Public policies. How to transform a health system – step by (small) step: a look at Norway

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Norway is moving along – in leaps and steps. We are leaving behind «user participation».

- National dialogue: we are changing how we speak, and how we think. We are leaving behind the «us» and «them» and meet as human to human.
- Human rights, autonomy is intrinsic and cannot be taken away. Everybody has a right to his/her own home, their own family and friends, work or meaningful activity, and to define - and work to attain - their own life goals.
- Individual choice, finding meaning in life, and being part of one’s community are as important as good scientific understanding of mental distress and mental wellbeing.
How could we not have asked the patient: what helps? What helped you? And chosen that route for services?

- How could we for years have been satisfied by thinking: they are so ill, how could they know?
- Where was our sense of urgency? Treating people into poverty. Treating people into loneliness. We know best, dear. Trust us. Stay in the ward. Broken relations. Homes lost. Careers lost. Life earnings never reached. Oh, the illness. So severe....
- But was it the treatment, as well? Our treatment? With the best of intentions? Why did we not ask?
- We did, actually. Like the Tube, in London. 20% said hell on earth, 20% you saved my life; heaven. (2012, Stavanger)
When we began working with these ideas, many different projects were in place. Some patients, but not all, met important, well researched recovery support:

- «Housing First»
- Individual Placement and Support (JobPrescription, SchoolPrescription)
- Recovery focus in two psychosis wards/Haugesund, Engelsvoll
- «The strengths model»-FACT/ACT
- Open Dialogue in a district psychiatric center (Jæreren DPS)
- Peer support in some teams

Transformation outside the box

- Two examples from Communities who redefined themselves as recovery supportive with good visions, plans and funding
- One example from a hospital-community-user organization network project – no funding
- Five voices from research, government and services
- Where to go from here: If you are looking for joy and meaning in your professional life, a Yes, we can attitude beats compliance every day.

HELSSE STAVANGER
The Bergen Community story of stepping into the patients’ shoes, began in 1993.

Support from the City Council, decisions at seminal turning decision points, and through all these years, municipality leaders and professionals across all sectors who shared the same values and never gave up. Public commitment, good web-site

Joint understanding of recovery, collaborative culture with user organizations, training and employing peer support workers, national network of recovery oriented communities, strengths model in FACT/ACT teams, recovery colleges or recovery education programs, individual placement and support, supported housing

Bergen
- has 35 employees with lived experience
- Created a teaching center for Peers early
- is establishing a Recovery College
- Yearly WAPR conference with international Recovery speakers
- A User Panel across services with 20 Lived Experience Experts
- Is a national center for Housing First
- Collaborates closely with research, but on the service users’ premises
The Sandnes Community story of recovery supporting implementation began in 2012. Support from the City Council. Professionals across the health and social care units reflected on recovery values and human rights. Municipality leaders gave their endorsement. Public commitment, good web-site

- trained all staff in mental health and addiction services in recovery thinking and developed daily recovery cards for continuing reflection
- 12 employees with lived experience created a self-help course for Peers together with Tilburg University, Netherlands and with PH.d students on board. Now continues with a national grant
- is establishing a Recovery College
- Uses Open Dialogue in treatment
- All services are focused on «What matters to you?»
2010-2012 in Stavanger University Hospital Sandnes District Psychiatric Centre (22 inpatients, outpatient consultancy). After 2 years with a recovery based program, in-bed days/beds for 30 patients were reduced from 1776 to 441. Voluntary days increased from 46 to 91.

2014-15 A recovery project began its planning phase: The Pathfinder Project went from grand design to what we could actually do.

In the organization: A long, uphill struggle. The nay-sayers had more power than the yea-sayers. All the users were for, but who cared?

«We do not need this – we are already doing it!»

Who were the power-players?

HELSE STAVANGER
Planning in partnership 2014

• Literature search and site visits. The board of directors went to IMROC. We assessed success factors where they had been supporting recovery based practice for 10-20 years: USA, UK, Australia, New Zealand, Europe.

• Our recovery forum agreed: Key factors for transformation were:
  • Training for all colleagues on personal recovery practices and autonomy for the patient
  • Peer support
  • Training for these new employees
  • A good employment structure for the peer supports
  • Wellness plans for self-help: «The Pathfinder»
  • Advanced directive and crisis plans to secure agency in crises: «The Toolbox»
  • Supported decision making
What is True North in Recovery? Recovery perspectives need to stay true to the civil rights approach (Scottish Recovery Network: Connecting Rights and Recovery in Mental Health | October 2015)
Reflections: can we be satisfied with small steps, when recovery supportive values and solutions are mandated by an international convention of human rights (CRPD 2007), ratified by Norway in 2013? Where are we, when the patients need us to be champions?
2015 A Network Project

Recovery values were being developed and discussed in 30 communities, 2 hospitals and many user fora and self-help groups.

A Network Project

- All participants bring in the projects and results they wish to and retain control of their own project.
- The Pathfinder Project’s role is to support the participants and build consensus where possible.
- Participants share their experience and results.
- Users and carers take part broadly.
January 2015: What if we did not wait for the project? The working group volunteers decided we needed the recovery self help tools. 15-24 people met every 3 weeks for half a year, 2 professionals, the rest with lived experience, in the afternoons.

In January, two Wellness and crisis plans/advance directives were translated from English, then revised, then piloted in June, and then we began anew, with an agreed product ready in October, piloted and revised and printed.

February 2016, the project design was decided upon. There were already two tools in place.
Created by our volunteers before the project was quite decided on. Printing costs covered by a disobedient department head.
An important formality was in place: The steering committee!

Appointed representatives from

- Both hospitals
- Both C-H Cooperating Committees
- User Advisory Boards of the hospitals
- Union representatives
We had learned from lateral thinking: What if we did not wait for funding, either?

- The original design wished to secure changes in the ordinary day to day service, and anchored in our leaders and budgets. We had planned on low cost innovation practices (snowballs) and beginning where we could harvest results fast (avalanches). Timing and sequence of sub-projects were aligned to achieve success in overall design.

- So what did we do, when we did not get support? No extra funding and the project was too big for small grants.

Resources exist where we are not accustomed to looking for them.
Knut-Jarle: I think we should create a course for people who wish to use the Pathfinder (our Wellness plan), Inger Kari. My social worker says it will qualify as my work training plan.

- What had we learned in the planning phase? Not to wait. Priorities must be in line with the original plan: but sequence of the sub-projects did not matter that much. We went with the energy, and what our users in the project team said was important, now.

Knut-Jarle, two weeks later: Is it ok if I bring a friend of mine? He has full disability but thinks this is important.

First one, then two men, then two couples, then three women, then we had workshops twice a week with 10-12 people, who chose projects, teaching themes for the Peer training, and generated new ideas for projects.

Open the doors to new resources and accept their priorities.
A grand design with grand resources

10-14 project team workers at any time. Volunteers lining up to join. Long and short term plans on the whiteboard. Aim: to get funding, but to not wait until..

Project tool: Trello
Continuing plan for the Peer Training Project:

Sum up the feedback from the participants: Our evaluation coach, Post doc Eva Biringer and a master student

Write a book with the content of the course, plus an exercise/work book.

Write a complete teacher’s manual

Create an exam and a certification test.

The volunteer teachers and course developers are working as we speak.

116 people have completed level 1 in the Peer Support course, 52 have completed level 2. It has become a requirement for hiring in some community services. Having the diploma is important to people.

All 27 teachers from the first team in 2016 till the last in October 2018 are or have been volunteers from our project team. 1/3 have new jobs
Rogaland and Sunnhordland 2018:
• Peer support workers are on their way
• Self-help has three important tools
• We are developing a program to teach recovery support and autonomy for citizens using services to staff and users/patients
• We have a self-help course for patients and ex-substance abusers in several communities – some of our trained peer supports are teachers
• We are looking into suicide prevention with a recovery focus by peer supports
• «No Force first»: we are looking at UK and US projects changing from risk thinking about restraint and force into a traumasensitive mode
• Human rights in our services: a new outlook on our very core – CRPD and recovery must go hand in hand

Recovery support: an «I» who meets a «you». Both parties receive, both parties give. The mutual humanness in mental health and addiction services put into practice
Five central voices in Norway 2018, November:

• A top level executive in the Health Ministry: «We still do not speak very much about recovery. The Minister focuses on the Patients’ own health service, which encompasses many aspects, like user influence, shared decision making, access, cooperation between services, coping and evidence based practices and planned treatment packages… I think we have not come as far as we could have. Possibly we are sending out conflicting signals to services.»

• Professor in mental health, Ottar Ness: «I do not think we have come very far in Norway. There is quite a lot of good talk, but it is not put into policy.»
Five central voices in Norway
2018, November, cont.: 

• Psychiatrist, CEO of Nordfjord Psychiatric Centre, participant in national work on reducing involuntary treatment, mentor in health policy Trond Aarre: «We are in a split. Many wish to work in a recovery-supportive way, but political and bureaucratic levels give us mandates and guidelines and economical incentives which lead in another direction. Community services can access funding for peer support, but specialist services are stalling. Are our users really satisfied with our services? Is the medical model actually helping people?»
Five central voices in Norway  
2018, November, cont.:

• Special advisor in mental health Audun Pedersen, Bergen Community: «The national government speaks with two tongues. Verbally, they are asking us in Minister’s speeches and vision statements, that we must be patient centered, and we should ask all patients: «What is important to you?», and support «Nothing about me without me!».
• When it comes to funding, they prioritize actions and ways of thinking that have been developed for somatics and when put into practice actually hinders a recovery supporting practice to happen.»
Head Steinar Trefjord, Sandnes Community, The Coping Unit, leader of newly started Recovery College: «Nowadays it seems to be «in» to use «networks» to facilitate change, rather than a clear policy and mandating action from government and down. The albeit good networks live their own lives, and are only sparingly in contact with each other. There is no systematic effort. And of course, the innovative pockets that we have, are too dependent on individuals with a passion for this. When we look at the educational institutions, the level of knowledge about recovery among the students we get in practice, is surprisingly low. There is little focus on recovery as a premise for services, in the educational system.»
All over Norway, recovery values are being discussed, roleplayed, implemented. Professionals, Peer supports, carers join in the redefinition of services.

- Some people think this will end services as we know them. I think not. My colleagues with lived experience say: Hey! Wait a sec! We want treatment. Good treatment. The best there is. But that does not mean I relinquish my agency. I am me, whoever that may be. I guess that is something I am working on. With a little help, of course.
- We do this in communities, hospitals, community services.
- We have a joint set of values: we are all humans together in this journey.
So what happened to risk assessment, evil acts, criminal and self-serving people who have made other choices: the ones we need to protect society against?

- Risk assessment: we ask: what is the matter? How can I help you? We share the risk, invite people to make an advance directive – and meet people in a trauma-sensitive way. Check out No Force First in Liverpool.
- Evil acts: I have no answer. Maybe our colleagues who have been victims to evil acts can inform us on this.
- Criminality: No need to mollycoddle our patients and service users who have been there. «I have chosen to put that way of life behind me. I want to build and be part of society.»
Norway is moving along – in leaps and steps. It is to do with values, not models. This is not rehabilitation. It is not control of symptoms. It is life. Human life, distress, the act of living.

- National dialogue: we are leaving behind the «us» and «them» and meet as human to human
- Human rights, autonomy is intrinsic and cannot be taken away. Everybody has a right to his/her own home, their own family and friends, work or meaningful activity, and to define - and work to attain - their own life goals.
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