Recovery in mental health – reshaping responsibilities

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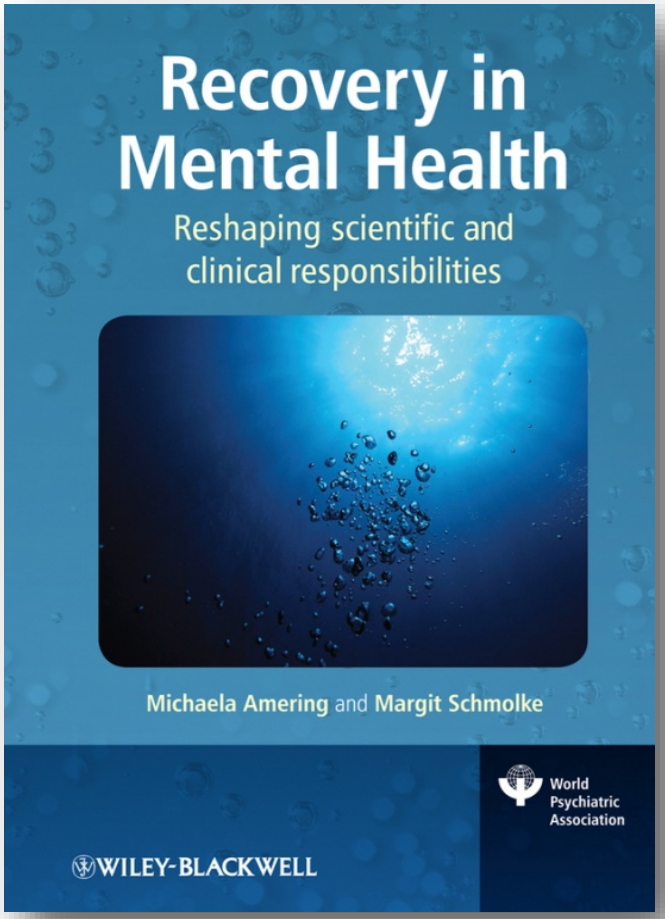
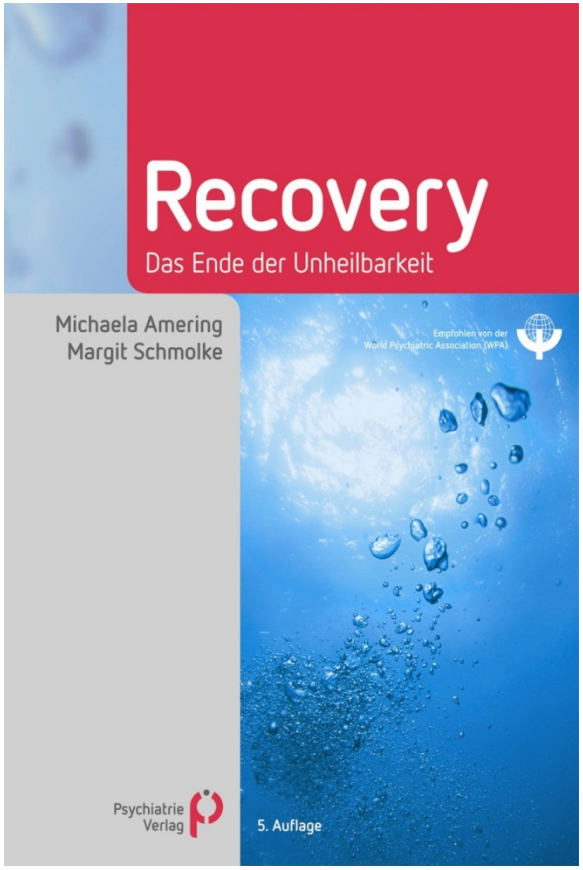
Recovery

Recovery is currently mental health policy in important english-speaking countries *(e.g. USA, CAN, UK, AUS)*



Recovery

as basic principle and goal of psychosocial interventions in the guidelines of the German Association of Psychiatry and Psychotherapie, the S3-Leitlinie ‚Psychosoziale Therapien bei Menschen mit schweren psychischen Erkrankungen‘ der DGPPN (2012 und 2018)



Recovery in mental health

Development and Significance

I. **First person accounts of people with severe mental illness, e.g. schizophrenia**

(D. Fisher, K. Jamison, Helen Glover, and many others)

- **Recovery – an Alien Concept** *(R. Coleman, 1999)*
- **Ownership of the experience**
- **… beyond the patient role** *(Pat Deegan)*

Recovery in mental health

Development and Significance

II. epidemiological data, especially, but exemplary, on the course of schizophrenia

- **Symptomatic recovery after early treatment**

  (e.g. Gitlin et al, McGorry et al, Hegarty et al)

- **Social recovery from long-term disabilities**

  (e.g. Harrison et al, Harding, Strauss et al, Richard Warner, Ciompi, Bleuler)

Recovery

- an outcome
- a process
  - both

Recovery
outcome

social roles

versus

symptomatology

leading a meaningful life

versus

service use reduction

Recovery in mental health

Definition - *process*

"… a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles.

It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness.

Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"

Anthony, 1993

Recovery Definition

Bill Anthony, 1993/Jan Wallcraft, 2012

'Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams.

Recovery is often a complex, time-consuming process. Recovery is what people with disabilities do.

Treatment, case-management and rehabilitation are what helpers do to facilitate recovery.'

Recovery
reshaping responsibilities

Outcome – leading a meaningful life *versus* symptom or service use reduction

Process – Connectedness, Hope, Identity, Meaning,

Empowerment – CHIME *(Slade et al, 2011)*, CHIME-D *(Stuart et al, 2017)*

Services – person-centered, integrative, mobile, collaborative commitment for change, self- and peer-help, advocacy

Context – human rights, patients‘ rights

PORT (Schizophrenia Patient Outcomes Research Team, 2009) through a Recovery Lens *Davidson, 2010*

'It is worth noting, in support of this perspective, that those interventions that had the most robust effect sizes were those that supported people in occupying normative adult roles while continuing to suffer from mental illness.

Arguably, the most effective breakthroughs in psychiatric practice for people with schizophrenia ……

……. in development of the psychiatric rehabilitation practices of supported housing and supported employment.'

Centrality of Community Activities in a Network Analysis of Outcome-limiting Factors: Implications for Recovery-oriented Strategies

(EPA Mucci 2018 on JAMA 2018, Galderisi et al)

- The high centrality of functional capacity and everyday life skills suggests that improving the ability to perform tasks relevant to everyday life is critical for any therapeutic intervention in schizophrenia.

- The data-driven analysis supports recovery-oriented approaches with a focus on basic functioning goals more than on symptom control.

‚First place then train‘

Instead of

‚First train then place‘

- **Individual Placement and Support/Supported Employment**
- **Housing First/ Supported Housing**
- **Supported Education**
- **Supported Parenting**
- **……**

Right to support for a self-determined life in the community

e.g. UN-CRPD Articles

Article 19 - Living Independently And Being Included In the Community

Article 23 – Respect for Home and the Family

Article 24 – Education

Article 26 - Habilitation and rehabilitation

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

Article 29 - Participation in political and public life

Article 30 - Participation in cultural life, recreation, leisure and sport

Why is the UN Convention on the Rights of Persons with Disabilities (CRPD) important?

…. rights to non-discrimination in key areas, including employment, housing, education, health, standards of living and social, political and cultural participation, along with the right to be free from exploitation, violence and abuse, …. ‘

Bartlett, 2012

UN-CRPD receiving unprecedented support worldwide

- **180 Ratifications**
  (= national law)

- **Slovakia 2010**

‚from charity-based to rights-based‘

‚from Rehabilitation to Recovery‘
‚from Education to Collaboration‘

Norman Sartorius on the current direction of mental health care, WCP Lisbon, 2019

UN-CRPD

UN-Convention on the Rights of Persons with Disablities

Historic Firsts:

- ***'Nothing about Us without Us!'***

- ***a proud victory –***
  ‚psychosocial disabilities' ***www.wnusp.net***

European Declarations, Strategies and Projects that emphasize service user involvement

- **UN CRPD, 2010**
- **European Union Strategy for Disability 2010-2020**
- **European Agency for Fundamental Rights (FRA) project on the fundamental rights of Persons with intellectual disabilities and persons with mental health problems, 2009**
- **European Parliament Resolution on Mental Health, 2009**
- **WHO Europe and European Commission funded project on service user and carer empowerment (2009-2011)**
- **The Mental Health Declaration/Action Plan for Europe, 2005**

  The mental health strategy for Europe: why service user leadership in research is indispensable. Callard, Rose (2012)

- **The European (as well as Global) Mental Health Action Plan 2013-2020**

www.euro.who.int

Recovery in mental health – reshaping responsibilities

User Involvement

- **Policy (‚Nothing about Us without Us‘)**
- **Planning of services (e.g. Crisis Alternatives)**
- **Delivery of services (e.g. Peers)**
- **Evaluation of services (e.g. User defined outcome measures)**
- **Research (e.g. User-led Research)**
- **Teaching (e.g. lived experience expertise)**

e.g.

- **Experienced Involvement = EX-IN in BRD, CH, A**
- **More than 10.000 Peer Support staff in USA *(Davidson, 2012)***
- **No research money without UI (UK, NOR)**

Recovery in mental health – reshaping responsibilities

'It is key that people in recovery lead the way'

Practice Guidelines for recovery-oriented behavioral health care (Connecticut/US) ***(Davidson et al 2007)***

‚Peer support is a key component of recovery'

Shery Mead & Mary Ellen Copeland, 2005

Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, Javed A, Katontoka S, Raja S, Rataemane S, Steffen S, Tyano S, Underhill C, Wahlberg H, Warner R, Herrman H

Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers.

World Psychiatry (2011) 10(3):229-36.

Recovery in mental health – reshaping responsibilities

„Bring the joy back to work!“

Courtenay Harding

Centrality of Community Activities in a Network Analysis of Outcome-limiting Factors: Implications for Recovery-oriented Strategies

(EPA Mucci 2018 on JAMA 2018, Galderisi et al)

- **The present findings have substantial treatment implications:**

  - **Positive symptoms do not play a key role in the chain of factors leading to real-life functioning, thus highlighting the need for treatment beyond antipsychotics.**

  - **The pattern of network node connections supports the implementation of personalized interventions for individuals with schizophrenia**

UN-CRPD et al

indignation, conflict, and need for discussion

Being there, helping out, and deciding for somebody who cannot is a precious good in human life

(with the risk of unwanted effects)

- **broad discussions are necessary –**
  - **in easy language**
  - **in Trialogue**

In Trialog-groups ...

1. users and ex-users
2. carers and
3. mental health workers

- meet regularly
- in an open discussion forum,
- that is located on "neutral terrain"
- outside any therapeutic, familial or institutional context –

- with the aim of communicating about and discussing the experiences and consequences of mental health problems and ways to deal with them –
- on equal footing – as experts by experience and experts by training or both.

Dorothea Buck

Trialog

The Trialog experience is indicative of our capacity for gaining from serious discussions of adverse issues as well as the great possibilities of cooperative efforts and and coordinated action.

Together we are stronger!

Recovery in mental health
Implications for Scientific Responsibilities

- **Civil rights movement versus evidence base**
- ***'Any services, or treatments, or interventions, or supports must be judged in these terms – how much do they allow us to lead the lives we wish to lead'*** **(Repper & Perkins 2003)**
- **‚Research is better than rhetoric'** ***(Salde & Hayward 2007)***
- **Subjectivity** ***(Strauss 2008 - 'whether a field that systematically ignores a considerable amount of data can be considered an adequate science')***
- **Multiperspective evidence-base** ***(Rose et al 2006)***

Dorothea Buck
* 5.4.1917

Recovery and Evidence-based Policy *(EBP)*

- **Developing a multiple perspectives paradigm in mental health‘** *Rose D, Thornicroft G, Slade M, 2006*

  e.g.

  - **Service User Involvement in Mental Health Research** *(e.g.Wallcraft, Schrank, Amering, Eds, 2009)*
  - **European as well as Global Mental Health Action Plan 2013-2020**
  - **WPA-Best Practices in Working with Users and Carers (*Wallcraft et al, 2011)***
  - **Trialog – Together we are stronger!** *(Amering et al, 2012; www.trialogue.co)*

Recovery and Evidence base

- **Ressources in MH: scarcity, inequity, and inefficiency** *(Global Mental Health, Lancet, Saxena et al, 2007)*
- **25% patients with serious mental illness receive treatment consistent with evidence-based recommendations** *(Wang, 2000; Lehmann 2001; Anthony et al, 2003)*
- **Treatment gap (WHO)**
- **Global mental health/global medicalization discussion (e.g. INTAR)**

Persons with a diagnosis of schizophrenia:

- **mortality gap** *(Hoang et al, 2013)*
- **Underdiagnosis and undertreatment of serious medical conditions** *(Fagiolini et al, 2009)*

➢ **First person narrative exposure effective in changing attitudes of medical students** *(Corrigan, 2007; Mann & Himelein, 2008; Galletly & Burton, 2011)*

Mental Health Crisis Alternatives

- **ACT *(Test & Stein 1980)***
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- **Open dialogue *(Seikkula 2006)***
- **Psychiatric Advance Directives *(Amering et al, 2005)***

- **User-controlled crisis services**
- **Peer respites**

www.power2u.org

Alternatives Beyond Psychiatry (Stastny, Lehmann, 2007);

www.intar.org - International Network Toward Alternatives and Recovery

CRPD
Support for Self-determination

Support for self-determined life in the community, supported living, working, family life etc.

Support for decision-making:

Supported decision making instead of substitute decision making

Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 2017

III. Global Burden of Obstacles

C. 27-29

Biased use of evidence in mental health

Recovery in mental health
Implications for Scientific Responsibilities

Research issues

(W Anthony, ES Rogers, M Farkas, 2003)

Focus on outcomes that are critical to people's recovery,
e.g. randomized designs for individualized outcomes

Advance use of qualitative and non-traditional measures,
e.g. testing complex interventions

Focus on program principles and practices, *e.g. not only the what, but also the how* (Mike Slade et al)

Operationalize and test the underlying values in our field,
***e.g. values-based practice* (Bill Fulford et al);**
***human centered psychiatry* (Michael Musalek; Ron Wintrop)**

evidence-based practice and recovery-orientation

- ✓ **Speakers for the most disabled patients lobby for evidence-based practice initiatives with a focus on consumer protection.**
- ✓ **Recovered consumer activists lobby for recovery-orientation with a focus on consumer autonomy, choice, and hope.**
- ✓ **Most patients want and need both.**
- ➢ **Lobby together! Research both!**

(Frese et al, 2001)

Recovery and Effectiveness

- Evidence-based Medicine

- Health Economy

- Human Rights

‚from charity-based to rights-based‘

Recovery in mental health
Implications for Clinical Responsibilities

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‘It is key that people in recovery lead the way’

(Davidson et al 2007)

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www.euro.who.int

Effectiveness of one-to-one peer support for patients with severe mental illness – a randomised controlled trial

Mahlke, Priebe, Heumann et al, European Psychiatry 2017

Comparable results re quality of life, social functioning, hospitalisations

(secondary outcome measures)

Significantly higher scores of self-efficacy (primary oucome measure)

The central role of self-agency in clinicl recovery from first episode psychosis

Bjornestadt et al, 2016, Stavanger Hospital

Results

Main theme:

Establishment of subjective self-agency

Subordinate themes:

1. ***Environmental support and gentle pressure,***
2. ***Individually tailored assistance,***
3. ***Antipsychotic medication: relinquishing personal responsibility, and considerable side effects.***

Use of Coercive Measures during Involuntary Psychiatric Admission and Treatment Outcomes: Data from a Prospective Study across 10 European Countries.

McLaughlin P, Giacco D, Priebe S, 2017

'Use of forced medication was associated with patients being significantly less likely to justify their admission when interviewed after three months.'

'Of the three coercive measures, forced medication appears to be unique in its significant impact on patient disapproval of treatment.'

Recovery in mental health

User Involvement

- **Policy**
- **Planning of services**
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- **Evaluation of services**
- **Research**
- **Teaching**

e.g.

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- **More than 10.000 peer support staff in USA *(Davidson, 2012)***
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Implement
what we already know

‚Eigentlich bin ich ganz anders,
aber ich komme so selten dazu‘

Ödön von Horváth (1901-38)

~ ‚Really, I am quite different.
I just so rarely find the time.‘

Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 2017

… and the Special Rapporteur proposes five deliberate, targeted, and concrete actions as follows:

(a) Mainstream alternatives to coercion in policy with a view to legal reform;

(b) Develop a well-stocked basket of non-coercive alternatives in practice;

(c) Develop a road map to radically reduce coercive medical practices, with a view to their elimination, with the participation of diverse stakeholders, including rights holders;

(d) Establish an exchange of good practices between and within countries;

(e) Scale up research investment and quantitative and qualitative data collection to monitor progress towards these goals.

Shared Decision Making

Mike Slade, World Psychiatry, 2017

Re CEDAR Study *(Puschner et al, 2016)*:

‚In orther words, outcomes were best when clinicians supported patient-led decision making.‘

‚Can and should we socialize clinicians into a professional role which gives primacy to patient-led decision making? Clinical practice would need to be oriented towards supporting this type of patient empowerment with a recovery-oriented culture in mental health systems which promotes the normal entitlements of citizenship.‘

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Meta-Analysis IPS (Individual Placement and Support)

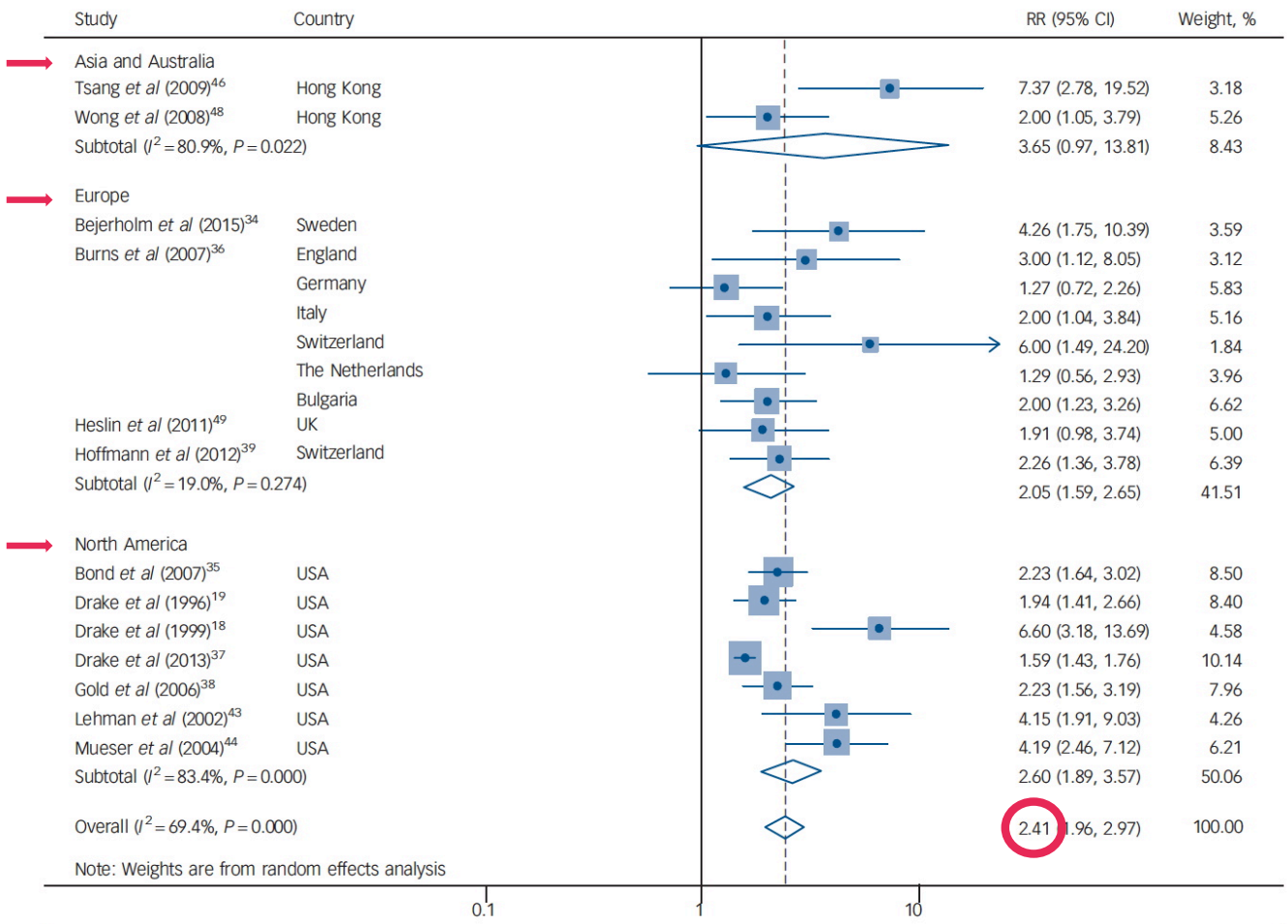

Fig. 4 Relative risk (RR) of competitive employment within 13–24 months of receiving individual placement and support compared with standard vocational rehabilitation.

Modini et al. 2016 in Holger Hoffmann, Bern, 2016

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‚psychosocial disability'

www.WNUSP.net

…. developed rights to non-discrimination in key areas, including employment, housing, education, health, standards of living and social, political and cultural participation, …. '

Bartlett, 2012

Recovery in mental health

Examples of new forms of clinical cooperations

- **Illness self-management**
- **Expert-patienthood**
- **Shared decision-making**

- **Personal diagnosis**
- **Personalized treatment**

- **Joint crisis plans, crisis cards, advance agreements**
- **Psychiatric advance directives**

- **Collaborative commitment for change**

CRPD
Support for Self-determination

Support for self-determined life in the community, supported living, working, family life etc.

Support for decision-making:

Supported decision making instead of substitute decision making

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www.power2u.org

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UN and Coercion in Psychiatry

Report of the UN Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, in February, 2013

General Comment on Article 12 of the CRPD - Equal Recognition before the Law – by the UN Committee on the Rights of Persons with Disabilities in May 2014

Report of the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Puras, in march 2017

UN-CRPD et al

indignation, conflict, and need for discussion

Being there, helping out, and deciding for somebody who cannot is a precious good in human life

(with the risk of unwanted effects)

- **broad discussions are necessary –**
  - **in easy language**
  - **in Trialogue**

MAXIMIZING SUPPORT FOR RECOVERY

- Peer Support workers/EX-IN
- Patientenverfügungen
- Wellness Recovery Action Plan (WRAP)
- Illness managment and Recovery (IMR)
- REFOCUS
- Strength model
- Recovery Colleges or recovery education programs
- Individual placement and supports
- Supported Housing
- Mental health Trialogues

Slade, Amering, Farkas et al, 2014

In Trialog-groups ...

1. users and ex-users
2. family carers and friends
3. mental health workers

- meet regularly
- in an open discussion forum,
- that is located on "neutral terrain"
- outside any therapeutic, familial or institutional context –

- with the aim of communicating about and discussing the experiences and consequences of mental health problems and ways to deal with them –
- on equal footing – as experts by experience and experts by training or both.

Dorothea Buck

Trialogue –

an exercise in communication between service users, carers, and professional mental health workers beyond role stereotypes

- people with a first hand lived experience
  (is there anybody without?)
- friends and family
  (is there anybody who is not?)
- people with a professional interest

! Nobody is left out !

Trialog

The Trialog experience is indicative of our capacity for gaining from serious discussions of adverse issues as well as the great possibilities of cooperative efforts and and coordinated action.

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A challenge

- Understanding the human rights perspective
- Appreciate the opportunities of the human rights perspective

- local
- national
- international

- for specific groups (e.g. women and girls, Persons with disabilities)
- for specific concerns (e.g. trade union organization)

- for all people
- as a potentially unifying political perspective

New thinking

To appreciate the significance and the potential of the CRPD, one need only think of the human rights challenges of another "group" – in fact the world's majority:

Legal capacity and non-discrimination, but importantly the right to act legal capacity: Article 15 of the Convention on the Elimination of All Forms of Discrimination Against Women, has and continues to have enormous consequences for societies worldwide.

Schulze, 2010; Amering & Schulze, 2013

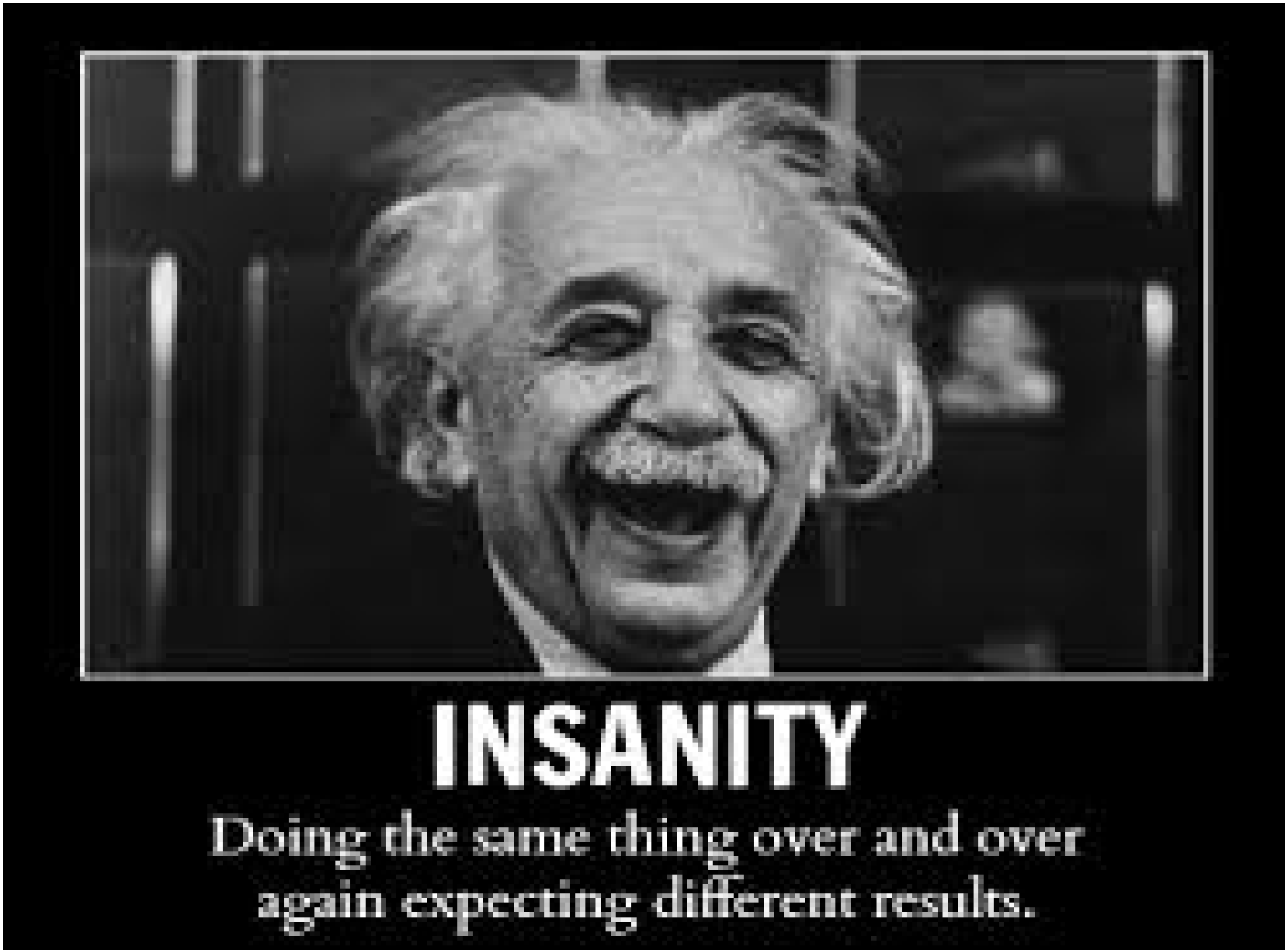
New thinking. and new acting.

And while there is still much left to do in gender equality, we are all aware that these developments are irreversible.

Currently it is the CRPD, which is causing significant societal processes, which require us to question old mantras and radical new thinking as well as acting, also in the field of psycho-social issues.

Schulze 2010; Amering & Schulze, 2013

Myth or reality?



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Recovery and Human Rights

- **Self-determination as a health ressource**

  (WHO Ottawa Charter, 1986)

- **Dignity of Risk** ***(Pat Deegan, 1996)***
- **Right to Make Mistakes** ***(Ron Coleman)***

- **Non-Discrimination:**
  UN Convention on the
  Rights of Persons with Disabilities
  (CRPD, 2006)

Nothing about Us Without Us!

CRPD Art. 4 (3) In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes, concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

CRPD Art 33 (3) Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

‚from charity-based to rights-based‘

Border Crossings

Border Crossings? Knowledge Production by Survivors of Psychiatry in Self-help and Advocacy, Survivor/User-led Research or Co-produced Research

9 October 2017 – 18:30 to 23.30– free event at the community centre ''Haus Eichkamp'', in 5 minutes' walking distance from the WPA XVII World Congress of Psychiatry Berlin 2017

Dorothea Buck
* 5.4.1917

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Recovery in mental health
Implications for Clinical Responsibilities

„Bring the joy back to work!“

Courtenay Harding

Reshaping Responsibilities

Recovery in Remitted First-Episode Psychosis at 7 Years of Follow-up of an Early Dose Reduction/Discontinuation or Maintenance Treatment Strategy

Long-term Follow-up of a 2-Year Randomized Clinical Trial

Lex Wunderink, MD, PhD; Roeline M. Nieboer, MA; Durk Wiersma, PhD; Sjoerd Sytema, PhD; Fokko J. Nienhuis, MA

Robin M. Murray, Diego Quattrone, Sridhar Natesan, Jim van Os, Merete Nordentoft, Oliver Howes, Marta Di Forti and David Taylor (2016)

Should psychiatrists be more cautious about the long-term prophylactic use of antipsychotics?

The British Journal of Psychiatry 209, 361–365

Reshaping Responsibilities

"If I had the chance to have a second career, I would try harder not to follow of the fashion of the herd. The mistakes I have made, at least those into which I have insight, have usually resulted from adhering excessively to the prevailing orthodoxy."

Murray, R. M., (2016). Mistakes I have made in my research career. *Schizophrenia Bulletin*.

Recovery in mental health
Implications for Clinical Responsibilities

„Bring the joy back to work!“

Courtenay Harding

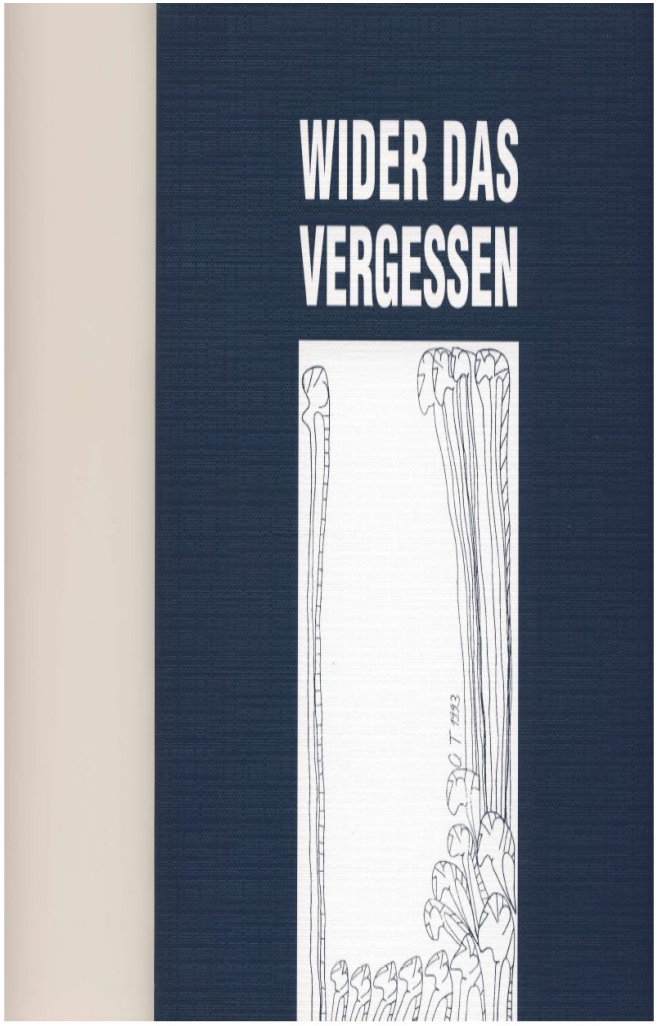
Dorothea Buck *1917

talks about how she *‘experienced the psychiatric system as so inhumane, because nobody spoke with us. A person cannot be more devalued than to be considered unworthy or incapable of conversation.’*

‚Seventy Years of Coercion in German Psychiatric Institutions, Experienced and Witnessed‘
Key-note at 2007 World Congress of Psychiatry

Discrimination and exclusion – then and now

In Austria Harald Hofer, a prominent survivor activist, focused in a commemorative speech 1995 on a *'conspiracy of indifference'* as the obstacle to recognizing victims of discrimination and exclusion - not only historically but also today.



Dorothea Buck, * 1917

- Sculptor, free artist, teacher at the Technical College for Social Pedagogy in Hamburg from 1969-1982.
- Since 1970, active in the self-help movement.
- 1992 – co-founder of the Federal Association of (ex-) Users and Survivors of Psychiatry now Honorary Chair.
- 1989 – co-founder of the 'Psychosis-Seminars'/Trialogues.

- Countless lectures in Germany and abroad and contributions in specialised journals and anthologies.

Dorothea Buck, * 1917

- **1997 – awarded with the "Bundesverdienstkreuz erster Klasse" (decoration of the Federal Republic of Germany for service to the community).**

- **2008, awarded with the Großes Verdienstkreuz des Verdienstordens der Bundesrepublik Deutschland, the greatest decoration of the Federal Republic of Germany for service to the community.**

- **Publications include:**

***On the Trail of the Morning Star: Psychosis as Self-discovery*, 1990;**

***Don't Give up: Texts 1968-2001*, 2002);**

Alternatives Beyond Psychiatry, published by Peter Lehmann Publishing

The Sky and Beyond – On the Trail of Dorothea Buck. Film by Alexandra Pohlmeier, 2008

Dorothea Buck *1917

- **5 stays in psychiatric hospitals between 1936 and 1959**
- **subjected to various forms of coercion, such as forced sterilization, cold wet sheet packs and forced injections and was never granted a single talk about the origin or meaning of her psychotic episodes.**
- **Facing the historical development of psychiatry and its effects on today's mental health system, she challenges a psychiatry, which rejects communication with patients**
- **She demands a paradigm shift toward a psychosocial system based on the wealth of patients' experiences and provides alternatives, such as the therapeutic principles of *Soteria* and Yrjö Alanen's *Need-Adapted Treatment*.**

www.bpe-online.de/english/dorotheabuck.htm

Dorothea Buck

„Seventy Years of Coercion in German Psychiatric Institutions, Experienced and Witnessed“

Key-note speech from June 7, 2007 at the congress "Coercive Treatment in Psychiatry: A Comprehensive Review", WPA, Dresden, Germany, June 6 - 8, 2007

youtube

www.bpe-online.de/english/dorotheabuck.htm

Stastny P/ Lehmann P (Eds.) Alternatives Beyond Psychiatry. Shrewsbury (UK): Peter Lehmann Publishing 2007

Recovery - CHIME *(Slade et al., 2012)*

Connectedness - with other people, but also with the wider community and to society as a whole;

Hope, usually defined as vital for recovery and referring to one's own outlook as well as that of people around and also that of mental health services and their staff;

Identity referring to a process of redefining and rebuilding a positive sense of self;

Meaning in terms of finding meaning in life and also meaning associated with the mental illness experience and ways to find meaning through social roles, goals, employment and meaningful activities;

Empowerment relating to a sense of empowerment within mental health services as well as in personal life and life in society.

President of the German Association for Psychiatry and Psychotherapy Frank Schneider in 2010

'I stand before you today as President of an association that has taken nearly 70 years to end this silence and recall the tradition of enlightenment through science in which it stands.

www.dgppn.de/english-version/history/psychiatry-under-national-socialism.html

President of the German Association for Psychiatry and Psychotherapy Frank Schneider in 2010

'….. In the name of the German Association for Psychiatry and Psychotherapy,

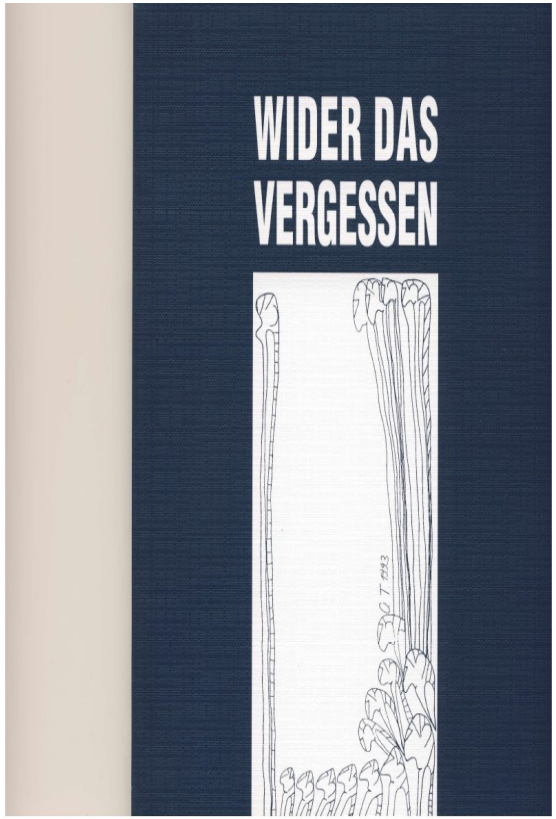
I ask you, the victims and relatives of the victims, for forgiveness for the pain and injustice you suffered in the name of German psychiatry and at the hands of German psychiatrists under National Socialism,

and for the silence, trivialisation and denial that for far too long characterised psychiatry in post-war Germany.'

www.dgppn.de/english-version/history/psychiatry-under-national-socialism.html

Dorothea Buck talks about how she *'experienced the psychiatric system as so inhumane, because nobody spoke with us. A person cannot be more devalued than to be considered unworthy or incapable of conversation.'*

In Austria the similarly difficult process of ending the silence following the same atrocities was greatly enhanced by the efforts of Harald Hofer, a prominent user/survivor activist. He focused in a commemorative speech 1995 on a *'conspiracy of indifference'* as the obstacle to recognizing victims of discrimination and exclusion - not only historically but also today.



In Trialog-groups ...

1. users and ex-users
2. carers and
3. mental health workers

- meet regularly
- in an open discussion forum,
- that is located on "neutral terrain"
- outside any therapeutic, familial or institutional context –

- with the aim of communicating about and discussing the experiences and consequences of mental health problems and ways to deal with them –
- on equal footing – as experts by experience and experts by training or both.

Dorothea Buck

Trialog - „Its normal to be different“

Bock Th, Buck D, Esterer I, Psychiatrie Verlag, Bonn, 1997

- **First Trialog in Hamburg in 1989**
- **well over 150 groups in Germany today**
- **~ 5000 people involved in Trialogue at any given time**
  (Bock & Priebe, 2005)

- **Trialogues in Austria, Switzerland, France, Lichtenstein, Poland; WPA Istanbul, Beijing, Buenos Aires et al**
- **Growing interest in english-speaking countries**
- **Mental Health Trialogue Network, Ireland – www.trialogue.co**

‚This openness must continue‘ -
Changes through trialogue identified by users, carers, and workers

von Peter S, Schwedler H-J, Amering M, Munk I (2014)

- **Communication in trialogue groups is clearly different from clinical encounters.**
- **All three groups cherish and aspire to interest for each other, good will and openness.**
- **Daily clinical routine with role prescriptions, power balance and constant pressure to act is experienced as an obstacle.**

➢ **Trialog facilitates a discrete and independent form of communication and acquisition and production of knowledge.**

Psychiatric Advance Directives (PAD): continuity of identity

„... that I have people, whom I have told: If I get ill,

I need you front and center to

remind people of who I am,

so that they do not get angry with me“

Amering M, Stastny P, Hopper K (2005) British Journal of Psychiatry

Recovery in mental health
Working in partnership

‚Recovery based practice is the synthesis of professional and lived experience knowledge bases, and is not simply an additional aspect to the way we already deliver services.

If recovery based practice knowledge is to be authentically developed then it will require constant attention to the synthesising of professional and lived experience knowledge, ultimately fusing into a shared knowledge base."

Helen Glover, 2005

Psychiatry

‚Eigentlich bin ich ganz anders,
aber ich komme so selten dazu‘

Ödön von Horváth

~ ‚Really, I am quite different.
I just so rarely find the time.‘

PADs - a complex process

- **procedural justice**
- **capacity building**

- **voluntarism** ***(Roberts, 2002)***

  possibly undermined by „pushed timing“

- **systemic commitment**
- **change in professional culture**

Amering, Stastny, Hopper, BJP 2005

Change in professional culture

F-PAD

Kim MM, Van Dorn RA, Scheyett AM, Elbogen EE, Swanson JW, Swartz MS, McDaniel LA (2007) Understanding the personal and clinical utility of psychiatric advance directives: a qualitative perspective. Psychiatry 70: 19-29

1. **PADs as tools for empowerment and self-determination**
2. **Limited knowledge of PADs among service providers**
3. **Difficulties communicating PADs to inpatient staff**

Kim MM et al (2007)
Understanding the personal and clinical utility of psychiatric advance directives: a qualitative perspective.

„In general, many participants expressed enthusiasm of the implementation of PADs but concern regarding clinicians' general lack of awareness about them.

Additionally, some consumers discussed discomfort in even mentioning that they had a PAD to clinicians for fear of a negative response from them, or some type of involuntary treatment during their hospitalization. “

Kim MM et al (2007)
Understanding the personal and clinical utility
of psychiatric advance directives: a qualitative perspective.

„Therefore, when working with individuals in psychiatric crisis who have a PAD, and who have never before experienced a sense of control over their own treatment, clinicians must recognize the potential ly troubling disequilibrium this sense of control may engender. “

The central role of self-agency in clinicl recovery from first episode psychosis

Bjornestadt et al, 2016, Stavanger Hospital

Results

Main theme:

Establishment of subjective self-agency

Subordinate themes:

1. ***Environmental support and gentle pressure,***
2. ***Individually tailored assistance,***
3. ***Antipsychotic medication: relinquishing personal responsibility, and considerable side effects.***

The central role of self-agency in clinicl recovery from first episode psychosis

Bjornestadt et al, 2016, Stavanger Hospital

Conclusions

We suggest that an increase in sense of personal agency is a core mechanism driving recovery for participants in the study sample.

Findings indicate that interventions aiming to boost subjective and behavioral agency in service users might be of great benefit, particularly in combating negative symptoms of psychosis.

Slade, Amering, Farkas et al (2014)
World Psychiatry 13:1

Maximize support for Recovery:

1. **peer support workers**
2. **advance directives**
3. **wellness recovery action planning**
4. **illness management and recovery**
5. **REFOCUS**
6. **strengths model**
7. **recovery colleges or recovery education programs**
8. **individual placement and support**
9. **supported housing**
10. **mental health trialogues.**

responsibilities

- Therapeutic relationship (including breaking rules und sprache ev.)
- Service provision (incl. UI incl. peers can strengthen the view… in teams …..
- Quality Assurance, evaluation (incl. UI)
- Policy (=problemsUSA und CRPD)

Stigma Resistance in Patients With Schizophrenia

Sibitz I, Unger A, Woppmann A, Zidek T, Amering M (2011)
Schizophr Bull 37(2):316-23

Two thirds of all participants (N=158) hold stigma resisting convictions.

SR is a seperate construct, ISMI and SR are not simply different sides of the same coin.

SR correlated positively with self-esteem, empowerment and quality of life and negatively with stigma measures and depression. Noteworthy exception: discriminiation experience.

A social network with enough friends, being single or married in contrast to being separated, and outpatient treatment were associated with higher SR.

Stigmaresistance qualitative study

(32 interviews; Sibitz, Schrank, Kollmann, Amering) -

- **With a diagnosis of schizophrenia stigma is omnipresent and people have to deal with it on an everyday basis.**

- **To be completely stigma resistant would be ideal, but it is a utopia since the stigma in society is enormous.**

➢ **Its a long way to stigma resistence – life long**

➢ **Its a hard way to stigma resistence – courage, stamina, good advice !!!**

➢ **ordinary *and* extraordinary – 3 levels of expertise needed**

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Stigmaresistance qualitative study

(32 interviews; Sibitz, Schrank, Kollmann, Amering) -

‚ordinary and extraordinary'

(1) The processes of development of stigma resistance described by our interview partners involve the common generic topics regarding the development of a mature personality and safe life circumstances on the one hand.

(2) On the other hand the specifics of having to deal with stigma and discrimination do taint all aspects of life.

(3) Moreover, the specifics of stigma and discrimination with regards to schizophrenia warrant further specific attention.

Therefore interventions needed to increase stigma resistance need to cover expertise for all three aspects.

What‘s Wrong?

1 “because people are not gonna believe what you are saying because you are mental, so they are not gonna believe you, so you gonna definitely have proof.”

4 “doctors are reluctant to sign this. They will also be reluctant to give you proof.”

1 “doctors don’t go against another doctor.”

Whats Wrong with Us?

„Doctors don‘t listen“

„At the mercy of a duty nurse who thinks it‘s his duty to tell people no“

What‘s Wrong with Us?

"So many times we ask our mental health professionals to be our ‚Holders of Hope‘.

Sadly most of them however can't be our ‚Holders of Hope‘ because they come from the 'mind set' that ‚I do not believe that you can recover, therefore you cannot recover'".

Helen Glover

JAMA Psychiatry. 2013;70(9):913-920

Recovery in Remitted First-Episode Psychosis at 7 Years of Follow-up of an Early Dose Reduction/Discontinuation or Maintenance Treatment Strategy

Long-term Follow-up of a 2-Year Randomized Clinical Trial

Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

CONCLUSIONS AND RELEVANCE Dose reduction/discontinuation of antipsychotics during the early stages of remitted FEP shows superior long-term recovery rates compared with the rates achieved with MT. To our knowledge, this is the first study showing long-term gains of an early-course DR strategy in patients with remitted FEP. Additional studies are necessary before these results are incorporated into general practice.

Therapeutic relationship and severe mental disorders

- ✓ **Predictive power for outcome in different patient groups and different settings**

- ✓ **Large general factor accounting for 2/3 of relationship variances**

  ? additional specific factors

McCabe & Priebe, 2004

Recovery is currently mental health policy in important english-speaking countries

(e.g. USA, CAN, UK, AUS)

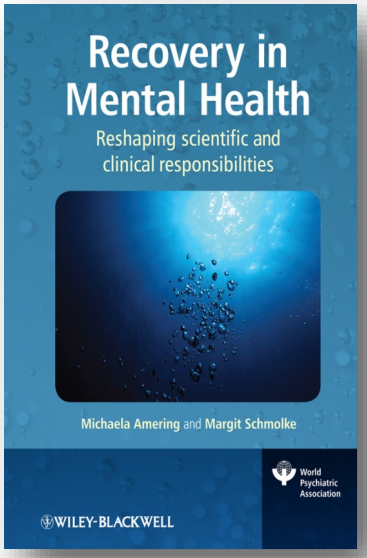
US Commission on Mental Health 2003 requests that:

‚… everyone … at any stage of life has access to effective treatment and supports – essentials for living, working, learning, and participating fully in the community ‘:

Overcoming:

1. **Stigma that surrounds mental illnesses,**
2. **Unfairness in health insurance, and**
3. **Fragmented mental health service delivery system**

Amering & Schmolke, 2009



PORT (Schizophrenia Patient Outcomes Research Team, 2009) through a Recovery Lens *Davidson, 2010*

'It is worth noting, in support of this perspective, that those interventions reviewed by Dixon et al (2009) that had the most robust effect sizes were those that supported people in occupying normative adult roles while continuing to suffer from mental illness.

Arguably, the most effective breakthroughs in psychiatric practice for people with schizophrenia ……

……. in development of the psychiatric rehabilitation practices of supported housing and supported employment.'

UN-CRPD and Rehabilitation

Article 19 - Living Independently And Being Included In the Community

Article 24 – Education

Article 26 - Habilitation and rehabilitation

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

Article 29 - Participation in political and public life

Article 30 - Participation in cultural life, recreation, leisure and sport

Article 31 - Statistics and data collection

Article 32 - International cooperation

CRPD Article 23
Respect for Home and the Family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

(a) …… marriage …

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

(c) …… fertility …

CRPD Article 23
Respect for Home and the Family

2. …….

States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. …..
4. …..
5. …..

The experience of Australian parents with psychosis

(N=1825; Campbell et al, 2012)

Over half of all women and a quarter of men are parents.

In contrast with general decline this proportion rising.

24% of women, 6 % of men living with children.

Most parents living with psychosis function well.

A significant proportion has impairments in parenting and general functioning that could have adverse consequences for both the parent and children.

Need for interventions to optimise successful parenting outcomes.

Custody loss ***(50% Schizophr, Seemann, 2012; 15% UMB-SMF, 2013)***

Supported Parenting ***(David, Styron, Davidson, 2011)***

INDEPENDENT BUT NOT ALONE

A GLOBAL REPORT ON THE RIGHT TO DECIDE

Inclusion International 2014

Recovery in mental health
Definition - *Anthony*

"… a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles.

It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness.

Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"

Anthony, 1993

Recovery Definition
Bill Anthony, 1993/Jan Wallcraft, 2012

'Recovery from mental illness involves much more than recovery from the illness itself.

People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams.

ABUSE 4. Compulsory detention and treatment aid Recovery
Zwangsunterbringung und –behandlung helfen Recovery

- ***UN-Convention on the Rights of Persons with Disabilities***

- *Rates and methods of coercion are very variable*
- *Given the right values, incentives and leadership, the use of coercion can be dramatically reduced*
- *Non-coercive hospital alternatives can provide effective treatment to a very large proportion of those who would otherwise need hospital care* *Warner, 2014*

Slade, Amering, Farkas et al, 2014

Zwang

Dramatische Reduktion von Isolierungen und Beschränkungen in USA durch Veränderung der Vorschriften ***(Warner, 2011)***

Fusion of mental health and incapacity legislation

(Dawson and Szmukler, 2006, Br J Psychiatry)

BRD Diskussion 2012/2013 ***(z.B. Zinkler)***

"I never thought this could happen to me"–

Impact of coercive measures on life stories: qualitative study.
Sibitz I, Scheutz A, Lakeman R, Schrank B, Schffer M, Amering M
(2011) British Journal of Psychiatry

- ***a necessary emergency brake***
- ***an unnecessary overreaction***
- ***a treatment in need of improvement***

- ***over and not to be recalled***
- ***a life-changing experience***
- ***motivation for political engagement***

The diverse and differentiated perspectives on coercive measures and the different styles of integration suggest that people may come to accept coercive measures as necessary when confronted with danger to self or others.

However, the implementation of coercion needs to be improved substantially to counteract possible long-term adverse effects.

Richard Warner

World Congress of Psychiatry, Madrid, 2014

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- ***motivation for personal/political engagement***

Empowerment and Recovery

- Recovery through Empowerment
- Empowerment through Recovery

Recovery und Menschenrechte

- **Selbstbestimmung als Gesundheitsressource**

  ‚Gesundheitsförderung zielt auf einen Prozess, allen Menschen ein höheres Maß an Selbstbestimmung über ihre Lebensumstände und Umwelt zu ermöglichen und sie damit zur Stärkung ihrer Gesundheit zu befähigen‘
  (WHO Ottawa Chart, 1986)

- **Die Würde des Risikos** ***(Recovery; Pat Deegan, 1996)***
- **Das Recht Fehler zu machen** ***(Ron Coleman, 1999)***

- **Nicht-Diskriminierung:**
  UN Konvention über die Rechte von Menschen mit Behinderungen (CRPD, 2006)

UN-BRK – Beispiele für Veränderungen

- **Sachwalterschaft/Guardianship/Betreuung**
- ***‚The intrusiveness of guardianship law on the individual's life means that implementation of Article 12 has been identified as a particular priority by the UN High Commissioner for Human Rights. Consistant with the social model of disability adopted in the CRPD, the focus is on provision of support, so that people with disabilities can make their own decisions.‘*** **Bartlett, 2012**

- **Supported decision making models (e.g. Canada, Sweden)**
- **Pilotprojekt zur unterstützten Entscheidungsfindung in Österreich**

- **Bildung und Arbeit – *Sonderschulen, ‚reasonable accomodation‘***

Alternativen für Krisen

- **ACT *(Test & Stein 1980)***
- **Home treatment *(Burns et al 2002)***
- **Crisis families *(Carling 1994)***
- **Soteria *(Ciompi & Hoffmann 2004)***
- **Open dialogue *(Seikkula 2006)***
- **Need adapted treatment *(Alanen, 1997)***

- **User-controlled crisis services**

Alternatives Beyond Psychiatry (Stastny & Lehmann, 2007)
Statt Psychiatrie (Lehmann & Stastny, 2007)
www.intar.org International Network Toward Alternatives and Recovery

Recovery and evidence-based interventions

- **25% patients with serious mental illness receive treatment consistent with evidence-based recommendations or guidelines** ***(Wang et al, 2000)***
- **Similar findings for schizophrenia** ***(Lehmann, 2001)***
- **Resources for mental health: scarcity, inequity, and inefficiency** ***(Global Mental Health, Lancet, Saxena et al, 2007)***
- **Treatment gap ~ 50% in ‚western industrialzed countries‘** ***(WHO mhGAP 2008)***

Recovery in mental health
Implications for Clinical Responsibilities

- **Sharing**
- ***Trialog – german speaking countries***
- ***Open Dialogue - Finnland***
- ***Shared Vision – NIoMH/UK***
- ***Sharing Voices – Bradford/UK***

- **Alternatives**
- ***Yearly conferences since 1985***

  2008: ‚Creating Community Through Active Citizenship‘
- ***‚Alternatives Beyond Psychiatry‘ (Stastny/Lehmann, 2007)***
- ***International Network Toward Alternatives and Recovery - INTAR***

ABUSE 5.

Recovery Orientation means closing services
Recovery-Orientierung bedeutet Hilfen reduzieren und Einrichtungen schliessen

- **social roles *versus* symptomatology**
- **leading a meaningful life *versus* service use reduction**

Slade, Amering, Farkas et al, 2014

Through the Recovery Support Strategic Initiative, SAMHSA has delineated four major dimensions that support a life in recovery:

- ***Health***: overcoming or managing one's disease(s) or symptoms and for everyone in recovery, making informed, healthy choices that support physical and emotional wellbeing.
- ***Home:*** a stable and safe place to live;
- ***Purpose:*** meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society; and
- ***Community***: relationships and social networks that provide support, friendship, love, and hope.

ABUSE 6.

Recovery is about making people independent and normal

Recovery heisst Leute unabhängig und normal machen

'The … "right to live independently and to be included in the community" (Article 19 CRPD) … is not contingent on "getting better" or living without support, and explicitly includes the right to access the "assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation".'

Slade, Amering, Farkas et al, 2014

Why is the UN Convention on the Rights of Persons with Disabilities (CRPD) important?

‚psychosocial disability', ‚a major victory'

www.WNUSP.net

…. Developed rights to non-discrimination in key areas, including employment, housing, education, health, standards of living and social, political and cultural participation, along with the right to be free from exploitation, violence and abuse, …. '

….. , the refocusing of lawyers and legal academics towards their community rights is long overdue.

Bartlett, 2012

ABUSE 7. Contributing to society happens only after the Person is recovered. Zur Gesellschaft beitragen erst nach Recovery.

CRPD

Article 24 – Education

Article 26 - Habilitation and rehabilitation

Article 27 - Work and employment

Article 28 - Adequate standard of living and social protection

Article 29 - Participation in political and public life

Article 30 - Participation in cultural life, recreation, leisure and sport

Slade, Amering, Farkas et al, 2014

‚First place then train‘

Instead of

‚First train then place‘

Meta-Analyse zum IPS

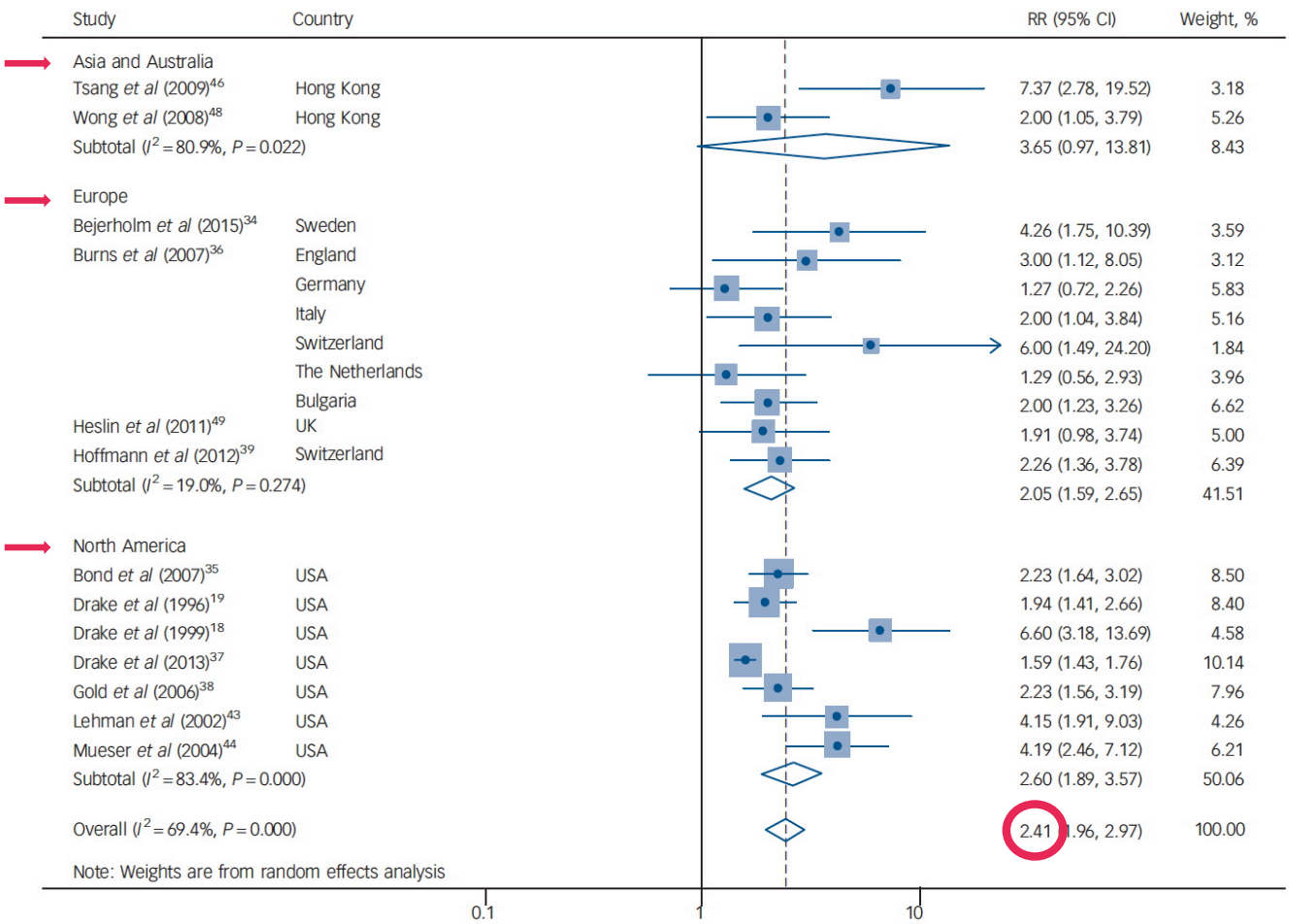

Fig. 4 Relative risk (RR) of competitive employment within 13–24 months of receiving individual placement and support compared with standard vocational rehabilitation.

Modini et al. 2016 in Holger Hoffmann, Bern, 2016

MAXIMIZING SUPPORT FOR RECOVERY

- Peer Support workers/EX-IN
- Patientenverfügungen
- Wellness Recovery Action Plan (WRAP)
- Illness managment and Recovery (IMR)
- REFOCUS
- Strength model
- Recovery Colleges or recovery education programs
- Individual placement and supports
- Supported Housing
- Mental health Trialogues

Slade, Amering, Farkas et al, 2014

Recovery in mental health

Definition

- **Process *versus* outcome**
- **Personal *versus* clinical**
- **Rehabilitative/social *versus* medical**
- **Consumer *versus* scientific**
- **‚in recovery' *versus* ‚recovering/recovered from'**

- **External factors *versus* internal factors**
- **Individual *versus* person in context**

- **Civil rights movement *or* mental health system guide**

Recovery in mental health

Definition

The national consensus statement of the Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services (SAMSHA) does not include the term 'mental illness':

'Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential.'

www.mentalhealth.samhsa.gov 2008

Recovery in mental health

Definition – *fundamental components*

SAMSHA's 10 fundamental components of recovery:

- **self-direction**
- **individualized and person-centered**
- **empowerment**
- **holistic**
- **non-linear**
- **strengths-based**
- **peer support**
- **respect**
- **responsibility**
- **hope**

www.mentalhealth.samhsa.gov 2008

MAXIMIZING SUPPORT FOR RECOVERY

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- Individual placement and supports
- Supported Housing
- Mental health Trialogues

Slade, Amering, Farkas et al, 2014

Recovery in mental health

‚Peer support is a key component of recovery‘

Shery Mead & Mary Ellen Copeland, 2005

‘It is key that people in recovery lead the way’

Practice Guidelines for recovery-oriented behavioral health care (Connecticut/US) ***(Davidson et al 2007)***

"As much as possible,
all servants are chosen from the category of mental patients.
They are at any rate better suited to this demanding work
because they are usually more gentle, honest an humane"

Jean Baptiste Pussin, in a 1793 letter to Philippe Pinel
(Superindendent of Bicêtre Hospice, Paris)

Davidson et al 2009; Roots of Recovery

Painting Tony Robert-Fleury

Peer support in Mental Health - Evidence and Experience

- **> 10.000 peer support staff in USA**

- **Research**

1. **Feasability studies; unspecific competencies =, >**

2. **Conventional roles (case manager, rehab and outreach workers) =, > difficult-to-reach-clients**

3. **Unique qualities:**

   Hope

   Role model

   Empathy

Davidson et al 2012, World Psychiatry

Peer Support: Evidence and Experience.

Davidson, 2014

- **First generation studies showed that it was feasible to hire people in recovery to serve as mental health staff**
- **Second generation studies showed that peer staff could generate equivalent outcomes to non-peer staff in similar roles**
- **Third generation studies are investigating whether or not there are unique contributions that peer support can make**

Uses and abuses of recovery:
implementing recovery-oriented practices in mental health systems

World Psychiatry 13:1 – February 2014

MIKE SLADE, MICHAELA AMERING, MARIANNE FARKAS, BRIDGET HAMILTON, MARY O'HAGAN, GRAHAM PANTHER, RACHEL PERKINS, GEOFF SHEPHERD, SAMSON TSE, ROB WHITLEY

Peer support workers

Slade, Amering, Farkas et al, World Psychiatry 2014

Informal peer support comes from natural supports such as family and friends. By contrast, formal peer support involves workers who are either

employed in autonomous peer-run services outside traditional mental health services, or partner with professionals within a traditional mental health or social service.

Peer support workers

Slade, Amering, Farkas et al, World Psychiatry 2014

Key features of their role are clear (Davidson et al, 2012), and implementation guidelines are now available (e.g. Repper 2013).

A substantial and positive evidence base now exists for

- **peer support services (Davidson et al, 2012),**
- **identifying the experience and benefits of being a peer support worker (Moran et al),**
- **changes in workplace structure made to sustain the delivery of peer support services (??)**
- **and description of changes initiated by peer support workers (e.g. choices, shared decision making).**

Peer support workers

Slade, Amering, Farkas et al, World Psychiatry 2014

Evidence from seven randomized controlled trials (RCTs) evaluating the impact of peer support workers found consistent benefits in relation to

clinical outcomes (engagement, symptomatology, functioning, admission rates),

subjective outcomes (hope, control, agency, empowerment) and

social outcomes (friendships, community connection) (Repper & Carter, 2011).

Peer support workers

Slade, Amering, Farkas et al, World Psychiatry 2014

RCTs on peer-led self-management interventions in the Netherlands (van Gestel-Timmermans et al, 2010) and USA (Cook et al, 2012ab) showed benefits in relation to

- **having a recovery role model, pursuing recovery, hopefulness,**
- **self-perceived recovery, symptom scores and quality of life.**

Peer support workers

Slade, Amering, Farkas et al, World Psychiatry 2014

A Cochrane review identified eleven randomized trials involving 2,796 people in three countries (Australia, UK, USA), showing equivalent outcomes from peer support workers compared with professionals employed in similar roles (Pitt et al, 2013)

Effectiveness of one-to-one peer support for patients with severe mental illness – a randomised controlled trial

Mahlke, Priebe, Heumann et al, European Psychiatry 2017

No differences re quality of life, social functioning, hospitalisations (secondary outcome measures)

Significantly higher scores of self-efficacy (primary oucome measure)

Recovery in mental health

Definition - *process*

'Recovery does not refer to an end product or result.

It does not mean that one is "cured" nor does it mean that one is simply stabilized or maintained in the community.

Recovery often involves a transformation of the self wherein one both accepts ones limitation and discovers a new world of possibility.

This is the paradox of recovery i.e., that in accepting what we cannot do or be, we begin to discover who we can be and what we can do.

Thus, recovery is a process. It is a way of life.'

Deegan, 1996

Recovery in mental health

Definition

'those who believe recovery is the absence of symptoms'

versus

,those who view recovery as a positive sense of self achieved in spite of continuing symptoms or in recognition of one's surmounting the social impact of illness' …..

,without necessarily calling for the absence of symptoms'.

(Onken et al 2007)

Recovery Definitions

Clinical *versus* **rehabilitative**

Davidson et al, 2007

Service-based *versus* **user-based**

Slade & Schrank, 2007

Peer Support: Evidence and Experience.

Davidson, 2014

- **First generation studies showed that it was feasible to hire people in recovery to serve as mental health staff**
- **Second generation studies showed that peer staff could generate equivalent outcomes to non-peer staff in similar roles**
- **Third generation studies are investigating whether or not there are unique contributions that peer support can make**

Galia Moran et al 2012-2014:

Employed peer providers experiences of their work role: potentials for unique processes of recovery and growth vs. personal challenges and environmental risks

Benefits ranged from improvement in functioning to self development. Growth processes included self acceptance, shedding of stigma and finding work as calling.

Quantitative and narrative analyses showed high scores on generativity - suggesting fulfilment and expression of the Eriksonian generativity developmental life stage.

Challenges experienced in peer work included emotional labor, building effective helping relationships, and their integration into traditional mental health systems.

Peer Support for Mothers - Data

Peer support and breastfeeding in LMIC: Systematic Review and Meta-Analysis *(Sudfeld, Fawzi, Lahariya, 2012)*:

- **Duration increased**
- **Research needed on timing and quantity of visist, integration in care packages, Formula Feeding Cultures**

Role modeling healthy behaviour: Peer Counselling for pregnant and postpartum women in addiction Recovery *(Sherman et al, 1998):* SISTERS:

- **more service use**
- **more satisfaction with counselor relationship**

Postpartum support Review *(Shaw et al, 2006)* :

- **Nurse home visits and Peer support both produced a significant reduction in depression scores of women at high risk.**

Recovery in mental health

User Involvement

- **Policy**
- **Planning of services**
- **Delivery of services**
- **Evaluation of services**
- **Research**
- **Teaching**

e.g.

- **Experienced Involvement = EX-IN in BRD, CH, A**
- **More than 10.000 peer support staff in USA *(Davidson, 2012)***
- **No research money without UI (UK, NOR)**

MAXIMIZING SUPPORT FOR RECOVERY

- Peer Support workers/EX-IN
- Patientenverfügungen
- Wellness Recovery Action Plan (WRAP)
- Illness managment and Recovery (IMR)
- REFOCUS
- Strength model
- Recovery Colleges or recovery education programs
- Individual placement and supports
- Supported Housing
- Mental health Trialogues

Slade, Amering, Farkas et al, 2014

Psychiatric Advance Directives (PAD): continuity of identity

„... that I have people, whom I have told: If I get ill,

I need you front and center to

remind people of who I am,

so that they do not get angry with me“

Amering M, Stastny P, Hopper K (2005) British Journal of Psychiatry

User involvement in mental health services

- ✓ in the interaction among service users - in the form of self-help
- ✓ in the interaction between individual users and professionals working with them
- ✓ in the management of local services
- ✓ in the training of staff
- ✓ in the planning of overall services
- ✓ in service evaluation

Tait & Lester, 2005

User involvement in mental health

- Policy

- Planning of services
- Delivery of services
- Evaluation of services

- Training
- Research

“its an extraordinary responsibility to fill out an AD”

“Its not just something. Its just too substantial a thing, too many aspects of your experience, that its just really hard”

M. Amering, P. Stastny, K. Hopper

“planning ahead”, “preparing for not getting sick”

“there is always something on record in case they don’t know what to do”

“I am willing to work with you and this is how I am willing to do that”

“...a contract…”

M. Amering, P. Stastny, K. Hopper

PADs - a complex process

- **procedural justice**
- **capacity building**

- **voluntarism** ***(Roberts, 2002)***

  possibly undermined by „pushed timing“

- **systemic commitment**
- **change in professional culture**

Amering, Stastny, Hopper, BJP 2005

Change in professional culture

F-PAD

Kim MM, Van Dorn RA, Scheyett AM, Elbogen EE, Swanson JW, Swartz MS, McDaniel LA (2007) Understanding the personal and clinical utility of psychiatric advance directives: a qualitative perspective. Psychiatry 70: 19-29

1. **PADs as tools for empowerment and self-determination**
2. **Limited knowledge of PADs among service providers**
3. **Difficulties communicating PADs to inpatient staff**

Kim MM et al (2007)
Understanding the personal and clinical utility of psychiatric advance directives: a qualitative perspective.

„In general, many participants expressed enthusiasm of the implementation of PADs but concern regarding clinicians' general lack of awareness about them.

Additionally, some consumers discussed discomfort in even mentioning that they had a PAD to clinicians for fear of a negative response from them, or some type of involuntary treatment during their hospitalization. “

Kim MM et al (2007)
Understanding the personal and clinical utility
of psychiatric advance directives: a qualitative perspective.

„Therefore, when working with individuals in psychiatric crisis who have a PAD, and who have never before experienced a sense of control over their own treatment, clinicians must recognize the potential ly troubling disequilibrium this sense of control may engender. “

Cochrane PADs 2009/2012
Campbell LA, Kisely SR

- **too few data**

- **no differences**

(other than less social worker time, less violent acts in PAD group)

Wegleitung ‚Patientenverfügung mit psychiatrischem Schwerpunkt' (2014)

I Allgemeine Hinweise

II Erläuterungen

A Personalien

B Diagnosen, Symptome, Beeinträchtigungen

C Meine Persönlichkeit

D Einweisung, Aufnahme und Behandlung

E Unterschriften

F Anhang

Impressum: Herausgeber Dr. Rene Bridler, Ärztlicher Direktor, Kilchberg, Schweiz

MAXIMIZING SUPPORT FOR RECOVERY

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- Mental health Trialogues

Slade, Amering, Farkas et al, 2014

Mary Ellen Copeland/USA:
Wellness and Recovery Action Plan (WRAP)

'Remembering Kate – A Story of Hope' ***(Copeland 2000)***

- ***When Mary Ellen was eight, her mother became ill at the age of 36 and spent the next eight years in a state mental institution diagnosed with a severe manic-depressive condition. The doctors said that she was incurable and would never recover.***
- ***Against all expectations, the mother did recover and stayed well until her death at the age of 82.***
- ***Mary Ellen assumes that one reason for her mother's improvement might have been the attention she received from a volunteer intern and another hospital worker, who had developed a particular interest in this patient.***
- ***Some of the mothering time she had lost with her own children, she devoted on very needy kids.***
- ***Her social net of mutual supports kept expanding, by the time she reached her old age she was embedded in loving relationships in her community, with friends, and a large family with 24 grand- and 19 greatgrandchildren.***

MAXIMIZING SUPPORT FOR RECOVERY

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Slade, Amering, Farkas et al, 2014

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Slade, Amering, Farkas et al, 2014

Dorothea Buck *1917

Dorothea Buck, * 1917

- Sculptor, free artist, teacher at the Technical College for Social Pedagogy in Hamburg from 1969-1982.
- Since 1970, active in the self-help movement.
- 1992 – co-founder of the Federal Association of (ex-) Users and Survivors of Psychiatry now Honorary Chair.
- 1989 – co-founder of the 'Psychosis-Seminars'/Trialogues.

- Countless lectures in Germany and abroad and contributions in specialised journals and anthologies.

Dorothea Buck, * 1917

- **1997 – awarded with the "Bundesverdienstkreuz erster Klasse" (decoration of the Federal Republic of Germany for service to the community).**

- **2008, awarded with the Großes Verdienstkreuz des Verdienstordens der Bundesrepublik Deutschland, the greatest decoration of the Federal Republic of Germany for service to the community.**

- **Publications include:**

***On the Trail of the Morning Star: Psychosis as Self-discovery*, 1990;**

***Don't Give up: Texts 1968-2001*, 2002);**

Alternatives Beyond Psychiatry, published by Peter Lehmann Publishing

The Sky and Beyond – On the Trail of Dorothea Buck. Film by Alexandra Pohlmeier, 2008

Dorothea Buck *1917

- **5 stays in psychiatric hospitals between 1936 and 1959**
- **subjected to various forms of coercion, such as forced sterilization, cold wet sheet packs and forced injections and was never granted a single talk about the origin or meaning of her psychotic episodes.**
- **Facing the historical development of psychiatry and its effects on today's mental health system, she challenges a psychiatry, which rejects communication with patients**
- **She demands a paradigm shift toward a psychosocial system based on the wealth of patients' experiences and provides alternatives, such as the therapeutic principles of *Soteria* and Yrjö Alanen's *Need-Adapted Treatment*.**

www.bpe-online.de/english/dorotheabuck.htm

Dorothea Buck

„Seventy Years of Coercion in German Psychiatric Institutions, Experienced and Witnessed“

Key-note speech from June 7, 2007 at the congress "Coercive Treatment in Psychiatry: A Comprehensive Review", WPA, Dresden, Germany, June 6 - 8, 2007

youtube

www.bpe-online.de/english/dorotheabuck.htm

Stastny P/ Lehmann P (Eds.) Alternatives Beyond Psychiatry. Shrewsbury (UK): Peter Lehmann Publishing 2007

President of the German Association for Psychiatry and Psychotherapy Frank Schneider in 2010

'I stand before you today as President of an association that has taken nearly 70 years to end this silence and recall the tradition of enlightenment through science in which it stands.

www.dgppn.de/english-version/history/psychiatry-under-national-socialism.html

President of the German Association for Psychiatry and Psychotherapy Frank Schneider in 2010

'….. In the name of the German Association for Psychiatry and Psychotherapy,

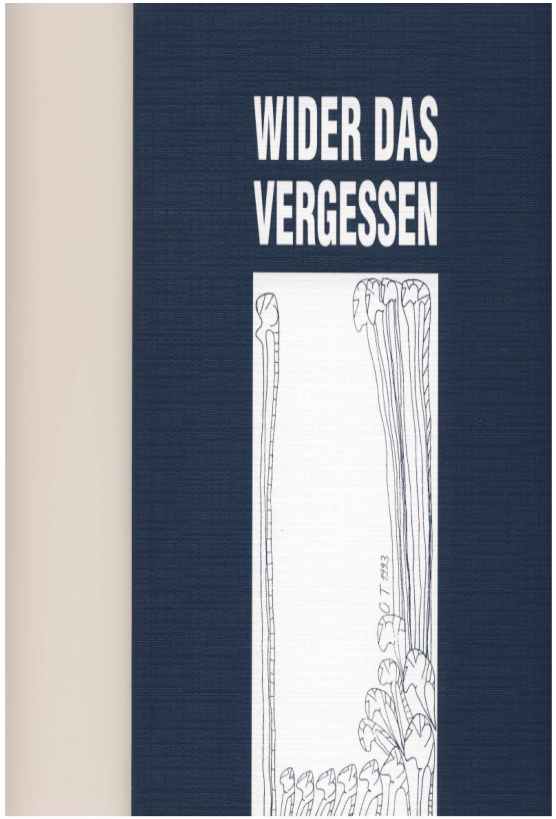
I ask you, the victims and relatives of the victims, for forgiveness for the pain and injustice you suffered in the name of German psychiatry and at the hands of German psychiatrists under National Socialism,

and for the silence, trivialisation and denial that for far too long characterised psychiatry in post-war Germany.'

www.dgppn.de/english-version/history/psychiatry-under-national-socialism.html

Dorothea Buck talks about how she *'experienced the psychiatric system as so inhumane, because nobody spoke with us. A person cannot be more devalued than to be considered unworthy or incapable of conversation.'*

In Austria the similarly difficult process of ending the silence following the same atrocities was greatly enhanced by the efforts of Harald Hofer, a prominent user/survivor activist. He focused in a commemorative speech 1995 on a *'conspiracy of indifference'* as the obstacle to recognizing victims of discrimination and exclusion - not only historically but also today.



In Trialog-groups ...

1. users and ex-users
2. carers and
3. mental health workers

- meet regularly
- in an open discussion forum,
- that is located on "neutral terrain"
- outside any therapeutic, familial or institutional context –

- with the aim of communicating about and discussing the experiences and consequences of mental health problems and ways to deal with them –
- on equal footing – as experts by experience and experts by training or both.

Dorothea Buck

Trialog - „Its normal to be different“

Bock Th, Buck D, Esterer I, Psychiatrie Verlag, Bonn, 1997

- **First Trialog in Hamburg in 1989**
- **well over 150 groups in Germany today**
- **~ 5000 people involved in Trialogue at any given time**
  (Bock & Priebe, 2005)

- **Trialogues in Austria, Switzerland, France, Lichtenstein, Poland; WPA Istanbul, Beijing, Buenos Aires et al**
- **Growing interest in english-speaking countries**
- **Mental Health Trialogue Network, Ireland – www.trialogue.co**

The "First Vienna Trialogue"
starting 1994

- **every second and fourth monday of the month**
- **10 to 40 people**
- **2 hours (+++)**
- **'neutral' ground**
- **rotating role of moderator**

Trialog - Topics

- Good and bad experiences with services
- Crisis management
- Stigma and discrimination
- Work and social inclusion
- Power, powerlessness, and empowerment
- When help has more unwanted than wanted effects
- Diagnosis as a trap – being put in a box
- Spirituality and mental health
- Silent users – who is helping them?
- Recovery

Trialogue groups differ from each other, e.g. re:

- Number of attendants
- Frequency of group meetings
- Ratio between the 3 groups

- Moderation/leadership
- Topics (free/preset/focus)

❖ recruitment (who is exposed to Info; who is specifically invited)

❖ proportion of long-term attendants/sporadic attendants

- circumstances of mental health professionals' attendance (working/training hours or private time)

Trialogue – qualities of possible impact

- Unusual setting
- all expertises acknowledged on equal footing
- no need for role compliance
- no obvious consequences

- Playful exchange and experiments with perspectives
- Learning, information gathering, asking questions
- Experiencing different interpretations of similar roles
- Abundance of expertise in one room

- ? Secure setting, rules, limits (time, communication style, …), power balance?

Trialogue
Research

- **Process**
- **Outcome (empowerment, self-esteem, connectedness, knowledge, attitudes, stigma resistance, …..?)**

- **Users**
- **Carers**
- **Workers**
- **Multiple roles**
- **Community**

- **Qualitative**
- **Quantitative**

‚This openness must continue‘ -
Changes through trialogue identified by users, carers, and workers

von Peter S, Schwedler H-J, Amering M, Munk I (2014)

- **Communication in trialogue groups is clearly different from clinical encounters.**
- **All three groups cherish and aspire to interest for each other, good will and openness.**
- **Daily clinical routine with role prescriptions, power balance and constant pressure to act is experienced as an obstacle.**

➢ **Trialog facilitates a discrete and independent form of communication and acquisition and production of knowledge.**

Psychiatry

‚Eigentlich bin ich ganz anders,
aber ich komme so selten dazu‘

Ödön von Horváth

~ ‚Really, I am quite different.
I just so rarely find the time.‘

Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, Javed A, Katontoka S, Raja S, Rataemane S, Steffen S, Tyano S, Underhill C, Wahlberg H, Warner R, Herrman H

Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers.

World Psychiatry (2011) 10(3):229-36.

Trialogue workshop WPA Beijing 2010

Trialogue –

an exercise in communication between service users, carers, and professional mental health workers beyond role stereotypes

- people with a first hand lived experience
  (is there anybody without?)
- friends and family
  (is there anybody who is not?)
- people with a professional interest

! Nobody is left out !

Trialogue – learning and preventing

- **A community with expertise in successful interventions with regard to secondary and tertiary prevention for persons with mental illness is likely to profit also in terms of primary prevention for the wider community.**

- **Learning about mental health and illness and helping community members with mental health problems can strengthen communities' mental health capacities and improve mental health literacy for everybody.**

- **The currently often hidden knowledge of a large part of the community – namely that of families and friends of people with mental health problems as well as the expertise of those who are dealing with or have overcome such problems in their own lives – should be validated and shared.**

Trialog

The Trialog experience is indicative of our capacity for gaining from serious discussions of adverse issues as well as the great possibilities of cooperative efforts and and coordinated action.

Together we are stronger!

Uses and abuses of recovery:
implementing recovery-oriented practices in mental health systems

World Psychiatry 13:1 – February 2014

MIKE SLADE, MICHAELA AMERING, MARIANNE FARKAS, BRIDGET HAMILTON, MARY O'HAGAN, GRAHAM PANTHER, RACHEL PERKINS, GEOFF SHEPHERD, SAMSON TSE, ROB WHITLEY

Slade, Amering Farkas et al (2014) Uses and abuses of recovery. World Psychiatry 13:1

An understanding of recovery as a personal and subjective experience has emerged within mental health systems. This meaning of recovery now underpins mental health policy in many countries. Developing a focus on this type of recovery will involve transformation within mental health systems. Human systems do not easily transform.

Slade, Amering Farkas et al (2014) Uses and abuses of recovery. World Psychiatry 13:1

In this paper, we identify seven mis-uses ("abuses") of the concept of recovery: recovery is the latest model; recovery does not apply to "my" patients; services can make people recover through effective treatment; compulsory detention and treatment aid recovery; a recovery orientation means closing services; recovery is about making people independent and normal; and contributing to society happens only after the person is recovered.

Slade, Amering Farkas et al (2014) Uses and abuses of recovery. World Psychiatry 13:1

We then identify ten empirically-validated interventions which support recovery, by targeting key recovery processes of connectedness, hope, identity, meaning and empowerment (the CHIME framework).

The ten interventions are peer support workers, advance directives, wellness recovery action planning, illness management and recovery, REFOCUS, strengths model, recovery colleges or recovery education programs, individual placement and support, supported housing, and mental health trialogues. Finally, three scientific challenges are identified: broadening cultural understandings of recovery, implementing organizational transformation, and promoting citizenship.

ABUSE 1. Recovery is the latest model
Recovery ist neueste Mode

- **Peers anzuheuern ohne andere Änderungen in Richtung Recovery-Orientierung kann deren Effektivität unterminieren.**

- **Personenzentrierung anstatt Institutionszentrierung**
  Lebensfeldorientierung, Kontinuität, Multidisziplinarität, Mobilität
- **Hoffnung, Zusammenarbeit FÜR Veränderung**
- **Selbsthilfe und Interessensvertretung**
- **Patientenrechte, Menschenrechte**

Slade, Amering, Farkas et al, 2014

ABUSE 2.
Recovery does not apply to ‚my' patients
Für ‚meine' PatientInnen ist das nichts

- **too ill**
- **not ill enough**

- **Psychosis**
- **Other diagnoses or contexts, e.g. eating disorders, Borderline, forensic, children, older patients, ethnic minorities**

Slade, Amering, Farkas et al, 2014

JAMA Psychiatry. 2013;70(9):913-920

Recovery in Remitted First-Episode Psychosis at 7 Years of Follow-up of an Early Dose Reduction/Discontinuation or Maintenance Treatment Strategy
Long-term Follow-up of a 2-Year Randomized Clinical Trial

Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

IMPORTANCE Short-term outcome studies of antipsychotic dose-reduction/discontinuation strategies in patients with remitted first-episode psychosis (FEP) showed higher relapse rates but no other disadvantages compared with maintenance treatment; however, long-term effects on recovery have not been studied before.

OBJECTIVE To compare rates of recovery in patients with remitted FEP after 7 years of follow-up of a dose reduction/discontinuation (DR) vs maintenance treatment (MT) trial.

JAMA Psychiatry. 2013;70(9):913-920

Recovery in Remitted First-Episode Psychosis at 7 Years of Follow-up of an Early Dose Reduction/Discontinuation or Maintenance Treatment Strategy

Long-term Follow-up of a 2-Year Randomized Clinical Trial

Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

DESIGN Seven-year follow-up of a 2-year open randomized clinical trial comparing MT and DR.

SETTING One hundred twenty-eight patients participating in the original trial were recruited from 257 patients with FEP referred from October 2001 to December 2002 to 7 mental health care services in a 3.2 million–population catchment area. Of these, 111 patients refused to participate and 18 patients did not experience remission.

JAMA Psychiatry. 2013;70(9):913-920

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Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

PARTICIPANTS After 7 years, 103 patients (80.5%) of 128 patients who were included in the original trial were located and consented to follow-up assessment.

INTERVENTION After 6 months of remission, patients were randomly assigned to DR strategy or MT for 18 months. After the trial, treatment was at the discretion of the clinician.

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Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

MAIN OUTCOMES AND MEASURES Primary outcome was rate of recovery, defined as meeting the criteria of symptomatic and functional remission. Determinants of recovery were examined using logistic regression analysis; the treatment strategy (MT or DR) was controlled for baseline parameters.

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Wunderink, Nieboer, Wiersma, Sytema, Nienhuis

RESULTS The DR patients experienced twice the recovery rate of the MT patients (40.4%vs 17.6%). Logistic regression showed an odds ratio of 3.49 (P = .01). Better DR recovery rates were related to higher functional remission rates in the DR group but were not related to symptomatic remission rates.

Einbeziehung der Betroffenen in die Versorgung

Persönliche Erfahrungen in Birmingham 2000-01

- **North Birmingham Mental Health Trust**
- **Betroffene als MitarbeiterInnen in allen Teams**

- **Betroffenen-geleitetes Krisenhaus**

- **Vermeidung von Gewalt in Aufnahmesituationen durch Teammitglieder mit eigener Erfahrung**

- **Betroffene als DozentInnen, SupervisorInnen**