

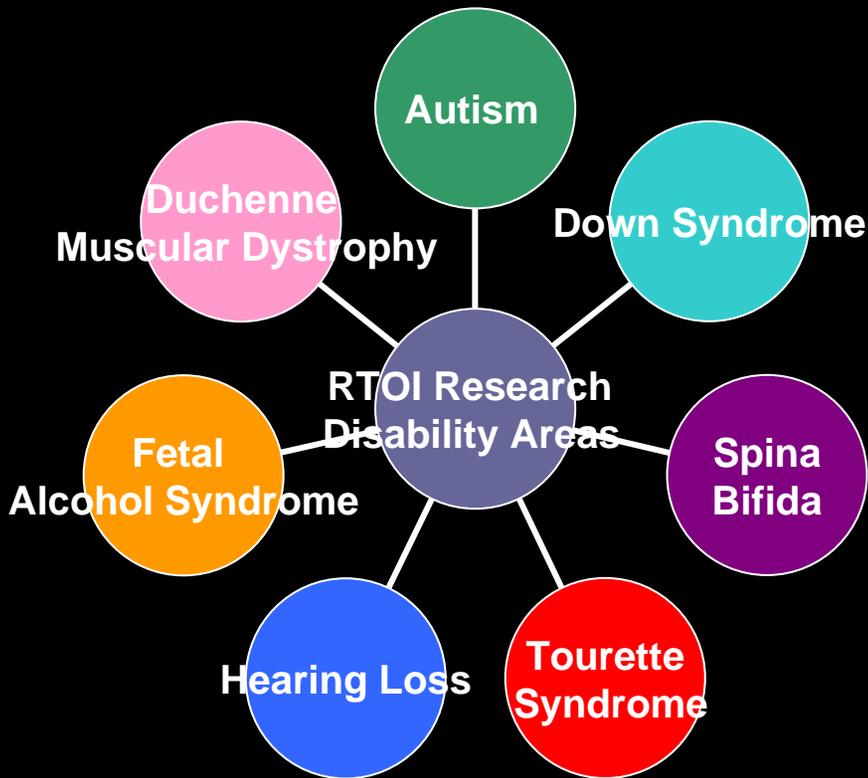
Overview of Secondary Condition Associated with Spina Bifida and Special Look into the Role of Assistive Technology Webinar

May 10, 2007

Presented by AUCD with support through the Cooperative Agreement with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at Center for Disease Control and Prevention (CDC)



NCBDDD-AUCD Cooperative Agreement



- Research: Eighteen Research Topics Of Interest (RTOI)
- Education: Fellowships and Collaborative Research Awards
- Dissemination: Webinars, Workshops, Symposiums

Webinar Agenda

Welcome & Introduction – Sue Lin, MS Project Director, AUCD-NCBDDD Cooperative Agreement

Presentation

- Secondary Conditions: The Need for Transition Services for Youth with Spina Bifida – Andrea Hart, PhD (AR UCEDD) & David Morrissey, MPS (AUCD Policy Fellow)
- Assistive Technology: Promoting health and reducing secondary conditions among young adults with Spina Bifida – Kurt Johnson, PhD & Brian Dudgeon, PhD (WA UCEDD)

Discussant

- Adriane K. Griffen, MPH, CHES (Spina Bifida Association)

Question and Answer

Presenters and Discussant



Andrea Hart, PhD

David
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Brian J.
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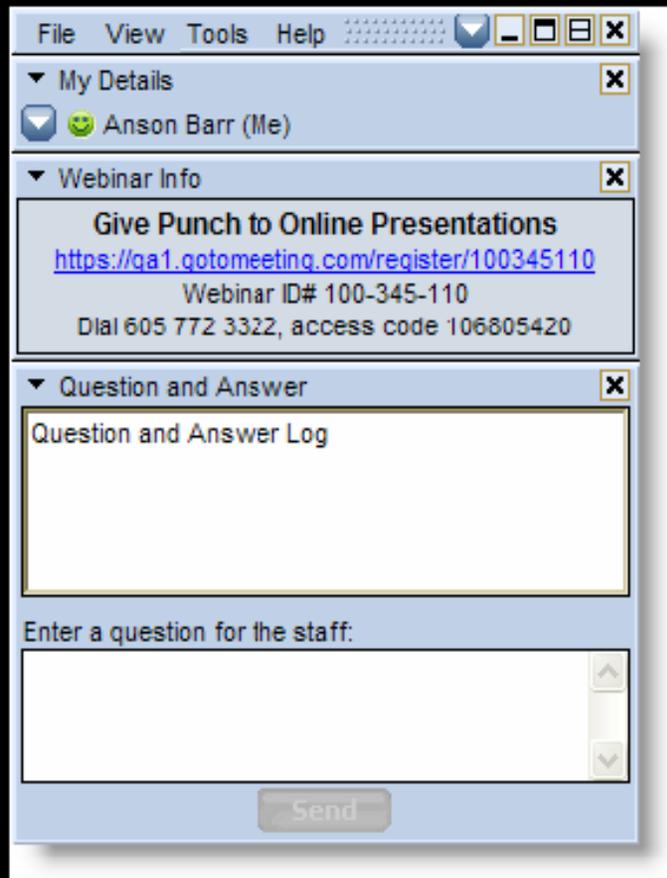


Kurt L.
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Webinar Guidelines



- Please MUTE your line by pressing *6 during the presentations
- Please unmute your line #6 for Q&A session
- You may submit questions online during presentation through Go To Webinar text box

Secondary Conditions: The Need for Transition Services for Youth with Spina Bifida

Andrea Hart, Ph.D., Betsy Johnson,
M.S.W., David Morrissey, M.P.S., &
Lorraine McKelvey, Ph.D.

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Thanks to our Partners:

Arkansas Spinal Cord Commission
Arkansas Spina Bifida Association

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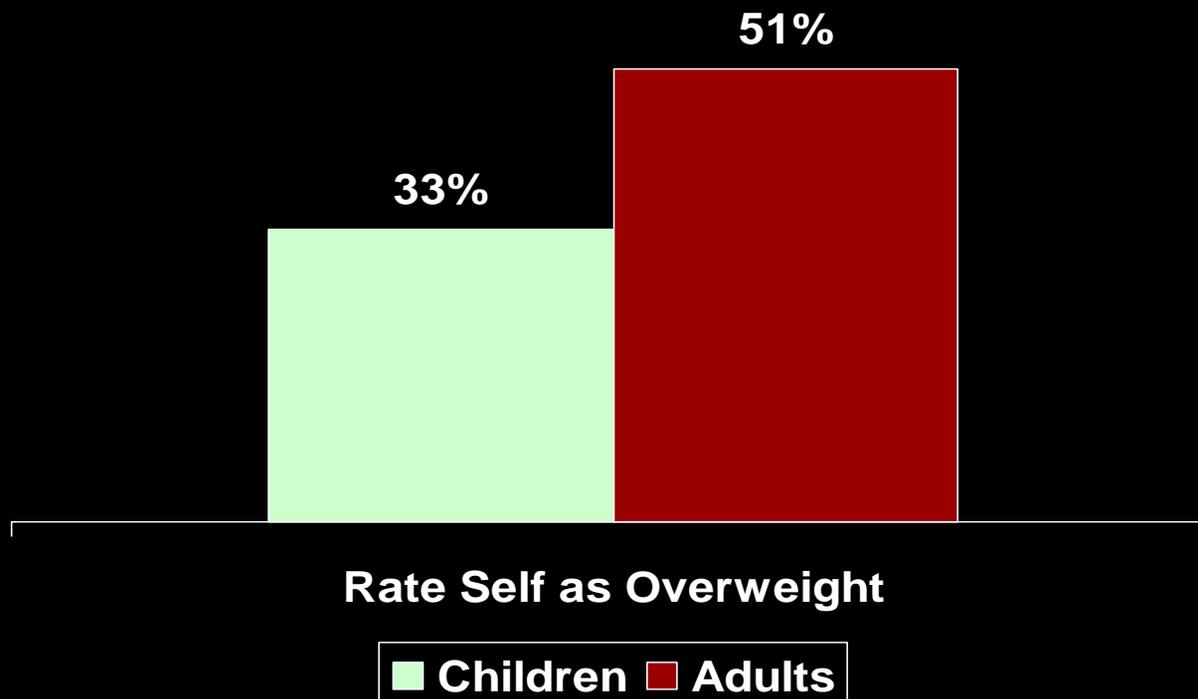
Research Goal:

Examine secondary conditions in children with Spina Bifida (*154 with SB ages 12-32 and parents*)

- Obesity
- Social isolation
- Depression
- Level of independence

Additional qualitative interview (*28 participants with SB*)

Self-Rating of Obesity



*Adults are 18+ years old

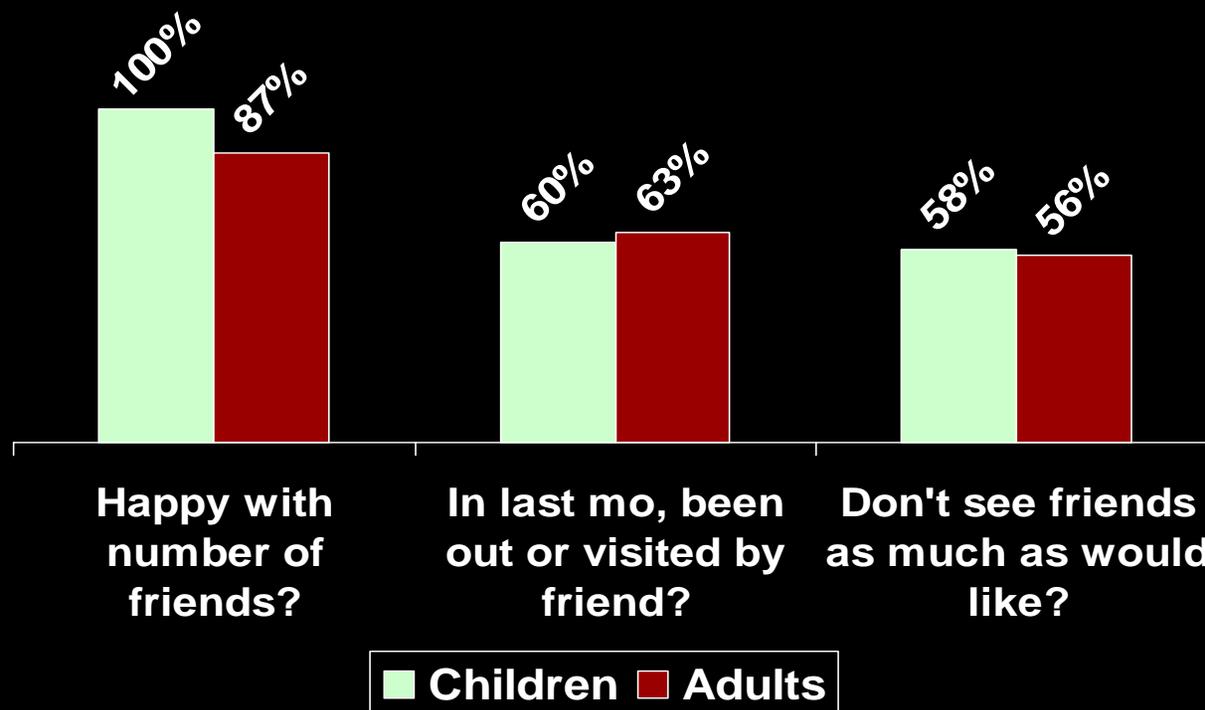
Obesity

- 33% of children and 51% of adults rated themselves as overweight.
- Those who are overweight express frustration about difficulty exercising due to mobility problems.

Respondent:

- “For the most part my life has been about my weight. And I mean everybody has a comment about how heavy I’ve been and how heavy I am and everything. And I mean, crap I can’t help it ...if it weren’t for the fact that I couldn’t get up and exercise like you, heck I would do it in a heartbeat.”

Self-Rating of Social Isolation



Social Isolation:

- Although 100% of children and 87% of adults say they are happy with the number of friends they have,
- 40% of children and 37% of adults have not been out or been visited by a friend in the last month.

Social Isolation:

- Additionally, 58% of children and 56% of adults don't see their friends as much as they would like.
- Although it is normal for both children and adults to want to see friends more often, in-depth interviews indicate that for persons with spina bifida, social isolation may be a function of the difficulties inherent in having spina bifida like lack of transportation or not having a job.

Respondent:

- “I have a lot of friends there [job] and everybody likes me and they don’t really see my chair. They just pay attention to me like I’m any other person. I’m [also] in a bowling league. I bowl every Tuesday and I have fun with my friends.”

Respondent:

- “And I had friends, you know; I mean I have always had friends. I don’t know if I have ever had a friend that would be willing to do anything with me. You know as far as recreation or whatever without apprehension or reservation. I mean...I’m certain they wouldn’t have ever said anything like that. They maybe would have made an excuse not to do it.”

Respondent:

- When asked about his life since graduating from high school he responded,
- “It stinks... since I graduated from high school there isn’t but about one or two friends that I associate with that care to come see me and even without me having to call them and make them come and get me. They are busy with their life and everything but that is understandable...but other than that if they don’t have nothing to do I have to be the one to call them up and make them come to see me.”

Social Isolation:

- Although some individuals are married or are in long-term relationships, others are finding it difficult to negotiate romantic relationships and often they refer to problems originating with being in a wheelchair as part of the difficulty.
- Even those who are currently in a long-term relationship discuss how hard it was in the past to find someone who could see past the wheelchair to the person.

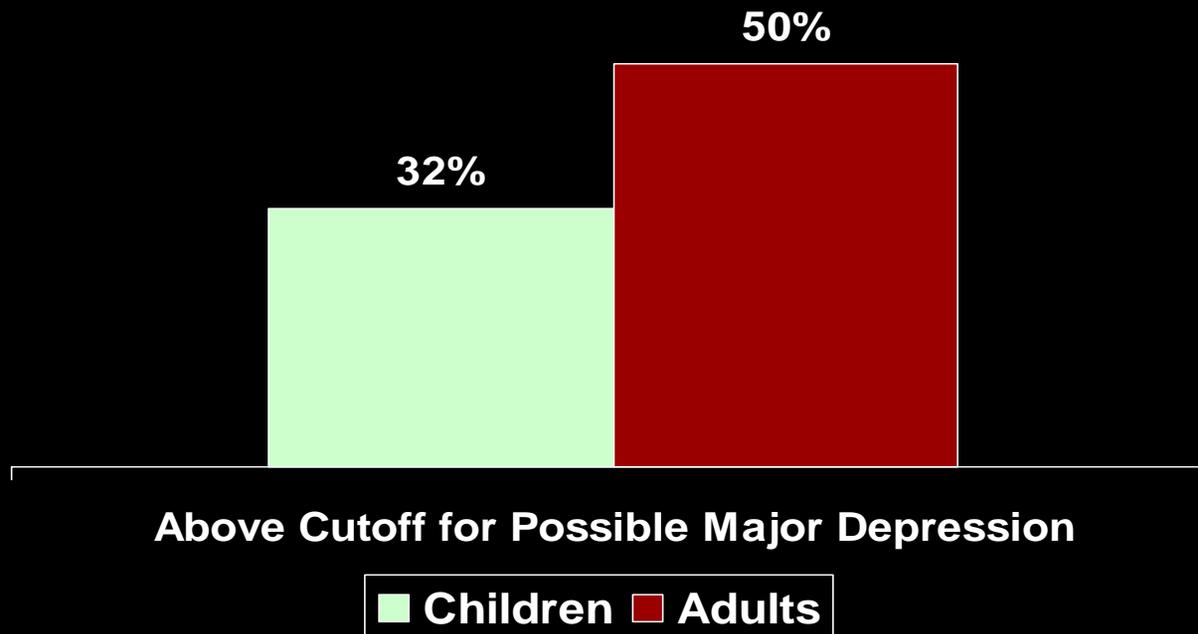
Respondent:

- “Well I know that I’ve never been much successful with girls ...every time I meet one all she seems to want to be is friends with me...I’m not necessarily looking for that [companionship] to make me happy. I had an incident once a few years ago, and I got a little offended because she didn’t understand my feelings...because it was almost like I thought ‘You know I may be in a wheel chair but I got feelings’ and what do I *not* have to give somebody? I don’t care if she is in a wheel chair or not. But she and I are friends now which is really good because now I’ve come to the realization, you know, that relationships are a dime a dozen; but friendships are hard to find.”

Respondent:

- When asked how he feels about dating, he responds, “It all depends on the person. I have no problem with it, it’s just hard to find someone that is understandable and willing to date someone that’s in a wheel chair. That’s the hardest part. Finding someone that’s willing to date a person that’s in a wheel chair and not quick to judge...Right now, I feel like I have a woman to care about me now. She’s much older than I am, but I feel like she cares about me, much more than the one I was with...it feels good. I would like to have a long term relationship, possibly marriage in the future. You see, I want to see what it feels like to be married also. To have someone to really care about me and love me because I’m willing to do the same.”

Self-Rating of Depression



Depression:

- 32% of children and 50% of adults are at risk for major depression.
- When depression was explored through interviews, it was found that feeling depressed is often related to other secondary conditions like not having a good social life and that they had difficulty obtaining treatment for depression.

Respondent:

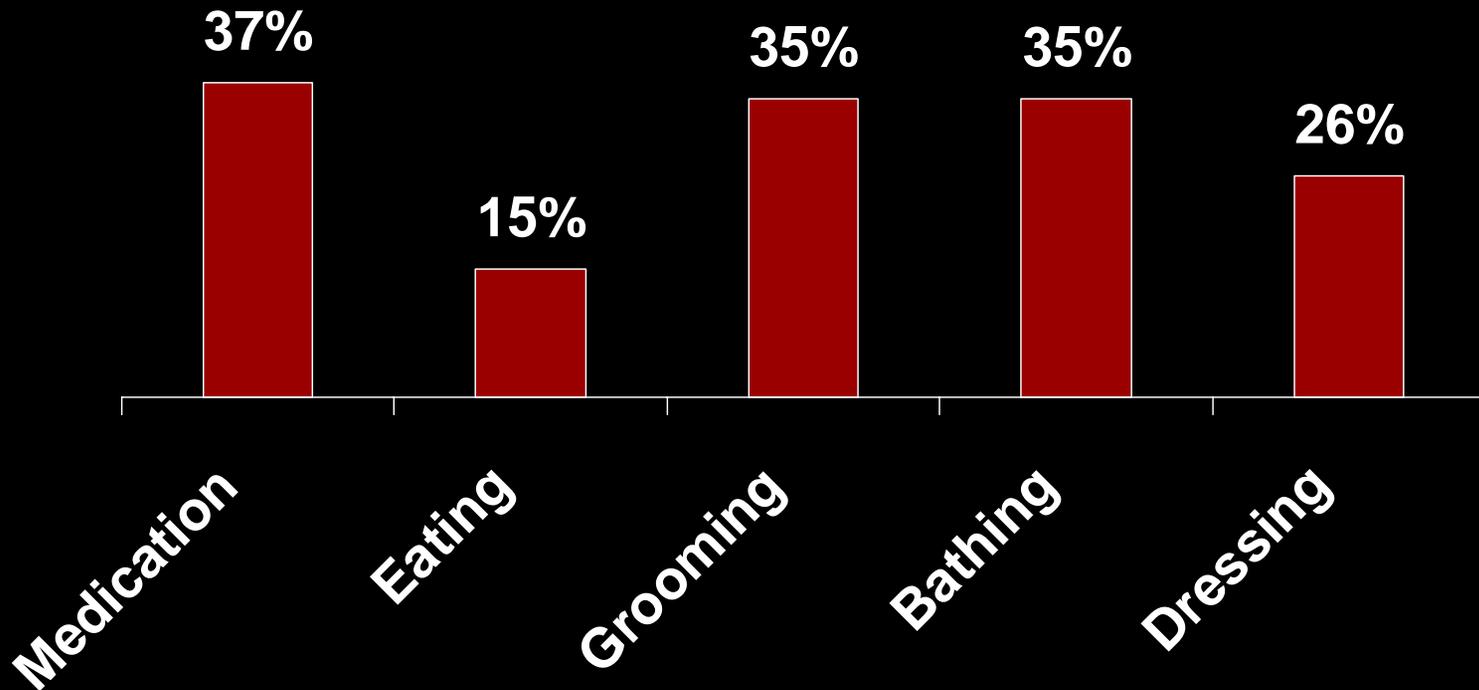
- When asked about the major source of depression, he responded,
- “Back in middle school or high school and times like that, there weren’t a lot of people that wanted to, say feed themselves while [I’m] in the wheel chair or whatever, so I didn’t have a great social [life].”

Respondent:

- “Well I had always felt severely depressed...but up until 18...I was living with my parents and my mother wasn't really too hip on the idea of even thinking that I had some sort of psychiatric thing going on. So when I was 18, when I was out on my own... I went and talked to a psychiatrist myself. Looking back on it... ever since my early teens I was depressed.”

Parent Rating of Independence

**Adults Rated by Parent on ADL's as
NOT Fully Independent**



Independence:

- When parents are asked to rate their adult child's level of independence on several activities, many rate their child as not fully independent.
- However, when children are asked about barriers to their own independence, many state that their parents don't support them in their search for independence.

Respondent:

- “I feel like I barely have independence ...had some of my best friends tell me that they were fixin’ to try to find a place and they wanted me to move in with them. Well I told my Mom about that and she flipped. I mean that is the kind of independence I’ve got...I feel stuck here, even though, I ain’t going to lie, I mean I love my Mom to death and it is good to spend time with her and see her every day, but actually I’ve become an adult now and I need to get out and experience the world.”

Transition Needs Identified

Focus on transition needs in 4 domains:

- ❑ School to Work
- ❑ Pediatric to Adult Health Care
- ❑ Family Home to Independent Living
- ❑ Family of Origin to Adult Relationships

Systems change: The case for transition planning

46 transition age youth with Spina Bifida (aged 16-20)

- 81% say they always or usually feel good about the future and 84% plan on living on their own sometime
- 39% still need help with either bowel or bladder routines
- 24% say their parents frequently or occasionally limit their independence
- 24% never stay home alone more than 2 hours at a time
- 48% are at risk for depression (24% taking medications for anxiety, mood, depression, or sleep)
- 35% always or usually wish they could have more respect for themselves

Systems change: The case for transition planning

Emerging themes related to health care policy change:

- Non-participation in health care decisions
- Support services and finances
- Shunt problems, tethered cord, and other physical injury

Systems change: The case for transition planning

Recommendations for health care systems change:

- Patient-participatory transition planning at age 14
- Respect for emotional disruption in transfer from pediatric to adult care
- Provider training in congenital health conditions for adults and associated secondary conditions—particularly mental health
- Health care financing

Next Steps: Transition Services in AR

- Internal grant to design an intervention using “Participatory Action Research” principles
- Building collaborations with local providers of healthcare and case management for children with Spina Bifida,
 - ACH Spina Bifida Clinic,
 - Arkansas Spinal Cord Commission
 - Spina Bifida Association of Arkansas
 - UALR, ACH, UAMS Departments of Social Work
 - Centers for Independent Living
 - UAMS Spine Center
- Apply for external funding to implement program

Assistive Technology: Promoting health and reducing secondary conditions among young adults with Spina Bifida

Kurt Johnson, Ph.D.¹, Principal Investigator

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Assistive Technology and secondary conditions

- Individuals with Spina Bifida (myelomeningocele) are likely candidates for uses of AT:
 - Mobility
 - Bladder and Bowel Management
 - Variety of challenges, learning disability
 - Latex and other intolerance phenomenon
- At risk for secondary conditions such as depression, pain
- Few systematic assessments of accomplishments or complications with *reliance on AT*
- Unclear difficulties with acquiring, servicing and fully participating with *reliance on AT*

AT & Accommodation Needs

- **Mobility:** Walking/transfers, wheeled mobility, transportation in accessible (Universal Design) environments.
- **Manipulation:** Special care routines for bladder and bowel management (e.g., CIC, digital stimulation) & Other personal care needs such as dressing, bathing, management of bracing, wheelchair devices; Instrumental ADL performance in Independent living.
- **Communication:** Written production, keyboarding, note-taking, & Internet skills
- **Cognition/Learning:** Learning disability: Strategies to participate and perform in school, work, community settings (e.g., reminders, organizers, scheduling)

Review of the literature on adolescents and SB

- Lower levels of functioning and participation
 - >20% continue to have personal ADL dependency
 - Frequent reports of bowel and bladder accidents – presumed implications include embarrassment and reduced participation.
 - Mobility is not *static* – *dynamic changes exist*
 - Half don't reach *optimal level of functioning* that would be predicted by neurological level
 - Move from ambulation to orthotics to aids to wheeling
 - Wear and tear with use of walking aids and wheelchairs
 - Demands on mobility grow as they age; transportation limited and inefficient
 - World not built for wheeling

Literature review

- Not functioning or participating as well as they would like
 - 65% report limited participation in structured and unstructured activities
 - Developmentally they remain different from their peers without disabilities.
 - High unemployment (like others with disability)
 - Engagement is difficult

Assistive Technology and ...

■ Phase 1: Analysis of Existing Patient Data

- PDMS™ (N=348; 14 – 27 y.o., Dx, AT & Function & Participation). Completed:
 - Johnson, K., Dudgeon, B., Kuehn, C., & Volan, T. (July, 2004). Assistive Technology and Spina Bifida. Paper presented at the annual meeting of the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control, Washington, DC.
 - Dudgeon, B., Johnson, K., Kuehn, C., (April, 2005). Assistive Technology use by Adolescents and Young Adults with Spina Bifida. Poster Session at the American Occupational Therapy Association Annual Conference, Long Beach, CA.
 - Kuehn, C., Dudgeon, B., DiGiacomo, A., & Johnson, K. (December, 2005). Mobility and personal care independence among adolescents and young adults with spina bifida. Paper presented at the annual meeting of the American Public Health Association. Philadelphia, PA.
 - Johnson, K., Dudgeon, B., Kuehn, C., & Walker, W. (2007). Assistive technology use among adolescents and young adults with spinal bifida. American Journal of Public Health, 97(2), 330 - 336.
- Washington State Medical Assistance Administration (Medicaid Database): Data analysis complete, manuscript in progress

Costs associated with the uses of AT among those with Spina Bifida

- Washington State Medical Assistance Administration
- Medicaid Database & Medicare Designations: 2001-2004
 - Under 16 (n=270)
 - 16-25 (n=163)
 - Over 25 (n=367)
- \$563,565 were billed and \$434,172 were paid annually for AT for the 848 average annual enrollees with spina bifida, accounting for 3.3% of all costs paid for this population.
- Orthotics and Prosthetics; Wheelchair & Related payments accounted for 56% of all AT related charges.
- Total AT costs per eligible enrollee were significantly lower for individuals 16-25 years of age compared to younger and older age groups.
- Overall, AT costs appear to be minor compared to other health related costs for this population.

Assistive Technology and ...

- Phase 2: New Data Collection
- Telephone surveys: AT Use, Secondary Conditions, Participation (N=63; 14-26 yr.)
 - Poster Session (Public Health)
 - Paper (data collected, manuscript in progress)
- In-depth qualitative interviews (N=8; 18-26 y.o., Spina Bifida and AT lifestyle)
 - Paper (data collected, manuscript in progress)

Transitioning to adulthood: A study of young adults and adolescents with spina bifida

- 63 adolescents and young adults (age 16-25)
- 60% reported using wheelchairs, 55% orthotics to aid mobility, and 75% reported bladder catheterization, 55% bowel care program
- Not using a whole class of AT that might have benefited them in school and later in employment
- Participated on a very limited basis in employment
- Participation is limited in community and home

Transitioning to adulthood: A study of young adults and adolescents with spina bifida (Conference Posters, Paper Writing)

- Remained for the most part dependent on their families, with few responsibilities with respect to *independent living*
- Physical and attitudinal barriers commonly reported; impacts on access to transportation, public and community programs, and community participation
- Modest satisfaction with their lives; moderate pain & typical depression
- *High risk for failing to make a successful transition into independent adulthood*

Spina Bifida and transitions with assistive technology and environmental design needs

- 8 Young Adults with Spina Bifida and AT Reliance
 - Qualitative methodology using interviews
- Matter of fact approach toward their condition and related difficulties
- Were *'just dealing with it;'* regarded challenges as being *'normal for me'*
- AT was often *'working for'* them, but change was inevitable and *'tough'* in terms of *'time,' 'costs'* and *'delay'*

Spina Bifida and transitions with assistive technology and environmental design needs

- *'Accessible environments' were 'not as advertised.'*
Trouble fitting into places and using transportation systems
- Transition time extended as they sought environmental access and to maintain *'just-right fit'* with uses of AT
- Cognitive issues interact with AT and access, e.g., low initiation
- Hopes remained 'high,' association 'with others like them' valued
- But, outcomes unclear & uncertain

Assistive Technology and . . .

- Dynamic and increasing needs for accommodations and AT
- Delayed or Failed Transitions
- Limited Participation in all Realms
- Limited Access to Necessary Community-Based Services

