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“HAND IN HAND”, GHENT BELGIUM  
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45 countries of the (OECD) Organization of Economic Cooperation & Development & Examples from Europe-Sweden, France

Psychiatric Beds per 100,000 1991-2011
Where mental hospitals dominate mental health care

“When countries spend the great majority of their mental health budgets on mental hospitals, relatively little is left for all other forms of mental health services.....They are an inefficient way to treat those in need...”

Deinstitutionalization as bed reduction; Psychiatric care beds per 100 000 population, 2011

OECD, 2014
What’s a policy maker to do?

Don’t move to community

- Increase in mortality; ‘Revolving Door Syndrome’; homelessness; transinstitutionalization; (Penrose hypothesis)
  - (Priebe, Frottier et al., 2005; Priebe, Badasconi et al., 2005; Davis et al., 199; Lamb 2015)

- Studies showed that community treatment no better than hospital care once supports are removed
  - (cited in Anthony, Cohen, Farkas et al., 2002)

Move to community

- Reduce relapses, reduce hospital admissions, shorten average length of stay
  - (European Commission, 2013; Stein & Test, 1978; Tyler Turner Johnson, 1989)

- People like living in community better
  - (Anthony, Cohen, Farkas et al., 2002; Taylor, Kilaspy et al., 2009)

- Reduction in beds do not lead to higher rates of incarceration
  - (Blumi, Waldhor, Kapusta, Vyssoki, 2015)

- Systematic review found homelessness, incarceration, suicide not related to bed reduction
  - (Winkler, Barrett et al., 2016)
Is treatment ‘in the community’ always the same as ‘deinstitutionalized’ care?

**EXAMPLES**

- **Compulsory treatment** was seen as effective way to care of people who cannot care for themselves “in the community”
  - In some international suggestions for community treatment, “closer monitoring” through compulsory community treatment is recommended (OECD 2014)
  - Systematic review of the literature on compulsory treatment orders found little evidence of effectiveness in terms of health service use, social functioning, mental state, quality of life (Kisley, Campbell, Preston 2011, Cochrane-Campbell)

- **Halfway Houses** used to be viewed as another tool to deliver ‘community care’
  - Evidence showed that halfway houses were not ‘halfway’ to anywhere – even more than 30 years ago (Cometa, Morrison, Ziskoven, 1979)
Main issue....

- Deinstitutionalization policy, in the form of bed reductions in long stay psychiatric hospitals, has now been institutionalized around the world—without those countries necessarily having also adopted the practices to support mental well being (OECD, 2014; Shen & Snowden, 2014; Thornicroft et al. 2016)

- Location is a limited indicator of better mh care or mental well being

- People can lead terrible lives of deprivation abuse, poverty, hopelessness inside a mental institution....or outside that institution.

- What does this mean?

- Solutions have to be beyond investing in certain kinds of buildings, wherever they are
So Freedom in a person’s life is not the same as Life in that freedom
adapted from William Anthony…

WHAT IS THE ALTERNATIVE TO THINKING IN TERMS OF HOSPITAL TRANSFER?
SHIFTING PARADIGM FOR MENTAL HEALTH SERVICES …….
Basic Elements of “Medical Model”

- **Good care was always seen as:**
- Assessments of illness, leading to problem solving by experts;
- Identification of specific treatments for the identified problem;
- The patient role was that of:
  1. A good reporter, providing correct information so that the correct treatment be delivered
  2. Follow the experts’ instructions
Based on Medical Model, what we had to offer was….

And…within that, being progressive in the 1960’s - 80’s meant…..

• Keeping people from going back to hospital
• Keeping people from having symptoms again
• Making sure they followed the treatment plan
• Best we could do was to help people survive and stay at whatever level of functioning they had
We began to see that a change was needed

BUT WAS THIS NEED FOR CHANGE A NEW IDEA??
<table>
<thead>
<tr>
<th>Ideas of...</th>
<th>Peer advocacy for reform - peer run services</th>
<th>Person centered care; right to respect</th>
<th>Right to life ‘in the community’ and ‘of the community’</th>
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</thead>
<tbody>
<tr>
<td>EUROPE</td>
<td>Spain</td>
<td>1536</td>
<td>St John of God Hospitals</td>
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<tr>
<td>Eurocentric areas</td>
<td>U.K.</td>
<td>1620</td>
<td>The “Petition of the Poor Distracted People” in the House of Bedlam</td>
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<tr>
<td>U.S.</td>
<td>1843</td>
<td>(Elizabeth Stone)</td>
<td>1910</td>
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<tr>
<td>South America</td>
<td>U.K.</td>
<td>1845</td>
<td>Society of Alleged Lunatics</td>
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<tr>
<td>Europe</td>
<td>Holland</td>
<td>1930's</td>
<td></td>
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<tr>
<td>South America</td>
<td>Italy</td>
<td>1960’s-80’s</td>
<td></td>
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<td>Asia</td>
<td>Westernization</td>
<td>70-80’s</td>
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<tr>
<td>U.S.</td>
<td>1800’s</td>
<td>(Clifford Beers)</td>
<td>Mental Health Assn.</td>
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<td>Africa</td>
<td>1970’s</td>
<td>Mental Patients Liberation Front</td>
<td></td>
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<td></td>
<td>90’s</td>
<td></td>
<td>i.e. Social inclusion - Law to close hospitals</td>
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<td></td>
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<td>- religious imperative for individual civil rights</td>
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What made it possible to think beyond maintenance as the goal?

<table>
<thead>
<tr>
<th>Country</th>
<th>Study</th>
<th>Sample Size</th>
<th>Length</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germany</td>
<td>Bleuler, 1972</td>
<td>206</td>
<td>23</td>
<td>53-68%</td>
</tr>
<tr>
<td></td>
<td>Huber et al., 1972</td>
<td>502</td>
<td>22</td>
<td>57%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>Ciompi &amp; Muller, 1976</td>
<td>289</td>
<td>37</td>
<td>53%</td>
</tr>
<tr>
<td>Japan</td>
<td>Tusuang et al., 1979</td>
<td>186</td>
<td>35</td>
<td>46%</td>
</tr>
<tr>
<td></td>
<td>Ogawa et al, 1987</td>
<td>140</td>
<td>22.5</td>
<td>57%</td>
</tr>
<tr>
<td>United States</td>
<td>Harding et al, 1987</td>
<td>269</td>
<td>32</td>
<td>62-68%</td>
</tr>
<tr>
<td></td>
<td>DeSisto et al, 1995</td>
<td>269</td>
<td>35</td>
<td>49%</td>
</tr>
<tr>
<td></td>
<td>Harrison et al. 2001</td>
<td>200-500</td>
<td>22-37</td>
<td>58%</td>
</tr>
</tbody>
</table>
International thoughts about what the word “Recovery” means...
Understanding Recovery as a concept/process

- UK, USA, Canada, Australia, N.Z.
- Hong Kong
- Systematic review across countries
- Personal experience of claiming or reclaiming meaningful life through home, health community, purpose
  - Anthony 1993; Farkas 2007; SAMHSA 2010
- 復元(fu yuan) meaning regaining vitality, life force
  - Tse et al., 2012
- Processes related to ideas of connectedness, hope, identity, meaning, empowerment
  - Slade et al, 2012
What exactly is recovered?

- A meaningful life
What is Recovery? Will’s story

- Since I was a child I’ve struggled with extreme emotions, voices, and powerful out of body experiences.

- I often hid away, alone, overwhelmed and unable to describe what was going on.

- At age 26, I hit a breaking point, and wandered the streets of San Francisco all night hearing angry voices telling me to kill myself.

- I ended up in the locked unit of public psychiatric ward in San Francisco.
I lost my job while in the hospital

But things changed for me

I got out and began to see myself as different, rather than broken

I met a social worker who helped me get a job – first a volunteer job; then a part time job for a few hours a week and then finally a “real” job creating graphics for a website company that paid a living wage with the possibility of a promotion if I did well

I am now 45 years old and have been out of hospital for 14 years
How did I do it? “Personal Medicine”

- I got off medication & learned to avoid milk, caffeine, and sugar, which make my anxiety and symptoms get worse
- I took classes in yoga and meditation and began to see an acupuncturist
- I learned to watch for early warning signs of problems, and through WRAP (Wellness Recovery Action Planning), have wellness tools to support myself, such as regular exercise & paying close attention to my sleep patterns
- I took classes in “Brain Fitness” and learned to organize, plan, focus and remember things
- Most importantly, I reached out to other people who had also been diagnosed as mentally ill, and we began supporting each other in discovering our own pathways to healing and rebuilding a life
What does what we have learned, mean for how services should act?
Implications of research for services....

Research taught us....

- Recovery is possible

- Recovery can occur with/without professional intervention

- People are interested in outcomes such as achieving a valued role (i.e. worker, student, homemaker); better physical health; feelings of well being, reduced symptoms, better interpersonal connections etc.

So Services need to understand...

- Just surviving in the community is no longer acceptable- people want and can have a life

- Leaving care may be a sign of health

- People have a level of expertise themselves

- Recovery has to be the vision for many different kinds of services — crisis intervention, case management, PSR , treatment etc.
Role of Services

- All should focus on one Recovery vision or goal
- Believe in person no matter what

Farkas 2011
Implications for Mental Health Services

**Research Findings**
- Recovery is important for families as well
- Culture can increase internalized stigma

**Implications**
- When involving families, must take the phases of their own recovery process into account (e.g. Davidson et al., 2005; 2006; Spaniol et al., 2000; Spaniol, 2010)
- Individual has same values, same sense of meaning, same expectations of mental illness as rest of culture they come from - these can become an obstacle to recovery (e.g. Corrigan, Watson & Barr, 2006)
Role of Family, Friends, Community

- Believe in person & possibilities even when person does not
- Be educated on recovery, interventions, research, services
- Be a role model, mentor, support as wanted & needed
Implications for mental health care

- Recovery is based on a set of values

- It is not just what you do that makes a difference—but how you do it (ie. practice with evidence + values = best practice)

- Farkas 2006
What we learned about Recovery, developed an accepted Value base for recovery oriented services

- Focus on people
  - (Strengths, talents, interests)
- Partnership
  - “Nothing about us without us”
- Choice / Self Determination
- Hopefulness
  - (Future orientation)

- not cases
- not compliance
- not coercion
- not helplessness

Adapted from Farkas, Gagne, Anthony, Chamberlin 2005; Farkas 2007
In the workshop today I described the elements of a recovery oriented service....what about the larger field? Are innovations putting these values into place?

SOME EXAMPLES FROM RESEARCH, KNOWLEDGE TRANSLATION AND MENTAL HEALTH SYSTEMS
Partnership: Peer Developed Interventions, Researched by non peers

- Example: WRAP, Wellness Recovery Action Plan-
- Mary Ellen Copeland and Sherry Mead (2015).

Partnership: Peer Developed Interventions, Researched by non Peers

Maria Restrepo Toro, Cheryl Gagne, Zlatka Russinova, Philippe Bloch, Sharon Pritchett et al., 2015
PARTNERSHIP: Leadership of MH services/system

Director, SAMHSA / CMHS, Paolo del Vecchio
CHOICE: Putting Recovery Values into Practice: Array of EBP/Promising Practices supporting recovery

- IPS
- Housing First
- Illness Management and Recovery (IMR)
- Cognitive remediation with Rehabilitation
- Psychiatric Rehabilitation approach/ Choose-Get-Keep
- Stigma Photovoice
- Peer support, Supported education, Recovery Colleges

Drake & Becker, 2014
Padgett, Gulcur & Tsemberis, 2006
Gingrich & Mueser 2010
McGurk, Shiano et al, 2010
Anthony et al, 2002; Shern et al, 2000; Swildens et al., 2011
Gagne, Bowers, Russinova, Bloc et al., 2010; Russinova, Rogers, Gagne et al., 2014
HOPE: Peers and non peer developed curriculum for vocational aspirations

Deborah Nicolellis, Marianne Farkas & Lyn Legere, 2015
Hope: Professionals with and without lived experience, developed tools to share inspiring messages

Recovery4US App

Russinova, Farkas, Mizock, Bloch et al., in preparation

Hope is a renewable option: If you run out of it at the end of the day, you get to start over in the morning." - Kingsolver"
Putting values into practice: Recovery Tools for the workforce

General Recovery Promoting Competencies

Core Skills: Partnering, Choosing, Teaching, Inspiring

Strategies to promote hope, self acceptance, empowerment

Discipline Specific interventions

Farkas, Hutchinson et al., 2016
So back to Deinstitutionalization.......  

As a “late adopter”, research shows us Belgium can reduce its beds more quickly than other countries have (Shen & Snowden, 2014)

Psychiatric beds per 100,000

2014, WHO Data on Psychiatric beds in Mental Hospitals
What lessons can Belgium incorporate from what research & experience taught us to date?
Actual Deinstitutionalization is a complicated long term process as is recovery

- Reduced bed capacity does not mean reduced need/demand for services
- Reconfiguring services doesn’t mean immediate improvements in clinical outcomes and quality of life for people
- Training workforce doesn’t mean staff immediately can/do use new skills
- Embedding alternative services in health care, mental health, employment, education, social services is required and does not cost less
- Recovery oriented community mental health care has to be a long term commitment by governments

Shen & Snowden, 2014; Thornicroft, Deb & Henderson 2016; WHO 2014; Anthony et al, 2002; Farkas & Anthony 2010
AND the outcome of real deinstitutionalization should be Recovery.

i.e. No less than....

LIVING THE LIFE PEOPLE THEMSELVES FIND MEANINGFUL