Sexuality is a complex phenomenon that involves intricate interactions between the individual's biologic gender; core identity (sense of maleness or femaleness); and gender role behavior (nonsexual and sexual). Sexuality continues to be a core and profound component of humanity in which human beings need other humans. This capacity for giving and receiving love and affection remains throughout life. The success or failure encountered by children and youth with regard to their sexual system development significantly contributes to the potential success or failure of their appropriate transition to adult life.

A common myth among parents and society in general about youth with disabilities or even chronic illness is that these children and adolescents are asexual, that they suppress their sexual needs because of their disability, are not subject to sexual abuse, and do not require any type of sexuality education. Parents and primary care clinicians must be educated that such concepts are not true and that all adolescents, whether healthy or not, are sexual human beings and need comprehensive sexuality education. Parents and clinicians must understand that normal development of adolescence implies that youth must learn to emancipate from parents and develop a normal sense of self-identify within the reality of their cognitive abilities. Youth must learn to understand who they are as functional and sexual human beings.
INTELLECTUAL DISABILITY

Mild Intellectual Disability

Youth with intellectual disability represent a subgroup of developmental disabilities complicating health care issues in these youth. About 3% of the general population has significant intellectual deficit and are classified as having mental subnormality. This includes over 1.2 million adolescents with about 100,000 individuals being born annually. Intellectual disability can be associated with various disorders, including those listed next. There is usually no identifiable cause for intellectual disability.

- Down syndrome
- Cerebral palsy
- Fetal alcohol syndrome
- Fragile X syndrome
- Prader-Willi syndrome
- Neurofibromatosis
- Meningomyelocele
- Autism
- Velocardiofacial syndrome
- Williams syndrome
- Others

Approximately 80% of youth with intellectual disability are classified as mild intellectual disability, with an intelligence quotient in the 50 to 75 range. These youth are trainable and potentially literate and employable with unskilled or semiskilled jobs. Although often limited to preoperational or concrete operational piagetian thinking levels, they go through the main psychologic stages their normal intelligence quotient peers go through. Youth diagnosed with mild intellectual disability are often painfully aware of their intellectual limitations and may have considerable difficulty emancipating from parents and establishing a secure self-image.

Youth with mild intellectual disability have the same needs for sexual development as their “normal” peers, but society (including parents and clinicians) is often unwilling and unable to accept such a concept. These youth have normal sex drives and desire for coital behavior that is comparable with their nondisabled peers. It is important that health care professionals address sexuality and vocational needs of their adolescent patients with intellectual disability to allow them normal eriksonian development. Indeed, these youth need to learn appropriate sexual behavior, including what is and what is not acceptable touching. The continuing development of sexuality in youth with intellectual disability often worries and frightens parents, who become concerned about the consequences of such issues as dating, sexual abuse, pregnancy, and sexually transmitted diseases (STDs). These youth must receive education to help avoid unwanted sexual exploitation, pregnancy, and STDs. Parents must be educated that mentally retarded youth have legal rights to such information and can be judged competent to handle sexual intimacy.

Moderate-Profound Intellectual Disability

About 12% of youth with intellectual disability are in the moderate range with intelligence quotient scores between 25 and 50. They are called “trainable individuals” who can be instructed in basic self-care, appropriate socialization, and basic verbal communication. They can perform simple chores and typically remain with the family or stay in a residential facility. Family members who keep these youth at home usually need guidance in maximizing their child’s or youth’s potential without negatively
impacting others in the home. These youth must be protected from sexual exploita-
tion. Those with intelligence quotients below 25 (severe or profound intellectual dis-
ability) are usually totally dependent on others and may be institutionalized in some
states. They need to be cared for with dignity; often have severe health care needs;
and must also be protected from being abused (sexually and physically).

ISSUES FOR PARENTS

Parents’ reactions to their developmentally disabled youth’s problems are very impor-
tant to the overall psychologic health of the parents and their youth. The birth of a baby can give parents considerable joy and start them off on a journey of
fantasy about the wonderful things their child may do that will make the parents very
proud and happy. It is a normal desire on the part of parents to want to produce a per-
fect child, one that is the best at some or all of the qualities these parents desire. Some
parents even live their lives and dreams through their children. Unfortunately, children
may not live up to such expectations. Many parents learn to accept such a reality and
learn to love their children in a realistic manner, usually understanding that their chil-
dren are simply reflections of themselves, negating the potential of perfection. Chil-
dren with disabilities also can be in this category, whether dealing with a child with
Down syndrome, intellectual disability, chronic illness, or other.

Parents may mourn the loss of their “perfect” child when confronted with a child
with developmental disability. The sense of loss may be complicated as the child
spends more time away from home in school or other facilities. Many adolescents
with or without developmental disabilities can become moody and irritable with
wide mood swings, transient school problems, and even suicidal thoughts as they pro-
ceed through adolescence. Youth may begin to question previously taught moral, eth-
ical, and religious views of parents as these youth seek to understand concepts and
perform tasks “their way” consistent with their abilities. Much of this is normal adoles-
cent behavior and parents can be taught what is normal and what is abnormal in these
areas.

Some parents develop guilt over producing a disabled child and seek to protect
their child from life’s many potential difficulties and impasses. Such overprotection
can force these youth to become too dependent on parents and not go through normal
adolescent stages of emancipation and identity formation. Developmental disabil-
ity with or without chronic illness or physical handicaps can limit the emancipation pro-
cess in these youth and overprotective parents can worsen this negative trend. It is
especially difficult for these parents to allow medically noncompliant youth normal
or any autonomy. The parent can be torn between fears of injury and even death for
their adolescent and the need to allow freedom and personal choice in various mat-
ters. Parents may interpret their adolescent’s noncompliance with medical recom-

dendations as their being irresponsible, convincing these parents that autonomy is
not a wise choice for their youth. Parents can even consciously or unconsciously
seek to prevent their youth from appropriately growing up, especially if this is the
last child in the home and the parents have no other interests.

PSYCHOLOGIC EFFECTS OF DISABILITY ON SEXUALITY

Disability may constitute a major block to adolescent growth and development by lim-
iting the youth’s developing self-image and removing or impacting a normal emanci-
pation process. The presence of developmental disability or chronic illness may induce major life changes that may impact sexuality development. Health
care professionals need to be aware that successful maturation may be made more
difficult by disability, impacting the development of normal sexuality, and healthy sexual functioning. Stresses produced by the youth’s attempts to negotiate sexual development successfully may in turn exacerbate effects of the disability or worsen the chronic illness that is present.

Rejection by peers because of being “different” can pose major hurdles for some youth, especially those with mental or physical handicaps.\textsuperscript{1,54} The youth with disability who has a poor self-image becomes easy prey for peers seeking to criticize and taunt others to deflect damaging criticism on them. Few if any can happily receive constant rejection or harsh criticism from their peers. All people are in various groups as children, adolescents, or adults. General acceptance by peers is vital to inner stability. The adolescent with developmental disability may conclude that she or he does not have access to this general acceptance.

As growth patterns begin to accelerate rapidly, and as body contours change dramatically with the development of secondary sex characteristics, adolescents become preoccupied with body image issues; they worry and wonder over the adequacy of this new body (Box 1; Tables 1 and 2). Adolescents with developmental disabilities have the added burden of attempting to tolerate real abnormalities and deviations from their idealized body image. Specific problems encountered with the disabled youth involve lowered self-esteem, unsatisfactory body image, and doubts involving future self-sufficiency and the ability to reproduce and parent. Even mildly disabled adolescents may have significant problems with identify consolidation, particularly if periodic or prolonged hospitalization and medical care become necessary.

Sexual adequacy and sexual activity are often altered by disability and physical illness.\textsuperscript{1,32,66} The timing of pubertal changes can normally vary considerably (Table 3) and such timing can impact youth considerably in terms of their developing a sense of sexual intimacy.\textsuperscript{11,60} Some problems can also cause delay in maturation, whether from an actual disorder (eg, in the Prader-Willi syndrome with development of a small penis and cryptorchidism in males or delayed puberty in females) or medications (eg, corticosteroids) used in treatment of medical conditions. The development of hypogonadism (as noted in some with Down syndrome or Prader-Willi syndrome) has major effects on these specific youth. Puberty may be early, however, in a number of conditions as follows:\textsuperscript{11,35}

- Cerebral palsy
- Hydrocephalus
- Obesity
- Intellectual disability

**Box 1**

Major physical changes of puberty

| Major increase in genital system (primary and secondary sex characteristics) |
| Gaining of 25% of final height (distal growth [eg, of feet] may precede that of proximal parts [eg, the tibia] by 3–4 months) |
| Doubling of lean and nonlean body mass (gaining by 50% of the ideal body weight) |
| Doubling of the weight of the major organs |
| Central nervous system maturation (without increase in size) |
| Maturation of facial bones |
| Marked decrease in lymphoid tissue |
Williams syndrome
Meningomyelocele
Neurofibromatosis

Early puberty that is a variant of normal or caused by disability or disorder may thrust the precocious child into issues of middle adolescence and beyond before she or he and parents are prepared. For example, sexuality issues become more developed in middle adolescence often with sexual experimentation taking place. Sexual adequacy for adolescent girls may be measured in terms of physical attractiveness. Unattractive physical features caused by a disease process or required

<table>
<thead>
<tr>
<th>Stage</th>
<th>Breasts</th>
<th>Pubic Hair</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>None</td>
<td>None</td>
<td>Birth to 15 y</td>
</tr>
<tr>
<td>II</td>
<td>Breast bud (thelarche): areolar hyperplasia with small amount of breast tissue</td>
<td>Long downy pubic hair near the labia; may occur with breast budding or several weeks to months later (pubarche)</td>
<td>8.5–15 y (some use 8 y)</td>
</tr>
<tr>
<td>III</td>
<td>Further enlargement of breast tissue and areola</td>
<td>Increase in amount of hair with more pigmentation</td>
<td>10–15 y</td>
</tr>
<tr>
<td>IV</td>
<td>Double contour form: areola and nipple form secondary mound on top of breast tissue</td>
<td>Adult type but not distribution</td>
<td>10–17 y</td>
</tr>
<tr>
<td>V</td>
<td>Larger breast with single contour form</td>
<td>Adult distribution</td>
<td>12.5–18 y</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage</th>
<th>Testes</th>
<th>Penis</th>
<th>Pubic Hair</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>No change, testes 2.5 cm or less</td>
<td>Prepubertal</td>
<td>None</td>
<td>Birth to 15 y</td>
</tr>
<tr>
<td>II</td>
<td>Enlargement of testes, increased stippling and pigmentation of scrotal sac</td>
<td>Minimal or no enlargement</td>
<td>Long downy hair often occurring several months after testicular growth; variable pattern noted with pubarche</td>
<td>10–15 y</td>
</tr>
<tr>
<td>III</td>
<td>Further enlargement</td>
<td>Significant penile enlargement, especially in length</td>
<td>Increase in amount, now curling</td>
<td>10.5–16.5 y</td>
</tr>
<tr>
<td>IV</td>
<td>Further enlargement</td>
<td>Further enlargement, especially in diameter</td>
<td>Adult type but not distribution</td>
<td>Variable; 12–17 y</td>
</tr>
<tr>
<td>V</td>
<td>Adult size</td>
<td>Adult size</td>
<td>Adult distribution (medial aspects of thighs, linea alba)</td>
<td>13–18 y</td>
</tr>
</tbody>
</table>
medical treatment often pose a severe threat to self-esteem, sometimes resulting in promiscuous attempts to prove one’s femininity and normalcy, leading to unwanted pregnancy and STDs. To reduce undesirable physical manifestations of the disease process or treatment sequelae, the clinician may need to schedule additional appointments to control medication, and when possible, explore alternative means of treatment. Cosmetic surgery may be a viable and important option in this regard for adolescents with orthopedic and other defects.

In adolescent girls, serious chronic illness (eg, diabetes mellitus, systemic lupus erythematosus, or rheumatic heart disease) or disability (eg, intellectual disability) can predispose the adolescent to a greater risk of pregnancy than others with less serious illness or disability. Pregnancy may be consciously or unconsciously viewed by these youth as necessary to prove that they are normal and may be part of a mourning process seen with acceptance of illness or disabilities.4,13,15

Adolescents with disability or chronic illness do not inevitably exhibit psychopathology, increased anxiety, or lowered self-esteem, however, compared with their healthy peers.66 Sexual interest and sexual activity in developmentally disabled youth should be assumed to parallel such interest and behavior seen in healthy peers, for often such is the case.33 These youth may become involved in such behavior as masturbation, oral sex, vaginal sex, same-sex behavior, and others.

Research notes that youth with disabilities and chronic illness are also sexual human beings and are involved to varying extents in coital behavior, sometimes at rates similar to or even greater than that seen in healthy peers.4,27,36,54 Those with disabilities or chronic illness that is not easily “visible” may have coital rates higher than seen in those with “visible” defects or illness.1,27 In any event, the normal need of all adolescents for sexual intimacy should not be ignored by clinicians or parents. Appropriate sexuality education is vital for these youth. Consequences of limited sexuality education may include sexual abuse, STDs, unwanted pregnancy, and sexual dysfunction. Appropriate gynecologic care for adolescent girls with disabilities is also important, as considered later in this article.

SEXUAL ABUSE

Sexual abuse is an unfortunate but common situation noted with many children, youth, and adults. Adolescents with intellectual disability and other developmental disabilities are at increased risk for being involved with violence including abuse, both physical and sexual.15,45,47,67–87 Three million cases of abuse are reported annually in individuals under age 18 whether disabled or not, and abuse cases are typically divided into neglect

<table>
<thead>
<tr>
<th>Pubertal Changes</th>
<th>Age Range of Appearance (y)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thelarche</td>
<td>8–14.8</td>
</tr>
<tr>
<td>Pubarche</td>
<td>9–14</td>
</tr>
<tr>
<td>Menarche</td>
<td>10–17</td>
</tr>
<tr>
<td>Testicular enlargement</td>
<td>9–14.8</td>
</tr>
<tr>
<td>Peak height velocity (male)</td>
<td>10–16.6</td>
</tr>
<tr>
<td>Peak height velocity (female)</td>
<td>10–14</td>
</tr>
<tr>
<td>Adult breast stage (V)</td>
<td>12–19</td>
</tr>
<tr>
<td>Adult genitalia (male V)</td>
<td>13–18</td>
</tr>
</tbody>
</table>
(53%); physical abuse (26%); sexual abuse (14%); and emotional abuse (5%). Sexual abuse has been identified in 13% of girls and 7% of boys in the eighth and tenth grades, whereas a history of sexual abuse is reported in 27% of adult women and 16% of adult men. The 2007 Centers for Disease and Prevention Youth Risk Surveillance Survey noted that 9.9% of 15 to 19 year olds have been hit, slapped, or physically hurt by their boyfriends or girlfriends with a prevalence as high as 15.7%; 7.8% were forced to have sex. The incidence of sexual abuse is especially increased in females with mild intellectual disability or physical disabilities versus normal peers.

Rape has become one of the fastest growing crimes of violence in the United States and most cases remain unreported. Although 50,000 to 70,000 cases of rape are reported each year, the actual number is estimated to be over 500,000. In 2006 there were 272,350 victims of rape, attempted rape, or sexual assault identified with 191,670 victims noted in 2005; over 40% of rape victims are under age 18 years with an estimated one sixth being under 12 years. Date rape is a well-known phenomenon of violence that can involve all youth and adult.

Incest represents approximately 40% of reported sexual assaults and can involve parents, siblings, and other relatives. One survey noted that 5 of every 1000 college females reported being victims of incest by their father. In the classic Weinberg study of 103 incest victims, 78% involved father-daughter assault, 18% involved brother-sister sexual behavior, 1% was mother-son assault, and 3% involved victimization by more than one person. The high divorce rates noted in contemporary society leads to a changing scene of step-parents, live-in-lovers of divorced parents, and changing sex partners, fueling the incidence of sexual assault on the children and adolescents in the home. Those with developmental disabilities are at increased risk in some families for incest. The consequences of such sexual assault are many including the following:

- Chronic drug abuse
- Chronic syncope
- Depression and other mental health disorders
- Eating disorders
- Enuresis
- Excessive masturbation
- Juvenile delinquency and other youth violence
- Juvenile prostitution
- Psychosomatic disturbances (chronic headaches or abdominal pain)
- Persistent hyperventilation syndrome
- Pregnancy
- Refractory seizure disorders
- Runaway behavior
- Severe parent-child or youth conflicts
- School failure and drop-out behavior
- Sexually transmitted diseases
- Sexual dysfunction
- Sleep disturbances
- Suicide attempts and completions

SEXUALITY EDUCATION

Comprehensive sexuality education is the key, as noted, which is directed at the specific patient. For example, discussion of masturbation can
be directed by the clinician to the parents of young children, children, and youth. For example, it can be noted that masturbation is a very common aspect of normal human sexuality and genital self-stimulation for pleasure is practiced by most adults in some manner. Parents can be reassured about the normalcy of masturbation and that harmful effects do not occur.

Genital self-stimulation in children or youth with developmental disabilities may also result from diaper dermatitis in infancy, pinworm infection, tight clothes, nonspecific pruritus, phimosis, or other medical conditions. Masturbation has been recommended by some therapists to help relieve sexual tension in adults. Youth should be warned, however, about the sexual asphyxia syndrome in which an adolescent or young adult seeks an intense orgasm by partially hanging while masturbating; this practice can lead to considerable harm including death.

Clinicians must realize that all children and adolescents, including those with developmental disabilities, are potentially subject to sexual assault and harassment, whether they are healthy, have developmental disabilities, or have chronic illnesses. The emotional and psychologic reactions to sexual assault should be understood and comprehensive management provided for these victims. Prevention of sexual abuse is important and measures include education about sexuality that includes teaching all children and youth about appropriate touching and self-protection skills.

If preventative measures are to have a lasting effect, comprehensive sexual health education for all children and adolescents is crucial to this goal of prevention. All adolescents including those with developmental disabilities should have access to accurate information about sexuality, contraception, STDs, substance abuse, and the myriad of topics relating to healthy behavior. Information about sexuality should be directed to the comprehension and specific needs of the adolescent patient.

Youth often have questions about their sexual behavior and clinicians can inquire about these questions while providing accurate, unbiased information without embarrassment. Ignoring these needs of adolescents because of the presence of developmental disabilities is to be avoided on the part of the clinician. The health maintenance examination may be the only opportunity for adolescents to ask about issues related to masturbation, menstruation, sexual activity, reproduction, contraception, and other topics of interest to them. It is understandable that parents often have a difficult time discussing such topics with their children and adolescents.

Clinicians can also assess the social skills of their patients with developmental disabilities and recommend places where such training can occur. The lack of access to age-appropriate peers and lack of access to privacy faced by some handicapped individuals can lead to various difficulties. Such youth need to have good social skills and understanding about healthy human relationships to avoid being bullied or victimized at school or even in the home and to be able to avoid unwanted sexual touching and assault. It is important to educate adolescents and parents about the danger of unwanted sexual overtures and harassment that occurs over the Internet.

GYNECOLOGIC CARE IN DEVELOPMENTALLY DELAYED ADOLESCENTS

Proper gynecologic care for all adolescent girls is important, regardless of their levels of physical, mental, or cognitive abilities; these youth should not receive substandard gynecologic care because neither clinicians nor parents are aware or appreciate these
Lack of training in residency and physician concern with lack of skills in this area should not compromise patient care.\textsuperscript{4} Gynecologic needs are similar for all adolescent girls but such health care may be more complicated by various factors sometimes seen in those with developmental difficulties (\textbf{Box 2}).\textsuperscript{20,33,73,106,162–171}

Gynecologic care should include a complete gynecologic history, physical examination, and selected laboratory testing.\textsuperscript{172} It includes education of the patient in appropriate developmental language, and the caregiver (when the patient is unable to physically, cognitively, or mentally deal with these issues). Education should stress the need for periodic examinations that may include gynecologic evaluations; breast examinations by the patient (or the caregiver if necessary); and options related to menstruation and, when appropriate, contraception.\textsuperscript{73,106}

In adolescent girls, a careful menstrual history should be obtained and should not be ignored simply because she has a developmental disability. The history includes menarche (age of menstrual period onset) and characteristics of the menstrual flow, such as its frequency, duration, and presence of menstrual cramps.\textsuperscript{172} Using a menstrual calendar is useful in pinpointing normal adolescent variations in menstrual patterns versus overt menstrual disorders (ie, dysmenorrhea, premenstrual syndrome, or menstruation-related moodiness or agitation).\textsuperscript{33,106,155,171,172} Plotting mood or behavior changes may even show cyclic behaviors before the onset of menses. The physical and behavioral changes that are present must be differentiated from a variety of gynecologic and urologic disorders.\textsuperscript{168,172}

Clinicians can look for clues to discomfort and disease in patients who have difficulty expressing themselves.\textsuperscript{73,106,155,163,167} For example, crying on urination with foul-smelling urine suggests a urinary tract infection, whereas a fever without clear cause may also represent a urinary tract infection. Excessive vulvar irritation may be caused by masturbation, whereas a vaginal discharge with history of frequent antibiotic use suggests \textit{Candida albicans} vaginitis. Vaginal discharge in children may have a variety of causes including nonspecific vulvovaginitis; foreign body vaginitis; allergic vulvovaginitis; or specific vulvovaginitis (ie, bacteria [\textit{Streptococcus, Shigella}], fungus [\textit{C albicans}], parasites [\textit{Trichomonas vaginalis, Enterobius vermicularis}], \textit{Phthirius}.

\begin{small}  
\begin{tabular}{|l|}
\hline
\textbf{Box 2}  
Factors complicating gynecologic care in females with developmental disabilities  \\
\hline
Increased communication difficulties in those with developmental difficulties  
Cognitive limits that may be found in some with developmental difficulties  
Increased neurologic problems in some with developmental difficulties (eg, seizures)  
Multiple joint complications in some developmental difficulties patients (ie, deformities, contractures, spasticity, autonomic dysreflexia) 
Increased presence of other orthopedic disorders (eg, kyphoscoliosis)  
Impaired sitting position in some with developmental difficulties (eg, decubitus ulcers)  
Increased nutritional issues in some with developmental difficulties (eg, feeding tubes or gastroesophageal reflux)  
Others  
Lack of knowledge on part of parents or clinicians regarding such care  
Parents’ or clinicians’ refusal to provide such care  
\hline
\end{tabular} 
\end{small}
Pruritus ani may be caused by infection with pin worms (Enterobius vermicularis). If T vaginalis is detected in the urine or on a Papanicolaou (Pap) smear, suspect coital behavior and possible sexual abuse.

If the adolescent girl is not sexually active (voluntary or involuntary), a pelvic examination is not necessary unless there is a history of a sexual assault or gynecologic symptoms. A pelvic examination is not needed initially if contraception is requested and the girl is not sexually active. Techniques for a pelvic examination for difficult patients (ie, those with cognitive limitations, contractures, others) are described in the literature. These techniques include various position adjustments (as frog-leg position, V-position, M-position, or leg elevation without hip abduction); use of the Huffman-Graves speculum (long, narrow type) or no speculum; cotton swab Pap smear; one-finger bimanual examination; or a rectoabdominal examination. An examination under sedation may be needed in some situations. Radiologic evaluation with a pelvic ultrasound, CT, or MRI also may be necessary.

Periodic Pap smears are recommended by 3 years from sexarche (onset of coital activity) or by age 21 if the patient remains virginal to screen for abnormal cervical cytology that may eventually lead to cervical cancer. Pap smear techniques may be conventional or liquid-based. In the liquid-based Pap smear one uses a cervical broom and places the specimen in a liquid container; in the convention Pap smear one uses a spatula and cytobrush or cervical broom and then smears the specimen on a glass slide after which a spray or liquid fixative is applied. The liquid-based technique may be helpful in increasing the adequacy of the specimen even when visualization of the cervix is difficult or impossible. Other advantages of the liquid-based Pap smear include increased sensitivity (versus the conventional Pap smear); reduced extraneous material on the smear; and the ability to test for certain STD microbes, such as Chlamydia trachomatis, Neisseria gonorrhoeae, and the human papillomavirus. Vaccination of girls with the human papillomavirus vaccine is recommended to reduce their risk for cervical cancer.

Instruction in proper hygiene may be an issue for some of these patients, whereas various methods are used to control problematic menstruation and related hygiene issues, including behavioral modification training, hormonal management (combined oral contraceptives, depo-medroxy-progesterone acetate, others), or gynecologic surgery (endometrial ablation or hysterectomy). In patients with significant cognitive limitations, education may be confined to hygiene improvement and prevention of sexual abuse.

Any adolescent girl may have breast and menstrual disorders, such as amenorrhea, abnormal menstrual bleeding, dysfunctional uterine bleeding, dysmenorrhea, premenstrual tension syndrome. They should be carefully evaluated and managed. Some conditions lead to increased incidence of menstrual disorders. For example, those with trisomy 21 are often associated with thyroid disorders that may lead to amenorrhea or dysfunctional uterine bleeding. Turner’s syndrome should always be considered in the differential diagnosis of the adolescent female with short stature and amenorrhea caused by premature ovarian failure. Patients with developmental disabilities may be placed on various medications that lead to menstrual dysfunction; these medications include anticonvulsants and neuroleptics.

**Contraception**

Contraception should be discussed with sexually active youth and those who are not sexually active but have questions in this regard. The risks of having
multiple partners should be discussed; some youth practice “serial” monogamy” in which they believe that having only one partner at a time and changing over time protects them from STDs. Those who are sexually active should be screened for STDs and placed on appropriate contraception if this is desired or accepted.4-20,36,73,106,143-149,157,166,167,169,171,174,179-181 Education about emergency contraception and use of condoms should also be provided.

Barrier contraception and the intravaginal ring may not be the best contraceptive choice for women with developmental disabilities unless they are motivated to use such methods and have the cognitive and physical abilities to use barrier contraception with each coital act or use the ring as directed.143,179-181 Concerns with oral contraceptive agents may include side effects, such as thromboembolic events noted with estrogen-containing methods or increased menstrual bleeding or bone mineral loss noted with progestin-only methods.143,144,179-181 Concerns of thromboembolism or bone density loss may be especially noted in those with limited mobility, such as those who are wheelchair bound.143,179-181 There are no data on the use of Implanon for adolescents with developmental disabilities.

The most popular contraceptive method for women with developmental disabilities is depo-medroxy-progesterone acetate because it is given intramuscularly and can lead to amenorrhea. Use of depo-medroxy-progesterone acetate must be balanced, however, with the loss of bone mineral density (with potential increase in fractures) that is associated both with this contraceptive agent and with developmental disabilities in some patients.182,183 Counseling before initiation of contraception with careful follow-up is important. Finally, sterilization of youth with developmental disabilities remains a controversial and complex topic.20,48,55,70,103,155,161,184-188

Sexual Dysfunction

The issue of physical sexual expression and reproductive capacity should be addressed during the adolescent years by an informed, sensitive therapist, counselor, or physician. This helps to correct misconceptions about sexuality and provides for healthy sexual functioning. Sexual dysfunction may arise because of lack of proper knowledge about sexuality. A variety of sexual dysfunctions, listed below, may develop in adolescents or adults with disabilities because of the disorder itself; medications needed for management of medical conditions; or complications found in their lives (eg, sexual abuse).189-191 Sexual dysfunction may develop in adolescence that continues into adulthood.192

Dyspareunia
Orgasmic dysfunction
Erection dysfunction
Ejaculation dysfunction (premature, retrograde, or retarded)
Others

Youth may have visible deformities that may interfere with sexual expression; these issues include paraplegia, amputations, ostomies, or abnormal genitalia that require special counseling.1 These youth may feel inadequate compared with their “normal” peers and develop various sexual dysfunctions. Performance pressure may predispose to sexual dysfunction in any individual. Chronic illness may create a setting in which actual enjoyment of sexuality is limited although physical functioning is normal. For example, youth with colostomies can be anxious about the odor coming from the ostomy; those with arthritis may be in pain; or those with spinal cord lesions may have painful bed sores or be worried about autonomic dysreflexia (a condition triggered by
sexual stimulation, constipation, genital examination, and other actions and might lead to various effects from simple tingling sensation to respiratory arrest). In considering one with sexual dysfunction, various psychologic and organic factors should be evaluated.

SUMMARY

Adolescence presents complex challenges for teenagers, parents, clinicians, and society. Youth with physical disorders and developmental disabilities present additional complications for parents and clinicians. It is important to provide sexuality education and reproductive care to all adolescents including those with developmental disabilities. Adolescents are involved in voluntary or involuntary sexual behavior and the presence of developmental disability does not exclude these youth from human sexuality and its consequences. Data from the 2002 National Survey of Family Growth reports that 47% of never-married girls aged 15 to 19 years of age have been sexually active (versus 46% of 15–19 year old boys). Prevention of sexual abuse in this population is vital to overall healthy development. The 2007 Youth Risk Behavior Surveillance of the Centers for Disease Control and Prevention reports that 47.8% of 15 to 19 year olds report being sexually experienced versus 46.2% in 1991. If the girl remains sexually active, contraception education and prescription that includes education in use of condoms is needed. The 2007 YRBS report notes that 61.5% of sexually active youth used a condom at last coitus versus 46.2% in 1991. Gynecologic care includes education about hygiene and management of various gynecologic issues, such as vaginal discharge, breast and menstrual disorders, and others as considered in this article. Provision of comprehensive care to all youth, including those with developmental disabilities and chronic illness, is part of the linchpin in the pediatric goal of allowing adolescents access to maximum success in adulthood by offering optimal care as children and adolescents along with transitioning to adult life. Adolescents with disabilities are just as much at risk, if not more than their “normal” peers. Those with disability may want to prove that they are “normal,” whereas the ones without disability may not.

REFERENCES


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