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# An Embodied Approach to Sexual Education: Developing a Method for Disabled Adults

Capstone Thesis

Lesley University

May 5, 2023

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Expressive Arts Therapies with a Specialization in Dance/Movement Therapy

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#### Abstract

Sexual education is often a topic that gets neglected when it comes to the general public. Schools lack thorough curriculums, often approaching the subject from a fear-based perspective of pushing abstinence only, as opposed to teaching about healthy and safer sexuality. One can imagine, then, the disparity in education among disabled populations. In this thesis, I create and enact a method to educate intellectually and developmentally disabled adults on topics relating to sexual education in an embodied way. This thesis takes into account the current research on dance/movement therapy, intellectual and developmental disabilities, and sexual and somatic psychotherapy to develop a method of creating sexual education workshops. The topics come from the current literature as well as directly from individuals who were to be participants. The topics include consent, boundaries, healthy relationships, and safer sex and dating. Each workshop consisted of psychoeducation, discussion, an embodied activity, and an art-based reflection. Reflections from the writer are included in the discussion.

#### Accessible Abstract

There is a lot of missing information when schools teach sexual education, especially for disabled people. Disabled adults deserve learning about and having sex if they want to. In this paper, I talk about creating workshops that teach sexual education to disabled adults. These workshops include activities that have to do with feelings in one's body. The topics of the workshops are consent, boundaries, healthy relationships, and safer sex and dating.

*Key Words:* intellectual disability, developmental disability, sexual education, dance/movement therapy, somatic therapy, boundaries, consent, disabled adults

Author's Statement: The author identifies as a white cisgender able-bodied neurotypical woman living in the Northeastern United States. For the purpose of accessibility, the author

*includes an abstract written in plain English, inspired by an article written by a group of self-advocates called The Speakup Committee* (Hollomotz & Speakup Committee, 2009).

# An Embodied Approach to Sexual Education: Developing a Method for Disabled Adults Introduction

Sexual education, a contentious subject often met with giggles or eyerolls, is imperative to the healthy development and understanding of adulthood. In the United States, there is a significant gap between the belief that sexual education is important for young people and the dissemination of medically accurate information regarding sex. Planned Parenthood reports that 39 states have regulations mandating sexual education to be taught in schools, but only about half of those states require the information to be medically accurate (Planned Parenthood, *Sex education laws and state attacks*). Whether the information is accurate is often left to individual districts to decide, often resulting in miseducation and an abstinence-only curriculum, which has been frequently proven to be ineffective (McCammon, 2017).

If this is what public schools' sexual education looks like for nondisabled and neurotypical students, one can only imagine the disparity in education among disabled populations. Intellectually disabled (ID) and developmentally disabled (DD) teenagers and adults are often completely forgotten when it comes to sexual education due to the stigma surrounding disability. Caregivers and family members may opt out of providing comprehensive sexual education due to the belief that disabled people are perpetually children and may not have the mental capacity to understand adult themes like sex. Unfortunately, this often results in harm against disabled people, who are seven times more likely to be victims of sexual violence than nondisabled people (Shapiro, 2018). The high rates of sexual violence for this population could be due to several factors: perpetrators seeing them as easy targets, inability to communicate verbally, or a lack of language or misinformation about sexual assault. It is my belief that if comprehensive sexual education was more widely available and prioritized in schools for both disabled and nondisabled people, there would be a decrease in sexual assault. Comprehensive sexual education has been cited as one of the most important preventative measures against sexual violence. (Hirsch, cited in Descoteau, 2021).

When a young adult learns about sex in a positive and non-stigmatized way, they are less likely to engage in risky sexual behaviors, will more likely use protection to prevent against sexually transmitted infections (STIs), and have a reduced risk of being a victim of sexual violence. This is not to say that victims have a role or are at fault for their assaults, rather, that when young adults are able to understand the nuances of sexual activity, consent, and their own limitations, they are less likely to be victims *and* perpetrators of sexual violence (Santelli et al., 2018). My hope is that through creating more opportunities and resources for an ID/DD population to learn about healthy sexuality, we can take one step closer to eradicating sexual violence.

I would also like to clarify that in this thesis, I will be utilizing identity first language (IFL) when referring to disabled people. Because my thesis focuses not specifically on any one intellectual or developmental disability, but rather an ID/DD population as a whole, I will be following what the majority of the literature recommends to use when speaking about disability (Botha et al., 2021). While ideally, I would want to prioritize what the preference is of the people I am speaking about, it would be impossible to find a consensus. For this reason, I am using IFL, as most disabled people find this to be less offensive than saying "a person with [their diagnosis].'

Despite the stigma surrounding disabled individuals and sex, current studies show that disabled teens are engaging in sexual behaviors at a similar rate to their nondisabled peers (Tice & Harnek Hall, 2008, p. 48, cited in Sinclair et al, 2015). However, the literature shows large

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gaps in this population's understanding of what healthy sexuality is (Schmidt et al., 2020). From my own experience of working with this population, I have seen the need for more training surrounding the foundations of healthy sexuality: consent, boundaries, respect, and healthy relationships. Not only have I witnessed the need for more skill-based experiences, I have also been able to hear directly from many of the clients I work with about what they feel would benefit them. Many of the topics that came from the individuals I work with relate to those previously stated: healthy relationships, how to manage conflict, and sexual relationships. Much of the literature also supports these themes. This shows that not only is there a clear gap in individuals' understanding of topics relating to relationships, but that there is also a lack of education on what is most necessary.

Due to this gap, I aimed to create workshops that would teach relational skills and truly allow participants to experience these skills in their bodies. Drawing on somatic psychotherapy (SP) and disability theory, as well as my dance/movement therapy background, I developed workshops that revolved around certain topics that included an educational component, a discussion, and an embodied intervention. These embodied interventions were created with dance/movement therapy principles in mind, with a goal to connect the mind and body with healthy relationship skills and sexual education. Sexual education relates directly to our bodies and others' bodies, so approaching the topic from a split mind and body is counterintuitive. Activity-based learning and experiential learning also aligns with the suggested best practices for teaching a disabled population (Schmidt et al., 2019).

In this thesis, I review current literature surrounding dance/movement therapy and ID/DD, disability theory, sexual education, and somatic psychotherapy. I then outline my development of a method for creating a series of sexual education workshops, what each

workshop entailed, and how it was received. This thesis ends with considerations and limitations, as well as future goals. All participants' names are excluded and no identifying information is shared.

# Literature Review

#### Working with the Body

#### Dance/Movement Therapy and Intellectual Disability/Developmental Disability

Dance/movement therapy (DMT) is a psychotherapeutic tool that posits that movement is our first language, and that through movement, one can access preverbal memories and nonverbal information stored in the body. DMT utilizes movement to "promote emotional, social, cognitive, and physical integration of the individual, for the purpose of improving health and well-being" (ADTA, 2020). DMT has been used with many different populations, including both children and adults with ID/DD. Despite this fact, the literature is still lacking in the benefits of DMT with an ID/DD population. Much of the current research on this population focuses particularly with those with an Autism Spectrum Disorder (ASD) diagnosis or those with Down Syndrome. Research also predominantly focuses on disabled children as opposed to disabled adults. More often than not, disabled children grow into disabled adults, and are frequently underserved in their adult lives once they age out of the school system at 22 years old.

While there is limited research about DMT with a general ID/DD adult population, there is still evidence that DMT can be beneficial. Takahashi et al. (2019) emphasize that while current research shows limited verifiability, it also shows that DMT sessions can provide positive reinforcement for participants and aid in developing social and communication skills (Takahashi et al. 2019). DMT interventions, especially the use of mirroring, where the client's movements and emotional state are reflected back to them in another person, either a dance/movement

therapist or another client, can help in the expression of emotions, synchronization, affective engagement, kinesthetic empathy, attunement, body-image, self/other awareness, and problem solving skills (Manders et al., 2022, Takahashi et al., 2019). Manders et al. (2022) also found that during playful improvisation with mirroring, a client with ASD had no significant changes to empathy, but did have increases in emotional inference, synchronization with his partner, and movement reciprocity. Difficulty connecting socially or empathically is a hallmark trait of ASD, and while there may not be a long-term fix or permanent increase in empathy, DMT can help bridge some social gaps to create social attunement in the moment. One can assume, then, that with repeated DMT interventions, these social skills could be extended to everyday situations and relationships.

Adults with ASD have reported wanting intimate and sexual relationships, similarly to those without a disability (Engelhard & Vulcan, 2021). Women married to partners with an ASD diagnosis have also reported loneliness and struggling within the relationship, which often leads to arguments and relational conflict (Engelhard & Vulcan, 2021). Through DMT, couples where one partner holds an ASD diagnosis, can increase their subjective sense of the relationship and attune to their partner's needs more closely. Partners also reported that by engaging in movement nonverbally, then verbalizing and adding meaning to the movement, they felt that their interpersonal communication increased. DMT is a unique intervention that relies on the preverbal and somatic language of the body as well as the verbalization of movement. This may be why it has shown to be beneficial for disabled individuals, whose receptive and expressive language and communication skills may not be as easily accessible as those without disabilities. DMT may also be used for disabled individuals who have limited or no verbal capacity. Through using the language of the body, one can connect to themselves and others. Within a couples'

therapy setting, researchers have also found that through body image and body awareness DMT interventions, couples report feeling more closeness to their partners and a deeper understanding of their actions, specifically in conflict (Koch et al., 2015, Koch et al., 2016, Lacson, 2020, Takahashi et al., 2019, cited in Engelhard & Vulcan, 2021). Body awareness skills allow for the development of the self and other, which is often a challenge for those with an ASD diagnosis. Current theories note the implication of the mirror neuron system in the development of self-other distinction and highlight that in cases of ASD, the mirror neuron system works not necessarily at a deficit, but in a different way than a neurotypical brain. Along with this is the common challenge with theory of mind, the ability to understand that other people have different mental states than oneself, which also underlies many social interactions (Brass & Wiersema, 2021). With an ASD diagnosis, an individual may not be able to understand that their partner experienced something differently than they did, or that their partner's feelings do not need to be their own. As clients engage in movement-based interventions, they can learn more about themselves on a somatic level, which can then be verbalized and developed in a relational context to their partner.

Body awareness skills are also often the first step in understanding physical boundaries. Majumdar, Ray, and Saqib (2022) explore the possible applications of DMT in teaching body privacy skills to children. Current dance/movement therapists reflected on DMT interventions that could help children understand the concept of "good touch, bad touch," (Majumdar et al., p. 284, 2022) as well as personal space boundaries. Possible interventions include body mapping, guided imagery, contact improvisation, and mirroring. These interventions allow the children to understand themselves as an independent being with autonomy, separate from other people. They can also learn to understand that the therapist is their own separate person with their own set of boundaries. By exploring boundaries in a somatic way, children may be able to understand when their boundaries are being crossed or they are being touched in an inappropriate or private way.

Casey (2018) suggests DMT as primary prevention against child sexual abuse (CSA) by focusing on three major themes that are found in the literature: "body awareness, boundary awareness, and communication" (Casey, p. 246, 2018). She posits that DMT can help develop these skills on both the individual and community level. By incorporating the individual and community through body-based DMT interventions, society can move from responding to the after effects of CSA to preventing it from happening in the first place. Casey states that DMT can be uniquely beneficial to the prevention of CSA: "Incorporating body-based methods of learning and exploring as utilized in DMT may help bridge the gap between the cognitive learning of skills and the change in behaviors and values needed for the eradication of CSA" (Casey, p. 246, 2018). Casey continues to emphasize the importance of utilizing the body in preventing CSA, as it can help people integrate their somatic senses with their cognition. Homann (2010) describes the neurological effect that movement can have on our bodies, resulting in calmer emotional states as our nervous system's fight or flight mechanism is lowered to a more relaxed state. When our bodies are in this relaxed state, we are able to make better decisions about ourselves and lay the groundwork for interpersonal connection. While my research does not specifically focus on sexual abuse, a large component of sexual education is preventative education against abuse. Children are an exceptionally vulnerable population for sexual abuse due to their lack of understanding about what their boundaries are and what is allowed.

Disabled adults, as previously stated, are also at much higher risks for sexual abuse. As Casey suggests, education can be preventative, and teaching vulnerable populations about boundaries and body awareness can aid in reducing sexual abuse. However, preventing sexual abuse should not fall on the victim. The responsibility, instead, relies on the community to educate everyone, to provide proper support to those who may become perpetrators, and to protect those who are vulnerable. While sexual education should contain information regarding sexual abuse, it should not be the focus, especially in continuing education for adults. Emphasis on avoiding sexual abuse can perpetuate a culture of victim blaming and removes all aspects of pleasure from sexuality, which, especially with adults, should be at the forefront of a sex-positive education. Holding all of these truths at once, research shows that DMT can aid in creating a deeper understanding of body privacy, boundaries, and self/other relationships, all which are imperative in a healthy sexuality.

# Sexuality and Somatic Psychotherapy

Somatic psychotherapy (SP) posits that embodied awareness can allow for self-reflection, and in turn, healing (Tantia, 2016). SP was developed from work done by Wilhelm Reich and Fritz Perls, who both moved away from traditional talk therapy or psychoanalysis of the time to focus more attention onto the body. "Embodied explorations of the psyche" (Tantia, 2016, p. 183) allows for clients to understand knowledge that they cannot yet put words to, release emotional tension in the body, and discover existential crisis. While much of the theory of SP is similar to that of DMT, in practice, both treatments look quite different. SP utilizes interventions such as sensation awareness of tensions, temperatures, posture, gesture, tracking, and grounding (Tantia, 2016). These techniques aim to help the client explore themselves and their interoceptive awareness of emotions.

Somatic sex psychotherapy relies on several of these principles to help the client integrate their sexual self. Melissa Walker, in her book, *Whole-Body Sex: Somatic Sex Therapy and the Lost Language of the Erotic Body* (2021), describes what clients may be experiencing while taking part in somatic sex psychotherapy. "Somatic sex therapy encourages the space for critical thinking of the sexual schemas..., then guides us through the somatic map of how the schema lives in the body...to carve a path of more expansive and integrated expression" (2021, p. 32). She emphasizes that to do this, techniques of focus, openness and curiosity, and understanding sex-negative beliefs come into play. She also emphasizes that pleasure should be at the forefront of a sexual exchange, but in a culture of sex that often denies pleasure, or posits that sex should look and feel a certain way, pleasure is difficult to access in the body. This may be even more difficult for disabled adults than a nondisabled client seeking sex therapy.

Most disabled adults who are interested in romantic and sexual relationships want what the average adult wants-care, love, intimacy, and fulfillment. Years of societal stigma may prevent disabled adults from even believing that they themselves have sexual desires, as they may have been taught from a young age to repress that part of themselves. When looking at the literature that discusses sexuality and SP, once again, disabled people are frequently left out. However, much of the literature can still be pertinent to this population, as long as abled-bodied people do not attempt to force able-bodied standards onto disabled people. For example, much of the basis for sexual dysfunction disorder diagnosis relies on Masters and Johnson's (1966) traditional sexual response model with four stages of sexual arousal- excitement, plateau, orgasm, and resolution (Di Giulio, 2003). However, for disabled people, especially those with physical disabilities, these stages may not happen in that exact sequence or at all. This model of sexual response has been critiqued for overemphasizing genital responses, performance, and an end goal of orgasm. Disabled people who engage in consensual sex acts with a partner may not fit into the socially constructed box of what "normal sex" looks like, but may experience just as much pleasure from it. It is important that professionals working with disabled adults on sexuality acknowledge this and do not overemphasize conforming to sexual norms.

As with sex, consent may look different for disabled adults. Disabled individuals may not be used to actively giving and receiving consent, may experience difficulty surrounding bodily autonomy, and may not be supported in making independent decisions as a result of how they are treated due to the nature of their disability. Recently, consent has stepped into many conversations regarding sex, but it is often only described in one way. Many sexual educators approach consent as something that *must* be verbal, ongoing, and enthusiastic. However, for nonverbal individuals, that is simply impossible. Reframing consent as working for the individual is an important and accessible way to allow people to explore sexually. Walker (2021) describes embodied consent: "We must cultivate a curious and welcoming space to learn how we and our partners express sexual consent and dissent nonverbally, while also encouraging but not expecting verbal communication" (p. 100). When negotiating consent, one must pay attention not only to the words that may or may not be said, but also the way the body is responding. Is there a tightness in your chest? A faster heartbeat? An open body posture? All of these are signs of nonverbal ways to say yes and no. Walker emphasizes that "arousal can make communication difficult" (100). Often, people's minds and bodies are highly aroused in a potential sexual situation, which may spark the body's fight-flight-freeze response, in turn, making any verbalization difficult (100). Learning how to find and know your own and your partner's embodied consent can help remove the gray areas surrounding consent. Both SP and DMT can allow for client exploration of what embodied consent looks like, albeit in different ways.

The same can apply to body boundaries as well. People likely experience a somatic or visceral reaction when someone crosses a physical boundary. The face and jaw might experience

tension, the chest may feel a tightening sensation, the abdomen may feel 'butterflies,' or a turning of the stomach. The body may physically shrink, freeze, or grow limp. In turn, when the body wants to welcome someone else into its personal space, it seems to naturally know how to do that. The body may lean towards that person, the face may show pleasure or happiness, and the body position opens up. Internally, the body may feel calm and in a state of rest. Learning how the body responds to boundaries may actually be a more comprehensive way to truly understand what we are and are not comfortable with. SP can help individuals understand their natural body boundaries, where their body is in space, as well as the boundaries held by their clothing and other extensions of the self, and relational boundaries, such as body posture and eye contact (Tantia, 2016). Adapting the techniques from SP may allow for disabled adults to explore healthy sexuality, and the embodiment of everything that goes into it.

#### **Disability Theory**

Current and past disability theorists have shaped the way that academia perceives disability–as an identity both socially constructed by the normative groups and, at the same time, salient to disabled people. The social model of disability arose from a rejection of the medical model of disability, which perceives disability as something that the individual must change about themselves as a medical diagnosis or disorder. The medical model views disability as needing to be cured or eradicated. Eli Clare (2017), disability and queer theorist, explains cure:

Cure saves lives and ends lives, propels eradication and promises us that our body-minds can change. It is a tool in the drive to normalize humans, to shrink the diversity of shape, form, size, and function among us...cure always revolves around the perception of a disease, infection, virus, chronic illness, dysfunction, disorder, defect, abnormality, or body-mind difference (p. 70). Here, Clare describes cure as another way of oppressing disabled people, in attempts to create a "normal" standard of humans. While cure can be helpful and important for people who also have severe health risks, the medical model of disability looks at everything that deviates from the norm as needing to be fixed, from diseases such as cancer, to deafness, to ID. However, while there may be medical ways to reduce unwanted symptoms, the medical model places pressure on the individual to fix themselves, which may never occur, especially in the case of ID/DD.

The social model, in turn, was created out of a rejection of the medical model by disabled theorists and activists. Instead of viewing disabled people as the problem, the social model views society as the problem, and emphasizes that it is society that creates the inaccessibility and oppression that disabled people face. Robert McRuer's crip theory relates heavily to the social model of disability. McRuer's Crip theory is built on dismantling what he names as "compulsory able-bodiedness," which creates disability, and "compulsory heterossexuality," which created queerness (Bennett, 2007).

In crip theory, disability and queerness are closely linked as identities that were created based on othering. McRuer states that it is this compulsory able-bodiedness that creates disability, a norm to compare everyone else to as abnormal. Who created the concept of "normal?" And who was left out of that conversation? Crip theory challenges us to look at who we perceive to be an able-bodied person, and who we see as disabled and why. Is someone with a disability truly disabled, or is our society simply inaccessible for anyone that deviates from the norm? McRuer also discusses disability in relation to capitalism. He argues that capitalism is the structure that perpetuates disability, as those who are disabled may not be able to contribute to the workforce, thus resulting in society viewing and labeling them as disabled or lacking value. As capitalism exploits bodies, able-bodiedness is prioritized in maintaining "good" workers to

contribute to the system. Those who are disabled, whether that be physically, developmentally, or intellectually, may not be seen as viable in the capitalistic system, which results in them becoming second-class citizens, often forgotten about. This is potentially why society enacts violence on disabled people, through stigma and lack of access in a multitude of different ways, including within the education system and in regards to sexuality and relationships. Understanding where disability theory began and where it is now can provide a window into how best to relate to disabled people, as Clare neatly states with the popular disability advocacy slogan: "Nothing about us without us," (Clare, 2017, p. 158).

# **Sexual Education and Disability**

The Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act of 1990 prohibits discrimination on the basis of disability and allows for disabled individuals to receive free public schooling specific to their needs (Cunningham & Oakland, 2013). Despite these regulations in place, sexual education is severely lacking for disabled individuals (Schmidt et al., 2019). Several studies have shown that disabled individuals have a lower level of understanding of sexual health than their nondisabled peers (Oakes & Thorpe, 2019). This seems to be true for disabled adolescents, young adults, and adults. This gap in knowledge about sexual topics unfortunately results in riskier behaviors. ID/DD individuals "are more likely to experience sexual victimization, have less knowledge of ways to minimize the risk of HIV/AIDS infection, and lower confidence levels in their ability to practice safer sex." (Oakes & Thorpe, 2019, p. 558). Other disparities in education include the topics of pregnancy and reproductive health, STIs, contraceptives, and personal safety (Schmidt et al., 2019, Schmidt et al., 2020). This is concerning, especially for disabled individuals who can get pregnant. Research has found that those with an ID/DD and capable of pregnancy are "more likely to smoke during pregnancy,

less likely to receive prenatal care during the first trimester, and are at an increased risk for adverse pregnancy outcomes" (Schmidt et al., 2020). By providing accessible and comprehensive sexual education, it is less likely that risky behaviors will take place.

Often, these gaps in knowledge do not stop simply at sexual behaviors. Research has also shown that ID/DD individuals struggle with knowledge about healthy relationships, boundary setting, and negotiation skills, which can often lead to mental health issues, such as low self-esteem, depression, and anxiety (Oakes & Thorpe, 2019, Schmidt et al., 2020). A study done by Cheak-Zamora et al. (2019), that interviewed adolescents and young adults with ASD, highlights the need for additional education, not only about sexual health, but "social/relationship skills building and courtship modeling" (p. 2605) as well. The disparities in sexual education for disabled individuals could be due to many reasons: social stigma, lack of educated professionals, opinions from caregivers or parents, and internalized ableism and oppression.

A commonly held belief by nondisabled people is that disabled individuals are sexually deviant–either asexual or hypersexual. However, research shows that disabled adolescents engage in sexual behaviors at about the same rates of their nondisabled peers (Tice & Harnek Hall, 2008, cited in Sinclair et al, 2015). Caregivers and parents may intentionally or unintentionally perpetuate the idea that disabled adults do not experience sexual feelings or desires, which results in constant infantilization. Because of these generalizations, disabled adolescents and adults are not getting the education they need to become autonomous in relationships and explore their sexuality. While most caregivers, group-home employees, and parents believe that sexuality and sexual education is a human right, their actions may not show that. Studies done by Oakes and Thorpe (2019) and Pebdani (2016) show that, for staff and group-home employees who work with disabled adults, there is a level of discomfort when

discussing sexuality, despite the common belief that it is normal and part of life. There may be levels of cognitive dissonance on the staff's part, who may not fully be comfortable with sexuality themselves. While they are able to say that sexuality is a right, when putting those words into practice, they may experience discomfort. Even though perceptions of sexuality have changed significantly over the last few decades, sexuality is still frequently seen as taboo in the United States. This could significantly impact staff's perceptions of sexuality, especially with those who are outside the "norm." This discomfort may only increase when other layers of intersections are added. For example, queer disabled bodies are considered "multiple minorities," (Sue & Sue, 2013, p. 70), as they experience oppression due to ableism and homophobia, biphobia, or transphobia. The further people deviate from the norm of the groups in power, typically seen as those being white, able-bodied, and cisgender, the more oppression and difficulty they will face. Current literature suggests more training on sexuality and its intersections can help staff feel more comfortable supporting disabled individual's autonomy surrounding the subject.

Current research lacks information about possible contraindications for providing disabled adults with opportunities to learn or engage in sexual education material/content. This may be due, in part, to an overall lack of information surrounding these topics, thus creating further gaps. Literature on the subject often seems to be a response to the societal belief that disabled people are asexual or hypersexual, as opposed to any research that suggests these stereotypes are based in fact. However, as sexual education is relatively taboo, no matter who is learning it, there are considerations to be aware of. Possible arguments against teaching these topics, including legality surrounding consent or predatory or abnormal sexual behavior may arise from such stigma.

Other barriers, aside from stigma, include the lack of educated professionals to provide sexual education. Most nondisabled adolescents receive some level of education in public schools on sexual health, but the depth and topics vary greatly from place to place. Parents and caregivers are also major sources of sexual education for disabled and nondisabled individuals. but once again, the topics and level of comprehensiveness varies widely (National Information Center for Children and Youth with Disabilities, 1992, cited in Sinclair et al., 2015). There are also discrepancies in what is seen as the main goal for teaching sexual education to a disabled population. Some may choose to focus on sexual safety, while other caregivers may emphasize reproductive health issues such as pregnancy and STIs. Others may be concerned about legal issues surrounding sexual education, especially when those who are teaching are not the legal guardian. Lack of consistency surrounding the topics covered as well as where the topics are coming from create gaps in understanding for disabled individuals. Research has also recommended that for this population, education should be repeated over time, as opposed to individuals receiving a one-off sexual education training (Schmidt et al., 2020). People who do receive multiple trainings over time may find that the information comes more naturally when needed.

Literature also shows that for those who are disabled, there may be some level of internalized ableism and self-stigma. In survey reports from disabled young adults, a common theme arose surrounding feeling outside pressure from caregivers and feeling incapable of having romantic or sexual relationships. If no one is supporting sexual autonomy, it can be assumed that sexuality is a taboo topic and that sexual feelings should be repressed. Disabled adults also reported that another barrier to sexual health education was feeling uncomfortable and awkward discussing sexuality related topics, much like staff and parents have reported about themselves (Oakes & Thorpe, 2019). Once again, this lack of discussion perpetuates the idea that discussing sex is dirty or taboo. In a qualitative study from Cheak-Zamora et al. (2019), college aged students reported that they sometimes talked about sex with parents and friends, but the content of those conversations was often lacking. Very few reported speaking to healthcare providers or other professionals about the topic. This same study also highlighted that while many disabled individuals desire a romantic relationship, they report not knowing how to begin one, difficulty within relationships, and that their relationships do not meet their ideal. Lack of privacy may also contribute to difficulties within relationships. Individuals living in a group home or with other caregivers may not have a private space to explore sexually, whether that be on their own or with a partner. Often, this lack of privacy in group homes results in unsafe behaviors such as engaging in sex in public places, such as in parking lots or public bathrooms (Hollomotz & SpeakUp Committee, 2009).

Other studies have also reported that disabled adults feel a "clear lack of control over relationships and sexuality related decisions" (Sinclair et al., p. 11, 2015) and a lack of autonomy (Oakes & Thorpe, 2019). For individuals that are not their own legal guardian, decisions regarding sexuality may not be completely their own, undermining their sexual autonomy. While these decisions may be made in the best interest of the individual, it may not support the idea that sexuality is a right and can contribute further to the oppression of disabled individuals.

This literature review summarized current, albeit limited, research on DMT with an ID/DD population, as well as the theoretical underpinnings of somatic psychotherapy. Studies have shown that DMT has many potential benefits, including improving communication skills, body awareness, and self-regulation skills. All of these skills can prove useful while in relation with others. A brief review of disability theory is included, contrasting the medical and social

models of disability. Finally, the literature review also described current limitations in the sexual education of disabled adolescents and adults, where stigma adds to lack of resources and clarity.

### Methods

For the purpose of accessibility and to not disengage myself from the method (due to the inherent biases and effects that I had on the results, consciously and unconsciously), from this point onward I will be speaking in a first-person narrative.

After reviewing the literature and working with many clients over the span of a year and a half, I created workshop topics based on what clients said they wanted to know more about, what I felt like could be useful from working with this population, and what the literature stated was missing. I landed on four workshop themes: Boundaries, Healthy and Unhealthy Relationships, Consent Everywhere, and Safer Sex and Sexuality. Each group was to last an hour and occurred in the day programs' afternoon activity time block. After proposing the workshop themes to my supervisor and creating a flier and summary of each topic, my supervisor suggested the idea to the day program directors, who all agreed that many of the individuals they work with could benefit. While I did intentionally ask clients what they wanted to know or learn more about, the clients I spoke to are not to be generalized to all disabled people. Just as neurotypical people have different needs and curiosities in regards to sexuality and relationships, so do disabled people. However, there were commonalities between what the literature found to be lacking in sexual education for disabled adults and about what my clients wanted to learn.

# Population

All the clients that participated attend a day program with a non-profit organization that serves adults with ID/DD in the New England area. The clients ranged in age from 23 to mid-40's. The clients had a range of diagnoses, some with just ID/DD, others with an ASD or

Down Syndrome diagnosis. Most clients were physically able-bodied, with some visual and hearing impairments.

After the clients were chosen to participate by their day program directors, predominantly based on who could benefit the most from these topics, a consent form went out to parents and/or legal guardians explaining my role in facilitating the workshops, and what each workshop would entail. Individuals and their guardians had the choice to opt out of any of the four workshops if they felt it was unnecessary. All together, there were twelve individuals who participated in at least one of the workshops, with a total of four individuals who participated in all four. There were several different reasons why clients did not participate in all four workshops, including testing positive for COVID-19, going on vacation for a portion of the weeks, opting out of one of the topics, or not being well suited for the group environment.

Each workshop followed the same general structure for the four week period. I utilized a person-centered and relational framework to allow for an emergent design, where each section built upon the previous one. I allowed the embodied activities to be determined by what I saw as best serving the group at that time. Typically, I arrived at the space with several different options of how to explore the topic in an embodied way, and chose spontaneously according to the group dynamics of the day.

The workshops, regardless of the theme, began with a verbal check-in and group norms. The next part of the workshop was a discussion and psychoeducational portion about the theme of the day. Depending on what the clients shared and how many questions they had, we would spend anywhere from 15 to 30 minutes on this. The next portion was always some type of embodied activity, which are described in detail in the following paragraphs and visually explained in Figure A. Lastly, as a closing ritual, I invited participants to add anything they wanted to an ongoing art piece, collaboratively created on a roll of butcher paper. After the participants left, I would take notes on my observations, thoughts, and feelings about the group to process.

# **Experientials**

The first workshop focused on boundaries and clients participated in two embodied activities to explore physical space and boundaries. The first, entitled, "Don't Pop My Bubble," consisted of several clients stepping inside hula hoops and holding them around their waist. The group was tasked with navigating the small space we were in without bumping into furniture, other people, or other people's hula hoops. The task was made more challenging when I prompted everyone to speed up their walk. This activity lasted for the length of two songs. The second embodied was a variation on Rena Kornblum's "Approach and Stop" experiential from her book, *Disarming the Playground* (2003). I invited participants to pair up and line up along two walls facing each other, assigning one side to be the movers, and the other side of partners to be the leaders. The leaders were prompted to ask the movers to come closer to them and to tell the movers to stop when they were a comfortable distance away. The movers were instructed to listen to the leaders and respect their words. After each partner participated in both roles, I asked everyone to repeat the activity, this time, only using nonverbal ways of expression. This activity was done without music, and lasted about ten minutes.

The second workshop's theme of Healthy and Unhealthy Relationships attempted to get clients to think about green, yellow, and red flags in relationships, as well as gray areas, where behaviors are not necessarily straightforward. The experiential was an embodied classifying game, entitled, "Red, Yellow, or Green Flag." The group stood in a circle around a chair with several notecards on it. Each person chose a notecard and read off the behavior. The group was then tasked with classifying the behavior as a green flag (healthy), yellow flag (in the middle), or a red flag (unhealthy). When the group made a decision, the client would stand next to the assigned color table.

The third workshop in the series focused on consent in all different environments. In the first embodied activity, "Can I have a hug?" I invited the participants to pair up with the person next to them and gave everyone a specific role. One person was to ask, "Can I have a hug?" while the other person was simply supposed to respond, "No." After each person had tried both roles, the group repeated the exercise where the responder could only use body language. Finally, when clients responded with no, I had the asker respond by saying a genuine thank you, to practice accepting no graciously. The next embodied activity, entitled, "Cookie Consent," was an embodied role-play, where each person was given four cookies. We then came up with a role for the person next to them, whose job was to ask for a cookie. The person with the cookies had the ability to say yes or no. Roles we created included a best friend, a sibling, a grandmother, a bus driver, an acquaintance, a boss, a police officer, and a stranger. The client would act out asking for a cookie as their assigned role, and would receive or not receive one, depending on what the person with the cookies decided.

The final workshop, Safer Sex and Dating, emphasized the importance of safer sex practices, while also attempting to show that sex and intimacy can and should be a pleasurable activity. The embodied activity, entitled, "Yes and No," was to find where the feelings of yes and no lived in clients' bodies. In the large group, I asked the group to think about when they say no to something and how that feels. I invited them to show what it looked like in their body when they wanted to say no to something. I then invited the group to think about how it feels to say yes

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to something, and where those feelings live. The group cycled through showing different ways to say yes and no, both verbally and nonverbally.

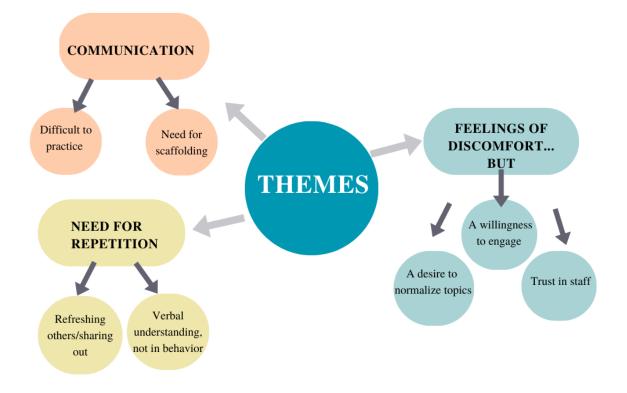
The results provide a description of how I saw the participants understanding these themes and their responses to the discussions and activities. Figure A provides a concise explanation of each embodied activity for easy referral in the results and discussion sections.

EMBODIED ACTIVITY	DESCRIPTION
Don't Pop My Bubble	Participants navigate the space holding hula hoops around their waist without bumping into people or furniture.
Approach and Stop	Participants line up in partners opposite each other. One side will approach the other side, but only when their partner tells them they can. Both verbal and nonverbal.
Red, Yellow, or Green Flag	Participants classify behaviors as healthy, unhealthy, or in the middle according to marked spaces in the room.
Can I Have a Hug?	Participants pair up. One person asks, "Can I have a hug?" The other person must say/show, "No."
Cookie Consent	Participants are given four cookies. The person next to them is assigned a role (i.e. neighbor, stranger, parent), and must ask for a cookie as that character. The person with the cookie must decide to give or not give them a cookie.
Yes and No	Participants explore where they feel yes and no in their body and embody how to say yes and no nonverbally.

Figure A.

# Results

As this development of a method was not a formal qualitative research study, my results stem from my informal observations and reflections on the workshops. Several common themes repeatedly appeared, and I decided to organize my findings in a group of themes and subthemes, inspired by a more formal coding process. The themes that I found fell into three main categories: Communication, Need for Repetition, and Feelings of Discomfort. Subthemes with Communication included *difficult to practice* and a *need for scaffolding*. Subthemes of need for repetition included *refreshing others/sharing out* and *verbal understanding, not in behavior*. Themes around feelings of discomfort included a *desire to normalize topics, a willingness to engage, and a trust in staff.* Figure B illustrates these themes and subthemes.



### Figure B.

#### **Boundaries**

As the workshop on Boundaries was the first in the series, the group began with an explanation of what everyone was there to do, what the group would be discussing, and creating group norms. This was also the first time that I was meeting about half of the participants from another day program within the organization, though many clients knew each other. About half of the clients came from the day program that I spent most of my time at, so they knew me and

felt comfortable with me. I noticed a high energy in the room from many, while a smaller number of people seemed slightly uncomfortable or unsure about the group. In discussion, many clients were able to explain their understanding of boundaries, but most commonly through physical boundaries. Clients seemed to have some difficulty understanding digital and emotional boundaries or coming up with examples. Several clients shared times that someone got in their personal space, but no one shared a time that they crossed someone else's boundary. When discussing what can be done when someone crosses a boundary or if we cross someone else's boundary, communication and apologizing were common themes that developed. Clients acknowledged that it may be hard to share boundaries or apologize, especially when it was someone they cared about.

While clients were engaging in the first embodied activity, "Don't Pop My Bubble," naturally, people began to communicate. I observed individuals pausing to let others pass by, as well as many saying things like, "You go first," "Sorry," and "Excuse me." Several clients approached this exercise playfully, and appeared to be enjoying how silly they felt walking around with a hula hoop. In the second embodied activity, the energy shifted a bit. I noticed one male client trying to pair up with one female client, who seemed uncomfortable with the idea. At this point, I intervened and suggested she pair up with another female client who did not yet have a partner. Clients needed several prompts to begin the "Approach and Stop," activity, potentially due to the discomfort of being the first to break the silence in the room. Here, I noticed some clients having difficulty listening to their partners and approaching people when they did not want them to. When the clients switched to only using nonverbal signals, most clients agreed that noticing and using body language felt easier than verbalizing. Finally, while clients engaged in a collaborative group reflection, I noticed not necessarily what was added to the paper, but rather,

the way that it happened. Clients seemed aware of the small space that the paper was on, and I noticed several clients communicating that they could wait until a space opened up and that they did not want to get too close to others.

# Healthy and Unhealthy Relationships

In the second workshop, I noticed the majority of the group wanted to share what we had done the week prior as we had some new participants. One client, who was new to the group, shared that another had "filled me [her] in about boundaries." Outside of the group environment, several clients greeted me by talking about boundaries, or stating that they remembered what we had talked about prior, which mirrors recommendations of repeated education from the literature (Schmidt et al., 2020). I also noticed that despite the verbal understanding clients had, several clients needed verbal reminders that they were in someone else's space, or touching people without their permission. This was seen in many clients, where, if I asked them to explain boundaries, they could tell me, but it would not show in their actions. Once again, creating embodied experiences over a repeated time period could aid in this gap.

While engaging in the "Red, Yellow, or Green Flag," activity, clients were able to clearly designate what they felt was healthy and unhealthy. However, there were several cards that stated a behavior that fell into a gray area. In these ambiguous states, I noticed confusion in the participants. Some immediately decided that it should fall to one end or another, but others began to debate for certain scenarios where it would be healthy or unhealthy, depending on context and the person. Naturally, I noticed that clients, when finding a behavior that they knew was healthy, such as "Someone who respects you," began to celebrate that positivity in their body. Many clients would nod, smile, and verbally share affirmations: "Healthy–yay!" At the same time, I noticed that the opposite was true when an unhealthy behavior was found. Clients would shake

their heads, groan, and say things like, "Oh no," or "That's *really* not good." The group naturally fell to nonverbal body signs while experiencing the activity, whether they noticed it or not. When I shifted the discussion towards what one could do if they found themselves in an unhealthy relationship, communication once again came up. However, clients did not seem to be able to share exactly how they would communicate that to their partner. The subtheme of a need for scaffolding in communication was noted here.

#### **Consent Everywhere**

While clients engaged in "Can I have a hug?" I noticed that several clients showed discomfort, even if they were paired up with someone they knew. I also noticed some clients agreeing to a hug, even though their job was to say no. Several clients, without realizing it, explained their no, saying things to the effect of, "I don't feel like it," "Not right now," or, "I don't want a hug but I'll give you a high five." When I pointed this out, a couple clients stated that they felt uncomfortable saying no, or that they felt like they needed to give a reason as to why they said no. When discussing why saying no was so hard, people brought up not wanting to hurt other people's feelings, not wanting to create a problem, or not wanting to disappoint someone. On the opposite end of the spectrum, one client stated that she enjoyed being able to say no, sharing that it felt "empowering" to be able to do so. I tried to facilitate the discussion to allow clients to understand that simply saying no is a full sentence, and that no one needs to provide a reason as to why they said no to something.

During the second activity, "Cookie Consent," I noticed hesitancy and feelings of discomfort once again. However, every participant engaged in the activity with a willingness that I did not expect. I believe that the two staff who were a part of the group greatly aided in a safe and trustworthy environment, where the clients were able to talk about serious matters in a relatively lighthearted way. This is shown in subthemes of a willingness to engage and a trust in staff. Clients were able to reflect on who they would say yes to and who they would say no to, and if most people would agree. One staff member brought up the idea of coercion, and helped clients determine if their giving of a cookie was freely given or coerced. Several clients shared that with strangers, it was much easier to determine what they would do than with people they trust. The idea of guilting someone into doing something was also discussed. We discussed how important it was to feel that saying no is possible, especially with people we trust.

# Safer Sex and Dating

In the final workshop, with arguably the most uncomfortable topic, the tension and embarrassment was palpable. Every client had the option to opt out of joining this group if they or their guardians did not feel it was necessary. Only one client chose to opt out due to the topic; others were unable to attend due to outside circumstances. The group began with myself attempting to break the awkwardness by naming it in the room. When I said that we were going to be talking about sex, several people began to giggle or groan. One person who seemed especially uncomfortable said, "It's normal though, it's just weird," as her face turned bright red. This seemed to be the general response from the group–acknowledging that sex is normal and fine to discuss, while also holding that it is quite uncomfortable at the same time, as shown in the subtheme of a desire to normalize topics. While engaging in "Yes and No," clients found where those feelings of yes and no lived in their bodies. Many clients relied heavily on the use of facial expressions and their hands to show a yes or a no. The group closed with clients finalizing the art piece, where several people signed their names, mentioned important words and themes, and what they felt they had learned. In my own reflections and observations, I noticed the themes that I have previously mentioned, as well as my thoughts and feelings. I stayed aware of moments that I felt discomfort in my body as well as noticing when something I said or explained did not convey what I was trying to get across. Before each group, I noticed some somatic symptoms of anxiety in myself as the facilitator, as I never knew how clients would approach the space. After the group finished, I found myself experiencing a large amount of adrenaline, often feeling the need to 'shake myself out' and tune into my breathing.

# Discussion

The purpose of this method was to explore sexual education themes and topics in an embodied and comprehensible way for ID/DD adults. While it was my observation that clients who participated were able to develop their knowledge, social and relational skills, and embodiment surrounding these themes, I am also aware that the curriculum itself may not have caused that. I knew many of the participants and had been working with the organization for about a year and a half, which could have influenced clients' willingness to participate. At the time of writing, I am in the middle of a second round of these workshops with two more day programs, at the directors' requests, because they felt their clients would benefit from participating. However, the results have been vastly different. One day program, where I am not as familiar with the clientele, sent five individuals, all who chose to no longer attend by the end of the second session. This suggests the necessity of developing a strong rapport with the clients to be able to discuss these topics in a safe environment. I have also noticed that several clients who are in the second group are in relationships, whereas very few in the previous group had romantic partners. Those who are in relationships may feel that they do not need to refresh on this information in comparison with their peers who may not have that experience. While this

may be true for some people, the literature has shown that those with an ID/DD who are in relationships feel that their relationships do not meet their standards (Cheak-Zamora et al., 2019). The literature has also shown that many with an ID/DD receive limited resources on sexual education, especially post-graduation (Oakes & Thorpe, 2019). While people may feel that they do not need help within relationships, many people are unaware of what they do not know. This was evident in many groups, as clients asked questions about who can get pregnant or what an STI was.

I also noticed the way the group dynamic switched from the first session to the next. In the second group, there were two clients in a relationship with each other, and discussing these topics together may have been uncomfortable. Gender may also have played a role in people's decision to cease attending, as one client in the first session opted out of Safer Sex and Dating because he felt uncomfortable talking about sex "with a girl," referring to myself. This comment also made me wonder if clients who identify as men would feel more comfortable discussing this with a staff member who shares that identity. How does my identity as a cisgender woman show up in the space? In the future, I wonder about the effects of splitting the groups up by gender–would it allow for a more comfortable and honest discussion? Or, is there more benefit to having these conversations in a group with many different identities? Bringing people's awareness to their intersecting identities could allow for a more meaningful experience, or, in turn, it could make people feel more uncomfortable if they do not feel as if they are in a safe environment.

As the first and second series of workshops were received vastly differently, I want to point out possible issues around providing this type of education to an ID/DD population. As previously mentioned, there is little academic research that suggests disabled adults should not

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learn about sexual education; however, I could imagine that these topics could be weaponized by the general public. Working with a population of adults who may not have the right to legally consent without a parent or guardian's approval brings complications as well. When I was proposing the workshops, I expected some backlash from parents or caregivers, especially in regards to the Safer Sex and Dating workshop. I was grateful that everyone and their caregivers seemed agreeable, but this may not always be the case. Some caregivers may feel that their child may never be at a proper "mental age" to engage in sex, and that teaching this may promote dangerous behavior. In the future, facilitation of these workshops should acknowledge this and include the parents, caregivers, and guardians every step of the way.

I also want to stay aware of the necessity of accessibility, and how, when working with clients with a range of disabilities, it can be difficult to cater to the group's needs as they may vary greatly from one person to the next. I believe that my familiarity with half the clients added to the success of the group, as I generally understood where I saw the gaps in knowledge. In the second round, clients seemed to have greatly different needs. The emergent design of the method attempts to account for this, but it is impossible to fully prepare when there is limited information available for each client. Along with accessibility is the consideration of dance/movement therapy and its role with those with physical disabilities. In the second series, there was also an individual who relied on a wheelchair to move around, whereas in the first group, all the clients were physically able to walk. While the client was still able to participate in the embodied activities, she required more support than others to move around the space. By introducing the group as drawing from DMT, she may have felt embarrassed or insecure about her physical capabilities.

Watching the method come to life and observing clients' participation reaffirmed much of what the literature stated: sexual education for this population should be consistent, comprehensible, and repeated over time. I have also found that familiarity with the clients and a non judgemental approach and attitude can create an environment of safety, which is more conducive to learning. Utilizing DMT and somatic techniques can allow for participants to find and understand inner sensations of the body, which can then be applied to everyday interactions with family, friends, and romantic and sexual partners.

### Conclusion

Sexual education has come a long way over the years, but it is clear that there is still much left to improve, especially in regards to those who fall outside of society's norms. For disabled populations, comprehensive sexual education can encourage the bodily autonomy and choice that societal stigma has taken away. By offering an emergent development of a method, I aimed to support the needs of many clients who have not had the access to comprehensive sexual education that accounts for the needs of the body. Exploring topics from a body-based lens can further promote the connection of the mind and body, so that the next time clients experience a somatic sign of discomfort, they may be able to name it as such. As a developing clinician, I plan on emphasizing the role that the body plays in sexual and romantic interactions so that clients are able to understand their needs, wants, and desires, as well as what their boundaries are. My hope is that sexual education that centers pleasure is no longer viewed as inappropriate for disabled adults, and that those in support roles, whether that be parents, guardians, group home staff, therapists, or teachers, can acknowledge that everyone has the right to sexual and bodily autonomy.

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# THESIS APPROVAL FORM

# Lesley University

# **Graduate School of Arts & Social Sciences**

# **Expressive Therapies Division**

# Master of Arts in Clinical Mental Health Counseling: Dance/Movement Therapy, MA

Student's Name: Eliza Owen-Smith

Type of Project: Thesis

Title: An Embodied Approach to Sexual Education: Developing a Method for Disabled Adults

Date of Graduation: May 20th, 2023

In the judgment of the following signatory this thesis meets the academic standards that have been established for the above degree.

Thesis Advisor: Wendy Allen, PhD, LPC, BC-DMT