

## SOCIAL WORK PRACTICE AND PEOPLE WITH DISABILITIES: OUR FUTURE SELVES

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**Abstract:** *During the past fifty years a revolution in how we recognize, advocate, medically treat, and interact with people with disabilities has taken place within contemporary society. From historical civil rights legislation to greater access to society's rights and benefits, to technological advances and population longevity, people with disabilities are integrating themselves into society. As we begin to explore the twenty-first century new concerns regarding the cost of chronic care and society's desire to fund these costs are beginning to emerge. The desire to qualify the cost of care by functional longevity has begun to emerge in both private and public service delivery systems. As professional social workers continue to expand their sociopolitical influence, they will be challenged to uphold the rights of self-determination that people with disabilities have striven to attain.*

*Keywords: Disability, Consumer Driven Care, Health, Quality of Life Measurement, Person Centered Planning*

### INTRODUCTION

Social work professionals have historically approached disability from a medical perspective where the definition of the problem was the physical, or behavioral impairment of the individual (Condeluci, 1995; Mackelprang, 2002). People with disabilities were treated by professional experts where the desired outcome was a cure. The affect of this approach to disability was to equate the cure as desirable and a failed attempt as a reason to discard or maintain the individual with disability. In essence, people with disabilities were oppressed by this societal medical perspective (Gilson & DePoy, 2002; Mackelprang, 2002).

In recent decades, as social service delivery systems matured, professional social workers utilized a social service/rehabilitation perspective when providing intervention to people with disabilities (Condeluci, 1995). This perspective views the individual with disabilities as having a lack of adaptability to the surrounding environment and views the experts as those providing the intervention. This perspective has been viewed as patronizing the person with disabilities by allowing little decision-making and control to the individual being helped (Condeluci, 1995). In the 1970's the independent living perspective began where the person with disabilities was viewed as a self-determining and independent person. The desired outcomes to this perspective were to challenge the existing status quo and empower the individual to define their own needs without the dependence on professionals and family (Condeluci, 1995). The independent living movement encouraged the development of federally funded Centers for Independent Living and passage of civil rights social policy and laws, such as The Americans with Disability Act (Mackelprang, 2002).

Within the past decade, access to technology and advanced medical interventions allowed people with disabilities to share with the rest of the U. S. population in longevity. Approaches to disability services began to embrace self-determination and self-directed care in order to maximize the functional ability of the individual. What has gradually emerged is a constructionist approach to disability, where the disability is viewed as interacting within a dysfunctional environment and that targeted interventions could address this interaction (Gilson & DePoy, 2002). Technological advances have raised concerns over costs and the quality of life at what price? New disease prevention and management approaches have been implemented primarily by private, public health and social service delivery systems in an effort to improve the overall health of populations with disabilities, thereby reducing costs.

According to the 2000 U. S. Census, 19.3 % of the noninstitutionalized U. S. population have some form of physical or mental disability (U. S. Census Bureau, 2003). In 2002, according to the National Health Interview Survey, 12.2 % of the noninstitutionalized U. S. population had some form of limitation in usual activities due to chronic conditions (U. S. Dept. of Health and Human Services, 2004a). With life expectancy for the year 2001 at 77.2 years (U.S. Dept. of Health and Human Services, 2004b) and with 41.9 % of those 65 years and older experiencing a disability (U. S. Census Bureau, 2003) we can expect a greater number of social work consumers manifesting some form of disability.

This article will highlight several traditional social work practice areas and their recent applications with people with disabilities. It will also address several new challenging areas of practice and their future applications. Reflecting on the numbers of individuals with functional disabilities as we enter the 21<sup>st</sup> century, social work professionals will be working, not only for the person with disabilities, but also for themselves and their family members. Disability exists among all cultural, economic, religious and racial groupings and due to its' heterogeneity, will require many different approaches and practice applications.

### CASE MANAGEMENT

Case management, although used frequently by social workers in health and social services delivery, has deep practice applications within several professions, specifically social work, nursing and later, in the for-profit health and service delivery industries (Patchner, 2004). Today, multiple terms are used to denote case management functions, such as: care management, utilization management, coordinated care, structured care, financial case management, disease management, service coordination, health care navigation and managed care. Many new applications of case management have emerged as a result of cost containment and disease prevention and chronic care management within private as well as public health care delivery systems (Carneal & D'Andrea, 2001; Patchner, 2002; Patchner, 2004; Smith, 1995).

Historically, case management strategies have fluctuated between consumer-driven to provider-driven approaches depending upon the current sociopolitical climate. There has been ongoing concern among social work professionals, whether case managers can function as client advocates and system agents simultaneously, and whether the desires and

needs of people with disabilities and the provider delivery system are consistent (Austin, 1996; Rose & Moore, 1995).

As western society becomes more sophisticated in delivering technology and information to all members of the population who have access to revolutionary advances, greater empowerment of the average individual has resulted (Maddox, 1991). People with disabilities and their families have been especially empowered and informed by the technology revolution. This allows them unprecedented access to more resources within modern society. As people with disabilities integrate more fully into their rightful place within the mainstream of society, will traditional social work case management be obsolete?

As the profession of social work endeavors to address issues of diversity and oppression in serving people with disabilities, attention to the changing role of the consumer in self-determining their needs and services needs to occur. Recent initiatives such as person centered planning and client directed treatment have facilitated consumers and their families in designing personalized service and treatment plans. Additionally, legislation and public policy are attempting to address the injustice and inequality that has been experienced by people with disabilities (The National Council on Disability, 2004).

Increasingly, people with disabilities and their families are acting as their own case managers as the contemporary delivery system has failed to understand and respond to the changing and complex needs of multiple consumers. Disability advocates have continued to advocate for the use of voucher systems whereby the consumer, and not the professional, would select from a menu of community based services that they believe are needed (Eidelman, 2004; Sheehan, 2004; Wehmeyer, 2004). Currently, many states are experimenting with Medicaid waiver arrangements where the consumer, with the assistance of family and friends if warranted, chooses an approved case management organization to arrange for services they deem as necessary for independent living. Beginning in 2001 the federal government initiated the New Freedom Initiative which provided grant money to states to improve community-integration services and remove barriers to community living by encouraging people with disabilities and their families to plan for their specific care needs (U. S. Dept. of Health and Human Services, 2003).

Social work professionals will modify their case management strategies as the sociopolitical landscape changes. People with disabilities will have better defined roles in the self management of their care.

### PERSON CENTERED PLANNING

People with disabilities and their families have long complained about navigating the disability service delivery system (National Council on Disability, 2004; Partnership for Solutions, 2002). A strategy that has been successfully used to ease service navigation is person centered planning. Person centered planning can be described as a systematic personalized information gathering process that focuses on the capabilities of the individual and has been used extensively with people with disabilities and their families over the past several decades. Originally developed by Karen Green-McGowan and Mary Kovaks for the Canadian National Institute on Mental Retardation, it quickly spread to the United States where it has been used most recently by both state and local agencies to assist persons with disabilities and their families in planning for the future (O'Brien & O'Brien,

2000a). It is an excellent application of consumer driven service delivery that involves group work, advocacy and case management.

The sharing of information between the person with disability, family, friends, care takers, teachers and others occurs in a supportive team setting. Components of the planning process include a personal profile, visions for the future, action plans and always a continuous modification of the visions and the action plans. Person centered planning attempts to empower the person with disability by exploring resources, recognizing lifestyle issues and the person's abilities while promoting accountability. It also allows the team to recognize that everyone on the team is both a part of the problem as well as part of the solution.

Although person centered planning appears seemingly simple in design and application, O'Brien & O'Brien (2000b) have indicated that politics, related to control, can creep into the process. This is especially evident as the role of the provider can change based on the realistic desires of the person with disabilities. People with disabilities can realistically articulate their vision for the future based on a menu of services and providers that they select from. As with a free market economy, people with disabilities can be empowered to support services and service providers that they desire and favor. For professionals involved with the person centered planning process it is important to remember that the process is a means to assist the person with disabilities to realize their wants and desires within larger systems that provide both opportunities and limitations. In order for person centered planning to empower people with disabilities, the focus must always be on the individual consumer and not the provider (Smull, 1996).

Due to our strong belief in self determination, social work professionals will act as consumer advocates in promoting person centered planning within their organizations.

### **CONSUMER DRIVEN SERVICE DELIVERY**

Terms such as consumer directed care, client controlled care, consumer case management and consumer driven service delivery are similar in meaning and all focus on the empowerment of people with disabilities to take control of their lives. The specific term consumer driven has been used by economists to describe the consumer as the demander of services, as conversely provider driven services is used to describe the supply of services available within the American health and welfare system.

Economic supply and demand is important whenever we apply them to the public market place which is artificially controlled by government regulation and spending unlike the private market system which strives to operate with the least amount of government intervention. In fact, the private market system strives to provide services that the consumer demands in order to make a profit. Within the new federalism and privatization of social welfare services the demand sided approach to service acquisition and delivery can affect which organizations will be utilized by people with disabilities (Tilly & Weiner, 2001; Herzlinger, 2004).

Research on consumer driven service delivery has indicated that consumers who are able to cognitively participate in decision making are generally pleased with the approach. However, seniors and those with cognitive disabilities were less inclined to like this ap-

proach. What has been recommended, is a systematic prospective study of this approach by both private and public funded health and welfare providers (Cuellar, Tilly, & Wiener, 2000; Tilly & Weiner, 2001; Herzlinger, 2004; Stone, 2004).

We can also anticipate that the evolution of technology will allow consumers greater access to information and providers. Fitch (2004) recently proposed a model for client control of case information that has the potential to improve access and quality of services. However, we do not have a clear strategy on how to equalize services to those who are unable to logistically or cognitively access providers of care.

Social work professionals will qualify their applications of consumer driven service delivery based on the needs of the individual. Although greater numbers of people with disabilities will embrace consumer driven service delivery, some consumers because of cognitive difficulties will require the assistance of family, friends or professionals to receive appropriate care.

### MANAGED HEALTH CARE

Early experimentation by the U. S. Dept. of Health and Human Services Health Care Financing Administration (HCFA) with consumer driven health delivery to people with disabilities was conducted in the 1980's and 1990's. With Medicare and Medicaid waivers the social health maintenance organizations (SHMO's) used a social case management model, and attempted to control costs while expand chronic care services through careful case management and coordination of services (Harrington & Newcomer, 1991; Leutz, Greenlick & Capitman, 1994). Findings from those demonstrations were mixed. Harrington and Newcomer (1991) reported that the demonstrations increased overall costs while Leutz, Greenlick and Capitman (1994) found that the SHMO's demonstrated that chronic care services can be integrated with acute care at manageable overall costs. As suggested by Leutz and other pioneers of the SHMO models, the linkages made during these early demonstrations, between integrating acute and chronic care needs, have had positive influences on current health delivery paradigms. A second round of SHMO's involving six demonstrations models, authorized by HCFA, was initiated in 1996. According to Goben (1997) the newer SHMO's were considered more of a medical model where a preventive health focus and a risk-adjusted payment system was utilized.

During the 1990's as Medicaid expenditures rose, states began to turn to the private managed care systems to provide solutions for publicly funded populations through the use of federal Medicaid waivers. Through the 1915(b) and 1115 waivers, there are now managed care systems funded under Medicaid in all states. The 1915(b) waivers are restricted to specific populations or geographical locations. The 1115 waivers came into active use after the defeat of the Clinton health care reform initiatives. These research and demonstration waivers are usually statewide and are mandatory for enrollment. The 1115 waivers also allow for expansion of coverage to individuals who would not otherwise be covered under Medicaid (HCFA, 1996). Even though the privatized managed care numbers have dropped in recent years, and the Medicare managed care enrollment is slowly increasing, the Medicaid managed care numbers have steadily increased (Centers for Medicare and Medicaid Services, 2004 & 2005; Gorin, 2003). For the year 2003, according to the Centers for Medicare and Medicaid Services (2004), 59.1% of the Med-

icaid population, were enrolled in managed care. The Medicaid population is considered an at-risk population due to the large numbers of enrolled persons with disabilities who can present with complex psychosocial needs.

What has emerged is a health care industry that is largely owned by private investors and which includes public subsidy through Medicaid and Medicare. Earlier managed care plans, which were not-for-profit, considered cost containment as an unexpected benefit rather than the central purpose, with profits invested in improvement in health care delivery. The newer generation of managed care which are for-profit and commercially influenced, invest profits in another realm, that of the investor. What has resulted is continuous debate regarding increasing Medicaid costs, while improving quality of care in order to prevent further costly disease and disability. As Goben (1997) asserts, containing costs is not the same as improving the efficiency of health care delivery. Increasing efficiency and effectiveness improves quality of health care, while containing costs without innovations in delivery leads to no improvement in health care services.

There continues to exist many unanswered questions regarding enrollment of people with disabilities into managed care systems which are accustomed to a healthy commercially employed population. Keigher (1995) reports that besides decreasing access and benefits as a response to budget cuts, state governments have increasingly enrolled Medicaid populations into managed care arrangements as a primary strategy for limiting escalating Medicaid costs. By controlling access and benefits in order to decrease inappropriate waste of health resources, while at the same time employing public health strategies for disease prevention, states hope for greater overall efficiency and effectiveness in health delivery. Some states under their Medicaid waiver arrangements have designed new public health strategies that contain linkages with community based providers and social service agencies so that individuals with disabilities have greater access to services at the local level (Centers for Medicare and Medicaid Services, 2004; Minkoff, 2000).

Due to fiscal concerns, social work professionals will need to advocate for people with disabilities to ensure that health and welfare care is not rationed and that there are appropriate channels to address appeals when denied services.

### **DISEASE PREVENTION AND MANAGEMENT**

As accountability for health care costs increase, interest groups, policy makers, and health delivery systems will strive for additional control over health and welfare outcomes among those served. In order to improve these outcomes, the traditional "supply sided" approach to services has begun to evolve into a "demand sided" approach where strengthened consumer relations would be sought through more self-determination and decision making on the part of the individual (Goldsmith, Goran & Nackel, 1995). Health and welfare service delivery systems will focus increasingly on promoting wellness, empowering the individual, providing for a continuum of care approach, accountability, appropriate level of care standards, and improved integrated delivery systems (Institute of Medicine 2004, Partnership for Solutions, 2002; Black, 1997).

In 1989, the U. S. Congress passed the Patients Outcome Research Act which stressed biopsychosocial measurement of health outcomes with the goal of measuring and ultimately preventing further disease and disability. Over the past decade numerous health

outcomes have been collected by the U. S. Department of Health and Human Services on Medicare and Medicaid populations. One such measure is the Minimum Data Set (MDS) which measures the medical and functional status of all nursing home residents in Medicare and Medicaid funded facilities (Patchner & Patchner, 2004). Health Plan Employer Data Information Set (HEDIS) health measurements are routinely collected by both publicly and privately owned health insurance systems for evaluation of quality, service access, patient satisfaction, membership, utilization, finance and health plan management (Stiles, Rahl, Bernstein, Halman, Harrison & Standiford, 2000). The National Academies (2004), (which includes the National Academy of Sciences, the National Academy of Engineering, the Institute of Medicine and the National Research Council), have called for a serious review and application of recent recommendations outlined in their publication: *Insuring America's Health: Principles and Recommendations*. This report calls for an integrated disease prevention and management approach to health care delivery with evidence-based research to examine health outcomes (Institute of Medicine, 2004).

A concern that arises is the validity of the health outcomes that are measured. With the complex maze of health delivery systems and the different mechanisms for data collection there is concern regarding the effectiveness of outcome studies. This is especially worrisome for those with chronic conditions including people with disabilities (Partnership for Solutions, 2002). A recent randomized national study conducted during May of 2001 found that U. S. patients with chronic conditions get insufficient care (The Robert Wood Johnson Foundation, 2005b). In yet another study conducted by RAND Health, it was also found that patients with chronic conditions get insufficient care (The Robert Wood Johnson Foundation, 2005a). In a recent article published by Maramaldi, Berkman & Barusch, (2005) the validity of patient-based assessments of health related quality of life when applied to cultural minority groups was questioned.

Social work professionals can anticipate collecting health outcome data on their consumers. With respect to people with disabilities, outcome data will be sought in order to manage chronic disease and disability and the costs associated with these conditions.

### QUALITY OF ADJUSTED LIFE YEARS

Interest in quality of life has been driven in recent decades due to longevity and the costs associated with health care delivery as we age and develop chronic diseases and disabilities. Quality of Adjusted Life Years (QALY's) measurements are a mechanism to quantify the quality of a person's life. As defined by the Centers for Disease Control and Prevention:

QALY's are estimates of person-years lived at particular levels of health. They are mostly used in cost-effectiveness analyses and clinical trials involving health conditions that consider the quality as well as the length of life. Quality is typically measured on a scale of 0.0 (death) to 1.0 (perfect health) by assigning various weights to potential health states (CDC, 2003, p. 5)

QALY's were originally designed by economists, using complex micro-economic models that theoretically quantify the benefits vs. the costs of disease and medical intervention. Today there are multiple means of assessment that are used to gauge quality of life. Some familiar forms are patient based assessments (PBA's), health-related quality of life (HRQL) questionnaires and the SF-36 health survey which has been rigorously tested for construct

validity and is currently used with QALY measurements (Nichol, Sengupta & Globe, 2001; Maramaldi, Berkman & Barusch, 2005).

Studies funded through the National Institutes of Health, the World Health Organization and the World Bank have utilized QALY's to gauge the overall health of a population and what medical treatments and interventions benefits populations the most for the money spent (CDC, 2003; Homedes, 2000). Both governments and private companies are interested in the health status of their populations, the health impact of utilitarian systems of care upon a population and how to gauge costs related to care. However, it is important to recognize that there are ethical criticisms in using QALY's.

Some of these criticisms deal with the inability of any micro-economic model to accurately reflect the quality of life (Sacristan, 2003; Duru, G., Auray, J. P., Beresniak, A., Lamure, M. Paine, A. & Nicoloyannis, N., 2002). QALY measurements are especially worrisome when applied to people with disabilities because they involve some subjective value judgments regarding human functional status (Homedes, 2000). The use of QALY's in health care decisions could compromise both individual patient autonomy and the clinical judgment of health and welfare providers (La Puma & Lawlor, 1990; Homedes, 2000). As we apply QALY's within the larger health delivery market we can expect the judicial system to become involved when there is conflict regarding the health rights of the individual. It is important for us to note, that the judicial system in the United States leans toward a utilitarian form of justice when interpreting the Constitution (Longest, 2002). As consumer advocates, social workers will attempt to modify health delivery decisions to the desires and needs of the individual with the disability.

Social work professionals will become increasingly familiar with QALY applications as both the private and public sectors attempt to quantify and measure all service delivery in an attempt to project costs, increase efficiency and increase effectiveness. It is possible that future social workers will be asked to justify the costs of our services associated with the meaningful longevity of the individual consumer or population with disabilities.

### **FUTURE PRACTICES IMPLICATIONS AND TRENDS**

As we enter the 21<sup>st</sup> century we can anticipate many changes to our traditional disability service delivery system and the services we provide. Individual autonomy and the civil rights of the person with disabilities will compete with larger utilitarian systems of care. Policy makers will struggle between the utilitarian vs. the egalitarian forms of justice as they attempt to meet the needs of people with disabilities.

Traditional case management services will evolve into consumer driven case management where a partnering between the consumer and the professional will occur by use of person centered planning or some related approach. Since the consumer will have greater control, we will be placing the interests of the person first and the needs of the organization that we work for second. As we place the consumer's interest above organizational interests, we can envision our existing disability service delivery system modifying into something less structured and more responsive to consumer needs. Some people with disabilities and their families will want to manage their own health and welfare service acquisition. For those who are unable to navigate service acquisition, social work professionals will be employed by people with disabilities under contractual arrangements made by the



consumer or their family. These contractual arrangements may involve a voucher payment system set up by a privatized managed care entity under contract with a public funder. We can expect that our professional services will be measured by both the health outcomes of the consumer and the satisfaction of the consumer with our services. Our employer may also have contractual arrangements with privatized managed care entities to assist in local community based disease prevention and health management activities. Social workers will be challenged to be good consumers as well as contributors toward evidence based research. A strong ethical understanding of the implications and flaws of measuring the human condition will be essential because we may be asked to measure the quality of life or to quantify what is meant by a meaningful life. Since functional disability will become more prominent as longevity increases, many persons with disabilities that we serve could be our friends, family members or our very selves.

## CONCLUSION

Current scientific and technological advances will continue to enrich and extend the lives of those with disabilities. Yet society has many unanswered questions on how best to proceed with caring for large populations who have multiple needs.

Future health and welfare policy for individuals with disabilities will undoubtedly be influenced by numerous inputs of information from the managed care industry, quality assurance initiatives, government entities, funded research, interest groups, medical providers, unions, employers, and consumer advocacy groups (Church, 1997). As these multiple groups attempt to influence future health and welfare policies, future strategies will have to recognize these stakeholders and integrate their multiple ideas into a cost effective and coherent system of care that improves the functional health of people with disabilities.

It is easy for policy makers to look at the larger population and describe it in utilitarian demographic terms, without addressing the many individual faces with unique needs that we, as social workers, are called to advocate for. Social work professionals must remain informed regarding evolving policy and consumer perceptions, as well as, newly emerging research developments so that they can provide services that address the needs of their constituents within a human rights context.

We, as a profession, will serve well by recognizing the dignity, self-determination and worth of every unique individual, regardless of health status and functionality. Only then can we implant the human rights context into the larger disability service delivery process.

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