

# *Treatment of Sleep and Feeding Problems in Individuals with Autism Spectrum Disorders*



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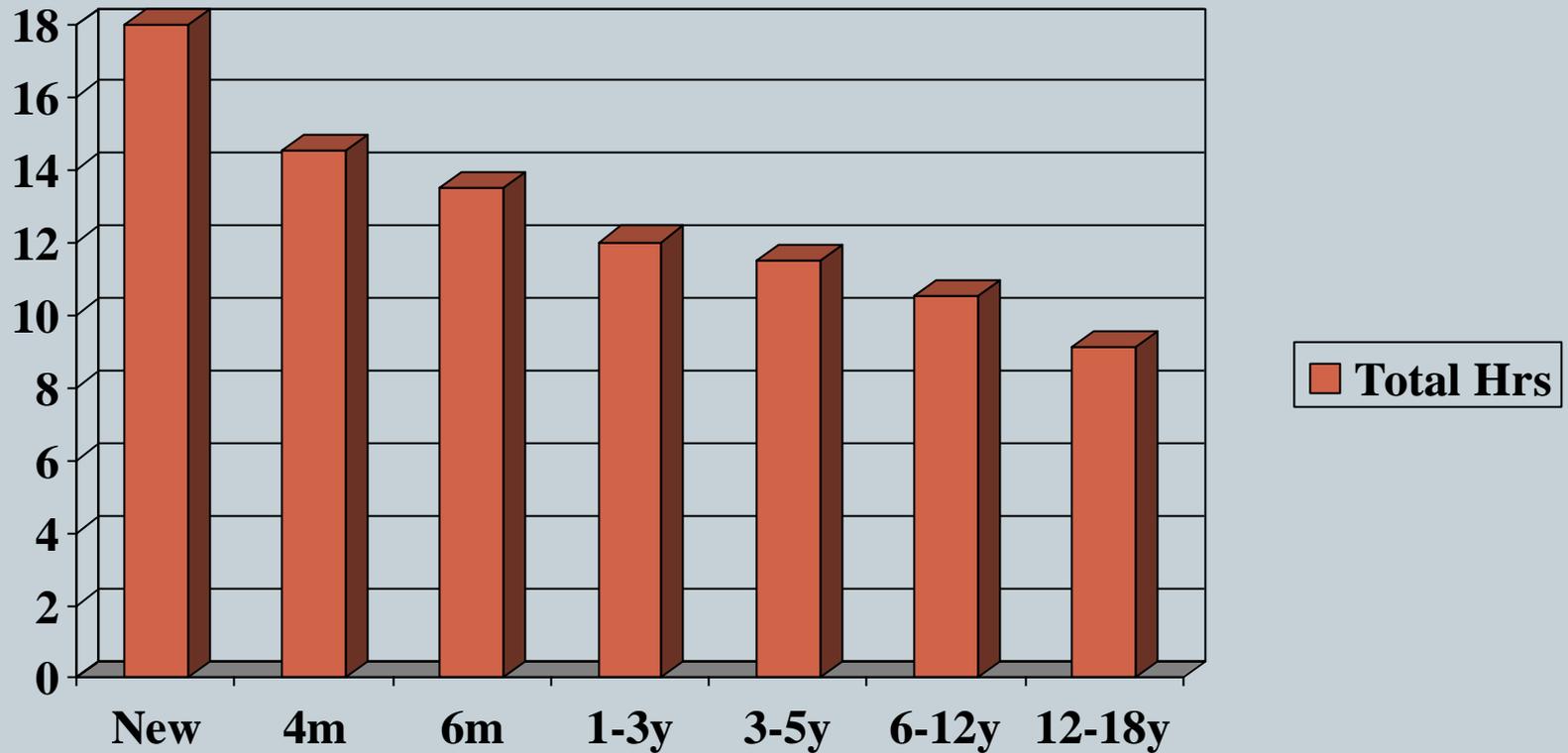
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# Typical Sleep Requirements



# Common Sleep Disorders



- Behavioral Insomnia
- Parasomnias
- Delayed Sleep Phase Syndrome
- Narcolepsy
- Sleep Disordered breathing
- Restless Leg Syndrome/ Periodic Limb Movement

# Impact of Sleep Problems



- Insufficient and poor quality sleep → daytime sleepiness, behavioral dysregulation, impaired executive functioning
- Sleep loss and sleep fragmentation → irritability, poor affect modulation
- Primary insomnia is a risk factor for developing later psychiatric disorders (depression, anxiety)
- Inadequate sleep → poor child health (cardiovascular, immune, metabolic systems), accidental injuries, overweight and obesity

# Autism and Sleep Problems



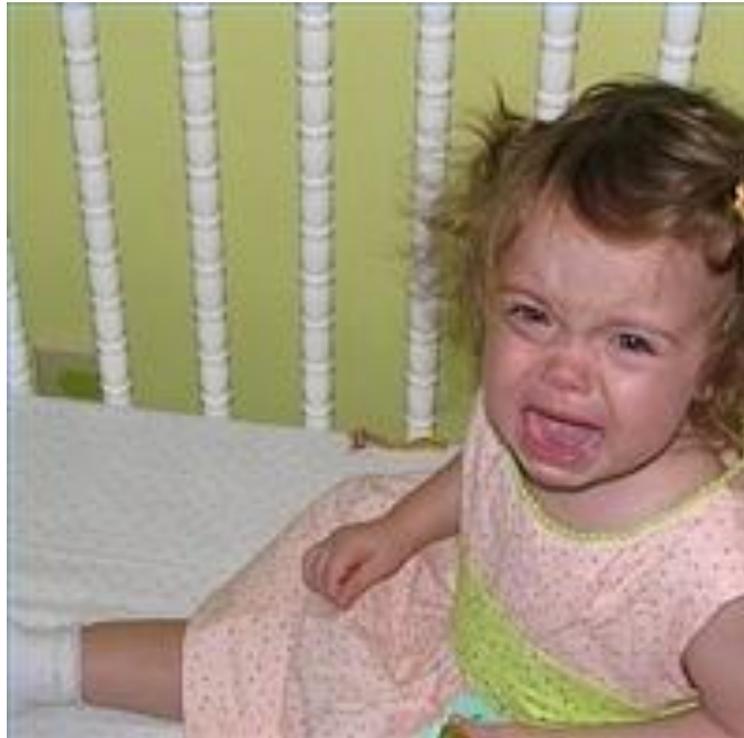
- Estimated 44% - 83% of children with autism have sleep problems (Liu et al., 2006; McDougall et al., 2005; Patzold et al, 1998; Richdale & Prior, 1995; Paavonen et al., 2008; Wiggs & Stores, 1996)
- Some evidence for discrepant duration and quality of sleep in children with ASD (Honomichl et al., 2002)
- Significant sleep onset and maintenance problems (Malow, 2005; Malow & McGrew, 2008)
- Irregular sleep-wake patterns, early waking, poor sleep routines (Clements et al, 1986; Honomichl et al, 2002; Hoshino et al, 1984; Patzold et al., 1998; Mindell et al., 2006; Quine, 2001)
- Associated with problems with daytime behavioral functioning (Malow et al., 2006; Schreck et al., 2004)
- Associated with sleep problems in parents of children with ASDs (Lopez-Wagner et al., 2008)

# Evidence



- Objective measures (actigraphy and polysomnogram) indicate that subjects with ASD have more disturbed sleep than typicals, even when parents are not aware that the sleep is disturbed (Wiggs & Stores, 2004)
- Several studies have demonstrated significantly lower nocturnal melatonin in subjects with autism compared with controls (Kulman, 2000, Nir, 1995, Tordjman et al, 2005)

# Treatment Interventions



# Good treatment is based on full assessment



- Full sleep history including sleep environment and psychosocial stressors
- Medical, neurologic, and psychiatric history: first treat organic sleep conditions and then apply behavioral interventions (Malow & McGrew, 2008)
- Sleep diaries, possibly actigraphy
- Physical examination
- Polysomnography: especially if SDB, PLMD/RLS or nocturnal seizures are suspected

# Pharmacotherapy



- **MELATONIN:** Growing evidence that melatonin is effective in treating sleep-onset insomnia and possibly middle/terminal insomnia ([Giannotti et al, 2004](#); [Goodlin-Jones et al., 2009](#); [Paavonen et al, 2003, 2004](#))



- **RISPERIDONE**

- Improved sleep quality in 5 y/o with autism and Intellectual Disability (ID) ([Demb HB, 1996](#))
- Case series of 11 male outpatients (mean age 18.3 yrs) with autism and ID ([Horrigan & Barnhill, 1997](#))



Aggression, explosivity, overactivity, and poor sleep hygiene (difficulty falling asleep & staying asleep) improved most significantly

# Behavioral Interventions



# Sleep Hygiene



- **Sleep schedule.** Bedtime and wake-up time should be consistent everyday. There should not be more than an hour difference between school nights and non-school nights.
  - Use the sleep diary and information about typical sleep needs for your child's age to determine how much sleep is needed.
  - Determine what time child needs to wake up given lifestyle needs.
  - Move backwards from desired waketime to set bedtime.
- **Bedtime routine.** A 20 - 30 minute bedtime routine that is the same every night is important in setting the stage for sleep. Routine should include calm activities (e.g., reading a book, talking about the day) with the last part occurring in the room where the child sleeps.
  - Routines can easily become rituals in children with ASDs. Parents should be cautious when introducing new routines and should consider building in variation from the outset.
- **Bedroom.** The bed and bedroom should be associated with sleep.
  - Comfortable, quiet, and dark (a dim nightlight is fine).
  - Cool (less than 75 degrees)
  - Avoid using a child's bedroom for time-out or as a punishment.

Adapted from Durand, V. M. (1998) & Owens, J. A. (2008)

# Sleep Hygiene



- **Snack.** A light snack (e.g., milk and cookies) before bed is a good idea.
  - Heavy meals within 1 – 2 hours of bedtime, particularly foods high in fat, should be avoided.
  - Foods that cause upset stomach or heartburn for a given child should be avoided (e.g., spicy, cucumbers and beans, MSG) should be avoided.
- **Caffeine.** Children should avoid caffeinated beverages in general, and particularly for at least 3 – 4 hours before bed.
  - Caffeine can be found in many types of soda, coffee, iced tea, energy and “performance” drinks and chocolate.
- **Evening activities.** The hour before bed should be quiet time.
  - Avoid high-energy activities, such as rough play or playing outside, or stimulating activities, such as playing computer games.
- **Television.** Keep the television set out of a child’s bedroom.
  - Children can easily develop the bad habit of “needing” the TV to fall asleep.
  - It is also much more difficult to control TV viewing if the set is in the bedroom.
- **Naps.** Naps should be geared to a child's age and developmental needs. However, very long naps or too many naps should be avoided, as too much daytime sleep can result in a child sleeping less at night.
- **Exercise.** Children should spend time outside every day and get daily exercise. Exercise too close to bedtime raises the body’s temperature and can interfere with sleep.
  - Engaging in at least 20 minutes of aerobic exercise 4 – 6 hours before bedtime is ideal to maximize the effect of the body's drop in temperature.

# Treatments for Delayed Sleep Phase Syndrome



- Strict adherence to a consistent 24-hour schedule
- Melatonin can be considered at bedtime
- Bright light therapy in the morning
- Chronotherapy for individuals with severe delays

# Treatments for Parasomnias



- **Nightmares**
  - “Magic” (e.g., sleep with a sword, dream catchers)
  - Relaxation
  - Paradoxical intention (DON’T go to sleep)
- **Partial Arousal Parasomnias (Sleep Terrors, Sleepwalking, Sleeptalking, Sleepeating)**
  - Avoid sleep deprivation
  - Scheduled awakening: Durand (2002) treated 3 children with autism by waking them 30 min prior to terrors to disrupt stage 3 and 4 sleep, after 7 nights without terrors, eliminate 1/7, and gradually proceed → reduced to 0 and maintained at 12 mos,  $M = 5.7$  weeks

# Teaching Sleep Independence



# Treatments for Bedtime Resistance



- **Intervention types** (Powers, M.D., Palmieri, M. J., D'Eramo, K. S., Powers, K. M., 2010)
  - Introduction of transitional objects to promote more appropriate & available sleep associations
  - Extinction & variants
  - Bedtime fading
  - Positive reinforcement



# Treatments for Night Waking



- **Intervention types** (Powers, M.D., Palmieri, M. J., D'Eramo, K. S., Powers, K. M., 2010)
  - Introduction of transitional objects to promote more appropriate & available sleep associations
  - Adherence to routine without unplanned daytime sleep
  - Graduated extinction
  - Sleep restriction
  - Scheduled awakening

# Case Review



**MOLLY**

# Background Information



- Age: 10 years, 1 month
- Diagnoses: Autistic Disorder, Pica, Behavioral Insomnia, Mild to Moderate Intellectual Disability
- Lives at home with parents and younger brother
  - Has her own room
- Attends a specialized school for individuals with intensive learning needs
- Several ongoing behavioral concerns including stereotypic vocalizations
  - These have particular implications for sleep hygiene
- Some tasks of daily living can be performed individually if taught with visual supports and repetition

# Sleep-specific background



- Organic diagnoses ruled out
- Evening routine is somewhat inconsistent
- Given 2mg melatonin with juice at 8pm at bedtime
- Falls asleep with a parent next to her every night either in her own bed or in her parents' bed
- Always moves to her parents' bed at some point during the night
- Attempts to have parents near her/touching her during sleep

# Intake Process



- Parents complete initial intake packet including Albany Sleep Problems Scale (Durand, 1996) and two weeks of data on sleep habits
  - Molly's activities immediately prior to bedtime vary and typically include scripted play with dolls, watching TV, sitting in a hot tub
  - Molly brings multiple dolls to bed and scripts with these at bedtime
  - Molly has a TV in her bedroom and watches this at bedtime
  - 57% of nights Molly started in her parents' bed and remained there all night
  - 43% of nights Molly began in her own room but transitioned to her parents' room before 2 am

# Intake Content Review



- Episode example

Time	Child's Behavior	Response
9:00p	Asked for our bed	"Get back in your bed Molly"
9:05	Whispering while walking down the hall, "Molly's bed, Mommy's bed please..."	"Daddy will go lay with you"
9:10	Crying, yelling, "Molly's Bed"	Dad trying to get her to lie quietly with no success
9:15	Came back to our room, on chaise lounge with Dad, yelling "Molly's bed"	Got into our bed and asleep by 9:30

# Treatment Begins



- Initial session with parents to discuss treatment options
  - parents choose to pursue aggressive treatment in which Molly is required to be in her room alone all night every night from the start of the intervention
  - A sleep hygiene plan is developed including a daily schedule to modulate access to highly stimulating activities, specific bedtime routine with visual schedule, plans for food consumption and exercise, etc.

# Parent training begins



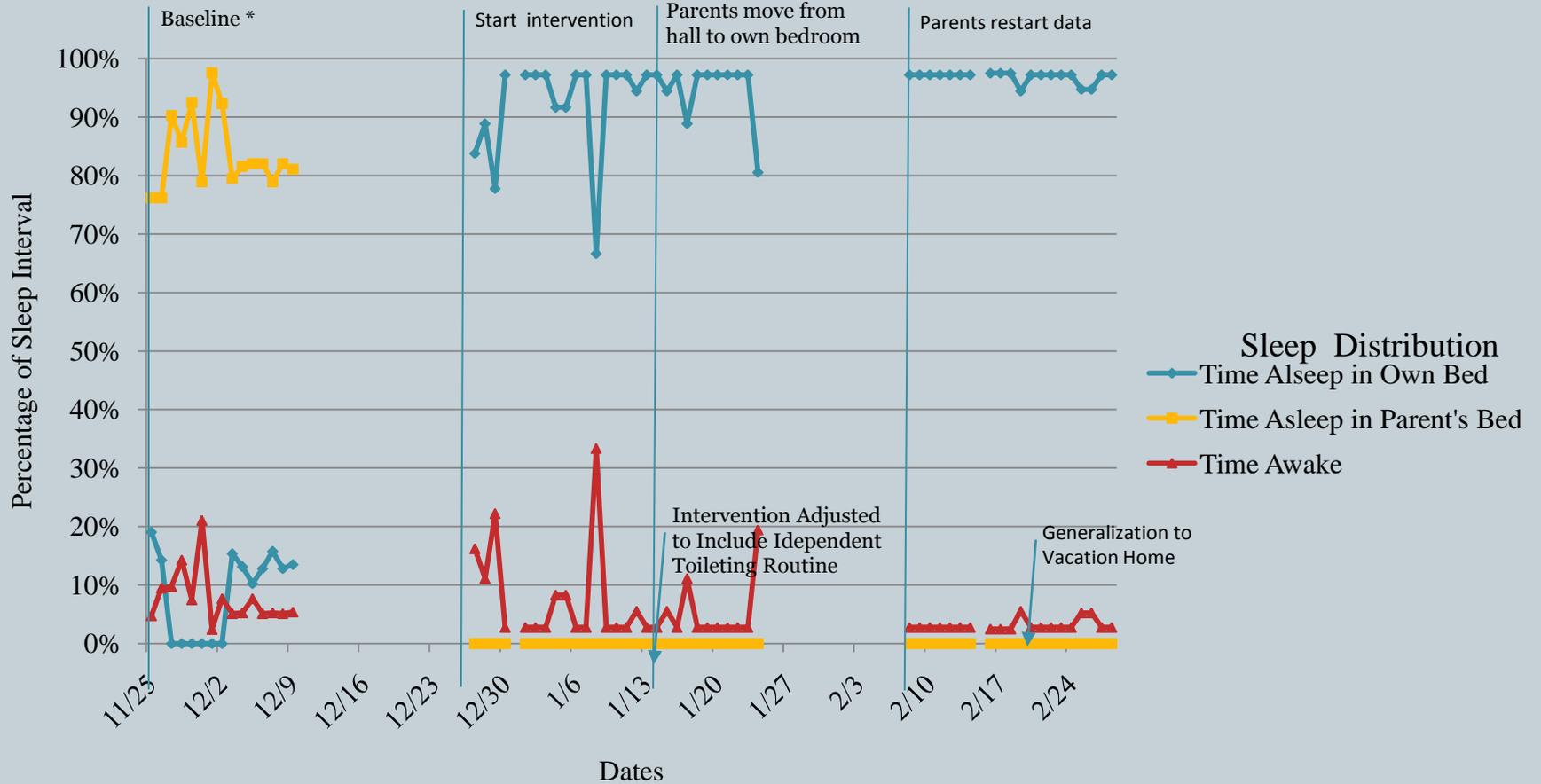
- After Behavior Support Plan is developed, parent training begins
  - Behavioral intervention and data collection procedures are reviewed and discussed
  - Intervention schedule is developed
    - ✦ Target behaviors: elopement from room and noncompliance (shouting, hitting/kicking door, self-injury, property destruction)
    - ✦ Replacement skills: (1) staying in her room, (2) sleeping in her bed, (3) maintaining safe behavior, (4) maintaining acceptable voice level
    - ✦ Reinforcement Protocol: if Molly meets target goal (initial goal is only to remain in her room until 6 am), parents enter her room and give her access to laptop computer
    - ✦ Safety procedures: objects removed from room to reduce risk of pica or other SIB, video monitor installed

# Intervention Process



- During initial week of intervention we have daily phone contact with parents
- Parent training sessions are scheduled weekly for first month and then biweekly for second month to monitor progress and make revisions to Plan
- Plan is modified several times to increase expectations, generalize across people and locations, increase Molly's independence with schedule, eliminate medication

# Results



\*93% of Baseline Nights onset was with parent nearby

# Intervention Outcomes



- Over the first three evenings notable challenging behavior topographies were present:
  - Night 1: Screaming 11%, Door hits 7.2%
  - Night 2: Elope attempts: 3.6%
  - Night 3: Safe Non-sleep: 5.4%
- Other behavior events
  - ✦ Turn on lights
  - ✦ Change shades
  - ✦ Singing

# Intervention Outcomes



- Following the 1<sup>st</sup> three nights:
  - 47 evenings of data collection
    - ✦ 10 evenings with events (21%)
      - 11 total events
      - ✦ Of these 11 events
        - 6 – woke and did not leave bed
        - 2 – bathroom attempts
        - 3 – left bed and moved to door
- Parents began fading Melatonin about 6 weeks after intervention started and completely eliminated medication within 3 days.
  - No change in overall behavior presentation
- Throughout the intervention 4 revisions were implemented in the BSP to adapt to Molly's present functioning
  - Examples: instruction on the bathroom, independence with schedule, contingency changes, parent placement changes
- Family generalized the procedure to a vacation home and trained a babysitter on intervention use

# Intervention Outcomes



- **Following Progress**

- Ongoing follow-up with the family on a monthly basis during the first six months following consistent treatment.
  - ✦ No issues with maintenance
- One and Two year follow-ups indicate that sleep patterns have maintained.
  - ✦ Data collection procedures utilized to measure patterns in a fashion consistent with the start of treatment.
    - No indications of difficulties

# Intervention Outcomes



- **Parent reports of adaptive improvements**
  - Use of the scheduling process across most parts of her day
  - Ongoing use of contingent reinforcement for sleep and other challenges
  - Training for various family members, including her adolescent brother, on how to reward her and shape compliance with evening routines
  - Parent advocacy for use of Applied Behavior Analytic intervention in the educational setting



# FEEDING

# Prevalence



- Parents and caregivers of children with autism spectrum disorders often report feeding difficulties. (Ahearn, Castine, Nault, & Green, 2001)
- Estimates of prevalence vary greatly
  - Historical: 94% of parents with autism note feeding difficulties vs. 59% of typically developing preschool peers. (DeMeyer, 1979)
  - 57% Selective, 87% Low or Moderate Acceptance. (Ahearn et al. 2001)

# Feeding Difficulties Impact:



- Increased prevalence rates and clinical impact of among individuals with autism spectrum disorders supports the need for comprehensive community-based treatment options. (Keen, 2008; Schreck et al. 2004)
  - Nutritional status
  - Quality of life within family structure
  - Social opportunities with peers

# Oral-Motor Skills



- The impact of oral motor skill deficits on adequate nutrition is cited as a concern for children with developmental disabilities, including children with autism spectrum disorders. (Collins et al., 2003; Gibbons et al., 2007 )

# Signs of Oral-Motor Deficits



- Persistent speech/articulation deficits over age 3
- Mouthing objects past 2 years
- Persistent oral reflexes beyond 8 months
- Food on face or dropped out of mouth while eating w/o awareness
- Drooling
- Pocketing of food

# Food Selectivity



- Food acceptance restricted by:
  - food category
  - texture
  
- Parents of children with ASD report:
  - refusing most foods
  - specific utensils/presentation required
  - low textured foods required
  - eat fewer foods from groups than peers

(Schreck et al., 2004)

# Specific Oral-Motor Deficits Identified in Children with ASD:



- Sucking Problems
- Poor Mandibular Stability
- Decreased Tongue Mobility
- Latent Oral Reflexes
- Tactile Sensitivity
- Oral Tone
- Subsequent impact of compensatory strategies (Amato & Slavin, 1998)

# Oral-Motor Component Analysis



- Postural tone and alignment
- Oral-facial observation (e.g., dentition)
- Oral tone
- Tactile sensitivity and oral-motor differentiation
- Oral reflexes (e.g., tongue thrust, gag)
- Jaw, lip, cheek and tongue control
- Coordination of Suck-Swallow-Respiration Control
- Bolus management
- Swallowing difficulties: risk of aspiration

# Defining Oral-Feeding Limitations



- **Can the patient:**
  - achieve lip closure around the feeding implement?
  - move food from one side of the mouth to the other with the tongue (tongue lateralization)?
  - take food or a feeding implement into the mouth without gagging?
  - execute a mature chewing pattern (typically a rotary chewing pattern)?
- **Remember:** these must be assessed with respect to a diverse profile of foods.

# Food Qualities



- Taste
- Temperature
- Texture
- Smell
- Sight

# Activities for Oral Motor Development



- Consider use of chewy tubes for jaw stability and advancement of chewing abilities
- Oral motor exercises to improve tongue, lip and jaw strength and mobility
- Use of Nuk to face and inside mouth for desensitization: Advance to Nuk with food
- Practice with food placement to develop rotary chewing patterns (side-side-front)
- Use of straw with thickened liquids to improve suck/lip control
- Practice with open cup with liquids

# Behavioral Considerations



- Form and history of behaviors occurring during mealtime (e.g., gagging, tantrums)
  - Behavior escalation patterns
  - Family behavior
  - Setting events
- Negative Reinforcement: Escape from food, mealtime, or meal setting most common finding
- Important emphasis on consequences of challenging behavior (e.g., escape, access to tangibles, attention)
- Consider changes that have occurred within home to avoid any behavior challenges
- Assess resources available in the home to intervene with feeding



# Behavioral Assessment



- Assessment of behavioral aspects of feeding involves determining the function of the behaviors associated with feeding. (Munk & Repp, 1994; Piazza et al., 2003; Williams et al., 2007)
  - Contributes directly to function-based behavioral intervention procedures

# Behavioral Assessment



- Common behavior topographies include vocal refusals, gagging, vomiting, aggression, tantrums (Ahearn et al., 2001; Kirkland, 1994; Williams et al., 2005)
- Systematic assessment applying environmental manipulations inform data-based treatment planning
  - Informed by indirect data collection procedures (behavior form, food preferences, likely antecedents)

# Treatment Process



- A multidisciplinary approach to feeding
  - Coordinating services
  - Functional assessment
  - Developing priorities
  - Direct treatment
  - Evaluating progress
  - Parent/Caregiver training

# Behavioral Treatment Features



- Set targets based directly on assessment data
  - Interview, oral motor assessment, behavioral assessment
- Targets and interventions include:
  - Shaping of target feeding-specific responses
    - ✦ Supported feeding to self-feeding
  - Escape extinction procedures
  - Reinforcement for success
    - ✦ Contingent access to preferred items/edibles
  - Alternative response training
  - Texture fading (Shore et al., 1998)
  - Parent training

# Treatment: Intervention Planning Considerations



- Individualization!!
- Oral motor training
  - Specific activities to be conducted within the home such as whistles and chewing practice
- Embedding choice making
  - Particularly if the functional assessment indicates the presence of escape maintained behavior
  - Choices for food tried
  - Gradual transfer of newly acquired foods into reinforcers
- Stimulus presentation: mixing target foods with preferred foods
  - Simultaneous Presentation
- Placement:
  - Placement of food in places in the mouth that is appropriate to the current skill profile of the individual
  - Placement of foods near one another when they are presented
    - ✦ For example: on the same plate)

# Treatment: Early “Desensitization” Strategies

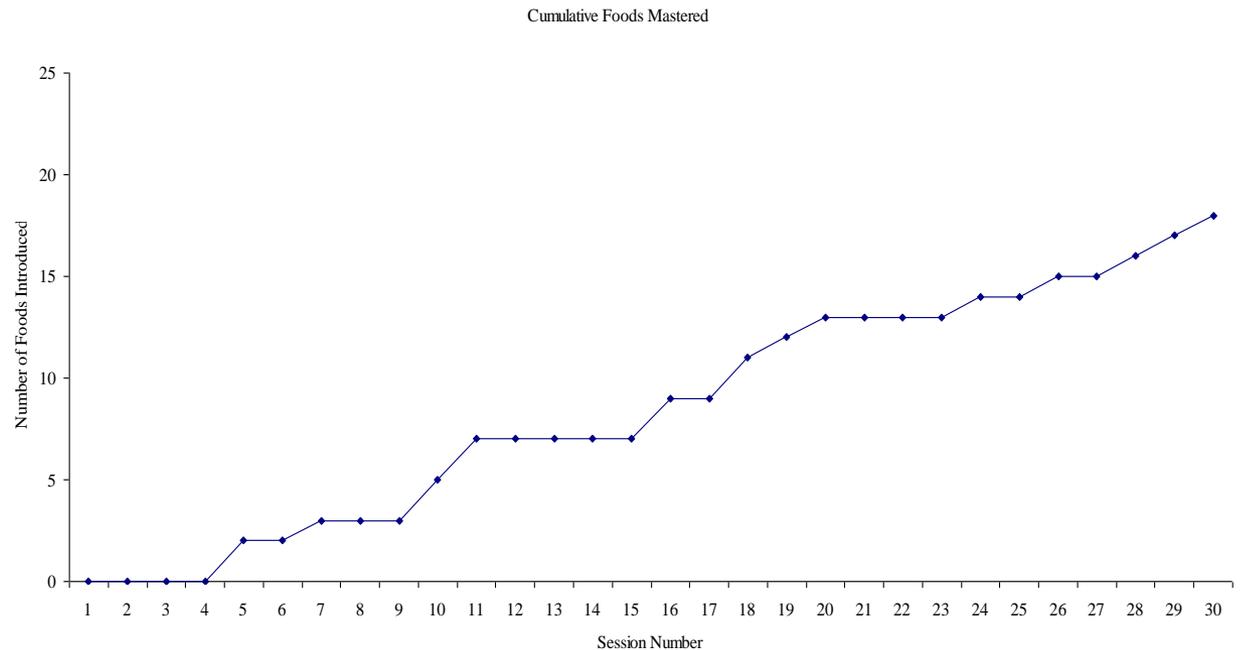


- Desensitization to visual cues
- Desensitization to olfactory cues
- Desensitization to tactile input
  - Oral-facial and intra-oral structures
- Desensitization to temperature, taste, texture



# Record of foods mastered

- Various levels of data collection are implemented to help guide treatment.
- Typically these will include measures of total progress and measures on individual factors such as food types, oral motor skills, or progress in a certain context

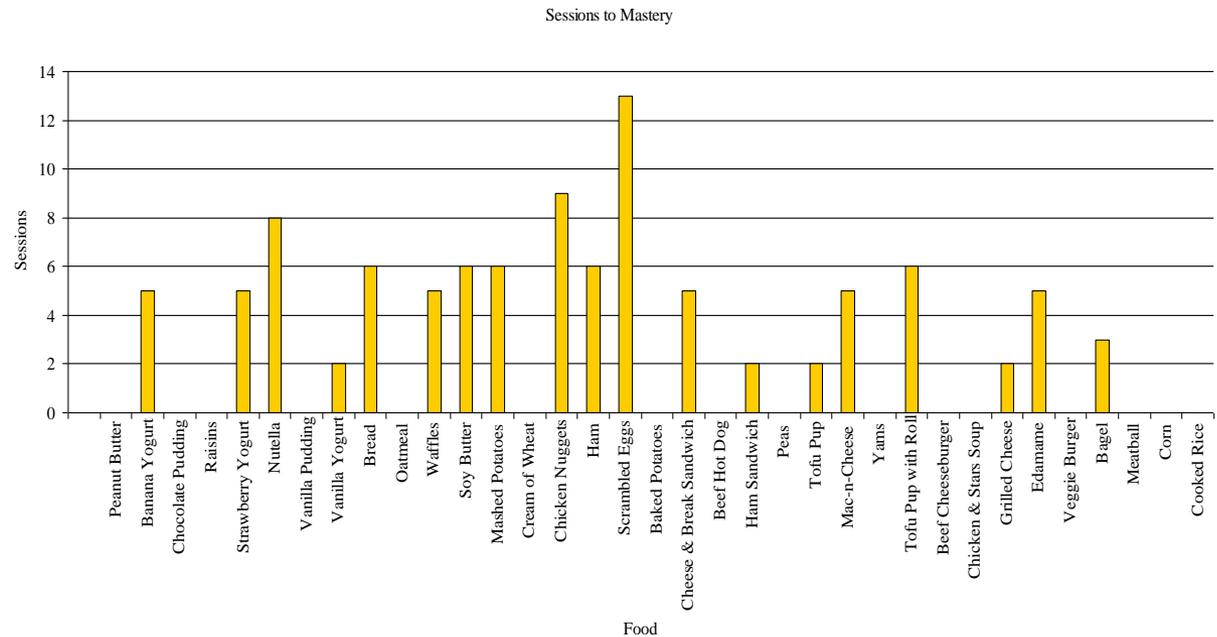




# Sessions to Mastery for each food

▪ Analyses will investigate the trend in duration to mastery, and any outlier foods that require further investigation for factors such as:

- Preference
- Motor deficiencies
- Communication needs



# Treatment: Progressing to Independence



- When do you terminate treatment?
  - This is an individual-specific process
  - General Indicators:
    - ✦ Patient is able to share full meals independently with her/his family
    - ✦ New foods are introduced and proceed to mastery within session or within few trials at home following in-session introduction
    - ✦ Caregivers can introduce and master new foods with patient outside of treatment
    - ✦ Oral motor competencies are well established
    - ✦ No ongoing nutrition concerns due to feeding limitations

# Adaptive Skill Instruction



## **OVERVIEW**

# Adaptive Skill Instruction: Overview



- To design treatment we must understand the needs of each individual
  - What is the nature of the deficit?
  - What are the functions of related challenging behaviors?
  - What are the prerequisite skills that must be addressed?
- Treatment follows a person-centered approach and involves the entire support system
- Treatment often proceeds progressively
  - Starting with more basic skills and expanding into complex repertoires

# Adaptive Skill Instruction: Overview



- Adaptive skill deficits often go untreated or under treated and as a result the overall quality of life of the individual and the family is impacted
  - Poor opportunities for functional independence
  - Limited community engagement
  - Ongoing need for extensive support for self-management
  - Substantial adjustments to the daily life of the family

# Adaptive Skill Instruction: Overview



- When treatment is approached from a skill-acquisition perspective we offer individuals chances to experience ongoing success and significantly increased levels of independent functioning
- We must support both the individual with an Autism Spectrum Disorder and the family with coping with the change process, particularly when the skill deficits have been present for many years.
- Adaptive skill deficits, while complex, are treatable and merit intensive, therapeutic supports
  - The impact of change is life-long and extremely profound

# Thank you



## QUESTIONS & COMMENTS

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