

Autism from a developmental perspective

New insights into autism spectrum disorders

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Summary

Autism Spectrum Disorders (ASD) are difficult to understand, partly because it is different for each individual. Despite an extensive research tradition is still little understood. The DSM-5 and ICD-11 explore new paths with pros and cons for autism. Meanwhile, new research opens new perspectives: autism could be considered as a 'delay' instead of a 'defect'. This paradigm shift has major implications for the diagnosis, treatment and education, so we could speak of a breakthrough, if not a revolution in relation to autism spectrum disorders. Although many theories have contributed to the understanding of autism, they deliver only a piece of the puzzle. There are overarching theories and treatments needed for the new perspective. The theory of the socioscheme with the MAS1P, the Mental Age Spectrum Within 1 Person, is based on delay and an accelerated development of the brain simultaneously.

From the onset of autism to the DSM-5 and ICD-11

Autism (Autism Spectrum Disorder / ASD), has always fascinated man and always posed riddles. Contact with someone with autism can sometimes make people desperate and impatient on one side and on the other hand, one can be impressed by the purity of people with autism. The research into autism has a long and intense tradition. There have been significant changes in the field of autism that, because of their size could be characterized as revolutions. The first revolution takes place in 1943-1944 when Leo Kanner (1943) and Hans Asperger (1944/1997) choose the term *autism* to define a group of people with characteristics that until that moment were classified in the schizophrenia group. The emancipation of autism begins with the specificity of its own diagnosis. Since then, the term 'autism' has been well established and has been extended with a number of sub diagnoses. With the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, version 5, expected in May 2013; APA, 2012) and ICD-11 (International Classification of Diseases, version 11, is expected in 2015; WHO, 2012) coming up the classification is brought back to one term: autism spectrum disorders, ASD. In this article, the terms autism, autism spectrum disorders and ASD are used interchangeably, in line with the DSM-5/ICD-11.

In the DSM-IV, still the prevailing version, a subdivision within Pervasive Developmental Disorders (PDD) was created with autism, HFA (High Functioning Autism), Asperger syndrome, Rett disorder, Desintegrative Disorder of Childhood (DDC) and the rest category Pervasive Developmental Disorder (PDD-NOS).

Because research does not distinguish between HFA and Asperger syndrome these terms are expected disappear. The sub diagnose Rett disorder will disappear from the DSM-5/ICD11, because an organic cause was discovered based on a genetic defect (the MECP2 gene; Kosai et al, 2005).

The classification strategies for the DSM and the ICD with respect to psychiatric disorders are mainly based on two pillars: 1: statistics, the statistical relationships concerning co-occurrence of behavior and 2: behavior, the classification is based on behavior and not on its origin. These two factors caused Rett disorder to be unjustly classified under PDD for decades. Another diagnostic classification that will disappear from the DSM, is the DDC. This disorder involves a significant regression in skills, often around two and a half years old. Because research shows no significant difference in behavior of children with and without a regression, again a statistical decision, not based on the origin of both. This means that children who, according to the DSM-IV would have been

given the diagnosis DDC, in the DSM-5 will be classified in the same way as children who show autistic behavior coming the genetic pattern. Autistic *behavior*, however, without being associated to the genetic pattern of autism, can evolve in response to neglect (Rutter et al, 1999), a disease or a traumatic experience, especially in children at a very young age. The cause of the behavior however, does matter and could be of importance for the choice of the treatment and the estimated prognosis. The loss of the DDC classification therefore may represent a considerable loss. Autistic behaviors are thus entirely equated with autism spectrum disorders as a general classification, without consideration for the source of the behavior. Rutter's research project on the Romanian orphans (Rutter et al, 1999) has shown that a significant percentage of these children were initially diagnosed with autism, but after placement in foster care families in many children the autistic features largely disappeared. The cause of the autistic behavior in this case was not autism, but neglect. He suggested the term QAP, Quasi Autistic Pattern for this problem. This name deserves a place alongside complex PTSD (DSM-5), because it is a specific pattern that looks like autistic behavior, but can arise from multiple sources, not just trauma. It could function as a differential diagnose for pure autism.

Another classification that is expected from the DSM5/ICD11 will disappear, PDD-NOS (Pervasive Developmental Disorder Not Otherwise Specified). The '-NOS' designation is the residual category that the DSM-IV used when a syndrome of certain elements are present, but not all. This category showed a high risk of error diagnostics to ensure and so the -NOS category the spearhead which the DSM-5 was renewed.

When a diagnosis is based on behavioral expressions it means that we must be very careful when assigning a diagnosis of autism as long as there are no biological markers that actually indicate that it is ASD associated to a genetic pattern. Discovering the genetic pattern is in fact the second revolution in the field of autism and took place around the eighties of the last century. Kanner and Asperger both thought that autism could be hereditary, but it was not until the eighties that the proof came with the discovery of the gene pattern. Until that time, under the influence of people like Bettelheim (1967) and Lovaas (1987) emphasis on education by the parents, especially the mother, was considered the cause of autism. As a result of the second revolution in relation to autism, the discovery of the genetic influence, thinking about autism shifted from malleable (education through the mother) to 'static' ('they are like that'). It was not necessary, but since then autism was considered resistant to treatment. The perspective on autism was and still is nowadays focused on learning to deal with autism as a defect. The key theories were: the theory of mind (Premack and Woodworth, 1978), the theory of central coherence (Frith, 1986/2003) and the theory of planning and executive functions (Ozonoff, Pennington, & Rogers, 1991). For treatment the key became: to learn to deal with it, deal with for instance lower socio-emotional insight, no eye contact, literally thinking. The idea therefore was psycho-education. For school education, the key words became: structure, icons and planning boards.

These ideas were applied to people diagnosed with autism, apart from the cause of their autistic behavior. A kind of reductionism took place in the sense that people with autism in general were reduced to their diagnosis: an autistic person instead of a person with autism.

From defect to delay

Besides developing theories, research about autism progressed also in the area of investigating the brain. An important step was the survey research of Bailey and colleagues (Bailey, Philips & Rutter, 1996) showing that autism is not associated with a specific abnormality in the brain nor does there exist a specific place in the brain that functions differently in the case of ASD, but that the brain as a whole functions differently. This means that the prevailing theories are all just a part of the puzzle and not an overarching explanation. Each of these theories suggests a specific abnormal of atypical functioning of the brain, but do not suggest an atypical functioning of the brain as a whole. These are

the three aforementioned theories (Theory of Mind / Central Coherence / Planning and Executive Function). Existing theories assume an abnormal development (except the theory of Baron-Cohen of the ESB brain: 2003 and the Socioscheme of Delfos: (2001/2011; 2005) and all (except the theory of Delfos which is about delayed and accelerated maturation of the brain and thus dynamic), offer a fairly static picture of people with autism.

Meanwhile, research is being published, that support the idea of a delayed development (Bastiaansen et al, 2011; Hazlett, Poe, Gering, & Smith, 2006; Hua et al, 2011; Levitt et al, 2003; Whitehouse, Maybery, Hickey et al , 2011). It is a delay in the maturation of the central nervous system. This argues against the static perspective on autism. In the studies of the Theory of Mind (ToM) it was already clear that people with autism could develop their ToM. One explanation for this was that they developed their ToM using their intelligence, as a kind of compensation. Now there is the idea of delayed development. Hazlett and colleagues (2006) showed that there is a delayed development in the brain (prefrontal cortex) and especially the left prefrontal cortex. Bastiaansen and colleagues (2011) spoke of a 'delay' instead of a 'defect' and focus on the stimulation of mirror neurons. Whitehouse and colleagues (2011) showed that girls with characteristics of ASD autism have a delayed menarche, on average two years later than girls without ASD characteristics. Hua and colleagues (2011) showed a delay in the development of areas of the brain associated with social interaction, repetitive behavior and communication, the key issues of ASD. Besides these examples of delay an acceleration in infancy followed by a delay is also observed (Courchesne, 2004).

The idea of a delay means that development that could be stimulated, later than expected in children without ASD, because the maturation progresses. Discovering the delayed developmental areas through observation of behavior, finding the maturation markers and encouraging the development of these areas could then become the focus of educating, treating and teaching people with autism. A delayed maturation in autism is consistent with the higher prevalence of ASD in males because boys basically mature later than girls with a difference of about two years. Autism could be considered as the most extreme form of the male brain (Asperger, 1944/1997; Delfos, 2001/2011; 2005, Baron-Cohen, 2003; Bejerot et al, 2012), for both men and women. Bejerot and colleagues (2012) demonstrated a higher level of testosterone and male characteristics in women with autism. On the basis of the Geschwind Hypothesis (Geschwind & Behann, 1982, 1984) is to be expected that an increased level of testosterone could be associated with a stronger delayed maturation of the central nervous system (Delfos, 2001/2011; 2005). In general the maturation of boys carries more risks for maturation problems and genetic abnormalities (Delfos, 1997/2012; 2004). In the case of ASD therefore further maturation problems are to be expected and even more genetic abnormalities alongside the autism. This blurs the picture of autism, because these abnormalities and disorders are not characteristic of autism itself, nor a part of the autism, but they are more common in autism spectrum disorders.

The perspective of a delay versus a defect has many consequences, especially in everyday life. It is not always easy to interpret behavior and the right way to go. A child of eight years old, with respect to certain subject can show behavior of a three-year old, like taking away the toys of another child, and will probably be considered 'childish'. If the child has normal mental abilities and the child is viewed from the perspective of what is normal at eight years old, the child may be considered as spoiled and selfish. If the child is diagnosed with autism, and the behavior of the child is viewed from the perspective of a defect, soon people give up changing the behavior, thinking that the child cannot help it and that 'it is the way it is'. When we view the child from the perspective of a delayed development with respect to that particular subject, we are inclined to 'educate', 'teach' the child or 'explain'. In the first case (spoiled, selfish) we will correct or punish the child. In the second case (defect) we are inclined to let it be. And in the third case (delay) we will try to encourage the development of the child. For the child it is very important which perspective is taken and what strategy is chosen.

The Socioscheme and the MAS1P

The core of autism spectrum disorders is the low social development. In the theory of Socioscheme (Delfos, 2004/2010) applied to autism (Delfos, 2001/2011; 2005), it is about a delayed development in specific areas, especially the social interaction, while in other areas the development of the child or adolescent does not have to be delayed, or even be accelerated compared to peers. This results in a broad age spectrum in each person with autism, the MAS1P, Mental Age Spectrum Within 1 Person (Delfos, 2010, 2001/2011; Delfos & Groot, 2012), a rainbow of mental ages throughout the day. The IQ shows a disharmonious profile. The IQ cannot cover the whole range of mental ages, but can only give an impression of them, because the IQ is an abstraction and deals with only a few areas of development. The broad age spectrum means that one and the same child shows many mental ages simultaneously. A child with autism of seven years old can be a child of three years in play behavior, a child of seven years in motor development, and can count as a child of ten years old, so ahead of his peers.

John-Arnie, a nine year old boy with autism, and his teacher are reading a children's book about aircrafts. When he sees an image of an airplane, he makes the sound of a plane, like a three year old would do. Some minutes later he explains in detail the role of the commander. At that moment he is significantly older than children of his calendar age.

An example of the MAS1P of a young man of twenty-one years old. He is intelligent and is verbally very articulate. He has autism. According to the DSM-IV diagnosis the diagnose would be Asperger's syndrome, according to the new DSM-5 it is probably: mild ASD, mild autism.

Martin is twenty-one years old and has autism. He made a complex analysis of the banking crisis, as he calls it. He makes use of a television soap which makes it very interesting. He makes connections explain what is happening in society. He also has a print of a woman in bikini, head and legs are not visible. He wants to see a bikini like that and wants to ask people gathered at a festival to ask if they could show him a bikini like that. He thinks there are people who could tell him where he could see such a thing. Martin is adult and a child at the same time, but also an adult child with opportunities.

The range of mental ages within a person is what makes upbringing, school education and treatment of people with autism so difficult. Finding the mental age in a particular area is not always easy and scientific research is needed to develop a diagnostic tool to assess the MAS1P per individual. It is further complicated because the discrepancy between chronological age and developmental age may result in behavior at a certain developmental age that is not literally a blueprint of that behavior when the calendar age and the developmental age are in line with each other. Attachment behavior of a child of eighteen months old, does not look exactly the same as the delayed attachment behavior in a child with autism eight years old, because the mental age occurs in a body that is physically developed with other capabilities than an eight month's old.

The MAS1P is about simultaneous delayed and accelerated development. We see that in the examples that came up during conversations with parents in studies in the Netherlands, Ecuador and Bosnia-Herzegovina.

A mother tells her child of six years old is often like a child of two to three years old. This is because he babbles and barely talks and because he often crawls over the ground. In order to come closer to him she often plays games like "hide and seek" which he finds fun. In other areas her son seems to be developing in an age adequate way. The mother says he is very skillful with computers and mobile phones. Another mother said the same thing: "My son is very skilled with the computer, just as skilled as his peers, but in social matters he cannot interact with them." In children with autism especially

the socio-emotional development is delayed and strikes. This mother also indicates that: "I estimate that my son is one to two years behind his chronological age of six years, in his social and emotional development. When calculations are concerned, he is far ahead of his peers, and that combination creates regularly problems at school. "

In order to encourage the development, it is necessary to connect to the mental age of the child with respect to a specific topic. Connecting to the mental age does not mean to approve everything, because setting limits is also necessary for very young children. It means to take the mental age as a starting point for stimulation and education, as parents normally do with their children when they mature and mental age and chronological age match. Delfos & Groot (2012) describe the consequences of the theory of socioscheme with the MAS1P in practical terms, extensively applied in the daily practice of people with autism. Just like parenting, it may take a while before the new behavior arises and internalizes, but sometimes the solutions are surprisingly simple with a quick effect.

Stuart is an intelligent young man of twenty-five years. He studied at the University and successfully completed his bachelor. His therapist explained that there is a lot he does not know, but that she does not know what he does not know and that he can ask her anything. "How long do you have to shower in the morning, because I'm always in a knot with going to the university?" "Until you're ready," is the answer. "Yes, but what is ready," is the next question. At that time the therapist realizes how parents teach their children: "Now we do your ears, your arms and your legs, and now we're ready!" With that in mind, the therapist replies: "Until you've been everywhere. 'Oh, that's it," replied Stuart. The shower problem was solved, his behavior was no problem any longer.

The key concept of the theory is the Socioscheme is the "me" placed in the world. This involves the unconscious and conscious knowledge of man about himself and of himself in relation to the world, including biological (immune inhibition) and psychological factors (inhibition me-other differentiation). Consistent with the effect of testosterone on the developing fetus, the development of the immune system is inhibited (via the thymus gland) and thus the biological self (Damasio, 1994) and by extension the psychological self (via the me-other differentiation) (Delfos, 2001/2011; 2005) are being limited. This, among other factors, is what causes an atypical development of the Socioscheme with a delayed development of the me-other differentiation. As a consequence, among others: less self-knowledge, less self-reflection, and are less able place oneself in other man's shoes, less focus on others, and less conscious of the other (Delfos, 2001/2011; 2005).

Within a very short time, usually already with babies, human are the main subject of interest, and there is a clear focus on people, other issues are 'classified' secondary. Research shows that male babies often look longer at objects and female babies look longer at faces. This is already the case from the first day after birth on (Connellan, Baron-Cohen, Wheelwright, Ba'tki, & Ahluwalia, 2001). Translated to the data of the influence of testosterone and the extreme male brain means that babies (male and female) with autism will continue to look longer at objects than male babies without autism.

An underdeveloped or developing more slowly socioscheme provides a lower consciousness of oneself and of the environment and a limited focus on people than we normally are used to. A limited and non-automated focus on people creates several problems, which can be felt in social interaction. The development of emotions, of emotional contact, of empathy, and insight in social interaction lags behind. The delayed development may become abnormal when the child is confronted with subjects connected to his calendar age and not connected to his mental age (with respect to that subject). This can sometimes produce strange patterns of behavior, frequently seen in people with autism. Because we do not realize that the behavior that we see has to do with delayed development and an inadequate connection to the mental age, we conclude - wrongly - that it is a

characteristic of autism and we are then surprised that not every child with autism shows the same behavior.

An example of a mental age that does not match the calendar age is the difficulty that people with autism seem to have to generalize newly learned behavior to other situations, because they still lack experience and a basic social understanding that gives an overarching insight. The application of this understanding is a daily activity in the normal education of young children. Because children with autism have more focus on objects rather than people, their parents often do not offer the necessary and logical education and so, parents miss the moment the child is mature to receive the associated education to the progress in maturation.

The risk of under-stimulation

A 'delayed development' in autism means that the mental age and their behaviors, lags behind the calendar age. The development of children proceeds generally according to fairly fixed, successive stages of development. In people with autism the same development stages can develop basically as in others, but (seriously) delayed in some areas and possibly accelerated in other areas. The perspective of delay opens the possibility of progress in development. The perspective of 'defect' means that many behaviors of people with autism are considered a hallmark of autism and not as an convertible phenomenon that requires connection to the mental age to be able to develop further. The result is that the children are not encouraged when opportunities arise and maturation has progressed. This leads to the risk of under stimulation with all the risks of conduct problems that also arise in other situations, such as boredom, repetitive behavior and indifference to the environment.

Children and adults with autism spectrum disorders often puzzle us with their range of mental ages (MAS1P). When strange behavior is exhibited, it is often helpful to try to discover what mental age is associated to that behavior. Strange behavior in the case of autism often proves to be normal behavior associated with another mental age.

There is still much research to be done on the theory of Socioscheme and the MAS1P. Above the recent studies are mentioned, also further support and internal consistency of the theory can be found in the basic book (Delfos, 2001/2011; 2005). With respect to the treatment based on the Socioscheme with MAS1P we refer to the work of Delfos & Groot (2012) and the treatment of adults developed at the Radboud University in The Netherlands is based on the Socioscheme (Kan, 2008). Meanwhile, people need a handhold in the transition from the perspective of defect / abnormal at issue, to the proposed perspective of delayed development. In order to explore the mental age it would be possible to use knowledge that people have about the development of children, education and developmental psychology in general. Through a simple rule, the mental age may be explored. If there is persistent behavior that amazes us, we can then apply the following rule (Delfos, 2001/2011; 2005; Delfos & Groot, 2012): *This is normal behavior at the age of ...?*

This may help to find the mental age and the associated education of parents at that age with respect to that subject. Then one can possibly offer the educational assistance from which new behavior may result.

A simple rule and therefore dangerous. There is a lot of knowledge, insight and experience needed to reach a correct answer. A wrong answer would do injustice to people with autism. The empowerment of people with autism itself is important. This could be done by explaining to them that there is much that they do not know, and that the people around them not knowing what they do not know and that they should ask questions. This is also what young children do when they reach a certain age, around four years, asking parents one question after the other. To lack this developmental stage of asking questions may mean a lot to the development of children.

In closing

There seems to be a change underway in the understanding of autism spectrum disorders: delayed maturation of the brain and development as a result instead of a defect. The perspective of a delayed and accelerated development (MAS1P), that is autism from a developmental perspective, provides opportunities to connect with the mental age of children, adolescents and adults with autism. Autism from a developmental perspective is not static but responds to the educational needs of people with autism.

To illustrate this the way several men with autism expressed the importance of their relationship / spouse:

She explains to me the world.

She is my gateway to the world.

In educating children probably experienced the same thing about their parents. Then we find the ordinary and we offer the child what it needs. In cases of autism spectrum disorders, we are still too little awareness of the perspective of delay and provides a static perspective sure that we autistic people - well meaning - rather than inhibit stimulate their development.

The theory of Socioscheme with the MAS1P is under development. There are a few places with promising results with respect to treatment (Kan, 2008; Delfos & Groot, 2012), additional research is still necessary.

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