

**Intellectual Disability And Sexuality:
Understanding And Protecting
Needs, Knowledge And Rights**


John D. Allen, Ed.D.
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Hartford, CT
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Recent Dramatic Changes

- Elimination of term “mental retardation”
- Inclusion of I/DD in popular culture
- Increased sensitivity

Objectives for Presentation

- Historical perspectives
- Study conducted in Connecticut
- Rainbow Support Group
- Professional considerations
- Your thoughts and concerns on sexual expression



Historical Perspectives

- Institutional life
- Disability and civil right movement
- Public awareness

What’s the Problem?

- People with I/DD are
 - sexual
 - entitled to education and support
 - viewed as asexual and childlike
- Sexual expression is a quality of life issue
- Many people with I/DD require assistance
- Historical precedence
- How to change organizational leadership and culture?

Southbury Training School, Connecticut



Mansfield Training School and Hospital, Connecticut



Willowbrook, Staten Island, NY



Vineland Training School, NJ & Dr. Henry Goddard, "Kallikak Study"



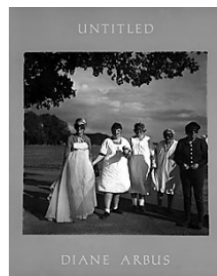
Willowbrook

"We saw children with hands tied and legs bound. we were convinced that one of the major reasons for the heavy use of solitary confinement and physical restraints was the extraordinary shortage of staff ..."

Burton Blatt, 1966
Christmas in Purgatory



Diane Arbus



Public Figures - Dale & Roy Rogers



President Kennedy and sisters Eunice and Rosemary



JFK & Eunice Shriver



Rosemary

Why is sexual expression important?

- Sexuality grounded in biological functioning
- Sexuality emerges in everyone
- Expressed by cultures through rules, attitudes, habits, behaviors, relationships
- Fosters responsibility and independence
- Reflected in popular culture
- But, sexuality is also contradictory, embarrassing, fearful, complicated

Demographic Information

- Estimates of 1-3 % experience I/DD, or 7.5 million people in the US (AAIDD, 2009)
 - 87 % slower than average learning new information
 - 13% score below 50 on standardize IQ tests
- 30 million people in the US are directly affected by a person with I/DD

Sexual Expression and Intellectual Disability in Connecticut

- Study of staff practices and barriers impacting sexual expression of people with I/DD

What is sexual expression?

Sexual expression is an inclusive term

- Sex
- Desire
- Education
- Gender
- Sexual orientation
- Dating, companionship, marriage, divorce
- Parenting

Research Questions

- What are the typical practices of human service staff in Connecticut who assist people with ID to experience sexual expression?
- What are the barriers for staff in facilitating sexual expression by people with ID?

Findings grouped into four themes

- Staff *Beliefs and Knowledge* About Client Sexual Expression
- Staff and Organizational *Practices* Regarding Client Sexual Expression
- Educational and Organizational *Barriers* to Client Sexual Expression
- Staff Perspectives About *Improving Clients' Sexual Lives*

2. Practices

- B. Organizations influence staff responses to client sexual expression
 - Safety is paramount – annual abuse and neglect training
 - Sexuality neither encouraged or denied
 - Self determination policy
 - Parental influence

1. Beliefs & Knowledge

- Staff believe in client entitlement to sexual expression
- Staff acknowledge clients are sexual

3. Barriers

- Staff receive limited training about healthy sexual expression
- Staff operate with compromised organizational support
- Tension between staff practices and barriers

2. Practices

- A. Staff respond to client sexual expression
 - Assess consent
 - Serve as role models
 - Rely on personal experiences
 - Safety is paramount
 - Erotica/novelties used for discussion
 - Sexual self-determination encouraged

4. Improving Clients' Sexual Lives

- Sexuality complicated with contradictions and uncertainty
- Training, not demographics, an indicator of staff permissiveness
- Staff speak of clients in familial terms

Conclusions

1. Staff encounter client sexual expression
2. Staff respond to client sexual expression
 - Assess consent
 - Serve as role models
 - Rely on personal experiences
 - Safety is paramount
 - Erotica/novelty used for discussion
 - Sexual self-determination encouraged

What's Next?

- Advocate for change
- Sexuality Support Groups
- Encourage sexuality training for people with I/DD and their caregivers

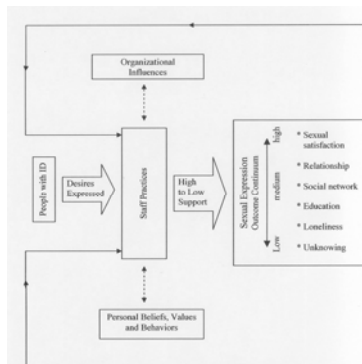
Conclusions

3. Lack of official conversation on client sexuality issues
4. Staff receive limited and incomplete sexuality training
5. Staff want sexuality training

Implications for Practice

- Practical application – incremental reforms
- Full participation in community life requires simultaneous attention:
 - DDS and service providers
 - Staff
 - IDT members - especially parents/guardians
 - Greater community
 - Schools
 - People with I/DD

Sexuality Continuum



Stonewall Inn June 1969



Rainbow Support Group at the Stonewall Inn



Sexual Education Curriculum Product	Provider
Circles Levels I & II: Intimacy and Relationships	James Stanfield Company, Inc. Santa Barbara, CA
F.L.A.S.H. – Family Life and sexual health: Secondary special ed	Seattle King County Public Health Seattle, WA
Life Cycle: How we Grow and Change	Life Cycle Education Consultants Silver Spring, MD
Life Horizons I: The physiological and Emotional aspects of being male and female Life Horizons II: The moral, social and legal aspects of sexuality	James Stanfield Company, Inc. Santa Barbara, CA
Positive Choices: A program on healthy relationships, sexuality and Safe Boundaries for Secondary Students with Intellectual and Developmental Disabilities	Oak Hill Center for Relationship and Sexuality Education Hartford, CT
Sexuality Education for Adults with Developmental Disabilities	Planned Parenthood of Northern NE Williston, VT
S.T.A.R.S.: A Social Skills Training Guide for Teaching Assertiveness, Relationship Skills, and ...	Future Horizon Arlington, TX
Teaching Sexual Health: Students of differing abilities	Alberta Health Services Calgary, AB (Canada)
YAI Relationship Series Part 1: Friendship Part 2: Boyfriend/Girlfriend Part 3: Sexuality	YAI, Inc. New York, NY

A Special Outing



Emerging Issues

- Gender specific, relational and sexual minority based advocacy groups
- Professional development for staff and caregivers
- Understand and put into practice how best to encourage sexual expression



Sexuality Curriculum

- Correct terminology and concepts
- Physiological and emotional aspects of human sexuality
- Relationships and dating
- Personal grooming and hygiene
- Recreational sex, pornography, novelties
- Birth control, abstinence, and STDs
- Abuse and illegal behavior
- Responsibilities of service providers and caregivers

The End



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