

Partnering with Public Health: Funding and Advocacy Opportunities for CILs and SILCs

by
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Laura Rauscher, former director of the Office of Health and Disability at the Massachusetts Department of Public Health, discusses how CILs and SILCs can use funding from the Centers for Disease Control and partnerships with public health agencies to provide innovative programs promoting the health of people with disabilities.

The CDC Office on Disability and Health heads a national program which includes funding cooperative agreements with state health departments. In the spring of 2001, CDC will re-compete the funding for the state-based programs. Centers and SILCs can play an important role in shaping the direction of these state-based projects and tap into an important source of funding.

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Access to quality health care has always been at the forefront of the independent living (IL) and disability rights movements' advocacy agenda. Maintaining health and well-being is recognized as important to achieving the goals of independent living. It is all too common that untreated secondary health conditions--such as pressure sores, infections, and respiratory conditions, as well as problems such as substance abuse, eating disorders, and poor personal care--can be the undoing of a person's hard won independence. Without access to adequate health care and treatment programs, IL consumers working toward independence can find themselves nearing the end of a long road, only to have to begin again.

Advocates have worked tirelessly to improve the quality of medical care and continue to fight for insurance coverage that allows people with disabilities to get the primary and specialty care they need. Access to a high quality, responsive, accessible, affordable health care system is a critical piece of the health puzzle, but there is more. With advocacy efforts focused on access to traditional health care, the importance of access to the myriad of prevention and health promotion programs for people with disabilities has not received sufficient attention. While preventive care is a component of good individual health care, many prevention and health promotion programs are offered outside the health care system. These programs are often funded or run by state or county public health departments.

Public health departments of the past historically focused almost entirely on tracking and preventing the spread of communicable diseases. Today's public health mission has been greatly expanded. Public health departments have emerged as an important source of leadership and funding to address a wide range of social, environmental and behavioral factors that can compromise health. While emphasis varies from state to state, today's public health departments strive to address a broad range of health needs among at-risk populations and employ a wide variety of strategies to keep all citizens safe and healthy.

Traditional health care systems focus on individual health problems, while public health looks at the health problems of whole communities and specific at-risk populations. By taking this perspective, public health can collect data and conduct research that leads to a better understanding of health patterns and common problems among people with disabilities. This approach leads to the understanding that people with disabilities have the same health needs as everyone else, but that we are also a unique population with unique health needs. Public health can then help to identify and implement prevention and health promotion strategies that can reach communities and at-risk populations such as the population of people with disabilities within a state. The disability community needs to look more closely at the role public health can and should play in addressing the health concerns of people with disabilities. It is important that we learn how to harness and direct the extensive resources the public health field has to offer.

Over the past 10 years, promoting the health and well being of people with disabilities has become an increasingly important and explicit goal of the national Public Health Service. Specific funding, through the Public Health Act, supports the Centers for Disease Control and Prevention's Office on Disability and Health. The Office on Disability and Health heads a national program to improve the health and well-being of people with disabilities by improving state and national data collection efforts, supporting essential research on secondary health conditions, and funding cooperative agreements with 14 state health departments for state-based capacity building projects.

Funding from the Centers for Disease Control's (CDC) Disability and Health Program has given states the opportunity to create a point of leadership within state government to begin specifically addressing the health needs of people with disabilities. People with disabilities are members of the "public," and public health departments are designed to serve all members of the public. As people with disabilities move out of isolation and segregated service systems and become more visible and active citizens in their communities, new demands are placed on health departments to consider and address their emerging needs. Policy changes, disability relevant research and the development of new community-based strategies for promoting the health of people with disabilities have begun to find their place on national and state public health agendas.

Much of this activity has been driven by the input of advisory committees created by each state that receives CDC Office on Disability and Health funding. These committees have included people with disabilities, community leaders, medical professionals, CIL and SILC staff, representatives of state agencies and others interested in working together for the health of people with disabilities. People with disabilities have also been hired in many states by the health departments as staff and consultants to provide direction and implement the CDC funded programs. Some states have forged alliances with individual centers for

independent living and state independent living councils to develop a useful conceptual framework for understanding health and disability, advocate for appropriate state policies and programs and implement strategies at the local level to promote health and prevent secondary conditions. Some of the projects that resulted from alliances that included CIL participation exemplify the possibilities for other states:

In Massachusetts, for example, five independent living centers received between \$15,000 and \$50,000 in CDC funding through the Massachusetts Department of Health's Office on Health and Disability to conduct "Access to Health" programs. The projects utilized the IL model of peer counseling, information and referral, skill building and individual and systems advocacy to specifically promote health among people with disabilities.

Massachusetts CILs also participated in a health survey of 800 IL consumers conducted in collaboration with Boston University. The survey focused on secondary health conditions and contributing factors among people with disabilities. The CDC funding to the state also provided the basis for leveraging additional state dollars from tobacco, breast cancer and substance abuse funding to develop programs for people with disabilities. Significant funding has also been committed to conduct a statewide comprehensive ADA compliance project for the public health department's 600-700 community vendors. CILs received funding under this program to provide local ADA technical assistance.

In Montana, Tom Seekins, PhD, at the University of Montana worked with CILs there to develop a wellness curriculum for persons with physical disabilities. The curriculum, "Living Well with a Disability," was delivered by community-based, consumer-controlled independent living centers in Montana. Adults with spinal cord injuries participating in the program experienced a 37 percent reduction in disability due to secondary conditions and reduced physicians visits by 45 percent over six months.

In Ohio, money was used to develop a health education program by and for women with disabilities that includes production and distribution of a monthly consumer health newsletter.

New Jersey held a statewide conference on secondary health conditions and health promotion in cooperation with the CILs there.

North Carolina has developed an access guide for health care facilities in cooperation with the Center for Universal Design.

Michigan used CDC conference grant money to hold a major national conference on preventing secondary conditions and promoting health among persons with disabilities.

Centers for independent living and statewide independent living councils have an important stake in the future direction of this national effort and should seriously consider getting involved in the activities within their state health departments. CILs and SILCs need to get informed, involved and excited about forging new alliances with their health departments. Centers and SILCs can play an important role in shaping the direction of these state-based projects. By getting involved now, centers and SILCs can tap into an important

source of funding to conduct programs that promote the health of consumers. Center related projects may be small at first, but over time CILs can influence the use of federal and state public health resources in their communities.

Public health programs must assure that they are accessible to persons with disabilities. They should also engage in planning, policy and program development, conduct research and develop effective strategies to address the unique health needs of the population of people with disabilities. With CIL and SILC involvement, dollars can be better directed to strategies that address the critical needs of consumers.

People with disabilities have a right to achieve and maintain their maximum level of health and well being and to live in safe, healthy and accessible communities. Once again, CILs and SILCs have a chance to shape the future by leading the way!

CILs and SILCs interested in getting involved in state and national efforts related to health and disability, should contact

Their state health department directly

Centers for Disease Control and Prevention <http://www.cdc.gov/>

The American Public Health Association www.apha.org/

Healthy People 2010 www.health.gov/healthypeople

About the Author

Laura Rauscher has been personally and professionally involved in the disability rights and independent living field for over 20 years. Rauscher holds a bachelor's degree in community services and a master's in social justice education/organizational development from the University of Massachusetts, Amherst. Rauscher's professional experience at the state and national levels includes administration and fiscal management; policy development and analysis; program design, planning, implementation and evaluation; design and supervision of research studies; and ADA/504 compliance monitoring in both the public and private sector. Additionally, she has done individual and group counseling, led a variety of community organizing, legislative, and advocacy efforts, and provided training and consultation to businesses and organizations regarding issues of disability, race, gender, and sexual orientation. Her work in disability related curriculum and training design is published in the book "Teaching for Diversity and Social Justice," Rutledge, 1997.

Early in her professional career Rauscher worked in both urban and rural CILs in Massachusetts, California, and Hawaii, where she held positions in direct services, community advocacy, and program development related to transportation, attendant care, housing, accessibility, special education and mental health issues. She was the recipient of a year long National Policy Fellowship with the National Council on Disability in 1985. Rauscher was director of the Office of Health and Disability at the Massachusetts Department of Public Health, funded by the Centers for Disease Control's Office on Disability and Health for nine years. In 2000, she was director of Disability Services and ADA/504 Compliance Coordinator at Smith College. She remains an active member of several community and state level committees and boards, including the Massachusetts State Independent Living Council.

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