Transition to Independence: What We Learned From You

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Objectives

- Understand current transition, self-management, and independence outcomes for individuals with spina bifida
- Describe an academic-community research partnership
- Discuss findings from a study of barriers and facilitators to self-management, self-advocacy and community inclusion
- Understand strategies for supporting independence across the lifespan in children and adolescents with SB

Spina bifida transition to adulthood

- 75 – 90% individuals with spina bifida live to adulthood
  - **More adults than children are now living with spina bifida**

- In a recent study, median age at death in 2011 was 41 years compared to 56 years in 2022 (36.6% increase)
- In 2022, 70.8% of those with spina bifida were 40 years or older when they died (compared to 52% in 2014)

» https://www.epicresearch.org/articles/spina-bifida-patients-are-living-15-years-longer-in-2022-than-in-2011

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Transition health outcomes

Adolescents and young adults with spina bifida transitioning to adulthood experience gaps in care and barriers to functional independence and community inclusion

- High rates of health care utilization[1], hospitalization, and secondary health conditions (e.g. skin ulcers, UTIs, pain)[2,3]
  - SBA Survey of US Adults reported[3]
    - 43.1% reported skin break down in past year
    - 32.7% UTI in past 12 months
    - 46.9% pain in past 7 days
- Increased risk of depression and anxiety[4]
- Declines in overall health[5]

[1]Davis 2006, [2]Young 2014, [3]Kim 2016, [4]Morley 2020, [5]Liptak 2010, [6]Young 2006, [7]Liu 2022, [8]Barf 2009

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Self-management - definition

- Self-management for youth and emerging adults with Spina Bifida is an active daily and flexible process in which youth and their parents share responsibility and decision-making for managing their condition, health, and well-being through a wide range of knowledge, attitudes, activities, and skills. The goal of this increasing responsibility is to develop the self-management behaviors needed to achieve independence and transition to adulthood and independent living[6,7]

Self-management/Self-advocacy outcomes

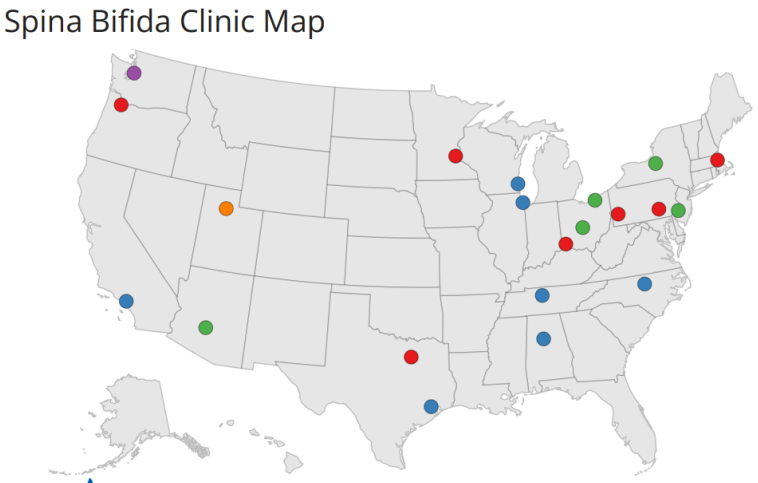
- Most children with SB achieve basic self-management and independence behaviors[8]
- Delayed levels of autonomy with self-care skills
  - Acquire skills 2 to 5 years later than their typically developing peers[9]
  - Executive functioning, inattention, and working memory issues can impact self-management learning
  - School age children perceive more independence than their parents[10]
- Healthy family functioning, with open communication and shared-decision making, is related to better self-management outcomes[11,12,13]

Education/Employment/Social outcomes

- Lower levels of education attainment and employment[5,14,15]
- Decreased levels of community participation[16]
- Fewer social relationships[5]
  - May need assistance with peer interaction skills, such as reading social cues, clarity of thought, and collaboration[17]

National Spina Bifida Patient Registry (NSBPR)

- Collects information from patients to better understand the associations between medical procedures and health outcomes
  - https://www.cdc.gov/ncbddd/spinabifida/nsbprregistry.html
- 21 clinics across the US
- 10,000 people



Employment/Education

Liu, et al 2022 (US NSBPR)[14]

- NSBPR 2009 – 2019: 1909 participants aged 18 to 26 years
- 41.8% had some post-high school education
- 23.9% employed
- Employment was associated with education level, lower extremity functional level, bowel continence, insurance, and history of non-shunt surgery
    - https://www.youtube.com/watch?v=tQBL6dqLc9I

Van Mechelen, et al 2008[18](Netherlands):

- 136 participants, age range 21 to 32
- 62.5% work participation, 22.4% in sheltered work place
- Only Level of education was predictor of work participation

Spina Bifida Coalition

- **Mission**
  - *To empower those living with spina bifida to achieve their maximum potential.*

- **Vision**

– *Empowering people. The Spina Bifida Coalition envisions individuals with spina bifida as confident, skilled and productive citizens, advocating for their own health and welfare. We see persons with spina bifida accessing a network of resources and educational opportunities to obtain transportation, explore secondary education options, make independent living choices, and acquire effective personal management skills.*
  – *We see the sharing of experiences and resources with expectant families, to ease their shift from an unexpected prenatal diagnosis to accepting a life with this complicated but manageable condition. We imagine helping families learn and implement effective advocacy skills.*
  – *We foresee a community that is knowledgeable about spina bifida, and free of misconceptions about the employability, social inclusion, transportation, and personal independence of people born with spina bifida.*

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Cincinnati Children's Spina Bifida Center

Vision

Help families and individuals with Spina bifida live life to the fullest

Mission

The Center for Spina Bifida will promote the highest level of health, quality of life, independence, and community participation for individuals with Spina Bifida through:

- Coordinated, family-centered care in a transdisciplinary model
- Delivery of care by a team of skilled, dedicated clinicians with expertise in the care of Spina bifida
- Collaboration with patients, families, health care providers, and the community
- Serving as an educational resource for patients, families, health care providers, and the community
- Promoting innovative research across the lifespan in response to the need for evidence-based care of individuals with Spina bifida

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Spina Bifida Center Multidisciplinary Team

Developmental Pediatrics:

- Jason Woodward, MD, MS
- Katherine Thoman, CNP
- Jessi Lauderman, CNP
- Jenetta Thomas, RN
- Rebecca Laiveling, RN
- Shelly Matzet, MA
- Marta Getz, MSW
- Sarah Munroe, RD

Urology:

- Brian Vanderbrink, MD
- Michael Daugherty, MD
- Katie Mueller, CNP (Bowel Management)

Neurosurgery:

- Smruti Patel, MD

Physical Medicine and Rehabilitation:

- Mary Anne McMahon, MD
- Ashlee Bolger, MD, MEd

Orthopedics:

- Junichi Tamai, MD

Research Coordinators

- Aine Powell, CRC I
- Sherrill Ingram, CRC III

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SBC & CCHMC SB Center Partnership Development

Spina Bifida Coalition &

Cincinnati Children's Spina Bifida Center

- Well-established academic-community partnership
- Long history of collaboration (educational webinars, camp, clinic-connect, etc.)
- CCTST Partnership Development Grant in 2019
  - Community Engaged Participatory Research

SBC-C & SBC Spina Bifida Action Research

- Long term goal: Develop evidence-based clinical and/or community-based interventions that improve the health outcomes, quality of life, and community participation of AYA with SB as they transition to adult health care and adulthood

- Critical need: to understand the **specific barriers and facilitators** that impact
  - the health, self-management, self-advocacy, and community participation of AYA with SB
  - transition to a healthy adult life for AYA w/ SB

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Community Based Participatory Research Method

Stakeholder Identification
(aka Study Population)

- Individuals with spina bifida 12 years and older
- Parents and primary caregivers
- Community and advocacy organizations
- Healthcare providers
  - Adult
  - Pediatric

For people with spina bifida

Academic-Community Research Team

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Ashley Jenkins

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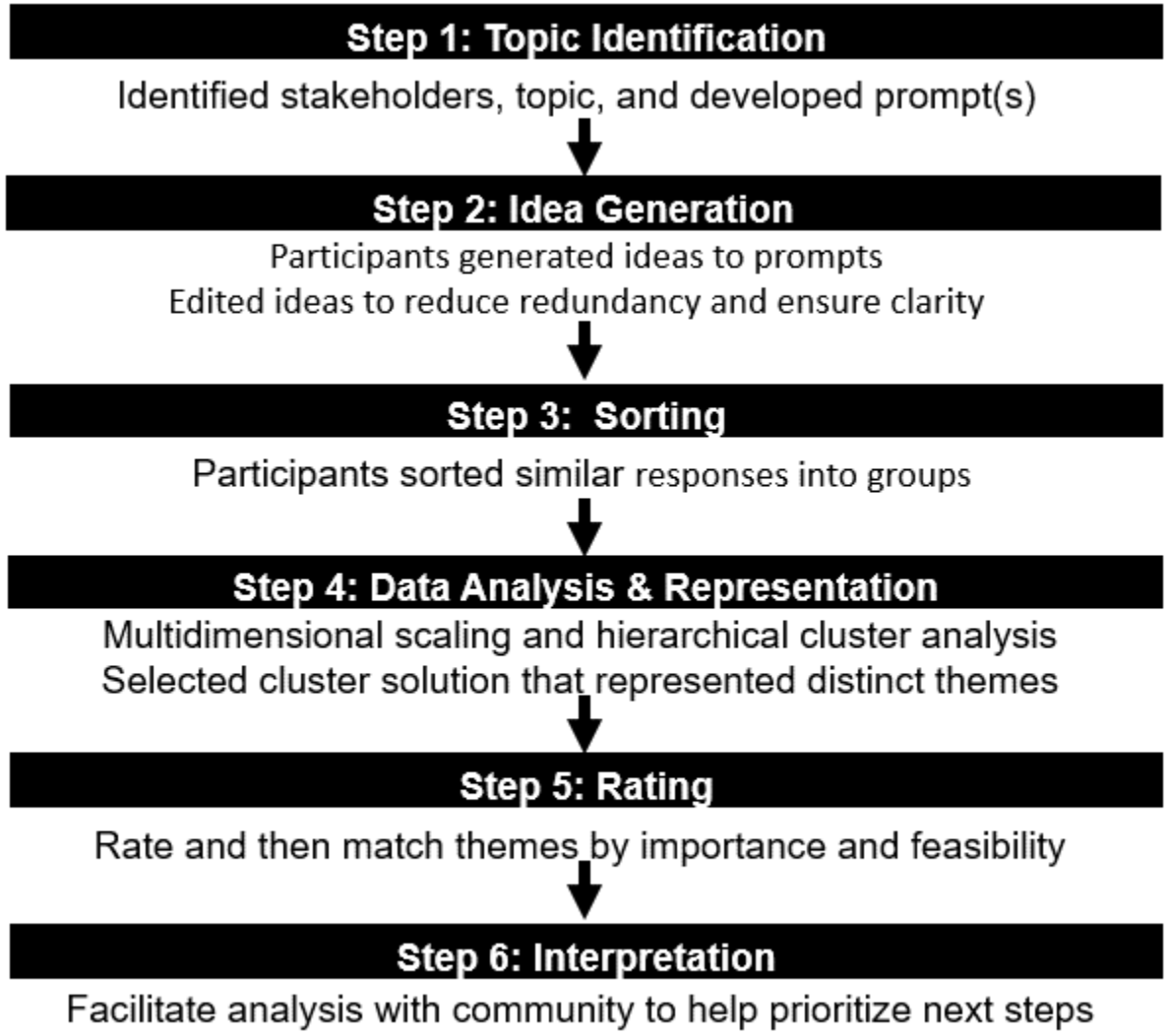
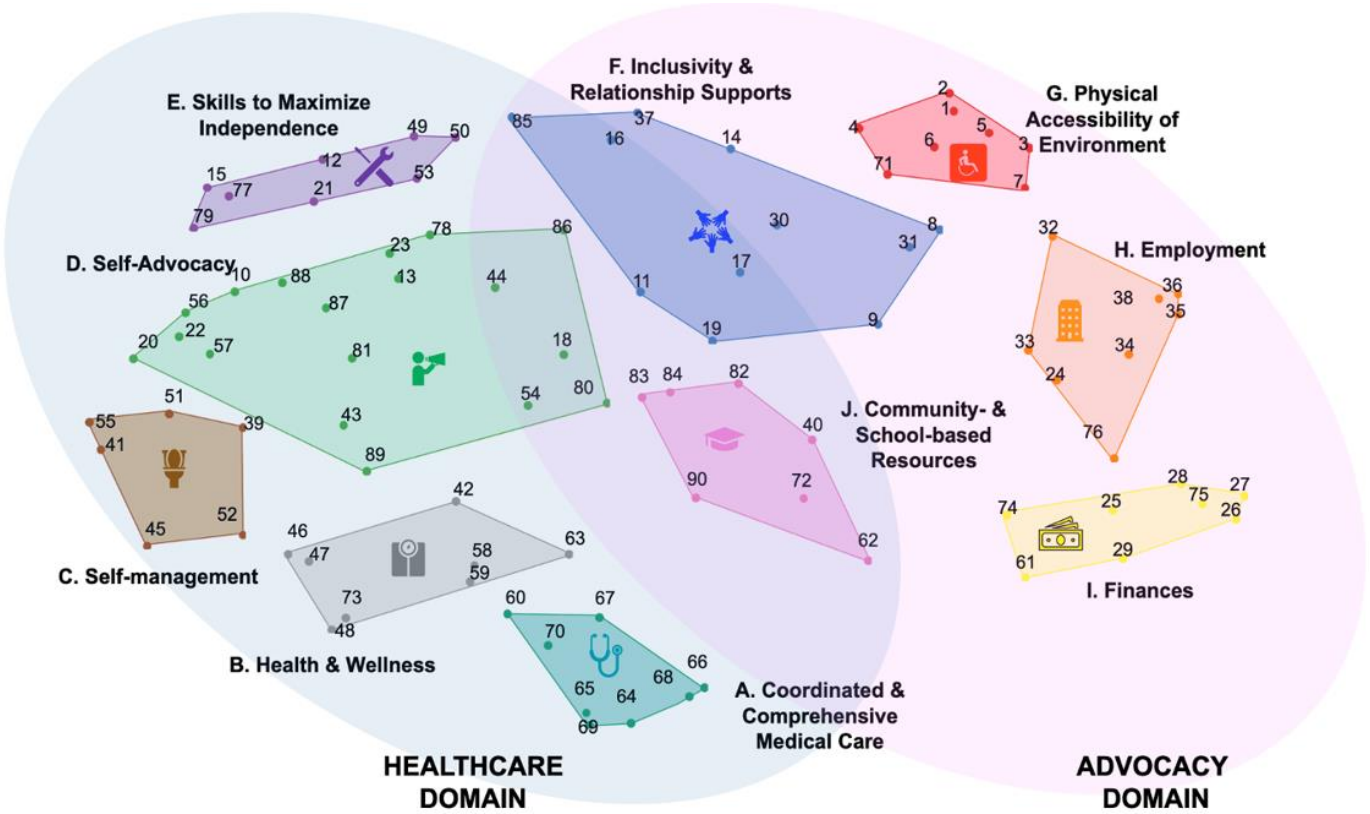
Concept Mapping Methods



SB Transition Concept Mapping Study

Concept Mapping Methods:

- “To be a healthy adult living with spina bifida, I believe I need… ”
- 97 Stakeholders generated 10-cluster concept map
- Prioritized 3 Transition Needs :
  - **Self-Management**
  - **Self-Advocacy**
  - **Community Inclusion/ Supportive Relationships**



[19]Jenkins *Acad Pediatr* 2021

Stakeholder Views of Self-management, Self-Advocacy, and Community Inclusion

Objectives

- To understand the barriers and facilitators that impact self-management, self-advocacy, and community inclusion and supportive relationships of adolescents and young adults (AYA) with spina bifida (SB) as they transition to adulthood

- To inform development of specific interventions to support successful transition of AYA with SB

Methods

- Mixed-methods study
- Focus groups and Informant Interviews (via Zoom)
- Surveys provided contextual and demographic information
- Participants:
  - Adolescents (14-19) and Adults (≥20) with SB
  - Parents/Caregivers of AYA with SB
  - Community Service Providers
  - Pediatric and Adult Healthcare Providers

- Recruitment: Spina Bifida clinic, SB Coalition events, newsletter, email listservs, flyers in pediatric/adult clinics, emails to providers

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Methods – Focus Groups/Interviews

- Paraphrased statements shared to facilitate discussion

Self-Management	• bathing regularly, brushing teeth, wearing clean clothes • doing bowel and bladder routines • planning daily activities
Self-Advocacy	• asking for what you need and have a right to in personal, work, and community settings • having a mentor with spina bifida
Community Inclusion/ Supportive Relationships	• inclusive camps, clubs, sports, etc. • a family that encourages you to work

- Focus groups recorded and transcribed
- Analysis in MAXQDA
  - Coded by 3 research team members (Woodward, Burns, Horick)
  - Themes developed through iterative coding process

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Domain	Focus Group - Example Questions
Self-Management	- Think about your self-management skills. What is/was most helpful in learning or consistently using these skills? - Think about your self-management skills. Are there things that make/made these hard for you to learn or do consistently every day? - When you think of your self-management skills, can you think of anything or anyone that would help you improve this skill?
Self-advocacy	- Think now about self-advocacy. Let's talk about how self-advocacy skills have been important in your daily life.
Inclusivity/ Relationship Supports	- Think about having supportive relationships and being more included in your community. How have these been important in your daily life? - What is or has been the most helpful to your having supportive relationships and being more included in the community?

Results - Participants

- 8 Focus Groups and 15 Interviews (4 AYA w SB +11 providers)
- Total of 40 study participants
  - 8 Adolescents and 10 Adults with spina bifida (SB)
  - 11 Caregivers of AYA with SB
  - 4 Pediatric and 3 Pediatric and Adult healthcare providers
  - 4 Community service providers (2 were also adults with SB)

- 29 AYA with SB & Parent/Caregivers:
  - most were female (21/29); white (25/27); with high levels of education (9/10 Adults with SB with some technical/college)
  - Mean ages: adults with SB = 31, adolescents = 16, and parents = 52

6 Themes

1. Attaining autonomy is complex
2. Planning and goal setting are necessary for autonomy and inclusion
3. Self-knowledge is critical to autonomy
4. A network of support facilitates independence
5. Constant care responsibilities and exhaustion inhibit engagement
6. Self-advocacy requires confidence and motivation

Attaining autonomy is complex

Facilitators

- Expectation of independence by family, school, providers
- Expectation of community inclusion by society – considering disability when designing activities and environments
- Developmentally appropriate and tailored life experiences

Barriers

- Not involving youth/young adult in care or decision making discussions
  - Eg. Providers talking to parents at appointments
- Caregivers not allowing extra time for youth/young adult's skill development

“And it may look different the way that I do things, even though it's the same task and the same end goal. And I think that we share that, whether we have kids or not, we do things differently in our lives. … we've got to figure it out for ourselves, how does this work? There is no right or wrong way to do something as long as it's done, is how I feel about stuff.”

- Adult with SB who is a parent

Planning and goal setting are necessary for autonomy and inclusion

Facilitators

- Detailed and regular planning for daily activities
  – Eg. transportation, accessibility, social-continence
- Realistic goal-setting
- Breaking goals into manageable steps and scaffolding
- Establishing routines

Barriers

- Lack of planning and the potential for negative health consequences
- Executive function challenges

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Regarding transportation:

“I want her to be involved in all kinds of activities and do what she needs to do and go out with her friends, but I don't always want to have to be the one to transport her. With other kids who may not have wheelchairs, they can just get a ride with their friends or their friends' parents can take them or their friends have cars and they can take them around. I don't have that option.”

- Parent of adolescent with SB

Self-knowledge is critical to autonomy

Facilitators

- Parents encouraging the youth to learn about health needs and to participate in health appointments and Individualized Education Programs from an early age
- Health care providers involving youth/young adults in health discussions and treatment options
- Peer relationships and online support groups
- Voc/Ed programs and Special Education staff in school

Barriers

- Unnecessary parental intervention
- Cognitive delays

One of the things I run up against is young people who are not quite as comfortable and educated about what their needs are. Their parents have done it all for them, and they either have not wanted to learn, have been hesitant to learn, or just weren't explained in a way that was understandable to them.

-Healthcare Provider

A network of support facilitates independence

Facilitators

- Mentors/Coaches/Camp Counselors
- Peer relationships with ***and*** without SB
- Community-based supports
- Parents

Barriers

- Parents/individuals not connecting to available supports
  - Eg. lack of awareness, motivation, concern over using limited resources

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I personally have multiple mentors that have made a huge impact on my life and career decisions, life decisions, personal things. And so, I look to a lot of these people for just advice. And so, I think that's so powerful.

-Adult with spina bifida

Constant care responsibilities and exhaustion impact engagement

Facilitators

- Scheduling bowel program around planned activities
- Utilizing outside supports
  - Eg. aides, respite, cleaning/laundry service, etc.

Barriers

- Physical daily activities are more taxing
- Time consuming and often unpredictable bowel regimen
- Excessive health responsibilities for individual, romantic partners, and family members can feel overwhelming
- Fatigue exacerbates executive function challenges
- No time left for pleasurable recreation

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But with the bowel routine, she's totally dependent on us. And then it affects social life and other things you want to do because you're spending so much time at and it's frustrating for them and to us. You basically have to schedule your whole life around doing that.

-Parent of adolescent with spina bifida

Self-advocacy requires confidence and motivation

Facilitators

- Making lists
- Breaks to de-escalate negative emotions
- Positive life experiences
- Opportunities for problem solving

Barriers

- Complex systems – Eg. insurance, waivers, etc.
- Executive function challenges
- Depression and anxiety

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When things don't go the way that I think that I know that they're supposed to, like they have in my past, like for a medical appointment or something I need to figure out like transportation…I will shut down and I will just not want to do it, not want to go, not want to do what I have to do, just say forget it.

-Adult with spina bifida

Strategies

- Planning daily activities, including bowel and bladder regimens and transportation, to promote community inclusion
- Setting realistic, achievable goals to increase confidence and motivation
- Educating youth about SB and its specific impact
- Increasing opportunities for mentorship and peer relationships
- Accessing supports outside of the family to alleviate feelings of exhaustion
- Modeling and scaffolding skills to increase development of autonomy
- Tailoring experiences to the appropriate level for the individual

Current /Proposed Interventions

- Multiformat parent education on importance of detailed daily planning, realistic goal-setting, breaking up tasks into smaller steps, allowing the time to practice and master skills, etc.
- Program that brings together adolescents and adults with SB for fun activities to organically foster mentorship and peer relationships

- Spina Bifida Center providers involve patients in discussions of their health and treatment options from an early age
- Proposed: Transition Coach/Navigator to connect emerging adults to resources (such as mentors), support planning and skill development, address barriers such as transportation, and promote adherence to healthcare guidelines for adults with SB

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I think there's an opportunity for a definite one-on-one, hands on type of thing. But even an opportunity for more of a hands off type of caregiver or coordinator or something like that, that is kind of tailored to the specific person. …. They have different levels of needs. And so tailoring what type of coordination or caregiving they need, I think that's huge.

- Parent of adolescent with spina bifida

Guidelines for the Care of People with Spina Bifida

- Initiative of the Spina Bifida Association
  - Fourth Edition
- 24 Work groups
  - Literature Review
- Provide the best, most scientifically-based and up-to-date care guidance for persons living with Spina Bifida
- More robust coverage of adult care needs
- New topics: Transition and Quality of Life

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Guidelines for the Care of People with Spina Bifida

- Each of 24 Topics includes:
  - Outcomes: Primary, Secondary, Tertriary
  - Clinical Questions and Guidelines
    - Organized by age groups: 0-11 months; 1-2 years; 3-5 years; 6-12 years; 13-17 years; 18+ years
  - Research Gaps
- Spina Bifida Association. Guidelines for the Care of People with Spina Bifida. 2018. http://www.spinabifidaassociation.org/guidelines/

- https://youtu.be/xQfgx3f5Svo

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Strategies to support Independence

Occupational Therapy Perspective and a Mom to Jackson

- “When preaching to the choir, remember that they are already believers, so focus on inspiring them to action” Unknown

Birth to 11 months

- Familiarize self with developmental milestones
- Independence with feeding, holding a bottle, sippy cup (adaptive devices PRN)
- Premobility- tummy time, rolling, sitting, balance, crawling, pull to stand (bumbo seats, boppy pillows, tummy time mats)
- Sensory play
- Referrals for Early Intervention or outpatient therapy
- Online supports for parents
- Community- play groups, Kindermusik

1 to 2 years 11 months

- Continue with mobility skills
- Refined self feeding, FM skills, sensory play
- Trial of devices, gait trainers, walkers, wheelchairs, bumbo wheelchairs, crutches, orthotics, adaptive bikes/trikes
- Environmental exploration, in home, community (malls, playgrounds, library, museums, community activities)
- Involve child in routine and decision making, allowing to choose between 2 items for picking out clothing, meals/snacks, books/toys
- Involve child in clean up of toys, clean up of ADL's
- Accessible playgrounds, water parks, SB events, community events
- Preschool (K2)
- Online supports for parents


EXPRESS
TICKETS

3 years to 5 years 11 months

- Transition to school (EI to school-based services, outpatient services)
- Bathroom equipment, grab bars, tomato toilet seat and others, shower chair/benches, step stools
- Wheelchair accessibility for sinks
- Upper body dressing
- Teeth brushing
- Hand washing
- Putting on/off slippers/socks
- Lower body dressing based on balance and orthotics (utilize bar for support)
- Bathing
- Fine motor skills (handwriting, coloring, crafts)
- Supporting advocacy skills
- Community (adaptive dance, gymnastics, tutoring, adaptive sports, Kindermusik, swim)

6 years to 12 years

- Routines/schedules/timers/watches/reminders
- Catheterization independence (may seem overwhelming, break into small steps) hand washing, supply gathering, hand over hand assist
- Set small achievable goals for yourself and child ☺
- Practice, practice, and more practice
- Bowel routines (Supply management, can vary based on individual bowel program)
- Skin care/ awareness
- Medication (remembering when, familiar with medication and what are side effects)
- Awareness of allergies
- Equipment management/care
- School routines, managing items at school, accessibility in bathrooms, adaptive PE or adaptations
- Start to initiate strategies to use as reminders, stay on task
- Advocacy skills continued
- Community supports (adaptive sports, theater, library-based programs, art programs, summer camps)
- School based therapy, outpatient

13 years to 17 years

- Cont with independence on ADLs all self care (bowel/bladder)
- May need to alter equipment if mobility changes as well as with growth
- Medication management, following a schedule
- IADLS (home management, making a snack, meal, chores, supply management)
- Transition to adulthood for independent living
- Assist in managing appointments
- Transportation
- Driving (Driving Specialist)
- Adaptations for driving
- Vocational Rehab/Transition programs in high school
- Community activities/accessibility
- Online support /safety with online
- School based therapy/outpatient

18-transitions to adulthood

- Cont to support independence with ADLs, IADLs, mobility, community mobility, transportation
- College
- Job Training (Voc Rehab)
- Altered schedules, part time vs full time
- Remote work
- Healthcare management (schedule appointments, medication management, equipment management, insurance, programs available for support)
- Financial planning
- Advocacy
- School based therapy/outpatient

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Resources

- http://www.spinabifidaassociation.org/guidelines/
- www.gottransition.org
- Health Care Transition Support Videos for People Impacted by Spina Bifida: https://www.aap.org/en/patient-care/spina-bifida/resources-for-families/health-care-transition-support-videos-for-people-impacted-by-spina-bifida/
- CDC - Living with spina bifida https://www.cdc.gov/ncbddd/spinabifida/living.html
- Spina Bifida transition readiness questionnaire https://www.etsu.edu/com/pediatrics/traq/default.php

Resources

Disability Services Resources

1. Disability and Health Information: www.cdc.gov/ncbddd/disabilityandhealth
2. Disability Services Information: https://www.usa.gov/disability-services
3. Social Security Disability (SSI and SSDI): https://www.ssa.gov/benefits/disability/ ; https://www.usa.gov/social-security-disability

Education/Employment Transition

1. Post-secondary Education for youth with intellectual disabilities: www.thinkcollege.net
2. Office of Special Education and Rehabilitative Services: https://www2.ed.gov/about/offices/list/osers/transition/index.html
3. Vocational Rehabilitation Resources: National Technical Assistance Center on Transition https://transitionta.org/topics/vr-transition-services/

Resources

Independent Living

1. Vocational Rehabilitation and Independently Living for Individuals with Disabilities: Raise Center /SPAN Parent Advocacy Network: https://raisecenter.org/about-raise/
2. Administration for Community Living: https://acl.gov/
3. Centers for Independent Living: https://acl.gov/programs/aging-and-disability-networks/centers-independent-living
4. Independent Living Resource Utilization: https://www.ilru.org/home

Self-Advocacy

1. Self Advocacy Resource and Technical Assistance Center (SARTAC): https://www.selfadvocacyinfo.org/
2. Self-Advocates Becoming Empowered: https://www.sabeusa.org/
3. Center for Parent and Information Resources: Best Practices in Self-Advocacy Skill Building https://www.parentcenterhub.org/priority-selfadvocacy/
4. The Arc: https://thearc.org/get-involved/self-advocacy

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Cincinnati Children's Adult Motor/Movement clinic (in DDBP)

- Adults with spina bifida, cerebral palsy, childhood physical disability
- Transition Medicine and Physical Medicine & Rehab
  - Jason Woodward, MD (Internal Medicine-Pediatrics doctor)
  - Jensine Clark, MD(Pediatric and Adult Physical Medicine&Rehab doctor)
  - 2nd Thursday each month in Division of Developmental & Behavioral Peds
- Assessment/management of general SB specific needs
- Assessment/management of rehab needs
- Referrals to needed resources
- Coordination with PCP, other specialists, and community organizations
  - **Call 513-636-4611 for info/ appointment**

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Questions?

- Jason Woodward, MD MS jason.woodward@cchmc.org
- Rhonda Horick, MSW rhonda.horick@sb-coalition.org
- Amy Wix, OTD OTR/L awix@radford.edu

- Spina Bifida Center at Cincinnati Children's Hospital Medical Center 513-636-4611
- Spina Bifida Center Family Advisory Committee
  - Contact Jenetta Thomas 513-636-8059 Jenetta.Thomas@cchmc.org

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