

Asian Americans with Disabilities: Influence of the Disability Rights Movement on
Culturally Competent Social Work Practice

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Abstract: This article discusses the implications for culturally relevant social work practice with Asian Americans with disabilities based on the goals and philosophy of the disability rights movement. Standards of practice within the social work profession, especially in the health care and rehabilitation settings, have included changes in conceptual framework and practice roles in response to the disability rights movement. Using a case study as an example, the article focuses on the cultural values of Asian Americans with disabilities to identify obstacles to incorporating mutually shared premises into social work practice. Some of the concepts of the disability rights movement need to be redefined in a culturally competent way so that social workers can respond appropriately to the needs of Asian Americans with disabilities. The implications are that social work practice must integrate and apply cultural values with support of the full functioning of people with disabilities.

Key Words: social work, culturally relevant approach, Asian Americans with disabilities

Introduction

In 1990, the United States Congress passed the Americans with Disabilities Act (ADA). This landmark legislation, designed to promote and protect the rights and interests of all people with disabilities, was one of the most significant pieces of legislation in the history of the disability rights movement. It is often referred to as the “emancipation proclamation” for persons with disabilities. The significance of this act is that it provided the full range of protections and rights as the 1964 Civil Rights Act did for other minorities (Meinert & de Loyola, 2002). The disability rights movement arose to respond to a newly identified social problem of oppressive marginalization of people with disabilities. The movement sought to empower people with disabilities to take control of their own lives and create public policy and practices that would eliminate or at least ameliorate the problem of systematic exclusion from mainstream society.

The movement embraced the social barriers model as one of several new models of disability, replacing the medical model as the existing framework. This model contends that it is society’s response to an impairment that disables a person, not the impairment itself (the actual bio-physical condition). Furthermore, this societal response limits disabled people’s ability to fully participate in society and to exercise their rights. From this perspective, disability is seen as a social justice issue; a societal induced oppression that could be remedied by societal action such as passing appropriate laws that would reduce or eliminate the oppression (Winter, 2003).

Another model developed during the disability rights movement was the minority group model. This model emerged as an alternative to the deficit orientation (Mackelprang & Salsgiver, 1996). The minority group model asserts that discrimination against people with disabilities is rooted in the cultural beliefs and values of the culture. From this perspective, the major problems confronting people with disabilities are similar to other disadvantaged groups that have encountered discrimination as a result of race, ethnicity, gender and age.

The expansion of the independent living center concept was a natural progression in the disability rights movement – the concept that people with disabilities can practice self-governance by making their own life decisions. Independent living centers define independence as the “freedom to choose”. The goals of the independent living center for people with disabilities are to increase self-determination and minimize dependency on others by offering services in the community that are consumer controlled (Winter, 2003). Consumers of these programs and services should be involved in their planning and implementation (Brown, 1994). Centers seek to minimize dependence on the intervention of professionals and maximize the use of advocacy, peer support, and self-help by assisting people with disabilities remove barriers that undermine the ability to carry out one’s own decisions (Winter, 2003).

The social work discipline shares many values parallel to the disability rights movement such as the focus on changing the environment and providing resources to clients based on an empowering process. Given the fact that the core values and underlying conceptual and philosophical underpinnings of social work and the disability rights movement are basically compatible, social work policy and practice should be more closely aligned with disability rights advocates in upholding ADA definitions of disability rights and moving toward the common goal of supporting the full functioning of people with disabilities. However, the social work discipline has not been committed to serving people with disabilities. Many students are ill prepared to work with this population.

Besides training to prepare social workers to work with people with disabilities, cultural competent social work practice with minority persons is virtually an untouched area of training and research in the social work profession. Most research on culturally competent social work practice focuses on how cultural norms, beliefs, and behaviors impacted the minority client’s interaction with the mainstream environment. There have not been many social work studies focused on working with minority clients with disabilities. It is unclear if the approach to assist clients with disabilities will be appropriate for minority clients with disabilities. By using client self determination as an example, the authors will illustrate how this widely accepted social work value that is consistent with the disabilities movement may actually be in conflict with providing culturally competent social work practice.

We ask the question: “What are the issues that must be addressed to ‘fit’ culturally competent social work interventions with Asian Americans with disabilities?” We use some of the concepts of the disability rights movement and redefine them in a culturally competent way so that social workers can respond appropriately to the needs of Asian Americans with disabilities. The focus on Asian American people for the discussion is mainly due to the growing number of this population nation-wide, and because some of their values conflict with those of the disability rights movement.

Using a case study, this article suggests some ways to make social work practice more culturally competent when working with Asian Americans with disabilities. The lack of disability rights perspectives in social work practices will also be discussed. Finally, a culturally competent social work model that focuses on self-determination and other concepts of the disability rights movement are redefined in a culturally relevant way so that social workers can respond appropriately to the needs of a diverse population group with disabilities.

Case Study

Mrs. Tran is a Vietnamese-Chinese woman diagnosed with stage-two breast cancer who was referred to the oncology social worker after her initial appointment with the oncologist. As part of the case management services in oncology, the social worker routinely assesses clients newly diagnosed with cancer. After a full assessment of her family situation and other psychosocial issues, the bilingual oncology social worker asked if Mrs. Tran had any concerns. Mrs. Tran started to become tearful and very upset. Mrs. Tran calmed down after some grief counseling and then asked the social worker, "How am I going to tell my daughter about my cancer?" The oncology social worker tried to work with Mrs. Tran regarding issues of communication within the family and suggested some ways of approaching such an important issue. Mrs. Tran then said to the social worker, "You don't understand, my daughter is deaf and she cannot understand me!" Mrs. Tran explained that she moved to San Francisco from China about 15 years ago. At the time of the immigration, her daughter Lia was one year old. Due to a high fever, Lia subsequently lost her hearing. Lia was referred to an agency that serves people with disabilities and a social worker was assigned to her case. Lia was admitted to a pre-school for deaf children when she was three years old.

When Lia was at home, Mrs. Tran tried to speak with her even though she was fully aware of Lia's disability. Due to long working hours and a lack of resources, Mrs. Tran did not learn to sign in English. As a matter of fact, to be able to sign Mrs. Tran would first have had to learn English. Mrs. Tran became frustrated in the process of learning English and gave up after a few months in the ESL classes. Although Lia was learning fast and able to adapt in the pre-school environment, both Mr. and Mrs. Tran communicated with Lia using some simple gestures. Lia was fourteen years old at the time of Mrs. Tran's diagnosis and was doing very well at school but basically didn't have any substantial communications with her parents.

Mrs. Tran also asked the oncology social worker why misfortunes had to happen to her family. She answered the question herself by saying it must be the punishment of their ancestors' sins. She believed in reincarnation and how the crimes and sins one committed in his/her last life could come back to haunt him/her. When asked if the case worker assisting Lia could provide her with resources to learn how to sign and teach Lia to write in Chinese, Mrs. Tran said that there was no social worker assigned to Lia anymore because Lia was doing well in school and seemed adjusted. Now Mrs. Tran was wondering how she could tell Lia about her diagnosis and how Lia would feel about it.

In order to provide a culturally appropriate intervention, the oncology social worker contacted the school Lia was attending and discussed the situation with her teacher. The teacher referred the oncology social worker to a bilingual classroom

assistant who also knew how to sign. A family meeting was set up for Mr. and Mrs. Tran, Lia, the oncology social worker and the bilingual classroom assistant. Many issues were discussed and many questions regarding Mrs. Tran's diagnosis were raised. Another family meeting was scheduled with the Tran family, the classroom assistant, the oncology social worker and the oncologist to further explore Mrs. Tran's treatment options and the care she might require once she started treatment. Although the long-term communication problem was not resolved, Mr. and Mrs. Tran were encouraged to learn simple sign language that is internationally used and easier to remember. By learning this kind of sign language, they did not have to be so fluent in English.

This case illustrates some of the barriers a monolingual Chinese family experienced when their child became deaf. A systems approach or "person-in-environment" perspective that emphasizes environmental influences on personal functioning should have taken into consideration the family structure and communication when the child was diagnosed with a disability. In this case, if Mr. and Mrs. Tran were taught to sign in Chinese and if Lia had learned both English and Chinese, the family might have been able to communicate with each other after Lia became deaf. By treating the individual only and not considering the functioning of the family as a unit, we risk minimizing the support family members can offer each other, especially when working with a culture that values family and interdependence.

Lack of Disabilities Rights Perspective in Social Work Practice

This case illustrates the lack of a social work case management model to work with this family that would promote not just personal adjustment, but the well-being of the family. There are other indications that the social work discipline is not well prepared in this area. Social work policy and resulting services to people with disabilities continues to be fragmented and contradictory in spite of the momentum of political and social changes that occurred as a result of the ADA in the 1990s. Long before the ADA, Howoritz (1959) recommended that social work should serve to enhance the social functioning of a person with a disability. However, social workers did not take leadership roles in the field of rehabilitation at that time and continued to focus on a more treatment-oriented casework model. This approach, based on the medical model, limited the role of the social worker and the scope of the involvement in advancing the disability rights movement.

Although some believed that social work was one of the few professions ready to assist with the complex needs of a person with a disability and the family (Quinn, 1995), the role of social workers in rehabilitation diminished in the 1970s and 1980s, neglecting a population that was severely lacking in services that could be provided by social workers (Meinert & de Loyola, 2002).

The lack of social work involvement in the disability area was due, in part, to the lack of a sufficient knowledge base about people with disabilities (Horowitz, 1959, Meinert & de Loyola, 2002). Furthermore, social workers were not trained to view disability using a human diversity perspective. Long held attitudes and perspectives needed to be realigned to view disability from other perspectives rather than just using the medical model. Social work educators needed to remind students to overcome their

own biases and prejudices and be aware that even when overt discrimination is not evident there is often a culture of benign neglect for persons with disabilities.

Today, there is evidence that more experienced and educated social workers generally recognize and accept change in their role and their relationships with their clients from one characterized more by paternalism and control to one of equality and partnership. However, an exploratory study of disabled individuals' experiences with social workers indicates that concerns remain about stereotyping and the lack of a focus on autonomy, self-determination, privacy, and equality. Specifically, less experienced social workers prejudge individuals on the basis of the disability label and fail to seek the advice of consumers themselves (Gilson, Bricout & Baskind, 1998). This suggests that social work training in this area should include the leadership role of people with disabilities, an approach that would include support for self-determination and empowerment of people with disabilities in a collaborative effort with the social worker (Stainton, 2002). Solomon (1976) defines empowerment as "aiming to reduce the powerlessness that has been created by negative valuations based on membership in a stigmatized group," and identifies several elements of social work practice that may enhance empowerment. These include collaborative partnerships, a focus on client strengths and a person's environment, and ensuring that people are active participants in determining their future direction.

Culturally Competent Social Work Practice and the Disability Rights Movement

The Asian American and Pacific Islander (AAPI) population (reported as an aggregate group until Census 2000) has doubled each decade from 1.5 million in 1970 to nearly 10.7 million in 2000. Since 1990, the AAPI population has grown 41 percent, faster than any other racial/ethnic group in the United States. Although often combined for political or data reporting purposes, Asians Americans and Pacific Islanders are, in fact, two distinct population groups, both of which encompass more than 35 distinct ethnicities, each with its own traditions, culture, and languages. More than 3,000 distinct languages and dialects are spoken by both Asians and Pacific Islanders and more than 100 languages are commonly spoken in the United States. In Hawaii more than 70% of the population is classified as Asian, or mixed Asian (Census Bureau, 2000). This large number of Asians living in Hawaii calls for special attention from social work providers to deliver culturally appropriate interventions. Several concepts pertinent to working with people with disabilities, and how these concepts are suitable to use with Asian Americans with disabilities, will be analyzed in the following sections.

Self-Determination, Individualization

Person-centered planning is a concept in the field of mental retardation that identifies a new approach (Russo, 1999). Brown & Ringma (1989) point out that a major review of disability services in Australia clearly promotes a consumer perspective in planning and managing services. The social work values of individual self-determination and promotion of social justice stress a commitment to identifying and acting upon a person's needs and expressed preferences in order to empower consumers toward self-development and actualization (NASW Code of Ethics, 1996). The concept of

autonomy, defined as the individual's capacity to formulate and act on plans and purposes that are self-determined, is a fundamental concept in most theories of rights and an explicit goal of the disability rights movement (Stainton, 1994).

It is important to recognize that the disability rights movement has historically been a self-help movement, and has sometimes taken an adversarial role toward professionals, including social workers, who disabled advocates perceive as consultants who are often unsupportive of self-determination (Mackelprang & Salsgiver, 1996). One of the main premises of the independent living philosophy is that people with disabilities are the true "experts" regarding their own needs and issues, and that those who have disabilities are best suited to understand and guide someone else in a similar situation through peer support (Brown, 1994). Independent living encourages people with disabilities to assert their capabilities and feel empowered enough to take control over their lives. Whether people with disabilities do in fact choose to act autonomously is not as important as that they have the means and capacity to do so if they wish. More recent studies in social work discipline indicated a change in how to work with people with disabilities. Beaulaurier & Taylor (2001) suggest that effective social work practice is going to require a refocused conceptual framework that will support and promote self-determination and respect for the uniqueness of each individual. They suggest that community organization, advocacy skills, and the role of the educator should take on more importance in working effectively with people with disabilities.

Within Asian American culture, the family provides an expanded version of "self" for many disabled individuals and is the largest single provider of support within the home and the community (Hsu, 1985). Social work practice can be consumer driven and still include the family as part of the treatment team, by incorporating a holistic view which focuses not only on the individual with a disability but also on the needs of the entire family unit. A holistic approach implies that the social worker practice from a family strengths perspective, especially in the presence of severe disability. It also validates the Asian American value of interdependence rather than independence (Triandis, et al., 1988). The social worker should facilitate identification of the unique needs, strengths, and cultural values of the family. A customized person-centered plan that incorporates this information can then be created. In particular, the role of the social worker as an educator would be more fully utilized. Many individuals and families need assistance in developing skills to explore the range of options and choices available, including community-based services and natural support systems such as churches, recreation centers, social organizations, etc. The family system would become the "experts" in identifying resources, services, and supports that would meet their needs. Individuals and families can then make decisions based on their own cultural values and identified natural supports. The social worker can act as a service broker, the "expert" in guiding the person-centered plan toward the goals in a collaborative partnership with the individual and the family (Kaplan, 1999). However, the Asian American individual or family may place a higher value on respect for authority and professional expertise than acting autonomously and may choose to exercise their option of deferring to the social worker as the decision-maker (Hirayama & Cetingok, 1988).

Social Barriers Model, Empowerment

Systems change should be another level of social work practice that could be incorporated into this model of responding appropriately to the needs of Asian Americans with disabilities. Social workers must gain knowledge about how particular issues are viewed by Asian American individuals with disabilities and their families, such as concerns about isolation and a lack of connectedness and support in the community.

Full inclusion into society and the community is a goal of the disability rights movement. For many families and individuals, “person with a disability” has gone from meaning “person with severe limitations” to “person with rights to accommodation and inclusion” (Beaulaurier & Taylor, 2001, pg. 84). This change in perception has resulted in a shift in the expectations of individuals and their families regarding the concept of quality. No longer are a majority of families satisfied with supports based on segregated custodial models. The demand is for individualized models that maximize the individual’s abilities, and full participation in home, school, work, and relationships. Families have also come to expect more teamwork from other professionals and community members who are involved in the life of the disabled individual in eliminating barriers to community inclusion (Gilson & DePoy, 2002).

Bradley (2000), discusses “inclusion” as a transforming goal directly related to the movement of people with disabilities out of institutions and re-entry into communities and families. Families are the largest single providers of support to people with developmental disabilities (Fujiura & Braddock, 1992, cited by Freedman & Boyer, 2000). Family members, usually parents, are the backbone of their community support system, often serving as an alternative to institutionalization. The notion of inclusion shifts the delivery of service from a system that was challenged to provide better surroundings and opportunities than those available in institutions to one that supported involvement in typical community activities based on the needs and choices of the individual. The goal is to help connect and support individuals with disabilities in school, home, community and work (Knoll & Peterson, 1992 cited by Bradley, 2000). This approach has as its basis individual self-determination and includes “circles of support;” friends, neighbors, family members, and the presence of brokers or facilitators. Circles of support can assist individuals in making social connections and getting access to other needed services and natural supports in the community.

The social worker should act as a facilitator and liaison to eliminate barriers to community participation. This should be a collaborative teamwork effort with the person with a disability, the family, community members, and other professionals who are involved in the life of the individual. The Asian American value of collectivism or shared responsibility validates the community as an important source of support. Inclusion and integration of the person with a disability into the community and settings that promote self-determination benefits the family as well, because others will support them as they provide stimulation, socialization, and assistance. Linking disabled people to community-based services and natural support systems may require outreach that is sensitive to Asian American cultural values of “shame” and a view of disability as a family matter. More traditional Asian families, as well as some newly immigrated families less acculturated to Western thinking, may still perceive disability as a punishment due to some wrong doing of their ancestors (see case study for details). This can be perceived as the negative effect of interdependence, that the family is also

stigmatized. This perception may prevent families from seeking assistance or declining services due to fear of losing confidentiality.

Lack of information due to language difficulties will require that interpreters and written material be available in an individual's and family's native language. Social workers must also be aware of the health literacy level of the Asian American individual or family, which is a measure of the ability to understand technical terms and professional jargon that goes beyond a basic ability to speak English (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Besides familiarizing themselves with the disability literacy and correct language to use when working with people with disabilities, social workers should also have an open mind regarding learning the experiences of the Asian American history of immigration and how this experience may impact the client's functioning and their perception as well as the community's perception of disability. Being cultural competent does not mean social workers have to speak all of the languages that their clients speak. It means an attitude of willingness to learn from their clients and to use critical thinking to analyze their clients' issues using a person-in-environment perspective. Social workers need to understand the reasons why clients decline services to rule out any reasons such as shame and fear rather than attributing refusal to a lack of self-determination and self-sufficiency.

The social work role of advocate should also be expanded. The individual and the family may need preparation to be more effective in dealing with professionals, agencies and bureaucracies in shifting the power of decision making from the professionals to consumer control. Intervention on a systems level often requires empowerment strategies such as advocacy to assure civil rights, eliminate oppression, and reduce marginalization. Helping Asian American individuals with disabilities and their families eliminate barriers to community inclusion may require a culturally sensitive redefinition of the empowering process. The cultural value of respect for authority may seem incompatible with self-advocacy. It is important to understand that questioning the judgment of professionals such as physicians might seem uncomfortable for individuals raised in a culture that emphasizes obedience. Issues of power and authority differentials between professions and consumers may not be a matter of concern to the Asian American. An important principle in social work is "start where the client is" which implies that the person with a disability gets to decide what he/she wants help with. Social workers who are experts in the disability field will have to learn more about culturally competent approaches to working with Asian populations. Likewise, social workers who are experienced in working with Asian Americans will need to familiarize themselves with the disability literature, to serve the Asian client with a disability in an appropriate manner and connect them to resources. Having a culturally appropriate attitude, and awareness of the perception of disability in a different culture, will help social workers to provide culturally competent services that will maximize the functioning of the person with a disability.

Conclusion

The profession of social work reflects selected social values and norms of our society. The philosophy of social work, which is based on altruistic values of helping people, needs to maintain this humanitarian philosophy (Pillari, 2002). Historically,

social work was embedded in a social and moral philosophy of help being “handed down” by the social worker who acted as the moral agent of the community. Through the years, social work practice has evolved to a more humanitarian philosophy based on the dignity and worth of individuals regardless of their issues or circumstances. But because the profession is still viewed as an agent of society in carrying out some of its responsibilities, it likewise has the potential to be a vehicle for influencing the attitudes and values of society. A stronger commitment to educating professional social workers in specific content about people with disabilities and the issues they face might enable the profession to become a stronger advocate for needed systematic and societal changes.

Passage of the Americans with Disabilities Act in 1990 provided the American with a disability the right to equal access and opportunity to be integrated into all areas of society. However, it is important to understand how each subculture in America, such as Asian Americans, interprets the meaning of disability as a cultural concept and views the implementation of the law through the lens of the culture’s value system. It is important to remember that all Asian Americans with disabilities are not the same nor do they all share the same values, norms, and beliefs. Asians are diverse peoples whose origins are of the Far East, Southeast Asia, and the Indian subcontinent. Generation and age are also factors in determining an individual’s particular value system. Independent living philosophy encourages people with disabilities to assert themselves and take control over their own lives. How and if this opportunity is acted upon by an Asian American person with a disability requires knowledge and sensitivity to the cultural nuances that are part of that person’s particular makeup. Social workers must be careful not to stereotype Asian American responses and respect individual differences.

More research is needed to understand how subcultures such as Asian Americans interpret concepts as “disability rights” and how a person with a disability is viewed within the family structure. Because there have not been many social work studies on working with minorities with disabilities, it is unknown if approaches and interventions that support and promote self-determination and empowerment to assist clients with disabilities are appropriate for minority clients with disabilities. This lack of knowledge must be addressed if social work practice with Asian Americans with disabilities is going to become a better cultural fit. Social work has the potential to bridge the gap between supporting the goal of self-enhancement by empowering people with disabilities to choose, and providing the cultural context of what that freedom of choice means to a particular Asian American with a disability.

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