# CONSIDERATIONS AND RESOURCES WHEN ADDRESSING PUBERTY AND SEXUALITY IN INDIVIDUALS WITH AUTISM

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#### **AGENDA**

Introduction

Why this matters

Considerations

What we have to think about and account for

Relationships and reciprocity

A universal concept

Resources

Things to know about

Questions and comments from you!

## FIRST, SOME EXPECTATIONS

There are NO dumb questions

I will model discussion of difficult subjects; You will hear explicit stories and words

It's ok if that's uncomfortable. It's ok to take a break

Engage if and how you are comfortable

Keep this a supportive and respectful space

# NOW, LET'S GET TO KNOW EACH OTHER

My story

Who are you -some questions

Roles

Worries

What or who is your "why"

#### WHAT YOU SHOULD KNOW:

Puberty is hard for everyone

Sometimes it's the hormones, not the disability

Failure is a part of life

This won't always work and it won't always be pretty, but it's worth doing

## WHAT ELSE YOU SHOULD KNOW:

Doing this work in schools is scary

Both transparency and discretion are needed

It usually isn't about sex

### **CONTEXT: PUBERTY AND AUTISM**

Adolescents with autism experience puberty and develop sexual urges and interest exactly like their peers (e.g., Girardi, et al., 2021; Koller, 2000)

## **CONTEXT: PUBERTY AND AUTISM**

Increased interest in and seeking of peer friendships with comorbid negative mental health outcomes due to failures (e.g., Barnard-Brak, et al, 2010; Browning, et al, 2009; Farrugia & Hudson, 2006; Kim & Lecavalier, 2021; Stewart, et al, 2006; White & Robertson–Ney, 2009)

Majority express desire for intimate relationships such as dating, marriage, & family (e.g., Baczewski & Kasari, 2021; Carrington et al., 2003; Daniel, et al., 2010)

Increased desire for friends + poor social skills = Increased risk for bullying and exploitation (e.g., Brown-Lavoie, et al., 2014; Furey, 1994; Holfeld, et al., 2019; Mandell, et al., 2005)

Desire for intimacy + Failure to distinguish social/non-verbal cues = Increased risk of negative social and legal consequences (e.g., Collins, et al., 2022; King & Murphy, 2014)

# CONTEXT: CRIMINAL JUSTICE

Lack of knowledge = increased risk of abuse, exploitation, and potential criminal behavior (e.g., Collins, et al., 2022; King & Murphy, 2014)

Inappropriate sexual behavior in public can have crippling social and legal consequences (e.g., Collins, et al., 2022; Sevlever, et al., 2013)

Individuals with ASD are 4-7 times more likely to encounter law enforcement than general public (Cooper, et al, 2022; OAR, 2014; Shea, et al., 2021)

Up to 30% of interactions lead to restraint or arrest (Cooper, et al., 2022; Salerno & Schuler, 2019)

Jailed at higher rates than peers for similar offences (Cooper, et al., 2022)

Being the perpetrator or victim of abuse second most common reason for encounters (Gardner, 2022)

Individuals with ASD are at higher risk:

Sexual abuse (Latvala, et al., 2022; Pfeffer, 2016; Sevlever, et al., 2013; Weiss & Fardella, 2018)

Experiencing bullying, assault, theft (Dodds, 2022; Gibbs, et al., 2022; Pfeffer, 2016)

Overwhelming majority of adults with ASD experience interpersonal violence from someone they know (Gibbs & Pellicano, 2023)

Individuals with ASD are at higher risk for:

Committing a sexual offence (Sevlever, et al., 2013;

Sperry, et al., 2021; Weiss & Fardella, 2018)

Significant trauma in childhood (Dodds, 2022)

This risk is higher if co-morbid conditions are present (Cooper, et al., 2022; Leydier, 2022; Miller, et al., 2022)

Rate of co-morbid mental health conditions is estimated to be as high as 70% (Chapman, 2019; Hossain, et al., 2020; Lugo-Marin, et al., 2019)

# SEXUALITY

It is vital that individuals with disabilities learn about healthy and appropriate sexual behavior:

Have right to full life experience, including intimacy (e.g., Benevides, et al., 2020; Koller, 2000)

They will be interested and try to learn anyway (e.g., Carrington et al., 2003; Nettelbeck & Wilson, 2002; Teti, et al., 2019)

# FROM CONTEXT TO CONSIDERATIONS

So, what do professionals need to know:

There is best practice

There are active communities

## THE GOOD NEWS!

A number of interventions used to develop social, relationship, and sexuality skills, including:

Video modeling

Script fading

Peer mediated strategies

**Teaching Interactions** 

Social stories

All have successfully taught these skills

#### MORE GOOD NEWS!

If you can teach a child to brush their teeth or play a board game, you can teach hygiene and sexuality skills

That said, just as with other specialties, there are resources and communities specific to this area

There is help out there!

## BEST INSTRUCTIONAL PRACTICES

(URBANO, ET AL., 2013)

Parent involvement and participation is critical

Must be taught in highly structured, way using concrete examples

Must be tailored to individual & family values, sexual identity, environmental context, and developmental level

## SO HOW DO WE INVOLVE PARENTS?

Transparency

Meet them where they are

Put it in a context they accept

Secure support for targets, interventions, and outcomes

Document it

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

**HOW MANY** 

OF THESE

ARE ABOUT

SEX?

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

LET'S PRACTICE

**HOW WE MIGHT** 

**ADDRESS THESE** 

IN SCHOOL

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

#### Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

LET'S PRACTICE

**HOW WE MIGHT** 

**ADDRESS THIS** 

IN ELEMENTARY

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

#### Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

LET'S PRACTICE

**HOW WE MIGHT** 

**ADDRESS THIS** 

IN HIGH SCHOOL

(CAUCHI, ET AL., 2023; GERHARDT, ET AL., 2022)

Public versus private behavior

Good touch versus bad touch

Proper names of body parts

"Improper" names of body parts

Personal boundaries/personal spaces

Masturbation ("Private Touching")

Avoidance of danger/Abuse prevention

Social skills and relationship building

LET'S PRACTICE

**HOW WE MIGHT** 

**ADDRESS THESE** 

IN MIDDLE SCHOOL

# BACK TO PARENT INVOLVEMENT: THE IMPORTANCE OF DISCRETION

Can this be addressed within standard curriculum/discipline policy?

Can this be addressed by teaching a "safer" alternative skill or coping strategy?

## A BRIEF BUT IMPORTANT DIVERSION

Relationships are building blocks of adult independence and happiness

Quality of life and successful independence closely tied to development of relationships

Positive relationships are a powerful protective factor

## **BUILDING RELATIONSHIPS**

It is important to teach how positive, healthy relationships form:

Relationships built on reciprocity

Ability to recognize reciprocity in others and to offer or refuse it yourself are two of the fundamental skills required to build, maintain, and end healthy relationships

#### BUILDING RELATIONSHIPS

Goal is to create relationships that involve regular, voluntary, balanced exchange of reinforcers between both people

Value of any given relationship is linked to amount of reinforcement being exchanged in BOTH directions

Several skills to use reciprocity as a relationship tool:

How to offer reciprocity first

How to recognize reciprocity in return

How to evaluate the equality of the exchange

How to REFUSE reciprocity

Prepare them to fail; teach an age-appropriate exit

Small initial offers are safer

Most initiations will evoke no response, and require no further action beyond stopping the attempt

Identify "limits" for attempts in a specific situation

How to REFUSE reciprocity:

Reciprocity is a CHOICE not an obligation

Avoid teaching that you "owe" someone in return

Avoid turning a choice into a power struggle

How to REFUSE reciprocity:

If you do not want to be in a relationship, the clearest signal is to NOT reciprocate

Importance of NOT saying that out loud –MOST of the time

Also: MUST teach skills to recognize and respond to highpressure or exploitative attempts at immediate reciprocity

#### BRIEF ACTIVITY

Think of a situation in which you've seen a student with ASD not recognize a reciprocity refusal.

Break down the initiation, how the refusal was communicated (or not) and what happened when the student didn't respect the refusal

# SOME COMMON RECIPROCITY ISSUES

Or, what I wish someone had talked to me about when I got into teaching social skills...

Some thoughts, some questions to ask yourself, some questions to guide students to ask...

# RECIPROCAL VS TRANSACTIONAL

They are NOT the same

One of the most common mistakes we all make

# Examples:

The library assistant

The class aide

# WHAT IS HEALTHY?

How do you identify if a relationship is healthy?

Do both want to be there?

Are both benefitting?

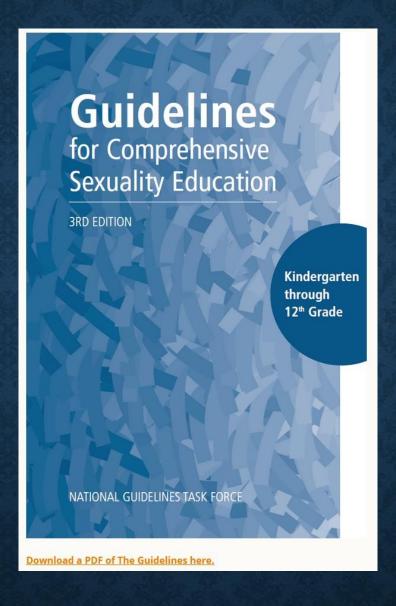
Is there coercion or imbalance?

Examples:

Lunch buddy

# NOW BACK TO PUBERTY AND SEXUALITY

There are standards and guidelines



https://siecus.org/resources/the-guidelines/

#### Guidelines for Comprehensive Sexuality Education: Key Concepts and Topics

#### Key Concept 1: Human Development

Topic 1: Reproductive and Sexual Anatomy and Physiology

Topic 2: Puberty

Topic 3: Reproduction

Topic 4: Body Image

Topic 5: Sexual Orientation

Topic 6: Gender Identity

#### Key Concept 2: Relationships

Topic 1: Families

Topic 2: Friendship

Topic 3: Love

Topic 4: Romantic Relationships and Dating

Topic 5: Marriage and Lifetime Commitments

Topic 6: Raising Children

#### Key Concept 3: Personal Skills

Topic 1: Values

Topic 2: Decision-making

Topic 3: Communication

Topic 4: Assertiveness

Topic 5: Negotiation

Topic 6: Looking for Help

#### Key Concept 4: Sexual Behavior

Topic 1: Sexuality Throughout Life

Topic 2: Masturbation

Topic 3: Shared Sexual Behavior

Topic 4: Sexual Abstinence

Topic 5: Human Sexual Response

Topic 6: Sexual Fantasy

Topic 7: Sexual Dysfunction

#### Key Concept 5: Sexual Health

Topic 1: Reproductive Health

Topic 2: Contraception

Topic 3: Pregnancy and Prenatal Care

Topic 4: Abortion

Topic 5: Sexually Transmitted Diseases

Topic 6: HIV and AIDS

**Topic 7:** Sexual Abuse, Assault, Violence, and Harassment

#### Key Concept 6: Society and Culture

Topic 1: Sexuality and Society

Topic 2: Gender Roles

Topic 3: Sexuality and the Law

Topic 4: Sexuality and Religion

Topic 5: Diversity

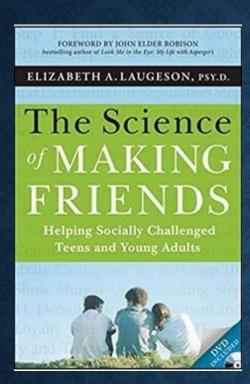
Topic 6: Sexuality and the Media

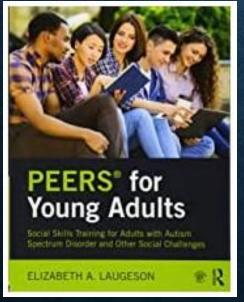
Topic 7: Sexuality and the Arts

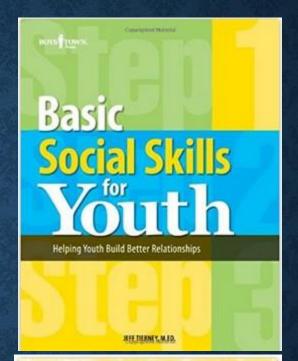
# SOME RESOURCES

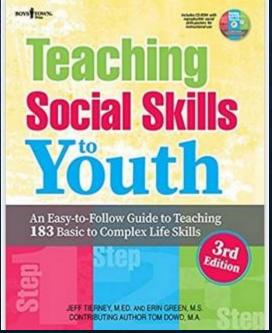
A number of free or low-cost resources with curriculum and training materials

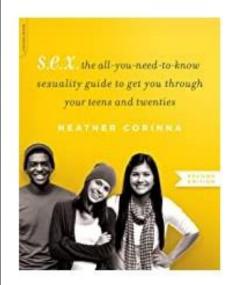
Include a variety of levels and skills











# S.E.X., second edition: The All-You-Need-To-Know Sexuality Guide to Get You Through Your Teens and Twenties

by Heather Corinna | Jul 12, 2016



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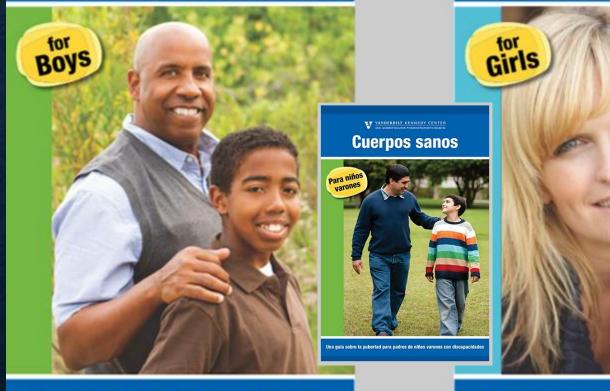
Ages: 12 years and up



# **Healthy Bodies**



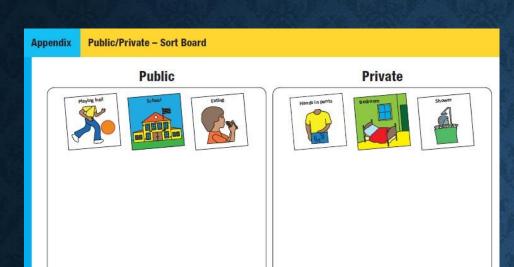
# **Healthy Bodies**



A Parent's Guide on Puberty for Boys with Disabilities

A Parent's Guide on Puberty for Girls with Disabilities

I.	Oh No! Here it Comes: Onset of Puberty Pg. 3  • Talking To My Son About These Things
II.	No Couch Potatoes! Helping Your Son Stay Active Pg. 4  • How To Start
III.	Phew! What's That Smell? Pg. 5-7 • Encouraging Good Hygiene • Common Trouble Spots
IV.	Oh Please, Not Here! Pg. 8-9  • Appropriate and Inappropriate Public Behaviors  • Teaching These Skills to My Son  • Touching Private Parts
V.	Peers, Hormones, and Mood Swings Pg. 10-11  • How You Can Help Your Son Socially  • Moods and Feelings  • More Than "Moody"
VI.	Boys Will Be Boys Pg. 12-13  • Nocturnal Emissions  • Preparing My Son for Nocturnal Emissions  • Erections  • Things That May Help  • Boxers or Briefs
VII.	Resources Pg. 15

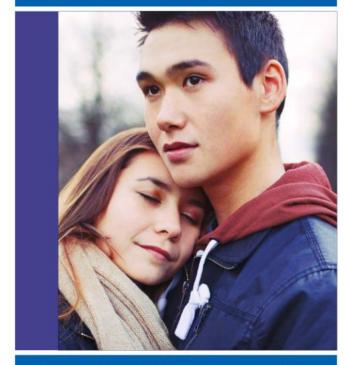


Appendix Public/Private Behaviors – Visuals





### **Puberty, Sex, and Sexuality**



**An Introduction for Autistic Teens and Adults** 



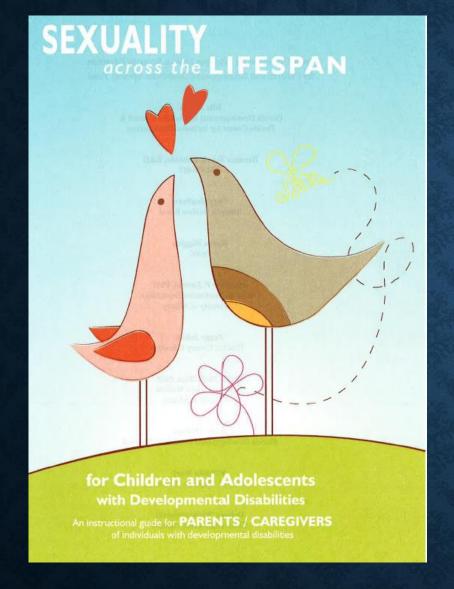
#### **Navigating Puberty, Sex, & Sexuality**

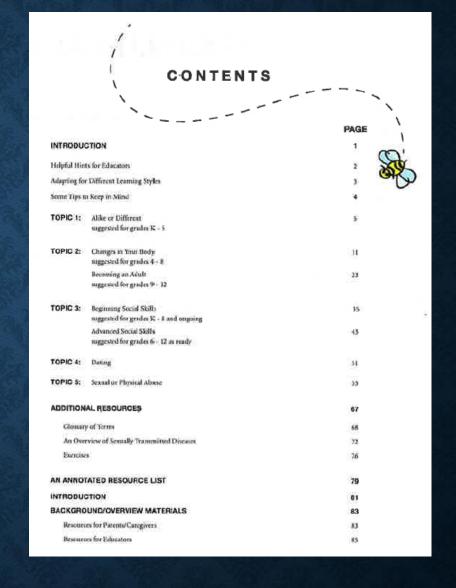


A Guide for Supporting Autistic Teens and Adults

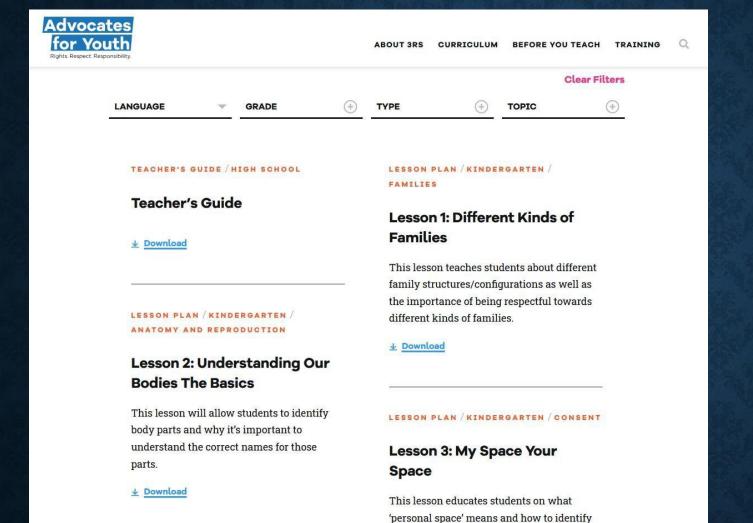
https://vkc.vumc.org/assets/files/resources/sexedtoolkit.pdf

https://vkc.vumc.org/assets/files/resources/sexuality.pdf





https://www.google.com/url?sa=i&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=0CDkQw7AJahcKEwiYvqjNyqyBAxUAAAAHQAAAAAQAg&url=https%3A%2F%2Fwww.uab.edu%2Fcivitansparks%2Fimages%2FSex\_Lifespan\_Prt.\_l.pdf&psig=AOvVaw03eD08IlkfiPgr61i55bA2&ust=1694865912083455&opi=8997



Rights, Respect, Responsibility is a sex education curriculum that fully meets the National Sexuality Education Standards and seeks to address both the functional knowledge related to sexuality and the specific skills necessary to adopt healthy behaviors. Rights, Respect, Responsibility reflects the tenets of social learning theory, social cognitive theory and the social ecological model of prevention. 2021 New and Updated Lessons

# AUTISM SPEAKS

# ATN/AIR-P Puberty and Adolescence Resource

Puberty can be a time of mixed feelings for parents and pre-teens. All parents eventually face the challenge of teaching their children about the natural changes of puberty. However, parents of pre-teens with autism may need the help of additional strategies to ease the transition.

Our aim in developing this tool is to provide guidance on puberty that can be directly applied to pre-teens with autism. In doing so, we hope to increase families' understanding of puberty and their ability to adapt to these changes with confidence.

#### Sections include:

- Body changes
- · Self-care and hygiene
- Public vs. private rules
- Staying safe: Strangers, secrets and touch
- Elopement
- · Safety planning for increased aggression
- Internet safety

"These materials are the product of on-going activities of the Autism Speaks Autism Treatment Network, a funded program of Autism Speaks. It is supported by cooperative agreement UA3 MC 11054 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program to the Massachusetts General Hospital. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the MCHB, HRSA, HHS, or Autism Speaks."

Download here

➤ SEXUALITY AND RELATIONSHIP EDUCATION FOR CHILDREN AND ADOLESCENTS WITH AUTISM SPECTRUM DISORDERS: A PROFESSIONAL'S GUIDE TO UNDERSTANDING, PREVENTING ISSUES, SUPPORTING SEXUALITY AND RESPONDING TO INAPPROPRIATE BEHAVIOURS BY DAVIDA HARTMAN

An excellent book for parents or professionals for understanding, preventing, supporting and responding to sexual issues that surface in childhood, preadolescence, adolescence and adulthood.

➤ SEXUALITY AND SEVERE AUTISM: A PRACTICAL GUIDE FOR PARENTS, CAREGIVERS AND HEALTH EDUCATORS

BY KATE REYNOLDS

This handbook helps the reader through the process of teaching about sexuality to people with more significant autism. The author shares ideas about when, what and how to begin the process of teaching and addresses both male and female puberty. Menstruation, public, private sexual behaviors, sexual abuse and reporting.

➤ SEXUALITY EDUCATION FOR ADULTS WITH DEVELOPMENTAL DISABILITIES BY PLANNED PARENTHOOD OF GREATER NORTHERN NEW ENGLAND AND GREEN MOUNTAIN SELF ADVOCATES

A unique curriculum designed to help people establish sexuality education groups and include self advocates as teachers. This comprehensive curriculum focuses mostly on relationships, both friendships and romantic relationships, and the skills and responsibilities needed within those relationships.

➤ SPECIAL EDUCATION: SECONDARY FAMILY LIFE AND SEXUAL HEALTH (FLASH) BY JANE STANGLE

A teacher-friendly curriculum that provides student lessons on teaching relationships, public and private, communication,

A teacher-friendly curriculum that provides student lessons on teaching relationships, public and private, communication body changes, feelings, reproduction, STDs, birth control and exploitation prevention. Geared toward high school students with mild/moderate cognitive disabilities. Distributed by Family Planning Publications, Seattle-King County Department of Public Health.

Online Resource List From Respect Ability

https://www.respectability.org/

resources/sexual-education-resources/

Resource List from Elizabeth Jackson

#### For children and adults with developmental disabilities

Janet's Got Her Period

Gray, J., Jilich, J. (1990). James Stanfield.

This program is for girls and young women with severe developmental disabilities. Consisting of a video and an illustrated storybook with full-color photographs, it tells the story of a young girl who learns menstrual self-care from her mother and sister. A teacher's guide is also included.

#### Circles

The Circles Curriculum teaches boundaries and relationship-specific behaviors, using a simple multi-layer circle diagram.

LifeSmart series (DateSmart, MoneySmart, SafteySmart, PeopleSmart)
The LifeSmart Curriculum uses humorous Smart/NotSmart vignettes to provide instruction on life's most important concerns.

#### First Impressions

Students will learn about the four basic elements that make an immediate impression on someone: hygiene, grooming, dress, and attitude.

For adults with developmental disabilities

The Whole Truth

By David Hingsburger and Joe Jobes, 2 disc and book set

Abuse prevention program hosted by adults with developmental disabilities, helps people with disabilities recognize and report boundary transgressions that lead to abuse

Hand Made Love: Guide for Teaching About Male Masturbation By David Hingsburger, 1995

Booklet and DVD set discusses privacy, pleasure, and the realities of sharing living space with others

Fingertips

By David Hingsburger and Sandra Haar, 2000

Teaches women with developmental disabilities about masturbation and confront typical myths about female sexuality.

https://humboldt-

dspace.calstate.edu/bitstream/handle/2148/1931/Jackson\_Elizabeth\_Sp2014.pdf?sequence=1&sa=U&ved=0CEIQFjAJahUKEwj\_tfX\_ho7JAhWIOj4KHZScDXk&usg=AFQjCNGAkARfsHcamONjdOLD-H84Af9hBQ



## ABAI Sexual Behavior Research and Practice SIG

Private group ⋅ 1.7K members





A Functional Contextual Approach to Working with Gender and Sexuality Therapeutically

# SEXUAL BEHAVIOR RESEARCH & PRACTICE SIG REFERRAL & CONSULTATION LIST and CONSULTATION LIST GUIDELINES

UPDATED: October 2021

Below is a list of potential consultants related to sexual behavior, relationship behavior, or gender and sexuality. This list has been compiled by the Sexual Behavior Research and Practice SIG of ABAI, and all persons listed have consented to be added to this list. Placement on this list does not guarantee that the person listed will be available for consultation and referral when contacted. Placement of this does not guarantee competency and all professionals are expected to adhere to the *Professional and Ethical Compliance Code for Behavior Analysts* (until December 31, 2021) and then the *Ethical Code for Behavior Analysts* (from January 1, 2022.)

#### Please read the sections after the names listed for important information about seeking consultation.

Frank R. Cicero, PhD, BCBA, LBA(NY) frankrcicero@yahoo.com

Problematic Sexual Behavior
Sexual Self Harm (ie - ineffective, damaging, or dangerous solo sex)
Sex Ed + Neurodiversity/Autism
Sexual Behavior Assessment + Intervention in Practice

Arin Donovan, MEd, BCBA, LBA arin.donovan@gmail.com Lesbian, Gay, Bisexual, Pansexual Issues Transgender Issues

Hi Everyone,

while back someone shared some menstruation visuals they had made. I'm searching for them but can't seem to find them in the files or photos. Does this ring a bell for anyone?

Edit: solved! https://www.positiveconnections.ca/resources

Thank you!



# QUESTIONS OR COMMENTS?

Remaining time for questions and additional discussion of resources, references, intervention, etc.

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