FROM EVIDENCE TO ACTION: What Worldwide Recovery Research Tells Us

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PLAN FOR PRESENTATION

- Show evidence of significant improvement and recovery in serious and persistent psychiatric disabilities
- The impact of rehabilitation in reclaiming lives
- Knowledge gained from patients and staff observations

TAKE HOME MESSAGES

- Even the worst cases can and do significantly improve and even recover
- See the person behind the disorder
- Build on relationships to surprise someone by seeing purpose & meaning for his or her life
- Be as creative as possible – work far outside the box

EVIDENCE FOR SIGNIFICANT IMPROVEMENT & RECOVERY IN EVEN THE MOST DISABLED OF PERSONS

TABLE 1
SEVEN LONG-TERM STUDIES

Study	Sample Size	Average Length In Years	Subjects Recovered and/or Improved Significantly*
M. Bleuler (1972 a and b) Burghölzli, Zurich	208	23	53%-68%
Huber et al. (1975) Germany	502	22	57%
Ciompi & Müller (1976) Lausanne Investigations	289	37	53%
Tsuang et al. (1979) Iowa 500	186	35	46%
Harding et al. (1987 a & b) Vermont	269	32	62-68%
Ogawa et al. (1987) Japan	140	22.5	57%
DeSisto et al. (1995 a & b) Maine	269	35	49%

*For schizophrenia subsamples

MORE STUDIES USING WIDER DIAGNOSTIC CRITERIA

STUDY Year & Place	# of Ss	Av. Years length	% improvement or recovery
HINTERHUBER 1973 AUSTRIA	157	30	74.8 %
KREDITOR 1977 LITHUANIA	115	20.2	84 %
MARINOW 1986 BULGARIA	280	20	75 %

Discuss the newest long-term study from Chicago!

FINDINGS

- 46-68 % OF EACH COHORT SIGNIFICANTLY IMPROVED AND/OR RECOVERED
- Recovered means:
  - No enduring symptoms,
  - No odd behaviors,
  - No further medication,
  - Living in the community,
  - Working, and relating well to others

- Significantly improved –means
  - Recovered in all areas but one
    - Harding et al, 1987

THE VERMONT LONGITUDINAL PROJECT

- The most chronic cohort ever studied
- The so-called “hopeless” cases
- Received an innovative biopsychosocial rehabilitation program (1955-1965)
- Clinical team operated both in hospital & in community long before CMHCs
- The longest study of deinstitutionalization
- The 2nd longest study of schizophrenia in world

32 YEAR FOLLOW-UP (ranging to 62 years after 1st admission)

- Funded by the National Institute of Mental Health
- 97% Found And/Or Accounted For of 269
- 5 + Hours Of Interviews & 2x
- Structured Interviews And A Life History
- Blind Interviewers, Record Abstractors, And Diagnosticians
- Reliably used current Dx criteria
  - Harding et al, Amer J. Psychiatry, 1987 a and b

Symptom Profiles

- Delusions
- Hallucinations
- Affective Flattening
- Poverty of Speech
- Avolution
- Loose associations
- Tangentially
- Word Salad

- Attention Deficits
- Impaired Memory
- Problems with Information-Processing
- Bizarre posturing
- ▲motor activity
- ▼awareness of environment

Original Functional Descriptions of the Vermont Cohort - 1955

- 16 years duration of illness
- 10 years being totally disabled
- 9 years from first hospitalization
- Middle-aged
- 5 of 6 single
- Impoverished
- Less than 9th grade education
- Isolated from family & friends
- Slow, poor concentration
- Impaired memory

Original Functional Descriptions of the Vermont Cohort in 1955 (b)

- Touchy
- Suspicious
- Temperamental
- Unpredictable
- Over dependent on others to make minor decisions
- No goals or unrealistic ones
- Peculiarities in
  - Appearance
  - Speech
  - Behavior
- Constricted sense of time, space, and other people
- Poor social judgment
- Little or no initiative

George W. Brooks, MD

- “ My ignorance saved me.”
- “What do you need?”

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965

(Chittick et al, 1961)

- Collaboration
- Client driven
- Innovation
- Done with small grant
- Positive messages about recovery
- Activities of daily living

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965 (b) (Chittick et al, 1961)

- Voc rehab – in/out
- Assessment, training, placement & after job supports; job/person match
- Low but therapeutic dose of meds

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965 (c)

(Chittick et al, 1961)

- Peer supports
- Patient gov. & Privileges
- Outpatient clinics
- Rehab housing
- Range of social supports
- Case management

VERMONT'S MODEL DEMONSTRATION REHAB PROGRAM 1955-1965 (d) (Chittick et al, 1961)

- Health watch
- Approaches to family
- Group therapy
- Social skills & problem solving
- Connection to natural community supports

THE MAJOR CROSS-SECTIONAL FINDINGS

- 68% Displayed Little Or No S/S
- 64% Had Less Than 2 Rehospitalizations In 20 Years Post Release
- Average Of Less Than 2 Years In Hospital Post Release For All

THE MAJOR CROSS-SECTIONAL FINDINGS -2

- 20% No Prescriptions Plus
- 30% No Use Of Drugs
- 25% Targeted Use Of Drugs
- 25% Religious Use Of Drugs

MORE MAJOR FINDINGS-3

- I.5% Involved With The Law
- 81% Able To Care For Self
- 40% Employed
- 20% Volunteer Work

MORE MAJOR FINDINGS-4

- 54% Using CMHCs - 46% Out of System!
- 67% Of Those Med Checks Only Every 3-6 Months
- 68% Had Moderately Close To Close Friends – Reconstitution Of Social Skills

What Vermonters said helped the recovery process .....

- Decent housing, food, and clothing #1
- People with whom to be
- Ways to be productive citizens
- Ways to manage medication and symptoms
- Individual treatment planning & case management
- Integration into the community

What the Vermont subjects said made the most difference in their struggles toward recovery ……..

- "SOMEONE BELIEVED IN ME"
- "SOMEONE TOLD ME I HAD A CHANCE TO GET BETTER"
- "MY OWN PERSISTENCE"

- Translates to hope and hope connects with natural self-healing capacities

FORWARD MOVEMENT TOWARD RECOVERY-BASED SYSTEMS OF CARE

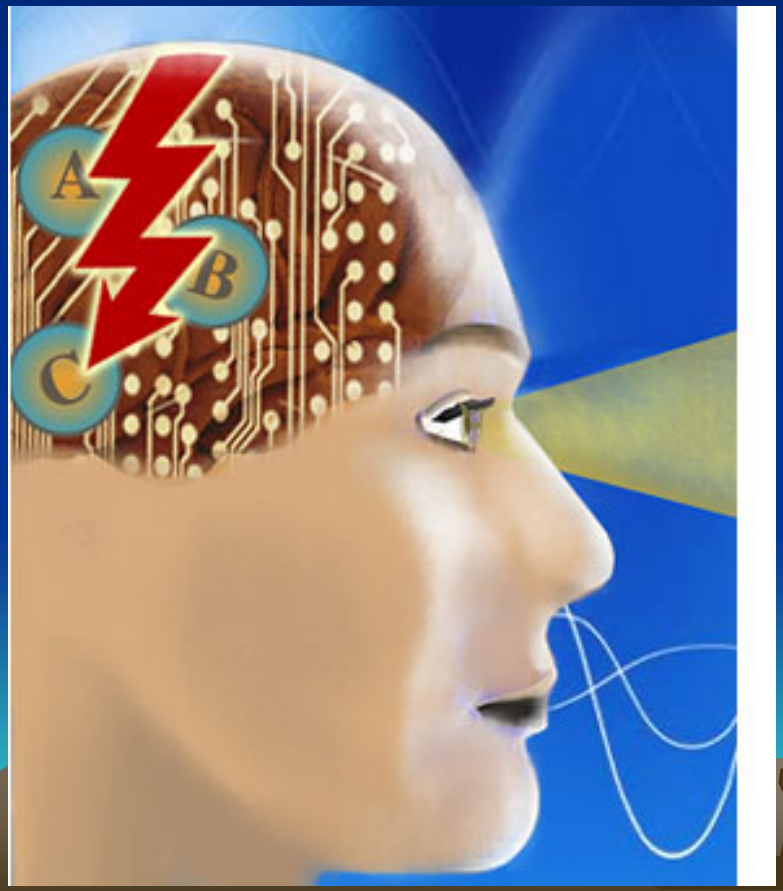
- "ACTION FOR MENTAL HEALTH" 1961!
- "The fallacies of 'total insanity' 'hopelessness' and 'incurability' should be attacked and the prospects of recovery and improvement through modern concepts of treatment and rehabilitation emphasized." (AMA, APA, Amer.Acad of Neurology and Dept of Justice)

In the past, resistance to these findings have been ……..

1) “They must have been misdiagnosed.”
2) “They must all be Affective Disorders.”
3) “They are not like my patients who are much sicker.”

Why do we consistently and persistently underestimate consumers of services?

Applying the principles of “BLINK” by Malcolm Gladwell (2005)



“Blink” is what happens

when you see someone and in an instant decide what you think about that person. It is also called “jumping to conclusions.”

Here is a metaphorical example using the blizzard of snow we had in Boston this year……..

Many people become invisible under the blizzard of diagnostic labels

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Did that model demonstration rehab program really help people dig out of the blizzard of serious and persistent illness and disability?

VERMONT - MAINE COMPARISON (a)

- MATCHED SUBJECTS
- MATCHED CATCHMENT AREAS
- MATCHED TREATMENT ERAS
- MATCHED DIAGNOSTIC CRITERIA
  - DeSisto, Harding, et al, 1995

VERMONT - MAINE COMPARISON (b)

- MATCHED PROTOCOLS
- INTRA-PROJECT RELIABILITIES
- INTER-PROJECT RELIABILITIES
- BLINDNESS
- ONLY ONE IN LIT
  - DeSisto, Harding, et al, 1995

THE VERMONT – MAINE COMPARISON FINDINGS (1)

- VERMONT MODEL

- REHABILITATION
- SELF-SUFFICIENCY
- COMMUNITY INTEGRATION
- av 32 years
- 97%

- MAINE MODEL

- MEDICATIONS
- ENTITLEMENTS
- STABILIZATION
- MAINTENANCE
- av 35+ years
- 94%

THE VERMONT – MAINE COMPARISON FINDINGS (2)

- WIDE HETEROGENEITY
- BETTER COMMUNITY FUNCTION
  p.<0.001
- MORE WORK
  p<O.0009
- LESS S/S p< 0.002

- MODEST HETEROGENEITY
- LESS COMMUNITY FUNCTION
- MUCH LESS WORK
- MORE SYMPTOMS
- (DeSisto, Harding et al, Bri J of Psychiatry, 1995)

VERMONT MAINE COMPARISON FINDINGS (3)

- REHABILITATION
- SYSTEM: COMPREHENSIVE/
- COORDINATED
- MISSION CLEAR

- NO REHABILITATION SYSTEM: UNCONNECTED & SPARSE
- MISSION CONFUSING

DeSisto, Harding et al, Bri J of Psychiatry, 1995 a and b)

THIS IS WHY WE NEED TO HAVE REHAB OPTIONS…1…

- The Vermonters were the worst cases with the most dire prognoses and they had the best outcome…

THIS IS WHY WE NEED TO HAVE REHAB OPTIONS…2…

- The model of rehabilitation, self-sufficiency, and community integration works in combination to helped achieve the best results for the toughest cases.

BUT……

THERE IS ALWAYS A “BUT”

IS THERE ALSO A QUESTION OF THE IMPACT OF NEURAL PLASTICITY?

Even though the people from Maine had a very poor system of care, 49% of such profoundly ill persons still moved toward significant improvement and the other studies with different strategies also moved forward….

THE BRAIN IN INTERACTION WITH THE MIND

- "... can lead to changes in a plastic brain which learns new ways to respond and adapt that are then translated into changes in how a person feels, thinks, and behaves. It [They], in its [their] own way, is [are] as biological as the use of drugs."
  - N. Andreasen, 2001 p.31

IN OTHER WORDS, LET'S WORK WITH MOTHER NATURE AND NOT AGAINST HER

WHAT ELSE HAVE THESE STUDIES TAUGHT US?

- 1) <u>Diagnosis and time</u>
  - Often not for a lifetime but a cross-sectional working hypothesis
- 2) <u>Symptom course</u>
  - Ever widening heterogeneity with early fluctuations and later decrease of virulence

WHAT HAVE THESE STUDIES TAUGHT US? #2

- 3) <u>Predictors of long-term outcome</u>
  - All classic ones weaken over time
- 4) <u>Social functioning</u>
  - Reconstitution and further development

WHAT HAVE THESE STUDIES TAUGHT US? #3

- 5) <u>Being able to work</u>
  - Not predicted by s/s or diagnosis or hospitalization
  - Need opportunities (assessment, training, placement in a job-person match, & continued work supports)

- 6) <u>Psychopharmacology</u>
  - Not necessarily lifelong

WHAT HAVE ALL THESE STUDIES TAUGHT US? #4

- 7)“Successful results can be achieved through totally different methods”
  - (M. Bleuler, 1978 pg. 441)
- 8) Type of treatment should fit the current need of the person and be modified over time

MORE FINDINGS……

- **Gender differences change**
  - **Males get stronger across time**
  - **Females lose their sturdy lead during menopausal years**
- **BUT……**
  - **Everyone at higher risk for higher mortality**

INTERVIEW ON NATIONAL PUBLIC RADIO

- Calls from the US, Canada, Panama
- “I once had schizophrenia but now I am a…….. (MD, nurse, professor, high school teacher, engineer etc.)”

TIME TO SHIFT FROM THE "DOMINANCE OF DEFICITS" PARADIGM

- Stop looking for and labeling deficits problems, pathology, & damage
- Finding shortcomings in the environment
- Blaming the victim

TIME TO SHIFT FROM THE "DOMINANCE OF DEFICITS" PARADIGM (2)

- Realize that community institutionalization is replacing the old state hospital
- Old models of care are in both in & out patient settings although the environment has drastically changed

Start looking for other things

- Strengths
- Interests
- Early goals
- Hopes
- Dreams
- Helpful behaviors
- Personality styles
- How did the person get into such a muddle?

SOME OF THE MANY STRENGTHS AND TALENTS FOUND WHICH WILL HELP FIND THE WAY OUTSIDE

- Intelligence
- Sense of humor
- Charming
- Persistent
- Musical talent
- Artistic
- Work histories
- Contributing to groups
- Feisty
- Cooking skills
- Neuropsych strengths
- Cultural heritage
- Athleticism
- Spiritual
- Educated
- Personable

THE GOAL

- Help to change someone from thinking that they could only be a patient to
- A person with a life and hopes and dreams and perhaps diminishing episodes of psychosis

THE SECRET

- Surprise and astonish by showing the person that you can see a real life for them
- Interest them in things that will enhance their sense of self

Lessons Learned from Ancient Greek Sculptures at the Harvard's Sackler Museum

Investigations with ultraviolet, polarized & raking lights, X-ray fluorescence, defraction analysis and infrared spectroscopy

Vinzenz Brinkmann and Raimund Wünsche (2007)
"Gods in Color: Painted Sculpture of Classical Antiquity"

WHAT ABOUT THOSE PEOPLE WHO SEEM TO STAY IN SERVICES?

NOT NECESSARILY VIRULENCE OF ILLNESS (≤5%)

- PERSONS WHO REQUIRE SOCIAL CONTROL (NGRIs & SEXUAL PERPETRATORS)
- LONG STAY FORENSIC PATIENTS FOR MISDEMEANORS NOT NEEDING SOCIAL CONTROLS
- UNRECOGNIZED AND UNTREATED TRAUMA
- AXIS II BEHAVIORS MISINTERPRETED AS CONTINUING AXIS I PROBLEMS
- LACK OF REHAB OPTIONS & OPPORTUNITIIES

WHAT ABOUT THOSE PEOPLE WHO SEEM TO STAY IN SERVICES? (2)

- INCORRECT DIAGNOSIS
- MEDICAL COMORBIDITIES
- CO-OCCURRING DISORDERS NOT TREATED SIMULTANEOUSLY
- ADDITIONAL NEUROLOGICAL IMPAIRMENTS
- UNTREATED FOR LACK COMMUNITY KEEPING BEHAVIORS
- IATROGENIC EFFECTS OF TREATMENT
- DEMORALIZATION & LOSS OF HOPE

WHAT ABOUT THOSE PEOPLE WHO SEEM TO STAY IN SERVICES? (3)

- WE NEED TO TAKE A SECOND, THIRD, AND FOURTH LOOK
- WE NEED TO UNDO THE DAMAGE DONE BY THE SYSTEM
- WE NEED TO DO MUCH BETTER FOR THE "OLDER SEEMINGLY CHRONIC PERSONS"
- WE NEED TO REMAKE OUR SYSTEMS TO REDUCE FUTURE CHRONICITY

TAKE HOME MESSAGES

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- See the person behind the disorder
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- Be as creative as possible – far outside the box