CLINICAL PRIORITIES TO IMPROVE THE NEUROPSYCHOLOGICAL CARE OF INDIVIDUALS WITH SPINA BIFIDA: A CONSENSUS STATEMENT OF THE SPINA BIFIDA ASSOCIATION AND THE SPINA BIFIDA AND HYDROCEPHALUS NEUROPSYCHOLOGY COLLABORATIVE

Jennifer Turek Queally, PhD

Veronica Bordes Edgar, PhD, ABPP

Spina Bifida Clinical Care Meeting

LEARNING OBJECTIVES

1. Participants will be able to discuss what a neuropsychological evaluation is and what it can offer.
2. Participants will be able to list the 3 levels of the UCO Care Delivery Model.
3. Participants will be able to describe barriers and opportunities for optimal care pathways.

How many of you have referred a patient for a neuropsychological evaluation?

How many are aware referrals are sent but don't actually do the referring?

Do you get information back to the clinic?

Have you ever sent a specific question for the referral?

DO YOU KNOW WHAT NEUROPSYCHOLOGY IS?

WHAT IS NEUROPSYCHOLOGY?

- Neuropsychologists are licensed psychologists
- They have additional training in brain development and brain/behavior relationships
- The goal is to evaluate a cognitive profile and relate it to:
  - Similarly aged typically developing/healthy individuals
  - Others with similar medical histories
  - Others with similar medical treatment histories
  - Their prior profile to assess for rate of progress

https://theaacn.org/

WHAT IS NEUROPSYCHOLOGY?

Neuropsychologists help families, teachers, and physicians to understand:

- How changes in brain may relate to changes in behavior
- How an individual learns best
- Why someone is demonstrating certain behaviors
- The etiology of changes in behavior
- The prognosis and potential for patients

HOW IS PEDIATRIC NEUROPSYCHOLOGY A BIT DIFFERENT?

Neuropsychologists tend to specialize…many in learning disabilities, psychiatric or behavioral health conditions, and sometimes specific age ranges

Some neuropsychologists specialize in medical conditions- changes in brain development that are secondary to either neurological conditions or the necessary treatments (e.g., chemotherapy, neurosurgery)

While most can work with a variety of medical conditions, many medical populations have teams of neuropsychologists (e.g., oncology, epilepsy)

WHAT PEDIATRIC NEUROPSYCHOLOGY IS OFTEN NOT

Many neuropsychologists working with patients who have spina bifida are hospital based pediatric neuropsychology

While all psychologists have training in psychotherapy, many do not provide psychotherapy to the patients that we evaluate

Those of us working in hospital systems often don't have the ability to go with families to IEP meetings (whereas a private practitioner might)

WHAT DO EVALUATIONS MEASURE?

Neuropsychological assessments are comprehensive and designed to assess for challenges we expect to see given

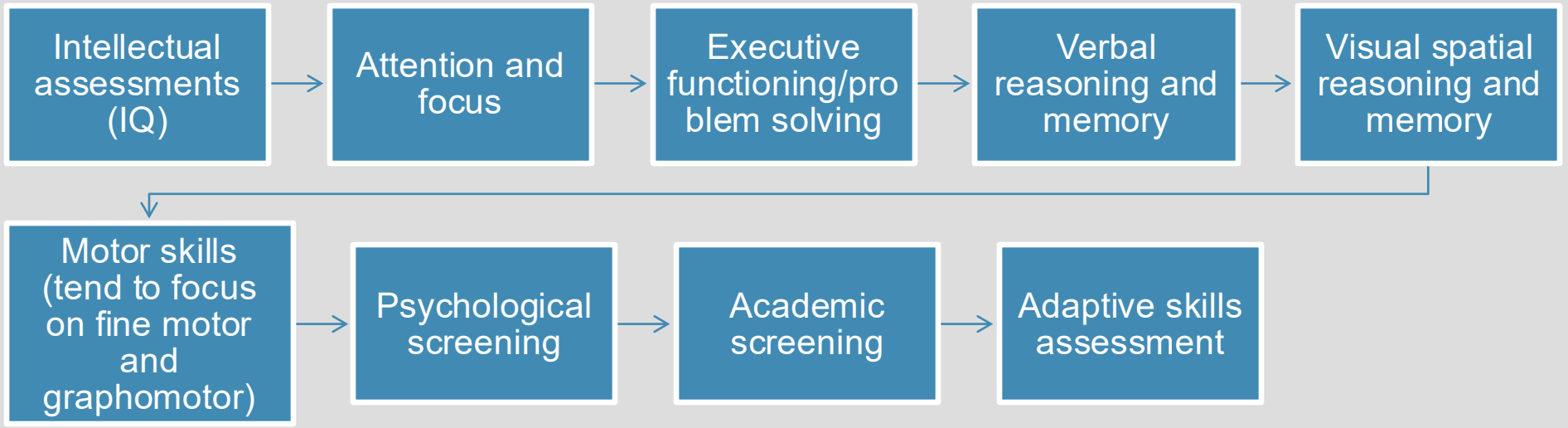
Medical history

Medical treatment history

Family history

Lived experiences

WHAT SPECIFIC DOMAINS ARE MEASURED?



PURPOSE OF THE CONSENSUS STATEMENT

BRIDGE THE GAP BETWEEN 2020 SBA GUIDELINES AND ACTUAL CLINICAL PRACTICE.

PROPOSE ACTIONABLE METHODS TO EXPAND HIGH-QUALITY CARE ACCESS.

ESTABLISH A UNIFIED VOICE FOR NEUROPSYCHOLOGICAL STANDARDS IN SB.

BARRIERS TO CARE

Limited specialized neuropsychologists in the U.S.

Traditional "day-long" assessment models are often inaccessible.

Geographical and socioeconomic hurdles for many families.

SB AS A NEURODEVELOPMENTAL CONDITION

SB INVOLVES COMPLEX BRAIN-BEHAVIOR INTERACTIONS (E.G., CHIARI II MALFORMATION, HYDROCEPHALUS).

IMPACTS COGNITIVE, ADAPTIVE, AND SOCIAL-EMOTIONAL SYSTEMS.

REQUIRES SPECIALIZED, LIFELONG MONITORING.

SPINA BIFIDA AND HYDROCEPHALUS NEUROPSYCHOLOGY COLLABORATIVE

Formed by a small group of neuropsychologists.

Includes pediatric and lifespan neuropsychologists from major medical centers.

Voluntary assembly dedicated to improving patient outcomes.

METHODOLOGY: THE EXPERT CONVENING

Two rounds of data/information acquisition in early 2023.

Formal convening at the Fourth World Congress on Spina Bifida Research and Care.

Collaborative consensus-building process.

APPROVAL AND OFFICIAL POSITION

Officially approved by the Spina Bifida Association (SBA) Professional Advisory Committee (PAC).

Serves as a position paper to guide national clinical standards.

THE "UCO" CARE DELIVERY MODEL

Universal (U): General information and community-based resources.

Core (C): Specialized outpatient assessment and consultation.

Optimal (O): Integrated multidisciplinary medical team care.

LEVEL 1: UNIVERSAL CARE OBJECTIVES

Ensure a baseline level of care for all patients.

Independent of direct proximity to a neuropsychologist.

Focus on empowerment through information.

UNIVERSAL CARE: EARLY SCREENING

Monitoring	Monitoring early developmental milestones.
Utilizing	Utilizing community-based tools (e.g., ASQ-3).
Identifying	Identifying "red flags" for early intervention.

UNIVERSAL CARE: PARENT EDUCATION

- Support for "Play and Learning Strategies" (PALS).
- Addressing medical traumatic stress and family adjustment.
- Empowering parents as advocates for their child.

UNIVERSAL CARE: SCHOOL RESOURCES

Educating educators on the "SB Cognitive Phenotype."

Identifying specific risks in reading comprehension and math.

Sharing SBA "Fact Sheets" with school teams.

UNIVERSAL CARE: PUBLIC/FEDERAL SYSTEMS

Guidance on IEPs and 504 plans.

Assistance with SSI (Supplemental Security Income) and state waivers.

Navigating Vocational Rehabilitation services.

LEVEL 2: CORE CARE DEFINITION

Direct neuropsychological services provided in outpatient settings.

Expands care focus to preschoolers and transition-aged adults.

Targeted assessments based on specific referral questions.

CORE CARE: EARLY CHILDHOOD PRIORITIES

Establishing	Monitoring	Screening
Establishing cognitive baselines.	Monitoring for shunt-related cognitive shifts.	Screening for co-occurring conditions (ADHD/Autism).

CORE CARE: SCHOOL-AGED EVALUATION

Assessing IQ, memory, and academic achievement.

Focusing on executive functions (planning, organization).

Supporting social independence and peer relationships.

CORE CARE: TRANSITION PLANNING

Evaluations for post-secondary education or employment.

Determining the need for supported decision-making or guardianship.

Preparing for the "hand-off" to adult medical systems.

CORE CARE: ADULT FUNCTIONING

Prioritizing functional skills: math calculation and reading for life tasks.

Adaptive functioning and medical self-management.

Maintaining cognitive health into middle and late adulthood.

CULTURAL AND LINGUISTIC COMPETENCE

Developing	Using	Addressing
• Developing resources specifically for Hispanic/Latinx communities (high SB prevalence).	• Using bilingual assessment tools where available.	• Addressing social determinants of health (SDOH).

LEVEL 3: OPTIMAL CARE DEFINITION

"Gold Standard" care: Neuropsychologist integrated into the SB clinic.

Real-time collaboration with neurosurgery, urology, and orthopedics.

Seamless communication between medical and cognitive specialties.

OPTIMAL CARE: STANDARDIZED PATHWAYS

DEVELOPING "CLINICAL PATHWAYS" FOR NEUROCOGNITIVE MONITORING.

BRIEF, TARGETED SCREENINGS DURING ROUTINE MEDICAL VISITS.

REDUCING THE BURDEN OF SCHEDULING SEPARATE TESTING APPOINTMENTS.

INTERPROFESSIONAL BENEFITS

- Providing immediate feedback to the medical team on a patient's cognitive capacity.
- Identifying how cognitive deficits might hinder medical compliance (e.g., catheterization).

DATA CAPTURE AND QI

- Using standardized data systems (e.g., Epic flowsheets).
- Facilitating Quality Improvement (QI) projects across multiple centers.
- Contributing to a national registry for SB outcomes.

WORKFORCE AND ACCESS CHALLENGES

- Need for more training programs focused on SB.
- Addressing the scarcity of adult-focused neuropsychologists.
- Leveraging telehealth to reach rural or underserved areas.

ASSESSMENT LIMITATIONS

Commercial tests often miss nuances of the SB phenotype.

Need for specialized tools to measure "assembled processing."

Moving beyond "global" scores to specific functional deficits.

THE DELPHI CONSENSUS PROCESS

A proposed systematic method to finalize assessment "core batteries."

Identifying which domains (e.g., attention, memory) are most critical to track.

INNOVATION IN TELEHEALTH

- Utilizing remote platforms for cognitive screening.
- Navigating interstate licensure (PSYPACT) to expand reach.
- Ensuring digital equity for families without high-speed internet.

SUMMARY OF STRATEGIC RECOMMENDATIONS

- Implement the UCO model to maximize existing resources.
- Prioritize early education and transition planning.
- Integrate neuropsychology into multidisciplinary clinics.

FINAL TAKEAWAY

Improving care doesn't always mean "more testing"; it means more *accessible* and *integrated* care.

Empowerment of the family and community is the first step toward better outcomes.

SPINA BIFIDA AND HYDROCEPHALUS NEUROPSYCHOLOGY COLLABORATIVE

- Current mission statement: **To develop and expand the workforce of neuropsychologists working with individuals with hydrocephalus and spina bifida by increasing access to neuropsychological care, advancing patient-oriented research, supporting advocacy efforts, promoting standards of care, and fostering collaboration, shared practice, and clinical guidance to improve outcomes across the lifespan.**

- https://www.sbhnc.org/

SPINA BIFIDA AND HYDROCEPHALUS NEUROPSYCHOLOGY COLLABORATIVE

Past Chair- Amy Hefflefinger (MCW)
Current Chair- Jennifer Queally (BCH)
Secretary- Jenn Koop (MCW)
SBA PAC representative – Camille Wilson (Nationwide)
HA representative- Jennifer Queally (MCW)

Research/Dissemination Committee Andy Zabel (KKI)

- Delphi Group- Yuri Shishido (CHOA)
- Database minders- Amy Hefflefinger (MCW)
- Education- Laura K. Winstone-Weide (PCH)
- Website/Communications- Tish MacDonald Wer (UTSW)

Clinical Care Committee- Veronica Bordes Edgar (UTSW)

- Cultural Considerations- Liz Jordan (Lurie)
- Multidisciplinary Care- Camille Wilson (Nationwide)
- Infants/Toddlers Care- Jasmine Hammer (TX Scottish Rite)
- School Age Care- Brian Shields (Penn State)
- Transition to Adulthood Care- Jennifer Queally (BCH)
- Adult Care- Caty Stephen (KKI)

THE CLINICAL NEUROPSYCHOLOGIST
https://doi.org/10.1080/13854046.2025.2566208

Routledge
Taylor & Francis Group

Clinical priorities to improve the neuropsychological care of individuals with Spina Bifida: A consensus statement of the Spina Bifida Association and the Spina Bifida and Hydrocephalus Neuropsychology Collaborative

T. Andrew Zabel[a], D. J. Bernat[b], Rosalia Costello[c*], Veronica Bordes Edgar[d], Amy K. Heffelfinger[e], Lizabeth L. Jordan[f], Jennifer I. Koop[e], Kara Leiser[g], Beatriz MacDonald[d], Lisa Stanford[h], Catherine Stephan[a], Judy Thibadeau[i], Camille Wilson[j] and Jennifer T. Queally[k]

[a]Kennedy Krieger Institute, Baltimore, MD; [b]WVU Medicine Rockefeller Neuroscience Institute, Morgantown, WV; [c]Texas Children's Hospital; [d]University of Texas-Southwestern Medical Center, Dallas, TX; [e]Children's Wisconsin, Milwaukee, WI; [f]Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL; [g]Gillette Children's, St. Paul, USA; [h]University of Pittsburg Medical Center, Pittsburgh, PA; [i]Spina Bifida Association, Arlington, VA; [j]Nationwide Children's Hospital, Columbus, OH; [k]Boston Children's Hospital, Boston, MA

SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Neuropsychology

Workgroup Members: Jennifer Turek Queally, PhD (Chair); Marcia A. Barnes, PhD; Heidi A. Castillo, MD; Jonathan Castillo, MD, MPH; Jack M. Fletcher, PhD, ABPP (ABCN)

REFERENCES & Q&A