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ABSTRACT
              Based on the experiences of the staff of the Community
Membership Project of Bloomington, Indiana, this paper discusses how
community builders have collaborated with 10 older persons with developmental
disabilities to increase their community participation. The paper addresses
the initial stages of community building with older persons, the process of
getting to know an individual and constructing a shared vision, and the
cultivation of social networks. The role of the community builder is
described, which includes helping to guide the individual toward situations
where he or she will be seen as competent and as someone who has something to
offer, rather than as a recipient of services, where he or she will be
treated as an ordinary person without labels and stereotyped preconceptions.
The community builder is as invisible as possible in the assistance given to
promote independence and provides invitations to exploration through
experiential opportunities. Experiences of the Community Membership Project
indicate that participants in the program have become independent and able in
many facets of their personal lives. (Contains 10 references.) (CR)

Getting To Know You:
Collaboration Between the Community Builder and the Older Individual to Discover Interests and Develop a Vision

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Getting To Know You: Collaboration Between the Community Builder and the Older Individual to Discover Interests and Develop a Vision

Introduction

In Bloomington, Indiana, older persons with developmental disabilities are finding a place for themselves doing things they enjoy. Through collaboration with community builders, they have: studied a musical instrument, been a foster grandparent, volunteered in a food kitchen and at a radio station, taken a class with a ceramics artist, played cards with groups of senior center members, learned some country line dancing, and crafted wood items "from scratch" for sale. Some are working on obtaining a better job or more autonomous living arrangements. As they begin to be participants in the life of their communities, they are exploring new opportunities for social relationships beyond the narrow confines of those afforded by paid service providers or a few family members, at best.

The varied roles and new relationships taken on by these individuals were accomplished through a community building process which, despite its rewards, is challenging and time consuming. Achieving membership in the community for older adults with disabilities entails a concerted effort to discover hidden capacities and to compensate for devalued roles. People are not able to take on meaningful activities until they and those who are supporting them have gotten some idea of who they are (independent of their reputations within the service system) and of their positive potential. This paper will discuss the initial stages of community building work with older persons, the process of getting to know an individual and constructing a vision with him or her, which must occur *prior to* the "getting connected" stage and the cultivation of social networks.

The paper is based in part upon experiences of the staff of the Community Membership Project, a grant which has been funded by Administration on Developmental Disabilities. This training initiative grant was awarded to the Center for Aging Persons with Developmental Disabilities at the Institute for the Study of Developmental Disabilities in Bloomington, Indiana. The project's staff has been working with 10 older individuals to enhance their social roles and relationships as part of a demonstration component of the grant.

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The Community Membership Philosophy

Community membership has been defined as "the intentional creation of relationships and social structures that... extend the possibilities for shared identity and common action among people" (O'Brien & O'Brien, 1996). In other words, the community building process changes the lives of persons both with and without disabilities. In welcoming people who happen to have a disability, one by one, the community becomes a better place for all. It is a search for what connects us, not what separates us (O'Brien, 1995). The community builder helps guide the individual towards situations where he or she will be seen as competent, as someone who has something to offer, rather than as a recipient of services, where he or she will be treated as an ordinary person, without labels and stereotyped preconceptions.

Effective community building takes as its scope the whole person; the quality of pursuits undertaken during the day or after work is not unaffected by the quality of the person's housing circumstances, health status, and, where applicable, employment.

> For 59 year-old Rita, the journey to community membership has meant working towards significant change in her life. She dreams of getting out of the nursing home where she resides and leaving the sheltered workshop environment for a more typical employment situation. Initially Rita was told that a group home placement would be her only alternative because of her physical disabilities. However, after staff of the Community Membership Project asked Rita to let them listen to her desires and preferences, it became apparent that her specifications could not be met by an agency-structured group residential arrangement. Her wishes include living near her family, having privacy, peace, and quiet, not having her possessions stolen, owning her own telephone, and taking showers when and as often as she desires. With this information and continued effort, it is anticipated that Rita will be able to find an apartment and the supports needed to provide daily assistance.
>
> Rita used to be confined to the nursing home during both the day and evening. Her community builder helped her through a nine-month process to obtain a power wheelchair through Medicaid and has acquainted her with accessible public transportation. She now travels on her own to a neighborhood "soup kitchen" where she is a volunteer wrapping silverware in paper napkins and preparing carry-out containers. She is very pleased to be able to do something for others. In the meantime, Rita and her community builder are also working on her other plan of obtaining competitive employment with the assistance of a local provider agency. (adapted from Kultgen, et al, 1997)

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The Job of the Community Builder

When a paid staff person takes on the role of a community builder, the traditional staff/client relationship must be recast. "Distinctions between staff and clients and family members and ordinary citizens dissolve as the familiar patterns of interaction that maintain them shift, and people discover new possibilities for shared action." (O'Brien & O'Brien, 1996) A staff member who is accustomed to performing the role of teacher and behavior manager must relinquish his or her position of authority and be on equal terms with the focal person. The community builder assumes that the individual is ready to be in the community and works towards identifying and strengthening skills which are already present. Rather than purposefully attempting to eliminate behavior difficulties, the community builder facilitates positive situations and relationships which render the behavior non-problematic.

The traditional staff/client interaction is based in part upon control. This new interaction is built upon collaboration (Lovett, 1996). George Ducharme and Pat Beeman (1991) describe it as "walking with" a person, a partnership. We accept where the person is, go at their pace, and maintain a stance of commitment, presence, and responsiveness. When Irene, a project participant who was struggling with obesity and diabetes, decided to quit going to her weekly Weight Watcher's meetings despite no loss of weight, the community builder did not challenge her decision. Instead, she noted Irene's statement that only people with her disease could understand her weight problems and found a diabetes support group affiliated with the local hospital. Irene was pleased with the new group.

The community builder should be as invisible as possible in the assistance that he or she provides. Obtrusive support can make the person with a disability appear incompetent and/or not inviting the assistance and involvement of ordinary citizens. The community builder seeks to bring non-paid relationships into the life of the focal person. This means staying out of the way at the right times. For example, when exploring a local fitness center, the community builder decided to *not* answer all of Charles' questions about how to use the weight lifting equipment. As a result, Charles successfully solicited help from others exercising near him. The community builder trusts that people in the community do not need academic or professional credentials to be able to relate meaningfully to a person with a disability. Portraying oneself as the expert can

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backfire. As Judith Snow (1993) has said, "If you want to encourage participation in the community, the last thing (if ever) you should do is *educate* people." If the community builder actively invites others to relate to the individual, they may begin to provide some of the necessary supports. Like a supported employment coach who gradually fades from the work site, the community builder must be willing to work him or herself out of a job.

The "Getting-To-Know-You" Process

During this initial stage of working towards community membership, the community builder uses experiences in local places to reveal hidden interests and abilities. The individual may have been previously known by means of a narrowly defined reputation, including a thick file of "information" about diagnoses, identified areas of deficit, strategies to reach habilitation goals, incidents of behavior difficulties, etc. To discover the person behind these labels requires spending a considerable amount of time, one-on-one, in a large variety of contexts outside of a service agency. Many older persons with mental retardation have had little opportunity to be exposed to the ordinary goings-on of their neighborhoods and towns. They may have no idea what their options are, much less where they might "shine." In addition, those around them may have difficulty understanding the preferences they do have.

Choice-making is a skill which requires practice. Sometimes it is necessary to start with small choices before more significant decisions can be tackled. The community builder must be active in providing invitations to exploration through experiential opportunities. "The process is not one of checking what a person says they want and then hunting for it in the community. It often seems to be a process of accompanying, encouraging and directly assisting the person to discover interests and possibilities by trying things with someone who gives them... a sense of safety and confidence." (O'Brien & O'Brien, 1996) When Rose, a project participant, was asked where she wanted to go or what she wanted to do, she invariably answered "I don't know," "Anything," or "Go to the mall." But after Rose was accompanied for an evening of country line dancing instruction, the community builder felt confident that this activity was consonant with Rose's genuine preferences.

In the beginning, familiar places facilitate the development of trust and rapport with the

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community builder. For example, in forming a relationship with Steven, who has a visual impairment and had almost never left his house, the community builder gradually worked up to taking a car ride to a drive-through at a fast food restaurant. The goal is to find environments which have the potential to bring out the capacities and gifts of the individual, but valuable information can also be gained from trying settings which turn out to be less successful. The task of the community builder at this stage is to introduce the individual to a variety of community locations and listen and observe carefully- no more, no less.

Places which help us get to know a person are those which allow spontaneous social interaction, those which offer opportunities for nonverbal participation, and places associated with the individual's past. If they are explored without preconceptions, unexpectedly helpful information emerges. Social encounters happen in parks, which are frequented by dog walkers, pets and children. Clerks and wait persons in small, friendly, not-too-busy establishments are more inclined to interact. Visits to a shopping mall may turn up someone whom the focal person has known previously. When John, a nursing home resident, walked through the mall, his enthusiastic attempts to interact with babies in strollers provided a clue to previously unarticulated interests. Now John works as a volunteer in the local YMCA child care center. Public events such as civic ceremonies (building dedications, holiday tree lighting festivities, Veterans' Day commemorations, etc.) and spectator sports also allow for social interchange.

Nonverbal activities may provide clues in getting know people who are verbal, as well as people who are not. Tactile or interactive exhibits at museums, petting animals, going to a greenhouse, getting one's hair done, trying weight lifting equipment, listening to music with headphones at stores and libraries, taking a walk in the woods, are examples of varied excursions which can be undertaken with little need for spoken communication. For Rose, who seldom chooses to talk, the experience of getting pampered with a hand massage and colorful manicure at a local beauty school seemed to temporarily trigger an unusually pleasant mood and a striking enthusiasm for initiating conversation.

For older adults, locations which are connected to memories are particularly helpful. This may help us become acquainted with forgotten skills or aspects of their lives which were particularly enjoyable. When Irene visited the county historical museum, she shared a childhood

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reminiscence of being allowed to whittle wood in her father's workshop. As a result, the community builder later decided to acquaint her with wood carving classes offered by the local arts center.

Stores are some of the most frequently visited public spaces in our culture. These establishments can be helpful in the "getting-to-know-you" phase if they are places where more goes on than buying and selling merchandise. For example, music stores often offer opportunities for customers to try playing various instruments. Some bagel shops allow patrons to watch the entire bagel making process. A yarn store may have a table where people can sit, look at books, and get needlework tips from employees.

Even rides in a car can reveal untapped capacities. When John pointed at all the construction sites he passed as they drove around town, the community builder knew that it would make sense to investigate related activities in which he could get involved. John has since become a woodworker and a volunteer with Habitat for Humanity.

In the initial period of community building it is helpful to allow for spontaneity. Although the community builder makes plans around specific ideas of experiences he or she wishes to introduce, the focal individual should be allowed to take the lead whenever possible. It is helpful to follow up on any expression of interest, sometimes literally following the person to see where they are drawn to. For the community builder, keeping an open mind and accepting the uncertainty and lack of structure of this time will pay off later. Serendipity is a welcome compensation. A trip to a baseball game with one project participant was expected to test a likely preference for sports, but it also revealed an unexpected talent for dancing, which was demonstrated in the bleachers as a show of team support.

Listening with More Than Your Ears

Attentive and active listening is essential for developing a vision with the individual as to where they might make a contribution in the community. We can make "respectful guesses" (Lovett, 1996) about the preferences of persons who don't speak. We can educate our guesses by watching body language. The way a person moves his or her body indicates a response to the environment, including: posture (relaxed or rigid, open or closed); facial expression; eye contact;

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vocal tone, pitch and speed; gestures; and focus of attention (What holds their interest? For how long?). Also, we can be aware that behavior often serves a communicative function. Pete engages many people he encounters, strangers included, with an overly lengthy hand shake. This habit becomes more understandable when one knows that Pete lives in a nursing facility where he has very limited social opportunities.

Listening well means not always taking words at face value (a "yes" may be an expression of a desire to please) and paying attention to silences. It means being nonjudgmental and giving people time to express themselves. Mayer Shevin (1997) has raised the issue of conversational equality with people with disabilities, and the necessity to be aware that the person who asks the questions has more power than the person being asked. It is important to be sensitive about the nature and frequency of inquiries, he says, and to invite them as well as to make them. If we feel it is essential to ask personal questions, we should be willing to disclose personal information about ourselves. Shevin has also suggested that the biggest barrier to listening with respect is the presumption of incompetence; we must assume the individual has something meaningful to communicate in order to hear what he or she has to say.

Developing a Vision

During the getting-to-know-you phase, the community builder learns first hand about the person's strengths and preferences by spending time in a multitude of community contexts. Some time should also be spent talking with family members or others who have known the person in the past. It is particularly important to find out about periods when things went well. Having kept a journal or log is useful, as is having simply recorded an on-going list of "Things That Work" and "Things that Don't Work." For one man, things that work included opportunities for conversation, singing along with hymns, humor, walking on an outdoor track, ice cream, and listening to bird calls. Things that don't work included having to be quiet when others are talking, bingo, unfamiliar environments, and new situations.

With the information gathered during the first phase, one can now begin to organize and define the vision. The Community Membership Project staff have found it helpful to use an adaptation of the "Capacity Inventory" developed by Beth Mount (1995). Unlike traditional

client files, this inventory focuses on positive attributes which can form the basis of new relationships and valued community roles. The inventory takes into account likes and dislikes, strengths to play up, social identities which are important to the individual, preferred environments, skills and interests, and dreams for the future. These elements are then distilled into a few brief statements which describe the capacities of the focal person. A capacity inventory completed for Charles identified his love of social interaction and performing, his musical and dance skills, his love of sports and the local university campus, and the importance to him of his religious beliefs and independence. Of course, there are many other effective ways to formulate a vision, including the various person-centered planning processes which bring together a group dedicated to identifying what the person wants and how to get it (for example, Mount & Zwernik [1988]; Pearpoint, O'Brien & Forest [1993]). It is important to realize that a person's capacities or gifts need not be extraordinary talents. Judith Snow (1993) defines a gift as "anything you have or do which allows for a meaningful interaction with at least one other person." Therefore, she says, difference itself is something which can be offered to others: "...walking is a gift and not walking is also a gift; knowing how to dress is a gift and not knowing how to dress is also a gift." (Pearpoint, Forest & Snow, 1992). Often the best clues to what we can do well are the things we enjoy or appreciate the most. Personal experience, both good and bad, can also form the basis of gifts. Roger, who was unhappy living in a group home and now enjoys renting an apartment, helped a woman who wanted to leave a nursing home make informed decisions about her future living arrangements.

Participants in the Community Membership Project have been thrilled to be able to host a party, present a hand-made gift, bestow a surprise bouquet of flowers, make a speech, send Christmas cards with personal news, or deliver "meals on wheels." Making a contribution of aspects of ourselves is deeply satisfying to many of us, and yet older people with disabilities have had few chances to be on the giving end. They have been seen as needing "help", as perhaps unable to give at all. When we have gotten to know individuals and their sometimes surprising and delightful capacities, when we have glimpsed their dreams and hoped with them for the future, we are ready for the next stage of the community membership process, building connections to particular groups and locations and facilitating possibilities for genuinely reciprocal

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relationships.

References

Ducharme, G. & Beeman, P. (1991, Spring). Perspectives. *Communitas Communicator*, pp. 2-3.

Kultgen, P., Holtz, P., Harlan, J., Todd, J. & Kim, K. (1997). *Training in aging and developmental disabilities: Cultivating community capacity* (grant application). Bloomington, IN: Institute for the Study of Developmental Disabilities.

Lovett, H. (1996). *Learning to listen: Positive approaches and people with difficult behavior*. Baltimore, MD: Paul H. Brookes.

Mount, B. & Zwernik, K. (1988). *It's never too early, it's never too late: A booklet about personal futures planning*. St. Paul, MN: Metropolitan Council.

O'Brien, C. L. (1995, June). *We belong to each other: Building community with people with disabilities*. Keynote address to the Summer Institute on Community Integration, Louisville, KY.

O'Brien, J. & O'Brien, C. L. (1996). *Members of each other: Building community in company with people with developmental disabilities*. Toronto: Inclusion Press.

Pearpoint, J., O'Brien, J. & Forest, M. (1993). *PATH: A workbook for planning positive futures*. Toronto: Inclusion Press.

Shevin, Mayer (1997, April). *Liberation and conversation, bungee-jumping and bridge-building: Envisioning and creating positive behavior supports for our friends with rotten reputations*. Workshop presentation, Bloomington, IN.

Snow, J. (1993, May). Presentation to staff of the Institute for the Study of Developmental Disabilities, Bloomington, IN.

Snow, J. (1992) Giftedness. In J. Pearpoint, M. Forest & J. Snow (Eds.), *The Inclusion Papers: Strategies to Make Inclusion Work*, pp. 109-110.

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