

A Language Primer

Good Words to use

Baby/Child/Person with Down Syndrome

Emphasis should always be on the person first, not the disability. When we take care to put children first, and let the disability remain in the background, we are teaching others where the emphasis needs to be

Developmentally Delayed

This term is the common reference to describe delays in development, such as language, walking and all other areas of a child's learning process. Most families find it less offensive than the term mentally retarded.

Has Down Syndrome

Someone who has Down Syndrome is not a victim of, diseased by, nor do they suffer from or are they afflicted with Down Syndrome. They simply have Down Syndrome.

Mental Retardation

This is an accurate term to describe developmental functioning level, but is less acceptable to many parents than the term "developmentally delayed." Please 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.

Big No-No's

A Down(s)

A person with Down Syndrome is not the disability. There are many other things that should, and do, define that person. It is dehumanizing and strips people of their dignity to be referred to as a disability. Instead of saying "He is a Down" or "She is Downs," try "He or she has Down Syndrome."

Trisomy 21

Trisomy 21 is by far the most common type of Down Syndrome (95%) and means that instead of two 21st chromosomes, a baby was born with three 21st chromosomes, thus causing them to have Down Syndrome. This chromosome division occurs immediately at conception, and the extra chromosome is found in all of the cells. Most people have 23 pairs of chromosomes.

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

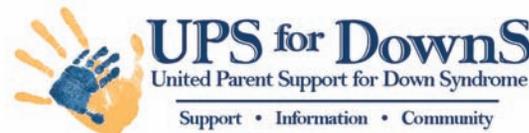
In translocation, a part of the 21st chromosome has broken off and attached itself to another chromosome, providing extra genetic material in all of a person's cells. Only 2-3% of babies with Down Syndrome have translocation.

The Bottom line?

If you do not understand a term or are uncertain about how to refer to something, please ask!

What is UPS for Downs?

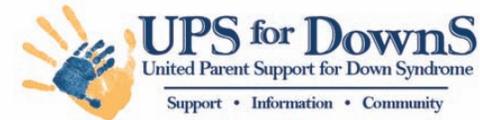
UPS for Downs, United Parent Support for Down Syndrome is a Chicago area, not for profit, volunteer organization providing support, information, and community opportunities for people with Down syndrome and their families



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HOW DO I
TALK ABOUT
Down syndrome?

a language guide for
friends, families & others



www.upsfordowns.org

Why should I read this?

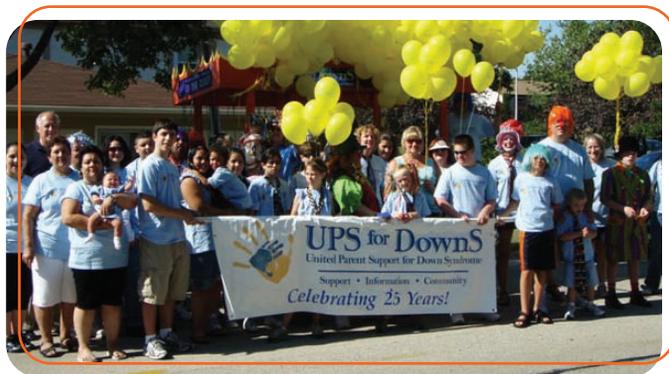
This guide is an effort to remind ourselves to communicate about children with Down Syndrome in a positive and accurate manner. It is an opportunity for us to address how to send conscientious messages to and about our kids so that we can **ALL** be better advocates!

UPS for DownS members have often heard that friends and family don't know what to say, so discussions are carefully avoided, or comments are unintentionally hurtful; we've heard stories about how an intended friendly comment in the grocery store has reduced a new parent to tears.

Coming from strangers is tough enough, but coming from us, the people our children interact with on a regular basis, or those who know our children, can be heartbreaking. Please don't take this as a crusade to be *politically correct*. We all want to do the best for our children and families. A simple start is to avoid using words that are hurtful or offensive and by gently correcting those who do so.

Why can't my _____ (brother, daughter, friend, client, patient) just tell me this themselves?

It's often difficult to tell a friend, loved one or professional that their words are hurtful. And something that deeply bothers one person may go completely unnoticed by another.



Big No-No's! (cont.)

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.

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

The best reference is developmentally delayed (for children) and developmentally disabled (for adults).

Mongolism

As most of us know, this is an extremely outdated term that was once used to refer to people with Down Syndrome. This word should never be used when referring to or about someone with Down Syndrome. (It pains us to even include it in this brochure.)

"They" as in "They are always so loving; they smile all the time; they are always happy."

Please don't generalize about people with Down Syndrome. "They" are not all alike; nor are people with Down Syndrome "eternal children." Much like non-disabled children, they will mature and grow into adulthood.

How mild/severe is it?

A person either has Down Syndrome or they don't. 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 increases significantly over the age of 35, there are far more children with Down Syndrome born to younger mothers - they have more babies!

Handicapped

Use "has a disability" instead

Downs or Down's Syndrome

There is no **s** or **'s** in the name of this syndrome

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. We must ensure we do not make anyone feel that Down Syndrome is something terrible or something to be ashamed about.

Words you may 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 provider.

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's just too much of it. Down Syndrome is not caused by anything that the parents did before or during pregnancy.