

Puberty and Down Syndrome

*Presentation for Waisman Center Day with the Experts:
Down Syndrome; Saturday March 18, 2017*

By:

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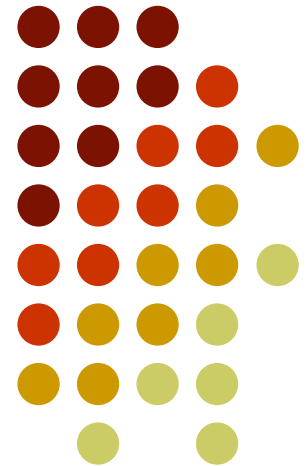
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■ Major points of the session:

1. Puberty is a time of great changes – for all adolescents, including individuals with Down syndrome. What is the impact for the individual with Down syndrome and the family?
2. Comprehensive sexuality needs to be addressed for adolescents with Down syndrome – using an individualized approach.
3. Due to the potential complexity of these issues, address the issues together as a team – individual, family and support providers.
4. There are resources available.



■ Puberty

A time of significant changes:

Physical – growth (height & weight), secondary sex characteristics (e.g. breasts, pubic hair), hormones (sexual feelings)

Developmental/psychological – increased self-awareness & sensitivity of the body, individuation from parents, importance of peers

Emotional/behavioral – desire for more independence, privacy

Puberty -- Impact on the person with Down syndrome & family



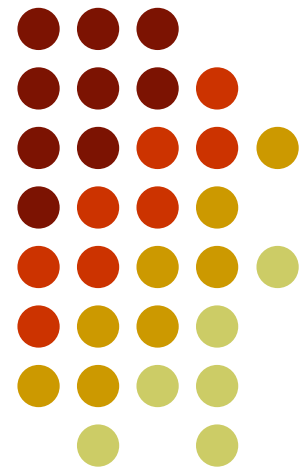
- Individuals with Down syndrome and their families are more alike than different from other youth and families
- Puberty occurs at the same time and with the same changes as typically developing youth
- Sexuality is an important part of total life experiences for all human being – often linked to need for sharing close, caring and emotional intimacy with others.
- There are, though, issues that need to be addressed.

Common Issues for Adolescents with Down syndrome & Their Families During Puberty



- Focus on body changes (Re-evaluation of sexuality education – it's never too late)
- Hygiene and grooming
- Awareness of sexual feelings
- Rules for public and private behavior
- Body ownership & boundaries for self and others
- Safety
- Behavior – school, home, workplace & community
- Parent/family needs

*Framework for Addressing
Puberty & Sexuality*



Comprehensive Definition of Human Sexuality



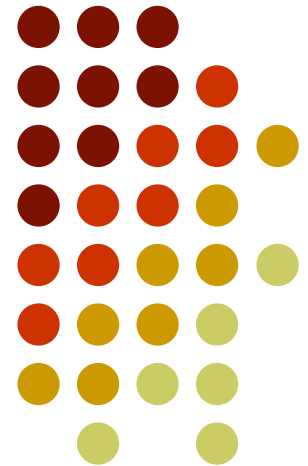
- Self-concept
- Physical maturation
- Social maturation
- Feelings
- Development of relationships
- Sexual Values
- Behaviors/expressions
- Personal rights
- Sexual learning
- Sexual health
- Future planning

Factors influencing sexuality for individuals with Down syndrome



- Communication
- Possible cognitive challenges
- Incongruity between chronological age and developmental age
- Dependency
- Compliance
- Nature of disability
- Personal history

*Strategies for Education
and Support*





■ Strategies for Families and Support Providers Include:

Sexuality Education --

- Think ahead – be proactive and begin sexuality education in early childhood.
- Begin early with body awareness and social skills development.
- Progress to include relationship building, body changes and social behavior.
- Not to worry – it is never too late to start.

Strategies for Families and Support Providers Include: (cont.)



Sexuality education:

- Figure out what to teach:
 - Approach the topic as you would for youth without disabilities at the same age.
 - Then individualize for your child with Down syndrome – both in content and techniques for teaching.



Training Techniques for Individuals with Cognitive Limitations or Difficulties with Abstract thinking:



- In general, use simpler words, slower pace, much repetition
- Use clear and explicit language
- Teach in small, sequential steps and with frequent reviews
- Keep lessons short and well-structured
- Information taught should be practical and relevant to life settings

Strategies for Families and Support Providers Include: (cont.)



Sexuality Education (cont.)

- Although parents are likely the most influential and consistent teachers of sexuality, support providers who know the youth ay also have an important role in teaching sexuality education to:
 - Share resource materials that are designed for youth with learning differences
 - Design alternative teaching techniques for addressing sexuality
 - Assist in identifying resources within the community
 - Supplement and reinforce sexual concepts within community environments

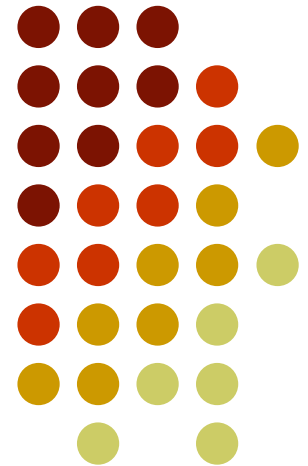
Strategies for Families and Support Providers Include: (cont.)



Consider own emotional needs along with comfort and knowledge for addressing sexuality

- Know yourself
- Seek out emotional support as needed –this time of obvious changes in the adolescent can be challenging for parents
- Examine own attitudes in order to foster a positive attitude
- Provide accurate information about sexuality
- Use a gentle and sensitive approach

*Consider using the
S.T.A.R.S. guidebooks as
teaching resources*



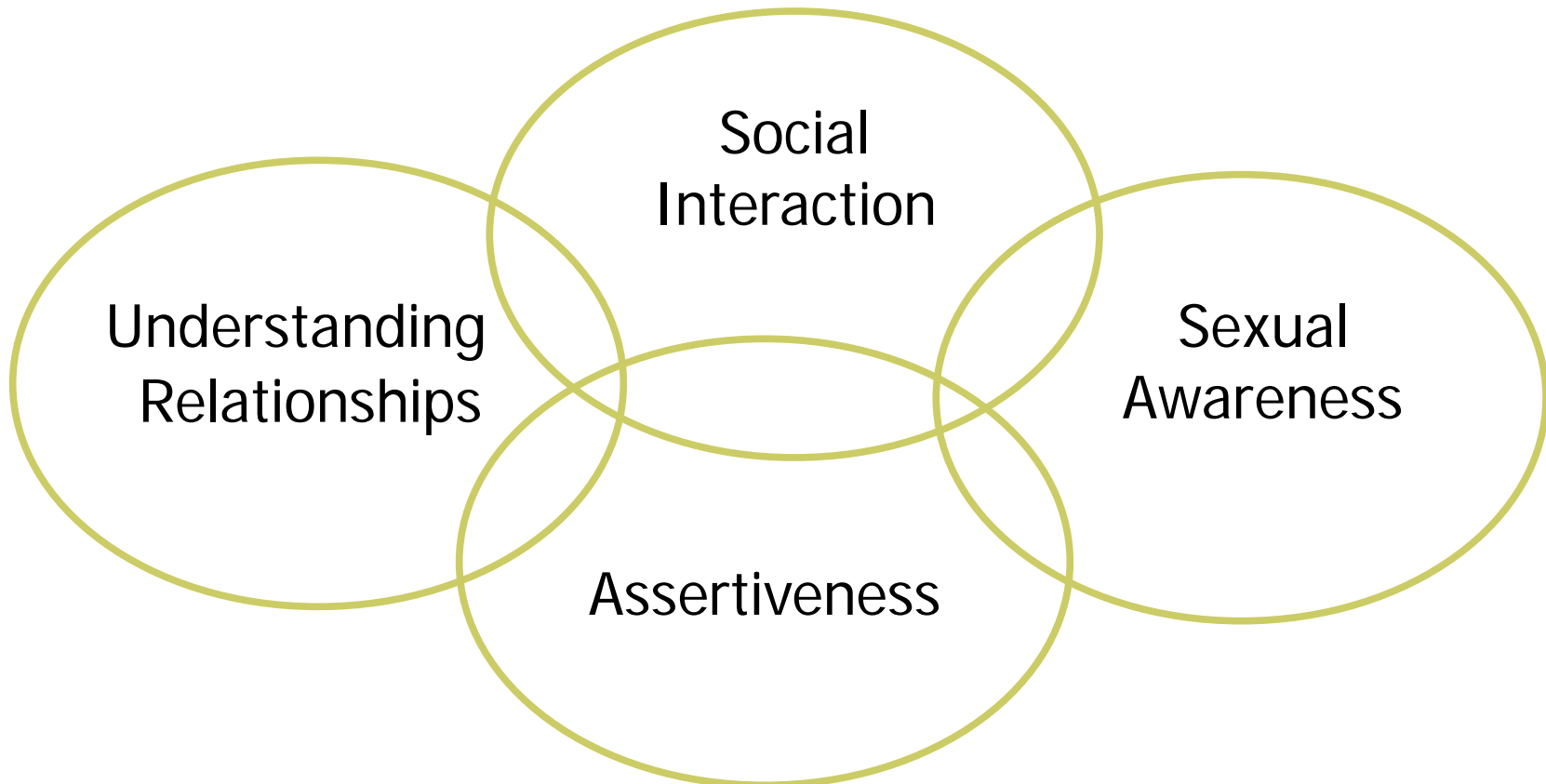
Approach of our *STARS Model*©



- Comprehensive approach to sexuality education for individual with disabilities
- To support positive expression of sexuality and facilitate the learning of skills to prevent sexual abuse
- “Building blocks” approach
- Not a curriculum, but a guide
- Encourage assessment of needs & individualize training
- 4 content areas with goals and activities

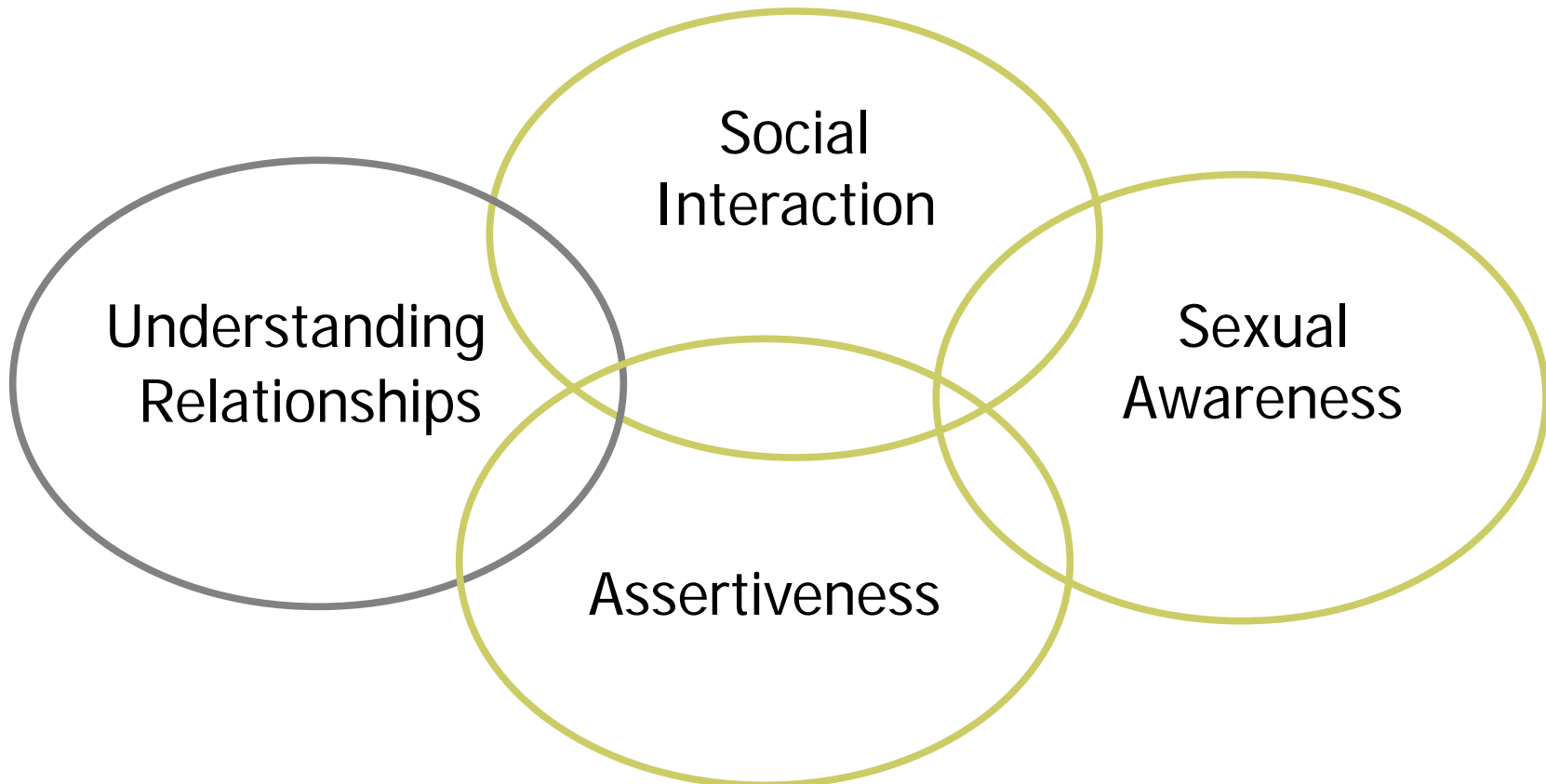


STARS Model©





STARS Model©

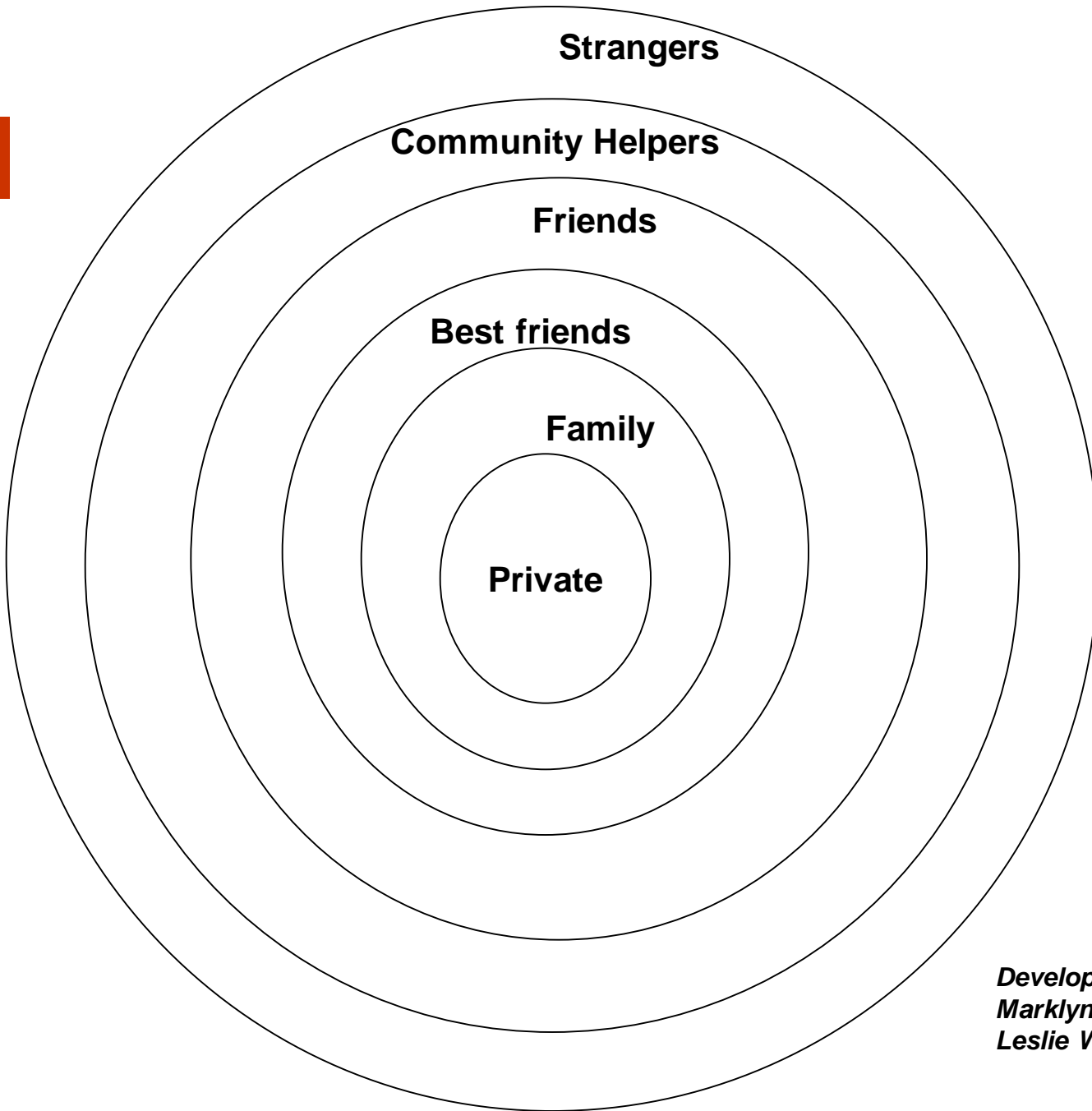




Understanding Relationships

Goals:

- Building a positive self-image
- Identifying people in one's life as family, friends, acquaintances, community helpers
- Learning behaviors appropriate for each type of relationship



*Developed by
Marklyn Champagne &
Leslie Walker-Hirsch*



Understanding Relationships

Example of activity

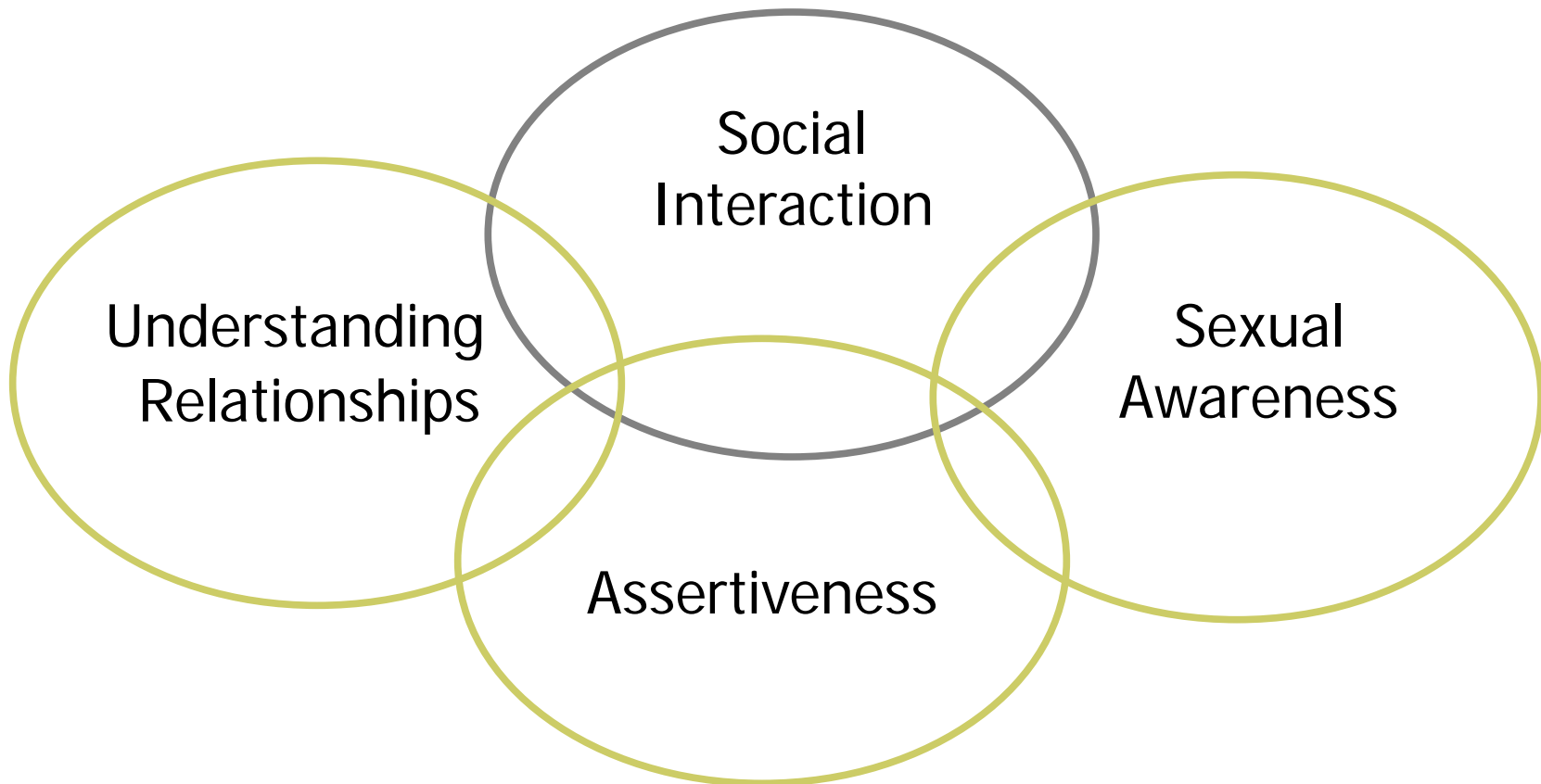
Circles Concept¹

- Teaches social distance and levels of familiarity through the use of colored concentric circles.
- Starting from the center circle, which is the self, each new circle represents behaviors appropriate to the relationship/distance from the center.

¹Marklyn P. Champagne & Leslie Walker-Hirsch, published by James Stanfield Film Associates. P.O. Box 1983, Santa Monica, California. ²¹



STARS Model©





Social Interaction

Example of Goals:

- Approaching, responding and conversing with people in different settings and situations
- Expressing preferences, making choices.
- Building friendships.
- Engaging in more mature relationships



Social Interaction

Example of Activities:

- Provide an opportunity to learn and practice social skills; need contact with peers.
- Support opportunities for establishing and continuing satisfying social relationships
- Teach social interactions skills, using “scripts” or specific approaches & responses to others.



■ Use “CIRCLES” illustration

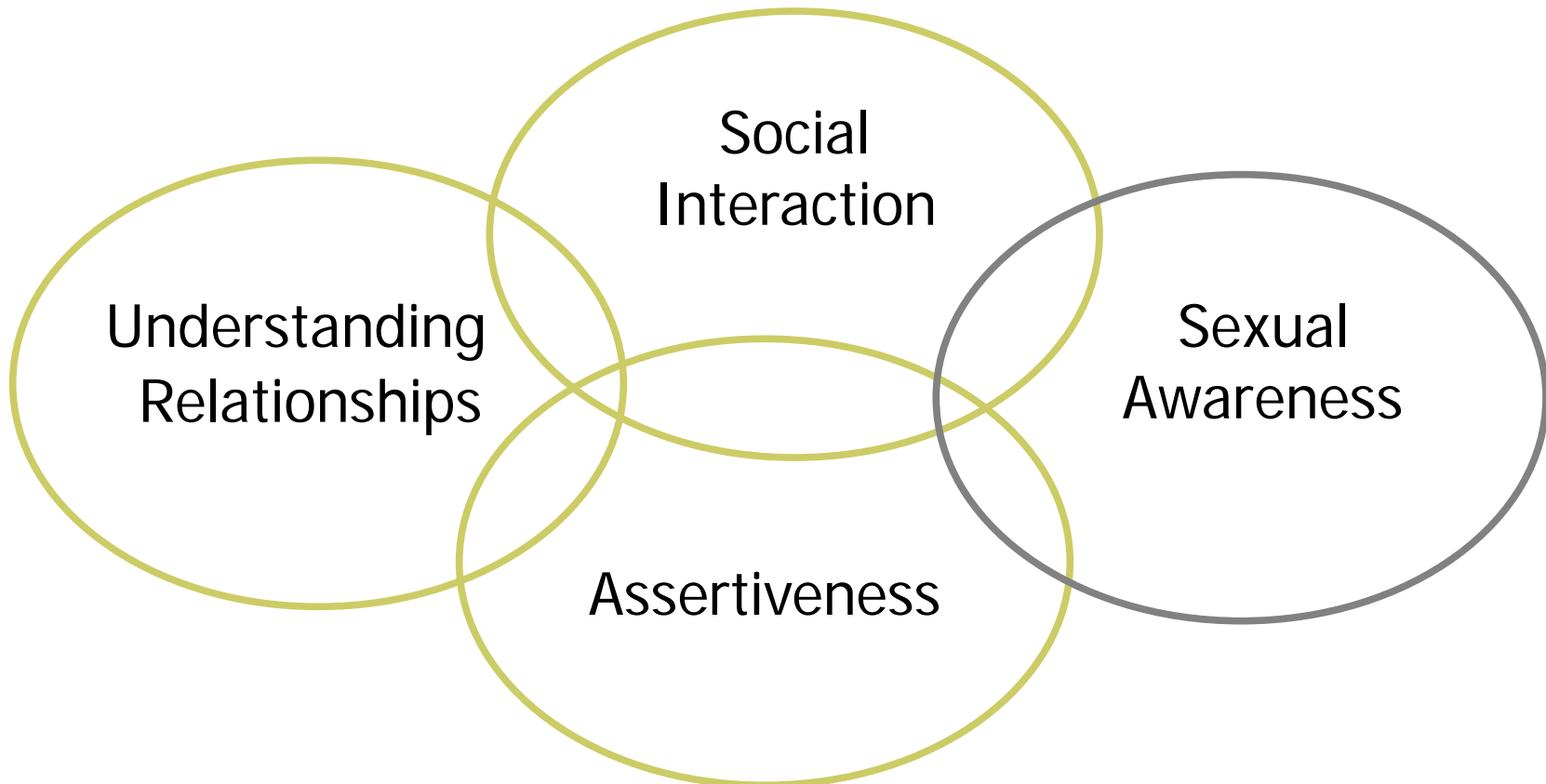
- Pair relationship with social behavior

For example:

- pair familywith hug
- pair community helper....with talking only
- pair strangerwith wave only or ignore



STARS Model©





■ Sexual Awareness

Examples of goals:

- Building a positive self-image and sexual identity
- Identifying male and female
- Understanding public and private behavior
- Identifying body parts and understanding their functions
- Differentiating between inappropriate and appropriate touching
- Understanding sexual feelings and behaviors

Sexual Awareness (cont.)



Examples of activities:

- Body parts – simplify, use “dictionary” words
- Important to teach concepts of private and public (body parts and behavior)
- Puberty -- provide information about body changes in simple, understandable terms.
- Have someone of the same gender teach the basics of safety and hygiene related to sexuality.²⁸

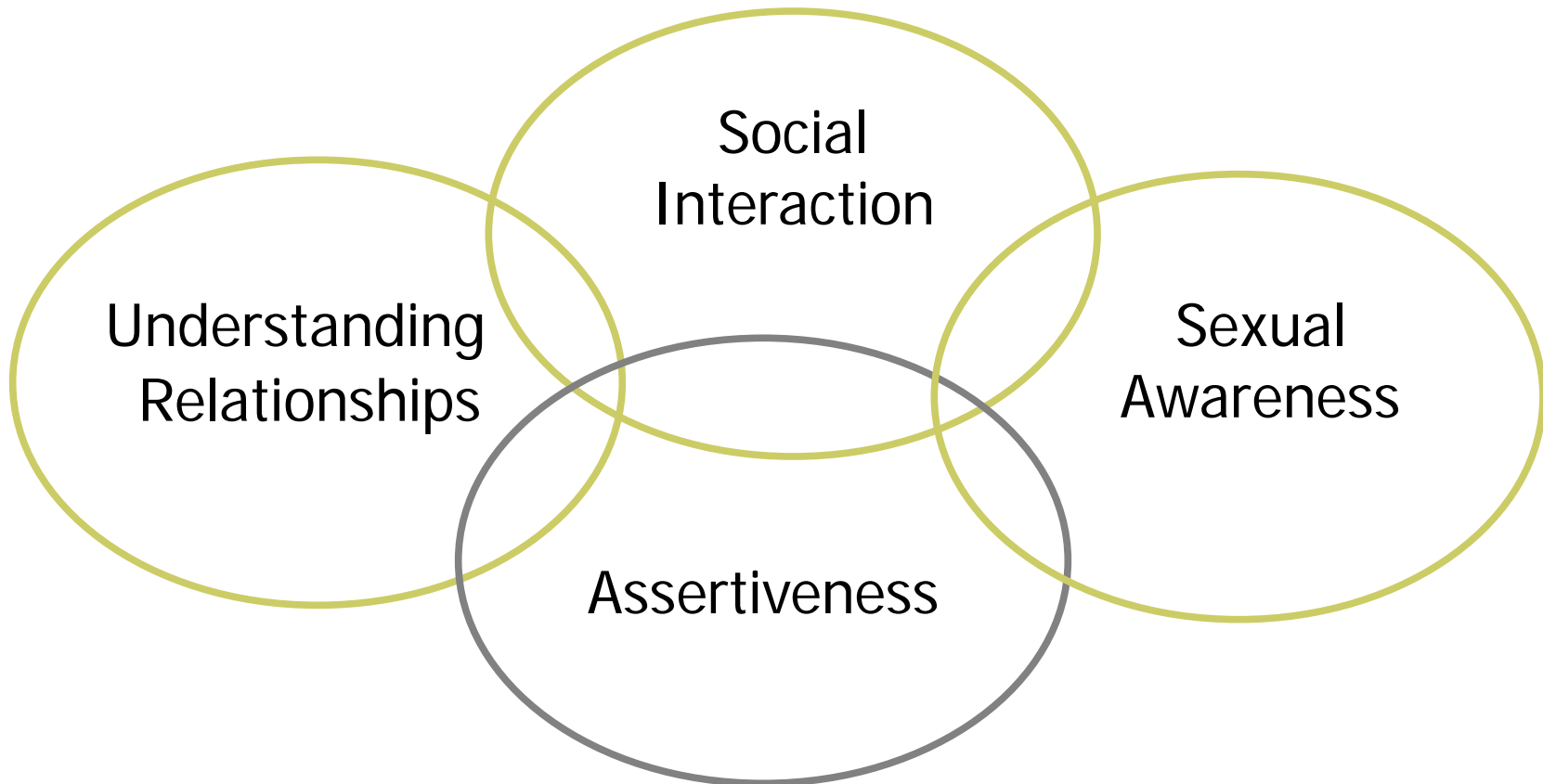
Address “inappropriate” sexual behaviors



- Example: *Touching others “inappropriately”*
 - Most likely curiosity similar to more immature behavior
 - Probably interested in others and have not learned how to approach others.
 - May have seen others do the same, but they were sophisticated enough to get away with it.
 - If behavior occurs suddenly and seems “over-sexualized”, may be related to sexual abuse.



STARS Model©





Assertiveness

Examples of goals:

- Increasing self-empowerment through words and actions
- Recognizing a situation as potentially dangerous
- Learning to say “no” and to use basic self-protection skills
- Knowing how and where to get help at home and in the community



Assertiveness

Examples of activities:

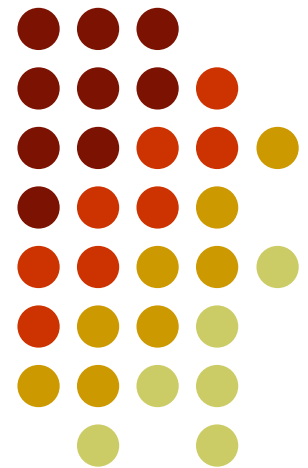
- Provide a safety net of supervision while learning skills for self-protection
- Promote understanding of dangers, don't use scare tactics
- Teach types of touch, “good” touch, “bad” touch & “confusing” touch
- Work on cues for discriminating safe and unsafe situations



In summary:

- Puberty is a time of significant changes
- There are resources and support to help.
- Youth and parents can make it through with patience, understanding and communication

Recommended Resources



S.T.A.R.S.: A Social Skills Training Guide for Teaching Assertiveness, Relationship Skills and Sexual Awareness (2008)

S.T.A.R.S 2: Relationship Building & Sexual Awareness for Kids (2015)

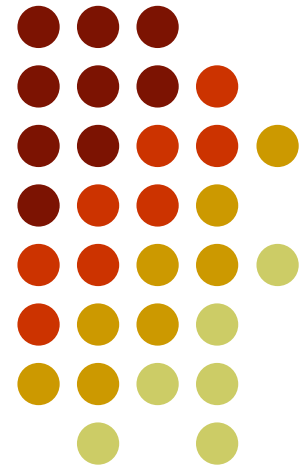
By Susan Heighway & Susan Kidd Webster

Published by Future Horizons, Inc.

Phone: 1-800-489-0727

Available from the website:

<http://fhautism.com/>





BOOKS



- *The Girls' Guide to Growing Up; Choices & Changes in the Tween Years.* (2011) by Terri Couwenhoven, published by Woodbine House. Written specifically for girls with intellectual disabilities.
- *The Boys' Guide to Growing Up; Choices & Changes during Puberty.* (2012) by Terri Couwenhoven, published by Woodbine House. Written specifically for boys with intellectual disabilities.
- *Teaching Children with Down Syndrome about their Bodies, Boundaries and Sexuality,* (2003) by Terri Couwenhoven, published by Woodbine House.
- *The Care & Keeping of You; The Body Book for Girls*(1998) by Valorie Lee Schaefer, published by American Girl.
- *Taking Care of Myself; A Hygiene, Puberty and Personal Curriculum for Young People with Autism* (2003) by Mary Wrobel, published by Future Horizons. Information is presented in Carol Gray's "Social Stories" style.



- Thanks for your attention
- Good luck, you can address the area of sexuality!