

# POSITIVE APPROACHES JOURNAL

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**Sexuality and Social Connectedness**

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**Positive Approaches Foreword**

*“In essence, Positive Approaches is a worldview, in which all individuals are treated with dignity and respect, in which all are entitled to Everyday Lives.”*

—Beth Barol, 1996

The first issue of the Positive Approaches Journal was published in the summer of 1996 and focused on positive approaches in four main domains, environment, communication, assessment and “hanging in there.” In the 25 years since that first edition, we have rebalanced our system so that most people are served in community versus facility settings. During this time, we have also witnessed significant advances in our understanding of trauma, brain development, genetics and treatment options. In spite of these advances, the lessons from that first edition of the journal still hold relevance for us today because, as a system, we still face challenges in supporting people with co-occurring intellectual or developmental disability and a serious mental illness to live Everyday Lives.

As our service systems continue to move away from institutional and congregate care and toward supporting people to be fully engaged in their communities, the need to revive the Positive Approaches Journal became clear to us. People who have dual diagnoses face some of the greatest challenges for true inclusion and being connected with their communities. We need to work together to develop best practices and appropriate services and supports. The Positive Approaches Journal is part of a broad effort to build this capacity and support best practice in service delivery for people with dual diagnosis. The Journal will also allow us to share, communicate and collaborate as we address this very important issue.

We are eager for the submissions that will come from practitioners and theorists here in Pennsylvania that will drive innovation at all levels in our service systems. It is truly very exciting to begin publishing the Positive Approaches Journal again. It is with great pleasure that we present, to you, the Volume 9, Issue 2

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### **Positive Approaches Journal Mission Statement**

To improve lives by increasing capacity to provide supports and services to individuals with mental health and behavioral challenges, intellectual disabilities, autism and other developmental disabilities, using the guiding principles of Everyday Lives and the Recovery Movement.

Through case studies, articles, interviews, and related academic sources, Positive Approaches Journal will strive to feature resources, observations, and advancements that are relevant and timely to professionals and supporters.

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## **Introduction**

Human beings are reciprocal. We feed off of the relationships that we build with those around us.

When an individual is unable to form healthy relationships or has achieved limited attachment to others, the needs the individual has can change, affecting every aspect of his or her life. In this issue of the Positive Approaches Journal, we bring you the importance of social connectedness and supporting people with disabilities in forming healthy and long-lasting relationships.

Most individuals are taught at a young age to greet those around them based on their relationship with others. They learn who they can interact with, how they can interact with them, and what situations they should work hard to avoid. For example, smiling at the person you pass on the street, not sharing personal information with people you do not know, and knowing it is okay to hug a grandmother whom you may not have seen in a few months. We are taught not to kiss our friends and the importance of proxemics (even if we are not taught that particular word for spatial awareness). By grade school, we acquire an understanding of private and public spaces, we have friends, and perhaps a romantic attachment to a peer. We get our hearts broken and we grieve losses but lean on those around us to get through heartache and loneliness. We share happiness with others who are closest to us.

For individuals with Developmental/Intellectual Disabilities and Autism (ID/A), the typical experiences can easily be tainted, skewed, misunderstood, or non-existent. Education in these areas is limited for children with disabilities, and even when that education is present, the information therein may not be retained or fully understood. Couple these factors with the high rate of abuse, neglect, sexual assault, domestic violence, high prevalence of paid caregivers, and institutionalization in the ID/A population, and developing healthy relationships with those around them becomes almost impossible. Therefore, it is ever important to educate and support the individuals we serve in the areas of healthy relationships and sexuality.

In a time where most feel disconnected from the world around them, it has never been more important to utilize a trauma-informed approach to support individuals in building and maintaining healthy relationships. The articles in this issue aim to support the supporters and inspire new ways to address the needs individuals with Intellectual and Developmental Disabilities and Autism have in these areas. The articles also address the essential components of understanding the effects of institutionalization, sexual assault, and domestic violence on relationship building. The reader will find ways to combat the effects on relationships in the face of necessary community restriction measures put in place as a result of the COVID-19 pandemic. By enhancing our understanding of these areas, we can help to build a community with meaningful and healthy connections and continue to move towards best practice for the individuals we support and serve.

Shannon Rico, MA, MS, ABD,

Office of Developmental Programs Clinical Director - Central Region

## The Impact of Internet Access and Social Connectedness Online on Mental Health

Social connectedness, poverty, and internet access are all factors that can affect a person's mental health. High levels of social connectivity have been shown to have a positive impact on a person's mental health. In contrast, findings also show that high levels of poverty are closely related to poor and deteriorated mental health. The COVID-19 pandemic has introduced new barriers to social connectedness, which may be exacerbated by limited access to internet. Not having the ability to connect with friends, classmates, or loved ones due to a lack of access may be further negatively impacting an individual's mental health during these times.

In this issue of Data Discoveries, we explored social connectedness on the internet through Facebook's Data for Good: Social Connectedness Index (<https://dataforgood.fb.com/tools/social-connectedness-index/>). The Facebook Social Connectedness Index dataset shows how strong the online connections are between two counties on a national scale. The map in the data dashboard on the tab labeled "Facebook Social Connectedness Index Map" shows the Social Connectedness Index of all Pennsylvania counties to the rest of the United States. To use the data dashboard, select a Pennsylvania county from the filter in the upper left-hand corner to see the Social Connectedness between the chosen county and the rest of the nation. To see a comparison of the two selected counties regarding poverty, minority population, and internet access, view the tables above the map.

The Facebook Social Connectedness Index measures the relative probability that two individuals across two locations are friends with each other on Facebook. Zoom and hover over the counties on the map to explore scores!



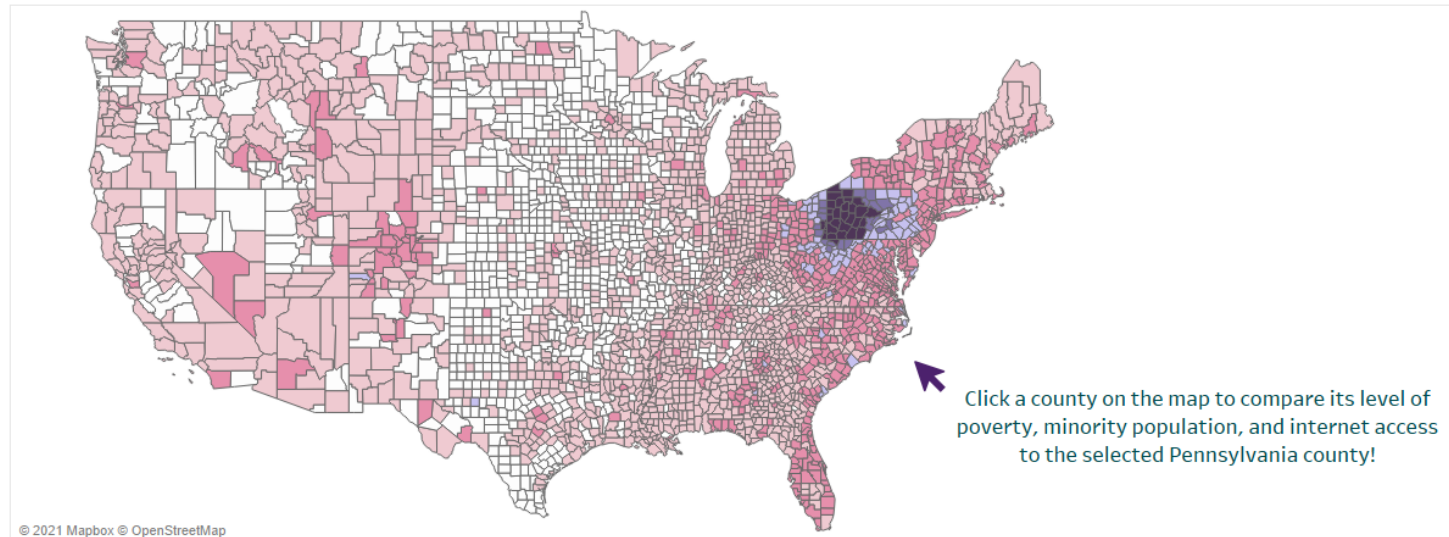
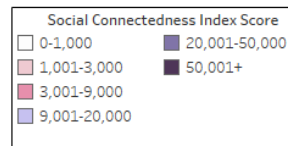
Choose a Pennsylvania County  
Allegheny County

User County: **Allegheny County, PA**

Percent of Population in Poverty: 11.2%  
Percent of Minority Population: 19.9%  
Percent of Households with Internet: 85%

Friend County: **Miami-Dade County, FL**

Percent of Population in Poverty: 16.7%  
Percent of Minority Population: 24.8%  
Percent of Households with Internet: 93%





## **Lessons from COVID-19: The Importance of Social Networks**

**Michael J. Murray, MD**

### **Abstract**

Social connectedness is an important factor in overall health and wellness. The COVID-19 pandemic has revealed the wide health disparities in our country and the enhanced vulnerability from poorly integrated social networks that many individuals with Intellectual and Developmental Disabilities (IDD) experience. This article reviews the structural and functional components of strong social networks, including a review of different types of social capital. Suggestions for evaluating and strengthening social networks according to an individual's expressed goals are offered.

In 1988, three researchers from the University of Michigan made what was for that time a startling claim, which was published in the prestigious journal, *Science*<sup>1</sup>. Their work suggested that “social relationships, or the relative lack thereof, constitute a major risk factor for health—rivaling the effects of well-established health risk factors such as cigarette smoking, blood pressure, blood lipids, obesity, and physical activity.” While the importance of social connectedness for good physical health is relatively well accepted today, this idea was somewhat shocking at the time. Moreover, fostering relationships as a critical component to safety and well-being remains a challenge today, especially for those disadvantaged by circumstance and/or need.<sup>2</sup>

Social isolation activates chronic stress reactions in the brain. This causes marked elevations in cortisol, the body’s main stress hormone. Chronic and repeated exposures to elevated cortisol have negative downstream effects in the body including heightened cardiovascular and inflammatory responses—such as elevated blood pressure and heart rate, chronic pain, and increased susceptibility to illness. Furthermore, this chronic elevation in cortisol—essentially a constant hyper vigilant state, the famed “fight or flight” response—results in greater tendency for impulsive behaviors which can further potentiate these health risks through poor lifestyle choices such as smoking or overeating. Epidemiological research done with large community samples consistently demonstrate that those who are more socially connected live longer and healthier lives.<sup>3</sup>

The COVID-19 pandemic has made even more clear the wide health disparities which exist in our country.<sup>4</sup> Individuals who are Black, Latinx, or Indigenous have more than twice the risk of dying from COVID-19 than White individuals. Additionally, there are also socioeconomic vulnerabilities associated with COVID-19 mortality risk with individuals from disadvantaged backgrounds at highest risk. The pandemic and the enacted infection control/containment strategies have been especially challenging for intellectually and/or developmentally disabled (IDD) communities.<sup>5</sup> At a time of extreme stress, individuals with very complex needs who benefit from high support and consistent routines were frequently provided neither. Furthermore, the community access restrictions enacted to limit the transmission of the virus revealed the social integration

vulnerability many with IDD experience which increases their stress reactions (and all of its downstream ill effects) for a population already at high risk.

### **Social Integration Patterns for Individuals with Intellectual and/or Developmental Disabilities**

Adults with IDD face greater challenges with social integration. Despite desiring a range of social relationships, they experience greater difficulty achieving true engagement due to skills deficits, inadequate supports, lack of opportunity, or some combinations of these factors. Lippold and Burns found that despite being involved in more community-based activities, adults with IDD have more restricted social networks than adults with physical disabilities.<sup>6</sup> Additionally, adults with physical disabilities had a greater balance of relationships with disabled and non-disabled people than adults with IDD. Social support and companionship for adults with IDD is mainly provided by family/caregivers, other individuals with IDD, and paid supports. For individuals with IDD, a key factor in determining successful social integration is the quality of their friendships—frequently by achieving greater balance in interactions with disabled and non-disabled peers.<sup>7</sup>

As the recent community restriction measures have painfully demonstrated, physical presence in a community through participating/attending community-based activities is not adequate for achieving true social integration in that community. As sites were restricted due to public health concerns, many individuals with IDD experienced heightened marginalization during the pandemic as their social integration was highly dependent on physically attending/accessing their familiar routine(s) rather than from the resultant relationships from community participation. In other words, much of their social connections relied on the scaffolding of shared experience (i.e. both doing the same the same thing at the same time) as would be seen with an acquaintance rather than shared friendship which would be less dependent on external structuring.

## Evaluating Social Networks

Post-pandemic, opportunities to safely reintegrate individuals with IDD with their communities will create opportunity for reevaluating community participation activities and the needed supports to achieve greater social integration. Realizing the vulnerabilities that many individuals with IDD face due to their lack of social integration, supporting individuals to develop more robust social networks—comprised of different types of relationships with different types of social partners serving different needs and functions—is of high priority.

When considering social networks, there are a few key concepts to keep in mind. *Social integration* refers to any type of social connection or relationships. Of note, this can range from the most superficial acquaintance to lifelong deep friendships. *Social networks* refer to the web of social relationships surrounding a person. This web crosses domains, settings, and includes relationships of varying degrees of integration. *Structural characteristics* of social networks include<sup>8,9</sup>:

- *Reciprocity*: extent to which support is received and given in a relationship
- *Intensity*: extent to which a relationship offers emotional closeness
- *Complexity*: extent to which a relationship serves many functions
- *Formality*: extent to which relationships exist within organizational or institutional supports
- *Density*: extent to which network members interact with one another
- *Homogeneity*: Extent to which network members are similar to one another demographically
- *Dispersion*: extent to which network members live in proximity to focal person of the network
- *Directionality*: extent to which members of the social dyad share power and influence

Individuals with strong social networks display variability across these domains; in other words, an individual with a strong social network would have some relationships with high reciprocity and intensity and some with low. The pandemic experience has demonstrated that many individuals with IDD social networks are dominated by relationships which are low in reciprocity, intensity, density, and bidirectionality, and high in formality and homogeneity leaving them highly vulnerable to social isolation when, due to public health measures, community settings and activities were not available to scaffold their social interactions.

Social relationships are collections of social behaviors superimposed over interpersonal emotions and attachment. These relationships can serve different *social functions* for an individual—that is what that relationship gives to the individual. *Social capital* refers to the impact of close, bidirectional relationships through providing high-value interactions and resources. Relationships which result in social capital are highly reciprocal and trusting. There are four primary forms of social capital: (1) *emotional capital* provides empathy, love, and caring; (2) *instrumental capital* provides tangible services or aid; (3) *informational capital* provides advice, suggestions, and information which can address problems; and (4) *appraisal capital* provides constructive feedback and affirmation.<sup>10</sup> Relationships can provide more than one type of social capital and the type(s) of social capital can change with time and circumstance.

There are other potential social functions to relationships. *Social influence* is the process by which thoughts, emotions, and/or actions are changed by the actions of others; this influence can be negative—such as imitating an acquaintance’s smoking behavior—or positive—such as exercising with a friend. *Social hindrance* is the process by which one’s attainment of goals is hindered by another’s expressed criticism or negative affect—such as an acquaintance making fun of the choice of a salad for lunch when someone is trying to lose weight. *Companionship* is sharing leisure and other activities with social partners—this is the function of many peer-peer relationships existing within highly structured social/leisure activities such as participating on a bowling team. *Social support* is giving and/or receiving support to another in the context of an ongoing relationship. This

differs from social capital in that these relationships are not highly reciprocal and typically are unidirectional and highly formalized. Most consumer-support professional relationships have this function.

Relationships can have more than one function at any given time. Additionally, relationships are dynamic, and the functions of a relationship are likely to change as the relationship evolves. Most relationships which have a social capital function initially start with a lower function such as companionship or social influence; it takes time and shared experience to develop the reciprocity and trust needed for social capital. However, relationships with social capital are the ones most individuals find most meaningful and which enhance quality of life. Research has demonstrated that social capital is also most influential on health behaviors.<sup>2,10,3</sup>

### **Supporting Social Networks**

A helpful step in supporting the development and enhancement of social networks is to evaluate an individual's current significant social partners and map how they potentially interact in his/her social network. *Table 1* provides a tool to evaluate the structure, function, and potential social capital for an individual's significant social relationships. Given the unique circumstances resulting from the pandemic, space is provided to provide assessment for relationship prior to enacted public health restrictions ("Pre-COVID-19") as well as plan for the initial community reintegration ("Post-COVID-19") and any long-term goals for relationship development ("Goal"). The individual should actively participate in the identification of significant social partners as well as plans/goals formation for potential relationship development as he/she is able. After completing these assessments for all significant relationships, any challenges to developing a strong social network for that person may be more apparent such as little variability in one or more structural components of the person's network or little identified social capital. *Table 2* provides opportunity to begin mapping the positive and negative components (contained across the sum collection of a person's relationships) of the individual's social network. Space is provided to document any identified missing components of the individual's network; of note, any identification of missing components

should reflect the individual's self-determined social integration goals. This mapping might help identify goals for the individual and her/his support team. For example, increased planning for diversifying community exposures may be needed to address high homogeneity and low density across relationships. Similarly, identified social skill deficits interfering with the development of social capital can guide ISP or other goal-setting planning.

Typically, social network interventions in support of health behaviors take one of four form<sup>8,9,11</sup>:

1. *Enhancing existing network linkages.* These types of interventions are useful when an individual identifies a change, he/she would like to see to an existing relationship such as hoping to develop more intensity or less formality to an existing relationship. Of note, for this to be successful, both individuals in the dyad need to be open to this change. Examples of interventions for enhancing existing relationships include specific training in effective communication strategies between individuals, supports to promote more time and diversity in interactions, and specific skills building to address identified deficits.
2. *Develop new social linkages.* These types of interventions are useful when an individual identifies low or absent social connectedness in an important domain such as a place of employment/volunteering or wants to explore new opportunities such as wanting to mitigate negative social influences by exploring new community settings. Intervention strategies here may include mentoring or buddy relationships for new opportunities or facilitating self-help groups for promoting greater self-advocacy.
3. *Enhancing networks through use of existing resources.* This type of intervention takes a systems level approach to promote greater efficacy of an individual's network. Frequently this involves increasing density of interactions of members in the target individual's network or looking for synergistic opportunities between 2 or more individuals' networks. This may take the form of more team meetings between an

individual's residential staff and employment specialists or creating opportunities for individuals and associated members of their social networks jointly participating in an exercise class (strategically blending networks with shared goals/interests to maximize impact).

4. *Enhancing networks through community capacity building.* A person's social network needs may not be easily addressed with existing community resources. This may require creativity in accessing non-traditional sources of support and/or development of novel services. The supports brokerage model reflects this frequent need for expansion of social networks outside of traditional supports.

Social network interventions should always reflect the individual's social integration priorities and are typically most productive when they utilize resources most meaningful to that person.

### **Case Example**

Jillian is a 28-year-old woman with Autism Spectrum Disorder (ASD) and a mild Intellectual Disability (ID) who lives in a group home with 2 other individuals. Prior to pandemic public health restrictions, her high-value community activities included working part-time in a grocery store, attending a community center pottery class, and weekly shopping trips with her housemates. She has not done any of these activities for over 6 months. Her social interactions have been restricted to daily contact with her housemates, regular contact with her residential support staff, and weekly video calls with her sister and parents. Of note, she has not had contact with her coworkers from the grocery store—several of whom she identified as being “friends”—and people from the community center.

To prepare for eventual safe return to community-based activities, Jillian and her Supports Coordinator completed relationship matrix assessments for Jillian's significant social relationships. Jillian identified her two housemates and two most favored staff as being the most significant relationships from her group home setting. She identified her sister, her parents, and one of her



aunts as being the most significant relationships from her family. She stated that two of her coworkers and one of her peers from the pottery class as being significant social partners for her from her community activities.

After completing an individual assessment for each of the identified social partners, Jillian and her support coordinator mapped Jillian's social network:

Function	Who: Relationship(s)	Where: Domain(s)	What: Supports to Maintain Bond
Companionship	Maggie (housemate)  Ella (peer)  Teresa (coworker/friend)  Bill (coworker)	Group home  Community Center  Work  Work	No additional supports  Transportation to CC  Continued employment  Continued employment
Positive Influence	George (staff)  Bill (co-worker)  Beth (sister)	Group home  Work  Family	Continued employment  Continued employment  Way to visit
Social Support	George (staff)	Group home	Continued

Function	Who: Relationship(s)	Where: Domain(s)	What: Supports to Maintain Bond
	Anita (staff)  Beth (sister)  Dominic (housemate)	Group home  Family  Group home	employment  Continued employment  Way to visit  No additional supports
Emotional Capital	Mom  Dad  Aunt Sue	Family  Family  Extended family	Continued health  Continued health  Continued health, way to visit
Instrumental Capital	Mom  Dad	Family  Family	Continued health and financial stability (both)
Informational Capital	Mom  Dad  Aunt Sue	Family  Family  Extended family	Continued health  Continued health  Continued health, way to visit

Function	Who: Relationship(s)	Where: Domain(s)	What: Supports to Maintain Bond
Appraisal Capital	Mom	Family	Continued health
Negative Influence	Teresa (co- worker/friend)	Work	Continued employment and overlapping shifts

They also identified Missing Components:

Function	Target Who	Target Where	Needed Supports and/or Skills
Increase all types of social capital	Beth	Family	Spend more time together and find more meaningful ways to interact
Find more positive influences	Ella	Community	Look for additional shared interests and ways to spend time together

After completing this exercise, Jillian and her team looked for additional ways of strengthening the two relationships which Jillian indicated were priorities for her. After having a discussion with Beth, the sisters decided to spend Saturday afternoons together as a way of increasing the reciprocity and intensity in their relationship which both admitted could be improved. Jillian was excited to share more of her sister's life more routinely and soon added her sister's boyfriend, Mike, to her list of positive influences as she got to know him better. Jillian's Supports Coordinator worked with Ella's supports broker to arrange for the two women to attend a Zumba class together which was also taught at the community center. Additionally, Jillian and Ella went out to dinner and a movie twice a month to spend time with each other outside of the community center. Ella also occasionally joined Beth and Jillian for lunch on Saturdays. At the three-month check-in when she and her Supports Coordinator remapped her social relationships, Jillian shared that she felt that her social network was both expanding and strengthening.

## **Conclusion**

The pandemic has created physical, mental, and social health consequences for most Americans. Due to their generally limited social networks, individuals with IDD may have been particularly vulnerable as the resulting social isolation created by needed public health measures led to significant social disengagement resulting in even greater overall health risks. Community reintegration efforts will allow for more thoughtful consideration of individual social integration goals and opportunity to address or strengthen identified relationship priorities. Examining the structural components of social relationships and then determining the function(s) of those relationships are critical to understanding an individual in the context of her/his social world. Mapping the interactions of these relationships helps identifies area(s) of strength and potential need. Supporting individuals with IDD to create robust social networks not only promotes higher quality of life and better health, it also can be highly rewarding work.

## Social Network Evaluation and Planning Tools

Table 1.

*Individual Relationship Matrix*

Social Partner:	Pre-COVID-19	Post-COVID-19	Goal
<b>STRUCTURE:</b>  <i>(high/medium/low)</i>			
Reciprocity  <i>Shared support</i>			
Intensity  <i>Emotional closeness</i>			
Complexity  <i>Multiple functions</i>			
Formality  Exists within			
Density			

Social Partner:	Pre-COVID-19	Post-COVID-19	Goal
<i>Interactions with other network members</i>			
Homogeneity  <i>How similar to you</i>			
Dispersion  <i>Near to where you live</i>			
Directionality  <i>Shared decision making</i>			
<b>FUNCTION:</b>  Influence:  <i>Positive or negative</i>  Undermining:  <i>Interferes with goals</i>			

Social Partner:	Pre-COVID-19	Post-COVID-19	Goal
<p>Companionship:</p> <p><i>Shared activities and interests</i></p> <p>Support:</p> <p><i>Giving/receiving support in relationships</i></p>			
<p><b>SOCIAL CAPITAL:</b></p> <p>For relationship high in reciprocity, intensity, and directionality</p> <p><i>(emotional/instrumental/ informational/ appraisal)</i></p>			

Table 2.

*Positive Network Components*

Function	Who: Relationship(s)	Where: Domain(s)	What: Supports to Maintain Bond
Companionship			
Positive Influence			
Social Support			
Emotional Capital			
Instrumental Capital			
Informational Capital			
Appraisal Capital			



*Negative Network Components*

Function	Who: Relationship(s)	Where: Domain((s)	What: Supports to Maintain Bond
Negative Influence			
Social Hindrance			

*Missing or Underrepresented Network Components*

Function	Target Who	Target Where	Needed Supports and/or Skills

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## **Biography**

Dr. Murray is an associate professor of Psychiatry and Behavioral Health at Penn State College of Medicine. He is the director of the division of Autism Services for Penn State Health and the director of the central region ASERT collaborative.

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## **Our Contribution to Healthy and Unhealthy Relationships**

**Sharon Mahar Potter, M.Ed.**

### **Introduction**

We, the families, teachers, support professionals, behaviors specialists, and a cadre of others, do our best to support people who have Intellectual Disabilities/Developmental Disabilities/Autism (ID/DD/Autism) For the most part we do a pretty good job. When it comes to sexuality and relationships, we can do better.

Sex is a difficult topic. As a society we use sex to sell pretty much everything from cars to clothing. Social media exposes all kinds of sexual behaviors; seductive language, revealing clothing, twerking! Sex is everywhere, yet we do not discuss it in ways that educate and help people navigate their world.

Depending on our age, our particular family, our religious affiliation, the messages we received about sex vary; “wait until marriage,” double standards for males and females, and ‘shaming’ related to masturbation and most likely no conversations regarding Lesbian/Gay/Bisexual/Transgender/Questioning (LGBTQ) people. Even if we develop our own values and beliefs, those messages remain. Sex education, if there was any, was usually taught separately to male and female students. The content was basic body ‘plumbing’, rarely discussions of intimacy and consent.

How do we actually learn about sex? Maybe we had “the talk” with a parent, or a book might appear, or conversations with friends could enlighten us. In other circumstances, introduction to sex might have been a positive one with romantic partner. For some, sexual abuse was the educator. Considering the rate of abuse among people who have ID/DD/Autism, which is seven times higher than the general population<sup>1</sup>, the issue of sexuality can be quite complicated. This is hard work. We must get out of our comfort zones and address very specific sexual issues in a nonjudgmental way.

We also need to help those we support to enjoy healthy relationships, including sexually intimate ones.

## Sex Education

When I am teaching a sex and relationship class or working privately with an individual, I always let them know they can ask or tell me anything. My classes include the following:

1. Identifying and naming (including slang terms) all body parts and their functions: It is important for everyone to know the proper terms for body parts, but there are many slang terms used as well. One exercise I use is to write one “proper” word on a large paper and ask for any words that mean the same thing. Not only is it educational, but it helps people to relax and perhaps laugh a bit.
2. Masturbation: Many people have been shamed and/or punished regarding masturbation. I emphasize that it is Normal, Healthy, and Private. The ‘Private’ part is critical. For instance, “in a private bathroom” vs. “a bathroom” (which could be a public bathroom such as McDonalds).
3. What is sex exactly? I begin by asking the question, “What is sex?” Responses vary from “doing it” to getting hurt.” Open, honest discussion regarding vaginal/penal intercourse, anal sex, oral sex, and masturbation follow. This overlaps with intimacy, in that you can have sex without being intimate and having both is lovely.
4. What is intimacy? Intimacy is a discussion that often helps people understand that you can have an intimate relationship with someone and not have sex. Many people do not have life partners, yet they have rich full lives filled with friends, family and sometimes pets. As an example, I often ask: “Who would you want to be with or talk to when you are very happy or very sad?”
5. LGBTQ: According to the Gallup/Williams, 2019 Poll, approximately 4.1% of the population is LGBTQ. For people with developmental disabilities who identify as LGBTQ, they often are dependent on Direct Support Professionals (DSPs) and agency resources for respect, privacy, and access to social and support services.

6. Consent: The ability to give and to ask for consent seems simple but it is not. For people with a history of abuse the lines can be blurry. We need to ask questions about knowledge of the law, public and private, conversations before engaging in sex, and the importance of stopping if either one becomes upset. For areas where there isn't a clear understanding, it is our responsibility to educate, or to provide counseling.
7. Safe sex and pregnancy: Although we may have discussed both these in some of the above conversations, we need to provide information on condoms and birth control methods. This is where I discuss STI (Sexually Transmitted Infections). Many people do not realize that oral sex is one of many ways to become infected.
8. What are some sexual positions? For people who have physical limitations, this is extremely helpful. I use a delightful book, *The Cookie Sutra*, which uses people shaped cookies in a variety of positions. I prefer not to use photos since they can be triggers for people with a history of abuse. (There is also a recipe for cookies at the end).
9. Discuss trust and peer pressure: Everyone wants to have friends, someone to go to the dance with; a boy or girlfriend. Unfortunately, "I will be your boy/girlfriend if you will (perform some sexual act)" is all too common. For those in positions of authority, trust can be the tool to offend. "You trust me and know I would never hurt you, right? Just do this one thing for me. It will be our secret." Discussing trust and peer pressure openly can lead to increased understanding and the confidence to say, "NO!"
10. Why is it important to talk about Post Traumatic Stress Disorder (PTSD) when discussing sex and relationships? Considering the rate of abuse related to people who have intellectual disabilities, the presence of Post-Traumatic Stress Disorder is possible. Discussing how past experiences can affect current ones is beneficial for several reasons. Hopefully, discussing the trauma with a professional will help the individual begin to heal and it should also enable them to develop healthy relationships in the future.

## **Lack of Basic Sex Education**

Over the years, there are a few situations that stand out for me. When I am asked to consult, I frequently find two constants. First, an individual struggling with a sexual issue and second, caring individuals who either do not know what to do, or because of beliefs, failed to support the person. Following are examples of information omitted, misunderstood or given in a manner that was confusing and caused unnecessary stress:

Bob, a gentleman in his 30's, lived with his cat, attended a day program and had a part-time job at a local market. He was referred to a therapist for 'suspected bestiality' after being observed holding his cat while aiming his penis at the animal. His cat was taken away. In the process of getting to the bottom of this situation, the therapist evaluated Bob's knowledge of sex and body functions. Bob had a fairly good grasp of basic sexuality except for one critical piece of information. Some well-meaning person told him that, "A liquid comes out of a man's penis and it makes babies." Bob's interpretation of this information was that if he urinated on his cat, she would have kittens. On the surface, rather funny, but not so much for Bob, or the cat! After the therapist provided accurate information and got Bob to repeat the information back to him, Bob eventually got his cat back and acquired a kitten as well.

Todd, a 37-year old man who had Down syndrome and was stealing women's underwear. While attending a birthday party for a female friend, he went into her bedroom and took panties and bras from her drawer. On another occasion, after a visit with his family, staff found undergarments that belonged to his sister. When shopping, he often headed to the lingerie department. Staff were concerned that he might 'escalate' and harm female staff. I met with Todd, and after a fairly brief discussion, it was clear that he believed he was female, technically, a transgender woman, and wanted to wear female underwear. The agency was concerned about his safety and would not agree to clothing that might encourage teasing, harassment or worse, although he was only interested in underwear, not exterior clothing. Following a discussion with Todd and agency staff, they



purchased female undergarments, subtle, but feminine, panties and a matching Cami tops in pale yellow, green, and blue. Once his needs were met, he no longer had a need to steal underwear.

I had a scheduled monthly meeting at a local agency to provide a class on relationships and sexuality. After coming and going for several months, a person with a disability, in his 20's who provided maintenance for the building approached me saying "Heh, you're the sex lady, right?" "Yep, that's me," I responded. He was a man of very short stature and he asked, "Do you know where I can get small condoms?" Although technically, the length doesn't vary much, there are 'snug' condoms which usually are appropriate for those with smaller anatomical needs.

### **Lack of Information Regarding Medical Issues**

Medical issues can be traumatic to say the least. Following are two examples of situations with serious consequence:

George, a delightful, outgoing man, lived in a group home and worked in a local restaurant. He loved his job and had an active social life. The agency that supported him began receiving phone calls from his employer. He was getting erections and bringing it to the attention of, well, anyone in close proximity. He lost his job. He consistently said he didn't want it to happen, but it kept happening. Unable to resolve the issue, I saw in his file that he had a medication change within the past 2 months and contacted the pharmacist who consulted to the state. We learned that one of the rare side effects of the new medication was involuntary erections. Although George was happy about the erections, his life was turned upside down. Another medication was identified, he got his job back and his life returned to normal. A huge thank you to the pharmacist. I highly recommend consulting medical professionals to rule out medications or other medical conditions.

On the 'life- threatening' end of things, I was asked to provide an assessment for Chad, who was hospitalized twice for anal bleeding. He was inserting objects, including ball point pens into his anus. After confirming his knowledge of sexual activity and discussing his injuries, I learned that when masturbating, he inserted 'objects' into his anus to stimulate the prostate, which intensifies

orgasm. With his permission, I met with his DSP and explained the situation. Then I asked, “Why hasn’t someone purchased a device made for this purpose?” The answer was that they didn’t think they could. It was resolved rather quickly. Chad, one of his staff, and I drove to an adult store where a device and lubricant were purchased. Chad was responsible for cleaning and storing the device and he has not had a hospital visit since. I am acutely aware that “topics such this” are difficult to deal with, but until we get out of our comfort zones and provide what adults need to be healthy and safe, people can literally die.

### **Post-Traumatic Stress Disorder**

PTSD is all too common regarding people who have ID/DD/Autism. Talking about sex and relationships can be triggers. I mention this before I begin all presentations or workshops. I spoke at a conference, which was attended by professional staff, family members as well as people who have disabilities. During a 15-minute break, three people who have ID/DD/Autism came to me and shared the following:

First, a woman approached me and crying, told me she had been raped as a teen and she never told anyone. Then a woman who broke up with her boyfriend, but wanted to remain friends, however he would only continue to be her friend ---if she performed oral sex for him--- which she was doing and it made her feel “yucky.” What should she do? Then a gentleman told me that he had touched his niece in her “privates” and knew it was wrong and asked, “What should I do?” Fortunately, there were support staff, therapists and agency personnel present, who stepped in and assisted the three people. The incident regarding the man and his niece was reported to the police. The reason I mention these three people and a connection to PTSD is because the information can trigger reactions, not only of people have disabilities but in the general population. Working in small groups is an opportunity to discuss and support individuals as we move from topic to topic. Susan, 32 and David, 40 were in love and wanted to get married. Although they spent as much time together as possible, they had not yet been intimate. I was asked to meet with them and determine what supports they needed to move forward. David was quite capable, living in an apartment with

some help related to finances and shopping. He had a job as a janitor, and he enjoyed cooking.

Susan had been in several abusive relationships, including being tied to a bed, beaten and raped at 13 and had a child at 14. This was her first consensual relationship. I asked Susan if it would be all right with her to talk with David about her earlier abuse. She agreed. During my next session with them, I said that when they had their first sexually intimate encounter, David might touch her body in a certain way or in a certain place and although David would never hurt her, her body could remember the pain and terror from years ago. We then were able to come up with ways to prepare them for a loving, trusting, sexual relationship. About a year later, they were married and doing just fine.

“Can you please come and help us? Doug is a great guy, he is 25, very athletic, but every once in a while, he beats someone up *for no reason*.” A few days prior to the call, Doug broke the nose of Joe, one of his favorite staff and spent 3 days in a psychiatric inpatient unit. Two months prior to the incident with Joe, a well-meaning woman took a warm towel out of the dryer, opened the bathroom door, just enough to offer the towel to Doug, who grabbed her arm and broke her wrist. Reviewing his history, I learned that as a child, he was sexually assaulted by his stepfather.

Beginning the assessment, I asked Doug to tell me what happened with Joe. He said, “I just got home from work and wanted to take a shower” and Joe said, “Hurry up, dinner is ready.” He didn’t remember what happened, except that everything got red and he hurt Joe. Proceeding with the assessment, Doug had a clear understanding of sexuality, relationships, and understood everything I asked him, including the meaning of consent. Already knowing about his childhood abuse, I asked him if anyone had touched him, sexually, without his consent. “Oh, yea, lots of times. My stepdad would take me into the bathroom and hurt me.” I told him I was sorry that he had been hurt, then I asked him to tell me about the abuse. He said his stepfather would grasp his shoulder and take him to the bathroom. Before he got into the details of the abuse, I asked him to close his eyes and tell me what happened with Joe. He repeated that he just got home from work and wanted to take a shower and Joe said, “Hurry up, dinner is ready,” but this time he motioned that Joe tapped him on

the shoulder. BINGO! I explained that sometimes our bodies remember bad things from the past.

Even though Joe is a man who would not hurt you and you are not a child; your body remembers that touch on the shoulder. He was quiet for a bit, then jumped up, went to the office and came back with Joe, back on the job with a broken nose and two black eyes. He said something like, “Listen Joe, when you touched my shoulder, it was like you were my stepfather and I was a kid, but I am grown, and I know you would never hurt me. I am so sorry.” I must say, it was one of the most profound experiences of my life. Although Doug’s trauma was documented in his file, no one connected the dots.

### **Trust and Peer Pressure**

We all want friends, relationships and social interactions. Things can become complicated when we trust and depend on others. I was seeing Katie, the young woman, mentioned above, whose former boyfriend, was pressuring her to perform oral sex. She now understood that if he really was a friend, he would not be treating her this way. She told him she didn’t want him as a friend, and she was doing very well. During counseling sessions, I sometimes use a simple game used to create situations and discussion. Three paper cubes. One has **names** (boy or girl friend, stranger, doctor, etc.). If I am working directly with a person, my name is on the cube as well. The second cube has **places** (in a movie theater, at the park, on a bus, in my bedroom, etc.). The third has **actions** related to sexuality (tries to kiss me, asks me to take clothes off, touches my breast, etc.). During our weekly meeting, we were sitting at a desk in her room and decided to play the dice game. What came up after tossing them was “Sharon asks me to take my clothes off, in my bedroom.” Katie said, “That’s a hard one.” I was slightly taken back, knowing how far she had come and asked, “Why is that hard?” to which she replied, “Because I trust you.” We continued our discussion to include what kind of things you do with friends, strangers, neighbors, teammates family, partners and people you trust.

## Well-Meaning People ‘Protecting’ Others

There are so many situations where good caring individuals make a situation worse. Families might not want their son or daughter to learn about sex and relationships. “They might want to do it,” or “They don’t understand.” They want them to be safe. My experience has been the opposite; not having accurate information increases vulnerability. Families can provide support in a way that results in confidence and the ability to explore relationships or they can discourage and sometimes shame their loved ones with words or actions that say “No, this is not for you”, or as one man told me “I cannot have a girlfriend because I am retarded.”

Phil lived with his parents until they both passed away, then he moved into an apartment in his sister’s house. There was an incident a few months prior to my involvement. Phil’s sister suspected that a local man, John, was taking advantage of Phil. She waited until she saw his car and called the police, who “caught” the two men involved in a sexual act and arrested John, who was now in jail. There was great concern from the community since Phil and John had been friends since they were children. I was asked to determine if Phil had the ability to give consent and understood peer pressure and boundaries. Following my discussion with Phil, there was no doubt that he and John were in a loving consensual relationship. I asked him if he could talk with his sister about his feelings for John and he said, “I tried, but she said I don’t understand, and I can’t be gay because I am retarded. Besides, she is the only family that I have.” I asked if he wanted me to talk with her and he did not. I was able to provide information confirming consent between the two men and John was released from jail. Needless to say, their relationship did not continue.

Finally, there are countless people who fall under the following scenario. Two people are “caught” involved in some sexual act. Questions are asked, often in a manner that is shaming or blaming, resulting in identifying a victim and an offender, when in reality, they were just trying to figure it all out. I am not suggesting that people with ID/DD/Autism are not capable of assault. I am suggesting that we need to spend time helping people make their way safely through the maze of sex and relationships.

## Conclusion

It doesn't always take an expert in human sexuality to teach and guide, but it does take an open, nonjudgmental mind. Many of us have developed an awareness of our own personal biases based on our experiences and beliefs. When it comes to support, we need to be thorough and precise with sex education, pay attention to medical issues, and seek expert help if necessary. Be aware that the rate of abuse is seven times higher for people who have DD/IDD/autism than the general population. What looks like aggression can actually be a defense mechanism. For well-meaning families and those of us who have earned the trust of people we work with, remember to encourage people to express their own thoughts and opinions, especially if they disagree with us. Saying "no" or "I don't like that" or "that makes me uncomfortable" is a step toward functioning in a complicated world. I love this work and have learned far more than I have taught. We owe it to people we support to teach, support, and guide them through the maze of sexuality and relationships.

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**Biography**

Sharon Maher Potter has experience in three specific areas: Sexuality and relationships and people who have intellectual disabilities, problematic and sexual offending behaviors, and support LGBTQ individuals with or without disabilities. She has a B.S. in Psychology, University of Scranton and M. Ed. In Human Sexuality, Widener University. She has worked in Pennsylvania Protection and Advocacy as an Early Intervention Project Coordinator (1989-1992), and as a Deputy Director (1992-2002). She is the founder of Common Roads, a support group for LGBTQ teens and young adults. She currently serves on CHATID, a committee of Geisinger Medical School that is addressing how the medical community supports people who have ID/DD/Autism.

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## **Building Healthy Relationships Together: Healing the Past to Promote a Positive Future**

**Melissa Skiffen & Shelbi-lynn Moonley**

### **Abstract**

Throughout this article we will explore the challenges that people with disabilities often experience in understanding and forming healthy long-lasting relationships and the detrimental impact this may have on our community. We will further discuss the collaborative effort between Blackburn Center, an agency providing services to victims of domestic violence, sexual assault, and other crimes, and Achieva, a disability service organization, to build a community of practice in order to address these challenges and further promote such healthy relationships among people who have disabilities through Person-Centered Planning and a Trauma-Informed Approach.

## Relationships

‘Relationships’ is a term that brings emotions of intimacy and togetherness for many people. A connection that makes us feel whole. However, what if this was a term that you did not feel applied to you because there was a cultural stigma that felt that you could not understand how to navigate the social normality and consequences of being in an intimate relationship. Therefore, you would fail to benefit from the education of learning about developing healthy relationships, furthering the divide between you and those who are seen as neurotypical. This is the truth for many people growing up with a disability. A student that is segregated in school and is not afforded the opportunity to learn alongside their typical peers may not have the tools needed to build healthy relationships as an adult in an inclusive setting. A sixty-year-old person who spent three decades living in an institution will not have the tools to form healthy relationships with the community they move into. A person who is transitioning from too many years in a 14(c) sheltered workshop to an inclusive workplace may not have the skills to fabricate a healthy relationship. These are only some examples of barriers people who have disabilities experience in forming healthy social connections as well as positive self-images and perspectives of self-worth. People with disabilities are often dismissed in the conversation when it comes to relationships and sexuality. This not only creates a divide in power and control, but further increases the risk of vulnerability to trauma from crimes such as domestic violence and sexual assault.

### **“Nothing About Us, Without Us.”<sup>1</sup>**

This call for policies to include people with disabilities has resulted in a growing movement to promote education and awareness for the needs and inclusion of people with disabilities. Yet, with such consciousness we must also understand the underlying trauma that the disability community has endured and continues to endure at a cultural level in connection to relationships and sexuality. We cannot undo the past, but by building upon two seemingly separate models we can construct a better future. Person-Centered Planning has been commonly used as a model by those who provide services to develop and meet the goals of those with disabilities whereas the Trauma-Informed

Approach has been used especially among domestic violence and sexual assault agencies as a method of addressing trauma. Through recognizing the intersectionality between Person-Centered Planning and Trauma-Informed Approach as well as embracing the lessons from each model we can effectively empower people with disabilities to develop safe and healthy relationships.

### **Person-centered Planning**

Person-Centered Planning places a person who has a disability in the driver's seat of their life. It allows them, often for the first time, to have a seat at the table. It assists them to identify what and who is important to them. What do they envision for a life of personal significance? What do they not want for their life? These are questions we need to be asking every person with a disability we support. Often, people with disabilities, from the time they obtain a diagnosis, have people who are, as Jack Butler, Achieva's Director of Person-Centered Planning describes, "prescribed to be in their lives" (personal communication, November 5, 2020). The Pennsylvania Department of Human Services describes this model as:

"Person-Centered Planning is unlike any other planning you've done before. It focuses on your interests and what you do well rather than on things you can't do or on your needs alone. A Person-Centered plan is a plan for you, not for a system. You, along with your planning group (circle of support) will create a vision for your future and focus on how to get started on working towards your dream. Your Person-Centered Plan will be especially for you and will be different from anyone else's plan since it is based upon you and created with you. You choose the people you want to help plan your life. Your plan is a working tool that puts your thoughts in order."<sup>2</sup>

Person-Centered Planning will organically support healthy relationships when done correctly, but it can overlook the covert signs of trauma and vicarious trauma of those supporting the person at the center of the plan. Hence, we need to incorporate an approach to enhance this model of supportive planning to assist in recognizing not only the signs of trauma but also to contribute to practices that may build upon principles that can potentially prevent re-traumatization.

## The Trauma-Informed Approach

This approach was developed by the Substance Abuse and Mental Health Services Administration (SAMHSA) has been widely utilized by those in the human services field, and is ingrained in the services provided by many domestic violence and sexual assault agencies such as Blackburn Center of Westmoreland County, Pennsylvania.<sup>3</sup> Although this approach was developed by SAMHSA to support those experiencing addiction and mental health concerns, the Trauma-Informed Approach has been evidenced to be utilized in developing tools to support survivors of abuse, and providing educational resources in an effort to support promoting healthy relationships such as through programs that teach empathy and consent. This approach provides a basis of understanding how trauma impacts those receiving support as well as vicarious trauma experienced by professionals, and helps those supportive systems work to resolve trauma-related issues. Rather than assuming that someone has never experienced trauma, it promotes systems that practice this approach to adopt an opposing view which helps to improve the outcomes of those we provide service to. The Trauma-Informed Approach is based on incorporating six key principles into our daily practices.<sup>3</sup> These principles as described below can be adapted to reinforce current supportive models including Person-Centered Planning:

1. *Safety*. Supporting a definition of safety that is determined by the person who is at the center of the plan. This definition encompasses more than one's physical safety but their psychological safety as well.
2. *Trustworthiness and Transparency*. Maintaining transparency in reference to the actions, policies, limitations, and decisions of the circle of support in an effort to build trust that can be modeled in a healthy relationship.
3. *Peer Support*. Highlighting the importance of developing natural supports from other people who have experienced similar events in addition to mutual self-help.

4. *Collaboration and Mutuality*. Reaching out to ensure that those at the center of the plan and supports have a role to play in sharing power and decision-making.
5. *Empowerment, Voice, and Choice*. This notion can build upon the previously mentioned “Nothing about us without us” movement.<sup>1</sup> This principle fosters the notion that people should be empowered and included in decision making, choices, and their goals that they set.
6. *Cultural, Historical, and Gender Issues*. Recognizing and actively responding to the difficult history of trauma endured by the disability community including institutionalization and cultural stigma.<sup>3</sup>

There has been an effort at a statewide level to meld practices that are Trauma-Informed as part of Pennsylvania Governor Tom Wolf’s administration plan that was released in July 2020, titled “Trauma-Informed PA” which brings together a multi-agency effort to “guide the commonwealth and service providers statewide on what it means to be Trauma-Informed and healing-centered in PA.”<sup>4</sup> This plan focuses on areas such as, “ensuring that PA state culture is Trauma-Informed through universal training”, “recognizing and healing from the traumas of major crises like COVID-19”, and “preventing and healing racial, communal, and historical traumas, whether they be individual or systemic.”<sup>4</sup>

### **How Can We Bring These Ideas into Practice?**

Relationships essentially are connections that we share. In order to help those we serve to promote healthy relationships we must model the principles of building such positive relationships ourselves. To implement this into practice it is recommended to include bringing representatives from each human service field into the conversation to see how we can naturally include disability and victim advocates. Part of the advantage of utilizing Person-Centered Planning is the notion that the person the plan is based around is the one that chooses who is included in helping to develop their plan. In order to organically incorporate both disability and victim advocates at the discretion

of the person at the center of the plan, we must recognize and respect the strengths that such fields possess. An advocate from a domestic violence and sexual assault agency may be easily recognized for their ability to offer a perspective on safety planning but also may be able to help with educational needs related to promoting healthy relationships by identifying issues of power and control as a preventive approach to abuse; whereas a disability family support advocate can help navigate the educational system to make these perspectives a reality as part of the person's individualized plan.

Through working together on a variety of projects that focus on supporting the disability community, we have found some practices that we have included to support those involved in Person Centered Planning through the lens of the Trauma-Informed Approach:

1. *Understand the limitations and strengths of local resources through active communication.*

This can assist in addressing barriers such as silos and providing warm handoffs between agencies.

2. *Empower the person with a disability at the center of the plan to develop their own team through openly providing options to include the support of those who can offer different perspectives.* Be sure to include coworkers, acquaintances, professionals, friends, family, and romantic partners in these team discussions.

3. *Ensure that those included understand and are able to model the six key principles included in the Trauma-Informed Approach.*

4. *Allow the person with a disability to define what they want and what they do not want from their relationships.* You may want to, as a team, collaborate to ensure that they have tools to identify different types of relationships including but not limited to that of romantic relationships in addition to crucial information about sexual health. Furthermore, advocate for continuous discussions about domestic violence and sexual assault.

5. *Actively look or collaborate to create opportunities to support and model healthy social connections.* Achieva for example, began a group called Empowered Voices to promote self-advocacy through peer support and regularly invites professionals from other agencies such as Blackburn Center to not only provide education and discussion but also to encourage a natural line of support to its services.

## **A Community of Practice**

Skiffen and Moonley began their collaboration with the hope that they could bring education and a proactive approach to healthy relationships with people who have disabilities. This effort started through a series of community presentations attended by people with disabilities, family members, staff, and other professionals. From there they began working with people individually to help them achieve their goals. Each plan should be unique to the person at the center. How does this all flow together? Below is one example:

A young person in high school began working with a disability advocate as they prepared for graduation. The advocate from Achieva introduced the idea of building a Person-Centered Planning team to help with this transition while utilizing principles involved in the Trauma-Informed Approach. We built upon the principle of ‘Trustworthiness and Transparency’ through getting to know this young person as we discussed what to expect from Person-Centered Planning as well as what was important to them. What did they want to do after high school? Did they want to work or attend a post-secondary education program? Did they want to live on their own or with their parents? Through these open discussions using the Person-Centered Planning model, it was revealed that they, like many people who have disabilities, had experienced trauma.

Therefore, in addition to their employment and living goals, we spoke about healing from the trauma they endured and building healthy long-lasting relationships going forward. For this young person, we needed to support the organic development of healthy relationships as

they transitioned from school age to post-secondary opportunities. Those future opportunities may include college, employment, and also the pursuit of relationships outside of the family home.

Continuing to utilize principles from the Trauma-Informed Approach such as ‘Peer Support’ and ‘Empowerment Voice and Choice’, the advocate offered the young person options of possible people to have join their team from different areas that might be supportive, including a person from a victims’ service agency who is well versed in Trauma-Informed Approach. They agree to an introduction to the victims’ services advocate at the next Person-Centered Planning meeting. At this point, it’s the young person’s decision whether to add the new person to his person-centered team or not. Moving forward his team could include the disability advocate, victims service advocate, job coach, support coordinator, direct support professionals, parents, romantic partner, etc. The Person-Centered Planning team moves forward to support all of the person’s goals while being aware of the trauma background and using a trauma informed approach.

### **Victim and Disability Service Programs Can Appear Seemingly Segregated at Times**

However, an understanding of each other’s practices and a collaborative relationship between these two fields are imperative not only for the movement to promote inclusion and equality for people with disabilities but to better respond and prevent victimization. Person-Centered Planning and the Trauma-Informed Approach each have one major concept in common, they meet people where they are. Through utilizing a Trauma-Informed Approach as a catalyst to guide the tangible models included in Person-Centered Planning we can help to understand trauma-related issues among those with disabilities that may be caused from experiencing institutionalization and other forms of victimization such as domestic violence and sexual assault. Through building a relationship between such practices, we can construct a community that supports a person as a whole and embrace their goals for a life of personal significance and meaningful connections.



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## **Biographies:**

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As an Outreach Advocate and Counselor part of Blackburn Center's Underserved Populations Program in Greensburg, Pennsylvania, Shelbi-lynn Moonley provides support to those affected by violence while navigating the criminal justice and medical systems. She received her undergraduate degree in Psychology with a minor in Women and Gender Studies from Clarion University of Pennsylvania. She further specializes in working with victims with disabilities. Shelbi utilizes her role to actively pursue systemic changes and training professionals and community members to recognize abuse and understand how to use Trauma-Informed approaches to better support victims.

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## **Toward the White Picket Fence: Experiences Providing Education on Sexuality and Healthy Relationships to People with Intellectual and Developmental Disabilities (I/DD)**

**Amy S. Tobolski**

### **Abstract**

While access to sexuality education for self-advocates has improved, and more people now recognize sexual expression as a basic human need experienced by people with I/DD, I still hear from special education teachers that their students are excluded from health classes when content related to sexuality is being taught. We still receive referrals requesting education for adult self-advocates who have made sexual behavior mistakes, resulting in adverse personal, social, or occupational consequences. This article outlines the implementation of a healthy relationships/sexuality curriculum with groups of self-advocates, what we have learned, and the barriers we have encountered. Since Dave Hingsburger lit the spark for me during a presentation I attended early in my career, I have taken advantage of every opportunity to increase my knowledge about the various aspects of sexuality in people with I/DD, including developing/fostering healthy relationships and abuse prevention, as well as supporting people who have engaged in problematic sexual behaviors and/or sex offenses.

Like so many people with I/DD, all she really wanted was what I typically refer to as “the white picket fence” – a husband, a home, and a couple of kids. I often wonder when she began to believe that her dream – at least, this specific dream -- was no longer possible. Was it when she moved into the group home upon the death of her family caregiver? During one of her multiple psychiatric hospitalizations? Or was it when she was brutally raped by an ex-boyfriend? Maybe it was the moment she understood the implications of a hysterectomy to resolve medical issues. I wonder how her life may have been different if she had grown up in a milieu where sexuality and intellectual disability were not considered by most to be mutually exclusive – if she had been given the information she needed when she needed it. She has had experience with sex – she figured that out on her own. But the physicality of intercourse has done little to meet her basic human need for emotional intimacy, connection, and love, nor has it enhanced her ability to manifest those things in her life.

### **Identifying Needs**

She is not alone. Many people with I/DD (self-advocates) struggle to recognize, develop, and maintain healthy relationships. When considering the multiple barriers to self-advocates expressing healthy sexuality and accessing sexuality education, three main themes have been identified in the literature: the perceptions of others, their perceptions of their own sexuality, and sexuality knowledge.<sup>1</sup> Furthermore, “Sexuality and relationship development fall within many professionals’ scope of practice. However, there is no one profession taking the lead.”<sup>2</sup>

As a Health Care Quality Unit (HCQU) in Pennsylvania, we provide medical and behavioral education and technical assistance to supporters and self-advocates within a nine-county catchment area in northwestern PA. Since our inception in 2002, we have received increasing numbers of requests to provide individualized education for self-advocates on aspects of sexuality and relationships (consent, public vs. private, etc.). The knowledge and skills needed to form and maintain healthy relationships – including the ability to protect oneself from abuse – build upon each other. A brief training or two is not enough for most, so we began to consider alternatives. I

was confident that we could implement a full sexuality education curriculum effectively; however, we are a relatively small HCQU. With two RNs, a Behavioral Health Specialist, and myself as potential educators, preparing for a comprehensive, lengthy training curriculum in addition to meeting our everyday training and technical assistance requests was daunting. Our fantastic team was up for the challenge!

### **Choosing a Curriculum**

Our choice of curriculums was guided by the *6 Rules of Presentation* outlined by Lisa Mitchell, LCSW-R – presentations on relationships should be simple, visual, individualized, repetitive, fun, and concrete.<sup>3</sup> Our team unanimously agreed upon *Positive Choices: A Program on Healthy Relationships, Sexuality, and Safe Boundaries for Secondary Students with Intellectual and Developmental Disabilities*.<sup>4</sup> It is easily modified for adult learners and has a consistent structure that allows for creativity in presentation. Visually, it uses a lot of photographs and large, clear drawings. It begins with three rules related to common themes throughout the curriculum that are reviewed prior to each class: respect, confidentiality/trust, and our legal obligation to report danger/harm to self or others.

### **Implementation**

We work through the curriculum in order, using multiple modalities, including discussion, role play, games, and videos, adapting activities to meet the needs of each unique group. Participants fill out relevant pages in their student manuals and we encourage them to use their manuals as a reference beyond the completion of classes. Skipping the sections on puberty and offering one-to-one education, if needed, on monthly self-exams allows extra time for activities and reviews, as well as a celebration on the final day of class. We typically plan for 30 hours, which we present in small chunks over several weeks. The length and frequency of classes are ultimately determined by the group and the host site.

## **Participants**

Thus far, a maximum of ten self-advocates per class has proved to be an appropriate number to promote participation while also providing for diversity of experience. Like any typical educational opportunity in the community, we do not request or receive extensive background information on participants. We know very little about them beyond what they choose to share with us. We do not currently accept adjudicated sex offenders, as they may require a therapeutic element that is beyond our scope.

We received several similar requests to provide sexuality education to self-advocates in the same area, making our pilot group easy to identify. They all lived in the community, either independently, with a significant other, or family. Most were or had been in at least one relationship. This group was contrasted by a subsequent group who all had one-to-one medical and/or behavioral supports and fewer experiences with relationships, both romantic and otherwise. These two diverse groups are representative of the marked differences in opportunity and experience that we have encountered thus far. For example, almost all of our pilot group were familiar with birth control and protections from sexually transmitted infections (STIs), while the opposite was the case for the one-to-one group. The pilot group was also much more informed about topics such as types of relationships, dating, the life cycle, and sexual orientation.

## **Involving Supporters**

While our “no staff” approach was welcomed by our pilot group, consultation with a sexuality educator and our own experience brought the realization that, for some participants, having a consistent supporter with them allows for review of class content outside the classroom. It also provides supporters the opportunity to improve their skills to the benefit of not only the participant, but potentially everyone they support. Prior to bringing supporters into the classroom, we ask participants if they are comfortable having them there as fellow learners. Supporters sign the same student contract as self-advocates at the outset and are included in class activities.

Before our first scheduled class, I offer supporters (including Supports Coordinators, provider staff, and family members) an opportunity to view the curriculum content, ask questions, and express concerns. I also provide suggestions for enhancing learning outside of the classroom. Most expressed concerns relate to the person's ability to self-protect from exploitation and abuse, STIs and unwanted pregnancy, and sexual behavior mistakes that are against the law. They can assess for themselves how well the curriculum addresses their concerns. I also point out how we will cover the foundational skills and abilities for self-protection by providing accurate information about anatomy and sexuality, so participants need not rely on potential sources of misinformation – peers, social media, and the internet. By building self-esteem, confidence, and assertiveness we can decrease the likelihood of participants complying with unwanted contact to gain connection. *Positive Choices* is about developing knowledge and skills to make responsible decisions and experience healthy relationships.

## **Data**

Since much of the curriculum relates to “soft skills,” like empathy, responsibility, and problem-solving, it is more challenging to capture hard data regarding efficacy. The curriculum contains a rubric for assessing the person's demonstrated knowledge and skills in all areas covered. Although lengthy, it is a simple check-box format, so we include it as part of the referral. By indicating which parts of the curriculum are less familiar to each participant, it guides our focus to the areas where people struggle most. We meet following each class to assess how our teaching modalities were received, as evidenced by attention and class participation. We ask each participant to complete an overall evaluation during the final class. Reviewing activities throughout the curriculum identifies any need for remediation.

The most elusive feedback is whether attending *Positive Choices* has improved the person's ability to make safer, healthier choices regarding relationships. Studies have shown that skills learned in sex education programs often are not generalized to real-life situations.<sup>5</sup> In an attempt to reflect lasting changes, we collect data six months following the completion of classes. We send a blank

rubric – the same one we used as part of the referral – to each referrer for completion based on current presentation. The reliability of our data is impacted by difficulties having the same person complete the rubric. Supporters aren't always in the same role with the same level of contact at the time of follow-up. Some have simply not been returned, particularly since the onset of the COVID-19 pandemic.

The rubric considers 46 specific skills and ranks the person's ability for each as Excellent (3), Satisfactory (2), or Developing (1). Assigning a numerical value to each allows us to quantify changes. For example, improvement from Developing to Satisfactory is denoted as a +1 change, while Developing to Excellent is +2. We are then able to compare and score improvement for each individual participant as well as the whole group. Our pilot group has the most complete data, with scores for seven of the nine participants (two moved away prior to follow-up). Among these seven, change scores range from 10 to 54, with a mean of 35 and a median of 36. The total change for the group was 246.

## **Challenges**

While we have prepared for and met many challenges along the way, there are still difficulties for which we have no clear solutions. While all our county Administrative Entities (AEs) have expressed the desire for classes in their areas, we have struggled to find host organizations. Some express concerns about the content of the class and its appropriateness to their environment, while some wish to avoid potential negative reactions from family members. These concerns tend to persist despite assurances that the classes are voluntary; and supporters -- including parents -- will have the opportunity to learn and ask questions about the curriculum to make an informed choice. We encourage parents in particular to attend informational sessions, as they have been found to benefit from education to increase recognition of their son/daughter's sexual interest and need for sexuality education.<sup>2</sup>

Supporters readily identify self-advocates who would benefit from the class but do not have



transportation to the host site. This occurs most often with those living independently in the community – those most vulnerable to misinformation while attempting to navigate relationships and protect themselves, typically doing so without a 24/7 support system. While our search for accessible in-person host sites is currently on hold, we are exploring the viability of live online classes during the pandemic. Our challenge is to ensure that the classes remain activity-based with minimal lecture, despite a virtual format.

## **Conclusion**

I believe that the greatest benefit of implementing a sexuality education curriculum is the opportunity it provides for self-advocates (and their supporters) to both learn with and from others. They begin to discover their own power to recognize dangers and protect themselves from being used or hurt. They receive the information they need and build skills to make healthier, safer choices. Relationships improve. A Program Specialist with a provider agency in Pennsylvania reported that attending *Positive Choices* classes “helped [her] understand that other people have these difficulties too, since it was a class with her peers. At first she would ask to leave class because there were other people [there]...By the end of the class she was planning lunch dates with other members of the class.” It is worth the time and effort when you can help people be safer, more knowledgeable, and maybe just a little less lonely.

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**Biography**

I am currently in my 30<sup>th</sup> year working in the field of I/DD. During that time, I have increased my knowledge, through presentations and conferences, reading, and consultation with a sexuality educator on topics including: developing and fostering healthy relationships, abuse prevention, and supporting self-advocates who have engaged in problematic sexual behaviors and/or sex offenses. I have been providing education to self-advocates for the past 18 years and implementing a comprehensive curriculum with groups of self-advocates for the past three years.

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## **Sexuality, Social Connectedness, and the Internet**

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### **Introduction**

In the ever-changing world of social media and the search for human connectedness, the internet is a place that holds the opportunity for exploration of sexuality and the opportunity for human connectedness. It can also hold opportunity for victimization and exploitation. Victimization refers to a person harmed by someone else and can take on psychological as well as physical forms, both of which are damaging to victims. Forms of victimization include (but are not limited to): bullying or peer victimization, physical abuse, sexual abuse, verbal abuse, robbery, and assault.<sup>1</sup> Exploitation is the action or fact of treating someone unfairly in order to benefit from their work.<sup>2</sup> Both can occur within the attempt to connect with others via the internet. The internet is the global computer network that links people to social media and other sources of information.

The use of the internet to link to social media has become more prevalent in the age of COVID-19 as social isolation becomes more of a norm. In the general population “the use of social media has also risen drastically, leading to a 27 percent increase in Facebook traffic and a 26 percent growth in quarterly sessions on LinkedIn. TikTok has seen a 25 percent rise in monthly downloads, and messaging apps such as WhatsApp are fielding twice as many video and voice calls. Social video apps have also seen a surge in popularity, with Bunch receiving 1 million downloads in just seven days and Houseparty seeing a 70 percent increase in monthly signups”.<sup>3</sup> While these statistics target the general population, The Arc promotes connectedness through the internet. Their position statement states, “In our hyper-connected world, technology was already what kept us connected from day to day. But as we limit

physical contact to stay safe, digital access has become more vital than ever. For people with Intellectual and Developmental Disabilities (IDD)—who have had to fight for decades for the chance to be included in their communities—access to the digital world ensures that progress is not lost and they can remain connected and engaged with the people and activities they love most”.<sup>4</sup>

## **Social Media and Disability**

Connectedness is therefore, attempted more frequently on the internet via social media. Instagram, Facebook, and a plethora of other social meeting places are available to anyone with a device and Wi-Fi access. Being able to access the internet as a connection to social media is also true for people with intellectual disabilities who may also have other cooccurring mental health disorders. According to The Arc's position statement "people have the right to access, discover and explore both sexuality and social media however, people with intellectual disabilities are a vulnerable population and this access causes concerns for both families and other caregivers".<sup>4</sup> According to the Traumatic Stress Institute, a developmental disability is a very broad term encompassing people ranging from intellectual disabilities to autism spectrum disorder to medically related impairments.<sup>5</sup> In addition, "Folks with intellectual disabilities are the perfect victim. They are people who often cannot speak, or their speech is not well-developed. They are generally taught from childhood up to be compliant, to obey, to go along with people. Because of the intellectual disability, people tend not to believe them, to think that they are not credible or that what they are saying, they are making up or imagining. And so, for all these reasons, a perpetrator sees an opportunity, a safe opportunity to victimize people".<sup>6</sup>

## **Establishing Guidelines**

It is important that families, caregivers, and support people, in general, understand and consider how to safely navigate sexuality and connectedness within the realm of internet access to social media. It is important that the needs of each person are considered individually. Human realities must also be considered. These are that, regardless of abilities, most people are sexual beings and people are unique sexual beings with biologically, socially, and culturally determined values.<sup>7</sup> Guidelines must also be considered to promote and honor individual needs, desires, preferences and safety. In 2018, the Pennsylvania Office of Developmental Programs devised broad guidelines for people to maintain an

Everyday Life to preserve their individual rights regarding sexuality and relationships. These guidelines are<sup>8</sup>:

- Individuals with disabilities are sexual human beings with their own cultural, religious/faith, ethnic, and family values
- 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.
- Individuals with disabilities have the same basic rights as individuals without disabilities to self-identify their gender, sexual-orientation, and sexual preferences.
- 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.
- 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.
- Individuals with disabilities have the right to enjoy relationships and to express their sexuality in a safe manner.
- 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.

While these guidelines are helpful in maintaining people's rights and inclusion, it remains a concern to caregivers of vulnerable populations how to honor and ensure these rights safely. When exploring and utilizing the internet and social media these concerns, as well as the complexities of sexuality, are many. These can include but are not limited to health education, attitudes, overall knowledge, capacity, and consent.

### **Decision Making, Capacity, and Consent**

“People with intellectual disability (ID) can experience deficits in thinking, problem solving, and decision making, which may hinder their full and effective participation in society on an equal basis with others. Lack of capacity can prevent participation in many of the activities that form part of daily life, with major implications for the person with ID”.<sup>9</sup> According to Hagiliassis and DeMarco<sup>10</sup>, the concept of decision making has changed in the last decade. A shift from protectionism to an approach attempting to achieve balancing duty of care and dignity of risk is occurring. Hailiassis and DeMarco also state that there is no one way to assess capacity and it remains greatly dependent on clinical judgement.<sup>9</sup>

According to the *Adults with Intellectual Disabilities Capacity to Consent to Sexual Activity*, Pennsylvania Coalition Against Rape, 2017; key questions for assessing the capacity to make a specific decision might include whether the person<sup>10</sup>:

- Understands information about the decision
- Is making the decision voluntarily without duress
- Normally makes decisions of this type
- Understands the potential benefits and risks in making the decision



- Has an appreciation of the impact on others in making the decision
- Has sufficient time to consider or weigh up the decision
- Is aware of where to go for more information, or about relevant complaint processes

A person's capacity can change at any given time for many different reasons. Some of them are<sup>10</sup>:

- Mental health symptoms increase
- Grief and loss issues past and present
- Trauma that can change people's view of the world
- Stress of any kind
- Medical issues that arise (i.e. experiencing chronic pain)
- Other occurrences such as drug/alcohol consumption or active addictions

Consent is another topic that needs to be taken into consideration when sexuality and relationships on and off the internet are being entertained. "Under Pennsylvania law, sexual contact with an individual who has a 'mental disability' that renders him or her 'incapable of consent' constitutes a felony, regardless of whether force was used (18 Pa.C.S.A. §§ 3121(a)(5), 3123(a)(5), 3125(a) (18 Pa.C.S.A., 3121(a)(5), 3123(a)(5), 3125(a)(6), 3126 (a)(6)).<sup>11</sup> It is critical to remember that a diagnosis of intellectual disability by itself, does not automatically mean that a person lacks capacity to consent to sexual activity. The presumption that a person with ID who engages in sexual activity is a victim would essentially nullify the sexual rights of people with ID".<sup>10</sup>

Education and assessment regarding consent and capacity are vital in navigating relationships and sexuality. The Pennsylvania Office of Developmental Disabilities, 2018 guidelines recommend that "a

person has the right to accessible and appropriate education, information, and resources that address their individual personal relationships, sexual health, and sexuality needs”.<sup>8</sup> These services are available through medical, clinical, and other therapeutic entities that can be accessed through state funding, private pay, or contracting with organizations who can provide these types of clinical expertise.

According to William Taverner and Christopher DeMarco<sup>11</sup>, who developed a tool to assess if, through an overall clinical impression of a person’s capacity to give informed sexual consent, can develop safe practices and plans related to a person’s rights and responsibilities. The tool does not provide a legal determination of a person’s capacity to give sexual consent. The following are five principles that are assessed to make a clinical determination and are only part of the assessment itself<sup>11</sup>:

1. The person demonstrates an awareness of the nature of the sexual act and demonstrates the ability to make a choice to engage in or abstain from the type of sexual act.
2. The person demonstrates an understanding of how to prevent unwanted pregnancies and sexually transmitted infections or diseases.
3. The person demonstrates an understanding of the need to restrict sexual behavior to certain times and places.
4. The person demonstrates an understanding that certain sexual behaviors are illegal in this state.
5. Demonstrates the ability to identify harmful situations and to avoid being exploited and harmed.

Along with consent and capacity the concept of human needs must be addressed. Human Needs, defined by the Glasser Institute for Choice Theory 2020<sup>12</sup>, includes the following:

- *Survival* - a physiological need encompassing everything you need to sustain life, such as health, shelter, and nourishment. Reproductive sex addresses this need in a global sense, relative to

survival of the species. The psychological component to this need involves feeling safe and secure.

- *Love and Belonging* - This includes the drive to be connected with others, such as friends, family, intimate partners, co-workers, pets, and other affiliated groups.
- *Power* - This need involves the desire to matter, make a difference, achieve, be competent, recognized, and respected. It includes self-esteem and a desire to leave a legacy.
- *Freedom* - The need for freedom is about having choices, being independent, and autonomous. Freedom is about being able to move freely without restriction which includes “Creativity.”
- *Fun* - This need encompasses pleasure, play, humor, relaxation, and relevant learning.

These human needs, when applied, connect to one’s relationships. Relationships can connect to sexuality. It is important that these concepts are examined more closely. Glasser’s Theory supports that if these human needs are not satisfied, people will seek them out. Within the theory’s assumptions, human needs must be met to experience contentment. These needs can be met in a responsible way, which is defined as not violating the rights of others. These needs can be met in an irresponsible way which is defined by violating the rights of others. When sexuality is thought of in these terms and applied to vulnerable populations, the impact of trauma can occur quickly without the proper tools, understanding, and knowledge to promote healthy and safe choices.<sup>12</sup>

According to Glasser<sup>12</sup>, the other concepts that are important to relationship building are Connecting Relationship Habits which are the actions of: supporting, encouraging, listening, accepting, trusting, respecting, and negotiating differences. There are also Disconnecting Relationship Habits. These habits include criticizing, blaming, complaining, nagging, threatening, punishing, bribing/rewarding to control. When support professionals and other caregivers engage in the connecting relationship habits, they will

be able to promote safe progressive development with a person in a trauma-informed way rather than engaging in the disconnecting relationship habits which may cause harm and/or trauma.<sup>12</sup>

Glasser's Theory<sup>12</sup> has a simple listing of Human Needs that can be defined specifically and lends itself to specifically defined safety i.e. responsible vs. irresponsible behavior and choices. Since this is a human needs framework, people with intellectual and developmental disabilities must also understand these relationship habits to remain safe and to progress in their growth and development. When teaching these abstract skills, it is important to know a person's learning style. Long, involved verbal directions and lengthy "lecturing only" methodology are ineffective teaching methods for most audiences. Most people are kinesthetic learners which means doing task in a "hands-on" way or "show me instead of tell me" are more effective than abstract styles. A hands-on approach is particularly helpful for students with ID. "They learn best when information is concrete and observed".<sup>13</sup> Visuals, videos, roleplay, and modeling are powerful teaching tools to use. Hands on learning and practice will often assist people in retaining information that they receive from trusted family members, trained clinicians, and caregivers.

## Conclusion

In conclusion, the internet and social media can be a high-risk opportunity when education is not specifically applied. Exploitation and victimization can occur when a person's human needs are not met and when they do not have the tools to meet their needs responsibly. Education and assessment are vital components to assisting with healthy, safe, connectedness within relationships and as people explore their sexuality. The ability to consent and current capacity must be taken into consideration. An educationally based curriculum is also necessary to assist caregivers, clinicians, and support professionals in navigating the pleasures and risks of social media and the internet. Community organizations such as the Pennsylvania Health Care Quality Units as well as the Pennsylvania Coalition Against Rape along with other providers of intellectual and developmental services such as Merakey use different resources and modalities to teach and promote protective skills. It is important that assessments and educational curriculum with methodologies that are proven successful with people with intellectual and developmental disabilities are used to promote growth and development as well as to increase health, safety, and wellness.

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## **Biography**

Robin earned her Master of Science Degree from Shippensburg University in Community Counseling and acquired her License in Professional Counseling (LPC). She has served adults with Dual Diagnosis for over 40 years. She has acquired the first ever Dual Diagnosis Certified Clinician credential awarded by the National Association for Dual Diagnosis. Robin is an Eye Movement Desensitization Reprocessing Therapist and has received a certificate in Trauma through Drexel University. Robin is the Co-chairperson of the NADD-CC committee and assisted in formulating a certification in Dual Diagnosis for licensed clinicians (NADD-CC). Robin has served as the Clinical Director for the Commonwealth of Pennsylvania, Department of Human Services, Office of Developmental Disabilities, Central Region. She is the former Vice President of Integrative Counseling Services, PC in Harrisburg, PA. In 2019, Robin won the NADD Earl L. Loschen Award for contributions that have resulted in significant improvement in the quality of life for individuals with intellectual and developmental disabilities as well as mental health needs. Robin has developed the Risk Screening for Best Practices Tool. She is a subject matter expert on Fetal Alcohol Spectrum Disorder “The Invisible Disability” and has articles published on the topic. Robin administers sexuality assessments for consent, knowledge and attitudes. She also administers trauma informed assessment for people with problematic and sex offending behavior. She is currently the Clinical Director for Merakey in the Central and Northeast Regions of Pennsylvania and assists with consultation services that include Merakey in New Jersey, Delaware, New York, and California.

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