



Language matters...

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 respectful and empowering, avoiding hurtful and offensive language.

The contents of this brochure have been modified and reprinted from "How do I Talk About Down Syndrome?" by UPS for Downs and the Down Syndrome Association of Los Angeles, nonprofit organizations supporting families with Down syndrome.

Facts about Down syndrome:

- Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes characteristics associated with Down syndrome.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 733 babies is born with Down syndrome.
- Down syndrome occurs in people of all races and economic levels.
- There are more than 400,000 people living with Down syndrome in the United States.



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HOW DO I TALK ABOUT DOWN SYNDROME?



A preferred language guide for family, friends and others



Down Syndrome Connection of the Bay Area
Empower - Inspire - Support

Use positive word choices



Consider saying:

Baby/child/person with Down syndrome (DS)

The emphasis should always be on the person first, not the disability. This is referred to as people-first language. When we 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.

Has Down syndrome

Someone has DS has DS; they are not a victim of it, diseased, or suffering from it.

Intellectual disability

This is a new legislative term replacing the outdated and offensive term of mental retardation.

Typically developing child

This is a positive way to refer to people who do not have DS, as opposed to using the word “normal”.

Instead of:

Down syndrome baby

This is one of the most common misstatements and often causes parents to cringe. We don't say “a diabetes child”, or “an asthma person”; put the person first, not the disability.

A Down(s)

A person with DS is not the disability. There are many other characteristics that define a person. Instead of saying, “he is Down's” or “Down's baby”, try “he has Down syndrome”.

How severe is it?

A person either has DS or doesn't.

“They are so happy”

Do not generalize about people with DS.

“They” are not all alike. Kids with DS have a full range of emotions.

But you're so young

Although the chances of a woman having a child with DS increases when is she is over the age of 35, 80% of babies with DS are born to younger mothers.

Retarded or handicapped

Use “has a disability” or “is developmentally delayed” instead.

Suffers from/afflicted with Down syndrome

Our children are not suffering, nor are they afflicted. We must instill a sense of pride and self-esteem in all children, so we should ensure that we communicate that DS is not harmful, terrible, or something to be ashamed of.

Terms to know

Early Intervention

Services provided to infants and toddlers ages birth to 3 and their families through a comprehensive program or providers.

IFSP/IEP

Individualized Family Service Plan (Early intervention document) and Individual Education Plan (public school document).

Speech therapy

Works on communication, language and feeding issues.

Occupational therapy

Works on fine motor skills, such as manipulating objects with one's hands.

Hypotonia

Low muscle tone can make babies with Down syndrome look and feel “floppy”.

Celebrate the baby!



Although the birth of a baby with Down syndrome may bring some sadness and a mix of emotions to new parents, they still have a baby who they will love and be a family with. It is an occasion to celebrate.