



Learning Among Children with Spina Bifida

August 2023

Overview

People with Spina Bifida (SB) can have many different learning strengths and challenges. Children born with open spinal lesions (called *myelomeningocele*, or MMC) are more likely to have learning problems. Children born with closed spinal lesions (like a meningocele) usually only have physical challenges with their bones or bladder/bowels, and often do not have learning problems. Whether a child has trouble learning can also depend on whether they have hydrocephalus and need a shunt. These patterns may change over time because of new treatments like fetal surgery.

Children with MMC often have a mix of learning strengths and weaknesses. Common strengths are:

- Strong vocabulary
- Good word reading and spelling
- Good memory for certain tasks

Common weaknesses are:

- Fine motor skills (like handwriting)
- Paying attention
- Staying organized
- Math
- Reading comprehension

Most children with MMC learn best when teachers show steps clearly and give lots of practice. They may have a harder time putting ideas together or making inferences.

Not every child with MMC is the same. Some follow these common patterns, some have very few learning problems, and others have their own unique learning challenges. A learning evaluation can help identify what a child needs in school.

There Are Two Main Ways to Get a Learning Evaluation

1. School-Based Evaluation

Public schools are required by law (IDEA) to check for disabilities and give support to students who need it.



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If a child already has an IEP, they are evaluated every three years.
If not, parents can request an evaluation.

A school evaluation may include:

- Reading, writing, and math tests
- IQ and attention testing by a school psychologist
- Help from physical therapists, occupational therapists, and speech/language pathologists

Benefits of school evaluations:

- Free
- School staff know how the child behaves in class and have easy access to a wide-range of school-based data (test scores, grades, etc.)
- Schools must give support if the child qualifies

Challenges:

- Many school staff may not know much about MMC
- Children with MMC can have complex learning patterns that are harder to understand

2. Private Evaluation

Families can choose an evaluation outside the school system. These are often done by clinical neuropsychologists who understand MMC.

Benefits:

- Evaluator usually has special knowledge of MMC
- Can give very detailed information

Drawbacks:

- Expensive (though insurance often covers much of it)
- Extra steps to share information with the school



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- Schools must *consider* private evaluations but don't have to follow all recommendations

Both school and private evaluations can be helpful. Often, the best plan is to use both.

If you find a neuropsychologist who knows about MMC and insurance covers it, this can be a good first step. Make sure the evaluator can speak to school staff and review school records. After the evaluation, share the report with the school so it can help with the child's IEP.

Managing Common Learning Problems in MMC

After learning your child's strengths and needs, you and the school can create a plan to help them. Children with MMC often have challenges in:

- Reading comprehension
- Math
- Writing
- Fine motor skills
- Processing speed
- Attention
- Executive functioning skills (like planning or organizing)

Academic Skills

Many people with MMC struggle with reading comprehension, math, and writing. Good school interventions usually have these features:

- Structured: clear plan and goals
- Explicit: teachers explain steps directly and show how to solve problems
- Individualized: matched to the child's needs
- Intensive: happens often, ideally daily or several times a week

Most help comes through the IEP at school. Some families also use private tutors, but tutors and teachers should use similar methods.



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Math Difficulties

Many children with MMC have math learning disabilities. They may understand a skill one day and forget it the next, which can affect their confidence.

They may struggle with:

- Multiplying, dividing, or other math steps
- Word problems
- Understanding place value or fractions

Best support:

- Structured, step-by-step math instruction
- Adults modeling a positive attitude about math
- Praising effort, not just grades

Reading Comprehension Difficulties

Children with MMC often understand individual words but struggle with:

- Understanding the “big picture”
- Summarizing
- Making predictions
- Making inferences (“reading between the lines”)
- Processing long or complex spoken directions

Helpful strategies:

- Build background knowledge about topics
- Teach comprehension skills directly (summarizing, visualizing, finding main ideas, previewing a text)



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Writing Difficulties

Writing is hard for many reasons, including:

- Fine motor challenges
- Trouble organizing ideas
- Trouble understanding information

Helpful supports include:

- Building background knowledge
- Occupational therapy for fine motor work
- Tools like speech-to-text or typing
- Step-by-step instruction in planning, drafting, and revising

Fine Motor Skills

Children with MMC may struggle with tasks like:

- Writing
- Cutting
- Fastening clothing
- Drawing

This can affect schoolwork. Occupational therapists can help. Some children may benefit from typing or speech-to-text instead of handwriting.

Processing Speed

Many people with MMC think or work more slowly than their peers. This may show up in writing or in general thinking tasks.

There is no strong treatment to make processing faster, but support includes:

- Giving extra time on assignments and tests
- Adults slowing down when giving instructions



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Attention Difficulties

Children with attention problems may:

- Get distracted easily
- Forget what they're doing
- Lose belongings
- Struggle to follow directions
- Have trouble starting or finishing tasks

About one-third of children with MMC have ADHD—usually the inattentive type (not hyperactive).

Support options include:

- Medication (may help but needs careful monitoring)
- Behavioral therapy
- Environmental support (checklists, timers, organized spaces)
- Healthy lifestyle (good sleep, exercise, managing health needs)

Executive Functioning Skills

Executive functions help people:

- Plan
- Start tasks
- Stay organized
- Make good long-term decisions

Children with MMC may struggle in these areas. Adults can help with:

Organization/Planning

- Break tasks into steps
- Use checklists
- Build routines



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Initiation (Getting Started)

- Help children know where to begin
- Use visual lists of needed materials and steps

Time Management

- Teach how to estimate time
- Use visual timers
- Practice prioritizing tasks

Working Memory

- Give short, clear instructions
- Use both spoken and written reminders
- Post checklists (morning routine, homework steps, etc.)
- Teach active listening

For more information, visit the Spina Bifida Association's Neuropsychology Guideline, part of the *Guidelines for the Care of People with Spina Bifida*.

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This information does not constitute medical advice. As specific cases may vary from the general information presented here, the Spina Bifida Association advises readers to consult a qualified medical or other professional on an individual basis.