

Recovery for real - relationer og samarbejde –

**Hvor kom vi fra – Hvor er vi nu – Hvor skal vi hen?
En rejse i det nationale og mentale recovery-
landskab**

Lisa Korsbek

”Recovery er tom og manipulerende retorik og et uvidenskabeligt pseudobegreb, der risikerer at gøre skade”.

Ugeskrift for læger 2005

Jeg husker et møde for 17-18 år siden, da jeg var lægechef på psykiatrisk sygehus i Hillerød. Her var en masse læger samlet for at høre en svensk og en dansk psykolog fortælle om recovery-tilgangen til patienterne.

Den svenske psykolog var meget skarp i sine formuleringer og radikal i sin tilgang. Jeg husker, at mange psykiatere sagde, at de slet ikke kunne forestille sig denne radikale recovery-tilgang overfor patienterne, fortæller han og trækker tråde op til i dag:

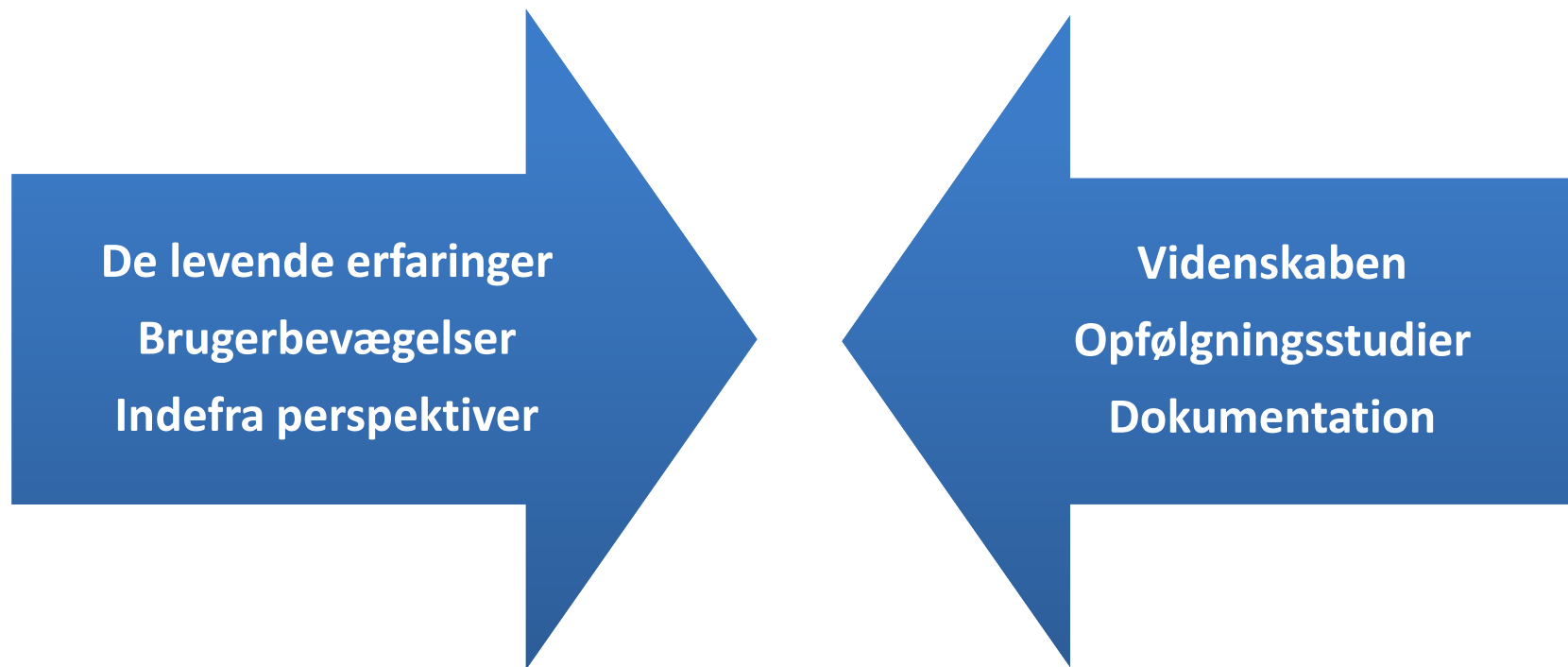
Når man så ser på, hvordan recovery-tilgangen lige så langsomt er blevet taget ind og hvordan vi lige så langsomt har arbejdet systematisk med det, så er jeg stolt over, at vi er nået så langt.

Mange af de ting som lægerne korsede sig over dengang er vi jo længst forbi – og vi er faktisk meget længere. Vi kan godt se patienterne i øjnene og sige: Vi tror på, der er håb. Og ikke bare tror på det, vi har en velbegrundet tro på, at der er håb for alle mennesker om et bedre liv.

Helt anderledes end det jeg blev opdraget til, da jeg startede som psykiater for 30-35 år siden”.

Hvor kom vi fra?

Recovery som en konkordans mellem
"new data" (evidens) og "consumer voices"/levede erfaringer/indefra-perspektivet



The Vermont Longitudinal Study of Persons With Severe Mental Illness, I: Methodology, Study Sample, and Overall Status 32 Years Later

Courtenay M. Harding, Ph.D., George W. Brooks, M.D., Takamaru Ashikaga, Ph.D., John S. Strauss, M.D., and Alan Breier, M.D.

The authors report the latest findings from a 32-year longitudinal study of 269 back-ward patients from Vermont State Hospital. This intact cohort participated in a comprehensive rehabilitation program and was released to the community in a planned deinstitutionalization effort during the mid-1950s. At their 10-year follow-up mark, 70% of these patients remained out of the hospital but many were socially isolated and many were recidivists. Twenty to 25 years after their index release, 262 of these subjects were blindly assessed with structured and reliable protocols. One-half to two-thirds of them had achieved considerable improvement or recovery, which corroborates recent findings from Europe and elsewhere.
(Am J Psychiatry 1987; 144:718-726)

Understanding of the long-term course and outcome of patients with prolonged psychiatric disorders is often thwarted by patient and clinician mobility (1, 2), short-term caseloads shaped by academic training and service delivery systems (3, 4), the magnitude of methodological hurdles (5-13), and disputes

over the classification of the disorders under study (10, 14-16). These conditions have produced sporadic, contradictory data and untested assumptions that undercut attempts to clarify the nature of psychiatric illness, erode the ability to target treatment interventions, and muddle efforts toward comprehensive public policies.

It is possible, however, to generate a longitudinal study that overcomes most of these obstacles (7, 17). What is required is an intact cohort of patients, selected for the established chronicity of their illness, who are prospectively followed over many years, with careful record keeping, structured and reliable protocols, operational definitions, and standardized assessments of psychopathology and psychosocial functioning. The Vermont longitudinal study meets these criteria.

Since the early 1950s, members of the Vermont Longitudinal Research Project have been prospectively following the course of an intact cohort of 269 patients from the back wards of Vermont State Hospital (7, 17-26) in much the same manner as the catamnestic studies of Manfred Bleuler at Burghölzli Hospital in Switzerland (27-33). Known in the literature as *The Vermont Story* cohort (26), the majority of these once profoundly ill, severely disabled, long-stay patients came from the sickest group in the hospital and met the DSM-I guidelines for the diagnosis of schizophrenia. They participated in an innovative pioneering rehabilitation program and were released to a hospital-run comprehensive community aftercare program between 1955 and 1965 (26).

Ten years after the inception of the program, we conducted a follow-up study, which indicated that two-thirds of the cohort were not hospitalized but were being maintained by heavy expenditures of clin-

Recovery from psychotic illness: a 15- and 25-year international follow-up study

G. HARRISON, K. HOPPER, T. CRAIG, E. LASKA, C. SIEGEL, J. WANDERLING, K. C. DUBE, K. GANEV, R. GIEL, W. AN DER HEIDEN, S. K. HOLMBERG, A. JANCA, P. W. H. LEE, C. A. LEÓN, S. MALHOTRA, A. J. MARSELLA, Y. NAKANE, N. SARTORIUS, Y. SHEN, C. SKODA, R. THARA, S. J. TSIRKIN, V. K. VARMA, D. WALSH and D. WIERSMA

Background Poorly defined cohorts and weak study designs have hampered cross-cultural comparisons of course and outcome in schizophrenia.

Aims To describe long-term outcome in 18 diverse treated incidence and prevalence cohorts. To compare mortality, 15- and 25-year illness trajectory and the predictive strength of selected baseline and short-term course variables.

Method Historic prospective study. Standardised assessments of course and outcome.

Results About 75% traced. About 50% of surviving cases had favourable

Study cohorts

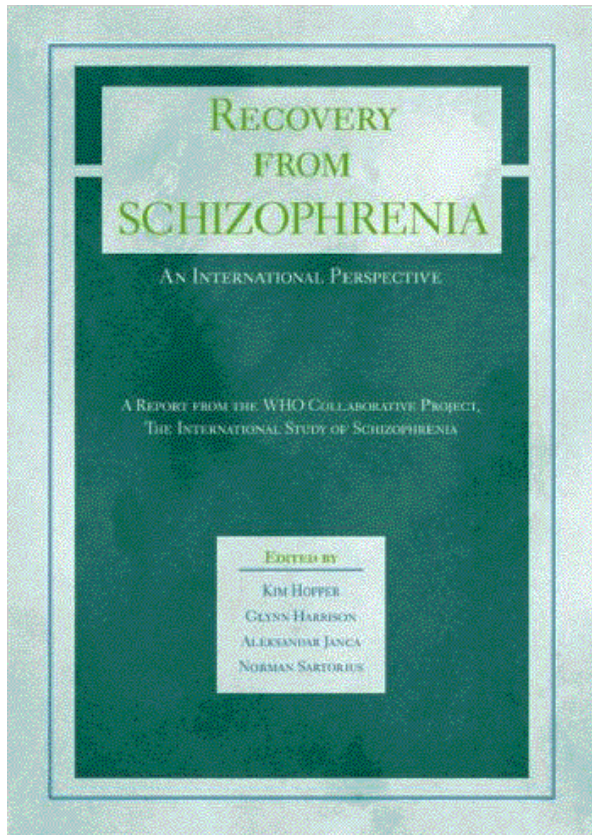
The International Study of Schizophrenia builds upon the results of earlier studies. The International Pilot Study of Schizophrenia (IPSS; WHO, 1973) reported better 2- and 5-year outcomes for patients in 'developing' centres. This finding was reinforced in the subsequent Determinants of Outcome of Severe Mental Disorders (DOSMeD) study (Jablensky *et al*, 1992), which traced treated incidence cohorts in geographically defined areas, using standardised methods of case finding and diagnosis. A third WHO study, the Assessment and Reduction of Psychiatric Disability (RAPyD; Wiersma, 1996), identified a further set of treated incidence case groups assembled from diverse catchment areas. These three cohorts offered a unique opportunity to carry out 15-year (DOSMeD, RAPyD) and 25-year (IPSS) follow-up studies. The cultural diversity of the sample was further enhanced by adding two incidence case groups and one prevalence case group to the field research centres (FRCs) recruited from the earlier studies (12 from DOSMeD and RAPyD, three from IPSS).

Table 1 lists the 14 treated incidence cohorts and four prevalence cohorts, totaling 1633 subjects. The treated incidence

In the last quarter of the 20th century, evidence for a more promising long-term course of schizophrenia accumulated across Swiss, German and British studies (Huber *et al*, 1975; Ciompi, 1980; Shepherd *et al*, 1989). Reconciling such findings with the sometimes markedly different picture reported in other studies is complicated, however, by unresolved design and measurement problems, including sampling biases, poor case definition, inadequate standardisation of outcome measures and differential attrition in follow-up.

Building upon earlier groundwork, the recently completed International Study of Schizophrenia (ISoS), coordinated by the World Health Organization (WHO), attempted to address these and related problems in a long-term follow-up study of 14 culturally diverse treated incidence

The International Study of Schizophrenia 2007



Skizofreni er ikke en homogen lidelse, hverken mht.:

- Symptomer
- Outcome/forløb
- Recovery-forløbet: Store individuelle forskelle mht. hvad der har betydning

but because our data are silent with respect to local cultural responses to early behavioural change, we cannot yet say how early intervention strategies might be designed to enhance their therapeutic impact.

The overarching message of ISoS is that schizophrenia and related psychoses are best seen developmentally as episodic disorders with a rather favourable outcome for a significant proportion of patients. Because expectation can be so powerful a factor in

recovery, patients, families and clinicians need to hear this. At the same time, the hope these data represent should not be overdrawn. Subjects with poor prognostic indicators were overrepresented in those lost to follow-up, and mortality was elevated throughout. A relatively modest proportion (about one-sixth) was judged as having achieved complete recovery, in the sense of no longer requiring any form of treatment.

Despite these notes of caution, the ISoS findings join others in relieving patients, carers and clinicians of the chronicity paradigm which dominated thinking throughout much of the 20th century. They offer robust reasons for therapeutic optimism and point


Judi Chamberlain: *On our own*, 1978 : Nothing about us without us
Patricia Deegan: *A Conspiracy of Hope*, 1987



Recovery, Rehabilitation and the Conspiracy of Hope, 1987

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also to refer to recovering from the effects of poverty, second class citizenship, internalized stigma, abuse and trauma sustained at the hands of some “helping professionals”, and the spirit breaking effects of the mental health system. Indeed, self help and social action cannot be arbitrarily separated. At some point helping ourselves includes joining together as a group to fight the injustices that devalue us and keep us in the position of second-class citizens.



Recovery does not refer to an end product or result. It does not mean that one is “cured”. In fact, recovery is marked by an ever-deepening acceptance of our limitations. But now, rather than being an occasion for despair, we find that our personal limitations are the ground from which spring our own unique possibilities. 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. It is an attitude and a way of approaching the day’s challenges. It is not a perfectly linear process. Like the sea rose, recovery has its seasons, its time of downward growth into the darkness to secure new roots and then the times of breaking out into the sunlight. But most of all recovery is a slow, deliberate process that occurs by poking through one little grain of sand at a time.

As the sea rose teaches us, the work of growth is slow and difficult but the result is beautiful and wondrous. We have chosen very difficult work. Sometimes I think we are a little weird for choosing this line of work. I mean, computers don’t ask that we grow and the pay is certainly better. But we stick with this work and are faithful to it. Why? Because we are part of a conspiracy of hope and we see in the face of each person with a psychiatric disability a life that is just waiting for good soil in which to grow. We are committed to creating that good soil. And so I celebrate you. I celebrate the strong and fiercely tenacious spirit of people with psychiatric disabilities. I celebrate the person within each of us. I celebrate hope. I celebrate our conspiracy. And I think we all deserve a round of applause. Thank you!

1993: Personlig recovery

Recovery er en dybt personlig og unik proces der muliggør det at leve et tilfredsstillende, håbefuldt og bidragende liv med de begrænsninger der er forårsaget af sygdommen.

Recovery indebærer udviklingen af ny mening og et nyt formål i ens liv, mens man vokser ud over den psykiske sygdoms katastrofale følger.

William A. Anthony

Centre for Psychiatric Rehabilitation, Boston 1993

Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s

Reprinted from *Psychosocial Rehabilitation Journal*, 1993, 16(4), 11–23.

William A. Anthony

■ William A. Anthony, Ph.D., is Executive Director of the Center for Psychiatric Rehabilitation at Boston University.

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Abstract

he implementation of deinstitutionalization in the 1960s and 1970s, and the increasing ascendancy of the community support system concept and the practice of psychiatric rehabilitation in the 1980s, have laid the foundation for a new 1990s vision of service delivery for people who have mental illness. Recovery from mental illness is the vision that will guide the mental health system in this decade. This article outlines the fundamental services and assumptions of a recovery-oriented mental health system. As the recovery concept becomes better understood, it could have major implications for how future mental health systems are designed.

Recovery i Danmark 2005/2006

Projekt Recovery-orientering

Projekt Recovery-orientering er slut

Projekt Recovery-orientering, som indledtes i foråret 2003 er nu slut. Projektet fremlagde sine resultater ved en velbesøgt konference d. 3. maj i København. Det er nu de to foreninger bag projektet, LAP og BEDRE PSYKIATRI, der arbejder videre på baggrund af projektets resultater. Resultaterne er bl.a. rapporten "En helt anden hjælp. Recovery i bruger- og pårørendeperspektiv", som er udkommet på Akademisk Forlag, 5 korte dokumentarfilm, og en gratis pjece med 15 forslag til hvordan man kan fremme menneskers mulighed for at komme sig. Se mere om materialerne nedenfor.



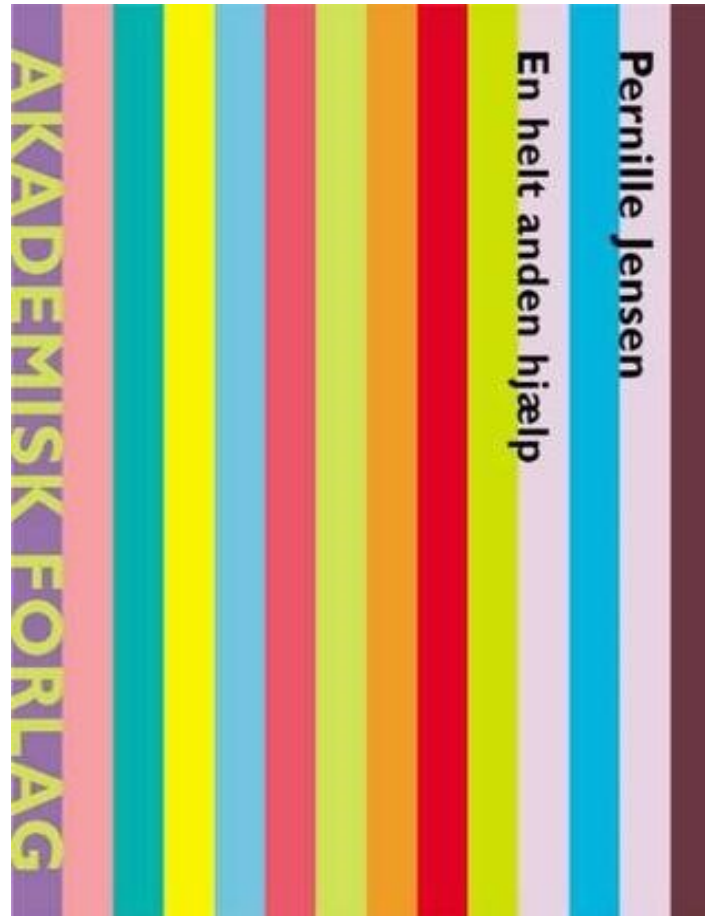
Den amerikanske psykiater Dan Fischer, projektleder Pernille Jensen og den svenske psykolog Alain Topor var blandt konferencens oplægsholdere.

Læs rapporten, de 15 forslag og se 5 spændende film

Projektets afsluttende rapport er d. 3.maj udkommet i bogform på Akademisk Forlag med titlen "En helt anden hjælp. Recovery i bruger- og pårørendeperspektiv." Forfatter er projektleder Pernille Jensen. Rapporten kan købes i boghandlen og lånes på biblioteket. Er du medlem af LAP eller BEDRE PSYKIATRI vil du få mulighed for at bestille bogen med rabat, ellers koster den 229 kr.



Deltagere i konferencens paneldebat var



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VIDENSKAB / 31. OKT 2005

Recovery og rehabilitering i psykiatrien

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Dato 31. okt 2005

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Ugeskr Læger 2005;167(11): 1269-1271

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Hvor er vi nu?

2005-2020 – fra periferi til centrum

Retorisk og strategisk

- Recovery er integreret i de fleste visioner og strategier for psykiatrien, regionalt og kommunalt
- Recovery er flyttet fra periferi til at være et omdrejningspunkt – fra noget, som blev formuleret af de mærkelige få til at være noget, alle italesætter

Stuerent....









Organisatorisk -

Det overordnede handlingsniveau

- Inddragelse af brugere og pårørende på udviklings- og beslutningsniveauer
- Recovery skoler, regionalt, kommunalt mv.
- Personalesammensætningen: Peers
- Patientstyrede indlæggelser
- Netværksbaserede tilgange
- Fælles beslutningstagning
- Matching: Når mennesker vælger deres egen behandler eller kontaktperson
- Antistigmatisering

Konkret.....?

-  ✓ Forandre karakteren af hverdagens relationer og kvaliteten af erfaringer
- ✓ Tilbyde en lang række brugerstyrede uddannelses- og efter/videreuddannelsesprogrammer
-  ✓ Etablering af et 'Recovery uddannelsescenter' for at sikre udvikling og udbredelse af programmerne
- ✓ Sikring af organisatorisk opbakning, udvikling af 'kulturen'
- ✓ Øget tilpasning til individet og flere valgmuligheder
-  ✓ En ny tilgang til vurdering og håndtering af risiko
- ✓ Redefinering af brugerinddragelse
-  ✓ Ændring af personalesammensætningen
-  ✓ Støtte medarbejdere i deres recovery-rejse
-  ✓ Styrke mulighederne for at skabe et liv 'ud over sygdommen'

Tabel 1: Forskelle mellem traditionel og recovery-orienteret praksis

Traditionel tilgang	Recovery-orienteret tilgang
Værdier og magtforhold	
(Tilsyneladende) værdifri	Værdicentreret
Medarbejderansvar	Personligt ansvar
Kontrolorienteret	Valgorienteret
Magt over folk	Vækker magten i folk selv
Grundbegreber	
Videnskabelig	Humanistisk
Patografi	Biografi
Psykopatologi	Negative erfaringer
Diagnose	Personlig mening
Behandling	Vækst og opdagelse
Medarbejdere og patienter	Ekspertes gennem uddannelse og eksperter gennem erfaring
Vidensbase	
Randomiserede, kontrollerede forsøg	Vejledende fortællinger
Systematiske vurderinger	Baseret på rollemodeller
Dekontekstualiseret	Inden for en social kontekst
Arbejdspraksis	
Beskrivelse	Forståelse
Fokus på sygdommen	Fokus på personen
Sygdomsbaseret	Baseret på personens stærke sider
Baseret på reduktion af negative hændelser	Baseret på håb og drømme
Personen tilpasser sig programmet	Medarbejderen tilpasser sig personen
Belønner passivitet og efterlevelse	Fostrer empowerment
Omsorgen koordineres af eksperter	Selvstyring
Mål med indsats	
Bekæmpelse af sygdom	Fremme af sundhed
Bringe under kontrol	Selvkontrol
Efterlevelse	Valg
Tilbagevenden til normalitet	Forandring

Mike Slade 2009: 100 ways to support recovery.
A guide for mental health professionals.

Praksis.... det konkrete handlingsniveau?

- Recovery-orienterede principper udfolder sig i sundhedsprofessionelles bevidsthed og talesprog, men det forstås meget forskelligt.
- De udfolder sig i retorikken mellem patienter og sundhedsprofessionelle. Men de udmønter sig ikke i handlinger eller i patienternes oplevelser.
- I stedet forhandles recovery-værdier indenfor en begrænset ramme: Patienten har indflydelse på små områder som på forhånd er besluttet af personalet som har den overordnede beslutningskraft.
- Recovery-orienterede principper underkendes af konkurrerende hensyn: Begrænsede ressourcer og arbejdsgange som ikke understøtter dem.

**Waldemar, A.K., Esbensen, B.A., Korsbek, L., Petersen, L. and Arnfred, S. (2018).
Recovery orientation in mental health inpatient settings: Inpatient experiences?
Int J Mental Health Nurs, 27: 1177-1187. doi:[10.1111/inm.12434](https://doi.org/10.1111/inm.12434)**

The ten top concerns about recovery encountered in mental health system transformation.

Davidson, L., O'Connell, M., Tondora, J. et al., 2006. *Psychiatric Services*, 57, 640–645.

1. Jamen, det gør vi jo allerede
2. Øget arbejdsbyrde og belastning
3. Man kan ikke tale om recovery hos alvorligt syge mennesker
4. Recovery er kun få de få - de i forvejen ressourcestærke
5. Recovery er bare endnu dille eller en trend og vil snart blive erstattet af en anden
6. Recovery lykkes kun for ganske få mennesker
7. Recovery er et resultat af behandling. Men mine patienter har ikke engang sygdomsindsigt
8. Recovery kræver flere ressourcer
9. Recovery er ikke evidensbaseret
10. Recovery øger medarbejdernes risici i det daglige arbejde

Fremherskende model i vores hverdag – ofte bestemmende for vores forståelse, tilgang og forventninger ift. også recovery



Forskning/videnskabelig dokumentation....?

Sygdomsindsigt hos mennesker med svære psykiske lidelser, herunder især skizofreni, siger noget om prognosen, fordi:

- En lav grad af sygdomsindsigt synes at korrelere med flere tilbagefald og hospitalsindlæggelser – med mere komplekse og langvarige forløb
- Omvendt synes en god indsigt til en vis grad at korrelere med en bedring i funktionsevnen og med en større grad af mulighed for mestring af symptomer

Amador, X. F., Flaum, M., Andreasen, N. C., Strauss, D. H., Yale, S. A., Clark, S. C., & Gorman, J. M. (1994). Awareness of illness in schizophrenia and schizoaffective and mood disorders. *Archives of General Psychiatry*, 51, 826–36.

Cuffel, B. J., Alford, J., Fischer, E. P., & Owen, R. R. (1996). Awareness of illness in schizophrenia and outpatient treatment adherence. *Journal of Nervous and Mental Disease*, 184, 653–659.

Lincoln, T. M., Lüllmann, E., & Rief, W. (2007). Correlates and long-term consequences of poor insight in patients with schizophrenia. A systematic review. *Schizophrenia Bulletin* 33, 1324–42.

**Den samme model - med et andet resultat/outcome end vi er vant til
at tænke og forvente**



Forskning/videnskabelig dokumentation....?

High levels of insight into one's mental illness can impair social functioning, hope and quality of life of people with SMI (Lysaker, Roe, & Yanos, 2007)

Konkret videnskabelig dokumentation for, at sygdomsindsigt korrelerer med:

- Selvstigmatisering
- Lavt selvværd
- Depressioner
- Øgede selvmordstanker og selvmordsadfærd (og selvmord....)

Lysaker, P. H., Roe, D., & Yanos, P. T. (2007). Toward understanding the insight paradox: Internalized stigma moderates the association between insight and social functioning, hope and self-esteem among people with schizophrenia spectrum disorders. *Schizophrenia Bulletin*, 33, 192–199.

Mintz, A. R., Dobson, K. S., & Romney, D. M. (2003). Insight in schizophrenia: A meta-analysis. *Schizophrenia Research*, 61, 75–88.

Amador, X. F., Friedman, J. H., Kasapis, C., Yale, S. A., Flaum, M., & Gorman, J. M. (1996). Suicidal behavior in schizophrenia and its relationship to awareness of illness. *The American Journal of Psychiatry*, 153, 1185–1188.

Evren, C., & Evren, B. (2004). Characteristics of schizophrenic patients with a history of suicide attempt. *International Journal of Psychiatry in Clinical Practice*, 8, 227–234.

Belvederi Murri, M., Respino, M., Innamorati, M., Cervetti, A., Calcagno, P., Pompili, M., Lamis, D.A., Ghio, L., & Amore, M. (2015). Is good insight associated with depression among patients with schizophrenia? Systematic review and meta-analysis. *Schizophrenia Research*, 162(1-3), 234-47.

Diagnose – selvstigma – engulfment - sygdomsidentitet

Engulfment: Når diagnosen bliver en identitet, der overskygger alt andet

Individuals who are unsuccessful in rejecting the mentally ill label increasingly organize self-concept, roles, and behaviors around that label.

Thus, the deviant label of mentally ill assumes a master role status.

Konsekvenser:

- Individet reorganiserer sin selvopfattelse, således at den stemmer overens med forståelsen af diagnose (*a reorganization of an individual's self-concept into a self-concept based on schizophrenia*).
- Individet *bliver* diagnosen/opslugt af den (*the individual's mental illness replaces the pre-illness self-concept in an all-encompassing manner*)
- Graden af engulfment er associeret med følelser af håbløshed depression, lav selvtild og lavt selvværd værd (*Levels of engulfment are associated with multiple measures: hopelessness, depression, low self-esteem, and decreased self-efficacy*)

Vining D, Robinson JC. Concept Analysis of Illness Engulfment in Schizophrenia.
Archives of Psychiatric Nursing. 2016; 30(3):370-4.

Indefra-perspektivet: Identitet og tilstand

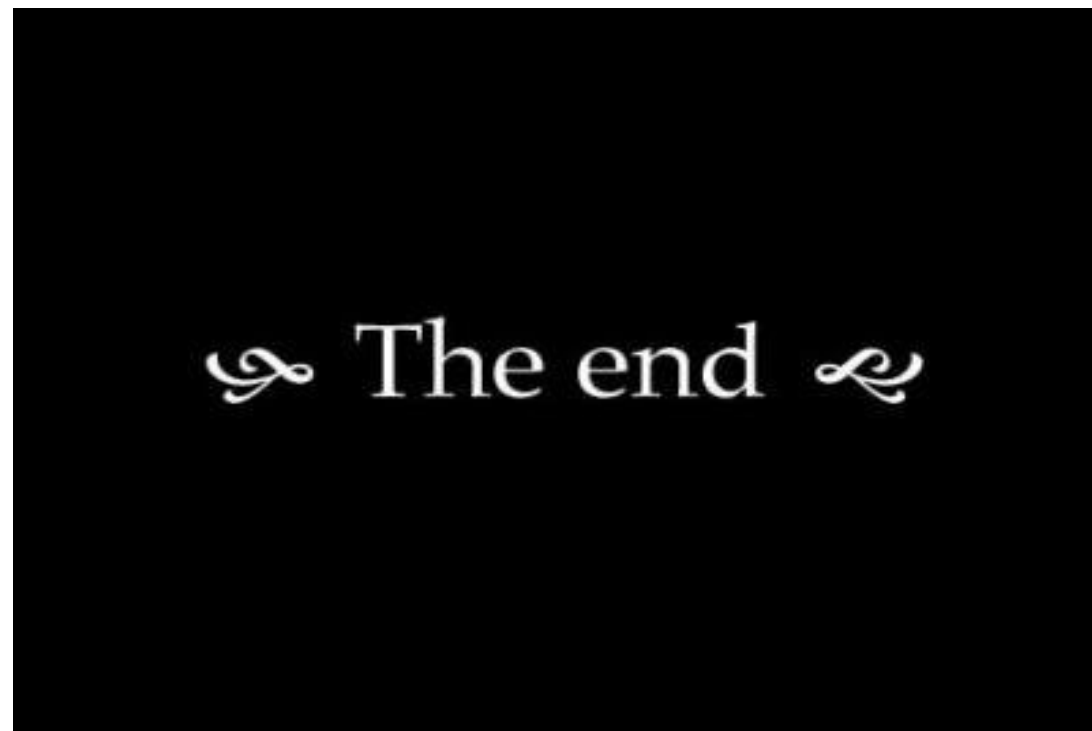
I struggled for many years to try to navigate in the field between illness and identity and expended much energy trying to understand the **discrepancy between my own experiences and clinical understandings.**

It was a long and arduous journey, because **I had internalized so much of what they called the disease, and thought it was at the core of my identity.** My experience also involved the mirroring that I received from the outside world, especially from staff at the hospital. I was mentally ill. What else was I? For a long period, I was nothing else and fulfilled the role of being not a person, but a mental illness.

To move beyond the false analogy between illness and identity required personal development and growth, and I was quite on my own. **Nobody taught me to separate illness and identity,** and so it was a very long process to rescue my personal identity and self-trust.

I felt it was my most decisive battle and that the need to win this battle **was essential for my onward journey.**

Korsbek L.: Illness insight and recovery: How important is illness insight in peoples' recovery process? *Psychiatric Rehabilitation Journal* 09/2013; 36(3)



Vendepunkter



- ✓ Samhørighed
- ✓ Håb
- ✓ Identitet
- ✓ Mening
- ✓ Empowerment

- Disclosure: What is the point and for whom? *Journal of Mental Health* 2013 22, 3, s. 283-290
- Illness Insight and Recovery: How Important is Illness Insight in Peoples' Recovery Process?, *Psychiatric Rehabilitation Journal* 2013. 36, 3, s. 222-225
- Corecovery: Mental health recovery in a dynamic interplay between humans in a relationship. *American Journal of Psychiatric Rehabilitation* 2016. 19, 3, s. 196-205
- How to Recover? Recovery in Denmark: A Work in Progress. *Journal of Recovery in Mental Health* 2017. 1, 1, s. 25-34 9

The CHIME framework for personal recovery



Relationer og samarbejde - hverdagspraksis

Brief INSPIRE

Folk taler om recovery på forskellige måder, men én måde at tale om recovery på er 'at leve et tilfredsstillende og håbefuldt liv'. Dette spørgeskema spørger, hvordan din behandler understøtter din recovery.

Dato:

Vær venlig at besvare alle spørgsmålene om:

.....
Navn på behandler(-e)

.....
Behandlingsform, f.eks. individuelle samtaler eller navn på gruppe

Sæt cirkel om det svar, som passer bedst passer til måden, du føler, at din behandler understøtter din recovery:

1.	Min behandler hjælper mig til at føle mig støttet af andre mennesker	Slet ikke	Lidt	I nogen grad	En hel del	Rigtig meget
2.	Min behandler hjælper mig med at have håb og drømme om fremtiden	Slet ikke	Lidt	I nogen grad	En hel del	Rigtig meget
3.	Min behandler hjælper mig med at have det godt med mig selv	Slet ikke	Lidt	I nogen grad	En hel del	Rigtig meget
4.	Min behandler hjælper mig med at gøre ting, som betyder noget for mig	Slet ikke	Lidt	I nogen grad	En hel del	Rigtig meget
5.	Min behandler hjælper mig med at føle, at jeg har kontrol over mit liv	Slet ikke	Lidt	I nogen grad	En hel del	Rigtig meget

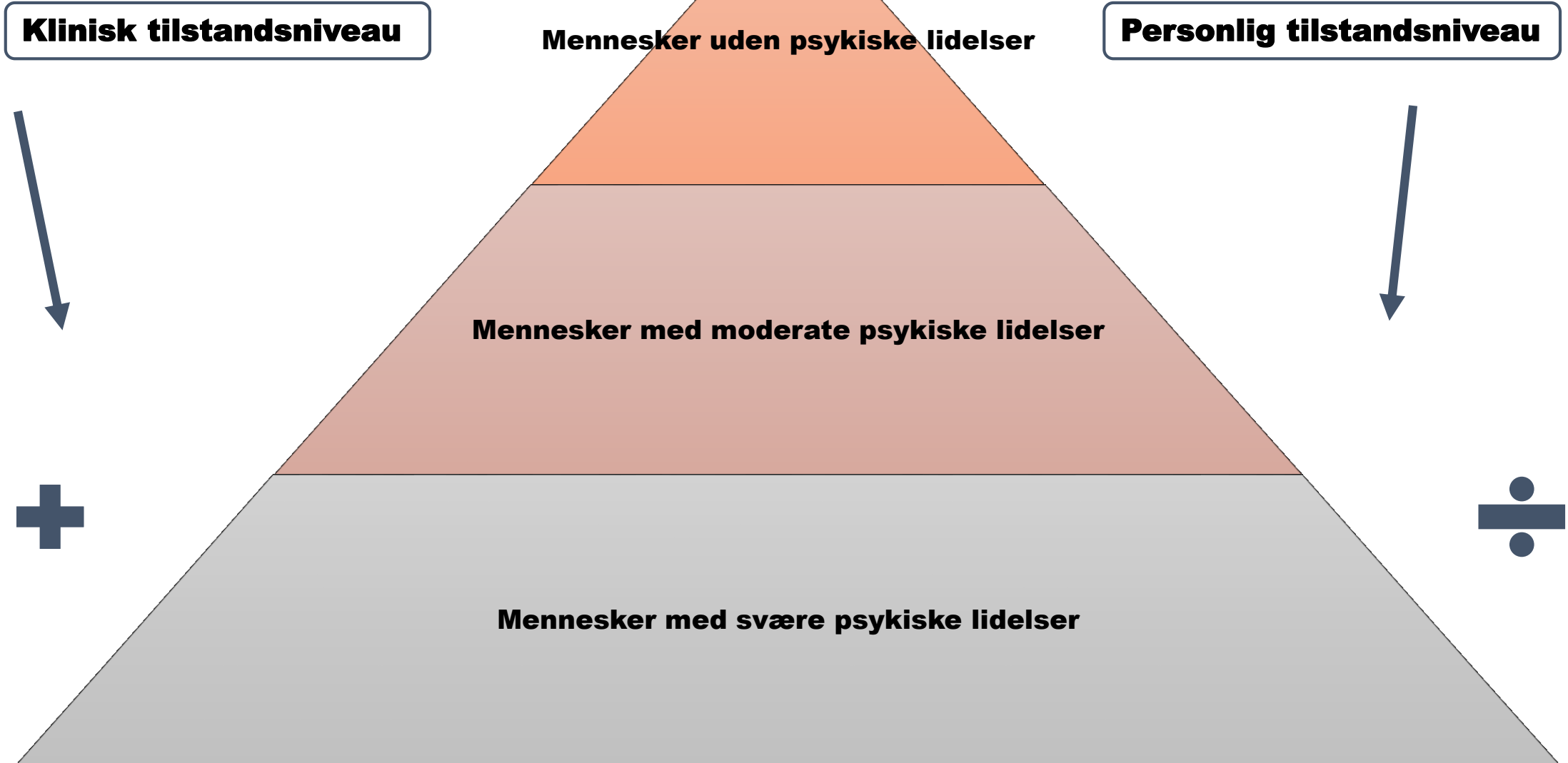
Recovery-orienting

“The ‘recovery orientation’ of services refers to the extent to which mental health staff and services attempt to facilitate or promote personal recovery, and encompasses the different aspects of service delivery and practices that are believed to do this.”

Williams J. et al: Measures of the recovery orientation of mental health services: systematic review,

Soc Psychiatry Psychiatr Epidemiol (2012) 47:1827–1835

Jakobs tese (eller: Hvor skal vi hen?)



Me

- I feel sedated
- I still hear distressing voices
- I can't think clearly
- I feel like the meds are controlling me
- I'm not myself anymore

Psychiatrist

- You are not psychotic
- You are not shouting at your voices anymore
- You are not thought disordered
- You are more in control
- You have returned to baseline

Patricia Deegan

Vi ved det godt! Og det er efterhånden også godt dokumenteret

- Personlig og klinisk recovery følges ikke nødvendigvis ad – faktisk oftest ikke
- Klinisk recovery er ikke en forudsætning for personlig recovery
- Sværhedsgraden af symptomer siger ikke i sig selv ikke noget om, hvorvidt man kommer sig eller ej
- Personlig recovery har ofte en større betydning for brugerne end klinisk recovery

- Roe D, Mashiach-Eizenberg M, Lysaker PH. The relation between objective and subjective domains of recovery among persons with schizophrenia-related disorders. *Schizophr Res.* 2011;131(1-3):133-138.
- Jørgensen R, Zoffmann V, Munk-Jørgensen P, et al. Relationships over time of subjective and objective elements of recovery in persons with schizopreni. *Psychiatry Res.* 2015;228(1):14-19.
- Van Eck RM, Burger TJ, Vellinga A, Schirmbeck F, de Haan L. The Relationship Between Clinical and Personal Recovery in Patients With Schizophrenia Spectrum Disorders: A Systematic Review and Meta-analysis. *Schizophr Bull.* 2018;44(3):631-642.
- Roosenschoon BJ, Kamperman AM, Deen ML, Weeghel JV, Mulder CL. Determinants of clinical, functional and personal recovery for people with schizophrenia and other severe mental illnesses: A cross-sectional analysis. *PLoS One.* 2019;14(9):e0222378.

Hvorfor har vi endnu ikke taget konsekvenserne af vores viden?

Implikationerne for praksis:

- Større eksplicit på personlig recovery i vores tilgang og behandling
- Kliniske effektmål på symptomer og funktionsniveau må ikke stå alene – personlige recovery i vores målinger

Forklaring på, hvorfor det ikke er tilfældet:

- Den manglende tiltro til brugerens evne til selv at vurdere den effekt, en behandling har på ham/hende
- Den manglende tiltro til selvrapporteringer

“Given the small to medium association between overall symptom severity and personal recovery, **explicit attention for personal recovery within treatment could better fit the needs of patients.** Besides that, our findings suggest that current outcome measures in clinical practice, which mainly focus on symptom remission and functioning, should be extended to include personal recovery.

The relative emphasis of the evidence-based medicine paradigm on objective (clinical) outcomes, possibly together with an implicit idea that individuals with mental health problems do not qualify as equal partners in the evaluation of treatment, might have been the reason that earlier findings of a small relationship between objective and subjective domains of outcome have not resulted in implementation of effective practices on a larger scale.”

Van Eck RM, Burger TJ, Vellinga A, Schirmbeck F, de Haan L. The Relationship Between Clinical and Personal Recovery in Patients With Schizophrenia Spectrum Disorders: A Systematic Review and Meta-analysis. *Schizophr Bull.* 2018;44(3):631-642

1991

Ingen har hørt om recovery

Lange indlæggelser

& patientidentitet



Konsekvenser

- Identifikation med sygdommen
- Isolation
- Håbløshed
- Selvstigma
- Problemer med at komme videre og genoptage en tilværelse udenfor hjælpesystemerne

2020

Alle har hørt om recovery

Korte indlæggelser

& hyppige genindlæggelser



Forglemmelser

- Recovery er ikke lineær
- Tilbagefald (og genindlæggelse) er ikke nødvendigvis et tilbagefald i et længerevarende perspektiv (i et recovery-perspektiv)
- Recovery kan ikke programlægges og følger ikke en masterplan eller de organisatoriske strukturer

The ten top concerns about recovery encountered in mental health system transformation.

Davidson, L., O'Connell, M., Tondora, J. et al., 2006. *Psychiatric Services*, 57, 640–645.

1. Jamen, det gør vi jo allerede
2. Øget arbejdsbyrde og belastning
3. Man kan ikke tale om recovery hos alvorligt syge mennesker
4. Recovery er kun få de få - de i forvejen ressourcestærke
5. Recovery er bare endnu dille eller en trend og vil snart blive erstattet af en anden
6. Recovery lykkes kun for ganske få mennesker
7. Recovery er et resultat af behandling. Men mine patienter har ikke engang sygdomsindsigt
8. Recovery kræver flere ressourcer
9. Recovery er ikke evidensbaseret
10. Recovery øger medarbejdernes risici i det daglige arbejde

Psykiatriløftet. August 2020

8 forslag til, hvad en 10-årig psykiatriplan bør adressere.

8 forslag til løft af psykiatrien

1 Løft socialpsykiatrien, så borgere med behov for social støtte hurtigt modtager en fagligt specialiseret, tilstrækkelig og stimulerende indsats.

5 Løft støtten til pårørende til mennesker ramt af psykisk sygdom.

2 Løft behandlingspsykiatrien, så kvaliteten styrkes, og alle, der har behov, kan (for)blive indlagt.

6 Løft den tidlige og forebyggende indsats for alle borgere med psykisk sygdom.

3 Løft indsatsen for borgere med behov for en samlet misbrugsbehandling og psykiatrisk behandling.

7 Et løft, så alle børn, der har behov, får en systematisk og effektiv tidlig indsats.

4 Et løft, så alle berørt af psykisk sygdom oplever, at hjælpen er koordineret mellem sektorer.

8 Løft mulighederne for psykiatrisk forskning.

2

Mennesker med psykisk sygdom skal kunne blive indlagt, når der er et behov, og det skal være muligt at forblive indlagt, så længe indlæggelse er den rigtige behandling.

Det er særligt vigtigt at kunne forblive indlagt for en mindre gruppe svært syge patienter, som i perioder kan have behov for længerevarende forløb af varierende intensitet, for at undgå en ellers stor risiko for tilbagefald.

Behandling og støtte under indlæggelse skal have fokus på borgerens recovery og på at give borgeren en meningsfuld hverdag.

15 anbefalinger - 2006

- 2.** Der skal overalt i landet være **adgang til akuttilbud uden forudgående visitation** til mennesker, der oplever alvorlige psykiske problemer.
- 3.** **Alle** mennesker med alvorlige psykiske problemer skal have adgang til hjælp fra personer med egne erfaringer på området.
- 5.** Alle, der ønsker det, skal have adgang til hjælp til **udtrapning** af medicinbrug.
- 8.** Der indføres ret til **betalt orlov for en primær netværksperson** i op til 6 måneder.
- 10.** Penge skaber nye handlemuligheder. Derfor skal der etableres forsøgsordninger med rådighedsbeløb ved handleplansarbejde og **eget budget** til helbredsfræmmende foranstaltninger.
- 12.** Mennesker med psykosociale handicap **ligestilles med øvrige handicapgrupper.**



Illustration: Eva Christensen (forunderli@gmail.com)
til den danske udgivelse af Patricia Deegans "Barrierer for
brugerinddragelse"
Dansk Selskab for Psykosocial Rehabilitering 2011

Projekt Recovery-orientering 2006. Et samarbejde mellem: LAP – Landsforeningen af nuværende og tidligere psykiatrirugere og Landsforeningen BEDRE PSYKIATRI

Tokenisme og tjeklister

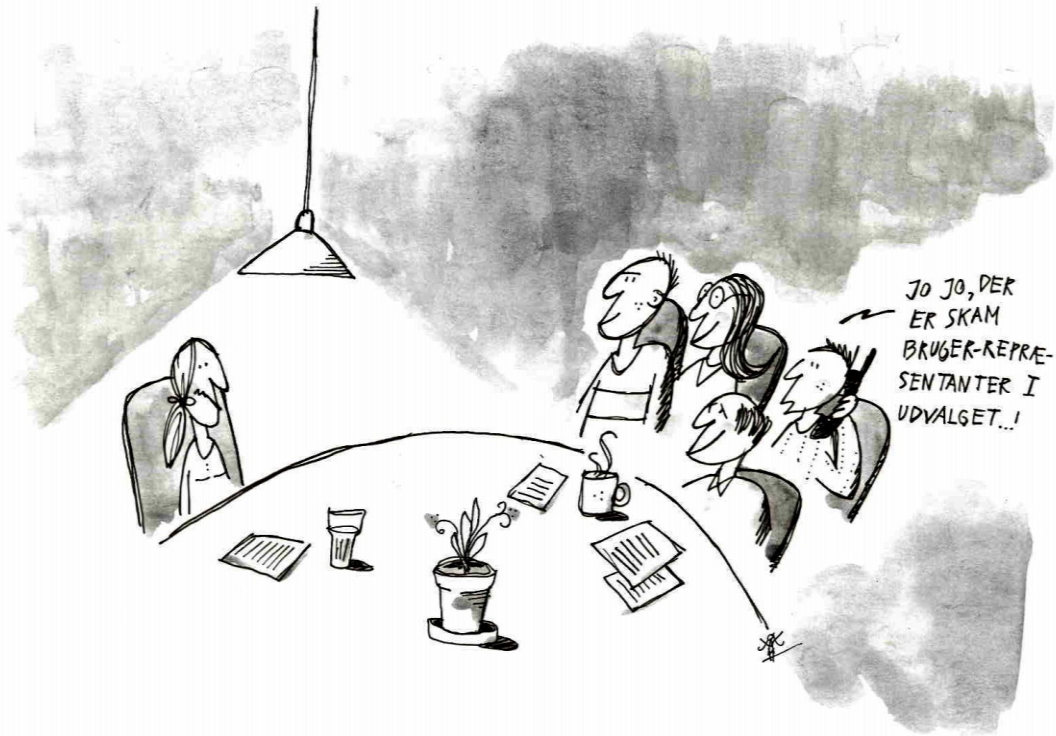


Illustration: Eva Christensen (forunderli@gmail.com) til den danske udgivelse af Patricia Deegans "*Barrierer for brugerinddragelse*"

Dansk Selskab for Psykosocial Rehabilitering 2011

Tokenisme, dvs. symbolsk inkluderende handling eller praksis:

- Når vi vælger de brugere ind, som ligner os mest
- Mener de samme ting
- Tænker på nogenlunde samme måde
- Har de samme prioriteringer
- Hvis (Når?) vi også gør det ved f.eks. ansættelser af peermedarbejdere

Tjeklister og pseudoinddragelse:

- So en ding muss wir auch haben
- En kan repræsentere alle

Recovery for real - i relationer og samarbejde

Turning points/vendepunkter...

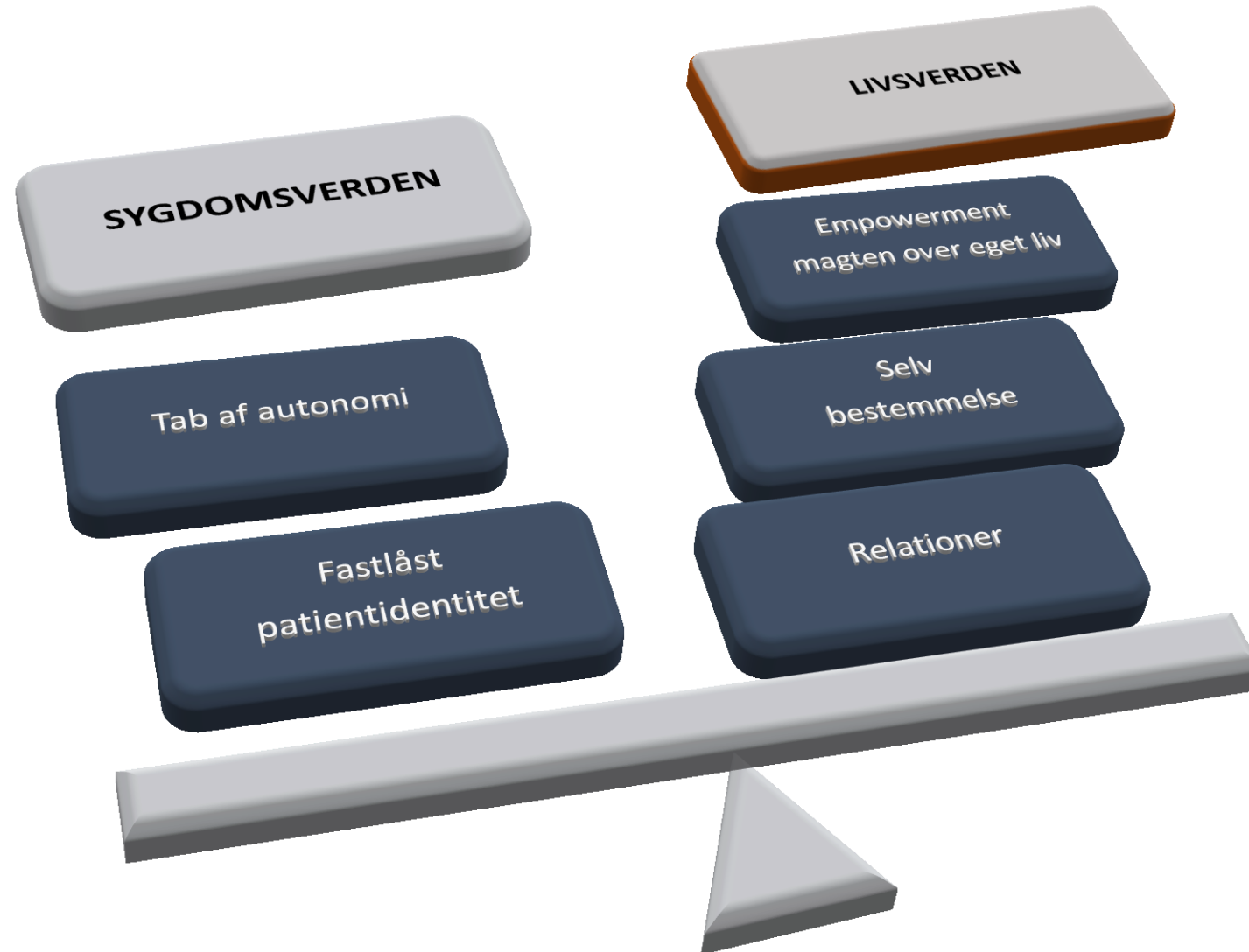
Recovery opstår sjældent i et tomrum, men oftest i: Relationer/social eller mellemmenneskelig kontekst

- Ofte gennem relationer med **betydningsfuld anden**, f.eks. en behandler
- Ofte i relationer med en betydningsfuld anden, der er i stand til at række ud (og af og til gå lidt ud over rammerne for kontakten)
- Som oftest inden for længerevarende kontakt/proces
 - Connectedness (tilknytning, samhørighed)
 - Betydningen af, at betydningsfulde andre, herunder behandlere, har en tro på, at recovery er mulig

Implikationer – anbefaling til professionelle:

”It is recommended that clinicians recognize the powerful position they occupy in relation to client’s hope and reflect on the ways in which they may be communicating their feelings, both explicitly and implicitly...”

Det mindste skridt kan være det største





**Dr. Philippe Pinel at the Salpêtrière, 1795 by Tony Robert-Fleury.
Pinel ordering the removal of chains from patients at the Paris
Asylum for insane women.**



**Illustration: Eva Christensen (forunderli@gmail.com) til den danske
udgivelse af Patricia Deegans "Barrierer for brugerinddragelse",
Dansk Selskab for Psykosocial Rehabilitering 2011**

Tak fordi jeg måtte bidrage.