

Help with Planning a Family for People with Disabilities

People with disabilities can have kids just like anyone else. But sometimes doctors might not give them the right help or advice.

It's good to ask questions and find a doctor who really understands what you need. You have the right to get help with having a family and making smart choices.

People Who Can Help

Look for experts who know how to help with planning a family and understand your needs. They can give you the right care.

Choices for Care

Services like preconception counseling, genetic testing, birth control counseling, and family planning services will help you prepare for a family and healthy pregnancy.

Questions For Your Doctor

Be sure to tell your doctor about your needs and how they might change things when you're having a baby.

Talk to your doctor about making a plan for you to have a family.

- Can your disability cause any health problems for your baby?
- Is it easy to get around their office or clinic?
- What are your choices if you want to wait to have a baby?
- Is it easy to use their check-up rooms and tables?
- If you become pregnant and are not sure what to do, it's okay to ask what your options are.

Costs To Think About

It might cost money to talk to experts. Know what your insurance can help pay for. This includes tests to check family health, certain medicines, and counseling. If you live in California, there are programs like Medicaid and California Family PACT that can help pay for these things.



Photo Credit: @juliet.ah.justice

Image Description: A happy family of four people with different skin colors are smiling. They stand in front of a peach-colored wall with yellow and pink flowers. The mom is in a wheelchair in the middle and has a baby about one year old on her lap. The dad is on one knee to the left and is wearing a dark blue shirt. A little boy who is four years old is standing on the right and also wearing a dark blue shirt.

Help with Planning a Family for People with Disabilities

Tools and Places

Ask if there are special tools or changes to the room that can make having a baby easier and more comfortable for you.

Use apps on your phone or computer that help you keep track of when your monthly cycle is. These apps can remind you of important dates.

Helpful Info and Tips

It is good to start getting your body ready when you start planning for a family. This can include regular exercise, healthy foods and making sure you get enough sleep.

Try to find a doctor that can care for you during your pregnancy before you get pregnant. This way you and your doctor can come up with a plan and you know what to expect during your pregnancy.

Helpful Resources

- [Plannedparenthood.org](https://www.plannedparenthood.org)
- [FamilyPACT.org](https://www.familypact.org)

Sources

Mosher, William et al. "Disparities in receipt of family planning services by disability status: New estimates from the National Survey of Family Growth." *Disability and health journal* vol. 10,3 (2017): 394-399. doi:10.1016/j.dhjo.2017.03.014

Tarasoff, Lesley A et al. "Health of Newborns and Infants Born to Women With Disabilities: A Meta-analysis." *Pediatrics* vol. 146,6 (2020): e20201635. doi:10.1542/peds.2020-1635

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Sexuality for People with Disabilities

People with disabilities have the same wants and needs when it comes to sex as anyone else. They might need extra help or tools to make things easier. Talking openly and learning about different ways to enjoy sex can make a big difference.

People Who Can Help

- Sex Therapists
- Occupational Therapists
- Medical Doctors
- Mental Health Therapists
- Gynecologists
- Hormone Specialists
- Sex Educators
- Pelvic Floor Physical Therapists

Questions For Your Doctor

- How can I make sex more comfortable?
- What tools or toys could help?
- How can I tell my partner about what I need?
- What should I be careful about when having sex?
- What can I do if I become pregnant and don't want a baby?

Cost To Think About

Some things like special pillows, toys, or seeing a therapist might cost money. It's good to know how much they cost and if there's a way to get help paying for them.

Tools and Toys That Can Help

Some people might like sex toys. Special cushions or positioning aids can make different positions easier.

Talking with Your Partner

Being open with your partner about what feels nice or not so nice is super important. You can use words, draw pictures, or even show them what you like. Being clear makes being close feel better for both of you.

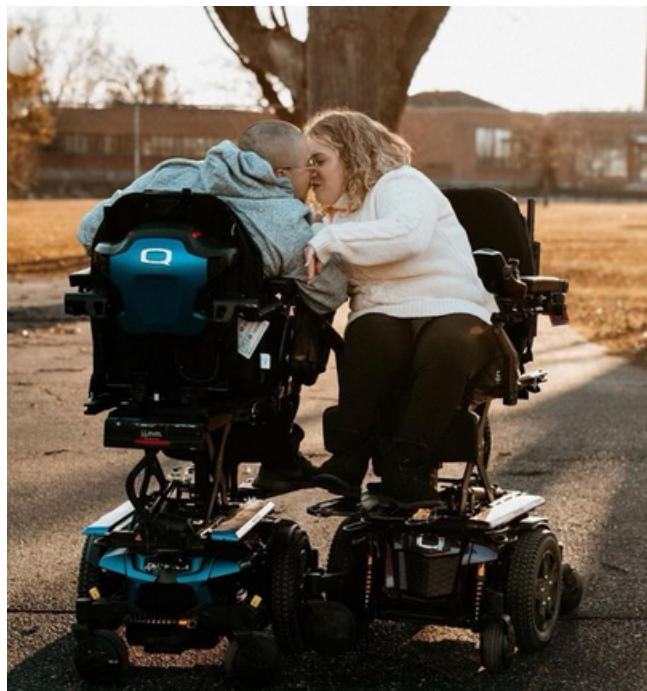


Photo Credit: Bleau Photography
Image Description: A man and woman are in a park and they both use power wheelchairs. They are kissing each other.

Sexuality for People with Disabilities

Facts About Sexuality and People with Disabilities

People with disabilities can have a happy and healthy love life. It might need some extra planning or special tools, and that's okay. Everyone is different.

Being close isn't just about one kind of sex. Things like kissing, touching or even talking are also ways of being close.

More women with disabilities have babies they didn't plan for compared to women without disabilities (56% vs 36%).

Both women and men with disabilities are more likely to face sexual violence and harm from people they are close to.

Problems People with Disabilities Might Have

Sometimes, things can make sex tricky. Like how people think about disabilities or getting the right help to enjoy sex. Talking to people who get it, finding out what is possible, and trying new ways can help get past these problems can help.

Sometimes doctors don't get why being healthy about sex is really important for people with disabilities, especially if they use wheelchairs. So be sure to be clear about your questions or worries.

Helpful Resources

- vmtherapy.com
- sexualityintransition.com

Sources

Basile, Kathleen C et al. "Disability and Risk of Recent Sexual Violence in the United States." American journal of public health vol. 106,5 (2016): 928-33. doi:10.2105/AJPH.2015.303004

Horner-Johnson, W., Dissanayake, M., Wu, J.P., Caughey, A.B. and Darney, B.G. (2020), Pregnancy Intendedness by Maternal Disability Status and Type in the United States. *Perspect Sex Repro H*, 52: 31-38. <https://doi.org/10.1363/psrh.12130>

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Breastfeeding Help for People with Disabilities

Some people with disabilities might find it hard to breastfeed. But with the right help and information, lots of parents with disabilities can feed their babies this way. Getting breastfeeding help can make your experience better and teach you why it's good for you and your baby.

People Who Can Help

Pick a support person who is easy to talk to and works with people with disabilities. Make sure to ask doctors you're thinking about if they know how to help people who have different needs.

- Lactation Consultants, Counselors, and Support Groups
- Occupational Therapists
- Infant Feeding Specialists
- Pediatricians
- WIC (Women, Infants, & Children) Peer Counselor
- Human Milk Bank

Questions to Ask Your Doctor

- What ways can I feed my baby?
- Can I use both formula and breastmilk?
- Can I pump milk and use a bottle?
- How do I keep milk safe?
- How can I get milk from someone else to give to my baby?
- How can I tell if my baby gets enough milk?
- What ways are good for holding my baby while breastfeeding?
- Are there things that can help make breastfeeding easier for me?
- Can I breastfeed if I'm taking certain medicine?

Costs To Think About

- Your insurance might pay for the breast pump and visits to a breastfeeding professional.
- You might have to pay for things like bottles.
- There may be free breastfeeding groups you can join in your area.
- WIC programs give free breastfeeding help to families who can't afford it.



Photo Credit: @adaptiveparentproject
Image Description: Photo of a woman in a wheelchair breastfeeding an infant using a supportive infant feeding pillow in her lap.

Breastfeeding Help for People with Disabilities

Tools That Can Help People with Disabilities:

- A machine that measures and mixes formula for you
- Pillows for breastfeeding that have straps
- Baby carriers like ring slings
- Step stools or other things to help you sit better
- A pump that you don't need to hold with your hands

Facts About Lactation and People With Disabilities

People with disabilities can breastfeed, but sometimes don't get to try breastfeeding as much as people without disabilities.

With the right help and tools, breastfeeding can look different ways and work for a lot of different people

Problems People with Disabilities Might Have

- Some medicines can make you have more or less milk.
- Some medications may need to be changed when you are breastfeeding.
- If your hands aren't very strong or you can't move well, it might be harder to get milk out by hand.
- If you have trouble with strength or moving, it might be harder to get the baby to latch on or stay in a good breastfeeding position.
- Not getting the help you need could make breastfeeding even harder.

Helpful Resources

- ilca.org
- kellymom.com
- Illi.org
- fns.usda.gov/wic

Sources

Brown HK, Taylor C, Vigod SN, et al. Disability and in-hospital breastfeeding practices and supports in Ontario, Canada: a population-based study. *Lancet Public Health*. 2023;8(1):e47-e56. doi:10.1016/S2468-2667(22)00310-3

Andrews, Erin E et al. "Experiences of Breastfeeding among Disabled Women." *Women's health issues* : official publication of the Jacobs Institute of Women's Health vol. 31,1 (2021): 82-89. doi:10.1016/j.whi.2020.09.001

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Parenting for People with Disabilities

Parents with disabilities might have some challenges when taking care of a family. But with the right help and support, being a parent with a disability can make you and your family strong and happy.

People Who Can Help

Pick people who are easy to talk to and support people with disabilities. Don't be afraid to ask if they know how to help people who have different needs.

- Lactation Consultant
- Occupational Therapists
- Birth and Parenting Educators
- Parent Support Groups
- Pediatricians
- WIC (Women, Infant, & Children) Peer Counselor
- Early Childhood Education
- Regional Centers

Questions to Ask Your Doctor

- What tests do newborns need to get?
- What do these tests look like?
- What help is there for parents with disabilities?
- Can you tell me where to go for more help?
- Will there be someone to help me and my child during check-ups if I need it?

Other things that can be helpful

Having people to support you is really important. This can be family, friends, people you pay to help, groups for parents, and more.

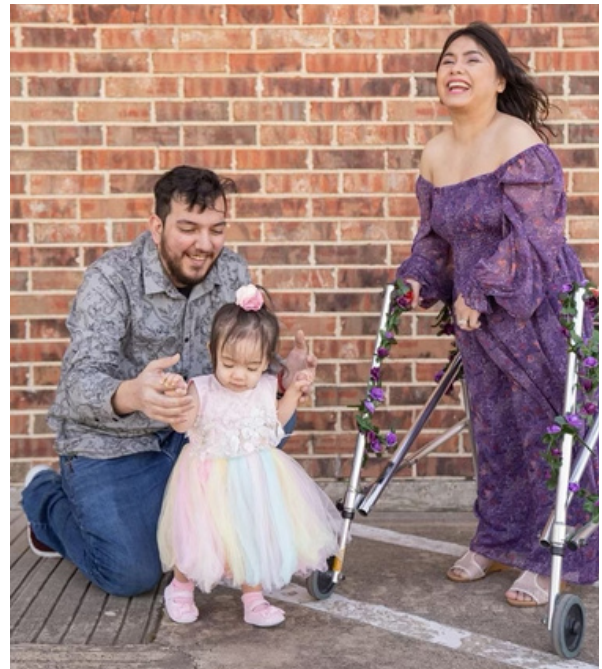


Photo Credit: Chevy Che Photography
Image Description: Photo of a light-skinned Asian woman in a walker wearing purple dress smiles at camera. Light skinned male with short dark brown hair and grey shirt kneels next to small child wearing rainbow tutu dress. Family poses in front of red brick wall.

Parenting for People with Disabilities

Helpful Things to Have

- A crib, bassinet or bed you can easily and safely lift a child in and out of.
- Car seats and strollers that are easy to move and put away
- Things that make carrying the baby easier like a baby carrier, a bassinet, or a lap belt for the baby when you're in a wheelchair
- Highchairs that have buckles you can use easily and room underneath for a wheelchair to fit
- Childproofing tools that parents with disabilities can still use
- Lights, noise machines, and baby monitors you can control with your voice or phone

What to Know About Parenting with Disabilities

People with disabilities can be parents just like everyone else.

Being a child with a parent with a disability has been shown to have benefits for them as they grow up.

People with disabilities can be amazing parents.

Challenges People with Disabilities May Have

It's good to have a pediatrician who supports your family and can speak up for you.

Parents with disabilities are sometimes not treated fairly because people think they can't be good parents.

Helpful Resources

- Adaptive Parent Project - AdaptiveParentProject.org
- Through the Looking Glass - LookingGlass.org
- Adapting Parenthood: AdaptingParenthood.com
- Sage Institute for Adaptive Parenting - AdaptiveParenting.org

Sources

Matin, B.K., Williamson, H.J., Karyani, A.K. et al. (2021). Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. *BMC Women's Health* 21, 44: <https://doi.org/10.1186/s12905-021-01189-5>

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Reproductive Health for People with Disabilities

Did you know some women with disabilities might not see the doctor as often as they should? They might miss important checks for things like breast and cervical cancer. It's important to remember to go to the doctor for these tests regularly.



Image Description: This is a picture of a woman getting a check-up at the doctor's office. She's lying on a bed with a blanket over her legs, and there's a pillow under one of her knees talking to the doctor.

Professionals That Can Help

Try to find doctors who specialize in reproductive health, nurses, and patient advocates who know a lot about helping people with disabilities.

Options for Care

Think about the idea of having the doctor come to your home for gynecological check-ups if it would make you feel better or if it's easier for you. Also, find out about things like medicine to help you relax and other ways to feel less nervous during exams.

Questions to Ask Your Doctor

- Can I get into your exam rooms and onto the tables easily if I have a disability?
- Will there be someone to help me when I come in?
- Can you spend extra time explaining things to me?
- Is there someone who can help me understand if I need translation?
- What choices do I have for birth control?
- How can I make sure I'm healthy if I want to have a baby?
- What do I do if it hurts or is hard to go to the bathroom?
- What should I do if I think someone is hurting me?

Costs To Think About

Your insurance might cover the cost of doctor visits. If you don't have a lot of money, programs like Medicaid and California Family PACT can help.

You might have to pay for some medicines or things like birth control. But sometimes, clinics can make it cheaper for you based on how much money you make.

Reproductive Health for People with Disabilities

Equipment and Tools

You can ask the doctor about things that can make your check-up easier, like a machine to help lift you or an exam table that can change height to make it easy to get on.

Facts and Tips

- Get regular check-ups and cancer screenings.
- Finding problems early is important.
- If you need more time to talk during your doctor visits, just ask! You can also bring someone with you to help you understand things better.
- Doctors have to ask if it's okay with you before they do any tests or treatments.
- If someone has hurt you or treated you badly, your doctor can help. It's important to know that people with disabilities are more likely to be hurt or treated badly by someone else.

Helpful Resources

- University of Michigan Gynecologic Care for Adolescents and Women with Disabilities
 - umwomenshealth.org/conditions-treatments/gynecologic-care-disabilities
 - 734-763-6295
- Access, Autonomy, and Dignity: Contraception for People with Disabilities Report by The National Partnership for Women & Families and Autistic Self Advocacy Network, September 2021

Sources

Mosher, William et al. "Disparities in receipt of family planning services by disability status: New estimates from the National Survey of Family Growth." Disability and health journal vol. 10,3 (2017): 394-399. doi:10.1016/j.dhjo.2017.03.014

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Helping People with Disabilities with Physical Medicine & Rehabilitation

People with disabilities may need special help to stay healthy. This can be special exercises or therapy like physical or occupational therapy. Getting this help often can make life easier and let people do more things on their own.

People Who Can Help

Look for people who are experienced in working with people with disabilities.

Options for Care

Include things like regular exercises with a therapist and help for daily tasks in your plan to stay healthy. Search for disability friendly gyms in your area. Some may offer financial assistance.

When you go to the doctor, ask for any special orders you might need. These could be for things like extra supplies, help with a wheelchair, or special tools to make life easier. This is sometimes called Durable Medical Equipment, or DME.

Questions to Ask Your Doctor

- Talk openly with your doctor about your disability and any extra help you might need.
- If you think it could help, ask your doctor to suggest a good physical or occupational therapists for you.
- Talk with your doctor about any hard things you might be going through. That way, they can help you figure out how to make things better.

Costs To Think About

Know how much you have to pay for your treatments and if your insurance helps with the cost. Find out the price of any medical things you might need.

If you need to see the doctor a lot and it could cost extra money, talk with them about how to handle these costs.



Photo Credit: @AllieKellyofficial
Image Description: A woman with blond long hair wearing a purple activewear top and black leggings stretches her legs on the floor using a red resistance band and yoga block between her feet while her back is supported by the wall.

Helping People with Disabilities with Physical Medicine & Rehabilitation

Equipment and Facilities

Don't hesitate to ask if there are any tools or changes that can make your treatments more comfortable and work better for you.

Also, find out if the clinic or rehabilitation center is set up for people with your specific needs and if it's easy for you to get around in.

Facts and Tips

- Make sure you know about the medicines you might need to help your body function best.
- Try to be careful and make sure your body isn't getting too tired from doing the same movements over and over again.
- Remember, you can ask for more time during your appointments if you need it. And if someone is helping you exercise at home, you can have them with you at your appointments too.

Helpful Resources

- National Rehabilitation Information Center (NARIC) - Provides a wealth of resources specifically related to rehabilitation for people with disabilities (<https://www.naric.com/>)
- United Spinal Association - Focuses on improving the quality of life for individuals with spinal cord injuries and disorders, including rehabilitation services. (<https://unitedspinal.org/>)

Sources

Jesus, Tiago S., et al. "Scoping review of the person-centered literature in adult physical rehabilitation." Disability and rehabilitation 43.11 (2021): 1626-1636.

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Primary Care for People with Disabilities

People with disabilities should go to their main doctor often, just like anyone else. It's important to tell your doctor if you're having any problems. Going to the doctor regularly helps keep you feel good and stay healthy.

People Who Can Help

It's important to find a doctor who understands your needs and who makes you feel comfortable.

If possible, try to find a doctor who works in a big hospital system. This way all your doctors that care for you can have access to all the same information in your chart and can work together to give you the best care.

Options for Care

- You should go to the doctor for check-ups as a normal part of taking care of yourself.
- If you would feel more comfortable having someone with you, it is okay to bring them. You may also be able to request support from a patient advocate at the hospital or your doctors office.

Questions to Ask Your Doctor

- It is important to talk openly with your doctor about your disability and any needs you might have.
- Don't be afraid to ask for extra time during your appointments if you need it.
- If you feel anxious or tense during medical procedures, talk to your doctor. They can help you find ways to feel more relaxed



Image Description: A woman sitting in a wheelchair, holding a newborn baby. Standing behind her are two males. A white male healthcare provider with light brown hair and a light green shirt. The other is a white male with dark brown hair and a dark blue shirt.

Primary Care for People with Disabilities

Costs To Think About

Know how much it costs to see the doctor, what your insurance will pay for, and how much other medical tools and equipment will cost.

If you have to go to the doctor a lot, talk to them about how much you'll need to pay.

Facts and Tips

- Find out how other people with disabilities take care of their health.
- A good primary care doctor can help you see other specialists and make sure everyone is working together to keep you healthy.

Helpful Resources

- Office of Developmental Primary Care <https://odpc.ucsf.edu/>
- Easterseals <https://www.easterseals.com>
- ADA National Network <https://adata.org>
- Disabled World <https://www.disabled-world.com>

Sources

Doherty, Alison Jayne, et al. "Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review." BJGP open 4.3 (2020).

Munthali, Alister C., et al. "'This one will delay us': barriers to accessing health care services among persons with disabilities in Malawi." Disability and rehabilitation 41.6 (2019): 683-690.

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Dentistry for People with Disabilities

It's important to know that some people with disabilities might not go to the dentist as much as others. This can make their teeth have more problems later on. It's important to find a dentist who knows how to help you and to see them a lot. Everyone can have healthy teeth if they get the right help and advice.



Image Description: Young white male with Down Syndrome is brushing his teeth while looking in the mirror.

People Who Can Help

Look for dentists and dental hygienists who are comfortable helping people with disabilities and are open to learning more about how to best support your needs.

Options for Care

- Remember to go to the dentist for regular check-ups, teeth cleanings, and any work your teeth might need. This is part of keeping your whole body healthy.
- You can talk to your dentist about maybe getting your teeth cleaned more often, like every 3 months instead of waiting 6 months. This may help reduce the chance of tooth decay and other dental problems.
- If going to the dentist makes you nervous, ask about ways to feel calmer. They might use medicine to help you relax or other ways to make you less anxious.

Questions to Ask Your Dentist

- It's important to talk openly with your dentist about your disability and what you might need to feel comfortable during your visit.
- If you get nervous, ask about using medicine, or even sleep medicine to help you relax.
- You can also ask about different ways to help you feel less tense or worried when you're getting your teeth looked at.
- If you need more time for your visit, don't be shy—ask for it.
- If you use a wheelchair that can lean back, ask if you can stay in it while the dentist takes care of your teeth.

Dentistry for People with Disabilities

Costs To Think About

Know how much you'll have to pay for your dental visits and any special treatments you might need. Also, check what your insurance will cover.

If you have to go to the dentist more often than most people, talk with your dentist about how that might cost more. Make sure you understand any extra costs.

Tools and Equipment Helpful To People with Disabilities

Using special tools like grips on toothbrushes or Velcro can make brushing your teeth easier. You can also use flossing picks and holders to help clean between your teeth. These tools can make taking care of your teeth simpler.

Facts About Dental Care

It's important to find a good dentist who understands what you need. Try to find a dentist who is willing to help you in the best way they can. This will make taking care of your teeth easier.

Helpful Resources

- Mouth Care Without a Battle <https://mouthcarewithoutabattle.org>
- American Academy of Developmental Medicine and Dentistry www.aadmd.org

Sources

Incentivizing Oral Health Care Providers to Treat Patients with Intellectual and Developmental Disabilities. National Council on Disability. Published on April 5, 2023. <https://ncd.gov/publications/2023/incentivizing-oral-healthcare-providers-treat-patients-IDD>

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