

# How to Integrate Neuropsychology into your Spina Bifida Clinic

Jennifer T. Queally, PhD

Pediatric Neuropsychologist

Neuropsychology Program and Center for Spina Bifida

Boston Children's Hospital

Assistant Professor of Psychology in the Department of Psychiatry



**Boston Children's**

Where the world comes for answers



# What is neuropsychology?



# Do you know what neuropsychology is?

- Do you think that your patients are evaluated by a neuropsychologist?
- How many of you have referred a patient for a neuropsychological evaluation?
- Have you every sent a specific question for the referral?



# What is neuropsychology?

- Pediatric neuropsychologists are licensed psychologists
- They have training in both clinical psychology and neuropsychology
- They have special training in how the brain develops
- They use this training to evaluate and help manage children with brain disorders
- Such disorders may involve brain injury, medical disease, or developmental problems

<https://theaacn.org/>

4



# What is neuropsychology?

Pediatric neuropsychologists help parents, teachers, and physicians to:

- Understand how problems with the brain may relate to problems seen at school, home, or with peers
- Understand how a child learns best
- Understand why a child may have behavior problems
- Help a child deal with thinking or behavior problems
- Identify neurological or psychiatric problems
- Help match expectations to a child's specific strengths and weaknesses
- Work with other doctors and teachers to develop the best treatment and school plan for a child

<https://theaacn.org/>

5



# How is pediatric neuropsychology a bit different?

- Neuropsychologists tend to specialize in patient populations
- There are specific neuropsychologists that work with learning disabilities, psychiatric or behavioral health conditions, and sometimes specific age ranges
- There is also group of neuropsychologists that 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 pediatric neuropsychologists can work with a variety of medical conditions, they often specialize



# What pediatric neuropsychology is often not

Many neuropsychologists working with patients who have spina bifida are hospital based pediatric neuropsychology. Therefore, it is appropriate to ask these questions of clinicians working with your patients.

- 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 may)
- Given our training in medical conditions, we often don't focus on autism or mental/behavioral health disorders; we can often diagnose or refer patients, but if this is your primary concern, there are often more appropriate referrals
- Other patients who may be seen in clinic (e.g., spinal tumors, spinal trauma) due to similar medical needs, may have a more appropriate neuropsychology referral

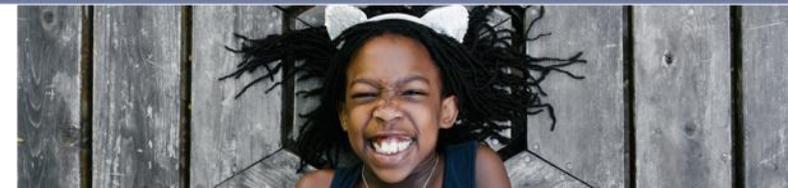


# What do evaluations measure?

- Neuropsychological assessments are comprehensive and designed to assess for challenges we expect to see given the medical history as well as family history and lived experiences
- They typically include:
  - Intellectual assessments (IQ)
  - Attention and focus
  - Executive functioning/problem solving
  - Verbal reasoning and memory
  - Visual spatial reasoning and memory
  - Motor skills (tend to focus on fine motor and graphomotor)
  - Psychological screening
  - Academic screening
  - Adaptive skills assessment



# Traditional use of Neuropsychology



# Referring out for an assessment

- A school age child presents with new challenges or struggles to the clinic
- The patient is referred to an outside clinician for an evaluation
- Patient and family receive information and a report
- Strategies are implemented in day to day life

Best case:

- Report gets back to the clinic
- Information on medication or other major recommendations is shared with providers
- IQ and adaptive scores are entered into the CDC registry



# How are neuropsychological assessments used?

Children are fundamentally different from adults;  
they are not born with full skill sets.

Given these skills develop over time, constant monitoring is essential to ensure that expected skills do develop at the rate and skill level expected -given the child's medical history and neuropsychological profile.



# How are neuropsychological assessments used?

Full neuropsychological evaluations are able to:

- Document the effects of changes in brain development (malformations, migrational disorders, or structural changes)
- Assess progress and development following intervention
- Evaluate developmental progress over time
- Assess for a change/loss of skills following a medical emergency or treatment/ intervention
- Help to differentiate between English as a second language status and underlying cognitive functioning challenges or between cognitive and social emotional challenges



# Specifically for Spina Bifida

- Our measures are reliable and sensitive enough to be repeated every 6 months for children who are being closely monitored
- We can easily assess for expected developmental progress and note changes in profiles
- Having a specialist who knows spina bifida makes a difference in understanding test findings
- school evaluations are often focused only on reading and math
- Sometimes neuropsychologists with different backgrounds/training do not know what to look for



# When are patients typically seen?

Neuropsychology covers the entire lifespan; your pediatric neuropsychologist likely works with children from toddlers through early 20s

- Infants/toddlers (0-3): neurodevelopmental assessments to identify emerging areas of deficits and ensure early intervention/birth to 3 services are in place; evaluating the onset of skills in motor and communication domains
- Early childhood(3-6): Following the transition into preschool (and ensuring eligibility); monitoring early academic skills and automaticity with early number and letter learning; focus on attention and self regulation skills
- Middle childhood (6-12): Ongoing monitoring of academic progress, particularly around the application of learned concepts; focused assessment of attention, executive functioning, coordinated upper limb, and memory domains, as well as adaptive skill acquisition



# When are patients typically seen?

Neuropsychology covers the entire lifespan; your pediatric neuropsychologist likely works with children from toddlers through early 20s

- Adolescence (13-17): Careful attention to the application of learned concepts and abstract reasoning; evaluation of social skills and level of social engagement; work on the creation of transition plans in the hospital and educational settings; consider documenting problem solving and decision making skills in anticipation of potential guardianship needs; monitoring compliance and beginning stages of engagement with the medical system
- Adults (18+): Consideration of post school plans- ranging from college accommodations to support around independent functioning; monitoring of compliance and engagement with the medical setting as an adult; recommendations focused on independent living; may not need follow up for multiple years at a time



# Common reasons for a more urgent evaluation:

- Parents are reporting “memory” or “attention” problems that may reflect a change in cognitive functioning; are these pre-existing or a failure of a system to develop as expected
- Recent neurosurgery, shunt malfunction, or reported change in functioning
- For slowly blocking shunts, we will often have parents report a change in learning/emotional status; this can often be documented on neuropsychological measures as a plateau or unexpected loss of skills
- For emerging syrinxes, we will often have parents report a change in fine motor skills; this can often be documented on neuropsychological measures as slowed fine motor skills and more impaired graphomotor production



# Bilingual populations need evaluations too

- Children who are learning English as a second language are often inappropriately labeled at school as just having ELL concerns and a physical disability
- A thorough neuropsychological assessment, with a bilingual neuropsychologist or even the use of an interpreter, can help to identify whether there are underlying cognitive challenges
- These patients are most at risk for not being referred for outside evaluations and being underserved at school
- Their parents often need the most support understanding our school systems, particularly if they have immigrated themselves, as well as our court system (if needed later for guardianship)



# How can we reimagine integration of neuropsychology



**Boston Children's**

Where the world comes for answers



# What we know so far...

## Typical Neuropsychological Profile

- Significant variability in skill levels
- Can be linked to lesion level, shunt status, complications, associated syndromes or constellation disorders
- Profile of strengths and weaknesses is often consistent; placement on curve is not
- Individual assessments are so important



# 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 Areas of Challenge in the Profile

- Information processing (detail focused, vulnerable to load, struggles with multitasking)
- Executive Functioning skills (initiation, engagement/adaptation of problem solving strategies)
- Attention (shifting)
- Visual spatial reasoning (mental rotation or inversion)
- Motor skills (fine and gross)
- Academics, particularly math applications and reading comprehension



# So what does that have to do with medical care?

- Information processing (detail focused, vulnerable to load, struggles with multitasking)
  - Executive Functioning skills (initiation, engagement/adaptation of problem solving strategies)
  - Attention (shifting)
  - Visual spatial reasoning (mental rotation or inversion)
  - Motor skills (fine and gross)
  - Academics, particularly applied math and reading comprehension
- ➔ • Compliance with medical regimens (particularly when multiple steps are involved), following lengthy presentations/explanations, cooking
  - ➔ • Reaching out to medical staff, identifying when a medical concern needs to be addressed, selecting alternate strategies to maintain compliance
  - ➔ • Stopping what you are doing to catheterize or take meds
  - ➔ • Catheterization (especially for girls in a mirror), community navigation
  - ➔ • Mobility, managing medical regimens like bowel plans, taking notes
  - ➔ • Money management and budgeting, following pre-procedure directions or medical recommendations



# So how do we get the information back into the system

- Having a neuropsychologist on staff in the clinic can be an extremely helpful way of integrating this information into clinical recommendations and care
- Neuropsychologists can work directly with families to address areas of concern (e.g., home, school, etc.)
- Neuropsychologists can also consult with colleagues around problematic areas of care
- This can be particularly important around concerns with capacity/adult decision making



# Integrated and patient centered care



**Boston Children's**

Where the world comes for answers



# Information gathering

Neuropsychological assessment typically include 3 to 6 hours of direct assessment of a child, without their parents (while conscious)

- This allows for us to evaluate what children can do independently without parental involvement
- These evaluations often includes direct consultation with schools or at least questionnaires documenting functioning (another location where kids are without their parents)
- It often provides a window into parenting styles and strategies, family dynamics, and other hurdles for compliance and engagement



# Clinical consultations

When you add clinical consultations and follow ups to neuropsychological care (evaluations are typically spaced around 3-4 years apart) it allows for:

- ongoing trouble shooting of preexisting challenges
- ongoing evaluation of problematic areas or emerging concerns
- ongoing feedback into the team about the families compliance with recommendations, understanding of their child's needs and abilities, and needs outside of their medical care
- neuropsychologists to provide information to their colleagues about the patient/families challenges to tailor recommendations
- the early identification of children who will not be able to function independently



# Clinic Roles for Neuropsychology



# What does our clinic look like?

My half time position in the Spina Bifida Center allows for me to complete:

- 15-30 minute clinic consultations with families during our multidisciplinary clinic (virtual and in person)
- 60 minute capacity evaluations with a small team to help with guardianship and consent issues
- Infant and toddler assessments
- Consultations with colleagues through weekly meetings and in the clinic context

I also work half time in our outpatient Neuropsychology Center, where I see (mostly) patients with spina bifida for full evaluations



# Clinic consultations

- 15-30 minute clinic consultations in our multidisciplinary clinic provide families the chance to discuss:
  - Emerging school issues
  - Evaluate progress over the past year
  - Follow up on prior neuropsychological evaluations
  - Planning the timing of the next recommended evaluation
  - Ensuring recommendations were put into place to support progress
  - Guidance around IEP meetings, school transitions, and working with staff
  - Compliance with medical recommendations, troubleshooting noncompliance
  - Focusing on transition readiness and functional independence skill building



## Case example:

- 18 year old male, with significant motor impairment
- Cognitive functioning was in the profound intellectual disability range (no verbal speech)
- Was meeting with the family to discuss guardianship when a urologist entered the visit to provide more information about potential surgical interventions to manage incontinence

Neuropsychologist was able to direct the conversation toward:

- The potential future placement in a residential facility
- Recommendation to decrease the number of times the young adult would have to be disrobed each day
- The young adults inability to assume responsibility of this care over the long term was an important factor
- Can we use a stoma to catheterize him so that he doesn't have to be undressed



## Case example:

- 19 year old female who experienced her fourth bladder rupture
- Met diagnostic criteria for a mild to moderate intellectual disability
- Medical team was ready to transition her to adult care, but she was inconsistent in coming to appointments and did not have a guardian
- Was living with boyfriend at the time
- Prior neuropsychological evaluation reports documented her reading comprehension skills were below a 1<sup>st</sup> grade level, so we were not able to mail a letter



# Case example:

- Morbidly obese, Spanish speaking 20 year old who used a wheelchair for mobility
- The medical team was concerned with her airway, which was compressed when she looked down
- A trach was recommended; the family did not want a trach
- Family met with nutrition multiple times, but the patient continued to gain weight
- I was asked to consult with the ethics team, given the patient's cognitive profile and medical needs
- I completed a full neuropsych to better understand her profile
- Was diagnosed with a moderate intellectual disability
- Following the evaluation, we met together with nutrition to review recommendations
- The patient had followed recommendations; stopped drinking soda (replaced with juice) and eating sweets (replaced with chips); she didn't understand the recommendations
- The patient was given a list of pictures of items she could eat; with basic measurements (smaller than your fist) and she was able to lose enough weight for the team to be happy with her airway



# Infant and toddler assessments

- One of my roles in our spina bifida clinic was designed around careful follow up and monitoring of children who are at risk or who have been recently treated for hydrocephalus
- We also carefully follow other infants/toddlers who are at risk for other reasons
- I complete infant and toddler assessments with children who are typically 6, 12, 18 & 24 months- including the Bayley-3, parent questionnaires, etc.
- This allows for very careful follow up on major milestones, as designed



# Infant and toddler assessments

This **also** allows for:

- A care provider who is focused on development rather than surgical management to meet with families regularly
- Providers to answer routine questions about babies that their PCPs or other care providers may not be helping with (e.g., managing the latex allergy)
- Support engaging early therapy services as well as transitioning into preschool
- Support developing a **parenting mindset** that will benefit their child- how to encourage, set expectations, and scaffold skill building
- It helps to make clinic a place where you go for your whole baby, not just the identification of what is wrong with your baby (medically)



# Assessing functioning

It is imperative that we as care providers...

- evaluate our patients to determine their ability to manage the responsibilities of adulthood
- honestly inform our patients and their families when we have questions about competence/capacity
- Consider formal evaluations to document time sensitive conditions such as an intellectual disability



# Competence vs Capacity

- Competence is a legal state, not a medical one; this refers to the degree of mental soundness necessary to make decisions; all adults are assumed competent unless a court determines they are not (judge's decision)
- Capacity is defined as an individual's ability to make an informed decision (medical provider's decision)

[https://lawprofessors.typepad.com/elder\\_law/2006/01/competence\\_vs\\_c.html](https://lawprofessors.typepad.com/elder_law/2006/01/competence_vs_c.html)



# Transition related visits

- Working with patients at the start of the multidisciplinary clinic to encourage adolescents to speak and adults to allow their adolescents to lead the visits
- Check ins around skill progress over time
- Assessing for ongoing skill goals and other necessary services
- Prepping physicians to engage with the young adult first, reminding them of their profile and strengths/weaknesses
- Working to devise strategies to get adolescents to engage (e.g., reviewing notes in the medical record)



# What should we look for?

- Open, frank conversations with kids and their parents
- Consider whether the difficulties are due to lack of experience or lack of ability
- Consider whether the adolescent's difficulties making decisions is temporary or assumed to be permanent
- Evaluate whether there will be a transient nature to their decision making challenges



How do we get these supports reimbursed?



# How do we get this paid for

Health & Behavior interventions: designed in 30 minute increments, with 15 minute increments added, to address concerns related to their medical conditions

- Individual (96158, 96159)
  - Group (96164, 96165)
  - Family with patient (96167, 96168)
  - Family without patient (96170, 96171)
- 
- This allows for consultation around changes in cognition, a new issue at school or home, analysis of independent functioning, and readiness for transition



# How do we get this paid for

I use interview codes when working with families to understand how kids are doing. These codes require the evaluation of a child/young adult and their mental status.

- Neurobehavioral Status exam, first hour (96116)
- Neurobehavioral Status exam, each additional hour (96121)



# How do we get this paid for

I use psychological and neuropsychological assessment codes to evaluate infants and toddlers, as well as to assess for independent functioning in adolescents.

- Psychological testing by PSYCHOLOGIST, first hour (96130)
- Psychological testing by PSYCHOLOGIST, each additional hour (96131)
- Psychological or Neuropsychological test and scoring, first 30 minutes (96136)
- Psychological or Neuropsychological test and scoring, each additional 30 minutes (96137)



# Summary



**Boston Children's**

Where the world comes for answers



# Neuropsychologists...

- Follow patients throughout the lifespan
- Can be utilized to respond to specific concerns about functioning; the information collated should influence medical care decision making
- Help to bridge gaps between families/patients and the clinical staff to help support communication and comprehension of medical treatment expectations
- Can be instrumental in the transition related process to identify cognitive challenges and craft plans for building skills
- Can take on a variety of roles within the program
- Are able to bill for these services



# We are looking for neuropsychologists

- During the creation of the Spina Bifida guidelines for care, other clinicians were clear it was challenging to find neuropsychological care for their patients
- A small group of my neuropsychology colleagues are working to collect data on the neuropsychologists roles in clinics, as well as access to these services in the community
- We are hoping to reach as many of the clinicians involved in the care of patients with Spina Bifida as possible to complete the survey and to consider working collaboratively on other projects



Thank You

