

Housing for People with Schizophrenia: Dilemmas of Care and Control

A Dramatic Reading

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Housing for People with Schizophrenia: Dilemmas of Care and Control

(Narrator)

*Hello. My name is Claude Mathieu and I want to welcome you to our presentation today. I will guide you through the presentation of our research on **Housing for People with Schizophrenia**.*

(Person 1 from the audience)

My research.

(Person 2 from the audience)

My research.

(Person 3 from the audience)

My research.

(All stand. Unison)

Our research.

(Narrator)

Research that we did on housing for people with schizophrenia.

(5 people remain standing. Everyone else sits. Person 5 is in the middle)

(Person 5)

A 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. 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.

(Person 1)

I was living with a couple of kids who had just gotten off the street.

(Person 2)

I ran out of money and I couldn't pay my rent. I was very delusional at that time.

(Person 3)

I was in the Peter Loughheed Hospital.

(Person 4)

Once you're in the medical system you can't get out of it.

(Person 1)

I don't know what they did with my rent money. They didn't pay the landlord.

(Person 2)

So my brother talked to my landlord and found out that I was about to be thrown out onto the street.

(Person 3)

My AISH worker phoned me, and she said that I was going to be cut off because I was in the hospital so long.

(Person 4)

If you try to get out of the system, then you don't get your meds, or you don't get your doctor, and you need those things.

(Person 1)

They moved out. The landlord didn't even know that I was there. So I was just out of a place. That's how I became homeless.

(Person 2)

He and the rest of my brothers and sisters went over to my place, and packed up all my things, and kept them at their places, while I was in hospital.

(Person 3)

My psychiatrist said, 'I'll talk to her for you,' and I never heard any more about it. If it wasn't for my psychiatrist, I could have lost my place, and I wouldn't have had anywhere to go home to.

(Person 4)

If you want to break away from the label, they say, "Well then we won't take care of you. You're uncooperative and you're uncompliant."

(Person 5)

If you don't have a home you're unworthy. If you don't have a job you're unworthy. We are still beautiful even if we don't have a life style. But we are treated as less than beautiful because we have slipped in our stability.

(Remain standing. Everyone stands.)

(Group 1)

Our voices

(Group 2)

Our voices

(All sit except narrator)

(Narrator)

*What you just heard are the voices of some of the people we talked to in our research on **Housing for People with Schizophrenia**. I want to introduce you to the other researchers on our project. My colleagues are Jamal Ali, Laurie Arney, George Benson, Cindy Calderbank, Mary Mitchell, Michele Misurelli, Dale Silbernagel, and Mark Sunderland. All of us have schizophrenia. We are all members of the Peer Support Unsung Heroes Program at the Schizophrenia Society of Alberta, Calgary Chapter.*

The photos you will see on the screen throughout our presentation were taken by members of our research group to illustrate what home means to us.

*The title of our presentation today is **Dilemmas of Care and Control**.*

As a group, under the guidance of Dr. Barbara Schneider from the University of Calgary, we chose the topic for the research and developed the research questions. We gathered and analyzed the data, and now we are sharing the research with you. We interviewed 30 people who have schizophrenia and have experienced housing instability. These included 8 members of our group and another 22 people outside our group.

Everything that we are presenting today comes from our research. The words you will hear are the words spoken by the research participants.

(All stand)

Care

Control

Compliance

Dilemmas

Do it our way.

Be grateful

Surveillance

Trust

Medication

The system

(All sit except narrator)

We want to tell you about the experiences of our study participants with medical and housing service providers. We will talk about how we feel about the care we receive, and how we feel when we are not listened to. We have chosen as our main theme, the tension between care and control in our relationships with medical and housing service providers. People who care for us want to help us. But they also have authority and power over us. A relationship intended to be positive, empowering, and enabling, is at the same time controlling and disempowering.

We need, want, and appreciate, the help and care we receive from family members, mental health professionals, government agencies, and housing and other social service providers. But, to receive that care, we must submit ourselves to intrusive surveillance and coercive control over many aspects of our lives. If we are not willing to do this, we run the risk that treatment and services will be withheld. But we are ambivalent about control. We don't like it, but sometimes we appreciate control that prevents us from doing things that have led to housing instability in the past.

Dilemmas

The tension between care and control creates dilemmas for us.

We are told that we are responsible for our own recovery, and for making our own choices. But we are limited by what service providers think are appropriate choices. The message we get is: Take responsibility, but do it our way.

We want to be regarded as normal people and live normal lives. But to get services, we have to present ourselves as people who have serious problems.

To get the care we need and want, we have to accept the label, person with schizophrenia, and the identity that goes with it. But once we have the label, we can't get out from under it in any area of our lives.

We must always be grateful for the help we receive, even when things are not really as we would like them to be. We are afraid of asking for even small changes for fear that we will lose what we have.

Those are some of the dilemmas we must deal with everyday.

Now we will let our research participants tell you in their own words how they became homeless, and how their relationships with parents, friends, roommates, and service providers either helped them or made things worse for them. We want to remind you that we are not speaking just for ourselves. The words you will hear were spoken by the 30 people we interviewed for this project.

Family, Friends, Roommates

Many of the people with schizophrenia we interviewed for our study experienced a fairly long period in late adolescence and early adulthood characterized by housing instability. They had conflict with family members and left home during their teens. They had roommates who asked them to leave. They had periods when they couch-surfed, lived in cars, roamed from town to town, stayed in shelters, or lived in cockroach-infested slums. Some moved as many as 30 times over the years, from one substandard place to another. For some, long-term hospitalization for schizophrenia threatened their housing.

My mom and dad, they're living in a world of shame, and so are my brother and sister. They called me names, they'd lock me up in the closet. My dad doesn't even talk to me. He says 'I want nothing to do with that girl, she's not my daughter, I disown her.'

Since I was adopted there have been problems in the home. I was always taken out of the home while there was a period for all of us to calm down. So I was used to saying, "Oh there's trouble, I'm going to split." When I became older I just started running away.

I ended up getting married. This was my third marriage. I thought I was going into a beautiful situation. But then he got so angry with me, and I got sick. Next thing I knew, he got me committed and moved all my stuff into storage. So I was homeless at that time.

I moved into a basement suite. There were mice, and mould, and mushrooms growing out of the carpet, and water seeping in. It was a dungenous place, but I had to live somewhere. I trapped ten mice and threw them in the garbage. The health inspector came, and he said, "Well there's nothing I can do, but, you know, you're living in mould."

I'd have visual hallucinations. I would go into my room, turn off the lights and lie down just to calm myself. My roommate used to come in. She'd grab me, and scream and yell at me, and say, "It's no wonder you have no friends."

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, there was nothing I could do. So I ended up homeless.

Many people got help from family and friends.

Without parental units that care, I would have been homeless many, many times. Your life skills are hindered and humbled as a result of your mental health challenge.

My sister taught me how to look after money, how to do the house cleaning, how to look after myself properly. And she helped me get my own place.

I was with my former roommate for six years, and he gave me great references. I was able to get my life back in order for a while with him.

I had a boyfriend who was on AISH at the time, and he said, “You know you just can’t live like this.” He took me to the AISH office. So that’s when I got on AISH, and was able to get my apartment.

But even help and support from family can seem controlling and disempowering.

When my mother died, I couldn’t handle the costs of the apartment. So my brother helps me out. I don’t know exactly what he has worked out. I often ask him what it is, and he just says ‘Oh, don’t worry about it.’ He won’t explain it to me.

I tried to tell my parents that my apartment manager was coming into my apartment without my permission. They said ‘It’s just your paranoia.’ When you have schizophrenia they can blame it on the paranoia and you can’t fight back. It’s not fair.

Family likes to believe that you’re doing well. It makes them feel good, so they’re not open to listening.

The System

Coming into contact with the medical and housing systems means that we have to learn about a whole new world, rather like moving to a new and strange country. Many of us have struggled with getting to know how the system works and how we can fit into it. We have had to learn to be “compliant.”

In ten years as a mental health consumer, what I’ve learned is you flounder at first, and it’s almost worse. It’s almost like an additional disease, just trying to understand all the agencies, and what they want from you, and what you’re supposed to do, and what your diagnosis is. And there’s no one to guide you through it all.

You really have to submit to the system in order to receive benefit from it. If you do not want to submit to the system, then tough nuggies, good luck. Because you’ve got to play ball or you’re not in the game.

When I was younger, in my late teens, early twenties, before my illness grabbed hold of me, I was concerned about how to fit into society. Now thirty years later with the help of Alberta Mental Health, I’ve found that I’m really in the middle of the system that I wanted to get into in the first place, except as a recipient instead of as a contributor.

Some people identified trust as an issue in their relations with service providers.

I began to trust them, and things started to work out from that point on. Part of it was that I started getting better. But the other part was starting to trust the medical community, which I hadn’t before.

I found that as long as I told my worker the truth then there was a level of trust between me and the person working with me in the Mental Health System.

Medications

Many of our participants describe years of being on and off medications, and connect this directly to their housing instability. These people think that taking medication helps them to maintain their housing, and for the most part, they appreciate the control that is exerted to make sure that they comply with medication orders.

Going off medication is my greatest fear, because it's a downhill slide, it's a shame. You can lose your AISH and your place. I don't want to shame my skin no more. I've had enough of it to realize that it's not fun. It seems fun at the time while you're off medication, but when you look back at it, you don't think so.

Medication does wonders for me. When I'm off the medication I get pretty sick. I need my medication because I get delusional, I have out of body experiences, I hear voices, I have episodes. I have got to be on my medication because it makes a load of difference.

I was on and off medication in my twenties and thirties. In the last four years I've hooked up with the assertive community treatment team who have helped me maintain a stabilized state of mind. They come to my door every morning and every night, and watch me take my medication.

The funny thing is, stability in housing contributes to me being well too. It was kind of a circle that helped me. It kind of feeds each other, if I know my medication is stable and my housing is stable.

Financial Stability

The people interviewed for our study are extremely grateful to be on the monthly disability pension in Alberta, Assured Income for the Severely Handicapped, or AISH. It provides much needed financial stability, which is essential to maintain housing.

If you're sick, you can't keep your job. If you can't pay your rent you can't keep your house. That's how it works for me.

Having a steady income has helped me to keep paying the rent even though I go through unstable periods because of my illness.

I was on medical welfare before I was on AISH, which was a bit difficult, because I couldn't afford to smoke or do the things I wanted to do. So I ended up picking butts off the street and picking bottles, just doing anything to survive. It was a bit tough before I was on AISH.

It was a big breakthrough when I was on AISH, because I was always struggling for money. I even had my boyfriend teach me how to live if I ever ended up homeless. He would take me to the garbage bins behind the houses. There's a lot of great things in the garbage. We'd wear gloves, and have coat hangars or sticks to pull things out with. And you used to be able to get pretty good food at the back of Safeway, but now they incinerate it.

But AISH is also an example of the control that accompanies care. We are frustrated with the surveillance we have to submit to. To continue to receive AISH, we must submit a complicated annual report and send in our tax forms every year. We have to report any additional income by faxing in every pay stub. We have to report any monetary gifts, even small gifts from our parents or grandparents. And we have to be available for random financial and personal audits in our own homes. We fear and resent the power that AISH workers have to cut us off.

You can scrutinize me and I'll try to stand up to it. But you don't have to scrutinize my brother, and my sister, and my mother, and the guy I was married to fifteen years ago. You really start to feel less than human.

I have to be in touch with Alberta Mental Health, and I have to go for appointments as part of my coverage for AISH. My Alberta Mental Health worker says, 'As long as you're working with us you're going to be okay. You can have your financial income as long as you work with us.'

I find that they want to scrutinize my past in order for me to receive what I'm entitled to. They hand you a page of personal questions, and it's like, I just want stability, why are you sniffing my butt? All I want to do is forget about what happened and have a normal life again.

I am extra nice to my AISH worker. So I don't get the threatening letters that others get. She has a reputation of being hard to get along with.

I have to report any extra income to AISH. If I make money one month, it is taken out of my cheque the next month. If I don't make as much money in that next month, I have to manage on less for that month. The paper work is overwhelming. It makes me not even want to work.

Getting on to AISH is essential, but learning to manage the money is important too.

I would go out on spending sprees, and spend until I had no money left in my account. Then I realized I didn't have any money for the rent. Now I have a trustee and I get money on the weekend, so if I foul up it's just for a week instead of a whole month.

I think we set up a dual account. I couldn't take money out unless I had the other person's signature. So I couldn't drink and do stuff like that. I felt that it was a good decision, and a good choice that I made, because I was not capable of seeing the consequences of my actions. I didn't see that I could end up...., well, I guess I sort of did see, that if I kept it up, I would end up homeless.

Service Providers

Many people in our study identified a particular medical or social worker who helped them to find housing and stability.

I just stumbled into AADAC, and there was a counselor. I still remember her. She was a very lovely lady. She said, "You know, there is another life besides this life." It was through her that I got involved in other organizations. I made a decision that I didn't want to live this kind of life anymore. I finally said no for the very first time. I never said no before, but this time I did.

The intake worker for the housing really advocated for me, tried to get me on the list, and up the list, and into the housing as quickly as possible.

I was able to get a place through the Assertive Community Treatment Team. They paid my damage deposit. I'm truly grateful for that. They are almost like family to me, because they helped me move, they paid my damage deposit, and they keep me on medication.

The social worker from the hospital went with me to check the place out. We talked about how much it was going to cost, and could I afford it, the whole works. He found out about all the utilities and things that were owing, and the damage deposit. He did all the footwork for me.

There's an ILS worker in my building from nine to five. When I have stress in my life I can sit and talk to him about that, and we can talk about what my symptoms are, and what I'm having trouble with.

Service providers were also seen as trying to control people. This led to conflict and was not seen as helpful in moving people toward stability. A number of our participants described situations in which treatment or services were withheld when they did not behave in ways that the service provider thought appropriate. Other people felt they could not accept the housing they were offered.

Most agencies are ineffective in connecting you or empowering you in your search for housing. They say, 'Well, look in the paper,' or 'sucks to be you, good luck.' Pro-active is not in the language of many agencies. They refer you, but will they champion your cause, or will they stand beside you? No, they'll just point you in the right direction and say, 'Happy Trails.'

It was impossible for me to get off the street because everybody I phoned, as soon as I told them I was living at the Drop In Centre, they said, 'We want somebody who's working or a student. We don't want someone who's been on the street, because we can't trust you.'

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.

They said I was completely defiant about the plans they had set up for us. I wanted my mom to be my trustee. ACT didn't like this, so they said, "We just don't want anything more to do with him. If that's the way he feels, then he's cut off."

I lived in an approved home for a couple of years, but I block that out of my mind because it was such a horrible experience. You start off by being agreeable, and then you find yourself becoming compliant. It's done through a bunch of rules and social policies that are the vehicle for developing submission. That's probably the one thing that really worries me. The idea of ever ending up in one of those places again.

It's just one-way communication, from them to us, and they expect it that way. There is just no compromising from them.

I was on the wait list for three years for Calgary Housing. I got a house at Bridgeland and I lived there for a couple of years. But then my diabetes got bad and the doctor said, 'You're not taking your insulin, you're not taking care of yourself. You have to move out of that apartment.' And that was the biggest mistake that I ever made, listening to him. I had to find someone to look after my daughter. I ended up in hospital and then I had nowhere to live.

They think we're always trying to manipulate them, and that just drives me crazy. We're manipulating to stay well, to be okay. I just call it survival. Why do you call it manipulation?

As long as you're in the system, you're not in control, your supports are in control. Not until you become independent in your own housing can you move away and beyond the system. But even then you still have to live in fear of it.

Landlords

Once people were in housing, their troubles were not over.

My apartment managers would come in anytime they wanted to, and it scared me. They stole my toilet paper, they stole my sheets, they stole my towels. I would tell and nobody believed it.

Once you stand up and speak your mind, and say, "You have no right to do this," they turn around and they berate you, put you down, call you names. So that's why I'm afraid to say something, because then I'll get on their bad side. If I get on their bad side my place won't be painted.

Even doing well can lead to housing instability.

I don't even want to ask about whether a person can become too high functioning for my supported apartment building. Someone might find out how well I am doing and ask me to leave. They don't really support in some ways the idea of being very high functioning. I don't even like the word high functioning.

Recommendations

We have some recommendations that we hope will help service providers to care for us without controlling us. We have divided these into three groups.

Providing Care.

We need a central agency for the city that knows about all the housing options for people with mental illnesses. Make sure that one person from this agency follows someone right through the system, A to Z, from homeless to housed, so people do not get lost in the system.

We need an advocate to mediate disputes between people with mental illnesses and housing providers or landlords.

Provide more education about mental illness to housing service providers and landlords. Many lack compassion and do not treat us with respect and dignity.

Families can be an important stopgap that catches you before you fall to the streets. Provide education for families about different housing options and offer more support for families.

Provide support to help us as we get more independence. We are very fragile when we start to do things. We need help with doing taxes, saving money, learning about insurance, providing for ourselves in the future, learning about nutrition, and managing stress.

Reducing Control while Providing Care

Don't ask us for compliance. Work with us to help us make choices, but do not tell us what we have to do. We do not want to be forced to live the way you think we should live.

Don't make us share with roommates unless we are willing to.

The fact that we are living with a mental illness and on disability pension does not mean that you have a right to intrude into our lives. Don't ask us to expose our whole lives.

Simplify the AISH system. Right now, if you start to work, the paperwork required by AISH is overwhelming. It makes you not want to work. As you start working, it should be easier instead of more complicated.

Expanding Access to Housing.

We should be able to live where we want to live. Most of us dream of living in our own homes in the community. Help us to make this a reality.

Housing should be permanent. We should not be moved without our consent. We should not have to move just because we reach age 65 or don't "fit in" to particular housing.

Housing should be flexible to accommodate people's needs. Provide more different ways of housing people, including people who have pets.

We need rent controls and more subsidized and affordable housing. Provincial and federal governments could give tax incentives for affordable housing, or require that builders make a certain percentage of their new units affordable housing. Society has to make this a priority.

Home

The participants in our study told us what home means to them.

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 addictions, 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 your home with you, how can you ever take your armor off?

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 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." That makes a big difference.

Home means having 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 banging 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 is the objects that surround me, and my two cats. Ideally I would love to have one of those little army houses up in the northwest, but I'm not going to have that. I'm pretty happy where I'm at.

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

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

One thing that I really like about my place now is that it has a little balcony. 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. A place where I can have family for celebrations. A place where I can create memories— safe, pleasant memories. Home is a place to be well, to be really well in.

We hope that through our research people will see a story of hope. There is hope for people who have schizophrenia. They don't have to live homeless anymore. And hopefully, in the future, there will be more income supports, more community supports, and more subsidized and affordable housing. We must find the "political will" to have more subsidized and affordable housing for people who have schizophrenia.

(3 stand and stay standing)

OUR RESEARCH

(3 stand and stay standing)

OUR VOICES

(3 stand and stay standing)

OUR RESEARCH

(All stand and stay standing)

OUR VOICES