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VIEWING INDEPENDENT LIVING WITH A CRITICAL EYE

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This speech was first presented at a Region 2 Independent Living Conference held in June, 1983, at the Human Resources Center in Albertson, Long Island, New York.

Let me introduce myself by saying that I have been involved with Independent Living Programs in some way for the past seven years. During that time, two words have played a prominent role in all Independent Living programs... Services and Advocacy. Furthermore, it has been my experience that Independent Living programs, which have a staff that provides services and advocacy, often have a difficult time developing substantial consumer involvement -in particular, a large community network of consumers who are willing to advocate for community change on an active basis rather than expecting the staff to advocate for them -consumers who control and direct the staff rather than being direct by the staff.

In view of this dilemma, I believe it is time we assessed services and advocacy and re-evaluated our approach to Independent Living.

Today, I am going to speak about grass-roots development to build an organization which is representative of the people, about the natural benefits of networking and peer support which evolve out of the development of a grass-roots organization, and I am going to talk about the negative implications of services and the serviced society.

First, I would like to discuss the power of community-based Independent Living programs. Once Independent Living programs have done their ground work and established themselves within the community, they immediately begin to be approached by all sorts of groups. Political candidates and elected officials take an interest in the program. There are approaches to be on study commissions, offers of political involvement and a multitude of other opportunities, or, depending upon how you look at it, aggravations which present themselves.

Throughout all this development, traditionally, the staff members are

the individuals who determine which opportunities are in the best interests of the Independent Living Program in which they are to become involved. Furthermore, once a decision is made, staff members are the people who represent the Independent Living Program at the meeting.

Herein lies the problem. Staff members become the knowledgeable, professional advocates, and more importantly, they become the power. The more the staff does in the way of advocacy, the more they act to contradict the Independent Living philosophy and to deter the democratic process of an organization. Let me point out the contradiction by definition.

Independent Living is the ability of an individual to control his own life and to make his own decisions. Yet, what is the definition of advocacy - one who argues or pleads another's cause; to act on one's behalf. The supposition is that the individuals can not do it themselves; they need someone to do it for them. In other words, the individual is powerless. The individual needs the help of a professional. Likewise, when advocating for community change, Independent Living staff members are seen as experts. In this regard, consumers are reluctant to get involved. Disabled individuals in the community develop the attitude:

"I can't resolve the problems as well as staff. They're the experts. I'll let them take care of it."

or

"I don't know all those rules and regulations. I don't know anything. I'll let the people who do know, handle the problems."

Therefore, a number of negative outgrowths occur: first, staff members become inundated with assignments as individuals in the community keep presenting more problems which need attention; secondly, the staff is caught in a Catch-22 of wanting disabled people in the community to get involved but unknowingly

ostracizing them. Oddly enough, the more successful staff are at what they do, the more difficult it becomes to develop reliable disabled citizens who actively participate in the organization.

The third problem involves the development of dependency upon the staff by consumers to resolve community concerns. Fourth, consumers are denied the opportunity for growth, contacts and learning experiences as staff members are the Independent Living Programs representatives on all committees, boards and councils. And, finally, without major active involvement by disabled consumers, a select few make assessments and decisions based on their beliefs rather than the beliefs of the consumers in the community.

Unfortunately, this comes dangerously close to that which Independent Living was originally trying to circumvent. As John Fish, the community organizer points out, these are the basic elements of professional control, that is, the service professional knowing what is best for the client, as, theoretically the client is unable to judge the adequacy of professional decisions, behavior and standards. It is such that in a serviced society the role of the individual is diminished and the role of the knowledgeable professional magnified. Furthermore, if the role of the individual is diminished and participation becomes limited, then democracy itself is threatened. To equate the democracy of Independent Living to the necessity of democracy in the general populace, I repeat what DeTocqueville gravely warned 145 years ago,

"That unless individual citizens were regularly involved in the actions of governing themselves, that self-government would pass from the scene."

Likewise, what we have developing within the Independent Living movement is a direct contradiction to that which we set out to accomplish. We have developed a professional corps of power elite within the staffs of Independent

Living centers while at the same time perpetuated the powerlessness of the majority of people with disabilities. In effect, by providing Advocacy Services, we are denying people the opportunity to self govern, and in so doing, are establishing an obstacle to enable people to make their own decisions and to control their own lives.

Let me pause for a moment to note the terms power and control. Independent Living uses the term control in most of its rhetorical philosophy. Likewise, I am using the term power today - the power of individuals to exert control over their environment. Unfortunately, as with any minority group, isn't the real concern an inability to overcome the powers that be? Therefore, what I am proposing today and proposing for Independent Living organization is an empowerment of the people. It is time to let people have the satisfaction of accomplishment, let the people develop and learn by their mistakes, and let the people be the controlling elements of the organization. To accomplish this, Independent Living programs must rethink the philosophy of serving or helping the people and in turn must force individuals to do for themselves. No longer can we do for others. No longer can we, the staff, advocate for change. We must accept the slow growth process of a membership organization which can do for itself.

In addition, we must spend the majority of the organization's time, as Miles Rapoport of the Midwest Academy states, building local bases, developing the membership and making local structures. This is imperative in order to perpetuate and strengthen the Independent Living movement. It is also imperative because the whole growth process is indicative of the Independent Living philosophy.

The beauty of a community based disabled citizens Independent Living

program lies in its democracy and its power. Knowledge of rules, laws, regulations and the like are not the important elements of the group; rather equality, social justice, commitment and leadership are the dominating factors.

The first, equality, establishes an environment of acceptance; everyone's input is important and all comments are encouraged. This helps reinforce the importance of individuals and encourages the growth of pride and self-esteem.

Secondly, social justice evolves because of the group. Social justice is important because it is based on that which is right rather than that which is law. Whether a law for barrier-free design exists or not, a powerful consumer group is able to make a building accessible. Therefore, the concept of social justice reinforces the importance of individuals. Individuals within the group take pride in themselves when they see what can be accomplished.

The third area is leadership. It should be noted, leaders are not individuals who are the most knowledgeable about laws, or the best advocates. They are not even, necessarily, the most proficient spokespersons. But rather leaders are people with followers. Leaders are people who truly represent the constituency rather than declaring they are an advocate for the thousands of disabled people in the area. Leaders produce members.

Finally, the fourth element is commitment. When people feel they are truly a part of an organization and that their voice is important, a natural commitment of ownership for the organization develops.

All of this fosters the growth of the individual and the concept of Independent Living. What occurs is the group chooses issues which directly concern them. By being involved in the initial decision making process, interest is generated much more readily within the group.

Natural outgrowths of this group process are a peer-support group, re-

available for information sharing and networking; skills development in a wide variety of areas; community contacts; personal growth due to a sense of accomplishment, and a host of other benefits.

In this entire process, the role of the staff radically changes. Staff members are no longer the professional advocates. They now become professional teachers. Self-interest, in the removal of barriers or revision of policies, is no longer the primary concern. In developing a grass-roots organization, the primary concern of staff members becomes empowerment of the people to resolve their concerns.

It is also important to note, in the early stages of development of the organization, or as the transition is being made from staff dominated group to a member dominated organization, that the issues chosen are very localized and specific. For instance, the group decision may be to get a curb cut in front of a local supermarket. This is completely opposite to the advocates' approach to lobby in the state capitol for passage of a law or revision in an administrative regulation. This localized, specific issue strategy is adopted because the group is attempting to test their power. Furthermore, the group members are making a commitment of themselves, speaking their own concerns, and displaying their own values. Therefore, dignity, a sense of rightness, and a firm commitment that this is important to the people being affected, is tantamount. It is extremely important that this concern and commitment develop for there is a dark side within all of us. As Saul Alinsky stated so eloquently,

"There are ever-increasing numbers of people who yearn for the dark side of dependency where they can be spared the burdens of decisions and of personal responsibility."

Independent Living must combat this attitude and foster an environment of growth. It is for this reason, until the group develops a tremendous following and until the group begins to initiate coalitions, that State and

National groups be developed. In actuality, the development of these groups is probably premature before establishing local grass-roots organizations. But in reality, there is a necessity to advocate on the state and national levels, as quite simply put, many issues cannot be resolved on the local level. Yet, the local level and grass-roots can organize the future of Independent Living.

In conclusion, I would just like to note, as Independent Living Centers become more powerful and services become more prominent, we must always be on our guard to avoid falling into the trap of becoming the professional servicing the client. We must always work to empower the people. For if not, we run a terrible risk. As the cartoon character Pogo pointed out, "We have met the enemy and the enemy is us." We must not allow this to happen to Independent Living.