
DOWN SYNDROME:

Guidelines for Inclusive Education

DECEMBER 2021

down syndrome
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For Roberta Buckley

In life you inspired those around you to consider new ways to improve education for people with Down syndrome and take action in the classroom. May your legacy be to inspire the next generation – and every next generation – of educators to do the same.



Acknowledgements

These guidelines draw on recommendations developed by an expert working group of a United Kingdom All Party Parliamentary Group on Down Syndrome (APPGDS), first published by the APPG in 2012.¹ The report is available at: <https://go.dselink.net/appg-education-report>

The National Down Syndrome Society (NDSS) and Down Syndrome Education International (DSEI) assembled a working group to adapt the APPGDS recommendations for the U.S. early intervention, preschool and school systems. The Guidelines Working Group includes several members of the NDSS Inclusive Education Task Force, a group of volunteers with a range of expertise and experience, dedicated to improving the lives of individuals with Down syndrome through the promotion of inclusive education.

NDSS extends our most sincere thanks to all those whose tireless efforts have made this resource possible, especially the esteemed members of the Guidelines Working Group:



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Justin Gilbert obtained his law degrees at Southern Methodist University (J.D.) 1993 and the University of Edinburgh, Scotland (LL.M.) 1994. He has focused on education and employment law. He has devoted substantial time to improving the lives and public school conditions for children with disabilities, including children with Down syndrome.

The **National Down Syndrome Society** (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities. Founded in 1979, NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming: Resources & Support, Policy & Advocacy and Community Engagement. NDSS engages in various activities and programs that provide support, informational resources and community engagement opportunities for individuals with Down syndrome and those who support them.

Down Syndrome Education International is a leading international research and support organization dedicated to raising levels of educational achievement among children with Down syndrome. Over the past 40 years, the charity has supported research into the children's specific learning needs and more effective teaching approaches and worked to disseminate evidence-based guidance and practical advice to families and professionals worldwide. By advancing evidence-based practice, Down Syndrome Education International leverages substantial public and nonprofit sector investments in early intervention and education services. Each year, the charity helps over 120,000 families, teachers, therapists, schools, nonprofit and government service providers in more than 170 countries to provide more effective support to young people with Down syndrome.



Contents

Executive Summary

7

General Introduction

9 Why action is needed to address the education of students with Down syndrome

9 What this guidance covers

10 A note about terminology

Section 1: A Call to Action for the Congress of the United States and the United States Department of Education

12 Foreword: Recognize the unique developmental and educational needs of young people with Down syndrome

13 Recommendation 1: Ensure effective planning and monitoring for this population of students

13 Recommendation 2: Develop substantive guardrails to ensure that programs serving young people with Down syndrome are grounded in evidence-based practices

13 Recommendation 3: Disseminate resources to help educators understand the learning profile of youth with Down syndrome

14 Recommendation 4: Develop evidence-based guidance on Down syndrome service delivery for educational professionals

14 Recommendation 5: Protect access to related services for students with Down syndrome

15 Recommendation 6: Recognize and meet the need for additional classroom personnel

Section 2: Down Syndrome: A Specific Profile of Strengths and Challenges Requiring Specific Interventions and Responses

17 What is Down syndrome?

17 How many young people have Down syndrome in the United States?

17 How does having Down syndrome impact learning and development?

18 The specific developmental profile associated with Down syndrome

22 The effects of health issues and additional diagnoses on development

25 Responding to challenges

26 Improvement and expansion of opportunities for inclusion in schools

27 The right to inclusive education in the United States

28 Legal rights to be protected and strengthened

Section 3: Principles for Effective Educational Practice for Youth with Down Syndrome

30	Staff training
31	Effective related service supports to schools
32	Achieving effective inclusive practices with support from administration
32	Issues for schools and other educational settings
37	Implementation of specific strategies to support learning
42	Checklist to evaluate implementation
44	Age- and grade-level best practices
-- 44	Recommended best practices in early intervention and preschool (birth to age 5)
-- 47	Recommended best practices in elementary and middle school
-- 50	Recommended best practices in high school
-- 55	Postsecondary education and training
57	Conclusion
58	References
67	Resources
70	Appendix A: American Legal History of Exclusion

Executive Summary

Improving evidence-based practice

This document aims to improve the development and educational outcomes for individuals with Down syndrome from birth to adult life by providing educators, therapists, early interventionists, parents and school districts with a guide to evidence-based practices.

Leading long and fulfilling lives

There are an estimated 5,200 live births of babies with Down syndrome in the United States each year and an estimated total population of around 214,000 Americans with Down syndrome. In recent decades, the median life expectancy for an individual with Down syndrome has increased to around 58 years. These individuals have a right to effective services, to being included in their communities and to continuing education that will help them reach their potential and lead meaningful, productive adult lives.

We have a knowledge base

Development for all children is a dynamic set of processes that unfold over many years. It is not fixed at birth but is influenced by biology, family environment, community, education and opportunities to learn. The same is equally true for babies, children and youth with Down syndrome. Research over the past 40 years has shown us the ways in which having Down syndrome may impact learning and development. When we understand these differences, we can design more effective interventions and educational strategies to support students with Down syndrome. We have evidence that adapting interventions and teaching to this specific learning profile improves outcomes.

Inclusion matters

We have also learned more in recent years about how development and learning is influenced by all interactions that children have with other children, family members, educators and the wider community. This is equally true for individuals with Down syndrome. Living with families rather than in institutions and being welcomed in communities has transformed lives. The



education systems in most countries have been the slowest to change, yet all the published evidence shows that children with Down syndrome achieve more when they are fully included in regular classes with their peers than when they are in segregated special education classes. Overwhelmingly, they progress further with academic outcomes including reading, numeracy, spoken language and social development. The peers that they learn with are better prepared to support them and fully include them in their communities throughout their childhood and adult lives. While the right to an inclusive education is enshrined in U.S. law, many children and youth with Down syndrome are still denied this opportunity. We aim to change this and ensure every child and youth with Down syndrome has the opportunity to be educated in fully inclusive classrooms.

Changing practice

We recognize that information and training are needed to enable educators to feel confident in providing a fully inclusive education. We now have many years' worth of research, publications and experience developing effective education for children and youth with Down syndrome. We share this in a practical way in this document and accompanying resources.

Changing identification and monitoring

We know that planning and monitoring at district, state and national levels are essential to the planning, funding and delivery of effective services and include a call for action to ensure these are in place.

General Introduction

This guidance document addresses the education settings that support students with Down syndrome, covering the period from early intervention and primary education through secondary and into higher education. Its primary focus is the K-12 space.

The information in this document may serve as guidance to educational entities including public schools, private schools, individual educators, families and agencies. It can inform national initiatives that promote effective use of resources and mandates to raise achievement for this population of students.

Why action is needed to address the education of students with Down syndrome

Currently, early intervention and education services in the United States vary widely in quality. Services are often not evidence-based, and many staff are not adequately informed about the research describing the specific educational needs of students with Down syndrome. Many families are concerned with the quality of services provided for their children.

High-quality services from birth will enable families to better support their children and ensure all students with Down syndrome have the opportunities and resources to help them meet their individual potential, in turn, enabling them to lead more independent lives and to contribute to the community and workforce.

As it currently stands, we have no way to measure the effectiveness of the services and education provided to students with Down syndrome due to the lack of data collection for this population in educational settings. Students with Down syndrome are generally classified under the educational category of intellectual disability but can also be given the educational classification of other health impairment, multiple disabilities, speech and language impairment or orthopedic impairment.

Classification in the category of intellectual disability is usually based on IQ scores. However, the learning profile of a student with Down syndrome with an IQ of 55 is quite different to that of a student with autism and the same IQ of 55. The two students will achieve the same IQ score with a different pattern of subscale scores reflecting different cognitive strengths and weaknesses, which means that effective teaching strategies will be different for these students.

What this guidance document covers

- **Section 1** outlines actions recommended to the Congress of the United States and the U.S. Department of Education.
- **Section 2** outlines the specific learning profile associated with Down syndrome, including strengths and challenges, that supports the call for Down syndrome-specific guidelines and the requirements needed to meet the unique needs of this population.
- **Section 3** describes good practice guidelines for intervention and inclusive education for young people with Down syndrome. The guidelines are evidence-based and informed by the experience of specialists, educators and legal practitioners. They provide standards that can be used to appraise the effectiveness of services and curriculum delivery to students with Down syndrome from birth through high school and postsecondary opportunities.

A note about terminology

Throughout this document there are references to the young people whose educational experiences and outcomes we seek to improve. Because they range in age from birth to adulthood – and are entitled to different legal protections and services determined by age – it is worth stating that commonly used age-based labels and groupings are not interchangeable, and improper use can result in unintended policy and service issues. This document will use these terms as follows:

- **“Children”** refers to individuals from birth up until the age of majority (in the United States, generally age 18). This term is synonymous with “minors.” In common special education parlance this term is typically used to describe individuals of elementary-school age or younger but begins to fall out of favor in adolescence, about the same time the provision of postsecondary transition services must begin (federally at age 16, though often younger per state statutes). This term should not be used to describe individuals who have attained the age of majority, as to do so would be disrespectful and infantilizing.
- **“Students”** refers to school-age individuals but does not include those too young for kindergarten. In other words, “students with disabilities” consist of the population served by the Individuals with Disabilities Education Act (IDEA) Part B (age 3-21) but not the population served by IDEA Part C (age 0-2). We do not use the term for individuals in postsecondary education (without a clear postsecondary descriptor) or employment.
- **“Youth / Young People”** is the broadest term we use and includes all individuals from birth up to early adulthood. IDEA services and protections extend to age 21 (with some state-level variation), but other protections and services, such as those under the Workforce Innovation Opportunity Act amendments to the Rehabilitation Act of 1973, extend past IDEA coverage. In common usage, this term does not have a fixed age ceiling, but we use it to extend up into the mid-late 20s.



Section 1:

A Call to Action for the Congress of the United States and the United States Department of Education: Increase and improve inclusive educational supports for young people with Down syndrome.

Foreword

Under the Individuals with Disabilities Education Act (IDEA), Down syndrome is not an enumerated disability establishing eligibility for special education and related services. Young people with Down syndrome are typically found to be eligible for those services under the broader category of intellectual disability. As a result, a dearth of Down syndrome-specific information and practice pervades the education field, negatively impacting – systemically – the quality of the education this population receives.

This resource presents information, gleaned from research, that outlines the specific learning profile associated with young people with Down syndrome (as a group), including the distinct and specific needs of the population. Further, it offers critical, evidence-based strategies to support individuals with Down syndrome and improve their educational outcomes. We offer this information to increase the capacity of educators to include young people with Down syndrome successfully in learning environments alongside their peers without disabilities and with other disabilities. Every individual with Down syndrome is unique, however, and it is our express intent that these guidelines not be used to segregate students.



While many of the difficulties experienced by individuals with Down syndrome are also experienced by other students, the overarching group profile of physical, developmental and educational needs associated with Down syndrome is unique and warrants distinct supports. Furthermore, the group of school-age young people with Down syndrome is no smaller than analogous groups with other disabilities, such as those diagnosed with hearing loss. While we cannot recommend at this time or in this document that Congress reauthorize IDEA, or exactly what approach to employ when the body eventually does so, we look forward to a future where the education of disabled youth truly reflects the strength and value of difference and is no longer based on the medical model of disability. Providing support does not need to be underwritten by a process of naming deficits. If, however, the legislation's current structure of listing disabilities persists, we recommend that Congress build in a mechanism for collecting detailed information about how well the Down syndrome community is being served. One way to do so would be by adding Down syndrome to the list of enumerated impairments qualifying individuals for special education and related services. To improve educational outcomes for the Down syndrome community, it is critical that disaggregated data be collected and analyzed.

Recognizing that it may be years before Congress does act to reauthorize IDEA and, furthermore, that students with Down syndrome deserve better educational outcomes immediately, we make the remainder of our recommendations based on the status quo. Also, due to legal inconsistencies between states, the following recommendations target the federal government specifically, but it is incontrovertible that states play a critical role in promoting good educational outcomes for all young people.

Recommendation 1: Ensure effective planning and monitoring for this population of students

Educators and families face challenges planning how best to support youth with Down syndrome because there is no centralized hub of Down syndrome-specific information and data at the U.S. Department of Education. While the National Center for Education Statistics (NCES), National Center for Special Education Research (NCSER) and Office of Special Education and Rehabilitative Services (OSERS) do house information pertaining to students with Down syndrome, this information is aggregated with others under the umbrella category of intellectual disability. As a result, families and practitioners cannot easily access Down syndrome-specific information. **We recommend the Department work to provide Down-syndrome specific information to the public by disaggregating its existing datasets and taking steps to modify reporting systems not defined in statute. We also recommend that the Department share Down syndrome-specific information in an online repository that is both user-friendly and accessible.**

Recommendation 2: Develop substantive guardrails to ensure that programs serving young people with Down syndrome are grounded in evidence-based practices

Many channels for the federal government to promote the utilization of evidence-based best practices continue to go unused. While it is true that Down syndrome is not one of the enumerated disability categories in IDEA's service-eligibility framework, it is nonetheless a recognized disability in both the education and medical communities. Furthermore, young people with Down syndrome are full-fledged participants in schools across the country, and the government has a moral imperative to improve their educational experiences as it does for all students. **We recommend that both the Secretary of Education and Congress explore the formation of a federal advisory committee whose purpose is to promote ever-improving educational opportunities and outcomes for young people with Down syndrome. We further recommend that members of Congress seek the counsel of the Government Accountability Office to recommend ways to achieve the same.**

Recommendation 3: Disseminate resources to help educators understand the learning profile of youth with Down syndrome

As will be discussed further in Sections 2 and 3 of this resource, some practices will serve students with Down syndrome better than others because they have been developed with the population's specific learning profile in mind. For example, the use of visual supports like signing, pictures and print can help reduce the effects of specific speech, language and short-term verbal memory difficulties most young people with Down syndrome experience. It is critical that educators have access to this type of granular information, along with guidance on how to operationalize that information as they work with students each day.

With this foundational knowledge, not only would practitioners be able to raise the overall quality of services offered to students with Down syndrome, but they would also naturally develop better relationships with families, reducing strain on the special education system, including the adversarial legal processes in place under IDEA. It is often the case that families will acquire, over the course of years, extensive knowledge about research, literature and effective interventions for young people with Down syndrome. Professional development of educators, on the other hand, is neither standardized nor iterative as a matter of course, leading to inconsistent preparation of teachers and creating innumerable situations where a family member's knowledge base exceeds that of an educator. This lopsided relationship can erode trust and stifle the development of positive working

relationships on individualized education program (IEP) teams, negatively impacting student services.

We recommend the Department promote and disseminate foundational information about Down syndrome to all educators.

Recommendation 4: Develop evidence-based guidance on Down syndrome service delivery for education professionals

In addition to deepening their understanding of the learning profile associated with Down syndrome, educators need guidance on how to improve their practice to serve students more effectively. **We recommend the Department develop a resource manual that outlines evidence-based instructional strategies for students with Down syndrome and disseminate it to local education agencies and providers.** Section 3 of this resource includes information that could be utilized for such a manual. This manual should include salient research funded by the National Center for Special Education Research (NCSER) and input from stakeholders, community members and, critically, individuals with Down syndrome. It should define and recommend best practices to maximize the inclusion of youth with Down syndrome in schools, including but not limited to the following:

- effective inclusive classroom practice in any setting;
- implementation guidance and strategies to support learning in the general education classroom, specifically;
- learning activities to support differentiated instruction and curricular modification in the general education classroom; and
- strategies to develop inclusive leadership and school administration.

Recommendation 5: Protect access to related services for students with Down syndrome

Many students with Down syndrome benefit from receiving related services, such as physical therapy, occupational therapy, speech and language therapy, learning support services, outreach services and advisory specialist-supported services and instruction. Access to these services is inconsistent – not just nationally but even within individual districts. Some families report highly valued, consistent and effective services, while others are totally unable to access key services. Due to the absence of teachers and/or administrators with expertise in Down syndrome, therapies that combine neurodevelopmental and sensory processing approaches or therapy services provided in the general education classroom might simply not exist at a student's school.

Additionally, some localities report provider shortages for children under the age of five entitled to early intervention and preschool services. Some children have little or no access to services and evaluations – despite an entitlement – simply due to a dearth of providers. Early intervention, often provided via related service, is pivotal for student success because of how interventions made early in brain development can alter a child's educational trajectory.

Because of the myriad financial ties between property values and educational quality, these large-scale inconsistencies in access to services exacerbate systemic inequities and continue to entrench cultural norms rooted in systemic bias. **We recommend that the Department act to correct these inconsistencies through innovative means, such as promoting locally supported online intervention from professionals with**

specialist-level knowledge about Down syndrome rather than restricting services to local practitioners with only a general caseload.

Recommendation 6: Recognize and meet the need for additional classroom personnel

One important factor in improving educational outcomes for students – whether they have Down syndrome, another disability or no disability – is access to knowledgeable educators in the classroom. Initiatives to improve educator quality usually revolve around licensed teachers, especially the contents of their pre-service training. But there are other adults in the classroom whose professional development is often overlooked – paraprofessionals. **We recommend that the Department produce and disseminate guidance to help states and districts provide professional development opportunities for paraprofessionals. We further recommend that the Department provide evidence-based substantive support to ensure these opportunities are rooted in inclusion, contain Down syndrome-specific information and have been developed to a high standard of quality.**

Section 2:

Down Syndrome: A Specific Profile of Strengths and Challenges that Require Specific Interventions and Supports

What is Down syndrome?

Down syndrome is caused by the presence of an extra copy of all or part of chromosome 21. Down syndrome is a common condition, present in around 5,200 live births each year within the United States.^[2-4]

The chance of conceiving a baby with Down syndrome is not influenced by racial or socio-economic background or the health status of the parents.

How many young people have Down syndrome in the U.S.?

In recent years, the wide availability of early screenings to identify the presence of Down syndrome, and the availability of termination options, has led to a reduction in live birth rates of around 33% in the United States. However, increases in the average age at which mothers give birth to their children has outweighed the effects of screening and, consequently, the overall live birth rate has risen in recent years - from around 10.6 per 10,000 live births in 1990 (1 in 948) to around 13.0 per 10,000 live births in 2014 (1 in 768).^[2,4]

Life expectancy has increased dramatically for individuals with Down syndrome, thanks to advances in healthcare. Median life expectancy for people with Down syndrome born in 1960 was around 39 years. By 2010, this had risen to around 58 years.^[5] This has led to a large increase in the number of people living with Down syndrome in the population—from around 50,000 people with Down syndrome in 1950 to around 214,000 in 2014.^[5,4]

It is therefore clear that students with Down syndrome represent a growing student population and will likely continue to do so for the foreseeable future (Figure 1).^[5,4] This fact alone demands better quality education in schools, higher education and employment training to enhance achievement and quality of life for people with Down syndrome across the lifespan.

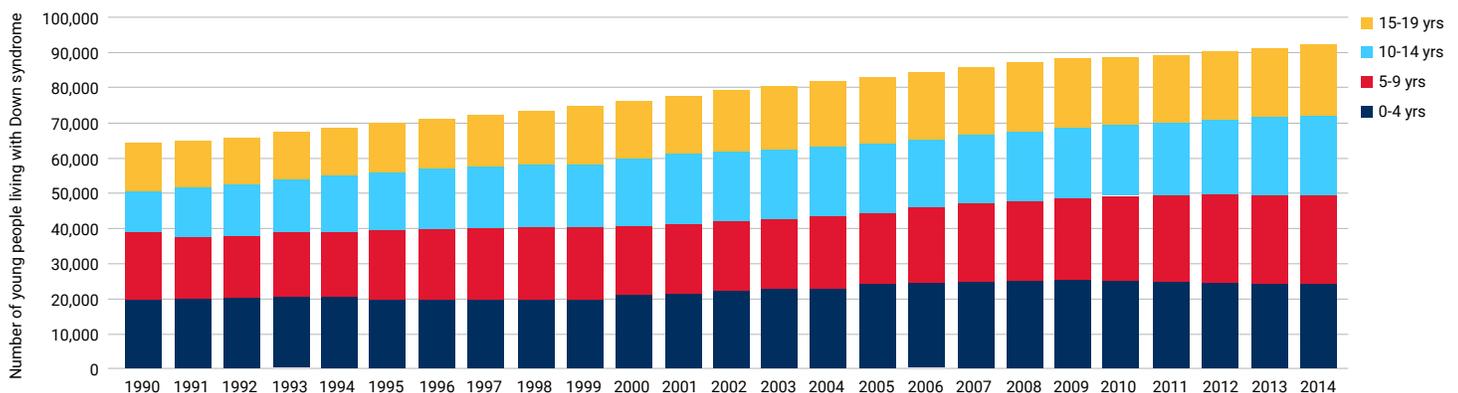


Figure 1 - The estimated population of young people with Down syndrome (under the age of 19) in the United States, 1990-2014.^[5,4]

How having Down syndrome affects learning and development

In the last 25 years, research has provided us with an increasingly detailed picture of the specific learning profile and educational needs of young people with Down syndrome.

When this information is used to develop specifically targeted early intervention and education programs, the effects of Down syndrome and subsequent disability can be reduced. As learning continues from birth into adult life, and does not stop or plateau, this information is relevant to all stages of education.

Young people with Down syndrome progress more slowly than typically developing children in various areas of development including social, motor, communication, cognition and self-help. However, the impact of Down syndrome on development varies across developmental areas. This is described as a specific profile associated with the condition, or a pattern of strengths and challenges (referred to as a behavioral phenotype in the research literature). The references noted below under each heading include indicative research papers and practical resources. This list of challenges can be a bit daunting, but the research identifying them has been the first step to delivering more effective interventions and education that can transform children's progress. Children with Down syndrome vary widely in their development, aptitudes and personalities. An individual child may not experience some of the challenges listed. Some children will experience a challenge to a greater extent than another, but it is important to consider each one for each child.

The specific developmental profile associated with Down syndrome

Many studies have identified that children with Down syndrome have a specific developmental profile of strengths and challenges and suggested that teaching and therapies should be adapted to take account of this knowledge. Most of this research has been conducted in the U.S. by Hodapp, Fidler and colleagues.⁽⁶⁻¹²⁾

Recently, they and others have asserted that language, reading and math interventions should take account of this profile research.⁽¹³⁻²³⁾ In addition, authors Jones, Neil and Feeley identify that this profile is relevant to managing behavior and setting up successful learning in the classroom.⁽²²⁾

A recent gold-standard randomized control trial of a reading and language intervention, which was specifically adapted to take account of this profile, has been shown to be successful and better than practice "as usual" for students with Down syndrome in inclusive primary classrooms in the United Kingdom.⁽²¹⁾ It also identified, as the research on their cognitive profiles would suggest, that reading is a relative strength for children with Down syndrome. That is, they often read better than would be expected for their current language and cognitive achievements. The children who received high quality daily reading instruction starting at 5-6 years of age made the fastest progress.

Education matters, and it can change expected profiles

Research suggests that a specific cognitive profile is typical for individuals with Down syndrome, with speech, language and verbal short-term memory lagging behind non-verbal abilities. However, it is essential to emphasize that cognitive development is a set of dynamic processes that are influenced by children's environments and opportunities to learn.⁽¹²⁾

This set of dynamic processes is demonstrated in a U.K. study of inclusion. In the study, adapting approaches to teaching based on the expected learning profile and full inclusion in general education classrooms changed the cognitive profile and closed the expected gap between speech and language and non-verbal cognitive abilities.^(24,25)

Research has shown that young people with Down syndrome not only take longer to learn new skills but also learn differently in some key areas. Additionally, they benefit from some teaching strategies that are different to those typically used in education. These strategies include approaches to reading, number skills and speech and language skills as well as a focus on social development and the prevention of behavior difficulties.

Figure 2 summarizes strengths and challenges associated with the main aspects of the specific learning profile for young people with Down syndrome as well as the unique range of sensory, physical and cognitive needs of this group of learners. The profile and its implications are set out in more detail below.

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.

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.

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.

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.

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).

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.

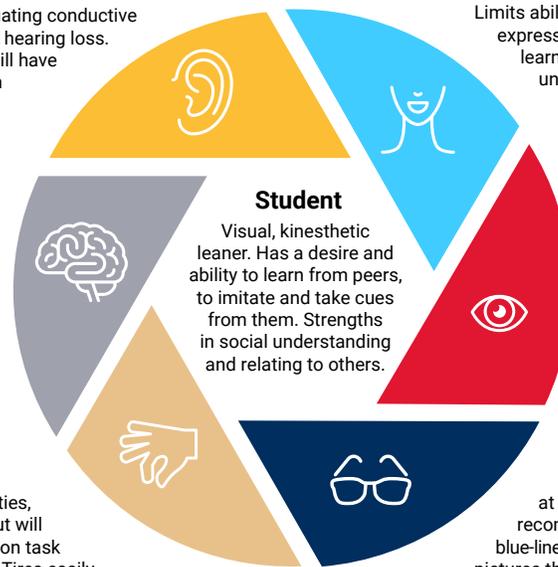


Figure 2: a graphic overview of the key strengths and challenges - adapted from Down syndrome: good practice guidelines for education ⁽¹⁾

The specific learning profile in more detail

Children with Down syndrome vary widely in their development. Most have mild or moderate intellectual disabilities, but some (about 15-20%) have more significant delays and complex needs. All of them tend to demonstrate the developmental and learning profile described above to varying degrees.

Strengths in social understanding and in relating to others. Children and students with Down syndrome show this is evident from birth through adult life. It is important to note this strength in social engagement and to build on it, as all early learning is done through social interaction, especially learning to talk. It is also important that parents and practitioners know how to build on this good social understanding to encourage age-appropriate behavior from the first months of life and through school years.^(26, 6-12)

Differences in fine motor and gross motor development. Delays in motor skills from the first year of life influence many aspects of children's development, including oral motor development and feeding. They also influence children's cognitive and social development because their motor delays mean that they are later than their peers in being able to explore objects, explore their environment, play and interact socially with others. Motor delays also influence physical development, mastery of self-help skills and handwriting. They can also influence school progress.⁽⁶²⁾ The input of physical and/or occupational therapists from infancy and into school years is essential. In the early months, expertise in feeding and oral motor development is particularly important.⁽²⁷⁻³²⁾

Speech and language delays. Delayed speech and language skills impact understanding and the use of spoken language. Expressive language is more delayed than expected for the child's non-verbal cognitive abilities, especially the mastery of grammar in sentences. Because children with Down syndrome show this gap between

non-verbal cognition and language, it has been described by experts as a specific language impairment (SLI). This means that their language delay is not simply a result of cognitive delay. Most children understand more than they can say, which leads to frustration and underestimating what they know. Children with Down syndrome usually want to communicate, and signing can support early communication until they can say words. The input of speech and language pathologists is essential from the early months of life through the adult years. Academic progress and socialization are significantly undermined when communication difficulties are not effectively addressed. Language development underpins thinking, reasoning, memory, planning and organizational abilities (executive functions). Limited communication ability increases the likelihood of behavior difficulties. Speech and language development should always be a priority in the school curriculum.⁽³³⁻⁴³⁾

Challenges in developing clear speech production. Often this results in poor intelligibility when talking, which can continue to limit communication into adult life, over and above the delays in expressive language development. Speech difficulties may be linked to attention, hearing, working memory and speech motor issues. Speech development begins in the first months of life as children learn the sounds of their language. Early speech perception and production influence vocabulary learning and verbal short-term memory development as well as the clarity of a child's speech over time. Intervention should start during infancy and continue until clear speech is achieved.⁽⁴⁴⁻⁵²⁾

Strengths in visual short-term memory but relative weaknesses in verbal short-term and working memory skills. The weakness in verbal short-term memory partly explains the delay in learning to talk from listening in early years. It also highlights the importance of using signs, pictures and print to support communication and all learning in the classroom. All these supports have a visual component and take advantage of better visual short-term memory abilities. Working memory abilities influence all learning in the classroom, and educators need to know how to compensate for working memory difficulties.⁽⁵³⁻⁵⁷⁾

Executive functions. Some studies have begun to explore broader executive functioning and confirm the need to address working memory as well as support planning, organization and task completion in the classroom. They show that executive functions predict academic progress in early school years. As noted above, these executive functions will be influenced by language development.⁽⁵⁸⁻⁶²⁾

Attention. There is growing literature on the role of attention in early cognitive development, short-term memory and language learning for young people with Down syndrome. Attention and concentration can be developed from early years as children share books with an adult, engage in one-to-one teaching activities, take part in group activities and learn to wait their turn. Interest in the task and motivation are two key factors that influence attention.⁽⁶³⁻⁶⁵⁾

Challenges in consolidating and generalizing learning. Once learned, information is retained in long-term memory. However, more practice and repetition are needed to consolidate learning to this stage. Tasks that seem to be mastered one week may seem to be forgotten next week, so regular review is needed.⁽⁶⁶⁻⁶⁷⁾ It is also important to teach generalization of learning and skills to new situations.

Strengths in reading. Students with Down syndrome often read better than would be expected in relation to their current language and cognitive abilities. This reading strength enables improvements in spoken language to be achieved using a 'language through reading' approach as print makes language visual. Sight word reading usually progresses before learning to use phonic strategies, but these can be mastered over time. Reading comprehension needs to be addressed from the start as it will be influenced by the student's language and working memory delays.⁽⁶⁸⁻⁷⁹⁾

Challenges understanding numbers and calculation. At present, studies show that numbers are challenging for students with Down syndrome, and many teenagers leave school with limited attainment in basic counting and calculation. In age-equivalent terms, number skills are often two years behind literacy skills. This may be due in part to both language and working memory delays. It is essential to ensure that early number understanding, including quantity, cardinality and equivalence, is consolidated with numbers 1-10 before moving on.⁽⁸⁰⁻⁸⁷⁾

Personality and motivational style. While children with Down syndrome show the same range of temperaments and personalities as all other children, research suggests that in learning situations they may show a certain motivational style. They may use their good social skills to distract teachers in learning situations, especially when faced with tasks they perceive as challenging. This research has also shown that they are sensitive to the level of difficulty, and fear of failure may lead to attempts to avoid tasks from infancy. This can seriously reduce their opportunities to learn. Educators need to design teaching to support success, for example, using errorless learning approaches* and being aware of children's use of social tactics to avoid the task. This needs to be balanced with encouraging persistence at tasks within the child's current abilities, as persistence in preschool years has been shown to influence academic outcomes for young people with Down syndrome in teenage and adult years over and above IQ.⁽⁸⁸⁻⁹²⁾

*Errorless instruction is a teaching strategy that removes the possibility of error in a child's response. Instruction is provided, and a child's response is supported, so that they always arrive at the correct answer. This instructional theory is based on the idea that, for a child with certain disability-specific cognitive habits, responding with the wrong answer may lead them to commit that information and process to memory and reinforce the wrong concept. In errorless instruction, a high level of prompting is provided and then slowly removed incrementally until the child can answer correctly on their own.

<https://www.fau.edu/education/centersandprograms/card/documents/errorlessteaching.pdf>

Additional issues which may develop but are not a primary part of the learning profile

At risk for challenging behaviors. This can be an issue for some but not all children and is influenced by management styles at home and at school. While research shows that children with Down syndrome exhibit fewer difficult behaviors than other children with similar intellectual disabilities, they may exhibit more than same-aged peers. This matters for inclusion in school and in the community. Children with a limited ability to verbalize are more likely to use behaviors for communication, and both schools and families frequently seek management advice. Families and practitioners need to encourage age-appropriate behavior and set clear boundaries, from the first year of life through school years, building on the child's social interactive strengths. Learning socially acceptable behavior and how to fit in with the peer group will profoundly improve an individual's life from early years through adult years. It will improve their ability to attend and learn in school and significantly reduce family stress. All intervention and education practitioners need to know how to support social development and prevent behavior difficulties.⁽⁹³⁻¹⁰¹⁾

Sensory processing issues. Sensory issues that may occur include hypersensitivity to noise and to touch, seeking out sensory stimulation and engaging in repetitive behaviors.⁽¹⁰²⁾ These may reduce over time with developmental progress but persist for some children. An occupational therapist with experience in therapy for sensory processing disorder should be consulted as these issues are becoming increasingly well understood.

Every person with Down syndrome is an individual

A wide range of individual differences. There is a wide range of variation in the developmental needs and attainment levels of students with Down syndrome. While considering information about the impact of Down syndrome on learning, support must therefore be tailored to individual presentation and needs. The list of

possible needs we document can be used as a checklist and their relevance for each child ascertained.

Presume competence. Teachers should have high expectations and assume that all students can participate in an age-appropriate general education curriculum and form meaningful relationships. Although students with complex needs may require additional help such as aids, learning tools and accommodations during assessments to achieve the same goals as typical students, there should be no prerequisites, especially regarding communication.⁽¹⁰³⁾

Children can be bilingual. Many children with Down syndrome across the U.S. will be growing up in bilingual homes or homes where English is not the family language. Studies show that many children with Down syndrome can become competently bilingual. The same accommodations should be made for them as are mandated for other bilingual children. It is also important that early intervention and education is provided for children and their families in their first language to optimize their progress.⁽¹⁰⁴⁻¹⁰⁷⁾

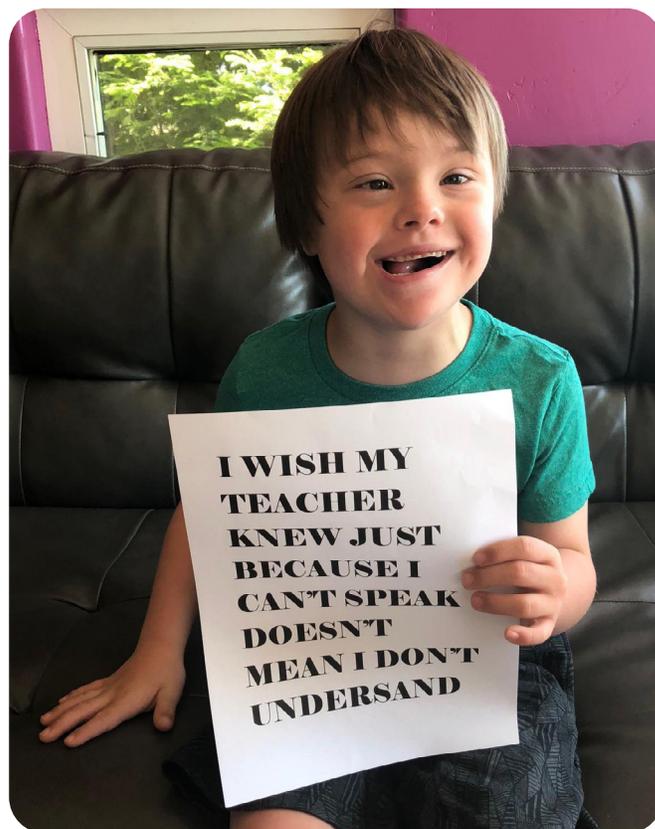
Learning can continue to adult years

No plateaus if opportunities to learn continue into adult life. Most young people with Down syndrome continue to learn and progress in all areas of their development throughout their school years and early adult life. There is no evidence of reaching ceilings in attainments when given opportunities to learn.⁽¹⁰⁸⁻¹¹⁰⁾ There is, however, a small group with additional needs whose development may slow or regress due to autism or for reasons not fully understood.⁽¹¹¹⁻¹¹²⁾

The effects of health issues and additional diagnoses on development

It is important to note that children with Down syndrome are at higher risk for some specific health issues that may affect development. In recent years the health and medical needs of children with Down syndrome have become increasingly well understood. For a full understanding and guidelines for management, please refer to the Down Syndrome Medical Interest Group (DSMIG) at <https://www.dsmig-usa.org/>. The impact of health issues on development should be considered when working with a child with Down syndrome.

- Periods of ill health or medical intervention may result in disruptions to development and times when learning is a secondary concern. These periods often happen during the first years of life, associated with the higher incidence of structural abnormalities of the heart and/or gastrointestinal tract and leukemia.
- Many children need support from relevant services to address feeding and sensory issues in their early years and in school.



- In addition, thyroid deficiency, sleep difficulties, including sleep apnea and hearing and visual impairments, are common and will influence development. Appropriate screening and timely treatments can reduce any impact on development and learning. Educators should check with families to ensure that the relevant screens have been carried out for children in their care as set out in the DSMIG guidelines referenced above.

The most important health issues for development

Congenital heart defects occur in 40-50% of children with Down syndrome. Some require surgery to repair their hearts, but most children recover well. All children with cardiac defects will be monitored as necessary by cardiac specialists who will advise if any adjustments need to be made in daily life or in school. Parents will be able to share that information.

There is a small amount of evidence that children who had surgery for the most common heart defect may be more delayed in motor, cognitive and language development in their early years than children with Down syndrome without heart defects.⁽¹¹³⁻¹¹⁴⁾ Larger longitudinal studies are needed, but practitioners working in early intervention should be alert to the extra attention these children may need to compensate for the effects on their development from the heart defect, surgery and hospital stays.

Thyroid deficiency is usually screened for at birth, but it can develop at any time and affects about half of all adults with Down syndrome. Annual blood tests are recommended as symptoms are not always obvious but may lead to tiredness and reduced ability to learn.

Hearing impairments are very common, with up to 80% of children with Down syndrome affected by fluctuating conductive hearing loss in their early years. This persists for some 40% of children into their school years. It can also lead to permanent hearing loss and to sensory neural losses in some children. Hearing should be assessed annually. Research shows that hearing loss in preschool years does affect both speech and language development of children in elementary school years.⁽³⁸⁾ All intervention and education practitioners should be aware of the hearing status of every child in their care and provide the appropriate adaptations drawing on the advice of a teacher of the D/deaf and hard-of-hearing. These may include sound field systems in classrooms, sitting near the front, reducing background noise, signing and the use of hearing aids. Hearing aids must be properly maintained and adjusted every day.⁽¹¹⁵⁻¹²²⁾

Vision impairments are also common, with 50-80% of children with Down syndrome wearing glasses to correct refractory errors. In recent years, the use of bifocals from an early age has been shown to be beneficial. Research suggests that all students with Down syndrome have impaired visual acuity causing them to see in “soft focus.” Therefore, experts recommend that materials need to be adapted, including 18pt+ fonts and strong contrasts (black print on white). Annual vision checks should be undertaken, and when young children wear glasses, it is an adult’s responsibility to see that they are well fitting and kept clean throughout the day. All intervention and education practitioners should be aware of the vision of the children in their care and provide appropriate adaptations drawing on the advice of the teacher of the blind and visually impaired.⁽¹²³⁻¹³⁰⁾

Sleep difficulties are common among children with Down syndrome. Some 30-80% may experience breathing difficulties (sleep apnea), but many children also have behavioral sleep difficulties such as difficulty settling, night-waking and early waking. Recent studies have identified that sleep difficulties influence both language and cognitive development and therefore should be addressed at a young age. Sleep difficulties will also influence daytime behavior and concentration, and they can significantly increase family stress.⁽¹³¹⁻¹³⁷⁾ All interventionists and educators should be aware of any sleep issues affecting children in their care so that they can encourage families to obtain appropriate health and/or behavioral services. They should also encourage daily communication from families so that they can modify the demands on a child whom they know has had poor sleep.

Children with additional needs

- Around 15–20% of young people with Down syndrome display additional difficulties to those described above. They require assessment and support tailored to their individual learning profile, and they require support from professionals who have knowledge and experience of the learning profile of young people with Down syndrome and additional complex needs.
- These include the children with the most delayed development, but without additional diagnoses, whose parents often feel that their child's needs are not well understood. They often struggle with behavior issues impacted by limited cognitive understanding and very limited communication abilities.
- A dual diagnosis is increasingly common among children with Down syndrome. Dual diagnoses might include autism spectrum disorder (ASD) and/or attention deficits, such as attention deficit hyperactivity disorder (ADHD). It is important for interventionists and educators to recognize that other diagnoses co-occur with Down syndrome and to be aware of any signs that might indicate a different or additional condition.

Autism Spectrum Disorder (ASD)

- ASD is seen in approximately 16% of individuals with Down syndrome according to a meta-analysis of studies,⁽¹³⁹⁾ though estimates have varied widely and have been much higher in some studies.
- Several studies have shown that some symptoms of ASD, including repetitive behaviors, are common among all individuals with Down syndrome making the dual diagnosis difficult and potentially leading to overdiagnosis. For example, a recent study showed that sensory processing difficulties and maladaptive behaviors were as common among children aged 2-10 years with a solo diagnosis of Down syndrome as those who had the dual diagnosis of Down syndrome and ASD.⁽¹⁰²⁾
- Diagnosis of ASD should only be made by an expert in ASD. Cognitive, motor and language delays associated with Down syndrome should all be considered. No gold-standard diagnostic instruments for ASD have been adapted for children with Down syndrome.
- The onset of ASD linked to regression may occur around age 5, which is later than in other children without a Down syndrome diagnosis.
- Several studies have reported that children with Down syndrome and ASD show less social communication impairment than children with only an ASD diagnosis. It is important to note this when planning interventions and involving experts working in ASD.⁽¹³⁸⁻¹⁴⁹⁾

Attention Deficit and Attention Deficit Hyperactivity Disorder (ADD/ADHD)

- Attention deficit and hyperactivity symptoms are more common in young children with Down syndrome than in children from the general population.⁽¹⁵⁰⁻¹⁵²⁾ Recent studies suggest that about 31-44% of children with Down syndrome between ages 2 and 15 may show some behaviors that occur in ADHD.^(151,152) It is important to note that a child can show behaviors of ADHD that stem from their Down syndrome diagnosis.

- Hearing and vision difficulties, gastrointestinal issues, thyroid issues and sleep issues are all medical problems that can look like symptoms of ADHD in children with Down syndrome. It is important for the family to consult with a pediatrician or psychiatrist if any increased hyperactivity is observed.

Responding to these challenges

When can we begin to use this information to improve outcomes?

Down syndrome is diagnosed at or before birth. This knowledge can be used from the first weeks of life to improve developmental progress. It can also be used to support families beginning at the time of diagnosis. This is relevant for all young people whether they are in a specialized or inclusive setting.

What additional intervention and educational requirements are essential for students with Down syndrome?

- staff trained in the specific learning profile and evidence-based approaches to inclusive instruction that effectively support young people with Down syndrome
- a support team that is aware of the evidence-based benefits of inclusion for educational outcomes
- speech and language assessment and intervention
- occupational therapy assessment and intervention
- physical therapy assessment and intervention
- assessment and intervention to address vision and hearing impairments
- assessment to identify additional needs and any sensory processing issues
- educational resources, accommodations and modifications that are quantified and clearly specified in an IEP, or its equivalent, to enable the student with Down syndrome to have access to the general education curriculum
- appropriate adaptation of teaching approaches, curriculum adapted to the specific learning profile, accommodation of individuals within the school community and effective inclusive practice
- additional staffing within schools to enable focused learning and participation under the direction of teachers, the director of special education and related service providers consistently available
- assistive technology, as required, considering the specific learning profile associated with Down syndrome
- services mandated for all bilingual students and English language learners (ELL) in the cases of bilingual students with Down syndrome

Improvement and expansion of opportunities for inclusion in schools

The benefits of inclusive education for children with Down syndrome

In recent years, several studies have evaluated the outcomes of fully inclusive education in general education classrooms compared to education in special education classrooms. Most of this research has been conducted in Europe. Gert de Graaf and colleagues in the Netherlands published an inclusion study⁽¹⁵³⁾ and a review of inclusion research up to 2012.⁽¹⁵⁴⁾

The main findings show that children with Down syndrome develop better spoken language and make better academic progress, particularly with reading, when taught in fully inclusive classrooms with typically developing peers of the same age.

In 2016, de Graaf and colleagues published landmark data showing that students with Down syndrome with IQs below 50 made more progress in general education classrooms than those with IQs above 50 in special education classrooms.⁽¹⁵⁵⁾ They also showed that their data on the benefits of inclusion replicated the findings of research conducted earlier in the U.K.⁽¹⁵⁶⁾

In the U.K. study, teenage students who had been fully included for their entire school career progressed more than two years ahead of their peers in speech and language and over three years in literacy. The speech and language gains included using longer sentences and having clearer speech production. They also exhibited fewer behavior difficulties and, as mentioned earlier, they no longer showed the expected gap between spoken language and other abilities. With the caution that this is cross-sectional data, inclusion in regular education classes appears to have resulted in more progress with language and literacy across teenage years compared to students in special education, who tended to plateau.

It should be noted that, according to the authors of this study, the teenagers' early intervention and education were adapted to the specific learning profile in addition to being fully included with same-age peers and having access to the general education curriculum. Both matter for designing optimally effective services.

Research conducted in the U.S. confirms these findings and shows that time spent in general education improves outcomes for reading and math for students with a range of disabilities, including those with intellectual disabilities such as Down syndrome.⁽¹⁵⁷⁾

Strategies for effective inclusive practice

We now have a number of studies that have looked specifically at what contributes to the effective inclusion of children with Down syndrome in the general education classroom.⁽¹⁵⁸⁻¹⁶⁷⁾ We have incorporated this advice into the guidance in Section 3. However, we note that the practices that have been shown to be most effective for students with Down syndrome are those that benefit all students. For example:

1. The best place for the student to learn is in the general education classroom with their peers
2. They benefit most from individual and small group rather than whole-group instruction
3. When included with peers in the classroom for learning, asked questions and involved in discussions, they are more likely to be socially included by peers outside the classroom
4. Computer-supported learning is beneficial for all children, as it is interactive, non-threatening and self-paced, reduces spoken language demands, supports repetition and consolidates learning

5. There is no need to modify the usual behavior rules
6. Praise is the best motivator and behavior management strategy
7. They make most progress when the class teacher takes full responsibility for the child's education and has time for planning with other support personnel working in the class
8. The teacher spends time teaching the child rather than leaving this to a paraprofessional

Several of these studies report that the teachers requested more training in the specific learning needs of students with Down syndrome and in effective inclusive practices.⁽¹⁵⁸⁻¹⁶²⁾

The right to inclusive education in the United States

The right to inclusive education is currently supported by the Least Restrictive Environment (LRE) section in Part B of the Individuals with Disabilities Education Act (IDEA).

In the national context, there has been a historical bias toward placing students with Down syndrome in segregated settings. The right to equal access to a free and appropriate public education (FAPE) was introduced in the U.S. with the enactment of Public Law 94-142 in 1975, the precursor to IDEA..

Research across decades has demonstrated that the proportion of students with Down syndrome who attend inclusive schools has varied greatly across different districts, and the overall trend was for students with Down syndrome in inclusive settings to transfer into segregated classes at some point during their school career. Anecdotal evidence indicates that for many families the decision to transfer to segregated settings occurs when inclusive settings fail to meet the support needs of individual pupils.

Research over the past 20 years indicates that successful inclusion from early years through higher and continuing education is not conditional on the ability or behavior of the child. Instead, it is dependent on the school's ability to accommodate and support the individual within the community and the structures of the educational setting. In turn, this depends on the school team having positive attitudes towards individuals with Down syndrome and believing inclusion is a right. With practice, outcomes in inclusive settings can improve for this group of students.

Socially, schools can provide daily opportunities for students with Down syndrome to mix with typically developing peers, learn from models for age-appropriate behavior and develop relationships with young people from their community. Successful inclusion is a key step toward enabling children with Down syndrome to become full and contributing members of the community, and society reaps the benefits. Students and the wider school community gain skills and knowledge about how to understand, support and include people with disabilities. Typically developing peers gain an understanding of diversity, disability and tolerance through being part of an inclusive school community.

Legal rights to be protected and strengthened

- Students have the legal right to a specialized education, which provides access to the general education curriculum and setting while meeting their additional educational needs. This currently takes the form of an Individual Education Program (IEP) for students who are determined to be eligible for special education services.

For a summary regarding the legal history of inclusive practices in the U.S. see Appendix A: American Legal History of Exclusion.

- Introduction of a proactive system of accountability and enforcement for local educational agencies would help ensure that they do not consistently breach legal requirements under IDEA. Currently, there is no proactive body to ensure that school districts comply with the existing requirement of LRE. The Department of Education (federal and statewide) and the Office of Civil Rights (federal and statewide) are responsible for investigating general complaints made by parents alleging the failure of schools to comply with IDEA's requirements regarding LRE and FAPE, but families are left to challenge school districts individually through the court system, which puts an immense financial burden on them and does not necessarily correct systemic faults.
- Speech and language therapy advice should always be a priority consideration as part of the initial evaluation and re-evaluation process for children with Down syndrome.
- Training on Down syndrome and the specific learning profile, inclusion, accommodations, modifications and differentiation must be included and strengthened in initial teacher training and certification programs for both general and special educators as well as related service providers.
- Annual review must focus more on goal and progress-monitoring as a mechanism to judge student success within the general education classroom and curriculum.
- Accountability measures and monitoring practices by the Office of Special Education and Rehabilitative Services or state level governmental agencies should be further developed to evaluate compliance and the effectiveness of strategies employed to promote inclusion and services for the population of students with Down syndrome.

Section 3:

Principles for Effective Educational Practice for Youth with Down Syndrome

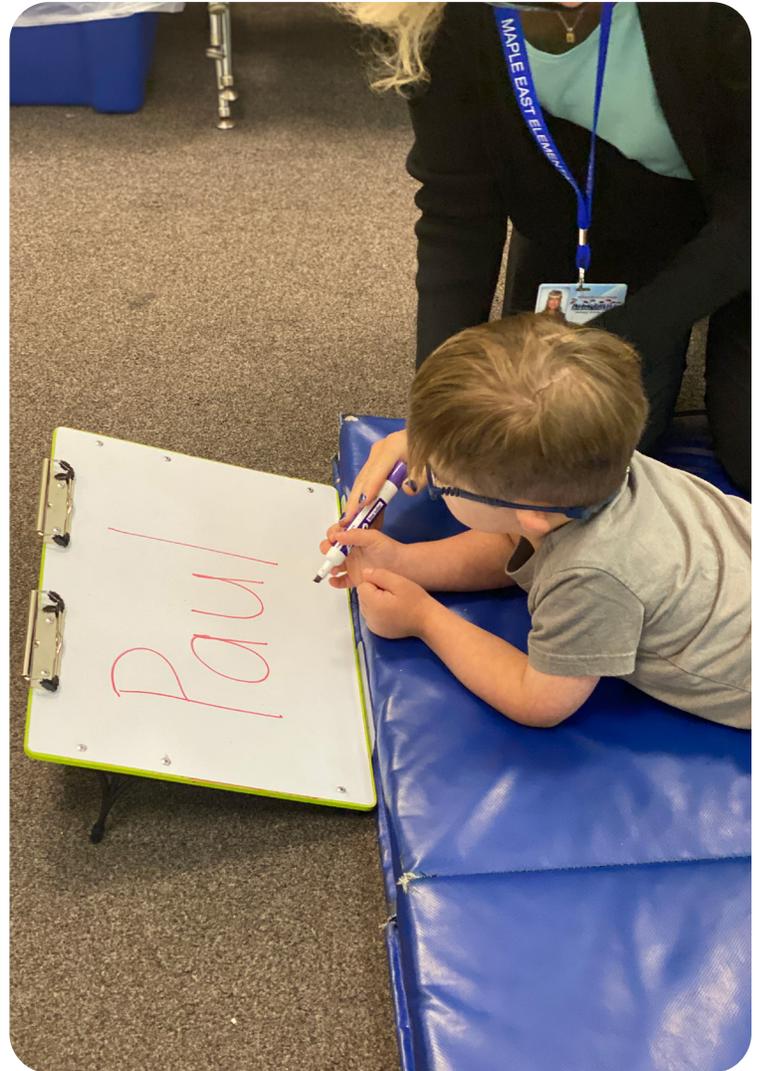
This section outlines effective educational practice for working with young people with Down syndrome. These practices apply broadly and can improve educational outcomes and experience across various settings and age groups. Guidelines specific to different stages of education are indicated later in this section.

Staff training

For educators to support young people with Down syndrome properly, it is critical schools provide Down syndrome-specific professional development opportunities for all staff and members of the learning community, ideally prior to the start of the school year. School staff will need to understand the specific learning profile of youth with Down syndrome and inclusive strategies and interventions reflective of that profile. Training should cover specific needs and strengths associated with Down syndrome across settings and age groups.

In-service professional development should include information about the following:

- The learning profile for students with Down syndrome and its implications for interventions, accommodations and modifications
- Speech, language and communication profile and strategies to promote development
- Hearing and vision issues
- Supporting social inclusion and friendships
- Support and adaptations for delays in fine and gross motor skills across all settings, i.e. in play, in the classroom, during physical education classes, on the playground, in the cafeteria and on the bus
- Strategies to support verbal short term and working memory difficulties across the curriculum
- Teaching reading using visual (whole word recognition) as well as phonic approaches and understanding how to use literacy to develop spoken language
- Number skills development, including implementation of visual and kinesthetic resources
- Accessing the curriculum through differentiation, specially designed instruction and curriculum mapping and modification
- Understanding and managing behavior, including functional behavior analysis and positive behavior supports



- Models of support such as co-teaching and multi-tiered systems of support
- Effective deployment of additional support, including teacher assistants and paraprofessionals
- Working effectively with families
- Updates on legislation relating to inclusion
- The research base that supports recommended approaches
- An overview of changing attitudes and opportunities for people with Down syndrome

Teaching assistants and paraprofessionals

School districts should include teaching assistants (TAs) and paraprofessionals in staff training and professional development. TAs and paraprofessionals should know how to break teaching tasks down into smaller steps and how and when to use support in order to promote independent working for as much of the lesson as possible. Some examples include using visual supports, repeating and reviewing key points and instructions, wait time, gradual release of responsibility, using open and closed questions, verbal and physical prompts as required, simplifying language, scribing key points on white boards, redirecting students when tired toward the end of lessons, reminding students of class rules, rewards and consequences and use of strategies to keep students focused and on-task. TAs and paraprofessionals must be closely overseen by a certified educator who is creating and adapting all lessons.

Effective related service supports for schools

Related service supports, sometimes from external providers, should be provided to school staff across all grades, ensuring that they apply specialist knowledge of the learning, social and emotional needs of students with Down syndrome. General and special education teachers, school psychologists and speech-language pathologists should all be included. Support from occupational therapists and physical therapists must be available to students with Down syndrome who require these therapies. There should also be access to advice from relevant experts on adapting for hearing loss and low vision.

Within each discipline, at least one member should have additional training and specialist knowledge in the learning, communication and social and emotional needs of students with Down syndrome. This individual should maintain links with professional networks and organizations promoting the development of practice for students with Down syndrome. As specialists in this field, they are responsible for developing the overall quality of local practice to support students with Down syndrome and for disseminating information to all members of their respective teams and disciplines and to school staff through consultation and training.

It is imperative that all staff providing support have knowledge of the specific learning profile for students with Down syndrome and their learning needs. They should also have knowledge and experience teaching in inclusive classrooms and should be aware of the curricular demands made on staff in inclusive settings.

Input from these specialists working with schools should include:

- joint planning with school staff
- providing training to school staff
- supporting school staff and families to address issues as they arise

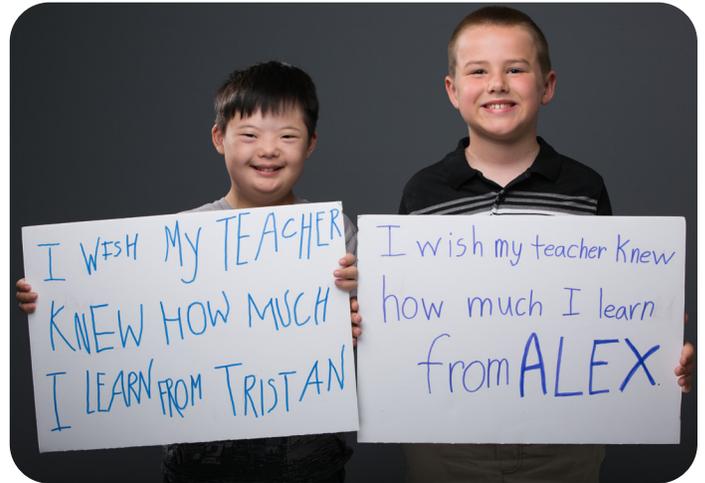
- working directly with students for the purposes of assessment and program planning
- embedding therapy targets into the curriculum as much as possible and reducing “pull-out” time

Achieving effective inclusive practices with support from administration

It is important for school leadership to model a positive attitude about inclusion for all staff, especially the principal, director of special education and members of the administration. Staff attitudes and practice should ensure the student is treated as an individual who has needs common to all students as well as distinct needs rooted in the specific learning profile of students with Down syndrome.

Good inclusive practices for individuals in schools:

- **Presence** – a full time placement at the student’s home school with typically developing peers where they spend their time in places and activities with other students of the same age from the local community
- **Participation** – taking part in and contributing to the school community and its activities: making relationships, joining in, learning and having fun alongside everyone else
- **Dignity and respect** – individuals are valued by staff and other students, and their talents and achievements are celebrated. Students are accepted by others in the school community and made to feel good about themselves
- **Independence and choice-making** – nurturing the expression of preference, the definition and pursuit of personal goals and development and the expression of individuality and autonomy
- **Achievement** – developing new skills, competence, confidence and self-esteem; realizing goals and focusing on what the student achieves—not their limitations



Practice should sit within a framework described in the school’s inclusion statement, linked to the school’s policies regarding special education. If a school district does not have an inclusion statement, members of the administration, instructional staff and families can work together to create one that reflects positive attitudes about inclusion and is tailored to the community.

Issues for schools and other educational settings

Access and organization of additional support

For schools to provide additional staff support, it is essential that Individualized Education Programs (IEPs) are specifically written to address the individual needs of a student to have access to and be educated in the general education classroom. In the case of private schools, where regulation permits, the service plan can serve as the instrument to accomplish this goal. Use of support staff and resources must be planned to meet the needs of individuals. Support from internal and external (related) specialist services must be deployed to meet the support needs of the team working with the student and to enhance practice in school.

Arrangements within schools

Same-age class peers

Young people with Down syndrome should be in age-appropriate classes and move up with their cohorts. This inclusive practice will help them maintain peer relationships and friendship groups and progress through the curriculum.

In exceptional cases, school staff, along with a school or educational psychologist, may propose that an individual repeat a year in the case of extended absence due to illness or if the individual has a late summer birthday making them one of the youngest in the cohort, especially in pre-kindergarten and kindergarten. In these cases, the team should give special consideration to potential impacts, both positive and negative. Parental input is critical, and if the individual is of sufficient age, self-advocacy as well. Those who have moved from their original age cohort should then advance with peers throughout their school career, and exceptional efforts should be made to ensure they do not skip another year at any stage. This is important for their social and emotional needs. They will reach puberty at the same age as their peers, leave school alongside their peers and will continue to need to be able to be included in age-appropriate social peer groups.

Grouping

Because of the specific learning profile and communication needs associated with Down syndrome and differences in skill levels, individuals' needs are often not adequately addressed. When considering small group assignments within an inclusive setting, young people with Down syndrome can be successful in any group configuration, not just with students who have similar needs, as long as the necessary supports are provided. These groups should be flexible and changed routinely.

When planning placement within groups, it is important to take into consideration that people with Down syndrome, as visual and kinesthetic learners, respond well to positive role models and should be placed with students who are good models of learning and behavior within the general education classroom. Good practice can include placing those with Down syndrome with peers who can provide support and encouragement.

Transitions

Effective transition planning is key to ensuring sustained progress and successful inclusion. Key transition points include when a child with Down syndrome starts preschool, when they transfer to elementary school, when they transfer to middle and/or secondary school and then when they move into postsecondary life. Activities to support transition should include sharing information and planning, teaching to prepare the individual and introducing the new setting. Transition activities should take place over several months, before and after the individual joins a new setting. Transition meetings and planning must involve key staff from both the origin and destination settings as well as families and external support staff.

Transportation

Students may have difficulty independently riding the bus due to being smaller oftentimes than their typically developing peers, and will have additional challenges with fine and gross motor skills. It is in the best interest of the student to remain on their neighborhood bus with proper supports, such as an aide or special seating and not be moved to a separate bus, which is a more restrictive placement.

Meeting personal support needs

Arrangements must be put in place to meet the individual's personal support needs. These include, but are not limited to, support for eating and drinking, toileting, washing and dressing. Strategies must be used that maintain the dignity of the person and promote skill development and independence, while minimizing impact

on social inclusion and learning. Appropriate, reasonable adjustments must be made to ensure that facilities and equipment are made available by the school. Schools must admit children into kindergarten according to state or local legislation and policy, including children who are not toilet-trained. Individual support for a child's personal care needs should be specified in their IEP.

For some, healthy eating and exercise will require ongoing focus in addition to curriculum subjects such as physical education.

Youth with Down syndrome should be included and take part in all activities of the school community, including the full curriculum, breaks, lunchtimes, routines, afterschool activities, extra-curricular activities, school trips and other communal and social activities (e.g., tutor group and mentor time, religious worship). Adaptations should be made to accommodate specific individual needs, and support should be provided by the school as needed for each individual child.

Working with families

Communication between families and schools should be open, timely, effective and include sharing achievements, concerns, priorities and strategies. Students should also be supported to share information between settings. Families should communicate with the identified case manager or equivalent, who is responsible for coordinating support for the student. To do this, the school team should work with families to identify the best method of communication.



Differentiation of the curriculum and learning activities to support the acquisition of new skills

Unless otherwise specified in their IEP, students with Down syndrome should follow the same full curriculum and school activities as their typically developing peers, including a modern foreign language, with accommodations and/or modifications as needed.

Differentiation of teaching methods must address individual learning objectives, content within topics, learning activities and learning resources.

Both the general education and special education teachers (who may act on a consultant basis) must take ownership of the student's IEP and use specialist advice and additional support to design and implement the plan. To do this most effectively, general educators and special educators should have joint planning sessions on a regular basis.

Schools should assess levels of attainment and measure progress for individual students. These must be referred to in data reports, such as progress reports and report cards, then revisited at annual review meetings.

Curriculum-mapping should be used for all curriculum subjects to identify appropriate content and learning objectives for each topic within the student's current working level.

TAs and paraprofessionals must have access to curriculum plans, provided in advance by teaching staff, for all curriculum areas.

Tools for exploring a student's views, including at annual review, must be tailored to the individual's communication skills. Standard questionnaires should be reviewed and adapted, identifying mechanisms that the student can effectively engage with and that capture views and opinions.

Developing age-appropriate behavior

Expectations for behavior should be appropriate to the individual's chronological age to support their full inclusion with same-age peers in school and in their social lives outside school. Models of appropriate behavior are essential. All staff need to understand that behaviors are learned and shaped by adult responses and that the responsibility for preventing behavior difficulties lies firmly with the adults.

Children and teens with Down syndrome can learn age-appropriate social behaviors if these are taught and rewarded. In addition, observational learning should also be supported with direct teaching of appropriate social skills, as well as sex and relationship education, with appropriate accommodations.

Becoming independent

For all young people, one of the overarching goals of education is to become as autonomous and independent as possible. This kind of growth must be considered while planning all learning activities and support for students with Down syndrome. Both classroom lessons and breaks, as well as mealtimes, should be opportunities for natural peer supports, and school staff should be sure not to diminish autonomy by over-supporting.

Fostering friendships

Schools should develop strategies to support friendship development through peer support, circles of friends and buddy programs. In addition, school staff should work to foster friendships by matching potentially compatible individuals and setting up activities as a context for developing friendships.

Planning may be required to enable students with Down syndrome to take part in classroom and social situations without direct TA or paraprofessional support. By putting in place peer support like facilitative seating arrangements or additional monitoring and prompting from lunchtime supervision staff, individuals with Down syndrome can become more independent, relying less on staff support and more on social cues and support from peers.

Classroom teachers, TAs and paraprofessionals should check that seating is arranged to facilitate social interactions and peer support. Research indicates that friendships are more likely to develop when students of different abilities work together, school staff present information on disability awareness and school staff and families arrange social events for all students.^(168,169)

Developing effective IEPs

IEPs should comprehensively outline needs in academic, social and behavioral development to guide the supports and interventions designed to assist a child in creating meaningful bonds with their peers.

IEPs should:

- presume competence, focus on strengths and build on talents and interests of the individual.
- demonstrate clear evidence of considering the specific learning profile associated with Down syndrome and how it manifests in an individual student.
- include goals that target skills and concepts that give the student direct access to the general education curriculum.

- identify accommodations and modifications that will give the student access to the general education curriculum in the general education classroom. These accommodations and modifications must comprehensively address areas of need for the individual that are not covered in the curriculum, lesson plans or work.
- specify the time and place where the student's education will be provided during the school week for each curriculum subject and how special education supports will be delivered during the specified times. IEP teams must remember that students are only removed from the general education classroom if progress is not made toward IEP goals, despite all supplementary aids and services (accommodations, modifications and related services) being provided with fidelity.

IDEA regulations state that, "to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services* cannot be achieved satisfactorily." 34 CFR 300.114(a)(2)(i-ii).

**The IEP team must ensure that all possible supplementary aides and services have been implemented with fidelity and that the student is unable to make progress towards achieving their IEP goals prior to considering a more restrictive support.*

Technology

Young people with Down syndrome are often very skilled at using tablets and computers from preschool years onwards. Digital activities play to their visual strengths and require a motor response, allowing participation without needing to provide a verbal response. Another added benefit is the ability to work at their own pace. Many apps even provide data and progress reports. There are a number of programs designed to support reading and writing development and access to the curriculum. Some examples are given in the Resources section of this document. High quality apps and software build in the repetition and practice needed for consolidating learning.

Throughout their education, youth with Down syndrome should take part in targeted learning activities that develop their skills using a variety of technologies. These activities should take into account their individual learning needs and the practical application of these skills in everyday life - currently and in adulthood - alongside their typically developing peers.

Individuals with speech delays greatly benefit from the use of an assistive communication device throughout the course of the school day and in the home environment. Districts should utilize assistive technology to meet the individual needs of each student with Down syndrome. Where staff are not comfortable making assistive technology recommendations, the district should seek out an assistive technology specialist or evaluation to inform recommendations.

Staff will require training in the use and current availability of relevant technologies to support learning, and students will need daily access to these technologies.

Homework

Schools should accommodate or modify homework to suit the individual needs of students, including the amount, which should be annually reviewed. Homework must be determined and differentiated by teachers in all academic areas and in response to the level of need and the learning profile of the individual as outlined in the student's IEP.

Schools may have homework clubs or extended-day programs that are available to all students. These types of opportunities are incredibly beneficial for many students with Down syndrome, allowing them to complete their homework in school, supported by school staff, rather than placing demands on family and caregivers at home.

Implementation of specific strategies to support learning

The principles set out here apply to young people with Down syndrome of all ages and expand on the practical implications that flow from what we know about their specific needs and learning profile as outlined in Section 2.

Supporting social inclusion and behavior

Several areas identified in the overview of the specific learning profile associated with Down syndrome in Section 2 are relevant for supporting social inclusion and behavior. We are addressing this topic first in this section because behavior difficulties can interfere so significantly with a student's social and learning opportunities. Fortunately, familiarity with the learning profile and good planning can often prevent behavior difficulties from developing. The emphasis below is on planning to ensure prevention of behavior difficulties. Advice on managing and changing behaviors is given later.

First, young people with Down syndrome have strengths in social understanding and relating to others. It is important to build on these strengths in all school settings and have high expectations for behavior. Students will learn the routines and behavioral expectations of the school setting from their peers when they are encouraged and supported to do so, regardless of their language and cognitive delays. Young people with Down syndrome are typically strong visual learners and learn by watching and imitating their peers. They will also relate to other children and make friends. Other children may need support to understand and adapt to the delayed language abilities associated with Down syndrome. It is important to make sure all appropriate behavior is explicitly taught and rewarded. All too often "good" behavior is taken for granted and the student only gets a reaction and social attention for "difficult" behavior.

Second, the personality and motivational style described suggests that students with Down syndrome may use their good social understanding to distract teachers from the task and may also be sensitive to failure. It is important that teachers are aware of this and plan lessons to support success. Tasks need to be broken down into small steps and lessons should be planned with a variety of activities and opportunities for breaks built in. Using modeling and errorless learning techniques will help. Errorless learning techniques include breaking tasks into small steps, modeling the task and giving prompts to enable the student to be successful from the outset. Avoidance of learning situations is often linked to a student's perceiving tasks as too difficult, fearing failure. This attitude can manifest when work is not differentiated appropriately, or lesson plans are not tailored to the



individual's current skills and support needs. A visual timetable or picture schedule, showing the student how tasks will be worked through in a lesson, may be valuable.

Third, all children with limited communication skills may use behaviors to communicate. This means developing their language and communication is a priority, as is using pictures, signs, print and symbols to aid essential communication. A visual timetable for the day will help young people anticipate what is going to be expected of them, reducing anxiety.

Supporting motor development

Delayed motor development impacts all learning and daily activities. Physical therapy and occupational therapy services, therefore, should be available to support progress in gross and fine motor development and to recommend equipment and accommodations needed from early years through school completion.

Motor skills develop over time. Motor plans are learned, and practice is an important part of progress for all motor activities. Many young people with Down syndrome achieve high levels of motor skills over time becoming dancers, gymnasts, skiers, swimmers and cyclists, demonstrating the importance of high expectations and opportunities. Adapted physical education needs to be considered for all ages.

Speech, language and communication

Developing the spoken language abilities of children with Down syndrome should be a priority from early intervention and throughout their school years. Many individuals will come to school with a limited vocabulary and will require speech and language services throughout their elementary and high school years.

Youth with Down syndrome require direct instruction of language skills which should include teaching of vocabulary, grammar and social communication skills. They will benefit from extensive use of visual supports to scaffold language skills.

They will also need to work on developing clear speech, and this process needs to be directly targeted alongside language work from the first months of life and throughout school years. Many young adults have plenty of language, but their speech production difficulties mean their words are often unintelligible, especially to those who don't know them well.

Staff should be guided by a speech-language pathologist, and activities should be practiced daily. This service is often appropriate to provide in the general education setting, the natural environment for academic engagement and social language use. Targets can often be embedded into the general education curriculum, linked to curriculum topics and reading activities.

Visual supports can be beneficial, and staff may use software and equipment to produce high quality visual supports using pictures, print and symbols to support learning. Visual supports do not have to be in color or developed with a special program. They can be created using whatever resources staff have access to.

The importance of the language environment

In addition, it is important to recognize that children are learning language all day, every day, through direct conversation. The quality and amount of direct verbal communication influences linguistic development for all children. Studies, including some involving children with Down syndrome, have shown that language delays in children often reduce the number of opportunities children have to be in conversation.^(170,171) All staff need to be aware of this and consider how to increase conversational opportunities with staff and peers, making sure others do not step in and "talk for" the student or too often ask "closed questions" (requiring a one-word answer – often yes or no) .

Augmented and Alternative Communication (AAC)

Children with Down syndrome have been shown to benefit from manual signs used to support spoken word learning as infants and toddlers. Research shows that in early years they can use signs to communicate before they can say the spoken words, and their signs increase their total productive vocabulary. Most children drop the signs as they begin to master spoken words at about 4-6 years of age. However, they will continue to use them when their speech is not understood, and some children with hearing impairments, more severe speech difficulties or more severe cognitive delays will continue to use signs as their main means of communication throughout life.^(33, 172-174)

Recent studies have also shown the benefit of using AAC, including speech-generating devices, to teach early vocabulary to children with Down syndrome. Similar to manual signs, some young people will benefit from using AAC devices in school years, including children with more significant delays and those with ASD.⁽¹⁷⁴⁾ Staff in services from early intervention through school years should have access to expert advice on the use of AAC for young people with Down syndrome. The availability of communication apps for phones and tablets is increasing rapidly.

Supporting verbal short-term memory

Delays in verbal short-term memory make learning from listening difficult. Children usually learn to talk from listening and most school instruction is spoken. The most important response to best support youth with Down syndrome is to make everything visual and support all learning with pictures, print, signs or whatever tools help each individual. This approach makes use of their better visual short-term memory. There is some evidence that memory games and memory training are also beneficial.⁽¹⁷⁵⁻¹⁷⁸⁾

Many young people, with and without disabilities, have similar difficulties in short-term and working memory, and the adaptations to support them are relevant for those with Down syndrome. Working memory, like most human abilities, develops over time during childhood and influences all learning including processing spoken language as well as academic progress in reading, especially reading comprehension, writing composition and math.

Working memory is measured when broader executive functions are assessed and is consistently identified as a weakness in children with Down syndrome. Planning, organization and focusing attention may all present issues which need to be considered and supported. Visual supports for planning and for organizing what is needed for a lesson, homework and electives such as physical education will help students become more independent.

As identified in the profile overview in Section 2, students with Down syndrome need support to synthesize learned material. Often, a student will seem to have mastered the new words in their reading book or the next step in math over a few days but have lost them by the next week. It is important to build in many opportunities to practice and review what has been learned in a systematic way as students move onto new tasks.

As mentioned, attention is often linked to motivation. Most students can attend for extended periods when the activity is enjoyable or preferred. Classroom learning is not always fun, especially when tackling new learning. Starting with a task that the student has already mastered is a good way to encourage them. Then, make sure new learning is broken down into small steps, model, and the student is prompted to complete it until they have mastered the new learning without the need for prompts.

Reading

Schools should implement a comprehensive and balanced intervention to teach reading and develop language in elementary years. This approach includes teaching sight words and phonics in the context of books that are carefully leveled to the child's ability. This approach is supported by a randomized control trial (RCT) which evaluates 5 to 10-year-old students with Down syndrome in inclusive classrooms.⁽⁷⁷⁾ Importantly, the intervention included a structured approach to developing language, as studies show delayed readers benefit from language instruction alongside literacy teaching.

It has been recognized for a number of years that children with Down syndrome can remember printed words from 2-3 years of age.⁽⁷¹⁻⁷³⁾ Teaching reading by using a whole word approach to match, select and name should continue in all settings until the student is skilled at decoding words through phonics. This may be in contrast with the approach for class teaching, and it is likely to be needed throughout elementary, middle and high school levels for many students with Down syndrome.

Phonics instruction should continue alongside developing reading using the whole word approach. It will support word learning and speech clarity as well as later reading and spelling skills. Children with Down syndrome may not be able to hear, discriminate or say all speech sounds as they enter elementary school, so it takes time for them to develop phonological awareness and phonics skills. Letters help to make sounds tangible and building words using letter tiles, magnetic letters and plastic letters will help.

Making sure that students understand what they can read should be a priority at every stage from reading first words to reading text. Children with language delays and working memory delays are always at risk for reading comprehension difficulties. Teachers need to be aware that texts must have content at the student's language level for the student to be able to read with understanding. It is also very important to teach comprehension strategies.

Math

Teaching numbers and the number system must take into account difficulties with abstract concepts, working memory and oral language in students with Down syndrome. It is important to include the use of visual images and kinesthetic strategies to develop awareness and representation of numbers and number patterns. To ensure early number understanding, it is essential to master quantity, cardinality, equivalence, ordering, simple addition and subtraction with numbers 1-10 before moving on.⁽¹⁷⁹⁻¹⁸¹⁾

Schools and teaching teams are encouraged to embed visuals such as manipulatives, 100s charts and number lines to help students gain number sense. Once this number sense is established, the use of a calculator and other accommodations, such as a checklist for multistep problems, may be used to ensure students continue to have access to and make progress through the general education curriculum.

Managing and changing difficult behaviors

The first step in managing and changing difficult behaviors is to plan well and ensure all strategies are in place to help the student learn age-appropriate social behaviors and to manage their impulses and emotions. However, when young people develop "challenging" behaviors, it is important for teachers and staff to understand the principles of behavior management and that, if a behavior persists, it is because it is being rewarded. The reward may not be obvious, but the student is gaining a reward. It is important to understand that the teacher or staff member's behavior and responses must change if the student's behavior is going to change.

A Functional Behavior Assessment (FBA) should be used to analyze and interpret behaviors that students may employ to get their needs met, particularly when they are unable to express these through verbal means. Sometimes a Board-Certified Behavior Analyst (BCBA) can be an effective resource to consult with or aid the team in completing the assessment. Following an FBA, when deemed appropriate, schools should develop

a behavior intervention plan (BIP) which utilizes positive behavior supports. The BIP should be implemented across settings at school where the behavior is occurring, and all staff should be aware of the positive behavior supports outlined in the plan and be able to implement them.

Applied Behavior Analysis (ABA) is a commonly used technique for individuals with disabilities, specifically autism. It should be noted there is no research supporting the effectiveness of instructing students with Down syndrome in self-contained classrooms using ABA, and it should be avoided.

Young people with Down syndrome may benefit from taking a slightly different approach to those used with typically developing children. Individuals with Down syndrome are very cued to finding social interactions positive and rewarding, even when the intention of the adult is to negatively reinforce an observed behavior. Trying to change behavior by telling the student what to do may not work because it is providing the student attention, and most of what is being said may not be fully understood. A resource by David Stein aimed specifically at understanding how to change behavior for students with Down syndrome summarized this as “the respond but don’t react method.” Dr. Stein’s book has been widely praised and is a valuable addition to all teachers’ toolboxes – see Resources.⁽⁹³⁾

Zero-tolerance policies are not recommended as they do not take into consideration the individual needs of the student. Physical contact policies should take into consideration the role of socially appropriate person-to-person physical contact (e.g., hand placed on shoulder) for students for whom oral language support, talking about emotions and offering reassurance may be less powerful due to language difficulties. Parental consent should be given for any response that involves physical contact with the student.

Seclusion and restraint of students with Down syndrome is a technique that is often used in schools to “manage” behavior. Seclusion should not be used in schools on any student. It is traumatizing, focuses on compliance rather than teaching a replacement behavior and often further exacerbates behaviors. Additionally, a student cannot experience an inclusive education if they are constantly being taken out of the classroom.

As a rule, restraint – whether mechanical, physical or chemical – should never be used against students.

In the most extreme circumstances – if and only if the student presents an immediate physical threat to themselves or others, and only if all de-escalation tactics have been exhausted – should properly trained professionals employ any kind of restraint. Unfortunately, restraints are often carried out by teachers and professionals who are not trained properly and can lead to injury or even death. For this reason, all teachers and staff should be trained and re-trained once per year on restraining techniques. Teachers must instead choose more positive intervention strategies when dealing with behaviors that arise in the classroom. Parents need to be contacted immediately following any incidence of restraint or seclusion.

Checklist to Evaluate Implementation (page 1 of 2)

Schools can use this checklist to assess their inclusive practices, whether they are being developed, have been established or are embedded in school practice.

Teaching approaches and lessons

- Teaching extends the student's learning.
- Lesson plans reflect differences in students' knowledge.
- Teaching styles and lesson plans accommodate differences in learning.
- The learning objectives for each student are clear.
- Students have opportunities to record their work in a variety of ways.
- Students are encouraged to take responsibility for their own learning.
- Lessons reflect consideration of all student needs (IEPs, related services, etc.)

Organization of the learning environment and support

- Students spend the majority of their time in school with groups of students without disabilities. One-on-one settings are only used when required to support specific learning goals for the individual. The general education classroom should be the predominant learning environment.
- Supplemental instruction (or intervention) is provided as needed and is provided in addition to time spent in the core content classes, not in place of it.
- Appropriate work situations are available, as needed, for individual learning and are accommodated in work environments such as classrooms, study rooms or library rooms, not the hallway.
- Classroom organization encourages independent learning.
- Support is sufficient to help students progress in their learning while allowing them to draw on the knowledge they already possess.
- Students learn collaboratively.
- Teachers, TAs and paraprofessionals encourage peer and other naturally occurring supports.
- Teachers share lesson plans and homework with TAs and paraprofessionals in advance of the presentation of new topics and individual lessons.
- TAs and paraprofessionals are involved in curriculum and lesson planning and review.
- TAs and paraprofessionals have planning time to make resources as directed by the teacher and to plan the differentiation with the teacher.

Checklist to Evaluate Implementation (page 2 of 2)

Lesson-planning and responding to learning needs

- Teachers, TAs and paraprofessionals aim to maximize the independence of students with Down syndrome.
- Assessments are implemented that identify the achievements of students with Down syndrome and gather data that inform effective planning.
- The program of activities and lesson plans are tailored to the individual's talents and interests and to be done within the general education classroom.
- Related services (OT, PT, speech, Etc.) are provided as needed. These services are provided through pushing into the general education environment. Pulling the student out of the classroom for therapeutic services should be limited to when it is absolutely necessary.
- Learning in school links with, and capitalizes on, activities and learning opportunities outside of school.
- Home-to-school links communicate and share priorities and strategies between different settings where the student spends time.

Age- and grade-level best practices

The following are guidelines that apply to specific ages and grade levels. The general principles outlined above should be considered across all ages and grades.

Recommended best practices in early intervention and preschool (birth to age 5)

Support needs

An Individualized Family Service Plan (IFSP) (and subsequently an IEP) should be created by a qualified comprehensive team of professionals in partnership with the child's parents and with input from specialist support.

The plan should be put in place as early as possible and must be formally reviewed, at least annually, in addition to being subject to continual progress-monitoring and adaptation as required. Lead teachers and providers must be identified with the responsibility of ensuring information about the child with Down syndrome is shared with all staff working with the student, communicating with parents regularly and advocating for the child within the educational setting.



Communication is a priority

Young children with Down syndrome have delayed spoken language skills compared with typically developing peers. A majority⁽¹¹⁵⁻¹²²⁾ will also have fluctuating hearing loss. For this reason, speech and language therapy should be started from infancy and continue through preschool.

Settings will need to make extensive use of visual communication strategies and make adaptations to language and routines to meet the individual's communication support needs.

The use of signing supports will aid young children with Down syndrome in understanding language, expressing themselves and participating in activities. Lead staff members may need training to develop signing skills and share necessary signs with all staff and other children who are regularly with the child with Down syndrome. Those responsible for directly supporting the child's learning should develop more extensive signing skills including specific vocabulary to support learning and language goals and use of signs linked into sentences. Parents can advise staff on the vocabulary of signs that their child currently uses. While staff should recognize a child's personal adaptations of standard signs, they should use standard signs in communication with the child.

Support to develop signing skills within the setting may include training from signing tutors, signing reference materials and visual displays that staff can refer to. Most children drop signs as they get to 4-5 years of age and can say words. At this point they will learn new words in their spoken form. It is important that signs are always accompanied by the spoken word and staff are aware the signing is being used as "a bridge to talking."

Implementation of activities to support speech production skills, devised and monitored by a speech-language pathologist, should include direct work on the perception, learning, discrimination and production of speech sounds from the first year of life to enable children to move from signs to spoken words as soon as possible.

This is also a priority because speech sound development influences vocabulary and verbal short-term memory

development. Support from the speech-language pathologist should include training for other educational staff.

Young children with Down syndrome will benefit from lesson plans that support learning to speak through learning to read, using a whole word approach with word matching, selecting and naming. It is essential that this is practiced daily with staff who are trained and that this is carried out alongside other practice in the setting to promote reading and early phonic skills.^(68,70)

Behavior and social development

Helping children with Down syndrome to develop self-regulation skills, manage their behavior and cooperate with others is essential from the first year of life. It starts with establishing sleeping and feeding routines and with learning to wait and take turns.

It is important for families and professionals to set clear boundaries, have effective behavior management strategies in place and expect and reward age-appropriate behavior despite their child's developmental delays. This will enable their child to learn in school and to enjoy social activities with family and friends. It sets a foundation for quality of life.

Social behavior is learned in social settings. Most children with Down syndrome are interested in others and have good imitation skills, which means they can learn social behaviors from their typically developing peers. However, these strengths can also be used inappropriately to draw a reaction from others. Oftentimes, "cute" social behaviors are used as a diversion to avoid the task at hand and are rewarded by the reactions of adults and other children. Behaviors that seem "cute" for a toddler may soon become a problem behavior. This should be always kept in mind while developing age-appropriate behavior.

Due to language delays, toddlers with Down syndrome are also at a greater risk of using behaviors to communicate. Always consider possible causes of behavior, such as health issues, pain, tiredness, stresses at home and changes in routine.

Communication between home and the daycare or preschool is essential. Make sure the child is prepared for transitions and changes by explaining, using visual representations and practicing ahead. Picture books using personal photos are also effective.

Children with Down syndrome can be very sensitive to negative emotional cues and may demonstrate unfavorable behaviors due to fear or anxiety around failure or disapproval that they pick up from an adult who is with them.

Motor development

Some children will be delayed in their gross motor skills and require support to move from sitting to standing, or to walk, while others will be able to walk and run but will have difficulty in jumping, hopping etc. Time will need to be dedicated to developing these skills and to refining fine motor skills. Advice from a physical therapist and/or occupational therapist will be needed.

It is also important to think of ways to compensate for fine and gross motor delays for this age group as motor delays may increase cognitive, language and social delays. Early learning involves handling and exploring objects and learning about their properties. Children can be supported to hold, feel and explore objects they cannot yet handle by themselves. Being able to move allows children to fetch a toy or take it to someone who will talk about it. Being able to stand and walk increases independence and increases conversations with others. It is important to think about what a child may be missing compared to others of their age and give them support to experience these things.

Learning how to learn

Children with Down syndrome will need to be taught how to improve listening skills and attention control, share toys, take turns, join in with group games and learn the rules of the setting, etc. alongside their typically developing peers. Learning to sit and attend can be encouraged in one-to-one teaching activities (“show me,” “give me,” “it’s your/my turn”) and in shared book reading.

Advice or consultation from an occupational therapist or others with specialist knowledge of sensory processing difficulties may be required for the management of sensory motivated behaviors and to promote progression with skills.

Seating and other equipment may need to be adapted to accommodate the student’s physical or sensory needs.

Support for toilet training and self-help skills

Children with Down syndrome in early Intervention or preschool settings may still be using diapers, so staff need to be familiar with toilet-training programs for children with learning and communication delays.

Settings need to identify and set up suitable toileting arrangements that maintain the dignity of the student and provide equipment for the stage of independence that a child has reached. In addition to equipment suitable for toilet-training, students may require additional equipment such as a step up to toilet and handholds (grabs or rails) to meet individual support needs. It must be noted that needing support for toileting is not a reason to keep students out of the general education environment.

Children will need help with dressing and undressing, e.g., taking off or putting on coats and changing shoes.

Eating and drinking skills are typically delayed for many children with Down syndrome due to differences of anatomy and physiology. Common features within this age group include sensitivity to consistencies, intolerance of certain temperatures, immature chewing patterns and refusal to vary from a limited set of foods and utensils. Advice from a speech-language pathologist or occupational therapist who specializes in feeding issues may be needed. These specialists can advise on the management of eating and drinking difficulties, aid in developing a multidisciplinary feeding team and train classroom staff on the nature of difficulties and appropriate responses.

Support for play

Children with Down syndrome may find it difficult to engage in, and learn from, opportunities for free play within the setting. Adult support and planned activities will be needed to establish positive engagement during free play opportunities and facilitate progression from parallel play (playing next to other students) to cooperative play (engaging and playing with other students). Clear routines, with modeling, praise and structured play tasks are effective at supporting learning. Establishing these should also consider how to involve other children in the setting.

Children should be encouraged to play as independently as possible within appropriate activities, which may need to be set up in addition to those planned for the group.

Using technology

Most preschoolers can use and learn from apps on tablets, so this support should be considered. Apps present information with visual supports, and the child responds with touch. This plays to their strengths as they do not have to speak to show they understand. An app can also support the repetition needed to consolidate learning in a fun way. The apps need to be chosen carefully to ensure they are suitable for children learning more slowly. Many are designed for typical preschoolers and do not teach in small enough steps. They may also have cartoon illustrations rather than photos or realistic pictures and too much music, etc. Most children will not be able to use apps effectively to self-teach at this age, so they should be supported by an adult and used as a learning aid. Some students may also be using and benefitting from AAC, speech-generating devices or communication apps.

Recommended best practices in elementary and middle school

The general principles outlined in the previous section for students in early intervention and preschool settings may require ongoing consideration for students at the elementary and middle school levels. These considerations should specifically include toilet-training, eating and drinking, as these skills may require support for development into the child's school-age years.

Speech, language and communication

Speech, language and communication will continue to be priorities for all children with Down syndrome. At 5-6 years of age, their individual progress will vary widely, with some children having 400-word vocabularies and talking in short sentences, while others have 50-100 words and talk in one-word utterances. Vocabulary development paces progress to sentences and grammar. Children need to have 50-100 different words before joining two words together and about 250-300 words before they begin to develop grammar in sentences. Teaching a wide range of vocabulary is an important target through these school years, as is teaching sentences and grammar. Most children will not be able to produce all speech sounds or say words clearly – this takes time and practice for all children, so speech work is also a priority.

These targets can be linked with reading and phonics teaching. Many speech and language goals can be embedded in the curriculum, but every child should have a speech, language and communication program designed and supervised by a speech language pathologist. Some children will benefit from continuing to sign and/or use a communication device.

Reading

Daily instruction in reading is vital throughout elementary school. Students with Down syndrome may have delayed language skills compared to their typically developing peers, but research shows that they should be taught to read by 5-6 years of age using a comprehensive approach, which includes teaching sight words and phonics in the context of finely leveled book reading.⁽⁷⁷⁾ Learning to read can enhance a student's articulation skills, and words that are learned in print first are then integrated into a student's vocabulary for expressive use.

Many students may have already begun to learn to read in their early intervention and preschool programming and services. It is essential that support to develop reading skills continues at the elementary level to continue progress in this academic domain. Initially, students will be taught familiar words, quickly building into phrases and then sentences.

Instruction should begin using a whole word approach and follow match-select-name methodology. Instruction in phonics should be provided alongside the whole word instructional approach and should focus on kinesthetic and visual approaches.



Learning letter-sound correspondences may improve a child's speech sound discrimination and production. High frequency words (e.g., the, a, is, who) that cannot be linked to concrete objects must be embedded into contextual phrases and sentences, not taught solely in isolation.

Reading comprehension activities are essential at all developmental stages of reading skill acquisition. Content of texts must take account the child's language comprehension level, or they will not be able to understand it.

Books that present information that is familiar to the student should be created (e.g., familiar experiences at home, in the school and in the community) and should use simple, familiar language. There are a number of apps that make it simple to take photos and develop topic books as the student works on a curriculum topic (see Resources).

When assessing a student's level of comprehension, alternate response methods may demonstrate a more accurate picture of the student's understanding (signing, pointing, choosing, drawing, etc.). The language in the individualized texts may also be reinforced by demonstrating the sign associated with the word. This strategy may improve word recognition.

For most children with Down syndrome, word-reading is a strength due to higher levels of information integration when presented in a visual manner. Some children with Down syndrome (10- 19%) will word-read at their expected chronological age/grade level because of the connection between written text format and the learning profile of a child with Down syndrome. Reading makes language visual and helps overcome the difficulties that children with Down syndrome may have with learning auditorily, due to poor verbal short-term memory.

Students should be included in literacy lessons with their typically developing peers. In addition, individualized instruction should also be provided during reading blocks for 10-20 minutes and may involve the student working with their special educator or with their TA or paraprofessional under the direction of the special educator or service providers. This could take place within the classroom or in a quiet setting depending on the concentration and motivation of the individual child. Children should also be involved in small group learning with their typically developing peers who have similar literacy-based needs. Reading lessons may require some accommodations in complexity of text and language as well as length. Lessons should use a variety of texts, including the above-mentioned individualized texts that include familiar circumstances, locations and events.

Comprehension skills are typically delayed compared to a student's skills in fluency and decoding. Comprehension skills must be considered and developed alongside word identification skills. Text selection must consider the complexity of the text in three different domains: reading level, appropriateness of language and topic content. Questions that assess comprehension should be reinforced by the accompaniment of visual supports (e.g., the question is written down, prompts to refer to text or illustrations, answers provided in multiple choice format).

It is not appropriate for students with Down syndrome to be grouped with students from a younger grade level for the purpose of literacy or numeracy instruction.

Writing

Writing skills, the ability to record work on paper, may be delayed due to the physical demand of writing tasks, motor challenges, hand structure, language difficulties, vision issues, delayed response in note-taking and/or cognitive deficits experienced by students with Down syndrome.

Producing written work is a highly complex task. Difficulties in short-term memory, speech and language, fine motor skills and the organization and sequencing of information negatively impacts the acquisition and progress of writing skills for most children with Down syndrome. Schools may consider the use of assistive technology, such as word processing software accessible through typing and/or voice-to-text, which may allow students with Down syndrome improved access to the general education curriculum.

Alternate methods of recording responses may be required for individuals with Down syndrome. These methods may include assembling picture lists and displays; building sentences with word cards; scribing; using whiteboards, markers or preferred writing tools; cutting and pasting; underlining and highlighting; introducing cloze procedures; using interactive technology (e.g., Co:Writer, smartboards), integrating augmentative communication devices, encouraging typing vs. writing, etc.

Activities to improve handwriting abilities should be informed by an occupational therapist, and limited handwriting ability should not prevent students from recording their thoughts or work. Most students improve their handwriting during elementary school years.

Math

This is an area where many students with Down syndrome struggle, and research shows many graduate high school with minimal understanding of numbers or the ability to calculate. This may be because not enough time is spent ensuring children learn to understand quantity, counting, cardinality and equivalence with numbers 1-10 before moving on.⁽⁸⁴⁾ Too often children can count or recite numerals from a number line with no understanding of how the count words or numbers represent quantities.

Students will benefit from number teaching schemes that use visual materials, but only if they already have the basic understanding above and can understand how the materials represent quantities.

Students with Down syndrome should be included as much as possible with whole group instruction and work in small group sessions with students who share similar numeracy-based needs within the general education classroom. Functional math should be taught in order to supplement, not supplant, the general education math curriculum. Functional math must focus on 21st century skills (i.e. using a calculator) unless otherwise specified in a child's IEP. Functional math topics may include numeracy, time, money, number skills for shopping and cooking, weighing and measuring.

Transition planning for the elementary and middle school student

Transition supports for moving on to middle school or high school should be considered the year prior to the child's final year in the elementary or middle school setting. The anticipated school staff and the student should be involved in the elementary or middle school annual review that outlines transitional supports during the student's final school year. The final annual review should be held during the fall semester to enable the transition plan to be put into place over the remainder of the academic year. Student input gathered at the annual review should be considered in schedule creation, elective selection and goal-setting. Transitional supports should include staff making reciprocal visits, progression toward several full day visits for the student at the new school and student attendance at welcome events and orientation at the middle school or high school that they will join.

Recommended best practices in high school

This section offers guidelines that are specific to the high school setting. The general principles previously outlined will apply to high schools, as will some of the instructional guidelines outlined in the previous section.

High schools should be supported in embracing the opportunity to include students with Down syndrome with typically developing peers. This support must include an understanding of the student's educational emotional and social needs. It is essential that staff recognize that the student must be treated in an age-appropriate way despite language and cognitive delays.

Many students with Down syndrome make significant progress in all areas of their development during their teenage years and early adult life, if given the opportunities to do so. They are teenagers when they reach high school and will be aware of and part of the local teenage culture (music, sports, fashion, etc.). Their physical development and the onset of puberty is at the same age as their peers. Like all young people, developing self-esteem and a positive self-identity is influenced by the way others treat them and the opportunities they have to learn, make choices and take responsibility.



Planning schedules and grouping

School staff should promote and develop independence in students with Down syndrome in lessons and in navigating the school setting, as well as during non-structured times (breaks and lunches). Students need to spend time with their typically developing peers with minimal to no adult support, to enable the development of peer support, friendships and independence.

Student schedules should be created with flexibility in order to meet individual needs and facilitate a mix of small-group and individual instruction (no more than 10-15% of the total school day) that complements the whole group activities of a typical grade-level schedule. Flexibility around scheduling during the high school years will be essential to meeting the individual learning needs and interests of students with Down syndrome. Schedules should be presented to students in a visual format to promote independence and understanding of each day's events.

Students with Down syndrome should spend most of their time in classes with their typically developing peers who are positive role models of learning and behavior. These inclusive environments are also rich in language and promote increased language and literacy acquisition for all learners. Some time may be spent in needs-based groups, depending on the student's ability in certain disciplines, usually for a portion of literacy and reading and math instruction. Groups should be created based on a similarity of need and should not be outside of the student's chronological age and grade level. Additionally, a small percentage of time may be spent in small groups for specific instruction in communication and social skills and sex and relationship education.

Withdrawal from whole or partial lessons with one-to-one support is generally required to address writing skills, reading skills, specific speech and language work and learning curriculum vocabulary. One to two lessons per week is likely to be required for focused, individualized work on objectives and developing these core skills.

For many students, this can be accomplished during a study hall period and will provide very little disruption to engagement in the general education curriculum.

Working with families

Parent or guardian support should be highly valued by staff in schools. School teams should use the parents' extensive knowledge base of Down syndrome and of the individual. Schools should make additional opportunities for ongoing communication between school staff and parents. This is essential due to the language and communication deficits of students with Down syndrome. It also ensures that skills taught at home and in the school setting are supported and generalized, leading to greater student success.

Day-to-day communication with parents may include support in the form of the student bringing equipment or materials to school each day, communication regarding homework and assignments, etc. One lead professional should be designated to communicate with parents, providing a single point of contact. This individual should also be the professional charged with managing the student's curriculum, goals and IEP. In addition to meeting with the special education and lead teacher, parents should be able to request meetings with all teaching staff (in a parent conference) at any time.

Professional development should be provided to key individuals who are able to disseminate information to staff as a student's support team may change from year to year.

Assessment and IEP targets

IEPs for students with Down syndrome must be clear, informative and show a good knowledge of the individual and their needs. They should include expected outcomes, who will be involved and when goals and targets should be achieved. At this stage, students with Down syndrome should be playing an integral role in creating their IEP.

Schools should also provide a summary that may include a photo of the individual strengths, weaknesses and needs of the student as well as strategies to accommodate expressed student needs for the many teachers, TAs and paraprofessionals who work across curriculum areas.

Teaching and educational staff support

Should issues arise, all members of an educational team (general educators, special educators, service providers, support professionals and administration) must be prepared to engage, support or intervene with the student with Down syndrome about both their learning and behavior. This requires everyone to have the same training and be familiar with strategies being used with a particular student to ensure consistency.

Special education teachers must plan for, and lead, differentiation and accommodations so students with Down syndrome can take part in the lesson, not "fill in" activities which are unrelated to the subject topic.

Differentiation must be carried out in accordance with the student's IEP for each subject by the team responsible for teaching that subject to the individual. The special educator (accommodation or modification specialist) and the general educator (content specialist) must work in conjunction to ensure that the general education curriculum can be accessed in a meaningful way by the student. If TA or paraprofessional support is required, this staff member will work under the direction of the special and general educators. Allocating subject-based TAs or a paraprofessional that is familiar with individualized approaches to the student may facilitate this process.

Teachers should be aware of the speech, language and communication abilities of students with Down syndrome and accommodate their teaching materials accordingly. Instruction should be accommodated with the related service needs and student learning profile in mind. Doing so will allow students to engage with the greatest level of independence.

Professional development in planning and accommodations should be offered regularly to ensure that special education teachers and other subject teachers working with the student are aware of appropriate strategies and best practices to support individual student needs.

Student records and instructional data, including present levels of performance, must be available in a common accessible location so that all teaching staff can access the information about the current levels of achievement for the student with Down syndrome. Access to up-to-date, comprehensive performance data will help teachers design student-specific instruction.

Often, committees on special education will recommend additional adult support in the form of a TA or 1:1 aide. This additional layer of support allows for more specialized instruction in social-emotional learning, academic skills and adaptive skills development. All of the aforementioned areas must be planned for, and lessons and interventions must be provided to a paraprofessional for delivery under the direction of the professional staff members. TAs and paraprofessionals are able, in addition to implementing these supports, to plan for and deliver instruction independent of professional staff.

TAs and paraprofessionals should work collaboratively with teachers as a full team member. They can become skilled at making resources to meet curriculum and learning needs, in consultation with the special education teacher and subject area teachers. Additionally, TAs and paraprofessionals can contribute to the assessment and monitoring of skill development and achievements of students.

Teachers must share planning and content for lessons and homework with TAs and paraprofessionals. These individuals should also be involved in curriculum planning and review.

Limited time available to teachers, TAs and paraprofessionals to meet and plan can be a huge barrier and must be considered by principals and special education directors. Additional time should be made available for teachers, TAs and paraprofessionals to meet and plan the accommodations and specially designed instruction for the student with Down syndrome.

TAs and paraprofessionals should have planning time to meet with teaching staff and make resources to support the teacher's lessons. TAs and paraprofessionals with these responsibilities must have protected, non-contact time and/or working hours beyond the student's school day.

Related services

High schools should utilize the support of related service providers in the creation and delivery of educational services to students with Down syndrome. Educational psychologists, special area teachers, speech and language pathologists and physical and occupational therapists are among the professionals that may have input regarding services and accommodations that will be appropriate to increase student success. Speech and language therapy services in high school should, at a minimum, involve quarterly visits to monitor student progress. This should also include consultation to the educational team regarding strategies for support, the implementation of programs to support language development as it relates to curricular needs, social language development and possibly advising a TA or paraprofessional in supporting social language skills during small group social and instructional activities.

It is important that information and reports from external specialists are available and accessed by staff who work with the student. The lead educator may oversee dissemination of this information to the team.

Supporting friendships in and out of school

Developing friendships is often a concern for both staff and families during teenage years. Many students with Down syndrome have friendships with typically developing students as well as friends with documented disabilities.

Promoting prosocial relationships with all peers should be a goal of an educational program that supports a student with Down syndrome.

The student's educational team should monitor the extent to which students with Down syndrome establish, maintain and enjoy real friendships with other young people both in and out of school and plan actions to promote this where needed. Students with Down syndrome can often list their friends both in and out of school.

As is common for young people in general, students with Down syndrome will want to have at least one close friend with whom they have a deeper bond as well as a wider circle of friends they spend time with at school. Young people with Down syndrome may find it more difficult to establish mutually supportive friendships with others who share their approach to life and their interests. These can be promoted and fostered by the actions of school staff and families.

While young people typically spend time outside of their school and home in community settings without adults, students with Down syndrome may continue to receive support and supervision in these settings to meet their support needs and in response to concerns about their vulnerability. Students with Down syndrome face challenges in mixing socially outside of school with their peers who may be attending social events such as dances, shopping in the community, etc.

Teaching of key areas

Teaching literacy and numeracy, basic reading and number skills should continue as most teenagers will be able to make steady progress, and some will show marked improvement in these academic skills during teenage years. They can be made meaningful and linked to practical applications that students see as relevant, including using social media.

Behavior and social skills should be addressed as key areas contributing to the development of the student with Down syndrome. Explicitly teaching age-appropriate behavior, social skills and social communication should be a priority for this age group.

Any behavior issues should be viewed within the context of general teenage development. Strategies should be developed to address negative behaviors and to promote the desired replacement behavior and positive social skills.

The intervention strategies employed should consider the specific profile of speech, language and communication needs associated with Down syndrome. Strategies must use a visual approach, simple, familiar language and praise for success. An example of behavior intervention includes an individualized social story. A social story is a short story that depicts a social situation that the student may encounter. These are used to teach communal skills through the use of precise and sequential information about everyday events that a student may find difficult or confusing.



Inclusive, positive attitudes to behavior should be shown by school personnel and the interpretation of behavior and discipline policies or codes of conduct should take into account the learning profile and any deficits of the student with Down syndrome. Sex and relationship education (SRE) during the high school years is best delivered in small groups in addition to whole-group instruction. Curriculum must include instruction in different types of relationships, ways of relating within different relationships and assertiveness, including concepts of consent. This instruction should cover a comprehensive range of skills that would typically be acquired through incidental learning during adolescence. Information about managing relationships and dating, as well as differentiated instruction (greater number of sessions and more in-depth, explicit instruction) of the school's SRE curriculum should be delivered to the student. For specific SRE resources for young people with Down syndrome, see the Resources section.

Diplomas and Credentials

In addition to celebrating the achievements of the student, consideration must be given to their achieving accreditation and/or qualifications that will enable them to realize their goals (e.g., achieving diplomas or credentials that are a prerequisite for specific courses, vocational or on-the-job training or employment opportunities outside of school). Each year, during the student's annual review, consideration must be given to the postsecondary goals of the student, and educational supports and programs should be incorporated to support those goals.

Many students with Down syndrome can complete high school-level cumulative assessments that are a prerequisite for a standard diploma or credential attainment (e.g., New York State Regents Exams or California High School Exit Exam). Accommodated and/or modified assessments need to be provided where appropriate and permitted for individuals with disabilities.

Independence skills

Not all students end up pursuing higher education after high school graduation. Some students choose to go directly into the workforce. It is important for schools to offer courses that teach skills needed in the workforce. However, these sorts of courses should not just be offered to students with disabilities. Independent skills and work experience courses benefit all students. Any work experience or life skills courses, such as cooking, can be done alongside typically developing peers.

Students with Down syndrome should participate in the same curriculum as their peers, and they should not be pulled out of the general education classroom to be taught a life skills or functional living-directed curriculum.

Students with disabilities should always be given the opportunity and choice to pursue a higher education if they wish to do so.

Transition planning for the high school student

IDEA mandates transition planning for students begin at age 16 and continue each year thereafter; many states require this work to begin even earlier. Transition planning should be student-centered, focusing on the individual's aspirations, talents and interests, and it should form the basis for planning into young adulthood, rather than focusing only on the next stage of education. Plans and opportunities should be sought to effectively prepare the young person for post-high school life and employment. To be of most benefit, transition planning should begin as early as reasonably possible but no later than age 14. It should address course of study, program goals, work-based learning experiences (to be done outside of school) and social skill development that will ensure post-high school success. The IEP team should deliberately seek out the direct input of the student by including them in meetings and incorporating their wishes as a primary component of the plan.

Families should elect to access local agency teams (e.g., ARC, ACCESS-VR, etc.) who provide essential support, respite care and funding. These agencies can also provide support for transitions after high school for students moving on to college or seeking employment.

Students with Down syndrome should have access to the same curricular choices during high school as typically developing peers. Such opportunities may include dual credit courses, vocational training and work-based learning placements in the community outside of school hours.

For more information on transition planning see “A Transition Guide” from the United States Department of Education: Office of Special Education and Rehabilitative Services. (<https://sites.ed.gov/idea/files/postsecondary-transition-guide-august-2020.pdf>)

Postsecondary education and training

While options for inclusive and supportive educational placements at the elementary and secondary levels are becoming more prevalent across the U.S., there remains a need to create inclusive opportunities at the higher education level. In the past, students with Down syndrome who had completed their elementary and secondary studies in inclusive environments may have been closed off to continuing educational courses due to the learning disabilities associated with the Down syndrome diagnosis. To date, there are an increasing number of institutions of higher education (community colleges, private colleges and universities) that are creating inclusive opportunities for students with various disabilities. For more information on higher education and training see Think College resources at <https://thinkcollege.net/>.

Young people with Down syndrome frequently lack meaningful access to inclusive postsecondary education opportunities because in almost all situations IDEA protections do not extend past high school. Despite significant improvements contained in the Higher Education Opportunity Act of 2008 and the Strengthening Career and Technical Education for the 21st Century Act of 2018, inclusive practice is not the functional norm in postsecondary education. As a result, young people with Down syndrome – and other disabilities – often have limited access to higher education, culturally-based developmental opportunities and vocational training. Practical barriers to inclusion in postsecondary education and vocational training need to be removed to make the transition to adult life and employment an equitable experience for all individuals. In July 2018, our colleagues on the Inclusive Higher Education Committee released a [report](#) containing recommendations to promote inclusion in postsecondary education through improved implementation and policy alignment.

Many students are denied access to vocational programs due to existing academic deficits (e.g., reading level). Accommodations should be made to support individuals to obtain the highest level of training that they are equipped to complete. Teachers need to be able to modify written materials and differentiate instruction and training in postsecondary programs.

Transportation is an issue that is often left unsupported when individuals with disabilities pursue vocational training at local community colleges. Support for safe and effective travel, to and from the educational site and within the educational site, should be considered by families, institutions of higher education and community agencies supporting the student.

The models of best practice identified in inclusive residential colleges, such as Marshall University and Inclusive U at Syracuse University, should be studied and replicated. Training to meet the needs of diverse learners, including the population of students with varying degrees of disability, should be considered a prerequisite qualification for educators at institutions of higher education and local community colleges.

Inclusive Higher Education Criteria

Checklist:

- Students take classes in the same classrooms and buildings as everyone else at the postsecondary school.
- Students can access accommodations or tutoring through their school.
- Students are allowed to choose an area of study and the classes they want to take.
- Students can receive a diploma or certificate from the postsecondary school or program as long as they complete the appropriate coursework and requirements.
- Students are allowed, and encouraged, to participate in any extracurricular groups or clubs on and off campus.
- Students are given the opportunity and supports to live on campus in a dorm or apartment if they wish.
- Students with Down syndrome are required to follow the same guidelines, laws and rules that all students on campus must follow.
- Students are able to access their own money, tuition costs, grants or scholarships and are given the autonomy to control their own bank accounts.

Action required

Equal access to vocational training programs and inclusive higher education opportunities should be provided by all accredited colleges and universities.

Removal of barriers to accessing funding, such as federal aid, grants or work study programs, for training or educational programs should be supported by supporting agencies and families.

College-level and vocational educators should receive regular training in accommodating and modifying instruction and materials to meet the needs of a diverse group of learners; some of which may have varying degrees of disability.

All universities that offer teacher training should require courses on inclusion of students with disabilities into the general education classroom and curriculum.

Students should be able to progress through general education courses, working at a level that is meaningful to the individual. All courses should be credit-bearing courses that are accommodated or modified in line with the student's needs. All progress should be recognized and celebrated.

Education and/or quality vocational training at a postsecondary level must build on skills and knowledge and contribute to the realization of individual potential and preparedness for adulthood. Appropriate opportunities will be tailored to individual needs and aspirations. A range of options for continued education should be available to this, and all, populations.

A vehicle should be added to federal data collection to include the number of students with disabilities being included as well as specific action steps to ensure the inclusion of all students in future years. Any district or state which is found to have stagnant or decreasing numbers of students included in the general education classroom should receive appropriate attention and support from state or federal Departments of Education.

Conclusion

It is our abiding belief that the information contained in these guidelines can benefit young people with Down syndrome – and those who are called to educate them – by breaking down barriers. These barriers exist not just in our schools, but in our communities as well. These walls have been built upon a faulty foundation – the conjured premise that, for some reason, difference requires division.

Years of research and experience have demonstrated that the best way forward is together; inclusive education leads to the best outcomes for young people with Down syndrome of all ages and abilities. The information and data presented here are meant to describe the precepts of effective teaching based on an understanding of the person, both as an individual and as an integral component of the group. It is our duty, and our joy, to share this information with as many educators, families and policymakers as we can.

Our final call to action is to you, the reader. Our ask is simple: please join us.

If you have learned from this work, please share it. Discuss it. Bring it to your schools and your communities. And then please connect with us so that we might learn more. It is our intention that these guidelines be a living document, growing and improving alongside an ever-changing cultural understanding of the potential of individuals with Down syndrome. The more people begin to understand that an inclusive society is a better society, the more we all will learn and the better off we all shall be.



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Supporting memory

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176. Broadley, I., MacDonald, J., & Buckley, S. (1994). Are children with Down syndrome able to maintain skills learned from a short-term memory training program? *Down Syndrome Research and Practice*, 2(3), 116–122. <https://doi.org/10.3104/reports.41>
177. Comblain, A. (1999). Working memory in Down's syndrome : Training the rehearsal strategy, *Down Syndrome Research and Practice* 2(3), 123–126.
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Teaching number

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Education and Inclusion Resources

Inclusive Schooling: <https://www.inclusiveschooling.com/> Dr. Julie Causton & Dr. Kristie Pretti-Frontczak offer resources supporting administrators, educators and families who wish to create more caring, creative inclusive schools for all learners. Check out their definition of inclusive education.

SWIFT school wide integrated framework for transformation <http://www.swiftschools.org/>

Ties Center. <https://tiescenter.org/> TIES Center is the national technical assistance center on inclusive practices and policies. Includes IEP resources at <https://files.tiescenter.org/files/jfFmPnDMMY/ties-brief-3>. You can find the more comprehensive resource at <https://publications.ici.umn.edu/.../comprehensiv.../main...>

New Jersey Coalition for Inclusive Education: see their work and resources <https://www.njcie.org/about-inclusive-ed>

Universal Design

CAST is a nonprofit that works to expand learning opportunities for all individuals through Universal Design for Learning (UDL). UDL is a framework to improve and optimize teaching and learning through flexible curricula for diverse learners based on how people learn.

http://www.cast.org/index.html#VTV-iH_D_ZQ

University of Maine's Inclusive Design Page

This page includes resources and considerations for designing environments so that the greatest number of people can use them without the need for adapting. Questions and resources specific to early childhood settings include how universal design applies to planning the curriculum, and the development of teaching practices and materials so the widest range of learners can participate.

<http://umaine.edu/expandinclusiveopp/what-is-universal-design/>

5mooreminutes.com

"Five Moore Minutes is a website with videos dedicated to empowering schools and classrooms to support All Learners! Created by Shelley Moore, this website is designed with teachers in mind. As educators, we don't always have time, so this website and video series offers resources, research, and professional development activities and inspiration in 5 minute chunks."

Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs (2015) United States Department of Health and Human Services' United States Department of Education. <https://www2.ed.gov/about/inits/ed/earlylearning/inclusion/index.html>

A Transition Guide, United States Department of Education: Office of Special Education and Rehabilitative Services. <https://sites.ed.gov/idea/files/postsecondary-transition-guide-august-2020.pdf>

[FINDING A GREAT FIT: IMPROVING THE SCHOOL CHOICE PROCESS FOR STUDENTS WITH DISABILITIES final_finding_a_great_fit_report_1.pdf \(crpe.org\)](#)

Causton-Theoharis, J. & Kasa, C. (2012). Achieving Inclusion: What every parent should know when advocating for their child. Pittsburgh, PA. PEAL Parent Center. [Inclusion – The PEAL Center](#)

Kasa, C., & Causton-Theoharis, J. (2012). Writing an Inclusive Individualized Education Plan (IEP). Colorado Springs, CO. PEAK Parent Center. [Writing an Inclusive Individualized Education Plan \(IEP\) | PEAK Parent Center](#)

Kasa, C., & Causton-Theoharis, J. (2012). Creating Successful Inclusive Placements: Practical strategies for teachers. Pittsburgh, PA. PEAL Parent Center. [Inclusion – The PEAL Center](#)

Jorgensen, C.M. (2018) It's More than "Just Being In": Creating Authentic Inclusion for Students with Complex Support Needs. Brooks.

GiGi's Playhouse Down Syndrome Achievement Centers: gigisplayhouse.org

GiGi's At Home and GiGi's On Demand: gigisplayhouse.org/gigisathome/

Down syndrome-specific resources

National Down Syndrome Society Resources

<https://www.ndss.org/>

NDSS Inclusive Education

<https://www.ndss.org/inclusive-education-resources/>

<https://www.ndss.org/ndss-inclusive-education-webinar-series/>

The Learning Program <https://www.dsfc.org/learning-program-orange-county/> Provides resources , online and face-to-face programs to support parents and educators.

Down Syndrome International <https://www.ds-int.org/> has developed education guidelines to support the development of inclusive education for children with Down syndrome worldwide and focuses on international human rights law and the policies which need to be implemented at state, school and in teacher education to achieve this <https://www.ds-int.org/blog/launch-of-our-education-guidelines>

DSEUSA Resources

DSE online training courses for preschool and school educators....

<https://www.down-syndrome.org/en-us/services/training/courses/>

See and Learn materials for developing language, reading and number

<https://www.seeandlearn.org/en-us/>

RLI Reading and Language intervention resources

<https://www.down-syndrome.org/en-us/resources/teaching/rli/>

The National Down Syndrome Congress www.ndsccenter.org actively advocates for inclusive education across the lifespan from early intervention through postsecondary education. NDSC collaborates with the U.S. Department of Education's TIES Center, which focuses on inclusive practices and policies for students with significant cognitive disabilities. NDSC also leads the Inclusive Higher Education Committee and plays a pivotal role in the development and accreditation of inclusive postsecondary education programs across the country.

Massachusetts Down Syndrome Congress Center on Inclusive Education - MDSC See their resources and their Meaningful Inclusion Manual for students with Down syndrome: Resource Guide for Educators. <https://mdsc.org/centers-of-excellence/center-on-inclusive-education/>

Down Syndrome Guild of Greater Kansas City See their resources <http://stg.kcdsg.org/seminarseries.php>, <http://stg.kcdsg.org/dsspecialists.php>

HEALTH - resources and guidance

Down Syndrome Medical Interest Group – USA <http://www.dsmig-usa.org/>

American Academy of Paediatrics – USA approved guidelines

<http://pediatrics.aappublications.org/content/pediatrics/128/2/393.full.pdf>

Down Syndrome Medical Interest Group – UK

<http://www.dsmig.org.uk/> - UK website

<http://www.dsmig.org.uk/information-resources/> - growth charts, personal child health record insert for babies with Down syndrome and much more

Down syndrome clinic to you – an online health service provided for families by the Massachusetts General Hospital/Harvard Medical School Down syndrome specialist clinic - <https://www.dsc2u.org/>

Some recommended books and links

Speech and language

Libby Kumin (2012) *Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals* (Topics in Down Syndrome). Woodbine House; 3rd edition

Education

R. Faragher & B. Clarke (Eds) *Educating Learners with Down syndrome*. Routledge. Excellent on behavioural approaches.

Behavior

D. Stein. (2016) *Supporting positive behavior in children and teens with Down syndrome; the respond don't react method*. Woodbine House.

Evanovich, L., Freeman, J., George, H., Simonsen, B., Sugai, G. (2019) *PBIS Practitioner's Guide: Preventing Restraint and Seclusion in Schools*. OSEPTA Center on PBIS, University of Oregon.

Autism and Down syndrome

M. Froehle & R. Zaborek. (2013) *When Down syndrome and autism intersect*. Bethesda, MD, USA: Woodbine House pp

<http://www.ds-asd-connection.org/> autism and down syndrome

Down syndrome and autistic spectrum disorder <https://www.ndss.org/resources/dual-diagnosis-syndrome-autism/>

Teenagers, puberty, sexuality and relationships

T. Couwenhoven. (2012) *The boy's guide to growing up choices and changes during puberty*. Woodbine House

T. Couwenhoven. (2011) *The girl's guide to growing up choices and changes during puberty*. Woodbine House

T. Couwenhoven. (2007) *Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality: A Guide for Parents and Professionals*. Woodbine House

T. Couwenhoven. (2015) . *Boyfriends & Girlfriends: A Guide to Dating for People with Disabilities*. Woodbine House

Useful apps

See and Learn programs are all available as apps as well as kits and use photos for realistic illustrations. Full details of the contents of each step, what they teach and the level to start them are on this site - follow the links from this page <https://www.seeandlearn.org/>

Apps to teach vocabulary and sight words include **Special Words** which uses cartoon illustrations and has a large vocabulary. You need to make your own choices of words to teach your child. <https://www.specialiapps.org/en/special-words>

Story making apps for books and themes include **Special Stories** which is very easy to use for all ages – I use it to make books for adults as well as children- and **Pictello** <https://www.specialiapps.org/en/special-stories> <https://www.assistiveware.com/products/pictello>

Special Sentences app is a sentence building app from the makers of Special Stories and allows you to build many different sentences. It is 'open ended' and you need to choose sentences that are at the right level for your child or young person. It will be useful for older children who already use more sentences. The Special Words and Special Sentences and Special Stories apps work together, and you can transfer content between them. <https://www.specialiapps.org/en>

A number of other software/apps that support the development of sentences and making books are listed below and these may be used in the schools your young people attend.

<https://www.widgit.com/products/symwriter/index.htm>

<https://www.cricksoft.com/uk/clicker>

[errorlessteaching.pdf \(fau.edu\)](errorlessteaching.pdf)

Appendix A

American Legal History of Exclusion

In the early 1970s, children with intellectual disabilities and, indeed, “a majority of handicapped children in the United States ‘were either *totally excluded* from schools or [were] *sitting idly* in regular classrooms awaiting the time when they were old enough to “drop out.”” *Board of Educ. v. Rowley*, 458 U.S. 176, 179 (1982) (emphasis added) (quoting H.R. Rep. No. 94-332, p. 2 (1975)).

Rise of the IDEA to Promote Inclusion

In 1972, in *Pennsylvania Ass’n for Retarded Children v. Commonwealth*, 334 F. Supp. 1257 (E.D. Pa 1971) and 34 F. Supp. 279 (1972) (“PARC”), a court ordered school districts to provide educational services to all children with disabilities and to provide them due process hearings. This decision became the catalyst for Congress to pass what is now known as the IDEA. *Rowley*, 458 U.S. at 180 n. 2.

Under the IDEA, the overarching goal of special education is to provide each child with a disability with a Free Appropriate Public Education (FAPE). 20 U.S.C. § 1412(a)(1)(A). Importantly, given the conditions in the 1970s, “special education” is not a place detached from the regular education classroom; quite the contrary, the goal of the IDEA is to bring children with disabilities into the regular education classroom “to the maximum extent possible.”¹

To accomplish this, the IDEA envisions that supplementary aids and services will assist children to become included with their non-disabled peers:

Supplementary aids and services. *Supplementary aids and services* means aids, services and other supports that are provided in regular education classes, other education-related settings and in extracurricular and nonacademic settings, to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate in accordance with §§ 300.114 through 300.116.

34 C.F.R. § 300.42; accord, 20 U.S.C. §1401(33).

Only when Supplementary Aids and Services are *not effective* in the regular education classroom can a school district even consider an alternative placement. Put differently, children should be removed from regular education only when Supplementary Aids and Services are unsatisfactory and, even then, they can be removed only to the *minimum extent possible*. This ensures that persons with an intellectual disability do not have to earn their way *into* an integrated setting by first proving themselves in a segregated setting.

¹ “Maximum extent appropriate” is the language which has given meaning to terms such as “least restrictive environment,” “mainstreaming,” or “inclusion.”

States Must Have Inclusive Procedures

Before accepting federal money, each state in the United States must have:

[P]rocedures to assure that, to the **maximum extent appropriate**, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, **and that special classes, separate schooling or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.**

42 U.S.C. 1412(5) (emphasis added); Bd of Educ v. Rowley, 102 U.S. 176, n. 24 (1982).

Inclusion and the IEP

The expectation of inclusion is also reflected at the local level—for parents, teachers and support staff. The legal contours of a child’s Individualized Education Plan (IEP) demand the regular education classroom be considered first.

Requirements in the IEP such as “present levels of performance (PLoPs),” “measurable annual goals (MAGs)” and “supplementary aids and supports (SAS)” all aim at regular education first:

The term “individualized education program” or “IEP” means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section and that includes—

(I) a statement of the child’s **present levels of academic achievement and functional performance**, including—
 (aa) how the child’s disability affects the child’s involvement and progress in the **general education curriculum**;
 (bb) for preschool children, as appropriate, how the disability affects the child’s participation in appropriate activities; and (cc) for children with disabilities who take alternate assessments aligned to alternate achievement standards, a description of benchmarks or short-term objectives;

(II) a statement of **measurable annual goals**, including academic and functional goals, designed to— (aa) meet the child’s needs that result from the child’s disability to enable the child to be involved in and make progress in the **general education curriculum**; and (bb) meet each of the child’s other educational needs that result from the child’s disability;

(III) a description of how the child’s progress toward meeting the annual goals described in subclause (II) will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided;

(IV) a statement of the special education and related services and **supplementary aids and services**, based on peer-reviewed research to the extent practicable, to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided for the child—

(aa) **to advance appropriately toward attaining the annual goals**;

(bb) **to be involved in and make progress in the general education curriculum** in accordance with subclause (I) and to participate in extracurricular and other nonacademic activities; and

(cc) to be educated and participate with other children with disabilities and nondisabled children in the activities described in this subparagraph;

(V) **an explanation of the extent, if any, to which the child will not participate with nondisabled children in the**

regular class and in the activities described in subclause (IV)(cc);

(VI) (aa) a statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on State and districtwide assessments consistent with section 1412(a)(16)(A) of this title ; and (bb) if the IEP Team determines that the child shall take an alternate assessment on a particular State or districtwide assessment of student achievement, a statement of why— (AA) the child cannot participate in the regular assessment; and (BB) the particular alternate assessment selected is appropriate for the child;

(VII) the projected date for the beginning of the services and modifications described in subclause (IV), and the anticipated frequency, location, and duration of those services and modifications; and

(VIII) beginning not later than the first IEP to be in effect when the child is 16, and updated annually thereafter— (aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; (bb) the transition services (including courses of study) needed to assist the child in reaching those goals; and (cc) beginning not later than 1 year before the child reaches the age of majority under State law, a statement that the child has been informed of the child’s rights under this chapter, if any, that will transfer to the child on reaching the age of majority under section 1415(m) of this title. 20 U.S.C. §1414(d).

Congress Again Supports Inclusion in 2004

Thirty years after PARC and the passage of the IDEA in the 1970s, Congress returned to the importance of general education for children with disabilities. Writing “Congress finds” into the 2004 Reauthorization of the IDEA, the law now states:

Congress finds the following:

Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by

A) having high expectations for such children and ensuring their **access to the general education curriculum in the regular classroom, to the maximum extent possible;**

C) ...children [will] benefit from such efforts and that special education can become a **service for such children rather than a place where such children are sent;** and

D) **providing appropriate special education and related services, and aids and supports in the regular classroom, to such children, whenever appropriate.**

20 U.S.C. §1400(c)(5).

Down Syndrome-Specific Cases and Challenges

Inclusion cases in the United States for children with intellectual disabilities, and Down syndrome specifically, support the inclusion preference. However, the legal tests, while similar, are not entirely uniform.

In the United States, children with Down syndrome have a legal right to a “challenging objectives.” For a child with Down syndrome, this is almost always the regular education classroom, not a segregated classroom where unchallenging curriculum often exists. As the United States Supreme Court found in 2017:

[A] student offered an educational program providing “merely more than *de minimis*” progress from year to year can hardly be said to have been offered an education at all. For children with disabilities, receiving instruction that aims so low would be tantamount to “sitting idly . . . awaiting the time when they were old

enough to ‘drop out.’ The IDEA demands more. It requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances.

Andrew F. v. Douglas Cty. Sch. Dist. RE-1, 137 S. Ct. 988, 1001 (2017).

As mentioned, in the United States, Courts of Appeals have used slightly differing analyses to assess inclusion for children with Down syndrome and intellectual disabilities. These cases are useful for reconciling the mandate of educating children, to the maximum extent appropriate, with their non-disabled peers, with the individualized determination of the least restrictive environment for each child.

A. The “Portability” Principle

The Sixth Circuit Court of Appeals covers Michigan, Ohio, Kentucky, and Tennessee. The “*Roncker* test” is used in these states. *Roncker ex rel. Roncker v. Walter*, 700 F.2d 1058 (6th Cir. 1983). The *Roncker* case involved a child with an intellectual disability who was placed in a separate county school without access to any children without disabilities.

Under *Roncker*, one must balance the benefit from inclusion with any benefit from the more intensive (segregated) setting. Then, importantly, one must ask whether the perceived benefit from the more intensive setting also can be provided in the inclusive classroom. If it can, it must be. This has become known as the “portability test”—asking whether any perceived benefit of the segregated classroom can be delivered (“ported”) into the regular education classroom.

As a practical example, if one-on-one time is a *perceived benefit* in a segregated classroom, *Roncker* would ask whether a paraprofessional or other aide may be able to deliver such time within the regular education classroom. This may be referred to as “push in” lessons. Alternatively, “pull out” or “resource” time in conjunction with the regular education classroom may prevent segregation to a separate classroom. If so, the perceived benefit is not met.

B. “Basic Disagreement” With Mainstreaming As a Concept

Roncker has another important lesson. Sometimes, school personnel will claim that inclusion is too difficult for a child with Down syndrome, or that a segregated classroom is “better” academically. This may reflect—and often does—a basic disagreement with, or lack of understanding, of how inclusion works. This is insufficient. “The perception that a segregated institution is academically superior for a handicapped child may reflect no more than a basic disagreement with the mainstreaming concept. Such a disagreement is not, of course, any basis for not following the Act’s mandate.” *Roncker*, at 1063.

The *Roncker* test has been adopted by the Fourth Circuit Court of Appeals which covers Maryland, North Carolina, Virginia, South Carolina, and West Virginia. *Devries v. Fairfax County Sch. Bd.*, 882 F.2d 876 (4th Cir. 1989). It was approved and updated by the Sixth Circuit in the expansive decision of *L.H. v. Hamilton Cty. Dep’t of Educ.*, 900 F.3d 779 (6th Cir. Aug. 20, 2018).

In *L.H.*, the school district proposed moving a child with Down syndrome from a regular education elementary school classroom to a separate school district where he would be placed in a segregated classroom. The school district argued that supports like “pre-teaching” and “re-teaching” were only available in the segregated classroom. The Sixth Circuit rejected that view, as such supports are readily available in the regular education classroom.

The decision in *L.H.* reminds judges that school district “expertise” is not paramount to the least restrictive en-

vironment decision; parental input is just as important. Additionally, echoing Roncker, “a placement which may be considered better for academic reasons may not be appropriate because of the failure to provide for mainstreaming.” *L.H.*, 900 F.3d at 789. In *L.H.*, the Sixth Circuit applauded the decision of the lower court, including the recognition that a child with a disability need not “keep pace” with students without a disability in order to remain included. *L.H. v. Hamilton Cty. Dep’t of Educ.*, 2016 U.S. Dist. LEXIS 153322 (E.D. Tenn. Nov. 4, 2016).

L.H. distilled Roncker’s inclusion analysis into three “considerations” for when inclusion is not appropriate: “(1) the student would not benefit from regular education; (2) any regular-class benefits would be far outweighed by the benefits of special education; or (3) the student would be a disruptive force in the regular class.” *L.H.*, 900 F.3d at 789.

C. Behavioral Challenges

A school district may cite a child’s *misbehavior* as a reason against inclusion. This can be a frustrating argument, as a young child with Down syndrome may need time or supports to adjust to a new setting. Other times, a child may misbehave simply due to an inability to effectively *communicate*, as behavior is a form of communication. The key to overcoming a behavior-based argument is to focus on whether the child was given behavioral supports to *manage* the behavior prior to being moved to a segregated classroom. Such supports may include, but are not limited to, a Functional Behavior Assessment (FBA) followed by a Behavior Intervention Plan (BIP), and an augmentative and alternative communication device (an “AAC”).

Where behavioral supports—such as a Functional Behavior Assessment and/or a Behavioral Intervention Plan—have not been afforded, then the behavior of a child with Down syndrome can *not* be used as the basis for segregating the child. *J.A. v. Smith Cty. Sch. Dist.*, 364 F. Supp. 3d 813, 831 (M.D. Tenn. 2018) (applying *L.H.* and rejecting district’s behavior argument where it had not provide supports); see also, *Oberti v. Bd. of Educ.*, 995 F.2d 1204 (3d Cir. 1993)(same). For this reason, it is important to analyse the extent to which any misbehaviors have been properly managed with supports. For a case documenting the need for, and a description of a communication device, see, *J.A.*, *supra*, 364 F.Supp. 3d at 822-23.

D. On Par Performance (“Mastery”) Not Required; Full Inclusion or Partial Inclusion

The Fifth Circuit Court of Appeals covers Louisiana, Mississippi, and Texas. In *Daniel R.R.*, 874 F.2d 1036 (5th Cir. 1989), the Court considered the rights of a six year-old boy with Down syndrome to be included.

The Court ably recognized that children with disabilities do not have to learn at the same rate, or mastery, as their non-disabled peers to enjoy inclusion:

We recognize that some handicapped children may not be able to master as much of the regular education curriculum as their nonhandicapped classmates. This does not mean, however, that those handicapped children are not receiving any benefit from regular education. Nor does it mean that they are not receiving all of the benefit that their handicapping condition will permit. If the child’s individual needs make mainstreaming appropriate, we cannot deny the child access to regular education simply because his educational achievement lags behind that of his classmates.

Daniel R.R. v. State Bd. of Educ., 874 F.2d 1036, 1047 (5th Cir. 1989).

The Court also recognized that inclusion involves more than purely “academic” benefits:

[E]ducational benefits are not mainstreaming’s only virtue. Rather, mainstreaming may have benefits in and

of itself. For example, the language and behavior models available from nonhandicapped children may be essential or helpful to the handicapped child's development. In other words, although a handicapped child may not be able to absorb all of the regular education curriculum, he may benefit from nonacademic experiences in the regular education environment.

Daniel R.R. v. State Bd. of Educ., 874 F.2d 1036, 1047-48 (5th Cir. 1989)

With these principles in mind, the Court adopted a two-part test. First, one must ask whether the child has received "supplementary aids and services" along with modifications to the regular education program. If that has not occurred, then the school is in violation of the IDEA and the inquiry stops there. But if supplementary aids and services and modifications have occurred, one must then consider whether the school delivered as much inclusion as possible. In other words, inclusion is not "all or none" proposition, but a continuum. This has given rise to considerations of partial inclusion versus full inclusion.

E. A Full Range of Supplementary Aids and Services: No Token Gestures; and Training for Teachers

The Third Circuit Court of Appeals covers Delaware, New Jersey, and Pennsylvania. In one of the most thoughtful opinions on the issue of inclusion, in *Oberti v. Bd. of Educ.*, 995 F.2d 1204, 1216 (3d Cir. 1993), the Third Circuit Court considered the needs of an eight year old child with Down syndrome. The school had recommended a segregated classroom consisting of only children with disabilities. The student's expert, a professor of education, recommended the following strategies for successful inclusion, which the Court found persuasive:

- (1) modifying some of the curriculum to accommodate the student's different level of ability;
- (2) modifying only the student's program so that he would perform a similar activity or exercise to that performed by the whole class, but at a level appropriate to his ability;
- (3) "parallel instruction," i.e., having the student work separately within the classroom on an activity beneficial to him while the rest of the class worked on an activity that the student could not benefit from; and
- (4) removing the student from the classroom to receive some special instruction or services in a resource room, completely apart from the class.

In deciding the case in favor of the student, the Third Circuit Court of Appeals explained how such a *range* of aids and services must be considered, not "mere token gestures":

Accordingly, the school "must consider the whole range of supplementary aids and services, including resource rooms and itinerant instruction," speech and language therapy, special education training for the regular teacher, behavior modification programs, or any other available aids or services appropriate to the child's particular disabilities. The school must also make efforts to modify the regular education program to accommodate a disabled child. If the school has given no serious consideration to including the child in a regular class with such supplementary aids and services and to modifying the regular curriculum to accommodate the child, then it has most likely violated the Act's mainstreaming directive. The Act does not permit states to make mere token gestures to accommodate handicapped students; its requirement for modifying and supplementing regular education is broad.

Oberti v. Bd. of Educ., 995 F.2d 1204, 1216 (3d Cir. 1993).

In a similar case involving an eight year-old child with Down syndrome, the *Oberti* approach was adopted by the Second Circuit Court of Appeals which covers New York, Connecticut, and Vermont. *P. v. Newington Bd. of Educ.*, 546 F.3d 111 (2d Cir. 2008). Finding in favor of the child, the Court said it must be deferential to state educational authorities, but not too deferential. "[E]ven when educational authorities act with the best intentions they may

sometimes fall short of their obligations under the IDEA, and courts must then act to ensure compliance with Congress's directives." *P v. Newington Bd. Of Education*, 546 F.3d 111, 120-121 (2d Cir. 2008).

F. Using Resource Rooms or Itinerant Instruction to Assist with Inclusion

The Eleventh Circuit Court of Appeals covers Alabama, Florida and Georgia. The case of *Greer v. Rome City Sch. Dist.*, 950 F.2d 688, 698 (11th Cir. 1991) involved a ten year old child with Down syndrome who sought inclusion.

The Court adopted the *Daniel* test from the Fifth Circuit Court of Appeals, noting that resource rooms and itinerant instruction are supports that must be tried in regular education:

[T]here is no indication that, in developing the IEP and [the student's] proposed placement, the school district considered the option of [the student] remaining in a regular education class with supplementary services such as a resource room, itinerant instruction by an instructor who travels from classroom to classroom, or curriculum adjustment.

Greer v. Rome City Sch. Dist., 950 F.2d 688, 692 (11th Cir. 1991)

G. Costs As a Factor

The Ninth Circuit Court of Appeals covers California, Arizona, Alaska, Guam, Hawaii, Idaho, Montana, Nevada, Oregon, and Washington. The *Rachel H.* case involved an eleven year old girl with a "moderate" intellectual disability. The school argued that the student should be included only for art, music, recess and lunch. The Ninth Circuit used a four-factor test to determine whether Rachel's full inclusion was appropriate:

- (1) the educational benefits of placement full-time in a regular class;
- (2) the non-academic benefits of such placement;
- (3) the effect the student had on the teacher and children in the regular class; and
- (4) the costs of mainstreaming the student.

Sacramento City Unified Sch. Dist., Bd. of Educ. v. Rachel H. by & Through Holland, 14 F.3d 1398, 1404 (9th Cir. 1994). Applying the factors, which included helpful testimony from the teacher, the Court agreed with the lower court judge and concluded that a full-time regular education classroom was appropriate for the student and, while costs are a factor, any costs could be offset by applying for a waiver to the state.

Summary

The IDEA itself has strong Congressional preferences for inclusion of children with disabilities with their non-disabled peers "to the maximum extent appropriate." Such inclusion is accomplished through supports, services, modifications, and teacher training. However, inclusion is not absolute. As a result, the Courts of Appeal all seek to honour the inclusion preference but with various individualized balancing tests. In all cases, parents, students and teachers should determine whether the student has been given a real (not token) opportunity to be included through supports, services, modifications and training. That includes not only supports for academics but also behavioral functioning. With these supports in place, removal of the student with Down syndrome from the general education classroom should be unnecessary.