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## “Why Should I Read this Brochure?”

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 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.

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## A LANGUAGE PRIMER

### Good Words to Use:

**Baby/Child/Person with Down Syndrome** - the 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.” 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.

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### 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.”

**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 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 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 - they are having more babies.

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## ***Big No-No's*** (continued)

**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, so should ensure that we do not make anyone feel that Down Syndrome is something terrible or something to be ashamed about.

### **Words you'll hear and 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 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.

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### **Words you'll hear and may not know:** (continued)

**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.

**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 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, ASK.

### ***What is UPS for DownS?***

UPS for DownS (United Parent Support for Down Syndrome) is a volunteer organization of parents of children with Down Syndrome based in the Northwest Suburbs of Chicago, with members throughout the Chicagoland area.

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# How Do I Talk About Down Syndrome?

*A Language Guide for  
Friends, Family and Others*

"How often misused words  
generate misleading thoughts."  
Herbert Spencer (1820-1903)



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