

family

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Abstract

This report is about the work of a small organisation in Alberta that focuses entirely upon connecting people with their communities. A major purpose of the organisation is community education and development. It describes the strategies used to foster successful inclusion, which include advocacy, sustained effort and focusing on the individual. **Keywords: Inclusion, Community Development**

PERSONAL COMMUNITY SUPPORT ASSOCIATION OF ALBERTA

"WHAT WE HAVE LEARNED". . .

Creating Opportunities for Adults to Participate in Community Life

A Report by Catherine Duchesne
In Consultation with Regional Staff

December 1992

Personal Communities: a description

Personal Communities has focused exclusively on community participation for three years. It is dedicated to rebuilding the capacity of community to welcome and include. It's activities focus on guiding individual adults who have been isolated into the hub of community life through membership in a community group which meets regularly for purposes of common interest to the members.

This is an intentional effort to enmesh persons with disabilities within community life. A Personal Communities Worker uses approaches which are enabling and empowering of both the individual and the association. The immediate benefit to the individual will be to experience membership, belonging, greater self esteem and will gain opportunities for personal relationships. The community association or group is strengthened by having a greater capacity to welcome and include. Further, this group becomes a model for other groups and individual members whose sphere of influence extends into the greater community.

In each of two rural (Lesser Slave Lake Area and Pincher Creek) and two urban (Edmonton and Calgary) communities, a "Personal Communities" worker is well connected in the interrelationships of community and the web of everyday life. They work from their homes, since their work is not done in an office but in environments such as restaurants, people's homes and meeting places. One full time worker actively supports about ten people each year. The support to one person often continues for many months.

Community education and development is a major purpose of Personal Communities. While supporting one individual to gain membership within a community group or association, the community gains first hand knowledge through the experience. As in a ripple effect, each member will carry this experience to other segments of society. While this kind of community education is by far the most effective, energies are spent in other methods. These may include hosting seminars and workshops to explore the concepts of community building and community inclusion, distributing stories, sharing our experiences, and providing in-services or encouraging joint meetings or study groups with parents, community groups and service providers.

In the past year, a summer project in one community in Calgary was implemented to center the efforts of inclusion in that community. A long time leader of that community

was hired to assist a few isolated community members be included. Her job also became one of leadership and teaching the community to become aware of all people within their community and to practice inclusion in all community activity. The community association was very enthusiastic about this project and have taken steps to continue the project on their own. This approach showed so much promise that Personal Communities will try it in other urban areas

... About the Individuals we support

Social supports/connections- All individuals who have come to us are very isolated. Some have the support of one or two family members or family friends. Most consider themselves ineligible to be a member of community groups. Their social experience is mainly with segregated groups, family gatherings, or present by not participating in community groups such as faith or community gatherings. Their role or potential value to the group is usually unrecognized.

Employment - Few individuals have had opportunity for employment. Some have volunteer positions in the community. Several individuals participate in segregated training programs.

Living situation: - individuals live in a variety of living arrangements:

- 1) "independent" apartment - person may live alone or with another person requiring support. Paid support may be provided a few hours per week to 24 hr. support.
- 2) group home - person lives with 3 to 6 people. Paid support is provided 24 hours per day.
- 3) family home - person lives with her/his family.
- 4) shared roommate - person shares his/her home with another (non-disabled) person.
- 5) two individuals share their home with spouse and new-born baby. Some paid support provided through an agency or community social service.

Decision making - Few opportunities exist for most individuals to exercise control over most aspects of their lives, especially their social lives. The large majority of adults supported have public or private guardians.

Economics - Most are dependent on social security support. These programs are basic support for survival, making it very difficult for most to rise above poverty. This makes it very difficult to participate in many community activities.

Disability - Individuals supported have a range of disability and severity. Although those individuals who have severe and multiple disabilities or who have mild barriers seem to be the most excluded, our experience shows that inclusion relates most closely to commitment and support of those around them. Type and degree of disability seems to be secondary.

Eligibility - Individuals often consider themselves ineligible for membership or citizenship within their community. Some have experienced enough rejection or have internalized such a negative sense of their own self worth that they fear exposing themselves through participation in the community.

... About the Communities we work within

1) Examples of community groups:

- faith groups: Church and auxiliaries
- service groups: Legion, poppy volunteer group, community food and relief, seniors volunteers, non-profit community radio broadcasting, fundraising activities
- commercial enterprises: hairdressing salon, donut and coffee shop 'regulars',
- women's groups: healing groups, support groups.
- cultural groups: Native Friendship Centers, Metis groups, pow wow celebrations.
- arts groups: volunteering at intensive arts Festivals (e.g. North Country Fair, the Fringe, the Works), music appreciation, church choir, arts guilds.
- recreational groups: crib club, ti chi group, craft classes, curling, aerobics groups.
- social groups: Mom and Tots, community association pub nights, singles groups.
- self improvement groups: TOPS, literacy tutoring, self advocacy.

2) Some communities are more inclusive than others:

- some religious congregations are inclusive by nature while others are quite exclusive, despite their talk or content of their faith.
- some community groups have nurtured a sense of community. Inclusion is not difficult in these communities.

3) Communities and their members are, in general, not prepared to take on an advocacy role on behalf of the members. Individuals with disabilities and others who are devalued are often left vulnerable and without power to speak on their own behalf.

... About service agencies and paid support people who collaborate with us

- inclusion is most successful when agencies are committed to the concept.
- deep personal relationships often exist between staff and those they are paid to support.
- awareness of the limitations presented by agencies and service providers is critical when agencies support community inclusion:
- few relationships survive job and career moves (turnover rates are extremely high in Alberta).
- individuals with disabilities are vulnerable because of their dependency upon paid support in areas such as:
 - decision making.
 - physical care.
 - economic control.
 - protection against exploitation, discrimination, mental and physical abuse.
 - opportunities for social interaction.
- some service providers unintentionally perpetuate an individual's "clienthood role" to justify paid service.
- segregation and congregation are barriers to integration and inclusion.
- loss of personalization and individualization are barriers to integration and inclusion.
- the delivery of paid service historically supersedes the social needs of the individual. Economies of time and money drive out intentions to prioritize the need for social supports.

- devaluation of social service (e.g., low wages, low social standing) perpetuate devaluation of the person.
- professionalization focuses on deficit, thus standing in the way of connecting a person's gifts, strengths and talents with community.

... About the facilitator

Qualities of the facilitator which have proven important:

- personal beliefs which:
 - considers inclusion for all people as important
 - values a sense of community, of belonging and being valued with and in a group.
- has experienced and participated in community life.
- has many community connections.
- is trusted by the community.
- understands the "wounds" experienced by marginalized people, especially people with disabilities.
- focuses on individuals' and communities' gifts rather than deficits.

... About strategies used by Personal Communities

- inclusion happens best when support and facilitation is individualized and personalized:
 - "one person, one at a time"
 - Individualization allows for the person to reveal him/herself beyond the disability.
 - relationships take time to develop. Knowing that we all take a lifetime to form relationships in community, facilitators are prepared to support the individual for many months.
- Inclusion happens best when there is commitment by all who impact upon the person's life.
 - the facilitator nurtures commitment of the individual, the family, friends, the community group, individual group members and service providers.
- Inclusion happens best when an individual is introduced by a trusted and well known community leader.
 - the facilitator usually makes connections with the leaders first and asks them to make the introductions.
- Inclusion happens best when the focus is on the person, not the disability.
 - the facilitator does not usually prepare the community group by describing the disability before they meet the person. They trust the group to learn about the person in the usual way. The facilitator usually acts as a model to teach the group to act appropriately and to encourage members to interact with the person in response to their common interests and activities of the group. The facilitator is careful not to come between the person and the community members.

- connections happen best when the individual and the group have common interests, and the individual has an opportunity to present his/her personal qualities
 - a great deal of time is spent by the facilitator getting to know and learning about the person.
 - since most individuals have had little opportunity to develop personal interests, the facilitator often assists the person in the beginning to 'discover' his/her own personal identity.
 - the facilitator is often required to "interpret" for the community members the persons interests, preferences, character, strengths and gifts. It is important that the person is presented in a positive and enhancing way.
- accommodation
 - facilitators may need to assist the organization to make changes or adaptations to the physical environment as well as to the usual methods of communication used by the group to allow for positive involvement of the individual.
- advocacy
 - facilitators must support and teach the community to use advocacy skills. This is an area which Personal Communities has only recently come to acknowledge. Facilitators are currently learning new ways to achieve this end.
- sustained effort
 - facilitators have found that their work often requires perseverance and hard sustained effort. Many times they were tempted to give up. New strategies, different perspectives from others close to the person, time, and sheer determination have all helped to encourage the facilitator, the individual and all others important to that person.

... About volunteers recruited by Personal Communities

Personal Communities is currently preparing a volunteer manual and policy for a volunteer component, using the expertise and support of a practicum student from Grant McEwan's Volunteer Management course. We are relying upon Citizen Advocacy methods of implementation and principles in the development of these policies.

Volunteers are occasionally recruited by a facilitator in situations when:

- the facilitator's age, interests or personal culture and connections are so different from those of the individual that it would be very difficult for the facilitator to effectively or naturally introduce him or her to a community group matching the interests of the person.
- the individual considers her/himself ineligible for membership in a group but is open to a one-on-one relationship.

Dilemmas presented by the volunteer component of Personal Communities:

- a volunteer, by definition, is not a relationship naturally established through community or personal connections.
- volunteers are usually recruited by and accountable to the agency (in this case it would be Personal Communities). Formal methodologies such as recruitment and

advertising, screening, police checks, training, volunteer support and follow-up are required for good volunteer programs but may also become barriers to equality in relationship between two people.

- a volunteer may too easily slip into the role of "authority", thus perpetuating the "clienthood role" which individuals with disabilities (who are embedded into a service system) are forced to assume
- the role of neighbor, fellow member, fellow citizen, friend, may be inadvertently replaced by the volunteer role, thus working against the original objectives of Personal Communities

Despite the above dilemmas, the strategy of using volunteers remains viable in certain circumstances. Awareness that facilitation can and should be done in multiple ways and by many people encourages us to cautiously continue this strategy

A Reconsideration of our Assumptions

In planning for our future, Personal Communities is first organizing a "Think Tank" in February 1993 which will re-examine the assumptions we use in our support to individuals and the community. Darcy Elks of Syracuse and Nicola Schaefer of Winnipeg have agreed to assist the Board and staff in the process of this event.

Once it has gained clarity in its assumptions through this event, our organization will develop a plan for its future.