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**ADVANCING HEALTH PROMOTION FOR
PEOPLE WITH DISABILITIES
ON THE
PUBLIC HEALTH AGENDA
PROCEEDINGS**



American Association on Health and Disability



**CENTERS FOR DISEASE
CONTROL AND PREVENTION**

Centers for Disease Control and Prevention

BWI Airport Marriott Hotel
Baltimore, MD
August 25-27, 2003

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Proceedings edited by Vera G. Kurlantzick, M.S.

Copies of this report may be downloaded from the website of the
American Association on Health and Disability
www.aahd.us

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Advancing Health Promotion for People with Disabilities On the Public Health Agenda

TABLE OF CONTENTS

Introduction	
About the Sponsors.....	6
Letters from Sponsors.....	7
Conference Overview.....	9
Roles of Participants.....	10
Executive Summary.....	11
Presentations and Discussions	
Making the Connection: Physical Activity, Nutrition, and People with Disabilities	
North Carolina Briefs.....	18
South Carolina Brief.....	22
Arkansas Brief	24
New York Briefs.....	26
Discussion Summary.....	30
Getting Women's Health Issues for Women with Disabilities on the Public Agenda	
North Carolina Briefs.....	32
Massachusetts Brief.....	38
New Jersey Brief.....	40
New York Brief.....	41
Discussion Summary.....	43
Including the Needs and Priorities of People with Disabilities in State-Level Emergency Preparedness Initiatives	
New Mexico Brief.....	46
Vermont Brief.....	47
Montana Brief.....	48
Iowa Brief.....	50
Discussion Summary.....	52
Information for Decision Making: The Role of BRFSS and Other Data to Influence Public Policy	
<i>State Uses of the BRFSS</i>	
Vermont Brief.....	54
Illinois Brief.....	56
New York Brief.....	58
<i>Variations on the BRFSS and Other Surveys</i>	
North Carolina Brief.....	59
California Brief	61
Washington Brief.....	63

<i>Administrative Data</i>	
Iowa Brief.....	65
South Carolina Brief.....	67
Louisiana Brief.....	69
Discussion Summary.....	71
Violence Prevention Programs for Persons with Disabilities	
Massachusetts Brief.....	73
North Carolina Brief.....	75
California Brief.....	77
Oregon Brief.....	78
Discussion Summary.....	80
Opening the Door: Marketing Health Promotion Interventions, Research Projects, and Advisory Boards to People with Disabilities	
South Carolina Brief	82
New Mexico Brief.....	85
North Carolina Brief	86
Iowa Brief.....	88
Discussion Summary.....	90
Health Promotion Curricula for People with Disabilities: What Works, What Doesn't, and Why	
Vermont Brief	92
Oregon Brief.....	94
New York Brief.....	96
Iowa Brief.....	98
Discussion Summary.....	100
Evaluating Health Promotion Programs for People with Disabilities and the Need for Common Evaluation Strategies	
Iowa Brief.....	102
South Carolina Brief.....	104
New Mexico Brief.....	106
Oregon Brief.....	107
Discussion Summary.....	108
Roundtable Discussions	
Accessing Public and Private Funding Opportunities.....	110
Strategic Planning and Advisory Group.....	112
Disability & Health Program in Rhode Island.....	113
Health Provider Education Initiative: Count Us In.....	114
Physical Access.....	116
Massachusetts Disability Access Project.....	117

Appendices

Appendix I - Conference Agenda.....	118
Appendix II - Disability and Health Program State Project Contacts.....	122
Appendix III - Attendees List.....	130
Appendix IV - Guidelines for Facilitators, Resource Speakers and Moderators.....	140

ABOUT THE SPONSORS

American Association on Health and Disability

The American Association on Health and Disability is a 501(c)(3) non-profit organization located in Rockville, MD and is governed by a board of directors. The mission of AAHD is to prevent additional health complications in people with disabilities, while reducing the health disparities between people with disabilities and the general population. AAHD accomplishes its mission through advocacy, education, public awareness, and research efforts at the federal, state, and local levels. AAHD's membership is comprised of people with disabilities, health care professionals, policy analysts, researchers, state and local agencies, and interested members of the general public.

On August 1, 2002, AAHD was awarded a five-year cooperative agreement grant from the Centers for Disease Control and Prevention (CDC). The overall purpose of the CDC Cooperative Agreement is "to determine and develop the training, research and program implementation needs to assist in building health promotion and wellness programs at the state levels which address *Healthy People 2010* focus area of Disability and Secondary Conditions." Presently, there are 16 states (AK, CA, IA, IL, MA, MT, NJ, NM, NY, NC, OR, RI, SC, VT, VA, WA) that receive grant support from CDC aimed at building their state capacity for implementing programs that support people with disabilities. These programs work to improve state surveillance activities, conduct health promotion interventions, develop and monitor policies affecting people with disabilities, and facilitate partnerships between state- and research- or service-based agencies.

Centers for Disease Control and Prevention Disability and Health Team

The Disability and Health Team, www.cdc.gov/ncbddd/dh, at the CDC is part of the U.S. Department of Health and Human Services, which is located within the newest center at CDC, the National Center on Birth Defects and Developmental Disabilities (NCBDDD). The goal of the Disability and Health Team is to promote the health and well-being of the estimated 54 million people with disabilities living within our country. In addition to in-house projects, the Disability and Health Team administers awards to state health departments, universities, and national organizations to:

- implement disability and health programs for people with disabilities through state health departments and their university affiliates.
- Promote health through interventions to reduce secondary conditions.
- Study disability across the lifespan by: A) assessing health status; B) identifying risks and costs associated with secondary conditions and poor health; C) developing, testing, and evaluating health interventions; and D) developing training for health professionals interested in the field of disability and public health.
- Track disability prevalence and improvements in health status and quality of life for people with disabilities.
- Support conferences to facilitate and stimulate the exchange of recent information about activities in the United States and abroad that address the health and well-being of people with disabilities; to establish research and policy priorities; and to outline and undertake next steps.



American Association on Health & Disability

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August 25, 2003

Dear Conference Participant,

On behalf of the American Association on Health and Disability (AAHD) and the Centers for Disease Control and Prevention (CDC) we welcome you to this conference of national significance. Let me take this opportunity to sincerely thank members of the Conference Planning Committee who have conscientiously assisted in the development of this Conference.

The topic of advancing health promotion for people with disabilities on the public health agenda clearly falls within the mission and objectives of our association. AAHD is committed to support CDC funded state health promotion programs with information and strategies to increase the effectiveness of programs in their respective states. Our association is dedicated to building a national network of state programs to improve the services and programs for people with disabilities.

We are aware of the considerable responsibility we have placed on you to deliberate on each of the four major questions within the time frames of the Conference. We are confident that together we will realize substantial progress in acquiring the important information requested. As a collective group of stakeholders, we will forge ahead in our efforts to identify better methods for successful interventions in advancement of health promotion and wellness programs for people with disabilities in this nation.

Thank you for your interest and participation in this conference. We look forward to a successful conference and to receiving your comments and recommendations.

Sincerely,

Ronald Blankenbaker, MD

President

American Association on Health and Disability



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30341-3724

August 25, 2003

To the Conference Attendees:

It is with great pleasure that I welcome you to the workshop "*Advancing Health Promotion for People With Disabilities on the Public Health Agenda*", focusing on the grantees from program announcement No. 02007 "State Implementation Projects for Preventing Secondary Conditions and Promoting the Health of People with Disabilities". This workshop is jointly sponsored by the American Association on Health and Disability, and the Centers for Disease Control and Prevention (CDC). We at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) greatly value your role in promoting health and well-being among people with disabilities.

Since 1988, when the CDC disability program was first created, state programs such as yours have played a key role in helping achieve our shared goals—improving state surveillance activities, conducting health promotion interventions, developing and monitoring policies affecting people with disabilities, and facilitating partnerships between state- and research- or service-based agencies. With continued diligence and endeavor, we can continue to progress toward these and other goals that are part of our ongoing agenda. It is in no small measure due to your unstinting efforts that we have come this far. It will be in great part your efforts that take us farther.

We at NCBDDD hope that during this conference you will be able to infuse new energy into your programs, forge new collaborations, and discover and generate new occasions for growth.

I wish to personally thank all those who worked so hard to plan and organize this meeting, including Roberta Carlin and Vera Kurlantzick at the American Association on Health and Disability, those who served on the planning committee, and the speakers and session organizers. Additionally, I wish to thank all of you who have taken time away from your homes and busy schedules to participate in this conference.

Once again, let me extend my warmest welcome and best wishes for an exciting and invigorating conference.

Sincerely,

José F. Cordero, M.D., M.P.H.
Assistant Surgeon General
Director
National Center on Birth Defects
and Developmental Disabilities

CONFERENCE OVERVIEW

The American Association on Health and Disability (AAHD) in collaboration with The Centers for Disease Control and Prevention (CDC) sponsored the Second Project Workshop Conference for state cooperative agreement recipients, *Advancing Health Promotion for People with Disabilities on the Public Health Agenda*. The purpose of this meeting was to enhance health promotion programs for people with disabilities in each of the states by providing staff of CDC funded states with information and strategies and to continue to build a national network of state programs.

The conference was designed to provide an environment conducive to dialogue among all the participants. Through structured discussion, staff of state programs, staff of the CDC Disability and Health Team, and others interested in health promotion in the states focused on eight topics developed on the basis of requests from state programs.

Each of the eight sessions was led by two facilitators, whose responsibility was to facilitate the discussion. Approximately four to five resource people spoke briefly about innovative program strategies that have worked for them on the topic area. Four overall questions were distributed before the conference to guide each discussion:

- What are the key issues facing each state relative to the issue? What are the key challenges facing each state on the topic?
- Has your state implemented strategies, programs or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from programs that worked and didn't work?
- How can we bring this topic to the attention of policymakers in the states to ensure a place for this topic on your state's public health agenda?
- What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work toward building a strong state network?

CONFERENCE COMMITTEE

Lisa Hershey (CA)
Meg Traci/Craig Raveslout (MT)
Tony Cahill (NM)
Marcia Roth (NC)
Roberta Carlin (AAHD)

Roger Chapman (IA)
Susannah Combs (NJ)
Fran Stevens (NY)
Marlo Thomas-Koger (SC)
Vera Kurlantzick (AAHD)

ROLES OF FACILITATORS, RESOURCE SPEAKERS, MODERATORS AND RECORDERS

Facilitators

The Facilitators had a critical role in moderating the session in order to engage the audience in fruitful and lively conversations about the topic, and encourage as many people as possible to contribute and to take ideas from the conference back to their states. The Facilitators worked with the identified Resource Speakers for their respective session before the conference.

Resource Speakers

The Resource Speakers were presenters experienced with an intervention, initiative or strategy willing to share their successes (near misses) with the conference participants. Resource Speakers spoke on a panel for approximately five minutes about their program and proceeded to participate in a dialogue with the audience, in a discussion guided by the Facilitator. Resource Speakers prepared a written summary about their program, which is included in these proceedings.

Moderators

Moderators were persons with experience on a particular topic, who facilitated a lunch time discussion with others who had knowledge to share or were interested in learning more about the topic from their colleagues. These sessions were informal in nature, and only two are summarized in these proceedings.

Recorders

Recorders took notes at the plenary sessions on a laptop computer. Recorders summarized the salient points for purposes of development of conference proceedings.

Executive Summary

Roberta Carlin, Executive Director
Vera Kurlantzick, Program Associate
American Association on Health and Disability

Conference Purpose

The workshop conference, *Advancing Health Promotion for People with Disabilities on the Public Health Agenda*, was sponsored by the American Association on Health and Disability (AAHD) and the Centers for Disease Control and Prevention (CDC) August 25-27, 2003, at the BWI Airport Marriott Hotel in Baltimore, Maryland. The purpose of the workshop was to enhance health promotion programs for people with disabilities by sharing information which would help conference participants attain goals shared by the programs and the CDC improving state surveillance activities, conducting health promotion interventions, developing and monitoring policies affecting people with disabilities and facilitating collaboration between state and research agencies.

The conference was attended by service providers and researchers whose work addresses the objectives of *Healthy People 2010* focus area 6, disability and secondary conditions. This included representatives of the sixteen states with health promotion programs for people with disabilities funded by the CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD) Disability and Health Team, staff from NCBDDD, Christopher and Dana Reeve Foundation, Special Olympics International, and Amputee Coalition of America. Professionals and consumers from many disciplines participated, including directors of state agencies and programs, social workers, epidemiologists, physical therapists, and academicians. Some participants had 30 years experience, and some were starting their careers.

Conference Format

The conference was designed to provide an environment conducive to dialogue among all the participants. Through structured discussion, 80 participants focused on eight topics developed on the basis of requests from state programs. The topics, all relating to people with disabilities, were: physical activity and nutrition, women's health, emergency preparedness, surveillance data, violence, marketing, health promotion curricula, and evaluation of health promotion programs.

Each of the eight sessions was led by two facilitators. Approximately four to five resource people spoke briefly about innovative program strategies that have worked for them on the topic area. The resource speakers prepared written briefs which are included in the body of the Proceedings. Four overall questions were distributed before the conference to guide each discussion:

- What are the key issues facing each state relative to the issue? What are the key challenges facing each state on the topic?
- Has your state implemented strategies, programs or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to

other states? What lessons can other states learn from programs that worked and didn't work?

- How can we bring this topic to the attention of policymakers in the states to ensure a place for this topic on your state's public health agenda?
- What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work toward building a strong state network?

In the Presentations and Discussions section of the Proceedings, following the briefs for each of the eight sessions is a summary of key points raised during the discussion, organized around these questions.

Concurrent roundtable discussions were held during lunch on the first two days of the conference on pre-determined topics, including: funding opportunities, strategic planning and advisory panels, health care professional training, access to health care services, the role of RRTC's, and CDC Interim Progress Reports. Briefs and summaries from four of these discussions are included in the proceedings, under Roundtable Discussions.

Cross Cutting Issues

During the course of each session, numerous challenges faced by staff of state programs and many inspiring initiatives were described. (Short versions of many descriptions can be found in the state briefs.) Across the session, regardless of the specific session topic, several issues were repeatedly identified as important to many states. It is these issues that are discussed here.

Data Initiatives and Challenges

One full morning was dedicated to discussion of state uses of the Behavioral Risk Factor Surveillance System (BRFSS), variations on the BRFSS, other surveys, and uses of administrative data. In addition, data was mentioned throughout the conference as being critical to health promotion programs. Among the key challenges facing program directors is their requirement to demonstrate the need for programs, estimate the size of target populations and disparities between people with disabilities and without, and demonstrate program efficacy. Data from the Behavioral Risk Factor Surveillance Survey (BRFSS) or similar surveys have formed the basis of estimates of numbers of people with disabilities an important part of the equation for calculating need. Surveys of special populations clarify specific issues. For example, the *California Women's Health Survey 2003* data will be used to show what barriers women with disabilities face in accessing health care. Washington State is able to estimate the population prevalence of adolescents with disabilities using their *WA State Healthy Youth Survey 2002*. New Mexico is conducting a statewide assessment to ascertain the needs of people with disabilities in the event of a large-scale public health emergency.

Another common usage for disability data is for program evaluation. To the extent that data on disability and health are routinely and systematically collected by the federal or state governments, program directors are able to use the data to assess the impact of their programs. Their ability to do this, however, depends upon an identifier for disability in the data. Because of the difficulty defining disability, a fully accurate measure is difficult to achieve. The same is

true for the concept of quality of life. While disability advocates prefer a functional or social model of disability, rather than a medical model, a method to measure disability based on these models has yet to gain common usage. To be useful, any measures of disability, health status, functional status, or quality of life need to be general enough to be appropriate for a wide range of applications, while specific enough to detect changes over time that result from program implementation. In addition, many local program organizers need local level data, which is available in few states. During the course of the conference, innovations to address the data challenges were described, such as specific questions on disability which individual states have added to their BRFSS surveys, modifications individual states have made to BRFSS for their own use, gender-specific surveys in New Jersey, and a successful strategy for administering local level surveys in New York State.

Several barriers to evaluating health and wellness programs for people with disabilities were described during the conference, including non-response to evaluation instruments. Paying clients to complete post-program evaluations, together with one-on-one support in filling out the form was a strategy successfully used in Iowa. Language on instruments, it was noted, had to take into account the consumers' age and reading and cognitive ability. Oregon and Iowa are among the states that have conducted research to develop or select their evaluation instruments. South Carolina has been systematically evaluating its health promotion program, *Steps to Your Health*, since its inception. Reliability and validity are particularly elusive in this field, in which some subjects may have cognitive or physical limitations that interfere with their ability to complete a questionnaire. Several states using *Living Well with a Disability* have agreed to a joint evaluation form, which will comprise part one of their respective evaluations.

Environmental Initiatives and Challenges

Mentioned during every conference session, access to health care and health promotion venues, such as fitness centers, by people with disabilities remains a very basic need. Not only are health care and exercise facilities frequently not physically accessible, transportation and coordination of services is insufficient. Many states' initiatives are aimed directly at improving the health care and physical fitness environment. For example, Massachusetts is increasing the physical, administrative, and operational accessibility of each of the states' 187 mammography facilities, as well as each of the states' rape crises centers. Other examples are North Carolina, South Carolina, and Illinois, which are working with fitness centers to purchase universal design equipment and improve physical access. Briefs on specific initiatives are in the corresponding sessions in the proceedings. Access issues also present themselves in emergency preparedness initiatives and other health promotion activities.

The ability of staff to work appropriately and effectively with people with disabilities is another environmental challenge facing representatives from all of the states. Special training of health care professionals was the topic of one roundtable discussion (as was access). Special training is also needed for fitness facility personnel. Everyone in the spectrum of delivery of care benefits from training: the receptionists learn to schedule longer appointment times for people with disabilities, nurses aides and technicians learn to assist people to position themselves in the way that they find most helpful, nurses learn additional questions to ask and techniques taking clinical measures, and physicians learn about the scope of implications of the disability. Many states have included in their programs training for various types health care practitioners, such as mammography technicians and physicians. Rhode Island, for example, has arranged for Continuing Medical Education credits through Brown University Medical School for physicians

who obtain such training. A challenge noted by many presenters that it is difficult to maintain full accessibility at any site because of staff turnover. Although all the staff at a given health care or fitness site may undergo training in working with clients with disabilities, staff turnover, which is common in the lower paying positions, leads to gaps in staff knowledge. Thus, both structures and processes need to be put in place in order to continuously achieve accessibility.

A third type of access involves the justice system. People with disabilities may be victims of domestic violence perpetrated by a family member or personal care attendant. In some states, the legal definition of domestic violence does not include anyone other than sexually intimate partners, preventing the victim from accessing services that would otherwise be available.

Behavioral Initiatives and Challenges

Conference participants were passionate in their praise of programs that teach and encourage utilization of health promotion skills, such as nutrition, exercise, self-advocacy and utilization of health care services, and coping with such issues as depression, violence, and addictions. Several models were presented, including the *Healthy Lifestyles Curriculum* from Oregon, *Living Well with a Disability* originally from Montana, *Steps to Your Health* from South Carolina, and a North Carolina worksite health promotion initiative, *Live Healthy, Work Healthy*. These programs are presented as workshops or classes that use a pre-specified curriculum over a set amount of time, ranging from two and a half full days to 15 weekly sessions. Most of them involve a person with disabilities as trainer or co-trainer. The specific target populations and outcomes sought by these programs differ, making direct comparisons difficult, but all are exhibiting successes through use of well-developed curricula, corresponding materials, convenient locations, and supports for trainers and consumers

Health promotion programs that seek to change behaviors through working directly with consumers rely on the interest and commitment of consumers and program personnel. Recruiting consumers into a program often involves partnering with an intermediary agency, such as a Center for Independent Living, an advocacy organization or a medical practice, convincing that agency's staff of the worth of the program, and then arranging for transportation and support to enable consumers to participate. Developing relationships with intermediary agencies has been an important factor in the success of these initiatives.

Discussants at the conference also indicated that involvement of one or more program enthusiasts to spread the word about health promotion initiatives has been critical to their success. Champions both with and without disabilities have been successful, as have teams of leaders with differing disabilities. The champions' role varies depending upon the type of initiative, but in all cases, the champion reaches out to people with disabilities, explains the benefits of participating in an initiative one-on-one, and gets people to participate. For health promotion classes or physical activity training, this social leader makes transportation arrangements and follow-up and reminder calls. During and after an initiative, the champion is involved in motivating consumers to participate in the research portion of an initiative, and he or she may personally assist in seeing that evaluation instruments are completed. In Iowa and Oregon, for example, "champions" have been Department of Health staff. For a fitness program in New York, the trainer, a YMCA employee, was the champion. In all cases, one can infer from conference discussions that an individual's commitment to making a program succeed by enabling the target audience to participate is a major determinate of success.

Policy

Across session topics and states, conference attendees shared similar strategies for advancing health promotion for people with disabilities on their state's public health agenda. One strategy, used particularly successfully in New York and New Mexico, is for health and disability staff to work with multiple state agencies and planning committees to ensure that people with disabilities are among the target audiences of all state health promotion and wellness activities, not only those originating in the office that deals specifically with people with disabilities. Attending committee meetings and conferences has been an important part of expanding programmatic possibilities. In Virginia, the Health Promotion for People with Disabilities Project Manager collaborates within her division to ensure that people with disabilities are represented in chronic disease prevention and control strategies including preventive screenings, physical activity, and social marketing campaigns. Other recommended strategies were to impress upon policymakers and stakeholders, both within and outside of state government, the importance of data collection, environmental access, provider training, and specialized training sessions for consumers. Reports on findings from surveillance data have been successfully used to document the need for changes in policy or increases in funding, and are considered critical by all states.

Collaboration

Conference participants frequently cited the desirability of sharing materials across states, as a means to save time and money. National Center on Physical Activity and Disability (NCPAD, Illinois) and North Carolina have developed assessment instruments for physical accessibility of fitness and recreation centers which are not state-specific. Multiple states have guides for communication with people with disabilities, guides for planning inclusive, accessible meetings, and guides on women's health and other health topics which can be utilized by other states. Manuals, such as the one Arkansas is creating, have been written up at the end of the evaluation cycle of nutrition and fitness workshops to enable similar workshops at Independent Living Centers, YMCAs, state health departments, and rehabilitation centers. Montana, Oregon, North Carolina, and South Carolina are some of the states that have developed special training programs for people with disabilities, and have written curricula and additional materials that are suitable for use elsewhere. Project staffs of four states using the Living Well with a Disability curriculum have jointly developed a common evaluation instrument for that program, reaping economies of scale and also allowing cross-state comparison.

Conclusion

Advancing health promotion for people with disabilities on the public health agenda is a continuing task, accomplished by dedicated professionals and consumers across the country. Throughout the forty four initiatives described in these proceedings with a wide range of focus areas, certain common challenges are being recognized and addressed to facilitate the success of these initiatives: access to medical care and other sites important to wellness, training for professionals in working with people with disabilities, data collection and development of measures, program evaluation, and sharing of materials, programs, and measures across states. Through meaningful exchanges, conference attendees gained insight and momentum to further their research and initiatives that will preserve and improve the health and wellness of our nation's citizens with disabilities.

Acknowledgements

AAHD staff thanks planning committee members Tony Cahill, Ph.D. (NM), Roger Chapman, M.S.W. (IA), Susannah Combs, M.A.S. (NJ), Lisa Hershey (M.P.H.) CA, Marlo Koger M.P.H (SC), Craig Raveslout, Ph.D. (MT), Marcia Roth, M.P.H (NC), Fran Stevens, M.S. (NY) and Meg Ann Traci, Ph.D. (MT), who spent many hours germinating and nurturing the conference concept and design. Most important to the realization of the conference, we thank Mary Helen Witten, M.P.H, M.S.W., and staff and officials of CDC for their support.

**ADVANCING HEALTH PROMOTION FOR
PEOPLE WITH DISABILITIES
ON THE
PUBLIC HEALTH AGENDA
PROCEEDINGS**

Presentations and Discussions

North Carolina Brief - 1
The North Carolina Office on Disability and Health
Removing Barriers to Fitness Environments: A Community Training Model

Chris Mackey, Physical Activity Specialist
North Carolina Office on Disability & Health

The North Carolina Office on Disability and Health (NCODH) is implementing a community-centered training model to improve the accessibility of fitness facilities. The goals of this project are to create fitness environments that are accessible, accommodating, safe, and supportive of persons of all abilities and to increase the knowledge and skills of service providers and community residents so that they can effectively initiate and sustain health promotion efforts. Specific training objectives include increasing fitness providers' knowledge of the Americans with Disabilities Act of 1990, universal design and adapted equipment, increased outreach and marketing to persons with disabilities, improved fitness facility accessibility, and expanded community partnerships.

Project Activities:

- Identification of a local advocacy or similar group to serve as a gatekeeper by identifying a lead fitness facility and participating in training.
- Convening an initial meeting with the administration of the lead fitness facility/agency for an overview of NCODH, discussion of agency interests and needs, brief site tour, and discussion of preferred training dates/times. (To date a variety of fitness environments have served as training sites.)
- Conducting a brief agency self-evaluation prior to the training to ensure the design of relevant training. Staff are surveyed on training objectives and related topics.
- Evaluation of agency accessibility by NCODH and community gatekeepers prior to workshop day training is provided based on the NCODH publication *Removing Barriers to Health Clubs and Fitness Facilities*. Numerous resource materials are provided.
- Developing an agency plan of action identifying needed changes, timetable, and possible resources.
- Provision of follow-up by NCODH based on plan of action.

Collaborators: have included disability advocacy organizations such as members of the NC ADA Network, regional senior center, parks and recreation departments, Independent Living Programs, CVH coordinator, public health department, rehabilitation center, university student recreation center, and community members with disabilities.

Outcomes and Measures: Measures of effect to date include modification of lead agency's policies and facility, increase in community partnerships, and collaborators sharing training information with other community fitness/health promotion agencies. Sample modifications have included installation of automatic doors, modification of parking areas, rearrangement

of fitness equipment to allow for greater access, staff training on the Relay System and evacuation procedures for persons with disabilities.

Challenges: have included lengthy amounts of time to schedule trainings. Also, post-training opportunities to assist collaborators in continuing to share training materials/information with other community agencies have been limited.

Policy: Information from this project has been used to influence public health policy particularly in the area of physical activity. NCODH has contributed information to the NC State Plan to Increase Physical Activity, and consulted and provided technical assistance to the state Division of Public Health and Department of Public Instruction in their efforts to promote the health of young people in our state. Additionally, the project promotes best process and practice for recreation and fitness providers seeking to serve a diverse population of users.

North Carolina Brief - 2
North Carolina Office on Disability
Work Site Health Promotion Initiative: Live Healthy, Work Healthy
Karen Luken, Program Director
North Carolina Office on Disability and Health

Description of Initiative: NCODH is developing a multilevel work site health promotion initiative with the goal of providing environmental supports for health promotion in order to improve the health status of individuals with disabilities. The targeted goals are to increase healthy activity and food choices available at work, encourage people to consider healthy choices, and support people when they make healthy choices. The program emphasis is on making the work site a place that models and supports healthy and realistic lifestyle choices, instead of directing all health promotion interventions at the individual, which is a very time-consuming, expensive and often unsuccessful endeavor. *Live Healthy, Work Healthy* purposefully acknowledges the impact of the environment on individual behavior and is developing an array of strategies that promote health and can be sustained by the agency.

Target audience: Adults with disabilities (including mental retardation, autism, cerebral palsy, co-occurring disabilities) who receive services at a community employment agency specializing in services for adults with significant disabilities.

Project activities include:

- Identifying best practice work site health promotion models and strategies.
- Securing the support of agency administration.
- Identifying insiders and outsiders who can nurture and sustain the program.
- Forming a wellness committee, which provides the foundation for all on-site efforts. It consists of individuals receiving services and agency staff and meets weekly to conduct business. Responsibilities include helping to select the weekly lunch-time wellness activities, encouraging participation in these activities, identifying desired environmental changes, such as vending machine options, placement of exercise equipment, choice of walking routes, design and maintenance of wellness bulletin boards, and incentives for walking club. Committee roles include meeting co-leader, lunchtime announcements, exercise assistant.
- Implementation of weekly lunch-time physical activities, with an emphasis on walking, stretching, and use of "low tech" equipment (hand weights, therabands, videos).
- Implementation of a series of 15 weekly group classes emphasizing physical activity, healthy nutrition, and personal goals.
- Developing plans for quarterly community speakers calendar and annual health fair.
- Visitation of other work site health promotion programs.

Collaborators: at site one are a community vocational center, a local Arc chapter, the County Human Services department, which includes public health, the community college, and local businesses. We anticipate similar partnerships in future sites.

Outcomes and Measures: A logic model was developed and targets measures of effect for the worksite including increase in environmental supports, modification of agency policies and practices, staff job descriptions, and expanded community partnerships. Measures for individuals include increased time spent in physical activity (with LHWH program and at other times) and decreased intake of high fat, high salt, and high calorie foods and drinks. Additional measures include number of persons involved in educational classes, group activities, walking club, number and types of products produced, and agency and participant satisfaction.

Challenges: to date include ensuring consistent onsite visibility of program, decreasing dependence on staff for organized fitness activities, acknowledgment that many individuals rely on others to prepare lunches and purchase food items, engaging the community in the health promotion needs of workers with disabilities, ensuring educational materials are appropriate for target learners.

Policy: Outcomes will be used to influence practices in other work sites and provider agencies and to inform public health efforts to address nutrition, physical activity, and obesity for persons with disabilities.

South Carolina Brief
SC Health and Disabilities Project-Fitness Component

Gerald (Jay) Daniels, M.P.H., Physical Activity Specialist
Palmetto Public Health District

South Carolina Department of Health and Environmental Control

The SC Health and Disabilities Project is a collaborative effort by SC Department of Health and Environmental Control and the USC School of Medicine's Interagency Office of Disabilities and Health. The objective of one component of the project is to increase the accessibility and user-friendliness of fitness facilities to those who have a disability. We ultimately hope to increase the number of individuals with disabilities who exercise, and thereby reduce the incidence of secondary conditions.

The fitness facility component had four parts: 1) Completion of surveys of each facility that gave management an idea as to how user-friendly and accessible their facility was to people with disabilities (PWD- both physical and cognitive). This also provided us with an idea as to which facilities (one public and one private) would require the least amount of work and the best opportunities for PWDs. 2) Working with facilities to purchase universal design equipment. Universal design equipment is designed to be as barrier-free as possible, thus serving a larger user base than traditional equipment, which is important to fitness facilities. 3) Training people in the fitness facilities to better understand PWDs, the issues that they deal with, terminology, how exercise can affect disabilities, and adaptive training. Adaptive training is how to make non-universal design equipment more useful to PWDs using non-traditional methods and accessories. 4) Finally, we have been marketing the fitness facilities through the Department of Disabilities and Special Needs, rehabilitation hospitals, Limitless Sports, newsletters sent out to special needs groups, and other means.

This project is ongoing and statewide, with the Myrtle Beach and Charleston areas as the next area of focus. We are currently in the process of obtaining data as to the numbers and types of PWDs using the facilities and once enough data is obtained, we hope to influence public health policy by showing the benefits to other PWDs, government agencies, and private and public agencies.

Barriers/ Challenges/ Facilitators.

Training. Comments from trainers that attended the training indicate that the training is long overdue, and many of the trainers are training PWDs currently. Most trainers and instructors are very interested and open to working with PWDs, especially if they have the training to do so. Very few people have indicated that they were not interested in working with this population; however, we did receive a comment from a hospital-based wellness facility that was not interested in pursuing this population. Private facilities seem to be more open to expanding their user base and capturing a larger share of a typically untapped market.

Fitness Facilities. When presenting this information to fitness facilities, potential funding sources, and how the information is presented may determine the facility's level of interest. ADA for public facilities comes into consideration, as well as market expansion for private for-profit organizations.

Types of Expertise. Having two crucial aspects of expertise was beneficial: weight-training/exercise science background in one person and having someone who was a wheelchair athlete. Exercise science, being very familiar with weight training equipment and biomechanics, became beneficial as equipment was examined and the training manual developed. Having a wheelchair athlete involved provided credibility, practical expertise, and intimate knowledge of the PWD aspect of physical training.

Arkansas Brief
**Living Well With Spinal Cord Disability:
Nutrition and Physical Exercise Promotion for
Persons with Spinal Cord Disability**

A Program of the Arkansas Spinal Cord Commission (ASCC)
and Partners for Inclusive Communities (Partners), UAMS

Mark Swanson, M.D., M.P.H., Executive Director
Partners for Inclusive Communities, University of Arkansas for Medical Sciences

Proper nutrition and physical exercise are often missing components in the lives of persons with spinal cord disabilities. This project was developed to promote healthy eating and physical activity in the lives of people with spinal cord disability.

The intervention was a two-day workshop on healthy eating and physical activity: one day of classroom instruction and participation, and a second day of hands-on, experiential activities. At the end of day two, participants set personal nutrition and physical activity goals they wanted to attain over the next year. Project staff will follow the participants through telephone interviews at intervals of three, six, and 12 months to determine long-term effectiveness of the training. ASCC organized the workshop and provided instruction and demonstrations in physical activity while partners provided instruction and demonstrations in nutrition.

The participants were individuals with spinal cord disabilities (of any etiology) who were enrolled on the ASCC registry. Participants with spinal cord injury (SCI) had to be at least one year post-injury. Adults with adequate cognitive skills, residing in private residences in eight central Arkansas counties, were invited to participate. There was no financial cost to participate; the cost of transportation was reimbursed if needed.

The workshops were held in a new, wheelchair-accessible, community recreation center. To increase attendance of students and those who work full-time, participants could choose between Friday or Saturday sessions. The first workshops were conducted on May 30-31, 2003, with the second workshops conducted on June 27-28, 2003. The month-long gap allowed participants to review and start using the material presented on first day and report their progress on their return a month later.

Seventeen persons, of 476 persons invited, attended the workshops. The mailing was targeted by computer query only to qualifying adults. Two mailings, one a letter of invitation and the second an informational flyer, were sent to qualified adults in a four-county catchment area. The response of the participants was enthusiastic. Participants were very interested in the material, motivated and ready to make changes in their lifestyle.

Before the start of the workshops, baseline data was collected on the participants' general health, eating habits, and their physical activities. These same questions will be asked at three, six, and 12 months post-intervention to determine workshop effectiveness. Participant progress will also be measured on attaining and maintaining their personal goals.

Making the Connection: Physical Activity, Nutrition, and People with Disabilities

At the end of the follow-up period, lessons learned from this pilot will be incorporated into a manual for others to use in conducting similar workshops at Independent Living Centers, YMCAs, state health departments, and rehabilitation centers.

New York State Brief - 1
Physical Activity for Persons with Disabilities
Phase I: Fitness Programming for Persons with Disabilities Workshops

Theresa Paeglow, Coordinator

New York State Department of Health Disability and Health Program (NYSDHP)

Description: The NYSDHP has collaborated with the Capital District YMCA (CDYMCA) to increase their capacity to serve individuals with physical disabilities within their eight branches. The NYSDHP developed two workshops for CDYMCA fitness staff that consisted of a combination of lecture and hands-on practical work with volunteers with disabilities. The first workshop covered the following topics: Disability Awareness for the Fitness Professional; Physical Disabilities: General Characteristics and Exercise Implications; Individual Assessment and the Development of Fitness Plans; Flexibility, Strengthening, and Cardiovascular Practical. Evaluations of the workshop identified additional training needs: further discussion of disabilities and implications on fitness programming, more information on the assessment process and how to design a fitness program, and more time for hands-on work. A second workshop was developed to meet these needs. This revised workshop was replicated with fitness staff from the southern tier region of NYS in collaboration with the Cortland YWCA.

Audience: YMCA fitness directors and specialists. A secondary audience was the membership directors and front desk staff. Volunteers with disabilities, recruited for the hands-on practical component, participated for the entire day to provide personal perspectives on the discussion of specific conditions and exercise implications.

Participation: The two workshops with the CDYMCA reached 37 fitness professionals and included 12 volunteers with disabilities. The replication in Cortland, NY, reached 27 fitness professionals from the region and included five volunteers with disabilities.

Duration: The two workshops held with CDYMCA staff occurred within an eight month period during 2001. The workshop held in Cortland, NY, occurred in November 2002.

Collaborators: The eight branches of the Capital District YMCA, local Independent Living Centers, and a physical therapist consultant. In Cortland, YWCAs and YMCAs from the region, the local Independent Living Center, and a physical therapist consultant.

Outcomes: Evaluations indicated the program helped to lessen fitness staff apprehension, increase their knowledge, and expand their skills in working with persons with disabilities.

Facilitator: We began meeting with the "P-Group," comprised of the fitness directors of each branch. In 1999, this allowed us to introduce ourselves and grow a relationship with them that allowed them time to "buy-in." There was a "champion" within the CDYMCA. This individual worked across branches to promote the workshops and emphasize the importance of working with individuals with disabilities.

Barriers/Challenges: Need for retraining due to fitness staff turnover. Getting persons with disabilities to view the YMCA as a viable option for them to access exercise programming.

Influence on public health policy: We have used our experience to motivate those programs within the NYS DOH that promote physical activity interventions in communities or through contracts to include persons with disabilities in their activities.

New York State Brief - 2
Physical Activity for Persons with Disabilities
Phase II: The YMCA Ready-Fit Program and
Persons with Physical Disabilities

Theresa Paeglow, Coordinator
New York State Department of Health Disability and Health Program

Description: Phase I culminated with a "Networking Event" to bring together Capital District YMCA (CDYMCA) branches and local disability service/advocacy organizations, and a "Health, Fitness and Disability Expo." These events were designed to promote the CDYMCA branches as fitness options for persons with physical disabilities. However, we did not see an increase in participation by persons with disabilities in fitness programming at the branches of the CDYMCA. Since our advisory group identified physical activity among persons with disabilities as a priority, we took our experiences back to them for recommendations on how to proceed. Their recommendation was to pursue implementation of the YMCA "ReadyFit" program among persons with disabilities. "Ready-Fit" program is a 12-week individualized fitness program geared toward improving cardiovascular fitness, strength, and flexibility. Participants meet with a "coach" for an initial assessment and design of a fitness program to meet their fitness goals. Three subsequent meetings occur during the remaining 12-week period to review and modify the program as necessary. The final meeting includes development of a fitness maintenance plan.

Audience: Individuals with physical disabilities over the age of 18.

Participation: Sixteen individuals with a variety of physical disabilities (CP, SMA, post-stroke, SCI, SB, MS) were enrolled in the "ReadyFit" Program. Two individuals withdrew from the program: one lacked commitment, the other moved out of state. Five are on hiatus due to medical issues. Nine have completed the 12-week program.

Duration: Began April 2003 – ongoing.

Collaborators: The eight branches of the CDYMCA and individuals with disabilities.

Outcomes: Baseline information on fitness (e.g., self-reported ease in ADL/IADLs) and well-being (e.g., selected QOL BRFSS items) were gathered upon enrollment, and the same information will be collected as participants finish their 12-week program. Questionnaires for each coach assessing their ability to implement standard "ReadyFit" program with their client will be gathered. A comparison group of CDYMCA members without disabilities who have participated in the "ReadyFit" program will be extracted to compare experiences between the two groups. For those individuals with disabilities who completed the 12-week program, memberships were funded for an additional nine months. Follow-up will be conducted with these individuals at three months and nine months post to determine continued exercise participation.

Facilitator: CDYMCA assigned a membership director as liaison between DHP staff and fitness staff. While this facilitated some aspects of the project, it hindered others.

Barriers/Challenges: Our intent was to evaluate the standard "ReadyFit" program among persons with disabilities. This "real-world" application required that DHP staff back off after enrollment. It was not until estimated "12-week" dates occurred, and we initiated follow-up contact, that we discovered medical issues that hampered participation, problems with coaches, etc. As always, transportation was a barrier (and a major cost).

Influence on public health policy: Unclear at this time, awaiting final data collection and analysis.

Discussion Summary
**Making the Connection: Physical Activity, Nutrition,
and People with Disabilities**

session facilitated by

James Rimmer, Ph.D., Project Director and Professor
Department of Disability and Human Development, University of Illinois at Chicago

Susan Gray, Acting Director
Office of Disability and Health, New Mexico Department of Health

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Recruiting participants
 - Identifying communities and specific fitness centers within communities in which to provide training on universal design and working with people with disabilities
 - Ensuring availability of trained staff, given frequent turnover of fitness staff in fitness and recreation facilities
 - Meeting the diverse needs of people of different backgrounds and different types of disabilities
 - Developing initiatives in rural areas where there are no fitness facilities
 - Developing initiatives in urban areas where there is a high crime rate
 - Overcoming obstacles to participation in physical activity and nutrition programs, including transportation, cost, and availability of appropriate equipment
 - Assisting participants who have various secondary conditions
 - Integrating nutrition into physical activity programs, given the prevalence of obesity among people with disabilities.
 - Developing accurate (reliable and valid) assessment tools that capture physical activity patterns and nutritional habits of persons with physical, cognitive, and sensory disabilities
2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?*
 - Promote healthy eating and exercise together.
 - Train local disability advocates to provide fitness centers with training on removing barriers.
 - Use a cross-disability training team.
 - Involve people with disabilities in each location in which there is an initiative.
 - Locate wellness programs that are accessible to people with disabilities at work sites.

- Coordinate with NCPAD, North Carolina, South Carolina or others to develop material on aerobic and anaerobic training, universal design, exercise, and physical activity resources.
 - Market physical activity including adaptive sports programs through newsletters, brochures, websites, TV, and newspapers.
 - Provide a continuum of support for health behavior change. Staff of fitness centers need to help people with disabilities integrate into their environment. Make use of motivational interviewing, stages of change theory, and other behavioral theories.
 - Plan for medical leaves, and train staff and participants how to re-enter the fitness environment after a medical leave.
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Participate in state public health planning committees for physical activity and nutrition initiatives to ensure inclusion of people with disabilities.
 - Work with other departments within the state health department to leverage inclusion of people with disabilities in requests for proposals, which may garner additional funding.
 - Obtain data on numbers and types of persons with disabilities using accessible physical fitness facilities or who would like to use a fitness facility. Influence public health policy by showing the benefits of physical fitness to other persons with disabilities, government agencies, and private and public agencies.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*
- Several states, such as North Carolina and NCPAD, have developed and made available paper and online instruments for measuring accessibility of physical fitness centers.
 - NCPAD and other sites have provided demonstrations of universal design exercise equipment to other states and have numerous materials, including online assessment tools in physical activity.
 - States with training programs for fitness centers on universal design and assisting people with disabilities, such as North Carolina and NCPAD, are open to training trainers from other states.
 - Business and industry are an untapped resource for assistance with physical activity and nutrition initiatives.
 - Rehabilitation Institute in Chicago holds seminars that are appropriate to multiple states.
 - Manuals, such as the one Arkansas is creating, have been written up at the end of the evaluation cycle of nutrition and fitness workshops to enable similar workshops at Independent Living Centers, YMCAs, state health departments, and rehabilitation centers.

North Carolina Brief - 1
NC Office on Disability and Health
Health Provider Education Initiative: Count Us In

Pamela Dickens, M.P.H., Women's Health Coordinator
North Carolina Office on Disability and Health
University of North Carolina - Chapel Hill

Description of Initiative. *Count Us In* represents a collaborative partnership between NCODH and Duke University Medical Center, Community and Family Medicine (PERT grant 2001-2003). The objectives of this project are to: (1) increase sensitivity and awareness of primary health care providers and share strategies to promote breast and cervical cancer screenings among women with disabilities; (2) increase sensitivity and awareness of lay health advisors and share strategies to promote breast and cervical cancer screenings among women with disabilities; (3) increase awareness and encourage screening among women with disabilities; and (4) test a variety of methods for engaging community health promotion initiatives in targeting health education communication promoting breast and cervical cancer screening for women with disabilities. The overall goal is to demonstrate the effectiveness of different approaches in achieving these objectives to develop procedures for integrating an emphasis on women with disabilities into community-based and state programs designed to improve screening utilization. Women with disabilities have been involved in all aspects of project development, delivery and evaluation.

Target Audiences. 1) Primary health care providers in training at Duke University Medical Center – physician assistants, family nurse practitioners, and family practice residents; 2) Lay health advisors participating in six community-based SELF-improvement projects (focused on nutrition, physical activity, and smoking cessation), and 3) women with disabilities who reside in 21 counties that are home to a SELF-improvement projects.

Activities:

- The women's magazine *Orchid* was mailed to 5,300 women with disabilities on Medicare in 21 NC counties that are home to SELF-improvement projects. Medical Review of NC identified women through Medicare claims data. *Removing Barriers to Healthcare* and a *Mammography Access Checklist* were sent to mammography sites in these 21 counties.
- Disability information was incorporated into the Duke curricula for students in nursing, physicians assistants, and family medicine residency.
- A disability teleconference was presented to the 16 SELF-improvement projects in NC.
- The Breast and Cervical Cancer Screening lay health advisor curriculum, developed by the NC Breast Cancer Screening Program, was reviewed and edited to become inclusive of women with disabilities.
- Utilizing the revised LHA curriculum, training was provided to lay health advisors in five selected SELF-improvement projects

Collaborators: NC Assistive Technology Program, NCODH Health and Women with Disabilities Task Force, NC Breast Cancer Screening Project, Medical Review of NC.

Outcomes and Measures. Changes in knowledge and attitudes of providers are being evaluated via questionnaires administered before and immediately after participation in the project. Some post questionnaires have not yet been administered. After pre- and post-test results are completed, changes will be evaluated across groups. Based on feedback from trainers with disabilities, faculty, and students, the "lab" format seemed the most effective strategy used to present material.

Barriers / Challenges. Some challenges have included coordinating meetings, schedules, and presentations with faculty at Duke; identifying and coordinating participation of women with disabilities as co-trainers; finding ways to incorporate disability information into the "crowded" academic curricula; sustainability of project.

Policy. Outcomes of the project will be used to demonstrate an effective approach to provider education for improving health care services and breast and cervical cancer screening for women with disabilities.

North Carolina Brief - 2
NC Office on Disability and Health
Breast Cancer Screening

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Description of Initiative

NCODH is developing a multilevel initiative with the goal of providing information and technical support to breast health care providers and women with disabilities in order to increase access to breast cancer screening for women with disabilities. The targeted goals are to increase awareness for both providers and consumers and to assist with environmental and behavioral changes as identified. The emphasis is on making the health care site a place that models and supports accessible breast health care for women with disabilities.

Target Audience.

Breast health care providers (mammography technologists, health care providers), mammography inspectors, BCCCP providers, and women with disabilities.

Activities:

- Networking with partners throughout the state.
- Conduct focus groups and site visits with mammography providers to identify issues and barriers to serving women with disabilities.
- Disseminate BRFSS, Medicare and Core Indicator Project data on disparities in breast cancer screening rates.
- Mailed *Orchid* magazine to women with disabilities (ages 50-64) on Medicare who have not received regular mammography screenings. Medical Review of NC identified these women through Medicare claims data.
- Participate in NC Advisory Council on Cancer Coordination and Control (ACCCC).
- Provide regular articles in BCCCP statewide newsletter.
- Presentations – Radiology Technologists State conference, BCCCP Annual Update, community college mammography course, ACCCC quarterly meeting, Cancer Information Service staff training.
- Reviewed / made additions to make inclusive of women with disabilities – *LHA Breast and Cervical Cancer Curriculum, NC Breast Cancer Resource Directory*
- Provide technical assistance to one mobile mammography unit in North Carolina during 2003-04 to improve access to screening services for women with disabilities.
- Submitted Triangle Affiliate Susan G. Komen grant (TASGK) in 2002 – not awarded.

- Developed position paper for Triangle Affiliate Susan G. Komen Breast Cancer Foundation regarding issues for women with disabilities and breast health and screening. Paper was presented to Komen review and education committees.
- In May 2003, Komen board voted to include women with disabilities as an underserved priority population on next RFP.
- Preparing TASGK grant proposal September 2003. Project will address improving breast cancer screening in one NC county targeting mammography sites, BCCCP program, health care providers, and outreach to women with developmental disabilities utilizing the *Women Be Healthy* curriculum. Goals are increasing disability awareness and improving environmental and information accessibility.

Collaborators

BCCCP, NC Radiation Protection Section, mammography sites, Cancer Information Service of Southeast, NC Breast Cancer Screening Program, Triangle Susan G. Komen Breast Cancer Foundation, American Cancer Society, Medical Review of NC

Outcomes and Measures

Process and outcome measures are developed for each discrete training, technical assistance, systems development and intervention activity.

Barriers / Challenges.

Challenges have included: continuous reorganization in BCCCP; identifying providers that have time, staff, and resources to participate; finding avenues to impact providers statewide; increasing disability awareness in the "breast cancer" professional arena; low reimbursement rates for mammography

Policy

Outcomes with mobile mammography and Komen project will be used to demonstrate an effective public health approach to improving breast health and breast cancer screening for women with disabilities. Emphasis will be on development of tools for replication at other sites.

North Carolina Brief - 3
NC Office on Disability and Health
Intervention: Women Be Healthy

Pamela Dickens, M.P.H., Women's Health Coordinator
North Carolina Office on Disability & Health
University of North Carolina - Chapel Hill

Description of Initiative: A women's health curriculum developed by Yona Lunskey at the Nisonger Center for Mental Retardation was revised by NCODH and developed into a trainer's curriculum, *Women Be Healthy*, in 2002. This eight week curriculum is designed to help trainers teach women with mild to moderate mental retardation about reproductive health and breast and cervical cancer screening and to promote active participation in their health care. This goal is met by: reducing fear and anxiety associated with medical procedures through progressive exposure to medical procedures and equipment and learning relaxation coping techniques; teaching assertiveness skills in medical situations through role plays; and providing reproductive health information. The NCODH field tested the curriculum at two sites, then began providing train-the-trainer workshops throughout the state. NCODH has developed *educational kits* (valued at \$1,000) for facilitators in North Carolina to borrow free of charge.

Target Audience: The target audience for participants in this eight week program is five to eight female adult women with mild to moderate mental retardation and their natural supports. These participants should have receptive and expressive communication and some abstract reasoning (for role-plays). (It is recommended to have two female facilitators for the program.)

Participants: NCODH piloted two initial *Women Be Healthy* class series in North Carolina – one community based and the second at a disability worksite. Since then, at least seven community agencies throughout N.C. have facilitated the *Women Be Healthy* program. Evaluative data regarding the exact number of participants from each of these classes is being collected, but is estimated to be ~75-100 women.

Activities: The *Women Be Healthy* program is organized into eight weekly 90-minute sessions. Each session includes discussion, videos, visual aids (posters, pictures, breast models), role plays, relaxation techniques, jobs for health (homework assignment), and feedback.

Collaborators: To build community capacity NCODH has collaborated with DD service providers, advocates, and compensatory education classes in the community college system since 2002. Training workshops have been cosponsored with The Arc of North Carolina. Workshops have been designed to inform participants about the curriculum and to increase their knowledge and comfort level with curriculum implementation. Thus far, seven community agencies have facilitated the *Women Be Healthy* program and utilized the kits of materials. NCODH is in the process of conducting a summative evaluation via a phone survey to gather more descriptive information.

Outcomes and Measures: In some of the sites, changes in knowledge and attitudes have been evaluated with some participants via individual interviews administered before and immediately after participation in the class series. A follow-up assessment has also been completed seven

Getting Women's Health Issues for Women with Disabilities on the Public Agenda

months post group to assess retention and behavior change. While the sample is small, findings demonstrate that this curriculum *effectively* prepares women for breast and cervical cancer screenings and empowers them to take a more active role in their health care

Barriers / Challenges: Some challenges have included time/staff to organize train-the-trainer workshops throughout the state; getting train-the-trainer workshop participants to then facilitate the *Women Be Healthy* program in their community; community agency recruitment of women for classes and retention of participants throughout the class series; community agency administrative support; expanding core training team; expanding partners to include women's health services, in addition to disability agencies.

Policy: Outcomes are being used to demonstrate an effective public health approach to improving health and health care access for persons with developmental disabilities. The intervention also informed the Council on Developmental Disabilities RFA on health promotion that was scheduled for release in August 2003.

Massachusetts Brief
Massachusetts Mammography Access Project

Lisa Maisels, M.S.W., M.P.H., Project Coordinator
Massachusetts Department of Public Health, Office on Health and Disability

The Mammography Access Project (MAP) responds to the finding from the Massachusetts BRFSS that women with mobility disabilities were significantly less likely to have had a mammogram in the recommended time frame than other women (46 to 62% of women with mobility disabilities vs. 75% of other women). This was particularly surprising because 98% of women with a mobility disability reported having had a routine checkup in the last year, as compared to 84 to 86% of other women. The purpose of MAP is to increase mammography screenings among women with mobility disabilities by improving access to mammography facilities, educating providers, and increasing awareness among consumers of the importance of mammograms and availability of accessible facilities. In the first half of our three-year grant cycle, we have focused on increasing the physical and programmatic accessibility of mammography facilities and gathering information that will enable a woman or her provider to find a site that will be accessible for her.

MAP addresses the objectives of increasing accessibility and gathering information through two strategies. First, we are assessing the accessibility of mammography facilities throughout the state. The Office on Health and Disability (OHD) has developed a survey tool to assess core elements of physical access, program access, and effective communication, as well as aspects of administration, training, and operations that create an accessible and inclusive environment. OHD staff and consultants are visiting each of the 187 mammography facilities in Massachusetts by the end of 2003 to assess access using this survey tool. The assessors use the site visit as an opportunity to briefly educate their hosts. The visits are followed by a letter outlining recommendations for improved access and resources. Once all site visits are completed, sites will be offered technical assistance to improve access. The results of these site visits will be disseminated to women and their providers through print publications and the web.

In later years, access at these sites will be reassessed by a combination of self-report and visits to a subset of sites. The success of our efforts will be measured by increases in accessibility over time. Second, we are conducting a pilot project at two mammography facilities that perform a total of approximately 35,000 mammograms per year. This project is designed to create a more accessible and inclusive mammography experience and to improve mammogram quality, through training and changes in scheduling practices. Mammography technologists at these sites have received a six-hour training on working with women with mobility disabilities, covering health disparities, disability awareness, positioning, and radiation safety issues. These trainings will be repeated in three different areas of the state. The effectiveness of the trainings is being evaluated through a pre- and post-test of trainees' knowledge of the areas covered in the workshop.

MAP has also developed a brief questionnaire designed to identify women with mobility disabilities and the type of assistance they will need. Each site administers this questionnaire when appointments are scheduled. If women use wheelchairs or scooters, a longer appointment and/or extra staff assistance are scheduled. Information from the questionnaire appears on the mammography technologist's schedule. This allows the technologist to prepare fully for the

Getting Women's Health Issues for Women with Disabilities on the Public Agenda

patient. The effectiveness of the strategy of modifying scheduling practices is being evaluated through a client satisfaction survey, data on the proportion of women who qualify for additional assistance, and focus groups with the participating mammography technologists.

New Jersey Brief
New Jersey Disability Health and Wellness Initiative
The New Jersey Capacity for Disability and Health Project

Susannah Combs, M.A.S., Project Manager
New Jersey Department of Human Services,
Division of Disability Services

Project Goal: This project will assist the Division of Disability Services and the Department of Human Services as a whole in our efforts to better serve the needs of New Jersey women and men living with disabilities.

Focus Groups: The Rutgers Center for State Health Policy (CSHP) is working with the Division to conduct 10 focus groups with individuals who live with disabilities. Half of the focus groups will bring together groups of women and half will convene groups of men. These groups will explore the health promotion and health prevention activities adopted by individuals of each sex and invite discussion about their primary health concerns as well as the access barriers they regularly encounter. All groups will explore participants' own experiences of using the health care system and inquire about ways in which it could better serve their needs.

CSHP is currently collaborating with the Division and with a diverse group of agencies and advocacy organizations to help recruit potential focus group participants. *However, the identity of individuals ultimately selected to participate in the groups will not be known to the Division.* The final participant list will include men and women of varying ages who live with a wide range of constraints; however, each individual focus group will consist of those participants with similar disabilities (physical, sensory, and cognitive). Special attention will be given to seniors living with physical disabilities in two focus groups dedicated to participants over the age of 45. Care will be taken to include individuals from across the state of New Jersey representing a range of income levels. Each group will consist of six to 10 participants and last for about two hours.

Survey: The Division is also working with the Center team and the disability community to develop two statewide surveys (one for women and one for men) in order to capture a wider range of individual experience and to assist both community and state entities in identifying and prioritizing new initiatives. Like the focus groups, these surveys will ask about participants' experiences with health care providers and invite them to share their most important health related concerns and opinions. Approximately 600 surveys will be administered.

New York Brief
**Getting Women's Health Issues for Women with Disabilities
on the Public Health Agenda**

Frances Stevens, M.S., Program Manager
New York State Department of Health Disability and Health Program

Description

The Disability and Health Program collaborated with the Cancer Services Program in a successful request for use of CDC funds to support the distribution of 20 accessible examination tables across NYS. The Cancer Services Program contracts with 53 community contractors and their coalitions called Healthy Women Partnerships (HWPs) to promote breast and cervical cancer screening for uninsured and underinsured women. Initiative components included: a survey of all HWP providers to assess current availability of accessible tables; a call for proposals from interested providers who met the criteria of demonstrated accessible site, willingness to collect data, and assurance to conduct outreach; conduct of five regional trainings across NYS focused on disability sensitivity, clinical assessment, and discussion of outreach to community organizations serving people with disabilities.

Audience

The target audience is women with physical disabilities.

Numbers

The tables were placed in June 2002 and baseline data was collected for two months prior to table placement. Baseline numbers indicate that for 15 provider sites, 403 women with limitations (13.1% of the total who completed survey forms) were being served prior to the initiative. This percentage is comprised of women who report having a limitation but not needing assistance as well as those who report a limitation and need assistance with personal care or routine needs. Data will be collected through August 2003 to assess changes in percentage and numbers of women with limitations served following table placement, staff training, and community outreach efforts. Total numbers served to date has not yet been tabulated. Three additional months of data on women who use the tables will be collected beginning in September. We will conduct a telephone survey on a sample of the table users to assess satisfaction with care as well as information on how women learned about the accessible tables.

Duration

Training of providers at five regional trainings – two months. Fifteen months of anonymous data collection (two months of baseline data prior to table placement plus thirteen months of anonymous data collection following table placement). Plans are to collect identifiable data on women who use the table from September through November 2004. Actual conduct of the initiative – 20 months.

Collaborators

NYSDOH Cancer Services Program staff, Advisory Group of Women with Disabilities, Northeast Disability ADA and IT Center, and Healthy Women Partnership Providers

Outcomes

Documentation of expected increase in number of women with disabilities served through this initiative awaits data analysis in October 2003. A one-page, five-item questionnaire comprised of BRFSS questions was to be completed by all women. Identifiers will be added to the questionnaire for the last three months for the purpose of conducting a telephone survey on a random sample.

Barriers/Challenges/Facilitators

Barriers: Data collection for overburdened sites; multiple part-time staff with no clear role definition for responsibility for outreach; HWP expansion to colorectal and prostate screening at same time this initiative underway

Challenges: Getting women with disabilities to a new provider and providing a statewide pamphlet in a timely fashion for provider use

Facilitators: Co-location of Disability and Cancer in same division; good relationships with Cancer staff; and collaboration with women with disabilities

Influence on Public Health Policy

More than 200 health providers received disability training who might not otherwise have been exposed. We will publicize results at multiple meetings and through multiple media to document how shared strategies increase outreach to at-risk populations.

Discussion Summary
**Getting Women's Health Issues for Women with Disabilities
on the Public Health Agenda**

session facilitated by

Marcia Roth, M.P.H., Program Manager

Office on Disability and Health

Division of Public Health

North Carolina Department of Health and Human Services

JoAnn Thierry, M.S., M.S.W.

Behavioral Scientist

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Informing health care providers, including mammography clinics, about the health care needs of women with disabilities
 - Developing an action plan for getting women's health issues for women with disabilities on the public agenda with the information available
 - Creating a plan for broad systemic change to make women's health issues for women with disabilities a standard part of the health care system
 - Collecting data on the status and health service utilization of women with disabilities, sufficient to be able to document health disparities between women with and without disabilities and promote the need for initiatives to reduce the gaps
 - Maintaining a high level of training among health care staff working with female patients who have disabilities despite high staff turnover
 - Providing information to policymakers about the importance of mammograms and regular reproductive care for women with disabilities
 - Finding ways to get disability included in current women's health activities provided by private practitioners as well as governmental agencies including the Department of Health
2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?*
 - Determined the health care needs of women with disabilities using surveys and focus groups.
 - Massachusetts conducted assessments of mammography facilities to determine accessibility.

- New York published a request for applications for sites seeking height-adjustable examination tables consisting of site wheelchair accessibility, rooms able to accommodate an accessible table, clinical and disability sensitivity training, outreach to women with disabilities, and data collection.
 - Massachusetts and other states provided information and education on how to provide mammograms to women with disabilities, including those in wheelchairs, the importance of complete exams, and disability sensitivity to mammography facility employees.
 - Used CDC funding for accessible exam tables.
 - North Carolina provided training to nurse practitioners, physicians assistants, and technicians about breast and cervical cancer screening for women with disabilities through local universities with hopes that this will be integrated into their curriculum.
 - Workshops provided health promotion focusing on anxiety reduction and self-advocacy to women with disabilities
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Expand the reach of ADA.
 - Present information to policymakers that the requirements of women with disabilities should be considered to be reasonable accommodations, rather than extraordinary and avoidable demands.
 - Inform the community through media outlets and others about how to serve women with disabilities.
 - Present data about successful changes in the provision of health care to women with disabilities.
 - Include training for mammogram technicians in their education, continuing education, and licensing.
 - Create demand for accessible women's health care providers by getting the word out with specific types of messages.
 - Provide training to policymakers on Section 504 and ADA.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*
- States may benefit from sharing knowledge in the following areas:
- Collaboration with statewide coalitions
 - Collaboration with cancer prevention organizations, health care professionals, hospitals, and program sponsors
 - Collaboration with state and federal Offices of Women's Health

Getting Women's Health Issues for Women with Disabilities on the Public Agenda

- Sharing materials about breast cancer screening for women with disabilities developed by New York, North Carolina, and others
- Creation of a sentinel system to keep this message going at the national and state level

New Mexico Brief
**The New Mexico Workgroup on Emergency Preparedness
for People with Disabilities, Seniors, People with a Chronic Mental Illness,
Chronic Substance Abusers, Children with Special Health Care Needs,
and Substance Abusers**

Susan Gray, Acting Director
New Mexico Department of Health Office of Disability and Health
Anthony Cahill, Ph.D., Senior Research Scientist and Head
Center for Development and Disability, University of New Mexico

What We're Doing

We're:

- Conducting a statewide assessment to find out about the needs of these groups in the event of a large-scale public health emergency from any source. Besides gathering information on the needs of these groups, the assessment will also help us discover gaps – things we don't know about the needs of these groups, but need to find out.
- Producing "tip sheets" for first responders and other emergency preparedness personnel to help them understand the needs of these groups. These tip sheets will give people responding to an emergency useful information they can use when interacting with these groups of individuals.
- Developing a training course for first responders and other emergency preparedness personnel on interacting with these groups.
- Working with agencies drawing up plans for Public Health Service Sites in the state to ensure that they meet the needs of people with disabilities relative to accommodations, etc.

Who We Are

Membership in the workgroup includes representatives of the New Mexico Department of Health, other state agencies, the Center for Development and Disability at the University of New Mexico and the private sector. This workgroup is one of several within the Department's Public Health Emergency Response and Preparedness Program. Funding for this effort is provided by the Centers for Disease Control and Prevention (CDC) and the Health Systems and Resources Administration (HRSA).

Vermont Brief
**Including the Needs and Priorities of People with Disabilities in State-Level
Emergency Preparedness Initiative**

Deborah Lisi-Baker, Executive Director
Vermont Center for Independent Living

The terrorist attack on 9/11/01 has heightened citizen and government concerns about the capacity of state and local emergency management programs to respond quickly and efficiently during a crisis. Individuals with disabilities and seniors are particularly vulnerable during an emergency. When emergency services and public information campaigns are not designed to be accessible to individuals with physical, sensory, cognitive, and psychiatric disabilities, they will not have equal access to the emergency services local and state governments offer other citizens. For example, many of the public awareness alerts during the September 11th crisis were not accessible to blind or deaf individuals.

In Vermont, the Vermont Center for Independent Living (VCIL) suggested a formal partnership between the State of Vermont, disability and deaf advocacy groups, local municipal offices and planning commissions, and nonprofit and community groups. Vermont Yankee needed to develop a plan for insuring emergency management services to individuals within a 10-mile radius of the power plant. Statewide partners agreed to start planning in this area of the state and develop a model for local initiatives that could later be replicated in other areas of Vermont.

VCIL's outreach coordinator for Southeast Vermont helped convene a local oversight committee in Brattleboro to coordinate community outreach and the development of a viable plan. Activities to date include: distribution of tone alert radios, medical IDs, and other emergency alert information and several presentations at senior and disability programs and at open meetings on emergency planning, transit coordination, and other related issues. Federal Emergency Management Agency (FEMA) funds covered the cost of VCIL emergency management staff attending a four-day training institute at the National Emergency Training Center. In addition to local media coverage, VCIL disseminated articles, fact sheets, and updates on these activities and on best practices in emergency preparation for individuals with disabilities in their homes, communities, and worksites through VCIL's website and *The Independent*, the statewide paper for seniors and individuals with disabilities.

The state office of Emergency Management recently contracted with the Red Cross to coordinate future activities and the Vermont Retired Senior Volunteer Program just launched a statewide "Preparing for the Unexpected" project funded by the Corporation for National and Community Service. VCIL is working with the state, RSVP, and the Red Cross to plan continued work on accessible outreach and service planning in Vermont communities. It has been difficult to focus the needed attention on local and statewide emergency planning activities given the fiscal uncertainty in other areas and dealing with the effect of long-term under-funding of other related services, such as public transportation, on effective and accessible emergency management. However we believe that the partnership model Vermont is using has significant benefits for both local and statewide planning and management of accessible and inclusive emergency management services.

Montana Brief
Montana's Triage System for In-Home Consumers

Joyce De Cunzo, Bureau Chief
Montana Department of Health and Human Services

Montana is the fourth largest state in the nation and meets the definition of "frontier," with fewer than six persons per square mile. Nearly one-third of the state's population lives in three cities separated by great distances. This one geographic factor makes serving individuals a huge challenge in the best of times. In times of emergency, the challenge is increased ten-fold.

The approaching end of the year 1999 suddenly made all of us acutely aware of the need to help people prepare for potential disaster. We established a comprehensive, but simple, statewide plan for our in-home services consumers. Every home care services agency (Home Health, Personal Assistance, HCBS waiver and PDN providers) was asked to triage their consumers. The levels included:

1. Consumers who would be in grave danger without services and have no one else to help them;
2. Consumers who would be in danger but for whom an alternate plan with family or others could be developed; and
3. Consumers who, with planning, would be able to be without services for several days.

About 75% of the provider agencies responded. Agency plans and lists of individuals, sorted by need, were sent to the Department, and many agencies also contacted their local disaster and emergency services personnel to alert them to the needs of the individuals who were at the grave danger level. Our state Division has a written emergency plan for staffing, and the information from all the agencies was collated for the Division team's use. While there was no Y2K emergency, this system worked beautifully in the summer of 2000 when Montana was described nationally as "on fire." Provider agencies were able to determine exactly where to put their efforts for individuals living in their own homes, who had to be evacuated or needed special help because of the air quality.

There were some unintended results of developing this plan. Most of our provider agencies had not previously had direct contact with their local disaster and emergency services personnel, so it was a good connection for them to make. In some counties, the DES agencies were very helpful, took the information, and assured the provider agencies that they would take special precautions with these individuals. In other counties, provider agencies were told that they should deal with the consumers themselves because the local DES personnel either did not have the expertise or did not have the desire to deal with individual situations. Individuals with very specific medical or mobility needs were most likely to require the help of provider agency personnel – consumers on vents, those with quadriplegia held the most concerns for DES personnel. Finally, many of our agencies did not have a planned, agreed upon agency emergency plan for their consumers and this exercise started them on that path.

While most DES plans deal with whole communities, this plan addresses specific individuals. There's a lot of work to do to make this triage system part of the community planning efforts but it was very successful when it was used, and we will continue to try to refine the process so it's part of each community's planning efforts.

**Iowa Brief
Preparedness**

Roger Chapman, M.S.W., Bureau Chief
Iowa Department of Public Health

Division of Health Promotion, Prevention, and Addictive Behaviors

Iowa Department of Public Health

Description:

Create educational presentations and conduct them at eight locations around Iowa.

Determine Content

- Focus groups
- Literature search
 - FEMA
 - Red Cross
 - Other

Content

- Natural disaster (fire, flood, tornado)
- Man-made problems (car, airplane crashes, toxic dump sites)
- Latest threats (nuclear, biologic, chemical)
- Develop a personal preparedness plan

Target Audience (about 100):

Long-term care staff/residents
Congregate meal site directors
Low income housing residents (variety of disability)
TBI survivors and families

Duration of Initiative:

Seven months to convene focus groups, do literature search,
Write lesson plan/participant guide

Collaborators:

Department of Elder Affairs
Area Agencies on Aging
Center for Disaster Operations

Voc Rehab
Centers for Independent Living
Emergency Management and Response
(Public Health) Division

Outcome Measures:

One month post presentation assessment of preparedness activity

Barriers:

Although nuclear, biologic, and chemical threats are mentioned, presenter does not have in-depth knowledge of subject matter.

Positive Outcomes

Increased awareness of evacuation issues by facility administrators
Opportunity to provide TA for planning

Influence Public Health Policy

Commitment Center for Disaster Operations to contribute to planning

Opportunities for Collaboration

Emergency Management Division Department of Public Safety lead agency for preparedness in Iowa

Department of Public Health responsible for:

- | | |
|---------------------|------------------------|
| 1) Public health | 3) Radiological health |
| 2) Medical services | 4) Mass fatalities |

CDC grant: Grantees must "describe activities to meet the needs of special populations"

Model Program

- County (LINN) voluntary registry system
- Allows emergency personnel to determine location and needs of Iowans with disabilities

Contact Information: Roger Chapman (515) 281-6646

Discussion Summary
**Including the Needs and Priorities of People with Disabilities in
State-Level Emergency Preparedness Initiatives**

session facilitated by

Anthony Cahill, Ph.D., Senior Research Scientist and Head
Center for Development and Disability, University of New Mexico

Juliana K. Cyril, M.P.H., Ph.D., Health Scientist
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Building statewide capacity to respond to emergencies that includes people with disabilities
 - Disseminating information about an emergency to people with sensory disabilities
 - Planning for transportation and other services for persons with disabilities while protecting confidentiality
 - Engaging local emergency planners in the need to have specific plans for persons with disabilities

2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?*
 - Involve people with disabilities in the planning.
 - Use the Medicaid database to identify persons with special emergency planning needs or use a voluntary registration system to prepare first responders.
 - Educate all the agencies and providers associated with emergency services.
 - Educate consumers about emergency preparedness.
 - Conduct statewide assessment of needs and existing plans.
 - Develop tip sheets and training courses for providers.
 - Present information to audiences of people with disabilities across the states; include resources such as FEMA, personal safety planning, and plans to evacuate.
 - In practice drills for emergency planning, involve people with disabilities rather than people pretending to have disabilities.

3. *How can you bring this topic to the attention of policy makers in states to ensure a place for this topic on your state's public health agenda?*

- Smaller states work from individual plans to community plans, to statewide planning.
- In larger states, persons with disabilities must be involved in statewide task forces while also working with local officials.

4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*

- CDC and HRSA have provided funding for training health care professionals and emergency personnel.
- Multiple agencies within states, such as Elder Affairs, Vocational Rehabilitation, Centers for Independent Living, Disaster or Emergency Centers, and Health Planning may be points of contact in states.
- Voluntary agencies involved in some states are Red Cross, Retired Senior programs, AARP, and disability organizations.

Vermont Brief
**Information for Decision Making: The Role of the BRFSS
and Other Data to Influence Public Policy**

David Baker, Program Manager
Vermont Disability and Health Promotion Project
Vermont Department of Aging and Disabilities

Vermont Disability and Health Promotion Project

- (1) **Description of the initiative/intervention/strategy:** Behavioral Risk Factor Surveillance System (BRFSS) survey
- (2) **Description of the audience or persons involved in the initiative/strategy:** All adults age 18 and over are potential participants in the survey; children and youth under age 18 are excluded. Since 2001, younger and older adults with disabilities (self-described) have been identified as such in the survey.
- (3) **How many people participated?** In 2003, there were 4,200 participants in the BRFSS survey in Vermont. In 2004, there will be 6,700 participants.
- (4) **What was the duration of the initiative?** The BRFSS survey is conducted annually; surveys are administered periodically throughout each calendar year.
- (5) **With whom did you collaborate to carry out the initiative?** The Vermont Department of Health (VDH) takes the lead in developing the final BRFSS survey questionnaire, in collaboration with the Departments of Aging and Disabilities and Developmental and Mental Health Services. VDH contracts with an organization to administer the survey; VDH staff do the actual analyses of the BRFSS survey data.
- (6) **Describe the outcome and what measures you used to determine the outcome:** The annual BRFSS survey consists of core questions, several modules, and several state added sections (e.g., questions on healthy aging, activity limitations/disability, smoking, depression, diagnosed conditions, and social support).
- (7) **List barriers/challenges/facilitators or strengths and limitations:**

Strengths: Statewide survey of adults with and without disabilities (since 2001)
 Tracking statewide trends over time
 Identifying health disparities between people with and without disabilities

Limitations: The BRFSS survey is administered by telephone and therefore excludes those without telephones, many people with developmental disabilities, those with other cognitive impairments, deaf people, and many refugees. Relies on self-reporting by survey participants.
 Data are available only on a state aggregate level or for larger counties.

- (8) **How have you used the outcome to influence public health policy?** Results reported in the "Successful Aging and Independent Living (SAIL) Report," "Healthy Vermonters 2010," etc. stress the importance of prevention as it relates to elders and younger individuals with disabilities. BRFSS survey results are used to monitor progress of several grant projects within the Vermont Agency of Human Services.

Illinois Brief
Information for Decision Making: Illinois

Bruce Steiner, Chief, Surveillance Section
Illinois Department of Public Health

1. Description: Since 1984, the Illinois Behavioral Risk Factor Surveillance System (BRFSS) has established itself as a unique database of behaviors and conditions related to the leading causes of death, injury, and disability among Illinois adults. The opportunity exists to prevent health problems by monitoring key lifestyle or behavioral risk factors including alcohol and tobacco use, unhealthy diet, and physical inactivity. The work of the BRFSS correlates with the mission to promote health through the prevention and control of disease by documenting the need for health programs, identifying population groups at greatest risk, evaluating past interventions, and guiding health policy decision making. Results of data analyses are widely distributed to community, state and national health professionals, and to the public through the web, printed reports, shared data sets, conference presentations, and personal communications. BRFSS partners include programs within the Department, other state agencies, universities, and community organizations.

The strategy in Illinois is to establish baseline data from the BRFSS to enable the University of Illinois at Chicago, Department of Disability and Human Development's National Center for Physical Activity and Disability (NCPAD). Currently, no Illinois Department of Public Health program has expressed a need for data on the number or severity of disabilities within the state's population. During 2003, the BRFSS is collecting limited information on physical, mental, or emotional impairment or necessity on special equipment. There is need for comprehensive state information if the public health community is to address disability issues facing many residents. Effective alliances with partners must be formed if the BRFSS program is to be an integral part in the "Advancing Health Promotion for People with Disabilities on the Public Health Agenda."

2. Audience: The two programs involved in the Illinois strategy are the NCPAD and the Illinois Department of Public Health's (IDPH) Behavioral Risk Factor Surveillance System. Other Illinois government units to be potentially involved include: the Arthritis Program, Division of Chronic Disease, Division of Health Policy, Office of Women's Health, and the Department of Human Services.

3. Target population: The Illinois BRFSS employs a split sample with a different form of the questionnaire used for half the sample. The sample size for each Illinois BRFSS questionnaire is 2,500 adult residents. The significance of the BRFSS is that it provides generalizable data for the entire adult population.

4. Duration: The collaboration between the BRFSS and NCPAD began spring 2003. The expectation is that this will be an ongoing collaboration.

5. Collaborators: At this time, the collaboration involves Department of Disability and Human Development at University of Illinois at Chicago and the BRFSS program. There is the expectation that as baseline data become available, more partners will become involved.

6. Outcomes: Expected outcome measures should exist at several levels. The first would be establishment of baseline data on disabilities among the Illinois population. The second measure would be an influx of collaborators advocating and planning for persons with disabilities.

7. Barriers: Fragmentation and unawareness of interested parties is the major barrier to this initiative.

8. How have you used the outcome to influence public health policy? At present, policy has not been influenced by BRFSS disability data.

New York Brief
**The New York Expanded Behavioral Risk Factor Surveillance System
(EBRFSS)**

Larry Steele, Ph.D., Research Scientist^{1,2}, Tom Melnik, DrPH,² and Colleen Baker²
¹Disability and Health Program, ²Chronic Disease and Risk Factor Surveillance Unit
New York State Department of Health (NYSDOH)

Description: The EBRFSS, modeled after the CDC's BRFSS, is a local-level telephone surveillance survey of the adult population in 38 localities across New York State.

Target population: The EBRFSS targeted the noninstitutionalized, civilian adult population of the state. The methodology apportioned an equal share of the sample to each of the defined localities. The estimates derived from this sampling methodology will be representative of each locality and the State in the aggregate with respect to the age, sex, and race (white vs. nonwhite) distribution in the respective geographic areas.

Survey size: The target sample size was 24,000 respondents, an average of approximately 630 per locality.

Duration: Data were collected from July 2002 through August 2003.

Collaborators: The counties became partners in the construction of the questionnaires, including selection of priority items for the core section and selection of optional modules. The provision of local data remains a high priority with New York State Association of County Health Officials (NYSACHO) and its Local Health Department (LHD) members. The NYSDOH Disability and Health Program advocated for the inclusion of two disability core items and the offering of an optional 11-item module.

Outcome: The EBRFSS will provide local-level baseline information on a variety of critical health indicators, including tobacco use, health care access, chronic disease prevalence and control, cancer screening, diet, physical activity, disability and quality of life, and weight status.

Strengths, limitations, and challenges: The strengths of the EBRFSS project are the provision of valid and reliable local-area data, and the involvement of the local departments in the design of the core and the selection of optional modules. The limitations are those traditionally associated with the BRFSS, including restriction of the sampling to the adult, noninstitutionalized population, limitations of self-reported data, and telephone non-coverage. A challenge is ongoing surveillance at the local level, as there is currently no solid plan for continuation, and resources have not been identified.

Influence on public health policy: The EBRFSS promises to provide baseline information that local departments will find valuable for health planning purposes. If funding permits further cycles of the project, the EBRFSS will enable LHDs to monitor trends in health behaviors and utilization of preventive services over time, to evaluate the effectiveness of interventions and utilization of resources, and to assess emerging health issues of importance to their communities.

**North Carolina Brief
North Carolina Office on Disability
Disability and Health Data – BRFSS, Core Indicators, YRBS**

Marcia Roth, M.P.H., Program Manager
Office on Disability and Health
Division of Public Health
North Carolina Department of Health and Human Services

Description of Initiative: The report "*Health and Disability in NC 2003*," in its final stage of development, presents highlights of what is currently known about the health status, health risks, and health related experiences of people with disabilities in North Carolina. It is based on a compilation of data from several important population-based surveys, the 2000 Census, the NC Behavioral Risk Factor Surveillance Survey (BRFSS), and the NC Youth Risk Behavior Survey (YRBS), as well as administrative data from the NC Core Indicators Project (NC CIP). These data sources can be used to identify population health disparities and serve as the basis for targeting public health interventions.

Target Audience: The NC BRFSS currently samples over 6,000 individuals annually and has screened for disability status since 1998. Despite different approaches, prevalence estimates used by the US Census and the NC BRFSS are comparable 25.0% for adults 21 and older in the 2000 Census and 25.3% for adults 18 and older for the NC BRFSS. The NC YRBS included three disability screening questions in the Middle School and High School Surveys in 2001 with a 23% prevalence of disability among high school students and 22% of middle school students in regular classroom settings. The Core Indicators Project has collected health indicator data from 946 adults with developmental disabilities living in the community in the two years of sampling (2000-2001, 2001-2002). Adults living in state operated mental retardation centers were excluded from these analyses to correspond to BRFSS methodology.

Collaborators: The State Center for Health Statistics, the UNC Center for Development and Learning (UCE), NC Council on Developmental Disabilities, DHHS Developmental Disabilities Section, Department of Public Instruction, DPH School Health Program, and School Health Infrastructure Project.

Outcomes and Measures: The report contains six main sections, presenting comparative data on adults and youth with and without disability in narrative and graphic format:

- | | |
|---------------------------|--------------------------------|
| 1) Population Description | 4) Cancer Screening |
| 2) Health Risks | 5) Oral Health |
| 3) General Health | 6) Mental and Emotional Health |

Each section concludes with a discussion of major findings and implications for service delivery and program and policy development.

Challenges: Historically, people with disabilities have not been recognized as a distinct population and there has been limited data on the health status and health-related needs experienced. As data serves as the foundation for public health action, people with disabilities

have been largely “invisible” to the public health community. In addition, differing definitions of disability (driven by government agencies to determine eligibility for benefits and services) has resulted in disability being measured in different ways across surveys and censuses. A definition of disability based on limitations in activity results in a broad definition of disability, with some disabilities being present from birth and others coming later in life as a consequence of injury, chronic disease, or aging. However, this definition is not fully embraced by the public health community. Finally, methodological issues of collecting data from the individual with a disability (without a proxy) present complex challenges, especially to capture information on individuals in a variety of community and congregate care settings.

Policy: We do not have a complete understanding of why disability is associated with health disparities but there is evidence that low socioeconomic status, limited access to preventive care and health promotion, and attitudinal, communication, and environmental barriers are among the underlying causes. This report, by capturing existing health disparities, can contribute to the effective allocation of resources for health improvement programs for North Carolinians, including the population of persons with disabilities. It will also be used to influence practices in disability and health provider agencies and to inform consumer-oriented public health efforts that address health risks and health behaviors.

California Brief
Information on Decision Making:
The Role of the BRFSS and Other Data to Influence Public Policy:
Lessons Learned from California

Galatea King, M.P.H., Program Epidemiologist
Office on Disability and Health
California Department of Health

1. **Survey:** California Women's Health Survey (CA WHS) 2003
2. **Target population:** California women ages 18 and older
3. **Sample size:** approx. 4,000
4. **Data collection:** The Survey Research Group of the Public Health Institute collected this data on a monthly basis, from January 2003 through December 2003.
5. **Collaborators:** The CA WHS is a collaborative effort of the California Department of Health Services, Mental Health, Alcohol and Drug Program, Social Services, California Medical Review, Inc., and the Public Health Institute.
6. **Methods :** CAWHS is an annual, population-based, computer-assisted telephone survey administered randomly to selected adult women throughout California. The survey consists of 200 questions about health-related attitudes and behaviors and the access of health care services. The Office on Disability and Health (ODH) held a question development meeting in July 2002, which included state agency (Department of Rehabilitation, Office of Women's Health) representatives, academic institution researchers, private researchers, and disability advocates from around the state, who later became members of the Advisory Committee. This meeting resulted in the development of four questions, which ODH submitted for inclusion in the CA WHS 2003. The questions included two disability screener questions and two questions about barriers women with disabilities face when accessing health care. After ODH staff presented the questions to the CA WHS research group, the research group recommended significant changes. The advocates did not support those proposed changes. After much further discussion and cognitive testing, the advocates agreed to allow the new questions with the condition that the ODH staff would work towards question development in the future.
7. **Strengths/Limitations :** The California Survey Research Group administers the CA WHS via telephone. This survey method excludes the institutionalized population, households without phones, people who are hearing impaired, and people with severe disabilities that prevent them from answering the phone. The screener question, similar to that used in the BRFSS, does not identify people with developmental disabilities. The strength of the CA WHS is that the sample size is large and allows for the diversity of California. In addition, this is the first time this information (barriers faced by women with disabilities in accessing health care) will be available on a statewide level in California. The interest shown by other programs ensures the screener questions will be a permanent part of the core CA WHS questions, which translates into the collection of this information on an annual basis.

8. **Influence on public health policy:** The California Women's Health Survey 2003 data will not be available for analysis until the spring of 2004. Upon analysis, the data will be used to show what barriers women with disabilities face in accessing health care. These findings will provide policymakers with the data necessary to act or create policies to increase access to primary care and to reduce barriers for women with disabilities. In addition, the permanent status of the questions in the CA WHS will allow for a tracking mechanism to determine if the policies are effective in years to come.

Washington Brief
Survey Information on Children with Disabilities, Washington State

Susan Kinne, Ph.D., Research Scientist
University of Washington
Center for Disability Policy and Research

Surveys and brief description:

- **BRFS Disability Supplement (BRFS-D) 2001 and 2003:** A stand-alone survey supplementing the WA State BRFS. The supplement included the BRFS QoL module, state-added questions on disability, a Children with Special Health Care Needs module, and questions on access to dental care and health care (2001); health insurance and child care (2003).
- **WA State Healthy Youth Survey 2002 (HYS,** the state's Youth Risk Behavior Survey, which included questions from other surveys). This used a Youth Quality of Life disability screener developed for adolescents to identify youth with disabilities.

Target Population/ Breadth of the Initiative: The objective was to estimate the population prevalence of children with special health care needs and adolescents with disabilities, and to collect data on areas of policy interest to the Department of Health (DOH).

Sample Size/ Duration of the Initiative

- **BRFS-D 2001:** (n=2,117 households) from 539 HH with one or more kids and a respondent knowledgeable about child health including 144 kids with SHCN. The 2003 data are now being collected.
- **HYS:** (n=45,126 6th through 12th grade students in 171 schools).

Data Collection/ Methods

- **BRFS-D:** standard BRFS RDD to select household respondent, and questions about (1) number of children under 18; (2) whether respondent was knowledgeable about children's health; roster of all children and use of screener questions for each child to identify all with SHCN; random selection of a child with SCHN if more than one child; random selection of a child without SHCN if no child had a disability, as a comparison group.
- **HYS:** The survey was administered in October 2002 to students in grades 6, 8, 10 and 12 in public schools statewide. Within participating schools, all students in the surveyed grades were surveyed. Response rate was 69% of the schools and 54% of the adolescents in the schools.

Collaborators

- **BRFS-D:** (2001, 2003) Assessment Coordinator, Washington DOH Children with Special Health Care Needs Program; (2001) Coordinator of Oral Health Program in Division of Maternal and Child Health, Washington DOH.
- **HYS:** DOH State Epidemiologist for Non-Infectious Conditions

Strengths/Limitations

- **BRFS-D:** methodologically sound way to estimate population prevalence of CSHCN. Limitations: (1) complex sampling design complicates analysis, (2) decision to restrict respondents to those who were knowledgeable about children's health improved validity, but meant that for a number of children, neither disability status nor other characteristics could be measured.
- **HYS:** The screener to identify youth with disabilities allowed comparison between youth with and without disabilities on risk and resilience factors for health risk behaviors among adolescents and Quality of Life. Limitations: The survey did not include adolescents who were in special education classes during the test administration.

Influence on Public Policy:

From both surveys, data on disability status of children are now available to DOH policymakers. Some of the data are being used to assess progress toward HP2010 goals for children's health.

Iowa Brief
Information for Decision Making

Roger Chapman, M.S.W., Bureau Chief
Division of Health Promotion, Prevention, and Addictive Behaviors
Iowa Department of Public Health

Description

A prospective cohort that initially identified a population-based sample of Iowa residents with mobility limitations and surveyed these individuals regarding secondary conditions occurrence and risk factors.

Access magnitude	Identify risk/protective factors
Identify secondary conditions	Evaluate health promotion intervention

Who was Included

Medicare	Iowa Birth Defects Registry
Medicaid	Iowa Brain/Spinal Cord Injury Registry

Sample Size

Number mobility screeners sent	10,141
Number responding	5,275 (52%)
(67% met definition of mobility impairment)	
Number of long surveys sent	3,542
Number of completed long surveys	2,611 (74%)

Data Collection Period

Approximately three years

Collaborators

Center for Disability and Development, University of Iowa
Department of Epidemiology, University of Iowa
Blue Ribbon Panel

Survey Questions

Mobility Screener

Use of "*special equipment*"

Personal Assistance

Long Survey (25 pages)

Current state of health

Physical

Psychological

Influence of health problems on social activities

Current living arrangement

Ability to "*go places*"

Conditions related to disability

Doctors diagnosed conditions

Health practices

Routine medical test

Problems with activities to stay healthy

Relating to physicians

Medical emergencies

Health care services

Support system

Use of alcohol

Barriers

Construction of new survey instrument
Need for physician consent to release birth defects registry names
Delays obtaining data

Influence on Programming

Findings:

- High incidence of arthritis
- Significant percent of people reported high blood pressure, stiff/sore joints, and inability to lose weight
- High incidence of fractures (falls in older Iowans)
- Older Iowans reporting medication side effects
- High incidence of depression (over 40%)
- High incidence reporting pain, weight-management problems
- Low percentage involved in exercise programs

Recommendations:

- Pursue the development of a state agenda for prevention/management of arthritis
- Expand the proposed pharmaceutical case management study for elderly Medicaid recipients
- Implement the University of Montana's *Living Well with a Disability* curriculum in Iowa

South Carolina Brief
Information for Decision Making: The Role of BRFSS and
Other Data to Influence Public Policy
South Carolina's Approach to the Use of Administrative Data

Virginie Daguise, Ph.D., Epidemiologist
Family and Preventive Medicine
University of South Carolina School of Medicine

Description of the Initiative:

To track the employment of individuals with cognitive disabilities in order to increase employment rates for this population.

Population of Interest

All 38 county disability providers (called boards) in South Carolina were asked to provide information on a simple chart for all individuals receiving at least one service from DDSN in a given year.

Sample Size/ Duration of the Initiative

YEAR	Number of Individuals Employed
1996	837
1997	1159
1998	1263
1999	1481
2000	1681
2001	1630
2002	1386

Collaborators

- Department of Disability and Special Needs (DDSN)
- University of South Carolina Center for Disability Resources

Survey Questions

- Name
- Social Security number
- Name of business
- Average wages per week
- Average weekly hours
- Job description
- Type of employment (competitive, enclave, mobile work crew, or workshop)
- Average weekly hours employed
- Reasons for job loss
- Barriers

In the past, we had asked only for those individuals making more than \$50 per week. Often records are not computerized by boards, leading to underestimating employment rates.

Inclusion Criteria

- 19-64 years
- IQs between 20 and 80
- Non-institutionalized

Influence on Public Health Policy

Feedback about each board and how they relate to others, to their regions and to the state is provided yearly. We also report on industries and businesses that provide employment for the most individuals per board and per region in South Carolina. An important strength of this research is that the data is requested by the director of DDSN, so response is timely. This year, a program coordinator was hired to provide consultation with the boards to help with increasing employment in boards that ranked low and to increase competitive employment for individuals in boards that had fewer people employed in competitive jobs.

Louisiana Brief
**Information for Decision Making: The Role of BRFSS
and Other Data to Influence Public Policy**

Sharon A. Holleran, Ph.D., Project Director
Louisiana Health and Disability Project
Louisiana State University Health Science Center

1. & 2. Description of the Initiative and Persons Involved. *An Inventory of Data Systems Relevant to Louisiana Children with Disabilities (CWD) or Special Health Care Needs (CSHCN)* was conducted by our Surveillance Committee, which is comprised of 20 members of the Advisory Committee or their designees with an interest in data issues (representing consumers, advocacy groups, state agencies serving CWD, public health professionals, and academic institutions). State and national data systems with the capacity to provide health-related information about CWD were reviewed. Available information was summarized and recommendations were made for additional surveillance activities to address information gaps and data quality concerns with the goal of facilitating data-based state planning on the part of the Advisory Committee.

3. Breadth of the Initiative. Thirty potential data systems were selected for review. Because few data sources directly address the health and HP2010, Ch. 6 status of Louisiana's CWD, potential datasets were considered broadly (e.g., relevant surveys that do not currently identify disability status were reviewed). Types of data systems inventoried included agency information systems (e.g., Louisiana Medicaid Management Information System), formal surveillance systems (e.g., Pediatric Nutrition Surveillance System), and periodic point-in-time surveys (e.g., National Survey of CSHCN).

4. Duration of the Initiative. Although originally conceived as a one-time effort to support initial project planning, the inventory will be updated periodically to promote awareness and utilization of key data systems and information.

5. & 6. Methods/Measures and Collaboration. A survey was developed based on the data collection instrument employed by the National Center for Injury Prevention and Control to produce an inventory of federal data systems for injury surveillance, research, and prevention (with their permission and guidance in terms of lessons learned). Key contacts for each data system were identified and personal appeals were made to gain approval for participation. Background research was conducted before surveys were administered during personal or telephone interviews with primary database managers. Information collected about data systems included: type; purposes; legal authority; inclusion and exclusion criteria; data sources and types; capacity for data linkage; geographic level of data collection and output; data collection procedures; data management and security; data analysis; data release; strengths and limitations; plans for modification; and disability-related features. Data system overviews, summary tables, and findings/recommendations were produced. Personnel from agencies representing 28 of 30 potential data systems collaborated with the Surveillance Committee to complete this project. In addition to participating in the survey, agency personnel reviewed and revised data system descriptions and summary table information.

7. Barriers and Facilitators

- Agencies responsible for two data systems declined to participate (unwillingness to devote time and personnel).
- The process of working through the chain of command to gain permission and schedule interviews with appropriate personnel was lengthy and arduous, as was the review process.
- Identification of gatekeepers and key contacts to make personal appeals was critical to gaining access to agencies typically disinclined to share information.
- The interview process served as an opportunity to raise awareness of health and disability issues generally, as well as the need to collect standardized information on disability status in existing data systems in particular. (By the end of the survey, several database managers reported failure to capture disability status information as a weakness of their data system.) Thus, the groundwork has been laid to include disability screener items in relevant surveys per HP2010, Ch. 6, Objective 6-1.
- Based on information learned during the inventory process, we are pursuing including CSHCN screener items on the 2004 Louisiana BRFSS administration (an increase in sample size of 1000 surveys per nine state regions is planned to provide regional estimates).

8. Influence on Public Health Policy. Inventory findings were designed to undergird the state plan for health promotion and prevention of secondary conditions among CWD. The Advisory Committee is presently developing the state plan, in which policy initiatives will be specified.

- Concurrent with the inventory process, Louisiana transitioned the lead agency for the Part C program from the Department of Education to the Office of Public Health (OPH). A host of recommendations were provided to OPH to influence development of the new Part C data system (e.g., incorporating outcome- vs. process-focused data elements).
- The Louisiana Children's Cabinet (which coordinates children's policy across state agencies and makes recommendations to the Governor on funding priorities for new and expanded programs for children and youth) has been an active supporter of the project and is planned to serve as the portal for information and technical assistance related to the inventory and associated data book.
- The Advisory Committee is considering pursuing integration of key child health information systems to improve monitoring of child health outcomes, including potential disparities among children with and without disabilities. Based on inventory findings, a legislative mandate will be sought to facilitate the success of the final strategy.

Discussion Summary
**Information for Decision Making: The Role of BRFSS
and Other Data to Influence Public Policy**

session facilitated by

Vincent A. Campbell, Ph.D., Associate Director for Science
Division of Human Development and Disabilities
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

Suzanne McDermott, Ph.D., Project Director
University South Carolina School of Medicine

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Developing baseline data on disability that is general enough to be broadly used while specific enough to detect changes over time resulting from program implementation
 - Attracting the interest of consumers and policymakers in the data collection planning process
 - Developing measurable concepts of "disability" and "quality of life"
 - Encouraging the use of functional and social models of disability
 - Obtaining data from subjects who are institutionalized, not adults, do not have telephones, or are unable to respond due to ability-limiting conditions
 - Raising response rates
 - Obtaining local data
2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?*
 - Survey for adolescents was created to screen for disability and measure quality of life, predicting risky behaviors.
 - Survey including specific conditions and health service utilization has been used to pursue development of state agenda for prevention/management of arthritis, expand proposed pharmaceutical case management study for elderly Medicaid recipients, and implement *Living Well with a Disability*.
 - Using Medicaid as sampling frame allows results to pertain directly to Medicaid policy.
 - Advisory panel and staff may disagree; panel must be walked through full political and analytical process.

- Interviewing state government staff and officials by appointment to obtain better response than self-directed survey.
 - All data sources need to be identified to locate useful data.
 - Use of administrative data to support and manage employment initiative.
 - Localities need to be combined into large enough groups to support local level survey; localities need to be involved in formation of groups.
 - State BRFSS coordinators needs to be included as collaborators or advisory panel members.
 - Combining Census, BRFSS, Youth Risk Behavior Survey and administrative data can identify population health disparities.
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Present the data with the program it supports, at the state or local level.
 - Present data specific to an agency's interests, such as data on smoking among people with disabilities to the public health department planning smoking cessation programs in order to ensure inclusion of PwDs in the initiatives.
 - In some states Medicaid is completely separate from the Department of Health, and therefore difficult to reach with BRFSS data.
 - Data need to pertain to issue of interest to officials.
 - When desired data do not exist, substitute committed voices of advocacy.
 - Data are useful in advocating for public health initiatives, but health departments are limited in their ability to change society and the environment.
4. *What opportunities are available for collaboration on this area across states to increase the influence of this initiative and work towards building a strong state network?*
- States may benefit from sharing knowledge in the following areas:
- Successful processes for involving researchers, consumers, and policymakers in the development of additional questions for BRFSS or entirely new surveys
 - Survey instruments or questions that have been validated
 - Presentation of data to policymakers
 - Program planning – comparing baseline data across states when considering importing programs from other states
 - Combining data sets across states

Massachusetts Brief
Violence Prevention Programs for Persons with Disabilities
Maureen Foley, M.P.H., R.N., Director of Office on Health and Disability
Division for Special Health Needs
Massachusetts Department of Public Health

**Massachusetts Department of Public Health Sexual Assault Prevention
and Survivor Services (SAPSS)**

Beyond the baseline of ADA compliance, the Office on Health and Disability (OHD) works with programs across the Department of Public Health to promote access. Prioritization of programs for OHD consultation is based on: a) evidence of unequal access to services they provide or fund; b) evidence of heightened need for their services among people with disabilities; or c) interest of program staff in promoting access for people with disabilities. These criteria led to collaboration among OHD, Women's Health, and the Violence Prevention Team.

SAPSS collaborates with a broad spectrum of stakeholders in the development and enhancement of programs to prevent sexual assault and domestic violence. A primary partner in this work is Jane Doe, Inc. (Jane Doe), which is The Massachusetts Coalition Against Sexual Assault and Domestic Violence, a nationally recognized leader in addressing domestic violence. SAPSS, OHD, and Jane Doe have collaborated on a series of initiatives to enhance services provided to all individuals who have experienced sexual assault or domestic violence. These collaborative efforts have included the development of educational and networking programs for domestic violence and sexual assault educators and disabilities rights' advocates and agencies; training manuals for Rape Crisis Centers' (RCC) counselors and volunteers; and protocols for the Massachusetts Sexual Assault Nurse Examiner (SANE) Program.

The curriculum for training rape crisis and domestic violence prevention educators on presentation skills entitled "Power of Prevention: Presentation Skills, Training and Resource Guide for Domestic Violence and Sexual Assault Educators" contains a section on improving accessibility of sexual assault and domestic violence prevention education programs to people with disabilities. Jane Doe's development of the curriculum: "Untold Stories, Unmet Needs: Understanding the Needs of Sexual Assault and Domestic Violence Survivors with Physical and Sensory Disabilities," which is used to train rape crisis and domestic violence counselors in working with survivors with disabilities, was sponsored by the CDC through OHD's grant. OHD staff also participated with SAPSS staff in the development of disabilities-related questions as part of an in-depth sexual assault follow-up survey to the MA BRFSS; the MA BRFSS found that 34% of women with disabilities vs. 18% of women without disabilities have ever experienced unwanted sexual contact. The MA SANE protocol was modified to address the needs of people with mobility impairments and approved in July 2003 by the SANE oversight committee, which includes the SAPSS and MA Disabled Persons Protection Commission directors.

In addition to the educational efforts described above, SAPSS and OHD have cooperated in the assessment of the accessibility of RCCs. During FY '01 and FY '02, OHD staff visited every rape crisis center DPH funds and provided TA regarding ADA compliance and access improvements. A test of the TTY system at each of these rape crisis centers was included in the review of accessibility. Since FY '04, SAPSS has conducted yearly site visits and tests of the TTY system at each rape crisis center. SAPSS staff then follows up with a report to the RCC requesting a corrective action plan if the facility did not meet the DPH's standards. SAPSS, in coordination with Jane Doe, Inc., continues to offer RCC facilities TA regarding ADA compliance, access, and cultural competence improvements.

For additional information, please feel free to contact Maureen Foley, Massachusetts Department of Public Health, Office on Health and Disability at (617) 624-5969 or e-mail: Maureen.Foley@state.ma.us or see www.state.ma.us/dph/fch/sapss for information about the DPH Sexual Assault Prevention and Survivor Services Program or www.janedoe.org for information about Jane Doe Inc: The Massachusetts Coalition Against Sexual Assault and Domestic Violence.

North Carolina Brief
NC Office on Disability and Health
Violence Intervention: *Access for All*

Pam Dickens, M.P.H., Women's Health Coordinator
North Carolina Office on Disability and Health
University of North Carolina – Chapel Hill

Description of Initiative: The NCODH was recently awarded a Governor's Crime Commission grant to implement *Access for All* during 2003-2005. The project responds to the needs and recommendations for improving domestic violence services for women with disabilities as identified in the NC Domestic Violence Programs Survey 2000. The survey was an outgrowth of the Violence Working Group of the UNC Injury Prevention Resource Center in which NCODH participates and provides BRFSS data on sexual assault. *Access for All* is designed to be an effective and practical community-based intervention for increasing victim access, identification, and referral to domestic violence and sexual assault services for women with disabilities.

Target Audience: The project will work in three NC counties to increase the accessibility of two shelters and four sexual assault/domestic violence agency offices. Limited grant funding will be available for each site to address accommodations through the purchase of adapted equipment and development of alternate formats.

Project Activities: A project coordinator and cross-disability team of four women will be involved in the following tasks:

- Review agency's environmental accessibility utilizing an accessibility checklist developed by NCODH to assess sites, develop summary reports and recommendations, and assist each agency to develop a plan of action.
- Review agency's information and communication channels, develop summary reports and recommendations, and assist each site to develop a plan of action.
- Increase domestic violence/sexual assault service provider/volunteer sensitivity and knowledge about disability through six hours of training on disability and violence. Utilizing materials from SafePlace in Austin, TX, and MA Coalition Against Sexual Assault, NCODH has developed a six-hour training curriculum - *Improving Access: Providing Disability-Friendly Sexual Assault and Domestic Violence Services*.
- Develop protocols for identifying and referring women with disabilities to victim services by establishing collaborative relationships between SA and DV agencies and community disability agencies.

Collaborators: NCODH will work with the Injury Prevention Research Center, the NC Task Force on Health and Women with Disabilities, four sexual assault/domestic violence agencies and two shelters in the targeted counties, The Arc of NC, and disability agencies within these communities. The project has also been endorsed by the Public Health Violence Alliance.

Outcomes and Measures: The Injury Prevention Research Center will serve as external evaluator for this project. The team has developed a logic model to guide evaluation. The

project coordinator will work closely with IPRC for process evaluation and related tasks. Following the implementation of the agency plan, outcomes will be identified in terms of new agency practices, policies, and tools such as a "best practices kit".

Challenges: Barriers have yet to be identified, with the project just beginning. Potential challenges may include: scheduling among staff and agency staff/volunteers from the six targeted sites; post-project sustainability; replication in new sites for year two; getting accessibility to be a standard part of budget and training activities; developing effective outreach to women with disabilities.

Policy: Outcomes will be used to influence practices in other DV and SA agencies statewide and nationally, as well as policy development, service delivery initiatives, training and resource development of state-level coalitions for domestic violence and sexual assault. It will also inform public health efforts to prevent and intervene in domestic violence.

California Brief
Project Access
The California Coalition Against Sexual Assault
Krista Flores, Project Access Manager
CALCASA-California Coalition Against Sexual Assault

Project Access is a collaboration of several national and state organizations addressing violence against women with disabilities. Funded under the Department of Justice, Office of Justice Programs, Office of Violence against Women, Education and Technical Assistance Grants to End Violence against Women with Disabilities Program, Project Access is the comprehensive technical assistance provider to 17 grantees, representing 16 different states funded under this grant. The goals of the program are to create greater options, services and remedies for women with disabilities experiencing sexual assault, rape, stalking, and domestic violence. The project will challenge barriers that exist within the service provider community and public institutions that limit women with disabilities who have experienced violence from accessing services, and create a national coordinated response among service providers, advocates for persons with disabilities and policymakers to enhance support for survivors with disabilities.

Through this project, CALCASA will develop and expand a National Clearinghouse on violence against women with disabilities, form a National Advisory Task Force comprised of experts in the field who will produce a white paper, create a monthly e-newsletter with resources for agencies to help serve women with disabilities who have experienced violence, and host the its first national conference on disabilities.

Project Access provides technical assistance to the grantees through the Clearinghouse, trainings, in-person site visits, mailings, video-teleconference meetings, grantee "Spotlight" meetings, and the National Conference.

For more information on Project Access or to receive the monthly e-newsletter, please contact: Krista Flores, Project Access Manager at (916) 446-2520 x317 or e-mail at Krista@calcasa.org.

Oregon Brief

Personal Power: Responding to Abuse, Neglect, and Exploitation

Willi Horner-Johnson, Ph.D., Research Scientist, OODH
Oregon Office on Disability and Health
Oregon Health & Science University

Personal Power provides knowledge, skills, and resources regarding abuse, neglect, and financial exploitation of people with disabilities. The goals of the intervention are to increase participants'

- understanding of the relationship between disability and maltreatment;
- ability to recognize different types of maltreatment; and
- knowledge of the resources and strategies available to combat maltreatment.

The intervention consists of a one-day workshop that includes lecture, group discussion, a video presentation, small group activities, and role-playing in an eight-module curriculum. The original curriculum was developed, implemented, and disseminated by the Department of Disability and Human Development, University of Illinois at Chicago. OODH has modified the curriculum for use in Oregon.

The target audiences for this intervention are adults with physical and/or sensory disabilities, family members, and other advocates. Twenty to 30 people attend each workshop. OODH plans to conduct two workshops each year. During our current funding cycle, 120-180 people will participate in Personal Power workshops.

The curriculum was developed in collaboration with people with disabilities, disability service providers, advocates, sexual assault and domestic violence service providers, and members of the legal community. It was modified for use in Oregon with assistance from service provider agencies including the Office of Investigations and Training and Aging and Disability Services. Workshops are implemented in collaboration with the Center on Self-Determination at Oregon Health and Science University, as well as community-based trainers.

The curriculum includes a pre/post questionnaire and a follow-up survey for evaluating the intervention. Evaluation data from 13 workshops in Illinois demonstrated that the intervention was successful in increasing the participants' knowledge of resources and strategies for responding to and preventing maltreatment. Also, based on the results of the follow-up survey, participants found that the tools and information they learned during the workshop were helpful in stopping and preventing incidents of maltreatment of people with disabilities. Data collected at the first Personal Power workshop in Oregon confirm that the curriculum significantly increases knowledge regarding disability and maltreatment issues.

Challenges in implementing the intervention include the intensity of the full-day workshop and the painful nature of the material for some participants. To address these challenges, the length of the workshop is broken up with different types of activities, presentation formats, and refreshment breaks. Workshops are conducted by a team of trainers so that someone can always be available to talk privately with any participant who wishes. A quiet space is available for participants to have private conversations or simply withdraw from the larger group for a while.

Community-based trainers and cosponsors greatly facilitate recruitment, workshop implementation, and provision of local resource materials at workshops.

The follow-up survey asks respondents to provide general information about maltreatment incidents or potential incidents they have encountered since the workshop and the steps they took to prevent or stop the maltreatment. OODH is currently developing a form for participants to send in information about incidents as they occur rather than only at the six-month follow-up point. To obtain broader information about violence against people with disabilities, we have added disability identifiers to the version of Oregon's BRFSS that includes questions about interpersonal violence. Questions about maltreatment are also included on a BRFSS callback survey of people with disabilities that will be conducted in Oregon later this year. Data from all of these sources will be examined in combination to inform public health policy regarding violence and people with disabilities.

Discussion Summary
Violence Prevention Programs for Persons with Disabilities

session facilitated by

Roger Chapman, M.S.W., Bureau Chief

Division of Health Promotion, Prevention, and Addictive Behaviors

Iowa Department of Public Health

Mary Keener Beresford, Ph.D.

University of New Mexico

1. What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?

- Nearly twice as many women with disabilities have experienced unwanted sexual contact as counterparts without disabilities in Massachusetts.
- States need data to assess the need for public health initiatives on violence prevention.
- In some states, the phrase "domestic violence," as used in the justice system, program administration, and data collection, refers only to violence between sexually intimate partners, and not all household members and caregivers who are potentially abusers of persons with disabilities.
- Domestic violence and sexual assault staff and agencies need to be responsive to disability issues of site accessibility, staff sensitivity, and staff turnover.
- Law enforcement agencies need training in sensitivity to the special risks facing persons with disabilities.

2. Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?

- Promoting environmental access to domestic violence and sexual assault treatment and counseling sites
- Training staff and volunteers at domestic violence and sexual assault centers on issues related to treating clients with disabilities
- Training staff of Centers for Independent Living in sexual assault issues so they can be of assistance to clients who are victims
- Working with law enforcement agencies by including them on state advisory panels and promoting disability sensitivity training to officers
- Holding workshops for people with disabilities and their families addressing violence awareness, empowerment and utilization of existing resources
- Addressing emotional responses to workshops focusing on abuse by making available a separate quiet room and additional facilitator for private consultation

Violence Protection Programs for Persons with Disabilities

- Teaching awareness of violence issues to persons with cognitive disabilities through presentation by a theater group with experiential emphasis
 - Screening caregivers for predatory behavior using criminal background checks and strategies used in aging programs
3. *How can you bring this topic to the attention of policy makers in states to ensure a place for this topic on your state's public health agenda?*
- Identify the policy makers and stakeholders within a state, both within and outside the state government. Work with them to demonstrate need for:
 - Data collection
 - Environmental access
 - Service Provider Training
 - Specialized workshops
 - Encourage funders to include persons with disabilities in all violence prevention initiatives.
 - Encourage funders of environmental access initiatives to include centers treating victims of violence or hosting violence prevention programs.
 - Place disability identifiers on relevant data collection instruments.
 - Become involved in advisory committees of boards adding disability issues to the discussion wherever possible.
 - Become involved in strategic planning. Assure that disability issues are represented and become incorporated in the written plan.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*
- Make use of training and workshop curricula and materials that have already been developed in California, North Carolina, Massachusetts, and Oregon.
 - Combine advocacy and data resources to seek additional federal funding for data collection.

South Carolina Brief
South Carolina's Advisory Board and Marketing
Strategy for IODH Collaborative Programs
Marylou Stinson, Recruitment/Assessment Coordinator
University of South Carolina School of Medicine

1. Description of Initiative/Intervention/Strategy

Advisory Board:

The South Carolina Developmental Disabilities Council (DDC), Office of the Governor, is the advisory council that provides oversight and guidance for the South Carolina Interagency Office of Disability and Health (IODH). The DDC is a diverse group of professionals, consumers, and family members who are actively involved in the planning and progress of IODH activities. Our IODH staff work through the DDC Prevention Committee to accomplish our objectives.

The DDC Three-Year State Plan is the strategic plan for the IODH. The plan is the official state plan and has been published and distributed to over hundreds of citizens and organizations. The plan is also a working document pertaining to health and wellness of individuals with disabilities as well as accessibility of facilities, and services are reflected in the overall IODH goals and objectives.

The DDC Three-Year State Plan reflects federal and state priorities for DDCs that oversee state programs for people with disabilities. South Carolina has always elected to have a state prevention priority that includes primary and secondary condition prevention. In addition, the priorities of employment, community living, systems coordination, and community education incorporate objectives that will impact the health and well-being of individuals with disabilities. The DDC has identified life domains that are priority areas throughout the state plan. These are: self-determination, employment, health, education, and community inclusion.

Marketing IODH Programs:

Marketing our work is an integral component of the work that we do. Our grant partners play a vital role in reaching out to our community. The focus is on delivering the message to people with disabilities, family members, and professionals who work with and provide services for people with disabilities. The IODH has a number of programs that enroll or impact consumers with disabilities on an ongoing basis. These include a recreation project for children and adults, a fitness/wellness facility project, a health education program, and a medical facility accommodations project. For each of these programs, we have a list of collaborators and a built-in mechanism for marketing. For example, we market recreation programs through brochures, flyers to school-aged children in special education, attendance at advocacy conferences, and a call-in referral service. In another program, we use our partners in the South Carolina State Office of Rural Health to alert all clinics that are applying for building renovation loans that we offer an accessibility survey.

*Opening the Door: Marketing Health Promotion Intervention, Research Projects, and
Advisory Boards to People with Disabilities*

2. Describe the audience or persons involved in the initiative/intervention/strategy.

The IODH is comprised of a diverse team of professionals representing the following organizations in South Carolina: American Cancer Society, Best Chance Network, City of Columbia Recreation Department, Irmo Chapin Recreation Department, Lexington County Recreation and Aging Commission, Richland County Recreation Department, South Carolina Department of Disabilities and Special Needs, South Carolina Department of Health and Environmental Control, South Carolina Developmental Disabilities Council, South Carolina State Office of Rural Health, and the USC School of Medicine - Department of Family and Preventive Medicine. All of our grant partners play a role in the continuous marketing of the programs.

3. How many people participated? (If the intervention was repeated, provide numbers/period and total numbers over a specified time frame) Advisory Boards:

The DD Council is comprised of 35 participants who are appointed by the Governor.

Marketing IODH Programs:

Approximately 20 consumer groups and organizations.

What was the duration of the initiative/intervention/strategy?

Advisory Board: The South Carolina DDC Prevention Committee has served as advisors to the IODH since 1997.

Marketing IODH Programs:

Marketing never ends with the work that we do. We continue to reach out to the people with disabilities, family members, consumer groups, and professional organizations.

4. With whom did you collaborate to carry out the initiative/intervention/strategy?

Advisory Board: Please see #2

Marketing IODH Programs: Please see #2

5. Describe the outcomes and what measures you used to determine the outcomes?

Advisory Board:

The DDC Three-Year State Plan is the strategic plan for the IODH. The plan is the official state plan and has been published and distributed to over hundreds of citizens and organizations.

Marketing IODH Programs:

One of the measures used to determine the success of our marketing efforts is based on the number of people who enroll in collaborative programs developed by the IODH.

6. List barriers/challenges/facilitators.

Advisory Board:

SC has always elected to have a state prevention priority that includes primary and secondary condition prevention.

Marketing IODH Programs:

The approach to marketing is a team approach.

7. How have you used the outcome to influence public health policy?

Advisory Board:

The plan is also a working document pertaining to health and wellness of individuals with disabilities as well as accessibility of facilities, and services are reflected in the overall IODH goals and objectives.

Marketing IODH Programs:

Serving people with disabilities has become a priority for the organizations that we have partnered with.

New Mexico Brief
Including People with Cognitive Disabilities as Full Partners

Judith Liddell, Associate Director
Center for Development and Disability
University of New Mexico

Often professionals are stumped about how to include people with cognitive disabilities as presenters, research consultants, and product reviewers and how their presence on advisory boards can be more than tokenism.

The Center for Development and Disability (CDD) has developed strategies to allow individuals with cognitive disabilities to contribute based on their capabilities. The self-advocacy movement for people with developmental disabilities has as their mantra: "Nothing about us, without us." The capabilities they bring to the process include their life experience expertise and credibility with other self-advocates. They provide valuable quality assurance and feedback.

The CDD has utilized people with developmental disabilities in the following kinds of roles: product designers and editors, subject matter experts, field-testing and critiquing products, and tools, co-authors, focus group co-facilitators, study and instrument design, trainers, presenters, advisory board and advisory committee members.

Strategies for including self-advocates include: analyzing roles and capabilities, existing and needed; honoring the ways that people want to participate; developing role descriptions; clarifying supervision and team; building in more time to be able to go at a slower pace; forecasting what's going to happen and what and where the person will contribute and when breaks and "the end" will happen; debrief to jointly identify what went well and what needs to change for the future; finding mutually convenient times and places to get together; determining and educating about communication preferences and systems; practicing "mutual mentorship"; offering orientation and training; respecting the person's thoughts, abilities and expertise (avoiding manipulation); being an equal partner; paying for time and expenses; helping with logistics like transportation; and making reasonable accommodations.

North Carolina Brief
North Carolina Office on Disability
Work Site Health Promotion Initiative: Live Healthy, Work Healthy

Karen Luken, Program Director
North Carolina Office on Disability and Health
University of North Carolina – Chapel Hill

Description of Initiative: NCODH is developing a multilevel work site health promotion initiative with the goal of providing environmental supports for health promotion in order to improve the health status of individuals with disabilities. The targeted goals are to increase healthy activity and food choices available at work, encourage people to consider healthy choices, and support people when they make healthy choices. The program emphasis is on making the work site a place that models and supports healthy and realistic lifestyle choices, instead of directing all health promotion interventions at the individual, which is a very time-consuming, expensive, and often unsuccessful endeavor. *Live Healthy, Work Healthy* purposefully acknowledges the impact of the environment on individual behavior and is developing an array of strategies that promote health and can be sustained by the agency.

Target audience: Adults with disabilities (including mental retardation, autism, cerebral palsy, co-occurring disabilities) who receive services at a community employment agency specializing in services for adults with significant disabilities.

Project activities include:

- Identifying best practice work site health promotion models and strategies.
- Securing the support of agency administration.
- Identifying insiders and outsiders who can nurture and sustain the program.
- Forming a wellness committee, which provides the foundation for all on-site efforts. It consists of individuals receiving services and agency staff and meets weekly to conduct business. Responsibilities include helping to select the weekly lunchtime wellness activities, encouraging participation in these activities, identifying desired environmental changes, such as vending machine options, placement of exercise equipment, choice of walking routes, design and maintenance of wellness bulletin boards, and incentives for walking club. Committee roles include meeting co-leader, lunchtime announcements, exercise assistant.
- Implementation of weekly lunchtime physical activities, with an emphasis on walking, stretching, and use of "low tech" equipment (hand weights, therabands, videos).
- Implementation of a series of 15 weekly group classes emphasizing physical activity, healthy nutrition, and personal goals.
- Developing plans for quarterly community speakers calendar and annual health fair.
- Visitation of other work site health promotion programs.

Collaborators: Site one has a community vocational center, a local Arc chapter, the County Human Services department, which includes public health, the community college, and local businesses. We anticipate similar partnerships in future sites.

Outcomes and Measures: A logic model was developed and targets measures of effect for the work site, including increase in environmental supports, modification of agency policies and practices, staff job descriptions, and expanded community partnerships. Measures for individuals include increased time spent in physical activity (with LHWH program and at other times) and decreased intake of high fat, high salt, and high calorie foods and drinks. Additional measures include number of persons involved in educational classes, group activities, walking club, number and types of products produced, agency and participant satisfaction.

Challenges: Ensuring consistent onsite visibility of program, decreasing dependence on staff for organized fitness activities, acknowledgment that many individuals rely on others to prepare lunches and purchase food items, engaging the community in the health promotion needs of workers with disabilities, ensuring educational materials are appropriate for target learners.

Policy: Outcomes will be used to influence practices in other work sites and provider agencies and to inform public health efforts to address nutrition, physical activity, and obesity for persons with disabilities.

Iowa Brief
**Marketing Health Promotion Interventions, Research Projects, and Advisory
Committees to People with Disabilities: The Iowa Approach**

Kay DeGarmo, Director
Prevention of Disabilities Policy Council
Center for Disabilities and Development, University of Iowa

The Strategy: Iowa's Dept. of Public Health and the UIHC Center for Disabilities and Development (Iowa's UCEDD) have a successful collaborative effort to offer a variety of research-based health promotion programs to people with disabilities. Currently, we offer:

- The University of Montana's *Living Well with a Disability* program for adults with mobility impairments and others through five CILs and two model rural delivery sites;
- The University of Iowa's *Continuing to Live Well with a Disability* (a "refresher course" for the *Living Well* program) for the same audience(s) at the same locations; and
- An adolescent health promotion program developed using the concepts of *Living Well* for adolescents with disabilities on career paths offered through community school sites.

Our strategy for marketing these programs to Iowans with disabilities involves extensive collaboration and takes to heart the disability community's axiom "nothing for us without us." We

- Introduced our programs to CILs and key consumer and provider groups through disability community leaders.
- Formed a *Living Well with a Disability* Advisory Committee composed of consumers, providers (many of whom are people with disabilities), and potential funders to establish policy related to program development, implementation, and evaluation. Seventy-five percent of the committee's membership is people with disabilities.
- Involved the Advisory Committee in the development of the *Continuing to Live Well with a Disability* "refresher course" and the adolescent health promotion program.
- Tapped a youth with disabilities advisory body from our *School to Work* program for input on the name and content of our adolescent program.
- Utilized people with disabilities as facilitators of our health promotion programs.
- Utilized facilitators (many of whom are people with disabilities) to explain the research portion of the project, obtain informed consent, and support participants in completing evaluation forms.

Our community providers find that recruitment of participants is best accomplished through personal contact to individuals, consumer groups, and organizations. Word of mouth from current participants is also useful. Advertisement through newspapers, radio, etc. has not been particularly successful.

*Opening the Door: Marketing Health Promotion Intervention, Research Projects, and
Advisory Boards to People with Disabilities*

Number of Participants, Duration, and Outcomes: 205 Iowa adults with disabilities have completed the *Living Well* program in the two-plus years we have offered the program; 76 adults have also completed the *Living Well* “refresher course” in the year since we began that program. About 80% of participants have agreed to enroll in the research phase of the program. Over 98% of those who completed the *Living Well* programs rated the program either a four or a five on a scale of one to five. Preliminary outcome data from a one-year study of health status, health promoting behaviors, barriers to health promotion, empowerment, and quality of life will be available soon.

Barriers and Challenges to Marketing: Use of the term “disability” can provide a barrier to marketing such programs to senior and adolescent groups. Research can be hard to sell to site providers such as CILs, and site providers generally require a fair amount of technical assistance to accomplish research protocols.

Influence on Public Health Policy: Development and implementation of such health promotion programs is part of our *Healthy Iowans* 2010 public health agenda; study outcomes will be reviewed by policy groups that include legislative members; and we are currently working with Medicaid to cover *Living Well* through our waiver programs.

Discussion Summary

**Opening the Door: Marketing Health Promotion Intervention,
Research Projects, and Advisory Boards to People with Disabilities**

session facilitated by

Tom Seekins, Ph.D., Director, RTC Rural
The University of Montana

Rural Institute: Center for Excellence in Disability Education, Research, and Service

Craig Raveslout, Ph.D., Director, New Directions for Living Well
University of Montana

Rural Institute: Center for Excellence in Disability Education, Research, and Service

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Spreading the word that the law obligates any facility offering services to the general public to remove physical barriers, provide effective information and modify existing policies for equal access
 - Identifying people with whom to partner at the local level who will encourage peer participation
 - "Selling" the program to the disability community, state government, funding agencies, and health care professionals
 - Partnering with people with cognitive disabilities in a meaningful manner
2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons have other states learn from other programs that worked and didn't work?*
 - Collaborate with recipients, providers, and funders.
 - Include persons with disabilities, including cognitive disabilities, as front-line marketers and personally committed champions of health promotion, fitness, and nutrition programs.
 - Include persons with disabilities, including cognitive disabilities, on advisory boards as subject matter experts, product designers and editors, field testers, and to provide feedback to co-trainers or presenters, and not as token participants.
 - Make use of advisory board's social acquaintances, community leaders, faith-based groups, advocacy newsletters, local events, and call-in e-mail referral services to identify potential participants.
 - Design promotional events to be fun social events.
 - Use inclusive language in marketing messages, and encourage fitness centers to make their messages inclusive.

*Opening the Door: Marketing Health Promotion Intervention, Research Projects, and
Advisory Boards to People with Disabilities*

- Obtain continuous feedback from consumers about what is working in the initiatives as well as marketing messages.
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Seek inclusion of programs in the Department of Health strategic plan.
 - Form coalitions with many partners, both within and independent of state government.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*
- Learn from positive and negative experiences of other states in all aspects of marketing: actions taken to attract the desired audience, assess customer satisfaction, and address customers' needs, desires, and demands.
 - Adopt inclusive, easily understood language in explanatory brochures and evaluation instruments, as described in Iowa and other states' publications on communicating with individuals with disabilities.

Vermont Brief
**Health Promotion Curricula for People with Disabilities:
What Works, What Doesn't and Why?**

Deborah Lisi-Baker, Executive Director
Vermont Center for Independent Living

The Vermont Department of Health and the Vermont Department of Aging and Disabilities contracted with a consulting firm to conduct focus groups to gather qualitative information from people with disabilities, their families, and disability advocates and service providers about health promotion for people with disabilities. Information gathered by the study will be used to inform the development of a state plan for health promotion for Vermonters who have disabilities.

Focus groups were held with six representative groups: adult women with physical and sensory disabilities; adult men with physical and sensory disabilities; youth ages 16 to 25 with physical and sensory disabilities; adults with developmental disabilities; family members; and disability advocates and service providers. Participation on the dates of the focus group sessions was high, with a mean attendance of 93%.

Participants in the focus groups demonstrated familiarity with the concepts of health promotion and wellness, as well as awareness that people with disabilities are at increased risk for developing secondary conditions. Most participants described health promotion as very important to them. However, full participation in community-based health promotion and recreation programs and activities remains a distant dream for them. Access and inclusion were the exception rather than the rule. Cost, transportation, and attitudes were cited as major problems in addition to physical and communication barriers. While participants reported access to some information about health promotion, there was a high degree of dissatisfaction with the quality of information about community activities.

Overall, participants expressed greater satisfaction with their health care providers than with community-based activities and reported few problems with inaccessible facilities. Most participants reported that their health care providers talked to them about health promotion both in relation to their disabilities and in relation to their overall health. There were differences between the groups in their perceptions of the attitudes of their providers towards them, ranging from good to poor. Health care providers were frequently described as making well-intentioned but unproductive suggestions because they lacked understanding of the context of their patients' lives and disabilities.

In addition, Vermont's Disability and Health Promotion Project is sponsoring a partnership between the Area Health Education Center Program at the University of Vermont College of Medicine and VCIL. We are developing videos and a shared presentation and discussion series for "Grand Rounds" trainings held for health practitioners affiliated with Vermont hospitals. The focus is on sharing research findings and the perspectives of individuals with disabilities on best practices and the prevention of secondary disabilities. Through a related partnership, VCIL is developing information and tools to promote informed decision making and effective planning

and communication between staff of primary care practices and the individuals with disabilities they serve. This project is building on the "chronic illness" model being used in several medical home projects to plan effective services in primary care settings and is funded by the Robert Wood Johnson Foundation through a grant to the Office of Vermont Health Access, the state's Medicaid office.

Oregon Brief
Healthy Lifestyles for People with Disabilities
Oregon Office on Disability and Health
Willi Horner-Johnson, Ph.D., Research Scientist
Oregon Office on Disability and Health
Oregon Health and Science University

The *Healthy Lifestyles* curriculum teaches participants to work toward improving their health from a holistic perspective that includes social, emotional, spiritual, and physical health. Workshops are 2 ½ days long and include three main segments: 1) encouraging participants to self-define a healthy lifestyle; 2) specific topics such as fitness, nutrition, stress, relationships, and preventing illnesses; and 3) developing an individual health plan and setting goals for implementing the plan. During the course of the workshop the participants engage in non-impact aerobics, yoga, and chair massage. After the workshop, *Healthy Lifestyles* support groups meet on a monthly basis. The support groups allow participants to share their successes and the challenges they face in meeting their healthy lifestyle goals. Between meetings, mentors work with the participants to assist them in reaching their self-selected healthy lifestyle goals.

Workshop participants include adults with a wide range of disabilities, including cognitive, physical, and sensory disabilities. Each workshop includes 10-17 people. OODH is currently conducting a series of 10 workshops as part of the three-year *Healthy Lifestyles* Evaluation Project. A minimum of 100 individuals will participate over the course of the project. The project is implemented in collaboration with Independent Living Resources, Portland's Center for Independent Living. OODH and ILR also collaborate with other CILs when implementing workshops outside Portland.

Before attending a workshop, all participants complete baseline data on health-related behaviors, using the Health Promoting Lifestyle Profile II (Walker, Sechrist & Pender, 1995). In each workshop location, half of the participants then attend a *Healthy Lifestyles* workshop. Data are collected again three months after the workshop to measure change in healthy lifestyle behaviors. The participants who have not yet attended a workshop are also evaluated at this point to provide a control group comparison. The control group members then attend a workshop themselves. Thus, all participants have the opportunity to receive the intervention. Follow-up data collection for both groups continues at three-month intervals after workshop participation.

Four workshops have been conducted so far. Although we are quite early in the data collection process and quantitative data have not yet been analyzed, participants' comments at support groups indicate that they have found the *Healthy Lifestyles* training to benefit them in several ways. Recent quotes include: "Healthy Lifestyles has helped me learn how to make friends and develop social interaction skills." and "I am eating more healthy foods, losing weight and focusing on what is important in my life!" Nutrition and exercise related to weight loss and maintaining a healthy weight have been major themes among participants.

Recruitment and retention of participants has been the primary challenge in implementing the *Healthy Lifestyles* Evaluation Project. Because we need participants to be involved for almost a year to collect all of the follow-up data, we over-recruit to counteract attrition. We also provide

monetary incentives and make multiple phone calls to participants to remind them to attend workshops and data collection meetings. Working with CILs facilitates the process of connecting with participants and keeping in close contact with them.

Overweight and obesity have been key issues in Oregon in general, as well as among *Healthy Lifestyles* participants. The state epidemiologist recently released data on the high rate of obesity among Oregonians. OODH then analyzed Oregon BRFSS data on obesity by disability status and found that obesity is almost twice as prevalent among people with disabilities as among people without disabilities. We are now using these data, and the information provided by *Healthy Lifestyles* participants, to push for inclusion of people with disabilities and disability-specific issues in state efforts to reduce and prevent obesity.

New York Brief
**Health Promotion Curricula for People with Disabilities:
What Works, What Doesn't and Why?**

Frances Stevens, M.S., Program Manager
Disability and Health Program
New York State Department of Health

Description

New York has sponsored *Living Well with A Disability* for three years. *Living Well with a Disability* is the eight-week peer-to-peer curriculum designed and evaluated by the University of Montana and the University of Kansas. It includes eight two-hour sessions. Topics include goal setting, problem solving, adopting an optimistic attitude, and overcoming depression. It covers communication skills, medical information seeking skills, changing nutritional intake and physical activity as well as advocacy skills.

Audience

The target audience is adults with physical disabilities.

Numbers

Numbers of participating organizations increased every year the program was offered from one in the first year to eight in year three. Total number of participants (excluding 2002-3 still underway) is 51.

Duration

The *Living Well* curriculum is carried out over an eight-week period. No follow-up segments were offered by New York.

Collaborators

Independent Living Centers were the only organizations eligible to respond to the RFP in the first two years. Due to a low application rate from ILCs alone, the list of eligible applicants was increased to include outpatient rehabilitation units and organizations serving people with disabilities with experience with peer training.

Outcomes

Data collected for the first two years used the research evaluation tool developed by the University of Montana. UM analysis of the first year of data showed a 28% reduction in limitation due to secondary conditions and a decrease in Medicare expenditures from \$2113 per person to \$1112, two to four months post intervention. The data from the first two years remain to be entered and analyzed due to lack of staff time and the complexity of the evaluation tool. The third year of *Living Well* is underway and uses a shortened evaluation tool developed by the University of NM in collaboration with UM, Iowa DHP, and NYS DHP.

Barriers/Challenges/Facilitators

A challenge was the initially very low number of ILCs interested in participating, influenced by the low reimbursement per ILC to conduct the program (\$4,500 per ILC). Although numbers of ILCs interested has increased, the low reimbursement remains a barrier in NYS. The addition of

outpatient rehabilitation and other agencies increased applications, but many did not have a firm grasp of the peer-to-peer model which may influence the structure of *Living Well*. An issue for all sites is a relatively high drop-out rate. A programmatic challenge is the low number of individuals participating in and completing the program. A facilitator is an organization leader with a genuine commitment to health promotion.

Influence on Public Health Policy

Because approvals for this RFP have been run through governmental approval channels so many times, there is recognition of a move toward health promotion for people with disabilities. As soon as numbers of individuals increase and we can document positive outcomes, the opportunity for more traditional funding streams (such as Medicaid or other insurance) to support this program should increase.

Iowa Brief

**Health Promotion Curricula for People with Disabilities: What Works,
What Doesn't and Why?: The Iowa Experience**

Kay DeGarmo, Director

Prevention of Disabilities Policy Council

Center for Disabilities and Development, University of Iowa

The Curricula, Audience, and Numbers Served: Iowa offers a variety of health promotion curricula for people with disabilities. The Iowa Dept. of Public Health and the UIHC Center for Disabilities and Development (Iowa's UCEDD) have partnered to provide:

- The University of Montana's *Living Well with a Disability* program for adults with mobility and other disabilities through five Iowa CILs and two rural county delivery sites. This program is offered at each site in both the spring and the fall. In the two-plus years we have offered the program, 205 individuals have completed the course.
- The University of Iowa's *Continuing to Live Well with a Disability* program (a "refresher" course to the *Living Well* program) for the same audiences at the same sites. This program is offered after completion of the *Living Well* program. In the year since we launched the extended program, 52 individuals have completed the additional course.
- An adolescent health promotion program, *Living Well and Staying Healthy: How to Live to Be 100 Years Old*, that will be offered to adolescents who are on career paths in community school sites. A first draft of the curriculum was offered in one program site to 16 students this past winter. The curriculum has now been revised and will be tested in three to four school sites this fall.

Experience/Outcomes to Date:

- The concepts contained in the University of Montana Living Well program are meaningful to participants of all ages. Over 98% of adult participants give the program and its concepts high marks (fours or fives on a scale of one to five).
- Facilitator observation and course process evaluations have shown that a significant number of participants have limited reading abilities and several learn better using other methods.
- In response, we've developed a handbook that highlights key *Living Well* concepts on one-page sheets that are written at a 4th grade reading level and utilize plenty of illustrations. Over 92% of participants indicate a preference for using both the manual and the handbook; nearly 8% indicated a preference for the handouts only; none indicated a preference for the manual alone.
- There is a huge benefit to delivering the adult curricula using a peer support model.
- Preliminary *Continuing to Live Well with a Disability* course evaluations show that the segments on safety and preventive health care are well received. However, they also show that we need to look further at how/when the course is offered.
- Our adolescent pilot showed that:
 - Many adolescents reacted negatively to the term "disability."

- The *Living Well* concepts are meaningful, but we need to select two or three primary concepts per chapter; also, using a variety of teaching modalities is best.
- Adolescents have difficulty setting personal goals in part because they rebel against the idea of more goals set by parents and educators and in part because they have no idea that they can set goals for themselves on topics that are important to them.
- Peer support is not readily attained with adolescents who tend not to feel safe when revealing personal information about themselves to their peers.
- Course evaluations can be extremely useful in determining what's working and what's not.
- Not just the curricula but also a facilitator's skill is critical to running a successful program. Based on our experience, we provide facilitators with 20 hours of initial training, provide mentors for their first round of classes, and provide ongoing support through retreats, etc.

Discussion Summary
**Health Promotion Curricula for People with Disabilities:
What Works, What Doesn't and Why?**

session facilitated by

Charles Drum, Ph.D., J.D., Director, Oregon Office on Disability & Health
Oregon Health and Science University

Anthony Cahil, Ph.D., Senior Research Scientist and Head, Center for Development and Disability
University of New Mexico

1. What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?

- Identifying and gaining support of partnering organizations to host programs and help identify potential participants.
- Imparting the importance of the use of the peer teaching, rather than medical teaching model to potential hosting partners.
- Recruiting participants for programs.
- Maintaining a critical mass of participants in a given session of a program, considering that "dropouts" due to medical problems are fairly common
- Garnering support for following a research protocol, by filling out multiple forms and evaluations, among hosting organization, lay leaders, and participants.
- Curricula, locations and evaluation instruments that are successful for adults are not necessarily suitable for adolescents.

2. Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons have other states learn from other programs that worked and didn't work?

- The key to success of the health promotion curriculum model is peer support.
- Additional peer activities, such as a walking club, can extend beyond the formal training program to encourage informal group support.
- Provide support to facilitators, as well as to participants. Hold retreats and additional training for peer facilitators.
- Extensive effort must be expended on engaging collaborative sites and enrolling participants. Suggestions include:
 - To obtain the desired level of enrollment, over-recruit with multiple follow-up telephone calls to ensure participation
 - Engage one committed Center for Independent Living staff member to successfully recruit throughout a state.
 - Partner with advocacy groups and provider groups to recruit participants.
 - Involve office managers in providers' offices in enrollment

- Recruit and run programs at work sites that employ numerous people with disabilities.
 - Seek technical assistance from the Department of Health for Centers of Independent Living involved in the recruitment process.
 - Engage staff from the Department of Health who themselves have disabilities to coordinate the health promotion initiative with Centers for Independent Living.
 - Many participants are not good readers and require written materials at fourth grade reading level.
 - In a well-established network, Internet meetings can be used effectively.
 - To obtain support from collaborators (host site and peer facilitator) for research protocol, clarify the importance of each piece of data, and make the forms easy to administer and complete.
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Having successfully run and evaluated their health promotion curricula initiative, Iowa plans to bring their results to Medicaid to seek coverage.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work towards building a strong state network?*
- States may import entire curricula with corresponding evaluation instruments, such as Montana's *Living Well with a Disability*.
 - States implementing a program developed elsewhere must carefully note the processes that have contributed to the program's success.

Iowa Brief
Evaluation of Health Promotion Programs

Roger Chapman, M.S.W., Bureau Chief
Division of Health Promotion, Prevention, and Addictive Behaviors
Iowa Department of Public Health

Description

Access the effectiveness of Iowa's implementation of *Living Well with a Disability* (Adult version).

- Eight-session curriculum
- Four-session refresher course (CLWD)
- Instrument developed by University of Iowa to measure risk and protective factors for secondary conditions
- Process evaluation
 - participant satisfaction
 - what worked, what did not work

Audience

Primarily Iowans with mobility limitations recruited through Center for Independent Living

How Many People Participated

About 150 so far

Collaborators -

- Iowa Department of Public Health
- Iowa Centers for Independent Living
- University of IA Center for Disabilities and Development
- The Prevention of Disabilities Policy Council
- University of IA College of Public Health

Outcomes

- Only preliminary data at this time

Challenges

- Developing survey instrument:
 - At the time it was developed (five years ago), no clear consensus about measuring secondary conditions
 - Narrowing the focus (began with 35-page survey)
- Blue Ribbon Panel
- Administering survey:
 - Four times/class

*Evaluating Health Promotion Programs for People with Disabilities
and the Need for Common Evaluation Strategies*

- Participation drop off
- CIL staff inexperienced

Positive Outcome

- Used by some facilitators to help retire personal goals of participants

Influence Policy

- Build case for Medicaid funding
- Provide evidence that LWD should be included as a part of the Healthy Iowans disability chapter at the mid-course review (2005).

Opportunities for Collaboration

- Involve other groups/organizations as *Living Well* expands throughout Iowa.

Contact Information - Roger Chapman (515) 281-6646

South Carolina Brief
**Evaluating Health Promotion Programs for People with Disabilities and
the Need for Common Evaluation Strategies
South Carolina's Evaluation of Steps to Your Health**

Virginie Daguise, Ph.D., Epidemiologist
Family and Preventive Medicine
University of South Carolina School of Medicine

1. Description of initiative/intervention/strategy

Steps to Your Health (STYH) is a health promotion program emphasizing lifestyle modifications for individuals with disabilities. STYH covers the following topic areas: nutrition, exercise, changing your way of thinking, communication styles, how to maintain a healthy lifestyle, and stress management.

2. Describe the audience or persons involved in the intervention

Adults with mental retardation, traumatic brain injury, and spinal cord injury.

3. How many people participated? (If the intervention was repeated, provide numbers/period and total numbers over a specified time frame)

During year one (April 2002-March 2003) of this grant cycle, 111 adults with mental retardation, traumatic brain injury, and spinal cord injury completed the *Steps to Your Health* Program. A completer is defined as an individual who participated in at least six of the eight group sessions, pre- and post- assessments sessions, and two home visits.

4. What was the duration of the intervention?

The class sessions are led by STYH trainers for an hour each week for a period of eight weeks.

5. With whom did you collaborate to carry out the intervention?

The South Carolina Department of Disabilities and Special Needs state office and 10 local Disabilities and Special Needs boards throughout South Carolina.

6. Describe the outcomes and what measures you used to determine the outcomes?

The goal of the intervention is for participants to increase fruit and vegetable intake, increase physical activity, and reduce their body mass index (BMI). To measure change there are pre- and post-intervention assessments with questions related to knowledge and attitudes, fruit and vegetable intake, and physical activity. Additionally, pedometer readings, blood pressure, weight, height, and waist circumference measurements are taken pre- and post- intervention. Participants also complete a one-day food diary pre- and post- intervention.

7. List barriers/challenges/facilitators.

Data collection is a challenge for the STYH facilitators. The facilitators enlist the support and help of family, friends, caregivers, and residential staff to ensure that accurate food diaries and pedometer readings are reported. Accurate reports of portion sizes are often difficult to get. The food diary asks individuals to report whether their portion was regular size or super size as many individuals are familiar with these differences in fast food restaurants. Pedometer readings are used to assess how much activity an individual engages in during the course of a day.

*Evaluating Health Promotion Programs for People with Disabilities
and the Need for Common Evaluation Strategies*

Facilitators request assistance from participants to help reset the pedometers and to remind them to wear them throughout the day.

8. How have you used the outcome to influence public health policy?

We anticipate sharing the results of the data assessment with the administration at the South Carolina Department of Disabilities and Special Needs. The hope is to encourage all of the 38 local boards to adopt STYH as a program that is offered on a regular basis to all interested individuals who receive services from them. Currently, the 10 local boards that are implementing the STYH program have made a commitment to encourage healthier food choices in their facilities and to include goals that are established through this program on the individuals' single plan.

**New Mexico Brief
Consortium to Evaluate the Efficacy of Health Promotion Interventions
for People with Disabilities**

Anthony Cahill, Ph.D., Senior Research Scientist and Head
Center for Development and Disability
University of New Mexico

Craig Raveslout, Ph.D., Director, New Directions for Living Well
University of Montana

Project staff of four CDC-funded state health programs (New Mexico, Montana, New York and Iowa) joined together to develop a methodology and a common evaluation instrument to evaluate the efficacy of two health promotion interventions: *Living Well with a Disability* and the *Take Charge Challenge*. In terms of intended impact, both interventions have a set of common outcomes, including:

- increasing the general physical health of people with disabilities;
- decreasing functional limitations;
- reducing the utilization of health care and thus health care costs;
- increasing their social and emotional health; and
- decreasing the incidence of secondary conditions.

The instrument developed by the consortium captures these intended outcomes utilizing questions and scales from the Behavioral Risk Factor Surveillance Survey (BRFSS). Use of BRFSS-generated questions has major advantages. First, the reliability and validity of the questions have been established through their use in repeated administrations of the BRFSS. Second, it allows a comparison of data gathered on the efficacy of interventions with data gathered from the general population through administration of the BRFSS.

The instrument was designed to be used by staff of state health departments and others who might wish to implement one of the interventions. It is briefer than previous research project-based evaluations. The instrument is now being used for pre- and post-test evaluations of the two interventions in New York, Montana, and New Mexico. With support provided by the CDC, research staff of the Center for Development and Disability at the University of New Mexico are entering and analyzing the data. Results are available to the agency that implemented the intervention, and at the same time a national dataset of evaluation data is being created.

Oregon Brief
Evaluating Health Promotion Programs:
The Need for Common Evaluation Strategies

Charles Drum, Ph.D., J.D.

Director, Oregon Office on Disability and Health
Oregon Health and Science University

Researchers are acutely aware of the need for measures that reliably and validly assess level of health and wellness at the individual and population levels, and the need for measures that are sufficiently sensitive to change. Such sensitivity is necessary to differentially measure change due to treatment as a means of assessing treatment effectiveness. Measures frequently used now to address wellness are typically limited to health-related quality of life measures. More importantly, many measures lack validity for measuring wellness for persons with a disability.

There is a pressing need to identify measures that best assess the dimensions of wellness as they pertain to persons with long-term disabilities. OODH regards wellness as a sense of harmony or coherence among the various domains or vectors of one's life. These domains typically include the physical (e.g., genetic inheritance, physical condition, gender), emotional/cognitive (e.g., feelings, self-esteem, memory, knowledge), spiritual (e.g., metaphysical factors, creativity, aesthetic self-expression), and relational (e.g., culture, community, family, social networks) spheres of one's life.

A popular wellness measure for generic populations is the *SF-36 Health Survey* (Ware, 1997). Meyers and Andresen (2000) describe modifications to the SF-36 that they found successful in making the measure more appropriate for people with disabilities. Words like "walk" and "climb" can be replaced with "go." These simple changes reduce some of the problems associated with the SF-36. Because the SF-36 is such a widely used instrument and has become a standard in health research, it is useful as a point of comparison with other measures. By itself, however, it does not address the multiple components of health.

Other instruments include the Mental, Physical, and Spiritual Well-Being Scale (Vella-Broderick & Allen, 1995); the Leddy Healthiness Scale (Leddy, 1996); the Optimal Living Profile (Renger, et al., 2000); the Perceived Wellness Survey (Adams, et al., 1997); the What's Right with Your Life?: Wellness Appraisal (Cannon, 2000); and the Health-Promoting Lifestyle Profile and Health-Promoting Lifestyle Profile II (Walker, Sechrist & Pender, 1987; in preparation).

The Health-Promoting Lifestyle Profile (Walker, Sechrist, & Pender, 1987) was developed to measure health-promoting behaviors in the domains of health responsibility, physical activity, nutrition, spiritual growth, interpersonal relations, and stress management. Internal consistency alphas for the subscales ranged from 0.70 to 0.92. Test-retest reliability correlation coefficients ranged from 0.81 to 0.91. The HPLP has since been revised to reflect more accurately current knowledge and practice. The internal consistency of the HPLP II subscales remains strong with alphas ranging from 0.79 to 0.94 (Susan Nobel Walker, *Personal Communication*, October, 2001). The measure is of a reasonable length (52 items) and has good face validity in terms of measuring the content areas of the *Healthy Lifestyles* training curriculum.

Discussion Summary
**Evaluating Health Promotion Programs for People with Disabilities
and the Need for Common Evaluation Strategies**

session facilitated by

Craig Raveslout, Ph.D., Director, New Directions for Living Well
Rural Institute: Center for Excellence in Disability Education, Research, and Service
University of Montana

Frances Stevens, M.S., Program Manager, Disability & Health Program
New York State Department of Health

1. *What are the key issues facing each state relative to the issue? What are key challenges facing each state on the topic?*
 - Measuring success in terms of the utility of and satisfaction with a training curriculum
 - Finding measures that address both the process used in the initiative and the outcome for the target audience
 - Deciding whether to measure morbidity and mortality, positive aspects of health and well being, wellness, or long-term adoption of behaviors learned from an initiative
 - Achieving a moderate length for survey instruments
 - Obtaining a good response rate to surveys
 - Overcoming inherent obstacles to sharing survey instruments due to differences in desired outcomes
 - Identifying existing scales, questions, and instruments that are valid for measuring wellness for people with disabilities

2. *Has the state implemented strategies, programs, or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from other programs that worked and didn't work?*
 - Assistance in data collection is obtained from family, friends, caregivers and residential staff to ensure accuracy of data recorded.
 - For nutrition surveys or diaries, "super size" was found to be an understandable measure of portion size for mental retardation and traumatic brain injury clients, contrasted with "regular size."
 - Four states (NM, MT, NY, IA) implementing *Living Well with a Disability* or *Take Charge Challenge* agreed upon five common outcomes that could be measured with a common instrument. Supplemental instruments would be used by states wishing to measure additional outcomes.
 - Using questions and scales from Behavioral Risk Factor Surveillance Survey (BRFSS) is beneficial because reliability and validity of the questions are established, and it allows for comparison of intervention groups with the general population.

*Evaluating Health Promotion Programs for People with Disabilities
and the Need for Common Evaluation Strategies*

- Oregon conducted an extensive review of published instruments. The revised version of Health-Promoting Lifestyle Profile has good validity, internal consistency, and relevance to Oregon's *Healthy Lifestyles* training curriculum.
3. *How can you bring this topic to the attention of policymakers in states to ensure a place for this topic on your state's public health agenda?*
- Results of evaluation have been used to get *Living Well with a Disability* included in *Healthy Iowans 2010* and to build the case for Medicaid funding.
 - Some states are seeking to present measures from evaluations compared to corresponding measures of the general population.
 - This work can be used to promote larger policy and environmental change, including getting health promotion services integrated into the health system and paid for by public and private health insurance.
4. *What opportunities are available for collaboration in this area across states to increase the influence of this initiative and work toward building a strong state network?*
- It is feasible to collaborate on a common evaluation instrument when parties can agree on the outcomes to be measured.
 - Use of published scales and measures (with known reliability and validity), when used by multiple programs, allows for the comparison of those programs and can increase the sample size for assessing results in a multisite evaluation.

**Roundtable Discussion Summary
Accessing Public and Private Funding Opportunities**

Karen Luken, Program Director,
North Carolina Office on Disability and Health

James Rimmer, Ph.D., Project Director and Professor
Department of disability and Human Development
University of Illinois at Chicago

**Importance of Identifying and Securing Funding
Outside of Primary CDC Grant Award**

Challenges:

- Less money available.
- More competition for available dollars.
- Funders desire an expanded (equitable) geographical distribution.
- Funders desire evidence of collaboration, which results in dividing the pie among more partners leaving fewer resources for the lead applicant and greater administrative overhead managing various partners.
- Increased accountability requirements (administrative burdens), including evidence-based health outcomes, cost effectiveness, and translational research that reaches "market" quickly.
- Time required to prepare grants and finding someone with good grant writing skills willing to take the lead.

Roles for state ODH:

- Identify state priorities and potential funders.
- Include disability-related health issues in state plan(s).
- Seek appropriate funds to further mission of state office, with an emphasis on non-CDC dollars.
- Share funding information with state partners, and encourage their application for local, state, and national funds that address health disparities, thereby building state capacity (and lessening the burden for state ODH).
- Encourage state programs that are addressing health disparities to include focus on individuals with disabilities, thereby expanding impact of these dollars (e.g., physical activity and nutrition programs, chronic care state collaborative).
- Serve as a reviewer for general/broad population based grant submissions to promote and ensure inclusion of individuals of disabilities.
- Utilize disability data and surveillance to impact resource allocation.

Roundtable Discussion Summary

- Develop key documents that serve as templates for funding requests.
- Share success strategies with others (within and outside the state).

Examples of North Carolina ODH Activities That May Be Helpful to Other States in Obtaining Additional Funding:

- Susan G. Komen Breast Cancer Foundation NC Triangle Affiliate: initial grant proposal denied as women with disabilities were not an established priority. NCODH submitted a position paper to the BOD that resulted in having women with disabilities identified as one of the four priority populations for this year's grant cycle. NCODH grant application is now pending.
- Reviewer for NC Health and Wellness Trust Fund grants to address childhood obesity. Served as a team manager, which allowed NCODH to promote inclusion of children with disabilities as a central expectation for each application.
- NC Governor's Crime Commission grant award to improve access to domestic violence services with the goal of impacting the state infrastructure and future agency funding.
- Serving as a clearinghouse for grants information for NCODH partners, with the goal of assisting others to prepare successful grant proposals that address state needs.

**Roundtable Discussion Summary
Strategic Planning and Advisory Groups**

India Foy, M.P.H., Project Manager
Health Promotion for People with Disabilities
Virginia Department of Health

Lisa Hershey, M.P.H., Program Manager, Office of Disability and Health
California Department of Health Services

Marcia Roth, M.P.H., Program Manager
Office on Disability and Health
Division of Public Health
North Carolina Department of Health and Human Services

Vera Kurlantzick, M.S., Program Associate
American Association on Health and Disability

Numerous individuals participated in this roundtable discussion. As a result, the round table broke into two separate discussions.

The moderators each shared some of their advisory committee and strategic planning processes and stories to date. These experiences stimulated conversations about the following issues:

- The importance of clarifying the mission, roles, and responsibilities of the Advisory Committee. For most states, the committees are there to provide input into planning, implementation, and evaluation, but not to direct the disability and health programs.
- We need to look at the continuum of public health as it relates to the disability community. For many individuals and advocates from various parts of the disability community, their primary exposure to health may be health care not public health; so, preconceived notions may exist that will require clarification.
- We need to be as inclusive as possible with our advisory committees and strategic planning processes (i.e., "Nothing About Us Without Us").
- People come to the table with their own agendas. We need to go through the full strategic planning process, with everyone actively participating to move toward a shared vision and concrete changes.
- The Logic Model may serve as a great tool for strategic and program planning.

Interestingly, the mentoring states shared with the new states that they have gone through similar processes and offered lessons learned to help the new states avoid similar pitfalls. The new states greatly appreciated all the helpful hints. And, the mentoring states recognized how far they had come.

**Roundtable Discussion Summary
Disability & Health Program in Rhode Island**

Michael Spoerri, PT, MPH, Program Specialist
Office of Special Healthcare Needs
Family Health Division
Rhode Island Department of Health

Program Description – The Disability & Health Program in Rhode Island is situated within the Office of Families Raising Children with Special Health Care Needs in the Division of Family Health. Program activities concentrate on surveillance, assistive technology, health promotion, school to work/life transition and coordinated disaster response for people with disabilities. Specific activities targeted to assist people with disabilities in RI are: (1) ongoing surveillance and publication of needs data; (2) elevate knowledge, awareness, and access to assistive technology particularly related to those with communication impairments; (3) health promotion and education; (4) system advocacy around transition; and (5) formulation and marketing of an emergency management statewide registry and response system for people with special needs.

Audience – People with disabilities in Rhode Island, healthcare providers, local agencies serving this community, other state agencies.

Collaborators – Brown University, PARI Independent Living Center, TechACCESS, Brain Injury Association, Governor's Council on Disabilities, Ticket to Work Implementation Team, Social Security Administration, Department of Human Services, Department of Education, and several other community-based and state Social Service agencies.

Outcomes – CME available to healthcare providers addressing the needs of people with disabilities available through Brown University Medical School. Several community members have been trained to provide education to consumers. Publication of disability chartbooks and fact sheets. Support of several annual community conferences.

Challenges – Implementing health promotion curriculum that encourages maximum participation by consumers. Ability to affect statewide health care systems with limited resources.

Influence Policy – The Disability and Health program in coordination with HEALTH's Facility Regulations Division is tackling communication issues for people seeking emergency medical care. The HEALTH / EMA Disability Registry revamps the emergency management response to people with disabilities.

Opportunities for Collaboration – Future opportunities for collaboration include greater efforts with existing collaborators, pursue new resources for additional collaboration and have a greater impact on state policy, additional emphasis on health promotion and access to care for people with disabilities, and formulation of statewide disaster response for people with disabilities.

Roundtable Discussion Summary
Health Provider Education Initiative: Count Us In

NC Office on Disability and Health

Pamela Dickens, M.P.H., Women's Health Coordinator

North Carolina Office On Disability & Health

University of North Carolina - Chapel Hill

Description of Initiative. *Count Us In* represents a collaborative partnership between NCODH and Duke University Medical Center, Community and Family Medicine (PERT grant 2001-2003). The objectives of this project are to: (1) increase sensitivity and awareness of primary healthcare providers & share strategies to promote breast and cervical cancer screenings among women with disabilities; (2) increase sensitivity and awareness of lay health advisors & share strategies to promote breast and cervical cancer screenings among women with disabilities; (3) increase awareness and encourage screening among women with disabilities; and (4) test a variety of methods for engaging community health promotion initiatives in targeting health education communication promoting breast and cervical cancer screening for women with disabilities. The overall goal is to demonstrate the effectiveness of different approaches in achieving these objectives to develop procedures for integrating an emphasis on women with disabilities into community-based and state programs designed to improve screening utilization. Women with disabilities have been involved in all aspects of project development, delivery and evaluation.

Target Audiences. 1) Primary healthcare providers in training at Duke University Medical Center – Physician Assistants, Family Nurse Practitioners, and Family Practice Residents; 2) Lay Health Advisors participating in 6 community-based SELF improvement projects (focused on nutrition, physical activity and smoking cessation), and 3) women with disabilities who reside in 21 counties that are home to a SELF Improvement projects.

Activities:

- The women's magazine *Orchid* was mailed to 5300 women with disabilities on Medicare in 21 NC counties that are home to a SELF Improvement projects. Medical Review of NC identified women through Medicare claims data. *Removing Barriers to Healthcare* and a *Mammography Access Checklist* was sent to mammography sites in these 21 counties.
- Disability information was incorporated into the Duke curricula for students in nursing, physician's assistants, and family medicine residency.
- A disability teleconference was presented to the 16 SELF Improvement projects in NC.
- The Breast and Cervical Cancer Screening lay health advisor curriculum, developed by the NC Breast Cancer Screening Program, was reviewed and edited to become inclusive of women with disabilities.
- Utilizing the revised LHA curriculum, training was provided to lay health advisors in 5 selected SELF Improvement Projects

Roundtable Discussion Summary

Collaborators: NC Assistive Technology Program, NCODH Health and Women with Disabilities Task Force, NC Breast Cancer Screening Project, Medical Review of NC.

Outcomes and Measures. Changes in knowledge and attitudes of providers are being evaluated via questionnaires administered before and immediately after participation in the project. Some post questionnaires have not yet been administered. After pre-and post-test results are completed, changes will be evaluated across groups. Based on feedback from trainers with disabilities, faculty, and students, the "lab" format seemed the most effective strategy used to present material.

Barriers/Challenges. Some challenges have included coordinating meetings, schedules, and presentations with faculty at Duke; identifying and coordinating participation of women with disabilities as co-trainers; finding ways to incorporate disability information into the "crowded" academic curricula; sustainability of project.

Policy. Outcomes of the project will be used to demonstrate an effective approach to provider education for improving healthcare services and breast and cervical cancer screening for women with disabilities.

Roundtable Discussion Summary

Physical Access

Roger Chapman, M.S.W., Bureau Chief
Division of Health Promotion, Prevention, and Addictive Behaviors
Iowa Department of Public Health

Description - Provide a physical assessment tool and technical assistance to health department programs to assure compliance with Americans with Disabilities Act.

Audience - Health department programs that provide services throughout the state (MCH, WIC, Substance Abuse, etc.).

How Many People Participated - As of June 30, 2003, twenty substance abuse clinics and forty-five other (MCH, WIC, local public health departments etc.) health care facilities had been evaluated.

Collaborators - The program collaborates with the state ADA coordinator (Department of Human Rights). Health Department Division Directors, and Bureau Chiefs assisted in endorsing the idea and contacting outlying clinics.

Outcomes - Participating organizations have used the survey to define barriers as a part of the required ADA transition plan.

Challenges - One Agency viewed the program as the "ADA Cops."
Convincing organizations this is a voluntary service that will assist them to prepare a transition plan.

Positive Outcomes - Increase awareness of the need for access.

Influence Policy - Substance abuse program requires completion of this survey as a part of the licensing process.

Opportunities for Collaboration - The access survey and technical assistance will be offered to other state government departments (Human Services, Employment Services etc.).

Roundtable Discussion Summary
Disability Access Project

Lisa Maisels, M.S.W., M.P.H., Project Coordinator
Office on Health and Disability
Massachusetts Department of Public Health

The goal of the Disability Access Project (formerly known as the ADA Compliance Project) is to ensure full physical and programmatic access by over 600 vendors contracted with MDPH to provide health promotion and preventive screening services. Each provider must document the accessibility of their physical site as well as policies and procedures that ensure effective communication and programmatic access. If necessary, providers must develop and implement a transition plan.

OHD consultants provide technical assistance and training to providers. A formal corrective action plan is implemented with providers who do not comply with the program.

Advancing Health Promotion for People with Disabilities on the Public Health Agenda
BWI Airport Marriott Hotel - Baltimore, MD
August 25-27, 2003

CONFERENCE AGENDA

SUNDAY, AUGUST 24, 2003

8:00pm – 9:00pm **Meeting for Facilitators, Resource Speakers,
Moderators and Recorders**

MONDAY, AUGUST 25, 2003

7:45am – 9:00am **Continental Breakfast**

8:00am – 9:15am **Registration**

9:15am – 9:45am **Welcome**
Ronald Blankenbaker, M.D.
President
American Association on Health and Disability

Edward Brann, M.D., M.P.H.
Director
Division of Human Development and Disability
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental
Disabilities

9:45am – 11:45am **Making the Connection: Physical Activity, Nutrition,
and People with Disabilities**
Facilitators: James Rimmer (IL); Susan Gray (NM)
Resource Speakers: Christopher Mackey (NC);
Gerald (Jay) Daniels (SC); Mark Swanson (AR);
Theresa Paeglow (NY)

11:45am – 1:15pm **Lunch: Roundtable Discussions**
Strategic Planning and Advisory Groups
Moderators: India Foy (VA); Lisa Hershey (CA);
Marcia Roth (NC); Vera Kurlantzick (AAHD)

Training for Health Care Professionals
Moderators: Michael Spoerri (RI); David Baker (VT)

Appendix I

CDC Interim Progress Reports

Moderator: Mary Helen Witten (CDC/NCBDDD)

1:15pm – 3:00pm

Getting Women's Health Issues for Women with Disabilities on the Public Health Agenda

Facilitator: Marcia Roth (NC)

Facilitator/ Resource Speaker: JoAnn Thierry (CDC/NCBDDD)

Resource Speakers: Pamela Dickens (NC);

Lisa Maisels (MA); Susannah Combs (NJ);

Frances Stevens (NY)

3:00pm – 3:15pm

Break

3:15pm – 4:45pm

Including the Needs and Priorities of People with Disabilities in State-Level Emergency Preparedness Initiatives

Facilitators: Anthony Cahill (NM); Juliana Cyril (CDC/NCBDDD)

Resource Speakers: Susan Gray (NM); Deborah Lisi-Baker (VT); Joyce De Cunzo (MT); Roger Chapman (IA)

4:45pm – 5:15pm

Introduction of New Tool

Speaker: Sharon Moore (CDC/NCBDDD)

6:00pm – 7:00pm

Reception for Conference Attendees

TUESDAY, AUGUST 26, 2003

7:30am – 8:30am

Continental Breakfast

8:30am – 9:15am

Keynote Address

José F. Cordero, M.D., M.P.H.

Assistant Surgeon General

Director, National Center on Birth Defects and

Developmental Disabilities

Centers for Disease Control and Prevention

9:15am – 12:15pm	Information for Decision Making: The Role of BRFSS and Other Data to Influence Public Policy <u>Facilitators:</u> Vince Campbell (CDC/NCBDDD); Suzanne McDermott (SC) <u>Resource Speakers:</u> <i>State Uses of the BRFSS:</i> David Baker (VT); Bruce Steiner (IL); Larry Steele (NY) <i>Variations on the BRFSS and Other Surveys:</i> Marcia Roth (NC); Galatea King (CA); Susan Kinne (WA); <i>Administrative Data:</i> Roger Chapman (IA); Virginie Daguse (SC); Sharon Holleran (LA)
12:15pm – 1:45pm	Lunch: Roundtable Discussions The Role of RRTC's: Collaboration and Partnerships <u>Moderators:</u> Charles Drum (OR); Anthony Cahill (NM) Disability Access Project <u>Moderators:</u> Lisa Maisels (MA); Roger Chapman (IA); Christopher Mackey (NC) Accessing Public and Private Funding Opportunities <u>Moderators:</u> Karen Luken (NC); James Rimmer (IL) AAHD: Year Two <u>Moderators:</u> Roberta Carlin (AAHD); Vera Kurlantzick (AAHD)
1:45pm – 3:15pm	Violence Prevention Programs for Persons with Disabilities <u>Facilitators:</u> Roger Chapman (IA); Mary Keener Beresford (NM) <u>Resource Speakers:</u> Maureen Foley (MA); Pamela Dickens (NC); Krista Flores (CA); Willi Horner-Johnson (OR)
3:15pm – 3:30pm	Break
3:30pm – 5:00pm	Opening the Door: Marketing Health Promotion Interventions, Research Projects, and Advisory Boards to People with Disabilities <u>Facilitators:</u> Tom Seekins (MT); Craig Ravesloot (MT) <u>Resource Speakers:</u> Marylou Stinson (SC); Judith Liddell (NM); Rene Cummins (NC); Kay DeGarmo (IA)
5:00pm – 5:30pm	Special Olympics

WEDNESDAY, AUGUST 27, 2003

7:30am – 8:30am	Continental Breakfast
8:30am-10:00am	Health Promotion Curricula for People with Disabilities: What Works, What Doesn't and Why? <u>Facilitators:</u> Charles Drum (OR); Anthony Cahill (NM) <u>Resource Speakers:</u> Deborah Lisi-Baker (VT); Willi Horner-Johnson (OR); Frances Stevens (NY); Kay DeGarmo (IA)
10:00am – 10:15am	Break
10:15am – 11:45am	Evaluating Health Promotion Programs for People with Disabilities and the Need for Common Evaluation Strategies <u>Facilitators:</u> Craig Raveslout (MT); Frances Stevens (NY) <u>Resource Speakers:</u> Roger Chapman (IA); Virginie Daguise (SC); Anthony Cahill (NM); Charles Drum (OR)
11:45pm – 12:15pm	Closing Remarks: Bringing It All Together <u>Facilitators:</u> AAHD/CDC/State Grantee Representatives

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)
NATIONAL CENTER ON BIRTH DEFECTS AND
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PRE-CONFERENCE GUIDELINES FOR FACILITATORS, RESOURCE SPEAKERS, MODERATORS, AND RECORDERS

GUIDELINES FOR FACILITATORS

OVERVIEW

In preparing for your session between now and August and in conducting the actual session at the conference, keep in mind the purpose of this meeting: to provide staff of CDC-funded state health promotion programs with information and strategies to increase the effectiveness of programs in their respective states, and to continue to build a national network of state programs.

Using these goals as your guide will allow you to be very active in preparing for and conducting your sessions. As a facilitator, you're the key to participants being ready and willing to share ideas, strategies that worked (and those that didn't), engage in fruitful conversation about the topic, and leave the conference with ideas to take back to their states.

BEFORE THE CONFERENCE

1. Contact your co-facilitator to work out who will do what and how you'll share the workload before, at and after the conference.
2. Contact the resource people for your session and make sure they understand their role -- being ready to speak for about 5 minutes about an innovation or strategy in their state on the topic, following the attached outline. Each of the resource people should send copies of their presentations to AAHD by August 1, 2003. AAHD will then put the presentations in a booklet for distribution at registration. The long advance receipt time will ensure that AAHD can have alternate formats available.
3. Use the CDC e-mail list, the AAHD list serve or both to let everyone in the state network know that you want their ideas and contributions as well. You might suggest that people e-mail you back with their ideas, questions, etc, so that you will have some material to work with in planning your facilitation. Some potential questions for state network members:

What are your questions, issues or problems you have with regard to [your topic]?

- a. What would be the most helpful thing that could happen at [your session] to make your work more successful?
- b. What are the one or two questions you'd like addressed at [your session]?
- c. Do you have any success stories, strategies that have worked for you that you would be willing to share at the conference? Do you have any stories of failures or misses that you think would be helpful for other network members to know

about (helping them avoid mistakes)? *(Remember, while the resource people have agreed to come prepared to speak briefly, the goal of the session is to have as many people as possible contribute. Urge network members to come prepared with handouts, one-page summaries, abstracts, or anything else generated in their state that would add to our knowledge of the topic).*

AT THE SESSION

1. Spend a few minutes (not more than 5!) introducing the session and yourselves.
2. Reiterate the common questions being used for all sessions:
 - What are the key issues facing each state relative to the issue? What are the key challenges facing each state on the topic?
 - Have your state implemented strategies, programs or initiatives that have worked to address this topic, or have not worked? Are the initiatives that worked transferable to other states? What lessons can other states learn from programs that worked and didn't work?
 - How can we bring this topic to the attention of policymakers in the states to ensure a place for this topic on your states public health agenda?
 - What opportunities are available for collaboration on this area across states to increase the influence of these initiatives and work towards building a strong state network?
3. Use these questions as a starting point. Be ready with probes, follow-ups, or points of clarification. Work out with your co-facilitator in advance how the two of you will run the session. (e.g., taking turns being the lead? Standing in different parts of the room and co-facilitate the whole session? Facilitators may choose to divide the four discussion questions, each facilitating two.)
4. Don't let anyone dominate the conversation, and find a nice way to cut off monologues – preferably with a little humor! For that matter, don't monopolize the conversation yourself!
5. Have at least a couple of “ringers” ready – people who have a question or comment who will, by prearrangement with you, wait until a lull or dead spot appears.
6. Make sure you move around the room, looking for people who have that “*gosh, I want to say something*” look on their face. Call on them!
7. Synthesize and summarize at appropriate points, but don't try and force conclusions too early. Remember, there will be time after the session for you, you co-facilitator and the recorder to make sense of, order and synthesize what happened at the session. Drawing either some lists or conclusions in each of the four discussion areas would be useful, provide a feeling of accomplishment, and would simplify the proceedings.
8. Never be afraid to use “challenges” to generate conversation: “*alright, that sounds like a great strategy. Is there anyone here who has tried that strategy and it hasn't worked?*”

9. For those old enough to remember Phil Donahue, use him as your role model. Your job is to elicit, encourage, and help find common ground and establish area of disagreement. If you can tap-dance or juggle as well, that's a bonus!

GUIDELINES FOR RESOURCE SPEAKERS

A Resource Speaker is a participant knowledgeable about an intervention, initiative or strategy in one of the eight topic areas listed below who will present a summary or vignette based on their experiences.

As a Resource Speaker, you are asked to speak on a panel in a plenary session with several others for approximately 5 minutes about the intervention, initiative or strategy with which your state is involved, and participate in a dialogue with the audience focusing on the four main questions described in the Conference Format section, above. Facilitators will guide the discussion.

Please prepare a **one-page summary** of interventions, innovations, or strategies in your state on the topic. Please use the following format for preparation of your one-page written summary. Send these summaries to AAHD by August 1, 2003, so they can be converted to alternate formats and distributed at the conference.

The one page summary should include the following:

1. Description of initiative/intervention/strategy
2. Describe the audience or persons involved in the initiative/intervention/strategy (e.g. people with SCI, TBI, DD, adults, children, etc.
3. How many people participated? (If the intervention was repeated, provide numbers/period and total numbers over a specified time frame)
4. What was the duration of the initiative/intervention/strategy?
5. With whom did you collaborate to carry out the initiative/intervention/strategy?
6. Describe the outcomes and what measures you used to determine the outcomes?
7. List barriers/challenges/facilitators.
8. How have you used the outcome to influence public health policy?

GUIDELINES FOR MODERATORS

Moderators will facilitate informal discussions during the Roundtable Lunch Discussions. You may want to prepare questions to start the discussion. Your role includes assuring that all roundtable participants have an opportunity to address issues of concern to them.