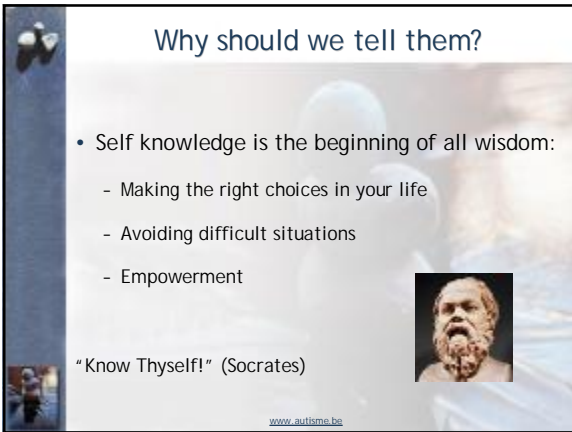




Jeg er noe helt spesielt!
 Psykoedukasjon for mennesker med autisme og Asperger syndrom

Peter Vermeulen
 Centre for Concrete Communication



Why should we tell them?

- Self knowledge is the beginning of all wisdom:
 - Making the right choices in your life
 - Avoiding difficult situations
 - Empowerment

“Know Thyself!” (Socrates)

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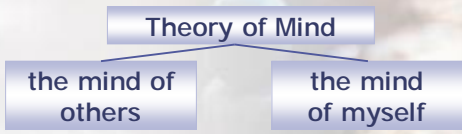
Mirror, mirror on the wall...

Can people with autism develop

- a realistic self-image?
- insight into their own autism?

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Theory of mind and self-knowledge




```
graph TD;
  A[Theory of Mind] --> B[the mind of others];
  A --> C[the mind of myself];
```

If people with autism have difficulties to know others the way we do, how can they know themselves as we do?

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Studies on self-image & self-esteem

- Capps, Sigman & Yirmiya (1995)
- Lee & Hobson (1998)
- Green et al. (2000)
- Toichi et al. (2002)
- Vermeulen (2002)

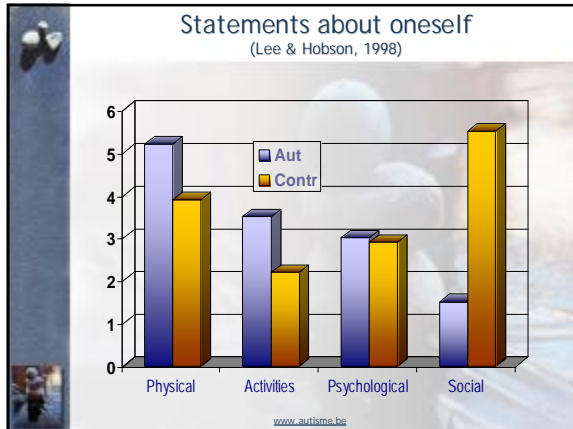


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Social self-image (Capps e. a., 1995)

- Observed social competence
 - Negative correlation with IQ
 - Negative correlation with emotional understanding

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Awareness of autism (Green e.a., 2000)

- Many have some notion, but only 15% have a realistic perception of their own disability
- Often no notion of what the real problems are in concrete everyday situations

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Self-concept

- Descriptive element: description of myself - self-image
- Element of evaluation: self-esteem

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Sense of self

Lack of "sense of self" in autism
(Jordan & Powell, 1995; Frith, 2003):

- Sometimes excellent self-description (see autobiographies), but...
- Deficit in "episodic memory"
- Limited "feeling" for what it means to be that person

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Self-concept of people with ASD

Not poorer but different:

- less socially anchored
- associated with (physical and factual) details!
- more objective than subjective
- often negative, sometimes too positive
- seldom 'accurate' en 'shaded'

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Consequences of autistic thinking

Autistic thinking: Context blindness

- Weak central coherence
- Literal understanding
- Focusing on details
- Rule-based reasoning



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Autistic thinking and self-concept

- Autistic thinking: black-white
too negative (black)
too positive (white)
- Autistic thinking: appearances
(details)
- Autistic thinking : misunderstandings
- Autistic thinking : calculating


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Self-concept of people with autism

- People with autism perceive and understand the world in an autistic way...
- ... so they also have an autistic self-concept

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Working on the self-image

- Self-evaluation in a concrete and explicit manner regarding concrete everyday situations.
 - No insight-oriented approach!
 - Increase the notion and knowledge of easier and potentially more difficult situations.

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Situation-based self-evaluation

Self-perception	Situation
I am good at...	Situation "W" is easy for me
I am not good at...	Situation "X" is difficult for me
I have a deficit in...	"Y" is hard for me
I get anxious about...	"Z" makes me anxious

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Situation-based self-evaluation

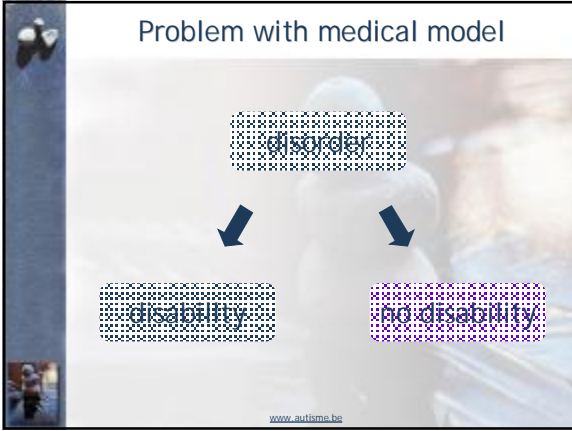
- Situations are more concrete than "the self"
- Situations are easier to visualize (video, photo, Social Stories™, comic strips...)
- Based on a social model of disability

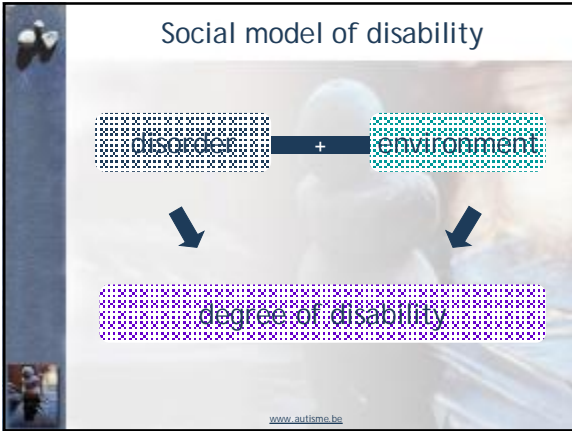
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Medical model of disability

The diagram consists of a rectangular box with a dotted pattern containing the word "disorder". A solid blue arrow points downwards from this box to another identical dotted box containing the word "disability".

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- ### Situation-based self-evaluation
- Situations are more concrete than "the self"
 - Situations are easier to visualize (video, photo, Social Stories™, comic strips...)
 - Based on a social model of disability
 - Easier for developing coping strategies

Working on the self-image

- Self-evaluation in a concrete and explicit manner regarding concrete everyday situations.
 - No insight-oriented approach!
 - Increase the notion and knowledge of easier and potentially more difficult situations.
- Increase the self-image by choosing and restructuring situations in such a way that they are successful.

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What mirror do we show them??

I have to go into therapy	➡	I am not OK, not normal...
I have to attend a social skills training	➡	I am not social
My behavior is a problem	➡	I am a problem
High expectations	➡	Low self-esteem

Our interventions:
treatment or cause of a negative self-esteem?

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Building a positive self-esteem

The basics

- Respect for the autistic culture:
"I am not a damaged version of...."
- An environment where people with ASD can develop their talents

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Indications

- They have questions about it
- But...
 - ...they don't always communicate them
 - ...they communicate them differently

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Indications

- Their motivation
- Our motivation
 - ...they "need it"
 - ...they will be less autistic
 - ...they will make the right choices

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Indications


~~• Should we tell Peter that he has autism?~~

- But:
 - Why tell Peter SOMETHING?
 - WHAT should we tell him?
 - HOW do we tell him?
 - WHEN do we tell something?
 - WHO will tell him?

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Start from their motivation

<p><u>Their point of view</u></p> <ul style="list-style-type: none"> • I don't understand other people • I have a lot of problems: I am stupid • I have the feeling being different but I don't understand 	<p><u>Our point of view</u></p> <ul style="list-style-type: none"> • A more realistic self-image • He has autism. So, he must learn to accept it. • He will lose his friends. • It is better for her integration in the classroom.
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Explaining autism is not easy!

Different names and definitions	↔	Need for clear information
Abstract topic	↔	Need for concrete information
Negative label	↔	Need for positive self-esteem

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Indications: when to start?

- No fixed age
- The person has questions
- "He/she needs it!" (consult the network!)
- Preventive, if there are no questions

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Indications and counter-indications

The person with ASD:

- Being able to reflect on oneself (social-emotional age of > 4 years)
- Realizing there is "something"
- Being able to "talk" and work together
- Not too negative self-esteem
- No severe behaviour problems or conflicts at the time

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Indications and counter-indications

The environment:

- Approval of the diagnosis of ASD
- Approval of the disclosure
- Willingness to work together on "I am special"

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Who should tell it?

- Preferably not the parents (but cooperation needed!)
- Someone with advanced knowledge of autistic information processing style
- An 'authority'
- Availability and continuity

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I am special

Place within treatment / education:

- **Informing** a person about his or her autism spectrum disorder
- Closer to education than to therapy:
psycho-education

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Psycho-education

- Psycho-education:
 - Increasing self-knowledge
 - Including the knowledge about one's disability
- Psycho-education as cornerstone in:
 - Empowerment
 - Counselling and therapy

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Goals of psycho-education

- Knowledge of own strengths and weaknesses
- Understanding autism
- Understanding the consequences of autism
- Identifying and defining difficult situations
- Identifying coping strategies
- Giving autism a self-esteem enhancing place in life

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Psycho-education

- Tailor made content and procedure:
 - Modular content
 - The word "autism" does not necessarily have to be mentioned
 - Inductive or deductive procedure
 - Fixed or flexible duration
 - Individual or group sessions

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Psycho-education

- Tailor made content and procedure
- Autism-friendly communication style:
 - Concrete communication
 - Visual support
 - Logical, "mathematical", "matter of fact" style:
 - Multiple choice
 - Grids and schemes
 - Systemizing approach: a lot of sorting!!

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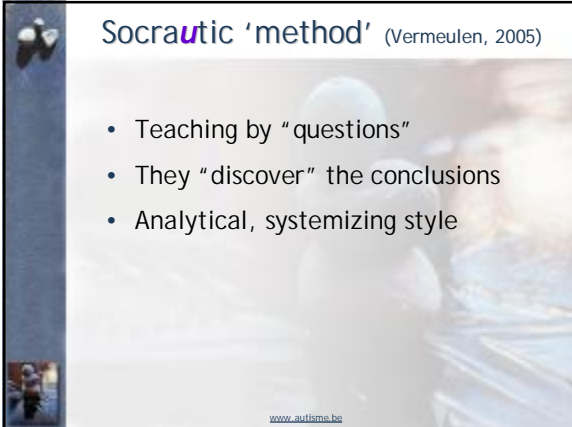
Psycho-education

- Tailor made content and procedure
- Autism-friendly communication style:
 - Concrete communication
 - Visual support
 - Logical, "mathematical", "matter of fact" style
 - Socra**u**tic method

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Socratic 'method' (Vermeulen, 2005)

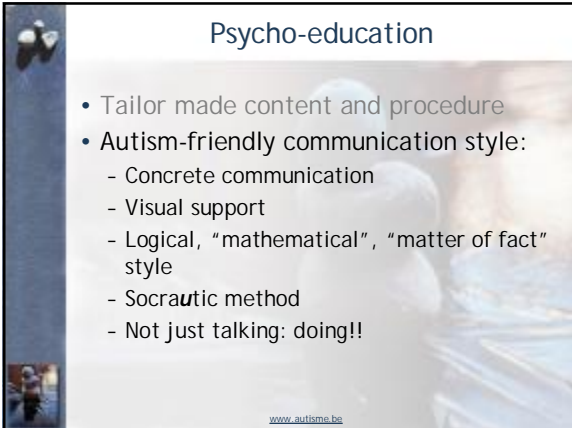
- Teaching by "questions"
- They "discover" the conclusions
- Analytical, systemizing style



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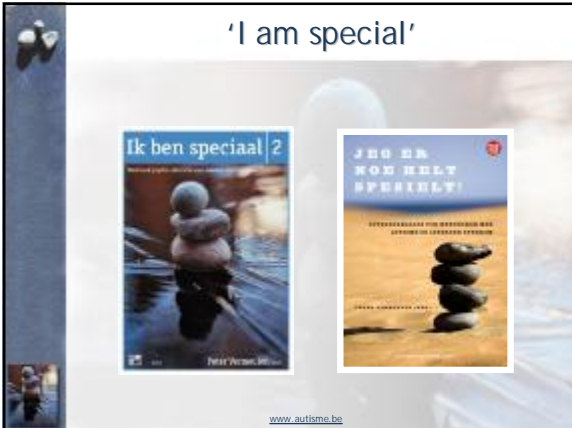
Psycho-education

- Tailor made content and procedure
- Autism-friendly communication style:
 - Concrete communication
 - Visual support
 - Logical, "mathematical", "matter of fact" style
 - Socratic method
 - Not just talking: doing!!



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'I am special'



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Differences with traditional explanation


- Personalized and individualized information
- Interactive
- "Work"-book
- Flexible use



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I am special: content


- **Part 1: I am unique**
 - my outside
 - my inside
interests and preferences, nature,
talents, not so strong points and
personality
 - I am unique!



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I am special: content

- **Part 2: My body**
 - the outside
 - the inside
 - my brain
 - my intelligence
 - we need our body



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I am special: content

- **Part 3: Being different**
 - illness and disease
 - disability - types of disability
 - special education and assistance
 - an adapted environment
 - people with a disability can be talented too
 - people with a disability are different, not less



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I am special: content

- **Part 4: Autism: a special disability**
 - A special disability (disorder, causes and disability)
 - What is more difficult because of autism (triad of impairments)
 - Autistic spectrum



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I am special: content

- **Part 4 (ctd): Autism**
 - An invisible disability...but not entirely invisible
 - Cannot be cured, but there is something that can be done about it!
 - People with autism have talents too!
 - People with autism are different and special!



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I am special: content

- What can I do about my autism?
 - learning new skills
 - using my talents to compensate
 - asking for help
 - using tricks
 - using specific tools (f.i. schedules)
 - avoiding the situation (escape-scenario)

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Variations and adaptations

- Version for younger children
- Version for 'siblings'
- "I am special" game
- Version for youngsters with learning difficulties
- Classroom version for co-students (school integration)
- Version for 'self-advocacy' groups (Asperger and HFA adults)

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Possible negative effects

- depression
- aggression
- denial
- confusion

... only when administered without thorough preparation and by unskilled people

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Effects: what **not** to expect

- Less autistic...
- Complete understanding of own autism
- Spontaneous transfer to daily life
- Less difficulties and problems


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Possible positive effects

- better dealing with the disability
- a positive and better-balanced self-esteem
- increased willingness to accept guidance
- shared self-advocacy

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Helping them to live with ASD



A lifelong **process**...

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