



Enhancing Independence in Adolescents
with Spina Bifida

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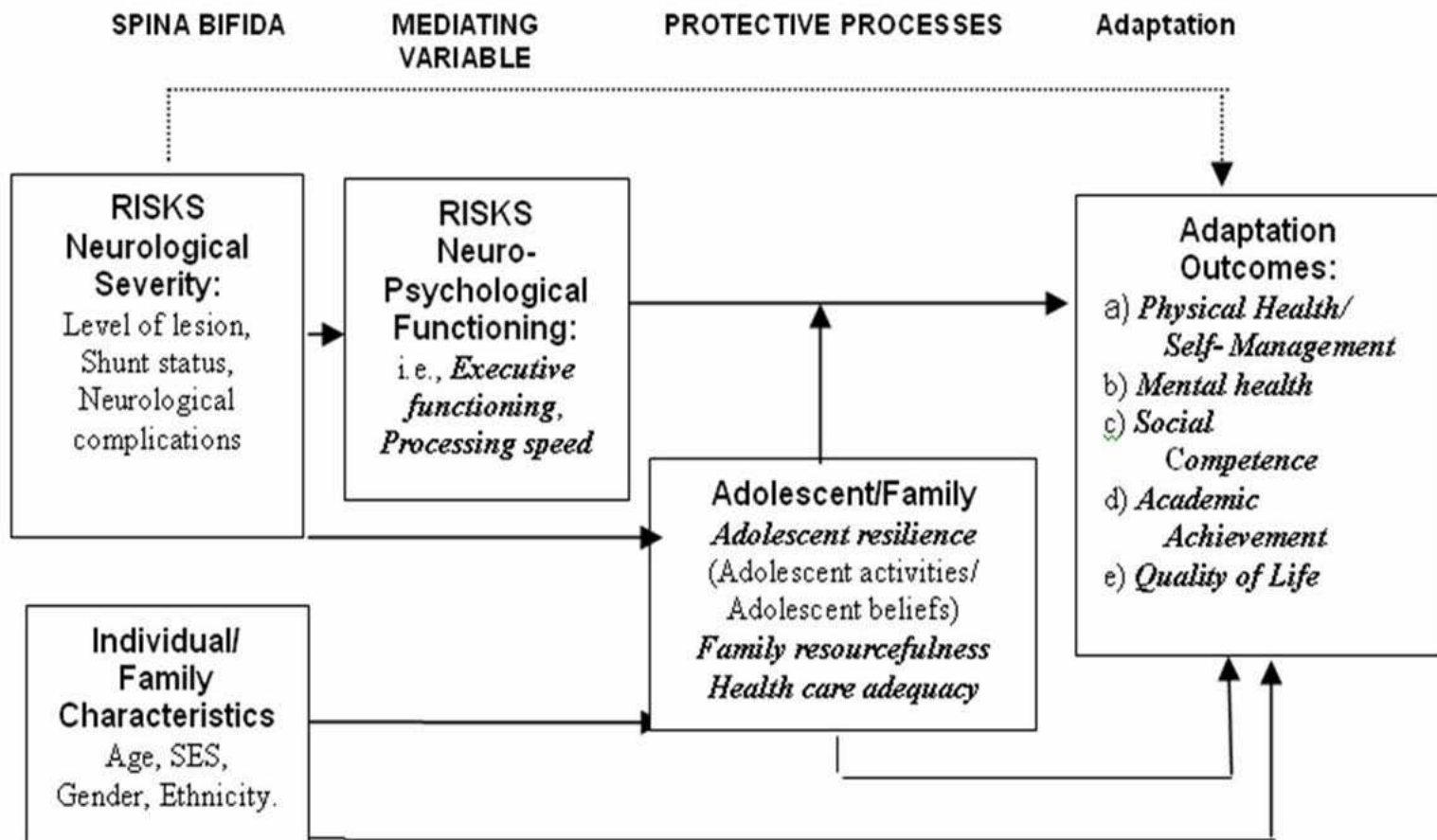


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Young at heart



Secondary Conditions and Adaptation in Spina Bifida



Self-Management

An ongoing process of shared decision-making and responsibility among youth with disabilities and their parents to achieve control *of their condition*, health and well-being through a wide range of activities and *skills*. *The goal of youth increasing responsibility is to develop skills needed for transition to adulthood and independent living.*

Adapted from Schilling, Grey, & Knafl, 2002, italics reflects adaptation

Purpose

- Share information regarding development of self-management and independence from our and other's studies of families with SB.
- Generate discussion regarding independence from an international perspective.

Why are we concerned about self-management and Independence?

Internationally young people with SB, even those with typical intelligence, have been found to:

- Lag behind their peers in autonomy skills
- Face challenges with employment
- Have been reported to have lower levels of independent living.

If these circumstances limit full participation in life then understanding the strengths and challenges youth with SB face in self-management and independence becomes important.

Just a Word of Caution

- We are all limited in our independence.
- Perhaps it is better to think about inter-dependence. We all depend on each other for support, guidance, and a helpful hand when we need it.
- However, being as skilled in managing our daily life as we can be and having independence skills are central components of being able to traverse into adulthood and being prepared to strive for a full life.
- Independence in our view can include taking responsibility for directing or arranging for an activity, not just doing it oneself.

Our Follow-Up Study Included

- 50 Families who have Adolescent or Young Adult (AYA) with SB from 2 of the 4 sites in our previous study. The previous study included 140 families with SB and a comparison sample of 100 families without SB.
- Study included:
 - AYA interview (and additional 2 week psychometric interview)
 - Parent interview (and additional 2 week psychometric interview)
 - Medical record review
 - Neuropsychological assessment in previous study and executive function by parent report in the follow up study
 - Teacher report of function and school data

Who was in our Studies?

AYA who were:

- Functioning at approximately grade level - not diagnosed with significant cognitive delay or “learning disabilities” (European term)
- English speaking
- No other major medical conditions unrelated to SB
- AYA aged 12-25 (14-25 in Follow Up)
- For Follow Up: Participated in larger study at one of two primary sites

The Tool we Used: The AMIS II*

- A practical measure of the adolescent's increasing responsibility and skills for self-management of their chronic condition/disability.
- Discipline-free instrument that has a structure compatible with a developmental-based scoring system.

*Adolescent Self-Management and Independence Scale

AMIS II

- AMIS II is a structured interview rated by health care providers.
- The instrument was designed to be complimentary to current instruments that measured basic activities of daily living (eating, bathing, grooming, dressing, mobility).
- Definitions were developed for each item as well as the scoring criteria for the item.

Scoring

- The instrument is scored based on how much assistance the individual with SB needs with the skill.
- 7 = totally independent
- 6 = modified independence
- 5 = supervision
- 4 = minimal assistance
- 3 = moderate assistance
- 2 = maximal assistance
- 1 = totally dependent

Reliability and Validity of the AMIS II

- Confirmatory Factor Analysis of parent and AYA data in this study was used to confirm 2 subscales:
 - Self-Management: Condition
 - Self-Management: Independent Livingand an overall AMIS scale.
- Cronbach alpha used for internal reliability.
- Inter-rater reliability was established and maintained with each data collector at .85 or above.

What Parents and Young People Told Us About Self- Management and Independence

Our Continued Questions About Independence

- How are AYA doing in self-management and independence?
- What expectations do parents and AYA have for self-management and independence?
 - Are there major differences in expectations between parents and AYA?
 - Are low expectations the factor we need to focus on?
- What is the average age that AYA achieve the self-management and independence tasks?
 - What is the lag between average achievement age and those who are that age but have not achieved?

Demographics of Original and Follow Up Study

	Study 1 (140 Families)	Follow Up Study (50 families)
Gender	53% female	58% female
Living situation	98% family home	95% family home
Ethnicity	97% Caucasian	96% Caucasian
Shunt	85% shunt	81% shunt
Age Range	12-25	14-25
Average Age	15.55 (SD=3.2)	17.30 (SD=2.6)

Condition Management*

<u>Items in Scale</u>	<u>Average Scale Score</u>	<u>Range</u>
Personal Safety	AYA 5.0	2.7-6.4
Condition Knowledge	Parent 4.8	1.9-7.0
Managing Meds		
Complication Prevention	* α =.72-.79	
Advocacy		
Accessibility		
Family Involvement		

AVERAGE SCORE REFLECTS SUPERVISION (and FOR SOME HANDS-ON ASSISTANCE)

Condition Knowledge

- Has adequate knowledge about (SB) condition.
- Knows basics of own health history.
- Is able to tell that information to others (such as health care providers).
- Knows the risks for secondary complications (complications like UTIs, skin problems, etc).

Complication Prevention

- Routinely and consistently performs preventive behaviors appropriate for the individual. This includes activities such as:
 - Monitoring headaches
 - Doing timely weight shifts, skin checks
 - Increasing fluids, generally and especially with UTI
 - Catheterizing at the appropriate times

Medication Management

- Knows names, dosages, and why the medication is used.
- Takes medications in appropriate way at appropriate time.

Condition Management

<u>Items in Scale</u>	<u>Parent Expected Average Age</u>	<u>% Achieved</u>	<u>Average Age Achieved</u>
Personal Safety	16.7 (3.9)	65%	17.5 (2.7)
Condition Knowledge	16.2 (5.0)	58%	17.3 (2.9)
Managing Meds	17.3 (3.9)	63%	17.3 (2.7)
Complication Prevention	17.8 (4.4)	42%	17.3 (3.3)
Advocacy	18.7 (3.3)	43%	17.2 (2.6)
Accessibility	16.0 (4.8)	65%	17.3 (1.4)
Family Involvement	21.0 (3.4)	12%	16.8 (2.4)

Condition Management

<u>Items in Scale</u>	<u>Parents Expected Average Age</u>	<u>% That Age Who Have Not Achieved</u>
Personal Safety	16.7 (3.9)	27%
Condition Knowledge	16.2 (5.0)	30%
Managing Meds	17.3 (3.9)	38%
Complication Prevention	17.8 (4.4)	24%
Advocacy	18.7 (3.3)	40%
Accessibility	16.0 (4.8)	28%
Family Involvement	21.0 (3.4)	38%

Independent Living Skills*

<u>Items in Scale</u>	<u>Scale Average Score</u>		<u>Scale Range</u>
Social Communication	AYA	3.3	2.6 - 3.8
General Problem Solving	Parent	3.2	2.5 - 3.2
Ordering supplies			
Making a Health Care Appointment			
Managing Money			* α =.83-.86
Making Money			
Managing Insurance			
Household skills			
Community Living skills			
Managing Transportation			

AVERAGE SCORE REFLECTS MODERATE ASSISTANCE NEEDED

Ordering Medications/Supplies

- Recognizes the need to order.
- Places the order.
- Knows how to arrange for payment and arranges for payment.
- Knows how to arrange for delivery/pick up and arranges for delivery and pick up.

Managing Money

- Understands purchases, cost, and taxes on purchases.
- Knows expected amount of change from purchases.
- Plans budget for typical teenage activities. Budgeting skills might include:
 - 1. Has own checking account and writes checks without assistance (or has own credit card and pays bills responsibly).
 - 2. Reconciles accounts (checking, credit card, savings) without assistance.
 - 3. Sets priorities for use of funds.
 - 4. Recognizes need to save money and does so.

Making Health Care Appointment

- Takes responsibility for making health care appointment.
- Understands medical problem/issues that require an appointment.
- Initiates and follows through in activities needed to make appointments (e.g. makes the phone call or makes the appointment).

Community Living Skills

- Plans a menu for self or family:
 - Plans for food purchases to support menu.
 - Knows cost and can think through the cost as a part menu planning.
 - Knows how much s/he has to spend.
- Goes grocery shopping to obtain materials needed.
- Prepares the meal.

Independent Living Skills

<u>Items in Scale</u>	<u>Parent Average Expected Age</u>	<u>% Achieved</u>	<u>Age Achieved</u>
Social Communication	16.8 (5.1)	53%	17.2 (2.8)
General Problem Solving	18.5 (4.2)	43%	17.5 (2.8)
Ordering supplies	19.0 (3.0)	30%	19.8 (2.9)
Making a Health Care Appointment	19.1 (3.0)	12%	19.8 (3.0)
Managing Money	19.2 (3.0)	12%	17.5 (2.6)
Making Money	19.2 (3.0)	12%	18.6 (2.9)
Managing Insurance	21.3 (3.0)	9%	17.0 (2.5)
Household skills	18.4 (3.6)	26%	17.2 (2.7)
Community Living skills	19.1 (3.3)	21%	17.5 (3.1)
Managing Transportation	17.5 (3.0)	16%	18.4 (3.4)

Independent Living Skills

<u>Items in Scale</u>	<u>Parent Average Expected Age</u>	<u>% That Age Not Achieving</u>
Social Communication	16.8 (5.1)	38%
General Problem Solving	18.5 (4.2)	38%
Ordering supplies	19.0 (3.0)	27%
Making a Health Care Appointment	19.1 (3.0)	11%
Managing Money	19.2 (3.0)	34%
Making Money	19.2 (3.0)	34%
Managing Insurance	21.3 (3.0)	09%
Household skills	18.4 (3.6)	38%
Community Living skills	19.1 (3.3)	36%
Managing Transportation	17.5 (3.0)	33%

Difference Between Parent and AYA Independent Living Skills

<u>Items in Scale</u>	Average Difference in Expectations Between Parent and AYA
Social Communication	2.90 years
General Problem Solving	2.50 years
Managing Insurance	2.50 years
Household skills	2.40 years
Managing Money	1.70 years
Making Money	1.30 years
Community Living skills	1.40 years
Ordering supplies	0.52 years
Making a Health Care Appointment	0.90 years
Managing Transportation	0.60 years

Difference Between Parent and AYA Condition Management

<u>Items in Scale</u>	Average Difference in Expectations Between Parent and AYA
Managing Meds	2.80 years
Complication Prevention	2.60 years
Advocacy	3.10 years
Accessibility	1.30 years
Family Involvement	1.90 years
Personal Safety	0.86 years
Condition Knowledge	0.50 years

Responsibility AYA takes for Self- Management

	Parent Average (SD) Median Range	AYA Average (SD) Range
Overall Responsibility	Average 64.63 (24.5) Median 60 Range 10-100	Average 75.22 (26.3) Median 85 Range 10-100
Overall Satisfaction	Average 64.42 (30.22) Median 70 Range 0-100	Average 82.10 (19.8) Median 90 Range 40-100
Comments	Parent data are bimodal Parents report AYA fall into 2 categories, those that do a little to a moderate amount and those that do a lot	

Satisfaction with Responsibility AYA takes for Self- Management

	Parent Average (SD) Median Range	AYA Average (SD) Median Range
Overall Responsibility	Mean 64.63 (24.5) Median 60 Range 10-100	Mean 75.22 (26.33) Median 85.00 Range 10-100
Overall Satisfaction	Mean 64.42 (30.22) Median 70 Range 0-100	Mean 82.10 (19.79) Median 90.00 Range 40-100
Comments	Parent data bimodal Parents report AYA fall into 2 categories, those that do a little to a moderate amount and those that do a lot	

What is related to Better SB Self-Management and Independence?

- Age Older AYA do better**
- Shunt status AYA with no/fewer revisions*
- Level of SB Those with more mobility do better*
- Neuropsychological functioning (e.g., executive functioning, working memory, processing speed) Those with better NP do better
- Decision Making AYA who make more decisions***
- Chores AYA who do more chores***
- Coping Those who cope positively**
- FAMILY Adolescents who are more satisfied with family**



Our Original Questions

- How are AYA doing in self-management and independence?
 - On average need supervision for Condition Self-Management
 - Need moderate assistance with Independent Living.
- What expectations do parents and AYA have for self-management and independence?
 - Parents have lower expectations than AYA but generally both are lower than peer norms when available.
 - Are there major differences in expectations between parents and AYA?
 - Perhaps for select Independent Living and Condition Items but sample to small to be confident of differences.
 - Are low expectations the factor we need to focus on?
 - For some items may be an issue.

- What is the average age that AYA achieve the self-management and independence tasks?
 - Varies by item –but Independent Living items generally much lower.
- What is the lag between average achievement age and those who are that age but have not achieved?
 - Substantial for many items

Take Home Message

- The Transition into Adulthood Begins in Infancy* is a critical expectation that needs to be fundamental to clinical practice.
- The learning issues for children with spina bifida mean that independence skills need to be addressed intentionally, introduced early, and practiced often to be internalized.
- Parents tell us they need to plan and health care providers can assist them in knowing how.

*Peterson, P.M., Rauen, K.K., Brown, J., Cole, J. (1994). Rehabilitation Nursing, 10(4), 229-238

Impact of Health Care Providers (HCP)

- HCP and Family expectations are key.
- Parents need to be in charge but children need to gain increasing skill throughout childhood.
- HCP can focus on helping families build in choices. Decision making begins at toddlerhood. Toddlers can choose:
 - Which of 2 breakfast cereals (chosen by parent) to eat
 - Which of 2 shirts (chosen by parent) to put on
 - Which of 2 directions (chosen by parent) to go on a walk
 - Which playground equipment to use first

Impact of Health Care Providers (HCP)

- Build a plan with families that starts early and builds decision-making skills in early childhood
- Encourage parents and kids to set priorities incrementally building skills.
- Confirm yearly goals and action plans with incremental components.
- Parents need to be in charge but children need to gain increasing skill throughout childhood.
- HCP can assist families to make a plan, revise it as needed and stay focused on the end outcome.

Expectations Are Key and Differ by Family.

Discovering Families' Expectations is Important

- “So I expect until she gets out and gets a full-time job, financially she’ll be, you know...insurance and stuff will be linked to us. But she’s becoming...she’s buying Christmas presents for the family with money that she earns and stuff.”
- “But I expect her to move out and get an apartment and, you know just, the thing is she does have to hook up with a good friend or someone who is comfortable just being kind of that right arm at times.”
- “We talked about the fact that she will probably never be able to live alone (sacral level with normal intelligence).”

HCP can Help Parents Increase Autonomy in School-Age Youth

- Giving your child a coupon book for prized activity (extra half hour of staying up, choosing dinner for the night, inviting a friend over).
- Giving your school-age child a weekly “allowance” for a prized activity. Perhaps s/he can watch 4 hours of TV on the weekend but they get to choose how to “spend it”.
 - Be careful to build in parent veto for consideration (e.g, with permission of parent, or with 2 days notice)
- Have your school-ager compute the tip every time the family eats out (calculator ok).
- Try computer games that have her “make brownies from a recipe” or “buy lunch from the cafeteria.” These programs promote independence skills using math problem solving which is an area kids with SB often find challenging.
- Have the child audio tape the instructions for a task – such as cathing. The child can use her own tape to help with learning. No one is telling her; she is telling herself.

Advancing Choices and Decision Making in Adolescence

- Two decades of research in the US and other countries confirm that parents who monitor their AYA activities closely, hold behavioral expectations for AYA, build in opportunities for choices, and build decision-making skills have adolescents with better outcomes (less risk-taking behavior, more pro-social behavior).
- Some literature to show these same qualities improve health outcomes for adolescents with chronic conditions.
- Finding opportunities for decision-making vary by family but should be thoughtfully planned.

Chores and Responsibilities are Key Skills

- Build the expectation for responsibilities based on:
 - Developmental level of the child
 - Unique components of her/his spina bifida
- Realize that children with learning problems often do not learn by “observation”. They may not push the envelope. They may wait for others to initiate activities.
- Typically developing AYA see peers or siblings do a task and learn from watching others.
- Parents and AYA with SB need to understand many AYA with SB do not learn that way. They need goals, actions broken down into steps and practice. Families told us they expected the independence skills to just “happen”.
- But frequently it just didn't.

Chores and Responsibilities are Key Skills

- In our data many adolescents had few chores or responsibilities.
- Find expectations that fit with the child's competencies. Parents tell us:
 - “Like an allowance, you know. He had to do things. Whereas his sister had to do other stuff to get part of her allowance. But at least that was something for him to have to be a part of.”
 - “He started carrying a wallet and keeping track of his own money. We have a little banking system at home here. He does chores and then gets points, And then the points convert to money and then he keeps track of saving money for whatever he wants.”

Parent's Advice About Chores

- “Another thing that works really good is like, you clean up the whole room....and then the only thing they have to do is pull the bedspread up. So you make the bed and then you pull the bedspread down and then you leave it very neatly looking like all you have to do is lift one corner, and look, the whole room is clean! And all you had to do is lift that one corner of the bedspread.”
- “Well, the next day, the bedspread is a little further down, you know. And look, the room is clean! And then the next day the bedspread is off the bed, because he tends to, they fly all over. And then each time you do it, so you do it in reverse. And so the end result is always that positive where, “Look, the room is clean!” you know, and it doesn't seem so hard if you always see that result right away.”
- “But if he just confronts a very messy room, like after the weekend the room gets really messy, it's just almost impossible for him to organize it. Like, “What do I do first? What do I do next?” you know.”

Parents are Experts

- “I try to structure things so that he can learn in a patient setting with few distractions, then we focus on different things. But if you push him really hard he just kind of jams up; that doesn’t really work.”
- “Well, patience is one thing, but then also have a plan. I liked watching the therapist at [Clinic] we go to. They had an excellent therapy program there and I really emulated how the PTs and the OTs worked with him and how positive they stayed. They tried to find what motivated him and make it fun, you know, and not make it a big deal.”

Role Models and Independence

- One mother indicates that role models are powerful and can convey the need for persistence in developing independence.
 - “There’s a couple of the older kids that are in, you know, that she’s met through ... (a mentoring program). And the one guy, you know, he says, ‘I might fail the classes the first time, but then I take it again, and then I just have to focus on it. And I have to know that I have to look at it over and over and over and over and over.’”
- Another girl (when talking about difficulty building driving skills said:
 - “It took me a long, long, long time. And I still don’t drive like on the expressway.”
- Another mother indicated resources help:
 - “New Mobility I think it’s called, for adults, helped me because it was written by adults.”

Moving the Safety Net Out Incrementally

HCP can help families increase autonomy appropriately.
Parents advise:

- “The other thing is, I let him go places a lot. Like on Tuesday he had a friend come home with us. ...Even though there was snow they wanted to go to [restaurant], which is about five blocks away. And I just gave him some money and they all went to... And he bought his brother a meal too, and then brought back the receipt and the change, and knows how to get the right change.”
- “But I let him get full of mud. I mean some parents wouldn't let him, you know they'd think, 'Oh, poor kid, can't walk' and 'Oh, he's going to get all full of mud.' I'm like, 'Go ahead! Get full of mud!'”

Parent's Advice—Pass It On

- “I guess if I could tell any parent of a spina bifida child something, it would be not to do everything for them when they're younger. Make them learn more things. That's probably something I probably failed to do, and it wasn't just him, I think I just did it with everyone.
- Teach your kid independence as much as they can do with the knowledge of them knowing that you're behind them just in case they stumble.-*Ah, like a safety net.* I think it's like the bicycle with training wheels type thing.

A Useful Model

- We know from the literature that parent involvement in self-management in adolescence (and maybe young adulthood) is associated with “doing better.”
- This involvement has to include skill building and decreasing parent role—become a “consultant”.
- For teens another useful comparison is a graduated drivers license model.
 - The teen gets a license after a long period of closely supervised demonstration of skill.
 - There are limits on driving (where and with whom the teen can drive.
 - Parents often have detailed problem-solving discussions about how to handle unusual driving situations before they let teen drive in a complex situation.

Resources to Help Families and Professionals?

- The adolescent autonomy checklist
Adolescent Autonomy Checklist
<http://depts.washington.edu/healthtr/Checklists/intro.htm>
- The AMISII (available from authors)
- Health Guide for Parents of Children Living with SB
 - Includes Health Care Records for Parent
- Health Guide for Adults Living with SB
 - Feeling Great
 - Looking Good
 - Living with SB
 - Managing my own Health
 - Includes personal health care record

- Have a great rest of the conference!
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