely does represent different levels of social hierarchy which creates a challenge in balancing power. A strategy that we used in Project REACH CAB and YAB discussions is making decisions based on consensus to ensure every individual in the decision-making process has an equal amount of say. Some partnerships may not have the means to compensate CAB members for their time and effort, but we luckily with Project REACH were able to fairly pay each member for each meeting.

A community advisory board can be an incredibly meaningful method for community-engaged research when the CAB members provide the focus for the research and fosters mutually beneficial research for both researchers and community members. CABs must be thoughtfully created from the beginning of the research process and maintained in collaboration with members. In terms of Project REACH, our CAB involvement is ongoing, and

we will continue to meet with the members of our CAB as they bring concerns and ideas to the table as our research progresses.

Our CAB will be involved in the next steps of our research process that include disseminating the materials we have created to explain exposure. For one, we have a one minute exposure explainer video animated by RISD students as desired by the CAB and YAB. We worked with a local Providence film studio to film testimonial videos from parents of children with anxiety and OCD, children and teens with anxiety and OCD, and a community health worker with experience working with families with anxiety and OCD. From a suggestion from a YAB member, we created mock exposure therapy session videos to demystify the experience and increase understanding of what exposure therapy actually looks like. RISD students also designed an infographic and one page flier to explain exposure therapy.

The CAB helped us to identify dissemination channels, and now that we have the materials, the CAB will continue to voice ideas regarding this dissemination. We plan to meet in the coming months to discuss the distribution of materials. Another aim of Project REACH is to test whether these new community co-developed materials increase parent and caregiver help-seeking behaviors for exposure therapy. In order to do so, we plan to conduct a pilot study for which we will need CAB member help with recruiting and developing best practices.

As Dr. Hannah Frank is a thoughtful implementation scientist, this experience with Project REACH has been great experience with meaningful community-engaged research. At every step of the way, we looked for feedback and ideas from community members as our entire goal in conducting this research is to change the behaviors of the community members to improve their mental health and help-seeking.

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