

Centre NewsReport

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A Celebration of Learning: 10 years of research and education in human services

Vol. 7:2

Part I

Fall/Winter, 1992

Welcome to our Special Issue entitled, "A Celebration of Learning: 10 years of research and education in human services".

We are approaching the Centre's 10th Anniversary and thought it appropriate to highlight key learnings that have emerged from our work over the years. Themes critical to innovation in human services are included such as organizational change, de-institutionalization, quality of life, and empowerment. A more in-depth focus on other key issues will be forthcoming in Part II to be issued early in 1993. We hope you enjoy this initial retrospective.

Personal Struggles Continue to Define Important Issues in Human Services

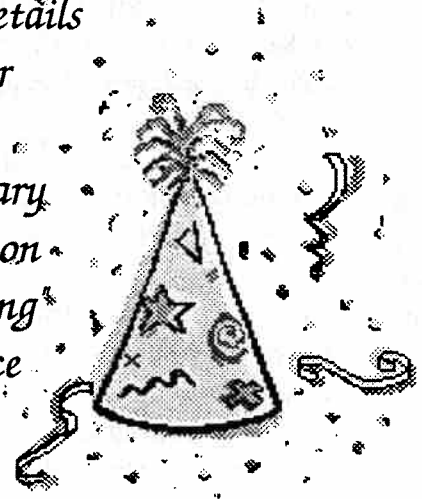
In the span of a few weeks, two events recently occurred in my community which illustrate the paradoxes that exist today in health and social services. The first story involves a woman who lived in an institution for 60 years and was returning to community life. With individualized funding, she is currently being supported in ways which enable her to experience real citizenship and empowerment. The second story is more tragic and involves a family who gave up, or "abandoned" their child (as one social service agency described it), because they found no support to deal with their son with complex needs.

The paradox of these stories is both cruel and confusing. While pockets of promising practices continue to expand, the threat and reality of funding cutbacks often jeopardizes community alternatives for vulnerable citizens. Progress has been made in many areas over the last decade. As we reflect on the learnings of the last decade, our challenge will be to address today's paradoxes as we try to build a better tomorrow.

*Gift idea for important people
in your network... make your
friends our "Friends" in 1993.*

For a novel holiday gift, consider passing along a subscription of the Centre NewsReport to a colleague, friend or family member. Every gift subscription of \$12.00 is tax deductible. If interested, please let us know, and we will send out the NewsReport with your best wishes for 1993!

*See inside
for details
about our
10th
Anniversary
'Celebration
of Learning'
Conference
in May
of 1993!*



Human Services Remain A Critical Social Change Issue by John Lord

The following article was originally printed in Vol. 1:1, Fall 1984 of the Centre NewsReport.

The Centre for Research & Education in Human Services was established in 1982 by a small group of concerned Canadians. An independent non-profit organization, the Centre works with researchers, advocates, educators, service providers, and individuals who use human services.

We live in a era when many different organizations provide human services, whether they be related to health, education, recreation, or social services. The Centre's concern is the need for research and education which will facilitate constructive social change and the development of human services which are responsive to all Canadians.

Many people wonder why human services are a critical social change issue. A few of the reasons, which help frame the Centre's research and education, will be briefly highlighted:

- There are almost 40,000 human service organizations in Canada.
- Many of these organizations are based on "models" which segregate and isolate people considered disadvantaged or devalued.
- Many human services address "symptoms" rather than root causes of issues.
- Values and procedures which guide human services have, in many cases, become extremely bureaucratic.
- Human services generally reflect the values of our society; for example, the rejection of people considered unproductive.

Centre research analyzes the context of human services in Canadian society, and tries to understand the impact of human services on the lives of individual citizens and communities. This work includes policy analysis papers of major social issues or legislation, qualitative research to better understand the lives of people affected by human services, and comprehensive documentation of human service alternatives. It is significant to note that some of the most profound human service alternatives reflect visions of positive human values and a **caring community**.

NEW PUBLICATION *More Than Just Another Human Service*

A study recently completed by the Centre on behalf of the Canadian Association of Independent Living Centres.

The focus of this descriptive study was the six Independent Living Centres in Ontario. Each centre reflects the unique characteristics of their community, while demonstrating the principles and core programs of the Canadian Association of Independent Living Centres. This report describes the context of the centres in the 1990s, and identifies major themes related to the philosophy and practice of the centres. The voices of centre members are presented throughout the document as well as descriptions of promising program initiatives. **Cost \$5.00**

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Some Keys to Organizational Change in Human Services

by Judith Sandys

Summary of the original article printed in Vol. 4:1, 1988 of the Centre NewsReport.

First and foremost, an organization needs a strong value base. It needs to be clear as to what it believes and what it envisions as a desirable future for the people who are the focus of the organization's efforts. It must ensure that this position is clearly articulated, and widely known and understood throughout the organization. It is the commitment to a set of shared values and a common "vision" which gives the organization its sense of purpose and the strength with which to face the inevitable difficulties that will arise.

Another key factor in organizational change is creating an environment in which people are encouraged to critically analyze what they are doing.... Despite our best efforts, the reality is that many people "serviced" by human service organizations are poor, attend predominantly segregated programs, and have few relationships with people other than with paid staff.

Third, a major factor contributing to a change-oriented environment, is the willingness to use existing resources flexibly and creatively ...[especially] their "people" resources.

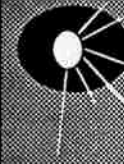
Fourth, a key factor in an organization's ability to respond to change is the willingness of its staff to assume new roles and to

change, this most often reflects the fact that change is being perceived as a "top down" process—something that has been decided by a small group of senior people and imposed on staff. Change occurs more effectively in organizations which encourage open communication; where everyone is involved in the problem-solving process, and where people at all levels of the organization are encouraged to seek new and creative strategies in response to the needs, interests, and wishes of those being served by the organization.

Finally, it is important that we do not become overwhelmed by all that we have yet to accomplish. The continuing isolation of people with handicaps (and other marginalized citizens) reflects the interaction of a number of complex historical, social, and political factors and is therefore not something which is likely to be "fixed" easily or quickly. It will require tenacity and perseverance, the willingness to take risks; and to learn from our mistakes. We must recognize that change, even when it is necessary and desirable, can be frightening and unsettling. It demands of people that they give up familiar, comfortable old ways as they begin to see and do things differently. It is therefore important that we be tolerant of each other and supportive of one another's efforts; that we learn to take pleasure from and celebrate our successes; and that we gain satisfaction from what we have

been able to accomplish even as we strive for greater accomplishments.

*Announcing the Centre's
10th Anniversary
"A Celebration of
Learning"
Conference
May 6 & 7,
1993*



Renison College
Waterloo, Ontario

Thursday, May 6th topics to include:

- deinstitutionalization
- family support
- community development
- consumer directed approaches
- individualized funding

Facilitators: Theron Keamer, John Lord, D'Arcy Farlow, Peggy Hutehison, Mary McGeown & Andrew Taylor. Other resource people to be announced.

Thursday evening banquet

Friday, May 7th
Concurrent workshops will be offered to foster skills and analysis development related to

Friends of the Centre will receive a brochure with complete details in early January.

Phone the Centre in January at 519-741-1318 for further details.

The ABC's of Happiness by R. Valett

ASPIRE to realize your potential

BELIEVE in yourself

CREATE a good life

DREAM about what you might become

EXERCISE frequently

FORGIVE honest mistakes

GLORIFY the creative spirit

HUMOUR yourself and others

IMAGINE great things

JOYFULLY live each day

KINDLY help others

LOVE one another

MEDITATE daily

NURTURE the environment

ORGANIZE for harmonious action

PRAISE performance well done

QUESTION most things

REGULATE your own behaviour

SMILE often

THINK rationally

UNDERSTAND yourself

VALUE life

WORK for the common good

X-RAY and carefully examine problems

YEARN to improve

ZESTFULLY pursue happiness

The Search for Capacity in People Who Have Been Labelled by S. Joyce

"Discovery consists of looking at the same thing as every-one else and seeing something different."

In early 1990 the Centre was involved in research concerning the quality of community and segregated services for people who have disabilities. In addition to a number of people who receive support, we interviewed a selection of service providers. One question we posed to the latter group was, "describe one person your agency serves in terms of his or her strengths and capacities."

The responses of these professionals, almost unanimously (and unconsciously), focused on the person in terms of his or her needs and deficits. Those who did attempt to outline someone's strengths stayed primarily within the confines of general personal attributes such as, "She has a nice smile" or "He's very friendly".

If we are to provide support and resources that assist people to become fully participating members of their communities, we will all have to become better at discovering the unique talents, skills, and gifts that each person possesses. While such a process may be simple once we have embraced the belief, it may take a while to change our focus to include what each citizen has to share and contribute.

John O'Brien and Beth Mount, in "Telling New Stories: The Search for Capacity Among People with Severe Handicaps" (1990), emphasize the importance of describing folks, not in terms of their I.Q., behavioural issues, or skills impairment, but rather according to their preferences, interests, and potential. Such an endeavour will lead us to assist the person to meet their real needs for friendship, learning, and involvement. An essential element of telling someone's story must include what they have to give back; their ability to meet some needs of their friends, families, staff, and community.

Highlighting a person's capacities sometimes requires inside-out thing, whereby an assumed minus is turned into a plus. John McKnight (1988) talks about Joe, who was always passing on the latest gossip at the local diner. Instead of viewing Joe's habit as annoying, or even harmless, his friends decided to find out who got paid for doing what Joe liked to do and now he is a dispatcher for one of the town's radio stations.

It will take time for us to learn to "think regeneratively", as Robert Rodale (1990) suggests; to explore, develop, and nurture what is already present rather than automatically trying to fix, to alter.

Originally printed in Centre NewsReport, Vol. 5:2, 1990

Integration and Attitudes Towards the Elderly

by Andrew Taylor

"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 . . . segregation 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" (Bauman, 1987).

Several issues have arisen out of recent Centre research which related to the struggle to make integration for the elderly a reality:

1. Some research suggests that society and elderly people often become "disengaged" from each other. Even when opportunities to leave an institution arise, for example, many elderly people are reluctant to leave. Furthermore, their families are sometimes resistant to the idea. Often, the process of reintegration is a slow one in which the person requires support to overcome their lack of personal confidence, and (justifiable) mistrust of people who say they value them.

2. "Integration" does not always look the way you expect it to. Many of the elderly people we have met are not interested in living in the same building as other age groups. They prefer to

keep noisy children at arms length, and to live with other elderly people. Just as important as integration, for many people, are privacy and control. Some older people like to retain ties with the institutions they have left - visiting with friends and going back for parties, for example. Not surprisingly, being physically "in" the community does not always lead to a feeling of integration into that community - some elderly people are very isolated and lonely in their apartments, and others are very involved in the community while living in institutions!

3. Important aspects of integration for many previously institutionalized older people include living closer to family members, having access to convenient transportation, and being able to entertain guests in a nice environment. However, individuals' wants and needs vary widely, and integration will likely take many different forms, and be more important as a personal goal for some people than for others.

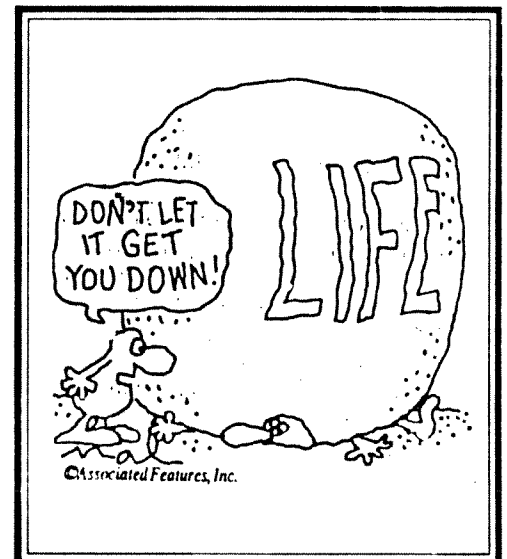
In 1987, Annette Bauman wrote that successful integration and attitude change will require that we interact with devalued people in a wide range of community settings, and engage in a variety of everyday activities with them. There is much ground still to cover, I think, to meet this goal. A current Centre evalua-

tion of the Alternative Community Living Program of York Region represents some progress made in this area. While living in a building situated in the community, elderly people can once again cook for their family if they wish. They must shop for groceries, fill their apartment with all the necessities of living, decorate, and manage their own money. Often, friends and family members have been involved in these activities, and consequently they have probably begun to widen the range of activities they engage in with elderly people.

Reference

Bauman, A. (1987) *Integration and Attitudes Towards the Elderly*. Centre NewsReport Vol. 3:2.

A special thanks to Jane White for giving us a "lift" with this cartoon (from the Western Producer, Oct. 1/92.)



The Many Facets of Deinstitutionalization by John Lord

The word "deinstitutionalization" can have a variety of meanings and understandings. For some, deinstitutionalization speaks to real progress in the quality of life of people with disabilities. For these people, it means community alternatives to the barren, isolated, restrictive setting of the asylum. For others, deinstitutionalization signifies major problems; it means dumping, abandonment and cost saving. That both these perspectives exist side by side illustrates the many facets of deinstitutionalization in Canada.

Let us first consider some of the *significant changes in deinstitutionalization during the last decade in Canada*:

- In the developmental disabilities area, significant reductions in institutional populations have occurred. The leading provinces in this area have been British Columbia, Newfoundland and Ontario. Zero admissions to institutions is now a stated policy in several provinces, and deinstitutionalization efforts are continuing in most provinces. Enlightened policy and economics are driving this important thrust toward closing institutions for people with developmental disabilities. As a leader in this area, British Columbia is expected to have all large facilities closed by 1995. In contrast, more than 5,000 people remain in large facilities in each of the provinces of Quebec and

Ontario.

- In mental health, some areas of the country have been quite creative in developing alternatives and allocating resources to the community to demonstrate that people from psychiatric hospitals can live more effectively outside the walls of the institution. The fact remains, however, that there has been little planned deinstitutionalization or community building in the mental health area. Expenditures on community health have increased significantly, especially in Ontario, but seldom in a way that enables more people to return from institutions. The large psychiatric hospital continues to stand as a symbol the medical model's failure in mental health.

- In the physical disabilities area, a significant shift in thinking has occurred in the last decade. Thirty to forty bed residences, which were commonly built in the 1960s and 70s are no longer seen as being a reasonable approach to community integration and independence. Policy changes and new program initiatives are allowing more and more people with physical disabilities to remain in their own homes or to access attendant services in apartment settings. At the same time, hundreds of people with physical disabilities continue to live in chronic care facilities in Ontario. In the last decade, we have learned that housing should not be linked to

the support the person needs, but that we must find ways to provide the support that people need wherever it is they want to live. This new emphasis in the physical disabilities area has been forcing a much needed debate on the role of individualized services and direct funding to the individual.

- In considering future policy and practice related to deinstitutionalization, it is important to reflect upon the *central lessons of the last decade*. There are at least **eight** such lessons:

1. Deinstitutionalization is often driven by economics.

Large facilities may require as much as \$15-20 million a year, which is a huge resource in times of financial restraint. In New Brunswick and British Columbia, advocates have been able to convince their governments that this money could be better spent by re-allocating it to community alternatives. These are examples of advocates creatively linking economics and enlightenment. Unfortunately, in many provinces, transitional funding has often been non-existent, thus limiting creativity in planning and implementation. That deinstitutionalization is often driven by economics means that advocates must pay close attention to government plans in their monitoring and assessment of any planning related to institutional downsizing.

2. *Current deinstitutionalization policy and practice in Canada is based on the assumption that community integration is only for some people who live in institutions.*

Despite extensive deinstitutionalization in the developmental disabilities area, the people who remain in facilities throughout Canada tend to be more severely disabled individuals. Similarly, hundreds of people with physical disabilities are living in chronic care hospitals because they are perceived to be "too severely disabled" to live in the community. Advocacy and public policy for the next decade is only beginning to address the issues of community support for people with complex needs. However, the research is clear - citizens with the most significant disabilities can live in the community when appropriate supports are provided. The most effective deinstitutionalization efforts provide an equal opportunity for all residents to leave the institution.

3. *We now know how to close institutions in a relatively effective manner, even though it has seldom been done in an effective manner.*

The vast experience with deinstitutionalization in Canada and the United States has produced some excellent research and documentation. Learnings from closures in Quebec, British Columbia, New Brunswick and Ontario point to the need for a comprehensive approach to in-

stitutional closures. Individual planning approaches, worker retraining, parental and family involvement, and individualized community service development are all part of the growing thrust towards deinstitutionalization and community integration. Consumer participation is an essential component in the process that ensures that the preferences of each person returning to the community are respected.

4. *Families can be reunited with a member from an institution when proper support is provided.*

For some people returning from institutions, significant efforts have been made towards increased family involvement with very positive success. Families who are cautious about community living tend to become quite supportive of community alternatives when they are involved in the planning process for their son, daughter or sibling. Family involvement can also be important as a way to expand the person's social network and relationships. Of course, it is not always appropriate to involve family, and this is where the principle of consumer preference is so critical.

5. *People who have moved out of institutions to live in the community are often dominated by service agencies as well as charity models.*

The group home model continues to be the dominant

approach to community living despite the fact that its development is often accompanied by paternalistic and controlling practices. In mental health, many of the community alternatives continue to be dominated by medical approaches which are very controlling of participants. In all areas of disability, new models and approaches are emerging which are 'enabling' rather than 'controlling', but it seems that much more conscious effort needs to be made to develop consumer-oriented alternatives.

6. *Communities generally respond fairly positively to people with disabilities from institutions.*

Research indicates that communities respond positively to individuals with disabilities, but less positively and sometimes negatively toward groups who are congregated. Some communities have welcomed back people from institutions, and the thousands of organizations that make up a community are only just beginning to be asked to participate with people with disabilities. The notions of community building, and enhancing personal support through friendship circles and other informal supports is a growing and important phenomenon. These approaches both decrease the person's dependence on service systems and enhance personal networks of support which can be empowering and supportive.

7. *Deinstitutionalization continues to have its detractors, and*

these are usually people with an investment in the institution.

There are naturally people who have vested interests in keeping institutions open. However, forces in favour of community alternatives can now argue that the methods, technologies, and expertise exist in communities for real alternatives to be developed. Until public policy supports institutional closure timetables in all areas of disability, the push for community living is far from over. Research strongly suggests that such timetables allow all those invested in the institution to adjust to new realities, and, with proper resources usually do a fair job with the closure process.

8. To avoid having to close or to ensure that they will not lose control, institutions often take on new "community" roles.

It is becoming common in Ontario for facilities to become community resource centres. This new role tends to ensure that the institution will not close, and, in some cases, means the

community has to use the institution if they want services. A related trend, especially in mental health, is to give the institution the primary responsibility for re-developing community resources. In practice, control usually remains centered in the facility and very weak community structures are developed.

The results of deinstitutionalization for people have ranged from very good to very bad. Neither result should be used to "prove" that all deinstitutionalization should be praised or condemned. Both results should compel us toward the development of quality of assurance in all future endeavors.

A decade of deinstitutionalization research and practice has helped us discover that changing professional systems is extremely complex. There are an enormous number of vested interests that want to maintain service systems as "closed" systems. Community-based services do not, by definition, mean that people are connected with

the community or that people have more control in their lives. In the decade ahead, we must be careful not to continue to simply replace large institutions with smaller institutions. We need to build on the important innovations that assist people with disabilities to participate more fully in community life.

Our ability to end closed systems which control consumers involves continuing to emphasize consumer control and community integration. Values which guide deinstitutionalization need to focus more on the empowerment of individuals and communities in contrast to the focus on the development of more and more "service systems". Though services have an important role to play in the lives of people with disabilities, they must be responsible to people's desire for personal empowerment and community participation.

This article was originally published in ARCH TYPE, Volume 10 No. 4(b), August 1992.

The Centre for Research and Education in Human Services is an independent, non-profit, Canadian organization. In utilizing primarily participatory and action research, we work with researchers, educators, advocates, service providers and human service consumers to create an understanding of policies and practices which affect citizens who have been disadvantaged in our society. If you would like to know more about the Centre and resources available, please contact us at the address below:

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