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“Everyone reads, some this, others that” (free after Martinus Nijhoff)

Multi-Sensory Storytelling (MSST) makes sense

Children with profound multiple disabilities enjoy story telling too as long as there is sensory stimulation, show personal experience and research of informal literature.

By Nelleke Boer and Carla Wikkerman

Translated by Renske Vos

Created in Great Britain, MSST is a method of storytelling to people with profound multiple disabilities. In the Netherlands this term is replaced by ‘voorlezen-plus’ (literally: storytelling-plus) to indicate that this method is about more than just storytelling; it is about telling a personal story made especially for a particular listener and in addition with sensory stimulation.

In this article we will describe our personal experiences with MSST, investigate what has been known so far about MSST and finally discuss the advantages of MSST.



Object: the book *Joyce takes a bath*. Text: Look! It's the book *Joyce takes a bath*. Question: Shall we read it together, Joyce?

Joyce takes a bath

Joyce van der Wijngaard (16) has some profound multiple disabilities. Together with her parents she reads the story *Joyce takes a bath* from an MSST book.

This theme is based on a weekly event in Joyce's life. Every Wednesday night Joyce's parents and brother visit her for a special bath ritual. Since this always is a fun night, Joyce's family chose it as the subject for their story.

The book is aimed at Joyce. Her possibilities are assessed by LAS, a list for adjusting activities and situations to the possibilities and preferences of children with profound multiple disabilities. In order to make contact with Joyce, one needs to know her well. Joyce reacts mainly to sensory stimulations like sound, bright colours and touch. Without them she closes up.

Joyce's mom had made a precise description of their bath sessions. Its most important aspects for Joyce are: change into bath collar, get the rubber duck, feel the water, dry off, use body lotion, blow dry hair, and look in the mirror.

These actions formed the basis of the story. There are objects with different sensory stimuli that match each single action. In creating the book, we took Joyce's sensory possibilities into account, her favourite colours and smells and her favourite body lotion.

For each page we chose one sentence. We always chose phrases that are often used by Joyce's parents themselves to increase Joyce's recognition of the bathing event. Joyce sometimes experiences concentration difficulties, so we kept the text short and simple. After these theoretical preparations the book had to be actually created.

Joyce's mother used the result to practice storytelling and soon after started to read together with Joyce wholeheartedly. Joyce's parents are delighted that next to the usual concerns about Joyce they now have something more positive to share with their daughter. They can read to Joyce, like they used to do to their son. As the story is being told more often, it is clear that Joyce responds sooner to what happens in the book. She smiles more often, moves into a listening position, turns her face into the direction of the stimuli and is more relaxed. MSST proves to benefit Joyce a lot.

Characteristics of MSST

Shape

- An MSST book is a big box with a short title and a tangible symbol.
- The story consists of seven different white A3-format cardboard pages (max.).
- Every page has its own object that stimulates one or more senses.
- The story has maximally two short and simple sentences per page.

Contents

- People who are close to the listener create the story (e.g. parents or carers) .
- The subject of the story applies to actual experiences from the daily live of a person, often something the listener particularly enjoys. E.g. taking a bath, having a party, going to the beach, or watch the football.
- When desirable, special learning aims can be included in the story such as learning to wait a moment, the difference between small and large, or developing hand motions.

Presentation

- Telling the story always happens in the same way and order, with a lot of intonation and at a low pace.
- Reading is an interactive process. The reader encourages the listener to investigate the objects (e.g. push a button for sound, feel a teddy bear, or smell the bath foam). Repetition results in recognition and predictability.

Stimulation

Chris Fuller, director of the Bagbooks Foundation in London, has created the basis for MSST with her tactile stories. She created the activity as a means to stimulate sensory experiences for children with profound multiple disabilities. PAMIS, a Scottish organisation that is dedicated to people with profound multiple disabilities as well as their carers, was struck by the idea and decided to further develop the initiative.

MSST uses objects that stimulate senses, such as a soft towel, a squeaking rubber duck or a special sent, the choice of which is determined by both preferences and possibilities of a particular listener. The story told has a direct link to actual experiences from the daily life of this listener as well.

MSST definitely shows similarities with existing methods such as basal stimulation, snoezelen, sensory integration, Shantala massage and the method *Just experience it* (Ervaar het maar). All these methods use sensory stimulation, however storytelling as such has never before been made accessible for people with profound multiple disabilities in the Netherlands. Anyone, regardless of personal possibilities or limitations can enjoy storytelling: atmosphere, individual attention, personal contact, peace and recognition of a story all contribute to a positive and fun experience for both audience and storyteller.

Common Knowledge

PAMIS (University of Dundee) has now gained considerable experience in making MSST books. Their project *Real lives: Real stories* resulted in 50 books. Of every book that is made, a copy is kept in their own library. Parents and caretakers that participated in the project agree unanimously on the positive effects of MSST. They see an increase in conduct as the story is told more often. Repetitive use of the sensory stimuli results in an increase of attention for the objects and the storyteller. The story motivates the listener to react. Increasing anticipation is interpreted as an increase of enjoyment, recognition and involvement in the story. These effects of the books have been analysed in two different ways: by comparison of the frequency of conduct during different sessions and by observation of the relation between conduct and stimuli within one session.

A second project exercised by PAMIS is the *Sensitive Stories Project*, a project that has resulted in eleven stories dealing with a more sensitive subject such as the dentist, epilepsy, menstruation, puberty. Research of this project consists of video recordings of storytelling sessions, behaviour analysis assisted by the Video-Pro computer programme, and interviews with parents and caretakers.

This research shows signs that MSST can influence alertness, concentration, listening skills, recognition of a story, anticipation to stimuli and motion development. Some listeners even showed to develop in language and its use.

In the Netherlands several MSST initiatives have now commenced. 's Heeren Loo is planning to carry out research in this area together with the University of Groningen. This research will focus on the process of creating a story, as well as on the effect of MSST on the listener and the interaction between audience and storyteller. Meanwhile, Reinaerde, de BOSK and Het Raamwerk have started MSST in practice. In Belgium, Multiplus and the University of Leuven have combined forces in their own research in the MSST field.



Object: rubber duck. Text: We'll take the rubber duck, it squeaks. Can you hear it too, Joyce?



Object: blow-dryer. Text: And now your favourite, the blow-dryer. I'll switch it on...1....2...3.
Question: Can you feel it blow, Joyce?

The Unknown

MSST is a relatively new method without many factual research conclusions. So far, there are no scientific publications on this subject. There is, however, plenty of informal literature on the matter such as leaflets, theses and articles in non-scholarly journals.

Research into people with profound multiple disabilities consists mainly of quality investigations. Validity and reliability still require attention and improvement. Research into MSST is complex and involves a high labour-intensity. The effects of MSST are difficult to measure and capture in clear figures because conduct and behaviour of people with profound multiple disabilities is difficult to interpret unambiguously. Additionally, it is possible that the presence of a camera can influence results, just as different ways of gathering information (time sampling – in relation to the process, or event sampling – in relation to actual conduct) can do so too. It is useful to combine conduct observation with other research methods (e.g. interviewing parents to find out how you can tell their child is having fun).

Countless questions about MSST are scientifically interesting: which conditions are needed for a first-class application of MSST? What are the effects on the listener and others involved? What makes MSST effective? What is the effect of systematically presenting sensory stimulations to the alertness of the listener? Is the contents of the story important? Does it make a difference who reads the story? Is it necessary to make a diagnosis on beforehand? What is the ideal construction of a story? How do you decide on a story? In short, there are many crucial questions that have not yet been systematically researched.

Advantages

From what we have seen, heard, read and experienced, we can conclude that a huge advantage of MSST is that both audience and storyteller enjoy this practice a lot. MSST gives all those involved a sense of satisfaction. MSST boosts personal contact, which can improve individual relationships.

MSST is a quality instrument for people with profound multiple disabilities and their social environment to spend time together. It is a useful extension to the activities already on offer for these people.

At the moment there is some speculation on the effects of MSST on different areas of development: locomotion, cognition, communication and socio-emotional development. So far, effects of MSST that have been researched correspond with studies on storytelling to (young) children. Storytelling often proves an important means for socio-emotional development as well as an valuable asset in establishing and improving attachment in relationships. Additionally it seems that if these social bonds are strong already, it can have a positive effect on the quality of how storytelling is experienced.

Children receive exclusive attention when they are told stories and they often experience a strong feeling of security. In addition, children can learn a lot from stories, such as how to direct themselves to someone, how to concentrate, and how to listen. Children relax while being told a story and reading books at regular times can help to bring structure and routine into the day. Telling a story before going to sleep can so be a good part of the bedtime ritual.

By adjusting storytelling to the possibilities of people with profound multiple disabilities, the above mentioned effects of storytelling can benefit them too.

MSST has a positive effect on the atmosphere within a family as well as on the cooperation between parents and carers. It also has several practical advantages: anyone can tell a story anywhere, anytime. You do not need to be a great singer or actor. Other children can join in listening. The material for a book is simple to make and to repair. When a book is finished, you can start almost immediately with reading.

Joyce's parents agree with all mentioned advantages. They told stories to their son, and now they tell multi-sensory stories to their daughter. It is a practical example of the valuable vision: *normally when possible, especially when needed (Gewoon waar mogelijk, speciaal waar nodig)*. In conclusion, there should be no doubt MSST should be further introduced, researched and applied in the Netherlands.

Nelleke Boer and Carla Wikkerman are employed as behavioural scientists at De Hafakker in Noordwijkerhout, The Netherlands. De Hafakker is part of Het Raamwerk Foundation. As a result of the VGN Masterclass Scientific Research into Care for People with Intellectual Disabilities 2007, they have drawn a proposal for a small scaled research project of MSST. This project has now been put into effect by Het Raamwerk.

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Used literature

Voorlezen, gewoon omdat het leuk is! Basisboek Boekenpret, Bus, A.G. en IJzendoorn, M.H. van in: Berg, I. van den, Middel, A. en Nouse, R. (1996), Stichting Lezen, Amsterdam, 222 pag., €14,98, ISBN 9080205486.

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Reaction

By Katja Petry

Storytelling has all kinds of positive effects attached to it. Stories contribute to the passing on of perceivably important values within a culture. They add to communicative, socio-emotional and cognitive development, they stimulate our fantasy and creativity, telling the story itself benefits the relationship between reader and child, overall storytelling is simply fun. So why wouldn't we tell stories to people with profound multiple disabilities?

In their article on MSST, Nelleke Boer and Carla Wikkerman rightly point out the existence of a method that makes the telling of stories to this particular group of people accessible. Through PAMIS, MSST has enjoyed wide support in Scotland for years. It is a unique method that completely adapts a story, through contents, shape and presentation to people with profound multiple disabilities and the individual client in particular. MSST enriches the current offer of activities and methods specifically adjusted to this particular group. We therefore agree with the authors when they call for the introduction, application and especially investigation of this method in the Netherlands and Flanders.

There is however, one important limitation in relation to this last point, the research. At the moment there unfortunately is not a lot of scientific knowledge available on the application and effectiveness of this method. The authors point this limitation out as well and justly indicate the difficulties with evaluating the application and effectiveness of MSST on people with profound multiple disabilities. People with profound multiple disabilities often communicate non-verbally through small, idiosyncratic signals. In order to determine whether a change in behaviour is a result of the method, one needs to make very careful observations and interview those that are closest to the client. Unfortunately, the authors do not give a lot of information on how they have determined progress with Joyce (e.g. listening position and anticipation). In addition to the effectiveness of this method there also is a lot unknown about the influence of different factors on the person with profound multiple disabilities (e.g. alertness, sensory possibilities), the storyteller (e.g. use of voice, intonation, enthusiasm, responsiveness, experience), the material (e.g. choice of stimuli, contents of story) and the actual situation (e.g. in a group or one-on-one, time of day). This information is however vital to optimally apply the method in practice.

MSST is unfortunately not the only method that lacks scientific knowledge on application and effectiveness. There are many activities and methods on offer for people with profound multiple disabilities that still need to be researched. This results in a practical difficulty to make an educated choice within the existing offer, while scientifically well-considered choices should prevail as self-evident decisions! With their research project the authors take a step ahead towards more evidence-based care.

Katja Petry teaches at the Centre for Family- and Orthopedagogy of the Catholic University of Leuven.