



# **GUIDE TO PARENT ADVOCACY**

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# Differences between EI, School, and Outpatient Care

As parents of growing children it can seem a daunting task to provide all the necessary foundations to ensure that our children grow up to be happy and healthy. For parents of children with disabilities, there is an additional layer of planning that must occur so that these children receive the necessary services to be able to actively participate in home, school, and community life. *You are the advocate for your child's future!*

As you navigate the process of your child transitioning from early developmental to school based services and beyond, it is important that you as the parent are aware of all of your child's options. You are an integral part of the team! So where do you start? Get Educated! The following information provides a basis for the types of services that may be available to you and your child as they grow from infancy to adulthood.

The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to eligible infants, toddlers, children and youth with disabilities free of charge. Related services are developmental, supportive, and corrective services that may assist the child to benefit from special education and include physical therapy, occupational therapy, transportation, speech language pathology and audiology, interpreting services, psychological services, therapeutic recreation, social work, school nurse services, and counseling services. IDEA is divided into 5 parts. Early intervention (EI) services for infants and toddlers with disabilities (birth-3<sup>rd</sup> birthday) and their families falls under IDEA Part C, whereas children and youth (ages 3-21) receive special education and related services under IDEA Part B.

## **Early Intervention (0-3 years old)**

### *What is Early Intervention?*

- EI services aim to enhance the development of infants and toddlers to minimize their potential for developmental delays, assist families to meet the special needs of their infants and toddlers with disabilities, and most importantly enable children to be able to **participate** in their family and community.
- Early intervention is described as part C of IDEA

### *Who Qualifies for EI?*

- In Illinois, early intervention services are offered to those children who are **less than 3** years of age residing in Illinois who has a documented developmental delay, or has a physical or mental condition, which typically results in developmental delay, or is at risk of having substantial developmental delays.
- To meet the criteria for a developmental delay a child must show at least a 30% delay in one or more of the following areas of childhood development based on standardized tests in relation to age-matched peers:

- Cognitive
- Physical (including vision and hearing)
- Language, speech and communication
- Social-emotional
- Adaptive self-help skills
- Some diagnoses automatically qualify for EI services (i.e. Spina Bifida and Cerebral Palsy) however these vary by state

### *What services are offered?*

- family training, counseling, and home visits
- special instruction
- speech-language pathology and audiology services, and sign language and cued language services
- occupational therapy
- physical therapy
- psychological services
- service coordination services
- medical services only for diagnostic or evaluation purposes
- early identification, screening, and assessment services
- health services necessary to enable the infant or toddler to benefit from the other early intervention services
- social work services
- vision services
- assistive technology devices and assistive technology services
- transportation and related costs that are necessary to enable an infant or toddler and the infant's or toddler's family to receive another service

*\*The services provided are determined based on the needs of your child and family and are detailed in an Individualized Family Service Plan (IFSP)*

### *Where are the services provided?*

- These services, whenever possible are provided in **natural environments**, including the home, and community settings in which children without disabilities participate.

### *What is an Individualized Family Service Plan?*

- The IFSP contains information about the child's developmental status, a summary of the family's strengths, resources, concerns, and priorities for enhancing the child's development, as well as their determination of eligibility.
- This document will include the desired outcomes (based on family concerns and expectations for the child), strategies for achieving outcomes and supporting the family, the provider of the services, and the frequency of the services.
- All service providers as well as the family meet once a year to evaluate and revise the IFSP as needed.

## **School Based Services (ages 3-21)**

School Based services include Special Education and related services

Special Education can be offered in various forms:

- Regular education with weekly monitoring from a special education provider
- Regular education with daily consultation from a special education provider
- Regular education with special education services and supports included in that setting which are aligned with the general curriculum
- Regular education with special education services provided for part of the day in a resource room or special education classroom
- Self-contained special education classroom
- Special day school (outside of the school environment)
- Residential treatment facility
- Hospital
- Detention facility
- Home

**To the maximum extent possible, children with disabilities are educated with children who are not disabled**

- The goal is to allow students with disabilities the same opportunities as their typically developing peers to learn and **participate** in the classroom environment.
- Your child's **independence** should be encouraged and the necessary modifications (alternative instruction/testing methods, adapted curriculum, adaptive devices, or assistive devices) provided for to enable your child to **participate** and learn.

*Who is eligible for Special Education?*

- A child who has a disability listed below and who needs special education and related services
- Disability Categories:
  - Autism
  - Deafness
  - Deaf-blindness
  - Developmental delay
  - Emotional disturbance
  - Hearing impairment
  - Mental retardation
  - Multiple disabilities
  - Orthopedic impairment
  - Other health impairment
  - Specific learning disability
  - Speech or language impairment
  - Traumatic brain injury
  - Visual impairment, including blindness

- If your child is eligible for Special Education, they may be eligible for related services under IDEA part B
- If your child's disability affects their participation in school but they do not qualify under IDEA, they may be eligible to receive related services under Section 504

### *What is the goal of school based occupational and physical therapy?*

- School-based occupational and physical therapy are services offered to qualified students to help them better function within the school environment and meet educational goals/objectives.
- **School-based therapy is not intended to meet all the therapy needs of a student but is intended to meet needs of the student to promote success in the educational environment.**
- All therapy within the educational setting must be tied to educational performance
- Occupational therapists and physical therapists in schools need to identify the educational significance of therapy provided to students in order for a service to be provided.

\*Although your child may not qualify for school based services, it **does not** mean that services aren't possibly needed. You may need to look into outpatient services to address your child's needs\*

### *What are common types of occupational and physical therapy services offered in the school setting?*

- Enhancing school mobility and participation in educational activities by increasing strength, accuracy and speed.
- Ensuring easier total care by maintaining flexibility.
- Improving hand function for self-care and paper/pencil tasks through reach, grasp and dexterity.
- Enhancing comfort, participation and attending by maintaining functional postures.
- Increasing functional use of hands and site by providing stable positions.
- Ensuring independence in feeding safety and nourishment.
- Maintaining functional movement by prevention of stiffness and deformities.
- Facilitating safety in the school environment by decreasing the possibility of injury to student's self or others as he/she moves or performs skills/tasks.
- Improving success for small muscle school tasks by increasing coordination of eye-hand movements.
- Facilitating access to and mobility within school by assessing and changing the environment.
- Increasing use of arms and legs through adapted equipment.
- Arranging preparation for vocational needs.
- Facilitating student's independence through access to assistive technology.

### **How are services typically given?**

- Hands on instruction (1-on-1)
- Group intervention

- Consultation

### **What is IDEA part B and who qualifies?**

- IDEA part B is a law that mandates assistance for education of all children with disabilities
- Special education and related services are provided without charge, meet the standards of the State educational agency include appropriate preschool, elementary school or secondary school education, and are provided in conformity with the individualized education program.
- 6 major principles of part B:
  1. Zero reject – schools must be willing to enroll all students
  2. Nondiscriminatory testing – schools must use non-biased testing methods, and multiple measure for determining eligibility
  3. Appropriate education – schools must meet the individual needs of each student
  4. Least restrictive environment – to the maximum extent possible, children with disabilities are educated with children who are not disabled
  5. Due Process - schools must inform parents of their rights, protect the rights of children with disabilities, and provide safeguards
  6. Parent Participation – schools must include parents on IEP teams and work together with parents to develop and implement IEPs

### **What is an IEP?**

- Individualized Education Program
- It is a legal document that details the types of related services needed and why, the annual goals of the family and child, and placement decisions – how and where services will be implemented.
- Those students whose disability adversely affects their **educational performance** qualify

### **What is section 504?**

- Section 504 is a law that mandates that schools take steps to provide needed accommodations and services to persons with disabilities.
- A student may receive services to decrease limitations or to participate in school activities, to allow them **access to education**.

## **Transitions**

### **Transition from EI (0-3<sup>rd</sup> Birthday)**

This can be a very difficult transition period for you as parents. There may be fears associated with transitioning from having services provided within the home by a now very familiar therapist to possibly school based services in an unknown environment. To ensure that this step is as smooth as possible here are some of the basics you need to know so that you can effectively advocate for your child as they enter the world.

### *When does transition out of EI begin?*

- As EI is provided for children **less than 3 years old**, at 2 ½ years old, the transition out of EI begins. There must be a transition plan in place at a minimum of 90 days and not more than 9 months before your child's 3<sup>rd</sup> birthday.

### *What is the purpose of a transition plan?*

- To prepare you and your child for the changes to come.
- The collaboration between programs is important in reducing gaps and ensuring that your child and family receive the necessary services and specialized instruction.
- There may be different paths after graduation from EI
  - Some children may need no further specialized services/or instructions as their determined delay has resolved
  - Some children may still have continued delay/disability and are in need of further specialized services and instruction including:
    - Early childhood special education as described under IDEA part B
    - or
    - Specialized services in another setting outside of school

### *What does the transitional plan include?*

- Preparation of your family and child for transition
- Looking at community programs with structure
- Program visitations and meeting with educators and support staff
- Making necessary changes in your child's eating and sleeping routines prior to transition.

*Understand that this can be a stressful time, however with the proper transitional plan and support this can be a smooth process for you and your child!*

### **Transition out of High School (age 21+)**

For any teenager, the transition into adulthood can seem daunting, however for those teenagers with disabilities this transition requires a bit more planning. As your child gets older it is important to think about their future beyond the school setting and ensure that the necessary plan is in place to provide your child with the tools necessary to navigate the adult world. It is important for you as parents to

begin to looking at your child's adulthood when your children are young. This will help ensure that the necessary ground work for your child is in place in order for your child to reach their full potential as an adult.

### *What is transitional planning?*

- Planning that helps you and your son or daughter move into post-school adulthood.
- Transition planning is used to identify and develop goals which need to be accomplished during the current school year to assist the student in meeting his post-high school goals.
- The transition plan should reflect the student's interests, preferences, accomplishments and skills, what they need to learn, and what they want to do. The focus should be on their abilities rather than on their difficulties.
- Your son or daughter's specific transitional plan should be incorporated into their IEP, and be revisited annually.

### *When should transition planning begin?*

- Under IDEA 2004, IEPs must include transition services for each student by age 16.
- You and your IEP team may wish to begin discussing transitional planning prior to your child turning 16. If the IEP team hasn't began focusing on this planning by the time your child has turned 16 it is important for you, as the parent, to initiate that process!

### *What are transition services?*

Transitional services are a coordinated set of activities for your family member with a disability that:

- a) Focuses on **improving their academic and functional achievement** to facilitate the movement from school to **post-school activities**.
- b) Is based on your **individual son or daughter's needs**, taking into account their **strengths, preferences, and interests**.
- c) Includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation

### *Who provides transition services?*

- The school should be providing these transition services – through each student's special education program.
- Special education staff provides assistance with counseling, identifying vocational interests, educational and vocational planning, goal setting, pre-vocational skills training, academic support, and linkages to specific programs and services
- There should be a coordinated effort between your child's school and community to provide the necessary services.
- Services vary from school to school, so it is important to communicate with your school district about the specific services they offer.
- There may be some transitional needs that are not provided for by the school therefore it may be important to seek out community services.

### *What are some possible transition options?*

- Post-secondary education



- Vocational education
- Integrated employment (including supported employment)
- Continuing and adult education
- Adult services
- Independent living
- Community participation

### *What role should my son or daughter have in their transitional planning?*

- According to IDEA, the student must be invited to all IEP meetings where the purpose of the meeting will be the consideration of their postsecondary goals for your child and the transition services needed to assist your child in reaching those goals.
- Young adults should be involved in the decision process for their future. It is their opportunity to take an active role in deciding on the future they want for themselves.

### *Other transition considerations:*

- Finding appropriate doctors:
  - Many pediatric physicians will no longer treat patients once they reach the ages of 18-22 because it is technically outside their pediatric specialty
  - Check with your child's doctors to determine their policy, and ask for referrals if necessary.
  - It is important that your son or daughter continues to receive care from providers who understand their unique needs; so starting this process early is very helpful.
- Respite care:
  - respite care provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs  
<http://www.illinoisrespitecare.org>

### *Suggestions for resources with in your community:*

- Rehabilitation Institute of Chicago:  
<http://lifecenter.ric.org/index.php?tray=default&tid=top0&cid=5009>
  - Has several programs and resources
- Center for Independent Living:  
<http://www.rampcil.org/about/cil.asp>
- Center for Independent Futures:  
<http://independentfutures.com/Default.aspx?tabid=168>
  - Offers services and resources to help individuals with disabilities work towards gaining independence as adults.
  - Services include:
    - Future Planning:
      - Helps individuals with disabilities and their families plan for the future
    - Community Living and Independent Living options/supports
    - Options for college success
    - Employment / vocational options

- Financial planning
- Social Networks
- Recreational options
- <http://www.disabilityresources.org/>

## **Outpatient Services**

Outpatient physical therapists treat children from the community and specialize in the evaluation and treatment of orthopedic, neurological, developmental musculoskeletal disorders, rheumatologic diseases, and wound care.

*Why outpatient services?*

- School based physical therapy addresses only those impairments that affects a child's educational performance or ability to participate in school activities, therefore one may seek additional outside services for those impairments not addressed within the school.

*Where are outpatient services delivered?*

- Private clinic
- Hospital affiliated outpatient clinic
- Home

*Goals of outpatient therapy:*

- The primary goals are having the child return to their prior level of function and engage in activities that are meaningful to the child and their family.

*\*You will want to contact your insurance provider to determine eligibility for outpatient services*

**Additional Resources for Families:**

1. Shonkoff JP, Meisels, SJ. Handbook of Early Childhood Intervention, 2<sup>nd</sup> edition. New York: Cambridge University Press, 2000.
2. Idea.ed.gov
3. [www.illinoiseittraining.org](http://www.illinoiseittraining.org)
4. Illinois State Board of Education (2003) Recommended practices for occupational therapy and physical therapy in Illinois schools. Springfield, IL
5. [www.ideapractices.org](http://www.ideapractices.org)

6. [www.nectac.org](http://www.nectac.org)
7. [www.dec-sped.org](http://www.dec-sped.org)
8. Information regarding Special Education Law and Advocacy - [www.wrightslaw.com](http://www.wrightslaw.com)

### References

- Initial and Annual Eligibility Determination. Illinois Department of Human Services Web site. <http://www.dhs.state.il.us>.
- Individual with Disabilities Education Improvement Act. (2004). Pub. L. 108-446, 20 U.S.C. 1413.
- Jackson, L.L. (Ed.). (2007). *Occupational therapy services for children and youth under IDEA* (3<sup>rd</sup> ed.). Bethesda, MD: AOTA Press.
- Jackson, R.M. (2011). Curriculum access with low-incidence disabilities: The promise of universal design for learning. *National Center on Accessing the Curriculum*.
- McEwen, I.R. (Ed.): *Providing physical therapy services under parts b&c of the Individuals with Disabilities Education Act (IDEA)*. Section on Pediatrics, APTA, 2009.
- National Information Center for Children and Youth with Disabilities. (2002). *All About IEPs*.
- Special Education and Advocacy. Wrights Law Web site. <http://www.wrightslaw.com>. Accessed April 3, 2012.
- Stranberry K. Transitional Planning for students with IEPs. Great Schools Web site. <http://www.greatschools.org/special-education/health/873-transition-planning-for-students-with-ieps.gs>. Accessed April 8, 2012.
- U.S. Department of Education Web site. <http://idea.edu.gov/>. Accessed April 3, 2012.
- [www.aota.org](http://www.aota.org)
- [www.apta.org](http://www.apta.org)

## **Funding for Adaptive Equipment and Supports**

Order of funding sources:

1. Primary insurance
2. Secondary insurance
3. State funding

4. Division of Specialized Care for Children (DSCC)
5. Trusts
- 6.

## **Insurance**

Most private insurance will only fund adaptive technology devices that are considered medically necessary and are prescribed by a physician. Medical necessity must be defined in the policy. Review your insurances' summary plan description and policy to determine the definitions, how a particular adaptive technology device fits in, what benefits are covered, and what procedures must be followed to obtain a device. (1)

### **Primary vs. Secondary insurance**

Insurance companies do not want their consumers to profit off of health insurance through double recovery. To prevent this, insurance plans have provisions on how much primary and secondary coverage is provided. Primary insurance is the main plan that you will purchase, used first in any medical issue. Secondary insurance is used when your primary insurance does not fully cover your medical expense and is usually cheaper than primary insurance. (2)

### **State Funding, Social Security**

Social security generally provides cash benefits to persons with disabilities in the form of either Supplemental Security Income or Social Security Disability Income. Social Security Disability Income is provided to those who have paid into social security while working and provides monthly cash benefits until the recipient is able to return to work. Supplemental Security Income is funded by federal tax revenues to help individuals with disabilities with little or no income to cover basic expenses like food and shelter. Social Security does not directly fund adaptive technology devices, but it does have work incentive programs that allow you to deduct the cost of adaptive technology devices from earnings. (3)

## **Medicaid**

Medicaid provides payment directly to vendors. Funding adaptive technology under Medicaid requires that the individual needing adaptive technology be eligible for Medicaid and that the device is considered medically necessary. To see if a child is eligible for Medicaid funding, the family should contact their local Medicaid office. In order to be funded by Medicaid, the adaptive technology must address a medical problem and be prescribed by a physician. (1)

### **Division of Specialized Care for Children (DSCC)**

The Division of Specialized Care for Children (DSCC) is the Illinois Title V agency that provides care coordination for families and children with special health care needs. DSCC can help families coordinate and pay for their child's specialized medical treatment when the child has an eligible condition and certain financial criteria are met. For more information, visit [www.uic.edu/dsc](http://www.uic.edu/dsc). (4)

## Trusts

Trust funds are set aside by a business to provide monetary compensation for individuals that win a lawsuit against them (i.e. a hospital). If a lawsuit is successful, generally a consulting agency will work with a vendor and present their case to a funding source. In order to receive funding, a physical therapist must justify the devices use. Cases where funding is not awarded occur when the family has a belief that a piece of equipment will improve some deficit (e.g. walking, talking), but the therapist cannot justify its use because the family's expectation is not realistic.

## IDEA part C and part B (Individuals with Disabilities Education Act)

Part C of IDEA was created to enhance the development of infants and toddlers with disabilities. Part C applies to children from birth to age two with developmental delays or who have been diagnosed with a condition that causes developmental delays. Under part C, if an adaptive technology is identified as needed in a child's Individualized Family Services Plan (IFSP), it must be provided by the child's school district, at no cost to their family. Part C is considered a "payer of last resort", meaning that other possible sources must be exhausted before Part C funding can be used. Part B of IDEA applies to children and youth between 3 and 21 years of age. Part B also states that an adaptive technology must be provided at no cost to the family if it is identified and needed in a child's Individualized Education Plan (IEP). (1)

## Other Resources:

### Illinois Assistive Technology Center

[www.iltech.org](http://www.iltech.org)

**Pass It On Center** – The Pass It On Center is a nationally funded adaptive technology reuse non-profit.

[www.passitoncenter.org](http://www.passitoncenter.org)

### Assistive technology resources from the Illinois Department of Human Services

<http://www.dhs.state.il.us/page.aspx?item=32088>

## Sources:

- (1) <http://www.rifton.com/adaptive-mobility-blog/funding-adaptive-mobility-equipment-for-young-children-with-disabilities/>
- (2) <http://onesinsurance.com/blog/health-insurance/primary-and-secondary-health-insurance-coverage/>
- (3) <http://www.atnet.org/resources/resources-funding/alt-funding-resources.php>
- (4) <http://www.uic.edu/hsc/dsccl/>

## **Equipment Tips for Parents**

Once you learn that medical equipment is necessary for your child, it is important to educate yourself about your insurance coverage as well as the types of equipment out there.

- Walk into your equipment evaluation informed about your individual insurance coverage
- If possible, bring your PT or OT to the equipment evaluation as a resource for your child

- Make sure the supplier of your equipment has the proper basic certifications (Do you want me to get into details about this?)
- If possible, physically come to an equipment clinic because many times they are located in close proximity to other resources for your child, which can save you time

All equipment suppliers can guide you toward the best piece of equipment for your child, but it's important for you to do as much research on your own as you can.

- Talk to the doctor, the therapist, and anyone else on your child's medical team
- look through the equipment brochures and do diligent research online
- In the end, however, putting trust in the professionals you work with is important – you can't buy a piece of equipment for your child by simply perusing the internet
- Some parents fail to realize equipment is out there that can drastically change their child's life because they don't ask professionals or do their own research

You must think about what equipment will work for your family in your home. But more importantly, you must communicate this information in your child's equipment evaluation. You can only blame yourself if you don't express your feelings, and then get something that doesn't meet your needs.

- What equipment can you handle emotionally – in your home and in public
- What can you handle physically – literally what can you lift and fit into your vehicle or home
- What can you handle cognitively – how complicated is the equipment and does it have a manual
- Will this fit smoothly into the family's daily routine

Please understand that each potential piece of equipment for your child must meet the criteria of "medical necessity". If professionals prove that your child meets the medical necessity, then the process can begin to try and get the equipment.

- equipment is never given out for comfort and convenience – it must meet the criteria
- The therapist, doctor and equipment supplier must work together to figure out what criteria your child meets
- The more specialists you can get to agree on the necessity of the equipment for your child, the more likely it is to be covered for your child
- But sometimes there are things the insurer will not provide even if it meets medical necessity due to its individual policy
- Remember, no matter how emotional this process makes you, this is simply a business transaction for the insurance company – know your rights and follow the right avenues
- If for some reason, you think the insurance company is not living up to its side of the bargain, start with a call to the Illinois Insurance Commission

What if you have a \$2000 insurance cap but your child needs a \$7000 piece of equipment?

- Equipment supplier will work to try and find a less expensive alternative to aid child



- Some suppliers work with individualized payment plans
- Individual community fundraisers for the child have been effective
- Consult DSCC
- Communicate with associations related to the child's disease if applicable
- Local Lions clubs and Elks clubs are possible funding sources
- Get creative to find the money that's out there, or analyze your current budget to see where other things can be cut to provide more resources for your child's equipment

One common mistake among parents is going around from place to place looking excessively for a different equipment answer for their child. This has the potential to leave various members of the medical team on different pages about the treatment direction for the child.

- Getting another opinion is appropriate, but shopping for the answer you want to hear is not
- If a different opinion on equipment is reached at a different source, you must inform the rest of the medical team to keep every resource informed on your child's direction

Following up with the equipment specialists is paramount.

- If your child catches up to milestones and gets discharged from therapy services, that does not mean they are automatically discharged from their equipment specialists
- If your child requires a large piece of equipment such as a power chair, they should be following up once a year, if possible, to prevent malfunction or injury to the child

In general, the equipment supplier's goal is to make your child as independently mobile as they can. Some kids just need varying equipment to accomplish this. Parents need to understand that if their child is getting something like a wheelchair, it doesn't mean the therapist and the team are giving up on the child ever walking again.

- Maybe the chair can facilitate independence
- Maybe the child gets around in the chair independently as much as possible so they have the energy to work on walking with the therapist for longer

\*\*\*EI monetarily covers all needed equipment in the home. However, nothing to mobilize the child outside the home is covered (i.e. adaptive strollers/car seats, etc.). Private insurance, Medicaid, or other funding sources must be used to cover this type of equipment.

## Stories

Her story: she was called over to a home to provide a power chair for a child. The therapist warned her before she came that the mother had zero interest in putting her child into a power chair. Their house wasn't ready for it, nor their car. She presented them with the training wheels version of a power chair called the "Skippy". It just so happened the child was wearing a black and yellow shirt that matched exactly with the black and yellow design of the "Skippy". When the child began moving around the house in the power chair independently, the mother was absolutely blown away. The child loved how fun it was, and the mom thought it was cute that the child matched with the chair. She was so relieved the child could actually be independent in the chair. The child asked the mom to be called "Skippy" during the equipment fitting.

One specific example: A mother was getting very little sleep because her child was at a high risk of falling out of bed at night. She did her due diligence by researching and talking to her professional team about what kind of equipment she could acquire to keep her child safe at night, and allow her to sleep soundly. After her research she came and met with the Midwest team and they figured out a way to enclose the bed safely for the child. The mom was ecstatic because she could finally get restful sleep.

## Parent Advocacy

Raising a child with a developmental disability can be demanding and stressful; but with support, planning, and access to the right resources, it will also be extremely rewarding. Having questions is completely natural, and unfortunately answers are rarely straightforward. This webpage is intended as a resource to provide you and your family with information and advice to help answer some of those difficult questions.

**As a parent, YOU are the most important advocate for your child!** You know your child better than anyone else; and you should play an active role in your child's development, healthcare, and education plan. At first, advocating for your child may feel completely overwhelming – this is

normal! This process involves lots of research, planning, and preparation, but there are several resources and professionals available to assist you.

### General Steps to become an effective advocate for your child:

- **Get Educated:** Learn about your child's disability, how it affects them, and special services or accommodations that may help them succeed.
- **Know your rights and responsibilities:** As a parent, it is important to understand your legal rights in regards to your child's medical care, developmental, and school-based services.
- **Build your team:** Develop positive relationships with your child's doctors, healthcare professionals, providers, and educators. Open communication is often the best way to create comfortable partnerships with your child's providers.
- **Don't be afraid to ask for help and support:** Getting to know other parents in similar situations or joining a support group is a great way to hear first-hand experiences, and provide a great network for advice. Social workers and experienced professionals are also available to help you navigate the system and feel more prepared.

Not sure where to start? Here are a few general resources:

Wright's Law: a comprehensive website offering information about parent rights, education law, and advocacy for children with disabilities.

<http://www.wrightslaw.com/>

Yellow Pages for Kids: A state-by-state directory to find health care providers, consultants, psychologists, support groups, advocates, and attorneys specifically for children with disabilities.

<http://www.yellowpagesforkids.com/>

This webpage includes an overview of parent rights and available sources to help you advocate for your child at the time of their birth, and within Early Intervention and School-Based services provided through IDEA. We hope to help answer general questions and provide valuable resources to help you effectively advocate for your child. Although it is important to understand your legal options, please know that **filing a lawsuit is only beneficial in specific scenarios, and should ONLY be used as a LAST RESORT after all other options have been exhausted!**

### AT BIRTH:

Medical Malpractice: What is it?

- Situation where doctor/medical provider has been negligent or careless in treating a patient, which resulted in injury.
- When to File a Malpractice Lawsuit:
  - **A negative treatment outcome in itself, although it may be devastating, does NOT mean malpractice occurred.** Malpractice claims are only warranted if injury/trauma resulted due to faulty medical treatment and / or gross negligence on the hospital or physician's behalf.

- Many potential cases involve negligence (i.e. failure to monitor vital signs closely or recognize a symptom soon enough) yet may be very difficult to prove.
    - For a successful case, It must be proven that the medical professional failed to provide the same treatment that other professionals would have under similar circumstances
    - Medical Malpractice claim is a right
    - It is important to consult with a lawyer who specializes in medical malpractice and birth injury
- *What if I'm not sure if a potential case exists?*
  - If you have substantial concerns that something went wrong, seeking legal advice is a good idea. Most law firms offer free consultations, which gives you the chance to state your concerns and receive a professional, honest opinion. Lawyers will only take on cases that they feel have a good chance to be successful.
- *How soon must I file a malpractice lawsuit?*
  - In the State of Illinois, there is technically no statute of limitations for children with disabilities.
  - It's best to get a lawyer involved as soon as you think your child may be a victim of malpractice
    - Information pertinent to the case may be time-sensitive; and your lawyer can assist with further decision-making and help expedite the process.
- *How do I find the right lawyer?*
  - Several law firms specialize in personal injury and medical malpractice
    - It's important to choose an experienced lawyer who you can trust. Interview several lawyers until you find one you feel is a good fit for your family.
    - Ask each lawyer you meet how much they charge and how their fee schedule works.
- *What if I can't pay costly legal fees or am having trouble finding a lawyer?*
  - Parents are often hesitant to seek help due to financial concerns, and it is important to understand the costs involved. However; several resources are available for consultation, and some even provide free legal representation.
  - In many cases; families pay no out of pocket expenses; but it is important to ask your lawyer about potential costs in advance so you know what to expect.
  - Possible resources for medical malpractice advocacy and legal representation:
    - <http://www.equipforequality.org/>
    - <http://moran-center.org/>
    - <http://www.rosenfeldinjurylawyers.com/>
    - <http://www.copaa.org>
    - <http://www.wrightslaw.com/>
- *What will result from filing a malpractice suit?*

- If malpractice or negligence by a health professional is proven, lawsuits usually result in monetary compensation for medical bills, homecare needs, and other expenses that resulted from the negligence.
- *What do I need to tell / bring to my lawyer?*
  - Tell your lawyer anything and everything you know about the situation, but whatever you tell them must be 100% truthful! Your lawyer needs to understand all aspects of the case in order to properly serve you.
  - Bring your child’s medical records (you have the right to request a copy from the hospital/doctor)
  - Bring any medical bills, receipts, pictures, or other evidence you think may support your claim
- *What happens during the lawsuit?*
  - Your lawyer will notify the hospital/health professionals involved that you intend to file a suit
  - “Discovery” Process: both sides collect information
    - you will likely be questioned at a deposition and asked for medical/financial records
    - your child may be required to undergo an Independent Medical Examination
  - Most cases are settled by reaching a monetary agreement
  - If a settlement cannot be made, your case will go to trial
- *How long does this process take?*
  - Filing a medical malpractice lawsuit can be a long, time-consuming, stressful, and expensive process.
  - the average “time to trial” for cases in Cook County is 30 months.
    - If a settlement is reached before trial; the process will likely be much shorter
    - The more medically complex the case; the longer it takes to resolve

Source:

<http://www.mymalpracticelawyer.com/filing-medical-malpractice-claim/>

## EARLY INTERVENTION:

*What are your legal rights involving Early Intervention Services?*

- **Evaluation:** Your child has the right to an evaluation by a multi-disciplinary team, within 45 days of the referral to EI. An IFSP (Individualized Family Service Plan) is required to be written by your child’s providers within 45 days of referral, and should include your child/family’s strengths, needs, priorities, and concerns.
- **Informed Consent:** Before your family begins receiving EI services, your service coordinator is required to give you information about the purpose of therapy, by who/how therapy will be

provided, and what will happen if you do not consent. Providers must also ask your consent before conducting evaluations, assessments, or sharing your family's information.

- **You have the right to refuse any service, at any time, without jeopardizing other/future services!**
- You may stop services and later re-enter the EI system (if child is still < 3)
- **Prior Written Notice:** Written notice must be provided of any meetings, as well as before any service provider makes changes to your child's EI treatment.
- **Review of Records:** You have the right to see any records related to your child's EI services, which must be provided within 5 days of your request.
- **Confidentiality of Records:** All information involving your family's EI services is confidential, and will only be shared among providers when relevant to best service your family.
- **Resolution of Concerns:** You have the right to disagree, and the ability to initiate a formal complaint process if you feel necessary.
  - However, in most cases the best place to start is with your child's providers. It's important to voice your concerns as soon they arise. Your child's providers want your feedback and are happy to collaborate and discuss alternate options with you.
  - If you still feel there are problems or you and your child's providers can't reach an agreement, your concerns about your child's EI services can be discussed with your regional CFC (Child and Family Connections Office).
  - *What if this doesn't resolve the issue?*  
Formal options for administrative resolution:
    - **Compliance Complaints:** You may file a written complaint with the Illinois Department of Human Services (IDHS) if you believe a provider has violated a law/rule regarding the EI program. IDHS has 60 days to investigate and write a decision and/or procedure to correct the cause of complaint.
    - **Mediation:** If you have a disagreement with a provider, your CFC, or IDHS, you can request a mediator, whose role is to help both parties talk and reach an agreement. This process is paid for by the state and voluntary, meaning you must freely agree to participate.
    - **Impartial Administrative Proceeding:** This is similar to a court hearing; where a neutral officer listens to both sides of the disagreement. You have the right to bring an advocate/attorney as well as your child to this hearing, which is open to the public. A copy of the written decision from the hearing will be mailed to you within 45 days. You have a right to appeal the decision.

- During the mediation/impartial proceeding process; your child will continue to receive appropriate EI services
- It is important to raise concerns as soon as possible to ensure your family benefits fully from EI services. Complaints must be filed within 3 months after the issue began.
- More detailed information is available in “State of Illinois Infant/Toddler & Family Rights under IDEA for Early Intervention System” (2007)  
<http://eicclearinghouse.org/documents/family-rights.pdf>

Sources - The Illinois Early Intervention Program: A guide for Families (July 2011)  
Family Intro to EI: <http://eic.crc.uiuc.edu/documents/family-intro.pdf>

## SCHOOL SYSTEM:

Remember, as a parent you have both the right and responsibility to be an active participant in your child’s education to ensure they receive proper services. Here are some important tips:

- **Plan and prepare**
- **Keep written records**
  - For example: meetings, written/oral communication with your child’s teacher or school officials
- **Ask questions; and carefully listen to answers**
  - Try to understand why your child’s educators are making certain choices or

suggestions. Although you may not always agree, your child's educators and service providers DO have your child's best interest in mind!

- **Identify problems; but also propose solutions**
  - You will likely need to collaborate with your child's school throughout their education. Be prepared to be flexible and suggest solutions that best fit the needs of all parties involved.

Parents have the right to disagree with decisions the school makes regarding their child with a disability about:

- Identification of child as having a "disability"
- Child's evaluation
- Child's educational placement
- Special education and related services the school provides to the child

*What do I do if I don't agree with my child's school regarding one of these issues?*

- When problems arise; the immediate response of most parents is to feel frustrated, angry, and confused. It is completely normal to have these emotions; but try not to act on them immediately
  - Take time to gather your thoughts, facts, and consider your options in order to avoid unnecessary confrontation.
- It's important to voice your concerns early, but constructively so members of the school district understand your needs. Open communication may help facilitate collaboration so that your concerns can be addressed effectively.
- If these strategies don't work and you cannot reach an agreement with your child's school, IDEA has several mechanisms in which parents and schools can resolve disputes.
  - Be aware that once these steps are initiated, they cannot be revoked – so carefully consider your options and only initiate the formal complaint process if you feel it is completely necessary.

*What options does IDEA provide to settle disputes?*

- The first step is **Mediation**: You will meet with representatives from your child's school as well as an impartial third person (called the "mediator") who will help both sides talk openly and try to reach an agreement.
- **Due Process Complaint**: If Mediation fails to resolve the issue, you can communicate in writing with the school system through a formal complaint process. This letter must include specific examples of IDEA regulations that you feel the school has violated.
- **Resolution**: This process begins once the school system receives your due process complaint. A Resolution meeting will be held between the child's parents and relevant members of the IEP team in order to attempt to reach a compromise.
- **Due Process Hearing**: If the resolution process fails, both parties will present their case to an impartial hearing officer, who then decides how to resolve the dispute.



- Each party has the right to be accompanied/advised by counsel and individuals with special knowledge about the specific scenario
- Each party can present evidence and confront, cross-examine, and call witnesses
- Parents have the right to appeal the hearing officer's decision.
  - Detailed information on this process available here: <http://nichcy.org/schoolage/disputes/hearings/details#appeal>
- **State Complaint:** If there are still issues, you may communicate in writing to the State Education Agency (SEA) and describe the parts of IDEA that you feel the school has violated. The SEA must resolve your complaint within 60 days.

More detailed information about each of the processes described above is available from the National Dissemination Center for Children with Disabilities (<http://nichcy.org/schoolage/parental-rights/disagree>)

If you choose to initiate a formal complaint process; you may want to seek the advice of an advocate or attorney:

- *What is an Advocate?*
  - Someone with a background in special education, worked in a related field, or has already been through the process with their own child or family member. Advocates can provide support, direction, encouragement, and comfort for families to secure the best possible education for their child.
  - Advocates are NOT licensed attorneys. However, they are usually well informed in laws and regulations of school districts, as well as state and federal education laws. The support and counseling of an advocate may help ease the anxiety of navigating the Special Education system.
- *When do I need an attorney?*
  - If the issue is not resolved and results in a Due Process Hearing, you will likely want to consider involving an attorney to help represent you.
- *How do I choose the right attorney for representation in school system issues?*
  - Select an attorney with special education expertise and experience
    - This is a very specialized area of law, so it is important that your attorney is familiar with federal and state education regulations.
  - Ask how the attorney charges for his/her work.
  - Some public service attorneys are available who work for free or reduced rates for eligible families.
- Understand your role as parents:
  - Your advocate or attorney can advise you on the status of the law and expected outcomes, but ultimately you remain the decision maker regarding your child's education.

Source: Lisa Madigan – Illinois Attorney General: <http://www.isbe.state.il.us/spec->

[ed/pdfs/attorney\\_guideline.pdf](#)

Resources to find Legal Representation in Special Education (advocates and attorneys)

- General Directories:
  - <http://www.yellowpagesforkids.com/help/il.htm>
  - <http://www.copaa.org/find-a-resource/find-an-attorney/>
  - <http://specialedlaw.blogs.com/>
- Law Firms specializing in Special Education Law in the Chicago Area (\*\*this is not an exhaustive list)
  - <http://www.specialedadvocacycenter.org/index.html>
  - <http://www.equipforequality.org/>
  - <http://moran-center.org/>
  - <http://www.lawforchild.com/sub/education-and-school-law.jsp>
  - <http://www.maukoconnor.com/index.html>
  - <http://attorneys4specialed.com/wordpress/>
  - [http://www.childrenslawgroup.com/services\\_services.html](http://www.childrenslawgroup.com/services_services.html)
  - <http://www.MikeKiserLaw.com/main.html>
  - <http://www.foxspecialedlaw.com/>

Other sources of help: Parent Training and Information Center (PTI) is available for each state:

<http://nichcy.org/families-community/states/>

Illinois State Board of Education:

-Due Process Information and official forms:

<http://nichcy.org/schoolage/disputes/hearings/details#appeal>

-Due Process Decisions – Sample Cases: <https://sec1.isbe.net/sedsinquiry/dueprocessdecisions.aspx>