Understanding the Neuropsychological Profile for Children with Spina Bifida

How to support development

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Objectives

- Due to changes in the development of the brain and spinal cord, many children can experience changes in the development of cognitive, executive, memory and learning, as well as academic and adaptive skills.
- These changes in development not only affect school, but also the development of social and adaptive skills.
- This talk will explain the typical neuropsychological profile as well as provide basic recommendations to address common aspects of the neuropsychological profiles of children with spina bifida.

Neuropsychology

- The study between brain functioning and behavior (learning, social skills, education, adaptive skills)
- Can help to explain strengths and weaknesses
- Can help to improve communication with the medical team and school system

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Typical Neuropsychological Profile

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- There is a lot of variability in the skill levels of patients with Spina Bifida, which can be linked to lesion level, shunt status, complications, or associated syndromes or constellation disorders.
- However, the profile of strengths and weaknesses is often similar.
- This is why individual assessments are so important, both during childhood and during the transition to adulthood.

Typical Strengths in the Profile

- Vocabulary (often know a lot of words)
- Memory: experiential learners, tend to do better with memorization rather than comprehension
- Socially: often friendly, outgoing, interact well/easily with adults
- Academics: reading fluency is often strong, do better in social sciences

Typical Weaknesses in the Profile

- Executive Functioning skills
- Attention
- Visual spatial skills
- Motor skills
- Academics, particularly math and reading comprehension

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The Details…

Detail Oriented, Linear Processing

- Tend to break apart information loads into smaller pieces, then process information in linear formats (e.g., bit, bit, bit)
- Takes longer to get through the pieces
- Takes more time to organize all of the information at the end to support comprehension
- Leads to problems across domains, including reading comprehension and drawing tasks
- At highest risk with large information loads

Executive Skills

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

Executive Skills: An Example

Think of a secretary (executive skills) for a CEO (other brain functions).

- The secretary's job is to manage information coming in by answering the phone, sorting mail, etc.
- Needs to plan ahead for upcoming events, pulling together information to select a strategy.
- Needs to create efficient strategies to support effective task completion.
- Pulling together information to put into storage or a filing cabinet (e.g., memory), where the folders need to be filed accurately to find them again later.

Development of Executive Skills

- In toddlers, initiation is most problematic, as it can be hard to act on the environment with motor challenges.
- In early childhood, problems with flexible thinking and problem solving can begin to affect learning and social interactions.
- In middle childhood, problems with organization and planning become more problematic.
- In adolescence, problems with integration of information and generalization of skills can limit independence.

Attention

- More often inattention than hyperactivity.
- It is sometimes linked to level of comprehension around them.
- Can get distracted by information they do understand or minor details that they recognize.
- Even when attention is appropriate, can be more at risk on dual attention tasks due to information processing loads.
- Etiology can be different from "traditional ADHD" which means medication doesn't always work.

Memory

- The linear processing style causes the systems to get overloaded quickly because they are breaking information down into smaller bits.
- When information is not integrated properly, the bigger picture is not created, which makes it harder to remember information.
- Tend to be stronger with rote repetition and memorization rather than comprehension and adequate storage.

Language

- Often strong vocabulary and good grammar.
- It is more difficult to organize thoughts and communicate them effectively because of executive (integration) problems.
- Integrating is hard, so connecting language with non-verbal cues and previous experiences can be more difficult.
- Integration issues raise risks for victimization and can affect advocacy efforts.

Visual Spatial Skills

- Children tend to do very well with photos and simple pictures.
- However, visual perceptual, visual spatial, and visual construction skills are often areas of weakness.
- Often attracted to one salient characteristic (such as color), missing other details and failing to comprehensively evaluate all of the information.
- Understanding how children's bodies move through space can also be difficult.

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Academic skills

Academic Skills: Development

- K-3: Usually easier grades for children with spina bifida because they thrive with memorization.
- 4-5: These grades can be more difficult as they require the transition to application of skills, such as reading for learning rather than learning to read.
- 6-8: Major transition due the increases in organizational, planning and mobility demands.
- 9-12: Requires substantial abstract and flexible reasoning abilities, as well as managing increases in information processing load.

Academic Skills: Reading

- Word identification skills are typically strong.
- Memorization of sight words can often be stronger than phonemic skills.
- Reading comprehension can often be difficult.
  - Children are able to recognize details presented in the text; the focus on details helps with this.
  - However, identification of themes and concepts relies on organization and integration of the information, which is harder.

Academic Skills: Math

- Math begins as memorization, and early development of math facts is generally intact.
- However, as math becomes more conceptual, it also becomes more difficult.
- Word problems are also more difficult, as you have to be able to read information for the most important factors and recognize cue words.
- Lots of sequential processes involved in multiple step tasks, such as long division, which taxes underdeveloped executive skills.

Academic Skills: Writing

- At times, motor skills and motor coordination can affect production of written content
- Children are often able to creatively construct topics and ideas, but have difficulty with the actual creation of the written content
- Similar to reading, pulling together concepts and organizing information can be difficult
- In addition, the multitasking demands of writing can often tax underdeveloped executive skills

Educational Programming

- Most children with spina bifida require at least medical supports at school, which can include:
  - Access to nursing services for catheterization,
  - Accommodations for latex allergy/precautions (e.g., gym, science classes, art erasers, etc.),
  - Mobility accommodations to maintain safety in the hallways, and in less structured group activities.

504 vs. IEP Education Programs

- 504 plans can provide accommodations in the classroom, including preferential seating, support with organization, and extended time.
- IEPs are necessary when educational curriculums need to be altered, such as introducing a new curriculum for math, slowing presentation of material, or providing more substantial repetition of material.
- Specialized therapies, such as Occupational, Physical, and Speech and language therapy, are often provided through IEPs.

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Adaptive skills

Self Care Skills

- Self care skills include tasks such as dressing, morning and bedtime routines, and toileting.
- For children who catheterize, learning the routine and keeping track of cathing schedules, as well as managing/ ordering supplies, can be very difficult.
- Putting on orthotics can affect their ability to put on and remove shoes.
- Depending upon mobility levels, changing clothing can also be more difficult.
- These skills are essential over the long term to maintain safety and allow for independence.

Community Navigation

- Concrete reasoning and struggles with effective and efficient problem solving can affect independence in the community.
- Having difficulties effectively communicating what you need can affect interactions in the community.
- Physical navigation can also result in issues, particularly in accessing public transportation.
- Due to these issues with navigation, we can often times diminish opportunities to practice in the community.

Home Care Skills

- Home care skills are highly dependent upon sequencing, multitasking, and prioritizing.
- Some safety issues are important to consider, such as accessing cook tops. However, it is essential to not "put off" learning these skills, as children can require additional repetition and support to learn skills.
- Most straightening and organization tasks, such as picking up a bedroom or organizing a closet, require strong executive skills (e.g., prioritizing, sequencing).
- It can be helpful to have multistep processes listed.