

**“How mild/severe is it?”**- A person either has Down syndrome or they do not. Down syndrome is not an illness. Having Down syndrome does not mean a person is sick.

**“But you’re so young!”**- Although the chances of a woman having a child with Down syndrome increase significantly over the age of 35, there are far more children with Down syndrome born to younger mothers.

**Handicapped** – Use “has a disability” instead.

**Downs or Down’s syndrome** – There is no “s” or “s” in the first name of this syndrome, and the “s” in syndrome is not capitalized.

**Suffers from/Afflicted with Down syndrome** – Our children are not *suffering* or *afflicted*. We must instill a great sense of pride and self-esteem in all children, so our language must show that Down syndrome is *not* harmful or terrible, or anything to be ashamed about.

Words you may hear and not know:

**Early Intervention** – Services provided to infants and toddlers with disabilities ages birth to three and their families through a comprehensive program or individual providers.

**IFSP/IEP** – Individualized Family Service Plan (early intervention document) and Individual Education Plan (public school document).

**Speech Therapy** – Works on language, listening and feeding issues.

**Physical Therapy** – Works on gross motor skills for large muscle groups, such as walking, sitting, crawling.

**Occupational Therapy** – Works on fine motor skills such as manipulating objects with hands.

**Hypotonia** – Low muscle tone, common in people with Down syndrome.

**Chromosome abnormalities** – It is an “abnormality” of the 21st chromosome that causes Down syndrome. All of the other chromosomes are normal. Even the 21st chromosome is *normal*. There is just too much of it. Down syndrome is not caused by anything that the parents did before or during pregnancy.

**Nondisjunction Trisomy 21** – This is the most common type of Down syndrome (95%). Most people have 46 chromosomes, but people with Down syndrome have 47 chromosomes. People with Down syndrome have 47 because instead of two 21st chromosomes, the baby was born with three 21st chromosomes. The extra chromosome is found in every cell. This addition often changes how the cells in the body work.

**Mosaicism** – This is the least common form of Down syndrome (1-2%). Chromosomes divide unevenly, but not until the second or third cell division after conception, meaning only some of the cells have the extra chromosome.

**Translocation** – A part of the 21st chromosome has broken off and attached itself to another chromosome, providing extra genetic material in all of a person’s cells. Only 2-3% of babies with Down syndrome have translocation.

**FOR MORE INFORMATION,  
CONTACT US:**

**DOWN SYNDROME GUILD OF  
SOUTHEAST MICHIGAN**

P.O. Box 522, Royal Oak, MI 48068  
248.646.0819 or [info@dsgsemi.org](mailto:info@dsgsemi.org)

# How Do I Talk About Down Syndrome?

## A Language Guide for Family, Friends, and Others

*“How often misused words generate misleading thoughts.”*

*Herbert Spencer*

Supporting families and individuals with  
Down syndrome



# Is reading this brochure really important?

Communicating about individuals with Down syndrome with both positive and accurate language is important in education and advocacy.

So often, family and friends do not know what to say, and it is often difficult for parents to confront someone who has hurt them with their words or labels.

Knowledge is key, so this simple guide is meant to help others speak in ways that are more politically correct, avoiding hurtful and offensive language.

Is reading this brochure really important? Yes! Using appropriate language when referring to Down syndrome is important. We want to do the best for our children, so using this guide can help us avoid choosing words that can be hurtful or offensive. If you don't understand a term or are unsure of how to refer to something, simply ask.

*The contents of this brochure have been modified and reprinted from "How Do I Talk About Down Syndrome?" by UPS for DownS (United Parent Support for Down syndrome, a volunteer organization of parents of children with Down syndrome based in the Northwest Suburbs of Chicago.)*

## Good Word Choices:

**Baby/Child/Person with Down syndrome** – The emphasis should always be on the person first, not the disability. This is referred to as “first person” language. When we take care to put children first, and let the disability remain in the background, we are teaching others to do the same.

**Developmentally Delayed** – This term is the common reference to describe delays in development and the learning process such as speaking and walking. Most families find it less offensive than the term *mentally retarded*.

**Has Down syndrome** – Someone who has Down syndrome has Down syndrome. S/he is not a victim of it, nor is s/he diseased by, or afflicted with it. One does not suffer from it.

**Mental Retardation** – This is an accurate term to describe developmental functioning level, but is less acceptable to many parents than the term “developmentally delayed.” Use it with caution.

**Typically developing/Non-disabled child** – Both of these terms are acceptable and positive ways to refer to people who do not have Down syndrome or another disability.

**Different Ability** - This is a wonderful term to describe my child who has Down syndrome as having a “different ability”. All students have different abilities, different languages if English is not the first language, different sports abilities, different leaning abilities....we are all unique. Different ability is a very positive way to describe a person.

## Poor Word Choices:

**A Down(s)** - A person with Down syndrome is not the disability. There are many other things that should, and do, define a person. It is dehumanizing and strips people of dignity when they are referred to as their disability. Instead of saying “He is a Down's baby” or “She is Downs,” try “He or she *has* Down syndrome.”

**Down syndrome child/baby** – This goes back to referring to the person first, not the disability. This is one of the most common misstatements made and often causes parents to cringe, at least inwardly. For example, we don't say “a diabetes child,” or “an asthma person,” so eliminating this reference is critical.

**Normal kids** – Please realize that we perceive our children as being pretty normal kids. Comparing them to *normal* children implies that a child with Down syndrome is something less than normal.

**Retard/Retarded** – Currently, the best reference is *developmentally delayed* (for children) and *developmentally disabled* (for adults).

**Mongolism** – This is an outdated term that was once used to refer to people with Down syndrome. The word should **never** be used when referring to or about someone with Down syndrome.

**“They” as in “they are so loving; they are always happy.”** - Don't generalize about people with Down syndrome. “They” are not all alike. Much like typically developing children, kids with Down syndrome have a full range of emotions and will mature and grow into adulthood.