

A congenital hand difference is a hand that is different than expected at birth. There are other terms commonly used when discussing hand differences. “Limb difference” can encompass any difference from the fingers to the shoulders, as well as from the toes to the hips. These differences can be congenital, meaning present at birth, or they can be acquired, meaning the person picks up the difference after birth.

Other terms such as “upper limb difference” or “upper extremity difference” can refer to the fingers, hands, arms, and shoulders; the terms “congenital upper limb difference” or “congenital upper extremity difference” distinguish between congenital and acquired.

There are many types of hand differences; some include webbed or fused parts of the hand, curved parts of the arm or hand, extra parts in the hand, missing parts, or parts that are larger or smaller than expected. Some hand differences are related to genetics, some are related to syndromes, and others happen spontaneously.

## The Science of Formation

During fetal development, the upper limb is formed between four and eight weeks of pregnancy. Many steps are needed to form an arm and a hand, and there could be any number of factors that affect the developing limb bud. Some of these differences have genetic causes, but many of these differences occur without a known cause.

The best theories as of now relate to decreased blood circulation during limb formation due to a clot, a disruption in blood flow, or smaller arteries. Researchers are trying to understand these processes, but no research as of yet suggests that hand differences are a result of something a child’s parents did or did not do during the pregnancy.

## Characteristics

Some congenital hand differences are easy to identify, but others can be more difficult because they have more than one feature. There are a few different classification systems from various disciplines such as surgery, genetics, and embryology. Some hand differences appear similar but have contrasting diagnoses due to the origination of the hand difference or how the hand difference presents.

Often congenital hand differences are misdiagnosed at birth, and it is important that your child be evaluated by a hand specialist to recommend treatment or if further evaluation for related syndromes is needed. Your hand specialist may refer you to a genetics specialist to help make an overall diagnosis for your child.

## Treatment

There are various treatment options for children with limb differences and their families. Conversations related to goals and expectations can help families make medical decisions, and it is important to communicate treatment options to the



Figure 1 - Syndactyly between long and ring fingers



Figure 2 - Polydactyly, with an extra little finger

child with a hand difference at a level that they understand. Research has shown that neurotypical children can make sound medical decisions at age 8, and it is paramount to include them in the decision-making process.

## Surgery

There are generally three types of backgrounds for hand surgeons: orthopedics (the surgical approach for bones), plastic surgery (the approach for skin appearance), and general surgery. All are qualified, and their training brings various skills to the operating room.

It is important to work with a surgeon who specializes in hand surgery and has completed a hand surgery fellowship, as there are many nuances in congenital hand differences that are familiar to hand surgeons and maybe unfamiliar to those who do not specialize in hand surgery. A directory of hand surgeons can be found [here](#).

Some surgical options might be more effective if they occur when the child is young (and maybe even too young to

be involved in the decision). Other times, surgery can wait until the child encounters barriers in life where a surgery to change the appearance and function of the hand is beneficial.

Examples of surgery include separating webbed fingers to provide more effective grips, the removal of an extra finger that is in the way, and moving the first finger to the thumb position for children who do not have a thumb, which can help facilitate power grips and opposition. Other options include moving tendons and bones to maximize the strength behind a certain movement.

### Prosthetics

A prosthesis (prosthetic device) is a tool designed to help increase the function of a limb with a difference. A prosthetist, who is trained in the field of prosthetics, will evaluate the child and discuss barriers, goals, and expectations for a device. They will review device system options and fit the device for the child. Some people with hand differences use devices, some do not them, and some use devices for specific tasks.

### Occupational Therapy

Hand therapy with an occupational hand therapist can help assess the barriers that children with hand differences face, and they can develop strategies for adaptive tasks, build or seek out adaptive tools, or facilitate exercises to increase strength and range of motion for the hand difference. Often after surgical interventions, especially if the hands or arms have been rearranged, a therapist will help children relearn how to use their hands.

If a child does receive a prosthesis, it is recommended they work with an occupational therapist for learning how to use the device.

It is important to note that present research and technology will not be able to replace a hand, arm, or shoulder. This is important to remember when creating and managing expectations for families and children. There are many tools and strategies to support kids growing up.

### Reactions to Hand Differences

So many parents share feelings of shock, anger, or guilt when first learning their child has a hand difference. These are valid emotions for parents to experience, and it is important to address these and acknowledge them as they are happening. Most of the time, there is nothing that parents or doctors could have done differently to prevent the hand difference.

As such, reactions might stem from larger societal themes of ableism and how those with disabilities are treated as a minority group. These are important themes to unpack. Families of kids with hand differences must face the fact that their kids will navigate the world a little differently, and parents need to acknowledge and support their kids' differences while trusting that they will live full and meaningful lives. Talk to your hand specialist about support groups or profes-



**Figure 3 - Thumb polydactyly, with duplication of the thumb**

sionals who can help. As parents raise children with hand differences, the children will learn from the parents how to respond about their hand.

Once neurotypically developing children with congenial limb differences approach about 8 years, they may experience their first crisis of understanding that they have something that is different and that this difference, at least in the current social landscape, is not the most preferred. These kids might experience the same medley of emotions as their parents had when they were born.

Talk with your health care team if you notice any big changes in your child's behavior. Health care providers can help develop strategies to address staring and being able to confi-