

Hearing (Our) Voices: Participatory Research and Creative Dissemination in Mental Health

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UNIVERSITY OF
CALGARY
COMMUNICATION
AND CULTURE

Two Research Projects

1. Communication between people diagnosed with schizophrenia and their medical professionals
2. Housing for people diagnosed with schizophrenia

Dependence/Independence

Paradox

- People diagnosed with schizophrenia are caught between their dependence on care and their desire for independent lives
- They need and want care
- They resent the control and surveillance of care and the requirement for “compliance”

Inclusion of People Diagnosed with Schizophrenia

- Inclusion in research
- Inclusion in decision-making
- Inclusion in public discourse

Inclusion in Research

Participatory Action

Research

- Tradition of cooperative inquiry that emphasizes working with community groups as co-researchers.
- Transforms social relations of research, overcomes power differential between expert researchers and objectified subjects.
- Participants are involved in all stages of research process.

Inclusion in Research

Three Goals of PAR

1. Produce knowledge
2. Take action
3. Be transformative

Inclusion in Research

- Co-Researchers
- Members of the Unsung Heroes Peer Support Group
- All diagnosed with schizophrenia
- 13 co-researchers in both projects

Inclusion in Research

- Co-researchers chose topics
- Research Design
- Interviews with 25 people
- Focus groups with 15 people
- Thematic analysis of data

Inclusion in Decision Making

- Care and Control
- A relationship intended to be positive, enabling, and empowering is at the same time controlling and disempowering.

Inclusion in Decision Making

Recommendations for Medical and Housing Service Providers

- Provide information about diagnosis, medication, and support
- Treat us with respect and dignity
- Include us as partners

Inclusion in Public Discourse

Taking action: Non-traditional modes of
dissemination

- Readers' theatre
- Photovoice
- Documentary film
- Graphic book
- Traveling exhibit
- Book and journal articles
- Website: <http://callhome.ucalgary.ca>

Searching for Sanctuary



Photographers

Cindy Carter
Cindy hopes this project will make a difference for people who struggle with mental illness and homelessness. Her photos reflect the importance of safety, security, and being able to make choices.

Clash Mathew
Clash's goals for the research are to bring awareness to those in need as well as to potential providers and benefactors. His photos show the importance of spirituality, relationships, church, and community.

Jamal Ali
Jamal describes himself as a mental health advocate. He hopes that this research project will result in more affordable housing for the mentally ill. His home is a place of happiness, love, peace, stability, and hope.

Jane Gray
For Jane, home means safety, security, and a place for her memories. She hopes that the research will help others realize how devastating mental illness can be and how people are often failed by the system.

Laurie Arroy
Laurie enjoyed the chance to make a difference - she hopes the research will make changes to the way the homeless are treated. For Laurie, home is a place to create, energize, grow, and find peace.

Mary Mitchell
Mary hopes the research will help to find meaningful ideas to create more stable housing. For Mary, home is a place to relax, socialize, and be an individual. Her photos show how important choices can be in helping people stay well.

Nancy Smith
Nancy's love of animals has made her an advocate for affordable housing that allows pets. She says that the companionship of a pet is important for single people as it can help them stay well.

Michelle Murrell
Michelle is a strong advocate for others who deserve safe, clean, and affordable housing. Her favourite photo is the view of the weather and shape, something she never had before.

What Home Means to Me

These photos were taken by a group of people with schizophrenia as part of a participatory action research project on Housing for People with Schizophrenia.

What Home Means

Home is a very safe place, a place where you don't have any fears or nightmares. It's a place where you know that you can trust, to go to bed and fall asleep and not worry about anything in a real sense, it's a real blessing.

Home is a safe, stable place, where I feel like I don't have to move. I'm not going to get thrown out because of my illness or admissions or anything else. It's safe, it's stable, you can build self-esteem around it.

Anything that's not temporary is home. Where you can take off your armor and really come back to yourself from the challenges of the day. You feel like a turtle carrying your home with you. When you're carrying home with you how can you ever take your armor off?

It's all about privacy and freedom. Choosing the people that enter your space. You have your own private thoughts and nobody can invade that space even if it is only twenty square feet. Where no one tells me I have to sleep or not, nobody tells me I have to do the dishes or make my bed, vacuum or whatever. I can do that whenever I want.

Home is a place of my own where I can be myself. You get such a sense of self respect when you walk into a place and you know no one is going to say, "You should when I say," or "You eat when I say," or "Things don't go there," or "You're not allowed to have that person here." That makes a big difference.

Home means the ability to entertain in privacy, so if I want to have dinner or share a bottle of wine with friends, nobody is going to be hanging on my door saying "You can't," "When I don't have a home, I have to entertain in public and some things you just can't do in public.

Home to me means love and a lot of security. A lot of unconditional love, where I don't have to behave a certain way or do a certain thing in order to be respected and appreciated.

I'd rather live in a house, for sure, where the beds are mine.

I do dream of a little house sometimes, with a yard and maybe a guest room, or at least a storage shed.

A dream of maybe visiting a island overlooking the ocean. That's my dream. Whether I can make it come true some day or not, I don't know.

One thing that I really like about my place now is it has a little balcony, and that's my little get away. I go sit on my balcony and I've got a nice view of downtown. That's what I like about it.

Home means a lot of laughter and fun. It is a place where I can have family for celebrations and where I can create memories - safe, pleasant memories. Home is a place to be well, to be really well in.



Searching for Sanctuary: What Home Means to Me
 Created by members of the Peer Support Group (Housing Program, Schizophrenia Society of Alberta, Calgary Chapter)
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 Research Assistant: Vanessa Robinson, Faculty of Communication and Culture, University of Calgary
 Funding by the Social Sciences and Humanities Research Council of Canada

Housing /

Home is a place to find sanctuary.



Housing /

Home is a very safe place, where I don't have any fears or nightmares.

I spent many nights not sleeping, wandering the streets. To go to bed and fall asleep and not worry about anything is a real treat. It's a real blessing.

Home is a safe, stable place where I feel like I don't have to move. I'm not going to get thrown out because of my illness. You can build self-esteem around it.

You get such a sense of self-respect when you walk into a place and you know no one is going to say, "You shower when I say," or "You eat when I say," or "Things don't go there," or "You're not allowed to have those friends here."

Home is a place of my own where I can be myself.

I do dream of a little house sometimes, with a yard and maybe a guest room, or at least a storage area.

Home to me is the objects that surround me, and my two cats.

I'd rather live in a house, for sure, where the locks are mine.

One thing that I really like about my place now is that it has a little balcony. That's my little getaway.

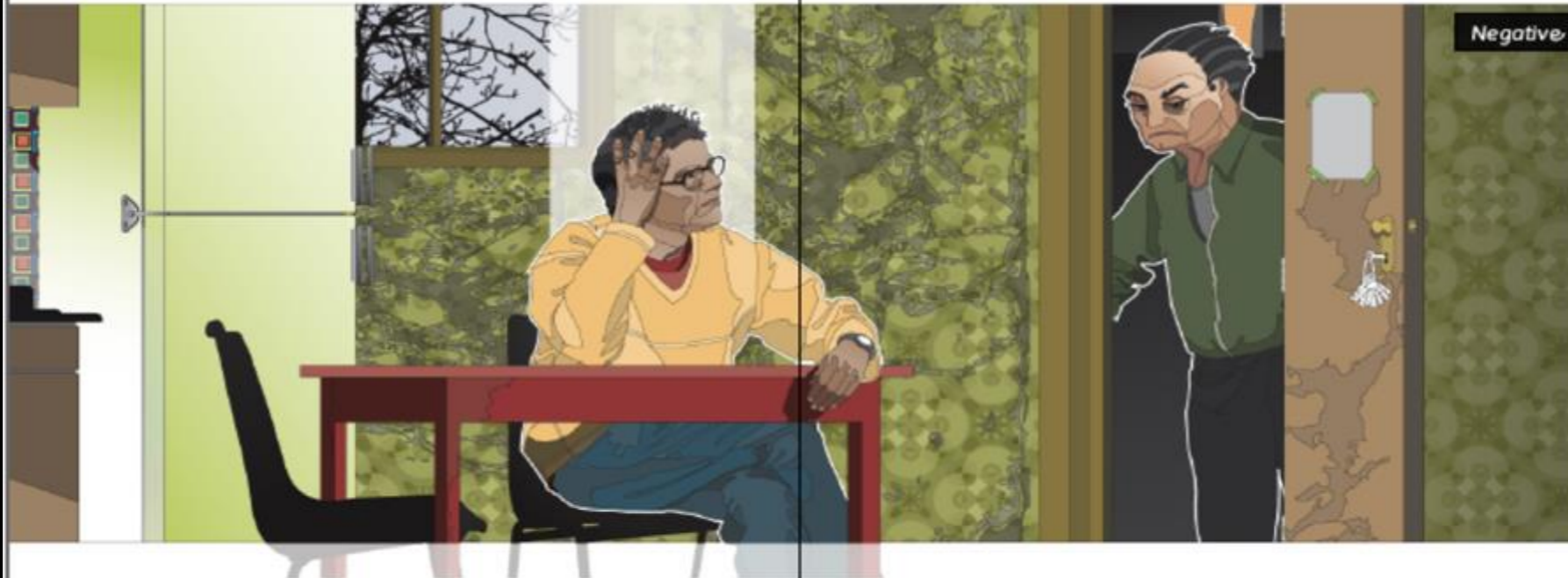
Home means a lot of laughter and fun. A place where I can have family over for celebrations. A place where I can create memories.

The funny thing is, stable housing contributes to me being well. Home is a place to be really well in.

Housing /

Dilemma: Should we live in supported housing with lots of help, but also rules and scrutiny? Or should we live where we pay high rent and eat macaroni but feel free?

Getting and keeping decent, affordable housing can be a challenge.



Housing /

If you're sick, you can't keep your job. If you can't pay your rent, you can't keep your house.

I lived in an approved home for a couple of years, but it was a horrible experience. You start off by being agreeable and then you find yourself becoming compliant. It's done through rules and social policies that develop submission.

I moved into a basement suite. There were mice, and mould, and mushrooms growing out of the carpet, and water seeping in. I trapped ten mice and threw them in the garbage. It was a dungenous place, but I had to live somewhere.

Once you stand up to the landlord and say, "You have no right to do this," they berate you, put you down, call you names. So I'm afraid to say anything, because then I'll get on their bad side.

As soon as I told them I was living at the shelter, they said "We don't want someone who's been on the streets because we can't trust you."

I got kicked out of there because my roommate was doing drugs. I asked her to smoke her drugs somewhere else, and she told me that I had to leave. And because I was renting, I ended up homeless.

I have to bring my cat. A lot of people don't understand that, but she's my whole world. I just can't give her up. I live for her. So because I had a cat, I had to go into slum housing.

I was living with a couple of kids who had just gotten off the street. I don't know what they did with my rent money, but they didn't pay the landlord. They moved out. The landlord didn't even know that I was there. So I was just out of a place.



Hearing Our Voices

a participatory research project on housing for people with schizophrenia



participants

performances

photovoice

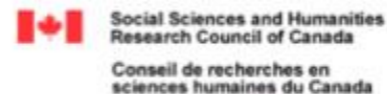
dvd

research

poster book

The struggle for **housing stability** is among the many challenges faced by people with **schizophrenia**. That struggle was the focus of a recent participatory action research project under the direction of **Barbara Schneider**, PhD, Faculty of Communication and Culture, University of Calgary, and funded by the Social Sciences and Humanities Research Council of Canada.

Participatory research involves members of a **community group** in meaningful participation in all stages of the research process, including developing the **research question**, gathering the data, analyzing the data, and **disseminating** and **using the results**.



Canada

<http://callhome.ucalgary.ca>



HEARING (OUR) VOICES

Participatory Research
in Mental Health

BARBARA SCHNEIDER

Inclusion in Public Discourse

- Taking action
- Enables people to advocate for inclusion in research and treatment
- Change how people diagnosed with schizophrenia are treated
- Transformative for co-researchers
- Move beyond dependence/independence paradox

Inclusion of People Diagnosed with Schizophrenia Citizenship

- Enables people diagnosed with schizophrenia to take their place as full members in society with the ability and right to speak about issues that concern them.

Hearing (our) Voices Recovering the Self through Participatory Action Research

Barbara Schneider, PhD

