

GLOBAL  
DOWN SYNDROME  
FOUNDATION®

# Global Down Syndrome Foundation A Unique Affiliate Model!

The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission, vision, values, and goals:

## Global & Affiliates



❖ **Global:** was established as a 501(c)3 in 2009 and is “Dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy”

❖ **Affiliates are:**

- Established with a lead gift from Anna & John J. Sie Foundation
- Must work closely together to benefit people with Down syndrome
- Must be self-sustaining financially



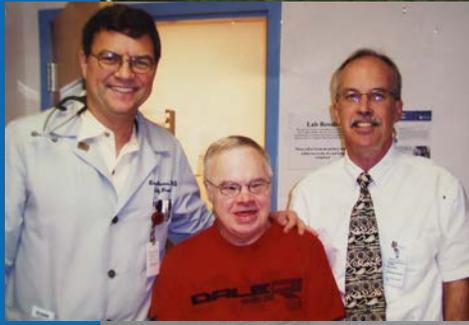
# Promoting Skills to Survive and Thrive in the Teen and Adult Years

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## Over the past 27 years

- At the Adult Down Syndrome Center
- Chicago (23 years) & Denver (past 3 years)
- We have seen over 6000 people with Down syndrome

# What we have learned

## Behavioral Characteristics

Incredibly consistent  
Strength or  
Weakness

Offer an Explanation  
-A way to solve  
problems &, not  
just a label  
people



# Six Behavioral Characteristics: Key to Everythings

1. Expressive & Receptive language
2. Social-emotional skills
3. Self Talk
4. “Grooves”
5. Visual Cues/Visual memory



# Communication: Receptive & Expressive Language

Strength 

Receptive language



Weakness 

Expressive language

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



# Host of problems: If people cannot easily verbalize the cause or source of a problem

- It is more difficult to Identify and solve problems & issues
- Makes people at greater risk for shutting down & depression
- Losing a good job etc



# Encourage other mediums:

Pair what they can **see & touch** (**concrete**) with the spoken word to communicate

**This may include:**

- **Pictures that show you**
- **Written word describes (still visual)**
  - **Notes**
  - **Journaling**
- **Theatre (act out – to show you)**



# People are not comfortable with verbal exchanges



- And they may have limited use of words to speak
- People tend to “Take the Fifth” (when talking to others) (“ I don’t know”... or other vague responses)
- Example: of an outgoing and creative man who used a **tiny voice with his MOM**

# In order to help people explain their world and experiences

Remember their world is

Concrete (and visual)

- Encourage them to use words that are concrete (& visual)
- ie., Something: They see & touch in their immediate world
- To explain their world



# Enhancing verbal Language add concrete & visual words

1. **Patrick's experience:**
2. "I want to quit" (a job he loved at Whole Foods)
3. "I hate that place" ...
4. Why? ..He is upset and can't say..
5. **We need to find a concrete and visual way to tell us.... What happened..**



# Patrick's experience: He is traumatized

- My guess: Something scared him
- **That he cannot verbalize**
- His mother & his job coach accompany him around the store (took some convincing)
- **He is able to point to the back room and show a bruise on his head**
- He is hurt/scared using a big trash compacter

Traumatized (he replays the negative event when he has a reminder)



# Enhancing problem solving

## Concrete & visual solutions



1. His job coach creates a detailed schedule
2. That he can see and touch (for his work day)
3. That keeps him out of the back room (agreed on by his boss)

# Despite expressive limitations, receptive skills are excellent

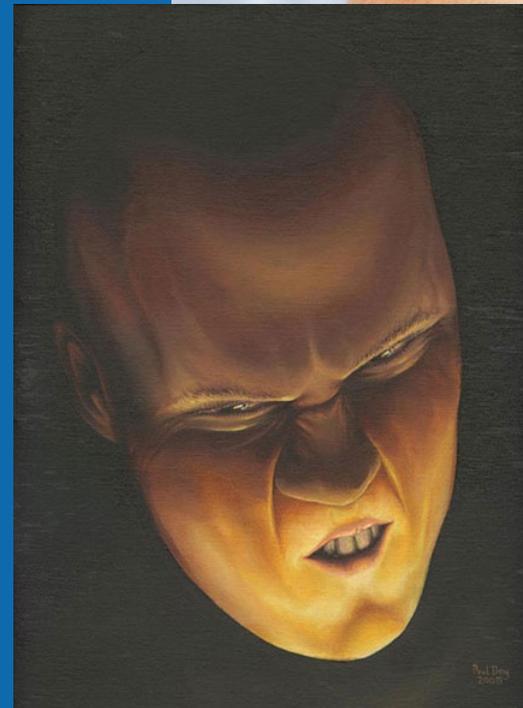
- Many people are very perceptive
- They have excellent intuition
- And an uncanny sensitivity to others (especially loved ones)





# Sensitivity to others

- People may be too sensitive
- Absorb conflicts, and stress from others
- 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

# They are also very sensitivity to you

- If you come on a little too strong they may shut down & shut you out
- Better to be **patient**
- Let them USE concrete & visual to explain their concerns
- For example Patrick:
  - Would not have gone back to his job
  - If his family and behaviorist were not patient and gentle with him &
  - Focused on visual and concrete



# Despite 25 Years of Papers, Books and Presentations on the Positive Nature of Self Talk

- Concern and controversy persists parents/ professionals)
- 2 major reasons
  1. For teens & adults: Self talk is not acceptable in public
  2. It can also be alarming - dramatic *even in a private space*
    - Includes fantasy play and imagined others



# Self Talk is revered in Child Development: Gives ALL children a needed boost when learning a new task; Basis of our mental thoughts

- 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 we also self talk we just keep it under our breath (inaudible muttering)
- **We do this when we face a challenge**



# 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. They may view this as a private space



# Self Talk: Viewed as a Social Skill Issue

- Just like any other social skill issue
- “Hugging, “M\_\_\_”
- Nothing wrong with it just....
- When, where and with whom
- Learning process over time
- Try to confine to private space
- Or learn “Inaudible muttering”



# Self talk can be a Spectacularly dramatic scene

- “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**



# How does Self Talk relate to concrete & visual thinking?

Again: Their world is Concrete & Visual

1. Self talk allows them to capture (superb visual memory) and bring in the raw (concrete) material from their lives
2. Into their personal “self talk” lab
3. To see, process and to try to make sense of it in their personal lab
4. Especially if they don't understand it or US



# Self Talk as a private theatre/lab



- Offers a window on peoples world
- A Change in tone, more anger or self criticism
- Gives us a way to identify a stressor or a scene from their lives
- That they cannot easily verbalize
- But can act out in their private theatre

People with DS have a reputation for being

- **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



# Benefits

- Careful with their appearance and grooming
- “Meticulous”
- Social benefits, **Public Relations (PR)**



# Grooves & Free Time Activity

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

- Like 'Yoga'
- Only cheaper



# 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



Another very effective way:  
'Reset' stuck grooves



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

# Visual and Grooves combine



# People with DS have exceptional visual memories

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



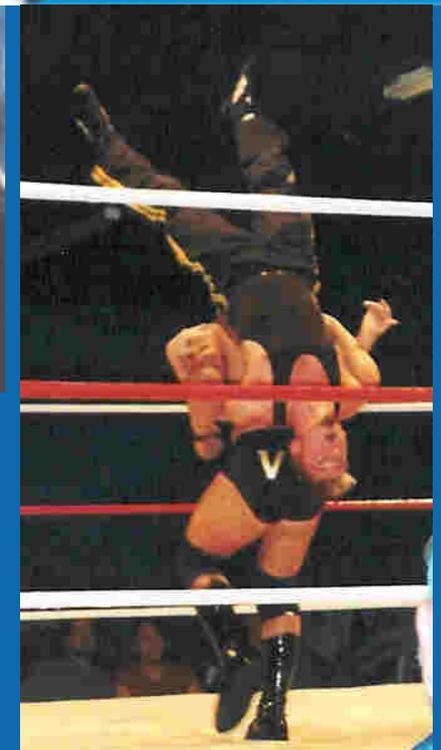
# Visual-spatial memory is superb

- Orientation to space is excellent
- Memory for directions is also excellent



# Movies & Television

- Visual images from movies and TV may be taken in “whole”
- And replayed over and over



# 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



# “In the moment” memory response may be a problem



- People may replay a traumatic memory over and over
- Such as when there is a major loss,
- More susceptible to PTSD
- Examples: ‘Parking lot’
- Patrick



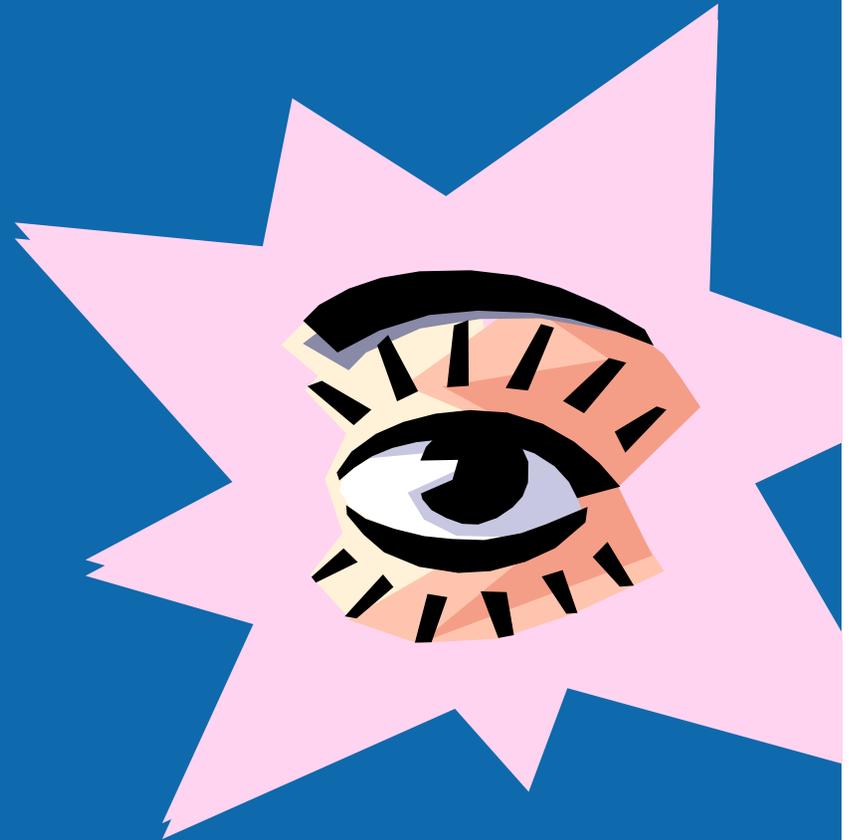
# Using unique memory skills to solve problems

- Memories of positive experiences with family & friends
- In the form of pictures, home movies etc
- May be substituted for negative memories



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



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

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



# How to enhance health and well being: Physical and nutritional health:



- Take advantage of these 2 attributes **visual** and the **groove**
- **Visual:** People love checklists and calendars
- **Groove:** People will have habits; **Why not good ones?**

# Visual Images Can Be Designed to Fit Problem: “Oppositional”

For example: Susan 16- year old having a problem (any age)

- Daily living tasks
- Battle for independence goes haywire
- The harder others try to help her the less she does

# Susan's Schedule



- \_\_\_\_\_ Get up on time



- \_\_\_\_\_ Take a shower



- \_\_\_\_\_ Get dressed



- \_\_\_\_\_ Breakfast



- \_\_\_\_\_ Brush teeth



- \_\_\_\_\_ Get on van



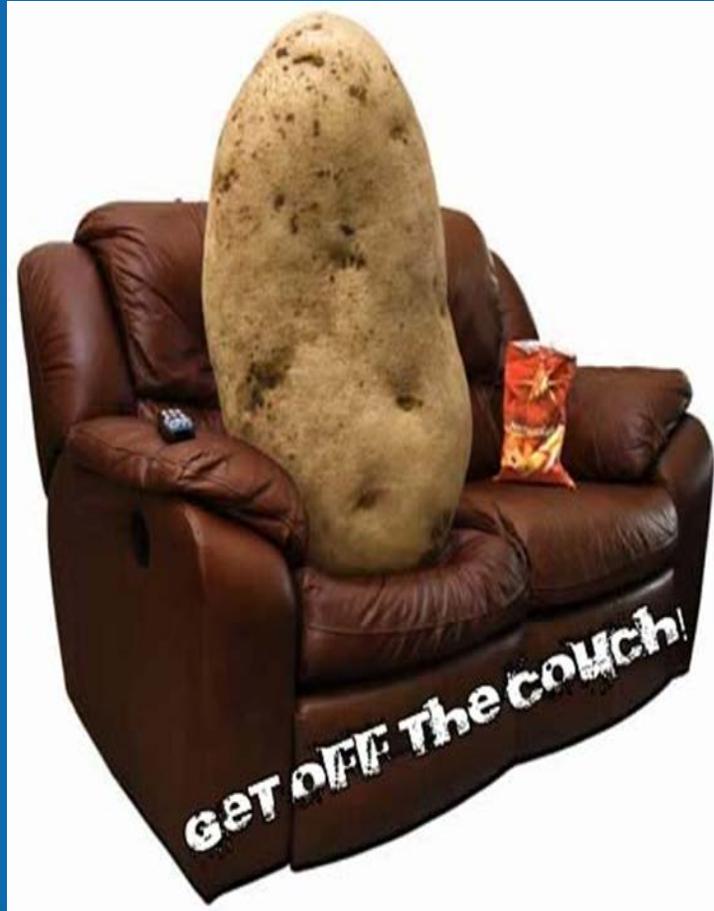
- \_\_\_\_\_ Do all for

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

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



# 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:

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# Problems: Bad eating habits

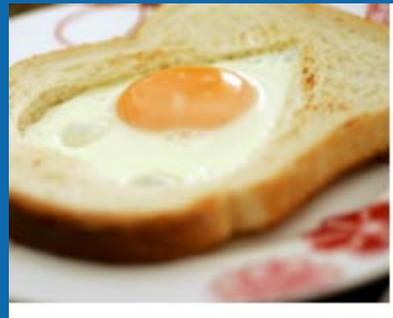
- May be particularly difficult habit to change



# Lists & pictures are very powerful

## Breakfast

- one egg
- one toast
- Cereal
- Juice



# Grooves create safe, consistent patterns that people rely on ( to protect and guide)

Routines for every aspect of every day:

- Home - Daily living skills
- Worksite – tasks
- Recreation activities
- Transport back and forth



Patterns & routines that people can rely on.... but

# Grooves create safe patterns and structures ( to protect and guide)

*What happens when the pattern changes or fails?*

- Reliance on concrete does not work
- Example: A bus people ride has an unexpected detour (construction) & the person with DS panic's and gets off



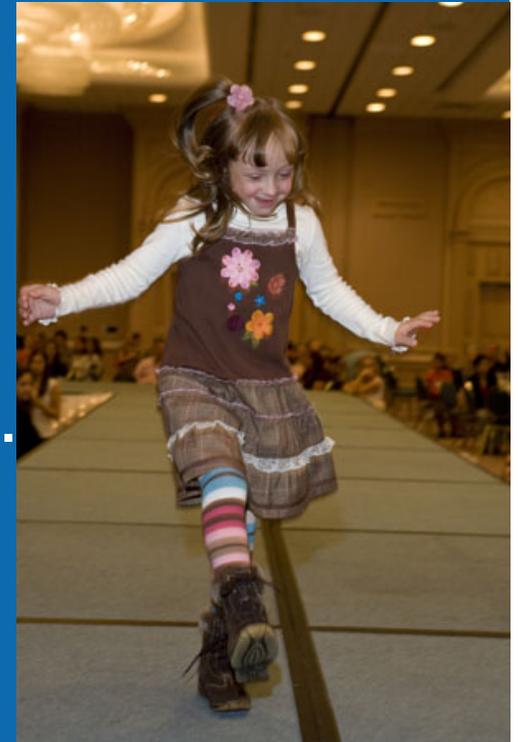
# Why concrete thinking creates challenges?

**Abstract thought:** allows one to see the relationship between things

- Not just the individual (concrete) case.
- Allows one to see other ways to deal with a problem or situation.

Examples: Bus route (changes)

- Or when safety training in groups, doesn't transfer to day to day life in community
- What to do?: We can use other characteristics
- Visual memory & grooves



## Use of strengths: to Change a unproductive pattern



- Analogy: Jet pilots who learn to over-ride panic when their plane is in trouble
- **By training over and over to do the right thing...**
- **Role play (the right thing) &**
- **Practice in community**
- **(Which then) Establish groves**
- **Back up the routine with a list on paper , ipad or cell phone**

# What you can do: Rely on strengths Grooves (concrete) and Visual

## Multi-step process

- Role play to build a repertoire (class) of appropriate behavior
- But this may not be enough to transfer
- **It need to be practiced in the community**
- “Teachable moments” intervening on the spot whenever and wherever the need occurs



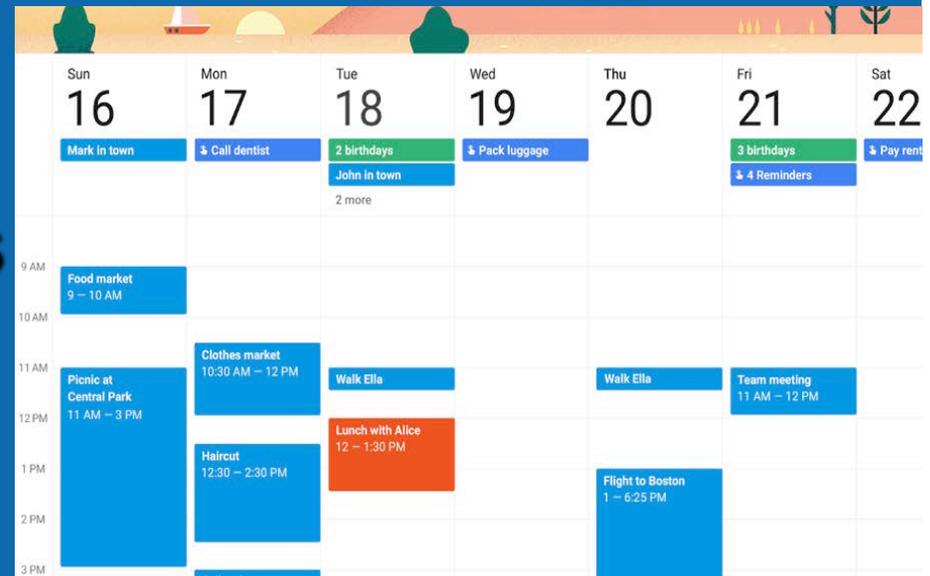
# Time may be too abstract for people with DS

- People get real time: (never miss shows, dinner etc)
- If you put something on a calendar They NEVER Forget
- What to do (use 'real time' – concrete visual)
- For example: Use clock hands for a break time not “fifteen minutes” etc
- Use calendar to change a time or put something on a calendar



# 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 plan and predict



## Great confusion when people talk in present tense about past (or future)

- Example: Yearly meeting “I was beaten”; Very upsetting to staff
- **Communication major irritation @ time**
- Repetitious questions may result “When do we go to Grandmothers” over and over
- **What you can do: Use strength**
- Use a calendar (you may choose to not talk but point)
- **Timing when to put an event is important may greatly minimize over focus and rumination**

# Humor & concrete thought

- Many have a wonderful sense of humor

Humor is often a big part of being socially skilled:

For example:

- Playful teasing in a relationship
- Repeating favorite jokes with favorite people



# Humor

- Visual humor is big in the world of DS



# Humor can be a problem

- Humor can be too easily misinterpreted
- As ‘laughing at me’
- Especially when the jokes are too abstract
- Or it can be seen as a criticism or belittling
- When the humor comes from people who are less familiar



# Solve this problem

- Be mindful of humor as tricky
- Try not to use jokes that are too abstract
- Sometime too a reassurance that this not about the person with DS can help



# the benefits of concrete thinking and behaving

- People with DS are “concrete”, but that also means practical..
- Down to earth, grounded...
- Live in the here and now
- Huge benefits (health and well being) from this...
- A key part and focus of all manner of spiritual practices (meditation, yoga, prayer)

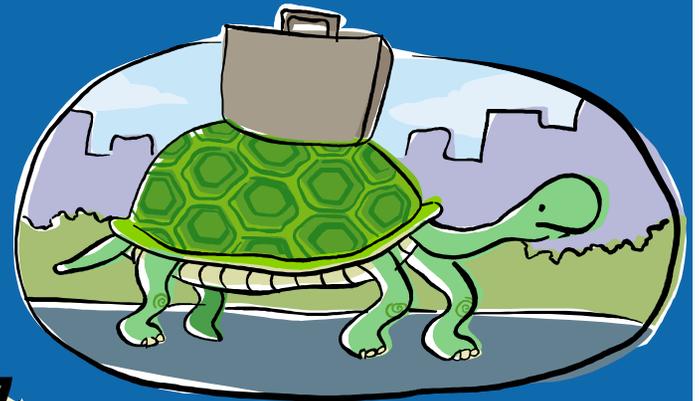


# “The Pace”

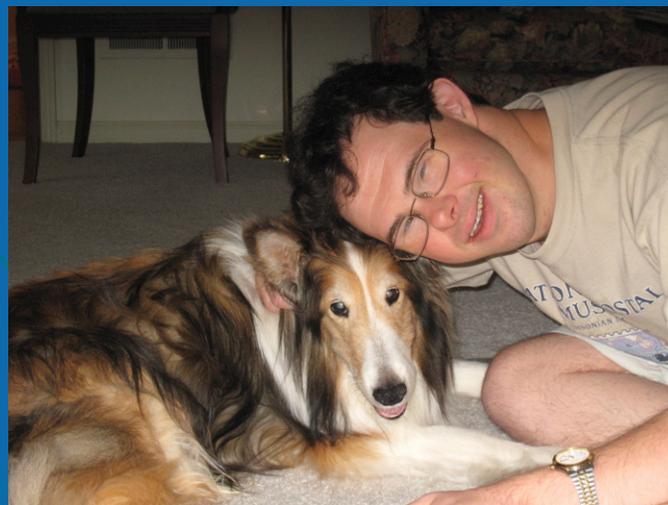
- People with Down syndrome have a reputation for having two speeds:

**SLOW**

and **SLOWER**



# We can learn so from how they live



# 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**”



# Most important benefit of concrete thinking

- It helps us to avoid pursuit of an abstract idea that may limit and or even hurt us
- For example: Over focusing on succeeding or “keeping up with the Jones”
- Results in a sacrifice of time with family and friends-
- Keeping us from “what really matters” (death bed admission)





GLOBAL  
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# Conflicts of Power and Control

Bryn Gelaro, LSW  
Director of Adult Initiatives & Special Projects  
Global Down Syndrome Foundation

*“Individuals have wills and purpose of their own and are not fitted to play a passive part in the world.”—Mary Richmond*

# Conflicts of Power and Control

- What causes them?
- How do these conflicts manifest in the behavior of teens and adults with Down syndrome?
- What are some tools to prevent these “battles of the wills?”
- What is person centered planning and how can it promote autonomy and self-determination?



# Conflicts of Power and Control



- Commonly emerges later than typical peers (Late 20s to 30s)
- Changing sense-of-self
- Post high school transition period
- Siblings and peers transitioning
- Siblings and peers hitting “milestones”
- Adult may feel stagnant in comparison

# Conflicts of Power and Control

## Remember!

- Adults with Down syndrome have dreams and aspirations
- Key to their self-esteem and feelings of competency
- But they are often told what to do and when to do it All. Day. Long.
- Even choices are “given” to them by someone else



Growing sense of independence and desire for control

**TYPICAL**



Prolonged & active parental/ caregiver involvement

**NOT TYPICAL** (In Western culture)

# How do we exercise power in a way that undermines an adult's sense of control?

## Concrete

- Manage schedule
- Do things for them (including speak for them)
- Oversee social interactions
- Control resources (food, money, shelter etc.)

## Conceptual

- Dictate what is good and appropriate
- Shape values and norms
- Make assumptions and biases about the adult's capacities and abilities

# Three common ways conflicts of power and control manifest in behavior:

1. Defiance and Opposition
2. Regulating Pace
3. Self-Talk



# 1) Defiance and Opposition



- Example: A 35 year old woman with Down syndrome in a group apartment
- Outgoing and engaged in activities
- Very controlling and bossy roommate-- Dominates space.
- Suddenly becomes withdrawn and says “no” to everything
- Family thinks it is depression-Diagnosed and given meds
- Actually-she was experiencing extreme loss of control and powerlessness. Saying no and refusing was her grasping for control in any way possible

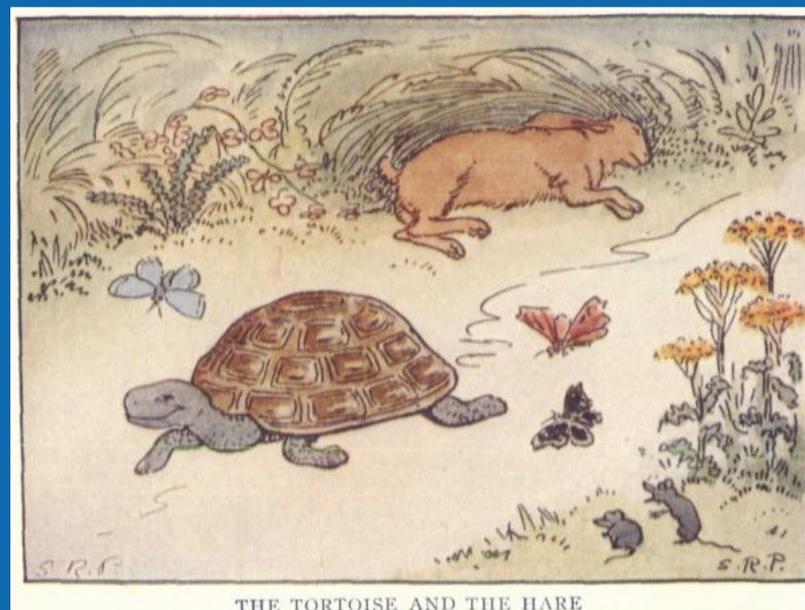
# 1) Defiance and Opposition (Continued)

- Their way of “drawing a line in the sand”
- Not just being “stubborn”
- Not specific to chores or work
- Even things they enjoy doing when constantly pushed and forced no longer become enjoyable
  - Ex: Dancing, bowling, sports



## 2) Regulating Pace

- When feel like their sense of self-direction is being infringed upon, the thing they can manage is the speed at which they complete the tasks
- “Obsessive Slowness”
- Rigid behavioral grooves can develop as a way to maintain a sense of order and control
  - Can become stuck!!!



# 3) Self-Talk

- Quality of the self-talk changes
- Frequency of self talk increases
- More absorbed and harder to redirect



# Self-Talk Continued...

- Scenarios revolve around bossing others around, directing a scene, playing the bully/teacher/parent
  - Looking for things to control and exercise autonomy
  - Examples: “You can’t tell me what to do.”
  - “I’m the boss.”
  - “Listen to me!”



# Strategies to empower adults and reduce power struggles:



- Self-Determination
  - Acting *with* instead of *for*
  - Allowing them to make mistakes
- Shift responsibility to them as much as possible:
  - Set watch reminders
  - Use wall calendar
  - Incorporate peer supports/ peer mentors
- Verbalize & praise progression and change
- The Independence Myth

# Person Centered Planning

- Person Centered Planning - A “process-oriented approach” that considers the desires, goals, dreams of the person with a disability first and foremost- Cornell Employment & Disability Institute
- Special consideration for the person’s built-in supports, their environment, and their on-board skills and strengths
- NOT include taking a person and fitting them into an agency or service
- Requires continual self-reflection, flexibility, creativity

# Person Centered Planning

- Example: 38 y/o man living at home
- Become completely stuck in self-talk about brother and parents had difficulty reaching him
- Wanted to move out—not in the budget and parents said not capable because he needed supports with medication
- Maybe they were correct—totally independent living was not a good fit
- They planned how to make the basement his apartment
- Recruited brother to present idea
- Very successful



# Additional Resources...

- Global Down Syndrome Foundation Education Series
- Cornell University, Person Centered Planning Education Website
- SupportedDecisionMaking.org
- The Arc



# THANK YOU!



Dr. Dennis McGuire