

# TOOLKIT FOR EDUCATORS

## PARENT SUPPLEMENT

### Introduction

Welcome to the *Toolkit for Educators: Parent Supplement*! This resource is the result of discussions surrounding the distribution of the *Toolkit for Educators* to school districts. Upon deciding that the *Toolkit* should be sent to parents as well as schools, the idea for a parent supplement was conceptualized. With the help of the SBANENY staff, educators, parents, and providers connected to the Spina Bifida community, the parent supplement was completed.

### Parents

This resource was created as a guide to provide information and resources that will help you navigate the education system while meeting your child's needs for the years to come! We want to start by acknowledging how important you are in this process. You are your child's first teacher, the expert on what your child's needs are, and an advocate for helping to meet those needs. The information provided will help you understand the federal laws and programs and services that are available to you as you begin advocating for your child in school.

*\*The reference to parents throughout this document includes all caretakers and guardians of children with Spina Bifida.*

*\*Refer to glossary for definitions of bold terms.*

### Federal Laws

Rehabilitation Act of 1973, Section 504: U.S. Federal Civil Rights Law that prohibits discrimination against people with

disabilities. Section 504 states: "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . ." ("Protecting People With Disabilities," n.d.).

Section 504 also applies to children who are not determined eligible for special education services through IDEA in a school setting. In this case, a 504 plan can be used for children with minimal supplementary educational needs to address other necessary **accommodations**.

No Child Left Behind Act of 2001 (NCLB): Schools must ensure that all children, including children with disabilities, receive a high-quality education ("A Parent's Handbook: Understanding Special Education Under NCLB, IDEA and Section 504," 2008) ("Health Guides for Parents of Children Living with Spina Bifida," 2006).

Individuals with Disabilities Education Act of 2004 (IDEA): 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 more than 6.5 million eligible infants, toddlers, children and youth with disabilities. Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B ("Building the Legacy: IDEA 2004," n.d.).

## Early Intervention (EI)

Early intervention services are provided for children from birth to age three with a confirmed disability or established **developmental delay**. Infants with Spina Bifida are often referred to EI as soon as they are discharged from the hospital because the earlier services begin, the better the chances are for making significant differences. Parents will need to call the county that they reside in to set up an **evaluation**. These evaluations are usually done in the child's home by a specialist. If the child is eligible for services, an Individual Family Service Plan (IFSP) will be developed, usually with a service coordinator and the parent, to outline areas that the child will be working on. Typically the EI services are home based. They may also be provided in a community setting such as a daycare or preschool that the child is attending. The IFSP will be reviewed every 6 months to assess progress and address any changes that need to be made ("Beyond Crayons: Resources that Promote a Healthy School Environment for Students Living with Spina Bifida," 2015). It is recommended that parents contact public schools when the child is 2 ½ years old to begin preparing for the transition to preschool ("Health Guides..." 2006). A variety of therapeutic and support services are available to eligible infants and toddlers with disabilities and their families. *Visit the link for more information on services and how to apply for EIP in NYS here: [http://www.health.ny.gov/community/infa/nts\\_children/early\\_intervention/index.htm](http://www.health.ny.gov/community/infa/nts_children/early_intervention/index.htm)*

## What is an Individualized Education Plan (IEP)?

An **IEP** is a written individual educational plan that is developed for a child with special needs. It is developed by the team of professionals that work with the child, their parents, and in some cases the child. The IEP presents **assessment** information (test scores in different areas of functioning), an overview of the child's present level of performance, the child's strengths and needs, and the goals and objectives to meet those needs ("Beyond Crayons..." 2015).

## Why was it created and how does it work?

All special education services, policies and procedures are governed by IDEA. Under this act, those with disabilities are eligible for services and support from birth through age 21. Eligibility is determined by evidence that there is a disabling condition that adversely affects the education of the student in the regular education classroom. Most children with Spina Bifida should be eligible for special education services. Of the 13 categories of disability covered by special education law, most children with Spina Bifida qualify under the category of orthopedic impairment. However, parents and others should be cautioned that classifying students in this way does not mean that other emerging disabilities or areas of needs (i.e. **learning disabilities**, attention problems) do not need to be addressed by special education services ("Beyond Crayons..." 2015). *Visit the "Quick Reference Guide for Educators of Those with Spina Bifida" chart on p. 18 of the Toolkit for more information on common learning challenges across developmental stages.*

An IEP is mandated by law for every child receiving special education services and/or related services such as occupational therapy, physical therapy, speech therapy and vision therapy. The IEP document is reviewed and rewritten, adding or omitting services, yearly at the child's annual review meeting with the Committee on Preschool Special Education (CPSE). The meeting will take place at the child's school district that they reside in. People attending the meeting will include the school team that works with the child, parents, the county representative, the chairperson of the committee, and a parent **advocate**. Each school district may have their own procedures, but federal regulations mandate a fairly uniform document which includes the following components: identification of the disability category under which the child qualifies for services, present level of performance, results of standardized testing and classroom observations, measurable annual goals and objectives that address areas of need, educational **placement** where the services will be delivered in the **least restrictive environment (LRE)**, identification of any related services, identification of any aides necessary to facilitate learning, and details of accommodations ("Beyond Crayons...", 2015).

IEP meetings can be overwhelming and anxiety provoking with up to a dozen or more school district functionaries present. The meeting can be fast paced and sped through leaving parent's confused and concerned. Here are some tips to help you during the process.

## Tips for IEP Meetings

- Gather educational, medical and other pertinent information about your child.
- Make a list of preliminary goals for your child.
- Write down information about your child to share and any questions or concerns you are having beforehand.
- Share information, ideas and questions!
- Talk about the IEP with your child and read carefully before you agree ("A Parents Handbook...", 2008).
- Consider bringing a special education advocate to the IEP meeting.

## Special Education Advocates

Given the complexity of different laws, regulations, and procedures, it is understandable that a parent may want to contact a special education advocate. These advocates can assist parents with knowledge and expertise of special education and ensure meaningful participation in their child's education. Special education advocates can be professionals with training in special education and advocacy, special education attorneys, educators with experience in special education, or other parents of children with disabilities. Advocates may or may not charge a fee for their services. Under IDEA, advocates are authorized to attend and participate in IEP meetings and processes as parents have the right to representation ("Advocates," n.d.).

Here is a list of agencies where parents can find information on special education advocacy OR find a special education advocate:

**Council of Parent Attorneys and Advocates, Inc. (COPAA):** COPAA is a national network of attorneys and advocates with the specific focus on the educational rights of students with disabilities. *For information on advocate training and certification and how to find an advocate, visit:*

<http://www.copaa.org/page/Advocates> (“Advocates,” n.d.).

**Parent Centers:** Provide workshops on parent rights, necessary services, advocacy and other relevant information for parents of children with disabilities. *For a full list of parent centers in NYS visit:*  
<http://www.p12.nysed.gov/specialed/publications/policy/parentsguide.pdf>

**Independent Living Centers:** Provide a variety of services including referral and advocacy. *Find your local ILC here:*  
<http://www.vesid.nysed.gov/lsn/home.html>

**Special Education Training and Resource Centers (SETRC):** Provide local information, training, and resources related to the education of students with disabilities. *For information on the SETRC office in your region:*  
<http://www.vesid.nysed.gov/lsn/home.html> (“Special Education in New York State for Children Ages 3-21: A Parent’s Guide,” 2002).

**Wrightslaw:** Provides reliable information about special education law, education law, and advocacy for children with disabilities.

*Find more information here:*

<http://www.wrightslaw.com/info/advo.index.htm> (“Advocates,” n.d.).

## School Years & Beyond

Based on information presented at the National Spina Bifida Association Conference in 2016, parents of children with Spina Bifida approaching school age (5-6) should consider a neuropsychological evaluation to assess learning. It is recommended that this type of evaluation occur prior to kindergarten, third or fourth grade, middle school, high school, and college to address any potential learning changes.

Just prior to kindergarten, children will transition to the Committee on Special Education (CSE). The process is very much the same; however, the team of individuals may change to include personnel from the special education department, special education teacher, a **general education** teacher, a school representative such as a principal or guidance counselor, a school psychologist, a parent, and the student if appropriate (“Beyond Crayons...,” 2015).

At age 14, parents should request to begin planning for transition services with the school team. Under IDEA, an **Individual Transition Plan (ITP)** should go into effect by age 16. This plan should establish annual goals related to post-secondary planning, such as transportation, post-secondary education, independent living, and employment (“Beyond Crayons...,” 2015).

For information on transition planning or assistance implementing services, visit the Transition and Youth Services page on the ACCES-VR website:  
<http://www.acces.nysed.gov/vr/transition-and-youth-services>

## The 504 Plan

Successful integration of a child with Spina Bifida into school sometimes requires changes in the school environment and/or the curriculum. Section 504 of the Rehabilitation Act of 1973 requires programs that receive federal funding to make their facilities accessible for all. This can occur through structural changes (i.e. adding elevators or ramps) or through schedule and location changes (i.e. offering courses on the ground floor). Students with Spina Bifida may require the modifications and accommodations set out in this plan to ensure that they have the same opportunities and learning environment as their peers (“Beyond Crayons...,” 2015). Visit the “Academic Accommodations” section on page 20 in the Toolkit to learn about potential accommodations for a child with Spina Bifida.

## Parent Rights & Safeguards

Every school district functions differently; therefore, it is important to know what your rights are as a parent advocate. Here are some of the rights and safeguards in place for parents when working with the school and utilizing special education services.

- Request an initial evaluation. In addition, if parents disagree with the school’s evaluation, they can request an independent evaluation.
- Refuse the school’s request to evaluate their child.
- Request another evaluation if their child does not originally qualify for special education services and does not have an IEP but seems to continue struggling in school.
- Ask for changes and additions to the IEP if they feel their child is not succeeding in school.
- Request to see school records and receive regular progress reports.
- Provide input about eligibility and placement decisions that affect their child (“A Parents Handbook...,” 2008).
- Schools must notify parents of any planned discussions about classifications, IEP development, or changes to the child’s placement or program (“Beyond Crayons...,” 2015).
- Parent’s consent is required before an evaluation or changes in the child’s education take place.
- School districts are required to provide home-based tutors for special education students who are unable to attend school for extended periods of time (“Health Guides...,” 2006).

## If a parent feels like their child's needs are not being met, here is an orderly way to address concerns and advocate:

- Talk with the child's teachers and school staff.
- Request a meeting at any time to review the IEP and address concerns.
- Request mediation and a neutral party to help resolve the disagreement with the school.
- If parents disagree with the decision, they can request a **due process** hearing. Current law provides for mediation, impartial hearings, and representation by an advocate or lawyer. Visit [idea.ed.gov](http://idea.ed.gov) for more information on **procedural safeguards and legal rights under IDEA** ("Beyond Crayons...", 2015).
- File a complaint with a state/local education agency, the U.S. Office of Special Education Programs, or the NYS Department of Education ("A Parents Handbook...", 2008).

## Tips for parents

- Ask questions and state your opinion to ensure your child is receiving the services he/she deserves.
- Be honest about what your child's needs are – this will only help when brainstorming possible solutions.
- Stay involved in your child's education by monitoring academic progress, attending and actively participating in IEP meetings, and ensuring the school is following the 504 plan/IEP.

- Review special education laws and parent rights; getting to know and talking with other parents involved with the school and special education can enhance confidence as an advocate.
- Share your expertise with your child's classmates and school personnel (teacher, nurse, psychologist, etc.); they will benefit from an explanation of his/her special needs.
- Encourage your child to become responsible as their own self-advocate by providing input at meetings about their needs as they age ("Health Guides...", 2006).

In summary, remember that you know your child best! It is your responsibility to make sure that they receive the services they need. The next page provides a glossary of common terms you may encounter along the way.

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## Glossary

**Accommodations:** Changes that help make it possible for students with disabilities to participate in academic and nonacademic school programs

**Advocate:** Communicates and promotes the rights, needs, and interests of an individual or group

**Assessment/ Evaluation:** A process used to learn about a child's strengths and weaknesses for the purpose of educational planning

**Developmental delay:** A child who has not attained developmental milestones expected for the child's chronological age, adjusted for prematurity in one or more of the following areas: cognitive, physical (including vision and hearing), communication, social or emotional development, or adaptive development ("Early Intervention Program," n.d.).

**Due process:** A formal process for resolving disputes between parents and a school. It can involve a hearing or mediation.

**Free, appropriate public education (FAPE):** The legal entitlement that public school students with disabilities have to an education program and related services to meet their unique educational needs free of charge to the parents.

**General education:** Regular classroom instruction

**Individualized education program (IEP):** A plan that outlines specific education goals for a student receiving special education,

and what educational services he or she will receive in order to help meet them

**Informed consent:** Written agreement stating parents have been informed about and understand the purpose and intent of special education evaluations and service decisions

**Learning disability:** A disorder affecting the way a person receives, processes or expresses information. The most common learning disabilities involve reading and language skills.

**Least restrictive environment (LRE):** Teaching children in situations that allow as much interaction as possible between students with and without disabilities.

**Placement:** The educational setting in which the student receives special education services.

**Procedural safeguards:** Legal requirements to help ensure that parents and children are treated fairly and equally in the special education decision-making process.

**Referral:** Written request for an evaluation to see if a child has a disability that could require special education services.

**Related services:** Additional services that a child with a disability receives (for example, physical therapy or counseling) so he or she can meet IEP goals.

**Transition plan:** Part of the IEP that outlines transition services and goals that need to be met for the student to meet post-high-school goals ("A Parent's Handbook...", 2008).

## Additional Resources

*A Parent's Handbook: Helping Children with Learning Disabilities.* South Deerfield, MA: Channing Bete Company, 2008. Print.

*A Parent's Handbook: Middle School Transition for Your Child with Special Needs.* South Deerfield, MA: Channing Bete Company, 2008. Print.

Mayerson, Gary. *How to Compromise with Your School District Without Compromising Your Child: A Field Guide for Getting Effective Services for Children with Special Needs.* New York, NY: DRL Books, Inc., 2004. Print.

Spina Bifida Association of Northeastern New York website: [www.sbaneny.org](http://www.sbaneny.org)

Spina Bifida Association website: [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

*Toolkit for Educators: Resources that Promote a Healthy School Environment for Students Living with Spina Bifida: Quick Reference Guide for Educators of Those with Spina Bifida* (p. 18). Scotia, NY: Spina Bifida Association of Northeastern New York, 2016.

## References

Advocates. (n.d.). Retrieved August 19, 2016, from <http://www.copaa.org/?Advocates>

*A Parent's Handbook: Understanding Special Education Under NCLB, IDEA and Section 504.* South Deerfield, MA: Channing Bete Company, 2008. Print.

*Beyond Crayons: Resources that Promote a Healthy School Environment for Students Living with Spina Bifida.* Arlington, VA: Spina Bifida Association, 2015.

Building the Legacy: IDEA 2004. (n.d.). Retrieved August 2, 2016, from <http://idea.ed.gov/>

Early Intervention Program. (n.d.). Retrieved July 20, 2016, from [http://www.health.ny.gov/community/infants\\_children/early\\_intervention/index.htm](http://www.health.ny.gov/community/infants_children/early_intervention/index.htm)

*Health Guides for Parents of Children Living with Spina Bifida.* Washington, D.C.: Spina Bifida Association, 2006.

Protecting Students With Disabilities. (n.d.). Retrieved July 20, 2016, from <http://www2.ed.gov/about/offices/list/ocr/504faq.html>

Special Education in New York State for Children Ages 3-21: A Parent's Guide. (2002, May). Retrieved August 19, 2016, from <http://www.p12.nysed.gov/specialed/publications/policy/parentsguide.pdf>

*Toolkit for Educators: Resources that Promote a Healthy School Environment for Students Living with Spina Bifida.* Scotia, NY: Spina Bifida Association of Northeastern New York, 2016.