



# SPINA BIFIDA COMMUNITY-CENTERED RESEARCH AGENDA

## 1. Bowel Continence

- 1.01 How do long-term, large volume bowel irrigations, antegrade and retrograde, effect colorectal health and bowel continence?
- 1.02 What is the association between bowel continence in childhood and early teen years on the transition to adulthood (specifically looking at outcomes of employment, college, intimacy, and independence)?
- 1.03 Does initiation of a bowel program before age 3 (or 5), predict long-term bowel management compliance? Does it predict short or long-term bowel continence outcomes?
- 1.04 Does close follow-up after changing a bowel program predict short or long-term improved bowel continence outcomes?
- 1.05 What clinical factors predict improved bowel continence?
- 1.06 What modifiable factors have the largest effect of closing the health disparity gap of fecal incontinence?

## 2. Mental Health

- 2.01 What is the correlation of depression and degree of involvement in community activities (working, volunteering, playing adaptive sports) for adults with SB?
- 2.02 Specific to children with SB, what are the mental health concerns faced by their parents, and what systems and structures are needed to address those effectively?
- 2.03 What generates Mental Health inequities faced by individuals with SB (e.g., lack of access to care, bias/discrimination in the healthcare system, lack of education among providers about how to meet the needs of individuals with SB, particularly those who are also part of other minority groups)?

- 2.04 What factors that support mental health are correlated to a better quality of life in those with Spina Bifida (e.g., social support, mentorship, physical activity, transportation, level of education, etc.)?
- 2.05 Do treatments for mental health disorders have significantly different effects in those with Spina Bifida?
- 2.06 What types of system changes are needed to confront MH inequities experienced by individuals with SB (e.g., more education for healthcare providers, etc.)?

### **3. Self-Management**

- 3.01 How do factors (e.g., cognitive ability, executive functioning, gross motor delays, surgeries, parental readiness, social factors) interact with introduction (i.e., early intervention) of self-management interventions to influence outcomes?
- 3.02 What self-management interventions for Spina Bifida are efficacious and available for various settings - educators, mental health providers, rehab specialists (i.e., PT, OT, Speech)?
- 3.03 How can we support individuals and families in the development of self-management skills, ability, responsibility, strategies, techniques, behaviors across settings and lifespan (early childhood, middle childhood, adolescence, young adulthood, adulthood, older adult, etc.)?
- 3.04 How do factors that predict self-management behaviors in youth impact outcomes (e.g., health, employment, quality of life) in adults and their family?
- 3.05 How does executive functioning of the individual (adult populations) play a role in their self-management ability?

### **4. Transition**

- 4.01 How can medical professionals help parents to support their children to become adults?
- 4.02 What can health care workers do to best support transitioning adolescents to adult services?
- 4.03 For adults with SB who are or were working, what helped make their move to employment successful?

- 4.04 Identify barriers specific to minority individuals with SB in acquiring the skills for moving into the adult world and ways to overcome them.
- 4.05 What are the most important actions that help or hinder children with SB in learning the skills needed to successfully become an adult?

## **5. Urinary Continence**

- 5.01 What is the change in continence for those who have a bladder neck procedure carried out (1 year, 5 year, 10 years post-op)? What is the change in continence for those who undergo bladder augmentation (1 year, 5-year, 10-year post-op)?
- 5.02 Is there a change in the number of confirmed UTIs an individual has after bladder surgery?
- 5.03 What is the association between time and type of training/information provided for intermittent catheterization and compliance?
- 5.04 What is the rate of frequency that urinary continence is discussed in relation to its effects on sexuality and sex?
- 5.05 Does proximity to a multi-disciplinary SB clinic affect urinary continence outcomes and renal function? What are modifiable factors that can decrease the health disparity of urinary continence in the SB population?

## **6. Weight Management**

- 6.01 For people with Spina Bifida who have been able to maintain and/or improve their health, what factors led to their success? (e.g., nutrition, physical activity, regular sleep, weight management, etc.)
- 6.02 What things make it difficult for someone with a disability to exercise regularly (e.g., expense of exercise equipment, cost of gym membership, lack of availability of disability-friendly gyms/classes, limitations of handicapped accessibility outdoors, etc.)?
- 6.03 What difficulties do adults with a disability encounter in healthy eating and independent food preparation (e.g., mobility obstacles in cooking, and grocery shopping, etc.)?
- 6.04 How do the habits of someone with Spina Bifida early in life affect physical mobility and function across their lifespan?