

THE IEP TOOLKIT

**Helping Families of Children with Down Syndrome
Become Knowledgeable, Prepared, and Empowered
Partners in the IEP Process**

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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:

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 be 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)

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)

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?)

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?)

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

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?)

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

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?)

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

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

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:

- | | |
|--|--|
| <input type="checkbox"/> Speech and Language Therapy | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Physical Therapy | <input type="checkbox"/> Medical/Nurse Services |
| <input type="checkbox"/> Counseling | <input type="checkbox"/> Psychological Services |
| <input type="checkbox"/> Transportation | <input type="checkbox"/> Training for Teachers (i.e. training in a communication device) |
| <input type="checkbox"/> Recreation/Physical Education | |

Possible Program Modifications:

- | | |
|---|---|
| <input type="checkbox"/> Visual Cuing/Picture Schedule | <input type="checkbox"/> Modeling |
| <input type="checkbox"/> Oral Testing | <input type="checkbox"/> Extended Time |
| <input type="checkbox"/> Modified Assignments/Tests | <input type="checkbox"/> Repetition of Directions |
| <input type="checkbox"/> Work Modified to Ability Level | <input type="checkbox"/> Copies of Teacher Notes Provided |
| <input type="checkbox"/> More Time to Answer Questions | <input type="checkbox"/> Preferential Seating |
| <input type="checkbox"/> Tasks Broken into Smaller Sections | <input type="checkbox"/> 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.