

family

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Abstract

This short article describes a small organisation in Alberta that focuses entirely upon connecting people with their communities. It believes positive stories must be told over and over so that people let go of their misgivings. The article includes the barriers people have faced as well as positive stories. **Keyword: Community Development**

The Community Experience for a Few Albertans Who Have Left Institutions

by Catherine Duchesne

Ryan, now in his early twenties, spent his teen years in a nursing home. During these important formative years he had little opportunity to make friends. He is, however, adept at getting people to "serve" him. He has limited awareness of his own talents and interests except a desire to make money and to learn to read. His understanding of relationships, including sexual relationships, was shaped by the TV and observation of institutional life. Recently, Ryan has helped at a community radio station, where he regularly meets people his own age and is beginning to recognize that he has something to offer.

David is approaching his sixtieth year. Although he lived with his family during childhood, he spent many years in a nursing home. David is very dependent on others. He was recently introduced to using a white cane and no longer requires someone to lead him everywhere. After sixty years, two wonderful talents have finally been recognized: he is proficient as a ballroom dancer and as an accordion and keyboard player. His goal is to play in a local band.

Personal Communities

"Community for Everyone" is the mission of a small organization in Alberta that focuses entirely upon connecting people with their communities. The Personal Communities group has its roots in the deinstitutionalization movement in Alberta beginning in the early 80s. Three years ago, after involvement in many advocacy campaigns, demonstration projects, individual sponsorships and community education events, the leaders of this group understood that technological and systemic change is not enough. The world of services, within the institution *and* the community, cannot replace what most people who live with a disability lack: a sense of belonging, acceptance, personal relationships and friendship. It was time to leave the service system to others and to turn their attention to creating opportunities for individual adults to participate in community life.

Personal Communities' activities now focus on guiding isolated individual adults into the hub of community life. This is through membership in an association or group that meets regularly to pursue an interest common to the members. This is an intentional

effort to enmesh persons with disabilities (representing a variety and complexity of needs) within community life. The Personal Communities worker uses approaches that support both the individual and the association. Each individual benefits by experiencing membership, belonging and greater self-esteem and by gaining opportunities to develop personal relationships. The community association or group is strengthened by having a greater capacity to welcome and include. Further, the association becomes a model for other groups and individual members whose sphere of influence extends into the greater community. In each of the five communities (two urban and three rural), the worker is well connected in the interrelations in the community and the web of everyday life.

Barriers

Ryan, David and others have made Personal Communities' facilitators and members aware of some barriers to participating in community experienced by people who have lived in institutions. Awareness of barriers allows us to consider new personal and social attitudes. The experiences of Ryan and David and their personal networks have reinforced the belief that communities have the capacity to include all people. The barriers can be overcome.

The barriers described below were observed and experienced by Personal Communities facilitators during the past few years:

- The institutional culture, expressed through unusual and ill-fitting dress, strange haircuts and use of foul language, is seen by the public as different; and the person is regarded negatively and with disapproval. While these barriers are the first and most apparent, they are often the easiest to overcome. If the individual is introduced positively and his or her personal characteristics can transcend the unusual appearance, behaviour and visual difference, the community is usually welcoming. Personal Communities has experienced a welcoming community more often than not.

Tom was institutionalized in early childhood. Today, as a young adult, Tom lives in a group home and has no family

involvement. Although he does not use words, he conveys his interests and excitement in his activities by making loud sounds. In public, people are taken aback at first but soon become accepting, taking cues from his companion. He has his own charisma, which is quickly recognized. Tom attends church weekly. Two church members routinely sit with him and are learning how to include him in their activities. Their goal is to include him in their young people's group in the fall. One of Tom's staff members has sponsored him to apply for membership at a nearby Legion. They have gone to the Legion frequently and Tom has become known among the members.

- Most individuals who move from institutions continue to be dependent on programs. In general, most of these programs continue to congregate and segregate people with disabilities though they live in the community. In some ways, their days and lifestyles are often very similar to those they experienced in the institution. Many individuals are so busy in these programs that they lack the opportunity to fit inclusive activities into their schedule.

Jean, 36, talks often about her wish to meet a man. Jean entered the institution as a child and is now living in her own well-appointed apartment attached to a group home. Although she has welcomed the companionship of a community facilitator, she resists involvement in a group. She finds it hard to reveal her wonderful humour and warm personality. Instead, Jean is busy with activities at specialized programs. She has recently, however, shown her respect for elders of her aboriginal people and will try to work with a group of volunteers who provide a weekly lunch for their seniors.

- Almost without exception, people who move from institutions live in poverty in the community. This determines where they live — often on the outskirts of town or in the inner city, away from established community activities. This physical isolation limits their choices in community involvement. Low income also limits their ability to participate as equal and contributing members in many community activities.
- Many individuals are saddled with severe addictions to cigarettes, caffeine, or prescribed narcotic, neuroleptic or psychotropic drugs. All too often, these addictions are established in the institution for behaviour control, to stem boredom or to reinforce cooperative behaviour. In the community, these addictions are costly to support and hamper the individual's ability to change and adapt to their new environment. These addictions demand support and priority before full attention can be given to community participation.

In his nineteenth year, Richard sustained a head injury. For the next 15 years, he lived in several institutions. There he attained a massive addiction to cigarettes which were used as reinforcement for "good behaviour". Today he shares an apartment with a friend whose six month commitment to help him out has turned into plans to continue to live together and to begin a business together. During those first six months, however, the two were evicted twice because Richard constantly approached other apartment dwellers for cigarettes and would use strange behaviour for seeking attention. Richard's current landlord was introduced to Richard immediately upon his moving in. They are now friends and exchange video tapes. He is blunt with Richard about his behaviour in the building. The behaviour has disappeared but he continues to struggle with his lack of money to support his addiction. Richard plays a mean hand of cribbage and is searching for a group who meets regularly to play.

- Another barrier is the community's lack of experience in understanding, accommodating, accepting and valuing the contributions of people who are different. Some communities are not inclusive. Others are inclusive by nature. Most communities require support for interpreting the needs of the individual, and need encouragement to be more inclusive.
- Institutional life often separates people who live there from their families. While there are many reasons for this, distance, resources, family dynamics and intrusion of professional and technical support are common problems. Returning to the community does not always reunite families. These individuals are therefore unable to participate in family activities and celebrations and miss out on possible opportunities to make further connections through family networks.
- Another barrier is simply a lack of awareness of the importance of community inclusion. Family members often have misgivings and are reluctant to commit their encouragement toward participation in the community. Our society and the human service system places an emphasis on professional supports, technical advantages and systemic security. Meanwhile, natural supports are de-emphasized and even disregarded and discouraged. For example, friends or relatives are often encouraged to take the role of care-giver. Yet there is no recognition of the important subtleties of intimate relationships, which include equality, reciprocity and interdependence. They inevitably become lost.

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Stories must be told

It is clear to Personal Communities that positive stories of people who are welcomed and included by community must be told over and over. In that way, individuals, families and significant people in their lives let go of their misgivings. We can do no better than to end this article with a wonderful story.

Gregory

Gregory is a ten-year-old boy who entered an institution for children labelled "medically fragile" at two-and-a-half years of age. For almost six years his parents, joined by his home community, the Alexander Reserve, worked the system to bring him home.

In early 1990, Gregory returned to his reserve where extended family, community members, community school, and chief and band council welcomed him with open arms. In the fall of 1991, a round dance was held in Gregory's honour. The entire community, and special guests who had helped Gregory and his community along the way, attended.

One by one, each person was invited to offer their part in Gregory's story. Community members admitted that they doubted their ability to support Gregory at first but are now proud of their accomplishment. Family members recognized the strength of his parents' vision and understood that Gregory's return was part of a community healing process. Professional and government officials spoke of their early disbelief that became scepticism and then finally confidence in the community's ability to welcome and support Gregory. The physician who attended to all the children in the institution admitted that he at first believed that Gregory would not survive life in the community. He now believes that Gregory would not have survived life in the institution!

The members of his community are surprised at the suggestion that they have "moved mountains". "It's a natural thing for us to do," they say. "We want all of our members here. It's no big deal."

Catherine Duchesne is the Executive Director of Personal Communities.

