Santa Clara County Office of Education

# A Guide for Supporting Students with Down Syndrome

Strategies Professional Learning Solutions

INNOVATIONS COLLABORATIVE

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# INTRODUCTION

The aim of this toolkit is to provide educators, school staff, and administration tools and information gathered on best practices for supporting students with Down Syndrome in school communities. The toolkit should enable readers to identify best practices to implement in their classrooms and campuses to best address the unique learning profile of students with Down Syndrome.

The Innovations Collaborative believes that every learner has the right to an equitable and inclusive learning community. This toolkit was written with this vision and mission in mind.

The toolkit is based on information gathered from various sources across the globe that have dedicated their work to disseminating best practice for supporting students with Down Syndrome from early intervention through adulthood (post secondary). Links and resources are shared throughout the toolkit.

This toolkit has been created through Santa Clara County Office of Education's Innovations Collaborative.

We hope this guide not only guides best practices in supporting your learners with unique learner profiles, but also gives information and context into the importance of implementing these strategies into the classroom.

# MESSAGE FROM THE COUNTY SUPERINTENDENT OF SCHOOLS

As I reflect on the power of inclusion, I am reminded of my own experiences growing up with my Aunt, who had Down Syndrome. Her vibrant personality, determination, and the joy she brought to our family were profound reminders that every person, regardless of their abilities, deserves to be fully included in all aspects of life. Watching her navigate a world that wasn't always accommodating opened my eyes to the importance of creating inclusive environments, especially within our schools.

At the Santa Clara County Office of Education, we are committed to ensuring that every student has what they need to thrive. We believe in creating safe, inclusive, and equitable spaces for all learners. This toolkit is a testament to that belief, offering resources, strategies, and tools for educators to support students with Down Syndrome and develop environments where all students, regardless of their learning profiles, can succeed.

We understand that inclusion is more than just a practice—it is a mindset that shapes our classrooms, relationships, and communities. We are stronger together when we embrace our diversity and work collaboratively to meet the needs of every student. This toolkit provides guidance on how to create these learning spaces and highlights the benefits of doing so—not only for students with Down Syndrome but for all students.

Thank you for your dedication to our students and for joining us in this mission to make our schools places of acceptance, belonging, understanding, and success for everyone.

Sincerely,

Mary Ann Dewan

**Mary Ann Dewan, Ph.D.**
County Superintendent of Schools
Santa Clara County Office of Education

# HISTORY AND BACKGROUND OF SPECIAL EDUCATION

Beginning with the Brown vs. the Board of Education (1954) court case which ruled for the desegregation of students, parents and families of students with disabilities have fought for a free and appropriate education for their children. In Mills vs. the Board of Education (1972), the case affirmed Brown and found it unconstitutional to segregate students with disabilities from their peers. In the PARC vs. the Commonwealth of Pennsylvania decision, schools were required to provide a free and appropriate education (FAPE) for students with disabilities.

Passed by Congress in 1975, the Education of all Handicapped Children Act (EAHCA) specifically highlights in the federal statutes the segregation and the educational disservice to students with disabilities. EAHCA was amended and eventually became the Individuals with Disabilities Act (IDEA) in 1990. Prior to EAHCA, most children with Down Syndrome were segregated from their peers and were not participating in and receiving appropriate educational services. Many students did not regularly attend school. Since then, IDEA has been revised numerous times to guarantee educational rights to all students with disabilities from birth to age 22. (Ways to Equity Playbook, 2020). In 1989 the court decision of Timothy W. vs Rochester School District led to the zero-rejection policy which states that all children no matter the severity of their disability have a right to FAPE.  In 1982, the Rowley decision created a new definition of FAPE as de minimus which was further clarified in the Endrew F. vs Douglas County School District, wherein the court ruled for a higher standard of FAPE for students with disabilities.

Of particular interest is the court case of Sacramento City Unified School District v. Rachel Holland. Rachel was a student with Down Syndrome who had a history of being placed in a variety of special education settings. Her parents requested that Rachel be placed in a general education setting in her neighborhood school, but the district offered a combination of general and special education settings in a different school not in the neighborhood. Rachel's parents decided to place her in a private school in a general education setting where she did well, made progress on her IEP goals, and required minimal assistance from her teacher. The hearing officer agreed with the parents that Rachel should be in a general education classroom since she benefitted from her interactions with her peers who were not disabled, was not a disruption to the classroom and did not consume an inordinate amount of the teacher's time. In addition, the hearing officer also discussed the cost benefit of placing Rachel in a general education classroom as opposed to the cost of placing her in a special education classroom.

The finding supports the research that students with disabilities generally make progress and if non-disruptive, as was Rachel, do not affect the progress of the non-disabled peers in the classroom.

Resources on Special Education Law and Court Cases:

**History of Special Education**

**Individuals with Disabilities Act**

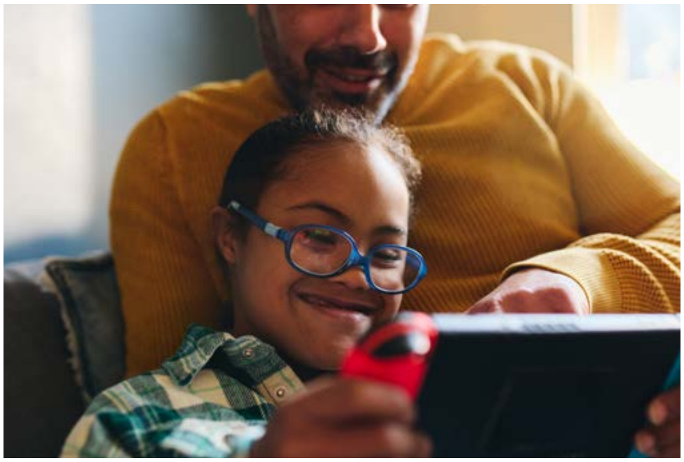
**Parallels in Time: A History of Developmental Disabilities**

**Wrights Case Law**

# WHAT IS DOWN SYNDROME?

Down Syndrome occurs when an individual has a full or partial extra copy of chromosome 21. There are different types of Down Syndrome including Trisomy 21 (nondisjunction), Mosaicism, and Translocation. Trisomy 21 accounts for 95% of all cases of the syndrome and is typically caused by an error in cell division referred to as "nondisjunction." In this process, three copies of chromosome 21 are made instead of the typical two copies. Mosaicism occurs when there is a mixture of two types of cells. Some of these cells contain the usual 46 chromosomes and some contain the typical 47. However, in Mosaic Down Syndrome, the cells with 47 chromosomes contain an extra chromosome 21. This type of Down Syndrome is the least common, and accounts for only 2% of all cases of Down Syndrome. Lastly, Translocation the total number of chromosomes in the cell remains 46, however a full or partial copy of chromosome 21 attaches to chromosome 14 (typically chromosome 14). This variation of Down Syndrome accounts for 3% of all diagnosed cases. While some research suggests differences in the presence of Down Syndrome, features across the different types of Down Syndrome, broad generalizations about these differences is not possible due to the wide range of abilities that people with Down Syndrome have (Facts about Down Syndrome, 2021). The main similarity is the mutation of the 21st chromosome. While much is still not known regarding the cause of the chromosome, research has suggested maternal age (e.g. if the mother is older, there is a higher risk) may increase the likeliness of a child being born with Down Syndrome. It should be noted, there is no current literature that correlates Down Syndrome with environmental factors present before or during pregnancy and Down syndrome occurs across all races and socio-economic levels (Center for Disease Control and Prevention, 2022).

In the United States alone, 1 in every 772 babies are born with Down Syndrome. Every year approximately 5,100 babies are born with Down Syndrome, making it the most prevalent chromosomal condition in the United States (Center for Disease Control and Prevention, 2022).  Due to advances in the treatment and understanding of Down Syndrome, people with Down syndrome are leading longer and healthier lives. However, many still have an increased risk for certain conditions such as heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia and thyroid conditions. Despite these risks, the life expectancy has increased from 25 in 1983 to the 60's in 2022. While every individual with Down Syndrome will present with a wide range of abilities, all people with Down Syndrome experience cognitive delays. Many people with Down Syndrome may also present with delays in speech and language delays, gross and fine motor skills, and behavioral/social-emotional skills. However, through quality educational programs, support across all settings (home, school, community), evidence-based interventions and ongoing positive support from individuals in their environment, people with Down Syndrome are able to live long, fulfilling lives (NDSS, 2021).



Below are health and additional considerations for people with Down syndrome:

### Speech and Language

Difficulties in the following areas: learning from listening, coping with long sentences, understanding new or subject specific vocabulary, word finding; forming sentences; speech articulation, understanding instructions. Weak comprehension skills. Weak generalization, thinking and reasoning.

### Hearing

70% of children experience conductive hearing loss – glue ear. Hearing can fluctuate or be permanently reduced. 15% have sensori-neural hearing loss. More difficulty listening to whole class input and discrimination between similar sounds. Learning and use of phonics can be problematic.

### Strong visual learning skills

The ability to learn and use sign and gesture, to learn to read and use the written word. Learn well from demonstration and visual resources – pictures, photos, letters, diagrams, symbols, concrete materials, ICT.

## Pupil

**Visual, kinesthetic learner. A desire and ability to learn from peers, to imitate and take cues from them. Empathetic and social.**

### Short term auditory working memory

(Listening memory) weak consolidation and retention skills. Difficulty memorizing sequences, retaining instructions, learning new vocabulary and information. Difficulty transferring recently learnt information to long term memory.

### Visual difficulties

For all pupils to some degree. All children have poor visual acuity – soft focus, and 80% have poor focus at close range to 22cm. Bifocals are routinely recommended. Difficulties in the following areas: writing using pencil on faint blue lines, reading font less than 18pt, coping with text/diagrams/pictures which are too busy, detailed or have little contrast.

### Fine & gross motor skills

Associated with low muscle tone/loose ligaments as well as poorer messaging systems. Affects ability to record work, access physical activities and resources. Delayed self help skills

### Short concentration span

Difficulty staying on task and multitasking. More distracted by other factors. Tire more easily.

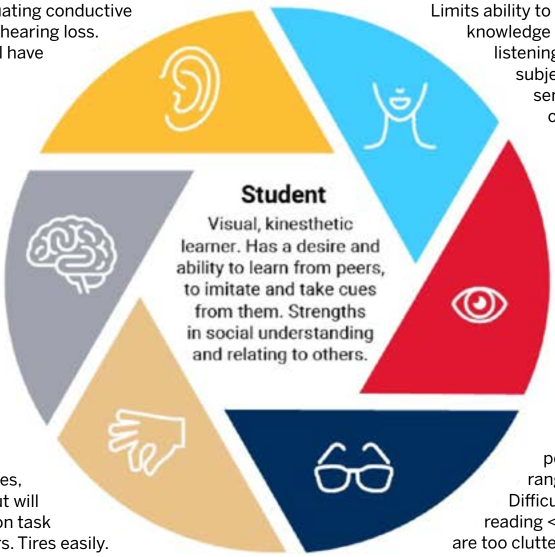
Adapted from the National Down Syndrome Society

# WHAT IS DOWN SYNDROME?

## Health Conditions

- **Congenital heart defects**
  - 40%-50% of children with Down Syndrome
- **Thyroid deficiency**
  - Screened early but may develop at any time
  - Can lead to tiredness and reduced ability to learn
- **Hearing impairments**
  - Up to 80% of children with Down Syndrome are affected by fluctuating conductive hearing loss in early years
  - 40% of children have this issue persist into their school years
  - This sometimes leads to permanent hearing loss and sensory neural losses
- **Vision impairments**
  - 50-80% of children with Down Syndrome wear corrective lenses to correct refractory errors
  - Research has suggested all children with Down Syndrome have visual acuity causing them to see in "soft focus"
- **Sleep difficulties**
  - 30-80% may experience sleep apnea
  - Other sleep difficulties include hard time settling down, night waking, early waking
  - Research suggests sleep difficulties influence both language and cognitive development

## A Unique Learning Profile: Students with Down Syndrome



**Student**

Visual, kinesthetic learner. Has a desire and ability to learn from peers, to imitate and take cues from them. Strengths in social understanding and relating to others.

### Hearing impairment

Some 80% of preschool children experience fluctuating conductive hearing loss with some 15% having sensori-neural hearing loss. For many, hearing loss persists in school years. Will have difficulty listening to whole class input, listening in noisy environments, processing spoken language, discriminating speech sounds, learning phonics.

### Speech & 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.

### 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.

### 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 and multi-tasking. Easily distracted by other factors. Tires easily.

### 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.

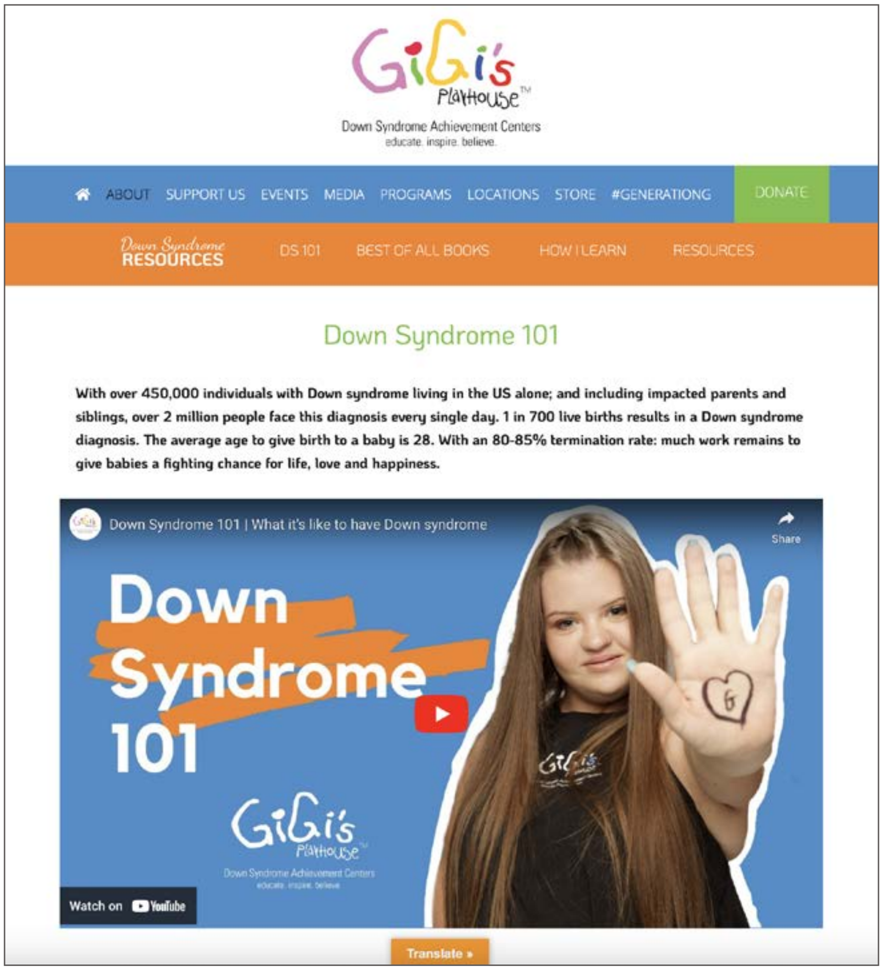
Adapted from *Down Syndrome: Good Practice Guidelines for Education*

## Additional needs: Comorbidities

Around 15-20% of young people with Down Syndrome display additional difficulties. Specific assessment and support are required to meet the unique learning needs of each individual student. Dual diagnosis is increasingly common amongst children with Down Syndrome. This comorbidity includes Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

- **Autism**
  - ASD is prevalent in approximately 16% of individuals with Down Syndrome
  - ASD onset is later than in children without a Down Syndrome diagnosis (age 5)
  - Students with both Down Syndrome and ASD show less social/communication impairment than learners with solely an ASD diagnosis
- **ADD/ADHD**
  - Studies suggest approximately 31-44% of children with Down Syndrome between ages 2 and 15 may show some behaviors that occur in ADHD

## Gigi‘s Voice



Down Syndrome 101

With over 450,000 individuals with Down syndrome living in the US alone; and including impacted parents and siblings, over 2 million people face this diagnosis every single day. 1 in 700 live births results in a Down syndrome diagnosis. The average age to give birth to a baby is 28. With an 80-85% termination rate: much work remains to give babies a fighting chance for life, love and happiness.

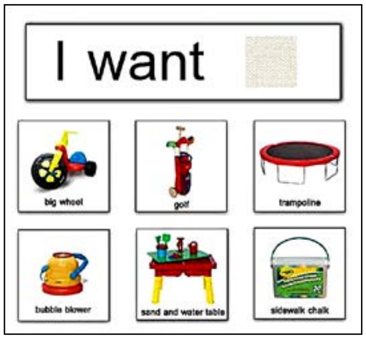
# EARLY INTERVENTION

Early intervention is a systematic multidisciplinary approach for the treatment of a wide range of neurodivergence (e.g. Down Syndrome, Autism, etc.) from birth to three years of age. Knowing the first few years of a child's life are critical to their growth and development. The sooner an individual receives therapeutic intervention(s) the greater the outcomes may be. Under the federal law, Individuals with Disabilities Education Act (IDEA), states are required to provide early intervention services for all who qualify. In California, Early Start, is the early intervention program for infants and toddlers, where families can access the interventions and supports needed until the child turns 3 years of age. For young children with Down Syndrome, physical therapy, speech and language therapy, occupational therapy, and applied behavior analysis (ABA) are the most common early intervention supports and services. The primary goal of early intervention is to build on the child's strengths and accelerate the development of skills that may require more deliberate and individualized support. One of the best features of the birth to three programming, is the support and information it can provide for the families of children with a neurodivergence. Many of the programs will help equip families with the best ways to meet their childs' needs, while also offering a network of support to navigate caregiving to a child with needs. After the child turns three years old, the public education setting (under IDEA), must provide a free, appropriate, public education for pre-school aged children with disabilities (*unless inconsistent with state law*) which will likely include many of the same supports and interventions provided under early intervention. Additionally, some families may continue to seek outside/private therapies in addition to what is provided by the school district.

Below are common interventions/supports for birth to three years of age based on area of need for a young child with Down Syndrome. Additionally, a Developmental Scale (Layton, 2019) for young children with Down Syndrome can also be useful in reference regarding milestones: **Milestones**

## Speech/Language

- **Visual communication strategies (e.g. pictures)**
  - This may include schedules, communication stems with pictures. See examples below:



- **Sign language**
  - Some students learn to first communicate using signs to communicate their basic wants, needs, and desires. The words selected should be a collaboration between family and professional (e.g. SLP) who specializes in alternative modes of communication, such as sign language

- **Object permanence**
  - Knowing an object or person still exists even when they are hidden and you can't see or hear them.
  - Examples of teaching this skill may include:

  - Peek-a-boo, hiding objects under or in a container, covering objects with a blanket and then revealing their existence
- **Oral-motor imitation**
  - Oral motor imitation is the imitation of others' actions that specifically involve the mouth or face
  - Examples of this may include: opening your mouth, blowing bubbles, making a "kiss" face, making raspberry sounds, inflate cheeks, etc.
- **Auditory processing/listenings skills**
  - The ability to detect a sound or to differentiate between sounds, and to tune into one particular sound or noise
  - Examples of how to target this skill may include:
    - Listening to novel sounds
    - Listening to music (and following directions in a song like the "hokey pokey")
    - Listening to a story
- **Supports for speech production skills**
  - Activities to support speech skills should target the discrimination and production of speech sounds, learning to combine sounds (starting with simple consonant-vowel combinations), and then rehearsing whole words (starting with one and two syllable words).
- **Shared reading with peers**

## Behavior and Social development

- **Following simple 1-step directions**
  - Teaching First/Then
  - First/Then
- **Imitation skills (gross motor and vocal/verbal)**
- **Attending to a task (preferred and unpreferred)**
- **Relinquishing items**
- **Visual tools to reinforce positive behaviors**

## Motor

- OT Success in Classroom
- **Support learning mobility skills such as walking, hopping, going from sitting to standing**
- **Toileting**
- **Drinking from a cup**
- **Feeding self with utensils**
- **Getting dressed/undressed**
- **Exploring different items and stimuli (e.g. textures, size, etc.)**
  - Learning to open and close items
  - Picking up and releasing toys of various sizes and shapes
  - Stacking and building with blocks
  - Manipulating knobs and buttons
  - Experimenting with crayons

# UNDERSTANDING DOWN SYNDROME

**Down syndrome is caused by an extra incomplete or full copy of chromosome 21 in a person's cells.** Although the condition cannot be cured, current medical technology and increased awareness have improved the quality of life of people with Down Syndrome. Yet low awareness and misconceptions about Down syndrome still abound, despite its being the most prevalent of all chromosomal conditions. When parents receive a Down syndrome diagnosis during pregnancy or after birth, they are sometimes unaware that their child can lead a happy, active life.

**~6000** **born** in US **annually**

**2/3** **aborted** after prenatal diagnosis

**1 in 30** **mothers 45 or older** conceive a baby with Down syndrome

## Despite misconceptions, many people with Down syndrome

- have **romantic** relationships
- attend **college**
- have a **career**

*Down syndrome is associated with greater risk for various conditions, many of which are treatable with modern medicine, including:*

- hearing/ear problems
- heart problems
- Alzheimer disease
- vision problems
- celiac disease
- obstructive sleep apnea

"retarded"

"suffering from Down syndrome"

"normal"

"intellectual disability"

"child with Down syndrome"

"typically developing"

## Public Figures with Down Syndrome

**Angela Bachiller**

Elected councilwoman in Spain in 2013, Bachiller is a hardworking advocate for citizens with disabilities, including for their right to vote.

**Lauren Potter**

Lauren played Becky Jackson, a character with Down syndrome, on *Glee* from 2009-15. She is a public voice against the word "retarded."

**Pablo Pineda**

Born in 1974, Pineda became the first college graduate with Down syndrome. He is also an award winning actor, TED Talk speaker, and author.

**Sources:**
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# PRESCHOOL

After early intervention services, many children with Down Syndrome will enter preschool programs provided by their local public schools. Depending on how much progress a child made during the intensive early intervention programs, the child's preschool experience could look different based on each learner's unique profile. Many children will still need support with their communication (sign language, vocal language, images, etc.), and many children with Down Syndrome will continue to need support with their muscle strength, coordination, motor planning, and following the behavioral expectations of being in a classroom (e.g. learning to learn skills). The goal of preschool should also be to target skills that will increase each child's success in an inclusive kindergarten setting.

Below are common interventions/supports for birth to three years of age based on area of need for a young child with Down Syndrome. Additionally, a Developmental Scale (Layton, 2019) for young children with Down Syndrome can also be useful in reference regarding milestones: **Milestones**

## Speech and Language:

- **Speech and Language Activities**
- **Comprehension (understanding, receptive language skills)**
  - Children with Down Syndrome often need new concepts and information repeated up to 200 times more than a typically developing child. In a fun and playful way, encourage students to repeat sounds, words and concepts as much as possible.
  - It is critical to provide ample wait/processing time
  - Teaching Reading to Students
- **Concept development**
  - See the Concept Development guide for ways to enhance critical thinking skills and a deeper understanding of concepts
- **Semantics (vocabulary)**
  - Repetition and prompting
  - Use of visuals (visual depiction or picture card of the word)
  - Teach items categorically
    - "Which items go together?" → while showing an image of a spoon and a fork

- **Morphosyntax (grammar and word parts)**
  - Use repetition
  - Incorporate visual representation of target words
- **Pragmatics (social language in daily living)**
  - Practice and role play with the learner
  - Watch clips of age-appropriate social skills to model appropriate social language
- **Oral motor skills**
  - Strengthening the jaw and facial muscles
  - Repeating and imitating sounds
  - Tactile movements using the tongue and moving the lips
- **Expressive language skills**
  - Turn taking skills
- **Attending and regulation/sensory integration**
  - Visual skills looking at the speaker
  - Listening to music and speech
- **Pre-literacy skills**
  - Make the most of visual cues
  - Multi-media tools can be especially helpful. Use graphics and video, colors, and shapes
  - Break teaching into small chunks of activity
  - Take frequent breaks and don't rush back to teaching
  - Be sensitive to the pace students respond to best
- **Lesson plans that support learning to speak**
  - Learning to read
  - Whole word approach with word matching
  - Selecting
  - Naming
- **Create a language rich environment**
  - Model language
  - Narrate what is happening
  - Use repetition to increase imitation of word

## Behavior and Social development

- **Learning about emotions and practicing regulation tools**
  - Brain Break Visuals
- **Clear expectations displayed visually (e.g. visual schedule, first/then chart)**
  - Visual Schedule Ideas
- **Providing positive reinforcement (e.g. verbal praise) for appropriate behavior**

- **Practicing social skills**
  - Sharing
  - Taking turns
  - Entering a group of students
  - Play skills (e.g. engaging with the group versus parallel play)
- **Short and explicit directions (e.g. “come here,” “stand up,” etc.)**
- **Creating predictable environments (e.g. daily schedule, repetition)**
- **Prime for transitions or changes in routine (i.e. “in 3 minutes we’re going to clean up”)**
- **Stay calm and neutral with tone and facial expressions**
  - Children with Down Syndrome can be very sensitive to negative emotional cues

## Motor

- OT Success in Classroom
- **Support learning mobility skills such as walking, hopping, going from sitting to standing**
- **Toileting**
- **Getting dressed/undressed**
- **Exploration of different items and stimuli (e.g. textures, size, etc.)**
  - Learning to open and close items
  - Picking up and releasing toys of various sizes and shapes
  - Stacking and building with blocks
  - Manipulating knobs and buttons
  - Experimenting with crayons
- **Holding crayons/markers/pencils**
- **Drawing (including scribbling)**
- **Coloring**
- **Stacking items**
- **Holding a scissor/cutting**
- **Tracing**

# ELEMENTARY

By now, many children have been in a preschool setting for 1-2 years, with many students still receiving a wide range of interventions/supports in the home and clinical setting. Kindergarten provides an opportunity for children with Down Syndrome to be in an inclusive environment amongst general education peers. This provides ample opportunities for students to imitate language, play skills, and learning skills needed to best access the kindergarten environment. After kindergarten, many students will be equipped with the skills needed to meaningfully participate in their elementary education. Teachers and administrators may find themselves needing to re-invent what the classroom, materials, curriculum, and pedagogy looks like in order to differentiate the academic expectations in a manner that will enhance learning outcomes for our learners with Down Syndrome. Many children with Down Syndrome will continue to receive specific individualized services through their IEP such as speech and occupational therapy, but the classroom environment is just as valuable for our learners to be able to develop critical social, behavioral and emotional skills.

Below are some examples of supports and strategies that may be helpful in increasing outcomes for our elementary-aged learners. A Developmental Scale (Layton, 2019) for young children with down syndrome can also be useful in referencing milestones: **Milestones** (up until age 6)

## Speech/Language

- **Vocabulary expansion**
- **Continued exposure to reading and literacy instruction**
  - Whole word approach
  - Match-select-name methodology
- **Teaching phonics**
- **Selection of books with familiar topics/themes**
- **Literacy lessons with typical developing peers (avoid grouping with younger students)**
- **Use of alternate response methods (point, sign, choose, draw, etc.)**
- **Social skills training**
  - Conversation skills
  - Entering and leaving play/engagement with peers
  - Social pragmatics (social use of language)
  - Developing and maintaining friendships
  - Visual mapping
- **Development of self-advocacy skills**

## Behavior and Social development

- **Continued use of visual supports (e.g. schedules, charts, etc.)**
- **Use of emotional regulation strategies**
- **Use of Behavior Skills Training (BST; Kumalasari & Kurniawati, 2018) to teach personal safety skills**
  - Behavioral Skills Training includes four steps to teaching new skills which are: Introduction, Model, Rehearse, and Feedback
  - Behavioral Skills Training

***Similar suggestions as mentioned above:***

- **Short and explicit directions (e.g. "come here," "stand up," etc.)**
- **Creating predictable environments (e.g. daily schedule, repetition)**
- **Prime for transitions or changes in routine (i.e. "in 3 minutes we're going to clean up")**
- **Stay calm and neutral with tone and facial expressions**
  - Children with down syndrome can be very sensitive to negative emotional cues

## Motor

- **OT Success in Classroom**
- **Writing support**
  - *May be appropriate to use voice to text versus writing to improve access to general education setting*

# MIDDLE SCHOOL

Middle school brings an exciting time for a child's growth and development. Middle school provides an opportunity for children to become more independent, become more socially connected to their peers, and have access to a wider range of learning opportunities that are typically not offered during elementary years. At this age, children are becoming more aware of what is happening in the world around them, which provides abundant opportunities to find ways for students with Down Syndrome to come into contact with meaningful learning opportunities that foster growth in a wide range of areas.

Schools will want to consider the following:

- **Using strategies to develop and promote independent navigation of school setting**
  - Use of visual supports, repetition, and modeling may support this
    - Visual supports supporting adaptive living and self-care
      - Visual ideas
  - Safety Skills through the use of role play and rehearsal may also be appropriate during this time (Kumalasari & Kurniawati, 2018)
      - This may include practicing how to walk across the street, what certain signs in the community mean (e.g. stop, yield, cross walk, etc.) or hazardous/harmful signs (e.g. poison)
- **Full inclusion with general education classrooms**
  - Promote increased language
  - Literacy acquisition
  - Grouping by age based on *chronological age – not ability*
- **Identified times of day/week where students will receive individual/small-group support. Areas may include:**
  - Writing skills
  - Reading skills
  - Specific speech/language
  - Vocabulary building
  - Social skills

# HIGH SCHOOL

As students with Down Syndrome transition into high school it is important to balance their academic, social, and vocational needs. The authors of *High Leverage Practices and Students with Extensive Support Needs* (Pennington, Ault, Courtade, Jameson, and Ruppar, 2023) and the authors of *High Leverage Practices for Inclusive Classrooms* (McLeskey, Maheady, Billingsley, Brownell and Lewis, 2022) stress the need to use practices that support the student in attaining their goals. These are the same types of practices that will assist students with the transition into adulthood and post-secondary programs. It is during this time that the focus is on getting the student to be college and career ready.

The Council for Exceptional Children outlines 22 high leverage practices that should be used when working with students with extensive support needs and for supporting inclusive practices. These practices should be used throughout the student's academic career and many can be used throughout their life. Since there is so much variability of ability with students with Down Syndrome there is not a set program that can be uniformly implemented for every student. The high leverage practices are designed to address the individual student's needs as they progress through their educational career. In this section of the toolkit several of these practices will be discussed.

When thinking about the participation of the student in high school and in the community, the social component is one of the most important. High school offers the student numerous opportunities and activities in which to be involved. In order to support the student in this area it requires a number of people collaborating to create a program that addresses the student's support needs. Collaboration amongst educators, support providers, the student, and family is essential for success (McLeskey et al., 2022; Pennington et al., 2023). When working with students with support needs and their families, educators need to be mindful and reflect on their own identities and any biases that they may have regarding the students' and families' backgrounds (e.g., income, race, ethnicity, gender, culture). When educators are aware of their own identity and how it may impact their interactions with students and families it allows for more meaningful and inclusive exchanges in meetings and communications (Francis and Howard, in Penington et al., 2023). This is also the time when human growth, sexuality and social relationships are important to address. It is essential that students understand the different levels of intimacy and relationships so that they are safe and maintain healthy relationships.

Collaboration between the case manager and the general education teachers provides opportunities for adapting and modifying the curriculum for the student. Co-teaching allows the student to have access to their non-disabled peers while accessing the core curriculum. Collaboration should take place before, during and after IEP meetings and should allow the student to participate as a member of their IEP team. If possible, students should lead their IEP meetings or at a minimum should speak about their long-term goals and interests. For students who have difficulty with printed text, icons can be used to scaffold the agenda. In *High Leverage Practices* in the chapter on leading effective IEP meetings, the authors give an example of an agenda that can be used to prompt the student during the IEP meeting (Francis and Howard in Penington et al., 2023).

# HIGH SCHOOL

Mullan, Prendeville, and Kinsella (2018), investigated the behaviors that were indicators of a successful transition from elementary to secondary school. The authors interviewed parents and teachers of transitioning students with Down Syndrome and found that communication and 'the balancing act' (e.g., fears and expectations, managing resources and making choices) were the two main themes in the study. Communication consisted of role identity, preparation for transition, getting to know the student, parents and schools as partners, and agency linkages. The study stresses the need for schools and parents to fully prepare the student for the transition to high school by working on organizational skills and as part of successful inclusion taking the student's social skills into consideration. The use of multiple sources of information to create a Student Learning Profile will assist in the student's teachers having a better understanding of the student and support the smooth transition from middle school to high school. The learner profile should be updated each year or as information changes for the student (McLeskey et al., 2022).

During this time the student should continue to learn, practice, and refine social communication skills. Educators should intentionally teach social communication behaviors to students that are age appropriate and strive to have them generalize across several settings. Building self-advocacy skills at school, home, and in the community serves as the foundation for better post-secondary outcomes. Mullan et al. (2018) discuss that students with disabilities are often 'on the outside' socially and do not necessarily fit in with their peers at school. In the two High Leverage Practices books (2022 and 2023) the authors stress the need for students with disabilities to be instructed in social behavior skills in order to be successful in an inclusive environment.

Schools, students, and families will want to consider:

- **Adapt curriculum tasks and materials for specific learning goals**
  - Choose one strategy at a time
  - Explicitly teach students how to use the strategy
  - Use resources from general education
  - Allow for varied response methods
  - Use Assistive Technology
- **Full inclusion with general education classrooms**
  - Promote increased language
  - Literacy acquisition
  - Heterogeneous grouping
- **Provide intensive and direct instruction in small group and individual settings. Areas may include:**
  - Writing skills
  - Reading skills
  - Specific speech/language
  - Vocabulary building
  - Social skills
  - Elective classes
- **Begin the transition process with an eye towards college and career readiness**
  - Development of the Individual Transition Planning in the IEP process
  - Address post secondary goals
  - Employment goals

  - Independent living goals
  - Transition Planning the Basics CA Transition Alliance
  - Workability
  - Video – College for People with Disabilities-Yes, it is Possible
- **Developing Self-advocacy**
  - Self-advocacy is an important skill for students. Students with strong self-advocacy skills are better equipped to understand and participate in their education and their future adult life. The Pacer Center has specific materials and resources that support the student with the transition from high school to adulthood.
  - Pacer Teens and Young Adults
- **Create, collaborate, and share Student Learner Profiles**
  - The use of Student Learner Profiles supports the student both inside and outside of the formal educational setting. The profile considers not only the academic skills of the student but addresses the social and behavior skills of the student and their desires and goals for the future.
  - An Educator's Guide to Learner Profiles for Students
  - Knowledge Works Learner Profiles
- **Develop a process and hold student led IEPs**
  - I am Determined Student Led IEPs
  - Twin Rivers Learning Institute Student Led IEPs
  - Parents Helping Parents Student Led IEPs
- **Address age appropriate social skills, relationships, human development and human sexuality**
  - Parents Helping Parents: Let's Talk About Sex
  - Circles Intimacy and Relationships

# POST-SECONDARY

Post-secondary programs provide the student with numerous opportunities to practice and learn new skills across different settings in the community. During this time students may attend classes at the local college, engage in employment, and participate in the community. Outside agencies collaborate with families and districts to provide a smooth transition into the adult world after the post secondary program is completed.

Person centered planning  at this stage offers the opportunity for self-advocacy and looking to the future for the student. Using person centered planning focuses on the individual's skills, interest and strengths and requires that they be involved in the planning and development of their goals (Sue Sawyer, CA Transition Alliance). This builds upon the transition planning from the high school and acts as the bridge to adulthood.

Depending upon the assets and skill set of the student there are agencies that will collaborate with the post-secondary programs, students and families to support the student in education, employment and their adult living situation. The Department of Rehabilitation (DOR) works with students with mild to moderate support needs between the ages of 16 and 21 who are seeking employment. The regional center works with individuals who require extensive support and continues to work with them into adulthood. They will work with the adult and their families to prepare the Individual Program Plan.  Milestones Autism Resources, a group that works with students with autism and developmental delays, has an Autism and Developmental Delay Adult Checklist to support students and families with the transition process from the school district into adulthood.

Schools, students, and families will want to consider:

- **Resources that inform and assist students and families in post-secondary transition planning for college and career**
  - CA Transition Alliance
  - Pacer Students and Young Adults Transitioning to Life after High School
  - National Technical Assistance Center on Transition
  - Transition Coalition
  - Pacer National Parent Center on Transition and Employment
  - Pacer Training and College Opportunities after High School
- **Agencies that support students and families with post-secondary transition and services for college, career and independent living**
  - DOR Department of Rehabilitation
  - San Andreas Regional Center
  - Disability Rights California
  - Social Services
  - Parents Helping Parents Connections to Adulthood
  - Independent Living Empowerment Project

**Welcome & Keynote**

100 Lessons You Can't Learn From a Book: The Impact of Inclusion

# EDUCATIONAL IMPLEMENTATION CHECKLIST (ALL AGES)

## Teaching approaches/lessons

- ☐ Individualized to each learners' unique learning profile
- ☐ Differentiation of instruction including accommodations such as:
  - ☐ Chunking of tasks
  - ☐ Less work presented on the page
  - ☐ Visual representation of material
  - ☐ Alternative methods of response (sign, write, have a scribe, dictate, draw, etc.)
- ☐ Clear and explicit directions and expectations
- ☐ Have students take responsibility for their own learning
- ☐ Learning reflects the consideration of all needs as stated in IEPs, related services, etc.

## Organization of the learning environment and supports

- ☐ Inclusive environment where learners are with groups of students without disabilities
- ☐ One-on-one setting used for individual services or support areas (e.g. speech, OT, social skills group, etc.)
- ☐ Supplemental instruction provided in addition to time spent in core content areas, ***not in place of it***
- ☐ Flexible work environments offered and used in lieu of hallways:
  - ☐ Classrooms
  - ☐ Study rooms
  - ☐ Library
- ☐ Classroom organized in a manner that supports independent learning
  - ☐ Consistent schedule
  - ☐ Repetition of routines
  - ☐ Visual supports
- ☐ Students learn collaboratively with peers
- ☐ All classroom support are made aware of lessons and homework prior to being taught to best assist in learning experience
- ☐ Time allocated to making appropriate resources for differentiation of the instruction

## Essential Requirements and Interventions

- ☐ Staff trained in specific learning profile and evidence based approaches to inclusive instruction
- ☐ Support team aware of evidence-based interventions provided by district
- ☐ Speech and language assessment and intervention
- ☐ Occupational therapy assessment and intervention
- ☐ Physical therapy assessment and intervention
- ☐ Functional behavior assessment (FBA; if necessary)
  - ☐ Recommendations in line with the discipline of Applied Behavior Analysis (ABA); it may be appropriate for some learners to receive ABA treatment in the school setting
- ☐ Assessment and intervention to address vision and hearing impairments
- ☐ Assessment to identify additional needs (such as assistive technology) and sensory processing issues
- ☐ Educational resources, accommodations and modifications specified in the IEP that enable student to access general education curriculum
- ☐ Differentiation of instruction
- ☐ Additional staffing within schools to enable focused learning and participation under the direction of teachers, director of special education and related service providers
- ☐ Access to supports and services for bilingual learners and english language learners (ELL) should there be bilingual students with Down Syndrome

# PARENT RESOURCES

**Lynda is a phenomenal parent, educator, and advocate. Lynda was asked to share a bit about her daughter, Cassie, what her educational experience encompassed (including challenges), her perspective on education for individuals with Down Syndrome and future hopes and dreams for her daughter. This is what she had to say:**


***Lynda Wootan and her Daughter, Cassie***

Cassie is an exuberantly spirited, determined and fiercely independent red headed girl. She has her own ideas about how she wants things to happen in her universe and has an uncanny ability to make them reality. These character qualities are the essence of why she is alive. She was born with her umbilical cord wrapped tightly around her neck twice, in respiratory distress, life threatening heart issues, the list goes on. So began our journey in unchartered waters. She spent the first three weeks of her life in the NICU, fighting to triumph over her medical issues. During this time, my prayer was that she would live and be able to smile at me. Her having Down Syndrome was not my primary concern. In many ways, her medical fragility made accepting Down Syndrome more manageable by putting things in perspective.

Cassie loves people and animals, singing, dancing, coloring, looking at magazines, taking road trips, eating and drinking diet coke. Cassie is very ritual oriented and has "routines" that she carries out daily. She insists on doing most everything independently. Social niceties that most people find helpful and courteous like opening a car door, or helping clean up after a meal she objects to will often lead to her announcing, "do it myself." She even gets annoyed when someone says "bless you" after she sneezes, again,"I'll do it myself".

Cassie attends an Adult Day Program 4 days a week for several hours a day. Her program offers a variety of activities and community outings. The staff are some of the most caring humans I have met, and feel like a family. She volunteers two mornings a week: one at a Therapeutic Horseback Riding program and another doing farm chores at Animal Assisted Happiness. She is also passionate about going to the dog park as many times a week as possible, even though we do not have a dog. She has made many dog and human friends there. Socially, her program, volunteer opportunities, and interactions at the dog park provide her with the opportunity to develop skills that build a strong foundation for her future. Most importantly, all of her activities are based on her love and passion, happiness is always first.

Cassie's best qualities include being friendly, social, independent, good at following routines (the ones she chooses), helpful and having strong leadership skills. She is also willing to work hard for something she cares about and always finishes what she starts. She has an incredible memory, especially for people and animal's names and events that happened long ago. Cassie is great at modeling what she sees. She can learn dances and physical routines with ease. This also goes for the undesirable things she witnesses, which she is equally adept at modeling.

Her challenges, (more accurately my challenges) are being extremely self-directed, having no concern for time or timing of events/deadlines. She is slow moving even in an emergency situation. Her own internalized routines and sense of order rule. She is also rather self-centric and has difficulty with transitions/change.

Cassie's school days were times of highly focused advocacy, educating and researching, relationship building, collaboration and soul-searching. I learned a lot about myself, my values, my ability to advocate for what we needed. I developed a strong sense of tenacity, out of the box thinking and problem solving skills. I learned to laugh in the face of "NO!" What I learned about educational settings was that there is no such thing as "the" way. I looked at general and SDC classrooms during Open Houses in the spring of each year. This allowed me to see programs without having a district person accompany me, and I could see many options in a single evening. I visited Homeschooling organizations and met students that were participating. I attended conferences and talked to many parents about what their experiences were in the educational realm. Most importantly, I met the students with Down Syndrome themselves and interacted with them. What I learned is that no setting (SDC/Homeschool/Private/Public SDC/Organized Homeschool organization) is specifically superior to another. Parents need to follow their hearts and do what is best for their individual child and their family system, considering their students strengths, needs, likes and interests. Also, we must keep in mind the result we are hoping to attain. For us, it was not about academic mastery, it was about real world navigation and function, and most of all happiness. The student that I met that I was most impressed by, who had amazing social skills was a 14 year old boy. He had been part of a Homeschooling organization for his educational experience. Later in the evening the night I met him, he received an award for accomplishing a goal that had taken many years to master: he could count to 14! This had a very big impression on me. I know that this young man will be happy in his life, because he knows how to be with others.

I had to make the best choices I could each year as Cassie developed to ensure that her needs were met. Her Preschool years were spent in a Parent Co-op Preschool (that both of her brothers attended) three sessions a week and a Moderate Severe SDC class three mornings a week. The Co-op was developmentally based and NAEYC accredited. It was primarily free choice play, art, making snacks each day independently with visuals to support each step, access to sand play, painting, books and anything else one could want. I accompanied her as her "aide." She was exuberant, had limited verbal skills and could be overly physical in the right situation. She was the first child with Down Syndrome to attend this program. She taught everyone a lot, teachers, parents, students and me!

During this time, she made her first real friend. He was the boy that slapped the teacher in the face one day when he was particularly frustrated. At the time, I naively thought to myself he would be someone we should avoid. Fast forward to a field trip at Vasona. For whatever reason, Cassie went up to this boy and slapped his face. He looked at her and promptly slapped her back, and then he announced, "you slapped me and I slapped you and now we are friends forever." They hugged, he grabbed her hand and they held hands for the rest of the field trip and all the way back to the cars. After that, he always looked for Cassie at school. He would pull her pants up (they were always sliding down), included her in his play, boosted her up when she wanted to walk on the benches and even invited her to his birthday party. I learned a lot from him - to never judge (the suitability of a playmate or) anyone else by their actions. Many times these passionate people are the ones who "get it," and make fabulous friends. The SDC class had a very loving teacher and was a very small group of children. She was well loved there, and I kept in close contact with all of the staff that worked with her. My only goal was for her to have fun and meet/work with new people.

There were definitely plenty of challenges dealing with Cassie's educational services. I made it my mission to educate myself on all things special education services by attending Wrights Law conferences, PHP seminars, and anything else I could find, including speaking with seasoned parents. I went to the annual NDSC and NDSS conferences and read books and assorted literature on Down Syndrome. I bought every book I could find on the development and education of people with Down Syndrome (actually I bought 2 of every book).I was fortunate to be a full time mom at the time and could invest time and money in my efforts. Perhaps the most difficult part of the process was deciding what to do and what not to do. There are so many potential therapies - OT, PT, Feeding, Speech, Oral Motor, Hippotherapy, animal therapy, music therapy, etc. I researched what was out there and then took some time to decide what I wanted our lives to look like.

The next pivotal step in our journey was writing a "vision statement" about what I wanted for Cassie in her life. My personal hope for Cassie is that she will be a happy and well-adjusted person, who carries her childlike passion for life with her wherever she goes. I wish for her rich and satisfying relationships with others, and the ability to communicate her thoughts, needs, and ideas freely. I hope that she will have the skills to pursue her passions, whatever they may be and that she continues to shine her bright light on the world. Above all, I was a parent of 3, not 1, and I wanted to have a balanced life and be involved in all three of their lives. We chose to do the activities that Cassie loved and that provided interaction with people she could build relationships with. I always found a teenager or young adult who I would hire to hang out with her and be her "friends". This brought us all an enormous amount of joy. She would do all sorts of activities with these friends such as swimming, cooking, hanging out with animals and with their friends' social circles. While Cassie received her educational services primarily in the SDC setting, she had many rich "inclusive" experiences in her daily life. These opportunities also provided many people who had no life experience with a person who had Down Syndrome a chance to have this life changing experience. She went to many of her brother's sporting events and was part of many team meetings, usually sitting front and center.

For more information regarding Lynda and her families journey, visit: **Anything is Possible**

## Parent Resources

- California Department of Education Resources for Family Involvement and Partnerships **(https://www.cde.ca.gov/sp/se/fp/)**
- Family Resource Networks of California **(https://frcnca.org/)**
- Gigi's Play House
- Pacer Champions for Students with Disabilities **( https://www.pacer.org/)**
- Parents Helping Parents **(https://www.parentshelpingparents.org/)**
- Understood **(https://www.understood.org/)**

# RESOURCES

## Websites

- CAST About Universal Design for Learning
- Inclusive Schools Network (https://inclusiveschools.org/#)
- National Down Syndrome Society (https://www.ndss.org)
- Down Syndrome Connection of the Bay Area (https://www.dscba.org/)
- Down Syndrome Education (https://www.down-syndrome.org/en-us/resources/)
- Down Syndrome Information Alliance (https://downsyndromeinfo.org/)
- Down Syndrome Affiliates in Action (https://www.dsaia.org/)
- Special Education Rights and Responsibilities (https://serr.disabilityrightsca.org/)
- Supporting Inclusive Practices (https://www.sipinclusion.org)

## Videos

- High Leverage Practices

## Learning Modules

- IRIS Modules
- MAST Person Centered Plans for Education
- Inclusive Schools Network Inclusion Basics
  (https://inclusiveschools.org/Course%20HTML%20Files/InclusionBasics/story.html)

## Books

- James McLeskey, Lawrence Maheady, Bonnie Billingsley, Mary T. Brownell, Timothy J. Lewis (eds). *High Leverage Practices for Inclusive Classrooms*. Routledge.New York. 2022
- Robert Pennington, Melinda Ault, Ginevra Courtade, J. Matt Jameson, Andrea Ruppar (eds). *High Leverage Practices for Students with Extensive Support Needs*. Routledge. New York. 2023

# CLOSING REMARKS AND FUTURE DIRECTIONS

Our hope in reviewing this guide, is that educators and caregivers will feel more equipped to support the unique learning needs of students with Down Syndrome in your classrooms. As demonstrated throughout this guide, learners with Down Syndrome have limitless potential and oftentimes can have the same expected outcomes as their neuro-typical peers.  While information is available, there appears to be a dearth of  resources and tools for learners with Down Syndrome when compared to other neurodivergent populations. Given the prevalence of Down Syndrome in the United States, toolkits such as this one, are needed to ensure people with Down Syndrome are given equitable and inclusive learning opportunities. Schools and educators are in a unique position where they can drastically improve the trajectory for learners with Down Syndrome by cultivating compassionate learning communities infused with the evidence-based best practices to meet each student's needs.

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