do engineers make good advocates?
diederik weve

You're looking at the spectrum of the sunlight.
We are not fooled by apparent whiteness of the sun. We have all learned that it's actually composed of a rainbow of colors
Don't be fooled by the continuous appearance of the rainbow. Upon closer examination you will find that there are distinct colors missing. You'r eye would never know.
People are a little bit like this. At surface you might experience a certain hue. And if you'd look closer then you might distinguish a number of distinct colors present and missing. The closer you look the better you can distinghuish them.
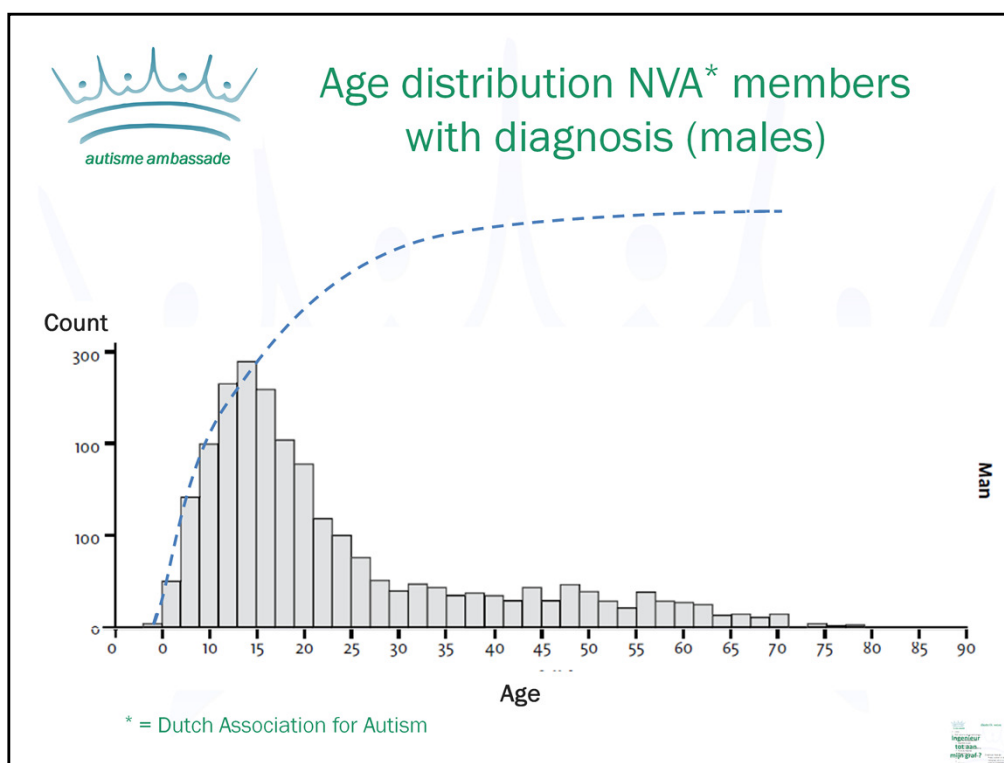
structure

autisme ambassade

- Role modelling
- Project Autism as a Diversity at Shell
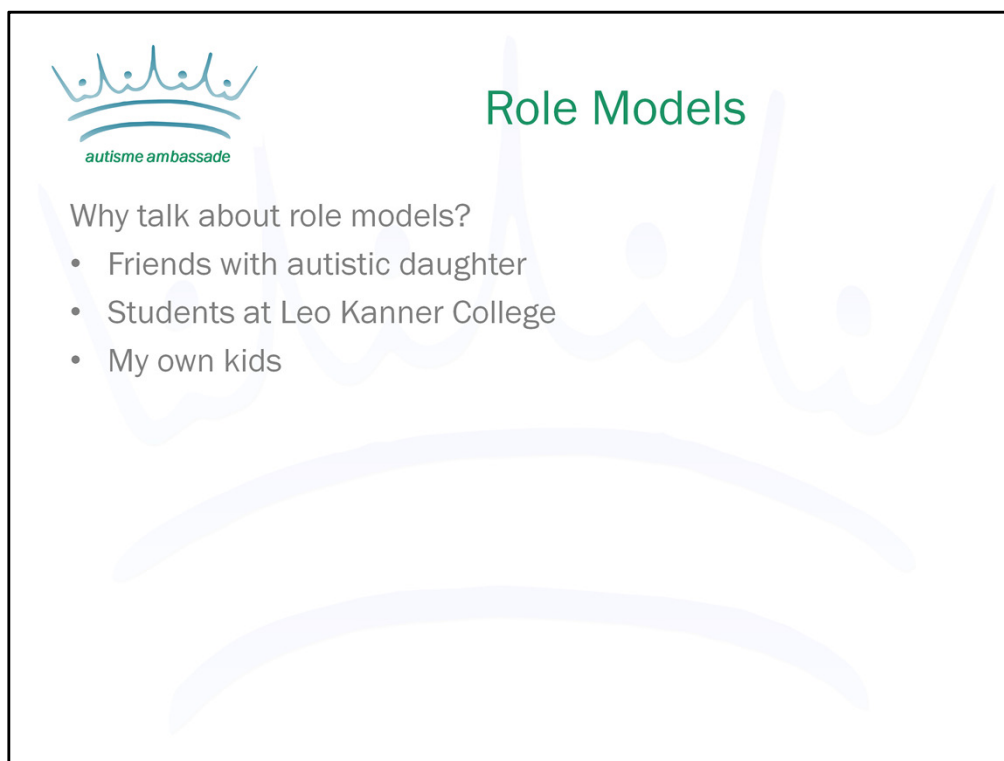- Autism Ambassador Project in NL
- Lessons / Discussion

This talk is divided in 4 parts

Age distribution NVA* members with diagnosis (males)

* = Dutch Association for Autism

Why role modelling: just look at the age distribution of the male members of the Dutch Association for Autism (NVA) that have an autism diagnosis

The dotted line I added myself and represents what one would expect: a gradual increase due to the fact that some people receive their diagnosis at an older age. There appears to be 'dark matter' –like in the universe- Where are the adult people with a diagnosis? Are they cancelling membership? Are they undiagnosed? Do they hide their diagnosis?

Funnily (or rather alarmingly) neither the NVA nor other organisations involved in (mental) health care pose this question or attempt to answer it.

Setting aside that I consider that unacceptable, there is another issue that I believe needs addressing: What are the consequences of autistic adults being missed or invisible?

Role Models

autisme ambassade

Why talk about role models?
- Friends with autistic daughter
- Students at Leo Kanner College
- My own kids

What about role models? Having examples of people with autism serving as inspiration, guidance, hope.

Our friends did not have a clue how their 4 year old PDD-NOS daughter might grow-up. A real concern if you are parent.

I once had 16 students from the Leo Kanner College over for an excursion at the Shell laboratories in Rijswijk. I told them about my work as a safety engineer and about how autism affects the way I work. For a reason I forgot I asked them 'How many of you know an autistic adult?'.

A hand rose in the air. A single hand. How can they grow up without an image of what they might be. Be, other than the label autistic.

We all need images, possible futures, heros and for them autistic adulthood was a void, a black hole.

And I could also talk about my own children. I want them to grow up experiencing that being open about ones own mental vulnerability is the better.
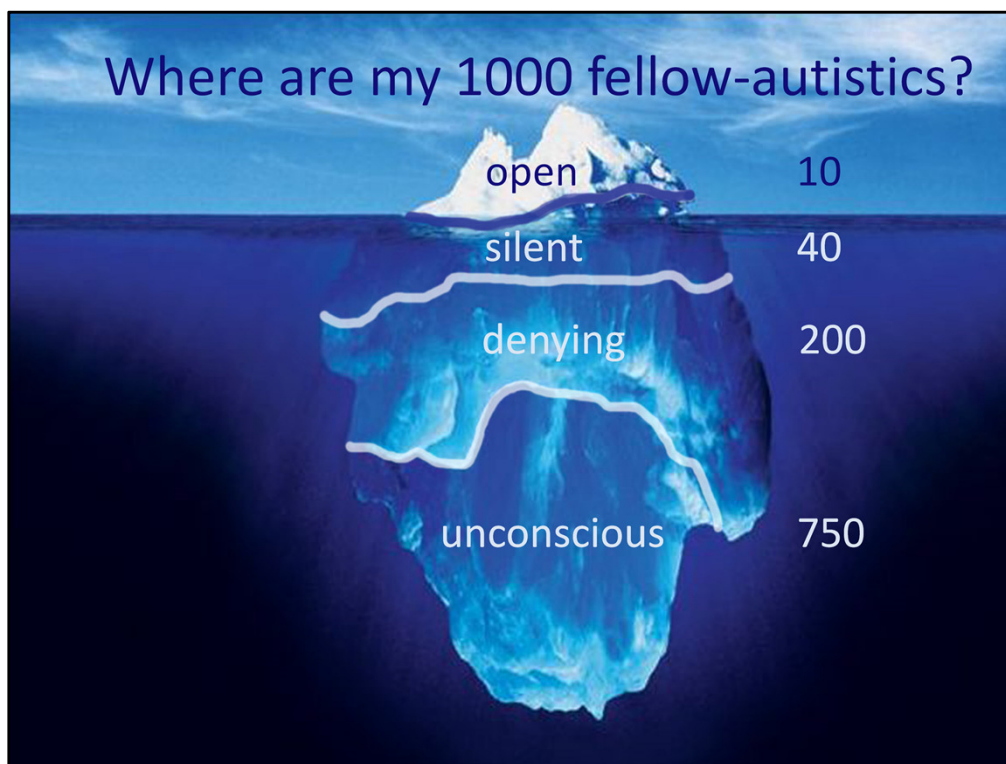
When I found about my own autism diagnosis aged 51 I started to look for autistic colleagues in Shell. I had done the math: 1% of 100,000 staff worldwide means 1000 of them. I searched but could only identify a single autistic colleague. With that sole autistic colleague I had probably hit just the tip of an iceberg. A single person in the Netherlands would equate to 10 worldwide.

Most colleague-autistsics however will be unaware of the fact that they are autistic. Personally I found out only after ¾ of my carreer and ¾ * 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.

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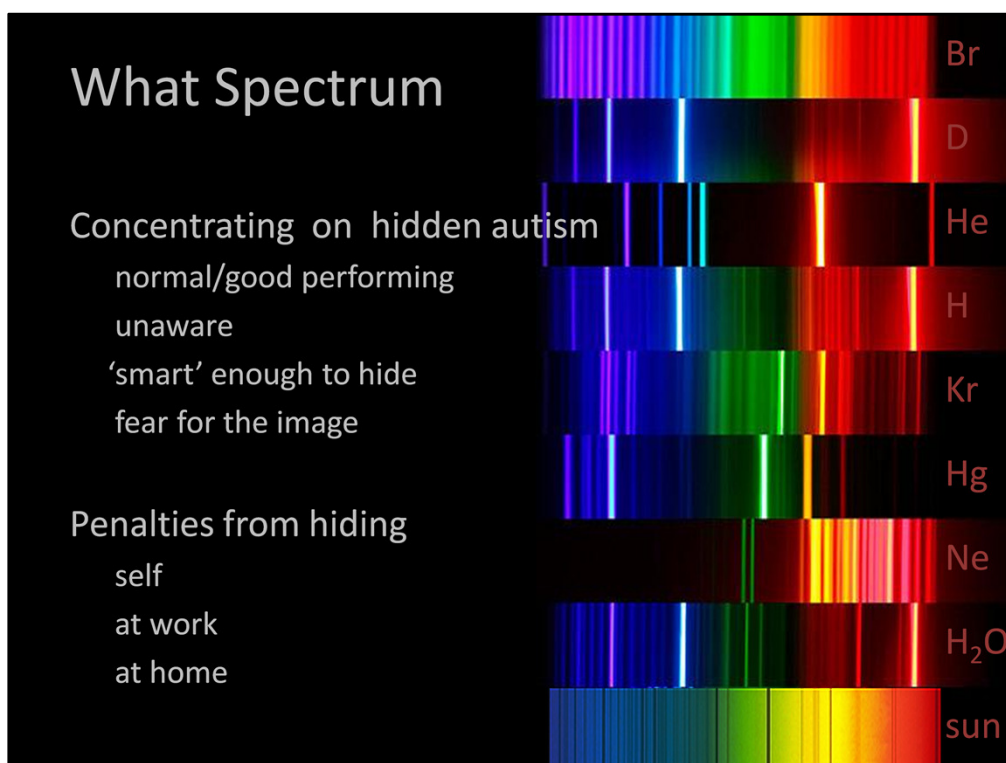
My project is aimed at only a fraction of all autistics, a part of the spectrum: the hidden autistics.

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 injust, so I want to break it.
Now... How to discuss the indiscussable in a company of 100,000 staff?

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.

I became board member of a Shell employee network for people with impairments and they helped me with execute my little project.
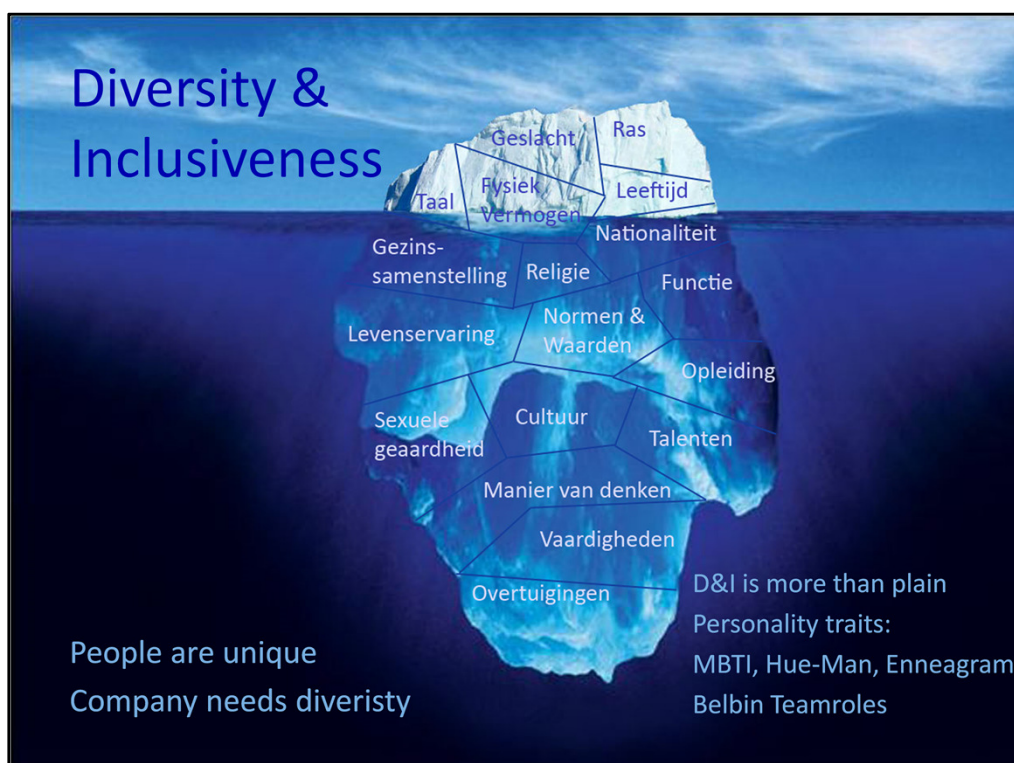
The company culture I'm reframing autism into is called Diversity & Inclusiveness.
This is not a Shell invention, but it was introduced in Shell 10 years ago so well known.
People are unique because of the variations in all the different aspects. This diversity is needed in the company.
However, people tend to base their interactions on visible aspects rather than invisible aspects, thus loosing 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 >20000 Yammerers

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

Good member growth
Limited discussions but fast response

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 that 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-documentairy 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 experiental learning where possible, I developed it together with a corporate D&I trainer.

Central in the workshop is experiencing autism. Theory of Mind and contextblindness 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, I can explain the difference in case of autism and they can understand the consequences, see & appreciate diversity and how they can contribute to being inclusive.

The participants are very enthousiastic.

What about my own experiences in this project: my biggest concern is getting the proper balance.
Making the indicussable 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.
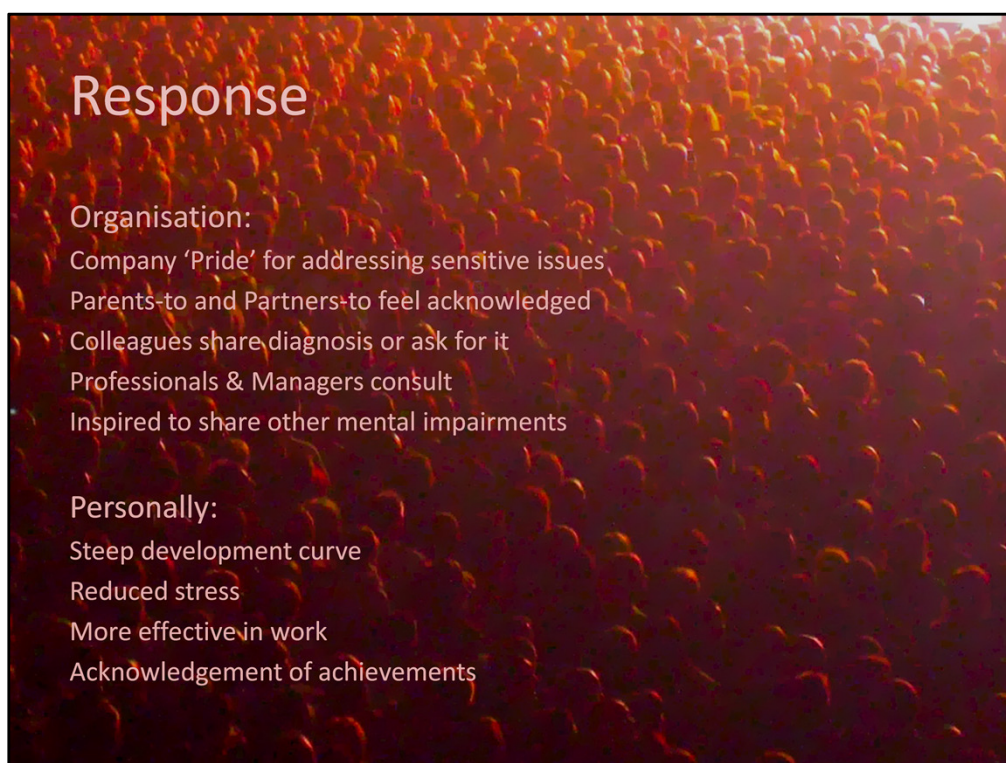
So a gold tray.
The problems deserve a solution, but should be framed as opportunities.
One can't discuss the strengths of autism without being realistic about the limitations.
It's tempting to use stereotypes when educating about autism but that would be counterproductive in view of the diversity in symptoms observed in autistics.
And "Coming out" means taking on a challenge, but that requires having a sense of security too.

Response

Organisation:
Company 'Pride' for addressing sensitive issues
Parents-to and Partners-to feel acknowledged
Colleagues share diagnosis or ask for it
Professionals & Managers consult
Inspired to share other mental impairments

Personally:
Steep development curve
Reduced stress
More effective in work
Acknowledgement of achievements

How did people respond so far to the project?
I received a lot of reactions, most by email, from Shell colleagues 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?

other NL companies
export to other countries
grow & active network

14000 read web-interview
800⁺ workshop participants
15⁺ autistics (& 53 parents/partner)

What have we achieved?
I think we have taken the first hurdle nicely. Awareness of autism has grown tremendously in Shell.
15 autistic colleagues have made themselves known to each other, exceeding my 2011 targets. Workshops were engaging and drew more than 800 participants worldwide.
14,000 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.

Shell enABLE
Be Yourself campaign 2013
https://www.youtube.com/watch?v=qbC4irVmsXU
or search Youtube for "Be yourself Shell"

Disclosure of impairments received more support in Shell and last year some 15 colleagues world-wide had their personal message recorded in a Be Yourself campaign. The compilation video can be viewed on Youtube.

Next project is the 'Autisme Ambassade', the Autism Embassy.
This is for large organisations and companies other than Shell.
It is a 2-year subproject under responsibility of a governmental taskforce.

Charter of Governmental taskforce VAB

- Taking the perspective of people with/close-to autism
  - Inventorise needs and problem areas
  - Identify and promote practical improvements
- Not limited to healthcare
  - Education, Work, Sports & Leisure
  - Diagnosis, Care, Support
  - Life-time, Living

vanuit **AUTISME** bekeken

In 2012 the Dutch governmental department for health formed a taskforce to address autism related problems. The uniqueness of the taskforce was that all major players were represented but that they were all required to take the perspective of autism rather than that of their own organisation.

The taskforce has initiated a number of projects and will be active until 2014 end.

I'm member of the taskforce because of my work in Shell and similar organisations…. and because I'm the one with the diagnosis.
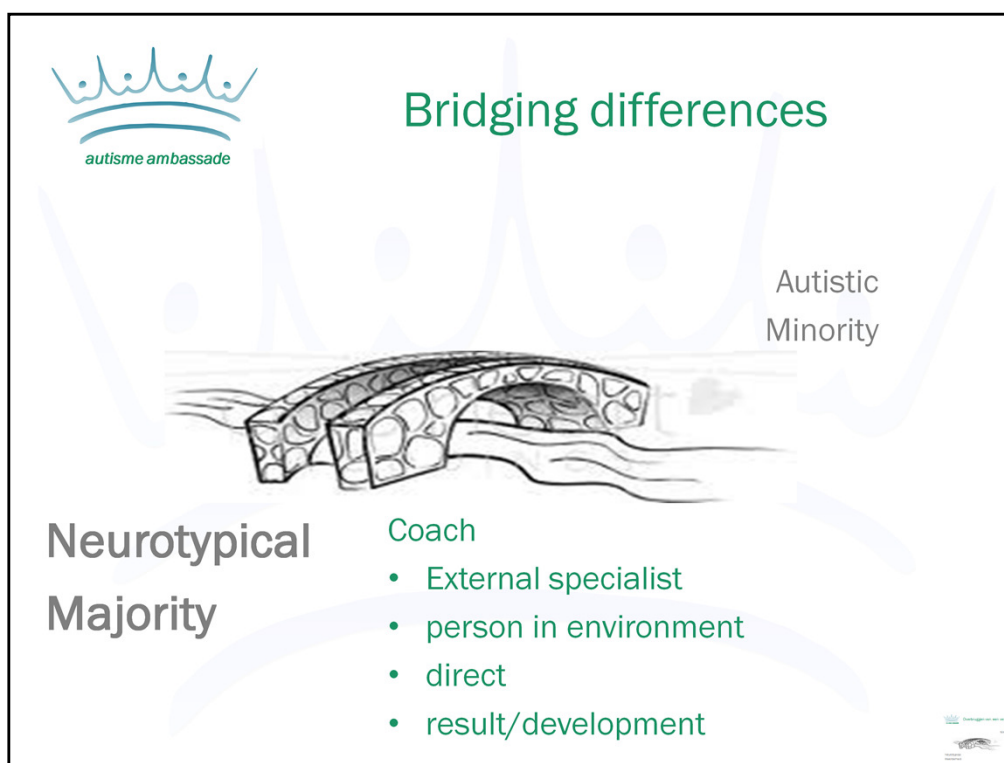
Autism in a neurotypical world requires communication about the differences. The ability to cross a bridge that connects two worlds.

Let's look at large organisations where people work together. These could be companies, public services, govermental etc.

Traditionally the bridging function is performed by someone from the majority', let's call him/her coach. The coach's activity is typically going to autistic territory, picking up a person and bringing him across the bridge to neurotypical world. Help the autistic person to fit in his environment.
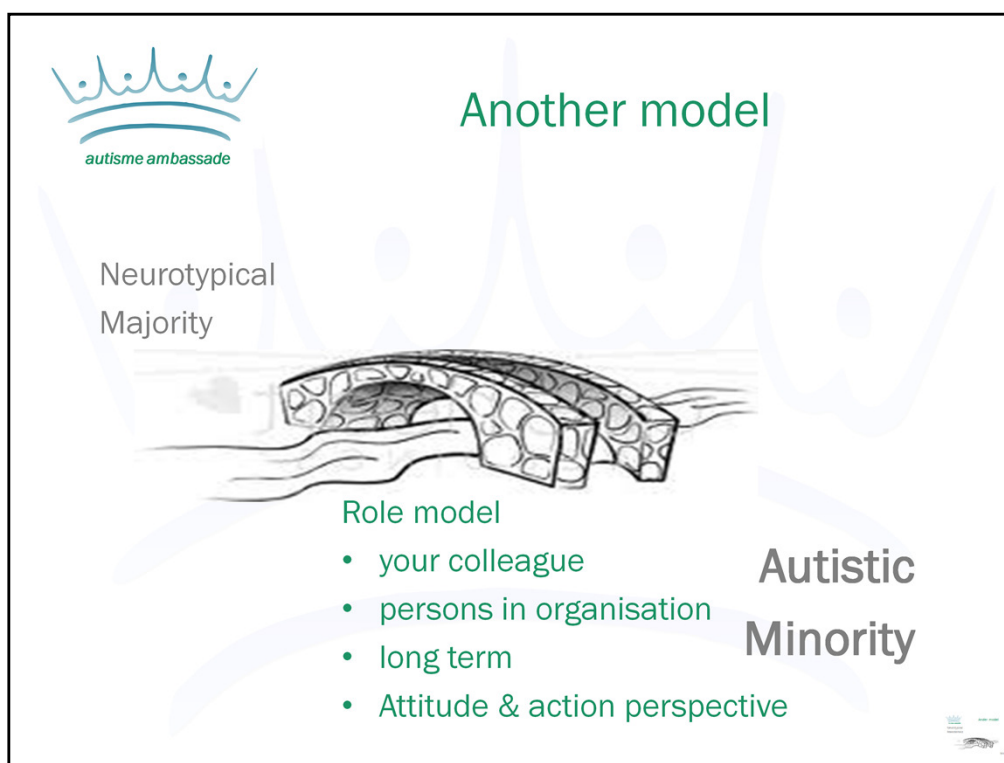
When changing the perspective to that from the autistic minority the following could be done: An autistic person in a role model can cross the bridge to the neurotypical majority and invite them to 'visit their autistic world' and learn from that. The role model addresses them in their capacity as colleague. Any colleague in their organisation for that matter, because this is about changing awareness and attitude in the entire organisation.
It's really like an embasador: transferring perspectives

The model is suited for large organisations. Such organisation have experience with employee networks to support ambassador activities (like those existing for LGBT, women etc).
In Shell I'm allowed to work 5% of my time on my autism.
Large organisations in fact provide a natural access to a large amount of people that have never been in contact with autism. It is easier to get 25 colleagues to listen to an autism story than 25 complete strangers.

The autism ambassador receives a 4 day training on content, themes, being professional about his/her autism, communication styles etc.

Just to clarify: this project is not about creating employment or helping individual people. It is about creating a proper atmosphere and realising inclusivity.

Autism Embassies

autisme ambassade

- Are (large) organisations
- Foster Diversity
- Want to support role models

ABN-AMRO

Shell

NS

Fontys
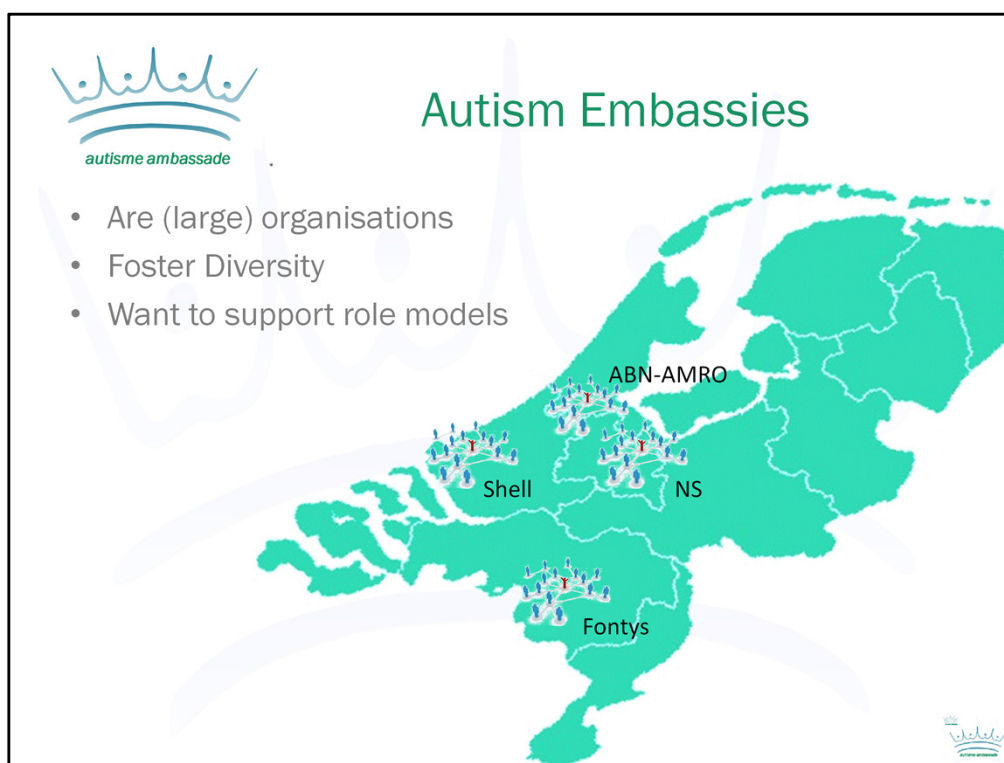
A number of large organisations now have an autism ambassador and we are training them. These are organisations that everybody knows and therefore also become a role model in themselves!

Furthermore we are hoping to extract some more embassies-ambassadors from our long list: 13 more organisations participated in a soft launch. 13 pairs of an autistic employee with their manager or HR professional jointly discussing themes like disclosure and improved communication.

Examples how to communicate

What now follows are examples of how we want to communicate
All slides are stand-alone stories
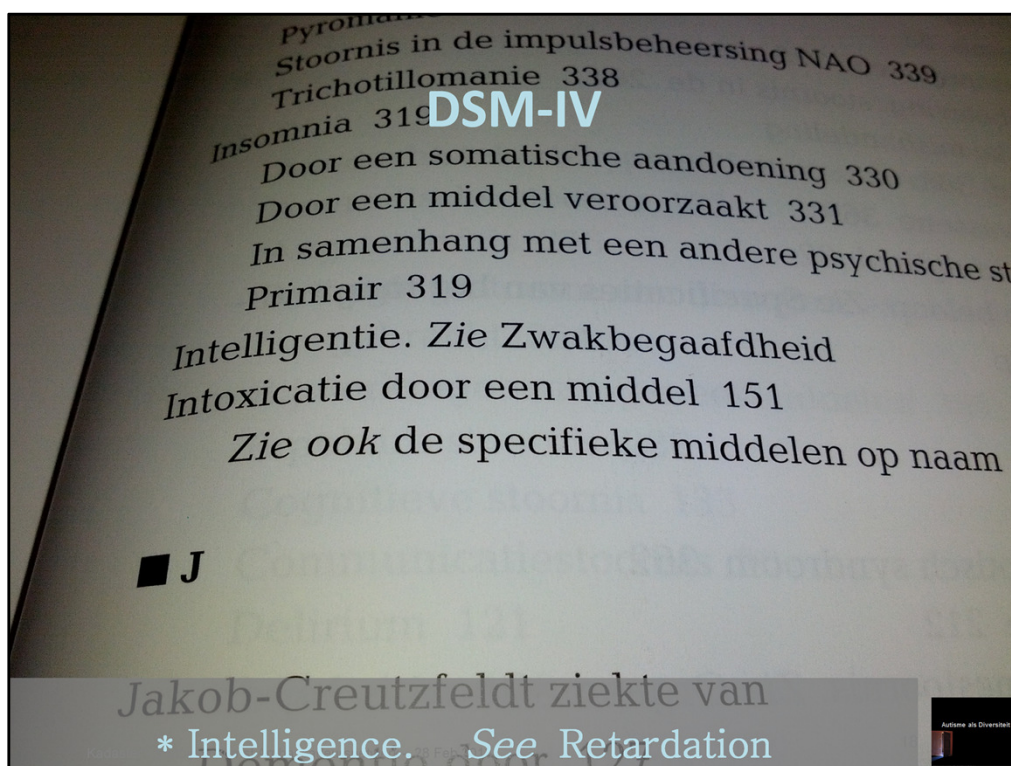
Autism is a mental condition that is described in the DSM, the Diagnostic Statistical Manual.

This is an index page of the Dutch version of the DSM. Under the letter I one can see the subject Intelligence, followed by the reference: see Retardation.

One can laugh and that would be just: we know there is more to intelligence than just what happens when it is much lower than average

One can be appaled but that would actually be unjust.

The medical profession only deals with negative consequences of physical or mental deviations from what is considered as normal for humans.

By definition. Society does not pay doctors to look at the positives.

It is the responsibility of us, society, to discover and share the positive aspects of autism.
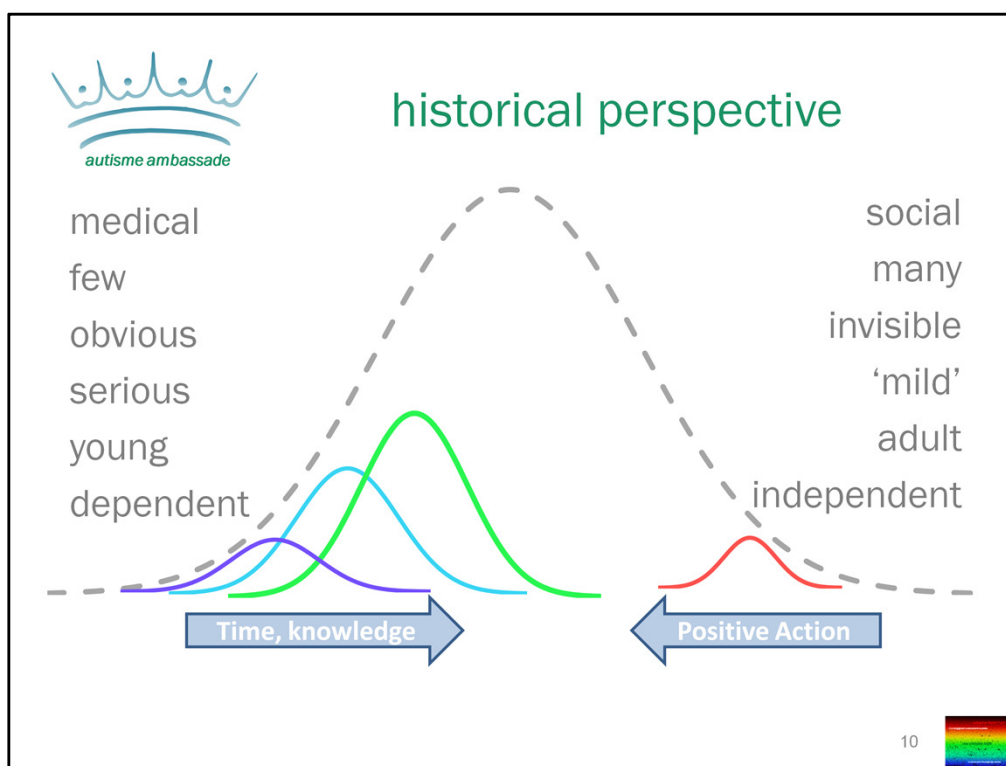
Our perspective on autism is a historical one. Let's see how that affects us using this scematic representation.

When autism was first coined by the medical profession (dark blue line), it was a very small group with obvious characteristics. Seriously enough to give it a name. These were all young persons and frequently dependent.

Later it became easier to recognise a somewhat larger group (light blue) with somewhat less obvious symptoms, typically somewhat older but young enough to be able to apply remedial teaching. Currently we also use work-coaching for an even older group (the green line) where autism is not neccessarily visible and where coaching means the difference between being dependent and independent. Some

So a general shift from left to right, all rooted however in the disability side.

The actual group of autistic people is probably the grey dashed curve, with many more autistics that currently somehow operate in our society.

With a continuously evolving society, optimising at 'standard people', these invisible autistic people are in fact in jeopardy.

Making this group visible would portray them as an extension of the earlier known groups, the historic disability perspective.

It is therefore important that well functioning autistic people become visible, operating at the right hand side (red curve).

Their disclosure will create 'space' for the much larger group.

Threading sensitivities

- I'm autistic
    - versus: I have autism

- I have a disorder

- I have an impairment

- I'm Dutch, I'm an engineer, I'm a man, I'm a father

- Just a deviation with unwanted consequences
    - Culture, Fashion
    - Majority defines

- … and learned to cope & compensate

Sensitive issues are not like mines that should be avoided. Instead I believe that they should be identified and defused.

The sensitivity means that the environment may experience barriers to engage, and such barriers will disadvantage the autistic person.

E.g. being autistic doesn't mean that I'm defined by autism alone. Autism is one of my many features influencing how I live and who I am. It is unseperable, not something to have.

Disorders: medically it requires two elements only: deviation (from norm) resulting in discomfort (from things happening). Both these elements are greatly influenced by the norms of the majority. The key to solving many autistic problems therefore lies in the hands of the majority. Learnings from homosexuality….

Impairments: these are not neccessarily negative only. Consider that impairments generally lead to the development of coping and compensating skills. As an example: my model based thinking was probably developed to compensate for my a lack of intuitive understanding. It now is the basis for my professionalism in my job. Furthermore it is frequently stated that people with impairments have a greater stamina, a can-do attitude.

Belbin Team Roles

allowable weaknesses

since...

inherent to
strong points

Team Role	Contribution	Allowable Weakness
Plant	Creative, imaginative, unorthodox. Solves difficult problems.	Ignores incidentals. Too pre-occupied to communicate effectively.
Resource Investigator	Extrovert, enthusiastic, communicative. Explores opportunities. Develops contacts.	Over-optimistic. Loses interest once initial enthusiasm has passed.
Co-ordinator	Mature, confident, a good chairperson. Clarifies goals, promotes decision-making, delegates well.	Can be seen as manipulative. Offloads personal work.
Shaper	Challenging, dynamic, thrives on pressure. Has the drive and courage to overcome obstacles.	Prone to provocation. Offends people's feelings.
Monitor Evaluator	Sober, strategic and discerning. Sees all options. Judges accurately.	Lacks drive and ability to inspire others.
Teamworker	Co-operative, mild, perceptive and diplomatic. Listens, builds, averts friction.	Indecisive in crunch situations.
Implementer	Disciplined, reliable, conservative and efficient. Turns ideas into practical actions.	Somewhat inflexible. Slow to respond to new possibilities.
Completer Finisher	Painstaking, conscientious, anxious. Searches out errors and omissions. Polishes and perfects.	Inclined to worry unduly. Reluctant to delegate.
Specialist	Single-minded, self-starting, dedicated. Provides knowledge and skills in rare supply.	Contributes on only a narrow front. Dwells on technicalities.

How to communicate weaknesses, or even disabilities in organisations?
I use the Belbin Team Roles model for discussing personality types. It applies to tasks that are so diverse or big that they cannot be performed by a single person.
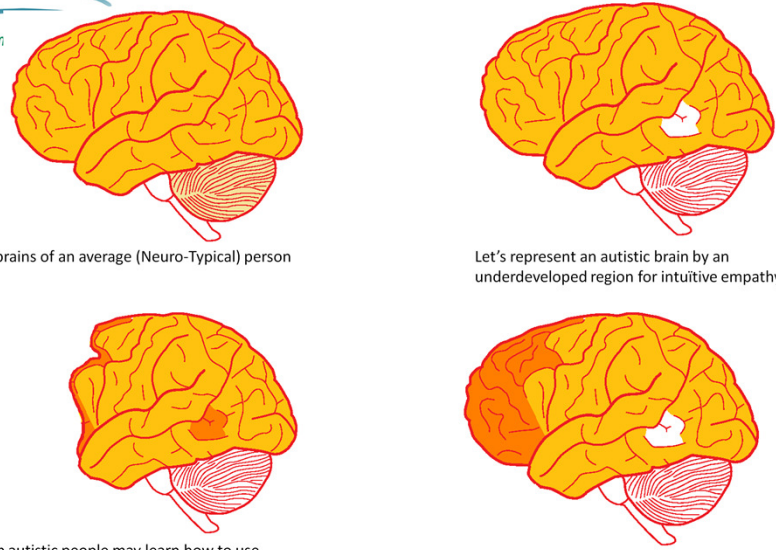The good thing is that it explicitly talks about 'allowable weaknesses'. Allowable because they are the flip side of the strong points where the person will contribute. This is only natural. If you're looking for a car, a carpenter or a piece of meat: you first select on the positive traits and then decide how to deal with the negatives.

I like it better than Myers-Briggs Type Identity (MBTI), Hue-Man Traits, Enneagram etc.
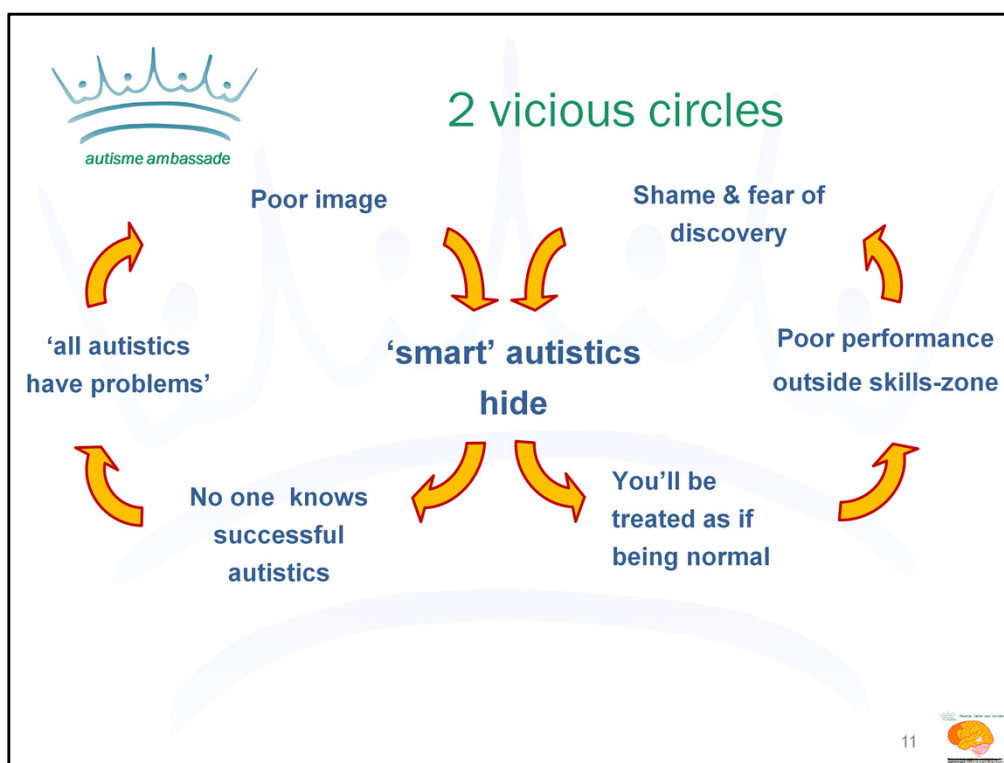
This slide discusses what happens if a 'smart' autistic person (that functions so well that disclosure is optional) decides not to disclose:

Of course there are many more things that are responsible for or reinforce the negative image, but this works well in work context.

Is it smart to compensate?

The brains of an average (Neuro-Typical) person

Let's represent an autistic brain by an underdeveloped region for intuïtive empathy

Although autistic people may learn how to use other –cognitive- brain regions to mimic empathy this will be at the expense of spare capacity for other tasks

It may be better to accept the existence of a 'hole' and leave the other brain regions doing what they are best at

28

Silent animation

play http://www.youtube.com/watch?v=nSk-KMTqFxY starting at 31:05

alternatively: Youtube.com search for "Heider Simmel"

autisme ambassade

- Play the silent animation
- Ask the audience what they saw
- Play the video again and explain that they unconsciously created their social stories. That this is the evolutionary solution to the inability to read each others mind.
- Who is impaired? Those that see social stories or those that don't?
- Build upon what happens if everybody unconsciously 'receives' the social story but except one....

This is an exercise that makes people aware of unconscious processing of information and the consequences of not having a level playing field.

Oak Processionary Moth

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 it's 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.

Why did this work out (at Shell)?

- Tradition of D&I Policies
- Disability Network
- Being a colleague

→ Repeat the trick of women, LGBT etc
→ Use their network & skills
"One-of-us"

- Personal stories
- Psychological tests
- Revealing blind spots

- Irresistible for NTs
- Experience subconsciousness
- Changing perspective

- No blame, no pity, no charity
- Openly discuss boundaries
  of impairments

- Respectful, enjoyable learning
- Develops disability confidence

Would this work in UK?

autisme ambassade

Need to find match

- Organisation/company
  - Values Diversity
  - Supports or provides Inclusiveness
  - Has employee networks, preferrably on diversity issues (women, LGBT, culture)
  - Backs individual to spend 5% of his time

- Existing employee
  - Not recently diagnosed
  - Performing normal or good (no current conflict)
  - Feels confident being open
  - Willing to engage with others on their turf