If you are viewing this course as a recorded course after the live webinar, you can use the scroll bar at the bottom of the player window to pause and navigate the course.

This handout is for reference only. It may not include content identical to the powerpoint. Any links included in the handout are current at the time of the live webinar, but are subject to change and may not be current at a later date.
Activities of Daily Living in Children and Adolescents with Spina Bifida: Developmental Considerations

Rachel Galant, MSNM, OTR/L
Debbie Victor, OTD, OT/L

August 18th, 2016

Objectives

- Demonstrate general understanding of spina bifida definition, prevalence, and special care needs.
- Describe typical norms for independence with ADLs for children with spina bifida and age of acquisition of typical adolescent skills.
- Describe challenges to independence for children with spina bifida.
- Describe the OT role in supporting transition for children and adolescents with spina bifida.
- Demonstrate understanding of teaching ADL skills with strategies, adaptive techniques and/or equipment.
- Demonstrate understanding of self-catheterization training and specific challenges to children with spina bifida.
Spina bifida

- **Spina bifida** is a general term that includes a wide assortment of neural tube defects. It describes children with no neurological dysfunction or with mild to very severe disability.
  - Normally the neural tube closes at 25 days gestation.
  - There is an abnormal opening of the vertebrae posteriorly.
  - The cells that become the spinal cord do not develop properly.
  - The spinal cord remains a flat plate of nerve cells as the neural tube does not close.
  - There is evidence that exposed neurons die due to a toxic amniotic fluid environment that develops at 34 weeks of gestation.

(Copp et al., 2015).

Occurrence

- In the United States prevalence of neural tube defects is .5 to .8 cases per 1,000 births.
- Approximately 3% recurrence rate for mothers with 1 affected child.
- Approximately 10% recurrence rate for mothers with 2 affected children.
- More frequent in China.
- In the United States, prevalence is now higher in Hispanic and lower in African American communities.

(Copp et al., 2015).
Statistics continued

- Mortality rate in 1950’s was 90%.
- With the addition of shunt in the 1960’s, the survival rate of the infant approached 90%.
- Today around 166,000 individuals with spina bifida live in the US (National Institute of Neurological Disorders and Stroke, 2015).
- Major issues faced are the transition to adult medical care, independent living, and social skills.

Detection and Prognosis

- Detected in utero via amniocentesis and ultrasound.
- Associated conditions: ruptured sac after birth, meningitis, hydrocephalus, Chiari II malformation, kyphoscoliosis, intellectual disability, and UTI.
- Ventriculoperitoneal shunt required for almost all children with thoracic-level lesions, about 85% with a lumbar-level lesion, and about 70% with a sacral-level lesion.
- Fetal myelomeningocele surgery, may have effects on neurological function, most notably reducing the need for shunt placement.
  - Typically completed between 19 and 25 weeks gestation.
- The rate of survival to the age of 40 is 20% for those with a lesion above T11 and 60% for lesions at L3 and below.

(Copp et al., 2015).
Etiology

- Unknown
- Believed to have hereditary component, as prevalence rates of various ethnic groups remain constant after these groups move to different locations.
- Lower levels of folate are known to increase likelihood of having a child with spina bifida. May also be linked to low vitamin C, serum vitamin B12, and low zinc intake.
- Affects females more than males.
- Other maternal factors include low socioeconomic status, diabetes, obesity, infection, psychosocial stress, smoking, use of alcohol, caffeine, and valproic acid.
- Environmental factors, such as pollution, can increase likelihood of having a child with a neural tube defect.

(Copp et al., 2015)
Special Care Needs

- Skin care
- Nutrition/weight management
- Latex/rubber allergy
- Bladder management
- Bowel management
- Education and learning
- Growing up

Activities of Daily Living & Instrumental Activities of Daily Living
**The presenters do not have any affiliation with any of the discussed products or resources and do not intend to endorse any. They are items that have been successful for us or others that could be recommended.**

Factors Affecting ADL Acquisition and Independence

- Sousa in 1983, differentiated between the initial skill completion vs. routine task accomplishment which can sometimes vary greatly.
- General factors: perceptual motor impairment, upper extremity incoordination, scoliosis, kyphosis, lower extremity contractures.
- Other factors:
  - Intelligence variability
  - Sex, social class, race, and environment
  - Level of motor paralysis
  - Differences in parental expectation and priorities
  - The philosophy of care under which a child receives medical management
  - Time constraints on the family

Comparison sample of ADL Development Milestones between SB (80th percentile) and Typically Developing (TD) Populations

<table>
<thead>
<tr>
<th>Dressing Task</th>
<th>TD</th>
<th>L2 &amp; above</th>
<th>L3, L2-4</th>
<th>L4 &amp; L5</th>
<th>S1 &amp; below</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remove socks</td>
<td>1-1/2y</td>
<td>9y</td>
<td>4 1/4 y</td>
<td>4y</td>
<td>4y</td>
</tr>
<tr>
<td>Remove pants</td>
<td>2-1/2y</td>
<td>10y</td>
<td>8y</td>
<td>6-1/3y</td>
<td>5-1/2y</td>
</tr>
<tr>
<td>Pull-over garment on</td>
<td>3-1/2y</td>
<td>10y</td>
<td>8y</td>
<td>6y</td>
<td>6y</td>
</tr>
<tr>
<td>Pants on</td>
<td>3y</td>
<td>12-1/2y</td>
<td>11-1/3y</td>
<td>7y</td>
<td>5-3/4y</td>
</tr>
<tr>
<td>Shirt on with buttons</td>
<td>4y</td>
<td>11-1/4y</td>
<td>6-1/2y</td>
<td>7y</td>
<td>6y</td>
</tr>
<tr>
<td>Remove braces</td>
<td>NA</td>
<td>9-1/4y</td>
<td>9-1/4y</td>
<td>7y</td>
<td>8-1/2y</td>
</tr>
</tbody>
</table>

(Sousa, 1983).

Continued ADL Developmental Milestones

<table>
<thead>
<tr>
<th>Eating</th>
<th>TD</th>
<th>L2 &amp; above</th>
<th>L3, L2-4</th>
<th>L4 &amp; L5</th>
<th>S1 &amp; below</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holds &amp; drinks from cup</td>
<td>1-1/2y</td>
<td>3y</td>
<td>2y</td>
<td>2y</td>
<td>2y</td>
</tr>
<tr>
<td>Uses spoon</td>
<td>1-1/2y</td>
<td>1-1/2y</td>
<td>2y</td>
<td>2y</td>
<td>1-1/2y</td>
</tr>
<tr>
<td>Cuts with knife</td>
<td>7-1/2y</td>
<td>10-3/4y</td>
<td>9y</td>
<td>9-1/4y</td>
<td>7-1/2y</td>
</tr>
</tbody>
</table>

Grooming

| Wash hand - no help     | 4y      | 9y         | 6-1/2y   | 6-3/4y  | 5-1/4y     |
| Dries after bath - no help | 5y    | 10y        | 9y       | 11-1/2y | 7y         |
| Bathes by self          | 8y      | 11-1/2y    | 9y       | 12y     | 9y         |

(Sousa, 1983).
### Personal-Social Milestones

<table>
<thead>
<tr>
<th>Personal-Social</th>
<th>L2 &amp; above</th>
<th>L3, L2-4</th>
<th>L4 &amp; L5</th>
<th>S1 &amp; below</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helps do small jobs</td>
<td>4-1/4y</td>
<td>8-2/3y</td>
<td>4y</td>
<td>3-3/4y</td>
</tr>
<tr>
<td>Takes part in simple group games</td>
<td>4y</td>
<td>5-1/3y</td>
<td>6y</td>
<td>4-1/4y</td>
</tr>
<tr>
<td>Crosses street without supervision</td>
<td>NA to majority</td>
<td>10-1/2y</td>
<td>11y</td>
<td>8-3/4y</td>
</tr>
<tr>
<td>Goes to friend's house to play</td>
<td>10y</td>
<td>6y</td>
<td>12y</td>
<td>8-1/2y</td>
</tr>
<tr>
<td>Paid for working outside the home</td>
<td>NA to majority</td>
<td>16y</td>
<td>13-1/3y</td>
<td>14y</td>
</tr>
<tr>
<td>Member of an organized group</td>
<td>NA to majority</td>
<td>13y</td>
<td>12-1/3y</td>
<td>10y</td>
</tr>
</tbody>
</table>

(Sousa, 1983).

### Current Supportive Research

- To reach independence in daily life, children with SB need specific guidance to overcome process deficits, to learn not only how to do things but also how to get things done (Peny-Dahlstrand et al, 2009).
- More detailed and precise prognosis can be given to parents about the functional independence of their child at adult age.
  - For example, if a child born with SB without hydrocephalus, we would expect this child to become independent in terms of ADL, except sphincter control (incontinence) (Verhoef et al, 2006).
- In children with MM, good muscle strength, mental ability, and being independent in mobility appeared to be much more important for daily life function and quality of life than other medical indicators of the disorder; it is suggested from the study that lesion level, mental status, contractures, and muscle strength of lower extremities particularly determine independence in self-care (Schoenmakers et al, 2005).
Age of Acquisition (AOA) of Skills for Adolescents

- Adolescents ages 12-18 are delayed 25-30% in autonomy skills and acquire these skills 2-5 years later than typically developing adolescents.
- Community skills acquired at median age 16 ½.
- The difference in cognitive ability explained the variance in the median age of acquisition with verbal IQ scores <80 as an important predictor.
- Those with lesion >L2 had most delays.

Skills Accomplished Before age 12

1. Dresses appropriately for occasion
2. Makes shopping choices
3. Cleans room
4. Independent in hygiene
5. Monitors time for activities
6. Knows phone number
7. Can use a phonebook
8. Reads time on a clock
9. Shops with assistance
10. Monitors time for special occasion
11. Participates in unstructured activities

(Davis, 2006).
Skills Accomplished During Adolescence (75<sup>th</sup> centile)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Saves money (13.2 yrs)</td>
</tr>
<tr>
<td>2.</td>
<td>Independent in toileting (13.3 yrs)</td>
</tr>
<tr>
<td>3.</td>
<td>Independent self-transfer (15.0 yrs)</td>
</tr>
<tr>
<td>4.</td>
<td>Counts change (14.5 yrs)</td>
</tr>
<tr>
<td>5.</td>
<td>Cooks pre-packaged meals (15.2 yrs)</td>
</tr>
<tr>
<td>6.</td>
<td>Plans activities with peers (16.1 yrs)</td>
</tr>
<tr>
<td>7.</td>
<td>Arranges own transportation (16.2 yrs)</td>
</tr>
<tr>
<td>8.</td>
<td>Participates in structured activities (12 yrs)</td>
</tr>
</tbody>
</table>

(Davis, 2006).

Skills NOT Accomplished During Adolescence >18.9 years

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Manages allowance</td>
</tr>
<tr>
<td>2.</td>
<td>Makes own appointment</td>
</tr>
<tr>
<td>3.</td>
<td>Bank account with assistance</td>
</tr>
<tr>
<td>4.</td>
<td>Cooks independently</td>
</tr>
<tr>
<td>5.</td>
<td>Does laundry</td>
</tr>
<tr>
<td>6.</td>
<td>Bank account without assistance</td>
</tr>
</tbody>
</table>

(Davis, 2006).
Skills Unique to MM (75th centile)

1. Knows signs of skin ulcers (16.2 yrs)
2. Knows signs of bowel problem (15.4 yrs)
3. Knows signs of shunt failure (17.0 yrs)
4. Knows signs of urinary tract infection (15.0 yrs)

(Davis, 2006).

Need for ADL Performance Evaluation and Monitoring in Children with Spina Bifida

- Physical limitations, learning difficulty, and frequent over-dependence on adults may interfere with performance of ADL’s.
- Key areas to assess: dressing, bathing, bowel/bladder management, feeding, toilet/tub transfers.
- OT plays an important role in assessing a child’s readiness to begin self-catheterization. Areas to assess for self-cath: self-care, level of participation in present cath program, general mobility, hand skills, cognitive/visual-perceptual skills.
- In a life satisfaction study for young adults with SB, it was found that most with SB were unhappy with their level of self-care skills than people in the general population. However, SB itself does not seem to be an important determinant of life satisfaction (Barf et al., 2007).
Treatment Ideas to Promote Early Independence with ADL’s

- Use adaptive equipment, methods or clothing.
- Recommend bath chairs, reachers, dressing aides, grab bars, and techniques for increased safety with bathroom transfers.
- Fine motor activities to improve hand function for self-catheterization and involve child in steps.
- Increase functional mobility for increased independence with tub/toilet transfers and self-catheterizing.
- Use of visual cues such as stop watches, sticker charts, reminder signs of steps or cell phone reminders, backward/forward chaining.
- Encourage families to have children use bedtime and weekends to be as independent as possible, since it can be hard to contend with time constraints before school when kids may need more help.

Need for IADL/Transition-Related Skill Performance Evaluation and Monitoring in Children with Spina Bifida

- Transition Services, are “[A] coordinated set of activities for a child with a disability that...is focused on improving the academic and functional achievement of the child...to facilitate the child’s movement from school to post-school activities, including:
  - Post-secondary education,
  - Vocational education,
  - Integrated employment (including supported employment),
  - Continuing and adult education,
  - Adult services,
  - Independent living, or
  - Community Participation”

Need for IADL/Transition-Related Skill Performance Evaluation and Monitoring in Children with Spina Bifida

- Adults with spina bifida are at risk for decreased community integration:
  - They have high unemployment rates.
  - They may be hospitalized due to preventable health-related conditions or reside in more restrictive settings due to dependence on others for self-management (Jacobson, et al., 2013).
  - They may participate less in general community activities (Mukherjee, 2007).

- Adults with spina bifida are at risk for receiving limited or inappropriate health care:
  - Limited access to specialty providers who are knowledgeable about spina bifida (Binks, Barden, Burke, & Young, 2007).

- Young adults have additional roles and challenges as they prepare for adult health care:
  - They can be responsible for teaching providers about spina bifida.
  - They may have to arrange transportation and travel long distances to access health care.
  - They may have limited information on issues related to aging with spina bifida.

- Young adults with spina bifida have had fewer opportunities to develop decision-making autonomy:
  - Parents can be more overprotective, and potential issues with executive functioning can lead parents to take over responsibility for making decisions and directing transition-related tasks.
  - Potential diminished social skills and communication with providers can hinder or delay medical management skills (Psihogios & Holmbeck, 2013).

- Occupational therapists are uniquely prepared to assess the interplay of an individual’s strengths and areas for growth with regard to the transition process.

Evaluation of IADL/Transition

- There is a paucity of available transition assessments that capture the complexity of the transition process
  - Skill
  - Routine Participation
  - Sense of readiness or self-determination
  - Environment
  - Family support

- Kennedy Krieger Independence Scales—Spina Bifida Version
  - Measures self-management skills
  - Parent report

- Adolescent Self-Management and Independence Scale-2
  - Assesses knowledge and behaviors needed for self-management of spina bifida
  - Self-report measure

Sample items from the Child Occupational Self-Assessment (COSA)

Jacobson et al., 2013)
Treatment Ideas to Promote Early Independence with Transition-Related Skills

- Therapists have an essential role in assessing skills, developing achievable goals, and providing skills training to maximize independence in IADL (Mukherjee, 2007).
  - Limited research on best practices for transition
  - Some research-based intervention tools have been introduced, including the Youth KIT (Gorter, et al., 2015).

- To support adolescents to have a successful transition towards an independent adulthood:
  - Increase knowledge base in transition areas
  - Assist in skill development
  - Encourage routine performance
  - Develop self-efficacy with independent living skills
  - Cultivate future planning skills when possible
  - Solidify decision-making and other self-advocacy skills

Transition Intervention: Cooking

- Discuss nutrition and planning healthy meals
  - www.choosemyplate.gov
- Become familiar with cookbooks and find a healthy recipe
- Generate shopping list
  - Categorize items by grocery store areas, use visuals when needed
- Shop for items at grocery store
  - Become familiar with universal cognitive aids (e.g. aisle markers)
  - Use adaptive equipment (e.g. reacher, basket on walker)
  - Ask for help when needed
- Discuss kitchen safety and accessibility and make changes to home kitchen as needed
  - Role play safety issues in therapy
- Learn how to handle tools and operate appliances
- Prepare meal
  - Integrate safety and access strategies
- Make a meal at home to reinforce skills and start home routine
Transition Intervention: Chores

- Care for clothing
  - Wash clothes
  - Fold clothes
  - Store clothes
  - Complete basic sewing tasks
- Clean and organize
  - Make a bed
  - Organize room
  - Wipe down tables
- Complete minor repairs
- Discuss housing accessibility
- Identify and apply chore routine at home, encouraging sense of contribution to home environment
  - Use organizational tool, such as chore wheel or “30/30” app for organizing chores and providing reminders
  - Post visual schedules for reminders of steps

Transition Intervention: Financial Management

- Learn values of coins/bills, count change, and complete basic monetary calculations
- Differentiate income versus expenditures
- Understand disability benefits
- Complete a basic budget
- Explain purpose of credit cards and bank accounts and review basic management skills
- Verbalize ways to avoid debt
Transition Intervention: Community Transportation

- Discuss accessibility features in community transportation
- Plan a trip using public transportation or paratransit service.
  - Google maps (https://www.google.com/maps)
- Adapt clothing or equipment for easy and safe access to transit card or money.
- Order transit card
- Complete a trip
  - Identify destination at correct time
- Refer to driving evaluation and vehicle adaptations
  - Association for Driver Rehabilitation Specialists (www.aded.net)
  - National Mobility Equipment Dealers Association Quality Assurance Program (www.nmeda.com)

Transition Intervention: Sports/Recreation

- Learn about, try, and become involved in community adaptive sports and recreation activities
- Determine appropriate adaptations to equipment, knowledge, or routine to support home fitness (e.g. seated aerobics)
- Work towards personal fitness activity goals
  - Physical activity and fitness are related to health-related quality of life in adolescents with spina bifida (Buffart, Van Den Berg-Emons, Van Meeteren, Stam, & Roebroeck, 2009).
- Utilize recreation therapy during clinic visits.
Transition Intervention: Employment

- Increase knowledge of student and family rights regarding employment preparation through school-based IEP process
  - Family Resource Center on Disabilities (http://frcd.org)
- Prepare and rehearse questions for IEP meeting
- Discuss the level of fit between interests, skills, learning style, desired education level, and areas of need
  - National Secondary Transition Technical Assistance Center (http://nsttac.org):
    - Age Appropriate Transition Assessment Toolkit
- Interview and shadow professionals in areas of interest
- Prepare for job seeking process
  - Fill out application
  - Create a resume
  - Rehearse interview questions and role play interviews
- Participate in supported employment opportunities
  - School store, structured jobs in therapy
  - Involve Vocational Rehabilitation and other community agencies

Transition Intervention: Medical Management

- Identify and explain spina bifida and associated medical conditions
  - What are the symptoms of latex allergy? Urinary tract infection?
- Complete Portable Medical Record and compile important medical documents
  - Spina bifida medical summary from the Spina Bifida Association
  - “Health” app for iPhones
  - My Health Passport (www.sickkids.on.ca/myhealthpassport)
- Know purpose and side effects of each medication. Take prescriptions according to schedule
  - “MedCoach,” “Mango Health,” or “Walgreens” apps for reminders to take medicines and refill prescriptions
  - My Med Schedule text reminders (www.mymedschedule.com)
### Transition Intervention: Medical Management

- Call to make medical appointments and order prescriptions
  - Use written phone call scripts if needed
- Prepare and rehearse questions to ask various health care professionals
- Encourage early exploration of medical transition to adult providers:
  - Improved transition outcomes given period of overlap and communication between pediatric and adult providers (Rauen, et al., 2013; Mukherjee, 2007).
- Locate medical and/or community resources for health management

---

### Equipment & Adaptive techniques

[Continued]
Adaptive equipment for dressing and bathing

- Sockaid
- Reacher
- Long-handled shoe horn
- Long-handled bath sponge
- Dressing stick
- Foot funnel®
- Spyrolaces

Dressing motivators

"I CAN DRESS MYSELF!!"
Dressing techniques

- Set out clothes the night before
- Allow enough time to complete
- Practice at night and on weekends
- Sit on the floor (possibly in corner if more support needed) or stable surface
- Don’t use adaptive equipment if it just gets in the way
- For donning pants, roll side to side in supine to pull them up all the way over bottom, and roll into prone position if that doesn’t do the trick
- For donning socks, position in long sitting and reach to feet or cross legs to access feet better if body position allows
- Consider pull-ups instead of diapers for leaks, since more like underwear

Adaptive equipment for toileting

*Toilet Aid

“The Answer To Personal Hygiene When Reaching Is Difficult...”

*Bottom Buddy™

*Easywipe
Inserting tissue:
Step 1: Hold tissue with the end of finger in the center of the tissue.

Step 2: Place finger over opening of Bottom Buddy head.

Step 3: Bend lower section down and insert tissue part way into opening. Remove finger.

Step 4: Smooth tissue over head.

Releasing tissue:
Point Bottom Buddy head down and push release button forward to release tissue.

Adaptive equipment for self-catheterization and skin inspection
Types of Catheters and Adaptations

- Catheter in bag/
  Closed system
- SpeediCath®
- Mitrofanoff
  Appendicovesicostomy
Durable medical equipment (DME) for the shower or bathtub

**Make sure you have a very good idea of home set-up, if child will be taking baths/showers/both, and get a very good sense of potential use. Also, will they be independent or have caregiver assist?**

More shower/tub seat options

*OTTER Bathing System

*Aquatec® Bath Lift
*Columbia™ Hi-back Wrap-around Bath Support

*Omni™ Toileting Reclining Transfer System

DME for toileting
A very popular potty seat for small children is the **Prince Lionheart Weepod**. (Some use the **Weepod** and others use the **Weepod Basix**.) They can be purchased online and in store at many retailers, including Amazon, Kohls, Target, and Walmart.

For larger children who outgrow toddler potty seats, a popular option is the **Special Tomato Reducer ring**. It can be purchased in elongated or round shapes depending on the shape of your toilet. Adaptivemall.com usually has this “on sale” for about $70.
Another piece of equipment that is popular for children who need trunk support or help with balancing on the toilet is the Rifton Toileting System. Parents also like it for the cone enema because you can get your hand underneath the child a little easier. Often, insurance will cover this equipment.

Besides a proper seat, you may also want to provide the child with a stool on which to rest his feet. Feet that are allowed to dangle for prolonged periods often lose circulation (especially true with Spina Bifida) and turn blue and cold. Many people also bring a TV tray into the bathroom. It can be used for leaning over during the administration of the enema as well as for homework, coloring, and watching movies.

If you need help, visit the Bowel Management for Spina Bifida Facebook group.

The Parents’ Guide to Cone Enemas, Edited by Colleen Payne

Self-catheterization training and challenges
Barriers

- Is the whole family on board?
- Motivation? For the child? For the caregiver(s)?
- Cognition and safety factors
- Positioning and mobility challenges
- Anatomy and body composition
- Prone to UTI’s
**Occupational Therapy: Catheterization Readiness Assessment**

**Date:** ________________  **MRN:** __________________

**Name:** ___________________  **Age:** ____________  **Gender:** Male/ Female

**Diagnosis:** ___________________  **Dominant Hand:** Right/ Left  **Males Circumcised:** Y/N

**Current Cath Program:** Y/N  **Motivated to self-cath:** Y/N

**Frequency:** 4hrs  6hrs  8hrs  When: ____________________________

**Where:**  ○ in bed  ○ toilet  ○ w/c  ○ other: ____________________________

**Cath size:**  ○ 10 fr  ○ 12 fr  ○ 14 fr  ○ ___ fr

**General Hygiene:** Dry/ Wet: a little/ a lot

**Level of participation:** ____________________________________________

### ADL Skills: (circle/check)

<table>
<thead>
<tr>
<th>Level of assist→</th>
<th>Mod I</th>
<th>Set-up</th>
<th>Min A</th>
<th>Mod A</th>
<th>Max A</th>
<th>D</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dons Pants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doffs Pants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dons Diaper/ Underwear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doffs Diaper/ Underwear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cathing hygiene (clean w/c)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel Program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Sitting Balance: (circle)**

<table>
<thead>
<tr>
<th>UE Support</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional Support</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Transfer/ Mobility Skills:**

<table>
<thead>
<tr>
<th>Primary means of Mobility:</th>
<th>Ambulates Y/N</th>
<th>Type of w/c: Manual/ Power/ NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ind.</td>
<td>Assist</td>
<td>Comments</td>
</tr>
<tr>
<td>Transfers to (primary cathing location)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short Sit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long Sit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ring Sit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shift Body Up/Down</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight shift with Posterior Reach</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Adequate Hip Abduction (females):** Y/N
### Hand Skills:

<table>
<thead>
<tr>
<th>Grip</th>
<th>Lateral</th>
<th>Finger Abduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>R L</td>
<td>R L</td>
<td>Adequate</td>
</tr>
</tbody>
</table>

#### Grasp Pattern: (check or circle)

<table>
<thead>
<tr>
<th>Pellet</th>
<th>Digital/</th>
<th>Digital/</th>
<th>Lateral/</th>
<th>Inferior/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Palmar</td>
<td>Palmar</td>
<td>3 point/</td>
<td>Fine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block</th>
<th>Digital/</th>
<th>Digital/</th>
<th>Lateral/</th>
<th>Inferior/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Palmar</td>
<td>Palmar</td>
<td>3 point/</td>
<td>Fine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>String/ Catheter</th>
<th>Digital/</th>
<th>Digital/</th>
<th>Lateral/</th>
<th>Inferior/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Palmar</td>
<td>Palmar</td>
<td>3 point/</td>
<td>Fine</td>
</tr>
</tbody>
</table>

---

**In Hand Manipulation:**

- **Right hand**
  - ___/5 marbles [finger→palm; palm→finger] Shits: Y/N
  - ___/5 marbles [finger→palm; palm→finger] Shits: Y/N

- **Left hand**
  - ___/5 marbles [finger→palm; palm→finger] Shits: Y/N
  - ___/5 marbles [finger→palm; palm→finger] Shits: Y/N

**Stereognosis:**

- **Right hand**
  - intact __/5 (___, ___) absent
  - intact __/5 (___, ___) absent

- **Left hand**
  - intact __/5 (___, ___) absent
  - intact __/5 (___, ___) absent

**String Beads:**

- ___/5 independently ___/5 ___/5 ___/5 ___/5 ___/5 ___/5 ___/5 ___/5

- Strings Cath thru Straw: Y/N

- Open/ Close: Y/N
  - Flip top: Y/N
  - Screw top: Y/N
  - Tear packet: Y/N

**Visual Perception Skills (circle):**

- Adequate
- Needs Further Assessment

**Cognitive Skills:**

- Attention: Adequate
- Fair
- Poor

**Behavioral Observations:**

**Problem Solving:**

- Adequate
- Fair
- Poor

**General Observations:**

**Sequences:**

- ___/8 self-cath flash cards “OR” ___/8 alternative flash cards

**Goals:**

---

**Therapist:**

---
Treatment Ideas to Promote Early Involvement & Independence with Catheterization

- Use adaptive equipment, methods or clothing as needed.
- Fine motor activities to improve hand function for self-catheterization and involve child in steps.
- Increase functional mobility for increased independence with tub/toilet transfers and self-catheterizing.
- Use of visual cues such as sticker charts, reminder signs of steps or cell phone reminders, backward/forward chaining.
- Encourage families to have children use bedtime and weekends to practice, since it can be hard to contend with time constraints before school when kids may need more help.

Teaching Tools

- Flashcards
- Cathing doll
- Online teaching tools
- Videos
- Anatomy review
- Hand sanitizer wash activity
- Reading books and coloring books on the topic
- Talking with others to see what has worked for them
- From bed, floor, wheelchair, and toilet levels
- HEP for variety of related skills
Challenges and successes

- Females: anatomy is much more difficult to navigate than males
- Sequencing of steps and remembering them all
- Very hard when child has NO involvement prior, e.g. have not washed hands, managed clothing, etc.
- Family members jumping in too much, not following through on having child do more, taking lead
- Success: when family follows through with the practice, seeing what works and what doesn’t
- Best case when family coaches but does not participate
- Encourage more independent problem solving instead of too many directives

Effectiveness of Inpatient Hospital Stays for Self-Catheterization and Independence for Children with Spina Bifida

- Retrospective Chart Review from 2007-2011
- Purpose: Analyze a group of pediatric patients with spina bifida (SB) who have undergone inpatient hospital stays to learn self-catheterization training with occupational therapists and nurses.
- Background: Individuals with Spina Bifida (SB) often have delays with activities of daily living (ADL) and executive functioning which makes independence training at home challenging. We sought to determine if a short, intensive hospital stay would provide the tools for children/adolescents with SB to be successful with self-catheterization.
- N=13 patients with SB, average age 11.2±2.4; 3M, 10F
- Children identified in clinic as a good candidate for catheterization training and participated in a 3-5 day hospital stay with bid OT and nursing team teaching.
Retrospective chart review (continued)

- OT interventions
  - Flash cards
  - Teaching doll
  - Anatomy review
  - Achievement charts
  - Aids used as needed

- Readiness activity skills
  - Fine motor strengthening
  - Dexterity
  - Perceptual motor
  - Visual perceptual
  - ADL
  - Bathroom transfers training

- Data was collected prior to training, at discharge and at clinic follow up

RESULTS

- Prior to training
  - 54% of participants were completely dependent for catheterization
  - 36% were dependent with catheter insertion but helped with pre-catheterization tasks

- At discharge
  - 31% required assistance with catheter insertion and cues for pre-catheterization tasks
  - 62% were independent except for verbal cues

- Clinic follow up (6.5 months)
  - One participant required assist with catheter insertion and cues for pre-catheterization tasks
  - 23% were independent with catheter insertion with occasional cueing
  - 62% were completely independent with all aspects

- Aids to catheterization
  - 50% of participants used a mirror in bed to complete the task.
  - 17% performed it in bed without aids
  - 17% used a toilet and mirror
  - 17% used a toilet with no aids
CONCLUSIONS

Utilizing this unique model of intensive inpatient hospital stay and OT intervention, most participants with SB made excellent progress in self-catheterization independence and maintained or surpassed that level at follow-up.

Collaboration with Families

- Parents and family members may be reassured to know:
  - that it is normal for their child to acquire these skills later than typically developing children.
  - that for their child, he or she can be assessed to determine when to expect certain skills to develop.
- Parent cooperation in accepting, learning, and teaching are crucial to the child’s success.
  - Caregivers should feel comfortable in the role of “coach” for their children, assisting in decision-making but not taking over that capacity.
- Families should feel empowered with knowledge and community resources to make informed decisions throughout their children’s life span.
Take Home Messages

- Kids with spina bifida CAN be independent with ADLs... it may just take longer than typical children
- Support families with encouragement, adaptive techniques, equipment, and strategies
- Think about the long-term future, start early, and focus on transition and life skills
- Self-catheterization independence is challenging and is only realistic if child has mastered other basic self-care skills

References

Spina bifida Information

Self-care
References

Transition

Thank You!!

Rachel Galant
rgalant@shrinenet.org
773-385-5575

Debbie Victor
dvictor@shrinenet.org
773-385-5430