Reproductive Health Care for Women With Disabilities

American College of Obstetricians and Gynecologists – 2010
http://www.acog.org  (search women with disabilities)

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Module 1

SCOPE OF DISABILITY

Employment and Disability
U.S. Women Ages 21 - 64


“A physical or mental impairment that substantially limits one or more major life activities.”
Summary – Scope of Disability

- Disability does not mean sickness
- Disabilities are prevalent: 12% of women age 16 to 64 identify as having a disability
- WWD face educational and economic barriers
- WWD have unmet health needs
Module 2

SEXUALITY
Information About Sexuality Offered to Women with Disabilities

Source: Beckman 1989
Sexual Physiology

- Sexual response mediated by nerve roots T10-L2 and S2-S4
- Vaginal lubrication involves S2-S4
- Up to 50% of women with spinal cord injury (SCI) can experience orgasm
- Most information is generalized based on more thorough studies among men with disabilities
Barriers to Knowledge
Women’s Sexual Health

• Research in female sexual function and dysfunction has lagged tremendously due to:
  – Inadequate funding of basic science research
  – Lack of basic science models of sexual response in female animals

• Limited research on sexuality and WWD

• Professional training in sexual health remains limited
Factors Affecting Sexual Function in WWD

- Physiologic or mechanical limitations
- Misconceptions and social stereotypes about ability to have and enjoy sex
- Fear of the safety of having sexual relations
- Concerns about body-image, self-esteem, self-concept
- Depression, stress and anxiety
- Fatigue
- Pain
- Life experiences (i.e. abuse)
Strategies to Optimize Sexual Functioning in WWD

• General considerations
• Dietary issues
• Medication administration
• Environmental issues
• Psychological issues
• Advocacy Issues
• Other provider counseling suggestions
Medications Affecting Sexual Function

- Anti-hypertensives
- Lipid-lowering agents
- Diuretics
- Antidepressants
- Immunosuppressive agents
- Anticonvulsants
- Anticholinergics
- Antispasmodics

- Oncologic agents
- Psychotropics
- Sedative-hypnotics
- Stimulants
- Anti-androgens
- Decongestants
- Antivirals
- Antiarrhythmics

Source: Nusbaum 2003
## Sexuality in Adolescent Girls With and Without Disabilities

### Girls’ Experiences at Age 16 by Physical Disability Status

<table>
<thead>
<tr>
<th>Physical Disability Status</th>
<th>Never Had Sex</th>
<th>All Consensual</th>
<th>Been Forced</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disability</td>
<td>66.3</td>
<td>27.7</td>
<td>6.0</td>
</tr>
<tr>
<td>Minimal disability</td>
<td>48.2</td>
<td>40.9</td>
<td>10.9</td>
</tr>
<tr>
<td>Mild disability</td>
<td>63.7</td>
<td>23.4</td>
<td>12.9</td>
</tr>
<tr>
<td>Severe disability</td>
<td>57.9</td>
<td>31.0</td>
<td>11.1</td>
</tr>
</tbody>
</table>

1994-1995 Wave 1 Data from the National Longitudinal Study of Adolescent Health Probability sample of adolescents in grades 7-12 in US Schools. N = 24,105

Disability severity index is set on a functional, self and parent defined scale at the time of the survey

Source: Cheng and Udry, 2002 (9)
Sexuality Considerations Adolescents with Disabilities

• Need sexuality education and open discussion
• May lack knowledge /skills for safe sex
• Different disabilities affect puberty at different rates
• Societal attitudes hinder sexual development more than their disability
• Past sexual abuse likely to affect sexual expression
Module 3

PSYCHOSOCIAL ISSUES
Case Study - Abuse

- Angie, age 40 with cerebral palsy
- Caregiver accompanies and answers when questions posed to patient
- Poor nutritional state, unexplained bruises and red marks on buttocks and thighs
- Patient fearful of abuse report
Psychosocial Issues
Module Quiz

True/False

1. Most women with disabilities are depressed.
2. It is important to consider the side effects of antidepressant medications when used for WWD.
3. Smoking is particularly dangerous for people with mobility disabilities.
4. The prevalence of domestic abuse with WWD is equal to that of women without disabilities.
5. If the patient is non-verbal it is not possible to determine if she has experienced a sexual assault.
6. Screening for abuse and sexual assault for WWD is similar to their peers without disabilities.
Part 2

Routine Gynecologic Health Care
Preparation for the Appointment

• Schedule a longer appointment
• Select the most accessible exam room and have necessary equipment available
• Practice with staff
  – Ask for patient’s preferences
  – Providing assistance
  – Safe transfer techniques
• Flag the chart to indicate patient requires accommodation
History: what to include

• Reason for the visit
• Menstrual history:
  – Menstrual calendars can be very helpful
  – Ask about specific symptoms associated with the periods, e.g. increased seizure activity, mood changes
• Sexual history:
  – Women with disabilities are often seen as asexual. Ask specifically about sexual activity, past and present, abuse history and need for birth control.
• Gynecological history
• Reproductive history and reproductive plans/desires
• Discuss past pelvic exam history and experience
Positioning on the exam table

Be aware of:

- Impaired balance, weakness
- Spasticity
- Skin pressure, especially over the sacrum
- Contractures
Coding Suggestions

• Understanding and using E/M service codes is essential for appropriate billing.

• See ACOG Quick Reference on CPT Coding for Women with Disabilities (12)
Summary –
The GYN Examination

Preparation and communication are key
• Prepare patient, space, staff, equipment
• Communicate with patient, staff
• Review and refine
GYN Cancer Screening
Attitudinal Barriers
Cervical Cancer Screening

WWD are seen as asexual and not at risk for HPV infection associated with cervical cancer.

HCP uncomfortable with the disability and fear **autonomic dysreflexia** from the exam.
Autonomic Dysreflexia (ADR)

- Occurs in women with spinal cord injury (SCI) at or above T6
- Response to noxious pelvic stimulation
- Requires immediate attention
  - Stop the examination
- Avoid ADR by emptying bladder and minimizing stimulation/discomfort
Breast Cancer Screening

• Women over age 65 with 3 or more functional limitations (FLs) were less likely (28.3%) to receive a mammogram in the last year than women with no FLs (37.9%). Chevarley, 2006\textsuperscript{12}

• Women over age 50 with self-reported cognitive limitation were 30% less likely than women without cognitive limitation to utilize mammography. Legg, 2004\textsuperscript{13}
Breast Cancer Screening
Women’s Identified Barriers

Difficulty getting into position (34%)

Had not been told by a provider to get a mammogram (25%)

Belief that they were at very low risk for breast cancer (24%)

Source: Nosek & Howland 1997

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Sexually Transmitted Infections

Informational Barriers

Informational barriers:

- Failure to ask about sexual practices and sexual abuse
- Failure to screen women for sexual activity and STI’s\textsuperscript{16}
- Failure to educate women about safe sex practices
- Failure to offer information on seeking help for sexual abuse.

Physical difficulty using barrier method of contraception\textsuperscript{17}
Skin Inspection

• Should be performed daily, but this does not often happen

• Positioning for pelvic examination is a critical opportunity to assess vulnerable skin overlying pelvic bones (ischial tuberosities and greater trochanters)
Grade 2 Pressure Ulcer

Partial-thickness skin loss involving epidermis, dermis, or both. Appears as an abrasion or blister.

Source: European Pressure Ulcer Advisory Panel \(^20\)
Part III

Medical and Reproductive Considerations
Module 1
Contraception
Contraception Information

WWD often do not get appropriate contraception information

Onset of disability

Contraception information was

Source: Beckman 1989
Contraception Considerations

When making recommendations and prescribing contraception

– Determine if method can be administered when needed by the woman or coordinated with home/partner assistance
– Consider side effects of contraception method
– Consider effects on menses
– Consider need for protection from STIs
– Consider cost – insurance coverage
– Consider need for legal consent (Link to Part IV- IDD)
Progestin-only Pills

**Advantages**

- An alternative to those who have contraindications to estrogen containing contraception

**Disadvantages**

- Irregular bleeding (link to Menses and AUB)
- Must be taken at the same time daily or efficacy is affected
- Some anticonvulsants decrease effectiveness. (Beck 1990)
Intrauterine Device (IUD)

Copper-T (10 years)
  May increase cramping, irregular and heavy menses

Levonorgestrel IUD (5 years)
  Irregular spotting in the first few months may be difficult to manage
  Amenorrhea may occur after 6 months

Advantages
• Long term reversible contraception (5 or 10 years)
• LNG-IUD decreases menses, may induce amenorrhea
• Does not contain estrogen
• Does not require assistance with daily or weekly administration

Disadvantages
• Caution for women with spinal cord injuries (Link Part 4 Module 1)
• Insertion may require anesthesia
The intrauterine device or IUD provides excellent long term, reversible contraception and can be an good choice for many women with disabilities.

There are two main types of IUDs currently being used:

– The Copper-T IUD is a non-hormonal contraceptive that can remain in place for 10 years. There is some risk of increased cramping and heavy menses.

– The Progestin-containing Levonorgestrel IUD has the benefit of decreased menstrual flow to amenorrhea after the first few months of use. It may be an ideal method of contraception as well as menstrual regulation for women with menstrual flow management problems.

• The IUD may be used by women at risk for thromboembolism or who have other barriers to estrogen containing contraception and for those who have difficulty in remembering or administering daily contraception.

However there are instances in which the IUD should be considered with caution.

• Women with a high spinal cord injury may develop Autonomic Dysreflexia (ADR) as a result of the stimulation caused by the insertion of the IUD. If at risk for ADR, anesthesia should be consulted for the insertion. Also, an incorrectly placed IUD may not produce the usual symptoms of pain and cramping.

• Patient positioning for IUD insertion may be difficult for some women with contractures or spasms or for those women who can not cooperate with a pelvic exam. In some instances difficult insertions may require anesthesia.

Example of Slide Notes - IUD
Emergency Contraception

• Do not forget to discuss with patients
• Give prescription in advance
• Can be used sparingly by those who cannot routinely use hormonal contraception (WHO 2004)
Summary

• Contraception options should be discussed with all women with disabilities.
• Considerations involve:
  – The physical and pharmacological interaction of the contraception method
  – The actual or potential conditions of the woman
  – The amount of assistance available to and required by the woman
  – Her lifestyle and self-care needs
  – Her goals for pregnancy
Module 2

Menstrual Considerations and Abnormal Uterine Bleeding
Impact of Menses for WWD

- Increased physical needs
- Increased social concerns
- Increased medical concerns
Incidence and Risk of AUB

WWD have greater incidence of conditions that may contribute to AUB such as

– Thyroid disease
– Polycystic ovarian syndrome in women with epilepsy
– Weight issues (Link to Part 3, Module 5)
– Often take antipsychotic and some GI medications can cause high prolactin levels

They also may report AUB more frequently due to difficulty with menses management
## Medical Management - AUB

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Advantages</th>
<th>Disability Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSAIDS</td>
<td>Decreases flow</td>
<td>Gastric distress</td>
</tr>
<tr>
<td></td>
<td>Non-hormonal</td>
<td></td>
</tr>
<tr>
<td>Combined oral contraceptive</td>
<td>Decreases flow</td>
<td>Immobility, Daily reminders</td>
</tr>
<tr>
<td>Contraceptive Patch</td>
<td>Weekly</td>
<td>Immobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patients with IDD may pull it off</td>
</tr>
<tr>
<td>Contraceptive Ring</td>
<td>Monthly</td>
<td>May be difficult to place</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patients with IDD may remove</td>
</tr>
<tr>
<td>Progesterone only pill</td>
<td>Daily</td>
<td>Daily reminders</td>
</tr>
<tr>
<td>DMPA</td>
<td>4 times yearly</td>
<td>Risk of low bone density with prolonged use.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Weight gain interferes with transfers</td>
</tr>
<tr>
<td>Progesterone containing IUD</td>
<td>5 years</td>
<td>Insertion issues</td>
</tr>
<tr>
<td>Implants</td>
<td>3 years</td>
<td>Irregular bleeding, insertion issues</td>
</tr>
</tbody>
</table>

Source: ACOG Committee Opinion 2009 in print
Module 3

Pregnancy and Parenting
Special Considerations for WWD and Pregnancy

Effect of the disability on pregnancy, labor and delivery

Societal pressure not to conceive

Effect of pregnancy on disability
Medication Considerations

• **Anticonvulsants**
  - Valproate – D
  - Carbamezepine – D
  - Lamotrigine – C
  - Phenytoin - D
  - Phenobarbital - D

• **Mood Stablizer**
  - Lithium – Category D

• **Antipsychotics**
  - Risperidone – Category C

• **Muscle Relaxants**
  - Baclofen – Category C
  - Dantrolene – Category C
Prenatal Considerations: Mobility Disability

• Increase in body weight and change in center of gravity: less stable transfers and risk of falls
• Changes in activity level due to fear of falling
• Increase in use of assistive devices
• Alterations in fit of prostheses
• Increased incidence of pressure sores
Postpartum Considerations

• “Congratulations!” Not “How can this work?”
• Antepartum rehabilitation nurse in-service to obstetric nurses
• Increased medical surveillance
• Potential increased length of stay
• Self and infant care adjustments
• Early involvement of pediatrician
• Effective family planning
Summary – Pregnancy and Parenting

Steps to prevent obstetric complications

– Preconceptional plan
– Meticulous management of concurrent medical conditions
– Adequate nutrition and hydration
– Appropriate use of prescribed and OTC medications
– Care coordination

Parenting considerations – Creativity is key
Module 4
Urinary and Bowel Considerations
Management of Neurogenic Bladder

- Manual bladder emptying
- Medication – Anticholinergics
- Intermittent catheterization
- Indwelling catheter
- Surgical procedures – Suprapubic tube, ileal conduit.
Module 5

Weight, Diet and Physical Activity
Weight measurement

Weight and weight change can be a critical measurement in obstetrics and for disease management.
Physical Activity for WWD

- Assistive devices are available to improve strength and fitness
- Enhances overall health, wellness and quality of life
- Multiple barriers to regular exercise

Saratoga hand cycle  www.randscot.com
Module 6
Adolescents with Disabilities
Sex Education for Adolescents with Disabilities

- Assess ability to consent
- Give age and development level appropriate education
- Assess Knowledge
Considerations for Care – Separation From Family

Encourage expression of fears and concerns
Taking A History

Include:

3 C’s and 3 S’s

Confidential

Contraception

Coercion

Sexual Knowledge

Safety

Substance Abuse
Summary - Adolescents

• Teens with disabilities need
  – Help to achieve independence
  – Assistance to transition from pediatrician
  – Attention to health risk behaviors and situations
  – Education and guidance on sexuality and contraception
  – Special care during GYN examination
  – Remember the 3 C’s and 3 S’s each visit
Peri-Menopause

- Women with developmental disabilities may have an unusual reaction to hot flashes
- Menstrual hygiene issues due to irregular menses
- Increase in disability symptoms
- Estrogen replacement therapy has risks associated
Part IV
Reproductive Health Specific to Disability
Module 1 - Physical Disabilities

- Cerebral palsy
- Spinal cord injury
- Multiple sclerosis
- Spina bifida
<table>
<thead>
<tr>
<th>Level</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1-C6</td>
<td>Neck flexors</td>
</tr>
<tr>
<td>C1-T1</td>
<td>Neck extensors</td>
</tr>
<tr>
<td>C3-C5</td>
<td>Supply diaphragm (mostly C4)</td>
</tr>
<tr>
<td>C5-C6</td>
<td>Shoulder movement, raise arm, flex elbow, supinates arm</td>
</tr>
<tr>
<td>C6-C7</td>
<td>Extends elbow and wrist, pronates wrist</td>
</tr>
<tr>
<td>C7-T1</td>
<td>Flexes wrist, supply small muscles of the hand</td>
</tr>
<tr>
<td>T1-T6</td>
<td>Intercostals and trunk above waist</td>
</tr>
<tr>
<td>T7-L1</td>
<td>Abdominal muscles</td>
</tr>
<tr>
<td>L1-L4</td>
<td>Thigh, hip muscles,</td>
</tr>
<tr>
<td>L4-S1</td>
<td>Hamstrings and dorsiflexion of foot</td>
</tr>
<tr>
<td>L4-S2</td>
<td>Plantar flexion of foot and toe movement</td>
</tr>
</tbody>
</table>

About Autonomic Dysreflexia

• Autonomic dysreflexia (ADR) is the most important ob/gyn concern for women with spinal cord lesions
• Spinal cord lesions at or above T6 segment – 50% incidence of ADR
• Causes severe hypertension
• Potentially lethal medical emergency
Pregnancy Complications for Women with SCI

- Urinary tract infections
- Decubitus ulcers
- Alterations in pulmonary function
- Deep vein thrombosis
- Increased spasticity
- Constipation
Medical Concerns in Women With Spina Bifida

Source: Suzawa, 2006
Spina Bifida - Pregnancy Considerations

- Bladder and urinary tract
  - Special care after urinary diversion surgery
  - Increased frequency of UTI
- VP Shunt failure
- Increased risk of back pain due to spinal abnormalities

(Link — Mod 1)
GYN Considerations of MS

• Possible worsening of neurologic symptoms with menses (self-report)
• 40-80% of women report sexual dysfunction
• Fatigue commonly contributes to sexual dysfunction
• Depression may be associated with CNS changes.
• Smoking may increase disease progression
MS- Postpartum

Breastfeeding encouraged, if no DMA is needed

Watch closely for perinatal and postpartum depression

Flare up/relapse often occurs within 3 months postpartum
CP - Reproductive Health Issues

• Increased spasticity and incontinence during menstruation reported

• Seizure medications may interfere with contraception methods — (Link Part 3-Mod 1)

• Pain and contractures may affect sexuality

• Contractures and deformities may require adaptive measures for mammograms (link Part 2-Mod 2) and GYN examinations. (link Part 2-Mod 1)

• Developmentally appropriate sex and contraception education
Sub-Module 5
Other Physical Disabilities
Osteogenesis Imperfecta
Post-Polio Syndrome
Module 2
Intellectual and Developmental Disabilities (IDD)
Reproductive Care Issues - IDD

- History taking and education
- Physical examination
- Menstruation issues
- Contraception – (link to Part 3, Module 1)
- Pregnancy
- Informed consent
- Aging and osteoporosis
Issues Seeking Health Care

Resistance to exams due to history of forced examinations causing

Pain  Anxiety  Hostility
Cyclical Behavior Changes

- Occurrence – 16% menstruating women with IDD
- Symptoms – temper tantrums, crying, autistic or self abusive behavior, seizures
- Diagnosis - Documentation
- Therapy –
  - First NSAIDs (behavior may be due to cramps)
  - Then try OCPs, DMPA, SSRIs

Source: Quint 1999
Menstruation onset and menstrual irregularities similar to general population

Impaired fertility has been noted

Only a few pregnancies have been described in women with DS with varying outcomes
Module 6
Sensory Disabilities
Hard of Hearing
Low Vision
Communication Facilitators for the Deaf and Hard-of-Hearing

• Free telephone relay services
• Text messaging
• Discounted communications equipment
• Tax incentives for providing accommodation
Communication Suggestions for the Blind and Low Vision

• Don’t make assumptions about functional effects of visual acuity
• Do not touch or remove mobility aids
• Describe procedures before performing them
• All written forms and documents should be read aloud in a private setting
• Reading aloud may not provide effective communication for some patients
• Use preferred techniques when handling money or credit cards
PART 5

Access to Health Care
United in Purpose

- Gaining voice
- Gaining political will
- Improving conditions
“I’m looking forward to the day when we can just assume that doctors’ offices and the people working there are aware of their responsibilities and how to treat all people. I want to see them know the law and run their offices in compliance with the law.”
—Marilyn Gelman Harelick

Report of the Women with Disabilities Health Care Summit 2001 (2)
Disability Etiquette

- Address the person directly
- Offer to shake hands
- Identify yourself to those who have visual impairments
- Offer assistance, wait for acceptance of help & instructions
- Treat adults as adults
- Do not lean on a wheelchair – respect boundaries
- Listen attentively to those with speech difficulties
- Place yourself at eye level when conversing
- Gain attention from one who is hard of hearing before speaking
- Ask if you are unsure

Adapted from: CIDNY, the Center for Independence of the Disabled in New York, Inc. (6)
Access in the Office Exam Room
Contents - Resources

- ACOG resources
- Federal and national resources
- Disability and women’s health - general information
- Sexuality
- Tobacco and substance abuse
- Domestic violence and sexual assault
- Women’s health examination
- Breast health
- Contraception

- Pregnancy and parenting
- Activity and weight control
- Adolescence
- Aging and osteoporosis
- Spinal cord injury
- Other physical disabilities
- Developmental disabilities
- Blindness and low vision
- Deafness and hard of hearing
- Advocacy and etiquette
- ADA and barrier removal
Aging and Osteoporosis Resources

• **Association on Aging with Developmental Disabilities**
  Develops, links and supports opportunities and services for older adults with developmental disabilities.
  website: [www.agingwithdd.org](http://www.agingwithdd.org)  Tel: 314-647-8100


• **Unanticipated Lives: Aging Families of Adults with Mental Retardation: The impact of lifelong caregiving.** Authors Seltzer MM, Larsonson BA, Makuch RL, Krauss MY, Robinson D. University of Wisconsin, Madison and Brandies University, 2000 – white paper.
  Overview available at: [www.chas.uchicago.edu/documents/MD0506/AnUnanticipatedLive.pdf](http://www.chas.uchicago.edu/documents/MD0506/AnUnanticipatedLive.pdf)

• **Wisconsin Aging and Disabilities Resource Center**
  Information for individuals, concerned families or professionals working with issues related to aging, physical disabilities, developmental disabilities, mental health issues, or substance use disorders, can receive information specifically tailored to each person's situation.
  website: [http://dhs.wisconsin.gov/LTCare/Generalinfo/RCs.htm](http://dhs.wisconsin.gov/LTCare/Generalinfo/RCs.htm)
Welner Enabled (WE) continues Sandra Welner, MD's legacy of advocacy for patients with disabilities.

WE designs and builds products and devices that enable people with disabilities and others with special needs to access medical diagnosis and treatment.

Website: www.welnerenabled.com
Tel: 800-430-9810
Thank You for participating in this program. This is a work in progress and we hope to be updating it regularly. Please contact ACOG for questions and comments: jmahoney@ACOG.org

Funded through a cooperative agreement from the Centers for Disease Control, NCBDDD

To access the recorded program directly go to: http://streaming.acog.org/WomenWithDisabilities/

To access the powerpoint program go to: http://www.acog.org/departments/dept_notice.cfm?recno=38&bulletin=4526