Northern Initiative for Social Action: An Occupation-Based Mental Health Program

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Northern Initiative for Social Action (NISA) is a consumer-run, occupation-based, nonprofit organization located in northeastern Ontario, Canada. The NISA organization has grown in response to research revealing few opportunities for participation in personally meaningful and socially valued occupation for persons with mental illness living in the community of study. This article describes a mixed-design research study conducted by the ParNorth Research Unit of NISA and an occupational therapist. The study purposes were to (a) better understand the emerging characteristics of the NISA program and identify which the participants found helpful; (b) evaluate whether participation in NISA improved members’ quality of life; and (c) ascertain whether participation reduced members’ need for more traditional and costly methods of care (e.g., hospitalization, crisis services).

Focus groups, daily participant observation, a quality of life interview, a consumer member survey, and objective review of hospitalization data were used for data collection. Qualitative results indicated that NISA helped to meet participants’ being, belonging, and becoming needs. Quantitative data indicated that overall, NISA members perceive an improvement in their subjective quality of life and sense of well-being. Their perceptions are supported by minimal use of crisis services and hospitalization, improved socioeconomic status, and several members’ success in obtaining paid employment either within or outside NISA.

Future challenges include the need to clearly describe the evolving NISA model and to ensure that the growth of this new organization does not exceed secured human or fiscal resources.


Mental health reform has been active for many years, especially in the United States. The literature identifies consumer initiatives, peer support, and consumer-run businesses as viable and effective alternatives to traditional services. Service providers are encouraged to provide services that directly involve consumers, that empower consumers to help themselves, and that assist consumers to move beyond the mental health system and to participate within communities of choice to their fullest capacity.

The occupational therapy profession seeks to enable the participation of people in chosen meaningful occupations within chosen environments regardless of disability, impairment, or handicap. Until recently, few empirical studies supported the use of occupation as means to mental health (Rebeiro, 1998) or provided evidence-based out-
comes to guide clinical practice in mental health. Several articles in the mental health literature assert the importance of occupation for persons with mental illness (Church, 1997; Mueser et al., 1997; Rebeiro, 1999; Rogers, 1998; Scheid & Anderson, 1995; Trainor & Tremblay, 1992; Van Dongen, 1996). Most view the issues of occupation, or work, from a personal problems or illness perspective (Jongbloed & Crichton, 1990; Mills, 1959) rather than reflecting a systematic examination of why occupation has not been more highly valued in mental health policy and practice. The literature supports positive relationships between occupation and mental health and well-being, subjective quality of life, self-esteem, and identity, yet very little movement has occurred in either policy or practice to fully realize the potential benefits of occupation within the community for persons with mental illness (Bray & Rebeiro, 1998; Legault & Rebeiro, 2001; Mallik, Reeves, & Dellario, 1998; Rebeiro & O’Brien, 2000; Rogers, 1998; Scheid & Anderson, 1995; Simmons, 1992; Trainor & Tremblay, 1992; Wahl, 1999; Wasylenki, 1989).

Northern Initiative for Social Action (NISA) is a local solution to the implementation of both occupational therapy philosophy and mental health reform ideals. This article describes a recent mixed-design research study conducted by an occupational therapist and consumer members of NISA, who are also coauthors of this article. The purpose of this study was to evaluate an evolving, occupation-based, consumer-run, mental health initiative. The article briefly reviews the literature to establish the background for assessing the NISA program and the relevance of the results. Implications for community-based, occupational therapy practice are offered.

**Mental Health Reform and Human Occupation**

Mental health reform has provided many challenges and opportunities for mental health care professionals, consumers, families, and policymakers. The ideals implicit in reform include having persons with mental illness live and work within their own communities. These ideals have been strongly advocated at many levels but, unfortunately, have been slow to realization. Community inclusiveness, acceptance, and full participation for all citizens remain ideas that many perceive will not occur without a dramatic and far-reaching overhaul of the mental health system; the paradigms that govern it; and, most certainly, the community (Simmons, 1992; Trainor & Tremblay, 1992; Wahl, 1999; Wasylenki, 1989).

Consumers, mental health professionals, families, and policymakers support a reformed mental health system that is client-centered and addresses issues of importance to consumers (Ministry of Health, 1988, 1993, 1999). Why, then, has the system been slow to realize the ideals of community integration for persons with mental illness and the expressed needs of this population? The first factor may be the current organization of power and decision-making structures within mental health systems and the government bodies that fund them (Simmons, 1992; Townsend, 1998). A second factor may be the actual economics of transferring mental health dollars from institutions to the community (Church, 1997; Lurie & Trainor, 1992; Mallik et al., 1998; Wasylenki, 1989). Lurie and Trainor (1992), for example, stated that “despite mental health policy in Canada being increasingly focused on community care for persons with a serious mental illness, there is concern that, in many provinces, mental health systems have problems with service coordination, resource allocation and priority setting” (p. 11). The discrepancy between policy and funding practice may contribute to a reluctance by governments to transfer dollars to consumer-run organizations to fund their own solutions.

Current social service and disability policies may also contribute to the problem, as when consumers discover that their attempts to participate in any occupation-based programs may in fact jeopardize their basic income security (Church, 1997; Mallik et al., 1998; Trainor & Tremblay, 1992). Mallik et al. (1998) examined perceived barriers to community integration for persons with psychiatric disabilities and reported that limited “employment opportunities and available resources to find, get and keep a job presented the greatest obstacle to community integration” (p. 178). Mallik et al. advocated for flexible funding policies that allow for employment resources for persons with a psychiatric disability. However, they conceded that this task would be a formidable one in an era of managed care in the United States because “vocational services are not typically included in medical necessity criteria that emphasize symptom control with interventions based on a medical model” (p. 178).

Trainor and Tremblay (1992) cited reduced recidivism and less reliance on traditional supports as compelling evidence of cost-effective approaches that deserve policies in support of businesses and programs run by mental health consumers. They suggested providing for secure and ongoing financial support, technical assistance, flexibility in working hours, and addressing the issue of economic disincentives as necessary steps to ensuring the success of consumer-run businesses.

A final contributing factor to meeting the challenges of mental health reform within the community and, ultimately, an individual’s successful participation in chosen occupations is stigma (Clark, 1995; Penn, 1998; Rebeiro & Allen, 1998; Wahl, 1999). Mental health consumers experience stigma from a variety of sources; their self-esteem is adversely affected by stigma; stigma management in the community wastes energy that could be directed toward participation; and despite recent advances in the treatment of persons with severe mental illness, their full integration into society remains hindered by lingering negative attitudes toward them (Penn, 1998; Wahl, 1999).

In summary, the literature strongly supports occupation, or work, as a means to bridge the ideals of mental
health reform for persons with serious mental illness and as a means of enabling these persons' reintegration in their communities (Bray & Rebeiro, 1998; Estoff, 1989; Mueser et al., 1997; Perese, 1997; Rebeiro & Allen, 1998; Rogers, 1998; Scheid & Anderson, 1995; Trainor & Tremblay, 1992; Van Dongen, 1996). Sadly, despite fairly compelling evidence, policy and funding support for programs that encourage participation in occupation has been slow to materialize. If the policy goal of mental health reform (and the aim of community-based mental health practice) is to improve the quality of life and well-being of consumers, to reduce the need for hospitalization and other costly services, and to empower consumers to become self-sufficient, then occupation must become a more integral focus of future policy, funding, and program initiatives.

Method
Research Design
A mixed research design was selected for the study for two reasons. First, mental health, illness, and recovery are subjective experiences and are most appropriately elicited with open-ended questions and exploratory and flexible qualitative designs (McCracken, 1988). Second, because the NISA program was in its early development when the study began, it was important to solicit and explore the program participants' experiences to further develop and define the program. The use of focus groups and participatory observation (Jorgenson, 1989) are appropriate methods with which to learn about an emerging, yet still undefined, consumer initiative program. Quantitative methods augmented or supplemented the qualitative data. These measures were used with the explicit purpose of providing requisite evidence to funding and policy sources. The Lehman Quality of Life Interview (QoL, Lehman, 1988) was used to measure the research participants' quality of life at baseline (T1) and every 6 months during the study period. In addition, a consumer member survey was also administered at baseline (T1), 6 months (T2), and 12 months (T3); the survey items addressed subjective quality of life, program satisfaction, mastery, and empowerment. Membership forms, a basic demographic sheet, and hospital records provided information on diagnosis, last hospital admission before starting NISA, psychiatric services and medications, and employment and educational histories.

The Research Team
The research team consisted of an occupational therapist and four consumer members of NISA active in the ParNorth research unit. The ParNorth program at NISA seeks to provide practical experience in conducting research and to answer research questions of interest to mental health consumers. One of the four co-researchers has had previous research experience. All co-researchers functioned as participant observers throughout the study period, actively participating in all focus groups and in data analysis meetings. The research design allowed for extensive input from the consumer co-researchers, and multiple sources of data were brought to bear on the final results.

The NISA Program
In 1998, NISA was established as a nonprofit, consumer-run charitable organization grounded in occupational therapy research. The program was further developed by marrying occupational therapy philosophy with local mental health consumers' needs and goals. Currently, NISA is partially funded through the Northeast Mental Health Centre for a small operational budget, including the occupational therapist's position and facility costs. The five paid staff positions at NISA are funded by an Ontario Trillium Foundation grant. NISAs objectives are to provide a safe and supportive work environment for persons with persistent mental illness, to permit regaining confidence and skills, to provide opportunities for participation in personally meaningful and socially valued occupations, and to support and empower members to become contributing members of society. An environment in which all persons are considered equal and capable, the empowerment of consumers to evaluate and direct their own solutions, and the use of occupation, are the cornerstones of the NISA program.

NISA strives to provide a working environment that is flexible enough to meet individual and collective goals. The program aims to awaken consumers' capabilities through its variety of initiatives and by actively participating in and contributing to the social fabric of the local community. The following programs are currently at NISA:

- The Writer's Circle, which publishes Open Minds Quarterly, a journal of mental health writing, viewpoints, and consumer experiences, and its counterpart, The Writer's Circle Online, a smaller Internet publication
- ParNorth, a participatory action research unit
- Warm Hearts/Warm Bodies, a program that makes patchwork quilts for persons who are homeless
- The Artist's Loft, which provides opportunity to participate in the fine arts and to exhibit in community settings
- Northern Computer Recycling Depot, which services and repairs used computers and donates them to persons in need
- The Community Kitchen, a program focused on meeting members' nutritional needs

In addition, NISA informs the public of the talents and creativity of consumers of the mental health system by fostering their participation in the community and through the expression and promotion of their life experiences. For a more detailed description of these programs, the reader is encouraged to view the NISA Web site at www.nisa.on.ca.
Currently, NISA has 38 participants, with an international outreach to more than 400 consumers through the Internet site and Open Minds Quarterly; of its local participants, 42% have schizophrenia; 16% have bipolar affective disorder; 23% have chronic depression, and 19% have other conditions. Eighty-four percent of the people who attend NISA are currently seeing a psychiatrist; 81% take some form of medication; and 85% live on supported income. Seventy-one percent of NISA participants had an admission to the hospital within 2 years before their starting NISA. Since attending NISA, members have collectively accrued only 3 inpatient days. Six members have moved off supported income since beginning participation at NISA.

Data Collection

Data were collected from a variety of sources. A focus group was held every 6 months over the 2-year study period, for a total of four sessions. Nine to 11 NISA participants comprised the focus groups, which were led by the occupational therapist. The research questions that guided the first and subsequent focus groups were: Why did you initially come to NISA? and Why do you keep coming? Subsequent focus groups were guided by the emerging categories and themes generated during data analysis. All sessions were audiotaped and later transcribed for analysis. One of the consumer researchers collected the data on the basic demographic information form, the consumer member survey, and the QoL before each focus group. Personal journals were kept by most members of the research team. The ideas and reflections contained in these personal journals were shared during data analysis sessions. The occupational therapist maintained a methods log throughout the study period and documented any changes to the original design as insights became available to the team. Basic data on hospitalization rates, medications, involvement with psychiatry, and other traditional mental health services have been tracked by the occupational therapist since NISA’s inception.

Data Analysis

The open conceptual coding method of data analysis as described by Strauss and Corbin (1990) was used to analyze the qualitative data collected in the focus groups. The focus group transcriptions were reviewed separately by each member of the research team and coded using preliminary categories. The field notes and personal journals were discussed in analysis sessions with the team. Analysis meetings were convened twice a week to discuss individual observations and emerging ideas. Analysis was circular and iterative, with an ongoing review of the data until an explanatory theory began to emerge. All participants reviewed the final analysis and confirmed it as credible in the third focus group meeting. A fourth member-checking meeting was convened with participants to review the study findings and to explore some of the discrepancies between the qualitative results and quantitative data.

The quality of life and consumer member survey results are provided as descriptive data. The small group of participants (n = 10) precluded the use of inferential statistical analyses, and data are presented for the purposes of discussion only. All NISA members (n = 38) contributed to the study results by virtue of their participation at NISA and the extensive participant observation throughout the study period.

Results

Qualitative Results

The qualitative (participant observation, focus groups, journals, methods logs) data analysis yielded three major themes that assisted in answering the research questions. Specifically, these results highlight and describe how NISA helps to address participants’ being, belonging, and becoming needs. These themes parallel and support the current occupational therapy theoretical literature, which suggests that being, belonging, and becoming are integral, necessary, and explanatory aspects of practice (Fidler & Fidler, 1978; Renwick & Brown, 1996; Wilcock, 1993).

Participants clearly indicated that they came to NISA because they had not successfully identified a place within the community with a congenial social environment, specifically that which was free from stigma, or the opportunity for “real work,” including opportunities for paid employment. Participants continue to attend NISA because they feel unconditionally accepted for who they are and a sense of belonging and because occupational opportunities exist to meet both individual and collective goals. In particular, NISA provides opportunities that address the questions, “Who am I?” “Where do I belong?” and “How do I become a whole, respected person in my community?”

The terms being, belonging, and becoming refer to specific levels or aspects of participation, and although not used exactly as presented in the occupational therapy literature, they were a natural fit with the data and analyses. Thus, these terms were used conceptually to frame the emerging analyses after the second focus group and were member checked during the third focus group. A description of each theme is provided and supported by excerpts from the focus group transcripts, analysis notes, and personal journals.

Being needs. Participants stated early in the research process that since becoming members of NISA they have had a “rebirth experience” with respect to their illness and identity. Members suggested that this internal process was very personal and hard to describe. Being needs, as expressed by the participants, are about self-love, about perceived self-worth, and “about a basic right to exist, to just be me.” Often, participants did not feel worthy of being
involved in the community because of pervasive stigma and their own low self-esteem.

Being needs are also about a rediscovery of oneself, many times in redefining oneself as an unqualified "person" versus a person with a psychiatric disability. Being needs are about allowing oneself the time to recover, as Leslie¹ explained:

I never had the opportunity to feel like I had something to contribute. Here, my needs are heard. I've always felt like I had to prove myself...and here I don't have to do that. I can be myself. At NISA, I am given the freedom to be me, with whatever wrinkles, quirks, or imperfections I may have. At NISA, it is ok to be here and to exist. I'm allowed to just be me, and this is very important when I feel the world is closing in on me. NISA often reminds me that I need to be compassionate towards myself, which is an ongoing struggle.

Participants spoke extensively about their initial and continuing difficulties in participating at NISA and about their need to continue to attend. After much discussion, it was discovered that until being needs had been addressed, participants found it difficult, if not impossible, to be actively involved in program initiatives. Clearly, their energy was being directed inward, addressing, most likely, the internal, rebirthing needs identified in the first focus group. Participants spoke of their internal struggles in meeting being needs and of the process of coming to self-acceptance, self-love, and self-worth. For example, Celia said:

The people here believed in me more than I believed in myself, which gave me the drive to keep coming. That's something new for me. Acceptance of others and of myself. I didn't have in myself the self-worth or the trust or even the thought that I would be able to give and be constructive to society again. NISA had faith in me where I had none. It's nice when you're not criticized for feelings or punished. You can screw up and that's fine. It's not what I do that makes me who I am. It's nice when you're not criticized for feelings or punished. You can screw up and that's fine. It's not what I do that makes me who I am. I've always felt like I had to prove myself, and here I don't have to do that. I can be myself. It means that people respect me and that I can be constructive to society again. The belongingness here has been very much at the heart of things for me. If I don't feel like I belong, then I can't begin anywhere. If I don't belong, I don't exist really.

Belonging needs. Interwoven with being needs are those for a place to go, a place to gather, and a place to belong. Participants cited several aspects of the environment as reasons why they continue to come to NISA. First was the element of choice. Participants are told that they do not have to come to NISA, and if they do, they can come as often or as little as they want. Additionally, their participation is self-directed; they determine what they will participate in and at what level.

Second, the environment is physically and emotionally safe. A safe environment is crucial to the process of healing and recovery as well as to addressing one's being needs: “NISA is one of my safe places when being with me is not,” says Bev. She considers NISA to be like a family and a place where members can belong: “I had a childhood where I felt I didn't belong. I didn't have a voice. That does a lot of damage. I feel I belong here more than I do with my own family.”

Finally, the provision of both private and community space fosters a sense of belonging. Participants stated that private space is necessary when addressing being needs, but the opportunity to visit others and to meet in more public spaces was important to addressing their social needs, for helping to form a group identity, and for meeting belonging needs. Actually, private space can be interpreted as providing participants with a place to transform being into belonging: It provides a social, material recognition of being and becomes part of the physical matrix of belonging. For example, Doug explained:

At NISA we have a place prepared for us. We need to have a territory of some personal space around us that we're not going to get shoved out of in order to feel secure. I find NISA my home—there's acceptance here where there isn't in the larger community. What I get out of NISA is equally essential, is to feel that I belong, that I have a social existence. The belongingness here has been very much at the heart of things for me. If I don't feel like I belong, then I can't begin anywhere. If I don't belong, I don't exist really.

Becoming needs. Participants spoke about the limited opportunity for occupation within the community that was personally meaningful and that held social value. Originally, NISA was founded on research that revealed very few local occupational opportunities for mental health service consumers (Rebeiro, 1999). In our society, personal identity is based largely on occupation and economic activity, perhaps especially for men. Thus, participants' becoming needs are driven by a lack of opportunity elsewhere in the community, by their needs to be active and to contribute to the community as an aspect of personal fulfillment, and by the implicit questions of who am I and what can I do in this life? In the focus groups, participants shared how NISA fosters their becoming needs, which, in turn, helped to explain why participants continue to come. In discussing becoming needs, Frank spoke about the importance of meaningful work:

All of a sudden I had a reason, a focus. This helped to take the focus off of existence of life and gave me a purpose. You tend not to think so much of the negative, you know, suicide. I'm identifying myself that way, I like what I'm seeing in myself. I think I started becoming who I was supposed to be—just me. Before, I didn't have a sense of purpose, and that was leading to death, an inner death. Now I can say, "I'm working at NISA." There's still that stigma [that] unless you're doing something, you're a nobody.

Participants also spoke of flexibility of work schedules and the importance of determining their own opportunities as vital to meeting becoming needs, as Joanne explained:

There's no other place where you can make your own opportunities, your own mistakes, and allow you to grow from those mistakes, where you can work at your own pace and allow you to find your niche, your special ability. The stuff that I did here meant something. It was an important task. I had something to call my own, and that gave me my own strength.

Perhaps the most compelling findings of the qualitative data are related to how participants came to redefine themselves and their situations as a result of collectively meeting their being, belonging, and becoming needs at NISA. As Andre explained:

¹Pseudonyms are used to protect participants' identity.
I began to believe that anything that we set our minds to we can accomplish. With the help of NISA, this new person I’ve become is a winner. I feel ok about who I am now. I have my dignity, my pride; I think I’m special. When I come here, I forget about my mental state, my chemical imbalance in my head. I feel pretty normal here. The more I challenged myself, the more I started to feel better about myself.

QoL Interview Results
The quality of life data are for descriptive purposes only because of the small sample size (n = 10) and revealed some interesting findings. For example, on the QoL interviews, all but two scores (i.e., domains of daily activities, legal and safety) improved over time and either approached or met the level of being mostly satisfied. Examination of the group means over time indicated that both social relations and finances were the most improved areas with the greatest percentage differences. A review of the data trends shows that both standard deviations and variances have consistently decreased over time, with a tendency for the individual scores to approximate the group means.

Consumer Member Survey Results
The consumer member survey measured change in the domains of subjective quality of life, empowerment, mastery, and program satisfaction. The subjective quality of life variable showed the greatest percentage change, and empowerment showed the least change, actually decreasing over the study period. The score trends show movement toward a positive change, and similar to the QoL variables, scores tended to show less variability and a decreased standard deviation over time.

A review of the quality of life variables indicated that the group means improved in five of the eight Lehman QoL domains. In the consumer member survey, the group mean scores improved on the variables that addressed subjective quality of life and program satisfaction, remained unchanged in mastery, and decreased in the empowerment, although still being rated with agreement.

Review of participants’ hospitalization and use of crisis services was encouraging in that one participant was hospitalized for 3 days, and of the other 37 NISA members at the time of the study, none were hospitalized or used crisis services during the 2-year study period. Many members have previously had at least one hospitalization per year, with an average length of stay of 6 weeks.

Discussion
This study defines the importance of being, belonging, and becoming needs to participants at the NISA program and helps to explain continued attendance. Of interest to occupational therapy practitioners is the discovery of the importance of meeting clients’ being and belonging needs before and concurrently with enabling occupational performance. This finding may help to explain client immobility or a lack of occupational engagement in clinical situations where the need to provide opportunity, versus prescribed treatment (Rebeiro & Cook, 1999; Rebeiro, 2000), has been considered. Further, the findings begin to explain how occupational therapy goals of enabling occupation require an appreciation of both the person (being needs) and the environment (belonging needs) and shed light on the importance of being and belonging needs to fostering becoming needs and quality of life.

The study also highlights the importance of social support, specifically how a safe, flexible, and supportive work environment can foster the occupational capabilities of consumers of mental health services. This study’s contribution to the knowledge base may lie in its further explication of those aspects of the environment that participants found helpful in establishing a sense of self and of community.

The study participants strongly suggested that the sense of community, family, and belonging at NISA were essential to meeting both being and becoming needs. As Doug had explained, “If I don’t have a place to belong, I don’t exist really.” Sadly, both NISA participants and previous research (Rebeiro, 1999; Rebeiro & Cook, 1999) perceive a real sense of community as nonexistent in the larger community. The present study would lead us to suggest that a continued absence of community is a barrier to meeting consumer’s being, belonging, and becoming needs and, ultimately, to their pursuit of, participation in, and enjoyment of occupation.

NISA represents an experiment in rethinking some of the usual ground rules of psychosocial rehabilitation. The program has developed as a dialogue among an occupational therapist, service providers (as initial hosts and sponsors of the program), and consumers to redress some of the failures and shortcomings of other community services. In the present study, we attempted to document the working of the NISA program and measure its effectiveness by asking why participants originally came to NISA and why they have continued to attend. Among the responses, the research team recognized a significant theme of mental health consumers exploring the community, searching for supportive social and economic resources, and seeking activities that could occupy their time and give meaning and structure to their lives. In other words, members typically came to NISA because they were not engaged in regular daily activities in the community and because the regular community supports were not adequate to satisfy their social and economic needs. The full range of benefits of NISA membership that focus group participants included were such diverse considerations as the availability of free food for lunch, social interactions and attachments, and the opportunity to learn new skills and do meaningful work. This reflects not only the range of needs that mental health consumers experience in the community, but also that the open-ended design of the NISA program allowed diverse needs to be recognized and addressed.
In analyzing focus group data, we adopted the terms *being*, *belonging*, and *becoming* to summarize different significant aspects or themes within the continuum of participant responses. Being needs had to do with individuals’ right to exist, to be who they were, and to look for support of their basic living needs. Belonging needs had to do with social interaction, support, and friendship. Becoming needs were about issues of skill development, the ability to work, and the prospect of economic viability.

Being, belonging, and becoming needs may be considered in different ways. For example, as a developmental series, being represents fundamental survival issues, belonging addresses socialization, and becoming deals with maturation and self-sufficiency. In the community, these concerns exist simultaneously. The NISA model, as it has evolved since 1998 and as reflected in our research data, recognizes that meaningful psychosocial rehabilitation must take account of all three levels of needs and that the need each consumer feels at the present time is relevant to progress and future success.

Asen (1986) argued that deinstitutionalization of psychiatric patients is based on a false assumption that a community exists to which they can return (at least not over the past 100 years). That is, the traditional structures of family and neighborhood that might once have offered support and continuity have been dissolved in the processes of geographic and social mobility and economic and technological change. Therefore, the present-day geographical “community” is no longer a meaningful framework of support for psychosocial rehabilitation.

Additionally, this study and previous research (Rebeiro, 1999) suggest that current community programs provided for mental health consumers in the modern noncommunity are only a substitute for real acceptance as real persons in the community (whether it is really a community or not). Thus, any refusal on the part of mental health consumers to join the current programs may be based on the unspoken understanding that what is being offered is only a substitute for what real, adult, socially acceptable people would expect and that by accepting the substitute, one would have to accept a definition of oneself as less than real.

Therefore, two related problems exist in trying to run meaningful community-based programs for psychosocial rehabilitation that current research attempts to address: (a) the fragmented, nonsupportive structure of communities (Rebeiro, 1999) and (b) the systemic hypocrisy of segregating persons with mental illness within the community and perpetuating both social and internalized stigma (Clark, 1995; Penn, 1998; Wahl, 1999) by “qualifying” clients on the basis of disability and offering underfunded programs (Lurie & Trainor, 1992; Trainor & Tremblay, 1992), inadequate economic supports (Church, 1997), and unconvincing substitutes for meaningful social or occupational opportunities (Rebeiro, 2000). By both the need to offer supports and the kind and quality of supports provided, community programs may serve only to distinguish their clients from the “real people” in the community.

Our experience at NISA suggests that these difficulties may be addressed by redefining the fundamental problems recognized in society. Members’ problems are not defined or assessed in terms of diagnosis or disability but, rather, in terms of social and economic opportunities. This study suggests that NISA helps its members to address a broad range of their being, belonging, and becoming needs. The program permits its members to become a sort of extended family, replacing or supplementing many of the supports that are missing or deficient in the larger community. Rather than judging members on their failure to achieve careers or maintain relationships in the “real” world, the research highlights the ways that dysfunctional social and economic systems waste human resources by dividing people into “winners” and “losers.” The study findings suggest that NISA helps members to enjoy a richer life in the community and that as an organization, may in fact help the community rediscover itself.

References


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