Evolution of a Lifetime Care Model in Spina Bifida Transition

Prenatal → Neonatal → Pediatric Clinic → Transition Clinic at COA → Transition Clinic at Spain → Adult Clinic

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Spina Bifida Program at Children's of Alabama/UAB

CDC Spina Bifida Meeting- Chicago, June 26-28, 2019

Evolution/Course of Transition/Adult SB Clinic at UAB

1. Born of necessity- graduate to cliff's edge
2. Add on to existing Adult Spinal Cord Injury Clinic- gracious collaborator
3. Early enthusiasm- depressing early results-"the dog days"
4. Development and Refinement of the Lifetime Care Model
5. Growth and Quantitative Evaluation of Patient Outcomes- "School and Stool"
6. Evolving view of the temporal course of care for Spina Bifida
7. Next steps- Evolving Course

Children's of Alabama

Previous "Transition" Model

- Transition patients determined by ANY 1 of the 12 providers feeling as if patient could be better served from adult facility.
- Patients sent to Spain Rehabilitation to be followed by a Physiatrist as well as Urologist.
- No care coordination or method for tracking patients after transition.
- No proper plan for neurosurgical or orthopedic transition
- Records not forwarded to all offices.
- Pediatric provider available but limited communication.

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Knowledge that will change your world

“Graduation to the Cliff’s Edge”- congratulations!!

The Comprehensive Spina Bifida Program Transition Process

Pediatric to Adult Care

"Talk with Betsy!"

Betsy Hopson (left) coordinates the transition process for all young adults. She will provide you with information about the transition process, help plan for the transition and aid you in setting goals for the upcoming change. Betsy will also be in charge of scheduling you for your first visit at the Adult Spina Bifida Clinic. If you ever have any questions or concerns about the transition process, call Betsy at 205.638.5281.

Our Goals for Transition

The over-reaching goal of our transition program is to set the national standard for excellence of care in transition from quality comprehensive pediatric care to equally dedicated, comprehensive multi-disciplinary adult care in Spina Bifida.

The Children's of Alabama Spina Bifida Clinic manages care coordination, as well as all surgical and clinical needs, until age 21.

Transition plans will be initiated and transition goals defined when you reach 19 years of age. This provides time to deal with any potential issues, answer all of your questions and help build your confidence with the upcoming changes.

It is important that you and your family work consistently with the transition team so that the transition process proceeds as smoothly as possible.

Your last routine visit to Children's Spina Bifida Clinic must occur while you are 20 years old; all transition activities must be completed by age 21.

At your last Children's Spina Bifida Clinic visit, the transition team will schedule your first visit at the adult clinic. From that point on, you will attend the Adult Spina Bifida Clinic held at Spain Rehabilitation on UAB's main medical campus.

BY THE NUMBERS

TRANSITION

19-20 You will begin planning for transition while still attending Spina Bifida Clinic at Children's of Alabama. Your pediatric team will continue to manage your care and meet your surgical and clinical needs.

All transition activities should be completed by your 21st birthday. Once completed, you will begin seeing physicians at UAB Hospital and attend Adult Spina Bifida Clinic for routine follow-up. **21**

Spina Bifida Comprehensive Lifetime Care Model

Children's of Alabama · UAB MEDICINE

Prenatal	Neonatal	Pediatric Clinic	Transition Clinic at Children's	Transition Clinic at Spain	Adult Clinic
UAB Maternal Fetal Clinic Women's and Infant Center 3rd Friday of the Month	Children's of Alabama NICU	Children's of Alabama Clinic 3 2nd and 4th Wednesdays of the Month	Plans are made beginning at age 19; final visit before age 21.	First visit to Adult Clinic at age 21. Meets at Spain Rehabilitation 3rd Wednesday of the Month	Meets at Spain Rehabilitation; continues throughout lifetime.

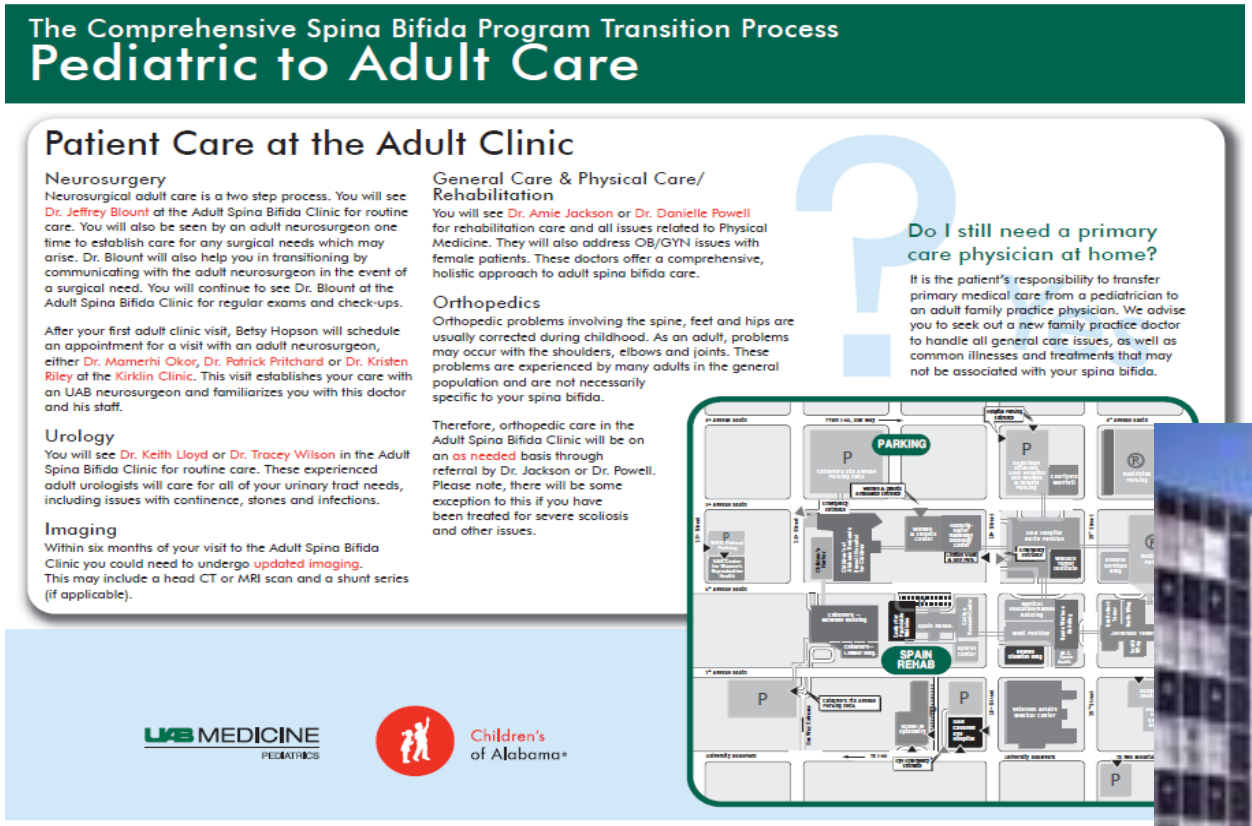
Results

- Currently following 225 patients in the Transition/Adult Clinic.
  - 78 patients transitioned for COA.

- Gender
  - Adult Clinic
    - 63% Female
    - 37% Male
  - Peds Clinic
    - 53% Female
    - 46% Male

- Insurance
  - 75% Public
  - 25% Private

- Diagnosis
  - 83% Open MMC
  - 14% Closed defect


The Comprehensive Spina Bifida Program Transition Process

Pediatric to Adult Care

Patient Care at the Adult Clinic

Neurosurgery

Neurosurgical adult care is a two step process. You will see Dr. Jeffrey Blount at the Adult Spina Bifida Clinic for routine care. You will also be seen by an adult neurosurgeon one time to establish care for any surgical needs which may arise. Dr. Blount will also help you in transitioning by communicating with the adult neurosurgeon in the event of a surgical need. You will continue to see Dr. Blount at the Adult Spina Bifida Clinic for regular exams and check-ups.

After your first adult clinic visit, Betsy Hopson will schedule an appointment for a visit with an adult neurosurgeon, either Dr. Mamerhi Okor, Dr. Patrick Pritchard or Dr. Kristen Riley at the Kirklin Clinic. This visit establishes your care with an UAB neurosurgeon and familiarizes you with this doctor and his staff.

Urology

You will see Dr. Keith Lloyd or Dr. Tracey Wilson in the Adult Spina Bifida Clinic for routine care. These experienced adult urologists will care for all of your urinary tract needs, including issues with continence, stones and infections.

Imaging

Within six months of your visit to the Adult Spina Bifida Clinic you could need to undergo updated imaging. This may include a head CT or MRI scan and a shunt series (if applicable).

General Care & Physical Care/ Rehabilitation

You will see Dr. Amie Jackson or Dr. Danielle Powell for rehabilitation care and all issues related to Physical Medicine. They will also address OB/GYN issues with female patients. These doctors offer a comprehensive, holistic approach to adult spina bifida care.

Orthopedics

Orthopedic problems involving the spine, feet and hips are usually corrected during childhood. As an adult, problems may occur with the shoulders, elbows and joints. These problems are experienced by many adults in the general population and are not necessarily specific to your spina bifida.

Therefore, orthopedic care in the Adult Spina Bifida Clinic will be on an as needed basis through referral by Dr. Jackson or Dr. Powell. Please note, there will be some exception to this if you have been treated for severe scoliosis and other issues.

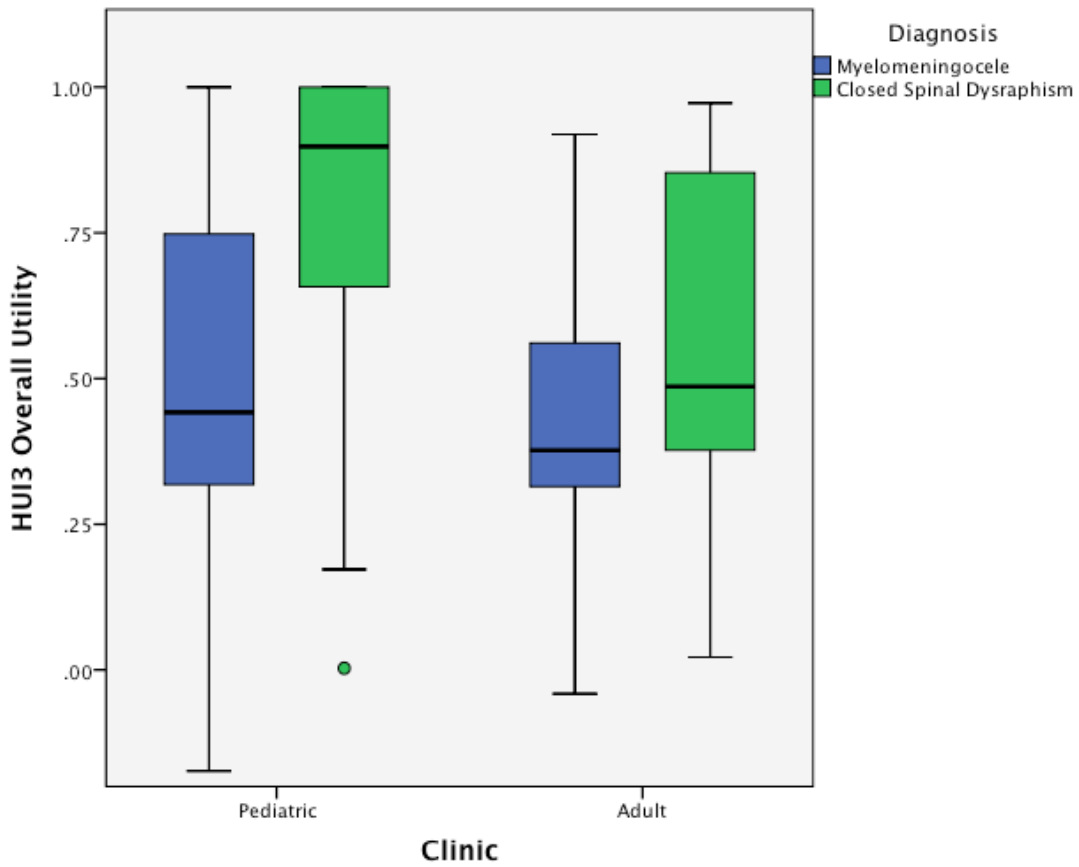
Do I still need a primary care physician at home?

It is the patient's responsibility to transfer primary medical care from a pediatrician to an adult family practice physician. We advise you to seek out a new family practice doctor to handle all general care issues, as well as common illnesses and treatments that may not be associated with your spina bifida.

UAB MEDICINE PEDIATRICS

Children's of Alabama

Summary- HUI-3 Outcomes in NTDs



<u>Adult:</u>

MMC	n=25
Closed Dysraphism	n=6

<u>Pediatric:</u>

MMC	n=125
Closed Dysraphism	n=33

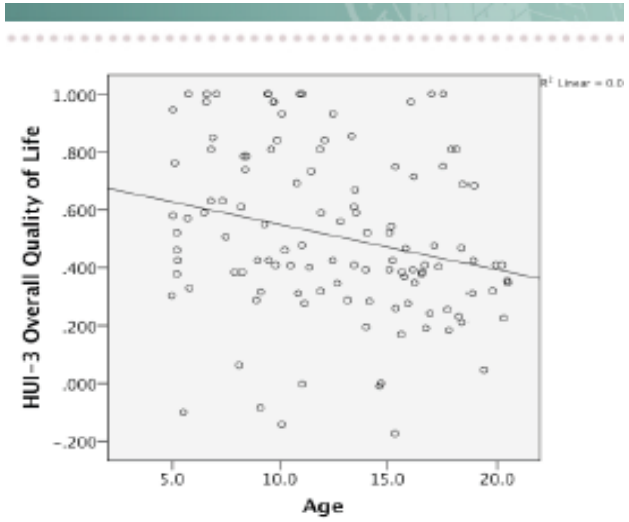
<u>Peds</u>:

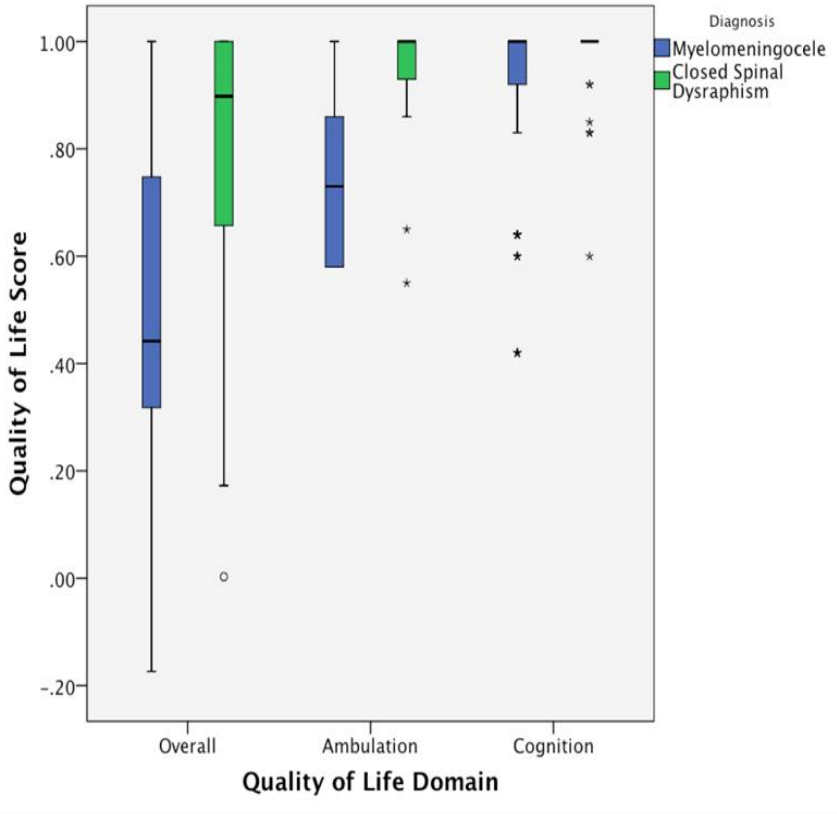
- Diagnosis greatest contributor
- QOL declines w age
- Shunts and C2MD both a/w signifcant decrease QOL

<u>Adults:</u>

- Min difference open/closed
- Surg procedures min impact
- Emotion, cognition, pain domains dominate

Peds HUI 3 Results





- (Open) MMC <<Closed Defect
  - Largest overall contribution to QOL was **diagnosis**
  - Domain subscores implicate **cognition** and ambulation
- QOL *declines with age* across childhood into adolescence
- One third continent (32%bowel/35%urinary) and continence a/w QOL

JNS PEDIATRICS

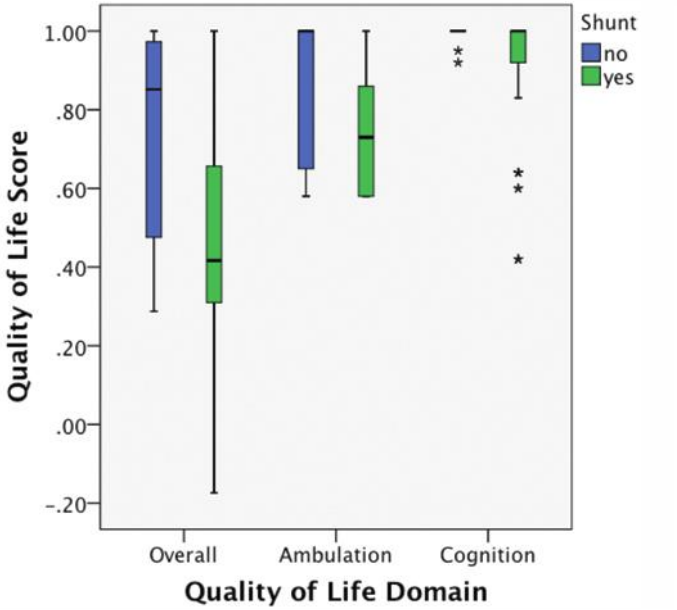
CLINICAL ARTICLE

J Neurosurg Pediatr 15:144–149, 2015

Assessing health-related quality of life in children with spina bifida

Brandon G. Rocque, MD, MS,[1] E. Ralee' Bishop, BS,[1] Mallory A. Scogin, MD,[1] Betsy D. Hopson, MSHA,[1] Anastasia A. Arynchyna, MPH,[1] Christina J. Boddiford, MPH,[1] Chevis N. Shannon, MBA, DrPH,[2] and Jeffrey P. Blount, MD[1]

[1]Pediatric Neurosurgery, Department of Neurosurgery, University of Alabama at Birmingham, Alabama; and [2]Department of Neurosurgery, Vanderbilt University, Nashville, Tennessee



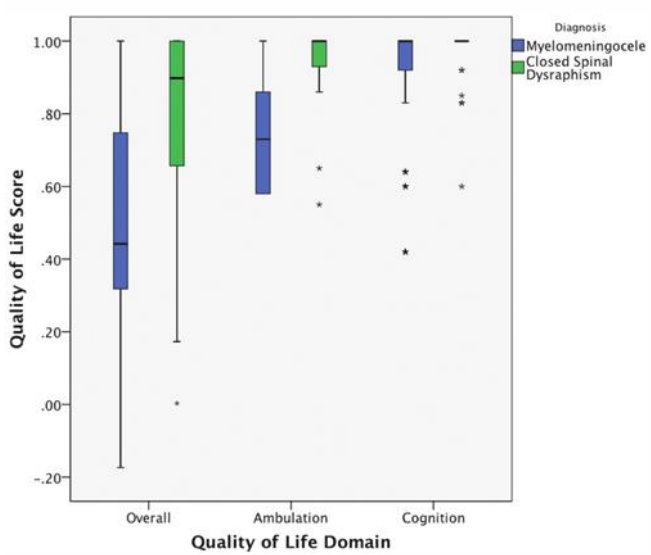


FIG. 1. Overall HRQOL, ambulation, and cognition subscores contrasting myelomeningocele patients with closed spinal dysraphism patients. The *solid lines* denote the mean; *boxes*, the interquartile range; *bars*, range; and *asterisks,* outliers. Figure is available in color online only.

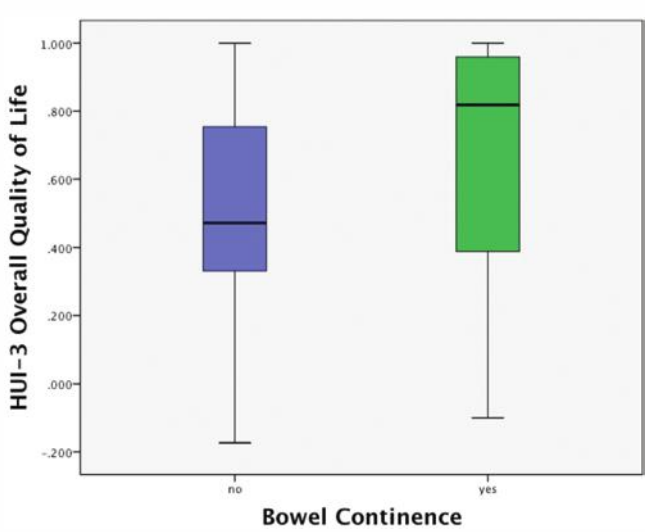
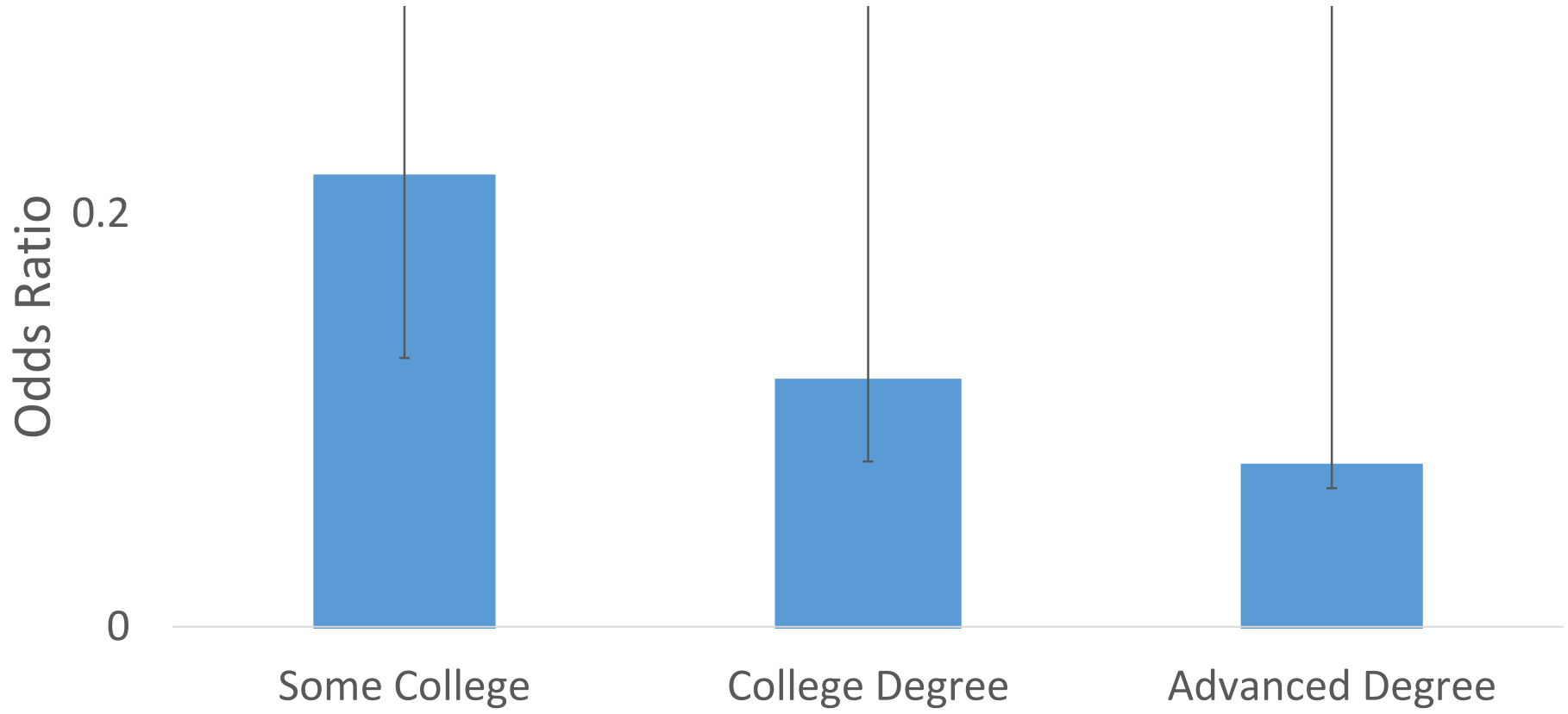
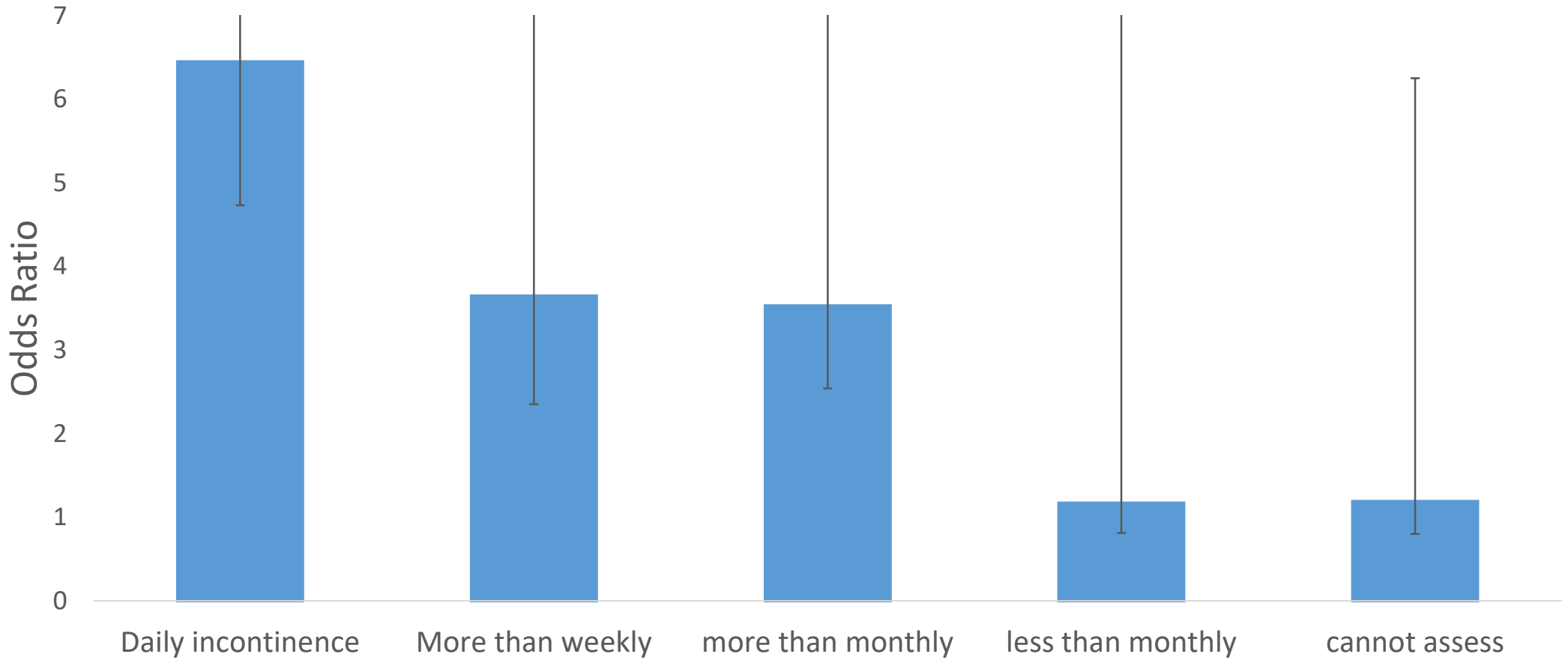


FIG. 2. Overall QOL comparing patients with normal bowel continence to those with incontinence. Figure is available in color online only.

Education predicts Disability



Stool incontinence predicts Disability



Independent association with “permanent disability”

“School and Stool”

Journal of Neurosurgery: Spine
Aug 2017 / Vol. 27 / No. 2 / Pages 169-177

Predictors of permanent disability among adults with spinal dysraphism

Matthew C. Davis, MD[1], Betsy D. Hopson, MSHA[2], Jeffrey P. Blount, MD[1], Rachel Carroll, MPH[3], Tracey S. Wilson, MD[3], Danielle K. Powell, MD, MSPH[4], Amie B. Jackson McLain, MD[4], and Brandon G. Rocque, MD, MS[1]

What is lifespan care?

- Begins with an honest assessment of where patients' needs aren't being met.
- Includes well thought out plan for each stage
- Includes coordination of care throughout the lifespan
- Care strategies and goals at each stage
- Dedicated providers throughout the lifespan
- Deliberate communication between care teams

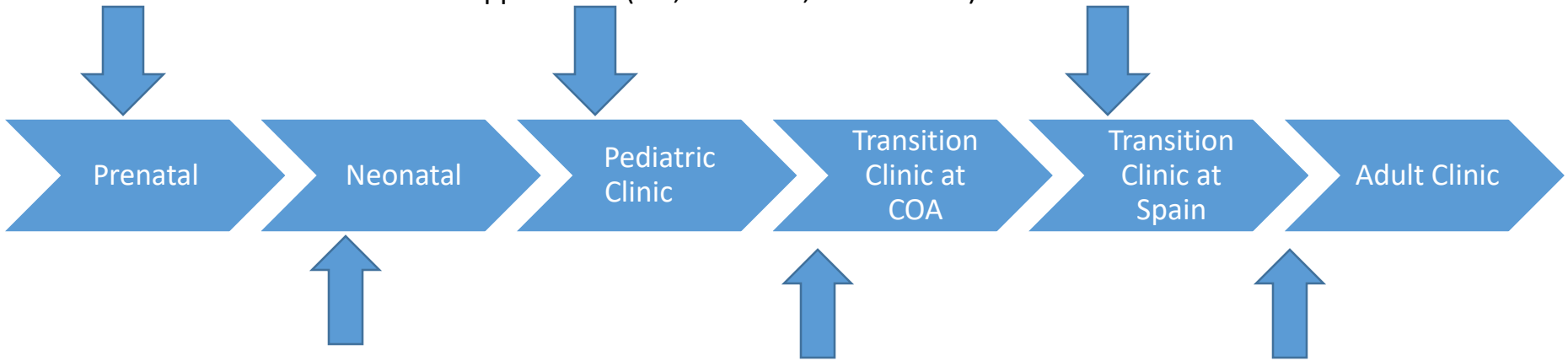
Even if I am not the one delivering the care at every stage what is the plan?

Lifetime Care Model

UAB Maternal Fetal Clinic
Women's and Infant
Center (3rd Friday)
-High risk- OB/GYN
-Neurosurgery
-Rehabilitation Medicine
-Genetics
-SB Coordinator

Children's of AL
Clinic 15 (2nd and 4th Wed.)
-Urology
-Neurosurgery
-Rehabilitation Medicine
-Orthopedics
-SB Coordinator
- Support staff (SW, orthotics, wound care)

-First Visit to Spain at 21
-transition readiness teaching con't
- Increase frequency of visits
temporarily to establish goals.



Children's of AL NICU

- Shift to patient run visits
-transition readiness
- teaching and goal setting
- Final Visit to COA at 20

Spain Rehabilitation Clinic
(1st and 3rd Wed.)
-Urology
-Neurosurgery
-Rehabilitation Medicine
-SB Coordinator
- Support staff

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Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 11 (2018) 323–334
DOI 10.3233/PRM-180548
IOS Press

The development of a lifetime care model in comprehensive spina bifida care

Betsy Hopson[a,*], Brandon G. Rocque[b], David B. Joseph[c], Danielle Powell[d], Amie B. (Jackson) McLain[d], Richard D. Davis[d], Tracey S. Wilson[e], Michael J. Conklin[e] and Jeffrey P. Blount[b]

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[b]*Department of Neurosurgery, University of Alabama at Birmingham, Birmingham, AL, USA*
[c]*Department of Urology, University of Alabama at Birmingham, Birmingham, AL, USA*
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Accepted 30 October 2018

Abstract

PURPOSE: To describe the development and implementation of the Children's of Alabama (COA) Spina Bifida (SB) Lifetime-Care-Model, including standardized care protocols and transition plan.

METHODS: In 2010, members of the pediatric team at COA began to evaluate limitations in access to care for patients with SB at various stages of life. Through clinic surveys, observations, and caregiver report, a Lifetime-Care-Model was developed and implemented. Partnerships were made with adult medicine colleagues to create an interdisciplinary model at each stage. Since developing this program, it has evolved to include standardized care protocols.

RESULTS: Since 2011, there have been 42 prenatal clinics; 114 families received counseling and prenatal care. Of these, 106 have delivered at our center and established care in our pediatric clinic. There are currently 474 patients in the pediatric and 218 in the adult clinics.

CONCLUSIONS: Our institutional experience suggests that patients with SB benefit from continuity of care throughout their lifetime. This article describes early failures which led to an evolution in approach and implementation of a Lifetime-Care-Model which results in a smooth transition between all phases of life. We hope that other institutions may adapt and build upon it to create programs unique to their specific patient needs.

Keywords: Spina bifida, transition, care model, disability, care coordination

Children's of Alabama

Original Slide

Current Model for Transition

- Begin discussing and preparing for transition at 19
- Educational tools to prepare for transition:
  - copy of transition guidelines,
  - Health Guide for Adults Living with SB
- Last visit to Children's clinic in the 20th year.
- First visit to multi-disciplinary adult Spina Bifida clinic by the 21st year
  - Routine f/u annual eval in ASBC
  - Urgent needs through ER as needed

Children's of Alabama

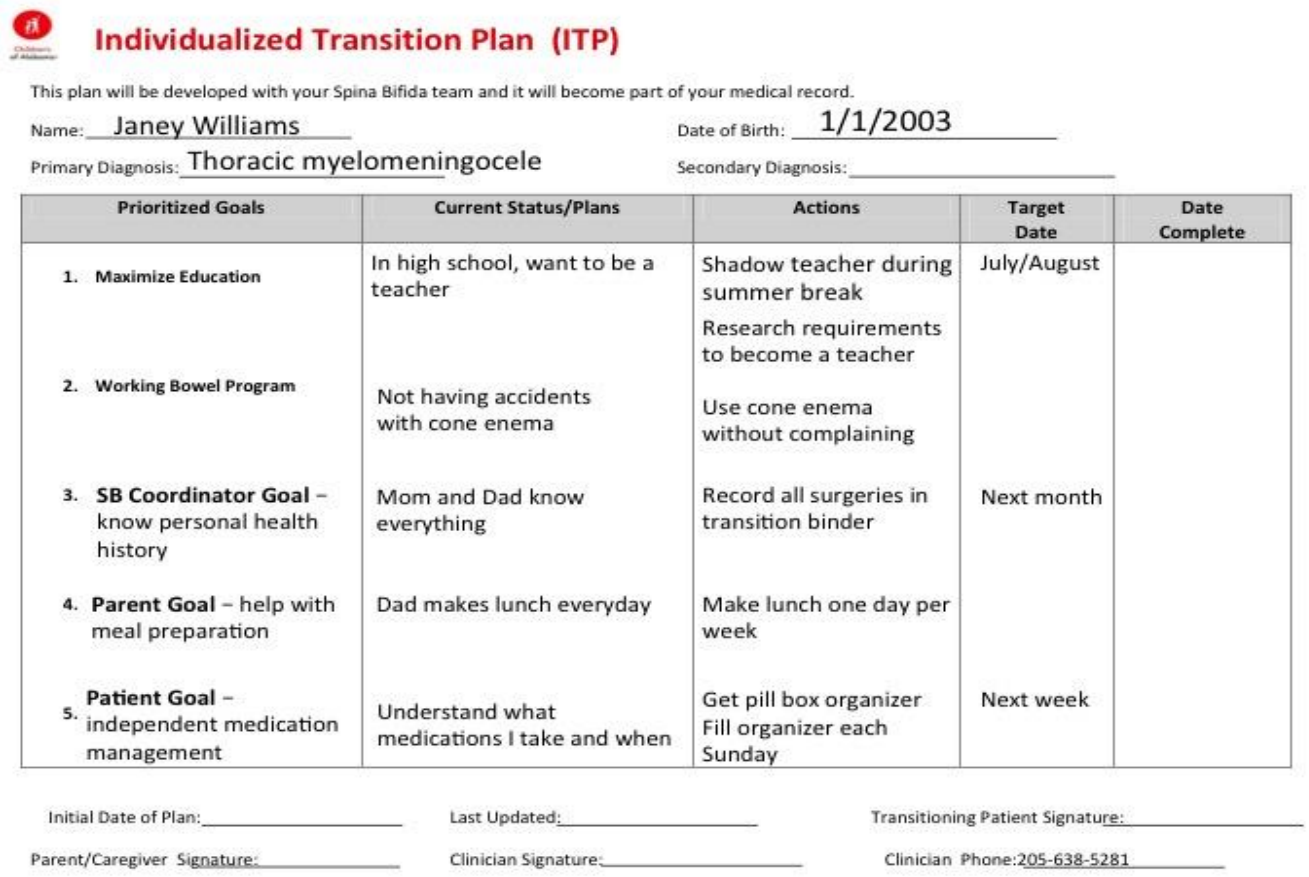
Current Model for Transition

- Transition Readiness Assessment at 13.
- Transition Initiated at 14.
- Develop Transition Plan/Goals.
- Last visit to Children's clinic in the 20th year.
- First visit to adult Spina Bifida clinic in the 21st year.
- Members of the pediatric team attend adult clinic.
- Clinic is multi-disciplinary including, rehab, urology, and neurosurgery.

Transition at COA

- TRAQ-SB
- PHQ-9
- Goal Setting
- Education/Career Planning

Stool and School



Individualized Transition Plan (ITP)

This plan will be developed with your Spina Bifida team and it will become part of your medical record.

Name: Janey Williams Date of Birth: 1/1/2003

Primary Diagnosis: Thoracic myelomeningocele Secondary Diagnosis: _____

Prioritized Goals	Current Status/Plans	Actions	Target Date	Date Complete
1. **Maximize Education**	In high school, want to be a teacher	Shadow teacher during summer break Research requirements to become a teacher	July/August	
2. **Working Bowel Program**	Not having accidents with cone enema	Use cone enema without complaining		
3. **SB Coordinator Goal** – know personal health history	Mom and Dad know everything	Record all surgeries in transition binder	Next month	
4. **Parent Goal** – help with meal preparation	Dad makes lunch everyday	Make lunch one day per week		
5. **Patient Goal** – independent medication management	Understand what medications I take and when	Get pill box organizer Fill organizer each Sunday	Next week	

Initial Date of Plan: _____ Last Updated: _____ Transitioning Patient Signature: _____

Parent/Caregiver Signature: _____ Clinician Signature: _____ Clinician Phone: 205-638-5281

Davis M, **Hopson B**, Blount JP, Carroll R, Wilson T, Powell D, McLain A, Rocque BG. *Predictors of permanent disability among adults with spinal dysraphism.* J Neurosurg Spine. 2017 Aug;27(2):169-177. doi: 10.3171/2017.1.SPINE161044. Epub 2017 May 26. PMID: 28548634

Summary- UAB experience

- Born of necessity- no model at that time. Many lessons learned hard way
- Early impressions dampened initial enthusiasm
- Studied patients and outcome predictors: BOWEL and EDUCATION (”Stool and School”)
- Prioritized preparations for transition- started earlier-
  - Transition readiness- ITP analogous to IEP in the school environment
  - Start early, involve families holistically, prioritize
- Neurosurgical needs evolve and acute needs decline

Why this model works

1. Unmet need/great demand for these supportive services
2. Flexibility and willingness to work beyond established “boundaries of service”
3. Supportive mission/service oriented fiscal infrastructure
   - Room to pursue/explore pursuits with initial modest reimbursement
4. Excellent collaborative partners- ownership/ professional identity
   - Danielle Powell MD- UAB Physical Medicine and Rehabilitation
   - Amy McLain MD- UAB Physical Medicine and Rehabilitation
   - Tracy Wilson MD – UAB Department of Urology
5. Exceptional Program Coordinator- Betsy Hopson

UAB Transition/Adult Clinic Observations

- Neurosurgical acute needs decline over the life span
- Urology and PMR needs persist/ threaten
- Orthopedic/ Plastic-wound needs are sporadic
- Bowel and Depression evolve to dominate QOL
- Adults with Occult Dysraphism live with constant pain that has never been comprehensively studied
- Pending crisis of providers as aging parents losing capacity to care for adult aged patients

Spina Bifida Lifetime Care Model

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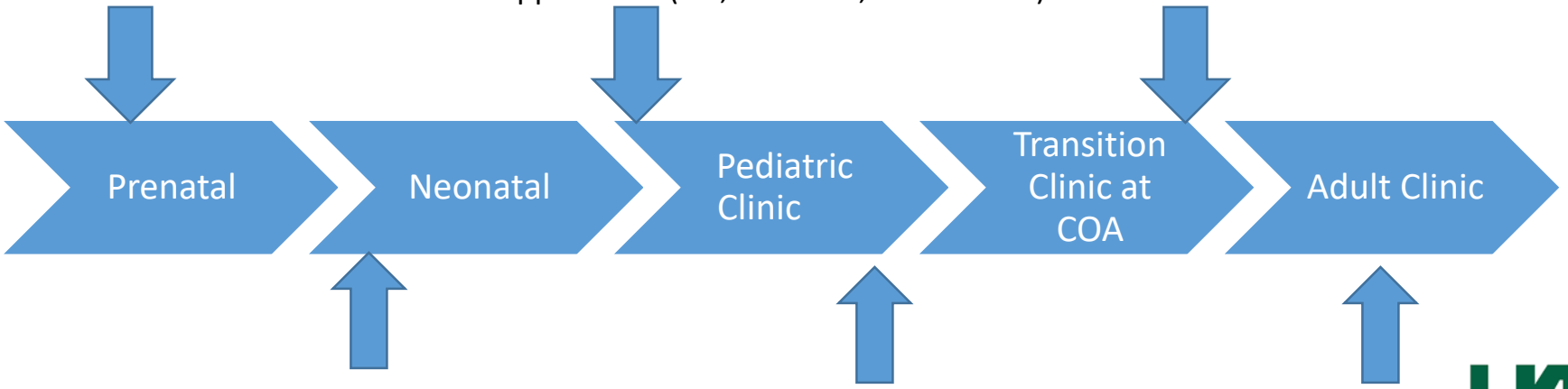

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Children's of Alabama

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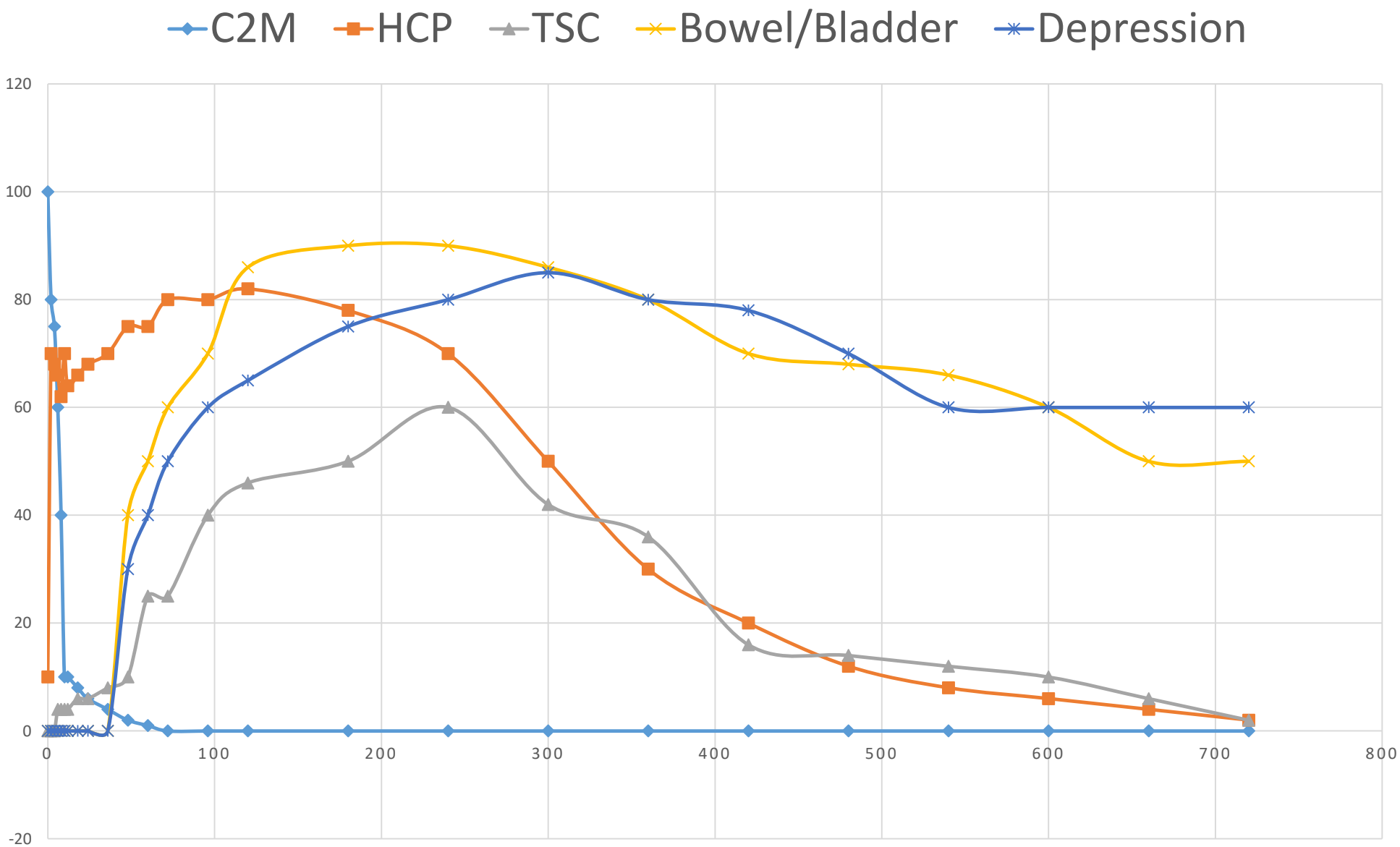
NEUROSURGERY IN MYELOMENINGOCELE ACROSS THE LIFE SPAN



The Next/Evolving Steps- 3 part approach to transition

1. UAB Medical Home for Transitioning Patients
   - Outpatient Clinic with primary dedication to pediatric patients with medical complexity transitioning to adult care
   - Staffed by Med-Peds physicians at UAB Clinic spaces

2. UAB/COA Surgical Center for Transition Patients
   - Specifically targets surgical needs that arise from extension of developmental or pediatric illnesses in early adulthood
   - Candidates are young adults with primary needs related to pediatric conditions
   - Advantageous Medicaid reimbursement for COA may make cost advantageous to both
3. UAB Transition Consultation Service
   - One stop call for any/all needs arising in patients who are involved in transitional care (young adults with chronic medically complex conditions that arose in childhood)

Evolution/Course of Transition/Adult SB Clinic at UAB

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2. Add on to existing Adult Spinal Cord Injury Clinic- gracious collaborator
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4. Development and Refinement of the Lifetime Care Model
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Thank you