Housing for People Living with Schizophrenia:

Dilemmas of Care and Control.

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This paper presents results from a participatory action research project undertaken by a group of people with schizophrenia who expressed a desire to investigate housing for people with schizophrenia, an area that they saw as a significant problem, both from their personal experiences and from their observations of others’ experiences. The project was carried out under the guidance of a university researcher. The focus on housing for people with schizophrenia grew out of a previous participatory project carried out by some of the group members and the same university researcher (Schneider et al., 2004). That project investigated communication between people with schizophrenia and their medical professionals. Group members chose the topic and research question, conducted the research interviews, and selected segments of the data for inclusion in a readers theatre performance that has been presented widely in Alberta, Canada. Perhaps even more importantly, it instilled in group members a sense that they could make a significant contribution to understanding of the point of view and experiences of people living with a psychiatric disability. An opportunity to submit an application for a grant to carry out a project investigating the problem of housing for people with schizophrenia presented itself, and we want to express our gratitude to the Homelessness and Diversity program of the Social Sciences and Humanities Research Council of Canada for their support of our project.

Schizophrenia is often described as a complex biochemical brain disorder that is estimated to affect about 1% of the population. It occurs in normal, intelligent people in all walks of life and affects perception, thinking, feeling, and behavior. Its symptoms
include, among others, hallucinations, delusions, and disordered thoughts. A significant literature exists that disputes the idea that psychiatric disabilities are illnesses at all (e.g. Laing, 1967; Szasz, 1974). However it is not our intention to explore this debate. The people who participated in this study regard themselves as having a mental illness, schizophrenia, so we use this term as though it were unproblematic.

It is generally believed that a significant percentage of the homeless population suffers from severe mental illnesses, primarily schizophrenia (e.g. Torrey, 2001). According to Frankish, Hwang and Quantz (2005), however, this is a misconception. They cite a study (CMHA, 1998) that found that about 6% of homeless people in Toronto suffer from schizophrenia. Affective disorders (e.g. bipolar disorder, depression) are much more prevalent (20-40%) in people who are homeless (CMHA, 1998). Perhaps more relevant to this study is the finding of Folsom et al. (2005) that 20% of approximately 5000 people treated for schizophrenia during the year of their study were homeless, and it is this fact that provides the motivation for our study. Providing housing for people with schizophrenia is widely regarded as extremely challenging as they are the least likely subgroup of the homeless population to gain access to housing programs (Tsemberis & Eisenberg, 2000) and, once housed, there is a high likelihood of a return to homelessness. While most of the participants in our study experienced longer or shorter periods of being without a permanent home, because of the difficulties of defining homelessness and the variety of people’s experiences, we have chosen not to use this word to describe their situations. Instead we use the terms housing stability and instability in our attempt to convey the complexity of people’s housing experiences.

Dilemmas of Care and Control
Members of the research group identified the tension between care and control in relations between people with schizophrenia and their medical and housing service providers as the main theme arising from the research. On the one hand, the participants in our research want, feel they need, and appreciate, the help and care they receive from mental health professionals, government agencies, housing and other social service providers, and family members. On the other hand, to receive that care, they must submit themselves to a variety of forms of what they regard as intrusive surveillance and coercive control over many (perhaps all) aspects of their lives. If they are not willing to do this, they run the risk that care will be withheld. However, they are deeply ambivalent about the control aspects of care: while they may chafe under it, they sometimes also want and appreciate the control that is exercised over them to prevent behaviours that have in the past led to instability.

As Lupton (1997) points out, “In the relationship between the carer and the cared-for, there is a continual tension on the part of the cared-for between wanting and appreciating care and resenting it” (p.105). This tension between care and control presents a complex set of dilemmas that play themselves out and must be negotiated in the everyday lives of people with schizophrenia. What follows is a description of how these dilemmas are experienced by the members of the research group. People are told that they are responsible for their own recovery and for making their own choices, but they are limited by what service providers think are appropriate choices. The message they get is, “Take responsibility, but do it our way.” They want to live normal lives, but in order to get services they must present themselves as troubled in various ways. They must accept the label, person with schizophrenia, and the identity that goes with it in
order to get the care they need and want. But once they have the label, they cannot get out from under the label in any sphere of their lives. They must always accept and express gratitude for the help they receive, even when things are not really as they would like them to be, and are afraid of asking for even small changes for fear that they will lose what they have. However, while they must negotiate these dilemmas, they are also genuinely grateful for some aspects of the control over their lives. They see benefits to themselves for having made or having been forced into certain choices, particularly taking medication. They are extremely pleased to be living in stable housing and are thankful every day for what they have achieved.

We call on the work of a number of scholars to understand this tension between care and control. Care is almost always seen as a good thing, and the word carries almost no negative meanings. Control, however, seems to be an inevitable consequence of the provision of care, even if not intended by carers. Indeed, many scholars go further and identify control as an explicit goal of care. Glasser and Bridgeman (1999) point out that “charity has always underlined the differences between giver and receiver, and serves as a powerful element of social control” (p. 40). Others (e.g., Lyon-Calio, 2004; Piven & Cloward, 1971) have identified social control of the poor as a goal of social welfare programs. For example, Allen (2000) describes social welfare on the one hand as being about helping people who are unable to “keep up” and on the other hand as being about “the regulation of people regarded as deficient” (p. 12).

Fox (1995) also notes the paradoxical nature of care. On the one hand, the act of caring comes from concern and a desire to provide for the needs of others. On the other hand, the disciplinary knowledge of the carer supplies “the basis for the authority and
power of those who practice care” (p. 111). A relationship intended to be positive, empowering, and enabling is at the same time disempowering and controlling. Fox describes what he calls the vigil of care as “the continual subjection of care’s clients…to the vigilant scrutiny of carers” (p. 112). He also notes that an expectation of reciprocity underpins the provision of care, in which people who receive care must return something to the carer. People who receive care can manage this expectation by “compliance or docility…or by ‘gratefulness’ for the expertise of the carer” (p. 118). In order to receive housing services and medical treatment, people must be compliant, that is they must agree to subject themselves to the surveillance and control that accompanies care, and they must express gratitude for that care.

In our data we see a more complex relationship between service providers and people with schizophrenia than simply one of service providers controlling care recipients and of recipients being noncompliant. It is a complex dynamic interaction in which some people do in fact appreciate the control and surveillance that accompanies care, and see some service providers as providing helpful care. As Fox (1995) points out, “the vigil’s disciplinary power is not situated outside the care setting—in policy or institutions…—but in the everyday practices of care, in the contact between the carer and the cared-for” (p. 109). The character of care and the outcome in the lives of the people receiving care can be found in the interaction between the care giver and the care receiver and in the way care is experienced and responded to by both the individual provider and the recipient. Thus services may be experienced differently by and lead to different housing outcomes for different recipients. This statement may seem to be rather banal and self evident. But as both the literature and our data show, no simple formula exists
for the provision of housing for people with schizophrenia or for the way in which the relationship between service provider and recipient should unfold. Some people are able and willing to subject themselves to the surveillance and control of care, that is, be compliant, and others are not. Failure to achieve housing stability is not just the “fault” of individuals, who need to shape up and take some responsibility for their situations and “do it our way.” It is also the result of interactions with agencies or care providers that produce people as problems through the imposition of behavioural and other rules and deprives them of housing when they do not follow the rules.

**Method**

The approach used in this study is participatory action research (PAR). PAR is embedded in a tradition of cooperative inquiry that emphasizes working with community groups as co-researchers (e.g. Balcazar et al, 1999; Campbell et al., 1999). Participatory research involves the members of the 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. Participatory research thus strives to transform the social relations of research by regarding all participants as both co-researchers and co-subjects (Oliver, 1992; Zarb, 1992). PAR regards the people who live the experiences that are being studied as the experts in those experiences. It assumes that knowledge is something that is produced through the active engagement and interaction of all participants.

Participatory research has emerged as an important and legitimate method of conducting research with people with disabilities. It has been used in research with people with physical disabilities (e.g. Stewart & Bhangwanjee, 1999; Campbell,
Copeland & Tate, 1998; Krogh, 2001) and with learning difficulties (e.g. Richardson, 1997, 2000). It has also been used with people with schizophrenia (e.g. Canadian Nurses Association, 1996; Davidson et al., 2001; Schneider, et al., 2004). Davidson et al. (2001) used a participatory approach to involve 12 people with schizophrenia in exploring reasons for relapse and designing a program to successfully avoid relapse. As Davidson et al. (2001) note, participatory research offers an alternative to conventional approaches that “provide yet one more source of the loss of self, unwittingly undermining rather than promoting recovery by treating the person with the disorder as a passive object to be investigated and acted upon by others” (p. 163).

The Research Group

In the current project, the research group consisted of nine members of the Unsung Heroes Support Group from the Schizophrenia Society of Alberta, Calgary Chapter, all of whom have schizophrenia. All but two members of this research group have experienced some degree of housing instability for some period of time. All members of the research group are now in stable housing. Some live in what is known as supported housing—apartments run by social agencies that provide support in the form of a social worker on site and group activities for residents. Others live on their own in the community; one for example has recently moved into a small townhouse built by Habitat for Humanity. All still feel the fear of losing their housing.

The research group had regular meetings twice a month for an hour starting in April, 2005. We used our first meetings to discuss our goals and procedures for carrying out the research. Group members wanted to talk to people who have schizophrenia and had experienced housing instability. We had carried out in-depth interviewing in our
previous project and group members wanted to do similar interviews in this project. We decided to also conduct focus groups in this project. We generated a list of topics and questions to ask in interviews and focus groups and invited a guest from the sociology department at the University of Calgary to come and talk to us about conducting focus groups. Ethics approval was received from the University of Calgary Research Ethics Board and all group members (including the university researcher and research assistants) and interviewees from outside the group signed consent forms.

Over the course of the next eight months, we interviewed 20 individuals, including 8 members of the research group, and conducted two focus groups with people outside the group. One of these groups consisted of 5 people from outside the group and 3 interviewers from the group. The other consisted of 11 people from outside the group (some of whom observed but did not participate) and 5 interviewers from the group. We relied on our interviewees to self identify as people living with schizophrenia rather than asking for medical evidence that they had schizophrenia.

We began by conducting interviews among group members at our twice-monthly meetings. These interviews provided a safe environment for group members to practice interviewing as well as to generate data. After we had conducted a few interviews, we had a workshop night in which group members identified specific interview strategies that they felt enhanced or impeded the interviews. We practiced the helpful strategies and critiqued each other. We then asked people from outside the group to come to our meetings to be interviewed. Typically, two group members acted as the primary interviewers, but others felt free to jump in if they had something they wanted to ask. The interviewee and the interviewers were seated together at one side of the room and other
group members were arranged around the room. We also interviewed people outside the group in a variety of locations, including in their homes, in coffee shops, and in rooms provided by service agencies that put us in touch with potential interviewees. One or two members of the research group attended each of these interviews along with the university researcher. We were assisted in organizing our focus groups by service agencies who canvassed their members and clients for people who would be interested in participating and provided us with a room to conduct the focus group.

Initially, group members found interviewing to be a very stressful and nerve-wracking experience, but as the project progressed, everyone became much more comfortable and several group members became extremely skilled interviewers. The interviews and focus groups were often very moving experiences for group members, as people detailed their sometimes very harrowing experiences leading up to diagnosis with schizophrenia and described their housing histories and experiences. The focus groups were regarded as highlights of the interviewing portion of the project.

All interviews were audio recorded and some were also video recorded. Anyone who was not comfortable being video taped was seated out of range of the camera and was not included in the video. Recordings of the interviews and focus groups were transcribed by a professional transcriber. Copies of the transcripts were given to research group members to read. Except for the university researcher, no one in the research group had attended every interview and focus group. Although not every member of the group read the approximately 400 pages of transcripts, those that did found that doing so gave them access to everything that had taken place in the project up to that time. Each person who read the transcripts wrote a summary of what they felt were the main themes and
important ideas in the interviews. Transcripts were also given to a research assistant who coded them using HyperResearch, a computer program for qualitative data analysis.

The analytic focus in the presentation of our results was developed by the members of the research group during the analysis phase of the research. This took place after the interviews were completed, as we continued our meetings, discussing what group members wanted to see in the analysis. These meetings were also recorded and transcribed. During these meetings we explored various ideas and themes, looking for a way to organize our data that would reflect both the group members’ experiences and those of the people we had interviewed. At one particularly dynamic meeting, we discussed the difficulties of being long-term care recipients, something that resonated deeply with all the members of the group. This meeting generated a tremendous outpouring of emotion as group members articulated the dilemmas of care and control and described their experiences of being caught in them. This became the focus of the analysis and the organizing theme for the results presented here.

The final phase of participatory action research involves action on the part of research participants to improve the lives of those affected by the problem being researched. Therefore, in addition to this article, we have written a script for a readers theatre performance that group members have presented at academic conferences and community events. Through this, group members, who have experienced schizophrenia and housing instability, have the opportunity to speak directly to medical and housing service providers about the experiences of people in their situation of being on the receiving end of care.

Results
Overview of Results

Our results show a complex pattern of housing stability and instability in which interaction with family members, roommates, individual service providers, and “the system” is a key factor in whether or not people with schizophrenia achieve housing stability. We have represented this complex pattern in Figure 1, although some members of the research group feel that it does not do justice to the complexity of the problem. The diagram places the person with schizophrenia in the centre. This person comes into contact with medical system, perhaps through hospitalization, gets diagnosed with schizophrenia and typically is placed on antipsychotic medications. They may have already experienced conflict with family, friends, and roommates that has moved them in the direction of housing instability. They may also experience help and support from family members that moves them toward stability.

They continue to be in contact with the medical system, and they also come into contact with housing service providers. But this contact does not in and of itself lead to housing stability. People with schizophrenia are not a homogeneous group, and can have very differing needs and desires, and these needs can change over time. At some times, some will have interactions with service providers that will move them toward housing stability. They will be willing to take on an illness identity and take medications, they will be willing and able to accept the control and surveillance inherent in care, they will have relationships with individual service providers that help them, and they will be able to accept the housing they are offered. At other times, they will receive very similar housing services, but stay in situations of housing instability. They may not be willing to take on an illness identity and continue to take their medication, they may not get along
with roommates they are assigned to, and they may not be able or willing to “follow the rules” of housing that is provided. For example, they may be unwilling to give up their pets or to abstain from illegal drugs.

As one group member put it, housing stability can change to instability in a flash. People can be asked to leave for various behavioural infractions such as not keeping the place clean or not attending 12-step programs; they may encounter financial problems or may experience an increase in symptoms leading to not being able to cope with housing rules; or landlords or other people in the building may make life difficult for them so they leave the housing. Even doing well can lead to instability. Becoming too “high functioning” can lead to people being asked to leave supported housing for housing in the community. Once people achieve long term housing stability, and some consistent or at least manageable degree of wellness, they may begin to achieve more independence and become integrated into the community. They are able to volunteer, work, and may even leave the illness identity behind. But even here, they experience the tension between care and control that characterized their relations with the people and agencies that continue to provide them with care.
Figure 1: Housing for People with Schizophrenia.

Family Relationships

Many of the people with schizophrenia 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 moved frequently, and they experienced periods of homelessness during which they stayed with friends (also known as couch surfing), lived in cars, roamed from town to town, lived in cockroach-infested slums, or stayed in shelters. Some moved as many as 30 times over the years. For some, long-term hospitalization for schizophrenia threatened their housing. Some described abusive relationships with parents and other family members that resulted in their leaving home. One woman described her youth this way: “My family 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.’” She ran away to Vancouver, where she found herself without money or housing, eventually hooking up with a pimp who provided
housing in exchange for the sale of her sexual services. One man started using illegal drugs in his teens, which led to arguments with his mother and resulted in him leaving home before he was seventeen. One woman described conflict with her third husband who finally had her committed, put her belongings in storage, and disappeared from her life, leaving her with no place to go home to after release from hospital.

Others had conflict with roommates. One told us, “I’d have visual hallucinations and I would just go into my room and turn off the lights and lay down to calm myself down. But she [my roommate] used to come in and she’d flip on the light and she’d grab me and she’d physically pull me up out of bed and force me to get up and stuff….She used to scream and yell at me and say things to me like ‘It’s no wonder you have no friends.’” Another objected to her roommate’s drug use, was asked to leave and was not able to find another affordable place. Another described having given his rent money to his roommates who used it for drugs rather than giving it to the landlord, which resulted in his eviction. Another told of having given money for rent and food to a roommate who then put all his belongings outside and changed the locks, leaving him with no money and no place to go.

On the other hand, many participants in our study also described supportive relationships with family or friends that have helped them to maintain stability in their lives. As one man said, “Without parental units that care, I would have been homeless many, many times.” Another described the help she had receive from her sister: “She taught me how to look after money, she taught me how to do the house cleaning, how to look after myself properly, and at that time she helped me get my own place.” Another described a time when she was on the verge of losing her housing because she ran out of
money: “I couldn’t pay my rent and I was very delusional at that time. So my brother talked to my landlord and found out that I was about to be thrown out onto the street and 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 until I was able to move out into a place in [another city].” Another got “great references” from a former roommate, and so was able to find housing. Another described a boyfriend who said, "You know, you just can’t live like this." He took her to the AISH office (Assured Income for the Severely Handicapped, the monthly disability pension in Alberta) and helped her with the forms. She was then able to afford a small apartment.

However, even help and support from family can be seen as controlling and disempowering. One woman told us that after her mother died her brother helped her out financially. But, she said, “I don’t know exactly to this day what he has worked out, but he helps me pay for the mortgage and I pay for the condo fees. But I don’t exactly understand what it is and I often ask him. He just says ‘Don’t worry about it,’ and he won’t explain it to me.” Another woman tried to complain to her generally supportive family that her apartment manager would enter her apartment without her permission. “They just said ‘It’s your paranoia.’ So when you have schizophrenia they can blame it on the paranoia and you can’t fight back. It’s not fair.” As one man said, “family likes to believe that you’re doing well there. It makes them feel good, so they’re not open to listening.”

*Getting Into the “System”*

Coming into contact with the medical and housing provision systems means that people have to learn about a whole new world, rather like moving to a new and strange
country. Many have struggled with getting to know “the system” and how they can fit into it. As one man said, “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 kind of guide you through it all.” One of the primary things people have to learn is how to be “compliant.” One man summed it up like this: “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, you know? Because you’ve got to play ball or you’re not in the game.” But many participants were genuinely grateful and pleased to have achieved compliance. This ambivalence about the control aspects of care runs as a thread throughout our data.

Trust

Several said that learning to trust their service providers was an issue for them, as paranoia is a characteristic of many with schizophrenia. One man said that at some point “I began to trust the guys and things started to work out from that point on. There was enough follow-through care after that with therapists and nurses. I started getting better was part of it, but starting to trust in the medical community, which I hadn’t before.” Another man said, “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.” He also said he received praise from agency representatives for his willingness to comply with agency expectations. “At least you tried to stay sober and at least you’re taking your medication, at least you’re doing something during the day….So I’ve found in my experience with the people in the mental health field, I’ve been getting credit for trying to
help myself.” Learning how to cooperate with service providers was seen as by these people as positive in helping them to move toward stability.

**Medication**

Most of our participants have come to appreciate the benefits of taking medication regularly. Many describe years of being on and off medications and connect this directly to their housing instability. These people know that taking medication helps them to be stable and to maintain housing, and they appreciate the control that is exerted to ensure that they comply with medication orders. They submit willingly to this control. As one said, “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’ve got to be on my medication because it makes a load of difference.” She described her relationship with the Assertive Community Treatment (ACT) team who come daily to her house to ensure she takes her medication and who have helped her “maintain a stabilized state of mind.” This team also paid her deposit for the housing she is currently in and helped her move in. Another woman said that her greatest fear is that she will go off her medication, because she knows this would lead to hospitalization and possibly losing her home. “It’s a downhill slide, it’s a shame. 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.” One man described his journey toward compliance. “Twenty years ago maybe you had a tenth, a fifth of the medications that you have now. The medications I was on, I was more or less blank. I didn’t have the cognitive capacity to make good choices. So with medications that have worked over the last ten or fifteen years, I find housing and getting along in the system has improved a
lot.” One woman noted a reciprocal relationship between housing and 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.”

One described what happened when she went off her medications a few years ago. “They threatened that I’d have to leave [my housing] if I didn’t comply. So I handed in my key and I left. Then the police came and they got on the bus and hauled me off the bus. It was kind of embarrassing that the police were involved.” She was taken to hospital and put back on her medication, which she now takes regularly. In some cases, people with schizophrenia provide this kind of control for each other. One person described a living situation in which the other people in the building, all of whom also have severe mental illnesses, provide the surveillance. When one resident went off his medications, the other residents got together to discuss his situation and began talking of trying to force him out of the building if he did not go back on his medications. He did go back on his medications, and was reported by the person we talked to as being glad he did.

Financial Stability

Another example of the control that accompanies care can be found in the administration of the monthly disability pension in Alberta, Assured Income for the Severely Handicapped (AISH). Most of the people interviewed for our study are on AISH and are extremely grateful for the financial stability it provides. There can be no doubt that the financial security AISH provides is an essential aspect of housing security. As one woman said, “If you can’t pay your rent you can’t keep your house, and if you’re
sick you can’t keep your job, so that’s the way it works for me.” Getting onto AISH was
a key turning point for many of our participants in achieving stability.

One man described his life before AISH. He found life “a bit tough before I was
on AISH.” He described being on Medical Welfare, which pays considerably less than
AISH. This was “a bit difficult because I couldn’t smoke or do the things I wanted to, so I
ended up picking butts off the street.” Another said that before being on AISH, “Stability
was a concern. If I had one week without income I had stress and without loved ones,
when you’re in crisis it’s huge, it’s not minor, it’s huge with a capital C. For those who
have no loved ones, who have burnt bridges and feel that the very act of reaching out is
too much, why not just slip between the cracks and pick bottles for a few years?” Another
said, “It was a big breakthrough when I was on AISH because I was always struggling for
money.” Another told us how she planned for possible homelessness before AISH. “I
even had my boyfriend teach me how to live if I ever ended up homeless. He would take
me to the bins behind houses. There’s a lot of great things in the garbage, in the bins.
We’d wear gloves and have coat hangars or sticks that you would pull things so search
and the things you take out would only be really, really clean stuff. And then at the back
of Safeway before they got the burner things in, you could get pretty good food too.”

It is clear that AISH has made a tremendous difference in the lives of the people
we talked to. However, they also expressed frustration with the surveillance they must
submit to. To continue to receive AISH, recipients must submit their tax forms every
year, report any additional income, including, for example, small monetary gifts to buy
cigarettes from parents or grandparents, and be available for random financial and
personal audits in their own homes. People fear and resent the power that AISH workers
have to cut them off and chafe under the control imposed on them. As one woman said, “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 so much? You really start to feel less than human.” Another said, “You can scrutinize me and I’ll try to stand up to it but you don’t have to scrutinize my brother or my sister and my mother and the guy I was married to fifteen years ago. That’s the kind of stuff that really upset me, coming out of the hospital the first time.”

One man said that he had to attend appointments with Alberta Mental Health to continue to receive AISH. He said that his Alberta Mental Health worker told him, “‘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.’ That’s part of the ground rules to be on AISH—I have to work with a Mental Health worker.” One woman described herself as being “extra-nice” to her AISH worker, who has a reputation of being hard to get along with. As a result, she said, “I haven’t received any of the threatening letters” that others receive from AISH. This woman also complained about AISH procedures for clawing back benefits when she receives income from other sources, saying that they produce instability in her life and make her reluctant to seek more employment. If she makes and reports money one month, it is taken out of her cheque the next month. If she doesn’t make as much money in that next month, she then has to manage on less for that month. Another described her difficulty getting onto AISH. “I was going to the library doing research and I ran into a booklet about welfare. It said, ‘To qualify for AISH you must have exhausted all resources within the community.’” I think now that I look back, that’s
why I was jumping through all the different hoops. They didn’t put me on AISH until four years after my first [psychotic] break.”

Getting onto AISH was essential, but learning to manage the money also was important. Here again we can see the ambivalence our participants feel about the control aspects of care. One man described the challenges. “I found that I would go out on spending sprees and spend until I had no money left in my account, and then I realized I didn’t have any money for the rent. And that’s when I started budgeting, but that was on and off. I could do it one month but I couldn’t do it the next month.” Several talked about the importance to their stability of the trusteeship relationship, in which individuals are required to turn over control of their finances to someone else. For example, one person said, “I think we set up a dual account. I couldn’t take money out unless I had the other person’s signature, so they restricted my financial means. 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 it that I could end up, well, I guess I sort of did see that if I kept it up I would end up homeless.” Another described his situation: “I get money on the weekend, so if I foul up, it’s just for a week instead of a whole month.” Another man described how his ex-wife acts as his trustee and manages his money for him, even though she is now living with another man. These people have accepted and even welcome the control that ensures their financial stability.

Relationships with Housing Agencies

Relationships with housing agencies also illustrate the dilemmas of care and control. One man said that in his experience that “most agencies are ineffective in connecting you or empowering you in your search for housing. They’ll say, ‘Well, look
in the paper, or sucks to be you, good luck.’ Pro-active is not in the language of many agencies. They’ll refer you, but will they champion your purpose or your cause or will they stand beside you? No, they’ll just point you in the right direction and say, ‘Happy Trails.’” In contrast, a number of participants identified a particular person at an agency as being the most important factor in helping them find stable housing. One woman happened into the AADAC (Alberta Alcohol and Drug Abuse Commission) office where a counselor suggested to her “You know, there is another life besides this life.” This counselor was instrumental in helping her to make “a decision that I don’t want to live this kind of life anymore….I finally said no for the very first time, I never said no but this time I did.” One person was driven around by his AISH worker to find a new apartment. Another was recommended by an agency representative to a supported housing complex that he still lives in. One told us that AISH threatened to cut her off while she was in hospital for a long period, which threatened her housing. Her psychiatrist talked to her AISH worker and resolved the problem. Another said that her psychiatrist had advocated for her with a housing agency. These service providers were remembered not just as instrumental but as essential in helping people to achieve housing stability.

On the other hand, some aspects of the relationship between agency service providers and our participants led to conflict with service providers and were not seen as helpful in moving people toward stability. A number of our participants described situations in which treatment or services were withheld when the person did not behave in ways that the service provider, whether medical or housing, thought appropriate. A number of participants told of having been kicked out of programs or shelters because of their behaviour. For example one man said he had been kicked out of a shelter for getting
in a fight with another man. Another told of being kicked out of two treatment programs for “acting odd.” Another said that a particular program did not want to let him back in because of his drug use and “because I'm having troubles following through with the discharge plan.” This same man said that he had been told that he “was completely defiant about the plans they had set up for us.” He wanted to change his financial arrangements (the agency was acting as his trustee) so that his mother would be his trustee. The agency told him that they wanted nothing more to do with him. “If that’s the way he feels, then he’s cut off.” Another was threatened with losing her housing if she did not keep the place clean. She was upset because she knew that others in her building had received help to clean their places, but she did not seem to be eligible for that help.

One woman, who has diabetes as well as schizophrenia, told us about how she had waited three years to get into subsidized housing. But because she was not taking her insulin as prescribed by her doctor, he insisted that she move out of her subsidized apartment and into a group home where her insulin regimen could be monitored. However, she could not take her daughter with her to a group home and so went to live with a family acquaintance who soon asked her to leave. This was the beginning of a period of housing instability during which she moved numerous times, and lived in substandard places, one of which had mould, mice, and mushrooms growing through the carpet. She now thinks that listening to her doctor was “the biggest mistake I ever made.”

Other people felt they could not accept the housing they were offered. For example, agencies that provide supported housing typically do not permit pets, so people who are not willing to give up their pets cannot be accommodated in supported housing. As one woman said about her cat, “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. ” People describe being placed with roommates not of their own choosing, which sometimes did not work out. One man described his experience in a group living situation: “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 and a lack of self worth and that develops them. That’s probably the one thing that really worries me, is the idea of ever ending up in one of those places again.”

Many of our participants told us about situations in which they had problems with the landlord or housing manager. Several told us of managers who entered their apartments without permission from them. “The managers would come in anytime they wanted to and it scared me. They just came in and they stole my toilet paper, they stole my sheets, they stole my towels.” Another person could never get his fridge fixed, no matter how many times he asked. He said, “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.” They also complained about agency rules that prevented people from getting the help they felt they needed. For example, one woman told us that, “The ILS workers [in her supported housing building] don’t have much power. They can’t take you and drive you to the hospital if they think you’re not doing well. They have to go through all the rigamarole.”
Sometimes even doing well can lead to instability, when people are asked to move when they become too “high functioning” for the supported place they are living in. One told us that, “My psychiatric nurse along with three or four workers came and did some kind of progress report and they decided that it was time for me to move on.” A member of the research group says she does not want to ask anyone about whether a person can become too high functioning for her supported apartment building for fear that someone might find out how well she is doing and ask her 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.” Referring to the arrows in our diagram, she said, “Well as long as you’re in those arrows 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 those arrows. But even then you still have to live in fear of them.”

Achieving Stability

When people achieve stability they are free to develop other aspects of their lives and integrate into the wider community. One woman said that now that she could count on stable housing, she had started to volunteer and participate in community activities. She said that many of the other people in her building had the same experience. Another woman started teaching an evening craft course for a school board program, where her identity as a person with schizophrenia is not relevant. Some are taking university courses offered by a street front program at a city shelter and are working toward university transfer. And the members of the research group stress the importance to them of being able to offer something through their work on this research project to help others in their situation. One man summarized his satisfaction at the change in his life circumstances. “I
remember 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 this society, how to fit into the system. Now thirty years later with the help of Alberta Mental Health, I’ve found that maybe not in a superior way but in an authentic way, 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.”

**Recommendations**

Group members generated recommendations that they hope will help service providers to care for them without controlling them.

*Providing Care.*

- Have 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.
- Provide 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 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 and need help with doing taxes, saving money,
learning about insurance, providing for ourselves in the future, 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 more affordable housing and society has to make this a priority. Provincial and federal governments could give tax incentives for affordable
housing or require that builders make a certain percentage of their units affordable housing. We must find the “political will” to have more affordable housing.

**Conclusion**

As our results show, the dual nature of care poses dilemmas for people with schizophrenia. Rather than viewing recipients of medical and housing services as simply “noncompliant” when they do not behave “appropriately,” and therefore not desirous or deserving of help or services, they can be seen as struggling to negotiate the complex dilemmas that being cared-for presents and the deep ambivalence they feel about the control aspects of care. If people reject care because of the surveillance and control they would have to submit to, this is not simply noncompliance. It is an interaction of the individual with aspects of what is provided—the service provider, the service setting, or the service itself. Success in moving people toward housing stability depends as much on the service provider and the care provided as it does on the recipient. In fact, if service providers insist on “compliance,” then housing problems for people with schizophrenia probably cannot be solved.

The dilemmas of care are not likely to disappear—it would be quite unrealistic to think that a long history of care as vigil (Fox, 1995) can be erased. However, Fox offers the possibility that care could be different. He describes care in the form of what he calls a gift, in which generosity is substituted for the vigil. Care as gift as is freely given without expectation of reciprocity (in the form of docility or gratitude), a gift that allows people to achieve personal growth and actualization. “This gift enables and empowers, it allows the recipient of the gift to ‘become other,’ to establish a new subjectivity” (p. 117). Fox acknowledges the difficulty of putting care as gift into practice, particularly as
he cannot provide a formula for doing care as gift. However, the onus to change the circumstances of care and to make it a gift would seem to be on service providers, rather than on service recipients who have schizophrenia.

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1 Greenwood et al. (2005) offer an example of what service providers might do. They draw on their experience in the Housing First program in New York city, in which people with severe mental illnesses are provided with housing without any requirements for sobriety and treatment. Their success with this program leads them to call for more consumer choice in provision of housing and psychiatric services, and to call for research to examine the characteristics of both continuum of care and consumer driven models of service provision that would allow for more choice.
References


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