

CENTRE NEWS REPORT

Centre for Research & Education in Human Services

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Community Integration

Since the Centre's inception, community integration has been one of the themes guiding Centre research and education. In the last decade, community integration has been increasingly articulated as both a goal and process for a variety of citizens.

Community integration as a goal expresses the desire of disadvantaged and marginalized groups to participate in the culture, to access needed resources, and to be accepted as valued citizens. Older adults, people with disabilities, women, and refugees all feel a minority group status which limits their integration. True integration challenges our neighbourhoods and our community organizations to involve people as citizens and equal members. Centre work suggests that when the goal of integration is met, people's sense of control in their lives is enhanced. Feelings of powerlessness are reduced.

Understanding the process of community integration has been more problematic. Many human service agencies, such as schools, residential services, and family support services have espoused the language of integration. Some service providers have begun to recognize and act on the importance of linking people with the resources and supports they need to participate in a range of community experiences. Our work suggests, however, that most service providers have not yet internalized either the goals or a process of integration.

In part, this sense of inertia results from vested interests. It is not uncommon, for example, for school special education departments to feel hesitant about integration; there is the fear of losing status and influence if all of one's "clients" become integrated.

Another perspective suggests that service providers, like many others, simply do not believe it is possible or desirable to facilitate integration, particularly with individuals who have more complex needs. The status of "client" for some people is thus valued and protected.

Increasingly, innovation in human services is characterized by strong leadership that is committed to community integration. For services that want to move beyond the language of integration, these pockets of innovation create vital settings for learning. It is becoming clear that people change their perspective about integration primarily by seeing alternatives and sharing ideas with people who have made it work. As Centre projects have continually demonstrated, the individuals and families who have experienced integration are the strongest allies in this educational process.

In this Centre NewsReport, we share resources and examples of some of the critical dimensions in the process of community integration.

Centre Updates

Return to the Community Generates Widespread Interest

Return to the Community, the Centre study on the process of closing an institution, has generated widespread interest across Canada and internationally. The study seems to have captured for people the essential issues in deinstitutionalization. The varied perspectives and stories have been particularly appealing to a range of readers. Several groups in at least three provinces are currently using *Return to the Community* as a basis for information sharing, education, or planning.

The popular media have also picked up on the themes of this Centre work, including a three-part series on Peter Gzowski's Morningside on closing institutions. Centre staff are responding to requests about the key issues on institutional closures and are designing some followup work to the closure study.

ReUniting Families: A Resource Guide for Family Involvement in the Closing of Institutions

This new Centre booklet is based on the information gathered for our institutional closure study. It chronicles the journey of several families from the time of hearing about the institution closing, to the actual move and community living of their family member.

Family involvement during the deinstitutionalization process is of vital importance. This booklet will be a resource for professionals and volunteers to share with families who are struggling with dilemmas and difficulties of an institutional closure.

Published by the Family Support Institute in British Columbia, copies are

available from the Centre for \$8.00 (\$6.00 for Friends of the Centre).

Advocacy Study Released

The long awaited Centre study *Advocacy in Psychiatric Hospitals: Evaluation of the Psychiatric Patient Advocate Office* was released in early February in French and English.

This comprehensive, qualitative evaluation describes the process of individual and systemic advocacy in ten psychiatric institutions in Ontario.

Highlights of the report include:

- the effectiveness of professional advocacy
- the impact of advocacy on individuals and policy
- the dilemmas of structuring an advocacy program.

This study is available free from the Queen's Printer, Toronto, or for \$5.00 from the Centre to cover postage and handling.

Support Services Review

The Centre is currently engaged in a comprehensive review of support services for adults with physical disabilities in Ontario. This Review will collect a wide amount of information from consumers, service providers and community groups. This Review will explore attendant care, the

most effective ways to provide personal support, and the role of individualized funding in human service delivery. The Review is expected to be released this summer by the Ontario Ministry of Community and Social Services.

New Projects-Empowerment and Supported Work

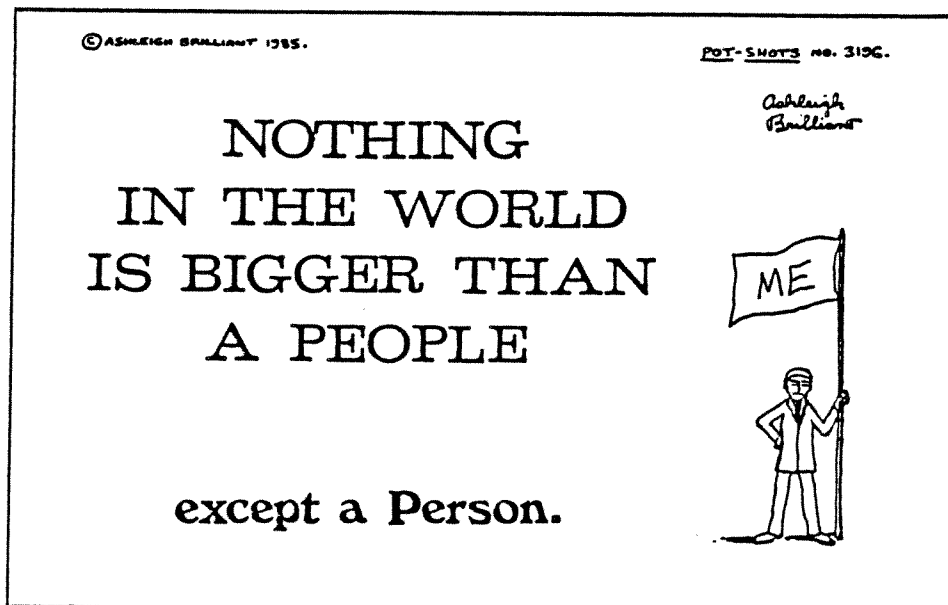
Over the next year, the Centre will be initiating two new projects related to the Centre themes of self help and community integration.

The *empowerment project*, which is expected to be a long term study, will initially try to develop more understanding about the process of personal empowerment. We are interested not only in the process whereby some people move from a state of dependence and powerlessness to political awareness and assertiveness, but also what factors seem to assist people in the process. Further down the road, we would

expect to develop more practical materials and resources which may assist community based groups and human services to provide support for the empowerment process.

Our second new initiative, a *qualitative study on supported work*, will initially examine a small number of individuals who have been "successfully" supported in regular employment settings. The goal will be to determine how integrated employment contributes to people's quality of life. Again, we hope that this supported work initiative will be the beginning of more extensive work in this area.

Centre for Research & Education in Human Services. P.O. Box 3036, Station C, Kitchener, ON N2G 4R5
519-741-1318 **Board of Directors:** Deb Woods, Peggy Hutchison, Frank Maidman, Theron Kramer, Harvey Savage, Judith Sandys, Beth Moore
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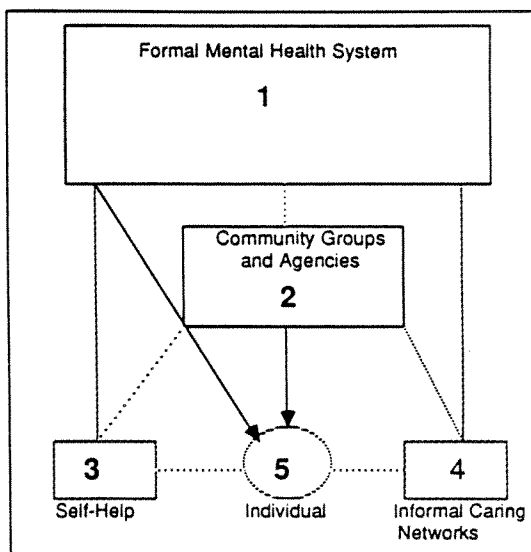
COMMUNITY REINVESTMENT: A Cornerstone of Integration

Many people with severe mental disabilities are struggling for survival. Employment opportunities are limited; poverty and homelessness are common. People who are frequent consumers of mental health services risk becoming disconnected from the web of relationships which constitute "community." Professional service providers alone cannot respond to the need for work, decent income and reciprocal relationships.

Individuals need support to assume greater control over their own lives, and to utilize the resources within their natural environment. Equally important is the deepening and strengthening of the community's capacity to welcome home people who have previously been rejected.

Currently, this kind of individual support and community capacity are rare. If we were to draw a diagram of the current mental health environment, it might look something like this.

CURRENT PATTERN OF INVESTMENT

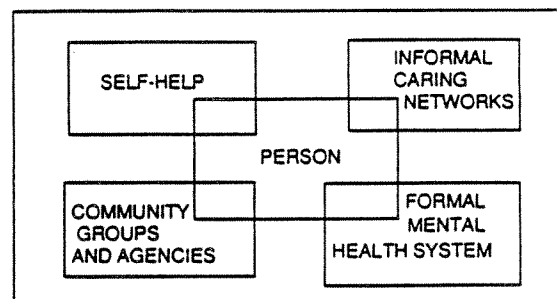


The major players in this picture are, primarily, the formal mental health

system and secondarily, community groups and agencies. Both of these systems may influence the individual's life, but with very little counter-influence in return. Most of our time, energy and the major portion of provincial health budgets are spent to maintain or develop the formal sector. In contrast, the disabled individual is almost an afterthought at the very bottom of the arrangement, on the receiving end of formal help, and connected only tenuously to the relatively weak support systems of self-help and informal caring networks. The place in the little circle at the bottom of the chart is usually a lonely and powerless one.

A preferred map of the territory is the "Community Resource Base." Here, all the individuals and groups identified as primary stakeholders are working together as equal partners. The individual is central, with his/her needs and aspirations the focus of attention for all the other stakeholders. All four support sectors function to link the person to the broader community.

COMMUNITY RESOURCE BASE



We know that this "Preferred Map" is still far from reality. Moving from the present to a future of better community integration based on more balanced sectorial relationships involves many elements. However, in jurisdictions where the balance has started to shift, some common "key

elements" for community reinvestment emerge. Some of these are:

- **FAVOURABLE POLITICAL CLIMATE**-an environment conducive to change
- **IDEOLOGY/VALUES**-articulated and explicit
- **LEGISLATION**-has the potential for directly establishing and mandating community support systems
- **REGIONAL PLANNING AND ADMINISTRATION**-effective when local regions are given the authority to fund and plan their own community services
- **LEADERSHIP**-could come from mental health professionals, legislators, or ordinary citizens, often working together in voluntary organizations
- **MECHANISM FOR FUNDING TO FOLLOW THE PERSON**-the same level of funding which supported the person in the institution is used to provide supports for that person in the community
- **FISCAL MECHANISMS**-these determine the degree to which mental health spending is consistent with mental health policy
- **MECHANISM FOR PROTECTION AND RETRAINING OF STAFF**-the potentially explosive issue of employee redundancies and layoffs must be anticipated and avoided
- **INDIVIDUALIZED SUPPORT IN THE COMMUNITY**-individual coordinators secure and monitor support and services in the community according to each individual's unique needs
- **STRONG CONSUMER GROUPS**-these can provide support and

advocacy, and can lead to participation in the larger community

- **PROMOTION OF NATURAL HELPING NETWORKS**-availability of supportive natural networks may lessen the need for hospital care and other formal services
- **PREPARATION OF COMMUNITIES BEFORE PEOPLE ARE RELEASED**-education and guidance for integrating people, ideally done by indigenous community members

In discussion at the Centre Workshop on "Rediscovering Community," participants explored some ways to apply these "key elements" to their local contexts. They suggested researching and sharing information about models that work, such as the Dane County Wisconsin example. As well, it was noted that the community should identify the decision-makers in the system. Advocacy through coalitions of community groups can then be directed at these individuals. Finally, ways of developing the capacity of informal caring networks was examined.

A look at how Canada's provinces spent their mental health dollars in 1986 showed, not surprisingly, that the vast majority of dollars were allocated to institutional services. By discussions such as the one held at the "Rediscovering Community" workshop we are taking the first steps toward shifting the balance of resource allocation, so that both individuals and communities can be more effectively supported.

Bonnie Pape
Canadian Mental Health Association
National Office

COMMUNITY INTEGRATION: FROM PRESENCE TO INTERDEPENDENCE

There appears to be a significant shift occurring in the thinking of many of those involved in the community living, deinstitutionalization, and independent movements. The main focus of all these movements has largely been on integration and supporting people to live and participate in community settings, alongside other citizens who are not devalued. This emphasis on physical presence seemed to be a logical one, since presence is a necessary prerequisite to more involved kinds of participation and relationship development.

Much of our recent Centre work has shown, however, that these integration movements have not significantly impacted on the lives of thousands of people. *Many* adults who are mentally handicapped still live in institutions, group homes, or at home with elderly parents with few friends or community experiences. *Many* people still end up in psych wards or hospitals - to avoid the streets, or when family break-up or unemployment become too stressful. *And many* physically disabled persons live in chronic care facilities, are forced to leave families in order to get accessible housing and supports, or are living isolated lives in their homes with few supports and friends.

Without strong relationships, people are left vulnerable to loneliness, depression, poverty and chronic institutionalization. While many of these integration movements have warned about "dumping" people in the community without adequate resources, the real meaning of community involvement and supports is only beginning to be understood. It seems that regardless of the areas of community life where people are being integrated - neighbourhoods, schools, work, or recreation - a general concern is emerging which is changing the focus of the integration efforts in each of these areas. The realization is that, *despite having been "integrated", sometimes for*

years, many individuals still lack strong friendships and support networks.

We need to analyze why previous integration efforts have not had high enough expectations in the area of relationship building. One central reason seems to be that integration has been too associated with formal environments and has not emphasized more informal ways of building relationships. We have been more concerned with programs and services than with true community participation. Similarly, perhaps the focus on independence as a goal of integration has misled many of us at a time when co-operation and interdependence are most needed for people in our communities.

Many of our recent Centre projects demonstrate that this aspect of friendships and relationships is at the forefront of many people's concerns. There is a realization that without strong relationships, many individuals are locked into situations where they are overdependent on services and professionals, are isolated and lonely, and are reliant on volunteers and other devalued participants as their only or main source of companionship.

What must be done to ensure that community integration becomes much more than mere physical presence? Some of the main learnings from our experience include the following:

1. When friendships are made the main goal of integration, it changes the way we go about providing supports to people.
2. The idea of friendship forces us to confront the reality that there are more important things in the lives of people than human services.
3. Similarly, it makes us realize the limitations of professionals and volunteers,

and that they cannot be a substitute for real friends.

4. Examining our own lives and how we make friends and with whom is the best guide for assisting others in strengthening their networks of support and friendships.

5. It is relatively easy to get a person physically present, but ensuring the quality of that presence through having continuous, life long friends is more complex, requiring time and often support.

6. Consumer participation in integration has been token at best; in developing friendships, however, the full involvement of the person is needed, because friendships can not be imposed on people who are unwilling or who are not compatible - and only the people in the relationship can *feel* if it is meant to be.

Successes in friendship development are beginning to emerge.

Friendships at school with children and teens have perhaps been given the most attention. But the learnings from this area are now being used to support the development of friendships in other areas, particularly in the workplace and in more informal community groups. Deinstitutionalization projects which understand the importance of relationships are re-connecting people to their family members and building support networks. The outcomes of these efforts are very different from those which fail to recognize the invaluable role that friends play in all our lives. The future of all integration efforts is being enhanced by this new focus on relationships and will hopefully lead to a better quality of life for people in their communities.

Peggy Hutchison
Centre Board Member

THANKS TO SOME IMPORTANT CENTRE PEOPLE...

- **Deb Woods:** who is soon to step down as President of the Centre, for a tremendous contribution over the last five years.
 - **D'Arcy Farlow:** who will soon reduce her centre work load to have another child; she will stay involved in our Empowerment Project.
 - **Keith Heimpel:** our volunteer accountant, for his support and labour on behalf of the Centre.
 - **Madeline Robb and Celia Blair:** graduate students from Wilfrid Laurier University, who have participated in the development and pilot work for our Empowerment Project
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Some Resources on Community Integration

Listed below are a number of resources on community integration, which highlight some of the most recent learnings and insights from the human services field.

• Taylor, S.J., D. Biklen and J. Knoll, Editors (1987). *Community Integration for People With Severe Disabilities*. Available from Teachers College Press, 1234 Amsterdam Avenue, New York New York 10027, USA.

Describes and analyzes a number of community based services and presents various strategies for supporting people with severe disabilities and the people who work with them in community settings.

• Pape, B. and K. Church. (1987) *Community Reinvestment: Balancing the Use of Resources to Support People with Mental Disabilities*. Toronto, Canadian Mental Health Association. 2160 Young Street, M4S2Z3

This resource describes the process of how to reallocate resources from institutions to the community (see article by Bonnie Pape in this NewsReport). It cites several important case studies and notes important factors which would facilitate reallocation and community integration.

• Marlett, N., J.R. Gall, and A. Wight-Felske. (1984) *Dialogue on Disability: A Canadian Perspective*. Calgary, University of Calgary Press.

This book highlights several Chapters which show the transition and change which is occurring in the development of service systems. Planning, housing, employment, child development and other issues are

discussed with a focus on community integration.

• Forest, M. (1987) *More Education/integration*. Downsview Ontario: G. Allan Roeher Institute.

This resource is a collection of readings on the integration of children with handicaps in regular school systems. A number of stories are shared with the reader, but it also includes a fair degree of theory and practical examples. The strategies are transferable to a range of children and settings.

Centre for Research & Education in Human Services

Several resources from the Centre for Research and Education highlight learnings about the community integration process. In particular:

• *Policy Analysis Paper on Special Education*

• *Return to the Community and Reuniting Families*, resources on deinstitutionalization and community integration.

• *Toward Independence and Community*, a qualitative study on Independent Living Centres in Canada.

INTEGRATION AND CANADA'S IMMIGRATION/REFUGEE POLICIES

Recent efforts by the federal government to control the influx of refugee claimants appear to be taking us in a direction which calls into question our reputation as a country doing its share to welcome some of the world's burgeoning refugee population. In an attempt to correct a system which has become notorious for its inability to stop those who would abuse it, the government has, through Bills C-55 and C-84, initiated a discussion that focuses not on how we might better integrate those who do make it to this country as refugees or immigrants, but rather on how we can keep people out.

Through these initiatives the government has pandered to the base instinct of self-preservation. In addition, it proposes punishing Canadians who, because of their broader vision of our capacity to accept those who flee oppression or economic hardship, attempt to assist refugee claimants.

Given the length of time it has taken to pass this legislation (it is now being reviewed by the Senate after introduction in the Commons over one year ago), the government might better have instituted a constructive process of national dialogue concerning our needs and our vision vis a vis our relationship to those wishing to come to this country as refugees and immigrants. Instead, one group rails against the abuses of our immigration system while others counter with charges of bigotry and inhumanity. Meanwhile, nothing is done to adjust our settlement and integration systems, which communities across this country have been saying for

years do little to help enhance the capacity of most immigrants/refugees for successful integration.

Through Centre staff and board involvement in a number of studies and initiatives addressing immigrant/refugee needs, we have become acutely aware of the inadequacies and unfairness of policies and programs at all government levels— inflexible English and French programs that result in many immigrants and refugees remaining disabled in a key skill required for integration; the refusal of educational, professional and skilled trade organizations and institutions to recognize the skills, training and education which immigrants/refugees bring to this country; the inability or unwillingness for mental health and other service systems to adapt to the multicultural reality that Canada has become.

With a population that has recently fallen below that of the State of California and with a birth rate that continues to be one of the lowest in the world, we not only can continue a generous immigration policy, we must if we are not to suffer economic stagnation. That being the case, we should be focusing on improving programs to support and encourage our immigrants and refugees in the development of their capacities and capabilities toward full and healthy community integration.

Theron Kramer
Centre Board Member

SAME OLD STORY...



WHAT'S YOUR
CURE RATE?



WE DON'T
CURE PEOPLE!



WHAT'S
YOUR
ADAPTATION
RATE?



WE DON'T
MAKE
PEOPLE
ADAPT!!



WHAT'S
YOUR
HAPPINESS
RATE?



PEOPLE HAVE
A RIGHT NOT
TO BE
HAPPY!!



YOUR FUNDS
ARE BEING
GUT.

PLEASE, NOT
WHEN WE'RE
HELPING
PEOPLE !!

COLLABORATION IN RESEARCH AND EDUCATION: Part II

In the last Centre Newsletter (Summer/Fall, 1987) we discussed the nature of collaborative research and education. The purpose of this article is to consider the contribution that collaborative research has made to the field of human services and to outline several issues raised by the use of collaboration in human service research.

Research must be seen as only one of the tools to shed light on human service concerns. At the same time, by increasing our ability to understand and implement a range of research methods, we will be better able to search for and to examine a variety of truths, realities and perspectives. Collaborative research, as discussed in the following section may enhance the use of both quantitative and qualitative research methodologies.

Contributions

The purpose of this section is to describe several contributions that collaborative research may make to the field of human services:

First, collaborative research encompasses, but is more than just another form of community development or public participation. The involvement of all the actors in a focused research process provides the additional element to collaboration.

The collaboration becomes critical during the feedback process and followup to the research. Researchers and participants engage in shared problem-solving, utilizing the research and other experiences of the participants.

Second, collaborative research may help to demystify the research process. At the mention of the word 'research' many people automatically defer to experts. Collaborative research is based on

involving all of the actors in the design and implementation of the research process. During Centre projects, for example, an Advisory or Steering Committee represents all the sectors (eg. consumers, service providers, etc.) to assist in designing the research process and to identify the goals and assumptions of the particular project.

Third, by effectively involving people in identifying their own needs, and in defining and implementing solutions that the people feel are appropriate, collaborative research helps to build competent communities. The potential of empowering people, both at the level of the individual and beyond therefore becomes a possibility.

Fourth, collaboration promotes a positive expenditure of energy, from the stage of project initiation through to implementation phases. Anger, conflict and hostility may arise because 'master plans' are presented as all but complete projects or, the rationale on which decisions are derived is not understood because they are based on inappropriate information. Successful collaborative research relies on a group process that is sensitively monitored and supported as required. Potential anger, hostility or conflict, therefore, may be avoided or managed over the course of the process.

Fifth, the involvement of people in various ways throughout collaborative research processes helps to spread new ideas related to substantive issues, strategies, and solutions. We know that innovative ideas in human services are passed on slowly. Engaging people in the process of information gathering and dissemination also helps ensure that ideas that are spread.

Sixth, integration of theory, research and practice occurs within the collaborative research process. At any

point feedback may lead to changes or fine tuning of the research problems. Because all of the actors are involved no one has to 'wait' for study recommendations-if something important is learned then it can be applied immediately.

At the Centre, we learn from every project. These learnings are used to build a knowledge base from which the Centre may design approaches to new projects. For example, in several projects we have noted that some people become empowered as a result of certain intervention. This has lead the Centre to initiate a major study on empowerment.

Perhaps collaborative resarch may be compared to the Native Canadian folklore of the medicine wheel. According to Castellano (1988), the medicine wheel represents an acceptance of differences which is based on the belief that if we can appreciate and make use of each other's gifts then we can all win. The contributions described in the preceeding section are only some of the examples of how we can appreciate each other.

Issues

There are many issues to be considered in relation to the use of collaborative research in the field of human services. Some are noted briefly:

- The education and training of human service planners and practitioners needs to provide a more broad based approach to the area of research methodologies and group processes.

- There may be concern related to representation Who should sit on research advisory committees? Who is responsible for deciding who should sit on committees?

- People who are devalued, alienated or without support systems are extremely vulnerable and the least likely to become involved in a collaborative process. How can human service planners and researchers mobilize people to participate in collaborative projects?

- Issues addressed through collaborative processes are often complex and, therefore, may tend to be avoided by politicians and decision-makers. There is a need for people undertaking collaborative research to have a clear understanding of the institutional (e.g. government or bureaucratic) arrangements which they will encounter or may need to address.

- There can be a fine line between successful collaboration and cooptation. All of the appropriate words may be used by those in power without the prerequisite underlying committment. An illustration of this is occurring in New Brunswick, where some people believe the government is employing 'self-help' language to dump social services on local level communities and the charity model (New Martimer,1988,p.9).

- There may be struggles among participants who want to shape the data according to their own perceptions and the researchers willingness to give up some control.

- Collaborative research processes may take more time, money and energy. For these reasons alone the approach is often hard to promote as a viable alternative to traditional research methods.

These issues must be dealt with by groups initiating research projects. The solutions to the issues raised by collaborative research will likely vary according to the needs of each project. As collaborative research is used increasingly by the Centre and other organizations, our base of knowledge and experience in what to do will also develop.

Mary McGeown,
Centre Associate,
Waterloo, ON

NewsReport Notes

- One indication of integration "potential" is the willingness of a community to accept diversity. In a recent Newsweek Poll in the United States, black and white Americans were asked if they would prefer to live in a neighbourhood with mostly whites, mostly black's, or in a neighbourhood mixed half and half. 68 per cent of blacks opted for mixed neighbourhoods while only 46 per cent of whites choose this option. Other studies also show that ethnic and cultural diversity may be other important indicators for integration potential in a community. (See, for example, the Rothman's study the *Willowbrook Wars*). People who are perceived as "different" will be more easily accepted in heterogeneous neighbourhoods and in community settings which value diversity.

- A story being told in mental health circles in Ontario illustrates the madness of some of the human services our society has created. One patient of a provincial psychiatric hospital saw seven doctors over a two year period, and had spent his time in and out of the hospital during that period. The total cost of this "support" was in the range of \$150 000. per year. And yet, each time he was released from the institution, his monthly pension totaled a little more than 400 per month. What a sad irony that public payments for medical care are often greater than the public income payments for food, shelter, and healthy community living!

- There are growing concerns about free trade and human services. While most of us probably think of free trade as being concerned with products such as forestry, wheat, alcohol, and fish, it is now fairly certain that free trade includes a number of human services. Ernie Ginsler and Ken Murdock from Social Planning

Councils in Kitchener-Waterloo and Winnipeg have each noted that American cooperations, under free trade, may well try to bring "profit-making" approaches to Canada in several human service areas, including management of hospitals. In separate reports, these authors suggest that health and social services could be influenced, including the operation of homes for the elderly, people with disabilities, single mothers, and foster care. Although government-provided services are excluded from the bilateral free trade agreement, it is of great concern that for many human services it will be increasingly difficult to maintain the character of "Canadian Services", which have generally evolved as a unique blend of provincial and local non-commercial service systems.

- For community integration and participation to have some chance of working, some people need a kind of bridge or mediating structure" to help them access needed resources. We have argued in the past, for example, that independent living centres often play this role for citizens with disabilities. For homeless people, these kinds of bridges or structures have generally been non-existent. For the last two years, however, Street Health in Toronto has provided community nursing stations for people who are homeless. Trained volunteers provide hands on nursing care, individuals are supported to access the health system, and people are provided with assistance with documentation, letter-writing, etc. The Street Health Board consists of six users and six other volunteers. Sponsored by All Saints Church, 15 Dunbar Road, Toronto, ON M4W 2X5