Recovery and social inclusion of people with severe mental illness:

Past, present, and future directions

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Stavanger, September 8th, 2014
Social inclusion
in the eyes of persons with disabilities

Critical themes:
- Recognized and accepted as an individual
- Personal relationships (family, friends, acquaintances)
- Involved in leisure and social activities
- Appropriate housing
- Employment and training/education
- Professional and natural supports, and developing personal abilities

(Hall, 2009)
Social inclusion

Requires social change, of two types:

1. Reducing social barriers to integration (refining accommodations)

2. Creating opportunities for social participation:
   • aimed at developing competencies of persons with SMI (lies within scope of MH services)
   • aimed at exercising competencies by persons with SMI (falls to the larger society)
Three topics

- From the past to the present: Growing optimism in the rehabilitation literature
- Present: State of the art of psychiatric rehabilitation today
- Future: Trending topics for the next decade
Ambitions and optimism in the rehabilitation literature (US)

Objectives:
- Full community integration
- Avoid placements in segregated settings
- Service users can experience change and growth
- Community is full of opportunities
- 'Flourishing, not functioning’ is the envisioned outcome

(Drake et al., 2005; Ware et al., 2007; Hopper, 2008; Corrigan et al. 2009; etc.)
Psychiatric Rehabilitation in the past

Douglas Bennett and Geoff Shepherd in the 1980s:

- The aim of rehabilitation is to enable clients to function optimally by addressing their ‘residual capacities’
- while recognizing that they still needed a supportive environment because of their permanent limitations
- In plain terms, it was about ‘making the best of things’.
Ambitions and optimism in the more recent rehabilitation literature (UK)

Definition of rehabilitation:

- “A whole systems approach to recovery from mental ill health which maximizes an individual’s quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future and which leads to successful community living through appropriate support”

(Killaspy et al., 2005)
Raising the bar: Why?

Trends in western societies:
- Emancipation of minority groups
- ‘Follow your dream’
- Positive psychology

Specific reasons in mental health:
- De-institutionalisation: higher expectations
- Government policy: social inclusion of disadvantaged groups
- Evidence-based interventions available (ACT, IPS, BU approach)
- Recovery movement: high ambitions (‘the dignity of risk’)
The recovery concept definitions

- “Recovery is a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993)

- “Recovery is learning to live better in the face of mental illness” (Davidson, 2009)
Recovery

Dimensions (Dröes & Plooy, 2010):

- Recovering (mental) health
- Recovering personal identity
- Recovering social roles in the community

- Danger of maintaining a fixed sequence: first..., than...
Recovery and rehabilitation
‘Two of a kind’

Similarities:

- The same principles:
  - emancipation, empowerment, self-determination, agency
- Risk taking is part of the game ('the dignity of risk'):
  - Responsible and irresponsible
  - Timing is everything (Wilma Boevink)
  - ‘mountain climbing ‘ (John Strauss)
- Active acceptance of limitations
Rehabilitation and recovery
‘world pole and self pole’

Differences:

▪ Rehabilitation: from the medical profession; recovery: from the MH consumers/survivors movement
▪ ‘Recovery is done by clients themselves’
▪ Partiality versus comprehensiveness
▪ Finite versus long-term processes
▪ Expectations and hope
▪ Outcome and their measurement (oil and water, or oil and vinegar?)
Present:
state of affairs & state of the art
Loss and desire

- National Panel ‘Severe mental illness’ (appr. 900 persons)
- Many unmet needs in the domains of:
  - Interpersonal relationships, employment (17% currently employed), community integration and active citizenship
National panel

Experienced negative discrimination, mostly in:

- Making and keeping friends: 30%
- Finding and keeping a job: 27%
- In his/her social life: 21%
- Most respondents felt the need to hide their diagnosis (67%)

Anticipated discrimination (‘Why Try?’):

Many felt inhibited because of their diagnosis to
- apply for a job or start new education (54%)
- start close intimate relationships (42%)

- “If men define situations as real, they are real in their consequences” (W.I. Thomas (sociologist), 1928)
Counteracting social isolation

Multiple causes:
- Troublesome symptoms & disabilities
- Lack of social experiences or skills
- Inaccessible public services and environments
- Financial constraints (poverty)
- Social rejection: stigma, (anticipated) discrimination
- Not in contact with positive role models

Multiple strategies:
- Effective treatment; self management of symptoms
- Rehabilitation programmes
- Community connecting; creating social niches
- Practical help; income support
- Anti stigma programmes
- Self help groups; peer-led recovery programmes
Rehabilitation in the NL: diversity in the delta

In the 1980s and 1990s inspired by:
- Social and independent living skills (SILS; Liberman c.s.)
- Boston University approach (Anthony c.s.)
- British approach: Douglas Bennett and Geoff Shepherd

Later also by:
- Strengths model
- IPS (and other EBPs, like ACT, IMR)
- Recovery concept
Rehabilitation
Similarities UK and NL

- Despite much lip service, rehabilitation has low status in MH field
- Vanguard of dedicated and innovative professionals and researchers
- Small but steadily growing evidence base of rehabilitation interventions
- Low status in academic psychiatry (although improving)
- Rehabilitation virtually absent in multidisciplinary guidelines for depression, bipolar and anxiety disorders
- Rehabilitation virtually absent in initial training of psychiatrists, nurses, and psychologists
- Knowledge base bigger in some domains (employment) than in others (housing, education, social relationships, daily activities)
- Implementation of evidence-based interventions mostly poor
Effectively working on rehabilitation goals: 24 month outcome of a randomized controlled trial on the Boston Psychiatric Rehabilitation approach

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Research funding: the Netherlands organisation for health research and development ZonMw
Objective

- Investigate the effect of Boston Psychiatric Rehabilitation (BPR) compared to Care As Usual (CAU) with patients with Severe Mental Illness (SMI)

- BPR systematic methodology; Anthony, Farkas et al.
- Explore. choose and realize rehabilitation goals
- Areas: work, daily activities, learning, social contacts
- Three phases
  1. setting a goal
  2. planning interventions; skill training & support
  3. carrying out interventions
% Success in rehabilitation. Defined as reaching a personal rehabilitation goal in one of the rehabilitation areas (n=156)

Outcome after two years

**BPR**
- No: 48%
- Yes: 52%

**CAU**
- No: 32%
- Yes: 68%

Risk difference: 21%; 95% CI <4% to 38%>; NNT = 5
Conclusion
Effectiveness BPR after two years

Primary outcome criterion:
BPR is more effective than care as usual in realising a personal rehabilitation goal (patients point of view)

Secondary outcome criteria:
- No (extra) effect on social functioning, quality of life and unmet needs for care
- A positive effect BPR on societal participation

NB: Work in progress: a multisite cost-effectiveness study on BPR in the NL
User run recovery programmes in NL: two recent RCTs

- Outcomes of TREE (Boevink et al, 2011)

- Outcomes of ‘Recovery is up to you’ (Van Gestel-Timmermans et al, 2011):
  - Both studies indicated favourable outcomes, notably on the dimension ‘recovery of personal identity’, and also on ‘recovery of health’ but not on the third dimension: ‘recovery of social roles’

The next generation of recovery programmes:
- Stronger focus on issues of participation and social inclusion?
Is employment good or bad for people with severe mental illness?

“For most people, most of the time, good work is beneficial for mental health” (Henderson, 2011)

“If you think work is bad for people with mental illness, try poverty, unemployment, and social isolation” (Marone & Golowka, 2000)
The importance of employment

- For most people *employment* plays a central part in their recovery stories
- But most also feel that services do not give them much encouragement in this area
- In addition, while expressing an interest in obtaining paid employment, most service users also (correctly) anticipate problems:
  - financial (loss of Benefits)
  - interpersonal (stigma issues) from employers and workmates
  - ‘illness-related’ (worries about precipitating relapses, ‘*becoming ill again*’
‘Individual Placement and Support’ (IPS)  
(Becker & Drake, 1994)  

- Competitive employment is the goal (whole or part-time)  
- No selection criteria, beyond expressed motivation, i.e. accessible to all who want to work (‘zero exclusion’)  
- Focus on consumer preference – ‘fitting the job to the person’  
- Based on rapid job search and placement. Minimises pre-employment assessment and training - ‘place-then-train’  
- Relies on close working between employment specialists and clinical teams  
- Provides individualized, long-term support with continuity  
- Builds a network of employment opportunities (job development)  
- Includes access to expert benefits counseling
Effectiveness of Individual Placement and Support for people with severe mental illness in the Netherlands: a 30 months follow-up Randomized Controlled Trial

Harry Michon, Jooske van Busschbach, Dennis Stant, Maaike van Vugt, Jaap van Weeghel, Hans Kroon

Psychiatric Rehabilitation Journal, Spring 2014
Follow-up 30 months main outcome (competitive work)
IPS model fidelity

- GGZE
- LENT
- PAME
- DIME

Moderate fidelity

1st, 2nd, 3rd
A glimpse at other results – T30

- In both groups increase in quality of life, mental health and self-esteem
- IPS group slightly stronger increase in quality of life and mental health condition (non sign.)
Conclusions

- Participants in IPS group found competitive work more often than participants in TVS.
- Substantive employment results considering baseline confirms effectiveness of IPS in terms of helping persons with SMI find paid employment.
- IPS not easy to implement; probably IPS effects even stronger if implemented properly.
IPS as a christmas tree
(add-on interventions)

- IPS plus modern pharmacological treatment
- IPS plus motivational interviewing
- IPS plus cognitive behavioral therapy
- IPS plus cognitive remediation
- IPS plus Work Place Fundamentals
- IPS plus self-management of symptoms
- IPS plus supported education
- IPS plus sociale support
- IPS plus WRAP (NL)
- IPS and disclosure
CORAL
(Conceal Or ReveAL)

- Decision aid (Henderson et al., 2013)
- Disclosure of mental illness in employment situations

Six themes:
1. Advantages and disadvantages of disclosure
2. Individual needs regarding disclosure
3. Personal values in this
4. When to disclose
5. To whom?
6. How to disclose
IPS Breakthrough project
early intervention psychosis

- 10 NL early intervention teams participate
- Shared Decision Making
- IPS (addressing both employment and education)
- Decision aid CoRAL (Conceal or Reveal; Henderson e.a., 2013), enabling disclosure
- Cognitive enhancement
- Multisite RCT: IPS (control) versus IPS plus cognitive enhancement (experimental condition)
Employment Specialist Role
(Corbière, 2012; Drake et al, 2006; Dreher et al, 2010; Rinaldi et Perkins, 2007; Rinaldi et al, 2008)

His/her role consists of several activities (not exhaustive):

1. Work closely with their client to plan work integration considering their interests and preferences;
2. Coordinate with other team members of the clinical team career goals of their clients;
3. Interact with key stakeholders (e.g. employers, case managers, family)
4. Provide advice to clients regarding benefits;
5. Work most of their time in the community to meet potential employers;
6. Provide support to people who are already employed;
7. Suggest work accommodation to facilitate work integration of their clients.
Employment specialist competencies needed to help people with severe mental disorders enrolled in SE programs

Marc Corbière, Evelien Brouwers, Nathalie Lanctôt, and Jaap van Weeghel

Journal of Occupational Rehabilitation, September 2013
Exploratory factor analysis results for the BAKES questionnaire (n=153) (Corbière et al., 2013)

1. Outreach and Work accommodations (12 items)
2. Support in identifying work interests and labor market (6 items)
3. Job search strategies (6 items)
4. Social behaviors and healthy lifestyle (6 items)
5. Adaptation to and dealing with the workplace culture (6 items)
6. Relationships with employers and supervisors (10 items)
7. Relationships with mental health professionals (9 items)
8. Dealing with stigma and self-stigma (7 items)
9. Support and client-centered approach (9 items)
10. Knowledge of clinical symptoms and health/vocational services (11 items)
11. Knowledge of the workplace (5 items)
12. Knowledge of the laws and policies related to disability (3 items)
Conclusion

- Our results paint a detailed picture of the employment specialists' competencies -- **90 competencies spread over 12 subscales** (dimensions).

- The subscale entitled *Relationships with employers and supervisors* is significantly related to work outcomes (obtaining and maintaining employment).

- This subscale is often translated in the literature as **systematic job development** and **follow-along support** (Drake, Bond, and Becker, 2012; Leff et al., 2005):
  - To cultivate a relationship with employers;
  - To offer individualized and continued supports for as long as the client wants and needs the supports.

- The BAKES can be a **useful tool for IPS programs** to verify if new employment specialists have integrated all competencies needed to improve their training.
To summarize: Best Practice in rehabilitation

1. Emphasis on client-centered services: empowering to make choices, to be as independent as possible
2. Start with rehabilitation at day-one (e.g. in treating early psychosis)
3. Focus on skills and supports needed in community life
4. Specificity: develop skills for particular tasks and individual settings
5. Rehabilitation embedded in broader community support system – partnerships with voluntary sector, mainstream colleges, employers, etc.
6. Early involvement in community activities (‘first place-then-train’)
7. Rehabilitation integrated with clinical services (multidisciplinary teams in community settings)
8. At public level: accommodation of legislation and regulations
9. Anti stigma interventions complementary to rehabilitation
10. Attract and train staff who are passionate about this service user group (high energy but low expressed emotion)
Future directions

- Innovate
- Evaluate
- Implement
# Psychiatric rehabilitation in NL: priorities in R&D agenda

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<th>Rehab. domains:</th>
<th>Innovate (new interv. needed)</th>
<th>Evaluate (effect studies needed)</th>
<th>Implement (nationwide)</th>
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<td>Comprehensive rehab. approaches</td>
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<td>Daily activities (other than work or education)</td>
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<td>Anti stigma programmes</td>
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Counteracting public stigma

Five principles:

- Organising contact between people with and without mental illness is the key issue
- Contacts must be targeted at critical groups in the community (e.g. employers!)
- Local contact programmes are more effective
- Contacts must have credibility (clients in the lead)
- Contacts must be continuous

(Corrigan, 2011)
Future directions in rehabilitation

- Continue to embrace the recovery framework for developing rehabilitation practices, also by using experts-by-experience
- Continue to have focus on social inclusion:
  ♦ through specific programmes to facilitate access to mainstream leisure, education and work, and to support them as needed with this
  ♦ (local) government policies supporting social inclusion of service users
  ♦ and by continuing to challenge stigma and discrimination at a local level (and by supporting national anti-stigma campaigns)
- Continue to develop the evidence base for rehabilitation services and interventions
- Implement interventions where there is already an evidence base (e.g. BU approach and IPS)
- Develop rehab-online programmes (self management in rehabilitation, with rehabilitation professionals as back-ups)
- Trending topics: parental roles, physical fitness
- Develop specific interventions (e.g. illness management at the work place) for the use of rehabilitation goals (e.g. securing employment)
- Have a loud voice at the policy level!

(Killaspy & Van Weeghel, 2011)
Form catenaccio to community participation

- Trieste was not only the source of the catenaccio system (Nereo Rocco, Triestina): extremely defensive football in the 1950s; Catenaccio means: chain.
- In the 1960s: Inter Milan successful with this system (H Herrera)
- Trieste was also the birthplace of the Democratic Psychiatry in the 1970s: a very offensive, progressive way of practicing psychiatry
- Key question: How to switch smoothly from a dominantly defensive (catenaccio) mode of working (solving problems, conflicts & crises) into an offensive, developmental approach (and vice versa).
- This is the objective of our current study VICTORIA: Societal participation and managing risks of victimisation among people with SMI
- We need an appropriate strategy for this, plus effective strikers and creative midfield players in the MH teams to implement it
Thank you for your attention