

The Need for Culturally Appropriate Strategies in Promoting Self-Determination Among
Individuals with Disabilities

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Abstract: While strategies promoting self-determination have been effective in the United States and other Westernized countries, these identical approaches and “best practices” are not necessarily effective in cultures that do not embrace the same individualistic values. In these settings and situations, culturally appropriate approaches are necessary to engage these individuals with disabilities and their families while promoting similar principles underlying self-determination, empowerment, social justice, and rights. This article provides an overview of some traditional strategies promoting self-determination and/or empowerment and then discusses how these are not always useful in practicing with culturally diverse population groups even in the United States. Alternative approaches are described such as the access to culturally diverse resources and community-based rehabilitation that adhere to specific cultural beliefs, values, and practices but still promote some level of empowerment among individuals with disabilities. Evidence drawn from the literature as well as professional experience will be used to discuss the relevance and implementation of these respective strategies in terms of their strengths – namely, empowering individuals with disabilities as well as supporting/embracing family, religion, spirituality, and overall cultural diversity.

Key Words: culture, empowerment, diversity

Introduction

There is increasing interest in the relationships between cultural diversity and self-determination as evident in the growing literature (Leake, Black, & Roberts, 2004; Richter, 2007; Trainor, Lindstrom, Simon-Burroughs, Martin, & Sorrells, 2008; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003; Wehmeyer & Schwartz, 1997; Wong-Hernandez & Wong, 2002). Although there have been multiple definitions of self-determination as employed within Western models, the following is commonly cited:

“Self-determination is considered a combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior. An understanding of one’s strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society” (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2).

Self-determination has benefited numerous individuals with disabilities in the West. It has fueled the international Disability Rights Movement resulting in beneficial policies, programs, and services. While practice and research indicates the benefits of certain strategies promoting self-determination in countries such as the United States and other Westernized countries, these identical approaches and “best practices” are not necessarily proving to be effective in cultures that do not embrace the same values.

Contrasting beliefs and practices regarding self-determination generally involve individualism, competition, future orientation, and self-help (Turnbull and Turnbull, 2001; Zhang, 2005). The importance of “normalization” including independent living and inclusion are not necessarily valued universally (Kim & Morningstar, 2005; Leake, Black, & Roberts, 2004; Richter, 2007; Trainor, 2002). It is the thesis of this paper that culturally appropriate approaches are necessary to engage culturally diverse individuals with disabilities, their families, and their communities to promote the general principles of empowerment, social justice, and rights.

Contributing to this growing concern is an important culturally-related trend emerging in many countries throughout the world, which involves the growth in immigrants, refugees, and cultural minorities over the past several decades. For example, there has been an increased influence of the Hispanic culture in the U.S. as the Latino/Hispanic population has become the largest ethnic minority group (U.S. Bureau of the Census, 2011). Historically, Hispanics in the United States have experienced a proportionally higher rate of disabilities than those identifying as non-Hispanics (U.S. Bureau of the Census, 2000).

Additionally, racial groups such as African Americans and American Indians/Native Americans have held higher disability rates than Caucasians and Asians in the U.S. Concurrently, there has been a disproportionate number of racial, ethnic, and cultural minorities including African American, American Indian, Asian, and Hispanic students identified as students in need of special education (Artiles, Rueda, Salazar, & Higareda, 2005; National Research Council, 2001; Richter, 2007).

In developing culturally appropriate services, it is imperative to consider ethnic and cultural sub-groups. Differences in disability prevalence exist between culture sub-groups. For example, Youngtae (2001) reported that among Asian-Pacific Islanders there is a higher risk of disabilities among Laotians, Hmong, and Cambodians followed by Vietnamese and Pacific Islanders. The failure to differentiate among sub-cultures of any racial or ethnic group is considered “racial lumping” (Sue, 1990; Wong-Hernandez & Wong, 2002). As emphasized by Wong-Hernandez & Wong (2002, p. 102), “If rehabilitation professionals are not sensitive to their consumers’ cultural needs and characteristics, the number of clients who achieve below their potential, drop out of programs, or who fail to become rehabilitated and employable will continue to increase dramatically.”

Importance of Culturally Tailored Practices

Westernized approaches to promote self-determination cannot necessarily be transplanted into non-Westernized countries. First and foremost, whether and how a society defines and recognizes disability will dictate whether and how they intervene, including the specific service delivery mechanisms they adopt. As indicated by Scheer and Groce, 1988:

“Universally, societies have explanations for why some individuals (and not others) are disabled, how individuals with disabilities are to be treated, what roles are appropriate (and inappropriate) for such individuals and what rights and responsibilities individuals with disability are either entitled to or denied” (p. 38).

Religious explanations, such as committing sin and offending spirits, often blame the disabled for their disability. Punishment often accompanies medical explanations for disability including punishment arising from accidents, alcohol and drug abuse, genetic disorders, infections, and injuries. These explanations serve as the foundation for the various responses of families and communities to individuals with disability. Many cultures that do not view disability as a matter of difference but rather as a handicap do not believe individuals with disabilities can be empowered.

While most world cultures appear to recognize that the environment creates disabling conditions, many individuals experience “powerlessness” and, consequently, do not think change is possible. As indicated in this quote:

“[Some persons] ... have so internalized the general negative attitudes towards them because of their disabilities that they cannot believe that collective action can improve their lives. They have seen the problems as inherent in their medical conditions and have not been urged to join others to demand structural changes that would render the environment useful for them” (Asch, 1986, p.13).

Finally, a significant number of cultures do not necessarily consider the traditional notion of self-determination as relevant especially to individuals with disabilities. One example involves the Japanese culture which places group needs and wants over individual needs and wants (Ritts, 2000 as cited in Brightman, 2005). For many, nuclear families if not extended families are strongly connected, and it is through these family ties that identity, support, and security is established. As indicated by Bremer, Kachgal, & Schoeller (2003), achieving self-determination is not just a matter of acquiring necessary knowledge and skills; it also involves having a conducive environment that is facilitated by key individuals and institutions.

Principles and Strategies Promoting Self-Determination

There are several core principles that characterize self-determination that are not universal across cultures. Individualism is one of these principles, in which primary emphasis is placed on virtues such as self-reliance, individual needs and individual rights (Leake, D. W., Black, R. S., & Roberts, K., 2004). Non-western culture groups may focus less on the individual and more on family through valuing relationships and interdependence (Hall, 1981). This is evident both in the Hispanic culture and among African Americans who have strong family ties which permeate throughout the community.

Another principle and commonly used strategy to promote self-determination in the United States involves independent living and the idea of fostering a least restrictive environment among individuals with disabilities. Again, this runs contrary to the cultural values of non-western groups. For instance, traditional Pacific Island cultures emphasize family life. As supported by McFarlane, Farley, Guerrero, and Galea'i (1996, p.24) “The concept of independent living when described by such terms as empowerment, advocacy, personal choice, and living independently, goes against Pacific Island cultural practices of respect... family choice and involvement, and living and being with the family.”

Alternative Culturally-Based Approaches to Self-Determination

Alternative approaches are being explored and implemented both in non-western countries and among non-western immigrant groups within the West. Two key approaches to reduce dependency and promote self-determination in culturally sensitive ways are (a) to increase the availability and access to culturally diverse resources; and (b) to implement community based rehabilitation (CBR).

Access to Culturally Diverse Resources

Although access to resources is an important element for meeting the needs of individuals with disabilities, access to “valued resources” is a crucial component for empowerment. Lord & Hutchison (1993) describe this distinction:

“When they experienced powerlessness, most of the participants had access only to resources which they perceived as being different or specifically for “rehabilitation” or “welfare.” Beginning to have access to the same valued resources and opportunities as other community members was important for people’s empowerment process” (p.14).

Access to culturally relevant valued services are necessary for culturally diverse individuals with disabilities. As recommended by Hampton (2000) in terms of services for AAPIs (Asian American and Pacific Islander) with disabilities, the same may be true for a wide range of cultural groups, i.e., services for culturally diverse individuals with disabilities must match the cultural, linguistic, religious, and psychosocial characteristics of that individual.

One of the most common factors contributing to the underutilization of rehabilitation and mental health services among Hispanic populations is that families serve as their own support services. The notion of actually needing professional services is not desirable. Therefore, Cuban immigrants generally do not seek advice from outside the family even from clergy although they usually have strong religious beliefs in Catholicism (Wong-Hernandez & Wong, 2002).

Similarly, there is a reported pattern of underutilization of social services (including mental health services) among Asians. Chinese immigrants to the United States frequently experience difficulties with counseling styles and approaches (Leong, 1986). Smith and Routel (2010) reported that professionals often develop goals that are incompatible with individual and family beliefs. Hence, many families decide to keep their issues private.

To address these challenges and eliminate barriers, resources must become more culturally relevant and available to the individuals, families, churches, and others that need them. Services must be delivered in a culturally competent manner guided by professionals and paraprofessionals who are culturally competent. Organizational staff must become knowledgeable of cultural values and norms of their respective community members and receive ongoing training in cultural diversity. At the very least, outreach services should include staff who are bicultural and bilingual to ensure more effective service delivery.

Relevant best practices and/or model programs that focus on delivering culturally competent services should be identified and adopted by all service organizations. This may involve family goal setting, rather than individual goal setting, as part of the self-determination process. Professionals, clients with disabilities, their families, and significant others (who may or may not be familial) should communicate. Networks within communities including partnerships

of service organizations, churches, and neighborhood groups should be established. Dissemination of information into the community must be available in native languages, perhaps using audio-visual materials to give “voice” to information.

It is important to note that culture is constantly changing, especially among second and third generation immigrants who may combine their parents’ cultures with aspects of their new culture. As a result, this dynamic may actually open the door and facilitate the adoption of new practices. At the same time, the dynamic nature of culture may create difficulties for traditional rehabilitation and social services to keep up with such cultural changes. Already these organizations may be struggling to effectively address the cultural and linguistic needs of diverse clients. This is true of most non-profit entities facing limited and/or diminishing resources themselves. As a result, another alternative strategy may be useful, that of Community Based Rehabilitation.

Community Based Rehabilitation in Culturally Diverse Settings

Over the past several decades, community based rehabilitation (CBR) has been used in developing countries with limited means and resources. CBR is considered “a strategy for enhancing the quality of life of persons with disabilities by improving service delivery, by providing more equitable opportunities, and by promoting and protecting their human rights” (Helander, 1993, p.8).

Community-Based Rehabilitation represents a participatory approach with a focus on assisting individuals with disabilities and their families, while supporting broader community development initiatives. The ideals of CBR echo those of self-determination in the recognition that individuals with disabilities deserve the right to quality of life. However any supports provided are to be compatible with local values and mores, inclusive of natural supports, and made available at low cost.

Evidence has emerged demonstrating the usefulness, effectiveness, and positive outcomes associated with the implementation of CBR in addressing not only the basic needs of individuals with disabilities but also in empowering them in the process (Mitchell, 1999; Wiley-Exley, 2007). Moreover, Community-Based Rehabilitation not only recognizes the role of culture as a common determinant of health, the CBR guidelines emphasize the need to consider cultural factors as an essential element for ensuring sustainability of CBR programs (World Health Organization, 2010):

“Cultures vary, and what may be culturally appropriate for one group of people may not be the same for another group. To ensure CBR programmes are sustainable in different contexts, it is important to consider how they will affect local customs and traditions, what resistance to the programme may be expected and how this resistance would be managed. It is important to find a balance between changing inaccurate beliefs and behaviours related to people with disabilities and adapting programmes and activities to the local context. Community-Based Rehabilitation is becoming increasingly widespread” (p. 37).

As indicated by Bwana & Kyohere (2001), regarding the development of the CBR program, The Association for Spina Bifida and Hydrocephalus (ASBAHU) in Uganda:

“Even the traditional cultural support system of the extended family seemed unsupportive. Since unity is strength, parents of ASBAHU came together under the old African Philosophy of, *‘I am, because we are’*. They chose interdependence over independence.”

While many CBR programs have been created through the grassroots organizing of families within communities, there are others that have been initiated in conjunction with religious institutions. One exemplary CBR program is the Karagwe Community Based Rehabilitation Programme (KCBRP) under the Development of the Anglican Diocese of Kagera in Tanzania, East Africa. Organized in partnership with the neighboring Anglican Church of St. Peter, its mission is to “enable the community to provide services with and for people living with disabilities in villages within the Karagwe District.” To be successful, KCBRP works with the local government and non-governmental organizations (NGOs) as part of their networking initiative.

It is important to note that self-determination as practiced within the CBR models is not about “independent living”, per se, but rather “to the extent that supports are provided to enable that person to retain control over the decision-making process and to participate to the greatest extent in the decision-making or problem-solving process, he or she can be self-determined” (Wehmeyer, 1998, p.10). According to the Center on Self-Determination (2011, p. 1):

“In order to care for oneself and be an active part of the community, people with disabilities may desire assistance. Each has the right to determine their life goals and what kind of support is needed to achieve them. Those who assist people with disabilities work towards providing access to life opportunities at the highest potential.”

Therefore, a community-based approach which relies upon the assistance of natural supports fits well with adhering to the underlying elements of self-determination.

As indicated throughout the literature, “community” is very much a component of the empowerment process. Wallerstein (1992) stated how empowerment is a “social-action process that promotes participation of people, organizations, and communities toward the goals of increased individual and community control, political efficacy, improved quality of community life, and social justice.” Even in the United States, culturally diverse groups prefer community supports (especially the church) as opposed to institutionalized care through traditional medical or rehabilitation systems (Leong, Wagner, & Tata, 1995). As described by Wong-Hernandez & Wong (2002):

“...the Hispanic culture of Cuba views life as a network of personal relationships. The Cuban relies and trusts persons; he or she knows that in times of trouble a close friend or relative can be counted upon for needed assistance. A Cuban relies less on impersonal secondary relationships and generally does not trust or place much faith in large organizations. Such an attitude is not unique to Cubans, but rather is typical of most Latin American Societies” (p. 9).

By embracing the notion of Community-Based Rehabilitation, individuals with disabilities are able to become more self-sufficient and contributing within the context of their own community. This creates a more sustainable, effective service delivery system that respects the central place of “family” and other “natural supports” in the life of community.

Conclusion

When supporting culturally diverse individuals with disabilities and their families, it is important to consider cultural factors and to implement culturally-tailored service systems.. Self-determination strategies are more likely to be successful when incorporating family and community into the empowerment process. As stated by Wehmeyer:

“When the emphasis is not placed on self-determination as independent performance, absolute control, and success, and instead on (a) providing individuals with adequate opportunities to be the causal agent in their lives, make choices, and learn self-determination skills; (b) enabling them to maximally participate in their lives and communities; and (c) ensuring that supports and accommodations are in place, people with significant disabilities can be self-determined” (1998, p. 14).

Implementation of these strategies – namely, empowering individuals with disabilities by supporting/embracing family, community, and overall cultural diversity is imperative in developing effective and sustainable policies and services.

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