Contemporary Mental Health Rehabilitation in the UK

Dr Helen Killaspy
Reader and Honorary Consultant in Rehabilitation Psychiatry, University College London and Camden and Islington NHS Foundation Trust, London

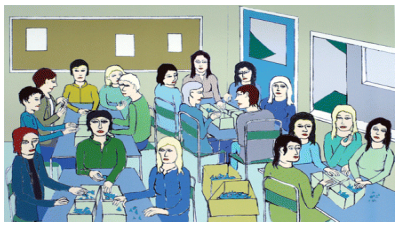
Chair, Faculty of Rehabilitation and Social Psychiatry, Royal College of Psychiatrists

1980s: rehabilitation

"The process of minimising psychiatric impairments, social disadvantages and adverse personal reactions so that the disabled person is helped to use his or her talents and to acquire confidence and self-esteem through experiencing success in social roles."

Wing, JK. (1980). Innovations in social psychiatry. *Psychological Medicine,* **10**, 219-230.

Rehabilitation in the asylum

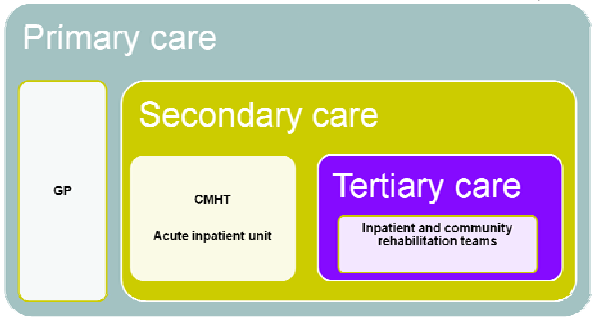


"Industrial Therapy"

by David Beales , 2006

1990s: rehabilitation and community "resettlement"

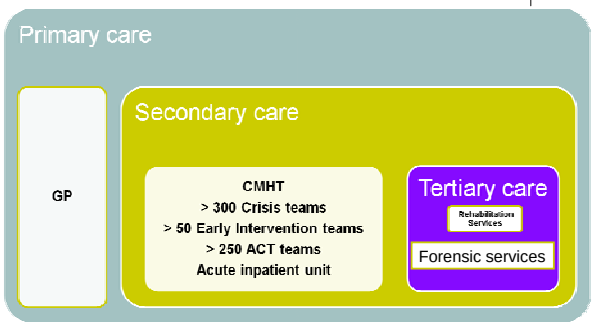
General adult mental health services in England: 1990s



Outcomes of deinstitutionalisation

- Trieman, N. & Leff, J. The difficult-to-place patients in a psychiatric hospital closure programme. TAPS Project 24. *Psych Med*, 1996, **26:** 765-774.
  - Majority of those who moved directly to community remained out of hospital.
- Trieman, N & Leff, J. Long-term outcome of long-stay psychiatric inpatients considered unsuitable to live in the community. TAPS Project 44. *BJPsych*, 2002, **181:** 428-432
  - Majority of those most "difficult to place" able to move on 5 years after closure of Friern Hospital.

10 years later….2000



2000: what is rehabilitation?

- Rehabilitation services missing from National Service Framework for Mental Health (DH, 1999)
  - Lack of clarity on what rehabilitation was
  - Who it was for
  - Whether it was needed

UK Mental Health Rehabilitation Services in 2007

(Mountain et al., *Psychiatric Bulletin*, 2009, **33:** 215-218)

- Most services had undergone multiple changes since 2004
- Reduction in resources in >50% services
- 33% reported reinvestment of rehabilitation resources into other specialist inpatient and community services
- 25% community rehabilitation teams rebadged as ACT teams
- 30% had low secure unit (doubled since 2004)

Re-institutionalisation

- Rise in independent sector beds 1990s onwards (Poole et al, 2002)
- 22% placements made out of area in 2008-9
- Huge expense to NHS and Social Services (£330m in 2008-9)
- Out of area placements cost, on average, 65% more than local placements
- Phenomenon across Europe (Priebe et al, 2005)
- Social dislocation, institutional practices, disincentives for move-on, variable quality, poor review systems (Ryan et al, 2004; 2008)
- "Virtual asylum"

The forgotten need for rehabilitation

Report by the Royal College of Psychiatrists (FR/RS/01: Holloway, 2005) emphasised need for:

- Local, specialist mental health rehabilitation services for small group of service users with complex needs
- Development of an evidence base for contemporary mental health rehabilitation services:
  - Nature and provision of rehabilitation services and service user characteristics
  - Cohort studies to identify factors associated with successful rehabilitation
  - Trials to test efficacy of rehabilitation service models and interventions
  - Cost-effectiveness studies

Contemporary mental health rehabilitation services in England

- >80% NHS Trusts have "short term" units (mean 3 units per Trust)
- 50% Trusts have longer term units too

Shorter term units:

- Accept referrals from acute admission wards and secure/forensic services
- 59% in community, 11% hospital wards, 29% houses in hospital grounds
- Mean beds = 14 (SD 5)
- Mean length of stay = 14 months (SD 11)
- Mean discharges per year = 13
- Multidisciplinary staffing: rehabilitation psychiatrist, junior Dr, occupational therapist, clinical psychologist, nurses, support workers
- 30% units employ ex-service users
- 56% services have community rehabilitation team

(Killaspy et al., 2005; Killaspy et al, 2011)

Contemporary definition of mental health rehabilitation

"A whole system 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)

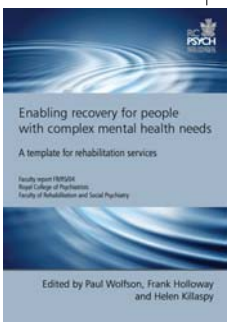
Users of contemporary mental health rehabilitation services

- 67% male
- 80% schizophrenia/schizoaffective disorder, 8% bipolar affective disorder plus:
  - treatment resistance; cognitive impairment; negative symptoms
  - poor social functioning
- 17% pre-existing/co-existing problems:
  - learning disability; developmental disorder; organic brain injury; depression, anx.
  - substance misuse (10%)
- 60% significant history of risk:
  - 20% previous admission/s to forensic/secure settings
  - 58% risk to others ever (21% in last 2 years, 2% serious assault in last 2 years)
  - 27% non-adherence and absconsion
  - 45% self-harm ever
  - 49% self-neglect ever
  - 25% vulnerable to exploitation
- Higher needs vs. community samples (including physical health)
- Mean length of psychiatric history = 16 years (SD 12)
- Mean admissions = 6 (SD 6)

(Killaspy et al., 2008; Killaspy et al., 2011)

Contemporary mental health rehabilitation services in UK

- Service users with complex needs
- Recovery orientation
- "Whole system" approach
- Work with service planners and other providers (voluntary and independent organisations)
  - Residential/housing
  - Socially inclusive activities
- Promote move-on ethos
- Minimise use of out of area placements
- Staff: low expressed emotion, high energy
- Therapeutic optimism
- Long term view



Rehabilitation tools

- NICE guidelines for the treatment of schizophrenia (2002)
  - Medication (limited evidence after clozapine)
  - Cognitive Behavioural Therapy
  - Family interventions
  - Vocational rehabilitation, especially Individual Placement and Support
- Occupational therapy & community activities
- Supported housing

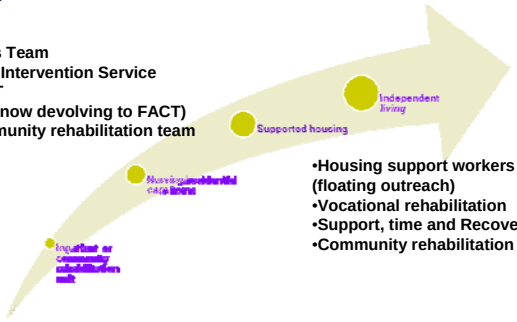
Cost of rehabilitation services

- About 1% of people with a diagnosis of scz receive treatment from a rehabilitation service in UK
- 15-20% of mental health beds are rehabilitation beds
- "Low volume, high need" group
- In 2009-10, 51% of total adult mental health and social care budget in UK (£6bn) spent on services for people with longer term mental health problems. Half spent on rehabilitation services and specialist mental health supported accommodation

(Mental Health Strategies, 2010).

Stepped care model of rehabilitation and supported accommodation in England

•GP
•Crisis Team
•Early Intervention Service
•CMHT
•ACT (now devolving to FACT)
•Community rehabilitation team



•Housing support workers (floating outreach)
•Vocational rehabilitation
•Support, time and Recovery
•Community rehabilitation team

Institutional care in Europe

- Muijen, M. Mental Health Services in Europe: An Overview, *Psych Services*, 2008:
  - Vast majority of people with mental health problems in Europe reside in an institution
- Priebe et al., 2003, *BMJ* 326, 175-6
  - "The private madhouse is back"
- Amnesty International, Mental Disability Rights International, Mental Disability Advocacy Center
  - Reports of abuses of care and appalling conditions in some countries
- Out of area placements in UK (Ryan et al., 2004; 2008)

Development of a Measure of Best Practice in Institutional Care for people with longer term mental health problems (DEMoBinc study)

- To build a toolkit to assess quality of institutional care for people with longer term mental health problems in countries at different stages of deinstitutionalisation
- Use "recovery model" as framework for assessment of dignity and human rights
- Include hospital and community based "institutions"
- Toolkit designed to be completed by unit manager
- Assess correlation between manager (toolkit) rating and service user experience (quality of life, autonomy, experiences of care, markers of recovery)

DEMoBinc consortium

Dr Helen Killaspy (co-ordinator), Professor Michael King, Tatiana Taylor, University College London and Dr Paul McCrone (Kings College London, health economist) - **UK**

Dr Christine Wright, Sarah White, Penny Turton, Husnara Khanom St George's University London - **UK**

Professor Dr Thomas Kallert, Dr Matthias Schuetzwohl, Mirjam Schuster, Technische Universitaet Dresden – **Germany**

Professor Jorge Cervilla, Dr Blanca Gutiérrez, Paulette Brangier, Danilo Manilos, Universidad de Granada - **Spain**

Professor Jiri Raboch, Dr Lucie Kalisova, Dr Martin Cerny, Alexander Nawka, Charles University Prague – **Czech Republic**

Dr Georgi Onchev, Dr Hristo Dimitrov, Alexiev Spiridon, Medical University Sofia – **Bulgaria**

Ass. Professor Giuseppe Dell'Acqua, Dr Roberto Mezzina, Dr Pina Ridente, Dr Kinou Wolf, Department of Mental Health, Trieste - **Italy**

Professor Durk Wiersma, Annemarie Caro, Ellen Visser, University Medical Centre, Groningen – **Netherlands**

Professor Andrzej Kiejna, Dr Joanna Rymaszewska, Patryk Piotrowski, Wroclaw Medical University - **Poland**

Professor Dimitris Ploumpidis, Dr Theodore Megaloeconomou, Frangiskos Gonidakis, George Konstantanopoulos, University Mental Health Research Institute, Athens – **Greece**

Professor Jose Miguel Caldas de Almeida, Ass Professor Graca Cardoso, Carla Coelho, University Nova Lisbon - **Portugal**

International expert panel

Recovery - Jerry Tew **(UK)**

Social care - Tony Ryan, Michael Clark **(UK)**

Rehabilitation - Dr Jaap van Weeghel **(Netherlands),** Dr Joanna Meder **(Poland),** Prof Geoff Shepherd **(UK),** Prof. Tom Craig **(UK),** Dr Frank Holloway **(UK)**

Service users - Maurice Arbuthnott, Vanessa Pinfold **(UK)**

Human rights law - Ass. Prof. Luis Fernando Barrios-Flores **(Spain)**

International mental health law - Prof. Peter Bartlett **(UK)**

International mental health policy - Prof. Jose Miguel Caldas de Almeida **(Portugal)**

Disability rights - Liz Sayce **(UK)**

Care standards - Dr Geraldine Strathdee **(UK)**

DEMoBinc Study 2007-2010

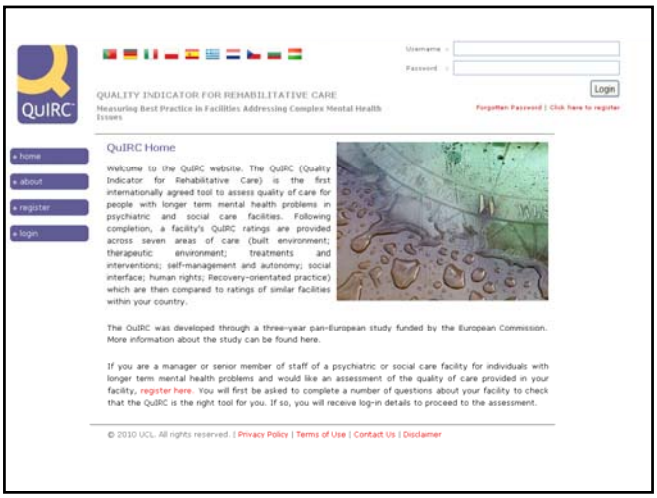
1. Identified "critical success factors" for recovery in institutional care from systematic review, international Delphi exercise and review of care standards
2. Built toolkit (>150 questions)
3. Assessed usability, usefulness and reliability of toolkit (>200 units)
4. Refined toolkit (factor analysis, feedback from managers)
5. Association between toolkit (manager) ratings and service user perspectives: autonomy; quality of life; therapeutic milieu and experiences of care (1750 service users)
6. Health economic component

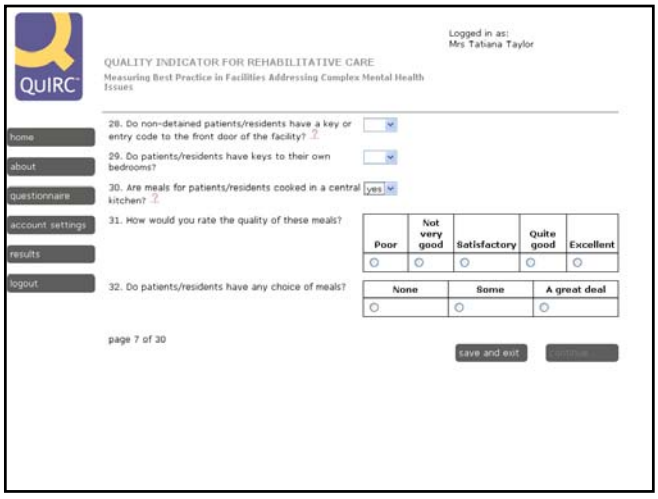
DEMoBinc toolkit

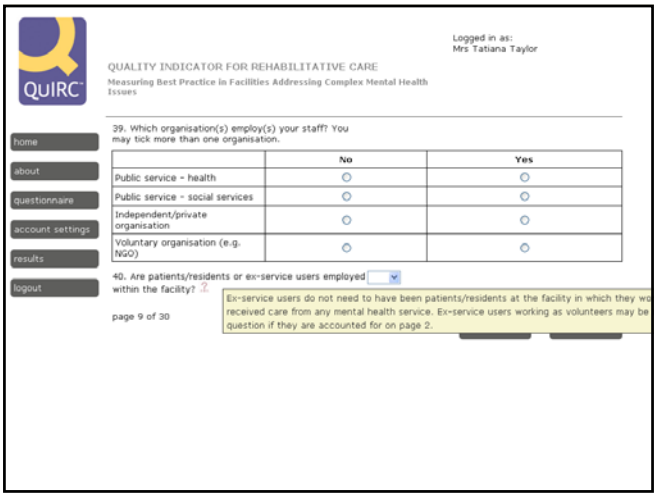
- Some descriptive items (don't contribute to score)
- Many questions contribute to > 1 domain
- Questions have different scoring structures
- Phrased to avoid "right" answers
  - Staffing, staff training, supervision
  - Built environment
  - Interventions, treatments and activities
  - Care planning
  - Service user involvement
  - Choice/autonomy, promotion of independence
  - Physical health promotion
  - Dealing with challenging behaviour
  - Access to and involvement in community
  - Family support and involvement
  - Complaints, confidentiality, access to advocacy/lawyer

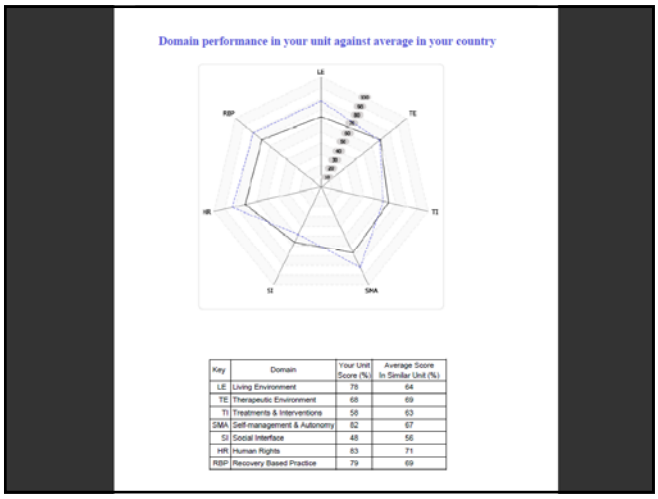
DEMoBinc results

- High reliability
- Factor analysis - 7 domains of care
- 145 questions – takes about an hour
- All domain scores associated with the degree to which the unit promoted service users' autonomy and with service users' experiences of care (but not quality of life or therapeutic milieu)
- Major variation in costs across countries and no consistent association with domain scores or service user characteristics





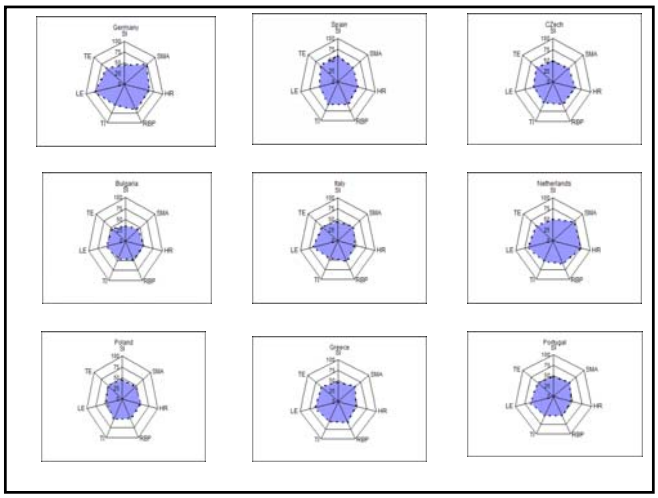




Key	Domain	Your Unit Score (%)	Average Score in Similar Unit (%)
LE	Living Environment	78	64
TE	Therapeutic Environment	68	69
TI	Treatments & Interventions	58	63
SMA	Self-management & Autonomy	82	67
SI	Social Interface	48	56
HR	Human Rights	83	71
RBP	Recovery Based Practice	79	69

Pan-European QuIRC domain scores

	Mean	SD	Min	LQ	UQ	Max
Human Rights	57	12.7	25	48	66	83
Living Environment	60	15.5	16	48	71	89
Recovery Based Practice	53	12.6	16	44	62	82
Social Interface	49	14.7	14	38	58	89
Self-Management and Autonomy	55	15.5	17	44	67	86
Therapeutic Environment	52	9.5	21	46	59	78
Treatments and interventions	51	9.1	28	45	56	80



Outcomes from DEMoBinc

- Reliable, comprehensive tool (QuIRC)
- Accessible
- Useful - local, national and international level
- Quality benchmarking (e.g. AIMS-Rehab)
- Audit
- Research:
  - evidence for rehabilitation/longer term mental health care
  - service quality and outcomes
  - guide investment and focus interventions

How effective is mental health rehabilitation?

- Few studies
- Contemporary rehabilitation poorly defined

- Harding, CM., Brooks, GW., Ashikaga, T., Strauss, JS., Breier, A. The Vermont longitudinal study of persons with severe mental illness, I: Methodology, study sample, and overall status 32 years later. *Am J Psychiatry,* 1987, **144**:718-726
  - Two thirds of long stay patients who had had a 10 year rehab programme (1955-65) showed no signs of schizophrenia at all 32 years later.

- Research findings from Netherlands (Boston model) – promising

Outcomes for service users with complex mental health needs in Ireland

(Lavelle, Killaspy, Ijaz, Holloway et al, 2011)

- 200 service users in five centres (Dublin N, Dublin S, Cavan/Monaghan, Clare, Wexford)
- 126 receiving rehabilitation and 74 wait listed
- Predictors of outcomes compared 18 months later:
  - Social functioning (Life Skills Profile)
  - Successful progress:
    - If inpatient at recruitment, discharged without relapse/readmission/loss of placement
    - If community patient at recruitment, maintenance of placement without admission and/or progression to less supported placement

Predictors of outcome at 18 months

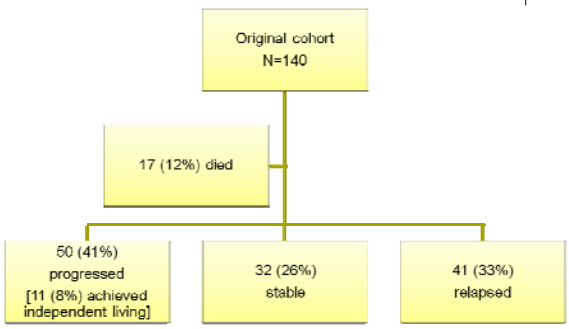
		Successful progress			LSP at follow-up		
		OR	95% CI	p	coef.	95% CI	p
Access to rehab	No	1					
	Yes	**8.44**	4.16 to 17.16	**<0.001**	**6.15**	3.28 to 9.02	**<0.001**
Length of illness	Per 5 yrs	1.06	0.92 to 1.21	0.421	-0.49	-1.14 to 0.17	0.143
Positive symptoms		0.96	0.90 to 1.03	0.241	-0.07	-0.42 to 0.28	0.692
Negative symptoms		1.00	0.95 to 1.06	0.919	0.19	-0.10 to 0.48	0.195
Unmet needs		**0.76**	0.66 to 0.88	**<0.001**	-0.39	-1.05 to 0.27	0.249
Substance misuse		**0.13**	0.04 to 0.47	**0.002**	**-5.73**	-10.49 to -0.97	**0.018**
Challenging behaviours		**0.51**	0.35 to 0.75	**0.001**	-0.76	-1.75 to 0.23	0.132

Components of rehabilitation associated with successful progress

		Odds Ratio (se)	95% CI	p-value
Inpatient status	Inpatient	0		
	Community	**14.39 (9.78)**	3.79 to 54.54	**<0.001**
Meaningful Occupation	Hours per week	1.01 (0.01)	0.98 to 1.04	0.508
Psychosocial intervention sessions	No. last 6 months	1.00 (0.02)	0.96 to 1.05	0.827
Length of time in receipt of rehabilitation services	Months	1.02 (0.01)	0.99 to 1.05	0.183
Prescribed Clozapine	No	0		
	Yes	1.56 (0.64)	0.70 to 3.50	0.280
Dose of antipsychotics	% BNF max	1.00 (0.00)	1.00 to 1.00	0.686

5 year outcomes for rehabilitation service users in Camden and Islington, London

(Killaspy and Zis, 2011)



Factors associated with not progressing

	OR (SE)	95% CI	p-value
Age in 2005	**0.929** (0.025)	0.885 to 0.976	**0.003**
Evidence of non-adherence with medication 2005-2010	**33.566** (0.745)	0.789 to 144.656	**<0.001**
Challenging behaviours (SPRS C Score) in 2005	1.292 (0.306)	0.710 to 2.351	0.402
Social functioning in 2005 (LSP Communication sub-scale)	0.887 (0.104)	0.724 to 1.088	0.250
Detained under MHA in 2005	1.905 (0.804)	0.394 to 9.174	0.423
History of physical abuse	1.230 (0.760)	0.277 to 5.464	0.785

The REAL study: Rehabilitation & Effectiveness for Activities for Life

Helen Killaspy - Clinical academic rehabilitation psychiatrist, University College London (UCL) and Camden & Islington NHS Foundation Trust (CIFT)
Michael King - Clinical academic psychiatrist, UCL and CIFT
Frank Holloway - Psychiatrist, South London and Maudsley NHS Trust (SLaM)
Tom Craig - Clinical academic psychiatrist, Institute of Psychiatry (IoP), SLaM
Sarah Cook - Academic OT, Sheffield Hallam University (SHU)
Cathy Hill/Tim Mundy - Organisational psychologist, SHU
Paul McCrone - Health economist, IoP
Rumana Omar, Louise Marston - Statisticians, UCL
Maurice Arbuthnott - North London Service User Research Forum
Dr Gerry Leavey - Social scientist, N. Ireland Association of Mental Health
Wendy Wallace - Chief Executive, CIFT
Gemma Dorer, **Marieke Wrigley -** rehabilitation OT collaborators (CIFT, SLaM)
Nick Green, Isobel Harrison - researchers, UCL
Melanie Lean - Research project manager, UCL
Local collaborators - in almost every Trust in England

UK Mental Health Research Network · UCL · NHS National Institute for Health Research · Camden and Islington NHS Foundation Trust

REAL aims to:

- Phase 1: Survey current provision and quality (QuIRC) of mental health rehabilitation services in England
- Phase 2: Develop a simple training intervention for front-line rehabilitation staff to facilitate service users' activities of daily living, ward and community based activities
- Phase 3: Carry out a cluster randomised controlled trial to investigate the clinical and cost-effectiveness of the staff training intervention in poorer quality services
- Phase 4: Carry out a naturalistic cohort study to investigate outcomes for rehabilitation service users in better quality services and identify service and service user characteristics that predict better outcomes

Phase 1 preliminary results

- National QuIRC domain scores in 133 units (91% Trusts)
- **What factors influence unit quality (QuIRC)?**
  - MINI (local deprivation/psychiatric morbidity) score has most influence on QuIRC domain scores - Living Environment, Self Management and Autonomy, and Human Rights
    (decreases scores by up to 9% for each point increase in MINI)
- **How does unit quality influence service user outcomes?**
  - All QuIRC domain scores positively influence service user autonomy (Resident Choice Scale) and experiences of care (Your Treatment and Care);
    44-48% variance in autonomy and ~12% variance in experiences of care explained when adjust for age, gender, GAF and MINI.

Summary

- Rehabilitation services facilitate successful community living for people with complex mental health problems
- Tertiary, expensive resource
- 2/3 people have a successful outcome over 5 years
- Active components of rehabilitation not yet clear
- Medication adherence important
- Unclear who most able to benefit from rehabilitation
- Unclear how best to focus resource and interventions
- Supported housing pathway important – future research

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Contemporary mental health rehabilitation in the NL

Jaap van Weeghel

'Op zoek naar een betere prognose van de psychose'
Afscheidssymposium prof.Dr. Durk Wiersma
Groningen, July 7th 2011

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)
- Concept of recovery

Six questions

1. **Do we need to promote rehabilitation and social inclusion of persons with severe mental illness in the NL?**
2. What constitutes 'good' community care for people with severe mental illness?
3. Higher standards for MH rehabilitation in the western world: why?
4. Do current recovery practices in the NL have an impact on social inclusion?
5. What is the evidence base of MH rehabilitation in the NL?
6. What is the way ahead in the UK and the NL?
   - key differences and similarities
   - best practice: an anglo-dutch perspective
   - future directions rehabilitation in UK & NL

National Panel 'Psychisch Gezien'

- Conducted by Trimbos Institute (Karin Overweg & Harry Michon) , in collaboration with LP GGZ, NIVEL and Kenniscentrum Phrenos
- Representative sample of people with SMI in the NL (appr. 900 persons)
- Objective: periodically gather facts, opinions, etc. regarding (needs for) care services, social inclusion and other important themes in the lifes of people with SMI
- First measurement: October - December 2010
  - number of sent questionnaires: 752
  - number of questionnaires returned: 602 (response: 80%)

Employment

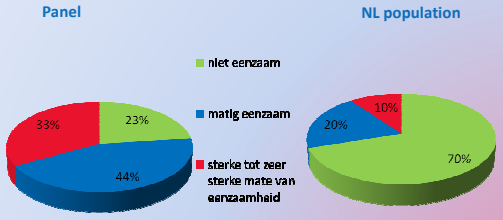
Participation

	Panel	CBS	NPCG
Paid job ≥ 12 hours	17% (13%-20%)	67%	36%
Volunteer job	41% (37%-43%)	42%	17%

Satisfaction

	Panel	NPCG
Paid job	66%	77%
Volunteer job	79%	93%

Total score loneliness



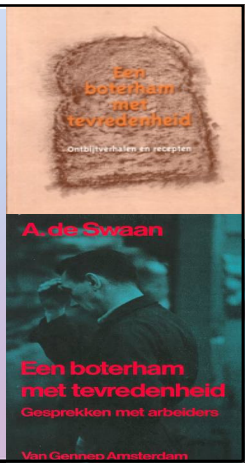
Loss and desire

Many unmet needs in the domains of:

- Interpersonal relationships, community integration and active citizenship

Quality of life

- Despite serious health problems, many social disadvantages etc. (i.e. low objective quality of life) many people with SMI do not report a low subjective quality of life
- "Een boterham met tevredenheid" (A. de Swaan, 1972). English title: "And a pat on the back to boot" (meaning lost in translation?)



INDIGO

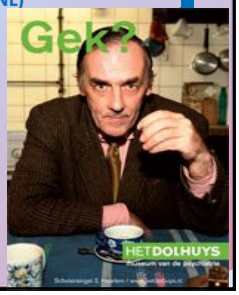
Study of discrimination against people with schizophrenia

Graham Thornicroft and the INDIGO study group (The Lancet, January 2009)
Dutch part: Annette Plooy & Jaap van Weeghel, (MGv, March 2009)

732 respondents in 28 countries (including UK and NL)

Key concepts:

- **Experienced discrimination:** Episodes and situations in which real negative discrimination occurs
- **Anticipated discrimination ('Why try'):** Refraining of activities in anticipation of social rejection



National panel

Experienced negative discrimination

Mostly in:

- Making and keeping friends: 30%
- Finding and keeping a job: 27%
- In his/her social life: 21%

Anticipated discrimination:

Majority felt inhibited because of their diagnosis to

- apply for a job or start new education (54%)
- start close intimate relationships (42%)

Most respondents felt the need to hide their diagnosis (67%)

10

Theorem of W.I. Thomas (sociologist)

"If men define situations as real, they are real in their consequences"

(Thomas, 1928)

Question 2

What constitutes good community care?

13-7-2011 12

The Janus face of deïnstitutionalisation

- **Dark side:**
  Neglect, stigma, victimisation, exclusion, care avoidance, homelessness
- **Bright side:**
  Recovery, rehabilitation, community care, social inclusion

Counteracting social isolation

Multiple causes:

- Troublesome symptoms & disabilities
- Lack of social experiences and/or skills
- Inaccessable 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; coaching
- Community connecting; creatin social niches
- Practical help; income support
- Anti stigma programmes
- Self help groups; peer-led recove programmes

The components of good community care for people with SMI

- Views of stakeholders: MH professionals, services users, carers (family), policy makers, other citizens
- in five European countries (Belgium, Greece, Italy, **Netherlands**, **United Kingdom**)

Objectives:

- Generate a common definition of 'good community care for people with SMI'
- Explore what values different groups of stakeholders attach to the key aspects of such a definition
  (J. van Weeghel et al. 2005)

A set of clear suggestions (consensus)

Good community care consist of:

1. Trusting and stimulating relationships (client seen as a competent person)
2. Effective treatment and rehabilitation, tailored to individual needs, related to community living (well trained, competent professional helpers)
3. Local availability of comprehensive and accessible services
4. Care provided by informal carers (family), whose support needs must be addressed

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Question 3

Higher standards for MH rehabilitation in the western world: why?

Ambitions and optimism in the 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)

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.)

Setting higher standards: Why?

Cultural trend in western societies:
- Emancipation of minority groups
- 'Follow your dream'

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

Rehabilitation addresses 'capabilities'

The concept of capability (Amartya Sen, 1992):
- Closely linked to freedom, social justice and social inclusion
- The substantive opportunity that a person has to have a life they value and choose, and have reasons to value and choose
- Accommodates variations in need, recognising that individuals who have greater needs will need more flexible institutional arrangements and greater material resources
- Focuses on the substantive freedoms that individuals have to achieve valuable objectives rather than on the outcomes themselves (Boardman, Currie, Killaspy & Mezey, 2010)
- Capability always refers to an individual's capacity in relation with a specific social context

Social integration
definition based on concept of capability

Social integration is not a static phenomenon, but a:
Process, unfolding over time, through which individuals who have been psychiatrically disabled increasingly develop and exercise their capacities for connectedness and citizenship (Ware et al 2007)

Implications:
- It posits growth and development, rather than stabilisation, as the object of psychiatric treatment
- It casts persons with mental illness as agents rather than 'consumers'
- It overlaps with the service user's conceptualisation of recovery from mental illness
- Social exclusion is at least a part of what is being recovered from

Social integration
of persons with SMI

Requires social change, of two types:
1. Reduction of social barriers to integration (refining accommodations)
2. Creation of 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)

Question 4

Do current recovery practices in the NL have an impact on social inclusion?

What is 'Recovery'?

Recovery principles come from a literature which tells the stories of people struggling to live meaningful and personally satisfying lives in the presence of mental health problems.

Key common elements are:

- An emphasis on (re)discovering a sense of personal 'agency' and control - over symptoms and personal goals
- A recognition that clients (and family and friends) are 'experts' too
- The importance of building a life '*beyond illness*', based on self-defined goals, not the 'realistic expectations' of professionals
- The need to use natural social networks and opportunities, in addition to formal services and 'sheltered' support
- The need always to maintain **HOPE**

Recovery: dimensions and tasks

Three dimensions of recovery (Dröes, 2009):

- Recovery from illness (health)
- Recovery of personhood (personal identity)
- Recovery of social roles (social identity)

Four recovery tasks (Slade, 2010):

- Developing a positive identity outside of being a person with SMI
- Developing a personally satisfactory meaning to frame the experience
- Taking personal responsibility through self-management
- Acquisition of valued social roles

Note:

- These dimensions and tasks of recovery are in constant interaction in a person's life
- There should be no fixed sequence in addressing these tasks or dimensions

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User run recovery programmes in NL: two recent RCTs

- Outcomes of TREE (Boevink et al, 2011): modest positive effects on MH confidence, depressive symptoms, negative symptoms and self esteem
- Outcomes of 'Recovery is up to you' (Van Gestel-Timmermans et al, 2011): positive effect on empowerment, hope and self-efficacy beliefs; weak positi effect on quality of life, task-oeriented coping and general mental health
- Both studies indicated favourable outcomes, notably on the dimension 'recovery of personal identity', and also on 'recovery of health' and 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?

Question 5

What is the evidence base
of MH rehabilitation in the NL?

Two systematic reviews

- Review of NL rehabilitation research findings 2000 - 2008
  (H. Michon & J. van Weeghel (Tijdschrift voor Psychiatrie, 2010)
- Chapter 'Participation and rehabilitation' in the updated multidisciplinary guideline for schizophrenia
  (in press)
- But first: how has the previous guideline (2005) been implemented?

.

Quality Assessment of Regional Treatment Systems for Schizophrenia (QUARTS)
A longitudinal study in eight regions in the Netherlands
J. van Weeghel, S. van de Lindt, C. Slooff, F. van de Kar, M. van Vugt, **D. Wiersma**
(Psychiatric Services, July 2011)

Main findings

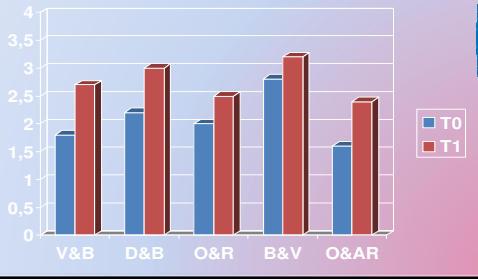
- Substantial improvements in care provision in all regions
- Aspects of care that showed adequate availability often belong to traditional core business of psychiatry, such as diagnostics and pharmacotherapy
- Rapid implementation of the (F)ACT model, which provides a good peg for other evidence-based practices
- Although IPS is feasible in the Netherlands, it is not widely implemented, indicating a lack of focus on the social inclusion of patients
- Half of all patients had no access to the various elements of the care standard. Partly for this reason patients and relatives rated many care elements as less than satisfactory

(Team) Assessment of Regional Treatment Systems for Schizophrenia

(QUARTS)

2003/2005 -2007/2009

Mean outcomes on five sections in 8 regions



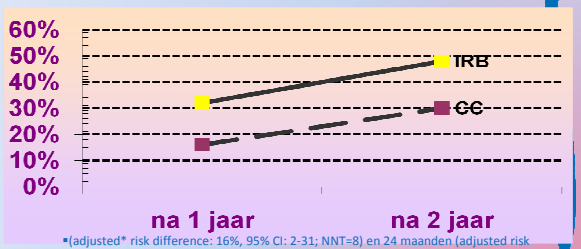
MH rehabilitation in NL: priorities in R&D agenda

Rehab. domains:	Innovate (new interv. needed)	Evaluate (effect studies needed)	Implement (nationwide)
Comprehensive rehab.approaches			+ (IRB)
Employment			+ (IPS)
Housing		+	
Education		+	
Social relationships		+	+ (peer support)
Community Support Systems		+	
Rehabilitation in (F)ACT		+	
Daily activities (other than work or education)	+		
Anti stigma programmes	+		

Multisite RCT in the NL: Is BU approach more effective after 1 and 2 years follow up?

W. Swildens, J. van Busschbach, H. Michon, H. Kroon, D. Wiersma (accepted)

Goal attainment higher in BU condition than in care as usual



▪(adjusted* risk difference: 16%, 95% CI: 2-31; NNT=8) en 24 maanden (adjusted risk difference: 21%, 95% CI: 4-38; NNT=5). *gecorrigeerd voor aantal contacten, psychopathologie (GAF-S), opleidingsniveau hulpverlener

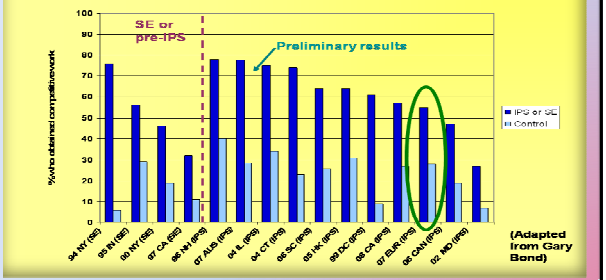
'Individual Placement and Support' (IPS)

(Becker & Drake, 1994)

1. Competitive employment is the goal (whole or part-time)
2. No selection criteria, beyond expressed motivation, i.e. accessible to *all* who want to work ('zero exclusion')
3. Focus on consumer preference – 'fitting the job to the person'
4. Based on rapid job search and placement. Minimises pre-employment assessment and training - '*place-then-train*'
5. Relies on close working between employment specialists and clinical teams
6. Provides individualized, long-term support with continuity
7. Includes access to expert Benefits counseling

Outcomes - IPS v. traditional models (Latimer, 2008)

Percentages of clients who obtained competitive work in RCTs of SE (or pre-IPS) and IPS



Research team Scion

A Study on Cost-effectiveness of IPS regarding Open employment in the Netherlands

- J. van Busschbach & H Michon (project supervisors)
- M. van Vugt, D. Stant (Core team, economic evaluation)
- L. Aerts Roorda, N. van Erp, H Kroon
- Advisors J. van Weeghel, H. Kroon, D. Wiersma
- Data coordinating from staff at the four Mental health Agencies
- Grant: UWV (add. funding for T30 by ZonMw)

RGOc-University medical center Groningen; Trimbos-instituut; Kenniscentrum Phrenos. GGzEindhoven, Lentis-UCP (Groningen), Parnassia-Bavogroep / Pameijer (Rotterdam), Dimence (Deventer / Almelo).

Follow-up 30 months – main outcome (competitive work)

Conclusion

- confirms effectiveness of IPS in terms of helping persons with SMI find paid employment
- stable effect, jump in T6-T18
- no detrimental secondary effect / no improvement either
- IPS not easy to implement; probably IPS effects even stronger if implemented properly

ACT teams have proven to be successful in:

- Maintaining ongoing contact with 'difficult-to-engage' consumers
- Keeping them out of psychiatric hospitals
- Helping them with finances and medications
- Reducing their psychiatric symptoms
- Clients are satisfied with ACT services and experience better quality of life

But hardly any evidence to demonstrate that ACT clients:

- Find employment or education more often
- Establish better social networks
- Feel less stigmatized
- Are better able to manage their illness

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Assertive Community Treatment in the Netherlands: Outcome and model fidelity

M. van Vugt, H. Kroon et al (Canadian Journal of Psychiatry, March 2011)

- Prospective longitudinal study in 20 (F)ACT teams
- Hight ACT model fidelity was associated with better outcome on the HoNOS and less homeless days
- Among all ACT ingredients, team structure was associated with better outcomes
- No associations between ACT model fidelity, number of hospital days, and CANSAS scores

NB:

None of the 20 ACT teams reached maximum fidelity

ACT: towards a full christmas tree

Not only:

- Small caseload
- Shared caseload
- Crisis management, stabilisation
- Casemanagement

But also:

- Recovery oriented
- Multidisciplinary: employment specialist, psychologist, addiction expert, experiential workers, etc.
- Evidence Based interventions: IPS, IDDT, IMR, family interventions, rehabilitation model, etc.

Recovery and rehabilitation in (F)ACT
twelve ways to fulfil a promise

a. Enhance and limit the (F)ACT model:

1. Introduce principles and methods of Strengths Model
2. Introduce elements Boston technology of rehabilitation
3. Refer stabilised consumers to other community-based team

b. Integrate specific interventions in (F)ACT:

4. Introduce Illness Management and Recovery (IMR)
5. Introduce Supported Employment (SE/IPS) (including Supported Education)
6. Introduce a social network approach

Strengthen consumer involvement

7. Introduce consumers as staff
8. Make use of peer support and recovery groups

d. Address wider support system and community

9. Build up a community support system
10. Promote community acceptance (anti stigma)

e. Implement strategies for quality improvement

11. Monitor ACT fidelity to guide programme change
12. Use outcome-based supervision to promote recovery goals

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Question 6

What is the way ahead for MH rehabilitation in the UK and the NL?

- key differences and similarities
- best practice from an anglo-dutch perspective
- future directions for rehabilitation in UK and NL

MH rehabilitation
differences UK and NL

United Kingdom
- Few hospital beds
- Rehabilitation: mission, method, **and** 'a whole system approach'
- Focus on developing rehabilitation **services**
- Built on strong UK tradition (Bennett, Leff, Shepherd) and Recovery Model influence
- MH strong focus on social inclusion and mainstream activities
- Assertive Outreach teams devolved
- Service user's recovery concept with strong focus on social inclusion

Netherlands
- Many hospital beds
- Rehabilitation: mission and metho but hardly 'whole system approac
- Focus on training professionals in rehabilitation **methods**
- Multiform practice (delta of diversity), with strong US leanings (Liberman, BU model, IPS, Stengths)
- MH cautious regarding social inclusion (focus on stabilisation)
- (F)ACT teams still booming
- Service user's recovery concept with strong focus on developing a new personal identity

MH rehabilitation
differences UK and NL (continued)

United Kingdom
- Rehabilitation professionals are psychiatrists (specialist training on top of general psychiatric training), nurses, occupational therapists, and social workers
- Rehabilitation mentioned a lot but no specific detail in NICE guidelines for schizophrenia
- Social inclusion is major focus in policy, including focus on combating discrimination
- National anti stigma campaign (Time to Change), and well-developed stigma research practice

Netherlands
- Rehabilitation professionals are specifically trained nurses, occupational therapists, and socia workers (no psychiatrists with specialist rehabilitation training)
- Rehabilitation distinct chapter in the updated multidisciplinary guidelines for schizophrenia
- Social inclusion ('participatie') is major focus in policy, but no focus on combating discrimination
- No national anti stigma campaign yet (in preparation), stigma research in its infancy

MH rehabilitation
Similarities UK and NL

- Despite much lip service, rehabilitation has low status in MH fiel
- 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

Best Practice
in MH 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: accomodation 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)

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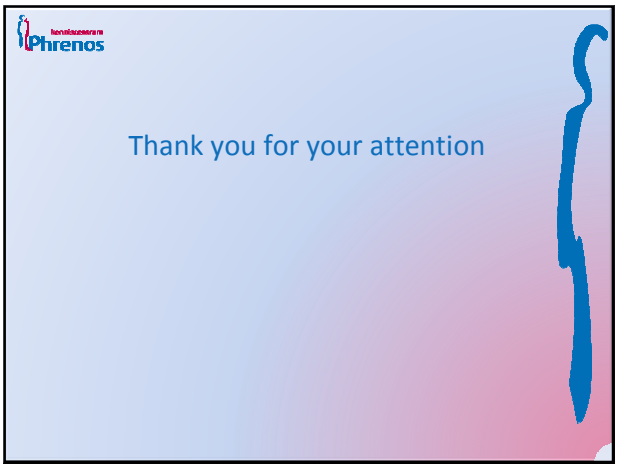
Future directions
in MH rehabilitation (UK and NL)

- 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)
- 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!


Phrenos
Thank you for your attention

The fate of evidence

Groningen, July 7th 2011

Mark van der Gaag

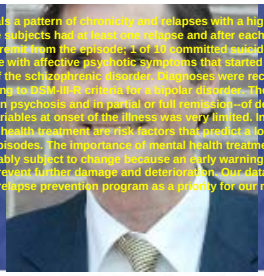
REJECTED

1

Natural Course of Schizophrenic Disorders: A 15-Year Followup of a Dutch Incidence Cohort

by Durk Wiersma, Fokko J. Nienhuis, Cees J. Slooff, and Robert Giel

Data The study reveals a pattern of chronicity and relapses with a high risk of suicide: Two-thirds of the subjects had at least one relapse and after each relapse 1 of 6 subjects did not remit from the episode; 1 of 10 committed suicide; and 1 of 7 had at least one episode with affective psychotic symptoms that started on average 6 years after the onset of the schizophrenic disorder. Diagnoses were reclassified in five patients, according to DSM-III-R criteria for a bipolar disorder. The predictive power--in terms of time in psychosis and in partial or full remission--of demographic, illness, and treatment variables at onset of the illness was very limited. Insidious onset and delays in mental health treatment are risk factors that predict a longer duration of first or subsequent episodes. The importance of mental health treatment in regard to outcome is probably subject to change because an early warning and intervention strategy could prevent further damage and deterioration. Our data support the need for an adequate relapse prevention program as a priority for our mental health services.



2

The curriculum vitae of prof.dr. Durk Wiersma and the topic of this lecture

- Over 30 years involved in research
- Served only One Lord: effective care and treatment for the severe mentally ill patients
- Served in the Era of Evidence Building

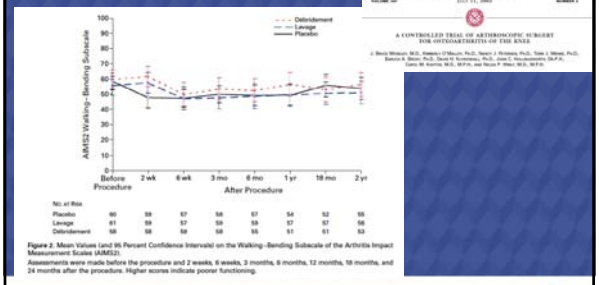
- The topic is this lecture:
- What is the evidence for psychosocial interventions?
- How do stakeholders (patients, relatives, professionals, administrators, politicians) handle evidence?

3

Matching scientific evidence with routine practice

	No evidence	Confirming Evidence	Disconfirming evidence
New procedure	Do research first	Dissemination	Disembark
Old procedure	Finally research	Continue	Stop routine

Why stop? Common sense tells us to clean up broken knees



5

Successful eliminations

- Animal magnetism (Mesmer)
- Disconfirmed by Lavoisier in 1784

- Insulin coma, disconfirmed in 1954

6

Evidence and implementation in routine care

	Evidence	Rejecting evidence
New procedure	Family intervention CBT HIT Peer Support groups IPT	ACT/FACT
Old procedure	Pharmacotherapy	Psycho-education Vocational training

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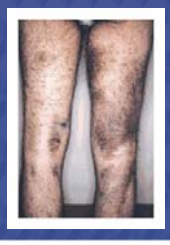
Evidence and implementation in routine care

	Evidence	Rejecting evidence
New procedure	Family intervention CBT HIT Peer Support groups IPT	ACT/FACT
Old procedure	Pharmacotherapy	Psycho-education Vocational training

8

An ancient plague: Scurvy

Between 1500 and 1800, it has been estimated that scurvy killed at least two million sailors. According to Jonathan Lamb, "In 1499, Vasco da Gama lost 116 of his crew of 170; In 1520, Magellan lost 208 out of 230;...all mainly to scurvy."



9

Ancient science

Lancaster tested the hypothesis of citrus fruit. He did a clinical trial in 1601!

1 experimental ship with three teaspoons of lemon juice every day

3 control ships with normal diet (rum and dried meat)

Results: 40% (110/287) of the crew on the control ships had died of scurvy before Cape Hope and 0% of the experimental crew with lemon juice diet

In: Berwick, D. M. (2003). Disseminating innovations in health care. *JAMA : The Journal of the American Medical Association*, *289*(15), 1969-75.

12/09/2011

Modern science :Family interventions have been evidence-based since two decades

Niveau 1	Het is aangetoond dat gezinsinterventies in vergelijking met de standaardzorg leiden tot minder heropnames aan het eind van de behandeling (NNT=4) en twaalf maanden na de behandeling (NNT=6). Het effect is niet meer aanwezig bij vierentwintig maanden. *A1 NICE guidelines 2009: o.a. B Bressi, 2008; B Carra, 2007; A2 Li, 2005; A2 Leavey, 2004; A2 Kopelowicz, 2003; A2 Dyck, 2000; A2 Barrowclough, 1999; B Bloch, 1995; A2 Buchkremer, 1995; B Xiong, 1994; A2 Zhang, 1994; B Glynn, 1992; B Vaughan, 1992*
Niveau 1	Het is aangetoond dat gezinsinterventies in vergelijking met de standaardzorg leiden tot een kortere duur van de heropnames tot minstens achttien maanden na de behandeling. *A1 NICE guidelines 2009: o.a. B Chien, 2004a; B Chien 2004b, B Chien, 2007, B Garety, 2008*

11

Implementation of family interventions in UCLA

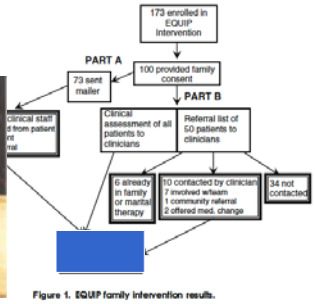
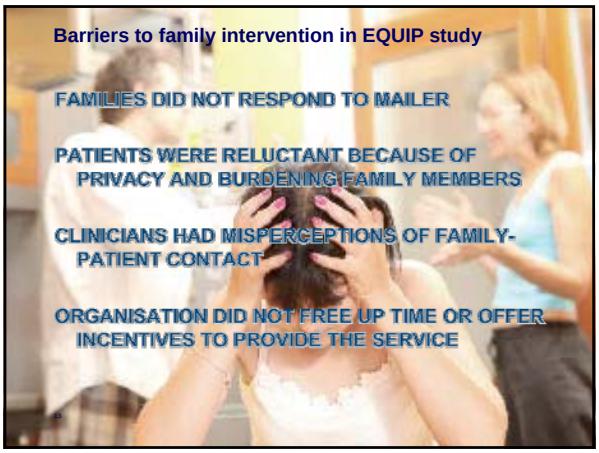


Figure 1. EQUIP family intervention results.

Cohen, A. N., Glynn, S. M., Hamilton, A. B., & Young, A. S. (2010). Implementation of a family intervention for individuals with schizophrenia. *Journal of General Internal Medicine*, *25 Suppl 1*, 32-7.

12

Barriers to family intervention in EQUIP study



FAMILIES DID NOT RESPOND TO MAILER

PATIENTS WERE RELUCTANT BECAUSE OF PRIVACY AND BURDENING FAMILY MEMBERS

CLINICIANS HAD MISPERCEPTIONS OF FAMILY-PATIENT CONTACT

ORGANISATION DID NOT FREE UP TIME OR OFFER INCENTIVES TO PROVIDE THE SERVICE

Implementation of family intervention after graduating an extensive training

6 studies in UK and Australia

Table 2
Rates of FI implementation post training

Study	Number of respondents (response rates given in percentage)	Mean number of families seen (minimum of three sessions) post training
Kavanagh *et al.* (1993)	45 (94%)	1.4
Fadden *et al.* (1997)	59 (70%)	1.7
Brennan & Gamble (1997)	18 (47.4%)	2.7
Baguley *et al.* (2000)	21 (100%)	2.5
Bailey *et al.* (2003)	15 (83%)	3.5

Mairs, H. & Bradshaw, T. (2005). Implementing family intervention following training: What can the matter be? *Journal of Psychiatric and Mental Health Nursing, 12*(4), 488-94.

14

Cognitive Behavioural Therapy: Evidence-Based since one decade

Niveau 1	Het is aangetoond dat cognitieve gedragstherapie psychiatrische symptomen vermindert tot twaalf maanden na de behandeling (PANSS, BPRS en CPRS). *A1 NICE guideline 2009: o.a. B Leclerc, 2000; A2 Gumley, 2003; B Jenner, 2004; B Startup, 2004; A2 Granholm, 2005; A2 Barrowclough, 2006; A2 Garety, 2008; A2 Lecomte, 2008*

15

Implementation of CBT and FI in CMHT

Table 1. Team audit data at follow-up

Team	Team 1	Team 2	Team 3	Team 4
Total team caseload	215	161	241	274
No. of care coordinators	8	7	12	15
Nurses	4	4	7	8
OT	1	1	1	1
Social worker	3	2	4	6
Psychology provision in team	0.6 WTE clinical psychologist 98 (46)	0.6 WTE clinical psychologist 61 (38)	0.2 WTE clinical psychologist 168 (70)	0.7 WTE clinical psychologist 161 (59)
No. of clients with SSD (% of total caseload)				
No. offered CBT for psychosis in the last 2 years (%)	19 (19)	4 (7)	16 (10)	33 (20)
No. of clients with family contact (% of those with SSD)	47 (47)	32 (52)	67 (40)	85 (53)
No. offered FI for psychosis in the last 2 years (% of those with family contact)	2 (4)	9 (28)	5 (7)	5 (6)

WTE = whole time equivalent.

All survey respondents had positive attitude to guidelines
Workload and time pressure created barriers to implementation
Lack of specialist staff (case load 1:425 patients)
Pessimistic views of recovery for clients

Prytys, M., Garety, P. A., Jolley, S., Onwumere, J., & Craig, T. (2011). Implementing the NICE guideline for schizophrenia recommendations for psychological therapies: A qualitative analysis of the attitudes of CMHT staff. *Clinical Psychology & Psychotherapy, 18*(1), 48-59.

16

The implementation of the NICE guidelines for schizophrenia: Barriers to the implementation of psychological interventions and recommendations for the future

Katherine Berry[1] and Gillian Haddock[2]*

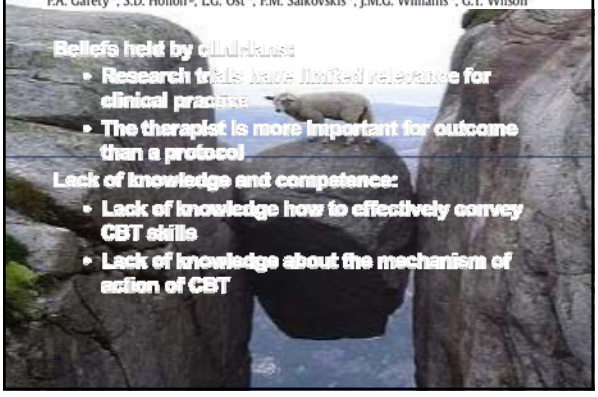
- After 6 years 46% had at least 1 session of CBT
- Many teams did not have adequately trained staff
- Care was focused on monitoring medication
- About half of the teams delivered psycho-education
- About a quarter of the teams delivered CBT

Berry, K. & Haddock, G. (2008). The implementation of the NICE guidelines for schizophrenia: Barriers to the implementation of psychological interventions and recommendations for the future. *Psychology and Psychotherapy, 81*(Pt 4), 419-36.

17

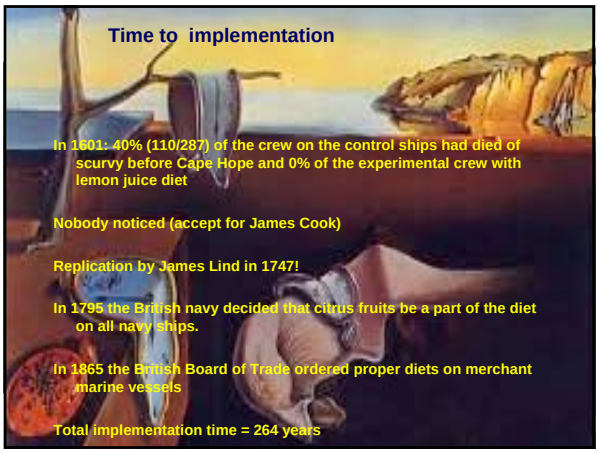
Mind the gap: Improving the dissemination of CBT

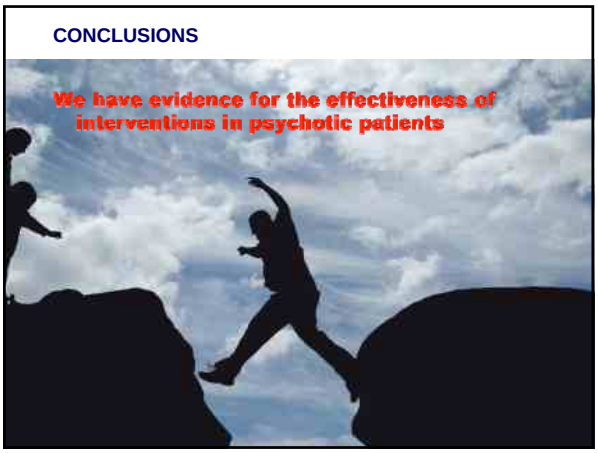
R. Shafran[a,*], D.M. Clark[b], C.G. Fairburn[c], A. Arntz[d], D.H. Barlow[e], A. Ehlers[b], M. Freeston[f], P.A. Garety[b], S.D. Hollon[g], L.G. Ost[h], P.M. Salkovskis[b], J.M.G. Williams[c], G.T. Wilson[i]

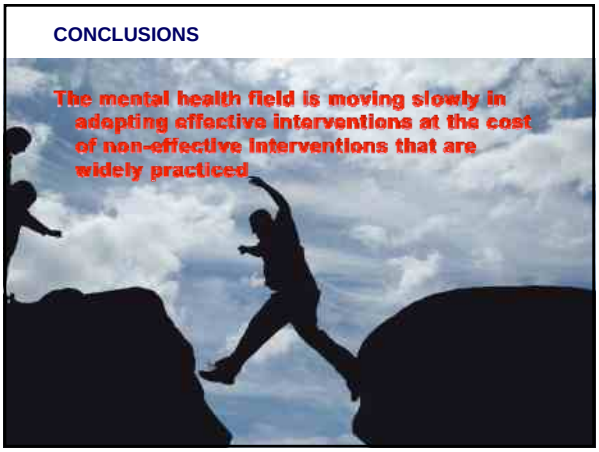


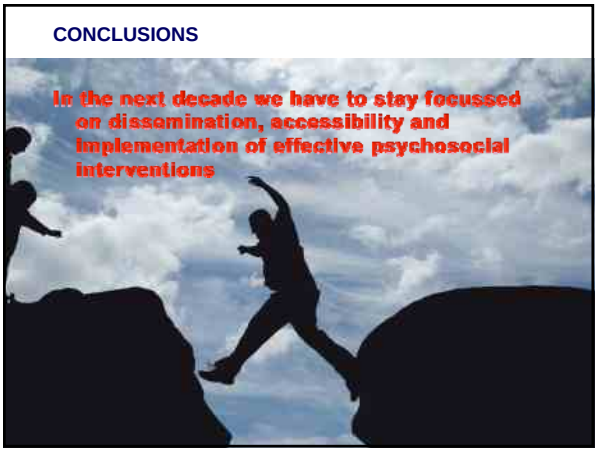
Beliefs held by clinicians:
- Research trials have limited relevance for clinical practice
- The therapist is more important for outcome than a protocol

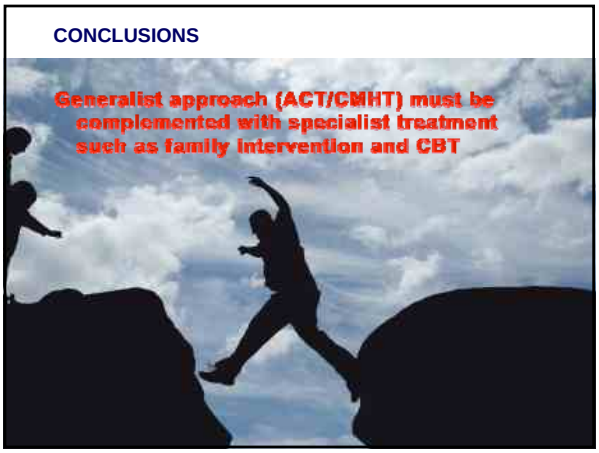
Lack of knowledge and competence:
- Lack of knowledge how to effectively convey CBT skills
- Lack of knowledge about the mechanism of action of CBT


Time to implementation
In 1601: 40% (110/287) of the crew on the control ships had died of scurvy before Cape Hope and 0% of the experimental crew with lemon juice diet
Nobody noticed (accept for James Cook)
Replication by James Lind in 1747!
In 1795 the British navy decided that citrus fruits be a part of the diet on all navy ships.
In 1865 the British Board of Trade ordered proper diets on merchant marine vessels
Total implementation time = 264 years


CONCLUSIONS
We have evidence for the effectiveness of interventions in psychotic patients


CONCLUSIONS
The mental health field is moving slowly in adopting effective interventions at the cost of non-effective interventions that are widely practiced

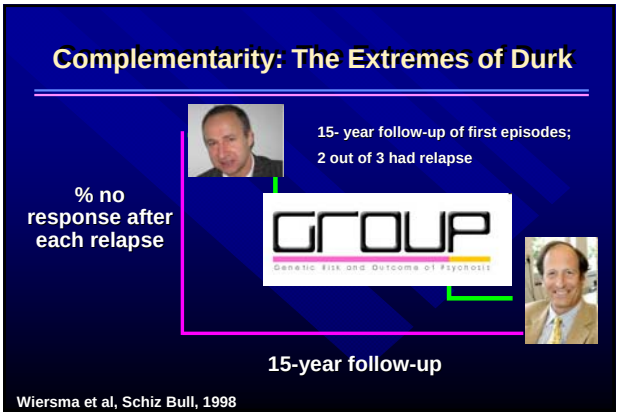

CONCLUSIONS
In the next decade we have to stay focussed on dissemination, accessibility and implementation of effective psychosocial interventions

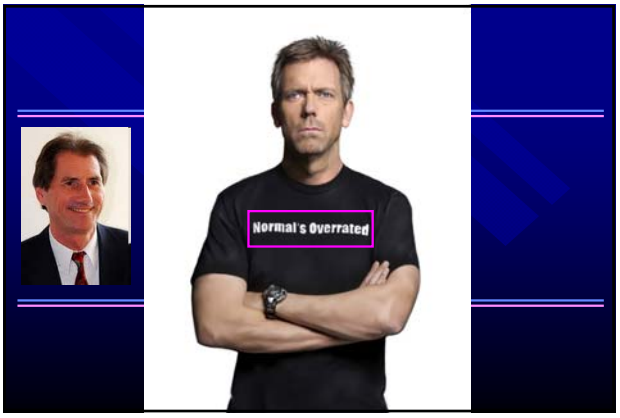

CONCLUSIONS
Generalist approach (ACT/CMHT) must be complemented with specialist treatment such as family intervention and CBT

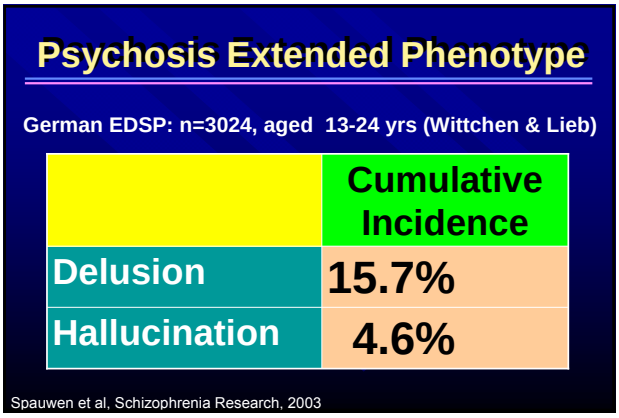

CONCLUSIONS
The courageous guy is actually Durk Wiersma
He leaps to his Emeritus Status

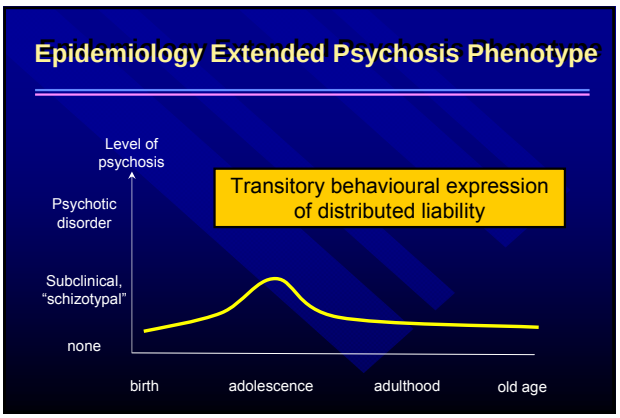

Durk bedankt voor al die productieve jaren!
25
Parnassia

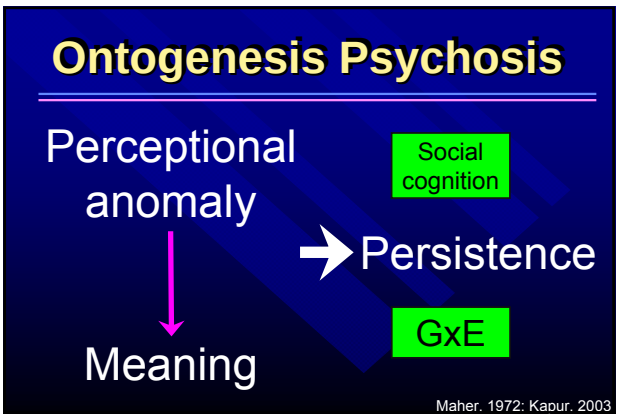

Groningen, 07-07-2011
GROUP


Complementarity: The Extremes of Durk
15- year follow-up of first episodes;
2 out of 3 had relapse
% no response after each relapse
GROUP
15-year follow-up
Wiersma et al, Schiz Bull, 1998


Normal's Overrated


Psychosis Extended Phenotype
German EDSP: n=3024, aged 13-24 yrs (Wittchen & Lieb)
Cumulative Incidence
Delusion
15.7%
Hallucination
4.6%
Spauwen et al, Schizophrenia Research, 2003


Epidemiology Extended Psychosis Phenotype
Level of psychosis
Psychotic disorder
Subclinical, "schizotypal"
none
Transitory behavioural expression of distributed liability
birth
adolescence
adulthood
old age


Ontogenesis Psychosis
Perceptional anomaly
Social cognition
Persistence
GxE
Meaning
Maher, 1972; Kapur, 2003

Persistent Psychotic Experiences

Available online at www.sciencedirect.com
ScienceDirect
SCHIZOPHRENIA RESEARCH
ELSEVIER
Schizophrenia Research 92 (2007) 1–14
www.elsevier.com/locate/schres

Psychotic experiences in the general population: A twenty-year prospective community study

Wulf Rössler [a,*], Anita Riecher-Rössler [b], Jules Angst [a], Robin Murray [c], Alex Gamma [a], Dominque Eich [a], Jim van Os [c,d], Vladeta Ajdacic Gross [a]

"Individuals with a persistently high level of psychotic symptoms over 20 years experienced significant deficiencies in social achievement and functioning."

Psychosis: Persistence-Transition

n=1628

0: OR=1
1: OR= 5.0 (1.6-15.9)
2: OR= 9.9 (2.5-39.8)

PSY — PSY — CLINICAL NEED

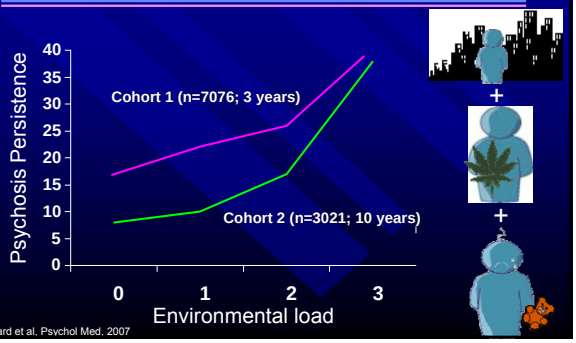
T0 — T2 — T3

5 yrs

10 yrs

Dominguez et al, Schiz Bull, 2009

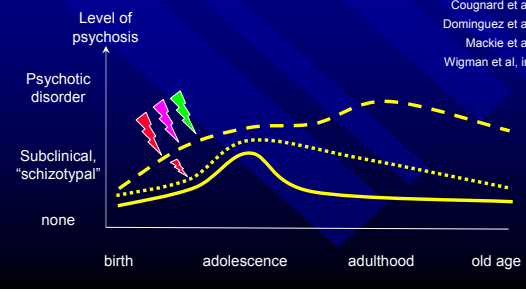
Psychosis Persistence and Environment



Cougnard et al. Psychol Med. 2007

From Subclinical Phenotype to Clinical Disorder

Collip et al, 2008
Cougnard et al, 2007
Dominguez et al, 2009
Mackie et al, 2010
Wigman et al, in press



Trauma and Psychotic Experiences

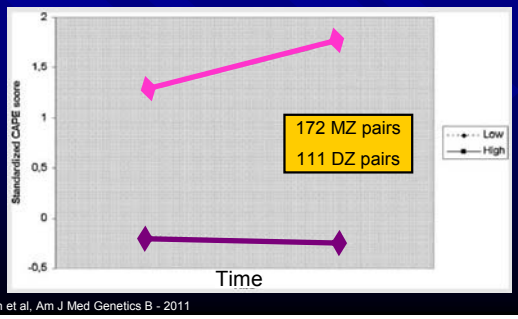
Psychological Medicine, Page 1 of 12. © Cambridge University Press 2010
doi:10.1017/S0033291710000449

Developmental trajectories of psychotic experiences across adolescence: impact of victimization and substance use

C. J. Mackie*, N. Castellanos-Ryan and P. J. Conrod

Psychol Med. 2010

Psychosis Persistence: Twin Study



Wigman et al, Am J Med Genetics B - 2011

2-yr Psychosis Persistence Rate in Twins

	Prediction Persistence Class
SLE	OR: 3.15, P=0.031
Childhood Trauma	OR: 3.26, P<0.0001

Wigman et al, Am J Med Gen, 2011

2-yr Psychosis Persistence Rate in Twins

	Co-twin 2-yr Persistence Class
MZ pairs	*49%* (OR: 9.32, P<0.0001)
DZ pairs	*14%* (OR: 1.56, P=0.42)
Interaction	$X^2(2)=22.97$; P<0.001

Wigman et al, Am J Med Gen, 2011

Follow-up of AVH in children

N=3870 representative sample (7-8 yrs)

Interview AVHRS

Urban>>Rural

15% significant suffering/problems

9% AVH (n=347)

N=167 AVH –

N=170 AVH+

5-year follow-up (12-13 yrs)

Bartels et al, BJPsych, 2010

Environment and Course AVH

170 AVH+ and 167 controls: 5yr follow-up (12-13 yrs)

9% Incidence

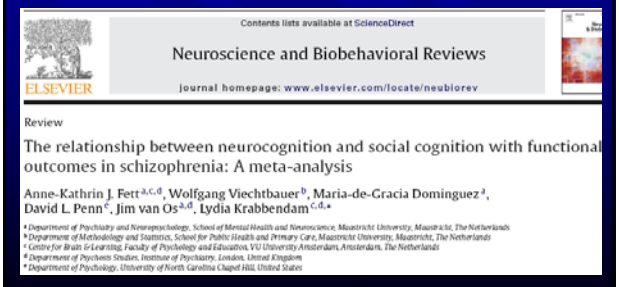
24% Persistence

Higher ToM score

Delusional Ideation

Bartels et al, BJPsych, 2011; Acta Psychiatr Scan, in press

Social Cognition Predicts Community Functioning



Contents lists available at ScienceDirect

Neuroscience and Biobehavioral Reviews

journal homepage: www.elsevier.com/locate/neubiorev

Review

The relationship between neurocognition and social cognition with functional outcomes in schizophrenia: A meta-analysis

Anne-Kathrin J. Fett[a,c,d], Wolfgang Viechtbauer[b], Maria-de-Gracia Dominguez[a], David L. Penn[e], Jim van Os[a,d], Lydia Krabbendam[c,d,*]

[a] Department of Psychiatry and Neuropsychology, School of Mental Health and Neuroscience, Maastricht University, Maastricht, The Netherlands
[b] Department of Methodology and Statistics, School for Public Health and Primary Care, Maastricht University, Maastricht, The Netherlands
[c] Centre for Brain & Learning, Faculty of Psychology and Education, VU University Amsterdam, Amsterdam, The Netherlands
[d] Department of Psychosis Studies, Institute of Psychiatry, London, United Kingdom
[e] Department of Psychology, University of North Carolina Chapel Hill, United States

Fett et al, Neuroscience and Biobehavioral Reviews, 2010

Social Cognition Predicts Community Functioning

Social cognitive domain	Neurocognitive domain	*k*	Diff	*P*
Theory of mind	Reasoning & problem solving	19	0.32	<0.001
	Processing speed	9	0.24	0.03
	Attention & vigilance	12	0.36	0.002
	Working memory	10	0.29	0.002
	Verbal learning & memory	19	0.24	0.03
	Visual learning & memory	8	0.31	0.005
	Verbal comprehension	4	0.31	0.01
	Verbal fluency	9	0.19	0.20
	Overall neurocognition	11	0.24	0.01

Fett et al, Neuroscience and Biobehavioral Reviews, 2010

Early Adversity, Cognition and Outcome

Do Theory of Mind and Executive Function Deficits Underlie the Adverse Outcomes Associated with Profound Early Deprivation?: Findings from the English and Romanian Adoptees Study

Emma Colvert · Michael Rutter · Jana Kreppner · Celia Beckett · Jenny Castle · Christine Groothues · Amanda Hawkins · Suzanne Stevens · Edmund J. S. Sonuga-Barke

J Abnorm Child Psychol (2008) 36:1057–1068

Substance Use and Social Cognition

Br J Clin Psychol. 2009 Sep;48(Pt 3):323-7. Epub 2009 Apr 25.

Social-cognitive difficulties in former users of methamphetamine.

Henry JD, Mazur M, Rendell PG.

School of Psychology, University of New South Wales, Sydney, New South Wales, Australia. julie.henry@unsw.edu.au

Abstract

OBJECTIVES: Methamphetamine (MA) abuse is associated with neurocognitive impairment. We investigated whether important aspects of social-cognitive function are similarly disrupted.

METHODS: A total of 12 adults with a history of MA dependence (average duration of use, 3.9 years), currently engaged in rehabilitation and abstinent for an average period of 6 months, and 12 MA naive participants completed measures of facial affect recognition, theory of mind, executive function and memory.

RESULTS: MA users were impaired on the measures of facial affect recognition and theory of mind (ds = 1.75 and 2.32, respectively), with the magnitude of these deficits comparable or larger to those observed on the cognitive measures.

CONCLUSIONS: Social-cognitive difficulties are associated with MA use and have potentially important implications for rehabilitative practice.

Deafness and Social Cognition

Understanding Theory of Mind in Children Who Are Deaf

Marc Marschark
National Technical Institute for the Deaf, Rochester Institute of Technology, U.S.A. and University of Aberdeen, U.K.

Vanessa Green
University of New South Wales, Sydney, Australia

Gabrielle Hindmarsh and Sue Walker
Queensland University of Technology, Brisbane, Australia

J. Child Psychol. Psychiat. Vol. 41, No. 8, pp. 1067±1073, 2000

Hearing Impairment and Psychosis

Social Cognition Predicts Community Functioning

Contents lists available at ScienceDirect

Schizophrenia Research

Evidence that the impact of hearing impairment on psychosis risk is moderated by the level of complexity of the social environment

Margriet van der Werf[a,*], Ruud van Winkel[a,b], Martin van Boxtel[a], Jim van Os[a,c]

Schizophr Res, 2010

Hearing Impairment and Urban Social Complexity

N=1823

T0

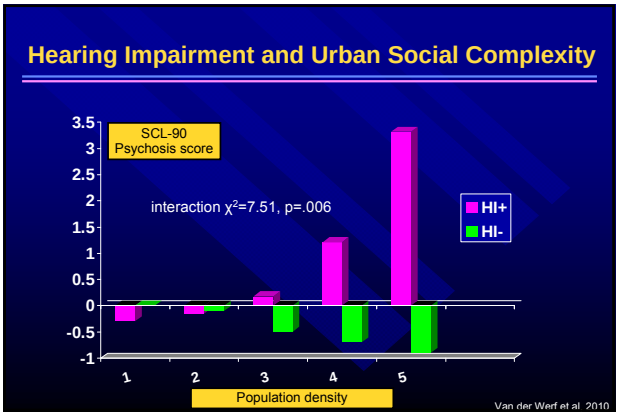
T1 (6yrs)

Pure tone audiometry

T2 (12 yrs)

Psychotic symptoms (SCL-90R)

Hearing Impairment and Urban Social Complexity



Ontogenesis Psychosis

Perceptional anomaly → Meaning → Persistence

Maher, 1972; Kapur, 2003

Munich EDSP Study Young People

Lieb, Isensee, Von Sydow & Wittchen, Eur. Add. Res., 2000

Back to Basics: Delusions and Hallucinations

	Hallucinations and delusions *expected*	Hallucinations and delusions *observed*
Lifetime	25 (1.0)	78 (3.1)
T2-T3 interval	8 (0.4)	43 (2.0)

Smeets et al, Schizophr Bull, 2010

Back to Basics: Delusions and Hallucinations

	OR Hal+Del *vs* Del only
Thoughts heard	3.9
Thoughts taken	8.5
Messages TV	5.9
Forced to move	4.0
Influenced by force	3.0

Smeets et al, Schizophr. Bull. 2010

Back to Basics: Delusions and Hallucinations

Non-genetic risk factors

	Early trauma
No symptoms	18.3%
Only hallucinations	13.9%
Only delusions	23.8%
Hallucinations & delusions	34.7%

Smeets et al, Schizophr. Bull. 2010

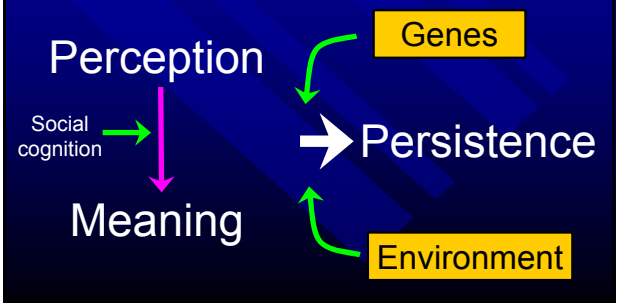
Back to Basics: Delusions and Hallucinations

Clinical outcome

	Help-seeking
No symptoms	0.1%
Only hallucinations	7.7%
Only delusions	8.7%
Hallucinations & delusions	35.5%

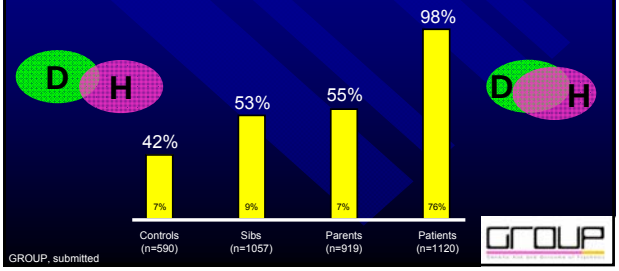
Smeets et al, Schizophr. Bull. 2010

Conclusions

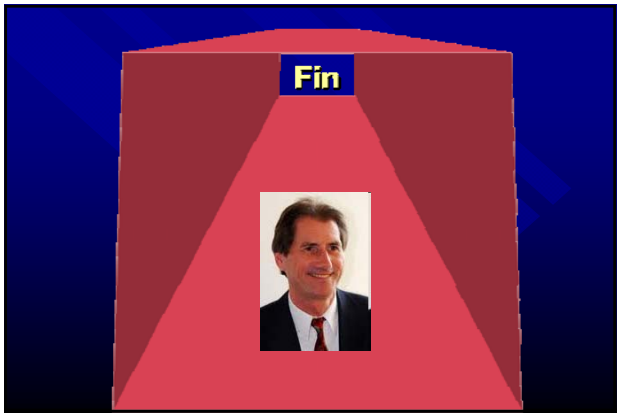


Familial Risk and Hallucinatory-Delusional Syndrome

P (lifetime delusional ideation) given lifetime hallucinatory experience (CASH)



GROUP, submitted



Op zoek naar de betere prognose van psychose

Een persoonlijke terugblik

Prof dr Durk Wiersma
Universitair Centrum Psychiatrie
Rob Giel Onderzoek*centrum* (RGOc)
Universitair Medisch Centrum Groningen

Donderdag 7 juli 2011

Onderwerpen

1. Kennismaking met psychosen: *hoe was dat?*
2. Beloop van psychosen: *hoe ging dat?*
3. Chronische psychiatrie: *wat gebeurde daar?*
4. Substitutie van bedden: *welke kant gaat het uit?*
5. Effectiviteit van behandeling: *helpt het wat?*
6. Conclusies: *hoe lijkt het voor de toekomst, een betere prognose?*

2

1. Hoe herken je aan iemand dat hij/zij mogelijk aan schizofrenie lijdt?

- Als iemand in uw omgeving ….
  - Contact gaat mijden
  - Hardop in zichzelf praat
  - Dingen ziet die anderen niet zien
  - Denkt dat hij Jezus is
  - Zegt dat anderen tegen hem samenzweren
  - ‘s Nachts leeft en overdag slaapt
  - Dus erg in de war is,

  …. Denk dan eens aan schizofrenie

volgens Maarten Vermeulen, vz Anoiksis (1996)

3

1. Hoe was het ? Krisiscentrum Groningen (1972-74)

- 1-2 weken opname op P4a vanwege psychosen, verslaving, persoonlijkheidsstoornissen
- Wie krijgt zorgplan en wat komt daarvan terecht?
- 75% krijgt ZorgPlan, een kwart volgt plan niet op
  - ZorgPlan meestal Opname in PUK of Inrichting (60%) of Polikliniek
  - Geen sprake van omschreven interventie
  - Methodiek van de crisisinterventie in de regel niet van toepassing
- Veel psychosociale problemen van lange duur die na 3 maanden eerder verslechterd dan verbeterd zijn
- Sociale omgeving ook in ernstige moeilijkheden waar niets mee wordt gedaan
- Discontinuiteit in “nazorg”, hulpkontakten bloeden dood

4

2. Hoe ging het (‘78-’95)? : Het beloop van psychosen….

- WHO-studie:
- psychologische functiestoornissen en sociale beperkingen
  - als gevolg van psychosen en schizofrenie
- Verschil schizofrene en reactieve psychosen ??
- Ontstaan psychiatrische invaliditeit, samenhang met symptomen?
- N=82 1ste psychose, follow-up na 1, 2 en 15 jaar,

5

Hoe ging het? het beloop na 2 jaar….. (1)

- 50 % Schizofrene en 50% Reactieve psychosen :
- Symptomen en Life Events: geen verschil!
- Beloop 2 jaar wel:
  - Bij schizofrenie: 75% chronisch
  - Bij reactieve psychose: 53% volledige remissie
- Invloed behandeling *niet* onderzocht
- Geldigheid van het begrip “reactieve psychose” ?
  - (proefschrift Slooff)

6

Hoe ging het? het beloop na 2 jaar….. (2)?

- Model van ontstaan van sociale beperkingen
  - Sociale beloop los van symptomatisch beloop
  - Psychiatrische invaliditeit trof 2/3 van patienten
- Toenemend verschil tussen schizofrene en reactieve psychosen
- 6% suicide!
- Besef van chroniciteit en hopeloosheid
  - (proefschrift de Jong)

7

Hoe ging het?: het beloop na 15 jaar….. (1995)

- Ongunstige beloop en chroniciteit op voorgrond:
  - suicide / overlijden (11%,)
  - toenemende chroniciteit na relapse,
  - veel wisselende onvervulde zorgbehoeftes,
  - onbehandelde ziekteduur en sluipend begin goede voorspellers van slechte afloop

MAAR:

- 25% volledige symptoom remissie
- Chroniciteit en invaliditeit op allerlei maten en uitkomsten duidelijk verminderd
- 15% behoeft institutionele verzorging & bescherming
- **Paradigma van Herstel (Recovery) wint terrein**

8

3. *Wat gebeurde er in de chronische psychiatrie '80-'90?*

- Focus op woonvoorzieningen in en buiten het APZ, en op ambulante patienten
- Bevindingen: >0,3-4 % van de bevolking; >50 jaar, M=V;
- veel onvervulde zorgbehoeftes, medicatiebeleid schrikbarend, geen dagstructuur, rehabvoorzieningen komen op gang
- *Hoe ernstiger psychologisch en sociale beperkingen hoe intensiever de zorg*
- Conclusie:
  - chroniciteitsdenken prevaleert,
  - moratorium actie strandt,
  - medicatie beleid wordt herzien,
  - rehabilitatievoorzieningen als DAC lijken gunstig te werken,
  - al met al weinig verbetering van de prognose te verwachten
- Proefschriften van Hoek (CIPS) en Tholen (Bewoners of patienten)

9

4. Substitutie van bedden: *kan het wel?* (1986-92)

- Deinstitutionaliseringsbeweging: het begin en het verzet (moratorium actie)
- Initiatief Inspectie (Verhoeff 1983)
  - I. nieuw type dagbehandeling met bijpassende extramurale en ambulante zorg
  - II. onderzoek naar vermijden van bedgebruik, verminderen van invaliditeit en chroniciteit en naar financiele haalbaarheid
- APZ L&K (acute opnamebedden) + RIAGG Drenthe:
- S-behandeling: opname screening, bed op recept (BOR), S-telefoon, dagcentrum de Es (10 plaatsen), continuiteit van zorg, extramurale zorgverlener hoofdbehandelaar, betrekken van systeem, mantelzorg en verwijzer

10

4. Substitutie van bedden: ja, het kan en goed ook!

- Haalbaar bij 40% van de opnamepatienten;
  - geen nieuwe doelgroepen, evenveel behandeltijd, hogere compliantie, iets langere behandelduur, ook in andere setting (Utrecht, Amsterdam) toepasbaar
- Substitutie: 3000 opname bedden (d.i. 33% van capaciteit)
- Preventie:
  - minder afzondering van normale bestaan, minder ontslag tegen advies, wel betere zelfzorg en participatie gezinsleven, grotere tevredenheid bij patient en familie, geen extra burden on family
- Functionele samenhang APZ en RIAGG, thuiszorg
- Kosten: budgetneutraal

Proefschrift Kluiter (Verschil van dag en nacht)

11

4. Substitutie van bedden *Wat betekent dit voor Zorggebruik?*

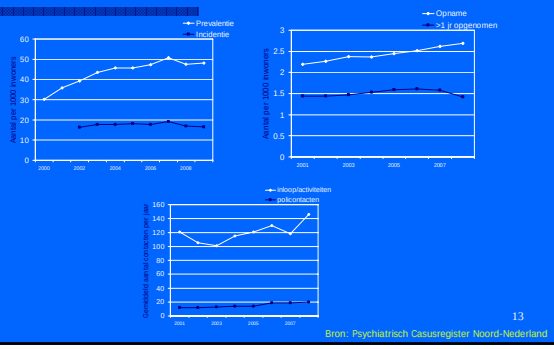
- Afname 'Long Stay' patienten (-26%)
- Kortere Opnameduur (-38%)
- Kortere tijd tot "nazorg" (-88%) met vermijding heropname (-58%)
- Toename Beschermd Wonen (+300%)
- Toename Intensieve Ambulante Zorg (+300%)

Zorggebruik Provincie Drenthe; casus register '90 jaren

12

4. *Hoe gaat het verder in Noord-Nederland in de 21ste eeuw?*

Prevalentie en incidentie / 1000 inwoners



13

Bron: Psychiatrisch Casusregister Noord-Nederland

4. MAAR: *is er nu afname of substitutie van bedden ?*

- Toestroom nieuwe patienten blijft constant
  - (rond 30.000 pj),
- jaarlijkse prevalentie is gestegen
  - van 3% naar 5% (d.i. 82.000)!!
- Aantal opgenomen patienten neemt toe
  - (van 3700 naar 5000),
- Verblijfspatienten (APZ/RIBW) constant
  - (ong 2400 pj)
- DUS: Geen sprake van afbouw of substitutie van bedden !!!

14

4. *Hoe stond het er voor met de psychosen zorg midden jaren 90?*

- 1996 jaar van de schizofrenie (28 februari: dag van..)
- urgentie van concerted action rondom vroegdiagnostiek, psychoeducatie, continuiteit zorg
- Schizofrenie is een hersenziekte (MRI, familie treft geen blaam)
- Relapse preventie en continuering medicatie (hoeksteen van de behandeling) tenminste 2 jaar
- Boodschap van komst van nieuwe antipsychotica, van noodzaak van rehabilitatie en van vroege interventie

15

5. *Is het ziektebeloop veranderd?* Vergelijking 2000 met 1980

- In 2000
  - kleiner risico op relapses (14% vs. 20%),
  - minder suicide (0% vs. 6%),
  - verbetering sociaal functioneren groter
- Maar ook
  - Kleiner percentage volledige remissie (10% vs. 27%),
  - geen verschil in het chronische beloop (18-19%)
  - Geen verschil wat betreft werk of studie (~50%)
- Invloed van Behandeling, extramuralisering en zorgprogrammering op het beloop? Niet onaannemelijk

16

5. Effectiviteit van behandeling: *helpt het wel ?*

- Druk op ontwikkeling kosten en baten analyses
- Schizofrenie Stichting Nederland: *met het oog op beter (1996)*
- Oprichting Rob Giel Onderzoek*centrum* (2000)
- Geestkracht programma's (ZonMw, 2001)
- Multidisciplinaire richtlijn schizofrenie (2005, 2011);
- Nieuwe ontwikkelingen hoopgevend (KRAS, QuIRC)

17

5. Rob Giel Onderzoek*centrum* (RGO*c*)

- 2000: UCP, Lentis, GGz Friesland en GGz Drenthe
- 2011: Mediant en Dimence

- **Missie en Doelstellingen RGO*c*:**
  - Patientgebonden en zorggericht onderzoek
  - Kwaliteit en (kosten-) effectiviteit van interventies (farmacologische, psychologische en sociale)
  - Bijdrage aan Evidence Base van de psychiatrie en de geestelijke gezondheidszorg (o.a. richtlijnen)

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5. RGOc Onderzoek Interventies: behandeling en zorg (1)

- Farmacologische interventies
  - Gerichte medicamenteuze therapie 1ste psychose (MESIFOS)
  - Farmacotherapie (klassieke, atypische, dosering, bijwerkingen)
  - Farmacogenetica
- Biologische interventies
  - Transcraniele Magnetische Stimulatie
- Psychologische interventies
  - Cognitieve Gedrags Therapie (CGT)
  - Hallucinatie Integratieve behandeling (HIT)

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5. RGOc Onderzoek Interventies behandeling en zorg (2)

- Psychosociale interventies
  - Arbeidsrehabilitatie (IPS)
  - IndividueleRehabilitatieBenadering (IRB)
  - Lotgenoten Kontakt
  - Psychoeducatie voor patient & familie
  - Vaardigheidstraining/Liberman module
  - Cognitieve Remediatie (CAT)
- Ambulante behandeling
  - (FACT/ACT/ACT+), thuiszorg en dagbehandeling
  - Kortdurende – langer durende opname, resocialisatie, verblijf, beschermd wonen
- Zorgprogrammering en Zorgpaden

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6. Hoe lijkt het voor de toekomst: *naar een betere prognose...?*

- Goede uitkomst of symptoom remissie > 50% patienten
  - follow-up van 3-15 jaar
  - >5 buitenlandse studies en reviews
- Symptomatische en sociale remissie (“recovery”) in ± 25 %
- Ook zonder antipsychotica is recovery mogelijk !
- MESIFOS-II studie (na 7 jaar):
  - Symptomatische Remissie bij 2/3,
  - Recovery bij 1/3.
  - Vroege discontinuatie: 40% recovery
  - Medicamenteuse onderhoudsbehandeling 18 % recovery

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6. Wat voorspelt functionele remissie en recovery het beste?

- Ontwikkeling en toetsing criteria voor remissie en recovery
- predictoren van een slechtere prognose
  - langere onbehandelde ziekteduur,
  - ernst van negatieve symptomen,
  - ernst van sociale beperkingen en
  - slechter cognitief functioneren
- Een predictor van gunstige prognose
  - combinatie van farmacologische & psychosociale behandeling

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6. Op zoek naar de betere prognose van psychose....?

- Betere detectie van 1ste psychosen (60% wordt gemist)
- Voortdurende toetsing en verbetering van farmacologische en psychosociale interventies
  - Meer dan medicatie alleen, minder hoeksteen.....
  - Monitoring (ROM) van ziektebeloop, remissie en recovery
- Verbetering implementatie (KRAS) en zorg (QUiRC)
  - leefomgeving, therapeutische omgeving, interventies, zelfbeschikking en autonomie, sociale inclusie, burgerrechten, herstel gerichte zorg
- Minder institutionalisering !!
  - (opneming, verblijf & wonen, al of niet met dwang en drang)

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..... resulterend in de uitkomst van ....

- 1/3 Funct+Symp Herstel (Recovery)
- 1/3 Symp of Funct Remissie
- 1/3 ‘op weg naar ....’
  - Afhankelijk van bezuinigingen GGZ ???

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Met heel veel dank aan …
(van toen tot morgen…)

- Stuurgroep Rob Giel Onderzoek*centrum:* Gerard Schaap, Rikus Feijen, Rob vd Bosch, Henk vd Berg, Corstiaan Bruinsma, Erik vd Haar, Hans Kedziersky, Robert Schoevers, Herma van de Wal
- De RGOc medewerkers: Rob vd Brink, Richard Bruggeman, Jooske van Busschbach, Sjoerd Sytema, Ellen Visser, Gerard vd Willige, Agna Bartels, Martha Messchendorp
- Beheer UCP: Harma Ensing, Eite Oosterveld, Jaap Jansen, Erik Reichman
- Het Psychose Netwerk: Cees Slooff, Rikus Knegtering, Lex Wunderink, Richard Bruggeman, Dick Smid, Johan Arends, Andre Aleman, Frederike Jörg, Marieke Pijnenborg, Stynke Castelein
- GROUP: Rene Kahn, Jim van Os, Don Linszen, Lieuwe de Haan, Richard Bruggeman, Wiepke Cahn, Carin Meijer, Lydia Krabbendam, Inez Germeys, Joyce van Baaren, Thea Heeren, Victor Vladar Rivero, Roelof ten Doesschate, en nog vele anderen
- Promovendi: Cees S, Peter dJ, Wijbrand H, Hilbert K, Jeanette K, Herman K, Esther H, Hugo W, Fons T, Agna B, Marte S, Piotr Q, Gunnar F, Nynke B, Nadine T, Charlotte dH, Irene L, Cees B, Erwin S, Frank van E, Anne-Neeltje S, Marrit dB, Grieke vK, Hans K, Lian vdK, Ando E, Mia S, Jorien vdV, Annerieke dV,
- En nog vele vele anderen .....

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Dank voor uw aandacht

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