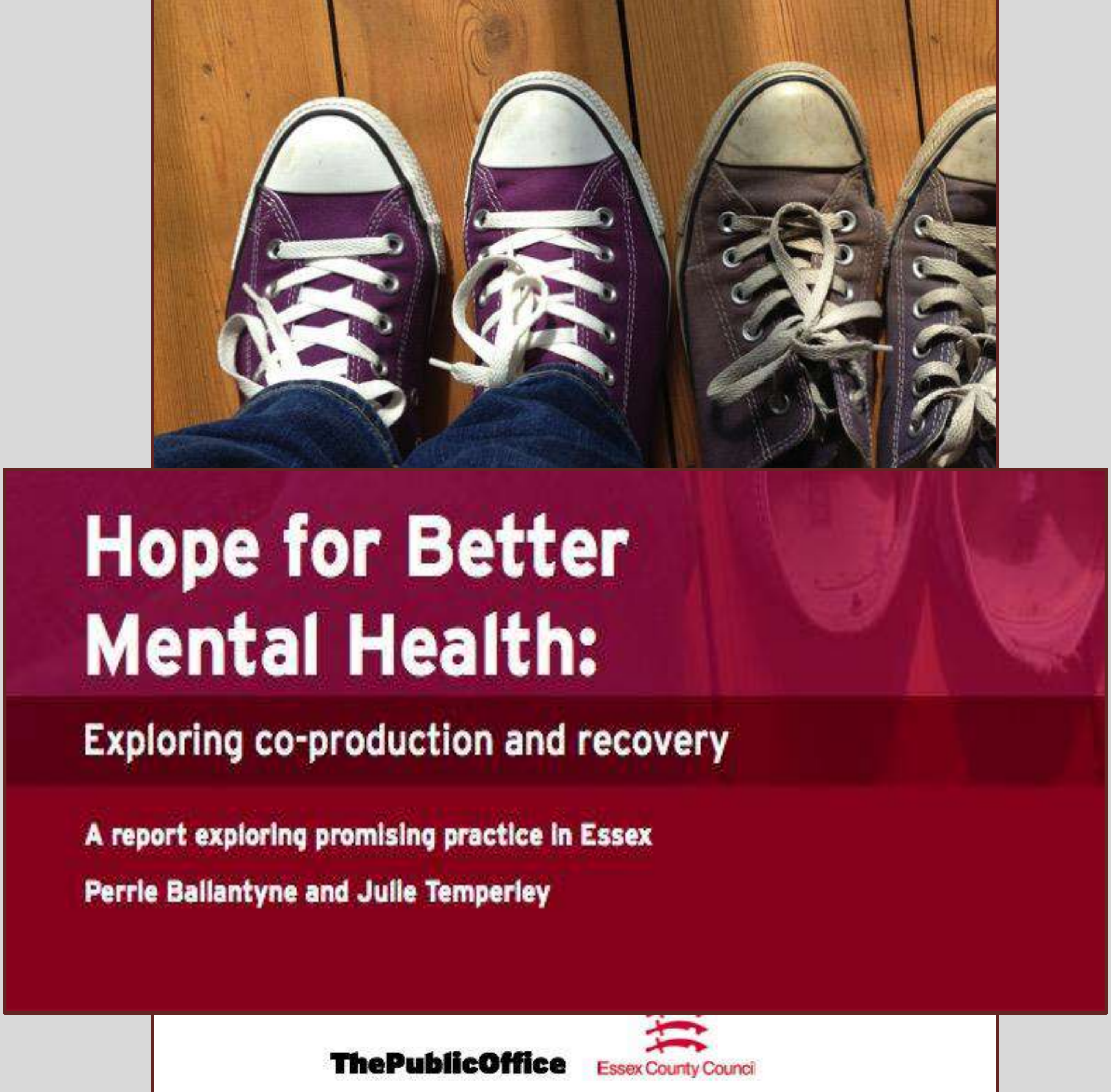
Recovery: una proposta per i servizi di salute mentale

L. Gavelli, F. Lucchi, D. Rancati



Hope for Better Mental Health:

Exploring co-production and recovery

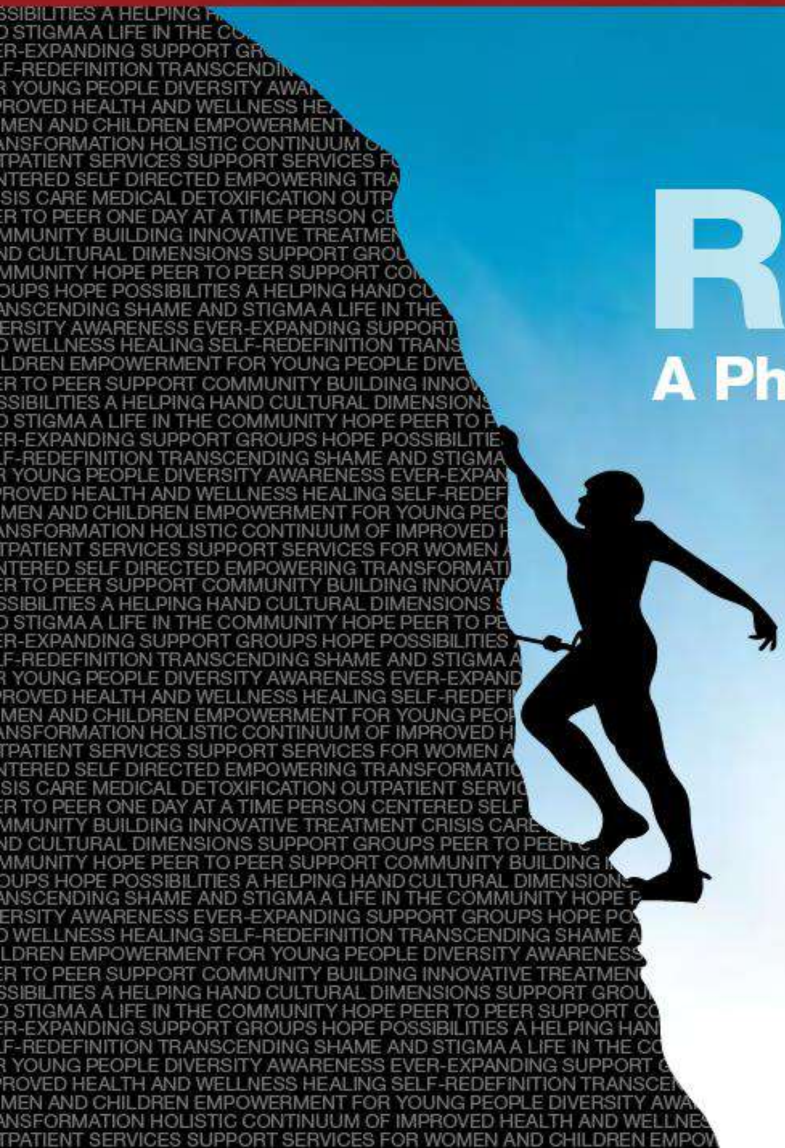
A report exploring promising practice in Essex

Perrie Ballantyne and Julie Temperley

ThePublicOffice

Essex County Council

A Life in the Community for Everyone
SAMHSA NEWS
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
SAMHSA's Award-Winning Newsletter
September/October 2009, Volume 17, Number 5



RECOVERY

A Philosophy of Hope and Resilience

A person's early days in recovery might be compared to a climber's first steps up a great mountain. There's a lot of work ahead. As time passes, healing occurs not only for the person in recovery but also for relatives, coworkers, business associates, and the community at large.

At its core, the philosophy of recovery embraces and encourages an individual's capacity for change and personal transformation. But that change does not happen overnight. Challenges can and often do crop up every step of the way.

As part of its mission, SAMHSA supports the concept of recovery on multiple levels Agency-wide. The Center for Substance Abuse Treatment (CSAT), the Center for Substance Abuse Prevention (CSAP), and the Center for Mental Health Services (CMHS) offer specific services and support to individuals and community organizations through discretionary grant programs, Web sites, policy resources, publications, and data.

MENTAL
HEALTH
ACTION PLAN
2013 - 2020
World Health
Organization

- Priorità sulla recovery e su come i servizi di salute mentale possono promuoverla.
- Riflessione sul tema “recovery vs cura”.
- “Engagement” degli utenti dei servizi come ingrediente attivo dei percorsi di recovery e di inclusione sociale.
- Diritti umani e di di cittadinanza per promuovere benessere psicosociale.

Promoting recovery in mental health and related services:

handbook for personal use and teaching

WHO QualityRights training to act, unite and empower for mental health

(PILOT VERSION)

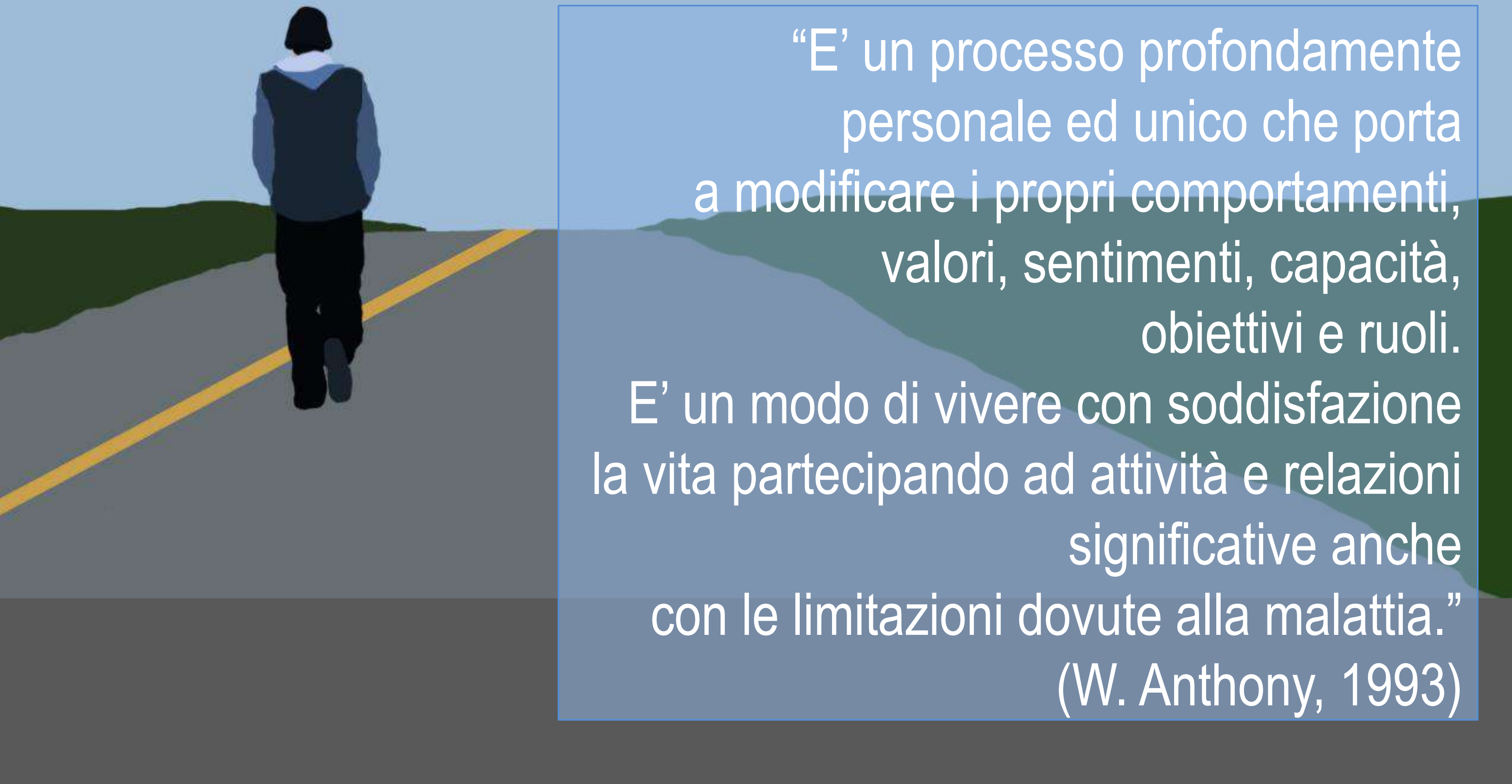
Contact Information:

Michelle Funk, Coordinator
funkm@who.int
Natalie Drew, Technical Officer
drewn@who.int

Prepared by
Mental Health Policy and Service Development
Department of Mental Health and Substance Abuse
World Health Organization, Geneva

World Health Organization

RECOVERY



“E’ un processo profondamente
personale ed unico che porta
a modificare i propri comportamenti,
valori, sentimenti, capacità,
obiettivi e ruoli.
E’ un modo di vivere con soddisfazione
la vita partecipando ad attività e relazioni
significative anche
con le limitazioni dovute alla malattia.”
(W. Anthony, 1993)

Una definizione sintetica

Recovery significa vivere una vita al meglio delle proprie possibilità.

South London and Maudsley
NHS Foundation Trust (2010)
Social Inclusion and Recovery
Strategy 2010-2015.
London SLAM

Guarigione clinica

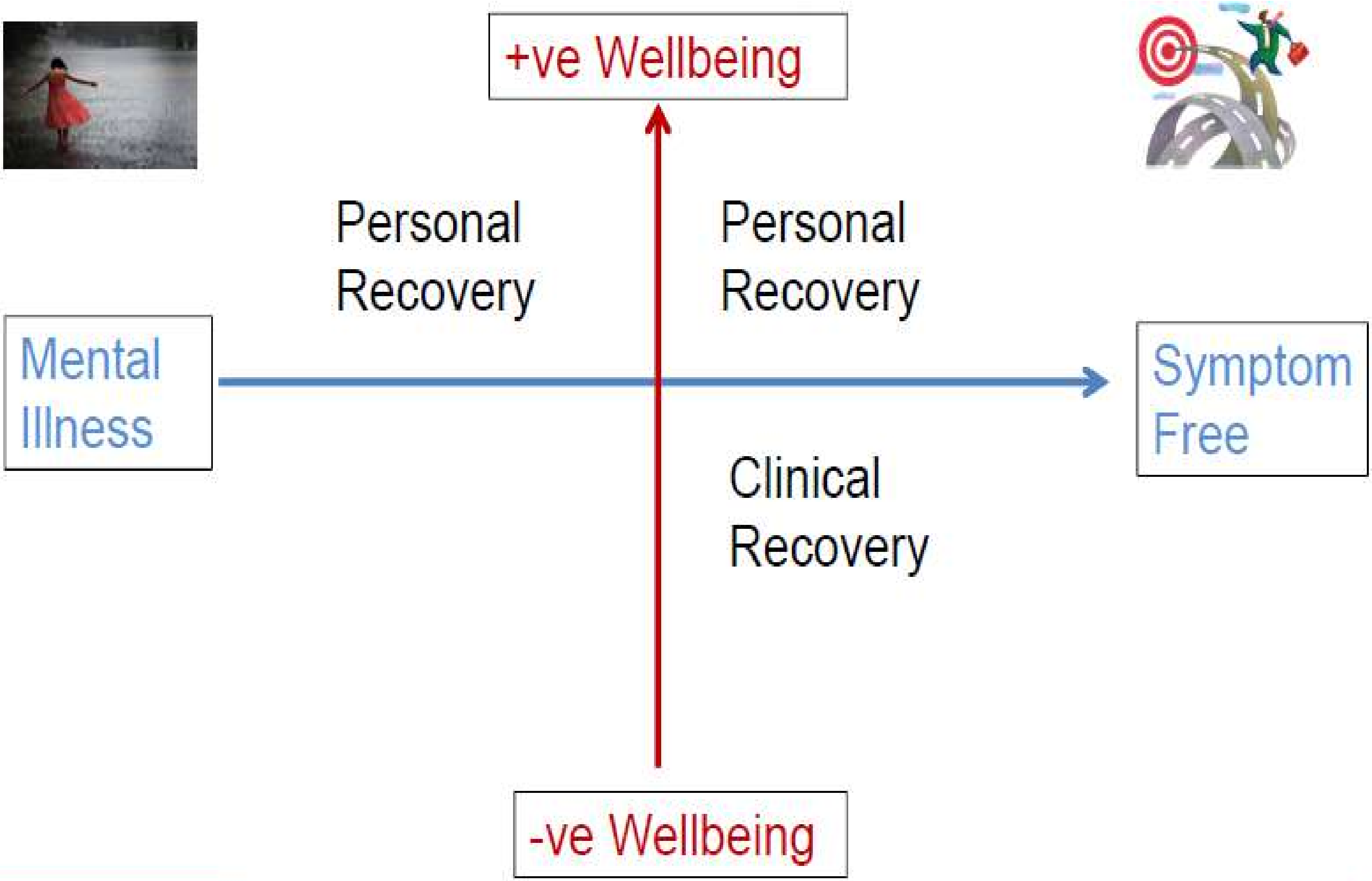
Remissione sintomatologica completa, impegno lavorativo almeno a tempo parziale, collocazione abitativa indipendente senza supervisione da parte di carer informali, avere amicizie con cui condividere attività per almeno un periodo di due anni.

Lieberman RP, Kopelovitz A:
Recovery from Schizophrenia.
International Review of Psychiatry.
14, 245-255. 2002

Recovery:
una parola con due significati

- Guarigione clinica:
  - ✓ Focus su criteri dei professionisti
  - ✓ Parzialmente operazionalizzata
  - ✓ Non sempre in accordo con il punto di vista degli utenti

- Guarigione personale
  - ✓ Focus sui significati e gli obiettivi personali
  - ✓ Non ancora operazionalizzata per fini di ricerca
  - ✓ Basata su elementi narrativi/descrittivi



+ve Wellbeing

Personal Recovery

Personal Recovery

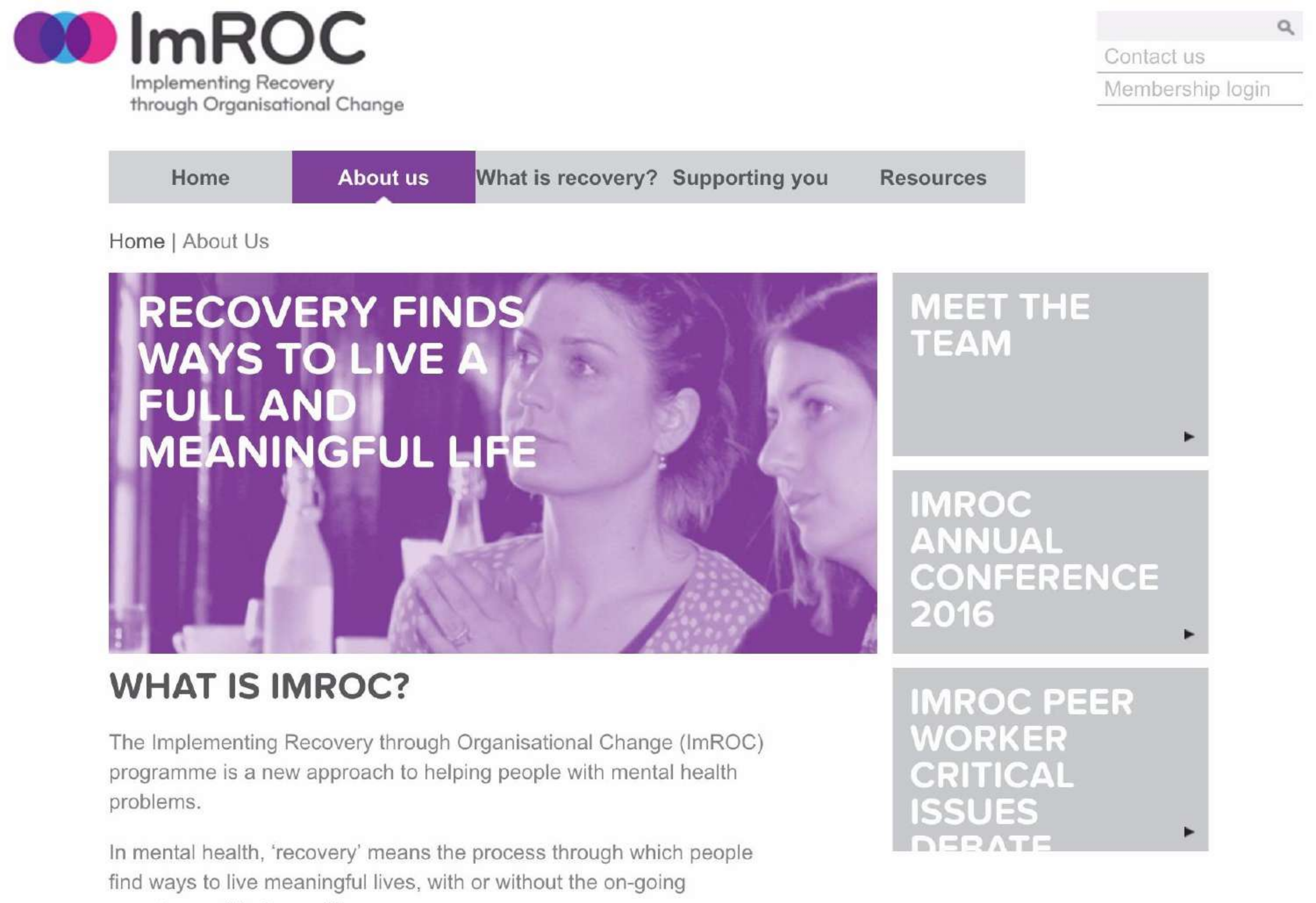
Mental Illness

Symptom Free

Clinical Recovery

-ve Wellbeing

Diet Coke


ImROC
Implementing Recovery through Organisational Change
Contact us
Membership login
Home
About us
What is recovery?
Supporting you
Resources
Home | About Us
MEET THE TEAM
IMROC ANNUAL CONFERENCE 2016
IMROC PEER WORKER CRITICAL ISSUES DEBATE

RECOVERY FINDS WAYS TO LIVE A FULL AND MEANINGFUL LIFE

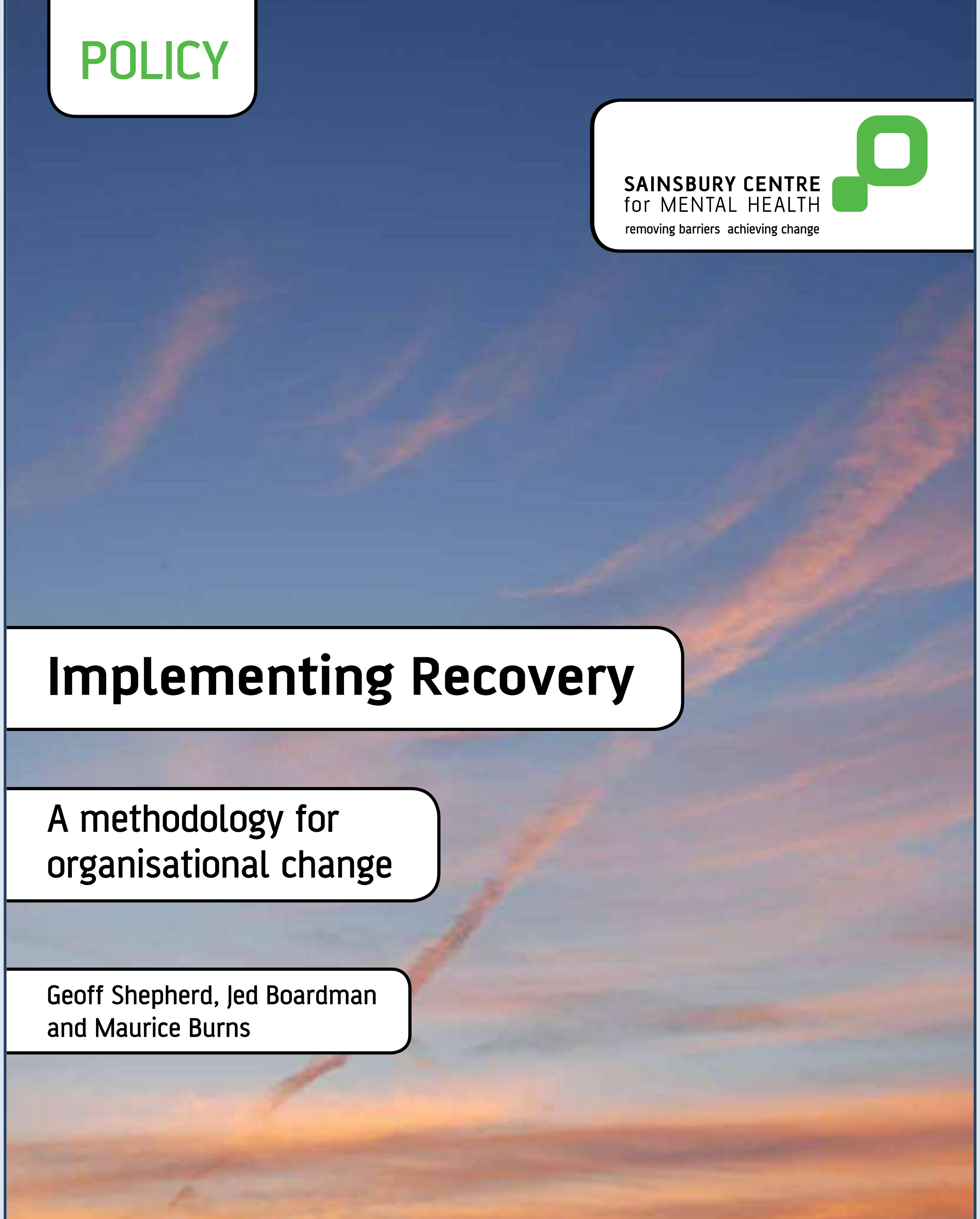
WHAT IS IMROC?

The Implementing Recovery through Organisational Change (ImROC) programme is a new approach to helping people with mental health problems.

In mental health, 'recovery' means the process through which people find ways to live meaningful lives, with or without the on-going

POLICY

SAINSBURY CENTRE
for MENTAL HEALTH
removing barriers achieving change



Implementing Recovery

A methodology for organisational change

Geoff Shepherd, Jed Boardman
and Maurice Burns

Recovery non è…

Centre for Mental Health

- Una versione aggiornata dell'anti-psichiatria contro i trattamenti tradizionali.
- Non è un approccio che vuole che i pazienti facciano quello che vogliono: gli operatori non devono "lasciare fuori dalla porta" le proprie considerazioni professionali ed etiche.
- Non è un insieme di "frasi naive" in base alle quali si curano i sintomi delle persone.
- Non è un metodo che gli operatori imparano ed applicano: gli operatori non fanno fare la recovery ai pazienti, sta a loro scegliere di andare in quella direzione…ma gli operatori ed i servizi possono favorire o ostacolare questo percorso.
- Non è un approccio che vale solo per la salute mentale: è utilizzato sempre di più per la gestione efficace di tutte le condizioni di lunga durata.

I principi della recovery

Centre for
Mental Health

La Recovery non è una teoria, né una tecnica: è un’insieme di principi che derivano dai racconti personali di persone che hanno descritto cosa è stato utile o inutile per vivere la loro vita con un disturbo mentale.

I principi sono i seguenti:

1. L’importanza di mantenere una aspettativa positiva (**Speranza**): credere cioè che sia possibile raggiungere gli obiettivi che ci prefiggiamo. Questa speranza spesso deve essere sostenuta anche da altri, anche da parte degli operatori dei servizi.
2. L’importanza di trovare un **significato personale** nell’esperienza della malattia mentale e recuperare il **controllo** sulla propria vita e sui sintomi che si possono avere e provare.
3. Avere la possibilità di fare scelte rispetto al modo di curarsi e alle fonti a cui chiedere supporto: **personalizzazione.**
4. Avere l’opportunità di costruire un progetto di vita con una **Identità** oltre la dimensione della malattia.

Recovery: una parola, due significati

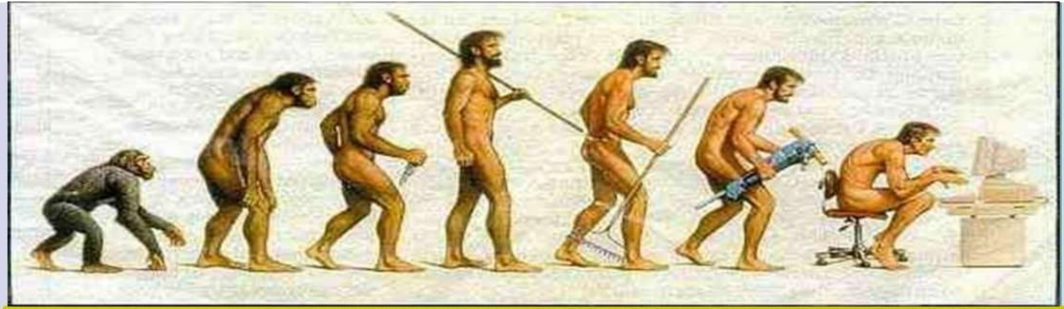
Recovery **clinica** → **ESITO**

Remissione dei sintomi e della disabilità, misurabile attraverso criteri standardizzati

Recovery “**personale**” → **PROCESSO**

Impegno attivo nel tentativo di ripristinare un certo grado di controllo sulla propria vita e di recuperare potenzialità e aspettative di realizzazione di sé, **nonostante la persistenza dei sintomi**

DEFINIZIONI DI RECOVERY



CRITERI
OGGETTIVI
E
MISURABILI

Recovery clinico

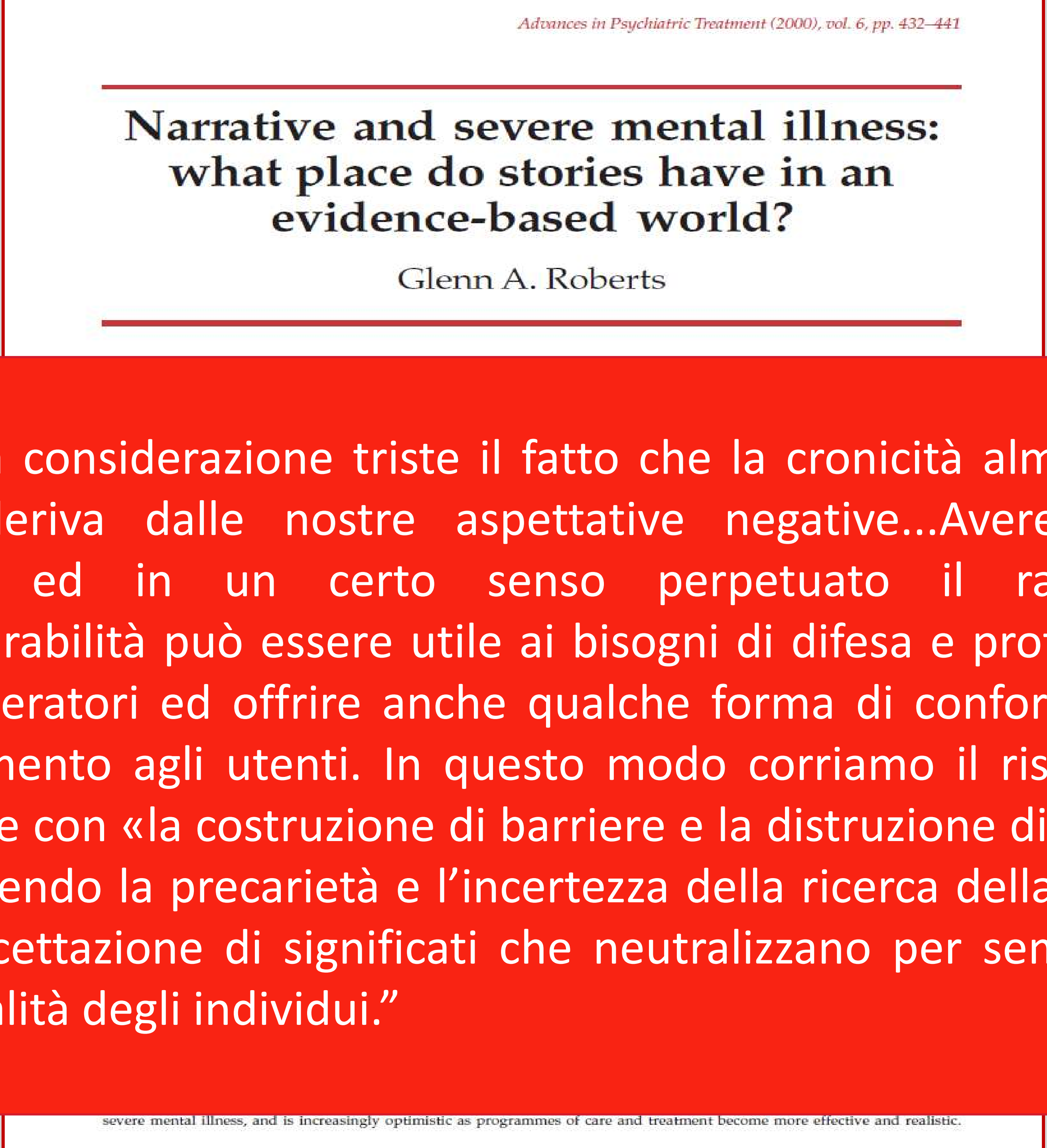
- remissione
- Aderenza
- Riduzione delle ospedalizzazioni

Recovery FUNZIONALE

- Lavoro e/o scuola
- Indipendenza/coinvolgimento vita familiare

Recovery PERSONALE

- SPERANZA PER UN FUTURO MIGLIORE
- EMPOWERMENT
- RESILIENZA
- AUTO-AIUTO



Advances in Psychiatric Treatment (2000), vol. 6, pp. 432–441

Narrative and severe mental illness: what place do stories have in an evidence-based world?

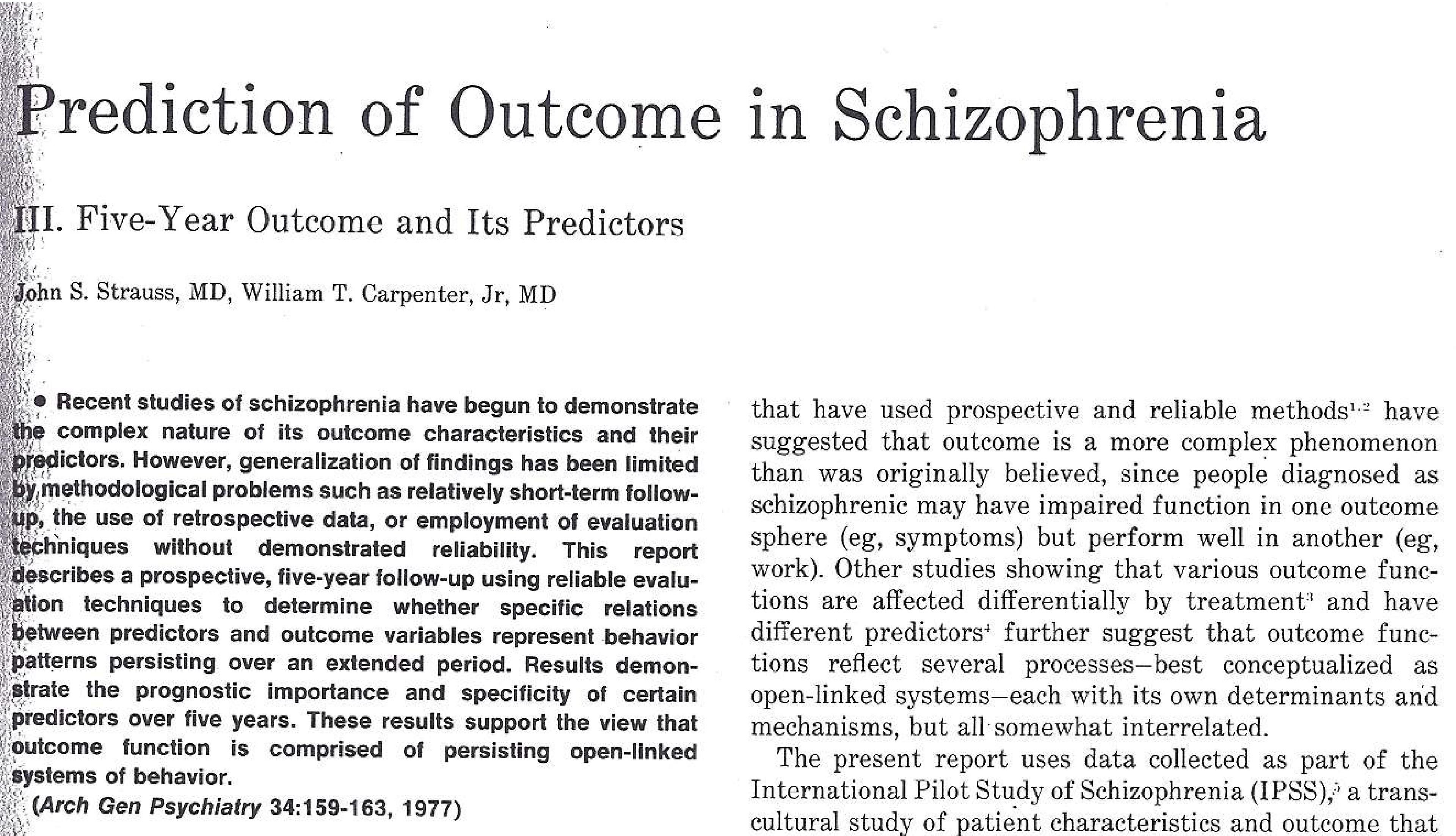
Glenn A. Roberts

severe mental illness, and is increasingly optimistic as programmes of care and treatment become more effective and realistic.

“...è una considerazione triste il fatto che la cronicità almeno in parte deriva dalle nostre aspettative negative...Avere fatto proprio ed in un certo senso perpetuato il racconto dell’incurabilità può essere utile ai bisogni di difesa e protezione degli operatori ed offrire anche qualche forma di conforto e di orientamento agli utenti. In questo modo corriamo il rischio di colludere con «la costruzione di barriere e la distruzione di ponti» confondendo la precarietà e l’incertezza della ricerca della salute con l’accettazione di significati che neutralizzano per sempre le potenzialità degli individui.”

John S. Strauss

Speaking the TRUTH
in times of universal deceit is a



Prediction of Outcome in Schizophrenia

III. Five-Year Outcome and Its Predictors

John S. Strauss, MD, William T. Carpenter, Jr, MD

• Recent studies of schizophrenia have begun to demonstrate the complex nature of its outcome characteristics and their predictors. However, generalization of findings has been limited by methodological problems such as relatively short-term follow-up, the use of retrospective data, or employment of evaluation techniques without demonstrated reliability. This report describes a prospective, five-year follow-up using reliable evaluation techniques to determine whether specific relations between predictors and outcome variables represent behavior patterns persisting over an extended period. Results demonstrate the prognostic importance and specificity of certain predictors over five years. These results support the view that outcome function is comprised of persisting open-linked systems of behavior.

(*Arch Gen Psychiatry* 34:159-163, 1977)

that have used prospective and reliable methods[1,2] have suggested that outcome is a more complex phenomenon than was originally believed, since people diagnosed as schizophrenic may have impaired function in one outcome sphere (eg, symptoms) but perform well in another (eg, work). Other studies showing that various outcome functions are affected differentially by treatment[3] and have different predictors[4] further suggest that outcome functions reflect several processes—best conceptualized as open-linked systems—each with its own determinants and mechanisms, but all somewhat interrelated.

The present report uses data collected as part of the International Pilot Study of Schizophrenia (IPSS),[5] a transcultural study of patient characteristics and outcome that

“Quando, seduto sul pavimento del soggiorno, ho iniziato a riesaminare tutte le elaborazioni grafiche relative ai soggetti inclusi nella ricerca, sono rimasto affascinato dalle cifre e dalla meravigliosa precisione…

Ma non riuscivo a riconoscervi le persone che avevo intervistato e conosciuto. Non ero più in contatto con loro…”

Riflettendo sul decorso del disturbo e osservando i grafici sparsi sul pavimento, mi sentivo sconcertato e mi rendevo conto che, più di ogni altra cosa, andava perduta la singola persona, con la sua specifica volontà…
Mi resi conto allora che si trattava di due diverse dimensioni: quella della persona, con la sua ricca e profonda esperienza umana; e quella del mondo dei dati, con la sua attendibilità e validità.

“[Qualche anno dopo] durante uno studio di follow-up che prevedeva interviste ripetute, una paziente mi disse: ‘Dottore, ma **perché non mi chiede mai cosa faccio io per aiutare me stessa**?’

Sto ancora cercando di rispondere compiutamente a questa domanda.

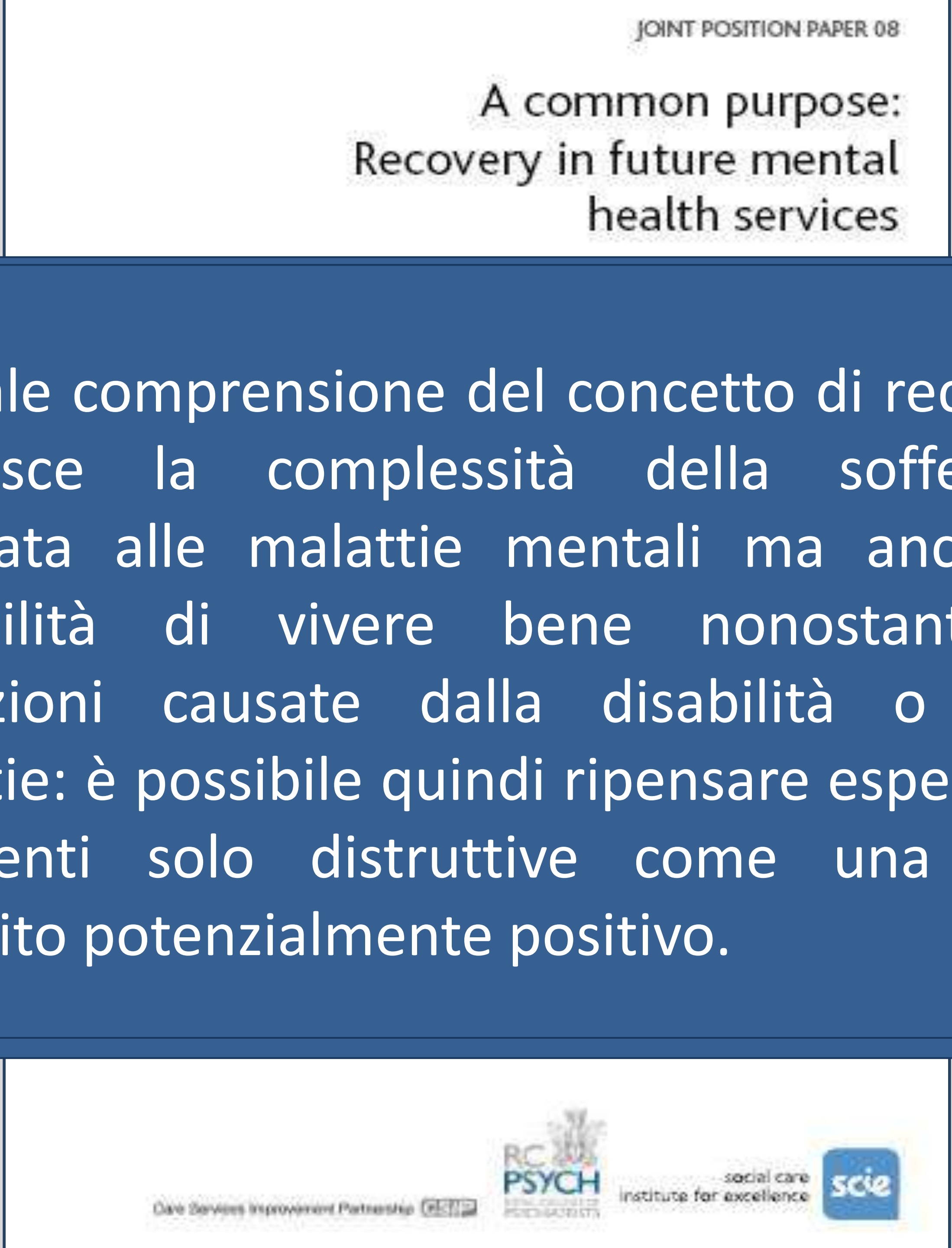
La paziente stava sollevando la questione della soggettività.

Non considerava sé stessa unicamente una vittima della sua malattia, un oggetto i cui sentimenti e le cui azioni fossero irrilevanti al fine di misurare il peggioramento o il miglioramento. Stava chiedendo perché io, noi operatori della salute mentale, non includiamo questi aspetti soggettivi nelle nostre teorie, nelle nostre azioni, nella ricerca.”

Strauss, 2008

In salute mentale, queste due dimensioni influenzano non solo le nostre idee, ma anche l’analisi dei dati raccolti: incidono su ciò che notiamo, tralasciamo, eliminiamo. Ma in realtà si tratta di due aspetti di un unico universo. Il nostro compito non consiste nello scegliere l’uno o l’altro, ma nel confrontarci con entrambi gli aspetti, che, congiunti, ci aiutino a capire cosa stiamo tentando di studiare, curare, prevenire”

Strauss, 1998



JOINT POSITION PAPER 08

A common purpose:
Recovery in future mental
health services

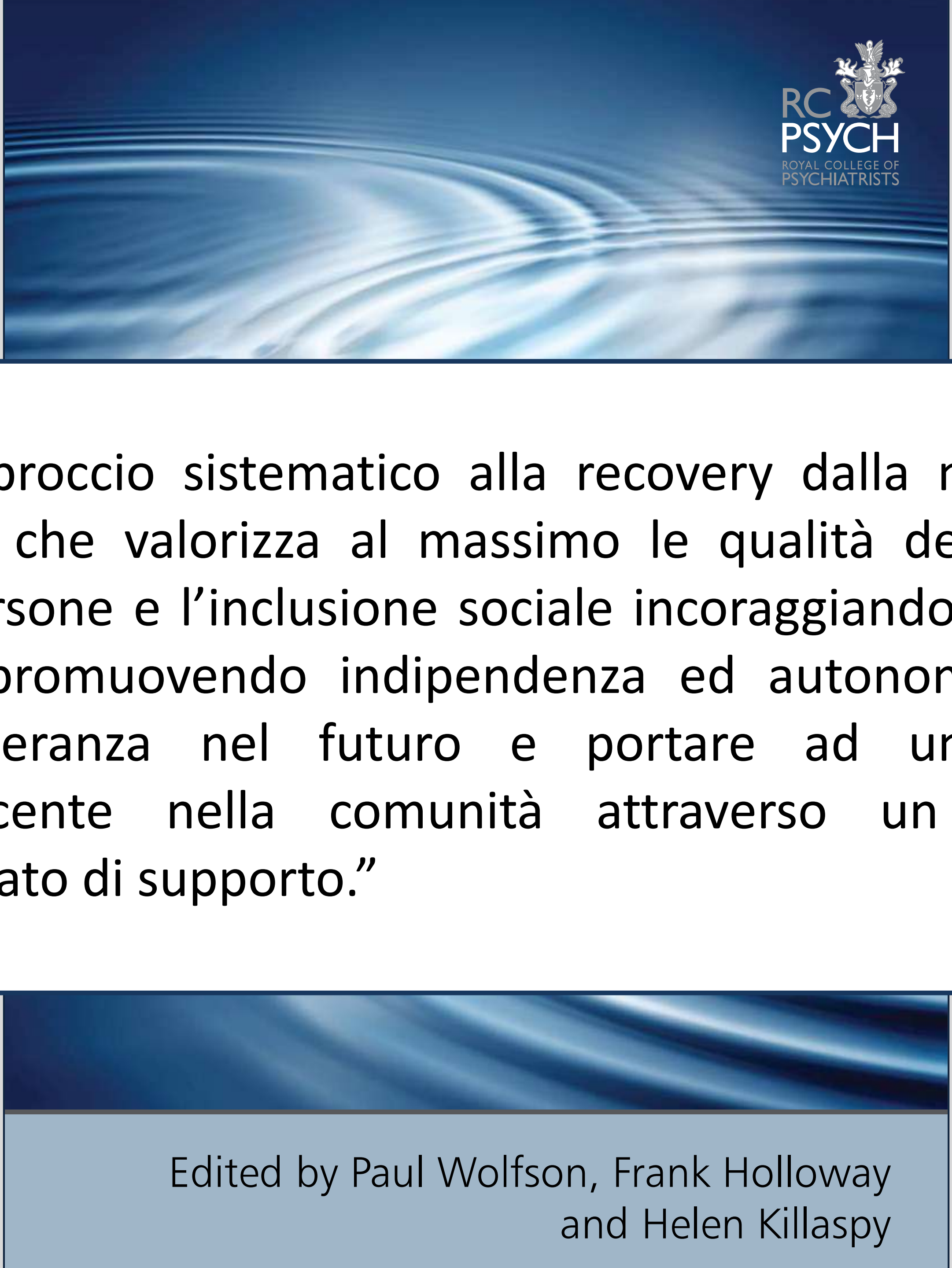
L’attuale comprensione del concetto di recovery riconosce la complessità della sofferenza associata alle malattie mentali ma anche la possibilità di vivere bene nonostante le limitazioni causate dalla disabilità o dalle malattie: è possibile quindi ripensare esperienze altrimenti solo distruttive come una sfida dall’esito potenzialmente positivo.

Care Services Improvement Partnership CSIP

RC PSYCH

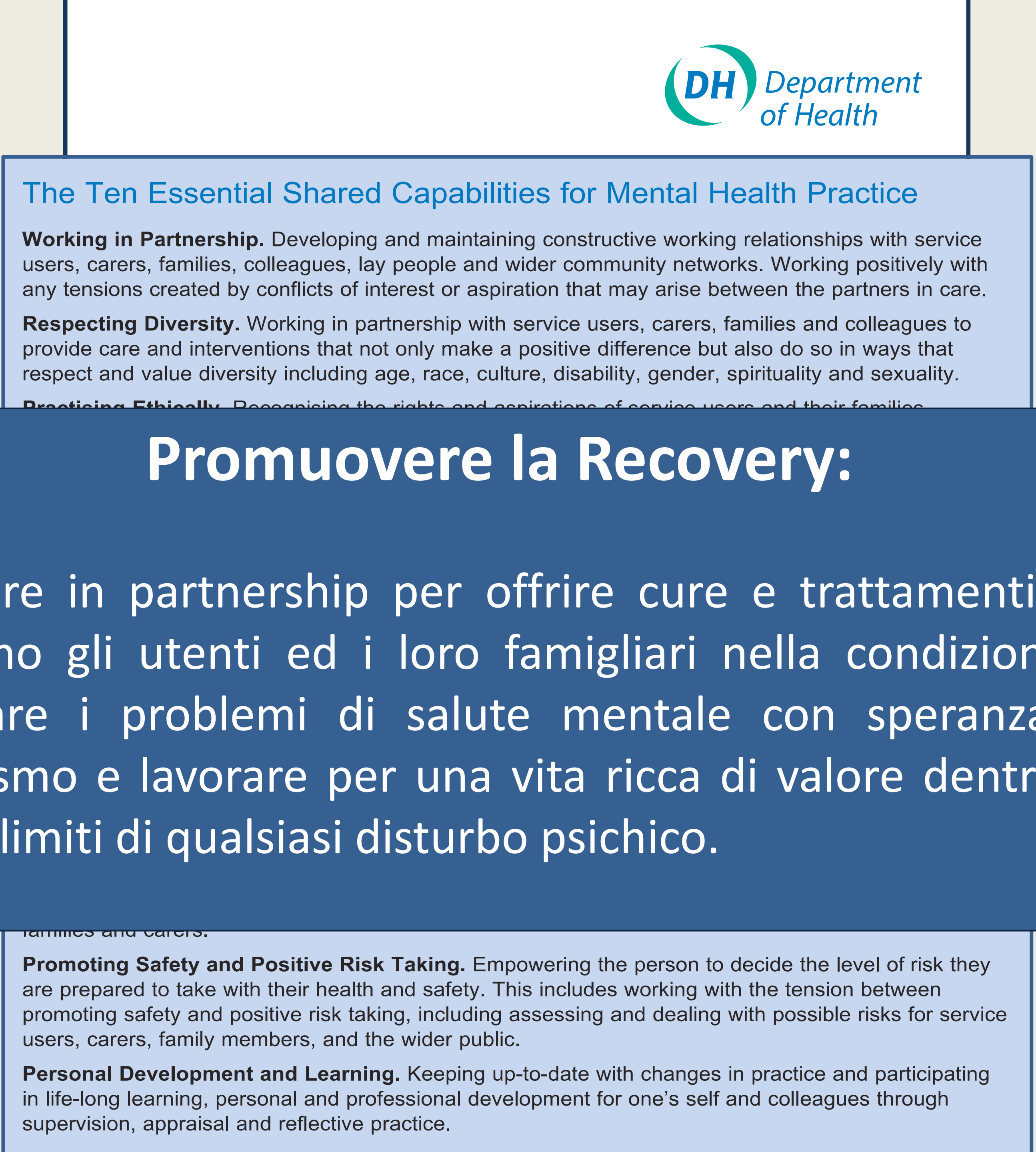
social care
institute for excellence

scie



"..un approccio sistematico alla recovery dalla malattia mentale che valorizza al massimo le qualità della vita delle persone e l'inclusione sociale incoraggiando le loro abilità, promuovendo indipendenza ed autonomia per dare speranza nel futuro e portare ad una vita soddisfacente nella comunità attraverso un livello appropriato di supporto."

Edited by Paul Wolfson, Frank Holloway
and Helen Killaspy



DH Department of Health

The Ten Essential Shared Capabilities for Mental Health Practice

Working in Partnership. Developing and maintaining constructive working relationships with service users, carers, families, colleagues, lay people and wider community networks. Working positively with any tensions created by conflicts of interest or aspiration that may arise between the partners in care.

Respecting Diversity. Working in partnership with service users, carers, families and colleagues to provide care and interventions that not only make a positive difference but also do so in ways that respect and value diversity including age, race, culture, disability, gender, spirituality and sexuality.

Practising Ethically. Recognising the rights and aspirations of service users and their families

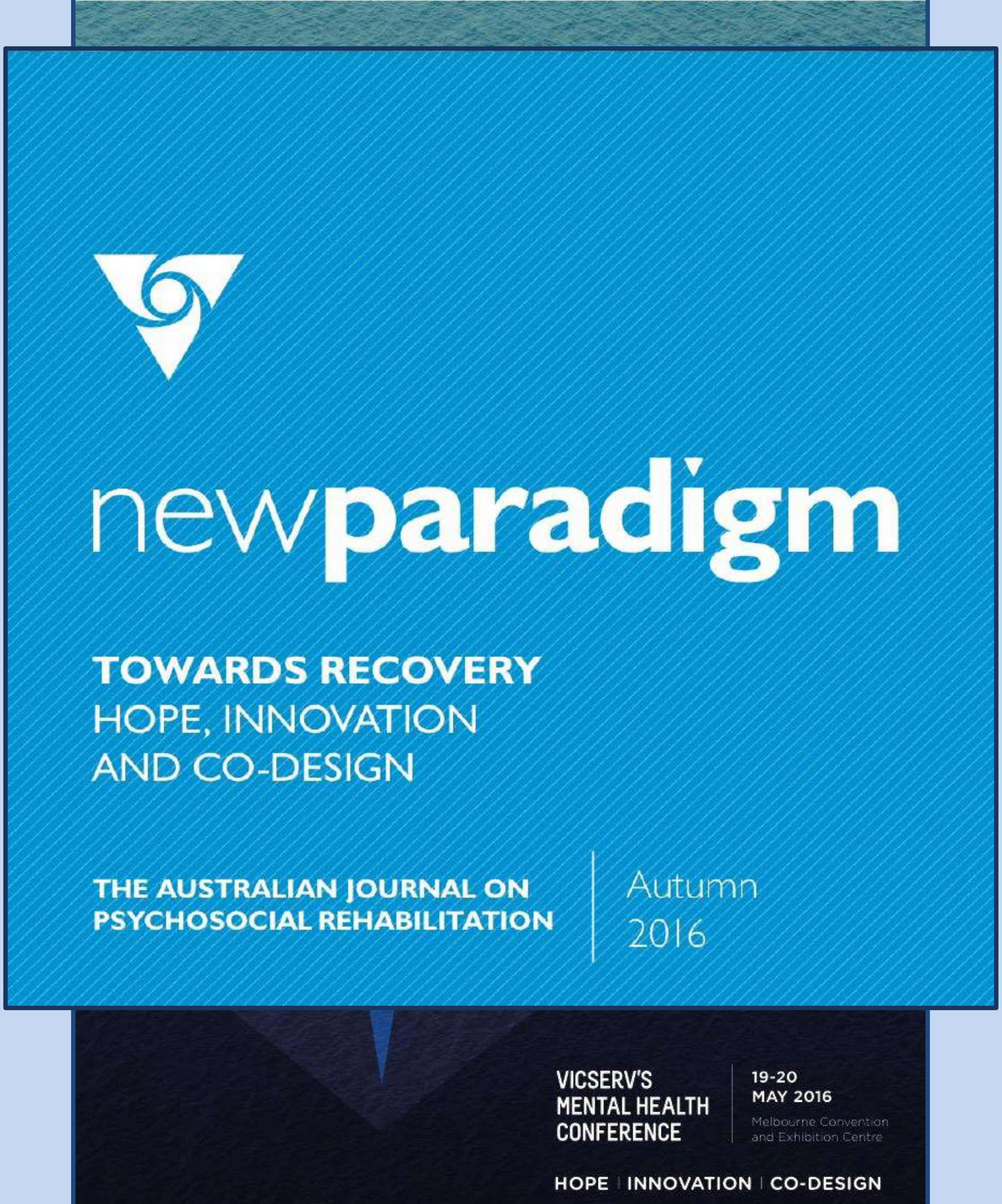
families and carers.

Promoting Safety and Positive Risk Taking. Empowering the person to decide the level of risk they are prepared to take with their health and safety. This includes working with the tension between promoting safety and positive risk taking, including assessing and dealing with possible risks for service users, carers, family members, and the wider public.

Personal Development and Learning. Keeping up-to-date with changes in practice and participating in life-long learning, personal and professional development for one's self and colleagues through supervision, appraisal and reflective practice.

Promuovere la Recovery:

Lavorare in partnership per offrire cure e trattamenti che mettano gli utenti ed i loro famigliari nella condizione di superare i problemi di salute mentale con speranza ed ottimismo e lavorare per una vita ricca di valore dentro ed oltre i limiti di qualsiasi disturbo psichico.



newparadigm

TOWARDS RECOVERY
HOPE, INNOVATION
AND CO-DESIGN

THE AUSTRALIAN JOURNAL ON
PSYCHOSOCIAL REHABILITATION

Autumn
2016

VICSERV'S
MENTAL HEALTH
CONFERENCE

19-20
MAY 2016
Melbourne Convention
and Exhibition Centre

HOPE | INNOVATION | CO-DESIGN

The empirical evidence about mental health and recovery: **how likely, how long, what helps?**

Prof Mike Slade
Dr Eleanor Longden
July 2015

Box 2: Evidence-based messages

Implications for resource allocation

Health and social care systems need to allocate resources, such as disability-related benefits. Typically this is done by allocating people to categories, e.g. Disabled versus Not Disabled, or No, Mild, Moderate or Severe Disability. Allocating people to categories has two problems in relation to people with mental health problems. First, it encourages a focus on 'objective' or observable measures such as the distance someone can walk or the weight someone can lift. These criteria disadvantage people whose health problems manifest less visibly, e.g. as cognitive or emotional difficulties. Second, it encourages a view that disability is a state and therefore permanent – someone 'is' disabled. This is unhelpful in the context of problems such as mental health difficulties which come and go in severity, and can have a negative impact in reducing hopefulness and increasing stigma.

How should resources be allocated? Identifying people with 'severe' mental illness has classically involved consideration of three criteria: diagnosis, disability and duration[119].

Diagnosis

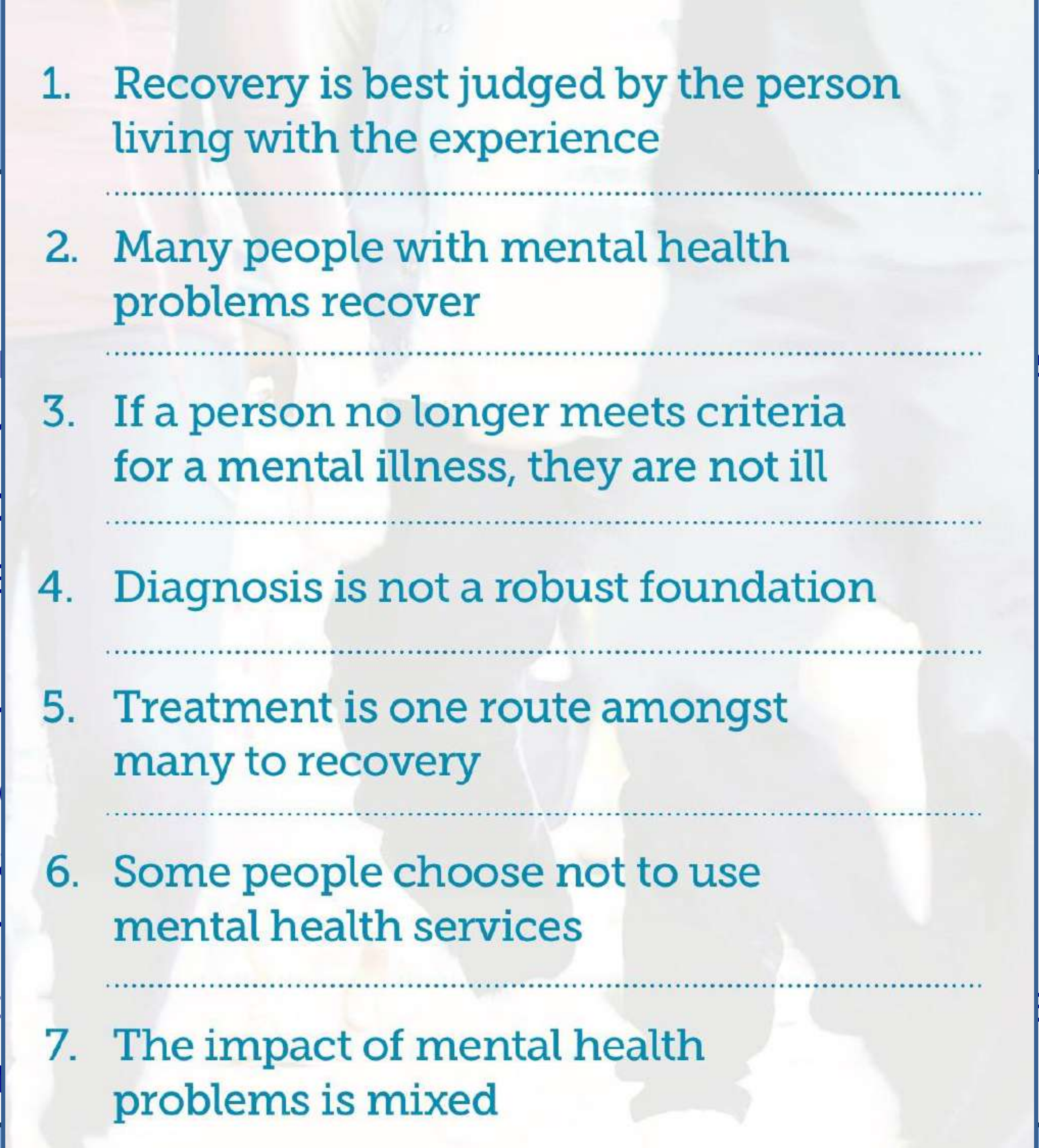
Although convenient, diagnosis in a mental health context is contested. Some people choose not to accept their diagnosis, and framing their experience in other ways has a positive influence on their recovery. Making people accept a label in order to access entitlements therefore has negative consequences. New approaches to allocating social resources are needed, which reduce rather than enhance stigma. In the short term, one step towards reducing benefits-related stigma would be to allow disagreement with a diagnosis to be recorded on claim forms without impacting on entitlement. In the longer term, less contested approaches than diagnosis are needed.

Disability

Criteria should be used which are sensitive to the types of problems (e.g. attention, memory, interpersonal) experienced by people with mental health problems.

Duration

The idea of 'permanent disability' in a mental health context is toxic, and should not be used. For duration, a time criterion relating to a reasonable review period should be used, such as 'expected to persist for at least one year'.



1. Recovery is best judged by the person living with the experience
2. Many people with mental health problems recover
3. If a person no longer meets criteria for a mental illness, they are not ill
4. Diagnosis is not a robust foundation
5. Treatment is one route amongst many to recovery
6. Some people choose not to use mental health services
7. The impact of mental health problems is mixed

1) La rte
per
2) Mo
gua
3) Se ci
per
1) Le
2) I tr
la r
1) Alc rvizi.
2) L'in

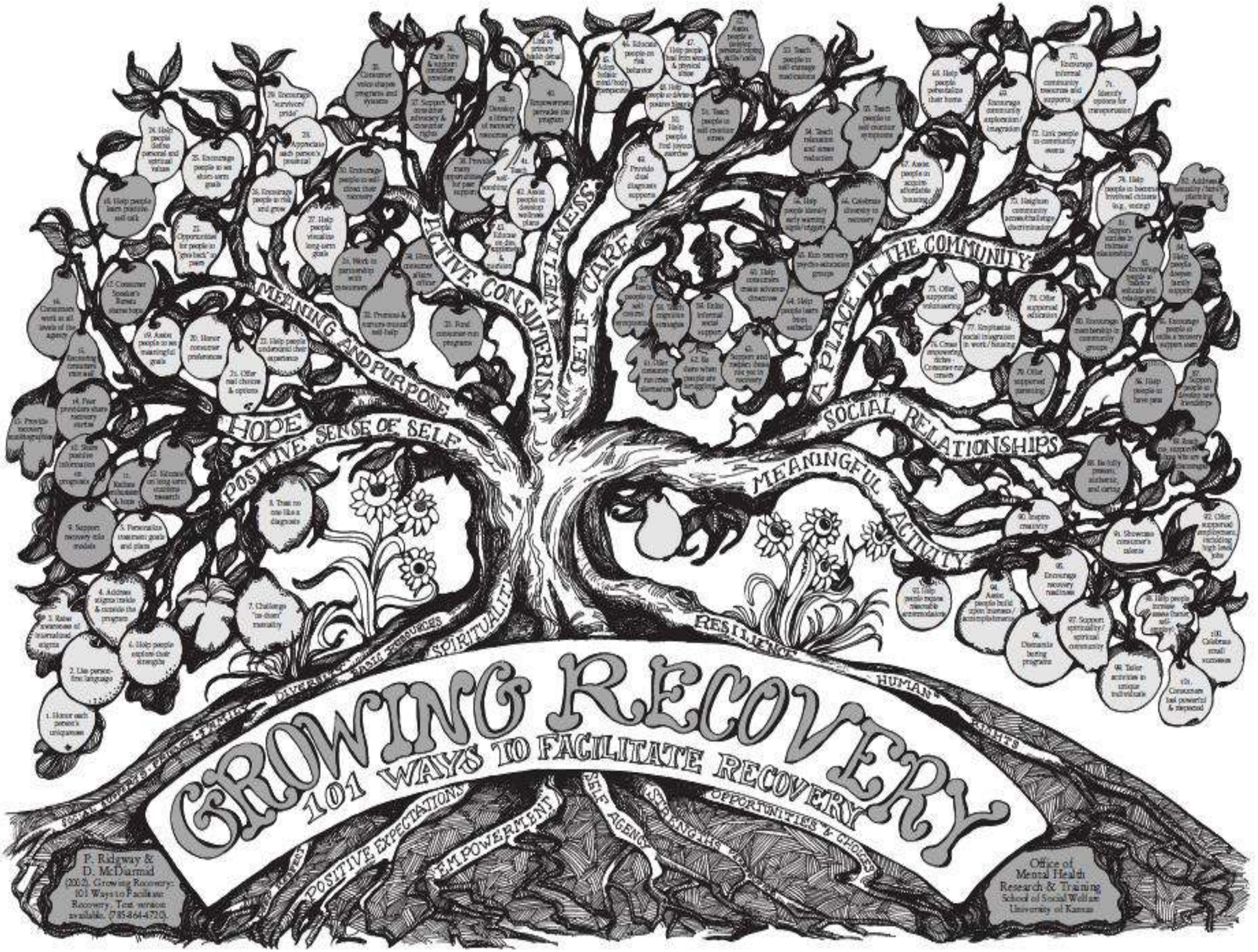
Recovery è…

ciò che una persona con malattia mentale fa per gestire la sua malattia

… ***mentre*** continua a perseguire i propri sogni e obiettivi

… ***mentre*** si costruisce o si ricostruisce una vita sicura, dignitosa, significativa nella comunità in cui decide di vivere

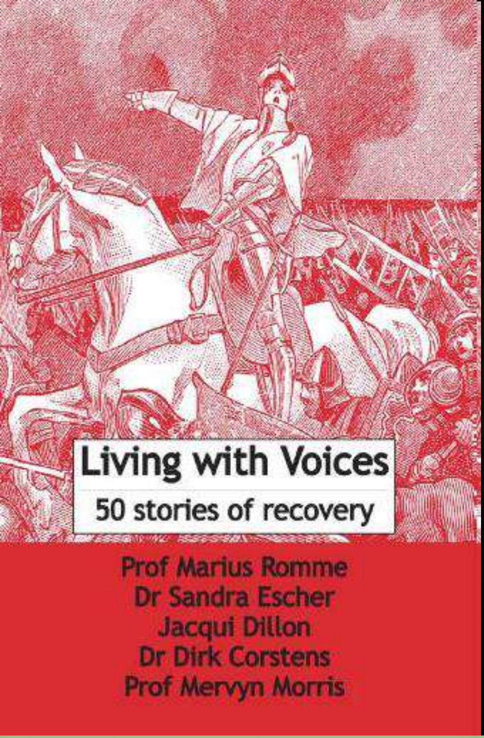
… ***mentre*** continua a occuparsi delle conseguenze di avere un disturbo mentale

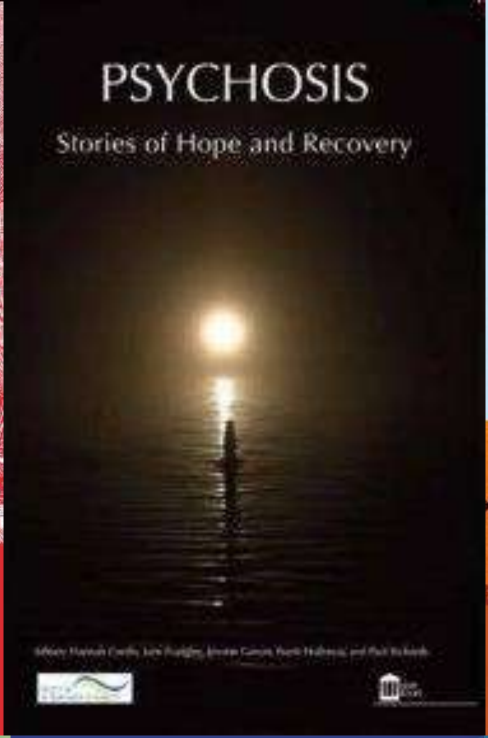

HOPE
POSITIVE SENSE OF SELF
MEANING AND PURPOSE
ACTIVE CONSUMERISM
WELLNESS
SELF CARE
A PLACE IN THE COMMUNITY
SOCIAL RELATIONSHIPS
MEANINGFUL ACTIVITY
SPIRITUALITY
RESILIENCE
HUMAN RIGHTS
DIVERSITY
POSITIVE EXPECTATIONS
EMPOWERMENT
SELF AGENCY
STRENGTHS
OPPORTUNITIES & CHOICES
1. Honor each person's uniqueness
2. Use person-first language
3. Raise awareness of internalized stigma
4. Address stigma inside & outside the program
5. Personalize treatment goals and plans
6. Help people explore their strengths
7. Challenge "us-them" mentality
8. Treat no one like a diagnosis
9. Support recovery role models
10. Share positive information on prognosis
11. Radiate enthusiasm & hope
12. Educate on long-term outcome research
13. Provide recovery autobiographies
14. Peer providers share recovery stories
16. Consumers work at all levels of the agency
17. Consumer Speaker's Bureau shares hope
18. Help people learn positive self-talk
19. Assist people to set meaningful goals
20. Honor consumer preferences
21. Offer real choices & options
22. Help people understand their experience
23. Opportunities for people to "give back" to peers
24. Help people define personal and spiritual values
25. Encourage people to set short-term goals
26. Encourage people to risk and grow
27. Help people visualize long-term goals
28. Appreciate each person's potential
29. Encourage "survivors' pride"
30. Encourage people to self-direct their recovery
31. Work in partnership with consumers
32. Promote & nurture mutual self-help
33. Fund consumer-run programs
34. Hire consumer affairs officer
35. Consumer voice shapes programs and systems
36. Train, hire & support consumer providers
37. Support consumer advocacy & consumer rights
38. Provide many opportunities for peer support
39. Develop a library of recovery resources
40. Empowerment pervades the program
41. Teach self-soothing
42. Assist people to develop wellness plans
43. Educate on diet, supplements & nutrition
44. Link to primary health/dental care
45. Adopt holistic mind/body perspective
46. Educate people on risk behavior
47. Help people heal from sexual & physical abuse
48. Provide dual diagnosis supports
50. Help people find joyous exercise
51. Teach people to self-monitor stress
52. Assist people to develop personal coping skills/tools
53. Teach people to self-manage medications
54. Teach relaxation and stress reduction
55. Teach people to self-monitor symptoms
56. Teach cognitive strategies
57. Teach people to self-control symptoms
58. Enlist informal social support
59. Help people identify early warning signs/triggers
60. Help consumers create advance directives
61. Offer consumer-run crisis alternatives
62. Be there when people are struggling
64. Help people learn from setbacks
65. Run recovery psycho-education groups
66. Celebrate diversity in recovery
67. Assist people to acquire affordable housing
68. Help people personalize their home
69. Encourage community exploration/integration
70. Encourage informal community resources and supports
71. Identify options for transportation
72. Link people to community events
73. Heighten community access/challenge discrimination
74. Help people to become involved citizens (e.g., voting)
75. Offer supported volunteering
76. Create empowering niches - Consumer-run centers
77. Emphasize social integration in work/housing
78. Offer supported education
79. Offer supported parenting
80. Encourage membership in community groups
81. Support success in intimate relationships
82. Address sexuality/family planning
83. Encourage people to balance solitude and relationships
84. Help people deepen family support
85. Encourage people to enlist a recovery support team
86. Help people to have pets
87. Support people to develop new friendships
88. Be fully present, authentic, and caring
90. Inspire creativity
91. Showcase consumer's talents
92. Offer supported employment, including high level jobs
93. Help people request reasonable accommodations
94. Assist people build upon interests/accomplishments
95. Encourage recovery readiness
96. Dismantle boring programs
97. Support spirituality/spiritual community
98. Tailor activities to unique individuals
100. Celebrate small successes
101. Consumers feel powerful & respected

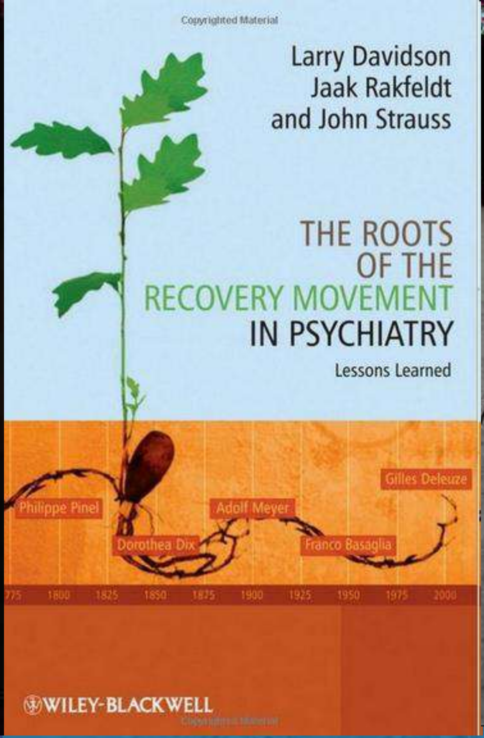
GROWING RECOVERY
101 WAYS TO FACILITATE RECOVERY

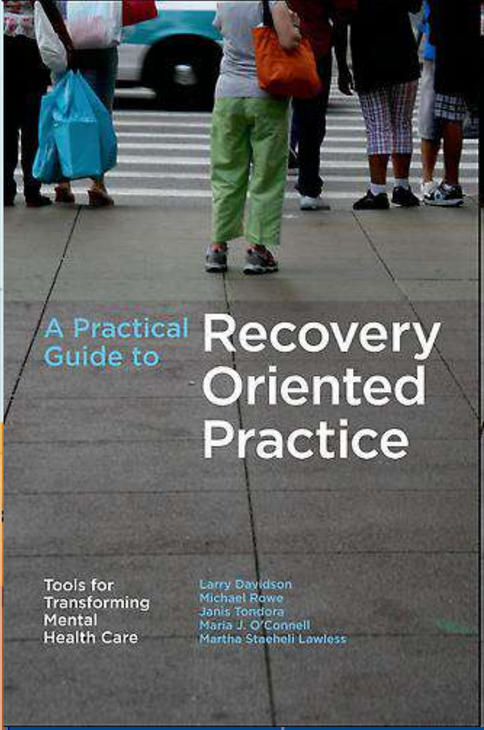
P. Ridgway &
D. McDiarmid
(2002). Growing Recovery:
101 Ways to Facilitate
Recovery. Text version
available. (785-864-4720).

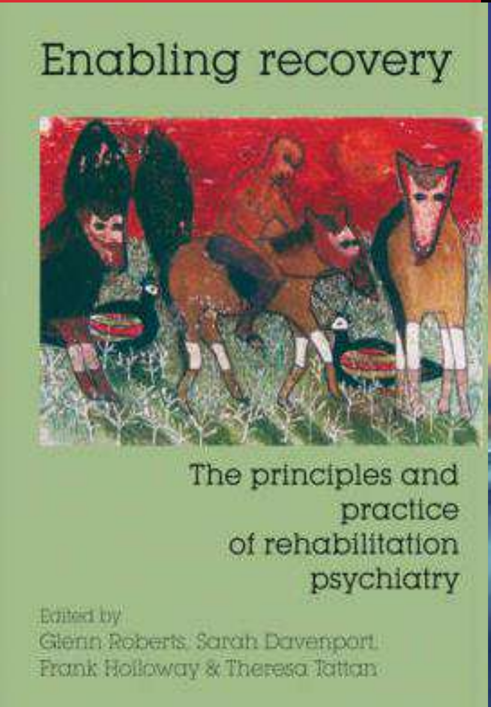
Office of
Mental Health
Research & Training
School of Social Welfare
University of Kansas

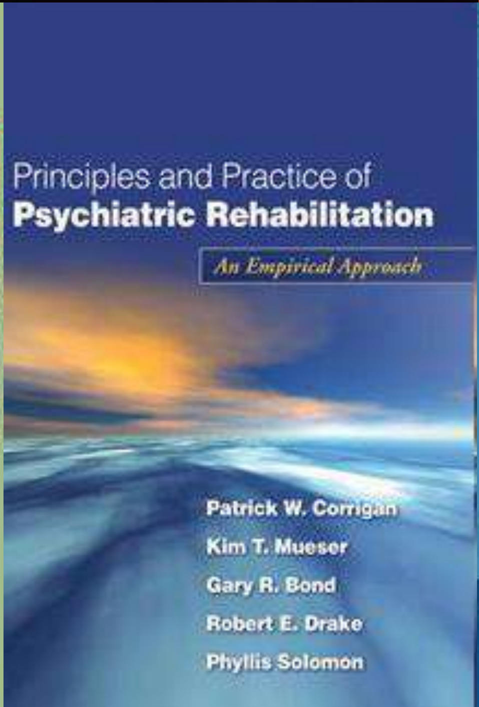

Living with Voices
50 stories of recovery
Prof Marius Romme
Dr Sandra Escher
Jacqui Dillon
Dr Dirk Corstens
Prof Mervyn Morris

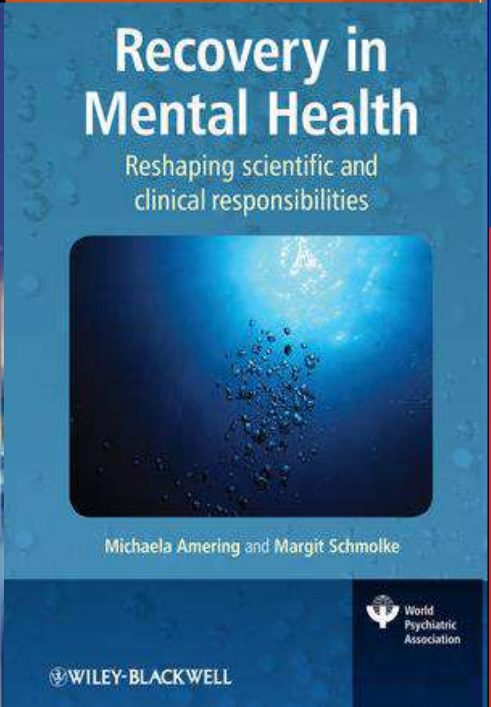

PSYCHOSIS
Stories of Hope and Recovery

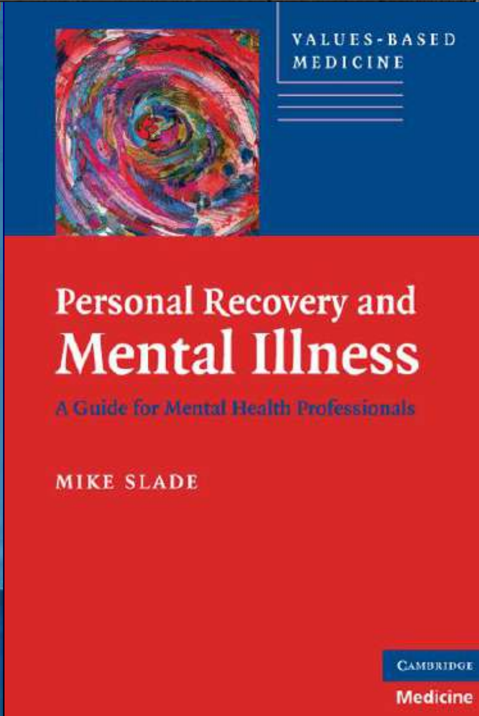

Copyrighted Material
Larry Davidson
Jaak Rakfeldt
and John Strauss
THE ROOTS OF THE RECOVERY MOVEMENT IN PSYCHIATRY
Lessons Learned
Philippe Pinel
Dorothea Dix
Adolf Meyer
Franco Basaglia
Gilles Deleuze
1800
1825
1850
1875
1900
1925
1950
1975
2000
WILEY-BLACKWELL


A Practical Guide to Recovery Oriented Practice
Tools for Transforming Mental Health Care
Larry Davidson
Michael Rowe
Janis Tondora
Maria J. O'Connell
Martha Staeheli Lawless


Enabling recovery
The principles and practice of rehabilitation psychiatry
Edited by
Glenn Roberts, Sarah Davenport, Frank Holloway & Theresa Tattan


Principles and Practice of Psychiatric Rehabilitation
An Empirical Approach
Patrick W. Corrigan
Kim T. Mueser
Gary R. Bond
Robert E. Drake
Phyllis Solomon

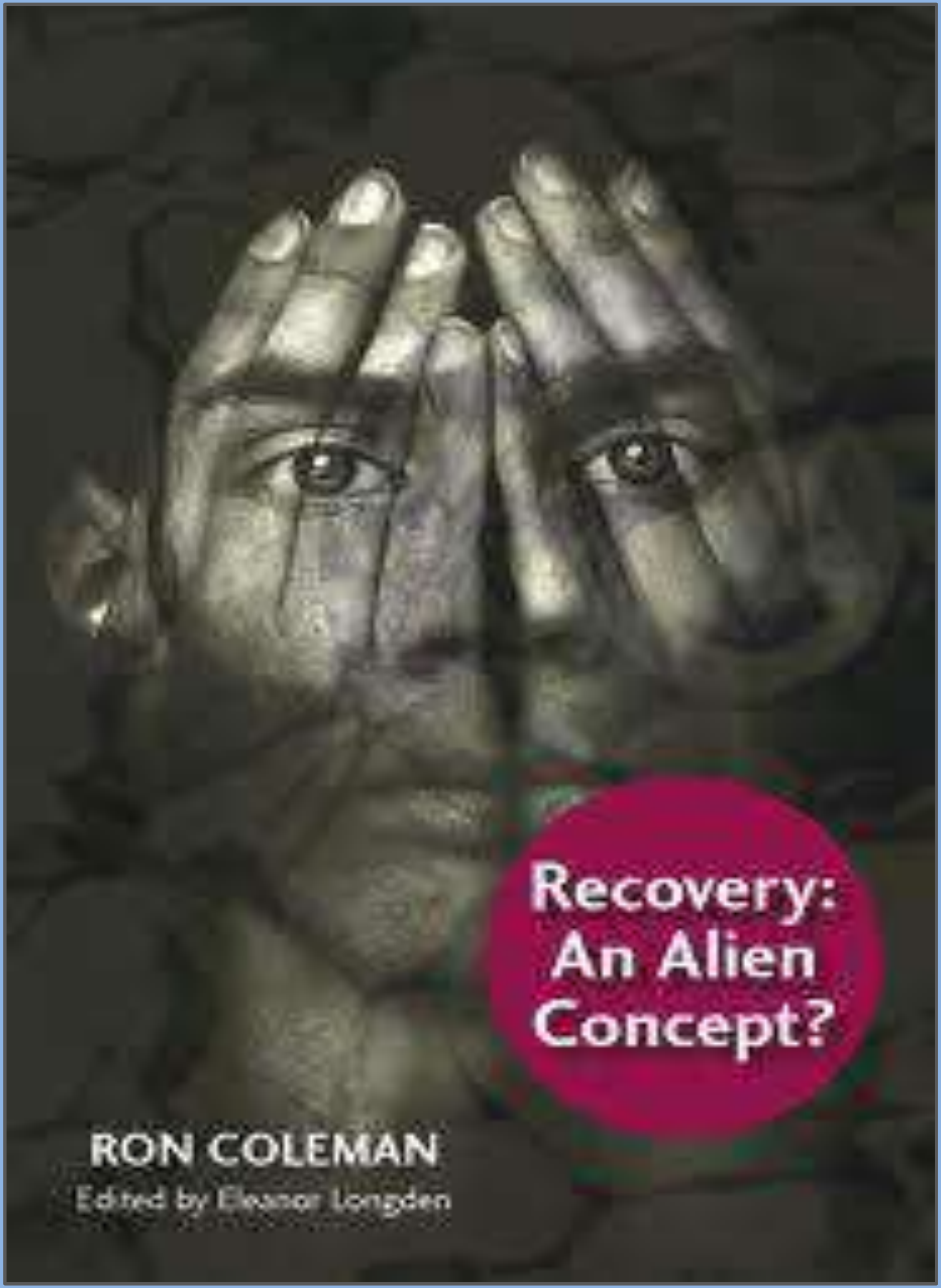

Recovery in Mental Health
Reshaping scientific and clinical responsibilities
Michaela Amering and Margit Schmolke
World Psychiatric Association
WILEY-BLACKWELL

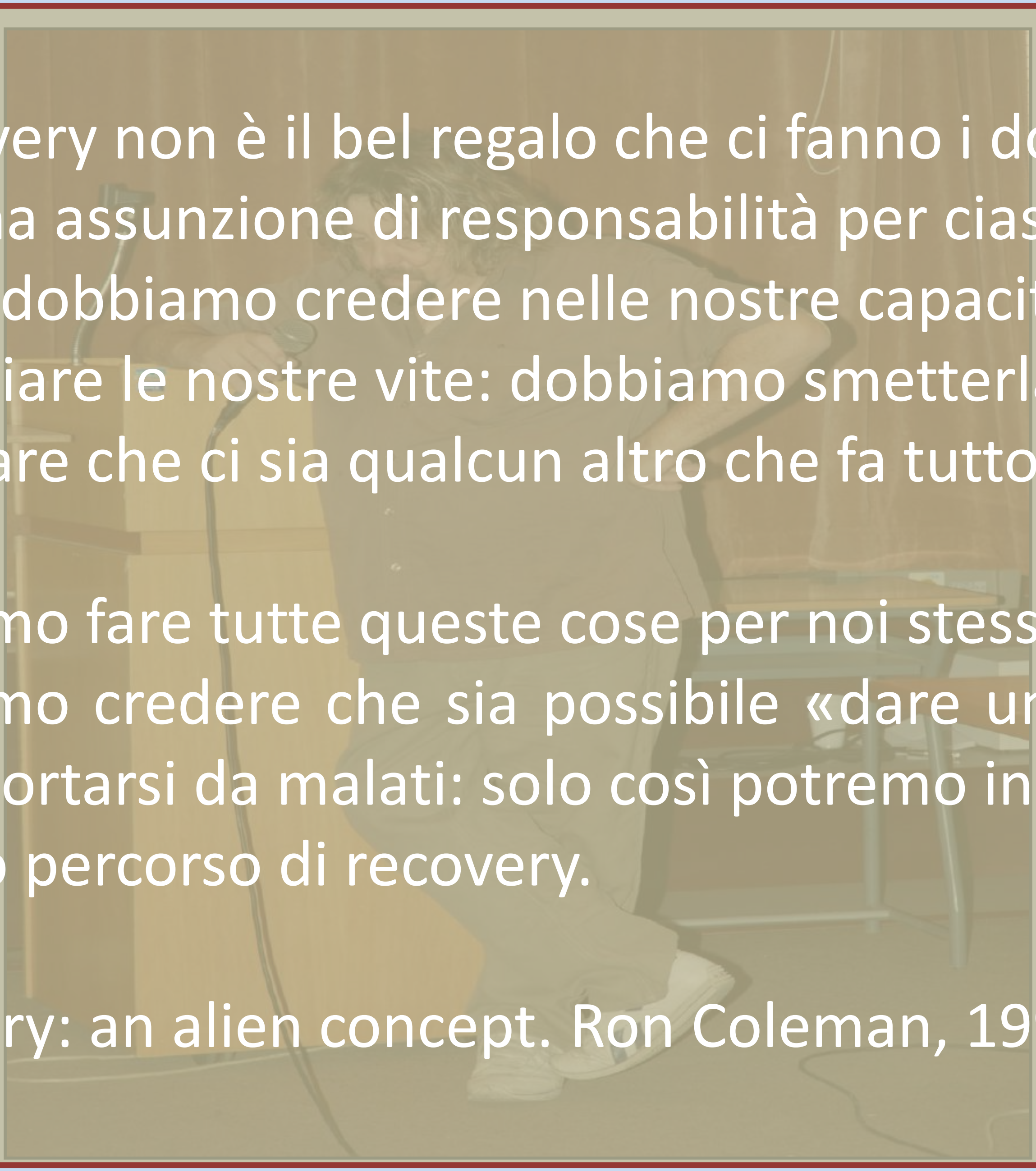

VALUES-BASED MEDICINE
Personal Recovery and Mental Illness
A Guide for Mental Health Professionals
MIKE SLADE
CAMBRIDGE
Medicine

I will live my life, not my diagnosis.

Pat Deegan

https://commongroundprogram.com


Recovery:
An Alien
Concept?
RON COLEMAN
Edited by Eleanor Longden

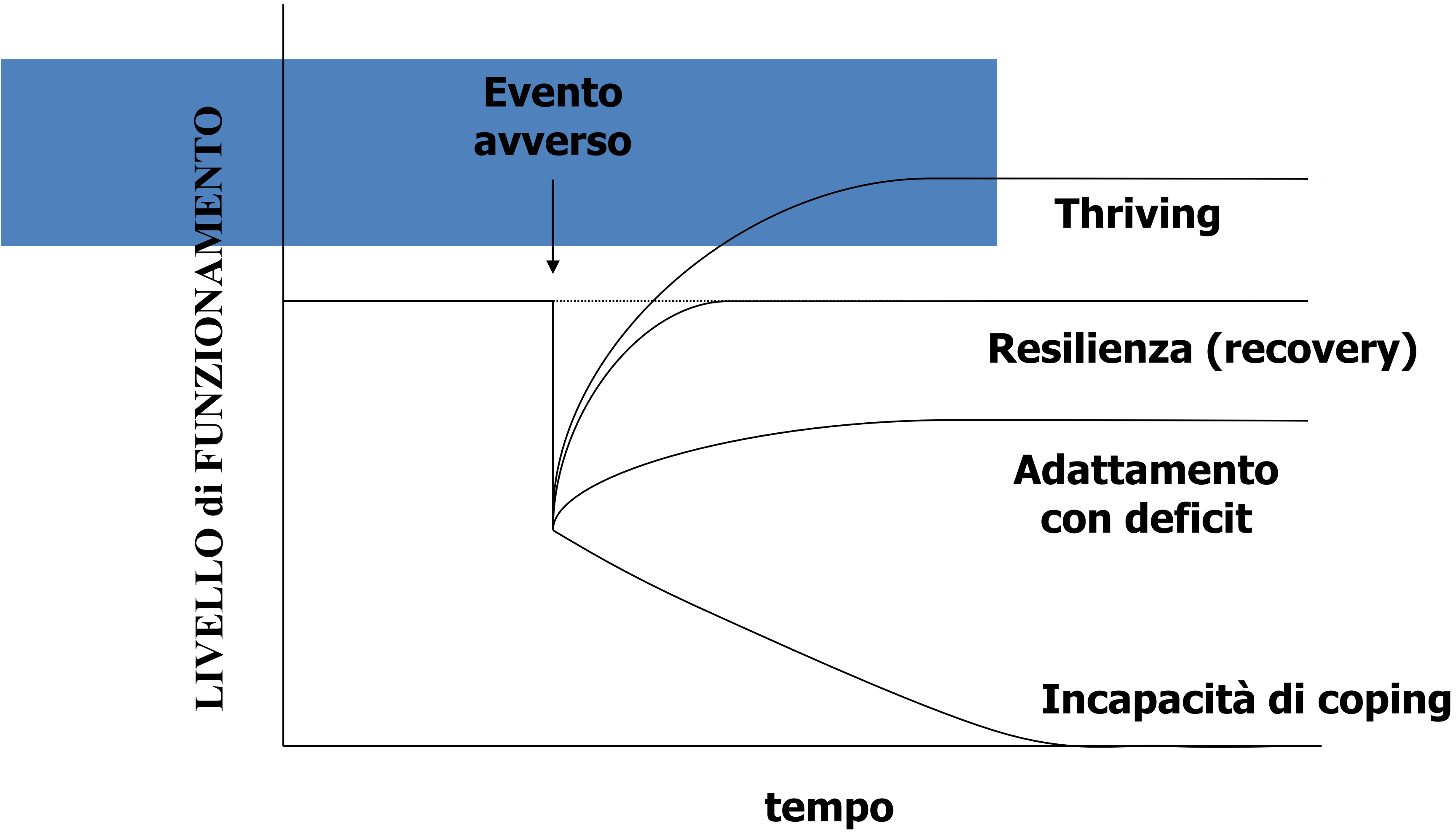


La recovery non è il bel regalo che ci fanno i dottori, ma è una assunzione di responsabilità per ciascuno di noi… dobbiamo credere nelle nostre capacità di cambiare le nostre vite: dobbiamo smetterla di pensare che ci sia qualcun altro che fa tutto per noi.

Dobbiamo fare tutte queste cose per noi stessi.

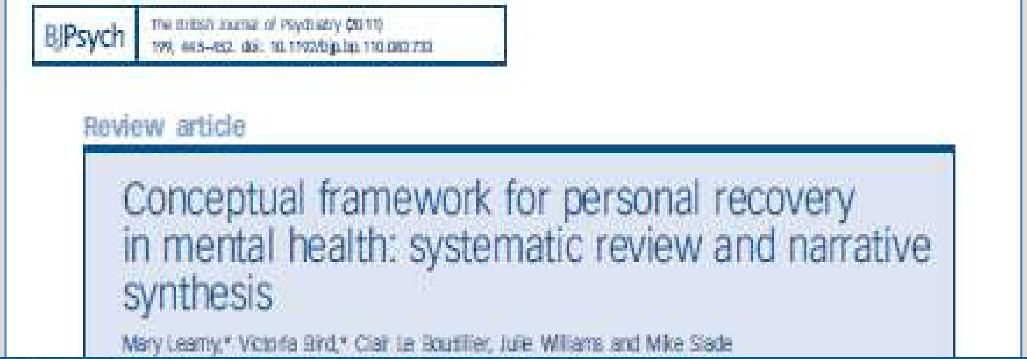
Dobbiamo credere che sia possibile «dare un taglio» al comportarsi da malati: solo così potremo iniziare il nostro percorso di recovery.

(Recovery: an alien concept. Ron Coleman, 1999)


Evento avverso
LIVELLO di FUNZIONAMENTO
Thriving
Resilienza (recovery)
Adattamento con deficit
Incapacità di coping
tempo

Risposte potenziali al trauma

(Carver, Charles A. (1998). Resilience and thriving: Issues, models and linkages. Journal of Social Issues, Vol. 54, No. 2, 245-266.)



BJPsych The British Journal of Psychiatry (2011) 199, 445–452. doi: 10.1192/bjp.bp.110.083733

Review article

Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis

Mary Leamy,* Victoria Bird,* Clair Le Boutillier, Julie Williams and Mike Slade

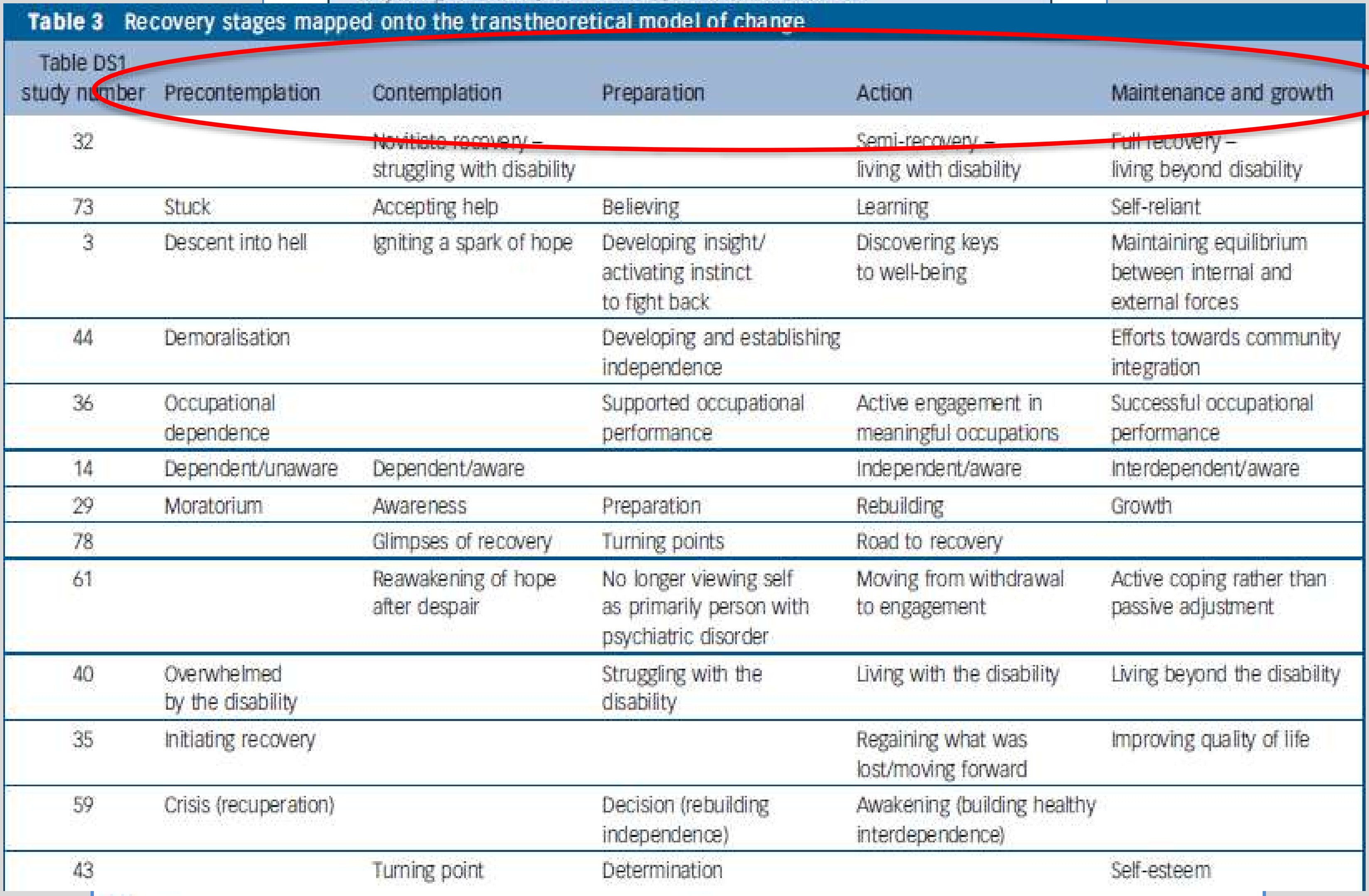
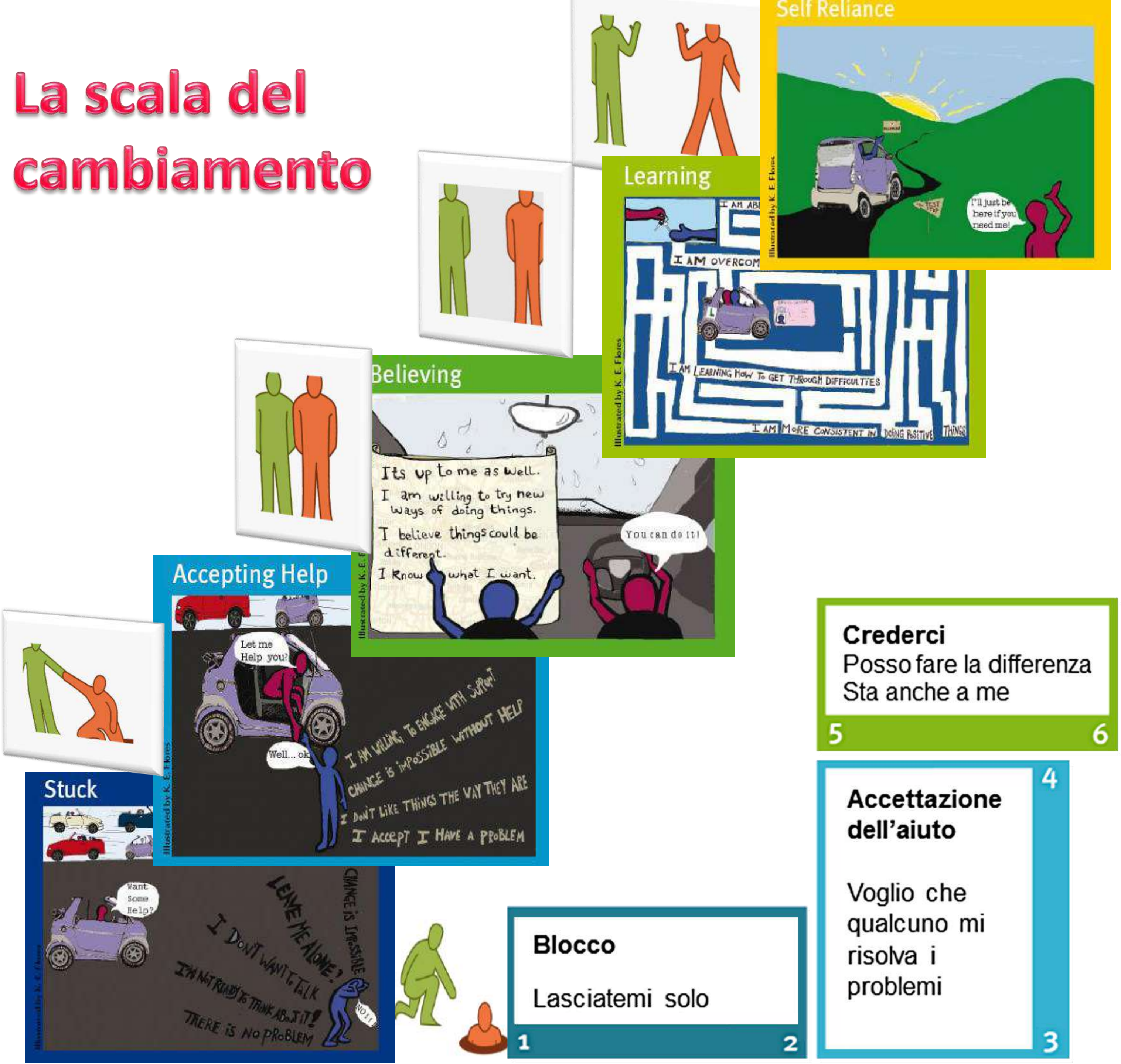


Table 3 Recovery stages mapped onto the transtheoretical model of change

Table DS1 study number	Precontemplation	Contemplation	Preparation	Action	Maintenance and growth
32		Novitiate recovery – struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
73	Stuck	Accepting help	Believing	Learning	Self-reliant
3	Descent into hell	Igniting a spark of hope	Developing insight/ activating instinct to fight back	Discovering keys to well-being	Maintaining equilibrium between internal and external forces
44	Demoralisation		Developing and establishing independence		Efforts towards community integration
36	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
14	Dependent/unaware	Dependent/aware		Independent/aware	Interdependent/aware
29	Moratorium	Awareness	Preparation	Rebuilding	Growth
78		Glimpses of recovery	Turning points	Road to recovery	
61		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
40	Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability
35	Initiating recovery			Regaining what was lost/moving forward	Improving quality of life
59	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
43		Turning point	Determination		Self-esteem

La scala del cambiamento


Stuck
Want Some Help?
LEAVE ME ALONE!
I DON'T WANT TO TALK
I'M NOT READY TO THINK ABOUT IT!
THERE IS NO PROBLEM
CHANGE IS IMPOSSIBLE
NO!!
Accepting Help
Let me Help you?
Well... ok
I AM WILLING TO ENGAGE WITH SUPPORT
CHANGE IS IMPOSSIBLE WITHOUT HELP
I DON'T LIKE THINGS THE WAY THEY ARE
I ACCEPT I HAVE A PROBLEM
Believing
It's up to me as well.
I am willing to try new ways of doing things.
I believe things could be different.
I know what I want.
You can do it!
Learning
I AM ABL
I AM OVERCOM
I AM LEARNING HOW TO GET THROUGH DIFFICULTIES
I AM MORE CONSISTENT IN DOING POSITIVE THINGS
Self Reliance
I'll just be here if you need me!
Illustrated by K. E. Flores

Blocco

Lasciatemi solo

1 2

Accettazione dell'aiuto

Voglio che qualcuno mi risolva i problemi

3 4

Crederci

Posso fare la differenza

Sta anche a me

5 6

Apprendimento

Sto imparando come si fa

7 8

Basarsi sulle proprie forze

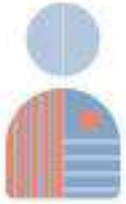
Posso farcela senza l'aiuto dei servizi

9 10

Cosa favorisce il percorso della recovery?

CONNESSIONI

- Buone relazioni
- Supporto fra pari
- La comunità



IDENTITA’

- Autostima
- Superare lo stigma
- Andare oltre la diagnosi

EMPOWERMENT

- Focus sui punti di forza
- Essere in controllo
- Assumersi responsabilità personali
- autogestirsi

SPERANZA

- Credere nel miglioramento
- Motivazione al cambiamento
- Pensiero e aspettative positive

SIGNIFICATI PERSONALI

- Avere scopi
- Sentirsi capaci
- In grado di contribuire

RECOVERY PROCESS (CHIME) **(Other super-ordinate categories: Characteristics of the Recovery Journey, Recovery Stages)**	**Connectedness**	• Peer support and support groups • Relationships • Support from others • Being part of the community
	Hope and optimism about the future	• Motivation to change • Belief in possibility of recovery • Positive thinking and valuing success • Having dreams and aspirations • Hope-inspiring relationships
	Identity	• Dimensions of identity • Rebuilding/redefining positive identity • Over-coming stigma
	Meaning in life	• Meaning of mental illness experiences • Spirituality • Quality of life • Meaningful life and social roles • Meaningful life and social goals • Rebuilding of life
	Empowerment	• Personal responsibility • Control over life • Focusing upon strengths

RECOVERY { NET

Slade et al. (2012) .“International differences in understanding recovery: systematic review”, *Epidemiology and Psychiatric Sciences*, 21: 353-364.

INSPIRE

Versione Italiana

'INSPIRE was developed in English by Julie Williams, Mary Leamy, Mike Slade and colleagues in the Section for Recovery, Institute of Psychiatry, Psychology & Neuroscience, King's College London.
Further information from researchintorecovery.com/INSPIRE.
This version was translated into italian by Saverio Randi and Nicolò Ratti.

Si può parlare di "recovery" ("recupero") in differenti modi, uno di questi è vivere una vita soddisfacente e piena di speranza. Tale questionario Le chiede come l'operatore supporta il Suo recupero.
La sezione "Supporto" chiede informazioni a proposito di aree che Lei potrebbe ritenere importanti per la Sua guarigione e di come l'operatore del servizio di salute mentale La sostiene in queste aree.
La sezione "Rapporto" indaga invece com'è il rapporto con il Suo operatore. Se non desidera rispondere a una domanda, lasci uno spazio vuoto.

Per favore risponda a tutte le domande a proposito di ....
(nome dell'operatore)

Sezione "Supporto dell'operatore"

La preghiamo di leggere ogni domanda e decidere se è importante per Lei o no. Se ha cerchiato NO può passare direttamente alla domanda successiva. Se la Sua risposta è SI, Le chiediamo di cerchiare nelle aree grigie la quantità di supporto che ritiene di ottenere dall'operatore in quella specifica area.

Una parte importante del mio recupero è...

Mi sento supportato dal mio operatore in questo...

S1 Sentirmi supportato dalle altre persone	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S2 Avere relazioni positive con le altre persone	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S3 Ricevere supporto dagli altri utenti del servizio	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S4 Sentirmi parte della mia comunità	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S5 Sentirmi speranzoso riguardo al mio futuro	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S6 Avere fiducia di potere "riprendermi"	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S7 Essere motivato a portare cambiamenti nella mia vita	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto

Sezione "Supporto dell'operatore"

Una parte importante del mio recupero è...

Mi sento supportato dal mio operatore in questo...

S8 Avere speranze e sogni per il futuro	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S9 Sentire di poter affrontare lo stigma	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S10 Sentirmi bene con me stesso	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S11 Essere rispettato riguardo alle mie credenze spirituali	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S12 Essere rispettato secondo la mia identità etnica, culturale e/o razziale	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S13 Dare un significato alla mia esperienza di salute mentale	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S14 Fare cose che per me significhino qualcosa	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S15 Ricostruire la mia vita dopo aver passato esperienze difficili	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S16 Avere una buona qualità di vita	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S17 Sentirmi in controllo della mia vita	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto

Sezione "Supporto dell'operatore"

Una parte importante del mio recupero è...			**Mi sento supportato dal mio operatore in questo...**				
S18 Essere capace di gestire la mia salute mentale	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S19 Provare cose o esperienze nuove	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto
S20 Basarmi sulle mie forze	No	Si:	Per niente	Non molto	Un po'	Abbastanza	Molto

Sezione "Rapporto con l'operatore"

Le chiediamo di cerchiare l'opzione che più si appropria alla Sua relazione con l'operatore

R1 Mi sento ascoltato dal mio operatore	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R2 Mi sento supportato dal mio operatore	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R3 Sento che il mio operatore considera seriamente le mie speranze e i miei sogni	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R4 Il mio operatore mi rispetta	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R5 Il mio operatore mi tratta come una persona, più che come una semplice "diagnosi" o "un'etichetta"	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R6 Il mio operatore mi supporta nel prendere le mie decisioni	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo
R7 Il mio operatore ripone speranza in me anche quando non sto bene	Fortemente in disaccordo	In disaccordo	Neutro	D'accordo	Fortemente d'accordo

Grazie per il tempo speso per questo questionario.

Commenti, suggerimenti, proposte:

Cognome:

Nome:

Data di compilazione:

Sono un:
☐ Paziente ☐ Famigliare ☐ Operatore ☐ Altro

Grazie per la collaborazione

Traduzione italiana nell'ambito del Programma FOR (www.programmafor.it) in accordo con gli autori

---

Hope Speranza
Agency Senso di controllo
Opportunity Opportunità

Questo è uno strumento per valutare gli esiti compilato dagli utenti, è stato coprodotto da utenti ed operatori del Southern Health Recovery College.
Le informazioni che ci darai saranno utili per rendere i nostri servizi più orientati alla recovery.
Quando avrai risposto a queste domande, un operatore potrà parlare con te delle risposte date.
Questo ci aiuterà a capire cosa è importante per te e a costruire insieme un progetto individualizzato.
Questo documento è tuo ed è una traccia del tuo percorso di recovery. Lascia pure un commento scritto se lo ritieni utile.

Recovery
Developed in association with the Southern Health Recovery College

Unità Operativa
di Psichiatria n. 23
Esperienza
FOR

Dipartimento di Salute Mentale

Sistema Socio Sanitario
Regione Lombardia
ASST Spedali Civili

Nell'ultima settimana quante volte ha provato un senso di...

1 Speranza:

- Vedere un futuro
- Credere che le difficoltà della propria vita possono essere superate
- Potere fare le cose che desideri

Credi di potere vivere bene, perseguire le tue aspirazioni ed obiettivi?

mai	raramente	qualche volta	spesso	sempre

Commenti:

2 Controllo:

- Potere scegliere ed essere informato rispetto al supporto che ricevi
- Sentirti in grado di potere gestire le difficoltà della tua vita
- Sapere come mantenere il tuo benessere

Senti di avere il controllo sulla tua vita?

mai	raramente	qualche volta	spesso	sempre

Commenti:

3 Opportunità:

- Di impegnarti e realizzare le cose in cui ti senti bravo
- di aderire al tuo ruolo sociale (famigliare, studente, lavoratore, etc.)
- di essere coinvolto nella tua comunità

Puoi fare la vita che vuoi con le opportunità di essere parte della società

mai	raramente	qualche volta	spesso	sempre

Commenti:

4 Relazioni di aiuto:

- Essere ascoltato da operatori sanitari e sociali che ti supportano
- Lavorare insieme per costruire il tuo piano di cura individualizzato
- Sentire che i tuoi operatori credono nel tuo percorso di recovery

Le relazioni con i tuoi operatori supportano speranza, controllo e opportunità per il tuo percorso di recovery?

mai	raramente	qualche volta	spesso	sempre

Commenti:

Il “cuore” dell’idea di recovery: AGENCY

- Traduzioni possibili: “agentità”, “esercizio dell’autodeterminazione”
- Il senso INDIVIDUALE di ciò che posso fare o pensare di poter fare
- La MIA PROPRIA capacità di intraprendere un’azione, sentirmi efficace, assumermi la responsabilità del mio comportamento.
- L’agency è un elemento ESSENZIALE per sentire il controllo della mia vita: credere nella mia capacità di gestire i miei pensieri per conto mio, sentire fiducia di poter gestire una serie di compiti e situazioni

Realising the Value
Empowering people,
engaging communities

At the heart of health

Realising the value of people and communities

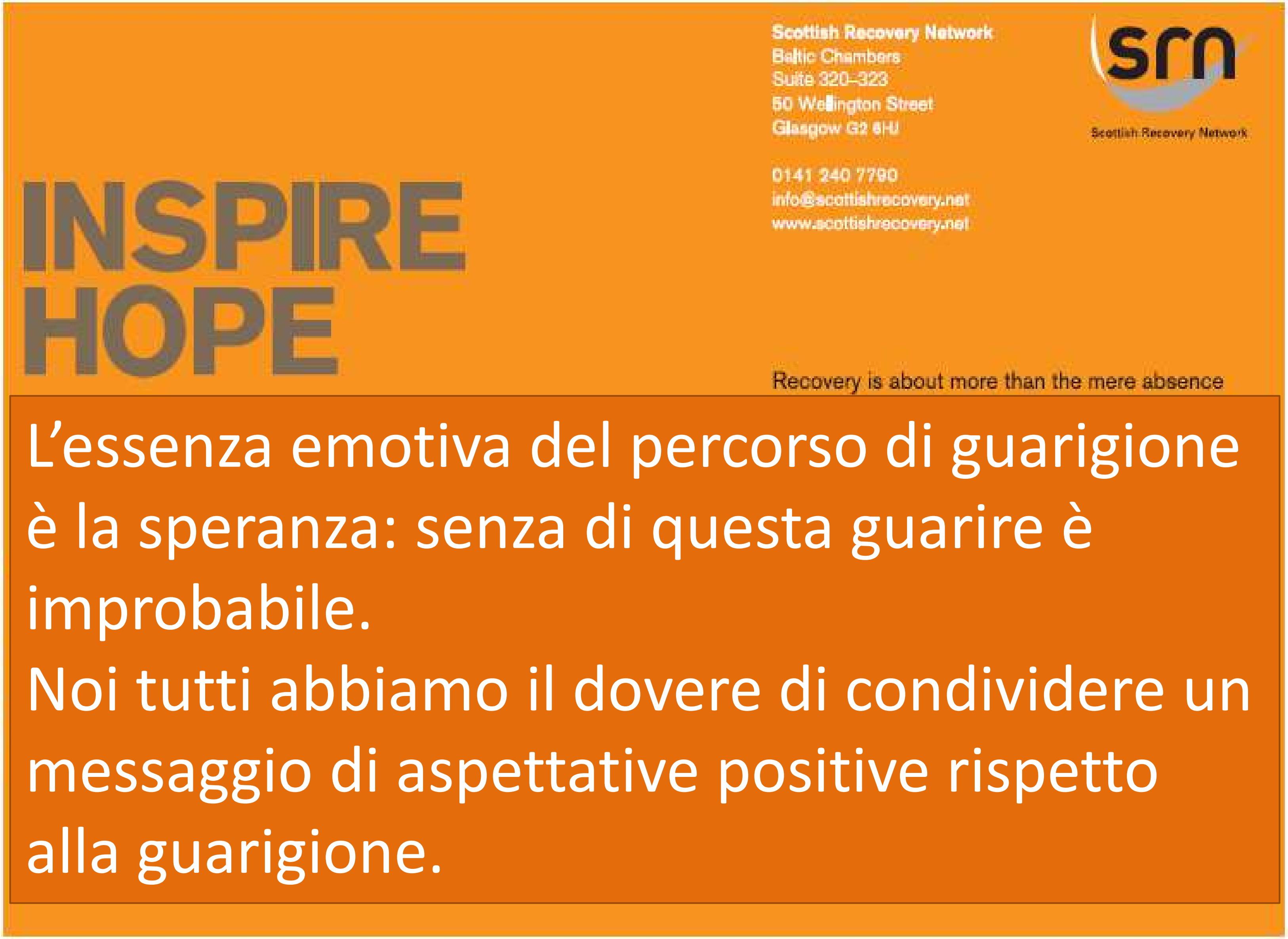
Report

March 2016

Di conseguenza, occorre una divisione del lavoro

Se ***recovery*** è ciò che la persona con un disturbo mentale fa,

l’assistenza orientata alla recovery è ciò che gli operatori della salute mentale possono offrire a sostegno degli sforzi che per conto proprio la persona fa per iniziare e portare avanti il suo percorso di recovery



Scottish Recovery Network
Baltic Chambers
Suite 320–323
50 Wellington Street
Glasgow G2 6HJ

0141 240 7790
info@scottishrecovery.net
www.scottishrecovery.net

Scottish Recovery Network

INSPIRE HOPE

Recovery is about more than the mere absence

L’essenza emotiva del percorso di guarigione è la speranza: senza di questa guarire è improbabile.

Noi tutti abbiamo il dovere di condividere un messaggio di aspettative positive rispetto alla guarigione.

It’s a personal thing

E’…è una cosa personale. Non puoi dire ad uno fai questo, fai quello e poi quest’altro e vedrai che starai bene…Devi prendertene la responsabilità, devi volere andare avanti.

Una delle cose che ho imparato è che se una cosa non funziona subito, non significa che non funzionerà mai.
E’ una cosa per la quale è il caso di insistere ed avere pazienza.

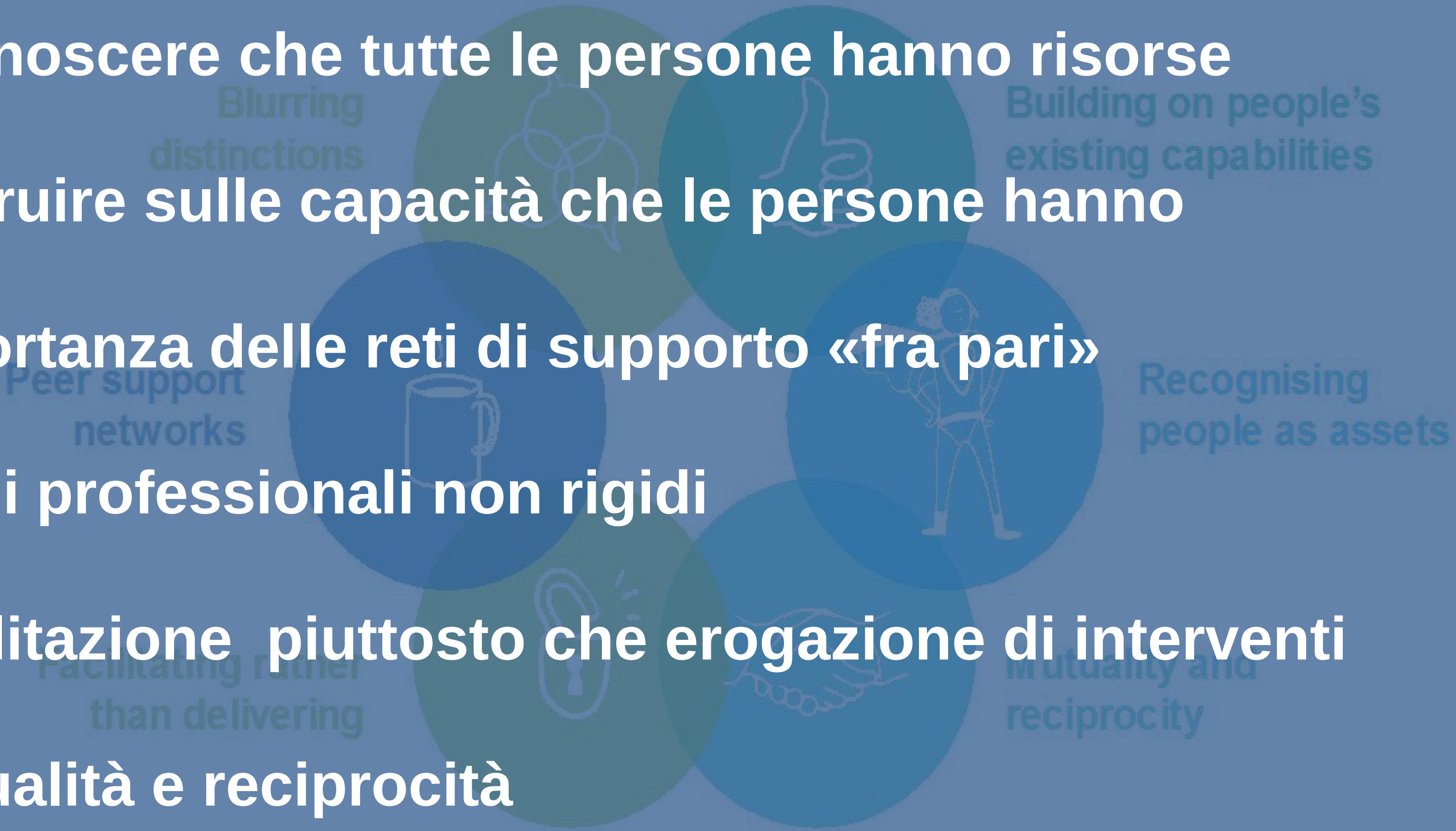
Brown and Kandirikirira, Recovery Mental Health in Scotland, 2007

NO BALL GAMES

“La più semplice definizione di co-produzione è:
le persone che usano i servizi contribuiscono a produrli”

Needham C., Co-Production: an Emerging Evidence Base for Adult Social Care Transformation, SCIE, 2012.

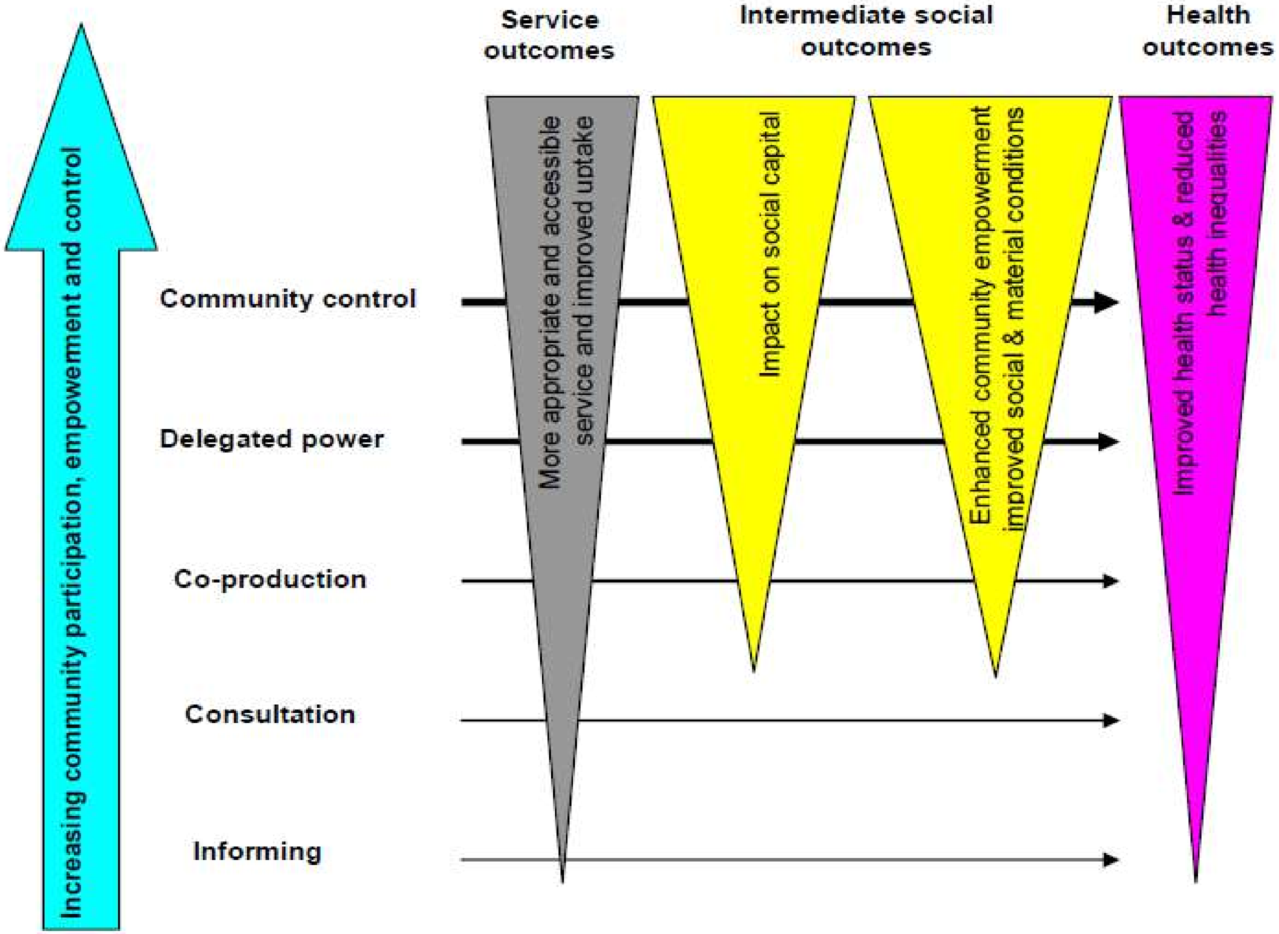
I sei principi della coproduzione


Blurring distinctions
Building on people's existing capabilities
Peer support networks
Recognising people as assets
Facilitating rather than delivering
Mutuality and reciprocity

- **Riconoscere che tutte le persone hanno risorse**
- **Costruire sulle capacità che le persone hanno**
- **Importanza delle reti di supporto «fra pari»**
- **Ruoli professionali non rigidi**
- **Facilitazione piuttosto che erogazione di interventi**
- **Mutualità e reciprocità**

(Coproduction: the modernisation of public services by staff and users. NEF e NESTA, 2013)

Pathways from community participation, empowerment and control to health improvement



Increasing community participation, empowerment and control

Community control

Delegated power

Co-production

Consultation

Informing

Service outcomes

More appropriate and accessible service and improved uptake

Intermediate social outcomes

Impact on social capital

Enhanced community empowerment improved social & material conditions

Health outcomes

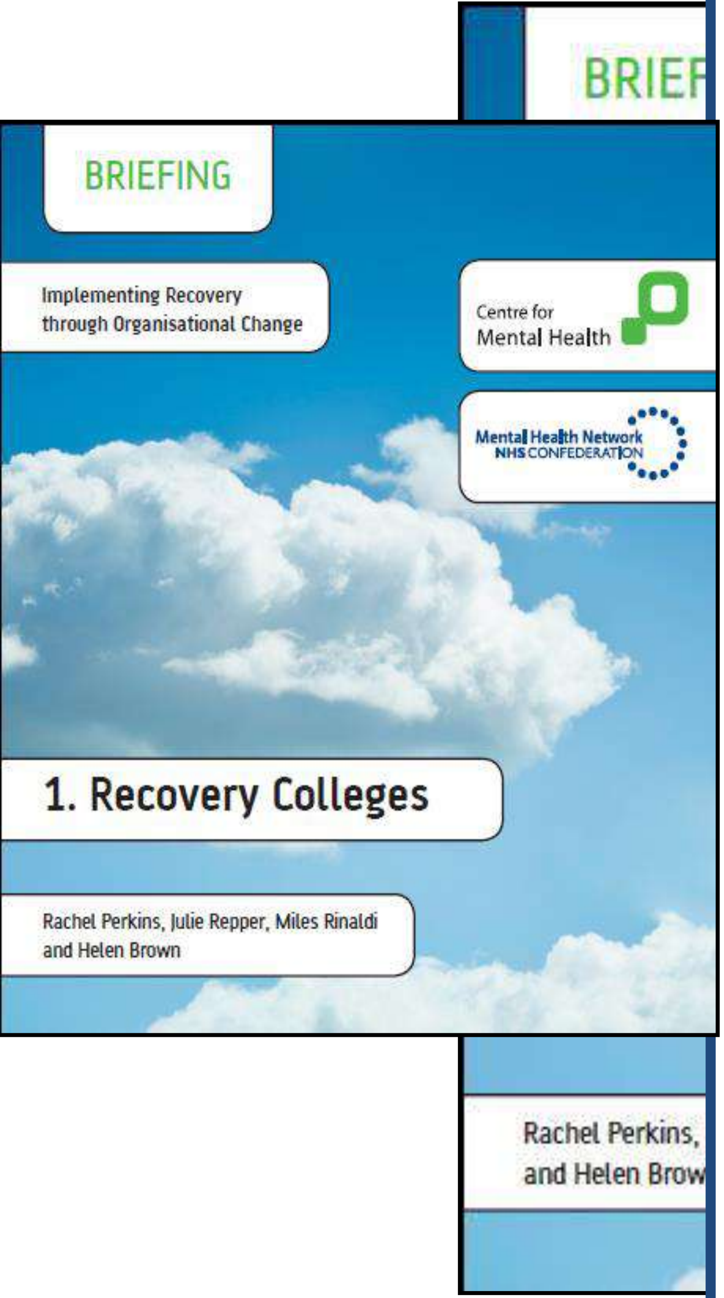
Improved health status & reduced health inequalities

(Source: Popay 2010)

Patricia Deegan

“Sono una persona unica, che lotta con un disturbo mentale; grazie alle mie attitudini e alle mie iniziative quotidiane, sono stata in grado di pretendere una vita degna di questo nome.

Voglio raccontare il mio percorso verso la guarigione (che continua tuttora) per permettere ad altri di fare percorsi simili”.



BRIEFING

Implementing Recovery
through Organisational Change

Centre for
Mental Health

Mental Health Network
NHS CONFEDERATION

1. Recovery Colleges

Rachel Perkins, Julie Repper, Miles Rinaldi
and Helen Brown

Feature

Learned recovery

Recovery Colleges, as they are known, began in Arizona: pioneered by a psychiatric ward patient who was disgruntled with services, alongside staff who wanted to help. Now, Recovery Colleges have started to spread across the USA and into the UK, Italy, Australia, the Netherlands, and Japan.

Casting my mind back to my own university days, they weren't the best days of my life. At 22, I'd just been diagnosed with paranoid psychosis. I'd expected to make friends but instead had crippling anxieties. Too scared to leave the dorms or turn up for lessons, I had the ailing grades and exam results to attest my absence.

So it was with trepidation that I arrive at Westminster University on this windy morning to attend the Central and North West London Mental Health NHS Trust (CNWL) Recovery & Wellbeing College. I'm booked on a healthy eating course. Being back on campus, now 34 years old and stable on medication, feels okay.

Dr Maria Clarke, a Consultant Psychiatrist at CNWL explains the college's ethos: "It offers a wide curriculum of courses, seminars and workshops. The Recovery & Wellbeing College focus is to support the journey that people take from a person that currently uses services, to achieving the best quality of life possible for them."

Wanting just that, I enter a small but air-conditioned room with 12 people, all with differing interests in mental health. If I had it my way, I'd be studying creative writing or English literature at Oxford. But psychosis shot through my early years like a shoal of fish, ravishing much of my hope for a good education. You could say I was growing bitter, so I turn my attention back to the room.

It's seated with two trainers to the front. We're asked to introduce ourselves and what we hope to gain from the day. I introduce myself as a person hoping to gain confidence in eating. It's encouraged here that we start the day on an equal footing with interests and aspirations rather than diagnosis in common.

Today, I discover that as a service user, I'm contributing to the course with other attendees as well as the trainers. We're promised certificates at the end of the day, but these are not formal qualifications.

Instead of academics, Dr Clarke says each course at CNWL is designed and presented by both a health-care practitioner and a person who has direct life experience of mental health difficulties. This is called "co-production", and provides the crux of how Recovery College courses are delivered.

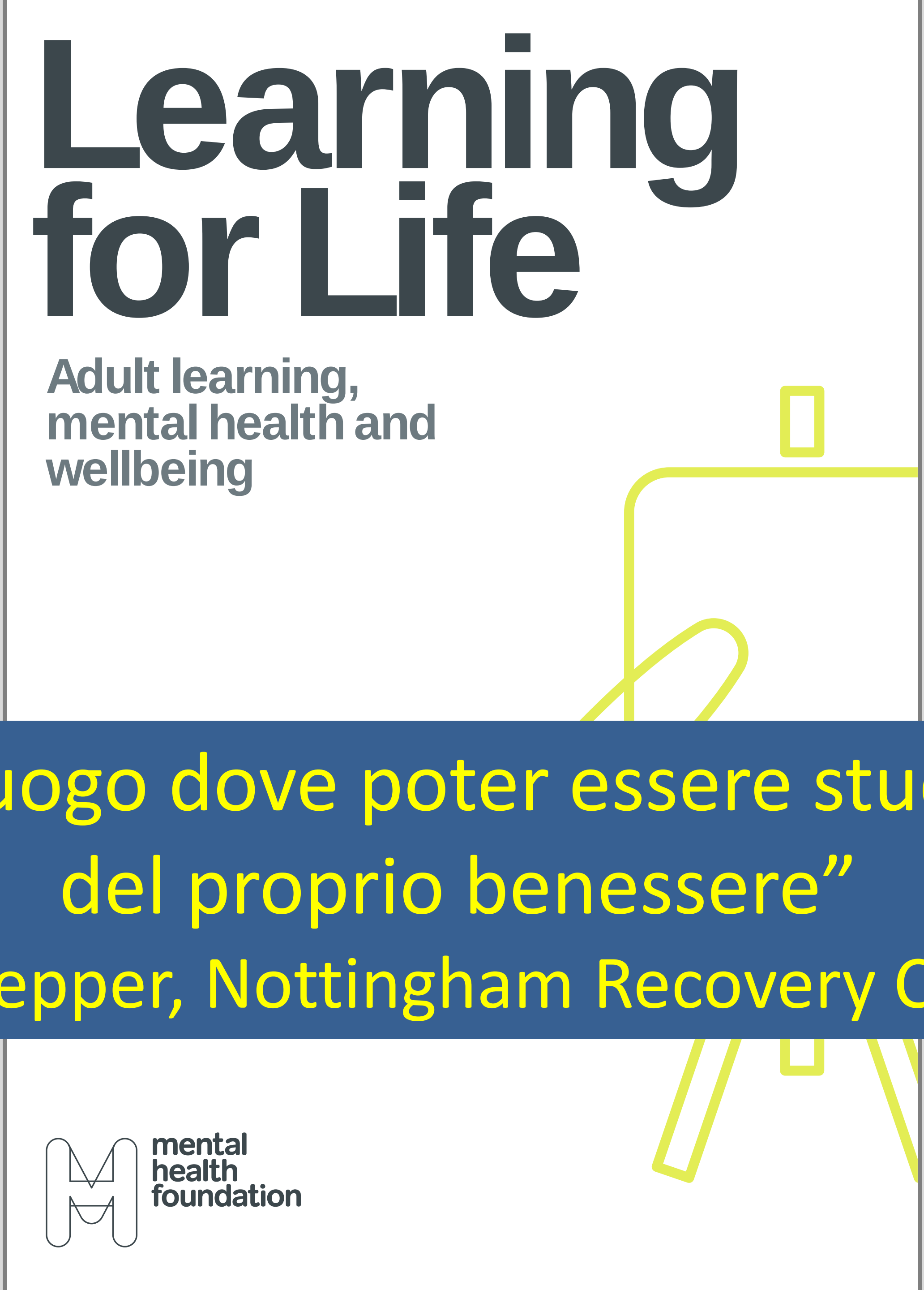
Today's training is led by a qualified social worker and a peer trainer, who has lived experience of mental illness. I'm told that this helps not only people attending but also the Peer Trainer's personal journey to recovery. As Angela Kinn, a Senior Peer Recovery Trainer at CNWL, states: "Before I started working as a Peer Trainer I feared that employment could be a risk to my recovery. It has proved to be the complete opposite. Working as a Peer Trainer has meant that I've been able to inspire people to recover by using my personal experience in my work and it's extremely rewarding as you see people turn their lives around."

Course times can vary from as little as one hour to several weeks. My course today is 10 am to 4 pm, but it doesn't really feel like studying. It's less formal, and presented more like a workshop.

The concept of Recovery Colleges appealed to the ambitious side of my nature, and it's a little bitter sweet that my day at Westminster University comprised small steps to eating well. As I leave through the campus I pass signs for creative degree courses and students carry portfolios in and out of class. There's a part of me that's sorry I ended up at a Recovery College at 34, and not with my BA (Hons) in Fashion Design at 22 (I dropped out in the second year—the bullying and stress got too much, and my weight had dropped to 5 stone, or about 30 kg).

I'm resigned to my situation; however, mental illness shows no discrimination in who it hits, only that it strikes so many of us down in our prime, our University days. I reason with myself that a nutritious diet may increase my lifespan, but will certainly help stop the psychosis coming back and assist recovery. I do feel a new-found confidence in my eating habits and I'm glad I'm enabled to take my time progressing through the day with regular rest breaks, too. This can only be a good thing.

Erica Camus



Learning for Life

Adult learning, mental health and wellbeing

mental health foundation

“Un luogo dove poter essere studenti del proprio benessere”

Julie Repper, Nottingham Recovery College

Spedali Civili di Brescia
Unità Operativa di
Psichiatria n. 23

Sistema Sanitario Regione Lombardia

Formazione e opportunità per la Recovery

Corsi 2015

PROGRAMMA
FOR

Quando il il desiderio ed il bisogno
di cambiamento si incontrano
si realizzano le condizioni
per trasformazioni sociali
innovative.

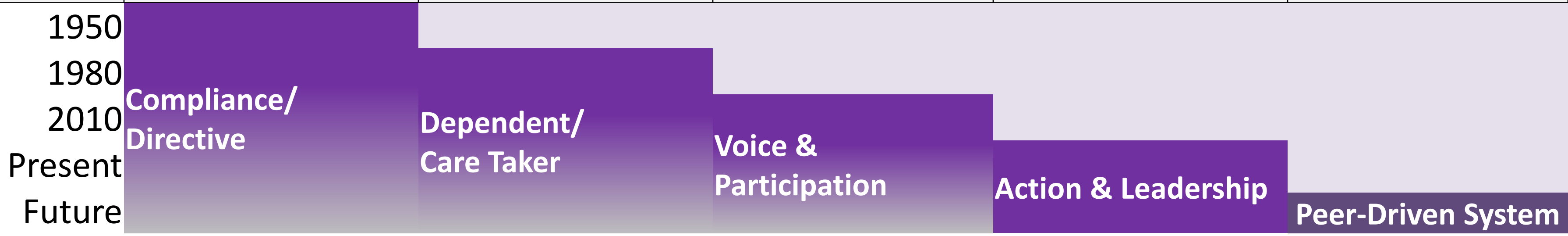
(Manuel Castells, 2012)

Grazie per l'attenzione.

Metamorfosi Festival: Scena mentale in cambiamento.
(Brescia, 2016)

Recovery Empowerment Continuum Characteristics

Perspective	Level 1	Level 2	Level 3	Level 4	Level 5
	Traditional Psychosocial Rehabilitation Philosophy/Continuum			Peer-Driven Care	Peer-Driven System
Motto	Done to	Done for	Done with	Done by	
Characteristics	Clinical team identifies goals and develops service plans. Compliance with directives is focal point activities.	Strong dependence on system & artificial (paid) supports with no individual risk taking or family engagement.	Genuine voice and participation with some support for individual risk taking & engagement in natural supports.	Self-directed care is a core value with peers holding some leadership and advocacy positions within the system.	Many roles in the system are filled by peers, including workforce, governance, etc. Not a token gesture.
Core Value	Clinically sound professional services & stability	Safety and security with a goal of stability	Personal recovery through collaboration	Personal recovery through self-directed care	Culture change through peer leaders and staffing
Person(s)	Compliant	Dependent	Respected (Voice)	Leader	Empowered
	Subservient	Institutionalized	Involved	Advocate	Leaders
Staff Member	Prescriptive	Caretaker	Partner	Consultant	Peers
	Directive	Protector	Guide	Support	Advocate
Organization	Clinically driven	Protective	Collaborative	Recovery driven	Peer-driven
	Provider is expert	Risk Averse	Engaging	Person is expert	Peer-staffed
Risk Taking	Discouraged	Blocked	Supported	Encouraged	Expected



"Students choose their own courses, work out ways of making sense of (and finding meaning in) what has happened and become experts in managing their own lives"

Il College non è un centro diurno, non offre trattamenti o percorsi di cura. Gli studenti si iscrivono scegliendo da un catalogo dei corsi e non c’è nessuno che dice loro a quali si devono iscrivere. La selezione non è basata su una diagnosi o una condizione clinica, non viene fatta una valutazione sui rischi per dire una persona è in grado o no di frequentare. Come in tutti i college, un piano degli studi descrive quali sono gli obiettivi che possono essere perseguiti e che cosa il College si aspetta dai propri studenti in termini di frequenza e modalità di comportamento.

(Centre for Mental Health , 2012)

Recovery colleges: un approccio formativo

Il modello terapeutico tradizionale	L'approccio formativo
Il focus è sui sintomi, problemi e deficit	Aiuta a riconoscere e usare le proprie risorse.
Supera i confini degli interventi terapeutici e diventa un paradigma dominante	Aiuta ad esplorare le propre potenzialità e a sviluppare le proprie abilità.
Trasforma tutte le attività in terapie	Supporta nel raggiungimento dei propri obiettivi e nelle proprie aspirazioni.
I problemi ed il tipo di intervento è scelto dagli operatori: c'è un esperto-l'operatore- ed un non esperto-il paziente.	Gli operatori aiutano gli utenti a trovare soluzioni nel modo più autonomo possibile.
Mantiene ruoli e rapporti di potere ben definiti rinforzando il concetto che gli operatori hanno tutte le competenze necessarie	Gli studenti scelgono in autonomia i corsi di proprio interesse, diventano esperti nel prendersi cura di sè.

Cross-national comparative mixed-methods case study of recovery-focused mental health care planning and co-ordination: Collaborative Care Planning Project (COCAPP)

Alan Simpson,[1,2]* Ben Hannigan,[3] Michael Coffey,[4]
Aled Jones,[3] Sally Barlow,[1] Rachel Cohen,[4]
Jitka Všetečková[5] and Alison Faulkner[6]

[1]School of Health Sciences, City University London, London, UK
[2]East London NHS Foundation Trust, London, UK
[3]School of Healthcare Sciences, Cardiff University, Cardiff, UK
[4]Department of Public Health and Policy Studies, Swansea University, Swansea, UK
[5]Faculty of Health and Social Care, The Open University, Milton Keynes, UK
[6]Independent Service User Researcher Consultant, London, UK

*Corresponding author

Declared competing interests of authors: Ms Alison Faulker received consultancy fees for her role in the project. The authors declare no other competing interests.

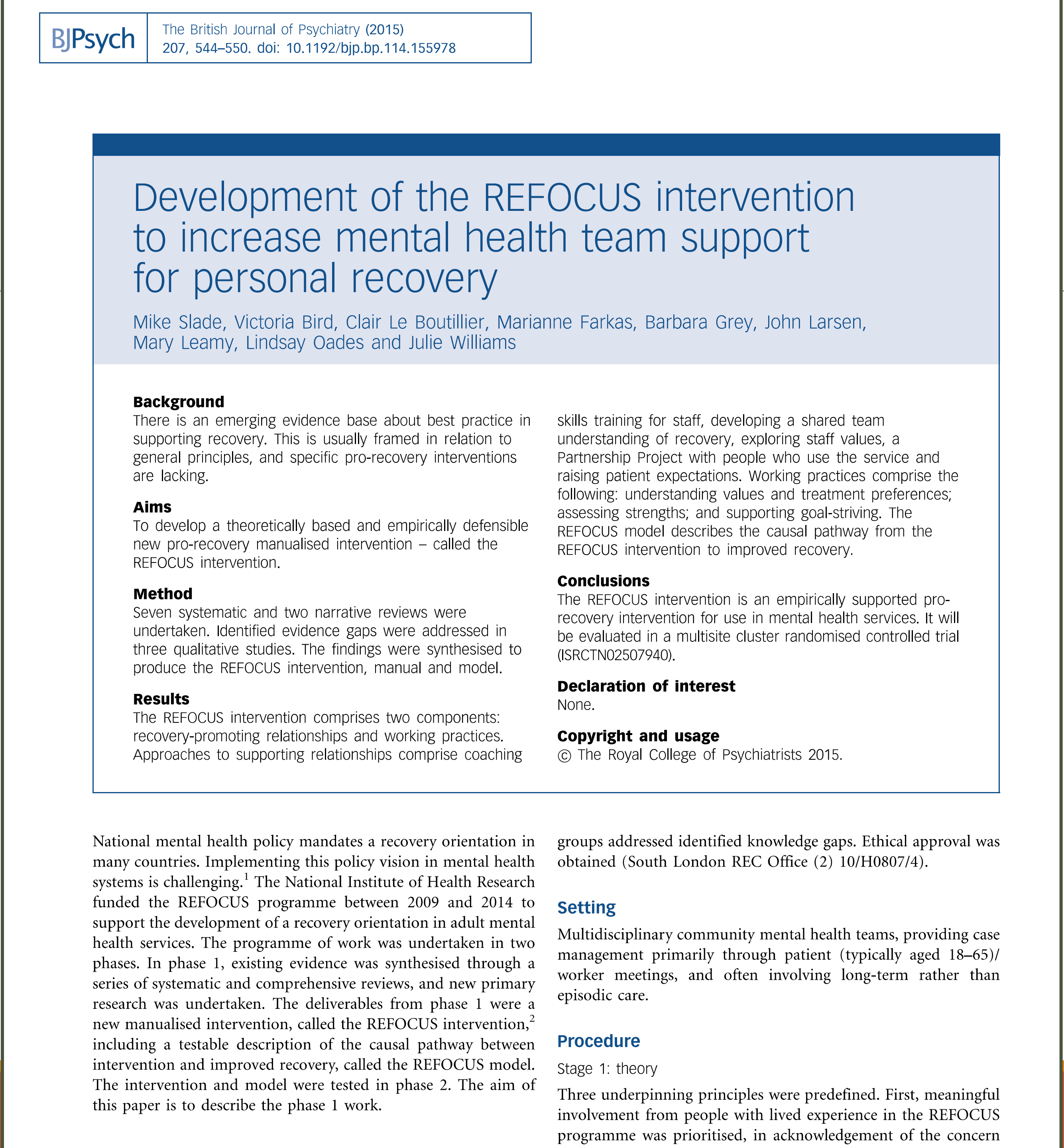
Published February 2016
DOI: 10.3310/hsdr04050

Guarigione personale

Un percorso profondamente personale di cambiamento dei propri comportamenti, valori, sentimenti, abilità e ruoli. E’ un modo di vivere una vita con soddisfazioni e speranze e risultati anche con le limitazioni causate dalla malattia.

La Recovery comprende lo sviluppo di nuovi significati e nuove progettualità nella vita delle persone nel momento in cui costruiscono una prospettiva oltre gli effetti catastrofici della malattia mentale.

Anthony WA: Recovery from Mental Illness:
the guiding vision of the mental health
services system in the 1990s.
Psychosocial Rehabilitation Journal, 16, 11.23. 1993



BJPsych
The British Journal of Psychiatry (2015)
207, 544–550. doi: 10.1192/bjp.bp.114.155978

Development of the REFOCUS intervention to increase mental health team support for personal recovery

Mike Slade, Victoria Bird, Clair Le Boutillier, Marianne Farkas, Barbara Grey, John Larsen, Mary Leamy, Lindsay Oades and Julie Williams

Background
There is an emerging evidence base about best practice in supporting recovery. This is usually framed in relation to general principles, and specific pro-recovery interventions are lacking.

Aims
To develop a theoretically based and empirically defensible new pro-recovery manualised intervention – called the REFOCUS intervention.

Method
Seven systematic and two narrative reviews were undertaken. Identified evidence gaps were addressed in three qualitative studies. The findings were synthesised to produce the REFOCUS intervention, manual and model.

Results
The REFOCUS intervention comprises two components: recovery-promoting relationships and working practices. Approaches to supporting relationships comprise coaching skills training for staff, developing a shared team understanding of recovery, exploring staff values, a Partnership Project with people who use the service and raising patient expectations. Working practices comprise the following: understanding values and treatment preferences; assessing strengths; and supporting goal-striving. The REFOCUS model describes the causal pathway from the REFOCUS intervention to improved recovery.

Conclusions
The REFOCUS intervention is an empirically supported pro-recovery intervention for use in mental health services. It will be evaluated in a multisite cluster randomised controlled trial (ISRCTN02507940).

Declaration of interest
None.

Copyright and usage
© The Royal College of Psychiatrists 2015.

National mental health policy mandates a recovery orientation in many countries. Implementing this policy vision in mental health systems is challenging.[1] The National Institute of Health Research funded the REFOCUS programme between 2009 and 2014 to support the development of a recovery orientation in adult mental health services. The programme of work was undertaken in two phases. In phase 1, existing evidence was synthesised through a series of systematic and comprehensive reviews, and new primary research was undertaken. The deliverables from phase 1 were a new manualised intervention, called the REFOCUS intervention,[2] including a testable description of the causal pathway between intervention and improved recovery, called the REFOCUS model. The intervention and model were tested in phase 2. The aim of this paper is to describe the phase 1 work.

groups addressed identified knowledge gaps. Ethical approval was obtained (South London REC Office (2) 10/H0807/4).

Setting

Multidisciplinary community mental health teams, providing case management primarily through patient (typically aged 18–65)/worker meetings, and often involving long-term rather than episodic care.

Procedure

Stage 1: theory

Three underpinning principles were predefined. First, meaningful involvement from people with lived experience in the REFOCUS programme was prioritised, in acknowledgement of the concern

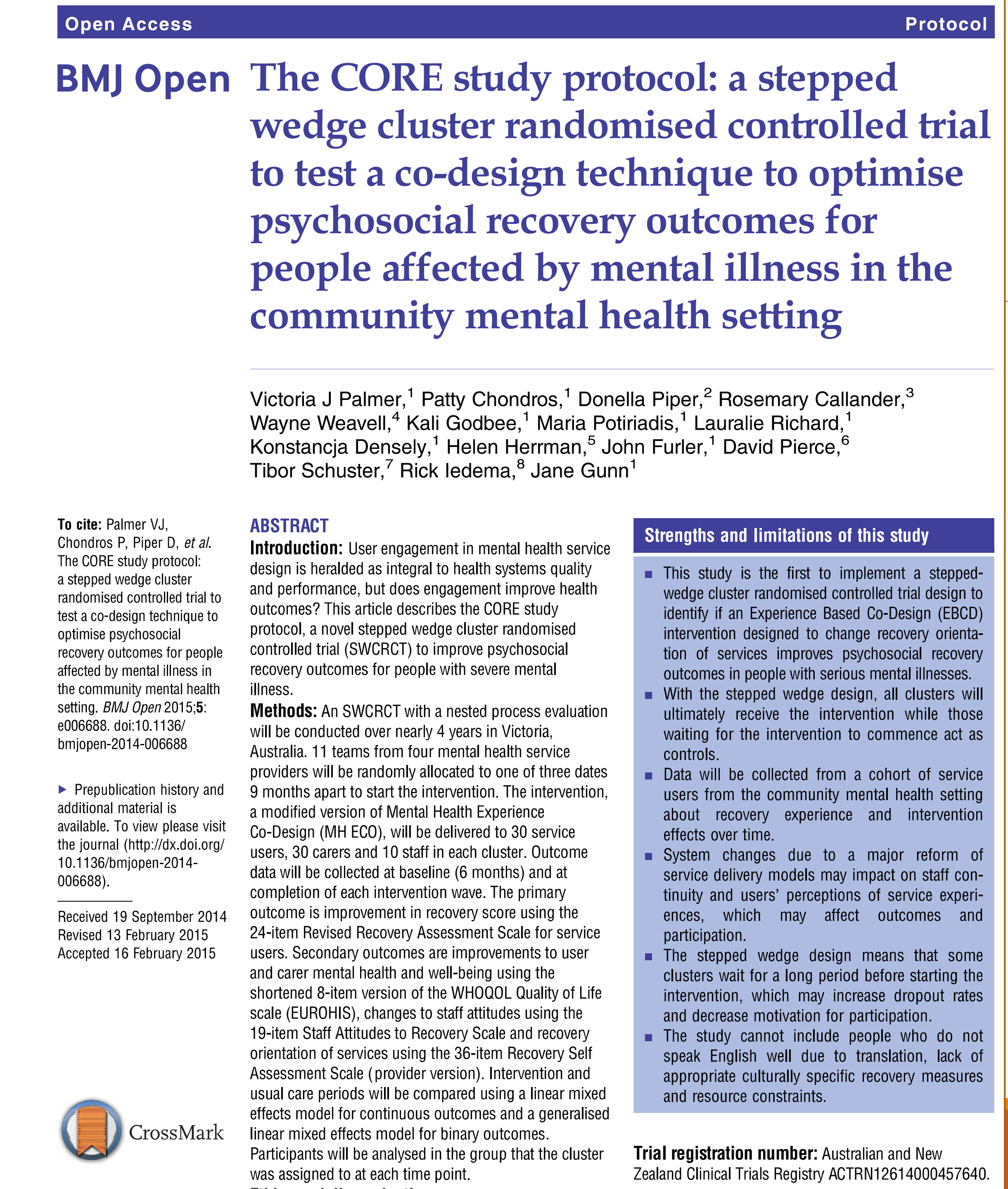
Principi emergenti dall’analisi della letteratura sull’argomento:

1) La Recovery significa qualcosa di più dell’assenza di malattia.

2) La Recovery è una esperienza personale: non può essere «fatta a qualcuno».

3) La valutazione ruotinaria dei dati di esito sulla recovery è funzionale a favorire la recovery stessa.

4) L’orientamento alla recovery per essere reale ha bisogno di essere un valore dell’organizzazione diffuso.



Open Access **Protocol**

BMJ Open

The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting

Victoria J Palmer,[1] Patty Chondros,[1] Donella Piper,[2] Rosemary Callander,[3] Wayne Weavell,[4] Kali Godbee,[1] Maria Potiriadis,[1] Lauralie Richard,[1] Konstancja Densely,[1] Helen Herrman,[5] John Furler,[1] David Pierce,[6] Tibor Schuster,[7] Rick Iedema,[8] Jane Gunn[1]

To cite: Palmer VJ, Chondros P, Piper D, *et al*. The CORE study protocol: a stepped wedge cluster randomised controlled trial to test a co-design technique to optimise psychosocial recovery outcomes for people affected by mental illness in the community mental health setting. *BMJ Open* 2015;**5**: e006688. doi:10.1136/bmjopen-2014-006688

▸ Prepublication history and additional material is available. To view please visit the journal (http://dx.doi.org/10.1136/bmjopen-2014-006688).

Received 19 September 2014
Revised 13 February 2015
Accepted 16 February 2015

ABSTRACT

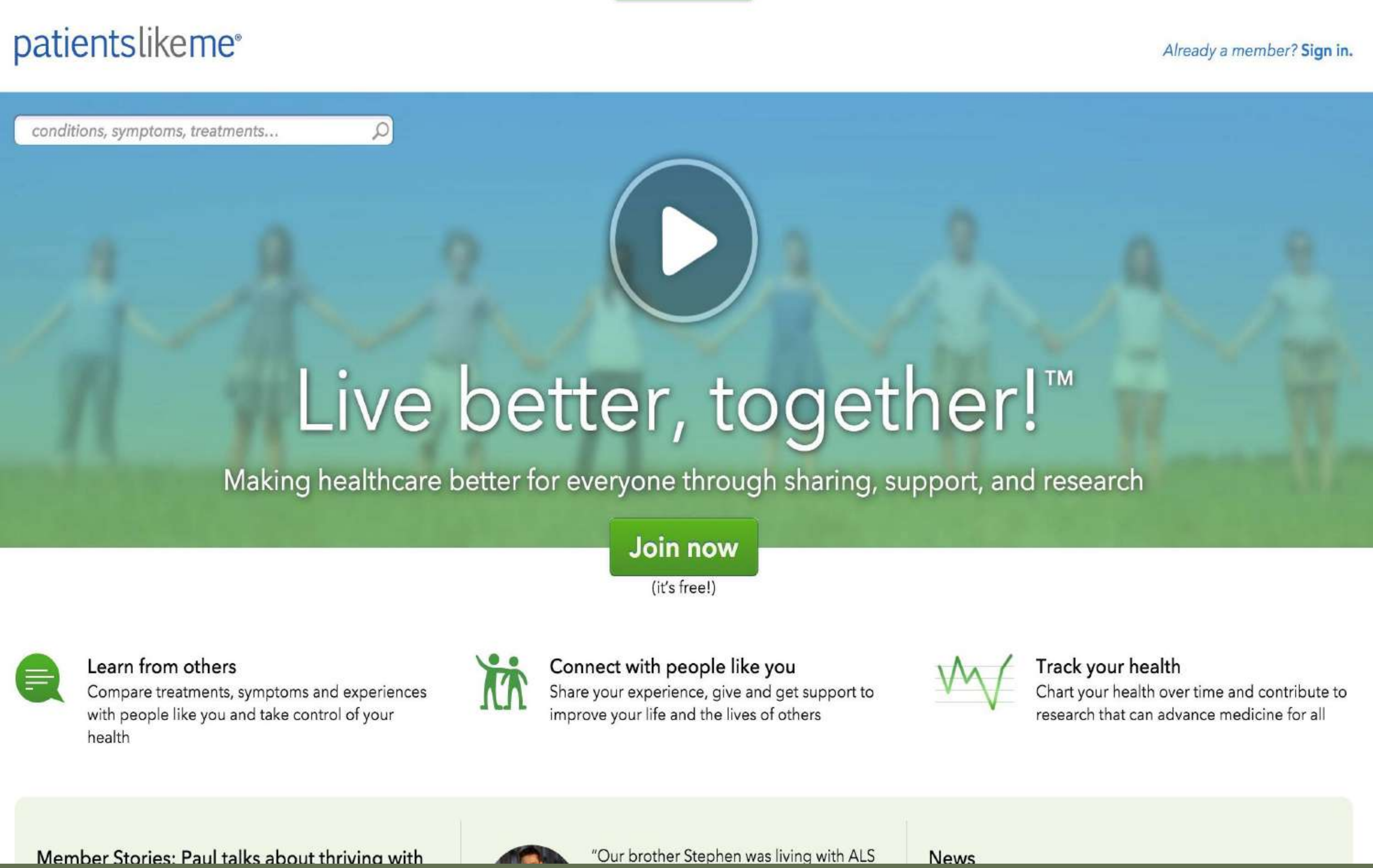
Introduction: User engagement in mental health service design is heralded as integral to health systems quality and performance, but does engagement improve health outcomes? This article describes the CORE study protocol, a novel stepped wedge cluster randomised controlled trial (SWCRCT) to improve psychosocial recovery outcomes for people with severe mental illness.

Methods: An SWCRCT with a nested process evaluation will be conducted over nearly 4 years in Victoria, Australia. 11 teams from four mental health service providers will be randomly allocated to one of three dates 9 months apart to start the intervention. The intervention, a modified version of Mental Health Experience Co-Design (MH ECO), will be delivered to 30 service users, 30 carers and 10 staff in each cluster. Outcome data will be collected at baseline (6 months) and at completion of each intervention wave. The primary outcome is improvement in recovery score using the 24-item Revised Recovery Assessment Scale for service users. Secondary outcomes are improvements to user and carer mental health and well-being using the shortened 8-item version of the WHOQOL Quality of Life scale (EUROHIS), changes to staff attitudes using the 19-item Staff Attitudes to Recovery Scale and recovery orientation of services using the 36-item Recovery Self Assessment Scale (provider version). Intervention and usual care periods will be compared using a linear mixed effects model for continuous outcomes and a generalised linear mixed effects model for binary outcomes. Participants will be analysed in the group that the cluster was assigned to at each time point.

Strengths and limitations of this study

- This study is the first to implement a stepped-wedge cluster randomised controlled trial design to identify if an Experience Based Co-Design (EBCD) intervention designed to change recovery orientation of services improves psychosocial recovery outcomes in people with serious mental illnesses.
- With the stepped wedge design, all clusters will ultimately receive the intervention while those waiting for the intervention to commence act as controls.
- Data will be collected from a cohort of service users from the community mental health setting about recovery experience and intervention effects over time.
- System changes due to a major reform of service delivery models may impact on staff continuity and users' perceptions of service experiences, which may affect outcomes and participation.
- The stepped wedge design means that some clusters wait for a long period before starting the intervention, which may increase dropout rates and decrease motivation for participation.
- The study cannot include people who do not speak English well due to translation, lack of appropriate culturally specific recovery measures and resource constraints.

Trial registration number: Australian and New Zealand Clinical Trials Registry ACTRN12614000457640.


patientslikeme®
Already a member? Sign in.
conditions, symptoms, treatments...
Join now
(it's free!)

Live better, together!™

Making healthcare better for everyone through sharing, support, and research

Learn from others
Compare treatments, symptoms and experiences with people like you and take control of your health

Connect with people like you
Share your experience, give and get support to improve your life and the lives of others

Track your health
Chart your health over time and contribute to research that can advance medicine for all

Member Stories: Paul talks about thriving with

"Our brother Stephen was living with ALS

News

collated for research.[17] Nelson illustrates the value of systematically collecting information on patients concerns and priorities at the point of care and using outcome measures that they identify.[18]

opportunities to harness the energy and expertise of patients. Clinicians and medical educationalists must catch up. Empowered, engaged e-patients are growing a social movement and spearheading a shift in roles “as profound as women’s

EDITORIALE

Giuseppe Tibaldi, Lia Govers[1]

EVIDENCE-BASED HOPE.
LA PROPOSTA DI UNA PROSPETTIVA COMUNE

■ TABELLA 2. I modelli a confronto

Modello della guarigione	Modello medico
Centralità dell'esperienza	Psicopatologia
Biografia	Sviluppo del disturbo
Interesse centrato sulla persona	Interesse concentrato sul disturbo
Promuovere la salute	Combattere la malattia
Centrato sulle capacità della persona	Centrato sui trattamenti offerti
Esperti in base alla propria esperienza	Medici e pazienti
Significato personale	Diagnosi
Comprensione	Coscienza di malattia
Centrato su valori etici	Apparentemente sganciato da considerazioni etiche
Umanistico	Scientifico
Crescita e scoperta	Trattamento
Scelta	Adesione alle proposte di trattamento
Riferimento a "eroi"	Sorretto dalle metanalisi
Resoconti personali	Studi randomizzati controllati
Trasformazione	Ritorno alla normalità
Gestione personale	Coordinatori espertti
Controllo di sé	Riportare sotto controllo
Responsabilità personale	Appropriatezza professionale
All'interno di un contesto sociale	Decontestualizzato

schizofrenici.

Loos *et al. BMC Psychiatry* (2017) 17:38
DOI 10.1186/s12888-017-1207-4

BMC Psychiatry

RESEARCH ARTICLE Open Access

Recovery and decision-making involvement in people with severe mental illness from six countries: a prospective observational study

Sabine Loos[1*], Eleanor Clarke[2], Harriet Jordan[2], Bernd Puschner[1], Andrea Fiorillo[3], Mario Luciano[3], Tibor Ivánka[4], Erzsébet Magyar[4], Malene Krogsgaard-Bording[5], Helle Østermark-Sørensen[5], Wulf Rössler[6], Wolfram Kawohl[6], Benjamin Mayer[7], Mike Slade[2] and CEDAR Study Group

Abstract

Background: Clinical decision-making is the vehicle of health care provision, and level of involvement predicts implementation and satisfaction. The aim of this study was to investigate the impact of decision-making experience on recovery.

Methods: Data derived from an observational cohort study "Clinical decision making and outcome in routine care for people with severe mental illness" (CEDAR). Adults (aged 18–60) meeting standardised criteria for severe mental illness were recruited from caseloads of outpatient and community mental health services in six European countries. After consenting, they were assessed using standardised measures of decision-making, clinical outcome and stage of recovery at baseline and 1 year later. Latent class analysis was used to identify course of recovery, and proportional odds models to investigate predictors of recovery stage and change.

Results: Participants ($n = 581$) clustered into three stages of recovery at baseline: Moratorium ($N = 115$; 19.8%), Awareness/Preparation ($N = 145$; 25.0%) and Rebuilding/Growth ($N = 321$; 55.2%). Higher stage was cross-sectionally associated with being male, married, living alone or with parents, and having better patient-rated therapeutic alliance and fewer symptoms. The model accounted for 40% of the variance in stage of recovery. An increased chance of worse outcome (change over 1 year to lower stage of recovery) was found for patients with active involvement compared with either shared (OR = 1.84, 95% CI 1.15–2.94) or passive (OR = 1.71, 95% CI = 1.00–2.95) involvement. Overall, both process (therapeutic relationship) and outcome (symptomatology) are cross-sectionally associated with stage of recovery.

Conclusions: Patient-rated decision-making involvement and change in stage of recovery are associated. Joint consideration of decision practise within the recovery process between patient and clinician is supposed to be a useful strategy to improve clinical practice (ISRCTN registry: ISRCTN75841675. Retrospectively registered 15 September 2010).

Keywords: Clinical decision making, Patient involvement, Recovery, Severe mental illness (SMI), Routine mental health services, Multinational health service research

---

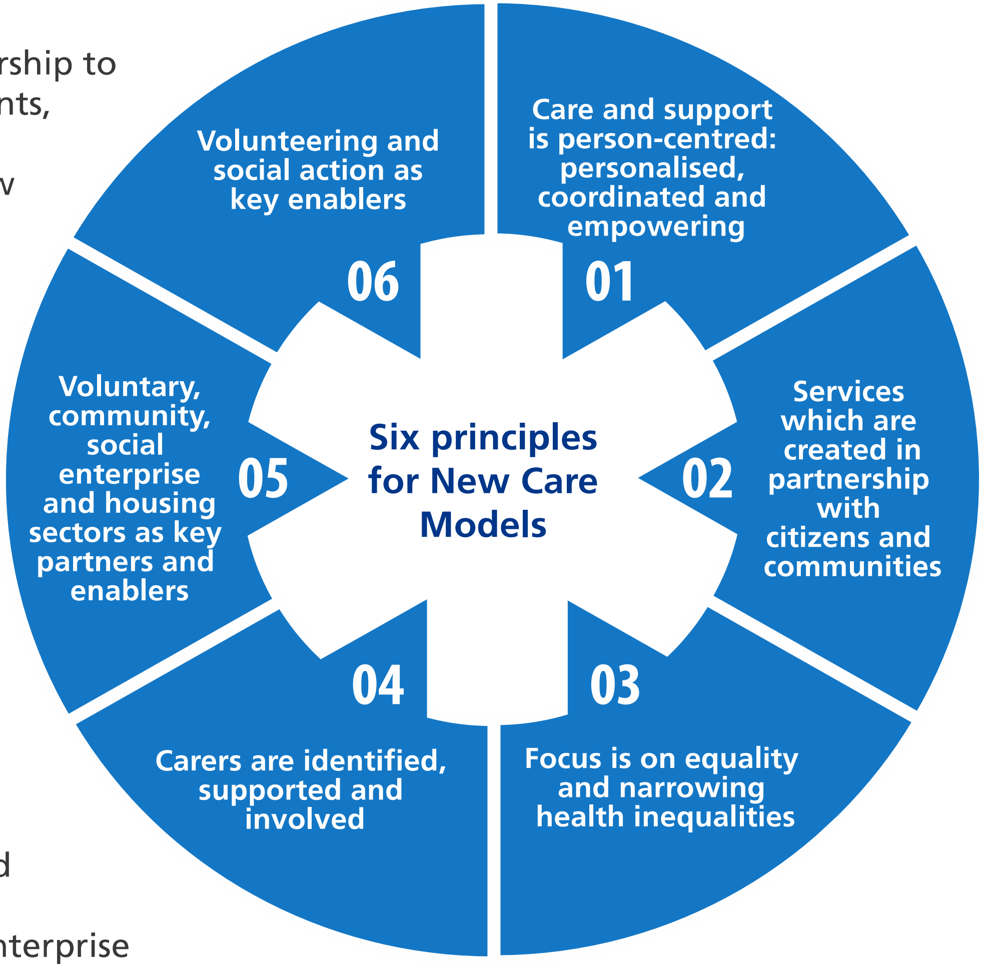
* Correspondence: sabine.loos@bkh-guenzburg.de
[1]Section Process-Outcome Research, Department of Psychiatry II, Ulm University, Ludwig-Heilmeyer-Str. 2, D-89312 Günzburg, Germany
Full list of author information is available at the end of the article

© The Author(s). 2017 **Open Access** This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made. The Creative Commons Public Domain Dedication waiver (http://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated.

The six principles explained

We need a new model of partnership to harness fully the energy of patients, local people and diverse communities. To support this new kind of relationship, the People and Communities Board, working with patients, the voluntary sector, vanguards and the wider health and care system, set out six principles for new care models:

- Care and support is person-centred: personalised and empowering
- Services which are created in partnership with citizens and communities
- Focus is on equality and narrowing health inequalities
- Carers are identified, supported and involved
- Voluntary, community, social enterprise and housing sectors as key partners and enablers



Six principles for New Care Models

01 Care and support is person-centred: personalised, coordinated and empowering

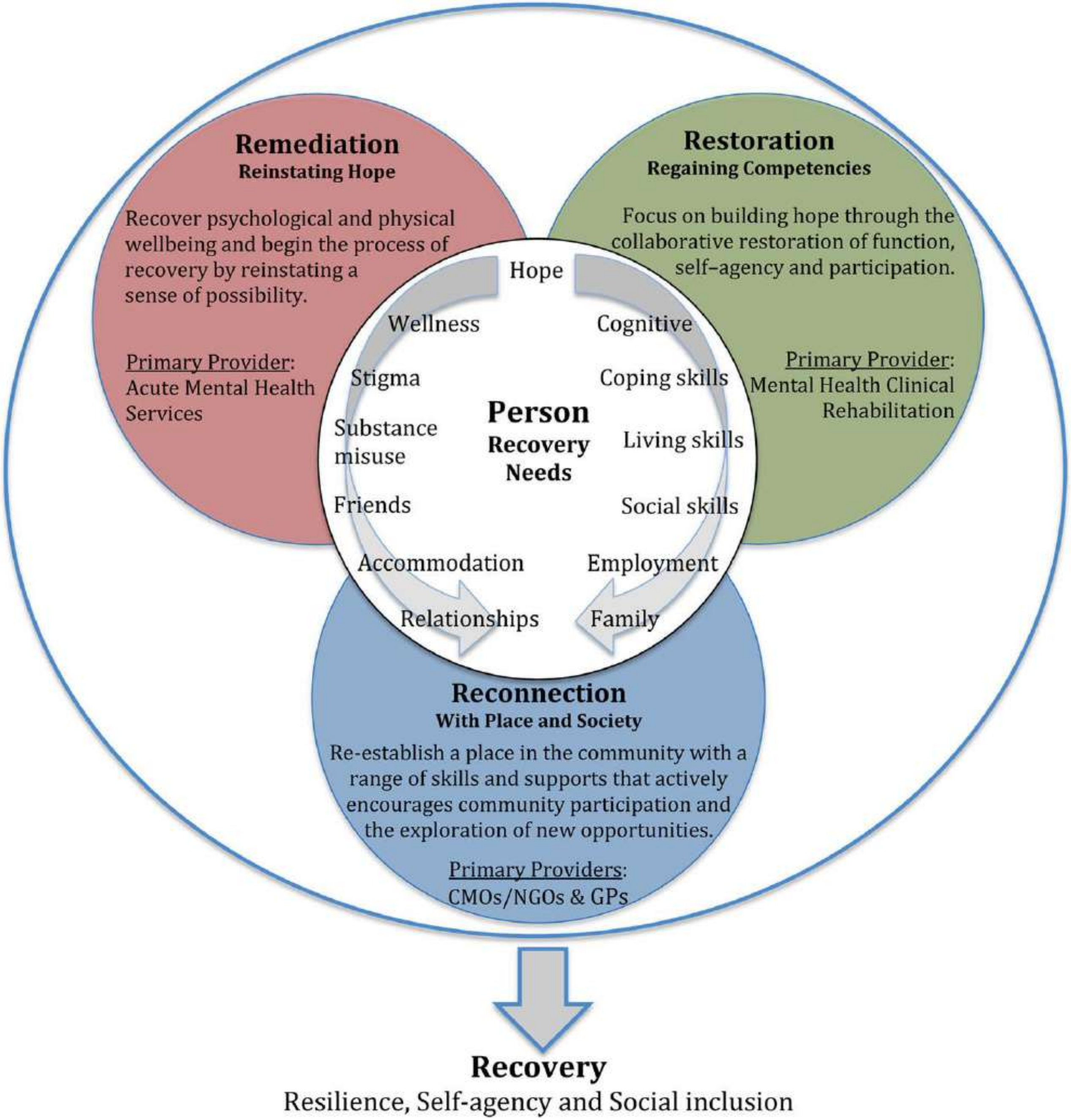
02 Services which are created in partnership with citizens and communities

03 Focus is on equality and narrowing health inequalities

04 Carers are identified, supported and involved

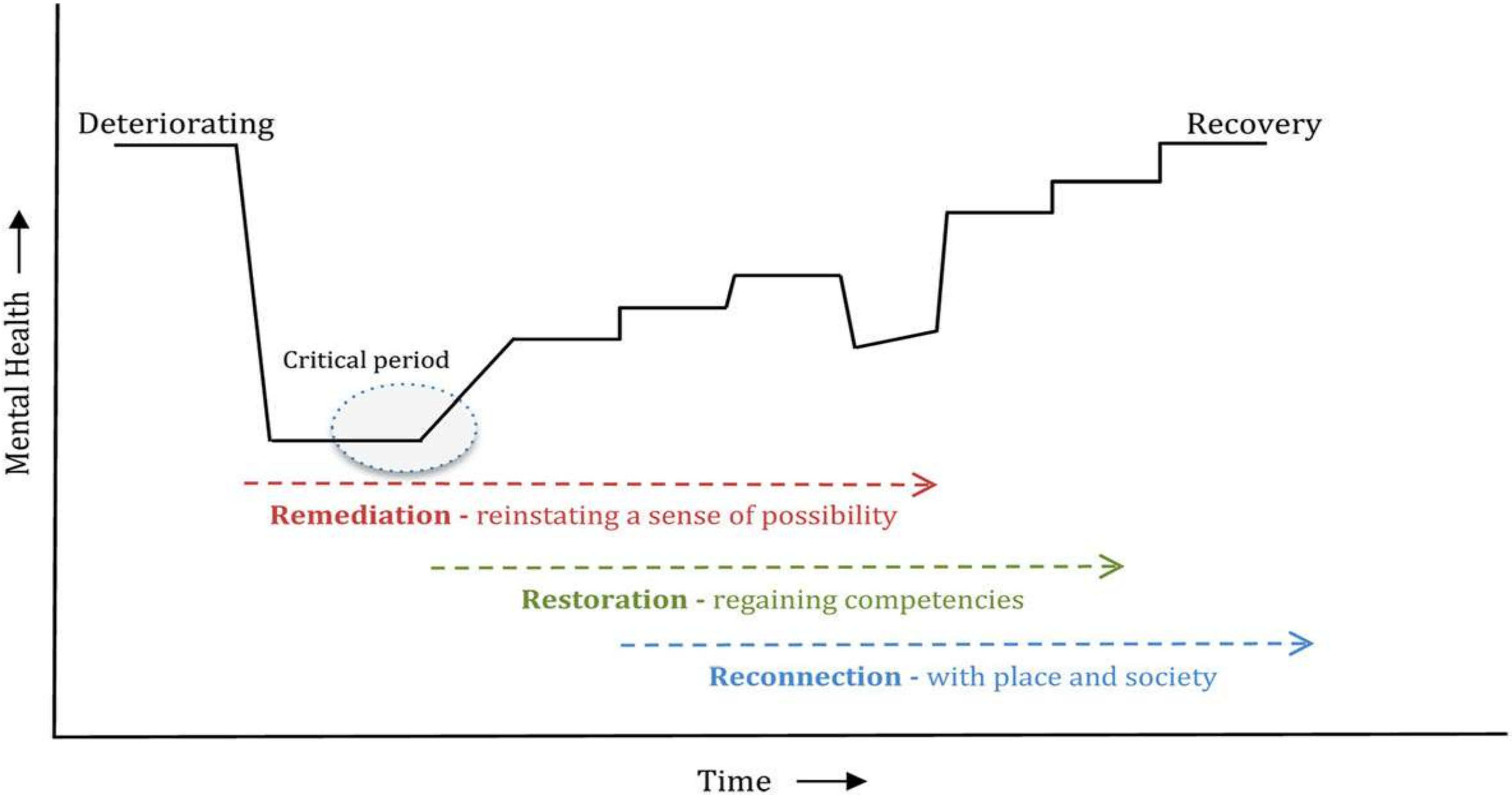
05 Voluntary, community, social enterprise and housing sectors as key partners and enablers

06 Volunteering and social action as key enablers



Remediation
Reinstating Hope
Recover psychological and physical wellbeing and begin the process of recovery by reinstating a sense of possibility.
Primary Provider:
Acute Mental Health Services
Restoration
Regaining Competencies
Focus on building hope through the collaborative restoration of function, self–agency and participation.
Primary Provider:
Mental Health Clinical Rehabilitation
Hope
Wellness
Cognitive
Stigma
Coping skills
Person
Recovery Needs
Substance misuse
Living skills
Friends
Social skills
Accommodation
Employment
Relationships
Family
Reconnection
With Place and Society
Re-establish a place in the community with a range of skills and supports that actively encourages community participation and the exploration of new opportunities.
Primary Providers:
CMOs/NGOs & GPs
Recovery
Resilience, Self-agency and Social inclusion

Fig. 1 Integrated Recovery-oriented Model (IRM) for mental health services


Deteriorating
Recovery
Critical period
Mental Health
Remediation - reinstating a sense of possibility
Restoration - regaining competencies
Reconnection - with place and society
Time

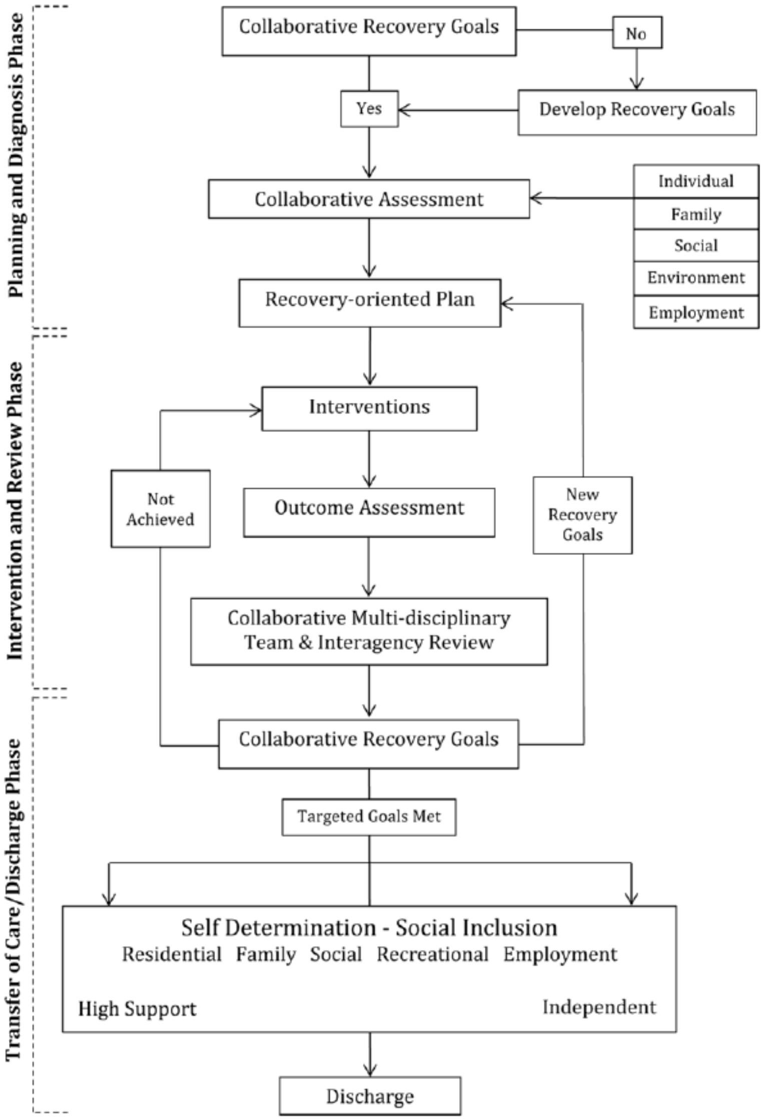
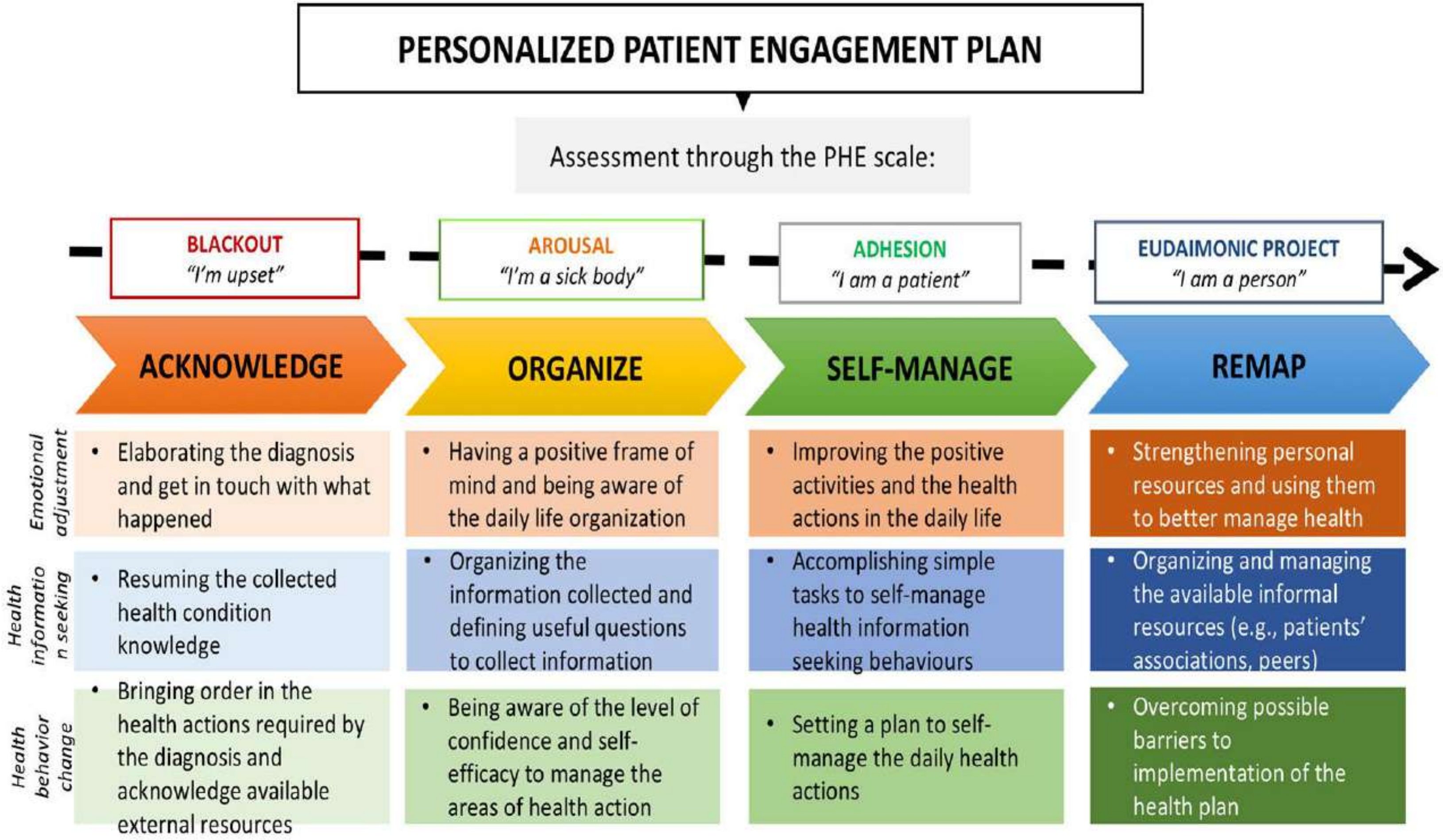

Planning and Diagnosis Phase
Intervention and Review Phase
Transfer of Care/Discharge Phase
Collaborative Recovery Goals
No
Yes
Develop Recovery Goals
Collaborative Assessment
Individual
Family
Social
Environment
Employment
Recovery-oriented Plan
Interventions
Not Achieved
Outcome Assessment
New Recovery Goals
Collaborative Multi-disciplinary Team & Interagency Review
Collaborative Recovery Goals
Targeted Goals Met
Self Determination - Social Inclusion
Residential Family Social Recreational Employment
High Support
Independent
Discharge

Fig. 3 Clinical Rehabilitation (CR) processes within the IRM supporting and promoting recovery

Table 1 Clinical rehabilitation (CR) processes

Planning and Diagnosis		*Intervention and Review*		*Transfer of Care/Discharge*
Recovery Goals	CR Assessment	Recovery Planning	CR Interventions	Clinical Review or Recovery-focused Tracking
Aspirations - Hope of a better life may include: wellness enjoyment, participation, contribution and opportunity. **Personal** - working with an individual's goals no matter how well grounded, is pivotal in fostering commitment to recovery processes. **Self-identified** – imposing goals that are incongruent with the individual's is simply counter-productive and diametrically opposed to the tenants of CR. **Well formulated** - using assessment tools[a] that have credibility with a person may assist in discussing and formulating recovery goals.	**Comprehensive** – thorough and holistic, not adopting a pathological view of SMI, but unashamedly a comprehensive appraisal of relevant factors to assist in the formulation of a collaborative recovery plan. **Multiple domains** - may include: medication, treatment, co-morbidity, substance-use, physical & cognitive issues, coping, daily living skills, living arrangements, education & employment, family interactions, social, sexual and existential needs & stage of change. **Function oriented** – may include an array of issues in domains of functioning, activity & participation, role & impact on environmental and personal factors. **Promoting hope** – the knowledge gleaned assists clinicians to work effectively with clients & their family in generating and validating hope.	**Collaborative** – may be developed using tools such as the MHRS[a]. Recovery-oriented plan outlines individual recovery needs and develops strategies dependent on motivation for change in specific domains. **Evidence-based -** guiding access to a range of interventions (e.g., cognitive remediation, skills training, family interventions, employment & education strategies), as well as support & environmental adaptation. **Delivery methods** - interventions may be detailed as concurrent, sequential, in individual or group settings, as well as identifying who participates (family, carers, friends, support workers). **Coordinated** – across clinical and non-clinical interfaces, as well as addressing the interaction of CR & pharmacological intervention.	**Goal focused** - related to a range of personal, social & environmental factors, not diagnosis dependent. Interventions assist in achieving goals & improving mental & physical health. **Individually tailored** – interventions are individually tailored but, to assist clinicians in recovery-oriented service provision, core interventions may be linked with domains of recovery (e.g., using the MHRS[a]). **Integrated programs** – provide a foundation for developing strategies and interventions. Core & elective programs operate in individual, group, milieu/residential and community settings. **Structured** – collaborative, goal focused, evidence-based and motivational to promote generalisation, and accommodate different learning styles and abilities. To support achievement, higher level therapy programs are run in parallel to compliment activity-based programs.	**Aim** to ensure the highest level of care & that: 1. Strategies are comprehensive, responsive & positive; 2. Support is available to the CR clinician at every step; 3. Continuity maintained through information sharing; 4. Concurrent interventions are implemented and monitored; 5. Early intervention strategies are available; 6. Multidisciplinary team skills are available; 7. Risks are quickly identified & resolved; 8. Interventions are evidence &/or practice-based; 9. Positive recovery-oriented outcomes are shared; 10. Care coordination facilitates high quality service; 11. Opportunities exist to build service networks and linkages; 12. Key performance indicators are discussed and reviewed. The review provides a forum to oversee, support & co-ordinate service delivery & maximise recovery possibilities. **Time demands** - time intensive due to complexity of issues & need to ensure a positive and productive milieu. Recovery trajectories are complex & dynamic. Work contexts can be demanding, particularly when the time course is extensive & progress minimal. **Processes** – innovative, recovery-focused, inclusive & holistic. Review should be led by a senior CR clinician due to complex processes & timeframes, & include client, family, peer-support & relevant agencies. Feedback informs goal development & collaborative interventions. **Recovery pathways** - may be simple & linear or interspersed with minor setbacks, even relapse. Incremental recovery in some domains & profound in others. Gains may be interdependent. Numerous reiterations of CR processes may be required to trigger a decision to adopt a more inclusive & adaptive approach (e.g., for SMI & substance misuse). **Achievements** – Clinical review can objectively affirm achievements; facilitate development of options &/or determine when another strategy is warranted; & aid making complex decisions regarding level of service need. Achievement of self-determination in several domains may require minimal short-term interventions accompanied by follow-up & review.

[a] For example, collaborative measures such as the MHRS provide a framework and shared language for discussing pathways to recovery and wellbeing that may be employed across a range of service settings including clinical and non-clinical. The strength of this particular tool lies in its ability to connect with people with SMI in identifying need, developing individually tailored recovery and relapse prevention plans, and reflecting progress along the recovery journey



PERSONALIZED PATIENT ENGAGEMENT PLAN

Assessment through the PHE scale:

	BLACKOUT *"I'm upset"*	AROUSAL *"I'm a sick body"*	ADHESION *"I am a patient"*	EUDAIMONIC PROJECT *"I am a person"*
	ACKNOWLEDGE	**ORGANIZE**	**SELF-MANAGE**	**REMAP**
Emotional adjustment	• Elaborating the diagnosis and get in touch with what happened	• Having a positive frame of mind and being aware of the daily life organization	• Improving the positive activities and the health actions in the daily life	• Strengthening personal resources and using them to better manage health
Health information seeking	• Resuming the collected health condition knowledge	• Organizing the information collected and defining useful questions to collect information	• Accomplishing simple tasks to self-manage health information seeking behaviours	• Organizing and managing the available informal resources (e.g., patients' associations, peers)
Health behavior change	• Bringing order in the health actions required by the diagnosis and acknowledge available external resources	• Being aware of the level of confidence and self-efficacy to manage the areas of health action	• Setting a plan to self-manage the daily health actions	• Overcoming possible barriers to implementation of the health plan

FIGURE 2 | The personalized patient engagement plan: Goals of the four training's paths basing on the baseline PHE phase.

The King's Fund Ideas that change health care

Supporting people to manage their health

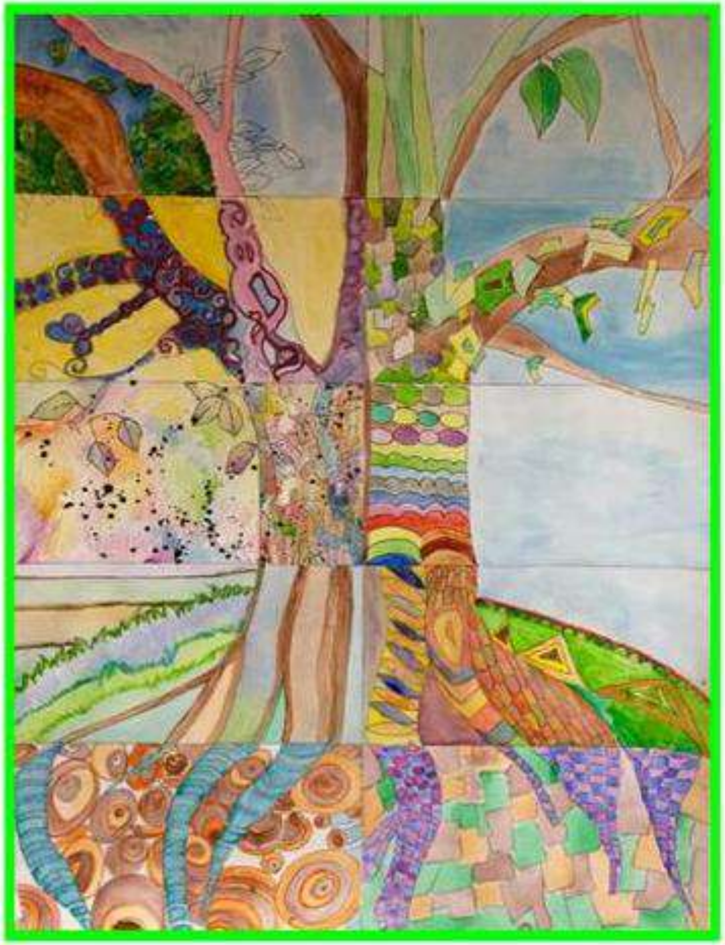
Table 1 The four levels of patient activation

Level 1	Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
Level 2	Individuals may lack the knowledge and confidence to manage their health.
Level 3	Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
Level 4	Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

AZIENDA ULSS 20
VERONA
Cod. Fiscale e P. IVA 02573090236

AZIENDA OSPEDALIERA UNIVERSITARIA INTEGRATA
VERONA

Dipartimento Interaziendale per la Salute Mentale di Verona



SETTIMANA
PER LA PROMOZIONE
DELLA SALUTE MENTALE
2016

7 – 14 OTTOBRE

L'Acquerello

- Simbolo degli eventi della Settimana -

e' opera collettiva degli Utenti del

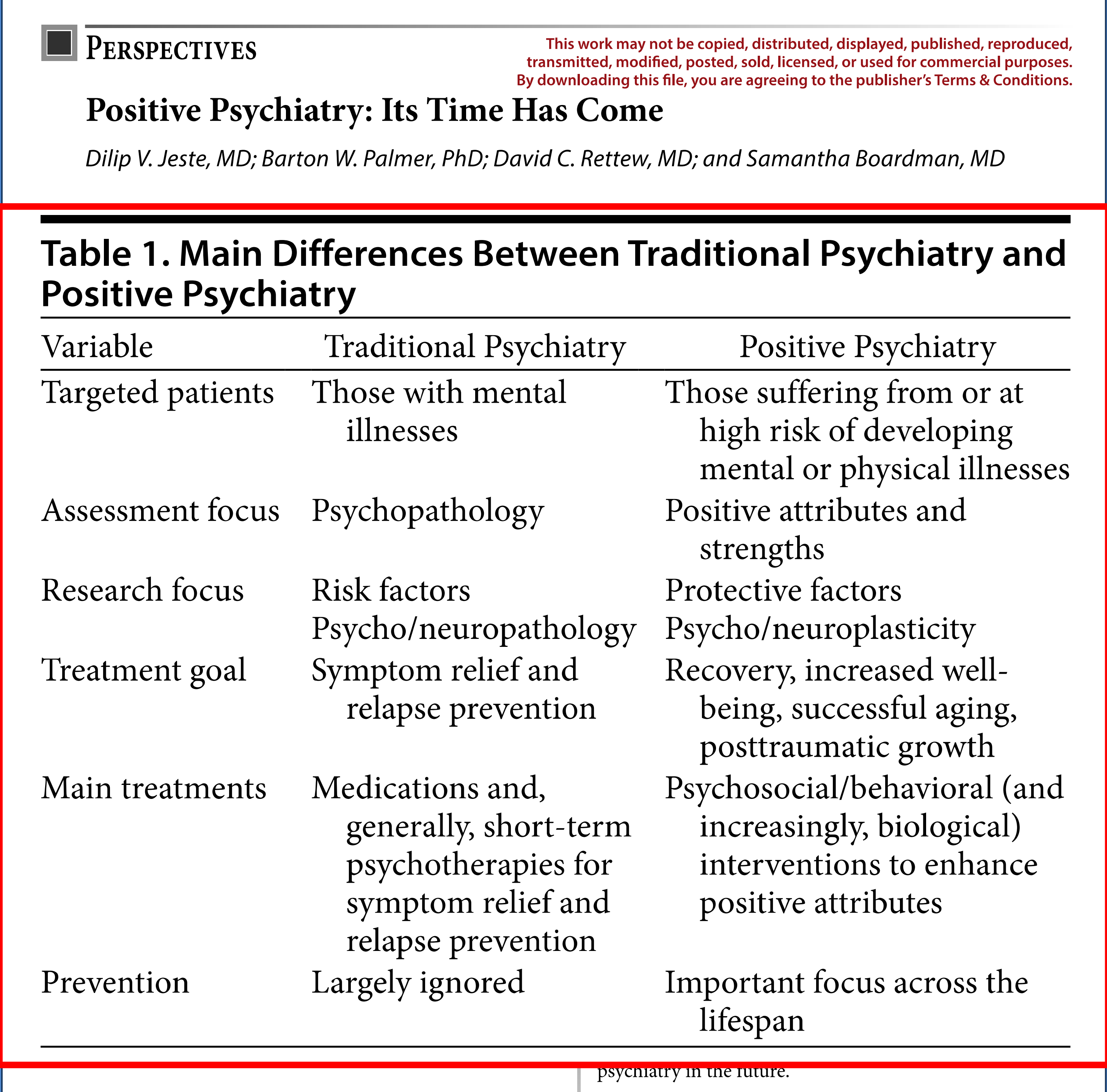
Laboratorio Artistico Espressivo

del 3° Servizio Psichiatrico Territoriale

del DISM.

Intende rappresentare le diverse fasi della vita
e l'eterogeneità con cui esse possono essere vissute.
Al contempo, desidera metterne in luce
la persistente aspirazione alla serenità e alla bellezza.

Promuoviamo la salute mentale partendo dalle risorse e dalle abilità di ognuno



This work may not be copied, distributed, displayed, published, reproduced, transmitted, modified, posted, sold, licensed, or used for commercial purposes. By downloading this file, you are agreeing to the publisher's Terms & Conditions.

Positive Psychiatry: Its Time Has Come

Dilip V. Jeste, MD; Barton W. Palmer, PhD; David C. Rettew, MD; and Samantha Boardman, MD

Table 1. Main Differences Between Traditional Psychiatry and Positive Psychiatry

Variable	Traditional Psychiatry	Positive Psychiatry
Targeted patients	Those with mental illnesses	Those suffering from or at high risk of developing mental or physical illnesses
Assessment focus	Psychopathology	Positive attributes and strengths
Research focus	Risk factors Psycho/neuropathology	Protective factors Psycho/neuroplasticity
Treatment goal	Symptom relief and relapse prevention	Recovery, increased well-being, successful aging, posttraumatic growth
Main treatments	Medications and, generally, short-term psychotherapies for symptom relief and relapse prevention	Psychosocial/behavioral (and increasingly, biological) interventions to enhance positive attributes
Prevention	Largely ignored	Important focus across the lifespan

psychiatry in the future.

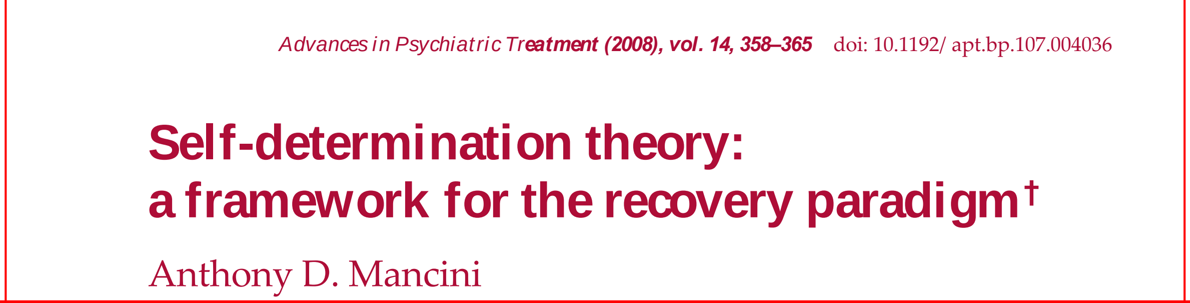
Self-Determination Theory

Tre bisogni umani fondamentali per la motivazione e il benessere:

- Bisogno di autonomia
- Bisogno di competenza
- Bisogno di relazionarsi con gli altri

Tutti gli esseri umani hanno una tendenza **naturale** a cercare risposte a questi bisogni

Ryan & Deci, 2000



Advances in Psychiatric Treatment (2008), vol. 14, 358–365 doi: 10.1192/ apt.bp.107.004036

Self-determination theory: a framework for the recovery paradigm†

Anthony D. Mancini

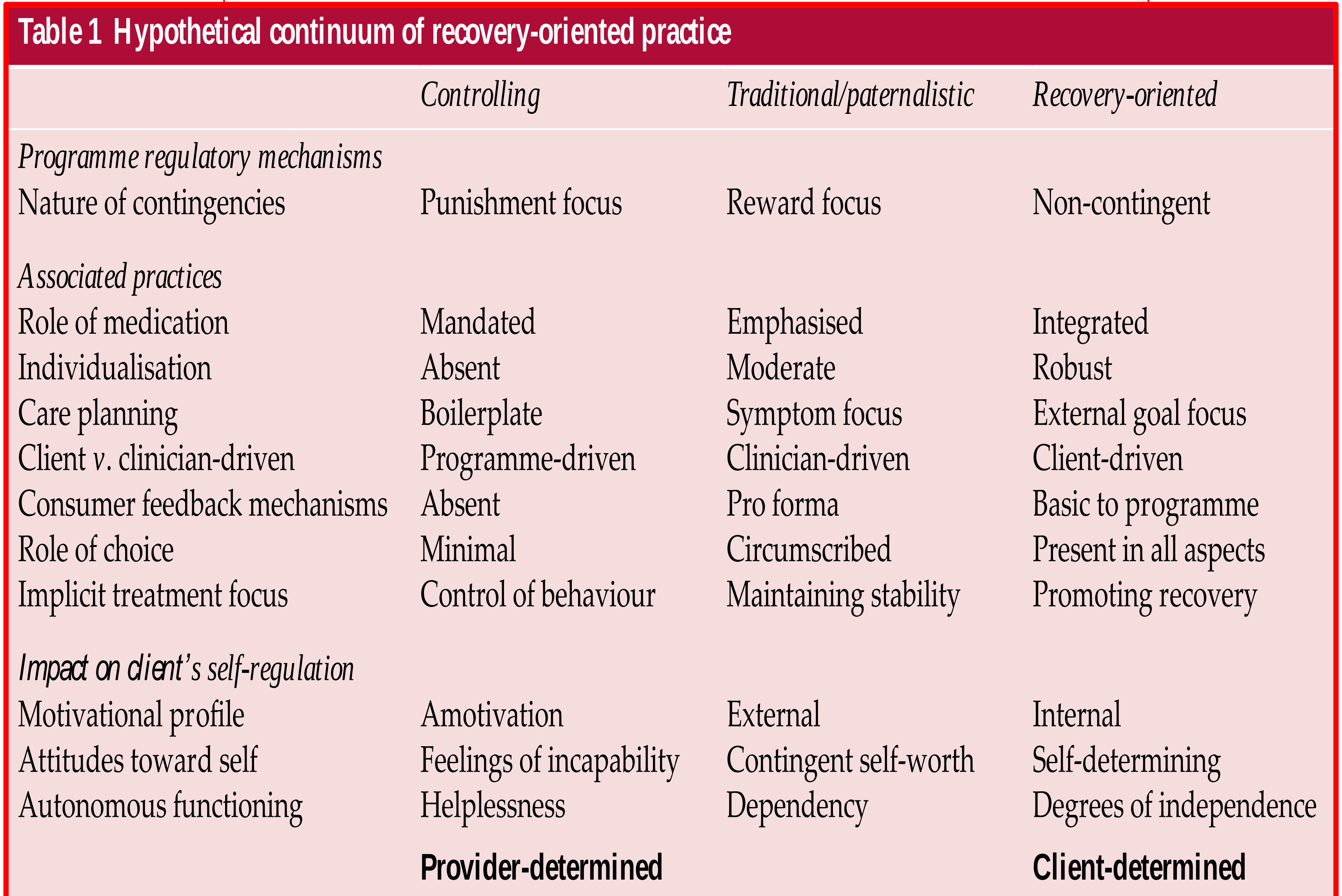


Table 1 Hypothetical continuum of recovery-oriented practice

	Controlling	*Traditional/paternalistic*	*Recovery-oriented*
Programme regulatory mechanisms			
Nature of contingencies	Punishment focus	Reward focus	Non-contingent
Associated practices			
Role of medication	Mandated	Emphasised	Integrated
Individualisation	Absent	Moderate	Robust
Care planning	Boilerplate	Symptom focus	External goal focus
Client *v.* clinician-driven	Programme-driven	Clinician-driven	Client-driven
Consumer feedback mechanisms	Absent	Pro forma	Basic to programme
Role of choice	Minimal	Circumscribed	Present in all aspects
Implicit treatment focus	Control of behaviour	Maintaining stability	Promoting recovery
Impact on client's self-regulation			
Motivational profile	Amotivation	External	Internal
Attitudes toward self	Feelings of incapability	Contingent self-worth	Self-determining
Autonomous functioning	Helplessness	Dependency	Degrees of independence
	Provider-determined		**Client-determined**

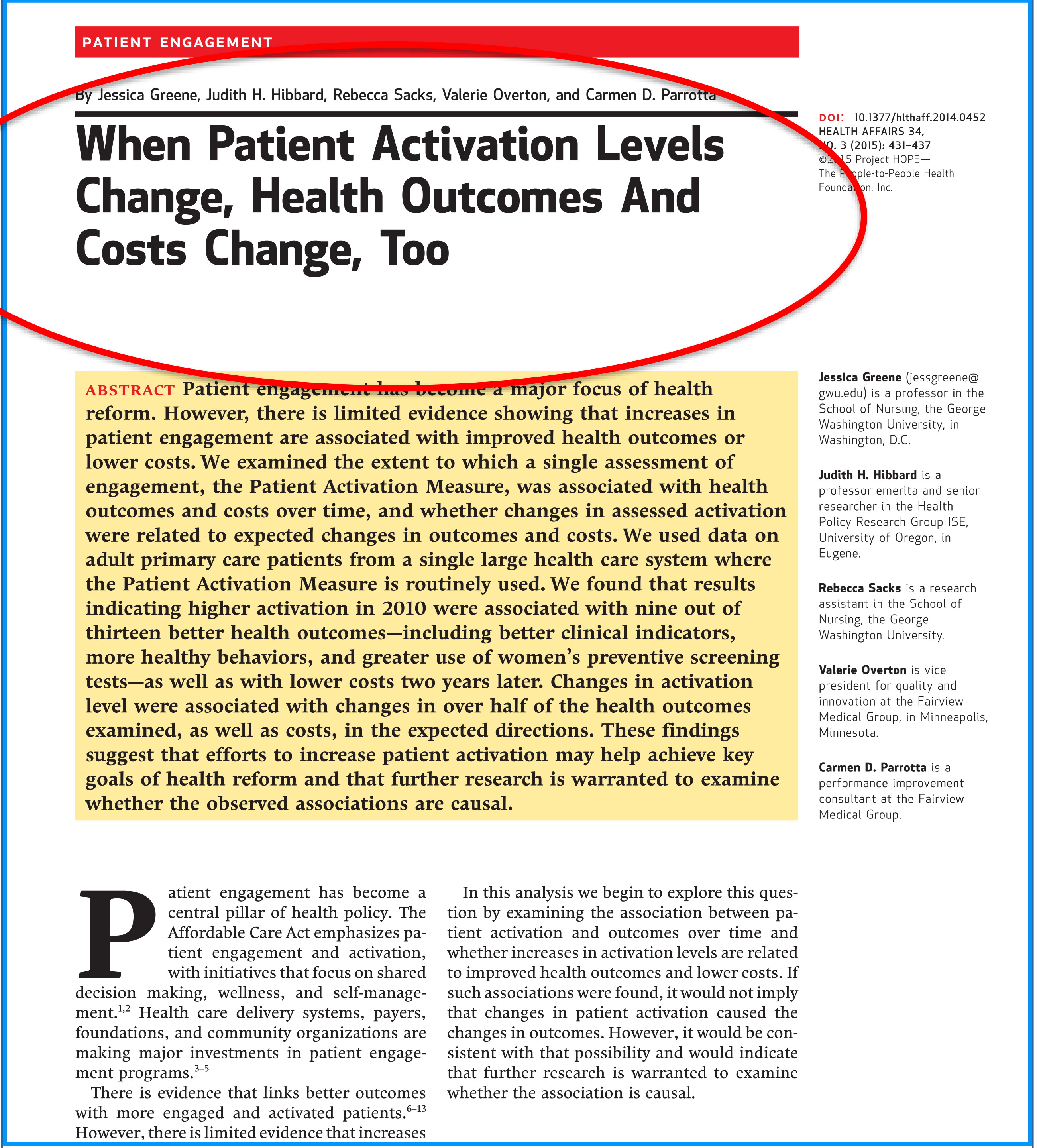
The King's Fund

Ideas that change
health care

Table 4 Tailoring support to patient activation levels

Level 1	Focus on building self-awareness and understanding behaviour patterns, and begin to build confidence through small steps. What a coach might say: 'Let's not try to tackle everything right now. Let's just focus on one thing...'
Level 2	Help patients to continue taking small steps, such as adding a new fruit or vegetable to their diet each week or reducing their portion sizes at two meals a day. Help them build up their basic knowledge. What a coach might say: 'You're off to a great start. Let's build on your success by reducing your portion sizes at lunch time too...'
Level 3	Work with patients to adopt new behaviours and to develop some level of condition-specific knowledge and skills. Support the initiation of new 'full' behaviours (those that are more than just small changes – eg, 30 minutes of exercise three times a week) and work on the development of problem-solving skills. What a coach might say: 'You're making great strides. Do you think you're ready to take your efforts up one notch?'
Level 4	Focus on preventing a relapse and handling new or challenging situations as they arise. Problem solving and planning for difficult situations to help patients maintain their behaviours. What a coach might say: 'You've had terrific success. Let's talk about how you can maintain that, even when life gets more stressful.'

May 2014



PATIENT ENGAGEMENT

By Jessica Greene, Judith H. Hibbard, Rebecca Sacks, Valerie Overton, and Carmen D. Parrotta

When Patient Activation Levels Change, Health Outcomes And Costs Change, Too

DOI: 10.1377/hlthaff.2014.0452
HEALTH AFFAIRS 34,
NO. 3 (2015): 431–437
©2015 Project HOPE—
The People-to-People Health
Foundation, Inc.

ABSTRACT Patient engagement has become a major focus of health reform. However, there is limited evidence showing that increases in patient engagement are associated with improved health outcomes or lower costs. We examined the extent to which a single assessment of engagement, the Patient Activation Measure, was associated with health outcomes and costs over time, and whether changes in assessed activation were related to expected changes in outcomes and costs. We used data on adult primary care patients from a single large health care system where the Patient Activation Measure is routinely used. We found that results indicating higher activation in 2010 were associated with nine out of thirteen better health outcomes—including better clinical indicators, more healthy behaviors, and greater use of women's preventive screening tests—as well as with lower costs two years later. Changes in activation level were associated with changes in over half of the health outcomes examined, as well as costs, in the expected directions. These findings suggest that efforts to increase patient activation may help achieve key goals of health reform and that further research is warranted to examine whether the observed associations are causal.

Jessica Greene (jessgreene@gwu.edu) is a professor in the School of Nursing, the George Washington University, in Washington, D.C.

Judith H. Hibbard is a professor emerita and senior researcher in the Health Policy Research Group ISE, University of Oregon, in Eugene.

Rebecca Sacks is a research assistant in the School of Nursing, the George Washington University.

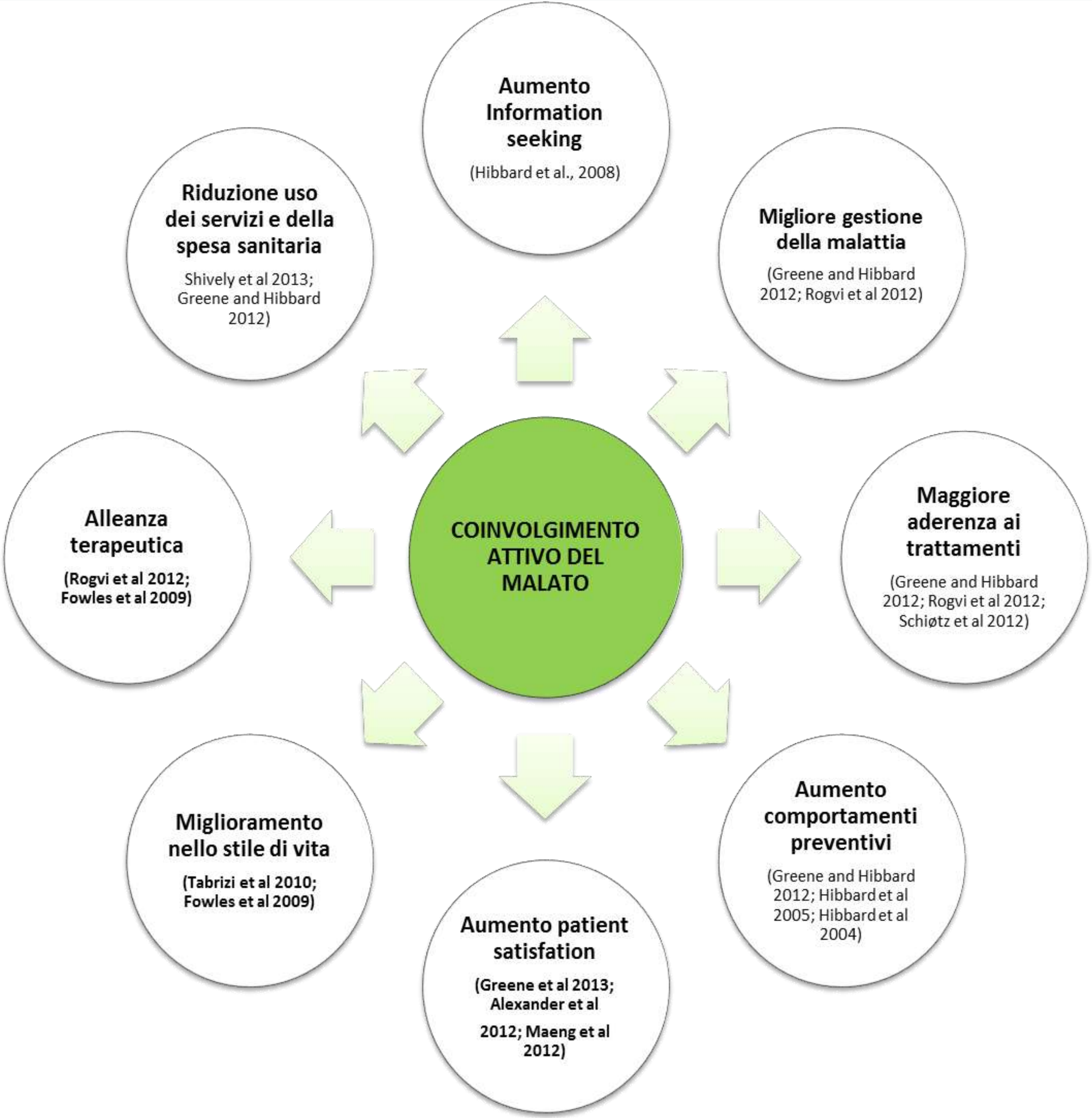
Valerie Overton is vice president for quality and innovation at the Fairview Medical Group, in Minneapolis, Minnesota.

Carmen D. Parrotta is a performance improvement consultant at the Fairview Medical Group.

Patient engagement has become a central pillar of health policy. The Affordable Care Act emphasizes patient engagement and activation, with initiatives that focus on shared decision making, wellness, and self-management.[1,2] Health care delivery systems, payers, foundations, and community organizations are making major investments in patient engagement programs.[3–5]

There is evidence that links better outcomes with more engaged and activated patients.[6–13] However, there is limited evidence that increases

In this analysis we begin to explore this question by examining the association between patient activation and outcomes over time and whether increases in activation levels are related to improved health outcomes and lower costs. If such associations were found, it would not imply that changes in patient activation caused the changes in outcomes. However, it would be consistent with that possibility and would indicate that further research is warranted to examine whether the association is causal.



COINVOLGIMENTO ATTIVO DEL MALATO

Aumento Information seeking
(Hibbard et al., 2008)

Migliore gestione della malattia
(Greene and Hibbard 2012; Rogvi et al 2012)

Maggiore aderenza ai trattamenti
(Greene and Hibbard 2012; Rogvi et al 2012; Schiøtz et al 2012)

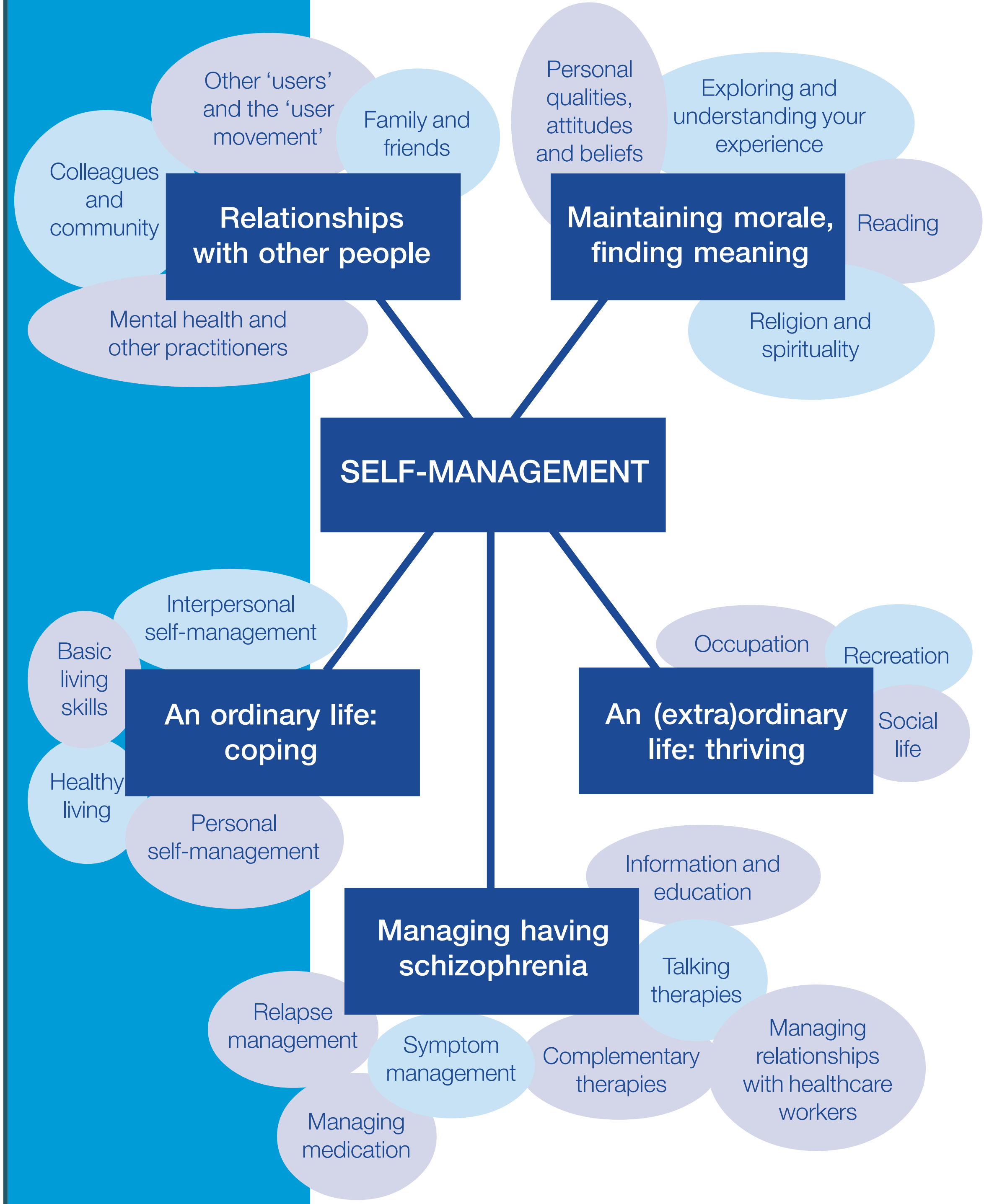
Aumento comportamenti preventivi
(Greene and Hibbard 2012; Hibbard et al 2005; Hibbard et al 2004)

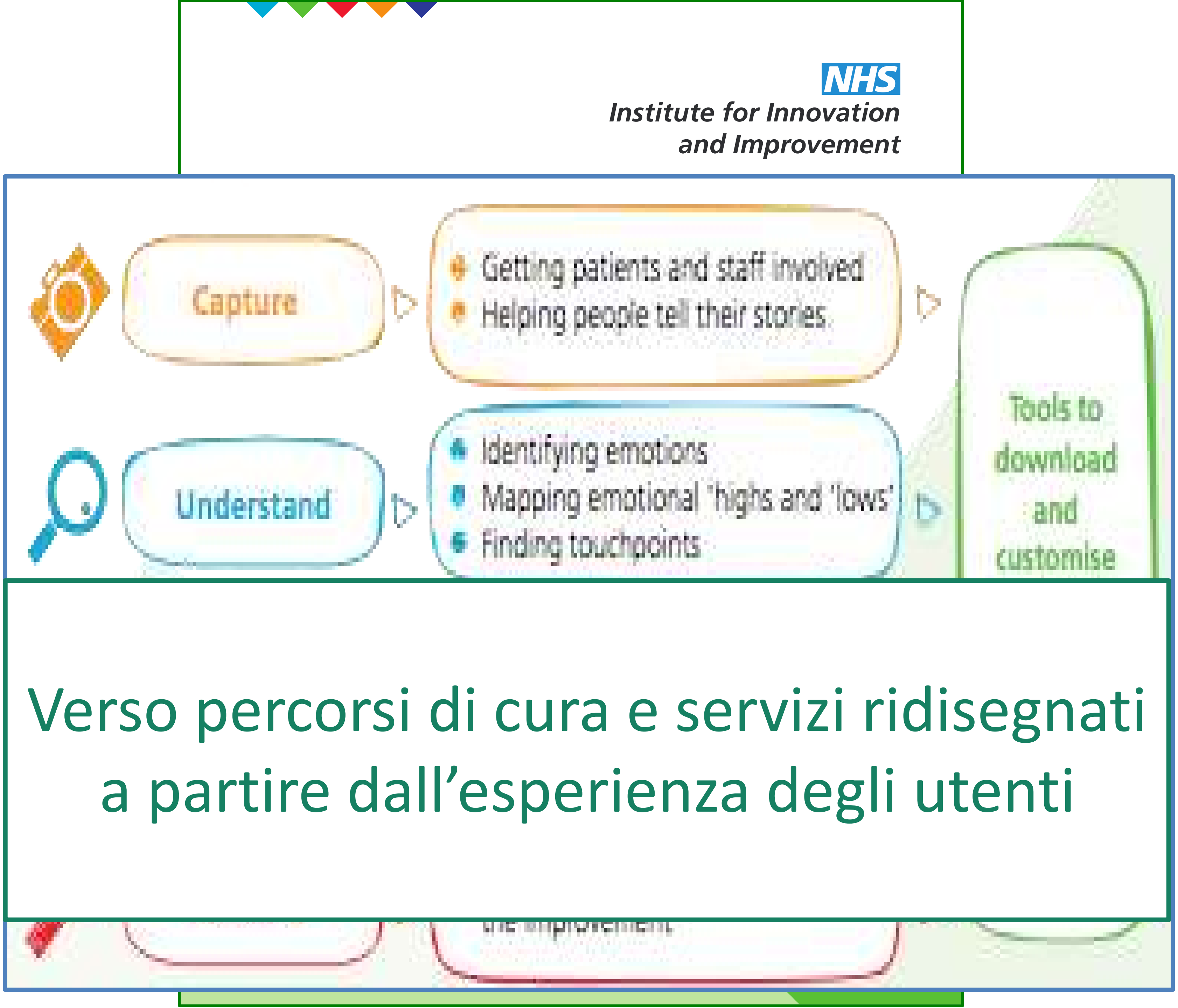
Aumento patient satisfation
(Greene et al 2013; Alexander et al 2012; Maeng et al 2012)

Miglioramento nello stile di vita
(Tabrizi et al 2010; Fowles et al 2009)

Alleanza terapeutica
(Rogvi et al 2012; Fowles et al 2009)

Riduzione uso dei servizi e della spesa sanitaria
Shively et al 2013; Greene and Hibbard 2012)


SELF-MANAGEMENT
Relationships with other people
Colleagues and community
Other 'users' and the 'user movement'
Family and friends
Mental health and other practitioners
Maintaining morale, finding meaning
Personal qualities, attitudes and beliefs
Exploring and understanding your experience
Reading
Religion and spirituality
An ordinary life: coping
Interpersonal self-management
Basic living skills
Healthy living
Personal self-management
An (extra)ordinary life: thriving
Occupation
Recreation
Social life
Managing having schizophrenia
Information and education
Talking therapies
Managing relationships with healthcare workers
Complementary therapies
Symptom management
Relapse management
Managing medication


NHS
Institute for Innovation
and Improvement

Capture
- Getting patients and staff involved
- Helping people tell their stories

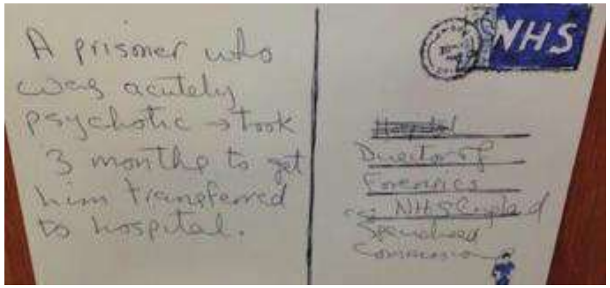
Understand
- Identifying emotions
- Mapping emotional 'highs and 'lows'
- Finding touchpoints

Tools to download and customise

the improvement

Verso percorsi di cura e servizi ridisegnati a partire dall'esperienza degli utenti

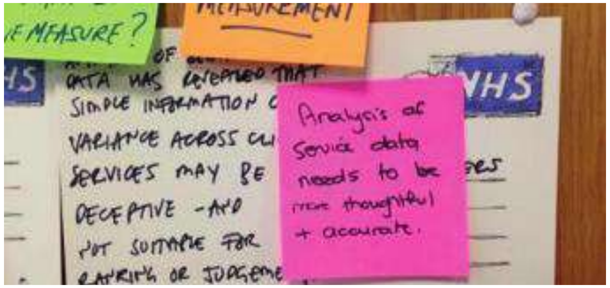
Pathways to recovery:
A case for adoption of systematic pathways in psychosis



A prisoner who was acutely psychotic → took 3 months to get him transferred to hospital.

~~Hospital~~
Director of Forensics
cc: NHS England
Specialised Commissioning

1. Attendees were invited to share personal experiences of psychosis which highlight areas for improvement and development



OF
DATA WAS REVEALED THAT
SIMPLE INFORMATION
VARIANCE ACROSS CL
SERVICES MAY BE
DECEPTIVE - AND
NOT SUITABLE FOR
RANKING OR JUDGEME

Analysis of service data needs to be more thoughtful + accurate.

2. We clustered these postcards to identify some key themes and opportunity areas

3. The teams then identify specific opportunities they wanted to work on during the afternoon – each team chose two opportunities.

4. Each team worked on a template to ensure they captured all relevant aspects of their proposed solution

IMPERIAL COLLEGE
HEALTH PARTNERS

WESSEX
ACADEMIC HEALTH
SCIENCE NETWORK
IMPROVING HEALTH THROUGH INNOVATION

RC
PSYCH
ROYAL COLLEGE OF
PSYCHIATRISTS

Rethink
Mental
Illness.

Position Paper:

Are mainstream mental health services ready to progress transformative co-production?

NDTi
National Development Team for Inclusion

A key ingredient in recovery is “giving people a chance to create meaning around their experience.” (Myers, 2015)

[illegible]

Il Luogo Ideale Per Una Vacanza Da Sogno Alle Maldive

[illegible]

Moved to Italy & have UK savings? Increase savings income by up to 40%

[illegible]

Cosa succede in caso di [illegible]

[illegible]

[illegible]

[illegible]

comments (14)

Sign in or create your Guardian account to join the discussion.

Order by Oldest ▾ Threads Collapsed ▾

atinyu17 [illegible]

Great that you can help but in the example:
"After that, he asked us to support him and we saw him on a daily basis."
How can that be reproduced on a countrywide scale when thousands are suffering from mental illnesses

Report

Jay Hibbins → atinyu17 [illegible]

Hi atinyu17. For the intensive period (usually around ten days but variable) we can see the client for an hour a day every day - longer if they are at imminent risk that day. The amount of contact reduces as they start to feel safer and the crisis subsides. That's similar to what mental health crisis teams do in terms of seeing someone every day during the intense crisis period (Crisis and Home Treatment teams).

Report

[illegible] [illegible]

This sounds wonderful, I wish there was something like this available in my area.

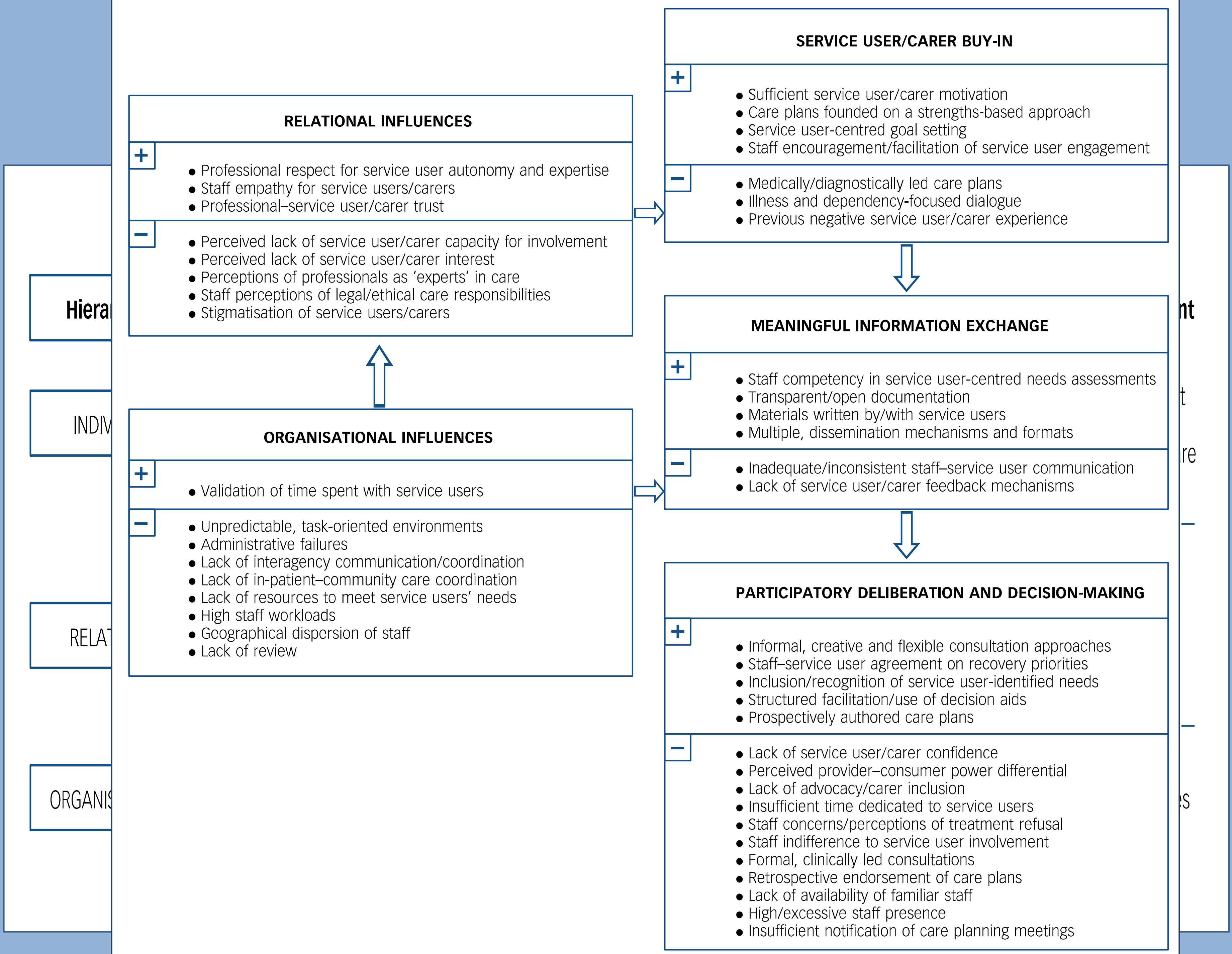
I'm currently suicidal and under the care of the crisis team, however they haven't been very helpful - they only visit once a day, often with hardly any notice so I worry about going out in case I miss them. I get seen by a different person every day so I can't build up a relationship with anyone, and one nurse who came round was so unhelpful and patronising he made me feel worse. He was majorly guilt tripping me which doesn't help when you're suicidal.

I am grateful for the extra help as I've never been seen by them before, every other time I've been suicidal and told my psychiatrist I've just been asked why I haven't done anything yet and told to come back in two months. But this time I was taken seriously which is good. The crisis team did say I would get the same attention as I would in hospital though which so far doesn't seem to be the case.

Report

Jay Hibbins → [illegible] [illegible]

I'm really sorry to hear that the crisis team haven't been helpful, [illegible]. And especially that one made you feel worse. I'm glad you say that you feel they are taking your risk seriously though - that's so important. Thank you so much for your kind comments.



RELATIONAL INFLUENCES

+
- Professional respect for service user autonomy and expertise
- Staff empathy for service users/carers
- Professional–service user/carer trust

−
- Perceived lack of service user/carer capacity for involvement
- Perceived lack of service user/carer interest
- Perceptions of professionals as ‘experts’ in care
- Staff perceptions of legal/ethical care responsibilities
- Stigmatisation of service users/carers

ORGANISATIONAL INFLUENCES

+
- Validation of time spent with service users

−
- Unpredictable, task-oriented environments
- Administrative failures
- Lack of interagency communication/coordination
- Lack of in-patient–community care coordination
- Lack of resources to meet service users’ needs
- High staff workloads
- Geographical dispersion of staff
- Lack of review

SERVICE USER/CARER BUY-IN

+
- Sufficient service user/carer motivation
- Care plans founded on a strengths-based approach
- Service user-centred goal setting
- Staff encouragement/facilitation of service user engagement

−
- Medically/diagnostically led care plans
- Illness and dependency-focused dialogue
- Previous negative service user/carer experience

MEANINGFUL INFORMATION EXCHANGE

+
- Staff competency in service user-centred needs assessments
- Transparent/open documentation
- Materials written by/with service users
- Multiple, dissemination mechanisms and formats

−
- Inadequate/inconsistent staff–service user communication
- Lack of service user/carer feedback mechanisms

PARTICIPATORY DELIBERATION AND DECISION-MAKING

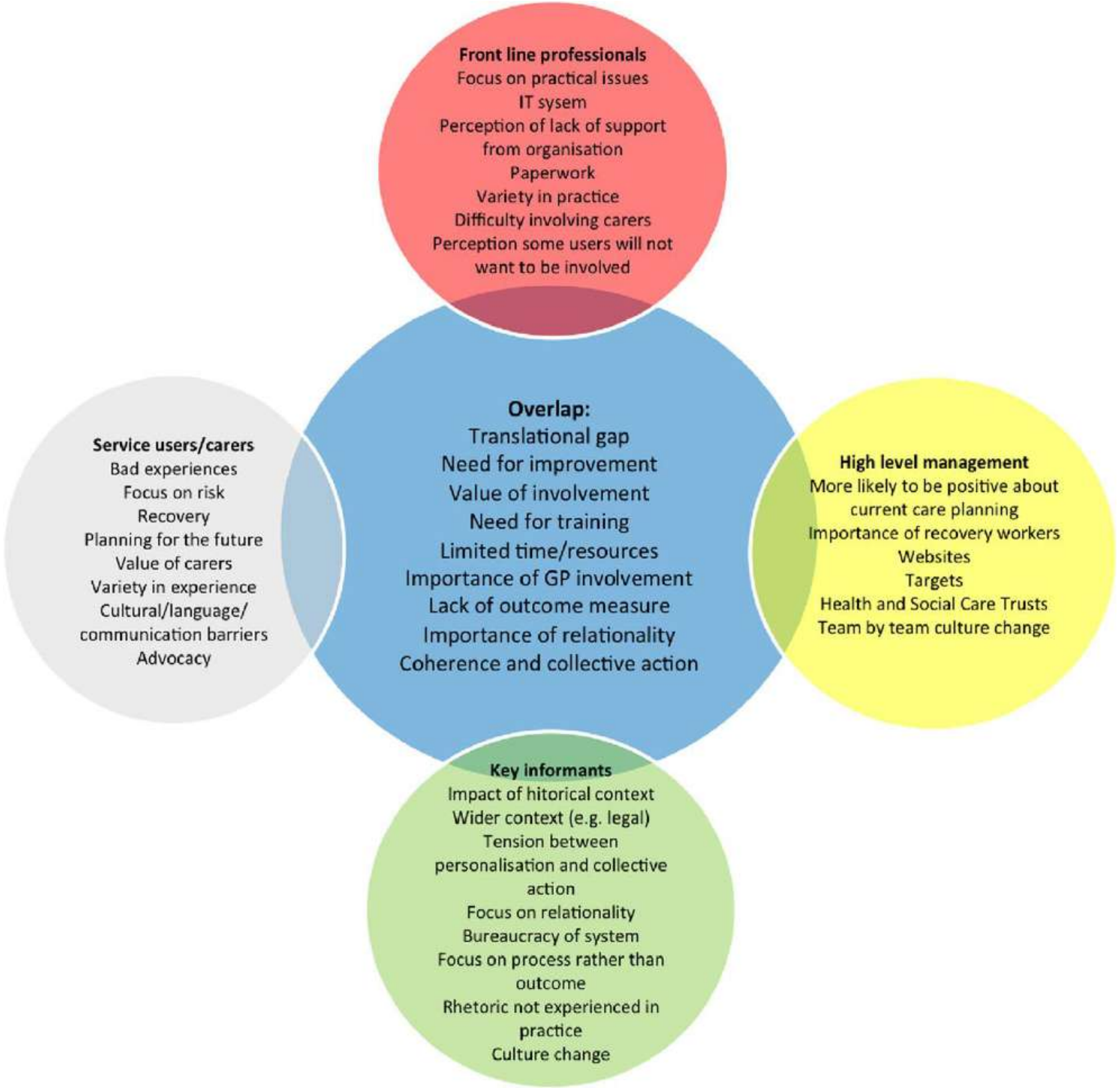
+
- Informal, creative and flexible consultation approaches
- Staff–service user agreement on recovery priorities
- Inclusion/recognition of service user-identified needs
- Structured facilitation/use of decision aids
- Prospectively authored care plans

−
- Lack of service user/carer confidence
- Perceived provider–consumer power differential
- Lack of advocacy/carer inclusion
- Insufficient time dedicated to service users
- Staff concerns/perceptions of treatment refusal
- Staff indifference to service user involvement
- Formal, clinically led consultations
- Retrospective endorsement of care plans
- Lack of availability of familiar staff
- High/excessive staff presence
- Insufficient notification of care planning meetings

Brooks *et al. BMC Health Services Research* (2015) 15:490
DOI 10.1186/s12913-015-1154-z

BMC
Health Services Research

RESEARCH ARTICLE Open Access



Front line professionals
Focus on practical issues
IT sysem
Perception of lack of support from organisation
Paperwork
Variety in practice
Difficulty involving carers
Perception some users will not want to be involved

Service users/carers
Bad experiences
Focus on risk
Recovery
Planning for the future
Value of carers
Variety in experience
Cultural/language/ communication barriers
Advocacy

Overlap:
Translational gap
Need for improvement
Value of involvement
Need for training
Limited time/resources
Importance of GP involvement
Lack of outcome measure
Importance of relationality
Coherence and collective action

High level management
More likely to be positive about current care planning
Importance of recovery workers
Websites
Targets
Health and Social Care Trusts
Team by team culture change

Key informants
Impact of hitorical context
Wider context (e.g. legal)
Tension between personalisation and collective action
Focus on relationality
Bureaucracy of system
Focus on process rather than outcome
Rhetoric not experienced in practice
Culture change

Hope for recovery

To get better from symptoms and distress
Get well
Get better from depression
Get help with handling obsessive thoughts
Experience less anxiety in social situations
Improve concentration
Drink less
Quit smoking cannabis
'Get through it'
Sleep better

To function like other people do
Become able to get up in the morning
Do domestic tasks
Keep appointments
Function as other people do
Not need special treatment
Get on with life
Move out from parents' home into one's own home

To get physically fit
Get fit
Get better from pains

To have a good family life
Find a partner
Have family and children
Function with a partner and children
Become able to take care of children
Become a parent who does not struggle with mental health problems
Enjoy being with grandchildren
Become able to visit one's parents without feeling a desire to leave again immediately

To have a social life
Become able to go out among people
Become able to be in a group of people without having feelings of discomfort

To get an education
Begin studies
Complete studies

To be able to work
Get a job
Earn well
Avoid getting disability pension

To experience enjoyable activities
Experience new things
Travel a lot
Have a fine spare time with one's partner

Developing understanding

To learn about the causes of the mental health problems
Understand why things are difficult
Learn about why one has the thoughts one has
Get to know the reasons why one reacted like one did
Understand why one ended up like one did
Learn more about the mental problems
Get an evaluation with regard to if one has a disorder or not
Get a diagnosis
Learn to function better
Learn to love oneself

To talk about the problems in order to understand and get better from them
To talk about the problems in order to see things one does not see oneself
Talk about the problems in order to get better from them

To learn to know oneself and early signals
Learn to know oneself better
Learn to become aware of signals that things are not as they should be

Finding tools for coping

To develop coping strategies
Get tools to keep emotional problems under control
Learn what to do to feel better
Learn how to sort out one's own thoughts
Learn to work things through on your own
Cope better with stress
Learn what one could get more energy from
Learn methods to reduce mood alterations
Learn a method for what to do to prevent oneself from ending up like this again
Develop one's own strategies to cope with social anxiety

To get help with pushing oneself to go out among other people
Get help 'pushing' oneself to go out among other people
Have a plan for training in social situations

To take medication that helps
Take medication that helps
Get counselling with regard to medication
When the time comes, get help with reducing medication
Stop taking medications

Receiving counselling and practical assistance

To receive advice about choices that have to be made in life
Get help with making decisions
Focus on whether to continue education or not
Get advice about where to be in the future

To receive help with family issues
Get help with family problems

To get assistance with coordinating practical and financial issues
Get help with planning future activities
Receive advice with regard to education
Get assistance with finding a job
Get help with getting support from the Labour and Welfare Administration with education, job, and financial issues

Journal of
MENTAL
HEALTH

http://tandfonline.com/ijmh
ISSN: 0963-8237 (print), 1360-0567 (electronic)

J Ment Health, 2017; 26(3): 264–270

© 2017 Informa UK Limited, trading as Taylor & Francis Group. DOI: 10.1080/09638237.2017.1294735

Taylor & Francis
Taylor & Francis Group

ORIGINAL ARTICLE

Antipsychotic treatment: experiences of fully recovered service users

Jone Bjornestad[1], Larry Davidson[2], Inge Joa[1,3], Tor Ketil Larsen[1,4], Wenche ten Velden Hegelstad[1], Johannes Langeveld[1], Marius Veseth[5], Ingrid Melle[6], Jan Olav Johannessen[1,3], and Kolbjorn Bronnick[1,3]

[1]TIPS – Centre for Clinical Research in Psychosis, Stavanger University Hospital, Stavanger, Norway, [2]Yale University, School of Medicine and Institution for Social and Policy Studies, New Haven, CT, USA, [3]Network for Medical Sciences, University of Stavanger, Stavanger, Norway, [4]Department of Clinical Medicine, Section of Psychiatry, University of Bergen, Bergen, Norway, [5]Faculty of Health and Social Sciences, Bergen University College, Bergen, Norway, and [6]Norwegian Centre for Mental Disorders Research, University of Oslo, Oslo, Norway

Abstract

Background: There is lack of long-term controlled studies evaluating treatment effects of antipsychotic medication. A complete investigation should include the service user perspective.
Aims: To investigate experiences of clinically recovered service users of antipsychotic medications during and after a first episode of psychosis.
Method: We used a thematic analytic approach within an interpretative-phenomenological framework. 20 clinically recovered service users were interviewed.
Results: Themes: (1) *Antipsychotic drugs reduce mental chaos during the acute phase*, (2) *Non-stigmatizing environments were perceived to increase chances of successful use*, (3) *Antipsychotic drugs beyond the acute phase – considered to compromise the contribution of individual effort in recovery*, (4) *Prolonged use – perceived to reduce likelihood of functional recovery*, (5) *Antipsychotic medication was considered as a supplement to trustful relationships*.
Conclusions: Acute phase antipsychotic treatment was mostly perceived as advantageous by this sample, who was in clinical recovery. However, costs were often seen as outweighing benefits beyond the acute stage. Findings clearly emphasize the need for a collaborative approach to be integrated across all phases of care. This study underscores the need to investigate sub-group differences with regard to long-term antipsychotic treatment.

Keywords

Recovery, clinical recovery, psychosis, first episode psychosis, antipsychotic, antipsychotic medication, service user, first-person accounts

History

Received 19 May 2016
Revised 11 January 2017
Accepted 1 February 2017
Published online 28 February 2017

In psychosis, standardized clinical treatment guidelines generally recommend that individuals should be treated with antipsychotic medication in the acute phase as well as throughout the protracted phases of maintenance and recovery (APA, 2006; Kreyenbuhl et al., 2010; NICE, 2014; Sohler et al., 2016). Antipsychotic medication has unequivocally proven effective in acute and short-term treatment (Bola et al., 2011; Leucht et al., 2012b). However, there is a lack of long-term, systematic double-blind controlled studies using clearly defined samples in terms of illness type, severity and duration (Adams et al., 2013; Sohler et al., 2016) evaluating treatment effect. This has resulted in a call for large-scale independent trials (Bola et al., 2011; Leucht et al., 2012a; Saha et al., 2016) in order to create a new and improved evidence base to sufficiently understand the long-term benefit/risk balance of antipsychotic drugs for different sub-groups of service users (Sohler et al., 2016). There is also a need for systematic investigations of different sub-groups of service users' perspectives on antipsychotic medication use throughout the course of illness. Such perspectives are necessary to develop clinically relevant hypotheses for the suggested large-scale trials, and to illuminate implications for different sub-groups of individuals.

Representing a step in this direction, this exploratory study aims to investigate clinically recovered service users' perspectives on the use of antipsychotic medication during and after a first psychotic episode. This was done by interviewing a sample of 20 first-episode psychosis service users in clinical recovery (Davidson et al., 2008), operationalized as the fulfillment of strict criteria of both symptomatic (Andreasen et al., 2005) and functional (Hegelstad et al., 2012) remission throughout the past year. Between 9 and 21% of service users with FEP achieve clinical recovery (Jaaskelainen et al., 2013), making this a highly relevant sub-group.

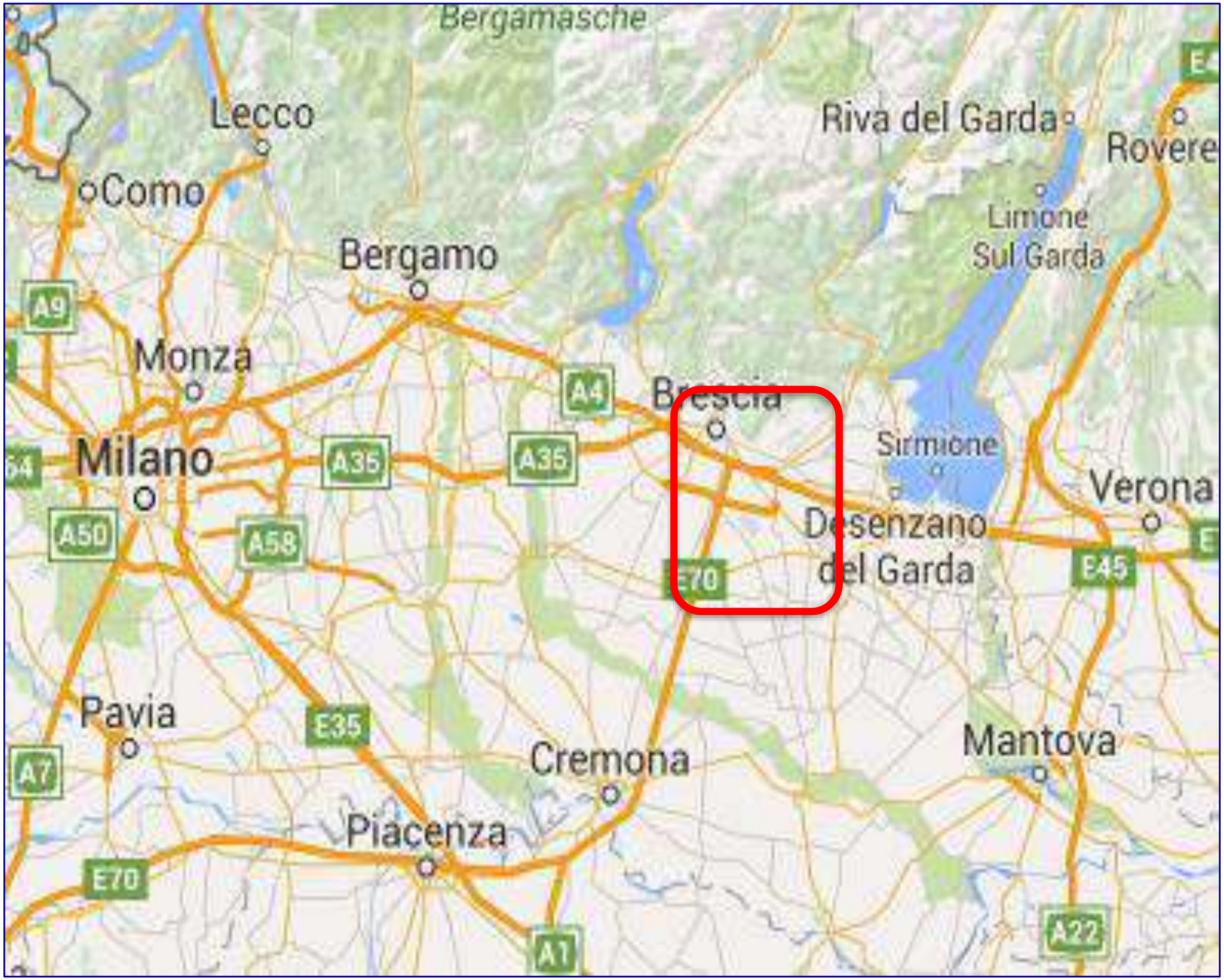
Method

We used a thematic analytic approach (Boyatzis, 1998; Braun & Clarke, 2006) within an interpretative-phenomenological framework (Gadamer, 1989; Heidegger, 1996). In this study, the interpretative element implies that data were both generated from a reflexive dialog between participants and researchers and involved a member checking procedure throughout the interview. The phenomenological element

---

Correspondence: Jone Bjørnestad, Stavanger University Hospital, Division of Psychiatry, Regional Centre for Clinical Research in Psychosis, P.O. Box 1163, 4095 Stavanger, Norway. Tel: +47 97141599. E-mail: jone.bjornestad@gmail.com

Il territorio di riferimento della Unità Operativa di Psichiatria 23-ASST Brescia



Bergamasche
Lecco
Como
Riva del Garda
Rovere
Limone Sul Garda
Bergamo
A9
Monza
A4
Brescia
Milano
A35
A35
Sirmione
Verona
A50
A58
Desenzano del Garda
E70
E45
Pavia
E35
Cremona
Mantova
A7
Piacenza
E70
A1
A22

positive
about integrated healthcare

Nottinghamshire Healthcare
NHS Foundation Trust
NHS

Changing the Conversation

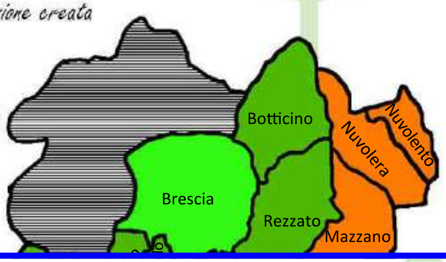
Recovery Strategy 2016 - 2021

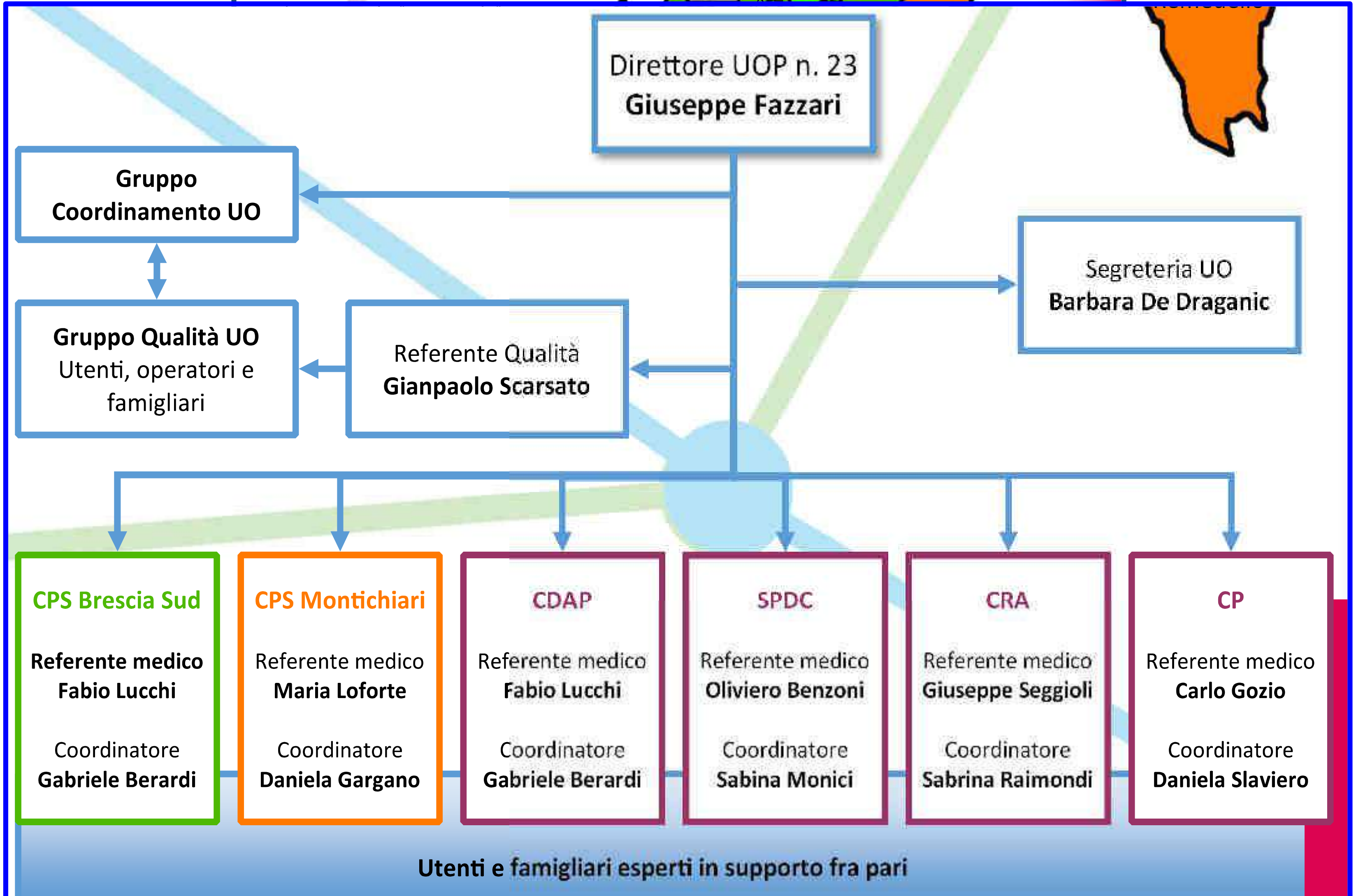
Changing the Conversation between ….		
health workers and the people they support (individuals, their family and friends)	**services and the people who use them**	**services and communities**
to enable ….		
shared decision-making and more equal partnership	**co-produced and co-delivered services**	**merging mental health system and community resources**
by ….		

L'unità Operativa di Psichiatria n. 23 (UOP n. 23)

L'Unità Operativa di Psichiatria n. 23 è un'organizzazione creata per gli utenti, con gli utenti.

La semplicità, l'ottimismo, la naturale cordialità, l'impegno quotidiano, l'apertura al nuovo, la sensibilità a cogliere le stimolazioni al cambiamento, che ci giungono attraverso lo studio della letteratura, dalle riflessioni sul nostro operato e dall'osservazione





Direttore UOP n. 23
Giuseppe Fazzari

Gruppo Coordinamento UO

Gruppo Qualità UO
Utenti, operatori e famigliari

Referente Qualità
Gianpaolo Scarsato

Segreteria UO
Barbara De Draganic

CPS Brescia Sud
Referente medico
Fabio Lucchi
Coordinatore
Gabriele Berardi

CPS Montichiari
Referente medico
Maria Loforte
Coordinatore
Daniela Gargano

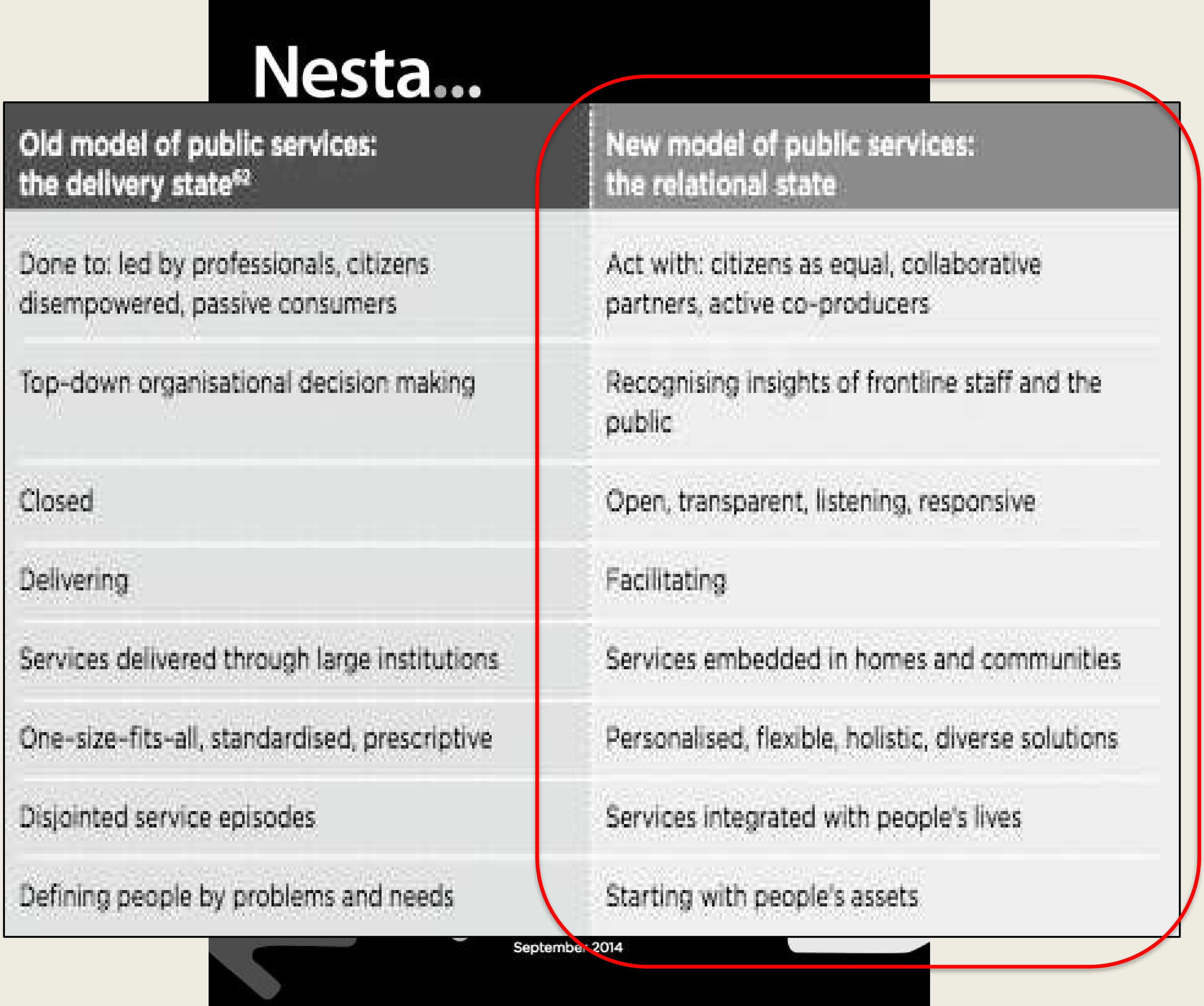
CDAP
Referente medico
Fabio Lucchi
Coordinatore
Gabriele Berardi

SPDC
Referente medico
Oliviero Benzoni
Coordinatore
Sabina Monici

CRA
Referente medico
Giuseppe Seggioli
Coordinatore
Sabrina Raimondi

CP
Referente medico
Carlo Gozio
Coordinatore
Daniela Slaviero

Utenti e famigliari esperti in supporto fra pari



Nesta...

Old model of public services: the delivery state[62]	New model of public services: the relational state
Done to: led by professionals, citizens disempowered, passive consumers	Act with: citizens as equal, collaborative partners, active co-producers
Top-down organisational decision making	Recognising insights of frontline staff and the public
Closed	Open, transparent, listening, responsive
Delivering	Facilitating
Services delivered through large institutions	Services embedded in homes and communities
One-size-fits-all, standardised, prescriptive	Personalised, flexible, holistic, diverse solutions
Disjointed service episodes	Services integrated with people's lives
Defining people by problems and needs	Starting with people's assets

September 2014

Jacqui Dillon, Lucy Johnstone & Eleanor Longden

Trauma, Dissociation, Attachment & Neuroscience: A new paradigm for understanding severe mental distress

Developmental psychology, traumatology and cognitive neuroscience literature suggests that psychosis and other forms of distress can be understood as meaningful responses to trauma and loss. Clinical and theoretical implications of this holistic, integrated paradigm are discussed.

Key words: sexual abuse, trauma, denial, dissociation, attachment, mental health service

A new and profoundly important paradigm for understanding overwhelming emotional pain has emerged over the last few years, with the potential to change the way we conceptualise human suffering across the whole spectrum of mental health difficulties. It is a strongly evidence-based synthesis of findings from trauma studies, attachment theory and neuroscience, which offers new hope for recovery. It also presents a powerful challenge to biomedical model psychiatry in that it is based on scientific evidence that substantiates and attests to what many individuals with first-hand experience of mental health problems have always known – that the bad things that happen to you can drive you mad. In this article we will summarise the key findings and reflect on the implications for current practice.

It should be noted that we do not accept the validity of diagnostic categories such as schizophrenia, psychosis and personality disorder; nor do we accept the biomedical model that is implied by terms such as symptom and delusion. However, much of the literature that we cite in this paper is framed in such terms; hence their use in parts in the article.