

CENTRE NEWS REPORT

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Advocacy in Institutions and the Community

We live in an era where advocacy has gained prominence. Advocacy in its simplest form is as old as human history -it is about people "pleading the cause of another." Historically, people "sticking up for each other" has been grounded in voluntary, highly personal commitments and actions.

Advocacy in our complex society is increasingly becoming professionalized. Recent work by the Centre in this area has shown that professional advocacy is double edged.

On the one hand, the appointment of paid advocates to carry out the instructions of residents in institutions creates an important support structure for some of our most powerless citizens. The effective advocate in such settings promotes self-advocacy, helps the person mediate and negotiate with an array of professionals, and whenever necessary, lobbies and confronts those in power to make appropriate changes.

On the otherhand, the growing movement to assign advocates to institutions and to our communities to "protect vulnerable people" also raises some inherent contradictions. First, we must remember that the substantial issues in our service system require systemic reform; advocates who work only at the "individual" level may have little impact on systemic change.

Second, not everyone in a certain category (e.g. aging, mental disability, etc). is "vulnerable." In our haste to help, we must be most cautious about not labelling people who we think need advocates.

Third, and a related point, is the tendency to want to surround people with advocates, while ignoring the conditions that caused the need for advocates in the first place. Poor people, for example, may from time to time need people to help them access resources, but most of all they need money so they can acquire the resources they need to live in dignity.

Many people are "over-served," yet unconnected to community, power, or resources. These may be the individuals who most need advocacy, whether it be paid advocates, family or friends, or volunteer community members. Yet, if such advocacy only supports people to become "better consumers" of those services, it may be a way of maintaining people in a devaluing status. Somehow, a clearer vision of advocacy needs to emerge -- a vision that emphasizes the need to empower individuals to gain a sense of control in their circumstances, to access resources, and to be part of community life.

Centre Updates

Return to the Community - Major Study Released

"This study has far reaching implications for a variety of jurisdictions," said Deb Woods, Centre President, as the Centre released its long-awaited study on the closure of the Tranquille Institution. Entitled *Return to the Community*, the study was released in Vancouver on October 1.

Several strategies emerged from this comprehensive study for future deinstitutionalization efforts including:

- the important role which local voluntary associations and advocate groups can play in developing and implementing a family support strategy and a personal support strategy for people leaving institutions.
- the value of a decentralized, regionally based approach by government ensures that "community development and animation" can occur within each regional and community context.
- the necessity that governments re-allocate resources from the institution to the community and the fact that a "limited time frame" for a closure may in fact increase the possibility that this will happen.
- the need to expand our definition of community services beyond the "group home model;" people returning to our communities can become isolated within service systems unless attention is paid to support networks and ways individuals can be reconnected with their communities and families.

Followup to Institutional Closures Project

In conjunction with the new Centre publication, *Return to the Community*, a number of followup activities are underway:

- Centre staff have consulted with associations or governments in British Columbia, Saskatchewan and Ontario regarding *strategies* for current or future closures in those provinces.
- The Centre booklet, *Reuniting Families*, is an educational and support resource for families in the process of bringing a family member home from an institution. The booklet will be "tested" in British Columbia and one other province prior to formal release early in 1988.
- The Centre is hoping to continue to study the quality of life being experienced by former Tranquille residents, over the next two years.
- The Centre now has a *number* of people in its network who have vast experience in closing institutions and building community alternatives. Groups or individuals interested in consultation from the Institutional Closures Project staff or network, should contact John Lord at the Centre.

Advocacy Study Soon to be Released

The Centre study on advocacy in institutions will soon be released by the Ministry of Health in Ontario. The report: *Advocacy in Psychiatric Hospitals: Evaluation of the Psychiatric Patient Advocate Office*, is a comprehensive qualitative study; indepth interviews have captured both the context and dilemmas of institutional advocacy. This first study of institutional advocacy in Canada identifies the process of professional advocacy as well as the impact and structural issues of advocacy.

Friends of the Centre will be informed when this study is released.

Rediscovering Community- A Centre Workshop

On October 27 and 28, the Centre sponsored an invitational workshop in

Kitchener-Waterloo. *Rediscovering Community: A Workshop for People Committed to Community, Human Services, and Change* involved almost 40 service providers, consumers, and volunteers from the areas of aging, disability, refugee settlement, and mental health. The day and a half long event enabled participants to examine problems and issues with current services and to consider the role of community and informal supports in empowering "consumers" of human services. Case studies on self-help, consumer participation, community integration, and reallocation of resources from institutions to the community were starting points for participants to develop strategies which they could apply to new service roles or in their efforts at community change.

Friends of the Centre from other communities interested in this workshop process can call John Lord or D'Arcy Farlow at the Centre.

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POT - SHOTS NO. 2627.

IN A DEMOCRACY,
EVERY LITTLE WRONG IDEA
MAY GROW UP
TO BECOME
NATIONAL POLICY.



Ashleigh Brilliant

Self-Advocacy: A Personal Choice

"You are being discharged," the resident informed me. I had not been consulted, not even prepared, and I felt they were making a mistake. I phoned my family, my friend, and a volunteer with the Mental Health Association. People in my support network, including my local doctor, trusted my self-assessment; the resident started getting phone calls. New plans were made.

After the delayed discharge I asked the resident, "What did you think when my friends started phoning on my behalf?" Without hesitation, she responded, "If I got three phone calls about each of my patients, my job would be a lot easier." A note of lonely responsibility crept into her voice.

People with various disabilities or illnesses are often intelligent, creative individuals. Decision-making skills can be impaired by crisis or depression, but even worry can be channelled as a positive stimulus to consider all the possible options. Fortunately, my friends believe in my problem-solving ability even when I am withdrawn and unresponsive. They help collect information, pressure me into action, and assist with arrangements. If I can not advocate on my own behalf, I can delegate the phone calls.

My personal support network includes family, neighbours, friends, the local G.P. and hospital, and a city psychiatrist and psych ward nurse. More casual contacts include people met through church, community service, and recreation. A mutual trust has developed among my network to share support and information. Family and friends know back-up is available. And I think the professionals appreciate that they will be contacted when needed.

A year ago I told the family doctor that I wanted to find a new psychiatrist. He seemed surprised, "Why?"

"Because I've been working with him for more than three years and I don't think we've gotten anywhere." This decision would not have been initiated by either the G.P. or the specialist. No neglect or malpractice were involved so a formal patient advocate would not have had a case. But friends researched possible therapists, stood by me when I had a couple of disappointing trial appointments, and made phone calls when I was ready to give up hope.

My new psychiatrist asked, "What do we do right?" I grinned, "You put together an excellent team... and then you made me the head of it." The psychiatrist, social worker, and nurses supply their perspective and treatment tools. But unless I'm slacking off or avoiding real issues, they let me choose areas of my greatest concern for sessions. Follow-up by long distance probably pushes me and the hospital staff into planning independence. Together we develop strategies to foster self-reliance.

Consumers and service providers must communicate to balance independence and structure. Consumers should be encouraged to appreciate their own strengths as well as recognizing signs of trouble. Professionals should discuss alternatives for intervention preferred by the person in case the support network must make decisions. Consumers enhance their skill through routine and post-crisis evaluation with formal and informal support people.

Consumers can advocate for themselves and also ask others to intervene on their behalf. Always, the individual is the key member of the team that co-ordinates personal, community, and professional contacts to enable optimum health and independence.

Building and maintaining a personal support network is important for everybody. In this network, the "consumer" expresses many identities: spouse, friend, client, neighbour, fellow volunteer, co-worker, parent, child, advocate... These roles affirm the individual's contributions and abilities. In times of crisis or disability, *people need encouragement to develop the personal support network that empowers self-advocacy.*

Advocacy should assist individuals to define their own problems; to search out resources; to consider alternatives; to devise personalized solutions; to make decisions; to evaluate results; and to develop confidence in ongoing self-advocacy.

One of the rules of successful advocacy might be, "Don't do something; just stand there." Standing by may feel more time-consuming, risky and frustrating than taking action, but the role of advocate is to help people control their own lives. Decision-making can be lonely, but the point is that we do not have to be alone -- if consumer and support people work together. To illustrate, I will close with a recurring conversation with a special friend.

"See?" she smiles, "You figured out how to help yourself." And I reply gratefully, "But I couldn't have done it without you there listening?" Now, did she tell me or did I?

Jane White*
Flaxcombe, Saskatchewan
Friend of the Centre

*Another aspect of Jane's story, about building and maintaining her social support network, is more fully developed in a recent Centre/CMHA publication, *Participating with People who have Experienced the Mental Health System.*



K. Melberg Schwier

Some Thoughts on Structuring An Advocacy Program

When determining how to structure an advocacy program, one of the most important factors to consider is the potential for conflict of interest. Even if the conflict of interest is only a perception, the program's credibility can be seriously undermined if the advocate does not appear to have complete impartiality and independence when representing his or her client.

A review of the literature indicates that the potential for conflict of interest is one of the major deterrents to housing a formal advocacy program within the organization that both funds the program and provides clinical services to its clients. Simply stated, advocates should not be placed in the position of having to advocate or speak out against the very body that pays their salaries. Wolf Wolfensberger is quite emphatic on this topic:

Whenever advocacy is intended to be defined as constituting a social institution (in the form of advocacy agencies, citizen advocacy, ombudsmanship etc.) it must be structured so as to be maximally free from conflict of interest. If it is not so structured, then the social institution that is being established should be defined as not an advocacy institution, but as some other service quality safeguard (Wolfensberger, 1977, p. 20).

On the surface, this issue seems very clear. However, when the Centre recently evaluated whether or not the Psychiatric Patient Advocate Office (PPAO) should be funded by and report directly to the Ministry of Health, the whole question of an independent structure became rather murky. We discovered that conflict of interest was only

one of many elements that needed to be considered when deciding how to structure an advocacy program.

Another element, for example, is *ministerial cooperation*. If the program's relationship with ministry decision makers is a good one, then the risk of cooptation may be offset by the benefits of having some direct impact on systemic and legislative change. It can be further argued that clients' rights may be enhanced as a direct result of a close relationship between an advocacy program and the upper echelons of management (e.g. the Ministry). On the other hand, the very closeness of this relationship means that the program is somewhat dependent upon the good will and philosophical commitment of a few key decision-makers. A shift in political agendas or the transfer of Ministry officials could prove to be disastrous for an advocacy program's autonomy. Safeguards need to be in place to ensure that the value base of an advocacy program is not vulnerable to changing political winds.

An additional element that must be considered when designing an advocacy program is access to information, to clients, and to service providers. If the program operates within the government delivery system, there will likely be easier access to a client's records or documents than would be possible with an external advocacy program. The internal advocate will also be more readily available to respond to the day-to-day concerns of clients. While external advocates could be ensured a degree of access to facilities and clients through legislation, what cannot be ensured is the daily access to service providers. The advocate who works within the system has the opportunity to

use quick and informal methods to resolve clients' problems. External advocates, on the other hand, tend to use the courts more often because they lack the internal relationships that allow for low conflict resolution. At the same time, it should be recognized that the external advocate has a variety of strategies at his or her disposal. Pressuring various government contacts, or mobilizing consumer groups and volunteers, are all powerful methods of effecting change. However, the complexity of these methods may mean lengthy delays for clients who languish with their problems unresolved.

A final factor that should be considered when structuring an advocacy program is the orientation of the program. As noted above, external advocacy programs tend to resort to the courts on a routine basis, whereas programs inside the system are more likely to develop internal grievance mechanisms. This gives external programs the reputation of being more confrontational.

As a further consequence of their limited access to the system and their lack of knowledge of day-to-day concerns, external advocates tend to focus on legal issues at the expense of therapeutic and social complaints. Finally, studies have shown that the orientation of an advocacy program

closely reflects the goals of the sponsoring organization. It is suspected, for example, that the Psychiatric Patient Advocacy program would become too legalistic if placed under the jurisdiction of the Attorney General's Office.

In summary, there are many factors to keep in mind when determining how to structure an independent, yet highly effective advocacy program. Safeguards need to be built into the program to diminish the potential for conflict of interest, but at the same time it is important to preserve relationships with key players in the system. Access to information, clients, and facilities is critical if the program is to avoid becoming too isolated and legalistic in its approach. Finally, decisions have to be made about the orientation of the program. If it is to focus on social and therapeutic issues, the program's sponsoring body should reflect these goals.

Our work on advocacy suggests that structuring an advocacy program is not a simple matter. It is clear that consumers and advocates must carefully weigh several key elements in planning an advocacy program.

Dr Arcy Farlow
Centre Researcher

Eek and Meek



Collaboration in Research and Education

As most Friends and Associates of the Centre are aware, the Centre is concerned with processes whereby social change and human service alternatives may be identified and implemented. People connected with the Centre believe that qualitative research and community education must work together to maximize our understanding of social change and human service alternatives.

Collaboration is central to the Centre's approach to research and education. As qualitative researchers, for example, we shape and reshape the specific themes, issues, and questions of our inquiries in a recurrent cycle of on-site gathering, data review and analysis, and reflection. In this way, qualitative research may be viewed as a process of collaboration with the participants of the programme or the consumers of a service.

A second way in which collaboration takes place is in the design and ongoing support provided for the research process. This occurs when the researchers interact with a reference group or advisory committee that includes staff, participants, family members or knowledgeable individuals concerned with the issue, service or programme that is being examined. In most Centre research projects, a group works closely with Centre staff in designing the study and reacting to data being generated or reports being drafted. Centre staff have found that this "participatory" approach has greatly enhanced the research process and impact.

In a recent article, Eash (1985) suggests three trends related to evaluation research which reflect the increasing significance of collaborative

research. First, he suggests that 'transactional research,' which calls upon the researcher and client to work together throughout the project in order to solve the problems related to the research design will continue. The second trend is that evaluation research designs will evolve on an ongoing basis during the project rather than being established at the start of the project. Finally, the context in which the study occurs will be recognized through the involvement of interest groups in the design of questions and the development of findings. For example, the policy analysis papers produced by the Centre are undertaken in the spirit of collaboration. A number of people, knowledgeable in the policy area, come together to brainstorm, discuss ideas and develop a perspectus. The perspectus is written up and drafted and redrafted by the group until the analysis paper is finalized.

In two separate articles, De Bevoise (1986) and Lieberman (1986), suggest some principles and guidelines for conducting collaborative research. According to both researchers, collaborative research requires:

- some kind of organizational structure and/or administrative support.
- a small group of people who are willing to really contribute, to share in the 'trenchwork'.
- a sense of realism related to resources such as the time and energy required when people work together.
- a 'community of believers' in which enthusiasm, flexibility and a shared language helps break down traditional institutional barriers.

- the work be geared towards consumer satisfaction.
- an effective delivery and reception systems.
- initially activities propel the collaboration, not goals.
- large superordinate goals for collaboration become clearer after people have worked together.
- ambiguity and flexibility more aptly describe collaborations than certainty and rigidity.
- conflict in collaborative work is inevitable; it has the potential for productive learning.
- shared experiences over time build mutual trust, respect, risk-taking and commitment.

Centre staff, board and volunteers believe that collaboration is essential at all levels of the research and education process. As Lieberman (1986) has stated:

None of us, no matter what our position, has the answers to the complex problems we face. The more people work together, the more we have the possibility of

better understanding these complex problems and acting on them in an atmosphere of trust and mutual support.

In the next Centre News Report, Part 2 of this article will describe valuable contributions that collaborative research has made to the field of human services and some of the issues raised by the use of collaboration in human service research.

Mary McGeown
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Researcher.

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Attitudes Towards Elderly Persons: Integration May Be the Best Solution for Everyone

As we all know, elderly individuals represent an ever-increasing percentage of the population. I believe that all elderly persons have many interesting stories to share with us and that they are able to make a valuable contribution to our society. Why then, I wondered, do we institutionalize so many of our elderly people and apparently hold them in relatively low esteem?

The attitudes which we hold toward a particular group of people affect the way we will treat individual representatives of the group. These attitudes are also frequently translated into policies which will affect all members of the group in question. However, these policies then function to further reinforce and perpetuate these attitudes. For example, if we force individuals to retire at the age of 65, segregate them in old age or nursing homes, and do not allow them to participate fully in our society, we are reinforcing the perception that older individuals have nothing of value to contribute to our society.

Sorgman & Sorensen argue that both the popular media and scholarly articles reinforce the theory of "disengagement". This theory postulates a process whereby the aged person and society cooperate in a process of mutual withdrawal from each other. However, these authors point out that there is little empirical evidence to suggest that disengagement is an outcome desired by most elderly people. Rather, it may be the result of living in a society that provides its elderly members with few alternatives.

My recently completed Master's thesis explored the relationship between interpersonal contact with elderly individuals and attitudes toward elderly persons. The following results speak in

favour of more integration of elderly persons.

- the "quality of contact with the most familiar elderly individual" is a significant predictor of attitudes.
- people participating in multiple activities with an elderly individual have substantially more positive attitudes than people who participate in only one activity with an elderly person.
- "talking" was the activity mentioned most frequently by young people involved with an elderly person. Almost half of the respondents reported engaging in multiple activities, usually mentioning: talking, eating, shopping, and playing cards—in that order.

These are all quite ordinary, everyday activities. They indicate that elderly individuals engage in the same types of activities as do the rest of us. These results, as well as the literature addressing cross category membership, reinforce the argument that *perceiving an individual in a number of different roles decreases the chance that stereotypical or extreme, one-sided attitudes will be held toward him or her.*

One of the best ways of reducing stereotypical perceptions regarding elderly persons, then, may be to integrate them more fully into the community and society at large, rather than segregating them into nursing homes or retirement communities. Segregating persons typically leads to heightened awareness of the differences between "them" and "us", whereas integration allows us to gain some appreciation of the fundamental similarities shared by all members of a community.

An individual does not suddenly become a totally different person when he or she reaches a particular age or stage in life. Rather, as indicated by the results of the present study, they continue to derive enjoyment from very much the same activities that they have always participated in. This argument is also supported by Matthews' 1983 study of friendships which indicates that individuals generally do not change their preferred "style" of life.

In conclusion, the type of contact that would lead to the most favourable outcome regarding attitudes towards elderly persons may be contact taking place in the community in the context of ordinary, everyday activities. From the literature on ethnic relations, however,

we have learned that such integration must be sanctioned by institutional support. In other words, if individuals perceive contact with members of another group to be undesirable in the eyes of the larger community or of society, they are less likely to initiate any such contact. Expanding community experiences for elderly persons, while developing constructive social policy and legislation, have the best chance of impacting attitudes towards elderly persons.

Annette Bauman
Centre Reseacher (part-time)

"It's in everyone of us to be wise."

Ann Mortiffee

"The capacity to care is the thing which gives life its deepest significance."

Pablo Casals

News Report Notes

- A recent article in the New York times says a great deal about elderly people in our society. An older couple who had committed suicide left a note regretting that they had ended life "under cover of darkness." The rising suicide rate among elderly persons may reflect the incredible alienation felt by many older people. This alienation is understandable, given the degree of poverty and institutionalization among older Canadians.
- A common complaint from human service managers is, "I don't have time." Many of these same managers will have been adding computers and other technology designed to give them more time to be innovative and reflective. Right? Wrong! In a startling new book entitled *Time Wars: The Primary Conflict in Human History*, Jeremy Rifkin shows that, as technology and "time-saving" devices have increased, our time dimension has accelerated rapidly. We go faster and faster, with more and more tasks to fulfill. In an equally important book called *Diffusion of Innovations*, Evertt Rogers points out that the development of innovations requires time, careful planning, and collaboration. Is it any wonder that human service managers who are under intense pressure to embrace technology, efficiency, and speed, are seldom able to develop and implement innovation in human services.
- Belief in the institution or asylum continues to be held by many people in the mental health field. Yet strong evidence is emerging from Europe and the United States that former institutionalized residents have improved their functioning over time when living in the community. The most recent study by Harding and his associates was based on a 32 year longitudinal study in Vermont. See *American Journal of Psychiatry*. (1987; pp. 144; 727-735).

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