

CPAP, Hearing Aids, and Glasses, Oh my! How to Help My Child to Wear Their Medical Equipment

Lina Patel, Psy.D.
Sie Center for Down Syndrome
Children's Hospital Colorado
University of Colorado School of Medicine
Lina.Patel@childrenscolorado.org



Financial Disclosure



Objectives

- ❖ Explain frequency of diagnoses and effects on development
- ❖ Explore factors impacting adherence
- ❖ Lay out a step by step plan for increasing use of medical equipment



Hearing Loss and Down Syndrome

❖ Prevalence of Hearing Loss and Down syndrome

- Some studies indicate 60-80% of individuals with Down syndrome will have some type of hearing loss

❖ Effects of Hearing Loss on Development

- It may cause delays in the development of expressive and receptive communication skills
- The language deficit may cause learning problems that result in reduced academic achievement
- Communication difficulties often lead to social isolation and poor self-concept.
- It may have an impact on vocational choices
- It will take six years to give your child as much listening experience as a normally hearing infant accumulates in one year (Stovall, D. 1982)





Frequency of Vision Impairment

- ❖ Vision Impairment and Down syndrome
 - By school age, 60% need glasses
- ❖ Effects of Vision Impairment on Development
 - Difficulty with mobility
 - Sleep problems have been reported for older adults with low vision or blindness
 - Safety
 - Adaptive behavior and cognitive functions that rely on visual processing



Frequency of Obstructive Sleep Apnea

❖ OSA and Down syndrome

- Studies show range from 50-100% with almost 60% having abnormal sleep studies by age 3.5-4 years (Shott 2006b)
- There is evidence that these numbers increase with age (Dyken 2003).
- 97% incidence of OSA in children with DS who snored, ages 0.2 to 19 years (Fitzgerald 2007)

❖ Effects of OSA on Development

- Cognitive abilities and IQ scores
- Behavior
- Growth rate
- Systemic hypertension, pulmonary hypertension and heart failure



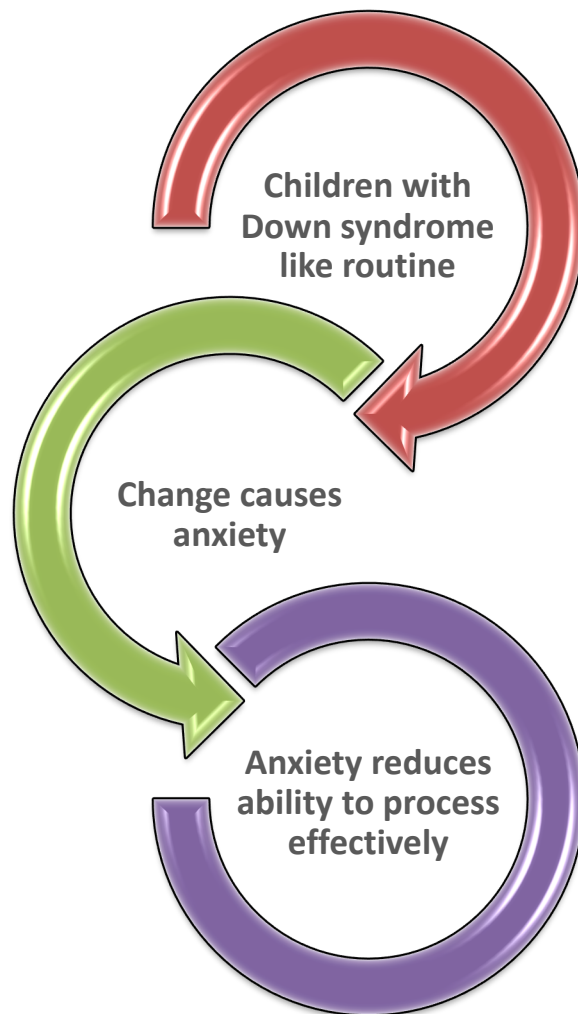


Reasons Wearing Medical Equipment is Difficult

- ❖ It's a change
- ❖ Lack of understanding of purpose of it
- ❖ It feels different
- ❖ Sensory issues: sensitivity or simply a change
- ❖ Developmental stage
- ❖ Kid “smarts”: refusal = parent attention
- ❖ Overall health: illness, teething, hunger, ear infection
- ❖ Wanting to be “normal”
- ❖ Anxiety
- ❖ Parental factors

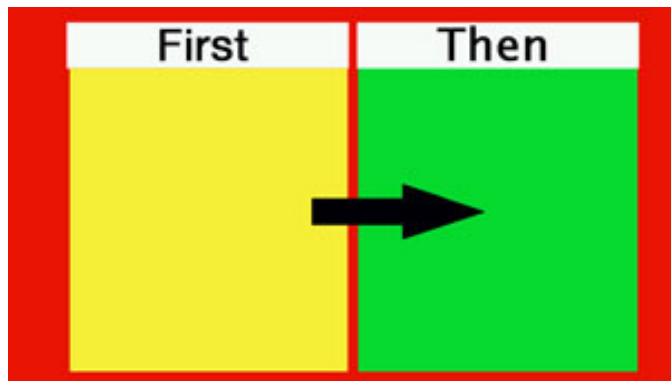


It's a change...



How do we proactively address change?

- ❖ Use first-then directives to motivate my child to wear the equipment during practice sessions.
- ❖ Start slow
- ❖ Use a timer
- ❖ Use a visual schedule





Lack of understanding....

❖ Why is this important?



How do we proactively address lack of understanding....

- ❖ Use a social story to help develop understanding of why it is important
- ❖ Give examples of others that use the equipment and how it helps them
- ❖ Videomodeling

But the mask does not hurt.
It looks silly!

HA! HA! giggle
giggle



It feels different...

- ❖ Tactile
- ❖ Auditory
- ❖ Visually
- ❖ Air pressure



Sensory Issues...

- ❖ Difficulty with auditory, visual, tactile sensitivities
- ❖ Over responsive
- ❖ Sensory seeking through movement, visual, tactile, proprioceptive and oral sensory seeking



How do we proactively address how it feels/ sensory issues...

- ❖ Appreciate the difference yourself
 - Providing a quiet area in the house (i.e., cozy corner) can be helpful for your child to go to if they are feeling overwhelmed at home to calm. Providing sensory soothing items in this space can help your child calm while the aids are introduced
 - Introduce gradually
- ❖ Check for fit
- ❖ Calming strategies used before or while wearing equipment
 - Using a visual schedule can indicate both the sensory strategies used to help calm your child and when and for how long you will practice wearing the aids
 - Prep their body by playing a game such as “Hot Dog Burrito Game” rolling your child up in a blanket and using firm pressure with your hands or a therapy ball to “pat” your child with condiments (i.e., patting ketchup, pickles and mustard) on their bodies. Providing firm touch can be soothing and calming
 - Movement activities (i.e., running, play outdoors or indoors) can not only help when prepping their body for wearing the aids but also can offer a fun distraction while the aids are on to increase wearing time.



How do we proactively address how it feels/ sensory issues...

- ❖ Decreasing anxiety related to new sensory experiences
 - Create a plan of what sensory activities you and your child can do if they start feeling worried about wearing the hearing aids (i.e. Deep breaths, heavy work activities, movement activities). Use these strategies before introducing the hearing aids to “prep” their body
- ❖ Normalizing child’s response to sensory experience
- ❖ Create smaller achievable goals



Developmental Stage....

Stage	Basic Conflict	Important Events	Outcome
Infancy (birth to 18 months)	Trust vs. Mistrust	Feeding	Children develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust.
Early Childhood (2 to 3 years)	Autonomy vs. Shame and Doubt	Toilet Training	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy, failure results in feelings of shame and doubt.
Preschool (3 to 5 years)	Initiative vs. Guilt	Exploration	Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.
School Age (6 to 11 years)	Industry vs. Inferiority	School	Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority.
Adolescence (12 to 18 years)	Identity vs. Role Confusion	Social Relationships	Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self.
Young Adulthood (19 to 40 years)	Intimacy vs. Isolation	Relationships	Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, while failure results in loneliness and isolation.
Middle Adulthood (40 to 65 years)	Generativity vs. Stagnation	Work and Parenthood	Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, while failure results in shallow involvement in the world.
Maturity (65 to death)	Ego Integrity vs. Despair	Reflection on Life	Older adults need to look back on life and feel a sense of fulfillment. Success at this stage leads to feelings of wisdom, while failure results in regret, bitterness, and despair.



How do we proactively address the developmental stage....

- ❖ Recognize what developmental stage your child is in
- ❖ Make a list of their strengths while in this stage and utilize to your advantage



Kid “smarts...”

- ❖ Getting rid of equipment
- ❖ Taking the equipment apart
- ❖ When I take it off, I get attention



How do we proactively address kid “smarts” ...

- ❖ Ignore when equipment is pulled out
- ❖ Praise and give lots of attention when wearing the equipment
- ❖ Practice only when I can give my undivided attention
- ❖ Remove equipment when transitioning from one location to another
- ❖ Be clear about expectations and tell what to do, instead of what not to do



Overall health....

- ❖ **Celiac disease:** 7-10% effected by celiac disease in individuals with Down syndrome.
- ❖ **Infections.** Down syndrome often causes problems in the immune system that can make it difficult for the body to fight off infections. Infants with Down syndrome have a 62-fold higher rate of pneumonia, especially in the first year after birth, than do infants without Down syndrome, for example.
- ❖ **Feeding.** 42.5% have feeding issues at birth.
- ❖ **Hypothyroidism.** The thyroid is a gland that makes hormones the body uses to regulate things such as temperature and energy. Hypothyroidism, when the thyroid makes little or no thyroid hormone, occurs more often in children with Down syndrome than in children without Down syndrome.
- ❖ **Hypotonia (poor muscle tone).** Poor muscle tone and low strength contribute to the delays in rolling over, sitting up, crawling, and walking that are common in children with Down syndrome.
- ❖ Not to mention basics like just not feeling well.



How do we proactively address overall health....

- ❖ Limit rehearsal to times when my child is healthy.



Wanting to be “normal” ...

- ❖ Especially during adolescence, many individuals with Down syndrome begin to realize that things are different. Medical equipment is just another way to feel different.



What do we need to proactively do to address wanting to “be normal” ...

- ❖ Connect them with role models who also use equipment
- ❖ Use social stories to help them understand how use of medical equipment positively effects their life

<http://theadventuresofnolan.blogspot.com/favicon.ico>

- ❖ Teach them to be more independent



Anxiety...

- ❖ Your anxiety
- ❖ Your child's anxiety



How do we proactively address anxiety...

- ❖ Tag team with another caregiver if my anxiety is too high when introducing aid practice.
- ❖ Start with practicing for the amount of time that I feel both my child and I can be successful.
- ❖ Practice when other demands are not being placed.
- ❖ Introduce specific input from senses during equipment practice so that they are not alarming.
- ❖ Practice using equipment in controlled locations before practicing in public settings.
- ❖ Help your child anticipate when they are practicing by using a visual schedule.
- ❖ Predetermine when to practice.
- ❖ Use adult directed choices.



Parental factors....

- ❖ Lack of understanding of the importance of use
- ❖ Anxiety
- ❖ Too many things to juggle



How do we proactively address parental factors...

- ❖ Find your village
- ❖ Meet with medical providers regarding my readiness to start having my child wear their equipment
- ❖ Read more about what my child is missing when they cannot fully access hearing, vision, etc



Assessment

- ❖ Fit
- ❖ Feel
- ❖ Level of Anxiety
- ❖ Sensory Issues





Planning for Equipment Use

Step 1

- ❖ With adult supervision, allow your child to hold his/her equipment in their hands
- ❖ Model for your child, showing them where the equipment belongs (For younger children, model how they would be worn on yourself or a stuffed animal)
- ❖ Praise and rewards even at this early stage is important to establish a positive relationship with the equipment
- ❖ Read a social story to your child
- ❖ If your child has sensory issues, determine what sensory calming strategies you plan on using to help your child prepare their body before placing the equipment on



Planning for Equipment Use

Step 2

- ❖ Determine how long you think they may be able to wear the equipment successfully (this means that they wear it, don't experience overwhelming distress, and allow it to stay on until **you** take it out for them)





Planning for Equipment Use

Step 3

- ❖ Think about when the motivator would need to occur and determine what type of motivator would work best for them...
 - During the time they are wearing the equipment
 - After the time for wearing the equipment



Planning for Equipment

Immediate Rewards/Motivators	Weekly Rewards/Motivators

Immediate	Weekly
Pick what to have for breakfast	Special play date or sleepover
Watch favorite YouTube video	Go to the park
Computer time	Go out to eat at chosen restaurant
Chore “excuse” note	\$5 prize
Special activity with a chosen person	Later bedtime

**Tip: Get them involved in the process! The more invested they are in the rewards, the better the outcome!*



Planning for Equipment

PARENT REWARDS

Immediate Rewards/Motivators	Weekly Rewards/Motivators



Planning for Equipment

Step 4:

- ❖ Determine how you will indicate that the time is up for wearing the equipment (timer, end of a show, end of an activity)
 - TIP: if they are not experiencing distress and are not fighting wearing equipment, you can introduce an extension of time by saying, “Your hearing aids are great! Would you like to wear them for 5 more minutes or 10 more minutes?”) Praise for success and allow for continuation. If you notice even a small amount of distress, end on a good note and then remind the child when the next practice session will be.





Planning for Equipment Use

Step 5

- ❖ Determine how you will remind them when practice will occur
 - Introduce them to a visual schedule
 - Use a calendar



Implementation

Step 6

- ❖ Try it out! Equipment introduction should be done during a child's preferred activity
- ❖ Track the times you practiced and the outcome



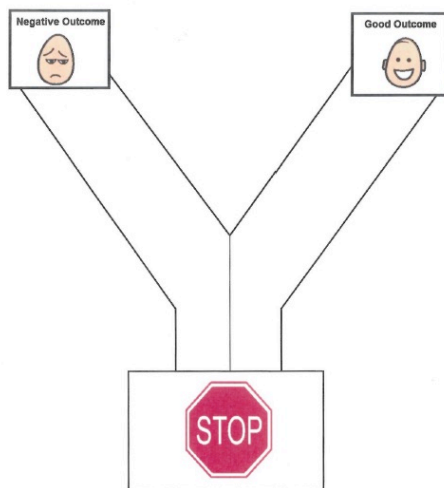
Tips

- ❖ Be clear that only a caregiver or adult is allowed to remove the equipment.
- ❖ Attention can be a *very* strong motivator. Remember this during times when you are practicing with the equipment.
 - Give attention for appropriate behaviors
 - Minimize for negative behaviors
- ❖ Be consistent.
- ❖ All caregivers should be on the same page and following the same rules/goals.
- ❖ Teach acceptance.
 - Have equipment for your child's favorite dolls, stuffed animals, or toys.
 - "Everybody counts!" Show peers how equipment works



Tips

- ❖ Remember that long term health is a reward/ motivator in and of itself.
- ❖ Use visual supports
 - Sensory Preparation activities
 - Visual schedules
 - Contingency maps
 - Token system



A blue rectangular form designed for visual scheduling. It features four empty square boxes arranged in a horizontal row at the top. Below these boxes, on the left side, is the text 'I am working for.....' followed by a larger empty square box for writing or drawing.



Tips

❖ Consistent plan of care of equipment

- Storage
- Cleaning
- Warranty/ Insurance
- Battery purchase/ storage availability when not at home

