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

**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 …

**Strength & weakness**

**Weakness**

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

“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 revered 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 the 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

- Choice board
- Schedules

![Visual cues & supports example](image)
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!
How Do I Get My Son or Daughter To...?
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 (e.g., 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
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”