GLOBAL DOWN SYNDROME FOUNDATION®

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**

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

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 [1]
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 EBTpsychotherapy[3] (←Made me feel brave!)

Why has this topic been overlooked?

- **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[4]
- **Some mental health changes commonly expresses 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

- **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**

Overview of common behavioral characteristics of people with Down syndrome

- **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 <u>working with</u> behavior or mental health**

Example: Working WITH on board strengths

- **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!

Mental Health and Medical Health

- **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

What am I looking for when I meet a patient?

- **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…..**

A note about 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: Traumatic Experience

- **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 times when behavioral & mental health comes up *(cont..)*

- **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

Example: Death/Loss/Grief

- **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

Mental Health Issues

- **Adults with Down syndrome can experience a wide range of emotions, behaviors and mental illnesses[4]**
  - 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 approprite[5]

Resiliency and Protective Factors

- **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[6]**:
  - Families are cohesive, flexible, affective supports
  - Self-Esteem and self-awareness
  - Supportive responsive environment

“Attentive Conductors”[7]

- **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!**

Visual Supports and Visual Cues

- **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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