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The Trojan Horse Effect: The Client Role and its Impact on Integration

Introduction Many people are familiar with the idea of the self-fulfilling prophesy, which has also been termed the expectancies construct. This construct asserts that people will fulfill the expectations held about them which will, in turn, further strengthen those expectations. At the core of this dynamic is the notion that people fill a variety of roles, defined as "…a combination of behaviors, functions, relationships, privileges, duties, and responsibilities that is socially defined, is widely understood and recognized within a society, and is characteristic or expected of a person who occupies a particular position within a social system" (Wolfensberger, 1998).

Such roles have a powerful impact on most aspects of our lives including our behavior, the activities we engage in, the people with whom we associate, where we spend time, and so on.

Often, people with disabilities (and other devalued people) fill roles that are largely negative. As Wolfensberger (1972) has written, such roles include non-human, object of ridicule, waste object, the object of pity, the burden of charity, the eternal child or child once again, the holy innocent, the sick or diseased organism, and once who is already dead or at least dying. In addition, the role of client has been discussed in the literature as having negative effects on those who hold it, particularly when those people have been devalued by society (Wolfensberger & Thomas, 1994; Lemay, 1999) The role of client, often considered to be benign, actually has powerful negative effects, especially since it has an insidious way of becoming life-defining once a person receives human services. One might consider this the "trojan horse effect" in the sense that the negative consequences of the role are packaged in the benevolent gift of service, only later to be set free to do their damage.

Some of this damage affects efforts to promote social integration. Although the past quarter century has seen tremendous strides in physical integration of people with disabilities, social integration lags far behind (Reidy & Sullivan, 2000). It is only within the last several years that I have become aware of the impact of the client role on social integration. This became clear as I was re-examining a definition of integration I had been using in my teaching. When teaching about integration, I had used the phrase "affording people the opportunity to participate in all aspects of community life" as the primary definition of integration.

Upon reflection, it became clear that this definition of integration was much too passive. "Affording people…the opportunity to participate" sent the message: We'll let you, we won't stop you, but we won't help you very much either."

In addition, this definition focused more on physical presence, not on relationships between persons. Nor did it adequately describe what contributions could be sought and made by people with disabilities. While physical presence was certainly important, and so was social presence, the deeper challenge seemed to be the process of uncovering a person's unique gifts or potential contributions and then finding a place within the larger community where those could be made manifest. Or, as O'Brien & Lyle (1986) write, "creating a context where a person's identity can emerge."

In order to reflect this deepening understanding of the true intent of integration, I revised my earlier definition to the following: "Integration is the process of helping people fill valued roles that are derived from their unique gifts and talents such that those are recognized and appreciated by other community members."

This definition made an explicit link between valued roles and a person's unique gifts and talents. It attempted to reflect a distinction between generic social roles, such as neighbor, citizen, friend, and personal social roles which allow expression of what makes us unique, of our identity. So the role of artist, or peacemaker, or giver of hospitality are expressions of one's personal social roles. It is not sufficient to merely to fill generic valued roles; there also needs to be an active process of discovering and enhancing each individual's personal social roles.

There is a dramatic shift in emphasis between these two definitions of integration. The first focuses largely on physical presence and can be accomplished by enabling persons with disabilities to co-exist in the community with other citizens, perhaps engaging in some mutual activities. The second focuses on the cultivation of a person's full identity—which includes both generic and personal social roles, gifts, as well as needs and vulnerabilities. Integration is seen as means toward a much more fundamental goal, that of the realization of each person's full identity through their participation in and contribution to community life.

With this shift in emphasis, a whole new set of concerns and considerations emerges. Rather than only focusing on the activities a person engages in, we need to pay more attention to the cultivation of relationships as well as opportunities for people's identities to emerge. When integration is viewed as a process rooted in the identification of each individual's interests, gifts and talents, the powerful obscuring effect of the role of client is revealed. When a person's primary identity is that of a human service client, it becomes far more difficult to envision and enlarge other, more positive and personal, aspects of their identity. In fact "client" is merely a sanitized version of equating a person with their disability, such as when we term someone "a cripple," "a downs baby" and so on.

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Although many citizens fill the client role at some points in their lives (e.g., by using lawyers, accountants, doctors and so on), there are key differences (for a more detailed analysis of the differences see Wolfensberger & Thomas, 1994). First, the client role is not life defining for most citizens. It does not supplant other, more positive, roles such as that of productive worker, contributing community member, friend or family member. Second, the client role does not have as many strings attached for most community members. People with disabilities who "accept" the client role pay a huge price in terms of limitations on their autonomy and control. In contrast, other community members who fill the client role retain their ability to choose from various options which may be presented to them while they fill that role, reserving the final option of severing the relationship with one's doctor, lawyer, etc., if the advice is found wanting. Third, the combination of the first two effects leaves people passive and powerless, perpetuating the sense of being a victim. Consequently, one of the key leadership challenges facing proponents of social integration is to assist people with disabilities to fill roles that supercede the role of human service client.

How is the Client Role Shaped?

Wolfensberger writes "Expectancies are a core element in the role concept, both in the minds of people who view another person as occupying a certain role, as well as in the mind of the person who fills a role, or is being role-cast. When a person is perceived—at least in a general way—to live up to the expectancies associated with a particular role, then people take for granted that the person is carrying out, or filling, that role" (1998). There are many ways in which these expectancies are communicated such as through the language used, activities, appearance, physical settings, and the other people with whom one associates.

There are a myriad of ways in which the client role is crafted. Any kind of "special service" contributes to the client role. It starts with "early intervention" programs, then proceeds to "special education," "turning twenty-two," "adult services," and so on. While it would be a useful exercise to thoroughly analyze the ways in which the client role is shaped and then communicated, an underlying belief is relevant to the discussion here: That persons with disabilities are not full persons with their own identity. If we believed in the full personhood of people with disabilities, we would have to acknowledge that they possess the whole range of human attributes, including both needs and gifts. As a master identity, the client role severely limits the possibility that someone would be seen as a person with something to contribute. The client role is a form of objectification when applied to people with disabilities: It changes the nature of human interactions, making it one-way, not mutual, removing the possibility of asking the question "Who are we in relation to one another?"

Others have written and taught about this topic for many years. What I am pointing out is not news. Yet, despite the fact that these ideas have been circulating in the field for a long time, the everyday lives of people with disabilities in the year 2001 rarely reflect this insight. If anything, at least in the arenas with which I am familiar, we have lost ground as the expansion and institutionalization of formal community services has proceeded.

Possible Effects of the Client Role on Integration

What impact on integration is likely when people with disabilities are seen largely as recipients rather than participants? First, it is likely that people's presence will be merely tolerated rather than welcomed within the settings where they are integrated. Unless people with disabilities (and their supporters) are seen as having something to contribute to a group, a neighborhood, or a community, they will be met with a lukewarm reception by other community members.

Second, the effort needed to initiate and sustain integration will be enormous and unrelenting, with most of the onus on someone from the "outside" (usually staff) to do the work. If there is no one from the outside, then nothing happens because the welcome is not on the basis of the person with disabilities having anything to offer. People working in supported employment have learned that they best way to help someone get and keep a job is to emphasize the skills a person possesses to perform the job, not focus on tax benefits (the carrot), the Americans With Disabilities Act (the stick) or other "special" incentives to hiring people with disabilities.

Third, people with disabilities themselves do not believe they have anything to offer, or see themselves as like (or perhaps equal to) other people. Such a self-perception can be deeply internalized and be virtually impervious to change even when a person fills what others perceive as valued roles in the community.

Fourth, the people around an individual make no effort made to identify and cultivate gifts and instead focus only on needs. At the systemic level, this results in continued expansion of formal services because the assumption is that "clients" need "services," leading to a greater and greater chasm between the "service world" and "community life," also leading to resentment from community members that resources have been siphoned away from their communities, with nothing being given back. And so we come full circle, with the presence of people with disabilities being merely tolerated in community life because they are seen as making no contribution.

Cultivating Valued, Personal Social Roles

It is difficult to imagine how people with disabilities might live in this day and age without at least some association with formal services, at least in developed countries. Given this reality, what are some strategies to reduce the effects of the client role and expand the number of valued roles a person receiving services might fill, even within the context of formal services? Others have written and taught at great length on this topic (see, for example, Bogdan & Taylor, 1999; O"Brien & Lyle-O'Brien, no date; O'Brien & Mount, 1989; Wolfensberger, 2000) For the purposes of this article, I would like to identify several approaches that seem to have made a difference in practice.

First, a deep consciousness of the deleterious effects of the client role as a life-defining identity seems to be important. This can be accomplished by a variety of educational strategies but the important part is to shake people from complacency. So often, people who have "grown up" in formal services as workers, service recipients, families, and so on become inured to the negative effects or take for granted that the reality they know is the only possible reality. It is especially difficult to envision that people with disabilities could live in the world as full persons when there are few examples of people with disabilities living rich full lives and filling roles that supercede that of client.

Along with a consciousness of the negative effects of the client role is a knowledge of the importance of valued roles and a clear understanding of strategies to help people fill valued roles. Many service workers and even families have a general idea of the importance of valued roles but lack a clear a systematic "roadmap" to enable people to fill those roles. Or, as mentioned earlier, people are focused on the acquisition of generic valued roles instead of tailoring these roles to the particular individual. What may be most effective is an explicit process to identify valued social roles that can be filled by each person and then to strategize about what specific skills a person would need to learn to fill those roles, what other supports would need to be in place, and so on. The clearer and the more personalized the better.

Individualized support practices must be in place, which start with some kind of person-centered planning engaged in by people who care about the person, can

envise the possibilities for the person to use their gifts, and who are willing to make a commitment to helping things happen. Such individualized support practices are best accomplished within a flexible organizational structure that is capable of implementing person-centered plans through such mechanisms as flexible staffing, individualized funding, individual or family governed services, and so on. At the very least, the organizational structure needs to be responsive to the individualized nature of this work and not consider group "community outings" or other such activities to be sufficient.

Another very important strategy is the deliberate cultivation of personal relationships with unpaid community people that emphasize the mutuality of the relationship, even if the person with disabilities needs support and assistance to do so. Without this emphasis, efforts to promote community participation will be forever linked to the presence of service workers and be constrained by staffing ratios. In addition, more efforts must be made to identify, cultivate, and support "champions" in all walks of life, whether they be families, service workers, or community people. A recent survey of integration efforts in Western Massachusetts (Reidy & Sullivan, 2000) showed that one of the most powerful preconditions for a person to be integrated was the presence of someone who could serve as a "champion."

The importance of leadership in promoting social integration by those who hold positions determining funding priorities and oversight cannot be over-emphasized. A long term commitment over many years, including the dedication of resources and policies supporting integration is responsible for the progress which has been made and will need to be sustained into the future.

Finally, commitment must be made to participate in broader community improvement efforts, linking the well-being of people with disabilities to that of all community members. This strategy is important if we are ever to get beyond the idea of integration as a "treatment strategy" (O"Brien, personal communication, 2000) intended to benefit only the person with a disability.

Conclusion

This paper has proposed that integration is a means toward a more fundamental goal than community presence: the realization of each person's full identity through their participation in and contribution to community life. By shifting the emphasis, the damaging effects of the client role have, hopefully, been highlighted. Although these ideas have been in circulation in the field for twenty or more years, physical presence and activity-based integration continue to be the standard by which success is measured. In order to make further progress, we have to think very differently about the role of people with disabilities in community life, which has broad implications. As Bogdan & Taylor (1999) write: "Thinking about community for people with developmental disabilities might help us think about it for ourselves. What we want for them—being part of the community—is what we search for…ourselves. To try to solve their problem is to address our own" (p. 3). Perhaps that is one of the gifts that people with disabilities offer to us all.

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