



SPINA BIFIDA  
ASSOCIATION

# Lifespan Model of Care

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**Children's of Alabama**

**University of Alabama-Birmingham**



Children's  
of Alabama

**UAB** THE UNIVERSITY OF  
ALABAMA AT BIRMINGHAM

Knowledge that will change your world

# Disclosures

I have no financial interests to disclose

# Introduction/Objectives

- In 2006 I began my career at Children's of Alabama
- Objectives
  - Describe life span care
  - Provide strategies for implementing a lifetime care model
  - Important role of the healthcare team at each stage
  - Share lessons learned

# Clinic to Program Evolution

The difference between a clinic and a program is the level of commitment to the lifespan of a population. A program, must identify, recognize, and solve issues related to the entire patient population and every age level, while a clinic can be very singularly focused on the needs of a particular segment of the population.

# 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?*

# Our Program

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

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### 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

# Lifetime Care Model

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

Children's of AL  
Clinic 15 (2<sup>nd</sup> and 4<sup>th</sup> Wed.)  
-Urology  
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- 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

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(1<sup>st</sup> and 3<sup>rd</sup> Wed.)  
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# Prenatal Stage: Challenges Identified

- Parents receiving prenatal neurosurgical consultation reported feeling overwhelmed
- Parents without prenatal consultation reported feeling isolated and uninformed
- Parents grossly lacked comprehension of extensive plan of care with late introduction of spina bifida team

# Prenatal: Strategies of Clinic Development

- Identify families early in diagnostic process
- Partnership with high risk OB/GYN office at UAB
- Determine key players
- Develop clinic structure
- Identify goals of the clinic

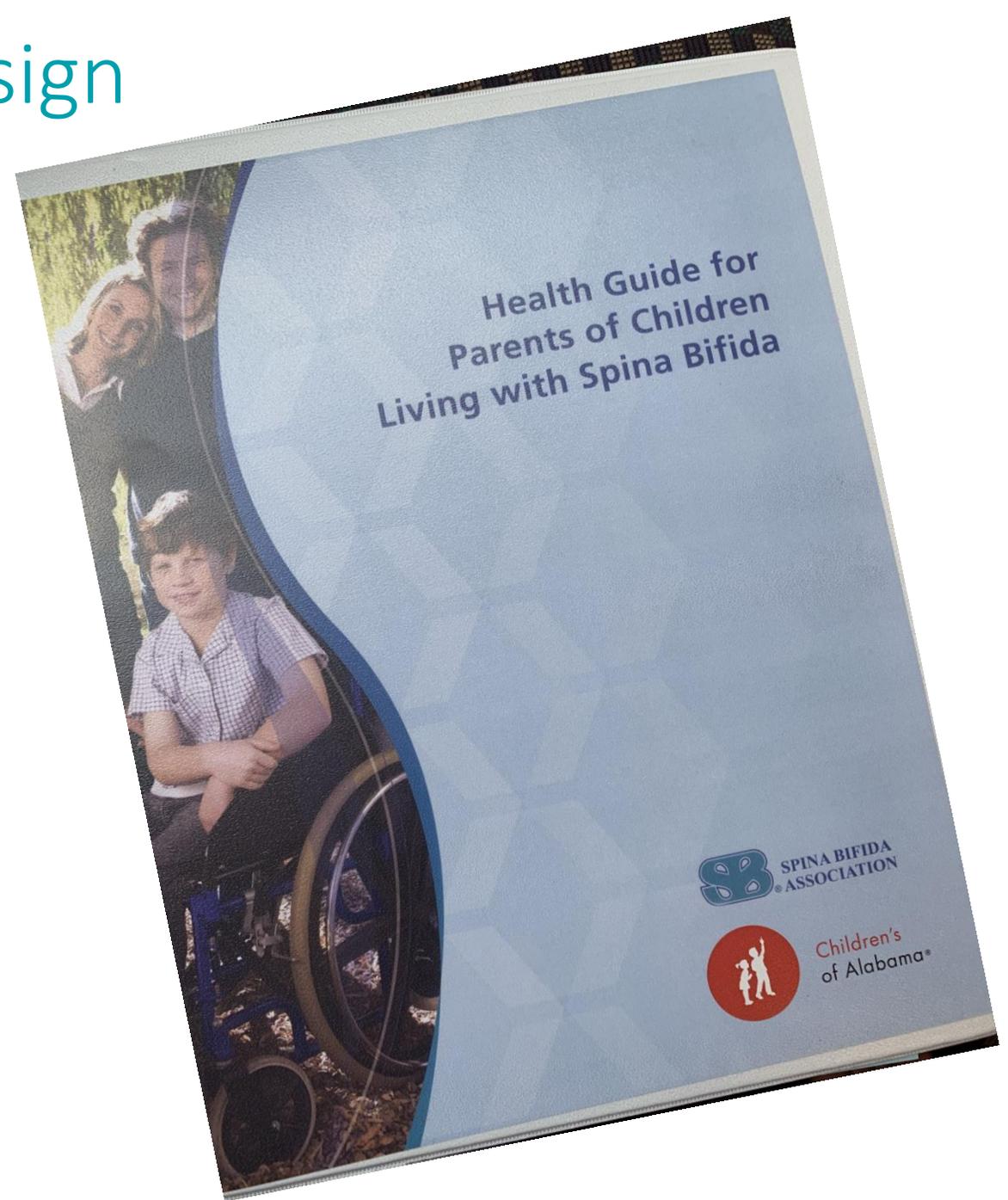
# Prenatal: Goals of Clinical Design

- **Clinic Goals**

- Alleviate anxiety related to diagnosis
- Address questions
- Provide education
- Predict outcomes
- Reinforce support systems

- **Take home for parents**

- Health Guide for SB
- A delivery plan
- Contact Information
- Better understanding of condition
- Expanded degree of support



# Prenatal: Observations

- Intentional attempt to meet families prior to delivery results in:
  - Anxiety being reduced.
  - Families appear more informed during hospitalization.
  - Prenatal education proved superior to post partum teaching.
  - Parents confidence level in their ability to provide care is reportedly improved.

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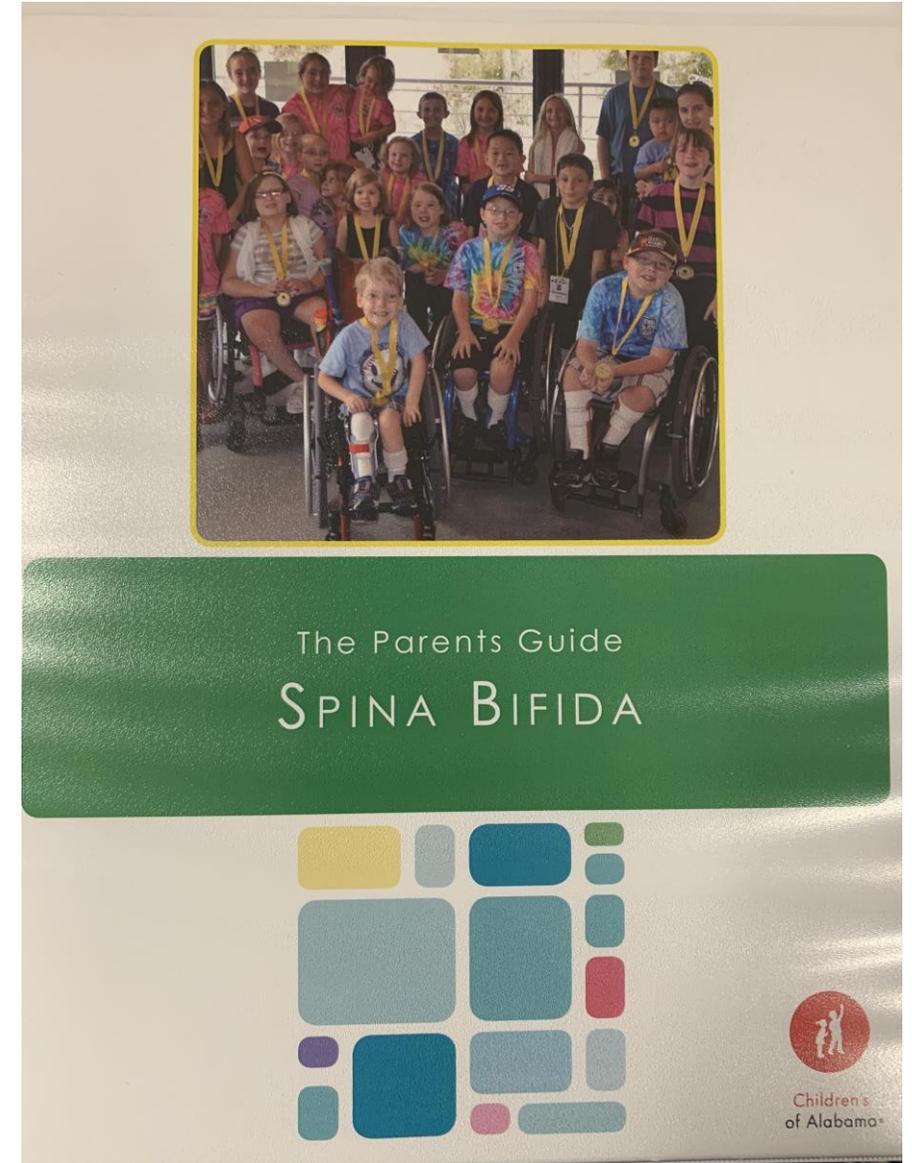
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# Neonatal

- Visit family during initial hospital stay
- Reinforce Relationship
- Parent-to-Parent talk
- Latex Teaching
- Provide New Parent Journal
  - Future Appointments
  - Patient Diary of Medical History
  - Track questions, visit info., test results, providers, etc.

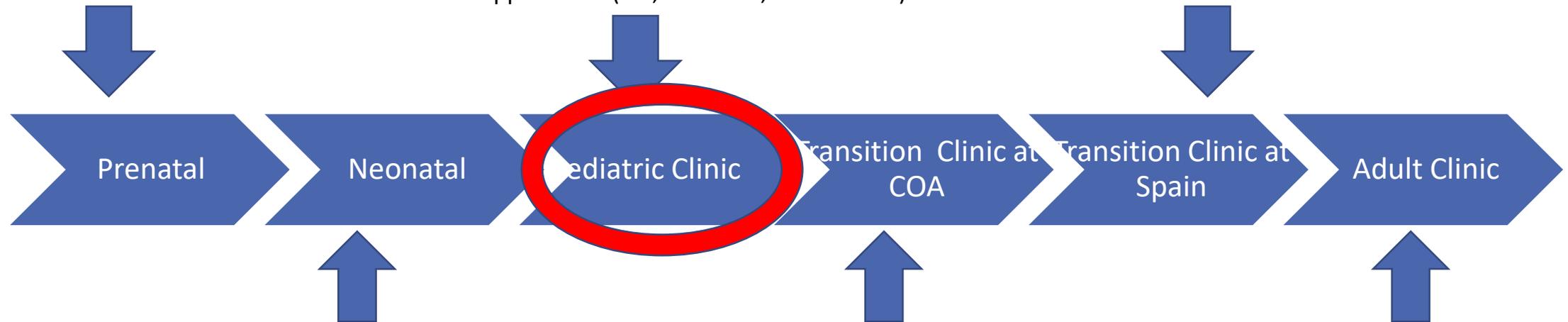


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# Pediatric Clinic

- Develop working bowel program
- Make contact with school
- Wound teaching
- Ensure developmental milestones are met

Again, I can't thank you enough for sacrificing your time to help [REDACTED]. I feel so much better about our plans going forward, and if you ever wonder if you're making a difference, just know you are making a world of difference! ❤️





# Background of Transition at COA

- Transition patients determined by 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.

# Standardized Transition Plan

## 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 14 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.

You will be given an Individual Transition Plan (ITP). It is important that you and your family work consistently with the transition team so that the transition process proceeds as smoothly as possible. Our goal is to prepare you for transition and life in the adult healthcare world.

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 13-20** 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  
PEDIATRICS

UAB Maternal Fetal Clinic  
Women’s and Infant Center  
3rd Friday of the Month.

↓  
PRENATAL

↑  
NEONATAL

Children’s of Alabama NICU.

Children’s of Alabama Clinic 15  
2nd and 4th Wednesdays  
of the Month.

↓  
PEDIATRIC  
CLINIC

↑  
TRANSITION  
CLINIC AT  
CHILDREN’S

Plans are made beginning  
at age 14; final visit before  
age 21. ITP developed.

First visit to Adult Clinic at age 21.  
Meets at Spain Rehabilitation every 1st  
and 3rd Wednesday of the Month

↓  
TRANSITION  
CLINIC AT  
SPAIN

↑  
ADULT  
CLINIC

Meets at Spain  
Rehabilitation; continues  
throughout lifetime.

# 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

# Development of Adult Clinic

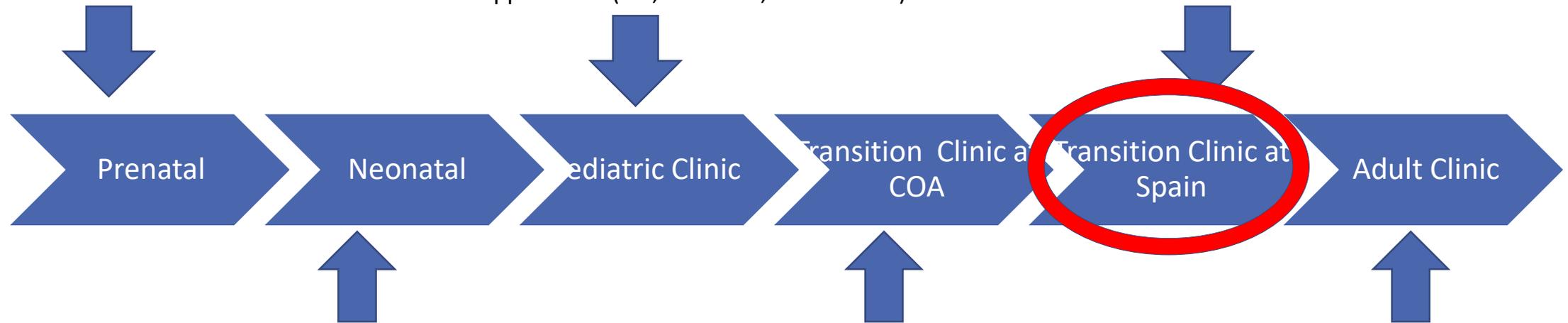
- Partner with existing clinics
- Find your champions
- Pediatric team to back adult providers
- Monthly meetings
- Two way communication

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# Transition at Adult Clinic

- Patient

- Is healthy.
- Attends first visit to adult clinic.
- Exhibits and verbalizes confidence in where to go and how to respond in case of emergency.

- Center

- Transferred records.
- Upload images.
- Hands off care.

- Coordination of care and Primary Care

- Still necessary

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# Components of Adult Visit

- Physical Exam with Motor and Sensory Status (Neurological Exam)
- Pain or Spasticity
- Skin Breakdowns or Pressure Ulcers
- Bladder Program
- Bowel Program
- Nutrition and Dietary Needs
- Evaluate for Sleep Apnea
- HPV Vaccines
- **For females:**
  - Menstrual Cycles and LMP
  - Reproductive Function and Pregnancy
  - Birth Control
  - Breast Exams and PAP Smears
  - Sexual Abuse
- **During or at the end of the visit - DME needs such as:**
  - Wheelchair / Cushion (New and Repairs)
  - AFOs
  - KFOs

# Early Failures

- Prenatal visits weren't offered routinely and were done in pediatric NSU clinic
- Transition based on “adult-like” behavior
- No Standardized Transition Policy
- We did not have partnerships with adult providers in our area.
- After transition program was developed, we began teaching at age 19 instead of earlier in adolescence which did not leave enough time to prepare them for transition.

# Lessons Learned

- Prenatal consultations are best done in group setting.
- Transition should be individualized to the patient but standardized to the program.
- Transition involves more than a location change.
- Communication lines need to stay open.
- Care coordination is needed at every stage.

# What's next?

*Our patients are outliving their caregivers*

# Advocacy

- Commitment to lifetime care is a commitment to advocacy:
  - Teal on the Hill
  - Share your story



# Conclusion

- Each stage requires an individualized well thought out plan
- Commitment to the patient and population regardless of the policy
- Evidence based program development
  - Be willing to change when it's not working

## Questions???

- Betsy Hopson, MSHA

Contact Information:

[betsy.hopson@childrensal.org](mailto:betsy.hopson@childrensal.org)

205-638-5281

