GLOBAL Down Syndrome Foundation
Webinar Series July 10th, 2024

How to Manage Swallowing Issues in Children with Down Syndrome

A Global Perspective

Arwen Jackson, MA, CCC-SLP
Jennifer Maybee, OTR, MA, CCC-SLP
Emily DeBoer, MD

Global Down Syndrome Foundation

A Unique Affiliate Model

The Global Down Syndrome Foundation is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome.

GLOBAL has donated more than $32 million to establish the first Down syndrome research institute supporting over 400 scientists and 2,500 patients with Down syndrome from 33 states and 10 countries.

Working closely with Congress and the National Institutes of Health, GLOBAL is the lead advocacy organization in the U.S. for Down syndrome Research, Medical Care, and related Advocacy, and Education.

Global has a membership of over 115 Down syndrome organizations worldwide and is part of a network of Affiliates - the Crnic Institute for Down Syndrome, the Sie Center for Down Syndrome, and the University of Colorado Alzheimer's and Cognition Center - all on the Anschutz Medical Campus.

Financial Disclosures

Emily DeBoer discloses

- EvoEndoscopy; Consultant, Founder (salary, patent/licensure)
- Boehringer Ingelheim; Consultant Clinical Trials (salary)
- Parexel; Consultant Pulmonary Fibrosis (salary)

Emily DeBoer Jennifer Maybee and Arwen Jackson

- Receive research support through Sie Center for Down syndrome
- Research support from Crnic Institute

Objectives

An overview of dysphagia (difficulty swallowing), including the characteristics and different types of dysphagia seen in individuals with Down syndrome

The impacts dysphagia can have on health and quality of life across the age span

How a medical team can support families and individuals with dysphagia

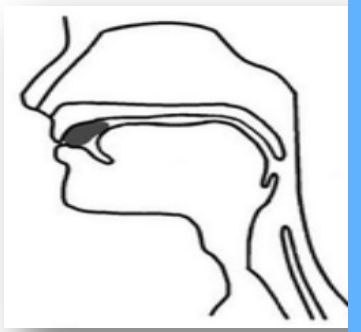
Tips for advocating for thoughtful dysphagia care and manageable feeding plans

Future directions: how research is exploring dysphagia in Down syndrome and how innovations in clinical care are being tested

Dysphagia Across the Age Span: What We Know and Treatment Considerations

Swallowing

Oral Preparatory



Food is mixed with sali
chewed, and moved through
the mouth to
prepare for swallowing

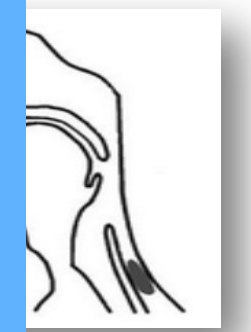
Oral Phase

the food/liquid by the tongue
to start the swallow

Pharyngeal Phase

Passage of the food/liquid
through the throat

Esophageal Phase



part of
the esophagus relaxes to move
the food/liquid from the
throat to the stomach

Dysphagia *is the overarching term for difficulty swallowing.* ***Aspiration****, is a common term people use when referring to dysphagia that specifically means that liquids/solids/other materials go into the airway or lungs, however, dysphagia encompasses much more*

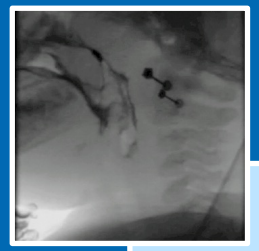
COMMON SIGNS OR SYMPTOMS OF DYSPHAGIA

- Choking/coughing
- Loss of food/liquid from the nose or mouth
- Red watery eyes
- Challenges breaking down food (chewing)
- Food remaining in the mouth after swallowing (oral residue)
- Congestion associated with eating
- Slow eating
- Self-limiting with certain foods, liquids, or drinking systems
- Complaint of food getting stuck

Clinical Feeding Assessment, VFSS, FEES

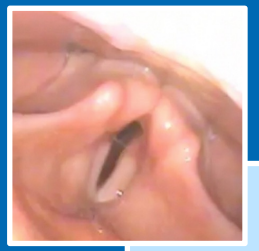
Clinical Feeding Evaluation

- Skilled observation of oral structures and feeding in a clinic or naturalistic setting
- Helps to better understand oral feeding challenges, selective eating, concern for growth/weight gain, report of gagging, mealtime behavior challenges
- Can determine if an instrumental assessment of swallowing is indicated



Video Fluoroscopic Swallow Study (VFSS)

- Completed in radiology
- Typically, the first instrumental assessment of swallowing (unless child is exclusively breastfed)
- Provides visualization of the oral, pharyngeal and esophageal phases of swallow
- A good repeat assessment of swallowing when change is anticipated



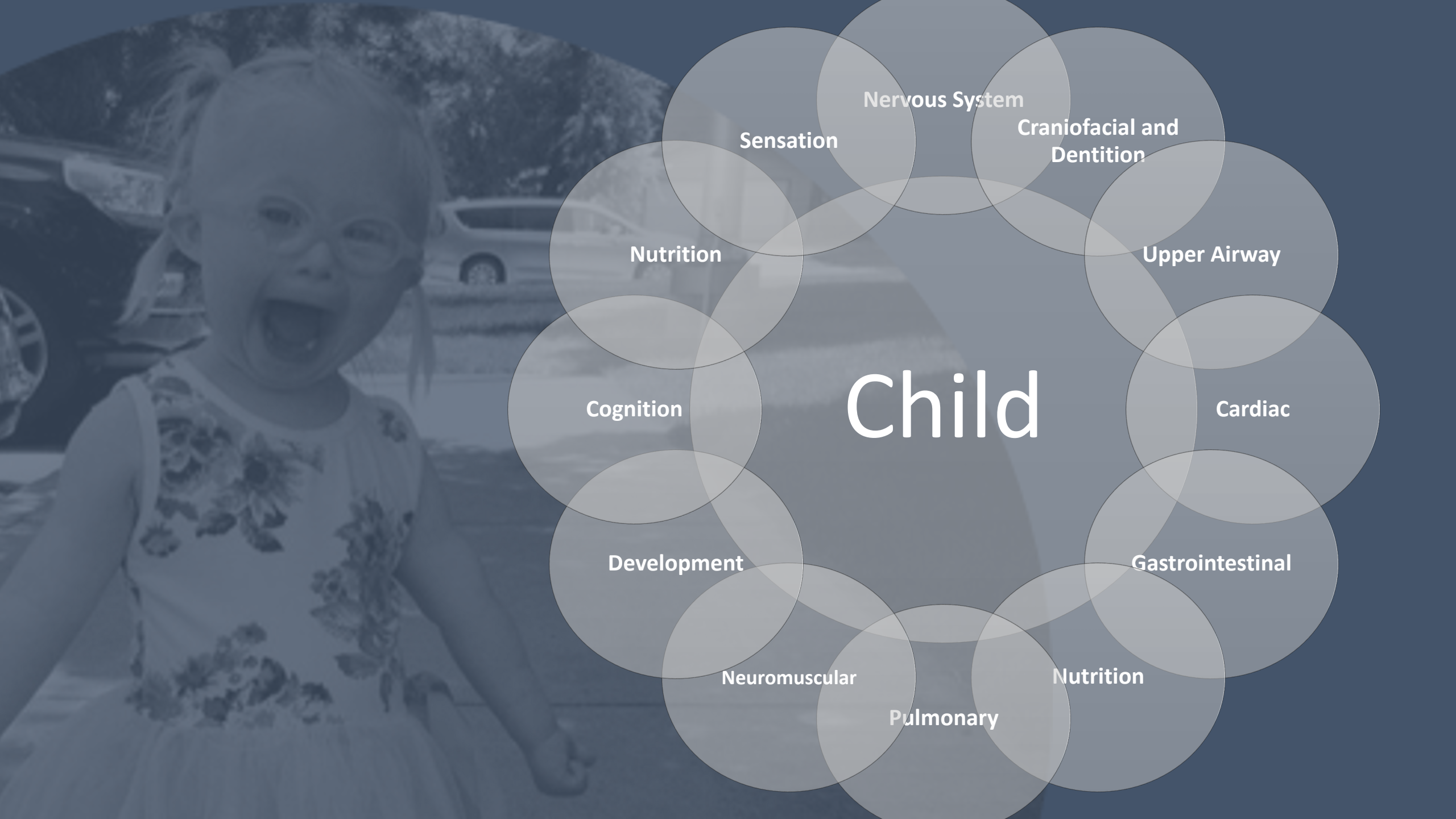
Flexible Endoscopic Evaluation of Swallowing (FEES)

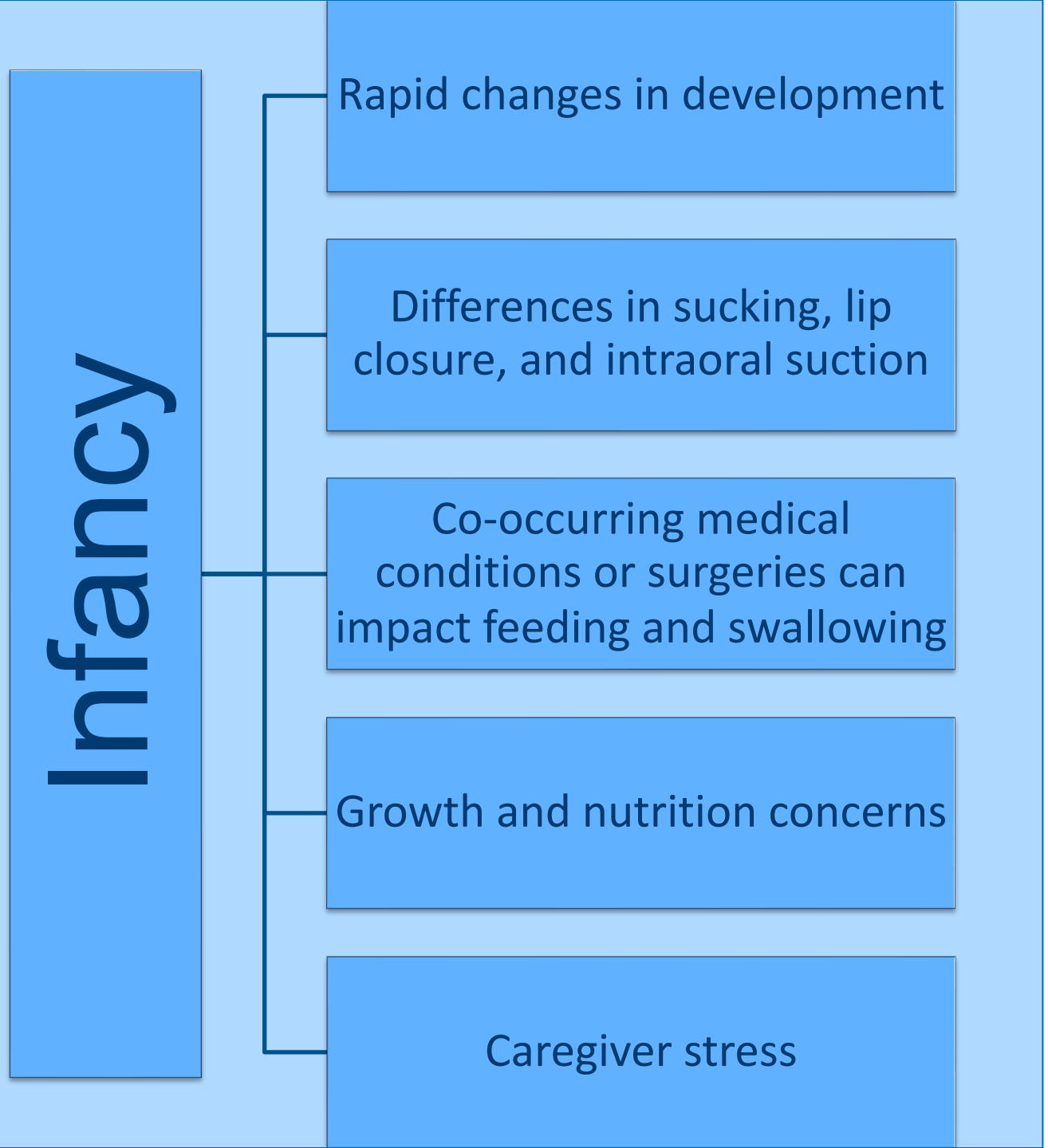
- Completed in ENT clinic
- Instrumental assessment of swallowing option for breastfeeding infants, when questioning pharyngeal secretion management, brainstem/cranial nerve or upper airway involvement, a child is accepting limited amounts, there are positioning challenges in the radiology suite, concern for repeated assessments

Key Dysphagia Research Findings

- Dysphagia is often found in children with DS when swallow studies are completed, and silent aspiration (no cough or other response) is common
- Limited data exists regarding the presence of esophageal dysphagia in DS; however, gastrointestinal anomalies resulting in esophageal dysphagia symptoms are more prevalent in individuals with DS and one study showed increased esophageal dysfunction compared to controls
- Limited qualitative studies exist on the impact of feeding and swallowing difficulties in individuals with DS and what has been published has primarily focused on parents of infants

Jackson et al., 2019; Stanley et al., 2018; Narawane et al., 2020; Stanley et al., 2018; Jackson et al., 2016; O'Neill and Richter, 2013; Capone et al., 2020; Chicoine, 2021; Zarate et al., 2001; Moore et al., 2008, Scala et al., 2015, Bianca et al., 2002; Freeman et al., 2009


Child
Nervous System
Craniofacial and Dentition
Upper Airway
Cardiac
Gastrointestinal
Nutrition
Pulmonary
Neuromuscular
Development
Cognition
Nutrition
Sensation



Treatment and Management Considerations

Slow flow bottles

Positioning

Pacing bottle feeds

Breast feeding support

Nutrition support

Collaborative decision making around the timing and type of swallow study

Poskanzer, 2020; Mizuno, 2001; Coentro, 2021; Barros, 2019; Cartwright, 2018; Jönsson, 2022

Toddler/Transitional Feeding

- Varied acquisition of developmental milestones can impact self-feeding, posture, communication, and progression of food textures
- Families may receive inconsistent advice regarding transition to solid foods
- Swallowing may differ with cups/straws in comparison to breast/bottle
- Food preference, restrictiveness, and differences in sensory processing could impact acceptance of a modified diet plan

Treatment and Management Considerations

Positioning across seating systems and settings

Slow flowing cups and straws

Flavoring/temperature of liquids

Timing of complementary food introduction based on development/dentition

Multimodal Communication

Cochran, 2022; Winders, 2019; Frank and Esbensen 2015

School Age

In a setting outside of the home, time constraints for mealtime preparation, shorter length of time to complete meals, and variable levels of one-one supports, may impact carryover of individualized feeding plans

Feeding and swallowing challenges could potentially impact school attendance or performance

For an adolescent with DS, the transition to more independent feeding, across settings, becomes an important consideration

Treatment and Management Considerations

- ***Treatment may transition or expand to include a school-based team.***
- ***Consider an Individual Health Care Plan or written care plan for students who have feeding/swallowing needs. Potential areas to address:***
  - *optimal positioning for feeding*
  - *safe food textures*
  - *instructions for thickening liquids*
  - *adaptations for cups/straw*
  - *environmental accommodations*
  - *assistance for attention*
  - *supports for self-feeding*
  - *level of supervision and support during meals/snacks*

Arvedson, 2006

Adulthood

- Accelerated aging and increased risk of Alzheimer's disease are known to be associated with a higher risk of feeding and swallowing difficulties
- Difficulties manipulating a spoon, slow rate of eating, coughing, as well as impaired lip closure, tongue movements, and mastication may be present
- More diminished functional reserve, places adults at risk for an adverse event related to eating/drinking
- Food refusal, choking, or a slowed pace of eating may be indicators of a change in swallow function

Treatment and Management Considerations

Environmental supports

Optimize nutrition

Modify food textures to decrease safety risks

Timing of meals

Observe for self-driven changes in feeding behaviors

Balance health, abilities, and individual/caregiver goals

Smith, 2014; Zigman, 2007; Lazenby, 2008; Wada, 2001; Priefer, 1997; Horner, 1994; Margallo-Lana; 2007; Lautarescu, 2017; Carr, 2014, Burt, 2005; Carmeli, 2004

Oral Characteristics of DS Impacting Feeding and Swallowing

Teeth

- Reduced size
- Differences in shape
- Delayed eruption of teeth, missing teeth
- Reduced risk for cavities but increased risk for gum disease, tooth grinding, tooth wear

Jaw relationships

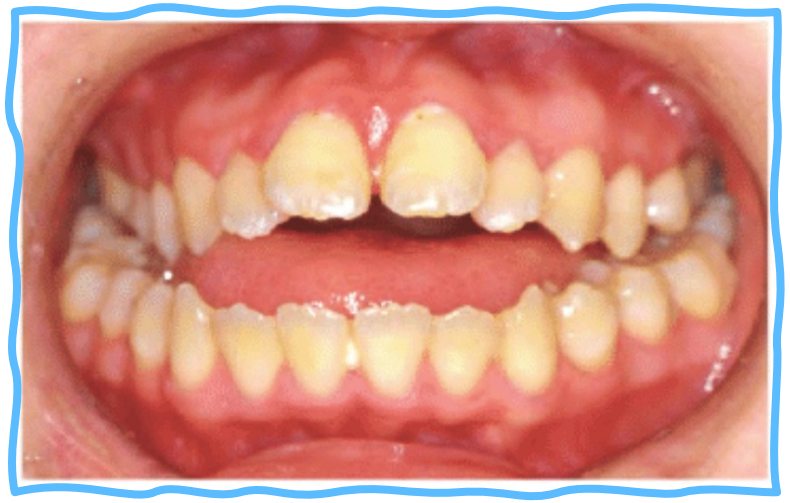
- Open bite (no contact between upper and lower front teeth when jaw is closed)
- Cross bite (upper teeth fall inside of lower teeth when jaw is closed)
- Reduced contacts between upper and lower teeth

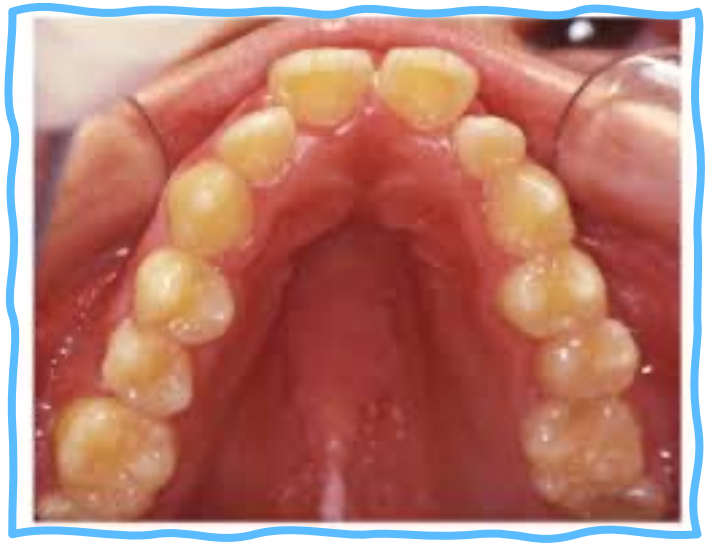
Palate/Roof of mouth

- Narrow, high arched

Tongue

- Large compared to size of mouth, low muscle tone





Doriguetto, 2019: Diaz-Quevedo, 2021; Oliveira, 2010, Farpour, 2021; Mazille, 2007; Allison, 2004; Wintergerst; 2021; Silva, 2020; Montserrat, 2016; Bell, 2002, Stein, 2022

Chewing

Down syndrome and Chewing Research Findings (from adult and child studies)

- Increased time to chew
- Challenges with moving tongue to the side of mouth
- More chewing cycles, holding food in mouth longer
- Residual food left in mouth
- Open mouth chewing
- Reduced chewing force, larger particle size after chewing
- Tendency to swallow foods whole
- Chewing difficulties may result in refusal of harder food textures, including whole fruits/vegetables
- Inadequate chewing of food may impact absorption

Faulks et al., 2008; Hennequin, 2005; Wintergest, 2021; in't Veld et al., 2020

When to Seek Help

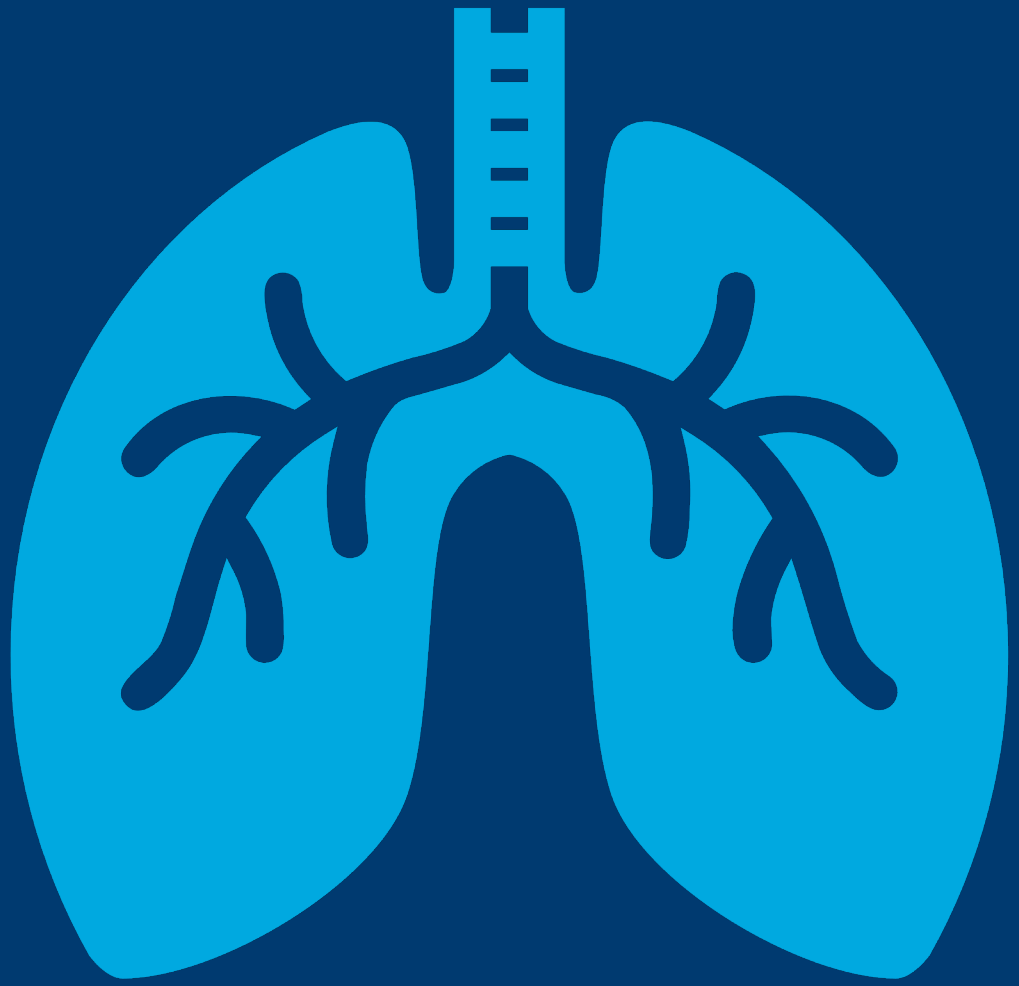
Concerns are impacting

- ✓ *participation in feeding/mealtime*
- ✓ *growth*
- ✓ *nutrition*
- ✓ *health*
- ✓ *family goals as it relates to feeding*
- ✓ *transition to daycare/school*
- ✓ *safety of swallowing*
- ✓ *ongoing cough / breathing symptoms*

Early detection is important

Collaborative Feeding and Swallowing Management

Pulmonary Health Considerations and Multidisciplinary Treatment Models



Increased Expression of Genes on Chromosome 21 Can Lead To:

- Differences in airways, facial features, and dentition
- Hypotonia

These lead to increased risk of dysphagia and aspiration

- More simplified lung development
- Immune differences

These may may lead to increased inflammation and increased consequences (airway scarring and pneumonia) from aspiration

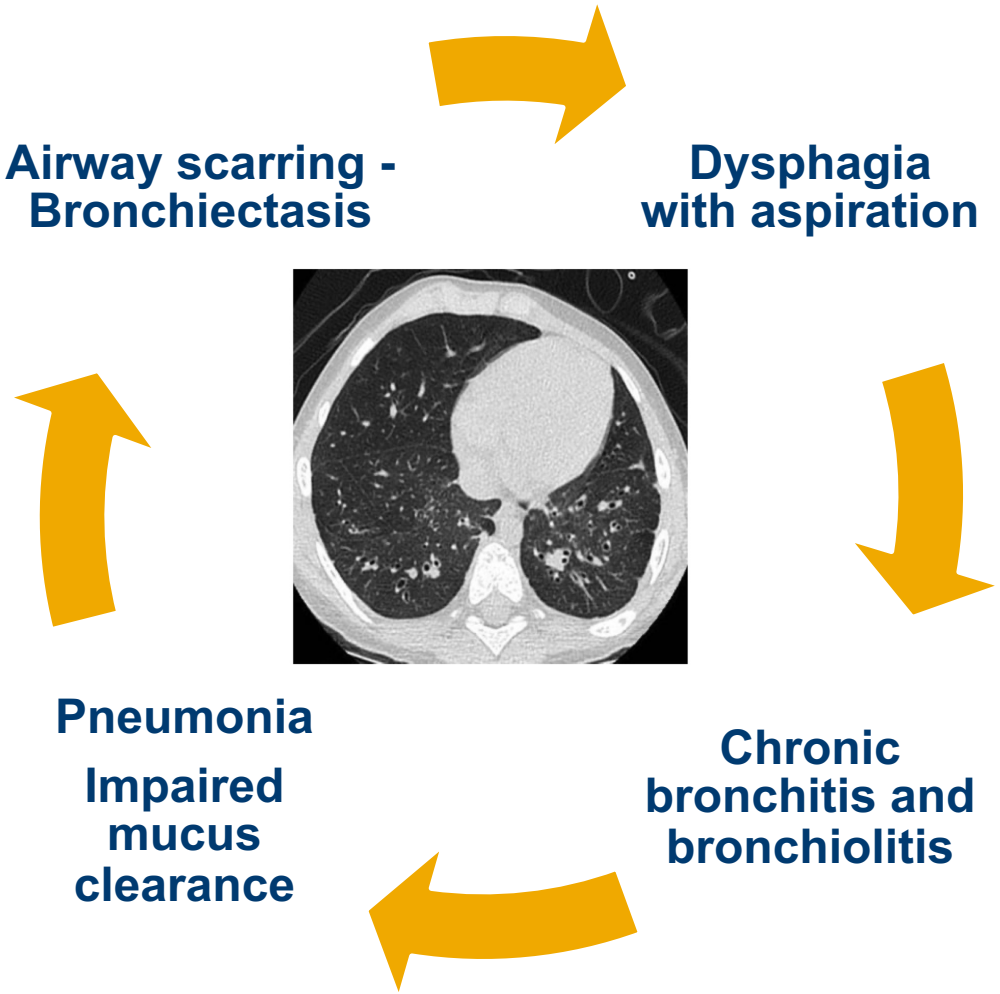
Malle *Curr Opin Immunol* 2021
Sullivan *Sci Rep* 2017
Bull *Peds* 2022
Fockens Ped Pulm 2021

Lung health – we worry about ***today*** and tomorrow

- Cough, congestion, rattle in the chest
- Increased risk of pneumonia
- Increased risk of bronchitis
- Increased inflammation on lung fluid obtained from bronchoscopy

Gurberg *Int J Ped ENT* 2015
Vielkind *Pediatr Pulmonol* 2022

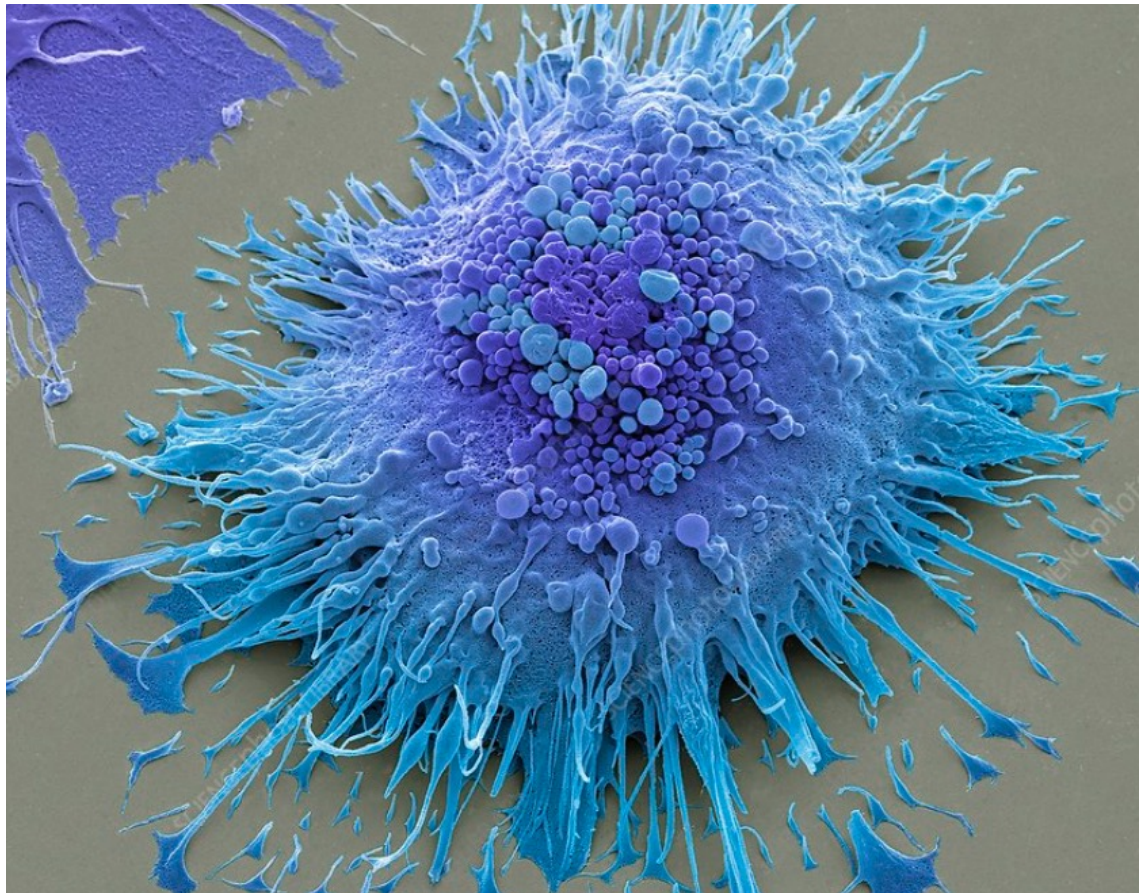
Lung health – we worry about today and ***tomorrow***



Piccione Pediatr Pulmonol 2012
Gurberg Int J Ped ENT 2015
DeBoer Pediatr Pulmonol 2016
Duncan Pediatr Pulmonol 2023

Our lungs are made to clean it up

- So some kids don't have symptoms – this is good news but it can be hard for families and teams to know that they need to make diet changes
- ***Given the frequency at which aspiration is silent, best practice suggests that changes in a feeding plan be done in consultation with the medical team***
- Because the timeline of the scarring / bronchiectasis is different for every individual, we strive to find a safe diet while balancing mealtime and family goals



Sie Center Dysphagia Management Clinic

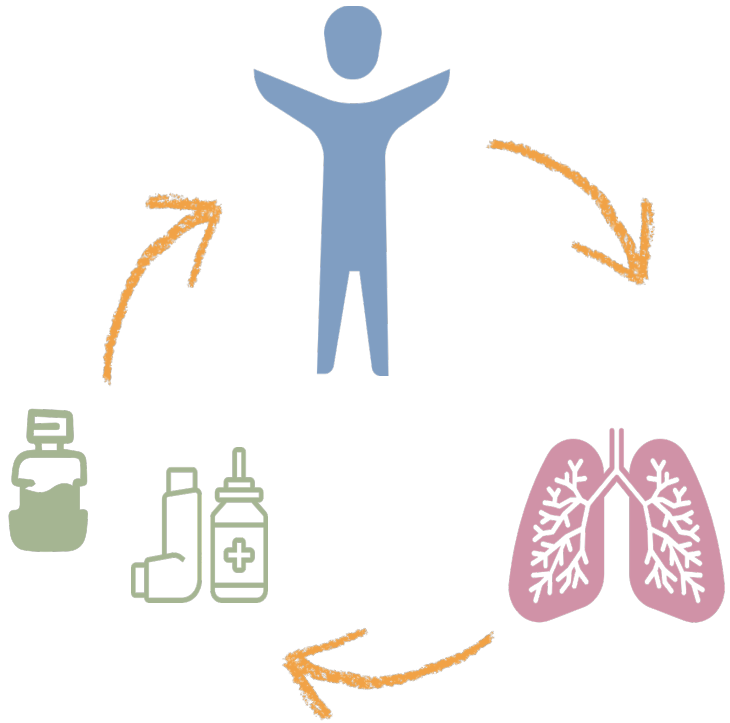
- Nursing
- Pulmonary
- Dietitian
- OT and SLP
- Social Work
- Family Navigator

How Do We Assess/Improve Lung Health (Today)?

- Symptoms – ask you about today
- Check your oxygen (more sensitive in Denver than at sea level)
- Chest xray – basic look for pneumonia / bad inflammation
- Have we implemented feeding changes – did symptoms resolve/change?
- If not, we will often add an inhaled steroid or other inhaled medications to “break the cycle” and resolve symptoms

How Do We Assess/Improve Long-Term Health?

- Referral to aerodigestive to add ENT and GI subspecialties to the medical team
- Triple scopes - Flex bronch with lung fluid, Rigid bronch, Esophageal scope
- Chest CT - to look for bronchiectasis or other lung disease
- Other referrals: pediatric surgery, dental, oral surgery, neurology
- Other ENT procedures – supraglottoplasty, laryngeal cleft repair, adenoidectomy and/or tonsillectomy
- Other esophageal tests of motility



Advantages of a Multidisciplinary Team

- The benefits of the Sie center teaming lets us support you in feeding goals, meal times and improvements to quality of life
- We need you to advocate for your goals so that we can make a plan that balances both goals
- Colorado is unique in pulmonary management of our large dysphagia clinic - other programs may have different team members
- You may need to advocate to ask your local health care providers to talk to each other and coordinate care

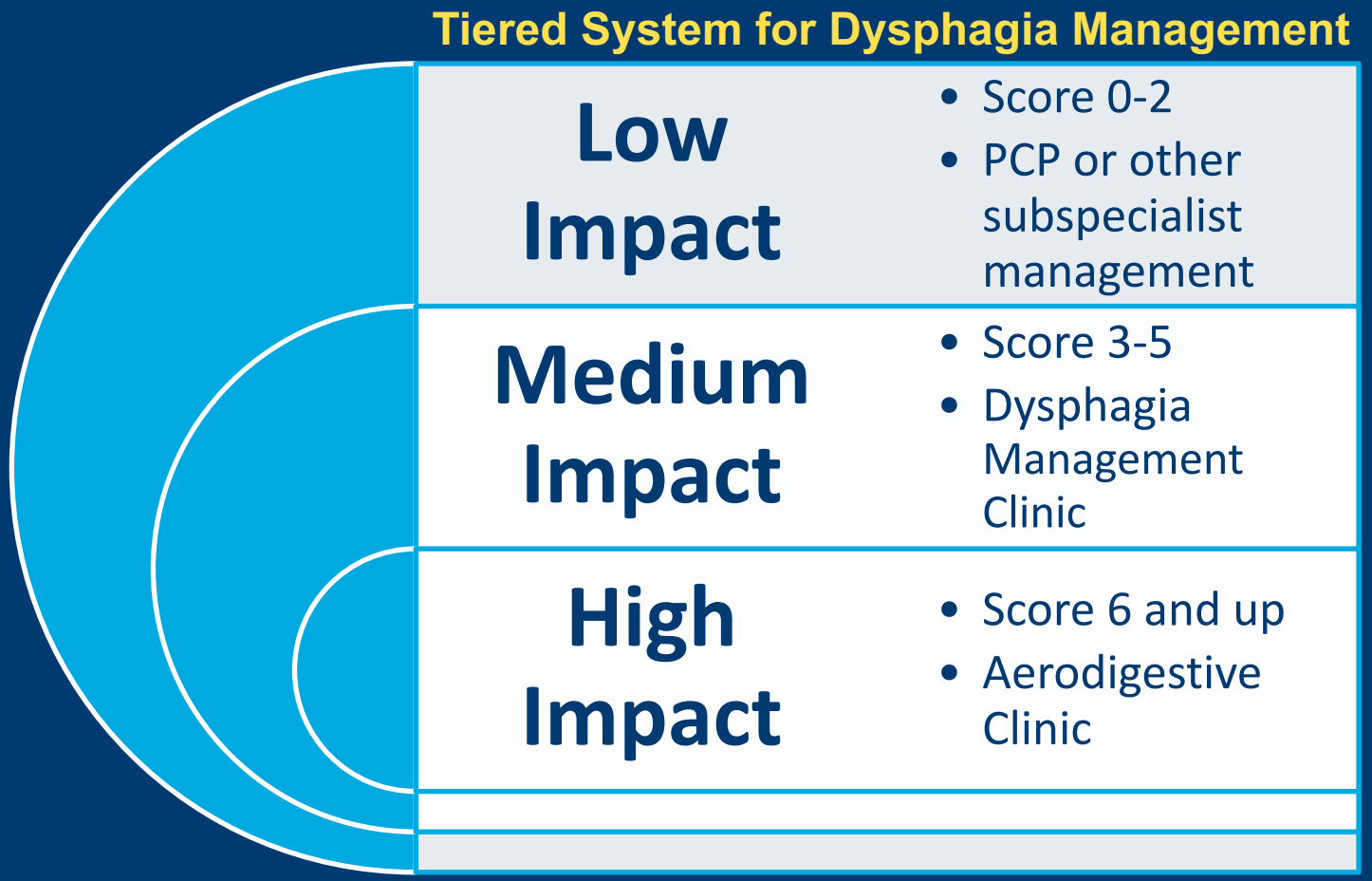
Research Findings from our Team, Future Research Directions and Resources

Knowledge Gaps for Dysphagia in DS

- Who needs a swallow study? Are there important health indicators or developmental stages when swallow studies should be considered?
- How common is dysphagia in adults with Down syndrome? What are its characteristics and best interventions for adults?
- How do sensory processing challenges contribute to feeding/swallowing problems in DS?
- How do orthodontic interventions impact feeding/swallowing in DS?
- Are dysphagia management interventions effective? What barriers exist to following them?

Childhood Dysphagia Management Scale (CDMS)

- Weighted scale developed to guide evaluations and interventions for children with dysphagia
- Section 1 score reflects the restrictiveness of the recommendations made during the instrumental swallowing assessment (VFSS or FEES); more restrictive recommendations receive a higher score
- Section 2 score reflects persistence of dysphagia; number of swallow studies requiring diet/feeding modifications
- Sections 1 and 2 are summed for Total Score, which determines follow up recommendation
- Feeding Referral (FR) designation can be used to indicate child needs further feeding assessment or therapy



Maybee et al., 2021

Providers by CDMS Level

PCP Management

Low Impact (0-2)

Other subspecialty management might be in place but not in a designated team setting

Dysphagia Management Clinic

Medium Impact (3-5)

- Pulmonologist and/or GI
- Feeding therapists (SLP, OT)
- Registered dietitian
- Social worker
- Nursing

Aerodigestive Program

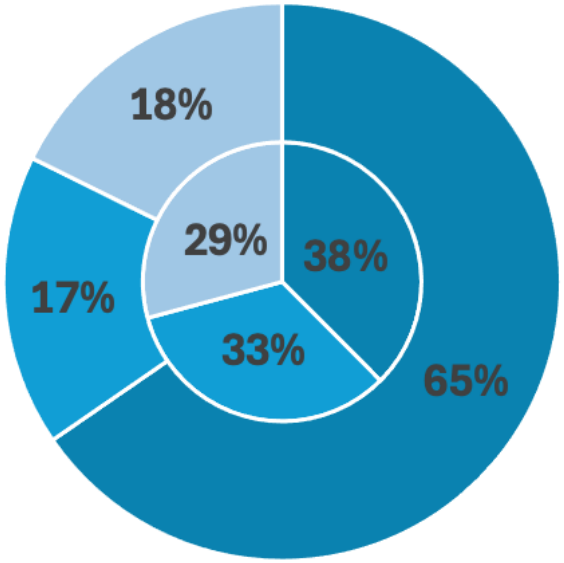
High Impact (6 and up)

- Nurse coordinator
- Pulmonologist
- ENT
- Gastroenterologist
- Anesthesiologist
- Radiologist
- Nursing
- Feeding therapists (SLP, OT)
- Registered dietician
- Social worker

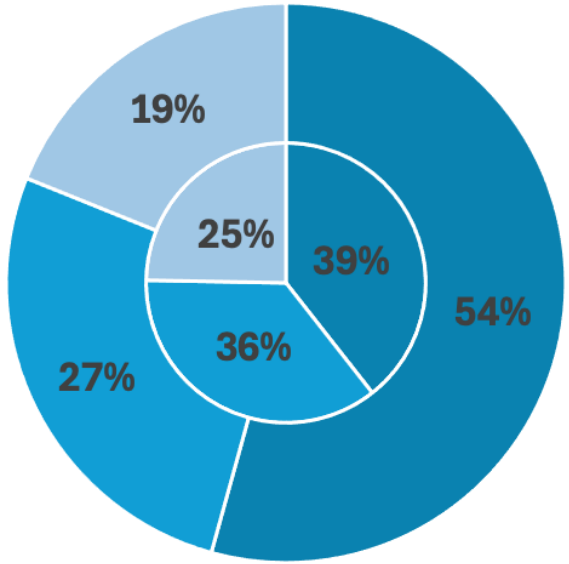
Need for Specialty Dysphagia Management Care: Childhood Dysphagia Management Scale Studies

- Children with Down syndrome have **more Medium Impact and High Impact scores**; meaning they need more diet modifications than the general swallow clinic population
- Children with Down syndrome **require specialized follow up** for dysphagia more often than the general swallow clinic population

2021 CDMS Validation Study; Down syndrome n=153; general clinic n = 130



2024 CDMS Validation Study; Down syndrome n=493; general clinic n = 4,709



Low Impact Medium impact High impact

Inner circles: children with Down syndrome, Outer circles = children from general swallow clinic

Maybee et al., 2021; Maybee Doctoral Dissertation. 2024

Referrals and Referral Match Pre-Post CDMS Implementation

	General Population Pre-CDMS Implementation (N=437)	*General Population Post-CDMS Implementation (N=443)*	*Down syndrome Pre-CDMS Implementation (N=96)*	*Down syndrome Post-CDMS Implementation (N=151)*
Was a referral made?				
No	321 (73.5%)	130 (29.3%)	59 (61.5%)	27 (17.9%)
Yes	**116 (26.5%)** →	**313 (70.7%)**	**37 (38.5%)** →	**124 (82.1%)**
Referral match				
Lower	307 (81.2%)	99 (28.0%)	69 (79.3%)	28 (21.5%)
Matched	**51 (13.5%)** →	**232 (65.5%)**	**13 (14.9%)** →	**84 (64.6%)**
Higher	20 (5.3%)	23 (6.5%)	5 (5.7%)	18 (13.8%)
Missing	59 (13.5%)	89 (20.1%)	9 (9.4%)	21 (13.9%)

	Swallow Clinic, no Down syndrome		***Down syndrome***	
FR Designation	**Pre-CDMS Implementation (N=437)**	**Post-CDMS Implementation (N=443)**	**Pre-CDMS Implementation (N=96)**	**Post-CDMS Implementation (N=151)**
Yes	176 (40.7%) →	217 (50.2%)	55 (58.5%) →	89 (59.7%)
No	256 (59.3%)	215 (49.8%)	39 (41.5%)	60 (40.3%)
Missing	5 (1.1%)	11 (2.5%)	2 (2.1%)	2 (1.3%)

Follow up and Follow up Match Pre-Post CDMS Implementation

	General Population Pre-CDMS Implementation (N=437)	*General Population Post-CDMS Implementation (N=443)*	*Down syndrome Pre-CDMS Implementation (N=96)*	*Down syndrome Post-CDMS Implementation (N=151)*
Follow-up visit within 6-months				
Yes	**208 (55.0%)** →	**214 (60.5%)**	**57 (65.5%)** →	**91 (70.0%)**
No	170 (45.0%)	140 (39.5%)	30 (34.5%)	39 (30.0%)
Six-month follow-up care match				
Lower	85 (40.9%)	92(43.0%)	26 (45.6%)	35 (38.5%)
Matched	**82 (39.4%)** →	**100 (46.7%)**	**23 (40.4%)** →	**49 (53.8%)**
Higher	41 (19.7%)	22 (51.7%)	8 (14.0%)	7 (7.7%)

Follow-up definition: Child was seen for a visit addressing dysphagia within 6 months following the swallow study; determined via EMR review of encounters and encounter note content.

Adherence and Barriers to Dysphagia Diet Recommendations; Impacts on Quality of Life

Design and Methods

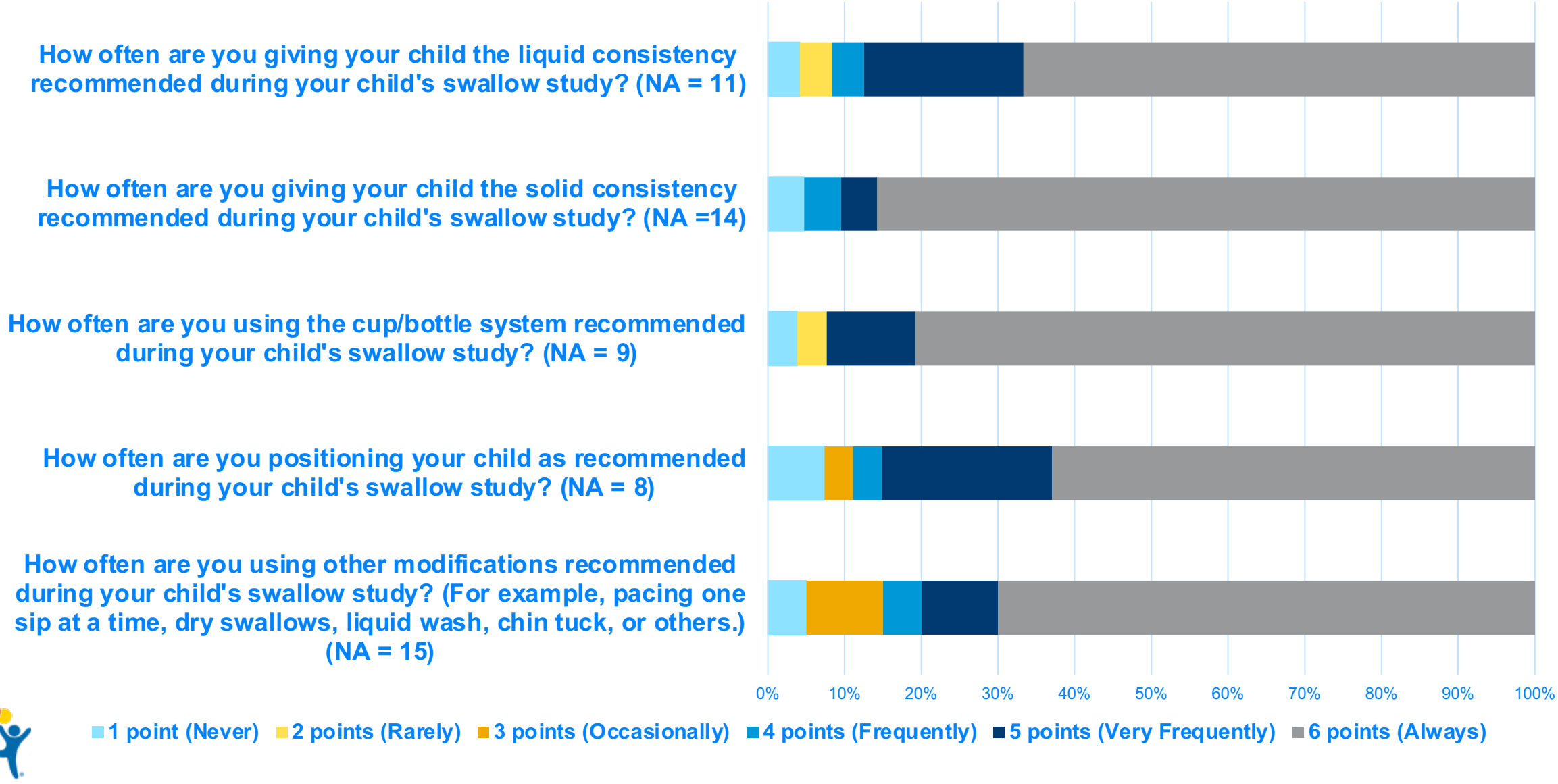
- Study completed as part of INCLUDE NIH project on pulmonary health and DS
- 30 children ages 4-17 years who had a swallow study; measured dysphagia severity and grouped patients accordingly
- Caregivers completed quality of life measures about feeding and general quality of life
- Caregivers self-rated how often they followed the dysphagia diet and barriers to following the diet using Pediatric Diet Modifications Survey, PDMS (Pilot version)

Findings

- Although a school-age population dysphagia was still found frequently (>50%)
- Scores on PedsQL revealed similar quality of life findings to other children with DS; lower quality of life than cohorts of typically developing children
- Scores on FS-IS indicated higher Worry, Daily Activities, and Feeding difficulties versus children without DS
- PDMS scores showed high self-reported adherence to dysphagia diet recommendations; caregivers frequently identified barriers to following (>50% of patients with active diet modifications)

Jackson et al.; in review

Pediatric Diet Modifications Survey-Pilot Likert Scale Results, N=29



Pediatric Diet Modifications Survey Open Ended Responses	
Diet Modifications	**Barriers to Following Diet Modifications**
CG 1: cutting food into small pieces, making sure he is not pocketing food, reminding him to chew and swallow his food, avoiding foods that may cause him to choke or modify their shape by cutting them into pieces	*CG 1: child's food and drink preferences are very limited. He pockets food often making feeding time double the normal time and he also stuffs his mouth with certain foods like bread, if not monitored at all times during feeding*
CG 12: Pacing sips, using a valved straw cup	
CG 13: Small bites, and checking for food to be gone before next bite	*CG 20: We are not at this point yet. I will comply w what my child needs.*
CG 14: Straw cup only	
CG 17: One sip at a time, chin support	*CG 23: Traveling with it, storage, altitude with it mixed spills in bottle.*
CG 20: Bitten straw to slow food	
CG21: Thickening between nectar and honey	*CG37: Needs monitoring to ensure good posture, good chewing, small bites, and proper swallowing*
CG 25: Pacing	

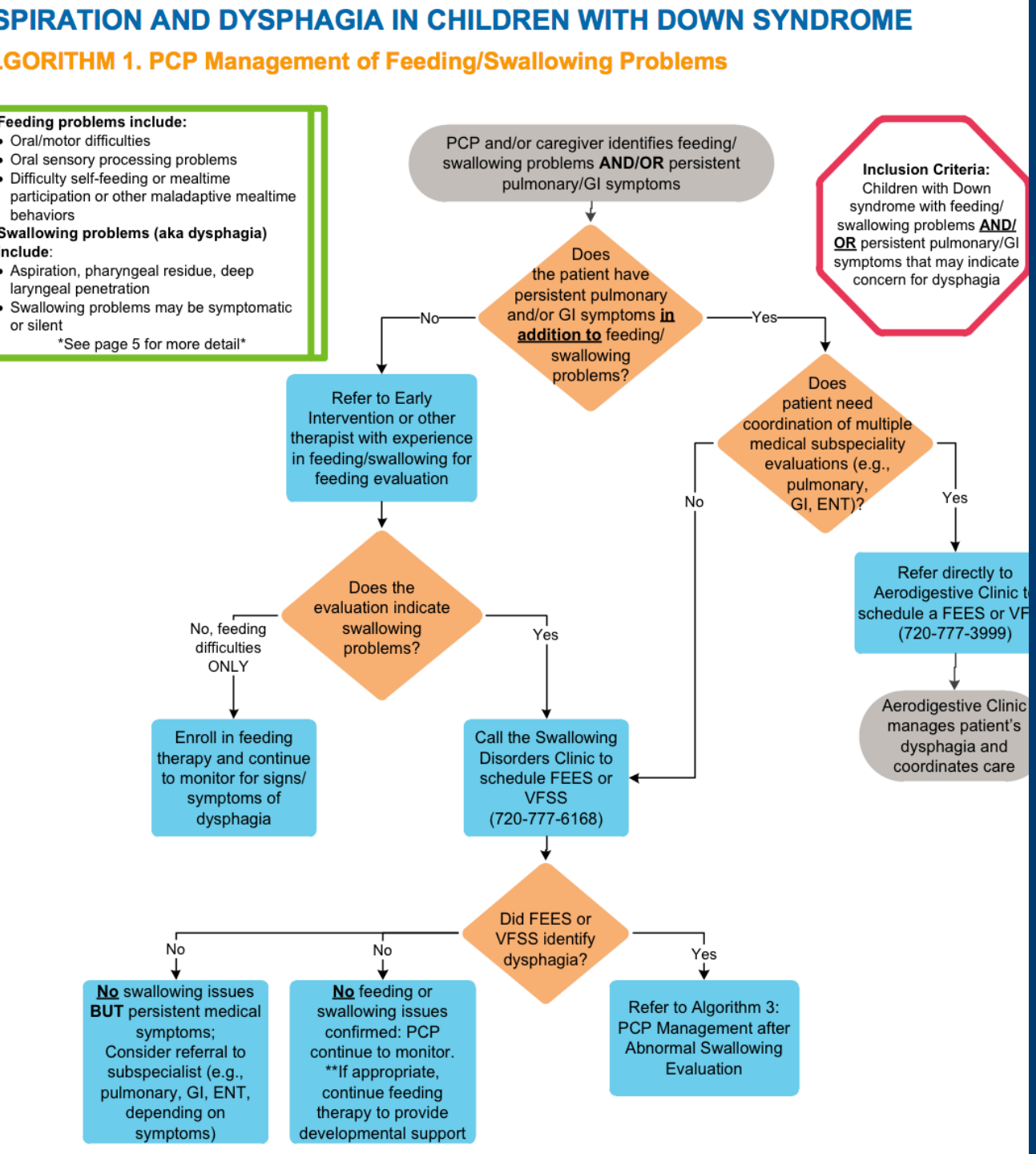
Future Research Directions

Pediatric Diet Modifications Survey: Study to further refine the survey with parent/caregiver input and validate it for general use

International Dysphagia Management Survey: Survey study measuring local available resources for dysphagia management, practice patterns, and barriers impacting whether patients receive follow up dysphagia management care

Pulmonary hospitalizations/dysphagia in Down syndrome: Evaluates how/whether swallowing difficulties impact risk for being hospitalized for pulmonary illness

Measuring dysphagia over time using the CDMS: Study to evaluate how dysphagia changes over time and when/whether it is expected to resolve in patients with different characteristics, including Down syndrome



Clinical Care Pathway for Aspiration and Dysphagia in Down Syndrome

- Uses the best available **evidence** and **expert consensus** (medical subspecialists, feeding therapists, family members, and primary care providers) to guide dysphagia management
- Algorithms for PCP management of feeding/swallowing problems, PCP management after abnormal evaluation, swallowing therapist's role (specific to CHCO process)
- Resources for PCPs, subspecialists and therapists regarding diagnostic evaluations and therapeutic interventions, CDMS (how to use) and parent education handouts

SIE CENTER FOR DOWN SYDROME

Feeding and Swallowing Needs at School

For children with special healthcare needs, adjusting to school can be hard. For many families, this is the first time your child will be away from home for long periods during the day. One common concern families have is if their child has trouble with feeding or swallowing (dysphagia) and finding ways to keep them safe at school. This guide is here to help you create a plan for your child's food and drink needs at school so staff can follow the same care instructions you use at home.

Children's Hospital Colorado

Where to start?

Before your child starts at a new school, or after a change in their feeding/swallowing status, it can be helpful to have a plan in place. This can include learning about mealtimes and schedules at school to make sure everything is ready at home.

Get to know the school's support structure around meal and snack times

Here are some important things to ask when getting your child ready for school:

- Does your team have any experience with students on modified diets?
- What does staff training on health care needs look like?
- What is the staff ratio during mealtimes?
- Are there multiple times during the day when students have access to food or drinks?
- Is there a drinking fountain readily available?

Set your child up for success

Pack S.M.A.R.T.

- **S**ize matters: Is it helpful to cut food into smaller pieces?
- **M**otor skills: Can your child open the food package? Or use utensils with minimal support?
- **A**bilities: Does this food align with your child's current self-feeding and oral motor skills?
- **R**eliable: Is this a food that your child is confident eating at home?
- **T**ime frame: Can your child meet their intake needs with this food in the allotted time?

Make a Plan

Students with Down syndrome usually need supports and services through an Individual Education Plan (IEP). An IEP is a legal document that outlines supports and services for students, ages 3-21, so they can take part in school and have access to learning. To start the IEP process, ask your child's school to schedule an IEP meeting with you, your child's team, including the school nurse.

While there are many parts to an IEP, the following sections are commonly used to support the feeding and swallowing needs of a student.

Health Care Plan

A Health Care Plan is under the Considerations of Special Factors section. It is used when a student has a medical diagnosis such as dysphagia. It requires an outline of what is needed from a doctor or specialist. A Health Care Plan is managed by the school nurse, who works to train staff who work with that student. A Health Care Plan could include:

- Aspiration (taking food/drink into the lungs)/Dysphagia Support:
  - Thickened Liquids: training staff in how to thicken liquids and knowing where "hidden liquids" exist
  - Prevention of child drinking non-thickened liquids: block access to drinking fountains, not allowing to take a school milk
  - Outlining what aspiration can look like and what to do when it happens
- Supervision of mealtimes above and beyond when there is medical acknowledgement of a high risk for choking on solid foods
- Training for staff on G-tube feedings

Accommodations

Accommodations are supports that allow the student to take part in school. These can look like:

- Reminders or cues to use utensils, start eating, pace child to prevent over stuffing
- Additional access to snacks or personal water bottle
- Extended time for feeding opportunities
- Help with opening packages
- Offering only food and drinks from home
- Letting caregivers know about classroom celebrations where food will be involved

Services

At times, other staff, such as a paraprofessional, may be needed to support your child. Other times, an Occupational Therapist (OT) or Speech Language Pathologist (SLP) can include feeding needs into therapy sessions. This can only happen when it is determined a necessity so that the student may fully participate in classroom activities. An SLP or OT can also make recommendations or include adaptive feeding equipment, such as modified utensils or seating to support an appropriate position. When these things are added to a child's program, they are considered Assistive Technology, and should also be included in the IEP.

Created by Arwen Jackson, Jennifer Harris, and Jenna Mathews, 2024

Resources

To access the clinical pathway for Aspiration and Dysphagia in Down Syndrome:

- https://www.childrenscolorado.org/globalassets/healthcare-professionals/clinical-pathways/aspiration-and-dysphagia-in-children-with-down-syndrome.pdf
- Or: Google “Clinical Pathways Children’s Colorado”

To access the what to expect for an instrumental assessment of swallowing video:

- Down Syndrome Specialists | Children's Hospital Colorado (childrenscolorado.org)

Global Down Syndrome Foundation Parent Resources:

Decoding Dysphagia Article

- https://www.globaldownsyndrome.org/blog/magazine

GLOBAL Webinars- Feeding

- https://www.globaldownsyndrome.org/global-webinar-series/

Feeding Matters Infant and Child Feeding Questionnaire©

- https://questionnaire.feedingmatters.org/questionnaire

THANK YOU

arwen.jackson@childrenscolorado.org
jennifer.maybee@childrenscolorado.org
emily.deboer@childrenscolorado.org

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