

Promoting the Health and Wellness of Women with Disabilities

Conference Program and Poster Abstracts

August 2-5, 1999. San Antonio, Texas



Conference Sponsors

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Program Presentations

Opening Moderator: JoAnn M. Thierry

- Welcome (Lesa Walker)
- CDC Activities for Promoting the Health of People with Disabilities (Richard J. Jackson)
- The Role of PHS Office of Women's Health in Assuring Inclusion of Women with Disabilities in HHS Activities (Wanda K. Jones)
- Overcoming the Odds Break (Margaret A. Nosek)

Reproductive Health Moderator: Danuta Krotoski

- Disabled Women and Reproductive Healthcare: A Contextual Overview (Anne Finger)
- Gynecological Care for Women with Disabilities (Sandra Welner)
- Sexuality and Intimate Relationships Moderator: Linda Mona
- Sexual Well-being Among Women with Disabilities: Acknowledgement, Expression, and Enjoyment (Linda Mona)
- Exclusion from Sexual Civil Liberties (Nora Baladerian)
- Barriers to Dating and Relationships (Carol Howland)
- Sexual Response in Women with Disabilities (Marca Sipski)

Reproductive Health Care Moderator: Ilene Zeitzer

- Reproductive Health Experiences of Women with Disabilities (Heather Becker)
- What Every Woman Should Know (Beverly Roberts)
- Reproductive Health Following Spinal Cord Injury (Amie Jackson)
- Preventing STD's including HIV/AIDS: Why and What You Need To Know (Barbara DeVore)
- Pregnancy, Labor, and Delivery Among Women with Disabilities Moderator: Ethel Briggs
- Infertility in Women with Causes, Evaluation and Treatment (Sandra Welner)

- Personal Perspectives on Pregnancy, Labor, and Delivery (Roseangela Berman-Bieler)
- Maintaining Your Health Through Pregnancy (Judi Rogers)
- Effects of Anesthesia on and Delivery (Glen Alper, invited)

Parenting Moderator: Denise Sherer Jacobson

- Deciding to Become a Parent (Corbette O'Toole)
- Early Caregiving and Attachment (Connie Conley-Jung)
- Preventing Secondary Injuries Resulting from Parenting Tasks (Judi Rogers)
- Challenges to Parenting Children (LaDonna Fowler)

Breast and Cervical Cancer Moderator: Elizabeth Dean-Clower

- Breast and Cervical Cancer Among Women with and without Functional Limitations (JoAnn M. Thierry)
- Breast Health Access for Women with Disabilities (Mary Smith)
- Personal Perspectives on Breast Cancer (Andrea Lynn Troncali)
- National Breast and Cervical Cancer Early Detection Program (Stephanie Dulin)

Perimenopause, Menopause, Osteoporosis and Osteoarthritis Moderator: Heather Becker

- Physiologic Changes in Menopause: Effects on Women with Disabilities (Sandra Welner)
- The Multidimensionality of Moving Through Menopause (MaryFran Sowers)
- Risk Factors for Osteoarthritis and Arthritis-Related Disability in Women (Joanne Jordan)

Health Promotion Moderator: Michael Marge

- Health Promotion for Women with Disabilities: Implications for Well-being and Quality of Life (Alexa Stuijbergen)
- Making Healthy Choices: Increasing Your Physical Activity Level (Terry Chase)

Prevention of Secondary Conditions Moderator: Renee Johnson

- Secondary Conditions: Issues in Definition and Measurement (Margaret A. Turk)
- Identifying Secondary Conditions in Women with Spinal Cord Injuries (Cheryl L. Vines)
- Secondary Conditions Among Independently Living Women With Major Disabilities (Monika Mitra)
- A Comparison of Secondary Conditions Among Women with Developmental Disabilities Living in Urban and Rural Communities (Szalda-Petree)

Physical Activity Moderator: Katherine Froehlich

- The Epidemiology of Physical Activity Among Women with Disabilities (Greg Heath)
- Increasing Physical Activity and Preventing Secondary Conditions for Women with Mobility Impairments (Glen White)
- Limitations in Physical Activity Levels and Barriers to Exercise Among African-American Women with Disabilities (Jim Rimmer)
- Personal Perspectives on Physical Activity (Sarah Snyder)

Stress Management Moderator: Jennifer Kemp

- Stress in the Lives of Women with Disabilities (Nancy Crewe)
- Perceived Stress in Individuals with Spinal Cord Injury (Diana Rintala)
- Staying Healthy When the Stress Gets to Be Too Much (Ginger Lane)

Diet and Nutrition Moderator: Margaret McLeod

- Weight Management and Chronic Disease (Dorothy Rea)
- Nutritional Status of Women with Spinal Cord Injury Living in the Community (Gladys Rodriguez)
- Personal Perspectives on Diet and Nutrition (Josephine Walker)

Adaptive Physical Activity and Sports Moderator: Kent Waldrep

- An Overview of Adaptive Physical Activity and Disability Sport (Karen DePauw)
- Barriers to Physical Activity: An Access Survey of Fitness Facilities in Kansas and New Mexico (Dot Nary and Linda McClain)
- Developing Community-Based Recreation Programs (Scott LeBlanc)
- The National Center on Physical Activity and Disability (Jim Rimmer)

Complementary and Alternative Practices: Implications for Women with Disabilities

Moderator: Carol Howland

- Potential Benefits of Complementary and Alternative Medicine for Women with Disabilities (Carol Howland)
- Use of Alternative Health Care by Individuals with Physical Disabilities (Herbert Krauss)
- Use of Complementary and Alternative Therapies in Rehabilitation (Ann Cotter)
- Dietary Supplements - The Good, the Bad, and the Unknown (Rossanne Philen)

Interventions to Promote Wellness Among Women with Disabilities

Moderator: Linda Gonzales

- The Impact of a Health Intervention for Women with Multiple Sclerosis (Alexa Stuijbergen)
- Wellness for Women with Polio (Sunny Roller)
- Promotion of and Wellness Among Women with Varying Disabilities (Nannette Vliet and Chari Cohen)
- Project W.E.A.L.T.H., Women Empowered, Aware and Learning Through Health Education (Joanne Scandale)

Aging with a Disability Moderator: Toby Lawrence (invited)

- Lifelong Disability: Premature Aging or Typical Development? (Margaret A. Turk)
- A Qualitative Exploration of the Perceptions of Women with Intellectual Disabilities Regarding Health and Aging (Allison Brown)
- Personal Perspectives on Aging (Patricia McKenna)
- Aging Gracefully with a Disability (Kathy Bishop)

Removing Barriers to Participation in Health Care Moderator: Margaret A. Nosek

This session is dedicated to the memory of Catherine F Bontke, M.D.

- Choosing the Right Doctor & Getting Appropriate Health Care: A paper by Catherine F. Bontke, MD (Margaret A. Nosek)
- Judy Panko-Reis: Development of a Health Care Clinic for Women with Disabilities
- Lorraine Woodward: Removing Barriers to Health Care: A Guide for Health Professionals
- Terry Malcolm: Working with Deaf and Hard of Hearing Women: Communication Tips and Strategies

Multicultural Health Issues Among Women with Disabilities Moderator: Ela Yazzie-King

- Jody Wildy: African-American Health Issues
- Jennie Joe: Native American Health Issues
- Lucy Wong-Hernandez: Latino Health Issues
- Corbette O'Toole: Lesbian Health Issues

Disability, Health, and the Media Moderator: Kym King

- Cyndi Jones: Disability Image in the Media
- Susan Starnes: How to Use Interactive Technology to Promote Women's Health
- Barbara Duncan: The Use of Video in Promoting a Contemporary Disability Message
- Louise Fisher: Translating Scientific Knowledge into Consumer Friendly Formats

Violence/Mental Health Moderator: Judith Heumann

- Mary Blehar: Women and Mental Health
- Carol Gill: As Bad As We Imagined: Empirical evidence of stress and distress in the Lives with Women with Disabilities
- Margaret A. Nosek: Abuse Interventions for Women with Disabilities, Going Beyond Assumptions

Recognizing Violence and Abuse Among Women with Disabilities Moderator: CDC Division of Violence Prevention Representative

- Abuse Screening in a Clinical Setting (Rosemary Hughes)
- In Their Own Voice: Definitions of Abuse and Strategies for Prevention (Susan Maley)
- Women with Developmental Disabilities and Sexual Abuse (Nora Baladerian)
- Don't Tell Me to Take a Hot Bath: A Research Project About Violence Against Women with Disabilities (Kathy Hawkins)

Depression Moderator: Hallie Duke

- Prevalence of Depression Among Women with Disabilities (Vincent Campbell)
- Factors that Relate to the Recognition of Depression (Kathy Magruder)
- Can You Manage Depression? (Mary Lee Stocks)

Strategies for Individual Change Moderator: Dot Nary

- Health Promotion Strategies for Individual Change (Gayle Timmerman)
- Readiness for Health Promotion and the Living Well with a Disability Program (Craig Ravesloot)
- The Arthritis Self-Help Course: A Successful Health Improvement Strategy (Teresa J. Brady)

Forging a State and National Health and Disability Policy Agenda Moderator: Michael Brown

- Developing Collaborations: Working with your State Office of Women's Health (Donna Scandlin)
- Integrating Disability into the Public Health Infrastructure (Deborah Allen)
- The New Healthy People 2010 Disability Objectives (Lisa Sinclair)
- Opportunities for Consumer Participation in Shaping the National Health Agenda (National Consumer Advocate)

Abuse Interventions for Women with Disabilities Moderator: Patricia A. Broderick (invited)

- Addressing Issues of Abuse within Centers for Independent Living (Nancy Swedlund)
- Educating Service Providers to Recognize Violence and Abuse Among Disabled Women (Peg Calvey and Meg McIntyre)
- Survey of Battered Women's Programs (Carol Howland)
- Domestic Violence Initiative for Women with Disabilities (Camille Ruff)

Organizing for Community Change Moderator: Kathy Martinez

- Principles of Community Engagement (Pam Wilkerson)
- A Community/Professional Partnership for Addressing the Health Concerns of Women with Disabilities (Judy Panko-Reis)
- The Tribal Disability Actualization Process: Lessons in Community Development (LaDonna Fowler)
- Development of a Community-Based Exercise Program for People with Disabilities (Bill Body)

Substance Use and Abuse Moderator: Katherine Seelman (invited)

- Prevalence of Alcohol and Illicit Drug Use Among Women with Disabilities (Jo Ann Ford)
- Eliminating Barriers to Substance Abuse Services for Women with Disabilities (Jan Garrett)

- Living Out Loud: Evaluation of a Substance Abuse Prevention Program for Disabled Female Adolescents (Ann Cupolo Freeman)
- Relief At What Cost (Kathy Hawkins)

The Intersection of Health and Employment Moderator(s): JoAnn M. Thierry and Kathy Martinez

- Welcome (Belinda Canton)
- Breaking Through Barriers to Good Health: An Overview of the Previous Three Days (Margaret A. Nosek)
- The Impact of Personal Assistance on Health and Employment (Judith Heumann)
- The Work Incentive Act: What it Means for You (Susan Daniels)
- The Presidents Initiative on Employment for Adults with Disabilities (Becky Ogle)
- Rural Issues Affecting Health and Employment (Judith Canales)
- Mentoring: A Stepping Stone to Employment (Hanilyn Rousso)
- Balancing Parenting and Employment (Pat Pound)
- What Every Woman with a Disability Should Know About Managed Care (Ellen Grabois)

Film Festival: Barbara Duncan

- I Am a Beautiful Person - Sexuality & Me
- Sexuality Reborn
- Reproductive Health for Women with Spinal
- What Every Woman Should Know
- Disability and Motherhood

Film Festival: Barbara Duncan

- Other Wise Women: Disabled Women Speak Out On Violence
- Issues & Insights: A World Forum on Women with Disabilities
- Towards Intimacy: Self Esteem, Sexuality & Love in the Lives of Women with Disabilities

Health Promotion Night Special Activities Henry B.Gonzales

Poster Abstracts

Secondary Conditions And Women With Physical Disabilities: A Descriptive Study

Nannette Vliet, MEd, Catherine Coyle, PhD, Mayra Santiago, PHD, Chari Cohen

Objectives: This study investigates self-reported health status and the prevalence and severity of secondary conditions in women with physical disabilities and examines the impact of these variables on life satisfaction.

Methods: Participants (n = 165) were randomly selected from the mailing lists of three major service organizations. The survey instrument queried participants about life satisfaction, self-reported health status, and 32 secondary disabling conditions.

Results: Neurological conditions, particularly MS, were the most often identified primary disability, followed by neuromuscular conditions, brain dysfunction, sensory impairments, and arthritic conditions. Participants reported moderate satisfaction with their current health status (M = 4.88, SD = 1.35). Despite this, an average of 12.02 secondary conditions were reported as occurring each year (SD = 6.11). Their average severity rating was 1.87 (SD = .47) indicating that secondary

conditions were viewed as moderate/occasional problems that limited activity 6 to 10 hours/week. The most frequently reported secondary conditions were fatigue, mobility, physical deconditioning, joint pain, and depression. Step-wise multiple regression analysis indicated that self-reported health status explained 50% of the variance in life satisfaction scores and the frequency and severity of conditions explained an additional 2% of the variance.

Conclusions: Self-reported health status and the frequency and severity of secondary conditions dramatically affect life satisfaction among women with physical disabilities. Although variations exist in the types of secondary conditions experienced by women with different disabilities, all women with physical disabilities routinely deal with these threats to their overall health.

Public Health Implications: Many of the secondary conditions experienced by women with physical disabilities are amenable to preventive and management strategies. There exists a pressing need to develop and disseminate materials addressing wellness issues and the prevention of secondary disabling conditions to educate not only women with physical disabilities, but health care professionals as well.

Women With Disabilities Learn Proficient Breast Self-Examination Using Adaptive Mammacare Mary Anne Mehn, PhD, Mark Kane Goldstein, PhD, H.S. Pennypacker, PhD

Objectives: This study examines the effects of Adaptive MammaCare on the Breast Self-Examination (BSE) skills of two groups of women with disabilities. MammaCare is the scientifically validated standard for teaching proficient BSE skills. MammaCare teaches BSE using tactually accurate breast models and audio/video instructions. For this study, we adapted both the breast models and instructional training protocols.

Methods: We measured the native BSE skills of 20 women who were blind or visually impaired and 18 women who were deaf or hard of hearing. We randomly assigned participants to one of two training conditions Traditional BSE (T) or Adaptive MammaCare (AM)-- in a crossover design where the effects of each training condition were measured for each participant.

Results: Using AM, participants found significantly more simulated lesions in the breast models ($P < .01$) and examined significantly more breast area ($P < .01$) than with T, independent of order of presentation.

Conclusions: The findings indicate that this group of women with sensory disabilities can reliably conduct a proficient Breast Self-Examination using Adaptive MammaCare.

Public Health Implications: An estimated 175,000 new cases of breast cancer among women will be diagnosed in 1999. The survival rate for early-detected, localized breast cancer is nearly five times greater than for breast cancer diagnosed after it has spread. Proficient, skill-based Breast Self-Examination is an effective component of early detection. Adaptive MammaCare enables women with disabilities to acquire this life-saving skill.

Age and Disease Stage Appropriate Vocational Services for Adolescent and Young Adult Females with HIV/AIDS. Patience H. White, M.D., Vincent Schuyler, B.S.W.

Objectives: The objectives of the project are threefold: 1) meet the need for, and provide a bridge to, vocational rehabilitation services for adolescents and young adults from minority populations, ages 14-26 years old with HIV/AIDS; 2) provide developmentally appropriate services according to the individual's age and stage of disease; 3) demonstrate that vocational intervention early in the disease process facilitates the transition from pediatric to adult based services and improves work readiness for this population.

Methods: Traditional and nontraditional vocational rehabilitation services were provided to adolescents and young adults with HIV/AIDS in the metropolitan Washington, D.C. area. The majority of the participants were African American females under the ages of 26 years old who lived below the poverty line and had minimal access to services.

Results: Project results will be presented for females including the following categories: 1) job placement rate; 2) educational attainment; 3) correlation of outcomes with: education level, access to health care, percentages of single mothers, numbers of children.

Conclusions: Findings indicate that in order to be successful with this population, service providers must be flexible, cognizant of the varied biopsychosocial demands placed on the patients, and able to provide services in a nontraditional manner.

Public Health Implications: As HIV/AIDS continues to make the transition from an acute short term disease to a long term chronic disease, auxiliary services, which compliment the need for continued health care, must be developed and provided for patients to maximize their resources and remain healthy and ready to work long into the future. Denial of access to the services offered by community fitness centers is a public health concern.

Fitness Center's Wheelchair Accessibility and

Inclusive Programs in Albuquerque: Advocacy Issues

Linda McClain, Roger Martin, James Hamon, and Kathy Dieruf

Objectives: The purpose of this study was to assess the degree of wheelchair accessibility (ADA, Title III compliance) of fitness centers in Albuquerque and to determine if community fitness programs were available to people with a variety of activity limitations.

Methods: Physical fitness centers (n = 25, 78% of the city's fitness centers) were randomly selected from the city's Yellow Pages. The first 25 centers contacted volunteered. An on-site evaluation (ADA compliance) and structured interview were conducted (177 items total).

Results: No facility met all of the ADA criteria. Percent compliance will be presented in bar graph format: Locker rooms 4%; Around equipment 25%; Customer service desk 32%; Restrooms 40%; Drinking Fountains 40%; Parking 56%; Telephones 56%; Path of travel 60%; Ramps 80%; Exterior doors 84%. (Specific problems will be presented.) All managers said they can provide 30 minutes of individual instruction, but few centers had personnel trained to work with people who have activity limitations. Nearly half of the facilities have educational resources for

clients and staff concerning fitness and disability. (Additional summaries of interviews will be presented.) A brochure of some of the more inclusive centers is available.

Conclusions: Title III (ADA) has not been fully implemented in Albuquerque's fitness centers. Discrimination exists. Managers appeared interested, but unprepared to provide programming.

Public Health Implications: Fitness contributes to maintaining or regaining physical health (strength, endurance, range of motion, cardiac benefits, digestion, etc.) and mental health (body image, socialization, self-esteem and mastery) for many persons. Fitness prevents a number of secondary health conditions that are linked to inactivity (obesity, weakness, depression, etc.). Denial of access to the services offered by community fitness centers is a public health concern.

Cancer Screening Among Women With and Without Disabilities in Oregon

Ann M. Pobutsky, PhD, Oregon Health Sciences University

Objectives: To examine differences in cancer screening among women in Oregon to assess whether women with disabilities avail themselves of preventive screening tests as often as women without disabilities.

Methods: Secondary analysis of data from the 1996 Behavioral Risk Factor Surveillance System (BRFSS) survey for Oregon was conducted. The CDC funded BRFSS is conducted annually in all 50 states to examine risk factors for chronic and infectious diseases; beginning in 1996, several states included questions about activity limitations (disability).

Results: More women with activity limitations indicated having ever had a mammogram than women without disabilities; interestingly, women with more severe disabilities (those requiring assistance with personal care/home management - PCHM) had the highest proportion indicating ever having a mammogram. Most women (over 90%) reported having breast exams and Pap smears. However, higher proportions of women with disabilities, especially severe (PCHM) disabilities indicated not having had mammograms, breast exams and Pap smears for longer periods.

Conclusions/Public Health Implications: This cursory examination of data from 1996 provides some evidence that women with disabilities in Oregon may not be getting adequate on-going preventive screening tests. Annual preventive cancer screening tests are important for early detection of cancer and this could be a focal point of health education concerns for women with disabilities.

Kansas Women With Disabilities at Risk for Poor Health. David Ehrenkrantz, Corinne Miller, and Dee Vernberg

Objectives: The Special 1997 Behavioral Risk Factor Surveillance Survey Questionnaire (BRFSS) was administered to determine what secondary conditions Kansans with physical and developmental disabilities are at risk for.

Methods: Three screening questions asked of approximately 3300 Kansans by telephone identified

520 adults with a disability. The questions pertained to limitations in activity, work, or if there was an inability to work due to an impairment.

Results: Kansas women with disabilities were found to be significantly more at risk for depression, obesity, chronic pain and fatigue, heart conditions, not having received a recent tetanus booster, and not having enough food for their family than their male counterparts. Women with disabilities were significantly less likely than women from the general population to have had a recent clinical breast exam, mammogram, or Pap smear.

Conclusions: Through the use of focus groups, the consensus of Kansans with disabilities is that physical and attitudinal barriers do much to jeopardize adequate prevention of the conditions mentioned above.

Public Health Implications: Interventions should be designed to heighten health professionals' awareness and sensitivity to the needs of women with disabilities. Such interventions can address access problems, such as those related to mobility or financial coverage. Others can relate to psychosocial issues, rather than just focus on physical conditions.

Health Status, Support Needs, and Life Satisfaction by Age, Gender and Geographic Area for Women with Disabilities: Findings From The District of Columbia Disability Surveillance System. La Verne Jones, MPH, Adenivi Ibikunle, MD, MPH, Adenike Bitto, MD, DrPH

Introduction: One in seven residents of the District of Columbia has a disability, 53.1% of whom are women. DC also ranks among the highest in the nation with regard to work disability.

Objective: In order to assess the magnitude of secondary conditions among persons with disabilities, the District's Department of Health (DOH), Bureau of Injury and Disability Prevention (BIDP) is expanding its surveillance capacity through the collection of epidemiologic data to determine the incidence and prevalence of secondary conditions.

Methods: Through the DC Behavior Risk Factor Surveillance System (BRFSS) questions that include a disability module, were asked through random telephone survey of the non-institutionalized population. Information on the health status, health care practices, quality of life, support needs, life satisfaction, work related injuries and activity limitations were documented including demographics and geographic area for women with disabilities. Additional data sources will be examined to determine the overall incidence and prevalence of secondary conditions among women with disabilities.

Results: Analysis of the frequency distributions will indicate the patterns and trends of primary disabilities and secondary conditions; health care habits and attitudes, and social support systems.

Conclusions: The data report will be disseminated to community leaders, grassroots organizations, research scientists and public health professionals.

Public Health Implications: Data must drive policy and program development, as well as indicate the effectiveness of existing health care and public health initiatives. This will allow for a greater involvement and participation of public and private agencies in disability-related issues.

Research To Practice: The Utilization of Data to Design and Conduct Health Education and Outreach to Women with Disabilities. Sherry Billings, BA, Adenivi Ibikunle, MD, MPH, Trina Stevens, BA, Alma McPherson, EdS

Introduction: Nationally, there are 54 million people with disabilities of whom 28 million are women. For the District of Columbia, there is an estimated 40,000 women with disabilities.

Objective: A major goal of the D.C. Department of Health (DOH), Bureau of Injury and Disability Prevention (BIDP) is the promotion of the health and wellness of all District residents.

Methods: A workshop session was held September 23, 1998 to discuss issues surrounding the health care concerns of women with disabilities. Several focus groups were held, in which approximately 75% of participants were women, to discuss issues related to the health and wellness of persons with disabilities, including addressing the specific needs of women.

Results: Female consumers stated that they were less likely to have diagnostic tests done because of the inaccessibility of health care offices, equipment and attitudes of health care providers. In addition, it was stated that a lack of exercise among women with disabilities may predispose them to cardiovascular complications.

Conclusions: Based on the outcomes of the workshop session and focus groups, a culturally sensitive curriculum, Leading the Community to Health, was developed to provide information, strategies, and resources to help in reducing the occurrence of secondary disabilities.

Public Health Implications: The prevention of secondary conditions will rely strongly on women with disabilities understanding and adopting lifestyle practices that will reduce or delay the development of such conditions.

Health and Wellness: Self-Definitions by Individuals With Disabilities. Pat Tangeman, Angela Weaver-Robuck

Objective: Using a focus group methodology, obtain self-defined definitions of wellness and healthy lifestyles, from homogeneous groups comprised of persons with disabilities.

Method: We recruited individuals with disabilities from local Independent Living Centers and D.D. Services in the Portland area. As compensation, we offered participants a \$50.00 stipend. With each participant, we also conducted a demographic and current health status survey, as well as obtained their consent. Finally, we analyzed the data by developing comparison groups.

Results: Results varied based on the homogeneous group. For example, the overall theme for defining wellness for two of the focus groups, one consisting of individuals with visual impairment and the other individuals with Spina Bifida, was obtaining and maintaining social connections and

meaningful employment. The prevalent theme for individuals of African descent with disabilities was maintaining strong family ties and religious affiliation and participation. The overriding theme for individuals with cognitive impairments was being able to access and participate in the activities of personal choice. The most consistent theme for all four groups was obtaining and maintaining social connections.

Conclusions: Good methodology for gathering this type of information. Strong basis for developing a training program. We have found that using this type of methodology has been beneficial in assisting us in deciding how to package the training materials to a particular targeted population.

Wellness and People with Disabilities: Moving Beyond the Medical Model of Disability as Illness Susan A. Maley, MPH, Training Coordinator. Oregon Institute on Disability and Development Oregon Health Sciences University

Objective: To identify how adults with physical and cognitive disabilities define wellness in their lives.

Method: As a participatory action research project, people with disabilities were involved in the planning of the project including framing the focus group questions. There were five focus groups consisting of 32 people with a range of developmental and acquired disabilities. Focus groups involved people using the services of United Cerebral Palsy, ARC of Multnomah County, and the Independent Living Resources Center in Portland, Oregon. Questions were asked about people's personal definitions of wellness, opportunities and barriers to achieving wellness and their proposed strategies for reaching their own desired level of wellness.

Results: The responses of the participants were coded and categorized into common themes. The most common definitions of wellness included physical health, socialization, and having information about how to achieve a good life. Participants most often described current opportunities as organized social and physical activities. Barriers included lack of accessibility and financial resources. More importantly, the most common barrier reported was the lack of public awareness that people with disabilities are not ill. This was especially stated in reference to health care providers.

Conclusions: The most prevalent strategy for reaching personal wellness was increasing public awareness about viewing people with disabilities as whole persons. The fact that disability does not mean illness is an important concept that needs emphasis for both health providers and the general public.

Public Health Implications: There is a need for better access to organized activities, greater awareness of the desire for wellness activities and their importance in the life of people with disabilities. The social perception of disability as illness is a barrier that prevents full access to the programs and resources that will enable people with disabilities to have the choices necessary for healthy lives, including the prevention of secondary disabilities.

Employment Skills: Enhancing Quality of Life. D.F. Rea, MA, C.M. Brownscheidle, PhD, K.M. Hovey, MS. Epstein MS, MEd, K.E. Van Slyke, C. V. Granger, MD and L. Jacobs, MD. Center for Women with Disability, Buffalo General Hospital, Buffalo, New York

The Center for Women with Disability meets the special medical, wellness, support, and risk management needs of women with physical disabilities in the eight-county Western New York region. The level of Physical disability of clients is assessed by a standard neurologic system, the Expanded Disability Status Scale (EDSS). Forty-three percent of women (mean age 43 years) with mild disability (EDSS 0-3.5) are unemployed in comparison to 78% of women (mean age 48 years) who are moderately to severely disabled (EDSS 4.0 or greater). Unemployment is associated with feelings of loneliness, pessimism, morbid or gloomy thoughts, and self-pity in 74%-76% of unemployed disabled women. Employment is viewed as a productive use of time that improves outlook on life and augments contribution to society. A Career Center within the Center for Women with Disability provided career counseling and aptitude testing, as well as individual and small group sessions in resume preparation, computer education, assertiveness training, career wardrobes, self-esteem building, interview skill development, provisions of the Americans with Disabilities Act, setting up a home office, and personal finance. The model can be implemented with little cost through the use of existing space and by drawing upon the expertise of presently employed staff through a mentoring program.

Transvaginal Ultrasound In Gynecological Care of Neurologically Impaired Patient D.F. Rea, MA, EM Gallagher, RN, NP, MSN., S.J. Epstein, MS. MEd, D.M. Weppner, MD, C.M. Brownscheidle, PhD, L. Jacobs, MD. Center for Women with Disability, Buffalo General Hospital, Buffalo, New York

Data from the Center for Women with Disability demonstrate that 43% of women with moderate to severe physical disabilities do not receive annual pelvic examinations. Gynecological care for neurologically impaired patients can be complicated. Patients may be difficult to examine manually because of their spasticity, decreased mobility, psychological distress generated by the examination, or hypersensitivity secondary to neurological impairment. Special consideration is also required for patients who cannot tolerate a full bladder. Ultrasound is an accurate and consistent method of imaging the uterus and ovaries and for identifying abnormalities in these organs and adnexal structures. Two ultrasound techniques are used in gynecological care: pelvic ultrasound and transvaginal ultrasound. Pelvic ultrasound is not invasive but requires a full bladder for accurate evaluation. The trans vaginal technique requires insertion of a probe into the vagina; a full bladder is not required. The transvaginal probe provides better image resolution because sound waves travel to a depth of only 1 to 2 centimeters before reaching the area under examination. Transvaginal ultrasound should be included in annual gynecological examinations for disabled women because it provides a mechanism for complete evaluation and care plan implementation during one office visit. Any method that is efficient and effective also enhances the compliance of disabled women in accessing gynecologic care on a regular basis.

Developmental Disabilities & Aging: Prevention & Management of Age-Related Secondary Conditions. Kelli Grogan, MPA, MRC, CRC

Objectives: (1) Identify many age-related secondary conditions faced by persons with disabilities;
(2) Discover barriers/gaps that prevent people from managing these conditions effectively;
(3) Understand effective strategies to prevent/ reduce the impact of these secondary conditions.

Methods: People with disabilities, as well as their families, physicians and other professionals came to a one-day forum to identify the major secondary conditions faced by persons with developmental disabilities. Those participating in the forum became resources for developing the curricula around these secondary conditions. A video and workbook are being produced to be available to the public at cost as early as September 1999.

Results: Flyers marketing these curricula will be part of the poster session. The poster session will have photo clips and significant information related to each of the targeted 27 secondary conditions.

Conclusions: During the lifespan, people with developmental disabilities often experience age-related health problems such as increased muscle weakness and joint pain, secondary conditions of the primary disability. Learn to recognize common secondary conditions among individuals with developmental disabilities, particularly those with Cerebral Palsy, Down Syndrome, Spina Bifida and Post-Polio Syndrome.

Public Health Implications: Understanding these conditions can help one manage them to reduce the impact on their lives or even prevent the secondary condition. The session will contain helpful prevention and intervention strategies.

Planning Committee

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Arlene Greenspan - Emory University

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Ela Yazzi-King - National Council on Disability

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Rehabilitation International: Barbara Duncan

Through the Looking Glass: Judi Rogers

Warm Springs Wheelchair Sports: Ross Davis, Scott LeBlanc, John Newinski, Diana Pisana,

World Institute on Disability: Jennifer Geagan

Other: Elizabeth Dean-Clover, Sean Ennis, Suzanne Levine, Mary Mehn, Carl Raskin, Sandra Welner

Volunteers

The Conference organizers would like to extend special appreciation to the following individuals who contributed significantly to the success of the Health Promotion Night.

Dance/Aerobics: Roger Chapman, Paula Gorman, Dawn Rodriguez

Fencing: Wendell Kubik

Fitness: Shannon Brofnahan, Elsa Moratto, Janet Weber

Golf: Scott LeBlanc

Health Screening: Tammy Perez

Self-Defense/Tai-Chi: Phillip Estrada

Wheelchair Basketball: David McGuire

Event Coordinators: Ross Davis, Scott LeBlanc, John Niewinski, Diana Pisana,