

# TOM'S DISRUPTED SENSORY PROCESSING

*The effect a change of environment has on stress*

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Tom is a 12-year-old boy. He is friendly and good natured. He's an only child and lives with his parents at home. He is born into a loving and religious home where it is considered essential important that one must do one's best and not burden others. Tom tries extremely hard to do this to his best ability.

Tom has Autism Spectrum Disorder. He is easily overstimulated. He withdraws into himself. As the years pass, Tom is growing more fearful. He is afraid of the dark and of places such as the attic and the backyard shed. Tom is also hearing voices.

When Tom is 8 years old, for a time, the family receives support at home from a mental healthcare organisation and Tom is enrolled in special education classes. At first, this seems to go well, and he seems to fit right in in his specialised class for children with ASD. But Tom has few friends and associating with fellow classmates seems to be difficult.

In the following years, Tom's problems at school steadily increase. He has more and more angry outbursts. Ultimately, he is sent away. Tom knows he is unable to do many things.

It's more peaceful and calmer at home for Tom. He has a daily programme which includes education, and ambulant carers to help teach him. Two days a week, Tom also goes to a farm where he helps care for the animals.

As time passes, Tom's angry outbursts get more and more intense, and he becomes physically aggressive towards his parents. They must hold him in their arms to get him to calm down, but that takes more and more strength as Tom grows bigger and stronger. Despite the targeted interventions and treatment provided by the mental healthcare organisation, the voices he hears, and his fears have not diminished. Tom's parents are struggling. Caring for Tom and coping with his behaviour mean they have few social contacts with others. They become more and more isolated.



The parents are in a vicious cycle, burdened by great concern about the future. They cannot continue to care for Tom and worry whether they are doing the right thing for him and if the current situation means that his development is at a standstill.

To try and break the cycle, his parents and the mental healthcare organisation are looking for a suitable home for Tom. But residential facilities for young children with autism are hard to find. The situation is becoming untenable.

### IDEOGRAPHIC THEORY

Tom is diagnosed with Autism Spectrum Disorder type MCDD, Multiple Complex Developmental Disorder. This is an autism spectrum disorder which is characterised by problems with regulating emotions and fears in addition to the more classic symptoms of autism such as problems with contact, communication, interests, sensory processing, and perception. MCDD is also characterised by thought disorder. People with MCDD have vivid imaginations, which sometimes means their thoughts run away with them, and they are unable to distinguish between fantasy and reality; for example, they hear voices, like Tom.

Tom's autism means that he has trouble understanding the world. The lack of clarity causes Tom a lot of stress.

Tom says he hears voices daily. This is often the case with people who have MCDD. The voices scare him and are very real to him, even though he knows other people do not hear them. He thinks that what the voices tell him is real and will really happen. Small changes in his environment or in his daily programme can trigger an increase in voices. The voices also cause Tom a lot of stress.



Tom has disrupted sensory processing, which often occurs in people on the spectrum. In the following interview clip, Hubine Moons explains what disrupted sensory processing is and how it can be assessed.

### **Interview clip 1 and 2**

Hubine Moons' assessment of Tom's sensory processing shows that he has difficulty processing information provided by the distal senses. These are the senses which as it were, bridge distances: sight, hearing, and, to a degree, smell. Tom has problems with visual and auditory stimuli. For example, when there are a lot of people near him, he must concentrate intensely to process any information. He often fails to do so, and so on top of feeling exhausted by that level of concentration, his failure makes him feel insecure about his immediate surroundings.

Processing information from the proximal senses such as touch, taste and the proprioception system is much easier for him. The proximal senses, particularly touch and the proprioception system deliver information which he can feel in his body. He uses these proximal senses in the physical activities he performs on the farm and when he is under the weighted blanket. These activities help him to regulate his stress.

The vestibular system, another proximal sense, helps to generate muscle tension and is unfortunately disrupted in Tom's case. It is difficult for Tom to keep and maintain his balance.

All these efforts and uncertainties mean that Tom gets overstimulated, which makes him more stressed. And this is when Tom says he hears voices. While hearing voices is associated with MCDD as a part of disrupted perception, we now believe they may be a sign of overstimulation. We have therefore removed this symptom from the ideographic theory.

Tom has a mild intellectual disability, but his emotional development is at the first socialisation stage. This means he is functioning at the age of an 18-



month-old. Tom has not developed object permanence, and so Tom needs the immediate presence of his @@@main caregiver in order to function.

Tom has disharmonic development. This makes it harder to correctly gauge Tom. He is able to do many things: he has good language skills, can dress himself, brush his own teeth, can build the most marvellous constructs with Legos, and seems very clever. However....because of his stagnated emotional development, although Tom has the skills and the cognitive development to perform all those tasks, he cannot handle actually doing any of them.

Because of his language skills, Tom seems able to understand a great deal, but he understands a great deal less than others expect of him. People around him easily overestimate him. He often doesn't understand spoken information well enough to know how to react or respond.

Simply existing in the world takes a lot out of Tom because of the discrepancy between his cognitive and his emotional development, but also because of his autism and the amount of energy he must expend to process stimuli.

### [ Interview with Hubine Moons ]

Tom keeps doing his best to meet his own expectations as well as the expectations of those around him. Because of his inability to do so, his stress level steadily increases and needs to find an outlet. Tom "explodes": gets angry, throws things, and gets into physical fights with his parents.

Tom being aggressive stops every single activity. To calm him down, Tom is allowed to lie down on the sofa under a weighted blanket, and if his aggression is at an extreme level, Tom is held firmly until he is docile. The firm embrace gives Tom some relief in the short term. Sometimes, he can then go back to whatever he was doing. Other times the aggression exhausts him, and he is too tired to do that.



The immediate ceasing of all activity temporarily lowers Tom's stress level. But he is continually overestimated and overburdened, so the stress quickly begins to build up again.

Stress is avoided whenever possible to prevent Tom from getting aggressive; for example by reducing the amount of contact he has with people outside of the family. This means that those not in Tom's immediate environment are not subjected to his rages. It also follows the family's adage that only good behaviour should be on public display. But the family is becoming socially isolated because of it.

Said social isolation does in fact translate into less stress for Tom, but that doesn't apply to the family as a whole.

In the end, there are very few people with whom Tom spends his time, because the fewer people he sees, the smaller the chances of him being overburdened. In line with his emotional age, Tom is increasingly focussing on his mother as his main other, with the result that his mother is unable to do anything but keep Tom company, keep Tom occupied, and she is becoming overburdened by caring for Tom.

Because he no longer goes to school, any activities are often brought to a halt, and his world is becoming smaller and smaller, Tom's development is insufficiently stimulated. The home schooling he is given is often stopped due to Tom's rapidly higher stress levels. Tom's development is in jeopardy.

To turn the tide and because Tom really wants to go to school and get a vocational education, we began implementing the following interventions.

## INTERVENTIONS

### INTERVENTION 1: THE THERAPEUTIC FARM

Working with Tom's parents, we looked at different possibilities aimed at relieving their social isolation without further overtaxing their systems. The



choice was made to send Tom to live at the local therapeutic farm. Tom will spend his weekends at home, and he will stay at the therapeutic farm during the week. At the farm, he receives individual coaching as well as group coaching, and he can do what he loves best: caring for animals.

Having Tom move out was not an easy decision for his parents, but the increase in Tom's challenging behaviour and the vicious cycle they had fallen into prompted this hard choice.

## **INTERVENTION 2: ADAPTING TO TOM'S EMOTIONAL DEVELOPMENTAL STAGE AND HIS AUTISME SPECTRUM DISORDER**

The residents of the therapeutic farm are all children on the autism spectrum, with or without intellectual disabilities. The carers there have specialised training to be able to interact with Tom in a way that is adapted to suit his emotional level and his perceptions and experiences.

Tom follows a daily routine, with carers always present in his immediate proximity. This reassures him and gives him peace of mind. In addition, carers help him to sort through all input and information, bringing clarity and organisation to his world. They discuss his daily activities with him, preparing him so that he knows exactly what is going to happen and exactly what is expected of him. When new activities are introduced, first they are demonstrated, then they are performed together with Tom, and only after that will Tom perform them alone.

Following a varied but predictable daily programme, Tom helps to take care of the ponies, the donkeys, and other animals. He also performs other activities he is interested in, such as carpenter work and playing guitar. The daily programme is the farm's guiding principle and will always proceed. Sometimes with a little help from carers, and sometimes with a lot.

The carers use pictograms to help give Tom an overview of his day. Pictograms have the advantage that they are permanent, as opposed to



speech, which disappears as soon as a carer has finished speaking. Tom can take all the time he needs to absorb the information in a pictogram. He can also review the information whenever he doesn't understand something. This also makes him a little less dependent on his carers.

Tom attends classes three times day. The classes are mainly practical, contain as little language as possible, and match his interests as much as possible. Step by step, lessons in subjects such as maths and geography are being resurrected. This is an ongoing and permanent part of his daily routine but can be adjusted to what Tom can handle at any given moment.

### **INTERVENTION 3: RATIONING AND MANAGING STIMULI**

#### **[ Interview with Hubine Moons ]**

All the recommendations made by Hubine Moons were accepted and put into practice. I would like to re-emphasize her final recommendation. Activities were added to Tom's daily routine which had proven to not be overstimulating for him, but which actually relaxed him and will help him to continue to develop. These activities primarily involve using the proximal senses.

The physical work at the therapeutic farm suit Tom extremely well. He trundles along pushing the wheelbarrow, clears out the stables, and, to meet his need for physical contact, he regularly rides the ponies, and he cuddles all the animals a lot

To relax, tactile experiences such as massages or stroking the animals are organised. The same effect is gained by lying down on the grass or in the hay.

Because of his need to be close with others, he often actively seeks contact with others. This includes physical contact: this helps him with his problems





with stability and reassures him. And jumping on the trampoline stimulates his underdeveloped vestibular system.

#### **INTERVENTION 4: PSYCHOEDUCATION**

Psychoeducation and training are a constant part of Tom's daily program and care. Interactions in the group are coached. Carers explain to Tom what is happening, and situations are given captions or subtitles, as it were. Carers also demonstrate possible responses for Tom. Step by step, he's learning what interactions are and how to react to them.

Using the signals plan that Hubine Moons advised, three stages in Tom's tension arc are defined. Each stage is explained to Tom using pictograms. He learns to distinguish between each stage and then to develop the appropriate behaviour. He's learning that the voices he hears are his own negative thoughts, so he learns that he need not fear these thoughts, and this will reduce his stress.

Tom's parents were given the scale of emotional development. This provided insight into Tom's delayed emotional development. It clarified that Tom is constantly being overestimated and overburdened. This insight laid the foundation for further psychoeducation for Tom's parents.

### **RESULTS**

#### **RESULTS FOR TOM**

Tom is having positive experiences, both at the therapeutic farm and at home, and achieving successes.

Activities are no longer halted; they always proceed. Tom is getting used to school activities and his development is back on track. He now attends vocational lessons in a special education class for children with autism.



Tom is no longer as overestimated or overburdened and this means he is less stressed and can manage more. He hardly ever has rages or hears voices anymore.

His social circle had been widened by the contact with carers and fellow residents. And contact with others has also improved at his family home.

Peace has descended on the family home; the parents' ability and capacity to cope with Tom has increased and on weekends the parents can now simply parent. Little outings and visits to relatives are possible again. His parents have a renewed faith in the future.

### LESSONS LEARNED

By means of a thorough investigation, we prevented the focus being placed on challenging behaviour alone and there is now movement in a situation which seemed stuck fast. Tom hearing voices and his aggressive behaviour was a reaction to constant overestimation and overburdening, which was overlooked because of misinterpretations of his level of development. By viewing the dynamics which underpin his behaviour in a different way, we created room for further development. Consciously breaking the cycle in which everyone had become trapped has resulted in being able to develop new behavioural patterns.

Mapping out Tom's emotional developmental level together with his parents created great clarity in how people were overestimating and overburdening Tom.

For children like Tom, with disharmonic development and disrupted stimulus processing, there are only a very few residential facilities available in the mental healthcare sector. The commitment of an organisation, in this case the therapeutic farm, to 'really go for children like Tom' was a huge advantage.



Lessons using sensory systems such as that of touch or proprioception instead of hearing or sight, made them more suited to children who learn best via experience.

## CONCLUSION

This was the case Tom's Disrupted Sensory Processing. I hope it helps people to find solutions for other children, like Tom.

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