

**RRTC: HEALTH AND WELLNESS CONSORTIUM
2002 POLICY FORUM PROCEEDINGS**

TUESDAY, JUNE 11, 2002
WASHINGTON, D.C.

DESCRIPTION OF SPONSORING ORGANIZATION

RRTC: Health & Wellness Consortium

The RRTC: Health & Wellness Consortium is a Rehabilitation Research and Training Center (RRTC) funded by the National Institute on Disability and Rehabilitation Research (NIDRR) to conduct research and training to support the health and wellness of persons with long-term disabilities. While the RRTC is charged to promote wellness for persons with the conditions of cerebral palsy, multiple sclerosis, post polio, amputation and spinal cord injury, it is committed to promoting wellness among all persons with disabilities. RRTC: NIDRR Grant No. H133B990019

www.healthwellness.org

TABLE OF CONTENTS

AGENDA	4
PARTICIPANT LIST	6
PRESENTATION BRIEFS	
▪ “HEALTH DISPARITIES” BY GLORIA KRAHN	9
WHAT WORKS	
▪ “HEALTHCARE ACCESS AND SECONDARY CONDITIONS” BY PHIL BEATTY	11
▪ “EFFECTIVENESS OF HEALTH PROMOTION” BY CRAIG RAVESLOOT	13
▪ “HEALTHCARE AND DISABILITY: POLICY OPTIONS AND OPPORTUNITIES” BY SIMI LITVAK	14
IMPLEMENTING WHAT WORKS	
▪ “BEST PRACTICES FROM ONE PLAN” BY JOHN TSCHIDA AND CHRIS DUFF	16
▪ “BEST PRACTICES ACROSS PLANS” BY JANNA STARR	18
WORKING GROUP BRIEFS	
▪ LEGISLATION AND REGULATION	20
▪ LEGAL AND ENFORCEMENT	22
▪ COMMUNICATION	24
▪ HEALTH PROMOTION PROGRAMS	26
CONCLUSION	29

AGENDA

RRTC Policy Forum, 6/11/02
Washington Renaissance Hotel – Marriott
Congressional Room A

TIME	Topic	Presenter(s)
8:00	Continental Breakfast – all morning sessions in Congressional Room A	
WELCOME:		
	“WELCOME FROM THE RRTC ON HEALTH AND WELLNESS”	Charles Drum Oregon Health & Science University
8:30	“Welcome from the National Institute on Disability and Dissemination Research”	Theresa San Agustin National Institute on Disability and Dissemination Research
	“Introductions, Objectives”	June Isaacson Kailes Disability Policy Consultant
8:45	“HEALTH DISPARITIES”	Gloria Krahn Oregon Health & Science University
WHAT WORKS – RESEARCH:		
9:05	“Health Care Access and Secondary Conditions”	Phil Beatty NRH Center for Health and Disability Research
	“Effectiveness of Health Promotion”	Craig Ravesloot Rural Institute on Disabilities
POLICY OPTIONS AND OPPORTUNITIES:		
9:45	“Healthcare and Disability: Policy Options and Opportunities”	Simi Litvak World Institute on Disability
10:05	Break	

IMPLEMENTING WHAT WORKS:

	“Best Practices from One Plan”	John Tschida Public Affairs and Research Courage Center
10:20		Chris Duff AXIS Healthcare
	“Best Practices Across Plans”	Janna Starr Oregon Council on Developmental Disabilities

WORKING GROUP REPORTS

	Work Groups Part I	
11:00	- Legislation and Regulation – Congressional Room A - Legal and Enforcement – Meeting Room 1 - Communication – Meeting Room 2 - Health Promotion Programs – Meeting Room 3	Small Groups
12:00	Lunch	
	Work Groups Part II	
12:45	- Legislation and Regulation – Congressional Room A - Legal and Enforcement – Meeting Room 1 - Communication – Meeting Room 2 - Health Promotion Programs – Meeting Room 3	Small Groups
2:30	Break	
2:45	Group Reports and Discussion Congressional Room A	June Isaacson Kailes Disability Policy Consultant
4:00	WRAP UP AND NEXT STEPS	Charles Drum Oregon Health & Science University
4:30	Adjourn	

PARTICIPANT LIST

Phil Beatty
Senior Research Assoc
NRH Center for Health and Disability
Research
1016 16th St NW, Ste 400
Washington, DC 20036

Alan Bergman
President and CEO
Brain Injury Association of America
105 N. Alfred Street
Alexandria, VA 22314

Ruth Brannon
Associate Director
Division of Research Services, NIDRR
330 C Street, SW, Room 3413
Washington, DC 20202

Larry Burt
National Center for Birth Defects and
Developmental Disabilities
4770 Buford Highway MS F-35
Atlanta, GA 30341

Michael Cheek
Project Director
NASMD/Center for Workers with
Disabilities
810 First Street, NE, Suite 500
Washington, DC 20002

Henry Claypool
1160 N. Quincy St. #202
Arlington, VA 22201

Carla Culley
RRTC: Health & Wellness Consortium
Oregon Health & Science University
PO Box 574
Portland, OR 97207

Charles Drum
RRTC: Health & Wellness Consortium
Oregon Health & Science University
PO Box 574
Portland, OR 97207

Chris Duff
CEO
AXIS Healthcare
2356 University Ave. W., Suite 405
St. Paul, MN 55114

Bonnie Gracer
U.S. Department of Education
National Institute on Disability and
Rehabilitation Research

Bob Griss
Director
Center on Disability and Health
1522 K Street, NW, Suite 800
Washington, DC 20005

Rita Hostak
Vice President
Government Relations
11510 Chestnut Hill Drive
Matthews, NC 28105

June Kailes
Disability Policy Consultant
6201 Ocean Front Walk, Ste 2
Playa del Rey, California 90293-7556

Deb Kaplan
Director
World Institute on Disability
510 16th Street
Oakland, CA 94612

David Keer
OSERS/NIDRR
Switzer Building Room 3431A
400 Maryland Ave, SW, Washington,
D.C. 20202-2646

Gloria Krahn
RRTC: Health & Wellness Consortium
Oregon Health & Science University
PO Box 574
Portland, OR 97207

Simi Litvak
World Institute on Disability
510 16th Street
Oakland, CA 94612

Don Lollar
4770 Buford Highway, F35
Atlanta, GA 30341

Michael Marge
Executive Director
American Association on Health and
Disability
449 Old Orchard Circle
Millersville, MD 21108

Kathy McGinley
NAPAS
900 2nd St., NE #211
Washington, DC 20002

Hunter McKay
US Department of Health and Human
Services
200 Independence Ave SW
Room 424 E
Washington, DC 20201

Steve Mendelsohn
528 W. 111th
New York, NY 10025-1934

Carey O'Conner
Elderly and Disabled Program
7500 Security Blvd
Mailstop S2-14-26
Baltimore, MD 21244
Ms. Marie Oser
9304 Quail Meadow Drive
Austin, TX 78758

Marie Oser
9304 Quail Meadow Drive
Austin, TX 78758

Patricia Owens
Patricia M Owens Consultations
28 Old Fulton St. #3E
Brooklyn, NY 11201

Craig Ravesloot
Rural Institute on Disabilities
52 Corbin Hall
University of Montana
Missoula, MT 59812

Theresa San Agustin
National Institute on Disability and
Rehabilitation Research
400 Maryland Avenue, S.W.
Washington, DC 20202-2572

Liz Savage
The Arc of the United States
1730 K St., NW, Suite 1212
Washington, D.C. 2005

Mark Sherry
RRTC: Health & Wellness Consortium
Oregon Health & Science University
PO Box 574
Portland, OR 97207

Paul Spooner
Executive Director, MetroWest Center
for Independent Living
280 Irving Street
Framingham, MA 01702

Janna Starr
Executive Director
Oregon Council on Developmental
Disabilities
540 24th Place N.E.
Salem, OR 97301-4517

Sue Suter
President
Administration on Developmental
Disabilities/ HHS
200 Independence Ave. Rm. 300F
Washington, DC 2001

Tawara Taylor-Goode
Project Director
National Center for Cultural
Competence
Georgetown Child Development Center
3307 "M" Street, Suite 401
Washington, D.C. 20007

John Tshida
Sr. Director for Public Affairs and
Research
Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422

PRESENTATION BRIEFS

“HEALTH DISPARITIES AND DISABILITIES: A BRIEF REPORT”

Gloria Krahn

Director

RRTC: Health and Wellness Consortium

PO Box 574

Portland, Oregon 97207

503 494-9557

503 494-6868 (fax)

krahng@ohsu.edu

www.healthwellness.org

Gloria Krahn, PhD, MPH is the Director of the Oregon Institute on Disability & Development/University Center for Excellence in Developmental Disabilities and the RRTC on Health and Wellness for Persons with Long Term Disabilities. She is currently a faculty member of Oregon Health & Science University with a long-standing interest in disability and special health care needs, health care policy, and advancing health promotion and wellness for persons with disabilities at the person, provider and policy levels. She is past -president of the Association of University Centers on Disability and a member of the executive committees of the American Public Health Association, Disability SPIG.

“Health Disparities and Disabilities: A Brief Report”

Health status is critically important to experiencing a quality life, being self-sufficient, and participating fully in society. For the 54 million Americans with disabilities, maintaining health and wellness is especially important to reduce the impact of impairment on functioning. Yet, people with disabilities may be the largest underserved subpopulation with evidence of health status disparities, stemming in part from preventable secondary conditions. Even in the absence of large-scale population based data, information from a number of reports documents that people with disabilities as a group experience worse health than the rest of the population.

Determinants of population health outcomes have been grouped into five categories: genetic predispositions, environmental conditions, social circumstances, behavior patterns, and medical care access.¹ While the determinants of genetics, environmental exposures, and social circumstances are less easily modified, others are open to intervention.

¹ McGinnis, M. J., Williams-Russo, P., & Knickman, J. R. (2002). The case for more active policy attention to health promotion. To succeed, we need leadership that informs and motivates, economic incentives that encourage change, and science that moves the frontiers. *Health Aff.(Millwood.)*, 21, 78-93.

The Institute of Medicine has identified a number of behavioral, social or clinical interventions that effectively address health promotion behaviors. Policy and systemic changes can be instituted that increase medical care access. Utilization of proper communication techniques as well as access to health promotion programs and medical care are factors associated with preventing poor outcomes of health and wellness for people with disabilities. Assisting some in changing their individual behaviors can improve health and wellness. These behavior changes do not take care of everything, but they can provide a better chance of living healthy and well.

Financial and organizational structures of the health care system such as: the restrictions of health plan benefits, concerns about referral patterns for tests and specialists, the lack of coverage for durable medical equipment, and the fragmentation of care coordination, are barriers which result in limiting access to needed health services. In developing or revising policies to address each of these key areas, a number of issues need to be addressed. These include: prioritizing key issues, engaging the relevant constituents, determining best practices in those areas, identifying available data and needed research, developing leadership and necessary partnerships to effect policy change, and identifying available resources.

WHAT WORKS—RESEARCH:

“HEALTH CARE ACCESS AND SECONDARY CONDITIONS”

Phillip Beatty, MA

Senior Research Associate

National Rehabilitation Hospital, Center for Health and Disability Research

1016 16th St NW, Ste 400

Washington, DC 20036

202/466-1914

202/466-1911 (Fax)

phillip.beatty@medstar.net

Phillip Beatty is a Senior Research Associate at the NRH Center for Health and Disability Research, where he manages a variety of projects that examine the health care and long-term care experiences of people living with disabilities. Through analyses of nationally representative data sets, and the collection and analysis of targeted surveys of people with disabilities, Mr. Beatty works to illuminate the strengths and weaknesses of the health care system from a disability perspective. Mr. Beatty has published a number of research articles in peer-reviewed sociological, disability, and rehabilitation journals. Mr. Beatty currently directs a national, longitudinal, primary data collection effort to examine the impact of managed care on access to, utilization of, and satisfaction with health care services among people with spinal cord injury, cerebral palsy, and multiple sclerosis.

“Consistent Access to a Broad Spectrum of Health Services”

While many researchers and policy makers have suggested that there is a relationship between access to services and secondary conditions among people with disabilities, it is difficult to draw a direct empirical link between access to care (or lack thereof) and secondary conditions. This project specifically examined whether or not access to medical and specialist services in 1999 was related to subsequent experiences of secondary conditions (such as pressure sores, spasticity and contractures) in 2000. The analysis combined results from round one and round two data of a national sample of 483 adults with spinal cord injury, multiple sclerosis or cerebral palsy. Among those with no Activities of Daily Living (ADL) limitations, about five percent of those who achieved access to specialists experienced pressure sores in 2000. This is compared to 11 percent in those patients who did not have access to specialists. When looking at people with at least one ADL limitation, however, the percentage that experienced pressure sores was greater. Twenty-two percent of those with consistent access experienced pressure sores compared to around 39 percent of those without consistent access. When researchers looked at the occurrence of contractures, there was no difference between people with and without access when there was no ADL limitation present. However, for those with at least one ADL limitation, a statistically significant discrepancy arose between those with and without access who presented with contractures. Forty-six percent of those with consistent access experienced contractures, while 60 percent of those with no access reported this secondary symptom. Similarly, there was not a difference in the experience

of spasticity for those with no ADL limitations, but an almost 20 percent discrepancy in those with at least one ADL limitation. The study concluded: 1) consistent access to needed health services works to reduce the rate at which people with disabilities experience secondary conditions and 2) consistent access to health services appears to be especially important for people with more severe disabilities.

“EFFECTIVENESS OF HEALTH PROMOTION”

Dr. Craig Raveslout
Rural Institute on Disabilities
52 Corbin Hall
University of Montana
Missoula, MT 59812
406-543-9356
raves@selway.umt.edu

Dr. Craig Raveslout received his Ph.D. in Clinical Psychology from the University of Montana in 1995. Dr. Raveslout is a Licensed Clinical Psychologist who has been researching disability issues at the Research and Training Center on Rural Rehabilitation since 1988. He specializes in program development and evaluation of health and human services for people with disabilities.

“Effectiveness of Health Promotion”

Researchers at The University of Montana, Rural Institute on Disabilities developed the Living Well with a Disability Program as a health promotion intervention to reduce secondary conditions among people living with disabilities. Following the Independent Living Model, the Living Well goal-setting process respects consumer choice of goals and the materials encourage consideration of important life goals (e.g. major daily activities, interpersonal relationships, living arrangements). Over 300 individuals have completed the Living Well workshop and filled out a series of surveys that focus on a variety of health issues. Measures were collected using the Secondary Conditions Surveillance Instrument that collects self-reported data on the extent of limitation due to 44 secondary conditions. It also collects data on the utilization of a variety of medical and social services. During this first intervention period, participants reported about a 25% reduction in experienced secondary conditions. The participants were then monitored using the same measures during the year following the study at intervals of two months, four months and 12 months. Analysis of the data showed that the limitations experienced due to secondary conditions decreased for at least 12 months post study. Implications for policy are based on the idea that the Independent Living model provides services on the grounds of Independent Living necessity. The notion of Independent Living necessity should be further explored on the basis of quality independent living, rather than just medical outcome. In that regard, Living Well may be significant in its ability to enhance participation, which in turn affects secondary conditions and quality of life.

POLICY OPTIONS AND OPPORTUNITIES

“HEALTHCARE AND DISABILITY: POLICY OPTIONS AND OPPORTUNITIES”

Simi Litvak, PhD

World Institute on Disability

510 16th Street

Oakland, CA 94612

Phone 510 251 4324, Fax 510 763-4109

simi@WID.org

Simi Litvak, Ph.D., OTR, is on leave from her position as Senior Research and Policy Analyst at the World Institute on Disability (WID). She is a former director of the Rehabilitation Research and Training Center (RRTC) on Personal Assistance Services at WID. Dr. Litvak has extensive research and publishing experience in the area of independent living and is a nationally known expert on independent living, PAS, income supports, and health care access for people with disabilities. She has over thirty-five years experience in the disability field as an educator, researcher, policy analyst, policy maker, author, speaker, and rehabilitation professional. Dr. Litvak served on President Clinton's 1993 Health Care Reform Task Force. She also was a member of the Long-Range Plan Committee and the Disability Studies planning group for the National Institute on Disability and Rehabilitation Research (NIDRR). Dr. Litvak has a Ph.D. in Rehabilitation Counseling and Behavioral Disabilities.

“Healthcare and Disability: Policy Options and Opportunities”

The World Institute on Disability (WID) conducted the Wellness Policy Study in collaboration with the RRTC on Health and Wellness Consortium. The study was a systematic analysis of the statutes, regulations, procedures and practices for healthcare provision as they impact access to and participation in health maintenance opportunities by persons with long-term disabilities. The project centered around three research questions:

1. What are values and ideal services that promote wellness for persons with a primary diagnosis of MS, CP, Post Polio, SCI or amputee?
2. What are evident barriers and facilitators to health maintenance and wellness for persons with these disabilities? More specifically, what are the barriers created by public and private health insurance legislation, implementing regulations, policies and practices?
3. What are the opportunities for policy change?

Based on a literature review, a document was developed and presented at the 2001 RRTC on Health and Wellness Policy Forum. Feedback from the meeting, as well as subsequent interviews with experts in the field resulted in a comprehensive document listing of the recommendations and ideas identified by key informants. The recommendations for policy changes were summarized in five categories. Within the

Legislation category recommendations addressed: Medicare, Medicaid, medical necessity, eligibility, waivers, the Rehabilitation Act, and private insurance. The category of Regulation also included Medicaid and the expanding set of services. Enforcement addressed recommendations concerning response enhancement, compliance review, Medicaid, and physical accessibility. The final category reviewed was Taxation.

IMPLEMENTING WHAT WORKS:

“BEST PRACTICES FROM ONE PLAN”

John Tschida

Sr. Director for Public Affairs and Research
Courage Center/ AXIS Healthcare
3915 Golden Valley Road
Golden Valley, MN 55422
763-520-0533
763-520-0562 (fax)
johnt@courage.org

&

Chris Duff

CEO, AXIS Healthcare
AXIS Healthcare
2356 University Ave. W., Suite 405
St. Paul, MN 55114
(651) 556-0863
(651) 646-1887 (fax)
cduff@AXIShealth.com

John Tschida, MPP, is Senior Director of Public Affairs and Research at Courage Center, where he leads the agency's legislative efforts, explores partnership and research opportunities, and assists in strategic planning. He has been a member of the AXIS Healthcare Board of Governors since 1999.

Christopher Duff is the President/CEO of AXIS, providing operational and strategic leadership, and management of stakeholder relationships. He was actively involved in the creation of AXIS, representing Courage Center, one of its founding organizations. He has worked in the rehabilitation field for 20+ years, having started a variety of home & community-based services, and provided programmatic leadership for a transitional rehabilitation facility.

“Best Practices from One Plan”

Several years ago, the state of Minnesota decided to implement a mandatory managed care program for people with disabilities receiving Medicaid benefits. At the time, the health care delivery system was comprised of many fragmented sects that had little or no communication with each other. This lack of interaction often left the consumer with little control over his or her own situation. In answer to this problem, the Courage Center partnered with Sister Kenny Rehabilitative Services to found AXIS Healthcare. AXIS brought together persons with disabilities, providers, and payors to learn what each

needed to create a better, more cost-effective health care model for people living with disabilities.

The AXIS model places the control in the hands of the plan member and their support person; services are determined in close coordination with the primary care physician and health coordinator. With a focus on the consumer, the support person, primary care physician, and health care coordinator provide the supports that an individual needs to be able to function as they choose in their daily life.

The program has proved to be an effective partnership. The health plan is efficient in regulatory compliance and processing claims. AXIS has taken some groundbreaking steps in trying to create a new design of care coordination in Minnesota. While the system may not be completely perfected yet, the idea of care coordination seems to be a useful tool in developing new health plans. The Boutique Model of care is an innovative and effective mode of establishing quality healthcare for people with disabilities—a population of people that has some more complicated healthcare needs. Through the care-coordination technique, a lot of the problems of fragmentation are resolved, allowing for a more complete picture of health care provision to meet the client's overall needs. This system allows for personal choice in services and communication between different sects of the individual's healthcare providers and services. In this way, the person with disabilities receives individualized care and better quality service. Axis Healthcare offers a good example to draw from when looking for information on how to improve healthcare for people with disabilities.

BEST PRACTICES IN HEALTH CARE:

WHAT MIGHT WORK IN THE FUTURE FOR PEOPLE WITH DISABILITIES?

Janna Starr
Executive Director
Oregon Council on Developmental Disabilities
540 24th Place N.E.
Salem, OR 97301-4517
(503) 945-9941; (800) 292-4154 (in OR)
ODDC@aol.com or jannastarr@att.net
www.oddc.org

Janna Starr is Executive Director of the Oregon Council on Developmental Disabilities in Salem, Oregon. Previously, Janna has held several prestigious positions including; Director of Public Policy for the Brain Injury Association of America, Inc., Senior Policy Associate with United Cerebral Palsy Associations, Inc., Policy Analyst for the Oregon Advocacy Center and Executive Director of The Arc of Oregon and The Arc of Austin, Texas. Janna's research and publications include work in the areas of consumer empowerment in managed care, state best practices under the State Children's Health Insurance Program (SCHIP), health outcome measures for children with special health care needs, and public spending in regards to traumatic brain injury.

“What Might Work in the Future for People with Disabilities?”

Upon examination of existing care coordination programs, five states were identified (Oregon, Arizona, Washington, Delaware, New Mexico) with care coordination plans for acute care coordination. All programs operated within a managed health care system. These five states include a number of different care coordination models. Some are statewide, some are regional, --but all can provide guideposts for other states interested in implementing care coordination programs:

1. The development of care coordination programs takes time.
 - Buy-in from health plans and/or providers is crucial
 - Getting the systems in place can be time-consuming
 - Keeping the systems dynamic and functional is essential
 - You can begin a care coordination program at any time in program development
2. Coordination takes coordination.
 - When examining models that are currently in place, it can be seen that care coordination plans take coordination of multiple partners. These partners include, professionals and non-professionals inside and outside the health and government arenas and strong input from the consumer.
3. It is important to develop a mutual definition and understanding of the service population and an overall agreement on the direction of the coordination program.

Current barriers include:

- Confidentiality issues
- Funding and rate-setting concerns
- Development of quality assurance standards
- Implementation of the necessary information technology systems

“Super” Care Coordination programs manage long-term care services and supports in combination with acute care services. These programs have proved to be highly effective. The provision of prevention and wellness services is an additional critical issue. Seventy-five percent of people over age 65 have three or more disabling or chronic health conditions.

Telemedicine and E-Health Care include the use of technology, i.e. phones, digital video technology, and computers, to assist care providers with remote monitoring of patients, as well as tools for assisting, coaching and teaching patients. Telemedicine and e-health can ensure a greater level of consumer empowerment with an emphasis on consumer participation in medical decision-making. Telemedicine also provides a measurement tool for consumer self-care, knowledge, satisfaction, health status, and the quality of care received. Coordination costs money, as does the provision of adequate benefits, research, technology, and education of both consumers and their providers.

WORKING GROUP REPORTS:

“LEGISLATION AND REGULATION”

Group members: Janna Starr, Gloria Krahn, Ruth Brannon, Henry Claypool, Rita Hostak, Deb Kaplan, Hunter McKay, Steve Mendelsohn, Marie Oser, Liz Savage

Reducing gross inequities of health services received by those living with a disability is a significant public health concern. Eliminating these inequalities will require invigoration of Federal, state, and privatized health care delivery systems. A thorough appraisal of the relationship between the Americans with Disabilities Act (ADA) and health delivery will be needed. The ADA has not yet been utilized to its full potential in the context of health care.

The disability community must let its voice be heard in the process of modernizing the Medicare system. There are many Medicare requirements that adversely affect those living with a disability. For example, to currently qualify for Medicare home health services, a person must be “confined to his or her home”; have a physician’s plan of care and written certification that he or she is homebound; and require part-time or intermittent skilled health services. Many of those living with a disability are liberated from a homebound condition due to the care that they receive through this Medicare program. However, once they are no longer confined to the home, they no longer qualify for these services, ultimately resulting in deterioration back to a homebound condition.

There are several bills currently before Congress that, if passed or even modified, will increase access for those living with a disability to Medicare benefits, thus reducing the number of people living in a home bound condition. We would like to see the Medicare home health benefit made mandatory for those living with a disability. There is currently a nursing home benefit mandatory for people who choose or are prescribed the option. Home health care benefits should be no different.

The Center for Medicare and Medicaid Services (CMS) is beginning to recognize the need to apply ADA standards to Medicare coverage. The disability community must make the most of this recognition and target specific areas of coverage. For example, many state programs are expanding Medicare to include prescription drug benefits to those over the age of 65 but not to those with disabilities under the age of 65. The disability community can use the ADA to expand this service to those living with a disability. The disability community must also advocate for Medicare coverage of durable medical equipment and assistive technologies. No standards currently exist in the Medicare nomenclature in regards to the provision of durable medical equipment or assistive technology. Standards must be set in order for all those living with a disability to achieve the highest possible level of independence.

Medicare also serves as the primary channel in which to focus educational initiatives. The primary goal would be to gain greater influence on the training of all levels of health care professionals to increase the general knowledge in the health care community

regarding disability issues and concerns. An educated health care community with increased knowledge and accurate information will serve as invaluable allies to advocate for the right to retain health care and achieve access and reasonable accommodation for people with disabilities. Other possible allies include state legislators and possibly even national agencies such as the AARP.

Government agencies should not be the only focus when advocating for equal access and reasonable accommodation for those with disabilities. The private health care system must also be targeted. Managed care and provider organizations with large markets are becoming de facto models in the provision of services to those with disabilities. For example, much can be learned from a class action suit brought against Kaiser by disability advocates in California. The suit sought to get the Kaiser HMO system to agree to a series of reforms designed to make various aspects of the care it provides more accessible. An oversight committee was formed to bring in these changes and designs. The oversight committee has also been designated to evaluate the changes over time. This close evaluation should demonstrate the effectiveness of ADA compliance in one cohesive setting.

The precedent being set of providing equal access to covered services is an obligation that every health care provider and health plan has. The disability community should be using The Kaiser settlement agreement as a model for all providers throughout the nation. However, plans to expand equal access beyond the Californian borders do not exist within the Kaiser organization, and many of Kaiser's competitors within the state are not following suit. It is the responsibility of the disability community to advocate for equal access and increase public awareness if such services will ever become universal aspects of insurance coverage.

Another example of a creative application of the ADA to health care occurred in Texas. In this example, a doctor was fired for not meeting the performance criteria that his plan required him to meet. That is, he didn't see as many clients as he was supposed to in an allotted time. The doctor in question was primarily involved with the treatment of clients with disabilities. He was unable to meet the performance criteria due to the individual needs of his clients. The doctor argued that the treatment he provided for those with disabilities offered him protection against discrimination under the association clause in the ADA. The case was settled out of court with the doctor returning to his position.

There is much opposition on the part of health care providers in providing equal access due to the costs of treatment far outweighing the retribution they receive for their services. This is perhaps the most common issue that the ADA has been used for in health care. However, it is essential that disability advocates get beyond simply waiting for individual complaints as the only means by which to utilize the ADA. The ADA must also be used as a tool for public accountability linked to equal treatment. The ADA even has the potential of being the framework from which to establish non-discrimination standards in health care delivery.

“LEGAL AND ENFORCEMENT”

Group members: Don Lollar, Charles Drum, Alan Bergman, Simi Litvak, David Keer, Kathy McGinley, Patricia Owens, John Tshida

The Americans with Disabilities Act (ADA) does not explicitly define its application in the health care sector. This omission has led to discrepant and often conflicting interpretations regarding the rights and responsibilities consumers and health providers have under the act. Litigation and enforcement have been the traditional means used to determine ADA compliance, but these methods alone cannot improve access to health services for those living with a disability. The “Legal and Enforcement Working Group” proposed five key issues needed in the process of clarifying the relationship between the ADA and the delivery of health services. The group also identified potential strategies for the implementation of each of these key issues.

The first issue is the need for basic analysis of the Americans with Disabilities Act (ADA) as it relates to access to health and health care for people living with disabilities. There has been much emphasis on studying the ADA as it relates to employment and several other areas in recent years, but very little emphasis on the basic analysis of how the role of the ADA and access to health care and impact on health status interact. There's a need for this kind of basic information to frame the legal and enforcement issues around access to healthcare for people living with disabilities. Part of the analysis would not only be an analysis of the ADA but the various complaints related to access to health services that have come in to either the Department of Justice or Health and Human Services or the Office of Civil Rights. Numerous organizations and/or individuals could be identified to do this research. An example would be for a University to have students in its law programs conduct an extensive analysis.

The second issue is the need for education efforts to increase awareness of people with disabilities on their rights to equal access to healthcare as stated under the ADA and other civil rights laws. All spheres related to the disability community including people with disabilities, employers, healthcare providers, advocates, and others need to be included in any educational efforts. Three strategies to address the need for increased education are to:

- 1) Provide professional CME's for healthcare providers that focus on the ADA and other civil rights compliance issues.
- 2) Recognize and promote best practices of health insurance program sponsored and public health education programs. An example is the Department of Public Health in Massachusetts that actively educates all groups who have contracts with them around ADA compliance issues.
- 3) Promote and support the dissemination of educational materials on the ADA and other civil rights laws. Examples of this is supporting and promoting the efforts of DBTACs and CILS across the country.

Implicit in these strategies are the partnerships that would need to be involved, including professional associations, insurance companies, public health departments and programs, DBTACs, CILs and others.

The third issue is the need for an advocacy campaign that educates people with disabilities on the procedures necessary to file a formal complaint if they are experiencing discrimination in the healthcare system. One possible strategy is to increase emphasis on promoting the role of CILs in obtaining and facilitating complaints of noncompliance of the ADA. For example, a woman with a disability could report to her local CIL when the exam tables in her physician's office are not high enough for to obtain her medical exams. The CIL could then help her through the formal complaint process.

Fourth, there also needs to be an organized advocacy movement to look at how one can go about implementing and generalizing decisions that are made from one state to another. For example, once a decision has been made in Connecticut that requires hospitals to have interpreters, the generalization and implementation of the decision in other states does not always occur. In addition, there has been a trend toward a more narrow judicial interpretation of the ADA recently. And therefore, it's important to look at how state laws could be strengthened in order to insure the rights of people with disabilities. Trainings for advocates could be developed with the help of legal groups. There may be groups of attorneys that focus on disability issues that could serve as trainers or as helpers in moving the agenda forward. CILs could take a leadership role in organizing such trainings.

The fifth issue is funding. Funding is needed for everything from educational efforts through enforcement issues. That is, there are not enough resources for the federal agencies that are responsible for educating, researching, monitoring, enforcing or regulating the healthcare system to implement the checks and balances that are needed to ensure equal access for all persons. Part of the issue is the need to identify specific government agencies that are responsible for funding research as well as programs and other activities to conduct research and look into the relationship of the ADA and other civil rights issues and how they affect or interact with health and health care.

These five key issues will be vital in the process of expanding the interpretation of the ADA and ultimately strengthening the application of the law to the health care sector. The Americans with Disabilities Act is a comprehensive civil rights law for people with disabilities offering legal protection in employment practices, access to programs and services, and public and commercial accommodation. When applying this legal protection to health services, we as leaders in the field must be cautious in our approach and focus available resources to ensure equal access for those with disabilities.

“COMMUNICATION”

Group members: George Jesien, Mark Sherry, Michael Cheek, Tawara Taylor-Goode, Bonnie Gracer, Bob Griss, Theresa San Agustin, Paul Spooner, Sue Suter

Ensuring effective communication that is culturally and linguistically competent in all aspects of healthcare delivery must be a primary goal in the delivery of equitable and quality health services. Using this goal as the focal point, the Communication working-group generated several policy level directions and research needs required for appropriate communication. Appropriate communication will empower those with disabilities throughout the health care process, and will help ensure access for people with disabilities across all age ranges, disability groups, and from culturally and linguistically diverse backgrounds.

Culturally competent, appropriate communication in the medical setting requires facilitating interactions through interpretation and translation, and ensuring that this interaction is appropriate for the communication modes of the person (i.e. signed, cue or oral language). Suitable financing for interpreters, assistive technologies, hearing aids, and translators must be a priority of all health delivery systems. Training of health care professionals, at all levels of care, will also be necessary to ensure utilization of functional communication techniques. In order to guarantee the effectiveness of technology being utilized, there must also be some level of monitoring or regulation in place to prevent fraud and unethical behavior behind the manufacturing and selling of assistive devices.

POLICY LEVEL DIRECTIONS

Six policy level directions and strategies for ensuring effective, culturally and linguistically competent communication in all aspects of healthcare delivery were identified:

- 1) Develop standards for the provision of medical interpretation and translation services in healthcare settings.
- 2) Ensure the provision of qualified sign language interpreters as defined by the Americans with Disabilities Act.
- 3) Ensure the provision of equal access to information and communication to people with cognitive impairments through the provision of sufficient time and the opportunity to support, promote and ensure understanding.
- 4) Create alternative formats and multiple language options for all materials. This includes the use of emerging technologies such as CART (computer aided real time translation).
- 5) Monitor and enforce applicable legislation, such as Title VI of the Civil Rights Act and the Americans with Disabilities Act in terms of its obligations around cross-cultural communication (cross-cultural communication involves social interaction between individuals from different cultures that results in an exchange of meaning through symbols and message systems).
- 6) Provide training in cultural and linguistic competence and alternative means of communication to health care providers and administrators.

FUTURE DIRECTIONS IN RESEARCH

Continued and expanded research on the role of competent communication as it relates to access to healthcare is needed. Some directions for future research include the need for:

- 1) Empirical data on the impact of communication barriers on health outcomes and health care access.
- 2) Data on the relative impact of various cultural factors in the communication process in health care.
- 3) Data concerning the efficacy of interpretation and translation services and alternative formats in the delivery of health care.

Creating and maintaining partnerships is crucial to continuing research and obtaining policy level changes in our healthcare system. Federal departments such as HRSA, OMH, NIH, NIDDR, CDC, CMS, DOJ, and the DOE will need to be involved. Private institutions such as the Kaiser Foundation, the Robert Wood Johnson Foundation, the Hablamos Juntos Program, the Casey Foundation, ADAARA Disability Organization, and others could also have a leading role in the progression toward culturally competent, effective communication. Reaching out to these groups and creating buy-in to this important issue will be a vital element to pushing this agenda forward.

It is important to note that the goal set out by the Communications working-group of “ensuring effective communication that is culturally and linguistically competent” is not specific to any one population. Several populations would benefit from such communication including many overlooked constituent groups that include the aging population, late deafened people, deaf/blind people, the hard of hearing, deaf people with minimal language skills, people with cognitive impairments, people with communication disorders, homeless people, psychiatric survivors, illiterate people, recent immigrants, groups with limited English proficiency, people with central auditor processing disorders, and so on.

Significant prejudices and negative attitudes towards these overlooked populations pose as considerable barriers in the development of effective, culturally competent communication the health care setting. It has been theorized that this lack of communication leads to health needs that are not being addressed, thus ultimately leading to poorer overall health.

“HEATH PROMOTION AND WELLNESS”

Group Members: Craig Ravesloot, Chris Duff, Carey O’Conner, Michael Marge, June Kailes, Carla Culley, Phil Beatty, Larry Burt, Craig Ravesloot

Much of the work in health and wellness for those individuals living with disabilities has occurred over the last 10 to 15 years. During this relatively short time frame, focus has shifted from wondering if promoting health and wellness for those with a disability had any significance, to the current situation of needing to disseminate valuable information that can greatly improve the lives of those living with a disability. Three groups, with respect to policy implications, were identified as target areas to disseminate this information:

- 1) Consumers
- 2) Providers
- 3) Policy Makers.

Consumers

Consumers need more information to make informed and empowered health promotion choices. In order for people to obtain optimal health outcomes, good information about health promotion is a necessity. The concept of empowered and knowledgeable consumers represents a paradigm shift for everyone involved the health care process. Informed consumers will go miles in terms of informing providers, but directly educating providers will also be a key focus to ultimately improving the lives of the consumers.

In the medical field, a frequent complaint expressed by those with disabilities is, “I was told nothing else could be done for me.” However, the underlying problem is generally not ‘that nothing else can be done’, but rather those receiving services are simply not being made aware of the available information on health and wellness. To improve health outcomes, consumers need information to be recruited into health promotion. Programs and policies often provide only minimal health promotion resources without recognizing the complexity of individual consumers. Health promotion is complicated because people are complicated. The convoluted, fragmented way health care is delivered further complicates the process of educating consumers.

Providers

Providers often lack the knowledge and opportunities to deliver complete health services to those living with a disability. Although there are numerous existing health promotion programs, such programs are rarely tailored to the specific needs of people with disabilities. The Clinical Prevention Services Manual lacks a disability component as well. Tools are available for providers, but these tools must be tailored to meet the specific need of those living with a disability. Tailoring the existing resources will allow for providers to deliver more culturally competent, patient-centered care.

Policy Makers

Policy makers, by and large, are not fully educated in respect to the health promotion and wellness needs for those individuals living with disabilities. To further acquaint policy makers to these needs, outcome evidence for both individuals with disabilities and specific health promotion programs is needed. Policy makers are involved in creating access and opportunities for people with disabilities to health promotion programs. Policy makers are instrumental in the financial coverage of these programs.

Several questions must be clarified before health and wellness programs can be implemented. These questions include: What choices are expected by consumers? What responsibilities do institutions have to tailor existing services or provide new ones to fit the needs of people with disabilities? What responsibilities do insurance companies have to cover such care? These questions will all need to be resolved by policy makers in order to move health promotion beyond its current characterization of being solely a self-management concern.

Promising Practices

There are a number of current programs available that seek to educate consumers about the choices in health promotion and wellness. For example, the Living Well with Disability Program in New Mexico is currently looking to increase physical activity levels among people with disabilities who are affiliated with independent living centers. Healthy Lifestyles, conducted by Oregon Health & Science University, is another example of a promising program that directly educates consumers on health and wellness concepts.

Many current programs are also designed to improve provider knowledge. The RRTC: Health and Wellness Consortium is developing a graduate level public health course that will be integrated into the Oregon MPH curricula. A network of CIL's in Maine have been involved in educating medical students in various aspects of independent living and general awareness around disability issues. The Teen Wellness Training, another Oregon program, is attempting to educate providers around health and wellness topics salient to teens living with a disability. The University of South Carolina Family Practice Program is an exemplary model from a medical school perspective as they include a health and wellness segment in their curricula for medical students and are now tracking the outcome data.

Best practices around informing policy makers are also developing. For example, the ad hoc movement is growing. As more people combine resources, increasing opportunities to educate policy makers will be made available. CMS is playing a big role in this, and in the future, many other federal agencies that are involved in health awareness will also begin to participate in an increasingly involved fashion

Potential Strategies for Implementation

Strategies to implement changes must be realistic. Potentially involving Social Security for example, would greatly benefit the process of informing consumers, but would require an enormous amount of bureaucratic restructuring and is therefore not currently a viable option. Turning towards a more feasible strategy, insurance companies could step

forward and say, as an insurance company, we want to provide information. Health and wellness promotion would ultimately lead to lower costs for insurance companies as secondary conditions would likely decrease with the introduction of a comprehensive health promotion program. Ultimately, linking Social Security into this endeavor would be ideal, but again may not be a realistic option. Engaging all the CIL's and their satellite associations, however, is a realistic option and would greatly help to inform consumers about choices in health care, health care access, and health promotion and programming.

Educating providers will require the targeting of medical schools and the accrediting bodies of those schools. Through the dissemination of emerging data, forming partnerships with various educational institutions, and by conducting educational programs in the schools, disability health promotion could potentially become required for accreditation purposes. Potentially, medical boards would also establish specialties, as people go in for their boards, which include as part of their curriculum health care and health promotion for people with disabilities. Further research is needed on the development of standards in order to include a disability section in clinical practice guidelines. Inclusion in these guidelines would greatly influence medical practice, both for health care access and health promotion for people with disabilities.

Influencing policy makers will require a great deal of advocacy. Consumers have historically been the most powerful force in the advocacy process. When a policy maker's constituents with disabilities step forward, they are much more likely to listen. This is one of the primary ways to affect policy makers to change what happens with respect to health promotion and wellness. Targeting policy makers with personal ties in the disability field will also play a part in this process. We must connect with, and know who these people are.

CONCLUSION

We must, as a nation, seek to improve the levels of health and wellness of persons of all ages experiencing disabilities. Efforts in this area are underway, but the quantity and coordination of work must increase. Key questions as to the nature of these differences and their determinants remain unanswered. A national agenda on health and wellness for persons with disabilities and their families must speak to their real, lived experiences. Health and wellness are dynamic characteristics that are often assessed relative to expectations given one's age, life circumstance, or context. For example, individuals report feeling well relative to their advancing age or to their disability status. This knowledge, however, should not be used to condone accepting a lower standard of wellness for any group of persons, including persons with disabilities. Instead, there is a clear and pressing need to understand the determinants of differences and address them directly. This includes the contextual circumstances of children, youth, adults and elders with special health needs and disabilities. It is time to go beyond mortality and morbidity as measures of health and success of interventions, and to routinely assess self-defined wellness and quality of life in research studies.

The 2002 RRTC: Health & Wellness Policy Forum provided a opportunity for dialogue on these issues to take place between health and disability researchers, policy analysts, and advocates. The recommendations recorded in the presentations and working group summaries reflect the thoughts and opinions of policy forum participants and are reported as such. The information, recommendations, and feedback generated by the Policy Forum was utilized by the RRTC: Health & Wellness Consortium to inform future Policy Forums, a State of the Science Conference, and other health and disability work including a position paper submitted to the journal *Health Affairs*. The RRTC: Health & Wellness Consortium would like to thank all the Policy Forum participants for their contributions.