Table Manners and Beyond

The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations

Edited by
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The sections of this manual covering alternative positions for the pelvic exam, transferring, and other special concerns were first published by Planned Parenthood of the Golden Gate in 1981 in a booklet entitled, Table Manners. Special thanks go to this organization for giving permission to expand upon and update their original work.

Significant contributions to content were provided by Susan Dupuis, MPH, Disability Program Manager, Planned Parenthood: Shasta-Diablo, and by Priscilla Abercrombie, N.P., Ph.D. Both women gave the handbook an intense professional review and provided many useful suggestions.

Suzanne Hobesh contributed three original sketches for the body of this manual; and Kevin Taylor provided the cover art. The design and layout of the manual were the work of Designs by Mort.

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Chapter 1 - Introduction

A. The Need for Services

All women need to receive regular gynecological exams. Women with disabilities should have exams at the same frequency and for the same reasons as other women.

However, this standard is rarely achieved. In a recent study in one Bay Area county, a survey of women with disabilities found that only 20 out of 450 women 18 years or older had ever had a Pap test. Even more troubling, only three out of 70 women over the age of 50 had ever had a pelvic exam. The Breast Health Access for Women with Disabilities Program in Berkeley estimates that nationally as many as 15 million women have functional limitations that may be barriers to clinical breast exams, mammography or breast self-exams.

When important prevention services such as these are reduced, there is a proven increase in the risk that serious health problems will go undetected and untreated.

The purpose of this manual is to help clinicians provide these services. To do this successfully, it is important to look at the reasons for decreased services, the many barriers to reproductive health care faced by women with developmental disabilities.

Access Barriers

There are physical as well as communication barriers to access.

- Medical staff are rarely trained to communicate with women who have disabilities that affect communication and learning.
- Health education materials in appropriate formats are not always available.
- Staff are not trained in alternative methods of providing the exam and transferring patients.
- Medical offices and equipment are not accessible.
- Getting to a clinic is often a major ordeal that involves coordinating assistance and finding accessible public transportation.
- Sign language interpreters are not available when needed.
Attitudinal Barriers
There is a common belief that women with disabilities do not need the gynecological exam because they are not – and have never been – sexually active. We cannot assume that women with developmental disabilities are not sexually active. A woman may seek sexual contact and conceal it because those around her disapprove. She may be sexually abused without her parents', care giver's or attendant's knowledge – or she may be abused by one of these people. She may not know that abuse is wrong, or understand why. She may not be able to verbally report her experiences, or she may have tried to tell someone but was not believed. Or, if abuse was combined with affection, treats, caring behavior and/or positive sexual feelings, she may feel ambivalent about the abuse or even participate willingly in activities, which others define as abusive.

Emotional Barriers
Many women are uncomfortable having a gynecological exam. A patient with a developmental disability may have additional concerns. She may have concerns about getting on the exam table or reading consent forms. She may be uncomfortable with touch or new environments. She may not know her “family history”. She may have never used a tampon or had intercourse. She may have been taught never to “touch herself.” She very likely has been taught not to let anyone else touch her “private parts”. She may have reached the age of 30 or even 40 without ever having had a pelvic exam. For some, coming to a clinic or taking a pill is in itself very frightening. Sometimes a cycle of problems is created. Any woman’s first exam can be frightening. Lack of sexuality education, discomfort with touch, or a history of sexual abuse can increase this fear. If the first exam results in trauma, the next exam is even more difficult, for both the patient and the health care provider. In addition, many women with disabilities are socialized to “please” and may find it difficult to voice their fears and concerns.

Financial and Systemic Barriers
Most health care systems face severe financial and time constraints. If gynecological health care begins at the appropriate age with adequate and appropriate health education and care, and that care is repeated at the medically recommended or indicated intervals, the gynecological exam will usually be much easier for the woman and both easier and quicker for the health professional. In addition, it has been proven that women with developmental disabilities who receive regular exams have better gynecological health, learn more about their bodies, and are more likely to report abuse.
B. Developmental Disabilities

Many misconceptions still exist concerning people with developmental disabilities. People with developmental disabilities are individuals, with a wide and often unpredictable range of skills, abilities and needs.

Developmental disabilities, as defined by California regulations, include "mental retardation, epilepsy, cerebral palsy, autism and other conditions similar to retardation that require similar treatment." These disabilities have an onset before age 18 can affect development.

Many state-funded services are provided to help children with developmental disabilities grow up and develop in healthy ways and experience the same learning opportunities that other people have.

Many people have disabilities that are not easily diagnosed. And some have more than one disability. For example, perinatal brain damage can cause mental retardation, cerebral palsy and epilepsy. Yet most people with cerebral palsy and epilepsy are not mentally retarded.

People with developmental disabilities are often harmed by the assumptions others make about their conditions and abilities. For instance, someone whose speech is severely affected by cerebral palsy or who is heavily medicated may not be able to develop her native intelligence because she is not given opportunities to learn language skills or engage in social learning experiences.

Developmental disabilities are not diseases and are not progressive, although secondary conditions may develop. Like all patients, those with developmental disabilities may have other related and unrelated conditions, health concerns and diagnoses as well.

An assumption that the disability is the patient's only problem may endanger the patient's health by causing other health issues to be overlooked or ignored. For example, one woman felt a lump in her breast and her doctor told her it was a bulging muscle from pushing her wheelchair. She was later diagnosed with stage three breast cancer, which ultimately proved fatal.

In another case, a young woman, with developmental and emotional disabilities, complained to her doctor of stomach pain and weight gain. The doctor assumed these were due to emotional distress. Pregnancy was not diagnosed until she was over five months pregnant.
Specific Developmental Disabilities

**Mental retardation** is a catchall term for impaired ability to learn and think either in the same way or at the same rate as the average person. Most people with mental retardation can achieve some independence as adults in their living situations, in their work, and in their relationships. Some genetic syndromes, such as Down's Syndrome, include mental retardation and have other implications for fertility, aging, pregnancy or other aspects of physical health.

**Cerebral palsy** is a set of chronic conditions affecting body movement and muscle coordination. It is caused by damage to one or more specific areas of the brain before, during or shortly after birth, or in infancy. People with cerebral palsy may have muscle tightness or spasms, involuntary movement, disturbed gait and mobility, abnormal sensation or perception, and/or impairment of sight, hearing or speech. A person with cerebral palsy may experience mainly stiff and difficult movement (spastic), involuntary and uncontrolled movement (athetoid), a disturbed sense of balance and depth perception (ataxic), or a combination of these effects.

**Epilepsy** occurs when there are recurrent sudden and usually brief changes in the brain function due to disturbed electrical activity. This can cause alterations in movement or consciousness. Epileptic seizures may be generalized, affecting all brain cells, or partial. Results range from total unconsciousness to a fleeting, staring, trance-like state. Epilepsy cannot be cured; it can usually, but not always, be partially or completely controlled by anticonvulsant medications. These medications may cause depression, loss of mental function, changes in sexual feelings and function, and other changes.

**Autism** affects an individual's ability to use and understand language and social cues and to interact with others. It is also characterized by repetitive body movements, behavior patterns and verbalizations and by impaired imaginative activity. People with autism often desire a full range of social, emotional, physical and sexual experiences, but their atypical response to sensory data may cause them to resist physical contact, make little eye contact, and avoid noisy and crowded environments. While autism is strongly associated with intellectual impairment, individuals with autism can be found with every level of mental ability and with a wide range of unusual "splinter skills". Autism is associated with many other conditions and syndromes, some of which may be considered the primary diagnosis, as in the case of Fragile X Syndrome. Autism usually appears in the first three years of life.
"What Do I Need to Know?"

Beyond the Diagnosis

Whatever a patient’s medical diagnosis, you will want to know how her disability affects your ability to provide medical care for her. You will want to ask functional questions such as,

♦ How will I communicate with my patient? What is her ability to talk and listen? Will I understand her? Do I need to hire a sign language interpreter? Does she use a communication device?

♦ Will she understand what I say and how will I know if she understands? Will we need pictures or videos to help explain our procedures? Will she be able to give informed consent?

♦ Will she be able to use my exam table and be examined? Is a better exam table available?

♦ Will I be able to answer her questions about sexuality and reproduction, such as questions about which birth control methods might work for her? Where can I find this information?

♦ Is it difficult for her to handle touch, pain, discomfort or a new situation? What can we do to prepare her?

♦ Will physical or sensory disabilities affect her ability to stand, lie still, see what I am doing, or learn breast self exam.

♦ Will limited sex education, sexual experiences, or contact with medical care providers make the exam more difficult for her?

♦ Will traumatic life experiences, such as a history of sexual or physical abuse, make the exam more difficult for her?

These and other questions will be addressed in this manual, and are further addressed in the resources outlined in the appendices.
C. Menarche and Menopause

Most women with developmental disabilities reach puberty and menopause at the same ages as the rest of the female population.

Menarche

Girls with developmental disabilities are often surprised by puberty because they have not received adequate education to prepare them for the changes. Those who are well prepared are better able to deal with the dramatic and often frightening changes to their bodies. Providers can help by urging parents to prepare girls before puberty starts. Remind parents of some of the signs of puberty that precede the onset of menses. Encourage parents to provide the sexuality education. Once fertile, all youth need to know the risks of pregnancy and STDs and how to prevent them.

The Bay Area has many good resources to help women with developmental disabilities find information and assistance. See Appendix III.

Menopause

Although changes such as menopause are predictable, many women with developmental disabilities are not prepared for them. Often care providers and medical providers are also unprepared. The identification and treatment of menopause-related concerns in the patient who is nonverbal is an especially difficult and uncharted territory. Appendix V is a handout that was prepared for patients and caregivers to alert them to the possible physical and emotional affects of menopause.

Like other patients, women with developmental disabilities should be offered a full range of menopause treatment options, with the information and education which will allow them to choose either natural, untreated menopause or an appropriate medical intervention.

There is some evidence that women with Down's syndrome or epilepsy have an earlier menopause than average. For an excellent discussion of aging and developmental disabilities, including menopause issues and treatment, and referrals to current research, see Aging with Developmental Disabilities: Women's Health Issues (on the web www.thearc.org).

Long term use of medication or years of living with physical stress can lead to new health problems and symptoms usually associated with aging. People with certain disabilities may feel the wear and tear of aging earlier than the general population. By the time she has reached her thirties, for example, a female patient with cerebral palsy may already be dealing with problems such as increasing joint and muscle pain, declining mobility, increasing respiratory problems, bowel and bladder problems, pressure sores and skin breakdown.
Chapter 2 - Assessment

Each woman with a developmental disability who comes to your office or clinic is unique. One patient may be quite comfortable with the gynecological exam procedure, while another patient's fear, anxiety or tension may make it impossible to complete the exam. There are many things a provider can do to help prepare a patient for the exam and make it a positive and educational experience.

A. Assessing Accommodation

Providers do not always know if a new patient has a disability. However, if you do know, it is important to talk to her to determine what accommodations, if any, she will need.

To find out what aspects of a woman’s disability are relevant to her visit, it may be helpful to ask, “Is there anything you think we might need to know about your disability?”

It may be necessary to talk to a patient’s care giver when you are assessing accommodation. If the patient can communicate ask for her permission to talk to the care giver or other third party.

Before the appointment it is especially important to assess:

♦ The amount of time needed for the appointment
♦ The accessibility of the clinic, exam room, and equipment
♦ The need for assistants to aid in transferring and positioning
♦ The need to arrange for a sign language interpreter
♦ The assistive technology that the patient uses and how it will effect the exam process.

To see a sample questionnaire on physical accessibility, refer to Appendix II.

Disability Rights Advocates, a San Francisco Bay Area organization (see Appendix III), is currently preparing a guide on rights to accommodation for patients with disabilities. This publication will help health care providers better understand and meet accommodation needs.
B. Preparing The Patient For The Exam

Helping the Patient Prepare Herself
When people have a sense of being in control, it is often easier for them to deal with an intimidating new experience.

Appendix I provides a checklist that patients can fill out prior to their first visit. It is called "I Would Like To" and lists various ways that an exam might be made easier or more comfortable. It lists things the patient can do as well as things the provider can do. You can adapt this list to include the kinds of adaptations that your office or clinic can provide. You can review this with a patient on a day before the exam, or she can fill it out on her own or with the help of someone she trusts.

Filling out this checklist will give the patient a feeling of better control over the impending new experience.

Let the patient know what clothing will need to be removed and what kinds of paper work, physical actions/motions and lab tests will be required. Suggest that she wear an easily removable skirt or pants and a button-up or loose shirt. If it is easier for her, let her bring a urine sample with her to the appointment.

Orientation
If the patient is apprehensive or lacks basic knowledge about the exam, education should ideally be provided before the day of the exam.

Orientation can include:

- A discussion of the importance of the pelvic and breast exam for good health.
- An illustration of the exam procedure using pictures, models and/or videos.
- A description of clinic procedure (including intake, lab tests, etc.).
- A tour of the clinic and the equipment.
- If at all possible, an opportunity for the patient to role play the exam, using dolls or models (this allows the patient to fully express her fears and worries about the exam).
C. Communication and Education

All women feel better when they understand what is happening to them during the exam. This is especially important for women who have problems learning or communicating.

- Look at the patient, and talk directly to her, instead of talking about the patient to others (such as a relative, friend, attendant or interpreter).
- Use easy words and short sentences. Explain terminology, such as “vagina”. Don’t talk down to the patient—respect individuality, experience, and age.
- Wait for answers; patients with disabilities that affect communication may take longer to put thoughts into words.
- If writing or reading is necessary, ask the patient if he or she would like some help.
- Use a variety of educational modalities, such as pictures and models as well as words and demonstrations. Simple line drawings, videos, pictures, anatomical dolls, rubber models of the genitals, plastic speculums help many patients understand better. Models of the penis or dildoes are helpful in teaching about intercourse or condom use. Make sure your patient understands the relationship of the model to the whole body. Use explanations such as, “If there were a window this is what you’d see.”
- Assess understanding. Never ask simply, “Do you understand?” Instead, ask questions that elicit knowledge, such as “Can you tell me how babies are made?” Or “Can you point to the place in a picture where the blood comes out when a woman has her period?”
- Patients may lack basic knowledge of anatomy and human development because education wasn’t provided or was not provided in the patient’s first language or in an understandable way.
- Give honest information. Many people with developmental disabilities have been misinformed and lied to.
- Patients may not know that the exam is a private medical procedure. They should be assured that their privacy and the confidentiality of the exam will be honored.
D. Reducing Stress and Anxiety

The Benefits of Complementary Medicine
Recently more and more health practitioners are finding that the many stress-reducing techniques of Complimentary Medicine are truly a "compliment" to their medical practices and exams, and actually make these exams more positive experiences for both the patient and the practitioner.

Complementary, or alternative, medicine is an umbrella term for healing practices that encompass all aspects of the persona - mind, body and spirit. Holistic medicine is most effective when the patient is involved through the practice of self-help. The self-help techniques discussed here have been selected for their simplicity, ease of application and ability to relieve pain and discomfort. They are gentle and non-invasive alternatives to sedation, and can be used during the examination by almost everyone. You can invite your patient to participate in making the experience less stressful for both of you.

We will introduce and briefly discuss acupressure, imagery and breath awareness. Practitioners may want to take the time to demonstrate and practice some of the techniques with the patient beforehand, as a few minutes preparation may ensure that the exam proceeds smoothly.

Both imagery and breath awareness can be used in conjunction with acupressure. The techniques will complement each other.

It is important not to assume that your patient can't do any of these things because of a disability. If one technique doesn't seem to work, consider trying another. Maybe you will find that the process can be relaxing and fun for you too.

Acupressure
Acupressure is the centuries-old practice of bringing harmony and balance to body mind and spirit by the use of gentle finger pressure at specific locations on the body. Chinese acupressure is the basis for the art and science of acupuncture. Light, sustained pressure with one or more fingers is sufficient. If pressure is uncomfortable, hard to sustain or contraindicated, simply contact the area with the palm of the hand or the fingers. Acupressure points are actually areas about the size of a quarter, so placing the hand in the general vicinity is sufficient.

If the patient is unable to use her hands, she can imagine invisible fingers on the area, or just focus her attention there. A patient may also imagine a color that they like filling that space. The longer the point is held the better the results, so the patient can be encouraged to hold one or several points for the duration of the exam.
The following pressure points come from Chinese medicine:

**Sea of Tranquility:** For relaxation and relief from fear and anxiety; frees the breathing

*Location:* On anterior median line at the level of the fourth intercostal space

**Joining the Valley:** For pain relief, fainting

*Location:* On the dorsal surface of the hand, in the angle between the proximal ends of the first and second metacarpal bones

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**Sea of Tranquility**

**Joining the Valley**

**Back of Hand**
Middle of a Person: For muscle cramps and spasms, fainting and dizziness and pain relief
Location: Between the upper lip and the nose.

Inner Gate: For fear and anxiety, frees thoracic area
Location: On the anterior surface of the forearm, between the tendons of the palmaris longus and the flexor carpi radialis
**Bigger Rushing:**

**Location:**

Alleviates over excitement and agitation, calming, pain relief

On the dorsal surface of the foot in the angle between the first and second metatarsal bones.

![Bigger Rushing](image)

**Jin Shin Jyutsu**

This is a Japanese acupressure practice that uses the fingers and thumbs to aid in the release of pain, and emotional stress and tension. Each digit controls specific body functions and emotions, and simply holding them individually with the fingers of the other hand can calm and dissipate emotions such as fear, anger and anxiety. The fingers and thumbs can be held sequentially, or one can be chosen for a specific need. It is not necessary to hold all the fingers, or to treat both hands. Simply wrap the fingers of one hand around the chosen finger or thumb. For example, if the patient is fearful, suggest that they gently hold the right index finger with the fingers of the left hand. There is no time limit, so the chosen finger or thumb could be held for the duration of the exam.
Imagery

Imagery is a way of harnessing the power of the imagination to heal and transform. It can help to ease pain, calm the mind and redirect negative thinking. Everyone, regardless of ability, can access the power of the imagination.

Researchers have found that the brain does not differentiate between a real or imaginary experience. If the brain registers a pleasing image, messages are transmitted to the emotional center and the autonomic nervous system, resulting in increased relaxation, lower blood pressure and a decrease in muscle tension. Visualization is the most common form of imagery, but for those who do not see mental pictures, engaging the other senses imaginatively -- touching, smelling, feeling and hearing to evoke images -- can be as powerful.

Relaxation is an important first step in the process. Simple ways to facilitate relaxation that will open the mind to imagery could include introducing pleasing sights and sounds into the office environment. Practitioners might direct the patient to look at a beautiful picture, listen to relaxing music, or think about something pleasant. This may also provide a partial distraction from anxiety and fear.

When a patient appears somewhat relaxed and receptive to suggestions, the practitioner can ask them to envision a favorite place. It can be somewhere familiar, or a place they’ve seen in a movie, or a book. It can also be entirely imaginary. You can make some suggestions, like the beach, a forest, a field, the mountains, their grandmother’s kitchen, while using a few key words to encourage them. The only requirements are that it be peaceful and that they feel safe in their “imaginary place”.

If the patient is verbal, allow a few minutes for them to assemble the image and then ask them to describe what they perceive. You can then prompt them to go deeper into the chosen image by going there with them and suggesting that they smell a flower, or touch a tree, look at the sky, or listen to the sound of the wind or the waves. The image the patient develops can be very simple, smelling a flower or petting a kitten. It is important, however, to let them develop the imagery themselves as you are merely presenting some ideas. Imagery is most powerful if it is personally meaningful.

It’s a good idea to check in periodically to determine if the patient is able to retain the images, or needs to be reminded of where they were. The mind has a tendency to wander, whether or not you are a person with a disability! Nonverbal patients who cannot be interactive might require more cues to help them stay focused. You might direct them to look around again to see if anything has changed. Sharing the details with the patient of their “imaginary place” can be done while the exam is being performed in order to reduce their awareness of any pain or discomfort. When the exam is finished, you can suggest that the patient remember the imagery and use it in other stressful situations.
Deep Breathing

Deep breathing is one of the most powerful tools we have for easing pain and reducing emotional stress and tension, though the common response to pain and stress is to restrict or hold the breath, thereby exacerbating the problem. Explaining the process and importance of deep breathing can be helpful in raising awareness and also provide a distraction from the unfamiliarity of the surroundings and the procedure. You can explain, for instance, that deep breathing helps to relax muscle tension and that they can imagine exhaling or releasing any pain or tension they experience.

It may help to breathe together with a patient so she can model her breathing on yours. She could touch your chest and feel your breath go in and out. Nonverbal patients, and many others, may find this helps them avoid the confusion of a more intellectual approach.

For people with cerebral palsy, it's counterproductive to ask them to take a deep breath, or to "relax." Since both breathing and relaxation are problematic for someone whose body doesn't always obey the mind, it tends to produce more tension and anxiety. Language that encourages relaxation might be an instruction to "just let go." You could use guided imagery techniques and suggest that they imagine smelling roses or fresh bread, the sea air, or another smell they find pleasing. Patients can also be instructed to "blow out the candles on a birthday cake"; or to fill up the two big balloons inside their chest. Many people also respond positively to colors, so they can imagine breathing in a favorite color and filling the whole body.

Sedation

Few patients request sedation for the pelvic exam. If a patient is anxious, suggest that she take an over-the-counter painkiller, such as Ibuprofen, before the appointment. Valium or stronger sedation should be used with caution and alternatives should be considered first.

Alternatives to sedation include the complementary medicine techniques described above; education about the exam and its importance; counseling about the fears associated with the exam; and desensitization training, such as visiting the clinic and meeting the clinician ahead of time.

Benefits of sedation: Sedation can help a woman go through a pelvic exam with less trauma by reducing pain and/or anxiety. It may help the woman lie still for the exam, and achieve and maintain the necessary positioning.

Risks of sedation: There are risks and side effects associated with different kinds of sedation. In addition, there are always the risks of diminished awareness. When sedated, patients are less likely to understand what is happening to them or to make informed decisions. They are more vulnerable. There is a long history of people with disabilities, especially those with mental retardation or mental illness, being anesthetized and then sterilized without their consent.
Many people with developmental disabilities have been abused by the misuse of sedation. This happens when sedation is used to manipulate a patient for the convenience of others. For example, when considering general anesthesia for a patient who is having difficulty with a pelvic exam, it is important to make sure that all less invasive options are considered, including education and behavioral interventions as well as the use of sonogram technology.

Many people with disabilities, especially those with developmental and emotional disabilities, have been sedated or over-sedated without their consent and any caution they express may be a healthy reaction based on real experiences. This caution needs to be acknowledged and validated as appropriate self-care behavior.

Responsibilities-Who should decide about sedation? The patient usually has the right to decide and should always be educated about her options. She should be able to choose among alternative sedations or to choose to remain as aware as possible during an exam. Remaining aware and alert will give her an opportunity to learn more about her body; she may have had few opportunities to learn about her body in a respectful and supportive setting.

A limited conservator or the parent or guardian of a minor can give consent for sedation, but should consider the wishes and needs of the patient, and the patient must be involved in education and decisions to the best of her abilities.

E. Gynecological Health Care and Informed Consent

Few people with developmental disabilities have conservators. This means that most have the legal right to consent and must sign a consent form, if there is one. The patient’s signature, even if it is an “X,” is the accepted legal consent.

Responsibilities of the health care provider regarding consent

- The fact that the patient does not have a conservator does not necessarily mean a patient can understand the clinical information to the provider’s satisfaction. It means the patient’s legal right to consent has not been formally limited. The provider must still assess each patient’s ability to understand the information.

- The provider should try to educate the patient to give adequate consent.

- The provider should look for any indications that the patient is being pressured or coerced into health care decisions or has been sexually abused. The local Regional Center and the Clients’ Rights Advocate at Protection and Advocacy (Appendix III) are resources in such situations.

- The provider has the legal responsibility to report any suspected abuse to the authorities.
Responsibilities of guardians and conservators regarding consent

- A guardian is appointed by the court to give substitute consent for a minor.

- A conservator is appointed by the court to give substitute consent for an adult. A limited conservator may give substitute consent for a person with a developmental disability, but only in designated areas (e.g. a Conservator of Person may consent for health care while an educational or financial conservator may not).

- Conservators and guardians, like the parents of a minor, do not have unlimited rights. They must consider the wishes of the conservatee.

- In certain situations, the Regional Center can provide written substitute consent for its clients.

- The signature of the closest living relative may have some legal standing, but it should not be accepted unless there is a prevailing reason to do so.

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<thead>
<tr>
<th>Service</th>
<th>Minor</th>
<th>Adult</th>
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<tbody>
<tr>
<td>&quot;Sensitive Services&quot;</td>
<td>Minor 12 or over may consent. Parent or guardian may consent</td>
<td>Unconserved adult may consent. Conservator may consent.</td>
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<tr>
<td>- Education &amp; Counseling</td>
<td></td>
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<tr>
<td>- STD testing &amp; treatment</td>
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<td>- Birth Control</td>
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<td>- HIV testing</td>
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<tr>
<td>Prenatal Care Abortion</td>
<td>Minor (emancipated because pregnant) may consent. Parent or guardian may consent</td>
<td>Unconserved adult may consent. Conservator may consent.</td>
</tr>
<tr>
<td>Sterilization</td>
<td>Illegal for minor unless life threatening situation</td>
<td>Must be over 18 (over 21 if on Medi-Cal). Must be able to give informed consent If conserved, case must go to court, unless life threatening.</td>
</tr>
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</table>

Resources: If a provider has questions or concerns about a patient's ability or right to give informed consent, helpful resources include Protection and Advocacy and the local Regional Center. See Appendix III.
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<tr>
<th>Name</th>
<th>Action</th>
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<tbody>
<tr>
<td>Administrator</td>
<td>Perform a detailed analysis and evaluation of the process, and identify improvement opportunities.</td>
</tr>
<tr>
<td>Analyst</td>
<td>Conduct a detailed analysis and evaluation of the process, and identify improvement opportunities.</td>
</tr>
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<td>Developer</td>
<td>Implement solutions and make necessary changes to improve the process.</td>
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Chapter 3 - The Exam

The gynecological exam can be a positive, educational experience. There are many techniques a health care provider can use to help women with developmental disabilities through the exam.

A. Tips for the Exam

The needs of individual patients will determine which of these tips are appropriate.

♦ It is generally advisable to defer blood drawing, giving injections, and other potentially disturbing experiences until after completion of the exam.

♦ If the patient wishes, let her bring someone with her into the exam room. Sometimes a relative or care giver will want to come into the exam room with the patient. Ask the patient in a private place what she wants and tell the care giver or relative that your protocol requires you to follow the patient’s choice.

♦ Be aware of the potential for sensory overstimulation related to lighting, air currents, the texture and noise of the paper on the exam table, etc. If necessary make adjustments to reduce sensory overload. Some people with disabilities such as autism may readily experience sensory overstimulation.

♦ Provide pleasant sensory experiences such as music, pictures on the ceiling, a pleasant atmosphere, and a comfortable temperature. Sometimes dim lights are soothing, though it is usually better if the patient can be alert and see what is going on.

♦ Go slowly. Talk the patient through the exam. Tell her what you are doing and have her control the speed. Let her know she can ask you to stop.

♦ Use a smaller speculum, a baby-sized speculum, or do a finger exam. Consider doing a “blind” Pap by inserting the swab without a speculum.

♦ Unless contraindicated by medical concerns, do the bimanual exam first. It may be psychologically less traumatic than inserting an instrument.

♦ If the patient cannot relax her abdominal wall, ask her to press her hand over her pelvic area and then place your hand over hers, although it may be more difficult to feel the uterus this way.

♦ Provide blankets as well as standard drapes to provide more security and privacy.

♦ Allow enough time for the patient to try different positions for comfort.
Mary's First Pelvic Exam
An example of positive provider/patient interaction

Provider: OK Mary, now I am going to put in the speculum. I have warmed it up. Can you feel how warm it is?

Mary: Yes, I can feel it.

Provider: Now I am separating the outer lips of your vagina and beginning to put it in. Can you feel it? How are you feeling now?

Mary: OK, I'm OK. (A little nervously)

Provider: I am going really slowly. Remember to breathe deeply. Are you still in your rose garden (or other "safe place")? What color are the roses? My favorite is yellow. How are you?

Mary: It's OK.

Provider: Tell me when you are ready to have me put it in further.

Mary: It's up to you.

Provider: Now I am putting it in further. How is this?

Mary: No. No.

Provider: OK. Now I have stopped. Breathe deeply, Mary. Smell the roses. Should we pick one? Are you still holding that finger? We just have a little further to go. Tell me when you are ready.

This provider, using the assistance of complimentary health techniques, helps the patient to retain control over her own body during this frightening procedure.
B. Tips for the Clinical Breast Exam and Breast Self Exam (BSE)

Adapt the breast exam to the needs of each patient. For example, if the patient has impaired balance or poor upper body control, you can do a visual inspection of her breasts while she is seated. Work with the patient to increase her ability to do BSE. But if her ability to do BSE remains quite limited, it is best to repeat the clinical breast exam more often than is typically advised for the general female population.

- Consider demonstrating parts of the exam on a friend, care giver or health care provider.

- For palpitation, stabilize the patient's arm with pillows or one of your hands, if necessary.

- The clinical breast exam is a wonderful opportunity to educate the patient on BSE.
  - Educational tools, such as breast models with lumps to find, are very helpful.
  - Guide the patient’s hands through a self-exam.

- If you have a pamphlet with illustrations of BSE, show it to the patient as you guide her through the steps illustrated in the card.

- Be sure your take-home materials match the techniques you are modeling.

- It may be possible for the patient to have a partner or friend help her do BSE at home. It may be helpful to involve this person in the clinic session.

- Point out and emphasize parts of the exam the patient will be able to do
  - Observing changes in a mirror
  - Noticing how her breasts feel
  - Examining the parts of her breasts that she is able to reach
  - Examining both breasts with one hand
  - Using thumb, palm, or back of hand in examination
  - Doing BSE in several shorter sessions

- Some women will find it easier to start doing BSE in the shower or bathtub, as this is a place they are accustomed to being naked and to touching themselves. The soap can also make it easier to move their hand over the skin.
C. Equipment and Equipment Modifications

High quality accessible equipment is now available. This equipment includes exam tables that can be lowered and offer side, foot, leg and knee support, and mammogram machines that enable women to have a mammogram without standing or leaning. Before purchasing new equipment, though, try to see the pieces in use and talk to both providers and patients who have used them. Equipment such as obstetrical stirrups and high-low exam tables facilitate safer, easier transfers and positioning, but vary in quality and “user friendliness”. Some women with developmental disabilities feel safer in a wide padded table. Side bars that can be raised and lowered can help a woman be and/or feel safer. (See Appendix III for detailed information about equipment.)

Preparing the Exam Room

- Make sure there is space for a wheelchair to turn or for a sign language interpreter to be visible to the patient. Move or remove furniture if necessary.
- Take the paper covering off the exam table if it hinders transfers and positioning
- Using padded and/or strapped stirrups can increase the comfort and safety of the patient.

D. Alternative Positions for the Pelvic Exam

Whenever possible, decisions about positioning should be made by the patient and the practitioner together, depending on each woman’s specific needs. Many women cannot comfortably assume the traditional (lithotomy) pelvic exam position. Alternative positions may be easier for women with a wide range of disabilities, including arthritis, multiple sclerosis, cerebral palsy, stroke and spinal cord injury. The conditions that may indicate the use of an alternative position include, joint stiffness and inflammation, paralysis, lack of muscle control, pain (hip, back, etc.), muscle weakness, spasticity, lack of balance, or muscular contractions.

In any position it is important that the patient feel safe and well supported and experience the least discomfort possible. If spasticity and lack of muscle control are problems, both she and the practitioner should be confident that she will not fall, be hurt, or hurt someone else.
The Knee-Chest Position
This position does not require the use of stirrups. It is particularly good for a woman who feels most comfortable and balanced lying on her side.

The patient lies on her side with both knees bent, her top leg brought closer to her chest; or her bottom leg can be straightened while the top leg is still bent close to her chest. The speculum can be inserted with the handle pointed either in the direction of the woman's abdomen or back. Because the woman is lying on her side, the practitioner should be sure to angle the speculum towards the small of the patient's back and not straight up towards her head. Once the speculum has been removed, the woman will need to roll onto her back.

The assistant may provide support for the patient while she is on the exam table, help the woman straighten her bottom leg if necessary, or support the patient in rolling onto her back for the bimanual exam. If the patient cannot spread her legs, the assistant may help her elevate one leg.

The Diamond-Shaped Position
This position does not require the use of stirrups. A woman must be able to lie flat on her back in order to use this position.

The woman lies on her back with her knees bent so that both legs are spread flat and her heels meet at the foot of the table. The speculum must be inserted with the handle up. The bimanual exam can be easily performed from the side or foot of the table.

The assistant may help the patient support herself on the table and hold her feet together in alignment with her spine to maintain this position. A woman may be more comfortable using pillows or an assistant to elevate her thighs and/or use a pillow under the small of the back.
The V-Shaped Position
This position may or may not require stirrups. The patient must be able to lie comfortably on her back to use this position.

The patient lies on her back with her straightened legs spread out wide to either side of the table. Or she can hold one leg out straight and keep one foot in a stirrup. The speculum must be inserted with the handle up and the bimanual exam can be performed from the side or foot of the table.

One or two assistants are needed to support each straightened leg at the knee and ankle. The patient may be more comfortable if her legs are slightly elevated or if a pillow is used under the small of her back or tailbone.

The OB Stirrups Position
Obstetrical stirrups provide much more support than the traditionally used stirrups. This position allows a woman who has difficulty using the foot stirrups to assume the traditional pelvic exam position.

The woman lies on her back near the foot of the table with her legs supported under the knee by obstetrical stirrups. The speculum can be inserted with the handle down. The bimanual exam can be performed from the foot of the table.

The patient may want assistance in putting her legs into the stirrups. The stirrups can be padded to increase comfort and reduce irritation. A strap can be attached to each stirrup to hold a woman’s legs securely in place if the woman prefers this increased support.
The M-Shaped Position
This position does not require the use of stirrups. This position allows the patient to lie with her entire body supported by the table.

The woman lies on her back, knees bent and apart, feet resting on the exam table close to her buttocks. The speculum must be inserted with the handle up. The bimanual exam can be performed from the foot of the table.

If the woman feels her legs are not completely stable on the exam table, an assistant may support her feet or knees. If a woman has two leg amputations, an assistant may elevate her legs to simulate this position.

E. Getting on the Table
One of the major benefits of hi-low exam tables is that transfers are simpler and safer for both patient and staff. The protocols of the clinic or medical office often limit what staff are able to do to assist a patient. The patient is the expert in transferring from the wheelchair or in using assistants to climb onto the exam table. The transfer method must be appropriate to the woman’s disability, the room space and the exam table. The woman, assistants and practitioner must all thoroughly understand the transfer method they are using before they proceed.

Pivot Transfer
Standing in front of the woman, the assistant takes the woman’s knees between her/his knees, grasps the woman around the back and under the arms, raises her to a vertical position and then pivots the patient from her wheelchair to the table. The exam table must be low enough for the patient to sit on; therefore, a hydraulic high-low table may be needed when using this transfer method.

Cradle Transfer
Kneeling beside the woman, the assistant puts one arm under both of the woman’s knees and puts the other arm around her back and under her armpits. The assistant stands and carries the woman to the table, or two assistants can grasp each other’s arms behind the patient’s back and under her knees.
Two-Person Transfers

In all two-person transfers, the assistants must work together to lift the woman over the arms of her wheelchair from a sitting position onto the exam table. A stronger, taller person should always lift the upper half of the patient’s body.

Method #1 requires the patient to fold her arms across her chest. The assistant standing behind her kneels down, putting her/his elbows under the patient’s armpits and grasps the patient’s opposite wrists. The second assistant lifts and supports the woman under her knees.

Method #2 can be used if the patient cannot fold her arms. The assistant standing behind the patient puts her/his hands together if possible so there is less likelihood of losing hold of the patient. The second assistant lifts and supports the woman under her knees.

Transfer Tips and Equipment

- The patient should direct the transfer and positioning process, if at all possible.
- Not all non-ambulatory women need assistance, and some ambulatory women may need assistance. Be aware of individual needs. Don’t stereotype.
- Assistants should keep their backs straight, bend their knees and lift with their legs.
- Assistants should not overestimate their ability to lift. Try a test lift or try lifting the woman just over her wheelchair before attempting a complete transfer.
- Assistants who feel that they may drop a patient during a transfer should not panic. Explain to the woman what is happening to reassure her. Assistants will usually have time to lower the patient safely to the floor until they can get additional help.
- Some disabled women use a slide board, which forms a bridge from the wheelchair to the exam table for the patient to slide across. In order for this method to work, the table and chair must be approximately the same height. Most exam tables are, however, quite a bit higher than most wheelchairs. High/low exam tables will facilitate the safest and easiest transfer. A wider table can also make transfers and positioning easier even if it is not adjustable in height.
- The patient or an assistant can help by preparing equipment. Women who use wheelchairs should explain how to apply the brakes, detach the footrests and armrests or turn off the motor in the case of an electric wheelchair. If the patient wears adaptive devices such as leg braces or supportive undergarments, she should explain how to remove them if necessary and where to put them.
- Women who use urinary equipment should direct assistants in the moving or straightening of catheter tubing. The patient may wish to unstrap her leg bag and place it on the table beside her or across her abdomen for proper drainage. Assistants should be reminded not to pull on the tubing or allow kinks to develop.
- Check with the patient to make sure she is comfortable and balanced after the transfer is completed.
- Watch out for jewelry, clothing, tubing or equipment that might catch or otherwise interfere with the transfer.
F. If Your Patient Is Blind or Visually Impaired

Prior to the exam, the practitioner can offer the patient the opportunity to examine the speculum, swab or other instruments, which will be used during the exam. Few patients will ask to do this, but most, whether or not they have a disability, want to. If three-dimensional genital models are available, they can be used both to acquaint the woman with her anatomy and to demonstrate the steps of the exam process. During the exam, explain what is happening and about to happen.

Practitioners or assistants should remember to identify themselves upon entering the exam room and inform the woman if it is necessary for them to leave.

Ask the patient what kind of orientation and mobility assistance she needs. Clinic or office staff should verbally describe and assist the woman in locating where she should put her clothes; where the various furnishings are positioned; where and how to take a urine sample, if one is needed; how she can approach the exam table; and how to position herself on the table and put her feet in the stirrups. Ask the patient for permission before touching her to guide or maintain contact with her.

A white cane and guide dog are mobility aids used by many visually impaired people. If a woman is accompanied by a guide dog, do not pet or distract the dog. The dog is trained to respond only to its mistress. A woman may prefer to keep her guide dog or white cane nearby in the exam room. Do not move either of these items without the patient's permission.
G. If Your Patient Is Deaf or Hearing Impaired

Prior to the exam, your patient may wish to examine the instruments that will be used during the exam. If three-dimensional genital models are available, they can be used to acquaint the patient with her anatomy as well as review the exam process.

The patient should choose which form of communication she wishes to use during her exam: a sign language interpreter, lip reading or writing. Although a patient may use an interpreter throughout most of the patient visit, she may decide not to use the interpreter during the actual exam. Many patients will feel more comfortable with a female interpreter. If an interpreter is used, the patient and the practitioner should decide where the interpreter should stand. The interpreter may stand by the practitioner at the foot of the table or, for more privacy; she may stand nearer the patient at the head of the table. When working with an interpreter, the practitioner should speak directly to the patient at a regular speed instead of to the interpreter. If the patient wishes to lip read, the practitioner should be careful not to move her face out of her sight without first explaining what she is doing. The practitioner should always look directly at the patient and enunciate her words clearly when lip-reading is preferred.

Ask the patient if she wants to see what is going on. Her head may be elevated so that she can see the practitioner and/or interpreter. The drape that is used to cover the woman's body below her waist can be eliminated or kept between her legs. Some patients may wish to view the exam with a mirror while it is happening.

If an American Sign Language (ASL) interpreter is needed, this service must be arranged before the day of the exam. See Appendix III for interpreter resources.

H. Other Exam Related Issues

Bowel and Bladder Concerns
Some women with developmental disabilities do not have voluntary bladder or bowel control (e.g., women with severe cerebral palsy). A woman's bladder or bowel routine could affect the pelvic exam.

A woman's bowel movement routine may require the same type of physical stimulation that she will experience during the speculum, bimanual or rectal exam. A bowel move-
ment can occur during the pelvic exam. The patient or the patient’s care provider should inform the practitioner if this might occur.

If a woman is catheterized, it is not necessary to remove the catheter, as it will not interfere with the pelvic exam in any way. An indwelling catheter need not be removed during the exam unless it is not working and another catheter is available for insertion. The two types of indwelling catheters are the urethral, which is inserted directly into the woman’s urethra, and the suprapubic, which is inserted directly into the bladder through a surgically made opening below her navel. Both allow urine drainage through tubing into a leg bag. The leg bag, usually attached to a woman’s leg by a strap, should be empty at the start of the exam so it will not need to be drained later.

If a woman uses an intermittent catheterization system, she urinates by manually opening her bladder sphincter at regular intervals during the day. Tactile stimulation in her pelvic area during the exam could cause her bladder sphincter to open, with resulting incontinence. The patient may consider scheduling her pelvic exam appointment around her urinary schedule.

**Hypersensitivity**

Before the exam, the patient may want to inform the provider of any hypersensitive areas of her body to help prevent possible discomfort or spasms during the exam. Some women may experience variable responses to ordinary tactile stimulation such as spasms or pain. Others experience generalized discomfort and agitation that makes medical care difficult. Often, sensitive areas can be avoided or an extra amount of lubricating jelly can be used to decrease friction or pressure.

**Spasticity**

Spasms may be a common aspect of a woman’s disability. Ranging from slight tremors to quick, violent contractions, spasms may occur during a transfer, while assuming an awkward or uncomfortable position, or from stimulation of the skin with the speculum. If spasm occurs during the pelvic exam, the assistant should gently support the spasming area (usually a leg, arm or abdominal region) to avoid any injury to the patient. Spasms should be allowed to resolve before continuing with the exam.

The intensity and frequency of spasms can be significantly affected by subjective perceptions such as feelings of physical security. A woman who experiences spasms should never be left alone on the exam table where a spasm could pose a serious danger to her. An assistant should stand near the exam table and maintain physical contact with the patient to ensure both safety and a feeling of security.
Chapter 4 - After the Exam

A. The Uncompleted Exam

- If a woman is unable to complete the exam, wait a few months and try again, unless there are urgent medical reasons to do the exam immediately.
- An external or partial exam is better than no exam.
- Consider providing an external or partial exam combined with a sonogram.
- General anesthetic is a last resort. The relative risks of deferring the exam and using general anesthetic should be assessed before proceeding with general anesthetic.
- It may be helpful to work with an occupational therapist or behavior specialist. These specialists can help develop behavior modification plans or adaptations of the exam environment.

B. Medical Records

People with developmental disabilities are often involved with multiple service delivery systems, such as case management, residential care and day programs. Parents and care providers for adults as well as minors often expect medical practitioners to share confidential information, including, for example, HIV status or pregnancy related decisions. Medical practitioners must be vigilant in obtaining the appropriate consent for both formal and informal sharing of information.

It is helpful for the practitioner to keep a record of how accessibility issues were addressed, in order to provide appropriate care during the next visit. Practitioners who document their efforts and successes in dealing with access issues will be rewarded with greater comfort and efficiency during subsequent contacts, both with the current patient with a disability and with those who come after her.

C. Follow-Up

"Will my patient be able to do breast self-exam, or watch for possible side effects of her new hormonal birth control method? Is she able to notice and report possible symptoms of menopause?" These are common concerns of providers.
There are several things providers can do to enhance follow-up.

- Provide simple take-home patient or care provider materials:
  ◦ There are many brochures available that illustrate BSE with simple pictures.

- If your patient lives at home or in residential care, you can ask her permission to involve a relative or care giver in her follow-up. With that permission, the care giver or relative could
  ◦ Remind the woman when it is time for BSE and, if useful, provide a shower card or even a videotape to remind the woman how to do self-exam.
  ◦ Help monitor side effects and symptoms through observation or through private conversations with the woman.
  ◦ For a list of reminders for care givers see Appendix V,

- The practitioner can also provide written instructions on side effects to look for, or the frequency of a follow-up activity such as BSE. These written instructions will help care givers as well as patients.
I Would Like To...

A Questionnaire to Help You Plan for Your Exam

Many people are nervous about having a medical exam, but there are things you can do to make the exam less frightening and more successful. These are some ideas that other people have used to help themselves. Please check any that might help you.

I would like to....

☐ Learn more about the exam before the visit.
☐ Visit the clinic, see the exam room, and meet the provider.
☐ Have help making the appointment for the exam.
☐ See a video about the exam.
☐ Have someone with me – a friend, partner, relative, etc.
☐ Watch someone I know have an exam (mother, sister, friend).
☐ See a provider of a certain gender:  ☐ A female provider
☐ A male provider

☐ See a provider who speaks/understands my language:

☐ Have the exam on an adjustable "high/low" table designed for people with mobility problems.
☐ Talk with someone about my fears.
☐ Practice breathing relaxation techniques to help me calm down.
☐ Bring and listen to my favorite music.
☐ Have a mild medication to help calm me down.
☐ Do other things before the appointment to help me be prepared:

________________________________________________________________________

☐ Do other things at the time of the appointment to help me to remain calm:

________________________________________________________________________

________________________________________________________________________

☐ Know that I took good care of myself by having the exam.
☐ Reward myself afterward with something special.
  My choice would be ________________________________

My name is: ____________________________________________
My goal is to have my exam by ______________________ 20__.
I have scheduled my appointment for ____________ ____ 20__.
I deserve to be congratulated!
I successfully completed my exam on ____________ 20__.

I know I can do it again.
I will plan my next exam for the month of ____________ 20__.

These things were helpful to me, and I will do them again for my next exam:
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
9. 
10. 

I will do these things differently for my next exam:
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
9. 
10.
Sample Questionnaire:
(based on Breast Health Access for Women with Disabilities intake)

1. Please Answer The Following Questions Regarding Your Mobility Needs:
   ___ No assistance
   ___ Motorized Wheelchair
   ___ Manual Wheelchair

   Walk with:
   ___ Cane
   ___ Walker
   ___ Furniture Support
   ___ Other __________________________

2. Do You Need Assistance For:
   ___ Rolling
   ___ Balance (___ Sit/ ___ Stand)
   ___ Bending/ ___ Reaching
   ___ Transfers
   ___ Walking

3. What Other Assistance Might You Use/Need In Exam Settings?
   __________________________________________
   __________________________________________
   __________________________________________

4. Do You Have Trouble Using Your Hands For:
   ___ Dressing
   ___ Hand to mouth
   ___ Grasp/ ___ Release

5. Barriers To Breast Self-Exam:
   ___ Lack of arm or hand control or coordination
   ___ Tremors
   ___ Impaired sensation in fingers
   ___ Cannot reach
   ___ Other (please specify) __________________________

   __________________________________________
   __________________________________________
   __________________________________________

35
Sample Questionnaire:

(Exercise: Please fill out the following questionnaire with the information provided.)

1. What is your name?

2. Where do you live?

3. What is your occupation?

4. Do you have any children?

5. What is your favorite hobby?

6. What is your favorite food?

7. Do you exercise regularly?

8. What is your favorite sport?

9. Do you have any pets?

10. What is your favorite color?
Appendix III

Resources

Patient Education Resources

BSE Shower Cards and other educational materials, American Cancer Society

The FDA has produced pamphlets in simple English and Spanish that can be downloaded from this website. Topics include Menopause, Birth Control, and Mammograms. http://www.fda.gov/opacom/lowlit/englowlow.html

Let's Talk about Health: What Every Woman Should Know: The GYN Exam
(S18) The Arc, (888) 368-8009; www.thearcpub.com
A video on the breast and pelvic exam, developed just for women with developmental disabilities.

Models of Human Genital Anatomy
Jim Jackson and Company, 33 Richdale Avenue, Cambridge, MA 02140, (617) 864-9063
Lifelike, life size rubber models.

Mother-To-Be: A Guide to Pregnancy and Birth for Women with Disabilities
Rogers, Judith and Matsumura, Molleen
MedDeck, 1991, Demos Publication, 428 East Preston Street, Baltimore, MD 21298-6564
Pregnancy and childbirth for women with disabilities.

Revised ARCA AIDS Education Curriculum (1992)
Marylou Scavarda, MSW, Lynne Muccigrosso, BA, & Patricia Present, MSW
Association of Regional Center Agencies (ARCA), 915 I St. Suite 1050, Sacramento CA 95814, (916) 996-7961
A six-session curriculum on HIV prevention education for adults with mild developmental disabilities.

Anatomical Dolls
You can look at anatomical dolls in various ages and skin colors at www.migima.com, www.feelingscompany.com or write: Teach-A-Bodies, 2544 Boyd Street, Fort Worth, TX 76109

The Gyn Exam Handbook and videotapes with teacher’s guide
Stanfield & Co., P.O. Box 1983, Santa Monica, CA 90406, (213) 395-7466
Photos, videotapes, and teacher’s guides designed to educate girls and women with special needs about breast and pelvic exams, the clinic procedures, and their importance for health care.
Resources on Informed Consent

Consent Manual
This manual looks at California law in depth.

edited by Ellen S. Fishman, J.D.
The Association of Regional Center Agencies (ARCA), 915 I St. Suite 1050, Sacramento CA 95814, (916) 996-7961.
Contains an excellent and comprehensive discussion of the legal and ethical factors surrounding HIV testing and treatment.

Informed Consent, Sexuality, and People with Developmental Disabilities: Strategies for Professional Decision-Making
Laura K. Griffin, J.D.
1996, ARC Milwaukee, 1126 South 70th Street, Suite N 408 B, Milwaukee, Wisconsin, 53214. (414) 774-6255.
Includes examples and discussions of many informed consent scenarios.

Informed Consent Videos
Infortronics at (800) 992-2040 or www.medbookstore.com produces several videos on informed consent for reproductive health care procedures such as laparoscopy.

Local Bay Area Resources

Alta Bates Medical Center
Breast Health Access for Women with Disabilities (BHAWD)
(510) 204-4866
www.bhawd.org
BHAWD is a unique program providing breast health services to women with disabilities, including adaptive BSE training, CBE, and referrals for wheelchair-accessible mammograms. It is a partnership of medical, disability and community organizations. In addition to direct services, BHAWD conducts research into breast screening rates and barriers to breast health services for women with disabilities.

Disability Rights Advocates (DRA)
Health Access Project
449 15th Street, Suite 303
Oakland, CA 94612
(800) 926-0274 / TTY (510) 451-8644
www.dralegal.org
DRA is developing written guides for practitioners and consumers on rights to health care access. These guides will cover all aspects of accessibility including access to health insurance. They will be available by summer, 2001. DRA will also be providing training around the state on access rights.
Hands On Sign Language Service
(800) 900-9478
TTY: (800) 900-9479
www.handsonsvs.com
Hands On arranges sign language interpreting services throughout the western states.

Through the Looking Glass
2198 6th Street #100
Berkeley, CA 94710
(510) 848-1112 (Bay Area)
(800) 644-2666 / TTY: (800) 804-1616 (beyond Bay Area)
www.lookingglass.org
Through the Looking Glass provides services, adaptive equipment and peer support for parents with disabilities, including parents with developmental disabilities.

Planned Parenthood: Shasta-Diablo
Disability Program
2185 Pacheco Blvd.
Concord, Ca 94520
(925) 676-0505
Planned Parenthood: Shasta-Diablo provides education, counseling and clinical services for people with disabilities, as well as training and consultation to health care providers, teachers and parents. Their library has many educational resources.

Protection and Advocacy, Inc. (P&A)
P&A is a statewide organization that is funded by the state to protect the rights of people with disabilities. Each P&A office has a Clients' Rights Advocate. P&A can also provide information on consent.
(800) 776-5746, (TTY) (800) 776-5746
www.pai-ca.org

The Committee on Sexuality: Advocating for People with Developmental Disabilities
21450 Bear Creek Road, Los Gatos CA 95030
www.w3ddesign.com/committee
The Committee puts out a newsletter, produces a symposium, and advocates for the sexual rights of people with developmental disabilities.

United Cerebral Palsy (UCP) of the Golden Gate
Women's Health Project
Oakland, CA 94612
(510) 832-7430
www.ucpogg.org
The Women’s Health Project is a partner in the BHAWD clinic. WHP also provides referrals to community health care providers who welcome women with disabilities into their practices or clinics. The Project sponsors yoga classes, acupressure and self-help workshops, and support groups for women with disabilities. The WHP staff provides in-service presentations for health care providers by request.
**Web Sites**

**www.ddhealthinfo.org**  
A site to help clinicians in California better serve people with developmental disabilities. It includes current research and physician-to-physician mentoring.

**www.4woman.gov**  
This is the federal government’s main web site on women’s health. It includes quite a lot of information for women with disabilities.  
At: www.4woman.gov/wwd_wwd.cfm?page=75  
You can find links to fact sheets on contraception for women with epilepsy or mobility impairments.

**www.sexualhealth.com**  
The Sexual Health Network provides sexuality information and other resources for people with disabilities, illnesses, or other health related problems.

**www.lookingglass.org**  
Through the Looking Glass offers resources and support for parents with disabilities.

**www.thearc.org**  
The Arc of the United States serves people with developmental disabilities. The web site includes a useful article on aging: *Aging with Developmental Disabilities: Women’s Health Issues* by Allison A. Brown and Leone Murphy, R.N.

**www/nresearch.ndss.org**  
The National Down Syndrome Society

**www.dralegal.org**  
Disability Rights Advocates publishes guides to health care accessibility rights for people with disabilities and for professionals.

**www.pai-ca.org**  
Protection and Advocacy provides state-funded legal advocacy for people with disabilities.

**www.bhawd.org**  
The website of Breast Health Access for Women with Disabilities provides information for women and providers to help increase access to breast health care.

**www.westernu.edu/cdihp.html**  
Site of a new organization to support training of health professionals in disability issues.

**www.ppfa.org**  
Up-to-date information on sexual health, including birth control, sexuality transmitted diseases and menopause.
Sources of Accessible Equipment

Physicianequiptment.com
Power examination tables

www.midmark.com
The Welner Patented Wheelchair Accessible Power Tables
welnersmd@aol.com

The Ritter 119 Power Examination Table
Cida Medical Products and Equipment

The Nevin 8800 Advantage Power Table
Nevin Laboratories, Inc.
5000 S. Halsted Street
Chicago, IL 60609
Phone: (312) 624-4330
Fax: (312) 624-7337
Toll Free: 800-428-2253

Cida Medical Products and Equipment

The Bennett Contour Plus Mammography System
http://www.trexmedical.com/

www.rpkco.com
800-933-7751
Appendix IV

Reproduction and Contraception

People with disabilities have experienced a great deal of pressure not to have children. In the past many were sterilized without their consent. Though illegal in California for several decades, the practice continues in other countries. Many parents who have disabilities have had to fight for their right to be a parent or to keep custody of their child. Almost all have had to fight hard and continually for the access, services, and resources they needed. There has been very little support for women with disabilities who want to have children. Through the Looking Glass in Berkeley remains the main organization focused on support and advocacy for parents with disabilities, and serves many parents with developmental disabilities. It also provides information on pregnancy and childbirth for women with physical disabilities. State funded Regional Centers for people with developmental disabilities may help parent find resources as well. (See Appendix III.)

Some parents with developmental disabilities have adopted. This is an important option for people who do not choose pregnancy, which can be difficult or dangerous for women with some disabilities. The Question of David by Denise Sherer Jacobsen is about one couple who adopted.

Fertility Issues

Very few disabilities affect fertility. However, an individual with a disability may experience infertility. Infertility is on the rise. Sexually Transmitted Infections (STIs) can lead to pelvic inflammatory disease (PID), which can cause infertility. In addition, fertility decreases with age. This is important information for all patients to have, including those with disabilities.

Genetic Counseling

Many people still assume that a disability, genetic or otherwise, is an automatic reason to have an abortion or sterilization. Occasionally infertility has a genetic basis and genetic counseling may be indicated. Some people with disabilities that may have a genetic or chromosomal basis may also choose to see a genetic counselor. In either case, it is important to see a genetic counselor whom they can trust to provide unbiased information and counseling. The genetic counselor should respect the client or client’s agenda and not focus on disability issues if infertility or another issue is the presenting problem.

Deciding on Contraception:

Patient and provider should discuss birth control methods together, looking at:
- The patient’s lifestyle and personal preferences
- Effectiveness and usability
- Potential side effects
- Interaction with the patient’s current medications
Patients may want to examine in-depth protocols or descriptions for using each method. Family planning clinics have this information, as does the handbook, *Contraceptive Technology*, which is updated every few years and can be purchased from Irvington Publishers, 522 E. 82nd Street, Suite 1, New York, NY 10028. The website, www.pfia.org has in-depth descriptions of each method for the layperson. The website www.sexualhealth.com has information specifically for women with disabilities. For fact sheets on contraception for women with epilepsy and mobility impairments, visit: http://www.4woman.gov/wwd/wwd.cfm?page=75

Consider all options. Low-dose contraceptives, including pills, Norplant and Depo Provera, are progesterone-only methods that increase the options for people with disabilities who cannot use estrogen-containing pills. The “female condom,” a sheath inserted in the woman’s vagina before intercourse, and the Mentor condom, which has a narrow band of adhesive to keep the condom on the penis without holding, may be more user-friendly condoms. The Avanti condom, made of polyurethane, can be used by those allergic to latex.

**Sterilization**

Many people still think sterilization will solve their concerns about the vulnerability, fertility or inappropriate behavior of their disabled child or client. Sterilization cannot protect from sexual abuse, or cure sexual acting out, abusive or inappropriate behavior. It has no effect on menstruation.

It is important to promote education as an alternative to sterilization. There are programs that will teach self-protection skills, like recognizing abusive situations and saying “no.” And even girls with severe disabilities can learn to handle their periods with early education and good behavior training programs.

Sterilization is the preferred birth control for couples who have had all the children they wish, and for a few people who do not want children. Some people with disabilities do choose sterilization. However, making a permanent decision such as this may be difficult for a person with a cognitive disability. Fortunately, other birth control methods such as Depo Provera and Norplant provide more options.

Some people cannot learn to give informed consent. For them to get sterilized, it is necessary for someone to become their conservator and go to court. It is almost always better to explore other birth control options.

**Sexually Transmitted Infections (STIs)**

Only barrier methods such as condoms and dental dams prevent HIV and other STIs. It is very important that everyone know how to use and obtain condoms. Practice, which can be done on a rubber or wooden model of a penis, is very important. Water based lubrication makes the condom easier to put on and reduces breaking.
Abortion
It is always important to obtain informed consent for an abortion and to counsel the patient to make sure she is making her own decision. Women with disabilities have been denied abortion — or pressured to choose abortion — by parents, care providers and others. A conservator can consent for a conservatee to have an abortion. If the provider feels that the patient is being pressured to do something she does not want, the provider should call Protection and Advocacy.

A Partial List of Contraceptive Implications for People with Disabilities

**Barrier methods**
- May be difficult to learn.
- Communication with partner about use of condoms may be difficult.
- Partner assistance may be necessary.
- Use may be painful for women with blood disorders or patients with skin problems that cause irritation.
- Careful hands-on instruction in use is important for most people.
- Condoms protect against STDs and are readily available.

**Oral contraceptives that contain estrogen**
- User may need help keeping track of schedule.
- May be contraindicated if circulation is affected, if a disability is due to diabetes, glaucoma, or vascular disease.

**Low dose or mini pill (no estrogen)**
- User may need help keeping track of schedule.
- Increased spotting may be difficult to manage.

**Depo-Provera**
- May interact positively with some seizure medication.
- Amenorrhea associated with Depo may be a plus — or a minus — for some patients.
- Long-term possible bone loss may be a concern.
- Provides protection for a longer period of time than barrier methods or contraceptive pills.

**Norplant®**
- Making a decision with a 5-year horizon may be difficult for some.
- Spotting may be difficult to manage.
- If disability affects upper limbs, may need to insert in leg.
- The feel of the inserts may be irritating.
IUD
- User may forget to check strings.
- Partner assistance may be needed to check strings.

Spermicides
- May cause irritation; this can be dangerous if it is not easily detected or if the individual is vulnerable to infections.
- Offer protection against STDs and are readily available.

Tubal ligation or vasectomy
- Must be eighteen (21 if on Medi-Cal) and able to give informed consent.
- User may have difficulty making a long-term decision.
Birth Control – How Care Providers Can Help

Be attentive to regular and new health care needs:
- Help patients schedule regular gyn/breast exams, mammograms or testicular/prostate exams.
- Remind clients once a month to do breast self-exam or testicular self-exam. Provide pamphlets with pictures or videotapes.
- Help clients obtain over-the-counter barrier methods such as water-based lubricants and condoms, in addition to prescription birth control methods. Keep extra supplies in the house where clients can get them.

Be prepared for changes in the client’s normal menstrual pattern:
- More frequent periods
- Skipped periods
- Very heavy periods - “flooding” & “gushing”
- Have menstrual supplies on hand to deal with heavier or more frequent bleeding.

Be prepared for changes in eating patterns:
- Some methods, like pills, cause an increase in appetite. Work with patients to notice the change and stay on a healthy diet.

Help patients watch out for side effects of new methods:
- Ask the doctor for specific side effects to watch for.
- Find out which ones are dangerous.
- Ask how long the patient should watch out for side effects.
Birth Control - How Care Providers Can Help

Be approachable to condoms and new family planning methods.

- Educate patients about different types of contraceptives and their benefits.
- Provide access to low-cost or free contraceptives.
- Offer counseling on family planning options.
- Encourage regular check-ups to monitor contraceptive effectiveness.
- Include family planning discussions in routine medical exams.
- Provide referrals to local family planning centers or clinics.

Be prepared for questions in the clinic’s routine monitoring patterns.

- Condoms
- Birth control pills
- Intrauterine devices (IUD)
- Implants
- Vasectomy

Be ready to answer questions about family planning.

- Discuss the risks and benefits of each method.
- Address common concerns and misconceptions.
- Provide education on how to use each method correctly.
- Encourage open communication with patients about their reproductive health needs.

Help patients make informed decisions about their health.

- Understand each patient's individual needs and desires.
- Provide support and guidance throughout the decision-making process.
- Help patients navigate the complexities of family planning.
- Remember that every patient is different, and their goals may change over time.
Midlife Issues

Menopause means the end of menstruation. By the time your client has reached menopause, she may have experienced 1 to 10 years of perimenopausal symptoms.

While 10-16% of American women experience no signs of menopause, another 10-15% become physically or emotionally disabled for various periods of time by conditions related to menopause.

What caregivers can do

- Educate and inform
  - Prepare the clients for changes. Menopause can be confusing and frightening for any woman. A woman who does not expect or understand the changes will be even more frightened and confused than the rest of us.
  - Make clients aware of the possible changes in their bodies
  - Offer information and supplies to cope with possible flooding

- Be attentive to regular and new health care needs
  - Regular Gyn exams & Breast exams, including mammograms
  - Offer traditional and alternative therapies for menopausal symptoms
  - Support clients' needs for additional counseling/psychological service

- Encourage exercise
  - Weight bearing exercises like walking, running, weight lifting
  - Kegel exercises

- Encourage proper nutrition
  - Provide a good diet rich in calcium and vitamin D
  - Offer vitamin and mineral supplements

- Offer additional supports to clients who are sexually active
  - Emphasize that fertility is intact during perimenopause and until well after the actual cessation of periods, i.e., menopause
  - Help clients who are sexually active to obtain lubricants
What you may notice
Indicators that your clients may be in Perimenopause, or “going through the change of life”:

- Exaggeration of symptoms commonly associated with PMS
  - Urinary problems
  - Frequent urination
  - Urinary urgency
  - Stress incontinence: urinary leakage with laughter, sneezing, etc.

- Poor temperature regulation in the body
  - Hot flashes
  - Extreme sweating
  - Night sweats

- Decreased moisture in the body
  - Dry skin
  - Hair loss and thinning hair
  - Vaginal dryness
  - Painful intercourse
  - Increase in vaginal infections

- New aches and pains
  - Headaches
  - Achy joints

- Mental and emotional symptoms
  - Emotional sensitivity
  - Changes in mood
  - Difficulty concentrating
  - Memory loss & forgetfulness

- Changes in sexual desire - either increase or decrease

- Disturbed sleep & related increased fatigue
  - Insomnia
  - Early wakening

- Changes in the client’s normal menstrual pattern
  - More frequent periods
  - Skipped periods
  - Very heavy periods - “flooding” & “gushing”

- Bone loss and osteoporosis
  - Back pain
  - Loss of bone mass
  - Brittle bones, which fracture easily