

LEARNING WITH SPINA BIFIDA: The Neurocognitive Profile for Patients with Spina Bifida



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What is a Neurocognitive profile?

- A set of strengths and weaknesses that are commonly seen in patients with a certain medical disorder
- Some differences are due to underlying changes in brain development and some due to the treatments for different conditions
- There is a lot of variability in childhood development, even more variability in skill levels for patients with spina bifida

What is a Neurocognitive profile?

- This profile does not reflect all patient's strengths and weaknesses, but reflects the most common strengths and weaknesses linked to the medical condition
- Patient's profiles still reflect the strengths and weaknesses of their parents and other family members, as well as their interests

Typical strengths and weaknesses in adolescence and adulthood

TYPICAL NEUROCOGNITIVE PROFILE

Typical Neurocognitive Strengths:

- Vocabulary: often know a lot of words
- Memory: strong experiential learners, do great with routines
- Socially: often friendly, outgoing, interact well/easily with adults
- Academics: reading fluency is often strong, do better in social sciences

Typical Neurocognitive Weaknesses:

- Information processing: vulnerable to processing load and complexity
- Executive Functioning skills: initiating, integrating, organizing
- Attention: switching, divided
- Visual spatial skills: mental manipulation
- Motor skills: fine, graphomotor, gross
- Academics: most often math, writing, geography

Lets talk about what these skills are and how they affect functioning

THE DETAILS

Attention

Attention is one's ability to identify what to focus on in their environment and what to ignore

- Focusing tends to be easy
- Shifting attention is hard
- Dividing attention is hard
- If problematic, inattention > hyperactivity
- Can be distracted by information they do understand or minor details that they recognize
- Careful not to confuse a lack of understanding for an attention problem

Information Processing style

Detail oriented, linear information processing style

- Often tend to break apart larger information loads into smaller pieces
- Focus on content bit by bit, memorizing
- Minimal focus on organizing and actively processing the information
- Takes longer to get through the pieces
- At highest risk with large information loads

Information Processing style

Given the detail oriented processing, learning can be:

- Slower as there are more details and less concepts
- More fragmented as information is memorized
- Concrete and less flexible, harder to use to build on or to problem solve with
- Driven to be more reliant upon routines than novel problem solving
- It can appear that there is only interest in familiar topics, but this is due to their familiarity with info and ability to actively organize that information

Executive Functioning Skills

EF skills are built on a circuit and are responsible for planning and problem solving

- Skill set is highly vulnerable to stress and changes in brain development
- An interactive set of skills that are interdependent and support goal directed or volitional behavior
- These skills include:
 - Initiation and switching between topics/concepts
 - Generation of problem solving strategies
 - Integration of details and generalization of concepts
 - Sequencing, organization, multitasking, and prioritizing

Executive Functioning Skills

Children and adults with spina bifida often have..

- Trouble identifying the task demands, which limits initiation and switching
- A need for rehearsed routines; multitasking and prioritizing are hard
- Difficulties with multitasking and information processing load
- Organizational challenges, as identifying the "bigger picture" is hard

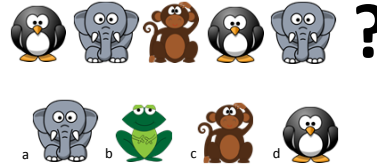
Language

Language is most often used for communication and learning

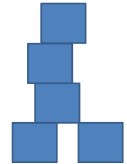
- Often strong vocabulary, good grammar
- More difficult to organize thoughts and communicate effectively/efficiently; can become tangential
- Integrating is hard, connecting language with non-verbal cues can be difficult
- Verbal memory can be limited by learning style, information processing load, and complexity

Visual Reasoning Skills

Visual perceptual (pictures)

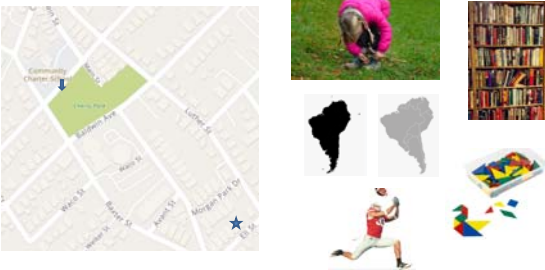


Visual construction
(building)



Visual Reasoning Skills

Visual spatial (how things operate in space)



Visual Reasoning Skills

Visual spatial and visual construction skills are often a significant challenge

- Detail oriented processing means be attracted to one salient characteristic (such as color), missing other details
- Challenges with integration can be hard
- Can benefit from language support of visual processing
- Can affect early letter and number identification

Memory

Memory is how information is processed and stored in the brain, which affects how it is recalled later

- Experiential learning is considerably stronger
- Systems get overloaded quickly by the load of memorized details
- Can be hard to find memorized information when it isn't understood, "file folders" aren't well labeled

Motor skills

Cerebellum is responsible for motor planning and motor coordination

- Coordination and speed of fine motor skills are often compromised
- Slower graphomotor (writing) skills limits production
- Gross motor issues often include strength, balance, and dexterity
- Dyspraxia (planning of motor movements) has been associated with the number of shunt revisions

Academic Skills: strengths

Rote skills that are supported with memorization are stronger

- Word identification/reading
- Grammar rules (not the exceptions!)
- One by one math facts
- Rehearsed math calculations
- History facts
- Memorization of songs and acronyms
- Learn best with reinforcement of structure

Academic Skills: challenges

Application of concepts in novel situations

- Reading comprehension
- Math word problems, spatial math
- Organization of written papers (trouble getting good ideas on paper)
- Geography
- Historical/ civics concepts
- Higher level sciences (e.g., physics)

Social skills

- Often very friendly and talkative; easily engages with others, particularly adults
- Prefers rule based over creative play
- Prefers individual interactions with others, rather than groups
- Can have interests that are “younger”
- Helpful to others, compliant with requests
- Can trust more than is earned, increasing potential for victimization

Adaptive skills

Adaptive skills are the day to day life skills that we need to be successful and to live independently

- Often very reliant upon routines, so if the timing or structure changes, can be hard to maintain
- Need to build skills sequentially, with step by step instructions
- Tasks with high visual spatial, motor demands, and information processing demands are more challenging
- Need more repetition and rehearsal to achieve skills, so we often need to start younger

STRATEGIES TO BUILD SKILLS

Learning strategies

- Always emphasize the concept or ideal behind the task, helping to “label the file folder”
- Help by connecting real life experiences to their didactic learning when possible
- Work to provide the external scaffolding before they begin the task
- Set routines and consistent learning environments whenever possible

Work with schools

- Very important to educate schools and teachers about how your child learns
- Provide direct feedback to teachers when your child does not understand tasks
- Identify the smaller aspects of tasks that are challenging
- Request teachers who tend to be more organized and structured, using a lot of routines
- Engage 504 Plan or special education services as needed

Working better at work

- Learn to advocate for your needs to support learning (ask for bullets, step by step instructions, completed project models)
- Seek support from a job coach or supervisor to observe your work flow and suggest improvements in efficiency or accuracy
- Solicit 504 Plan (Americans with Disabilities Act) accommodations if needed, including physical and task oriented supports

Evaluating skill development

- Seek evaluation regularly in order to ensure you understand your child's current needs
- Schools are focused on access to the academic curriculum, parents are focused on long term success- those are different
- Just as you involve therapists to rehab after surgery and teachers to support learning at school, accept/seek support from the community to help manage other learning challenges

To support independent functioning

- Encourage your child to share responsibility for their care and personal management (*Scaffolding* their learning – building skills incrementally)
- Implement organizational and support strategies to help with the transition
- Begin involving the child in decision making processes, including participation in medical visits and IEP meetings
- Help medical teams appreciate your child's strengths, vulnerabilities and capacity for skill building
- Provide opportunities for rehearsal and practice
- Use their strengths to support their weaknesses

How to help build independent functioning skills so that they can successfully move out

HOW TO SUPPORT INDEPENDENCE

Learning to be independent

- Use similar strategies as used in formal educational settings
- Repetition and rehearsal of routines is the most effective; build skills step by step
- Specific teaching on how to identify problems or emergencies is essential
- Acknowledge that "their way" isn't wrong if it is different

Daily living skills

- 1st step: is aware of daily routines and the timing
- 2nd step: can participate in the steps of routine
- 3rd step: can complete steps of the routines with cueing from others
- 4th step: can engage technology to support task completion/provide cueing
- 5th step: Can complete routines with minimal cueing at home
- Long term goal: can engage in all expected routines without cueing from others ACROSS ALL SETTINGS

Health self assessment

- 1st step: knows major medical issues or can point to affected body parts (e.g., can't walk, can point to a urological surgery scar)
- 2nd step: knows when they are getting sick or having symptoms, can tell parent what is wrong/how they feel
- 3rd step: knows many of their doctors names and knows what they do
- 4th step: has a sense of how often they see certain doctors and why they see them
- 5th step: can name their care locations
- Long term goal: can differentiate between different symptoms that may be similar (pulled back muscle vs kidney infection)
- Long term goal: can tell a stranger (ED MD at adult facility) about their symptoms and medical history if needed

Communication with medical providers

- 1st step: can greet doctors, make eye contact, shake hands, address basic questions (what they are doing, school progress, etc.)
- 2nd step: tolerates a "new" doctor
- 3rd step: can form questions for providers, even if asking their parent a question to ask the doctor
- 4th step: can ask a question when provided support in advance (may be written)
- 5th step: can "lead" an appointment, answering most questions
- 6th step: can meet alone with a provider and summarize the info later
- Final goal: can summarize some/most of the information provided during a visit
- Extra credit: can ask for a private visit if they have a question or don't want to share information with parents

Use of medications/medical supplies & equipment

- 1st step: knows names of equipment, supplies and medications
- 2nd step: can remember that they need to do basic tasks, even if the timing is off
- 3rd step: begins helping with tasks rather than just cooperating with parents
- 4th step: can tell parents they are running low on supplies
- 5th step: can identify problems with supplies or equipment
- 6th step (a): knows their pharmacy name and town/location
- 6th step (b): can help parents to help fill a prescription
- Long term goal: with training, can call and refill a script or supply order (or use an online ordering system) with help
- Long term goal: can identify problems with supplies or equipment

Access to insurance/medical records

- 1st step: understands there is a medical record, and that information is private but accessible
- 2nd step: knows that they have insurance that helps pay for medical bills; knows to give the desk their insurance card during check in
- 3rd step: understands that permission needs to be given for doctors to talk to other people
- 4th step: knows the name of their insurance company
- 5th step: can share if they have a Health Care Proxy or Medical Guardian
- Extra credit: can actually talk to an insurance company and get their questions answered

Management of lifestyle choices

- 1st step: knows basic safety rules (e.g., no touching in swim suit area)
- 2nd step: has an understanding of eating healthy, exercise
- 3rd step: knows to be honest with doctors about their behaviors
- 4th step: understands dating and romantic relationships
- 5th step: knows the difference between consensual sexual relationships and assault, understands emotional and physical abuse are not normal
- Long term goal: understands that drugs and alcohol are not healthy; has an emergency plan in case of need
- Long term goal: knows when to tell others about touching, inappropriate "games" or activities