"It’s Important to be Proud of the Place You Live In": Housing Problems and Preferences of Psychiatric Survivors

Cheryl Forchuk, RN, PhD, Geoffrey Nelson, PhD, and G. Brent Hall, PhD

TOPIC. It is important to understand housing and mental health issues from the perspective of psychiatric survivors. This paper reports findings from a series of focus group meetings held with survivors of mental illness to address issues concerning housing preferences and housing needs.

METHODS. The discussions were recorded, transcribed, and analyzed using an ethnographic method of analysis. The themes that emerged related to oppression, social networks and social supports, housing conditions, poverty and finances, and accessing services. Participants described the ongoing stigma, discrimination, and poverty that reduced their access to safe, adequate housing.

FINDINGS. They preferred independent housing where supports would be available as needed. Participants described the dilemma of having to choose between the housing they wanted and the supports they needed, since supports were often contingent upon living in a less desirable housing situation.

CONCLUSIONS. Nurses and other mental healthcare workers need to be aware of these issues for discharge planning, community support, and ongoing advocacy. The survivor voices need to be heard by decision-makers at various levels of government in order for housing policy to become more receptive to their realities.

Search terms: Housing preferences, focus groups, supportive housing, psychiatric, stigma, discrimination, poverty

Cheryl Forchuk, RN, PhD, University of Western Ontario
Lawson Health Research Institute, London, ON, Canada;
Geoffrey Nelson, PhD, Wilfrid Laurier University,
Waterloo, ON, Canada; and G. Brent Hall, PhD,
University of Waterloo, Waterloo, ON, Canada.

Deinstitutionalization, health system restructuring, and a move to supported community living for persons with severe mental illness have created the necessity for a comprehensive understanding of needs, gaps, and barriers that exist to acquiring and maintaining housing. The issues related to mental health and housing are varied and complex. Research has shown that persons with severe mental illness are at risk of losing their housing, living in substandard housing that is not aligned with their preferences, or being placed in inappropriate housing (Goering, Tolomiczenko, Sheldon, Boydell, & Wasylenki, 2002; Nelson, Hall, & Forchuk, 2003; Rochefort, 1993). We believe that it is important to understand housing and mental health issues from the perspective of psychiatric survivors.

Researchers have collaborated with community members and psychiatric survivors to conduct surveys of survivor preferences for and barriers to obtaining housing and supports (Friedrich, Hollingsworth, Hradek, Friedrich, & Culp, 1999; Goering, Paduchak, & Durbin, 1990; Goldfinger & Schutt, 1996; Massey & Wu, 1993; Minsky, Riesser, & Duffy, 1995; Rogers, Danley, Anthony, Martin, & Walsh, 1994; Schutt & Goldfinger, 1996; Tanzman, 1993). These surveys provide a great breadth of information about survivors’ preferences for housing and support, with several consistent findings emerging. First, most survivors prefer to live in their own homes or apartments rather than in other forms of housing offered by social services. Second, survivors want staff support to help them deal with a variety of day-to-day challenges of living independently in the community,
and they want control over staff support. For example, survivors do not want "live-in" staff, but rather staff who are "on-call" and who can provide support when needed. Third, the barriers to obtaining their own housing are primarily financial in nature. Most survivors cannot afford market rents because of dire poverty.

An alternative research approach to understanding survivor preferences for housing and support involves qualitative data. Qualitative interviews have the potential to provide more depth to understanding people’s lived experiences, needs, and preferences as well as a richer understanding of their life contexts (Patton, 2002). While there have been a few studies that have used qualitative methods to evaluate different types of housing for consumers (Boydell & Everett, 1992; McCarthy & Nelson, 1993; Parkinson & Nelson, 2003; Walker & Seasons, 2002), there have been very few needs assessment studies with survivors conducted in Canada that have examined their housing and community experiences (Herman & Smith, 1989; Lord, Schnarr, & Hutchison, 1987; Morrell-Bellai, Goering, & Boydell, 2000). Some of the themes that have emerged from these studies are consistent with the quantitative research, namely lack of support (both formal services and informal support networks), the stigma that is attached to mental illness labels, poverty and unemployment, and living in poor-quality housing. One limitation of these qualitative studies is that they did not examine survivors’ preferences for housing and support.

District Health Councils (DHCs) in Ontario, Canada, were requested by the Ministry of Health and Long-Term Care in June to August of 2001 to conduct focus group meetings with mental health survivors and their families to identify housing-related issues. Data were collected with the objective of informing preparation of a comprehensive mental health housing policy and an integrated approach to delivering housing for the range of persons with serious mental illness. The Thames Valley DHC, the Essex Kent Lambton DHC, the Grey Bruce Huron Perth DHC, and the Waterloo Region Wellington Dufferin DHC partnered with a Community-University Research Alliance (CURA) on mental health, housing and community economic development to assist with data collection and analysis. Two guiding research questions were addressed in this qualitative needs assessment, namely: (a) What issues of concern do psychiatric survivors identify related to their current housing situation? (b) What preferences do they identify related to housing?

**Methods**

Psychiatric survivor groups across the southwest region of Ontario recruited a purposive sample of participants for 14 focus groups. The focus groups were held in both rural and urban areas. A common set of open-ended research questions and prompts were used as guides for all groups. Transcripts were entered into the Non-numerical Unstructured Data Indexing Strategizing and Theorizing (NUD*IST) software package to assist analysis. An ethnographic method of analysis (Leininger, 1985, 1987) was employed. Ethnography uses both interaction and observation to describe and analyze life ways or particular patterns of groups or cultures in their environment (Leininger, 1985, p. 35). This method included identifying and listing descriptors which were developed into patterns, and then synthesizing several patterns to obtain broad themes. The themes were then tested by reviewing them against raw data (Leininger, 1985). Additional steps in this analysis included initially having the data analyzed independently by two team members. Following this, the two team members compared and revised the coding schemes used independently. As well, in addition to reviewing the themes against the raw data, the themes were presented to the CURA on Housing and Mental Health advisory group and the annual CURA conference for feedback from psychiatric survivors and other CURA participants. No changes were suggested from this process.
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The sample consisted of 133 participants in the 14 focus groups. There were 63 female, and 70 male participants. The number of people per group ranged from 1 to 17. Two of those 14 focus "groups" contained only one participant and must therefore be considered interviews rather than focus groups; and one group had three participants. The remainder had five or more survivors in attendance. The content of the interviews was compared to the focus groups and revealed great similarity. These two transcripts were included in the analysis.

Results

A number of interconnected themes are summarized in Table 1. The themes were analyzed from the perspectives of the two research questions and therefore broadly grouped under the themes of concerns and preferences/desires. A number of issues were raised that superficially appeared to go beyond the issues of housing. The psychiatric survivors' perspective was that these broader issues, such as societal oppression and available supports,

<table>
<thead>
<tr>
<th>Domain</th>
<th>Problems/concerns</th>
<th>Preferences/desires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oppression</td>
<td>stigma, discrimination, labeling, being treated differently</td>
<td>• acceptance</td>
</tr>
<tr>
<td>Social networks</td>
<td>landlords—inattentive to needs (e.g., repairs), power to evict residents out of housing</td>
<td>• advocacy</td>
</tr>
<tr>
<td>and social support</td>
<td>having to choose between housing that emphasizes support and independence; loneliness and dependence</td>
<td>• education of consumers regarding their rights as tenants, education of landlords</td>
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<tr>
<td>Housing</td>
<td>lack of affordable and desirable housing</td>
<td>• finding a balance = support and independence</td>
</tr>
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<td></td>
<td>homelessness or precarious housing situation, frequent moves</td>
<td>• need more social interaction and contact, peer support, drop-in settings</td>
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<tr>
<td></td>
<td>undesirable housing—poor quality, too small, lack of privacy, restrictive rules, poor neighborhood</td>
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<tr>
<td></td>
<td>gender and child issues—changing family situations in conflict with rules around number of rooms allowed, rate of subsidy, access to child care, safety for women and children</td>
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<tr>
<td></td>
<td>victimization—break-ins, stealing by other people in residence, proximity to drug and sex trade, fear of sexual abuse (re-abuse)</td>
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<tr>
<td>Poverty, finances</td>
<td>poverty, low-income, disability program difficulties</td>
<td>• want a home that is stable, desirable and affordable</td>
</tr>
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<td>Accessing services</td>
<td>lack of crisis support in independent living</td>
<td>• desirable housing—small setting, privacy (own room), modern facility, pets allowed, collective decision-making</td>
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<td></td>
<td>transportation, accessibility problems</td>
<td>• freedom to make choices</td>
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<td></td>
<td>inaccessibility of medical and mental health services</td>
<td>• choice over gender of living companions</td>
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<td></td>
<td>having to move to get needed services</td>
<td>• safe place that is appropriate for children</td>
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<td></td>
<td></td>
<td>• want safety and security, a lock on the door</td>
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| Preferences/desires | • need more financial support, especially re: access to desirable housing |
|---------------------|• want around-the-clock support available, drop-in services |
|                     |• affordable transportation |
|                     |• more readily available support services |
|                     |• getting the right services in the right place |
were directly related to their ability to obtain and keep housing.

Oppression

Issues related to oppression were the primary concerns raised. The concerns included stigma, discrimination, being labeled, and being treated differently. Survivors identified stigma as a ubiquitous deleterious influence in their lives. They experienced stigma when dealing with public sector bureaucracies, healthcare professionals, private landlords, and employment situations. Quotes from participants that exemplify this theme included the following:

If you’re a psych patient in [city name] they have you on record in the computers when and if you come into emergency. So as they type you on record into the computer your name comes up. So if a person comes into emergency with a broken arm or whatever, they must see the crisis team first even when their ailment is physical.

Low labels are pinned on you. “That one is on welfare! She’s wearing Goodwill clothing.”


The participants said they wanted acceptance and advocacy. For example:

Remove labels given to people.

No matter what the client’s problem is there is no reason not to treat everyone with respect.

We give back by volunteering in the community.

Be my voice.

Social Networks and Social Support

Issues related to social networks and social supports were raised as instrumental to securing and maintaining desirable housing. Problems related to landlords were highlighted. Participants often described landlords as being inattentive to their needs. For example, repairs were often delayed after being reported. Participants were very concerned about the perceived power of landlords and feared being evicted. This created a sense of vulnerability since it was feared that if their housing was lost, it would not be easy to replace it. As a result, participants often remained silent and did not complain about their concerns. Examples of these concerns included:

I don’t complain [to the landlord], because I don’t want to lose the apartment. I’m not going to bug him about it, because I like the apartment.

Do your chores. Don’t cause problems.

In describing their preferences, other survivors focused on the importance of education of consumers regarding their rights as tenants, as well as the importance of education of landlords. For example:

They don’t believe anxiety is a problem since you’re not bleeding.
People don’t know their rights.

Landlords should have to take a course once a year or something, telling them what to do [their obligations].

Participants described dilemmas related to housing and available supports. Often the housing they desired was in a different place than the support they perceived that they needed. A dilemma that was expressed concerned whether survivors should live where they want, or get the services they need. There was often a struggle with having to choose between support and independence, and between loneliness and dependence. One participant noted: “I’m torn. I like my independence, but I like the company too.” This quote also highlights the fact that the key supports desired would address a sense of isolation and loneliness. This was echoed by many participants. For example:

I’m a very lonely person and I’m gonna have to deal with that.

What do you do alone when you don’t like TV?

The solution desired by participants was to have both support and independence rather than one exclusive of the other. For example, survivors wanted to have support available around-the-clock, but not physically present when not needed. This expressed in the following quote: “We want people to come, but we want them to leave.”

Participants wanted services that emphasized social interaction and the development of social networks. Survivors described a variety of supports such as peer supports, employment supports, family, friends, and professional as essential components of a support network. Survivor organizations, peer support, and drop-in centers were all seen as examples of services that can specifically address the issues of isolation and loneliness. For example: “I want to be part of what everyone else has to do. By myself, I drive myself crazy.” And, “If this peer support thing comes through, I think it will work.”

Housing

Concerns were expressed regarding the lack of affordable and desirable housing. Participants wishing independent living had great difficulty finding desirable housing that they could afford. For example: “Why [city name] has such horrible housing available I don’t know.” And, “If you spend 5 years on the list for geared-to-income housing, you may as well say it doesn’t exist.”

The difficulty in finding affordable housing created a sense of vulnerability among participants. They described themselves as at risk for homelessness or enduring precarious housing situations. Many described frequent moves in the search to find something both affordable and desirable. Comments included: “Most of us are one paycheck away from being on the streets.” “Got kicked out of residence in the middle of winter and had to sleep in a car 2-3 nights.” And, “I could not believe that me of all people could be homeless.”

Because desirable housing typically was unaffordable, participants described the undesirable housing that they could obtain. They described their housing as often being of poor quality, too small, and lacking privacy. In group situations, there were often restrictive rules. Participants complained of being forced to live in poor neighbourhoods. Since there were so few affordable options, participants felt they had no choice about where to live. Comments include:

You should see the dump I live in.

There are affordable apartments but you wouldn’t believe the neighbours you have to live with.

Where I’m at, you can’t call that home.

I took the apartment without looking at it.

Perspectives in Psychiatric Care Vol. 42, No. 1, February, 2006
The challenges were even greater when children were involved as the rules within the public assistance programs create additional difficulties. For example, the number of rooms allowed was dependent on the number of children. However, with access being lost and gained, or adolescents moving between home and other settings, the number of children was not a constant. One woman described having to move three times in 1 year as her teenage daughter kept moving back and forth between parents. Further, locations where housing was available were sometimes not near available day care and safety was a major concern for participants. Many felt they were easy prey for victimization and several settings were not perceived to be safe for women or children. When living independently, survivors were often located in neighborhoods that had frequent break-ins. When they lived in group-living situations they described stealing by other people in the residence. The neighborhoods they were placed in were described as being in close proximity to drug and sex trades. Women participants often had a fear of sexual abuse (or re-abuse) due to the perceived safety of the neighborhood. Women who had been sexually abused in the past were often not comfortable in settings that included men. Sample comments provided on this theme are as follows:

She was in there [hospital] because she was sexually abused. She was placed in a home with two guys. When she complains, they tell her that she is lucky to be out of hospital.

Being on the third floor of a complex with no elevator which is not practical with two infants, and the presence of a child molester in the same building.

A [woman's] house has been broken into three times.

Crime is a problem in the lodge, lots of pilfering.

Participants wanted a home that is stable, desirable, and affordable. There was a strong preference expressed for independent and supported apartments.

There is some nice geared-to-income housing here if you can just get into it.

[Housing agency] is probably the best you can get, because it's modern housing.

We need supportive apartment units.

A perfect place would be my own apartment.

Desirable housing was consistently described. Participants preferred small settings rather than those where large numbers of persons reside. They wanted privacy that included their own room and modern facilities. It was very important to many that pets were allowed. In group-living situations, they wanted collective decision-making, while having the freedom to make their own choices, such as choice over gender of living companions. For families it was important to have a safe place that is appropriate for children. Sample participant comments included:

It's important to be proud of the place you live in.

Some people need a garden.

I've got a perfect place... own room, goldfish in room, television in room, can use phone... I can do everything except smoke.

[We] need choice because everyone has different preferences.

I feel there should be one house with all women, one men, and two that are mixed.

Participants wanted the very basic needs of safety and security met. For many this was symbolized by
the simple ability to be able to lock the door. For example:

I think it’s a safe place (has a lock on the door).

I double check that the door is locked and my roommate triple checks.

**Poverty, Finances**

Participant's choices were limited due to lack of finances as many were on government disability support programs. Some were on general welfare programs, while a few were employed. In Ontario, the provincial disability support has not increased for a decade and the housing allowance is far below market housing values. If a person is on general welfare, the level of support is even lower. This financial gap limited the choices available to participants. For example:

Try living on $300 a month. Half my rent comes out of that.

Try to save, say $1,500 for first and last month’s rent, to try to move, impossible. Those places where first and last month are not required are usually dumps.

**Participant’s choices were limited due to lack of finances as many were on government disability support programs.**

In addition to the obvious preference to increase levels of support, participants also described the need for easier access to the higher paying disability support in order to access housing. For example: “[I] need easier access to disability. I can’t work, but I was turned down for [provincial disability income support] because I wasn’t severe enough.” And, “Some people wait 1 to 2 years to get on disability [income support].”

**Accessing Services**

The issues of housing and ability to access services were seen as interwoven. Keeping housing was seen as related to continued access to supportive services. As well, current address could effect which services could be accessed. Specific service gaps were identified by participants. A major problem was the lack of crisis support in independent living. Many felt that they had to give up their supports in order to live independently. For example: “I would have been okay if someone had visited me, but they didn’t and I was alone. This led to some trouble with the law. The whole thing could have been avoided if someone had just come over.”

Frequent problems with lack of transportation, and accessibility were primarily identified by the focus groups that were held in the smaller rural communities. This could lead to a situation where participants from rural communities had to move in order to get needed services. Once again the dilemma appeared to be either to live where one wanted or get the services one needed: “Low-income housing is not centrally located, and shops and services are inaccessible. This is especially problematic for the elderly who cannot walk as far. There is no public transportation in (rural community). Grocery stores are on opposite ends of town and the very edges of town. Cabs are too expensive, and [provincial disability support] does not allow for transportation.”

Why should we have to travel an hour to (larger city) to see a doctor? How are you going to get there?

I lived in a bachelor apartment. I was happy. But, it was so far. For 19 months I walked the hills. No
buses went out that far. Moved. Really enjoyed living there, but there was no transportation.

The perceived inaccessibility of medical and mental health services was shared by the rural and urban groups. Many described long waits or long waiting lists. For example:

I waited 7 hours once suffering from a panic attack in emerg.

There aren’t enough doctors and psychiatrists, and the government has limits on the number of visits, so the consumers are actually referred to us [survivor initiative].

Waiting lists are false hopes.

Participants had specific suggestions that would help address the accessibility of services. An affordable public transportation system or access to other more affordable forms of transportation was seen as important to many. They wanted around-the-clock support available to them upon their request. This help could be something accessed by telephone rather than in close physical proximity. Further, they wanted supports that could be accessed on a drop-in basis, rather than requiring referrals and waiting lists. Support services need to be more readily available and to be personal from someone they trusted. They wanted to get the right services in the right place. For example:

I’m getting help. I have an excellent aftercare worker and doctor.

I need someone to walk me through things. My worker does.

To get growth, one must go back to one’s roots, to their hometown. One must then seek services there. Get help. Get an apartment, learn to cook, etc. You have to go where you feel comfortable.

Discussion and Implications

Some of this study’s findings reaffirm existing qualitative and quantitative research (e.g., Friedrich et al., 1999; Walker & Seasons, 2002). While the same general issue of housing suitability is at the heart of our discussion, this study evokes not only the actual voices of psychiatric survivors to express their concerns, but it also provides a powerful complement to previous research in that it systematically reviews and presents survivor preferences for housing and support. The participants have not only described issues and concerns that are relevant to them, but also what they see as some potential solutions. Moreover, the findings from this qualitative research provide more depth and texture to the experiences and desires of psychiatric survivors than is the case with existing quantitative survey research on consumer preferences (Tanzman, 1993).

The participants in the study expressed a consistent preference for independent living arrangements such as supportive apartments, and the issues of oppression/stigma and poverty were pervasive. Consistent with previous first-person accounts (e.g., Capponi, 1992), detailed information about the kinds of supports were provided, including advocacy, various forms of social supports through government and community-based agencies, and better access to services, that would assist survivors to achieve their desired housing. Survivors wanted ready access to help, but did not want live-in, 24-hour support, which they perceived to be invasive and inconsistent with “normal” living. Further, the dilemma of either having the supports they need or living where they want adds an additional dimension of coping that cannot easily be resolved, as the housing choice constraints are such that achieving adequate supports and choice of residential location together is often unfeasible.

A basic form of general life and residential satisfaction for any individual or household stems from living in a preferred location, subject to affordability constraints, having fundamental independence in daily living, and, for psychiatric survivors, having access to
the supports they feel that they need. In contrast, survivors have been forced to regard these dimensions of residential satisfaction as competing and choose between them, thereby diminishing their overall life satisfaction. Linking supports to a person’s address tends to perpetuate this dilemma rather than solve it (Parkinson & Nelson, 2003), as appropriate supports provided to an individual living in an inappropriate residence fulfills only part of the individual’s life satisfaction needs.

Addressing transportation issues is essential to improve access to services such as health care. In particular, survivors residing in rural areas of southwestern Ontario often commented that they had to decide between living in their preferred home community and living somewhere where they could have ready access to appropriate services. Again, this reflects a dilemma of living that creates a fundamental dislocation between the comfort of choosing somewhere preferred and comfortable, relative to somewhere that may not be preferred and uncomfortable solely for the purposes of service accessibility.

While there are clearly preferences and constraints that affect residential decision-making for all individuals and households, the choice set for psychiatric survivors is so constrained that inevitably at least one aspect, and often more, of fundamental importance for leading a balanced and fulfilling life has to be sacrificed to find somewhere to live. While solutions to these issues are not immediately apparent, discussion of them with survivors prior to and during discharge planning, and promoting their fulfillment through ongoing community care, is centrally important.

Issues of oppression and poverty that were raised by numerous individuals in the focus group discussions, which is quite consistent with what survivors have been saying for some time (e.g., Capponi, 1992). These issues are systemic and, as such, they require systemic responses. Reducing the influence of stigma in the experience of persons with a severe mental illness will enhance their quality of life satisfaction across multiple domains including housing, employment, and utilization of supports. However, this is a long-standing problem that is not easily addressed by anything other than a systemic response. Many problems raised by participants related to financial issues, often stemming from the Ontario Disability Support Program. As noted earlier, this provincial income support had not been increased for a decade while the cost of living has steadily increased, with housing costs having increasing considerably.

Conclusions

This qualitative study has added to the largely quantitative literature on housing needs and preferences among those who have experienced a severe psychiatric illness. The preference for independent housing with adequate supports is reaffirmed with this study. Similarly the ongoing changes related to stigma and discrimination are described by participants. Using the voices of focus group participants as a form of resonance for the housing problem, it was possible to distill elements of need and preference that are relatively easily resolved through effective policy formulation and a commitment to addressing needs by the provincial government in Ontario.

Collectively, as a society, we need to meet the challenge placed before us by one of the participants who poignantly requested,

“Be my voice.”

Many housing challenges are faced by psychiatric survivors. Some of these challenges can be addressed by the mental health system, such as not linking services to location. Others, such as transportation and
adequate income will require a broader societal response, involving more than provincial government ministries. Healthcare practitioners can play a lead advocacy role in advocating for fundamental changes in the way that these needs are met. For example, nurses and nursing organizations can advocate strongly for bringing about the systemic solutions that are needed, including increased funding for income supports and for public awareness campaigns to address discrimination. These needs stem from pre-discharge planning within hospitals and flow outward through post-discharge follow-up and consultation with community advocacy groups, especially within the nonprofit housing sector. Advance practice nurses are frequently involved in both discharge planning and system advocacy. In both these roles an understanding of the complexity of housing issues, including the consumer perspective, is essential. Collectively, as a society, we need to meet the challenge placed before us by one of the participants who poignantly requested, "Be my voice." Without this avenue of expression, the voices of the many individuals who participated in the focus groups, and indeed those who are similarly affected but did not have the opportunity to participate, remain unspoken and thereby unheard. Equally, it is not enough simply to hear the pleas for assistance. Only through action, based upon the needs expressed in this paper, at the policy level and beyond to policy implementation and planning can the current housing crisis for psychiatric survivors begin to be resolved.

Acknowledgment. This research was supported by a grant from the Social Sciences and Humanities Research Council of Canada for a Community-University Research Alliance. We would like to thank the psychiatric consumer survivors who participated and the following district health councils who collaborated on this project: The Thames Valley District Health Council, the Essex Kent Lambton District Health Council, the Grey Bruce Huron Perth District Health Council, and the Waterloo Region, Wellington Dufferin District Health Council.

Author contact: cforchuk@uwwo.ca, with a copy to Editor: mary@artwindows.com

References


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