



Promoting Personal Safety for People with Intellectual and Developmental Disabilities: Options in Policy, Procedures and Planning

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Learning Objectives

- Identify personal safety needs of people with Intellectual and Developmental Disabilities (I/DD).
- Discuss the importance of establishing person centered policy, procedure, and programming that promotes personal safety for people with I/DD receiving services in the community.
- Review sample sexuality policies from provider organizations.
- Review of existing sexuality education resources.
- Identify next steps in the development of a sexuality policy.

Abuse, Neglect and Exploitation

The infliction of physical, emotional, or psychological harm to a person. Abuse also can take the form of financial exploitation or intentional or unintentional neglect by the family, a friend or a caregiver.

- Abuse can be:
 - Physical
 - Sexual
 - Emotional
 - Neglect
 - Financial

Vulnerability

- In the US each year 20% of females and 5 - 10% of males are sexually abused.
 - 90% of people with ID will experience some form of sexual abuse during their life time. (Valenti-Hein & Schwartz, 1995)
- People with I/DD, especially women, are at heightened risk for abuse.
 - 2-4x higher than people without disabilities. (Baladerian, 1991; Horner-Johnson & Drum, 2006)
- 44% of the abusers are people like staff, transportation providers, and personal care attendants. (Baladerian, 1991)
- Dependence on others for assistance with personal care creates an opportunity for sexual abuse to occur while decreasing the likelihood that such abuse will be reported (Collier, et al, 2006)

Vulnerability to Abuse

- Perpetrators are likely to target the most vulnerable and easily manipulated to whom they have access, who they believe will not report, and who are socially isolated
- People with intellectual disabilities generally receive some paid or unpaid support services, which often causes them to be dependent on others in secluded environments
- Those sexually abused themselves are at increased likelihood to become a sexual abuser in the future

Vulnerability to Abuse

- Social powerlessness
- Unable to defend oneself
- Communication deficits
- Impaired judgment
- Isolation
- Lack of socialization
- Living arrangement
- Lack of contraceptive choice
- Stereotyped as easy prey
- Denial of sexuality
- Economic dependence
- Denial of feelings and human emotion

**Grieveo, et al., 2006;
Sullivan & Caterino, 2008**

- Some characteristics and behavior that contribute to an increased risk include
 - misjudgment of others' motivations,
 - lack of sexual knowledge,
 - a tendency to show compliance and affection towards others, and
 - limited communication abilities

Sexuality Education as Abuse Prevention

- Increases the understanding of what constitutes abuse
- Increases body awareness
- Increases assertive communications. Helps people find words to report abuse
- Helps individuals advocate for their rights
- Empowers individuals to advocate for their wants and needs
- Increase awareness of supports and resources

The Truth

- Men and women with intellectual disabilities are less likely to receive any form of sexual education in school or elsewhere, including training on assertiveness, healthy relationships, proper feel and touch, or warning signs of sexual abuse.
- Men and women with intellectual disabilities are often socialized to be compliant; are more likely to live in poverty and remain substantially more dependent on caregivers than nondisabled men and women.

The Truth

- Sex and Relationships are very important
 - 63% of Administrators of State Residential Facilities where 50% of more adults have mild/moderate ID report that sex occurred sometimes or often
 - 100% of Service Provider Agencies supporting people with severe/profound ID reported masturbatory behavior
- Secret Sexual Lives (leads to violation of sexual rights)
- Lack of privacy in many residential settings
 - may lead to hurried, unprepared sexual activity
- Isolation and Rejection is painful

Sexuality

- Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.
- Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.
- Sexual health is 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.

Sexual Rights

Statement People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.

Position

- Every person **has the right** to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.
- All people **have the right** within interpersonal relationships to:
 - **Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose;**
 - **Dignity and respect, privacy, confidentiality, and freedom of association.**

Sexual Rights

With respect to sexuality, individuals **have a right** to:

- **Sexual expression and education**, reflective of their own cultural, religious and moral values and of social responsibility;
- **Individualized education and information** to encourage **informed decision-making**, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases; and
- **Protection from sexual harassment and from physical, sexual, and emotional abuse.**

With respect to sexuality, individuals **have a responsibility** to consider the values, rights, and feelings of others.

Sexuality

Joint Position Statement of AAIDD and The Arc

Historical Issue:

- people with I/DD thought to be asexual, having no need for loving and fulfilling relationships with others
- Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has negatively affected people with intellectual disabilities in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior.
- People with intellectual or developmental disabilities frequently lack access to appropriate sex education in schools and other settings.
- At the same time, some individuals may engage in sexual activity as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality.

Barriers to Sexual Expression

- History of abuse & trauma
- Lack of self-confidence & esteem that impairs their ability for intimacy
- Attention to medical, functional, and behavioral supports may shift focus away from addressing sexuality*

Barriers to Sexual Expression (cont'd)

- Lack of healthcare for people with disabilities
- Segregation/isolation and lack of opportunity to socialize with peers
- Limited autonomy
- **Lack of support from providers & family to have relationships**

What it means to your agency:

System and Cultural Barriers

- Disability organizations in general have lack of information and resources on sexuality and abuse prevention for individuals with I/DD
- Lack of resources and coordinated response
- Attitudinal barriers
- Oppression and devaluation of people with disabilities
- Discrimination and oppression become internalized and results in poor self esteem

Reactive vs. Proactive?

Reactive

- In response to a situation
 - i.e. no more hot dogs at the company picnic because someone choked on a hot dog the year before.

Proactive

- Assessing the person as a whole (wants, needs, interests)
- Creating or modifying a situation by causing something to happen rather than responding to it after it has happened (of a person, policy, or action)

REAL LIFE EXAMPLE

(Hingsburger example)

Consequences of a Reactive Approach

As sighted The Colorado Developmental Disabilities Council Sexuality Policy (2011)

WHY IGNORING 'THE' ISSUE CAUSES HARM

The person learns that...

- all sex is wrong
- there is no time or place that is appropriate
- sex is not an ok expression of affection
- sex is something to avoid talking about and doing
- sex is to be punished and never to occur under any circumstance
- there's no context to discuss the topic much less grow and develop as a part of experience and discussions
- there is no way distinguish between health and unhealthy sexual experiences

Continued...

- Oppression and avoidance of sex will lead to the oppression of natural desire and behavior and may lead to other much more serious problems. Obtaining legal guardianship will not stop people with disabilities from being sexual.
 - As sighted The Colorado Developmental Disabilities Council Sexuality Policy (2011)

Starting Point: Policy

- Commit to change and communicate it across your agency
- Prioritize the sexuality needs of the individual (putting supports in place)*
- Make it a team effort (connect with other professionals, collaborate)
- Don't recreate the wheel (learn more about sexuality education, review what has already established)

Start with Philosophy/Communication

- YAI example:

“Sexuality is a basic biogenic need and integral to the total way in which an individual relates to his or her world as a male or female. It includes not just sexual activity, but also the acknowledgement of feelings, ways of relating to self and others, self-esteem, gender identification, and sexual orientation. Individuals with ID/DD share the need to love and be loved, and as consenting adults to establish relationships with person of their choice and to express their sexuality so long as they are not injuring themselves or others. Staff need to be trained to help consumers develop healthy and functional expressions of their sexuality.”*

Informing Policy

- Center the person (creating a safe space for the person to talk about sexuality)
- Avoid judgment and projection of personal values or discomfort
- Ensure the privacy of each individual
- Promote self-care and social independence among persons with disabilities
- Advocate for appropriate sexuality education
- Help provide knowledge and/or identify a source of information

LET'S LOOK AT
SOME EXAMPLES



People living with a cognitive or developmental disability have the right to:

- ▶ develop self-identity, self-esteem, and self-respect;
- ▶ make choices regarding healthy and safe relationships and sexual expression;
- ▶ be supported to make informed choices;
- ▶ grow up and be considered an adult by their family and support team;
- ▶ be treated with respect and dignity;
- ▶ be supported in their decisions about sexual relationships through a person-centered process;
- ▶ have the support they need to meet their goals and aspirations, including sexuality and relationships.

Sexuality refers to the whole self—our thoughts, feelings, beliefs, behaviors towards ourselves and others...It is also our understanding of our own body and how it works...it is an intrinsic part of who we are, how we perceive ourselves and how we are perceived by others.

The Down Syndrome
Association of Malta



To ensure this happens, the support team will:

- ▶ Value the voice of, and advocate for the rights of, people living with cognitive and developmental disabilities;
- ▶ Support and advocate with families;
- ▶ Promote inclusion;
- ▶ Involve people in decisions about their own lives;
- ▶ Provide support that promotes self-development and independence;
- ▶ Treat people and their families with respect;
- ▶ Respect the cultural, family, and community values of each person and their family.

YAI Sexuality Policy

Impact

Published by the Institute on Community Integration (UCEDD) & Research and Training Center on Community Living



As Nick (left) was growing up, he and his father David (right) found ways to have meaningful conversations about life, including sexuality, which helped Nick become a confident man who has strong relationships. See story below.

Identity, Disability, and Sexuality: Reflections From a Son and His Father

by Nick and David Wilkie

We – Nick and David – are a colorful son and father duo who reside in the Twin Cities. We both work in the human services field. David (dad) works in health care and Nick works for the Metropolitan Center for Independent Living. For this article we were asked to reflect on the father and son conversations about sexuality we've had over the years. In order to write it we really needed to do some thinking about who we are, and the philosophical approach we have taken toward the topic and our lives. These are our reflections. We hope you enjoy them.

Nick's Perspective

I feel very fortunate to have grown up in a household where my differences and challenges were not the first thing everyone talked about. This was a key part of the philosophy that my dad took on in raising me. When my dad would introduce me to people he would say, "I would like you to meet my son Nick," and not, "I would like you to meet my son with a disability." This was crucial in my identity development. To have that separation between me and my disability made all the difference in the world. Carrying that separation throughout the rest of my family and friends was challenging at times, but overall it proved to be very successful. Once family and friends saw that my disability did not change the way my dad saw me, or the way that he treated

[Wilkie, continued on page 34]

*Feature Issue on Sexuality and
People with Intellectual, Developmental
and Other Disabilities*

Volume 23 - Number 2 - Spring/Summer 2010

From the Editors

As this *Impact* issue is about to be published, one of the pioneers in sexuality education for persons with disabilities has just passed away. Her name is Winifred Kempton and one of the reasons this *Impact* issue is able to provide the depth and breadth of information it does is that she was among those who, over 40 years ago, publicly acted on her conviction that individuals with intellectual, developmental and other disabilities have the right and need to receive information about sexuality. The tools she created for sexuality education (including a dozen books as well as sexuality education programs she authored or co-authored) approached individuals with disabilities as fully-formed people with an intrinsic right to know about and participate in this part of the human experience. She was a genuine advocate in the truest sense, and will be missed.

Today, other pioneering voices are carrying on that advocacy and education work, and in this issue of *Impact* readers will have the opportunity to hear from some of them as they talk about the range of issues that are part of sexuality in its fullness. It's our hope that the articles gathered here will provide information and inspiration that further support the right and opportunity for people with intellectual, developmental, and other disabilities to understand and express this essential dimension of human life.

What's Inside

Overviews
Personal Profiles
Resources

COLLEGE OF EDUCATION
+ HUMAN DEVELOPMENT

UNIVERSITY OF MINNESOTA

YAI social/sexual areas addressed:

- Choices of consent
- Friendships and relationships,
- education and information,
- sexual expression,
- Reproduction and contraception
- Sexual behaviors

Slide Source:

<https://ici.umn.edu/products/impact/232/>

Guiding Principles

- People with developmental disabilities have sexual feelings, needs and identities and have the right to privacy and sexual expression.
- People with developmental disabilities have the right to develop consenting intimate relationships, live with a partner or to marry.
- People with developmental disabilities have the right to have their sexual orientation respected.

Background

Sexuality is a complex and challenging subject area, especially with respect to people with developmental disabilities for whom sexuality has often been denied, ignored or repressed.

Historically families, professionals and policy makers have erroneously believed that people with developmental disabilities are not able to make responsible choices in regard to sexuality issues. Consequently they have been denied access to sexuality education, freedom to establish loving relationships and freedom of sexual expression. Attempts by persons with disabilities to express their sexuality have often been discouraged and interpreted as being socially inappropriate.

Lack of awareness and information about sexuality leaves people with developmental disabilities vulnerable to sexual abuse. Research has indicated a higher incidence of sexual abuse of people with disabilities and that the majority of sexual abusers are well known to the victim.



**Advancing Rights, Building
Awareness, Inspiring Action**

Since 1955

Policy Statements

1. People with developmental disabilities have the right to:

- be provided with information and education on human sexuality;
- express their sexuality;
- establish relationships;
- marry or live together;
- have children; and
- make choices in all areas of human sexuality.

2. People with developmental disabilities have the right to be supported to access sexual and reproductive health care

3. Care providers have the responsibility to ensure that people with developmental disabilities have access to sexual and reproductive health care.

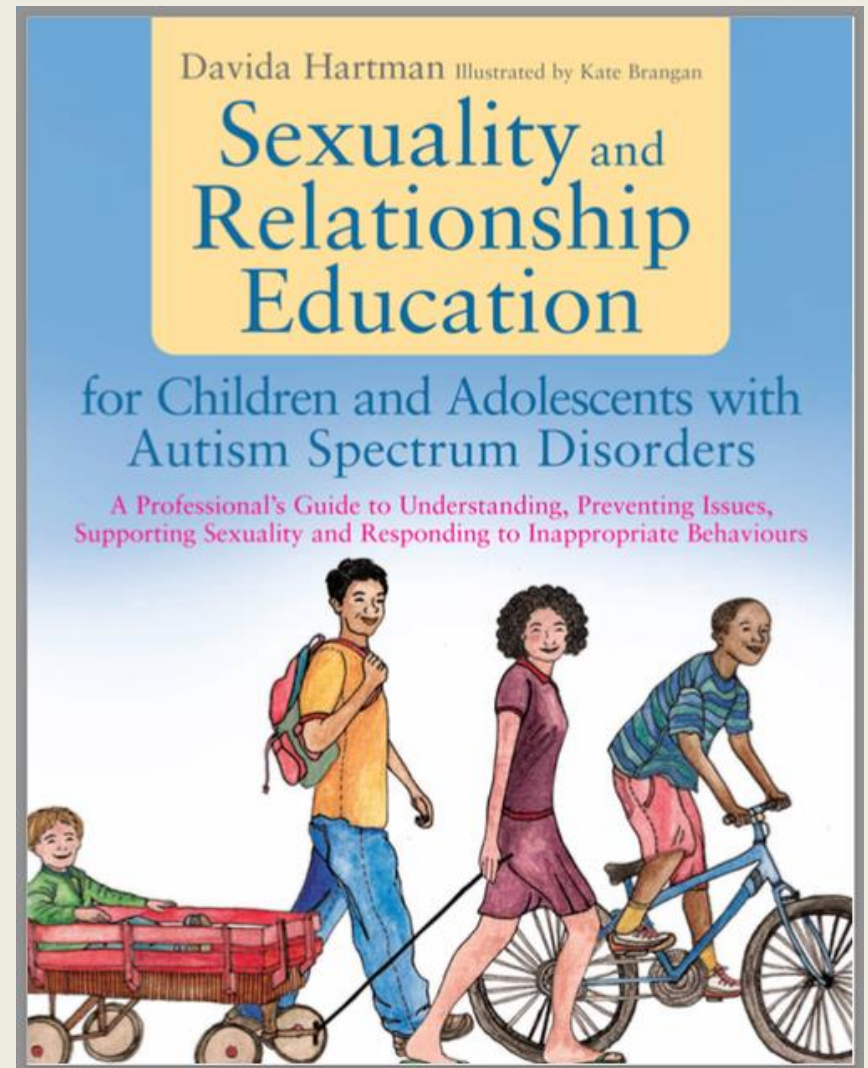
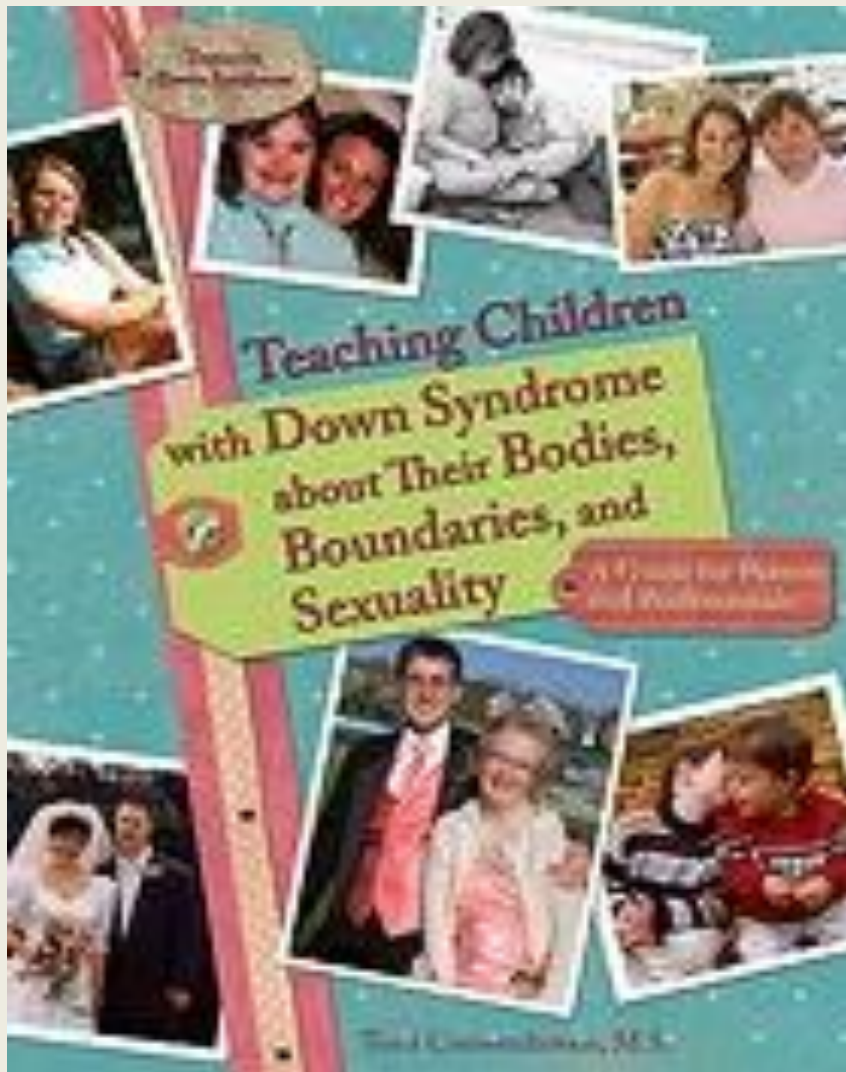
4. Care providers have the responsibility to deliver supports and services in a way that respects a person's sexuality.

EDUCATION
IS THE MOST
POWERFUL WEAPON
WE CAN USE
TO CHANGE THE WORLD

- NELSON MANDELA



Resources



YAI Relationship Series

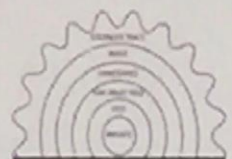


- **DVD #1:** The Friendship DVD and CD-ROM Workbook
- **DVD #2:** The Boyfriend/Girlfriend DVD and CD-ROM Workbook
- **DVD #3:** The Sexuality DVD and CD-ROM Workbook



Leslie Walker-Hirsch & Marklyn Champagne

- Teaches about relationships, socially appropriate behaviors, and boundary setting.
- CIRCLES: Safer Ways addresses communicable disease and STI prevention

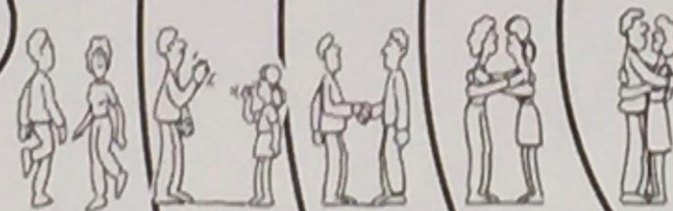
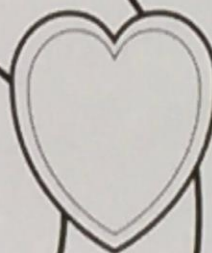


CIRCLES

PERSONAL GRAPH



TOUCH TALK TRUST



Public Health — Seattle & King County

Public Health Centers and other office locations

[Birth control and STD clinics](#)

[Sexuality health education](#)

[FLASH curricula for schools](#)

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FLASH lesson plans for Special Education

While transparencies are embedded in some of the lessons, they have also been pulled out and separately indexed in PowerPoint format to make it easier to access and print those off.

Section	Title	PowerPoint	Updated
Overview	Overview		Jan./12
Lesson 1	Introductory Class	PowerPoint	Dec./05
Lesson 2	Private & Public		Dec./05
Lesson 3	Relationships, Day 1: Self-Esteem	PowerPoint	June/13
Lesson 4	Relationships, Day 2: Gender Identification		June/13
Lesson 5	Relationships, Day 3: Families		June/13
Lesson 6	Relationships, Day 4: Friendships & Dating		June/13
Lesson 7	Relationships, Day 5: Acquaintances & Strangers	PowerPoint	Dec./05
Lesson 8	Communication, Day 1: Non-Verbal Communication		Feb./06
Lesson 9	Communication, Day 2: Assertiveness		Feb./06
Lesson 10	Communication, Day 3: Asking for What You Want	PowerPoint	Feb./06
Lesson 11	Communication, Day 4: Hearing "NO"		Feb./06
Lesson 12	Communication, Day 5: Saying "NO"	PowerPoint	Feb./06



*An Effective Strategy-Based Curriculum for Abuse Prevention
and Empowerment for Individuals with Developmental
Disabilities -- Now*

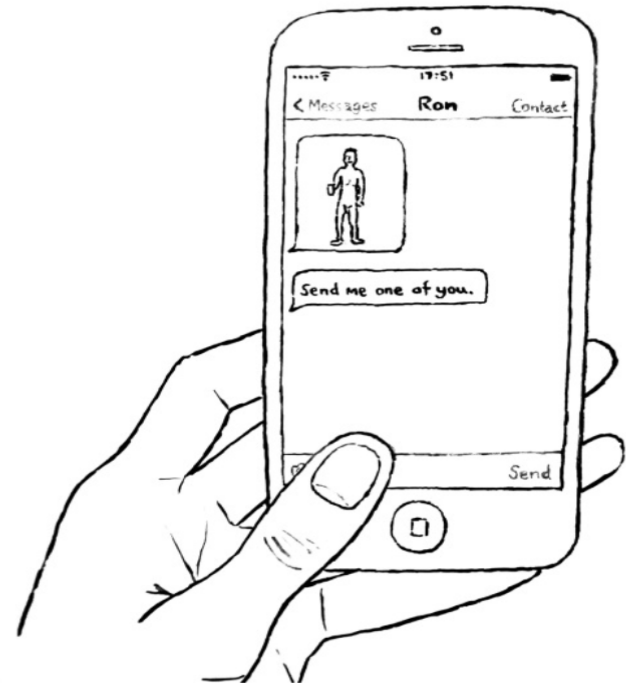
www.escapenow.wikischolars.columbia.edu

Ishita Khemka, Ph.D., Associate Professor, St. John's University &

Linda Hickson, Ph.D., Professor Emerita, Teachers College, Columbia
University

Jamal works at the supermarket. Jamal's boss, Ron, asks for Jamal's phone number so that he can send Jamal his work schedule for the next week. When Jamal gets home, he has a text message from Ron with a naked picture of Ron and a message that says, "Send me one of you."

(Vignette 5)



Tyrone lives at home with his grandmother. Sometimes, Tyrone's grandmother asks him to do something for her. Whenever he makes a mistake, his grandmother pushes him very hard.

(Vignette 8)



STEP 1: PROBLEM?

How does _____ feel?

Is there a problem of abuse in this situation?

 Hurt on purpose and Upset
ABUSIVE RELATIONSHIP

or

 Safe and Respected
HEALTHY RELATIONSHIP

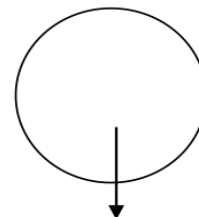
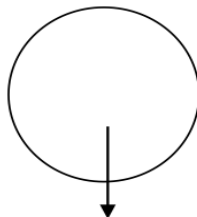
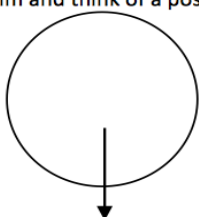
☐ Yes, there is a problem.

☐ No Problem!

STEP 2: CHOICES?

What are the possible choices?

Be calm and think of a possible choice.


STEP 3: CONSEQUENCES?

Would the choice meet the 2 safety goals?

1. Safe Now
2. Safe Later

Would the choice meet the 2 safety goals?

☐ Yes,
choice meets
both safety goals
(Safe Now and
Safe Later).

☐ No,
think of
another
possible
choice.

DECISION

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DECISION
STEP 4: DECISION?

Decide how to act upon the selected choice?

What can _____ do to stop the abuse right away? _____

What can _____ do to make sure that the abuse does not happen again? _____

ESCAPE-NOW: Basic Structure

ESCAPE-NOW consists of 3 units:

- **Unit I:** Knowledge of Abuse & Empowerment (Lessons 1-5, approximately 30 to 45 minutes per session)
- **Unit II:** Decision-Making Strategy Training (Lessons 6-12, approximately 30 to 45 minutes per session)
- **Unit III:** Support Group Sessions (6 sessions, approximately 30-45 minutes per session)

Connect with Us!

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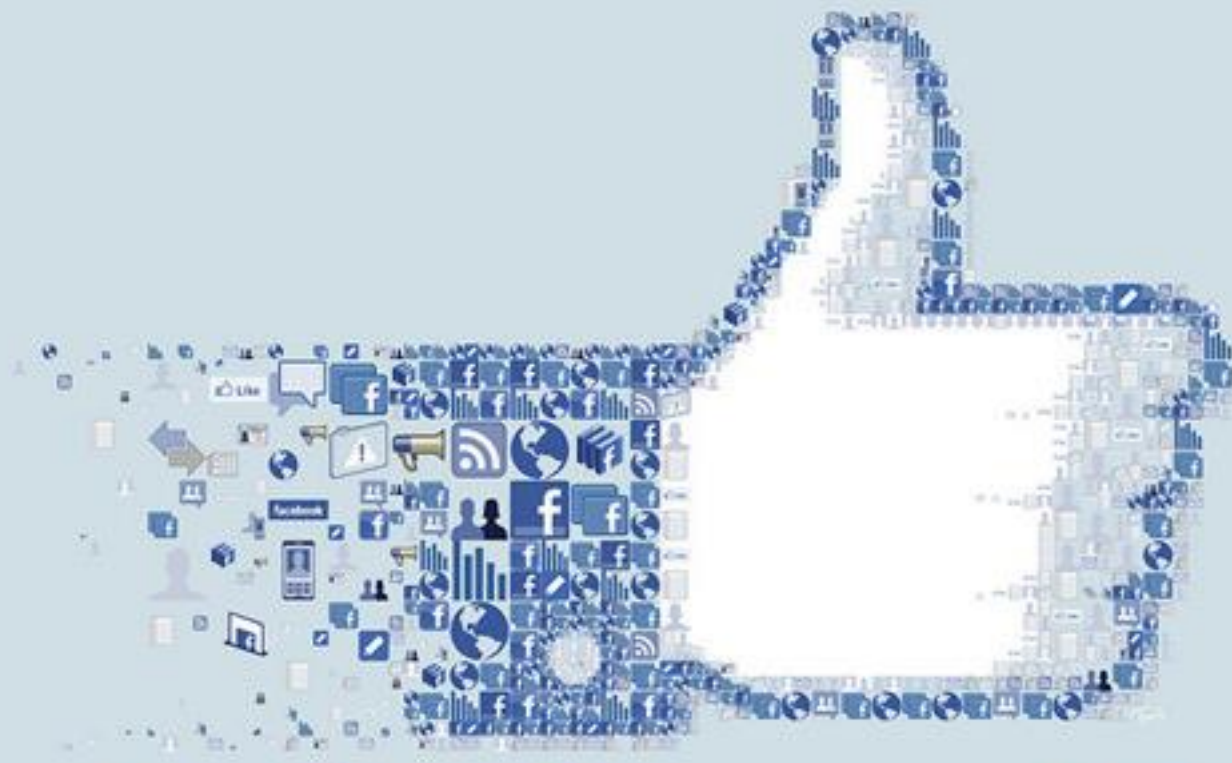
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*Putting You **FIRST!** Finding **I**ndividuality, **R**espect, and **S**afety **T**ogether*



What's next?

Next Steps:

Remember...

- Commit to change and communicate it across your agency
- Prioritize the sexuality needs of the individual (putting supports in place)*
- Make it a team effort (connect with other professionals, collaborate)
- Don't recreate the wheel (learn more about sexuality education, review what has already established)

Q&A



Sexuality Policy Resources

- **Inclusion BC:** <http://www.inclusionbc.org/about-us/social-policy-positions/sexuality>
- **Colorado Developmental Disabilities Council:**
coddc.org/Documents/Sexuality%20Policy%20rev%202-19-2016.doc
- **University of Minnesota Institute on Community Integration Impact:** <https://ici.umn.edu/products/impact/232/15.html>
- **Partners for Inclusion (UK source):**
www.partnersforinclusion.org/documentdownload.axd?documentresourceid=39

Sexuality Education Resources

- **CIRCLES Programs are distributed by the James Stanfield Company**
<https://www.stanfield.com/product/circles-curriculum-bundle-w1037-3/>
- **YAI Relationship Series:**
<https://www.yai.org/trainingstore?title=field+value=&field+topic+value=Social+Skills+%26+Sexuality&field+store+category+value=All>
- **Sexuality Information and Educators Council in the United States:**
https://www.adolescenthealth.org/SAHM_Main/media/2017-Speaker-Handouts/Sexuality-Education-Resources-for-Intellectually-Impaired-Adolescents-docx.pdf
- **ESCAPE NOW:**
www.escapenow.wikischolars.columbia.edu

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