



---

# Learning Among Children with Spina Bifida

---

August 2023

## Overview

People with Spina Bifida (SB) show a wide range of learning abilities and disabilities. Children born with open spinal lesions (myelomeningocele, or MMC) are at risk of learning challenges. Children born with a closed spinal lesion, such as a meningocele, often show only orthopedic and bladder/bowel difficulties and typically don't have learning impairments. Whether a child has learning difficulties is also influenced by whether they develop hydrocephalus that requires a shunt. These patterns may be changing because of the impact of fetal surgery.

Children born with SB myelomeningocele (MMC) often show a complex learning profile that includes strengths in some areas and weaknesses in other areas. Some of the most common strengths include vocabulary, word reading, spelling, and certain types of memory. Some common weaknesses include fine motor skills, attention, organization, math, and reading comprehension. In general, children with MMC are rule-based learners. They do best when procedures are broken into steps and taught through association and repetition. They have more difficulty integrating information, especially if it requires them to make inferences or make connections between different ideas.

No two people with MMC are the same. Many show the most common profile of strengths and weaknesses, but some people with MMC don't have any particular learning challenges. Still others have a different complex learning profile. An individual learning evaluation can provide information about the child's profile and suggestions for educational interventions.

## The evaluation process

There are two main options for seeking an individual learning evaluation for a child with MMC. Public school districts are required by the Individuals with Disabilities in Education Act to identify children with disabilities and to provide them with appropriate supports. Any child with an Individualized Education Program (IEP) has already participated in a school-based evaluation and must be re-evaluated at least every three years. If a child does not have an IEP, an evaluation can be requested through the child's public school. School-based evaluation can include detailed assessment of the child's reading, writing, and math skills. A school psychologist may be involved to assess intellectual functioning (IQ), attention and organization, and emotional/behavioral functioning. School-based physical therapists, occupational therapists, and speech/language pathologists often participate in the IEP evaluation as well.

There are some advantages to school-based evaluations. First, they are entirely free. Second, the school team should have a good understanding of how the child behaves in the classroom and have easy access to an abundance of school-based data (test scores, grades, etc.). Finally, if the evaluation reveals learning challenges, public schools are required by law to provide appropriate interventions. In other words, if the school-based evaluation shows that a child needs more help at school, then the school district must provide that help.



---

# Learning Among Children with Spina Bifida

---

August 2023

There can also be challenges in the school evaluation process. A common challenge is that most school-based professionals do not have specialized expertise in MMC and the ways in which it can impact brain functioning. Many children with MMC show a complex learning profile that may be confusing to professionals without specific training in this area.

Another option is to seek private evaluation outside the school system. The main advantage of private evaluation is that the child's medical team can choose an evaluator who has specialized knowledge about MMC and the ways it can impact children's development. Usually, this type of evaluation is performed by a clinical neuropsychologist or other clinical psychologist with expertise in children with MMC. The child's medical team or other parents in the community may be able to recommend a clinical neuropsychologist to conduct the evaluation. Some neuropsychologists work with a multidisciplinary team that includes physical therapists, occupational therapists, and speech/language pathologists.

There are also disadvantages of a private evaluation. A big one is that they are expensive. For children with a chronic medical condition (including MMC), medical insurance will often cover most of the cost. However, specific policies vary by insurance company and you may still be responsible for a deductible or co-insurance/co-pay. Second, there are more steps involved in making sure the evaluator has access to school-based data. Finally, school districts are required to *consider* the results of a private evaluation, but they are not required to follow the recommendations.

You don't have to pick just one kind of evaluation or the other. For many children and families, a combined approach works best. If it's feasible, private evaluation by an MMC expert can be helpful. At the same time, involving the school closely in the evaluation process is important because your child spends so much time there and because much of the intervention will be provided through the school.

If you can identify a local clinical neuropsychologist or psychologist with expertise in MMC and most of the cost of private evaluation will be covered by insurance, that may be a good place to start. Make sure to provide consent for the psychologist to speak with your child's teacher and to review school records. After the evaluation is complete, provide a copy of the evaluation report to the school. The information about your child's learning profile and recommendations should be considered in developing or updating your child's IEP or other educational support plan.

## Managing common learning problems in MMC

Once you and the school team have a good understanding of your child's learning profile, you can develop a treatment plan to address any areas of weakness. The following are common areas of weakness in children with MMC, as well as suggestions for supporting them.

**Academic skills:** Areas of school learning that are often challenging for people with spina bifida include reading comprehension, math, and writing. Each of these is described further below.

Regardless of the specific skill involved, interventions for academic learning difficulties share some common features. First, effective interventions are **structured**. They follow a clear plan with specific learning goals, and



---

# Learning Among Children with Spina Bifida

---

August 2023

progress in an orderly fashion from one learning target to the next. Effective instruction is also **explicit**. This means teachers explain concepts directly and model how to approach problems or tasks, often with step-by-step instructions and supervised practice. Some educational approaches are the opposite of explicit—they rely on children making their own discoveries about how to solve problems. Such approaches may be appropriate in some settings, but they are not very effective for teaching academic skills to children with learning challenges. Third, the instruction is **individualized**—lessons are at the child’s level and targeted to specific weaknesses. Finally, the intervention should be **intensive**, especially if the child is functioning well below grade level in that area. This means that intervention should be provided in a one-on-one or small group setting daily, or at least a few days per week.

Academic intervention is typically provided primarily through the child’s school, usually as part of an IEP. Most children with learning challenges related to MMC should qualify for an IEP as a student in the “Other Health Impaired” category. Some families also hire a private tutor to provide additional practice at home. If you do involve a tutor, it is important for the different educators working with the child to use coordinated approaches.

**Math:** Many people with MMC have a learning disability in math. This can cause difficulties learning math calculation procedures (such as multi-digit multiplication or long division), solving word problems, or both. You may also notice weaknesses understanding key math concepts, such as place value and fractions. People with a learning disability in math often show frustrating inconsistencies. They may seem to understand a math concept one day and forget it the next. They might have trouble “translating” a math word problem to the necessary calculation steps (subtracting when the problem requires dividing, for example). Over time, these learning struggles can impact a child’s attitude to math and even their self-esteem. The child may avoid math tasks and might make comments like, “I’m bad at math,” “I’m stupid,” or “I hate math.”

The main treatment for math learning disabilities is individualized, structured, explicit, intensive remedial math instruction as described above. To support a child who dislikes math, adults working with children can model a positive attitude to math tasks. You may also be able to help improve a child’s feelings about math by focusing on their effort rather than on their math ability or specific grades or test scores (“You worked hard on that problem!” or “You’ve learned so much this year.”)

**Comprehension:** Children with MMC often have difficulty understanding complicated concepts. They may know a lot of information but tend to have a literal or “surface-level” understanding. Many people with MMC struggle to make connections between ideas and to process information at a deeper level. In school, this causes problems with listening comprehension and with reading comprehension, which usually parallel one another. People with MMC may be able to read individual words as well as most of their classmates but struggle to get meaning out of a book or written passage. They may remember specific details from a story but miss the “big picture.” People with reading comprehension difficulties struggle to summarize what they have read, make accurate predictions, and make inferences (“read between the lines”). Because of the difficulties in listening comprehension, a person with MMC may have trouble processing the meaning of complex spoken information when a teacher is delivering a lesson even when they understand individual vocabulary words.

One of the best ways to support comprehension is to increase background knowledge. The more people know about a topic, the better they will understand information they hear or read about that topic. Structured, explicit,



---

# Learning Among Children with Spina Bifida

---

August 2023

reading comprehension instruction often focuses on teaching specific comprehension strategies. These include teaching children to: visualize what is read; summarize; perform regular comprehension checks; extract main ideas from text; preview reading material; and attend to key terms, headers, and titles. You can learn more about supporting reading comprehension in the Reading Comprehension Difficulties and Spina Bifida Information Sheet.

**Writing:** Writing is a complex skill that develops gradually over many years of schooling. Being a strong writer requires many different competencies, so there are many different reasons that people can struggle with writing. Children with MMC often have difficulties with writing that are related to underlying weaknesses in comprehension as well as to fine motor skills, attention, and executive functioning skills (discussed further below).

Just like for reading comprehension, increasing background knowledge can support better writing. Everyone writes better when they know a lot about the topic. The reasons behind a child's writing difficulties will guide the treatment. If the main challenge is in fine motor skills, then treatment by an occupational therapist and accommodations such as using speech-to-text will go a long way. However, if the main challenge is in organization, then a different type of intervention would be needed. (Some suggestions for supporting organization are provided below). Individualized, structured, explicit, intensive instruction focused on skills such as planning, drafting, and revising is often helpful.

**Fine motor skills:** People with MMC often have difficulty coordinating the small muscle movements needed to perform manual activities like fastening, cutting, handwriting, and drawing. They may not be able to complete these tasks as well or as quickly as their peers, and they might also find them fatiguing or frustrating. At school, fine motor difficulties can interfere in a child's ability to produce written work in any subject. Occupational therapists are trained to evaluate and treat fine motor difficulties. Treatment may involve a combination of direct strengthening and coordination activities, as well as accommodations or strategies to "work around" the challenges. For example, children with fine motor weaknesses may benefit from using keyboards or speech-to-text technology instead of handwriting.

**Processing speed:** Professionals use the term "processing speed" to talk about a kind of brain efficiency. People with strong processing speed can perform tasks quickly *and* accurately. People with MMC often have slower processing speed than their peers. Sometimes, the slowing will be most obvious when tasks require writing or another motor response. Other people with MMC experience a more general slowing impacting verbal processing and other mental tasks.

We don't yet have very effective treatments for directly improving processing speed. However, people with MMC can learn to work around this weakness with appropriate accommodations. At school, this often means relaxing or eliminating time constraints on assignments and tests. People with slow processing speed need more time than their peers so that their work reflects what they know rather than how quickly they can produce. When working with a child with slow processing speed, adults can also slow down their own pace so as not to overwhelm the child.

**Attention:** Children with attention difficulties may:



---

# Learning Among Children with Spina Bifida

---

August 2023

- Be easily distracted
- Have trouble getting started with or finishing tasks, especially those that are boring or difficult for them
- Forget what they are supposed to be doing
- “Tune out” when adults are speaking to them
- Have trouble following multi-step instructions
- Lose track of their belongings
- Appear lethargic or under aroused

Attention difficulties can also cause inconsistencies in children’s performance, which are frustrating for parents and teachers and especially for the children themselves. Adults often misjudge children with such inconsistencies. If a child can accomplish a task one day but not the next, adults may assume that the child is being lazy or willful. Often, however, a brain-based attentional weakness is the reason for these struggles.

About a third of people with MMC have attention problems that are significant enough for a diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD). The name is confusing because not everyone with ADHD is hyperactive. In fact, most people with MMC and ADHD are not hyperactive. Instead, they have the predominantly inattentive type of ADHD, which means they have many of the symptoms listed above. Whether or not a child with MMC has full ADHD, many of the home and school supports used for children with ADHD can help address attention challenges in a person with MMC.

There are four main types of interventions for attention problems:

- 1) *Medication.* Many children with ADHD symptoms benefit from medication to help them focus better. You can talk to your child’s pediatrician or family doctor to learn more about whether medication might be appropriate for your child. There is much we need to learn about the use of medications for attention problems in MMC. Clinical experience suggests that it often does not work as well as in children with developmental forms of ADHD and that lower doses may be effective. But in any child for whom medication is considered, it is important to start on a low dose and increase it until an optimal response is observed, which requires liaison among the physician, school, and parents.
- 2) *Behavioral therapy.* Parents can work with a licensed mental health provider to develop a positive behavior support plan that encourages more on-task behavior in a child with attention problems. At school, a school psychologist or behavioral specialist can design a similar plan to be used in the classroom setting.
- 3) *Environmental modifications.* Children with attention problems benefit from increased structure, which can be provided through checklists, timers, calendars, and physical organizers (binders, folders, etc.) Reducing clutter and other distractions in workspaces is also beneficial.
- 4) *Lifestyle supports.* Attention can be heavily influenced by factors such as illness, sleep, and exercise. You can support your child’s attention by helping them manage chronic medical issues, go to bed on time, and get regular aerobic exercise.



---

# Learning Among Children with Spina Bifida

---

August 2023

**Executive functioning skills:** The term “executive functions” describes a set of skills that become increasingly important as children move towards adulthood. Together, executive functions guide future-oriented behavior. They allow us to do what is best over the long-term, rather than making all our decisions based on what we want right now. Many people with executive functioning weaknesses make choices that feel good in the moment but that could harm themselves in the long run. For example, a child with MMC may not stop playing a favorite video game in order to self-catheterize—playing the video game feels good right now, while the consequences of not catheterizing will not become a problem until later.

Executive functions are closely related to attention and processing speed. Often, if a child struggles in one of those areas, they struggle in the others as well. Executive functioning difficulties can also contribute to significant school struggles, especially in middle school, high school, or beyond. Suggestions for supporting common executive functioning weaknesses are provided below.

1. *Organization/planning:* Increasing structure of tasks and using routines will assist in supporting a child’s organization/planning skills. Break down large tasks into clearly defined subtasks and provide a list of steps to be followed. For younger children, questions need to prompt each step (“What do you have to do first? What do you have to do next?”) but for older children and adolescents, prompts can become more general (e.g., “Let’s make a list of all the things you have to do to complete this task.”). Help your child create checklists to keep organized and identify an organizational system to fit with your child’s style and needs.
2. *Initiation:* Challenges with initiation are often a result of not knowing where or how to start a task. For example, a child with MMC may feel overwhelmed with the number of steps and materials needed to self-catheterize and therefore delay or avoid the task entirely. You can support children’s initiation skills by helping them break down the task into small, manageable steps. Then create a visual to-do list that includes a list of materials needed for the task as well as a list of the steps needed to complete the task.
3. *Time management:* Children with time management challenges tend to have difficulty estimating how long tasks will take, prioritizing tasks based on deadlines, dividing time between tasks, and pacing themselves. Teaching time management skills explicitly will be helpful for children with these challenges. Here are a few examples: 1) Practice prioritizing with multiple tasks (one way to do this is make a list of assignments and go back and order them by importance); 2) Practice estimating time for different tasks (e.g., “How long do you think it would take to clean your room?”), and 3) Use a visual timer to show how much time is left for a specific task.
4. *Working memory:* Working memory allows us to keep information “online” and use it to guide our actions. To support a child with working memory challenges, present information in small chunks. Keep instructions clear and concise. Providing both written and oral instructions is often helpful. Visual reminders placed in a prominent place can help cue a child to tasks that need completion. For example, post a “morning routine checklist” on a child’s bedroom door or bathroom mirror. Teaching a child active listening (e.g., stop what I am doing; focus my attention; ask questions) and to paraphrase what was said are helpful skills to support working memory difficulties.





---

# Learning Among Children with Spina Bifida

---

August 2023

For further reading, please visit the Spina Bifida Association website to access the Neuropsychology Guidelines for the Care of People with Spina Bifida: [Guidelines for the Care of People with Spina Bifida - Spina Bifida Association](#)

*By Robin L. Peterson, PhD, ABPP-CN and Tess S. Simpson, PhD*

*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.*