

## Why Should I Read This Brochure?



As a friend, family member, or community member of a person with Down syndrome, your words can impact the way that people feel about themselves or are viewed by others. By speaking about Down syndrome and people with Down syndrome in a positive and accurate manner, you have the opportunity to help shape perceptions.

Together we can use our words to make individuals with Down syndrome and their families feel empowered and welcomed in our communities.

### Keep In Mind:

**The correct name of this diagnosis is Down syndrome...** not "Downs" or "Down's". The "s" in syndrome is not capitalized (syndrome). It is named for John Langdon Down, the 19th century physician who first classified the condition. It is also acceptable to refer to Down syndrome as Trisomy 21. This is a technical term used because Down syndrome is caused by the triplication (trisomy) of the 21st chromosome. Down syndrome is the most commonly used name.

**People with Down syndrome are people first and foremost.** Saying "Down's person" or "Down Syndrome person" implies that Down syndrome should be the focus. Down syndrome is something someone has, not something that someone is. Keep your emphasis on the person, not the disability. Try saying "person/child/baby with Down syndrome" instead.

### Keep In Mind: (continued)

**A person has Down syndrome, but it doesn't define him or her.** People with Down syndrome have unique personalities and traits that are not related to Down syndrome. When speaking, say that a person "*has* Down syndrome," not that a person "*is* Down syndrome." This places the focus on the person, not the disability.

**People with Down syndrome have an intellectual disability (ID).** The United States government, American medical and psychiatric professionals, and the World Health Organization no longer use the term "mental retardation." Instead, use the term "intellectual disability." "Mongolism," "mongoloid," and "handicapped" are also outdated terms. It is most appropriate to say a person with Down syndrome has an intellectual disability (ID), a development delay, or developmental disability.

**End the R-word.** It is not okay to say "retard" even if you are not talking about someone with a disability. The R-word is hurtful and represents the discrimination and degradation of people with disabilities. Using it in this manner equates unintelligent or silly behavior with having an intellectual disability, which is cruel and unfair to the millions of thoughtful, capable, contributing members of our society who do have a disability.

**Use neutral terminology.** A person has Down syndrome, rather than "suffers from," "is the victim of," or "is afflicted with" Down syndrome. It is important to instill a sense of pride in *all* children. Having Down syndrome is *not* something terrible or shameful.

**Normal is a setting on a washing machine.** "Normal" is a subjective word. By referring to someone without Down syndrome as "normal," we imply that there is something wrong with people who are different. When speaking about a person

### Keep In Mind: (continued)

who does not have a disability, refer to him or her as "typically developing" or "does not have a disability." These terms are accurate and neutral.

**People with Down syndrome are not all the same.** Try not to use stereotypes and clichés when describing an individual with Down syndrome. For example, people with Down syndrome are not always happy. They experience complex emotions, just like everyone else. These types of stereotypes take away a person's individuality and prevent others from seeing who he or she really is.

**There is no such thing as "a little bit of Down syndrome."** A person either has Down syndrome or does not. There is not a scale for Down syndrome. There is no such thing as severe or mild Down syndrome. Down syndrome impacts people differently because people are different. People with Down syndrome have different strengths and weaknesses just like all human beings, not because they have varying degrees of the condition.

**Talk about the person, not the diagnosis.** Most importantly, look at a person with Down syndrome as an individual. Your family member, student, coworker or new friend has lots of unique personality traits, interests and skills. Acknowledge his or her individuality and accomplishments. Remember that a person with Down syndrome is just that—a person.

**That doesn't mean you can't talk about Down syndrome!** It's okay to ask a person with Down syndrome or a family member about the diagnosis as long as you ask in a manner that respects the individual and his or her privacy. If you don't understand a term, or are unsure about what language is appropriate, just ask. We are all learning together.

## New Words You May Hear:

**Chromosome Abnormalities** — Chromosome abnormalities refer to any difference in chromosomal makeup. The addition of an extra 21st chromosome that causes Down syndrome is a chromosomal abnormality because it is different than the typical chromosomal makeup.

**Trisomy 21** — Most people have 23 pairs of chromosomes in every cell of their body—one from the mother and one from the father. Trisomy 21 is a triplication of the 21st chromosome, meaning there are 3 copies of the 21st chromosome in every cell of the body instead of 2. This is caused when a person receives an extra chromosome from a parent, occurs at conception, and exists in every cell of the body. Trisomy 21 is the most common form of Down syndrome (95%).

**Translocation** — In translocation, a piece of the 21st chromosome breaks off and attaches itself to another chromosome, providing extra genetic material in all of a person's cells. The chromosome to which it attaches varies and can impact the effect this has on the person with translocation. Only 2-3% of babies with Down syndrome have translocation Down syndrome.

**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 cells have the extra chromosome.

**Hypotonia** — Low muscle tone is a common condition in people with Down syndrome.

**Congenital Heart Defect (CHD)** — Nearly half of all babies with Down syndrome are also born with a congenital heart defect. Sometimes, the defect is minor or corrects itself with time, but often surgical intervention is required.

**Early Intervention** — Services provided to

infants and toddlers with disabilities (ages birth to 3 years) and their families through a comprehensive program or individual providers.

**Individualized Family Service Plan (IFSP)** — The IFSP is the form used in the state of Michigan to document services and supports provided to families of infants and toddlers with disabilities.

**Individualized Education Plan (IEP)** — An IEP is a form used to outline special educational supports and services for school age children with disabilities.

**504 Plan** — A 504 Plan addresses environmental and physical barriers to education for school age children who do not require and are not eligible for special education services.

**Speech Therapy** — Therapy to support development of communication, language, and the muscles associated with speech and eating.

**Occupational Therapy** — Therapy for the development of fine motor skills involving small muscle groups, for example manipulating small objects with the hands and fingers.

**Physical Therapy** — Therapy for development of gross motor skills involving large muscle groups, such as crawling, walking, and sitting up.

### The Bottom Line?

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

# Let's Talk About Down Syndrome

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



“How often misused words generate misleading thoughts.”  
- Herbert Spencer



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