Self-Management

The work group used a primary definition of self-management from the literature on spina bifida delineating self-management for youth and emerging adults: An active daily and flexible process in which youth and their parents share responsibility and decision making for achieving control of their condition, health and well-being through a wide range of activities and skills. The goal of this increasing responsibility is to develop self-management behaviors needed for transition to adulthood and independent living. (Sawin, Bellin, Roux, Buran & Brei, 2009 adapted from Schilling Grey & Knafl, 2002).

Users may also find the following definition helpful “Self-management is the interaction of health behaviors and related processes that patients and families engage in to care for a chronic condition (Modi et al, 2012)”

Primary Outcome

Children, adolescents, and adults with SB perform self-management behaviors at the highest level of their ability.

Secondary outcome

Interventions that address the foundational skills necessary for self-management and complex self-management behaviors are introduced throughout the life span as appropriate. Self-management goals are evaluated yearly with the family, child, adolescent, and adult.

Tertiary Outcome

Adolescents transitioning to adulthood with a guardian responsible for their health care, perform condition self-management behaviors in the areas of medication management, prevention of complications, implementation of bladder and bladder program, skin surveillance, and communicate findings to their guardian and/or health care providers at their highest level of their ability.

Young adults without a guardian are fully responsible to implement condition and advanced self-management behaviors (e.g., making appointments, ordering medications, arranging for transportation, conducting basic living skills [cooking and laundry], managing money, managing insurance, and communicating with their health care provider).

Prenatal/Infancy (Through Age One Year)
Clinical Questions
	• What are the approaches that optimize individual and family self-management?

Guidelines
	• Provide orientation to families that include the expectation for optimal self-management according to individual’s SB status and age (see prenatal guidelines).
	• Provide instruction and support to families regarding knowledge and skills needed to manage their infant’s SB and related issues.
	• Evaluate and support family function (see family guidelines).
	• Identify and makes referrals to early intervention programs.

Evidence Available
	No evidence available.

TODDLER (1-3 YEARS)

Clinical Questions
	• What are the approaches that optimize individual and family self-management?

Guidelines
	• Provide anticipatory guidance regarding developmental needs of children (such as exploration of environment, routines, and age-appropriate choices).
	• Provide instruction and support to families regarding knowledge and skills needed to manage their toddler’s SB and related issues.
	• Teach families to offer daily age-appropriate choices such as choice between two articles of clothes, two cereals for breakfast, and two books to read, etc.
	• Encourage families to expect participation in daily life activities, including such things as picking up toys, cleaning up, and imitating housework.
	• Identify and make referrals to early education programs.

Evidence
	In all children autonomy and independence is fostered by opportunity to make choices and to develop a sense of mastery. The foundation for self-management is begun when children can learn to make choices. To develop autonomy skills, children need to have experience making choices throughout childhood, beginning in the toddler stage.

PRE-SCHOOL (3-5 YEARS)

Clinical questions
	• What are the approaches that optimize individual and family self-management?

Guidelines
• Provide instruction and support to families regarding knowledge, skills, and behaviors needed to manage their pre-schooler’s SB and related issues.
• Discuss the need to expand range of daily life activities and chores and the use of strategies to achieve this expansion that accommodates the child’s learning style and/or mobility.
• Provide guidance that developing autonomy skills is maximized when there are clear and consistent consequences for inappropriate behavior (see mental health guidelines).
• Identify and makes referrals to community resources which promote self-efficacy such as early education programs.

Evidence
Research on self-management skill development in pre-school youths with SB is sparse. A recent systematic review of self-management interventions identified only two studies specific to SB populations, and neither included pre-school aged samples (Lindsay, Kingsnorth, McDougall, & Keating, 2014). However, findings from cross-sectional research with interdisciplinary healthcare providers suggest that (a) SB self-management education efforts should be initiated during the pre-school period and (b) a developmentally appropriate SB self-management task for youths aged 3-5 years with moderate severity (e.g., low lumbar lesion level, ambulation with ankle-foot braces, shunted hydrocephalus) is assisting parents in catheterization (Greenley, 2010). Since most SB providers surveyed perceived all bowel, bladder, and skin care skills as attainable for youths with low-to-moderate SB severity, tailored education on these topic areas is critical in clinical counters with pre-school aged children and their parents.

SCHOOL AGE
Clinical Questions
1. What are the approaches that optimize individual and family self-management?
2. What self-management skills, abilities, and behaviors should be targeted at school age?
3. Does specific self-management skill training improve self-management behaviors (e.g., taking medication)?
4. What instruments are available to measure self-management skills, abilities, and behaviors in school age youth?

Guidelines
• Provide instruction and support to youth and families regarding knowledge and skills needed to manage SB and related issues. Teach child basic self-management skills, including skills to prevent secondary conditions (CIC, skin care, equipment care, bowel and bladder care, wheelchair maintenance and propulsion) based on individual abilities. Youth with SB may develop foundational skills and SM behaviors at a slightly later age (2-5 years delay) and may need more deliberate practice. However, most SM behaviors are achievable by most young adults with SB.
• Assist families in knowing how to incrementally involve the child in organizing school work and self-management activities and how to begin to transition to parental supervision.
• Discuss the need to expand range of daily life activities and chores and the use of strategies to achieve this expansion that accommodates the child’s learning style and/or mobility.
• Serve as a resource to school systems regarding transportation, learning skills, health
issues, and development of self-management skills.

- Emphasize positive attitudes, self-esteem, assertiveness and self-empowerment.
- Assess peer relationships and encourage peer involvement.
- Assess bladder and bowel management programs for eventual independent self-management.
- Consider using an age-and condition-appropriate assessment instrument (see SM instrument appendix) especially if the child has executive functioning impairments.
- Discuss with parents the need to help their child develop basic money management skills.
- Support the development of language with purposeful interactions and activities.
- Encourage use of technology to enhance self-management.

Evidence

Adolescents with Spina Bifida have been found to need longer to learn autonomy skills than peers (Davis, Shurtleff, Walker, Seidel, & Duguay, 2006). The patterns of self-management differ from children with other chronic health conditions. We can assume that these challenges begin in the school age period and appear to be associated with neurocognitive functioning (Heffelfinger et al., 2008). Studies of adolescents found responsibilities such as chores and higher decision-making were related to increased SM behaviors (Buran et al. 2004). Although no study addresses these typical responsibilities in school agers, these skills are developmental and need to be started in the pre-school years and expanded substantially during school age years. Children with SB who have working memory and executive functioning problems may need more practice and supervision to gain these skills than typically developing peers (Heffelfinger et al., 2008). In addition, there is a positive relationship between language and performance of independence tasks (Vachha & Adams, 2009). Survey research with 97 multidisciplinary providers at SB clinics across the US identified the following self-management behaviors as expected milestones for school-age youths with moderate condition severity: (a) assist parent in completing bowel program; (b) perform pressure relief exercises/weight shifts correctly and complete skin inspections daily; (c) identify objects that may contain latex; (d) perform self-catheterization independently; (e) recognize signs of bowel problems, urinary tract infections, or skin problems and report to parent; and, (f) clean up following bowel or bladder accident (Greenley, 2010).

Intervention research to enhance self-management in school-aged youths with SB is similarly modest in scope. Camp-based psychosocial interventions promoting skill-building have shown promise in developmentally diverse samples of youths with SB inclusive of children as young as 7-12 years (Holbein et al., 2013; O'Mahar, Holmbeck, Jandasek, & Zukerman, 2010). Self-report and parent data suggest improved condition self-management and independence following child participation in (a) goal-setting facilitated and monitored by trained counselors and (b) daily group psychoeducation workshops. A second SB specific intervention used a problem-solving model delivered over two 60-90 minute sessions to help parents and children with SB (8-17 years) identify barriers to self-management and set goals to improve child self-management skills through joint education and home/community practice (Greenley, Holmbeck, Zukerman, & Buck, 2006). Preliminary findings indicated improved child self-management skills and decreased parent burden.

Longitudinal studies have also increased awareness of the complexity of self-management skill development in school-age youths with SB. Major findings reveal discrepancies in how school-age children with SB and their parents rate independence and
shared responsibility in the medical management of SB, with children perceiving themselves as being more independent relative to parent assessment (Psihogios & Holmbeck, 2013). Challenges with the family and child carrying out diet recommendations and skin care protocols also surface in the school-age developmental period (Psihogios, Kolbuck, & Holmbeck, 2015). In addition, outcomes are enhanced when parents are involved in self-management for school age children and early adolescents (Psihogios & Holmbeck, 2013).

A specific instrument (Kennedy Krieger Independence Scale—SB Version) address SM in those with executive functioning challenges (Jacobson et al., 2013). Learning skills affect the child’s capacity for self-management and may require specific interventions.

**TEEN AGE**

1. What are the approaches that optimize individual and family self-management?
2. What self-management skills, abilities, and behaviors should be targeted to the adolescent?
3. Does specific self-management skill training improve independence with self-management behaviors (e.g. taking medication, skin checks)?
4. What health care self-management skills are most important for those with SB to master, or most impact health outcomes?
5. How can comprehensive preparation for self-management be integrated into a complex multi-disciplinary clinic?
6. What instruments are available to measure self-management skills, abilities and the actual performance of self-management behaviors in adolescents?

**Guidelines**

- Evaluate self-management in appropriate areas (e.g. managing medications, prevention of complications, skin care, equipment care, and bowel and bladder care, ability to make health care appointments. Assuming responsibility for health care encounters and other self-management of Spina Bifida is sequential. Full responsibility for self-management is critical for successful transition.
- Initiate discussion and develop action plans to address deficits in SM skills, abilities and behaviors as needed.
  - Use a valid and reliable instrument to assess self-management skills, abilities and actual performance of SM behaviors in adolescents.
  - Encourage increasing responsibility for behaviors such as adolescent management of medication, bowel and bladder programs, skin-monitoring.
  - Support development of skills necessary for SM (e.g., decision making, goal setting, self-regulation and communication).
  - Evaluate and monitor cognitive functions as they underpin decision-making, goal-setting, self-regulation, self-management, socialization, and transition issues (see neuropsychology guideline)
  - Assess ability to use transportation; encourage enrollment in drivers education, (adaptive) if the teen possesses cognitive/motor abilities. If driving not realistic teach (or have family teach) adolescent how to use alternate transportation (e.g., public transportation, van services for individuals with disabilities, etc.).
• Expand self-management interventions to encompass everyday living activities such as laundry, meal preparation, managing finances, making health care appointment and ordering supplies.
• Encourage family to expand range of responsibilities for daily life activities, chores, and jobs.
• Encourage participation in IEP planning that addresses self-management in transition (see transition guideline).
• Support family functioning strengths related to self-management (family satisfaction, family resources –see family guidelines).
• Discuss sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, and folic acid supplementation (see sexuality education guidelines).
• Assess individual and system barriers to self-management (e.g., school services, advocacy, assertiveness, and insufficient adult services).
• Encourage use of technology to enhance self-management.

Evidence

Self-management behaviors have been reported as low in youth with SB (Buran et al., 2004; Davis et al., 2006; Psihogios et al., 2015) with Davis et al detailing behaviors achieved in those 12-18 years old with IQ of 80 or better as 2-5 years later than typically developing peers (TYP). It is not clear if this lag is developmentally appropriate for those with SB or due to lack of expectations and support. They found basic behaviors achieved by age 12 included dresses appropriately, making shopping choices, cleans room, knows phone number, and shops with assistance. Other behaviors such as saves money, cooks pre-packed means, plans activities with peers and arranges own transportation were generally achieved during adolescents but 2-5 years later than TDP. Advanced behaviors achieved by TDP and generally not achieved by youth with SB by age 18 included does own laundry, cooks independently, manages bank account without assistance, manages allowance, makes own appointments. Participants did not generally enter adolescence with high levels of SB knowledge but developed them during adolescence (knowing signs of skin ulcer, blow problems, shunt failure and UTI). Adolescents report “every present” catherization and bowel management were seen as part of the journey of skill-building to achieve independence and report a “dance of individuation” where they need their parents involvement—but not too much (Sawin, Bellin, Roux, Buran, & Brei, 2009).

There is evidence that responsibility (chores, general decision making) are related to these SM behaviors (Buran et al., 2004; Sawin, Buran, Brei, & Fastenau, 2003). Intervention research to enhance self-management in adolescents with SB is also modest in scope. There are inconsistent findings regarding the relationship between LOL and SM behaviors, with some supporting the relationship (Bellin et al., 2011; Sawin et al., 2003) and others finding the relationship was with IQ and LOL did not add any additional explanation (Davis et al., 2006). Further, studies of adults indicate that they enter adulthood with secondary conditions
that impact their SM behaviors. Interventions to increase SM behaviors were proposed to decrease these secondary conditions (Wagner et al., 2015).

Self-management interventions for adolescents with SB and other CHC generally show at least one significant improvement (Lindsay et al., 2014). However, a short workshop-based intervention for adolescents yielded no significant differences in groups (Betz, Smith, & Macias, 2010). Camp-based psychosocial interventions promoting skill-building have shown promise in developmentally diverse samples of youths SB. Family oriented interventions may be most effective in younger adolescents (Greenley et al., 2006; Lindsay et al., 2014). Most health care providers expect young adults to have self-management skills related to bowel/bladder programs, skin checks etc. However recent data indicated both families and youth with SB have most difficulty with SM behaviors related to checking skin and managing bowel program (Psihogios et al., 2015).

There is support for the evaluation of self-management skills and behaviors with several instruments which have reliability and validity in youth with SB (Jacobson et al., 2013; Sawin et al., 2003; Sawin et al., in press)and in transition age youth generally (see appendix A). Providers need to initiate discussion of SM behavior deficits as soon as they are identified (Davis et al., 2006; van Staa, Jedeloo, van Meeteren, & Latour, 2011) to strengthen SM behaviors which are critical for transition to adulthood. Support for decision making has been shown to be important (Wagner et al., 2015) as is family support for SM (Bellin et al., 2012; Sawin et al., 2009). Monitoring of cognitive functioning is critical to SM (Heffelfinger et al., 2008; Holbein et al., 2013). Assessing system barriers can be useful (Psihogios & Holmbeck, 2013; van Staa et al., 2011). Families should be encouraged to expand range of every-day living skills and responsibilities (Buran et al., 2004; Davis et al., 2006; B. E. Dicianno, Gaines, Collins, & Lee, 2009; Peny-Dahlstrand, Åhlander, Krumlinde-Sundholm, & Gosman-Hedström, 2009; Sawin et al., 2003; van Staa et al., 2011). Although tested mostly in adults, technology holds promise for expanding SM behaviors in adolescents as well (van Staa et al., 2011). There are reliable and valid measures of SM available to clinician to assess interest in and achievement of SM. Further there are generic “readiness” scales that may be useful to assess interest in, abilities in and achievement of SM behaviors (see Appendix A). Data support some difference in report of SM behaviors between parent and adolescent although the relationship of parent and adolescent SM scores is fairly high in later adolescents/young adults than in earlier adolescents (Psihogios & Holmbeck, 2013; Sawin et al., 2006; Sawin et al., in press) and generally there is more agreement on SM behaviors when compared to other less concrete beliefs (Sawin et al., 2006).

ADULT

Clinical questions

1. What are the approaches that optimize individual and family self-management?
2. What self-management skills, abilities, and behaviors should be targeted at young adulthood?
3. Does specific self-management skill training improve independence with self-management behaviors (e.g., taking medication, monitoring skin status)?
4. What are the most effective methods for promoting self-management?
5. Is performing more self-management behaviors independently related to improved health or functional outcomes (depression, QOL, secondary conditions such as UTI, pain)?
6. Does increased independence with health care self-management increase community participation?
7. How can comprehensive preparation for self-management be integrated into a complex multi-disciplinary clinic?
8. What instruments measure the individual’s performance of self-management behaviors in adulthood?

Guidelines

- Evaluate full responsibility for self-management behaviors in appropriate areas as needed (e.g., managing medications, prevention of complications, skin care, equipment care, and bowel and bladder care, ability to make health care appointments).
- Evaluate if adult has expanded self-management to encompass everyday living activities such as laundry, meal preparation, managing finances, making health care appointment and ordering supplies.
- Initiate discussion and develop action plans to address deficits in SM skills, abilities and behaviors as needed.
  - Use a valid and reliable instrument to assess self-management skills, abilities and actual performance of SM behaviors in adults.
  - Support development of skills necessary for SM (e.g., decision making, goal setting, self-regulation and communication).
  - Evaluate and monitor cognitive functions as they underpin decision making, self-management.
  - Assess ability to use transportation; encourage enrollment in driver's education, (adaptive) if the adult possesses cognitive/motor abilities and has not done so already. If driving not realistic teach (or have family teach) adult how to use alternate transportation (e.g., public transportation, van services for individuals with disabilities, etc.).
- Encourage use of technology to enhance self-management.
- Expand discussion of sexuality, contraception (including latex allergy precautions), marriage, childbearing issues, genetic counseling, and folic acid supplementation (see sexuality guidelines).
- Encourage involvement in empowerment activities (e.g., sports, organizations, mentoring, camp etc.).
- Support family functioning strengths related to self-management (family satisfaction, family resources –see family guidelines) (Bellin et al., 2012).
- Assess individual and system barriers to self-management (e.g., advocacy, assertiveness, insufficient adult services).
- Encourage planning and use of support services (e.g., services for students with disabilities in college setting) for self-management in new environments (see transition guidelines).
- Evaluate if systematic evaluation of SM behaviors with valid and reliable instruments and
subsequent action plans to address SM deficits yield change in health status.

Evidence

Young adults with SB transitioning to adulthood are generally poorly prepared to self-manage their condition. There is support for the evaluation of self-management skills and behaviors (Jacobson et al., 2013; Sawin et al., 2003) as predictors of health status (Mahmood, Dicianno, & Bellin, 2011) and independent living (Bellin et al., 2011). Degree of disability is linked with self-management behaviors in adults (Bellin et al., 2011). Support for decision making has been shown to be important (Holbein et al., 2013; Vachha & Adams, 2009) as is family support for SM (Bellin et al., 2012; Sawin et al., 2009; Wagner et al., 2015). Monitoring of cognitive functioning is critical to SM (Heffelfinger et al., 2008; Holbein et al., 2013). Assessing system barriers can be useful (Psihogios et al., 2015; van Staa et al., 2011). Families should be encouraged to expand range of every living skills and responsibilities to full responsibility by adulthood (Buran et al., 2004; Davis et al., 2006; B. E. Dicianno et al., 2009; Peny-Dahlstrand et al., 2009; Sawin et al., 2003; Verhoef et al., 2006). There is emerging evidence that technology can enhance SM skills in adults (B. Dicianno et al., 2016; van Staa et al., 2011) and there is some support that increase in SM is related to decrease in depressive symptoms in YA over time (Bellin et al., 2012; Holbein et al., 2013). In adults both community experiences such as camp (Holbein et al., 2013), rehabilitation approach or sports (Khan, Amatya, Ng, & Galea, 2015) can be used to empower adults to increase SM behaviors. Use of resources can enhance transition to college or employment (B. E. Dicianno et al., 2009; Wagner et al., 2015). Wellness programs for adults and technology innovations show promise for improving SM behaviors in adults (B. Dicianno et al., 2016; Fairman, 2013; Parmanto, Pramana, Yu, Fairman, & Dicianno, 2015; Parmanto et al., 2013).

Research Gaps

- What are the foundational skills and abilities that need to be developed in toddlers, preschool agers, and school agers that facilitate the development of SM behaviors in adolescents and young adults?
- Interventions optimize the development of these foundational skills and abilities early in childhood?
- What interventions are effective in closing the gap between SM behaviors in adolescents/young adults with SB and their typically developing peers?
- How can interventions to enhance SM be integrated into clinical care?
- What interventions need to be targeted to mid and older adolescents and their parents to change their roles in self-management?
- Do additional components need to be delivered outside of clinical care?
- What structure(s) of clinical services are optimal for coordinated, comprehensive transition to adult care?
- Does routine clinical assessment of SM behaviors with the development of action plans with the adolescent and their family enhance yield improved outcomes?
# Appendix A. Self-Management Instruments

<table>
<thead>
<tr>
<th>Name, yr Reference</th>
<th>Short Description Age range</th>
<th>Reliability and Validity</th>
<th>Recommendations for use.</th>
</tr>
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<tbody>
<tr>
<td>The Kennedy Krieger Independence Scales–Spina Bifida Version: A Measure of Executive Components of Self-Management. (Jacobson et al., 2013)</td>
<td>Psychometric study to evaluate the KKIS-SB, a caregiver-reported measure of self-care skills based on assumption that self-care skills are based on adequate executive functioning and that other scales do not assess the executive burden of these tasks. Parents of 100 youth and YA with SB 4 factors and two primary subscales: • initiation of routines (keep room clean; finish cores; catheterize on time; out of bed on time; hygiene on time; take medication on time). • Prospective Memory (arrive at appointment on time; arrange transportation; look for pressure sores’ start bowel program; perform pressure relief; write scheduled appointments</td>
<td>Exploratory factor analysis, reliability and construct validity BRIEF (Behavior Report Inventory of Executive Function) Internal reliability =0.89 Correlations between KISS-SB initiation of routines and Brief Scales: both BRI and MI summary scales r= -.031-.056) and 5 of the 8 BRIEF subscales (inhibit, shift, working memory and monitor) (r= -.29 to -.62) support validity. Age related changes support both subscales with ability increasing with age approximately 6 points KISS-SB also related to scales of the ABAS II Parent scales with reliability and validity. Child scales also have psychometric support data (not published). KISS-SB supplies a highly-specialized assessment of SM abilities based on a known area of challenge in individuals with SB (executive functioning).</td>
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<tr>
<td>The Development of the Adolescent/Young Adult Self-Management and Independence Scale -AMIS II: Psychometric Data (Sawin, Brei, &amp; Holmbeck, 2017)</td>
<td>Goal: to evaluate the reliability and validity of the 17-item Adolescent/Young Adult Self-Management and Independence Scale II which measures self-management behaviors 201 AYA and 129 of their parents from 3 studies of AYA with SB Age range for instrument 12-adult (only tested in ages 12-25)</td>
<td>The exploratory factor analysis was conducted with parent data and Confirmatory factor analysis with AYA data. Chronbach alpha was used for reliability, Intra-Class Correlation (ICC) for stability and Pearson’s correlations for evaluation of concurrent validity with other variables. All analyses support the 2 factor AMIS II; Condition Self-Management and Independent Living Self-Management CFA=GFI and CFI=86-.95; RMSEA=.057 and α=.72-.89. ICC=0.82). Has established R and V and has been used in adolescent and adult populations. Recommended for use.</td>
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<tr>
<td>Extending the Adolescent/Young Adult Self-Management and Independence Scale from Interview to a Self-Report Format Presented at World Congress 2017 (Paper)</td>
<td>The development of this self-report version of the AMIS II was carried out by a team of four authors in medicine, nursing, and psychology who had used Using an interactive iterative process, the team created, reviewed, and revised items that captured the content of the interview version</td>
<td>Originally the AMIS II was designed to be used in collaboration with the Functional Independence Measure®. Thus, items specific to bowel and bladder programs were not included in the AMIS II. However in an effort to have one comprehensive tool, questions to address SB-specific issues were included in the SR/SB version Two SR versions of the AMIS II are now available for field testing: A 28-item generic AMIS II-SR/G and a 36-item AMIS II-SR/SB. Until sufficient sample analysis of the subscales has been collected, item and total Can only be recommended for use if contributing to psychometric analysis. General use until R and V established is not recommended.</td>
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<tr>
<td>Study</td>
<td>Description</td>
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<tr>
<td>Sawin, Hombeck, &amp; Brei, 2017</td>
<td>Measurement of medical self-management and transition readiness among Canadian adolescents with special health care needs</td>
<td>To examine psychometric properties and concurrent validity of a new tool to measure transition readiness among Canadian adolescents with special health care needs. 49 11-18 year olds and their parent from a neurology clinic in Canada (only 1 person with SB). Psychometric study. Means SD and correlations to demographic and Scales of Independent behavior. 21 questions that measure “awareness”. Stems are primarily know, can, understand. Others are behaviors (I take part, I keep track, I have discussed.) No factor analysis. Internal reliability strong (0.89 to .93 Adolescent/parent) and moderate correlations Adolescent to parent (r=0.56). No stability assessment. Concurrent validity – weakly related to age (parent report only), no relationship to parent education or transition program. Relationship to Scales of Independent behavior (SIB) a measure of skills needed to function at home, school or work (r=0.44; 0.74 Adolescent/parent report.</td>
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<tr>
<td>Williams et al., 2011</td>
<td>To examine psychometric properties and concurrent validity of a new tool to measure transition readiness among Canadian adolescents with special health care needs. 49 11-18 year olds and their parent from a neurology clinic in Canada (only 1 person with SB). Psychometric study. Means SD and correlations to demographic and Scales of Independent behavior. 21 questions that measure “awareness”. Stems are primarily know, can, understand. Others are behaviors (I take part, I keep track, I have discussed.) No factor analysis. Internal reliability strong (0.89 to .93 Adolescent/parent) and moderate correlations Adolescent to parent (r=0.56). No stability assessment. Concurrent validity – weakly related to age (parent report only), no relationship to parent education or transition program. Relationship to Scales of Independent behavior (SIB) a measure of skills needed to function at home, school or work (r=0.44; 0.74 Adolescent/parent report.</td>
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<tr>
<td>Condition self-management in pediatric spina bifida: A longitudinal investigation of medical adherence, responsibility-sharing, and independence skills</td>
<td>SB Self-Management Profile (SB-SMP) based on Diabetes measure, parent reported adherence to treatments (diet, catheterization, bowel program, skin checks and exercise subscales) indicates that task is being completed but not who did it. Sharing of SB responsibilities Scale (SOSBMR) 34 items – who primarily responsible for each task (parent child equal or NA). Medial Independence Skills – Parent evaluation of child’s knowledge and ability to do SB skills (yes, no, not sure or NA). No reliability computed due to large number of NA. Adherence scoring system (1,0) created for all domains.</td>
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<tr>
<td>Psihogios et al., 2015</td>
<td>Included here due to “independence scale”</td>
<td>Survey compared SC residents to others compared. The online QOL questionnaire was created by using questions from pre-existing surveys: the American Community Survey (ACS), the National Longitudinal Transition Study-2 (NLTS2), and the RAND-36 Measure of Health-Related Quality of Life (RAND-36). Exploratory FA identified five QOL factors: emotional health (EH), physical health (PH), independence (IND), activity limitations (AL), and community participation (CP). There were no significant differences between the 3 disability groups for the EH, AL, or CP factors. The SB group reported significantly higher IND scores, the FXS group reported the highest PH scores, with the MD reporting the lowest PH scores, and the SB group reported having more of the following items than the MD or FXS groups: More of a QOL instrument but may be useful.</td>
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<td>(Deroche et al., 2015)</td>
<td>Development of a tool to describe overall health, social independence and activity limitation of adolescents and young adults with disability. (manuscript examines initial psychometric analyses)</td>
<td>Survey compared SC residents to others compared. The online QOL questionnaire was created by using questions from pre-existing surveys: the American Community Survey (ACS), the National Longitudinal Transition Study-2 (NLTS2), and the RAND-36 Measure of Health-Related Quality of Life (RAND-36). Exploratory FA identified five QOL factors: emotional health (EH), physical health (PH), independence (IND), activity limitations (AL), and community participation (CP). There were no significant differences between the 3 disability groups for the EH, AL, or CP factors. The SB group reported significantly higher IND scores, the FXS group reported the highest PH scores, with the MD reporting the lowest PH scores, and the SB group reported having more of the following items than the MD or FXS groups: More of a QOL instrument but may be useful.</td>
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</table>

Scale scores are recommended for the AMIS II-SR/SB.
drivers licenses, allowances, credit cards, and savings and checking account ownership.

- In AL SB group reported problems related to health but only slight interference with social activities (FXS group higher interference)

**Generic Transition readiness instrument – no reported use in SB**

| TRAQ (Transition Readiness Assessment Questionnaire) | 23 items with responses 1-5. Question such as Do you answer questions that are asked by the doctor, nurse or clinic staff? Do you ask questions of the doctor, nurse, or clinic staff? Do you take your prescription medications correctly and on your own? Do you fill out the medical history form, including a list of your allergies? Item responses:
1 = I do not know how to do this, 2 = I do not know how, but I want to learn, 3 = I am learning how to do this, 4 = I have started doing this, 5 = I always do this when I need to. | Item response was created to reflect the stages of change (not thinking of change, considering change, learning the change, beginning to change, implementing change. Generic instrument Widely used as a measure in clinical setting. Good assessment (mean for most assessment = learning). Does not measure increased responsibility for implementing the behavior. | Especially useful in assessing stage of change the adolescent is in. |
| UNC TR(x)ANSITION scale. A clinical tool to measure the components of healthcare transition from pediatric care to adult care: (Ferris et al., 2012) | Scale was developed and pilot tested using 185 Adolescents/Emerging adults age 12-20 with different chronic illnesses. Scale uses a semi-structured interview format and does not rely solely on patient report. Verified with information from the medical record. 33 items 10 domains (Type of illness, Rx=medications, Adherence, Nutrition, Self-management, Informed-reproduction, Trade/school, Insurance, Ongoing support, and New health providers) | Inter-rater reliability was strong ($r = 0.71$); item-total correlation scores were moderate to high. Content and construct validity were satisfactory, and the overall score was sensitive to advancing age. | Review items to determine use |

References


Khan, F., Amatya, B., Ng, L., & Galea, M. (2015). Rehabilitation Outcomes in Persons with Spina Bifida: A Randomized Controlled Trial. *Journal of Rehabilitation Medicine, 47*(8), 734-740.


