

# My Story of Strength: Drawing From Lived Experience

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## Story

- Childhood and Family
- Teenage Years and High School
- Mental Health Challenges in College



## Recovery & Policy

- Access to Health Care
- Early Intervention
- Community-Based Treatment



## TD & Mental Health

- What are the Telehealth Challenges?
- What are the Health Equity Issues?
- How to work with Patient's preferences?

# Childhood and Family Dynamics

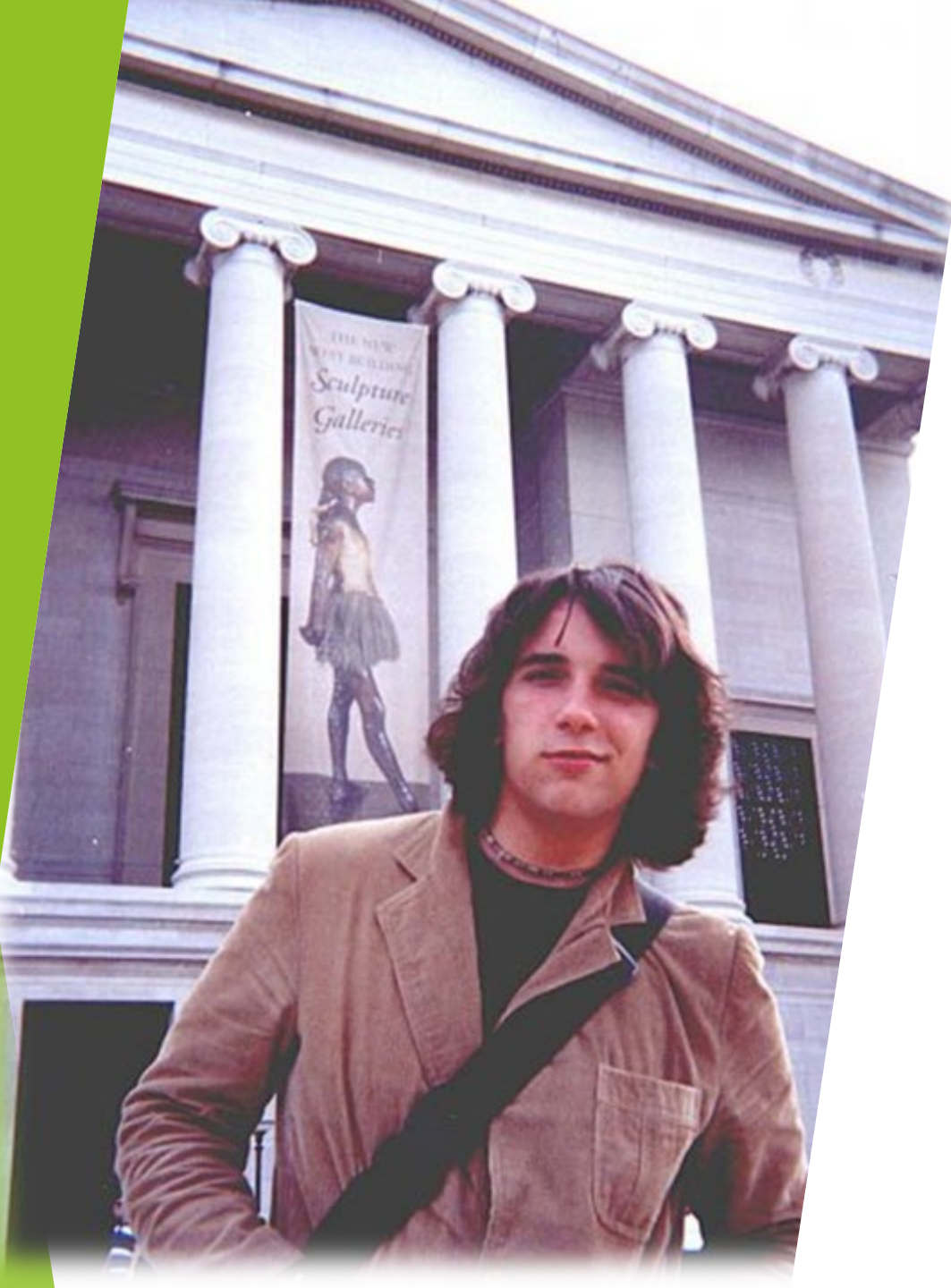
- ▶ First generation born in the United States as the son of Cuban-American Immigrants.
- ▶ Parents provided a healthy and normal middle-class upbringing: private school education, summer vacations, little league sports, etc...
- ▶ Parents used corporal punishment in a context that was normal for their background and culture.





# Teenage Years and High School

- ▶ High-achieving in High School: National Hispanic Scholar and admitted into Early Admissions Program for Medical School at Ohio State University.
- ▶ Personality changes began in adolescence: becoming more introspective, isolating and identifying with peers in party-subcultures.
- ▶ Becoming a daily user of Marijuana and other drugs.



## Mental Health Challenges in College

- ▶ Struggled at Ohio State University: G.P.A. dropped to 1.8 and I asked my mom if I could come home after the first year away at college.
- ▶ Returned home and then left again to New College of Florida to complete Bachelor's degree.
- ▶ By senior year at NCF I was floridly psychotic: eating out of trash cans, picking cigarettes off the ground and losing touch with reality.



# Access to Health Care

- ▶ I had health insurance coverage because the Affordable Care Act required that plans offer coverage until an adult child reaches the age of 26.
- ▶ We spent at least 6 months seeing a dozen mental health professionals in a variety of settings: private practice, hospital-based, etc..
- ▶ I was diagnosed with adult-onset Schizophrenia one week shy of my 23<sup>rd</sup> birthday.

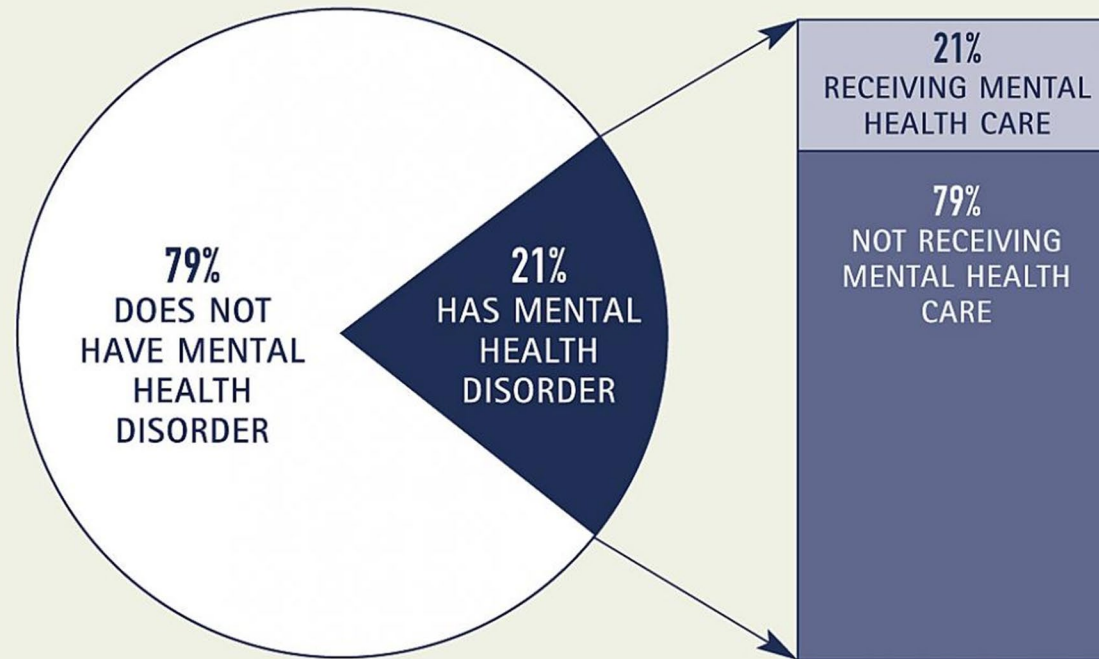




# Unmet Need for Mental Health Care is High

FIGURE 1

## Use of Mental Health Services for Children and Adolescents



**SOURCES:** U.S. Department of Health and Human Services (1999), *Mental Health: a Report of the Surgeon General*, and Kataoka, S.H., Zhang, L., and Wells, K.B. (2002), Unmet need for mental health among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry* 159(9), 1548–1555.

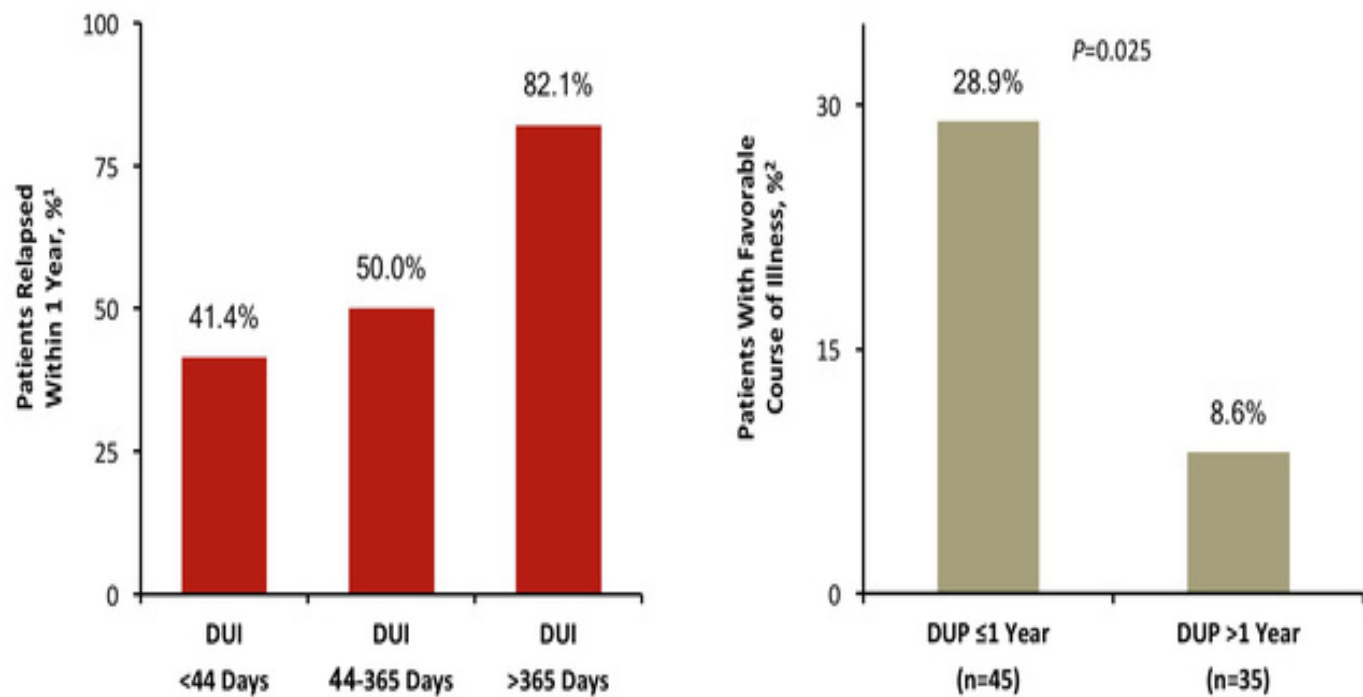
# Early Intervention

- ▶ An informal intervention took place: friends and family felt that something was “*Off*” with my behavior.
- ▶ Approximately 1 year to 1.5 years between the onset of psychotic symptoms and treatment with prescription medication.
- ▶ I started gaining insight that I would need to manage a chronic and serious health condition after I began taking medication.





## Shorter Duration of Psychosis Led to Improved Outcomes in Patients With First-Episode Schizophrenia



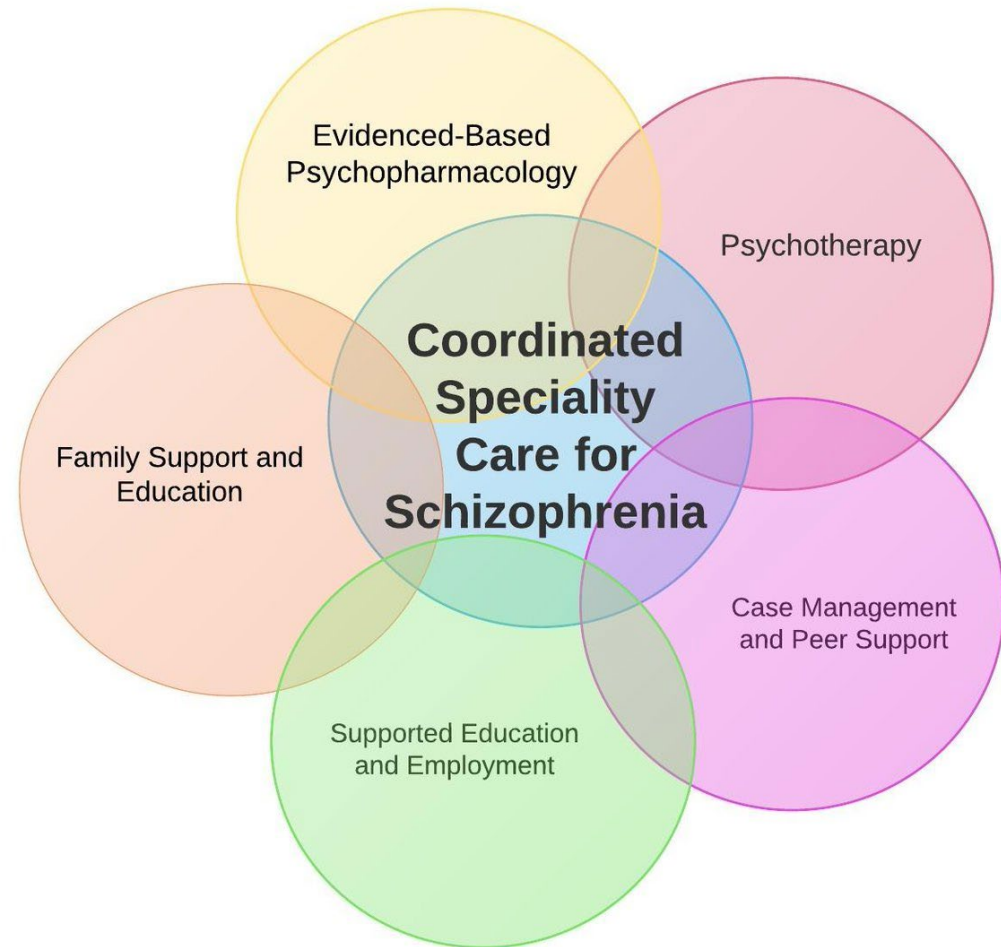
DUI=duration of untreated illness; DUP=duration of untreated psychosis.

<sup>1</sup> Owens DC et al. Br J Psychiatry. 2010;196(4):296-301.

<sup>2</sup> Primavera D et al. Ann Gen Psychiatry. 2012;11(1):21

# Community-Based Treatment

- ▶ People must have access to treatment, rehabilitation, and support services *within* the community.
- ▶ My recovery has been facilitated by a community-based treatment which includes:
  - ▶ Diagnosis and medication management
  - ▶ Supportive school and work environment
  - ▶ Supportive family/home
  - ▶ Social relationships
  - ▶ Volunteer advocacy
  - ▶ Psychotherapy
  - ▶ Education
  - ▶ Support groups
  - ▶ Diet and lifestyle
  - ▶ Peer Support





















# TD, Mental Health, & Telehealth

- ▶ The APA recommends clinical assessment for TD at each visit and assessment with a structured instrument, such as AIMS:
  - ▶ If a new onset or exacerbation, every 6 months in patients at high risk, and every 12 months in other patients.
- ▶ In-person assessments should be utilized when possible.
- ▶ However, there are no significant differences between telehealth and in-person evaluation with standardized movement scales, including AIMS.
- ▶ Regardless of the setting, the standard of care should be maintained.
- ▶ Recommend that a caregiver or staff be present during the visit to assist with camera positioning and other aspects of the examination.





# Health Equity for TD Treatment

- ▶ Minorities face multiple barriers to access and adherence with prescription medicines as a result of:
  - ▶ Costs
  - ▶ Lack of insurance
  - ▶ Implicit Racial Bias in Prescribing Practices
- ▶ Here are a Three Key Policy Proposals:
  - ▶ Push to Expand Medicaid
  - ▶ Promote the ACA and an Essential Benefits Package
  - ▶ Reduce Implicit Bias in Prescribing



## Honoring Patients' Preferences

- ▶ Shared decision making is a key component of patient-centered health care.
- ▶ SDM is a communication process by which patients and clinicians work together to make health care decisions that align with what matters most to patients.
- ▶ What are the benefits of SDM?
  - ▶ Helps achieve informed consent and addresses issues with the current informed consent process
  - ▶ Helps bridge health disparities
  - ▶ Can positively impact the quality, cost, and safety of health care delivery
  - ▶ Ethically correct



# Conclusion and Take-Aways



- ▶ Share your story! We help each other recover and live healthier lives through talking about our lived experiences.
- ▶ Recovery is made possible through increasing access to health care, early intervention services and community-based treatment.
- ▶ We should ensure that TD treatments, assessments, and access adhere with standards of care, are equitability available, and are consistent with patients' preferences.



**YOU ARE NOT**

**ALONE**