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LIVING WELL WITH SEVERE, LONG-TERM MENTAL ILLNESS

A Presentation By
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SEVERE LONG-TERM MENTAL ILLNESS

- Typical images are misleading
- But many people with serious, long lasting mental illness have difficult lives and are unable to manage in the community without substantial assistance
  - Low life expectancy
  - Poor physical health
  - Limited access to decent health care
  - Frequent co-occurring disorders
  - Elevated risk of depression and dementia
  - Often live in poverty and in squalid and/or dangerous housing
  - Frequent homelessness
  - Disproportionately incarcerated in jails and prisons
  - High rates of suicide
  - Mostly unemployed
  - Limited access to the mainstream , even houses of worship

RECOVERY IS POSSIBLE

- Some achieve full recovery of function
- Many have lives that are personally satisfying and meaningful despite continuing mental illness
  - Including some who are paid peer specialists
  - Some who are leaders of advocacy and service organizations

WHAT DOES IT TAKE FOR PEOPLE WITH SERIOUS, PROLONGED MENTAL ILLNESSTO HAVE SATISFYING LIVES?

- SAME FUNDAMENTAL NEEDS AS ALL PEOPLE
  - A decent place to live
  - Income
  - Health and longevity
  - Satisfying family and social relationships
  - Engaging and meaningful activities including work, art, advocacy
  - A sense of connection and belonging in a community they value
  - Spiritual opportunities

HISTORY

- Historically, this population has been the **core responsibility of mh system**
- Late 18th to mid 20th centuries: **state asylums and hospitals**
  - Horrendous living conditions, no effective treatment, exploitation for labor
  - Racially segregated (separate and unequal)
- Post WW II, support in the community
  - Reliance on state hospitals peaked in 1955 (at most 1/3 of SPMI)
  - 1956: Public assistance for people with disabilities
  - 1963 CMH Centers Act
  - 1965: Medicaid and Medicare
  - About 1968: aggressive deinstitutionalization
  - 1977: NIMH introduced the Community Support Program (CSP/CSS)
  - Now: 2/3 get treatment,
  - Many get rehab, specialized housing, care/case mgt., etc.

CURRENT SYSTEMIC PROBLEMS

- 35% do not get any treatment
  - **More among people of color**
- Homelessness and squalid/dangerous housing
- Unstable and inadequate income
- Mixed quality of mental health services; often not even “minimally adequate”
- Shortage of coordinated care
- Fragmented and chaotic non-system
- Overuse of jails and prisons
- Inadequate crisis services
- Limited access to the mainstream

NEED FOR VAST IMPROVEMENT

- Housing
- Income
- Health Care
- More Effective Psychiatric Treatment
- More Widespread Psychiatric Rehabilitation
- More Personalized Care Management
- More Humane Crisis Intervention
- Outreach To Find People Who Do Not Come To Designated Places For Care And To Connect With Them Before They Are In Crisis
- A More Just Criminal Justice System
- Greater Access To The Mainstream, esp. spiritual opportunities
- Greater Respect For Their Rights As Human Beings

- **Address racial disparities**
- Address needs of **older adults** with SMI

IDEOLOGICAL DISAGREEMENTS IMPEDE IMPROVEMENT

- MORE LONG-TERM INPATIENT CARE VS. MORE COMMUNITY CARE
- MORE COERCION VS. MORE OUTREACH AND ENGAGEMENT
- THESE DISAGREEMENTS MAKE MH ADVOCACY INEFFECTIVE
- NEED TO UNITE AROUND AGREEMENTS
- DIFFICULT DUE TO DIFFERENCES IN FUNDAMENTAL PERSPECTIVE

    - TREAMENT ORIENTED: WHAT SERVICES DO SPMI NEED?
    - RECOVERY ORIENTED: WHAT DOES IT TAKE FOR SPMI TO HAVE SATISFYING LIVES?

HUMANITY FIRST

RECOVERY-ORIENTED AGENDA FOR IMPROVEMENT

- INCREASE LIFE EXPECTANCY
  - SUICIDE PREVENTION
  - ACCESS TO GOOD HEALTH CARE
  - WELLNESS
- ADEQUATE HOUSING
  - HOUSING FIRST
  - SUPPORTIVE HOUSING
  - SUBSIDIES
- SECURE INCOME
  - SSD TRUST FUND
- ACCESS TO THE MAINSTREAM
  - HOUSES OF WORSHIP
- WORK
  - SUPPORTED EMPLOYMENT
  - PEER SPECIALISTS
- OUTREACH AND ENGAGEMENT
- FAMILY SUPPORT
- IMPROVE TREATMENT

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