Building an Inter-disciplinary Team for Children with Spina Bifida:

Blending Mental and Medical Health

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The Why

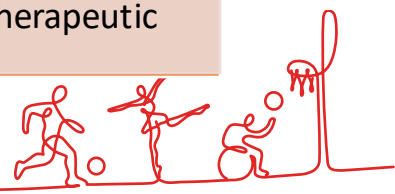
"Why is a team needed?"

Why is blending mental and medical health so crucial for these children?

The situation requires *creative and novel solutions*	Addressing *complex problems*	Would likely NOT be optimally managed by multiple individual interventions.

Spina Bifida care involves management across multiple domains

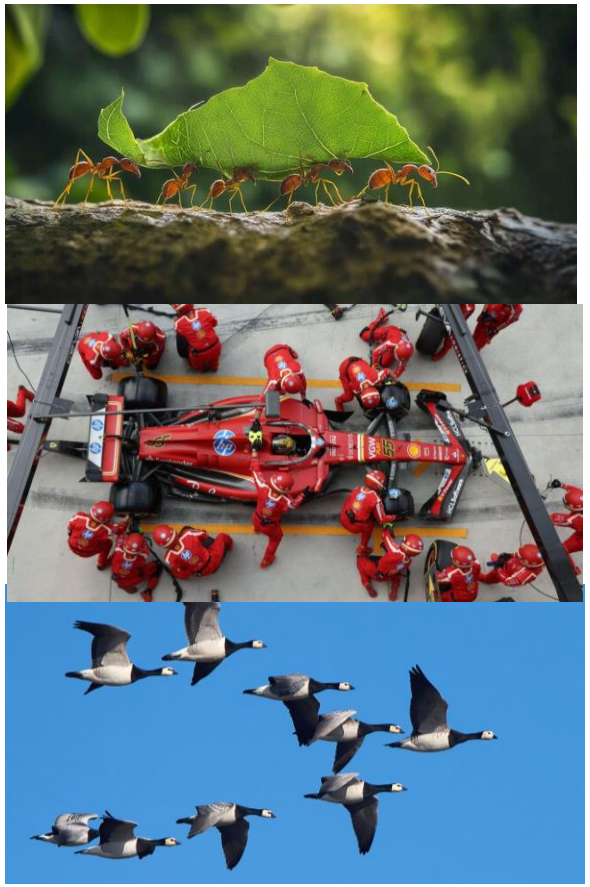
Medical	Neurocognitive	Psychological	Social	Physical/Therapeutic



Value of the Interdisciplinary Approach

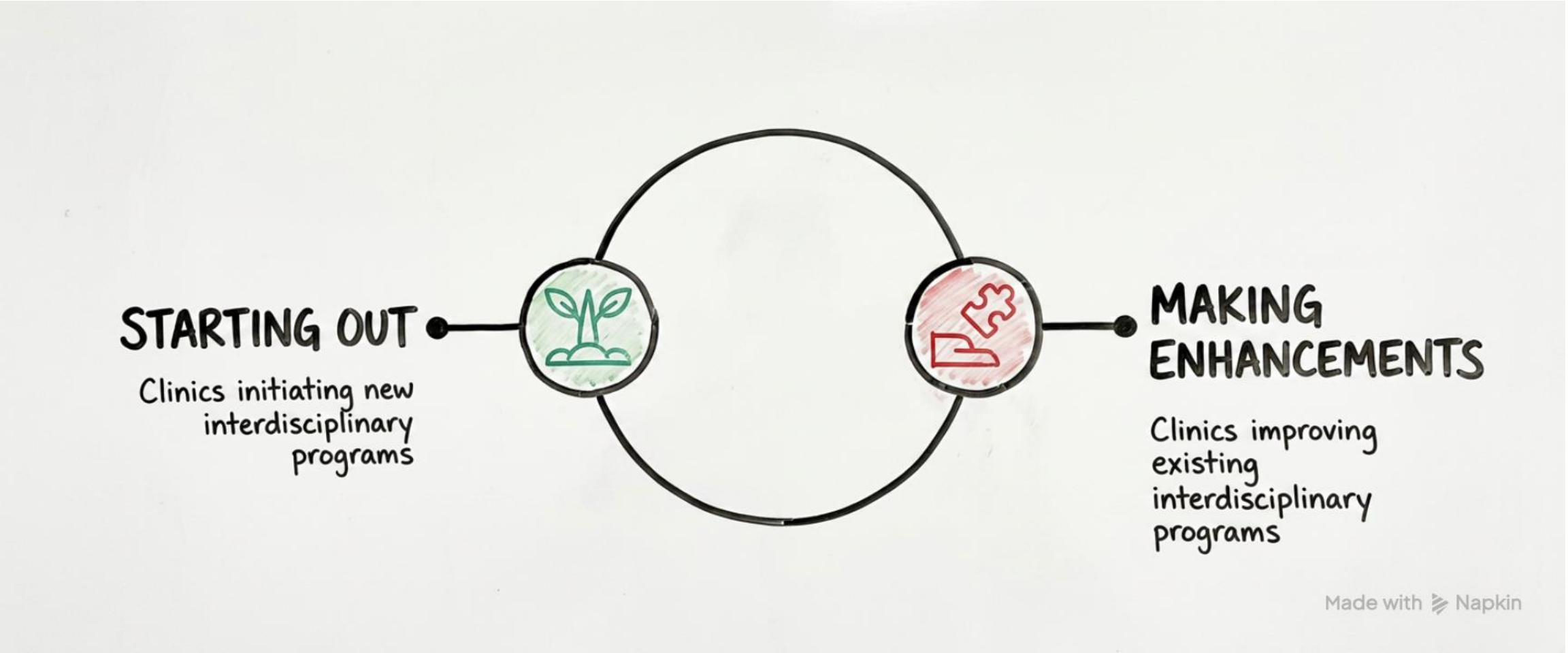
- Inter-disciplinary, collaborative care team models = “best practice”
  - Formally cited by AACAP (The American Academy of Child & Adolescent Psychiatry) as a mandate for comprehensive cross-disciplinary cooperation.
- Avoids fragmentation of care, poor communication and delay of care
- Improves accessibility, shared decision making and buy-in for the treatment plans

Teams take work!

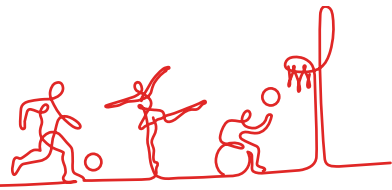


- Teams don’t emerge on their own
- Developing a team requires ***administrative time, resources***, ***space,*** and a method for ***synchronous communication***
- If ineffectively formed, teams can be counter-productive and inefficient

Audience Poll



Building the Team



“Team” – What do you mean?

1. Group of individuals with a **commitment to a shared purpose & presence**
2. Members have both **individual and mutual accountability**
3. **Willingness to sacrifice** some individual goals for the better success of the team’s mission
4. Members come with **diverse perspectives** and **skills** but with **shared values**
5. The group creates **informal or formal ground rules/boundaries**

Elements to Consider

Finding the Right People

- *Shared goals, complementary skillsets and perspectives, talented team members/stakeholders*
- *Don't define/restrict goals and vision before assembling the key members*

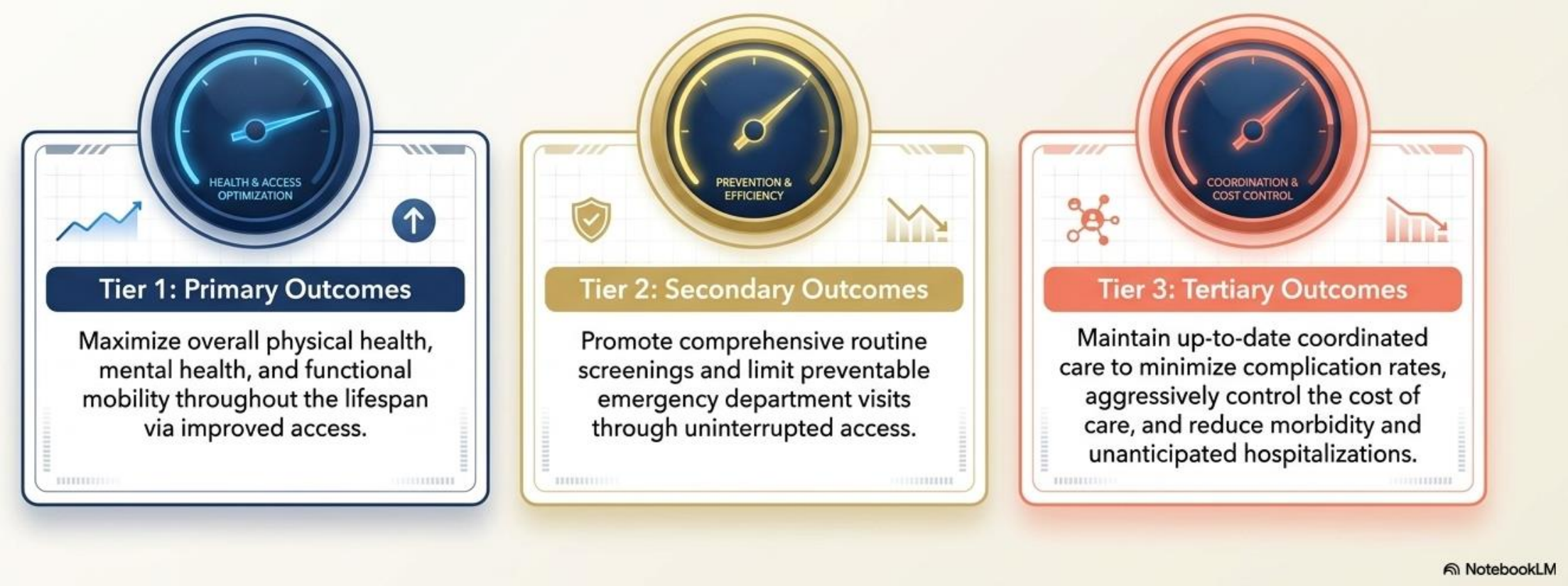
Create a Framework

- *Structure, resources needed, "rules of conduct" and leadership structure*

Define the Collaborative Vision and Mission

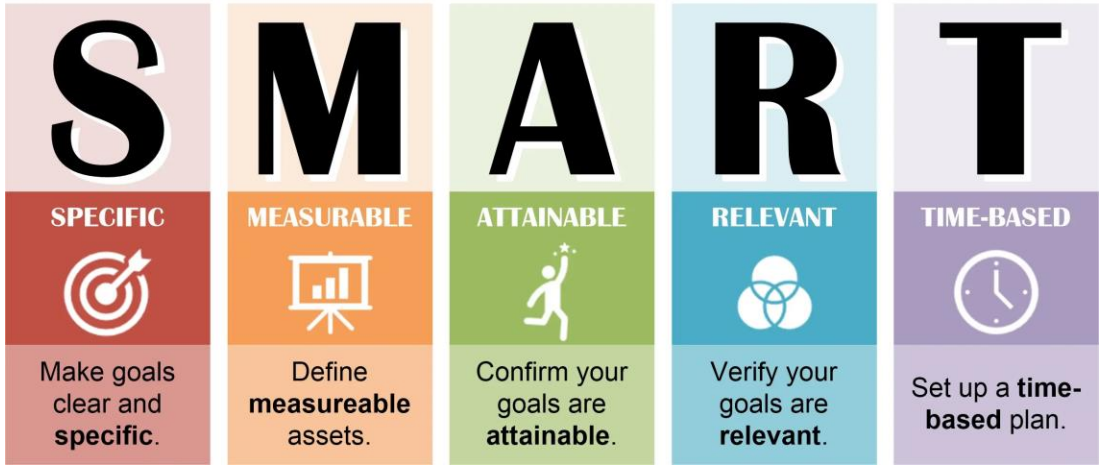
- *<u>Vision:</u> Long term outcome of the team's existence*
- *<u>Mission</u>: Main goal of the team is identified.*
  - ➢ *Broken down into actionable tasks*

Vision: Long Term Outcome of The Team's Existence



SMART goals

- Specific, Measurable, Achievable, Relevant, Timed
- Help guide measurement of outcomes

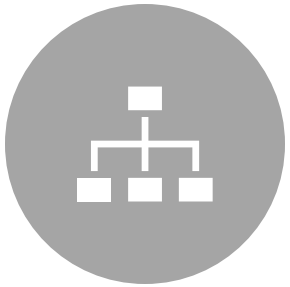


Measuring Outcomes for each Domain

- **Medical/System-Specific Outcomes**
  - Bladder/Bowel Continence and Independence (by a certain age)
  - Shunt Revision
  - Appropriate referrals (Sleep study)
  - Periodicity of routine labs, neuroimaging and follow up appointments
- **Functional/Adaptive Outcomes**
  - Standardized measures (Vineland-3)
  - Measurement of Development/Cognitive Functioning
    - Neurocognitive endpoints/trajectory
- **Mental Health outcomes**
  - Depression and suicide screening
  - Adjustment to disability

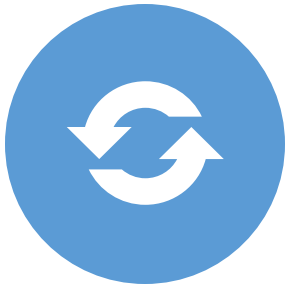
Keys for Success

1. Leadership



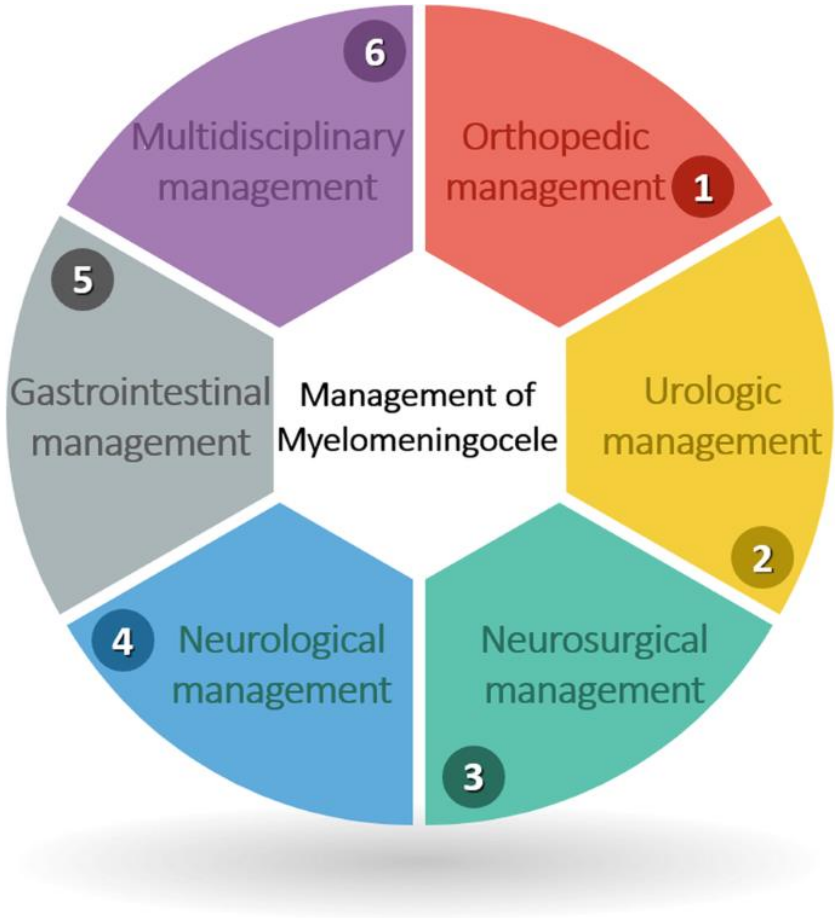
2. Care Coordination

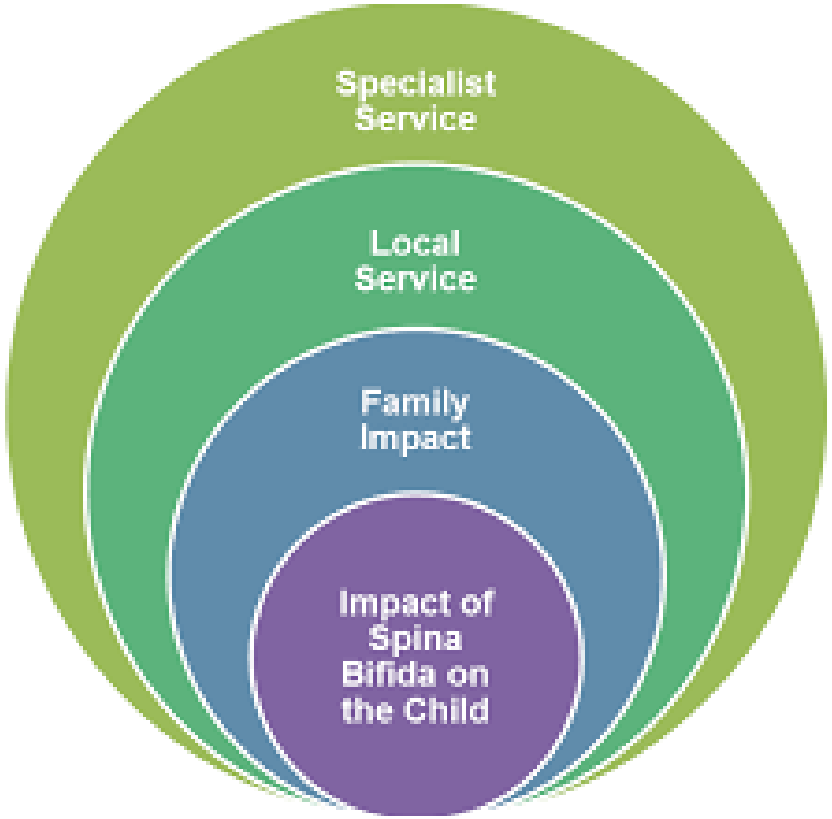
3. Communication



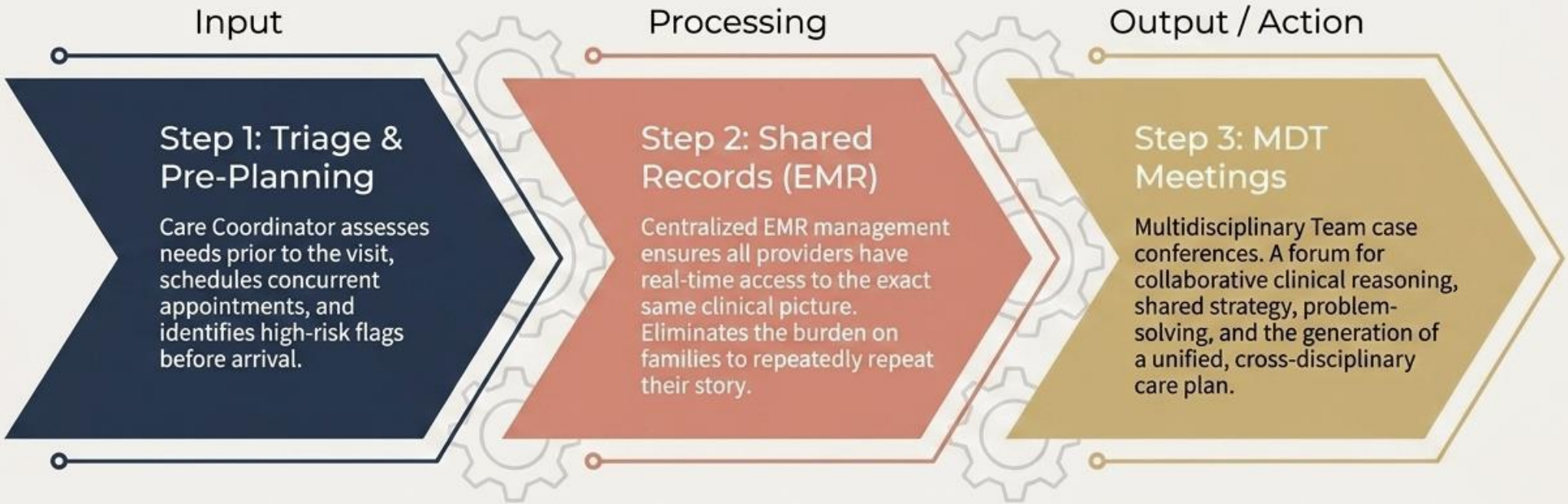
4. Continuous Improvement

Care Coordination of Child with Spina Bifida





Logistics of Collaboration

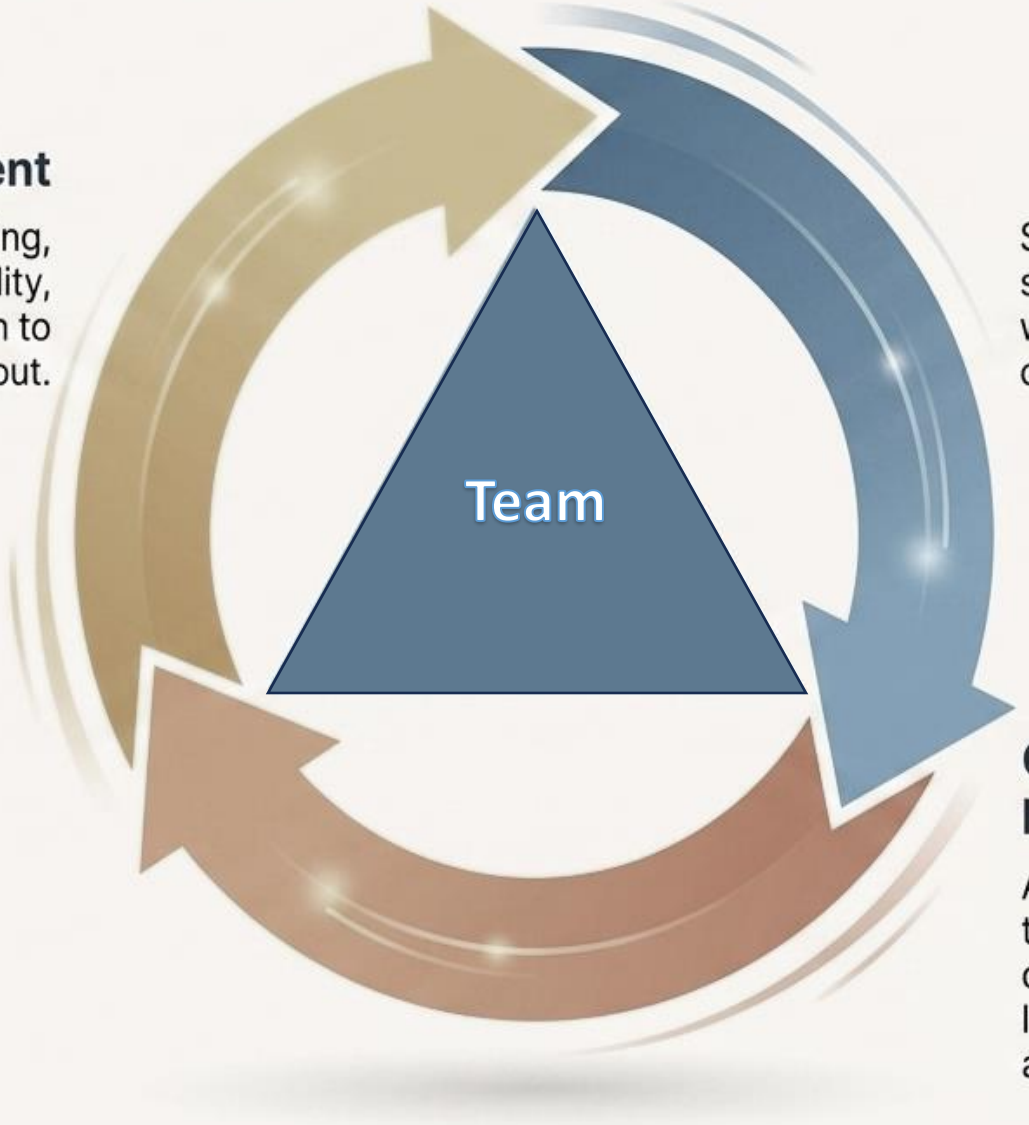


NotebookLM

Sustaining the Team

Individual Fulfillment

Fosters personal learning, enhances individual capability, and ensures staff satisfaction to prevent burnout.



Team Structure

Shared goals, complementary skills, and collective accountability within a supportive organizational context.

Culture of Continuous Improvement

A psychologically safe environment to detect errors early, review operations, and milk experiences for learning without mutual antagonism.

NotebookLM

Continuous Analysis and Improvements

- Consider goals and measurements
- Continue to explore ways to improve the clinic
  - Identified problems that come up
  - Adding relevant team members
    - Neuropsychology, psychology, social work, speech therapy, nutrition/dietary, wound care
  - Need for updated goals
    - Area to intervene
    - Need more data
  - Need for additional care/clinics
    - Transition supports

Case Example

Initiating an Inter-Disciplinary Spina Bifida Program

Case Example:

Initiating an Inter-Disciplinary Spina Bifida Program

Jim Roach, MD
Orthopedist

George Hurt, MD
Urologist

Stephani Brigger, RN
Director, Ambulatory Care

Ken Shapiro, MD
Pedi Neurosurgery

Blanche Carpenter, PT

Richard Adams, MD
DBP

Case Example:

Initiating an Inter-Disciplinary Spina Bifida Program

George Hurt, MD Urologist	"I can fix his bladder; but who is looking at the WHOLE child ?"
Jim Roach, MD Orthopedist	"We need these kids in optimal health to undergo complex spine surgery"
Ken Shapiro, MD Pedi Neurosurgery	"We need help with triage; who really needs to see us sooner than later"
Stephani Brigger, RN Director, Ambulatory Care	Family Centered Care and mental health – missing pieces
Blanche Carpenter, PT	"We know these kids and we need evidence-based medicine"
Richard Adams MD Dev-Beh Peds	How can I help?

Case Example:

Initiating an Inter-Disciplinary Spina Bifida Program

Medical Nutrition	Weight (too much, too little); Bone health; Renal health
Jim Roach, MD Orthopedist	Clinic focus on up-coming surgeries; General wellness from early childhood. Help post-op.
Ken Shapiro, MD Pedi Neurosurgery	Prioritize patients to be seen. Increase communication.
Stephani Brigger, RN Director, Ambulatory Care	Formalize Family Centered Care across all disciplines
Blanche Carpenter, PT	Monitor measurable outcomes. Set measures at certain intervals.

Richard Adams MD
Dev-Beh Peds

Case Example:

Initiating an Inter-Disciplinary Spina Bifida Program

Create the “Spina Bifida Team”

- Meet monthly
- Mission Retreat every ~3-4 years
- Team members from every discipline involved in Spina Bifida Clinic
  - Developmental Disabilities, Urology, Neurosurgery. Orthopedics, Med Nutrition, OT, PT, Orthotics, Social Work, Therapeutic Recreation, Administration, Research Associate
- Over Lunch
  - Education, logistics, problem identification, team building, etc.

Case Example

Routine visit in an interdisciplinary team model

15yo female, Presenting for Routine Follow up

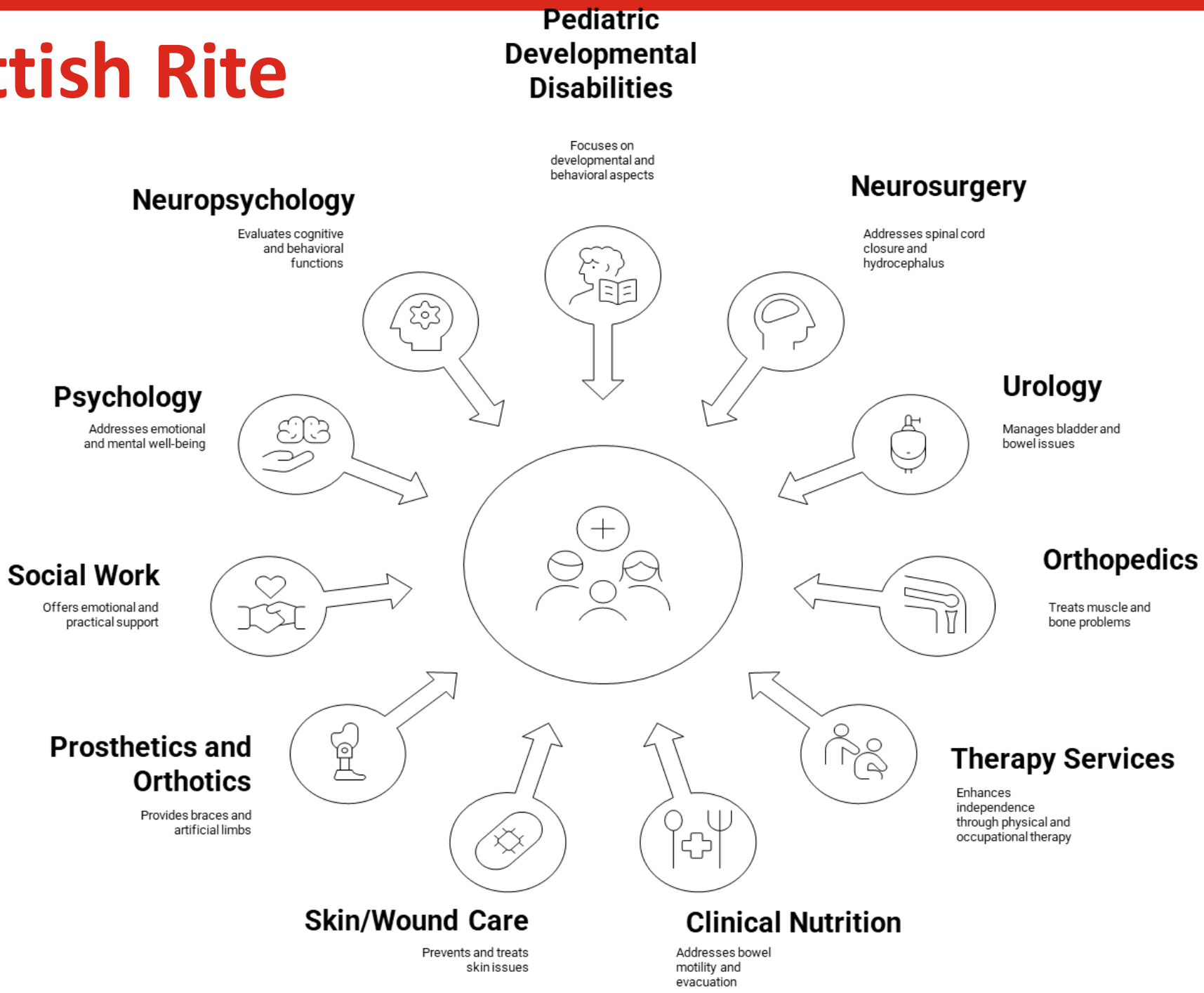
History

- Postnatal closure of myelomeningocele
- Functional level of thoracic spina bifida
- Spinal arachnoid cyst
- Chiari II malformation
- Hydrocephalus, s/p VP shunt
- Neurogenic bowel, ACE (Antegrade Continence Enema) cecostomy
- Neurogenic bladder, clean intermittent catheterization (CIC) through the APV (Appendicovesicostomy)
- Clubfoot, flexion contracture of hip, s/p bilateral foot triple arthrodesis
- History of dysphagia, weight loss, Gtube for perioperitive weight gain
- History of fractures, osteopenia
- Scoliosis, history of halo, s/p anterior spinal fusion s/p posterior spinal fusion
- Anxiety, mild neurocognitive disorder due to spina bifida

Current

- Doing well with the ACE, more independent now
- Applying to attend Camp TLC
- New wheelchair feels uncomfortable
- Needs to change out her button for ACE
- ADHD not diagnosed, but mom advocates for accommodations
- Picky eater, food gets stuck sometimes
- Takes vitamin D as recommended and tums for calcium
- Follow up with Urology planned for same day
- Due for Neurosurgery follow up

SB at Scottish Rite



13-year-old Male

Background information

- Postnatal closure of myelomeningocele
- Hydrocephalus, s/p VP shunt
- Last MRI: Stable
- Neurogenic bowel
- Neurogenic bladder; Vesicostomy
- Bilingual (Spanish/English)
- Special Education -> Other Health Impairment

Day of testing

- Significant bullying
- Depression
- Challenges with adjustment to disability
- Parent disconnect
- Language barrier

13-year-old Male

Individuals with myelomeningocele (spina bifida) can often have difficulties in

- **Visual reasoning/problem-solving**
- **Word retrieval and fluency**
- **Memory retrieval and visual memory**
- **Abstract Verbal Language**
- **Attention**
- **Executive Functioning**
- **Motor functioning** and Fine motor dexterity
- Academic problems in **mathematics**, reading comprehension, and written expression

- Results
  - *IQ: Standard Score of 63*
  - *Adaptive Functioning Below Average*
  - *Visual = Verbal*
  - *Memory area of challenge*
  - *Word retrieval and fluency challenges*
  - *Significant Language Challenges*
  - *Attention/Executive Functioning*
  - *Motor functioning and Fine motor dexterity*
  - *Academic problems in mathematics*
  - *Mood: Adjustment to disability*

Follow-up with the Team

- Discussion with the PSB Physicians and Nurses
- Continued neurocognitive follow-up
- Referral and discussion with Psychology
- Consultation/Discussion with interpreter services
- Follow-up with educational team

Camp TLC

Summer Camp For Kids with Spina Bifida

VOLUNTEERS NEEDED!

LOCATED AT CAMP JOHN MARC

June 6-7, 2026

HOSTED BY: SPINA BIFIDA ASSOCIATION OF NORTH TEXAS

We Need You!

NURSES

We need 25-30 nurses for the week of camp. Duties include:

- Reviews camper medical forms & information prior to camp and helps check campers in at Scottish Rite on Sunday morning
- Administering meds & doing skin checks
- Interacting with campers & counselors during activities, especially swimming, horses, zip line
- Keeping medical records
- Responsible for bowel program and catheterization schedules
- Giving campers a positive medical experience & assisting them with becoming independent on skills such as cathing

COUNSELORS

Supporting Happy Campers!

Counselors are an integral part of our campers time at camp and duties include:

- Staying in the same cabin with 6-7 campers
- Making sure campers get to activities, and support CJM staff during activities
- Assisting with personal care as needed
- Work as a team with nursing & CJM staff
- Help foster independence with campers with grooming, hygiene, personal care, transferring
- Creating a positive, encouraging atmosphere

HORSE SIDEWALKERS

Sidewalkers assist in the horse arena & ensure the safety of campers in the horse arena. Duties include:

- Assist CJM staff during horse activities
- Volunteer in other areas where needed when away from horse arena
- No experience necessary

NO EXPERIENCE NEEDED FOR SIDEWALKERS OR COUNSELORS!

- Counselors MUST BE at least 18 years old and graduated from High School
- Sidewalkers MUST BE 19 years old and over a year graduated from High School (CJM requirement)

MORE INFO? VISIT WWW.CAMPTLC-SBANT.COM

Take Home Thoughts

1. Inter-Disciplinary team models are natural bridges for access to mental/behavioral health services and bio-psycho-social supports
2. When functioning with good communication, the model is very effective in approaching uncommon, complex clinical questions
3. The “developmental stage” of the team can vary over time as key personnel enter/exit
4. Critical to Success:a culture of collaboration / communication

   a culture of continuous improvement

   a culture supporting adaptation to change

Questions

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What challenges has your clinic faced in establishing interdisciplinary care or communication?

What best practices or logistical solutions have worked well for your teams?