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The Interaction Between Pregnancy and Disability

It can be difficult for a pregnant woman to know whether she is experiencing a pregnancy-related problem or a disability-related problem. So, if you are considering pregnancy, it is important to follow Heather's advice: "Try to know your body. Become aware of what is normal for your body so you can decipher what is a pregnancy symptom and what is a disability symptom." Sometimes it may be more important to pay attention to other health conditions that may not be directly related to your disability. For example, if you have a tendency to become constipated, pregnancy could exacerbate this problem. The prenatal vitamins (with or without iron) that are commonly prescribed during pregnancy can also cause constipation.

Common Problems

Specific problems sometimes associated with disability, such as kidney dysfunction, can affect pregnancy and must be evaluated before conception. Other disability symptoms may be worsened by pregnancy. For example, a woman with respiratory problems may have more difficulty breathing during late pregnancy, when pressure from the uterus causes many women to become short of breath; others may go into remission. Some women who have been on medication to control, treat, or reduce disability symptoms may have to stop the medication because of possible harmful effects on the fetus. Therefore, it is important to know the classification of the medication you are taking. It is important to find either alternative medication or alternative treatments if you have to stop a particular medication. Rachel said, "I cleared myself of all medication. I was taking some strong rheumatoid arthritis drugs: methotrexate, Aquanal®, and prednisone. I stopped taking them all about 2 months before we tried to conceive. I started seeing a naturopath. I started changing my diet, which always seems to help a little bit. I also started to get some acupuncture. The acupuncture was amazing. Although it didn't necessarily help my joints, it helped my muscles and my frame of mind."

Olivia said, "I cut my medication in half after I found out I was 3 weeks pregnant."

All medications are classified into the following categories: Class A drugs are safe in pregnancy. Class B is known not to have caused harm in animals but has not yet been studied in humans. Class C is known to cause adverse effects in lab animals. Class D is known to cause fetal harm. Class X is contraindicated.

The medications that are often prescribed to people with disabilities include:

- Class B: oxybutynin chloride (Diptropan®)
- Class C: interferon (Avonex®, Rebif®, Betaseron®), tizanidine hydrochloride (Zanaflex®)
- Class D: carbamazepine (Tegretol®)

You can check the classifications of your medicine(s) in the most recent edition of the *Physicians' Desk Reference,* or you can ask your pharmacist for the package insert.

Women with physical disabilities are likely to have increased mobility problems and fatigue during pregnancy. Most insurance plans allow a person to get one mobility aid once every 5 years and, therefore, it is important to consider your mobility needs before pregnancy. It is also important to consider what your needs might be during pregnancy and the early parenting years. Some women may need two different mobility aids. Some women prefer to walk around the house and use a wheelchair when they are out in the community. Therefore, you may want to purchase the cheaper aid and let the insurance company buy the expensive one. Many women who are able to walk around the house may be unable to walk carrying a baby in their arms. A four-wheeled walker that uses a baby seat attached to the walker's seat was designed by TLG to solve this problem. Since its inception in 1982, TGL has worked with disabled parents, offering both direct services and research. TLG designs accessible baby equipment.

When ordering a power wheelchair, consider the features that you might use while pregnant, even though you do not need them at present. For example, tilt and recline features can help you change position in order to relieve pressure points.

Effects of Specific Disabilities on Pregnancy

LOWER LIMB AMPUTATION

Women who have lower limb amputation may need to modify their prostheses due to problems related to weight gain and edema. Dennis Swigart, former chief of prosthetics at Stanford University, said, "Prostheses with silicone or gel liner and pin-locking suspension are probably the easiest to modify. The number and ply of socks worn between the liner and frame can be adjusted as the volume of the residual limb changes. Also, the liner itself can often be changed from thicker to thinner materials to allow for more comfort. Rigid sockets are more challenging to modify but can be enlarged by grinding down or otherwise opening up the brim. Finally, it is possible to fabricate a temporary socket if the prosthetic limb needs to accommodate large volume changes.

"Women who use belts for suspension of a prosthesis will need to change to a different system, because tight straps across the abdomen are not comfortable during pregnancy. During routine exams, the prosthetist should check for abnormal wear and tear of components and for poor alignment of the prosthesis. Prosthetic feet are rated according to the wearer's weight and activity level. The extra weight during pregnancy can increase the risk of breakdown in the foot. Call your prosthetist immediately if you hear strange noises or the foot feels odd. The knee can become unstable if a woman becomes too sedentary and develops tight muscles, which will require adjustments to the alignment. Adjust your sock plies before skin breakdown. It is also advised to shower at night and wear a shrinker sock to bed in order to maintain a smaller limb volume for putting the prosthesis on comfortably in the morning" (11).

ARTHROGRYPOSIS

The arthrogryposis national Web site did a survey of pregnancy. As with most of the disabilities, there is not a large enough sample to make any recommendations, but here is the information collected. A total of twenty-one responses were received. Of those, seventeen did not know the type of arthrogryposis they had or they did not state it. There were two cases of *distal* arthrogryposis, one *amyoplasia* and one *genetic*. A total of thirty-four children were born to the twenty-one women. Nine mothers had more than one child and twelve had one child. The average age of the interviewees at the birth of their first child was 24 years. Of those who responded, seven were currently in their 20s; ten were in their 30s; one was in her 40s; one was in her 50s; and two were in their 60s. Of the thirty-four births, fifteen were carried to term; seven were not carried to term; and twelve did not state. One of the thirty-four babies died at the age of 7 months of unknown causes. Twenty pregnancies were listed as having no complications. Problems with balance, mobility, or driving were mentioned in nine of the pregnancies. Of those, three women mentioned using a wheelchair during part of their pregnancy. Problems not related to arthrogryposis were mentioned in five pregnancies. These include high blood pressure, morning sickness, and low platelets. Two persons reported back or hip pain.

It is unknown from this data if the interviewees who miscarried were severely affected by having multiple contractures—in other words, did the contractures cause poor circulation and did the poor circulation, in turn, cause an increased risk of miscarriage (12)?

CEREBRAL PALSY

Many women with cerebral palsy experience increased muscle spasms during pregnancy. A small study by Winch and colleagues that analyzed twenty-two women with cerebral palsy found that the rate of caesarean section was about the same as "…from the general population.…Nine of the 28 births in our sample were by caesarean section.… All eight of the women who were delivered by caesarean section had lower extremity motor deficit, although some women with contractures delivered vaginally" (13).

DWARFISM

A study in Scandinavia by Kappel and colleagues (14) found that the need for caesareans was three times higher in those with dwarfism than the general public. This study also found higher rates of "intrauterine asphyxia, intrauterine growth retardation, and low *Apgar* scores" in babies of women with dwarfism. The Apgar test is given at the time of delivery; the possible scores range from zero to ten, with ten being the healthiest for a newborn. Having an X-ray prior to pregnancy will help determine the width of the pelvis. A study from India by Desai and colleagues found that many of the fetuses were in the breech position (15). The Indian study found that there was a higher incidence of stillbirth and neonatal death. This study also found increased need for caesarean section. In an article from Canada, Carstoniu and colleagues (16) stated that "the risks of general versus *epidural* anesthesia must be considered for each patient, as the severity of the spinal abnormalities can vary considerable." One may conclude that it is important to follow the growth of the fetus to prevent intrauterine growth, which can result in *intrauterine asphyxia* (the result of any process that deprives the fetus of oxygen).

Diastrophic Dwarfism. Women who have diastrophic dwarfism are at risk for cardiac arrest if the baby shifts against the diaphragm during the third trimester.

HYDROCEPHALUS

Children born with this condition have a shunt inserted to relieve pressure on the brain. There are two different types of shunts, which vary in where the end of the shunt is placed. The *ventriculoatrial* shunt (VA) ends in an *atrium* (one of the chambers of the heart). The end of this type of shunt usually stays open; but, as children grow, the process of growing tends to pull the shunt out-of-place. Therefore, more revisions are required during childhood with the VA shunt, compared with the *ventriculoperitoneal* shunt (VP), which ends in the space inside the abdomen. This type of shunt generally will require fewer revisions during childhood.

According to N. K. Bradley (17), decisions regarding the course of pregnancy with shunts need to consider:

- The relative value of specific shunt configurations
- The monitoring of late term headaches and other neurologic symptoms
- The management of delivery
- Pregnancy outcomes
- Unusual complications

According to Farine and colleagues (18), women should be "aware of the potential significance of headaches, drowsiness, irritability, and neurologic signs. Although these signs and symptoms may be nonspecific in pregnancy, they may also imply *shunt occlusion*."

According to N. K. Bradley (19), "A ventriculoatrial (VA) shunt should be considered the shunt configuration of choice for all young women" who will consider pregnancy. Women who had VP (ventriciloperitoneal) shunt "were not without shunt-related complications."

MULTIPLE SCLEROSIS

Many researchers have written on the issues that must be considered by women with multiple sclerosis who desire to have a baby:

"In women with multiple sclerosis, the rate of relapse declines during pregnancy, particularly in the third trimester, and increases during the first 3 months [postpartum] before returning to the pre-pregnancy rate, as compared with the rate during the year before pregnancy" (20).

"The increased frequency of relapses during the postpartum period can reduce the ability of the mother to provide care for her newborn." (21). This study also found "that epidural analgesic and breast-feeding did not increase the risk of relapse or of worsening disability in the postpartum period."

Dr. Stone of the Edward J. and Louise E. Mellen Center for MS Treatment and Research at the Cleveland Clinic stated in an article in *InsideMS* (22): "If an MS relapse does occur, the use of the steroid *methylprednisolone* is okay, especially after the first trimester. But some neurologists are uncomfortable treating a relapse during pregnancy with steroids."

Dr. Patricia Coyle from State University of New York at Stony Brook "sees nothing to indicate that it is dangerous to use steroids to shorten MS relapses. At one time pediatricians were concerned regarding steroids, but sometimes steroids are in order for a woman who has to deliver early because they help mature a preterm infant's lungs. In other words, while a severe MS relapse during pregnancy is trying for everyone, there are safe and effective treatment options."

"Further studies have concluded that MS has no effect on pregnancy, but female offspring do have a 5 percent risk of developing MS. This is a 50-fold increase over the general population."

Dr. Lael Stone noted, "Most doctors recommend that women discontinue disease-modifying drugs for 1 month, or one cycle, prior to conception. In order to help women, the length of time they need to stop taking disease-modifying drugs is a question of heightened significance to older women, who may need more time to conceive." Dr. Stone recommends using ovulation kits and other non-medical methods to beef up the odds. She observed, "Theoretically, most fertility treatments are safe in MS, but there is virtually no data on this."

MYASTHENIA GRAVIS

In 1998, a study by Batocchi and colleagues (23) was completed that found "pregnancy does not worsen the long-term outcome of myasthenia gravis (MG). The course of disease is highly variable and unpredictable during gestation and can change in subsequent pregnancies." This study examined forty-seven women who had myasthenia gravis and became pregnant after receiving the diagnosis. "During pregnancy, MG relapse occurred in 4 of 23 (17 percent) asymptomatic patients who were on therapy before conception; in patients taking therapy, MG symptoms improved in 12 of 31 pregnancies (39 percent); remained unchanged in 13 (42 percent); and deteriorated in 6 (19 percent). MG symptoms worsened after delivery in 15 of 54 (28 percent) pregnancies. *Anti-acetylcholine receptor antibody* (anti-AchR ab) was positive in 40 of 47 mothers and was assayed in 30 of 55 newborns; 13 were positive; and 5 of 55 (9 percent) showed signs of neonatal MG."

NEUROMUSCULAR DYSFUNCTION

Charcot-Marie-Tooth

There seems to be no evidence of any ill effects of pregnancy on disability. The article that is cited here was based on a case study that stated: "Although respiratory difficulties may be worsened due to the increased respiratory demands of pregnancy.... This is the first report of artificial ventilation in a pregnancy complicated by Charcot-Marie-Tooth disease and illustrates that with careful maintenance of normal ventilation by mechanical assistance, as necessary, a successful outcome may be expected" (24).

In a case study from Israel, the authors wrote that a woman "with juvenile muscular dystrophy including severe scoliosis and severe *kyphoscoliosis* should be advised to avoid pregnancy or consider therapeutic abortion." Although this woman "with juvenile muscular dystrophy" had a difficult pregnancy, her major problem was "severe scoliosis and kyphoscoliosis." The authors also quoted an article that stated: "Cases of severe scoliosis or kyphoscoliosis should be considered high-risk and thus should be carefully monitored for clinical condition, lung function, and blood gases, and managed with hospitalization, respiratory support, intubation, and institution of mechanical ventilation when indicated. This should improve the prognosis of such pregnancies" (25, 26).

Facioscrapulohumeral Muscular Dystrophy

In a study reported in 1997 by Schoneborn and colleagues (27), women with facioscrapulohumeral muscular dystrophy "generally coped well with their muscle disease in pregnancy and after delivery." Three women out of eleven "reported an aggravation of symptoms related to pregnancy. Nonetheless, most patients recovered quickly in the postpartum period."

Friedreich's Ataxia

Respiratory difficulties increase with this condition, and pregnant women may experience frequent periods of shortness of breath. This was the experience of the two interviewees who have Friedreich's ataxia, and while it may indicate a trend, it is not enough of a sample from which to draw a conclusion.

Limb-Girdle Muscular Dystrophy

Schoneborn and colleagues (27) reported, "No deleterious outcome of pregnancy and labor was observed" in a study of twenty-seven women with different myopathies. This group of women had more caesarean sections, however. Moreover, it was noted there was "a significant aggravation of symptoms in gestation with early onset and progressive myopathy than in those with a stable disease course." Five out of the nine women reported a "weight-related worsening of weakness in pregnancy that did not improve after delivery," except for one woman. "All patients had a noticeable worsening of symptoms after delivery and needed a long time to recover postpartum."

In a case study reported in *The Journal of Reproductive Medicine* (28), a woman who had two successful pregnancies did not have any respiratory problems. There was no report of complications during either pregnancy. She delivered both babies vaginally without any complications.

Spinal Muscular Atrophy (SMA)

If lung function is already affected, it is probable that this system will be further distressed during pregnancy. This conclusion was drawn not only from the interview for this book, but also from an article based on two case studies (29). This article also concluded that women with SMA could have a "successful" pregnancy and delivery provided there is "close observation and a careful management planning." It also stated that there was no "obvious deleterious effects of the pregnancy on the progression of the disease."

Osteogenesis Imperfecta

There are four types of *osteogenesis imperfecta* (OI). Type 2 is the most severe form; a few people with this type have lived into early adulthood. Types 1 and 4 are the mildest forms of OI. "Pregnancy does not appear to have a significant adverse effect on the milder forms of OI. Women with OI Types 1 and 4 may experience loose joints, reduced mobility, increased bone pain, and dental problems during pregnancy."

Women with Type 3 have short stature and curvature of the spine. They "may be at risk for medical and obstetrical complications." In women who have severe scoliosis "the likelihood of heart and lung difficulties is increased. As the uterus grows, the shortened distance between the thoracic (rib) cage and the pubic bone can cause discomfort and result in a need for extended bed rest.

"Pregnancy has not been associated with an increase of maternal fractures. However, trauma during pregnancy or obstetrical manipulation at the time of vaginal delivery may result in fractures." Women who have a history of fractures of the pelvis or a contracted pelvis or Type 3 OI should have a caesarean section. "In general, decisions about the best mode of delivery (vaginal versus caesarean section) should be made on an individual basis. There are no definitive research data showing that caesarean delivery is safer than vaginal delivery in women with OI who have normal pelvic dimensions and no other significant complications. A recent study by Cubert (30) found evidence that caesarean delivery did not decrease fracture rates at birth in infants with non-lethal forms of OI, nor did it prolong survival for those with more severe forms. Some physicians believe it is appropriate when planning a mode of delivery to assess the degree of mineralization of the baby's skull. Theoretically, there is an increased risk of central nervous system injury with vaginal delivery when the baby's skull is poorly mineralized. Most caesarean deliveries in a recent study were done for the usual obstetric indications."

Post-Polio Syndrome

The effects of post-polio syndrome on pregnancy depend on an individual's particular symptoms. Women whose mobility is very limited are at risk for developing *deep vein thrombosis* (clots) during pregnancy.

Back deformities resulting from polio might make pregnancy and/or delivery more difficult.

Polio survivors are very sensitive to muscle relaxants because they have fewer neurons to block. "Past reports of not being able to reverse muscle relaxants, most likely due to drug overdose, have contributed to the fear of general anesthesia" (31).

One aspect to consider for women with post-polio syndrome is the effect of pregnancy on breathing. Some post-polio patients—especially those who used an iron lung or other ventilator when they were acutely ill—have poor respiratory reserve. They may even normally use a ventilator at night or during the day. The increasing size of the baby can interfere with marginal ventilation and full-time ventilator support may be needed. Ventilator support should be continued during labor and delivery. As pregnancy proceeds, repeated pulmonary function tests need to be done. A pulmonologist should manage this aspect of care.

Regional anesthesia, which is given near or at the spinal cord, can be used for post-polio patients, especially epidural anesthesia. There can be some technical problems when placing an epidural or spinal if scoliosis is severe, but usually these can be solved. Harrington rods can present a formidable obstacle to epidural or spinal anesthesia, but there are case reports of epidural anesthesia in the presence of Harrington rods. Because of recent information about the effects of local anesthetics on the spinal cord itself, it is probably wise to avoid spinal anesthesia, if possible, and use epidural instead. There is no specific evidence that spinal anesthesia should not be given to post-polio patients. This is a theoretical risk. The risks of all factors for an individual patient should be evaluated and a suitable choice made for that patient. If an epidural is not in place, two other useful techniques may be performed by the obstetrician: paracervical and pudendal blocks. These techniques use a local anesthetic injection around the nerves that carry the pain of labor and delivery. A paracervical block, given through the vagina, anesthetizes the nerves to the opening of the uterus and can be used for labor pain. A pudendal block, also done through the vagina, is used for anesthesia of the perineum (pelvic area). This block is used for the pain of delivery; it is also useful if lacerations occur and repair is needed. Both are useful in relieving pain when an epidural cannot be placed. Other choices for labor pain relief include intravenous narcotics or natural childbirth techniques; however, narcotics can affect the baby and cause a delay in the start of breathing after birth. Natural childbirth techniques need to be learned well before delivery, and classes are available in most parts of the country. A labor coach is also needed and a partner or helper should make a commitment to attend the classes and then help throughout labor (32). (The preceding section was written for this book by Dr. Selma Calmes.)

It is also important that "any blood loss should be promptly replaced" (31).

Rheumatoid Arthritis and Juvenile Rheumatoid Arthritis

"Complete remission of all signs and symptoms leading to no need for medication has been described in about 65 percent of pregnancies that show improvement of disease activity" (33). "Complications during pregnancy are not increased in *ankylosing spondylitis* and fetal outcomes are not compromised" (34). If arthritis has caused hip or spine deformities, delivery may be complicated and caesarean delivery may be necessary.

Nonsteroidal anti-inflammatory drugs (NSAIDs) are generally considered safe in early pregnancy, although studies in animals suggest that they may be associated with infertility related to *blastocyst*. Except for low-dose aspirin, NSAIDs should be discontinued 6 to 8 weeks prior to delivery, in order to avoid both maternal and fetal effects (3).

Gold compounds do not appear to impair fertility or cause neonatal malformations, but most rheumatologists recommend discontinuing these injections.

Scoliosis

The Alfred I. DuPont Institute studied 355 women to determine the impact of scoliosis on pregnancy. Each woman had *idiopathic* (of unknown cause) scoliosis. Of the 355 women, 178 had never been pregnant and 177 had at least one pregnancy. In the women who were observed but not treated, curvature increased more than 10 degrees in 9 percent of the pregnant and 11 percent of the nonpregnant women. In the women whose curvature was treated by surgery, there was almost no curvature progression in either group (pregnant or nonpregnant). Only two women out of sixty-five in the pregnant group had curvature progression of less than 10 degrees in the unfused segment. None of the nonpregnant women had any progression in the unfused segment. It was also found that, in the women who were treated by bracing, there was a greater difference between the pregnant and nonpregnant groups. Among these women curvature increased more than 10 degrees in 11 percent of the pregnant women and only 2 percent in the nonpregnant. The cause for the difference in this group is unknown. An analysis determined that there was a 10 percent higher risk of curvature progression for the thoracic area. Their conclusion was that pregnancy does not increase the risk of curve progression after skeletal maturity (35).

Spina Bifida

The average incidence of spina bifida is one in 1,000 births. Folic acid deficiency is one of the known causes of spina bifida. Prenatal intake of 400 to 800 micrograms of folic acid can prevent up to 70 percent of *neural tube defects*. The neural tube closes completely by day 21 of pregnancy, before most women even know they are pregnant. Therefore, all women of reproductive age should take folic acid regularly *before* they become pregnant. The recurrence risk is plus 5 percent after having one child with spina bifida, and women with spina bifida should take higher doses of folic acid. Spina bifida will not affect the ability to deliver vaginally, but hydrocephalus associated with spina bifida can influence the type of delivery.

Spinal Cord Injuries

Bladder infections are likely to become more frequent. Care should be taken to prevent severe infections, which can cause premature labor. Constipation may also worsen. Pressure from the uterus or impacted fecal matter could worsen breathing difficulties if the diaphragm is paralyzed. Dr. Amie Jackson did a comprehensive study (36) comparing pregnancy with pre-and post-spinal cord injury that indicated an increase in leakage around indwelling catheters and more frequent bladder spasms that expelled the catheter. Other complications, such as morning sickness, anemia, *toxemia*, and vaginal bleeding, did not increase.

Women with injuries at or above the T-6 level (sometimes T-8) have an increased risk autonomic dysreflexia during pregnancy. Autonomic dysreflexia will also occur during labor. Dysreflexia during pregnancy may increase the risk of miscarriage or premature labor.

Systemic Lupus Erythematosus (SLE) (Commonly referred to as "Lupus")

"Successful pregnancy is now achievable by 85 percent of women with SLE" (37). It is best to wait until one is in remission for 6 months before trying to become pregnant. Some women who have SLE seek the help of a fertility specialist to get pregnant and stay pregnant. Lupus activity during pregnancy has been studied in recent years, and the conclusions reached were that SLE may flare at any time during pregnancy. These flares are usually mild and generally affect the skin and joints. They usually do not affect fetal outcome unless the kidneys are involved. Diagnosis of flares during pregnancy is difficult to determine and should be examined through clinical and laboratory assessment. No evidence supports the belief that steroids prevent flares during pregnancy and prednisone should not be given *prophylactically*. Flares are treated, depending on severity, with nonsteroidal anti-inflammatory drugs such as Plaquenil® or prednisone (38).

"Active renal disease and maternal hypertension are predictors of fetal loss and premature birth, respectively" (39).

Most researchers agree that SLE symptoms can occur during any trimester and postpartum. Control of SLE symptoms in pregnant patients with medications is frequently needed prior to, during, and after pregnancy (40).

"Available data support the use of *hydroxychloroquine* during pregnancy, especially if cessation would risk a flare of disease. This is particularly true for women with SLE, when a flare maybe life-threatening to both the mother and fetus" (3). Most flares are mild and easily treated with small doses of corticosteroids.

Another complication is *pregnancy-induced hypertension*. If you develop this serious condition, you will experience a sudden increase in blood pressure, protein in the urine, or both. Pregnancy-induced hypertension is a serious condition that requires immediate treatment, usually including delivery of the infant.

About 25 percent of lupus pregnancies end in unexpected miscarriages or stillbirths. Another 25 percent may result in premature birth of the infant. Although prematurity presents a danger to the baby, most problems can be successfully treated in a hospital that specializes in caring for premature newborns. About 3 percent of babies born to mothers with lupus will have *neonatal lupus*. This type of lupus consists of a temporary rash and abnormal blood counts. Neonatal lupus usually disappears by the time the infant is 3 to 6 months old and does not recur. About one-half of babies with neonatal lupus are born with a heart condition. This condition is permanent but can be treated with a pacemaker.

Check your health insurance plan. Make sure it covers both your health care needs and those of your baby for any problems that may arise.

Getting Pregnant: Fertility Issues

A home monitoring electronic device called the *Clear Plan Easy Fertility Monitor*™ identifies when a woman is most likely to conceive.

"Ovulite™ is a home fertility test that uses a woman's saliva to predict the best time to conceive. The manufacturers claim 98 percent accuracy" (41,42).

One of the new fertility methods involves harvesting multiple ova (eggs) from a potential mother. This procedure requires medication to stimulate ovarian follicle growth. There is a risk that this procedure may increase the chance of blood clots. This is a consideration for women who have limited mobility and may already be at risk for blood clots. A multiple pregnancy is another risk factor. "Pregnancies associated with assisted reproductive technology (ART) and drugs that induce ovulation are more likely to result in multiple births than spontaneously conceived pregnancies in the United States. Triplet and higher-order multiple births are at greater risk than single births to be preterm, low, or very low birth weight, which may result in higher infant morbidity and mortality. This report estimates the connection between these birth outcomes and ART and ovulation-inducing drugs in 1996 and 1997. It also summarizes the trends that indicate ART and the use of ovulation-inducing drugs have increased the ratio of triplet and higher-order multiple births during the 1980s and most of the 1990s (43).

Chelsea, a woman who has triplegic cerebral palsy (three limbs affected, two legs and an arm), decided after her fortieth birthday that it was more important to be a mother than to continue in her long-term relationship without children. She found a supportive infertility doctor and a donor. Chelsea also had the IUI (intrauterine procedure). She did not need any fertility drugs and got pregnant. She paid for the procedure herself.

Diane said, "It took us quite a long time to get pregnant. We were impatient and we did not want to wait any longer, so we talked to a fertility person. I was a little nervous because I wondered what would happen if I had more than twins. I got scared because I knew my body couldn't handle that." The doctors also posed that scenario. Diane said, "I prayed real hard that I would not have more than twins." She had bed rest and delivered two healthy babies.

Although Jackie had juvenile rheumatoid arthritis, she was able to get pregnant twice, but she lost both fetuses. Jackie moved and found a new obstetrician, who found Jackie's inflammatory levels to be mildly elevated. She was put on methotrexate for at least 8 months. During this time, the obstetrician decided to take films of her uterus and ovaries. The test found a fibroid tumor that was acting like an IUD, so that the fetus could not implant into the uterine wall. This illustrates how important it is for the doctor to investigate the more common problems that any woman might have.

Taryn Dion was put on Clomid® for two cycles without a pregnancy. She told her doctor she had noticed she did not have much cervical mucous while taking the drug. Her doctor told her it was possible that the Clomid® was actually blocking her production of estrogen, preventing her from getting pregnant. The doctor advised her to take it for one more cycle "and just before you ovulate, we'll do an ultrasound and measure the thickness of your uterus." Taryn Dion said, "Sure enough, I was just about to ovulate and my uterus wasn't thick enough to support egg implantation. The doctor wasn't sure it was going to work, but she gave me an estrogen patch to put some of the estrogen back into my system. It worked, and that was the month I got pregnant."

Joy tried to get pregnant for 2 years and saw a fertility specialist. She was on fertility drugs for approximately a year and a half. Joy said, "It was finally determined that I probably wouldn't be able to have children unless I had artificial insemination." She and her then husband decided to wait. Joy had experienced a bad flare-up of her arthritis because of the combination of taking fertility drugs and being off her arthritis medication for the past 2 years. She got pregnant with a new partner 7 years later.

Find the Most Current Information

In addition to the information in this book, disabled women who want to get pregnant should look for the most current medical information available, because it changes as new research is done. For example, not very long ago women with MS were told that pregnancy might cause their symptoms to flare up, but more recent studies show that "conception, gestation, and epidural anesthesia will not alter the natural history of their disease" (21). Contact organizations with information about your specific disability, especially if new information might change your course of action.

Your doctor may be able to advise you in more detail about the interaction between pregnancy and your disability, but he may not offer specific advice on your first visit. He may want to review recent research or consult other specialists before making any suggestions. It is usually best to begin by seeing a disability specialist. If you are seeing an obstetrician or family practitioner, you might wish to share the written information you have about your disability. Your doctor may also need to order some diagnostic tests. Blood tests will be done to evaluate kidney function and/or pulmonary function. These tests show whether women with respiratory or kidney difficulties can withstand the additional stress of pregnancy. Hip or spine X-rays or MRIs should be ordered to determine whether spinal anesthesia can be used safely. It is also important to determine whether intubation during anesthesia might be necessary and whether it might injure a woman with arthritis.

Below are several questions you may want to discuss with your doctor:

- Will my disability affect the health or development of my baby? For example, "Can my dysreflexia cause premature labor or labor complications that would endanger the baby?"
- What problems or pregnancy complications might my disability cause?
- How severe could these complications (if any) be? Mildly painful, severely painful, life-threatening? Would they be likely to temporarily or permanently worsen my disability?
- Could complications be treated or prevented? For example, autonomic dysreflexia, which causes high to extremely high blood pressure, occurs in people with a high spinal cord injury when pain or discomfort occur, as from an over-full bladder or bladder infection, or skin irritation caused by tight clothing, sunburn, or other irritant, including labor. "Inability to sense these irritants before the autonomic reaction begins is a major cause of dysreflexia" (9). This condition can be life-threatening. "Uncontrolled release of norepinephrine causes a rapid rise in blood pressure and a slowing of the heart rate. These symptoms are usually accompanied by throbbing headache, nausea, anxiety, sweating, and goose bumps below the level of the injury. The elevated blood pressure can rapidly cause loss of consciousness, seizures, cerebral hemorrhage, and death. Dysreflexia can generally be managed with medication. Women who have experienced dysreflexia during labor have successfully given birth with epidural anesthesia."
- Do the treatments for complications have any risks or disadvantages? For example, could medicine prescribed for a given problem have unpleasant side effects or be dangerous for the fetus?
- What could be the long-term effects of treatment?

- Is my disability likely to cause problems during labor or delivery? For example, if you have hip dysplasia, you can discuss whether it is severe enough to necessitate caesarean surgery.
- Is there anything that can be done before pregnancy to prevent or minimize problems? For example, you may want to follow an exercise program to strengthen low back muscles before the stress of pregnancy, or change a medication regimen. Tina went to physical therapy for 10 months and worked on both TOS and lower back pain. She said, "We worked on strengthening my core, which includes mostly working on your stomach muscles. Then we looked for gym equipment that is functional in terms of getting you stronger, but not flaring you up."
- Are there resources within a prospective clinic or hospital that could be useful during my pregnancy? For example, you may want to consult with a physical or occupational therapist for ideas about taking care of yourself and your child.

Many women said that they had received different advice from different doctors. What then? Chapter 5 examines this question from the viewpoint of women who are pregnant or those who want a child. For them the question is "How will I find the right person to help me carry out my decision?"

It may be that doctors who disagree are both (or all) correct. Perhaps different research has different conclusions, and each doctor is inclined to rely on the research that confirms her own experience. Or a doctor may justifiably believe that a research finding or a method of treatment is too new to be relied upon. To understand differences of opinion, tell your doctor that you have read or heard different advice from different sources and you would like to hear his opinion. Bring any written articles to your doctor(s) and include them in the discussion.

If it seems to you that there really is room for legitimate differences of opinion, rely on the advice that makes the most sense to you and your husband or partner. Or, make your decision on another basis. For example, Michelle had no way of knowing whether pregnancy would end her remission of MS. She decided, "Even if I'd have to be permanently disabled, I'd rather take the consequences than not have the baby." Remember, ultimately *you* are your own expert.

Additional Concerns

In thinking about the interaction of pregnancy with your disability, you need to be concerned about safety. Another concern is what discomfort or inconvenience may occur. How would you feel about living with certain discomforts? Answering this question is not easy, because no one can predict the severity of discomfort or what discomfort will be experienced, including morning sickness, fatigue, or other problems that can occur with pregnancy. Becoming acquainted with other women's experiences may put the possibilities in perspective. Denise compared her pregnancy with women whose diagnosis is diastrophic dwarfism versus women whose diagnosis is achondroplastic dwarfism. The length of the torsos is different and, therefore, the pregnancies may have different discomforts. Some women compared their pregnancies with those of able-bodied women:

Claudia: "It felt good to be part of the sorority."

Sylvia: "I got jealous of women who had easier pregnancies."

Patricia: "It made me feel good because I had a better pregnancy than they did."

When Naomi compared her pregnancy with those of other women, she found that she experienced no nausea, although she felt worse in other ways because she was quite physically immobilized.

Other women compared the pregnancies they had before the onset of disability with those occurring after onset.

Samantha had two children before her spinal cord injury and one afterward. Samantha said, "I naturally compared. I had a friend who delivered 3 weeks before me, and we compared a lot. This pregnancy was so much like the other two. My second and third were almost the same."

Paula also compared pregnancies before and after polio: "Compared to the first it was different. Physically I was in totally different shape; I wore two leg braces. But I thoroughly enjoyed being pregnant. Not worrying about the baby—that part felt intact—it felt so nice."

Renee had experienced the first, painful onset of rheumatoid arthritis while she was pregnant with her first child. Later, she heard that women sometimes have a remission of symptoms during pregnancy. She was not sure at first that she wanted another pregnancy because she feared that, after she gave birth, the return of her arthritic pain would be unbearable. She eventually decided to have another child.

Sylvia had the most difficult pregnancy, physically, of anyone who was interviewed. She experienced severe muscle spasms, bowel problems, and autonomic dysreflexia. The dysreflexia caused episodes of premature labor and several other problems that were milder but still unpleasant. Not surprisingly, she sometimes wondered, "What the hell am I doing?" Later she said, "I came to the realization that 9 months is a long time. I kept wondering if it was ever going to end."

Even when pregnancy is comfortable and free of problems, it can seem as though it will never end. The mother-to-be can grow tired of carrying the extra weight, waking up several times a night to urinate, and finding comfortable positions for sleeping. But some of the other physical changes that take place may heighten your sense of anticipation. The sight of your growing abdomen is visible proof that something really is happening. The changes in your breasts can be satisfying if you are planning to breast-feed. Probably most exciting is the sensation of fetal movement. In spite of all her problems, Sylvia recalls the joy she felt when her baby moved, "It was great to notice the difference between the baby and her bowels and gas."

Whatever problems or discomforts occur, your way of coping will affect how you feel about your pregnancy. Pam needed bed rest to relieve many discomforts, but it was hard for her to slow down. She wore herself out even more when she resisted the need to rest. Pam commented, "I had learned to manage by pushing myself and ignoring my limitations. It was hard to adjust to being pregnant. I didn't rest as much as I should have because it felt like I was pampering myself."

Indeed, a woman with physical disabilities often has to meet life's obstacles with great stubbornness and a powerful refusal to be held back by her physical limitations. Her experience has taught her not to "pamper" herself. It can be difficult to change these patterns.

Arlene, who usually resented having to rest, thought, "Having a baby was a great reason to rest. I was able to say to myself, 'I'll have more time to read'." Some women tell themselves, "I'm not being lazy when I lie down. I'm working hard at growing a baby."

You may want to consider adoption if you think pregnancy may be too hard on your body and you are open to growing your family in a different way. "Women with significant disabilities who are attempting to adopt need to be prepared to address the wide range of barriers that they might encounter" (44). Yet, there are many adoptive parents with disabilities. Orielle had difficulty adopting 10 years ago, but since the birth of her child she has been able to adopt two children. Orielle credits the American with Disabilities Act (ADA) with creating an environment that supports disabled women's right to options.

Physical Consequences of Childcare

Portia, who has five children, stressed that the problems of pregnancy are temporary. When asked what advice she would give to women considering pregnancy, she replied, in part, "Pregnancy, labor, and delivery are the first steps you go through to reach the goal of being a parent." But afterward, as any mother will tell you, caring for children can be exhausting. Knowing this, Stephanie was pleased and excited to have children, but she was also reluctant because of the physical care of the children. Marsha's doctor did not worry that pregnancy would worsen her MS, but he worried that she would be overly fatigued by caring for a toddler. In fact, Marsha found that toddler care was not too hard for her, but that breast-feeding was exhausting.

Like the difficulties of pregnancy, the body's responses to the physical stresses of childcare are unpredictable. Dr. Amie Jackson, who did a comprehensive study of women with spinal cord injuries, stated that "the abortion frequency was higher in post-injury pregnancies" (36). This may be due to the mothers' concern about being able to physically care for a baby. Results of TLG research found that a majority of women are able to be the primary caretaker if they have the proper equipment, learn baby care techniques, and have adequate support.

Women whose disabilities are worsened by fatigue may want to consider the following issues:

Loss of sleep: Newborns have irregular sleeping patterns and may need middle of the night feedings and comfort. Toddlers and small children wake up with wet diapers, wet beds, nightmares, and illness. You may expect to feel tired and sleepy all the time during early parenting.

Physical stress: Being a playmate in your child's active games or supervising an especially active and curious toddler can be very tiring.

Emotional stress: Sometimes your child will be difficult to live with. The "terrible twos" and the teenage years are the most notoriously difficult stages of development. Some children will be more difficult, especially if your temperaments are not an easy fit. For example, you may prefer to be sedentary but your child is very active.

The physical demands of parenting may be fulfilled, but many of the interviewees did not seek possible solutions. Sara, who felt "overwhelmed" by both of her pregnancies, said, "I was more concerned about birth defects and not so much concerned about the physical aspects of taking care of children." Some people recommend babysitting as a way to learn about caring for a child. This may help you determine what kind of help and adaptive equipment you need.

The Possibility of Having a Disabled Child

One set of questions included in the interviews was, "What were your expectations, fears, and fantasies about the baby? Were they related to your disability? If so, how?" Sara's answer touched on many themes:

"My first thought was the baby could be disabled. I just hoped it would be okay. I didn't know whether my disability was hereditary, but if the child was disabled, I knew I'd be the best person to cope with whatever was there. I had constant fear that the baby would be disabled and I went to the university hospital to make sure it wasn't hereditary. When I found out it wasn't hereditary, I was able to breathe easier."

Naomi pointed out other reasons besides disability that may cause a woman to be concerned about getting pregnant. She said, "My strongest fear might have not been due to my disability. My mother died when I was 12." Naomi's fear was probably increased because she did not want her child to go through the painful abandonment and mourning she went through.

Dorothy pointed out a different opinion held by many in the disability movement: "Many people do not get the humanity wrapped around disability." Dorothy felt that the person with a disability has many other characteristics that make up a person. Some of the problems of being disabled have more to do with how you are viewed than with the disability itself.

I talked to Nora soon after her first child was diagnosed with Charcot-Marie-Tooth. She said, "It was hard to get that diagnosis, but I'm glad I had children. It was one of my biggest desires."

Some of the interviewees had been afraid that their children would be disabled. Several women with spinal cord injuries also worried that their babies would have physical problems. Sometimes it seemed that a woman's own difficulties or discomforts during pregnancy made her more pessimistic. Some women, like Dawn, felt that "my fear was not related to my disability. Every mother goes through that." Sasha's fear was certainly related to her disability, and she was surprised that she could do anything as normal as getting pregnant. She could only imagine that she would have a disabled child.

Some women felt that their concerns about the health of their babies were caused by their feelings about their own disabilities. Several women explained, "Since my body didn't work in other ways, I couldn't help feeling that it wouldn't work when I was pregnant." Celeste doubted she would be able to produce a healthy baby. She had always felt less competent than her able-bodied mother and could not help feeling, "If my mother had a disabled kid like me, I couldn't do any better." Clara's comment was especially illuminating: "I was really excited to have a baby and I did not want my kid to be disabled. Being disabled myself and working with disabled people gave me a fear that physical disabilities are much more common than they really are, and that was scary."

Some of the interviewees reacted to their fear with denial. Celeste was so afraid that her baby would be stillborn that she protected herself "against having any expectations." Others tried to suppress the fear itself. Arlene said she felt some fear but she did not let it rule her. Corinne said of her fear, "I didn't dwell or obsess on it." Tina said, "During my pregnancy I was pretty much in denial until the ninth month when I went to TLG and found out about the adaptations that I would need."

Corinne and Arlene did not dwell on their fears because they had sought information assuring them that their disabilities were not hereditary.

Hilary also consulted a genetic counselor in order to reassure her parents-in-law. Leslie's pregnancies always involved the risk of miscarriage, and she pointed out that sometimes the choice to live with some fear is simply an aspect of trying to have a child. There are really *two* separate questions to ask about how your disability might affect your fetus:

- Will my disability affect fetal development, labor, and delivery?
- Can my disability be inherited?

It is important to convey your acceptance of your own disability when you meet with a genetic counselor about the possibility of having a disabled child. Olivia said, "The genetic counselor offered the grim opinion that my baby could already have broken bones, but I held onto the vision of having a healthy baby." Diane said, "I'm pretty healthy and I turned out okay, so we figured why not."

Some women with disabilities might have a greater risk of giving birth prematurely or of having difficult labors that could affect their babies. For example, the high blood pressure of dysreflexia might precipitate premature labor, and premature birth can cause disability.

Another concern may be having a child with a congenital disability. The term *congenital disability* can be confusing. *Congenital* refers to a disability that is present from the time of birth, but although the two words sound familiar, not all congenital problems are genetically caused. Some congenital disabilities are due to problems in the prenatal environment such as certain illnesses in the mother. A well-known example is hearing loss in children whose mothers had *cytomegalovirus* infection during pregnancy. Research into the causes of congenital disability continues and, thus, a genetic counselor can give you the most recent information. Also, ask what immunizations are needed to prevent some disabilities. German measles vaccine, for example, is given in childhood, but to be safe from German measles while pregnant, you need a booster vaccination at least 1 month before you try to get pregnant. Chickenpox is another important vaccine that protects both the mother and the baby (45).

Some congenital disabilities can be inherited and it is important to consult a genetic counselor. Counselors have found that parents often over- or underestimate the likelihood that their disabilities will be inherited. Many genetic counselors do not understand that recommending the abortion of a fetus with the mother's disability is like saying, "YOU should not have been allowed to exist." Some caution should be taken, therefore, in selecting a genetic counselor.

Orielle went to a genetic counselor "because we would receive the best medical care for the baby if the baby had OI (*osteogenesis imperfecta*). We were afraid if the baby had OI it would not be seen on only one ultrasound. They may not do as many ultrasounds as they should to make sure the baby is doing okay." If the baby has OI, it will need special medical care. Although one ultrasound may not pick up OI, it is highly likely that having several ultrasounds will pick it up. She thought that going to a genetic counselor would insure good follow-up during pregnancy.

Some genetic conditions are inherited and a specific gene is passed from generation to generation. This means at least one parent is carrying a specific gene in every cell of his or her body. For example, all the cells of the body contain the gene for eye color. *Tay Sachs* disease and *sickle cell anemia* are examples of inherited disorders. Some other genetic conditions are *not* inherited. That is, the parents do not carry the gene in their bodies; instead, when a sperm or ovum cell was being formed, a change was made in the formation of the genes. Most instances of *Down's syndrome* are examples of this kind of disorder, although some cases of Down's syndrome are familial. A person who has relatives with an inherited disorder, such as Tay Sachs disease (there are five different forms), should absolutely have genetic testing. Someone who has a relative with a disorder such as Down's syndrome may not have a greater than average risk of having a child with this problem. A genetic counselor can advise you about the appropriateness of testing.

Spina bifida is an example of a *multifactorial* condition, one that appears to result from a combination of genetic, non-genetic, and environmental factors. Some families seem to be more susceptible to this condition, although most cases occur in families with no previous history of the problem. It is also known that lack of folic acid is crucial, and someone with spina bifida may need to take more folic acid before becoming pregnant and during pregnancy. Furthermore, there also may be a viral component that interacts with the genetic background of susceptible individuals. Some families have a tendency to be susceptible to ear infections and others to sore throats. *Celiac disease* presents another example of multifactorial illness. Celiac disease is "a lifelong digestive disorder that is found in individuals who are genetically susceptible. It causes damage to the small intestine, which, in turn, interferes with the absorption of nutrients" (46). Celiac disease also may increase the risk of autoimmune diseases.

It is important to remember that new discoveries about the causes of congenital disorders are constantly being made. Hilary received different advice from genetic counselors at different times. Ask your counselor when the research about your disability was conducted and whether any new studies are in progress.

Many genetically caused disorders and the genes responsible for them have not been identified, but literally hundreds of disorders—most of them extremely rare—can be diagnosed, and this number is growing.

A counselor may be able to give you statistical information on the likelihood that your disability can be inherited when prenatal testing is not possible. The genetic counselor will help you assess the likelihood of your child's inheriting your disability according to your age and your family medical history. She will also order blood tests, sonography, analysis of the amniotic fluid (fluid surrounding the fetus), and examination of fetal cells. There are two methods for collecting the cells: *amniocentesis* and *chorionic villus* sampling (see Chapter 8). In both procedures, the fetal cells that have been obtained from within the uterus are analyzed for the presence of genes that cause specific disorders.

In deciding whether to use genetic testing, you need to weigh your desire for information against the possibility a test could cause a miscarriage. Your genetic counselor can provide statistics that will help you compare the risks of having a child with a particular disability versus the risk of the procedure. For example, it is known that the risk of having a child with Down's syndrome is greater for women over the age of 35 than the risk that amniocentesis will cause a miscarriage.

Amanda was advised in her first pregnancy to have amniocentesis because of a low amount of amniotic fluid in the sac. She said, "I chose not to. I felt if there was low amniotic fluid, why were we taking some out? Plus, the doctors stressed that there was a chance of leaking more amniotic fluid after the procedure. I felt there was way too high of a risk for a spontaneous abortion to happen after the procedure."

Felicia was also afraid of a miscarriage and relied on AFP testing. Unfortunately, this test is not completely reliable. The *AFP test* is sometimes called the *MSAFP* or *maternal serum AFP*. Levels of AFP can be checked by drawing a sample of the mother's blood. This test is generally used for detecting neural tube defects, but it can also indicate abdominal wall defects, esophageal and duodenal *atresia*, some renal and urinary tract anomalies, Turner syndrome, some low birth weight fetuses, and placental complications. A low level of AFP could also indicate Down's syndrome (47).

Sophia Amelia had a level two ultrasound during her first trimester, which is more detailed and has better contrast and definition than the typical ultrasound. The technician found "choroid plexus cysts on the brain." A doctor came in to interpret the ultrasound and told Sophia Amelia that "there is a high correlation between choroid plexus cysts and Down's syndrome or trisomy 13 or trisomy 18. Sophia Amelia said, "I was very angry with the doctor for the way he explained the findings to me, especially since he seemed to be fairly young. He told me I could have an amnio done and get the results back 'just in time to terminate the pregnancy.' He explained Down's syndrome as: 'well there's that kid that acts on that TV show (Chris Burke from *Life Goes On*), but most kids with Down's syndrome are severely to profoundly retarded. If you're lucky they can live in a group home and work in a sheltered workshop.' I am glad I have personal knowledge of disability and have friends with Down's syndrome or who have children with Down's syndrome. Many people would have heard such advice from a medical professional and never questioned it. I looked up 'choroid plexus cysts' and learned that they were just deeper than average wrinkles on the brain and 50 percent of the population is found to have them when an autopsy is performed. It has now been removed as one of the indicators of Down's syndrome. I wanted to be happy when my daughter was born, no matter what. I didn't want to go through the shock or adjusting to her having a disability. I wanted to have the appropriate medical staff there when she was born to make sure she would get the best medical treatment possible. Even if my baby had trisomy 13 or 18, which is considered incompatible with life, I wanted this child to born. I wanted this child to be born and live however long it was going to live. The amniocentesis was traumatic, too. I watched them stick the needle in. And on the ultrasound, I watched the baby bat at the needle and [metaphorically] say 'get the hell out of my room!'"

Unlike many of the other interviewees, Tessa wanted amniocentesis and felt that by having a child with a disability she might injure herself further because the disabled child would require more care.

Sabine likes to be prepared with lots of information, so she opted for an amniocentesis, even though she was unsure whether she would have an abortion if the results were problematic. Sabine said, "It was recommended that I get an amniocentesis. I was much more into doing what the doctors said. The doctors thought it would put my mind at ease because I was worried." Also, she had many friends who had opted for this procedure and "it was no big deal." Unfortunately Sabine had a miscarriage at 5 months due to the amniocentesis. The urologist who performed Sabine's reconstruction surgery thought that Betadine® did not kill the germs that were naturally around the *ileostomy*, which produces different flora. He thought the needle introduced germs and the infection caused a miscarriage, but others I consulted (Sandy Welner, M.D., an obstetrician; Dr. Norman Moscow, a radiologist; and Dr. Lee, a urologist) all thought that the germs were killed by the Betadine®. Dr. Lee added that the needle would be far from where the ileostomy bag attaches so it could not have been a factor. Dr. Moscow said, 'This procedure is done by an obstetrician, but I'm unaware of any increased incidence of complication when there is a urinary diversion. This procedure [amniocentesis] comes with a small amount of risk.'"

Taryn Dion was afraid of a miscarriage from amniocentesis and was also afraid of not being able to get pregnant again. She was able to have a *nuchal translucency*, a specialized ultrasound that measures the thickness of the skin on the back of the fetus' neck. The test is performed by either *transabdominal* or *transvaginal* ultrasound scan, and 95 percent of women tested will have a normal result. The test will pick up 80 percent of pregnancies affected by Down's syndrome. The test itself does not carry any risk to the pregnant woman or the baby. If a test is positive (the recalculated risk is greater than 1:300) an invasive test is usually recommended to determine the baby's chromosomal pattern. This may be chorionic villus sampling (CVS)—performed at 11 to 14 weeks—or amniocentesis performed at 16 weeks of gestation. Both amniocentesis and CVS carry a risk of miscarriage of greater than 1 percent (48).

Some genetic counselors believe that, unless a woman plans to terminate a pregnancy if the test results are positive, she should not have genetic testing. They pointed out that the same information will be available when the child is born. This is particularly important for women who have OI. Orielle wanted CVS at 10 weeks to know if her baby had OI so that she and the baby could be monitored more closely. Orielle had ultrasounds every 2 weeks starting at 6 months. Other counselors believe the risk is worthwhile because, if the information is available sooner, parents have more time to adapt emotionally and plan ways to cope with any problems that are diagnosed. A genetic counselor can provide information about agencies to contact for help in the care and education of disabled children.

A genetic counselor can also help you sort out your feelings about the possibility of raising a disabled child. This question was not fully explored in our interviews, partly because none of the women who were interviewed had disabled children, and they focused on pregnancy and birth. Looking back on her pregnancy fears, Margie commented, "I didn't worry as much before my kids were born. Then they were still abstractions. Now that I know them, I worry more about something happening to them."

There are as many different opinions about the possibility of raising a disabled child as there are women who have considered having children. When participants in one survey were asked whether a woman should have an abortion if she knows her child will be disabled, their responses strongly reflected their feelings about themselves. Some women favored abortion, emphasizing the loneliness and unhappiness disability had caused in their own lives. Others rejected abortion, explaining that their lives had been worthwhile. Moreover, they disliked the implication that they should not have been born. Others said that the decision should depend on whether the parents feel able to raise a disabled child. Although some women may be satisfied with their lives, others may not want a child with a disability. Like most parents, Sherry Adele wanted a healthy child. She found that having amniocentesis and knowing her baby had no abnormalities gave her peace of mind.

Oprah had a philosophical point of view: "You take what is given to you and enjoy it."

Your partner's feelings are also important to consider. One of the questions posed was, "Did you have or want amniocentesis? If so, why?" Mimi's answer was, "Yes, because my husband couldn't handle both my disability and a child with chromosomal problems."

When a woman with a disability considers what life might be like for a disabled child, she brings special empathy and insight to the question. Like any other parent, she may have trouble making sure she does not project her own feelings onto the child and assume that the child feels (or would feel) what she feels.

Ask yourself these closely interrelated questions:

- How will I feel about my child growing up with the possibility of physical or psychological stigma? Remember Margie, who—when she had a real child in her arms—felt strongly that she did not want the baby to have a disability.
- How did you feel about yourself while growing up and how do you feel about yourself now? Many people feel differently about themselves as adults than they did as children. Often they have conquered frustration and loneliness and like themselves much better. Moreover, having yourself as a parental role model could make it easier for your child. If you have friends with disabilities, then those friends will also be role models.
- What was it like growing up with a disability? Answering questions two and three can help you imagine how life would be for your child, but this must be balanced by answering question four.
- Will my child's life be like mine? Will circumstances be different, making my child's experiences different from mine? Have there been improvements in therapy for my particular disability? Will improved educational opportunities and adaptive devices for children with disabilities make a difference?
- Have you compared your childhood experiences with those of other disabled people? Doing so will help you decide which of your experiences and feelings were typical—and, therefore, likely to be shared by your disabled child—and which were unique to you.
- How will having a disabled child change my life? How is this different from having an able-bodied child? Would it be possible to provide the extra care a severely disabled child might need?
- What will the physical toll on your body be from taking care of a child with a disability? Can you physically continue to transfer your child year after year, as the child gains more weight? If you think you will be unable to transfer your child, how else could it be done?

Other Special Issues

Your thinking will be colored by memories of growing up with your parents. But it would be different for your child with you as the parent. You will bring to the situation different strengths, different weaknesses, and different knowledge. Sasha felt that her parents' overprotectiveness had led to her lack of self-confidence, and she would try to avoid being overprotective herself.

Sara had a special advantage in mind: "I knew I'd be the best person to cope with whatever happened." Most disabled children never hear about successful disabled people; they see no lists of famous disabled Americans to parallel books about famous minority Americans. Often they do not even see disabled adults in everyday life. Some even fantasize about growing into able-bodied adults. But in you and possibly your friends, your child would have a constant example of disabled persons meeting the challenges of adult life.

Although few people with disabilities have felt angry with their parents for bringing them into the world, most are angry at how the world treats *them*. It is not a surprising reaction in a child, no matter how illogical. They may feel angry, even though their parents did not know they might have disabled children. How would you feel about encountering this anger if you had known you would give birth to a disabled child?

There might be situations in which you feel as though you are reliving your own childhood. For example, on a day your child is particularly frustrated by physical therapy exercises, you might recall the anger and helplessness you felt as a child in a similar situation. Your insight into your child's feelings might enable you to give him understanding and support in dealing with the frustration. You might be able to help the therapist find a more effective way of approaching your child. You might identify with your child's feelings so intensely that it will be difficult to work and communicate with the therapist. Working with educators, therapists, doctors, and possibly social workers, you may frequently find yourself retracing the path of your own childhood. How ready and willing are you to handle these situations?

The Decision to Have More Than One Child

Naomi said, "My reasons had to do mostly with timing. Once the questions about whether I could carry a pregnancy to term without unpleasant effects related to my disability were answered affirmatively with the birth of my firstborn, I wanted to have a second as soon as I thought I could handle being pregnant and still take care of my firstborn. I knew being pregnant would not allow me to carry my son at all, and that I would be quite fatigued most of the time. That meant he had to be old enough to do a lot for himself. But I didn't want to wait too long because of my age. We decided that getting pregnant when my son was around 20 months would be perfect. That would make the kids about two and a half years apart. I wouldn't be really heavy until he was over two. It has worked out quite well—our plan was a good one and the kids are close friends now."

Shanna decided to have a second child before the first child was four because they want to get the diapering over with while they are still used to doing it.

Sophia Amelia said, "I wanted to space the children far enough apart to avoid the financial burden of having two children in full-time daycare at the same time. We wanted our first child to be out of preschool."

Amanda's decision to have a second child "was solely based on the aptitude of my first child. I felt like my oldest child needed to stay by the car door and not run away while I was getting the second one out of the car."

Closing Comments

Having information about the impact of pregnancy on disability is usually not enough for women to make a decision on becoming a parent. Most women want to know what it is like to *be* a parent. They want to understand the different aspects of parenting, including the ability to take care of the baby, the emotional aspects of parenting, child development, and the mother's relationship to her partner, community, and job. The next chapter will explore these issues.