Feeding Development in Down Syndrome

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Presentation Goals

1. Learn what factors affect feeding development
2. Share ideas for supporting optimal development
3. Look at possible sources of support
Health status
Child’s current health status will affect behaviour, skill, and sensory abilities.

Social & emotional state, and learning
How your child responds to others affects willingness to try something new. Learning challenges affect skill acquisition.

Behaviour
Include what the child does with food and at the table

Negative behaviours often begin as a response to sensory or motor difficulty – but can progress from there

Skill
Eating skills include chewing, swallowing, and moving the food around in your mouth.

Influenced by mouth and body structures (like shape of the mouth, muscle tone, teeth eruption)

Sensory
Includes sensory preferences (like favourite flavours) and challenges (difficulty tolerating and recognizing certain textures or flavours)

These factors are related in development and affect each other
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What happens when we eat?

✓ Accept the food
✓ Move the food around and chew it
✓ Move the food to the back of your mouth
✓ Swallow safely (with a protected airway)
✓ Keep the food down
A note on safety!
Physical Skills for Feeding

- Chewing
- Sucking
- Swallowing
- Breathing
When should you request a swallowing evaluation?

Some signs are easier to see:

• Appears to struggle with liquids (coughing, arching back, changing color, gasping)

• Choking episodes
Some signs are not as easy to recognize!

- Long lasting, wet cough
- Aversion to feeding
- Frequent pneumonia
- Otherwise unexplained combinations of fevers, chronic coughing/wheezing, difficulty with gaining weight, low oxygen levels
- A history of feeding difficulties, feeding refusals, difficulty gaining weight
Talk to your pediatrician about having a swallowing assessment.
What are some ways to help a child swallow more safely?

Give the swallowing system the best chance by:

– Slowing the flow rate of liquids
– **Slowing down the pace** (eg. by tilting the bottle or giving more breaks)
– Change in positioning

• More serious issues may need:
  – Thickened liquids or change in texture
  – Temporary tube-feedings to allow more time for development

*make sure you continue with oral stimulation program!
Head positioning for bottle feeding

From: Dunn-Klein & Delaney, 1998
Body positioning for Bottle feeding

This

Not this
Positions for Breast Feeding

- Ears above mouth
- Ears at same level as mouth
Proper alignment: 90° 90° 90°

“What you see in the body is what you get in the mouth”
Supportive seating helps kids use sensory and motor skills to the best of their ability.

- Back straight
- Non-slip seat or trunk supports can help
- Feet able to rest flat
- 90° between neck and chin
- Hips bent 90°
- Knees bent 90°
When to introduce solid foods?

• Look for developmental readiness, rather than following “typical” milestones
• Oral motor skills generally don’t outpace gross motor skills
• Look for:
  – Ability to sit unsupported
  – Good head and neck control
  – Ability to move hands to mouth while sitting
What happens in the mouth?
What happens when we eat?

Take the food in, move it from side to side to chew it up, keep it in.

Move food to the back of the mouth to start the swallow.
What happens when we eat?

Purees:

• Sucking motion, tongue moves mainly back and forth
• Some up and down jaw movement and smacking (munching)
What happens when we eat?

• Lumpy or thick purees, very soft solids
  – Up and down jaw movement (munching)
  – Tongue up and down to palate (tongue mashing)
  – Cheeks and tongue work to gather food, seals against roof of mouth to get ready to swallow
What happens when we eat?

• Regular solids
  – Rotary chew (jaw all directions)
  – Tongue moves side to side to place and hold food on teeth
  – Cheeks and tongue work to gather food, seal tongue against roof of mouth to swallow
  – If there’s a mixed texture (eg. Cereal with milk) mouth needs to protect airway from solids washing down with liquids
What happens when we drink?

Open cup

• Stable jaw allows for stable lower lip
• Mouth senses the ‘right amount’ of liquid for a swallow
• Tongue raises to swallow liquid in a controlled way
What happens when we drink?

Straw

• Stable jaw allows for lips to close and seal around the straw (rounded lips)
• If straw is in the front of the mouth (short straw), then the tongue pulls back and lowers to draw liquid in
• Mouth senses the ‘right amount’ of liquid
• Tongue raises to swallow
Structural differences affect eating success

- Low tone and open posture of lips means food and liquid can escape
- Relatively larger tongue and less mobile tongue makes it harder to move food/liquid effectively
- Misaligned bite makes it harder to chew
- Lax ligaments and low tone can make it harder to chew and can make it easier to tire out
- Food can get stuck in a high palate
- If tongue can’t effectively raise to create a seal on the palate, then tongue thrust swallow will result
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Tactile Skills in the mouth:
Our sense of touch helps us figure out what and where something is, and if it’s safe for us to swallow.
Clues there might be a sensory issue

- Swallows food that isn’t chewed well enough
- Puts non-food items in mouth (after a certain age)
- Stores or pockets food
- Gagging
- Lots of drool or very messy
- Intolerance of smells, sights, textures, temperatures, colors, sounds

Overland, Merkel-Walsh, 2013
Picture from http://www.lexistential.com/
So how can we help to conquer or prevent sensory issues?

• Provide and support many opportunities for sensory and exploratory play
• Infant massage
• Face and mouth massage
• Exploring toys with mouth
• Include various food textures, tastes, and presentations early on to avoid getting ‘stuck’
Sensory Preparation Activities – ‘Wake ups’

Infa-dent finger Massage

From: Dunn-Klein & Delaney, 1998
Hard Munchables:
Using a thick carrot, celery, broccoli, as a ‘spoon’ to promote texture tolerance
Household items for developing chewing and oral proprioception
What might be different for children who have sensory and motor delays in their mouth?
What’s different for children who have sensory and motor delays?

- Poor postural control
  - delays coordination

- Poor sensory awareness
  - I can’t feel where the food is
  - I can’t tell when it’s chewed enough
  - I gag easily

- Infant reflexes last longer than typical
  - I push food out of my mouth
  - I clamp my teeth down hard
What’s different for children who have sensory and motor delays?

- Compensatory patterns develop
  - jaw and tongue move incorrectly
- Jaw and tongue are unstable or uncoordinated
  - the food falls back and I gag or cough
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Some health concerns that can directly affect feeding

• Food sensitivities
• Tooth decay
• Fatigue, low arousal
  – eg. from thyroid disfunction
• Heart and respiratory complications
• GERD
• Constipation and intestinal disorders
• Digestion and absorption issues (eg. Celiac)
• Additional Diagnoses (eg. ASD, OCD)


Bull et al., 2011
Tips for Managing GERD

• Positioning
  – Upright for at least 30 minutes
• Smaller volume of feeds
• Change in diet
• Medication

*See your Dr. or GI specialist!
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Is your child resistant to eating? Scared of the spoon?

- Negative experience with food
- Fear response
- Avoidance behaviours
Difficult Behaviours and Eating

Before you focus on dealing with the behaviour, ask yourself:

“Where did this behaviour come from?”

If the sensory and motor system can’t handle something that’s repeatedly offered, the child’s way to deal with it will be “fright, fight, flight” (Overland, 2010)

Or, a big reaction followed by food refusal & avoidance behaviour.
Mealtimes – What’s your routine?
Remember: Eating is *learned*!

**Things to think about:**

- Establishing routines that work
- Only reinforcing the behaviours you want to see
- Setting up the ‘just right challenge’ for new skills and behaviours
- Modeling
You can do it!

Consider trying **Positive Behaviour Support** to develop strategies that can help to improve mealtime behaviours!
Behaviour support

“It is essential in incorporate behavioural and sensory components into a feeding program ... in conjunction with a motor-based pre-feeding approach”

- Lori Overland
Sensory-motor Feeding Therapy

1. Improving sensory-motor skills
2. Modifying food characteristics and mealtime for current skills/needs = safety
Sensory-motor Feeding Therapy

3. Use positive behaviour support techniques to support the learning process and break through negative cycles of reinforcement and anxiety

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Feelings are intertwined with behaviours

Reinforcement Trap!

- Negative reinforcement
- Food is offered
- Everyone feels better: child and adults anxiety are lowered
- Child feels very anxious
- Adult rescues
- Child avoids

www.anxietybc.com
Supporting the learning process:

• What are you asking your child to do?
  – Is it too hard a skill right now?
  – Find the just right challenge level

• How does your child learn and follow directions best?
  – Visuals learning > auditory learning

• Is there motivation to try something new?

• Do you and your child have strategies to manage anxiety and fear?
Supporting the learning process:

• Is there motivation to try something new?
  – May not be as ‘intrinsically motivated’ to try something that’s hard for them

• Do you and your child have strategies to manage anxiety and fear?
  – Learn triggers and proactively prevent shutdowns
  – Monitor your own feelings and expressions

• Seek support!
A Feeding Team

- Respiratory specialist
- Nutritionist
- OT
- PT
- SLP
- Gastroenterologist
- Otolaryngologist (ENT)
- Psychologist
- Behaviour consultant
- Pediatrician
- Family supports
- Others?
Who can help?

- **SLP**: CASLPO private practice listings
  - [www.caslpo.com](http://www.caslpo.com)
- **OT**: COTBC private practice listings

- Developmental pediatrician
- Dentist
- ENT
- PT
- Dietician/nutritionist
- Gastroenterologist
Knowledge = prevention!
Be prepared and start early
Take Home Messages

• Oral-motor and sensory challenges are common in Down syndrome.

• Health challenges can further compromise development.

• We can positively affect developmental outcomes through intervention.

• You’re not alone! Find resources in your community to support your child’s development
Resources: Mouth Development and Feeding

• Nobody Ever Told Me (or my Mother) That!: Everything from Bottles and Breathing to Healthy Speech Development, Diane Bahr, 2010
• A Sensory Motor Approach to Feeding by Lori Overland, Robyn Merkel-Walsh, 2013
• Feeding and Nutrition for the Child with Special Needs: Handouts for Parents Paperback, Marsha Dunn Klein, 2006
• Pre-Feeding Skills: A Comprehensive Resources for Mealtime Development Paperback, Suzanne Evans Morris & Marsha Dunn Klein, 2000
• Just Take a Bite: Easy and effective answers to food aversions and eating challenges. Lori Ernsperger and Tania Stegen-Hanson, 2004
Resources: Nutrition

• Super Baby Food – Ruth Yaron, 1997
• Down Syndrome and Vitamin Therapy - Kent MacLeod, 2003
• The Down Syndrome Nutrition Handbook: A guide to promoting healthy lifestyles - Joan Guthrie Medlen & Timothy P. Shriver, 2006
Resources: Sensory Processing

The Out of Sync Child – Carol Kranowitz
The Out of Sync Child Has Fun – Carol Kranowitz
Pathways to Play: Combining Sensory Integration and Integrated Play Groups – Glenda Fuge and Rebecca Berry
Resources: Gross and Fine Motor Development

• Gross Motor Skills In Children With Down Syndrome, Patricia C. Winders, 2013

• Fine Motor Skills in Children with Down Syndrome, Maryanne Bruni. 2006
Resources: Speech & Language Development

• Early Communication Skills for Children with Down Syndrome, Libby Kumin, 2012
• Helping Children with Down Syndrome Communicate Better, Libby Kumin, 2008
• Teach Me to Talk!: The Therapy Manual, Laura Mize, 2011
• Building Verbal Imitation in Toddlers, Laura Mize, 2012
• It Takes Two To Talk: A Practical Guide For Parents of Children With Language Delays, by Jan Pepper and Elaine Weitzman, 2004
Resources: New Parents


• Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome, Jennifer Graf Groneberg, 2008

• Gifts, Kathryn Lynard Soper, 2007

• Babies with Down Syndrome, Susan Skallerup, 2008

• (DVD) Down Syndrome: The First 18 Months, Blueberry Shoes Productions, Will Schermerhorn, 2004
References


http://pediatrics.aappublications.org/content/128/2/393.full.html

References


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