Open letter to experts in ASD/ High Functioning Autism

May 24, 2014.

Try to imagine the following scenario: You live with a blind spouse who is not aware that he is blind and that other people actually can see. He does not know what “see” means. He has always been helped by others.

One day, after several years struggle, you succeed in convincing him it is a good idea to consult a doctor and get a formal diagnosis of blindness. Together you walk into the doctor's office, and the doctor asks your husband:

“Tell me, why do you want to have a diagnosis?”
“I don’t know,” your husband answers. “It's my wife…”
Doctor: “Do you have any problems being blind?”
Husband: “No, I have no problems.”
Doctor: “Well then I see no reason to spend more time here. Have a nice day!”

You tell me this scenario is unthinkable. Of course it is unthinkable if it only concerns a normal lack of sight. No blind person would ever behave so selfishly and disrespectfully towards their wife and family: to those people who are always available for support of their blind loved one. And no doctor, I believe, would refuse to make a diagnosis of eye blindness because a diagnosis is crucial to get the needed support which society provides to blind people and to also enable the validation which you and the children, as the family of a blind man, need from other people.

But if your spouse instead suffers from a much more severe disability than eye blindness; if he suffers from mindblindness, which is a key feature for people with Autism Spectrum Disorder (ASD, AS), then the reality of the Health and Medical system is somewhat different.

This is my experience with a psychiatrist and highly esteemed specialist in Asperger’s syndrome and Autism Spectrum Disorders:

*

In 1997 I married Harry after we knew each other for 2 years. There were already weird behaviours, but I never heard of Asperger’s syndrome or High Functioning Autism. I was in love.

After the wedding the weird behaviors increased rapidly. A friend of ours was worried. He was very conscious of Harry’s strange conduct. He liked him a lot, but couldn’t understand what was going on. The behaviours did not fit anything recognisable as people’s general oddities. On the one hand Harry seemed to be a kind person making great effort for people to like him. On the other hand, our friend noticed that Harry lacked common sense, treated me unfairly, hurtfully and dishonestly without showing the slightest regret or remorse. When Harry caused problems and hurt people around him, it seemed like he didn’t understand the link between cause and effect. Instead he blamed everybody else, and on rare occasions when faced with his culpability, he either denied it or switched immediately to victimhood.
Our friend saw how much I suffered. Together we started to search for "something" that could explain the various cognitive, mental and physical symptoms we noticed. Because of those

symptoms we looked in the neurological field. There it was: Asperger’s syndrome; High Functioning Autism.

Scary

It was a wake up for me. Asperger’s! No doubt. Flapping hands, no eye contact, lack of empathy, unable to maintain a reciprocal conversation, lack of impulse control, endless monologues about his special interests, childishly eager to satisfy his own needs, no striving for mutual understanding, no responsibility for his own conduct - and at the same time having an impressive knowledge about topics that interest him.

I was relieved: relieved, because I understood Harry’s behaviour had nothing to do with me. It was all about a disorder on the Autism Spectrum: an invisible, but pervasive and severe neurological disorder.

I didn’t say a word to Harry about Asperger’s syndrome. I felt he would not be able to cope with the truth. Furthermore, I felt intuitively, it could be dangerous for me to tell him. So far, the knowledge was a help for me to interpret my husband’s intelligence gaps and socially inappropriate, egocentric behaviour. I used this insight to support Harry as best I could.

A couple of years later, sitting in the kitchen in the evening, Harry was verbally unusually cruel. At that time I knew all about the Asperger’s arrogance and uncontrollable urge to belittle anyone who didn’t have his special knowledge and didn’t share his opinions. It was exposed to me almost every day and I had trained myself not to pay attention because it was too stressful for me. But this time he was unusually verbally cruel. He did not respond to my requests to stop, but increased the cruel verbal abuses. He hurt me again and again, and I just knew: I have to tell him. I was exhausted and despaired at trying to understand and cover up for the man I loved and at the same time being abused and belittled.

“I have to tell him,” I thought. And I did.

I didn't even finish the words "Asperger's syndrome". All I managed to say was, “Harry, I think, you possibly have a disorder called Asperger's syn…"

Smash. He struck me violently. I lay on the kitchen floor and bled. He kept beating me hard. At every stroke he shouted furiously: “I've never hit you, I've never hit you. I’ve never hit you".

I was terrified. He went on and on, I couldn’t move. He did not stop beating me, until I begged: "It is my fault, pleeease forgive me".

Should I have gone to the police?

I didn’t. Instead I called our friend; the only person who knew the truth. He talked to Harry, and I was stunned how Harry spoke with such control and so friendly on the phone as if nothing had happened. As soon as our friend was on the phone Harry had full control over himself; in a split second he was able to change from a scary and violent man beating his wife, into a charming pleaser. It was only her who was hysterical he said cheerfully to our friend. “Everything is OK!”

It was bizarre. How can anyone behave so comfortably right after he has beaten his wife, drawing her blood?

To me it is a mystery how a person who normally is passive and extremely slow to react: if he reacts at all to his family’s attempts at interactions, suddenly was able to transform himself into a vicious assailant, and then a moment later, as soon as our friend came on the line, was immediately able to transform himself once again: this time into a cheerful “nice guy”. Is that what some people who advocate for those on the spectrum call “honest, naive and innocent”?

I am deeply grateful that our friend did not let himself be manipulated. Instead he told Harry **about** Asperger’s syndrome. Told him his assessment that Harry had an autism spectrum disorder called Asperger’s syndrome and suggested to him that he be properly diagnosed.

No remorse

Our friend’s support and validation was invaluable to me. But what I couldn’t imagine that frightening evening in the kitchen was that our friend would turn out to be the one and only person around us who understood the truth; consistently showing support and validation which helped me to survive.

Harry never apologized after the violent abuse. He never expressed any remorse. But over the next few days he was subdued. After a week I told him gently that I had found a private person who could test him informally just to see whether it was Asperger’s or not. That day I experienced a miracle: Harry said, “I’ll go and see that man. I’ll prove to you, that you are wrong."

Harry came back from the test almost singing to himself and in a good mood.

He said, "Well it seems like I have this asp thing,” while laughing to himself. “People with Asperger's are highly intelligent!"

I managed to suppress the smile that bubbled up in me. I was familiar with the misleading myth of “high intelligence”, that some people with Asperger’s autism constantly repeat to each other.

“This man you visited”, I asked. “Is he on the autism spectrum?”

“Yes”, Harry said. “He has Asperger’s syndrome. He is a very nice guy.”

This narrow-minded focus could not be the end of our journey towards an honest and responsible management of reality. That’s what I thought as I relied on the expert! So I planned for another miracle. I already had the name of a Scandinavian specialist: a psychiatrist and expert in this area of neurological disorders. I told Harry that it was a good idea to make an appointment and get an official diagnosis.

Harry’s response was, "Why? He is a psychiatrist? I'm not mentally ill.”
I replied, "He is ALSO a specialist in this Asperger's syndrome."
I couldn’t believe what happened. Harry was willing to contribute to the next miracle: consulting the specialist and getting a formal diagnosis.

We stipulated an appointment for a tele-conference with the psychiatrist. The day arrived, and with me beside him, Harry actually phoned this specialist at a prestigious hospital.

“Have a nice day”

This was the precious moment in a long marriage: when my aspie-spouse was actually willing to do the right thing: namely to clarify the reality and truth about his suspected diagnosis. A clarifying, which obviously is a prerequisite for being able to handle the challenge in a marriage, where I am the other half.

I was fully aware of the precious moment. Among the severe characteristics of Asperger’s syndrome is the mindblindness and lack of acknowledgement of their own disorder. But with the violent incident still in mind, including my bruises and wounds, and with Harry’s self-understanding as a good person, this was the rare moment, where a diagnosed “excuse” for his behaviour would be easier to swallow for Harry than the idea of being a violent wife-beater.

Harry got the specialist on the phone. He asked Harry some questions on the telephone to get a picture.

“It sounds a lot like Asperger’s. Can very well be”, the psychiatrist said, explaining that Harry would have come to his office for a proper clinical diagnosis, which Harry declared he was willing to do.

Then the psychiatrist asked:

“Why do you want to get diagnosed? Why do you need it?”

Harry replied, “I don't know. It's my wife…”

Psychiatrist: “Do you have any problems on the job or with your family life?”

Harry lied, “No, I have no problems.”

Psychiatrist: “Well, if you don't have any problems possibly having Asperger's syndrome, then I see no reason to spend more time on this. You just go on with your life! Have a nice day!”

I was paralyzed. I couldn’t breathe. This could not be happening.

Harry turned to me and said, “The doctor says there is no reason for seeing him! You just ask him!”

Harry handed me the phone.
“But," I stammered into the handset.
No reply. Gone was the expert. Gone was the precious moment.

The betrayal

A month later, Harry denied he ever had been to the first private practitioner and denied he got an informal diagnosis. He denied the tele-conference with the psychiatrist. He denied everything.

In despair I contacted the psychiatrist for a final attempt. I told him about the denial. Tried to make him understand that a correct diagnosis was important for our life, for other people's wellbeing and important for the public health care system which risks committing medical errors to Harry's detriment, as he frequently consulted physicians about his various health problems.

The psychiatrist didn't care.

The primary betrayal by a spouse on the autism spectrum is horrific. But the secondary betrayal by an expert, who is supposed to help and is even paid by the tax-payers, is worse.

I had lost. Respect for the medical truth was lost. The professional's ethical responsibility, that I as a matter of course expected, was non-existent. Instead, this health authority representative sent my nice, but mind-blind and neurological disordered husband away with the false perception that his conduct did not give rise to any problems! Just as if an ophthalmologist had encouraged an eye-blind person to move around in traffic as he pleases, because: You don't have any problems! It's just all the others out there in the traffic, who see the problems!

I sank into despair and loneliness. Life went on. The psychiatrist went on sitting in his office writing forewords about ASD, while the problems around Harry caused by his severe disorder, piled up.

I spent all my spare time helping my husband legally solve dozens of complaints against him coming from his colleagues and from the parish council, where he was a vicar. In my head the psychiatrist's untruthfully answered question resounded: “Do you have any problems on the job?”

Adults with Asperger's/High Functioning Autism *always* have problems on the job and in family life. Hfa sufferers are dealing with a pervasive, severe disorder, that by definition affects all areas of human relations, and which by definition (lacking Theory of Own Mind/insight) implies lack of self-awareness by the person, who has the disorder. No responsible and decent expert would ever base his assessment on a brief telephone statement from a mindblind person.

Absence of ethics

This expert did. But what the expert *did not* do was to ask me (and Harry) the most fundamental questions, that anyone with common sense and a basic knowledge about Aspergers syndrome knows are essential, when you are dealing with a possible Autism Spectrum Disorder:
Does Harry have children? Are there siblings on the autism spectrum? Problems with impulse control? Beaten his spouse? Pushed her violently down the stairs? Has Harry a Firearms Licence? Other diagnoses, e.g. Tourette's syndrome or epilepsy? Suffering from legal drug abuse? Anxiety? Depression? Eating disorders? Gut problems? Skin problems? Ludomania? Consulting medical specialists because of sensory problems with sound and light? Violating other people with exhibitionistic behaviour?

The great majority of these questions can in this case be answered with a “Yes”, which in turn places a clear responsibility on the health authorities who accordingly would have relieved the spouse and possible kids from some of the traumas and continuous stress and fear.

I was never relieved for anything. Complaints from colleagues and the parish council continued and continued. Some people in the ecclesiastical bureaucracy did everything to get Harry fired. There were times where Harry had long periods of sick leave. For years I found myself in a state of despair, stress and depression. I managed to protect Harry from their “projectiles” and get the malicious complaints rejected as unjustified. At the same time it was obvious to me, that these people understood "something" was wrong. It was just that they had no idea what this “something” was. Instead, they fabricated the most vicious lies and accusations. I was the one who suffered. I couldn’t bear to witness the evil that was unleashed against my husband. At the same time I felt abused by Harry because he refused to cooperate and deal with the truth in terms of his diagnosis.

Harry was 54 years old when the precious moment occurred – and was lost, thanks to an irresponsible expert. The words “Asperger’s syndrome” are still taboo. Harry’s denial of that which a competent expert would have removed by virtue of his authority, keeps life on eggshells.

Stop explaining away the truth

I have no illusions that life would have been seamless if Harry at that time had been met by a responsible and dutiful health care person. But I know for sure that dealing with ASD requires more from a professional than the lazy question, “Do you have any problems?”

Today, more than ten years later, I have had contact with hundreds of neurotypical (NT) spouses in Scandinavia and many more from around the world. What shocks me is that so many NT spouses experience the same kind of dismissal from autism experts as I experienced at that time. Can it be true, that only a few pioneering medical experts around the world have a vision of the whole family's well-being, when an adult in the family suffers from High Functioning Autism/Asperger’s syndrome?

My request to all autism experts is this: Stop explaining away the reality of Asperger’s/High Functioning Autism. It is self-evident that autism- as other disorders - is nobody’s fault. But when the scientifically proven devastating effects on children and families of adults on the Autism Spectrum are ignored by experts, this part of the problem’s complexity *becomes* your fault. As experts and medical professionals you have an ethical responsibility. Use your expertise to make accurate diagnoses for adults and reluctant AS/Hfa then accurately inform the public how AS/Hfa affects spouses and families of people on the spectrum.

It helps no one, least of all persons with AS/Hfa and their caregivers inside the families, when the severe effects of their disorder are wrapped away in cotton candy.

© Sofia Morgan
Scandinavia

May 24, 2014