

# Our Sexuality, Our Health:

A Disabled Advocate's Guide to Relationships,  
Romance, Sexuality and Sexual Health



**Office of Developmental Primary Care**  
Improving health outcomes for people with developmental disabilities

# Our Sexuality, Our Health:

## A Disabled Advocate's Guide to Relationships, Romance, Sexuality and Sexual Health

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# About this Guide

Hello! Welcome to the Sexuality and Developmental Disability Resource Guide! I'm Melissa Crisp-Cooper. I live in Oakland, California with my husband Owen and our feline friends. I am not an expert on sexuality and developmental disabilities or a health care professional. I am however, deeply interested in how people of all abilities think about these very basic aspects of life. In these pages, I

*Hopefully, this guide will offer an open and honest conversation about a topic that connects us as humans.*

will highlight positive notions, generate creative thinking, and debunk some common misguided perceptions. I have athetoid cerebral palsy. My disability primarily affects my muscle coordination and speech. I spent a great deal of my late teens and twenties trying to figure out how my own desire for love, companionship, and physical intimacy fit together with my disability.

I am a white, straight, married, cis woman. I have taken one path and speak from my own perspective. Of course, this is not necessarily the perspective of others in the large and varied disability community. I will do my best to represent other perspectives, but acknowledge that my own lack of understanding and biases may cloud my ability to accurately tell these stories. When possible, people will have the opportunity to speak their own truths.

Although many topics discussed here will be relatable to everyone regardless of ability, certain parts of this guide will focus primarily on women with physical disabilities. As a female wheelchair user, this is where I happen to have the most personal life experience.

Hopefully, this guide will offer an open and honest conversation about a topic that connects us as humans. Some subjects discussed may be quite sensitive in nature to certain readers. I apologize in advance if anything written here stirs up negative emotions or reactions. While sex and sexuality are generally positive topics, they can have a dark and painful side for some people.

Not everything in this guide will apply to all readers. We all come to this topic with different identities, experiences, and levels of information. The information presented here may prove useful and relevant for both people with disabilities and other interested folks such as family members, educators, and health care professionals.

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# Introduction

Way back in the late 1980's, when I was a hormonal teenager, there were few images of people with disabilities involved in well-adjusted romantic, sexual relationships in the media. I remember the occasional big screen movie about either an inspirational character who miraculously found love or an angry, sad sack person with a disability who deemed themselves unworthy of a romantic relationship. They were almost always saved from the brink of self-destruction by a heroic, nondisabled big name celebrity.

Yet, by fifteen I knew these stories did not reflect my reality. I was not going to overcome my cerebral palsy and run into the arms of my perfectly abled lover, but I had a smart, sassy personality. So why couldn't I find love and share my first kiss with the cute guy in my algebra class? I wanted to see people like me in films, on TV, and in advertisements. I wanted my adolescent-focused magazines to feature teens with disabilities on their covers and publish realistic articles on dating with a disability.

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advertisements.*

Like my able-bodied high school friends, dating, relationships, and sex were popular topics of conversation among my friends with disabilities. We longed to be seen as datable, had questions about how our health conditions would affect our relationships, wondered about our futures, fantasized about our weddings, and imagined having passionate sex. Unlike many of our nondisabled peers, some of my disabled friends received little to no formal sexuality education from their families or the school system. Society failed to see them as people capable of having questions about their sexuality or the ability to act upon their adolescent desires.

Although the disability rights movement was gaining momentum during this period, the historic Americans with Disabilities Act (ADA) of 1990 had not yet become law. Many public places remained inaccessible to those of us with physical disabilities. Outside of our special education classrooms, we saw few real life examples of people like us in love. We rarely saw someone in a wheelchair holding the hand of a lover or someone with a visual impairment or intellectual disability kissing a partner.

Perhaps this lack of inclusion explained why I stared in amazement at the love struck couple in power wheelchairs as they enjoyed a meal and each other at a local diner. I watched them sip wine through straws, pick up grilled cheese sandwiches with jerky hands like mine, and laugh at a scrambled conversation that only they understood. This couple could not have known how their private date would impact the way I imagined my future.

Almost three decades later, our lives are still vastly underrepresented in public policy and in the media. We still cannot get legally married without the risk of losing our Supplemental Security Income and health insurance benefits. However, we are rolling forward. Since the passage of the ADA, we have become more visible in society. While some movies still play up the pity angle when telling stories about disability, love, and sexuality, the media is slowly starting to take a more progressive

approach. They now sometimes highlight stories where we are depicted as sexual beings with the same curiosities, desires, and needs as our nondisabled peers.

# Sexuality Education

Perhaps we should start off with a more expansive definition of sexuality. In Rhoda Olkin's book, *What Psychotherapists Should Know about Disability*, she goes beyond the standard definition of sexuality as a state of being sexual. She argues that sexuality is comprised of many different biological, physical, and emotional components, such as: sex drive, desire, body image, sexual functioning, and interpersonal relationships (p. 227).

Those of us with disabilities can attest to the many misconceptions that surround these aspects of our sexuality. Not only do these misconceptions affect how we are seen by society, they are also harmful to our self-esteem when we internalize them as our truths. We may hear that negative voice inside our heads tell us that we have nothing to contribute to a relationship or that we will only be a burden to a potential partner. Olkin uses the term "internalized ableism" to describe how we often start to believe the same negative ideas held by society. (Many of the following points will be discussed in greater detail in later chapters.)

## Common Misperceptions

1. **We are all asexual or heterosexual.** First, people with disabilities fall along the same sexuality spectrum as nondisabled folks. We desire intimate connections and have sexual relationships. We represent every sexual orientation. Our preferences and partners are as complex and varied as those in the larger population. A small number of us identify as asexual. Although we may not experience sexual attraction, we may still want close relationships.
2. **We only date other people with disabilities.** Our disabilities represent one aspect of our lives. We come to relationships with lots of different beliefs, intersecting identities, personality traits, and quirks. Like everyone, we want potential romantic interests to see our many layers. We date and fall in love with people of all abilities.
3. **We do not understand appropriate sexual behaviors and boundaries.** With the right education, support, and practice, we can and do have healthy sexual relationships. We can understand the unwritten rules of sexual encounters and respect boundaries.
4. **We don't have the capacity to give consent.** We can give or deny consent. Our consent is not optional. If we are nonverbal, our partners still must obtain our consent through other means of communication.
5. **Sex must be spontaneous.** It might take us a little extra time and planning to prepare to have sex. We might need help removing our clothes or getting into the right position. Think about this time as our way of building up the anticipation! Most of the time, we are worth the wait.
6. **We don't need privacy.** We have the right to privacy just like everyone else. So, please don't enter our bedrooms or bathrooms without permission. Don't listen to our private conversations, or read our email and texts without asking. Privacy is often complicated if



you happen to live in a larger group setting or rely on others for assistance with personal care tasks.

7. **We cannot become parents.** Our reproductive systems usually work in exactly the same way as the systems of our nondisabled peers. Many of us conceive or go through the adoption process. With access to the right resources and support, we can become loving, capable parents.

Everyone, regardless of ability, has similar dreams and needs when it comes to sexuality and intimate relationships. Many of us have received negative messages about the dangers of sex and intimacy. These messages make me sad. Sexual connections are pleasurable and positive parts of life. Sometimes they are how we bond. With the right person, at the right time, they have the power to make us feel loved and secure.

In order to have healthy, responsible relationships we all need quality sexuality education in accessible formats. This might mean getting books on changing bodies in Braille from our school or plain language pamphlets on safe sex from our doctor. Conversations and teachable moments should happen before puberty and continue throughout our lives at school, home, and during routine medical appointments. Talking about sex doesn't typically lead to an increase in sexual behavior. These conversations will just make us more comfortable with the topic.

I received the standard sex education in my high school biology class. Since I didn't have a boyfriend or date, either my parents assumed I had no interest in the subject or would never have the opportunity to have consensual sex. I remember my dad issuing a quick warning to "be careful" the night before I left for college. As people with disabilities, we don't always have exposure to the same social experiences as our siblings and peers. So, we may need a little extra support when it comes to trying to read nonverbal cues like body language, respecting personal boundaries, or the emotional and physical consequences of sex.

For more information on the rights of people with disabilities in terms of sexuality, please check out the Green Mountain Self-Advocacy website at <http://www.gmsavt.org/sexuality/>.

## Respecting Power

Please start conversations about respect and power when we are young and continue to have them on a regular basis. Some of us may need concrete instruction to recognize the difference between good and bad touch or other forms of abuse. We should be given explicit permission to trust our instincts and our bodies. We need control over who has access to our private body parts. We should feel safe with our caregivers and know they will treat us with respect. Most of all, we need a voice, advocacy skills, and the power to say no!

It has been shown that when we learn to say no or ask for help, we are safer than when we solely rely on other people for our protection. Some programs offer specially tailored classes for people with developmental disabilities that focus on sexuality and ways to have healthy, safe relationships.



Encourage us to not be compliant when someone disrespects us or our bodies. Support us when we want to talk about negative situations. Empower us when we are ready to report any type of sexual abuse to the authorities. As a young girl, I wish someone had given me this sense of power over my body.

Unfortunately, sometimes there are real dangers involved with sex. I cannot end this chapter without a frank discussion about sexual abuse, domestic violence, assault, and trafficking. This is a major cause for concern in our community. The numbers are heartbreaking. According to several studies, people with disabilities are two to ten times more likely to become victims of some form of sexual violence. These incidents are vastly underreported and successful convictions are difficult to achieve.

Most abuse stems from an imbalance in power. More often than not the perpetrator is someone in a support role like a family member, attendant, or staff at a day program. These people help us with tasks of daily life. Sometimes these are super personal tasks like going to the bathroom and getting dressed. If we are dependent on them for our physical care, affection, or financial well-being, they may see us as vulnerable, easy targets. Many times we have learned from experience to be compliant, to go along with the abuse in order to get our needs met.

Advocate and blogger, Jessica Grono, recently wrote about domestic abuse in her weekly column for Cerebral Palsy News Today. To read Jessica's powerful story, please visit:

<https://cerebralpalsynewstoday.com/2018/05/01/cerebral-palsy-despite-overcame-domestic-violence/>

## Connection, Touch, Isolation

Having a disability is a lot like living as a stranger in a strange land. Few of the natives look like you. If you happen to need communication support, the natives might have a hard time understanding your speech attempts. You may use foreign mobility or medical equipment. Sometimes, being different is awesome! You have many incredible experiences and meet fabulous people that you never would have encountered as a nondisabled native. Yet, other times, being different can be isolating and lonely. It's often harder to engage in the social side of life when you have to deal with transportation issues, difficulties with crowded environments, or architectural barriers.

Some of us have lots of people touching our bodies in order to get our daily needs met. If we have a visual impairment, we may hold onto an assistant for guidance. For those of us with mobility challenges, we may require support getting dressed, transferring into our wheelchairs, or using the restroom. These physical maintenance-related tasks are not a substitute for social contact or more intimate forms of touch. When acquaintances are leery of shaking our hands or giving us a friendly hug, we can feel disconnected from the world. This especially holds true when people avoid dating us because they fear the more physical aspects of intimacy.

I definitely felt disconnected when I moved into my first apartment. Since I can perform most body care tasks without assistance, I would often go for weeks without any form of human touch. I spent many nights in the sole company of my cats. I remember feeling like an untethered balloon, not connected to anyone.

A few months after my now husband and I started dating, we were lying in bed on a lazy Sunday morning. As I gently ran my fingers across his back, he released an almost primal sound. My heart identified this sound as someone else whom had waited a long time for an intimate human connection. Now, I smile when he slips his hand in the space between my shoulder blades and the back of my wheelchair as we stroll down the street.

Of course, we are not all the same. Some people with disabilities can be uncomfortable with close contact. We all have our own unique comfort levels. Like anyone, our level might change given our mood or a particular situation. Don't assume you know how we feel about personal contact. Please ask us how we would like to interact. We will let you know if we want a hug, are ready for a steamy kiss, or desire an action of a more sexual nature.

# Talking to Your Doctor about Sex and Family Planning

Most health care professionals receive little to no training in the intersection between disability and sexuality. In addition to holding many of the same misconceptions discussed in an earlier chapter, clinicians may falsely believe that we are perpetually concerned with our medical or disability issues. They often assume that we don't have the time or head space to show an interest in our own sexuality. They may see us as broken bodies or eternal children in need of care.

*Doctors need to see us as whole people with the same questions, life goals, and desires as everyone else.*

I was in my early thirties when I shocked my gynecologist with a simple question about contraception. She knew nothing about my serious relationship or my sexual history. She looked bewildered after my attendant translated my speech so she could understand my question. I clearly remember her asking my attendant if I was really

having sex. Doctors need to see us as whole people with the same questions, life goals, and desires as everyone else.

Many of us have questions or want more information on topics related to sexual health, yet we might be hesitant about broaching these sensitive topics with our doctors. A medical office should be a safe space to collect accurate information. We may need reassurance that our questions are normal and appropriate. We want to know that we won't be judged if we admit to a lack of knowledge. Perhaps both health care professionals and those of us with disabilities can get better at starting these conversations. Doctors can let go of their preconceived assumptions and we can take a more active role in gathering information about our sexual well-being.

## Adolescents

As we mature, sexuality becomes an even more important aspect of our overall health. By considering what we will need as we leave childhood, our supporters and doctors will help us begin healthy adult lives. Initiating these conversations when we enter puberty will allow us to feel more comfortable with our changing bodies, new physiological responses, and unfamiliar emotions. When our bodies begin to change, our needs will change as well. This is still true even when the rates of our physical and social development don't quite align. Ideally, these conversations should continue as we transition from pediatric care to adult health care.

As we enter this new stage, teach us about good hygiene. If possible, ask us if we know the names and functions of parts of the reproductive anatomy. Give us opportunities to experiment, explore and get to know our own bodies. Show us how to use condoms, other forms of birth control, and how to protect ourselves from sexually transmitted infections. Make yourself available to answer our

questions. Accept us however we happen to identify our gender or sexual orientation. Help us to see ourselves as worthy of love and respect. Instill in us the power to make decisions about our bodies.

We need practice making these decisions. Assure us that we can trust our doctors with personal information. Ask our doctors to explain that unless we are being abused or in a dangerous situation,

*Ask us all the standard questions and help us find the appropriate information and support.*

they will respect our confidentiality. If at all possible, they should see us without our parents or caregivers. At the very least, we should have a way to privately communicate with our doctors and the medical staff. Depending on how we best communicate, this might mean having a closed door office chat, using a communication device, sending a secure email or text, or asking questions via phone.

During our appointments, physicians might make incorrect assumptions about our need for birth control or how much we understand about staying safe during sexual activity. They might feel that we are always under the watchful eye of a protector and cannot possibly become victims of sexual violence. We deserve the same thoughtful care from our physicians as our peers. Ask us all the standard questions and help us find the appropriate information and support.

## Questions about Sex

We may want to know how our disabilities will affect our sex lives. Most of the research in this area has focused on men with spinal cord injuries. Some doctors can assess our specific needs and offer us tailored, creative advice. They know that factors like anxiety, pain, history of abuse, fatigue, spasticity, and the side effects from prescription medications can all impact the enjoyment we get from pleasurable sex. They may ask to see us with our partners in order to form a more complete picture. If a health care professional doesn't understand our conditions well enough to make solid, practical recommendations, they should be willing to help us investigate the topic or refer us to someone with the appropriate knowledge.

## Contraception

If our bodies are physically ready to reproduce, don't shy away from a conversation about contraception. We should be prepared to ask questions and doctors should be prepared to explain our options. They should evaluate our capacity to give consent. These are ongoing conversations. Our needs will change over time. Capacity to give consent can also change as we gain knowledge, experience, and skills.

Discuss our reasons for requesting contraception. What are our goals? Some women with disabilities use contraception simply to regulate or lighten their monthly menstrual cycles. Our cycles frequently intensify the symptoms of our disabilities and make personal care tasks harder. Many of us are sexually active and want contraception to prevent unwanted pregnancies or to protect us from

sexually transmitted infections. On rare occasions, a request for contraception may indicate a coercive or abusive situation.

### **Contraception: Questions to Consider**

- What is the birth control method and how is it used?
- Do we need more than one method for different situations?
- Do we have the physical and cognitive capabilities to use a particular method correctly?
- Do we need a long-lasting method?
- How well do we tolerate repeated procedures?
- Do we have reliable transportation in order to receive regular injections?
- Do we have known allergies to latex?
- Can a condom be removed from a package and snugly fit over a penis?
- Will we remember to take a pill on a daily schedule?
- What are the known interactions with our prescribed medications?
- Are there risks of blood clots or other disability-related problems?
- What methods will our insurance cover?

Men with disabilities also need information about birth control and prevention of sexually transmitted infections. Some men may need assistance with putting on a condom. The motor skills can be taught, a partner can help, or protocol can be developed, and staff trained to assist.

Sterilization is the most controversial and permanent method of contraception. In the past, this method was often performed on women with disabilities without their consent. Today, it has many legal and ethical concerns. Doctors should always protect our autonomy and only offer sterilization as an option when we are no longer interested in pregnancy or as a last resort.

Disabled sex educator Robin Wilson Beattie wrote a fabulous, easy to read article on more things to consider when thinking about disability and birth control. To read her piece, please visit:

<https://www.bedsider.org/features/1026-what-you-should-know-about-birth-control-when-you-have-a-disability>

## **Tips for Successful Medical Appointments**

Often those of us with disabilities have undergone many medical procedures so we may associate medical appointments with pain. This unpleasant association can lead to feelings of anxiety and hostility. In order to decrease these negative feelings, doctors should ask us directly what we need or what has worked well in the past; ask us how we best communicate and how we would like to handle the physical logistics of an appointment. Avoid talking only to our supporters about our medical issues and current needs. Remember, we are the actual patient. Without a basic level of respect, doctors will

have a difficult time gaining our trust. We need to take part in all conversations about our sexual health to the absolute greatest extent possible.

Doctors and medical staff can do many other things to make us comfortable during invasive, tricky procedures like pelvic exams, rectal exams, testicular exams, pap tests, and mammograms. Before beginning any of these invasive exams, our doctors should ask questions about our gender identity, sexual orientation, menstrual cycle, family history, experience of sexual assault, past and current sexual activity, erections, our risk factors for sexually transmitted infections, our desire to become parents, and our need for contraception. The answers to these questions may determine what parts of a complete exam are medically necessary. Sometimes this can present a double-edged sword. Is the doctor avoiding certain age and gender recommended procedures because they feel our disabilities add too many logistical complications? On the other hand, is the potential information gained from these tests worth our physical effort and psychological stress?

We all should be educated about signs and symptoms of sexually transmitted infections and screened at appropriate intervals. Both men and women require age-appropriate cancer screenings regardless of our functional limitations. People with male genitals should be educated about testicular and prostate cancer signs and symptoms and asked about erectile function and ejaculation. In sexually active people, pap tests greatly reduce the risk of cervical cancer. Likewise, regular mammograms are the best way to detect breast cancer in people of a certain age or those with a family history. Unfortunately, we are far less likely than nondisabled people to get screened for these cancers. The U.S. Preventative Services Task Force's standard of care guidelines are available at: <https://www.uspreventiveservicestaskforce.org/Page/Name/recommendations/>

*Before starting the actual procedure, it's helpful if doctors explain what will happen.*

Before starting the actual procedure, it's helpful if doctors explain what will happen. This is especially important if we have a sensory impairment. Doctors can let us see or feel the equipment. They can tell us how the equipment will be used and how our bodies might feel during a particular procedure. Some of us

might even want to know why a certain piece of equipment must be used or understand the reasons behind all the individual steps. For people who are anxious, practicing the steps of an exam in advance may help. Some people might benefit from pictures or watching a video showing what to expect.

If at all possible, we should not remain in our wheelchair during genital exams. This seated position will not provide optimal results. An accessible room and medical equipment such as height adjustable exam tables and Hoyer lifts will make it easier for some wheelchair users to transfer onto the table.

When scheduling our appointments, make sure we have enough time to complete all the physical tasks associated with the procedure. We may need more time to use the restroom before an exam, undress, and get on the table. Since a medical office is not set up like our home environment, our supporters may need extra help assisting us with these tasks.

Please help to preserve our dignity. Try not to have multiple people come into the room as we get undressed or during the exam. Assign patient, respectful medical staff to assist us before beginning any potentially complex exam. It's an even bigger bonus if this person has done a good job assisting us during past appointments. Also, it might take a little longer to complete the exam. Doctors should prepare to use slow, gentle movements and allow us to take breaks if the exam is painful or we become overwhelmed.

Our exams will be much more successful and tolerable if we are comfortable in the room and on the table. If possible, please adjust the lighting and temperature. Many of us are sensitive to bright lights. Hot or cold room temperatures can impact how well our muscles function in certain situations. Blankets, pillows, and other props can help us get into position and remain comfortable throughout the exam.

With a little creative thinking, doctors can help us find a position that works for our individual bodies and allows them to perform the genital exam. This might be quite different from the standard prone position. For example, for a pelvic exam, we may be unable to keep our feet in the stirrups, yet we might be able to lie on the table in a diamond-shaped position. Before beginning a pap test, consider the size and type of speculum. Also, it may be helpful to warm up the instrument. Consult us and our assistants before providing assistance with transfers or positioning.

Personally, I like it when my doctor engages me in an interesting conversation during a pap test. I find it easier to control my spasticity when I'm not constantly told to relax (as in relax or this will hurt more) or to stop moving. A good conversation gives my brain something else to focus on besides what the doctor is doing between my legs. If I'm really anxious and super spastic, I will take a low dose of a prescribed muscle relaxant before my appointment. Other women with disabilities prefer to listen to music during these procedures. Doctors can work with us to find the best environment for our unique needs.

The Office of Developmental Primary Care has created a handy resource to help medical professionals better navigate these exams. To read [Tips for a Successful Pelvic Exam](http://odpc.ucsf.edu/clinical/tips-for-organizing-visits/tips-for-a-successful-pelvic-exam), please visit: <http://odpc.ucsf.edu/clinical/tips-for-organizing-visits/tips-for-a-successful-pelvic-exam>

### **Medical Appointments – Tips for Clinicians**

- Talk to us directly about our medical issues and current needs.
- Before beginning an invasive exam, ask us questions about our gender identity, sexual orientation, experience of sexual assault, etc.
- Educate us about the signs and symptoms of sexually transmitted infections and provide screenings at appropriate intervals.
- Before starting a procedure, explain what will happen.
- If at all possible, we should not remain seated in our wheelchair during genital exams.



- Schedule longer appointments so that we have enough time to complete all of the physical tasks associated with the procedure.
- Help us preserve our dignity by limiting the number of people who come into the room while we are undressing and during the exam.
- Use slow, gentle movements and allow us to take breaks if the exam is painful or we become overwhelmed.
- If possible, adjust the lighting and temperature – many of us are sensitive to bright lights and room temperature can impact how well our muscles function.
- Consult us and our assistants before providing assistance with transfers or positioning.

## Breast Health

Many doctors fail to recommend routine mammograms to people with disabilities at risk for breast cancer. Even though these are vital, life-saving cancer screenings, doctors and those of us with disabilities may falsely believe that we are less likely to get cancer. We may think that it will be difficult to move our bodies or hold the correct positions while the technician takes the images. These misguided beliefs often have negative consequences for our health. With a little ingenuity, successful mammograms are quite possible for most.

While I'm not a huge fan of smashing my breast inside a giant vice grip, I do understand the importance of the procedure. Luckily, my health care facility has an adjustable mammography machine. I still need several pillows and two calm, creative technicians to help me maintain the right positions.

We may also need instruction or assistance performing monthly self-breast exams. This might be a routine task for a trusted attendant or a fun activity for a sexual partner.

## Before We Leave any Medical Appointment

At the end of all medical appointments, doctors can save time and reduce stress during future visits if they note the use of any adaptive techniques, props, or suggestions in our medical charts. It's helpful to record the names of the staff and technicians who assisted us during our visit. Also, we should receive any written information in an accessible format. If this is not possible, doctors need to make sure that we and our supporters have a clear understanding of the information and any instructions.

## Important Things for Our Doctors to Know about Sexual Violence

Unfortunately, we are often victims of sexual violence or human trafficking. If our doctors know how to identify signs of potential abuse and neglect, they can help us change harmful situations. In many instances, health care professionals are mandated reporters. In addition to physical signs of abuse, many other signs typically seen in nondisabled abused patients will also apply to our patient population. These General Red Flag warning signs may include:

- Unexplained injuries or delayed treatment
- An incident that appears inconsistent with a given description. (Like when a supporter tells a doctor an unlikely story of how a particular injury or trauma occurred.)
- Changes in mental health or sleeping patterns
- Poor appearance or nutrition

Doctors need to be especially vigilant when we are nonverbal or don't have the expressive vocabulary to describe a bad situation. Certain signs may be more likely to appear in those of us with developmental disabilities:

- Increased incontinence or changes in toileting routines
- Uncomfortable with familiar people and places
- Increased levels of anxiety or frustration
- More frequent self-injurious behavior
- Unexplained evidence of sexual activity (sore genitals or unexplained pregnancy)
- Heightened interest in sexual behavior

When abuse is suspected, doctors can give specific assessment screenings for patients with disabilities. Once the abuse is confirmed, it is critical that doctors reassure us that the abusive situation is not our fault. If a caregiver is suspected of abuse, make sure they are not present during the physical examination or private conversation. If it is safe, the person accused should be separated from the person with a disability while it is being investigated. Know that we may be dependent on this caregiver in order to meet our basic needs so we may require lots of extra support and many follow-up visits to change a dangerous situation.

# Dating

Let's face it; most of the time, dating with a disability can be quite a daunting feat. Our society and the media places great importance on having a beautiful, fully functioning body. There's often limited space in the dating world for people who happen to look different or don't follow every social norm. Yet, many of us with different bodies and unique minds want to visit the land of available singles.

If every journey begins with one step or wheel turn, then seeing yourself as datable is the first step in preparing to visit the strange wonderful land of dating. Those of us with disabilities need to recognize our own self-worth and realize that we have something valuable to contribute to any relationship. When we feel good about our smart, funny, caring, sexy, interesting, talented, handsome, beautiful, emotionally vulnerable sides, we start to become more attractive to potential partners. Some of us may be older than our nondisabled peers when we begin our journeys. Whenever we begin these adventures, we should be open to meeting new people and engaging in new experiences.

## Online Dating

Online dating has opened up a whole new porthole for finding casual dates or lifelong soulmates. During the initial stages of getting to know someone new, we don't have to worry about transportation issues or having a conversation in a crowded, noisy space. We can seek out people who share our interests from the comforts of our connected devices.

Yet, online dating can be particularly tricky for those of us with disabilities. We must decide if and/or when to disclose our disability in our personal profile. For some of us, the decision not to initially reveal our disability represents an opportunity to introduce ourselves without having the obvious parts of our conditions take center stage. On the flip side, if we ever want to meet potential matches in real life, we have to eventually come clean about whatever sets us apart from the average online dater.

I had to make this decision twelve years ago when I initially rolled through the land of cyberlove. At first, I chose not to disclose my cerebral palsy. I found the idea of not being the chick in the wheelchair super alluring. Then, this decision came back to bite me in the back side when I fell hard for a guy. I had to explain my wheelchair and scrambled speech before we met for coffee. He did not respond well, and after a few more awkward chats I never heard from him again.

When my broken heart began to heal, I decided to disclose my disability. I tried putting a positive spin on this facet of my life, saying something like "Don't let my wheelchair fool you; I can still kick your butt at trivia!" Other people show the playful and sexy side of dating someone with a disability. One profile highlighted the fact that a mate could undress her and toss her into bed although this approach might lead to unwanted questions about sexual function and capabilities. I had more success on a dating website specifically for people with disabilities. If I wanted someone to accept my limitations, I needed to do the same for a possible love interest.

To read the entire saga of my first online dating adventure, follow this link:

<http://newmobility.com/2006/05/rolling-through-cyber-love/>. Unfortunately, the relationship chronicled at the end of this article only lasted for about a year and a half. I did meet my husband on a general interest website for people with disabilities. Alas, this particular website no longer exists.

## Online Dating Safety

We must keep our personal safety in mind when dating online. A small percentage of internet users have sexual fetishes that primarily focus on the bodies of people with disabilities. They are commonly known as devotees. While there are both positive and negative feelings within the disability community regarding devotees, we should be especially aware of potential dangerous situations when interacting with people in this group.

There are many more precautions we should each take to ensure our online safety. Here are just a few suggestions for staying safe while you look for dates and mates.

### Staying Safe

- Don't disclose any personal facts like addresses, phone numbers, passwords, places of employment, or financial information in your username, profile, or on a first date.
- Take it slow even if there's great chemistry! Make sure the other person's conversations are consistent and that they have revealed their true identity.
- Trust your instincts! If there's a bad vibe, end the connection immediately.
- On a first date, always meet at a public, well-trafficked location. If possible, meet somewhere close to home or have reliable transportation. Don't ride with your date or be caught waiting for the bus or paratransit if you need to leave in a hurry.
- Let your date know if you will need assistance eating or with other activities.
- Tell someone you trust the details of the planned date. Keep your phone with you. Have an escape plan if the date goes bad or you feel unsafe.
- Meeting someone new for the first time can be scary. Consider bringing along a friend. This wingman doesn't necessarily need to join the date, but can remain nearby for additional support. (I wanted extra communication support for my first date with Owen so my best friend tagged along.)
- Maintain good judgment throughout the date by limiting your alcohol consumption.

## Real Life Romantic Encounters

Not everyone meets that special someone on a dating website and not everybody can use the internet. Plenty of people still make love connections through real life encounters. Sometimes people get introduced by friends or family members. They might meet at a specific place like school or work. People are often drawn together by their common interests or religious associations. Let people you trust know that you're ready to meet someone. Putting yourself out there can be intimidating, but it's often worth the emotional risk.

Dating also requires plenty of patience! It's often a series of hits and misses punctuated by long dry spells. Keep busy during these dry spells with fun, interesting activities. Go dancing, hang out with friends, find an adaptive yoga class, or join a disability advocacy group. Chance encounters can occur when you least expect them so try moving outside of your normal comfort zone. All the safety precautions for online dating listed above apply to meeting dates in real life.

### **Relationship Do's & Don'ts**

#### Do's:

- Be yourself, relax and have fun! Think of dating as a big adventure!
- Know that you have many awesome qualities and you're not defined by other people's opinions.
- Remember that romantic relationships take time to grow and develop. Often good friendships develop into the best life partnerships.
- Always respect your date's personal boundaries. Learn how they communicate and obtain consent before engaging in any sexual activity.
- Realize that no two people are absolutely perfect matches, but every relationship needs a foundation of respect and acceptance.
- Be honest about your capabilities and support needs.

#### Don'ts:

- Love and attraction are both two way streets. Don't try to force someone to like you or accept your disability. The other side of this advice is settling for someone will never make your heart happy.
- Never go into a relationship expecting to fix someone's abilities, personality traits, quirks, and psychological issues. Know your deal breakers.
- Avoid asking someone to stay in a relationship when they want to leave. I know from personal experience that this usually leads to resentment and hurt feelings.

## **Moving In Together**

The decision to move in together represents a big step in any relationship. While there are religious and personal views about when couples should live under the same roof, there are also certain factors to consider when you have a disability. If you are the one making the move, will you have the services and supports you need to remain as independent as possible? Sometimes it can take a long time to establish services and supports in a new location. It took me about three months to set up attendant services after I moved in with Owen.

If the home doesn't meet your accessibility needs, ask if modifications can be made prior to your move-in date. When these home modifications are not possible, talk about finding a new, more suitable place together. I have lived in Owen's split level condo for almost nine years; so believe me, moving can become more challenging once you've become rooted somewhere as a couple.

It's also important to think about what your life will look like in this new environment. Before moving, investigate employment, school, or volunteer opportunities. Check out social activities like exercise classes or book clubs. Sometimes it's easier to adjust to a new living situation if you don't rely solely on your partner for social connections.

Living with a romantic partner requires lots of communication, organization, and teamwork especially when you have different levels of abilities. Yet, once you find the right support and work out a system, cohabitation can strengthen your relationship and deepen your shared history.

# Sex

As Olkin said in her book, for those of us with disabilities, sex is often the forgotten activity of daily living. Some nondisabled people believe we don't have sexual feelings or capabilities so information about healthy, respectful sexual relationships is frequently left out of life skills curriculum. Supporters may be leery of planting sexual thoughts and desires in our minds. They don't always tell us about the good, fun parts of being sexual. They can forget to prioritize our sex lives when helping us to determine our wants and needs. This can limit our opportunities for self-exploration or intimate relationships. If your sexual needs are not being factored into your life, go to a trusted, knowledgeable source like a doctor or service coordinator for help getting your needs met and all your questions answered. You might even want to ask for more private space to explore your body or have sex with a partner. Mother and activist with autism, Ivanova Smith, had this to say about sexuality:

*"I would say that people with developmental disabilities are sexual just like anyone else. Lots of time, we are not given any education on this topic and we are not aware of many things that have to do with sexuality. It's important to know about consent. If a person touches you in a way that makes you uncomfortable, you don't have to stay in that situation and you can say no. We are all different and we experience sexuality differently."*

## Consent

Before engaging in sexual activities with other people, make sure that you understand all the rules of sex. These rules are not always clear so it's good to know the basics before you decide to have sex.

### Basic Rules of All Sexual Encounters

- Sex is a voluntary activity! Each person in a sexual partnership has the right to say yes (consent) or no (deny) to any sexual action. Consent is never optional. Get and confirm consent. Always respect the decision. Strong, positive consent usually leads to good sex!
- No one should ever force or threaten you to do anything that hurts, makes you uncomfortable, or you simply don't like.
- You can refuse at any point. You might be happy kissing your partner, but don't want them to touch your private body parts. Let them know how far you want to go. Every encounter is different. Your body and mind probably won't feel the same way in every situation.
- Sex should only happen in private spaces between unrelated, consenting people.
- Sexual activities or favors are usually not done in exchange for money or gifts although this can present a tricky grey area. Be aware of age, capacity, and consent issues under the law before engaging in these types of activities.
- There are appropriate times and places to talk about things of a sexual nature and to have sex. Make sure you have permission to talk about or touch someone's body. Use caution and common sense when commenting on sexual subjects. Ask if you are unsure about someone's body language.



## Let's Talk about Good Sex

There's no single way to define sex. Good sex is fun, pleasurable, and a way to connect. It can be tender, rough, frivolous, and quite messy. It certainly is not limited by specific body parts, genders, sexual orientations, sensations, or physical abilities. The movements and positions involved with sex can always be adapted and modified to work for your unique body. Pillows, wedges, toys, and silky

*Good sex is fun, pleasurable,  
and a way to connect.*

sheets make great adaptations. Having a disability can be exhausting. Plan sexual activities during times when your energy level is high. This plan has the potential to decrease the spontaneity, but it could increase your motivation and sex drive.

Honest communication with your partner about how your body works and what support you need will go a long way towards making each encounter satisfying for everyone. Disabled sex educator Robin Wilson-Beattie offers more creative solutions for making sexual acts possible and fun when you have a physical disability. Engage in these activities at your own risk!

*"Masturbation is one way that people explore sexual pleasure. When it comes to experiencing self-pleasure, some people with disabilities need to make adaptations and be creative in figuring out how to make pleasure possible. Sex toys are one way to help you achieve orgasm, and can be used by people with disabilities who have difficulty with masturbating solely on their own. There are different ways to use sexual aids, and a variety of products people can find and try. Not all toys will be right for everyone, but there are a variety of fun toys out there to choose from. Some issues to consider when selecting a product are if you need assisted masturbation. Assisted masturbation is where a toy is placed and turned on, either by yourself, or someone else, so that you can experience stimulation. For positioning toys, you can hold them in place with pillows or use sexual furniture designed for positioning of toys and bodies. Some people with some finger or arm mobility can use toys with a long handle for self-pleasure. Vibrators are sex toys that provide sexual stimulation in the form of intense vibrations that feel pleasurable on various parts of the body. Vibrators can be put inside a person's pants, placed on top of an erection, or strapped on to the body or bed, so that someone can lay on the stomach or on the side for better positioning. Important features to consider when choosing a toy are, is it waterproof? Can the item be recharged, does it need batteries, or will it require being plugged into an outlet while operating it? Make sure your toys and products are made of body safe materials, in order to avoid injuries.*

*When having sex with partners, sometimes people with disabilities need to use some creativity and ingenuity to achieve the goals of giving and receiving pleasure. You can purchase sexual aids, such as furniture for positioning. There are also sex toys that are specifically designed for mutual pleasure. You can also utilize familiar supportive equipment that you already use and incorporate it into your sex life. Some people with disabilities who use manual and power wheelchairs, have found that they enjoy engaging in partnered sexual activity in their chairs. A power chair can recline, allows the person to remain supported, and as such can provide great access for sexual positioning (just remember to power it off!). A Hoyer lift is usually used to make transfers easier; this equipment could also be used as a sex swing, it provides supportive access that is non weight-bearing."*

To have good sexual experiences, you must be comfortable with your chosen partners and the environmental conditions. Your sensory, physical and psychological needs should be met in the best ways possible. You should feel respected. Sex is all about surrendering control. It can be hard to give yourself over to the intense physiological reactions of pleasurable sex when your disability makes your body fight to maintain control. Orgasms, for instance, have the power to send a thousand waves of energy through your body. Mix this energy with spastic, uncoordinated muscles or active minds and sparks will fly. Explain to your partners how you might react both physically and psychologically. They should know about things like flying limbs or what happens when you're over-stimulated. They deserve to know when to get out of the line of fire!

Traditional heterosexual penis/vagina intercourse is only one off ramp on the highway of sexual destinations. You decide where you want to go by focusing on what makes you feel good. Some other exciting destinations include:

- Sensual massages (after all, skin is the largest sexual organ when it comes to pleasure)
- Colorful dirty talk
- Masturbation (either alone with an adapted sex toy or in tandem with a partner)

There are other attractions along this highway like giving and/or receiving oral sex, and participating in role play or fantasy creation. Sex doesn't have to go from slow to fast and an orgasm doesn't have to end every trip. Remember, we all have vastly different needs and desires, so not everything will work for everyone.

# Marriage

One evening in May of 2011, I noticed that Owen was unusually quiet. He's normally a super talkative guy, but on that particular evening, I could barely pry a complete sentence out of him. This strange silence annoyed me to no end. After a long battle of wills, Owen asked, "Are you sure you want to know what's going on right now? Once I do this, I can't exactly do it over," he explained but I still didn't catch a clue. Of course I wanted to know the reason for this sudden lack of communication. I was even more confused when he stormed up the stairs in the middle of our heated conversation. Yet, everything became clear when he descended the stairs with a small, white ring box! This may not have been the romantic marriage proposal that I had fantasized over as a teenager, but now our engagement is one of my favorite chapters in our love story.

We were married in October of 2012. As two people with disabilities, we were fortunate to have the financial means to get legally married. Marriage is not a viable option for many couples in the disability community. Most federal income supplement and health insurance programs include what is commonly known as the marriage penalty. These programs frequently reduce a recipient's benefits and other services once a marriage is legally recognized. Until our community obtains total marriage equality, we will not be able to fully participate in this sacred institution open to so many of our nondisabled peers. Committed couples usually find ways of being together that do not involve the legal structure of marriage.

For some couples, there's a certain comfort that comes from sharing a similar disability. As my writer friend Denise Sherer Jacobson explained:

*"So many variables go into having a successful marriage. After 35 years with Neil, I've most appreciated never feeling I had to explain what it means to live with a disability in this society. Since, like me, Neil has cerebral palsy, he's experienced the negatives--the condescending remarks, the challenges of being underestimated, and the positives--the strength of persistence, the absolute necessity of a sense of humor to maintain one's sanity. It's this basic understanding that's given our relationship a synchronicity no matter what other differences we have, and believe me, we have quite a few!"*

Follow this link from SF Gate to read more about Neil and Denise's lasting relationship:

<https://www.sfgate.com/style/article/Jokester-s-laugh-caught-her-ear-and-heart-2371752.php>

Like any committed relationship, those involving disability require teamwork, compromise and communication. Both partners should be honest and realistic about their capabilities and capacity to provide the necessary support. Today, many couples no longer subscribe to traditional marital roles. Even though these roles are more fluid, things like child care, cooking, and yard work still must be accomplished.

Dividing up these tasks can be difficult when functional limitations are added to the equation. Tasks can sometimes be broken down into smaller pieces, modified, or adapted in order to utilize one partner's capability. For example, Owen is the household chef, but I make frequent grocery runs in

my power wheelchair. Other disabled partners take on the role of lead planner and organizer of family life. It's also good to realize when more help is needed with personal and household tasks. A relationship can become strained if one person is responsible for most aspects of a spouse's personal care and the daily domestic operations of a house. Good attendants or house cleaners often play a crucial role in the continued health of strong partnerships.

# Pregnancy and Parenting

Many people with disabilities are parents. This statement goes against the popular assumptions made by many nondisabled people. Misguided assumptions are often made about our ability to become pregnant. When this ability is recognized, we can feel pressure not to conceive from society, medical professionals, and our families. Here's a simple example to illustrate this point: As newlyweds, we are rarely asked if we want children or when we will start trying to conceive.

After we become pregnant, many of us worry that child welfare agencies will determine that our disabilities will make us unfit parents and take away our children. Since there has been little formal research conducted regarding our ability to be good parents, the common misconception that we are unable to care for our children continues to persist throughout our society. Yet, with the right support and some pretty amazing adaptations, the vast majority of us continue to demonstrate that nothing could be further from the truth.

Monique Harris is the proud mother of Brandon. She has severe cerebral palsy. During a recent chat about motherhood, she told me about the initial stages of her pregnancy.

*"When my mom had my baby brother, I knew I wanted to have my own little boy someday. After I got pregnant, I was terrified the state would take him away from me. I was worried that they would think I couldn't be responsible enough to care for my own baby. In fact, when I went to confirm my pregnancy, the medical staff automatically assumed that I needed an abortion."*

## Pregnancy

No two women or pregnancies are alike. With this in mind, let's look at a few possible considerations for pregnant women with disabilities. Every woman's body changes during pregnancy. For those of us with mobility impairments, these changes may make movement and balance more difficult. The extra weight and movement restrictions sometimes cause fatigue or a heightened fear of falling. Many of us will probably want additional physical support with activities like transferring during this period. We may also benefit from an increased use of mobility devices.

Quality prenatal care is essential. Sometimes it's wise to visit a new Ob-Gyn before becoming pregnant. This visit will ensure that the doctor is willing to treat a patient with a disability and is open to learning about any potential issues. Along with all the standard recommendations and appointment checkpoints, our doctors should take into consideration the possible interactions between our prescription medication and a developing fetus. Since maintaining maternal weight and nutrition are important factors during a healthy pregnancy, a wheelchair accessible platform scale is a useful piece of medical equipment. The exam tables and bathrooms should also be accessible to you.

Our doctors should also be aware of how specific conditions might respond to the physiological changes that occur during the different stages of pregnancy. Certain symptoms (like seizures, fatigue,

and urinary tract infections) associated with our disabilities may get worse during these nine months. On rare occasions, some women with disabilities have reported a noticeable decrease in symptoms.

If appropriate, doctors should offer genetic counseling. Remember, many of us with hereditary conditions welcome the idea of raising a child with same the condition. Respect our decisions and help us find support. Be careful not to make assumptions about our support needs during pregnancy, labor and delivery, and once we have given birth. Work with us to identify these needs.

*Those of us with disabilities are quite accustomed to adapting everyday tasks and asking for assistance when necessary.*

A different set of considerations should be taken into account during labor and delivery. Plan ahead for this event by determining what anticipated support needs must be covered. Ask us if we have a reliable source of transportation for when we go into labor. Think about how we can best deliver our baby. How will we be the most comfortable and best able to participate

in this process? Do we need help to position our body? If we have lots of involuntary movements, is it recommended and safe to use an epidural? After we deliver, will we need a longer hospital stay or additional follow-up appointments?

Monique explained that the hospital staff was extremely supportive throughout her delivery. She went on to say, "I didn't have an epidural or pain medication because of my involuntary movements. I really didn't want to have a C section because the recovery would affect my ability to crawl around my house. A nurse and my attendant had to hold my legs apart! Since I had the son that I wanted, I decided to have my tubes tied after Brandon was born."

For most of us, having a baby is a joyous, life-changing occasion. Offer us the same sincere, heartfelt congratulations and well wishes that you would offer to any other new parents. On the other hand, the loss of a baby is devastating. We have imagined our lives with this new little person and now they are gone. Support us through our grieving process, even when our grief doesn't fit a standard pattern or follow a typical path.

## Mothers and Fathers of Invention

Those of us with disabilities are quite accustomed to adapting everyday tasks and asking for assistance when necessary. We are master life hackers. So figuring out workable adaptations for routine baby and child care activities can become second nature. Eventually parent and baby will also learn to adapt to one another. Neil and Denise Jacobson are married and both have cerebral palsy. In 1987, they adopted an infant son named David. During an interview, Neil beautifully illustrated the process of David learning to adapt to Neil, "I'm always amazed at how patient he is with me. He's all over the place for other people, but for me he's a wonderful boy." Denise goes on to say, "I'm more concerned with his safety and happiness than I am with how we do things or when they get done."

### To Learn More

Discover more about the Jacobson Family:

- *A Question of David: A Disabled Mother's Journey through Adoption, Family and Life.*  
[https://www.amazon.com/Question-David-Disabled-Mothers-Adoption/dp/1460999282/ref=sr\\_1\\_1?ie=UTF8&qid=1527895937&sr=8-1&keywords=a+question+of+david](https://www.amazon.com/Question-David-Disabled-Mothers-Adoption/dp/1460999282/ref=sr_1_1?ie=UTF8&qid=1527895937&sr=8-1&keywords=a+question+of+david)

The following videos show a younger Jacobson Family in action and highlight a number of issues faced by parents with disabilities. Even though these videos are dated, many of the issues are still relevant.

- Interview with Neil and Denise:  
<https://www.youtube.com/watch?v=V9Zk9kTtOMk&feature=youtu.be>
- ABC News Primetime Live Report: My Child.  
<https://www.youtube.com/watch?v=txkFgP9PPrw&feature=youtu.be>

Everyday mother and baby activities like breast feeding can be modified for moms with limited mobility. For moms who use wheelchairs, these meals on wheels are adapted using raised platforms or pillows to position the baby. Doctors should consider any possible interactions between disability-related medication and breast milk.

Monique told me a bit about how she cared for Brandon as a single mom during his baby and toddlerhood.

*"I did a lot of stuff for him while we were both on the floor. I used pull-ups instead of diapers and I had someone cut larger holes in the nipples of baby bottles. He sucked baby food through the hole when he got a little bigger. I didn't get much support from my family, but I did have a wonderful attendant. She helped me raise my son."*

To watch a sweet video of a mom in a wheelchair using a modified crib, follow this link from the Able Thrive website: <https://ablethrive.com/parenting/quadruplegic-mother-gets-baby-out-accessible-crib>

When parents cannot perform every physical care task for their young children, they are able to provide an abundance of love and emotional support. This is how blogger Jessica Grono describes her experience as a mom of two children:

*"In 2006, I became a mother to an awesome little girl. To many women giving birth isn't such a big deal, but I have severe cerebral palsy. Being a mother with cerebral palsy is not very common especially back when I had my daughter. Society has a hard time believing people with disabilities are capable of anything. Luckily, the times are changing and more people with disabilities are involved in relationships, getting married, and having children."*

*When I was little, I had high aspirations of being a mother. It never entered my mind that having cerebral palsy would interfere with my parenthood goals. My form of cerebral palsy affects my speech and fine and gross motor control. I use a motorized wheelchair to get around, and when I'm at home, I am out of my wheelchair and can crawl. I need assistance eating, transferring, dressing, and with other daily tasks."*



*My first marriage happened to be a bumpy one, but one amazing thing we did was having my daughter. Finding an obstetrician didn't come easy. In fact, many turned me down because they didn't understand cerebral palsy. We finally found someone to be my doctor, and he was terrific. Laura came three weeks early without any complications. Six months later, my first husband passed away due to mental illness, and I was a single mother. A few years later, I married again and had a son. Now we are a happy family of four!*

*Parenting with a disability is a selfless, rewarding, and frustrating lifestyle. Babies require an abundance of physical care, and I cannot provide this care due to my coordination. But, I can*

*Having a disability doesn't end a happy life but only enhances it by allowing us to rise to any challenge we might face.*

*offer more love than a thousand universes and family organization. I know what I can and cannot handle, therefore, I know in what areas that I need help. I made sure that I had the assistance needed to help take care of my babies. Being organized kept the care process so much smoother.*

*Since I cannot physically do everything that my baby needs, I had to watch and supervise when someone else cared for them. It isn't easy to watch when all you want to do is to do it yourself. I tried to always be present and talk to them during feedings or diaper changes. Being a good parent includes being selfless by putting your child's needs before your own needs. Being selfless doesn't stop with babies, but it happens all throughout childhood and adolescence. Certain things aren't physically attainable, but you still need to figure out how to make them happen.*

*What I can do, however, is love my children. What I can't do physically, I make up for it emotionally. I'm there to listen, talk, to be silly, to cry to, to support, to help, and to teach. My children aren't lacking in the things that will last - a mother's time and love. My disability hasn't negatively impacted my parenting or marriage. I do have a speech impediment, but the kids speak clearly. My husband knows my physical limitations and we adjust accordingly. Having a disability doesn't end a happy life but only enhances it by allowing us to rise to any challenge we might face."*

## **To Learn More**

Organizations like Through the Looking Glass in Berkeley, California offer different levels of training, support, advocacy, and modified baby equipment to parents with disabilities throughout the country. To learn more about their services, please visit: <http://lookingglass.org/local-services/services-for-parents-with-disabilities>

The Disabled Parenting Project is part of the National Research Center for Parents with Disabilities. This website offers many valuable resources, a forum for sharing experiences, advice, information on adaptations, and much more. Follow this link to visit the Disabled Parenting Project website: <https://www.disabledparenting.com/>

The National Council on Disability published a toolkit, "Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children." It can be found at:

<https://www.ncd.gov/publications/2012/Sep272012/>

## Conclusion

Those of us with disabilities must have the power to control our own sexuality. Since we have many of the same questions, wants, and desires as our nondisabled peers, we need accurate education in fully accessible formats. We have the same right to get to know our own bodies, receive quality healthcare, form intimate relationships, and engage in appropriate sexual activities.

Our bodies are unique, precious, and deserve to be treated with respect. Most of all, we have the basic right to feel safe in our chosen environments. Given the proper advocacy tools and support, we can choose who touches our bodies. The people who support us need to know the signs of sexual violence. They should instill in us the power to change negative situations.

*We have the same right to get to know our own bodies, receive quality healthcare, form intimate relationships, and engage in appropriate sexual relationships.*

We want others to see us as potential dates and love interests. We date and fall in love with people of every ability, gender, and sexual orientation. In sexually charged encounters, we can acknowledge boundaries, understand body language, and give or get consent. Our consent is never optional!

Almost every one of us, regardless of ability, craves human connection. This might mean forming a close friendship, trying our luck at online dating, marrying the person who makes us laugh, or having a family. It may take time to find and develop strong intimate relationships, but these relationships are not necessarily limited by our disabilities. Many of us have found highly creative ways of engaging in a variety of sexual activities. We each define our sexuality in ways that work for our bodies and personalities. Support us when we are ready to learn more about ourselves and discover all of the amazing possibilities!

# Resources

## Articles

Bedsider. "What You Should Know about Birth Control when you have a Disability." Robin Wilson-Beattie. <https://www.bedsider.org/features/1026-what-you-should-know-about-birth-control-when-you-have-a-disability>

New Mobility Magazine. Melissa Crisp-Cooper. "Rolling through Cyber Love." 2006. <http://newmobility.com/2006/05/rolling-through-cyber-love/>

New Mobility Magazine. Regan Linton. "Sex, Wheels, and Relationships 22.0". Pages 24-28. February 2017. [http://www.unitedspinal.org/pdf/NM\\_Feb\\_17.pdf](http://www.unitedspinal.org/pdf/NM_Feb_17.pdf)

SF Gate. "Jokester's Laugh Caught Her Ear, and Heart." May 2011. <https://www.sfgate.com/style/article/Jokester-s-laugh-caught-her-ear-and-heart-2371752.php>

## Blog

How I Overcame Domestic Violence Despite My Disability. Jessica Grono. May 2018. <https://cerebralpalsynewstoday.com/2018/05/01/cerebral-palsy-despite-overcame-domestic-violence/>

## Books

*A Question of David: A Disabled Mother's Journey through Adoption, Family, and Life.* Denise Sherer Jacobson. 1999.

*Reproductive Issues for Persons with Physical Disabilities.* Cole, Gray, and Haseltine. 1990.

*The Ultimate Guide to Sex and Disability: For all of us who live with disabilities, chronic pain & illness.* Kaufman, Silverberg, and Odette. 2003, 2007.

*What Psychotherapists Should Know about Disability.* "Dating, Romance, Sexuality, Pregnancy, Birthing, and Genetic Testing". (Chapter 10). Rhoda Olkin, 1999.

## Conference Lectures

University of California, San Francisco. Developmental Disabilities: Update for Health Professionals. March 8 2018. Clinical Pearls for Contraceptive Management of Women with Developmental Disabilities (pages 97-115). Michael Policar MD, MPH. <https://www.uctv.tv/shows/Clinical-Pearls-for-Contraceptive-Management-of-Women-with-Developmental-Disabilities-33513>.

University of California, San Francisco. Developmental Disabilities: Update for Health Professionals. March 8 2018. Healthy Sexuality and Adults with Disabilities (pages 84-96). Erica Monasterio MN, FNP. <https://www.uctv.tv/shows/Healthy-Sexuality-and-Adults-with-Disabilities-33512>.

## Interview

Denise and Neil Talk about Parenting. Neil and Denise Jacobson. <https://www.youtube.com/watch?v=V9Zk9kTtOMk&feature=youtu.be>

## News

ABC News Primetime Live: My Child. <https://www.youtube.com/watch?v=txkFgP9PPrw&feature=youtu.be>

NPR. Morning Edition. Hidden Epidemic of Sexual Assault. Joseph Shapiro (01/08/2018) <https://www.npr.org/2018/01/08/576428410/npr-investigation-finds-hidden-epidemic-of-sexual-assault>

## Podcast

The Moth Podcast: The Italian Stallion. Janice Bartley. <https://themoth.org/stories/italian-stallion>

## Publications

Office of Developmental Primary Care. What's Next?: A Self-Advocate's Guided Tour through Transition for Parents and Other Supporters. Melissa Crisp-Cooper. October 2016. <https://odpc.ucsf.edu/advocacy/transition-successful-community-living/whats-next-a-self-advocates-guided-tour-through>

Office of Developmental Primary Care. Tips for a Successful Pelvic Exam. November 2013. <https://odpc.ucsf.edu/clinical/tips-for-organizing-visits/tips-for-a-successful-pelvic-exam>

## TEDx Talks

Every Body: Glamour, Dateability, Sexuality, and Disability. Danielle Sheypuk. <https://www.youtube.com/watch?v=7PwvGfs6Pok>

Sexuality and Disability: Forging Identity in a World that Leaves You Out. Gaelynn Lea. <https://www.youtube.com/watch?v=akGYugciSVw>

Sexuality and Disability: A Seat at the Table. Cheryl Cohen Greene. <https://www.youtube.com/watch?v=gds2RvmCBKE>

## Television Series

A&E. *Born this Way*. <https://www.aetv.com/shows/born-this-way>

## Toolkits

Autism Now. Relationships and Sexuality. <http://autismnow.org/wp-content/uploads/2013/02/Relationships-and-Sexuality-Tool.pdf>

ASAN. Real Talk: Provider Toolkit: Improving Quality of Sexual Health Care for Patients with Disabilities. <http://autisticadvocacy.org/wp-content/uploads/2015/12/realtalk-toolkit-v2.pdf>

## Video

Able Thrive. Quadriplegic Mother Gets Baby out of Accessible Crib. Rachelle Chapman. <https://ablethrive.com/parenting/quadriplegic-mother-gets-baby-out-accessible-crib>

## Webinars

American College of Obstetricians and Gynecologists. Interactive Site for Clinicians Serving Women with Disabilities. (Parts 1-4). <https://www.acog.org/About-ACOG/ACOG-Departments/Women-with-Disabilities/Interactive-site-for-clinicians-serving-women-with-disabilities>

Futures without Violence. Collaborating to Address Trafficked Survivors with Disabilities. 01/19/2017. <https://www.futureswithoutviolence.org/collaborating-to-address-the-needs-of-trafficked-survivors-with-disabilities/>

## Websites

Disabled Parenting Project: <https://www.disabledparenting.com/>

Green Mountain Self-Advocates: <http://www.gmsavt.org/sexuality/>

Sexuality and Disability: <http://www.sexualityanddisability.org/having-sex/being-sexual/>

Through the Looking Glass: <http://lookingglass.org/local-services/services-for-parents-with-disabilities>

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