

# The International Journal for Direct Support Professionals

## Relationships & Rollercoasters Supporting People with IDD throughout Relationships A Trauma-Informed Approach

By: Erick Dominguez & Heather Hermans

The pandemic and the experience of isolation have taught the general population the importance of having relationships and social contact, and how difficult it can be without this contact. For the widespread public, the reassurance that this isolation from their social connections would not be a permanent situation was reassuring and provided a sense of hope. However, people with intellectual and developmental disabilities (IDD) often experience isolation from all forms of relationships as their norm within their everyday lives.

Historically, people with IDD have been denied rights to sexuality and relationships, such as the right to marry and parent. In Canada, some people with IDD were surgically sterilized without consent until approximately 1986, when the Supreme Court stopped the Sexual Sterilization Act. In addition, people with IDD have a significant increase in being vulnerable to bribes and false promises of friendship due to their isolation. People with IDD living in government-run institutions experienced trauma through learned compliance, lack of privacy, exposure, abuse, and very limited education regarding their rights and healthy sexual relationships. Many adults with IDD were transitioned out of these institutions and into government-funded Community Living programs with no therapeutic supports for their past traumatic experiences.

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A number of factors make having healthy relationships challenging for persons with IDD. Ruth Ryan (1994) found almost all those with IDD referred for treatment had experienced at least one severe traumatic event. People typically learn about relationships through their families and their social peer groups. However, families are often hesitant to teach and support their youth/adult children with IDD about these relationships due to fear of them being vulnerable to others. This well-meaning protection can create a very unsafe situation for a person with IDD who wants to have a relationship or the ability to know they can say, “no” to a relationship. In addition, people with IDD who have ongoing paid support are two times less likely to have friends (Friedman, & Rizzolo, 2018). This lack of knowledge, isolation, and history of trauma often triggers several survival mechanisms to navigate relationships with others and with themselves. Therefore, trauma-informed approaches, including education and knowledge are powerful defences against abuse and retraumatization.

Other barriers to the development of healthy relationships for persons with IDD include a lack of access to appropriate, accessible education formats about human rights, abuse, sexuality, and relationships. For example, Heifetz's (2020) research study identified that 85% of IDD people reported an immediate desire for a romantic relationship; however, only 35% were currently in a relationship. There are also myths about the IDD community and their sexuality that continue today, creating attitudinal barriers to healthy relationships and education, such as individuals with IDD being non-sexual or over-sexual. Being aware of these barriers, as well as the impact of trauma on people's lives and relationships is critical for Direct Support Professionals (DSPs) in having a trauma-informed approach when supporting and teaching about relationships.

## **Providing A Trauma-Informed Approach to Supporting Relationships and Sexuality**

### **1. Focus on safety for everyone**

Education is the first defence for safety – provide accessible information in the preferred communication style for each individual you support. People with IDD often learn best from repetition, and it is recommended that this be used when learning about relationships and sexuality. Meet the person you are supporting where they are with their knowledge and understanding, and the words that they use. Education should not be about shaming or blaming for not knowing something. Taking one class-and-done approach will often not be successful for people with IDD. Yearly refresher education classes and/or access to daily learning strategies may be needed for some individuals. There should never be a 'one-size-fits-all' approach to education for people with IDD. Individualizing accessible material and frequency will be needed.

Safety also means knowing proper terminologies. However, prior to teaching these concepts, it is essential to be aware, as professionals in the field, that culture and trauma can impact someone's comfort level with discussing sexuality, making it important to go at the individual's pace. People with IDD need to understand what consent means, how to give and obtain it, who can and cannot provide consent, and all the pieces that come with consent. Knowing it's ok to say, "NO" and practicing how, as well as learning how to report abuse are important safety components. It is also important that people know the names for their body parts, i.e., penis, breasts, vulva/vagina, so they will be understood when reporting abuse. Knowing the difference between an acquaintance, friend, and romantic partner is also essential, including the healthy progression of these relationships. However, expectations should not be different for people with IDD than the general community regarding their choices and values when implementing the healthy stages of a relationship. Often, people have higher expectations for people with IDD to follow the social etiquette rules than they do for the general public. Role-plays can help as a practice tool to build social skills and self-advocacy skills. Using teachable moments can be great learning opportunities, for example, discussing if boundaries are being respected while watching a TV show or movie. While providing education and support, DSPs are encouraged to recognize and address their own biases to ensure they do not interfere with the care and support we provide to people.

### **2. Being aware of our language (not just the words)**

Dave Hingsburger taught us, "Words hit like a fist." The words we use have power, and when we use them from a place of privilege, it can compound the effects upon oppressed individuals and communities. In addition, what we communicate can create stigmas and hate through words and non-verbal communication. Therefore, being aware of what we say and how we say it when supporting people with IDD in the areas of sexuality and relationships is very important. Having a supportive and calm tone of voice and non-threatening body language helps create a supportive environment. Remember, the person you support has a right to choose their sexuality; this is not about your values or opinions. Use your active listening skills to help the person think through the situation and develop possible solutions. Having them actively involved and making choices provides autonomy and control over their lives. They are getting the power

back into their lives by making these choices. Be aware of demeaning and degrading outdated language. If you are unsure what language to use, that's ok – it's better to ask someone! It shows that you care. Communicate respect for their choices by supporting them and following through with their choices. Respect for selection can be as simple as helping someone prepare their chosen clothing for a party and assisting in tying their tie. If you use the wrong language, it's ok; language changes and grows. Apologize, learn from your mistake, and move forward. It is not about finger-pointing. It's about learning and respecting others, and that includes yourself.

### Helpful Terms & Language

**Pronouns (she, her, him, he, they, them)** – We should never assume to know someone else's pronouns. Pronouns can also change throughout someone's life. Having fluidity is part of the right of choice of sexuality. We will often use the pronouns “he” or “she” when addressing people who identify as male or female. However, not everyone identifies as male or female. Some people's gender identity is fluid between male and female; others do not identify with a gender. “They” is most commonly used by people who do not identify with one gender. Use their pronouns when talking to the person and when talking about them.

**Transgender, trans, non-binary, gender fluid, agender** – A person's gender identity does not match the sex they were assigned at birth. The umbrella term ‘trans’ is often used for people whose gender identity and sex assigned at birth differ. While the word does not fit everyone, the intention is to be as inclusive as possible.

### 3. Choice

People with IDD should be asked and encouraged to identify their pronouns the same as the general public is. The Direct Support Professional providing space for this choice allows for the person being supported to have power over their sexuality. A DSP should not be surprised if someone they support chooses to alter their pronouns one day, as their sexuality is fluid and can change. The very next day, they may decide they have changed their minds again – it is their right of choice. Experimentation with sexuality is also a right. The decision to have friends, or romantic relationships, or not to is also a choice. However, a person with IDD often requires the support of a DSP to assist them with their relationships. This is an essential responsibility of the DSP. Just as the DSP would help with what was needed for a health care appointment or the transportation required for a family visit, the supports required around friendships, dating, or romantic relationships should not be any different.

### 4. Honesty & Trust

When using a trauma-informed approach, creating a relationship with a person based on honesty and trust is essential for future skill building and education. Never make false promises about future relationships or expectations in a relationship for that person. For example, it can be challenging to listen to someone you support talk about how much they would like to have a significant other in their life. However, making promises of it happening sets up the person for failure and disappointment when it doesn't occur. Instead, help individuals develop a consistent schedule within their communities (virtually or in-person) that allows them to have social connections and build healthy relationships naturally. Being trustworthy also means respecting their confidentiality and privacy. This means having private conversations in environments that support this; even if the person you support doesn't appear to mind openly discussing their sexual relationships or desire for a romantic relationship, it is your responsibility to teach these boundaries.

## The Rollercoaster

Love, dating, and romance can bring forward a lot of beautiful feelings such as happiness, joy, fulfillment, appreciation. However, love, dating, and romance can also incite jealousy, disappointment, and sadness. Some of the most confident people I know become insecure when adding a date to their weekly calendar. People with IDD generally have more difficulty regulating their emotions. They don't feel any differently, but they may have more difficulty controlling the feeling and knowing what to do with the emotion when they feel it. DSPs can help with emotional self-regulation strategies. However, DSPs must be mindful of several factors, and potential pitfalls. Direct Support Professionals are encouraged to practice self-awareness and understand their biases in all aspects of their role, including assisting people with IDD in maintaining and developing relationships. With the number of different DSPs that people living with IDD interact with throughout their lives, the thought of how many different opinions and beliefs on the matter that have been thrust upon them becomes overwhelming. Navigating these complex emotions and social interactions is difficult enough without dealing with others imposing their countless stances upon you.

### Emotion Self-Regulation Strategies

- Deep breathing exercises
- Counting
- Muscle relaxation exercises
- Grounding strategies
- Meditation scripts
- Mindfulness walking
- Putting your thoughts on trial – what is true and what is fiction

Love, dating, and romance are also about actions, and these things can often be hard to achieve when systems and practices prevent a person with IDD from expressing their love for someone.

Love, dating, and romance are also about negotiation, problem-solving, and empathy. Unfortunately, these social skills are not easy to navigate at the best of times. When they are tangled with love, dating, and romance, they can become even more difficult.

## Conclusion

The goal of creating and fostering meaningful connections is one that all of us share. Yet, whether we are the DSPs or the person living with IDD, we sometimes get off track pursuing this goal. A trauma-informed approach recognizes that despite the twists and turns in our lives, the traumas lived and perpetuated, paths forward are possible. No matter who you are, attaining meaningful relationships can be more than a dream when empowered and supported with safety, trust, respect, and choice.

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