# INTERDEPENDENCE, INCLUSION and SELF-DETERMINATION

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## 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, 2009). 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                           |  |
|-----|------------------------------|-----------------------------------|--|
| Fo  | cuses on Capacities          | Focuses on Deficiencies           |  |
|     | esses Relationships          | Stresses Congregation             |  |
| Dri | ven by the Person/Disability | Driven by the Expert/Professional |  |
| Pro | omotes 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 disabilities, 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 disabilities focus on these technical or clinical efforts.

Still, people with disabilities are excluded. Try as we might, the traditional medical/clinical model of disability 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 disabilities when the very structure of organized disability 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 disability 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:

<u>Common Theme</u> – 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.

<u>Membership</u> – 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.

<u>Rituals</u> – 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.

<u>Patterns</u> – 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.

<u>Jargon</u> – 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.

<u>Memory</u> - 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.

<u>Gatekeepers</u> – 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 disabilities 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.

(Please feel free to explore more about Interdependence, Inclusion, and Self Determination by visiting <a href="https://www.alcondeluci.com">www.alcondeluci.com</a>)

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