**Mental wellness and good health in older adults with Down syndrome**

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**Multidisciplinary Clinic: Health & Mental Wellness**

- Since the Clinic opened in Jan 1992
- We have seen over 5500 people
- "One stop shop" - primary care
- Mental health care (1/3 of patients)

**Two Reasons for Our Success**

1. Multi-disciplinary:
   Far more successful in identifying and treating problems
2. Work closely with families
   - Repeatedly told us: "Behavioral attributes"

**Attributes Key to everything; Strength or weakness, teen – late adult**

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

**Behavioral Attributes : Strength or weakness**

1. Strength
   - Receptive language
   - Self talk (Private space)
   - Social skills
     - {Sensitive/responsive} Serves in so many positive ways
       - Family, friends, bosses
   
   Weakness

2. Expressive language
   - A social skill problem (outside)
   - **Highly sensitive to negative feelings and emotions

**KEY Behavioral attributes : Strength or weakness**

1. Strength
   - Groove (rely on set patterns routines)
   - Visual strength (show)
   - Photographic-like memory
   - **Replay memories, movies etc as if occurring now (original feelings)

2. Weakness
They are affected by others emotions (even if not directed at them)
If they lose interest in things they love (eg., food, music, movies, dancing)
Repeatedly told us:
Receptive language
Key to everything:
Visual Cues
Patience Patience Patience
Who may also know a good psychiatrist
Look to good local agency serving people with ID
They tend to replay memories over and over: and be overcome with emotions each
When done, divert to something else
People may grieve differently (because of photographic visual memory)
of skills in the person themselves
Social
And not mom and dad, or staff
primary care
Get a physical before going to a psychiatrist!
Self Talk
Special recreation
“Expressive language
Predators > target the Innocent & uninformed
Give control back to person with DS (whenever possible)
Pride (Hygiene)
Groove: People will have habits; Why not good ones?
But
If continuous: look for triggers (what sets off)
Special Olympics
Most
Many have social life far greater than you and I

We all have the right to our dreams
Let it be
What to do with the Dream?


Some caregivers are also concerned with people who have wilder fantasies




Just like for us: Some form of the dream can become a reality for a few




Dreams: Some caregivers are concerned with people with DS who are

The Dreams of people with Down syndrome
We can learn so much from people with Down syndrome
1. Risk of phobia’s and PTSD
   2. Preferred method of escape
   {Bored or stressed}

Key Issue for older Adults with DS. Loss of a loved one: How does it relate to Attributes
   o People may grieve differently (because of photographic visual memory)
   o They tend to replay memories over and over: and be overcome with emotions each time
   o But...it is “in the moment” not long lasting
   o When done, divert to something else
   o If continuous: look for triggers (what sets off)

Key issues for older adults with DS? Independence??
Mid to late adult years: Fight for independence that continues
   ❖ Due to delay in development
   ❖ Absence of true adult independence for many adults
   ❖ May not be recognized by others as a “teen-like push for independence”

How to encourage independence and emotional well being for older adults:
   o Take advantage of 2 of the attributes visual and the groove
   o Visual: People love checklists and calendars
      • Groove: People will have habits; Why not good ones?

Visual images can be designed to fit problem: “Oppositional adult”
For example:
   ● Battle for independence over the wrong things
   ● Daily living tasks

Classic example: Visual lists can be especially helpful to encourage independence
   ● “The list” tells ‘me’ what to do
   ● And not mom and dad, or staff

People with DS no matter what age/stage of life (like anyone else):
   ■ Requires some “hands on” success in day to day life
   ■ They NEED to do for self

Promoting independence & competence: May be difficult
   ■ Because there is a wide range of skills between different people with DS

More Importantly there is an Uneven-ness of skills in the person themselves
   ■ Many strengths: good social skills; exceptional memory
   ■ There are also limitations of skill and maturity in specific areas
Promoting competence: May be difficult! (Because of the complexity of people with DS)
- Encourage greatest skill & independence
- But recognize and shore up areas of true weakness or need

Example of scheduling problem:
- People are very independent
- Need help with arranging for social and recreation activities
- Otherwise TV is their only friend or activity
- Withdrawn and depressed

Does social life and activities end in older adult years?
- Many have social life far greater than you and I
- Special Olympics
- Special recreation
- Many continue to win gold medals in their 40’s 50’s

How to get son or daughter to:

Put activities
- On a calendar
  And they will remind you

Lists are also very powerful: FOOD
- Breakfast
  __ one egg
  __ one toast
  __ Cereal
  __ Juice

Create mental wellness: Remember ‘Grooves’ are “onboard equipment”
- Introduce change carefully (whenever possible)
- Patience Patience Patience
- Don’t push or rush people
- Give control back to person with DS (whenever possible)

How to create an environment where my adult with DS will have mental wellness?
- Because people with DS are highly sensitivity to feelings and emotions in others
- They are affected by others emotions (even if not directed at them)
- Find environments that are positive

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)
When I need to consult with a mental health professional?
- Most will not have a multi-disciplinary clinic
- You can often patch together a team
  - Look to good local agency serving people with ID’s & learn the name of an experienced social worker/ psychologist
  - Who may also know a good psychiatrist
  - Get a physical before going to a psychiatrist!
  - Behaviorists can help (Have they raised their own kids?)

2. “SEX”

“Sex Ed” is so much more than “Sex”
- Pride (Hygiene)
- Learning appropriate boundaries
- Predators > target the Innocent & uninformed

3. Finally: “The Pace”

We can learn so much from people with Down syndrome

The Dreams of people with Down syndrome
- Like us they tend to dream of doing what others do, college, marriage, to live independently etc

Dreams: Some caregivers are concerned with people with DS who are described as:
- “Story tellers, fibbers & dreamers” who are “out of touch with reality”
- Who talk of marriages, careers and other “fantasies”
- That will simply not happen (for most)

The Dream, In fact:
- We all have dreams
- Daniel J. Levinson: “Seasons of a Mans Life”

The Dream
- We rarely attain our dreams
- We really don’t need to
- The dreams are still very important nonetheless
- They give us a goal, direction and inspiration

Just like for us: Some form of the dream can become a reality for a few

For others: Unlimited outlets
- Star
- Musician
- Athlete

In daily life
- Employee
Teacher/advocate lecturer
- Child Care
- That can make people happy & Fulfilled

37 Some caregivers are also concerned with people who have wilder fantasies
- Who really get into characters
- Who seem to believe movie characters are real
- Who want to meet or even marry movie characters

38 What to do with the Dream?

Unless it interferes in day to day life
Let it be

We all have the right to our dreams