



IF WE CAN TALK ABOUT THIS, WE
CAN TALK ABOUT ANYTHING:

ADDRESSING SEXUAL RIGHTS, RESPONSIBILITIES, AND RISK, FOR
PEOPLE WITH INTELLECTUAL DISABILITY

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QUICK EXERCISE

- Write down a relationship or sexual decision you or 'a friend' has made that may have led to 'extra' consequences if done by a person with I/DD?
- Now – share this with the people at your table who will read it out loud and they will write up your plan...

JUST KIDDING...NOT SERIOUSLY...OK – YOU CAN
STOP NOW...TMI...

BUT – CONSIDER THE FACT THAT WE ASK MANY
OF THE PEOPLE WE SUPPORT TO DO JUST THAT
ALL THE TIME

- What would this do to your own concepts of sex or ‘privacy’ or
‘appropriate’?

GOALS AND OBJECTIVES

- EXAMINE HOW ATTITUDES TOWARD SEXUALITY HAVE MIRRORED OVERALL SYSTEMS OF SUPPORTS FOR PEOPLE WITH ID IN THE UNITED STATES.
- INTRODUCE THE THREE R'S OF SEXUALITY - RIGHTS, RISK, AND RESPONSIBILITY ALONG WITH ASSOCIATED PRACTICE IDEAS
- DISCUSS THE IDEA OF 'STANDARDS OF HUMAN BEHAVIOR' AND HOW THESE MAY BE HIGHER FOR PEOPLE IN SUPPORT PROGRAMS
- REVIEW COMMON MISTAKES MADE IN SEXUAL RISK SITUATIONS
- INTRODUCE A MODEL FOR CONSIDERING RISK→CARE DECISIONS

ATTITUDES TOWARD SEXUALITY AS A MIRROR FOR THE STORY OF SUPPORTS

Since the 1800s and continuing to today,
perspectives on sexuality have played a key role in
the formation of our systems of supports for
people with intellectual disability.

(Scheerenberger, 1983; Trent, 1994)

ATTITUDES TOWARD SEXUALITY AS A MIRROR FOR THE STORY OF SUPPORTS

“[O]ur culture’s inability or refusal to deal with very real sexual needs of [people with ID] has been the primary impediment to every farsighted ideological proposal since Wilbur’s advocacy of community placement in the 1850s”

(Conway, 1976, p. 62).

Students → Wards → Threat to Society → Society as a Threat to ‘Them’ → Advocacy/Human Rights → Risk

HEALTHY SEXUALITY

“People with developmental disabilities can develop
healthy sexual relationships
if they live in healthy systems”

(Hingsburger & Tough, 2002, p. 8).

- We are ‘the system’

- Are we ‘healthy’?

WE'VE TALKED ABOUT THIS BEFORE...

IN 2020 WE DID A SIMILAR TOPIC INTRODUCING MANY
OF THESE CONCEPTS.

QUESTION:

AFTER THAT TALK, DID ANY OF YOUR SUPPORT
SYSTEMS CHANGE IN REGARD TO SEXUALITY?

IF NOT, WHY NOT?

THE THREE R'S OF COMPREHENSIVE SEXUALITY SUPPORTS

RIGHTS

-Safety, Education, Privacy, Dignity, Relationships-

RESPONSIBILITY

-Self-Management, Honesty, Boundaries-

RISK

-To Self, To Peers, To Staff, To The Community-

RIGHTS

RIGHTS

“There are things you can replace, and others you cannot.
The time has come to weigh those things...”

Robert Hunter and Jerry Garcia – Althea

BE CAREFUL WHAT YOU ‘TAKE AWAY’, INTENTIONALLY OR NOT.

STATE OF ILLINOIS PUBLIC ACT 101-0506

(SEC. 4-211)

- “Healthy sexual practices’ means a state of physical, emotional, mental, and social well-being in relation to sexuality”
- “...access to sex education, related resources, and treatment planning that supports his or her right to sexual health and healthy sexual practices and to be free from sexual exploitation and abuse”

STATE OF ILLINOIS PUBLIC ACT 101-0506

(SEC. 4-211)

- “Substantial emphasis on prevention of pregnancy, STIs...and stress that abstinence is the ensured method of avoiding pregnancy and STIs”
- “Teach recipients to avoid behavior that could be interpreted as unwanted sexual advances, and how to reject unwanted sexual advances; and...”
- “Explain signs of possible dangers from potential predators”

RIGHTS

SAFETY

Freedom from abuse

Access to lifelong education

System-wide trauma-informed practices

Privacy

Dignity

Relationships

RIGHTS

“It is unethical for therapists to take away one behavior without replacing it with another”

(Hingsburger & Tough, 2002, p. 8)

RIGHTS

BUT...

HOW DO YOU 'REPLACE' SEXUALITY?

RIGHTS

“It would be cruel to work with people with disabilities to incorporate sexuality and eroticism into their sense of self and their expectations and [then] leave them in the very system that forced them to divorce themselves from their sexuality in the first place”

(Hingsburger & Tough, 2002, p. 10).

RIGHTS

Question:

In your role in the system, what will you commit to do to improve the access to relationship and sexual rights of the people you support?

RESPONSIBILTY

RESPONSIBILITY

“You can't overlook the lack, Jack
Of any other highway to ride.
It's got no signs or dividing lines
And very few rules to guide.”

Robert Hunter and Jerry Garcia – New Speedway Boogie

THE GUIDEPOSTS, FACTORS, AND SUPPORTS DIFFER FOR EACH PERSON

RESPONSIBILITY

To go back to the top...

Do we (at least sometimes) hold the people we support to higher standards than we hold ourselves?

Why is that?

RESPONSIBILITY

“If you judge a fish by its ability to climb a tree, it will spend its whole life believing it is stupid”

Unattributed but found in Human Sexuality and The Mentally Retarded, de la Veck and Cruz, 1974

RESPONSIBILITY

In other words...

If we are going to hold people accountable, we need to make sure they understand what they are accountable for and are provided the tools and ongoing support to follow through...

The responsibility, therefore, starts with us.

RESPONSIBILITY

EDUCATION

Understanding Relationship Development

Concepts of Boundaries

Practicing Honesty and Self-Advocacy

Improving Self-Management

RESPONSIBILITY

Question:

In your role in the system, what will you commit to do to improve understanding of relationship and sexual responsibility for the people you support?

ADDRESSING RISK

ADDRESSING RISK

“Watch each card you play, and play it slow.”

Robert Hunter and Jerry Garcia – Deal

**ONCE A SEXUAL BOUNDARY EVENT OCCURS
THERE IS NO TAKING IT BACK**

ADDRESSING RISK

TO HOUSEMATES

To Other Peers

To Self

To Staff

To The Community

ADDRESSING RISK

There is no 'one way' to manage and mitigate risk.

BUT...

Containment is not your friend. (Haaven, J., continuously)

Cost (ethical and monetary), Complacency, Little
Evidence

ADDRESSING RISK

~ Effective Planning ~

Requires Screening of Critical Risk Factors with Matched Supports that are *Adjusted Over Time and Based on Objective Data*

Sexual Drive and Preoccupation

Deviance ('Counterfeit' and Actual)

Offense Management (Self-Management)

Social Connectedness

Individual Contextual Variables

(Medical/Psychiatric, Trauma History)

ADDRESSING RISK

COMMON ERRORS

Failure to take contextual factors into account

- *New housemate(s)*
- *New residence*
- *Life changes (e.g., new job, loss of relationship)*
- *Turnover of key staff*

ADDRESSING RISK

COMMON ERRORS

Failure to account for external and internal destabilizing

factors:

- *Mental Stability/Instability*

- *Medication*

- *Media*

ADDRESSING RISK

COMMON ERRORS

Over-reliance on Yes/No deterministic prediction

It is almost never that simple...

Where, When, With Whom, Doing What, etc...

The intersection(s) of person + environment(s)

ADDRESSING RISK

COMMON ERRORS

“It’s OK in the bathroom”

“Everyone needs a hug”

“Our staff party (or church...) is safe”

“I know why he is staring”

“Family knows best”

“Just another behavior”

“Make sure s/he looks away/Step in immediately”

“We can’t do sanctions”

“I think we should keep this to ourselves/ It’s a private matter”

“The victim isn’t with our agency so...”

“He’s doing fine now so no need to keep talking about this”

ADDRESSING RISK

QUALITIES OF BEST PRACTICE SYSTEMS

Proactive not Reactive

Acknowledgement and Honesty

Individualized Screening and Planning

That is Replicable and Sustainable Across System

Driven by Evidence - Not Assumptions

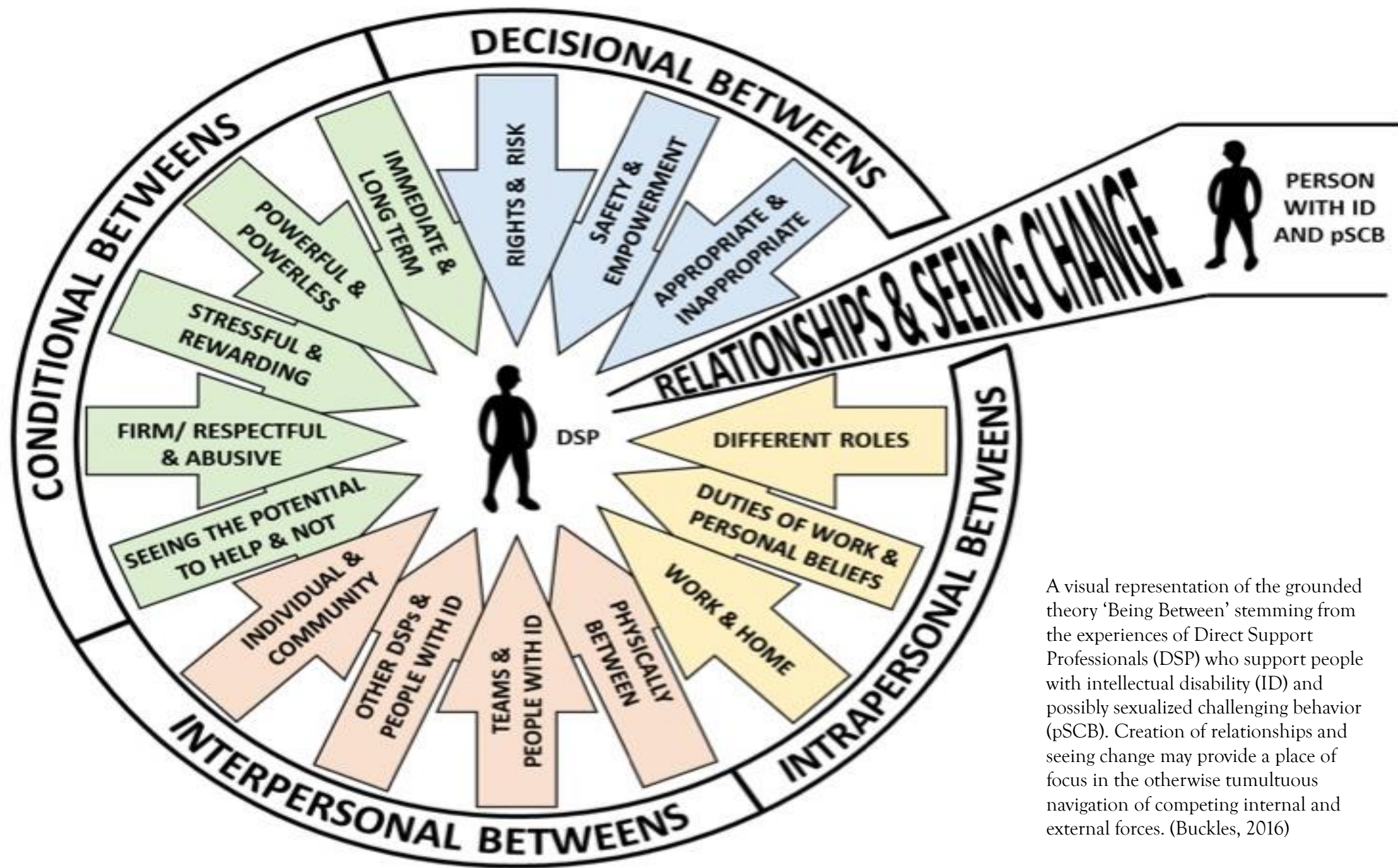
Longitudinal and Updated

Multi-Tiered Clinical Perspectives

Accountability

ADDRESSING RISK

The irreplaceable role of staff and family supports
in the algebra of rights and risk.



A visual representation of the grounded theory 'Being Between' stemming from the experiences of Direct Support Professionals (DSP) who support people with intellectual disability (ID) and possibly sexualized challenging behavior (pSCB). Creation of relationships and seeing change may provide a place of focus in the otherwise tumultuous navigation of competing internal and external forces. (Buckles, 2016)

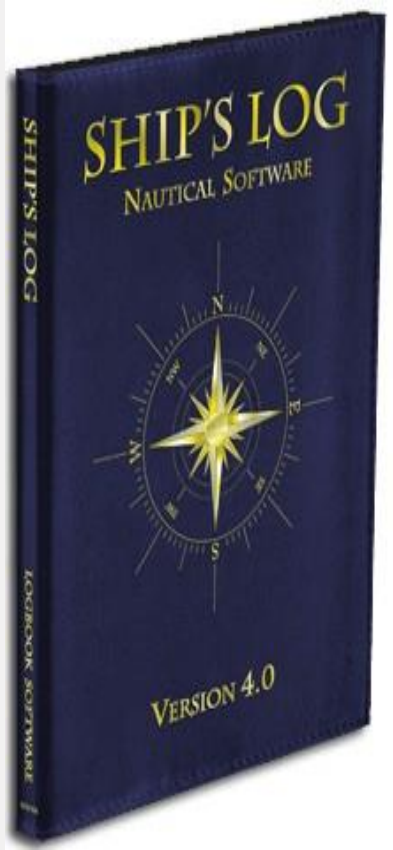
ADDRESSING RISK

Question:

In your role in the system, what will you commit to do to begin to better address sexual risk situations and support staff and families in these efforts?

DECISION MAKING

Sailing The Seven 'C's of Risk/Care Decisions



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CONSIDERATION
CALMNESS
CONSULTATION
COMPROMISE
COLLABORATION
CONSENSUS
CONSENT (*Informed*)
...An ongoing process...

*No action without information.
No information without action.*



THANK YOU

(AND LET'S KEEP TALKING ABOUT THIS..)