Housing For Persons with Mental Illness:

Understanding Their Experiences

Submitted by the Schizophrenia Society of Alberta, Edmonton & Area Chapter

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We are grateful for the contributions of all of our survey respondents and especially the interview participants who gave their time in order to help us understand their experiences getting and keeping housing in Edmonton.

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Final Report

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I. Overview

Abstract

In its current research project, the Schizophrenia Society of Alberta, Edmonton and Area Chapter (SSAEA) asked members of its organization to share their thoughts about long-term housing options for mentally ill persons in Edmonton.

Objective: To better understand the experiences of persons living with mental illness and their family caregivers in finding appropriate and affordable housing with necessary supports.

Method: We asked both persons with mental illness and their family members to share stories about their quest for housing, mailing out a short survey to members and conducting thirteen in-depth follow up interviews based on the survey results.

Results: Interviewees expressed housing concerns that fell into the following categories:

(1) Income and Financial Stability. Interviewees mostly relied on income support (such as AISH) or a pension due to a diagnosis of mental illness, and/or part time or temporary work, and many reported that the amount received was inadequate to provide them with appropriate housing. Many were forced to live in the inner city, in "shoddy" and "run down" housing, where they were vulnerable to victimization and where support services were lacking.

(2) Housing Support Services. Interviewees called for a continuum of support service levels, individualized according to (sometimes fluctuating) needs. Interviewees thought that those who work with the mentally ill need to have more appropriate training and flexible attitudes, and that they should facilitate skill and responsibility building in mentally ill persons where possible.

(3) Home and Social Environment. A safe and healthy home environment with a reasonable measure of privacy, positive peer relationships, and suitable options for recreational, vocational or personal time during the day was seen as ideal. A harm-reduction approach to smoking, drinking and drug use was favoured over zero-tolerance policies. Family involvement in residents' lives was also seen as a necessary part of building stability in a housing situation.

(4) Health and Social Services. Interviewees expressed a need for coordinated management of care services for the "whole person" provided by understanding professionals continuously from the hospital to the community (and back) based on need. Interviewees also commented that sufficient legal mechanisms needed to be in place to help the family intervene to prevent deterioration in their loved ones.

(5) Additional Concerns. Other difficulties related to housing for the mentally ill were the high demand for this kind of housing (with few options and a long waiting list), caregiver stress and burnout, difficulties caused by the nature of mental illness and its treatment, stigma, and the few options available for the especially hard-to-house (e.g. those with a dual diagnosis).

Conclusion: More research is needed, but the findings suggest that a reassessment of Edmonton's current housing and support system with an eye to providing safe, affordable housing with flexible and comprehensive care for the "whole person" could go a long way towards providing stable, long-term housing options for the mentally ill.

Project Goals

The purpose of this research project was to gather and analyze data to be used to better understand the experiences of persons living with mental illness and their family caregivers in finding appropriate and affordable housing with necessary supports. The project aimed to:

(1) Derive key themes corresponding to the diverse range of experiences of persons living with mental illness and their families in securing appropriate housing and supports; and
(2) Identify major issues related to key themes, as well as potential ameliorative steps indicated by respondents.

Background

There is considerable evidence that persons living with mental illness face a disproportionately higher risk of becoming homeless. Their family members, who are more often than not implicitly responsible for their well-being, find themselves scrambling to secure appropriate housing for their loved ones. For those people who do not have family or friends to fall back on, the streets are an all too probable outcome of a fruitless search for a place to call home.

Persons living with mental illness are a very heterogeneous group. Some require considerable supports throughout their time in the community, thus finding services to go along with their housing is paramount. Others are more or less independent, but may experience brief periods of relapse that could result in eviction or other loss of their homes. There are also those for whom independence is practically an unreachable goal: their ability to live in the community relies on a combination of housing and supports similar to that provided in hospital. This diverse group is also at increased risk of

substance abuse, criminal records, low income, and negative stigma among the general public, which further complicates the search for housing.

Because of the heterogeneous nature of the mentally-ill, the Schizophrenia Society of Alberta, Edmonton & Area Chapter (SSAEA) undertook this research project to better understand the nature of these perspectives and experiences. The findings will help us plan the potentially ameliorative steps to take in order to prevent this at-risk population from becoming homeless and/or to prevent their mental and physical conditions from deteriorating.

II. Process

Data Collection and Evaluation

Surveys (included as Appendix A) were created by the SSAEA Executive Director and Program Coordinator and mailed to all 220 current SSAEA members, excluding honorary and complimentary members. Since most SSAEA members are family members of persons with a mental illness and not ill themselves (and so answered the survey on their loved one's behalf), some surveys were given to Prosper Place Clubhouse and the Canadian Mental Health Association for distribution among the persons who make use of their programs to gather more first-hand accounts. A few surveys were also taken by SSAEA volunteers to distribute to appropriate family members or friends who are not SSAEA members. The SSAEA research team received ninety of the approximately 250 surveys back for a response rate of 36 %. The data from the surveys was consolidated by a volunteer research assistant who signed a confidentiality form (included as Appendix D).

The bottom of the survey asked respondents to write their name and contact information on the line provided if they would be interested in participating in an interview about their housing experiences, and a small honorarium was offered for their help (this information was removed by the Program Coordinator before being passed on to the research assistant for survey data entry). Thirty four survey sheets with name and contact information were received: nine from persons with mental illness and twenty five from family members of a person with mental illness. Of the total thirty four, fifteen respondents were chosen to be interviewed: six persons with mental illness and nine family members. The Program Coordinator's choice of interview candidates was based on each respondent's answers on the survey. She chose

as diverse a sample of respondents as possible, including persons who reported little trouble finding appropriate housing as well as those who expressed a great deal of frustration with the process; persons who had been homeless and persons who had not; and persons who experienced extra difficulty due to, for example, a dual diagnosis (a mental illness along with a drug addiction), as well as persons with relatively more "manageable" illnesses.

All respondents who indicated interest in participating in an interview were contacted and thirteen interviews were completed: one person with mental illness changed his mind at the last minute and one family member did not respond to the contact in time to set up an interview, bringing the ratio to five interviewees with mental illness and eight interviewees who were family members. Each participant was provided with an information letter and a consent form. The purpose of the study as well as any risks and benefits were explained to each person prior to asking for their consent. The relevant letters and consent form are included as Appendix C.

Interviews were conducted by the SSAEA Program Coordinator in a private room at the SSAEA office, in the interviewee's home, or in a private room at Prosper Place Clubhouse. All interviews were tape recorded. The interviewer asked three broad questions: firstly, she asked the interviewees to relate their story of trying to find housing for themselves or their mentally ill loved one, from start to present; secondly, she asked them to relate any second-hand stories they might have of the same; thirdly, she asked what should be done to improve the housing situation in Edmonton. Interviews lasted from twenty minutes to an hour and twenty minutes. After the interviews, a $25 gift card to Safeway was mailed to interviewees.

The tape-recorded interviews were sent to a transcriptionist (who signed a confidentiality form), and then the Program Coordinator altered the identifying names of persons and places mentioned by interviewees in the transcripts. The Program Coordinator kept five transcripts herself, sent three to the SSAEA Housing Committee Chairperson, and the remaining five to the SSAEA Executive Director to be "coded"—key phrases, words and concepts were identified and extracted from within the interview text. A chronology was also made for each individual's experience, which can be found in Appendix C.

The Housing Committee Chairperson, the Executive Director and the Program Coordinator then held a work session to amalgamate and analyze the data, using an adapted grounded theory approach. First, each wrote "codes" that represented positive factors from their assigned transcripts on a whiteboard. They grouped the codes under broader themes and then into four overall categories. "Exceptions" were written in a separate space. Next, codes that represented negative factors were written on the board and were used to enrich the data in each category. Negative factors that did not fit under existing categories were grouped under "exceptions", to be discussed individually in the report. A draft of the report was then compiled and sent to the interviewees for feedback to ensure that interviewees felt their responses were sufficiently anonymous and that their comments were related in accurate context.

Limitations

1. Sample Population. The bulk of the surveys were sent to SSAEA members, who are by and large family members with a strong commitment to helping their ill loved ones. Some surveys were copied and forwarded by recipients to Prosper Place Clubhouse and the Canadian Mental Health Association. This unplanned distribution served to

capture the opinions of more persons with mental illness who did not necessarily belong to the family movement. However, the number of family members still outweighed the number of mentally ill persons, both in the survey and the interviews. A future study would ideally send surveys to patients at Alberta Hospital as well as homeless shelters in the city to capture the opinions of those who may not be functioning well and may not have any family members to help and support them.

2. Possible Researcher Biases and Lack of Expertise. The study was conducted by SSAEA members: two staff members and a volunteer board member, and the majority of the surveys were filled out by members of the SSAEA. Since our organization's focus is on the family experience of mental illness, the findings will likely be weighted in that direction. Also, none of the investigators were professionally trained qualitative researchers, and only the Executive Director had basic experience using qualitative methodology, particularly the grounded theory method we adapted to conduct our study. These problems might be corrected by employing professional researchers who are less familiar with the family movement and more rigorous in their method.

3. Time Constraints and Sample Size. The researchers had three months in which to complete this study, which precluded the option to enrich the data by conducting additional interviews with each interviewee. It also meant that the interview sample size was quite small. With a longer time period, more surveys would be sent, more persons would be interviewed, and follow-up interviews would be employed.

III. Findings

PART A. Survey

Summary

Firstly, it is important to note that 78% of survey respondents were persons responsible for a family member with mental illness, and therefore answered the survey questions on their family member's behalf. Given that SSAEA is made up mostly of family members, this value is not surprising. However, since "respondents" in this summary will refer to the ill persons in question, it is useful to remember that most of these answers represent a well-informed but second-hand report which, where subjective judgments are required, may or may not differ from the response that would have been given by the ill person him or herself. As one respondent wrote:

> I am answering for our granddaughter because I am a bit fearful of her reaction. She might be offended. On the other hand, she might answer with the same circles and checkmarks as mine.

Respondents were mostly between the ages of twenty five and fifty five, and 75% were male. The vast majority (93%) received income support or a pension due to a diagnosis of mental illness. In 71% of cases, respondents answered that they currently lived in permanent or long-term housing. Of these, 79% felt that this housing met their needs, however the comments provided in the space beside a positive response were sometimes ambivalent. For example, one comment read:

> The housing meets his physical needs, he is sheltered and fed, meds are given. He is compliant. He used to be unable to housekeep on his own. I wash his clothes, clean his room. He sleeps 16 hours/day. There are no activities planned for him.

Although housing may generally be considered a basic "physical need", this response suggests that the distinction between physical needs and psychological needs is not

always discernable in the case of a mentally ill person, and such a factor should be taken into consideration when housing the mentally ill. Other examples of ambiguity in responses were those who answered that their current housing was adequate but that the person lived in the family home (and they had not yet tried to find alternate arrangements), or in housing that they feared would not be permanent. Importantly, 61% of respondents spent more than one third of their income on housing costs.

Respondents reported trouble in trying to find housing in 64% of cases. They were given a list of five specific difficulties and asked to check all that applied to their experience. The following results were reported:

- 27% did not know where or how to start looking
- 20% found the application process too difficult or confusing
- 31% said housing waiting lists were too long
- 32% could not afford the place they wanted
- 24% could not get the supports they needed at the place they wanted.

Additional comments were also invited, and here respondents mentioned a lack of upkeep, lack of safe locations, lack of appropriate training for staff (and staff turnover), lack of availability, inappropriate rules and arrangements in general, lack of transitional housing, evictions based on the symptoms of illness and feelings of segregation.

Of note, in the last ten years 49% of respondents had been resident in the hospital for more than two months and 51% had lived in their parental home. 22% of respondents had lived in an emergency shelter in the last ten years, and 25% reported having been homeless at one time in their lives.

Detailed survey results appear in Appendix B.

PART B. Interviews

Summary

Housing concerns and experiences expressed in the interviews were divided into five major categories of concern: (1) Income and Financial Stability, (2) Housing Support Services, (3) Home and Social Environment, (4) Health and Social Services and (5) Additional Concerns. Each category is subdivided into themes, as outlined below.

CATEGORY 1: Income and Financial Stability

THEME 1: Sufficient income is required to afford appropriate housing.
THEME 2: Employability and income from work.
THEME 3: Sufficient rental subsidies and assistance.

CATEGORY 2: Housing Support Services

THEME 1: Need for continuum of service levels, individualized according to needs.
THEME 2: Need for facilitation of skill and responsibility building, when possible.
THEME 3: Appropriate training and working conditions and attitude for staff who work with those with limitations.

CATEGORY 3: Home and Social Environment

THEME 1: Safe and healthy home environment with reasonable measure of privacy and positive peer relationships.
THEME 2: Suitable options for recreational, vocational or personal time during the day.
THEME 3: A harm-reduction approach to smoking, drinking and drug use.
THEME 4: Encouragement of family involvement and advocacy in residents' lives.

CATEGORY 4: Health and Social Services

THEME 1: Coordinated management of care services for the "whole person" provided by understanding professionals continuously from the hospital to the community (and back) based on need.
THEME 2: Sufficient legal mechanisms for family intervention to prevent deterioration.

CATEGORY 5: Additional Concerns

THEME 1: High demand for housing with few options and a long waiting list.
THEME 2: Family is forced to intervene, resulting in caregiver stress and burnout.
THEME 3: Public misperception of mental illness and homelessness.
THEME 4: Difficulties caused by the nature of mental illness and its treatment.
THEME 5: Few options for the hard-to-house.
THEME 6: Innovative models of supportive home-ownership.

Examination of Data

CATEGORY 1: Income and Financial Stability

THEME 1: Sufficient income to afford appropriate housing.

"Affordable housing" takes on a special meaning for persons with mental health concerns, as housing costs often include fees for various support services depending on need. Support services can range from simple room and board to 24-hour supervision and supports. Interviewees reported receiving income from medical welfare, assured income for the severely handicapped (AISH), part-time work, pension and disability payments, full-time work, or a combination of these. Quite a few interviewees commented that their needs were barely met or not met when living on a fixed income, especially in reference to AISH. Often income covered basic expenses at the sacrifice of a good location, as many cheap independent and supported living environments are located in the inner city, which was considered an undesirable, frightening and/or dangerous place for vulnerable individuals.

Several family members spoke of "subsidizing" their ill loved ones to get them into an appropriate housing / care arrangement, and a few remarked that they were "lucky" that they could afford to do this. Some commented that they were unsure if knowledge of such supplements would threaten their child's already inadequate AISH payments.

THEME 2: Employability and income from work.

An ill person's ability to work and therefore maintain an income sufficient to pay for living arrangements was highly dependent on the degree to which the person was impaired because of his or her illness. Some individuals were simply too ill to

contemplate work, and so relied entirely on government or former employer disability payments and/or financial support from family members. Others were able to take jobs depending on how well they were at different times, and did so to feel a degree of independence and increased stability, and/or earn "pocket money" to supplement a fixed income. However, the changeable nature of mental illness means that an ill person may very well be fit for work at certain periods of time and not at others.

The social pressure to work was quite strong, especially in circumstances where individuals had college or university degrees. This caused a considerable amount of stress in some cases. As one woman put it:

> People say 'you're lazy, you're just a bum! You look like you can work, and how come you're on AISH?'

This woman moved from job to job, being fired or forced to quit as the stress became too much for her to handle, causing her to lose her income security and eventually to lose her apartment too. She then moved back in with her parents. Another interviewee talked about "burning bridges" in reference to his job experiences before he was on medication. These two individuals lacked good references when applying for other jobs, making it harder to get subsequent employment.

Only one interviewee was employed steadily full time and did not receive any subsidies, a triumph that allowed him a considerable amount of freedom to chose where he wanted to live, and to move to another place when "they weren't fixing things" at the old one. His experience contrasted that of many others, who were forced to live in housing that was in ill repair because they had no other options.

THEME 3: Sufficient rental subsidies and assistance.

A very positive model of subsidy was reported in reference to Capital Region Housing Corporation (CRHC) projects, where rent is set to one third of an individual's income. This kind of housing was scarce, however. While many of the interviewees referred to it, none had actually been able to procure it. Interviewees reported two and two and a half year waiting lists as well as flat-out refusals to even be added to the waiting list.

Another helpful model was a fixed-rate subsidy, also from CRHC. One recipient on a fixed income reported that the subsidy was a welcome relief to the notice that her rent was about to increase by $75. She had resided in the same privately-operated apartment building, paying roughly the same rent for well over a decade, and believed that the recent increase had to do with the booming rental market in Edmonton. She expressed concern about the dangers of the rising cost of housing in Edmonton for those on a fixed income.

Another individual had a mental illness but also qualified for Persons with Developmental Disabilities (PDD) funding, which paid for him to reside in a home with a woman who had considerable training and experience managing persons with cognitive disabilities. In his mother's experience, such caretakers were a luxury (outside the hospital) for persons with mental illness.

CATEGORY 2: Housing Support Services

THEME 1: Need for continuum of service levels, individualized according to needs.

Simply securing a "roof over one's head" was, in many cases, not enough for those with mental illness. While opinions about the necessary level of support differed among

interviewees depending on their own needs, most required some level of support. A need was seen among interviewees both for different kinds of supportive housing, as well as a capacity for different levels of care within one housing facility, that is, an ability to tailor care to the individual.

Stories abounded of loved ones being placed in a home that simply lacked sufficient supervision. This was especially the case in approved homes, in which the owner of a home gets a stipend from the government for renting to persons with mental illness in exchange for providing some guidance and care to those they take in. There were many disagreements between family members and approved home operators as to how much care was expected of approved home operators. Some family members complained that their loved ones stopped taking their medications due to a lack of monitoring, even when such supervision had been assured by the approved home operator. The approved home operator would not take care of laundry duties as had been promised, and ill individuals were sometimes expected to make meals and also to clean up after themselves when they did not have the capacity to do so. Although the approved home operator would often be described as "good" and "kind" in these cases, the level of care was simply not suitable. This likely relates to an insufficient level of training for operators (see theme 3).

The demand for group homes with a high level of support made it impossible for one interviewee to find a group home for his son. He reported that his son's level of functioning was so low that no group home would take him, and since the hospital had discharged him, the son had to live at home, placing a great deal of stress on his father.

In all types of housing, cooking and cleaning (including laundry) services were reported as top concerns. It was mentioned many times that the family had to clean up after ill individuals, both for persons living in independent housing and in group and

approved homes. One woman who had moved around to many different types of housing hoarded garbage in her room and was never made to clean it out, leaving her mother to constantly do it for her. Another couple spent much of their time apologizing to landlords and well-meaning friends who had given their son a place to stay, as the son would leave these places in an appalling mess. Many individuals were evicted for the messes they created.

Many interviewees expressed the desire for the ill person to maintain the highest level of independence possible. However one woman observed that adequately determining an ill person's level of functioning was sometimes the root of the problem. When her son unexpectedly qualified for funding for a developmental disability in addition to his mental illness, she explained that the circumstances:

> just underlined how hard he'd battled and how hard he'd struggled to maintain some type of normalcy and how good he was at hiding things, his true situation.

A number of other family members said that they were sometimes convinced that their loved ones could care for themselves (for example, do their own cooking and cleaning), only to find out that they could not perform these duties when left to themselves. This discrepancy resulted in a need for the family's intervention and/or a move to a different kind of housing that provided more support. This was mostly a process of trial and error. As one interviewee put it:

> the more we live through, the more limits we see for our son…we have to have hope, but we have to be realistic.

The problem was heightened when individuals fluctuated between low and high-functioning. One woman expressed the desire to see her son move from independent living to group homes and back again as need dictated. Another interviewee's daughter seemed to function well enough to live independently until she stopped taking her medications and the paranoia that is part of her illness took over. She was then often found living on the streets in cities thousands of kilometers from Edmonton.

Many people complained that there simply was not enough supported housing in Edmonton. One interviewee was able to get her 40-year-old daughter into an assisted living apartment when no other suitable option presented itself. However her daughter encountered an unwelcoming atmosphere and all-out hostility from the other residents for appearing "too young to be there". As a woman who had spent years advocating for housing for the mentally ill and researching potential housing projects, she made the comment that,

> getting the money for the building is not the hard part. It's getting the money for the support services.

In line with this, one interviewee told a second-hand story of a couple who sent their son to live in a "brand new building" dedicated for persons with mental illness. The son had to come home after two weeks because he was unable to cope with the lack of supports. Another interviewee told of a new group home in one of Edmonton's surrounding communities that is never filled because, in the interviewee's opinion, a zero tolerance policy on drug use has caused them to evict many potential long term clients rather than help them modify their behaviors. Overcrowded homeless shelters, also noted by interviewees, further reduced the choice of housing options.

There was a complaint from high-functioning individuals that group homes rules sometimes infringed too far on their freedom. One group home resident complained that he was not allowed to use the kitchen to cook his own meals, even though he was able to and wanted to do so. Another stressed that, in his words, a "laissez faire" attitude towards group home residents was most needed, and that having inflexible rules made for a stifling atmosphere.

There were other requests for an amount of care that fell between 24-hour supports and "laissez faire", such as an arrangement in which the group home operator lives out of the home, but comes by to deliver medications and one or two hot meals a day. Some

would prefer the owner to do the dishes and the cleaning, and others would prefer that the residents learn to do these tasks themselves, depending on their capacity to do so.

Transitional housing in which a person received support and life skills training meant to prepare them for an increased level of independence was a very helpful step for many people, and resulted in some success stories. Other stories, however, focused on the maximum time-limit uniformly imposed on all residents of transitional housing. The time limit made family members feel that their ill loved ones were being shoved out the door to fend for themselves before they were ready to be more independent.

THEME 2: Need for facilitation of skill and responsibility building where possible.

Many interviewees stressed the need for (or helpfulness of) programs that encouraged residents to perform duties like cooking and cleaning by themselves, with guidance from the staff. The individual who was able to graduate to independent living and a full-time job sums up his success with reference to transitional housing:

> I couldn't have gone all the way from Alberta Hospital to independent living in one shot. I had to go through the stages to get there.

He was especially appreciative of the help he received in one group home in which each member was asked to prepare a meal for the rest of the members once a week. Another interviewee made it clear that there was a difference between skill building and "warehousing" ill persons—that is, not providing residents with any recreation programs or incentive to improve their levels of functioning. This was an undesirable solution. However, it was also clear that there are often limits to rehabilitation. The aim of skill building cannot always be independent living, nor even semi-independent living. After her hard-to-house son's second hospitalization, one interviewee described institutionalization or its equivalent as possibly the ideal situation for her son:

> His world was simplified. He was in a lockdown situation….it was a very structured and safe place…they started their day with a walk, they had regular meals, quiet space. They had

> therapy. They had classes and such, but it felt to us that he was settled there…and compared to the uncertainty and the danger in the community, without the supports that our son seemed to need, we had no objection to the institutional placement at all…although I suppose institutions can be misused and seen as limiting, the other side of it would be that they can be safe and liberating.

This interviewee's son qualified for developmental disability funding in addition to his mental illness funding. In this new situation, the interviewee's son experienced better quality of care. The interviewee was able to put him in a home where the caretaker had, as the interviewee explained it, "a much better understanding of memory loss and cognitive impairment" than in previous group homes for the mentally ill. The caretaker set up a behavior modification program similar to one used at Alberta Hospital; as the interviewee described it:

> [the caretaker follows] a system of reward and consequences and so his behaviors are really quite closely monitored, and he is rewarded for his successes.

She felt that the difference lay in the caretaker's "initiative to tailor a program to the needs of the individual."

THEME 3: Appropriate training and working conditions and attitude for staff who work with those with limitations.

Interviewees mentioned that the level of training received by group home and approved home operators was inadequate. One individual suggested that conditions at regular hospitals provided a good example for how staff should be rotated in community-based facilities to prevent burn out. She said:

> With rotation of staff no one gets burned out. Worries of eviction would be alleviated. The risk of change would be less than approved or support homes where caregivers/operators routinely go on holidays, move, are occupied with family pressures, etc.

Flexibility and patience were also important. The woman whose son is in a home for the developmentally disabled praised the caretaker's ability to make light of her son's

incorrect behavior and take steps to help him correct himself, rather than kicking him out.

A factor at least as important as training seemed to be whether or not the caretaker took a personal interest in her/his clients and treated them with respect. One interviewee described the woman who ran his boarding house as "probably the best psychiatrist in western Canada", although the woman was not a medical professional. She was flexible when it came to rules and even rent payment, reducing rent for someone if they helped with maintenance around the house. Another man said that his son "just worships" his landlady because of the personal interest she showed to her residents, and that the home she ran was "about the best thing that's happened to him." In the interviewee's opinion, the success of this situation was mostly due to the way the arrangement is understood by both the landlady and her tenants. He explained:

> Our son does not live in a group home. He lives in a home rented out to five men who all happen to be mentally ill. I think this is why they all do so well. Their landlady sets the rules and she is the only authority over them.

This landlady provided support to the residents, whom she affectionately called "her boys", by doing the cooking and some cleaning, and also by picking up her residents' medication and delivering it to the house. She had renovated the house and even bought her "boys" a pet. When the interviewee's son went back and forth to the hospital several times, the landlady saved his room for him rather than renting it out to another person. The advantage of the official classification of this arrangement as equivalent to room and board, rather than as a group home, was that the house was understood to "belong" to the tenants. They were proud of having a space of their own.

A sensitive regard for a client's capacity was also a factor that influenced housing stability. Another interviewee attributed part of her daughter's current stability in

housing to the respect given to her daughter by a new nurse and psychiatrist. She asserted:

> People living with [mental illness] are intelligent, are often well educated, held jobs, traveled, etc., and must not be treated as children.

CATEGORY 3: Home and Social Environment

THEME 1: Safe and healthy home environment with reasonable measure of privacy and positive peer relationships.

Safety was a big concern for family members. The fact that many supported and independent living arrangements are located in the inner city was a source of frustration. A few interviewees expressed their loved ones' terror of shelters downtown, commenting that their loved ones' naiveté made shelters a dangerous place where belongings were constantly stolen. There were several stories of what one man called "moochers" who would prey on vulnerable individuals. Moochers would manipulate an ill person into giving them money and sometimes, in a few cases where the ill person was living independently, a place to live rent-free.

Many homes were described as run down, "shoddy" and "shabby". Upgrades and simple maintenance were neglected due to lack of funding. Interviewees also described a poor quality (and lack of variety) in meals provided: too much pasta and not enough fresh produce. One interviewee expressed concern for a friend who was a diabetic and was fed "nothing but macaroni" in her group home.

Interviewees were interested in striking a balance between social atmosphere and privacy in group living. In shelters and transitional housing (and in hospital) it was common for residents to share a room, which was often less than adequate. Ill persons,

especially if they are experiencing paranoia, have the potential to feel fearful or distressed when not given their own space, which can exacerbate their symptoms. Therefore a private space was key. But the potential to form friendships with others in similar situations also characterized a good housing arrangement. For example, one interviewee described his son's boarding house very positively because all the residents were friends and often went out together to play pool. However, another interviewee described her daughter as very reluctant to "be around sick people all the time". Her daughter wanted to be more integrated into the community and felt "institutionalized" in a group home. The daughter also felt that there was a hierarchy among staff and residents under which the residents were second-class citizens (for instance, staff members would not eat with the residents). Other interviewees shared a concern regarding the lack of empathy on the part of staff.

A number of interviewees commented on the extent to which residents were made to feel welcome and stable. Some family members made the observation that their loved ones felt uncomfortable, especially in approved homes. As one interviewee put it:

> When he was in those homes, it just didn't feel like his house. He felt he was imposing on them, and if he wanted to come upstairs—in the one house the TV was upstairs—she said, 'Well, I guess you can come up.'

This man's son now lives in a rental home with a few other men who also have mental illness. Their landlady lives elsewhere, and they feel they can call the home their own. The interviewee said:

> They all have a key and they're all responsible to keep the place locked up, just like any tenants, you know?

Another woman said that her daughter was uneasy about living in a house where new people constantly moved in and out, as she seemed always to be living among strangers. There were also problems reported with differences between roommates, or

with roommates who had a "bad influence" on others in terms of encouraging drug use or threatening others.

THEME 2: Suitable options for recreational, vocational or personal time during the day.

Family members were often concerned that their loved ones be provided with some structure to their day and be given the opportunity to enhance their social and vocational skills whenever possible. Day programs, such as those offered at the Canadian Mental Health Association, were cited as a positive and stabilizing factor in some cases. At the same time, they were also sometimes considered inadequate. One woman commented that her daughter found her day program "boring" and "repetitive".

Other options for daytime activities were low-stress jobs in supportive environments. A positive model of vocational experience was the one offered at Prosper Place Clubhouse, where members are involved in supervised employment opportunities in the Clubhouse and in the community. The comment was made that supervision in such temporary work allowed for reduced stress on the part of the working individual, as well as a way to supplement a fixed income. Some ill individuals were also able to hold regular full-time or part-time jobs in the community.

Assigning residents chores and responsibilities in a group environment, such as cooking a meal for all residents once a week, was often seen as a very positive requirement that built life skills and a sense of responsibility, hopefully preparing the person for increasingly independent living arrangements. However, it was important that this was done with respect for a resident's capacity to perform chores and with supervision or follow-up from the staff.

It was mentioned several times that inflexible meal-time policies in some group homes and approved homes were unreasonable. It was often the case that, if a person was not present at the designated meal time, they were not given a meal at all. This restricted an individual's freedom to go out and about and was problematic for those whose work schedule was irregular.

Both ill persons and their family members had strong reactions against the approved home lockout policies under which residents must be out of the home for a certain number of hours every week day. (A similar policy is in place at homeless shelters and received similar complaints from interviewees.) Some residents were expected to attend day programs or work, and others were expected to simply find a warm place to be. As mentioned above, opportunities to attend a day program or work were often positive factors, however it was considered inhumane to lock residents out of what is supposed to be his or her home. One interviewee who was diagnosed with depression and not sleeping well was particularly upset to be forced out onto the street every morning.

Many interviewees agreed that planned recreational activities were desirable. The interviewee's daughter who thought her day programs were boring was very pleased with organized group activities like bowling. As another interviewee put it:

> Many clients…they're not inclined to go out and do a program, and if the program isn't there and organized for them, they just sit.

One interviewee was hopeful that group home staff would actively encourage her daughter to participate in group activities because the daughter liked to do so but her anxiety often prevented her from joining in if left to herself. However, there was a difference between providing residents with a sense of structure through opportunities for daytime activities and forcing the activities upon them, as with lockouts: an individual's choice must be factored in.

THEME 3: A harm-reduction approach to smoking, drinking and drug use.

A dual diagnosis—mental illness coupled with a substance addiction—is a common problem in the mentally ill population. It seemed that many if not most homes for the mentally ill espouse a zero tolerance policy towards drugs and alcohol, a principle that met with mixed feelings from the interviewees. While no one wanted their loved one to be given the impression that an addiction was acceptable, simply evicting individuals when they were caught drinking or using drugs was not viewed positively. One interviewee actually fought to prevent her son, who had a dual diagnosis, from being placed in a home where drugs and drinking were acceptable:

> we asked if it was [the placement worker's] opinion that if our son was placed in a home like that, if he would have the strength to pull himself up and to get out of a place like that, or if that would be the end of him. It was difficult for her to, I think, comprehend a situation like our son would be in, and I don't think she saw that much hope for him…and she didn't have any alternative suggestions.

Many individuals also talked about having been evicted for smoking in their rooms. In one case, this was no longer a problem when the person entered a group home that had a designated smoking room.

The best prospect seemed to be a home that did not allow drugs or alcohol, but was compassionate about an occasional slip, that is, a home that espoused some kind of harm-reduction strategy. One interviewee talked about a home at which, when she saw evidence of her son using marijuana, she was able to inform the staff, who then moved him to a room that was closer to their office, thereby putting in place "a preventative measure that worked."

THEME 4: Encouragement of family involvement and advocacy in residents' lives.

Because the family is often in the best position to know the needs and limitations of their loved ones, cooperation between family members and housing support staff makes for optimal care. However in the interviews it became clear that input on care from family members was sometimes less than welcome. One woman was told that if she did not stop complaining about the conditions at her son's group home, her son would be evicted. Since her son was difficult to house, she simply had to stop speaking up for him. As another interviewee put it:

> It's really hard to know when to back off and not interfere and when to step in because you're afraid for someone's safety.

She talked about a time when her son and his housemates, who were living in an approved home, were suddenly told that the caretaking family would be going away for a month, so their residents would have to find another place to stay for that time. The interviewee was able to take her son into her home, but the situation left her worried:

> The very fact that this happened so fast and that what if our son didn't have anybody to fend for him?…it appeared that the other gentleman in the house didn't have family speaking up for him and watching over him.

Another interviewee stressed that family involvement was paramount to an ill person's success in living outside the home:

> I think one thing for sure is that…they have to have family support or they're not going to do it.

He also stressed that relationships between families and housing support staff can work very well:

> Because we gave our son a lot of support, I think we got support back from the people [i.e. medical and support workers] that had the ability to give it to us.

Many interviewees expressed gratefulness to shelter, hostel and group home staff who kept them informed of their loved one's whereabouts, progress and current condition.

CATEGORY 4: Health and Social Services

THEME 1: Coordinated management of care services for the "whole person" provided by understanding professionals continuously from the hospital to the community (and back) based on need.

Interviewees reported many difficulties with getting their ill family members diagnosed, into the hospital, and from the hospital into housing with an appropriate level of support. Equally important was the ability to get an ill loved one back into hospital upon relapse, and many cited a "good psychiatrist" with whom the family has contact as the key to success. A positive model of cooperation was offered in the case of one interviewee's son, whose social worker, landlady and psychiatrist were all constantly in contact with one another and with the son's family. If the son was ever suspected to be experiencing relapse, the social worker or the landlady would get into contact with the psychiatrist, who was able to get the son admitted to the hospital.

The point was brought up that an independently-living person who had more frequent contact with a social support team (a nurse, psychiatrist or others) would likely be less vulnerable to "moochers" (see category 3, theme 1). Another aspect of caring for the "whole person" included treating a concurrent drug addiction along with the mental illness (explored above under category 3, theme 3).

An additional positive model of care was that put forward by an interviewee whose son was a part of the Edmonton Early Psychosis Intervention Clinic (EEPIC). This interviewee had experienced difficulty trying to locate a psychiatrist for her son in the first place, and was then very unhappy with the psychiatrists she was able to get because they left the family without an adequate idea of what to expect from the illness

or from the medications. When she was referred to EEPIC, she said the difference was "like night and day". She explained as follows:

> EEPIC seemed to deal with the whole person…[they] began to create bonds of trust and support and they knew how frightened we were and how little we knew about this disease and the process we were going to have to go through. They supported the family as well as supporting our son…then very systematically they began to build up, first of all build our son up with the medication, the hospital spell, with the follow up, the regular appointments, and then they began educating all of us…then they began to help with the housing in the best way they could.

This story underscores the importance of building stability around the ill person before putting them into a community housing placement.

Often in the interviews, patients were released from hospital before they were well enough to be in the community, which ended in relapse and eventually re-hospitalization, if they were lucky. As one interviewee said of her daughter:

> I think the first thing that went wrong was not adequate hospitalizing in the first place. It set her on kind of a pattern of moving, moving, moving.

With no follow-up support at discharge, her daughter was continually found living on the streets in cities far from home; her parents had little choice but to track her down and bring her back for her own safety every time this happened. Non-compliance with medication was also often cited as a reason for a break down in housing stability. When houses became messy or rent was not paid, often the ill person had stopped taking his or her medication. This was a situation that, in some cases, may have been prevented with supervision and support from a network of caring individuals.

As helping professionals, the police are also expected to adopt an understanding attitude when dealing with the mentally ill. More than one respondent had kind things to say about the way the police had treated them or their loved one. One young man who was picked up and taken to Alberta Hospital described the policemen involved as "really nice guys." On the other hand, another interviewee who had spent time living on the streets described being verbally abused by a policeman in reference to his mental

illness. He was also charged with loitering, and because he did not have a home to go to, he felt this charge was unjust. This same respondent also made allegations of physical abuse and false accusations by both police officers and security guards.

THEME 2: Sufficient legal mechanisms for family intervention to prevent deterioration.

Ill persons were often surviving on a very low fixed income, a problem exacerbated by the fact that many individuals were unable to properly manage their money, especially in cases of dual diagnosis when rent money was liable to be spent on drugs or alcohol. Therefore, an application for either public or private trusteeship was often pursued for the benefit of the ill person. The possibility of trusteeship was a relief to many concerned family members.

Going to court to get a loved one committed to hospital was mentioned by family members as a welcome option for getting a loved one into necessary treatment. Since compliance with medical treatment is a significant stabilizing factor, one woman expressed relief that her daughter now lived in another province with community treatment orders. The community treatment order mandates that the daughter can be released from the hospital on the condition that she continues to take her medications. If she fails to do so, she will be readmitted to the hospital. Her mother said, "at least right now…I know there are several people keeping an eye on her." The daughter herself finds the situation satisfactory, as the arrangement allows her the freedom to live independently with frequent but relatively little monitoring.

Guardianship was also considered beneficial for family members of an ill person. One interviewee had a son who agreed to live at a group home but refused to sign the proper documentation because of his paranoia. As legal guardian, however, his father was able to sign in his stead.

CATEGORY 5: Additional Concerns

Theme 1: High demand for housing with few options and long waiting lists.

The high demand for appropriate, affordable housing for those with mental illness was mentioned incidentally and implicitly throughout this study, and supply is clearly lacking. People described years-long waiting lists, especially for CRHC projects. A lack of housing choice leaves those who already have housing and some level of support feeling trapped in situations that they consider less than adequate. As one interviewee who was unhappy with her current housing arrangement put it:

> There's nothing we can do about it. They just say, 'move out and find another place' but we can't! We just can't.

With Edmonton's booming economy and the rising cost of housing for people in general, this problem is expected to get worse.

Theme 2: Family is forced to intervene, resulting in caregiver stress and burnout.

Parents expressed extreme anxiety as to how their ill loved one will survive once the parents pass away, and with good reason: persistent intervention from family members was often cited as the only reason ill loved ones were not living on the street. Parents provided significant financial support, and often the parental home was the only alternative to homelessness when an ill person was evicted or unable to cope with a housing situation. Living at home was rarely an ideal option in these cases as the parents, many of whom were elderly, were unable to provide sufficient support and manage difficult behaviours. One woman was fortunate enough to be able to take several months off from work to care for her son, who had a dual diagnosis, when he was released from hospital. She felt that her care was indispensable:

> [It was] absolutely necessary to help my son maintain the stability he gained in the hospital…so I acted as a watch dog and protector and kept him from harm and for the number of months that

> he was at home, I made sure that he got to all of his appointments and I just watched over him. And I cannot imagine what would have happened to [him] if I hadn't been there or someone hadn't been there in my place.

Even if a person was able to provide care for a sick loved one, the stress was often overwhelming. One woman talked about the abusive language that was one manifestation of her son's illness:

> There was no way I could have him live with me, because I couldn't operate that way…when you have somebody being sick, and they're being passive or peaceful or quiet, you can do anything for them, but if they're attacking you verbally, [expletive]!

Unfortunately, caring for passive and quiet individuals can be equally challenging. One interviewee dealt with a son who at one point spent most of his time in a fetal position. He had to "wrestle him into the car" to get him to the hospital. This individual jokingly described the stress that overwhelmed him another time when the hospital was going to release both his wife, who was also mentally ill, and his son to his care:

> I couldn't figure at the time having her come back in the state she was in. My son wasn't very good either at that time, so I said well, that they could have the house and look after it and *I'd* leave!

The hospital therefore kept his wife and son for four months longer than intended, and his wife was eventually placed in a nursing home. The interviewee speculated that the money spent on keeping two of his family members in the hospital for that period of time could have been more efficiently spent on supported housing.

Even families who considered theirs a "success story"—that is, those who seemed to have found a stable, long-term housing solution for their ill loved one—worried about what might happen should the situation change for the housing provider. They expressed anxieties about, for example, the compassionate group home owner who nevertheless "won't do this forever". Families who were able to buy their loved one a permanent private residence were for the most part still unwilling to do it, as they had anxieties over their loved one not receiving support sufficient to maintain them in that

home. They were also concerned about their loved one's ability to take care of the property. Further, AISH places restrictions on assets and investment income. Such restrictions make setting up trusts an ineffective strategy for financially supporting loved ones after parents pass away.

Theme 3: Public misperception of mental illness and homelessness.

The amount of stigma attached to a diagnosis of mental illness is hard to overestimate. One interviewee put it well:

> The difficulty in housing is more in many people a difficulty with acknowledging the fact that they do have a problem. If you have a broken leg, it's pretty obvious you're going to go to the doctor and get a splint and wear crutches. There's no stigma. But if you're [mentally ill], then there is a tremendous stigma.

The interviewee's son refused treatment for a long time. After he accepted treatment, he still went off his medications regularly, often leading to behaviors that caused evictions. Another interviewee lamented the fact that friends were evicted for strange behavior:

> The landlord just tells them to get lost instead of seeing it as an illness and trying to be compassionate.

He also mentioned stigma in reference to getting a job:

> From that time on [after being released from hospital], I was volunteering all these different places. But they're wondering, 'why is he volunteering? He's 40 and doesn't have a paying job?' So I would go from place to place and no one would hire me.

When this man was finally able to find a full-time job, he went off income assistance and was able to live independently.

Theme 4: Difficulties caused by the nature of mental illness and its treatment.

Mental illness produces disordered thinking in an individual as well as a propensity to isolate oneself, neglect self-care and sometimes attempt suicide. This means that individuals often cannot take care of themselves, let alone their living space. The

number of evictions simply due to "messiness" found in these interviews attests to this issue. Anosognosia, or a lack of insight into one's own mental state, is a symptom that precludes self-care entirely, and often leads to ill individuals refusing help from those who have their best interests at heart because they do not believe that are ill in the first place. The paranoia that sometimes accompanies this illness has a similar effect, as ill persons can believe that their loved ones are purposely trying to harm them. Medications pose another difficulty, as they can have distressing side-effects, and it sometimes takes months or even years to find the right combination of medications and dosage level. All these things, along with the stigma of having to take medication for a mental illness, contribute to non-compliance. Individuals stop taking their medication, which often leads to psychotic relapse and the need for further hospitalization. Even with optimal medical treatment, ill persons are liable to have relapses that send them back into the hospital. Some interviewees talked about the stress caused when their loved one entered the hospital due to relapse and his or her living space was rented to someone else. Appropriate (and scarce) housing arrangements were thereby lost to them.

Theme 5: Few options for the hard-to-house.

A sub-category of mentally ill persons find it especially hard to locate (and keep) housing because of difficulties they face in addition to the symptoms of mental illness. Examples in our pool of interviewees included those with drug or alcohol addictions (dual diagnosis), violent tendencies, and criminal records, as well as persons who were extremely low-functioning (and did not qualify for government programs that provide comprehensive services and funding like PDD) and those who refused to seek medical treatment. These people tended to be evicted for not following the rules in their housing arrangement, or they were refused housing altogether.

Theme 6: Innovative models of supportive home-ownership.

In terms of novel ideas for housing initiatives, one interviewee wondered what it would be like if family members got together to open their own group home, sharing the cost. Another interviewee talked about a new housing project under which an older building has been converted into an assisted living residence for disabled people. This "inclusive community" is open to people of all ages and all disabilities, including people with mental illnesses. It has on-site medical support services that are flexible according to need, and the facility itself includes a pool, a gym, a craft room, and an auditorium. The most exciting part for the interviewee was the attachment being built onto the existing facility, which will be made into condos that families can buy. For this interviewee, the possibility of a permanent home with supports was "our dream-come-true. I couldn't believe anything could be that perfect."

IV. Discussion

Discussion of Data

Mentally ill persons and their caregivers experience a litany of difficulties in coping with their day to day lives. Stable, long-term, affordable housing comes out, as one interviewee remarked, "on the top of everybody's worry list". It is also clear from the findings that the quality and level of support provided to residents must be considered an integral part of the housing problem.

Firstly, it is clear that the amount of financial assistance given to those with mental illness must be revisited if the housing situation in Edmonton is to improve. Vulnerable ill persons are often not provided with an income sufficient to escape inner city housing or housing that is in ill-repair. But having the financial ability to live in a "nice" part of the city is not enough. Supports must be in place as well. Monies available for the support of other disabled groups of people, such as seniors in nursing homes and those with developmental disabilities, seem to significantly outstrip monies available to support those with mental illnesses. This is an area that should be addressed.

The need for provision of an adequate, flexible level of care is probably the strongest overall theme that emerged from these interviews. Throughout the data collection process, individuals apologized for "rambling" or "going off topic" when detailing the trials of their own or their loved one's illness. But, as one man commented,

> to forget about the illness and just talk about housing doesn't work. It's all wrapped up together.

Symptoms of illness (and related issues such as addictions and non-compliance) vary widely amongst those diagnosed with mental illness, as well as within the same individual at different times. This means that a variety of levels of support and flexibility within each individual's care program is necessary to house ill persons safely

and happily. Those who work with and care for the mentally ill need to be adequately trained and attentive to the individual needs of their clients. As the family is often afraid to complain about inadequate group and approved home conditions due to a perceived lack of other options, a review of government policy for this kind of housing seems necessary. Patient, persistent and personal interest, from family members and/or very special support and health workers, often made all the difference when it came to keeping ill individuals in housing and off the streets. Therefore, the encouragement of family involvement (through legal mechanisms where appropriate), and a network of care that bridges family, support workers and medical workers would be ideal.

When it comes to support services, there is sometimes a thin line between allowing for ill persons' independence and failing to provide them with enough support. Again, individualized attention and assessment is critical. Residents must be made to feel welcome, be given social and recreational opportunities, and treated like adults with varying abilities to cope with daily tasks, not children or second class citizens. However, it must also be recognized that many persons will continue to need a great deal of assistance for day to day living. While skill building is plainly preferable to "warehousing", the goals of skill building must be in keeping with the individual's ultimate capacity, which will often remain limited. Teaching individuals to cook, clean and do their own laundry was seen as a positive initiative where appropriate, but failure to provide these services where needed often meant the failure of the housing arrangement as a whole. While transitional housing was seen as an excellent idea, more care and sensitivity to diverse needs must be exercised. One of the survey respondents put it forcefully:

> After being let out of the hospital, and finding a group home, we have found the lack of supports put in place are inexcusable. How does one expect someone in this frame of mind to follow up themselves with appointments and medications? The transition period from hospital to wherever they reside to become independent is such a fragile period, if it's done fast the individual winds up in the cycle again – hospital/streets/or worse.

The cyclical housing pattern mentioned here is also evident in the interviewees' housing chronologies (see Appendix C). It was found that ill persons without an adequate level of care often deserted their living arrangements, were evicted and/or were vulnerable to those who would take advantage of them.

Finally, it must be acknowledged that some persons with mental illness will be harder to house than others. Symptoms of illness and compliance with treatment will vary from person to person and, to an extent, within the same person at different times. Some ill persons will have additional problems with violence, criminal records, and addictions. These problems can lead to behavior that is difficult for caretakers (both professionals and family members) to deal with, leaving some ill persons in increasingly desperate situations as they are evicted or refused housing. In these cases a compassionate, harm-reducing approach in a home with patient, well-trained, rotating staff would provide an alternative to homelessness. Ironically, while being well enough to live in relative harmony with caregivers and housemates often determines one's degree of housing stability, having a stable and supportive living arrangement is also a requirement for becoming well. After reading a draft of this report, one interviewee aptly commented:

> Being in a stable housing situation that will last is paramount to whether or not a person will get "well", take meds, etc. If he has to worry about having a roof over his head, he won't be concentrating on getting well.

Conclusion

It is expected that the results of this preliminary project will lead to further, more extensive information gathering initiatives involving multiple players. The ultimate goal of SSA Edmonton is to develop a project that would directly help persons with mental illness find suitable housing with appropriate supports, either through a capital, social service, or advocacy initiative. However, determining the best path to take in this regard requires much more intensive study of the issues arising from this research.

Appendix A – Survey

SCHIZOPHRENIA SOCIETY OF ALBERTA
EDMONTON & AREA CHAPTER
A REASON TO HOPE. THE MEANS TO COPE.

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January 17, 2007

Dear Friend,

The SSA, Edmonton & Area Chapter has received financial support from the Edmonton Joint Planning Committee on Housing to do some preliminary research on the experiences of persons living with mental illness, and their family members, in finding appropriate housing. We need your help with this.

The short survey included with this letter will give us a starting point from which we can begin to actively address the housing problem in Edmonton.

Because every one living with mental illness has different experiences related to housing (some find it easily, others have a really hard time), we need to learn more about what is needed out in the community. **This is why we want to know about your experiences.**

If you are a person with mental illness, we need your first-hand knowledge of the housing situation in our city. If you are a family member, we want to hear about your experiences trying to find (or help find) housing for your loved one with mental illness. **Please mail your completed surveys to us using the prepaid envelope by February 9th.**

We will follow up the survey with interviews with willing participants. These interviews will allow us to get into the details regarding people's experiences so we can better understand the realities of finding housing when dealing with mental illness. **We hope you will choose to help us further by participating in an interview.** A small honorarium will be provided as a token of appreciation.

This short research project – which needs to be finished by the end of March 2007 – is being conducted by Tara Koehler, Program Coordinator. She will be assisted by Giri Puligandla (Executive Director) and Carla Semeniuk, M.Urb.Pl. (Board member and Housing Committee Chair), in addition to our invaluable core of Edmonton Chapter volunteers.

We have been talking about a housing project for some time now: your contributions to this research phase will help shape it and ensure that it is based on what is really needed by our people.

Thank you in advance for any help you can provide in this research project. If you have any questions about this project or the survey, please contact Tara by calling 452-4661 or emailing tara@ssa-edmonton.com.

Yours sincerely,

(originals signed)

Giri Puligandla,
Executive Director

SSA Edmonton & Area Chapter Member Housing Survey

*If you are a **person with mental illness** please answer this survey based on your own experience. If you are a **family member of a person with mental illness**, please answer the survey in regard to your loved one who is ill.*

INSTRUCTIONS: Please answer the following questions by circling "Yes" or "No", or by putting a check in the appropriate box. Note that "loved one" here refers to a loved one with mental illness.	
Have **you** been diagnosed with a mental illness?	**Yes / No**
Are you a **family member** who feels responsible or provides any support for a loved one with mental illness?	**Yes / No**
Do you (or does your loved one) receive income support or a pension due to a diagnosis of mental illness?	**Yes / No**
When were you (or when was your loved one) diagnosed?	☐ **less than 5 years ago** ☐ **5 to 10 years ago** ☐ **more than 10 years ago**
What is your (or your loved one's) gender?	☐ **male** ☐ **female**
What is your (or your loved one's) age category?	☐ **under 25** ☐ **25-40** ☐ **41-55** ☐ **over 55**

INSTRUCTIONS: Please answer the following questions by circling your answer and/or by checking the appropriate box. Note that "loved one" here refers to a loved one with mental illness.	**Please use this space to write any comments you may have about these questions.**
Do you (or does your loved one) have a place to live that is expected to be long-term or permanent? **Yes / No**	
If you answered yes to the question above, do you think that this housing meets your needs (or the needs of your loved one)? **Yes / No**	
Is more than 1/3 of your (or your loved one's) income spent on housing? **Yes / No**	
Have you (or has your loved one) ever had trouble finding satisfactory housing? **Yes / No**	
If you answered yes to the question above, what was the trouble in finding housing? *(please check all that apply)* ☐ I didn't know where or how to start looking ☐ I figured out where to look for housing, but the process was too long, difficult or confusing ☐ Waiting lists for what I wanted were too long ☐ I couldn't afford the place I wanted ☐ I couldn't get the supports I needed at the place I wanted ☐ Other *(please explain in the box provided to the right, or on the "Additional Comments" sheet provided)*	

please turn over →

Have you (or has your loved one) used any of the following in the last 10 years? *(Circle "Yes" or "No". Then check the boxes that describe your [or your loved one's] living arrangement at the current moment.)*

Group home	**Yes / No**	☐ **currently**
Emergency shelter	**Yes / No**	☐ **currently**
Continuing care ("nursing") facility	**Yes / No**	☐ **currently**
Hospital (longer than 2 months)	**Yes / No**	☐ **currently**
Rental assistance or subsidy	**Yes / No**	☐ **currently**
Subsidized public housing	**Yes / No**	☐ **currently**
Supportive housing	**Yes / No**	☐ **currently**
Housing that you own	**Yes / No**	☐ **currently**
Regular rental unit (shared)	**Yes / No**	☐ **currently**
Regular rental unit (not shared)	**Yes / No**	☐ **currently**
Family home	**Yes / No**	☐ **currently**
Transitional (hospital → community) housing	**Yes / No**	☐ **currently**

If you've used anything not listed to the left, please tell us about it in this space or on the "Additional Comments" sheet provided.

How strongly would you agree or disagree with the following statements about your (or your loved one's) current housing?

This housing is in a nice neighbourhood.	1 (disagree)	2	3	4	5 (agree)
This housing provides ready access to transportation services (bus, LRT, etc.).	1 (disagree)	2	3	4	5 (agree)
This housing offers ready access to amenities like grocery stores.	1 (disagree)	2	3	4	5 (agree)
Health care is reasonably accessible.	1 (disagree)	2	3	4	5 (agree)
This housing is reasonably near to leisure or recreational facilities.	1 (disagree)	2	3	4	5 (agree)

Have you (or has your loved one) ever been homeless, that is, "lived on the streets"?

Yes / No

Please use the "Additional Comments" sheet provided to write out anything else you would like to say about housing for persons with mental illness in Edmonton. Then put the survey and your "Additional Comments" sheet into the envelope provided and drop it in the mail. Prompt replies are appreciated!

THANK YOU FOR PARTICIPATING IN OUR SURVEY!

Would you agree to participate in a 60-90 minute interview about housing for persons with mental illness in Edmonton? If yes, please write your name and phone number on this line:

_____

A small honorarium will be given for your participation in an interview.

Appendix B - Survey Results

Have **you** been diagnosed with a mental illness?

Yes **45%** No **55%**

Are you a **family member** responsible for a person diagnosed with mental illness?

Yes **78%** No **22%**

Do you (or does your loved one) receive income support or a pension due to a diagnosis of mental illness?

Yes **93%** No **7%**

When were you (or when was your loved one) diagnosed?

less than 5 years ago	5 to 10 years ago	more than 10 years ago
16%	**22%**	**62%**

What is your (or your loved one's) gender?

male **75%** female **25%**

What is your (or your loved one's) age category?

under 25	25-40	41-55	over 55
9%	**38%**	**42%**	**11%**

Do you (or does your loved one) have a place to live that is expected to be long-term or permanent?

Yes **71%** No **29%**

*If you answered yes to the question above, do you think that this housing meets your needs (or the needs of your loved one)?

Yes **79%** No **21%**

Is more than 1/3 of your (or your loved one's) income spent on housing?

Yes **61%** No **39%**

Have you (or has your loved one) ever had trouble finding satisfactory housing?

Yes **64%** No **36%**

*If you answered yes to the question above, what was the trouble in finding housing?

- I didn't know where or how to start looking…… **27%**

- I figured out where to look for housing, but the application process was too difficult or confusing…… **20%**

- Waiting lists for what I wanted were too long……..… **31%**

- I couldn't afford the place I wanted…….. **32%**

- I couldn't get the supports I needed at the place I wanted…… **24%**

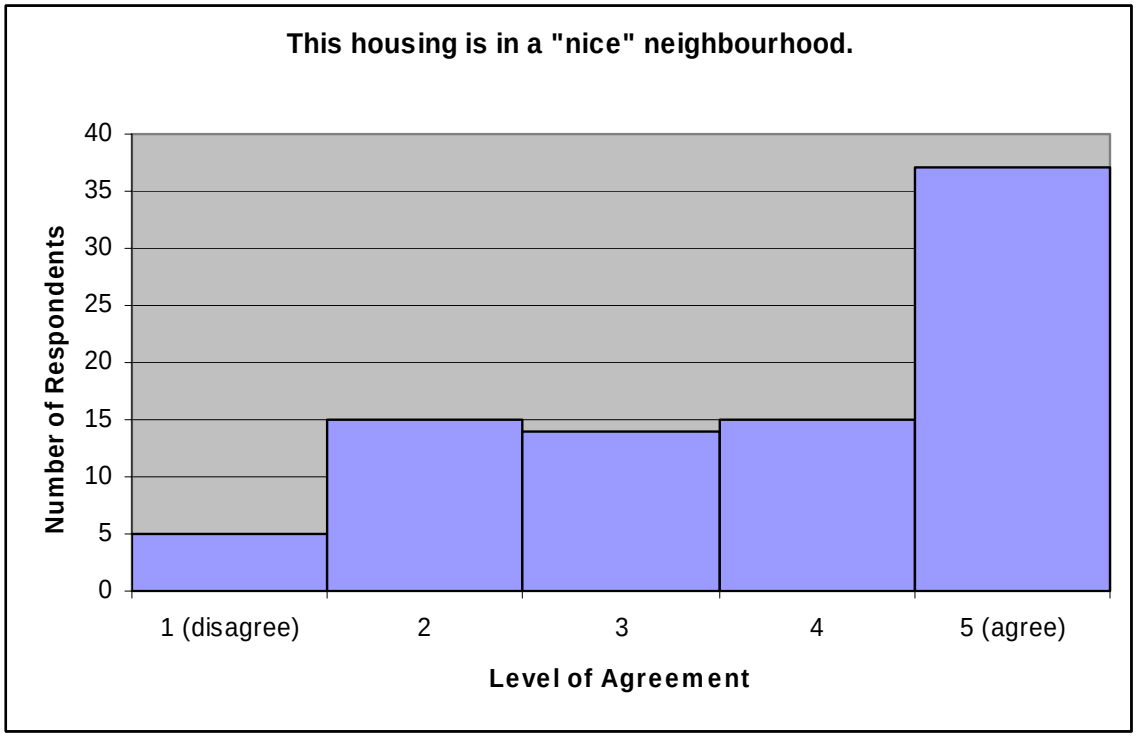
Have you (or has your loved one) used any of the following in the last 10 years?

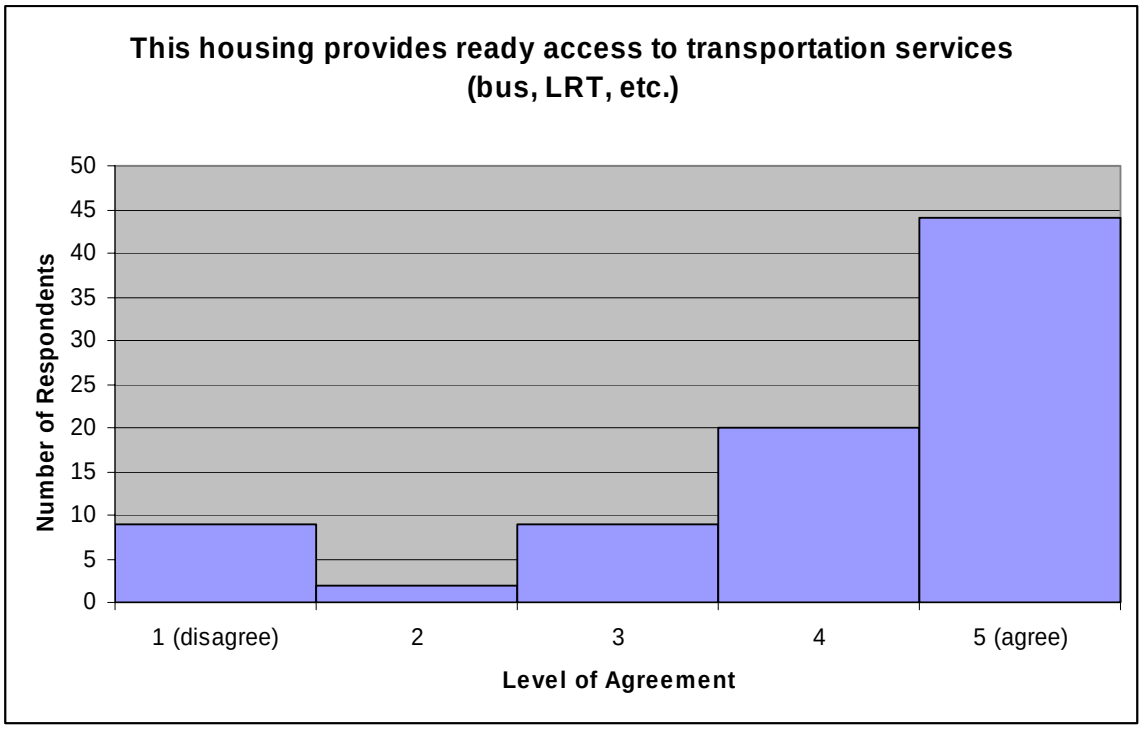
Group home…….……	Yes	**34%**	No	**66%**	Currently	**66%**
Emergency shelter……..….	Yes	**28%**	No	**72%**	Currently	**1%**
Continuing care ("nursing") facility……	Yes	**10%**	No	**90%**	Currently	**6%**
Hospital (longer than 2 months) ……	Yes	**54%**	No	**46%**	Currently	**4%**
Rental assistance or subsidy……..….	Yes	**31%**	No	**69%**	Currently	**16%**
Subsidized public housing……	Yes	**15%**	No	**85%**	Currently	**12%**
Supportive housing……	Yes	**20%**	No	**80%**	Currently	**8%**
Housing that you own……..…….	Yes	**26%**	No	**74%**	Currently	**14%**
Regular rental unit (shared) ……	Yes	**26%**	No	**74%**	Currently	**6%**
Regular rental unit (not shared) ….……	Yes	**45%**	No	**55%**	Currently	**14%**
Family home……	Yes	**61%**	No	**39%**	Currently	**28%**
Transitional housing……..….	Yes	**23%**	No	**77%**	Currently	**5%**

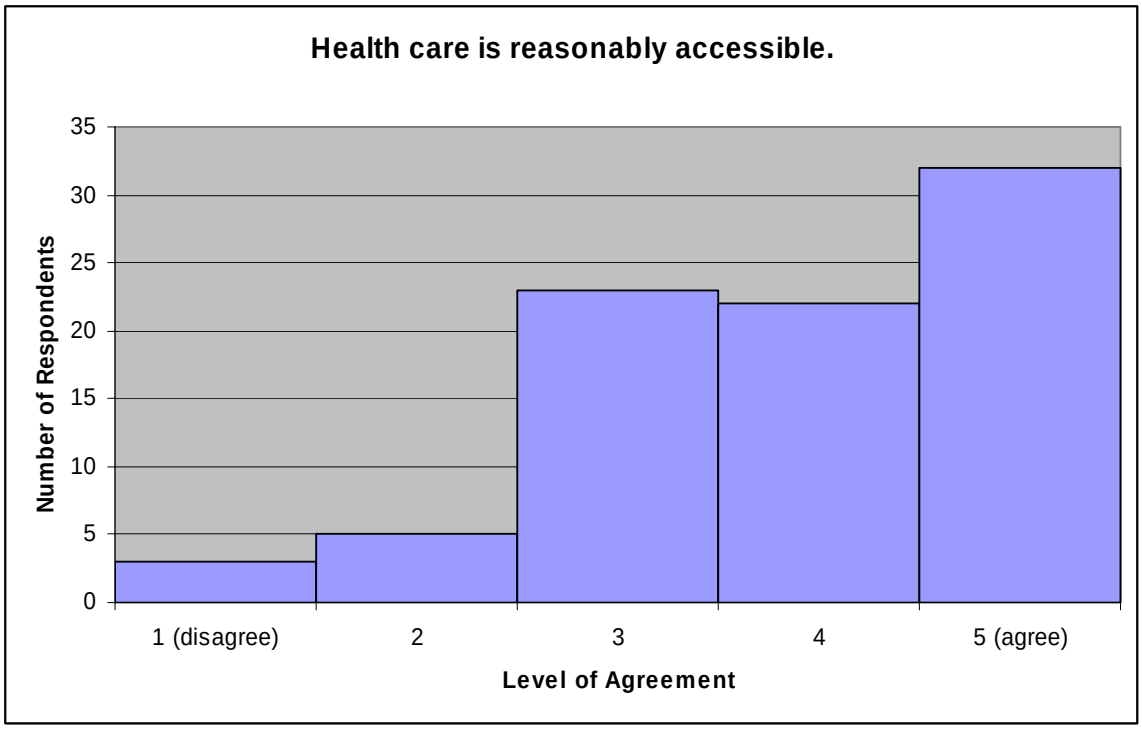
Have you (or has your loved one) ever been homeless, that is, "lived on the streets"?

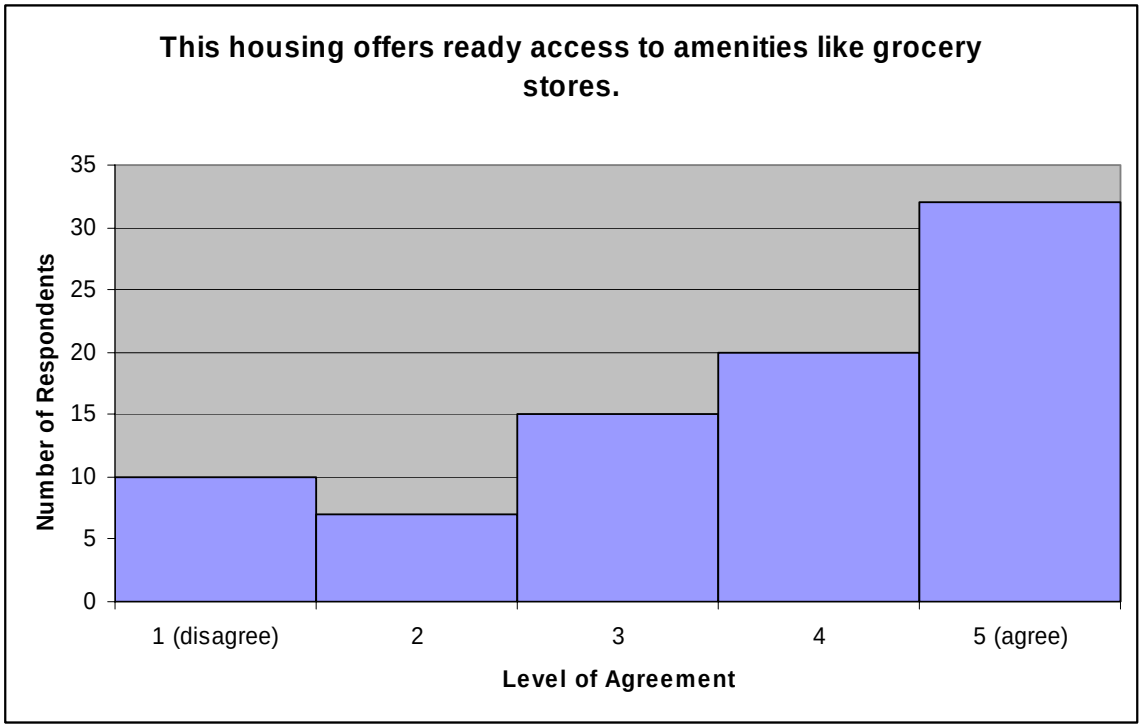
Yes **25%** No **75%**

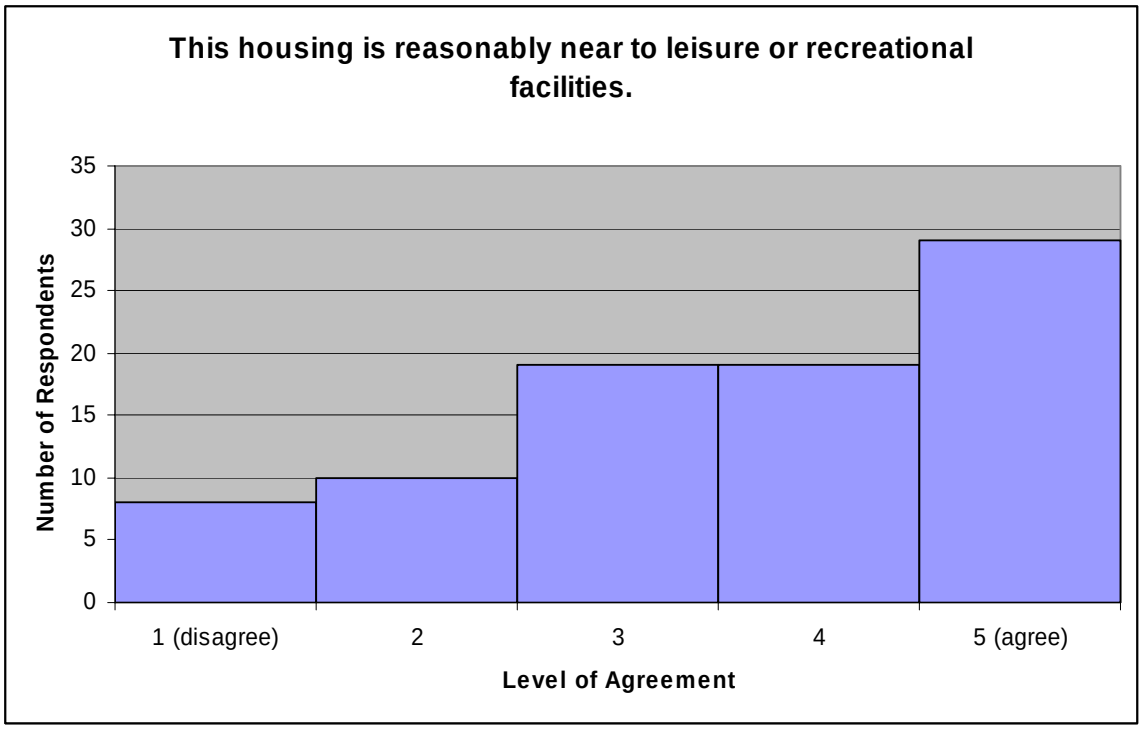
How strongly would you agree or disagree with the following statements about your (or your loved one's) current housing?






Health care is reasonably accessible.
Number of Respondents
35
30
25
20
15
10
5
0
1 (disagree)
2
3
4
5 (agree)
Level of Agreement

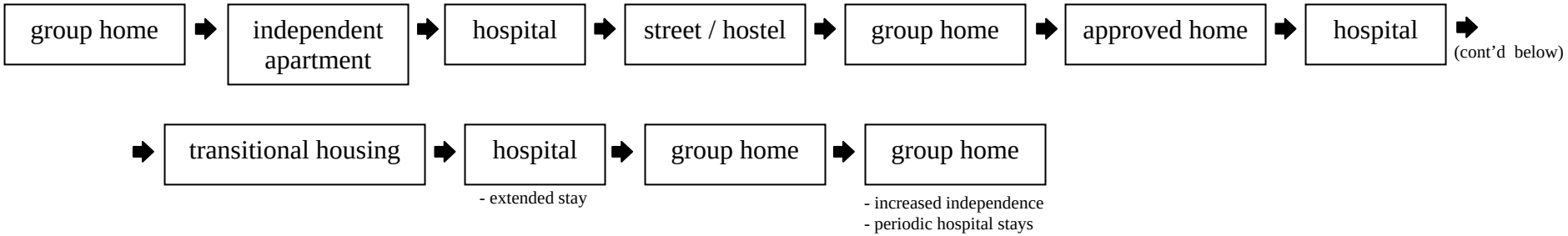

This housing offers ready access to amenities like grocery stores.
Number of Respondents
35
30
25
20
15
10
5
0
1 (disagree)
2
3
4
5 (agree)
Level of Agreement


This housing is reasonably near to leisure or recreational facilities.
Number of Respondents
35
30
25
20
15
10
5
0
1 (disagree)
2
3
4
5 (agree)
Level of Agreement

Appendix C - Housing Chronologies

The following maps briefly summarize each interviewee's housing experiences, and are presented in order to capture the range and number of housing situations experienced by persons with mental illness.

Interviewee #1



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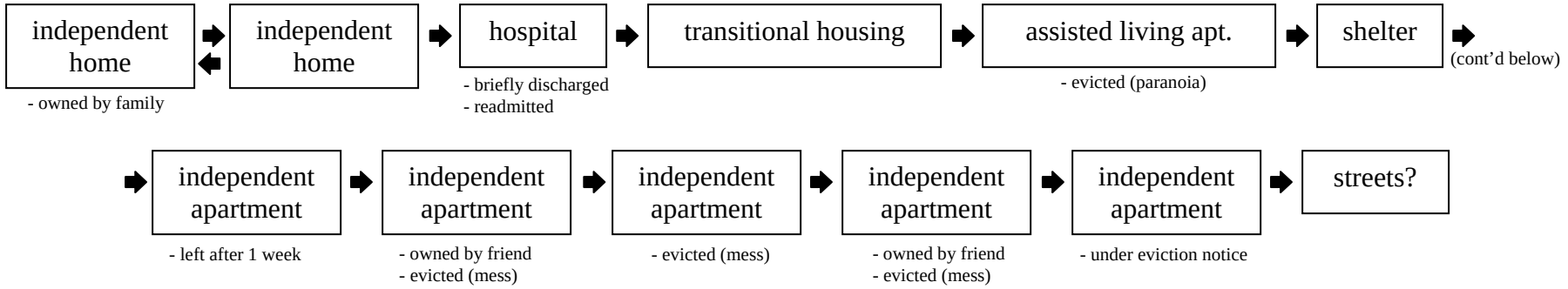
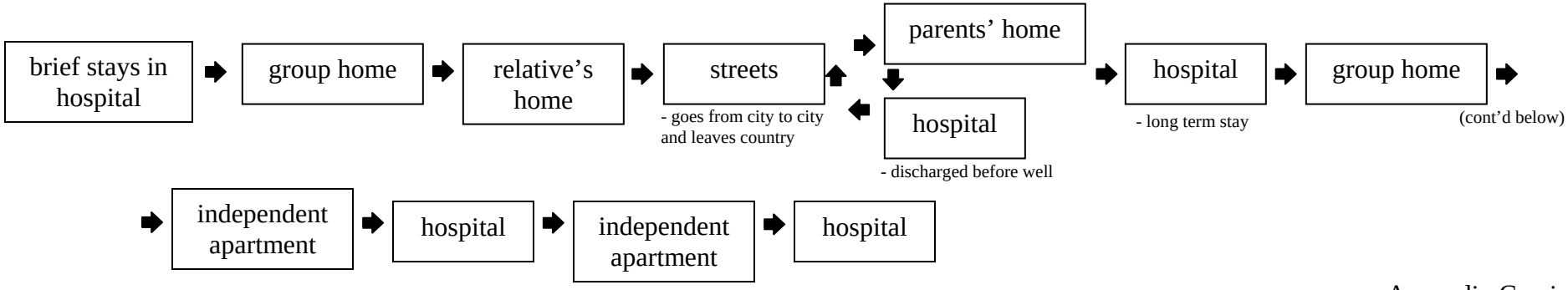
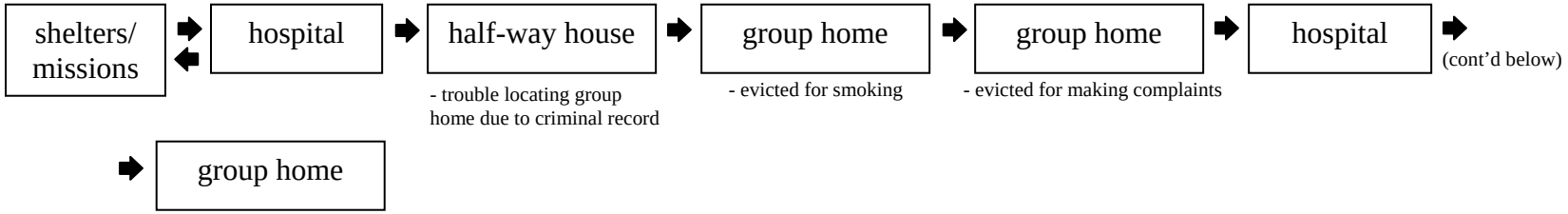


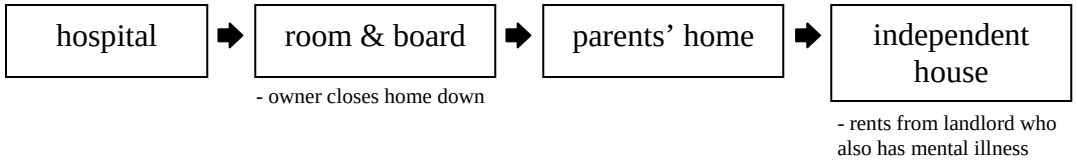
Interviewee #3



Interviewee #4



Interviewee #5



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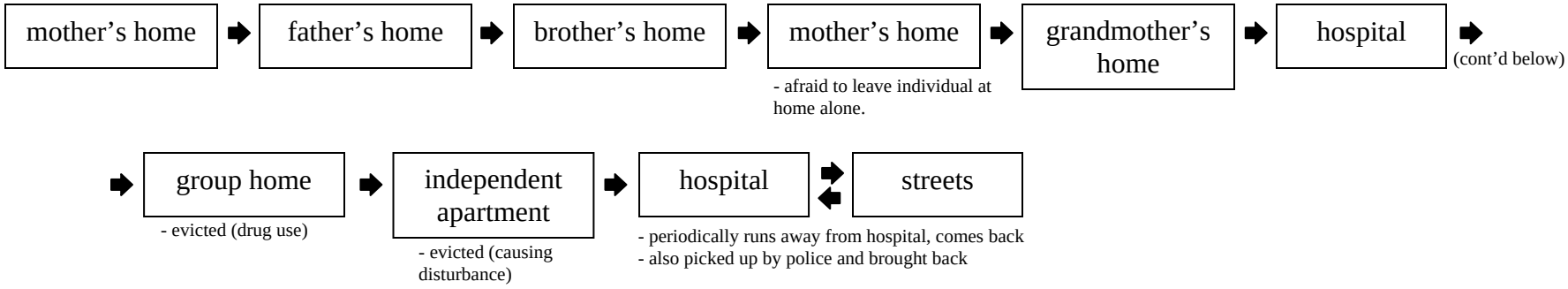
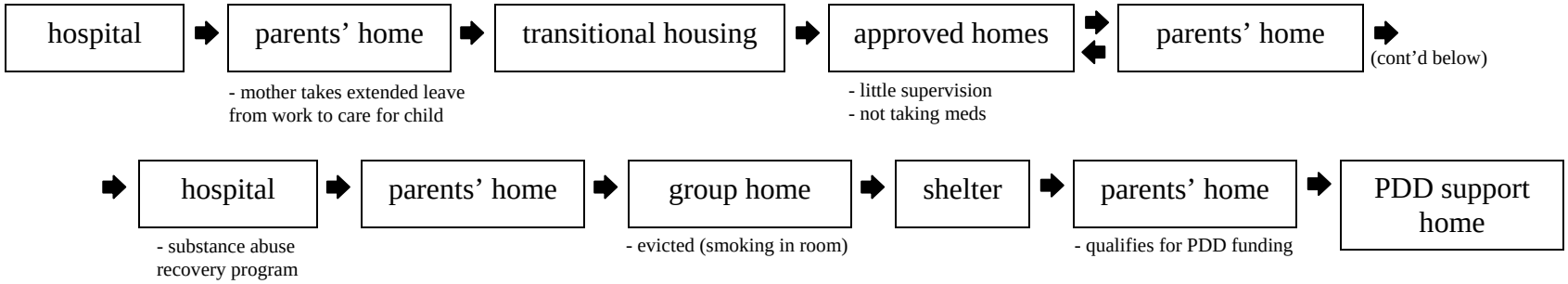
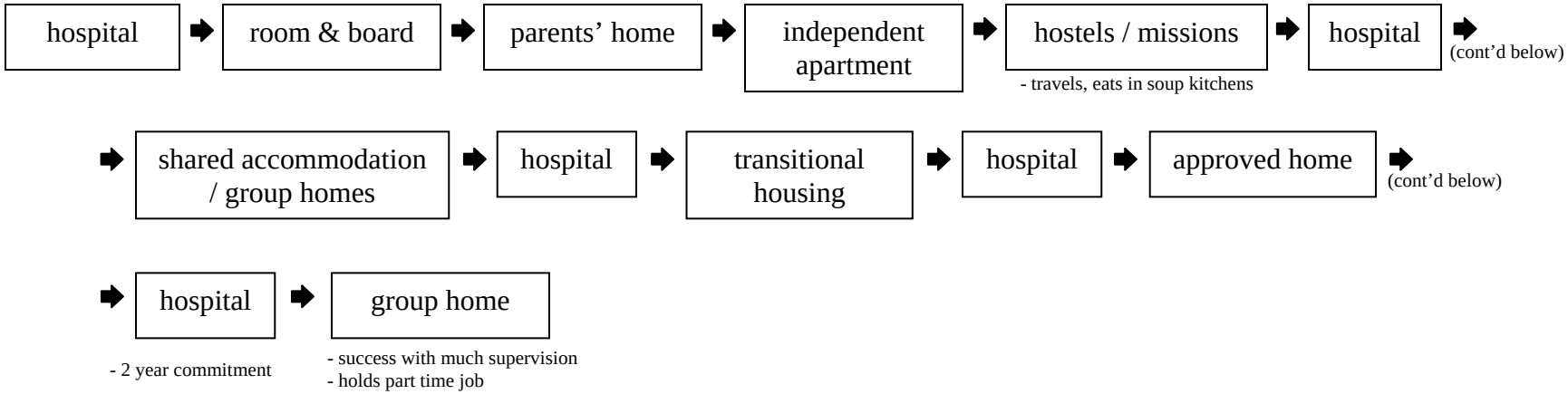


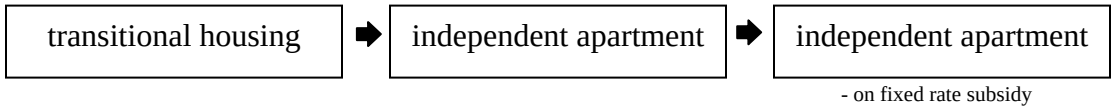
Interviewee #7



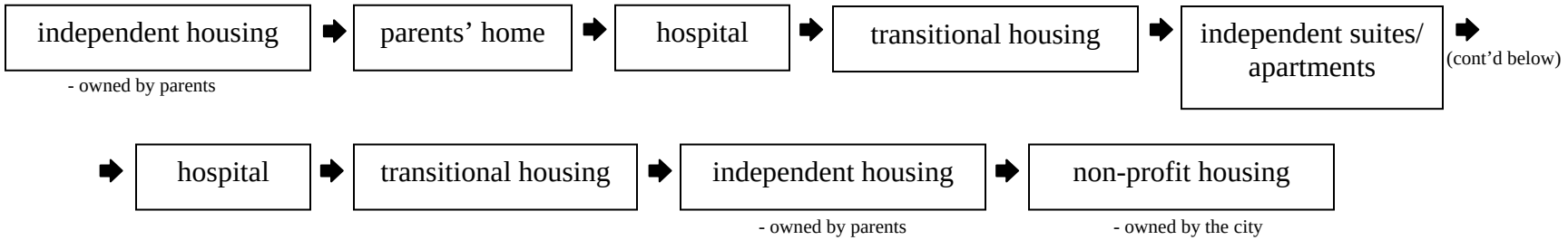
Interviewee #8



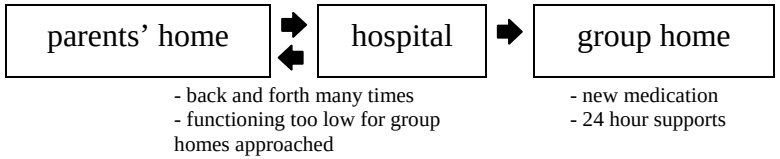
Interviewee #9



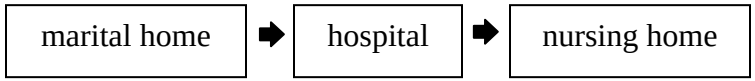
Interviewee #10



Interviewee #11 a. (child)



Interviewee #11 b. (spouse)



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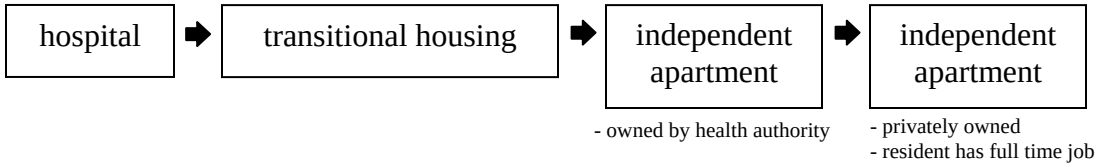

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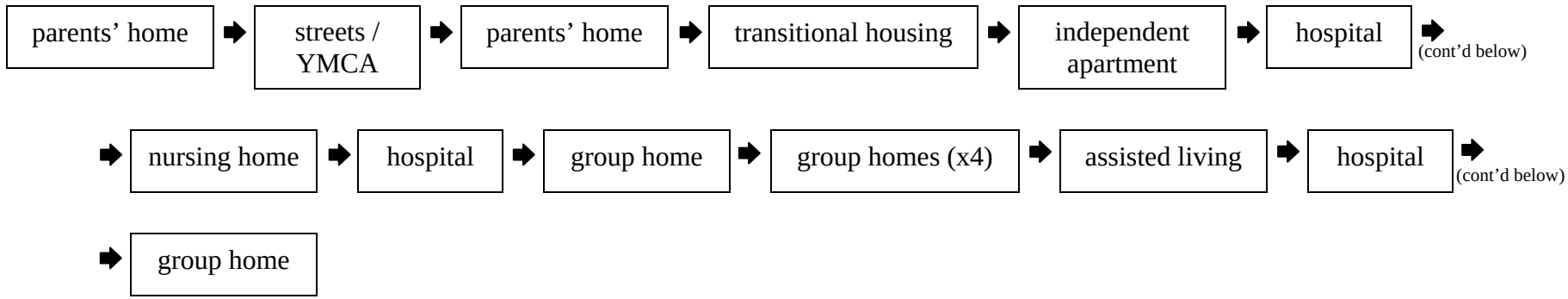

Appendix D – Interview Documents

(1) Information Letter (for persons with mental illness)

(2) Information Letter (for family members)

(3) Consent Form

SCHIZOPHRENIA SOCIETY OF ALBERTA
EDMONTON & AREA CHAPTER
A REASON TO HOPE. THE MEANS TO COPE.

#201, 10621 - 100 Ave | Edmonton, AB | T5J 0B3
tel: (780) 452-4661 | fax: (780) 482-3027
info@ssa-edmonton.com | www.ssa-edmonton.com
Charitable Registration Number: 13048 - 5816 - RR0001

Title:
Housing for Persons with Mental Illness: Understanding their Experiences

Investigators:

Tara Koehler, Program Coordinator (Interviewer)	Giri Puligandla, Executive Director (Project Manager)	Carla Semeniuk, M. Urb. Pl. Secretary & Housing Committee Chair (Project Advisor)

Purpose of this Study: The purpose of this study is to learn about the difficulties and successes experienced by persons with mental illness and their caregivers when searching for appropriate housing for a mentally ill person.

Background: Finding housing with appropriate levels of support is one of the toughest challenges faced by persons with mental illness and their loved ones who are trying to help. This study will explore the experiences of Schizophrenia Society of Alberta, Edmonton & Area Chapter (SSAEA) members in the quest for housing for the mentally ill. Because everyone living with mental illness has different experiences related to housing (some find it easily, others have a really hard time), we need to learn more about what is needed in Edmonton.

Procedure: By putting your name and phone number on the line at the bottom of the survey sent in January, you agreed to allow us to contact you for a more in-depth interview about housing experiences. If you agree, you will participate in a 60 to 90 minute interview, during which you will be asked to share in detail your experiences with trying to find housing. The interview will take place in your home or any other private area you choose. The interview will be audio taped and a written copy of the audiotape will be made.

Risks: You may experience sad feelings while remembering the experiences you have had. If the interview is too uncomfortable you can stop, delay, or quit the study at any time. You can be referred to support services if you need it.

Benefits: Your contributions to this research phase will help shape a future SSAEA housing project and ensure that it is based on what is really needed by our people. This study may not be of any help to you and your experiences. However, talking about your experiences may help you express some of your feelings about the experience. You will be given a small token of appreciation for participating in this study.

Confidentiality: The researcher Tara Koehler and her supervisory committee will maintain the privacy of the interviews. The information will be kept in a locked filing cabinet. Your name or any other information that might identify you will not be attached to the information you give. Names will never be used in any presentation or publication of the study results. All information will be held confidential and private, except when required by law or in the event you express harmful thoughts regarding yourself or others.

Freedom to withdraw: You will be free to withdraw your consent or stop participation in this study at any time. You do not have to give a reason.

Additional Contacts: Any questions or concerns about this research study, should be reported to:

Giri Puligandla, Executive Director,
Schizophrenia Society of Alberta, Edmonton & Area Chapter
Phone: (780) 488-2342 Email: giri@ssa-edmonton.com

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INTERVIEW PARTICIPATION CONSENT FORM

Title of Project: Housing for Persons with Mental Illness: Understanding their Experiences

Interviewer:	Tara Koehler Program Coordinator
Project Advisor:	Carla Semeniuk, M. Urb. Pl. Secretary & Housing Committee Chair
Project Manager:	Giri Puligandla, Executive Director Phone (780) 488-2342

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate, or to withdraw from the study at any time, without consequence, and that your information will be withdrawn at your request?	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?	Yes	No

This study was explained to me by: _____

I agree to take part in this study and understand the potential risks and benefits, if any.

_____	_____	_____
Signature of Participant	Date	Printed Name of Participant

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____	_____	_____
Signature of Interviewer	Date	Printed Name of Interviewer

Appendix E – Confidentiality Agreement

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Charitable Registration Number: 13048 - 5816 - RR0001

CONFIDENTIALITY AGREEMENT

I understand and accept the following conditions:

Any and all information regarding research participants shall be respected and handled confidentially. All information concerning research participants shall be confidential and shall not be disclosed to or discussed with anyone other than those authorized to receive such information, unless disclosure is authorized by law.

I understand that intentional or involuntary violation of this duty of confidentiality may lead to disciplinary action. Furthermore, I understand that such disclosure violates standard ethical and legal statutes that protect people's rights to privacy. I may be subject to sanctions as deemed appropriate by the Schizophrenia Society of Alberta, Edmonton and Area Chapter Board of Directors.

This obligation of confidentiality and non-disclosure as outlined shall survive the term of my involvement with this research project.

Signed at Edmonton, Alberta, Canada, on the _____ day

Of _____ , 20____.

_____
Signature

_____
Print Name