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The Centers for Disease Control Program to Prevent Primary and Secondary Disabilities in the United States

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Synopsis

The Disabilities Prevention Program builds on traditional Centers for Disease Control (CDC) strengths in public health surveillance, epidemiology, and technology transfer to State and local governments in translating the findings of research into prevention programs.

The objectives of the CDC program are to provide a national focus for the prevention of primary and secondary disabilities, build capacity at the State and community levels to maintain programs to prevent disabilities, and increase the knowledge base necessary for developing and evaluating effective preventive interventions.

During 1989, CDC, in consultation with the National Council on Disabilities and members of the disability community, has elected to focus its effort in three areas: developmental disabilities, injuries to the head and spinal cord, and secondary complications among persons with physical disabilities.

RESULTS OF A 1986 HARRIS POLL showed that 15 percent of the U.S. population over the age of 16 years—27 million persons—reported a disability. A disability in this study was defined as the existence of a limiting health condition that interfered with normal activities or limited the ability to work (*1*). Survey results also showed that citizens with disabilities are often poor (50 percent of those with disabilities versus 25 percent of persons without disabilities reported household resources of less than $15,000), that two-thirds of disabled Americans between the ages of 16 and 64 are not working (although two-thirds of those not working want to work), and that 25 percent have encountered job discrimination because of their disability. The most significant measure of the impact of a disability is that a large majority of persons with disabilities report that their disability has prevented them from reaching their full potential.

Examining these data further, one finds that disabilities affect persons of all ages, but the impact and the nature of the causes of disabilities vary in different segments of the population (see table). For children and young adults, developmental disabilities and unintentional injuries from motor vehicle crashes and recreational activities are of foremost importance. In older age groups, injuries from falls and chronic diseases become increasingly important, as do intentional injuries from assault, especially among the elderly in urban areas.

Background

The National Council on Disabilities (NCD, formerly the National Council on the Handicapped), an independent Federal agency whose members are appointed by the President of the United States, is charged with reviewing all laws, Estimated impact of disabilities in the United States, by age and etiology, 1986

Onset	Primary etiology	Number of persons (millions)	Percent	Survival (years)	Years of disability: Number (millions)	Years of disability: Percent
Birth–15 years	Developmental disabilities, injury	5.6	20	50	280	35
16–34 years	Injury	7.0	25	40	280	35
35–54 years	Injury, chronic diseases	6.4	23	25	161	20
55 years and older	Chronic diseases, injury	8.7	31	10	87	10

SOURCE: 1986 poll conducted by Louis Harris and Associates, Inc., for the National Council on the Handicapped.

programs, and policies of the Federal Government that affect persons with disabilities. The Council makes recommendations to the President, the Congress, the Secretary of Education, the Commissioner of the Rehabilitative Services Administration, and the Director of the National Institute of Handicapped Research. In 1986 the Council presented to the President and to Congress, "Toward Independence," an assessment of Federal laws and programs affecting persons with disabilities (*2*). In that report, the Council recommended a Federal initiative to prevent disabilities through both Federal leadership and the coordination of prevention programs at the local, State, and Federal levels. This initiative included the development of a national plan for disability prevention, the authorization of a grant program to support prevention efforts by States and local communities, the development of methods for preventing secondary complications among persons already disabled, and a subsequent evaluation by the Congress's Office of Technology Assessment of the status of disability prevention in the nation.

In recognition of the importance of these recommendations, Congress and the President approved the establishment of a disabilities prevention program at the Centers for Disease Control (CDC) and appropriated $3.83 million in both 1988 and 1989. CDC was chosen for the Federal focus on disability prevention for several reasons. As the lead agency for prevention in the Public Health Service, CDC already had programs in injury control, developmental disabilities, lead poisoning, and chronic diseases that could complement an effort in disability prevention. The Disabilities Prevention Program builds on traditional CDC strengths in public health surveillance, epidemiology, and technology transfer to State and local governments in translating the findings of research into prevention programs. One objective of the CDC program is to provide a national focus for the prevention of primary and secondary disabilities (secondary disabilities, or complications, are disabilities that develop in persons who are already disabled). These disabilities may or may not be more likely to occur because of a primary disability (for example, chronic renal disease in persons with paraplegia). A second objective of the CDC program is to build capacity at the State and community levels to maintain disability prevention programs. The third objective is to increase the knowledge base needed to develop and evaluate effective interventions that prevent disability.

During 1989, CDC, in consultation with NCD and members of the disability community, has elected to focus its effort in three areas: developmental disabilities, injuries to the head and spinal cord, and secondary complications among persons with physical disabilities. Head and spinal cord injuries were selected for an initial focus because the clinical course of these injuries so often leads to disability.

Magnitude of the Problem

Developmental disabilities include cerebral palsy, mental retardation, hearing and vision impairments, seizure disorders, autism, and structural birth defects such as spina bifida, which cause physical impairment that cannot be corrected by surgery. These developmental disabilities are diagnosed in an estimated 80,000 children a year (M. Adams, Centers for Disease Control, memorandum of December 15, 1988). Estimates of the prevalence of these disabilities vary between 3 million and 4 million persons, depending on which disabilities are counted (C. Wistar, draft report to New York State Development Disabilities Planning Council, 1986). About 250,000 of these persons with developmental disabilities are in long-term facilities (*3*). In 1984, the total expenditures from Federal, State, and private sources were about $16.5 billion (*4*). Significant proportions of State expenditures for chronic diseases and maternal and child health are allocated to persons with developmental disabilities (*5*).

An important, preventable cause of mental retardation and learning disability is lead poisoning of children. Results of the National Health Assessment and Nutrition Evaluation Survey conducted between 1976 and 1980 showed that an estimated 675,000 children between 6 months and 5 years of age had blood lead levels over 30 μg per dl, the then recommended threshold for lead toxicity (*6*). The current CDC threshold for lead intoxication is 25 μg per dl (*7*). Because so much lead has been removed from the gasoline used in the United States, the number of children with elevated blood lead levels has decreased. In 1988, an estimated 200,000 children under 6 years were found to have blood lead levels above this lower threshold (*8*). It has been estimated that as many as 50 percent of children with blood lead levels over 25 μg per dl have impaired intelligence or adverse neurologic effects (*9*). Some investigators have concluded that lead levels even lower than 25 μg per dl result in impaired intelligence and may induce hyperactivity (*10,11*). Lower thresholds for risk (for example, 15 μg per dl) would, of course, mean that additional children would be at risk for adverse effects. Currently, each year only about 11,500 children under 6 years are identified through screening programs as lead intoxicated (*8*). Planned CDC activities in the prevention of childhood lead poisoning will supplement ongoing efforts to prevent developmental disabilities attributable to this source.

Several measures are effective in preventing developmental disabilities. In addition to lead screening and environmental lead abatement, effective interventions include screening of newborns for phenylketonuria and congenital hypothyroidism, childhood immunization, and prenatal diagnosis of abnormalities. Other prevention strategies, such as ensuring adequate nutrition for the newborn, may also prove to be useful in preventing developmental disabilities. The means for preventing many birth defects and developmental disabilities are, however, not known.

Each year approximately 1.3 million persons suffer head injuries, and more than 50,000 survive with severe, permanent disabilities (*12,13*). Most of these persons are under 30 years of age. In 1982, the national medical bill for head injuries required an estimated $9-$12.5 billion to cover acute and long-term care costs (*14*).

Each year between 10,000 and 20,000 persons, mostly those between 15 and 24 years of age, are hospitalized with spinal cord injuries (*15,16*). Less than 7 percent of persons with paraplegia and quadriplegia from spinal trauma recover full function of their limbs. Less than 30 percent of persons with spinal cord injury are employed 5 years after their injury (*17*). The average person with a spinal cord injury survives about 30 years; between 110,000 and 230,000 persons with serious spinal cord trauma are living in the United States today (*18-22*). Each year government spends an estimated $4 billion at all levels on direct medical costs of spinal cord injury (*22*). Lost earnings associated with spinal cord injury are estimated to be $3.4 billion a year (unpublished data of the Department of Rehabilitation Medicine, University of Alabama in Birmingham).

The causes of head and spinal cord injury are similar. Nationally, motor vehicle crashes cause about 30-50 percent of these injuries, followed by falls (20-30 percent), assaults (10-33 percent), and injuries incurred during recreational activities (5-15 percent) (*18,23,24*). In many urban areas, however, the leading cause of these injuries is assault, particularly with firearms (*25*). The effects of prevention measures on reducing head and spinal cord injuries are well recognized, but these measures have not been adequately implemented. Proper use of seat belts, airbags, and motorcycle and bicycle helmets and tighter enforcement of drunk driving laws have been shown to reduce injury caused by vehicular collisions (*23*).

In the area of sports safety, prevention efforts have also become more effective; these efforts range from banning unsafe toys and equipment (*26*) to making playgrounds safer (*27*) and having stricter diving regulations (*28*). In contrast, the key to the prevention of intentional injuries is research to develop effective means of preventing injuries related to the misuse of alcohol, drugs, and handguns (*29*).

The Disabilities Prevention Program

The CDC Disabilities Prevention Program has four foci: (*a*) capacity building at the State and community level to coordinate disabilities prevention activities; (*b*) establishing systems of public health surveillance for selected high-priority disabilities; (*c*) using epidemiologic methods to establish priorities and target effective interventions; and (*d*) providing State-based technical assistance. In 1988, CDC awarded cooperative agreements to nine States—five for State capacity building projects to develop a State focus and implementation plan and four for State prevention and evaluation projects in States that already have a State focus and plan for disabilities prevention (see map).

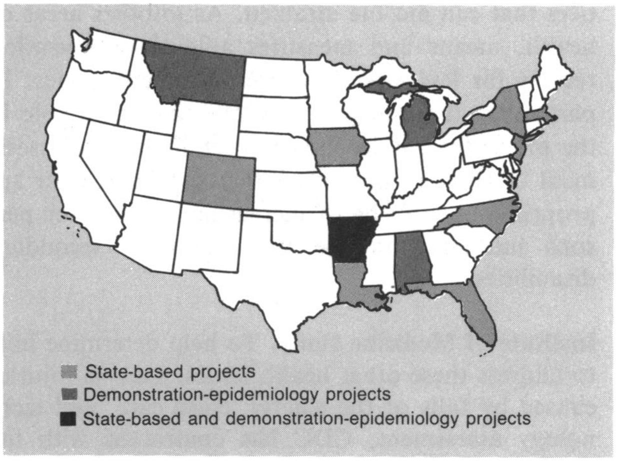
National data on secondary complications among persons with disabilities are scarce. In this important area, CDC and NCD hope to build epidemiologic capacity in States and universities, beginning with four cooperative agreements in 1989. Through such support, CDC encourages researchers to define better the scope of this problem and to identify cost-effective prevention methods. The University of Alabama in Birmingham will develop appropriate surveillance programs for the early identification and management of urinary tract infections occurring in patients with spinal cord injury, evaluate the efficacy and cost of interventions, and create management guidelines. Researchers at University of Michigan hospitals will study secondary disabilities and the sociodemographic context in which they occur in a population experiencing the late effects of poliomyelitis. At the University of Montana, researchers will develop two models—one for collecting and analyzing epidemiologic data from rural communities and one for a rural outreach program to prevent secondary disabilities. The Arkansas State Spinal Cord Commission will document the incidence and cost of decubitus ulcers among persons disabled by spinal cord injuries and then implement an intervention program. The intervention program will include visiting participants in their homes to reduce the incidence of ulcers.

Future Directions

Future activities in disability prevention can expand into other important health areas such as injuries from falls of the elderly and from chronic diseases. These activities should also expand into fields that have an important impact on persons with disabilities. Two such fields are child care and technology assessment.

Child care. In the United States today, child care has been recognized as an important issue, and public health responsibilities and opportunities have been delineated (*30*). Important to any consideration of disability prevention is the fact that of the more than 4.3 million children and youth between 3 and 21 years in the United States with disabilities, more than 250,000 are preschoolers (*31*). Results of a community study in Victoria, BC, showed that 9.7 percent of children in preschools and day care centers had disabilities (*32*). Children with disabilities have special needs in terms of access to care outside the home, special resources, specially trained staff, and specific concerns, such as the impact of child care shared by children with and those without disabilities. In a 1980 Washington, DC, study of 70 licensed day care facilities, results showed that 40 (57 percent) of these centers were willing to accept children with handicaps, but only 13 (19 percent) reported a willingness to accept these children if they were not ambulatory or toilet trained (*33*).

States with cooperative agreements in the disability prevention program of the Centers for Disease Control, 1988-89



Certain public health concerns and opportunities for prevention are relevant to disabled children needing child care. First, child care is a potential focus for the early detection of disabilities, and it affords an opportunity for referral for appropriate interventions. Second, although children with disabilities may acquire the same diseases and injuries as other children, their disabilities may put them at increased risk for additional disabilities; furthermore, they may need particular attention or some adaptation in the environment (for example, ramps). Finally, disabled children are at risk of secondary disabilities. A child with the primary disability of paraplegia is at high risk of having renal failure due to recurrent urinary tract infections.

Technology assessment. Technological resources enable the person with disabilities to function more effectively in his or her environment. In a 1982 report, the Congressional Office of Technology Assessment concluded that the current system of disabilities-related research, development, evaluation, diffusion, and use of technologies has significant weaknesses (*34*). The Federal Government spends $36 billion annually to supplement the income of persons with disabilities, but only $66 million for research on equipment, devices, and practices that can aid the disabled. As in other areas of health, means and measures aimed at prevention receive far less attention than therapeutic ones. In particular, technologies may play a critical role in the prevention of secondary disabilities. The assessment of these technologies, the costs, and their appropriate use will be of increasing concern for persons interested in the prevention of secondary disabilities.

Institute of Medicine study. To help determine how to address these other health issues, such as injuries caused by falls of the elderly, child care, and technology assessment, CDC has contracted with the Institute of Medicine (IOM) at the National Academy of Sciences to establish a committee to review the disability problem in the United States. IOM has been asked to develop recommendations for a national agenda for disability prevention. To do this, the committee will collect and analyze available data on disabilities and describe State, Federal, and private prevention activities. IOM has also been asked to identify a national coalition of persons and organizations active in disability prevention that can be used to establish a broad national consensus on future directions in disability prevention. The 1985 IOM report, "Injury in America," has been a catalyst for national action in injury prevention and control (*35*). The IOM committee is expected to help focus prevention efforts in the areas of disability prevention.

Sizable amounts of public and private resources are spent on disabilities, but, on the whole, there is much to be learned, especially in the area of prevention. NCD activities have created the opportunity to apply public health principles to disability prevention. Public health surveillance, applied research in epidemiology, and effective community interventions can help decrease morbidity and mortality from disabling conditions and increase the number of persons with disabilities who live independent and productive lives.

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Correlates of Participation in AIDS Education and HIV Antibody Testing by Methadone Patients

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Synopsis

The authors examined the factors associated with methadone patients' decisions about participating in a clinic-based AIDS prevention protocol. Despite the offer of incentives, only 27 percent attended AIDS education and only 12 percent obtained voluntary HIV antibody (ab) testing. However, AIDS education was attended by proportionately more of those who were at highest risk for AIDS because of current intravenous drug use. The availability of HIV-ab testing neither encouraged nor discouraged participation in AIDS education.

Patients who were relatively more likely to choose HIV-ab testing were older, had been or were married, had plans to have children, believed the test to be useful, and believed that their counselors support their decision to be tested. Those who declined to be tested were reluctant to confront the emotional aspects of their risk status, were concerned about possible breaches of confidentiality, and doubted the value of testing.

The implications of the findings for implementing AIDS prevention measures in methadone programs are discussed. Programs need either to require attendance at AIDS education or give patients an incentive to attend. HIV-ab testing should be available but should remain voluntary. A stronger medical rationale for testing is developing and may increase future participation. Methadone programs must continue to engage patients actively in AIDS risk reduction efforts.