



The Experience of Parenting an Individual with Spina Bifida

**International Federation for Spina Bifida and
Hydrocephalus Conference
Spina Bifida Hydrocephalus Ireland
May 12, 2010
Dublin, Ireland**

Timothy J Brei, MD, FAAP

Medical Director, Spina Bifida Association
Associate Professor of Clinical Pediatrics
Indiana University School of Medicine

Kathleen J. Sawin, PhD, RN, CPNP-PC, FAAN

Professor, Research Chair in the Nursing of Children
Children's Hospital of Wisconsin and College of Nursing
University of Wisconsin - Milwaukee

Collaborative Research Team

- **Colleagues at Wisconsin**
 - Kathleen J. Sawin, PhD, RN, CPNP-PC, FAAN
 - Karen Rauen, MSN, CNS, BCIAC-PMDB
 - Sue Cashin, PhD,
 - Amy Heffelfinger, PhD, Jennifer Koop, PhD, Lisa Conant, PhD
- **Colleagues at Indiana**
 - Timothy Brei, MD, FAAP
 - Constance F. Buran, DNS, RN
 - Philip Fastenau, PhD
- **Colleagues at Virginia**
 - Suzanne S. Rubin, PhD
 - Jay Neufeld, MD, Eugene Monasterio, MD
 - Julie Neblett, PhD
- **Colleagues at Ohio**
 - Tom Webb, MD, Douglas M. Ris, PhD
- **Project Advisory Committee**



INDIANA UNIVERSITY
SCHOOL OF MEDICINE

Riley Hospital *for* Children



Children's Hospital
PEDIATRIC SPECIALTY CARE OF RICHMOND, VA.

Young at heart



Purpose

- Share information about parenting in Spina Bifida
- This information has come from some of our research and those of colleagues and friends
 - Pilot work with 66 families with an Adolescent/Young Adult (AYA) in one setting
 - Multi-site study of 140 families with an AYA with SB.
 - Follow up study of 50 of these families
 - Work from our colleagues (Holmbeck et al 2010 and Bellin et al 2010, Special issues of Developmental Disabilities Research Reviews, Volume 16, No 1, 2010
- Generate discussion so that we can all learn from each other

Outline

- Thoughts about Development and the path to independence
 - Beliefs, attitudes
 - Skill-building
 - Spina Bifida influences on development
- What do parents tell us about parenting?
- How parents can help the path toward self-competence and independence
- Ideas and discussion



Parents
YOU MAKE A DIFFERENCE!

Understanding Development

- Development is an ongoing process
- All development takes place in the context of meeting and responding to challenges
- Accomplishing early developmental tasks lays the foundation for what happens later
- The fundamental accomplishments of child and adolescent development are social and development of overall competence

The Developmental Path to Independence – Promoting Self-Competence

- Promoting Self-efficacy
 - Beliefs about our abilities and capabilities to achieve goals
 - Contributes to a sense of self-esteem
- Promoting effective coping strategies
 - Our abilities and capabilities to manage undesirable events
 - Also contributes to a sense of self-esteem
- Promoting activities with peers
 - Contributes to social competence and self-esteem
- Promoting skill-building
 - Opportunities for decision-making, problem-solving activities and other autonomy experiences
 - Contributes to effective self-management and independent living skills

Differences in Spina Bifida

- For persons with Spina Bifida
 - Mobility challenges affect access both at home and in society
 - Different social experiences may alter social development
 - Learning issues in Spina Bifida may impact the acquisition of living skills and school/vocation skills
 - Temperament may be different – more content to let others do than to try themselves
- For parents
 - Life with a child with Spina Bifida may be more complex
 - Altered family relationships
 - May experience more social isolation themselves
 - May have increased risk of depression
 - Additional financial stresses

Learning Issues in Spina Bifida

- Approximately 80% of persons with SB have normal cognition
 - Mean IQ slightly lower than general population
- Majority of children with SB appear to have learning problems
- Estimated 30-40% of children with SB have attention problems
- Concept of Non-verbal Learning Disabilities (NLD)
 - Distinct patterns of strengths and weaknesses in how the brain processes, manages, learns and remembers information

Non-Verbal Learning Disabilities

- Processing Strengths
 - Verbal-auditory learning
 - Verbal memory
 - Rote (memorization) learning
- Processing Weaknesses
 - Visual-spatial learning and attention
 - Comprehension
 - Bringing together parts to make meaning out of a whole
 - Underlying meaning as opposed to rote memory
 - Executive functions

Executive Functions Definition

- “The cognitive process that regulates an individual’s ability to organize thoughts and activities, prioritize tasks, manage time efficiently, and make decisions.”

The American Heritage® Stedman’s Medical Dictionary, 2nd Edition Copyright© 2004 by Houghton Mifflin Company. Published by Houghton Mifflin Company. All rights reserved.

- Executive function skills components
 - Attention
 - Mental flexibility
 - Organization
 - Novel problem solving

How NLD Affects Everyday Life

- “The brain you have is the brain you have”
 - Learning problems reflected at home as well as school
- As one moves into adulthood increased demands on executive function skills
 - Increasing importance of reasoning, problem-solving and organizational skills
 - Increasing importance in social skills
- Age does not determine our ability to function independently

Parenting in Spina Bifida

- Recognition of the intersection of medical issues, social environment, family styles and learning issues as important influences that affect progress toward independence.
- Recognition that what is happening in our lives as parents and our style of parenting influences our children's experiences and beliefs that promote independence and mental health
- Parents can make positive changes at all ages to help foster skills important for promoting independence

What Parents of Adolescents and Young Adults (AYA) with Spina Bifida tell us

Four Themes

- Daily life experiences
- Dance of individuation
- Reflections on parenting an adolescent with Spina Bifida
- Practice implications

Daily Life Experiences

- Ever-present monitoring and managing
 - The uncertainty of SB
 - “I’m scared about what is going to happen next”
 - Worry about typical adolescence
 - “The responsibilities are there. We’ve had problems with that [glued to the TV when chores are to be done] and that has nothing to do with her limitations or her disabilities. It’s just being lazy and that’s being a typical teenager”
 - Managing SB on a daily basis
 - “Keeping doctor appointments and medications. So much to keep straight, things can go wrong and with out everyday life”

Daily Life Experiences

- Sense of feeling overwhelmed with daily family responsibilities
 - “If I get overwhelmed, it’s not with Spina Bifida – it’s being so involved with everything else....”
- Coping strategies
 - Communication is a really big plus and don’t sweat the small stuff..”
- Family Relationships
 - “Anything as a family we’ve always done together”
 - “As the kids grew up they were more sensitive to other people..”
- Restrictions on family social life
 - “we have to change our schedule because of going to the doctor a lot”

Dance of Individuation

- Skill building
 - “One of the things I think he should be able to do now – needs to learn to do – a little more things for himself”
- Levels of protection
 - Overprotective parents
 - “I think he can handle a lot more than I think he can, [but] you know, I still think of him as a little boy”
 - Blended parenting
 - “Sometimes I am overprotective, ‘you’re not going to do that, you’ll get hurt.’ But I also want to see her be out on her own and be independent and see how she can do a and get a job”

Dance of Individuation

- Levels of protection
 - Fostering independence
 - “I’ve kind of learned to take her and help her so far and let go”
 - Parents do report concerns that their decision to foster independence may put their child at risk
 - Parent and adolescent tension over the push for independence
 - “She’s real independent, she’s always argued with me that she can do it herself, that she doesn’t need my help”

Dance of Individuation

- Levels of protection
 - These may almost be thought of as 4 stages of parental involvement moving from overprotective to more independence
- Style utilized may vary based on:
 - Parents
 - Youth's age and developmental status
 - Situation

Dance of Individuation

- Overriding worry
 - Living independently
 - “...I think about that a lot now if she will be able to take care of herself”
 - Potential social vulnerability
 - “...I just worry about if he’ll have girlfriends”
 - Health and financial
 - “You can’t work at McDonald’s and pay these medical bills...”
- Range of expectations
 - Parents reported a range from “treat them the same” to “expect less of them”
 - “Has the same rules everybody else does”
 - She didn’t have as many chores... so probably treat her a little different because she couldn’t do it as easily...”

Reflections on Parenting an Adolescent with Spina Bifida

- Rewarding
 - “We don’t think of it as a problem, it’s just our life. She’s a blessing”
- Personal growth through parenting experience
 - “I have learned so much through her”
- Cautious optimism about achieving developmental goals
 - “I see her driving a little car, and you know, working somewhere and trying to get her first apartment, you know”
 - I don’t think academically she’s going to make it [to college]...but I think that if she got into some type of trade school”

Practice Implications for Healthcare Professionals

- Expressed a need for increased communication, teamwork partnership among healthcare professionals, educators and the family
 - “I would like to see the hospitals feed their information to the schools letting them know...I think they [healthcare professionals] should educate the teachers”
 - “If I would have known there was help out there...no one told me”

So what have parents told us

- Overall positive experience rearing an adolescent with Spina Bifida
 - Overall positive attitude about their adolescent
 - Possibility of enhanced family life
 - Personal growth opportunities
- But...
 - Balancing act between a desire to protect and the push for independence, with a tendency often to overprotectiveness
 - Concern over possible vulnerability of the teen
 - Worry about what the future might hold

Research Related to Development of Self-Competence

- Adolescents and young adults (AYA) experience:
 - Relatively low levels of decision-making participation related to activities and events going on in their lives
 - Low participation in household chores
 - Few consequences for not doing chores
 - Comparatively few activities with peers
 - Relatively more activities that centered around the family
 - Most frequent activity reported by AYA with both peers and family was watching TV
 - Decision-making maturity is less well developed, indicating generally high parental involvement in most decisions
 - Appears to go on even into late adolescence / young adulthood

Research Related to Development of Self-Competence

- Activities, decision-making participation and decision-making maturity correlate most with outcomes related to functional outcomes
 - Activities of self-care, mobility, etc
 - More complex self-management skills – ordering medicines and supplies, money management, personal advocacy skills, etc.
 - “Practice makes perfect”

Research Related to Development of Self-Competence

- AYA had overall positive beliefs and attitudes
 - Felt hopeful about the ability to achieve positive outcomes
 - Mildly positive attitude toward their condition
 - Use fewer negative coping strategies
 - Generally positive expectations about the future
- Overall self-esteem also generally positive
 - Though individual skill specific competencies lower
 - Correlates most strongly with beliefs and attitudes and family cohesion and satisfaction rather than functional status

Research Related to Development of Self-Competence

- AYA beliefs and attitudes correlate most strongly with mental health and quality of life outcomes
- Age correlates to mental health
 - Older age associated with higher levels of depression and anxiety
- Pain also associated with increased levels of depression and anxiety
 - Is the only physical factor associated with mental health outcomes

Research Related to Development of Self-Competence

- Measures of family functioning correlate with AYA mental health outcomes
 - Family satisfaction, mastery and esteem contribute to improved mental health outcomes
 - Effect may be indirect, by influence on AYA beliefs and attitudes
- Parenting styles also influence AYA outcomes
 - Parenting which is warm, responsive but with high expectations associated with improved functional status, coping and self-esteem
 - Parenting which is overprotective associated with less decision-making and lower AYA self-esteem

Research Related to Development of Self-Competence

- Family functioning in Spina Bifida
 - May see increased occurrence of family dysfunction and lower family cohesion in Spina Bifida but many often exhibit high levels of resilience
 - Difficulty maintaining clear roles and responsibilities within the family
 - Studies regarding marital functioning are mixed
 - Significant minority of parents appear to experience depression and anxiety
 - Feel less satisfied and competent, more isolated
 - Functioning worse with parents who are single and lower socioeconomic status

Discussion and Questions

- What questions do you have about the information presented?
- Do you have some of the same feelings and descriptions that parents expressed to us?
- What are some of the most enjoyable things about parenting a child with Spina Bifida?
- What are some of the harder things about parenting a child with Spina Bifida
- Is it hard to let go and let them be more independent?

Ideas for Intervention and Discussion

- Parents – Take care of yourselves
 - What can parents do to take care of themselves?
- View SB to be a manageable challenge and take the long view
 - Are the things I, as a parent, am doing today promoting skills for independence in my child as an adult?
- Set positive expectations
 - Do you expect your child to achieve self-competence / independence?
 - Is this hard to do?

Ideas for Intervention and Discussion

- Provide and support meaningful roles
 - Chores, chores, chores
 - Developmentally appropriate “creative parenting”
 - Praise and consequences
 - What would help encourage this to happen? (This is important in all stages of development)
- Increase opportunities for independence
 - Developmentally appropriate “anticipatory” parenting”
 - What’s happening in people two years older than my child?
 - Is this scary to do?

Ideas for Intervention and Discussion

- Increase opportunities for personal skill development
 - Recognize that learning in SB is often different so how skills are taught often needs to be different
 - Building new skills requires a teacher or mentor and a supportive environment and LOTS of practice to become part of our everyday routine
 - Develop an organized plan for learning new skills
 - Find ways to “step back” as skills being learned
 - Do you find this hard?
- Don't fix every challenge
 - Developing coping skills is important for independence
 - But challenges should be manageable
 - How difficult is this to do?

Ideas for Intervention and Discussion

- Support and encourage peer interactions and friendship building
 - Social skills for friendships also require LOTS of practice
 - What are ways to facilitate this?
- Focus on building special interests and strengths
 - What hobbies / activities are available to you that you can expose your child to?
- Incorporate child, when possible, into family problem-solving activities
 - Parents actively problem-solve all the time but don't think about the steps of problem-solving
 - What ideas are there to help accomplish this?

Summary

- Parenting in Spina Bifida is important
- Think developmentally and take the long view
- Take care of yourselves
- Understand how your child learns and develop strategies to working at building independence that account for learning styles

Resources to Help AYAs, Families and Professionals from the Spina Bifida Association (SBA)

- Health Guide for Parents of Children Living with SB
 - Includes Health Care Records for Parent
- Encouraging Social Development of the Young Person Living with Spina Bifida
 - Includes specific strategies to address social competence
- Sexuality and Spina Bifida
 - Includes sections on relationship skills
- Health Guide for Adults Living with SB
 - Feeling Great Looking Good
 - Living with SB Managing my own Health

[AVAILABLE AT: www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

(click on marketplace-publications)

Contact Information:

tbrei@iupui.edu

sawin@uwm.edu

Thanks to the families, individuals with SB, and other people who made our work possible

Funded in part by:

Association of University Centers on Disability in collaboration with Center for Disease Control (CDC), which funded the overall study (Cross-sectional interviews and neuropsychological assessments).

American Association of Spinal Cord Injury Nurses which funded interviews of a small sub sample of longitudinal subjects.

Alpha Chapter, Sigma Theta Tau which funded initial development of the Adolescent Self-Management and Independence Scale.