

posy

MAGAZINE ABOUT
MENTAL HEALTH
AND ADDICTION

YEAR 16 NO 4
APRIL 2012

**'EMPOWERMENT
AMERICAN STYLE'**

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photo: Agnes Willems

TO THE CRADLE OF RECOVERY

A colorful group of experience experts, professionals and managers visited Kansas and New York in January. Looking for the cradle of strength, recovery and empowerment. "I wish something like SIDE existed in the Netherlands."



photo: Susan McSpadden



photo: Susan McSpadden

January 2012, a clear, cold afternoon on a bare street in a suburb in Kansas, United States. I am standing with Annelies Hoefsloot outside a meeting center, run by clients, housed in a small building. We are smoking a quick cigarette. Tears are rolling over the cheeks of Annelies. “What I see here is so incredibly beautiful. But dammit, it makes me so sad when I think about the Netherlands. The client interests office, the only thing we had that was run for and by clients in the Ede area, had to close. Apparently there was no more money available for it.” The contrast could not, indeed, be greater. Inside, we had just been impressed by the success of the American clients: SIDE = Socialization, Interdependence, Development, Empowerment, a meeting center set up and managed by themselves. Consumer-run, this is called. It is empowerment, strength, in its purest form. Outside, Annelies dries her tears. She won’t let her grief get the better of her during this trip, she decides. On the contrary, she is absorbing all her experiences, in order to put every effort into her objective to work as an experience worker in the Netherlands, preferably in a Regional Sheltered Housing Institution. “Come on,” she says, pulling herself together, “let’s go back in, because I don’t want to miss anything.”

With a group of 19 people from the Netherlands, we travelled around the United States for a week at the end of January. First Kansas, then New York. Looking for the cradle of *strength*, recovery and experience expertise. Our travel group is a colorful one, featuring experience experts, teachers, rehabilitation coaches, managers, team leaders and department employees. Each person has their own expectations, but one thing binds us together: curiosity about American practices. Rokus Loopik, who has worked for many years in Amsterdam as social psychiatric nurse in street psychiatry, is the organizer and trip leader. He drags us tirelessly from one project to the next. But always with the same purpose: seeing and experiencing how patients’ own strength can bring about recovery. And how important passion is in working with people who suffer from mental illness. “In America they are at least five years ahead of us in the Netherlands,” is the firm conviction of Rokus Loopik. And it’s precisely for these reasons that he started organizing these trips eight years ago, so that participants could see with their own eyes what could be achieved. “It is certainly not a holiday, rather an *experience*, a submersion at the American pioneers of recovery and experience work. My hope is that the participants will devote themselves even more, when they return to the Netherlands, to tapping into clients’ own strengths,” says Rokus, stamping out a cigarette. He summarizes the differences between America and the Netherlands as follows: “If you are floored by a serious mental illness in the Netherlands, care professionals there often seem to think that nothing can be done about it. That the patient will remain a patient for the rest of his or her life. In America, I see the exact opposite. There, they say: ‘A mental illness? Okay, and what else can you do?’ See, that’s a totally different approach.”

Prejudice and gossip

Back to SIDE. A cacophony of discussions between the Dutch and the SIDE employees dominate the room. They are talking, singing, clapping and *hugging*. The walls of the room are full of drawings, paintings and patchworks made by clients. I regularly see the eyes of my fellow travellers filling with tears when they hear the stories. People whose lives were sometimes completely in pieces talking without restraint about their experiences, their battles to gain recognition and a better life. Telling is a skill that is well-developed in many Americans. Take Cherie Bledsoe, who, as executive director, is supported by a board made up of twelve consumers. She radiates peace and confidence. But for a long time, she did not have these in her life. She had spent time in a long-term care department in neighboring Wyandot County Hospital, she tells me. Hopeless, with no prospects of recovery. She wanted to get out of there, to raise her own children. The thought that her kids would come and visit her occasionally in the mental hospital was horrible. With the help of several compassionate employees of Wyandot Hospital in Kansas,



photo: Susan McSpadden

she took a course to become an experience expert, then went to work there. She has now been the director of SIDE for the past twelve years. A driving force: everyone turns to Cherie. On behalf of the employees of SIDE, she presents the Dutch group with two books: *Pathways to recovery* and *The trail is the thing*. Both the books were compiled and written by clients. They prefer to refer to *consumers*, or even *betterpeers*, *members* or *participants*. These terms better express the strengths hidden in each of us, they say. *Pathways to recovery* is a workbook with a plethora of examples and assignments which help readers to

Annelies Hoefsloot, nurse and experience worker

“I came back with huge amounts of energy. I’ve noticed this in the people around me. My energy is rubbing off on them. My hope and dreams appear to be infectious. I start each day with *The Trail is the Thing*. And I am working on *Pathways to Recovery*. We should get these books translated: they are so helpful for so many people I know!”



photo: The Bridge

Henk Schreurs, director at GGZ Oost Brabant
(East Brabant Mental Healthcare Department)

“Broad deployment of experience workers in the organization really works. I experienced that strongly in America. Internally I am currently shaking things up in order to get more experience workers recruited here. The development towards basic care is visible everywhere. I think that experience workers could also work very well as practice support staff for general practitioners.”



photo: Susan McSpadden

Helen: "I am a survivor"



photo: Susan McSpadden

look ahead, discover their talents and to pursue their dreams. “Here at SIDE we work a lot with one another using these books,” says Cherie Bledsoe. We set our own goals, everything is possible, and we talk about everything. This could be anything from our day-to-day concerns, spirituality or sexuality, everything is possible.” “Yeah!! We’re certainly not all virgins,” shouts Mary, a participant, accompanied by loud laughter and clapping. “Exactly!”, says Madeleine Prinsen from the bottom of her heart. She is one of the experience experts in the travel group, and runs her own training and recovery business in Tilburg. “And don’t forget intimacy. There is so little spoken about this, at least among us in the Netherlands. I see an incredible amount of power here. I hope that we can bring this back with us to the Netherlands,” she says. *Take us with you!*”, some of the SIDE employees call out. Madeleine is deeply moved by SIDE. Twenty years ago, she had several psychotic episodes, and since then she has been fighting to be treated as a person and not as a patient. “I haven’t had any psychotic episodes for a long time, but the stigma has stuck with me since then.” Madeleine may be small in size, but her anger about the stigma is huge. During the trip, we see it a few times: red in the face and stamping her feet, angry because people are only seen as patients. But shortly afterwards, she shakes her hands. “Let it go, let it go, pfff,” she grins. “If only something like SIDE existed in the Netherlands. We haven’t been able to get this off the ground yet, the stigma is too great!” Board member Kathy brings her back down to earth shortly afterwards. “We often talk with one another here about prejudice and gossip, that we should also avoid them. We need a lot of forgiveness in our hearts. Because here in Kansas there are a lot of people who also reject us and push us into the ‘weird’ corner. And then we say: oh well, so be it, we are who we are.

Fallen sparrow

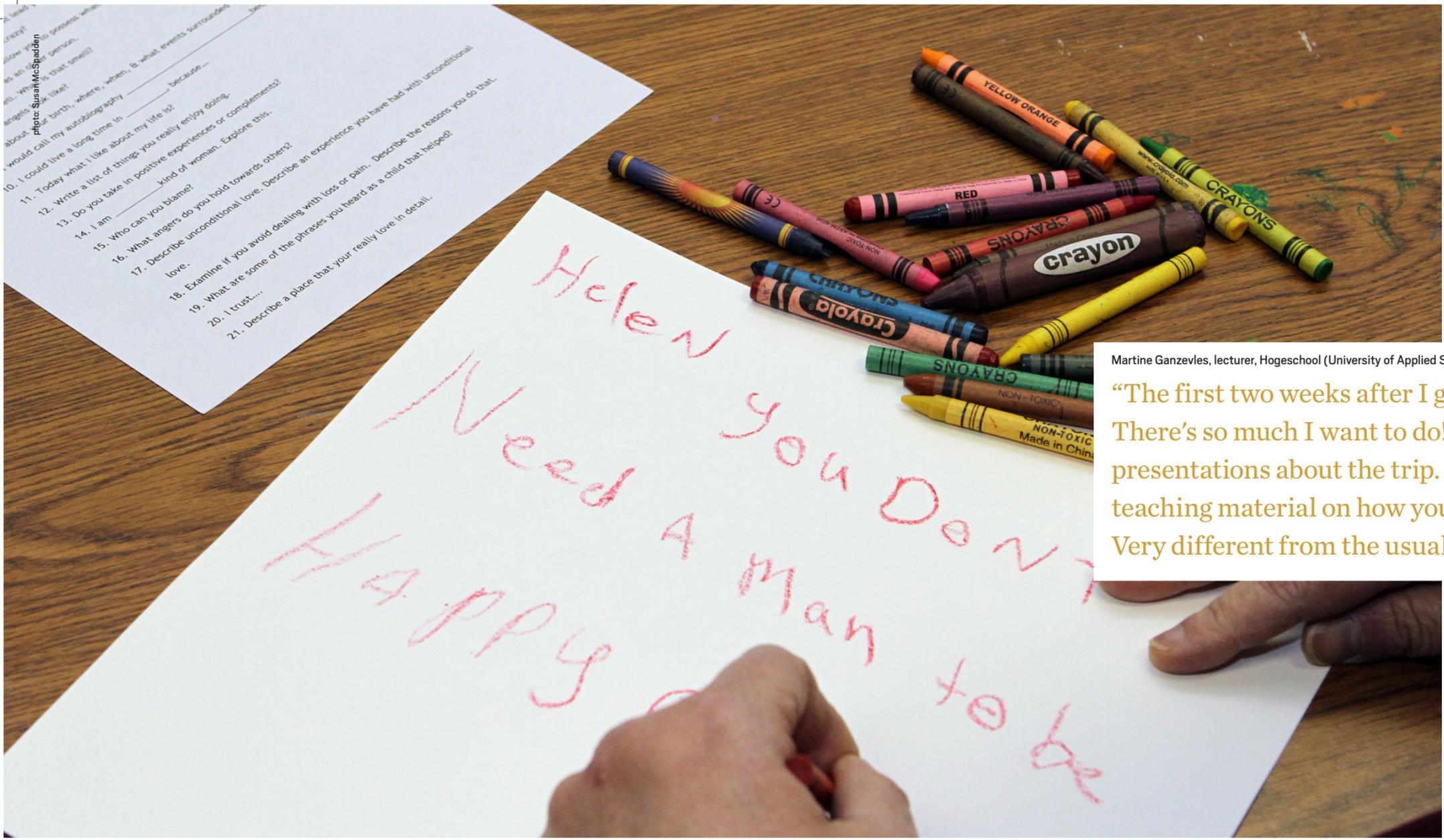
Various members of SIDE in turn present their stories about the groups they organize. They do this with passion, and it sounds very different to a Dutch conference, at which the speakers usually recite their speeches from paper, dry as a bone. It is part of the recovery: tell your story. There are women’s groups, men’s groups, a Bible group and a group to encourage people to stop smoking. Brandon, who leads a men’s group, says “I want to show men something other than the monotonous existence of a patient that they have often come out of. A museum, a film, another city. If I succeed in putting a smile on their faces, that makes my day. Then Helen jumps up to tell her story. I had walked past her one-hour previously: a heavyset woman breathing from an oxygen bottle, with a baby doll in her arms, looking curiously at everyone in the room, but from a distance. Now she is energetically walking side to side in front of the group. “I lived on the streets for 10 years. So... I know how to survive there. And that is exactly what I can teach you, because before you know it you can find yourself

back on the streets. And you had better be well prepared for that. I was lucky enough to find a group of Vietnam veterans from whom I learned a lot: how do you get food stamps, how does social services work, how do you find a lawyer? What do you do if a guy walks up to you and wants to punch you in the face? What do you do? I don’t run away, I take the fight to him.” With her imposing build, Helen makes herself big and threatening for the imaginary *face hitter*.



photo: The Bridge

“YOU WANT SOMETHING OF THIS?” she shouts at the top of her voice. “Look,” she continues after a while, when the laughter has died down, “if someone out there comes up to you and behaves crazily, you have to make sure that you behave even crazier. A man tried to pick me up once, he thought I was a hooker. I led him straight to the cemetery, and there I rolled out the blanket me and my son slept on, on a gravestone. I laid down on it and said “we can do it here, this is where we always sleep.” He couldn’t get away quickly enough. I also learned about living on the streets by listening carefully to people, and watching them. That’s something I’m good at, and I would like to teach it to you. *That’s it, I’m a survivor!*” We sit listening to her, speechless. Such life energy! Even businesslike, experienced care managers such as Henk Schreurs (GGZ Oost Brabant) and Peter Gerritsen (RIBW Gelderse Vallei) are visibly moved. A short time later, Helen again has her doll in her arms, and is sucking her thumb. She tells me later that she has three grandchildren that she regularly sees. Her father and mother were heavy drinkers. She suffered from a serious mental illness as a teenager. “Something like this overwhelms you, there’s nothing you can do about it. You have to learn to live with it. When I came here



to SIDE for the first time, I sat in silence at a table, and didn't move. Fear. And look where I am now!" Helen has Irish and Scottish blood, but is also part Native American, Apache Indian. "What is your *native* name?", asks Rokus casually. "Fallen sparrow". Now it was my turn to fight back the tears. My brother Michel died exactly a year ago. He struggled with mental illness all his life. And as often happens, he also had major physical problems. But nevertheless, his - natural - death came

Martine Ganzevles, lecturer, Hogeschool (University of Applied Sciences) Utrecht

"The first two weeks after I got back from America I was full of adrenaline. There's so much I want to do! At the College I've already given a number of presentations about the trip. I will be focusing much more from now on in my teaching material on how you can stay close to the customer as a professional. Very different from the usual 'professional distance'."

suddenly. On the street. A painter friend, Alex Verduijn den Boer, heard about his death. At that moment, he was painting a dead sparrow, which his predatory cat had brought into the house through the catflap. "I kept thinking about your brother when I was painting it," said Alex later, and he gave me the painting as a present. A beautiful gesture. I still look at it often. Happily, *sparrow* Helen is still very much alive.

Tutorial on strength model

In our eyes, SIDE is unique, but this week we have met quite a few clients, *survivors*, and also professionals, who are making passionate use of their experiences and skills. SIDE can be seen as the ultimate result of the *Strength Model*, developed at Kansas University in Lawrence by Charles Rapp. We spent a full day taking tutorials on this model at the university in Lawrence. Rapp has just retired, but his successor Rick Gosha and staff member Ally Mabry are tireless promoters of the model. The core aspect is that it is primarily about real contact with the patient. For Gosha and Mabry it is a clear issue: if a care professional is unable to see the patient as a normal human being and is unable to put himself in the patient's shoes, he should get out of the profession there and then. "With new professionals, I think it is more important that they have this in them than that they can show you lots of nice qualifications," says Gosha. "Of course they have to master the model, but passion and involvement are the key factors for me."

The strength model itself is fairly simple in structure. The starting point is that everybody – however ill they feel – has wishes and goals. Right from the start, clients work on setting their goals, writing down their wishes and listing their

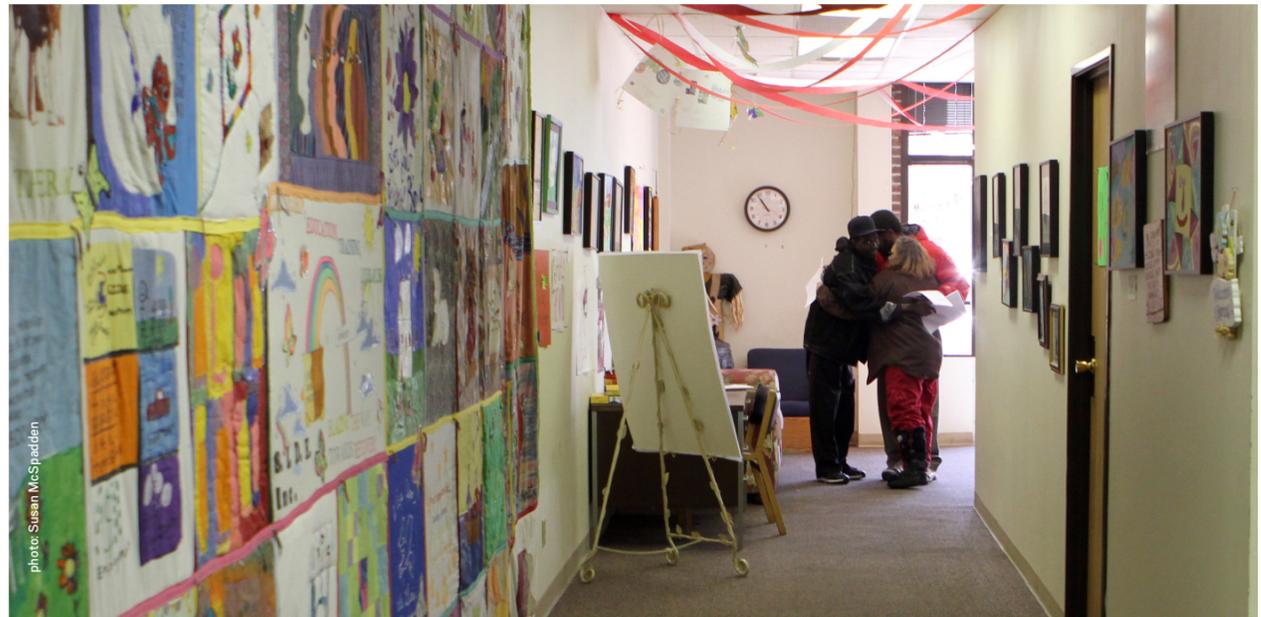




photo: The Bridge

The Bridge in New York focuses on recovery. Clients themselves run the kitchen and the restaurant.

talents. “Whether the goal is learning to paint, tidying your room better or becoming President of the United States, it doesn’t matter,” says Ally Mabry. “The next step is looking at how that goal can be achieved. In this way, you work with people on a future, rather than getting stuck in a past full of problems.” By consistently sticking to the patient’s own goals and working on them, demonstrably good results have been achieved in Kansas. To such an extent that the government has decided that institutions will receive extra funding if they work with the Strength Model. “But the most important thing is the conviction that each patient can realize goals,” argues Gosha. This requires not only the support and good intervention of a team leader, but also the support and

conviction of a board. This is why it is better to start small, and then to roll out the strength model gradually across an organization. And this is a slow process.” Aly Fidom, rehabilitation coach at Kwintes, is delighted about the presentations by Gosha and Mabri. “These alone have made this trip worthwhile for me,” she says. She is working at Kwintes on implementing the strength model in the organization. “I now see that we want to do too much at once, we want to get working with the model in too many different departments. But I think we’d do better putting more energy into starting in a single department.”

Resistance

In Kansas, they have already been working with the model for thirty years. Rapid spreading is difficult, it appears, because it has not been implemented everywhere, by a long way. “It’s all about resistance,” explains Ally Marby. “When we go somewhere for the first time, you quickly hear ‘Yes, but we’re doing that already, aren’t we?!’ But there is a big difference between a case manager imposing goals on a patient, because that list has to be completed, after all, and actually spending time together and allowing the client his or her own quest. It can sometimes take a long time before someone finds a goal that they want to pursue with their heart and soul. Through the years, increasing numbers of experience experts have become involved in the strength model in practice. This works very well.” Some of the travelling companions nod in agreement, and mutter that the resistance is very recognizable. Nevertheless, the strength model is slowly spreading across the Netherlands. RINO Groep and Fonds Storm Rehabilitatie are both promoting it strongly. Dirk den Hollander is the head trainer at RINO and has been trying for years, together with several sympathizers, to get the model accepted. He is being increasingly successful at this: Emergis and GGZ Noord-Holland-Noord are two of the departments

Aly Fidom, rehabilitation coach

“Thanks to the stories I heard in America, I can now share my own experiences in psychiatry more easily. That’s because it’s very normal to talk about it there. This leads to wonderful discussions. Some of my colleagues fall off their chairs when I tell my story. But the members of the client board were not impressed: ‘So what?’”

which are now using it. And Pro Persona team leaders Dick van den Heuvel, Els Makaay and Agnes Willems came along on this trip specially, in order to expand the strength model further in their departments.

Ten thousand patients on the street

In Kansas, the strength model of Charles Rapp rules. In Philadelphia, they work with WRAP, *wellness recovery action plan*, while in New York it is known as *PROS: personalized recovery oriented services*. The common denominator is the patient’s own strength. Furthermore, experience experts play a major role. We come across them everywhere: in mental healthcare institutions, as outpatient mental healthcare professionals, as job coaches, in community centers. Partly voluntary, partly paid. Why are they so far ahead of the Netherlands in the United States? In New York, we put this question to Peter Beitchman, for more than 25 years director of The Bridge, an organization that focuses strongly on recovery. The main building of The Bridge looks somewhat shabby, but every square meter of it is in use. And every wall is full of artwork by clients. There is no luxury, it is clear that the money is not being spent on



photo: iStock



photo: Rokus Loopik

Overcoming stigma?

It cost **Richard Weingarten**, director of a self-help organization, years to overcome his stigma. It is a story of two steps forward, one step back. “When I became ill, I took on the many stigmas which society has about people with a mental illness: dangerous, unpredictable and incompetent. I was 28 when I had my first psychotic episode in 1986. At that moment I was out of work. I lost all confidence in myself, I knew for sure that I would never get another job. I had previously worked as a correspondent in Brazil for *United Press International*. After five stays in a psychiatric hospital, I have been symptom-free since 1994.

I am currently the director of a peer-support organization in Connecticut. When I first fell ill, I was completely blocked, comparing my life to the lives of former classmates who had built up careers and started families. A friend of mine said “It’s pointless staring at them. Life is not a competition with other people, you primarily have to do battle with yourself.” That helped enormously. But I wasn’t there yet, not by a long way. I kept getting setbacks. During one of my stays in hospital, a friend came to visit. I was hoping she would be interested in more than friendship. She kept looking nervously at her watch. I suggested we go for a walk in the park, and once outside I said “I’ll

be home soon, let’s arrange to meet then.” She looked at me coldly “I never want to see you again. You don’t have any future.” She turned around and walked away. Of course I was hurt, but I believed her: I was a man without a future. Much later, during a job interview at a newspaper, I mentioned that I had had psychotic episodes, and that I was no longer suffering from them, but was only taking medication. The interview, which had been going well up to that point, was immediately ended. “You won’t be able to handle the stress of deadlines.” This kind of experience taught me not to always bring up my psychiatric past. I slowly rediscovered my strengths. I started keeping

a diary, started writing articles about my experiences. And these were published! I also started giving presentations about them. I initially thought “I’m staying at home, I can’t do this”. Until I realized that giving presentations was pretty much the biggest source of fear for everyone. I was terrified the first time, I thought that everyone would leave the hall. But they remained seated!

My self-confidence grew, I started teaching Portuguese and continued to give presentations. This help me conquer my own stigma. After this, I broadened my mission – now I wanted to conquer the stigma in society. In Connecticut I trained 15 people,

who also started giving presentations about their mental illnesses in combination with the video *In our own voice*. During the first year we gave around one hundred presentations. These were hugely successful, and I won an award: *stigma buster* of the year. But is the stigma gone now? Of course not, it is just as bad as it was ten years ago. But we are still telling our stories. We provide the facts as well as hope, because some things are improving. The fact that a lot more *peers* now work in mental healthcare makes the system a great deal more hopeful.”

Money for recovery

It would seem that initiatives of American clients who set up their own projects and deploy experience workers on a broad basis do a lot better than in the Netherlands. Have the government and health insurance companies there understood things better? According to Rokus Loopik, who regularly visits the US, this is only partly true: "In America, the start of a project is often largely based on *private funding*. It's hardly surprising that there are often large dinners held purely for the purpose of fundraising. The invitees pay a large amount to attend, and people in the target group are awarded certificates and prizes during the evening. This encourages the invitees to make even more donations. There is a far greater fundraising culture in the US. Each website of a mental healthcare institution has a button for donations. You don't get that in the Netherlands."

As soon as a project starts, researchers get to work straight away: what are the effects and do the costs weigh up against the benefits? Take *Pathways to housing*, the analysis came out positive in this case. A stay in a psychiatric hospital costs \$1185 for one day, whereas a day living in a Pathways house costs \$57, including all intensive help. If the results of the research are positive, the government and insurance companies are prepared to subsidize the organizations. But they monitor the organizations critically. Are they maintaining their performance level? If not, the funding is withdrawn.

In New York, there's been a thorough shakeup of a wide range of organizations for the homeless. Most of them lost their subsidies several years ago, after a new tendering process. The homeless organizations that are left are paid on a piece rate: they receive money for each homeless person they 'recruit', and even more if they are able to keep them in the house. As a result, it is becoming increasingly difficult to get homeless people off the street in the Bronx. The system has been so successful that the streets have been emptying.

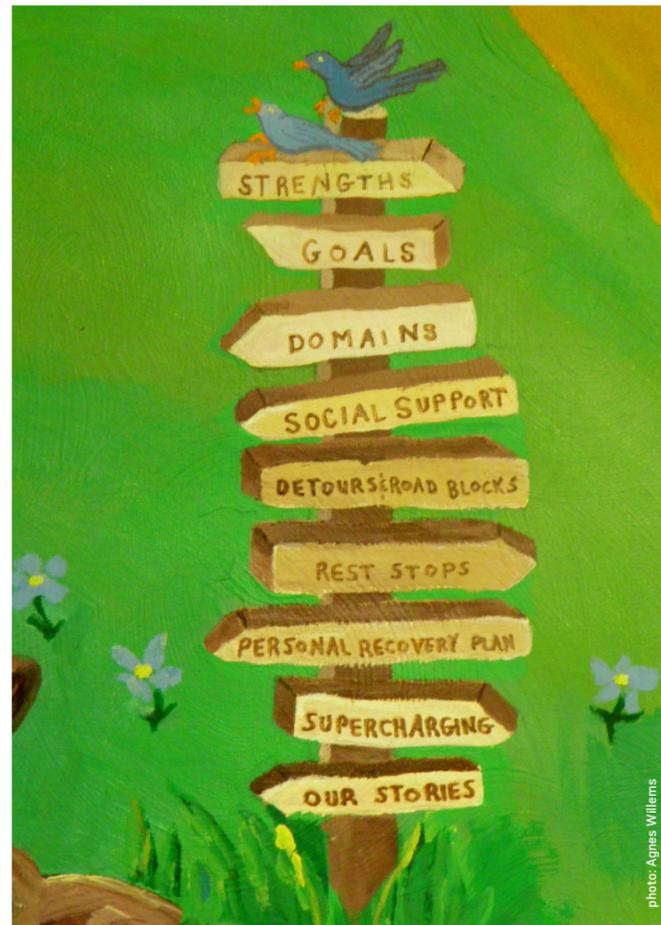


photo: Agnes Willems

expensive office furniture. In the painters' studio at The Bridge, Beitchman tells his story, surrounded by colorful paintings. His answer is as simple as it is perplexing. "The Bridge was set up in 1954 by patients. It was born out of pure necessity. Do you know why? At the start of the 1950s, huge numbers of patients were released from the county hospitals. These were terrible institutions, where no one had the slightest interest in the needs of the patients. They were given a bottle of pills to take with them, chlorpromazine, the first psychomedication. 'There you go, and good luck with the rest of your life.' But these people, who had often lived for decades in an institution, had no idea how to survive in society. They usually did not have any family or friends they could go to. So they fell back on one another and set up The Bridge, a *social club* where they found support for one another." Other similar initiatives sprung up elsewhere, but they didn't come close to meeting all the needs. Because in those years, patients were put out on the street in their tens of thousands, in the state of New York alone. They neglected themselves, became homeless or lived in miserable hostels. Eventually money was made available for better care, and from the early 1970s, The Bridge became an organization which also employed paid professionals. Clients were able to rely on care again. At that time, care was very paternalistically structured, based on a view that patients had had a bad childhood and had to be raised again, as it were, with the care professionals as surrogate parents. But once again it was the clients themselves who brought changes to this: at the end of the 1980s, they contacted Beitchman: we are being well looked after, but we are bored to tears, was the message. This heralded a major change. These days, it is an organization with a strong emphasis on recovery programs, with three hundred clients taking part, who set their own goals and work in a targeted manner on achieving them. Experience workers play an important role, there is a great deal of contact with other institutions in New York which apply the same basic principles. Many of them leave here a great deal richer, Beitchman assures us.

Old-fashioned psychiatry

Involvement, belief in the possibilities of the other person, however ill that person is. These are attitudes characterized by Beitchman. We have also noticed them in the many experience workers and mental healthcare workers we have met this week. American mental healthcare appears to be a great deal further along in terms of recovery and rehabilitation. I have been able to see this with my own eyes. But the United States also has 'old-fashioned' psychiatry. Henk Schreurs, director of GGZ Oost Brabant, noticed this coincidentally when he was in Philadelphia visiting a department of a county hospital. "It was incredible," he says. "Patients were walking around like zombies,

and they were all wearing the same sack-like clothes, just like in *One Flew Over the Cuckoo's Nest*. So that also still exists!"

That's right, you can still read plenty about this dark side of psychiatry in American publications and in books in which clients or their close relatives describe their experiences. Read *Hurry Down Sunshine* by Michael Greenberg, for example. A sad tale by a father whose daughter ended up in a psychiatric ward.

But the purpose of this journey was to show what the effect is of human engagement and commitment. "That's what this is all about," says Kathy of SIDE. "As a child, I was mistreated and abused. I fled into a tree behind our house and didn't come down again. That way my mother couldn't hit me any more. And actually I stayed in that tree for years, nobody showed any interest in me. Later on, my mother threw me out of the house. After I had lived on the streets for a month, I stank terribly. I was lucky that I then came across a care professional who saw the person behind the stink. That

Agnes Willems, rehabilitation coordinator, Pro Persona

"A small-scale crisis refuge in an ordinary house, by experience experts: that made a big impression on me. That's something I'd really like to set up here. Because the peace that reigns in such a house is a lot more effective than a busy psychiatric ward."

person let me in, and from that moment I was able to move forward. And look at where I am now: chairman of the board! Here I will never show someone the door. We are all people, that's something we must never forget." "Exactly!", as Madeleine Prinsen would say.

This article came about thanks to the Fonds Storm Rehabilitatie. The fund paid for the travel of the journalist of *Psy*. Storm Rehabilitatie is an idealistic charity which supports initiatives targeted at vulnerable people. See www.stormrehabilitation.org



photo: Susan McSpadden