



# **HEALTHCARE DISPARITIES IN PATIENTS WITH DEVELOPMENTAL DISABILITIES: LIVE FROM THE TRENCHES**

Felissa P. Goldstein, MD, DFAPA, DFAACAP  
Board Certified Adult, Adolescent and Child Psychiatrist

I AM SPEAKING BASED ON MY PERSONAL AND/OR PROFESSIONAL EXPERIENCES. ALTHOUGH I AM A FACULTY MEMBER AT THE UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE AND EMPLOYED BY NORTON HEALTHCARE, MY OPINIONS AND REMARKS ARE NOT REPRESENTATIVE OF THE UNIVERSITY OF LOUISVILLE OR NORTON HEALTHCARE. I HAVE NO ADDITIONAL DISCLOSURES.



ALL PATIENT EXAMPLES ARE FICTION.  
THEY ARE COMPILED FROM NUMEROUS  
PATIENT, PROVIDER AND CAREGIVER  
EXPERIENCES.





# WHO AM I?

- Board Certified Adult, Adolescent and Child Psychiatrist
- I specialize in working with patients with developmental/ intellectual disabilities
  - Marcus Autism Center 2006-2016
  - Lee Specialty Clinic for 3.5 years 2016-2019
  - Bingham Clinic 2019-present
  - Telehealth clinics for patients with autism spectrum disorder 2006-2016 and 2019-present



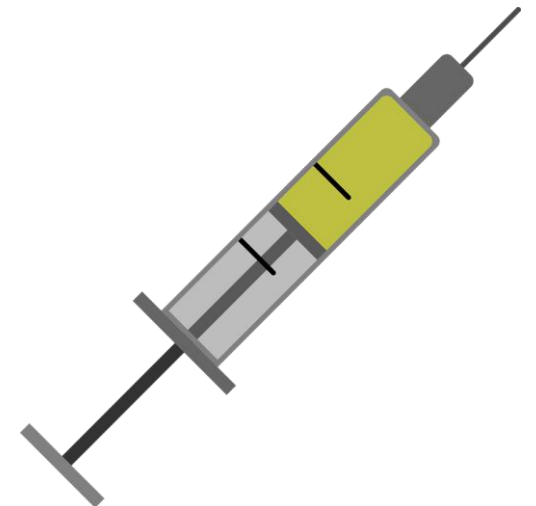
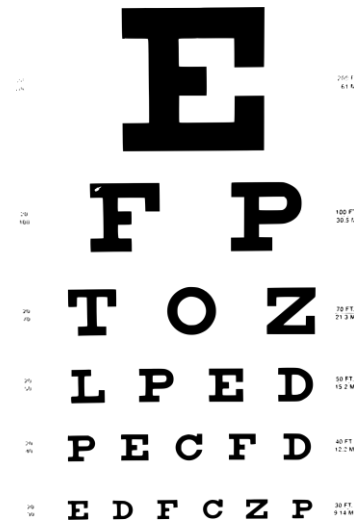
# THE BACKGROUND

- Disability costs in KY are 5.8 Billion per year (ages 18+)
- 25.6 % of people in US have some type of disability and 34.6 % of people in Kentucky have some sort of disability
- American Academy of Developmental Medicine and Dentistry, AMA, and ADA have designated people with developmental disabilities as medically underserved.



# THE BACKGROUND

- People with ID/DD are:
  - socioeconomically disadvantaged
  - Higher rates of certain diseases
  - More deaths than the general population
  - Less likely to have cervical and breast cancer screenings and gynecological visits
  - Fewer dental visits
  - Limited hearing and vision screenings
  - Receive timely vaccines



# “SAM”

- 21-year-old M with Bipolar Disorder and average intelligence
- In midst of manic episode
  - No sleep for 4 days
  - 5000 dollars worth of damage to house when raging
  - Multiple sexual partners
  - Locked self in car with gun to head
- Brought by police to Emergency Room.



# “SAM”

- Outcome:
- Patient is medically cleared
- Sent to EPS for evaluation
- Subsequently admitted to OLOP for hospitalization





## "AMY"

- 21-year female with Bipolar Disorder, IQ of 60, and Down's Syndrome
- No sleep in 7 days
- Eloped from house in middle of night in 30 degree temperatures and found laying in middle of road barefoot 2 miles away
- Stating she wants to die
- Recent history of touching herself and others excessively and inappropriately
- Caused \$5000 worth of damage in house

## “AMY”

- Brought to emergency room by police
- “Medically cleared” in regular ER
- Brought to psychiatric emergency room for evaluation

## “AMY”

- Sent home because: (Choose one or multiple reasons )
  - Patient's IQ means she will not benefit from hospital milieu (unable to participate in groups)
  - Presenting problems are just the behaviors from Down's Syndrome (example of what families are told)
  - Intellectual Disability leads to these types of behaviors
  - No reasons found for behaviors and so discharged home despite caregivers' safety concerns and statements that patient is not acting right
  - State hospital is unable to accept patient due to fear that patient is at high risk of injury from other patients' on unit

# “AMY”

- Patient placed with emergency caregiver
- Remains severely depressed – not talking or eating but is crying and angry
- gives emergency caregiver a concussion when she throws her against a wall
- Patient brought back to ER
- Again sent home saying this is her behaviors and she won't benefit from inpatient admission



## “AMY”

- Caregiver tries to drive patient to outpatient psychiatrist's office – patient opens car door while car is moving and she tries to jump out
- Caregiver calls 911
- Patient brought to ER
- Medically cleared

## "AMY"

- Received three injections of Geodon 60 mg over 24 *hours*
- ER doctor places patient on Risperdal 2 mg BID and discharges patient home after AMY waits 3 days hoping for psychiatric placement somewhere
- Patient has Bipolar Disorder just like other patient but is denied admission to any psychiatric hospital

# REQUESTS FROM THE FIELD

- Patients with Developmental Disabilities and Psychiatric Disorders need psychiatric units that can keep them safe, adjust their medicines and teach coping skills at the appropriate developmental levels
- Psychiatric units that will accept patients with IQs under 70 (especially adults), nonverbal patients or patients that need assistance with ADLS.
- Caregiver training when patients are medically and psychiatrically complex
- Enable systems to admit patients with Developmental Disabilities quickly to hospital to avoid multiple ER visits without any treatment

# WHAT IF IT IS A CHILD? MEET SUSIE

- 8 year -old female with Autism Spectrum and Bipolar Disorders and Intellectual Disability
- Several weeks of depression with:
  - social isolation
  - frequent episodes of crying
  - excessive sleeping
- Manic presently:
  - Inappropriate touching on herself and others,
  - tried to jump off a tall slide at a park to see if she could fly
  - No sleep in 4 days





# WHAT IF IT IS A CHILD? MEET SUSIE

- Brought to ER by ambulance
- Patient is medically cleared in ER
- Admitted to inpatient unit for patients with developmental disabilities and psychiatric disorders

THE MISATTRIBUTION OF PHYSICAL  
SYMPTOMS TO PATIENT'S PREVIOUSLY  
DIAGNOSED MENTAL ILLNESS

# **Diagnostic Overshadowing**



# “JOHN”

- Functioned well in the community- held a part time job
- Mostly nonverbal
- Recently began:
  - Crying intermittently
  - Banging head frequently and often
  - Is asked to take a few days off from work due to new behaviors
- Sees outpatient psychiatrist and is put on new medicine for depression and anxiety



# “JOHN”

- Family and caregiver verify nothing untoward happened recently
- Continues to cry despite medicine change
- Caregiver calls psychiatrist begging for medicine change saying medicine is not working
- Psychiatrist changes medicines again







# “JOHN”

- Patient continues to cry
- Out of desperation, caregiver brings patient to ER
- Patient is examined and found to have bilateral ear infections
- During abdominal examination it is tender and patient cries
- Abdominal x-ray series shows moderate to severe constipation



# REQUESTS FROM THE FIELD

- More thorough education of physicians, allied health personnel, caregivers, and parents that behavioral changes can often be a sign of a physical illness. Do not assume it is psychiatric until after all avenues are pursued.

# MEDICINE EFFECTS

- Patients sedated heavily to be driven “safely” to dr. appointments, arriving unresponsive and requiring ambulance transport to hospital
- Daily sedation to minimize behavior problems or ensure patient sleeps for a long time
- Polypharmacy is the rule instead of the exception
- Doctors prescribe additional medicines without trying to remove medicines.
- Doctors & caregiver are too fearful to deprescribe. (no systems in place to provide additional in-home supports.)



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# LACK OF OR INAPPROPRIATE CARE

- Caregivers and patients asked to leave providers' offices because they scare away other patients
- Doctors refusing to see patients due to behavior or low IQ
- Doctors and caregivers ignore or talk over patient during appointment
- Supported decision making is discouraged
- Others make decisions that are "in the best interest of the patient" without consulting the patient



# REQUESTS FROM THE FIELD

- Physician and allied health professional training to encourage discontinuation of medicines.
- Psychiatrists who can consult with general practitioners, allied health professionals and other prescribers to help with complex patients . ( There was a Model system like this in Massachusetts). Psychiatrists provide a curbside consult to the prescriber . This is especially useful in rural areas where psychiatrists are scarce.
- Training all doctors, nurses and office staff to be sensitive to the needs of patients with developmental disabilities.
- Facilitate legalization of supported decision making and provide training on its appropriate usage.



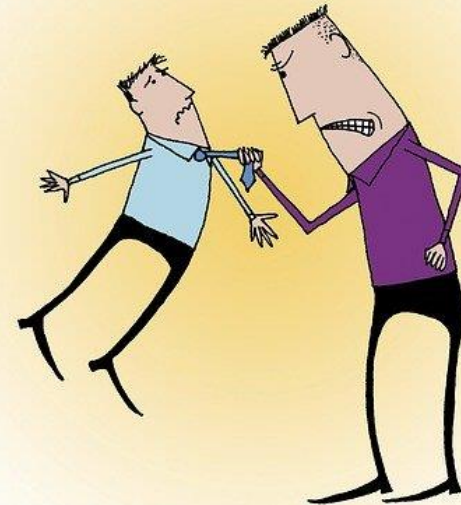


# REQUESTS FROM THE FIELD

- Develop improved in home behavior programs with additional people support so that there is a decrease in the use of medications for behavior management.

# PATIENTS WITH AGGRESSION

- Wait months or years to receive coordinated care that may involve multiple procedures or specialists and sedation (Often requiring high amounts of staff time to arrange)
- May have to be sedated prior to arriving at hospital
- Require a team to get them on an ambulance gurney and then hope that oral medicines received that morning will calm them enough until anesthesia can medicate them for the procedures



# PATIENTS WITH AGGRESSION

- Patients always being taken to the operating room and requiring general anesthesia for all visits because providers don't want to use behavior techniques to help manage behaviors
- Difficult, sometimes impossible to find places that will allow dental procedures in an operating room setting





# REQUESTS FROM THE FIELD

- Encourage facilities to utilize behavior supports to help manage patient behaviors. Improve reimbursement for behavior interventions and behavior support staff.
- Utilize coordinators to help facilitate when patients require multiple procedures in multiple departments in one day.

# BEHAVIORAL HEALTHCARE ISSUES

- Professionals refusing to see patients
- Adult psychiatrists not comfortable seeing adult patients with intellectual disability
- Counselors refusing to see patients with assistive technology devices – patient who speaks through device by blinking her eyes or moving her head. Counselors feel like they are not trained to do that or don't have enough time in their day





# BEHAVIORAL HEALTHCARE ISSUES

- Patients sit in psychiatric hospital ER waiting rooms for hours and then are told that the hospital has nothing to offer and they need to be evaluated at another place. Patients often are found to have a physical health issue
- Counselors refusing to see adult patients with intellectual disability
  - Ex. A patient's family was killed in a house fire. She needs therapy to help deal with her grief and the stress of a new home and caregiver. Case manager can't find counselor who will utilize play therapy with patient so that patient can be approached by her developmental instead of chronological age.



# REQUESTS FROM THE FIELD

- Work amongst educational programs to train providers how to communicate with patients using assistive devices
- Train providers in all fields to be comfortable working with patients with developmental disabilities. Positive reinforcement for providers to help incentivize them to continue seeing patients with developmental disabilities.

# CRISIS SERVICES

- It takes several hours for help to arrive during a crisis
- By the time help arrives patient is calm and deemed not in crisis
- Once crisis team arrives limited help available and it is time limited
- Caregivers have to call repeatedly so that there is a log of crises
- Usually requires multiple calls to crisis before family gets any in home assistance, emergency waiver services, respite care or any additional help





# REQUESTS FROM THE FIELD

- Universalize crisis services throughout the state.
- Lessen the time it takes for crisis help to arrive at homes
- Increased ability to provide in home supports to keep patients out of emergency rooms and hospitals

# “BEN”

- Ben lived in a residential facility for years
- Discharged to new home
- No chance to say good-bye
- Medical and dental care were not completed before transition





## “BEN”

- Community agency was not properly trained in patient's needs and how to handle behavior issues
- Follow up mental health, dental and physical health care were not set up
- Ben ran out of medicine and nobody was willing to refill
- He became aggressive, attacked caregivers and injured them
- Ben ends up back in hospital and then transferred to residential facility again



# REQUEST FROM THE FIELD

- Develop transition plans with timelines and ensure that all healthcare service providers are aware
- Needs final dental and physical prior to discharge to ensure that all needs are met.
- Patient needs prescriptions plus at least one month refill.
- Patient should have scheduled follow ups as soon as possible with new providers or scheduled follow ups with old ones.
- If appropriate patient should be able to say good bye and have closure.

# SYSTEM ISSUES

- Agencies such as law enforcement and fire department ignore calls for help due to repeated episodes by same patient
  - Ex. Patient ran out and laid down in middle of road- agency called police and nobody came



# SYSTEM ISSUES

- Caregivers/ Staff:
  - Abandon patient at first sign of problems
  - High staff turnover makes staff training difficult i.e. assisting patients with brushing teeth, showering, checking blood sugars
  - Inadequate food supplies or poor food options in home
  - Lack of consistent health and dental care
  - Not always doing it for right reason and have competing interests
  - In it for the check
  - “Love can’t conquer all”





# SYSTEM ISSUES

- Caregivers do not receive adequate training to manage patients with complicated medical or psychiatric needs such as:
  - Proper patient transfers
  - Bed sore prevention
  - Incontinence care
  - Special diet management i.e. Diabetes or cardiac
  - Improper or excessive restraints





# SYSTEM ISSUES



**NO VIOLENCE**

- Patients' are abused either intentionally or accidentally
  - Patients teased and made fun of by caregivers
  - Caregivers drop patients when doing transfers
  - Patients experience verbal, physical or sexual abuse

# REQUESTS FROM THE FIELD

- Ensure systems like fire departments, police departments and EMS understand the needs of patients with developmental disabilities.
- Assess for proper nutrition in homes and caregivers abilities to cook for patients . Provide nutritional and cooking classes
- Adequate training for all staff to conduct proper patient transfers, incontinence care, and bedsore prevention. Even emergency caregivers need to have this training prior to taking on a client.
- Caregiver training in emotional and cultural sensitivity

# MISC.



- Patients:
  - Donating blood in order to have money to buy food after food stamps run out
  - Surviving on microwave meals because that is all that they or their caregivers know how to cook
  - Having multiple teeth extractions or extensive dental work because patient is never brought to dentist or family can't find dentist





# THANK YOU FOR YOUR ATTENTION

Please contact me with questions.

Felissa P. Goldstein, MD. DFAACAP, DFAPA

Norton Children's Medical Group Bingham Clinic

200 East Chestnut Street

Louisville, KY 40202

Cell (404) 539-6333

[Felissa.Goldstein@nortonhealthcare.org](mailto:Felissa.Goldstein@nortonhealthcare.org)