



GLOBAL

DOWN SYNDROME FOUNDATION®

Making the Most of a Behavioral Health Consult 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 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!
- ❖ All stories included are fictional case examples and do not represent actual individuals



My Background

- ❖ **B.S. Psychology The Pennsylvania State University**
- ❖ **Direct care provider in an adult group home**
- ❖ **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 past 2 years**
- ❖ **Licensed Social Worker**



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 - Significantly improve the lives of people with Down syndrome through **Research, Medical Care, Education & Advocacy**:

Global & Affiliates



- ❖ **Global**: fundraising, outreach, advocacy for Global and four Global Affiliates.
- ❖ **Sie Center**: over 1,700 unique patients from 28 states and 10 countries with 8 clinics (2 first in-kind)
- ❖ **Crnic Institute**: over 200 scientists working to elongate life and improve health outcomes for people with Down syndrome.
- ❖ **RMADC**: Leukine and other important breakthroughs.
- ❖ **Adult Clinic**: Pilot phase. Goal is to have a world-class feeder for the Sie Center.

Welcome!

- ❖ Today we will cover:
 - ❖ What is Behavioral Health?
 - What impacts Behavioral Health?
 - What are the unique considerations for adult with Down syndrome
 - What can you expect in a behavioral health appointment or consult?
 - Why/when/how to do it?



There is a lack of literature and evidence addressing clinical concerns of adults with Down syndrome!

❖ Evidence-Based Practice

❖ People with Down syndrome are not well represented

❖ This is part of what drew me to the field



What do we “know” about mental and behavioral health for adults with Down syndrome?

- 1. Interaction between physical health and mental health cannot be underestimated**
 - ❖ Example: AD, Hypothyroidism 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**

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
- ❖ **Some mental health changes commonly expresses themselves in late teen to early 20s**

What are the benefits of a behavior consult with a DS professional?

- ❖ **Limited idea about what is behavioral/mental health**
- ❖ **What if an adult is doing well?**
 - ❖ What does “doing well” look like?
- ❖ **Establish a baseline**
- ❖ **Proper behavioral health attention can elevate interfering behaviors, promote overall wellbeing, can help identify or rule out other concerns**

Mental Health and Medical Health

- ❖ Not as simple as separating these out!
- ❖ Ex: Having a procedure and behavior changes afterward
- ❖ Ex: Sleep hygiene



Behaviors

- ❖ Behaviors is communication!
 - ❖ Especially the case depending on someone's verbal communication skills
- ❖ Working to depathologize behavior
- ❖ The dreaded B word: “They are having ‘*behaviors*’ ”



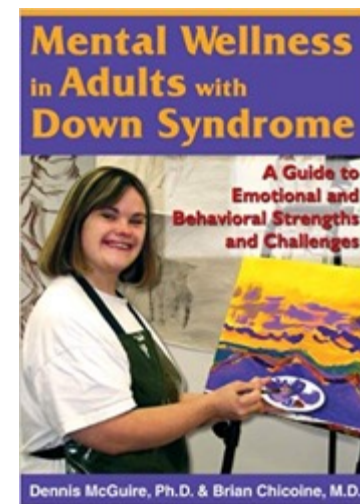
The question I am asked most often:

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

It depends!

Overview of common behavioral characteristics of people with Down syndrome

- ❖ We all have our “Strengths and Stretches” and many behaviors can be both! (*credit Shelley Moore*)
- ❖ Common behavioral characteristics as per Dr. Dennis McGuire:
 - ❖ Sensitivity to others
 - ❖ Self talk
 - ❖ Concrete thinking
 - ❖ Photographic Visual Memory
 - ❖ In the moment
- ❖ These on-board strengths can be so useful when working with behavior or mental health



Common Behavioral Characteristics

❖ How can it be both strength and weakness?

❖ Example: “Gooves”-Dr Mcguire

❖ Fit Bit

❖ “Don’t talk to Strangers”

❖ Why is this a good thing?

❖ Why am I reviewing these?



Working “with”...

- ❖ Core principle of Person-Centered supports
- ❖ Working “with” as opposed to “against”

With	Against
Redirecting Channeling Supporting	Challenging Confronting Opposing



Preparing an Adult with Down syndrome for a behavioral consult

❖ Who:

- ❖ Explain it's not like a doctor like they see when they are sick

❖ What:

- ❖ Confidential, honest, safe, don't have to talk to them if you don't want to

❖ Why:

- ❖ They are not in trouble
- ❖ Trying to figure out how to make them feel better

❖ How:

- ❖ They will ask you questions about your life, about your feelings

Psychosocial Assessment

Social & Environmental

- Family/Friends
- Living environment
- Community
- Service supports

Functional & Adaptive Skills

- Activities of daily living (bathing, dressing, toileting)
- Communication
- Socialization style
- Money/Time

Psychological

- Behavior
- Mood
- Tolerate stress
- History of mental health concerns & medication
- Change, loss, trauma

Establishing a baseline

- ❖ **What does this mean?**
- ❖ **When could you do this?**
 1. At current moment
 2. When noticing a change
 3. When trying to change or influence a behavior
- ❖ **Especially important for adults with multiple staff/caregiver environments!**

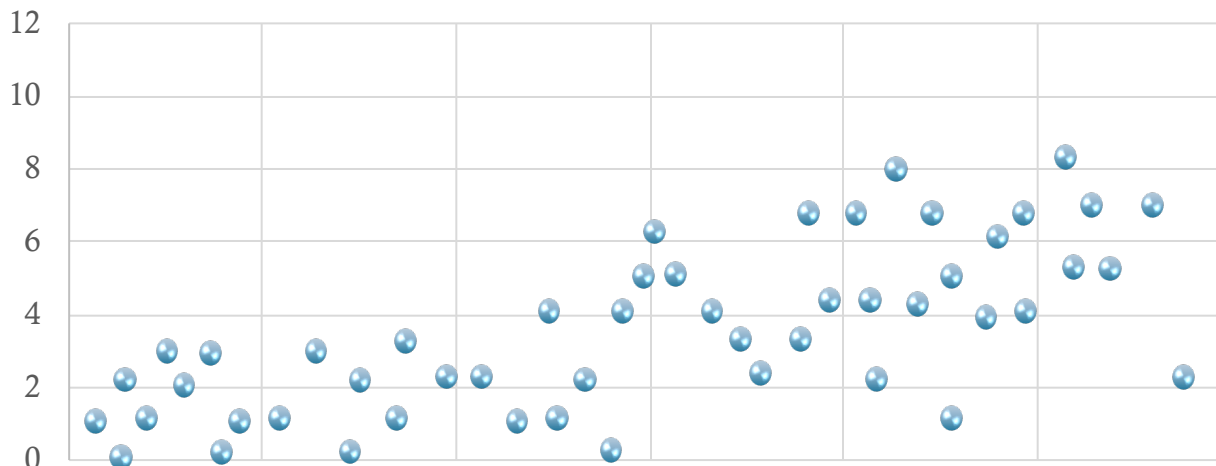
Establishing a behavioral or functional baseline

Ex 1:

January 2017	January 2018	March 2018	August 2018	February 2019
Showers independently	Showers independently	Refusing to shower	Showers semi independently needs hand over hand shampoo	Showers independently

Ex 2:

Verbal Prompts needed to get changed in evenings



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/Greif**
 - ❖ 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...**

Mental Health Issues

- ❖ 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, 2001)
- ❖ **Note about Psychosis**- Blurring reality, fantasy and self talk can look like hallucinations or delusions but can be benign and cognitively appropriate (Dykens et al., 2015)



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?**
 - What is it's Function?
 - 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?**
 - ❖ Person Centered

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...**

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: Death/Loss/Grief

- ❖ **Death of a loved one can be hugely impactful**
 - ❖ Sadness, disbelief, complicated feelings, sudden or not sudden, unanswered questions -same reasons as anyone else!
 - ❖ What could make a death especially “derailing” for a person with Down syndrome?
- ❖ **There is sometimes a failure to discuss death with person with Down syndrome**
- ❖ **Also, death is very abstract and different families have different believes and practices around death**
 - ❖ Use their strengths: Concrete (dead not lost), visual books and reminders (photographic memory), talking/journaling



**And now for some really
great news.....**

Resiliency and Protective Factors

- ❖ **Not always possible to pinpoint exact causes and widely recognized that behavior is multi-determined**
- ❖ **A single experience alone may 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/ID⁶:**
 - ❖ **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
- ❖ 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!**

Tips for finding a behavioral health provider...

- ❖ **Contacting local DS Clinic**
- ❖ **Contacting local DS organization**
- ❖ **People with Down syndrome are excellent judges of character**
- ❖ **Do they need to be Down syndrome experts?**
- ❖ **Red Flags:**
 - ❖ Don't follow your/self-advocates lead
 - ❖ Not include adult with Down syndrome
 - ❖ Not open to learning about Down syndrome
 - ❖ Assume they have the answers
- ❖ ***Medical Care Guidelines for Adults with Down syndrome to provide guidance soon!!!***

THANK YOU!



DOWN SYNDROME GUILD
OF DALLAS

Q + A