Supporting the Student With Down Syndrome in Your Classroom

Information for Teachers
What is Down Syndrome?

Down syndrome is a genetic condition that occurs in 1 of every 691 births. It affects people of all ages, races and economic levels and is the most frequently occurring chromosomal abnormality. More than 350,000 people have Down syndrome in the United States alone. The most common form of Down syndrome, Trisomy 21, occurs when there are three instead of two number 21 chromosomes in every cell of the body. Instead of 46 chromosomes, a person with Trisomy 21 has 47. This extra genetic material alters the course of development and causes the characteristics associated with Down syndrome.

Common Myths

Although information about Down syndrome is increasingly more accurate, there are still a few misconceptions that the general public may have about this condition.

Myth: Down syndrome is a rare genetic disorder.
Truth: Down syndrome is the most commonly occurring genetic condition. One in every 691 live births is a child with Down syndrome, representing approximately 6,000 births per year in the United States alone. Today, more than 400,000 people in the United States have Down syndrome.

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

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

Myth: People with Down syndrome are severely “retarded.”
Truth: Most people with Down syndrome have IQs that fall in the mild to moderate range of intellectual disability (formerly known as “retardation”). Children with Down syndrome fully participate in public and private educational programs. Educators and researchers are still discovering the full educational potential of people with Down syndrome.

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

Myth: Parents will not find community support in bringing up their child with Down syndrome.
Truth: In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.
Myth: Children with Down syndrome must be placed in segregated special education programs.
Truth: Children with Down syndrome have been included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom for all subjects. The current trend in education is for full inclusion in the social and educational life of the community. Increasingly, individuals with Down syndrome graduate from high school with regular diplomas, participate in post-secondary academic and college experiences and, in some cases, receive college degrees.

Myth: Children with Down syndrome “plateau”.
Truth: Learning is a lifelong experience for people with Down syndrome, just like everyone else. The idea that a child with Down syndrome would “plateau” or decline in rate of development is more likely due to an educational program that does not continue to meet the needs of the student.

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

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

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.
Truth: People with Down syndrome date, socialize, form ongoing relationships and marry.

Myth: Down syndrome can never be cured.
Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Is it Downs, Down’s or Down?

The correct terminology is Down syndrome. There is no apostrophe and there is no capital “s” in syndrome. The syndrome is named after the physician, Dr. John Langdon Down, who identified the common characteristics as a syndrome in 1866. A child with this condition is a child with Down syndrome, not a Down’s child or the Down’s kid in Mrs. Hall’s class. Parents will greatly appreciate your sensitivity when you address their child as a “person first” and not merely as a syndrome.
Health Concerns That May Affect Learning

Health Conditions Associated with Down Syndrome

In general, the following reminders and practices will promote improved classroom success:

- Be aware of physical characteristics and health conditions that may affect classroom success. It is important to note that behaviors you witness in the classroom may have a medical or health basis. Speak with the student’s parents to identify previous health conditions and ongoing medications, as these can affect ability to listen and follow directions. Recognize that unusual behaviors or situational responses may signal an illness which the child is unable to communicate.

- Ask parents to alert you to changes in their child’s health or sleeping patterns, as these factors can detract from their ability to solve problems. Schedule the most challenging academic areas in the morning. Tiredness at the end of the school day can significantly increase the time required to process information or directions and cause frustration and perceived behavior problems.

- Students with Down syndrome may require additional recovery time from illness; consider alternative activities and additional periods of rest in these cases. Recognize that non-routine activities (field trips, parties, etc.) can be physically or emotionally draining for students with Down syndrome. Avoid situations that set up a student for failure.

The following are some of the physical characteristics and health conditions that may affect the classroom success of students with Down syndrome:

**MUSCLE HYPOTONIA**

Hypotonia is a medical term used to describe decreased muscle tone (the amount of resistance to movement in a muscle). Symptoms of hypotonia include problems with mobility and posture, breathing and speech difficulties, lethargy, ligament and joint laxity, and poor reflexes.

To understand the physical demands that low muscle tone places on children with Down syndrome, imagine cooking dinner while wearing socks on your hands. Students with Down syndrome can get frustrated when their abilities to complete tasks are hindered by low muscle tone. Muscle development can require repetitive training.

- Allow extra time for a student with Down syndrome to complete tasks.
- Provide increased opportunities for practice.
- Work with physical therapists to identify and improve specific muscle development needs.
- To support fine motor development, use wrist and finger strengthening activities. Multisensory activities and materials work well. Provide opportunities to practice self-help skills such as using buttons and zippers.

**SPEECH INTELLIGIBILITY**

Speech intelligibility refers to the ability to be understood when speaking orally. This can be difficult for students with Down syndrome because of low muscle tone, jaw movement difficulties and motor planning difficulties.
To understand how your student with Down syndrome may feel, imagine communicating your needs while your mouth is full.

- Upon evaluation, many students with Down syndrome exhibit great differences between receptive (understanding) and expressive (spoken language production) language abilities. For this reason, their intelligence is often underestimated.
- Recognize that situational factors can impact communication and classroom performance, e.g., an impatient listener, anxiety, perceived pressure, embarrassment or lack of confidence.
- Use simple questions (5Ws and H), and allow extra response time. If your student uses American Sign Language (ASL), learn basic signs and teach them to the class.
- Peer group acceptance may hinge on the ability to communicate intelligibly. Goals for the classroom should include teaching the student with Down syndrome to communicate, in addition to teaching peers how to engage in meaningful interactions.
- Work with your district’s therapists to assist students with Down syndrome:
  - Speech therapists can design a speech remediation component to the IEP.
  - Occupational therapists can work on postural control required for speech.
  - Audiologists measure a child’s ability to hear.
  - Aides can provide one-to-one instruction for articulation skills.
- Students may exhibit an increase in stuttering when under stress. Attempt to ease stress by increasing the comfort level of the classroom.

**MEMORY**
Most students with Down syndrome will have short term or working memory difficulties. This makes it harder for them to access, understand and process information at the speed of other students, but it does not prevent them from learning the same information. Individual motivation is the key to learning!

Present information in a clear, ordered manner. Explain the links between information to build a system of knowledge.

- Allow more time to learn.
- Allow more practice to apply knowledge.

**COMPACT STRUCTURE OF EAR, NOSE AND THROAT**
Students with Down syndrome typically have compact bone and soft tissue structure of the ear, nose and throat. This increases their susceptibility to, and the severity of, upper respiratory and sinus infections. It may also increase sensitivity to loud sounds or vibrations. A child with Down syndrome may cover his ears or avoid activities that create loud noises. Be aware of the activity noise levels in and around your classroom. If appropriate, headphones can limit auditory distractions.

**SLEEP APNEA**
Recent studies indicate that as many as forty-five percent of individuals with Down syndrome may suffer from sleep apnea. This is the term used when someone stops breathing for very short periods of time, usually ten to twenty seconds, during sleep. Sleep apnea can cause memory loss and intellectual impairment, and may make a student more tired and lethargic. Alternatively, it may result in hyperactivity (which is often inaccurately interpreted as an attention deficit disorder). If you recognize these issues in a student with Down syndrome, explore sleep patterns
(including snoring) with parents. Medical interventions can improve your student’s quality of life and school performance.

HEARING, VISION AND THYROID PROBLEMS
It is estimated that sixty-five to eighty percent of children with Down syndrome have conductive hearing loss, and that fifty percent have vision problems. There is also a higher rate of hypothyroidism, which can cause sluggishness, weight gain and mental impairment.

Perform an annual hearing and vision screening. Note that hearing loss may fluctuate when fluid is present or when a student is experiencing ear pain. A student may not be “ignoring” your instructions, but may not be able to hear you. Inform parents of your observations. When left untreated, these problems can significantly affect a student’s ability to succeed academically and socially.

The following tips and tactics are recommended to improve the listening environment:
- Place the student at the front of the class.
- Speak directly to the student and supplement with signs, gestures or expressions.
- Use visual aids, e.g., write on the board.
- Rephrase and repeat questions or instructions often.

The following tips and tactics are recommended to support visual skills:
- Place the student at the front of the class.
- Use larger font.
- Use visual aids, e.g., signs on floors or walls.

HEART CONDITIONS
Forty to forty-five percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo cardiac surgery and can participate in classroom activities without restrictions. If a student has had or is scheduled to have surgery, ask the parents if it is appropriate to teach his or her classmates about the condition.

PAIN TOLERANCE
A recent study has confirmed what parents already knew. Individuals with Down syndrome express pain more slowly and less precisely than general population.

However, they are not insensitive to pain. They may not exhibit signs of distress when exposed to painful stimuli. Their pain threshold appears to be higher than the general population. Therefore, a teacher may have to be alert to other signals from the child to determine if they may not be feeling well or are injured.

References
Communication

Each student with Down syndrome is a unique individual and the same speech therapy approach will not be effective for every student. Therapy is always individualized based on a child’s particular strengths. Students with Down syndrome clearly want to communicate and many will need special techniques, strategies and exercises to assist them in their communication development. Refusal to comply or stubborn behavior may actually be caused by a student’s frustration with their ability to communicate effectively. The **Speech Therapist** will be able to offer suggestions for strategies to use in your classroom. Visuals like photographs are great tools for communication.

Gross Motor Skills

**Desk height** - It is important that all children have a comfortable workspace. It is especially important for a child with low muscle tone because proper support will help to alleviate fatigue.

**Foot Support** - Check to see that your student’s feet are not dangling from his chair but rather resting flat on the floor. Proper foot stability will not only lessen fatigue but will also provide trunk support.

**Hypotonia** - Low muscle tone may affect some body parts more than others. A student with Down syndrome may have difficulty sitting for an extended time on a floor without proper back support. Provide something to lean against.

“W” sitting should be discouraged as it stresses joints in the knees and hips.

Please consult with your student’s Physical Therapist for suggestions on increasing gross motor skill development.

Fine Motor Skills

Several factors may affect the fine motor skill development of children with Down syndrome.

- Low muscle tone, or hypotonia
- Shortened limbs - hands may be 10 to 30% shorter
- Ligament or joint instability

These factors may contribute to difficulty with small muscle activities such as handwriting. In addition, children with Down syndrome may have wrist bones that develop more slowly, decreased skin sensation or a delay in the maturation of the palmar reflex. Please consult with your student’s Occupational Therapist for suggestions on developing these skills.
How Do Children with Down Syndrome Learn?

As with all children, there is a wide range of abilities, behavior and physical development among children with Down syndrome. However, as a general rule, most children with Down syndrome learn best with a multi-sensory based program.

Teaching strategies for the student with Down syndrome

- **Visual Learners:** pair pictures with spoken word, demonstrate, model, visual cues, kinesthetic reinforcement, color coded, highlighted.
- **Auditory memory and auditory processing weak:** ALWAYS allow adequate response time.
- **Fewer short-term memory channels:** Break down directions into smaller steps, repetition. Repeat, repeat, repeat, small chunks of information.
- **Literal learners:** best to avoid slang, multiple meaning terms.
- **Learns:** at slower rate than typical peers

Curriculum Adaptation
Simplify, Supplement, Alter

There is no magic formula for adapting your classroom curriculum for your students with Down syndrome. Each student’s needs are unique. The process is simple, but it does require that all team members work collaboratively.

**Subtle adaptations** - Subtle accommodations to daily work will assist your student without drawing attention to the adaptation. For instance, textbooks with the same cover but different contents will minimize the variation.

**Same timetable/same subject** - Materials and methods may vary but if all students work on the same subject matter at the same time a student’s sense of competence will increase.

Allow **adequate response time**. Some students need time to process your question. Be patient.

**Visual accommodations** work best for your students with Down syndrome. Visual schedules may help compensate for memory difficulties.

A Word About Hugs

As with all children, it is also important to help children with Down syndrome learn appropriate social boundaries. Although hugging your teacher is encouraged in the early grades, children need to learn when this has become inappropriate and how to replace hugging with more appropriate social gestures. A hand shake, pat on the back, high 5, thumbs up sign, etc are all great replacements to hugging.

Consult your student’s Occupational Therapist for sensory diet needs.
The Home and School Partnership

The Down Syndrome Association of Greater St. Louis (DSAGSL) strongly believes that creative collaboration between all team members is the best strategy for success. Each child possesses a unique potential and when the parents, teachers, assistants, specialists, school administrators, bus divers, etc. all work in the best interest of the child, your student will have a productive year. We offer a Down Syndrome Specialist Training Program for the team of general education and special education staff. Please contact us to enroll.
Great Resources for Teachers

Please call the DSAGSL at 314-961-2504 for information on any of these items. Many are available for loan in our library.

- **High Noon Books**. Adapted chapter novels. [www.academictherapy.com](http://www.academictherapy.com).
- Sandall, Susan & Schwartz, Ilene. **Building Blocks for Teaching Preschoolers with Special Needs**, Brookes, 2002

**Websites that may be helpful:**
- Inclusion Solutions, [www.kcdsg.org](http://www.kcdsg.org) – Educators’ newsletter.
- Helpful newsletters at [www.dsgc.com](http://www.dsgc.com)
- Teaching math at [www.numicon.com](http://www.numicon.com) and [www.touchmath.com](http://www.touchmath.com)
- Excellent auditory and visual memory programs at [info@littlegiantsteps.com](mailto:info@littlegiantsteps.com)
- Materials to download from the Learning Program at [www.dsgoc.org/learning_program.htm](http://www.dsgoc.org/learning_program.htm)
Other Programs and Services offered by the Down Syndrome Association of Greater St. Louis

New/Expectant Parent Support Program
Medical Outreach Program
Family Conference
Educational seminars
Down Syndrome Specialist Program
Lending Library
Family Connections newsletter
Website: www.dsagsl.org
Friday E-mail blast
Speaker’s Bureau
Community Groups
Helpline/Information and Referral
Family Events
Bike Camp
Healthy Lifestyles program for teens & adults
Advocacy and Public Awareness

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The Mission of the DSAGSL is to benefit the lives of people with Down syndrome and their families through individual and family supports, information, public awareness, and advocacy.

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Down Syndrome Association of Greater Cincinnati
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NDSS
PREP Program
THE IEP TOOLKIT
Helping Families of Children with Down Syndrome Become Knowledgeable, Prepared, and Empowered Partners in the IEP Process

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The Jane and Richard Thomas Center for Down Syndrome
Division of Developmental and Behavioral Pediatrics
Cincinnati Children's Hospital Medical Center
This toolkit was written for you.
The special education system can be confusing, frustrating, and overwhelming. The Individualized Educational Plan (IEP) is the written document that outlines your child’s specific educational program. We know a strong IEP is necessary for our child’s individual needs to be met. Yet it is common for us to feel insecure and unprepared during our child’s IEP meeting. Surrounded by teachers, administrators, and special education personnel, our voice can get lost. This toolkit was written to help you find your voice.

As family members of a child with Down syndrome, we come to IEP meetings with love for our child and a commitment to his or her education. We must also come with a strong understanding of the IEP itself, detailed information about our child’s specific needs, and an understanding of appropriate goals. This IEP Toolkit is designed to help you gather the necessary information. Focused preparation is essential to the development of an effective educational plan, and a strong IEP leads to improved educational success for your child.

How to make this toolkit work for you:
The toolkit is structured very much like your child’s IEP. To help you prepare for your child’s IEP in a purposeful way, important sections of the IEP will be discussed and you will learn helpful ways to prepare for each section. Examples of weak and strong IEP components will also be provided. Most importantly, you will have an opportunity to write down specific information to be included within the various sections of your child’s IEP. Your completed toolkit can then be used to guide you as you engage in your child’s IEP meeting, increasing your knowledge, preparedness, and confidence.

Before you begin:
The IEP is driven by your child’s specific educational needs. In order to fully understand what those needs are, it is extremely helpful to gather information that answers the question, “What do I know about my child, his skills, and his progress?” To answer that question, gather as much meaningful information as you can about your child. Keep this information in close proximity as you complete the Toolkit as it will guide your planning. Information might include:

- Past IEPs
- Progress Reports
- School Evaluations (MFE, ETR)
- Therapy Reports (Speech, OT, PT)
- Report Cards/State Testing Results
- Work Samples
- Independent Evaluations
- Medical Information

If you do not have the information listed above, you can request much of it from your child’s school. It is always a good idea to make your request in writing, and be sure to date your request. Even if you are unable to gather a lot of information, continue to move through the Toolkit. Your personal knowledge of your child will still allow you to prepare for a strong IEP meeting.
Future Planning Section

Most IEPs begin with a section titled “Future Planning.” The purpose of this section is to give family members, as well as the individual with a disability, the opportunity to share their vision for the future. Although often given little attention in the IEP meeting, this section offers you an important opportunity to describe your vision for your child’s future. The goals on your child’s IEP should be written with your “Future Planning” goals in mind.

When shaping your future planning statement, consider your vision for your child’s academic levels, communication abilities, behavior, attention, independence, future education, and employment. A strong and detailed Future Planning statement sets the tone for a strong and detailed IEP.

Weak Future Planning Statement: “Mr. and Mrs. Jones would like John to do better in school and get a job.”

Strong Future Planning Statement: “John loves baseball and socializing. Upon graduation from high school, John sees himself working in a sports-related field. He hopes to have an apartment and continue to see his friends. Mr. and Mrs. Jones would like to see John’s communication, reading, and math skills improve so he can live independently and enjoy a paid job in a field of his choice.”

To Do: Take a few moments to consider your future desires for your child. If your child is able to discuss this with you, ask your child what he/she hopes to do in the future and incorporate your child’s vision in the Future Planning section. You might even record your child’s response so you can transcribe it for the IEP team. Write your ideas below and share them with the team at your IEP meeting.

Future Planning Ideas:

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Present Levels Section

The purpose of the Present Levels section is to provide a detailed description of where your child is today. This is one of the most important sections of the IEP, as it provides the reference point from which the IEP is written. If the Present Levels of Performance are incorrect or incomplete, it is likely that the IEP will be inappropriate or incomplete.

You may not be a teacher or evaluator, yet as a family member of a child with Down syndrome, you have invaluable information about your child’s present levels of performance. For example, you observe your child’s social skills, watch him read and write, and see his general attention span.

Weak Present Levels Statement: “Sarah is not reading on grade level.”

Strong Present Levels Statement: “Sarah can read about 20 sight words. She knows the sounds for about 15 letters, but cannot sound out unknown words. When a story is read to her, she is able to answer short questions about the story but cannot retell the story without adult help. On standardized testing, Sarah’s word identification skills fell at the 1.3 grade level on the Woodcock Reading Mastery Test.”

To Do:
Drawing upon your intimate knowledge of your child, consider your child’s present levels of performance in the areas listed below. You might consider what you have observed at home and in the classroom, your child’s work samples, and discussions with teachers. Write down your observations, ideas, and concerns. Make sure you consider tasks your child can do as well as tasks your child is struggling with or has not mastered. You may choose to make lists, jot down notes, or write complete sentences. Use the format that works best for you. The goal is to organize and clarify your knowledge about your child so you will able to develop strong IEP goals.

Reading (Consider letter/sound knowledge, sight word recognition, reading speed, comprehension of what is read, and reading testing results)

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Writing (Consider your child’s ability to form vertical/horizontal/diagonal lines, write letters, spell, write a sentence, write paragraphs or stories, and writing testing results)

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Math (consider counting, number recognition, calculation skills, money, time, math reasoning, and math testing results)

Language (consider ability to gesture/sign/speak, articulation, intelligibility, length of utterance, vocabulary, grammar, expressing needs, social communication, understanding language, following directions, and language testing results)

Attention (consider ability to focus and maintain attention, time on task, transitioning from task to task, impulsivity, and fidgetiness)

Behavior/Social Skills (consider response to teacher direction, following rules, conduct, frustration tolerance, interaction with peers, and solving social problems)

Gross Motor/Fine Motor (consider walking, running, movement up/down stairs, balance, strength, pencil skills, scissor skills, buttoning, and zippering)

Additional Areas of Importance (feeding, toileting skills, use of technology, etc.)
How to use the information you gathered:

Bring the above notes with you to the IEP meeting. As the team reads and/or discusses the Present Levels of Performance section, share your notes. If you feel the Present Levels section is not accurate or complete, ask that your information be added. It is important to note that your information may contradict what the school has stated. For example, the school may state, “Sarah is able to make 3-word utterances” when you have observed Sarah to make 5-word utterances. In that case, it is appropriate for you to ask that the school add the statement: “In the home environment, Sarah is able to make 5-word sentences.” In this way, your voice is heard and your specific knowledge of your child’s abilities is reflected in the IEP.

Measurable Annual Goals and Benchmarks/Objectives Section

Annual Goals:
The purpose of the Annual Goals section is to create a list of goals that will meet your child’s specific needs. Annual goals set the course for your child’s special education plan, and are designed to enable your child to progress in the general curriculum. Goals can be focused, strong, and encourage independence and learning. Goals can also be vague, weak, and result in minimal progress.

What makes a solid IEP goal?
- It Addresses a Need
- It is Specific
- It is Measurable
- It is Appropriately Challenging

Weak Annual Goal: “Ben will improve his reading skills.”

Strong Annual Goal: “Ben will demonstrate increased phonetic decoding and sight word identification skills.”

Benchmarks and Short-Term Objectives:
Special education law no longer requires the IEP team to come up with "benchmarks" or "short-term objectives." However, IEP teams can and often do write short-term objectives as a part of the Annual Goals section. Think of the goal as your final destination and the short-term benchmarks as the necessary stops along the way. The short-term objectives take us from where we are today (as listed in the Present Levels of Performance) to where we need to go (as listed in the Annual Goal).

What makes a solid IEP Benchmark / Short-Term Objective?
- It Breaks the Goal into Defined Steps
- It is Specific
- It is Measurable
- It is Appropriately Challenging

Weak Benchmark: “Ben will read one-syllable words.”

Strong Benchmarks: “By the end of first quarter, Ben will be able to use phonetic decoding to sound out consonant-vowel-consonant words with 75% accuracy. Ben will be able to read 20 sight words from the First Grade Dolch Word List with 80% accuracy.”
To Do:
IEP goals and benchmarks are driven by your child’s specific needs. Needs can be academic, behavioral, social, and functional. Read through the notes you took on the Present Levels section of this toolkit. Based on what you wrote about where your child is today, list what you believe your child needs in each area. For example, if you noted your son does not understand money, a need might be, “Brian needs to know coins and their values.” This need can then become a goal or objective on the IEP.

**Literacy/Reading Needs** (Does your child need to acquire or improve letter/sound knowledge, sight word recognition, reading speed, or comprehension of what is read?)

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**Writing Needs** (Does your child need to learn how to make lines/circles, copy or form letters, spell words, write a sentence, or write paragraphs or stories?)

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**Math Needs** (Does your child need to learn basic math concepts, counting, number recognition, computation, money, time, or how to solve math reasoning problems?)

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**Language/Communication Needs** (Does your child need to learn how to communicate with a technological device or through signing? Does your child need to improve articulation, intelligibility, length of utterance, vocabulary, grammar, social communication, or the ability to understand and follow directions?)

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Attention Needs (Does your child need to increase his focus, attention, time on task, or ability to transition from task to task?)

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Behavior/Social Skills Needs (Does your child need to improve his ability to follow teacher direction, follow rules, demonstrate good conduct, manage frustration, or interact with peers?)

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Motor/Physical/Functional Needs (Does your child need to improve fine motor skills, gross motor skills, balance, strength, feeding skills, or toileting skills?)

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Additional Needs (Does your child need to learn how to use a communication device, learn to sign, or learn vocational skills?)

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How to use the information you gathered:

Bring the above notes with you to the IEP meeting. As the team reads and/or discusses the Goals and Benchmarks and Short-Term Objectives section, check to see that the needs you have listed are included in the goals and objectives. If your listed needs are not reflected in the IEP, ask the team to write additional goals and objectives.

Warning! For children with Down syndrome, it is not uncommon for goals to be set rather low. Even with the best of intentions, special education teams may set a goal or objective for your child that he or she is already mastering or is close to mastering. For example, if your child can easily count to 15, the goal of “John will count to 20” may not be appropriate and should be set higher. Special education law mandates that we have higher expectations for children with disabilities. If you believe the goals are set too low or will not allow your child to progress in the curriculum, request that the goals be adjusted.
Measuring Student Progress Section

The purpose of this section is to explain both how progress will be measured and when you will be provided with the progress report. In other words, how will you know if your child is (or is not) achieving his goals?

To Do:
In the IEP meeting, review the Student Progress section. Schools will often list “observation” and “work samples” to indicate how progress will be measured. It is also important to ask for standardized measures as well, such as measuring progress using a standardized test and/or curriculum based test. Concerning when you will receive feedback, you are legally entitled to receive periodic reports on progress on the same timeline that non-disabled peers receive progress reports. In the IEP meeting, make sure that you will be receiving “quarterly written progress reports,” as you will need detailed, written reports to measure progress. Remember: the more specific and measurable the IEP objectives are, the easier it is to see if adequate progress has been made.

Specially Designed Services and Related Services Section

The purpose of this section is to list the special education and related services that will be provided to your child. In other words, what services does your child require so that he can attain his annual goals and progress in the general curriculum? Services can include specially designed instruction, related services (i.e. speech therapy), assistive technology, program modifications, accommodations, and/or training for school personnel. This section also indicates who will provide the services, when the services will start, how long the services will be provided, and the frequency your child will receive the services.

To Do:
Look through the list below and check off all special education and related services that you believe your child requires to progress in the general curriculum. These are some of the most common services, but you may add your own as needed. You can then discuss your list at the IEP meeting and ask that the needed services and modifications be included in your child’s IEP.

Possible Special Education and Related Services:

- Speech and Language Therapy  
- Physical Therapy  
- Counseling  
- Transportation  
- Recreation/Physical Education  
- Occupational Therapy  
- Medical/Nurse Services  
- Psychological Services  
- Training for Teachers (i.e. training in a communication device)

Possible Program Modifications:

- Visual Cuing/Picture Schedule  
- Oral Testing  
- Modified Assignments/Tests  
- Work Modified to Ability Level  
- More Time to Answer Questions  
- Tasks Broken into Smaller Sections  
- Modeling  
- Extended Time  
- Repetition of Directions  
- Copies of Teacher Notes Provided  
- Preferential Seating  
- Fewer Concepts Presented
Least Restrictive Environment Section

The purpose of this section is to explain the extent, if any, to which your child will not participate with nondisabled children in the regular classroom and in school activities. It also addresses the important question: Where will my child’s IEP goals be carried out? Will your child receive services within the regular education setting, within a special education classroom, or in a combination of the two? For parents of children with Down syndrome, the issue of participation with nondisabled peers can be the most important issue raised in the entire IEP process. Many experts in the field of Down syndrome support the idea of inclusion, believing that children benefit academically and socially when they are “included” and participate within the regular education setting.

Key Idea for Parents to Know: Least Restrictive Environment

According to special education law, placement decisions must be made according to the Least Restrictive Environment requirements. This means that, to the maximum extent appropriate, children with disabilities must be educated with children who do not have disabilities. As a parent, you are a key player in the placement decision. You have the legal right to be a part of the process that determines your child’s educational placement.

To Do:
Consider the following continuum of placement options. Think about your child’s particular strengths and abilities, as well as his or her specific needs. Ask yourself, “Can my child be educated within the regular education classroom with proper aids and supports?” If not, will a combination of placements allow my child to be appropriately educated? Remember, the law states that a child can only be removed from the regular education classroom if education in the regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. Consider the list of possible placements below and mark the placements that you believe meet the Least Restrictive Environment requirements for your child. Discuss your beliefs at the IEP meeting and ask the team to consider your desires when making placement decisions.

Possible Placements:

___ Full-time participation in the regular education classroom.
___ Full-time participation in the regular education classroom with consultative support.
___ Majority participation in the regular education classroom with pull-out intervention for therapies (i.e. speech, occupational therapy, physical therapy, etc.).
___ Majority participation in the regular education classroom with pull-out therapies and pull-out special education intervention (i.e. pull-out speech therapy and instruction in resource or special education room to work on IEP goals).
___ Majority participation within the special education setting (i.e. majority of day in resource room or self-contained classroom with inclusive participation in “specials” such as art, music, physical education, lunch, recess).
___ Full-time participation in the special education classroom and adapted "specials."
Additional IEP Sections:

Participation in State and District Tests
The IEP will likely state the type of state and district tests your child will receive during the year. The three most common testing options are:
1. Your child will take the regular state and district tests with no modifications.
2. Your child will take the regular state and district tests, yet your child will be given modifications such as extended time, having the test read to him, etc.
3. Your child will not take the regular state and district tests but will take an “alternative test” that the team determines to be more appropriate given your child's disabilities.

Transition Service Needs
If your child is 14 years of age or older, the IEP will include transition services needs which is a description of the services that will be needed to help your child transition from school to postsecondary education, employment, and/or independent living. When completing this section, you should consider college education, work experience, vocational training, etc., as well as your child's specific interests, talents, skills, and needs.

Special Instructional Factors
The law requires that the IEP team consider “special factors” when creating the IEP. Although these factors may not pertain to your specific child, the team will need to consider:
1. Behavior: If your child’s behavior interferes with his or her learning, the team must consider interventions and strategies that will address the behavior issues. If your child is exhibiting behavior that interferes with his or her learning, ask the team to conduct a formal behavior assessment and include a behavior plan in the IEP.
2. Limited Proficiency in English.
3. Visual Impairment: If your child is blind or visually impaired, the IEP must provide appropriate supports (i.e. Braille).
4. Communication Needs: If your child has communication needs that interfere with learning, the IEP team must address the issue in writing on the IEP.
5. Hearing Impairment: If your child has a hearing impairment, the IEP must address how your child's communication will be supported (i.e. sign language).
6. Assistive Technology: The IEP team must consider whether your child needs assistive technology and, if so, what required technology will be included on the IEP.

Final Thoughts
It is true that the IEP process can be overwhelming and exhausting. As parents, we may feel “outnumbered” by teachers and administrators within the IEP meeting. It is also true, however, that we know our children intimately. We have relevant information to share and a legal right to share it. As parents of children with Down syndrome, it is important that we prepare ourselves for the IEP process in order to provide our children with an appropriate and comprehensive educational plan that meets their needs and encourages learning and independence. You are an equal participant in the development of your child’s IEP, and your voice needs to be heard.
Additional Tips and Strategies for Successful IEP Meetings:

Ask the school to provide you with a draft of your child’s IEP prior to the formal meeting. You can then compare the school’s draft with your own ideas after you complete the IEP Toolkit. You can make notes directly on the IEP draft, preparing your thoughts in each of the important IEP sections. You may also consider giving the school team a copy of the Toolkit prior to the meeting. They may find it helpful in the preparation process.

Find out the time allotted for the IEP meeting so you know how much time you have. Also, be prepared to ask for a follow-up meeting in writing if you were not able to accomplish all of your goals.

Encourage warm introductions at the beginning of the meeting to set a cooperative tone.

Consider bringing snacks and water to the meeting.

Bring support to the meeting. This can include a spouse or partner, an advocate, friend, relative, teacher, or private therapist. You might ask the support person to take detailed notes for you to provide you with an informal written record of the meeting.

Just as you need to make your voice heard, listen respectfully to the thoughts, concerns, and ideas of the others members of the team.

If You Do Not Agree with the IEP:

Families and educational teams should work collaboratively to create an IEP that is accepted by all parties. If, however, you feel you can not accept the IEP as written, you do not have to sign it. You can write your objections clearly on the IEP itself, creating a written record of your specific concerns. It is also recommended that you write and date a follow-up letter to the school stating your specific concerns and asking for another IEP meeting to modify the IEP.

If you can not come to an acceptable agreement about the IEP at the next meeting, it is recommended that you ask for written information pertaining to due process, the formal procedure to resolve disputes between parents and schools. Options include filing a complaint with the state department of education, mediation with an impartial third party, or a formal due process hearing. Information about due process is available on your state board of education website. Contact www.ed.gov for a list of state departments of education.
Stubborn is... as Stubborn Does
By Carol Johnson, Calgary, Alberta, Canada

It is interesting to me how many people talk about their child's stubborn behavior as if it was part and parcel with having Down syndrome. It isn't. There are many people who are stubborn who do not have DS. In fact, in some situations, being stubborn is seen as a positive trait. I have heard people say that the reason they came out as winners in a situation was because... "I was stubborn and no one was going to push me around." They thought I would cave, but I was too stubborn to give up easily. "So, what is this stubborn behavior that we see with students who have DS and how can we think about it?

I see stubborn behavior as a direct result of lacking the skills and/or language to negotiate a position. Often, we will take a stance on something we care about and, right or wrong, stick to that stance until we understand or agree with another's view. A student with DS will continue to do things in a specific way because it is safe, it is known and it has worked in the past. When we try to change their behavior, when we try to introduce new things, we threaten their "safe place."

Some of us are open to change and will accept change far better than others. This is the same for students with DS. Some of us are able to argue our side of the issue, some of us can be persuasive and bring people to our view and not have to change - the other person changes. Students with DS cannot do this as well. They lack the language, the cognitive flexibility needed in verbal discourse and the larger world view to win many verbal arguments. So... they look stubborn.

Think about it. If you were in a situation where you did not understand what was going on around you and people were trying to get you to do something you were unsure of, what would you do? You would resist, you would stay doing what you know, you would be seen as stubborn. What if you did not have the language skills to share your views, what if the other party did not understand you or did not care about what you had to say? Then, you were punished or censured because you were seen as stubborn. How would this affect your level of cooperation the next time?

How would you respond to these people who "made you do something you did not understand nor even agree with?" You may become even more stubborn or resistive. And, they, in turn would see this as "noncompliance" or as a "problem." They would respond in a way that assumes that your stubbornness is something that exists on its own; apart from you having a different view of the same situation or apart from your being unable to communicate your point of view successfully.

How can we change the pattern?
By letting go of the myth of stubbornness and seeing stubborn behavior as resistance. Resistance to something new, resistance to something that is not understood, resistance to having others be in control, resistance to someone they may not trust or understand. The only way to help anyone become less resistant is to help them to feel safe enough to try something new or different.

When children are young, they will not respond very well to changes and will withdraw. As they grow older, they will use strategies that have worked in the past... withdrawing, not looking, pouting, sitting, throwing
themselves down (stubborn-looking behaviors). The more stubborn a student looks, the more useful this behavior has been in the past; using this repertoire of strategies has allowed the student to remain in a safe place.

**Adults are part of the problem.**
We have taught children what they need to do so we will stop pushing or so we will leave them as they want to be. Then, sometimes, we become angry. As we become angry, children resist further as they do not understand what is happening and are often upset with the situation as well. How many of us respond to anger if we are nervous about a situation? How many of us would become less "stubborn" if someone demands that we do something that we are not sure about?

**When faced with a student who appears to be stubborn, think about the following:**

1. Although this makes sense to you, it must not make sense to this student. How can you help the student gain a better understanding of what it is you are wanting? Remember, saying that it is "good" for them is not helpful. Can you show, act out, the positive outcome of the request? Can they try it in small steps? Can you find a way to make it clearer, less threatening? What kind of language are you using?

2. Is there a way to help the student use other means to say... "no," "wait," "this is scary," "you want me to do what?" other than the behavior that is being seen? Until a student has some way of communicating with others, the resistance will look like stubborn behavior.

3. Follow the old adage "Win them over with honey." Any human being will respond to positives over coercion. Always enter a new situation using something that the student likes from other situations, go from what the student already knows and build on it. Pair a new experience with something that is already successful and liked by the student. Use play, songs, games, etc. to help a student deal with new experiences. Watching another student have success may not work as some students do not learn from watching others so they may not understand that they too could have that success.

4. You need to have a trusting relationship with anyone before they will try something new just because you told them to do it. Some students take a long time to reach that level of trust. You cannot be the "punisher" and build a trusting relationship with a student. You cannot coerce some behaviors and reinforce others; this inconsistency will cause stress; students may never feel safe enough with you to let go of those behaviors that help them feel safe.

5. When you feel yourself becoming angry, stop, laugh, walk, relax, count, etc. Release the tension in the situation and then try again...maybe in a different way. Sometimes students will come around just because you have calmed down and re-entered the relationship in a way that is not threatening.

Some of the best people are just stubborn enough to hang in there when many others have given up on a child. So, join them. Be stubborn about a child's ability to learn and help him or her to feel safe enough to venture into new territory with you alongside.
All About Me!

Contact Us
(314) 961-2504
website: www.DSAGSL.org
We are pleased to share our All About Me booklet with you. This booklet contains a lot of information about our child ____________ and our family.

We hope that this information will help you to get to know our child and some of his/her interests, strengths and skills.

We have high expectations for our child as other parents do for their children. We hope he/she will follow school rules, perform to the best of his/her ability and be a contributing member of the class. Good teaching and positive peer role models will help our child be successful.

If you have any questions, please call us at home ______________ or at work ______________. The best time to reach us is__________.

We look forward to working with you this year.

Please let us know how we can help make this a great school year.

Sincerely,
When our child was born we worried about:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

Our hopes for this year are:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

Our lifetime goals for our child are:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

Here are some ways we think you can help our child be successful:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________
Here is My Family

My name is:____________________________________________________

My Mom’s name is:______________________________________________

My Dad’s name is:_______________________________________________

I have _____ Brother(s) Their names are: ____________________________

I have _____ Sister(s) Their names are: ____________________________

We have a pet:_________ My pet’s name is: _________________________

Other family or friends that I want you to know about are:

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

My favorite activity is:________________________________________

My favorite color is:__________________________________________

When I go outside, I like to:____________________________________

My favorite hobby and other activities are:
________________________________________________________________
________________________________________________________________
________________________________________________________________

Three things that really motivate me are:
________________________________________________________________
________________________________________________________________
________________________________________________________________

When I grow up I want to:
________________________________________________________________
________________________________________________________________
________________________________________________________________
Here are some things you may need to know about my health:

Surgeries:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Current Medication (s):
________________________________________________________________________
________________________________________________________________________

I wear glasses: Yes No I wear hearing aides: Yes No

When I am not feeling well I might:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Other things you need to know about my health:
________________________________________________________________________
________________________________________________________________________
Things that make me feel happy:
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Things that might upset me:
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

It’s hard for me to:
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

Things I may be afraid of:
_______________________________________________________________
Here are some places that I like to go to with my family:

_______________________________________________________________
_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

My favorite vacation was when my family went to:

________________________________
________________________________
________________________________
________________________________

My favorite places to go in my neighborhood are:

________________________________
________________________________
________________________________
________________________________
Here are some things you may need to know about how I communicate:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

My parents would prefer that you communicate with them by:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If I am frustrated I might:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Here are some things I do to help around the house:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

Here is a list of things I do in the community on a regular basis:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

Here are some things I can do if someone helps me:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
Pictures of Me!
Myths & Truths
About Down Syndrome

Myth: Down syndrome is a rare genetic disorder.
Truth: Down syndrome is the most commonly occurring genetic condition. One in every
800 births is a child with Down syndrome. There are currently 350,000 people in the U.S.
with Down syndrome, with 5,000 to 6,000 births per year.

Myth: Most children with Down syndrome are born to older parents.
Truth: Eighty percent of children born with Down syndrome are born to women younger
than age 35 due to higher fertility rates. However, research has shown a link between the
incidence of Down syndrome and maternal age.

Myth: Down syndrome is hereditary and runs in families.
Truth: Most cases of Down syndrome are sporadic, chance events. In general, Down syn-
drome does not run families and a sibling or aunt has no greater chance of conceiving a child
with Down syndrome.

Myth: People with Down syndrome have severe cognitive delays.
Truth: Most people with Down syndrome have cognitive delays that are mild to moderate.
IQ is not an adequate measure of the functional status of people with Down syndrome. Peo-
ple with Down syndrome have great potential if given opportunities.

Myth: The life expectancy of people with Down syndrome is 30.
Truth: Thanks to advances in medical and clinical treatment and opportunities to thrive, as
many as 80 percent of adults with Down syndrome reach age 55, and many live longer.

Myth: Behavior problems and depression are just part of having Down syndrome
Truth: Often, medical or mental health problems go untreated due to the assumption that it
is typical of having this genetic condition. Complete examinations by appropriate health
care professionals should always be pursued.

Myth: Children with Down syndrome are placed in segregated special education pro-
grams.
Truth: Children with Down syndrome are included in regular academic classrooms across
the country. Students may be integrated into specific courses or fully included in the regular
classroom for all subjects.

Myth: Adults with Down syndrome may be unable to work.
Truth: Businesses seek young adults with Down syndrome for a variety of positions. They
are employed by banks, corporations, nursing homes, hotels and restaurants. They work in
the music and entertainment industry. People with Down syndrome bring to their jobs en-
thusiasm, reliability and dedication.
Home and School Communication Binder

This binder is for use by [Student Name]’s classroom teacher, paraprofessional, resource teacher, specials teachers, therapists and [Student Name]’s parents.

We hope this can be one place where we can pass information to each other. This can include homework assignments, therapy notes, information from [School Name], etc.

[Student Name] will send her daily classroom homework assignments back to school in her homework folder (like the other kids do).

The binder should go with [Student Name] to resource and therapy. Please let us know if we need to add anything to the binder or if you feel it may not be the best tool for communication.

Thanks,

[Parents’ Names]
(Student’s Name) Day at School

Date: ____________

☐ OT  ☐ Resource  ☐ Speech  ☐ Art  ☐ Music  ☐ PE  ☐ Computer

Here is something we learned about at school:

I interacted with others:
☐ Most of the time  ☐ Some of the time  ☐ Not much

Here is something I did well, learned or had fun doing:

I followed directions/cooperated:
☐ Most of the time  ☐ Some of the time  ☐ Not much

I had trouble with this today:

Notes for Home:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________