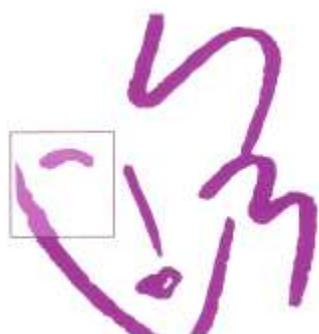


**Improving the Health and Wellness of
Women with Disabilities:
A Symposium to Establish a Research Agenda**

Executive Summary

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Center for Research on Women with Disabilities
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The study of health and wellness in the context of disability for women is relatively new, coming to light after researchers realized that disability is not necessarily the opposite of health, nor is it necessarily a gender-neutral experience. Interest in research on documenting and removing health disparities for women with disabilities has followed a decade after the rise of interest in women's health, but now professionals and consumers are demanding much more. Researchers from across the country, clinicians, educators, representative disabled women, and policy makers from federal funding agencies worked together over a two-year period to discuss what is known and what needs to be known about these health disparities. They convened in Houston in June 2003 to develop research recommendations. This report summarizes their work.

Health Disparities among Women with Disabilities

There are 28 million women with disabilities in the U.S., constituting 21% of the population of women. Functional limitations affect women more severely as they age, increasing from 6% of women ages 18-44 to 40% of women age 65 or older. Women with more extensive functional limitations are significantly more likely than women with no limitations to live alone, be divorced, have less education, be unemployed, and live in poverty. In terms of health care needs, women with functional limitations, especially younger women, are more likely to delay getting care due to cost, and be unable to get care for general medical conditions or surgery, mental health needs, dental needs, prescription medicine, or eyeglasses. Many women with disabilities face compounded barriers to health care and are underserved or unserved due to racial or ethnic minority status, sexual orientation, disability type, rural residence, or economic disadvantage. Although hypertension, depression, stress, smoking, and being overweight are concerns for women in general, these problems are significantly greater among women with functional limitations. Nearly a third of women with extensive functional limitations rate their overall health as poor compared to less than 1% of women with no limitations. These dramatic statistics warrant expanded research and dissemination of findings on improving the health of women with disabilities. For more information on the health of women with disabilities, please go to www.bcm.edu/crowd/.

Overarching Recommendations

Several themes cut across all issues related to improving the health and wellness of women with disabilities. For all of the topics listed below, each of these recommendations has a specific relevance.

- *Provider Education and Training.* Develop minimum competencies in reproductive and general health care for women with disabilities that could be included in medical school and continuing medical education curricula. Develop, evaluate, and disseminate materials and instructional programs to achieve these competencies and to increase awareness and sensitivity among health care providers about the health care needs of women with disabilities. Develop and conduct programs to encourage girls and women with disabilities to pursue careers in the sciences.
- *Measurement.* Develop and validate measures of health and health behaviors in women that carry no penalty for disability-related functional limitations. Develop and validate measures for secondary conditions that appropriately consider the disability context. Develop and validate reliable, disability-sensitive, disability-specific health outcome measures for a cross-disability population of women, including the physical, psychological, social, and spiritual domains of health.
- *Health Communication.* Determine effective methods for creating and delivering health promotion messages to girls and women with disabilities across the life span. Examine the impact of this information on the health promoting practices and health outcomes of women with disabilities. Evaluate strategies to promote effective communication between women with disabilities and their health care providers.
- *Barrier Removal.* Investigate the extent to which environmental, program, and policy barriers limit the participation of women with disabilities in health promoting activities (e.g. exercise, recreation, weight management, screenings, smoking cessation). Evaluate and implement strategies for the removal of these barriers. Determine the effect of barrier removal on the health promoting practices and health outcomes of women with disabilities.
- *Health Promotion Intervention Research.* Develop and evaluate theory-based health promotion interventions. These interventions should be grounded in the principles advanced by the women's rights movement and the disability rights movement. They should address issues of concern to women with disabilities in all age groups, using a variety of research methodologies including qualitative techniques, randomized controlled clinical trials, and longitudinal research designs. Examine strategies for integrating these interventions into programs for the general population. Evaluate the improvement in health outcomes in women with disabilities who participate in these specially designed programs compared to women with disabilities who participate in generic programs offered for women in the general population.
- *Policy Issues.* Provide input to Federal funding agencies to ensure the inclusion of issues of concern for women with disabilities in their research priorities. Identify strategies to promote inclusion of women with disabilities in medical and public health research, including clinical and drug trials.

- *Cost-Effectiveness and Evaluation.* Examine the costs and benefits of preventing, screening for, and treating secondary conditions in women, including the direct and indirect costs absorbed by families.

Specific Recommendations

Access to Health Care

Many of the health disparities identified through research on women with disabilities may be traced back to problems in accessing health care or lack of providers who are informed about health in the context of disabilities. To address these serious problems, we recommend a multi-disciplinary, multi-faceted approach to improving the availability of accessible, informed health care for women with disabilities.

- *Awareness.* Evaluate the level of awareness and understanding among primary and specialized medical providers of health and wellness in the context of disability and the connection between the accessibility of health care and health outcomes in women with disabilities.
- *Preventive Care.* Inform health care professionals about disparities for women with disabilities in preventive screenings, such as for cancer, blood pressure, cholesterol, osteoporosis, depression and sexually transmitted diseases. Develop and disseminate information resources on counseling about appropriate contraceptive techniques and reproductive health promotion for women with disabilities.
- *Accessible Diagnostic Techniques.* Examine the sensitivity and accuracy of diagnostic technology and various methods used for medical screening when applied to women with disabilities. Examine factors that influence the sensitivity and accuracy of diagnostic technology and various methods used for medical screenings for women with disabilities. Evaluate the effectiveness of different types of diagnostic and screening equipment on the quality of health care for women with disabilities.
- *Primary Care.* Identify environmental, informational, psychosocial, and economic factors that make women with disabilities less likely than women without disabilities to receive well-woman exams, screenings, and other general health care services, such as prescription medications, eye glasses, dental services, and mental health services. Develop strategies for reducing barriers to these products and services. Develop and evaluate strategies to improve access to primary health care for women with disabilities, including rural and underserved populations.
- *Rehabilitative Care.* Evaluate the standard of practice in physical medicine and rehabilitation in terms of general health and rehabilitation outcomes for women compared to men with disabilities. Examine the history and potential impact of

expanded complementary and alternative interventions (e.g. massage, acupuncture, herbal remedies) on rehabilitation medicine for women with disabilities.

- *Health Insurance.* Evaluate the impact of various types of health coverage (or the lack of it) on access to primary and specialty health care services for women with disabilities. Evaluate health benefit plans regarding cost/benefit, quality, comprehensiveness, accessibility, seamlessness, and satisfaction for women with disabilities.
- *Quality of Health Care.* Determine the adequacy of quality health indicators for women with disabilities. Examine the transition of adolescent/young adult women with disabilities to adult health care, and develop and evaluate strategies for making that transition more effective. Compare models of health care delivery as they affect the health outcomes of women with disabilities. Identify best practice models by cross-disability, specific disability, and/or specific health condition.
- *Technology.* Identify and evaluate barriers facing women with disabilities in obtaining and using assistive devices. Support collaborative relationships among health care providers, women with disabilities, and equipment developers to remove these barriers. Evaluate the costs and benefits of different types of durable medical equipment relative to health outcomes for women with disabilities. Determine the effectiveness of using telemedicine and other technologies to improve access to health care and assistive technology for women with disabilities in rural and other underserved areas.

Secondary Conditions

Disability is usually accompanied by numerous health problems, some of which are inevitable consequences of the disability and may be managed but not prevented, others may be preventable with appropriate life style modifications and appropriate health care. There is an urgent need for more information and interventions related to these conditions to reduce their impact on women with disabilities.

- *Secondary Conditions in Women.* Examine secondary conditions as they are experienced and managed by women with disabilities, addressing definitions, risk and protective factors, and self-management techniques. Conduct longitudinal studies to determine prevalence and incidence of secondary conditions in women with disabilities. Identify disparities between women with disabilities and women in general on common chronic conditions, such as hypertension, obesity, heart disease, vaginal infections, and sleep problems.
- *Impact of Secondary Conditions.* Examine the impact of secondary conditions on health, functioning, and self-perceived quality of life of women with disabilities.

- *Prevention, Screening, and Treatment.* Develop and evaluate interventions to prevent, screen for, delay the onset of, and treat secondary conditions in women. Special focus should be placed on pain, osteoporosis, weakness, fatigue, and obesity. Examine the utilization, risks, and benefits of complementary and alternative interventions on prevention and treatment of secondary conditions in women.

Reproductive Health

More and more women with disabilities are giving birth to robust children; however, the road to motherhood and reproductive health is filled with many barriers and stereotypic attitudes. General misunderstanding of the sexuality of women with disabilities has manifested in a serious lack of information and services to meet their reproductive health needs.

- *Sexual Health and Functioning.* Examine the causes and develop effective methods for treating sexual dysfunction in women with various types of disabling conditions. Examine sexual risk behaviors and develop strategies for educating teenagers with disabilities about sexual health, including abstinence and safer sex practices in relation to their disability. Develop, test, and disseminate interventions to enhance sexual esteem and reproductive health empowerment in women with disabilities.
- *Reproductive Health Status of Women with Disabilities.* Identify disparities in reproductive health between women with disabilities and women in general. Investigate the association of reproductive health problems and disability-related factors. Examine the extent to which the reproductive health care needs of women with disabilities are being met across age, geographical, cultural, and socioeconomic groups.
- *Hormonal Effects.* Investigate the reciprocal effects of natural hormonal changes during menstruation, pregnancy, and menopause with the symptoms of various disabling conditions. Examine the effects of natural and synthetic hormonal treatment on the symptoms of various disabling conditions and the risk of secondary conditions, including interactions with disability-related medications. Develop interventions to remediate or manage complications related to menstruation, pregnancy, and menopause.
- *Contraception.* Evaluate the safety, effectiveness, applicability, and affordability of current contraceptive methods used by women with various disabling conditions.
- *Pregnancy, Labor, and Delivery.* Examine reproductive decision-making by women with disabilities. Evaluate the quality of pre-pregnancy counseling for women with disabilities. Evaluate the availability, appropriateness, and accessibility of prenatal, delivery, and postpartum care for women with a variety of disabilities. Examine

pregnancy and birth outcomes across various disabilities. Develop, evaluate, and disseminate curricula for genetic counselors, primary care providers, and obstetricians/gynecologists on issues of pregnancy-related risk management and pregnancy management in the context of disability.

- *Healthy Parenting.* Promote awareness of women with disabilities as mothers. Develop, evaluate, and disseminate information for women with disabilities who are or would like to be mothers. Evaluate the effect of environmental access and social support programs on the ability of women with disabilities to care for their children and be involved in their children's activities.
- *Technology.* Develop assistive devices and products to facilitate menstrual and incontinence management for women with functional limitations. Evaluate the usefulness and safety of currently available child care equipment for women with disabilities and the effect of this equipment on their ability to care for their children. Research, develop, and market assistive devices for pregnancy management, birthing, and child care for women with functional limitations.

Psychosocial Health

Women with disabilities are faced daily with environmental barriers, lack of information about wellness in the context of disability, and negative social attitudes. Many are highly resilient to the effects of these inequities, but others do not have the positive upbringing or social support to maintain their sense of personal value. Significant disparities have been documented in mental health problems and measures of social health among women with disabilities.

- *Sense of Self.* Identify the factors that comprise and contribute to positive sense of self in women with disabilities; and evaluate the importance of sense of self in a relational context among women with disabilities, with emphasis on the impact on health. Develop, implement, and evaluate culturally appropriate measures and interventions for improving sense of self and building healthy relationships for women with disabilities.
- *Mental Health.* Identify the factors that comprise and contribute to positive mental health for women with disabilities, including coping resources, peer support, and peer mentoring. Evaluate the relation of these factors to physical health. Develop and test culturally appropriate measures and interventions to explore the etiology, prevalence, impact, risk, and protective factors for stress, anxiety, depression, and other mental health problems across the lifespan for women with disabilities, including unserved and underserved populations. Examine the prevalence of postpartum depression and its interaction with various disabilities, particularly

those involving the central nervous system, and the most effective methods for managing postpartum depression in women with disabilities.

- *Substance Abuse*. Identify the prevalence and incidence of drug and alcohol abuse, including abuse of prescription drugs, and smoking among women with disabilities of all ages. Examine the accessibility and effectiveness of existing prevention and treatment programs, identify the unmet needs of women with disabilities of all ages who experience these problems, and develop and test disability and culturally appropriate programs for underserved and unserved women with disabilities.
- *Abuse and Violence*. Identify factors that contribute to abuse and violence against women with disabilities and determine the effect it has on their lives, including on their physical and mental health. Evaluate cultural differences in definitions of violence, treatment of women, and treatment of people with disabilities and the impact of these culture-based attitudes on women with disabilities. Develop and test the effectiveness of culturally appropriate screening approaches; measures for determining prevalence, incidence, and impact; and interventions for abuse and violence against women with disabilities that can be used in clinical, community, and educational settings. Examine accessibility and compliance with the Americans with Disabilities Act among battered women's shelters and sexual assault/domestic violence service agencies.

Conclusions

The population of women with disabilities is growing at an accelerated rate across all age groups due to advances in neonatal through geriatric medicine, and for this reason it is becoming one of the most important forces in the rapidly changing dynamics of U.S. society. As more women survive disease, traumatic injury, and the consequences of war and environmental degradation, they will be resuming their social roles with functional limitations and will present even more complex medical needs to a health care system that is unprepared to handle them. This situation demands the attention of all sectors involved in creating a health care system for the twenty-first century. Increasing visibility of these issues and emerging collaborations among clinicians, health care educators, researchers, funding sources, feminist disability rights activists, and the media have the power to ensure a place at the planning table for women with disabilities.

The recommendations that have resulted from this project will serve as the seeds for new and expanded funding channels for research and training in a wide variety of disability- and health-related topics. We look forward to the day when collaborations and communications initiated through this symposium will result in print and web-based information that will be easily available to consumers, clinicians, researchers, and

educators so they may be empowered to do all within their power to improve the health of women with disabilities.

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