

Over the past 27 years

- At the Adult Down Syndrome Center
- Chicago (23 years) & Denver (4 years)

We have seen over 6000 people with Down syndrome

- A one stop shop

# What we have learned: Behavioral Characteristics

Incredibly consistent  
Strength or  
Weakness

Alternative to Mental  
health Labeling

Explanation:

A way to solve a  
problem &, not  
just a label



# **Behavioral Characteristics Key to everything: Strength or weakness**

1. Expressive language
2. **Self Talk**
3. **Social-emotional skills**
4. **Grooves**
5. **Visual Cues**
- **Visual memory**



# Receptive & Expressive Language



Strength &  
weakness



Weakness



## Receptive language

- Seem to Take in everything
- **But** don't always know how to interpret



## Expressive language

- Verbal language not a strength
- “Not good on their feet” with spoken word
- Better mediums ...

# Lack of safety in the verbal realm: “Taking the Fifth”

- **When asked** “How was your day”?
- **Or questioned about something they did...**
- Many will answer “I don’t know ..or try to avoid an answer”
- **Just not comfortable or on an equal footing with** verbal exchanges

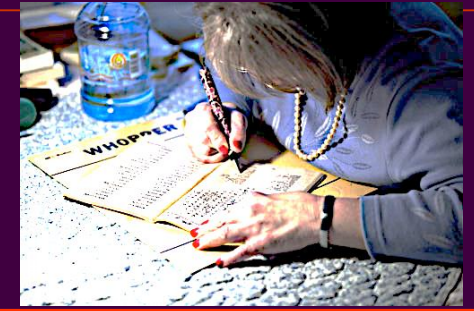


# Encourage other mediums: to open their world to you (especially now)

- A picture can be worth a thousand words {especially to people with DS}
- Imagine a different scene from a typical day “Taking the Fifth” response
- When asked what they did ....
- They show you pictures (coupled with a few choice words) “play”, “work”, “care” “dance” etc



# Encourage other mediums of expression:



- Remember the written word is visual

- Write in - Notes - Journals

- Example: Capable Young man terrified to talk to his mom (wrote in a journal)



- **Art:** A phenomenal medium for people with Down syndrome to express themselves

& spend hours after hour of quality time

- They may just need crayons, colored pencils & paper













# Despite too expressive limitations, social receptive skills are excellent

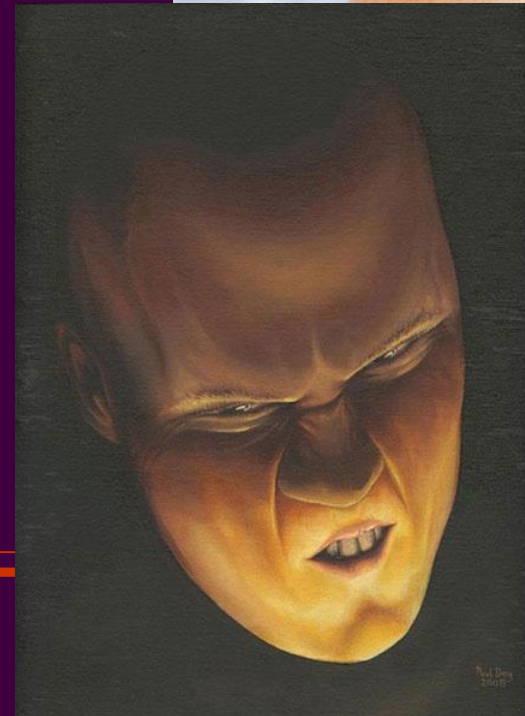
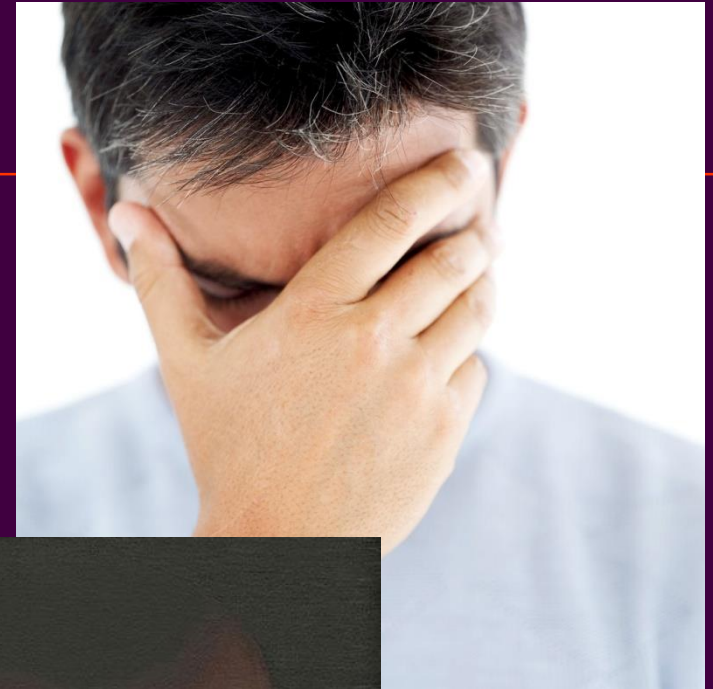
- Many people are very perceptive
- They have excellent intuition
- And an uncanny sensitivity to others (especially loved ones)
- Builds good will





# Sensitivity to others

- People may be far **too** sensitive to negative emotions
- Especially **ANGER**



# People are too sensitive and empathic



- Often not able to block negative feelings and emotions encountered
- **Even when not directed at them**
- They will take the feelings onto themselves

# Self Talk

© Cartoonbank.com



*"I will not talk to myself, I will not talk to myself."*



# Despite 30 years of articles and presentations on the positive nature of Self talk

---

- Concern and controversy persist in parents/professionals
- 2 major reasons
  - 1 For teens & adults: Self talk is not acceptable in public {Clearly not as big a concern}
  2. It can also be very alarming - dramatic to family *even in a private space (one's bedroom)*  
Includes **fantasy play and imagined others**

# Self Talk is reversed in Child Development: It gives ALL children a needed boost when learning a new task (guided action)

- Research: Self talk is gradually Internalized (into our inner speech)
- By about the age of 7 in children
- **BUT** Much later, (up to 12) in typical children with challenges (learning problems, ADHD, Hearing or visual.
- “Because they need the boost that the SELF Talk gives them”



# Researchers Tell Us Self Talk CONTINUES in All of Us

- Resurfaces (becomes more overt) whenever we have a challenge for which we *need a boost*
- For “typical adults” (you and me) it shows up as inaudible muttering (muttering that is low but still heard )
- It appears then that WE ALL have Self Talk
- It's just that People with Down syndrome
- May not be as sensitive or aware of the need to cover it up



# Self talk continues In people with Down Syndrome for 3 compelling reasons

---

1. They need the extra boost that Self talk gives even more than typical children who are challenged
2. **BUT (unlike us)** They are may not be as sensitive or aware of the need to cover up...

Families tell us this with some amazement:

- When chastised (told what to do etc)



3. {As with us}...It will resurface under times of Stress (staying at home with family for weeks on end)

# Self talk can be a spectacularly dramatic scene...at home {in one's bedroom}

- “May include the full range of facial expressions, hand gestures and body movements
- Appears as if the person is on a stage and fully enacting a scene
- With at least one **imaginary other**



# These private 'self talk sessions': Become important personal learning labs

- They bring **the raw material** from their lives {incredible visual memory}
- Into their personal 'self talk lab'
- To see, process and to try to make sense of it in the lab
- **Especially** if they don't understand it



# Self talk and Imaginary friends

- Offers a window on people's thoughts and feelings
- A way to identify a stressor
- Even when they cannot tell you
- **Change in tone, more anger or self criticism**



# People with DS have a reputation “S”

- **Stubborn**
- **“Grooves”**
- **Set patterns and routines**
- **That can drive others a little crazy**





# There are many benefits to “grooves”

- It gives structure and order to peoples daily lives



# Increases independence at home and work

- Once the task is part of a daily routine
- It will be repeated reliably



# Grooves & Free Time Activity

A way to relax by repeating a favorite activity in a quiet space

- Like 'Yoga'



# Grooves and Stress

- Under stress a ‘groove’ can become
- Less productive ...
- (AKA an “obsession or compulsion”)
- Groove may be a conduit for stress (Like headache, stomach issues for others)



# For stuck grooves reduce any stressors:

- Do not force a change
- Gently establish new more productive grooves



A very effective way: 'Reset' stuck grooves

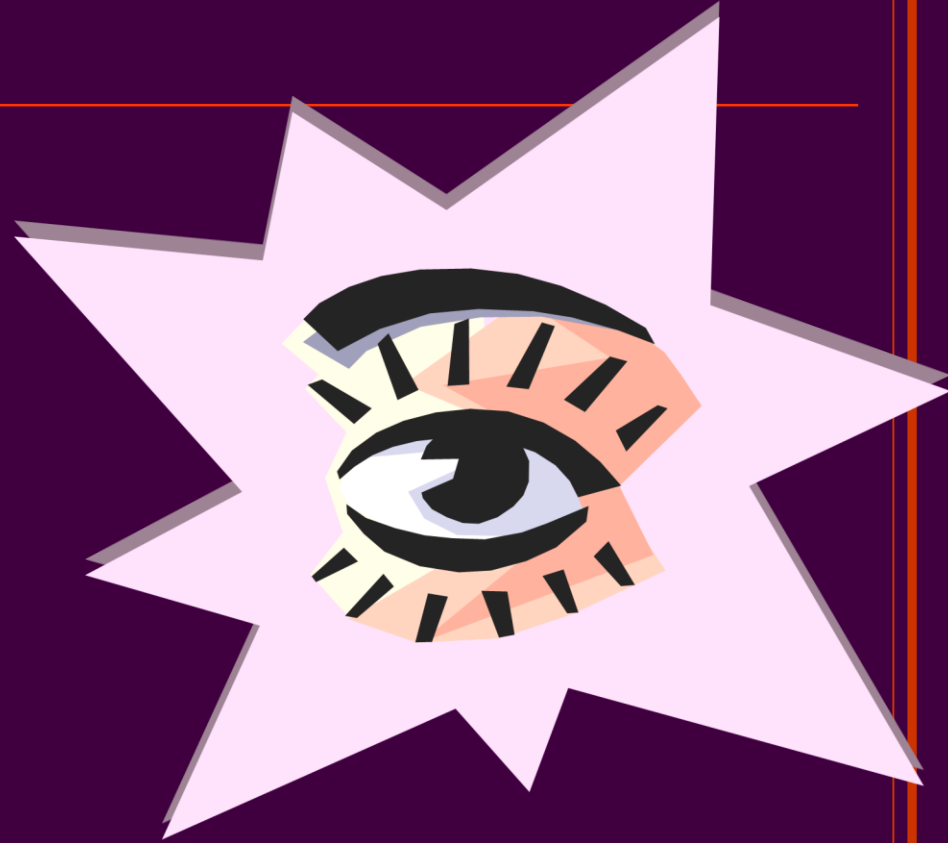
---



- Use of visual cues
- Then help people establish a new more positive routine/groove

For people with DS: Grooves are 'onboard', but **visual is king**

- They are visual learners
- They love movies and pictures
- They remember everything they see



# Visual Memory “Photographic like”





# Many people with DS have exceptional visual memories

---

- People often remember past people, places and events in great detail
- And in living color



# Visual memory has a major glitch: time

- People replay events as if happening **NOW !**
- **With same feelings and emotions of the original event**
- **This may be good or bad depending on the memory**



# Memory: Helps to explain phobias



# More susceptible to Trauma



- People may replay a traumatic scenes over and over
- More susceptible to PTSD
- Examples: **‘Parking lot’**
- Or McDonalds employee



# Research Has Clearly Shown an Auditory Deficit and a Visual Asset

- People are far less likely to remember if told something

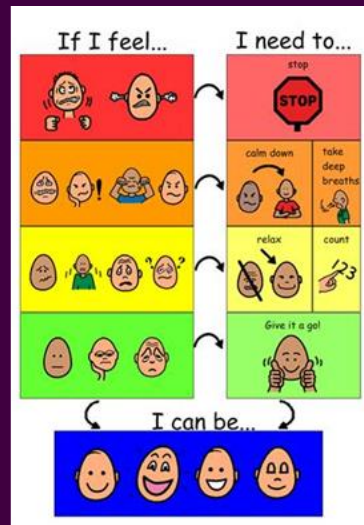
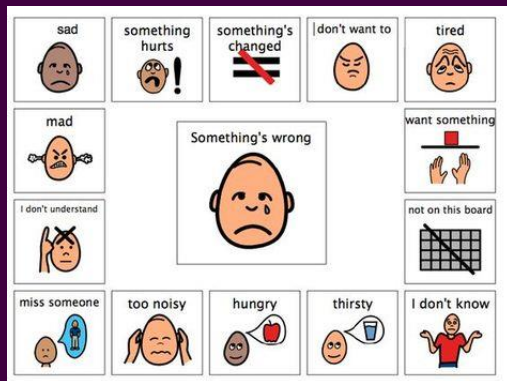


- People are far far more likely to remember if shown something



# Use of **visual cues & supports** are limited only by your creativity; Preference of Son/daughter

- Social skills
- Naming & managing emotions/behavior
- Choice board
- Schedules



Classic example : Visual lists can be especially helpful to encourage independence

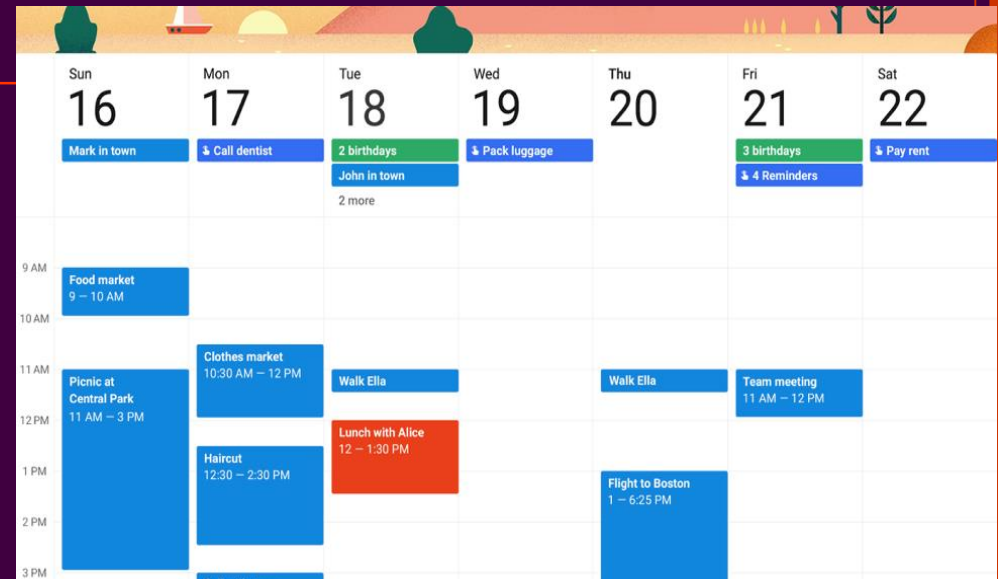
---

- “The list” tells ‘me’ what to do
- And not mom and dad



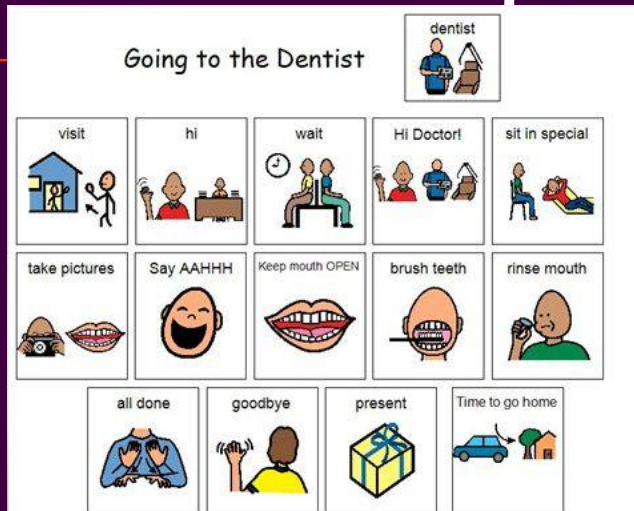
# Why calendars are so popular for people with Down syndrome ?

- Time too abstract
- 5 minutes or 5 years means Nothing
- But people easily memorize a calendar
- Allows them to See, plan and predict





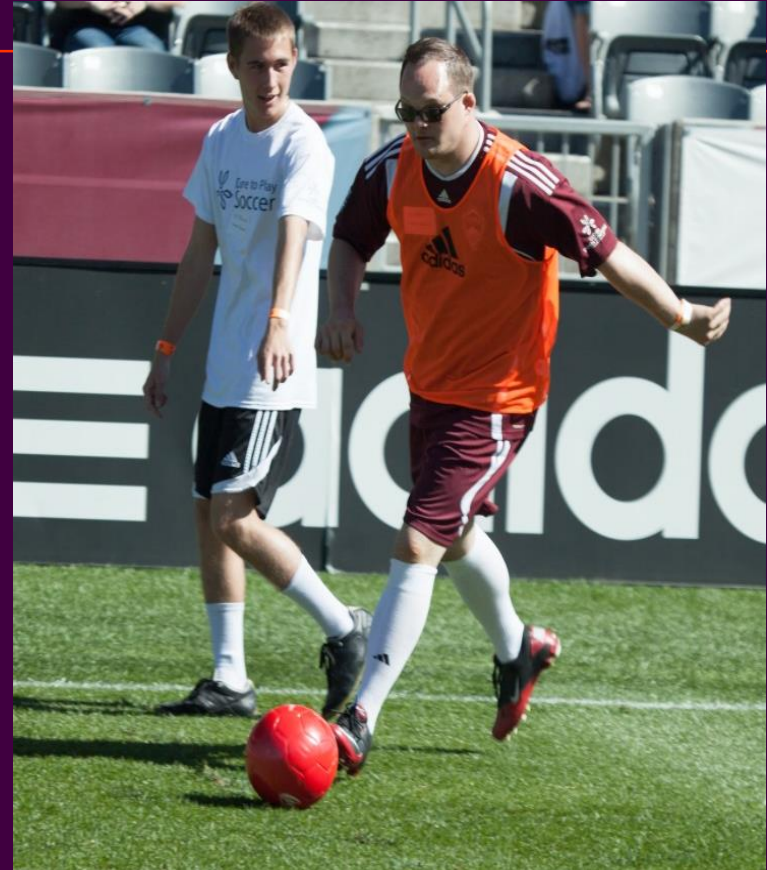
# Visual maps take you anywhere



# How Do I Get My Son or Daughter To...?


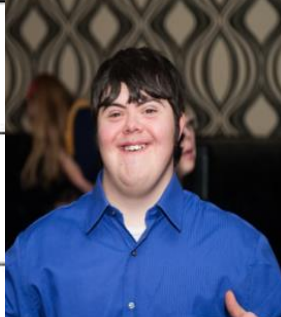




# Put Activities on a Calendar, and Go!





WWW.HOOVERWEBDESIGN.COM

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						

NOTES:

---



---



---



---

# How Do I Get My Son or Daughter To...?



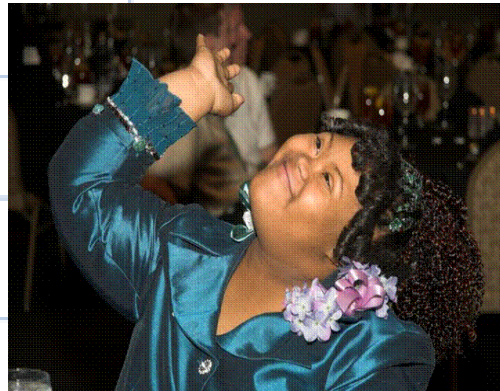
Date

To Do



Date

To Do



Who needs a partner? Who needs to leave the house?...just dance

---



# How do I know something is wrong ? 3 key ways



1. If they lose interest in things they love  
(eg., food, music, movies, dancing)

---

2. If they have more anger/ self criticism  
in their self talk
3. If they have grooves that get stuck  
(a key vehicle for expressing stress)

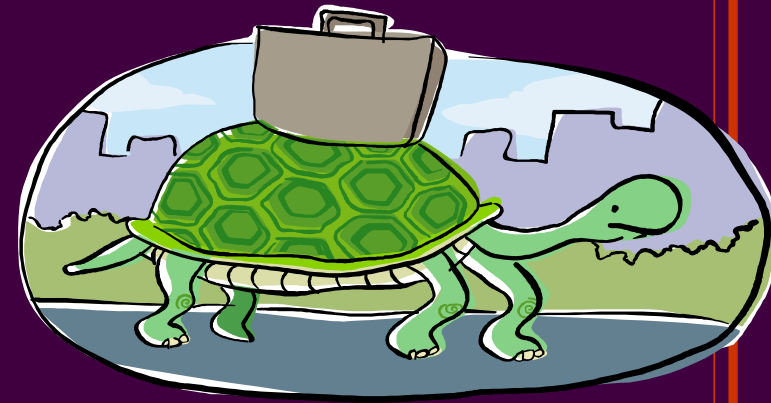


### 3. Finally: “The Pace”

- People with Down syndrome have a reputation for having two speeds:

**SLOW**

and **SLOWER**



# We can learn so much from people with Down syndrome



# Healthy Ways of Living and Looking at Life

They have the ability to teach us lessons

- on slowing down
- and experiencing the joys and pleasures of the here and now

Martha Beck: People with DS literally and figuratively “**stop to smell the roses**”

