

## Research Articles and Essays

### Community-Based Participatory Research (CBPR) Outcomes: 2023 Pacific Rim Conference Accessible and Affordable Housing Discussion

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#### Abstract

How do we understand the challenges, and policy driven advocacy approaches for people with intellectual and developmental disabilities seeking housing? Using community-based participatory research (CBPR), researchers and advocates from the Center on Disability Studies, University of Hawai'i at Mānoa partnered with community organizations to discuss housing challenges during the 2022 and 2023 Pacific Rim International Conference on Disability and Diversity. The goal was to use CBPR approaches and discussions to develop data-driven strategies for policy makers. Discussion points included: government initiatives to address housing issues; post-pandemic economic development, State of Hawai'i housing policies, along with socioeconomic challenges among the intellectual disability and developmental disability (IDD) community. Outcomes from the discussion include the need for disability data, awareness of housing options, and community-based working groups.

*Keywords:* accessible housing, affordable housing, intellectual disability, developmental disability, policy

## **Community-Based Participatory Research (CBPR) Outcomes: 2023 Pacific Rim Conference Accessible and Affordable Housing Discussion**

With the passage of the Americans with Disabilities Act of 1990 and Individuals with Disabilities Education Act (IDEA) of 1973, individuals with disabilities have been able to experience greater access and inclusion in society; however, they are still underserved and underrepresented in many areas (Resnik & Galloway, 2020). Affordable housing is one such area that needs more attention (Resnik & Galloway, 2020). As parents of individuals with disabilities age, affordable housing for their adult children becomes a key concern. Parents are left to decide what housing options may be most appropriate for their adult children to live in that best meets their needs. While legislation may vary by state pertaining to housing for individuals with disabilities, the issues are similar. Nationwide, common issues include: types of housing available (single dwelling, group home, community setting, developmental disabilities domiciliary homes; independent living; assisted living), housing adaptations and accommodations to name a few (Dunn, 1990; Mackie, 2012). In the State of Hawai'i, cost is also a significant consideration as the cost of living in Hawai'i is the highest in the nation (MERIC, 2023). As a result, securing housing for individuals with disabilities in Hawai'i is more challenging than in the Mainland US. Regardless, finding the most suitable option for an adult child with disabilities is critical for them to live to their fullest potential (Mackie, 2012).

One way to determine housing issues in a given geographical area throughout states and regions is to use a community-based participatory research (CBPR) model.

Community-based participatory research (CBPR) is a research model that utilizes a collaborative approach involving researchers and community stakeholders addressing critical issues such as housing for adults with disabilities and engaging in the decision making process (US Department of Health and Human Services; US HHS). The key to the CBPR model is community engagement to ensure that interventions developed align to identified community needs (Blumenthal, 2011; US HSS). To accomplish this, community stakeholders and researchers collaborate on all aspects of the research including needs assessment, planning, intervention design, implementation, and evaluation (US HSS). The CBPR model is typically used to address health behaviors, health outcomes, and health disparities (US HHS), and has been used among other researchers to address housing challenges (MacKinnon, 2018). Affordable housing for individuals is directly related to health outcomes. The ability to live in an environment suitable for individual needs affects overall health and wellbeing.

Creating collaborative discussions in familiar and safe spaces in Hawai'i such as the Pacific Rim International Conference on Disability and Diversity (Pac Rim) allows engagement from advocates, researchers, practitioners and community members. In addition, the mission of Pac Rim conference is to provide a forum for participants from around the world to share the latest disability and diversity research and best practices and to connect with each other with the aim of taking what was learned and sharing or implementing these ideas in their own settings. Capacity-building workshops and lunchtime discussions are typically used to provide an opportunity for community members and stakeholders to meet and discuss important issues with the goal of developing and strengthening processes and resources that communities need.

This article will address outcomes from a facilitated housing discussion that presented

findings from the 2022 Pac Rim Conference and provided further findings from the 2023 Pac Rim Conference facilitated by Dr. Kelle L. Murphy, Dr. Patricia Morrissey, and Daintry Bartoldus, with contributing team members Genesis M.K. Leong and Saint-Marie Gough. To provide a background to the 2023 lunchtime discussion, we will first briefly mention the outcome of the 2022 workshop. Both the workshop and lunchtime discussion utilized a CBPR model.

### **2022 Pacific Rim Conference**

During the 37th Pacific Rim International Conference on Disability and Diversity, advocates, community stakeholders, individuals with IDD, and local politicians collaborated on a workshop entitled “Expanding Hawai‘i’s capacity to House and Support Individuals with Intellectual and Developmental Disabilities (IDD).” This workshop served as Phase I of a CBPR approach to the topic. The purpose was to have an open discussion to identify housing needs and challenges specific to the disability community in Hawai‘i. The end result was the development of a committee charged with writing and sending a letter with recommendations to address housing issues in Hawai‘i to the former Governor. The committee consisted of five members: 4 parent advocates and directors of various non-profit organizations for individuals with disabilities and 1 representative in higher education. Committee members later met with the new Governor to discuss the recommendations made in the letter and to discuss his plans to address affordable housing for the disability community in Hawai‘i. His plan at that time was to assign a Housing Czar to address housing issues, something he has since done.

## 2023 Pacific Rim Conference

The 38th Pacific Rim International Conference on Disability and Disability lunchtime discussion hosted on Tuesday, March 7, 2023 served as Phase II of a CBPR approach to the topic and was entitled “Accessible and Affordable Housing: Challenges for Creating Housing Options for Adults with Intellectual and Developmental Disabilities.” Parents, advocates, individuals with disabilities, and community stakeholders were in attendance. The goals were: 1) understand challenges and issues; 2) understand what actions have been taken since Pac Rim 2022 workshop; and 3) offer suggestions for moving forward. The discussion focused on the following guiding questions:

1. How do we assist families and people with IDD to navigate housing options in Hawai‘i?
2. What are the barriers to promoting and acquiring more accessible affordable housing?
3. How can we create representation that includes parents, advocates, and individuals with disabilities in housing working groups?
4. How do we motivate and promote these housing issues in a systematic way?

### Results of Audience Discussion

The following suggestions were given by audience attendees to continue to adequately address the topic in Hawai‘i:

1. **Working group for Governor’s task force** - It was determined after the 2022 Pac Rim workshop that a working group designated by the Governor was needed and was one of the recommendations. The suggestion is that the group should include community members

directly impacted such as individuals with disabilities, parent advocates, community stakeholders, as well as politicians. The disability perspective is critical to include in policy-making conversations. The recommendation was made to the current Governor, and he has appointed a Housing Czar to address the issues. The creation of the working group would be the next step.

2. **Data collection** - Appropriate data for policy and decision making is needed and the state of Hawai'i lacks data pertaining to housing issues for the IDD community. In addition, data collection needs to be continuous to be able to make comparisons and determine trends over time. Suggestions for types of data collection included: transitional housing approaches; housing that meets cost of living for IDD; impact of housing on disabled families; inaccessible housing; and unsustainable capital and asset loss. Audience attendees felt that addressing different ways people identify or do not identify with IDD to avoid skewed data is important. They felt that there is a need to address disability within a diversity, equity, and inclusion (DEI) framework.

3. **Educational seminars** - Navigating the system can be both overwhelming and confusing. Educational seminars that teach steps to navigate, alternative solutions, terminology, along with various types of housing options and how to determine which would be most appropriate and affordable was a recommendation by the audience attendees. The thought was that more education on the process would lead to more confidence for advocates to be able to successfully navigate the complex system.

### **Conclusion**

While both the workshop and discussion resulted in productive outcomes, there clearly is more work that needs to be done to adequately serve the disability community in Hawai'i. Involving those directly impacted by the policies and allowing their opinions and

voices to be heard is a critical piece that has been missing from the process. Adequate housing affects a person's overall health and wellness. When housing is comfortable and appropriate for individual needs, their overall wellness increases. This needs to be a priority for all citizens.

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