

Spina Bifida Association Clinical Care
Meeting 2026

Neuropsychology and Adult Issues / Challenges

Presented by:

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children'shealth[?]

Disclosures

Dr. Costello does not have any disclosures.

Dr. MacDonald Wer does not have any disclosures.



Objectives

1. Characterize the “typical” neuropsychological profile in adult patients with Spina Bifida (SB).
2. Identify how neuropsychologists gauge “transition readiness” in adolescents and young adults who are preparing to transition to adulthood.
3. Describe how to best support adult patients with SB during transition and beyond.



Profile in Adulthood

- **Core Impairments:** Deficits in working memory, inhibitory control, and cognitive flexibility.
- **Severity Predictors:** Presence of hydrocephalus and history of shunt revisions significantly worsen outcomes.
- **Cognitive Trajectory:** Deficits are persistent across the lifespan but follow a parallel path to typical aging.
- **Real-World Impact:** Impairments directly limit functional independence and everyday self-management.



Memory Profile & Clinical Care

Memory Impairments

- Childhood Persistence: Memory deficits identified in youth remain stable into adulthood.
- Structural Correlates: Reduced hippocampal volume correlates with episodic and prospective memory loss.
- Prospective Memory: Key mediator between brain structure and functional independence.

Clinical Implications

- Rehabilitation: Goal Management Training (GMT) effectively ameliorates congenital deficits.
- Neuropsychology: Routine assessment is critical to optimize medical adherence and self-care.
- Longevity: No current evidence supports accelerated cognitive aging in the SBM population.

Neuropsychology's Role

- Evaluating neurocognitive profile
- Tailoring teaching of self-care routines
- Informing school supports and accommodations
- Holistic picture: socioemotional status, family systems, resources and barriers to care
- Culturally-informed, values-based definition of independence
- **Gauging transition readiness**





Standards of Care

The Spina Bifida and Hydrocephalus Neuropsychology Research Consortium:
Zabel et al., 2025



Universal Care

Core Care

Optimal Care



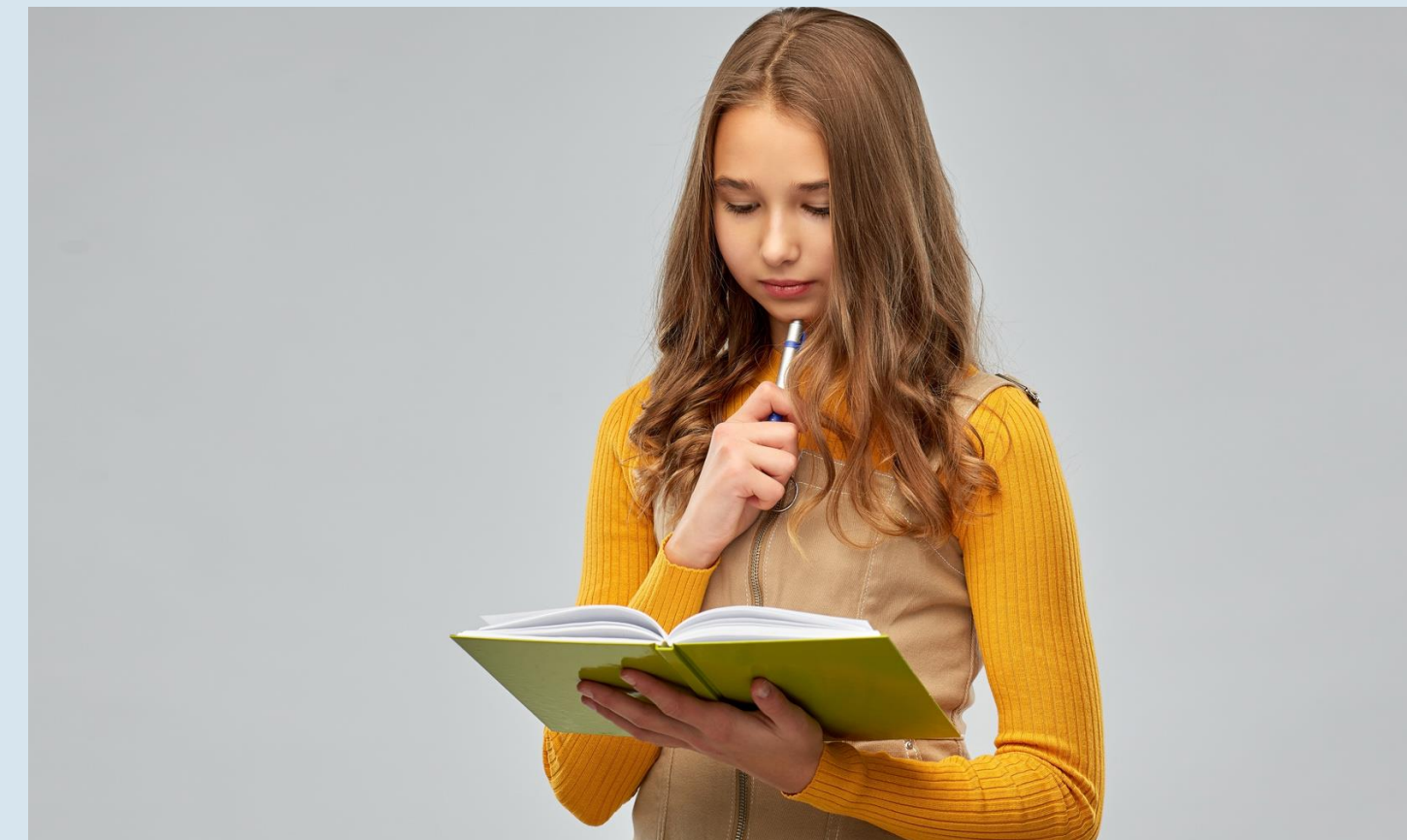
Neuropsychological Profile

With variability based on...

Verbal vs. Nonverbal thinking and reasoning

“Assembled” vs. “Associative” skills

Attention and Executive Functioning





Executive Functioning

What is it, and why does it matter?



“The patient has demonstrated a willingness to stay dry with regular self-cathing and the ability to perform the routine in clinic...”

“My teenager has always been a high achiever in advanced classes, but lately his grades have significantly declined...”

“The family is doing everything for the patient; I’m concerned he’s not on track for independent living.”





Executive Functioning

How do we measure it?



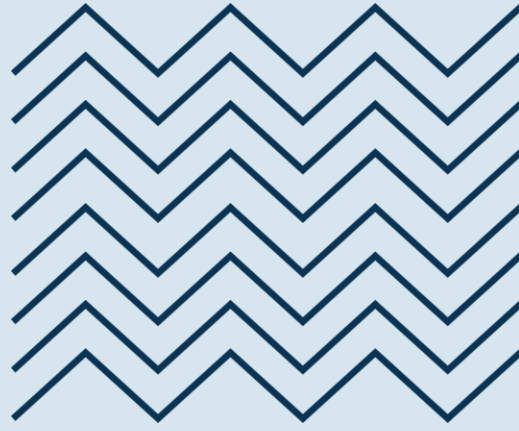
Standardized testing: looking
at impulse inhibition, set-
shifting, cognitive flexibility

Standardized questionnaires:
completed by caregiver
informant, patient

Clinical interview: with a
parent, family member, or
spouse; with patient



Predictors of “Degree” of Independence in Adults



IMPORTANTLY:
QOL and “independence”
should be defined by the
patient and their family.



Medical Comorbidities

Executive Functioning

Activities of Daily Living: CLC

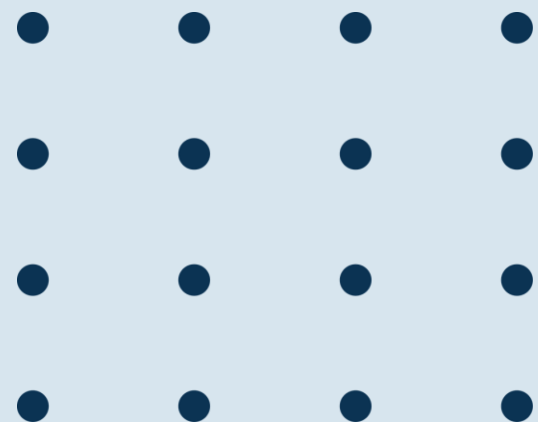
Goal Management Training



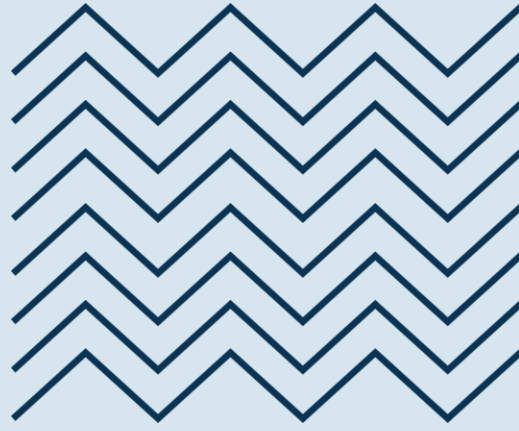
Can executive functions
be improved?



Do the benefits of
executive functioning
coaching generalize to
everyday life?



The Aging Brain in SB



**NO evidence for
accelerated cognitive
aging**

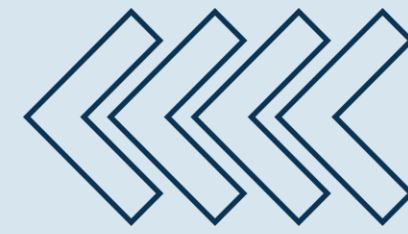
**Stability of any cognitive
difficulties present in
childhood**



Research is limited, but attention and executive functioning difficulties appear to persist; importantly, there is no evidence for accelerated aging.

Common comorbidities (like hydrocephalus or corpus callosum abnormalities) can play a significant role in the overall neurocognitive profile in adults.

Common Barriers in the Transition to Adult Care



- As compared to pediatric care, adult care typically requires more self-initiating, planning, and management (fewer reminders)



- Adults are less likely to have access to a multidisciplinary clinic
- Patients often report difficulty identifying individual adult providers to take over their care



Culturally-Informed, Values-Based Care

Keeping patients at the center of treatment

| The Four Pillars of Care



Collaborative Goals

Aligning clinical management with personal identity and specific life aspirations like employment or family.



Community Integration

Respecting interdependent family structures and cultural definitions of "independence."



Health Equity

Proactively addressing barriers, social disparities, and linguistic needs for marginalized populations.



Holistic QoL

Prioritizing social participation, spiritual wellness, and presence in one's own community life.

Culturally-Informed, Values-Based Care

Keeping patients at the center of treatment

Shifting the Clinical Paradigm

DIMENSION	CLINICAL-ONLY APPROACH	VALUES-BASED CARE
Primary Goal	Clinical Stability (e.g. Skin Health)	Functional Participation in Life
Communication	Directives & Medical Jargon	Shared Decision-Making (The "Why")
Independence	Living alone / Solo management	Autonomy within cultural context
Compliance	"Patient failed the medical plan"	"The plan failed to align with values"



Conclusion

- **Cognitively:** patients with SB have a wide range of intellectual abilities
- **Executive functioning** difficulties can make it challenging for individuals to demonstrate their true potential
- **Support** patients by identifying cognitive strengths and weaknesses early, monitoring over time, and **intervening** with compensatory strategies as appropriate
- **Involve** patients and their families when defining goals for independence

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