

## Carrie Case Information Points

### Preparing Office Staff

Many individuals are apprehensive about medical care due to a variety of factors, including previous experiences with clinicians, parental influences, or innate fear of the unknown. Individuals with intellectual disabilities are no exception, and in fact may be more frightened due to lack of exposure to care, painful physical conditions, or difficulty at times in understanding the purpose of medical treatment. Reception personnel are typically the first contact for patients with disabilities, and are in a unique position to make a welcoming first impression.

The primary care provider should make a careful assessment of the patient's cognitive and developmental levels in order to facilitate the appropriate level of communication. Medical office staff should be educated/prepared concerning specific issues that may arise when providing care to individuals with developmental disabilities. These issues include the need for flexibility in scheduling, flexibility in positioning, potential behavioral interventions, and the need to convey an attitude of patience and respect. It is particularly important that the clinician emphasize to the reception staff the need to schedule more time for individuals with special needs. This simple accommodation will save valuable time in the long run.

Many individuals with intellectual disabilities may benefit from a gradual, desensitizing approach to medical care. By this, we mean that cooperation may best be gained by utilizing some preliminary techniques - such as reading "social stories" describing what will happen, modeling, and/or scheduled "warm-up" visits to the primary healthcare provider before the day of the actual appointment. For an example of a social story, see the Resource Document "Social Stories: A Woman's Health Example" in the Resource Section at the beginning of this module.

Practical oral care for people with Down syndrome (n.d.). Retrieved January 16, 2019 from <https://www.nidcr.nih.gov/sites/default/files/2017-09/practical-oral-care-down-syndrome.pdf>

### Interacting with Persons with Disability

Many persons without disabilities feel uncomfortable around individuals with disabilities. Although the ADA removes many barriers, the law cannot eradicate invisible attitudinal hurdles. Sometimes, individuals avoid people with disabilities or exhibit awkwardness towards them. Much of this discomfort stems from misunderstanding and lack of contact with people with disabilities. There are several steps that can be taken to help ease a sense of awkwardness. These include the following:

- Feel free to offer assistance to a person with a disability or ask how you should act or communicate, but do not automatically assume that the person needs assistance.
- Look directly at an individual with a disability when addressing him or her, even if a companion or sign language interpreter is present.
- Adults should always be treated as adults.
- Do not assume that a person with a disability is more fragile or sensitive than others.
- When meeting a person with a visual impairment, always identify yourself and anyone else who may be with you.
- When conversing with a wheelchair user or a person of short stature, try to be seated to facilitate eye contact.

### Importance of Establishing Rapport

Primary care providers may need to invest additional time, while conveying a competent and relaxed demeanor, when attempting to build rapport with individuals having an intellectual disability. It may prove challenging for the clinician to establish a trusting working relationship with women with intellectual and/or developmental disabilities who may have experienced emotional, physical, and/or sexual abuse.

Research indicates that patients treated with respect, dignity, and empathy are typically better satisfied with healthcare provision. The adage, "talking saves time" is really true. When the clinician takes extra time to communicate and build rapport with his or her patient and/or caregiver, valuable information is gained which saves time in the long run. It is the clinician's duty as a professional to convey an image of both competency and empathy.

Establishing communicative rapport is an integral part of the clinician/patient relationship. Many medical personnel have received little training toward the development of this important component of practice.

## Legal Issues Surrounding Guardianship/Informed Consent

Guardianship is established by a legal proceeding in which a court determines if the severity of a person's disability renders the person incompetent to make certain types of decisions. Other considerations include whether or not the person requires protection, or if there is a less restrictive alternative to guardianship. States vary in their definitions of mental incapacity and/or incompetency, as well as the required legal procedures to file for guardianship and the limitations of guardianship. The law presumes that all adults have the mental capacity to make their own decisions unless they have been found unable to do so through a formal legal process.

Depending on the specific state and the outcome of the guardianship proceedings, full (also known as plenary) guardianship may be declared over the person (thereafter referred to as "the ward"), or the court may declare limited guardianship, such as guardianship specifically related to financial or medical matters. It is important for the primary care provider to clarify the guardianship status of the patient, if it is in question. If the guardian has some type of limited guardianship, he or she may lack broad decision-making power with regard to the patient. Not all individuals with intellectual and/or developmental disabilities (ID/DD) require guardianship. There are several alternatives to full guardianship which preserve more of the person's rights and autonomy.

Health care providers must obtain informed consent from patients either through written or verbal means, depending on the specific situation. When written informed consent is required, care should be taken to ensure that the materials are presented in a way that are both accessible and developmentally appropriate for the patient. If the primary care provider is uncertain about the patient's capacity to consent to a particularly procedure, he or she may request a review.

\*For more detailed information about guardianship and informed consent, see the Resource Document: [Legal and Ethical Issues](#) in this module.

## Reproductive Healthcare History

Healthcare providers should understand the significance of obtaining thorough medical histories, and develop adequate interpersonal interviewing skills to secure them. Healthcare history provides valuable information to the clinician that may significantly influence decisions regarding both diagnosis of presenting conditions and appropriate treatment. Reproductive healthcare histories should include previous illnesses, diseases (STDs), or chronic conditions, along with past or present treatments and outcomes. Additionally, information regarding previous hospitalizations, past surgical procedures, frequency of healthcare visits, pregnancies, contraception, and adverse or allergic reactions to medication should be obtained. Note any medication allergies in a conspicuous location in the patient's record. Most hospitals require that allergies be posted on the outside of the patient's chart.

Obtaining reproductive healthcare history is particularly important in women with developmental and/or intellectual disabilities who may not have had consistent or adequate access to preventative reproductive healthcare services. Important information may be obtained during the history concerning the woman's past experiences with gynecological examination. Past experiences with gynecological visits involving excessive anxiety, discomfort, or fear may be identified and explored with the patient and/or guardian. Screening for sexual abuse may be indicated.

When past experiences with gynecological examination have been clearly negative for the patient, it may be necessary for the primary care provider to employ pre-visit desensitization strategies. These strategies may include:

familiarizing the patient with the examination room before the day of appointment, using specialized instructional materials such as social stories or videos that describe the gynecological visit, and/or collaborative coaching by the patient's caregiver/parent. Information concerning any needed physical accommodations during the examination should be solicited during the history portion of the visit.

## Evaluating the Level of Sex Education

For the adult patient with intellectual and developmental disabilities, appropriate and thorough sex education is not only a key component in abuse prevention and identification, but also in promoting sexual health. Appropriate sex education also helps develop the person's capacity to consent to sexual activity (Murphy & O'Callaghan, 2004).

Informal assessment of sexual knowledge and behavior is perhaps the most practical approach for most primary care providers. When evaluating patients with intellectual disabilities, it is important that the primary care provider ask the questions in a way tailored to the patient's intellectual abilities. Questions should be open-ended, yet specific, concrete, and concise. For example, instead of asking a question like, "Do you have sex?" a better alternative would be to ask, "What do you know about sex?" Questions may need to be presented more slowly. The primary care provider should be aware that people with intellectual and developmental disabilities may require more time to formulate and express their answers.

People with intellectual disabilities are often encouraged to be very compliant and agreeable, particularly when talking with perceived authority figures. Consequently, the patient may assent, acknowledge, or deny in response to questions if they perceive that a particular answer is either desired or discouraged. The particular method of questioning and topics covered should accommodate the patient's level of intellectual functioning, life situation, and current concerns.

## Sexuality and Self-Determination

According to Wehmeyer, self-determination is "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (1996, p. 18). The concept of self-determination has gained prominence in the area of advocacy for and by people with intellectual and developmental disabilities (ID/DD) over the last two decades. Sexual self-determination has proven to be a controversial topic, however, for a variety of reasons. Agencies which provide support services tend to fear legal liability for the consequences of sexual activity by individuals served, and may restrict or prohibit sexual activity or specific types of sexual activity. Family members and service providers may not accept the sexual needs and rights of a person with ID/DD and may seek to restrict or deny the person's expression of sexuality. Lastly, there is an inherent tension between the responsibility of agencies and guardians to protect the safety of the person, and the person's right to the dignity of risk that is an inextricable component of sexual self-determination. There is no simple answer or approach that resolves the tension between safety and self-determination. Each family and individual's unique issues in this area must be addressed on an individualized basis.

The primary care provider is in a position to provide education and support to families and to promote healthy sexual self-determination for the individual. The primary care provider should inform individuals, guardians, and caregivers that it is healthy and normal for individuals with ID/DD to have sexual rights and needs. The provider may also provide sex education and or sex education resources as needed. Finally, the provider may advocate for the patient's right to sex education, privacy, and self-determination.

\* See [Resource Document](#) for more information and references.

## Reproductive Management/Contraception

Women in the United States with intellectual and/or developmental disabilities who lack either the cognitive or physical ability to manage reproductive care issues have historically had these issues managed for them, both by caregivers and medical providers, at the discretion of their legal guardian. Reproductive healthcare decisions related to menstruation, hormone administration, contraception, pregnancy/parenting, and surgical sterilization have been made with little regard for the individual's preferences or legal rights.

Contraception for women with significant intellectual and/or developmental disabilities is a controversial subject among caregivers, guardians, healthcare providers, and lawmakers alike. Women with intellectual disabilities may or may not be capable of consenting to sexual relations. However, primary care providers caring for women with intellectual or developmental disabilities should not assume that the woman is not at risk for pregnancy. An individual with a legal guardian in some situations may still be capable of consensual sexual activity. Furthermore, women with intellectual or developmental disabilities are at increased risk for sexual abuse - which may result in pregnancy.

Although, historically, hysterectomies were frequently performed on women with intellectual and developmental disabilities to stop menses and prevent pregnancy, there are many far less invasive forms of contraception available today which efficiently prevent conception - with relatively few side effects.

\*See Resource Document "[Reproductive Management Strategies](#)" for more extensive information on specific non-surgical and surgical forms of contraception available.

## Breast Self-Examination (BSE)

Breast cancer is a leading cause of death for women in the United States and worldwide. In 2005, an estimated 211,240 American women were diagnosed with breast cancer and 40,410 American women would die from the disease during the year. Risk factors include family history of breast cancer, increased age, nulliparity, Caucasian race, menses before age 12, fibrocystic breast disease, oral contraceptive use, hormone replacement therapy, alcohol consumption, and obesity. Women with intellectual disabilities frequently experience nulliparity, a factor associated with as great as a four-fold increase in risk of developing breast cancer. Women from minority and low-income groups experience a higher mortality rate from breast cancer; this may be related to the decreased accessibility of healthcare for women in this population.

Early detection and treatment of breast tumors are keys to improving survival rates. Although routine annual checkups and mammograms are indicated, they do not detect tumors which may develop between visits. Breast self-examination is a vital preventative measure which may be used by all women over the age of twenty. The American Cancer Society recommends that women of average risk in their twenties and thirties have a breast exam performed by a qualified clinician at least every three years, and that women over forty receive annual screenings. Cure rates for tumors detected early approach 100%.

Family members and/or staff caring for women with intellectual disability have a crucial role to play in ensuring that the woman is educated concerning breast self-examination (BSE) and capable of performing BSE herself, or receiving BSE monthly from a qualified individual.

\*See Resource Document on [Preventative Reproductive Healthcare](#) for detailed information and links to instructional materials.

## Sedation and General Anesthesia

Although sedation is sometimes necessary for patients with intellectual disabilities, it should not be considered a first-line intervention. Non-pharmacological techniques - such as relaxation, distraction, and previsit desensitization - are often effective in gaining cooperation in patients with intellectual disabilities, and are a primary consideration for all patients. Sedation, however, may be necessary for individuals with extreme phobia concerning medical treatment, and/or those patients with involuntary movements - such as tics or other neuromotor symptoms. Sedation may also be necessary for those patients whose intellectual disability is such that they cannot comprehend the need for

medical care, nor understand the intent of the healthcare provider, despite attempts to explain procedures and gain compliance.

Types of sedation range from light, or conscious, sedation, to general anesthesia. It is important for the healthcare practitioner to limit the use of sedation only to specific instances when there is no other recourse. Light oral sedatives commonly used include diazepam (Valium™), Ativan™, and Benadryl™.

General anesthesia is occasionally used to facilitate pelvic examination when other strategies to obtain the exam have been exhausted. Patients may also require IV sedation or general anesthesia for more invasive procedures such as colposcopy or cone biopsy. It is important that the practitioner obtain informed consent before administering anesthesia, independent from consent obtained for the gynecological exam.

## Endometriosis

Endometriosis is a relatively common gynecologic disorder, characterized by the presence of endometrial glands and stroma outside the uterine structures. Lesions associated with endometriosis are most common in the dependent areas of the pelvis, including ovaries, bowel, rectum, and bladder. The disorder can cause pain, bleeding, and infertility.

Endometriosis may be associated with a wide variety of symptoms, or present as asymptomatic. Symptoms include painful menstruation, painful bowel movements, premenstrual spotting, backaches, dyspareunia, and worsening primary dysmenorrhea. Aberrant endometrial growth may cause symptoms such as pleuritic chest pain, pleural effusion, pneumothorax, or cyclic hemoptysis. Physical findings specific to endometriosis are rare. Tender nodules may be detected during pelvic examination, particularly on the posterior vaginal wall, adnexa, or in healed scars.

Definitive diagnosis may be made by laparoscopy and/or other diagnostic tools including magnetic resonance imaging, pelvic ultrasonography, and measurement of serum proteins such as placental protein 14.4.

Treatment strategies focus on hormonal regulation of the patient's menstrual cycle. Severity of pain, disease progression, and the patient's desire for future childbearing should all be considered. Although pain management may be achieved via nonsteroidal anti-inflammatory agents, most symptoms can also be relieved through the inducement of pseudopregnancy via oral contraceptives containing estrogen and progesterone. Danazol treatment may be considered over pseudopregnancy-inducing drug regimens, but has androgenic (and often irreversible) side effects. The efficacy of a variety of surgical techniques, ranging from conservative laparoscopic endometrial ablation to hysterectomy, has not been established.

## Sexual Abuse

It is estimated that 50%-90% of people with intellectual and developmental disabilities (ID/DD) will experience sexual assault, sexual abuse, or sexual exploitation in their lifetime (Cox-Lindenbaum & Watson, 2002). Perpetrators may be service providers, family members, acquaintances, strangers, or other individuals with disabilities.

Several risk factors increase the vulnerability of individuals with ID/DD to sexual abuse. People may require assistance with hygiene activities. This need for intimate care necessarily results in situations in which the service provider/caregiver is alone with the individual. High turnover rates for direct service workers may result in individuals being exposed to numerous staff members with multiple opportunities for abuse to occur. Group living situations also increase risk of sexual victimization, not only by staff but by other residents of the facility. Additionally, individuals may not have the knowledge and skills to identify or escape abusive situations.

It is critical that primary care providers be alert to the possibility that patients with ID/DD may be experiencing or may have experienced sexual abuse. When a patient with ID/DD relates that he or she has experienced sexual abuse, the primary care provider should immediately take the appropriate steps to ensure that the patient is protected and that the abuse is reported (see the resource document on [LEGAL and ETHICAL ISSUES](#)). If the individual is nonverbal,

there is an array of red flags which may indicate abuse: the emergence of self-injurious or aggressive behavior, unexplained mood changes, sleep or appetite changes, unexplained cuts or bruising, excessive or inappropriate sexual behavior, avoidance of specific settings or people, withdrawal, substance abuse, injuries to the genital area, and/or sexually transmitted diseases.

\* See [Resource Document](#) for references and more information.

## Sexually Transmitted Disease

The incidence of sexually transmitted diseases (STDs) in the United States is higher than any other country, with approximately 15 million new cases diagnosed each year. It is estimated that approximately two-thirds of these cases are represented by two diseases, trichomoniasis and human papilloma virus (HPV). Furthermore, an estimated 65 million people are living with an incurable STD. Sexually transmitted diseases include those produced by fungal, bacterial, and viral pathogens, as well as parasitic infection with pubic lice (commonly called 'crabs') and scabies (caused by mites). These diseases may produce symptoms ranging from mild to severe, and may result in simply a minor nuisance, or potentially be life-threatening if left untreated.

The incidence of STD's specifically among people with intellectual disabilities is not well-documented. However, it should be assumed that people with intellectual disabilities who are sexually active are at similar risk as the general population. Furthermore, individuals with intellectual disabilities experience an increased risk of sexual abuse. Such abuse may expose them to sexually-transmitted pathogens, even when they are not voluntarily sexually active. Considering these factors, it is important to screen all women, including those with intellectual disabilities, for sexually transmitted disease during routine gynecological exams.

It is important that primary care providers be aware of the issues surrounding sexuality and sexual expression in persons with intellectual disabilities.

\*See Resource Document "[Sexually Transmitted Diseases](#)" for detailed information on types of sexually transmitted diseases, diagnosis and treatment.