Parenting with a disability has its ups and downs, just as it does for all parents. Dianne, a mother with post-polio syndrome, reminisced about the day she brought home her newborn son and faced the difficulties of getting the baby in and out of the crib and carrying him around the house. "I was isolated," she said, "and didn't have many resources or support. I learned the value of preparation the hard way and was better equipped and prepared for the arrival of my daughter three years later."

Silvana, another mother with a disability, said she agrees with Dianne. "No amount of written information can really prepare you for the birth of a baby. The most important thing you can do is to work out what you will need to care for your baby, both financially and in terms of how much physical help you will need. Make sure you will have enough support, for yourself and for the baby, once the baby arrives," she says.

But being prepared can mean something different for everyone. The many books, articles, and videos on various aspects of pregnancy, adoption, childbirth, child development, and parenting may be good starting points. You may need to dig for more information, advice, and support that relate to your specific disability. The good news is that, increasingly, there are more materials available geared towards parenting with a disability.

Talking with other mothers, both with and without disabilities, may be a better strategy for some women. Nancy, a mother who has a spinal cord injury, now shares with mothers her experiences about everything from breastfeeding, diapering, the terrific two's, and school transitions. She said that the worst of all for her was knowing that when she and her husband were working through their parenting dilemmas on their own, somewhere out there other couples were doing the same. "We parents were not benefiting from each other," said Nancy. "I'm glad to finally have the opportunity to keep another parent from having to start totally from scratch; and, in a larger sense, to celebrate with others the experience of parenting as a viable and rewarding option for persons with a disability."

Another way to stay ahead of the curve is to see your needs as a mother as an ongoing process. Your needs and your partner's will change throughout pregnancy, as your child grows, and also as your disability changes. One good way to start, according to the *Parenting Book for Persons with a Disability*, is to complete a *Child Care Abilities Survey*. This survey helps the prospective parent with a disability identify the specific skills they will need in order to care for a child, the adaptations they may need to make around the house, and how much extra physical support they will need.

The survey was published as part of the 1995 publication, *Parenting with a Disability: Assistive Devices and Adaptations for Child Care* by Elaine Carty. It's available for $15 from Elaine Carty, School of Nursing, University of British Columbia, T201-2211 Westbrook Mall, Vancouver, BC V6T 2B5; fax: 604-822-7466; email address: <carty@nursing.ubc.ca>

Children and adapting

While you'll no doubt learn to adapt to your child's needs, your child will learn to adapt to your needs as well. Patti explained how her daughter also learned to adapt to her, "When she was a toddler and wanted me to hold her, she would go to the sofa and pat the cushion. She learned quickly that I needed to sit down in order to hold her."

Mothers with disabilities do face extra challenges; life does not get any simpler as children grow up. In a 1996 survey by Berkeley Planning Associates, 792 parents with disabilities reported their greatest challenges were:

- Keeping up with errands and appointments for their children
- Chasing and retrieving children
- Making recreation opportunities available to their children outside the home
- Finding accessible parking near child care, school activities, or events

Not only does a mother face challenges related to the physical aspects of getting her child from place to place in her busy life, but interpersonal issues around disability may come to light as she and her child grow together. Somewhere around the middle school years, things may change. Your child might feel both embarrassed by your disability and guilty. Children have to take on what society is teaching them about disability and also what they learn at home. They also have peer pressures and fears about being different.

For example, Karen, who uses a scooter, tells of her son, who at an early age, thought everyone was like his mom. When he was a bit older, he was proud when they went shopping and would say, "I'm related to this scooter." By age ten, he would not acknowledge his mother when she passed him and his friends on the street. Karen cautioned that it was also important to remember what was a normal teenage reaction to a situation.

Children will become increasingly aware of your disability and have more and more questions as they mature. It is important to help your child understand about disability. Discussing this issue will likely become a recurring theme in your lives.

Keeping the lines of communication open, inviting children to talk about their feelings and discomfort, and telling them that you understand they may feel uncomfortable are techniques a parent can use to deal with difficult times.

Keep in mind that all children do not necessarily respond in the same way to a parent with a disability. On the positive side, it has been said that in families where a parent or parents have disabilities and differences are discussed, lived with and valued, children may have a better chance of developing a built-in open-mindedness about diversity. This was echoed in the survey results by Berkeley Planning. Overwhelmingly, parents reported that the greatest blessing is that their children have learned to be compassionate, accepting and open to diversity.

Excerpted from *The Parenting Book for Persons with a Disability: From Planning Your Family to Raising Adolescents,* sold by the Parenting with a Disability Network at the Centre for Independent Living in Toronto, Inc. (CILT), Canada, for $25 (Canadian). 416-599-2458. CILT is a consumer-driven, community-based organization assisting people with a disability to gain independence and integrate into the community. CILT was "founded on the philosophy of the independent living movement and encourages people with disabilities to exercise their rights, make their own choices, and take control of their lives."

"MOMMY, WHY DO YOU WALK WITH A CANE?"

What you say in response to your child's questions or what you choose to tell them must be in line with their developmental stage in order to get the right message across. Also, it's best to give some thought to how you approach the subject. You will want to be up front and comfortable with what you are saying as you won't want them to grow up with a sense of shame about your disability.

Here is a general guide to discussing disability with your children adapted from *How to Help Children Through a Parent's Serious Illness.* This publication can be obtained by contacting the publisher. The reference for the book is: Kathleen McCue, M.A., C.C.L.S., *How to Help Children Through a Parent's Serious Illness*, New York: St. Martin's Press, 1994.

All ages—tell them:

- Mom has a disability
- The name of the disability
- Your best understanding of how your disability affects your abilities and activities

Preschool age—explain the disability on their level

- Use dolls or puppets to help
- Don't go past their attention span
- Don't go beyond their ability to understand

School age—tell them:

- Nothing they did caused the disability
- They can't catch the disability from you
- Who will take care of their needs (if the disability is a progressive one)

Teen age

- Give lots of detailed information
- Answer every question fully
- Make sure there is someone outside the family with whom they can talk on a regular basis
- Be prepared for anything

According to one mother, "When explaining disabilities to my children, I am open and honest and tell them what the disability is and what caused it. If I had told my children that I didn't carry the shopping, hang out the laundry, pick up heavy items, vacuum, etc., because I didn't want to, they would have grown up thinking that their mother was lazy and wanted them to do all of the work. Because they know the truth, they have an appreciation for my problem and do not feel indifferent towards me for it. I explained to them that perhaps their acceptance of disabilities may be a part of their career in the future."

PARENTING **RESOURCES**

Disability Pregnancy and Parenthood International
Quarterly journal and a United Kingdom information service. DPPi promotes the networking of information and experience on all aspects of disability, pregnancy and parenthood among disabled parents, potential parents and the professionals who work with them.

<freespace.virgin.net/disabled.parents/Default.htm>

Mother to Be: A Guide to Pregnancy and Birth for Women with Disabilities
by J. Rogers and C. Matsumura.
New York: Demos Publishers. 1991.
800-532-8663.

Parents with Disabilities Online
<www.disabledparents.net/adaptive.html>

The Parenting Book for Persons with a Disability
Centre for Independent Living in Toronto, Inc.
205 Richmond St. West, Suite 605
Toronto, Ontario, M5V 1V3. 1999.

Through the Looking Glass
2198 Sixth St. Suite 100
Berkeley, CA 94710-2204
510-848-1112.

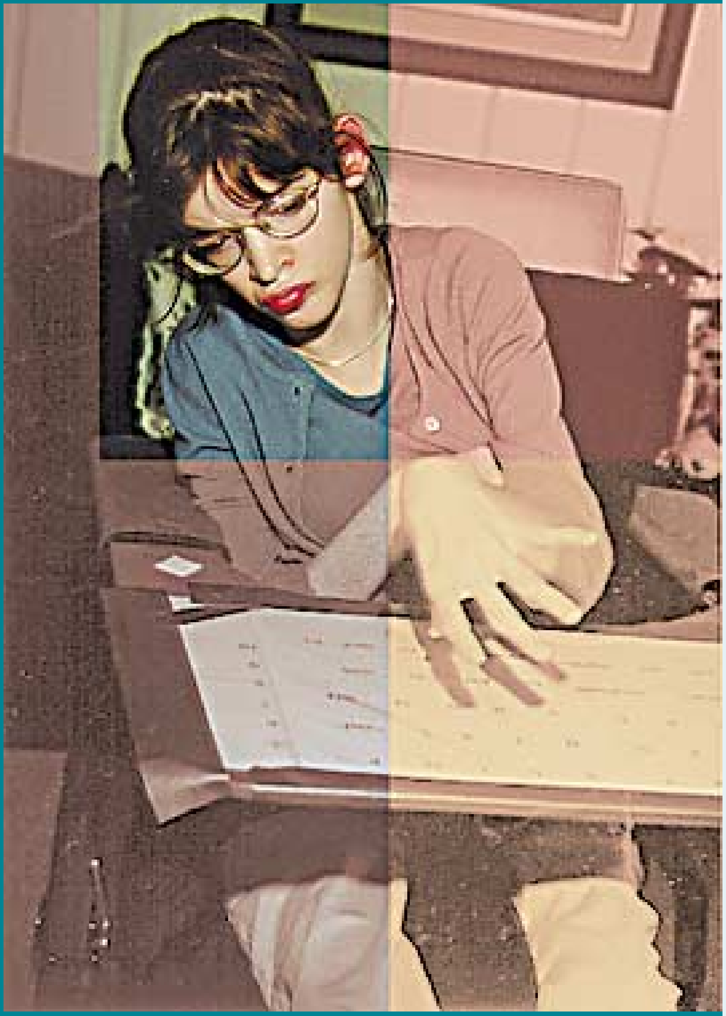
<www.lookingglass.org>

This organization has information on parenting, adaptive equipment and clinical support services for families with a member who has a disability and providers. Their resources include:

Adaptive Parenting Equipment Idea Book
Adaptive Baby Care Equipment Book
***Parenting with a Disability* newsletter**

The journey to self-acceptance

> "As I get to know more and more of my self-worth, it sort of helps me to identify myself, thinking I am a woman created by God and I am so precious and I am so loved and I have so much beauty inside of me. I should let it come out. I should not hide it."



"You may not believe this, but I don't consider myself disabled." Lara, 29, has an undergraduate degree, serves on an advisory board, and lives in her own apartment. Also, she has cerebral palsy, uses a wheelchair, sits only with support, is nonverbal, and has very limited use of her hands.

Lara's success and sense of accomplishment are due in part to her high self-esteem and self-confidence. A streak of stubbornness and supportive parents haven't hurt either.

Caroline, who has had a disability since birth, agrees, adding, "I believe that almost a hundred percent of disability is a state of mind. I don't think that I'm disabled. I can do anything I want." She has used her self-confidence to move forward with her professional career and to pursue an active social life.

Self-esteem is a vital component in how we face the challenges of life. It is not difficult to understand why a woman's self-esteem may suffer when she has a disability. Women with disabilities are routinely denied acceptance in areas from transportation and schooling to employment. In the media, people with disabilities are often portrayed as victims or brave fighters who triumph. In a world that cherishes youth, beauty, vitality, good health, and self-reliance, people with disabilities have to battle constantly for the fundamental human rights simply to be who they really are.

Developing a positive self-image and building self-esteem is a process. Sometimes, the first step is to give yourself permission to like yourself. By developing self-compassion, self-acceptance and self-love, you empower yourself to accomplish your goals and improve your relationships with others.

"I'm in a place now where I can say I have a disability and it's okay," said Pam. For her, it was children who brought her to this realization. She worked with preschoolers for 12 years, a healing time for her in coming to terms with her own disability. The kids she worked with on a daily basis helped her become more comfortable with her disability and build her self-esteem.

She loves to tell the story about a four-year-old who asked why she wore one big shoe (a shoe with a lift) and one regular shoe. The little girl was very impressed and said, "Just think, Pam, if you had two short legs you could wear two big shoes!"

For Pam, her increased self-esteem over the years has enabled her to start trying more things. She's learning that she can find ways to do things like water skiing, wall climbing, and snow skiing that she didn't think she could do before.

Parents and friends

How your parents, friends and society react to your disability has a great impact on your self-perception and self-esteem. According to Caroline, "My parents have never said there's something I couldn't do. When I went to camp, I found out that many of the campers felt limited at what they could do because they grew up being told they couldn't do things."

Annette echoed these sentiments. "I was raised with the idea that I can do anything I want to do. My parents supported and encouraged me in all I did. My disability is a fact in my life—it doesn't determine who I am. Having the disability determines how I go through the world, not what I do."

According to the Center for Research on Women with Disabilities in Houston, TX, "Parents who encouraged their teen-age daughter to go out and meet people, who gave her the expectation that she could marry someday if she wished, who equipped her with the information and social skills she needed to attract dates, and most importantly, who made her feel valued and attractive, set the stage for having positive dating relationships."

How can a person with a disability effectively fight society's negative messages, build self-esteem, and reject conscious and unconscious feelings of unworthiness? Clearly, it is a difficult and challenging task. But it is also a rewarding experience that can form the basis for more positive interactions in every aspect of social and romantic relationships.

The advice offered by Edmund Hopper and William Allen in *Sex Education for Physically Handicapped Youth*, a self-help book for teens with disabilities, can be a good starting point for people of any age: "Self-esteem can be a 'Catch-22' situation—you need confidence to build confidence. You can choose to have a proud, positive self-concept or a weak, distorted opinion of yourself. To have a strong self-image is not to deny that you have a disabling condition. It's just to understand that the disabled parts of your body are only part of your whole body machine that makes you the very special human being that you are."

Take care of yourself

One way to boost your self-esteem is to take care of yourself. Your positive self-image will grow when you show yourself respect and love. Take a warm, fragrant bath. Get a back rub from a friend. Try a new, flattering haircut. Exercise and eat a healthy diet. Pamper yourself.

Another way to build self-esteem is to exercise it. When people don't seem to know how to act around you, make the first move; smile and say "Hello." Strike up conversations. Maintain eye contact. Your confident attitude will not only make you feel more comfortable with yourself, but also it will benefit those around you.

Some tips for creating the positive you:

- Get to know your assets and strengths. Find a picture of yourself that you like and display it.
- Share information with others about the things you like about yourself.
- Risk social rejection at least once a week by initiating meaningful contact with one new person.
- When talking with friends and co-workers, keep the conversation upbeat, rather than negative. Affirm, don't complain.
- Let others know what you like and admire about them.
- Keep your emotional neediness in check. Don't alienate people by clinging or manipulating.
- Become more active in ways that are stimulating or energizing. Try an activity that interests you—a hobby, an exercise, or a community program.
- Get current information about sexuality and get in touch with your own sexuality.

According to the Center for Research on Women with Disabilities, "As women with disabilities, we must begin to challenge the perceptions of body beautiful, and ignore the notion of the body perfect. Disability challenges all notions of perfection and beauty as defined by popular, dominant culture. We must reclaim what has been traditionally viewed as negative and accentuate the reality that 'different' carries with it exciting and creative opportunities for change. As we begin the process of reclaiming and embracing our differences, let's celebrate our range of sizes, shapes, and abilities."

By Sally McCormick, Woodward Communications
and Pam Dickens, NC Office on Disability and Health

Editor's note: This article and the related sidebar on intimacy include excerpts from:

The Center for Research on Women with Disabilities, Houston, TX, 713-960-0505 <www.bcm.tmc.edu/crowd/>

"Sexuality R Us," an article at Disability Cool <www.geocities.com/CapeCanaveral/Lab/1383/discool.html>

"Road to Intimacy," an article by Jean Dobbs, executive editor of *New Mobility* magazine, Horsham, PA 215-675-9133 <www.newmobility.com/>

THE ROAD TO INTIMACY

Today, Bonnie Jones, 40, enjoys a healthy intimate relationship with her partner, Richard, with whom she shares a home. But the journey, she says, was far from short and far from easy. "At first, I was judging myself so harshly that I saw a person who had nothing to offer," she says. "Eventually, I realized that I still had the person I was inside, but I was pushing her down."

Bonnie's experience reflects that of many women with disabilities who struggle to build close relationships. Some obstacles are givens: feelings of loss and shame, awkward new beginnings and, usually, at least one bad match. But the road to intimacy doesn't have to stop there.

Bonnie said, "Can you have it all—the security, the love, the pleasure of intimacy? You don't have to settle for anything less. There are those out there who can deal with the physical and emotional issues that go with disability. They're out there, but you'll never find one unless you believe you deserve it. It was an accepting of myself to let someone really care for me—to feel like I was worth being cared about."

For Bonnie, that self-acceptance was hard to win. She said, "You have to develop yourself in other areas of life that make you an interesting person—not just a disabled person. In the beginning, you're so busy licking your wounds that you can't see that life can still happen for you. I wish someone had told me that and I wouldn't have wasted so many years worrying so much."

Could she have heard it then?

"That is a really good question," replies Bonnie. "Maybe I heard it when I could."