Addressing Menopause and Health Across the Life Course for Dually Eligible Women with Disability (WWD)

Credit Information

- This program is Approved by the National Association of Social Workers (NASW) (Approval # 886791040-3038) for 1 continuing education (CE) contact hours.
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- The audio portion of the presentation will automatically stream through your computer speakers. There is not a phone dial-in option.
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Platform Tips

Addressing Menopause and Health Across the Life Course for Dually Eligible WWD

Overview

- This session will include presentations, followed by a panel discussion and live question and answer (Q&A) with panelists and participants

- Video replay and slide presentation are available after each session at: https://www.resourcesforintegratedcare.com

Accreditation

- **Individuals are strongly encouraged to check with their specific regulatory boards or other agencies to confirm that courses taken from these accrediting bodies will be accepted by that entity.**
- The NASW is accredited to provide CE for social workers.

CE Information

If You Are A:	Credit Hour Option	Requirements
National Association of Social Workers		
Social Worker	The NASW designates this webinar for a maximum of 1 CE credit hour. **Please note:** New York, Michigan, and West Virginia do not accept National CE Approval Programs for Social Work. New Jersey, Idaho, and Oregon do not recognize NASW National Approval.	1. Complete the pre-test at the beginning of the webinar 2. Complete the post-test with a score of 80 percent or higher by 11:59pm **October 17, 2023**

Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.
- To learn more about current efforts and resources:
  - Visit https://www.resourcesforintegratedcare.com
  - Follow us on X (formerly Twitter): @Integrate_Care
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Webinar Outline

- Introductions
- Learning Objectives
- Polls
- Background
- Speaker Presentations:
  - Health Equity for WWD: Future Connections, Practices, and Action – Dr. Beth Marks, PhD, RN, FAAN
  - Supporting WWD During Menopause: Considerations for Providers – Dr. John Harris, MD, MSc
  - Enhancing Disability-Competent Care (DCC) for Dually Eligible WWD Across the Continuum of Care – Claire Abenante, RN, BSN
- Panel Discussion
- Audience Q&A
- Closing Remarks

Introductions

- **Beth Marks, PhD, RN, FAAN**

  Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago;

  Former President, National Organization of Nurses with Disabilities

- **John A. Harris, MD, MSc**

  Director, University of Pittsburgh Medical Center (UPMC) Magee-Womens Hospital Center for Women with Disabilities;

  Assistant Professor, Magee-Womens Research Institute, University of Pittsburgh

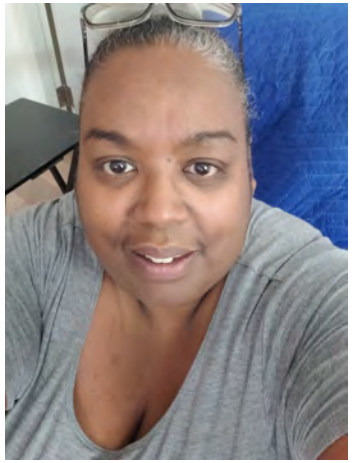
Introductions, cont.

- **Claire Abenante, RN, BSN**

  Director of Primary Care and Women's Health Access Program, Independence Care System (ICS)

- **Evelyn Castillo**

  ICS Member, Disability Activist, Facilitator, and Crisis Responder



Learning Objectives

- Identify the unique challenges experienced by dually eligible women living with disability with a particular focus on preventive health and health equity.
- Describe actionable strategies that providers or health plans can use to enhance DCC for women living with disability pre-menopause and post-menopause.
- Discuss approaches that support health promotion for WWD during and after the menopausal transition.

Poll

In what care setting do you work?

- Health Plan
- Ambulatory Care Setting
- Long-Term Care Facility
- Home Care Agency
- Community-Based Organization
- Consumer Organization
- Academic / Research
- Other

Poll

Which of the following best describes your professional area?

- Health Plan Case Manager / Care Coordinator
- Health Plan Customer Service
- Health Plan Administration / Management
- Medicine / Nursing / Physician Assistant / Other Provider
- Pharmacy
- Social Work
- Advocacy
- Other

Background

- In 2020, 12.2 million individuals were dually eligible for Medicare and Medicaid. Fifty-one percent of those dually eligible individuals qualified for Medicare based on disability status. Fifty-nine percent of those dually eligible individuals were female.[1]
- In the U.S., approximately 1.3 million women transition into menopause each year, which typically begins between the ages of 45 and 55.[2]
- For every year older a woman is when reaching menopause, her breast cancer risk increases by three percent.[3]
- Postmenopausal women are at a higher risk of osteopenia and osteoporotic fracture and may experience changes in cardiovascular health.[4]

Background, cont.

- WWD or impairments that affect their mobility are at an increased risk for conditions associated with menopause, including heart disease and osteoporosis.[5]
- Women living with disability are less likely than women without disability to receive preventative health care.
  - These include pelvic exams, mammograms,[6] and bone density screenings.[7]
  - Reasons for this include a lack of accessible facilities, equipment, health care provider awareness, or transportation.[8]
- This webinar builds on information shared during the Resources for Integrated Care (RIC) webinar *Supporting the Preventive Health Care Needs of Dually Eligible Women with Disability*, held in 2021.

Health Equity for WWD: Future Connections, Practices, and Action

Beth Marks, PhD, RN, FAAN

Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago;

Former President, National Organization of Nurses with Disabilities

UIC University of Illinois at Chicago Department of Disability and Human Development
College of Applied Health Sciences

UIC University of Illinois Chicago
Institute on Disability and Human Development

HealthMatters™ Program

Presentation Focus Areas

- Health Care Interactions: Identify structural or social determinants of health (S/SDOH) for WWD to ensure access to settings-based health care.
- Health Advocacy: Discuss health and social justice landscape for WWD to uproot structural and systemic bias and ableism.
- Universal Health Care Access: Apply the full continuum of essential health services, from health promotion to disease prevention, treatment, rehabilitation, and palliative care reflecting disability cultural humility.

Evolving Language: Person-First and Identity-First Language

- Attitude and words matter, and language is not one-size-fits-all.[9]
- Person-first language intends to:
  - Fight back against stigma
  - Emphasize personhood
  - Remind that a person is more than their disability
- Identity-first language intends to:
  - Recognize “disability” and “disabled” as an indicator of identity
  - Value disability as a source of positive identity, pride, and solidarity

Photo: Knežević, M. (2015). Life of “Wheelchair Bound” and “Confined to a Wheelchair.” *Spinal Cord Injury Zone.* Retrieved from https://spinalcordinjuryzone.com/info/15523/life-of-wheelchair-bound-and-confined-to-a-wheelchair.

Definition of Disability

An individual with a disability is defined by the Americans with Disabilities Act (ADA) of 1990 as a person who…

- Has a physical or mental impairment that substantially limits one or more major life activities,
- Has a history or record of such an impairment, or
- Is perceived by others as having such an impairment.[10]

The ADA Shifts Our View of Disability From a Medical Model to a Social Model

- Medical Model:[11]
  - Assumes that an individual's autonomy is limited because of their disability or impairment, and consequently has a limited ability to participate in society, leading to social exclusion.
  - Tasks medical professionals or specialists with rectifying or curing the impairment.
- Social Model:
  - Focuses on the external environment causing the problems that disable the individual, suggesting that disability is socially constructed.
  - Advocates for the removal of social barriers; promotes inclusion and social change leading to societal transformation.
- With the ADA, we can understand and dismantle the external structural and systemic barriers for people with disability to access equitable health care versus a sole focus on "curing" people's "impairments" or disability.

Health Disparities Knowledge Can Impact Physician Attitudes

Results from a 2023 ADA survey of 714 US physicians in outpatient practices:[12]

- Over 70 percent did not know who determines accommodations.
- About 68 percent felt at risk for ADA lawsuits.
- More than 35 percent reported little or no knowledge about their legal responsibilities.
- At least 20 percent could not identify who pays for needed accommodations.

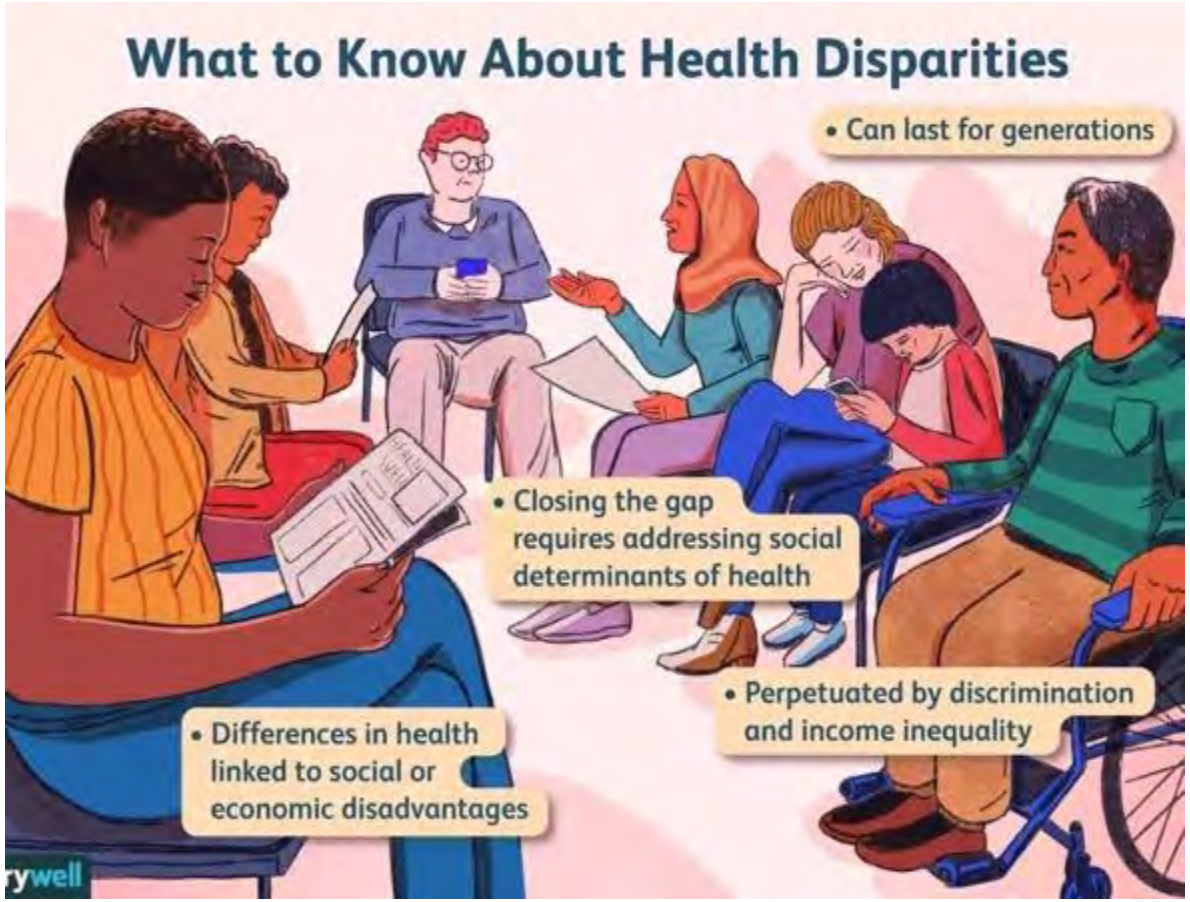


Photo: Madamba, D. (2023). *What to Know About Health Disparities*. Verywell Health. Retrieved from https://www.verywellhealth.com/health-disparities-4173220.

People with Disability are Family, Friends, and Neighbors

- Approximately 16 percent of the global population lives with disability.[13]
- Medical advances are supporting more people with disability.
- Most disabilities are non-apparent.

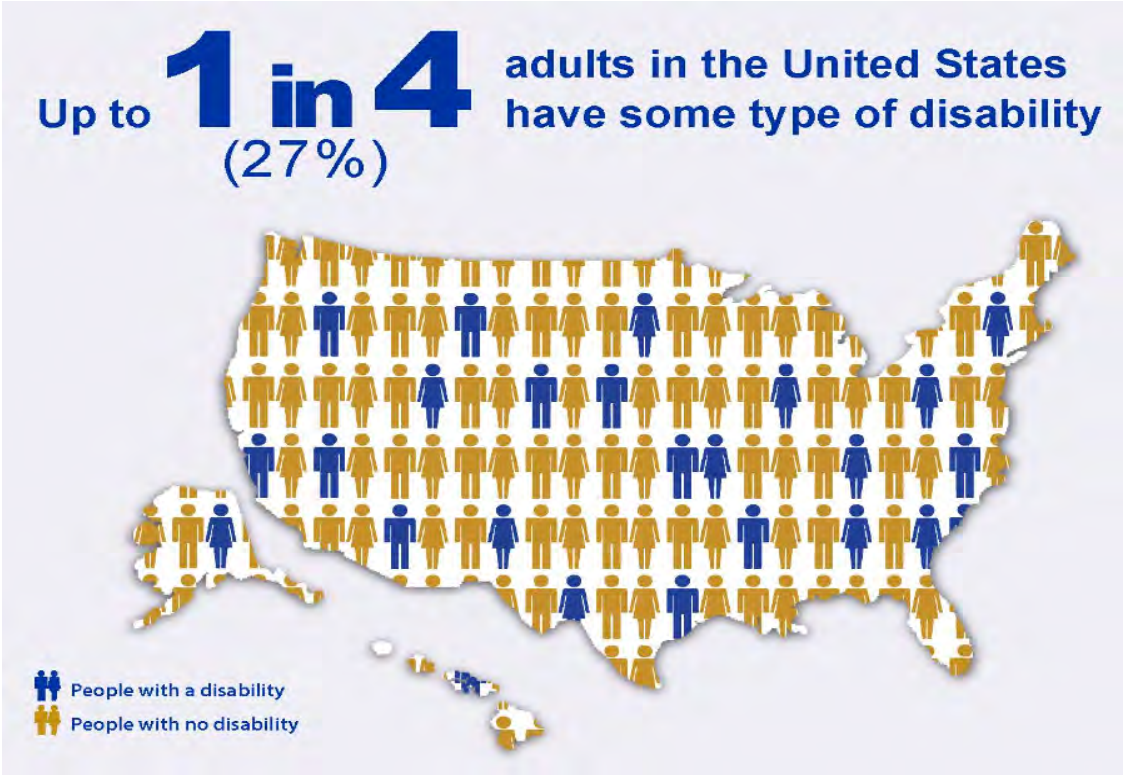


Photo: Centers for Disease Control and Prevention. (2023). *Disability Impacts All of Us*. Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html.

People with Disability are Family, Friends, and Neighbors, cont.

The Centers for Disease Control and Prevention (CDC) reports the following population estimates for people with disability:[14]

- Serious difficulty walking or climbing stairs affects 12.1 percent of people.
- Serious difficulty concentrating, remembering, or making decisions affects 12.8 percent of people.
- Difficulty doing errands alone affects 7.2 percent of people.
- Deafness or serious difficulty hearing affects 6.1 percent of people.
- Blindness or serious difficulty seeing affects 4.8 percent of people.
- Difficulty dressing or bathing affects 3.6 percent of people.

Legal and Social Landscape Changes

"Disability Is A Natural and Beautiful Part of Human Diversity" - Disability Pride Parade Mission Statement[15]

1935

Access to Medical Care
Title V:
Grants to States for Maternal and Child Welfare

1973

Access to Social Environments
Section 504 of the Rehabilitation Act of 1973

1975

Right to Education
The Education For All Handicapped Children Act of 1975 (renamed in 2004 Individuals with Disabilities Education Act)[16]

1990 & 2008

Access to Social Environments (public and private)
ADA of 1990; ADA Amendments Act (2008)

2014

Access to Employment
7 Percent Rule – Office of Federal Contract Compliance Programs Section 503 of the Rehab Act of 1973

2021

Diversity, Equity, Inclusion, and Accessibility (DEIA)
Executive Orders 13985/14035[17]

2023

National Institute on Minority Health and Health Disparities
Designates people with disability as a population with health disparities[18]

Top Photo: Winter, M. (1990). *American Disabled for Attendant Programs Today*. ADAPT. Retrieved from https://adapt.org/1990-washington-michael-winter/.
Bottom Left Photo: Maggiora, V. (1977). *Heumann Protests in 1977*. San Francisco Chronicle/Polaris. Retrieved from https://time.com/5870468/americans-with-disabilities-act-coronavirus/.
Bottom Right Photo: Crip Camp. (2020). *Crip Camp: A Disability Revolution*. Retrieved from https://cripcamp.com/.

Unmasking Health Care Ableism

- Ableism starts with an attitude that people with disability are intrinsically "less than," and is rooted in the assumption that people with disability require "fixing," and defines people by their disability.[19]
- Like racism and sexism, ableism classifies entire groups of people as "less than," and includes harmful stereotypes, misconceptions, and generalizations about people with disability.
- Discrimination experienced by people with disability is often seen as a social etiquette issue (or common sense) versus a social justice or equity issue.
- Providers consciously have good intentions and positive attitudes toward people with disability, but research indicates pervasive, implicitly negative attitudes.[20]

Improved Cultural Humility and Equitable Health Outcomes

A 2020 study reported that 83.6 percent of health care professionals implicitly preferred people without disability.[21]

- Professionals may view individuals with disability as *having lower quality of life or being unwell* as a result of their disability.

The CDC describes health care access barriers for working-age adults:[22]

- One in four adults with disability (18-44 years) do not have a usual health care provider.
- One in five adults with disability (18-44 years) have an unmet health care need because of cost in the past year.
- One in four adults with disability (45-64 years) did not have a routine check-up in the past year.

Accessing Equitable Health Care: Lifelong Challenges for Women

- People with disability are often “on their own” in obtaining health care and may be denied care due to outdated attitudes.
- People who are born with a disability or acquire a disability often do not share their disability identity with families and supports.
- Role models, including disabled health care professionals, can:
  - Model advocacy skills.
  - Teach strategies to navigate access to disability legal and civil rights.
  - Demonstrate the value of their disability and disability history as a source of pride.

Disparate Health Outcomes and "Weathering" Among WWD

- WWD experience "weathering" as a chronic, stress-related biological process increasing vulnerability with earlier onset and more chronic diseases, which is magnified among women with multiple underserved identities and disabilities, especially people with intellectual and developmental disability.[23]
- WWD are more likely than women without disability to have chronic conditions.[24]

Disparate Health Outcomes and "Weathering" Among WWD, cont.

Compared to women without disability, WWD experience:[25,26]

- Less health care access.
- More intimate partner violence (e.g., sexual and physical violence, stalking, psychological aggression, and control of reproductive or sexual health).
- Lower rates of breast and cervical cancer screening.
- Higher rates of breast cancer mortality among women with circulatory or respiratory conditions.
- Earlier death.

Considerations for Improving the Health Outcomes for WWD

Plans and providers can support dually eligible WWD in living longer with new health conditions and health care needs, in a context with significant disparities in health care and health outcome due to S/SDOH, by:

- Working towards changing attitudes and expectations about living meaningful lives with a disability.
- Supporting women's access to *shared experiences with other women or role models with disability.*
- Understanding that multiple chronic conditions is an under addressed issue for people with different types of disability.

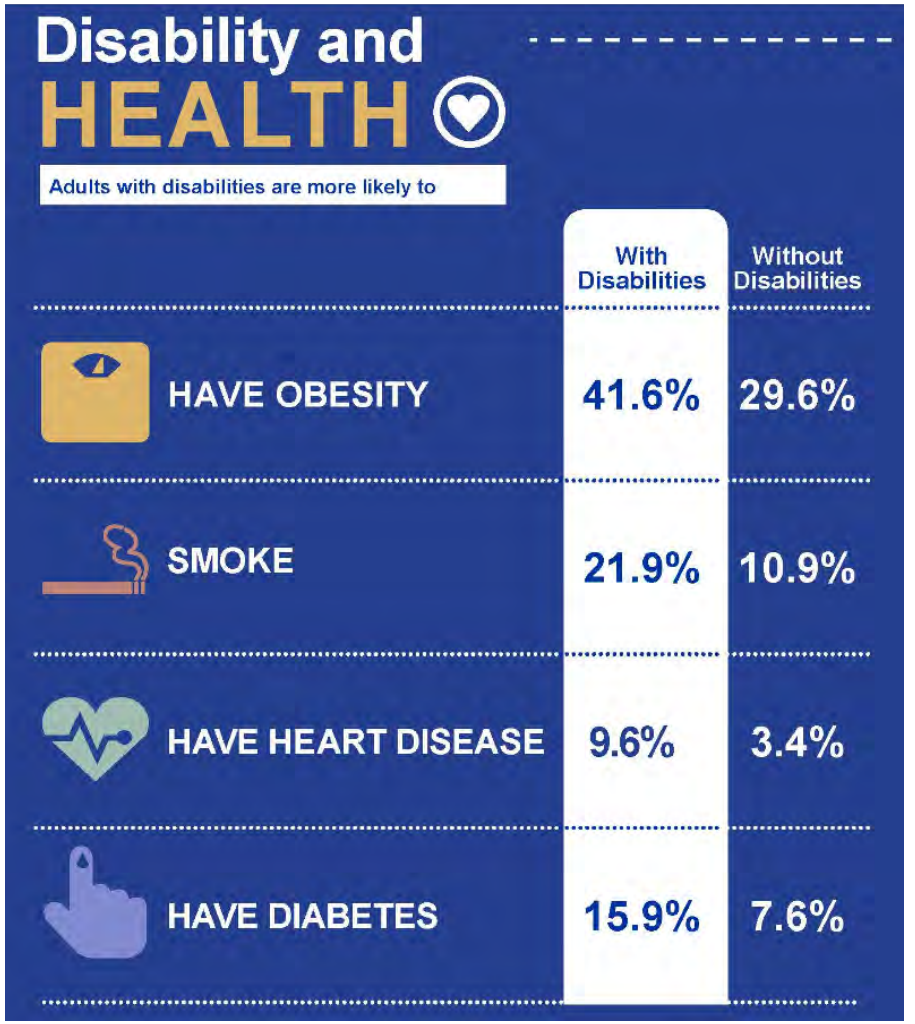


Photo: Centers for Disease Control and Prevention. (2023). *Disability Impacts All of Us*. Retrieved from https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html.

Considerations for Treating Comorbidities

Health plans and providers can address complex health conditions by focusing on disability-related care.

- **Avoid diagnostic overshadowing**, the assumption that an individual's symptoms are due to their disability.[27]
  - Diagnostic overshadowing may be more of a concern with *poorly managed multiple chronic conditions* (e.g., high cholesterol, hypertension, cardiovascular disease, obesity, mental health concerns).
- **Complete screening tests regularly**.[28]
  - Undetected health issues can be due to a lack of screening and prevention for vision, oral health, hearing, mental health, fitness, and cancer.

Considerations for Improving Health Care Access

Health plans and providers can improve access to health care in multiple ways:

- **Ensure accessible health care spaces** by considering buildings, practices, equipment, and communication (e.g., structural barriers) through a lens of accessibility.
- **Educate clinicians** about the care of people with disability and person-first and identify-first language.
- **Improve health literacy** among people with disability to increase engagement or participation in their care.

Health Plans Can Improve Access and Uptake of Preventive Services

- WWD exist across many communities experiencing inequities related to race, gender, ethnicity, and sexual orientation.
  - Health plans can ensure screening tools such as the **EveryONE Project** and the **Neighborhood Navigator** are used to assess, discuss, and include strategies to address S/SDOH impacting WWD in treatment plans.
- Universal Design and accessible communication strategies can help health systems welcome women across all communities.
  - Universal Design refers to the practice of intentionally designing spaces or materials to best support the accessibility needs of a large range of people.[29]

Policies to Improve Health Care Equity

Health plans and providers can adopt these policies to improve equity:

- Ensure compliance with the requirements of the ADA of 1990 and the ADA Amendments Act of 2008.
- Provide equitable reimbursement to providers for accommodations.
- Avoid inequitable discharge of people with disability from their practices.
- Provide interprofessional provider education to eliminate bias and reluctance to care for people with disability.
- Expand beyond a medicalized view of disability as an inherently negative trait to a view of disability as a marker of diversity.
- Provide information on respectful interactions for all individuals.
- Advocate for accessibility and use disability-friendly expressions.

Practices to Improve Health Care Equity

Health plans and providers can take these steps to improve equity:

- Address attitudinal, physical, communication, social, financial, transportation, and policy-based barriers.
- Ensure compliance among providers in the health plan or system by:
  - Participating in disability education and training programs to understand disability and legal and civil rights.
  - Improving clinical knowledge and care for WWD, including assessment skills to properly examine WWD and assessing sexual history, sexual violence, reproductive preferences, pregnancy intention, and preventive health screenings.
  - Practicing person-centered care with all health encounters; emphasizing respect for individuals' preferences, needs, and values.
- Reduce structural barriers for persons with disability.

Considerations for Moving Health Care Upstream to Address S/SDOH

By addressing S/SDOH up front, providers can intervene before there becomes a need for urgent, reactive care.

- **Downstream Care** – treat immediate health needs.
- **Midstream and Upstream Action** – midstream (i.e., intermediary determinants such as housing and employment) and upstream interventions (i.e., structural factors that support health equity) to address S/SDOH that shape care and management of various conditions.
- **Screening S/SDOH and Action Plan** – assesses housing, food, utilities, childcare, transportation, employment, education, finances, and safety needs.
  - **S/SDOH Questionnaire** – individuals may disclose more information if they answer the S/SDOH tool by themselves.
  - Neighborhood Navigator – interactive tool to connect individuals with support resources in their neighborhood.[30]
  - **Teachable Moments** – support individuals to treat symptoms and diseases with support from local community services.

Provider-Patient Concordance: Education and Career Gaps

- **Recruit and employ** health professionals with disability.
  - Percentage of graduates with a disability in:
    - Nursing school: unknown
    - Medical school: <5 percent (disclosed)[31]
  - According to 2022 data from the Department of Labor, the labor force participation rate is 38 percent for people with disability versus 77 percent for people without disability.[32]
  - Expand talent pool beyond disability; increase talent as workforce ages.
- **Create a new vision** of the future and learn about disability advocacy, identity, and pride.
- **Encourage health care providers with disability** to offer unique perspectives and skills.
  - Enhance appropriate cultural and language care.
  - Improve individual involvement and satisfaction.
  - Achieve equitable health care and health outcomes.

Supporting WWD During Menopause: Considerations for Providers

John Harris, MD, MSc

Director, UPMC Magee-Womens Hospital
Center for Women with Disabilities;

Assistant Professor, Magee-Womens
Research Institute, University of Pittsburgh

MAGEE-WOMENS RESEARCH INSTITUTE

Background on UPMC Magee-Womens Hospital Center for Women with Disabilities

- Caring for about 420 individuals each year, 61 percent of whom are dually eligible.
- Providing well-woman care, gynecologic consultations, pregnancy consultations, and surgical consultations.
- Supported by several key staff, including:
  - Sandra Welner, MD (1959-2001)
  - John Harris, MD, MSc
  - Julie McKechnie, CNM
  - Peter Bulova, MD
  - Jennifer Stephens, RN

Challenges to Providing DCC

Challenges facing DCC provision include:

- **Facility accessibility:** Ensuring availability of facilities, equipment, and appointment time slots.
- **Communications accessibility:** Communicating with people with disability takes humility, openness, and requires curiosity about an individual's abilities and preferences.
- **Tailored decision-making support:** People with disability face unique risks and benefits to traditional treatment pathways. Physicians must communicate these parameters in a way that empowers WWD to make an informed decision.

Best Practices for Providing DCC

Providers can adopt these practices to enhance DCC:

- Get to know the specific needs and past experiences of each dually eligible WWD.
  - Spend more time asking questions and listening to answers.
- Acknowledge that each person is different, as are their capabilities relating to performing the routine tasks of an office visit (including history taking and physical examination).
  - Spend more time explaining the exam and performing the exam.

Reflecting on Facility Accessibility: Preparation and Training

To assess facility accessibility, consider the following:

- Does the team know what each individual needs before they come?
  - Types of transfer and equipment needed
  - Plan space utilization or scheduling
- Does the team have the staffing to be able to provide necessary care?
  - Often need two staff members to assist for transfers or exams
  - Are staff trained on how to make people with autism spectrum disorder and intellectual disability comfortable?
  - Do all staff have adequate training with specialized equipment?
- Can the facility provide access to other services scheduled on the same day?
  - Radiology visits, subspecialty care (e.g., oncology, urogynecology, dentistry)
  - Are radiology departments or sites accessible?
- Do staff understand the historical challenges for people with disability and the need to avoid stigma or bias when providing care?

Reflecting on Facility Accessibility: Location and Access

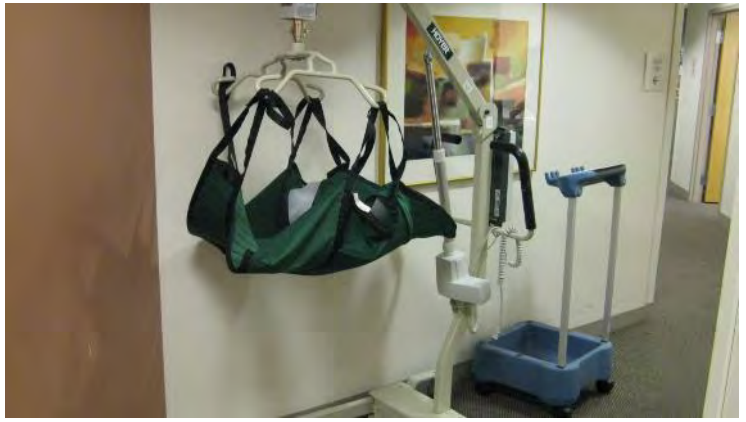
To assess facility accessibility, consider the following:

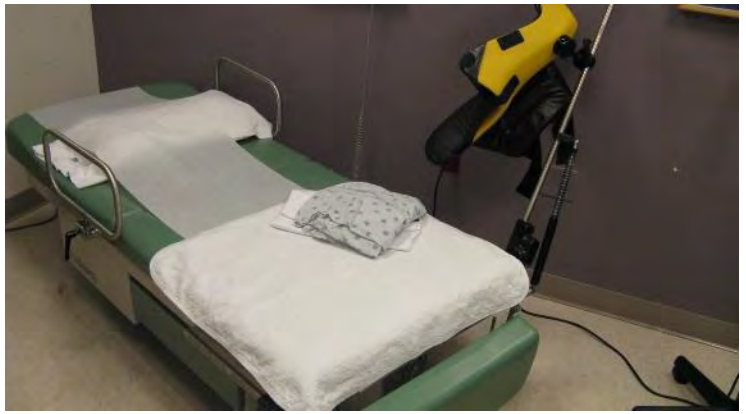
- How accessible is the health care location?
  - Where are handicap parking spaces?
  - Where will a wheelchair accessible van drop off individuals?
  - How much does parking cost? Are vouchers available?
  - In large buildings or hospitals, do front desk personnel know where the clinic is?
- How accessible is the specific clinic space?
  - Is the check-in desk of the clinic low enough so that people using wheelchairs can communicate with staff?
  - Does the waiting area allow space for wheelchairs?
  - Is the design of the facility or physical space, including the waiting area, accessible for women with intellectual disability?

Reflecting on Facility Accessibility: The Clinic Room

How accessible is the specific clinic space?

- Is there a wheelchair-accessible scale?
- Is there enough space for a wheelchair or stretcher and a transfer to the exam table?
- Is the exam table low enough to allow transfers?
- Is there a Hoyer lift available? Where is it? Who is trained to use it?
- Is there an option for full support leg rests for gynecologic exams?
- Are there tools available to help make people with intellectual disability or autism comfortable?
- Do most offices have a large exam room with a powered exam table?





Menopause-Related Conditions: Menopausal Symptoms

- Menopause screening tools
  - The North American Menopause Society Menopause Health Questionnaire[33]
  - Menopause Quick 6 (MQ6)[34]

1. Any changes in your period?
2. Are you having hot flashes?
3. Any vaginal dryness or pain, or sexual concerns?
4. Any bladder issues or incontinence?
5. How is your sleep?
6. How is your mood?

Menopause symptoms may include:	
Hot flashes, night sweats	Cognitive changes
Depression and anxiety	Genitourinary syndrome of menopause
Sleep disturbances	

- Symptoms for people with intellectual disability may be associated with behavior changes and agitation.
- Hormone replacement therapy can help treat and relieve some menopause symptoms.

Menopause-Related Conditions: Preliminary Considerations

- For people with intellectual disability or cognitive impairment:
  - Individuals may experience early initiation of menopause (e.g., individuals with Down Syndrome often experience premature ovarian syndrome).[35]
  - It may be difficult for providers to obtain symptom history.[36]
- For people with mobility disability:
  - Menopausal symptoms may present differently (e.g., as increased irritability or different physical sensations of common symptoms) for some conditions associated with mobility disability.[37]
  - There are higher risks for bone loss, cardiovascular disease, weight gain, and impaired balance.

Menopause-Related Conditions: Preliminary Considerations, cont.

For people with sensory disability:

- There is a greater need for accessible menopause education materials.
  - A survey conducted in the U.K. from 2018-2019 with deaf and hard of hearing women found that only seven percent of these women were able to access menopause health information in British Sign Language (BSL), while 83 percent indicated they would like to access this information in BSL.[38]
- Physicians often rely on written materials for individuals who are hard of hearing. In a time-constrained office visit, often other medical conditions will take precedence over providing additional clarification around menopausal concerns.
- Providers must conduct expanded screening for atypical menopausal symptoms (e.g., bladder infection screening).

Menopause-Related Conditions: Consequences of Estrogen Deficiency

- Bone loss[39]
  - Screening: A bone and mineral density scan is often used to screen for bone loss.
  - Management: Many medications that can be used for osteoporosis in the general population are appropriate for people with disability.
- Cardiovascular health
  - Challenges: Estrogen could increase thromboembolism risk, especially in women who use wheelchairs for mobility. Estimating thromboembolism risk can be difficult.
- Weight gain
- Impaired balance
- These consequences of estrogen deficiency are especially important to consider for women with mobility disability.

Menopause-Related Conditions: Role of Hormone Replacement Therapy

- Physicians must thoughtfully assess the risks and benefits associated with using hormone replacement therapy to treat or relieve some menopause symptoms. Women and their caregivers should be seen as shared decision-makers in this decision.
- The risk calculation varies according to several factors, including:
  - Current quality of life compared to quality of life before menopause.
  - Personal risk of cardiovascular disease, blood clots, osteoporosis, and cancer.
  - Relative degree of mobility and independence and concern for decreasing mobility and independence.

Take Action: Steps to Support Dually Eligible WWD

Health plans and providers can take several steps to support improved care and health outcomes for WWD:

- Health plans can encourage, support, and potentially incentivize providers through an improved accessibility initiative to update facilities to be more accessible (e.g., exam table purchases, restroom remodel, etc.).
- Health plans can provide education to providers on biases, disability stigma, and accessible care.
- Providers can support or improve data collection efforts by ensuring early bone mineral density measurement among people using wheelchairs.
- Health plans and providers can support research on menopause and dually eligible WWD.

Enhancing DCC for Dually Eligible WWD Across the Continuum of Care

Claire Abenante, RN, BSN

Director of Primary Care and Women's Health Access Program, ICS

Independence care system

Independence Care System (ICS) Background

- ICS was created to fill the gap in managed long-term care for people with physical disability, particularly those with mobility impairments (formerly a Managed Long-Term Services and Supports plan).
- ICS consistently lived its mission: **to support the health, mobility, and independence of adults with physical disability so they can live full, productive lives in the community.**
- Common conditions among ICS members include:
  - Stroke
  - Muscular dystrophy
  - Cerebral palsy
  - Spina bifida
  - Rheumatoid arthritis
  - Parkinson's disease
  - Spinal cord injuries
  - Multiple sclerosis
  - Amputation of extremities

ICS Demographics

- Total members in ICS Health Home: 1,805
- Percentage of members who are dually eligible: 39%
- Percentage of members who are women: 61%
- Percentage of members who are dually eligible women: 25%
- Percentage of members who are women of color: 39%
- Serving all five boroughs of New York City (NYC)

Health Home

- In 2019, ICS became a “Health Home” for people with physical disability.
- A Health Home is a Medicaid-funded program consisting of a group of health care professionals who ensure members get the care and services they need to stay healthy **in the community**. The focus is on serving vulnerable populations, including individuals experiencing:
  - Chronic health conditions
  - Mental illness
  - Substance use disorder
  - HIV/AIDS

ICS Health Home Specialization

ICS's Health Home is the first and only Health Home in New York State specializing in working with adults with physical disability. In addition to general Health Home services, the ICS Health Home program provides DCC management, which includes access to specialized programs such as:

- Care transitions
- Wheelchair services
- Wound care and prevention
- Primary care program for women's health
- Independent living
- Durable medical equipment and supplies
- Benefits resources for S/SDOH (e.g., assistance submitting accessible housing applications)
- Member programming
- Advocacy

Demographic Information for WWD

- The World Health Organization estimates that 60 percent of people living with disability are women.[40]
- WWD are more likely to have unmet health care needs than women living without disability, such as lower prevalence of up-to-date breast cancer and cervical cancer screenings.[41]
- Women living with a disability that affects their mobility are at an increased risk of developing conditions such as heart disease and osteoporosis, both of which are associated with menopause.[42]

Barriers to Receiving Care

Women with physical disability face a myriad of barriers to receiving quality care:

- Physical barriers
- Attitudinal barriers
- Lack of DCC
- Lack of oversight or enforcement of the ADA, or state and local disability laws

Physical Barriers

- Lack of automatic entry doors
- Narrow doorways
- Lack of or flimsy wheelchair ramps
- Inaccessible bathrooms
- Narrow dressing rooms
- Small examination rooms with no turning radius for a wheelchair
- Lack of accessible medical equipment
  - Height adjustable exam table
  - Transfer lift
  - Wheelchair scale

Attitudinal Barriers

- Holding a deficit-based view of individuals can impact physicians' understanding of or approach to providing appropriate care for WWD.

> *"It is presumed that women with disabilities don't need gynecological care and there is an assumption they are not sexually active"*
>
> *- Marilyn Saviola, ICS, Founder of the Women's Health Access Program*[43]

- Providers and plans may benefit from seeking resources to help them better understand and address human potential for bias, and systematic factors that can influence implicit stereotyping or stigma in care delivery.[44,45]

Lack of ADA Enforcement in Health Care Facilities

- There are several structural factors that can lead to the inadequate enforcement of the ADA.
- Professional accrediting bodies do not provide oversight or incentives to maintain ADA compliance, for example:
  - Joint Commission accreditation does not include ADA compliance in their accreditation standards.
- The onus is on the individual to report violations.
  - New York State/NYC Human Right Commission enforces Human Rights Law, however it's the responsibility of the individual to file a complaint.

Lack of DCC

- Medical and nursing education is often inadequate and does not mirror real-world conditions for treating people with disability.
- Most medical and nursing students learn about disabling conditions in their respective schools; however, many medical students reported no simulation training with a person with disability and reported not learning how to make accommodations to complete a physical exam.[46]

Lived Experience with Barriers to Access

> *"There are very few places for women who are wheelchair users to get comprehensive gynecology services"*
>
> *– Marilyn Saviola, ICS, Founder of the Women's Health Access Program.*[47]

- Inaccessible exam spaces can lead WWD to delay or forgo necessary gynecological care.
- WWD often need frequent gynecological care to address incontinence, skin break downs, and rash.

ICS Women's Health Access Program Promotes Physical Accessibility

- Since 2008, the ICS Women's Health Program has provided women with physical disability appropriate preventive and gender-specific services.
- Primary care services, including preventive health screenings and gynecological exams, were added to services offered in 2020.
- Funding from the Greater NYC Affiliate of Susan G. Komen for the Cure, as well as public funds received in partnership with NYC's Health and Hospitals Corporation (HHC).[48]
- Partnership with HHC has supported expansion into additional HHC facilities, including renovations to physical spaces, such as:
  - Installing adjustable height exam tables.
  - Installing lifts to more easily transfer individuals from their wheelchairs to the exam table.
  - Renovating mammography rooms to increase space and improve wheelchair maneuverability and accessibility.

Clinical Considerations for the Gynecological Exam for WWD

Actionable recommendations for providers and health plans providing DCC:

- Request a private interview without aides or family members to identify potential signs of abuse (e.g., dehydration, skin integrity, and lack of adequate nourishment).
- Defer to the individual about transferring and positioning.
- Consider using knee crutch stirrups and a safety belt. If unavailable, involve extra staff to help hold the individual's legs.
- Ask individuals with a neurogenic bladder to void prior to their appointment and have straight catheters on hand if needed.
- Consider that individuals with spinal cord injury T6 or higher are most at risk for developing autonomic dysreflexia.
- Ask individuals who experience muscle spasms to pre-medicate prior to appointment.

Impetus for the ICS Women's Health Program

WWD had higher breast cancer mortality rates and were less likely to undergo standard therapy after breast-conserving surgery than other women.[49]

Addressing Barriers to Care: ICS Women's Health Program's Approach

- Developed relationships with health care facilities that serve dually eligible individuals.
  - Increased leadership buy-in and provider willingness and engagement, which are foundational to the success of the partnership.
- Conducted environmental assessments of physical sites and recommended common sense solutions to increase accessibility, including:
  - Moving furniture and removing clutter in exam rooms to allow for a wheelchair to easily maneuver.
  - Purchasing barrier-free equipment, including height adjustable exam table, wheelchair scale, transfer lift, sliding board, and knee crutch stirrups.

Addressing Barriers to Care: ICS Women's Health Program's Approach, cont.

- Provided disability sensitivity and awareness or clinical competency training to ICS partner clinicians and health centers within NYC Health + Hospitals system.
- Provided disability relevant health navigation and coordination to dually eligible members (e.g., completed functional assessments and sent in advance of appointments so the facilities could adequately work to overcome barriers to care).
- Offered an ICS Nurse Educator to accompany women to their exams, providing support and recording information on barriers and solutions.

Accessibility in Action: Lived Experience

Evelyn Castillo

ICS Member, Disability Activist, Facilitator, and Crisis Responder

Discussion Panel

Beth Marks, PhD, RN, FAAN

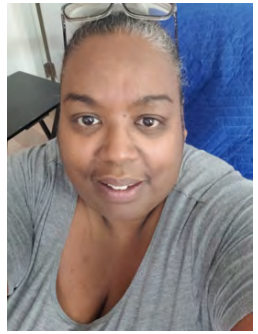
Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago

John Harris, MD, MSc

Director, UPMC Magee-Womens Hospital Center for Women with Disabilities

Claire Abenante, RN, BSN

Director of Primary Care and Women's Health Access Program, ICS



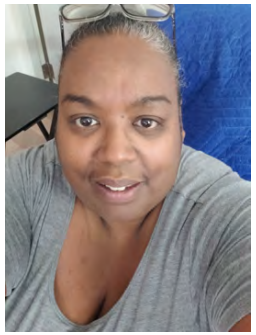
Evelyn Castillo

ICS Member, Disability Activist, Facilitator, and Crisis Responder

How would you recommend providers and health plans better support WWD?

Claire Abenante, RN, BSN

Director of Primary Care and Women's Health Access Program, ICS



Evelyn Castillo

ICS Member, Disability Activist, Facilitator, and Crisis Responder

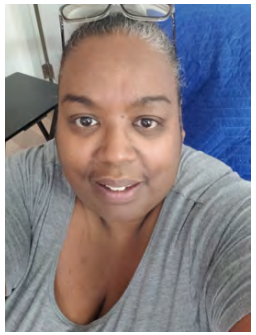
What's an example of an attitudinal barrier that limits access to health care for WWD, and how can this barrier be overcome?

Beth Marks, PhD, RN, FAAN

Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago

Claire Abenante, RN, BSN

Director of Primary Care and Women's Health Access Program, ICS



Evelyn Castillo

ICS Member, Disability Activist, Facilitator, and Crisis Responder

What are long-term risks of underscreening for menopause symptoms in populations of dually eligible WWD?

Beth Marks, PhD, RN, FAAN

Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago

John Harris, MD, MSc

Director, UPMC Magee-Womens Hospital Center for Women with Disabilities

Claire Abenante, RN, BSN

Director of Primary Care and Women's Health Access Program, ICS

What steps should be taken to improve DCC education in the health care professions education system?

Beth Marks, PhD, RN, FAAN

Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago

John Harris, MD, MSc

Director, UPMC Magee-Womens Hospital Center for Women with Disabilities

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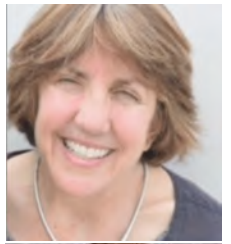
Audience Q&A

Beth Marks, PhD, RN, FAAN

Research Associate Professor, Department of Disability and Human Development, University of Illinois Chicago



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Thank You for Attending!

- The video replay and slide presentation will be available at https://www.resourcesforintegratedcare.com
- If you are applying for NASW CE, you must complete the post-test in order to receive credit:
  - NASW CE: https://www.surveymonkey.com/r/JMSSBKH
  - You must earn a score of 80 percent or higher on the post-test to receive NASW CE. You may take the post-test multiple times.
  - If you complete the requirements to earn NASW CE, we will email you a certificate of achievement.
- Questions? Please email RIC@lewin.com
- Follow us on Twitter at @Integrate_Care to learn about upcoming webinars and new products!

Webinar Evaluation Form

- Your feedback is very important! Please take a moment to complete a brief evaluation on the quality of the webinar: https://www.surveymonkey.com/r/MBQBZHZ.
- We would also like to invite you to provide feedback on other RIC products as well as suggestions to inform the development of potential new resources: https://www.surveymonkey.com/r/BW2H79Y.

RIC Resources

- Updated DCC-START Resource Guide – now available!
  - The Disability-Competent Care Self-Paced Training Assessment Review Tool (DCC-START) is intended to assist health plans, health systems, and health care provider organizations strengthen their efforts to provide integrated, coordinated care to their members with disability. The DCC-START assesses an organization's Disability-Competent Care (DCC) training materials and identifies opportunities for augmentation and enhancement.
  - The DCC-START complements the Disability-Competent Care Self-Assessment Tool (DCCAT), which is used by health plans and organizations to evaluate their DCC capabilities.
  - The updated DCC-START Resource Guide provides a detailed list of resources that can be used to address the opportunity areas identified by the DCC-START.

RIC Resources, cont.

- Supporting The Preventive Health Care Needs of Dually Eligible Women with Disability
  - This webinar from 2021 explores barriers faced by WWD in accessing screenings and health services and highlights promising practices providers and health plans can employ to achieve better integrated, person-centered care.
- Promoting Disability-Competent Care During COVID-19
  - This webinar provides an overview of RIC's DCC Model and includes presentations from health plans sharing promising practices and innovative strategies for addressing the unique needs of dually eligible individuals with disability during the COVID-19 public health emergency.
- Understanding the Lived Experience of Disability
  - This webinar explores the experience of living with a disability from the perspective of persons with lived experience.
- Tip Sheet: Using Person-Centered Language
  - This resource includes guidance for plans and providers serving individuals dually eligible for Medicare and Medicaid for using person-centered language.

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