

"To promote the health and well-being of all Californians with developmental disabilities."

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# Wellness Digest

Volume 3, Number 1

CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

## Gender Specific Health Care

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People with developmental disabilities are no less susceptible to developing serious health conditions than the rest of the population. However, people with developmental disabilities may be at greater risk for a negative outcome due to inadequate diagnosis and treatment. A recent study by the Center for Research on Women and Disabilities found that women with physical disabilities do not receive the same quality of gynecological health care as women without disabilities. This study also found that women with significant functional challenges were the least likely to have access to thorough examinations, resulting in delayed diagnosis and treatment.



Preliminary research in this area suggests a similar disparity for men, as well.

This issue of the Wellness Digest discusses some of the most serious gender specific health concerns for both men and women. It includes information about risk factors, symptoms, and strategies for successful diagnosis and treatment. Also included are tips for overcoming the barriers that often prevent access to reproductive health care for people with developmental disabilities.

*...women with physical disabilities do not receive the same quality of gynecological health care as women without disabilities.*

### Did you know?

- 1 in 8 women in the US develop breast cancer each year, and 1 in 28 women die from the disease.
- 1 in 11 men develop prostate cancer each year, and almost one-third die from the disease.
- More than 500,000 Americans die each year from heart attacks caused by heart disease. Even though men are at greater risk, heart disease is the leading cause of death for both men and women.
- More than 20 million Americans are affected by osteoporosis. Women are thought to be at greater risk for developing this condition, but the risk to men is generally under-recognized.

# From the Director

## Wellness - A Way of Living

Cliff Allenby, Director



Since 1999, \$4.3 million has been allocated for 51 DDS Wellness Projects to increase access to and the quality of health care services to Californians with developmental disabilities. Health professionals continue to receive training on health issues to better treat persons with developmental disabilities. Recent training sessions include: *The 2001 Wellness Forum*, presented by DDS and ARCA in collaboration with the UC San Diego School of Medicine; *A Primer for Primary Care Providers*, presented by DDS and UC San Diego School of Medicine; *Directing and Managing the Care of Persons with Developmental Disabilities*, funded by DDS and hosted by UCLA's School of Nursing; and *Identification & Management of Developmental Disorders for Primary Care Providers*, funded by DDS and hosted by UC Davis Health System.

DDS and regional centers have collaborated with universities, State organizations, professional organizations, and service agencies to provide education, outreach, and consultation to healthcare providers, as well as improved access to quality health services for consumers. Here are some of the many resources that have been developed to assist in these efforts:

- *PACT Net*, developed in partnership with the UC Davis M.I.N.D. Institute, provides free consultations to community physicians, nurse practitioners, physician assistants, pharmacists, dietitians, and psychologists who are treating persons who have developmental disabilities and complex medical conditions.
- *Health Notes: Care of Children and Adults with Developmental Disabilities* is a special publication completed in partnership with the California State Board of Pharmacy and highlights subjects of importance to California pharmacists.
- *The Road to Wellness: Accessing Medical Services and Navigating the Managed Care System* was created in collaboration with the California Medical Association Workgroup on Health Care for Persons with Developmental Disabilities and serves as a guide for consumers and their families.
- A major health web site, [www.ddhealthinfo.org](http://www.ddhealthinfo.org), is funded by DDS and is coordinated by the Center for Health Improvement and the University of California School of Medicine. This site summarizes critical information to assist health care providers in caring for persons with developmental disabilities and to support consumers and their families in making informed health care decisions.

The Wellness Digest is another excellent resource and continues to be a way for us to share information on important health topics. This issue focuses on gender specific health care issues. I hope you will take a few moments to become familiar with some of the significant health issues facing both men and women. By expanding our knowledge and efforts, we can improve the health and the quality of life of Californians with developmental disabilities.

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The DDS Wellness Digest provides tips and information on a variety of health issues. This newsletter is not intended in any way as a substitute for qualified medical advice from a medical professional. If you have a health concern, always consult with your physician or other qualified health care practitioner for advice relating to a medical problem or condition. Never disregard medical advice or delay in seeking it because of something you have read in this newsletter. References in this newsletter to any specific commercial product, process, service, manufacturer, or company does not constitute its endorsement or recommendation by the DDS.

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## Dysmenorrhea

Dysmenorrhea is abdominal pain and cramping that many women experience just before and during their menstrual period. Although many women experience some discomfort during their menstrual period, some women experience severe pain that radiates into the back and upper thighs. Pain may be accompanied by other symptoms such as:

- nausea and vomiting
- headache
- diarrhea
- fatigue
- nervousness or dizziness.

Dysmenorrhea may be primary or secondary. Primary dysmenorrhea has no obvious pathological cause and almost always first occurs in women younger than 20. Secondary dysmenorrhea may be due to endometriosis, adenomyosis, pelvic infection or congestion, cervical stenosis, or stress and tension.

Oral contraceptives and nonprescription pain relievers are typically used to treat primary dysmenorrhea. Nonprescription drugs and the recommended dosage include:

- Ibuprofen (Motrin IB, Advil, or Midol): 200 to 400 mg every 4 to 6 hours, not to exceed 1200 mg in 24 hours.
- Naproxen Sodium (Aleve): 220 to 440 mg every 8 to 12 hours, not to exceed 660 mg in 24 hours.
- Ketoprofen (Actron or Orudis KT): 12.5 to 25 mg every 4 to 6 hours, not to exceed 75 mg in 24 hours.

These drugs should be taken with food to avoid upsetting the stomach. One helpful hint is to take them regularly for two days prior to the anticipated onset of pain. Women who have severe pain and discomfort should see their physician to rule out other potential conditions causing secondary dysmenorrhea. This is particularly important for women who:

- are older than 30
- have a history of irregular menstrual cycles
- experience pain for longer than 48-72 hours
- experience pain at times other than the beginning of their menstrual period.



## Endometriosis

Endometrium is the tissue that lines the inside of the uterus. This tissue is shed each month during menstruation. Endometriosis is a disease in which endometrium tissue grows outside of the uterus and becomes implanted in other areas of the body. Just like the lining of the uterus, changes in hormone levels during the menstrual cycle cause this abnormal tissue to break down. But unlike the lining of the uterus, this tissue has no way of leaving the body and can cause internal bleeding, inflammation, and the formation of scar tissue.

Positive diagnosis of endometriosis is only possible through exploratory surgical procedures, most commonly done through a laparoscope. Misdiagnosis is common because symptoms are similar to those of other conditions. Additionally, symptoms vary widely from woman to woman. Some women experience severe pain while other women with the disease have no symptoms at all. The classic symptoms are:

- dysmenorrhea,
- painful sexual intercourse,
- infertility.

Other symptoms of endometriosis include:

- irregular menstrual periods
- cyclic abdominal pain
- painful bowel movement
- painful urination.

Symptoms can usually be successfully treated and managed with medical or surgical therapy. For mild symptoms medical therapy is often used. Over the counter pain relievers taken during menstruation may be adequate. Birth control pills can significantly reduce the cyclic pain, particularly when taken continuously (skipping the week of inactive pills) to stop menstruation altogether. Hormonal agents are often prescribed in more severe cases to control the growth of abnormal tissue. Surgical therapy is performed when the endometriosis tissues are removed, often burning them with a cautery or laser through a laparoscope. Surgical removal of the uterus (hysterectomy) and the ovaries (oophorectomy), can also provide relief. Many women continue to have symptoms following a hysterectomy from the endometrium tissue that remains in their bodies.

## Vaginal Infections

The following table describes some vaginal infections. These can and should be identified and treated.

Condition	Symptoms	Treatment/Prevention
<b>Yeast infection</b>	Vulvar and vaginal itch, white cottage cheese discharge	Over-the-counter antifungal creams; if symptoms persist, see your doctor
<b>Bacterial vaginosis</b>	Vaginal odor, thin gray discharge	Treat with metronidazole or clindamycin cream or pills
<b>Trichomoniasis</b>	Copious wet, green vaginal discharge	Sexually transmitted infection; treat with metronidazole; partner should be treated

## Breast Cancer

Breast cancer is the most commonly diagnosed cancer in American women. It is a leading cause of cancer-related death in women between the ages of 40 and 55. All women are at some risk for breast cancer, especially as they age, but those at greatest risk include women who:

- have an immediate family member (mother, sister, or daughter) who has had breast cancer
- have a history of previous breast cancer or benign breast disease
- have never given birth or had a first pregnancy after age 35
- began menstruation at an early age or entered menopause late in life
- have high dietary fat intake or are obese.

The rate of breast cancer cases has been steadily increasing in the United States since 1940, but the overall mortality rate for those diagnosed cases has been declining since 1990. The use of mammography screening to detect breast cancer at earlier stages, when treatment can be most effective, may have contributed to this decline. In addition to mammograms, self breast exams and clinical physical examinations can increase the likelihood of early detection. Symptoms to be alerted to include:

- a painless lump in the breast
- unexplained pain in the breast with no lump
- unexplained discharge from the nipple
- inversion or retraction of the nipple
- a thickened area of skin on the breast
- scaling or erosion of the nipple.

## Recommended Breast Cancer Screening Methods

Screening Method	Age Group	Frequency
Breast Self Exam	Age 20 and older	Each month after the menstrual period
Physical Exam by a Health Practitioner	Age 20 to 40 Age 40 and older	Every 3 years Yearly
Mammogram	Age 40 to 49 Age 50 and older	Every 1 to 2 years Yearly



### Other things every woman should know

Physicians recommend that women who are planning to get pregnant or who may become pregnant take a daily multivitamin containing folic acid and see a doctor about preconceptual care.

Emergency contraception is available for women in the event that they are exposed to the risk of an unwanted pregnancy. For example, if a condom breaks or slips, and a patient calls her doctor within 72 hours of the event, the doctor can prescribe birth control pills to prevent pregnancy.

## Ovarian Cancer

Ovarian cancer is the leading cause of gynecological cancer death in women in the United States. One woman in 70 will develop ovarian cancer during her lifetime. Known as a “silent killer”, there are typically no symptoms of the disease until the advanced stages, when treatment is less effective. Although the causes of ovarian cancer are not known, certain risk factors have been identified. These include:

- **Age:** Women over 40 are more likely to develop ovarian cancer, with postmenopausal women being at greatest risk.
- **No Pregnancies or Late Pregnancy:** Never having had children, or having a first pregnancy after the age of 35, increases the risk of ovarian cancer. However, the use of oral contraceptives reduces a woman's risk of developing the disease.
- **Family History:** Women with a family history of ovarian cancer are at greatest risk of developing the disease. In addition, genetic studies have linked ovarian cancer with specific types of breast and colon cancers.

Early detection of ovarian cancer is difficult. Screening with ultrasound or blood test (CA125) has not been found useful in the general population. Women who experience unusual bloating, persistent indigestion symptoms, or recurrent abdominal discomfort should see their physician as soon as possible for a thorough physical and pelvic examination. This is especially critical for women who are going through, or have gone through, menopause. Other serious conditions, such as cervical and uterine cancer, can also be detected through such examinations. Women with a family history of ovarian cancer should consult their doctors about the options of taking birth control pills or removing the ovaries to prevent ovarian cancer.

## Menopause

Menopause is that point in time when monthly menstruation, or periods, stop permanently. The median age of menopause for American women is 51.3 years. It results from loss of ovarian activity, a normal biological process in which the ovaries begin to produce less of the hormone estrogen. Some women with developmental disabilities may begin the process earlier. During this transition, women may experience some of the following symptoms:

- irregular menstrual cycles
- hot flashes
- insomnia
- night sweats
- anxiety or irritability
- mood swings
- headaches
- vaginal dryness
- loss of concentration or memory
- painful sexual intercourse
- decreased libido
- urinary incontinence.

In addition to the symptoms listed above, the reduction in estrogen associated with menopause can lead to serious long-term medical problems. Among these are osteoporosis and heart disease (please see the section *Health Concerns for Both Genders*, below). Hormone Replacement Therapy (HRT) is often recommended to treat the symptoms and conditions associated with reduced estrogen levels. HRT is the administration of the hormones estrogen and progesterone, usually in a pill form. Because HRT has potential side-effects, these must be considered before choosing it as an option. Although an increased risk of breast cancer is commonly associated with HRT, thus far clinical studies have not been able to conclusively prove that a link exists. To determine if HRT is a viable option, women should discuss the pros and the cons of this therapy with their physician.

### Some Pros and Cons to Hormone Replacement Therapy (HRT)

PROS:	CONS:
Relief from hot flashes, mood swings, and other symptoms related to menopause.	Possible return (or continuation) of monthly menstrual periods.
Reduction of the bone loss associated with osteoporosis.	Possible increased risk for breast and uterine cancer.
Reduced risk of heart disease.	Possible increased risk of blood clots, especially for women who have had a recent heart attack, a history of blood clotting problems, or conditions that result in decreased mobility.

## Benign Prostatic Hyperplasia

The prostate is a small, walnut shaped gland located between the bladder and the rectum. This gland surrounds the urethra, the canal that expels urine from the bladder. At about age 30, the inner part of the prostate begins to gradually enlarge. This normal enlargement is known as benign prostatic hyperplasia.

Most men are unaware of this gradual change in the prostate gland unless it begins to press against the bladder or urethra, making urination painful or difficult. By age 60, more than fifty percent of all men will experience such problems and about twenty-five percent will require treatment. Surgery to remove excessive tissue inside the prostate is the most common treatment method.

Benign prostatic hyperplasia is often confused with prostate cancer, but the two conditions are very different. Prostate cancer affects the outer portion, rather than the inner portion, of the gland. However, the two conditions share some of the same symptoms. They can also exist at the same time. Men who experience any of the following symptoms should see their physician as soon as possible for a physical exam:

- pain or burning sensation while urinating
- difficulty in urination, including a weak or interrupted urine stream
- need to urinate frequently, especially at night
- Blood in the urine
- consistent pain in the lower back, upper thighs or pelvis.

## Prostate Cancer

Prostate cancer is the most common cancer found in American men and the second leading cause of death behind lung cancer. The exact causes of prostate cancer are not known but researchers have identified the following risk factors:

- **Age:** The chance of developing prostate cancer increases as men get older. Men over 50 years of age are at greater risk.
- **Family History:** Men with a father, brother, or son who has had prostate cancer are twice as likely to develop prostate cancer than men who have no family history of the disease.
- **Race:** African American men have the highest incidence rates of prostate cancer and are two to three times more likely to die from the disease than other men.



- **Diet:** Some researchers believe that prostate cancer may be associated with a high-fat diet. Excessive alcohol consumption may also be a factor.

Although there are usually no symptoms in the first stages of prostate cancer, early detection is essential for effective treatment and a positive outcome. African American men over the age of 40, and all other men over the age of 50, should have an annual prostate screening. The most common screening methods include the digital rectal examination, the prostate-specific antigen (PSA) blood test, and transrectal ultrasound. Men of all ages should consult their physician immediately if they experience any of the symptoms described earlier for benign prostatic hyperplasia, as these are the same for prostate cancer.

## Testicular Cancer

Testicular cancer is cancer that develops in the testicles. Unlike prostate cancer, testicular cancer tends to affect younger men. Men ages 15 to 35 are at greater risk of testicular cancer, but it can develop in males of all ages. Other risk factors include:

- **Family History:** Males in families with a history of testicular cancer are at higher risk of developing the disease. Males who have had cancer in one of their testicles have an increased risk of developing cancer in the other testicle.
- **Undescended Testicles:** Fourteen percent of all cases of testicular cancer occur in males who had an undescended testicle at birth. However, undescended testicles are not the cause of the cancer. Researchers suspect that the cause of the undescended testicles may also be the cause of the cancer.
- **Race:** White males have much higher incidence rates of testicular cancer than males in all other racial and ethnic groups.

When detected and treated in the early stages of the disease, cases of testicular cancer are cured 90 percent of the time. All men should perform monthly self-examinations as most testicular cancers are detected by men themselves. It is also important that men get regular checkups that include a testicular exam.

Symptoms of testicular cancer include:

- a lump in a testicle
- any enlargement of a testicle

- a feeling of heaviness in the scrotum (the pouch of skin that contains the testicles).
- a sudden collection of fluid in the scrotum
- a dull pain in the lower abdomen or groin
- a change in the way a testicle feels
- any pain or discomfort in the testicles or scrotum.

### Can Men Get Breast Cancer?

Yes they can, but it is very uncommon. Information about male breast cancer is included here, however, because some men are at greater risk. Among those are men with Klinefelter's syndrome, a genetic condition in which men

have an additional X chromosome in their chromosomal arrangement. The syndrome is often associated with physical, developmental, and learning challenges. It occurs in approximately 1 in every 500 to 1,000 male births, making it one of the most common chromosome anomalies.

Symptoms of breast cancer in men are basically the same as those in women (please see Page 4 on *Breast Cancer* under *Women's Health Issues*). Likewise, early diagnosis and treatment is as critical for men as it is for women. All men, but especially those at increased risk for the disease, should have routine breast exams. This includes self breast exams as well as clinical exams performed by a healthcare provider.

## Health Concerns for Both Genders

### Heart Disease

Heart disease is caused by the narrowing or clogging of the coronary arteries, the arteries that provide oxygen-carrying blood to the heart. When the blood supply is completely cut-off, a heart attack occurs and the part of the heart that does not get oxygen begins to die. Following an attack, surgery is often required to re-route the arteries from the areas of the heart that were damaged. Recognizing the risk factors and symptoms of heart disease is important to the prevention of heart attacks.

Although the risk factors and symptoms are generally the same for both men and women, most people think of heart disease as a condition that primarily affects men. But one in every nine American women between the ages of 45 and 64 has some form of heart disease. Because men have a higher overall risk, many women do not seek medical attention until the disease is at an advanced stage, when treatment is less effective. Following menopause, women are at equal risk for heart disease as men.

Risk factors of heart disease include:

- *High Cholesterol:* Cholesterol forms fatty deposits in the arteries which slow or block the flow of blood. The higher the level of cholesterol in the blood, the greater the chance it will be deposited onto the artery walls.
- *Smoking:* Smoking decreases the oxygen in the blood which makes the heart work harder. Chemicals in tobacco smoke contribute to the formation of fatty deposits in the arteries.

- *Hypertension:* Chronic high blood pressure (over 140/90) is a serious risk factor for heart disease. Overweight people are at greater risk for high blood pressure. People with high blood pressure, high cholesterol and who smoke are eight times more likely to develop heart disease than people who have none of these risk factors.
- *Physical Activity:* Exercise can strengthen the heart muscle, help control cholesterol levels, and reduce blood pressure. People who are physically inactive are at greater risk for heart disease and heart attacks.
- *Family History:* Individuals from families in which parents or siblings developed heart disease prior to the age of 55 are at increased risk. There is additional risk if there is a family history of diabetes.

The symptoms of heart disease can vary greatly from one person to another. Some people experience no symptoms at all while others may have symptoms that are severe enough to disrupt their daily activities. Whether intermittent or steady, medical attention should be sought when an individual experiences any of the following symptoms:

- Pain, tightness, or burning in the chest accompanied by shortness of breath.
- Pain or numbness concentrated behind the breastbone, or that travels up to the shoulders, arms, neck, and jaw.
- Chest pain or pressure accompanied by sweating, nausea, indigestion, lightheadedness, fainting, or fatigue.

## Healthy Living For A Healthy Heart

<b>Diet:</b>	Increase the amount of fiber by eating whole-grain cereals and breads, rice, pasta, fruits, and vegetables.
	Decrease the amount of red meat, bacon, eggs, and dairy products. Limit sodium by avoiding products with high salt content, such as canned foods, luncheon meats, and snack foods.
	Increase heart healthy mono-unsaturated fats by using canola and olive oils in cooking. Avocados, nuts, and peanut butter are other good sources.
<b>Exercise:</b>	Establish a routine that includes 30 minutes of moderate exercise each day. Simple activities like walking and gardening can be beneficial.
	Exercise with friends.
	Vary the routine so you don't get bored.
<b>Other</b>	Have blood pressure and cholesterol checked regularly.
<b>Activities:</b>	If you smoke, QUIT.
	Consult your doctor about taking HRT.

## Osteoporosis

As we age, our bones become thinner and more fragile. This loss of bone density may lead to osteoporosis, a condition in which the bones become so thin that they are easily broken or fractured. Osteoporosis is responsible for over 1.5 million fractures in the United States each year. Typically, there are no visible signs of the disease until a fall or strain causes a bone to break.

Although osteoporosis has long been considered a disease that primarily affects postmenopausal women, experts now conclude that the risk to men has been under-recognized. This is because men have more bone density than women, so the effects of osteoporosis take longer to be noticed. The National Institute of Health estimates that one in two women and one in eight men over the age of 50 will experience a fracture due to osteoporosis.

### What are the risk factors for osteoporosis?

- A history of taking certain medications, including anticonvulsants, thyroid hormones, and corticosteroids.
- Physical inactivity, including a condition that limits movement.
- A family history of osteoporosis.
- Menopause, especially prior to age 45.

- A diet low in calcium or vitamin D.
- A history of over-dieting or excessive weight loss.
- High intake of alcohol or coffee.

### Steps to reduce the risk for osteoporosis:

- Eat three or more servings each day of foods that are high in calcium, including broccoli, spinach, and other dark green leafy vegetables. Salmon, dairy products and calcium-enriched orange juice are other good sources.
- Take a calcium supplement daily.
- Do weight-bearing exercises.
- Use alcohol only in moderation (1 to 2 drinks per day).
- Don't smoke.
- Consult your physician about hormone replacement therapy if you are a postmenopausal woman.



## HIV, Hepatitis C and Other Sexually Transmitted Diseases

Sexually transmitted diseases (STDs) are infections passed from person to person through sexual intercourse or genital contact. Never share needles, syringes or other personal items that could be contaminated with blood or other body fluids.

Practice abstinence to prevent HIV, Hepatitis C, and other STDs. Use latex condoms to reduce the risk of contacting HIV, Hepatitis C, and other STDs.

Condition	Symptoms	Treatment *
<b>HIV</b>	Rapid, unexplained weight loss, fever and night sweats, severe fatigue, swollen glands, unusual sores on the skin or in the mouth, and unusual cancers and infections. A person may have no symptoms but can still transmit the disease.	Treat with combination anti-viral agents including zidovudine (AZT). Prophylaxis against opportunistic infections such as PCP, tuberculosis and mycobacterium avium complex vaccination. Consult your health care provider regarding specific vaccinations.
<b>Hepatitis C</b>	Constant fatigue, sore muscles, headache, nausea, abdominal pain, dark urine or light (clay colored) stools, loss of appetite or weight loss. Jaundice is a less common symptom.	Long term (chronic) hepatitis C may be treated with antiviral medication, such as interferon and ribavirin, if the person meets specific criteria.
<b>Gonorrhea</b>	Often no symptoms; discharge. Women may experience bleeding after sexual intercourse.	Treat with ceftriaxone or ofloxacin. Partner(s) should be treated.
<b>Chlamydia</b>	Often no symptoms; discharge. Women may experience bleeding after sexual intercourse.	Treat with doxycycline or azithromycin. Partners should be treated.
<b>Warts (Condyloma Accumunata)</b>	Masses of variable size & appearance (pinhead to cauliflower) on labia or penis but could spread elsewhere.	Caused by human papilloma virus (HPV). Treat with medication, freezing, burning, or laser.
<b>Genital Herpes</b>	Painful blisters (vesicles) on labia and surrounding areas or the penis, may recur with period, stress or illness.	Caused by herpes simplex virus (HSV). Treat with acyclovir or similar antiviral agents; taking acyclovir prophylactically may reduce frequency of recurrence.
<b>Pelvic Inflammatory Disease (PID) (Women Only)</b>	Pelvic pain, fever, foul vaginal odor.	Caused by gonorrhea, chlamydia & other bacteria. Treat with multiple antibiotics. Delay in treatment can lead to infertility.
<b>Syphilis</b>	Symptoms are often indistinguishable from those of other diseases. Starts with a single sore (called a chancre) that will heal itself. Then rashes can appear anywhere on the body. If untreated, the bacterium remains in the body and begins to damage the internal organs, including the brain, nerves, eyes, heart, blood vessels, liver, bones, and joints. This damage may be serious enough to cause death.	Treat with the antibiotic penicillin. Home remedies or over-the-counter drugs do not cure syphilis.

\* All treatment should be administered and closely monitored by a physician.

## Access Barriers

The need to provide routine health services for men and women with developmental disabilities is often under-recognized, and in many cases dismissed entirely. Anecdotal reports indicate that physicians often assume that all people with developmental disabilities are not sexually active and,

therefore, do not need reproductive health examinations. The connection between reproductive health and the acknowledgement of a patient's sexual activity contributes to many of the barriers people with developmental disabilities face in accessing these types of services. Care providers and family

members may feel uncomfortable and apprehensive about assisting individuals in obtaining these types of services. Given the intimate nature of reproductive health care services, individuals sometimes experience so much fear and anxiety that it is difficult for them to successfully complete an examination. This is especially troublesome for individuals who have been the victims of sexual abuse.

Additional challenges faced by people with developmental disabilities in obtaining needed reproductive health care services include:

## **Communication Issues**

- Individuals who do not use speech to communicate typically have less access to needed health care because they are unable to verbalize about the symptoms they are experiencing. Often, a change in behavior is the first indication of a serious medical condition.
- Medical language can be very technical. Many people find medical terms confusing and difficult to understand. Individuals with developmental disabilities may need extra assistance in communicating with health providers about their symptoms, conditions and course of treatment.

## **Physical Access**

- People who have physical challenges often do not get thorough examinations because of the positioning difficulties they experience. Many facilities do not have accessible examination rooms, tables, or other adaptive screening equipment. Most physicians and their office staff will not lift an individual onto an examination table or provide the needed support to maintain the proper position for an exam. Additional support may be necessary to help individuals find accessible facilities and health care providers who have experience in providing care to persons with physical challenges.

## **Distaste For Examinations: Doesn't Everyone Prefer Not To?**

- Most physical examinations are unpleasant, embarrassing, and uncomfortable. Reproductive health examinations are often viewed as exceptionally so. Knowing about serious health conditions, and understanding the importance of early detection for successful treatment usually motivate people to have routine exams. Ensuring that health information is clearly explained in a respectful manner can help lessen resistance to examinations.

## **Tips for Enhancing Health Care Services**

### **Questions to ask before the medical appointment**

- Is the doctor experienced in caring for individuals with disabilities?
- Is the doctor willing to accept the health plan?
- Does the doctor have staff with experience in special needs who can facilitate access to services?
- Is the office accessible and what are the accommodation procedures?
- Is there adaptive equipment available?
- What are the office hours?
- Is there someone available to help after-hours, for advice or referrals?
- How soon can I be seen for an office visit?
- How much time is allowed for an office visit?
- Will the doctor discuss health questions or treatment over the phone?
- Does the doctor offer an advice nurse telephone service?

### **Tips for a productive office visit**

- Prepare a list of questions and concerns before your appointment. Refer to the list during your appointment so you do not forget anything.
- Gather information ahead of time that your doctor will need to know, such as current medications, allergies, record of menstrual periods, and any other relevant health history.
- Utilize desensitization approaches with individuals who are particularly anxious. This could include a photographic review of the clinic and procedures, visiting the clinic office ahead of time, meeting the office staff and clinician, and specific education as to what to expect during an exam or procedure.
- Provide additional support during the examination by having a familiar and trusted person present during the exam or procedure. Because of the personal nature of these health care services, such support should be provided only if acceptable to the individual, and only with greatest respect for their privacy.

## **Sources**

The Centers for Disease Control and Prevention  
[www.cdc.gov](http://www.cdc.gov)

The ARC of the United States  
<http://thearc.org>

## Resources

The National Institutes of Health

[www.nih.gov](http://www.nih.gov)

The College of American Pathologists

[www.cap.org](http://www.cap.org)

The National Library of Medicine

[www.ncbi.nlm.nih.gov](http://www.ncbi.nlm.nih.gov)

Center for Research on Women with Disabilities

[www.bcm.tmc.edu](http://www.bcm.tmc.edu)

Health Information and Referral Center for Women provided by the Department of Health and Human Services

[www.4women.gov](http://www.4women.gov)

Women's Cancer Network

[www.wcn.org](http://www.wcn.org)

University of Texas: Houston Medical School

<http://medic.med.uth.tmc.edu>

*Treatment of Postmenopausal Women*, by RA. Lobo, Raven Press, 1994.

*Clinical Gynecologic Oncology*, by DiSaia and Creasman, Mosby, 1997.



## Off the Net

The Department of Developmental Services (DDS)

[www.dds.ca.gov](http://www.dds.ca.gov)

DDS' Wellness Home Page

[www.dds.ca.gov/wellness/main/well01.cfm](http://www.dds.ca.gov/wellness/main/well01.cfm)

The Center for Health Improvement and Golden Gate Regional Center have developed [www.ddhealthinfo.org](http://www.ddhealthinfo.org)

This web site showcases current California – based developmental disability programs for health care providers provided by DDS & UCSD School of Medicine.

U.S. Department of Health and Human Services and the Office of Health Promotion and Disease Prevention

[www.healthfinder.gov](http://www.healthfinder.gov)

National Women's Health Information Center of the U.S. Department of Health and Human Services Office of Women's Health [www.4women.gov](http://www.4women.gov)

Centers for Disease Control and Prevention [www.cdc.gov](http://www.cdc.gov)

This site offers information on a wide range of health issues, including data and statistics, and links to other sites.

Women's Health Specialists [www.fwhc.com](http://www.fwhc.com)

American Urological Association, Incorporated

[www.auanet.org](http://www.auanet.org). Provides an on-line referral service for finding a urologist. Under the patient information tab, go to "Find a Urologist".

**Wellness Initiative Projects**, funded by the DDS Wellness Initiative:

- Central Valley Regional Center, *Woman's Health* provided women's health screenings to over 50 underserved consumers (559) 276-4322
- Far Northern Regional Center, *Expanded Health Services for Women* provided monthly clinics for women with disabilities and developed a training curriculum for care providers and community health care providers (530) 222-8795
- Frank D. Lanterman Regional Center, *Reproductive Health of Women With Developmental Disabilities* organized a peer-advocacy training, a self-advocacy training, and a health provider training focused on advocating for the reproductive health of women with disabilities (213) 383-1300
- Redwood Coast Regional Center, *Enhanced Access to Women's Health Services for Individuals Unable to Cooperate for Exams* trained staff from three clinics regarding the various needs of women with developmental disabilities (707) 445-0893
- Regional Center of the East Bay, *Increased Access to Women's Health Services for Women with Developmental Disabilities* provided support to women receiving gynecological care from trained and knowledgeable health care providers (510) 383-1209

**Alta Bates Medical Center**, Breast Health Access for Women with Disabilities  
Berkeley (510) 204-4522

### Women's Health Specialists

Chico (530) 891-1911,  
Redding (530) 221-0193,  
Sacramento (916) 451-0621,  
Santa Rosa (707) 537-1171

### The Physician Assistance, Consultation and Training Network (PACT Net)

is a cooperative program between DDS and the UC Davis M.I.N.D. Institute to provide consultation by telephone to physicians, nurse practitioners, physician assistants, pharmacists and psychologists who are treating persons who have developmental disabilities and complex medical conditions.

1-800-4-UCDAVIS

Let the health care professionals caring for you know about PACT Net by bringing the above phone number with you to your next check up!

## Our Thanks to

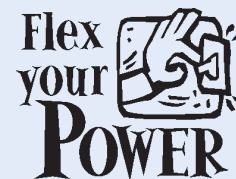
### Michael C. Lu, MD, MPH



Our consulting editor for this issue of the Wellness Digest is Michael C. Lu, M.D., M.P.H.

Dr. Lu is an Assistant Professor in the Department of Obstetrics and Gynecology at the UCLA School of Medicine. He also holds a joint faculty appointment in the Department of Community Health Sciences within the UCLA School of Public Health. Dr. Lu is the Medical Director of the UCLA Sexual and Reproductive Health Program, which has partnered with Lanterman Regional Center in designing, implementing and evaluating a peer advocacy program to improve the reproductive health of women with developmental disabilities. He received his MPH from U.C. Berkeley, and his M.D. from UCSF.

**Energy conservation** succeeds only with everyone's participation. Please join the effort with these energy saving tips. Putting the following tips into action can reduce both energy consumption and electricity bills at home and at work.



#### At Home: Energy Saving Tips

**Eliminate wasted energy** by turning off lights and appliances when not in use. Unplug electronic devices and chargers when they are not in use.

**Monitor your thermostat** by setting it at 78 degrees in the summer and 68 degrees in the winter.

**Use your appliances wisely** by avoiding use until after 7 p.m. Use only cold or warm water for laundry and let your dishes air-dry.

#### At Work: Energy Saving Tips

**Turn off** all lights when leaving a room and at the end of the day, and turn off your computer, monitor, and printer when you leave work.

**Use task lighting and daylight** instead of overhead lights when possible.

**Use the energy saving features** on all office equipment, including photocopiers.

For more energy saving tips, visit [www.flexyourpower.ca.gov](http://www.flexyourpower.ca.gov).