Leading Health Indicators: Physical Activity, Overweight and Obesity, Tobacco Use, and Access to Care

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This Forum was hosted by the Disability and Health Team of the National Center on Birth Defects and Developmental Disabilities, CDC and presented the current state of knowledge and identified commitments to strategies to achieve the Healthy People 2010 health promotion and community integration objectives for people with disabilities. Proceedings are forthcoming.

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Abstract

Health promotion and disease prevention activities (HPDP) targeting people with disabilities are crucial to both increasing years of healthy life for the whole population and to reducing health disparities. Leading Health Indicators identify important health concerns and motivate programs, policies, and the availability of data to measure progress. We present cross-cutting issues and suggest activities for a national agenda to improve the health of people with disabilities with emphasis on four selected Indicators: physical activity, obesity, tobacco use, and access to care. People who have disabilities are more likely than persons without disabilities to report lower levels of physical activity, to exceed the recommended body mass index for weight and height, to smoke currently, and to face financial barriers to health care.

People with disabilities rarely receive the range of HPDP activities they may need or want, although they are susceptible to other chronic conditions to the same or greater degree than the general population and are at risk for secondary conditions. Standard public health preventive services often do not reach this population. Furthermore, the main focus of public health is on primary prevention of disability. Less emphasis may be given to preventive efforts for people with existing disabilities. Because of the socioeconomic disadvantages and stigma experienced by persons with disabilities, HPDP strategies must build upon improvement in meeting the basic needs of employment, housing, and income, reduction of discrimination, and enhancement of community participation. Time and effort costs must also be addressed. Only then will programs be successful in the encouragement of individual resources and skills. All programs need to pay attention to individual goals, expectations, and concerns.

At least three major activities are necessary to provide effective HPDP activities for people with disabilities: design and dissemination of culturally appropriate and accessible programs and policies, improved coordination of social and health care to meet individual health promotion needs, and an improved evidence base on the effectiveness of personal and community prevention that is inclusive of people with disabilities.

Programs and protocols designed by and with people with disabilities will be most effective. Policy changes are necessary to provide increased participation of people with disabilities in the social and individual determinants of health and to improve the cultural competency of programs and personal services. Finally, wide dissemination of programs and policies depends on studies involving people with disabilities in the growing evidence base on HPDP. Using controlled and observational studies, existing prevention guidelines need to be tested, protocols for preventing secondary conditions developed and tested, and health promotion programs evaluated. The health-related quality of life and health risk of persons with disabilities should be monitored at national, state, and local levels to evaluate progress and make mid-course changes.
Leading Health Indicators: Physical Activity, Overweight and Obesity, Tobacco Use, and Access to Care

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.¹ Many people with disabilities report that traditional health promotion is a lower priority for them than just “getting through the day” at home and at work. Accessing adequate housing, education, employment, income, personal assistance, and medical care trump going to smoking cessation programs or the gym, following weight loss regimens, or engaging in other health promoting activities. Other evidence suggests that the same barriers to health promotion reported by people without disabilities, i.e. motivation to begin and adherence to on-going activity, also are the principal barriers for people with disabilities.²

At present, people with disabilities rarely receive the range of health promotion and preventive services they may need or want.³ 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.⁴

Health promotion and disease prevention activities targeted to people with disabilities are crucial to fulfilling the two goals of Healthy People 2010—increasing years of healthy life and reducing health disparities.¹ The 10 Leading Health Indicators (LHIs), used to measure the health of the nation, reflect the major health concerns in the United States. These Leading Health Indicators were selected on the basis of their ability to stimulate change, the availability of data to measure progress, and their importance as public health issues. This paper suggests activities for a national agenda to improve the health of people with disabilities with emphasis on four selected indicators: physical activity, overweight and obesity, tobacco use, and access to care.

Risk Profiles

The Centers for Disease Control and Prevention have analyzed data for people with disabilities in eight states and the District of Columbia, in which disability identification questions were asked and benchmark objectives for the LHIs were captured.⁵ Respondents in the Behavioral Risk Factor Surveillance System were asked the following disability identification questions: “are you limited in any way in any activities because of any impairment or health problem” and “if you use special equipment or help from others to get around, what type do you use?” Although results are not descriptive of the US population and are limited to the nine states, the data identify the LHIs for which significant differences were noted for people with disabilities and people without disabilities.
For a number of LHI's, persons with disabilities are at "indeterminate" risk or report no disparity. In a few instances, such as the use of smokeless tobacco, people with disabilities use these substances less often than persons without disability. Persons with disabilities however were more likely to report current smoking. Persons with disabilities who report less exercise to reduce the risk of cardiovascular disease are more likely to report weight that exceeds the recommended body mass index for sex, and to be at a weight that exceeds ideal weight. A higher percent of persons with disabilities also report that costs prevented them from seeing a doctor in the past year.

Obesity is among the issues currently at the top of the health agenda of the nation. A report from CDC indicates that people with disabilities regardless of sex, race/ethnicity, or age, experience higher rates of obesity than people without disabilities. These data suggest that obesity often accompanies disability and illustrates the need to develop public policies and programs to prevent or reduce the risk that overweight and obesity represents for people with disabilities.

**Conceptualizing Health Promotion for People with Disabilities**

To guide the design and evaluation of interventions that meet the full range of health promotion and disease prevention activities appropriate for people with disabilities, the Center for Disability Policy and Research proposed a 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 health-related quality of life. An updated version of the model is shown in Figure 1.

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 research 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.

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 do and should play the central 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. This participation is important both in prevention design and in community-based participatory research.
At least three major activities are necessary to provide effective health promotion activities for people with disabilities: design and dissemination of culturally appropriate and accessible programs and policies, improved coordination of social and health care to meet individual health promotion needs, and an improved evidence base on the effectiveness of personal and community prevention that is inclusive of people with disabilities.

Design of Culturally Appropriate and Accessible Health Promotion Programs: Toward Disability Competency

Resources for action are provided in HP2010 for the Leading Health Indicators. For example, the President’s Council on Physical Fitness and Sports\textsuperscript{11} is a listed resource for action in Physical Activity and the Weight Control Information Network of the National Institutes of Health\textsuperscript{12} is a resource for Overweight and Obesity. In addition, the Public Health Service-sponsored U. S. Preventive Services Task Force and the non-federal Task Force on Community Preventive Services provide evidence-based guidance on recommended preventive actions.\textsuperscript{13, 14} Evidence would suggest that the resources, guidelines, and programs developed for people without disabilities can and should be applied to programs targeted to people with disabilities, using a culturally competent model of program design and implementation.\textsuperscript{1}

Consistent with the methods of the two task forces on prevention, we developed and applied the steps and format for the design of preventive intervention protocols for people with disabilities.\textsuperscript{15} Health promotion programs to address the four LHIs are amenable to the design of such protocols. Testing of these protocols, sponsored through existing and new research mechanisms, would be an important step in developing health promotion programs for people with disabilities. The types of protocols and examples are shown in Table 1. Although the exact formats of protocols have been determined for the two existing task forces, the information needed in protocols for people with disabilities is shown in Table 2.

In some instances, protocols exist currently that have been evaluated and dissemination is the issue, for example, aquatic exercise for people with arthritis or self-care protocols for diabetes and arthritis.\textsuperscript{16, 17} Some well-known physical activity interventions require evaluation, such as Special Olympics, not only for their benefits in terms of physical activity but also for social and opportunity benefits. Mass media interventions promoting activity for people with disabilities, smoking cessation telephone hotlines especially for people with disabilities, or school-based weight loss programs for overweight youth with disabilities are examples of protocols that might be developed and evaluated.

In developing health promotion programs and protocols, participation by people with disabilities is critical to assuring that programs are “disability culturally competent”. Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system or agency or among professionals that enable effective interactions in a cross-cultural framework. Culturally competent health promotion programs for
people with disabilities recognize and respect the differences in terms of the values, expectations, and experiences with health care and prevention.

Disability communities and people with disabilities are simultaneously universal and “unique”. One can view people with disabilities as a cross-cultural population that reside within the larger culture. Yet all persons have some understanding of disability as a restriction in activities related to health and function that is not compensated by the environment, either for themselves or for loved ones and friends. Health promotion programs have been recognized to produce stigma for people with disabilities. There may be unintended, even harmful consequences of prevention strategies for people with stigmatized conditions, such as “blaming the victim”. Disability competency entails a wide variety of values, attitudes, and behaviors that recognize both the individual and universal aspects of each individual in a health care system or health-promoting environment. Health professionals can learn these skills in interaction with people with disabilities or through special cultural competency training in disabilities.

Disability competency implies that all resources for health and health promotion programs should be viewed according to the needs and wants of people with disabilities. The guidelines should specifically address disability and how to tailor activities and disseminate programs to people with disabilities. The National Center on Physical Activity and Disability is a stellar example of such tailoring within a specialized agency. This kind of tailoring should be possible in overweight and obesity and tobacco use programs. Creation of centers that focus on obesity and on tobacco use by people with disabilities is one important option for consideration.

The Development of Policy

For people with disabilities, appropriate preventive strategies promote more effective use of personal preventive services in primary care as well as greater responsibility for one’s own health. This emphasis shifts utilization away from more expensive specialty services. Currently, people with disabilities may be disadvantaged not only by their impairment and disability, but also by how health care is delivered. Much of their care is provided by a wide variety of different practitioners, sometimes specialists who are knowledgeable about the specifics of disabling conditions, but often do not take on the responsibility of overall health management and prevention. Conversely, primary care providers, who are trained in managing overall health, frequently lack the expertise to manage the complexities presented by disabling conditions. Few primary care providers have sufficient patients with any one disabling impairment to become expert within these impairment groups.

Improved coordination of social and health care is needed to meet individual health promotion needs. For persons who are able to manage their own health and health care, there is a growing industry of self-management programs available for different conditions and target populations. Many people with disabilities, however, may not feel they have the expertise to manage health care decisions even if their personal health choices are within their own control. Thus the question of assisting people with
disabilities in making choices about health care and health promotion remains a challenging issue that requires innovative managed care solutions.

Public health interventions, directed mainly at primary prevention, may not reach people with disabilities. Community-based strategies that address the problems of people with disabilities require a public health partnership not yet well-formulated. The same principles of cultural competency relevant to programs apply to all prevention and health promotion policy for people with disabilities. Prevention policy should focus on promoting equal access to primary care and preventive services.

Better communication strategies are needed to relate the knowledge about health and recommendations for health improvement to people with disabilities. The use of the internet and world-wide web has increased, and many people with disabilities use these resources. Tailoring the messages and providing special attention to people with disabilities are required to make these even more accessible and “Bobby-approved”.

Better communication to the public and to decision makers about health promotion needs is also needed. This communication requires leadership by people with disabilities and their advocates. People with disabilities live in complex environments and will be the best advocates for public health policies that address the intersection between environment, personal values, and behaviors that influence health outcomes.

Incentives are needed to promote change in health promotion policies for people with disabilities. Economic incentives and disincentives need to be examined as possible arenas for promoting health. For example, support for accessible hiking and wheelchair trails in state and national parks could help promote increased physical activity. Economic incentives have long been successful in the fight against tobacco. The opposite of taxation and constricting smoking policies would be reimbursement for physical activity interventions and smoking cessation programs that are physically and culturally accessible to people with disabilities.

Access to health care for people with disabilities is a particular public policy challenge. Although people with disabilities use health care services more frequently than other populations, formidable barriers continue to be commonplace. The risk profile shows financial and health plan coverage barriers are most significant. The physical, social, communication, and cultural barriers, however, are important and the evidence base less developed.

Gathering the Evidence

Data on the health risks and health behaviors of persons with disabilities should continue to be collected routinely through the surveys mounted by the Centers for Disease Prevention and Control. The Behavioral Risk Factor Survey for adults is now able to identify people with disabilities and provide a risk profile.
Risk Factor survey needs to develop this capacity and to report annually health risk and perceived health of youth with disabilities.26

Special attempts are needed to translate these risk data for guiding policy and programs. Assessment of the health and disability environment is needed with special attention to community access to health promoting activities for people with disabilities. These individual and environmental assessments must involve comparisons to populations without disabilities and the measurement of disparities.

Comprehensive preventive intervention protocols designed for people with disabilities are in the early stages of development.15 Demonstration of such interventions in clinical and community settings is needed to identify barriers to implementation, and evaluation is necessary to test the efficacy of these interventions in halting or reversing the disabling process. The current prevention taskforces could provide a clearinghouse for this evidence base.13, 14

Using controlled and observational studies, existing prevention guidelines need to be tested, protocols for preventing secondary conditions developed and tested, and health promotion programs evaluated. Funding will be needed by the National Institutes of Health, Centers for Disease Control and Prevention, foundations, and other sources of public and private funding. In some cases, current protocols can be modified for people with disabilities. In other cases, experience shows that special protocols are needed, such as those for bowel management or pressure ulcer prevention in persons with spinal cord injury developed by the Consortium for Spinal Cord Medicine of the Paralyzed Veterans of America27, 28.

Finally wide dissemination is necessary of preventive protocols. Consistent with the recommendation for increased communications, these should be available via the World Wide Web, included in practice handbooks for primary care practitioners, and widely referenced. Such wide dissemination of programs and policies depends on studies involving people with disabilities and their advocates in the growing evidence base on HPDP.
Figure 1. A model of health promotion for people with disabilities

**Table 1.** Types of Preventive Strategies by Locus of Intervention and Participants

<table>
<thead>
<tr>
<th>Preventive Strategy</th>
<th>Locus of Intervention</th>
<th>Persons with Disabilities</th>
<th>Families</th>
<th>Advocacy Groups</th>
<th>CDC, State &amp; Local Health Departments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of the disabling process</td>
<td>Clinical <em>(e.g., prevention of contractures)</em></td>
<td>Physical therapy</td>
<td>Physical therapy</td>
<td>Access to physical therapy</td>
<td>Surveillance, case management</td>
</tr>
<tr>
<td></td>
<td>Community <em>(e.g., prevention of substance abuse)</em></td>
<td>Self-help, education</td>
<td>Support, role modeling</td>
<td>Information, services</td>
<td>Surveillance, services</td>
</tr>
<tr>
<td>Promotion of opportunity</td>
<td>Community <em>(e.g., return to work)</em></td>
<td>Employment skills</td>
<td>Support</td>
<td>Job placement, on-site support</td>
<td>Surveillance, coordination with voc rehab</td>
</tr>
<tr>
<td></td>
<td>Clinical <em>(e.g., teaching self-care skills)</em></td>
<td>Self-care management</td>
<td>Support, case management</td>
<td>Access</td>
<td>Surveillance</td>
</tr>
</tbody>
</table>

Table 2. Preventive Intervention Protocols for People with Disabilities: Format and Content

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe population</td>
<td>• Diagnostic criteria, primary impairment, and description of total population affected</td>
</tr>
<tr>
<td>State problem</td>
<td>• Risk factor in total environment: the disabling process, e.g., secondary condition, component of opportunity&lt;br&gt;• Prevalence and incidence of problem&lt;br&gt;• Impact of problem on disabling process including modifiable and non-modifiable risk factors, protective factors&lt;br&gt;• Interaction between primary impairment and problem&lt;br&gt;• Impact on opportunity and barriers to quality of life</td>
</tr>
<tr>
<td>Level of prevention</td>
<td>• Prevention or modification of risk factors (primary prevention), prevention or interruption of disabling process (secondary prevention), or promotion of opportunity (tertiary prevention)</td>
</tr>
<tr>
<td>Target population</td>
<td>• Description of target population for protocol by age, gender, severity of impairment, and other relevant exclusion or inclusion criteria</td>
</tr>
<tr>
<td>Participants</td>
<td>• Persons with disability, family members, clinicians, educators, advocacy groups, administrators, peers, others</td>
</tr>
<tr>
<td>Locus of intervention</td>
<td>• Clinical or community-based setting</td>
</tr>
<tr>
<td>Recommendations of Others</td>
<td>• Recommendations for prevention, re-others search phase targeted in recommendations, target population of recommendations, evidence of effectiveness</td>
</tr>
<tr>
<td>Proposal for intervention</td>
<td>• Theoretical rationale for intervention&lt;br&gt;• Intervention methods by participant and their respective roles&lt;br&gt;• Specification of outcomes and measurement&lt;br&gt;• Criteria to be used in evaluating intervention and measurement</td>
</tr>
<tr>
<td>Research phase</td>
<td>• Basic research, hypothesis development, pilot applied research, prototype study, efficacy trial, treatment effectiveness trial, implementation effectiveness trial, demonstration, cost-effectiveness study</td>
</tr>
<tr>
<td>Recommendation</td>
<td>• Recommended actions/interventions&lt;br&gt;• Relevant literature&lt;br&gt;• Strength of recommendation and quality of evidence</td>
</tr>
</tbody>
</table>


22. McGinnis M, Williams-Russo P, Knickman J. The case for more active policy attention to health promotion. To succeed, we need leadership that informs and motivates, economic incentives that encourage change, and science that moves the frontiers. *Health Aff (Millwood).* Mar-Apr 2002;21(2):78-93.


