

Sexuality and Autism Spectrum Disorder

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Based on the work of many Autism Specialists at
The TEACCH Autism Program



Curriculum Areas for Children and Concrete learners

- ▶ Social Rules and Safety
- ▶ Body changes during puberty
- ▶ Masturbation
- ▶ Interpersonal issues

Sexuality

- ▶ Historically importance debated, but not anymore
- ▶ Limited data yet, recent research shows that most individuals with autism engage in sexual activity and/or show sexual interest

Sexual Behaviors in Individuals with Autism and Intellectual Disabilities

- ▶ Parent reports of concerns
 - ▶ Inappropriate touching or talking about sex in public
 - ▶ Having their behaviors be misinterpreted
 - ▶ Being victimized by others

Sexual Behaviors in Individuals with Autism and Intellectual Disabilities

- ▶ Caregiver reports and direct interviews:
 - ▶ Haracopos & Pederson (1992) Denmark
 - ▶ Van Bourgondien, Reichle, & Palmer (1997) North Carolina
 - ▶ Konstanareus & Lunsky, 1997

Sexual Behavior in Individuals with ASD and ID

- ▶ Masturbation occurs in majority of individuals with males greater than females. Most achieve orgasm.
- ▶ Erotic stimuli may include objects
- ▶ Great variability in person oriented sexual behaviors (~ 1/3) from kissing and caressing to sexual intercourse

Sexuality education should be proactive and direct

Griffiths, (1999) notes that most learners with a developmental disability receive sexual education only after having engaged in sexual behavior that is considered inappropriate, offensive or potentially dangerous. This may be considered somewhat akin to closing the barn door after the horse has run.

Sexuality is part of every person's life, no matter what the age

► Preschool Children

"How did I get in your tummy?"

"Where was I before I got in your tummy?"

"How did I get out?"

"Where do babies come from?"

"How come girls don't have a penis?"

► School-age Children

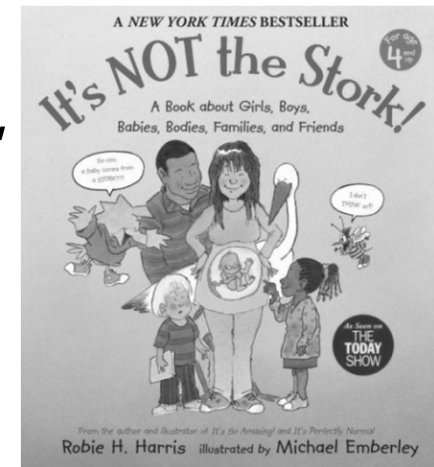
"How old do girls have to be before they can have a baby?"

"Why do boys get erections?"

"What is a period?"

"How do people have sexual intercourse?"

"Why do some men like other men?"



ASD and Parent Concerns: Similarities

- ▶ Generally anxiety over when's the right time
- ▶ Difficulty with managing own personal discomfort with topics
- ▶ Fears that sexuality education may lead to:
 - ▶ ↑ adolescent sex
 - ▶ ↑ premarital sex
 - ▶ ↑ unsafe sex

ASD and Parent Concerns: Differences

- ▶ Other curriculum areas may have higher priority (Still working on...)
- ▶ Overwhelmed by how to discuss and teach in concrete, detailed, & visual manner
- ▶ Difficulty with accessing information and relevant teaching materials
- ▶ More challenges with understanding social, emotional, & interpersonal level

ASD: Top 5 Parent Concerns

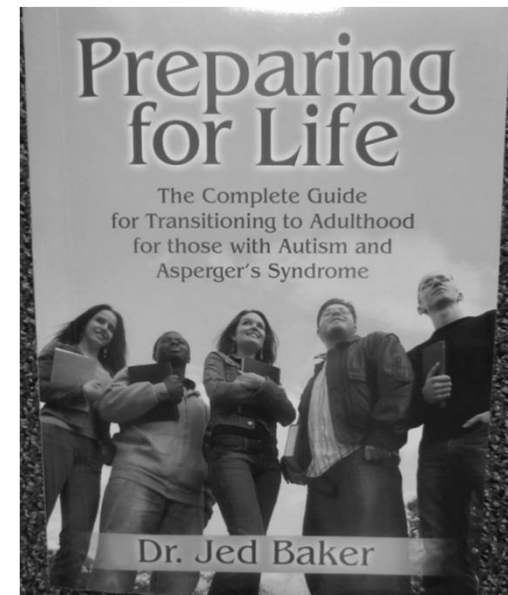
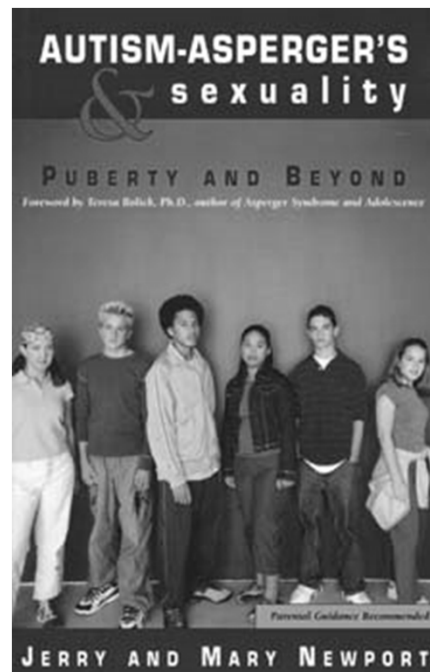
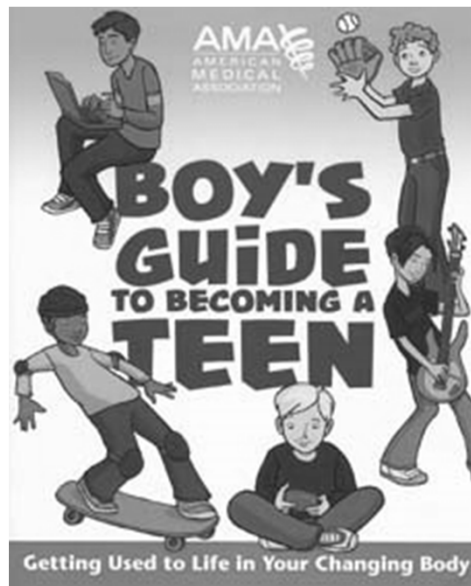
- ▶ Sexual interest without solid foundation
- ▶ Knowledge about topics of sex from pop culture
- ▶ Imitation of inappropriate social behaviors
- ▶ Sexual harassment charges from others (People and/or object obsessions)
- ▶ Potential target of sexual abuse



Social expectations change over time

- ▶ Likes kissing babies
- ▶ **3 years old** - really cute
 - ▶ Kisses strangers' babies; both parents find adorable
- ▶ **7 years old** - maybe cute; possibly not
 - ▶ Mother tries to get him to ask other parent' s
 - ▶ permission before kissing
- ▶ **10 years old** - concerning, annoyed, rude
 - ▶ Other parents are uncomfortable; may address with you or others
- ▶ **12 years old** - possibly illegal
- ▶ Where is he touching child? What intent may be INFERRED? Indecent liberties between children?
- ▶ **16 years old** - taking indecent liberties with a child?

Treatment/Educational Approaches to Sexuality



Values

What should we teach?

- ▶ Family values
- ▶ Societal values
- ▶ Religious values
- ▶ Individual perspective

SURVEY RESULTS: PROFESSIONALS (US/SWE/CAN/ENG/GER (N=340))

Behavior	Yes
Engage in Masturbation	253
Teach to masturbate	174
Engage in Fondling or Kissing	172
Sexual Interests in Objects	132
Sexual Interests in Photographs of People	215
Sexual Interests in Body Parts	138
Sexual Interests in Someone	240
Dating	196
Marriage	141
Intercourse	147
Have a Child	77

SURVEY RESULTS: PARENTS US/SWE/CAN/GER (N=83)

Behavior	Yes
Engage in Masturbation	62
Teach to masturbate	26
Engage in Fondling or Kissing	42
Sexual Interests in Objects	12
Sexual Interests in Photographs of People	41
Sexual Interests in Body Parts	27
Sexual Interests in Someone	61
Dating	55
Marriage	51
Intercourse	52
Have a Child	31

Intimate Relationship Meets Complex Needs

- ▶ Physical pleasure seeking
- ▶ Tension release
- ▶ Social contact/caring relationship

Adolescents and Concrete Learners and Sexuality

Assessment

- ▶ What does learner know or understand?
- ▶ Is there a "concern" or "problem"?
- ▶ Whose problem is it?
- ▶ How do all parties view the concern?
- ▶ What vocabulary is used to describe the concerns, body parts, sexual activities?
- ▶ Data records

CHARTING BEHAVIORS

Participant: _____				“Private Time” Data	
Date	# of Episodes	Where Happened	Any Associated Stimulus	Average Duration	Comments/Initials

Confidentiality/ Rights Protection

- ▶ Guardian
- ▶ Individual with autism
- ▶ Caregivers

Curriculum Areas for Children and Concrete learners

- ▶ Social Rules and Safety
 - ▶ Modesty
 - ▶ Physical Space
 - ▶ Privacy

Innocent Behaviors

Potential problems

Inappropriate Behavior

- ▶ *Problem is not that student is doing **WRONG** thing.*
- ▶ *Problem is that student doesn't know what is **RIGHT** thing to do.*



Potential Safety Issues

- ▶ Limited understanding of personal space
- ▶ Touching self
- ▶ Touching others
- ▶ Poor dressing skills
- ▶ Pulling down pants, pulling up dress or pulling up shirt
- ▶ Poor sequencing skills
- ▶ Taking off clothing at home
- ▶ Taking off clothing when upset
- ▶ No awareness of unwritten social rules
- ▶ Not understanding private topics versus public topics
- ▶ No concept of strangers
- ▶ Interest in other peoples clothing, hair, glasses, or body parts

Good Space

Bad Space

Proactive Teaching

Teaching work skills:
Keep hands busy

Redirect to activity

Identify Issues Early

6 years old

14 years old

Think Visually

Not good sitting

Good sitting

Teach Concepts

Concrete Sorting Activities

Picture Stories with Words

Teaching Safe Toileting Skills

1. Teach skills starting with toddlers
2. Monitor independent toileting
3. Coach parents to teach and maintain skills
4. Teach concrete skills – good habits versus sophisticated concepts
5. Some skills to teach
 - Keeping your clothing on
 - Where to pull down pants
 - Locking the door
 - Selecting the stall versus the urinal
 - Learning to manage clothing for urinal

Teach Skills

Use pictures & simple
language


Teach a routine

Easy Visual Rules


Teach Manners

Where to Look

Urinals in Men's rooms are side by side.



Boys and men follow rules for privacy.
When men and boys use the urinal they
look at the wall or the pipes



Or they look at the urinal to aim.
It is not good manners to look at another
man or boy when they are at the urinal.

Post Rules as Reminders



- Urinal Rules**
1. Use your fly
 2. Look straight ahead
 3. Watch your aim
 4. No talking
 5. Finish quickly and leave

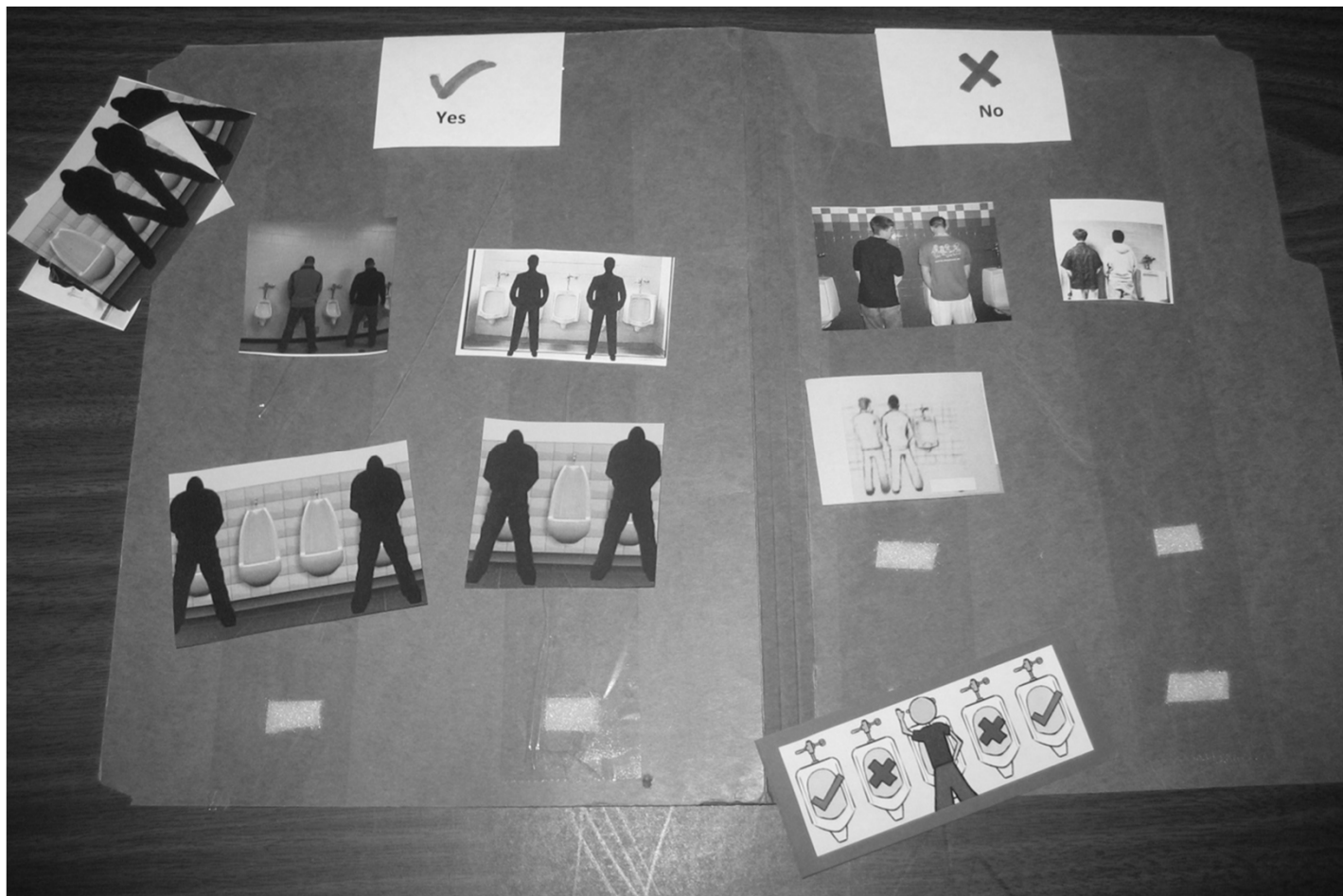
Portable Reminders to Generalize



Use Visual Reminders



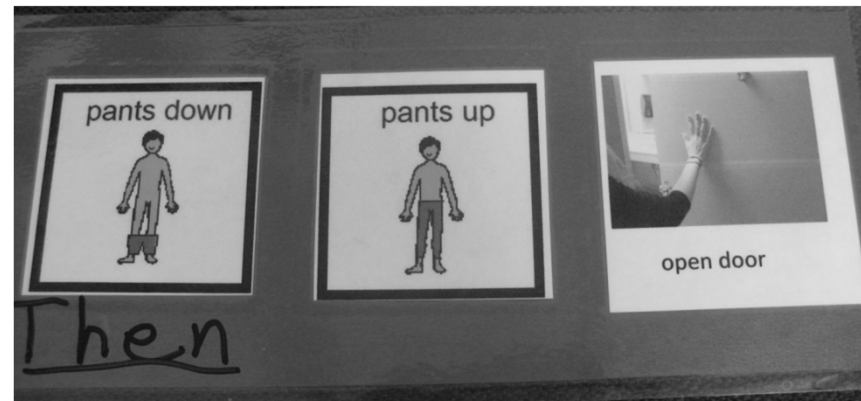
Make Activities to Practice



Clarify the Concept

Easy to use

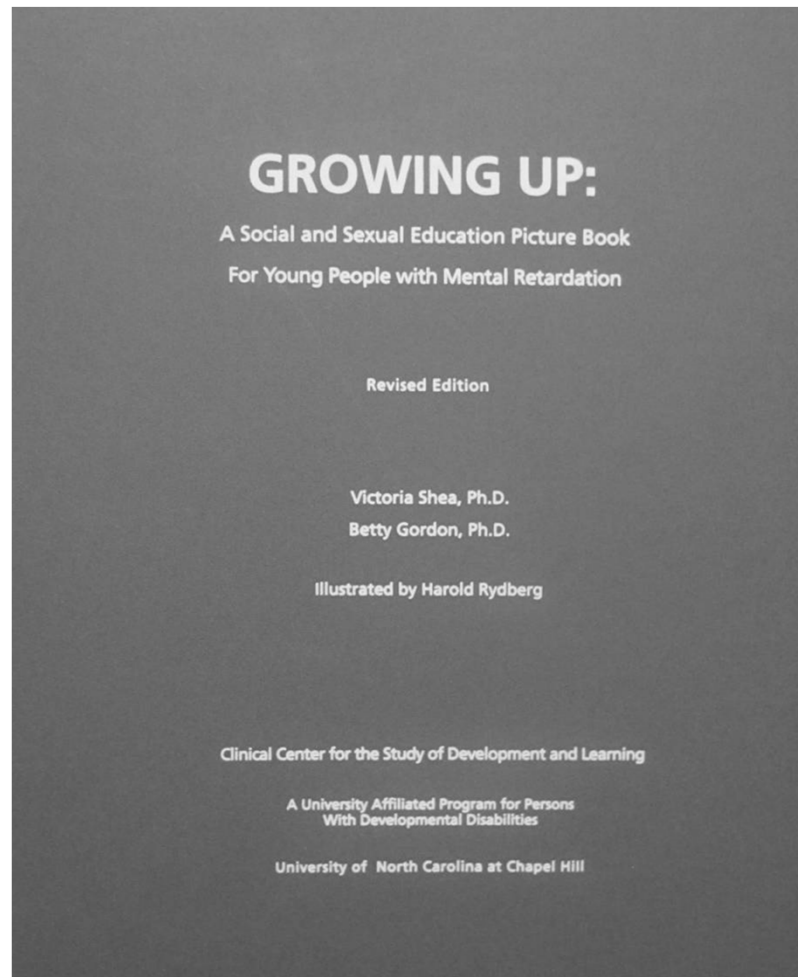
Simple Sequence In
Pictures



Curriculum Areas for Adolescents and Concrete learners

- ▶ Social Rules and Safety
 - ▶ Modesty
 - ▶ Physical Space
 - ▶ Privacy
- ▶ Body changes during puberty
 - ▶ Know your body and the names of body parts

Teaching about Your Body



Differences Between Sexes

Changes in Puberty

New Hygiene Routines

Sexual Health

- ▶ Daily hygiene
- ▶ Monthly Testicular self checks
- ▶ Monthly Breast self exam
- ▶ Annual Physicals for males and females
- ▶ Rashes, Pain, Discharge
- ▶ Medications with sexual side effects

Having Your Period

Menstruation

- ▶ Keep a calendar and wear a pad prior to expected menses
- ▶ Practice wearing pads and tampons of differing sizes and styles to find some that are comfortable
- ▶ Use a schedule for changing rather than judgment
- ▶ Keep a supply of hygiene gear at school or work
- ▶ Consider continuous hormonal treatment

Awakening Sexuality

Spontaneous Erections

- ▶ Sit down or stay seated if possible
- ▶ Wait for it to pass while thinking of something else (usually something negative)
 - ▶ Have a plan for what to think about
- ▶ Cover area with book or jacket as walking
- ▶ Wear closer fitting underwear and looser pants

Curriculum Areas for Adolescents and Concrete learners

- ▶ Social Rules and Safety
- ▶ Body Changes during puberty
- ▶ Masturbation
 - ▶ Where and When TO masturbate
 - ▶ Where and when NOT TO masturbate
 - ▶ What to call masturbation
 - ▶ How to start and stop masturbation session
 - ▶ Cleaning up
 - ▶ And?

Masturbation

Researcher Laumann, Gagnon, Michael, and Michaels (1994) studied reasons why people masturbate.

- ▶ For relaxation
- ▶ For relief of sexual tension
- ▶ Because a partner is not available or does not want sex
- ▶ For physical pleasure
- ▶ To help them fall asleep
- ▶ To avoid sexually transmitted infections

Masturbation

- ▶ Most common concerns
 - ▶ Unable to masturbate properly
 - ▶ Frequency or length of masturbation
 - ▶ Inappropriate locations
 - ▶ Inappropriate objects or other means to masturbate
 - ▶ Becomes frustrated or aggressive during or after
 - ▶ Masturbates to point of self-injury

(Cambridge, Carnaby and McCarthy, 2003, Walsh 2000)

Teaching Privacy and Safety

- Where and when to masturbate?



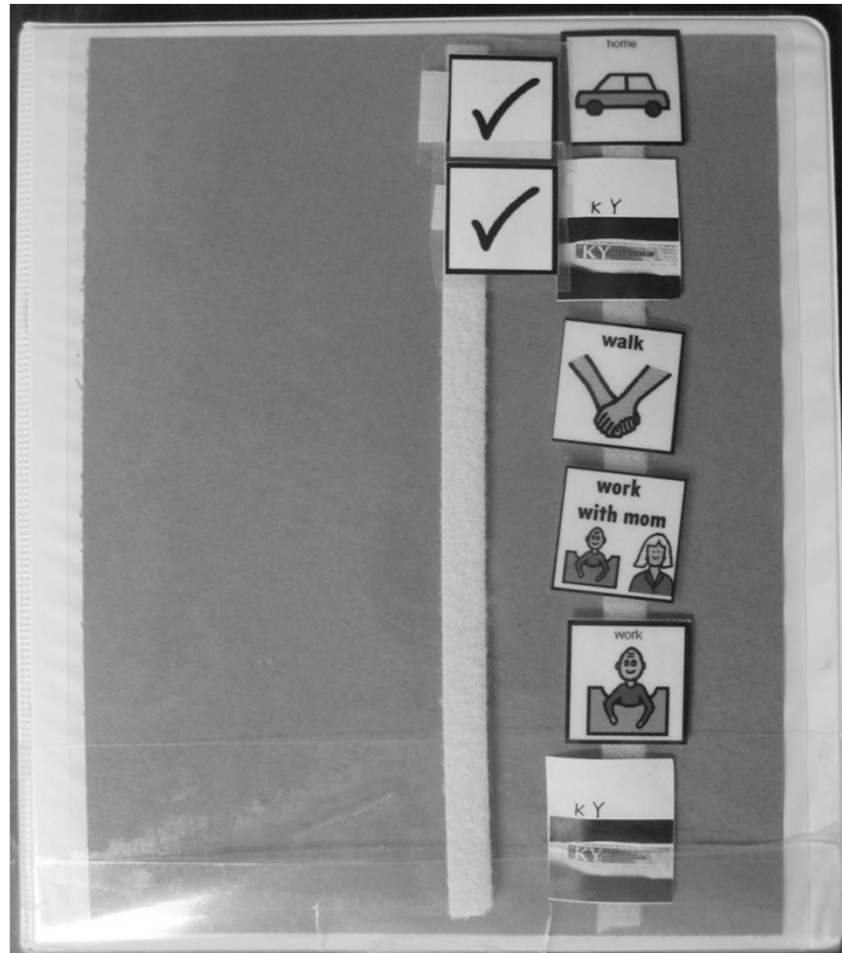
Where and When

► In the Toilet?

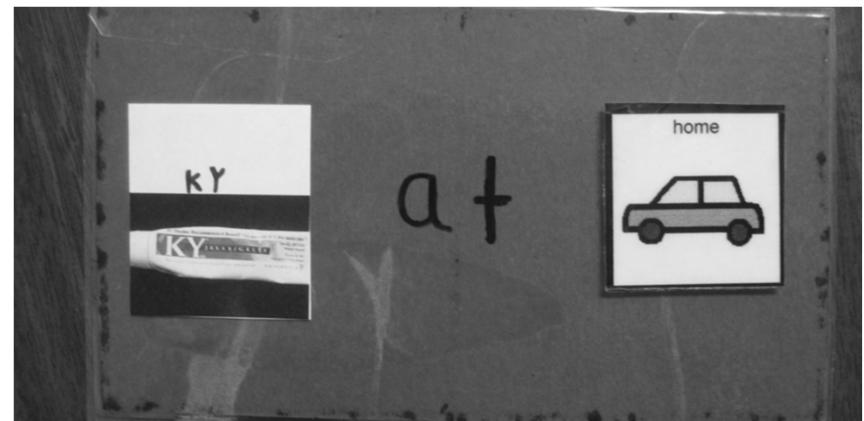
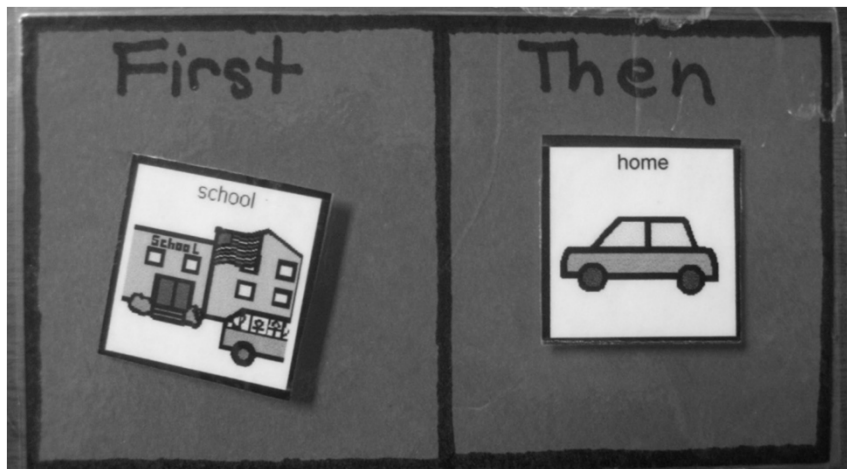
- Needs of others
- Is it OK at school?
- Public toilets?
- Poor choice



Use Schedule



Management at School



Teaching Privacy and Safety

- ▶ Where and when to masturbate?
- ▶ Where and when not to masturbate?
- ▶ What to use to masturbate?



Teaching Privacy and Safety

- ▶ Where and when to masturbate?
- ▶ Where and when not to touch/masturbate?
- ▶ What to use to masturbate?

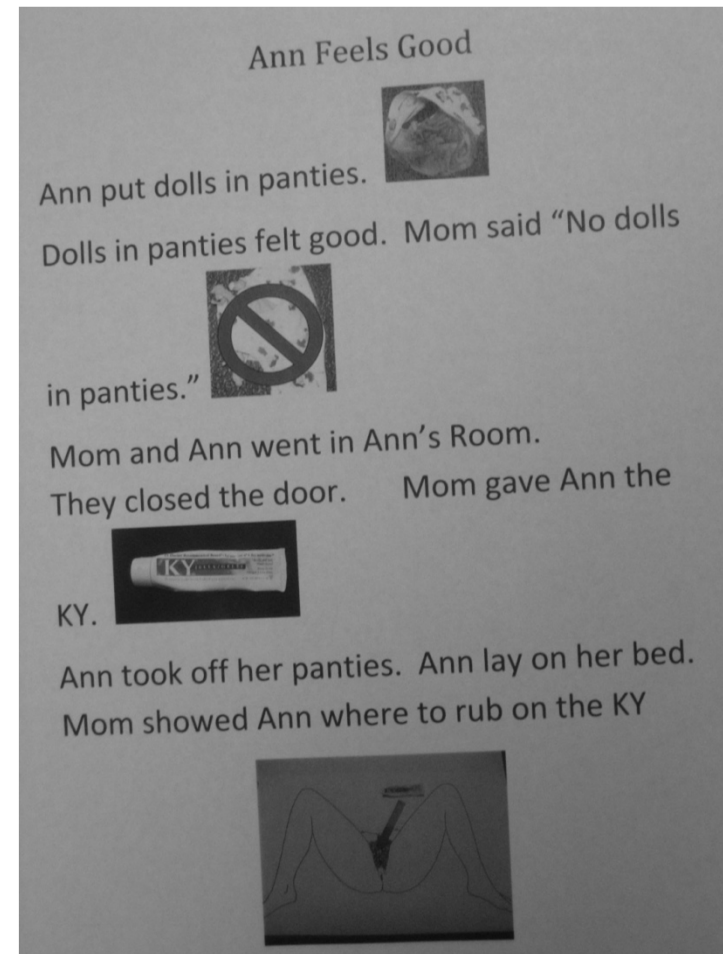
- ▶ What to call masturbation?
 - ▶ Feeling good time
 - ▶ Ky time
 - ▶ Ann's time
 - ▶ Private time

Sexual Skills Training

- ▶ Who does the teaching?
- ▶ How to teach?
 - ▶ use of vibrators, lubricants
 - ▶ picture sequences
 - ▶ picture/written manuals
 - ▶ videos
 - ▶ discussions

Teach Skills

- ▶ Give a unique name
- ▶ Need visual reminders
 - ▶ Where to keep



Masturbation

- ▶ Inappropriate locations or times
 - ▶ Proper underwear and pants
 - ▶ Sorting activities
 - ▶ Engaging, preferential, two handed activities
 - ▶ Redirection to appropriate location and time
 - ▶ Visual reminders of appropriate location and time
- ▶ Frequency
 - ▶ Schedule
 - ▶ Satisfaction
 - ▶ Rich activity selection
 - ▶ Exercise

Masturbation

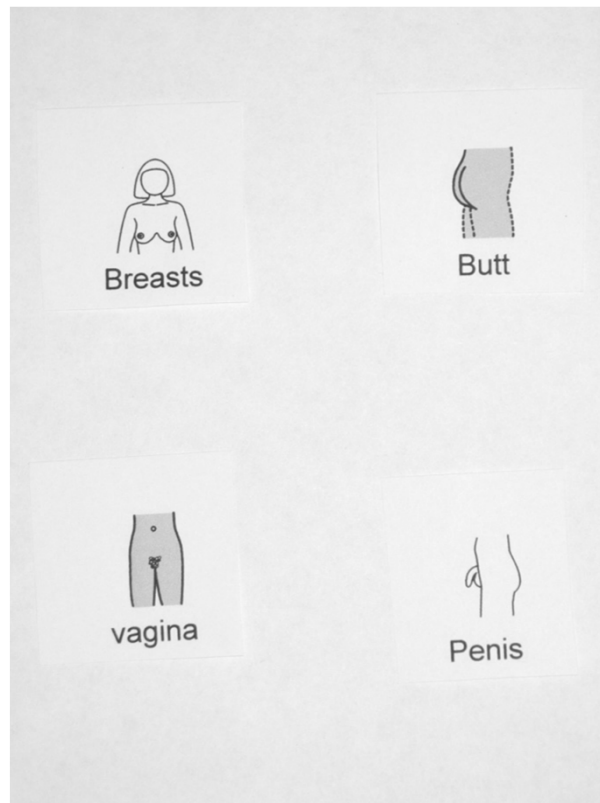
- ▶ Inappropriate materials or techniques
 - ▶ Sorting activities
 - ▶ Provide appropriate materials
 - ▶ Visual sequence
 - ▶ Activity system for masturbation
 - ▶ Redirection to appropriate materials
 - ▶ Visual reminders of appropriate materials

Interpersonal Issues

- ▶ Public versus private body parts, activities, places

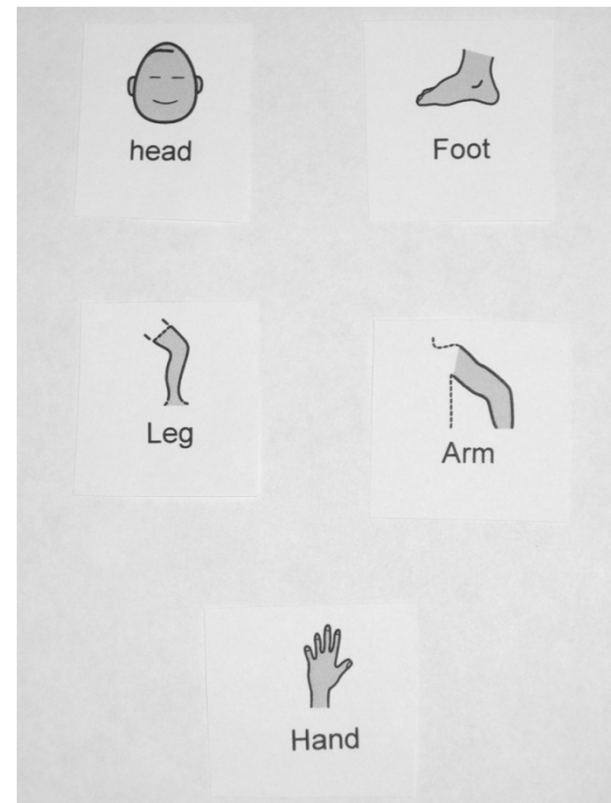
Private

Do not show others

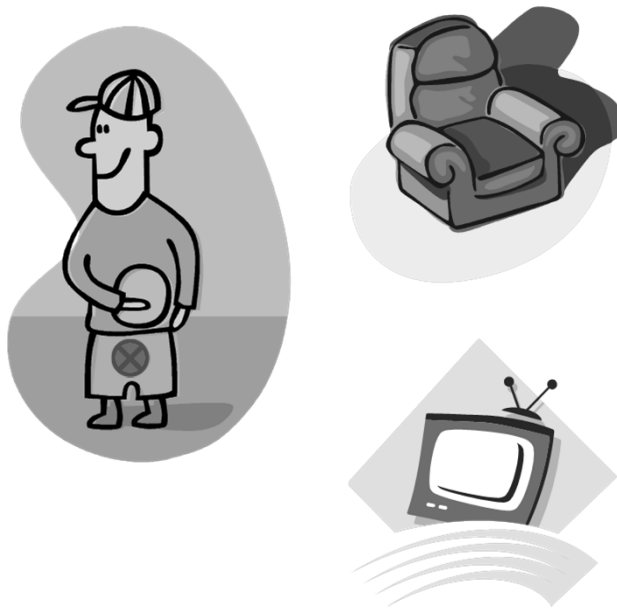


Public

Others can see

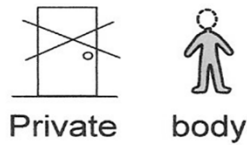


Public Area
Living Room
No Touching Penis

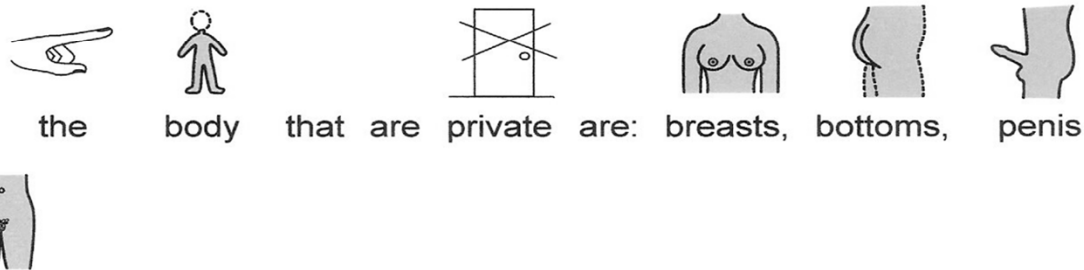


Private Area
Bathroom
Can Touching Penis





Everyone has parts of their body that are private.



and vaginas.

No one can touch your privates except your parents and doctors.

You cannot touch anyone in their private area.

It is against the law. You will get in trouble.

Two parts of a boy body that are PRIVATE

- 1) Penis
- 2) Butt

Three parts on a girl body that are PRIVATE

- 1) Breast
- 2) Genitalia
- 3) Bottom or Buttocks

Body Parts

Public	Private
<ol style="list-style-type: none">1. Eyes2. Nose3. Mouth4. Ears5. Legs and Arms6. Hands and Feet	<ol style="list-style-type: none">1. Penis2. Bottom/Butt3. Underwear4. Breast
<p><i>Who can see these?</i></p> <ol style="list-style-type: none">1. Friends2. Anybody else	<p><i>Who can see these?</i></p> <ol style="list-style-type: none">1. Doctor2. Mom, Dad and Brothers
	<p><i>What do you do if someone other than your doctor, mom, brothers or dad touches your private parts?</i></p> <p>Tell them to stop and go tell mom, dad or brothers</p>

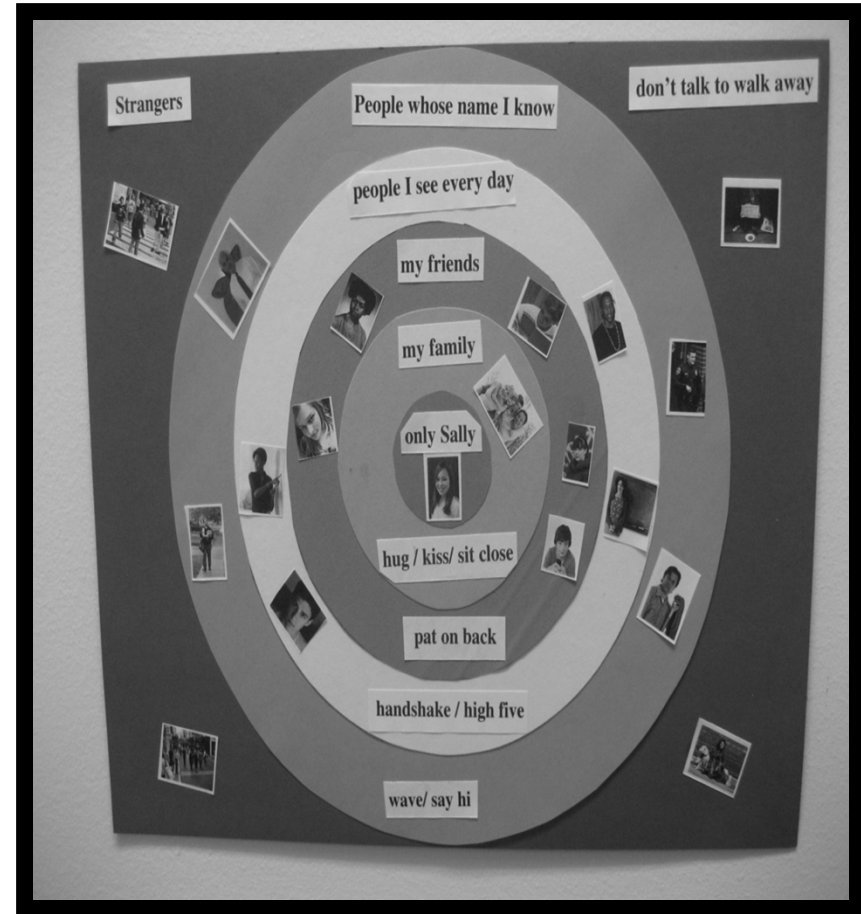
Interpersonal Issues

- ▶ Public versus private body parts, activities, places
- ▶ Strangers versus not strangers/friends

Teaching Concept of Stranger



Circles Curriculum

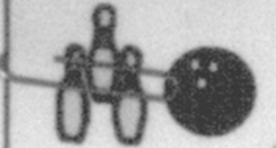


- ▶ Adapted from Circles Curriculum; Dr James Stanfield
- ▶ <http://www.stanfield.com>


Interpersonal Issues

- ▶ Public versus private body parts, activities, places
- ▶ Strangers versus not strangers/friends
- ▶ Appropriate touches/looks/approaches

bowling




Wendy, size 7




Wendy's Rules

Shake hands



Shake hands to greet other

Hands on lap




Keep hands on other leg!

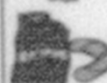
Ask to see other's things

Earn


Yes No




chips




pretzel




cookies




Chips/ Salsa



ginger ale



soda



Show CARD

Show card

EARN

☒

Schedule

Robbie's choices
for GOOD Outings

NO BAD TOUCHING
STAFF OR
STRANGERS

BAG OF chips

Piece of Candy



Interpersonal Issues

- ▶ Public versus private body parts, activities, places
- ▶ Strangers versus not strangers/friends
- ▶ Appropriate touches/looks/approaches
- ▶ Special Interests - seams, body parts, children
- ▶ Vulnerability to suggestions and advances from others

SAYING “NO”

- ▶ Increase person’s own sense of their body vs other’s bodies
 - ▶ Don’t hover over back of person
 - ▶ Decrease hugging and touching outside the family
 - ▶ Use visuals to reduce need for hand over hand prompting
 - ▶ Develop independence in dressing, toileting, bathing as strategies to decrease opportunities for unintended touch and abusive touch and to increase clarity for person activities done alone or in private
 - ▶ Create routines for necessary body checks

SAYING “NO”

► Increase Clarity

- Identify with whom and where they may be nude
- Identify with whom and where being nude is unexpected/inappropriate

SAYING “NO”

► Increase Communication

- Use strategy for telling about day, everyday that includes expected and unexpected events



Emily

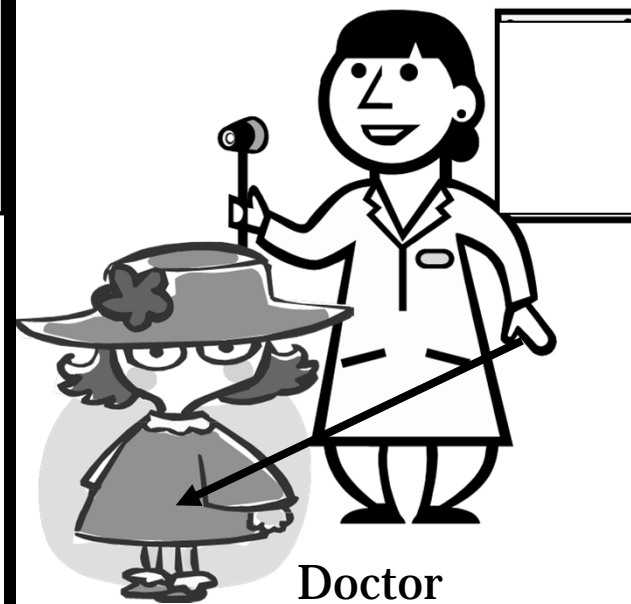
Doctor's Office



Emily

Doctor

Doctor can touch private parts



Emily

Doctor

Teach to say “NO” or “Stop”



Summary

- ▶ Educate parents
- ▶ Start early
- ▶ Informal assessment
- ▶ Use basic elements of Structured TEACCHing
- ▶ Develop visual teaching materials
- ▶ Generalize to natural environments

Safety and Sexuality in Children and Adult Concrete Learners

► Summary

- Approach teaching as any other skill: visual, hands on, matter of fact, no assumptions, consistent,
- Likely won't generalize so will need teaching for vacation, family visits, new job.
- Don't forget to include a schedule rich in exercise and other activities of high interest

Intimate Relationship Meets Complex Needs: Plan for how to meet all needs

- ▶ Physical pleasure seeking
- ▶ Tension release- Exercise!!!
- ▶ Social contact/caring relationship



Selected References

- ▶ Autism -Asperger's & Sexuality: Puberty and Beyond by J. and M. Newport
- ▶ Asperger's In Love M. Aston
- ▶ Growing Up by Shea and Gordon
- ▶ Sexual Behaviors in Adults with Autism (1997)
JADD Van Bourgondien, Reichle, & Palmer
- ▶ Intimate Relationships and Sexual Health
Catherine Davies, Med, MSc, CPsychol, LMHC, &
Melissa Dubie, MS

Selected References

- ▶ *Talking together...about sex and relationships.* L. Kerr-Edwards and Lorna Scott. 2003, Family Planning Association www.fpa.org.uk
- ▶ *Asperger's Syndrome and Sexuality.* I. Henault. (2006) Jessica Kingsley Pub.
- ▶ *Autistics' Guide to Dating* E.Ramey & J. Ramey. (2008). Jessica Kingsley Pub.
- ▶ *Making Sense of Sex.* Sarah Atwood. (2008). Jessica Kingsley Pub.

Free Resources

- ▶ <http://teachers.teachingsexualhealth.ca/lesson-plans/>
 - ▶ (free lesson plans with line drawings)
- ▶ <http://www.albany.edu/aging/IDD/documents/parentworkbook.pdf>
 - ▶ (free 60 page parent guide)
- ▶ <http://www.visualaidsforlearning.com/>
 - ▶ (free great color drawings)
- ▶ <http://www.easyhealth.org.uk/categories/health-leaflets/>

