Spina Bifida Transition to Adulthood - The Genesis of a Program

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Introduction/Objectives

• In 2010 the Adult/Transition Program at Children’s of AL/UAB began.

• Objectives
  – Comprehensive overview of development.
  – Lessons learned.
  – Current research findings.
  – Strategies for successful transition.
  – Unique partnership ideas and interventions.
Transition Evolution

Advancements in care → Improvement in lifespan

Success breeds urgency

- Who should provide care
- What should be included
- Where should it happen
- How is it done

Children’s of Alabama
What is Health Care Transition?

• Health care transition is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.

Gottransition.org
Spina Bifida Transition

- > 90% of people living with SB are expected to live well into adulthood.
- Where should adults receive care?
- Who will provide the care?
- What services do they need as adults?
- Why can’t patients with SB continue to be seen in the pediatric clinic?
  - Insurance restrictions
  - Anesthesia
  - Licensing
  - Equipment diagnostic testing
  - Nursing support
  - ER/ICU
  - Gynecologic/Obstetric
  - Conditions unique to adults
Barriers to Transition

• Too “young” for adult facility
• Lacking “warm and fuzzy” care
• Emotional investment
  – Patient/Family/Physician
    • multiple visits - job disruption
• Current adult care – piecemeal
  – lack of continuity across disciplines
• Financial limitations
  – Age out of Medicaid after 21
  – Supplemental Security Income (SSI)
    • reduced benefits after 18
Background

• COA represents only multi-disciplinary SB clinic in the state.
• 565 pediatric patients currently.
• Clinic is multi-disciplinary:
  – Urology
  – Neurosurgery
  – Orthopedics
  – Rehabilitation Medicine
  – Support staff (orthotics, PT, SW, wound care, etc.)
• Pediatric clinic NOT a SB Program. What’s the difference?
Previous “Transition” Model

- 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.
### Challenges to Success

<table>
<thead>
<tr>
<th>Challenges Observed</th>
<th>Method to Address Challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of standardized plan for transition</td>
<td>Developed a plan for transition based on real age not “adult-like” behavior.</td>
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<tr>
<td>Lack of accurate data to track patients after</td>
<td>Developed method for tracking transitioning patients through use of Webtracker and excel.</td>
</tr>
<tr>
<td>transition</td>
<td></td>
</tr>
<tr>
<td>Lack of infrastructure</td>
<td>Began utilizing UAB systems to facilitate ease of access to adult records to aid in care</td>
</tr>
<tr>
<td></td>
<td>coordination and tracking.</td>
</tr>
<tr>
<td>Lack of easy access to a process for timely</td>
<td>Utilized willing participants at Children’s of Alabama to facilitate proper transition</td>
</tr>
<tr>
<td>transition</td>
<td>(Dr. Jeffrey Blount, Betsy Hopson).</td>
</tr>
<tr>
<td>Lack of evidence based methods for adult patients</td>
<td>Began enrolling patients in the CDC project to begin tracking outcomes in adults with SB</td>
</tr>
<tr>
<td>with SB.</td>
<td>and began developing plan of care guidelines for adults.</td>
</tr>
</tbody>
</table>
Development

• Discover areas for improvement

• Find your “CHAMPIONS”

• Develop a standardized plan

• Jump off the ledge
  – Avoid Analysis Paralysis
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.
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
- 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
Spina Bifida Program
at
Children’s of Alabama
University of Alabama at Birmingham

UAB Women and Infant
Prenatal
Neonatal Care

Children’s of Alabama
Neonatal Care
Pediatric Care
Pediatric Clinic

UAB Spain Rehab
Adult Outpatient

Knowledge that will change your world
The Comprehensive Spina Bifida Program Transition Process
Pediatric to Adult Care

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
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.

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Spina Bifida Comprehensive Lifetime Care Model

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

Neonatal
Children’s of Alabama NICU

Pediatric
Children’s of Alabama NICU

Clinic
Children’s of Alabama Clinic 3
2nd and 4th Wednesdays of the Month

Transition Clinic at Children’s

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

Transition Clinic at Spain

Plans are made beginning at age 19; final visit before age 21.

Adult
Meets at Spain Rehabilitation; continues throughout lifetime.

“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.
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. Mameri Okoye, 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 would 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.
Completed Transition

• 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.
Number of Patients Transitioning

- 2011 ~ transitioned more adult patients than we had new patient births.

- We are transitioning ~ 1-3 patients/month into the adult clinic.

- Only 38% of total adult population transitioned from COA.
Results

• Currently following 204 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
Challenges Adults with Spina Bifida Face

- Intimacy and sexual well-being.
- Obesity.
- Cardiac disease.
- Pregnancy.
- Mental Disorders.
- Health-risk Behaviors.
- Pain
- Renal Failure
- Shunt related issues
Clinical Observations

• Diminishing Hope
  – 56% self identify as permanently disabled unable to work, seek work, or volunteer

• Primary Concerns/Issues
  – Bowel Management
  – Renal Function (stones, UTIs)
  – Wounds/Pressure Sores
  – Pain
  – Depression/Anxiety
  – Employment/Motivation

• Other Observations
  – Only seek healthcare emergently
  – Desire to give back
  – Desire to work is present but finding work is difficult
• **Education/Employment**
  - 58% high school education or less
    - 25.7% are employed
  - 27% have had some college
    - 66% are employed
  - 11% college degree
    - 70% with college degree are employed

• **Bowel Management/Employment**
  - Daily Stool Accidents
    - 6 times more likely to be unemployed
  - Weekly Stool Accidents
    - 3 times more likely to be unemployed

### Employment Table

<table>
<thead>
<tr>
<th>Education</th>
<th>Odds ratio</th>
<th>Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary/secondary</td>
<td>ref</td>
<td>ref</td>
<td>&lt;0.001</td>
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<tr>
<td>Technical school</td>
<td>0.01</td>
<td>0-0.40</td>
<td>0.021</td>
</tr>
<tr>
<td>Some college</td>
<td>0.22</td>
<td>0.08-0.53</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>College degree</td>
<td>0.06</td>
<td>0.003-0.66</td>
<td>0.019</td>
</tr>
<tr>
<td>Advanced degree</td>
<td>0.12</td>
<td>0.03-0.45</td>
<td>0.002</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stool incontinence</th>
<th>Odds ratio</th>
<th>Confidence Interval</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>ref</td>
<td>ref</td>
<td>0.065</td>
</tr>
<tr>
<td>At least daily</td>
<td>6.41</td>
<td>1.56-32.90</td>
<td>0.009</td>
</tr>
<tr>
<td>Less than daily, more than weekly</td>
<td>3.43</td>
<td>1.10-11.89</td>
<td>0.033</td>
</tr>
<tr>
<td>Less than weekly, more than monthly</td>
<td>3.31</td>
<td>0.77-16.12</td>
<td>0.109</td>
</tr>
<tr>
<td>Less than monthly</td>
<td>0.97</td>
<td>0.16-6.77</td>
<td>0.974</td>
</tr>
<tr>
<td>Cannot assess</td>
<td>1.01</td>
<td>0.19-5.42</td>
<td>0.992</td>
</tr>
</tbody>
</table>
Bowel Management

Frequency of bowel Incontinence

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>42.30%</td>
</tr>
<tr>
<td>Less than once/month</td>
<td>7%</td>
</tr>
<tr>
<td>At least monthly</td>
<td>17%</td>
</tr>
<tr>
<td>Weekly</td>
<td>20.40%</td>
</tr>
<tr>
<td>Daily</td>
<td>11.30%</td>
</tr>
<tr>
<td>Cannot Assess</td>
<td>2.10%</td>
</tr>
</tbody>
</table>
Other Interesting Research

- **Pediatric Health Related Quality of Life (HRQOL)**
  - Prospective cohort of 159 patients
  - Patients with Myelomeninocele (MMC) had significantly lower HRQOL scores than patients with closed defects
  - Among patients with MMC, younger patients had a higher HRQOL score.
  - History of shunting and Chiari decompression correlate with lower HRQOL scores

- **Adult Health Related Quality of Life (HRQOL)**
  - Prospective cohort 31 patients
  - Negative correlation between age and emotion
  - Patients followed in the adult spina bifida clinic have significantly lower HRQOL scores than those in the pediatric clinic

- **Sleep Study**
  - Retrospective chart review of all patients in clinic from March 1999-July 2013.
  - Out of the 52 patients who received a sleep study, 80% of those patients were diagnosed with sleep apnea
  - 31% fell into the categories of moderate or severe sleep apnea
Patient Feedback

- Feedback uniformly positive
- More confidence in system
- Improved patient satisfaction
- Reduced anxiety about change

They do still miss their pediatric doctors...
Provider Feedback

• Grateful for the plan

• Request made to pediatric docs
  – Parents leave the room
  – Teach patients to talk
  – Promote early independence
  – Begin discussing sexual function and abuse
  – Study adult outcomes
  – Make sure records are updated and forwarded

• Open lines of communication
Lessons Learned

• Determining ways to address their specific problems will improve adherence.

• Collaboration between pediatric and adult care providers create an atmosphere for successful transition. (outcomes dictate effort)

• Transition model must be clearly defined and agreed upon by all team members and their families.

• More education is needed with adult providers.

• Continued care coordination is needed for adults.

• Answers best obtained by the patients.

• Quality of life measures are needed.
Next Steps

- Focus Group
- Transition Binder
- Study Outcomes
Getting Patients Ready

• Individualized Transition Plan
• Goals
• Creating Independence
• Stage appropriate teaching
Getting Parents Ready

• Helicopter parent to Lighthouse parent
• Spoke to Hub
• Advocate while fostering independence  
  – This must be taught...
“I never knew I could do all the things I see these amazing people doing. Look, Emily got married, now I know I can get married, too. And Michelle had a baby, I didn’t even know I could have a baby. Josh has his driver’s license I now want to get mine too. And Kerri has her PhD… who knew that was possible. This weekend has taught me that if they can do this so can I”
“Spina Bifida Adult Retreat cured my headaches… I didn’t realize my pain was caused by depression until I wasn’t depressed anymore”
The Camp Effect

Toni Clark Jorenby
Thanks so much Kaylan Dunlap for all the info you shared with my young adult with Spina Bifida... Dylan Jordan Wilson.... Today he has decided to make all kinds of list and get things in order.... He wants to start handling his finances more and making lists for things he needs at the beginning of the month when he gets his check....also asking all kinds of questions I think we're sparked by the Retreat this weekend.. Like symptoms of UTI's etc.... That retreat really lit a fire under him!!!! Thank you so much for your input.... He is just amazed at the work you do and how ABLE you are!!!! Yesterday at 5:44 PM · Like · 1 · Reply

Toni Clark Jorenby
This also goes to Kerri Vanderbom who was amazing too...... Ps thanks fit the chips sat night!
Yesterday at 5:48 PM · Unlike · 3 · Reply

Kaylan Dunlap
So much from so little. I'm quite inspired by this group of young folks. He'll do alright with his finances if he handles them like he did his poker chips. he was stingy with those! He's a good young man from what I've seen. You should be proud, Mama.

And the whole UTI thing is sooooo important. I
In Their Words...

Shandra Oliver
Yesterday at 1:58 PM · Instagram · Edited

So after going to camp this weekend I think I'm gonna set a goal to get my drivers permit!!! Time to start reading!! 🚗🚗🚗🚗

Elizabeth Renee Wooten
Monday at 12:35 PM ·

This is Sarah. She is just one of the people that I had the privilege of getting to know this weekend. Within just a few hours of sitting and talking, we decided that we must be twins! God did a good thing this weekend and I know that there is more to come!
Ideas

• Group visits

• Collaborate with community partners

• Success breeds success (peer-to-peer)

• Streamline resources (work opportunities)

• Optimize transition period to discourage diminishing hope
Conclusions

• Evidenced Based Transition

• Program evolves constantly

• Monthly team meetings

• Find nontraditional approaches

• Find adult champions
Questions???

Contact Information:
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  205-638-5281