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

*For schizophrenia subsamples
MORE STUDIES USING WIDER DIAGNOSTIC CRITERIA

<table>
<thead>
<tr>
<th>STUDY</th>
<th># of Ss</th>
<th>Av. Years length</th>
<th>% improvement or recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>HINTERHUBER</td>
<td>157</td>
<td>30</td>
<td>74.8 %</td>
</tr>
<tr>
<td>1973 AUSTRIA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>KREDITOR</td>
<td>115</td>
<td>20.2</td>
<td>84 %</td>
</tr>
<tr>
<td>1977 LITHUANIA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MARINOW</td>
<td>280</td>
<td>20</td>
<td>75 %</td>
</tr>
<tr>
<td>1986 BULGARIA</td>
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</tbody>
</table>
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 1\textsuperscript{st} 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, \textit{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

(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

- 1.5% 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
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
<table>
<thead>
<tr>
<th>VERMONT MODEL</th>
<th>MAINE MODEL</th>
</tr>
</thead>
<tbody>
<tr>
<td>REHABILITATION</td>
<td>MEDICATIONS</td>
</tr>
<tr>
<td>SELF-SUFFICIENCY</td>
<td>ENTITLEMENTS</td>
</tr>
<tr>
<td>COMMUNITY INTEGRATION</td>
<td>STABILIZATION</td>
</tr>
<tr>
<td>av 32 years</td>
<td>MAINTENANCE</td>
</tr>
<tr>
<td>97%</td>
<td>av 35+ years</td>
</tr>
<tr>
<td>94%</td>
<td></td>
</tr>
</tbody>
</table>
THE VERMONT – MAINE COMPARISON FINDINGS (2)

- WIDE HETEROGENEITY
- BETTER COMMUNITY FUNCTION
  \( p < 0.001 \)
- MORE WORK
  \( p < 0.0009 \)
- 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)
• The Vermonters were the worst cases with the most dire prognoses and they had the best outcome...
The model of rehabilitation, self-sufficiency, and community integration works in combination to help 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) Diagnosis and time
   - Often not for a lifetime but a cross-sectional working hypothesis

2) Symptom course
   - Ever widening heterogeneity with early fluctuations and later decrease of virulence
WHAT HAVE THESE STUDIES TAUGHT US? #2

- 3) **Predictors of long-term outcome**
  - All classic ones weaken over time

- 4) **Social functioning**
  - Reconstitution and further development
WHAT HAVE THESE STUDIES TAUGHT US? #3

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

• 6) **Psychopharmacology**
  • 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, and 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

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

• 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 – far outside the box