

Down Syndrome Association of Central California

A Grandparent's Guide



Down Syndrome Association of Central California

The mission of Down Syndrome Association of Central California, aka DSACC, is to enhance the quality of life for all people whose lives are touched by Down syndrome. The goal of the organization is to provide programs that promote greater awareness of the developmental, educational, and social potential of people with Down syndrome. In particular, these programs benefit people with Down syndrome, their family members, and the social science, education, and medical professionals who support them. We serve people with Down syndrome and their families, healthcare providers, and educators. Our catchment area includes six counties: Fresno, Kings, Tulare, Madera, Mariposa and Merced.

The organization was founded by five families from the Central Valley who began meeting in June of 1999 to lay the foundation for the association that we know today. We were originally known as Fresno Area Down Syndrome Society and changed our name in September of 2009. We are a nonprofit 501(c)(3) corporation officially established in January of 2000. DSACC is managed by a Board of Directors consisting of an Executive Board and Members at Large.

Welcome to Down Syndrome Association of Central California (DSACC)

As a grandparent with a grandson with Down syndrome, I know what a joy they can be. I also know how unsure you can be when you first learn that you will be welcoming a new little one into your family with Down syndrome. With this booklet, we would like to help you through the first intimidating but then joyful experience of adjustment that comes with your new family member.

Grandparents are so special. They are there to help the parents in their new journey of raising a child with Down syndrome. They need someone to talk to, lean on, and babysit! They are also there for their new grandchild to help them grow, learn and experience the world.

Times with your grandchild are treasures to be remembered. Their milestones are a time to celebrate. We invite you to join us so we can take this journey together.

*-Dorothy Crass, grandmother
of Kyle Harder*

DSACC Office
4277 W. Richert Ave., Suite 102, Fresno, CA 93722
(Just off Golden State between Shaw Ave. and Ashlan Ave.)
559-228-0411
www.dsacc.org

You are not alone...

God sent us a beautiful little spirit in Brayden. Watching him experience life, his eyes and expressions tell us his thoughts. What a blessing he has been. I feel such great joy every time I'm with my grandson. Everyone should be lucky enough to experience these feelings. I love my Brayden!!! -Brenda Miller, grandmother of Brayden Lehnick



Kyle Harder is my little sweetheart. He is 5 years old and in transition Kindergarten in Kingsburg. He adores his brothers, looking up to his older one (Luke), and playing with his younger one (Cole). He loves to watch sports, play with balls, read books, listen to music, going to school, and going to Grandma's house. An adult once said to Luke that Kyle was very lucky to have him as a big brother. However, Luke's answer was, "No, I am the one that is lucky to have him as my brother." God did make us all special! -Dorothy Crass, grandmother of Kyle Harder

We couldn't love our little Ava more. Whenever she sees her Papa she says "Papa." She also says "Papa" when she sees Gramma. The day Ava was born we knew we had a very special little angel and we really understood what the word "special" meant. She constantly brings so much joy to our lives. The Lord truly gave us a gift in Ava. -Paul and Denise Bealessio, grandparents of Ava Fernandes



Join us!

On September 19, 2007 a joyous occasion happened when Emme Ann joined our family. Emme is so full of life that she raises the whole family up. When we are together she makes sure she spends time with each of us. Our lives would not be the same without her. -Patty Henderson, grandmother of Emme Ann Morris



My daughter will tell you that after my grandson, Charlie, was born and diagnosed with Down syndrome that we got stuck on the flavor! Well, she is right. Three of our eleven grandchildren have Down syndrome. Over the years, I have discovered that all of my grandchildren have unique personalities and that our grandchildren with Down syndrome have turned out to be more alike than different. Their influence on our family has been profoundly positive and inspiring, and I wouldn't change any one of them for the world! -Carole Pero, grandmother of Charlie, Ryan and Sara Allshouse

It's been a rollercoaster for us because she has heart problems; we were worried. There have been highs and lows, but God has sustained us. She is such a blessing of love and laughter in our lives. -Jim and Nancy Berna, grandparents of Ava Cortez

God gave us this beautiful gift. We think that we are trying to give to her, but she is the one. She is the one that gives to us. And, to see our son as a father, so involved, we are overwhelmed with joy! -Gilbert and Alicia Cortez, grandparents of Ava Cortez





Learn More 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 the characteristics associated with Down syndrome.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies is born with Down syndrome.
- There are more than 400,000 people living with Down syndrome in the United States.
- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But, due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

- A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.
- Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.



Myths about Down syndrome

Myth: People with Down syndrome have a short life span.

Truth: Life expectancy for individuals with Down syndrome has increased dramatically in recent years, with the average life expectancy approaching that of peers without Down syndrome.

Myth: Most children with Down syndrome are born to older parents.

Truth: Most children with Down syndrome are born to women younger than 35 years old simply because younger women have more children. However, the incidence of births of children with Down syndrome increases with the age of the mother.

Myth: People with Down syndrome are severely “retarded.”

Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of intellectual disability. Children with Down syndrome fully participate in public and private educational programs. Educators and researchers are still discovering the full educational potential of people with Down syndrome.

Myth: Most people with Down syndrome are institutionalized.

Truth: Today, people with Down syndrome live at home with their families and are active participants in the educational, vocational, social, and recreational activities of the community. They are integrated into the regular education system and take part in sports, camping, music, art programs and all the other activities of their communities. People with Down syndrome are valued members of their families and their communities, contributing to society in a variety of ways.

Myth: Parents will not find community support in bringing up their child with Down syndrome.

Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current trend in education is for full inclusion in the social and educational life of the community. Increasingly, individuals with Down syndrome graduate from high school with regular diplomas, participate in post-secondary academic and college experiences and, in some cases, receive college degrees.

Myth: Adults with Down syndrome are unemployable.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small and medium-sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions, childcare, the sports field and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They experience the full range of emotions. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Truth: People with Down syndrome date, socialize, form ongoing relationships and marry.

Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Developmental Milestones

Milestones	Child with Ds	Typical Child
<i>Gross Motor Skills:</i>		
Sitting Up	6-30 months	5-9 months
Crawling	8-22 months	6-12 months
Standing	1-3.25 years	8-17 months
Walking	1-4 years	9-18 months
<i>Language Skills:</i>		
First word	1-4 years	1-3 years
Two-word phrases	2-7.5 years	15-32 months
<i>Personal/Social Skills:</i>		
Smile	1-5.5 months	1-3 months
Finger feeding	10-24 months	7-14 months
Drinks from a cup	12-32 months	9-17 months
Using spoon/fork	13-39 months	12-20 months
Bowel control	2-7 years	16-42 months
Dressing unassisted	3.5-8.5 years	3.25-5 years

what it means to be a grandparent

Remember that it all begins with love. You love your child, who may now be facing parenthood a bit differently than they expected. You love your family and always want the best for everyone, for everyone to feel accepted and cherished. And of course you love your grandchild. This little one is first and foremost a baby, a sweet little child who needs to be held and fed and played with and loved. And in the big picture, what you will do to love your grandchild is much the same as you would do for any child.

You are not alone. There are many families with children with Down syndrome living in your area and our support groups welcome grandparents. By attending a family support group, you will have the chance to talk with others, learn more about Down syndrome and show support for your child (*the new parent*).

You are a role model. Being a role model in the love and care you show for your grandchild, and in the respect and love you practice for the new parents, will help other family members and friends have a positive approach to the situation and bring more support to the family. When the family and friends are supportive, everyone's life is elevated to a better place.

You are special in the lives of your grandchildren. The old expression, "Don't worry, you're in your Granny's!" means that when you are a child, you feel cherished and carefree when you are with your grandparent. Grandparents often have more time and patience to read books or throw a ball, to endlessly answer the question "why?" or have a tea party, to make up silly riddles or go to the park. That loving time builds a bond between grandchild and grandparent like no other.

How Grandparents Can Help

*Nobody can do for little children what grandparents do.
Grandparents sort of sprinkle stardust over the lives of little children.*

-Alex Haley

Learn as much as you can about Down syndrome, what it is and is not. You can get more information from DSACC, other organizations listed in this booklet and from publications. Having a better understanding of the situation will help everyone in the family embrace this wonderful new child.



Know that feelings are feelings. What you and the new parents may be feeling about the birth of this new child is normal. You may feel joy and sadness, fear and hope, even bewilderment and empowerment. Try to think of feelings as neither “good” or “bad,” feelings just exist. Be understanding and comforting toward the new parents, whatever feelings they may share with you and be sure to give yourself that same comfort for your feelings, too.

Don't be afraid to hold your grandchild. Sometimes when a child with medical issues is born, we are afraid to touch or hold for fear of hurting them. But, studies show that the human touch is very healing, and an absolute necessity for the development of infants and children. You can be a part of the progress your grandchild makes through touch. And while you're at it, don't forget to give your child a hug to show your care and concern for them, as well.



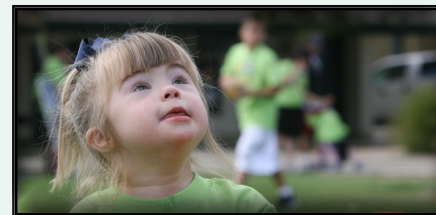
Remember to give some attention to your new grandchild's

brothers and sisters. New babies are always the center of attention. Sometimes when one child is attended to because of a diagnosis, or conversations in the family are focused on what is happening to the special needs child, other children can get lost in the shuffle. Call to talk just to them, and when you visit, go out of your way to spend some alone time and consider bringing a special small gift to them.



Listen to your grandchild's parents. They may need to talk, to get your advice, to just express their feelings about being a new parent. Take opportunities to ask about how things are going, how your grandchild is doing. Whatever the response may be, be supportive. Remember that this is a whole new world for you and the new parents.

Ask how you can help with the new baby. If you are near enough to offer practical help, that may be very much needed. Cooking a dinner or doing a load of laundry while you babysit the other children or while the new parents take a break can be a real lifesaver. And, keep offering from time to time, new parents may feel that they have to do everything themselves at first, but later realize that, as they say, 'it takes a village to raise a child.'



Grandparents can make a big difference

Playing games to help your grandchild communicate

A big part of inclusion is the ability to communicate with others. For children with Down syndrome, this can be challenging and it may take some time for them to be able to physically say words. Think of how frustrating it must be for your grandchild to want to tell you a story or ask for something, but to not be able to make you understand. But the good news is that you can help, you can make a big difference in the communication skills and vocabulary of that child.

Things you can do today:

Learn Baby Sign Language

Simple sign language can help your grandchild express themselves before they can physically say the word.

Teaching them to sign will be a great bridge to spoken words and help everyone feel less frustrated.

There are many DVD resources that you can watch with your grandchild to learn simple signs together. Make a game of it and you will both benefit.

Narrate the World

As you go about your daily chores and errands, point out objects and say the word then ask the child to repeat the word.

Even emotions or concepts can help vocabulary building. See a baby crying? Say “sad” or “mad.” At the playground? Say “up” at the top of the slide and “down” at the bottom!

Use “Total Communication” Methods

Total Communication (TC) is an approach to education that aims to make use of a number of modes of communication such as signed, oral, auditory, written and visual aids, depending on the particular needs and abilities of the child.

Being a grandparent can be a joy!

Being a grandparent of a child with Down syndrome can be a great joy. You have the opportunity to see your own child become a nurturing parent and feel a swell of pride as they experience parenthood for themselves. You have years of parenting knowledge to draw upon if you are needed (that phone call asking if you think the baby is ready to start solid food or should he stay on formula, etc). And then, the most important part, that beautiful child! Whether they are fussy or funny (and let’s face it, they all are at one time or another) they bring joy to your life. You can bring them the loving relationships they need to thrive.

The US Census Bureau estimates that at least 3 million children are left in the care of their grandparents at some time each week. For the parents and grandparents of a child with Down syndrome, this relationship can be especially important. You can provide both emotional and practical support for parents as well as providing your grandchildren with an increased range of close relationships. Having grandparents on hand to share in the care of children is usually a great help to families. Some children with Down syndrome have special health concerns and can’t be cared for by just any babysitter. They may require a particular healthcare routine and also need someone who knows them well, someone who can tell when “something just isn’t right” so that a doctor’s care may be sought. Grandparents can fill this role so well and give welcome respite to the parents of a special needs child. Even when the extended family members are not geographically close, they can be an important source of emotional support.

All children (and their parents) need good role models. This is another area where grandparents can excel, offering a guide for how to manage in the world, how to handle emotions in a healthy way, how to fight for what is right and how to remain positive. You’ve been through it all and made it this far. This is the strength and the wisdom of a grandparent.

Feelings and Emotions



How does it feel to be a new
grandparent of a child with *Down syndrome*?

"My granddaughter was such a beautiful baby, but I was worried about her future."

"I thought, if only I was younger, I could cope better."

"It was difficult to accept and at the same time, I wanted to do more to help."

"I was so worried about my son and my grandson, would they both be OK?"

"I was angry. Why did this happen to us?"

"I didn't know how to help my daughter and her husband, I just waited for them to ask."



Feelings and Emotions

Having a grandchild with Down syndrome has an effect on everyone in the family: parents, siblings, aunts and uncles and yes, grandparents. The experience is unfamiliar and unexpected. You may need more information about Down syndrome to know what to do and when to help your grandchild's parents. And, because every child (and every situation) is different, you won't always know how to predict what's next. You may go through a full range of emotions, from anger and helplessness to immense joy and fulfillment.

People you know, your friends and neighbors, may also have questions and find it difficult to understand your new situation. You may get tired of explaining things to them and repeating the same thing over and over until they do understand. And, you may be worried about your own child and how they are coping, and wonder how you can help.

Many grandparents who have a new grandchild with Down syndrome have found that local support groups and others in the same situation are very helpful. There are many who have traveled this path before you, and they are willing to listen to your concerns, help you find resources, and also sort through any issues that may leave you feeling overwhelmed or confused.

Still, there is a very blissful part of this, an opportunity to be all the wonderful things a grandparent can be – that hasn't changed just because your new grandchild happens to have Down syndrome. The things you hoped for when you heard that your grandchild was on the way, perhaps some of the things that you remember about your own grandparents, can still happen. Becoming that very special person in this child's life, sharing secrets, spending a whole day at play (with fewer responsibilities than a parent), can all still be a part of the picture. You will build forts in the living room, make Halloween costumes, marvel at the giraffes at the zoo, and read Cat in the Hat for the millionth time!

People First Language

The difference between the right word and the almost right word is the difference between lightning and the lightning bug.

-Mark Twain

People with disabilities are – first and foremost, people – people who have individual abilities, interests and needs. For the most part, they are ordinary individuals seeking to live ordinary lives. People with disabilities are moms, dads, sons, daughters, sisters, brothers, friends, neighbors, coworkers, students and teachers. About 54 million Americans – one out of every five individuals – have a disability. Their contributions enrich our communities and society as they live, work and share their lives.

As the term implies, “People First Language” refers to the individual first and the disability second. It’s the difference in saying the autistic and a child with autism. (See the examples.) While some people may not use preferred terminology, it’s important you don’t repeat negative terms that stereotype, devalue or discriminate, just as you’d avoid racial slurs or say women instead of gals.

Equally important, ask yourself if the disability is even relevant and needs to be mentioned when referring to individuals, in the same way racial identification is being eliminated from news stories when it is not significant.

Emphasize abilities not limitations. Never equate a person with a disability – such as referring to someone as retarded, an epileptic or quadriplegic. These labels are simply medical diagnosis. Use People First Language to tell what a person HAS, not what a person IS. Avoid negative words that imply tragedy, such as afflicted with, suffers, victim, prisoner and unfortunate.

People First Language Examples

People First Language SAY:	Instead of Labels that Stereotype and Devalue DON'T SAY:
<ul style="list-style-type: none"> • People/individuals with disabilities • An adult who has a disability • A child with a disability 	<ul style="list-style-type: none"> • The handicapped • The disabled
<ul style="list-style-type: none"> • People/individuals without disabilities • Typical kids 	<ul style="list-style-type: none"> • Normal people/healthy individuals
<ul style="list-style-type: none"> • A person who has Down syndrome • People with intellectual and developmental disabilities • He/she has a cognitive impairment 	<ul style="list-style-type: none"> • The mentally retarded; retarded people; he or she is retarded; the retarded; he/she's a Downs kid; a Mongoloid; a Mongol
<ul style="list-style-type: none"> • A person who has a learning disability 	<ul style="list-style-type: none"> • He/she is learning disabled
<ul style="list-style-type: none"> • Accessible buses, bathrooms, etc.; reserved parking for people with disabilities 	<ul style="list-style-type: none"> • Handicapped buses, bathrooms, hotel rooms, etc.; handicapped parking

What Do You Call People with Disabilities?

Men, women, boys, girls, students, mom, Sue’s brother, Mr. Smith, Rosita, a neighbor, employer, coworker, customer, chef, teacher, scientist, athlete, adults, children tourists, retirees, actors, comedians, musicians, blondes, brunettes, SCUBA divers, computer operators, individuals, members, leaders, people, voters, Texans, friends or any other word you would use for a person.

Excerpted from material from the Texas Council for Developmental Disabilities

A Bright Tomorrow

When a child with Down syndrome is born, many people – from experts to family members – will tell you they “know” what that child will accomplish in life. While there are many guidelines regarding physical and cognitive development, it is impossible to predict the future of a child with Down syndrome – just as it is with any other child. No professional can look at a child and tell you how intelligent, successful or independent he or she will be in 20, 30 or 50 years.



Don't lower your expectations because your grandchild has Down syndrome. You will never know what your grandchild is capable of if you don't give him or her the chance to succeed. Today, individuals with Down syndrome are achieving more than we ever thought possible – due in part to higher expectations and more opportunities. They are living independently, working and volunteering in the community, graduating from high school and attending post-secondary education programs. People with Down syndrome have meaningful relationships and some marry. Whether or not your grandchild accomplishes these things, it is never wrong to challenge children to do their best.

Adapted from DSACC Parents Guide



Your grandchild has been born into a world of possibilities never before imagined for people with Down syndrome. The National Down Syndrome Society has worked since 1979 to ensure that all people with Down syndrome have the opportunity to achieve their full potential.

Together, we have celebrated many advancements through the years, but there is still far to go.

We envision a future in which your grandchild realizes dreams that today we cannot even imagine.

Books, DVDs and websites

Babies with Down Syndrome: A New Parents' Guide.

Skallerup, Susan J. (Ed.) Third Edition. Bethesda, MD: Woodbine House (2008). <<http://www.woodbinehouse.com>>

Gifts: Mothers Reflect on How Children with Down Syndrome

Enrich Their Lives. Soper, K. (Ed.) Bethesda, MD: Woodbine House (2007). <<http://www.woodbinehouse.com>>

Gifts 2: How Children with Down Syndrome Enrich the World.

Soper, K. (Ed.). Bethesda, MD: Woodbine House (2009). <<http://www.woodbinehouse.com>>

Supporting Siblings and Their Families During Intensive Baby Care.

Rector, L.. Baltimore, MD: Brookes Publishing (2007). <<http://www.brookespublishing.com>>

Down Syndrome: The First 18 Months. DVD. Written, Produced and

Directed by Will Schermerhorn. Blueberry Shoes Productions LLC. <<http://www.blueberryshoes.com>>

Discovery: Pathways to Better Speech for Children with Down

Syndrome. DVD. Written, Produced and Directed by Will Schermerhorn. Blueberry Shoes Productions LLC. <<http://www.blueberryshoes.com>>

“Down Syndrome: Health Issues.” A website about healthcare and Down syndrome. <<http://www.ds-health.com>>

“Down Syndrome Web Portal.” Stanford School of Medicine, Down syndrome information Portal - 20 articles on aspects of Down syndrome. <<http://dsresearch.stanford.edu/resources/>>

“Family Village Resources: California Disability Resources.” <<http://www.familyvillage.wisc.edu/comm/california.html>>

Resources

DSACC

Down Syndrome Association of Central California
4277 W. Richert Ave., Suite 102
Fresno, CA 93722
559-228-0411
www.dsacc.org

NDSS

National Down Syndrome Society
800-221-4602
www.ndss.org

NDSC

National Down Syndrome Congress
800-233-6372
www.ndsccenter.org

CVRC

Central Valley Regional Center
4615 N. Marty Ave.
Fresno, CA 93722
www.cvrc.org
Fresno - 559-276-4300
Merced - 209-723-4245
Visalia - 559-738-2200

Parent and Family Resource Center

(at Exceptional Parents Unlimited)
4440 N. First St.
Fresno, CA 93726
559-229-2000
www.exceptionalparents.org



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is to enhance the quality of life for
all people whose lives are touched by Down syndrome.*

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