

2011 congress on autism organised by the Dutch Association for Autism NVA

Nederlandse Vereniging voor Autisme (www.autisme.nl)

7 & 8 oktober 2011, attendance > 2500 participants

From the brochure:

Autism at Work

Ir. Diederik Weve is field-expert and works as a process safety specialist at Shell

Where are all colleagues with autism in the company I work?

Globally, there should be 1000 at least, but why are they invisible?

Shortly after receiving my Asperger diagnosis I started searching but repeatedly met the response: “good question, but I’m afraid I don’t know anybody”

In a technical company, large and specialised, autism isn’t visible necessarily. Neither is it bound to be problematic, because there are numerous positions in which the qualities of autism are more important than the limitations. In contrast with that there is shame and fear to disclose ones autism. This increases stress and poses a barrier in the search for better work-arrangements.

I started a search for a way to include autism in the company culture and initiated a number of activities to provide autistic colleagues with an excuse to have a coming-out: information, workshops, twitter-groups. I will share my experiences.

Autism at Work

NVA Autism congres 2011



Diederik Weve 7-8 october 2011

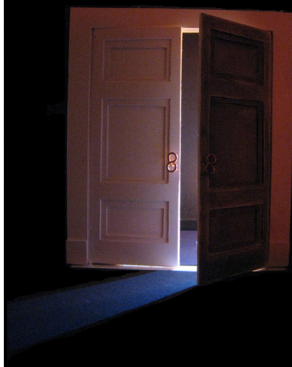
Commentary to the slides.

My story starts about 2 years ago when I received the diagnosis of Asperger's
I started searching for colleagues with autism almost immediately but failed to identify
any; well just 1 to be exact.

Being an engineer at Shell I had already done the maths: 1% of 100,000 staff globally
would equate to 1000 colleagues with autism.

I had a suspicion as to the cause and started a project...

Coming out for Autistics

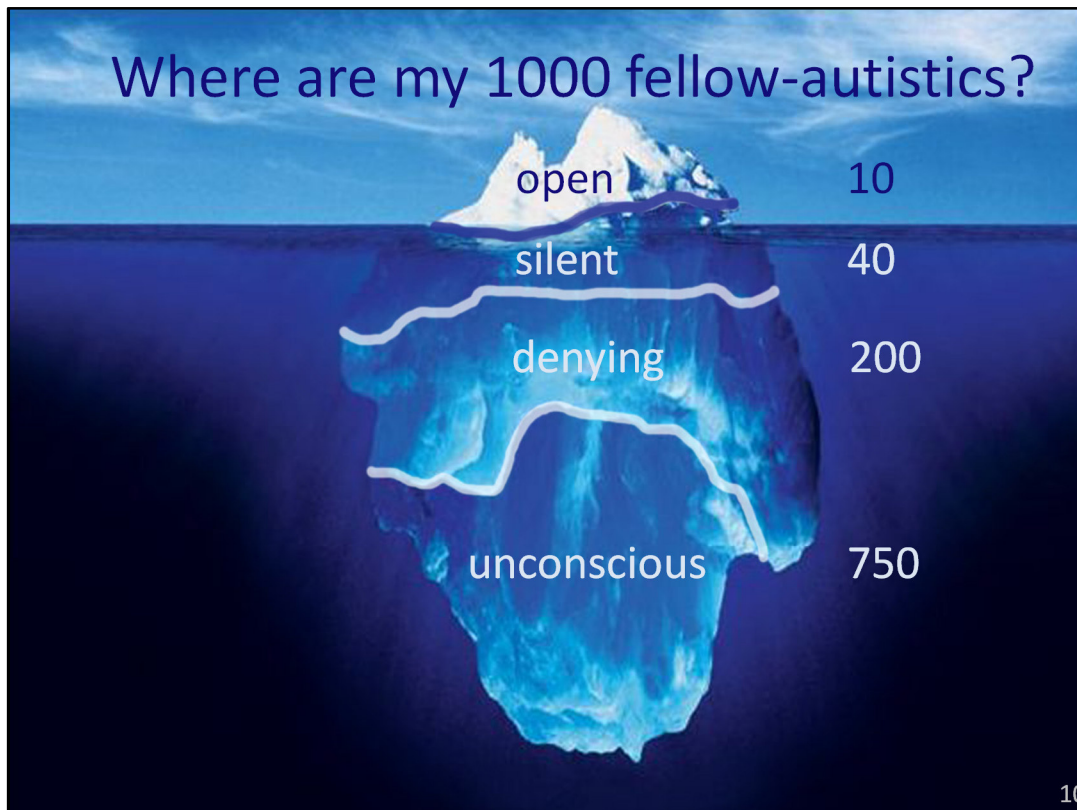


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Coming out for Autistics

At work I frequently use a more neutral term, but you get the message: this story is about shame and fear.

Of all projects I have done within Shell, I find this the most important and challenging. For your clarification: I will use the term autism/autistic when referring to the full spectrum of Autistic Spectrum Disorders.



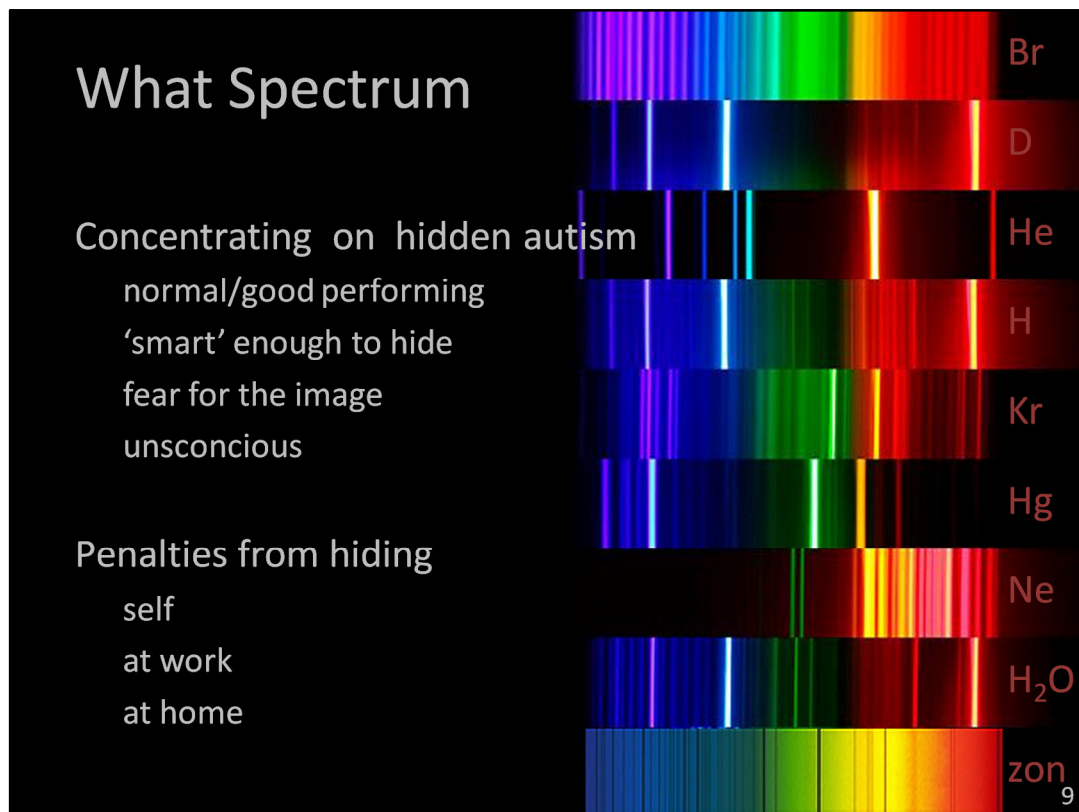
With that sole autistic colleague I had probably hit just the tip of an iceberg. A single person in the Netherlands would equate to 10 worldwide.

Most colleague-autistics however will be unaware of the fact that they are autistic. Personally I found out only after $\frac{3}{4}$ of my career and $\frac{3}{4} * 1000$ would mean 750 unconscious globally.

Obviously there are many autistics that do know –or at least suspect it- because they have a child or a parent with autism; however they don't want to know; they reject the mere possibility of being autistic: the denying.

Lastly, there will be a group that accepts the diagnosis, but selects not to disclose that to others: the silent.

All these numbers are just a guess.



My project is aimed at only a fraction of all autistics, a part of the spectrum: the hidden autistics.

They are performing normal or good at work. Apparently they are smart enough to compensate their weaknesses, or even deliberately hide them. The latter case may happen if they fear the image, the image that autism doesn't mix with being smart and having a regular or good job. Now please note that through this hiding they maintain the situation they fear: the poor image of autism. As long as all smart autistics with good jobs keep hiding this image will not change.

Hiding however isn't that smart at all: denying your own personality, creating stress through keeping up appearances, work cannot improve, at home this doesn't help either.

It's a vicious circle that I find undesirable and unjust, so I want to break it. Now... How to discuss the indiscussable in a company of 100,000 staff?



Moving course in a company?

Reframe

- Fit in company culture
- Limitation → diversity
- Case for Action

Testing ideas

- HR
- Company health physician
- Employee networks

Execute

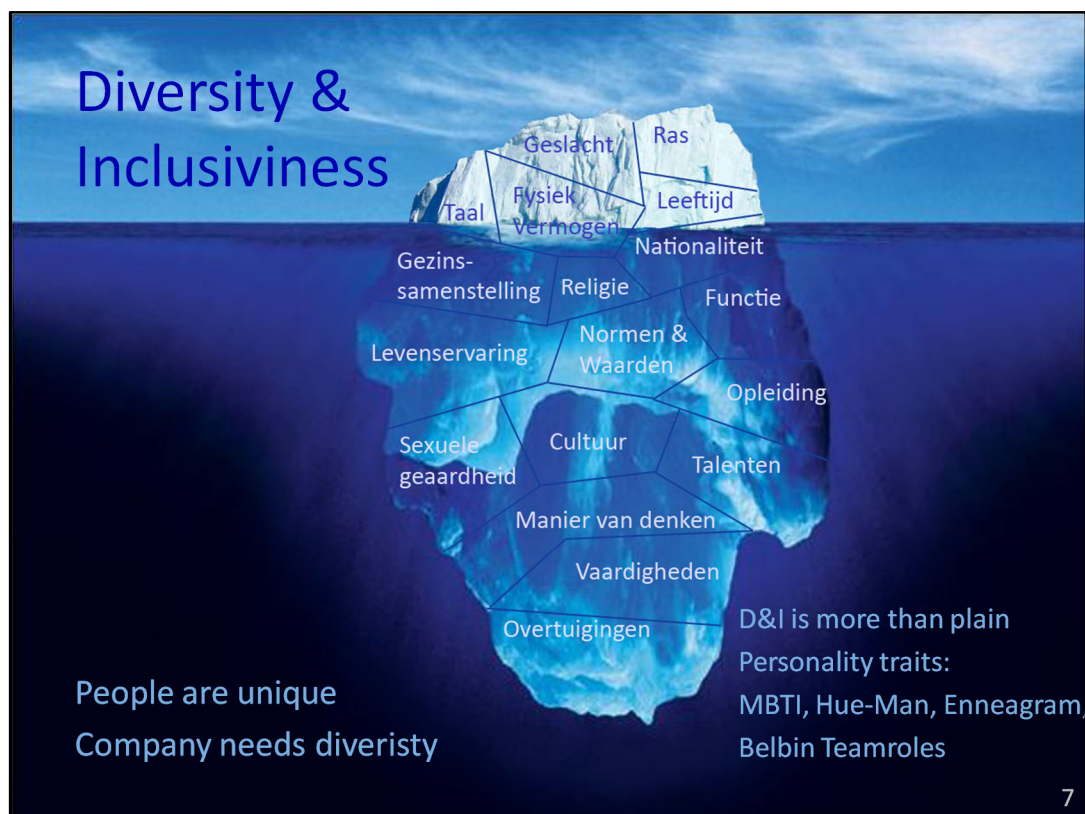
- Materials matching the group
- English language (10 000 → 100 000 staff)
- As board member of an employee network enABLE NL

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Moving a company with a workforce of 100,000 staff, that's like steering a Ultra Large Crude Carrier. I can't steer that, the captain does, the Chief Executive Officer of the company.

What I CAN do is finding out how autism does fit the company and communicate that. I thought I could 'reframe' autism as a diversity case in our company culture.

I tested my ideas with people I could trust and started the execution phase.



The company culture I'm reframing autism into is called Diversity & Inclusiveness. This is not a Shell invention, but it was introduced in Shell 10 years ago so well known. People are unique because of the variations in all the different aspects. This diversity is needed in the company.

However, people tend to base their interactions on visible aspects rather than invisible aspects, thus losing the benefits of diversity. Inclusiveness means ensuring that all aspects, also the invisible ones are respected in interactions.

I position autism as "Thought processes" primarily, "Skills" and "Talents" secondly. So I don't need to change anything in Shell just explain how autism fits in the D&I culture.

That's a solid concept and I started using that in a variety of activities, two of which I will discuss.

Soon I found myself twittering.

Yammer (=corporate twitter)

modern audience
global >12000 Yammerers

3 groups

- Autistics (private groep)
- "Autism Works"
- Parents-to

Good member growth
Low but increasing participation (10-20% messages)

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Shell has a company-version of twitter called Yammer.

I formed 2 groups around autism: a group for autistic colleagues, a private group so that identity and discussions are visible to members only. Secondly a group called Autism Works, in which I invite all Shell staff to openly discuss autism as to help break the stigma and remove the barriers.

A Parents-to group already existed and this group is important too since a fraction of the parents may prove to be autistic too.

Yammering works fair: it reaches the entire world and the groups grow faster than the Yammer community as a whole. The group members start to participate more and more.

However I also need to be able to tell the story in more detail and in direct contacts: in workshops.

Workshop 'Autism as a Diversity'

Myth or Fact?

Video-documentary of a geologist

Autism facts

Experiencing ToM & context blindness

Group assignments

discussion



The workshop 'Autism as a Diversity' was developed to create awareness for autism in a 1.5 hour workshop.

The program is varied and uses experiential learning where possible, I developed it together with a corporate D&I trainer.

Central in the workshop is experiencing autism. Theory of Mind and context blindness are two frequently used concepts in autism and participants will experience through many small psychological tests and games details of their own perception and how that influences thinking and acting. Once they understand that, we can explain the difference in case of autism and they can understand the consequences, see appreciate diversity and start being inclusive.

The participants are very enthusiastic.



What about my own experiences in this project: my biggest concern is getting the proper balance.

Making the indiscussable discussable is by definition a delicate process and a small error can easily increase the stigma.

Furthermore I'm trying to communicate to a diversity of groups: not just all autistics, but also the colleagues and managers.

On top of that, very little is published about 'High Functioning Autists' and there are no precedents for such initiatives.

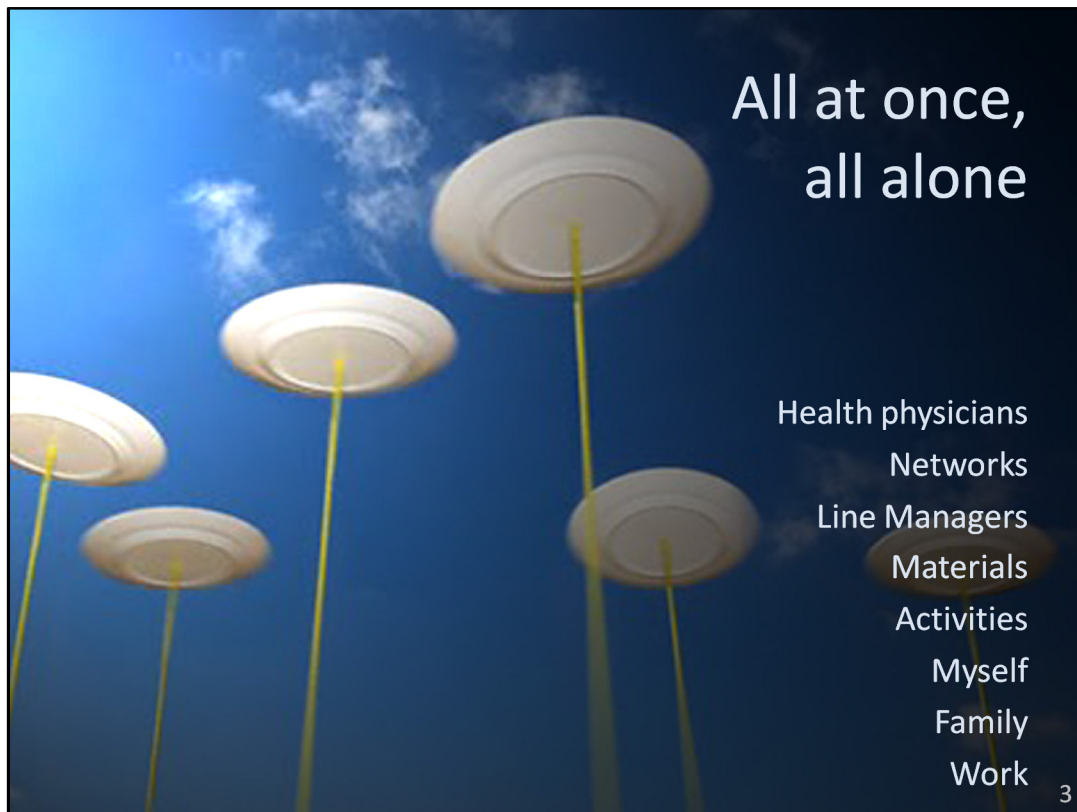
So a gold tray.

The problems deserve a solution, but should be framed as opportunities.

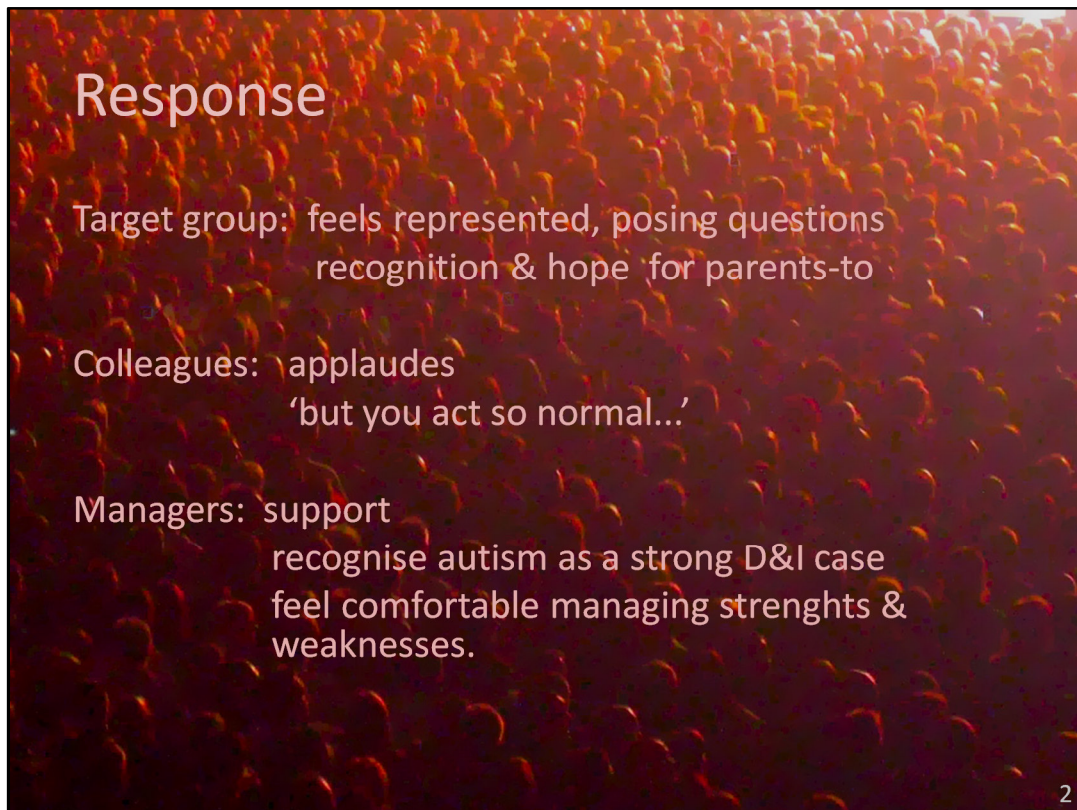
One can't discuss the strengths of autism without being realistic about the limitations.

It's tempting to use stereotypes when educating about autism but that would be counterproductive in view of the diversity in symptoms observed in autistics.

And "Coming out" means taking on a challenge, but that requires having a sense of security too.



A lot of discussions, activities to engage in, materials to develop. Mostly simultaneously, but pioneering, so without the aid of other autistics in Shell.



How did people respond so far to the project?

I received a lot of reactions, most by email, from all over the world.

The target group of autistics recognises themselves and I also received requests for information from colleagues who suspected autism. Parents sensed recognition for the qualities of their autistic child and hope for a normal future.

Colleagues applauded but some of those that knew me expressed surprise: "But, the way I know you, you act so normal". Indeed, I do my best.

Managers provide support, implicitly and explicitly. Some of the feedback I received during workshops is that the knowledge about autism helped them understand some of the true nature of D&I. And with respect to managing strengths and limitations in people: they are used to that.

So responses are overwhelming. Where did they take us?



What have we achieved?

I think we have taken the first hurdle nicely. Awareness of autism has grown tremendously in Shell.

12 autistic colleagues have made themselves known, exceeding my 2011 targets. Workshops were engaging. 14000 colleagues took the action to read the interview published on the web.

Responses show that I need to continue but I need fellow-autistics for that. I hope to grow the autistic network and can welcome other active autistics. I cannot determine the course on my own. This will also involve exporting the concept to other countries.

At the far end of the horizon but in fact really close is connecting to other companies and large organisations in the Netherlands. I would welcome sharing experiences.



I would like to conclude this story with the tale of the oak processionary moth. The reason is that it answers the frequently posed question: is autism a limitation or a strength?

The oak processionary moth received its name from the behaviour during the last phase of its caterpillar phase. It forms a procession to find the next tree, have a last meal and then evolve in the moth, and complete the reproductive cycle. It follows the tail of another caterpillar because it has no choice: it is genetically programmed to do so.

But that also raises another interesting question: if all it can do is following tails, how does it find the next tree?

As it happens –and it is biologist Midas Dekkers who pointed that out- 1 in a 100 caterpillars has a defect: it does not follow tails and therefore acts as leader. The poor caterpillar is completely unaware of its role as part of the reproductive cycle and the existence of the species.

The answer, therefore, to the question limitation or strength is: both and neither, foremost it is a diversity.

Thank you for your attention.