

Supporting and Balancing:

A Person's Right to a Healthy, Consensual Sexual Life

The Arc Alliance Advocacy Services

Presented by
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It's About You

Your experiences, whether professional or personal, shape the perspective you ultimately bring to bear on how individuals with disabilities receive the services and supports that you provide.



Pandora's Box

Anxiety/stress

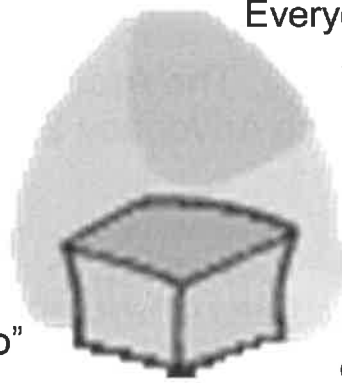
Everyone not on the same page

Fear

Uncertainly

Lack of "how do"

Personal experiences



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Making the Connection

- ▶ Sexual Health
 - Boundaries, Rights, Responsibilities
- ▶ Vocabulary, Sexual Verbal Expression
 - Understanding social contracts
- ▶ Criminal Justice System
 - Equal Justice for
 - Victims, witnesses, defendants

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Positive Environment

People with IDD have the rights to sexual expression and information about their bodies and sex.

Support workers need comprehensive education on issues of homophobia, hetero-sexism, and the spectrum of orientations: LGBTQQIA – lesbian, gay, bi-sexual, transsexual, queer, questioning, intersex and asexual.

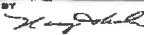
Support workers do not have to agree or share the same values as the people they support; but, should respect the values and attitudes of the people they support.



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OFFICE OF DEVELOPMENTAL PROGRAMS BULLETIN

ISSUE DATE April 13, 2018	EFFECTIVE DATE April 13, 2018	NUMBER 00-18-01
SUBJECT Guidelines Concerning Sexual Health, Personal Relationships, and Sexuality		BY  Nancy Thaler, Deputy Secretary for Developmental Programs

SCOPE:

Individuals and Families
Administrative Entity Administrators or Directors
County Mental Health/Intellectual Disability Program Administrators or Directors
Supports Coordination Organization Administrators or Directors
Providers of Targeted Support Management
Providers of Consolidated, Person/Family Directed Support, Community Living, and Adult Autism Waiver Services
Providers of Adult Community Autism Program Services

PURPOSE:

The purpose of this bulletin is to distribute "Sexual Health, Personal Relationships, and Sexuality Guidelines" and encourage provider agencies to develop policies consistent with the Guidelines.

BACKGROUND:

In 2016, the Office of Developmental Programs contracted with the Institute on Disabilities at Temple University to form a cross-system, statewide committee of individuals with disabilities, professionals, family members, provider organizations, educators, medical professionals, and direct care staff to review and update the Department's Guidelines Concerning Sexuality, which were distributed in 1998. The committee has developed "Sexual Health, Personal Relationships and Sexuality Guidelines" to support the sexual health and relationships of individuals with disabilities.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The appropriate Regional Office of Developmental Programs

Visit the Office of Developmental Programs Web site at
<http://www.dhs.pa.gov/provider/developmentalprograms/index.htm>

DISCUSSION:

Sexuality at it's core is a natural and integral part of who we are. It begins at birth and extends over our life span. It influences how we feel about ourselves and our relationships. The Guidelines are being issued to:

- Promote an environment where individuals with disabilities can pursue personal relationships and their sexuality.
- Promote an environment where individuals with disabilities can receive objective, non-judgmental, comprehensive information regarding sexual health and relationships.
- Establish an expectation that provider agencies develop policies on sexual health, personal relationships, and sexuality consistent with the Guidelines.

ATTACHMENT:

Attachment 1 – Sexual Health, Personal Relationships, and Sexuality Guidelines

OBSOLETE BULLETIN:

Bulletin 00-96-23, "Guidelines Concerning Sexuality," issued December 31, 1996

The Objectives of These Guidelines Are to:

1.Promote an environment where individuals with disabilities have the right to pursue personal relationships and their sexuality and experience a life that is no different than that of individuals without disabilities, without being neglected, exploited, or abused.

2.Ensure that individuals with disabilities have the same opportunity to receive accurate sexual health and relationship information as individuals without disabilities.

3.Establish an expectation that provider agencies develop or review their policies on sexual health, personal relationships, and sexuality. The policies should support the concept of Everyday Lives and be consistent with the below considerations.

Everyday Lives Values as They Apply to Sexual Health, Personal Relationships, and Sexuality

1. Individuals with disabilities are sexual human beings with their own cultural, religious/faith, ethnic, and family values.
2. Individuals with disabilities have the right to enjoy their personal relationships and sexuality in a safe, consensual, and legal manner, while respecting the rights of others.
3. Individuals with disabilities have the same basic rights as individuals without disabilities to self-identify their gender, sexual orientation, and sexual preferences.
4. Individuals with disabilities have the right to accessible and appropriate education, information, and resources that address their individual personal relationships, sexual health, and sexuality needs.
5. Individuals with disabilities have the right to privacy when accessing supports and have the right to have information about their personal relationships remain private unless they consent to a disclosure. Privacy covers all forms of communication. Information regarding an individual's personal relationships, sexual health, and sexuality should be considered private and must be treated with respect and dignity.
6. Individuals with disabilities have the right to enjoy relationships and to express their sexuality in a safe manner.
7. Individuals with disabilities have the right to have their sexual health and personal relationships supported by knowledgeable provider agency staff and a knowledgeable Individual Support Plan team.

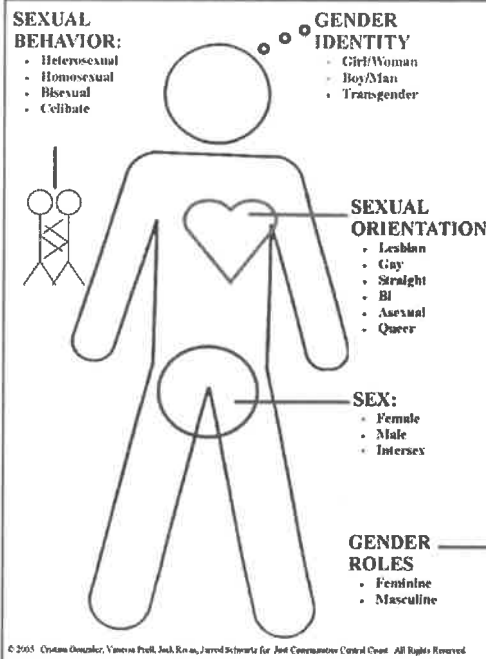
Recommendations for Providers That Are Consistent with Everyday Lives

1. Provide an environment where individuals with disabilities can live like individuals without disabilities and not be neglected, exploited, or abused.
2. Allow individuals with disabilities to access supports in a manner that ensures their privacy. Privacy covers all forms of communication. Information regarding an individual's sexual health, personal relationships, and sexuality is private and must be treated with respect and dignity and handled in a professional manner.
3. Have a positive policy on sexuality that is consistent with the values of Everyday Lives. A positive policy is one that acknowledges and supports a person's right to have a healthy, consensual sexual life, such as hand holding, going on dates, etc., opposed to a negative policy that focuses on "no and can't" in terms of personal relationships. The policy should be reviewed annually by a cross-disciplinary team that includes administrators, direct support professionals, individuals with disabilities, and family members.
4. Provide accessible and appropriate education, information, and resources that address sexual health, personal relationships, and sexuality needs.
5. Ensure that organizational and managerial resources are available to staff to support individuals with disabilities that have issues related to sexual health, personal relationships, or sexuality.
6. Provide resources and training for all staff on understanding, supporting, and responding to sexual health, personal relationships, and sexual issues.

Five Components of Sexuality



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Sexual Development

People with intellectual disabilities experience the same sexual feelings and desires in response to the same situation and stimuli as people without intellectual disabilities.

Sexuality Is More Than Just What You Do

Over the course of a life time individuals will be faced with many decisions around sexuality and relationships.

These may include:

- How to express their sexuality
- When, where, and/or how to become emotionally and/or sexually involved with another person
- Understanding the meaning of “consensual”
- How they want to be treated in a relationship
- How to practice safe sex
- How to take care of their sexual health

Confusion: Public or Private?



SEX, SEXUALITY and TECHNOLOGY

Sexuality

- * Is a continuous experience
- * Is an integrated experience
- * Is shaped by family, culture, religion, education, personal experience, the media

Sexuality

- ▶ Sexuality is the lens of being a male or female through which a person views and responds to the world. (American Association of Intellectual and Developmental Disability, 2009)
- ▶ Sexuality is an integral part of a person's adult life and often a part which is inaccessible or denied to adults with intellectual disabilities. (A. Noonan & Taylor Gomez, 2011)
- ▶ Sexuality is often the source of our deepest oppression; it is also the source of our deepest pain. (Brown and Brown, 2009)

Pervasive Sexual Attitudes Toward People with IDD

Two Assumptions:

1. A person is asexual or hypersexual; or
2. If the person is sexual, they are heterosexual.

Heterosexuality is reported to be the dominant sexual identity in the United States.

Challenges

- ▶ People with IDD are seen as perpetual children who do not need to know about sex, or
- ▶ They are seen as sexually dangerous individuals because they are unable to control their sexual feeling in an appropriate manner.
- ▶ Exclusion and powerlessness perpetuate the conditions which make people with IDD vulnerable to sexual abuse and exploitation.

Unexpected Consequences of Good Intentions

- ▶ Concrete teaching in a fluid world
- ▶ Not my child
- ▶ Friendly ≠ Friend ≠ Friendship
- ▶ “Hovering” parents are not restricted to college students
- ▶ Avoiding “the” conversation isn’t about safety and protection

Concrete versus Abstract

What’s a friend?

How long must you know someone before you are friends?

How do you distinguish between a boy friend and a boy who is a friend?

What’s the difference between flirting and sexual harassment?

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Social/Sexual Perceptions and Consequences: Who Decides ?

- Smirk and a smile
- Hug and hold
- Pat and slap
- Crush and stalking
- Appropriate and Inappropriate behavior
- Inappropriate behavior and criminal behavior

TOUCH

GOOD TOUCH/BAD TOUCH

Touch is tangible and reciprocal (concrete).

Describing touch is based on speech, vocabulary, experience, culture, and more (abstract).

When describing touch both the sender and receiver must be on the same page, understand the intensity and emotion of the touch.

Concrete vs. Abstract Thinking



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When is an Embrace a Hug or a Hold?

How do you tell the difference?

- ▶ Personal experience
- ▶ Professional experience

Are the consequences the same?

Is a "label" created?

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Communication

Language... Vocabulary

- ▶ *Generational*
- ▶ *Cultural*

Communication

- ▶ Vocabulary
- ▶ Technology
- ▶ Non-verbal
- ▶ Concrete versus Abstract
- ▶ Binary Thinking
- ▶ Euphemisms
- ▶ Sexual
- ▶ People First
- ▶ Identity First

Vocabulary

- ▶ We change our vocabulary depending upon who we are talking to.
- ▶ Parents/guardians often give names to their child's genitals.
- ▶ Can be confusing because of the many different names/meaning given to one word.

Consent

<https://www.youtube.com/watch?v=oQbei5JGiT8>



Take the first
step...you don't have
to see the whole
staircase, just take
the first step.

Martin Luther King, Jr.



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