



Your Child's *Journey* Workbook

When families are knowledgeable about special education and medical services, they become advocates for their child and can communicate more effectively with professionals and providers who provide care. This workbook will serve as a resource and navigation tool. It is our goal to help you increase your confidence, knowledge, and skills so you can help your child obtain education, health care and other services they need.



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Your Workbook

In this workbook, you will find information and tips to help you organize information regarding your child's disability or chronic health condition. Caring for a child with special health needs often leads to receiving information and paperwork from many sources. The workbook will help you keep track of important information about your child's education and health care, and will make it easier to share with your child's care team, childcare, school, and family members. Each section includes resources relevant to that particular section's subject matter. Finally, planning for the variety of changes and transitions that will happen at different times throughout your child's life starts now, and your workbook will help you along the journey. You know your child and have your child's best interests at heart, so you are in the best position to advocate for your child. You are the one most familiar with your child's history and the best one to document it. This workbook tells your child's story, and you and your child are the authors.

This workbook will help you:

- **Keep important information** in an easy to find central location.
- Advocate on behalf of your child since information will be readily available **if you need to prove there is a need.**
- **Share information** between educators and doctors. This is important for the **coordinated care** of your child.



Helpful tips of what to include in each section along the way:

- Consent Forms
- Medical test results
- Development or educational results
- Medications
- Financial/Insurance information
- Plan Revisions
- Important Dates
- Progress Notes
- Intervention or treatment plans
- Specialists

Family Connection is South Carolina's Parent Training and Information Center. Our goal is to provide accurate, relevant information to parents, young adults and professionals so they can be the best advocates.

For more information visit **FamilyConnectionSC.org**

or call **1-800-578-8750.**

Para Español: **1-888-808-7462.**

Your Child's *Journey*



All About Me



The most important piece of this notebook is your child. Therefore, the first section is called All About Me. This section is devoted to your child, allowing others to get to know him or her and understand how their disability impacts different areas of their life. Many families choose to include their child in completing this section and like to decorate the cover of their Journey Workbook with their child's artwork or photos.

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Child's Name

Birthday

Nickname

child's
photo here

Things my child **does well**

Things my child **needs help with**

Empty box for notes under 'Things my child does well'

Empty box for notes under 'Things my child needs help with'

A little about my child

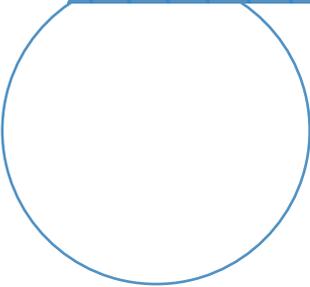
Things they do in the community:
(school, activities, clubs)

Favorite Food

Favorite Music:

Favorite Color

Favorite Games:



Family and friends

Pets

Diagnoses:

How my child communicates and learns



When my child is happy they...

When my child is sad they...



When my child is shy or nervous they...

Things my child likes	does NOT like

The form consists of two columns. The left column is titled "Things my child likes" and has a green header. The right column is titled "does NOT like" and has an orange header. At the bottom left corner of the left column is a yellow emoji with a closed, smiling mouth and closed eyes. At the bottom right corner of the right column is a yellow emoji with a wide-open mouth as if crying and closed eyes.

Describe how your child interacts with other children and adults:

How does your child show affection, share feelings, or play with other children?

Describe your child's favorite things to do and any special family traditions or customs that are important to you:

When I grow up I want to be:



Goals

--

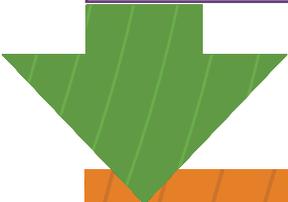


Next Steps to Reach Goals

People who can help

--

--



Outcomes

--

Babysitter / Childcare Instructions

Medical Emergency Instructions: FOR LIFE THREATENING EMERGENCY, DIAL 911

First call to: _____

Hospital of choice: _____

Primary doctor: _____

Primary doctor phone: _____

Insurance provider: _____

To whom it may concern, I, _____, give permission to qualified medical personnel to provide care recovery, as well as to protect life and limb.

Known allergies: _____

Date: _____ Authorizations expires: _____

Home Address: _____

Parent/Guardian phone: _____

Other contact person phone: _____

Significant events during the last 48 hours, or symptoms to watch and report:

Medication: _____ Dosage: _____ Time: _____

Medication: _____ Dosage: _____ Time: _____

Medication: _____ Dosage: _____ Time: _____

Special Instructions:

Family Support Resources

Parent-to-Parent: _____

Phone: _____

Email: _____

Parent Group: _____

Phone: _____

Email: _____

Religious Organization: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Service Organization: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Counseling Services: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Other: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Your Child's *Journey* Healthcare



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A toolkit to organize your child's medical information

During your child's journey, you will need to keep track of information regarding the medical services your child receives.

This information will be useful when you take your child to a new physician, when your child becomes involved in a school program, or for other occasions when you need to share information about your child's medical history.

Use this section to record your child's progress, including development and medical history, medication tracking, notes regarding changes in your child's condition or care, preparation for appointments, plan for care, and therapy information.

Health History

Birth Weight: _____ Birth Height: _____

Full Term: _____ Premature: _____ Weeks Gestation: _____

Past Surgeries:

Type: _____ Date: _____

Hospital: _____

Physician: _____

Type: _____ Date: _____

Hospital: _____

Physician: _____

Type: _____ Date: _____

Hospital: _____

Physician: _____

Assessments / Testing:

Type: _____ Date: _____

Practice Name: _____ Physician: _____

Results: _____

Type: _____ Date: _____

Practice Name: _____ Physician: _____

Results: _____

Allergy Record

Date	Allergy	Cause of Reaction	Type of Reaction	Medications & Instructions			

Adaptive Equipment

In many cases, children use equipment to ensure ability of communication, mobility, and eating necessities.

Does your child use adaptive equipment? Yes No

If yes, what kind of adaptive equipment is used?

When should the equipment be used?

Does your child use a specialized communication device? Yes No

If yes, how is the device used and where?

Home School Daycare Extra Curricular Activities

Where is the equipment located and where should it be placed when not in use?

Medical Contacts

Primary Care Physician: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Specialist 1: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Specialist 2: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Specialist 3: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Specialist 4: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Medical Contacts

Dentist:

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Pharmacy: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Preferred Hospital: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Physical Therapist: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Medical Contacts

Occupational Therapist: _____

Address: _____

City: _____ State: _____ Zip: _____

_____ Phone: _____

Email: _____

Speech-Language Therapist: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Early Interventionist: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Insurance Worksheet

Service			Date
	Payor #1	Payor #2	Payor #3
Insurance Name			
Date Bill Submitted			
Amount Paid			
Date Paid			
Balance			

Service			Date
	Payor #1	Payor #2	Payor #3
Insurance Name			
Date Bill Submitted			
Amount Paid			
Date Paid			
Balance			

Service			Date
	Payor #1	Payor #2	Payor #3
Insurance Name			
Date Bill Submitted			
Amount Paid			
Date Paid			
Balance			

Immunizations

Please add a copy of your child's updated immunization form in this section.

Evaluations/Assessments/Testing

Please add a copy of any of your child's records in this section.

Specialist Reports

Please add a copy of your specialist reports in this section.

Your Child's *Journey* Workbook



A toolkit to organize and prepare for education meetings



This workbook will provide you with additional information and support as you continue your child's educational journey.

The handouts and tip sheets provided in this workbook will serve as a resource and navigation tool to help ensure your successful involvement throughout the process. It is our hope and intention to increase the confidence, knowledge, and skills needed to help your child obtain the education, health care, and supplemental services they deserve.

This workbook includes useful information to plan for special education meetings, such as an Individualized Education Plan (IEP), 504 and Individualized Family Service Plan (IFSP). If your child is found eligible for special education services, you will participate in a meeting to develop your child's IEP. As part of the IEP team, you will help plan and make important decisions about your child's future educational needs.

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Before the Meeting:

- Know the purpose of the meeting and who will be attending.
- Review your child's records (current IEP and any recent evaluations).
- Request copies of records if you do not already have a copy (IEP, evaluation, Behavior Intervention Plan (BIP)).
- Write down questions beforehand to ensure you do not forget to ask a question in the moment. Leave a space under each question to write answers that correspond to each question.
- Research your child's disability (be informed).
- Know your child's strengths and weaknesses. Use the worksheets to write down specific examples.
- Communicate concerns with your child's teacher prior to meeting date.
- Request a draft of the IEP.
- Read assessment reports carefully and ask about parts you do not understand.



During the Meeting:

- Come to all meetings with an open mind.
- Be confident and ask questions.
- Bring the current IEP with questions or areas of concerns marked.
- Bring any outside reports and evaluations to review with the team. This gives everyone a better picture of your child.
- Ask for clarification if anyone uses a term or abbreviation you do not understand.
- Remember the IEP is to be individualized and child centered.
- Ask for additional time to consider important decisions if you are uncomfortable making them on the spot at the meeting or you want to get additional input.
- Look for opportunities to express gratitude to teachers and related staff.
- Be sure everything the IEP team discussed and agreed on for your child is written into the IEP.

After the Meeting:

- Review the meeting minutes and the IEP. If important discussions are missing, write a letter to the school thanking them for their time and note the information missing from the minutes.
- Maintain an organized binder of all of your child's IEP documents, testing, progress reports and other school records.
- Parents and school personnel must work together to make the IEP and placement work for the child by maintaining open communication.
- Parents should receive reports on child's progress toward IEP goals. Keep track to see if your student's goals are being mastered or if they need to be revised at the next meeting.
- Encourage your child, and have high and realistic expectations for them.

Education – Meeting Preparation

Child's Name: _____ IEP Meeting Date: _____

Purpose of the meeting: _____

My child's strengths:

My child needs the most help with:

My child learns best by:

What supports would help in class?

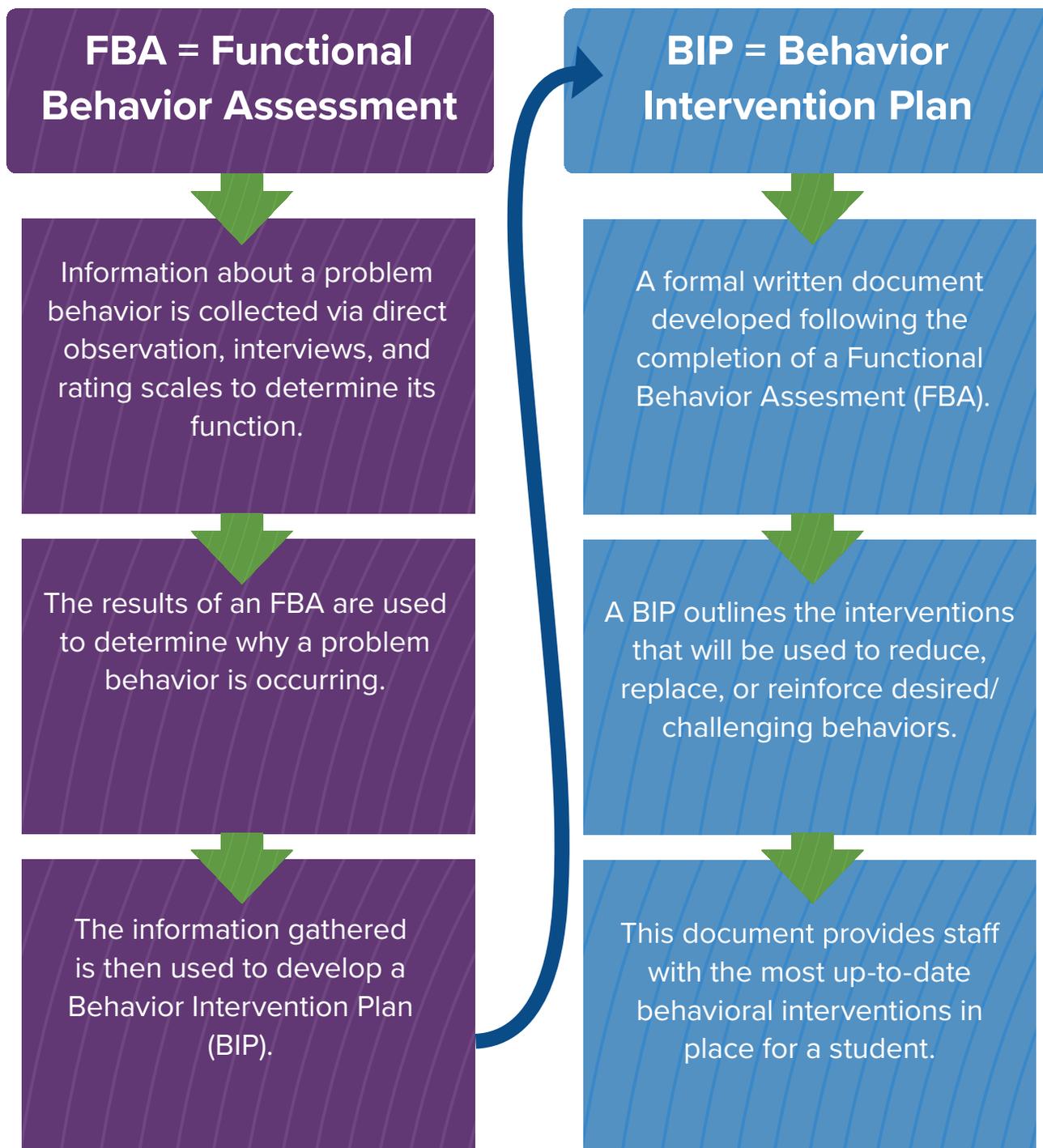
Information I would like to share:

Concerns I would like to discuss:

Questions for the team:

FBA and BIPs

When you have a child with academic, social, or behavioral challenges, your goal is to provide them with the best support available. If your child engages in challenging behavior, additional supports, assessments, and written plans are necessary. These documents provide the educational team with a protocol or plan. This helps them to work collaboratively to reduce challenging behaviors and teach replacement behaviors to your child.



Tips for a Successful Education Meeting

As schools and families navigate communication, virtual meetings to discuss special education services are becoming a new normal. Below are tips to help family members prepare for remote meetings to discuss a student's Individualized Education Plan (IEP), a Section 504 Plan, evaluation for special education services and other related issues.

- Determine a regular communication plan for regular check-ins with the school. That may include email, telephone, text, web-based meetings, U.S. mail, packet delivery by school bus or any other delivery method for corresponding.
- Family caregivers may request meetings and we have provided a template to formalize the request. Please see the sample letter for requesting a meeting on the next page.
- Ask school staff how privacy and confidentiality are protected when a meeting platform has been confirmed. Have any passwords or PINs ready to use when you log in or call into a meeting.
- Before a meeting, ask to sign any necessary paperwork or releases to have special education records sent electronically via email. Special education records can include meeting notifications, IEP or Section 504 documents, assessments, progress reports, Prior Written Notices that describe meetings and planned actions, or other materials that contribute to the program review and goals.
- Review records before the meeting and write down questions to ask during the meeting. We have provided pages for meeting minutes in this section.
- Carefully review goals, services, accommodations, modifications and consider how they might apply or need to be adjusted for current circumstances. Think creatively and prepare to collaborate and request expertise from school staff.
- Consider whether the student will attend the meeting.
- Communicate early—before the scheduled meeting—to request updates about progress, a student's present levels of performance, or other concerns.
- As with in-person meetings, family participants may invite others for support. A friend or family member might be able to attend and take notes.



Sample Letter for Requesting an Education Meeting

[Date]

Ms. Jane Doe [Call district office for director's name], Title [Call district office for director's title]

Name of School District

Address of District Office

Re: [Student's name]

Dear Ms. Doe:

I am writing this letter to request that a full and individual initial evaluation be conducted for my child, [student's name], to determine if [he/she] is a child with a disability under the Individuals with Disabilities Education Act or Section 504 of the Rehabilitation Act of 1973.

[You should then describe your child's school situation or why you believe an evaluation is needed. You could state that he/she is failing classes or the teachers say he/she has behavior problems. You can also describe any disability you are aware of and include copies of medical records about that disability.]

I request that the evaluation be conducted as soon as possible. I understand that South Carolina follows federal regulations requiring that initial evaluations be conducted within 60 days of a parent's consent. Please provide me with proper information and a consent form.

You may contact me at [give your phone number(s) and times you can be reached; try to give a daytime number].

Sincerely,

[Your signature] [Your printed or typed name] [Your address]

Enclosure(s): [List any medical records or other papers you are sending with the letter; you should NOT send original records]

Copy to: [Name and address of principal of school where your child attends]

[You may want to send your letter "CERTIFIED MAIL, RETURN RECEIPT REQUESTED." This will give you proof that it has been received. If you personally deliver it, ask the school staff to make a copy. Then ask the staff to write "RECEIVED" on the copy and sign and date it for you to keep.]

Education – Meeting Preparation

My Concerns	Based on	Result / Decision

I think my child needs	Based on	Result / Decision

IEP Meeting Agenda

Having a general idea of what to expect during an IEP meeting can lessen a parent's worry and help you get organized before the meeting. Below is a flexible agenda to help you prepare for your next education meeting. As you read over these, look back at your meeting preparation notes and worksheets. Have you covered all the information you want to bring to the meeting? Remember to email any documents you want to share before the meeting.

Introductions: Names, Titles and Roles.

Discuss the purpose of meeting.

Establish goals and set ground rules.

Review testing or screening if needed.

Discuss present levels and progress.

Discuss academic and behavioral needs.

Share proposed IEP goals.

Look at strategies to address the child's needs.

Determine what accommodations are needed.

Determine a schedule of services and classroom placement.

Summarize meeting.

Documents are sent to all team members. If the meeting is held in person, documents are signed to show attendance and agreement.

Be sure to leave with a clear action plan.

Here are key questions to have answered:

- What will happen?
- Who is responsible?
- When will the actions happen?
- Are there timelines?
- How will we communicate for follow through?



TIPS:

Remember to take notes

Ask for copies of all paperwork

Ask questions

As with any meeting, any unresolved issues can be addressed in a follow-up meeting

Quick Look • My Child's IEP / 504 plan

Schoolwork Assignments:

Testing:

School Services:

Technology Accommodations:

Seating Accommodations:

Goals:

Ways to Help:

Education / Employment Opportunities:

Please attach copy of IEP or IHP

I go to school at: _____ Phone #: _____

Teacher: _____ School: _____

Nurse: _____

School OT: _____ Phone #: _____ Frequency: _____

School OT: _____ Phone #: _____ Frequency: _____

School OT: _____ Phone #: _____ Frequency: _____

What is your child's work potential and employment history?

What kinds of support do they receive and from which agencies?

Current Place of Employment: _____

Contact Person : _____

Address: _____

Phone Number: _____

Hours/Days worked: _____

Previous Employment: _____

Contact Person : _____

Phone Number: _____

What are your child's capabilities and skill levels?

What other opportunities would you like to see happen?

IEP Binder Checklist

Complete the worksheets in this booklet (you may want to make extra copies of blank worksheets first). Keep the documents listed below in a folder and keep it with this workbook. Having all your documents together in one place will help when planning and communicating with your school in the future and with tracking your child’s progress.

Communication		Dates updated		
School contact list	Yearly or as new members join the team			
Communication log	Every time you have a meeting, call, or other important interaction with the school			
Letters and emails to and from the school	As often as needed (File after noting them in communication log)			
Evaluations		Dates updated		
Request or referral for evaluation	Every three years or more often, if needed			
Consent to evaluate	(Tip: Keep this — and the referral — on top to help check if the evaluation is done in a timely manner)			
School evaluations	At least every three years			
Private evaluations (if any)	Every time your child is evaluated privately			
IEP		Dates updated		
Parent’s rights & safeguards	Yearly			
IEP	Yearly or more often, if changes are made (and, if your child has had a 504 plan, include that too)			
Prior written notice and meeting notes	Yearly or more often, as needed			
Grades and Work		Dates updated		
Report cards and progress reports	As often as they come from the teacher or school			
Samples of schoolwork	At least monthly or as often as you see signs of progress or concern			
Standardized tests	Whenever the results are sent home			
Behavior		Dates updated		
School agenda or planner	Yearly			
Behavior intervention plan	Yearly or as often as changes are made			
Disciplinary notices	Any time your child receives one			

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#MakingConnections

#RaisingAwareness

#PromotingInclusion

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