

Introduction to the Special Issue:
“Self-Determination” as a Social Construct: Cross-cultural Considerations

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This special issue of the *Review of Disability Studies* is meant to stimulate thinking and dialogue about how self-determination is conceived and promoted by and for people with disabilities, and how the concept and its application might be enhanced to better empower and improve the quality of life of people with disabilities around the world. We decided to devote time and effort to this topic because of our observations that self-determination as typically presented is not a good fit for cultural milieu in Hawaii and across the Pacific region. A likely reason for this lack of fit emerged as we read a large proportion of the many publications on self-determination and people with disabilities: the self-determination concept as typically defined is rooted in the individualistic values common to Western cultures, whereas most residents of Hawaii and other Pacific Islands come from collectivistic cultural backgrounds.

In line with the *Review of Disability Studies*’ status as an international journal, our call for papers for the special issue sought analyses of self-determination from cross-cultural and international perspectives. This introduction is intended to help set the stage by briefly outlining how self-determination has come to be such a prominent topic in the disability-related literature, while also noting how this literature remains isolated from other potentially relevant literatures, such as that of social work.

Roots of the Focus on Self-determination for People with Disabilities

The concept of self-determination or personal autonomy can be identified in various philosophical tracts from across the ages. The historical roots of the current prominence of self-determination in disability-related fields have been traced by Frankland, Turnbull, Wehmeyer, and Blackmountain (2004). The earliest known English-language use of the term “self-determination” was in 1683 by John Locke in the context of philosophical debate over whether human behavior is the result of free will or pre-determination. Within the developing Western science of psychology in the late 1800s and early 1900s, the debate shifted from the role of God to the determination of behavior either by unconscious forces (e.g., Freud’s id and superego) or the environmental contingencies of behaviorism. Beginning in the late 1930s, the development of personality psychology by Gordon Allport, Abraham Maslow, and others fostered theorizing about internal psychological causes of behavior. From this perspective individuals could be viewed as having psychological needs that they seek to meet through cognitive goal setting and decision making. Decades later, Deci and Ryan (1985) posited self-determination as an innate impulse shared by us all.

The idea that a people have the right to political self-determination is implicit in the 1776 Declaration of Independence for the United States. In 1918, US President Woodrow Wilson specified national self-determination as one of the principles that should guide world affairs after World War I. This principle has since been used to

promote empowerment and rights for oppressed or marginalized groups of people through out the world. Nirje (1972) contended that people with significant disabilities as a group have been denied their right to exercise personal self-determination. The disability rights movement that emerged into prominence during the 1970s in the US and elsewhere in the West included greater self-determination among its demands, as reflected in the rallying cry “nothing about us without us” (Fleischer & Zames, 2001). The success of this movement is reflected in the explicit recognition and promotion of self-determination in a broad range of legislation in numerous countries. Notable legislation in the US at the federal level includes the Rehabilitation Act Amendments of 1978 (which established Independent Living Centers), the Americans with Disabilities Act of 1990 (which created broad civil rights protections), the Individuals with Disabilities Education Act of 1990 (which promotes the involvement of students with disabilities in developing their own Individualized Education Plans and Individualized Transition Plans), and the Patient Self-Determination Act of 1990 (which requires that individuals receiving Medicare and Medicaid services be able to participate in and direct health care decisions that affect them).

The response of the US Department of Education’s Office of Special Education and Rehabilitative Services (OSERS) to the disability rights movement included a self-determination initiative launched in 1988. This initiative created avenues for people with disabilities to participate at the policy making level, and also funded 26 projects to develop and demonstrate effective practices fostering self-determination for students with disabilities (Ward & Kohler, 1996). These projects were a major reason for the emergence during the 1990s of self-determination as an area of focus in the fields of special education and transition-to-adulthood (Frankland et al., 2004). Notably, the OSERS-funded projects represented an evolution in efforts to promote self-determination for people with disabilities, with the focus shifting from securing rights to self-determination to supporting individuals to be better able to exercise their rights and be more self-determined in their daily lives. The primary target populations for these efforts have been people with disabilities who may be at risk to be placed under the control of others. Examples include special education students and adults with intellectual or psychiatric disabilities who are subject to guardianship and possibly institutionalization.

Whose Life Is It?

Not surprisingly, the OSERS projects, which were all conducted in the US, identified personal attributes congruent with American individualism as essential components of self-determination. These attributes typically include a number of “self” words that are rarely associated with collectivistic values, such as self-advocacy, self-awareness, self-competence, self-direction, self-efficacy, self-evaluation, self-expression, self-realization, self-regulation, self-reliance, and self-responsibility. The approach taken in the numerous projects supported in the US by OSERS and other funders has generally been to identify specific attitudes, skills, and knowledge needed for self-determination and then provide training and opportunities for practice, with the aim of boosting the capacity of individuals to act as independently as possible to achieve their own goals.

However, questions have been raised about the utility and relevance of such approaches for people with collectivistic cultural backgrounds (Black & Leake, 2011). The self-determination literature tends to be based on a range of interrelated “constructs” commonly employed in Western psychology, such as intrinsic and extrinsic motivation, locus of control, and self-efficacy. By contrast, cross-cultural researchers often stress that their findings challenge the original formulations of such constructs because they were developed by scholars who, as Markus and Kitayama (1991, p. 224) phrase it, used a “monocultural approach” rooted in the assumption that “the so-called Western view of the individual as an independent, self-contained, autonomous entity” corresponds to a universal human nature.

One construct at the heart of the contrast between individualism and collectivism is that of self-construal (how people perceive the relation of the self to others). In a widely cited article, Markus and Kitayama (1991) present a wealth of evidence that people in individualistic cultures view themselves as independent, with each person being a separate unit complete in itself, whereas in collectivistic cultures people consider themselves to be interdependent, that is, as part and parcel of a larger group. For example, people in traditional Pacific Island cultures have been described as developing “shared identities” as the result of “sharing food, water, land, spirits, knowledge, work, and social activities” (Linnekin & Poyer, 1990, p. 8). In other words, “The relationship defines the person, not vice-versa” (Lieber, 1990, p. 72). According to Imamoglu (2003), an inherent assumption of American-style independent self-construal is that when human development proceeds as it should, maturing people cast off their dependencies, bonds, and ties, and so become more and more independent from others – and the more independent, the higher the level of maturity. However, in a collectivistic culture, it is more likely that maturity is associated with increasing interdependence and orientation to achieving group goals.

The concept of “cultural competence” has been strongly promoted throughout the West in recent years as essential for the provision of effective educational, social, and medical services for the increasing numbers of residents of ethnic/racial minority heritage. However, Western professionals may face conundrums about what to do in the face of cross-cultural conflicts. The goals or paths chosen by their students or clients may clash with their own Western values. Alternatively, Western professionals may face the risk of being drawn into family conflicts, as often happens when parents try to maintain cultural traditions while their children adopt Western ways that give priority, for example, to self expression over obedience to authority (Sands & Wehmeyer, 1996). The example of independent living is often mentioned in the literature. Opportunities and supports for independent living have been among the major goals promoted by disability rights movements in the West (Fleischer & Zames, 2001). For many collectivistic cultures, however, multigenerational households are the norm and independent living is an alien concept that may not be readily accepted (Geenen, Powers, Vasquez, & Bersani, 2003).

The contrasts between individualism and collectivism with regard to self-determination are reflected in possible answers to the question, “Whose life is it?” The strong tendency in individualism is to respond that everyone’s life is entirely their own,

to make of it what they will, while in collectivism the response tends to focus on doing what's best for the group, which may well involve following the decisions of others (Shore, 1996).

Cross-cultural Perspectives on Self-determination in Social Work

The contrasts between individualism and collectivism raise the question of whether self-determination understood and promoted from an individualistic perspective is relevant or translatable for people from collectivistic cultures. Because this question is rarely addressed in the disability-related literature, we turned to the modern technique for finding answers, the Internet search.

It was surprising to discover that cross-cultural issues for self-determination are indeed a concern for a discipline that frequently touches the lives of people with disabilities, i.e., social work. It appears that despite having many common interests, the literatures of disability and social work scholars seldom make reference to each other. However, social work must surely offer useful insights into self-determination, given that the field adopted client self-determination as a guiding principle and goal nearly 50 years before Nirje identified it as an important issue for people with disabilities (Biestek & Gehrig, 1978). Later, during the 1950s, as Western-style social work practice began to be widely exported, scholarly debate burgeoned on how to best adapt social work to local cultural contexts while maintaining adherence to the principle of self-determination (Bar-On, 1999; Ejaz, 1991).

Bar-On (1999) provides a good overview of the complexities of the relevant issues for Africa, where there is generally a mismatch between the Christian individual-oriented values that launched the social work movement in the West and indigenous kinship-based collectivistic values. Of particular relevance to self-determination: every African kin group member "is an incumbent of a position with predetermined responsibilities towards every other member" (p. 13); maintaining social acceptability by fulfilling one's responsibilities is a pervasive concern; those in leadership positions are accorded great status and are expected to lead and others to follow; and consensus is highly valued (and people of subordinate status are unlikely to express disagreement).

Similar attributes characterize numerous cultures around the world, leading to significant differences compared to the West in how social workers interact with those they aim to support. In India, for example, many social workers set aside self-determination as a primary guiding value because their clients tend to resist the process of setting their own goals and developing action steps to address their problems. Instead, in line with longstanding relationships of dependency on and compliancy with people higher in the caste system, they tend to prefer being told what to do. Nonetheless, insightful social workers find ways to promote empowerment, for example, by using fatalistic attitudes as a vehicle for change, by supporting clients who believe in rebirth to build good *karma* in order to improve their situations in their next lives (Ejaz, 1999).

Ewalt and Mokuau (1995) also discuss the lack of relevancy of the American mainstream view of self-determination for many Native Hawaiians and other Pacific

Islanders. They point out that for most professionals trained in the West, the family or society in general might be viewed as an obstacle to individual choice and self-determination. As a result, “rarely is contributing to the group’s well-being considered integral to self-determination, and rarely is placing the group’s well-being first seen as signifying maturity” (p. 169). Yet people who grow up in collectivistic cultures are likely to develop goals that are more group-oriented than self-oriented, so that “self-directedness may require a strengthening rather than a dissolution of the person’s connection with and commitment to the group” (p. 170) – an assertion they point out is likely to seem “paradoxical” from the individualistic perspective.

In a similar vein, Gair, Miles, and Thomson (2005) argue that social work practice frequently fails Australia’s Aboriginal population because it:

“...often reflects values of individualism. These include the centrality of the individual as the focus of social work theory and practice, the focus on individual pathology, and solutions that are defined by values of individual self-determination, self-help, and confidentiality. For indigenous peoples, a focus on individualism may exclude cultural and community values” (p. 182).

Furlong (2003) is one of a number of social work scholars who argue for a reconceptualization of self-determination based on cross-cultural considerations such as those noted above. He proposes that social workers should take a more flexible view of self-determination and support their clients to establish a balance between interdependence and autonomy that fits their particular situations. Falck (1988) asserts that a more accurate term would be *social self-determination*, because people everywhere set goals and make decisions in the context of webs of relationships among *social selves*. He points out that while it was laudable for social work to adopt the principle of self-determination to celebrate and support the integrity and autonomy of all human beings, it must be recognized that integrity and autonomy depend on and emerge from social relationships.

The Special Issue Articles

The first of the special issue articles, by Karen Applequist, Lissa Keegan, Jose Benitez, and Joshua Schwalbach, describes the ingredients of self-determination for an American Indian with learning disabilities who attended college far from his reservation home. The authors note that this individual enjoyed substantial advantages that included strong family support and an athletic scholarship accompanied by close supervision to keep him on track academically, raising questions about the prospects for self-determination for American Indians with disabilities who have few support resources. The next article, by Xiaoyi Hu and Susan Palmer, provides insight into self-determination in China through a case study of a young woman with hearing loss who graduated from college and established her own art studio. The article includes discussion of how the operationalization of self-determination may be impacted by the evolution of traditional Confucian values, such as growing acceptance of independent living. David Leake follows by outlining the case that the collectivistic value of interdependence is actually essential for self-determination in all cultures, because interdependent social relationships

yield the social capital that most people need to achieve their self-determined goals. The logic parallels that of Falck (1988) noted above promoting the term *social self-determination*. Patricia Saleeby, writing from a public health/social work perspective, then discusses how self-determination and empowerment can be promoted for diverse people with disabilities through culturally tailored practices. She describes the examples of access to culturally diverse resources and community-based rehabilitation, which involves promoting and supporting group action by families, communities, and people with disabilities themselves. James Skouge and Mary Kelly describe how easy-to-use multimedia technologies can support the self-determination of young adults with significant disabilities of all cultural backgrounds by enabling them to communicate their strengths and “visualize” their preferred futures. They call on professionals and “critical friends” to re-tool their technology skills so that the people with disabilities they support can have more of a voice in the decisions that impact their lives. Finally, Angi Stone-MacDonald provides an in-depth review of the English-language literature concerning how disabilities are commonly conceived of and responded to in East Africa. An area of particular concern is that increasing migration from rural to urban areas tends to erode traditional protections for people with disabilities, making it ever more likely they will end up lacking social supports and among the poorest of the poor.

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James Skouge is a traveler and teacher who has dedicated his career to “giving voice” to children, parents and teachers -- including persons with and without disabilities. Since 1992 he has promoted “digital storytelling” in Hawaii, American Samoa and Micronesia. Currently, Dr. Skouge is an associate professor in the Department of Special Education at the University of Hawaii.

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