



Special Needs, Practical Guidance

Insight, information and inspiration to help your child thrive.



checklists



tips



to-dos

more

LifeEvents.

Special Needs Children Inspire a Very Special Kind of Love. With Great Love, Your Child Can Make Great Strides.

“The central struggle of parenthood is to let our hopes for our children outweigh our fears.”

– Ellen Goodman

If you have a child who faces challenges because of a medical, emotional, or learning problem, chances are you envision a difficult road ahead. But you should also know that with the right care and support, many special needs children grow up to lead happy, healthy, and fulfilling lives. A positive outlook combined with an informed and balanced perspective can help put you at ease and unlock your child’s potential.

This guide will help you:

- Identify warning signs.
- Partner with your pediatrician.
- Find programs and services.
- Understand special education.
- Manage stress and emotions.

Important: Always consult the appropriate health, education, or counseling professional regarding the welfare, care, and treatment of your child.



Going the extra mile. The fact that your child needs extra love means your love is that much greater. It also makes it important to go the extra mile as you navigate the twists and turns, ups and downs of dealing with his or her disability. But to make sure you’re headed the right direction and balance the trials and joys of raising a special needs child, you should be as well informed as possible.

Find comfort, encouragement, and support in these pages:

- Early Warning Signs: Watching Out for Developmental Delays
- How to Talk with the Doctor: 3 Crucial Steps
- School Services FAQs: Understanding What’s Available
- School Services FAQs: Understanding the Laws
- Blueprint for Building an IEP for Your Child
- The A-B-Cs of ADHD (Attention Deficit Hyperactivity Disorder)
- Autism: Understanding, Coping, Combating
- Glossary: Special Terms for Special Needs

Early Warning Signs: Watching Out for Developmental Delays



Complete the checklist below to determine if your child is showing signs of developmental delays. "Yes" is normal, but every "no" signals a possible problem that you should discuss with your child's doctor.

2 Months: Does Your Child ...

- Respond to loud sounds? Yes___ No___
- Watch things as they move? Yes___ No___
- Smile at people? Yes___ No___
- Bring hands to mouth? Yes___ No___
- Hold head up when pushing up on stomach? Yes___ No___

4 Months: Does Your Child ...

- Watch things as they move? Yes___ No___
- Smile at people? Yes___ No___
- Hold head steady? Yes___ No___
- Coo or make sounds? Yes___ No___
- Bring things to mouth? Yes___ No___
- Push down with legs when feet are place on a hard surface? Yes___ No___
- Have trouble moving one or both eyes in all directions? Yes___ No___

6 Months: Does Your Child ...

- Try to get things that are in reach? Yes___ No___
- Show affection? Yes___ No___
- Respond to sounds? Yes___ No___
- Lift things to mouth? Yes___ No___
- Make vowel sounds? Yes___ No___
- Roll over? Yes___ No___
- Laugh or make squeaking sounds? Yes___ No___
- Show a suppleness in the muscles? Yes___ No___
- Not have the floppiness of a rag doll? Yes___ No___

9 Months: Does Your Child ...

- Bear weight on legs for support? Yes___ No___
- Sit with help? Yes___ No___
- Babble sounds like "mama" and "dada?" Yes___ No___
- Play games with back-and-forth play? Yes___ No___
- Respond when addressed by name? Yes___ No___
- Recognize faces that should be familiar? Yes___ No___
- Look where you point? Yes___ No___
- Transfer toys from one hand to the other? Yes___ No___

1 Year: Does Your Child ...

- Crawl? Yes___ No___
- Stand when supported? Yes___ No___
- Search for things that he or she sees you hide? Yes___ No___
- Play games with back-and-forth play? Yes___ No___
- Say single words like "mama" or "dada?" Yes___ No___
- Learn gestures like waving or shaking head? Yes___ No___
- Look where you point? Yes___ No___
- Transfer toys from one hand to the other? Yes___ No___

Did You Know?

2 out of every 8 babies are at risk for a development delay. That's **5 million** children, the vast majority of which don't receive early intervention.

Sources: http://www.cdc.gov/ncbddd/actearly/pdf/checklists/all_checklists.pdf
https://www.facebook.com/easterseals/app_212612525516207



How to Talk with the Doctor: 3 Crucial Steps

You are concerned about your child's development and need the guidance and support of your pediatrician. Fears race through your mind as you try to organize your thoughts into the basis of a rational and productive discussion. The following tips help you break down the process so you can get the most out of your meeting with the doctor and determine what, if any, intervention services your child requires.



1. Prepare for your visit.

- Alert the doctor's office that you need to discuss your concerns about your child's development.
- Compile a detailed written list of your questions and concerns for the appointment.
- Be ready to discuss milestones that you feel your child may not be reaching.
- Talk to other adults who know your child well to see if they share your concerns.
- Arrange to have another adult with you at the appointment to occupy your child while you concentrate on your discussion with the doctor.



2. Ask all of your questions during the visit.

- Be clear about your concerns, check off each question on the list you've prepared, and jot down notes.
- Make sure you fully understand the doctor's answers and don't hesitate to ask for clarification.
- Don't rush through your visit; if the doctor doesn't have sufficient time to address all your concerns, schedule another visit.
- Review your child's most recent developmental screening results with the doctor. Schedule a screening if your child hasn't had one already.
- Discuss next steps and include them in your notes.



3. Confirm the course of action you outline with the doctor.

- Don't leave without making sure all your questions have been answered.
- If you are still unclear about anything you discussed with the doctor, have the doctor explain it again or in a different way.
- Go over your notes and make sure you have all the information you need, such as the phone number of a recommended specialist or early intervention program.
- Review your notes again when you get home and call the doctor with follow-up questions.
- Follow through on the doctor's recommendations and circle back to discuss the outcome.

School Services FAQs: Understanding What's Available



Federal and state laws entitle children with special needs to services in school. While the process can be intimidating and confusing, the information below will help you advocate for your child and be proactive in ensuring he or she gets the right services.



What Problems Do Services Cover?

Educational challenges that may warrant federally or state-funded services range from problems with concentration, learning, language, and perception to problems with behavior and/or making and keeping friends.



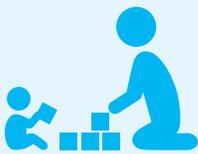
Who Provides the Services?

Because Federal law mandates that every child receives a free and appropriate education in the least restrictive environment possible, public schools are legally obligated to provide special services or accommodations.



What Services Are Available in Your State?

Different states have different criteria for eligibility, services available, and procedures for implementing these laws, so it's important to do your homework regarding these laws and related regulations in your particular area.



How Will Your Child Be Evaluated?

You're entitled to request an evaluation of your child's needs for special education and/or related services. The evaluation may include:

- Psychological and educational testing
- A speech and language evaluation
- Occupational therapy assessment
- Behavioral analysis



What Steps Do You Need to Take?

1. Meet with your child's teacher to share your concerns and request an evaluation by the school's child study team. You can also request independent professional evaluations.
2. Submit a written, dated request for evaluations and services and keep a copy for your records.
3. Maintain detailed records, including insights and observations from your child's teachers and any communications (notes, reports, letters, etc.) between home and school.



What Happens After the Evaluation?

- Your child's eligibility for services is contingent upon the results of the evaluation.
- Based on the evaluation, an Individualized Education Program (IEP) is developed.
- IEP services include: Occupational Therapy, Physical Therapy, Speech and Language Therapy, and/or the provision of a classroom aide.

Did You Know?

If not satisfied with the findings of the evaluation, you can dispute them with a formal appeal. Your child's school is required by law to provide you with information about how to make an appeal.

School Services FAQs: Understanding The Laws

What Laws Mandate School Services?

To support their ability to learn in school, three Federal laws apply specifically to children with special needs:



The Individuals with Disabilities Education Act (IDEA) governs all special education services for children in the United States. Your child may be eligible for special education under IDEA if he or she is in one of the following categories:

- Serious emotional disturbance
- Learning disabilities
- Mental retardation
- Traumatic brain injury
- Autism
- Vision and hearing impairments
- Physical disabilities
- Other health impairments

Section 504 of the Rehabilitation Act of 1973 is a civil rights statute which typically covers children who either have less severe disabilities or other disabilities that don't meet IDEA eligibility requirements. The statute:

- Considers any person with an impairment that substantially limits a major life activity (including learning and social development) to be disabled.
- Requires that schools not discriminate against children with disabilities and provide them with reasonable accommodations.
- Covers all programs or activities, whether public or private, that receive any federal financial assistance.
- Ensures that disabled children receive reasonable accommodations, including untimed tests, sitting in front of the class, modified homework and the necessary services.

The Americans with Disabilities Act (ADA):

- Requires all educational institutions, other than those operated by religious organizations, to meet the needs of children with psychiatric disorders.
- Prohibits the denial of educational services, programs or activities to students with disabilities.
- Prohibits discrimination against all such students.

Blueprint for Building an IEP for Your Child

What an Individualized Education Program could mean for your child.

What is an IEP?

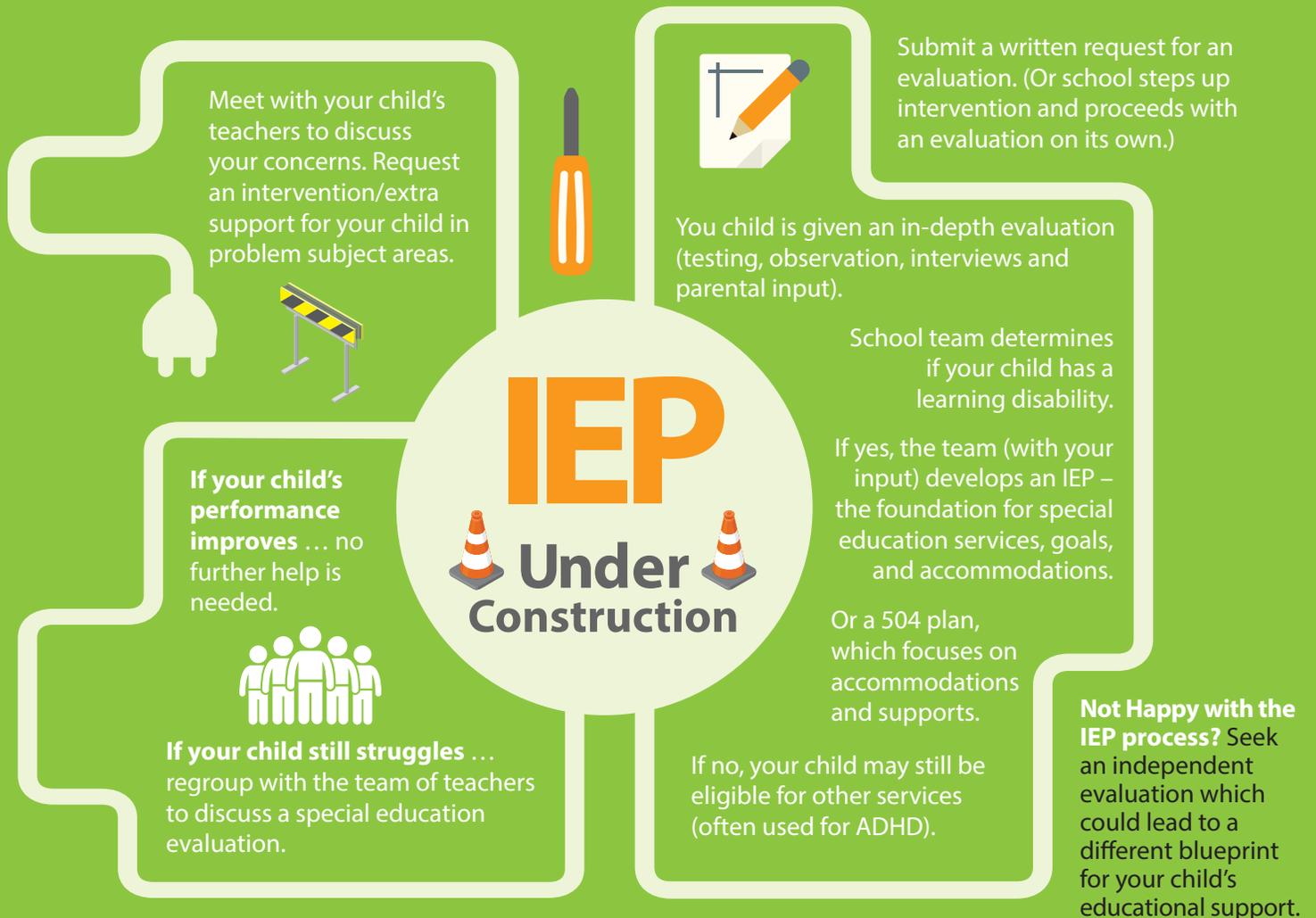
A written plan describing the special education and related services designed to meet the unique needs of a student with a disability. An IEP:

- Contains goals and objectives based on the student's educational struggles.
- Specifies the educational placement and setting.
- Describes the services and supports included in the special education program.

Who is Eligible?

- The Individuals with Disabilities Education Act (IDEA) covers a wide range of disabilities.
- If your child has a learning disability, attention deficit hyperactivity disorder (ADHD), a mental disorder, mental retardation, or pervasive developmental disorders, he or she may be eligible for special education and related services under IDEA.

What is the Process?



Sources: <http://elearninginfographics.com/the-individualized-education-program-roadmap-infographic/>
<http://www.hpaped.com/blog/individualized-education-program-iep-meeting-checklist>

The A-B-Cs of ADHD (Attention Deficit Hyperactivity Disorder)

As one of the most common neurodevelopmental disorders, ADHD affects up to 8-10% of school-age children. The following information will give you important insight into this often-diagnosed condition which, without proper treatment, could severely hamper your child's educational and social development.

3 Types of ADHD

Once known as attention deficit disorder, or ADD, ADHD is now broken down into three subtypes, each with its own pattern of behaviors:

A. Inattentive

- Severely limited attention span
- Careless and sloppy schoolwork
- Inability to focus on tasks or play activities
- Trouble listening
- Difficulty following instructions
- Problems with organization
- Low capacity for mental effort
- Tendency to lose things like toys, notebooks, or homework
- High level of distractibility
- Forgetfulness in daily activities

B. Hyperactive-Impulsive

- Fidgeting or squirming
- Difficulty remaining seated
- Excessive running or climbing
- Difficulty playing quietly
- Always seeming to be "on the go"
- Excessive talking
- Blurting out answers before hearing the full question
- Difficulty waiting for a turn or in line
- Problems with interrupting or intruding

C. Combined

- A mix of symptoms from both inattentive and hyperactive types
- Child struggles with paying attention as well as regulating behavior

Mistaking a Disorder for Disobedience: While kids with ADHD can test your patience, it's important to remember they aren't "bad," "acting out," or being difficult on purpose. Without medicine or behavioral therapy, they struggle to control their symptoms.

Types of Treatment

Pharmacological:

Your pediatrician can prescribe medication to improve your child's attention and regulate his or her behavior.

Behavioral:

A licensed child psychologist or therapist can use behavior modification strategies to help your child exercise greater self-control and better judgement.

Parent/Teacher:

Partner to identify problem areas and set expectations for improved behavior and the completion of tasks.



Did You Know?

At a rate of 2 to 1, ADHD is more common in boys than girls.

Sources: http://kidshealth.org/parent/emotions/behavior/adhd.html#a_Symptoms
<http://nsp4kids.com/wp-content/uploads/2013/09/ADHDinfographic1.jpg>

Autism: Understanding, Coping, Combating

Autism spectrum disorder (ASD) is a complex developmental disability that affects more than 2 million Americans. If you're concerned that your child has the disorder, you should know that signs typically appear during early childhood and could inhibit your child's ability to communicate and interact with others. The following facts and stats will help you piece together the puzzle of autism and provide insight into how to protect your child against this national epidemic.

A Growing Problem



1 in 68

8-year-old children has been identified as having autism

30%

increase from 2008-2010

5x

more prevalent in boys than girls.

Good News: Research confirms that the earlier the intervention, the better.

Bad News: While children can be diagnosed as early as age 2, most are not diagnosed until after age 4.



The Autism Spectrum



PDD-Nos (Pervasive Developmental Disorder – Not Otherwise Specified)

Fewer and milder symptoms
Might cause only social and communication challenges

Asperger's Syndrome

Some milder symptoms
Might have social challenges and unusual behaviors and interests

Autism

Significant language delays
Social and communication challenges
Unusual behaviors and challenges

What Causes Autism?

There is no known single cause, but here are a few commonly recognized factors:

- Brain structure or function abnormalities
- Heredity
- Fragile X syndrome, tuberous sclerosis, Down syndrome and other conditions
- Exposure to toxins like mercury
- Being born to a mother over 35 and a father over 40

RED FLAGS – Your child does NOT:

- Respond to his or her name by 12 months.
- Show interest by pointing at objects by 24 months.
- Make eye contact.
- Prefer interaction to being alone.

What's the most effective way to treat autism?
Early intervention. To delay contacting your pediatrician about having your child evaluated could be to delay your child's development.

Sources:

<http://www.cdc.gov/ncbddd/autism/infographic.html>

<http://graphs.net/wp-content/uploads/2014/03/2.-The-Numbers-behind-the-Autism-Tsunami.png>

<https://s-media-cache-ak0.pinimg.com/736x/41/d0/67/41d067a38265cca31f46b2184e582e64.jpg>

Glossary: Special Terms for Special Needs

Having a child with special needs is difficult enough without being able to decipher to jargon used in reference to your child's condition, services and accommodations. The definitions below will help familiarize you with certain key terms and acronyms.

ARC (The Arc): Advocates for the Rights of Citizens with Developmental Disabilities and their families. The organization advocates for the rights and full participation of all people with developmental disabilities.

Advanced Practice Registered Nurse (APRN, also called ARNP or APN): a nurse with an advanced degree (Master's or Doctorate) and the corresponding knowledge, skills and scope of practice, often in a specialty area.

Care Coordinator: a person who connects and coordinates support, services and resources for children with special health care needs and their parents at home, in child care, in school, or in health care or community settings.

Case Manager: a person who coordinates and connects support, services and resources for children with special health care needs and their families. Case management services can occur in schools, health care settings, in child care facilities and in communities.

CD: Communication Disorders

Child Life Specialist (CLS): a pediatric health care professional who work with patients, their family and others involved in the child's care in order to help them manage stress and understand medical and various procedures.

Children with Special Health Care Needs (CSHCN): those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Children with Special Health Care Needs (CSHCN) Coordinator: a public health nurse who coordinates services and care for children with chronic health conditions.

Clinical Nurse Specialist (CNS): an advanced practice nurse, with graduate preparation (earned master's or doctorate) who is a clinical expert in the diagnosis and treatment of illness, and the delivery of evidence-based nursing interventions.

CNA: Certified Nursing Assistant

Continuous Process Improvement (CPI): A process being used at health care organizations with the goal of improving systems of care for patients, families and staff.

DD: Developmentally Disabled, Developmental Disability

Developmental Delay: when a child's cognitive, physical, communication, social, emotional or adaptive/self-help abilities are at a level that is less than typical peers of a similar age. A developmental evaluation must be completed to assess the level of delay.

DH: Developmentally Handicapped

Family Centered Care (FCC): assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family centered care is the standard of practice which results in high quality services.

Genetic Services: include evaluation, diagnosis, follow-up, and treatment for inherited disorders and birth defects. They can include a review of family and medical history, physical examination, counseling, education, laboratory testing, and referral for appropriate management. Services provide individuals and families with information about inherited disorders, how genetic conditions are passed on in families, and the risks that a condition will affect other family members.

Health Insurance Portability and Accountability Act (HIPAA): provides rights and protections for participants and beneficiaries in group health plans. HIPAA includes protections for coverage under group health plans that limit exclusions for preexisting conditions; prohibit discrimination against employees and dependents based on their health status; and allow a special opportunity to enroll in a new plan to individuals in certain circumstances.

Health Maintenance Organization: a managed health care plan, public or private, that provides health care services to their members through networks of doctors, hospitals and other health care providers.

HI: Hearing Impaired

Individual Health Plan (IHP): a document that outlines health care to be provided in the school setting, created by the school nurse in conjunction with parents.



Glossary: Special Terms for Special Needs

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Individualized Family Service Plan (IFSP): a written document that is developed by the child's family and a team of professionals; the plan include the necessary early intervention services that will be provided, outcomes or expected gains from the intervention services, and methods to assist parents/primary care givers to support the child's development.

Institutional Review Board (IRB): a committee that formally approves, monitors, and reviews research with the aim to protect the rights and welfare of those who participate in research.

LD: Learning Disabled

Maternal and Child Health Bureau (MCHB): a federal organization that provides national leadership in partnership with States, communities, public-private partners, and families to strengthen the maternal and child health (MCH) infrastructure. It assures the availability and use of medical homes, and builds knowledge and human resources in order to ensure continued improvement in the health, safety, and well-being of the maternal and child health population.

Medical Home: an approach to delivering primary health care through a "team partnership" that ensures health care services are provided in a high-quality, cost effective and comprehensive manner.

National Organization for Rare Disorders (NORD): an organization dedicated to helping people with rare "orphan" diseases through programs of education, advocacy, research, and service.

Natural Environment: Individuals with Disabilities Education Act (IDEA) requires that services be provided in a child's natural environment, meaning where a child normally lives, works or plays.

NICU: Neonatal Intensive Care Unit

Parent to Parent: an organization that provides peer support and information to families of children with special needs and/or disabilities.

Parents Are Vital in Education (PAVE): a parent-directed organization that works with families, individuals with disabilities, professionals and community members to provide information, training and support.

Sibling Support Project (SSP): a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.

Social Security Administration (SSA): a federal program that administers a retirement program and other programs including supplemental security income (SSI)

Statewide Children's Health Insurance Program (SCHIP): a federal program that gives funds to states in order to provide health insurance to families with children.

STOMP: Specialized Training of Military Parents

Supplemental Security Income (SSI): a monthly stipend provided to aged (legally deemed to be 65 or older), blind, or disabled persons based on need.

SW: Social Work/Worker

TDD: Telecommunication Device for Deaf, Hearing Impaired, and Speech-Impaired Persons (also know as TTY – Teletype).

VI: Visually Impaired

WIC: Women, Infants and Children Supplemental Nutrition Program