

Judith

What are some of the most effective ways of assisting people who have lived most of their lives in places such as government institutions, nursing care facilities, and group homes to express their needs and desires to have a home that is their own? Jay Klein, Institute on Disability, University of New Hampshire, Oct. 31, 1999

This question reveals in part the nature of the discrimination or lack of understanding that faces people who are labeled disabled. A person who is considered to be an ordinary citizen express a need or desire in certain ways. Needs and desires are viewed and expressed differently when a person is considered to be disabled.

Typical citizens are perceived to have value to society at large. Value accrues to an "ordinary" person due to the various roles he or she plays or potentially will play in community. Such roles include child, spouse, parent, employee, employer, voter, member, decision maker, spectator, witness, and many more.

The words "need" and "desire" are used in relation to society's explicit or implicit obligation of providing citizens with the structures, supports and resources they require to fulfill these roles. For example it is considered "obvious" that a child needs an education in order to step into adult roles as he or she matures. Lively discussion takes place as the best methods of providing education but there is little question that education is necessary. Another example is when a person who "desires" both to be an employee and a parent "needs" to have child day care available to him or her.

A somewhat different use of the words "need" and "desire" arises from the increase in our culture of structuring relationships and activities based on commerce, or the exchange of money. Citizens are expected to have desires and to be willing to spend money in order to fulfill these desires. In a commercial context individual desires are encouraged and cultivated through such means as information and advertising.

This process creates a level of "need" that is no longer connected to role fulfillment and social obligation. Instead this sort of "need" is connected to a manufactured social structure that facilitates money exchange. In today's parlance it does not sound out of place to say: "I need an ice cream cone." or "I need a face lift."

In the realm of disability the word "need" is not connected to the word "desire", and neither the word "need" or "desire" is connected to social or commercial relationship. A person who has been labeled disabled is considered to be defective or deficient in some body part or physical, emotional or cognitive function. This defect or deficiency places the person outside ordinary social roles and so the person essentially loses citizenship in fact if not in name.

The person is also very likely to find themselves outside of most or all exchange relationships. This happens because the person is playing few or no typical social roles and so does not "fit" in ordinary exchange structures. For example, little advertising and information reaches persons who are labeled disabled. That which does very often does not connect with any actual ability to spend money. Thousands of dollars, even hundreds of thousands of dollars, may flow around a person who is considered to be disabled, but the actual individual personally rarely gets to make any decisions about how it is spent. Rather, the money is exchanged by various service providers, and the actual person is interacted with in many situations as if they were the exchanged commodity.

When a person is considered to be disabled our society attributes "need" to them. That person is considered primarily to "need" help and therapeutic or supervisory service. The individual is expected to "desire" therapy and service in order to fix or cope with deficiency and deficit. Only if such therapy and service were to result in this person no longer being perceived as being disabled, and as an ordinary citizen would they enter fully the social or commercial realms of "need" and "desire".

Consequently, if a person who is labeled disabled says that they want a home of their own, most people in our culture will interpret that statement to mean that the person wants to live in a residence where therapeutic or custodial service is provided and where this service is delivered in a context that does not include other individuals who also require therapeutic or custodial service, or perhaps only one or two such other people.

In order for a person to be able to express a social or commercial desire to have a home of their own, in the ordinary sense of that phrase, first they must have people around them who can listen to what they say in the same way that other people mean it. If a person is surrounded by people who think they need to be "fixed" or "supervised", no expression of desire will be heard in an ordinary way.

Secondly, the person themselves must be able to believe that they can and should have a place in the ordinary world of citizens. If they have come to believe that they are only disabled it would not occur to them that they can play roles and exchange resources in the same way that other citizens do.

The processes called person centred planning are a group of listening techniques that some people have used successfully. Such methods have allowed people to encounter the ordinary citizen in each other. These methods all include opportunities to discover the real interests, resources and abilities of people who have been excluded from community. They also reveal the commitment and creativity necessary for people to overcome the architectural, attitudinal, environmental and

other barriers that have limited people from participating fully as citizens.

In A Little Book About Person Centred Planning, by John O'Brien and Connie Lyle O'Brien, published by Inclusion Press, Toronto, 1998, I wrote the following comment:

"As I remember it there was no Person Centered Planning in 1978. This (book) could not have been thought up a mere twenty years ago.

I believe that the widespread adoption of planning that is focused on an individual with a disability label is a marker of a quiet revolution. Some perceptions have changed in some of our culture as this practice is taking hold.

First of all we have begun to believe that individuals who are called disabled are first of all people. Not many years ago this thought would be dismissed politely but quickly - still is in some places. Formerly the universal perception that disability invalidated all other characteristics of an individual gave rise to blanket, usually mass, treatment of labeled people. Instead "they" were viewed as dangerous, burdensome, non human creatures. To have a disability was to be without the capacity for relationship, participation, responsibility or intimacy. Now some of us are willing to see and support these human capacities in everyone.

Secondly, we have begun to believe in and experience the value of planning with individuals. To plan is to believe that the future is not already given - that it can be guided into better directions. Even more importantly we are willing to try planning alternative futures that may be better not just for the individuals themselves but also for the various communities that they may come to participate in. We dare to carry out our planning in ways that encourage communities to encounter the capacities, contributions and differences of labeled people in ways that benefit as many people as possible.

Thirdly, we are not centering our efforts on the caregivers and providers, as important as they are. We are focusing on the individual made vulnerable by being physically or functionally "different". We have created vehicles for discovering and giving strength to the directions desired by the central individual. By doing so we have stood behind our ethic that

normal is not always the best and usual is not always the way things have to be. In this we have added our voices to other voices of the latter part of this century. We are speaking against our cultural and political myopia. We are asserting that diversity in all of life is of great value and we plan to keep diversity as a regular part of our communities."

Of course person centred planning is not the only way that people have discovered to listen to a person so that he or she discovers a pathway to citizenship. Any method that causes people to get beyond the mask of disability can reveal that every person has many gifts to contribute to ordinary community. Once this mask is pierced people can become very creative in finding ways for people to be present in ordinary places and contribute uniquely to ordinary social and commercial situations.

Sometimes we want to assist people in listening past the mask of disability. We may want to use these methods, such as person centred planning, and teach these methods so that their power will be used more widely. There is a trap in this, however, since once we try to "help" people to be better listeners and to see the gifts in people who have been excluded, we also are treating them as if they needed expert intervention. This alone can stop people from acting as citizens who are creatively capable of devising ways to include unusual people in ordinary relationships and settings.

So
Discipline
Talent

There is no certain method that can be recommended to be sure that citizens are not disempowered by efforts to guide and teach. It is a matter of discipline to work with members of communities in such a way that their capacity governs the pace and direction of the work. Someone who wishes to assist people who have been labeled disabled to find homes in ordinary communities will cultivate this discipline gladly because in doing so the wall of disability that separates people in our society is broken down.

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The ordinary
Planning
Interdependence as a hidden
understanding as well
as value -