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ScreenABLE: Breast Cancer Screening among Women with Disabilities from Community Identified Challenges to Community-Based Programs

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Abstract

Background: Women with disabilities are an unrecognized cancer disparities population who experience well-documented barriers to breast cancer screening. There is a critical need for targeted, community-directed programming to address these disparities.

Objectives: To describe the trajectory of a long-term community-academic partnership aimed at understanding and addressing breast cancer screening disparities among women with disabilities.

Methods: Phase 1 was a thematic qualitative focus group study ($n = 40$) with women with physical disabilities to understand their breast cancer screening experiences. Phase 2 was the application of an equity-focused knowledge translation (KT) process that brought together breast cancer survivors with disabilities and graduate applied health students in KT collaboratives to create innovative, evidence-informed knowledge products. Phase 3 included the development of community-based programming.

Results: In phase 1, women with disabilities identified provider and patient barriers to breast cancer screening, includ-

ing a lack of provider knowledge and respect for individuals with disabilities, lack of accessibility, the history of stigma and mistreatment within the health care setting, and treatment fatigue. In phase 2, KT collaboratives created the short film "ScreenABLE" to educate providers and community members about physical and attitudinal barriers to cancer screening. In phase 3, community, academic, and clinical partners collaborated to create ScreenABLE Saturday, a wellness fair and free accessible mammograms, for women with disabilities with programming developed to directly address cancer screening barriers identified from the phase 1 research.

Conclusions: Long-term sustained partnerships between academic, disability, and clinical partners are needed to address the complex issues that perpetuate breast cancer screening disparities among women with disabilities.

Keywords

Health disparities, women with disabilities, breast cancer, health care access, health care facilities, manpower, and services

The impact of breast cancer screening on the early detection of cancer is well-documented.¹ Increasing access to screening has contributed to reducing mortality disparities of women from ethnic/minority communities,²⁻⁵ yet the accessibility of screening services remains woefully inadequate for women with physical disabilities. Although a growing body of research documents breast cancer

screening disparities among women with disabilities,⁶⁻²² they remain largely absent from cancer disparities agendas.

Far from an isolated group, approximately 27 million American women aged 18 to 64 live with physical, sensory, and/or mental health/cognitive disabilities.²³ Disability cuts across all boundaries of race, ethnicity, and socioeconomic status. In their report "The Current State of Health Care for

People with Disabilities,” the National Council on Disability showed that women with significant disabilities were 56% less likely to report receiving mammograms than their nondisabled peers, regardless of age.²⁴ When women with disabilities do seek cancer screening, they experience significant barriers, including physical and procedural barriers (such as examination equipment that does not adjust for women who use wheelchairs), a lack of provider knowledge about disability, inaccessible health information, and even their own self-perceptions that they will not get cancer.^{25,26} Failure to receive timely cancer screenings contributes to diagnosis at later stages and higher mortality rates compared with women without disabilities.^{12,27} To address cancer screening disparities, it is critical to understand and reduce the common barriers that women with disabilities encounter. Community-academic partnerships are a powerful way to ensure that community needs and priorities are addressed.

The purpose of this article is to describe a long-term community-academic collaboration aimed at identifying and addressing barriers to breast cancer screening among women with disabilities. We will describe three distinct phases in the collaborative process: phase 1, original qualitative research to understand women with physical disabilities’ breast cancer screening experiences; phase 2, co-creation of educational knowledge products to communicate research findings to diverse stakeholders, and phase 3, the development and implementation of community-based programming to promote breast cancer screening among women with disabilities. We describe the expanding network of collaborators during each phase.

THE DISABILITY RIGHTS MOVEMENT AND THE USE OF COMMUNITY-BASED PARTICIPATORY RESEARCH

With the mantra “Nothing About Us, Without Us,” the disability rights movement has sought to counteract the marginalization of people with disabilities and the dominance of the medical model in the lives of people with disabilities.²⁸ There is growing recognition that disability research is most appropriately conducted in partnership with people with disabilities. This process helps to rebalance power relationships and ensure that research questions and solutions are relevant to the needs and priorities of the disability community. Thus, to address breast cancer screening disparities

among women with physical disabilities, the research team has used community-based participatory research throughout this project.

METHODS

From its inception, this work has been intentionally collaborative and participatory. The community principal investigator (PI) is a nationally recognized disability community health leader who identifies as a woman with a disability (J.R.). She has played important leadership roles in national and statewide initiatives to increase breast cancer screening about women with disabilities, including the Centers for Disease Control and Prevention’s “Right to Know Campaign” and several Illinois Ticket for the Cure grants aimed at improving disability knowledge among mammography technologists. The academic PI (S.M.) is a career scientist whose research focuses on health care justice for people with disabilities. The two partners had previously established a collaborative partnership across multiple projects rooted in their shared commitment to decreasing health and cancer disparities among people with disabilities. Over the course of the projects described in this article, community partners (J.R., T.W.) were members of the health policy team at Access Living, a nationally recognized disability rights organization in Chicago. Access Living’s mandate is diagnostically agnostic and committed to serving the cross-disability community. This characteristic sets them apart from many disability organizations that tend to be organized around a single condition or disability type. This emphasis on the cross-disability community permeates our collaborative efforts. Access Living is part of a state-wide network of 22 centers for independent living (CIL). CIL are community-based, nonprofit, non-residential disability rights organizations run by people with disabilities for people with disabilities. The community team members played a central role in all phases of the research process from identification of the issue, to writing the grant proposal, data collection, analysis, dissemination, and community programming. Institutional review board approval was obtained through the University of Illinois. Community partners completed certification training, a facilitated community directed version of the CITI training developed at the University of Illinois at Chicago to break down barriers to research participation among community partners and

ensure access to full participation in all research processes. The following is a description of the three distinct phases used in our collaborative process.

Phase 1

To understand women with physical disabilities' experiences related to breast cancer screening, we conducted six qualitative focus groups across Illinois (three in Chicago at Access Living and three in other CIL in central and southern Illinois) in a convenience sample of women with self-identified physical disabilities. In collaboration with the four CIL, study flyers were mailed by the local CIL staff to their female members inviting them to participate. Interested individuals contacted the research team for additional study details and were screened for eligibility. Inclusion criteria were that participants self-identified as a woman with a physical disability, between the age of 21 and 64 years who was able to communicate in English, tolerate travel to CIL site, and participate in a 90-minute focus group with 6 to 10 other people. The study age range was selected to reflect our community partners' emphasis on women with disabilities who receive their health care funding primarily through Illinois Medicaid. There were no additional exclusions.

Setting. Informed consent processes and data collection were conducted in a private room at local CILs. As a disability accommodation, personal attendant services were provided.

Data Collection. The interview guide was developed collaboratively by the academic and community partners and pilot tested with a member of the target population.

The focus groups were cofacilitated by one academic and one community partner. Focus groups lasted 60 to 90 minutes and were audio-recorded and transcribed verbatim with identifiers removed. All transcripts were reviewed for accuracy. Facilitators debriefed after each session and the academic partner wrote a field note to synthesize observations.

Analysis. We used a two-phase thematic coding process proceeding from descriptive open coding of verbatim transcripts to conceptual coding. All transcripts were dual coded using an iteratively evolving coding dictionary. The coders met to discuss additions to the coding dictionary. Discrepancies were reconciled through multiple rounds of discussion and debate. The broader team then organized the descriptive codes into meaningful conceptual categories.

Atlas-ti 7.0 (Berlin, Germany) was used for coding and data management. A saturation grid was constructed to ensure adequacy of the sample.

RESULTS

A total of 40 women with physical disabilities participated across 6 focus groups. Group sizes ranged from five to nine women per group. The women were predominantly White and ranged in age from 24 to 63 years. Participants had both congenital and acquired disabilities, including spina bifida, cerebral palsy, stroke, traumatic brain injury, autoimmune conditions, multiple sclerosis, chronic pain, spinal cord injuries, and other neurological and musculoskeletal conditions.

Provider and patient-side barriers to breast cancer screening were identified, including a lack of provider respect for and knowledge about disability, lack of accessibility, stigma, and history of mistreatment within the medical system, and treatment fatigue. Figure 1 provides a schematic representation of the identified themes. Each theme along with related subthemes is described below supported by representative quotations.

Lack of Accessible Examination Equipment

Despite laws like the Americans with Disabilities Act that mandate full and equal access for people with disabilities and federal accessibility guidelines for health care settings, women described inaccessible clinical spaces that compromised their care.

My real challenge is with the mammogram. My chair can go in there but the different positions, then, they have to take more pictures because at the time I'm not positioned right and it hurts more when you sit down . . . because you have to be a certain way and in a chair you can't do it like you're standing up. (FG1)

Participants emphasized that 25 years after the passage of the Americans with Disabilities Act, there was no excuse for the continued inaccessibility of services.

It's never our fault that they don't have the training or the equipment to make it a safe clinical experience for us. Because it's all out there. The training is out there. The equipment is out there. (FG4)

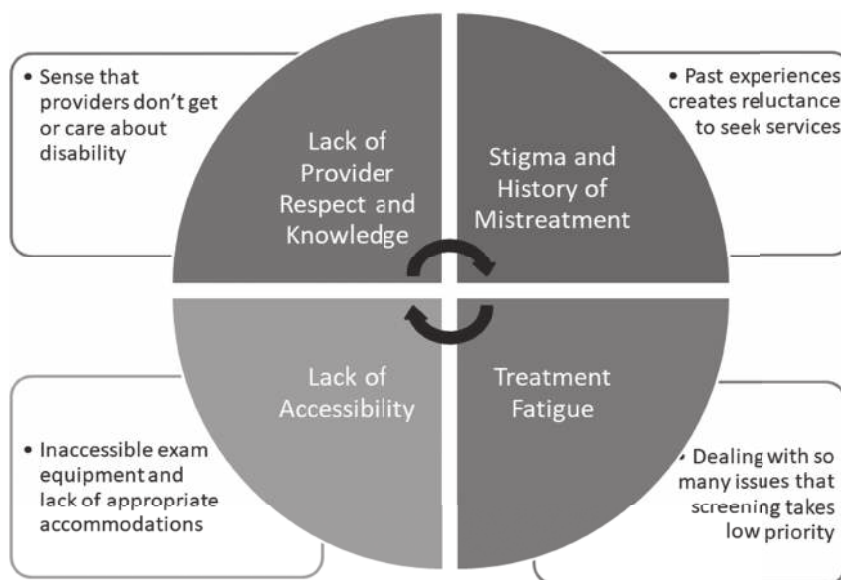


Figure 1. Providers and Patient-Side Barriers to Breast Cancer Screening Among Women with Physical Disabilities

Note: Issues of care provision and inaccessible services play a significant role in the construction of patient-side barriers.

Lack of Disability Competence

Participants indicated that the lack of accessible equipment led to inappropriate, even dangerous, accommodations that compromised both the women's safety and dignity.

They were more concerned about trying to get me to stand up straight which won't happen, with spinal stenosis . . . They just act like they don't have a clue of what you're telling them. If you say you can't, then you know figure out some other way to do it. But they only have it in their head this is the way I was trained to do it . . . They don't have a clue sometimes of how to help people. Sometimes it's their own lack of personal judgement. They think they know what they are doing and they make matters worse . . . I could tell them some of the easier ways to do it but they weren't interested in taking my advice. (FG6)

The lack of accessible equipment leads to important services delays. For example, one woman described her experiences trying to receive a mammogram at a local hospital.

This last mammogram was not good because the same routine with her assisting me, pulling me forward and getting the breast on the little plate and then to squeeze it. She was having a hard time, not I. I felt that she

wasn't trying hard enough because . . . she was quick to get rid of me and recommend that I go to the bigger hospital because . . . she was just frustrated . . . At that point, I really don't even want it. I never went back and it's been over a year. (FG4)

Even when women are able to receive mammograms, the lack of physical accessibility was perceived to compromise the quality of the screening. As one woman explained:

It's very difficult when you are sitting down to get an accurate reading . . . It takes three people to position me . . . to be honest it's a bit degrading . . . And this past year I was diagnosed with breast cancer. And I felt it myself . . . like 3 or so months after that mammogram . . . They never did know if the mammogram didn't pick it up or what. It is just a very difficult process trying to manipulate and get an accurate reading. (FG2)

Participants attributed the lack of disability competence to a general lack of respect for people with disabilities.

They're not used to taking disabled people seriously and it's almost like you're not supposed to have a health problems outside of your disability. (FG 5)

Prior History of Mistreatment within the Health Care System

Participants described how previous negative experiences within the health care system prevented them from seeking out and scheduling screenings.

During one of my annuals . . . I said, “Is there anything medically to prevent me from having children. She said, “People like you just shouldn’t have children.” . . . She just threw her opinion at me, which was completely ablest and ignorant. That happens more still . . . It makes me very reluctant, very reluctant to have to do it. (FG3)

Negative experiences also lead to a learned defensiveness and further delayed screening.

I get tired of advocating for myself. We all do . . . A lot of times people will say I come in with an attitude. That attitude is not like all attitude. It’s armor . . . It’s so easy to avoid getting these exams to begin with . . . and then we have the additional thing of knowing we have a disability and basically going into combat. (FG4)

Treatment Fatigue

Participants indicated that, because of the demands of dealing with multiple health and disability related concerns that they tended to deprioritize cancer screening.

The reason I didn’t go is because . . . I’m just so mentally exhausted with all my other health issues that I’m like this can wait. . . . Just the thought of getting that done and being uncomfortable for a while, it’s like I just don’t want to do it. (FG3)

These themes together expose the myriad of complex structural, systemic, and attitudinal barriers to care that contribute to the statistically significant disparities in breast cancer found in women with disability.

Phase 2: Development of a Knowledge Product Based on Phase 1 Findings

At the end of the research study phase 1, the team recognized that our findings were confirmatory of the growing body of knowledge around breast cancer screening disparities. We were struck that 20 years after Nosek et al²⁹ published their

ground breaking research about cancer screening disparities among women with disabilities, the disparities persisted. The project team determined that continuing to wait for the gap in screening rates to close was not an option. Instead we sought to actively translate the study findings to diverse stakeholders, including women with disabilities and health care providers. The team also recognized the need for creative strategies to reach target audiences.

We identified a synergy between our commitment to cancer health equity and the academic PI’s (S.M.) mandate as a university educator to develop a graduate elective that addressed an educational need. With the increasing attention to evidence-based practice in all aspects of health care, researchers and health care providers need skills to effectively translate research into practice. Within academia, students are one of our greatest resources—smart, motivated, and thirsty for real-world, hands-on experiences. We thus created a graduate elective on KT.

KT seeks to bridge the gap between research and practice to improve health services and systems.³⁰ With supplemental grant funding, we developed an innovative curriculum model that brings together graduate health science students with members of the disability community to form KT collaboratives. Specifically, we recruited two women with spinal cord injuries who were cancer survivors through our community networks to participate in the class. Community members received a small honorarium to acknowledge their time and contributions to the project. KT collaboratives work together over the course of the semester as co-learners and co-creators of KT products. KT collaborative members engaged in didactic education on the theory and practice of KT, while simultaneously immersing the qualitative phase 1 data. With support from an interdisciplinary team of mentors, including policy experts, clinical experts, graphic designers, and film makers, the graduate students and community partners synthesized the research findings and created targeted knowledge products about disparities in breast cancer screening.

The community partners applied their lived experience of disability and cancer care to increase the relevance of the final products. This collaborative approach facilitated team members’ experiential and transformational learning through an equity-focused KT model.³¹ Reflecting on the collaborative process, one graduate student on the team wrote, “This

experience working with consumers has given me a better understanding of meaningful research . . . I can now fully grasp the importance of community relationships.”

The KT Collaborative created a short film titled “ScreenABLE” to translate the study findings to diverse audiences, including health care providers to raise awareness of this disparity and broaden the definition of accessibility in women’s health care, and consumers to inspire self-advocacy of an accessible mammography experience. With the help of a professional film maker, the team members all took on different roles within the process of planning, writing, acting, and producing the film. Clinical partnerships also contributed to the successful creation and dissemination of this film. For example, mammography technologists educated the team members about mammography and also allowed their clinic to be used for filming. Use of nontraditional mediums for KT—such as videos and visual graphics—help audiences to better understand research findings and their relevance.^{32,33}

The community-engaged process of bringing together diverse stakeholders was both a strength and a challenge in the creation of the ScreenABLE video. Considerable time and debate were required to set the appropriate tone and focus of the video. Of particular concern was retaining the power of the phase 1 data while making it accessible and acceptable to providers of breast cancer screening services. The use of an adversarial tone could alienate the target audience and decrease the video’s impact. Consultation with service providers helped the team to refine the tone and framing to create an end product that emphasized collaboration and empowerment. We also worked hard to avoid stereotypical representations of cancer and disability typically used in film to evoke pathos and pity. Such tropes are widely considered to have a detrimental impact on target communities.³⁴

The “ScreenABLE” video emphasized how the physical and attitudinal barriers women with disabilities face when receiving mammograms. The film was served as a catalyst for discussion on how diverse groups can work together to decrease the barriers and improve health care equity for women with disabilities. Particular emphasis was paid to the identification of target audiences and opportunities for dissemination.

The video was screened widely at community events and townhalls, both those targeting disability audiences

and those target cancer health equity audiences, primarily under the auspices of the Chicago Community Health Equity Collaborative. As “ScreenABLE” reached different audiences, new opportunities arose to continue the conversation about accessibility. The film offered an opportunity to reach audiences that had not been possible through more traditional academic mediums. The ScreenABLE initiative was discussed with relevant community members at the Chicago Community Trust’s On the Table, an event that promotes social activism and civic engagement. The Acting Up Awards are small grants offered by the Chicago Community Trust to select On the Table participants to help put ideas generated at these community forums into action. Based on the discussions at the community forum, the team proposed the idea of ScreenABLE Saturday, which replicates the University of Illinois’s Walk-in Wednesday initiative that devotes 1 day a month to the provision of free screening to women who are uninsured or underinsured on a walk-in basis.

Phase 3: Development and Implementation of Community-Based Programming to Promote Breast Cancer Screening among Women with Disabilities

ScreenABLE Saturday was designed to directly target the physical and attitudinal barriers identified in the phase 1 qualitative research. The academic team fostered relationships within the Chicago Cancer Health Equity Collaborative, the University of Illinois Cancer Center, and at the University of Illinois Mile Square Health Center and Mammography Clinic to create a day where women with disabilities could receive accessible mammograms from disability-competent providers on a walk-in basis. Phase 3 activities also capitalized on the ScreenABLE video’s success for community outreach and to get buy-in from clinical partners.

As a part of ScreenABLE Saturday, mammograms were provided to women regardless of insurance and documentation status. By keeping patient loads low, we were able to ensure that mammography clinic staff had the time to provide disability-competent care, including spending extra time with women with disabilities to ensure that they felt comfortable and supported throughout the entire screening process from completing registration materials, to donning the gown for examination, to the screening itself. Emphasis on a welcoming, unhurried, disability-competent environment was essential

in light of our research findings that many women with disabilities have histories of negative health care experiences.

Additionally, an infrastructure was put in place to ensure that reasonable accommodations were available to support women's participation in the screening process, including transportation reimbursement, in-person American Sign Language interpreters, and personal attendant services. Transportation reimbursement was vital, because problems with transportation is a barrier for breast cancer screening among women with disabilities.³⁵

By partnering with the Chicago Cancer Health Equity Collaborative and University of Illinois Health System, the team was able to build on the infrastructure and processes implemented for Walk-In Wednesdays, including the provision of vouchers for free mammograms for women without insurance and as well as a clear mechanism for follow-up care, which has been shown to increase adherence to regular screening

The importance of celebrating wellness for women with disabilities, rather than only providing mammograms, was emphasized by disability community partners and helped to broaden the scope of the event to include health promotion

programming. As occupational therapy practitioners, the research team recognized the value of not just learning about health, but actively engaging in accessible, affordable health-promoting activities. The wellness fair component of ScreenABLE Saturday included interactive demonstrations and workshops that emphasized exercise, nutrition, mental health, self-care, and health promoting behaviors. Table 1 provides information regarding the areas of health promotion and the types of activities and information made available. We had workshops and booths on a wide range of topics, such as a low-cost healthy cooking and nutrition demonstration, adaptive exercise, smoking cessation, case management for pregnant women with disabilities, reproductive health, accessible and adapted breast self-examinations, gardening, manicures, and stress management. Workshops led by disability community members included adapted yoga, mixed ability dance, and mammography education. Space for conversation and socialization were available. To support the sense of community and fun, we included a cookie decorating station, smoothie bar, manicure station, and a photo booth.

Table 1. Health Promotion Priorities and Associated Activities and Informational Resources

Targeted Health Outcome	Active Engagement Activities	Informational Resources
Physical activity	Adapted exercise demonstration and consultation	—
Physical activity	Adapted yoga led by person with a disability	—
Mental health	Integrated dance class	—
Physical activity, mental health, Nutrition	Interactive gardening station (able to pot and take pea shoot and mint) Gardening workshop	Physical and mental health benefits of gardening infographic Pea shoot recipe and card
Nutrition	Healthy cooking demonstration and sample Smoothie bar	Nutritious, low-cost bean soup recipe card Three-ingredient smoothie recipe card Information sheets on adding fruits and vegetables to diet
Stress management and self-care	Manicures and hand massages	Stress management pamphlet
Health promotion and prevention	Workshop on breast health self-advocacy for women with disabilities led by community partner Demonstration of adapted breast self-check for women with disabilities	Adapted breast self-care pamphlet Information on smoking cessation
Social engagement sense of community	Sitting areas for conversation and community Large cadre of friendly volunteers with and without disabilities	
Just for fun	Photo booth, bra-shaped cookie decorating, raffles	
Accessibility	American Sign Language interpreters, transportation reimbursement, personal care attendants	

In its inaugural year, ScreenABLE Saturday served 16 attendees, 3 of whom received mammograms. In year 2, the size doubled to 31 women, 5 of whom received mammograms. One participant had an abnormal mammogram and received follow-up evaluation. The community collaborators are working to sustain and grow the event to continue to address the needs of the underserved community of women with disability. Women who participated in ScreenABLE Saturday included several women who reported never having a screening despite being of advanced age as well as those seeking a welcoming environment to celebrate disability, health, and womanhood.

The research team encountered some challenges when building and executing the ScreenABLE Saturday event. Ensuring follow through from all collaborators required persistence and clear communication from the ScreenABLE team. The time, duration, and location of the event changed on multiple occasions owing to conflicts with other health events planned and scheduled for the clinical and event space. ScreenABLE Saturday was originally planned for October, breast cancer month, but given the crowded field of screening events the event was moved to November, potentially lessening people's focus and attention on breast cancer screening. Persistence and passion from multiple stakeholders helped overcome these challenges and make for a well-coordinated and supported event. Community outreach was also a major challenge when promoting the event. There is so little programming targeted at women with disabilities that there are limited existing networks and infrastructures for community outreach. Women with disabilities are also geographically and socially diverse, and targeted advertising to this hard-to-reach population is an ongoing challenge. The university-based medical center mammography clinic is unfamiliar to many women and may not be perceived as a welcoming gathering space. Additionally, given the challenges of accessible disability transportation and impairment issues that are exacerbated by environmental factors, cold rainy weather on the morning of the event in 2017 may have posed barriers to participation for some women.

Collaboration between the academic, clinical, and community partners was key to ScreenABLE Saturday's success. By sharing power, resources, and creative brainstorming, we were able to develop an event that combats the barriers to breast cancer screening that we identified in our qualitative research.

DISCUSSION AND CONCLUSION

Overall, our phase 1 findings were consistent with and contribute to the emergent body of evidence on the existence and experiences of breast cancer screening disparities among women with disabilities nationally. At a local level, these data provided our CBPR partnership with concrete examples of four categories of modifiable and actionable barriers to screening that women with disabilities experience, including a lack of physically accessible examination equipment, a lack of disability competence amongst mammography technologists, the women's histories of stigma and mistreatment within the health care system, and treatment fatigue. What is unique from this study's research findings is the processes it informed and how this knowledge was disseminated.

By working within the KT Collaborative framework, women with disabilities actively engaged with clinical and academic partners to create knowledge products (phase 2) to raise awareness among key stakeholders, especially providers of screening mammograms and cancer center leaders. By galvanizing support, we were able to create public health programming (phase 3) to directly target identified barriers to breast cancer screen and to implement more generalized health promotion activities that emphasize nutrition, exercise, and breast self-care. There are limitations to our study including a focus on a very specific community of people in one large urban center. Moreover, we only used an example from breast cancer screening and this approach may not work with other cancers. Nevertheless, this phased project can serve as an example of how a long-term community-campus partnership with the strategic addition of clinical partners around an area of community concern can lead to actionable, sustainable change in the community. Future community-engaged research leveraging this phased approach can be used to expand the focus to include people with other types of disabilities and cancers.

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