SPINA BIFIDA COMMUNITY-CENTERED RESEARCH AGENDA

1 – Bowel Continence

1.01 How do long-term, large volume bowel irrigations, anterograde 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?