

Stigma, Mental and Neurodevelopmental Disorders, and Families: A Core Frontier for Human Rights

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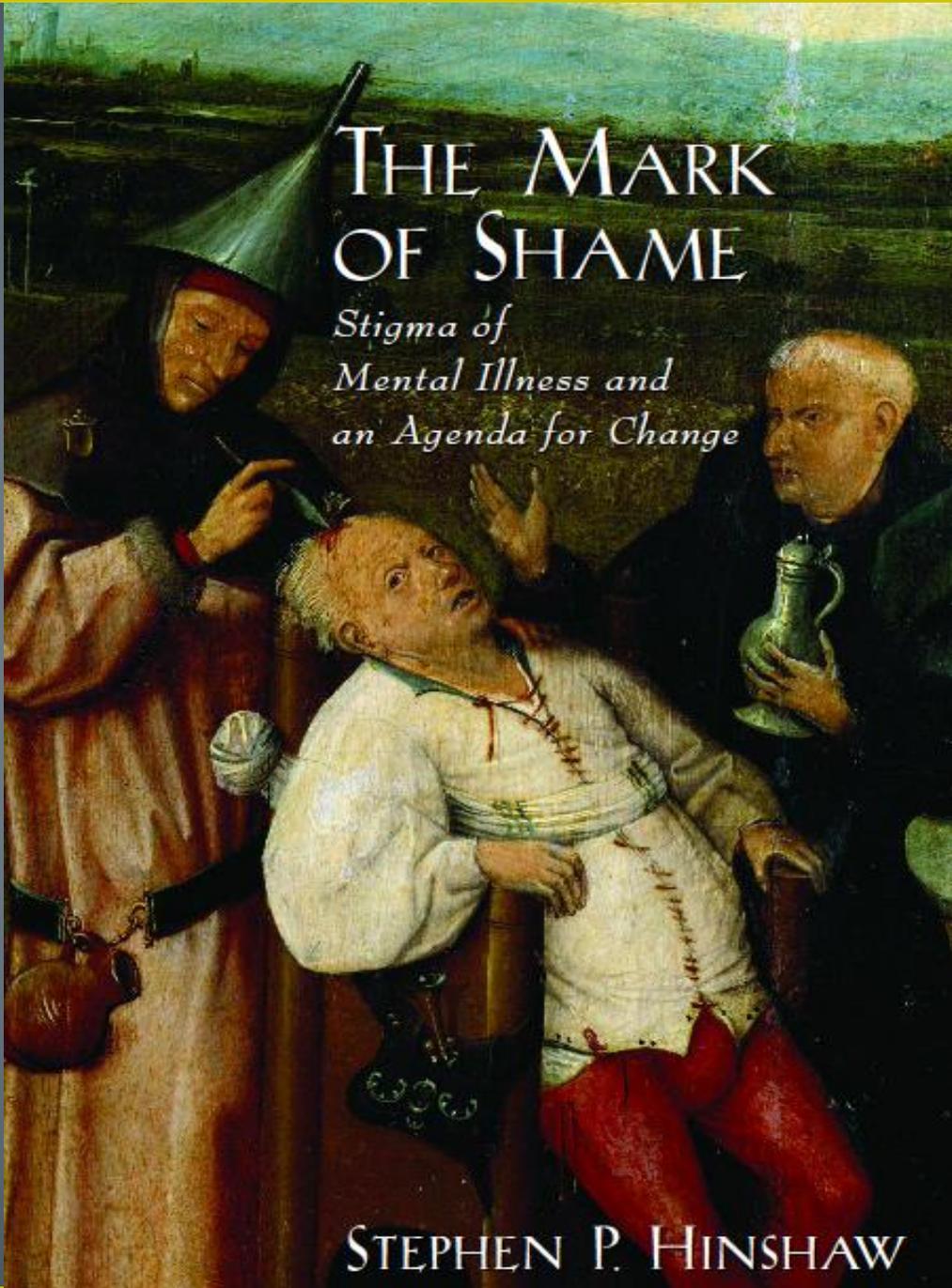
HELP Group Summit

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Stigma

Hinshaw (2007), *The Mark of Shame* (Oxford U. Press)

- **Ancient Greece: Literal ‘mark of shame’**
 - Brands placed on slaves or traitors
 - Today, usually psychological /social “branding”
- **Which groups are stigmatized?**
 - Racial minorities, sexual minorities, women, left-handers, physical disabilities, adoptees, obese, delinquent youth, many more...
 - Can things change? See attitudes re: gay marriage
 - Thus, hope for optimism—malleability of social/cultural views
- **Most stigmatized today:**
 - *People with mental illness, homelessness, substance abuse*



THE MARK OF SHAME

*Stigma of
Mental Illness and
an Agenda for Change*

STEPHEN P. HINSHAW

Major Change in Perspective

- **1950s: *The Authoritarian Personality***
 - Certain personality types are bigots (or stigmatizers)
- **Today:**
 - Stigmatizing processes part of 'normative' social cognition
 - Important distinction between explicit and implicit bias/stigma
- **Thus, distinguish...**
 - Stereotypes (cognitive)
 - Prejudice (affective)
 - Discrimination (behavioral)
- **Stigma**
 - All this plus the *global* nature of castigation/self-fulfilling prophecies
 - Everything about you relates to your group membership

Evidence for Stigma and Discrimination

- **Studies of overt attitudes**
 - As noted, the most stigmatized attributes are mental illness, substance abuse, and homelessness
 - S. Fiske: *“lowest of the low”*
 - *Perceived as lacking in both warmth and competence*
 - *Insula--‘lights up’ with relevant images (disgust)*
- **Studies of covert/implicit attitudes**
 - Rejection occurs at unconscious level
- **Examination of laws and everyday practices**
 - In many states, no vote/ jury/driving/run for office/child custody
 - Media portrayals (still dominated by school shootings)

Self-stigma (internalized stigma)

- **Nearly all members of stigmatized groups are aware of the culture's stereotypes/beliefs/practices**
 - Thus, likelihood (though not certainty) that such individuals will internalize these beliefs
 - Antidotes: identity, group solidarity
 - Black power, women's movement
 - Double whammy: disorders themselves likely to fuel demoralization, but self-stigma multiplies the risk
- **Important research findings:**
 - Even covarying initial levels of symptoms, self-stigma predicts (a) lack of treatment seeking and (b) early termination from treatment

Courtesy Stigma

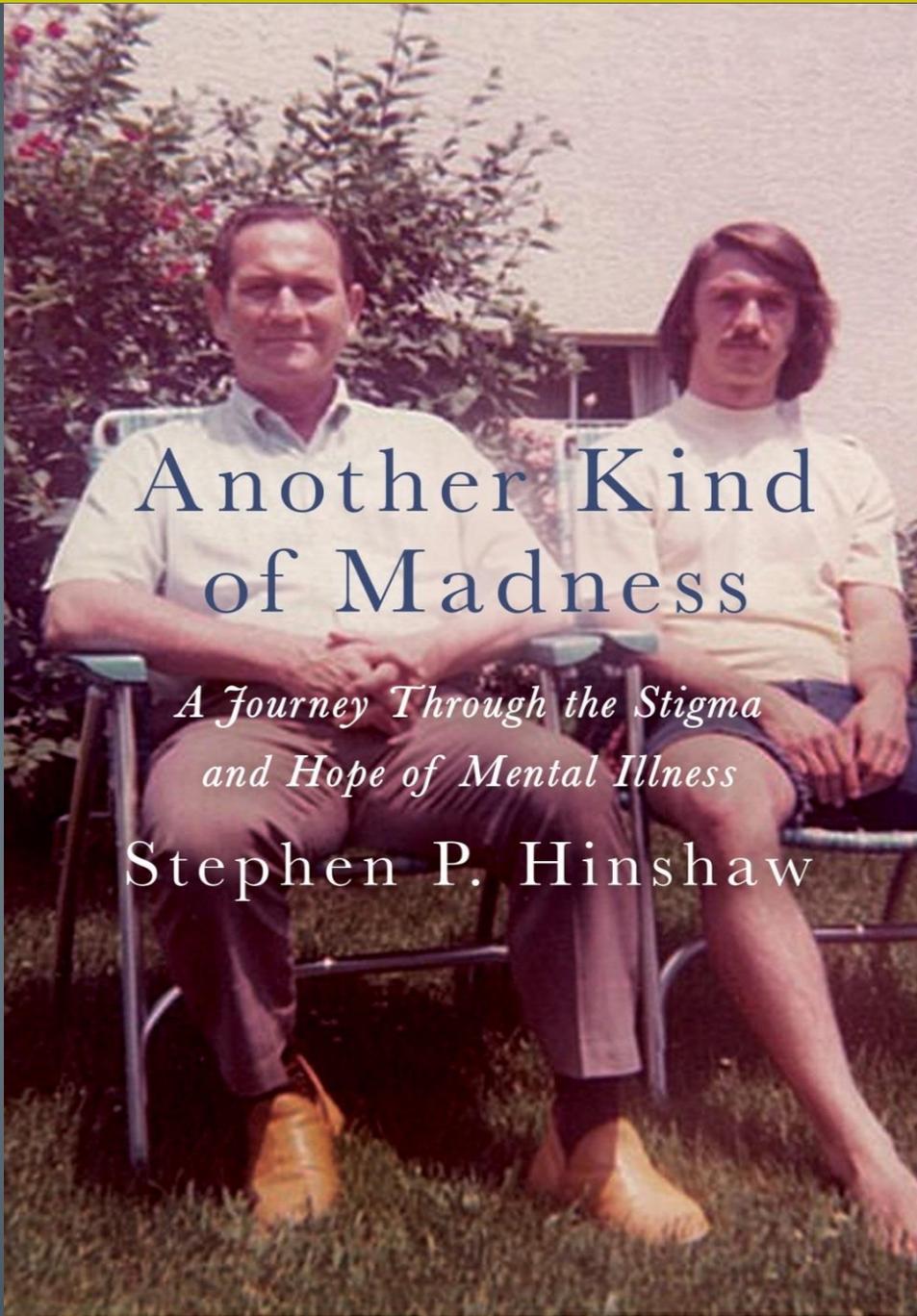
- **Goffman (1963):**
 - If society has stigmatized a given class of people, it's common courtesy to stigmatize those *associated* with such individuals, particularly family members
- **Parents of youth with mental disorders: Directly blamed for offspring's problems for decades**
 - Even genetic transmission leaves blame on parents
- **Objective burden and subjective burden**
 - Subjective burden usually experienced as worse
- **Mental health professionals/scientists 'in the shadow'**

MI Stigma is Decreasing, Right??

- Public knowledge of MI far greater than 50-60 years ago
- But no fundamental change in stigma levels from 1995 -2005
 - ▣ Greater knowledge does not necessarily translate to greater empathy
- Actually, *higher* rates of violence beliefs in 2005 than 1955
 - US public 3 times more likely to believe that MI linked to violence
 - Involuntary commitment laws: 'danger' to self/others; public homelessness
- Why?
 - Deinstitutionalization, commitment laws ('danger'), gun violence ascribed to mental illness per se

Stigma and NDD's

- Why would neurodevelopmental disorders be stigmatized?
 - ADHD: Inconsistency of behavior
 - 'Why can't he or she control it?'
 -
 - ASD: Inconsistent or underdeveloped social abilities
 - Humans are 'inherently' social
 - Intriguing: parents report *more* stigma related to high-functioning ASD than more severe forms (Gray, 2002)
- Parents
 - Feel stigmatized, too
 - Remember, a la courtesy stigma
 - 'Refrigerator' parents were thought to cause autism



Another Kind of Madness

*A Journey Through the Stigma
and Hope of Mental Illness*

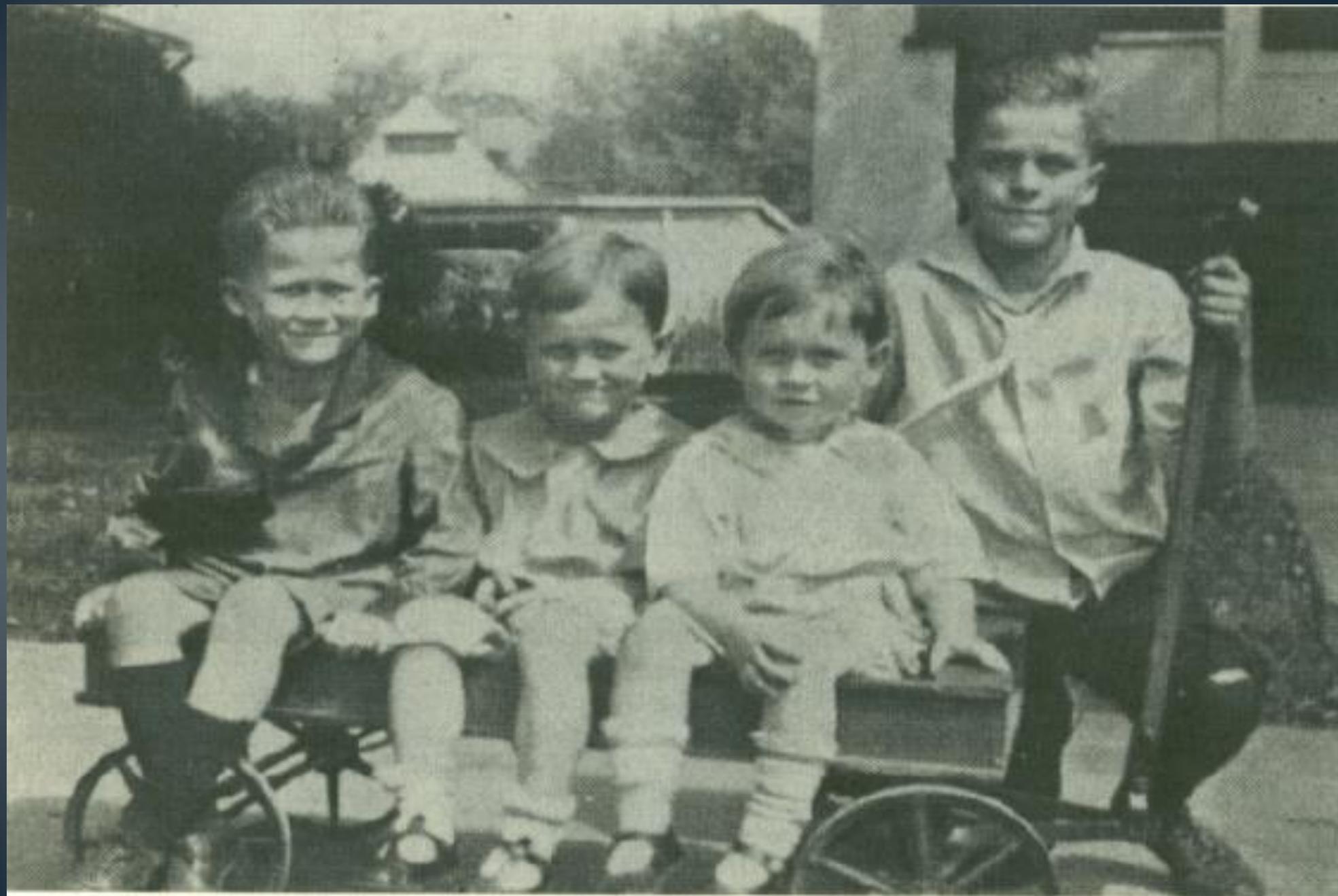
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When parent has disorder...

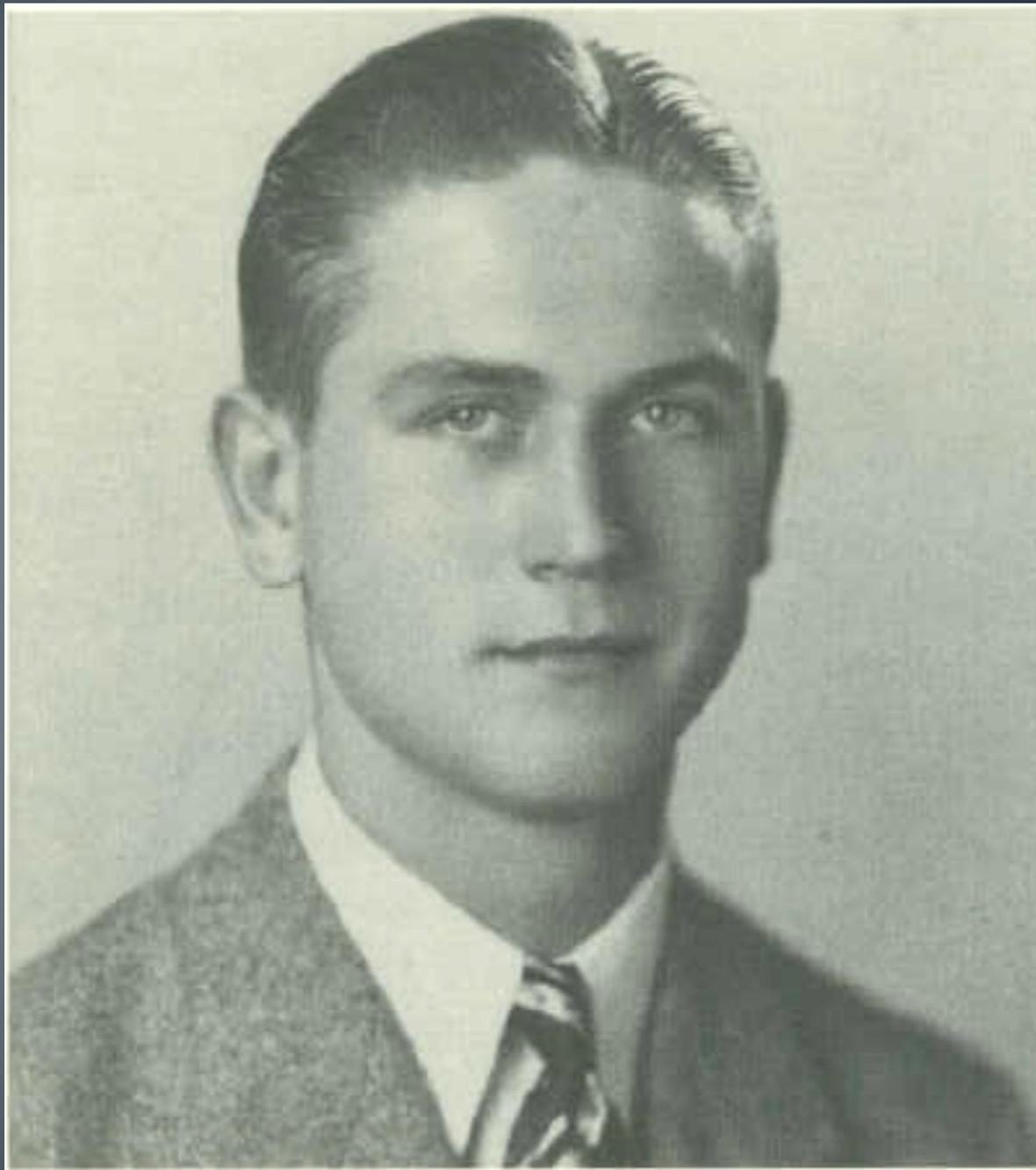
- **Passages...**
 - **Why this provocative title, “Another Kind of Madness”**
 - **James Baldwin quote, from “Giovanni’s Room”**
 - **In this case ‘another kind of madness’ is stigma per se**
 - **Where did things start? Pasadena in the 1930s**
 - **“Flight”**

Background

- **Virgil Hinshaw Jr.**
 - Born 1919, outside Chicago
 - Fourth of four boys
 - Quaker, Prohibitionist father
 - Missionary mother
 - Death of mother at age 3



- **Move to California, stepmother**
 - **Blend of praise and abusive treatment**
- **Great Depression**
- **Age 16 episode**
 - **Norwalk: nearly dies, identity on back ward**
 - **Regroups, college and grad school**
- **Stanford, Iowa, Princeton**
- **Age 25 episode**
 - **Hospitalized at Byberry**
 - **Ongoing diagnosis of schizophrenia**
 - **Delusion of concentration camp**



And then...

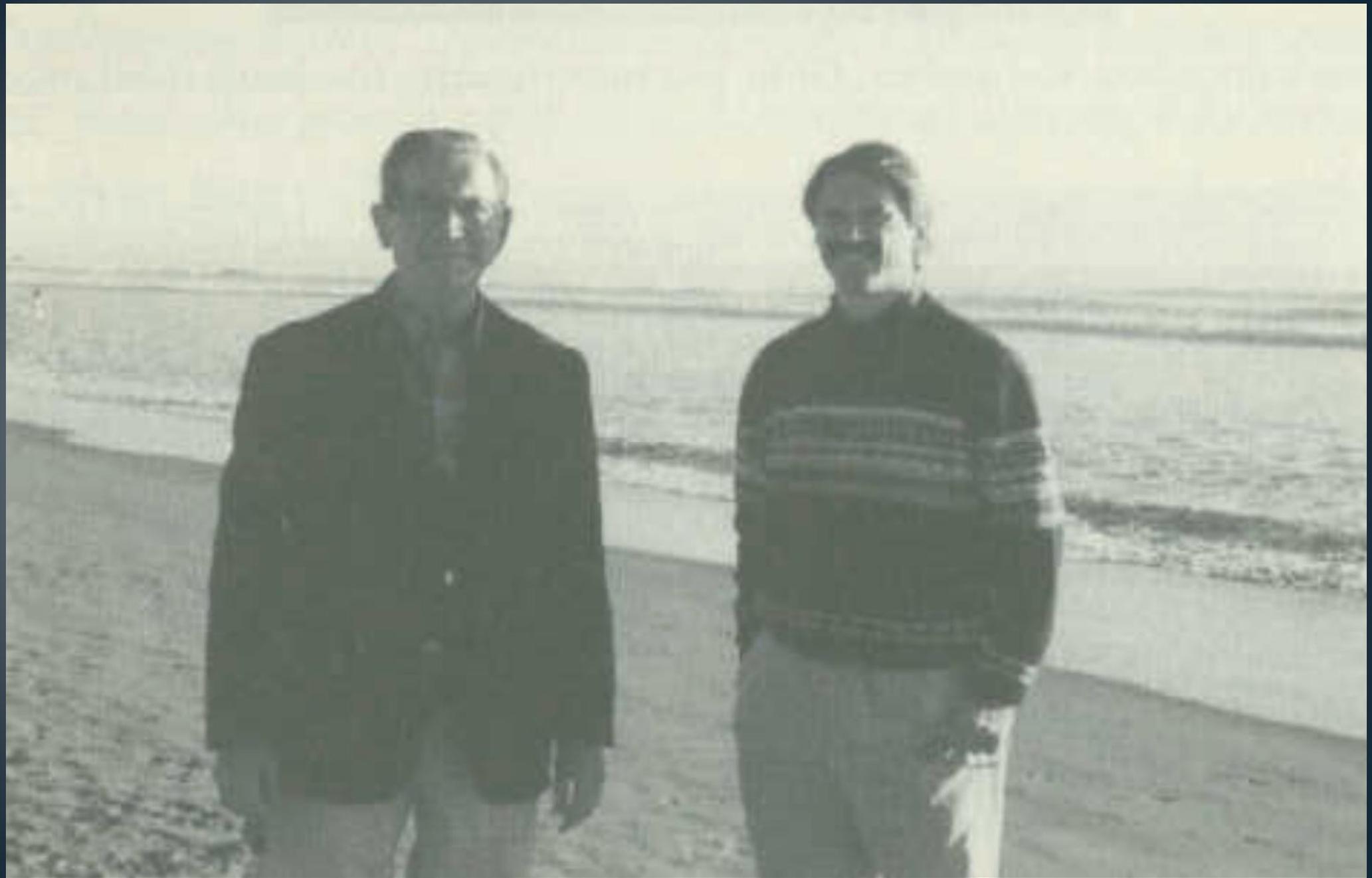
- **Professorship, marriage**
 - **Episodes, treatments of 1950's and 1960's**
 - **ECT, neuroleptic medications**
 - **“Never tell children” about mental illness**
 - **My own life: silence, internalization, shame**
- **Passages:**
 - **Poison balloons; Midnight drive**
- **1970's**
 - **Once I departed for college, our talks began**
 - **Conflicts: Mission, genetic legacy, sleeplessness, control, children?**
 - **Finally, accurate diagnosis and lithium**
 - **UCLA/grad school—Passage: The Thought Experiment**



Final Years

- Parkinson-like illness, cognitive decline
- Related to untreated/maltreated episodes?
- Gratitude for life
- Greatest disclosures in last years of life:
 - Journals, letters
- My own perspectives:
 - No accident re: career choice
 - Understanding of mental illness will take extensive knowledge of science AND extensive investigation of narrative





1. Resilience, Strength, Courage

- **Mental disorder's devastating impact**
- **Yet, resilience and positive outcome possible**
- **Resilience: Individual, social, broader levels**
 - **Humor**
 - **Intelligence**
 - **Religion**
 - **Work ethic/future orientation**
 - **My mom's unflagging support**
 - **Tenure**
- **Narrative: break stereotypes, humanize**

2. Genes AND Trauma

Post & Leverich: High heritability and maltreatment potentiate...

- * earlier onset
- * more cycles
- * heightened suicide risk
- * less treatable

3. Language

- **Dad told me he wished for a real illness, not 'mental illness'**
 - Wished he'd had cancer...
 - Maybe one's identity is shaped early on....
- **Are labels dehumanizing or empowering?**

4. Family Silence and communication: What to tell children?

- Anything better than nothing, than silence
- Child's tendencies:
 - Internalize; blame self; caretake?
- Beardslee's approach for families in which a parent is depressed:
 - Family tx in which narrative constructed
 - Beardslee et al. (2003), *Pediatrics*: Short and longer-term effects on offspring
 - Communication cuts risk for depression by 40%

5. Tell our stories, humanize

- **This may be the most important factor of all, and one promoted heavily by The HELP Group
- **Stigma reduction: multifaceted
 - *Antidiscrimination, parity
 - *Access to evidence-based care
 - *Improved/accurate media depictions
 - *Contact and humanization
 - *Teens: Bring Change to Mind high-school clubs

THANKS....

*The HELP Group

*You, the audience