Sexual Boundary Violations by People with Intellectual Disability: A Statewide Screening Program

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“[O]ur culture’s inability, or refusal, to deal with the very real sexual needs of [people with intellectual disability] has been the primary impediment to every farsighted ideological proposal since Wilbur’s advocacy of community placement in the 1850s” (Conway, 1976, p. 62).
“It can be easy to feel an urgent need to use whatever means are necessary to reduce risks as quickly as possible. It can be easy for professionals to lose sight of just how much power they hold over people in their charge. Finally, it can be easy to believe that one is not capable of causing harm to people in our care...” (Prescott, 2014, n.p.; ATSA Blog)
~GOALS OF THIS SESSION~

• Brief overview of New Mexico’s current demographics and Waiver program;

• A brief history of the situation in New Mexico that led to our current systems of supports;

• Description of the development and current components of our Preliminary Risk Screening (PRS) program;

• How the PRS program fits in with our overall systems of supports.
First... A Clarification of Terminology

• Yes, the title of this webinar is ‘Sexual Boundary Violations’...

• BUT: Using this term may cause confusion, over-investment in ‘the problem’, misinterpretation of the meaning of a person’s actions etc.
  ▫ In general, the field appears to struggle with what term(s) to use...’sexual offense’; ‘problematic sexual behavior’; ‘inappropriate sexual behavior’; ‘sexualized challenging behavior’; etc.

• For a recent related discussion ~ see Griffiths et al. (2013). ‘Counterfeit deviance’ revisited.
First... A Clarification of Terminology

- Overall—what we are talking about revolves around behavioral patterns that:
  - (a) ‘appear to be’ or ‘are interpreted as’ sexual in nature; and
  - (b) are reported or described as concerning by individuals on the support team.
The Lay of The Land in New Mexico

from: www.census.gov

New Mexico is:

- A very **large state geographically** (5th);
- That is relatively **small population-wise** (36th);
  - 2.08M – almost ½ live in or around Albuquerque
- And very **spread out** (avg of 17 persons/sq. mi; 47th);
- While also being **very diverse**:
  - 39.8% white – non-Hispanic; 47% Hispanic/Latino; 10.2% Native American representing 19 pueblos, 3 reservations; 2% African American; 1% other; 36% of households report language other than English as primary.
- And **generally low income**:
  - $23,749 per capita; $44,886 household

*(Also - an incredibly beautiful, somewhat forgotten, place to live)*
The Lay of The Land in New Mexico

New Mexico’s Waiver System:

- Currently supports approximately **3,900 individuals**;
  - There is a significant registry of individuals awaiting allocation to the waiver as well.

- Provides options for a **wide array of services**;
  - Residential, job development, customized community supports, therapies (OT, SLP, PT), behavior support consultation, case management, respite, sexuality education, preliminary risk screening, crisis supports, etc.

- Over half of the individuals supported on the waiver receive services related to mental health, behavioral concerns, and/or sexuality.
How did we get here? - A (very) brief history

• Institutional History
  ▫ NM had 3 major institutions that served hundreds of individuals with ID;
  ▫ 2 were traditional ICFs; 1 more focused on psychiatry.
  ▫ Now – all large scale residential institutions are closed and the overwhelming majority of individuals are supported in community based settings.

• The Jackson Class Action Lawsuit
  ▫ Allegations of Human Rights Violations in the institutions;
  ▫ Had (still has) portions that relate to provision of behavioral services and sexuality specific tasks.
How did we get here?...

- As part of the 1997 Plan of Action (PoA) from the Jackson litigation, the Department of Health was directed to adopt a **Sexuality Services Plan** to include:
  - a process for “assessing risk, evaluating needs, and planning, delivering, and monitoring supports to persons with sexually inappropriate or sexually offending behavior” (PoA, p. 98).
How did we get here?...

- In response to this plan, New Mexico contracted with James ‘Jim’ Haaven to assist in development of this burgeoning system.
  - This has been a ‘grassroots’ effort, tweaked over time to address/ accommodate unique aspects of our provider network and geography.
Foundational Visions

- **LONGITUDINAL/DYNAMIC IN NATURE**
  - Not based on one-time or solely static assessments.

- **MUST INCLUDE SEXUALITY/RELATIONSHIP CURRICULUM**
  - Available to all ~ individuals receiving support, direct support personnel, families, therapists and so forth.

- **NON-PATHOLOGIZING**
  - A focus on the *whole person, in context* – not ‘just the problem’;
  - No diagnosis;
  - The ‘challenge’ mostly resides within the system – not the person.

- **USER FRIENDLY**
  - Teams are already overwhelmed;
  - Provide a product they can *use* not just file;
  - Provide a way for teams to get further assistance.
Foundational Visions

**MOST IMPORTANTLY**

Our PRS process is intended to be an ongoing educational process for all members of the team.

- Which factors relate to risk and which do not;
- What methods of support mitigate risk vs. what methods may actually increase risk;

Each involved team member works for multiple individuals supported on the waiver. Each PRS session is akin to making multiple ripples in how those who work in this system conceptualize and navigate perceived risk...
So...how do we do it?

• Cast a ‘wide net’:
  ▫ It’s better to have consultation than not...
    • Again, opportunity for education – spreading the knowledge of *risk*;
  ▫ Almost never is an individual ‘screened out’ at intake ~ only if the presenting concern is clearly non-sexual.
    • These can range from aspects of how an individual is treating his/her own body to discrete history of adjudicated sexual offense against others.

• Involve *everybody* – invite disagreement/discussion:
  ▫ *Direct support professionals*, team members, family etc;
  ▫ Consensus decisions and liability.

• Educate to achieve supports that *match the risk*:
  ▫ A focus on ‘Goldilocks’ supports;
What does a PRS session look like?

• In essence:
  ▫ A large-group, face-to-face, facilitated discussion (1-2 hours);
  ▫ Facilitated by a trained screener;
    • Screening - not ‘assessment’- using the ARMIDILLO-S (Boer, Haaven, Lambrick, Lindsay, McVilly, Sakdalan, & Frize, 2013 ~ see www.armidilo.net);
      • Dynamic and Static Risk Factors
      • Dynamic and Static Protective Factors
      • Dynamic and Static Client and Environmental Factors
  ▫ Review of relevant history, current status, and the team’s ‘take’ on what’s going on and what to do.
  ▫ Concludes with a verbal summary and general ideas of what may be changed, adjusted, considered etc.
The Product

- Within a short time after each PRS session teams receive:
  - A summary note (1-3 pages) addressing:
    - The content of the screening;
    - Any recommendations made such as:
      - Immediate actions necessary for safety (if applicable);
      - Areas in need of more information/data;
      - Aspects of support to discontinue, adjust, reconsider;
      - Potential external consults (treatment, formal assessment/evaluation); and
    - Methods of accessing more focused technical assistance from my bureau;
    - A timeline for the next PRS session if applicable.

- In certain complex or concerning situations the team may be provided with a more thorough PRS Report that details more specific history and analysis.
The Numbers

• Since 2006:
  ▫ Approximately 600 separate PRS sessions held;
  ▫ Representing ~180 individuals and their respective teams;
  ▫ Number of sessions range from 1 to 10+ per individual;
  ▫ At any one time we have approximately 90 active cases statewide.
What We Have Found

• Many teams are doing an exemplary job.
  ▫ The balance of risk and rights:
    • E.g. Ioannou, et al. (2014).
  ▫ Increasing social relationships;
  ▫ Eliminating unnecessary restrictions, reducing supports;
  ▫ Providing access to education, training, and treatment where indicated.
What We Have Found

• The main **challenges** we see are:

1) **Overestimation of risk**, which can lead to:
   
   • A pathologizing perspective, ‘over-support’, unnecessary restrictions, human rights concerns.
   
   • These types of ‘over the top’ interventions may actually serve to *increase* the risk ~
     
   • People are ‘boxed in’, frustrated, irritated etc.

**IDEAS:** Ongoing outreach and education. Patience, persistence, and follow-up.
What We Have Found

The main **challenges** we see are:

2) **Getting started/Keeping momentum – Team Level**

- Taking the first steps away from ‘containment at all costs’ can be difficult;
- Even small ‘bumps’ (whether real or perceived) can set progress back significantly.

**IDEAS:** Focused technical assistance from the Bureau of Behavior Supports.
What We Have Found

• The main **challenges** we see are:

3) A difficulty retaining focus on **development of relationships** (not necessarily sexual in nature).
   • Peers, social relatedness
   • This is a key factor in risk management/reduction:
     • connectedness, accountability, having ‘a *life*’

IDEAS: Again – persistent small steps, education, and finding/highlighting ‘success stories’
What We Have Found

• The main **challenges** we see are:

4) **This all can easily slip away...**
   • If the PRS system is such a good idea, why is buy-in so difficult at times?
   • There are natural barriers to implementation and continuation on most teams:
     • Fear, conflicting opinions, accountability...

**IDEAS:** Education; outreach; working-through rather than against.
How does the PRS service fit in the larger system?

- **BEHAVIOR SUPPORT CONSULTATION (BSC)**
  - Part of the general support services funded on our waiver;
  - Mental Health Counselors, Social Workers, BCBAs – Approximately 250 statewide;
  - Provide the written assessment and plans regarding behavioral concerns;
  - Translate the PRS recommendations into the overall Positive Behavior Support Plan.

- **FRIENDS AND RELATIONSHIP CURRICULUM**
  - A home-grown curriculum;
  - Now also a funded part of the services available on the waiver;
  - 3 series (each series is 8 sessions over 8 weeks) covering everything from stranger → acquaintance → friend to objective/detailed sexuality education;

- **BUREAU OF BEHAVIORAL SUPPORT**
  - Part of the Department of Health;
  - Oversight and technical assistance regarding BSC to all teams statewide;
  - *Sexuality and Intellectual Disability* – required training for all DSPs, BSCs and other providers. Available to all other interested parties;
  - Involvement in the PRS system development and maintenance.
From Here - Where?

- **Integration of PRS into Medicaid funded services:**
  - **Achieved** as of 2012 NM DD Waiver
  - Now a part of the funded service packages available to all waiver participants statewide!
    - Used to be fully contingent on separate allocated funds on a yearly contract basis.

- **Development of local PRS facilitators:**
  - 4 local providers in various stages of completion;
  - Eventually fade out the use of external consultant in facilitating all of the PRS sessions and move to a more traditional consultant relationship.

- **System Sustainability:**
  - To go beyond this ‘original crew’;
  - This may always be a tenuous topic – easy for the vision and practice to drift or disappear...
References


QUESTIONS, COMMENTS?

Ask them now if there is still time OR

Please feel free to contact me at:

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