



The IEP Toolkit

Empowering Parents to be their Children's Best Advocates

An Individualized Education Program (IEP) is a written statement of the educational program specifically designed to meet the individual needs of your child with autism. A strong IEP is an important part of ensuring your child's success at school. Parents are a vital part of the IEP planning team; YOU are the expert on your child's needs and strengths. Yet sometimes, parents can feel insecure or unprepared for their role as an equal member of the team.

About the toolkit

This toolkit is for families whose children have autism and receive – or expect to receive – special education services in a public school in North Carolina.

It is intended to help parents:

- understand the IEP process
- prepare for their school meetings
- participate effectively as a vital member of the IEP team

Empowering parents to be their children's best advocates is the guiding principle for this toolkit.

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Beyond the toolkit

There is so much helpful and in-depth information now available about the IEP process that each of these sections could be a book on its own! If you would like to read more, please refer to the end of the toolkit for additional information sources that are recommended by the Autism Society of North Carolina (ASNC) Advocacy and Bookstore staff. To keep updated on the latest books and DVDs on education and autism, we invite you to connect with the ASNC Bookstore on Facebook, at https://www.facebook.com/AutismBookstore, or by emailing staff at books@autismsociety-nc.org to tell them you would like to join the newsletter mailing list.

If this toolkit raises new questions for you and you want to talk with someone about your child's education or IEP, ASNC can help. In every NC county, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism educators and advocates. You can find contact information for the Autism Resource Specialist in your community here: http://bit.ly/AutismResourceSpecialists.

The ASNC Autism Resource Specialists also hold IEP workshops across the state. To find an IEP workshop in your area, go to the schedule on the ASNC website (http://bit.ly/ASNCWorkshopCalendar) or contact the Autism Resource Specialist in your community.

IEP Basics

What is an IFP?

An Individualized Education Program, or IEP, is the document that provides the direction for your child's education as well as specifying the amount and type of services your child will receive. The IEP can be understood as the blueprint for the special education experience of your child with autism in the school environment.

The school environment has three main areas:

- general education curriculum
- extracurricular activities
- nonacademic activities

General education curriculum is the subject matter provided to children without disabilities that they are expected to learn and apply. Examples include math, language arts, science, etc. Much of the IEP process will focus on how your child will relate to the general curriculum.

Extracurricular activities and nonacademic activities are school activities that fall outside the general curriculum. Usually voluntary and social, they typically involve school peers and are supervised by school staff. Examples: sports, clubs, lunch, recess, band, field trips, etc.

The IEP has two general purposes:

- to set appropriate learning goals for your child
- to state the special education and related services that the school district will provide

Related services help children benefit from special education by providing extra support in needed areas. Examples: speech, occupational or physical therapy, therapeutic recreation, interpretation services, school health and social work services.

The IEP comes from the Individuals with Disabilities Education Act, or IDEA. This federal law guarantees a free, appropriate public education (FAPE) for all children with disabilities who need special education and related services.

IDEA outlines a structure and process to address your child's individual needs and enable your child to participate in general education and school activities, learning alongside nondisabled peers to the maximum extent appropriate.

Important IDEA terms:

FAPE: free, appropriate public education

LRE: Least restrictive environment is a foundational concept in IDEA. It means children with disabilities should be educated with children who are nondisabled to the maximum extent appropriate. Special classes or separate schooling should occur only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

An IEP team may include:

- the parents
- a special education teacher
- a regular education teacher
- someone to explain evaluation results, such as a school psychologist
- a school representative, also referred to as the LEA (Local Education Agency) rep. The LEA rep should be a person who can provide or supervise special education, is knowledgeable about the general education curriculum, and is knowledgeable about the availability of resources of the school district and can commit them.
- staff who provide related services, if involved, such as speech, occupational, or physical therapy

Who is covered by an IEP?

A child with a disability ages 3-22 is eligible if that child needs special education and related services. If a student turns 22 during the school year, that student is allowed to finish the year. Preschool services are based upon the needs of the child and are not necessarily provided for a full day. After high school, there is no requirement for services.

How does a child become eligible for an IEP?

- 1. Request for Evaluation: If a parent or a teacher suspects that a child may have a disability, a written request for an evaluation should be made to the special education teacher, a regular education teacher, or the principal. If a teacher initiates the request, the school must try to obtain informed consent from the parents.
- 2. School Follow-up: Once the written request has been turned in to the school, the school has 90 days to:
 - Perform an evaluation of the child, especially in the area of the suspected disability. (For autism, specific autism screenings and evaluations must be performed)
 - Decide whether the child is eligible under IDEA for special education services (For more on this, see the FAQ section on "Do all children with autism qualify for an IEP?")
 - Meet to present their results to the parents
 - · Complete an IEP if the child does have a disability
 - Begin to provide special education services
- 3. Invitation to Conference: If the child is eligible for special education services, an Invitation to Conference is sent to the parents, preferably 10 days in advance, stating the purpose of the meeting, date, time, and who will be present. This should be returned promptly to the school with alternate dates or times if the suggested date is not convenient. The meeting should be held at a mutually agreed upon time.

How is an IEP developed?

The IEP is developed by a team that includes key school staff and the child's parents. The team meets to review the child's evaluations and design an educational program with annual goals to address educational needs that result from the child's disability.

Can students be involved in developing their IEP?

The child with the disability can also be included, especially at age 14 and older. (IDEA requires they be invited at age 14 to start transition planning.) The student can attend any or all of the IEP meeting based on their ability to participate. This can be a good way to start helping the student develop self-advocacy skills.

Do all members of the IEP team have to be present at all meetings?

If the parents and the school agree, a member of the IEP team can be excused from attending under two circumstances:

- The team member's area of services is not being discussed or modified during that meeting.
- The team member submits written input for the IEP prior to the meeting.

IDEA also permits video conferencing and conference calls as alternative forms of meeting; this may be especially helpful to parents who cannot leave their work or home to attend.

When is an IEP developed?

An IEP meeting must be held within 30 calendar days after a full and individual evaluation determines that a child has one of the disabilities listed in IDEA and needs special education and related services.

How often are IEP meetings scheduled?

After the initial IEP meeting, the child's IEP must be reviewed at least annually to determine whether the annual goals are being achieved. It may be amended at any time:

- Amended without a meeting: After an IEP has been written for a school year, the parents and the school can agree to make written changes to the annual IEP without a meeting. If this is done, then the entire IEP team must be notified of the changes. The parents should request a revised copy of the IEP with the amendments included.
- Amended with a meeting: Any member of the IEP team can request a meeting. It is always a good idea to make this request in writing, offer several times and dates when you are available, and request a response within a reasonable time.

What documents need my signature?

The only time your signature is required is:

- when the school needs your permission to evaluate your child, and
- the initial placement of your child in special education services

You will be asked to sign the IEP document once developed, but your signature indicates only that you were in attendance at the meeting. Signing does NOT mean you agree with everything – you can note any objections in the margins. If you don't sign the IEP, there is no concrete evidence you were present. If you think you might lodge a complaint, it might be useful to make it clearly known that you were present.

Can the IFP team change an IEP without the parents?

If a school has tried and cannot reach the parents, or the parents do not show up for a scheduled meeting, then the school can proceed with the IEP meeting and make changes, but the school must document their attempts to contact the parents.

What are the policies and procedures that govern IEPs?

Federal and state procedures and policies affect IEPs:

Federal: Individuals with Disabilities Education Act (IDEA) is the federal law that sets the minimum standards for special education services

State: NC Policies Governing Services for Children with Disabilities (http://ec.ncpublicschools.gov/ policies/nc-policies-governing-services-for-children-with-disabilities) specifies the standards for North Carolina. In some cases, NC policies are more comprehensive than IDEA. (For example, NC requires a transition plan at age 14 instead of the federally mandated age of 16.)

What do accommodations and modifications mean in an IFP?

Individualized instruction is an important part of special education. Instruction and schoolwork are tailored to the needs of the child. Sometimes a student may need changes in class work or routines because of his or her autism. This may include what a child is taught and how a child works at school. Sometimes people get confused about what it means to have a modification and what it means to have an accommodation.

A modification is a change in what is being taught to or expected from the student. Modifications are adjustments in the requirements for the student, making the requirements different than for students in regular education. Making an assignment easier so the student is not doing the same level of work as other students is an example of a modification. Changes are made in

- what the student is expected to learn
- the instructional level
- the number of key concepts
- the content

An accommodation is a change that helps a student work around the disability. Students who have accommodations do the same assignment or test as students in regular education, but adjustments are made in:

- format
- time
- setting
- presentation
- response

Allowing a student who has trouble writing to give his answers orally is an example of an accommodation. This student is still expected to know the same material and answer the same questions as fully as the other students.

Both modifications and accommodations are meant to help a child to learn.

Writing the IEP

In every state, each child's IEP must contain specific information that is listed within IDEA, the federal special education law.

In North Carolina, each school district may use a different IEP form, but the information included must be the same as on the IEP form from the NC Department of Public Instruction (DPI) website: http://ec.ncpublicschools.gov/policies/forms/ statewide-forms.

Often, the EC teacher will develop a draft IEP in advance to save time and have a starting point at the meeting. It is helpful to ask for the draft prior to the actual meeting so that you can review it.

In the meeting to write the IEP, the team will proceed through the IEP form, filling out the sections as needed.

Here are the sections of the IEP:

Area of Eligibility: This is the section where the diagnosis that affects your child's education is stated.

Student Profile: This section focuses on the student's strengths and challenges as well as parental concerns.

Student strengths: Each child has areas of strength that may not be as apparent in the school environment. This is your opportunity to be an ambassador for your child. Share your child's strengths with the school, such as your child appreciates dry humor, is very creative, transitions well, enjoys physical activity, etc. This is also where you share their challenges about their education, their social skills, or their skills and ability to function in and outside the school.

Parent Concerns: Don't leave this space blank. Consider educational, functional, social, behavioral, and health concerns. Given the extremely small space for comments, we recommend you write "see attached" in this space and attach a brief summary of your child's strengths as well as your concerns.

Consideration of Special Factors:

This section includes the following questions:

"Does the student have behaviors that impede his/her learning or that of others?"

If answered yes, then the IEP must address this through:

- annual goals (what the student will learn)
- a Behavior Intervention Plan (BIP)
- or both

The sections of the IEP:

- Area of Eligibility
- Student Profile:
 - Student strengths
 - Parent Concerns
- Consideration of **Special Factors**
- Present Level of Academic & Functional Performance
- Annual Goals
- Benchmarks or Short-Term Objectives
- Least Restrictive Environment
- NC Testing Program
- Frequency and Location of Services
- Continuation of Alternative Educational **Placements**
- Eligibility for Extended School Year
- Signatures



For children who have behaviors that affect their own learning, there must be a process for addressing those behaviors and replacing them with more acceptable ones. A Functional Behavior Assessment (FBA) and a Behavior Intervention Plan (BIP) can be critically important tools to analyze the function or purpose of behaviors and develop effective plans for changing them. Both of these are developed by the IEP team and become a part of that document. See our Behavior Toolkit for more on these topics.

"Does the student have any special communication needs?"

If yes, you should ask what services and supports would address this need. This section is not just for deaf or hard of hearing students. Most children with autism will have special communication needs.

Present Level of Academic and Functional Performance:

This section describes how the child is currently doing in school and how the child's disability affects his/her involvement and progress in the general curriculum. It's a very important part of the IEP, because the student's annual goals are based on these levels.

Annual Goals:

This section is where the IEP team designs academic and functional goals that:

- meet the needs that result from the child's disability
- enable the child to be involved in and make progress in the regular education curriculum
- can be reasonably accomplished in 12 months

Annual goals must be measurable. Make sure you understand how the goals will be measured and reported to you.

Benchmarks or Short-Term Objectives: While the annual goals are a broad statement of what the child needs to accomplish by the end of the year, the short-term objectives are the steps needed to achieve that goal. Although IDEA 2004 eliminated the requirement for short-term objectives, most NC school districts are keeping the short-term objectives for now.

Least Restrictive Environment: This section addresses:

- the support that the child will need to access the regular education curriculum
- how much of the school day the child will be educated separately from nondisabled children or not participate in extracurricular or other nonacademic activities such as lunch or clubs
- what accommodations and modifications the child will need

When determining the least restrictive environment (LRE), the team is also required to explain why the student is removed from nondisabled peers, as well as how and when parents will be informed of the student's progress toward the annual goals.

NC Testing Program: IDEA requires that students with disabilities take part in state or districtwide assessments. The IEP team must decide whether the student needs accommodations in testing or another type of assessment entirely. In this component of the IEP, the team documents how the student will participate, including:

- which accommodations will be used
- which test type will be taken
- why alternate assessments might be appropriate

Possible accommodations for testing include:

- Allow more time to prepare for the test
- Provide lesson plans for the student (and family)
- Give exams orally
- Allow open-book or take-home tests
- Allow essay questions to be completed on a computer, especially if the student has fine motor problems
- Break tests into sections to prevent overwhelming the student

- More multiple choice and fewer essay responses
- Allow student to mark answers in the test book; have staff transfer the answers to the answer sheet
- Avoid the pressure of timed testing or competition
- Provide a guiet place free from distractions for testing
- Allot extra time and allow breaks

Note: These accommodations should be used in every testing situation – not just during exams – to allow the student to be familiar with the accommodation.

Specially Designed Instruction and Anticipated Frequency and Location of Services:

The earlier IEP sections on placement (LRE), the accommodations/modifications, and the type of testing all help decide the amount of special education services that the child needs as well as the frequency and location of services. This will determine which type of classroom the child is placed in:

- regular education
- separate

resource

• some other type

The special education services can be listed as sessions per week, per month, or per reporting period.

The location can be either in a special education classroom or in the total school environment (in a regular education classroom).

Continuation of Alternative Educational Placements:

The discussion about the type of classroom should follow the previous sections on the least restrictive environment, accommodations, type of tests taken, and frequency and location of services.

It is NOT acceptable to discuss the type of classroom BEFORE discussing the type of services needed, although that mistake is not uncommon.

The decision between regular, resource and separate is primarily a mathematical one: how many minutes will the child spend with nondisabled peers, and how many minutes will the child spend in a separate classroom?

Each of these three categories requires a certain percentage of the school day - 6.5 hours for most elementary students – to be spent with nondisabled peers.



General options are:

• Regular (80% or more)

- This means 312 minutes (5 hours, 12 minutes)
- Example: A student in the regular placement would receive special education services for 20% (78 minutes or 1 hour, 18 minutes) or less of the day.

• Resource (40-79%) This breaks down to:

- 40% = 156 minutes (2 hours, 36 minutes)
- 79% = 308 minutes (5 hours, 8 minutes)
- Example: A student in the resource placement would receive special education services between 21% (82 minutes or 1 hour, 22 minutes) and 60% (234 minutes or 3 hours, 54 minutes) of the day.

• Separate (39% or less)

- This calculates to 152 minutes (2 hours, 32 minutes)
- Example: A student in the separate placement would receive special education services for 61% (238 minutes or 3 hours, 58 minutes) or more of the day.

Note: Rounding errors exist. When daily schedules vary during the week, it might be necessary to look at placement based on a weekly time frame instead of a daily time frame.

Eligibility for Extended School Year:

This section addresses the specific requirements to qualify for this service. A student might be eligible if:

- Educational regression over the summer is significant/takes longer than nine weeks to recover
- An important skill, such as toileting, is emerging, and the long summer break could result in the loss of the skill
- An important skill, such as reading, is likely to be lost without the reinforcement and consistency of school

Signatures: The IEP team members must sign to signify that they were present and participated in the development and writing of the IEP. Only those who were present and participated should sign, not someone who was in the room for only a brief time.

Signing does NOT mean you agree with everything – you can note your objections in the margins. If you don't sign, there is no concrete evidence of your presence.

Finally:

- Review minutes at the end of the IEP meeting for accuracy, especially if there was a difference of opinion.
- Do not leave without a copy of the IEP, the minutes, and any other papers that were discussed.

Frequently Asked Questions

Can the parents bring someone with them to an IEP meeting?

Yes. In fact, we often recommend that parents have someone with them for moral support: anyone with "knowledge or expertise regarding the child." An IEP meeting can be an emotional time, and it is very helpful to have someone who can observe the interactions, take notes, and be supportive.

Is there an IEP team leader? Do we vote on the IEP?

While someone from the school will conduct the meeting, there is no "leader" of an IEP team. All decisions are made by consensus, meaning all team members should agree or at least consent to the decision. This is not a voting situation! In some cases, the school district may refuse a request, in which case it is time to consider other means of resolving the disagreement.

What do I do if I disagree with the IEP?

You have several options, ranging from further discussions to a lawsuit. It is usually advisable to start with the least confrontational method and proceed from there.

- Call another IEP meeting and bring someone with you; you can record the meeting if you notify the school. They will also then record it.
- Request a facilitated IEP meeting; the Department of Public Instruction (DPI) will
 provide a person to run the meeting, free of charge. This person is not involved
 in the discussions other than to manage the process; they keep people on track,
 focused, and civil.
- Call DPI and lodge either an informal, verbal complaint alleging a violation of law, or a formal, written complaint. These are investigated and resolved within 60 days. The school will be contacted, as will the Exceptional Children's (EC) Director for the school system. There must be a specified violation of either IDEA or NC Policies: a denial of a free and appropriate public education, refusal to educate in the least restrictive environment, or failure to implement the IEP, for example. DPI will not investigate if the complaint is about a poorly written or ineffective IEP.
- Request mediation, also through DPI and free of charge. An impartial mediator
 will contact both parties, the parents and the school, to hear their positions, and
 then schedule a meeting to attempt a compromise. Typically, this process results
 in an agreement.

Do I have to sign the IEP??

While you do not have to sign, your signature merely indicates that you were present and participated; if you disagree, you can note on the form that you disagree and with which parts. The form says "present and participated in the writing and development of the IEP" — don't you want it known that you were there and helped?

• The last resort is to file for a due process hearing, a legal method. This must also be filed with DPI, the Office of Administrative Hearings, and the school system's Superintendent or the EC Director. The statute of limitations for filing due process is one year; it can take quite some time to investigate and adjudicate. The paperwork is very detailed and must follow strict procedures as well.

All complaints to DPI must be related to the identification, evaluation, or educational placement of a child with a disability, provision of FAPE or a manifestation determination. For information on what constitutes a manifestation determination, please see our Behavior Toolkit.

For more detailed information on these options, please see DPI at http://ec.ncpublicschools.gov/ parent-resources/dispute-resolution.

What if I disagree with the school system's evaluation or eligibility determination?

If you disagree with the evaluation conducted by the school system or your child's eligibility, you can request (in writing) an independent evaluation, to be paid for by the public school system. The school system must agree to this and provide for it promptly or file for a due process hearing. While the school system may ask for a reason, they may not require one. Only one independent evaluation may be requested each time evaluations are performed.

How often does the school system have to re-evaluate my child? What if the school system tells me that my child does not need to be re-evaluated?

The re-evaluation process must occur at least once every three years but not more than once per year. During this process, the IEP team reviews the information available about the child and decides the scope of next steps:

- The school may skip the re-evaluation if the IEP team agrees that the information is not needed.
- The team can decide a re-evaluation can be performed to assess only a related service area such as speech or occupational therapy – or to determine continued eligibility, or it can be a comprehensive assessment.

Given that everyone changes, it makes sense to re-evaluate at least every three years. It is a particularly good idea to have high school seniors evaluated well before they graduate.

There is no timeline for performing a re-valuation, although it is supposed to happen in a timely manner.

How do I change my child's placement?

Placement is commonly confused with location. In special education, placement refers to the type and amount of special education services that a child receives, not the location or the specific type of the classroom. When considering which parts of the day that a student can spend with nondisabled peers, don't forget lunch, recess, morning announcement time, and specials (art, music, PE, foreign language).

From there, it is a matter of calculating the minutes spent in the regular education class to determine whether the placement is regular, resource or separate. The type of classroom is not changed by the IEP team, but the amount of special education services is.

What if the child or the families' native language is not English?

According to IDEA, all assessments and other evaluations should be administered in the child's native language or other mode of communication and in the form most likely to yield accurate information on what the child knows and can do academically, developmentally, and functionally.

What happens to an IEP when a family moves from one area of NC to another?

If a child moves from one part of NC to another, the new school system must provide comparable services, meaning similar to those provided by the previous school system. While the new school system may call an IEP meeting to make some changes based on their observations of the child, the old IEP is in effect until that time.

What happens when a child moves to NC from another state?

The school system is required to provide comparable special education services while beginning the process of evaluation and placement. Although the school system must base its services upon the previous state's IEP, the child is treated as newly referred to the special education process. This means that the school system has 90 days to administer the evaluation assessments if the IEP team decides that new evaluations are needed rather than accepting the previous state's evaluations, write a new IEP, decide on the placement or amount of special education services, and begin to provide those services.

What if you decide to place your child in private school?

It may be possible to receive some special education services in private or home school settings. The services provided may be limited in scope. Each school system apportions funds for this expense category differently; ask how the system spends its 6B Grant money. For example, the school system might decide to allocate their funds for speech therapy.

When does a child need a more definitive diagnosis than "developmentally delayed"?

By the age of 8, or upon entering third grade, a child must be re-evaluated and receive a more definitive diagnosis. These children may be diagnosed with Autism Spectrum Disorder, which includes PDD-NOS, Asperger's Syndrome, etc.



Do all children with autism qualify for an IEP?

To qualify for an IEP, the IEP team must review all required screening and evaluation information about your child, including a discussion of the student's strengths and needs.

Based on information from a variety of sources that have been documented and carefully considered, the IEP team determines whether:

- The student meets criteria for one or more of the fourteen disabling conditions in IDEA.
- The disability has an adverse effect on educational performance; and
- The disability requires specially designed instruction.

More information: http://ec.ncpublicschools.gov/policies/forms/statewide-forms

Not all children with autism will qualify for an IEP. For a child with autism who does not need special education, a Section 504 plan may be an option. Section 504 of the Rehabilitation Act of 1973 provides protection from discrimination based upon a child's disability, if that disability substantially limits a major life activity, such as talking, walking or learning. Any facility that receives federal assistance is covered by this civil rights law.

Is the only way to resolve disputes with the school system to engage an attorney?

If there are disagreements that cannot be resolved by the IEP team, consider the options available through the NC Department of Public Instruction (DPI):

- formal complaints
- mediation
- facilitation
- due process hearings

For more details, go the DPI website:

http://ec.ncpublicschools.gov/parent-resources/dispute-resolution.

Once an attorney represents a parent/child, the school system must also engage their attorney, which means that the school system will no longer speak directly to the parents. The situation can become more volatile, more antagonistic, and less open to negotiation. Consider:

- What are my goals?
- What will I gain by legal action?
- Will my child benefit?
- Will the process take longer than my child will be in the situation?

Additional Resources:

ASNC's Autism Resource Specialists are available to help families with school issues. Find the Autism Resource Specialist in your area here: http://bit.ly/AutismResourceSpecialists.

Links

- US Department of Education's website on IDEA2004: http://idea.ed.gov/
- NC Department of Public Instruction's website on exceptional children: http://ec.ncpublicschools.gov//
- A good place to start unravelling the mysteries of the IEP is Wrightslaw.com, where you'll find articles, law and regulations, tactics and strategies, tips, books, and free publications about IEPs. www. wrightslaw.com/info/iep.index.htm
- Wrightslaw offers us all a "Roadmap to IDEA 2004: What You Need to Know About IEPs & IEP Meetings." www.wrightslaw.com/idea/art/iep.roadmap.htm

Books: All of these titles are available in the ASNC Bookstore. Shop online at www.autismbookstore.com to benefit ASNC.

- Getting to Yes: Negotiating Agreement Without Giving In Roger Fisher, William Ury and Bruce Patton
- Creating a "Win-Win IEP" for Students with Autism Beth Fouse
- Wrightslaw: All About IEPs Pete Wright
- Wrightslaw: Special Education Law, 2nd Edition Pete Wright
- Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide – Pamela and Pete Wright
- The Complete Guide to Special Education: Expert Advice on Evaluations, IEPs, and Helping Kids Succeed – Linda Wilmshurst and Alan W. Brue
- Autism: Asserting Your Child's Right to a Special Education – David A. Sherman
- How to Compromise with Your School District Without Compromising Your Child – Gary Mayerson

- When the School Says No, How to Get the Yes! Vaughn Lauer
- The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives – Diane Twachtman-Cullen and Jennifer Twachtman-Bassett
- Implementing Ongoing Transition Plans for the IEP: A Student-Driven Approach to IDEA Mandates – Pat McPartland
- Complete IEP Guide: How to Advocate for Your Special Ed Child Lawrence M. Siegel
- A Parent's Guide to Special Education Linda Wilmshurst, Ph.D., ABPP, and Alan W. Brue, Ph.D., NCSP
- Special Needs Advocacy Resource Book: What You Can Do Now to Advocate for Your Exceptional Child – Rich Weinfeld and Michelle Davis
- We Said, They Said: 50 Things Parents and Teachers of Students with Autism Want Each Other to Know – Cassie Zupke

Creating an IEP Notebook

Managing the needs of our children with autism can be a full-time job. Add to that the mountain of paperwork that comes from doctors, evaluations, schoolwork, and IEPs, and you can quickly find yourself overwhelmed.

Turn that mountain back into a molehill; prepare for your next IEP meeting by condensing all essential papers into a well-organized notebook. The notebook is a very powerful tool in reviewing your child's history, recording what other professionals have said about your child, and keeping an accurate record of what the school has committed to and what they have actually done. Written evidence about your child speaks for itself, removing you from the middle.

Having a notebook with all essential records and documentation can be a huge help when you sit down for your annual IEP meeting. Whether you've just finished your IEP meeting or are anticipating one, there is no time like the present to make sure you have the papers you'll need at your fingertips.

What do I need to get started?

First, obtain a three-ring binder with dividers or an accordion file. A binder that has a plastic sleeve in the front where you can place a picture of your child is a good reminder of who you are doing all of this for!

If you use a three-ring binder, you will want to have a three-hole punch or plastic sleeves that you can slide your paperwork into. One advantage to using plastic sleeves is you avoid punching holes into documents that may not have margins wide enough to accommodate them. Be sure to have dividers that are easy to label so you can organize your notebook into as many sections as you need.

Next, gather all of your child's paperwork. What kind of paperwork should go into your notebook? Here are a few suggestions:

- Your child's IEP or 504 plan
- Medical/psychological evaluations and testing
- Diagnostic reports
- Academic evaluations (by the school and/or independent evaluators)
- Recent report cards and progress reports
- BIP (Behavior Intervention Plan) and discipline records
- Written correspondence with teachers or school administrators
- Communication log documenting conversations with teacher or school administrators
- Contact information for important professionals, such as doctors, private speech therapists, etc.
- Samples of your child's work, showing strengths and weaknesses, including classwork, homework, and tests
- Standardized test results

Putting it all Together

There are two schools of thought on organizing all of this information:

- One method is to create categories such as Evaluations, Correspondence, IEP, Work Samples, etc.
- The other method, which is recommended by www.WrightsLaw.com, is chronological. You create a
 master list of documents at the front of the notebook to easily locate the contents. When you add
 a document to the notebook, you simply add it to the master list, which functions as your table of
 contents. One benefit of the chronological method is that as you acquire papers, you just add them
 without worrying about categorizing.

There is no right or wrong method to organizing the information. What matters is that it makes sense to you and that you are able to access what you need quickly.

You may want to keep your IEP binder in a tote bag where you also include supplies such as pencils, pens, highlighters, and an IEP guidebook.

When you arrive at your next IEP meeting, you will now have all of the tools you need to advocate for your child, as well as a renewed sense of confidence that you are organized, knowledgeable, and prepared.

A Few Tips on Documentation

Always keep the original document in your notebook. If you want to keep extra copies, create a box or filing system to keep your notebook from filling up too quickly.

Dates are important! Every piece of paper should have the date that you received it – marking this in pencil is fine. It is important to note the following dates:

- Meetings with anyone at the school
- When you send or receive key documents
- When you tell the school specific information, such as "My child is spending hours on what should be a 15-minute assignment."
- Any time your child is disciplined or suspended.

If it is in your notebook, it needs to have a date on it. This is very important when you need to establish a timeline.

Locate the Autism Resource Specialist in your area here: http://bit.ly/AutismResourceSpecialists. They offer a workshop on organizing IEP notebooks.

A Sampling of ASNC Workshops

A calendar of workshops can be found online at: http://bit.ly/ASNCWorkshopCalendar

- Autism: Building on Strengths to Overcome Challenges
- After the Diagnosis: Get Answers, Get Help, Get Going!
- The IEP Process: Building Success for Your Child at School
- IEP CLINIC
- IEP Basics: Frequently Asked Questions
- Beyond the IEP Basics
- IEP Notebook: Taming the Paper Monster
- Taking Autism to the Doctor/Dentist
- Taking Autism on the Road
- Wading Through Therapy Options: Where to Begin
- Developing an Individual Transition Plan: ITP @ 14
- Journey to Adulthood
- The Importance of Developing Self-Advocacy Skills
- Making the Parent-Professional Relationship Work
- Considering College? Prepare, Plan, Succeed
- Preparing for College Starts at Home
- Guardianship: What You Need to Know
- The Next Step: Residential Options for Adults with Autism
- Managing Stress: Taking Time to Breathe
- Staying Two Steps Ahead: Safety Considerations for Caregivers
- IPads, Mobile Technology and Autism
- Tips and Tricks for iPads and Autism
- Navigating Services
- Civics 101: Understanding How Government Works for You
- Civics 201: Practical Strategies for Advocating for Change

About Autism

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities — including classic autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome — that affect a person's ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, social interaction, and behavior.

Individuals with ASD typically have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people with ASD are the same. As its name implies, ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities.

It is estimated that up to 1 out of every 68 children has some form of ASD. Evidence suggests that the prevalence rate in North Carolina is even higher than the national average, at 1 in 58. More than 60,000 individuals live with ASD in North Carolina.

The overall incidence of ASD is consistent around the globe, but it is five times more prevalent in boys than in girls. ASD knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of occurrence. While ASD is typically diagnosed in children, it is a lifelong disorder that affects individuals of all ages.

What Causes ASD?

Although it was first identified in 1943, to this day no one knows exactly what causes ASD. However, research to discover its cause is ongoing. Many researchers believe that there is a strong genetic component. Some research suggests a physical problem that affects the parts of the brain that process language and information; other research points to an imbalance of brain chemicals. A variety of possible external or environmental triggers are also being studied. It is possible that ASD is caused by a combination of several factors.

Signs and Symptoms

People with ASD may have problems with social, behavioral, and communication skills. They might repeat behaviors and might not understand change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things.

A person with ASD might:

- have severe language deficits or differences
- talk about or show interest in a restricted range of topics
- not point at objects to show interest, such as an airplane flying over
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- laugh, cry, or show distress for no apparent reason
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- be oversensitive or under-sensitive to pain
- lose skills they once had (for instance, stop saying words they were once using)



The Autism Society of North Carolina is the leading statewide resource organization serving people across the autism spectrum throughout their lifespans. We understand the challenges of the autism community because we work with individuals with Autism Spectrum Disorder (ASD) every day.

ASNC works to directly improve the lives of individuals and families affected by autism through advocacy, training and education, and direct services.

Advocacy: We are the only autism-specific advocacy organization in North Carolina, and it is the heart of what we do. We find resources for families, assist with school issues, educate families through workshops, help individuals navigate the services system, and host local support groups. We also give those with autism a voice in public policy by maintaining relationships at the state legislature and other policymaking entities.

Training & Education: We focus on evidence-based best practices that empower self-advocates, families, and professionals. We also work to increase understanding and acceptance of people with ASD in the community.

Services: ASNC is a direct care service provider, and a recipient of the highest level of accreditation by the Council on Quality Leadership for exemplary service provision. Individuals with ASD receive a variety of residential, recreational, vocational, and community-based services that are designed to meet their needs, interests, and strengths.

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Connect with us on social media: facebook.com/AutismSocietyofNorthCarolina twitter.com/AutismSocietyNC