Sexuality, Social Connectedness, and the Internet

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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 opportunities for victimization and exploitation. Victimization refers to a person being harmed by someone else, and it 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 (Wikipedia, 2021). Exploitation is the action or fact of treating someone unfairly in order to benefit from their work (Microsoft Dictionary, 2021). 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 (Cohen, 2020). 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 one million downloads in just seven days and Houseparty seeing a 70 percent increase in monthly signups” (Cohen, 2020). 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 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” (The Arc, 2021).

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. This ability to access the Internet as a connection to social media is also available for people with intellectual disabilities, who may also have other co-occurring 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” (The Arc, 2021). According to the Traumatic Stress Institute, a “developmental disability” is a very broad term encompassing people with diagnoses ranging from intellectual disabilities to autism spectrum disorder to medically related impairments (TSI, 2020). However, research, not surprisingly, has found that people with developmental disabilities have alarmingly high rates of trauma. One review of the available literature concluded, “a conservative estimate is that people with developmental disabilities are 4 to 10 times more likely to be victims of crimes than individuals who do not have developmental disabilities” (Sobsey et al., 1995). Sobsey and Doe (1991) found that 83 percent of women with intellectual disabilities in their sample had been sexually assaulted and that of those, nearly 50 percent had been sexually assaulted 10 or more times (National Research Council, 2001). 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” (Thaler, 2018).

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 (Merakey Sexuality Guidelines, 2020). Guidelines must also be considered to promote and honor individual needs, desires, preferences, and safety. The Pennsylvania Office of Developmental Programs in 2018 devised broad guidelines for people to maintain an everyday life to preserve their individual rights regarding sexuality and relationships. These guidelines are:

- 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 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 (Sexual Health, Personal Relationships, and Sexuality Guidelines, 2018).

While these guidelines are helpful in maintaining people’s rights and inclusion, a concern to caregivers of vulnerable populations remains 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.

“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” (Hagiliassis and DiMarco, 2015). According to Hagiliassis, et al., 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 against risk is occurring. Hagiliassis also states that there is no one way to assess capacity and it remains greatly dependent on clinical judgment.
According to “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:

- 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 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:

- Mental health symptoms increase
- Grief and loss issues past and present
- Trauma that can change someone’s view of the world
- Stress of any kind
- Medical issues that arise (e.g., 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. According to PCAR, “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). It is critical to remember that a diagnosis of Intellectual Disability by itself does not automatically mean that a person lacks the 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” (PCAR, 2017).
William Taverner and Christopher DeMarco developed the Verbal Informed Sexual Consent Assessment Tool (VISCAT) in 2006 to assess whether, through an overall clinical impression of a person’s capacity to give informed sexual consent, safe practices and plans related to a person’s rights and responsibilities can be developed. The tool does not provide a legal determination of a person’s capacity to give sexual consent. The following are five principles that are considered to make a clinical determination; these are only part of the complete assessment.

- 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.
- The person demonstrates an understanding of how to prevent unwanted pregnancies and sexually transmitted infections or diseases.
- The person demonstrates an understanding of the need to restrict sexual behavior to certain times and places.
- The person demonstrates an understanding that certain sexual behaviors are illegal in some states.
- The person demonstrates the ability to identify harmful situations and to avoid being exploited and harmed.

Also involved in these complex issues may be a history of trauma. Each of these issues has an impact on how connectedness can occur safely when using the Internet and navigating social media applications. “Decisions about sexuality and relationships are no different for people with ID” (Pennsylvania Coalition Against Rape, 2017). These decisions can be central to the human experience. Individuals with IDD have a fundamental right to sexual expression. The AAIDD and The Arc issued a joint statement in 2008 affirming that people with IDD “like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected” (AAID and The Arc, 2008).

When embarking on any challenging issue or project, it is important that a framework is chosen and followed. In therapeutic services, such as individual therapy, group therapy, and behavioral therapy, as well as in project-management services such as marketing and budgeting, some practices are evidence-based and some are not. Using evidence-based practice (EBP) is the idea that occupational practices should be based on scientific evidence (Wikipedia, 2021). These
practices can also be based on published, peer-reviewed research. This framework is just one view and is threaded through essential lifestyle- and person-centered planning, co-developed by Michael Smull beginning in the early 1980s, specifically recognizing and realizing people’s human needs. William Glasser’s Choice Theory offers several concepts that meet the needs of human beings in a safe, responsible manner. The essence of this theory is that human beings are born with innate human needs. According to the theory, if these human needs are not met, anxiety, depression, and other mental health disorders can occur or be exacerbated.

Human needs, defined by the Glasser Institute for Choice Theory (2020), include the following:

- **Survival** — This is 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 the 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, coworkers, pets, and affiliated groups.
- **Power** — This need involves the desire to matter, make a difference, achieve, and 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; this includes creativity.
- **Fun** — This need encompasses pleasure, play, humor, relaxation, and relevant learning.

These human needs connect to one’s relationships, and relationships can connect to sexuality. It is important that these concepts are examined more closely. Glasser’s theory suggests that if these human needs are not satisfied, people will seek them out. Within the theory’s assumptions, human needs must be met if someone is 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 also 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.

According to Glasser, 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, and bribing or 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.

There are other frameworks that have been adapted for people with intellectual disabilities. These include but are not limited to Julie Brown’s Skills System, adapted from Marsha Linehan’s dialectical behavior therapy, and Michael Smull’s person-centered planning, which threads Carl Rogers’ person-centered theory throughout its framework. Connie Romer-Quirin’s intensive systems therapy, adapted from Carl Beck’s cognitive behavior theory, and Karyn Harvey’s positive identity development, based on Erik Erikson’s Stages of Psychosocial Development, are effective when promoting safe and encouraging environments. Finally, Steven Reiss’ work in human needs and intellectual disabilities based on his own work with motivation and adapted from his book *Who Am I?* is also a competing theory. In contrast, however, Glasser’s theory 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” methodologies are ineffective teaching methods for most audiences. Most people are kinesthetic learners, which means doing tasks in a “hands-on” or “show me instead of tell me” way is 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” (American Addiction Centers, 2020). Visuals, videos, role-play, and modeling are powerful teaching tools to use. Hands-on learning and practice will often assist people in retaining information they receive from trusted family members, trained clinicians, and caregivers.

Education and assessment regarding consent and capacity are also vital in navigating relationships and sexuality. The Pennsylvania Office of Developmental Disabilities in 2018 recommended 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. These services are available through medical, clinical, and other therapeutic entities that can be accessed through state funding, private pay, or contracting with organizations that can provide these types of clinical expertise.

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 users 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 to help 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 curricula 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.

Robin Van Eerden 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 more than forty years. She has acquired the first-ever Dual Diagnosis Certified Clinician credential awarded by the National Association for Dual Diagnosis. 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. 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. She is currently the clinical director for Merakey in the Central and Northeast Regions of Pennsylvania.
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References


