**SLIDE 1:**

**People Power! Working Towards Truly Inclusive Disability Community Research**

**Partnerships**

**Community Living Equity Center**

**Centro para la Equidad en Vida Comunitaria**

**Co-Investigator**

**Kimberly The, PhD**

**Lived Experience (LE) expert**

**Tyree Brown**

**NCIL Program Director**

**Mary-Kate Wells**

**Alt text: Image of Community Living Equity Center logo featuring 3 people (2 with arms raised and one in wheelchair). Brandeis Logo.**

**SLIDE 2:**

**Overview of Presenters**

**Co-Investigator**

**Kimberly The, PhD**

**Senior Research Associate**

**Brandeis University**

**Alt text: Image portrait of Kim The, a woman with black hair.**

**Lived Experience Expert**

**Tyree Brown**

**Freelance Artist**

**Brandeis University**

**Alt text: Image portrait of Tyree Brown, a wheelchair user with black hair.**

**Program Director**

**Mary-Kate Wells**

**National Council on Independent Living**

**Alt text: Image portrait of Mary-Kate Wells, a woman with brown hair smiling at the camera.**

**SLIDE 3:**

**Objectives**

**Learn why it’s important for disability community members to contribute to disability**

**Learn about challenges associated with doing collaborative research**

**Evaluate what constitutes a good research study worth**

**Express personal needs and expectations that need to be met in order to contribute to disability research**

**SLIDE 4:**

**Participating in Research**

**Subject**

**About people with disabilities**

**Audience**

**For people with disabilities**

**Reviewer**

**Reviews product in an almost finished state to provide feedback**

**Reader/Tester**

**Gauges the quality of factors of the project or product**

**Advisor**

**Provides guidance and insight to stakeholders and disabled people outside of the project**

**Researcher**

**People with disabilities are employed as co-researchers**

**SLIDE 5:**

**Importance of Disability Community in Research**

**Lived experience**

**Produces research that is better tied to disability advocacy efforts**

**Findings that actually matter**

**SLIDE 6:**

**Beyond the Project**

**Skill Development:**

**Interviewing**

**Data Analysis**

**Software Training**

**Network Creation:**

**Building networks between disability research and disabled people**

**Connecting people with disabilities with other opportunities**

**Work Experiences:**

**Presentations and conferences**

**Potential publication**

**SLIDE 7:**

**What are your Hesitations About Participating in Research?**

**SLIDE 8:**

**Should You Join a Research Study?**

**Funding**

**Expectations**

**Alignment with values**

**Timing of the ask**

**Power dynamics**

**Other disabled people?**

**Researcher’s relationship to disability**

**Don’t settle!**

**SLIDE 9:**

**Barriers and Facilitators in Access to HCBS for People of Color**

**Barriers and Facilitators in Access to HCBS for People of Color**

**(Kim The, Miriam Heyman)**

**Qualitative interviews with disabled people of color living who have experienced placements in nursing homes and other institutions and have transitioned to the community**

**Experiences with cultural and linguistic access to HCBS**

**Alt text: Image showcasing group of disabled individuals of color smiling in a bright green background.**

**SLIDE 10:**

**Community Advisory Committee**

**Christine Liao,**

**American Association of People with Disabilities**

**Dr. Janie Mejias, Women Enabled International**

**Dr. LaWanda Cook, Cornell University**

**Andy Arias, Self-Advocate and Policy SME**

**Bernard Baker, Self Advocates Becoming Empowered**

**Melody Cooper, Self Advocates Becoming Empowered**

**Conchita Hernandez Legorreta, Mentoring Engaging and Teaching All Students**

**Tyree Brown, Self-Advocate and Visual Artist**

**Jean-Luc Pierite, Indigenous Activist and Designer**

**Elaina Seep, Aniwahya Consulting Services**

**Germán Parodi, The Partnership for Inclusive Disaster Strategies**

**SLIDE 11:**

**Approach to PAR**

**Lived Experience (LE) Experts**

**→ Involved in all elements of the research from development of the interview guide to data analysis​**

**→ LE experts for this study are disabled people of color of different sex, age, geographic location, and educational level.**

**SLIDE 12:**

**Research process**

**Alt text: Image titled "Our project roadmap."**

**Image has a road with checkpoints. At the bottom of the image are 3 disabled people of color with different disabilities.**

**Image of research process. There are three major checkpoints along an image of a road- planning and training, data collection and analysis, and writing and dissemination.**

**Under planning and training there are 2 parts- develop interview guide and interview training.**

**Under data collection and analysis there are 2 parts- do interviews and analyze data.**

**Under writing and dissemination, there are 2 parts- write up results and discussion and share results.**

**SLIDE 13:**

**Experiences of a Peer Researcher**

**The opportunity to be a part of a study that connects directly to me.**

**Learning new skills about research.**

**Offering information that may not be known from researchers who have not experienced the research topic.**

**SLIDE 14:**

**Experiences of NCIL Staff**

**Outreach and dissemination**

**Opportunity for our network to engage in research and support core services**

**Resource building**

**SLIDE 15:**

**Discussion**

**Would you participate in research?**

**Why or why not?**

**What type of research are you interested in engaging with?**

**What role would you like to have?**

**What are some deal breakers that you have for deciding whether you want to engage in research?**

**SLIDE 16:**

**Recruiting**

**Research**

**Participants**

**Alt text: Image of checklist with the title “Looking for Disabled People of Color Who Have Lived in Nursing Homes or Other Institutions to Share their Experiences?”**

**-Are you a person with a disability who has lived in a nursing home or other institution?**

**-Are you now living in the community and receiving Medicaid Home and Community-Based Services (or want to)?**

**-Are you a person of color?**

**-Are you 18 years of age or older?**

**You may be eligible to participate in a research study Brandeis University is doing.**

**SLIDE 17:**

**Connect With Us!**

**Email Us:  CLequity@brandeis.edu**

**Follow Us: @CLpolicy**

**Website:  CommunityLivingEquity.org**

**Questions?**

**Reach out to Kim!**

**Email: kimberlythe@brandeis.edu**

**Phone Number: 781-736-3911**