Behavior and Mental Health:
The Missing Piece in the Wellness Puzzle for Adults with Down Syndrome

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Scary Disclaimer:

- I am not a medical doctor and none of this is medical advice. Please consult your doctor for that!

- I also do not know your individual person with Down syndrome! You know them best!

- If anything here resonates, consider consulting your doctor or behavioral health expert!
My Background

- B.S. Psychology The Pennsylvania State University
- Direct care provider in an adult group home—Defining experience in my life!
- Completed AM (MSW equivalent) University of Chicago
  - Masters Field Work completed at Adult Down Syndrome Center in Chicago
- Consulted for Global 2 years prior to current position as Director of Adult Initiatives and Special Projects
- Licensed Social Worker
  - Dr. Dennis McGuire, LCSW clinical supervisor and mentor
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
What do we “know” about mental and behavioral health for adults with Down syndrome?

1. Interaction and overlap between physical health and mental health cannot be underestimated
   ❖ Example: AD, Hypothyrodism and Depression

2. Lack of professionals familiar with adults with Down syndrome and lots of misinformation in out there

3. People with Down syndrome might not meet diagnostic standards in all cases and may present signs and symptoms differently

4. Behavior is communication and provides crucial insight
Need more literature and evidence addressing clinical concerns of adults with Down syndrome!²

❖ **Evidence-Based:** minority populations not well represented historically
  ❖ Including people with disabilities

❖ **This is part of what drew me to the field**
  ❖ Meant there was a lot of work needing to be done
  ❖ Having no “guidebook” for what works treatment and intervention wise can be difficult
  ❖ Drawn to the opportunity to be creative therapeutically—the quality of the relationship (“therapeutic alliance”) correlates with successful outcomes more so than the type of EBTpsychotherapy³ (↩ Made me feel brave!)
Misconception about moods & emotions
  - ALWAYS HAPPY!

Mental health has its own history of stigma
  - “It’s just Down syndrome”

Don’t always fit into neat diagnostic boxes
  - Example: Depression Criteria

Some mental health changes commonly express themselves in late teen to early 20s
  - Not always the case that adults with Down syndrome had avg. lifespans into the 60s like today!
Behaviors is communication!
- Especially the case depending on someone’s verbal communication skills

The dreaded B word: “They are having ‘behaviors’”
- We are all having behaviors all the time
- I choose to focus on interfering, harmful, changing behaviors

Working to depathologize behavior
We all have our “Strengths and Stretches” (credit Shelley Moore) and many behaviors can be both!

Common behavioral characteristics as per Dr. Dennis McGuire, LCSW:

- Sensitivity to others
  - High degree of Emotional Intelligence
- Self talk
- Concrete thinking – Literal
- Responsive to visuals/ Visual Memory
- In the moment

These on board strengths can be so useful when working with behavior or mental health
❖ Young woman recently moved into semi-independent apartment
  ❖ Family surprising her with weekend visits---very disrupting!
  ❖ Difficulty adjusting when brought back—different expectations!

❖ She really loved her paper calendars for marking TV shows

❖ Use calendars (using on board visual skills) to plan and prepare!
  ❖ One at apartment showing visits, one at family’s showing returns
  ❖ Predictable, scheduled, routine, has a degree of control, knows what to expect
The question I am asked most often:

“Is it ‘normal’ if....?” Or “Should I be concerned if...?”

It depends!
Not as simple as separating these out!
- Can directly impact the other
- Incomplete picture without the other

Ex: Sleep hygiene

Ex: Having a procedure and behavior changes afterward
What am I looking for when I meet a patient?

- What is going on and is it disrupting or negatively impacting the life of the person with Down syndrome?
  - Is it Functional? Is it working for them? Is it helping them cope?
  - Ex: Self-talk

- Does the person with Down syndrome identify this as something they want to change or are willing to work on?
  - This is what ensures we are supporting people with Down syndrome and not forcing compliance
  - When am I willing to overlook this: threats to safety, health, wellbeing or interfering with ability to be successful
When and where is it happening?
- If it is happening in certain places and not in other places, certain times, certain people—pay attention!

What are changes in environment, routine, people in their life?

Has this behavior changed, morphed, disappeared, reappeared, increased, intensified, etc…
Common times when behavioral & mental health comes up

- **Underlying medical health concern**—Always make sure check with a doctor

- **Periods of transition or stagnation**
  - End of high school, starting new program or job, alterations in schedule
  - Puberty!

- **Loss/Grief**
  - Death of loved one, breakup, roommate moving out
  - Complicated grief (ex: Parent illness/decline)

- **Changes in environment**
  - Feeling powerless or lack of control (could apply to most of these categories!)

- **Other experienced traumas…..**
Remember: Trauma is about the person’s experience of the event, not the event itself.

What does this mean?

For adults with Down syndrome there may be an increased susceptibility to trauma due to:

- Sensitivity to environment and others
- Highly developed visual memory skills leads to increased intrusion of flashbacks
- Inability to communicate and integrate a narrative
Example: Young adult working at a restaurant and the fire alarm goes off

- Sensory/energy overload → Stress response → terrified to go back to work
  - Maybe triggered by fire trucks
  - Restaurants

- If a family or provider doesn’t know this happened or doesn’t understand the event itself is not a trauma, the adult may suddenly be labeled: defiant, oppositional, paranoid
Common precursors for mental health concerns or behavior changes are not much different from typical peers, but may differ in:

- Timeline
- Attention it receives from others
- Ability to communicate or identify issue
- Presentation
- Availability of experienced professionals to support
Death of a loved one can be hugely impactful for any one
- Sadness, disbelief, complicated feelings, sudden or not sudden, unanswered questions – same reasons as anyone else!
- What could make a death especially impactful for a person with Down syndrome?

There could be a failure to discuss death with person with Down syndrome
- Misconception they won’t understand or will be too frightened

Also, death is very abstract and different families have different beliefs and practices around death
- Use their strengths: Concrete (“dead” not lost), visual books, pictures, and reminders (photographic memory), talking/journaling
Adults with Down syndrome can experience a wide range of emotions, behaviors and mental illnesses. Depression, Anxiety, Self Injury, Phobias, Obsessive Slowness.

Prevalence estimates depend on criteria used for diagnosis (clinical, DSM, Self-report).

30%--Estimate given in the 2001 Health Care Management for Adults with Down syndrome (Smith, D. 2001)

Note about Psychosis - Blurring reality, fantasy and self talk can look like hallucinations or delusions but can be benign and cognitively appropriate.
Not possible to pinpoint exact causes and widely recognized that behavior is multi-determined

- Equifinality

A single experience usually not predict behavioral change or mental health concern

Everyone has different degrees of resiliency and protective factors

- Fostering mental wellness throughout life as a way to protect against future issues and better future outcomes

Example of protective factors adults w/learning disabilities:

- Families are cohesive, flexible, affective supports
- Self-Esteem and self-awareness
- Supportive responsive environment
“Attentive Conductors”

❖ All credit and accolades to Jeff Levy, LCSW, CTRS
  ❖ https://liveoakchicago.com/describing-psychotherapy-metaphors/

❖ The metaphor of the train track

❖ Derailing events
  ❖ Traumas, illness, hurt, loss

❖ Attentive conductors
  ❖ Parents, siblings, teachers, friends, support staff, professionals
  ❖ Attuned and aware of the person
  ❖ Notice derailments and get them back on track!

❖ Be an attentive conductor for the adults with Down syndrome in your life!
Gives them the tools to succeed
  - Encourages them doing for themselves

Uses their keen visual memory skills
  - Makes the abstract concrete
  - Can use for time management, learning steps, mastering skill, grounding them, preparing for change, transitioning, continuity—memory

Have to be relevant to the adult!
  - Include them in creating
  - Use things they already use or do
  - Don’t use pictures if they don’t like pictures

Use real pictures of the person themselves!


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