

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

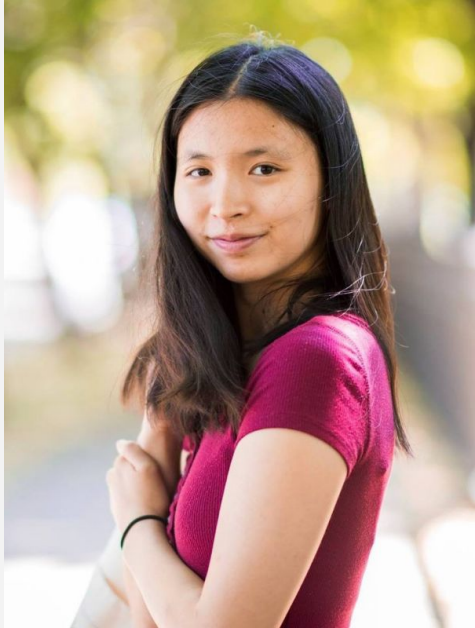
Lived Experience (LE) expert
Tyree Brown

NCIL Program Director
Mary-Kate Wells

 **Brandeis**

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT
Lurie Institute for
Disability Policy

Overview of Presenters



Co-Investigator

Kimberly The, PhD
Senior Research Associate
Brandeis University



Lived Experience Expert

Tyree Brown
Freelance Artist
Brandeis University



Program Director

Mary-Kate Wells
National Council on
Independent Living

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

Participating in Research



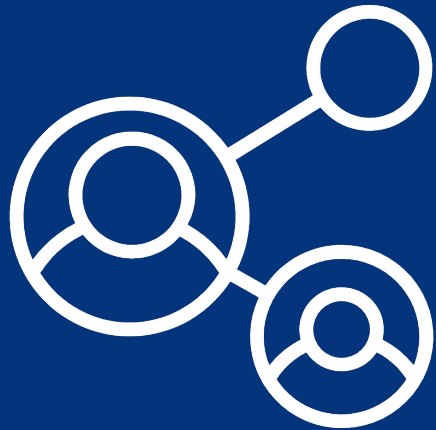
Subject	About people with disabilities
Audience	For people with disabilities
Reviewer	Reviews product in an almost finished state to provide feedback
Reader/Tester	Gauges the quality of factors of the project or product
Advisor	Provides guidance and insight to stakeholders and disabled people outside of the project
Researcher	People with disabilities are employed as co-researchers

Importance of Disability Community in Research

- **Lived experience**
- Produces research that is better tied to **disability advocacy** efforts
- Findings that **actually** matter

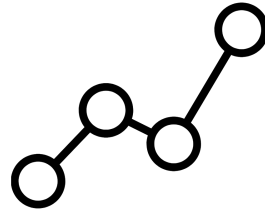


Beyond the Project



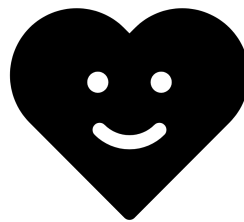
Skill Development:

- 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

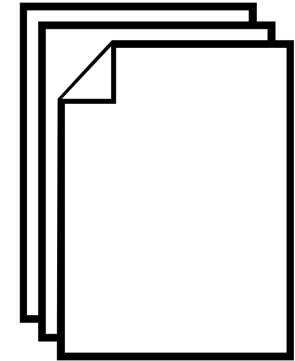
What are your Hesitations About Participating in Research?



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!



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



Community Advisory Committee

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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



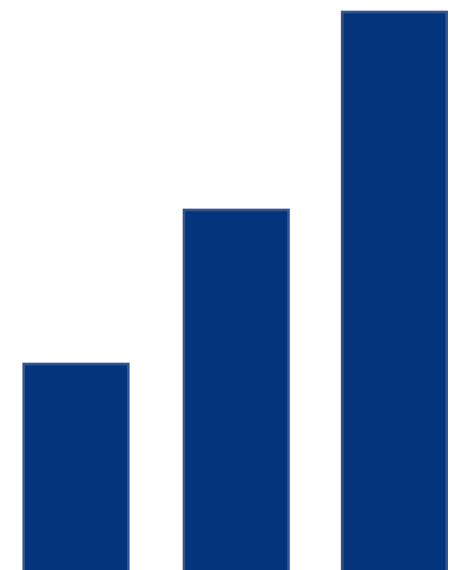
Jean-Luc Pierite,
Indigenous Activist
and Designer



Elaina Seep,
Aniwahya Consulting
Services



Germán Parodi,
The Partnership for
Inclusive Disaster
Strategies





Approach to PAR



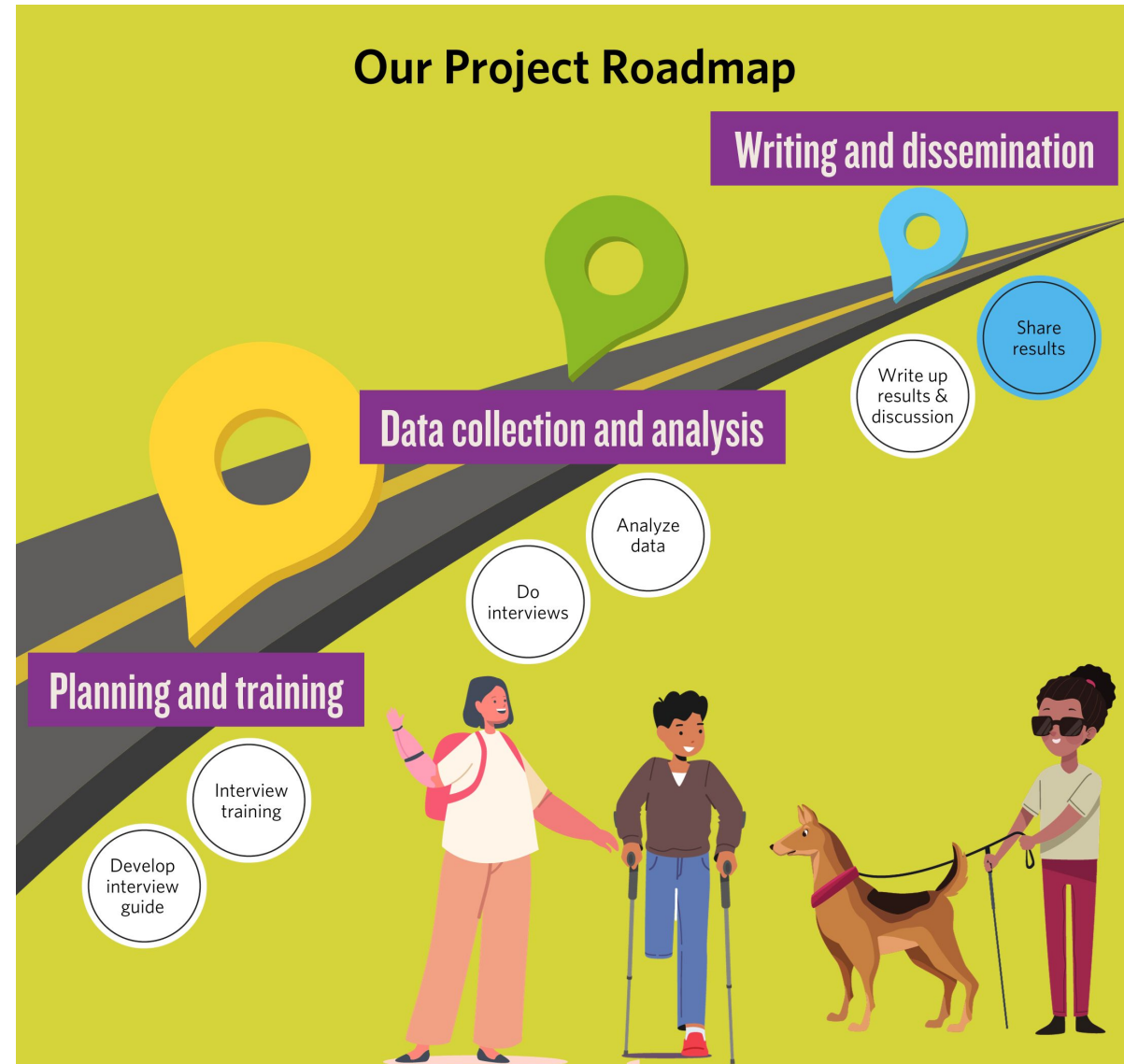
Lived Experience (LE) Experts

→ 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.



Research Process



Experiences of a Peer Researcher

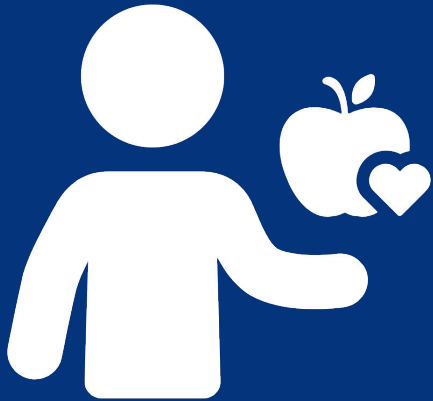
- The opportunity to be a part of a study that connects directly to me.
- Learning new skills about research.
- Offering information that may not be known from researchers who have not experienced the research topic.



Experiences of NCIL Staff

- Outreach and dissemination
- Opportunity for our network to engage in research and support core services
- Resource building

Discussion



- 1. Would you participate in research?
Why or why not?**
- 1. What type of research are you interested in
engaging with?**
- 2. What role would you like to have?**
- 3. What are some deal breakers that you have for
deciding whether you want to engage in
research?**

Recruiting Research Participants



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.*

Connect With Us!

Email Us: CLequity@brandeis.edu

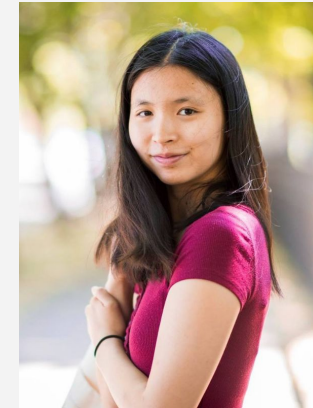
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Website: CommunityLivingEquity.org



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Questions? Reach out to Kim!



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