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A National Disgrace: Health Disparities Encountered by Persons with Disabilities

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A review of the literature documents that disparities exist between the health of persons with disabilities and the general population. Goal 2 of the Healthy People 2010 calls for the elimination of health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation (US Department of Health and Human Services, 2000). The purpose of this article is to review the literature, examine the current state of knowledge, and identify research needs to meet Goal 2 for persons with disabilities.

A "disparity" is defined as difference in quality of health care received by a segment of the population (in comparison with the general population) that is not due to access-related factors or clinical needs, preferences, and appropriateness of interventions. People with disabilities are identified as persons having an activity limitation, who use assistance, or who perceive themselves as having a disability. In 1994, 54 million people in the United States, or roughly 21 percent of the population, had some level of disability (Altman, 2001). Although rates of disability are relatively stable or falling slightly for people aged 45 years and older, rates are on the rise among the younger population (Kapell et al., 1998).

Recent Reports

The Surgeon General highlighted disparities for people with disabilities with the February 2002 publication of Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation (Blueprint) (US Public Health Service, 2002). In that publication, the Secretary of Health and Human Services, Tommy G. Thompson, stated that individuals with mental retardation are more likely to receive inappropriate and inadequate treatment, or be denied health care altogether. Also in that report, the Surgeon General stressed that a quick glimpse at the health status of persons with mental retardation, both children and adults, reveals glaring deficiencies that must be addressed. Although the Blueprint was specific to mental retardation, as stated in the report, most, if not all, of the content of that publication is generally applicable for any population with disabilities.

Other disparities in health care received further attention with the publication, in March 2002, of the report by the Institute of Medicine entitled Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Disparities in health care pose moral and ethical dilemmas because health as a resource is tied to social justice, opportunities, and quality of life (Smedley et al., 2002).

The National Organization on Disability addressed the issue in its "The State of the Union 2002 for Americans with Disabilities" (www.nod.org), stating that "health care is less accessible to Americans with disabilities, who, ironically are often the citizens needing it the most." By providing inadequate levels of primary and secondary prevention, these disparities have long-term implications for health care expenditures. Persons with disabilities who do not receive adequate preventive care and routine health maintenance care may require more expensive tertiary care. They may also develop secondary conditions that may further limit their functioning, quality of life, and life expectancy.

The disability movement did not become seriously engaged in health-policy issues until the 1990s. The movement generally identified the medical community as a source of social oppression. The movement rejected the assumptions of the "sick role" and the medical model that rendered individuals with a disability passive recipients of services over which they had little control (Zola, 1997). The movement viewed the health care system as intrinsically paternalistic (DeJong & Basnett 2001). The disability movement also pragmatically understood that until there were significant numbers or more people of "significance" it was better to have health care of any quality than to have none at all. Any attempt to address this issue was further compromised because of the lack of political will at the local, state, and national government levels. The number of voters in the disability community was considered too small to deserve attention by policy makers.

ADA and Health

Interestingly, there appear to have been few lawsuits under the Americans with Disabilities Act (ADA) related to health services. In 2001, Kaiser Permanente, the nation's largest non-profit Health Maintenance Organization (HMO) settled a class-action lawsuit, the first of its kind in the nation (Lewin, 2001). In that settlement, Kaiser agreed to revamp all its California health facilities and policies to ensure that people with disabilities have access to the full range of health care. However, this settlement only addressed accessibility for one geographic area for Kaiser and did nothing for people served by other providers in other facilities and locations.

Attitudes of Health Professionals

Primary care for people with disabilities often concentrates on medical conditions relating to the disability to the exclusion of preventive health services (Iezzoni et al. 2000; Chan, 1999). Providing medical care for patients with mental disabilities may be challenging and financially unappealing because of the need for extra time and effort (Councilman, 1999). People with disabilities report vignettes of negative encounters with health-care providers (French & Swain, 2001). Nurses questioned the relevance of health promotion to those with spinal cord injuries, describing them as "clients who will never get well" (Allen-Wright, 1999).

One of the most poignant stories in the literature is by a physician, who was able-bodied at the beginning of his career, but became quadriplegic following a spinal cord injury while playing rugby (Basnett, 2001). He describes how health professionals can develop a view of disability that is at substantial variance from its reality for many disabled people. This variance can affect vital decisions at an individual clinical level, at a policy level, and at a health-system level. One reason for the inadequate, improper, and insensitive attitudes may be the relatively few persons with disabilities who are employed in health professions. Little affirmative action to recruit persons with disabilities into health-care professions has occurred.

Over the past decade, a great deal of training to change attitudes has occurred with pediatricians and health-care providers of services to young children with disabilities. Currently 36 programs are funded in 29 states to provide Leadership Education in Neuro-developmental and Related Disorders (LEND) by the Maternal and Child Health Bureau. These programs have trained pediatricians and graduate allied-health practitioners to better understand the needs of children with disabilities and their families.

However, no comparable outreach has been made to train providers of adult health-care and medical specialists to understand the needs of persons with developmental disabilities and to equip them to respond to those needs more effectively. As a result, transition from pediatric care to adult medical care is an issue. Many pediatricians continue to provide primary care to adults with developmental disabilities into their second, third, and fourth decades of life. As one parent of a twenty-something said recently, "Turning the care of Brian over to anyone other than his pediatrician would be the same as signing his death certificate."

But while persons with disabilities and their families may feel more comfortable remaining with their pediatrician, the pediatrician many not always have the knowledge and skills to respond to adult medical needs. Whereas in previous decades, many individuals with developmental disabilities lived in institutions where staff physicians provided care, the current national trend is to deinstitutionalize adults with mental retardation and place them in community residential settings, which requires that community-based primary care physicians assume responsibility for their medical care (Tyler & Bourguet, 1997). One report suggested that because medical services have declined with community placements, the death rate is higher for people with mental retardation living in the community than for those living in institutions (Smith, 2002).

Research and Database

The Centers for Disease Control and Prevention (CDC) fund 26

Prevention Research Centers; however, a review of their research themes indicates that no Center is addressing issues of health disparities in persons with disabilities. Most of what is known about the health status of people with disabilities across the nation is based on information gleaned from the Disability Follow-back Survey of the National Health Interview Survey (NHIS-D) conducted each decade by the US Bureau of the Census, most recent in 1994-95.

The child questionnaire is 39 pages long and addresses a myriad of issues, which include home care services, work/child care, medical services, assistive devices and technologies, other services, educational services, coordination of services, physical activity, personal adjustment and role skills, impact on the family, mental health, housing and transportation, health insurance, and respondent information. The adult questionnaire is 89 pages long. It questions the respondent about initial screening, housing and long-term care services, transportation, social activity, work history/employment, vocational rehabilitation, assistive devices and technologies, health insurance, assistance with key activities, other services, self-direction, family structure, relationships, and living arrangements, conditions and impairments, health opinions and behaviors, community services, and interviewer observations.

The shear size of these questionnaires is daunting. The questions are answered by an informant or by the disabled individual. Although the questionnaires are comprehensive, the quality of the information is dependent on the knowledge and attitude of the respondent. No objective data based on a medical examination are provided. Since data from the questionnaires are available to researchers on a CD-ROM, this data forms the basis for much of the published research on this population. The information is aggregated at the national level, but not disaggregated to paint a local picture of the health status of persons with disabilities in a state or community. Although these surveys are a major source of health information on this population, the surveys are not participatory action research in which persons with disabilities and their families participate in the planning and implementation. Perhaps this is why there has been little research on practice occurring.

Special Olympics, as an organization, has done significant research on the health status of persons with disabilities (Spar, 2001; Block, 1997; Feldman, 1997). In March 2001, Special Olympics published The Health Status and Needs of Individuals with Mental Retardation (Horwitz et al.). In addition to this thorough review of the literature, Special Olympics has commissioned a number of other draft discussion papers. Unfortunately, this information has not been published in refereed journals, and the results have not been widely disseminated.

Disability has not been a major research area in medical sociology (Turner, 2001). Studies of disability typically appear in research on aging, where the studies are listed under the heading of "dependency" (Hocking and James, 1993). Within this setting, disability became associated with the negative images of aging (Featherstone and Wernick, 1995). Access to primary health care among people with physical disabilities has also been a neglected research area in Canada (Campbell, 1998). Veltman

(2001) found that in Canada, 17.4% of the persons with disabilities who were surveyed had difficulty obtaining services, and 8% had been refused medical treatment because of their disability.

Differing Needs

People with disabilities experience most of the same health conditions as others but are at greater risk for certain common conditions. Many adults with disabilities, their families or guardians were never told of these risk factors or told how they might be prevented. While health-care needs are not unique to this patient population, those needs become compounded or exacerbated in people with disabilities (Thomas, 1999). DeJong (1997) outlined eight ways in which the health needs of persons with disabilities differ from the general population: 1) a thinner margin of health, which must be carefully guarded; 2) lack of opportunities for health maintenance and preventive health care; 3) an earlier onset of chronic health conditions; 4) with a new health condition, individuals may acquire a secondary functional loss; 5) individual may require more complicated and prolonged treatment; 6) may required sustained pharmacologic support; 7) may need durable medical equipment and other assistive technology; and 8) may require long-term services, including personal assistants.

Co-morbidity is another condition facing persons with disabilities; however, very little work has been done on the causes of co-morbidity. Co-morbidity is defined as the presence of a coexisting or additional condition to the index condition (e.g., hypertension in a person with cerebral palsy). Co-morbidity in general has been associated with higher mortality, lower quality of life, and poorer health care (Gijsen et al., 2001). According to Healthy People 2000, people with disabilities have increased health concerns and susceptibility to secondary conditions. Health promotion programs for people with disabilities should reduce co-morbidity from secondary conditions (obesity, hypertension, pressure sores) to maintain functional independence, to provide an opportunity for leisure and enjoyment, and to enhance the overall quality of life by reducing environmental barriers to good health (Rimmer, 1999).

Children and Adolescents

Based on data from the 1994 NHIS-D, children with chronic conditions were less likely than other children to receive the full range of needed health services, a situation that exists across income levels (Silver & Stein, 2001). Children with functional limitations were more likely to live in families with limited resources and have greater exposure to secondhand smoke. They were also less likely to have access to health care and have a lower health status. Additionally, these children were more often delayed or prevented from getting necessary health care due to cost or lack of insurance (Hogen et al., 2000).

In January 2002, a review was published that identified the strengths and weaknesses of private health insurance coverage for children with special needs (Fox et al., 2002). That review found that for about one-fifth of the children covered under private health insurance, although they have access to benefits for most basic medical services, they are unable to have their extended needs met for behavioral health and most specialized health care services. Services frequently needed by children with disabilities, audiology, optometry, mental health and substance abuse, partial hospitalization services, nutritional counseling services, and medical supplies, were not covered in a quarter or more of the plans that were examined.

At the Special Olympics World Games in 1995, dentists and optometrists screened participating athletes. The results and attitudes uncovered were appalling, indicating previously unrecognized disease and health-care neglect. Half the athletes had eye problems, and one in three had untreated dental decay, with one in five reporting dental pain. Nearly 15 percent of the athletes screened suffered from acute pain or disease. One of the screeners suggested the following reason why so many athletes had problems.

> Few eye doctors want or know how to treat these patients. But even when they do, it's "quick and dirty": Give them a quick look, give them some glasses and send them on their way. They're not driving, they're not reading. What difference does it make whether they see clearly. (Shriver, 2002).

Adolescents with developmental disabilities face special problems in getting the confidential care they need to address issues of puberty (Quint, 1999). A 1995 survey of teens with disabilities found that many had no one to talk to about typical teen concerns such as drugs, alcohol, sexuality, anger, or despair (Shapland, 2000). Youth with disabilities are four times more likely to be sexually abused or exploited than their typical counterpart (Focht-New, 1996; Shapland, 2000). Few adolescents with disabilities, who have frequent health encounters, are taught to question health providers who may perform personal procedures inappropriately. Some report feelings that they have no control over their bodies because of their dependency on having these procedures done routinely. A disproportionate number of special education teens become pregnant (Wagner, 1993). Youth with disabilities are more likely to experience depression (Huurre & Aro, 2000) and disability-related eating disorders (Neumark-Sztainer et al., 1998). To address these needs, a manual was developed to provide a forum for professionals to become sensitized to issues of health and wellness for teens with disabilities (Krahn et al. 2001).

Women

Disparities appear to be greater for disabled women than for disabled men. Older women experience a high burden of chronic illness, disability, and co-morbidity, and this burden is highest among socio-economically disadvantaged and minority women (Bierman & Clancy, 2001). At older ages, women are more likely to be disabled than men (Iezzoni et al., 2001). The NHIS-D, looking at screening and use of preventive service for adult women with disabilities living in the community, demonstrated that preventive needs and well-women needs were not being met (McRae, 1997). Disability was associated with higher age-adjusted rates of poverty, living alone, low education, inability to work, obesity, and being frequently depressed or anxious.

According to Shabas and Weinreb (2000), the health maintenance of women with disabilities and chronic conditions has been neglected by the medical professions. They found that disabled women with major mobility difficulties in lower extremities had much lower rates of Pap smears, mammograms, and smoking queries. Interest in their health promotion has been eclipsed by a narrow focus on underlying conditions. In a survey of 220 women with multiple sclerosis, 50% did not have regular preventive check-ups, 25% did not have regular pelvic examinations, and 52% did not have yearly mammograms. Despite higher risk for osteoporosis, 85% had never had bone density testing, 50% were not taking calcium supplements, and 71% were not taking vitamin D. The most severely disabled reported fewer Pap smears and mammograms when compared with able-bodied women (Chan et al., 1999).

A recent study has examined the effects of race and poverty on breast cancer outcomes (Brawley, 2002). That article found that "it is bad to have cancer; it is worse to be poor and have cancer; and it is even worse to be poor, black, and have cancer." Unfortunately, the study found that the poorest outcomes were among those with comorbid conditions which might have played a role in preventing those women from receiving what is considered standard care for breast cancer screening and treatment (Bradley et al., 2002). Among those comorbid conditions were chronic health problems and disabling conditions.

The importance of having a health-care provider with whom one is comfortable is important to women with disabilities because of their increased vulnerability to violence and abuse. One study reported than more than 70 percent of women with developmental disabilities are sexually assaulted in their lifetime. This rate is 50 percent higher than the rest of the population (Petersilia, 2000). Sobsey and others (1995) reported that nearly 50 percent of those who had been raped had been sexually assaulted ten or more times. Revictimization is frequent because a high percentage of perpetrators are care providers or family members, and certain disabilities can prevent a victim from verbally reporting, running from, or fighting the attacker. Especially for more significantly developmentally disabled women, it is uncertain whether known cases of rape are reported by the family, caregivers, or physicians, even though it is a crime that by law requires reporting. The extent to which crisis services are available for developmentally disabled women who have been raped is unknown. Equally unknown is the amount of training police personnel receive in how to sensitively process the rape of developmentally disabled women.

Managed Care

Financial incentives in managed care may threaten access to the health care services that persons with disabilities need to maintain their health and functional independence (Sutton & DeJong, 1998). Managed care is how health plans and providers organize and manage the delivery of health services in a more coordinated fashion, often at a fixed price. As high-cost users of health care, people with disabilities or chronic conditions are vulnerable to risk selection.

The ADA prohibits most forms of risk selection, but it does not prevent all disability-based distinctions in insurance practices (Batavia & DeJong, 2001). The 1994 NHIS-D indicated that working-age persons who are limited in one or more activities of daily living constitute only 1.1% of the working-age populations, but they account for 7.5% of all physician visits, 9.1% of hospitalizations, and 15.8% of hospital days.

Compounding Risk Factors

Having a disability is only one of the characteristics by which persons define themselves. Age, gender, socio-economic status, ethnicity, and sexual orientation represent significant other characteristics of persons with disabilities that may further contribute to increased health disparities.

Poverty increases risk for disabilities (Fujiura & Yamaki, 2000; Seelman & Sweeney, 1995). Poverty also increases risk for more adverse educational outcomes for students with disabilities (Park, Turnbull & Turnbull, 2002). Health is impacted by hunger, under-nutrition during pregnancy, and limited access to health care. Smedley et al. (2002) found that lower socioeconomic status is more important than race in determining the medical care for women with breast cancer. Women on Medicaid were 41% more likely to be diagnosed with breast cancer at a later stage and were 44% less likely to receive radiation therapy.

Race and ethnicity are also important facets of disability. Because of continuing concerns about racial and ethnic disparities in special education, the 1997 Amendments to IDEA required a study of the issue. That study, conducted by the National Academy of Sciences, was released in January 2002. The study emphasizes the relationship of poverty to the over representation of minority students in special education (Reschley, 2002). Minority sexual orientation, among persons with disabilities, can also add an additional factor associated with increased health risks (Mays et al., 2002).

Summary

The test of any health care system is not how it addresses the needs of the majority who are fairly healthy, but how it meets the needs of the minority who need it most (DeJong & Basnett, 2001). An analysis of existing information suggests that, by this test, the nation's health care system is found wanting in how it meets the needs of persons with disabilities in at least the following dimensions:

Health disparities among persons with disabilities are a reality;

Those disparities are further exacerbated by gender, age, race, sexual orientation, and poverty;

Heightened vulnerability of persons with disabilities to violence, sexual assault, and abuse and neglect create a greater need for a consistent health-care provider who is understanding and knowledgeable;

Health-care personnel are often reluctant to treat persons with disabilities because of preconceived perceptions of inadequate training to meet their health-care needs;

Health facilities and equipment are often not accessible to persons with disabilities;

Information on health status is limited and not available at a community-level.

Current research efforts are inadequate to address the need.

Hopefully the publication of Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation (2002) will spur renewed interest in the funding of research with the findings to be translated into policy and practice to remedy this situation. Included among the questions that need to be addressed are the following:

What is known about the health of persons with disabilities and what resources are available to improve their health?

What health-care barriers do persons with disabilities encounter?

What is the knowledge and attitudes of health-care providers regarding serving persons with disabilities?

What changes in policies, training, and resources could reduce and eventually eliminate health disparities encountered by persons with disabilities?

How can persons with disabilities contribute to improving the health-care system for themselves and others?

2010 is less than eight years away. If Goal 2 is to be achieved relative to persons with disabilities, much work remains to be done. Persons with disabilities and their families must be actively involved in all aspects of this effort.

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