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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Surgeon General's Call to Action
To Improve The Health And Wellness Of Persons With Disabilities - 2005

Goals involve:

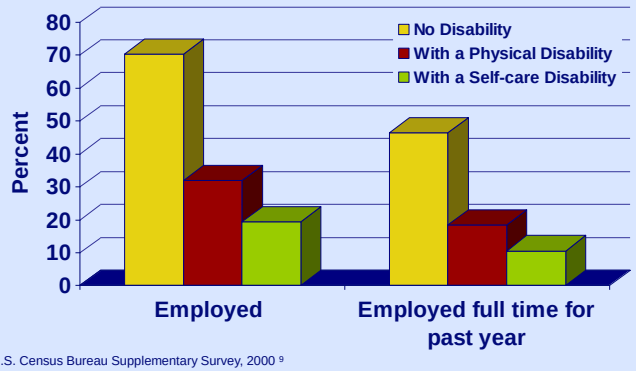
public awareness, → health care provider knowledge, → personal life style change, → accessible services

"A physical or mental impairment that *substantially limits* one or more *major life activities*."

Module 1

SCOPE OF DISABILITY

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



Source: U.S. Census Bureau Supplementary Survey, 2000 [9]

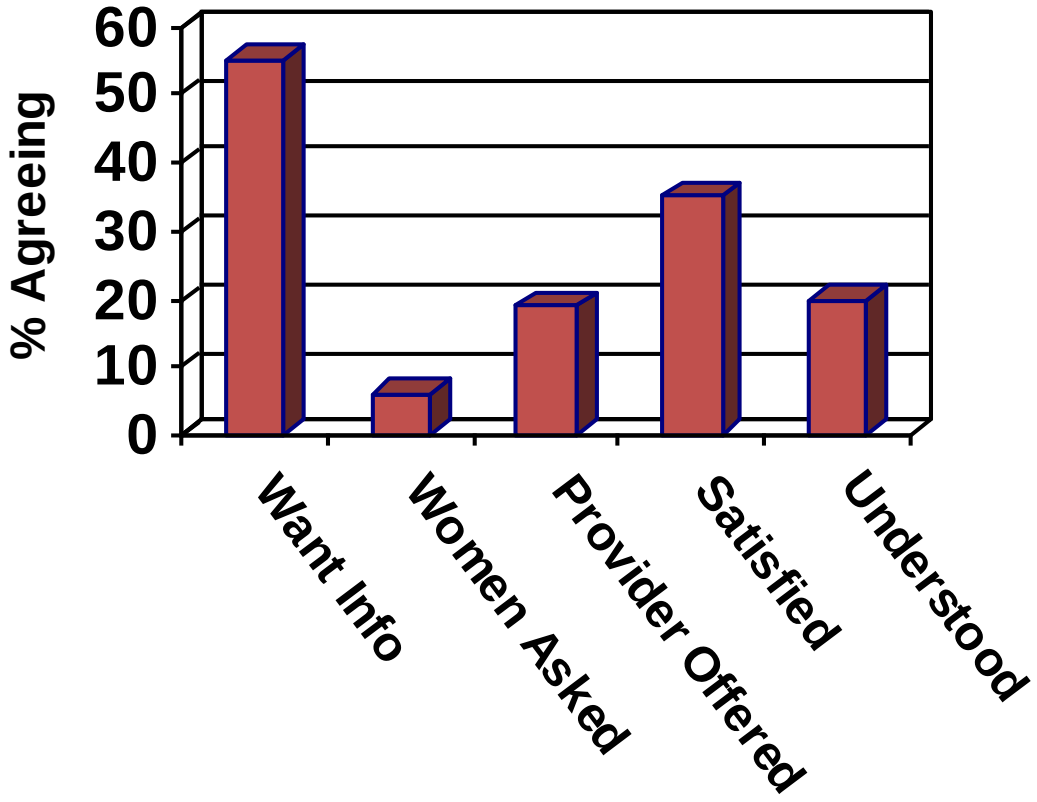
Summary – Scope of Disability

- 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

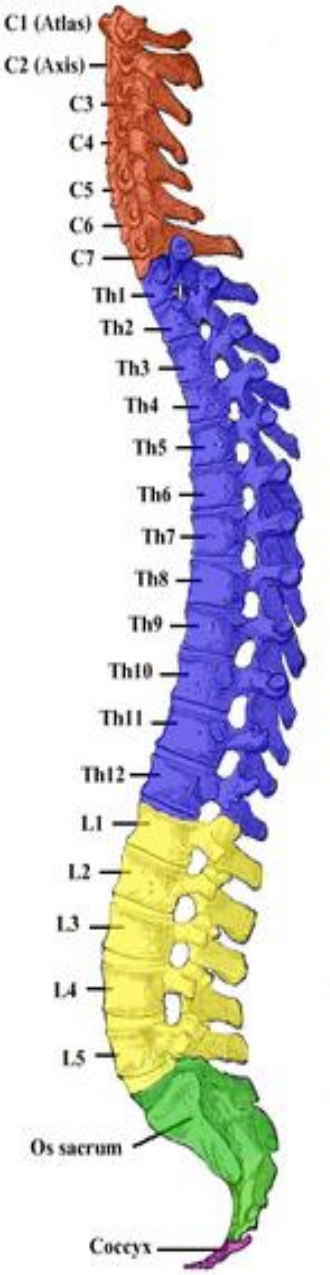
Module 2

SEXUALITY

Information About Sexuality Offered to Women with Disabilities



Source: Beckman 1989 [1]



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[2]
- 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[7]

Sexuality in Adolescent Girls With and Without Disabilities

Girls' Experiences at Age 16 by Physical Disability Status

Physical Disability Status	Never Had Sex	All Consensual	Been Forced
No disability	66.3	27.7	6.0
Minimal disability	48.2	40.9	10.9
Mild disability	63.7	23.4	12.9
Severe disability	57.9	31.0	11.1

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

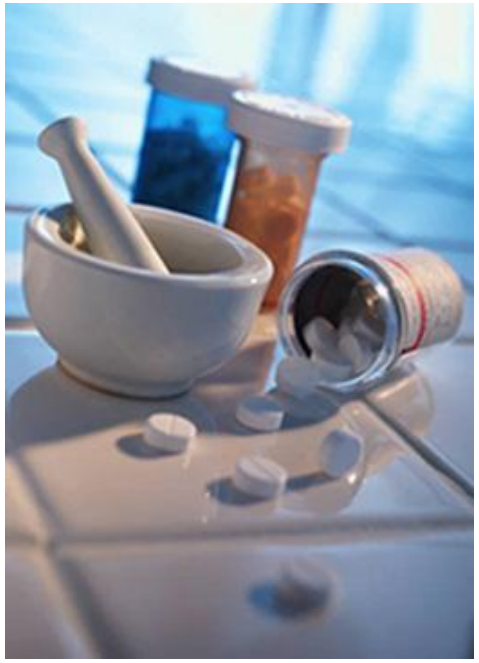
Source: Cheng and Udry, 2002 (9)

Sexuality Considerations Adolescents with Disabilities

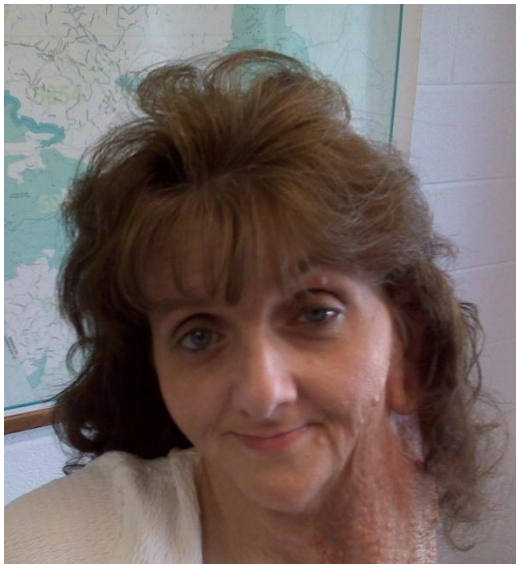
- Need sexuality education and open discussion
- May lack knowledge /skills for safe sex
- Different disabilities affect puberty at different rates
- Societal attitudes hinder sexual development more than their disability
- Past sexual abuse likely to affect sexual expression

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

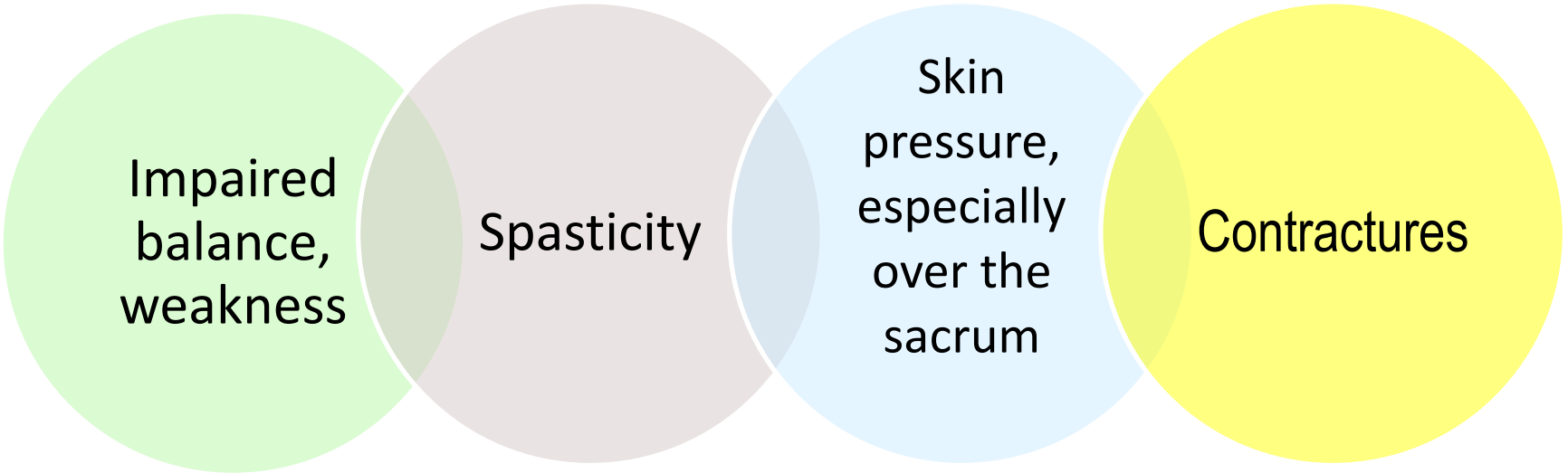
- Flag the chart to indicate patient requires accommodation

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

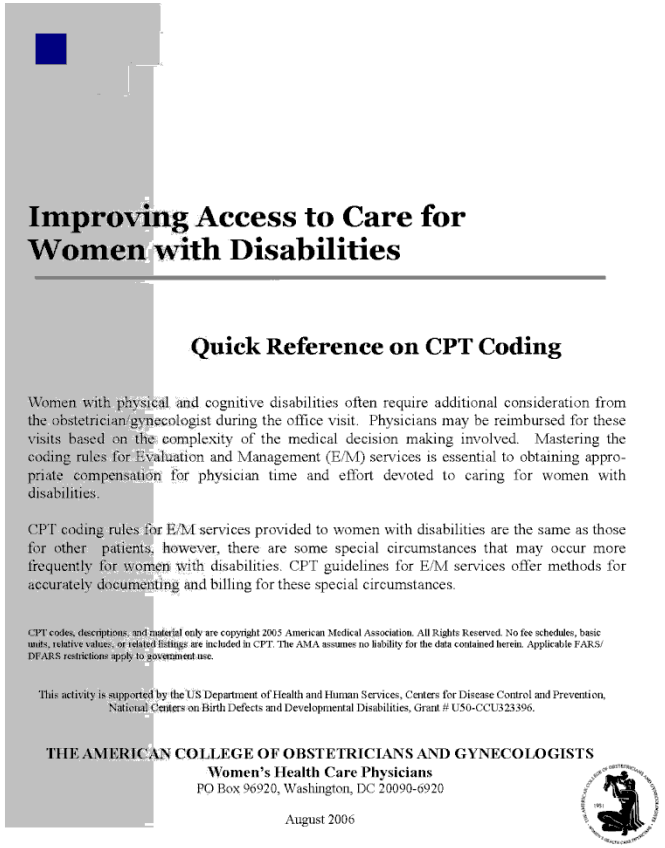
Positioning on the exam table

Be aware of:



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)



Improving Access to Care for Women with Disabilities

Quick Reference on CPT Coding

Women with physical and cognitive disabilities often require additional consideration from the obstetrician/gynecologist during the office visit. Physicians may be reimbursed for these visits based on the complexity of the medical decision making involved. Mastering the coding rules for Evaluation and Management (E/M) services is essential to obtaining appropriate compensation for physician time and effort devoted to caring for women with disabilities.

CPT coding rules for E/M services provided to women with disabilities are the same as those for other patients, however, there are some special circumstances that may occur more frequently for women with disabilities. CPT guidelines for E/M services offer methods for accurately documenting and billing for these special circumstances.

This activity is supported by the US Department of Health and Human Services, Centers for Disease Control and Prevention, National Centers on Birth Defects and Developmental Disabilities, Grant # U50-CCU323396.

THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS
Women's Health Care Physicians
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August 2006

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

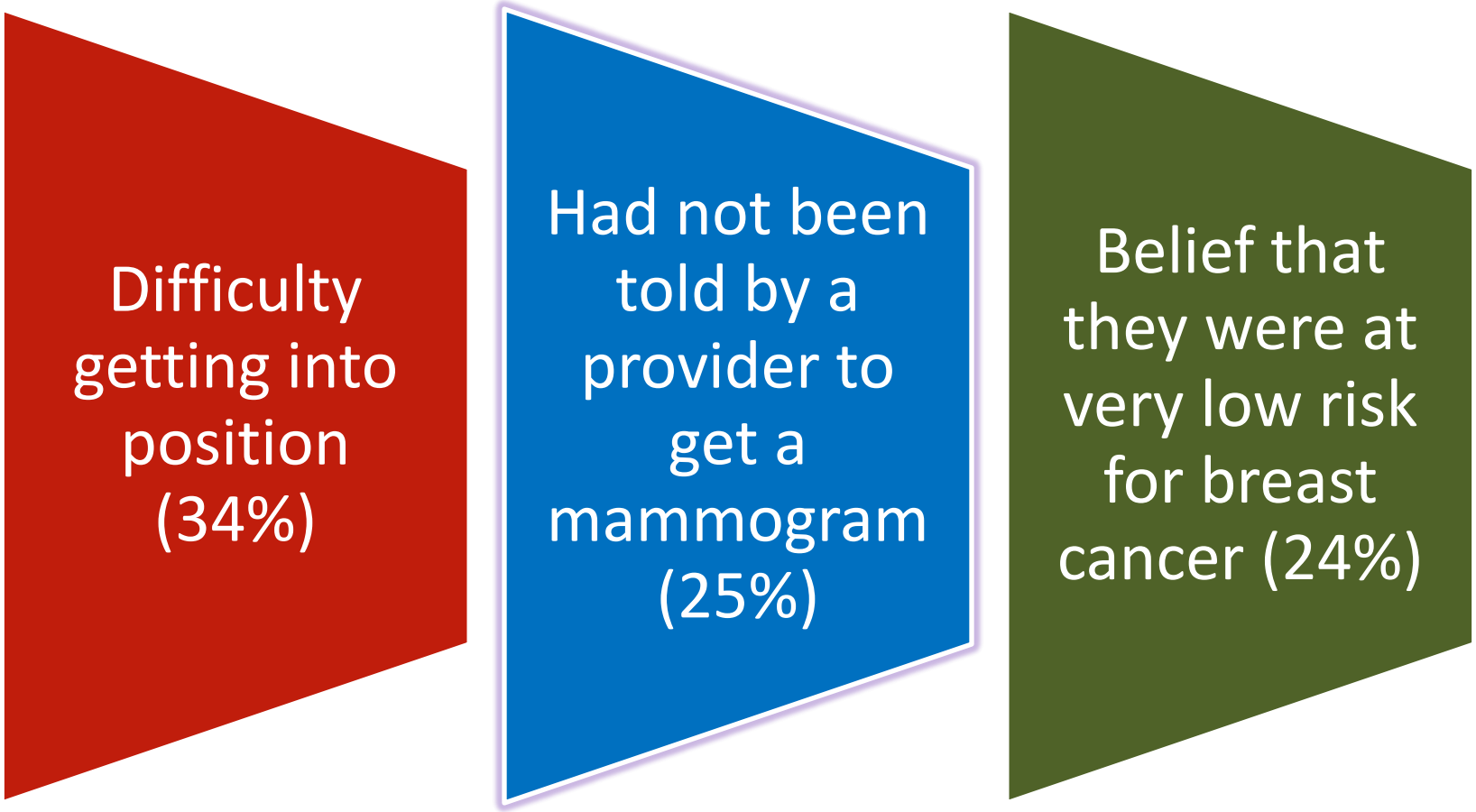
– Stop the examination

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[12]
- Women over age 50 with self-reported cognitive limitation were 30% less likely than women without cognitive limitation to utilize mammography. Legg, 2004[13]

Breast Cancer Screening
Women's Identified Barriers



Source: Nosek & Howland 1997[4]

Sexually Transmitted Infections Informational Barriers

Informational barriers:

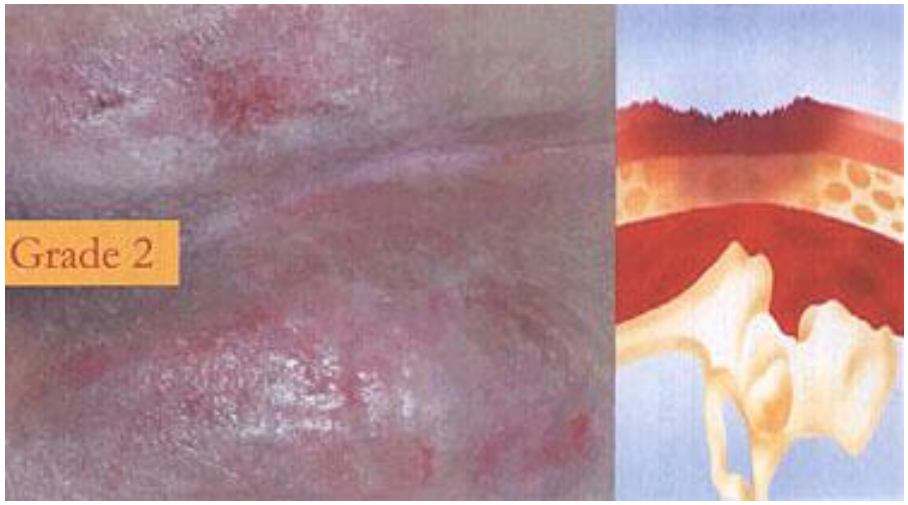
- Failure to ask about sexual practices and sexual abuse
- Failure to screen women for sexual activity and STI's[16]
- Failure to educate women about safe sex practices
- Failure to offer information on seeking help for sexual abuse.

Physical difficulty using barrier method of contraception [17]

Skin Inspection

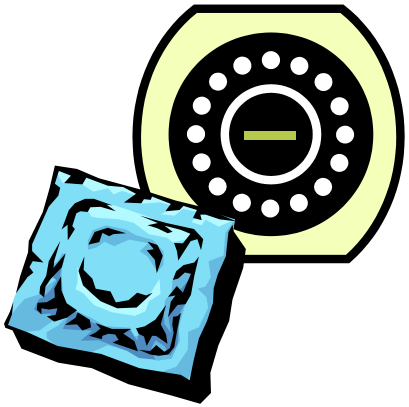
- Should be performed daily, but this does not often happen
- Positioning for pelvic examination is a critical opportunity to assess vulnerable skin overlying pelvic bones (ischial tuberosities and greater trochanters)

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]



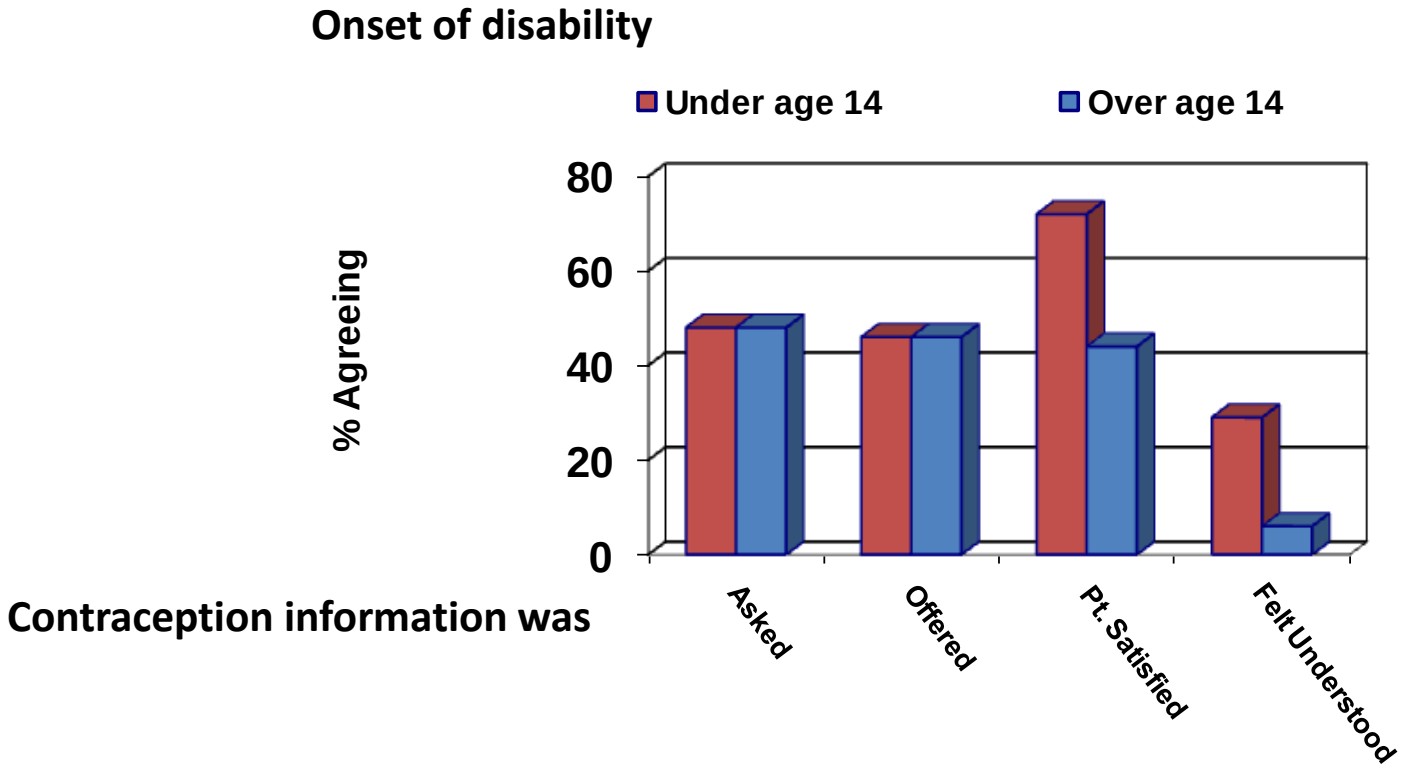
Part III

Medical and Reproductive Considerations

Module 1
Contraception

Contraception Information

WWD often do not get appropriate contraception information



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 !V- IDD)

Progestin-only Pills

Advantages

- An alternative to those who have contraindications to estrogen contain 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

Example of Slide Notes - IUD

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 <u>difficult insertions may require anesthesia.</u>

Emergency Contraception

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

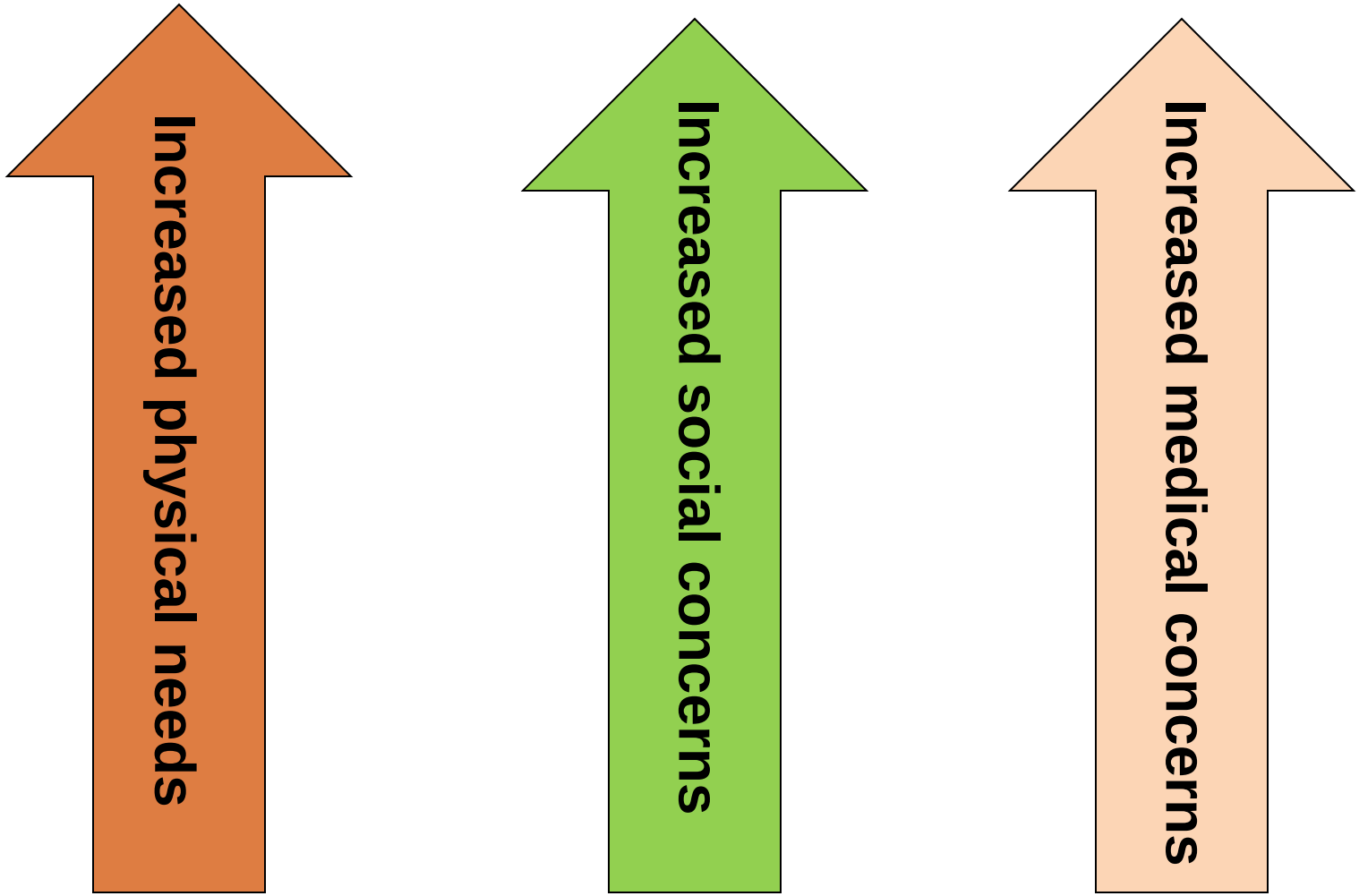
Summary

- 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



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

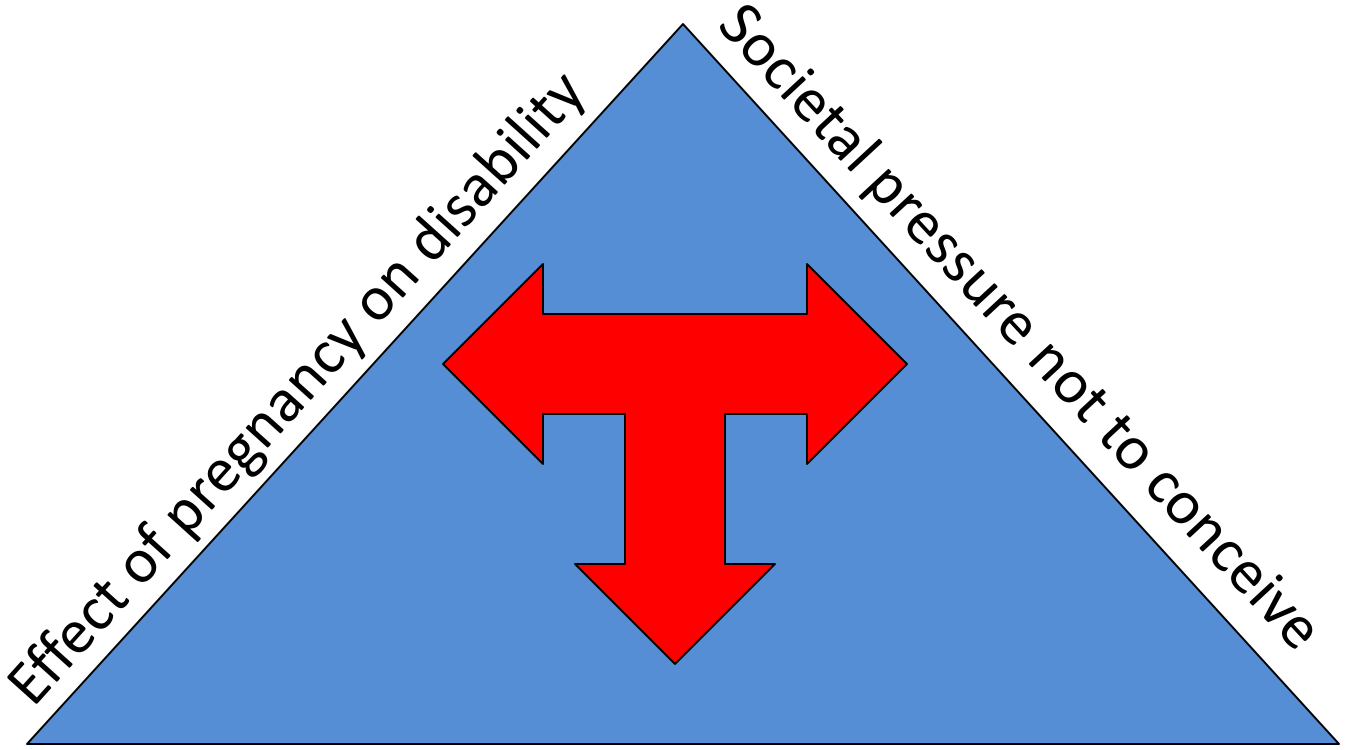
Treatment	Advantages	Disability Concern
NSAIDS	Decreases flow Non-hormonal	Gastric distress
Combined oral contraceptive	Decreases flow	Immobility, Daily reminders
Contraceptive Patch	Weekly	Immobility Patients with IDD may pull it off
Contraceptive Ring	Monthly	May be difficult to place Patients with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

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

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

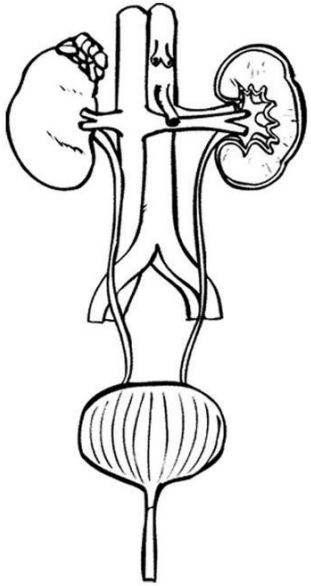
- “Congratulations!” Not “ How can this work?”
- Antepartum rehabilitation nurse in-service to obstetric nurses
- Increased medical surveillance
- Potential increased length of stay
- Self and infant care adjustments
- Early involvement of pediatrician
- Effective family planning

Summary – Pregnancy and Parenting

Steps to prevent obstetric complications

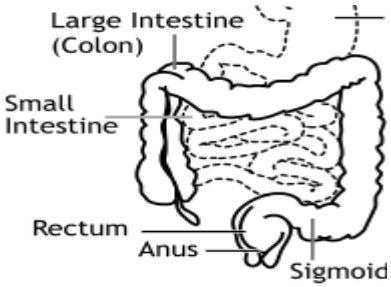
- Preconceptional plan
- Meticulous management of concurrent medical conditions
- Adequate nutrition and hydration
- Appropriate use of prescribed and OTC medications
- Care coordination

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

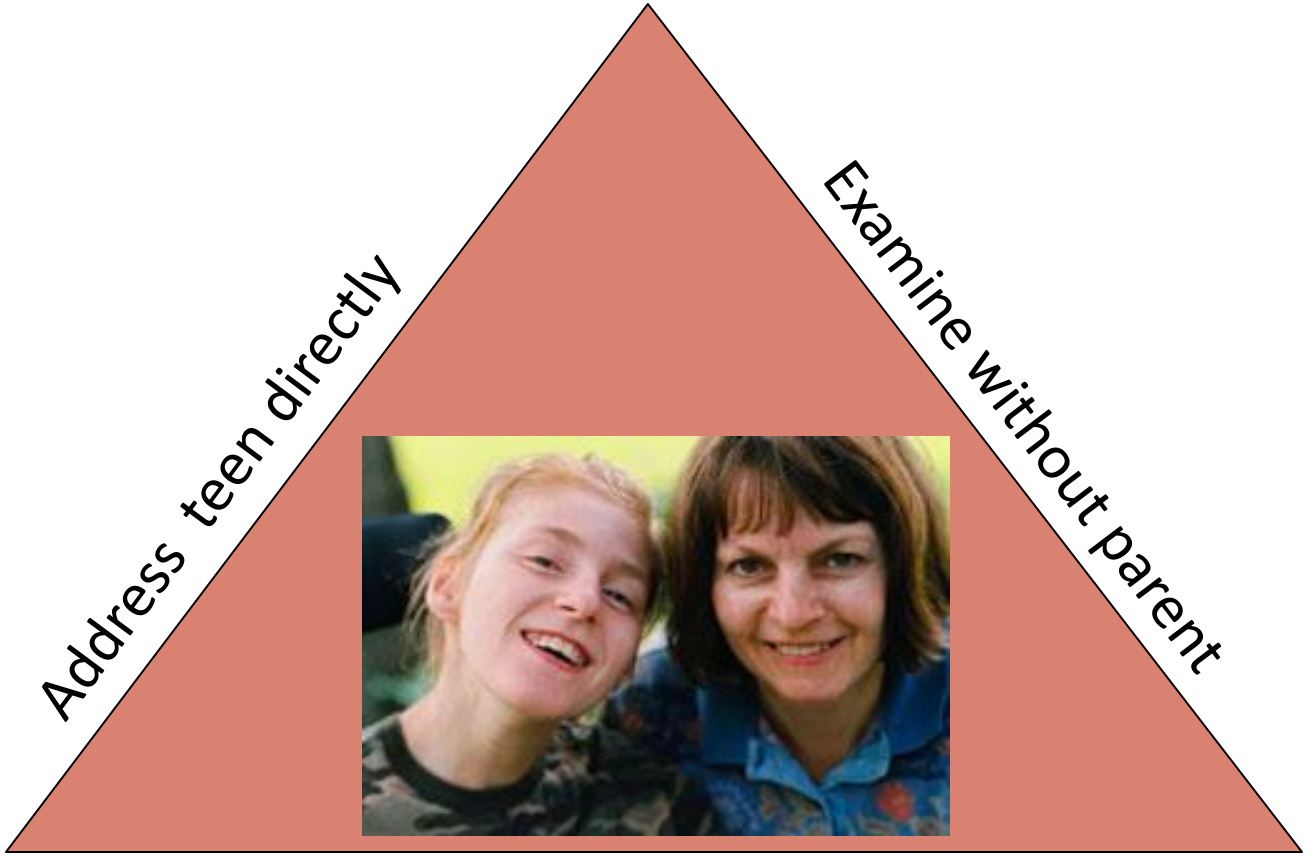
Sex Education for Adolescents with Disabilities

Assess ability to consent

Assess Knowledge

Give age and development level appropriate education

Considerations for Care – Separation From Family



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

Module 7

Aging and Osteoporosis

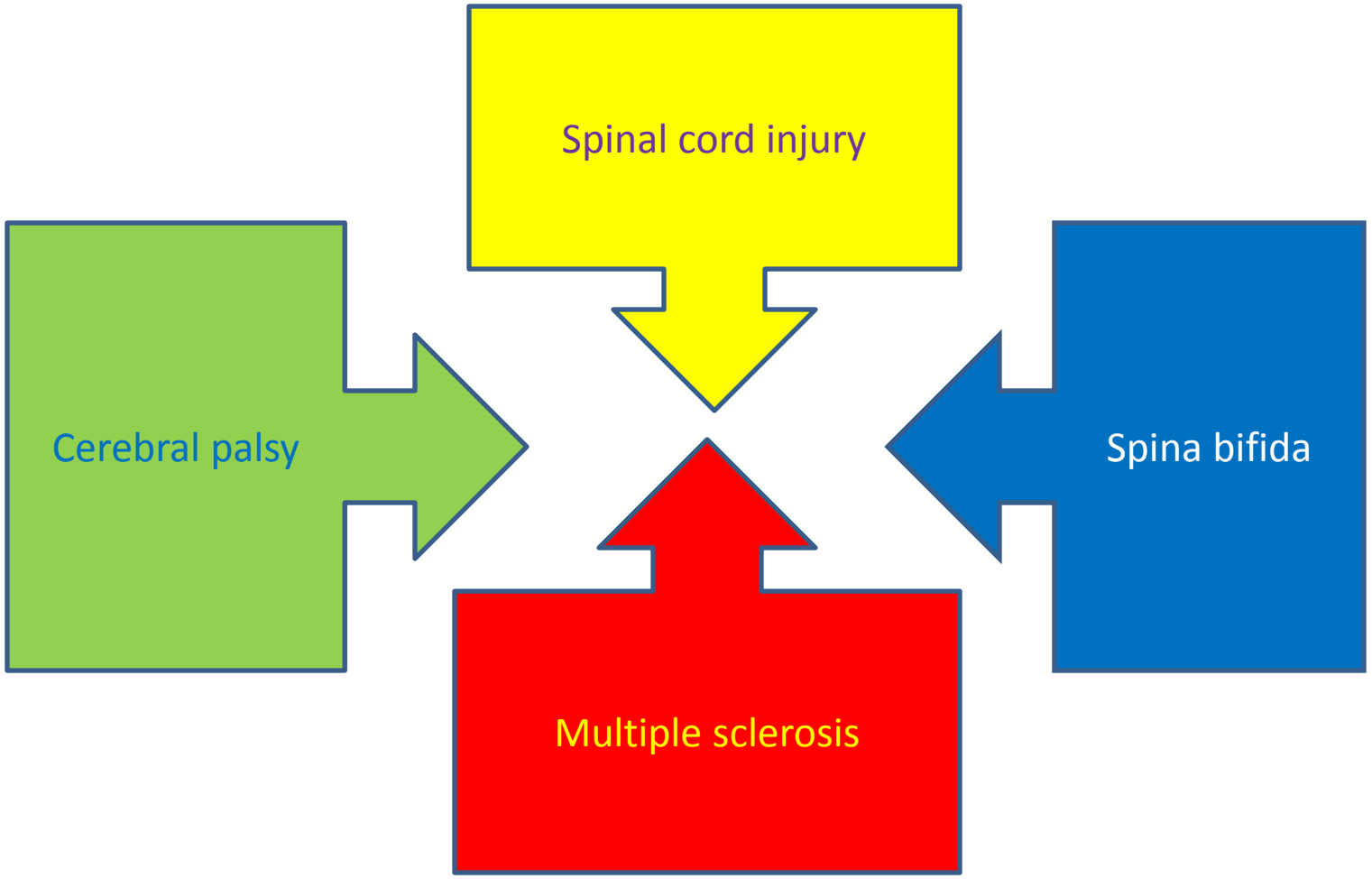
Peri-Menopause

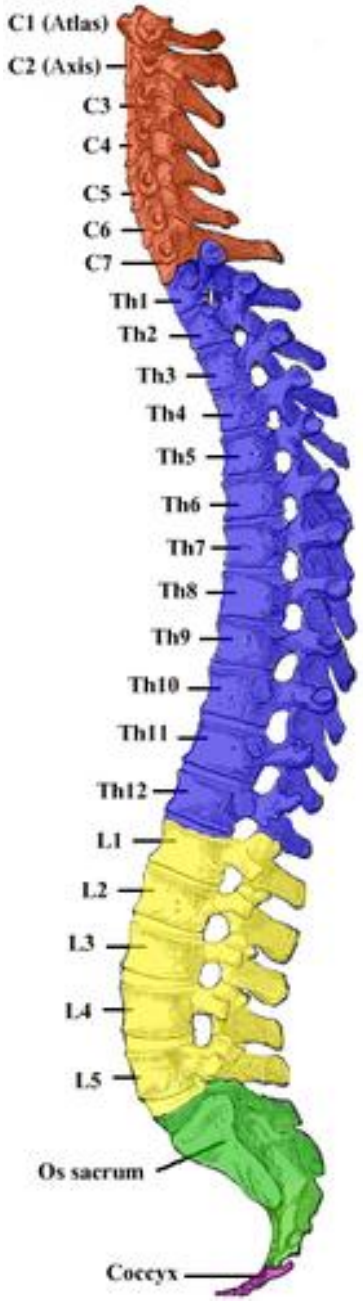
- Women with developmental disabilities may have an unusual reaction to hot flashes
- Menstrual hygiene issues due to irregular menses
- Increase in disability symptoms
- Estrogen replacement therapy has risks associated

Photograph by Alice Elliott

Part IV
Reproductive Health
Specific to Disability

Module 1 - Physical Disabilities





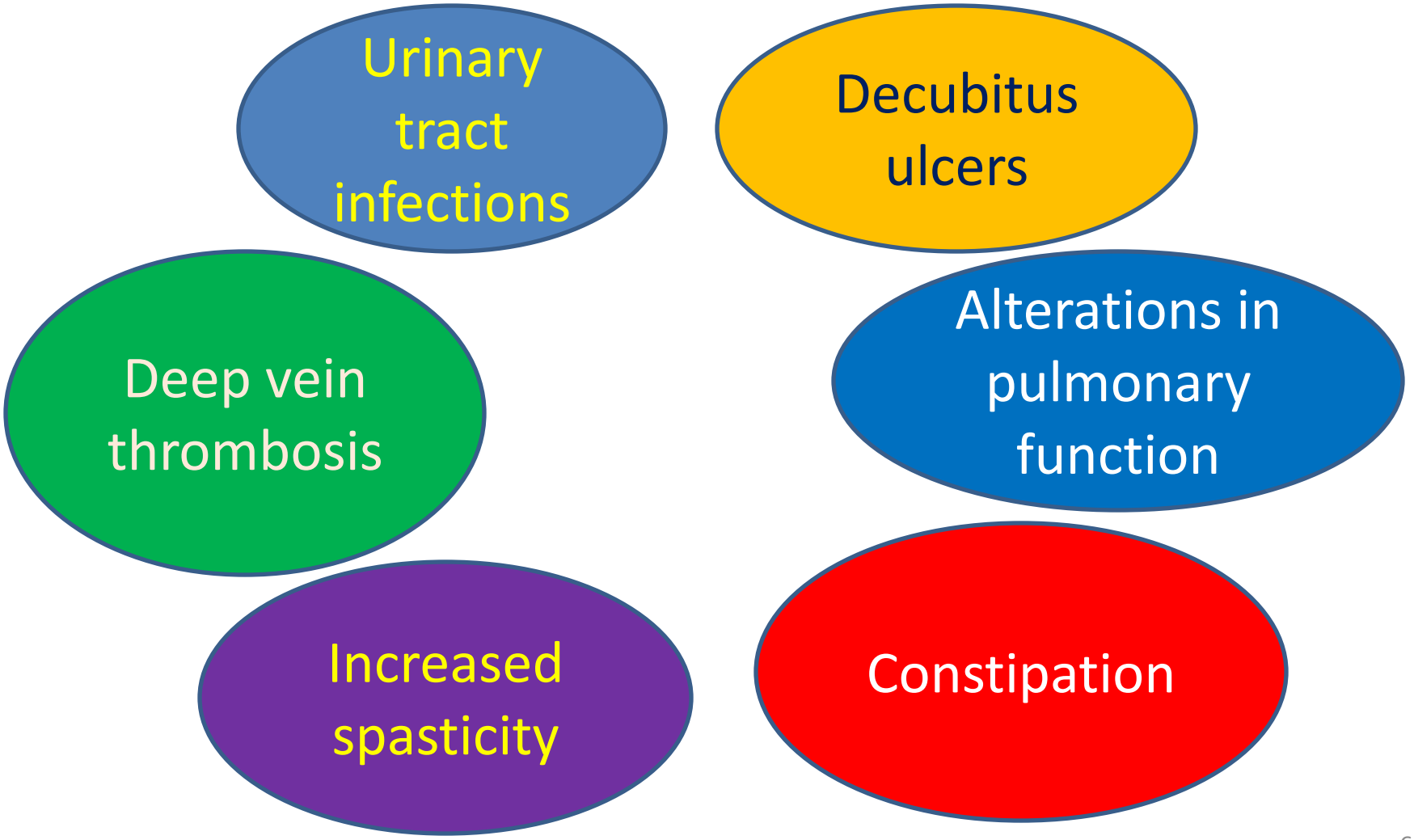
Source: Wikipedia, 2008

Segmental Spinal Cord Level and Function	
Level	**Function**
C1-C6	Neck flexors
C1-T1	Neck extensors
C3-C5	Supply diaphragm (mostly C4)
C5-C6	Shoulder movement, raise arm, flex elbow, supinates arm
C6-C7	Extends elbow and wrist, pronates wrist
C7-T1	Flexes wrist, supply small muscles of the hand
T1-T6	Intercostals and trunk above waist
T7-L1	Abdominal muscles
L1-L4	Thigh, hip muscles,
L4-S1	Hamstrings and dorsiflexion of foot
L4-S2	Plantar flexion of foot and toe movement

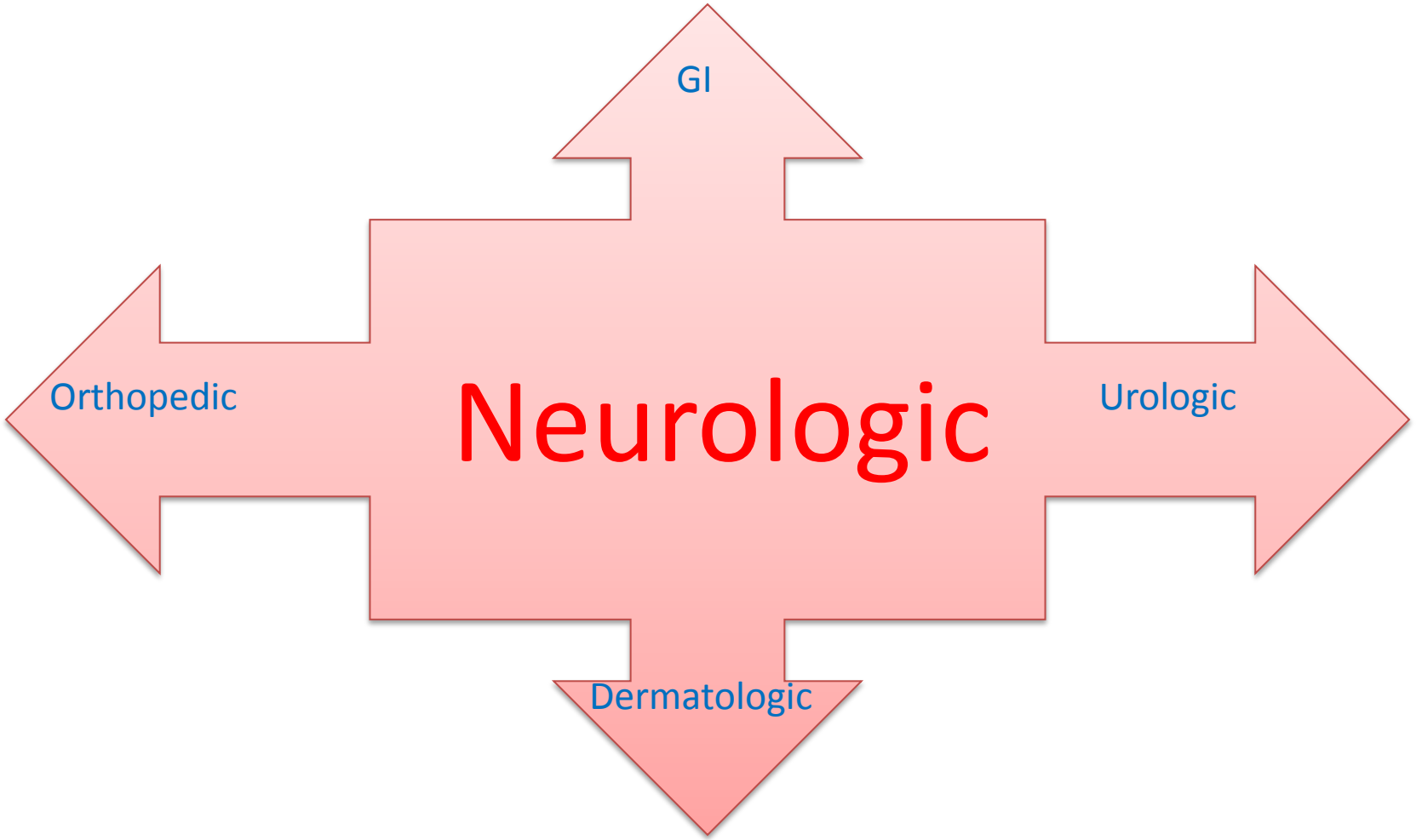
About Autonomic Dysreflexia

- 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



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)

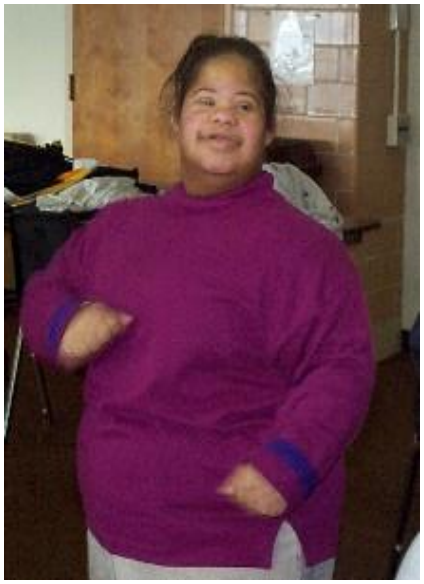
Reproductive Care Issues - IDD

- 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

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

Down Syndrome - Reproduction

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

CONSUMER ATTITUDES

"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 cil , 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 Tel: 314-647-8100

- **Healthy Aging – Adults with Intellectual Disabilities: Women's Health and Related Issues.** Authors: Walsh PN, Heller T Schupf N, van Schrojenstein Lantman-de Valk H. Report for the Scientific Study of Intellectual Disabilities, World Health Org. Geneva and Univ. of Wisconsin
  Access at: www.who.int/mental_health/media/en/20.pdf

- **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

- **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

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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