

What is the "Problem?"

by A.J. Hildebrand

Why is it that there are so many people in our community who are set apart, excluded, and forgotten? The "problem" is defined by the norms and values of our culture. In a culture that values health, wealth, productivity, achievement, beauty, intelligence, etc., those people who are perceived as lacking in these qualities (people who are "sick, poor, unproductive, unsuccessful, ugly, stupid") tend to be devalued, i.e., seen as having less value, perhaps even as less than human. Our culture has defined such people as needing specialized "care," and has invented sophisticated ways of setting people apart via segregated services and creating "client worlds" for people to live in.

A professional sub-culture has developed during the past fifty years which has defined people with disabilities as needing professional, institutional care, whether these be institutions out in the middle of nowhere, or right in the center of town. Two generations of citizens have grown up with the myth that people with disabilities "need" professional care. There is a grain of truth to this. Professional competence is important for certain needs. If one has a problem with mobility, then it is certainly important for someone who is an expert on adaptive mobility equipment to bring his or her knowledge and expertise to bear on the mobility problem. In another realm, if someone has severe emotional problems, a therapist can help put such problems in perspective, and may even be able to assist his or her client in finding healing and renewal.

The problem is not that professional services are not needed to help address some needs, the problem is that professional services have usurped the prerogative, and the responsibility, for meeting many needs which by definition must be met by "ordinary" people. The most basic need which by definition must be freely-given is the need to be loved. Love cannot be bought and paid for, nor can it be forced. Love is neither a requirement nor a duty in a job description. Love cannot be prescribed. Love, if it is love, can only come from one heart to another, from person to person. While to some people, this may sound trite, it is essential truth. All people need friends, not just friendly staff, but friends. We all need a home, not a place that is "home-like," but home. We all need something meaningful to do, not "simulated work." How do most people find friends, or a home, or something meaningful to do? Most people find these things through people who are a part of their lives—family, neighbors, friends, and associates. Obviously, we all want people in our lives because they care about who we are as people and have faith in our capacities, abilities, and gifts. We need to take the obvious seriously.

Many people have become subtly convinced that people with disabilities need to live in special places, with other special people, riding on special vans, going to special activities, and who in short, are made to live in a special world. When these dynamics are combined with a fear of the unknown, a fear of differentness, then not only are people with disabilities separated physically, but socially. They become "those people." "Those people" come to be seen as so different that many ordinary experiences, such as having a friend, owning a house, having a job, learning how to read, are not expected to happen—not expected by service providers, or by families, or by neighbors, or sadly, even by people with disabilities themselves.

The combination of dynamics described above results in a disenfranchisement of both people with disabilities and people without disabilities. Disabled people are seen as powerless clients who must have programs administered to them. Neighbors and friends are seen as "not qualified" to do anything relevant to the needs of people with disabilities. The mythology of a professional culture develops its own language and fancy acronyms that convince families, neighbors, and people with disabilities that their world must forever be a world of therapists, counselors, aides, doctors, houseparents, resident advisors, and so on. As one friend of ours put it, "There are two kinds of people, clients and staff."

When people with disabilities live in a clientized world, routines and roles become well-established. People (including the clients and staff) are expected to act in certain ways. Anyone who deviates from these expectations is at risk of being severely punished, either overtly or covertly. For example, someone who refuses to screw nuts and bolts together day after day at an activity program may be seen as "non-compliant." Someone who is expressing anguish over never having been loved may be interpreted as psychotic. Staff members who step out of their professional role are cautioned against "getting too close to the clients."

Fortunately (and ironically), we have found that there *are* people in our community who have not been socialized into the professional human service subculture. There are also some human service workers who do not identify with the professional mythology and who are able to keep their professional role in perspective. There *are* people who can and will strive to make a difference through a personal, committed relationship. There are people who, given the opportunity, will use their common sense, get involved, and share their lives.