

Summary Bulletin

A Longitudinal Study of Consumer/Survivor Initiatives in Community Mental Health in Ontario: Individual-level and System-level Activities and Impacts

2004

Consumer/Survivor Initiatives in Ontario: A Unique Component of the Mental Health System

Consumer/Survivor Initiatives are self-help/mutual aid organizations that have been developed exclusively by and for people with serious mental illness. Consumer/Survivor Initiatives are not services, but rather supportive settings that offer one or more of the following program activities: self-help groups, one to one support, community-economic development, education and training for the public and mental health professionals, advocacy to create systems-level change, opportunities for consumer/survivors to develop their skills, the creation and distribution of resources based on consumer/survivor knowledge, and artistic and cultural activities. Consumer/Survivor Initiatives are guided by a set of values that include member empowerment and participation, social justice, sense of community and peer support, and mutual learning. The Consumer/Survivor Development Initiative, now called the Ontario Peer Development Initiative, began in 1991 with funding from the Ontario Ministry of Health and Long-Term Care. Currently there are over 50 funded Consumer/Survivor Initiatives across Ontario. While Consumer/Survivor Initiatives were initially funded as autonomous organizations, several Consumer/Survivor Initiatives are now funded through another transfer payment agency (e.g., a local branch of the Canadian Mental Health Association). It is unclear as to whether Consumer/Survivor Initiatives that are funded through a transfer payment agency have shifted away from the original mandate of a non-service, peer support approach.

A Participatory Action Research Study with Four Consumer/Survivor Initiatives

A collaborative study between 4 Consumer/Survivor Initiatives in southwestern Ontario (Cambridge Active Self Help, the Consumer/Survivor Initiative of Niagara, Mental Health Rights Coalition of Hamilton, Waterloo Region Self Help) and a group of researchers was conducted under the auspices of the Community Mental Health Evaluation Initiative. This research is funded by the Ontario Ministry of Health and Long-term Care (through the Ontario Mental Health Foundation) and the Canadian Institutes of Health Research from 1998 to 2004 and is being managed by the Centre for Research and Education in Human Services. The project is guided by a Steering Committee, which is composed of the research investigators, representatives of the 4 Consumer/Survivor Initiatives, and a representative from the Ontario Peer Development Initiative. A consumer representative from one of the Consumer/Survivor Initiatives has chaired this committee since the inception of the project in 1998. The Research Team included consumer/survivor researchers from each of the 4 Consumer/Survivor Initiatives, who did most of the interviews of participants in the study. The purpose of the research was to examine: (a) individual-level activities and impacts of the Consumer/Survivor Initiatives on new members and (b) system-level activities and impacts related to systemic change. Both quantitative and qualitative data were gathered to examine the individual-level and system-level activities and impacts.



Individual-level Activities and Impacts

The Characteristics of Participants in Consumer/Survivor Initiatives

The individuals in the research sample who were active participants in the 4 Consumer/Survivor Initiatives had an average age of 39 years, had completed 13 years of education, and had an average monthly income of \$1400. There were equal numbers of men and women; 80% were white; and 79% were single, separated, divorced, or widowed. The most frequent diagnosis was mood disorder (64%), followed by schizophrenia (33%). The vast majority of participants were taking some psychotropic medication (90%); 75% had a primary therapist or caseworker; and roughly half (49%) were also involved with some other community mental health agency.

One question that is sometimes asked about people who use Consumer/Survivor Initiatives is whether they are similar to or different from people who use more traditional community mental health services, such as intensive case management or Assertive Community Treatment (ACT). We were able to shed some light on this question by comparing active Consumer/Survivor Initiative members with new and continuing clients in 4 ACT programs in eastern Ontario who participated in a study of ACT. Consumer/Survivor Initiative members and ACT clients are similar on many dimensions of well-being and quality of life. However, Consumer/Survivor Initiative members have higher rates of completing high school, current employment, and involvement in vocational-educational programs, suggesting higher levels of well-being than ACT clients. On the other hand, Consumer/Survivor Initiative members have higher levels of symptom distress, physical health problems, housing instability, and emergency room utilization than ACT clients, suggesting that they have more difficulties than ACT clients. Also, Consumer/Survivor Initiative participants were more likely to have a diagnosis of mood disorder or anxiety disorder and less likely to have a diagnosis of schizophrenia than ACT clients. In summary, while people who use Consumer/Survivor Initiatives are somewhat different than people who use ACT, it is important to note that Consumer/Survivor Initiative members experience a number of significant social and health challenges, some more serious than those who use ACT.

Individual-level Activities

For the 61 participants who were active in the Consumer/Survivor Initiatives over the first 16 months of their involvement, the average number of events attended over the 16-month period was 65 (range was 2 to 380), and the average number of hours of participation was 114 hours (range was 4 to 902). Thus, participants averaged 4 events and 7 hours of Consumer/Survivor Initiative participation per month, or about 1 event and 2 hours of participation per week. These members participated in a number of ways in the Consumer/Survivor Initiative: (a) internal activities, such as membership meetings, social-recreational events, committees (32%), (b) one to one peer support (25%), (c) drop-in (20%), (d) self-help groups (13%), and (e) external activities, including public education, community planning, advocacy, and action research (10%).

Individual-level Impacts

Quantitative data. To examine the impacts of Consumer/Survivor Initiatives on new members, we compared 61 new members who became active in the Consumer/Survivor Initiatives with a comparison group of 57 people who were eligible to participate in but who were not active in Consumer/Survivor Initiatives. The two groups were comparable at baseline on demographic variables, self-reported diagnosis, service use, and the outcome measures. These individuals were interviewed at baseline (within 3 months of joining the Consumer/Survivor Initiatives for the active members), 9-months, and 18-months.



Active members participated at least 4 hours in the Consumer/Survivor Initiatives over the 18-month period. There was a 26% dropout rate from the study (not from Consumer/Survivor Initiatives) between baseline (161 participants) to the 18-month follow-up (118 participants). Those who dropped out were experiencing more psychosocial and mental health problems than those who remained in the study.

There are several findings that suggest positive impacts of Consumer/Survivor Initiative participation on the well-being of new members. First, active Consumer/Survivor Initiative members showed a significant decrease in Symptom Distress over time, while those in the non-active comparison group showed no such change. Second, active Consumer/Survivor Initiative participants showed a greater reduction in the utilization of hospital services. Across the 18-month follow-up, days of psychiatric hospitalization for the past 9 months dropped significantly for active Consumer/Survivor Initiative members, while there was no change for those in the comparison group (see Figure 1 at right).

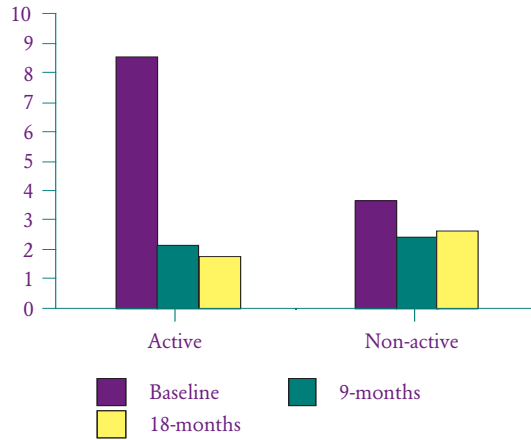


Figure 1: Average Number of Days of Psychiatric Hospitalization in the Past 9 Months at the 3 Time Periods for Participants Who Were Active and Not Active in Consumer/Survivor Initiatives

Third, compared with the non-active comparison group, active Consumer/Survivor Initiative members showed a significant increase in social support over the 18-month period. Fourth, compared with the non-active comparison group, active Consumer/Survivor Initiative participants showed a significant increase over the 18-month period on a measure of Quality of Life - Daily Activities (see Figure 2 below). For this measure, participants rated items such as spending spare time, chances to enjoy pleasant or beautiful things, amount of fun, and amount of relaxation, on a 7-point scale from Terrible (score of 1) to Delighted (score of 7). Finally, non-active participants showed a significant drop on a combined measure of employment and education from baseline to 18 months, while there was no significant change from baseline to 18 months for active participants (see Figure 3 on the next page).

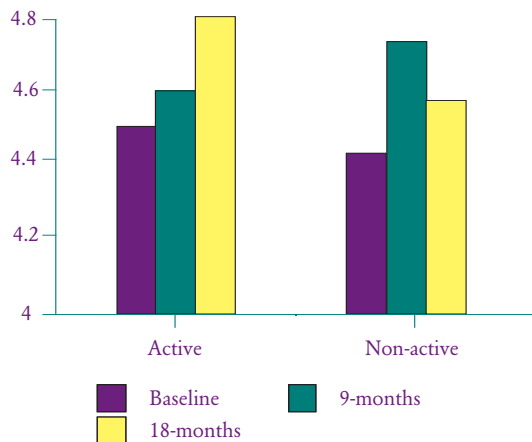


Figure 2: Average Score on a Measure of Quality of Life - Daily Living Activities at the 3 Time Periods for Participants Who Were Active and Not Active in Consumer/Survivor Initiatives (scores can range from 1 to 7 with higher scores indicating a higher quality of life)

Qualitative data. We also gathered qualitative data through in-depth interviews with 15 active and 12 non-active Consumer/Survivor Initiative participants. These individuals were interviewed at baseline, 9, and 18-month follow-up intervals. The in-depth, semi-structured interviews typically lasted one to two hours. They covered topics such as what life was like when mental health problems were first experienced, past experiences with services and supports, and personal life changes that occurred in the 9 months leading up to the interview.



There are three main findings from the qualitative interviews. First, while both Consumer/Survivor Initiative members and those in the comparison group voiced many concerns about their mental health during the baseline interviews, at the 9 and 18-month interviews, Consumer/Survivor Initiative members were more likely to report improvements in their mental health.

“Overall I just feel better. I don’t feel hopeless around and unsure of what to do now. Before it felt like I had no options and I’m trapped.” (Consumer/Survivor Initiative member)

“About three weeks after I moved out [from father’s home], I just really kept getting better and better...and three weeks later I could honestly say I felt good. And then I’ve been feeling better ever since. I haven’t had any depression, like I felt sad about stuff, but I haven’t had any depression since I’ve moved out on my own.” (Consumer/Survivor Initiative member)

Second, over time, Consumer/Survivor Initiative members were more likely to maintain social support compared with those in the comparison group.

“I felt isolated, I didn’t have any contact with peers who were going through the same situation. . . It does make quite a difference for an individual to contact his peers and go through what they have gone through and give each other support.” (Consumer/Survivor Initiative member)

Third, Consumer/Survivor Initiative members were more likely than comparison participants to maintain employment, sufficient income, and education and training.

“I did well in my first semester courses, so that gave me something to stand on. I felt like I’d accomplished something. So, I felt like I had what it takes to get through the rest of it, which made me feel stronger.” (Consumer/Survivor Initiative member)

Summary of Individual-level Activities and Impacts

On average, active Consumer/Survivor Initiative members in this research participated in 1 event for 2 hours per week over a period of 16 months. Moreover, Consumer/Survivor Initiative members participated in a number of different ways (e.g., self-help groups, drop-in, one to one peer support). The quantitative and qualitative findings converge around three themes related to the positive impacts of Consumer/Survivor Initiatives on individual members: (a) less symptom distress, fewer days of hospitalization, and improved mental health over time, (b) increased social support, quality of life related to daily activities, and improved relationships over time, and (c) enhanced employment/education over time.

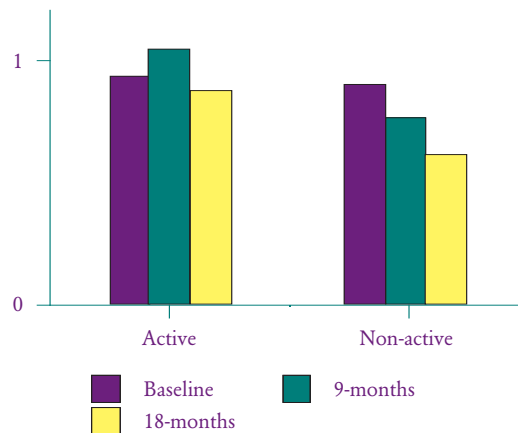


Figure 3: Mean Scores on Measure of Employment and Education in the Past 9 Months for Participants Who Were Active and Non-active in Consumer/Survivor Initiatives at Baseline, 9, and 18 Months (scores can be 0, 1, or 2 with 0 = not currently involved in employment or education, 1 = currently involved in employment or education, 2 = currently involved in both employment and education)



System-level Activities and Impacts

System-level Activities

While individual-level activities focus on supporting individuals directly (whether one to one or in groups), system-level activities work to create environments that are more supportive for people who have experienced mental health challenges. Based on the analysis of information gathered from a systems tracking log by Consumer/Survivor Initiative staff at three project sites, there are four main system-level activities: (a) public education and relations (activities designed to increase awareness or change public opinions about mental health issues and people who experience mental health issues), (b) political advocacy (activities trying bring about changes in social policies and practices), (c) community planning and collaboration (activities bringing about changes in planning practices and existing services, as well as the creation of new supports and services), and (d) action research (activities gathering information to support the previously mentioned system-level activities).

“system-level activities work to create environments that are more supportive for people who have experienced mental health challenges.”

Consumer/Survivor Initiatives participated in a high number of system-level activities: 665 system-level events were recorded across 3 of the 4 sites (one site did not complete the data collection) over the 25-month period. This means that more than 1 system-level event was recorded for each working day. Community planning was consistently the most common category (see Figure 4 on the next page).

A total of 949 members were involved in system-level activities, and 887 times staff participated in these events. There was a difference in the number of activities across sites over time, largely due to the type of community within which the Consumer/Survivor Initiative was located and due to emerging issues. For example, a participant from one site said: *“We do a lot of informal community advocacy. I work with different boards and committees that we sit on. I will make sure that our voice is heard.”* Also staff emphasized that there are not enough resources to invest in more than a few activities at one time.

System-level Impacts

Based on the analysis of four focus group interviews with Consumer/Survivor Initiative staff and members and 13 individual interviews with service-providers and health planners familiar with the Consumer/Survivor Initiatives, system-level impacts were examined. Overall there are two main types of impacts: (a) *changes in perceptions* – perceptions about mental health or mental illness, perceptions about the lived experience of consumer/survivors, and perceptions about the perceived value of Consumer/Survivor Initiatives by service-providers, policy-makers, or members of the general public, and (b) *concrete changes* – tangible changes in service-delivery practice, service planning, public policy or funding allocations.

With regard to the impacts of **public education** activities, there were 2 main findings. First, the general public *gained important knowledge* about various aspects of mental health, including consumer/survivors – their experiences and rights, and the importance of Consumer/Survivor Initiatives for the mental health system. Second, service-providers were influenced regarding how they could better support consumer/survivors, and changed professional practices based on knowledge they gained from

Consumer/Survivor Initiative members. For example, one local hospital saw the effectiveness of Consumer/Survivor Initiative peer support and began hiring peer support workers to work within the hospital. Another example was increased referrals to Consumer/Survivor Initiatives. *“All over the place, people [are referred to us by doctors]... [staff person] is getting referrals from GPs and hospitals that I have never had contacts with before.”* (Consumer/Survivor Initiative focus group member).

Political advocacy activities served to *increase awareness about consumer/survivor perspectives* among policy-makers and within the broader community. Also, there were *changes in public policy, legislation, and funding*. One example was the advocacy efforts of the Executive Director of one of the CSIs who was instrumental in securing 50% of the housing spaces for her region under the provincial government’s funding for homelessness dedicated to her city, because she documented clearly that her city was an underserved area in terms of supportive housing. In another Consumer/Survivor Initiative, members lobbied the local municipality to reinstate bus pass subsidies for people living in residential care facilities, many of whom were consumer/survivors (their efforts were so successful that the subsidy was not only brought back, but increased to a full 100%).

Community planning activities contributed to *changes in perceptions* that included acknowledging consumer/survivors as a needed partner within the mental health system, influencing committees’ positions and perceptions of consumer/survivors, and increasing the Consumer/Survivor Initiative profile in the community. Participants also reported *changes in practice, policy, and funding within the community*. Through involvement in planning endeavours with bodies such as the District Health Councils (regional health planning bodies) and other coalitions or groups, funding was obtained for Consumer/Survivor Initiatives; new services were designed; and existing services were redesigned. For example, in one community, participants mentioned that the local hospital had improved its services, thanks in part to a Consumer/Survivor Initiatives input. Another Consumer/Survivor Initiatives played a critical role in creating a new service for homeless people in the community. *“We went out to Toronto and checked out the programs there and we came back with the ‘Out of the Cold’ option as something which could be started very quickly.”* (Consumer/Survivor Initiative focus group participant)

Action research activities were seen to *heighten the credibility of Consumer/Survivor Initiatives* by providing tangible documentation about research findings to present about the benefits of alternative supports housed within Consumer/Survivor Initiatives.

“The most significant [outcome] and the one that got my hopes up was when [researcher] and I walked into that Ministry Implementation [Task Force] meeting and we were able to say if you put peer support in place with post discharge at a certain level, if you put both of those things in place, after 1 month alone, rehospitalization is reduced by 50% roughly. Ears and antennae went up.” (Consumer/Survivor Initiative key informant)

Consumer/Survivor Initiative members were also able to *offer recommendations for public policy* based on action research. Examples of concrete *changes in community practice* included increased referrals to one

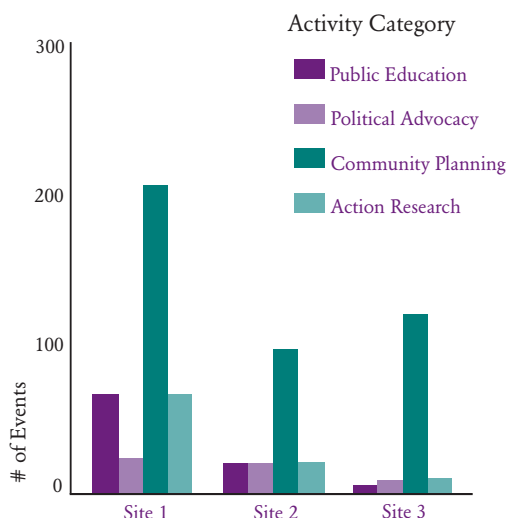


Figure 4: Total Events by Site and Activity Category Across Time Periods



Consumer/Survivor Initiative from a local hospital based on a research study's findings. Another Consumer/Survivor Initiative also joined with a coalition of other organizations to use research findings to develop a collaborative funding proposal for supported housing.

Summary of System-level Activities and Impacts

System-level activities appear to be a key component in fulfilling the Consumer/Survivor Initiative mandates of contributing to transformative social change. Consumer/Survivor Initiatives are working to create environments that are more supportive for not only their own members, but for other consumers as well. The findings demonstrate that Consumer/Survivor Initiatives are effective in benefiting their communities. Within the current context, the 4 Consumer/Survivor Initiatives that participated in this study opted to be active participants in a variety of community partnerships. Many benefits were seen as resulting from consumer/survivors from Consumer/Survivor Initiatives being "at the table" to plan community programs. The challenge lies in the minimal resources they have to carry out these types of activities. One participant summed up the benefits of Consumer/Survivor Initiatives in the following quote.

"And then the sheer fact of how long we've been around, it validates that fact that it [self-help] works. Because people like it. Somebody just backs up and says to you 'Take a bunch of crazy people and let them structure their own place and let them decide what their own direction is going to be.' It works!"

(Consumer/Survivor Initiative focus group member)

Recommendations

The recommendations stemming from this research fall into four categories: (a) increased funding for Consumer/Survivor Initiatives within the overall mental health budget (b) provincial and regional network-building, (c) enhancement and expansion of individual Consumer/Survivor Initiatives, and (d) further research with Consumer/Survivor Initiatives.

Recommendation #1: Increased Funding for Consumer/Survivor Initiatives Within the Overall Mental Health Budget

The importance of Consumer/Survivor Initiatives in a balanced mental health system has been underscored in the provincial policy documents, *Putting People First* (1993) and *Making It Happen* (1999), and also in the recently released Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs, *The Time Is Now: Themes and Recommendations for Mental Health Reform in Ontario* (2002). While the research findings of this study of 4 Consumer/Survivor Initiatives demonstrate positive impacts on consumers using Consumer/Survivor Initiatives and on community systems, Consumer/Survivor Initiatives are seriously under-resourced. The same conclusion was reached in an earlier evaluation of the Consumer/Survivor Initiatives that demonstrated positive impacts of participation in Consumer/Survivor Initiatives (Trainor, Shepherd, Boydell, Leff, & Crawford, 1996, *Consumer/Survivor Development Initiative: Evaluation Report*). Out of a total mental health budget of \$2.7 billion, Consumer/Survivor Initiatives have a budget of about \$5 million, or less than .2% of the budget.



- We recommend that the Ontario Ministry of Health and Long-Term Care double the funding available to Consumer/Survivor Initiatives within 1 year and that it allocate 5% of its mental health budget to Consumer/Survivor Initiatives within 5 years.
- The need for an expanded role for Consumer/Survivor Initiatives is consistent with current trends in mental health reform, based on the concept of recovery (*The Time Is Now: Themes and Recommendations for Mental Health Reform in Ontario*, 2002). One of the basic notions of a recovery-oriented system is that people with serious mental illness need supports and resources, not just professional mental health services. Supports and resources include peer support, housing, employment, education, and income support. Consumer/Survivor Initiatives can play an important role in the community capacity-building outlined in the Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs.

Recommendation #2: Provincial and Regional Network Building for CSIs

Based on the findings of the earlier evaluation of the Consumer/Survivor Initiatives (Trainor, Shepherd, Boydell, Leff, & Crawford, 1996, *Consumer/Survivor Development Initiative: Evaluation Report*), a number of issues and directions for the Consumer/Survivor Initiatives were identified (*The Consumer/Survivor Initiative: Issues and Directions*, 1995). These directions included: (a) the need for technical assistance to support the growth and development of Consumer/Survivor Initiatives, (b) the establishment of regional networks, and (c) the active role of consumer/survivors and Consumer/Survivor Initiatives in mental health reform. These issues remain important today.

- There is a need to strengthen the capacity of the Ontario Peer Development Initiative to provide technical assistance and support to Consumer/Survivor Initiatives and to bring Consumer/Survivor Initiatives together on a more frequent basis. Gathering together is important for building the consumer/survivor movement and enhancing its role in mental health reform.
- There is a need to strengthen the regional networks of Consumer/Survivor Initiatives. Gathering at a regional level is needed for building solidarity and support, sharing approaches and experiences, and gaining access to training and technical support.
- There is a need to come to a common understanding of how Consumer/Survivor Initiatives define and “do” peer support and to emphasize the role of consumers in recovery-oriented mental health reform.

Recommendation #3: Enhancement and Expansion of Individual Consumer/Survivor Initiatives

Consumer/Survivor Initiatives do a great deal of beneficial work for both individual members and for their communities. However, with an average budget of \$160,000 (range is \$115,000 to \$240,000 for the 4 Consumer/Survivor Initiatives participating in this study), they have limited funds to coordinate and carry out individual-level and systems-level activities, maintain and renew their organizations, and pay for a suitable physical setting. The 4 Consumer/Survivor Initiatives participating in this study are stretched to capacity. However, with a more adequate financial base, the Consumer/Survivor Initiatives could extend their range of activities to address the determinants of health and community capacities that are a necessary part of a recovery-oriented approach to mental health reform. Potential new directions for Consumer/Survivor Initiatives that could be supported through additional funding include:

- Peer-supported employment and education – the “supported” approach to employment and education, which has been implemented on a more widespread basis in the United States than in Canada, is an area in which Consumer/Survivor Initiatives could make a contribution. The philosophy of consumer choice and support underlying supported employment and education is quite consistent with the values of Consumer/Survivor Initiatives.



- Consumer-run housing – One innovation in the field of supported housing in mental health in Ontario could be the development of consumer-run housing. In Vancouver, the Mental Patients Association, a consumer-run self-help organization, has become a major provider of housing for people with serious mental illness.

Pilot projects in consumer-run housing and peer-supported employment and education could be funded by the Ontario Ministry of Health and Long-Term Care as innovations in mental health reform with an evaluation component.

Recommendation #4: Further Research with Consumer/Survivor Initiatives

With this study, Consumer/Survivor Initiatives have joined the ranks of intensive case management and ACT as evidence-based practice approaches to supporting people with serious mental illness.

- Since this study was limited to 4 Consumer/Survivor Initiatives in southwestern Ontario, further research is needed to determine the generalizability of the positive findings of this research to other communities, especially Consumer/Survivor Initiatives in rural and northern communities.
- Based on the experiences of the stakeholders of this research, it is imperative that further research with Consumer/Survivor Initiatives be done using a participatory action research approach that is consistent with the values of Consumer/Survivor Initiatives.
- Another direction for further research with Consumer/Survivor Initiatives would be to develop a mentoring and training program in which consumer/survivors and Consumer/Survivor Initiatives develop the capacity to conduct their own research investigations.
- Finally, research and evaluation could be conducted on new Consumer/Survivor Initiative directions and innovations, including pilot projects on supported employment and education and consumer-run housing.



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