

## Best Practices for Feeding and Swallowing with Infants, Toddlers, and Young Children who have Down Syndrome

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## Disclosures

***Non-Financial Disclosure:***  
Michelle L. W. Dawson, MS CCC-SLP is Immediate Past President (2019-2020) of SCSHA (SC Speech Language Hearing Association). She is also the Treasurer of CSAP (Council of State Association Presidents) for 2018-2020 cycle. They do not compensate her for speaking here today.

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Michelle L.W. Dawson, MS CCC-SLP is Member-Manager and Speech Language Pathologist for HeartWood Speech Therapy, LLC, in Columbia, SC. However HWST, LLC does not compensate her for speaking here today. I receive royalties for this presentation from ARSHA. I also receive royalties for similar lectures from PESI, Inc., SpeechTherapyPD.com, and from First Bite: Fed, Fun, Functional PodCourse, however I did not receive compensation from them for this course.


## Program Outline

- + Speaker Disclosure/Introduction
- + Anatomical/Structural Considerations
- + Concomitant Diagnoses/Disorders
- + When and How Do I Refer?
- + Treatment Tools
- + Piecing it Together
- + Conclusion

## Introductions

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- + Old Dominion University  
BS Speech Language Pathology
- + James Madison University  
MS Communicative Sciences and Disorders
- + Public Schools, In-Pt and Out-Pt Hospital, Early Intervention, Private Practice
- + SCSHA President Elect-Elect 2016-2017
- + SCSHA VP Governmental Affairs 2015-2017
- + SCSHA Convention Co-Chair 2016 and 2017
- + Currently pursuing my BCS-S



## Tell Me About You?

<ul style="list-style-type: none"> <li>+ Parents?</li> <li>+ Infants</li> <li>+ Toddlers</li> <li>+ Young Children</li> <li>+ Older Children/Adults</li> </ul>	<ul style="list-style-type: none"> <li>+ Practioners?</li> <li>+ SLPs?</li> <li>+ SLPAs?</li> <li>+ OTs?</li> <li>+ COTAs?</li> <li>+ EI?</li> </ul>
<ul style="list-style-type: none"> <li>+ Students?</li> <li>+ Undergrad</li> <li>+ Grad</li> </ul>	<ul style="list-style-type: none"> <li>+ Did I miss ANYONE?</li> </ul>

## DS and Pediatric Dysphagia

## Anatomical/Structural Considerations

## A Thought to Ponder



## Hypotonia

- + Low Muscle Tone
- + Floppiness
- + Root Cause?
- + Hypotonia vs. Apraxia?

(Kumin, L., 2006) (<http://talk-ds.org/2013/05/03/apraxia-and-children-with-down-syndrome>)

## Craniofacial Considerations

- |  |                                    |
|--|------------------------------------|
| + Hypotonia  | + Periodontal Disease              |
| + Hypertrophy of Adenoids and Tonsils (Lingual/Palatine) | + Bruxism                          |
| + Macroglossia   | + Laryngomalacia                   |
| + Narrow/Short/High Palate                               | + Tracheomalacia                   |
| + Midface Hypoplasia                                     | + ...so about that Grand Canyon... |
| + Reduced Saliva   |                                    |

(Cooper-Brown, L., et al., 2008)  
(Dinwiddie, R., 2004)

## What does that sound like?



## Pulmonary Considerations

- + Hypertrophy of Adenoids and Tonsil Tissues
  - + Respiration vs. Deglutition
- + Obligatory Mouth Breather?
  - + Obstructive Sleep Apnea

(Dinwiddie, R., 2003)  
<https://share.es/1eOxY>

## Gastrointestinal Considerations

### + CONSTIPATION

???

- Hypotonia
- Hypothyroidism
- Delayed GI Motility (Esophagus to Large Intestines)
  - Delayed Gastric Emptying
  - Hirschsprung Disease
  - Celiac Disease

All This impedes the recognition and development of HUNGER CUES

(Cooper-Brown, L., et al 2008)  
<https://share.es/1e9kQ>

## Cardiac Considerations

- + Most Common Cardiac Conditions:
  - Atrioventricular Septal Defect
  - Persistent Ductus Arteriosus
    - Tetralogy of Fallot

???

These Closing Issues cause the heart to work harder to supply oxygenated blood to the body

<https://share.es/1eDV4>,  
 (Cooper-Brown, L., et al 2008)

## Cardiac Before and After

## Final Thought about DS

Milestone	Range for Children with Down Syndrome	Typical Range
<b>GROSS MOTOR</b>		
Sits Alone	6 - 30 Months	5 - 9 Months
Crawls	8 - 22 Months	6 - 12 Months
Stands	1 - 3.25 Years	8 - 17 Months
Walks Alone	1 - 4 Years	9 - 18 Months
<b>LANGUAGE</b>		
First Word	1 - 4 Years	1 - 3 Years
Two-Word Phrases	2 - 7.5 Years	15 - 32 Months
<b>SOCIAL/SELF-HELP</b>		
Responsive Smile	1.5 - 5 Months	1 - 3 Months
Finger Feeds	10 - 24 Months	7 - 14 Months
Drinks From Cup Unassisted	12 - 32 Months	9 - 17 Months
Uses Spoon	13 - 39 Months	12 - 20 Months
Bowel Control	2 - 7 Years	16 - 42 Months
Dresses Self Unassisted	3.5 - 8.5 Years	3.25 - 5 Years

<http://www.ndss.org/PageFiles/2872/Developmental%20Chart.jpg>

## Tour it AGAIN...

- Grand Canyon at work via the intersection of hypotonia, craniofacial structures, pulmonary, GI, and now have swallow fatigue due to cardiac issues...
  - So burning a lot of calories...
  - discuss with MD before increasing volume

## Concomitant Disorders/Diagnoses

### GERD

- + Gastroesophageal Reflux Disease
- + Stomach contents (acid) flow back into esophagus
  - + 1-5% prevalence rate
- + s/s vomiting, crying, PO avoidance
- + **Damages** the esophagus +
- + **Aspiration** risk factor

<http://www.mayoclinic.org/diseases-conditions/gerd/basics/definition/con-20023201>  
<http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Gastrointestinal-Tract-Down-Syndrome/>

### Autism Spectrum Disorders

- + Dual Diagnosis Prevalence varies between 5-7%
  - + Small *n* studies as high as 12-16%
- + Higher prevalence than general population
  - + c/b developmental regression
  - + c/b food refusals/aversions
  - + c/b severely limited communication
  - + c/b "classic" ASD behaviors

<https://shar.es1.juo5>  
 (DiGiuseppe, C., et al., 2010)

### Seizures/Infantile Spasms

- + Seizures more prevalent than the General Population
- + Infantile Spasms or West Syndrome most common
  - + IS is a "Catastrophic Seizure Disorder"
  - + Prevalence of 1-3% up to 13% for IS
  - + Significant developmental regression
  - + Pharmacological Treatment Implications
    - + Ketogenic Diet Considerations

(Arya, R., et al 2011)  
 (Heyn, S. 2008).  
<http://www.globaldownsyndrome.org/sie-center-for-down-syndrome-takes-on-infantile-spasms/>

### Front Line Pharmacological Treatments for IS

Medicine	Impact on Swallowing
+ Adrenocorticotropic Hormone "ACTH"*	+ Rage/Aggression
	+ Lethargy
+ Prednisone	+ Decreased appetite
	+ Constipation
+ Sabril**	+ Drooling
	+ Slurred Speech
	+ Difficulty Breathing
	+ Metabolic Changes

(Carl, L.L. & Johnson, P.R. 2006)  
 (Pellock, et al, 2010)

All These Factors Equate to your child's **FOOD AGE**

## When and How do I Refer?

## ASHA Guidelines

- + Principle of Ethics I
  - + B. Individuals shall use every resource, including referral and/or interprofessional collaboration when appropriate, to ensure that quality service is provided.
- + Principle of Ethics II
  - + G. Individuals shall make use of technology and instrumentation consistent with accepted professional guidelines in their areas of practice. When such technology is not available, an appropriate referral may be made.
- + Principle of Ethics IV
  - + A. Individuals shall work collaboratively, when appropriate, with members of one's own profession and/or members of other professions to deliver the highest quality of care.

## How Do I Do This?

- + Pick up the phone and call the PCP
- + Pick up the phone and call the Special Needs Coordinating Nurse
- + Fax SLP evaluation
- + Attend an MD apt



## What s/s would indicate a referral?

## Pulmonologist

- + c/o "not sleeping"
- + c/o "stirring/restless sleep"
- + s/s of bags/dyscoloration under eyes
- + s/s shortness of breath with movement
- + s/s of shortness of breath with PO intake
- + s/s of inhalation/exhalation stridor
- + s/s of discoloration with activities

## Otolaryngologist

- + c/o "not sleeping"
- + c/o snoring when sleeping
- + c/o "excessive spitting-up"
- + s/s of bags/dyscoloration under eyes
- + s/s of open mouth breathing
- + s/s of inhalation/exhalation stridor
- + s/s of dysphonia
- + s/s intermittent low grade fevers
- + s/s of overt aspiration with PO
- + s/s of oral tethering

## Gastrointestinal

- + c/o emesis or excessive "spitting-up"
  - + c/o "not hungry"
- + c/o infrequent bowel movement
- + s/s of pain or discomfort with PO intake, or shortly thereafter
- + PMH of GI following, d/c, changes in fxn

## Allergist

- + Family PMH of Food Allergies
- + c/o and s/s of changes in bowel consistency after introduction of new food(s) and/or changes in formula(s)
- + c/o and s/s of discomfort/pain after introduction of new food(s) and/or changes in formula(s)

## Registered Dietician

- + WORK TOGETHER and RESPECT THIS PROFESSION
  - + c/o several different formal changes
- + c/o and s/s of FTT or slow weight gain
- + Concerns for excessive weight gain


## Occupational Therapist

- + c/o and s/s of Postural Support for PO Intake
  - + c/o and s/s Fine Motor Delay
  - + c/o and s/s Sensory Aversions
  - + Overlap of Scope of Practice

## Physical Therapist

- + Postural Support for PO Intake
- + Communicate Concerns for:
  - Mobility impacting GI which impacts hunger cues
  - Positioning for GERD during sleep

## "Equipment Guy"


- Customize Your Size ...
- 
- The diagram illustrates the process of customizing a baby's shell and cushions. It shows a baby's shell and a cushion, with a plus sign between them. Below this, an equals sign is followed by a larger, more complex shell and cushion assembly, representing the final customized postural support device.
- + Postural Equipment for PO intake
  - + Work with the team PT/OT

# Treatment Tools




## Preparatory Phase Cues

- + Stage 1: Hand to Mouth
  - + Hand over hand on spoon, feeder, or bottle
  - + Tap spoon to side of bowl to add additional auditory cues



## Preparatory Phase Cues



- + Give the Play-by-Play
- + Pick **ONE** verbal cue "Eat, Eat, Eat"
- + Critical for Cortical Vision Impairment

## Infant Techniques

<h3>Pacing</h3> <ul style="list-style-type: none"> <li>+ Transition Sucking                             <ul style="list-style-type: none"> <li>▪ 6-10 suck/swallow/respiration with <b>disorganized</b> breathing during pause/burst</li> </ul> </li> <li>+ Immature Sucking                             <ul style="list-style-type: none"> <li>▪ Less than 30 suck/swallow/respiration per burst...with swallow and respiration during that burst</li> </ul> </li> <li>+ Mature Sucking                             <ul style="list-style-type: none"> <li>▪ Up to 30 suck/swallow/respiration at a 1:1 rate</li> </ul> </li> </ul>	<h3>Chin &amp; Cheek Support</h3> <ul style="list-style-type: none"> <li>+ Lateral Cheek Support                             <ul style="list-style-type: none"> <li>▪ To stabilize cheeks and produce tighter labial seal</li> <li>▪ Increase alertness for feeding</li> </ul> </li> <li>+ Mandible Support                             <ul style="list-style-type: none"> <li>▪ May help establish a more efficient rhythm</li> </ul> </li> </ul>
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(Hwang, Yea-Shwu, et al, 2010)  
(Law-Moristatt, L, et al 2003)

## Medicine Pacifier



## Some Thoughts on Bottles...

- + Flow Rate of Bottles can be impacted by:
  - Infant's craniofacial structures
  - Infant's skill set:
    - Transition, Immature, Mature Suck Patterns
  - Pliability of Nipple
  - Internal Pressure
  - Pressure at Ring

Law-Morstatt, L. (2003).  
(Ross, E. & Fuhrman, L., 2015)

## Bottle Suggestions

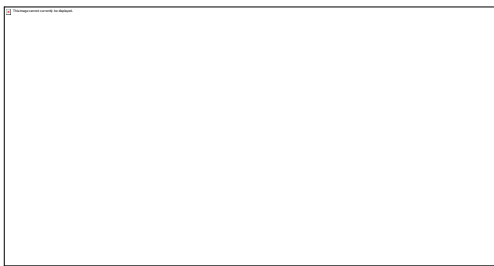


## Hard Nosed Sippy Cups

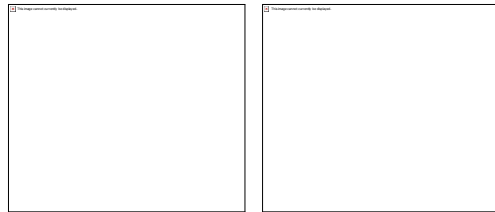


©Michelle Dawson/NSS

## Transition Cup



## Net Feeders





## Know your Taste Buds!

- + Change the Temperature
  - + Drinks
  - + Foods
- + Know your Spice Rack
  - + Sweet
  - + Salt
  - + Sour
  - + Umami

Roach, M. (2013).

## Know your Olfactory System!

- + Dad can't get them to latch? Try Momma's sweaty shirt!

Marshall, J. (2011) Infant neurosensory development: Considerations for infant child care. *Early Childhood Education Journal* 39(3), 275-281.

## Piecing it Together

## Practice What You Preach!

So I need a couple of Volunteers...

- + **Let's Consider:**
  - Tone and Posture
  - Obligatory Mouth Breather
  - Delayed Fine Motor Skills
    - Tactile Aversions

**Enjoy!**

## Conclusion

## Celebrate!

- Celebrate...Where your child or patient is today!
- Celebrate...Quality over Quantity
- Celebrate...Your child's Team and forward moving treatment plan!

**Questions**

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**References**

**References**

- + @. (n.d.). Childhood Apraxia of Speech: Overview. Retrieved November 9, 2016, from <http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935338>
- + Arya, R., Kabra, M., Gultai, S. (2011). Epilepsy in children with Down syndrome. *Epileptic Disorders*. 13(1), 1-7.
- + By World Wide Gifts - Flickr: USA - Arizona - Grand Canyon - South Rim - Hermits Rest Route - Panoramic View, CC BY-SA 2.0, <https://commons.wikimedia.org/w/index.php?curid=24572372>
- + Carl, L.L. & Johnson, P.R. (2006). *Drugs and dysphagia: How medications can affect eating and swallowing*. Austin, TX: Pro-Ed.

**References**

- + Carnicer J, et al. (2001). Prevalence of coeliac disease in Down's syndrome. *European Journal of Gastroenterol Hepatol*. 13(3): 263-7
- + Cooper-Brown, L., Copeland, S., Dailey, S., Downey, D., Petersen, M.C., Stimson, C., Van Dyke, D.C. (2008). Feeding and swallowing dysfunction in genetic syndromes. *Developmental Disabilities Research Reviews*. 14, 147-157.
- + DiGuseppi, C., et al. (2010). Screening for autism spectrum disorders in children with Down syndrome: Population prevalence and screening test characteristics. *Journal of Developmental and Behavioral Pediatrics*. 31(3), 181-191.
- + Dinwiddie, R. (2004). Congenital upper airway obstruction. *Paediatric Respiratory Reviews*. 5, 17-24.
- + Dual Diagnosis of Down Syndrome & Autism. (n.d.). Retrieved November 10, 2016, from <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Dual-Diagnosis-of-Down-Syndrome--Autism/>

**References**

- + Ear, Nose & Throat Issues & Down Syndrome. (n.d.). Retrieved November 9, 2016, from <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Ear-Nose-Throat-Issues-Down-Syndrome/>
- + Gastrointestinal Tract & Down Syndrome - National Down ... (n.d.). Retrieved November 9, 2016, from <https://www.ndss.org/Resources/Health-Care/Associated-Conditions/Gastrointestinal-Tract--Down-Syndrome/>
- + GERD. (2014, July 31). Retrieved November 11, 2016, from <http://www.mayoclinic.org/diseases-conditions/gerd/basics/definition/con-20025201>
- + Hwang, Yea-Shwu, Lin, Chyi-Her, Coster, W.J., Bigsby, R., Vergara, E. (2010). Effectiveness of cheek and jaw support to improve feeding performance of preterm infants. *American Journal of Occupational Therapy*. 64(6), 886-894.

**References**

- + Heyn, S. (2008). News & Views. Retrieved November 11, 2016, from [http://dsresearch.stanford.edu/community/archive\\_issue\\_10.html](http://dsresearch.stanford.edu/community/archive_issue_10.html)
- + Infantile Spasms in Children with Down Syndrome: Investigating a Rare but Serious Condition. (2014). Retrieved November 10, 2016, from <http://www.globaldownsyndrome.org/sie-center-for-down-syndrome-takes-on-infantile-spasms/>
- + J. (2013, June 3). Apraxia and children with Down syndrome [Web log post]. Retrieved October 24, 2016, from <https://talk-ds.org/2013/06/03/apraxia-and-children-with-down-syndrome>
- + Kurmin, L. (2006). Speech intelligibility and childhood verbal apraxia in children with Down syndrome. *Down Syndrome Research and Practice*. 10(1) 10-22.

## References

- + Law-Morstatt, L., Judd, D.M., Synder, P., Baier, R.J., Dhanireddy, R. (2003). Pacing as a treatment technique for transitional sucking patterns. *Journal of Perinatology*. 23, 483-488.
- + Marshall, J. (2011) Infant neurosensory development: Considerations for infant child care. *Early Childhood Education Journal* (39), 175-181.
- + Obstructive Sleep Apnea & Down Syndrome. (n.d.). Retrieved November 9, 2016, from <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/Obstructive-Sleep-Apnea--Down-Syndrome/>
- + Pellock, J., Hrachovy, R., Shinnar, S., Baram, T., Bettis, D., Dlugos, D., . . . Wheless, J. (2010). Infantile spasms: A U.S. consensus report. *Epilepsia*, 51(10), 2175-2189.

## References

- + The Heart & Down Syndrome. (n.d.). Retrieved November 9, 2016, from <http://www.ndss.org/Resources/Health-Care/Associated-Conditions/The-Heart--Down-Syndrome/>
- + Ross, E & Fuhrman, L. (2015). Supporting oral feeding skills through bottle selection. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*. 24(2) 50-57.
- + Zachor DA, et al. (2000). Prevalence of celiac disease in Down syndrome in the United States. *Journal of Pediatric Gastroenterol Nutrition*