NETWORKING SESSION RECAP

Transition Assessment Instruments:

Turning Data into Action in Spina Bifida Care

Three validated tools, one shared goal — **TRAQ-SB · AMIS-II · KKIS-SB**

Plenary summary of last night's workshop session

Spina Bifida Association Clinical Care Meeting

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WHY THIS SESSION

Transition doesn't happen by accident

It happens when the right tool is used the right way, at the right time. We focused on three measures and on translating their scores into individualized transition plans.

- What each tool measures, who it was validated for, and the evidence behind it
- How and when to use each — by age, cognitive profile, and clinical presentation
- How to operationalize results into goals, care pathways, and the ITP
- How motivational interviewing builds self-efficacy and mastery
- How to track progress over time for quality improvement and research

THE THROUGH-LINE

A score is not the destination.

Each instrument turns a clinical impression into a measurable, trackable behavior — the starting point for a conversation, a goal, and a plan.

Assess → target → plan → track

AT A GLANCE

Three lenses on one question

TRAQ-SB

Transition Readiness Assessment Questionnaire — SB

"Am I ready?"

MEASURES
Behavior-based readiness, by stage of change

REPORTER
Youth self-report (ages 12–25)

LENS
Intent & momentum toward change

AMIS-II

Adolescent/Young Adult Self-Management & Independence Scale

"What can I actually do?"

MEASURES
Achieved self-management & level of assistance

REPORTER
Youth interview / self-report (18+)

LENS
Actual behavior, condition + daily living

KKIS-SB

Kennedy Krieger Independence Scales — SB Version

"Can I do it on my own?"

MEASURES
Executive components: initiation + prospective memory

REPORTER
Caregiver report (ages 10–29)

LENS
The executive "how" behind the skill

TOOL 1 — READINESS

TRAQ-SB: where is the patient on the change ladder?

Wood, Hopson, Rocque et al. — a spina bifida–specific extension of the TRAQ

WHAT IT IS & HOW IT WORKS

- 12 SB-specific items added to the 20-item TRAQ; captures both general self-management and condition skills (bladder, bowel, skin, shunt).
- Self-administered in 5–10 minutes at a ~5th–6th-grade reading level; free, with 15+ language versions.
- Built on the Stages of Change model — each item scores intent and action from “I don't know how” to “I always do this.”
- The score reflects behavior, not knowledge — and movement up the ladder is the clinical goal.

THE EVIDENCE

α = 0.90

Internal reliability across 90 youth, ages 12–25 (Wood et al., 2019)

↓ 3

Higher scores linked to less urinary & stool incontinence and skin breakdown

IN THE CLINIC

Send before the visit, score by domain, and trend over time. Pair the score with motivational interviewing and patient-chosen goals in the lowest-scoring areas; document with Z71.89 and the ITP.

TOOL 2 — ACHIEVEMENT

AMIS-II: what does the young adult actually do?

Sawin et al.; trajectory evidence from Ridosh et al. (2023)

WHAT IT IS & HOW IT WORKS

- A structured interview (with a parallel self-report, SB-SR) measuring achieved self-management — not the capacity to perform skills.
- 17 items on a 7-point scale, from total assistance (1) to complete independence (7).
- Two subscales: condition self-management (7 items) and independent living self-management (10 items).
- Longitudinal data show self-management rises with age, with growth differing by sex and race/ethnicity — useful for spotting subgroups who need support.

THE EVIDENCE

17

Items across condition and independent-living self-management

18–27

Age range in the trajectory study (99 young adults)

IN THE CLINIC

Use it to quantify how much assistance is still needed in each domain. Re-administering over time reveals whether independence is actually being acquired — or whether a plateau needs intervention.

TOOL 3 — EXECUTIVE CAPACITY

KKIS-SB: can they initiate and remember on their own?

Jacobson, Zabel et al. (2013) — the executive components of self-care

WHAT IT IS & HOW IT WORKS

- A caregiver-report measure (with a self-report version) targeting the executive burden that adaptive scales miss.
- 18 skill items rated Yes / Maybe / No (3 / 2 / 1), focused on timely, independent initiation of self-care.
- Two subscales: initiation of routines and prospective memory — the ability to "remember to remember" a task.
- Validated against the ABAS-II and BRIEF; scores rise with age, and community-living young adults score higher than those still at home.

THE EVIDENCE

α = 0.89

Excellent internal consistency across 100 youth & young adults

10–29

Age span — adolescence through young adulthood

IN THE CLINIC

When a young person knows how but still doesn't do it independently, KKIS-SB tells you why — pinpointing whether to target initiation, cueing/reminders, or prospective-memory supports.

THE BIG PICTURE

Complementary, not competing

Each tool answers a different question, from a different reporter, across overlapping ages. Used together, they triangulate a complete readiness picture.

TRAQ-SB

Am I ready?

Captures: Readiness & intent

Reporter: Youth

Ages: 12–25

AMIS-II

What do I do?

Captures: Achieved behavior

Reporter: Youth

Ages: 18+

KKIS-SB

Can I, alone?

Captures: Executive capacity

Reporter: Caregiver

Ages: 10–29

Together: readiness × achievement × executive capacity — spanning self- and caregiver report from early adolescence into young adulthood. Pick the tool that fits the patient's age and cognitive profile; combine them to see the whole trajectory.

THE WORKFLOW

Turning data into action

The shared clinical pathway demonstrated across all three tools:

1

Assess

Choose the right tool for the patient's age and cognitive profile.

2

Score & trend

Score by domain and track over time — never a single snapshot.

3

Target

Pick patient-driven goals in the lowest-scoring areas.

4

Plan with MI

Use motivational interviewing to build self-efficacy and mastery.

5

Document

Record in the ITP and bill the work (e.g., Z71.89).

6

Follow up

Re-administer; use the data for QI and research.

RECAP

Four things to carry forward

01 Match the tool to the patient

TRAQ-SB for readiness, AMIS-II for achieved self-management, KKIS-SB for the executive 'how' — guided by age and cognitive profile.

02 Trend, don't snapshot

All three are most powerful longitudinally; growth (or a plateau) is the signal that drives intervention.

03 Pair every score with action

Patient-driven goals plus motivational interviewing turn a number into momentum toward independence.

04 Document, bill, and study it

Capture in the ITP, bill transition counseling, and feed the data into quality improvement and research.

THANK YOU

“The assessments are only as good as the connection that is made with the patient/family to help them with their goals”

TRAQ-SB measures readiness · AMIS-II measures achievement · KKIS-SB measures the executive capacity behind it. Together they help us turn assessment data into action.

Questions & discussion