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# Access to Primary Health Care Among Persons With Disabilities in Rural Areas: A Summary of the Literature

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**ABSTRACT:** *Despite the prevalence of disabilities among persons living in rural areas, scarce data exist on their health care needs. While rural residents generally experience barriers to access to primary health care, these problems are further exacerbated for people with disabilities. This article summarizes findings from the published literature on access to primary health care among people with disabilities living in rural locations. A comprehensive computerized literature search turned up 86 articles meeting the study criteria, focused on the following rural populations affected by disabilities: children and adolescents, working-age adults, the elderly, the mentally ill, and people with AIDS.*

*For each of these populations, substantial problems in accessing appropriate health care have been documented. The literature consistently emphasizes the failure of local health care systems in nonmetropolitan areas to adequately address the complex medical and related needs of individuals with disabilities. In the absence of specialized expertise, facilities, and primary care providers trained specifically to care for disabled persons, local programs rely heavily on the use of indigenous paraprofessionals and alternative models of care. Further research is needed to identify and test the efficacy of innovative service delivery strategies to improve health care access for this population.*

**D**espite the prevalence of disabilities among people living in rural areas, scarce data exist on their health care needs (Burns, Batavia, Smith, & DeJong, 1990; Dana, Tielsch, Enger, Joyce, Santoli, & Taylor, 1990; Greenwood, 1985). Many individuals with severe disabilities suffer from associated health problems, yet few programs address their primary or acute health care needs (Burns, Batavia, Smith, & DeJong, 1990). Chronic

conditions, such as diabetes and arthritis, and certain vision and hearing impairments are especially prevalent in rural populations and result in higher reported overall days of activity limitation among

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rural versus urban residents (Department of Health and Human Services [DHHS], 1988). Although rural Americans account for a greater proportion of the population with disabilities than urban residents, they receive fewer formal or specialized services, travel further to obtain health care services, pay a greater proportion of their income for health care services and generally receive poorer quality care than their urban counterparts (Offner, Seekins, & Clark, 1992).

To ascertain patterns of health care utilization among this population and the adequacy of such care, staff at the University of Washington's Center for Disability Policy and Research and the WAMI Rural Health Research Center conducted a comprehensive review of the recent literature on access to primary care among persons with disabilities living in rural areas. This review was one of three components of a project funded by the Agency for Health Care Policy and Research to establish a comprehensive picture of access to primary health care services for people with disabilities living in rural America. Other project components included secondary analyses of national data sets and interviews and focus group sessions with key informants in rural communities across Washington state. This article presents key findings from the literature review conducted to expand the knowledge base in this crucial area.

This review was conducted based on the following assumption: If there is strong evidence of significant barriers to health care access for people living in rural communities and there are significant barriers to health care access for people with disabilities in general, then it would follow that the barriers to health care access would be significantly compounded for people with disabilities living in rural communities.

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## Methods

### Definitions.

**Disability.** The project used the definition of disability contained in the Americans with Disabilities Act (ADA), which defines disability as "a physical or mental impairment that substantially limits one or more major life activities of an individual, a record of such an impairment, or being regarded as having such an impairment."

Determining the appropriate terminology to use and definition of "disability" in policy and professional arenas has been historically the subject of heated debate. For example, the use-disability ratio is a measure of access to medical care based on the distri-

bution of physician visits relative to disability days, defined as days when the individual's usual activities are limited (Aday, Andersen, & Fleming, 1980). They state that "...the intent of the use-disability index is to reflect access for those who seem most in need of the curative resources of the health care system" (p. 188). It follows that the population defined by this scale includes those whose disabilities are defined by the health care system (the medical model) as an illness that benefits from (or is cured by) access to medical resources. A more useful index of access may be the symptoms-response ratio that is a need-based indicator taking into account the "appropriateness" of the care and access to it (Aday, et al., 1980).

In the mid-1940s, the World Health Organization (WHO) introduced the concept of health as not simply the absence of disease or infirmity but as a state of well-being (physical, mental, and social), a more qualitative model of health status (Aday, 1989). Since 1980, a more common practice has been to view health and disability as expressed by indicators of functioning. For example, Aday (1989) distinguishes impairment, disability, and handicap according to the WHO definition as follows: Impairment refers to reduced physical or mental capacities that result from some organic disturbance or malfunction, such as impaired vision. Many impairments can be corrected (by wearing glasses, for example). If impairments are not corrected, disability (a restriction on a person's ability to perform his or her normal physical or social roles or functions) may result. Handicaps reflect situations that result in social disadvantages (such as social stigma or loss of one's job) arising from the person's disability. It is important to point out that the same condition may have a different effect on different people's levels of functioning (p. 149).

This conceptual definition of disability has extended into the medical diagnostic market, as well as to education. For example, the American Medical Association (AMA) publishes the Guide to the *Evaluation of Permanent Impairment* as a standard for physicians to use when evaluating a patient's impairment. The guide specifically differentiates between impairment-a condition where a person's limb, organ, muscular system, or skeletal system doesn't function normally-and disability-a condition whereby a person's impairment prevents him or her from working or conducting activities of daily living (Cottman, 1995). Disability is the "...gap between what the person can do and what the person needs or wants to do" (p. 1).

Much of the debate regarding definitions of

disability comes from institutions and special educators who established a professional language for communicating among the various disciplines that served primarily school-age children and youths with disabilities. The language, however, was inadequate as advocacy groups, family members, policy-makers, and consumers demanded socially acceptable, respectful, "people-first" references to all people with disabilities.

The importance of terminology has become increasingly clear in terms of the effect labels have on individuals. Like the AMA, educators distinguish between the terms disability-which refers to a condition-and handicap-which describes the consequences of the condition. While the term "handicapped" was initially used in the Education for All Handicapped Children Act (EHA), it was changed to "disability" with the passage of the Individuals with Disabilities Education Act (IDEA) in 1990, with the understanding that the definitions, as social creations, must serve the needs of the individuals they describe.

In 1992, the ADA went into effect. Unlike the definitions founded on the medical model, or the EHA and IDEA definitions that emphasize education and provide parameters for children and youths up to age 21, the ADA is responsive to a wide spectrum of disabilities, regardless of age, with an emphasis on quality of life. It provides a comprehensive, broad application, the "...most encompassing civil rights public policy affecting the lives of persons with disabilities to date" (Meyen & Skrtic, 1995, p. 69).

**Primary Care.** Initially the subcontract specified that this study investigate access to "primary" care among persons with disabilities who reside in rural areas, but it became apparent in the literature that the issues governing access to primary care were intertwined with issues of access to specialized care. Thus, the review became broader and more comprehensive. While the major focus is access to primary care in general (e.g., care for the flu or for dental or gynecological problems), this review extends to access to care needed to address disability-related health problems as well, including secondary conditions or complex medical problems stemming from the disability. At issue is what types of providers are available in rural areas to address health problems that arise among persons with disabilities and whether they have the experience, expertise, and willingness to do so.

**Rural.** Several definitions of "rural" are commonly used in health care research. These include, for example, the "rural population" defined by the Bureau of the Census, the "nonmetropolitan popula-

tion" defined by the Office of Management and Budget, and the Department of Agriculture's Rural-Urban Continuum Codes (Butler, 1990; Office of Technology Assessment [OTA], 1990). Because many discrete definitions of rural are employed by researchers, the term was not strictly defined for this literature review but rather was left to the discretion of the authors of the articles that emerged from the rural-focused literature search.

Generally, the more remote the area in question, the greater the problems of access to medical care due to geographic distances, transportation problems, lack of insurance, and an inadequate supply of local providers (OTA, 1990).

**Procedures.** A computerized literature search of health and medical databases was performed with the expert assistance of the chief research librarian at the University of Washington Health Services Library. The parameters of the search were as follows:

1. Rural health or rural population or hospitals, rural or poverty areas.
2. United States (including regional and state citations).
3. Terms from a hedge (a grouping of terms developed at the University of Washington using MESH software) that encompasses chronic disease, handicapping, and disability terms. These include, for example, musculoskeletal diseases (e.g., arthritis), neurologic diseases (e.g., cerebral palsy), ocular diseases (e.g., blindness), neonatal diseases and abnormalities (e.g., spina bifida occulta), immunologic diseases, injuries, occupational diseases and poisoning, cognitive disability (e.g., Down's syndrome, depression), and frail elderly.

This search initially turned up more than 400 articles. Judging by the article titles and abstracts, approximately 200 met the study criteria and were retrieved. Upon review of these articles, 86 found to be relevant to this study were abstracted, resulting in a 60-page document. Articles were categorized by type of disability using the following broad classifications: disabilities among children and adolescents, working-age adults with disabilities, disabilities among the rural elderly, mental illness among people in rural areas, and disabilities associated with AIDS among rural residents. General deterioration of functioning associated with terminal diseases was excluded from the study, with the exception of HIV infection/AIDS. There are numerous recent articles discussing how this illness and consequential disabil-

ity have not been adequately addressed in rural areas.

Few of the rural-focused articles targeted adults with developmental disabilities or sensory disabilities among rural persons, such as deafness and blindness, or other physical impairments. For example, Dana, et al., (1990) note the scarcity of information regarding the prevalence, distribution, and causes of visual impairment for poor and isolated rural populations. Thus, the population categories considered in this article reflect those groups most often described in the literature.

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## **Overview**

There is abundant evidence that rural residents in general experience serious obstacles in accessing primary health care. Geyman and Hart (1994) report that 17 million Americans live in rural areas with a shortage of primary care physicians. Rural individuals have more chronic disease, are in poorer health, experience more injuries, and perceive themselves as less healthy than do their urban counterparts. They bear the added burden of inadequate access to health care resources, alarming rates of rural hospital closures, and persistent shortages of medical providers (Blondell, Norris, & Coombs, 1993; Offner, Seekins, & Clark, 1992). Additional obstacles to health care for rural residents include inadequate training and evaluation resources, insufficient referrals, lack of transportation options, remoteness of secondary and tertiary facilities, lack of financial resources, and absence of current information on disabilities (Offner, et al., 1992).

Persons with disabilities represent 10 percent of the world's population, yet they are among the most underserved groups (Frye, 1993). Many lack access to preventive, curative, or rehabilitative services (Chermak, 1991). Persons with physical impairments often lack opportunities to engage in preventive health care activities and do not have adequate access to primary care, hospital care, and long-term care services (DeJong, Batavia, & Griss, 1989). The problems in accessing health care in rural areas noted above are further exacerbated for individuals with disabling conditions. Effective chronic disease management is hampered by poor availability of, or access to, services targeting rural persons with disabilities (Henry, 1991). Rehabilitation services reach less than 2 percent of the population with disabilities and are usually based in large urban areas (Frye, 1993).

Greenwood (1985) underscores the need for

primary health care to prevent disability and deterioration resulting from a disabling condition. Poor access to primary care services in turn may delay access to needed hospital services until a crisis occurs. Appropriate levels of care can avert the use of more intensive, costly services (DeJong, et al., 1989).

The limited empirical studies of disability in the literature point consistently to serious neglect of the complex medical and social service needs of individuals residing in rural communities. Omohundro (1983) found that noninstitutionalized persons with disabilities in rural locales suffered from limited access to a range of services available in urban areas, few sought or obtained professional help, and many were unaware of the availability of needed services. Overall, health services for rural residents with disabilities were found to be lacking, resulting in a reliance on nontraditional approaches such as indigenous paraprofessionals, outreach workers and aides, mobile units, and professional teams. A study examining the nature and intensity of services provided to persons with developmental disabilities in rural Wisconsin showed that, despite a variety of severe medical and psychological difficulties, a minimum of documented medical and psychological services was provided (Slater & Black, 1986).

Burns, et al., (1990) indicate that access to primary care services for this population is impeded by the inability to use customary sources of primary care after the onset of a disability; they suggest that this is due to insufficient training in treating this problem, a focus by primary care providers on the disability *per se* rather than the presenting problem, and physically inaccessible physicians' offices. Offner, et al., (1992) report that specific disabilities are not prevalent enough in remote areas to support the development of specialized expertise.

Limited availability of, and access to, essential primary health care services for rural residents with disabilities persists across diverse subgroups, as described below.

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## ***Disabilities Among Rural Children and Adolescents***

An absence of information on the prevalence and severity of chronic illness or the health services utilization patterns of rural children and adolescents with disabilities has resulted in a lack of attention to this problem and reduced ability to address the health care needs of this population (Newacheck,

1989). McManus, et al., (1990) report lower use of physician services by rural as compared to metropolitan youths due to geographic and financial barriers, and advocate strategies to expand primary care services and comprehensive school health services to better serve rural youths. Despite a higher proportion of disabilities among rural children living in poverty, compared to their urban and nonpoverty counterparts, poor rural children experience even greater problems related to access to pediatric care, greater travel time to health care providers, and discontinuity of sick and well care (Levey, Curry, & Levey, 1988).

Efforts have recently focused on improving services to children with special health care needs (Ireys & Nelson, 1992) by emphasizing family-centered, community-based, and coordinated services (Fiene & Taylor, 1993; Malach & Segel, 1990). The 1989 Omnibus Budget Reconciliation Act requires that all children with special health care needs have access to an appropriate, community-based system of care (Ireys & Nelson, 1992).

Unfortunately, barriers to health care persist, particularly among culturally diverse, low-income, and rural families (Malach & Segel, 1990). Centers for the treatment of children with physical disabilities are usually located in centralized urban areas and are often inaccessible to rural children (Steel, Spasoff, & Alexander, 1985). Families of children with disabilities living in rural communities must typically seek services outside of their areas of residence at great financial and personal cost (Page, Bornhoeft, Barcome, & Knowlton, 1985). These same authors add that locally available services are offered infrequently, are usually fragmented, and are often obtained from itinerant providers. Appropriate interventions at the local level would reduce costs and disruption to patients, result in earlier evaluations, and involve primary care physicians more directly in the management of their patients with disabilities.

Clark (1990) describes dilemmas in caring for medically fragile children in rural areas, including limited availability of qualified home care personnel and support for patient care. She claims that intensive in-service education is needed by local individuals responsible for the medical management of these children, given the constraints of small rural communities. The author recommends improving the communications networks between tertiary care centers, local providers, and other community agencies to better address the health care needs of rural children and youths with disabilities.

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## **Working-age Adults with Disabilities**

DeJong, et al., (1989) report that 62 percent of those with a major activity limitation are working-age persons. The majority of articles concerning disabilities among working-age adults in rural areas focused on occupational injuries and illnesses, with few articles focused on adults with developmental disabilities, sensory impairments, or physical impairments not related to occupational injury or illness. In one of the few articles examining the plight of rural adults with developmental disabilities, Slater and Black (1986) report that rural communities may be slower than urban areas in developing a full range of supportive community services for this population.

Death and injury rates for agricultural workers are nearly five times that of individuals in other occupations (Donham & Thu, 1993). Emanuel, et al., (1990) assert that, as with the other rural subgroups, access to health care among agricultural workers is constrained due to the lack of practitioners within a reasonable traveling distance, limited access to technological advances, recent rural hospital closures, and lower health care funding in rural areas. These same authors describe a regional framework for health care delivery to meet the needs of rural residents, a system in which high quality primary care would be locally available but would be integrated into a regional referral system of backup, secondary, and tertiary care.

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## **Disabilities Among the Rural Elderly**

The elderly comprise the largest number of persons with disabilities, with the size of the elderly chronically disabled population expected to increase dramatically as a consequence of the aging of the general population and increased life expectancy (Manton, 1989). Manton estimates that the number of physicians required to continue current levels of service for the elderly will increase by 150 percent, with similar increased demand expected for nurses and home health workers. This is even more of a problem for this population living in rural communities. The rural elderly report more chronic illness and physical impairment than their urban counterparts, yet they have substantially less access to health services due to a dearth of health professionals, limited financial resources, and low residential density (Dwyer & Miller, 1990).

Clark (1992) reports that urban elderly persons with chronic disabilities are more likely than rural residents to receive formal assistance in every activity of daily living, while rural residents are more likely to receive informal assistance. Diminished function due to age-based frailty and chronic disease decreases options for independent living (Lang, 1982). Comparing nonmetropolitan to metropolitan areas, a greater proportion of elderly in nonmetropolitan areas assess their health as fair or poor, but a lower proportion report using home health services (Centers for Disease Control and Prevention & National Center for Health Statistics, 1993).

While a network of community-based and in-home services has been developed to provide long-term care to the elderly and chronically disabled, the problem of service delivery is intensified in rural areas with dispersed populations (Lang, 1982). Halpert (1988) emphasizes that even when available, these services are underused by rural residents due to suspicion, lack of awareness, a strong sense of independence, and a greater reliance on family, friends, and neighbors.

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### ***The Disabled Mentally III***

Evidence suggests that the risk of psychiatric illness is at least as great in rural as in urban areas, and recent increases in mental illness have been attributed to stressors such as the depressed agricultural economy (Bachrach, 1983; Pothier, 1991). Despite the fact that an estimated 23 percent of the population lives in rural areas (Bureau of the Census, 1988), only 6 percent of visits to psychiatrists are nonmetropolitan (Bachrach, 1983). Meyer (1991) notes that fewer than 10 percent of all psychiatrists in Minnesota are located outside primary population centers and that only one in five persons in rural America who needs mental health services is seen by a mental health professional. He adds that four out of five rural residents go to their primary care providers for mental health problems.

The ability of rural mental health providers to offer services such as suicide prevention, crisis intervention, and individual counseling is limited, and sources of care such as nonprofit foundations are less often available in rural than in urban areas. Furthermore, rural mental health professionals have fewer training opportunities or colleagues with whom to consult, and have more diverse demands than their urban peers. Much of the mental health

care in rural areas is provided by primary care practitioners who have limited training in mental health diagnosis and treatment (OTA, 1990).

Barton (1992) suggests that there is usually an insufficient caseload in local general hospitals to warrant full-time staff for psychiatric emergencies, a shortage of trained personnel to respond to this type of crisis, and frequent failure to seek treatment for mental health problems due to lack of resources. Mick, et al., (1993) report that only one in five rural hospitals studied in 1988 had alcohol and drug abuse services, largely due to lack of psychiatric staff in rural areas.

Bachrach (1983) attributes low use of psychiatric services in rural areas to social factors (e.g., poverty, low levels of education, ignorance of mental illness and associated treatments), geographic and climatic conditions that limit access to health care facilities, demographic factors (e.g., a limited population base, prohibitive costs of psychiatric services), socioeconomic factors (e.g., conservative rural culture, limited resources such as aftercare facilities and residential alternatives, personnel and training problems), and interpersonal and ideological factors (e.g., lack of anonymity for patients, stigma attached to mental illness). Pothier (1991) enumerates unique barriers to seeking and providing mental health services in rural communities, such as a tendency to value self-reliance and to keep personal matters within the family, denial, isolation and distance from services, and difficulties in attracting and retaining qualified professionals in remote areas. Stigma remains a substantial barrier to seeking mental health care for people living in rural areas (Rost, Smith, & Taylor, 1993).

A deficit of mental health services in rural communities has made necessary the establishment of community mental health centers and the linking of health and mental health services (Wagenfeld, 1990). It has also broadened support for community care, in which local resources are mobilized to coordinate and carry out treatment plans (Runyan & Faria, 1992; Santos, et al., 1993). However, because many of the community mental health centers lack sufficient staffing, primary care physicians are often called upon to fill the service gap (Thomas, 1988). If properly trained, primary care physicians can be instrumental in early identification and management of a variety of mental health problems affecting rural residents, including alcoholism (Seale, Williams, & Amodei, 1992) and chronic pain associated with psychosocial factors (Sullivan, Turner, & Romano, 1991).

Strategies to improve access to mental health services in rural areas include involving community

residents in peer-counseling networks, increasing the number of local mental health professionals, using outreach services and community care teams, and incorporating mental health treatment into the regular practices of rural family physicians (Meyer, 1991). Meyer points out certain problems concerning an expanded mental health role for family physicians, including time and financial burdens, overreliance on medications, and lack of adequate training. This suggests the need for rural family physicians to develop greater ties with the mental health community and to enhance their skills in identifying and treating psychiatric problems among their patients.

### ***Disabilities Associated with HIV Infection and AIDS***

The incidence of HIV infection and the number of cases of AIDS are rapidly increasing in rural America (Carwein, Sabo, & Berry, 1993). There is growing concern about the inability of rural systems to provide appropriate health care and social services needed to cope with this disease (Tokarski, 1990). Tokarski suggests that AIDS patients in rural locations are victimized by discrimination as well as shortages of health care personnel and support. Physicians who treat people with AIDS are generally not available in small towns, so patients must travel considerable distances to obtain care (Rounds, 1988). Rounds cites other barriers to health care among AIDS patients in rural areas, including fear and hostility among members of the community, issues of anonymity and confidentiality, denial, and geographic distances. Alsup and Narramore (1992) assert that early medical intervention for treatment of AIDS in rural areas is complicated by the tendency for rural populations to underestimate their risk of infection, a lack of medical insurance and public clinics, long travel distances required to seek care, delays in testing due to the public perception that AIDS is not a rural problem, and the absence of rural physicians with the skills and experience needed to manage AIDS-related illnesses.

Most primary care physicians practicing in rural communities have not been adequately prepared to diagnose and treat AIDS. A recent study estimating the seroprevalence of HIV-1 infection in persons seeking care from rural primary care providers demonstrated that the clinicians of 32 percent of all infected persons failed to recognize the presence of risk factors among these patients; consequently,

many of those at risk were unlikely to be screened (Calonge, Petersen, Miller, & Marshall, 1993). Montgomery and Lewis (1991) reveal that staffs of small rural hospitals demonstrate greater fear of contagion than do staffs at urban hospitals. Staver (1988) alludes to rural physicians' inability to handle complications experienced by individuals with AIDS, fear of treating AIDS patients, and failure to believe that AIDS poses a significant problem in rural areas. Staver recommends that primary care physicians take mini-courses and become more involved in the care and treatment of people with AIDS.

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### ***Discussion***

While there is a dearth of literature in the area of access to primary care for persons with disabilities residing in rural areas, existing evidence consistently demonstrates both the widespread prevalence of a range of disabilities among rural populations and major barriers impeding access to appropriate local care. Rural areas have difficulties in attracting and retaining qualified health care professionals, and they lack the population base and resources necessary to offer highly specialized services. Primary care physicians are the major source of medical care for rural citizens, but by virtue of their broad scope of practice, they generally lack the training and experience to treat some of the complex needs of individuals with disabilities.

The consensus among those who have examined these issues appears to be that: (1) primary care providers need special training to better prepare them to identify, treat, and refer people with disabilities, and (2) alternative service delivery strategies are needed to address the health problems of persons with disabilities in rural communities. These include, for example, regional centers of specialized care; use of trained nonprofessional community workers, outreach teams, and mobile service units; use of telemedicine to provide consultation by urban specialists to practitioners in remote areas; better networking to reduce the isolation of rural health care providers; coordination and case management; more efficient use of available local resources; and community workshops to raise citizen awareness of the needs of people with disabilities.

Finally, there is a critical need to conduct research to identify and test effective models of care specifically targeted to rural populations with disabilities. Furthermore, once these models are identified, demonstration projects and evaluations are needed to test their feasibility and efficacy.

It has been suggested that the effectiveness of efforts to prevent or reduce consequences of disability is dependent on improved access to primary health care (Chermak, 1991; Greenwood, 1985). Henry (1991) argues that the availability of hospital-based chronic care services as an adjunct to local physicians' practices would allow the management of chronic disease to remain in the hands of primary care physicians. Frye (1993) advocates integration of rehabilitative services into community-based primary health care delivery at the local level and recommends dissemination of locally produced technical aids that can be used in remote areas, development of training curricula for health care providers oriented toward addressing the needs of individuals with disabilities, and training of rehabilitation providers within local health care settings. Until changes such as these are implemented and evaluated on a widespread basis, the rural health care system's ability to care for and manage the disabled population will itself remain impaired.

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