

IEP Essentials for Parents

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The Federal Individuals with Disabilities Education Act (IDEA) mandates that schools provide a Free and Appropriate Public Education (FAPE) for all students.

Section 1400(d) of IDEA states that the main purpose of the law is:
to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living”

While not all students with Tourette Syndrome (TS) will require an Individualized Education Plan (IEP) in order to receive a FAPE, there are some students with Tourette Syndrome for whom an IEP is an educational necessity.

An IEP is a document developed by the IEP team (the composition of the team is described later in this article) outlining the individualized accommodations, modifications, special education and related services to be provided to a student in order to meet his/her specific and unique academic and functional needs.

NOTE: Often parents and educators believe that if a child is achieving average to high academic grades, he is not eligible for an IEP. However, the federal Individual with Disabilities Act (IDEA) states that an IEP must address the academic and the functional needs of the child. ‘Functional needs’ are generally defined as abilities that enable individuals to maintain their independence in the general population. Some students have high grades but have social skills delays, and/or communication and written language deficits that interfere with their ability to learn appropriate social interactions and communicate in an effective manner. It’s important to recognize that

schools are preparing youngsters not only for the next grade level but also for life after school that includes “further education, employment, and independent living”

This article will discuss the initial IEP process as required by the federal IDEA. However, it is advisable to check your State Department of Education Regulations, as they may be slightly different. (Links for all state special education regulations may be found at: <http://nichcy.org/state-organization-search-by-state>). Please be advised, however, that “A State may establish laws or regulations for IEP meetings, but must ensure that in doing so it does not establish provisions that reduce parent rights or are otherwise in conflict with the requirements of the IDEA and the Federal Regulations.” (Questions and Answers On Individualized Education Programs (IEPs), Evaluations, and Reevaluations <http://idea.ed.gov/explore/view/pl/root,dynamic,QaCorner,3>.)

STEPS FOR OBTAINING AN IEP

• Requesting Evaluations

A parent requests, in writing, an initial evaluation and an IEP meeting. (A sample letter and additional information can be found in TSA’s article “Getting Help in School” (http://www.tsa-usa.org/aeduc_advoc/getting_help_at_school.htm). The evaluation is typically referred to as a Psycho/Educational assessment. This assessment must include all areas of concern and parents are encouraged to ask, in writing, that specific areas which they believe may be impacting their child be included in the evaluation. Psychological testing, in general, measures a student’s potential instead of what has been learned. It clarifies the nature of possible processing deficits. Educational assessment

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measures what has been learned in reading, math, spelling and other academic areas documenting how the disability negatively impacts a student.

An IEP meeting is then scheduled to determine if the child is eligible for special education and related services. School officials may also initiate an evaluation, but typically it is the parent who begins the process by writing a letter to the school's pupil services or special education director. Generally, school districts require that a parent sign a Parent Consent form in order to begin the IEP process.

- Initial Evaluation
 - According to federal regulations, an initial evaluation must be conducted within 60 days of receiving parental consent. Some state education regulations have different timeframes but cannot exceed 60 days.
 - Student is to be assessed in all areas of suspected disability.
- It is critically important that parents include all disabilities when requesting an evaluation. Parents may, also, request an additional evaluation at a later date, if there is evidence that something else is interfering with the child's education. It is not unusual for students with TS to have related disorders that begin to interfere academically and/or socially as the student matures. A student who has strong academic abilities may have hidden skills deficits that impact ability to complete work, remember materials and assignments, copy notes, write lengthy answers/essays, etc. The articles "Red Flags" (http://www.tsa-usa.org/aeduc_advoc/Red_Flags.htm) and "TS is More than Tics" (http://www.tsa-usa.org/aeduc_advoc/morethantics.htm) may help in recognizing common related disorders and how they impact the education process.

IEP MEETING

The following is a list of people that one would expect to see at an IEP meeting as their attendance is required according to IDEA:

Parents of the child

Parents are vital members of the IEP team. They have an expertise regarding their child which no one else can provide. Meetings must be scheduled in a manner that allows parents an opportunity to attend either in person or via phone/internet.

The Student

A student attending his/her IEP meeting is important, particularly in the higher grades. This allows the IEP team a better sense of who the child is, while also providing an excellent opportunity for the student to learn self-advocacy skills. Parents of younger children often have their child attend only part of the meeting.

Special Educators

Teachers with knowledge regarding special education services provide important information for the IEP team when determining which services are appropriate for a specific student.

General Educators

If the child is participating in the general education environment, or if that is a possible placement, IDEA requires that at least one of the child's general educators be included on the IEP team.

Representative of the School District

A person representing the school district must be in attendance who

- Is knowledgeable about the availability of resources of the school district
- Has the power to commit the resources needed so that services can be provided as described in the child's IEP
- Is able to ensure that whatever services are described in the IEP will actually be provided.

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Interpreter of Evaluation

It is preferable if the school personnel who conducted the evaluations/assessments, often the school psychologist, attend the meeting to interpret and discuss the results of the testing and what it means in terms of instruction for this specific student. If this person is not available, a person who is qualified to interpret evaluations and provide information regarding the impact of the deficits on the student's social, emotional, physical and academic growth must be in attendance.

Others with Knowledge or Special Expertise About the Child

- The parents and/or the school district may invite additional individuals who have knowledge or special expertise about the child to be members of the IEP team.
- Parents may invite a friend or relative who knows the child, a professional with special expertise about the child and his or her disability, or others who can talk about the child's strengths and/or needs. Many TSA chapters have volunteers who, when possible, attend meetings to provide information regarding TS and related disorders. It is wise for a parent to inform the school at least a week prior to the meeting that an additional person is invited to attend the meeting. Conversely, the school must inform the parent if they are inviting any additional personnel to the meeting.

The following quote from the U.S. Department of Education highlights the fact that TS is a complex disorder which is too often misunderstood:

"... we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs."

(<http://idea.ed.gov/explore/view/p/.root.regs.preamble2.prepart2.A.94.>)

An understanding of TS and related disorders is essential for determining appropriate services. Providing accurate information is key to understanding TS. This can be accomplished through offering appropriate literature and/or including a person with in-depth knowledge of TS in the classroom, school and community on the IEP team in order to ensure the best outcome.

Eligibility for an IEP

- The IEP team first must reach a consensus regarding whether the student meets the definition of "a child with a disability" as described in IDEA and is, therefore, eligible for an IEP.

NOTE: Many people assume that if a child has a diagnosed disability that he/she is automatically eligible for an IEP. However, for a child to receive an IEP, the IEP team must first determine that the student requires special education and related services and, therefore, is eligible under the guidelines of IDEA. Many students with TS are eligible for an IEP. However, if a student requires only accommodations/modifications in order that they receive **equal access to an education, and by doing so, are not discriminated against for having a disability**, a 504 Plan may be appropriate. Examples of IEP services would be working with a speech therapist, counselor, or occupational therapist. Examples of 504 Plan accommodations/modifications are providing extra time for tests, using a computer, taking tests in a separate location, having notes provided, accessing resource room support, etc. These can also be provided on an IEP. Refer to "Important Changes Regarding Eligibility for 504 Plans" (http://tsa-usa.org/aeduc_advoc/audio_conferenceTSA.htm#elig_chg_504) - audio conference/slide show and link to article) and/or "IEPs and 504s; Compare and Contrast" (http://tsa-usa.org/aeduc_advoc/audio_conferenceTSA.htm#ieps504- audio conference/slide show).

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- Once the team determines that the student is eligible for an IEP, the team must then agree under which definition the student will be classified. The definitions include: mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in IDEA as emotional disturbance), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disability, and who, by reason thereof, requires special education and related services.

NOTE: In 2004, Tourette Syndrome was included under the Federal IDEA definition of other health impairment and is the appropriate classification for students with a primary diagnosis of Tourette Syndrome.

- IDEA states that no single measure or assessment may be used as the sole criterion for determining whether the student is 'a child with a disability' and when developing an appropriate educational program.

NOTE: Often, students with TS receive high scores on IQ and academic evaluations/assessments. These cannot be the only measures when determining eligibility for an IEP or services. In fact, if the student's scores indicate average to above-average abilities but he/she is not earning grades that reflect those abilities, other tests from the assessment must be considered. For example, processing speed, memory, written language, reading comprehension, problem solving and executive functioning scores, to name a few, must be discussed in order to determine what is interfering with the student's ability to demonstrate the child's true abilities. Examining discrepancies may be critical in determining appropriate services. For instance, a student may receive average overall scores in reading. But on further examination,

while her reading speed places her in the 98th percentile of other students her age, comprehension is in the 6th percentile. Averaging these results creates a false impression that she has average abilities in reading while the reality is that she requires support in reading comprehension.

- The team must consider information from a variety of sources, including aptitude and achievement tests, parent input, teacher recommendations, physical condition, social or cultural background, and adaptive behavior.

NOTE: There is often an assumption that if an outside specialist states that the child requires specific services or placement that this must be adhered to. It's important to recognize that the law states that the team needs only to consider information from a variety of sources.

Developing an IEP

- The IEP must consider:
 - The strengths of the child;
 - The concerns of the parents for enhancing the education of their child;
 - The results of the initial or most recent evaluation of the child; and
 - The academic, developmental, and functional needs of the child.
- IEPs must contain:
 - A statement of the child's present levels of academic achievement and functional performance, including how the child's disability affects his or her involvement and progress in the general education curriculum;
 - A statement of measurable annual goals, including academic and functional goals;
 - A description of how the child's progress toward meeting the annual goals will be

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- measured, and when periodic progress reports will be provided;
- A statement of the special education and related services and supplementary aids and services to be provided to the child, or on behalf of the child;
- A statement of the program modifications or supports school personnel will provide to enable the child:
 - to advance appropriately toward attaining the annual goals;
 - to be involved in and make progress in the general education curriculum
 - to participate in extracurricular and other nonacademic activities;
 - to be educated and participate with other children with disabilities and nondisabled children;
- If applicable, an explanation of the extent to which the child will not participate with nondisabled children in the regular class and in extracurricular and nonacademic activities;
- A statement of any individual accommodations that are necessary to measure the academic achievement and functional performance of the child on State and district-wide assessments;
- The projected date for the beginning of the services and modifications, and the anticipated frequency, location, and duration of those services and modifications.
- Some schools require that parents sign the IEP before it can be enacted.

NOTE: Federal Regulations do not require a parent's signature in order for the IEP to be implemented, however some states provide this additional protection. If a parent refuses to sign

the IEP, the IEP is not followed until the disagreement is resolved by additional meetings, mediation or impartial hearing. This is called 'Stay Put'.

However, in school districts that do NOT require a signature, in order to achieve 'Stay Put', it is imperative that the parents indicate their disagreement with the IEP in writing as quickly as possible. Otherwise, the IEP will be implemented.

It is important that parents determine whether their signature is required by asking school, researching or contacting their State's Department of Education.

- After the IEP is completed
 - If there is no 'Stay Put', the IEP is shared with school personnel who are involved in providing the supports and services on an IEP. This could include:
 - regular education teachers
 - special education teachers
 - related service providers, speech therapists, occupational therapists, counselors, paraprofessionals, consultant teachers, bus drivers, cafeteria staff and all staff who are responsible for any part of the child's education
 - The IEP team meets, at a minimum, annually, to review the progress of the student, the current achievements and level of performance, and whether services need to be revised.
 - Parents may request a meeting prior to the annual date if the child's situation has changed and a new meeting is warranted.

Resources and Additional Sources for Special Education Information:
<http://nichcy.org/schoolage/iep/team>
<http://idea.ed.gov/explore/home> - U.S. Department of Education, Office of Special Education Programs' (OSEP's) IDEA website
http://www.tsa-usa.org/aeduc_advoc/audio_conferenceTSA.htm TSA Education Audio Presentations

Visit "Living with TS" at <http://tsa-usa.org/aPeople/LivingWithTS/LivingTS.htm>

Free articles cover topics including Exercise and Sports, Avoiding Medical and Alternative Health Scams, Getting Older, Airline Travel, Dating, Ticking in Public, Military Service, Benefits, College, Self Advocacy, Health Insurance Issues, and TS and the ADA.

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Available in our Online Store (<http://store.tsa-usa.org/>) for a nominal charge are publications such as *Getting Into College - TSA's Complete Guide to the Applications & Admissions Process* (Publication #E110 and downloadable Publication #E110DD), and *TS in the Workplace: Issues & Solutions* (Publication #A114, and downloadable Publication #A114DD), and the DVD, *I Have Tourette's, but Tourette's Doesn't Have Me* (DVD13). An up-to-date Catalog of Publications and Videos may be obtained by going to TSA's Online Store, and clicking on the "Download Catalog" button on the left of the screen, or calling TSA at 718-224-299, Ext.231.

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Free Online Videos

Mike Higgins: Overcoming the Odds (approx. 5 minutes) – an extraordinary individual with Tourette Syndrome; and Paul Devore on Self Esteem – an inspiring practical video, giving guiding principals (with a downloadable transcript). For a listing of these and all TSA Free online videos go to: http://tsa-usa.org/aabout_tsa/videos.html

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