

SURVIVING PUBERTY WITH TEENS WHO HAVE AUTISM OR INTELLECTUAL DISABILITY

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THERE'S GOOD NEWS, AND THERE'S BAD NEWS...

BAD NEWS...

Puberty can be a tough time

GOOD NEWS...

Puberty is time-limited

PUBERTY IS NOT FOR THE FAINT OF HEART...

- Physiological and emotional changes can be confusing for typical teens, and even more so for teens with IDD/ASD
 - Try to remember what it was like for YOU to be a teenager!
- For example, it is important to consider the diagnostic criteria for Autism Spectrum Disorder and how these characteristics may impact adolescence such as:
 - Qualitative Impairments in Social Skills
 - Qualitative Impairments in Communication
 - Ritualistic, repetitive behaviors or areas of interest

Warning: I will be discussing some topics some may find embarrassing. Try to stay open minded and objective!

INDIVIDUALIZED APPROACH

- Each family needs to address certain areas of puberty (e.g., sexual development, relationships) according to their own set of beliefs and values
- Need for honest discussions between parents and support team ahead of time to make sure that everyone is on the same page





PUBERTY VERSUS ADOLESCENCE

- *Puberty*: Physiological changes which allow an individual to be sexual and reproduce
- *Adolescence*: Emotional and social transition from childhood to adulthood

A DISJOINTED PATTERN OF DEVELOPMENT

- Physiological changes occur during puberty regardless of the presence of IDD/ASD
- A teen's cognitive or social abilities are often "behind" the timeline for body changes

Therefore, many individuals with IDD/ASD show delays in social and emotional maturity although the physiological signs of puberty are occurring within typical age range

GENERAL COMMENTS/QUESTIONS

- It is natural to feel uncomfortable talking about some of these topics:

TRY TO STAY OBJECTIVE

- Who should teach the individual?
 - Professional staff versus parents, or both?
- Need to gauge your approach to match the teenager's cognitive and communication levels
- Need to make sure that your own embarrassment/discomfort doesn't negatively impact teaching or communicating
- Tendency for children with IDD/ASD to think literally
 - Therefore, descriptions and expectations need to be objective and clear rather than using "euphemisms"



IS THIS JUST TYPICAL TEEN BEHAVIOR?

- Separating “typical teen behavior”
- Typical adolescents shows a wide range of responses linked to puberty, reacting to the demands of adolescence, etc.
- Sometimes the *behaviors* may be typical for all teens, but the *intensity or manifestation* may be different for teens with IDD/ASD



START EARLY...

Typically puberty begins around age 12 for males and 11 for girls, but should start at an earlier age in terms of:

- Teaching privacy
- Modeling (e.g., appropriate hygiene behavior)
- Use the correct language for body parts and body functions
- Talking about how everyone's body changes as they grow older
 - Do not want the "tween" with IDD/ASD to be caught off guard when faced with...
 - Menses
 - Spontaneous erections and "wet dreams"

HOW TO TEACH MORE ADEPT TEENS ABOUT PUBERTY

- Open discussions, providing rationales, watching movies/pausing/pointing out behaviors linked to puberty, etc.
- Videos on various websites showing a wide range of skills:
 - [Role Play Videos | Semel Institute for Neuroscience and Human Behavior \(ucla.edu\)](#)
 - [Amaze.org/educators/toolkits](#)

HOW TO TEACH LESS ADEPT TEENS

- In addition to verbal explanations, you may need to use visual supports such as visual schedules, model, videomodeling, Power Cards, Social Stories, puberty-related simple books and videos, accurate drawings that show body changes, Amazing 5 Point Scale, roleplaying, etc.
 - Examples will be included throughout this presentation
- May also need to implement a tangible reward systems for when teen displays appropriate behaviors, even though this may not seem “age appropriate”

HELPING TEENS THROUGH PUBERTY



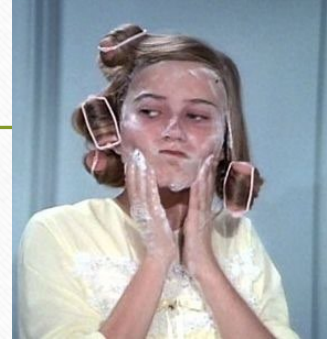
HYGIENE



- Helping the tween or teenager to understand that bathing needs to be more frequent as puberty begins
 - Issues of sensory aversion to showers often seen in children with ASD
- Teenagers with IDD/ASD often are unaware of/don't care about social expectations regarding body odor
- May need to establish new “rules” rather than rely upon the teenager with IDD/ASD to spontaneously attend to hygiene
- Need to balance privacy and increased bathing requirements (all the more important to teach effective washing when the child is young)

MARCIA BRADY KNOWS HOW TO TAKE GOOD CARE OF HERSELF

Marcia remembers to wash up every day



Marcia makes sure her clothes are clean



Marcia picks out her clothes and gets dressed by herself



HAIR GROWTH

- Giving a heads up about increased hair growth on various parts of the body
- SHAVING FACE OR LEGS
 - Safety issues (use electric shavers)
 - Mechanical sounds or tactile input of shaving may be aversive
 - Use of depilatory creams (e.g., “Nair”)

BREAST GROWTH

Baby Show



- Wearing a bra
- Sensory issues
- May need to start early with “training bras” to help desensitize the feeling of wearing a bra
- Increased breast growth usually occurs about one year before menstruation, which allows parents to have a “ballpark” idea of when to bring up the subject

MENSTRUATION

- Early discussions with female “tweens”
- Pads versus tampons
 - Can consider using specialized underwear for menstrual pads
- Cramps
 - Many teens with IDD/ASD have difficulty describing physical pain since it is abstract
 - Using a visual support (e.g., “Incredible 5 Point Scale”) to measure level of pain
 - May want to use over the counter medications on a preventative basis

CHECK IN



OUCH! THIS REALLY HURTS!

I NEED TO LIE DOWN AND REST RIGHT NOW

I REALLY DON'T FEEL SO GOOD

MY STOMACH IS STARTING TO HURT A BIT

NO PAIN! I FEEL GREAT!

MENSTRUATION (Cont.)

- Signs of PMS and possible interventions
 - Teaching the adolescent girl to understand that her emotions are linked to hormones rather than to the environment.
- Birth control?
 - To protect the teenage girl with IDD/ASD
 - Limits number of menses per year

Sample Video Regarding Menstruation

- <https://www.youtube.com/watch?v=RX4NJrJxwss>

TEACHING PUBLIC VERSUS PRIVATE BEHAVIORS

- Dressing/Undressing
 - Who can see “private body parts” (others’ body parts as well as the child’s)
- Especially difficult to teach if the teenager still requires others’ assistance to complete activities of daily living (e.g., toileting, dressing)
- Private behaviors could include...
 - Picking your nose
 - Scratching private body parts
 - Talking about private parts



MASTURBATION

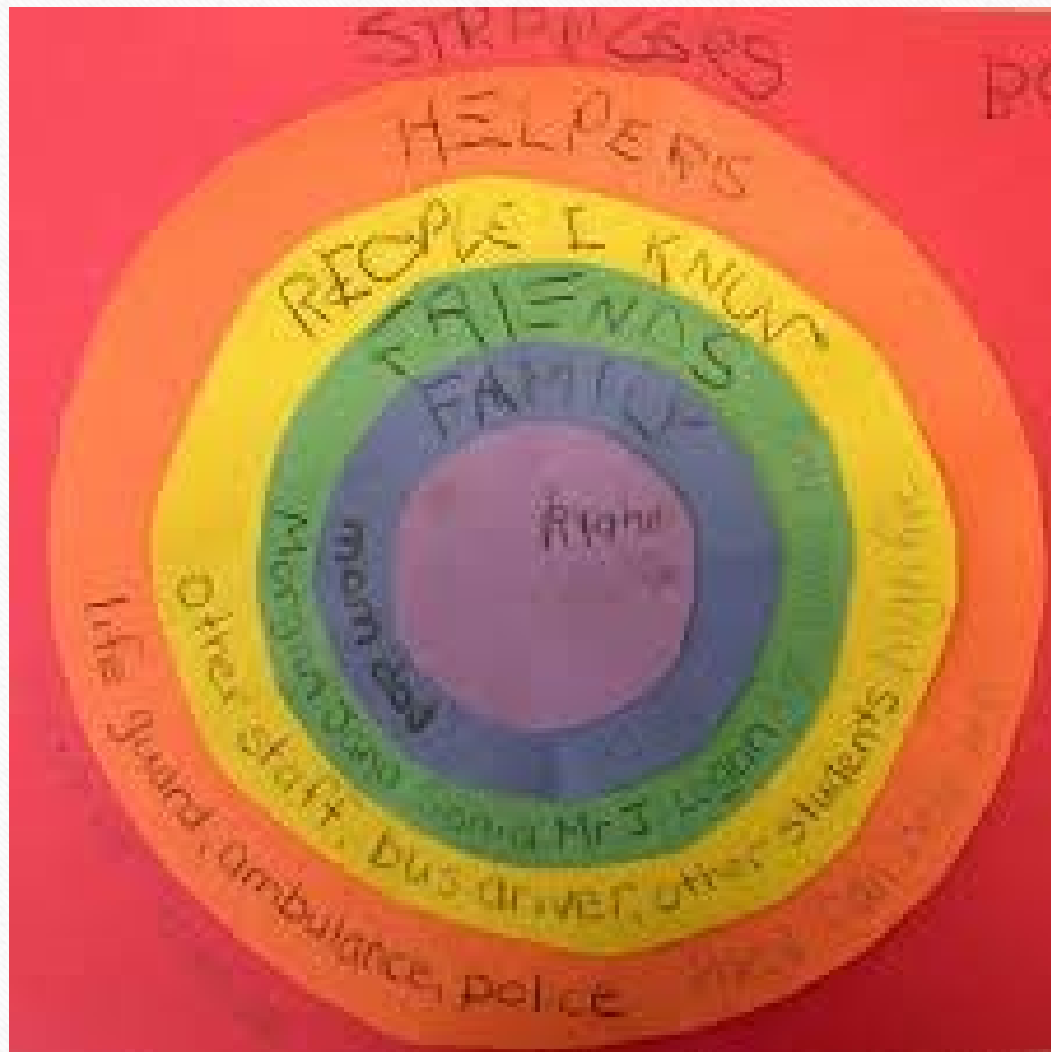
- This is a natural inclination for all teenagers, so do not try to prohibit the behavior altogether
- Need to teach “where” and “when” it is appropriate to masturbate
 - In your bedroom or bathroom with the door shut
 - NEVER outside of the home





FAMILIAR VERSUS UNFAMILIAR PEOPLE

- “Circles Program” to teach appropriate behaviors across different levels of familiarity
 - Can individualize according to teen’s passions (e.g., train visual)
- Need to operationally define a “stranger” in clear, consistent fashion
 - Can’t just give simple explanations such as “Strangers are people who you don’t know their name”
- List behaviors which are appropriate/not appropriate dependent upon level of relationship
 - Touching/hugging/kissing
 - Private versus public information to share





INTENSE EMOTIONS

- Need to explain to the teenager that this is due to hormonal changes in their bodies
- Increased possibility of frustration, stress, anger
- Dealing with possibility of challenging behaviors such as physical aggression, “meltdowns” due to emotional lability
 - Teenager is now bigger and stronger (and therefore behaviors possibly more dangerous)
 - Considering safe physical intervention techniques (e.g., restraints) if behavior is truly dangerous to self or others

INTENSE EMOTIONS (Cont.)

- Need to implement antecedental, proactive strategies (e.g., teach coping skills, identify initial signs of emotional escalation and redirect, promote communication, etc.)
- May need to implement more tangible reward systems even though it may not seem “age appropriate”
- Possibility of medication, counseling, etc.



AMAZE Video About Mood Swings

- Amaze.org/video/educators
 - Scroll down to multicolored topics list
 - Click on Puberty
 - Select “Teen Angst” from list of topics

The Power Rangers know that it is important to **STAY SAFE** and **CALM**



The Power Rangers say “okay” when someone says “no”!

The Power Rangers know how to wait patiently!

The Power Rangers follow the rules every day!

The Power Rangers stay calm when something doesn’t go their way.

THAT’S BECAUSE THE POWER RANGERS ARE AWESOME!

CONCERNS REGARDING SEXUAL ABUSE

- Balance between understandable concerns and being over protective
- Especially important for children who are nonverbal or minimally verbal
- Defining different parts of the body as “ok to be touched” versus “not okay to be touched”
- Teaching child what to do if someone begins to touch them inappropriately
 - Can roleplay what he/she can do (e.g., shouting, “NO!” and leaving immediately)
- Teaching teens what they should do if they are the victims of abuse
- May need to subtly look for any physical signs of abuse
- What to do if child tells you he/she has been abused

INTERNET USE



- Many teenagers with IDD/ASD are drawn to the computer
- Need for setting up parental controls
 - Even “benign” searches may inadvertently identify dangerous websites
- Communicating with strangers on the Internet
- Teaching what type of personal information should/should not be shared
- Possibility of misinterpretation of social connections, cyberbullying, identity theft
- Establish concrete, consistent rules about using the Internet and monitor how well the teen follows these rules

RESOURCES REGARDING SAFE INTERNET USE

- **Online Safety for Children and Teens on the Autism Spectrum: A Parent's and Carer's Guide by Nicola Lonie**
- **Online safety for young people with intellectual disability report.pdf** (By Esafety Research)
- **<https://www.autismspecialtygroup.com/blog/autism-and-the-internet>**
- **<https://autismspectrumnews.org/technology-safety-guide-for-parents-of-children-with-autism/>**
- **Keep Youth with IDD Safe Online (hhs.gov)**

PROMOTING INDEPENDENCE



- Becoming a young adult means increased independence
- Balancing independence with safety can be difficult, especially for parents
- Use various strategies to allow increased independence while promoting safety
 - Identification (in wallet, shoe tags, bracelets, etc.)
 - Ways to track the adolescent's location
 - Can meet with local First Responders ahead of time to inform them
- Financial planning for the teen's independence as enters adulthood



FRIENDSHIPS

- What constitutes being a “friend”
- Telling the difference between affectionate teasing versus bullying
- Recognizing when the teen with IDD/ASD is being “set up” or exploited
- Balancing the wish to protect the teen with IDD/ASD from their peers and allowing for some genuine disappointments as learning lessons. (Teaching assertiveness skills.)
- Don’t assume that the teen will blossom into a social butterfly. The general population reflects a wide range of interest in social activities.
- Capitalize on the teen’s “passions” (e.g., anime, videogames, etc.) as a way of developing friendships (e.g., structured groups and activities linked to the teen’s area of interest)

ROMANTIC RELATIONSHIPS

- Teenager romance is difficult for everyone!
- Helping the teen with IDD/ASD
 - Understand dating norms
 - When/how to ask someone out on a date
 - How to act on the date
 - Accepting rejection
 - Identifying the true intensity of a romantic relationship
 - Learn to navigate sexual behaviors and urges
 - How to respond to peer pressure



UNDERSTANDING SUBTLE SOCIAL CUES TO GAUGE INTEREST

- Making eye contact
- Initiating an interaction
- Smiling
- Complimenting you
- Leaning towards you
- Laughing at your jokes
- Continuing the interaction
- Not making eye contact
- Flat, unhappy, frustrated or angry facial expression
- Not answering when you talk to them
- Walking away
- Laughing *at* you rather than *with* you

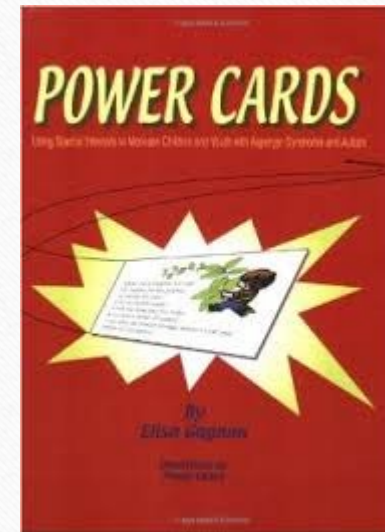
(Puberty and Autism Fact Sheet at Autism Speaks website)

TEACHING SELF-AWARENESS

- Need to help the teen with IDD/ASD have as clear an understanding as possible about their own strengths, abilities, and uniqueness
- Autistic Self-Advocacy Network
 - “Nothing about us without us”
 - Website: <http://autisticadvocacy.org/>

USE OF VISUAL SUPPORTS

- May need to use visual supports such as create visual schedules, model, Videomodeling, Power Cards, Social Stories, “Puberty” books and videos, etc.
- Pictures of body changes
 - <http://kc.vanderbilt.edu/healthybodies/>



Video for Adolescents with High Functioning ASD

- <https://www.youtube.com/watch?v=tVnYASiEY34>

YOU MAY NEED TO TEACH WHAT SEEMS “OBVIOUS”

- Don't assume that the teenager with IDD/ASD will pick up on social cues, subtle descriptions of explanations, the need to learn from observing others, etc.
- Better too clear than not clear enough
- Being a “Social Detective”



THINKING AHEAD...

TRANSITIONING INTO ADULTHOOD

- Goals and expectations need to be talked about early and often
- Modify as needed: Nothing is written in stone
- Need to create a “transition team” composed of people who know the teenager (home, school, community members)
- Educational requirements mandate that these discussions begin at age 14
- Where will the young adult with IDD/ASD live?
- Post secondary education?
- Vocational goals?

ISSUES WHICH MAY ARISE WHEN PLANNING THE FUTURE

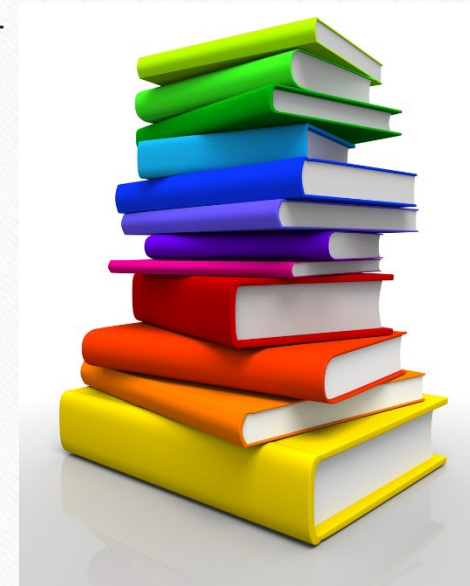
- What if the teenager has “unrealistic” expectations?
- Decreased funding when teenager leaves educational system
- Tendency for individuals with IDD/ASD to find change and transitions difficult
- Parents expecting less than receptive siblings to become guardians



KEEP
CALM
AND
MAKE
PLANS

RESOURCES

- Autism Speaks' "Puberty and Adolescence Resource (P.A.R.) Booklet" (See: <https://www.autismspeaks.org/sites/default/files/2018-08/Puberty%20and%20Adolescence%20Resource.pdf>)
- Puberty and Adolescent Fact Sheet from AMAZE
- Many books, videos and websites available (see list)



FINAL COMMENTS

- Remember, puberty and adolescence are time limited experiences
- Increased independence and growing up can actually be a very good thing
- Remember the need to teach rather than assume skills will occur naturally
- Remain honest, objective and proactive and you will all survive!

