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### A good read

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## Summary

In order to include persons with profound intellectual and multiple disabilities (PIMD) into our storytelling culture, multi-sensory storytelling (MSST) was developed in the UK. Within MSST, the emphasis is not so much on comprehending the content of the story, but more on apprehending. To achieve this, MSST books contain sensory stimuli that support the verbal text. The books are tailored to an individual with PIMD; and both the form as well as the content are adjusted to the abilities and preferences of this individual. MSST's main purpose is to be an enjoyable activity for both listener as a storyteller. But the reading can also serve more educational goals, for example to increase the involvement of the listener during storytelling, to achieve recognition of the book, to provide information about how and in what way the listener responds to the stimuli, or to promote the interaction between storyteller and listener during the storytelling session. An alert listener with attention to the reading activity is essential for enjoying the story, but also essential for achieving the educational goals described above.

Several guidelines for making and reading an MSST book have been drawn up by the developers of MSST.. These guidelines are meant to enhance the listeners ability to be alert and attentive during storytelling. An MSST book consists of six to sixteen sentences, and six to eight stimuli. The story is relatively short (four to six minutes) and every one

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or two sentences are supported by a stimulus that is related to the sentences. Stimuli are presented on a neutral background (A3 size), so they are easily visible for the person with PIMD because of the contrast with the background. The stimuli are presented in such a way that the listener can manipulate the stimulus and actively explore it. If necessary, the stimulus can be taken from the background, and, for example, can be placed in the hands of the listener. A story script is present on which the text of the book, the way the stimuli should be offered and the ideal context for reading is described. The MSST book is read repeatedly in the same way: storytellers are advised not to deviate from the text on the story script.

To date, there has been very little research conducted on both the content of MSST books for persons with PIMD, as on the extent in which readers meet the guidelines described above. Also, research into the effects of MSST on the listeners' attention and alertness is lacking. These data will contribute to the knowledge on persons with PIMD with respect to the focus of attention and the nature and degree of engagement with their surroundings. In addition, research is important because there is as yet only a small number of evidence-based interventions available for the described target group.

**Chapter 1** provides background information on the reading method MSST and purpose of this study. The purpose of the study described in this thesis is to assess the effectiveness of MSST, and getting a better understanding of the process of making and reading an MSST book.

Also, in Chapter 1 an overview is given of the structure of this dissertation.

**Chapter 2** analyzes the content of 49 MSST books. In addition, the extent in which the books were made and read in accordance with the guidelines set by the developers of MSST was examined. Results show that the subject of most books covers the daily life of the listener; the focus of the content of the books was on outings, such as looking at the horse on the farm. Despite the fact that within MSST different stimuli can be used, primarily auditory and tactile stimuli were selected, and often one stimulus addressed several senses. When MSST books were made, the majority of the storytellers applied the guidelines. During reading, storytellers often deviated from one or more guidelines; in only two percent of the storytelling sessions all guidelines were followed.

In the study described in **chapter 3** we examined whether the use of the guidelines for reading the book, is related to the attention of the listener during storytelling. In total, 45 persons with PIMD participated in this study. The results show that as the book was read more often, the listeners' attention increased, and then decreased slightly. More attention from the listener was observed when stimuli were offered actively by the storyteller. No relation was found between the use of neutral backgrounds or using the original text, and the attention of the listener for the activity.

**Chapter 4** again studied the presentation of stimuli; in 27 individuals with PIMD we verified whether the active presentation of stimuli was related to the course of the listeners' alertness during the storytelling. For

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this purpose, a time-window sequential analysis was carried out. During storytelling mostly passive alertness was observed, active alertness and withdrawn behaviour were less common. When stimuli were presented in an active way, more active alertness was observed by the listener. The active alertness increased after the presentation of an active stimulus, and decreased when the stimulus was removed. At that moment, passive alertness increased.

In **Chapter 5**, we found that the storytellers who participated in this study scored 'mediocre' on the seven dimensions of interactive style; "sensitivity", "responsivity", "effectiveness", "acceptance", "enjoyment", "expressiveness" and "warmth". This study showed that on average, the lowest observed score during MSST was seen for "warmth", and the highest score for "expressiveness" of the storytellers. The interactive style of the storytellers did not change as the book was read more often, and also did not appear to be related to the characteristics of the storytellers or the listeners with PIMD.

In **chapter 6**, three dyads of storytellers and listeners were followed while making and reading an MSST book. Using a structured questionnaire the knowledge of the storytellers about the contextual, motor and sensory preferences and abilities of the listener with PIMD was inventoried. This was done prior to storytelling, and then again after ten and after twenty reading sessions. In addition, the storytellers were asked about their expectations and experiences with storytelling. The results of the questionnaire showed that all three storytellers gathered new knowledge about the preferences and abilities of the person with

PIMD. The storytellers also indicated to have gained new knowledge. This new knowledge reported by the storytellers appeared to differ from those collected with the questionnaire. The questionnaire showed that after ten reading sessions, knowledge about the reading context was collected, and that knowledge about the motor abilities was collected throughout the whole duration (20 sessions) of storytelling. The storytellers indicated that they had collected most knowledge about the sensory preferences and abilities. Nevertheless, the questionnaire showed that in this area, still a lot of knowledge is lacking. Storytellers made minimal changes in the MSST book in response to their newly gained knowledge.

In **Chapter 7**, the attention during reading MSST books, was compared to the attention during reading regular books. For this purpose, for 45 people with PIMD an MSST book was made and read, for 31 people with PIMD regular books were read. Results show that the listeners were more than twice as much as attentive to the book and /or stimuli during the MSST books, compared to regular books. The attention of the listener for the storyteller is comparable in both reading conditions (MSST and regular). The level of attention changed between the two conditions; for MSST books, an increase in the level of attention was observed during the fifth reading session, while for regular books a slight decrease in attention was observed during the fifth session.

Finally, in **Chapter 8**, the main findings of the studies that we carried out were described. Based on the results it can be concluded that MSST, in addition to a pleasant activity, educational goals as for example

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having attention for the environment are reached. While the listener pays attention to the book and the storyteller, the storyteller has the opportunity to get to know the listener better. Repeating the book and active presentation of stimuli appear to be related to the attention of the listener while reading MSST books.

In this study, the behaviour with respect to the attentiveness of the person with PIMD during storytelling was observed. The study did, however not address the extent to which the listener really understands the content of the story. Meanwhile, 'sensitive stories' based on MSST are developed (Young, Fenwick, Lambe & Hogg, 2011), these stories explicitly focus on topics that may prepare the listener for specific events, such as a visit to the dentist. In addition to further research into the effectiveness of such sensitive stories, the sixth chapter also provides an impulse for further research: the case study shows promising results with respect to the acquisition of new knowledge about a person with PIMD. Further studies with larger groups are necessary to generalize the results to the entire population of persons with PIMD.

The current study into MSST offers several tools for practice. To promote alertness and attention of the listener, the storyteller should present stimuli in such a way that the person with PIMD can manipulate or explore them. Too, the book must be read repeatedly in the same way. The storyteller should also be alert to (changes in) the behaviour of the listener, and respond to them. MSST is thus one of the few evidence based interventions that have been developed specifically for individuals with PIMD.