Red-Green experiment affecting the most vulnerable patients

In Region Stockholm, the Red-Green coalition is closing down the most effective eating disorder treatment in the country for ideological reasons. This is taking place against patients' will, and 30 years of research and proven experience, writes Stefan Stern.

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August 24, 2023

My first political assignment was at the Swedish Ministry of Health and Social Affairs in the midst of the economic downturn of the 1990s. 8 percent of GDP would be shaved from the state's coffers, and for reasons that are easy to understand, it was our ministry that would have to do the heavy lifting. This was where some of the largest areas of government spending were, in the hundreds of billions.

As we tightened the massive transfers and subsidies of the welfare system, we adopted a guiding principle based on ethics – to protect the core functions of health and social care for patients wherever possible. Despite the fact that soaring interest expenses were literally bleeding the state budget dry. Because childhood and old age will never come again. For a seriously ill individual, life is always a matter of here and now. A treatment or intervention cannot be postponed until after the financial crisis.

30 years later, as Chair of the Mandometer Clinics, Sweden largest clinical program specialized in eating disorders, together with its founders, Professor Per Södersten and Doctor Cecilia Bergh, I will be thinking about this experience when I'm called to a meeting with Region Stockholm. Mando's specialist care is based on many decades of research at Karolinska Institutet (KI), and the first patient was treated during the economic crisis of the 1990s.

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Since the days of the austerity measures, more than 2,000 patients have achieved full remission from their severe eating disorders.75 percent of Mando's patients, regardless of their eating disorder diagnosis or age, become symptom-free after on average 12 months. An outstanding outcome and result. Södersten and Bergh have dedicated their lives to helping severely ill patients from all over Sweden.

The founders from KI are also alone in the world in having created a five-year follow-up program to clinically observe all eating disorder patients in remission over time. Healthy patients are called back to the clinic after 1, 2, 3, 6, 9, 12, 18, 24, 36, 48 and 60 months. Mando's research program has therefore demonstrated that the treatment results in long-term remission for 90 percent of the patients.

Young, and not infrequently severely ill, patients, mostly girls, have therefore been able to live a full and normal life with realized dreams, their own children, education and a career. In Stockholm, Mando's specialized treatment is currently provided in clinics at Karolinska University Hospital in Huddinge, Danderyd Hospital, Sophiahemmet and Hötorget.

I would like to say now that this text will be difficult to read. It is long and full of facts. But I believe this story should be given space. It is a concrete example of how bad things can get when ideology is allowed to override knowledge, treatment outcomes and patient safety.

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The message from the new Red-Green regional government in Stockholm to the KI-based founders could not be mistaken at the aforementioned meeting. In just 25 minutes, it was announced that Region Stockholm wanted to immediately remove the Mandometer Clinics from the list of designated National Specialized Medical Care (NHV) services. This was despite the fact that many months previously, the National Board of Health and Welfare had already included Mando in that role in collaboration with the Region's own clinic (SCÄ) in Region Stockholm's application. This type of NHV designation has no fixed time and, according to the regulations, can include both public and private services. But according to the Red-Green announcement, Mando would be replaced by Stockholm's Child and Adolescent Psychiatry (BUP) in collaboration with SCÄ.

Just a few days after the short meeting, the decision to try and change the national designation was passed by the Region's psychiatric committee, and with a minimum political majority. In the minutes of the same committee meeting, Board members could read in a review by the Region's auditors that BUP did not have sufficient expertise in the treatment of children and young people with eating disorders. The report also stated that 'due to the long waiting lists for the sub-specialized eating disorder treatment, many children and young people who have been treated in hospitals must be referred to BUP before they can be admitted to the sub-specialized eating disorder treatment.'

For anyone who follows the media, the range of problems associated with BUP are no surprise, including the excess mortality rate while waiting for relevant and effective treatment. The psychiatric committee's minutes contained no information at all about treatment outcomes at the regional clinic on Södermalm. Quite simply, there are no tables with outcome data. Essentially, SCÄ has not reported any outcome data to the National Quality Register for Eating Disorders (RIKSÄT) since 2019.

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The new Regional Council is therefore, contrary to the application already approved by national regulators, about to push through a new and revised plan for NHV, where national specialized eating disorder treatment is entrusted to BUP and the Region's own clinic on Vollmar Yxkullsgatan (Stockholm).

This is what Stockholm Region is undertaking under its own management as of December 1 this year, at a time when 40 percent of Mando's patients have actually been referred to our clinics by BUP and general psychiatry. Of Mando's approximately 1,100 patients per year, 40 percent are children. Mando runs 41 of the 58 inpatient beds for eating disorder patients in Region Stockholm. Despite this, the Red-Green coalition has promised both the National

Board of Health and Welfare and the Region's voters that care will not be affected, that it will actually improve. BUP and SCÄ will be allocated additional resources and skills development.

Since the announcement was made, scores of patients and their families have expressed concern about these rapid changes.

Some time later, Professor Södersten and Doctor Bergh were informed that all Mandometer clinics in Stockholm would also be closed down next year. Trying to exclude Mando from the list of national specialized medical care services was just the first Red-Green step towards a complete public takeover of care, and a transfer of most patients who are currently receiving specialized treatment back to general psychiatry. No consideration of treatment outcomes was said to be included in the decision.

Since the announcement was made, scores of patients and their families have expressed concern about these rapid changes. In recent weeks, two petitions have been created to gather signatures. One petition from a family member with their own experience of the treatment they received before contacting Mando and receiving help, and the other from an association of parents of children with eating disorders with many similar experiences. Local media in Stockholm have started to report on the situation.

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The fact that the two decisions are so obviously ideological has not prevented the Red-Green coalition from trying to back them up with seemingly factual arguments.

The claim is that all inpatient treatment for eating disorders must be provided by the Region since involuntary treatment, by law, may only be provided by the Region, and this change will mean that patients no longer need to change doctors or any other staff when their need for care and support is greatest.

When professionals are asked about this claim from politicians, they look very puzzled. Because, in most cases, involuntary treatment is initiated when the patient is undergoing outpatient care and unfortunately refuses admission to inpatient care. It is correct that involuntary treatment must always be provided by a Regional player by law, but this takes place in inpatient units with no outpatient care. In involuntary treatment, the patient will therefore meet new staff and doctors even if the Red-Green coalition introduces its ideological concept of all care being provided by the Region. In addition, experience shows that patients do not feel they can trust staff who initially provide involuntary treatment, and afterwards provide voluntary outpatient care.

Another factor is that there is no difference in Region Stockholm between privately run Mando or publicly run SCÄ in this respect. Both of these clinics send very few patients with a medical certificate to another Regional psychiatric unit, because even though SCÄ is owned by the Region, the clinic has neither the nurse anesthetists or anesthesiologists that are required for involuntary treatment.

It also sounds from the argumentation that all eating disorder patients who are deemed to need inpatient care will be committed to involuntary treatment. But that is also incorrect. The vast majority of patients agree to voluntary inpatient care.

The Red-Green coalition also claims that patients with eating disorders should be treated at specialist clinics like the Mandometer Clinics, i.e. not by general psychiatry, since so many of these patients have high comorbidity.

It is true, and also applies to Mando's patients, that more than 40 percent of the patients undergoing treatment have other psychiatric or somatic diagnoses. And virtually all eating disorder patients develop psychological symptoms such as anxiety, depression and obsessive or compulsive behavior. But these symptoms gradually disappear as eating behavior is normalized. The symptoms are treated as part of the eating disorder treatment, while severe conditions are treated by a specialist psychiatrist in combination with the eating disorder treatment.

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Two important facts that research has shown is that only 0.7 percent of women and men who are diagnosed with anxiety and obsessive-compulsive disorder develop anorexia. The majority of patients with anorexia develop anxiety and depression instead, as a result of their disordered eating. In its research at KI, Mando has shown that the symptoms subside and disappear when disordered eating and weight are normalized and has used the research to explain how the brain is involved in the process.

It is also important to know that treatments for anxiety, which usually help other types of patients with anxiety disorders, have no effect on either anorexia or anxiety in patients with anorexia.

This is where the fact-free local politics become frighteningly dangerous.

The Red-Green coalition also claims that since comorbidity in patients with eating disorders is high, all children and young people with psychiatric diagnoses should, in future, be treated together in a special youth facility. This is where the fact-free local politics become frighteningly dangerous.

In its clinic at Karolinska University Hospital in Huddinge, for example, Mando has mixed inpatient and outpatient care of eating disorder patients with great success. The more seriously ill patients in inpatient care are very inspired by the patients who have made progress and are closer to discharge.

But the idea of knowingly and systematically mixing today's eating disorder patients with all types of young patients regardless of their psychiatric diagnosis should be considered a very high risk. It should be noted here that 20 percent of the individuals who die prematurely due to anorexia nervosa take their own lives.

In the 1990s up to 2000, patients with eating disorders were moved out of psychiatric institutions in Region Stockholm. Prior to that, drug and alcohol abuse, self-harming behavior, other psychiatric diagnoses and eating disorders were all treated in the same clinic. Unfortunately, patients with eating disorders learned about self-harm from the other patients.

For this reason, the profession in Sweden started specialist units with multidisciplinary teams as far back as 50 years ago.

With today's specialist care, Mando has unbroken chains of treatment in the same unit, from assessment to inpatient and emergency care, and all the way to treatment termination.

The Red-Green coalition also claims that the changes in Stockholm will not affect freedom of choice for eating disorder patients, despite attempts to close all private clinics down, because a new procurement framework for general psychiatry will later welcome new private providers.

But this procurement is designed with surgical precision to exclude a specialist clinic like Mando, which has established its own complementary approach to conventional psychiatry based on research over the past decades.

All general psychiatry practitioners offer the same treatments. With the exception of cognitive behavioral therapy (CBT), none of these treatments are evidence-based. And the evidence for CBT is weak – we don't actually know whether CBT has any long-term effects.

History has shown that it takes an average of 17 years for research evidence to reach clinical practice in specialist care. What the Red-Green coalition wants to do now is to close down the treatment approach that has proved successful and adapted for individuals who have not been helped by BUP and standard psychiatric care. Patients will be denied this individualized treatment and if referral to Mando is no longer possible, patient safety will unfortunately be jeopardized.

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However, these ill-founded arguments do not stop there. As patient concerns have grown, and the debate has now begun in earnest in the region, local Red-Green politicians have also engaged in a game of political Chinese whispers.

First of all, Mando received signals that the Red-Green coalition had generally whispered about 'irregularities' at Mando. When a journalist from a major national newspaper reviewed the threats of closure, the allegations escalated into a formal letter from Region Stockholm based on spot checks in an audit. After that, the Red-Green politicians announced their allegations in public, in debate articles and social media, all of which are completely wrong and can be strongly refuted.

One allegation refers to duplicate billing which, according to the accusations, was based on the registration of simultaneous day patient visits. A full internal review by Mando of all such visits over the past three years shows that the Region's allegations are based on a misinterpretation of entries to medical records. These contain no information about when a visit starts or ends, only the time when the actual entry was made.

The other Red-Green allegation refers to parts of Mando's complementary online treatment which, allegedly, is no longer eligible for funding. Reports are spreading in the media that significant amounts must therefore be paid back.

But if the Region unilaterally, as here, changes the definition of online treatment in the agreement, anyone who has been involved in contract law knows that both parties need to sign the change for it to be legally valid.

Even with the Region's unilaterally changed definition, however, Mando meets the requirements. Within its treatment framework, Mando has several technical aids, such as a medical device that restores the body's hunger and satiety signals in behavior modification. When the Region now alleges that a patient cohort's eating training once per day at home can no longer justify funding, they are ignoring the fact that this training is monitored by the therapist, after which Mando's physical team makes an assessment with feedback and an evaluation of the patient's progress.

The approach is based on research that shows how the reliability of many patients in some situations is greater when a technical aid is used to encourage a return to normal eating behavior, than when a family member or health care professional puts pressure on them to eat what's on their plate.

Furthermore, the Red-Green coalition is spreading the inaccuracy that not all of Mando's patients are allowed to meet registered professionals.

That is also incorrect. All eating disorder patients meet registered professionals. Mando has 270 employees – doctors, nurses, dietitians, behavioral scientists, social workers, CBT therapists, social educators, nursing assistants, teachers and self-experienced (former patients in remission who treat and inspire). According to public policy however, the care agreements with Mando do not stipulate the exact professions that must be employed, since the intention of the procurement was to promote more successful approaches alongside of psychiatry. But the allegations of the Red-Green coalition are still spreading.

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In this way, the Red-Green coalition in Stockholm is systematically using public policy to allege inaccuracies about Mando. Long after the political decisions to close the Mandometer Clinics, a formal warning is issued. Some allegations sound very serious, but that is the actual point. This new approach would need a special political science review, especially if this kind of political implementation of public policy is spreading to other political assemblies in addition to Region Stockholm.

In addition, the Red-Green coalition produced a professor of psychology for the media who claims that Mando's reported treatment outcomes are not trustworthy. "They are simply too good to be true."

The fact that this 'independent expert' is associated with SCÄ, which will be allocated all resources in one fell swoop in accordance with the Red-Green coalition's decision, was overlooked by some journalists is simply poor source criticism.

Furthermore, the professor claimed that registry studies of the outcomes in the national quality registers have no value. SCÄ, on the other hand, does not report any such results, and the studies of registry outcomes that are already available have so far shown that Mando's approach is better for both patients and taxpayers, since every patient in remission entails average savings of SEK 4 million for society.

This kind of attitude to general psychiatry by so-called experts is rewarded by the new Red-Green management, because the Region's clinic will also avoid having to compare its own results now in a randomized controlled trial (RCT). The trial was established in the regional

NHV application to the National Board of Health and Welfare, but that requirement has now been removed by the Red-Green coalition, which must be considered serious because patients and their family members in Region Stockholm will not therefore know how the Region's eating disorder treatment will be delivered.

All serious attempts to seek new and more reliable knowledge are being stopped.

The trial would have been highly relevant at national level as well. But all serious attempts to seek new and more reliable knowledge are being stopped.

Claims such as 'the results are too good' are also based on the premise that Professor Södersten at KI is exaggerating his research findings. In partnership with KI, Mando has published 13 doctoral theses, around 40 Master's theses and about 250 scientific articles. This was made possible by research grants and reinvestment of the surplus from the clinical programs in research.

Following a peer review process, much of this research is published in the world's most respected scientific and medical journals. So the allegations are also based on the premise that the peer reviews of the world's top scientific and medical journals are seriously flawed.

Regarding the attempt to exclude Mando from the list of national specialized medical care services, the Red-Green coalition claims that this decision is best made by the local political majority on its own, whereby the national authority will then be informed as a formality.

But the Swedish government's intention with NHV is to concentrate the most highly specialized care to a few dedicated centers of excellence of national interest – not to standardize the care.

If the Mandometer Clinics disappear, Region Stockholm will certainly succeed in its intention to remove non-regional patients from its 'own' already long waiting list in the capital region.

BUP and regional-operated eating disorder care within general psychiatry in other parts of the country will rarely refer patients to the same kind of standardized service in another region. Since the treatment methods and outcomes of the Mandometer Clinics differ from conventional care, the Mandometer Clinics are crucial for patients who have not been helped by all of Sweden's BUP units or services similar to SCÄ.

Mando receives about 100 referrals from other regions every year, and from 18 regions in the past year. About half of these patients are so seriously ill that they qualify for the National Board of Health and Welfare's definition of individuals in need of national specialized medical care. Mando receives another 40 such referrals from Region Stockholm's care, so there is a lot of experience here from the kind of patients to which NHV refers.

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Is it really in the National Board of Health and Welfare's interest that a single region can drive away a research-intensive, uniquely well-functioning specialist care service that has proved important for patients across the entire country?

Is it really in the government's interest – which wants to see more state control of health care, and increased mobility and access to the best care for patients throughout the country – that a local and ideologically driven narrow majority is able to close down the country's most successful specialist health-care service. A government that also recently called for alternatives to the use of restraint and other coercive measures in conventional psychiatric care for eating disorders?

Both the National Board of Health and Welfare and the government should ask themselves what makes parents from many parts of the world, as a last resort, put their daughters on a plane to a faraway country in northern Europe when they have almost lost hope after years of treatment in the general psychiatric care of their own countries. It should be one of the last things that any parent would want to do when the illness is life-threatening, but they travel to the Swedish Mandometer Clinics.

And now that foreign letters are flowing in to the government and the authority from researchers and family members, this is also adding a special dimension. Swedish care is not normally attractive.

I believe that responsibility in this respect needs to be taken at national level to prevent the serious situation that is now unfolding for Sweden's most vulnerable patients due to the NHV decision by Region Stockholm.

However, the Red-Green coalition in Stockholm bears sole responsibility for its other decision, to close down the most effective and most advanced eating disorder care in Stockholm based on an ideological concept that everything should preferably be public-sector driven and as little as possible be run by the private sector.

This Red-Green coalition's care experiment is being rolled out in the capital region, and will be a national showcase for how bad things could get when a local political coalition puts itself above knowledge, treatment outcomes and proven experience.

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