Spina Bifida and Sexuality

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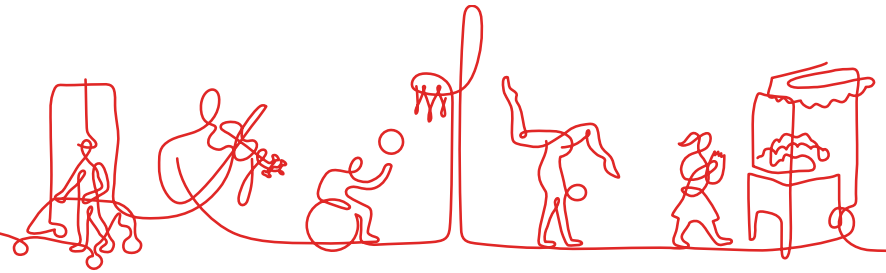

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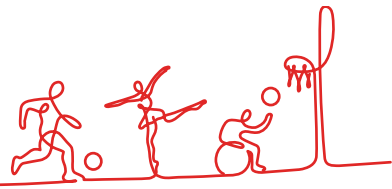


Sexual Health: WHO

"…a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled." *(WHO, 2006a)*

https://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/

Sexuality: WHO

- "…a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors." *(WHO, 2006a)*

Holistic View of Sexuality

- WHO 2006:

-sexuality is central to humanity and encompasses sex, intimacy, and sexual identity

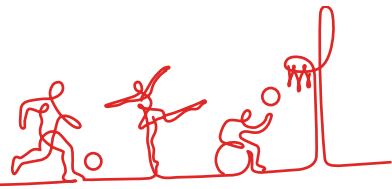
-experienced through thoughts, desires, attitudes, behaviors, and relationships

-integral to healthy human development, and closely linked to high relationship quality and psychological wellbeing across the lifespan

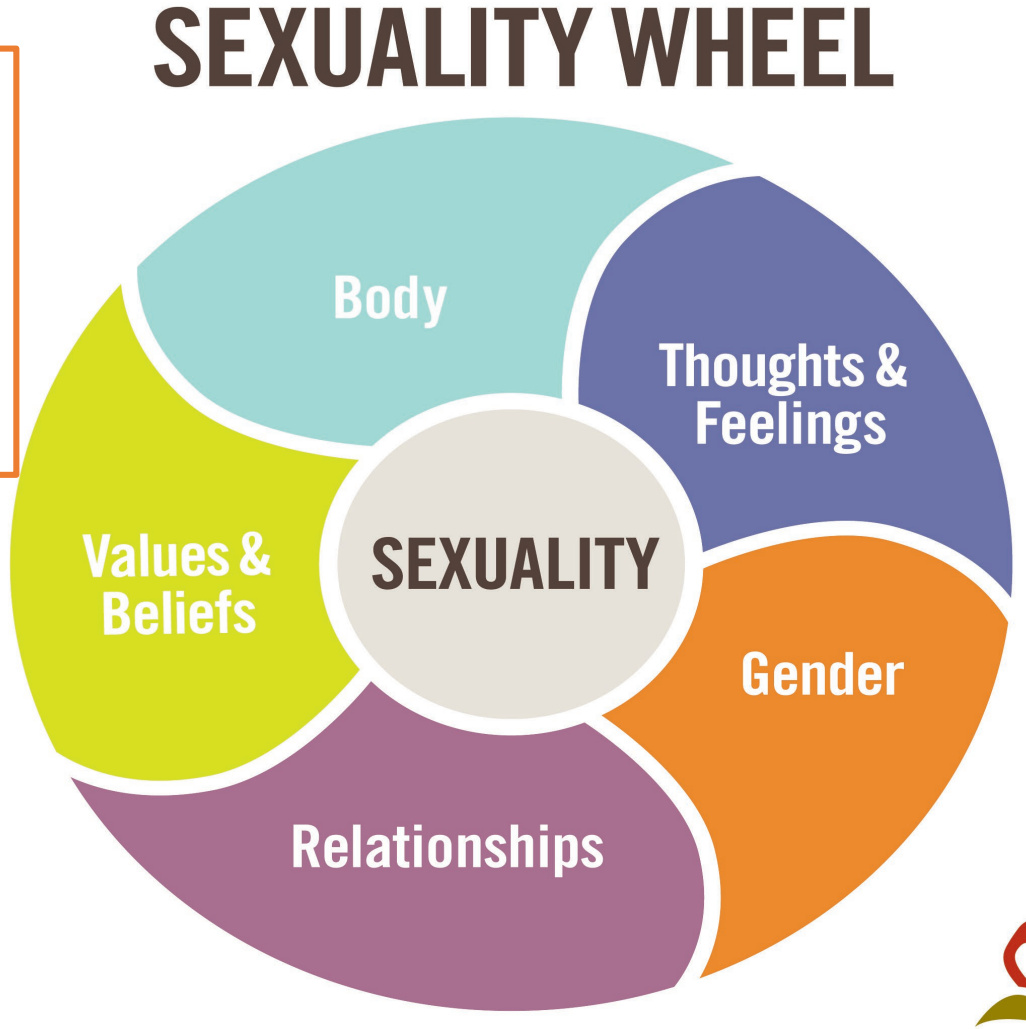
- American Association on Intellectual and Developmental Disabilities, 2008

-People with intellectual and/or developmental disabilities have inherent sexual rights to: dignity and respect within relationships; sexual expression and individualized education to encourage informed decision-making; protection from sterilization solely because of their disability

Aaidd.org; https;//www.who.int/reproductivehealth/topics/sexual.health/sh.definitions/en/; Pecora et al. 2016



- Each part of the wheel represents one part of who we are
- These parts are all connected and influenced by each other
- When every part is healthy our sexuality is healthy



teachingsexualhealth.ca

SERC
SEXUALITY EDUCATION RESOURCE CENTRE MB

Stage	Physical Changes	Social Emotional Changes	Cognitive Changes
Early (ages 10-13) **May be as early as 8 in girls; 9 in males**	• Growth spurt: girls earlier • Growth of Axillary & Pubic Hair • Growth of breasts & testicles • Menarche 2-3 years post onset of breast development	• Curiosity, anxiety • Gender Identity questions • Increased need for privacy and independence from parents/family • Self-conscious, feel judged by peers	• Concrete thinking • Black/White, All/Nothing • Self-centered, egocentric • Exploration of boundaries
Middle (ages 14-17)	• Most boys have started growth spurt • Voice changes • Acne • Most girls have periods and have nearly completed growth/physical changes	• Interest in romantic/sexual relationships • Question & explore sexual identity • Self-simulation, masturbation: both genders • Struggle for independence, arguments with parents	• Increased ability to think abstractly • Still may lack ability to apply "big picture" thinking in the moment • Emotions may drive decisions
Late (ages 18-21+)	• Physical Development Complete	• Stronger sense of identity and values • Separation from family with re-establishment of adult relationship with parents • More stable friendships and romantic relationships	• Future focused • Decisions based on hopes and ideals • More impulse control • May be better able to weigh risks and benefits

healthychildren.org

- Privacy regarding areas “covered by bathing suit” should be emphasized beginning in early childhood
- Teaching regarding touch, appropriate (high five, fist bump, side hug) vs. inappropriate, should also begin early and is especially important when parents, caregivers, nurses are performing bowel and bladder routines

-important for them to know that inappropriate touch may be associated with pleasure and at the same time may make them feel confused, fearful

- Facilitating independence in self-care reduces vulnerability
- “The Talk” happens over time and details are added as the individual matures cognitively, physically, emotionally, and socially, and as interests change

-information offered and advice given should be tailored to individual’s cognitive level

Streur 2019

When to Start Talking?

- Early Childhood, BUT it's NEVER TOO LATE
- Even if you give them "too much," they will absorb some of it
- Giving information is not giving permission: children who get the facts wait longer before having sex than children who are told nothing
- Find out what, if anything, the school is covering

http://www.srcp.org/for_some_parents/typical_development/the_basics/whatwhenTD.html

Discussion Starters

- When you get older, do you want to have a boyfriend or girlfriend?
- When you get older, do you want to hold hands with a boyfriend or girlfriend?
- When you get older, do you want to kiss a boyfriend or girlfriend?
- When you get older, do you want to get married?
- When you get older, do you want to have children?
- Is it okay to touch your private parts in public? Why not?
- Is it okay to touch your private parts when you're alone at home in your own bedroom?
- Last question: Is it embarrassing to talk about these things?

http://www.srcp.org/for_some_parents/developmental_disabilities/activities_to_use_with_your_child/startersDD.html

Tips for Talking

- Talk with them regardless of their age
- Choose a good time and place: quiet, comfortable, relaxed setting with enough privacy
- Be ready to initiate the conversation
- Listen more than you talk
- It won't be one "Talk," there are too any topics to cover and knowledge needs will change with development
- Look for everyday opportunities to use in teaching:

  -a TV show about people who are dating, kissing

  -a friend of the family who is pregnant

http://www.srcp.org/for_some_parents/developmental_disabilities/the_basics/tipsDD.html

Tips for Talking

- Let them “overhear” adult conversations to use as starting points, as they may be too embarrassed to bring up subjects on their own

  -at dinner pick a relevant topic from TV/news to discuss with your child and your partner, if applicable

- It’s okay for you to feel embarrassed and acknowledge that: emphasize that it’s your embarrassment, and that it doesn’t belong to the child or subject matter
- Start by being concrete, using anatomically correct dolls, three-dimensional models, drawings, photographs, and videos. Adjust based on child’s age and developmental level

http://www.srcp.org/for_some_parents/developmental_disabilities/the_basics/tipsDD.html

Tips for Talking

- Practice skills in safe settings: e.g. using pads/menstrual hygiene supplies, putting on a condom
- Books are wonderful resources to look at together and/or for child to review on their own
- If you don't know the answer to one of their questions, search for it together, using internet, at doctor's visits
- If a question "throws you for a loop," say you will get back to your child with the answer, ad make sure you really do
- You have the right to "pass" on personal questions: this will help children develop their own boundaries

http://www.srcp.org/for_some_parents/developmental_disabilities/the_basics/tipsDD.html

Tips for Talking

- Less is more: give simple responses first and build on these based on your child's interests and follow-up questions
- Practice pays off and will make it easier over time. Try imagining the hardest question they could ask and how you would answer it
- Be aware of your body language: match it to your words and overall message
- Be patient, some questions will be repeated
- Respect teenage relationships: "crushes," "puppy love" are at the center of their universe and can lead to great conversations
- Keep your sense of humor…remember how you were at their age

http://www.srcp.org/for_some_parents/developmental_disabilities/the_basics/tipsDD.html

Tips for Talking

- Ask for their opinions: this will build their self-respect
- Share your values, even if they seem indifferent

-the need to know what your values are about body image, friendships, bullying, dating, relationships, respect for others, and respect for oneself. Your values will be the foundation they rely on and, as they get older, the barometer for assessing the values they want to hold

- Teach them that sexuality goes beyond having sex

-Tell them about affection, trust, respect, responsibility, and intimacy, and practice the behaviors you would like them to adopt. Remember, giving information is not giving permission – it is ignorance that leads to bad decisions.

http://www.srcp.org/for_some_parents/developmental_disabilities/the_basics/tipsDD.html

Goal: Healthy and Happy Lives

- Give them information and skills they will need to make responsible decision
- Encourage them to take good care of their bodies and health
- Help them become confident so they respect themselves and others
- In turn, earn their respect, so they are more likely to turn to us and other trusted adults for information when they need it

http://www.srcp.org/for_some_parents/typical_development/the_basics/whatwhenTD.html

Sexuality includes…

- Body parts and sex, but much more than this
- Our gender identity (the core sense that we are female, male, both, neither, or somewhere in between)
- Our gender role (the idea of how we should behave because of our gender identity)
- Our sexual orientation (heterosexual, homosexual, bisexual, asexual, or other identities)
- How we feel about our bodies: "body image," and poor body image can have a profound effect on our ability to have healthy relationships. A person with poor body image may not think they deserve a good partner, and so they may be willing to settle for someone who will not respect them or who may even abuse them.
- Our sexual experiences, thoughts, ideas, and fantasies
- The way in which the media, family, friends, religion, age, life goals, and our self-esteem shape our sexual selves
- How we experience intimacy, touch, love, compassion, joy, and sorrow.

"Sexuality is expressed in the way we speak, smile, stand, sit, dress, dance, laugh, and cry."

http://www.srcp.org/for_some_parents/typical_development/the_basics/whatwhenTD.html

Questions that Children with Developmental Disabilites have asked

- How do you handle people – strangers – making passes at you in public?
- Is it okay to date older men?
- How can you tell if someone is interested in you?
- How do you change the way a boy kisses?
- Should you wear condoms?
- I really want to be married. I really want to be pregnant.
- Can I get a disease if I touch sperm with my hand?
- Can you get in trouble by looking for sexual answers on the Internet?

http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

Questions Children with Developmental Disabilities Have asked

- How do I get girls to like me?
- How can you know whether you're gay?
- How long should you wait to have sex?
- Is it okay to touch my own private parts?
- What do I do if my parents won't let me have a boyfriend?
- What happens when you have sex?
- Is a person interested if they keep looking at you?
- Is it okay if a boy holds my hand on the first date and I'm nervous to say "no"?
- My boyfriend told me to take off everything and do the sex.

http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

Diversity of Developmental Levels

- Some children with spina bifida may not have the ability to ask these kinds of questions and some may never have sexual relationships with other people.
- Important to tailor the approach to the cognitive, emotional, social, behavioral uniqueness of the child and let their developmental level guide the process
- Even a child who is nonverbal will need information and skills regarding sexuality – to protect them from sexual abuse and to prevent them showing their private parts or masturbating in public.

http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

Diversity of Developmental Levels

- For children who are nonverbal and have intellectual disability or autism along with spina bifida, the goal is to be attuned to their expression of their needs, frustrations, preferences, sources of comfort, fears

  -this may be communicated through facial expressions, vocalizations, grunts, repetitive behaviors, changes in sleep, feeding, activity level

  -our awareness promotes safety, dignity, quality of life, connectedness

http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

Masturbation

- Common throughout life, both for men and women
- Children masturbate from an early age, although the behavior usually increases during adolescence. Masturbation is a healthy thing for children and adults to do, but many people still feel guilty about masturbating.

  -help relieve sexual tension

  -provide a sexual outlet for people without partners

  -be a source of comfort or security to some individuals

http://www.srcp.org/for_some_parents/developmental_disabilities/index.html

Excessive Masturbation

- when there are personal emotional problems
- when there is an irritation such as a skin rash (e.g. an allergic reaction to a new soap or detergent)
- when clothing is too tight
- when there is an infection (for example, a yeast infection or a sexually transmitted infection)
- when a physical disability affects sensitivity to pain or pleasure
- when an individual has a general tendency to engage in obsessive, repetitive, and/or self-abusive behavior

Excessive Masturbation

- when an individual with autism has an underdeveloped sense of touch

  -the individual may need to masturbate longer or more forcefully just to get sufficient sensations
- when an individual is not masturbating to orgasm
- when an individual is taking medications that affect sexual function (as a side effect)
- as an attention-getting behavior
- when an individual has been sexually abused

  -look at caregivers, contexts, other behaviors and general health

  -activate law enforcement and CPS if appropriate

  -start with visit to general pediatrician if situation less clear

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html

- Masturbation may seem excessive because it occurs in inappropriate places

  -an individual may have no appropriate places to masturbate

  -may not have been taught where it is appropriate to masturbate.

- Masturbation cannot be ignored when
  - it is done in a public place
  - it is done in a private place (such as a bedroom), but when other people are around
  - it interferes with daily living (the individual no longer finds time for family or friends, other interests, schoolwork, or their job)
  - an individual is rubbing so hard or so often that there is soreness or bleeding

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html

Teach/Redirect about Masturbation

- Should be done in a private place at home
  -bedroom or a bathroom with the door closed and the curtains drawn
- Private behavior that should be done alone
- Use a sexual lubricant such as KY Jelly (available at pharmacies) if there is soreness
- Clean up after masturbating
  - wiping off the genitals, wiping up semen (for males), and washing hands
- Should not be discussed in public places with family, friends, or strangers
- Discuss in private with a doctor, nurse, parent, or other appropriate, “safe” person

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html

Dealing with Inappopriate Masturbation

- Be clear about your rules
- Respond to inappropriate masturbation in a calm, non-judgmental manner

  -use clear language, “It’s not okay to masturbate here. You can do that in the bathroom.”
- Be on “same page” at home and school: so that you and all school or work staff are giving consistent messages.
- Look for possible causes if the inappropriate behavior persists
- Behavior modification techniques can be applied to inappropriate masturbation

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html

Use techniques that have worked in the past for other problem behaviors exhibited by your child. Possible techniques include:

- Encourage other, incompatible behaviors

  -your child won't be able to masturbate if their hands are busy doing something else

- Reward appropriate behavior or the absence of inappropriate behavior
- Extinguish attention-getting behavior

  - ignore it or calmly redirect your child.

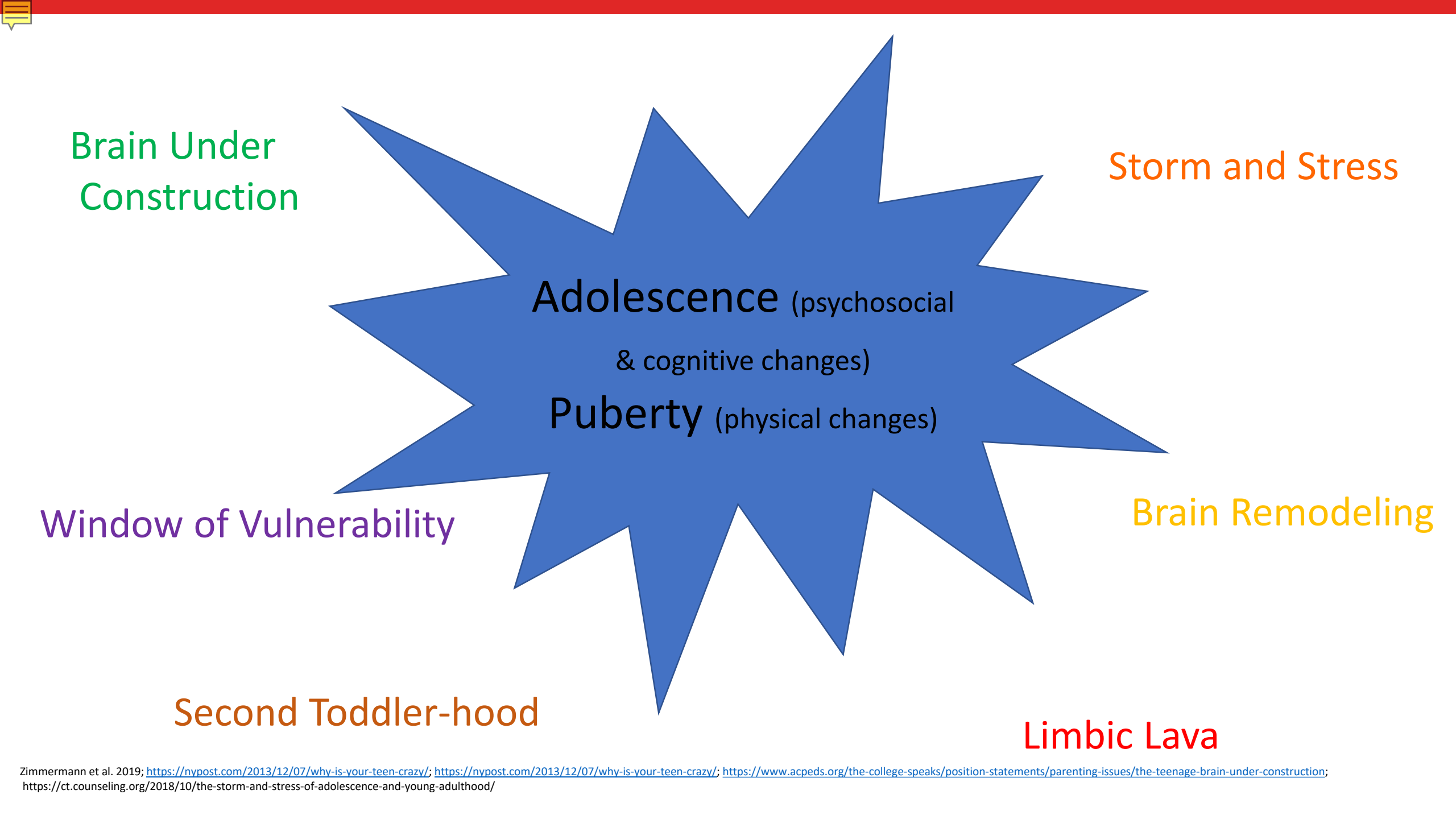
  -may be difficult – masturbation is a very private behavior, seeing it in public may cause feelings such as anger, fear, or disgust.

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html

- Masturbation: usually pleasurable, may be impossible to eliminate completely
- Teach appropriate places and times for masturbation

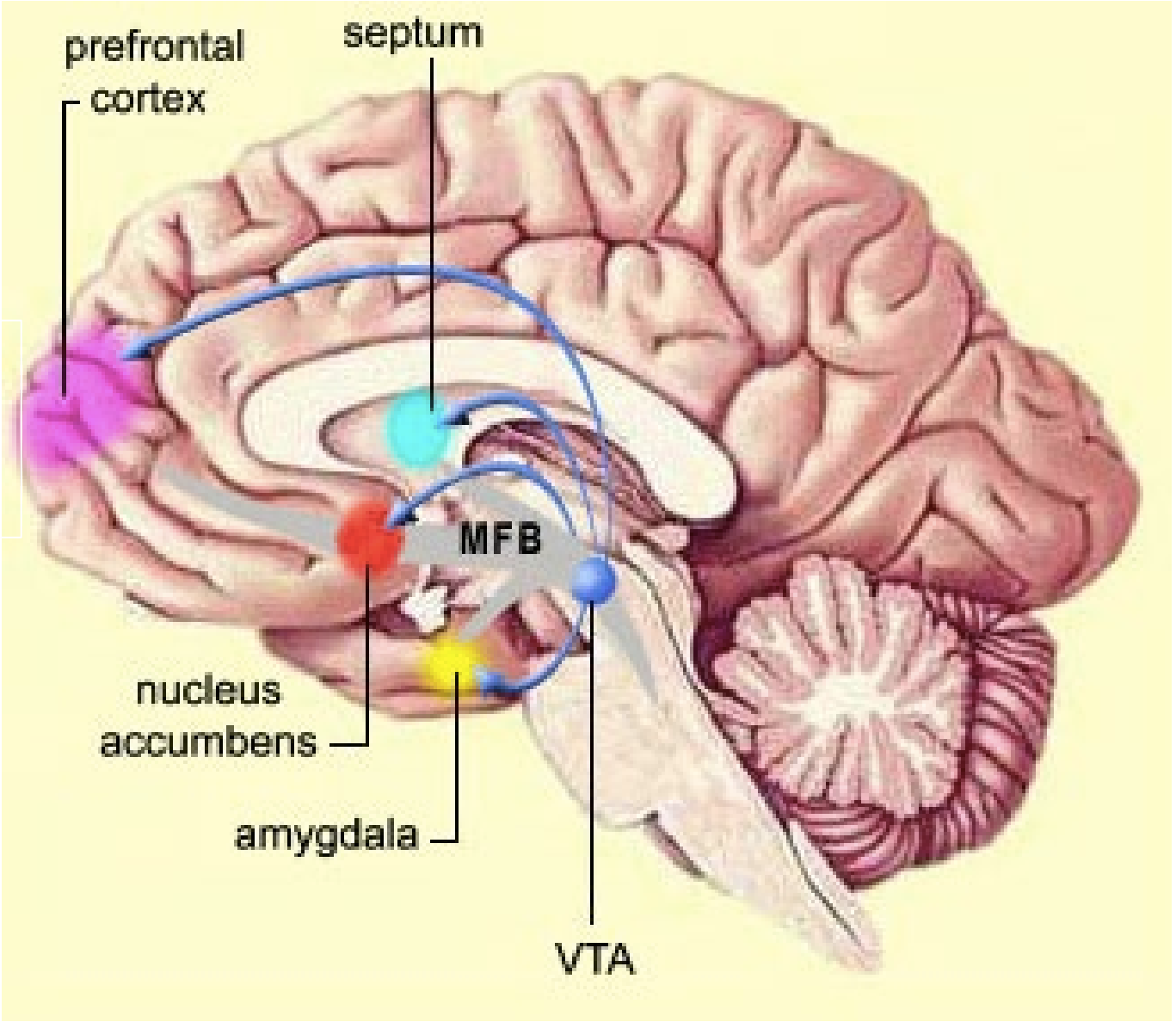
  -make sure there are such places and times in your child's life
- Usually more effective than trying to eliminate the behavior completely

http://www.srcp.org/for_some_parents/developmental_disabilities/the_specifics/mastDD.html



Zimmermann et al. 2019; https://nypost.com/2013/12/07/why-is-your-teen-crazy/; https://nypost.com/2013/12/07/why-is-your-teen-crazy/; https://www.acpeds.org/the-college-speaks/position-statements/parenting-issues/the-teenage-brain-under-construction; https://ct.counseling.org/2018/10/the-storm-and-stress-of-adolescence-and-young-adulthood/

Hydrocephalus
Chiari II Malformation
Ventriculomegaly
Ventriculoperitineal Shunt



- Challenges with Executive Functioning
- Inattention
- Nonverbal Learning Disability

thebrain.mcgill.ca

The Adolescent Brain

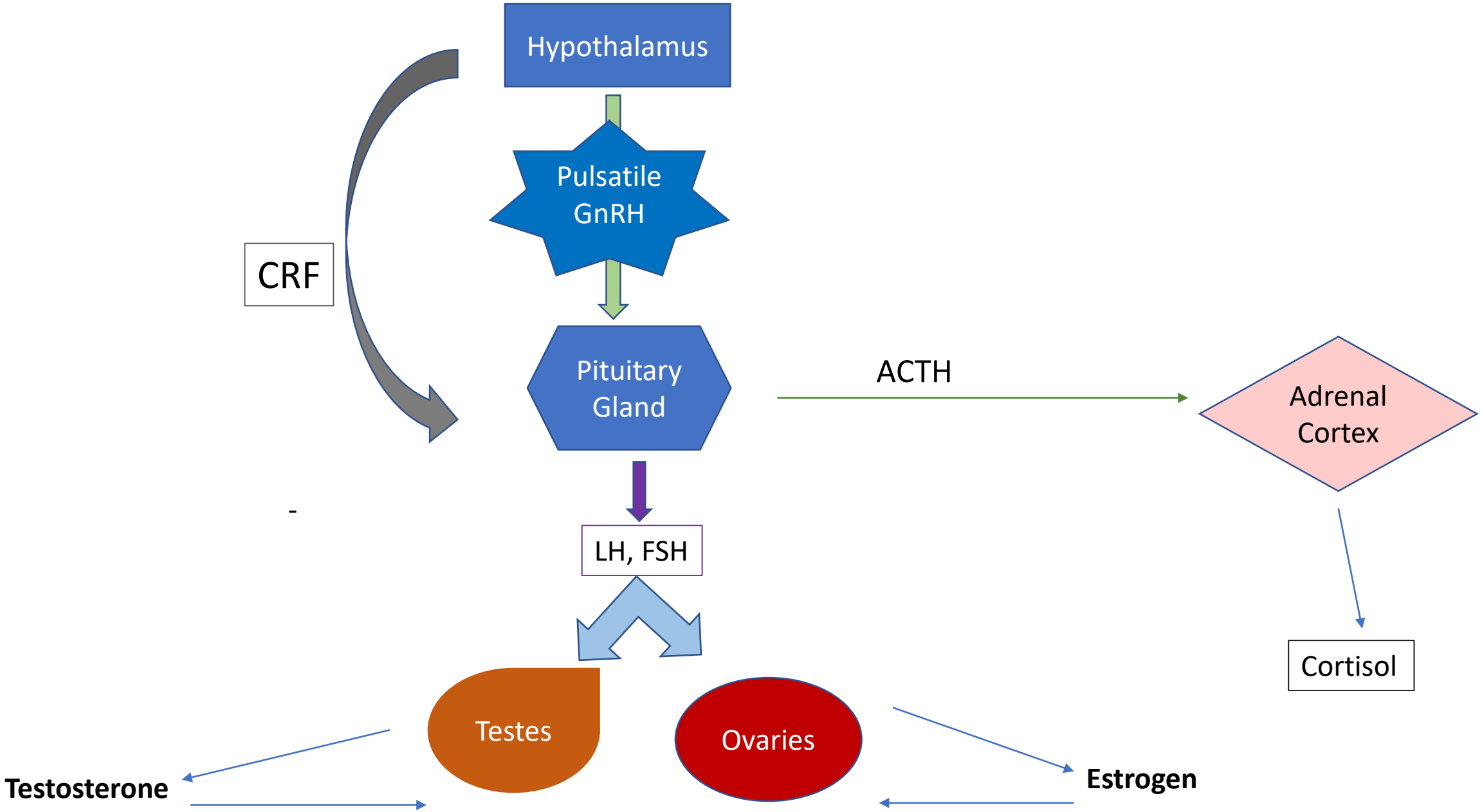
- Not yet fully mature
- Greatest period of brain growth after infancy: sensitive to hormones inlcuding testosterone, estrogen, progesterone
- Different growth rates for different brain structures; connections between them need to be strengthened
- Amygdala matures earlier: role in emotion, aggression, instinctual responses (together with hippocampus and hypothalamus forms limbic system, involved with emotions, motivation, survival)
- Prefrontal Cortex Matures Later (mid-20s): role in regulating mood, attention, impulse control, abstract thinking; planning ahead and seeing consequences of behavior
- Changes in Ventral Striatum: increased reward sensitivity, risk-taking and motivational behaviors

Arain et al. 2013; Breiner et al. 2017; healthychildren.org; Tottenham & Galvan 2016

The Adolescent Brain: Changes in Neurochemicals

- Decreasing dopamine (mood swings)
- Decreasing serotonin (decreased impulse control)
- Increasing melatonin (increased need for sleep)
- Highly vulnerable to stressors

Arain et al. 2013; healthychildren.org; Tottenham & Galvan 2016



Blakemore et al. 2010

Adrenarche and Pubarche

- Premature Adenarche with Pubarche:

-Growth of axillary and pubic hair stimulated by hormones from the adrenal gland and not necessarily predictive of central precocious puberty

-Common in patients with neural tube defects, spina bífida, hydrocephalus

Zacharin 2013; McLay et al. 2015; Siddiqi et al. 1999; healthychildren.org

Precocious Puberty and Growth Hormone Deficiency

- Common in patient with complex central nervous system anomalies
  -hydrocehalus, Chiari malformation
- Precocious Puberty: Boys <9, Girls <8
  -premature stimulation of the hypothalamic-pituitary-axis
  -higher incidence in girls (obesity is a contirbuting factor)
  -Diagnosed by checking LH, FSH, bone age (“advanced”)
- Growth Horomone Deficiency
  -Diagnosed by checking IGF-1 levels and bone age (“delayed”)
- Delayed puberty (boys >14; girls> 13): very thin child, low fat stores, inadequate nutrition

Zacharin 2013; McLay et al. 2015; Siddiqi et al. 1999; healthychildren.org;
Trollmann et al. 2000; Li et al. 2017

Considerations +/-

- Seizures: may increase at puberty
- Bone Health: delayed puberty may limit bone accumulation and increase fracture risk, especially for those with mobility challenges, inadequate Vitamin D, on anti-epileptics
- Obesity: early puberty may limit linear growth potential; consider Growth Hormone deficiency; consider hormonal treatment for early puberty
- Discussion of these can provoke anxiety and distress in parents/family, youth, as well as providers/health care team

Zacharin 2013

Menstruation

- Requires careful attention to hygiene, bowel and bladder routines to avoid urinary tract infections and skin breakdown
- Hormonal management may be required if periods are heavy, irregular, and/or if they are very distressful to the individual given cognitive and sensory profile
- May take up to 3 years to become “regular”

Biopsychosocial Factors

- Hormonal/physical changes may come faster than cognitive, social, and language development: challenges in expressing thoughts, needs, desires
- Female pelvic and male genitourinary exams and lab/testing procedures should be adjusted for cognitive, sensory, motor, communication, behavioral differences
- Some youth may lack awareness of public vs. private: i.e. masturbation, demonstration of affection; increased risk for abuse
- Some youth may begin to have new behavioral difficulties at the time of puberty: social, cultural, religious, familial, medical contexts are clues to solutions
- Gender Identitiy and Orientation: these are as much a consideration as for youth who are typically developing

McLay et al. 2015; Murphy & Elias 2006; Dewinter et al. 2017; George & Stokes 2018

Myths: Adolescence/Puberty for Youth with Neurodevelopmental Disabilities

- Will remain child-like, need to be sheltered
- Not interested in relationships
- Lack sexual urges
- Deviant or hypersexual
- Parents and professionals may not recognize potential of children with disabilities to enjoy intimacy and sexuality in relationships
- Although more recently there has been ideological shift away from these views, research on sexuality and sexual behavior in youth with disabilities is lacking
- Appropriate sexuality education for youth with disabilities and their families is also lacking

McLay et al. 2015, Murphy & Elias 2006

Youth with Spina Bifida would like to know about

- Romantic relationships
- Sexuality
- Fertility and parenthood
- Additional sexual education

Akre et al. 2016

Sexuality

- In a survey of patients ages 14-23, 95% of patients and 59% of their parents reported inadequate education about reproductive health related to spina bifida
- Healthcare providers frequently feel unprepared to discuss issues of sexuality with patients with spina bifida and cite

  -a lack of formal training

  -knowledge gaps on the topics of sexuality, fertility, and pregnancy
- This demonstrates provider's inability to meet patient's needs: 93% of patients and 100% of their parents report that they would definitely talk about these issues if the physician initiated a conversation

Patel et al. 2019

Contraception

- People with spina bifida were less likely to use birth control when sexually active, as compared to controls without health problems
- This may be due to inadequate sexual education

For Individual with spina bifida who have seizures:

- More than half of providers are unaware that antiepileptic drugs that increase breakdown of hormones in liver can increase risk of contraception not working
- Lamotrigine (Lamictal) level can be lowered by birth control and this can lead to breakthrough seizures or changes in side effects (does not affect how well the birth control works at lower doses)

Linroth 2019; epilepsy.com

Seizure Medications that Decrease Effectiveness of Oral Contraception

- Carbamazepine (Tegretol, Tegretol XR, Carbatrol, Equetro)
- Clobazam (Onfi)
- Eslicarbazepine (Aptiom)
- Felbamate (Felbatol)
- Lamotrigine (Lamictal) at dose of 300 mg daily or more
- Oxcarbazepine (Trileptal)
- Phenobarbital
- Phenytoin (Dilantin)
- Primidone (Mysoline)
- Rufinamide (Banzel)
- Topiramate (Topomax) at doses of 200 mg daily or more

More Findings

- 50% of individuals with spina bifida report dissatisfaction with their sex lives
- Although sexual satisfaction and intimacy are directly related to quality of life, they are rarely studied
- Sexual activity in people with spina bifida starts later
- People with the lowest lesion levels had the highest chance of finding

a partner and engaging in sexual activity

- Lower lesion levels are associated with sexual satisfaction

Linroth 2019

- In general, having hydrocephalus predicted more problems with sexual function and relationships
- Urinary incontinence was associated with altered sexual functioning in multiple studies, but not all.
- Bowel and bladder incontinence has been demonstrated to interfere with sexual activity

    -Continence improves sexual functioning
- Restored penile sensation is associated with improved sexual health and satisfaction

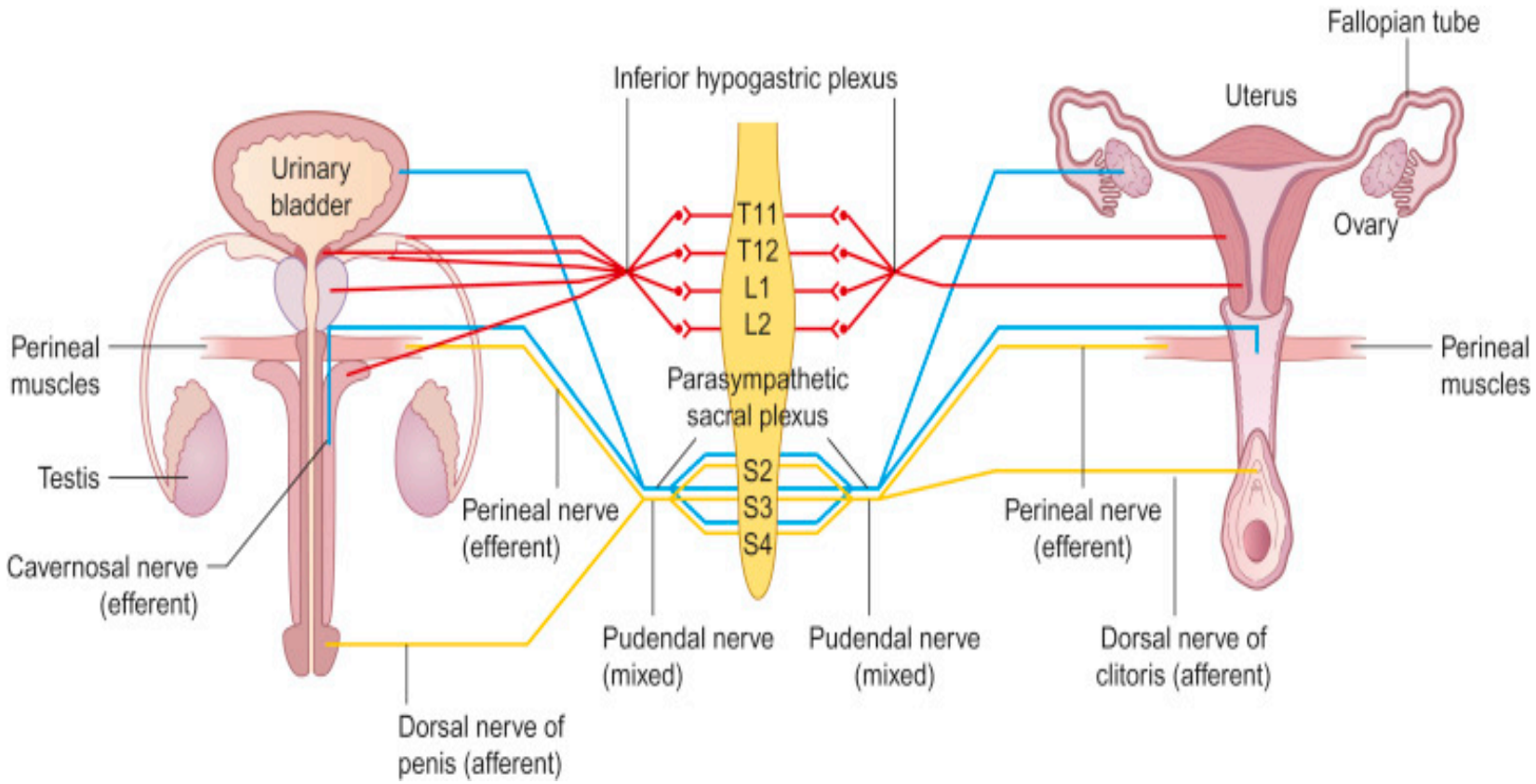
Linroth 2019

Common Physical Challenges for People with Spina Bifida

- Orthopedic issues:
  - -Scoliosis may make laying on back uncomfortable
  - - May be unable to move hips or legs
- Latex sensitivity or allergy: need latex-free condoms
- Loss of sensation or altered sensation in skin and genital sensation
- Possibility of incontinence of Bowel and Bladder

Linroth 2019

The nerves and reflexes that connect to bowel, bladder and sexual organs are all in the same area



Sciencedirect.com

Catheterization with Sexual Intercourse

- For men:

  - catheterization may stimulate an erection (“reflex”) that can be used for intercourse

  - it is recommended to leave a large loop of catheter at the end of the penis, so that if the person has an erection there is enough catheter for the penis to climb, and then pa condom can be placed over it

- If a person does not get a great reflex erection, the penis doesn’t get real hard, the rigidity of having the catheter run down along the side of the penis can help stimulate their partner.

- For women, tape the catheter on the abdomen, out of the way

  -the catheter is entering the urethra, not the vagina

  - it will not affect sexual activity greatly

Linroth 2019

Challenges with Sexual Arousal

Women

- Painful intercourse
- Lack of vaginal lubrication, may not produce vaginal secretions
- Inability to orgasm or recognize orgasm

Men

- Achieving, sustaining erections
- Ejaculation (retrograde)

Both women and men may be anxious about performance and this may interfere with arousal; they may fear failure fear and bowel and bladder accidents

Linroth 2019

- May have enhanced sensation above the lesion

  -arousal and satisfaction depend on stimulation there, sensual massage

- Gradual dilation of vagina using dilators may be helpful
- Vibrators may also improve the experience

  -these may heat up in 15 minutes or less so it is important to be careful with areas of skin with reduced or absent sensation

Linroth 2019

Women

- 90% interested in marriage
- 76% would like to have children

Streur 2019

Women

- 80% of women have some genital sensation
- Rare when lesion is above L2
- 37% of women experienced an orgasm
- Map out sensation, pleasure zones and let partner know

Sawyer & Roberts Dev Med Child Neurol 1999; Linroth 2019

Women

- Need 4-5 mg of folic acid daily to prevent spina bifida
  - this dose requires a prescription
- May urinate with orgasm
- Important to empty bladder before intercourse
  - incontinence still may occur
  - use mattress protectors
  - place chucks pads under sheets, discrete
- Talk with partner about this to prepare them

Linroth 2019; Streur 2019

Women

Bowel Incontinence

- Watch diet before sexual activity
- Empty bowels before having sex, especially if anal penetration

  -Mattress protector

  -Wipes
- Talk with partner before to help prepare them

Streur 2019

Women: Pregnancy

- Most women with spina bifida are fertile
- 70% who become pregnant have successful pregnancies
- Pregnancy (gravid uterus) can affect shunt drainage, bowel and bladder function, pulmonary function, balance and ambulation
- A study of 40,000 patients showed

    -women with spina bifida have a higher rate of c-section (53% vs. 32%)

    -women with spina bifida who had c-sections had a higher rate of complications than other women: urinary tract infections, premature delivery, need for blood transfusions

    -in the 47% of women who had vaginal deliveries, a higher rate of complications compared to other women was not detected

Patel 2019

Women

- Build confidence to improve satisfaction
- Find an affirming partner

    -Selectively choose a partner

    -Give feedback

    -Seek satisfaction for both

    -Seek advice and counseling

        -physical therapist may be able to help with positioning

Linroth 2019

Sexual Identity and Orientation

Online international survey of 119 women

- Sexual Identity:
  - -99% of women identified as female
- Sexual Orientation:
  - -85% heterosexual (lower than general population)
  - -3% homosexual
  - -10% bisexual (higher than general population)
  - -1% asexual
  - -2% other

Szymanski KM et al. J Pediatr Rehabil Med 2017; Linroth 2019; Streur 2019

Family Planning

- Many adolescent and adult women with spina bifida do no believe they can become pregnant
  - -assume they cannot because of spina bifida
  - -Providers tell them they cannot
- Unintended pregnancies occur in this population
  - -few women use birth control
  - -they have problems finding supportive providers and information
- Women value provider's willingness to help them reach their sexual and reproductive health goals more than their experience and expertise in the area

- Streur CS et al, Disabil Health 2019; Linroth 2019

Men

- Experience bowel and bladder incontinence during sexual activity but not as frequently as women
- More common when there is urinary continence at baseline

Szymanski, AUA 2018

Men: Sexual Identity and Orientation

- Identity
  - -96% male
- 1% each
  - -female
  - -transgender
  - -other
- Orientation
  - -92% heterosexual
  - -7% homosexual
  - -2% bisexual

Szymanski, SPU 2017

Men

- Multiple studies from around the world show significant proportion of men with spina bifida have small testicles (which make sperm and testosterone)
- Smaller proportion have low testosterone levels
- Most report that they are unable to maintain erections
  - -80% improvement with Sildenafil
- Essential to ask about erectile function

Weiner 2019

Men

- Options to help erectile function

  -Constriction ring – non-latex, must be removed

  -Vacuum pump

  -PDE-5 inhibitors

  - Injection therapy

  -Surgery? – TOMAX, rerouting of ilioinguinal nerve (L1) to pudendal

  -penile prosthesis

Weiner 2019

Problems with Ejaculation and Orgasm

- 73-88% report ejaculation
  - -higher than normal erections and orgasms
  - -most experience dripping, not with orgasm
- 20-66% report orgasm

Weiner 2019

Men: Types of Sexual Activities

- 91% masturbation
- 62% vaginal intercourse
- 35% anal intercourse

Weiner 2019

Men

- Important to focus on quality of life

  -Lassman 2007 found that 70% desired children

- Highlight sexual abilities and strength

Weiner 2019

Women

- Pelvic Pain
- Bleeding from vagina between periods
- Burning or itching around the vagina
- Pain deep inside the vagina during intercourse

Women and Men

- Abnormal discharge from penis or vagina
- A burning sensation during urination
- Sores, bumps, or blisters near mouth, rectum, or genitals
- Flulike feelings
- Redness and swelling in the throat
- Swelling in the groin area

Linroth 2019

Promote Positive Adjustment

- Level of knowledge about sexuality
- Openness and communication with partner
- Self-esteem

Disability and Illness: SCI 5/04/2005; Linroth 2019

- Assessment of sexual function should be included in transition care for adolescents and routine care for adults with SB
- Open, frank conversations without parents/family present
    - -Focused questions and dedicated listening time
    - -Nonjudgmental attitude
    - -Should follow patient's cues, concerns
- Consults to adolescent medicine, urology, psychology, therapists as needed

Weiner 2019

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