

Planning for Today, Thinking of Tomorrow

**California's 2011-2016 Strategic Directions for
Promoting the Health of People with Disabilities**

*California Department of Public Health's
Living Healthy with a Disability Program and
Living Healthy Advisory Committee*

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SECTION I: INTRODUCTION

Public health priorities have changed drastically in the last 60 years. Elimination or control of infectious diseases was the emphasis of public health in the early 1900s until the 1950s. Now the United States population is facing serious health epidemics associated with chronic diseases, such as obesity, cancer, cardiovascular disease, diabetes, asthma, and hypertension due to lifestyle choices and unhealthy environments. To become a healthier nation, public health has to address these issues through public policy and systems change. This can be achieved through promoting healthier lifestyles such as eating nutritiously dense foods, becoming physically active, quitting smoking, and getting regular preventive health screenings. Adopting a healthier lifestyle is difficult for most people but people with disabilities face additional challenges when exercise facilities, recreational settings, and medical offices are physically not accessible and health information is not available in alternative or accessible formats. There is a concomitant need to design neighborhoods and communities to make it easy for people with disabilities to initiate and maintain these healthy behaviors. Compared with people without disabilities, people with disabilities are more likely to:

- 👤 Experience difficulties or delays in getting the health care they need.
- 👤 Not have had an annual dental visit.
- 👤 Not have had a mammogram in the past two years.
- 👤 Not have had a Pap test within the past three years.
- 👤 Not engage in fitness activities.
- 👤 Use tobacco.
- 👤 Be overweight or obese.
- 👤 Have high blood pressure.
- 👤 Experience symptoms of psychological distress.
- 👤 Receive less social-emotional support.
- 👤 Have lower employment rates.¹

The Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities* places the health of people with disabilities central among other public health issues.² Public health has an important role in the promotion of the health of people with disabilities through monitoring trends, preventing secondary disability, and reducing health disparities. This imperative is evident in both Healthy People 2010 and the newly released Healthy People 2020, a national program that sets science-based objectives for improving the health of all Americans.³ Healthy People 2020 iden-

tifies the following ways that public health can expand the knowledge base and raise awareness about determinants of health for people with disabilities: increase the inclusion of people with disabilities in public health data collection efforts across the lifespan; increase the inclusion of people with disabilities in health promotion activities; and increase the expansion of disability and health training opportunities for public health and health care professionals.¹ Using a public health approach, incorporating ideas from Healthy People 2020 and the Surgeon General's new report, using recommendations from the Institute of Medicine (IOM) Report 2007, and leveraging existing opportunities, the Living Healthy with a Disability (LHD) team and the Living Healthy Advisory Committee (LHAC) have proposed policies and interventions to prevent secondary conditions and increase participation in health promotion opportunities for Californians with disabilities.

History

In 1992, the Centers for Disease Control and Prevention's (CDC) Disabilities Prevention Program awarded the California Department of Health Services (CDHS) a four-year grant to build state and local capacity in disability prevention. This support helped California establish the Office of Disability Prevention (ODP) and create a central coordinating focus for primary and secondary disability prevention, facilitating collaboration and planning for the first time among state entities and organizations serving persons with disabilities.

As part of this effort, ODP and its Disability Prevention Advisory Committee created *From Vision to Action: A Strategic Plan for Preventing Disabilities in California, 1997-2001*. Although the Plan served as an important first step, the nation and California have since shifted their disability and health focus from prevention of disabilities to promotion of health and prevention of secondary conditions. In step with the new national agenda, ODP renamed its Office of Disability Prevention as the Office on Disability and Health (ODH).

Then, in April 2002, CDHS received a grant from CDC's National Center on Birth Defects and Developmental Disabilities to create a new strategic plan focusing on building state and local capacity to address quality of life across the lifespan for people with disabilities.

In January 2003, ODH convened the LHAC charged with developing a strategic plan for health promotion and prevention of secondary conditions for people with disabilities. The resulting *Universal Livability: A Dream for Tomorrow, A Plan for Today, 2005-10*, provided a policy framework to guide CDHS' future directions and serve as a benchmark to measure California's progress towards the Healthy People 2010 objectives for the nation.

In 2007, California was one of 16 states to receive funding from CDC for five more years (2007-12) to continue to build capacity within the California Department of Public Health (CDPH – formerly part of CDHS) for a coordinated approach to prevent secondary conditions and promote wellness for people with a disability. In 2010, ODH, now known as the Living Healthy with a Disability (LHD)

Unit, was charged with updating the Strategic Plan. The following intervening major events necessitated considerable directional changes for the Plan:

- 🌱 CDHS, where LHD was housed, split into two departments creating a CDPH and a California Department of Health Care Services (CDHCS) – each with its own mission and mandates.
- 🌱 The Surgeon General’s Report, *Call to Action to Improve the Health and Wellness of Persons with Disabilities* was released.
- 🌱 CDC’s focus changed from funding states to perform disability research to enhancing disability surveillance.
- 🌱 Healthy People 2020 was created with new disability and health objectives.
- 🌱 Health care reform legislation became law and formally recognizes disability as a health disparity.
- 🌱 New priorities were set by CDC such as obesity prevention, reduction of tobacco use, and emergency preparedness are likely to inform future funding cycles.
- 🌱 The major economic downturn of the past three years has increased the stress and strain on families and persons with disabilities while reducing the resources at state and local levels for support and services.

Purpose, Structure, and Function of the Plan

The new Strategic Plan, *Planning for Today, Thinking of Tomorrow*, reflects these directional changes with major shifts in its goals and the elimination of objectives in favor of strategies that provide a general outline of select actions rather than the actual roadmap for promoting the health of and reducing secondary conditions among people with disabilities. The LHD team/LHAC agreed on the following criteria in selecting new recommendations: Priority as a public health issue; Impact on overall quality of life; Leverage of existing opportunities; Sustainability; Availability of resources; and, Ability to track progress using data.

The new Plan has four goal areas: Infrastructure and Capacity Building at the State Level; Analyze, Distribute, and Publish Disability Data; Health Promotion and Community Outreach; and Professional Development. Health care access goals were eliminated due to the shift in locus of control when DHS split into two departments. CDPH, where LHD is housed, is focused on prevention and health promotion rather than provision of direct clinical services. Acknowledging the importance of access to health care services for people with disabilities, the Plan now includes a Professional Development Goal to influence health care professionals’ knowledge of working with people with

disabilities through higher education curricula and supporting and marketing relevant continuing professional education opportunities.

The Plan also includes strategies that LHD and its LHAC will initiate by partnering with the larger disability community and state and local agencies that can play a critical role in implementation. The strategies include: change institutional policies and organizational practices, collect and analyze specific disability data, provide sustainable professional education and training opportunities, and increase access to health promotion opportunities. The strategies are randomly listed in the Plan and are not in any particular order of importance or priority. Much can change in five years and it is important to provide flexibility to be able to leverage new opportunities and respond to emerging issues. LHD and its LHAC partners will revisit this plan annually to gauge progress and adjust priorities in light of new potential partners and available resources.

Magnitude of the Problem

According to the Surgeon General's Report, more than 54 million Americans, or more than one fifth of us, are living with at least one disability.² Each of us is at risk for acquiring a disability; some individuals are born with a disability while others acquire them over the course of their lifetime, through an illness, an injury, genetics, the aging process, or any number of other causes. We experience disability "second-hand" as well among our families, friends, colleagues, and neighbors. With the "baby boom" generation approaching later life, and with people with a disability living longer lives, the overall number of people with a disability is expected to increase exponentially and should begin to demand increased public attention.

Some of the challenge in understanding disability in California lies in the quality of relevant data. Disability is often not included as a comparison variable in health reports, and significant gaps in the availability of disability data exist.⁴ In California, there are several large surveys designed to monitor adult health status and health behaviors. While all of these surveys include some measure of disability, it is not standardized and can be difficult to make comparisons about disability between surveys. The severity and duration of disability are not measured and certain subgroups of people, particularly those with intellectual or developmental disabilities may be under-represented. However, despite these limitations we are able to follow general trends in disability as well as assess how disability varies in different populations and how various health behaviors and conditions differ among people with and without disability.

In California alone, 5.7 million adults, or 23 percent of the adult population, have a disability.⁵ When we look at this population, we find that people with a disability are not a random cross-section. The proportion of the population with disabilities increases with age and among females and African American, non-Hispanic white, or American Indian/ Alaskan native populations. People with disabilities are also more likely than others to be poorly educated, unemployed, and living below the poverty level.⁵

People with disabilities need health care and health programs for the same reasons anyone else does—to stay well, active, and a part of the community. It is a common misperception that disability equates to poor health. It is true that people with a disability are three times more likely than those without disability to report their health status as only fair or poor. However, nearly two-thirds of people with disability report their health status as good, very good, or excellent.⁵ While disability does not have to mean poor health, people with a disability do tend to face more challenges to being healthy and alarming disparities exist in some areas of health. In addition to being more likely to be impoverished, people with a disability report higher rates of many chronic conditions including diabetes, asthma, arthritis, and high blood pressure and cholesterol levels.⁵ Greater rates of depression and mental health needs have also been found among California women with a disability.⁶ Adults with a disability are also more likely to smoke and to be physically inactive and overweight or obese; all factors that contribute significantly to poor health.^{5,7}

People with disabilities also face a variety of barriers that make it more difficult to get the help and care needed to prevent further health problems. Californians with a disability are less likely than those without a disability to be covered by a health insurance plan, and among working-age adults that have health coverage, those with a disability are much more likely to use Medicare/Medi-Cal as their main coverage.⁵ It has been found nationwide that people with disabilities are less likely to have up-to-date preventive care including annual dental visits, and recommended mammograms and Pap tests.³ Research in California has also shown that not only are older women with disabilities less likely to have had recent Pap tests and mammograms, but they are also more likely to have these recommended preventive tests in response to symptoms rather than as part of a routine physical exam.⁸

This data clearly shows that disability affects all Californians, either directly or indirectly, and particularly those in vulnerable groups such as the elderly and impoverished. People with a disability face more challenges to staying healthy than others and more barriers to receiving care they need. This issue clearly warrants a strong public health response in order to support all Californians, including those with a disability, to live healthy and productive lives.

SECTION II: THE PLAN

MISSION STATEMENT

To promote the health and quality of life of people with disabilities and to prevent or lessen the effects of secondary conditions through collaboration, environmental policy and system change, leadership, science, and service.

GOALS AND STRATEGIES

INFRASTRUCTURE AND CAPACITY BUILDING AT THE STATE LEVEL

GOAL 1: In concert with partners, develop and implement State-level policies and programs to quantifiably improve the health status of people with disabilities.

Rationale

Public health has a long history of working on the prevention of disabilities, but its involvement in improving the health and quality of life of people with disabilities is relatively recent and still evolving. Public health personnel are coming to realize that people with disabilities are capable of living longer and healthier lives and that this population needs to be included in the application of the public health activities of surveillance, health promotion, and prevention.⁹ This change has been integrated into Healthy People 2020. At CDC, work is being done to use this model to emphasize the inclusion of people with disabilities within mainstream health promotion and service delivery systems.⁹ This perspective also underlies current efforts to create an inclusive public health agenda to ensure that *all* areas of public health represent people with disabilities.¹⁰ Public health has an important role in making institutional changes to improve access and participation in health promotion, wellness, and prevention and self-management of chronic disease programs for people with disabilities.

The Affordable Care Act (ACA) and Healthy People 2020 both recognize that people with disabilities and people from racial and ethnic minorities equally are groups that face health disparities. In light of this new policy, it is incumbent on State-sponsored programs to include people with disabilities in Request for Applications (RFAs), interventions, and outreach campaigns. Implementing state-level policies that acknowledge these disparities would ensure that a standard is being met by the State and that training and technical assistance are provided when necessary.

Strategies

- 👤 Embed LHD within CDPH.
- 👤 Serve as the catalyst to initiate policy and systems change across public health programs.
- 👤 Assist CDPH's Office of Civil Rights with the department-wide compliance of the American with Disabilities Act (ADA), California Title XXI (state ADA regulations), and other disability-related civil rights and laws within CDPH through training.
- 👤 Serve as a CDPH resource for related preventive disability and health issues.
- 👤 Develop and disseminate a disability and health-related resource packet to appropriate CDPH programs to guide/enhance inclusion of people with disabilities.
- 👤 Identify and pursue funding to enhance LHD resources available to CDPH.
- 👤 Participate in appropriate CDPH workgroups that can enhance the integration of people with disabilities into programs.

Accomplishments from Last Strategic Plan Related to New Goal

In October 2010, LHD sponsored a Disability Policy Summit for managers and supervisors of CDPH and CDHCS. The purpose was to examine ways disability issues could be integrated into the administrative and programmatic practices of CDPH and CDHCS. As an outcome of the Summit, LHD staff is developing policy recommendations for Department leadership to consider that can guide more inclusive future programmatic planning and internal administrative operations.

Analyze, Distribute, and Publish Disability Data

GOAL 2: Conduct innovative and timely data analyses on health-related issues of the disability population; widely disseminate data and related articles.

Rationale

Data serves as a foundation for public health priorities and initiatives. Data informs the design, monitoring, and evaluation of policy and health intervention strategies. In addition, data can assist advocates, policymakers, and researchers to make informed decisions. Disability as a demographic variable needs to be included on existing surveys in a consistent manner. It is important that all the health surveys have comparable and standardized data in order to compare health status over time and across sub-groups. Once the data is analyzed, this information needs to be made available and accessible to the community, programs, and policymakers.

Supporting Data

Published health reports typically do not include disability status as a comparison variable, leaving the areas of people with a disability and the health disparities they experience largely unexplored. In the *Health Disparities and Inequality Report*, recently published by CDC, it was concluded that there are significant gaps in the data available. Only 8 of the 22 disparity topics analyzed in this report included disability.⁴ Efforts to increase the availability and comparability of disability data available are being made. *Healthy People 2020* has an objective to include a standard set of disability questions in the core of all relevant data systems.² Additionally, new statutory requirements to collect disability and inequity data exist in the recently enacted Affordable Care Act.

Strategies

- 👤 Serve as a technical resource for CDPH and disability constituents on disability and health data analyses, responding to community requests and disseminating results as resources allow.
- 👤 Work with data colleagues in chronic disease programs to identify disparities in chronic disease prevalence for people with disabilities.
- 👤 Monitor progress toward achieving Healthy People 2020 disability-related objectives.
- 👤 Seek extramural support to add/maintain the inclusion of standardized disability-related questions on California-based surveys to support research and data needs.
- 👤 Encourage cross-program analyses of disability data as it relates to chronic disease risk factors, health behaviors, and emerging health issues.

Accomplishments from Last Strategic Plan Related to New Goal

LHD staff wrote and published several articles for the Office of Women's Health (OWH) Data Points publications. These articles include *Food Security and Health Status among California Women with a Disability*; *Overweight, Obesity, and Lack of Physical Activity among California Women with a Disability*; and *Mental Health Needs among California Women with a Disability*. LHD has also produced a comprehensive fact sheet *Disability in California Adults*. The information gleaned from *Food Security and Health Status among California Women with a Disability* was so compelling that it is being expanded and will be submitted as a full journal article in a scholarly publication.

HEALTH PROMOTION AND COMMUNITY OUTREACH

GOAL 3: Increase participation of the disability community in health promotion programs.

Rationale

People with disabilities are highly susceptible to secondary health conditions such as osteoporosis; osteoarthritis; decreased balance, strength, endurance, fitness, and flexibility; increased spasticity; weight problems; depression; and other conditions. In addition, people with disabilities are un-served or underserved and less likely to participate in health promotion and physical activity programs. Investing in resources that empower people with disabilities to improve and self-manage their own health through appropriate health promotion and wellness programs can have an enormous impact on improving quality of life, reducing morbidity, and ultimately decreasing health care costs. Strategies that support the participation of people with disabilities in wellness and health promotion programs also benefit a larger segment of the population as they age or develop chronic diseases.

Supporting Data

People with a disability are more likely to be involved in a variety of behaviors that negatively impact their health. For example, in California, 30 percent of adults with a disability do not engage in any physical activity, compared to 20 percent of adults without disability. People with a disability also have much higher rates of obesity than those without. Additionally, 19 percent of adults with disability are smokers compared to 14 percent of those without disability.⁵ While there are a number of interventions available to help prevent these behaviors, they do not always include or accommodate people with a disability and/or are not always completely accessible to this population.

Strategies

-  Collaborate with existing CDPH and State-sponsored programs to ensure that health promotion strategies, education, and services include methods and formats that will reach people with disabilities and that the associated materials and communications are accessible.
-  Assist in community systems change efforts that promote safe, healthy, and accessible environments.
-  Facilitate the implementation of evidence-based self-management programs in a variety of locations throughout California.
-  Market health promotion self-management programs to people with disabilities and disability organizations to encourage participation in health promotion.

- 🧑‍🦯 Assist in developing plans to improve community social and physical environments to ensure that communities establish and implement universal design principles.
- 🧑‍🦯 Assist in distributing health promotion and prevention materials to people with disabilities through local disability providers.
- 🧑‍🦯 Update the LHD website with current resources, information, and activities, and market the website to people with disabilities and disability organizations.
- 🧑‍🦯 Ensure people with disabilities' participation in health promotion programs through community outreach and marketing.
- 🧑‍🦯 Assist the California Smokers' Helpline in disseminating information on its tobacco cessation outreach program for people with disabilities.
- 🧑‍🦯 Collaborate with CDPH programs to include people with disabilities in advisory committees, work plans, strategic plans, and RFAs for health promotion/physical activity interventions.

Accomplishments from Last Strategic Plan Related to New Goal

LHD funded the development and pilot testing of a Health Risk Appraisal (HRA) tool by Dr. Harriet Aronow, a researcher at Cedars-Sinai Medical Center. The HRA is a reliable multi-dimensional health appraisal for persons with disabilities and permits comparison among different disability groups as well as broad generalizability to the general population at wide levels of literacy and English proficiency. This HRA can be used as a health outcome measure as well as the basis for preventive health care interventions among persons with traumatic brain injury (TBI) as well as other groups with acquired and life-long disabilities. It has already been integrated with a home-based advance practice nurse preventive health care intervention. LHD has met with Medi-Cal and the Long Term Care Unit on the adoption of HRA for use within the health care system when people with disabilities initially enroll in Medi-Cal. Future discussions will help to determine next steps in this advancing this practice.

PROFESSIONAL DEVELOPMENT

GOAL 4: Increase the number of health care professionals who have knowledge of how to work effectively with the disability community.

Rationale

Health care professionals need more information, training, and support to provide the kind of services that are accessible and amenable to people with disabilities. These services need to be equal to the services provided to people without disabilities. Comprehensive, efficient, and accessible health care is important to everyone but is critical to people with disabilities to stay well and be able to function in society. Health care professionals are not adequately trained on how to care for people with disabilities so continuing education opportunities are critical. The issues are many, ranging from learning about appropriate and accessible office equipment and how to provide health care information in alternative formats to the need to allow more time for appointments and in ensuring the office setting is accessible. Practitioners need to understand the complex needs of people with disabilities.

Supporting Data

People with disabilities can encounter health care providers who are not prepared to treat their primary and secondary health conditions, or who do not provide the same array or frequency of preventative services that they provide to their patients without disabilities.¹ For example, a 2004 national study found that internal medicine and family practice physicians engaged patients with intellectual disabilities in health promotion practices less frequently than their patients without disability.¹¹ CDC reports that there are a number of issues that providers need to address regarding patients with a disability including: addressing the medical needs of the whole person, not just the disability; recommending preventive services as much as they do with other patients; and seeking training on disability competence for health professionals.¹²

Strategies

- 👥 Develop partnerships with professional organizations, health plans, and medical group practice/medical home providers to enhance professional development opportunities about disability issues and to be able to work effectively with people with disabilities.
- 👥 Develop relationship with the California Department of Mental Health (DMH) to promote dissemination of appropriate disability related educational materials.
- 👥 Expand disability-focused professional development continuing education opportunities available to health care professionals across disciplines, including allied health workers.

- 👤 Provide health care professionals with tools they need to train their front-line staff on disability issues and to enhance their ability to work effectively with people with disabilities.
- 👤 Market disability curriculum development website to health care professionals.
- 👤 Coordinate disability awareness and sensitivity training for targeted health professionals.
- 👤 Distribute education and training materials to health professionals which focus on the health care and wellness needs of people with disabilities.
- 👤 Maintain, update, and disseminate information from the professional development website.

Accomplishments from Last Strategic Plan Related to New Goal

LHD collaborated with the University of the Pacific School of Dentistry, UCLA Nursing School, and the University of New Hampshire School of Nursing on a project to develop an oral health module for training nursing students to increase knowledge and skills to recognize oral diseases and provide oral health counseling to people with disabilities. As part of the project, a training module was developed and the advanced practice nursing students went into the field and implemented it with persons with intellectual and developmental disabilities (IDD). The nursing students used a new oral health screening tool for non-dentists for individuals with developmental disabilities.

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