



# Grandparents Guide



## Resources and Family Tool Kit







Dear New Grandparents,

Congratulations on the birth of your grandchild! The arrival of a baby is a time for celebration and joy. While this little one may not be exactly as you imagined, please remember that they are more like other babies than not.

Like all babies, this child needs the whole family for nurturing, guidance, safekeeping, and most importantly, love and acceptance.

We understand that the birth of a child with Down syndrome can introduce the entire family to a new and sometimes confusing world filled with intense emotions.

Our hope is that with information and support, you will gain a deeper understanding of both your feelings and the special needs of this child who will bring so much love into everyone's life. We encourage you to learn as much as you can and to be a strong support to the parents.

Remember to treat this baby just as you would any other. This packet includes information about Down syndrome and tips for family members.

Congratulations again!

Warmest wishes,  
Club 21







## What is Down syndrome?

- Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome, which 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.
- 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.



- People with Down syndrome attend school, work, and contribute to society in many wonderful ways.
- 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.
- With early intervention, people with Down syndrome are graduating from high school, going to college, working at various jobs, living independently, and leading meaningful lives.



## Becoming a grandparent to a child with Down syndrome



- You adore your child who might be experiencing parenthood in an unexpected way. You love your family, and you always want everyone to feel accepted and cherished. And you love your grandchild, who is first and foremost a baby needing care and affection. In the big picture, your love for your grandchild will be the same as for any child.
- Being a role model in the love and care you show for your grandchild with Down syndrome, and in the respect and support you offer the new parents, encourages other family members and friends to take a positive approach. This support brings more strength and unity to the family, uplifting everyone's lives.

## How you can help your grandchild with Down syndrome

- Show your unconditional love and acceptance to your grandchild with Down syndrome. Treat them just as you would your other grandchildren, giving them equal time, attention, treats, and discipline.
- Presume competence! Have high expectations for your grandchild, regardless of their age or apparent abilities. While their paths may differ, with support, they can reach their highest potential.
- Focus on your grandchild's strengths, positive efforts, and achievements. This perspective helps parents see and appreciate their child's abilities as well.
- Engage in the same activities with your grandchild with Down syndrome as you do with your other grandchildren. For example, if the others enjoy board games and the child cannot play in the same way, team up with them or modify the game to include them.



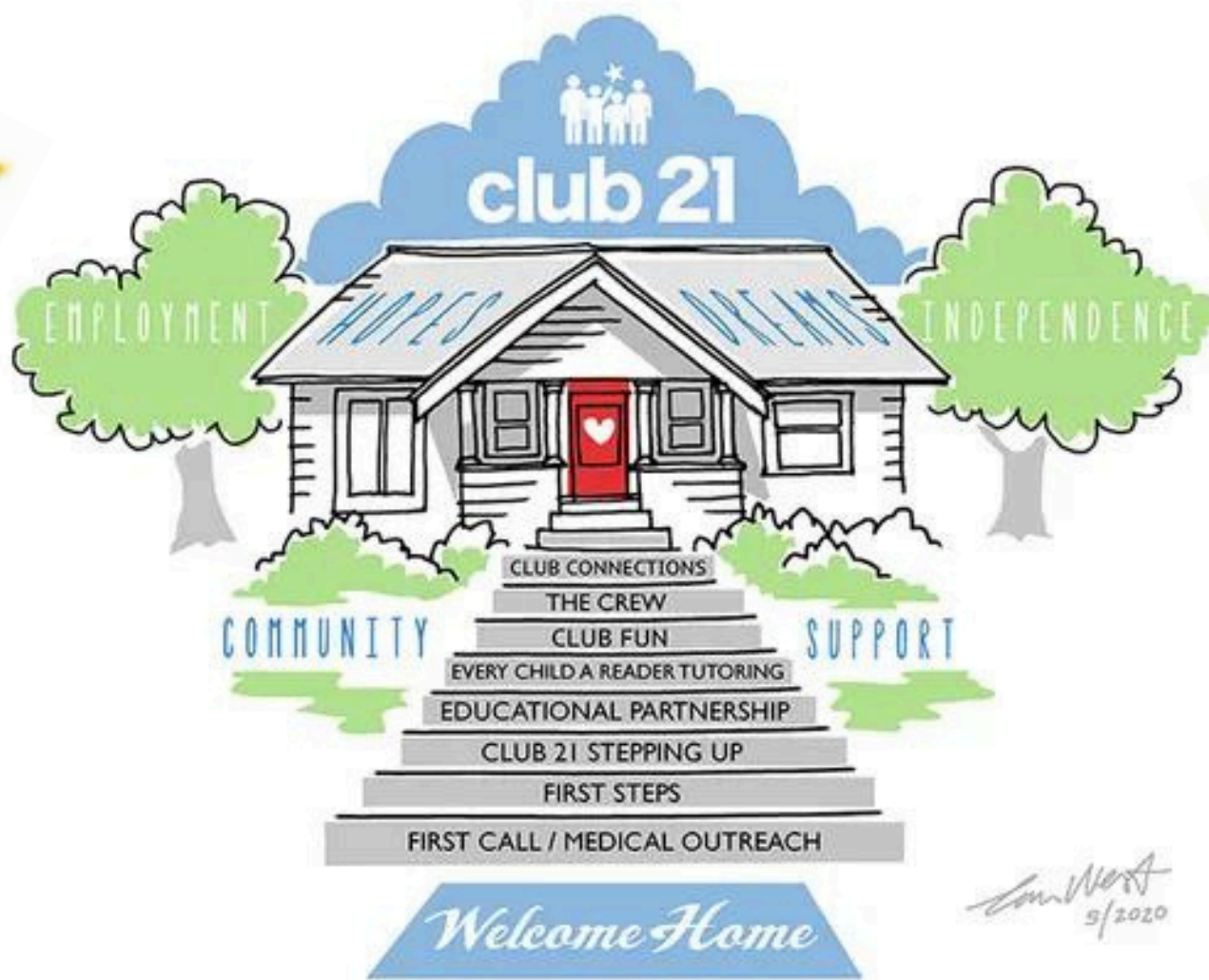


## Ways you can support

- Families experience a rollercoaster of emotions. This is normal. One of the best things you can do is listen. Try to be sensitive to your child's feelings.
- Be as positive as you can and stay in the present. Although it may be hard to feel positive in the beginning, remember that this is a journey.
- Show your acceptance of the new baby, offer empathy, but not pity.
- Learn as much as you can about Down syndrome. Offer to help the new parents by doing some research. There's a lot of information to sort through, but focusing on one specific issue can be very helpful.
- If you live close, come to Club 21 events, and/or reach out to Club 21 for support/information.
- If you are near enough to offer practical help, that will be a gift. Cooking 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.
- Simple sign language can help your grandchild express themselves before they can physically say the word. There are many resources that you can watch with your grandchild to learn simple signs together.
- Learning commonly used terminology that is associated with Down syndrome. (See terminology section)







## Educational Pathway Programs at Club 21

- **First Call/First Steps (Diagnosis–3 years)**

Events and opportunities for new parents to connect with a peer mentor, learn alongside other families, and gain access to professional advice from therapists.

- **Stepping Up (18 months–8 years)**

A program specifically designed for families of young children as they transition from Early Intervention services with their regional centers through the early years with their school districts. Parents develop a clear understanding of how their child learns and how best to support their child's educators while their child practices fundamental motor, learning and social skills.

- **Every Child a Reader (ECAR)**

Weekly one-to-one tutoring program Kindergarten through High School focusing on the development of reading skills.

- **Club F.U.N. (Friends Understanding Nuances) Ages 8–12 years**

A social competencies program that uses Social Thinking Vocabulary and concepts to enhance understanding and build social skills.

- **The CREW (Middle School)**

Continues to build the social skills for fostering friendships with peers and the pathway toward independence.

- **Club Connections(High School–Age 25)**

Teens and Young Adults learn social competencies and foundational skills relationships, independence, employment) that will help each individual achieve a life of their choosing.

- **Educational Partnership (School Aged)**

Parent education and educator professional development throughout the year to prepare both groups to best support their students with Down syndrome in inclusive school classrooms.

- **Transition Support (age 13 +)**

Parents learn about the mandatory Transition IEP process and how to navigate school and support systems, as well as opportunities and resources to map out a path for a meaningful life of belonging after high school.

- **Transition Pathway (18–30 years)**

A program specifically designed for families of young children as they transition from Early Intervention services with their regional centers through the early years with their school districts. Parents develop a clear understanding of how their child learns and how best to support their child's educators while their child practices fundamental motor, learning and social skills.

- **IEP Support (Individual Education Plan)**

Regular workshops for parents, led by experts in the field, to learn about their rights, the document process and how to best advocate for their child.

- **Self Determination Learning Circles (all ages)**

Parents learn about the new California Self Determination Program (SDP) and how to transition from services approved through the traditional regional center model to more autonomy and options for their child with SDP.

- **Community Support Groups**

Community support groups create opportunities for families to network, share common interests, concerns, and information through community events, informational meetings, playgroups, and online chat groups. These include Sibshop, Dads Appreciating Down syndrome (D.A.D.S), Mom's Meet Up, Bienvenidos, and Dual Diagnosis Groups.

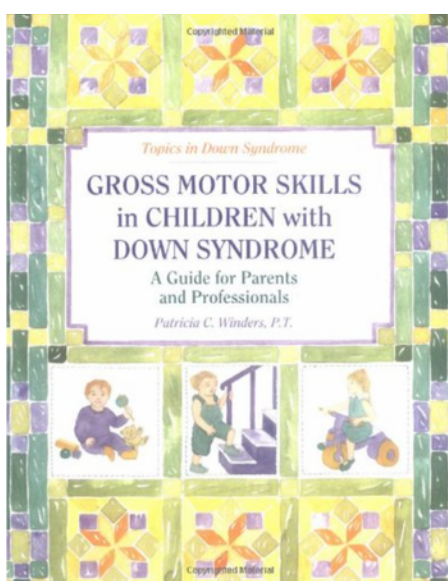


## Common Terminology

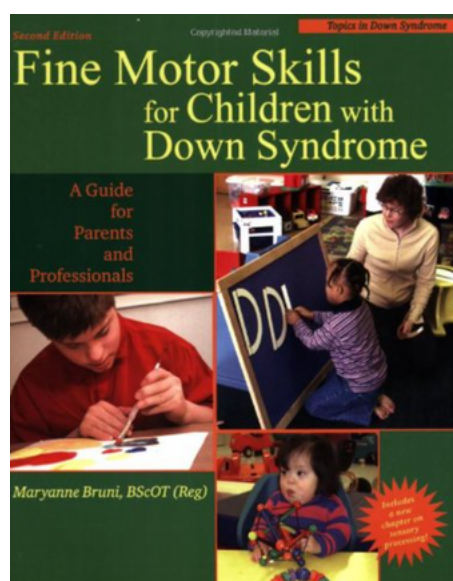
- **Person-First Language:** a child with Down syndrome is a person first, not their disability. For example, “My granddaughter with Down syndrome just turned 3” instead of, “My Down syndrome granddaughter.”
- **Ds:** Down syndrome
- **EI or EIS:** Early intervention services
- **IDEA:** Individuals with Disabilities Education Act
- **IEP:** Individualized Education Plan
- **IFSP:** Individualized Family Service Plan
- **OSEP:** the Office of Special Education Programs
- **OT:** Occupational Therapy
- **PT:** Physical therapy
- **DT:** Developmental Therapy
- **ST:** Speech Therapy



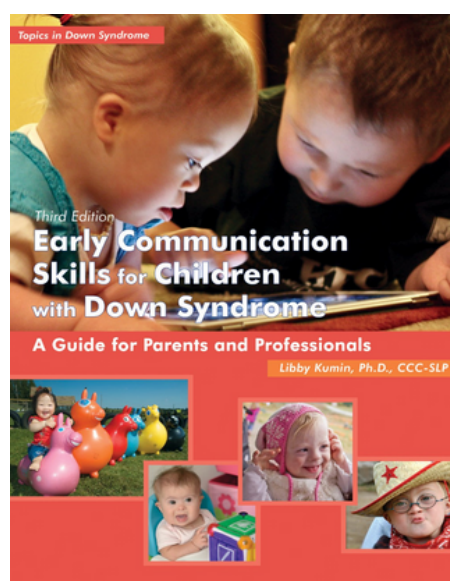
## Literature



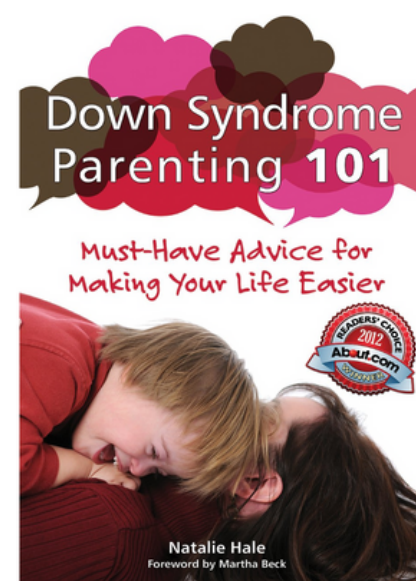
[Gross motor skills](#)



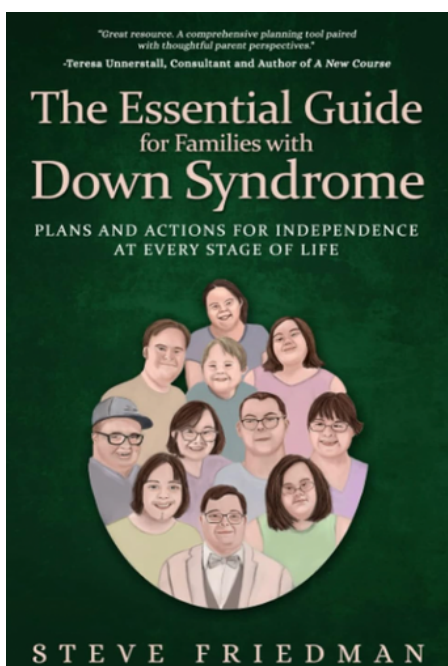
[Fine motor skills](#)



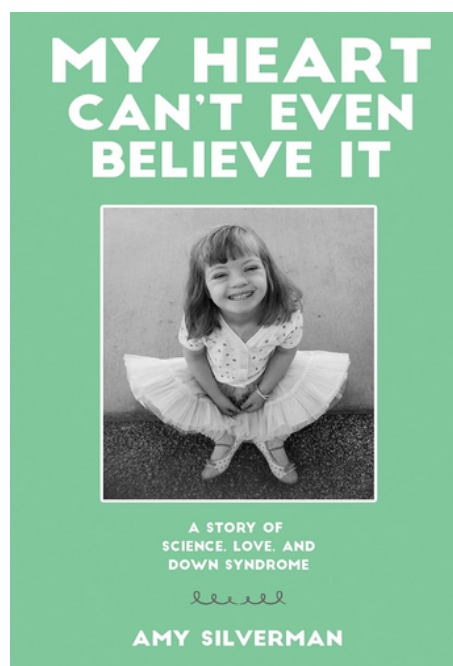
[Early communication](#)



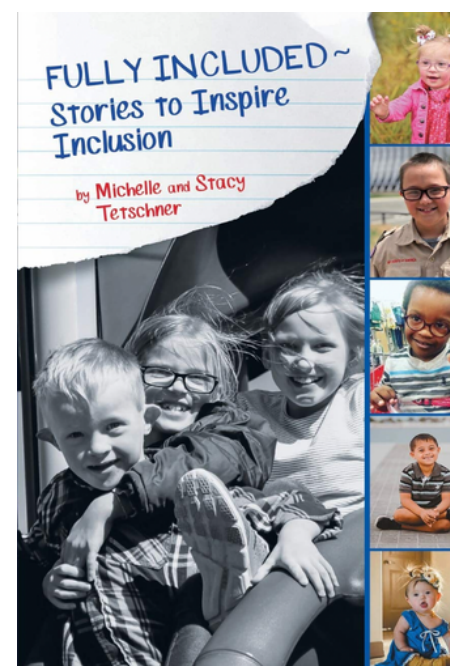
[Parenting 101](#)



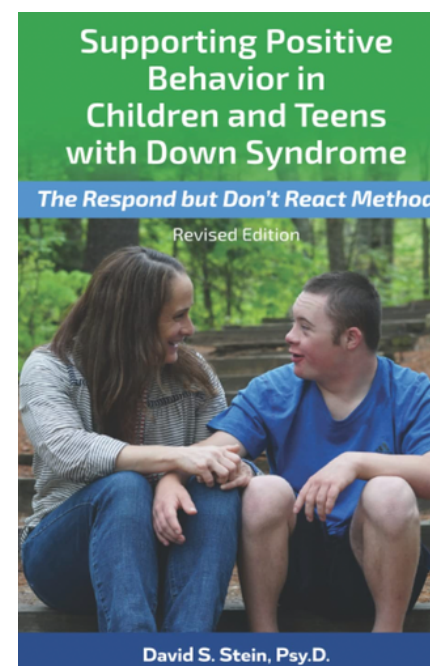
[Essential guide](#)



[My heart can't believe it](#)



[Fully included](#)

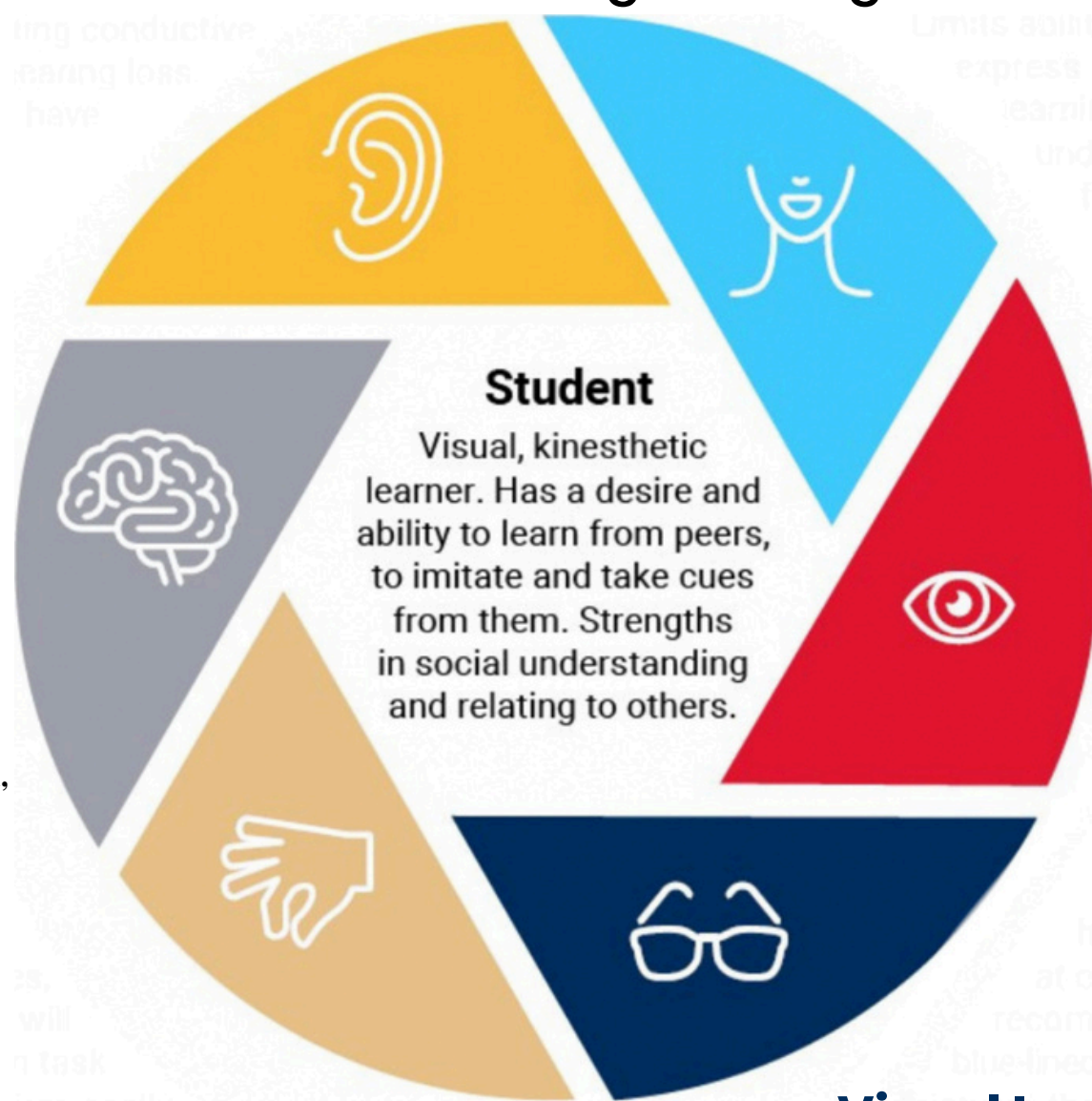


[Positive behavior](#)



# Learning Profile

Children with Down syndrome have a specific developmental profile of strengths and challenges. This graphic summarizes the strengths and challenges associated with the Down syndrome learning profile. Understanding this learning profile will help teachers and families support teaching skills that lead to life-long learning.



## Hearing Impairment

About 80% of preschool children experience fluctuating conductive hearing loss, and around 15% have sensorineural hearing loss. Many continue to have hearing loss during their school years, leading to difficulties with listening to whole-class instruction, understanding spoken language in noisy environments, distinguishing speech sounds, and learning phonics.

## Verbal Memory Weakness

Difficulty learning from listening - maintaining attention, retaining instructions, memorizing sequences, learning new vocabulary and information. Challenges in retaining and consolidating learning into long term memory.

## Speech and Language Delay

Limits ability to communicate. Understand more than can express - knowledge may be underestimated. Will influence learning from listening, processing long sentences, understanding new or subject specific vocabulary, word finding, forming sentences, understanding instructions, reading comprehension skills, thinking and reasoning.

## Visual Impairment

Occurs for all students, to some degree. All children have poor visual acuity (soft focus) and 80% poor focus at close range (up to 10 inches). Bifocals are routinely recommended. Difficulties with: writing using a pencil on blue-lined paper, reading < 18 point font, coping with text/diagrams/pictures that are too cluttered, detailed, or have little contrast.

## Visual Learning Strengths

Ability to learn and use sign and gesture, to learn to read and use written word. Strengths in learning through imitation, from modeling and demonstration. Learns well from visual resources (pictures, photos, diagrams, symbols, concrete materials, digital technologies and apps).

## Delayed Motor Skills

Linked to low muscle tone, loose ligaments and developing motor plans. Affects all physical activities, delays self-help skills and handwriting progress but will improve with practice. May have difficulty staying on task & multi-tasking. Easily distracted by other factors. Tires easily.

Click link to view pdf of learning profile:  
[Learning Profile](#)



## Resources



[NDSC](#)



[DSDN](#)



[GDSE](#)



[NDSS](#)

## Ages and Stages



[Birth to 2](#)



[3 to 5](#)



[Elementary](#)



[Tweens and  
Teens](#)



[Transition to  
Adulthood](#)



[20's and 30'a](#)

## Additional Sources

- [Online guidance courses](#)
- [LP Online: equips participants with knowledge and tools to work effectively with students with Down syndrome in home and school settings.](#)
- [DSE: US and International Education](#)
- [Grandparents Facebook group](#)

