DISABILITY ISSUES – an Overview

Al Condeluci
412-683-7100

Historic Devaluation

History is riddled with examples of groups of people who have been oppressed and shunned by societies. From religious persecution in earliest times (and still today) to ethnic devaluation and cleansing various peoples of the world have been stigmatized and through this stigma, devalued. In more recent times forms of genocide in Germany, apartheid in South Africa, aboriginal separation in Australia, ethnic cleansing in Bosnia and racial discrimination in the United States have offered vivid examples of how people can be treated in hostile ways.

All of these forms of discrimination and devaluation have some common tracks that are easily seen when looking at these cultures. These are:

- The devalued people are labeled and stereotyped.
- These people are often congregated in formal ways into their own space.
- The devalued people are thought to be a problem, or pose a threat to those in authority.
- The devalued people are seen through their label or difference from those in authority.
- The devalued people cost the society in either material or economic ways.

If we look at society today, perhaps the most discriminated block of people in the world are people with disabilities. Every society on Earth have had difficulty including and welcoming people with disabilities. Certainly in the United States, the climate for inclusion and full community participation for people with disability is still a major challenge.

If you consider the actions of discrimination listed above, people with disabilities are clearly caught in this web of devaluation. In spite of services, treatment, legal rights (ADA), and charitable approaches, people with disabilities (and how they are viewed) are stark when considered.

- People with disabilities are labeled at the drop of a hat. Usually these labels are medical in nature and create huge cultural stereotypes.
- People with disabilities are still readily institutionalized. Although these institutions have shifted from large, gothic settings to smaller group facilities, they are still institutions in format. In fact, the public funding for community supports for people with disabilities is only offered as a “waiver” to the institutional bias of Medicaid.

- People with disabilities are thought to be a problem for society. Our federal and state governments look to offer funds to address the “disability problem.” Beyond this, citizens have grown cautious of having people with disabilities move into their neighborhoods into group homes. Even with the Fair Housing Act, some communities actually have ordinances that specify how much distance must be allowed between homes or places where people with disabilities live.
- Once labeled, people with disabilities become that label in the greater community. Notions like “Jerry’s kids,” “TBI’s,” “CP’s,” “MR’s” are all labels that seemingly identify a class of people. These labels begin to dwarf any similarity that people might have to others.
- For any given classification of disability there are efforts to promote funding to address the problems posed by the disability. To this extent disability has economic costs the society.

The Medical Model

The lens that society generally uses to address disabilities is found in a medical model. That is, the framework for treatment, and the overarching perceptions that typical members of community have about disability is that of illness or sickness. Certainly in the area of Brain Injury Rehabilitation, the medical model is prominent and influential.

Many theorists have looked at the Medical Model as a framework for services. This framework is summarized as follows (Condeluci, 1991):

Medical Paradigm

- The Problem – the person with the condition
- Core of the Problem – rests in the person
- Actions of the Paradigm – to classify/congregate/treat
- Power Person – The Expert (doctor or therapist)
- Goal of the Paradigm – to fix/heal/change the patient

Since the medical paradigm is so persuasive in human services a deeper examination is warranted. Consider these variables (Zolla,1986):

- The profession is expert and in charge of the care/treatment
- Care/treatment is administered through a chain of authority
- The person who receives the treatment is labeled and expected to cooperate
- The main purpose of entry to the paradigm is to restore or fix the person to fit in
- The ailment that brings the person to the paradigm is labeled via a diagnosis

- Literature and research is done and utilized in understanding the specific features of the ailment
- The patient is usually offset and congregated with other like situations
- Most options for control are held by the expert or representatives of the paradigm
- Usually the ailment is overshadowed through the therapeutic approach
- The ailment can only be treated by the expert or their agent
- Usually the expert has some credentials or license to treat the ailment
- The patient is exempt from any real responsibility
- Most aspects of the ailment are treated in separate and distinct facilities designed for the ailment

Further exploration of the medical model identifies the following aspects. Each of these aspects has both internal and external ramifications. Internally they begin to shape how the "patient" sees him or herself and creates a "sickness identity." Externally these elements begin to shape how the greater community comes to think about, and then treat, people with disabilities.

- <u>Deficiency Orientation</u> – Without question, medical paradigms focus on what is wrong with the person. They initiate on problems, abnormalities, deficits and struggles. Classic medical interpretations ask: "What is wrong with you?" "Where does it hurt?" "How long have you had this problem?"
- <u>Cause and Effect</u> – Since medical paradigms are scientific in nature, they usually function from a point of cause and effect. That is, as the paradigm prompts a study and analysis of the ailment, it is drawn to make predictions about what to expect. This focus on predictability is not necessarily negative, however, when coupled with a deficiency orientation it has a tendency to lean toward the negative.
- <u>Treatment from a Diagnosis</u> – Most people with disabilities have some diagnosis that sets them apart from the norm. This diagnosis defines the parameters of the deviance and gives the expert some anchor to understand their ailment. Indeed, the labeling process creates an entire tone about the person and sets everyone up to expect certain things to occur. To this extent it begins to look for problems.
- <u>The Sick Role</u> – perhaps the most powerful manifestation of the medical paradigm is found in review of the concept of the sick role. Here the person is given the authority to be sick and to surrender autonomy to the agent of the paradigm so that they may be made better. In most cases it is the paradigm that defines what is well and what is sick. Further, only the paradigm can decide if sickness has indeed turned to wellness. It sets the rules, decides who fits, determines what the outcomes should be, establishes its own mechanisms to measure success, and then retains authority to proclaim wellness (Illich, 1976).

- Micro Change – A key point in the medical model is that of fixing people. The onus for change rests squarely on the shoulders of the patient. It is he or she who must change, adapt, or adjust to the existing world. Very little attention is paid to macro (environmental) change.
- Clinical Efficacy – This relates to the strong drive that medical model agents have to validate their practice. Most agents of the medical paradigm must have a license or some sort of sanction to practice. To achieve this, the budding professional must put in countless hours of schooling and tutelage under the direction of those thought to be the masters. However, these same masters, in a way, are guardians of the paradigm. They are rewarded and validated by the paradigm so protection and defensiveness is not difficult to understand.

In and of itself, the medical model is not bad. Indeed, all of us have had some good experiences with the medical model because it does work – when the goal is to address sickness. However, the goal of brain injury rehabilitation is not to eradicate sickness, but to return people with disabilities to their community. Our real goal is not to fix the disability, but to help change the community to accept and respect differences that people with disabilities might have. Before we examine the elements of community, we must focus our goal.

INTERDEPENDENCE, INCLUSION and SELF-DETERMINATION

Interdependence

To frame a philosophy for community demands that we find a paradigm that goes beyond the medical model. To this extent, the Interdependent paradigm has been suggested (Condeluci, 1991). The term interdependence is not a new one. Although it has been used in human services, it is more popularly applied to geopolitical issues. Quite simply it is a tem that implies an interconnection, or an interrelationship between to entities. It suggests a connection or partnership between these entities in an effort to maximize potential for both groups.

Interdependence is about relationships that lead to a mutual acceptance and respect. Although it recognizes that all people have differences, as a paradigm, it promotes an acceptance and empowerment for all. It suggests a fabric effect, where diverse people come together in a synergistic way to create an upward effect for all.

Interdependent Paradigm

- The Problem – Limited or non-existent service
- Core of the Problem – In the system or community
- Actions of the Paradigm – To create supports and empower
- Power Person – The person with the disability

- Goal of the Paradigm – Develop relationships

Perhaps the best way to appreciate an interdependent paradigm is to consider it compared to the Medical Model.

Comparison of Paradigms

Interdependence	Medical
Focuses on Capacities	Focuses on Deficiencies
Stresses Relationships	Stresses Congregation
Driven by the Person/Disability	Driven by the Expert/Professional
Promotes Micro/Macro Change	Promotes that the Person is Fixed

This review offers a fundamentally different perspective on disability; the approach is a radical shift. Most of what happens in the early stages of brain injury rehabilitation is offered in a medical model. As we look to prepare folks for return to community, and indeed, those services that are designed to be offered in the community, must be addressed from an Interdependent model.

Inclusion

If there were one word that captures the ultimate goal of rehabilitation for people with brain injuries, that word would be "inclusion." Inclusion means to be incorporated and welcomed into the community as you are.

In thinking about inclusion we must be sure not to mix it up with the concept of "integration." The notion of integration is very different from the concept of inclusion. To a large extent, integration demands that people fit in, be alike and reach for similar standards. Although one might be able to make this fit in the civil rights movement, the notion of having to fit in, or be like the "majority" is not realistic in the disability rights movement. To expect people who might not be able to achieve a sense of similarity to be like the majority is insensitive and inappropriate.

Inclusion, on the other hand is a concept of bringing people to the community regardless of their differences. Rather than attempting to change or alter their differences, or trying to create a forced similarity, inclusion suggests that people join in as they are. Inclusion respects differences and honors diversity, but still allows for full community participation. It is a term that implies a welcoming to all.

In thinking about traditional efforts to achieve inclusion for people with brain injuries, the effort is typically on functional or technical elements. That is, the system has been lured into thinking if only people would be able to walk, talk or think better, these gains would lead to greater options for success in community.

Consequently the majority of programs for people with brain injuries focus on these technical or clinical efforts.

Still, people with brain injuries are excluded. Try as we might, the traditional medical/clinical model of brain injury rehabilitation has not achieved the outcomes everyone wants. In some simple way this should not seem strange or odd. Indeed, how can we truly include people with brain injuries when the very structure of organized brain injury programs is to diagnose, assess, congregate and offset these same people. The very nature of the medical/clinical model is to exclude.

To address inclusion or to create an inclusive organization is to stop excluding people and find ways for them to become included in their communities as they are. To suggest that people must pass some readiness test, to be fully fixed, or to jump through any other hoop is to focus energy on the wrong aspects.

To be more inclusive is to change the very foundation of our perspective on people. We need to understand that the microscopic medical model format of typical brain injury programs is often a detriment to inclusion rather than a path to the community.

Self-Determination

Self-determination is a key concept in human services today. Building on the concept of consumer choice and control, self-determination is defined to be another way of saying freedom. It means that people with disabilities have authority over how their lives will be lived, where and with whom. It also means that people have control of the resources needed for their support.

Within the past 5 years, the concept of self-determination has been focused and explored around the United States. Most students of self-determination agree that the concept revolves around 4 critical principles. These are:

- Freedom: The ability to plan a life with supports rather than purchase or be referred to a program.
- Authority: The ability to control a certain sum of dollars to purchase supports.
- Support: Through the use of resources, arranging formal and informal supports to live within the community.
- Responsibility: Accepting a role within the community through competitive employment, organizational affiliations, and general caring for others within the community; and accountability for spending public dollars in life-enhancing ways.

Recently a number of states within the United States have begun to incorporate the concept of self-determination into the public funded human service system. The key actions they recommend to achieve self-determination are:

- Transfer of financial control to the consumer through individual budgets.
- Use Person Centered Planning for people's choices.
- Promote cooperation and collaboration.
- Community awareness activities of resources.
- Communication and information sharing.
- Change in laws, rules, policies and procedures that empower people.
- Training, education and leadership development for people with disabilities.
- Data gathering and analysis.
- Quality enhancement and evaluation activities.

Beyond these items, self-determination is a principle that will continue to factor into rehabilitation and will be sure to influence brain injury rehabilitation. We need to listen to people and assure that they are heard. We must also understand the elements of community resources. To this extent, an understanding of the community is critical to framing a philosophy of treatment. It is imperative to know that brain injury rehabilitation is not really the target or end point of our efforts – IT IS THE SUCCESSFUL RETURN TO COMMUNITY.

UNDERSTANDING CULTURE AND COMMUNITY

Defining Community

Community is a network of different people who come together on a regular basis for some common cause or celebration. A community is not necessarily geographic, although geography can define certain communities. More to an understanding of community is to appreciate that community is really based on the relationships that form, not on the space. Indeed, space can be an abstract notion when it comes to understanding community. Think about the global community created by the Internet. These communities are not bound by geography, but are relationships forged by commonalities found in cyberspace.

The term community is the blending of the prefix, “com” which means “with” and the root word, “unity” which means togetherness and connectedness. The notion of being “with unity” is a good way to think about the concept of community. When people come together for the sake of a unified position or theme, you have community.

The term culture is analogous to community, but culture relates more to the behaviors manifested by the community. People bound together around a common cause create a community, but the minute they begin to establish

behaviors around their common cause they become a culture. In a way, culture is the learned and shared way that communities do particular things.

This basic definition of community and culture blend two key features. One is the fact that community is a network of different people. Often these differences may be vast or prominent. Still, the second feature, that of common cause, is what pulls them together. The similarity of the common cause and the regularity of the celebration is the glue that creates the network. Regardless of who the members of the network are as people, their common cause will override whatever the differences they may have and create a powerful connection. Then, as this collection of people begins to frame behaviors and patterns, they become a culture.

Elements of Community

There are a number of key elements that come to define communities. These are:

Common Theme – All communities rally around a common theme or point of reference. This theme is very essential, because it frames the community's reason for being. For families it is the lineage or heritage. For workers it is the mission, vision, or agenda of the organization. For religions, it is the theology or belief structure. For any gathering there is a reason. This is the common theme of community.

Membership – The people who gather to celebrate the theme are called the members of the community. These are the individuals who show an interest or passion for the theme.

Rituals – Any time two or more people come together on a regular basis around a common theme, one of the first things that develops are community rituals. A ritual is a deeply rooted behavior that the community holds as important. The rituals can be deliberate or habitual, but all the members of the community feel they are important and carry them out.

Patterns – The patterns of a culture refer to the movements and territory of the members of the community. These patterns relate to not only territory, but to social relations between the members. Patterns disclose not only where people position themselves, but whom they care about as well.

Jargon – The jargon of a community are the words, phrases or language that the community needs to celebrate its theme. These words are specific to the community and the sooner members know the words, the sooner they become successful in navigating the community.

Memory - Memory relates to the history and legacy of the community or culture. Memory captures and retains key elements of the past and serves as the glue of culture.

Gatekeepers – The gatekeepers of a community are influential members of the community who hold formal or informal power or authority within the culture. Gatekeepers can be either positive towards new things, or negative. The gatekeepers play a critical role in community because they either escort or reject new people, ideas or products into the community. The positive gatekeeper is the key to community inclusion because they create the first step for cultural shifting toward something new or unique. Without a gatekeeper, new things rarely penetrate into culture.

These elements of community are critical to understand if we are to focus a philosophy related to brain injury service. If we don't have a solid sense and understanding of our goal and target, how can we ever expect to make it happen for the people we serve?

CONCLUSION

All of the items discussed in this section become integral to a philosophy of treatment. For far too long people with brain injuries have not experienced the successes in community that all of us desire. Keeping these elements in mind set a framework for refocus and are step stones to community inclusion.