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[SPEAKER\_00]

Hearing the voice of people with lived experience of discrimination is key to promoting recognition and anti-discrimination competence.

In this episode, we hear the story of Morel that inspired Café Morel and the Morel Consortium.

Welcome to Café Morel and conversations about stigma, discrimination and recognition.

[SPEAKER\_03]

Hello, my name is Siv Sebiansen and I would like to tell you the story of my lovely little girl Mirelle.

And this is also the story behind my motivation to develop this project, the Mirelle Project.

Back in 1990 I had the great joy of becoming Mirelle's mother as a foster mother when she was barely one and a half years old.

It felt like winning the lottery to me.

She was my baby girl and she loved to dress up.

Mireille was a lovely and vibrant cuddle girl.

She was a mama's girl with a lot of humor.

She was musical, skilled at drawing, gymnastics, swimming.

She had many good friends and she was very fond of horses.

But when she was about nine and a half years old, the world collapsed.

I divorced from my husband and in connection with the divorce, beyond my decision, she was moved away from me.

This was very traumatic for her, for me and for all of us in the family and friends.

And Mireille, she just wanted to come home.

In later years, she told me that she went to the doctor with her despair when she was 15 years old, resulting in the doctor prescribing her the highly addictive medication called Sobril, which is a benzodiazepine.

This eventually developed into a big problem for her.

She moved out on her own when she was only 18 years old, but after a few years she moved in with me and my new husband to get away from too much partying and drugs and to get help to get her life back in order again.

She worked her way up and forward while she lived with us.

We went on trips together and had many nice times, but there was always the problem underlying and lurking.

Here you can see Mirelle with her foster brother, my son Daniel, at our home.

At that time she had bought her own apartment and she had a nice car, she had a good job in a bank, but the medication that she first received as a band-aid for her wounds became an increasingly larger dependency problem for her.

She also struggled with anxiety that I and others whom she loved would be harmed, get sick, disappear or somehow be taken away from her.

In recent years she was also psychotic several times, always suffering from paranoia.

She lost her job, she lost her driver's license, her car, her apartment.

And eventually she also admitted to herself that the problem has now become so large that she needed professional help.

But she struggled very much with trusting in the helpers who always, as she said, had to diagnose her, document everything and to define her.

And she said they did not want to listen to what she believed she needed in

terms of help.

In encounters with public helpers, she very often felt that they looked down on her.

She also had physical complaints and felt that she was not taken seriously regarding that.

And in the last few months she wanted to be admitted for treatment, that is, substance abuse and psychiatry, because outpatient help had now proved again and again to be insufficient for her.

It was only occasionally that she managed to make it to an appointment.

It was then noted that she did not show up and thus that she was not motivated. This is from Christmas 23.

At that time she was very mentally unwell and she was admitted to psychiatric care a couple of days later.

Only a few weeks before this picture she finally managed to rent an apartment, but she never managed to feel comfortable living alone.

she was admitted to psychiatric care twice and i asked them not to transfer her to substance abuse treatment it was called afr in bergen because then they seem to forget everything else than the substance issues however if you have a known substance problem that's where you get placed that's how it is

In February 2024, she was admitted to AFR for a couple of weeks, but then she was told that they could not offer her a seamless treatment process.

There were no available spots.

So she had to leave again after a couple of weeks and then try to manage on her own.

She would only get outpatient consultations until the next treatment facility could accept her at the end of April.

Even though we all knew that outpatient consultation would not work for her at all.

She was so afraid of how it would go.

But she was also very determined that she now wanted to make it.

She was going to make this.

She said that now she needed our support even more than ever before.

Because this was the hardest of all.

In the morning, March 2024, I was knocking on Mirelle's door as we had agreed late the night before that we would come there to help her to get to the hospital appointment.

She was very anxious to miss that appointment because she had been diagnosed with benign tumours on the liver and she had been informed that they would be surgically removed.

After that message, the confidentiality between the various helpers in her life was lifted so that they could communicate better to help her.

The hospital also gained insight then in her substance abuse problem.

From then on, she felt that the hospital went back on the promises of surgery and instead trivialized the problems that she had.

They said that her pain was only psychosomatic.

Mirelle died maybe less one hour after we talked to her on the phone that night.

The autopsy report concluded that she died from poisoning from the medications that she usually used in a combination with severe liver disease.

She had two large tumors on her liver.

She had cirrhosis, she had fatty liver and chronic hepatitis.

If they had operated on her, they would have seen this.

Why did they downplay her problems?

The reasons could have been many for this.

But we ask ourselves, if she had got this diagnosis when she was still alive, would she then have been offered a different kind of help?

And would she then have managed to stop taking drugs?

Mireille experienced many beautiful things and much joy in her life, but also far too much pain in a life that was far too short.

She never turned 35.

Mireille did not always receive understanding and dignified treatment from either child welfare, social welfare, nor the healthcare system.

She could indeed behave in a very uncharming and unsympathetic way, as people in crisis very often do.

But are professional helpers not trained to meet users with dignity and respect, with recognition, regardless of this?

It is the difficult situation and the very need for help that cause this very difficult and challenging behaviour.

Mireille's story is not unique.

She and many others can check all of these.

Difficult childhoods in various ways, substance abuse issues, mental health issues, problems maintaining employment and pursuing education, poor finances, housing problems, that is to get it, to keep it and to live there.

Crime and constant experiences of violation.

In addition, they also have other health problems such as most people have.

They may not have the same diagnosis, but they have many common traits and they are a group that often fall between two stools.

The aim of the Mireille project is to develop knowledge and tools that can contribute to ensuring that people with dual diagnosis are met with recognition and respect and that they receive the help they need and the help that they in fact are entitled to.

Thank you very much.

[SPEAKER\_00]

We now hear from two members of the Morel Consortium, Sivsa Bjornsson from Mold University College in Norway, the mother of Morel and the leader of the Morel Consortium.

She talks with Mira Marlow from the University of Stavanger, an expert in narrative methods.

Their conversation explores the story behind Morel.

[SPEAKER\_01]

The story of Mireille that I have heard, it's very touching and I would want to just ask some questions and I have based these questions on that previously recorded story of Mireille.

At that story, you talk about your foster daughter, Mireille, who was a bright little girl who enjoyed dressing up, had a great sense of humor and was physically active in many ways.

And you told that the change happened in her behavior after that.

You got divorced and she was moved without hers or your wishes to other place.

But can you tell more about this change that happened in Miralles?

[SPEAKER\_03]

So what happened was a change in her life because she was removed away from me.

She was my little daughter, my foster daughter, but still my daughter.

And she was moved away from me.

It was really, really traumatic for her and for me and for all of us in the family.

And I think as a result of that, she also had many, many difficulties in life. So, she always wanted to come back home. And also, as I told you in the recorded story, that she went to the doctor when she was very young. To tell him about all her problems, she needed help. And what she got was medication, medicines. As we also know now, that she became addicted to this medication, or addicted to drugs, actually. What drugs did to calm her problems, her bad feelings. She was still a lovely girl. She still had all these good skills, but her problems took more and more over. She still had a good sense of humor, but her anxiety, her need for the drugs and all the problems that she stumbled into because of this... made her life so difficult that we saw her more and more as somebody who strove so hard to hold her life together, all the loose ends. And when your life are so troubled as Mireille was, there are less time for laugh and for humor and all the good things. But she still had these valuable skills and characteristics. But for many years, you couldn't see it because I think what she did, she had initially or as a teenager, a problem with her anxiety, depression, and maybe also she felt so violent or maybe that came later.

[SPEAKER\_01]

Yeah, but you are telling quite nice about Mirella's struggle to be recognized as a young woman with these beautiful skills that she has and when the problems overrun the good. good things what was in Mirelle's life and in Mirelle. So you're describing about like the issues with the drug use and as well like mental health challenges. How did you, can you elaborate a bit more? How did you experience all of this as a mother?

[SPEAKER\_03]

She hardly recognized herself or never admitted, actually, at least not officially, that she had mental health problems. But I think that was her problem initially, or at least loneliness, feeling left alone and these things, that she needed to compensate for that somehow and that the medication helped her with that. And so did also alcohol and maybe also other drugs later on. She wouldn't admit that she had a mental health problem. That's what she was covering up for, I think. It became harder and harder because addiction is a beast. And she more and more often, well, she tried to get help from several kinds of welfare services. You need money, you need a place to stay, you need something to help you physically if something is wrong. But she more and more often reported, oh, this was a disaster. I went to this doctor. I went to this NAV, social security system. I went to this. And you know what they said to me? They looked at me like I was somebody not good. And she felt that she was treated like somebody that she wouldn't identify herself as.

And that started many, many years before she died.  
But it became stronger and stronger and it happened more and more often.  
I'm not sure if I answered your question or maybe just reflecting on... I think you answered very well, actually.

[SPEAKER\_01]

Like you are...

Like showing quite a lot about like what is like the labeling and as well like what was the stigma of having mental health issues.

[SPEAKER\_03]

Yeah, she very often talked to me.

She used me as her discussion partner.

And we both knew that that was...

not so good she should have somebody else to talk to as well because i was exhausted from this she didn't only talk to me she also yelled at me when she was angry she had a very difficult life and people in crisis they they don't always behave so nicely and as a mother you get it in the face and you also get the love and the hug you know the good things but

But she needed somebody else to talk to, and she tried to find somebody.

And I suggested for her to go to see a psychologist and several people.

But she always had problems.

I can't remember anyone that she came back and said, this was a good match.

Once or twice maybe, this might be okay, I'll give it another try.

But she had the feeling that they had already labeled her, so they wrote, and when they were taking notes,

In the dialogues with her, they were taking notes, and first they were the ones to ask all the questions, and they were the ones to take the notes.

And this was what she had experienced from when she was a child.

Everybody else diagnosing her, telling her what she is and who she is.

and what help she needed and she wanted to tell them what help she needed and when she did they never listened to that she never felt that they wanted to listen to her and that she got the help that she thought she needed

Instead of giving up this project with having somebody to talk to, because she knew she needed that without admitting that she had a mental health problem, she understood that she needed somebody to talk to about everything going on inside of her and the traumas.

So I remember I helped her to find a psychosomatic physiotherapist.

And that was just focusing on the body, but still talking, somebody to talk to regularly every week or something like that.

And that worked fine for a time.

But she also had physical problems.

This physiotherapist, she also suggested for her, it would be so good if we, the other helpers around you, could talk to each other.

And I am also a professional.

I had my PhD in interprofessional collaboration.

So it's a good thing to encourage to collaborate.

confidentiality, so that the different helpers could talk to each other about you to help you better.

But in fact, what she experienced is that when she lifted the confidentiality, then

Everybody, even the doctors that she was seeing due to the liver problems, severe liver problems actually, even the doctors, they now had a big label coming up in their face when they were taking up her medical records.

And this was her dual diagnosis, or never diagnosed, but still co-occurring problems.  
And then she also experienced that they wouldn't help her anymore.  
I was thinking that, okay, now the specialist didn't want to do the surgery anyway, because even if they had already said that they were going to remove the tumors, they now went back on that.  
And I imagine that was because they knew that she would need medication and that would just give her more problems with addiction or add to the problems that she already had.  
But I miss somebody who could draw the things together and talk to her, somebody with knowledge about addiction.  
And also at the same time seeing her in need of physical help for the somatic diseases.  
But instead of connecting everything together, it seems like everything fell apart.  
And it also did for her.  
And at a point of time, she had not a place to live.  
She lost her driver's license and everything.  
She didn't have anything.  
And she still had a very traumatic childhood and a difficult life.  
And she didn't have money.  
She didn't have the somatic help that she thought she would get.  
She didn't have a place to live.  
She didn't get any of the welfare services that we are so happy about here in Norway.  
And when she could, she took it out on me, or who else should she talk to?

[SPEAKER\_01]

I think what you are now describing is actually like public and structural stigmatization and discrimination because she was stigmatized because of her drug use problems and as well  
Maybe as well because of her mental problems.  
And then she was not anymore seen as a help for her physical illnesses.  
And that's how she actually got kind of like off written for the like, well, now, like what you told us on the story that they saw only like now these ones like drug related or like as well like imaginable rather than like something what is real.  
Can you like tell a bit like how did all this like affected Mirella's like like of course we know like the how it affected like that she unfortunately she died because she did not get help that she needed.  
But before that like all this labeling and stigmatization like how did this like affect Mirella's identity?  
How did she see herself?

[SPEAKER\_03]

She actually was a very strong woman in many ways.  
So she was very stubborn.  
She wasn't easily giving up on and letting them just labeling her.  
When she met new faces in the service system, I think she very often met them with an angry face.  
She wouldn't let them start stigmatizing her.  
She was offensive, so she was never like a poor little lamb or something that you would care for.  
You could see that she was beautiful and she could speak very well.

She was very strong verbally.  
And maybe that scared some people.  
It could.  
Yeah.  
Yeah.  
I can understand that it could.

[SPEAKER\_01]

Describe her as a strong person.  
Even though she had these people who have written how she actually is and what are her problems, she did not actually internalize these ones as part of her life.  
identity, or do you think that's a different story?

[SPEAKER\_03]

No, I think as long as she could.  
She tried to keep on, I am who I am.  
And I also supported her in that.  
And also what I think, being her mother,  
I knew something about this already as a practitioner, a social work practitioner myself, working with this group of people or patients.  
I know that it would be difficult to be a parent or a care person for somebody like Miral.  
And now I was in this situation myself.  
And that was... I'm thinking about it now...  
after all this time, that how hard this is for parents or for carers.  
I knew it was hard, but still, you want so much to help that you walk another step, another step, another step, even if you know that there will be...  
There is a limit.  
You can't go beyond that one because then you will ruin yourself or the rest of your family.  
But you keep on trying and trying and trying and trying.  
And the more you go, the more you see that the other helpers, they are leaving the scene because it's too difficult.  
And I think it's so complicated when you need help on...  
on all these areas in life, and you also behave like somebody not very charming always, then  
I think this is not very professional.  
Huh?  
Is it?  
How could we develop services with skilled professionals that would stand up, even if they met these angry faces and these yelling, ugly words?  
Because we know that they come from frustration and really life crises.  
The welfare services that...  
can't be handled by the family i mean the help that you needed that couldn't at a certain point be been taken care of by the family should should more than any problems be taking care of the public welfare system that we have but instead they lose here because the professionals also would like to help the easy patients or maybe that's too harsh

[SPEAKER\_01]

I think it's like, yeah, when I was thinking about, like, when I'm listening to you about, you're talking about, like, the professionals' inability to actually recognize the intersections between, like, mental health and drug abuse issues,

and then as well, like...

what is the co-product of this, and then the frustration which happens in the intersection of these co-existing problems.

You talk about the frustration which actually made Mirelle act how she did.

What about you?

How was this as a mother?

Because you were very much involved, but how was that all affected to you?

[SPEAKER\_03]

It was hard.

And I was a private person and a mother more than anything.

But also that I was a professional social worker and also that I had been studying these problems from a professional point of view.

That also helped me a bit because I could...

Use my, for example, my own advices that I would have given to that I have given to other parents or care persons in similar situations.

I could use a bit of that myself.

And also I could speak the professional language.

welfare service language so contacting somebody on her behalf to help her she

very often asked me can you please call this and this and this for me to say

that because i always get in their face i'm so angry with them and i did

And that was easier for me because I already knew the language.

I knew the area.

I knew the problems.

And I also would know a bit of the feeling that I could easily also put myself in the situation of the professional helpers.

So to me, this was easy.

But I was thinking also, so many people

people have experienced it we know that this dual diagnosis or co-occurring problems it's it's so it's such a huge problem and what if the parents or the carrier themselves have the same problem yeah and that will happen in many many situations how would they feel trying to help their daughter or son how would they feel would would they ever be listened to by the gp for example

[SPEAKER\_02]

Yeah.

[SPEAKER\_03]

So I think in many ways I was lucky, but I was not lucky.

But in many ways, for me, it was easier.

And that's why I also so strongly feel that I would like to use this advantage to try to help others or try to help doing something to the system.

Because this is not...

I mean, individual helpers would really like to help.

That's why they got this job.

There is something that is too complicated.

We need to find some keys.

How can we build a stronger welfare system that also encompasses people like Mireille in her situation.

So I would like to use my advantage, because I think I have, compared to those who have not my background, for example.

And I think also there will be others in similar situations, similar situations like me, that can have something to contribute, in addition to professionals and researchers.

Because we need to do something about it.  
And it's not only in Norway.  
We know that.  
It's all over the world.  
Even in Tanzania, we know they have also similar problems.  
We should try to think together.

[SPEAKER\_01]

What do you want to say to a mother or a colleague or a health professional who are meeting these people, who are in close contact with people who have these co-occurring problems?

[SPEAKER\_03]

I think I would give the same advice that I have given to others in my previous professional life, that if you are a parent or a carer, you should set a limit for yourself because you can spoil all your energy and everything you are and have to help one.

So you need to set a limit.

It's too much for the family to try to help persons in so complicated problems.

So it's important to set this limit.

And I would also say for professionals, try to see them, try to see them in their eyes.

Ask them, what would you really like?

What would you really like if you could choose on the top shelf?

What kind of help would you pick?

How should it look?

Listen and see, is it possible to go that way?

Instead of telling them, this is the form we have and we are going to squeeze you in.

And if you don't fit, sorry for you, then you lose.

[SPEAKER\_00]

Thank you for listening to an episode of Café Morel.