OUTCOMES:
Across the lifespan, individuals with SB will:

- **Primary**: Increase (or maintain) the amount of daily physical activity participated in at the different age levels.
- **Secondary**: Increase knowledge and awareness of physical activity (i.e., benefits, safety, what/how to do it)
- **Tertiary**: Improve health outcomes through physical activity participation across the lifespan (holistically- maintenance of function, prevent secondary conditions, mental health)

**Infancy**

- **Clinical Questions**
  1. Is there evidence that the early motor skill intervention increases physical activity across the lifespan?
  2. How early should doctors and therapists talk to parents/caregivers about physical activity for infants/children with SB?
  3. Are physical activity goals included the Individual Family Service Plan (ages 0-3) (beyond physical and occupational therapy)?

- **Guidelines**
  - Conduct infant motor skills assessment to evaluate motor dysfunction in infants with SB to determine the best intervention to improve motor outcomes.¹
  - Provide guidance to parents, and include physical therapists, about how to encourage movement and activity in their infant.²
  - Inform parents of their child’s rights to early intervention services that include adapted physical education/activity and encourage parents to advocate for physical activity goals to be added to the IFSP plan.³

**Toddler**

- **Clinical Questions**
  1. What strategies work to educate parents about physical activity importance and ways to get their child involved?
  2. How early should parent education about physical activity start? What resources are available?
3. What is the most successful way to encourage parents to invest (time and money) in physical activities for their young children with SB?

**Guidelines**

- Discuss with parents the importance of involving toddlers with SB in formal and informal recreation, physical activity, and social programs/services where they can be actively engaged with their disabled and non-disabled peers.
- Discuss with parents the benefits of physical activity to both physical and mental health.
- Discuss the importance of parental modelling physical activity as part of a healthy lifestyle.
- Provide parents with information and/or resources about adapted and inclusive activities for their child.
- Use motivational interviewing techniques to talk about physical activity goals and work through barriers.4
- Inform parents of their child’s rights to adapted physical education/activity and encourage parents to advocate for physical activity goals to be added to their Individualized Family Service Plan.3

**Preschool**

**Clinical Questions**

1. Given that many of these children will be limited in their physical function, when and what activities should they be exposed to (e.g., typical kids start playing baseball, soccer and other team sports at age 4-5)?
2. Should kids with SB start similar activities at the same age?
3. What training will coaches need to welcome our kids to meaningful play?
4. How does proper/improper mobility equipment affect the youth’s ability to participate in physical activity (e.g., a wheelchair that fits properly, proper seating and back set up, AFO’s, crutches, etc.)?
5. Related to physical activity/exercises that help maintain function- upper and lower body- Who can parents and doctors consult (e.g., PT, OT, Recreation Therapists, fitness staff, NCHPAD)?

**Guidelines**

- Discuss with parents the importance of involving children with SB in formal and informal recreation, physical activity, limiting sedentary behaviors and social programs/services where they can be actively engaged with their disabled and non-disabled peers.5
- Discuss strategies that balance the parent’s involvement with their child’s need for independence to participate in physical activity.6
- Discuss life-long benefits of physical activity e.g. active adults with SB report more functional independence and a higher quality of life compared to those with SB who are inactive.7
• Use a team approach and include PT/OT’s to work with parents to ensure kids have proper fitting mobility equipment to maximize physical activity participation.
• Educate parents of their child’s rights to adapted physical education/activity in preschool and encourage parents to advocate for physical activity goals to be added to their Individualized Family Service Plan.³,⁸

School Age

➢ Clinical Questions

1. What are life-long activities that do not predispose to shoulder injury or skin injury? How young can these realistically be started (e.g., snow skiing, riding, power soccer, sled hockey)?
2. What are some strategies to continue physical activity (or physical education) when in the hospital or after a long hospital stay (e.g., Theraband stretches, increasing knowledge of physical activity-reading/lecture style- if no PA/movement is allowed)?
3. Is there evidence about the benefits/effects on physical activity levels of youth with SB advocating for themselves on their physical education goals in their Individualized Education Program meetings?
4. Does the evidence support adapted physical education vs. Inclusive physical education? Is this support related to health or socialization, something else, or all three?
5. What training do schools need to include children with SB in meaningful play throughout the day (at recess, physical education class, on-site afterschool programs)?
6. What are some ways that physical education teachers can be more inclusive of children with SB? How do we start this process as early as possible?
7. In school age and older age groups, address how sports can improve self-esteem. The vast majority of people in adapted sports programs are people with adult onset conditions so it is important to know how involving kids with SB at early ages could improve self-esteem (as opposed to getting them involved later as teens).
8. Are kids more likely than adults to join adapted sports programs? Does getting a child engaged in sports at a young age improve the likelihood that they will remain engaged in activity throughout their lifespan?

➢ Guidelines

• Discuss with parents the importance of involving children with SB in formal and informal recreation, physical activity, limiting sedentary behaviors and social programs/services where they can be actively engaged with their disabled and non-disabled peers.⁵
• Advocate for the participation of all children, including those with SB, in sports and physical activity programs.⁹
• Inform parents of their child’s rights to adapted physical education/activity and
encourage parents to advocate for physical activity goals to be added to their child’s Individualized Education Plan.

- Encourage parents to consider the environment in which their child feels most comfortable being physically active—some children feel more comfortable with other children who have similar abilities. Others want to be included in activities alongside people with all abilities.¹⁰
- Support parents to develop an action plan of behavioral strategies to support their child’s physical activity.¹¹
  - Develop a local/regional therapeutic recreation and adapted sport resource guide.¹⁷
  - Identify and provide addition support to parents for youth with shunts and lower motor function.¹⁷
  - Discuss strategies that balance the parent’s involvement with their child’s need for independence to participate in physical activity.⁶

Teenage

- Clinical Questions
  1. Do adapted physical education programs in schools adequately prepare (via transition plan) students with spina bifida to lead physically active lifestyles?
  2. What are the physical activity contraindications for teens with SB?
  3. What are the types of physical activity used or recommended in the literature specific to teens with SB (resistance, cardio, incidental activity vs. planned physical activity/exercise)?
  4. What is the best setting for physical activity for teens (e.g., in a group, at home, etc.) where they are most comfortable and likely to continue participation?
  5. What are the doses of physical activity used or recommended in the literature for teens with SB? Are they effective for health changes?
  6. Is physical activity included in the teen’s Individualize Transition Plan (the plan post high school graduation)?

- Guidelines
  - Discuss with teens with SB the importance of reducing sedentary behaviors and being involved in physical activity where they can be actively engaged with their disabled and non-disabled peers.⁵
  - Prescribe physical activity for youth with SB.¹²
  - Educate the teen and parents of their right to adapted physical education/activity and encourage the teen and parent to advocate for physical activity goals to be added to their teen’s Individualized Education Plan.
  - Explore the settings where teens with SB feel most comfortable being physically active—some teens feel more comfortable with other children who have similar abilities. Others may want to be included in activities alongside people with all abilities.¹⁰
    - Use motivational interviewing techniques to talk about physical activity goals and work through barriers.⁴
    - provide a local/regional therapeutic recreation and adapted sport
resource guide to teens.

• Highlight that adolescence is a critical period for building physical activity into the daily routines of persons with SB in an effort to preserve overall lifelong satisfaction and community participation.13

For all children & teens:

• There are no national guidelines specific to the amount of physical activity that children and teens with SB should participate in, however, there are national guidelines for the general population of children/teens (ages 6-17 y/o).14 These guidelines should be followed as close as possible for children/teens with SB unless medically unsafe as advised by a doctor.
  
  ▪ 60 minutes of physical activity or more each day14:
    
    o Aerobic activity should make up most of the youth’s activity each day; vigorous intensity aerobic activity should be done at least 3 days/week
    
    o Muscle strengthening activities should be done at least 3 days/week as part of the 60 or more minutes
    
    o Bone strengthening activities should be done at least 3 days/week as part of the 60 or more minutes

• Include a discussion on physical activity at yearly doctor’s appointments and follow up in subsequent years to check on goals met.

• Understand the benefits of the participation of youth with disabilities in sports and physical activities.9, 15

• Perform pre-participation evaluations for youth with disabilities in collaboration with the youth and family, pediatric specialists, therapists, coaches, and others to identify medical risks participating and modifications that can be made to ensure participation.9
  
  ▪ Identify strategies to minimize risks of illness and injury related to participation through activity adaptations and safety precautions.9

• Recognize and reduce child, family, and societal barriers to the participation of youth with disabilities in physical activity and sports.9
  
  ▪ Work with the youth with SB and their family to address personal barriers such as bowel/bladder care, medical events, assistive devices, as well as environmental factors.16

Adult

➢ Clinical Questions

1. What are the physical activity contraindications for adults with SB?

2. What are the types of physical activity used or recommended in the literature specific to adults with SB (resistance, cardio, incidental activity vs. planned physical activity/exercise)?

3. What is the best setting for physical activity for adults (e.g., in a group, at home, etc.) where they are most comfortable and likely to continue participation?
4. What are the doses of physical activity used or recommended in the literature for adults with SB? Are they effective for health changes?

**Guidelines**

- Include a discussion on physical activity at yearly doctor’s appointments and follow up in subsequent years to check on progress made towards goals.
- Discuss the importance of physical activity and physical activity options with adults with SB and use motivational interviewing techniques to talk about physical activity goals and work through barriers.4
  - Emphasize that any movement is beneficial.14
- Prescribe physical activity to adults with SB.12
- There are no national guidelines specific to the amount of physical activity that adults with SB should participate in, however, there are national guidelines for the general population of adults.14 These guidelines should be followed as close as possible for adults with SB unless medically unsafe as advised by a doctor.
  - All adults should avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits.14
  - For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.14
  - For additional and more extensive health benefits, adults should increase their aerobic physical activity to 300 minutes (5 hours) a week of moderate-intensity, or 150 minutes a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount.14
  - Adults should also include muscle-strengthening activities that involve all major muscle groups on 2 or more days a week.14
RESEARCH GAPS

1. What are the barriers and facilitators to meeting the required weekly moderate to vigorous physical activity at different ages across the lifespan?
2. What are the different physical activity strategies needed for individuals with SB living in rural areas v. cities at different ages?
3. What are the social/environmental strategies/solutions (e.g., need for accessible facilities, knowledgeable staff, etc.) needed to get individuals with SB physically active?
4. What are the strategies/solutions needed to intrinsically motivate individuals with SB to be physically active (e.g., peer support, increased knowledge, self-efficacy, etc.)?
5. What are the consequences of sedentary behavior specific to individuals with SB and how early are the consequences of sedentary behavior evident?
6. How can we best educate and train parents and individuals with SB to be advocates for their inclusion in physical activity in their communities at large?
7. What physical activity resources are available for doctors nationwide, locally? What resources need to be created?
8. What physical activity and/or exercises can help maintain function- upper and lower body during the different age groups?
9. Is there (or what is the strength of) evidence that physical activity prevents secondary conditions?
10. What is considered excessive physical activity/exercises that may cause injuries?
11. What are the social/health benefits of participating in physical activity for individuals with SB at different ages?
12. What resources or programs are available to increase physical activity at different life stages?
13. Are there any treatments to increase physical activity in PT or OT that are being developed or researched?
14. Which types of exercise are best for certain age groups? For example, if an adult has not tried any exercises, are there recommendations for where to start out? Or, are the recommendations the same as for the general population?
References:

5. Law et al., 2007. Patterns of participation in recreational and leisure activities among children with complex physical disabilities