

## Common Disabilities Present at Birth

One out of every 100 or so babies has a disability that is obvious at birth. There are many different types. In this chapter we describe a few of the most common: cleft lip and cleft palate, extra or joined fingers or toes, and limbs that are short, missing, or not typical in other ways. We also discuss children born with multiple contractures (arthrogryposis). Please also refer to the chapters on club feet (Chapter 11), and spina bifida (Chapter 22).

### CAUSES

In many cases, the cause of a disability at birth is not known. But some of these disabilities may be caused by one of the following:

- **Poor nutrition during early pregnancy.** This is thought to be one cause of cleft lip and palate.
- **Genetic (hereditary).** Some disabilities run in families. For example, if one parent was born with an extra thumb, there is a greater chance that a child will be born with a similar disability. One or both parents may be carriers of the factor that causes a disability without having it themselves. However, it may be present in relatives. Often both parents must be carriers for a child to be born with the disability. For this reason, disabilities present at birth are more common in children whose parents are closely related, and who therefore are both carriers of the same disability-causing factors.
- **Medicines, pesticides, chemicals, pollution, and poisons.** Especially during the first 3 months of development, a baby in the womb can easily be harmed by chemicals and poisons. **Many medicines, drugs, and pesticides** (plant, insect, and rat poisons) can cause disabilities present at birth if a pregnant mother is exposed to them.
- **German measles (rubella).** If the mother gets German measles during the first 3 months of pregnancy, it can cause disabilities in the baby. These usually affect the senses (hearing and seeing), the brain (cerebral palsy and cognitive delay), or organs inside the body (heart, liver). Sometimes the baby is born with "rubber band-like" grooves on the limbs, or limbs or fingers that are missing or not typical in other ways.
- Children born to **mothers 40 years of age or older** are more likely to have Down syndrome and disabilities related to the hands, feet, or organs inside the body (heart, liver). In this age group, about 1 mother in 50 will have a child born with Down syndrome or another disability. If both parents are this age, the chance is even more.



The mother of this girl with cleft lip and palate did not get enough to eat while she was pregnant.



A doctor gave this boy's mother a medicine for morning sickness.



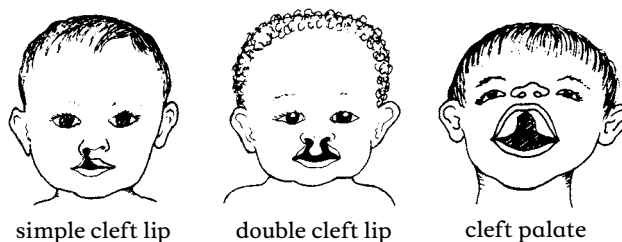
This boy's mother was 45 years old when he was born.

For ways to prevent disabilities present at birth, see p. 124.

## CLEFT LIP AND CLEFT PALATE

A cleft lip is an opening or gap in the upper lip, often connecting to the nostril.

A cleft palate is an opening in the roof of the mouth connecting with the canal of the nose.



Throughout the world, about 1 in 700 children is born with a cleft lip, cleft palate, or both.

Babies with these conditions often have trouble sucking, and may choke or gag on food that gets into their nose. Usually breastfeeding is the best way to feed these children.

Put the breast deep into the mouth so that the milk comes out on the back of the baby's tongue.



Occasionally the mother may need to get milk from her breasts by squeezing them, and then feed the milk to her baby with a spoon.



To prevent choking, feed the baby while he is sitting up with his head tilted forward a little.

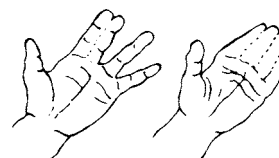


These conditions can also affect tooth formation. Cleft palate may cause ear problems that can lead to hearing loss. Correcting cleft lip and cleft palate with surgery can improve the child's ability to eat, speak, and hear, and their quality of life. Cleft lip surgery is usually done around 3 to 6 months of age, and cleft palate surgery is usually done around 12 to 18 months of age.

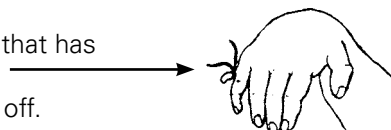
A child who has had surgery to repair a cleft lip or cleft palate may still have speech problems. Help the child practice speaking and show them exercises to strengthen their lips and tongue (see p. 314). If a child cannot have surgery or has hearing loss because of cleft palate, learning sign language can help them communicate (see p. 266).

## JOINED FINGERS AND EXTRA OR DIFFERENTLY SHAPED FINGERS OR TOES

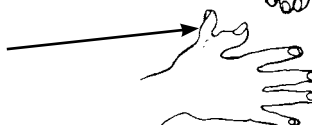
Some children are born with 2 or more fingers joined together. This does not cause much difficulty in use of the hand. However, the joined fingers can often be separated by surgery.



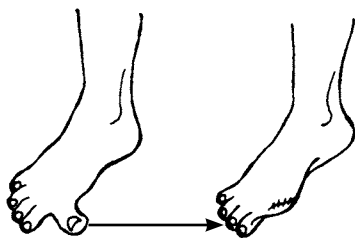
When a child is born with a small extra finger or toe that has no bone in it, you can tie a string tightly around it, like this. In a few days the finger will dry out and fall off.



Larger extra fingers or toes, if they get in the way, can be removed by a surgeon.



A child who is born with a toe that sticks out may need surgery in order to wear shoes. The toe can sometimes be put straight. At other times it may be simpler to remove it.



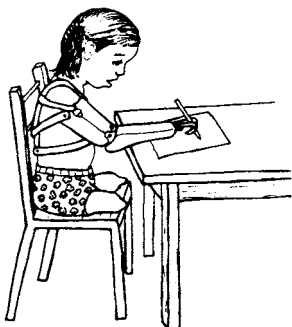
To get the best results, the surgery should be done by a specially trained orthopedic or plastic surgeon.

## INCOMPLETE OR MISSING ARMS OR LEGS

Sometimes medicines a mother takes early in pregnancy cause a child to be born with missing or incomplete arms or legs, or both.

A child born without arms but with typical legs and feet can often learn to use his feet almost as if they were hands: for eating, writing, drawing, playing games, and doing many kinds of work.

**It is important to encourage the child to use her feet, or whatever part of her body possible, to do everything she can for herself.**

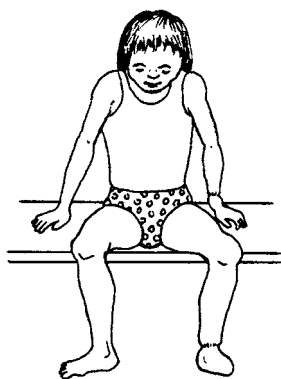


The child who is born with incomplete arms and legs can be helped a lot by artificial arms with hooks for grasping (see p. 230).

We do not give instructions for making these arms in this book, as they are fairly complicated. However, try every possibility to get artificial arms for the child. They can make a very big difference in her life. If possible, the child should get her first limbs by age 3.



For ideas about aids and artificial limbs for children born with missing or differently formed hands and feet, see Chapter 27, "Amputations," and Chapter 67, "Artificial Legs."

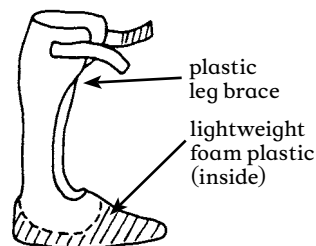


This little girl was born with "rubber band-like" constrictions in her hand and leg, and with parts of her fingers and foot missing. This happened because her mother had German measles when pregnant.



Her foot looked like this.

Village rehabilitation workers made her a plastic brace with a partial foot built into it, so she could wear a regular shoe or sandal.



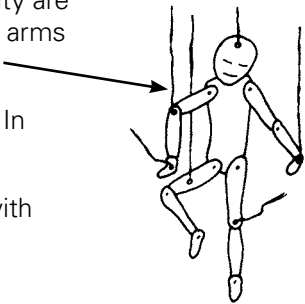
A firm foam-plastic foot was shaped and attached to a plaster mold of the foot (see Chapter 58). The plastic brace was heat molded over this.

ARTHROGRYPPOSIS (Multiple contractures from birth)

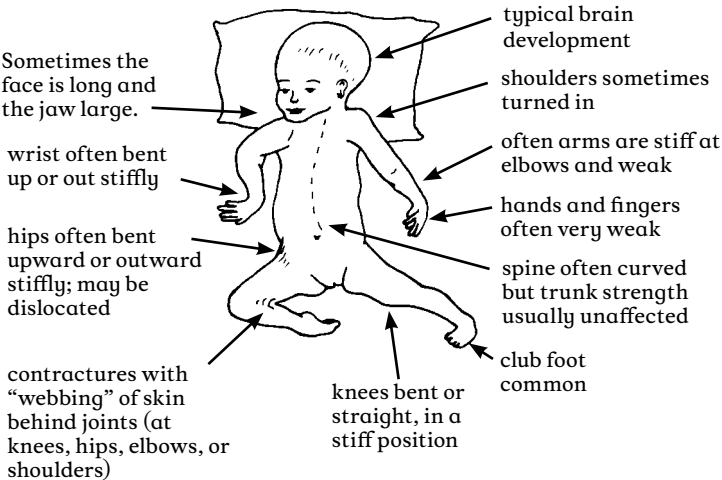
Arthrogryposis means “curved joints.” Children with this disability are born with stiff joints and weak muscles. The unusual position of arms and/or legs may give a child the look of a wooden puppet.

In some children, both arms and legs may be severely affected. In others, only the legs or feet, or hands or arms may be affected.

A child born with clubbed feet and with one or both arms stiff with hands turned out, may have arthrogryposis.



TYPICAL BABY WITH ARTHROGRYPPOSIS



The cause of arthrogryposis is not known. It may be a virus infection of the mother, during pregnancy. Arthrogryposis is a rare condition in most of the world, but for unknown reasons, in parts of Central and South America it occurs more frequently. (In PROJIMO, in Mexico, 1 of every 100 children with disabilities seen has arthrogryposis.)

Rehabilitation of the child with arthrogryposis aims at helping the child do as much for herself as possible.

Some children with arthrogryposis are able to walk, especially if contractures are corrected. Correction of club feet (see p. 115) and hip and knee contractures should begin gradually, and without forcing, soon after birth, with casting (see p. 565), positioning, and/or range-of-motion exercises (see p. 115).

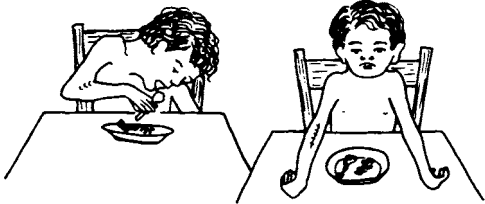


TYPICAL STANDING POSITION OF A CHILD WITH ARTHROGRYPPOSIS

If both hips are dislocated, surgery to put the bones back into their sockets is not usually helpful. The child walks as well without surgery. If only one hip is dislocated, surgery may help.

Often, however, contractures of arthrogryposis can only be corrected by surgery. The possible benefits and losses which surgery may bring should be carefully evaluated. For example, a stiff elbow in a bent (contracted) position may be much better for eating than an elbow that has been straightened, and will not bend.

MORE USEFUL LESS USEFUL

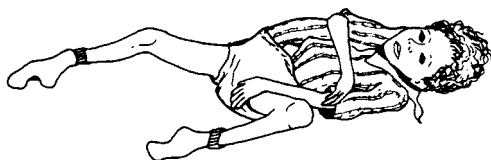


**WARNING:** A STIFF ELBOW IS OFTEN MORE USEFUL LEFT BENT.

Most children with arthrogryposis have typical cognitive development. If given a chance, many can learn to do a lot of things for themselves. Often they try hard and are eager to learn. It is very important that these children be encouraged and helped to do as much as they can for themselves, and that they go to school. The following story may help give you an idea of the possibilities of a child with arthrogryposis.

### SIMPLE STEPS TOWARD INDEPENDENCE—A true story

Gabriel is 7 years old. He lives with his family in Mazatlán, Mexico. He was born with arthrogryposis. Some of his joints are stiff and straight, others are stiff and bent. He lacks most of the muscles in his arms, legs, and hands. He cannot sit alone or lift a hand to his mouth.



Gabriel's parents love him dearly and care for him tenderly. However, when he was born, doctors told them that nothing could be done for him. So his parents grew used to doing everything for him. As he grew older, they carried him in their arms, changed his diapers when he dirtied them, and gave him food in his mouth. They treated him like a baby—though he no longer was one.

When his mother learned of PROJIMO, she took Gabriel there, hoping that with surgery or special medicine, he might improve. The village rehabilitation workers at PROJIMO investigated all possibilities. They even took him to a famous hospital for children with disabilities. But the specialists said they could do nothing for Gabriel.

Fortunately, therapists who were visiting PROJIMO as instructors explained to the team that in fact there was a lot that could be done, not to help Gabriel walk, but to help him do more for himself—within his possibilities. The team began to work with the family, to help Gabriel become more independent.

Now, with the help of the village rehabilitation workers and his family, Gabriel is able to meet some of his basic needs for himself. He feels less like a baby and more like a young man. He has stopped using diapers; he asks when he needs to go to the toilet. He has learned to use his mouth like a hand, to hold and do things.

He has learned to feed himself. He swings his arm onto the table using his neck muscles, and hooks his hand over a spoon. Using the edge of the table and the rim of the dish to push against, he see-saws the spoon to his mouth. To drink he uses a straw with a bend in it.



Gabriel's family has joined Los Pargos, an organized group of families of children with disabilities. He attends school in a specially-adapted wheelchair that he can move himself. He is learning to read, write, paint pictures, and to play with other children.

There is much more that Gabriel and his family will be able to achieve, now that they all see how much he can do for himself. Gabriel is happy and eager to learn more.



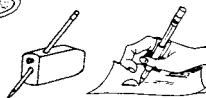
Gabriel wrestling with another child with disabilities.

Various aids and adaptations can help children with arthrogryposis or similar disabilities become more independent:

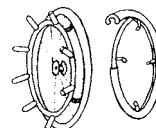
Eating aids are described on pp. 330 to 332.



Writing aids are shown on p. 5, p. 230, and p. 501.



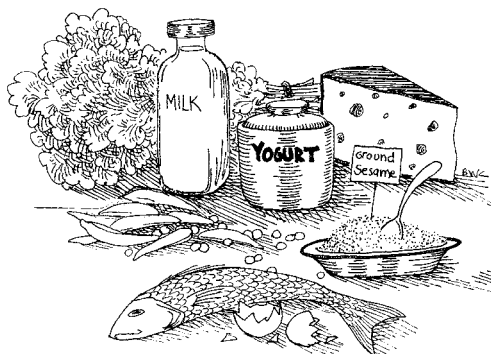
Wheelchair aids are shown in Chapter 64.



## PREVENTION OF DISABILITIES PRESENT AT BIRTH

It is not possible to prevent all disabilities present at birth. Some babies form differently inside the womb and no one knows why. But many of these disabilities can be prevented. For ways to make it less likely that children will be born with disabilities, see Chapter 3. To reduce the chances of having these disabilities, pregnant women must stay in good health and avoid certain dangers:

- **Eat well during pregnancy.** Eating enough good food gives strength, prevents infection, builds a healthy baby and helps prevent too much bleeding during birth. Be sure to eat food that has enough folic acid (see *Where There Is No Doctor*, Chapter 11 and *Where Women Have No Doctor*, Chapter 11).
- **Avoid medicines and drugs during pregnancy** unless you are sure they will not injure the baby. (Vitamins, some vaccinations, some antacids, and iron in the correct dose are alright.) Alcohol and tobacco during pregnancy can also injure the developing child.
- **Avoid contact with chemicals, pesticides and other poisons.** If a pregnant woman's partner or family members must use pesticides or poisons, they should wash their own clothes, and protect the pregnant woman from the chemicals.
- **Avoid having children with close relatives.** When close family members have children together, the children are much more likely to have disabilities present at birth.
- While pregnant, stay far away from anyone with German measles (rubella) if you have never had it. If you are not pregnant, try to catch it before you get pregnant. Vaccines give protection against German measles but you should not become pregnant for 1 month after rubella immunization.
- Getting syphilis or herpes when you are pregnant can cause the baby to be born with disabilities. Make sure you and your partner are tested and treated early for sexually transmitted infections.
- Be aware of your risk of having children born with certain disabilities so you can take this into account when building a family. Risk increases as parents get older, and if family members have certain conditions.



Most disabilities present at birth can be prevented when women can afford good food to eat, when they do not have to work with toxic chemicals, and when they have good health care.

These disabilities should not be treated as a challenge for families to deal with on their own. Their causes affect the whole community, and to prevent disabilities, we must change the world we live in so that it is safer for all people.