Autism
&
intellectual disabilities

How to deal with confusing concepts

dr. Gerard J. Nijhof

- Orthopedagogue / GZ-psychologist

- PhD, Free University Amsterdam

- Private practice

- contact@gerardnijhof.nl

- +31 355418572 / +31 681462141

Contents

1. The diagnosis dilemma: an example
2. Autism & intellectual disabilities: some remarks
3. Intellectual disability (ID):
   - levels of ID
   - percentage subdivision
   - basic criteria
4. Stereotypes / repetitive behaviour
5. Sensory phenomena
   - what makes the difference?

Cont.

Contents

Continued

1. The diagnosis dilemma

A practical example

Client example
Diagnosing problems (1)

- John: 4 years old.

- Keeps on running to and fro, rocks his trunk.

- Knows a few words and keeps repeating them.

- When asked something he usually does not understand.

- He is minding his own business and does not ask for involvement of his parents.

Client example
Diagnosing problems (2)

- Sometimes he uses gestures and sounds for his mother to pick up something he wants.

- He smiles a lot, but you don't know why he smiles.

- He plays apart from other children, not wanting to participate (but somehow he is in their proximity).

- Objects are moved to and fro a lot.

- To eat he needs assistance.

- He only accepts certain kinds of food.

Client example
Diagnosing problems (3)

- John is afraid of many things - everything must stay the same.
- He accepts his mother holding him, not his father.
- When his mother is not in sight he is very anxious.
- He smells to all kinds of objects.
- Sometimes he is crying and cannot be comforted.

Client example
Diagnosing problems (4)

- John experiences the world as an insecure place he dares not to explore.

- He does not understand what is happening and what other persons are intending.

- Sometimes his body freezes, making it impossible for him to act.

- His main interests are his own interests, he is not interested in what others are doing.

Client example
Diagnosing problems (5)

- Later in his development it was possible to share experiences with him like rolling a ball or playing with a car.

- Later sometimes he could come to the conclusion that his mother was angry or happy (... a progression that pleased his mother ...).
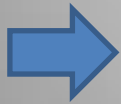
Client example
Diagnosing problems (6)

What can be concluded from this case?

Can something be said about the diagnosis?

What kind of child is described:

- A child with a normal development and some (severe) problems?

- A child with an intellectual disability?

- An autistic child?

- A child with autism and intellectual disability?

I hope I can make it clear that there is a good reason to return to these questions not until the end of this lecture!

2. Autism & intellectual disabilities

Some introduction remarks

Autism & intellectual disability (1)

- Occurrence of both intellectual disabilities and autism has an important impact on how autism is manifested.

- Intellectual disabilities bring with them a lack of cognitive compensation options for persons with autism.

- Approximately 75% of the children with Autistic Disorder (PDD) have intellectual disabilities.

Autism & intellectual disability (2)

- It is hard to distinguish symptoms of autism from symptoms characterizing a severe intellectual disability.
- Some symptoms of autism are consistent with normal behaviour of very young children.

  Example: motor rituals or stereotypes can also be seen in young children

- Older children with intellectual disabilities also show motor rituals in behaviours that are quite normal for young children (toddlers).

Autism & intellectual disability (3)

- Children and adults with intellectual disabilities:
  - have a retardation
  - show behaviour of an earlier developmental period
- Autism:
  - show behaviour of an earlier developmental period
- Difficult to make a clear diagnosis:
  - PDD (autism)
  - Intellectual disability
  - Intellectual disability *and* autism

Autism & intellectual disability (4)

Kraaijer (2002) - persons with intellectual disability:

- About 40% functioning on a *profound* or *severe level* have a pervasive developmental disorder (autism).

- About 20% functioning on a *moderate level* have a pervasive developmental disorder.

So a higher prevalence of autism is seen in the lower intellectual disability region.

- Persons with *DS* (Down Syndrom) and *profound intellectual disability* have *PDD* just as often as persons with a *profound intellectual disability without DS.*

- The combination of DS and severe or moderate intellectual disabilities shows a much *lower* frequency of PDD.

3. Intellectual disability

levels of ID

basic criteria of ID

Levels of intellectual disability

Kraijer (2002):

level of functioning	developmental age range	IQ range
• MILD	6.6 - 12.0 year	50/55 - 70
• MODERATE	4.0 - 6.6 year	35/40 - 50/55
• SEVERE	2.0 - 4.0 year	20/25 - 35/40
• PROFOUND	0.0 - 2.0 year	< 20/25

Levels of intellectual disability
percentage subdivision

Level of functioning	percentage
Mild	85%
Moderate	10%
Severe	3-4%
Profound	1-2%

Conclusion: limited occurrence of *profound* intellectual disability within the intellectual disability population

Intellectual functioning
basic criteria

Generally accepted for intellectual disability:

- Significantly sub average intellectual functioning (*intelligence criterion*).

- Substantial limitations in adaptive skills (*adaptive criterion*).

Persons with autism:

- 75 % has an intellectual disability.

- All persons with autism show limitations in adaptive skills.

4. Stereotypes / repetitive behaviour
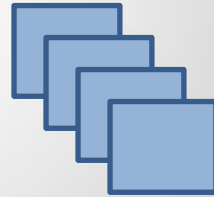
Stereotypes / repetitive behaviour (1)

Autistic people with an intellectual disability exhibit
a large part of the time (80%) stereotypes / repetitive behaviour.

- In the normal development of children there is a period marked by repetitive behaviour.
- Repetitive behaviour is quite normal for toddlers.
- These repetitive behaviours look strange when occurring later in the developmental stages.
- With children with intellectual disabilities the repetitive behaviour can persist, mainly on a primitive level of motor skills.

Stereotypes / repetitive behaviour (2)

- Children with PDD can also stay with repetitive behaviours, many times one sees a rich repertoire of stereotypic behaviour.

- Mostly one sees clumsy and stereotypic ways of movement.

- Stereotypic behaviours are increased when intellectual disabilities are more severe.

- PDD is the strongest predisposing factor for stereotypic behaviour! So more stereotypic behaviours can be observed when both PDD and ID are present…

5. Sensory phenomena

What makes the difference?

Phenomena in autism

- Stuck in an early stage of development - with tasting, licking and touching.

- Primary senses are used to recognize the world (i.e. touching behaviour: approach and touch).

- Often: enhanced hearing sensitivity.

- Often: persons with autism pushing their earlobes... shutting themselves off for all kinds of noises, sometimes actively regulating the noises around them.

- Marked tiredness resulting from (daily) impressions.

What makes the difference (1)

- At first: familiarity with the combination of autism and intellectual disability.

- In the institutions for persons with intellectual disabilities the prevalence of autism is about one third to one fourth of the inhabitants.

What makes the difference (2)

- In practice *intellectual disability* means an inability to act. There is a knowledge problem: not knowing what to do (lack of understanding).

- In practice *autism* often also means a inability to act. There is a lack of understanding in the *feeling* area, a lack of understanding the intentions and reactions of others.

What makes the difference (3)

In the field of autism - Theory of Mind (TOM):

- The ability to take into account one´s own and other´s mental states in the understanding and prediction of behaviour…

- … attributing ideas and feelings to the other person…

- … serving as a direction for one´s own response to the other person.

- By making a representation of the mental processes of others we can predict and understand the behaviour of other people.

What makes the difference (4)

- Children with intellectual disabilities can have difficulties to construct a Theory of Mind.

- A normal child also needs time developing the skills necessary for using a Theory of Mind.

- In normal development first there is *joint attention* as a precursor for developing a Theory of Mind.

What makes the difference (5)

- Joint attention occurs when two people share interest in an object or event and ….

- they understand that they are both interested in the same object or event.

- Joint attention should emerge around 9 months of age and be very well established by 18 months of age.

- We are concerned about joint attention when we work with children with autism …..

- It provides a basis for social, cognitive and language development.

- Joint attention is difficult for almost all children with autism.

What makes the difference (6)

- When a child points to something it wants and shifts its gaze to the parent and then back to what it wants, the purpose is non-social. Children with autism are pretty good in getting what they want.

- When a child points to something, not because it is wanting something, but because it wants to bring it to the other´s attention, the purpose is socially oriented. This is the joint attention we aim to develop.

6. joint attention

Theory of Mind

Shared experiences
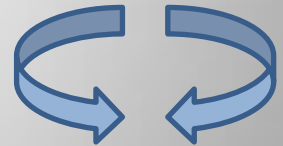
Joint attention (1)

www.youtube.com/watch?v=tif4U3OjT2M

Joint attention differs for the normal child, the child with Down Syndrome and the child with autism.

Joint attention (2)

- Persons with a profound or severe intellectual disability behave on a lower functional level. This is the reason that there is no development of a Theory of Mind.

- Persons with autism also have difficulties developing a Theory of Mind. Many times they remain on the same social and emotional level as a toddler.

- The combination of profound or severe ID and autism makes it practically impossible for developing a Theory of Mind. These persons are very much living in a world of their own.

Joint attention (3)

- For children, but also for adults and for the elderly, it is important to train the joint attention event.

- Joint attention is a precursor to obtain a Theory of Mind.

- By focusing attention on an object or event one can evoke the feeling that there is a *shared experience*.

- Examples of games in which joint attention can be trained: rolling a ball to each other, playing peekaboo, together watching a toy car, watching each other.

- It is important that these skills are taught in an everyday life situation.

Joint attention (4)

- For people with autism and intellectual disabilities there are problems in *transferring* what has been learned from one to another situation.

- Social skills are learned by encouraging joint attention, by imitating other people's behaviour and by playing together with others.

7. Anxiety

Anxiety

- It is important to prevent the onset of fear: people with a profound or severe intellectual disability and people with autism develop anxiety because *they do not understand the world around them*.

- A lot of fear can be avoided by explaining what is happening.

- Sometimes verbal support is helpful, at other times it can be wise to mainly render physical reassurance.

- Holding hands or laying a hand on the shoulder really can help in preventing anxiety.

- Social avoidance treated early in life leads to less problems with it later.

8. Attachment disorders

Attachment disorders (1)

- Consistently not understanding the world is very threatening. It is a condition that facilitates the emergence of attachment disorders.

- Attachment disorders are very hard to avoid. The insecurity generated by attachment disorders is one of the causes for behaviour problems.

- In education it is important always having in mind how to make the world a safe place for people with autism and ID.

- This is especially important while getting on with very young children.

- Prevention of anxiety by explaining the world around us and also by mere reassuring diminishes the risk for attachment disorders.

Attachment disorders (2)

- Courage: the child needs the other as a safe base from which he can start to explore the world.

- When the world becomes diffuse or leads to frustrating events the child needs the other to experience the world as a safe place again. It needs the other as a safe harbour to return to when the world becomes too complex to deal with.

9. Behavioural blockades

executive problems

together 100%-principle

Behavioural blockades (1)

- There are blockades to be seen in the behaviours of people with autism and intellectual disabilities (*executive problems*).
- These blockades can easily be demonstrated - examples:
    - stay put for a threshold, moving back and forth
    - difficulty to turn off a water tap, turning it ever on
- It is important to realize that these blockades are quite common.
- Sometimes blockades are autonomous and determined by the body.
- The impact of environmental factors can be substantial: crowds, noise, stress evoking events.
- It is important to realize that the blockades are not intentional.
- There is a need for help to restore the ability to act.

Behavioural blockades (2)

- Executive problems can be resolved using the ´together 100%-principle´.
- The caregiver takes a complementary role while acting.
- Sometimes the contribution of the caregiver is hardly necessary.
- Sometimes support of the caregiver is very much needed.
- Client and caregiver are always together (together 100%-principle).

- Sometimes the caregiver has to accept that acting is impossible for some time.
- Acceptance can mean that the client needs some time to recover.

10. Central coherence
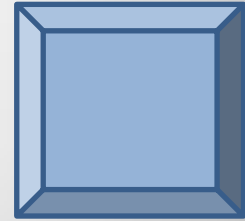
Central coherence (1)

We understand the world by *contextual information*. In advance it is difficult for a child to understand what is happening in the world around it..

- For a normally developing child parents or significant others play a crucial role in learning to interpret a situation.

- Children with intellectual disabilities have difficulties to attach meaning to a situation because of a lack of knowledge. Knowledge acquisition is delayed and sometimes not at all possible.

Central coherence (2)

- A child with autism (PDD) has difficulties understanding a situation. Maybe the knowledge is available, but often the *feeling* is lacking to understand another person or some situation.
- The combination of autism and intellectual disability makes it very hard for someone to understand what´s going on and to act appropriate.
- So many times we see an inability to act appropriate. Accordingly there is a lot of fear and a basic feeling of incompetence.
- It is the duty of the caregivers to ´explain´ the world and to help to ´do the right things´. That is: make "together 100%".
- It is the responsibility of the caregivers to prevent overcharging.

In conclusion…

Finally (1)

Do we have any clear cut answers for the questions posed in the beginning? Some points…

- *Labeling* is not the main thing (´normal development´, ´autism´, ´intellectual disability´).

- It is important to get a good picture of the behaviours, abilities, restrictions and the context typifying a certain client.

- We need to find individual solutions that work for a client, a child. Also we need to make these transferable.

- ´Together 100%´ (or even more…) is one of the possibilities for making one´s way in the world of autism and intellectual inability.

Finally (2)

´It´s not a bad thing returning home with more questions than answers...´

This lecture is based on my own practical experience and on the experience of many others.

Thank you for your kind attention

Gerard Nijhof, 2014