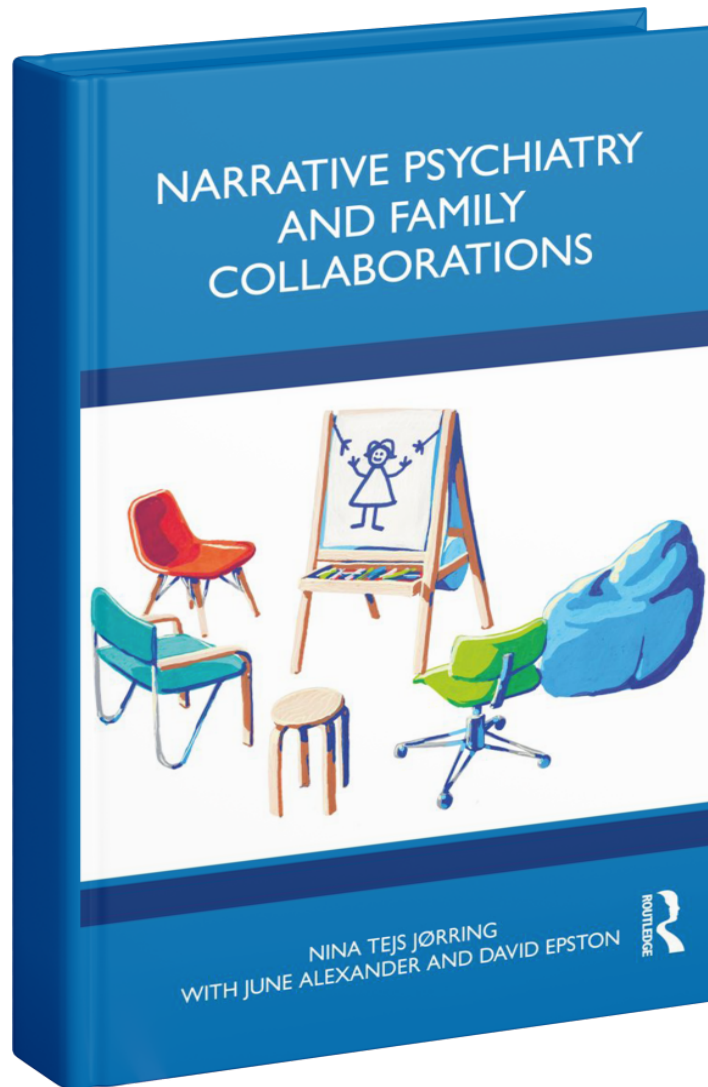


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Intro:

Imagine a young child with severe psychiatric problems, and that not only the child, but the whole family was provided with collaborative help and support by professionals.

Imagine that you were the one suffering, and your whole family were invited to receive help. How would that make a difference to you?

Imagine that:

- Professionals and families are collaborating with each other with respect, curiosity, trust and hope, and that they all share the same goal of the family being able to live the best possible life.
- That you conduct treatment, clinical conferences, and meetings in ways, that make all members of the family experience being heard & seen, understood & empowered, and able to participate on equal ground.
- That you talk about problems, diagnoses, and difficult family experiences so that they become manageable, and the family members can free themselves from the negative influences of those problems.
- That your patient's family are your collaborators. You are in it together.

This book contains exemplary stories about how we do this work with the people we meet.

Chapter Nine

Naming? How might a diagnosis be best for me?

When I asked my nine-year-old patient, Oscar, for advice on helping families and children like him with Attention-Deficit Hyperactivity Disorder (ADHD), he said:

Tell them that you must talk about the same thing again and again and again and again. But that this does help. And remember to tell the parents that volcanos are also fun. I was really glad when you explained that.

“Volcano” had become a metaphor for Oscar’s diagnosis of ADHD. Diagnoses are medical tools that guide a doctor’s understanding of complex problems. Diagnoses for children and youth are moving targets, socially constructed, and not absolute truths (Conrad, 2014; Stein et al., 2020). Diagnoses can have hurtful consequences (Lebowitz & Ahn, 2014; Lebowitz, 2019). This chapter discusses how we can talk about and use diagnoses, so that they have positive effects and make sense to children and their families.

Diagnoses are the doctor’s externalization of the problem

We all have problems, somatic and mental. If our problems become bothersome, most of us will ask for help. If the helper is a medical doctor, our problem will be given a name from the International Classification of Diseases (ICD)(WHO, 1990)¹. The naming helps doctors to categorize and study the problems, give insight into characteristics, and causes of each type of problems, the prognosis,

and helpful treatments. However, these reasons for using diagnoses often disappear in discussions of economy, labelling, taboo and stigma (Garand, 2009).

A diagnosis is not a label that describes a person's identity, but a way of describing the problems that are troubling the person (Mogensen, 2015). The narrative language, where we externalize problems, supports this understanding.

The specific diagnosis can be critical in determining what treatment the patient will receive. Whether we live in a country with a national health care system that provides treatment, or we access help through a private health provider, all patients need a name for their illness. They need a diagnosis that entitles them to treatment. Therefore, diagnoses are also used for economic purposes.

However, we know from research, that the diagnoses are not stable entities and, for children especially, they can be fleeting in nature (O'Connor, 2020). Many diagnoses for children's mental health problems change over time, and many children are affected by multiple problems over time.

Discussions about which diagnosis is "correct" can deflect attention from understanding how a specific child and family is suffering, and from deciding the best help for that specific child and family (Ilgen, 2016). We might lose sight of what purpose the illness has, or what problem the illness is trying to communicate or help solve for the child. In short, we might lose sight of how we may best help the family.

The families that our team meet have often found the diagnostic process to be more bothersome than helpful. Usually, a family seeks a diagnosis to make sense of why their child is suffering. Unfortunately, the diagnosis itself seldom gives a helpful answer to their “Why?”

When a family refers to the specific diagnosis, we ask family members to explain what this means to them. Then we do a joint exploration of their specific problems, to understand how those problems relate to the specific diagnosis, and why this or that diagnosis might or might not be a helpful name for their situation.

We might also suggest that certain problems that have led to a particular diagnosis, seem to be shared by one or both parents. We might suggest that the parents could have received that same diagnosis, had they lived at this specific time and in the same environment as their child. Many parents enjoy this relaxed and shared approach to understanding diagnoses. It helps the family to make sense of their suffering. The story about the Braveheart family in Chapter One is an example of practising this principle.

Struggling with understanding diagnoses

A diagnosis can be hurtful if it becomes the identity of the person (Yanos, 2010). But a diagnosis is also a tool that can open the door for receiving specialized support in a school, financial help for a family, psychotherapy, medicine, and other benefits.

Brigitte, a 15-year-old girl, who had been diagnosed with anorexia came to see us. We re-evaluated her symptoms and concluded that her disordered eating was due to not being seen as a girl with

autistic problems. We wanted to focus on helping with Brigitte to manage her autistic challenges. I was anxious about Brigitte's reaction to receiving yet another diagnosis, since she hated and opposed her anorexia diagnosis. However, when we told her about Asperger's Syndrome, her reaction was one of relief.

"If that Asperger's diagnosis can get me into a school where I am accepted as who I am, why shouldn't I be grateful for receiving this diagnosis? And then you will understand that my food intake is restricted because of my autism, NOT because I have anorexia," Brigitte said.

The last sentence was delivered with a powerful pose. Within a few weeks of starting conversations about nutritious food, the biological needs of a body, and how autism (or people with autism) loves routines, Brigitte was eating in a healthier way.

[Seytan or OCD? What and how might it be most helpful to the family?](#)

As a resident at an adolescent outpatient unit, I inherited a case from a doctor who had treated a boy with Cognitive Behavioural Therapy (CBT) for Obsessive-Compulsive Disorder (OCD) with insufficient effect. This was one of my first cases using narrative therapy.

The boy, Ahmed, and his parents had lived for a time in a refugee camp before settling in Denmark. The father had Post-Traumatic Stress Disorder (PTSD) and the municipality had supported the family in settling into their new country.

I continued the practice of individual therapy and met only with Ahmed. His mum stayed in the waiting room, gave me a polite nod, but didn't shake my hand or engage in any verbal communication.

To start with, I asked Ahmed to describe what he had done in therapy so far and how it had helped him. He spoke positively of different CBT models and home exercises that he had been told to perform, but most often he had forgotten to do. I asked what he hoped to get out of the treatment but got no real answer.

I tried to externalize the OCD: "What does the OCD demand of you?"

Ahmed: "I don't know! You guys say it's OCD, I don't know what OCD is. Aren't you supposed to know what it does to me?"

Ahmed now had my attention! This child had gone to therapy for OCD and was claiming that he had no understanding of what the diagnosis meant. I jumped into what I call my teacher-role and explained OCD to him. He listened patiently and looked a little overbearingly at me; he clearly had heard all this before, and it meant nothing to him.

For many people, diagnoses are common knowledge, and they have a sense of what they mean. A diagnosis can be a short and efficient way of talking about what can be big, complex problems. But health professionals must pause and consider what words and sentences are most appropriate to use in different contexts, depending on the intentions and effects of using a diagnosis. We must step away from our professional positions and respectfully enter our patient's world, be curious about

how they think, their knowledge, and what words and sentences they use to communicate about their lives. We must not expect or demand that the patient steps into our world and uses our language, just because that's easiest for us.

Consider how often you have gone to a lawyer, a philosopher, an auto mechanic, or anybody with expertise who has their own language and terms, and heard a problem explained in a way that you did not understand.

The issue is not about learning another language as such but being aware of differences in word usage and interpretations. I find being observant about how words are used and what they mean is one of the most fascinating aspects of psychiatry. I like playing with words. Sharing this joy with the families is one of the most therapeutic techniques I know.

Remembering my narrative self, I asked Ahmed, "So how do you talk about your problems at home? What do you call it?"

Ahmed: "Seytan".

Nina: "What? What's that? A Satan?"

Ahmed: "Seytan! It means 'devil'."

Nina: "Oh ... wow, tell me about that! Is Seytan in your home? How does it work?"

My thoughts ran ahead, “This is great! The family has already externalized the problem at home!” But other thoughts also ran havoc and I wondered, “Is the family superstitious? Is this good or bad? Is this part of Ahmed’s culture? Something that I have no knowledge about? Oh, no....”

Both lines of thoughts tricked me into adopting the knowing-it-all-position of, “I have to know it all and I am entitled to judge whether the boy and his parents are on the right track or not”. But that position was wrong. The only proper response I could give was to be curious and respectful. I decided to trust and hope that an inquiry along this path would be helpful for our collaboration and for Ahmed’s healing from this ailment, that was named OCD by the hospital and Seytan by the family.

My internal dialogue was intense. I had to shove aside my eagerness to act on this new insight and remain in the curious position. Learning as much as possible was imperative. I did not want to make more wrong conclusions. I pondered how my colleagues had assumed the boy knew he had OCD and had agreed to the diagnosis and treatment. I tried to address the wrongness of these assumptions. I began from scratch, exploring Ahmed’s problems with him.

I came to know Ahmed as a sweet, fun, and conscientious 14-year-old. He was a talented soccer player who liked school and got good grades. His family was religious. He found his parents very strict compared with Danish parents. He loved, and was proud of, his parents’ achievements and had vivid memories of the refugee camp and flight to Europe.

I learned that as Ahmed entered his teens, a very bossy Seytan invaded his home-life. Seytan demanded many different rituals, starting the minute that Ahmed arrived home from school. He had

to change all his clothes before entering the apartment, he had to engage in long washing rituals, and his mum was required to participate in these and other weird habits around using his computer and doing homework.

So began an exciting collaboration, where Ahmed taught me about his family, their culture, and their dreams for a life in Denmark. We explored how Seytan had tried to prevent him and his mum from living life as they wanted to, and how love and respect for his parents' native culture was difficult to nurture in a Danish society.

We concluded that "OCD" was just a "doctor-name" that didn't give this family a helpful explanation in handling their problems (see Chapter 12 for a continuation of this story).

Ahmed's story is not unique. Other parents have said, "I do not understand. I thought that a diagnosis would help me understand, but I still don't know WHY my kid is suffering or how to help." Parents hope for guidance to manage problems. Diagnoses give health professionals, but not always the families, this guide. We must acknowledge and meet the needs of the family, not in a derogatory way, but with respect (Pellicano, 2018).

What makes sense, how is it helpful?

Do you see a boy with OCD and autism, or an autistic boy with OCD?

Or OCD as a symptom of an unacknowledged autism?

I met Isaac and his parents when he was six-years-old. He had psychotic symptoms and many ritualistic behaviours, that were diagnosed as OCD. Isaac was on anti-psychotics, ADHD medicine and anti-depressants. He was charming and did not present with problems of autism, such as difficulties in social communication (Lord, 2020). OCD seemed the best explanation and had everyone's focus, even though Isaac also had an autism spectrum diagnosis. Everyone saw a child clearly suffering, but Isaac loved his school, wanted to be normal, to do things on his own, and be a good boy. He also had his own understanding of the OCD and how to combat it.

The autism spectrum diagnosis helped several years later by giving the family a nuanced understanding. By now, Isaac was 12 years' old. He was placed in a new school environment with an autism-friendly structure and a more nuanced understanding. However, many different professional helpers continued to give different advice to the parents according to their private understanding of Isaac and his diagnoses.

Isaac lived in two families, changing house once a week with his older brother. His mother re-married, to a woman, and his dad also re-married and gave Isaac a younger brother when he was 12-years-old. Isaac experienced great joy in the adoring physical hugs and kisses from this brother.

Early on, all four parents accompanied Isaac to his sessions. But we soon learned that meetings with only the parents also provided opportunities for adult talk. Sometimes Isaac's biological parents came together, sometimes one of the couples came alone.

We discussed the different diagnoses. What understanding might help best? What diagnosis had the best prognosis?

I wrote this letter after a session with all four parents, when Isaac was 13-years-old:

Dear Parents to Isaac,

At the end of our conversation Abigail said, “We must talk at some point, about what drives our actions. What will happen to Isaac? He asks about this himself!”

Is your hope that Isaac will become an ordinary boy?

You wondered how his handicap will make itself known in adulthood.

What won't he be able to do, that you have been dreaming about him doing?

What is most important for him to learn to do? Is this realistic?

I ask these questions because they also might provide good guidelines, when preparing your big family party, and when planning for other parts of his upbringing.

Must Isaac always have an escape route that he knows he can use, and enables him to feel he is a good boy, no matter what?

Consider this statement: If autism-pedagogy is used, Isaac will not learn and develop useful life competencies such as social skills. However, if a normal standard is demanded, and a higher goal is set, he will advance further.

Or the opposite statement: If applying autism-pedagogy, Isaac has optimal possibilities for growth and development; but if normal standards are demanded, he will experience failure upon failure and deteriorate.

I know you have been exposed to both statements.

How can we talk about the future, without destroying your hopes?

Does Isaac feel like a failure or a hero?

Can a person preserve hope and be realistic?

What can your hopes and dreams be about?

How do you want Isaac to think about himself?

Will you encourage him to try new things, exert himself to make an effort?

Do your thoughts align with those of Isaac on what is necessary to be a hero?

I am convinced that Isaac felt like a hero when he said, "I made it, I went to my brother's baptism!"

I also believe he needs to see the meaning and the advantages for himself, if he is to attempt anything that demands that he confronts/endures psychic pain, obsessions, or meltdowns.

What do you think about such statements?

Nina

At this point, the parents asked for Isaac to have conversations alone with me to get a better understanding of his diagnoses, and what they could mean to him.

The first e-mail after our first individual conversation:

Dear Parents,

I hope you will read this attached letter and read it together with Isaac. I suggest that reading the letter with Isaac several times during the next three weeks will be helpful. He might not like the idea of you reading it aloud to him. He might say that he will read the letter by himself. But I believe it is important that you read and talk about the letter together.

Nina

Dear Isaac,

I hope my letters help you to remember what we have talked about. I hope they help you find ways to live that give you more time to enjoy being “you”, the way you see yourself: small, a tad skimpy, good at things demanding technique, light on your feet,

which is a good thing when climbing trees or being a swordsman, training, and doing things you like to do.

You said that you want to be “a good boy”, and that you do not want to hurt anybody. This is troublesome, because you hold back when fencing with your older brother, but he does not hold back and kicks way too hard. You believe he does not understand the word “training”. You don’t like him picking on you. Rather, you want the two of you to have a good time together. I wonder if Sebastian knows this is how you feel? Do you think Sebastian might be able to change a little?

You also said that you are not that good at fighting, because you have no drive for winning. Therefore, football is no good for you.

However, you are immensely knowledgeable on the Middle Age, warfare, and historical European martial arts. You can spot which webpages expose “bullshit”. You can explain how to find trustworthy homepages with big truth value.

You say that the obsessions try to persuade you that people do not see you, as you see yourself. You are a boy with brown hair and brown eyes. But the obsessions insist that others see you with blonde hair and blue eyes. The obsessions say things like, “If you do not do this, then there is a big risk that...”

Together we decided the obsessions are “bullshit”, just like some webpages are bullshit. But you do not have much faith that things can change. Your experience is

that if one obsession disappears, another takes its place. I predicted we cannot prevent thoughts from showing up, but we agreed that they should not force you to do rituals. That is malicious.

You have no energy for a fight between you and the obsessions. We considered whether other techniques might help you avoid following their demands.

I asked about your undone shoelaces. At first you did not think the laces had anything to do with obsessions. They did when you were younger, but now they were just a bad habit. However, when I suggested lacing them for you, you got worried that the obsessions might become angry at you. Since we did not want a fight, we agreed you will think about other techniques you can use, so that I can lace your shoelaces without the obsessions interfering. We might talk about this next time we meet.

You said that when doing activities you like, the obsessions seem to have more difficulty sneaking up on you. At such times the obsessions seem to stay away and don't care. I am wondering, can you make the obsessions care more, and care less? Can you possibly lure the obsessions into not caring? Are there things you would like the obsessions to care less about?

See you in three weeks,

Nina

This is my very last letter to Isaac, several months later:

Dear Isaac,

Oh my, I am going to miss you! I think back on the times we have shared together; I have learned much from you and your parents about helping families. I want to give you my biggest thanks!

When I met you for the first time, you were a small, fast-talking boy. I recall you wanting to know about OCD, and this is how you remember those early meetings too. Today we know your autism made it impossible for you to learn about OCD. Back then, you could only care about what was interesting to you, right at that minute, and when you spoke about the OCD, you were “teaching” us. I tried to follow you and to make you curious about thinking differently. But I could not. You were a little boy and the autism stood tall in front of you, making it impossible for you to hear another person’s perspectives. But that is not how it is for you today!

At first, we all thought the OCD was your main problem. Nobody thought your autism was anything special. You were viewed as a boy who wanted to do everything in his own way. You say today, “My dad wants to do everything in his own way. That is why it is difficult for him.” Maybe, initially, everyone thought, “like father like son”?

You are a charming, talkative, and bright child. These three qualities have helped you enormously. They are another part of you, the opposite to what we see when your autism challenges you. Those three qualities also make it hard for us to see that autism makes many things difficult for you, and to appreciate how much help you need.

We have learned that you need to know things in advance, and that you need to have plans, preferably a plan A and a plan B. Your autism is the kind that makes you feel insecure if there is too much unplanned or unknown. However, you have an elephant's memory, so when plans have been laid out, you don't need to look at them to know what to expect.

Your autism likes to have systems and ensure that everybody sticks to certain rules. So, difficulties arise when others want to act spontaneously.

Your autism tries to convince you that you prefer to do things alone. It thinks that being with other people is troublesome. It is troublesome for you if there are too many people, or if they behave unpredictably, or are opposite to you. You are a very calm person, so it's unpleasant if people are too hot-headed or worrisome.

But you have learned that although people might be troublesome, this does NOT mean that you have to do things alone. You now know that asking for help is good. This is an enormous gift that you have figured that out. You are now very good at asking for and accepting help, especially from your "True Amigos"².

We have learned a lot about your OCD. OCD promises that "everything is in control". For a boy like you, who couldn't make sense of or understand all that was going on in your school and in your family, OCD could easily convince you that it could help you and give you control.

Doing your rituals did give you a sense of control and quiet. You could stop your entire family in their tracks; you were in control and made everything quiet. But this approach created many frustrations, quarrels, and scolding. You didn't know that OCD was "lying" and that you didn't need to listen. OCD seemed like your very own thoughts.

One day, you will have enough control over your own life and feel sufficiently safe, that you won't need to do rituals anymore. But for a period, you will still need to think, "I will make a small ritual inside my brain, to make myself quiet". And those rituals are okay!

When you were younger, your parents had to learn that if they gave demands to you that your autism couldn't cope with, your OCD would appear, demand rituals, and promise to give you quietness inside your head.

Your parents had to learn how to plan and schedule a daily life for you as a boy with autism, so you didn't feel anxious. That challenge was difficult. But as you say, "My true Amigos are very clever". You have gained much faith in your parents, seeing how they have worked to understand you and how they can help you.

Isaac, you are a good boy!

Isaac, your parents are lucky to have you. They know this! And Sebastian knows he has a wonderful brother, even when you get mad at each other.

I wish you and your family all kinds of happiness and joy in life. I will remember you always. You are one of those families that I will tell others about. Just like I have told you about other boys I have met. You are part of my treasure chest of wisdom about children and childhood.

Thank you for spending time with me and for being such a pleasant person to be with.

Yours sincerely, Nina

When to use, and why use, a diagnosis

The need for, and use of, diagnoses by a doctor, child, adolescent, parent or society can differ greatly. These different perspectives contextualize how we talk about, give, and use the diagnoses.

The stigma that normally accompanies a diagnosis presents an obstacle. For example, stigma can occur when a diagnosis is used in an either-or manner instead of as a spectrum trait. We need to learn to share our thoughts about diagnoses such as autism and ADHD with a special focus on the spectrum and personality traits, not as fixed diagnoses (Adam, 2013; Aggernæs, 2018).

Two letters from parents with two very different children, who could have received a diagnosis, but didn't get it, illustrate this point. Neither of the children exhibited enough suffering or enough

symptoms to meet the medical criteria for a diagnosis. But talking about the diagnosis, and gaining an understanding of their children's special needs and personalities, was helpful for the parents.

From a father:

One thing that meant a lot to me, were the conversations we had about our child; where you dared to say what we have always had in mind, about the innate personality traits that might well be contained within the light part of the autism spectrum. Our conversations on this means a lot to our approach to dealing with things, when occasionally life gets difficult. I wish someone had spoken with us about this years ago. Not everyone needs diagnoses, but those around the child need the understanding in relationship to the challenges one faces as a family.

From a mother:

The real breakthrough for us came when we met with you, and you made the right diagnosis. It was certainly true that our child would not have benefited from a diagnosis at that time. But today, as things have settled down, we benefit from a more nuanced understanding and being able to put words to it. We can laugh and joke together about reaction patterns like knowing what's going on, having systems, and so on. That's helpful.

Diagnoses for children and youth are moving targets and are socially constructed, not absolute truths. Care needs to be taken to ensure psychiatric diagnoses are not either-or or are perceived as a negative label.

Ideally, our society will cater for a greater diversity of children, where the present narrow template for normality has been broadened considerably so children don't grow up feeling wrong (Pellicano, 2018).

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¹ When it's a mental health problem, both the ICD and the DSM (Diagnostic and Statistical Manual of Mental Disorders) (APA, 2013) can be used.

² "True Amigoes" was Isaac's collective name for his three mothers.