

Rethinking Prevention for People with Disabilities Part I: A Conceptual Model for Promoting Health

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PURPOSE

Health promotion and disease prevention activities tailored to people with disabilities are crucial to fulfilling the goals articulated in the Americans with Disabilities Act (ADA). We propose a conceptual model to facilitate design and evaluation of health promotion strategies across the life course of people with disabilities. Components of the model, described as planes of experience, integrate the individual's total environment, the disabling process, opportunity and quality of life. Cost and outcomes re-search is recommended for the evaluation of prevention effectiveness. This model informs a U.S. disability policy that emphasizes environmental modification, prevention of secondary conditions and functional decline, promotion of independence and autonomy, and improvement in individual quality of life.

DISCUSSION

Preventing disease and promoting the health of all Americans has typically received a low priority in the allocation of health resources, representing less than 3.4% of health expenditures nationwide.¹ Health promotion and disease prevention interventions that focus on people with disabilities have received even less attention than such strategies for the public at large.² The Americans with Disabilities Act (ADA) takes aim at discrimination against individuals with disabilities and articulates goals for equal opportunity, full participation, independent living, and economic self-sufficiency.³ Fulfilling those goals, however, extends beyond implementing the immediate provisions of the ADA. For people with disabilities, managing health requires innovative strategies at the policy, group, and individual level. These strategies should address complications related to disabling conditions and should equip individuals with disabilities with the personal and social resources to monitor their own health, engage in health promotion, and enjoy an enhanced quality of life.

At present, people with disabilities rarely receive the range of preventive services they may need or want.⁴ Preventive services may be overlooked in clinical settings because of the focus on treatment of the disabling condition. Standard public health preventive services may not reach this population; furthermore, the main focus of public health is on primary prevention of disability and less emphasis may be given to preventive efforts for people with existing disabilities.

People with disabilities, however, are susceptible to other chronic conditions to the same or greater degree than the general population and are at risk for secondary conditions that result from their primary impairment.² In addition, the promotion of opportunity is not among traditional clinical or public health objectives. Therefore, to guide the design and evaluation of interventions that meet the full range of prevention activities appropriate for this group, we propose a new model of health promotion for people with disabilities. This model builds upon previous conceptions of disability, but it extends and re-formulates these conceptions to place emphasis on the points of health promoting interventions and the evaluation of outcome through measurement of quality of life.

The novel contributions of this model are the separation of areas of opportunity from the disabling process and the clarification of components' specifications and suggested relationships of experiences of persons with disabilities. The model helps define prevention for people with disabilities and helps design preventive strategies with the goals of modifying the disabling process or promoting areas of opportunity. The model applies across the continuum of disability, from mild to severe, and takes into account all disabling conditions: physical, emotional, cognitive, and sensory. It can also be used to evaluate prevention effectiveness by assessing the cost and effectiveness of alternative prevention strategies.

A Conceptual Model of Disability in the Life Course

Disability occurs across the life span and is the consequence of physical and/or mental impairments that are congenital or may begin early in life (e.g., developmental disabilities), occur as a result of injury, or develop later in life (e.g., chronic conditions). Disability has been defined as a limitation in function or a restriction in major life activity as a result of mental, emotional or physical health conditions.^{5,6} The ADA expanded this concept to describe disability as "a physical or mental impairment that substantially limits one or more of the major life activities of such individuals, a record of such impairment, or being regarded as having such an impairment."³ According to this definition, people are not always disabled or disadvantaged by their impairments, but in some circumstances they may be disabled by the way society treats them.

In order to develop a conceptual model for health promotion for people with disabilities, we build upon previous models of disability developed by the World Health Organization,⁷ the Institute of Medicine,⁸ Verbrugge and Jette,⁹ and the working papers on the prevention of primary and secondary disability compiled by the Centers for Disease Control and Prevention in its Disabilities Prevention Program.⁴ In Figure 1, we propose a model that shows determinants of the disabling process and the promotion of opportunity that influences quality of life. The model shows points of intervention to prevent the onset and progression of disabling conditions, to promote opportunity, and to increase quality of life.

The conceptual model shown in Figure 1 shows four major planes of experience, depicted as layers, that together describe the context of life for a person with disabilities: the total environment, the disabling process, opportunity, and quality of life. Among the elements of each plane and across the four planes, interactions occur that provide opportunities for intervention. The model illustrates these interactions with arrows. Elements within the planes do not constitute a linear or temporal process - that is, for the most part they do not proceed in an entirely one-way direction. Two individuals with similar life circumstances, similar impairments, and similar opportunities may experience disability and preventive efforts differently. For example, two people with spinal cord injuries with comparable impairments and opportunities might have different reactions to a program that promoted exercise because of their perceptions of disability as well as their individual and environmental barriers.

The disabling process may be halted or reversed at the interaction points in the model. Some interventions may be designed to prevent progression of disability. These interventions have the goal of maintaining or restoring functional status, i.e., mitigating functional limitations and activity restrictions and preventing secondary impairments or conditions that exacerbate disability or cause new disabling conditions.^{10,11} For example, an intervention might be designed to screen, detect, and provide early treatment for pressure ulcers secondary to spinal cord injury, the primary impairment. This intervention could reduce functional limitation and activity restrictions and improve quality of life.

Interventions may also be designed to promote opportunity by reducing the disadvantage associated with non-participation in community life, thereby increasing social and psychological well-being. For example, job training programs and supported employment for persons with cognitive and physical impairments can promote independence and economic self-sufficiency and improve quality of life. Changes to the physical environment such as curb cuts and accessible public transport can influence both the disabling process and opportunity by

reducing activity restrictions and promoting opportunity towards full participation in community life.

Our model addresses the growing gap between known determinants of health and quality of life, such as coping with stress and acknowledging that the primary focus of health policy looks to physical treatment for disabling conditions.¹² The planes of experience emphasize that improving health-related quality of life for people with disabilities entails not only altering physical processes but also changing the individual behavior of the physically disabled individual, the social environment, and the response of the health care system. All planes are influenced by the allocation of resources and the prevailing ethics of the culture.¹³

Table 1 describes the components of each plane in the model. The individual's total environment, represented in the first plane of the model, encompasses individual biology, demographic or life course, social and physical environments (including cultural and economic influences), and the individual's behavior. Events leading to disabling conditions, including infections, injuries, or the natural processes of development and aging, occur at all stages of the life course. These intrinsic and extrinsic components of the environment, and interactions among them, can be viewed as risk factors for developing disabling conditions or for restricting opportunity. Risk factors may be amenable to intervention to prevent disabling conditions and promote opportunity.

Table 1
Components of a Model of Health Promotion for People with Disabilities

Plane of Experience	Components
Total environment	individual biology: genetic susceptibility , aging, race, gender Life course: parent, infant, child, adolescent , middle adult , older adult Health care: primary and specialty care, rehab services Physical environment: buildings, exposures Social environment: culture, economics, social supports Lifestyle and behavior: smoking, exercise, diet, risk-taking
Opportunity	Independent living, i.e., community residence outside institution Economic self-sufficiency: job opportunities or income support Equality: having same rights or status as others Full participation: taking part in community activities such as work or recreation to extent possible
The disabling process	Disease or injury: cellular and tissue changes Impairment: organ-level loss or diminution of function Functional limitation: limitation in ability to carry out actions Activity restriction: restricted capacity to perform social role activities

Quality of life

Personal evaluation of position in life on multiple domains, including physical, psychological, level of independence, social relationships, environment , spirituality

The second plane, at the bottom of the model, shows the disabling process and describes the progression from the disease or injury itself to disability. This process may not occur in sequence, and prevention activities may be designed to interrupt and/or reverse the process at any stage.⁸

Opportunity, the plane shown in the middle, represents the interaction between the total environment of the individual at his or her particular stage of the life course, and the disabling process. The parameters of opportunity have been defined by the ADA.³

At the right of these three planes is the experience of quality of life, the fourth major plane. Quality of life is viewed as people's perceptions of their position in life in the context of their particular culture and value system and in relation to their personal goals, expectations, standards, and concerns.¹⁴ These perceptions may be influenced by all aspects of their total environment, their experience with health care and the disabling process, and their opportunity. Society's response to an individual person, in his or her attempts to gain access to full participation, independent living, self-sufficiency and quality, will also influence perception of quality of life.

Quality of life is the final outcome of the influence and interaction of environmental risk factors, the life course of an individual or group, the disabling process, and opportunity. Enhancing quality of life is the ultimate goal of health promotion and disease prevention for people with disabilities.¹³ Quality of life must be assessed from the individual's perspective as closely as possible.¹⁵ Improved quality of life can in turn be an influence that helps reverse the disabling process or helps modify risk factors.

Not all possible interactions can be represented in the depiction of planes and relationships shown in Figure 1. The person's objective (income, housing, etc.) and subjective well-being, defined by the person and by others, can and does influence a person's response to the risk factors for disablement and the outcomes of the disablement process. For example, socioeconomic status, educational attainment, or physical surroundings are among the many influences that are risk factors for disablement and modifiers of response to disability.¹⁶ Personal perceptions of life quality, such as satisfaction with health and life circumstances, are key subjective responses to the experience of functional limitations, disability, and activity restrictions.¹⁷

Conclusion

This model is a guide to conceptualizing prevention for people with disabilities. Preventive interventions and policies must be tailored to the specific needs of different groups of people with disabilities in order to be acceptable and effective. At the same time, these interventions must be incorporated into clinical practice and population-based community health promotion efforts. People with disabilities and their advocates can and do play a major role in designing and implementing health promotion programs aimed at preventing the disabling process and promoting opportunity. Potential beneficiaries of prevention programs or policies must contribute to the knowledge, experience, and values important to finding strategies that result in improved quality of life.

Competing prevention strategies, including those for people with disabilities, should be rigorously evaluated for their comparative cost and outcomes in terms of intermediate outcomes of behavior and environmental change and the ultimate outcome of quality of life. Health promotion and disease prevention for people with disabilities should play a central role in a U.S.

disability policy that promotes health as well as prevents and eliminates disadvantage through the promotion of opportunity.

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