

"Read to me"

The effectiveness of Multi-Sensory Storytelling intervention on the responsiveness of youth with profound multiple disabilities in a Children's Home and associated day-care centres in South-Africa.

Utrecht University, Master Developmental Psychology

Nicky Hogewind (3640329)

First supervisor: Yolanda van Beek

Second supervisor: Marthe Stoffer (Development manager at the Children's Home)

18th of September 2015, Utrecht

Abstract

Purpose: The effectiveness of an adapted version of Multi-Sensory Storytelling (MSST) was examined in a sample of forty-four youths and young adults with Profound Multiple Disabilities, in a residence and associated day-cares in South Africa. MSST aims to improve responsiveness through reading stories with multi-sensory stimuli.

Method: Development in responsiveness was examined on measures assessed during training, as well as a generalization test where a new untrained story was introduced. A matched therapy- and control-group as well as a within-group comparison was used to measure this progress.

Results: Development in responsiveness after 10 training sessions was found, mainly during the second half of the training (after 5 sessions). The positive effects on the responsivity to the untrained story were small and were lost after a period 6 weeks without MSST. Also, the growth in responsiveness for the untrained story of previous year's research was not maintained after 8 months of low frequency MSST training either.

Conclusion: The findings suggest that MSST is a useful intervention method for individuals with PMD in South Africa, in that responsiveness increases during training. However, positive effects on the responsiveness with another untrained story were limited, and this gain was lost when training was stopped or continued with lower frequency. Further research on generalization and maintenance effects are recommended.

Samenvatting

Doel: Huidige studie evalueert de effectiviteit van een aangepaste versie van de Multi-sensory Storytelling (MSST) in een steekproef van vierenveertig kinderen en jongvolwassenen met een Ernstige Meervoudige Beperking (EMB), in een weeshuis en bijhorende dagcentra in Zuid-Afrika. Het doel van MSST is om de responsiviteit te vergroten door middel van verhalen met multi-sensorische stimuli.

Methoden: Vooruitgang in responsiviteit werd gemeten zowel tijdens de training, als een generalisatie-test waarbij er een nieuw ongetraind verhaal werd geïntroduceerd. De vooruitgang werd gemeten door de therapiegroep te vergelijken met een controlegroep en middels een herhaalde meting design.

Resultaten: Er werd groei in responsiviteit gevonden na 10 sessies MSST, vooral tijdens de tweede helft van de training (na 5 sessies). De positieve effecten van het ongetrainde verhaal op de responsiviteit waren klein en verdwenen na een periode van 6 weken zonder MSST. Ook de groei in responsiviteit van het ongetrainde verhaal van het onderzoek van vorig jaar ging verloren na 8 maanden waarbij MSST met een lage frequentie werd gegeven.

Conclusie: De bevindingen suggereren dat MSST een bruikbare interventie is voor mensen met EMB in Zuid-Afrika, omdat de responsiviteit toeneemt tijdens training. De positieve effecten op de responsiviteit bij een andere ongetraind verhaal zijn echter beperkt en deze

toename ging weer verloren toen de training was gestopt of minder frequent werd gegeven.

Vervolgonderzoek naar generalisatie- en onderhoudseffecten wordt aanbevolen.

Introduction

Young children learn and develop themselves through exploring the world around them. They need stimulation and support from the environment to actively construct more sophisticated understandings of themselves and their environment (Smith & Thelen, 2003). Youth with Profound Multiple Disabilities (PMD) are impaired in these fundamental abilities that they need for developmental tasks. Profound multiple disabilities refers to severe restrictions in cognitive and motor functions which are caused by a variety of reasons (American Association of Intellectual and Developmental Disabilities, 2015). In particular, youth with a mental disability have a lower mastery motivation for pursuing challenging tasks or activities (Majnemer et al., 2013). Furthermore, they tend to have a shorter attention span and their executive functions are impaired (Bottcher, 2010). These factors help to explain why these children and young adults have increased social and learning problems and need extra stimulation and support, as compared to youth with no developmental problems, to fully develop themselves (Brodin, 1999; Case-Smith, 2013). This is especially important for youth with multiple disabilities in developing countries like South Africa, where interventions or therapy are usually not part of daily care. Since the facilities in these countries are limited and most care workers in South Africa are not highly educated, interventions need to be easy to implement and perform. The goal of this study was to evaluate the effect of such a program, the Multi-Sensory Story Telling intervention (MSST), on the development of a group of youths and young adults with PMD in a residence and associated day-cares, located in rural parts of South Africa.

MSST

MSST is a structured stimulation program where trained childcare workers read stories to youths with PMD. A short story is being told with an emphasis on sensory experiences and social interaction (Penne, et al. 2012). Reading stories to children is an old and cross-cultural tradition that stimulates the cognitive and social development. Reading to a child stimulates language development and the early communication skills, i.e. anticipation, turn taking and joint attention (Penne, ten Brug, Munde, van der Putten, Vlaskamp & Meas, 2012; Glazer & Burke, 1994; Miller & Pennycuff, 2008). Reading stories can even be useful for children who cannot talk or understand verbal language (Lacey, 2006), and can experience emotions within a story without a literal understanding (Penne, et al. 2012; Multiplus, 2008). The goal of the story reading in the MSST training is to stimulate the youths with PMD to socially interact

with and respond to other persons and the environment and develop communication skills (Pamis, 2002, 2004).

MSST is developed for individuals with a profound mental disability (possibly in combination with a physical disability). The development of these individuals lies within Piaget's sensory-motor stage. In this stage, children begin to coordinate their sensory input and motor responses in order to explore the environment (Gibson, 1988). The therapy elements of the MSST-stories is adapted to the cognitive needs and capabilities belonging to the mental age of these participants in terms of the length, structure and the language used. The stories are short, are told in the same order, use the same words, and have a clear beginning and ending. The length of stories is adapted to the short attention span of individuals with PMD (Penne, et al., 2012, Bottcher, Flachs, Uldall, 2010).

An important part of the MSST-stories is repetition. Piaget emphasizes the importance of repetition in the development of children in the sensory-motor stage (Piaget, 1951, 1952; Brodin, 2005), and other researchers confirmed this (Vaughn, Kim, Sloan Hughes, Elbaum, & Sridhar, 2003). A sense of self-efficacy and the feeling of knowing what to expect can positively influence the person's sense of involvement and well-being (Petry, Maes & Vlaskamp, 2005). This fixed narrative structure makes the stories more predictable and understandable and benefits the development through evoking a sense of having control over the environment (Grove & Peacy, 1999; Monaghan & Rownson, 2006).

Another element of MSST that stimulates predictability is the use of objects. Each page in the story is supported by an fixed *object of reference*. The objects of reference are not limited to objects only but include visual, auditory, olfactory, tactile, and gustatory experiences (Multiplus, 2008; Pamis, 2002). The inclusion of objects in the story has some major advantages. Firstly, the objects catch the attention of the child, invite him to exploration and support the understanding of the story ((Longhorn, 1988; Hotz, Castelblanco, Lara, Weiss, Duncan, & Kuluz, 2006; Pamis, 2002; Multiplus, 2008). Secondly, the objects make the interaction during MSST more suitable for individuals with language disabilities (Arthur, 2004). Lastly, multi-sensory objects engages a broad group with individuals with a wide variety of disabilities, because all the different senses are stimulated. It also contributes to the apprehension of the story (Hogg, Cavet, Lambe, & Smeddle, 2001; Shams & Seitz, 2008; Farrell, 2012) and stimulate the individuals with PMD to play an active role in their own development. Research has proven that children with disabilities show more motivation to

play and also engage in more frequent play behaviour (Brodin, 1999) when provided a stimulating and structured situation.

Social learning

Beside the elements discussed above, the motivational and social aspects of the childcare workers play an important part in the MSST training. As discussed earlier, the development of the MSST-participants lies within the sensory-motor stage. In this stage there is a focus on social learning. Young children learn through modelling, joint attention, imitation and other social techniques. There is an emphasis on the importance of learning with the help of parents or other adults like teachers. Vygotsky postulated that knowledge is acquired in social interactions and shaped by language (Vygotsky, 1978). Adults support the child and help him perform tasks which the child cannot complete on his own. The difference between what the child can achieve on his own and what he can achieve under adult guidance is called 'the zone of proximal development' (Vygotsky, 1978). In MSST, the childcare workers play an important role in encouraging and supporting the child to explore the world, without the child getting frustrated or helping the child too much. This requires sensitivity for the capabilities and social signals of the participants, and the childcare worker needs to give the participants enough time to respond to and explore the objects provided. The signals that individuals with PMD communicate with are often very subtle.

Communication in this developmental stage requires so-called 'intuitive parenting' (Papoušek & Papoušek, 1995), i.e., adjusting to the developmental level of the child by simplifying and exaggerating emotional messages in face and language, use of short repetitive verbal messages with clear melodic contours, and by prompt and consistent responses to utterances of the individual. Through intuitive parenting, communication becomes easier to understand for a child and it helps to sustain the child's attention (Papoušek & Papoušek, 1995; Gogate, Bahrick, & Watson, 2000). Normally, adults naturally adjust their language and manner of speaking to the developmental level of their child. However, with youths and young adults with PMD, this might be challenging. A possible explanation of this lack of adjustment may be found in the discrepancy between the biological age and the mental age of the youth and young adults with PMD. Therefore, in MSST trainers are specifically instructed to show all these 'intuitive parenting' characteristics during the reading sessions.

Effectiveness

There is almost no published research on the effectiveness of the MSST intervention. Unpublished research can be found on the website of the organisations that developed MSST: Pamis (2002), which show promising results. Therefore, it was of importance that proper research was done to study the effectiveness of MSST. Since 2011, the effect of MSST on responsiveness is studied in the same facility that was used in this research. A new observation instrument was developed in 2011. The term 'responsiveness' was chosen as the outcome measure of MSST, as responding to the environment is a first step in exploration. In Piagets view, every response, whether it is a social, cognitive or a behavioral response, is seen as an attempt to exploration and thus progress (Piaget, 1962). Preliminary research was done every year, usually showing small positive effects of MSST on the responsiveness of the participants of the residence, when compared with a control group (Halfens, 2011; Van Eyk, 2012; Willems, 2014). Last year, the research group was expanded by including youths from the associated day-cares, who had never been trained with MSST before. A significant effect of responsiveness in the day-cares was found, but no longer in the residential group (Willems, 2014).

Present study again examined the effect of MSST. In the facility where this research took place, a fixed yearly intervention training pattern was followed. Between February and June MSST was given at a high frequency, the other months MSST was trained at a lower frequency. The first research question of present study was: Could the responsiveness of youths and young adults with PMD be further improved after re-intensifying MSST training? First, development during a ten session training was examined. An important factor to keep in mind was that the participants in the residence received MSST for four years since 2009. This could be an explanation for last year's lack of further improvement in the residential group. Maybe the participants were at the top of their capabilities making further development more difficult. Therefore, the training sessions this year were performed with new stories. It was expected that the re-intensification with a new story had a positive effect on the responsiveness of youths and young adults with PMD.

Furthermore, the importance of repetition was examined by training the participants with one story for ten sessions. The progress in responsiveness for this story was measured after five and ten MSST sessions. The second sub-research question was: "Is there a difference in progress between the first five sessions and the last five sessions of MSST-training? Because of the importance of repetition for individuals with PMD, it was expected

that they showed the most progress in the second half of the training. Furthermore, the increase in responsiveness during MSST training was especially expected for the participants in the day-cares, because for them MSST was relatively new, they were younger and had a different social background (as they are still living with their parents, siblings or guardians). In last year's research no control group was used in the day-care centres, due to a small sample size. Therefore, this year, the day-care group was expanded with more participants and a control group was used.

Beside examining the development of responsiveness during training, it was also studied whether responsiveness to another new and untrained story increased after de MSST period. One of the goals of MSST is to stimulate the cognitive development of the participants and that they generalize the new skills to different (everyday) situations. This form of learning is also called 'learning by analogy'. This involves finding certain correspondences between two events or domains of knowledge and then transferring this knowledge from one to the other (Keane, 1988). Chen and colleagues (1997) found that 13 month old infants could transfer an analogous solution from one task to others. It was examined whether participants were able to transfer the learned responsivity to another story. This untrained story had the same structure and setting as the one used during training but differed in the topic and objects of reference. This story was performed before and after the MSST training. It was expected that, also for this story, responsiveness after MSST training would be higher than before.

Another issue concerned the maintenance of a positive intervention effect. Research on maintenance found that individuals with disabilities often find it difficult to maintain their new skills (Frey & Kaiser, 2011; Case-Smith, 2013). In present study, a short term maintenance effect was examined by measuring if the progress in responsiveness remains after a period of 6-8 weeks without MSST. As discussed, the participants at the residence have been trained since 2009, which might make it hard for them to develop further in terms of responsiveness. However, in present study, with the new stories, it was expected that the participants would again show progress in responsiveness and would maintain (or slightly improve) during this period of no MSST-training. Also, a long term maintenance effect was examined, by comparing the level of responsiveness at the posttest in 2013 (Van Eck, 2013) with the level of responsiveness at this year's first measurements wave, after a period of 8 months low frequency training. It was expected that the participants would maintain their level of responsiveness during this period.

The group of participants in the present study was very diverse. Therefore, it was

important to examine whether MSST is suitable for every child. Of great importance are the objects of reference and the response to and manipulation of these objects. Therefore, it is likely that motor functioning has a moderating effect on MSST. As such, as a final question, we also investigated the moderating role of the initial level of motor functioning of the participants on the progress in responsiveness. The child care workers were trained to be sensitive to the motor functioning of the participants, tailoring the offering and showing of the objects to the skills of the child. However, it could have been that participants with higher initial levels of motor functioning showed a higher sense of involvement and motivation, due to fewer movement limitations (Petry, Maes & Vlaskamp, 2005; Ben-Itzchak & Zachor, 2007; Majnemer et al., 2013). Therefore, it was expected that participants with higher initial motor levels of functioning were making more progress in responsiveness.

Methods

Participants

Forty-four children and young adults (22 boys and 22 girls) from a residential home (n=31) and associated day-care centres (n=13) in South Africa were selected to participate in the Multi-Sensory Storytelling Intervention. At the residence, children and youth live there and receive 24-hour care. The day-care centres are located in three different townships, where youth with (multiple) disabilities can come during the day from Monday until Friday for care and activities. These youth are still living with their parents or legal guardians.

MSST is originally developed for children and young adults with PMD, in the sensory motor stage. As the facility of this research is located in a developing country, without a well organized non-private healthcare system, most participants were not properly diagnosed. It was attempted to select participants who suited the MSST program. Selection was done by the program manager of the residence, based on her professional judgment and findings from previous years about the mental and physical capabilities and disabilities of the participants. All the participants have a profound intellectual disability, most have indications for Cerebral Palsy n=41) and/or other impairments such as visual impairments (n=3), hearing impairments (n=1), hemiplegia (n=2), autism (n=1) and microcephaly (n=1).

Age of the participants ranged between 2 and 37 years ($M_{age} = 17,55$; SD=9,87). On average the participants in the day-care centres were younger ($M_{age} = 7,00$; SD=3,56) than the

participants in the residence (M_{age} =21,97; SD=8,13). It is not possible to correct for age in the analyses, because of the different age-composition in the different groups.

Procedures were performed in compliance with the relevant South-African laws and guidelines. Because the residence is now the legal guardian of the participants, the institutional committee has approved the procedures on behalf of the participants. For the participants in the day-care centres, the parents, siblings or guardians signed an informed consent.

Multi-Sensory Storytelling Intervention

Multi-Sensory Storytelling (MSST) originates from Park's 'multisensory interactive drama' (Park, 1998) and Chris Fuller's 'Bag books' (Fuller, 1999) and was further developed by Pamis (2002). The stories are adapted to the possibilities, mental age and interests of the child with PMD. The length of the stories is short and they are divided in short paragraphs, with one or two sentences per page. The stories are structured: they are presented in a red box to mark the beginning of the training, they have 7 or 8 pages and a clear ending. The language of the stories is simple, with short sentences, formulated in the present time and some words are used frequently. On the front of the page, the story is written in English, on the back in Zulu (the locally spoken language). The story is read in the language of the individual participant. The name of the child is used frequently to involve the child in the story and hold his or her attention. Each page in the story is supported by an *object of reference*, to stimulate an effective way of learning through multi-sensory information. Furthermore, the objects of reference contribute to the structure of the story.

In 2009 MSST was first implemented in the residence by Nispel and Vermeer (2010). The 11 stories that they developed have already been used for all the children. The stories developed by the program manager assisted by Halfens (2011), Eck (2013) and Willems (2014) were also used for almost all the participants. Therefore, new stories have been developed in collaboration with the childcare workers. To prevent high costs and because their lives are very similar (living in the same circumstances), the content of the stories regards general topics that can be used by multiple participants, instead of using individualized stories. The new stories have the following titles: Going to the doctor, Going to the park, Going to town, Getting a haircut. Two stories (Going to the beach & Taking a bath) developed in last year's research, haven't been used at the day-care centres and will be implemented there. The stories took between 4 and 8 minutes. They were stored in a red box,

to improve the recognisability for the participants. A box consists of seven to eight A3 pages, belonging objects, and an instruction manual. The stories are divided into two levels, with the level 2 stories more physically challenging (e.g. more advanced movements required) and more cognitively challenging (e.g. more abstract topic). For each participant, it was individually decided which story was the best fit, based on their physical and intellectual functioning. Thirty-seven participants had level 1 stories and 7 participants level 2 stories. All analyses presented in the results section were preliminary tested for effect of level. Level had no influence on the outcomes, although the level 2 group is too small to draw definite conclusions. Only findings for the complete group will be reported.

It was checked whether the baseline responsivity scores of the trained story and untrained story were comparable. Analyses showed no significant differences between the baselines of level one stories 'Doctor' (M=7.30, SD=4.42) and 'Parc' (M=6.26, SD=5.23) and the level two stories 'Haircut' (M=17.94, SD=9.10) and 'Town' (M=14.69, SD=5.98).

Procedure

The organization follows a fixed yearly intervention pattern. Every year, between February and June research is conducted. During this period, MSST is trained frequently (2 sessions a week), combined with supervision of the researcher. This research period is followed by a vacation of a couple of weeks without MSST, then a period of weekly MSST and finally a summer vacation without MSST in December and part of January. Due to a lack of practice in this period, it is likely that the quality of the therapy and the knowledge of the staff decreased. Therefore, before re-intensifying the training in February 2014, the childcare workers received a workshop to again discuss the procedure and the required actions from the childcare worker. To further increase their knowledge about the stories and their motivation, the staff was involved in the development of the new stories.

At the Home as well as at the day-care centres, two other interventions are given as well. Previous years, the childcare workers carried out all three of them. This year, the staff in the residence specialized in one therapy, to relief their workload and increase their motivation for and knowledge about the therapy. In the day-care centres this change was not possible, because there are too few childcare workers and less children to divide between them.

The participants were matched to a childcare worker to ensure the continuity of the storytelling. This was also important to establish a good and trusting relationship and to stimulate the aspects of intuitive parenting. These matches were made by the development

manager of the Children's Home in South Africa, based on her professional judgement. The MSST sessions took place in the bedrooms of the participants in the residence and for the participants in the day-cares outside or on a quiet place inside. This was a familiar place for the participant as well as the childcare worker, which helped to make them both feel comfortable and focus on the therapy. The childcare worker was sitting on a chair during the therapy. The positioning of the participants was individually adjusted to optimize the possibilities he/she had to respond to the story (e.g. see the objects/ page/ childcare worker, manipulate the objects, etc.) and to what was the most comfortable for them, either laying down, sitting in a wheelchair or on a chair.

Design

The participants were divided into two groups, which were matched based on the responsiveness scores of their first measurement. One of the groups received therapy in the first six week period, the other group served as a control-group and started after this first period was finished. To examine the progress in responsiveness of each participant during training, an experimental design was used. The design is shown in Figure 1.

The recordings were made on a distance of one to two meters from the childcare worker and the participant. At this distance, even small facial expressions could be observed. Sessions 1, 5 and 10 were videotaped and responsivity was scored during the therapy training period to measure the effect of MSST and examine the learning curve of the participants.

Pretest A	Pretest B	Training	Half-way	Training	Posttest B	Posttest A
		period	Test B	period		
Story A	Story B	Story B	Story B	Story B	Story B	Story A
(1 session)	(1 st session)	(3 sessions)	(5 th session)	(3 sessions)	(10 th session)	(1 session)

Figure 1. The experimental design used during the training period

Note: Story A is a new and untrained story that was given before and after the ten sessions with story B. Story B is also a new story.

Responsivity to the untrained story was scored from video at three waves. The design is shown in Figure 2. This design allows comparison of group 1, who received therapy the first period, with group 2, who served as a control group in this period. The two groups are matched as well as possible, but the nature of the disabilities of the participants is very

diverse. Therefore, the effectiveness was also examined by comparing the responsiveness scores of group two in the second period with their own responsiveness scores of the first period (where they didn't receive training). A short term maintenance effect was measured with the untrained story by comparing the responsiveness scores of wave 3 with wave 1 and 2, for group 1, who received MSST training during the first period, but not in the second period.

Group 1:	Wave 1	Therapy	Wave 2	Control	Wave 3
	(n=22)		(n=22)		(n=22)
Group 2:	Wave 1	Control	Wave 2	Therapy	Wave 3
	(n=22)		(n=22)		(n=22)

Figure 2. The experimental design used for the new untrained story (story A in figure 1) *Note:* At each wave responsivity was measured by means of observations from video.

Lastly, the long term maintenance effect of MSST was examined by comparing the pre-test of the new untrained story of both groups with the post-test of last year's research (Willems, 2013) after a period of 8 months with lower frequency training. Because present study used new stories this year, the untrained story used in the pre-test of present study is a different story than the one used at the post-test of last year's research.

Instruments

Responsiveness Scale (RS). The behavioural responses which the participants showed were scored on 13 items. The 13 items with definitions are shown in Table 1. The items were scored on the frequency of showing a specific behavioural response per page and scored in the time that a page and/ or object were presented to the participant (frequency per minute). The scores of every page were summed and divided by the total therapy time. This with the exception of the item 'positive facial expression' (PFE), were the duration of the response was measured. The item PFE was scored by a Likert-Scale measuring the percentage of time that the participant showed a positive facial expression per page (0% = score 0, 1-10% = score 1, 10-40% = score 2, 40-60% = score 3, >60% = score 4). For this item, the scores of every page were summed and divided by the number of pages. The sum of the 13 item-scores represents the total responsiveness score. Cronbach's Alpha of the total RS of the trained story was between .65 and .68, and for the untrained story between .71 and .77 for all three waves,

which is considered good, as due to the large diversity in this group of participants, not every response is expected to be equally likely in every participant.

To determine the inter-observer reliability of the RS, ten randomly selected videos of Willems (2014) research were also scored by the current researcher and compared. Analyses showed that the mean reliability over all items was excellent (rs=.95, n=10, p<.001).

Table 1 The 13 items with definitions of the Responsiveness Scale

13 items	Definition	
Positive facial expression	Smile: form one's features into a pleased, kind, or amused expression, typically with the corners of the mouth turned up.	
Happy vocalizations	Laughing or other happy sounds.	
Looks at object	Eyes are focused on object and the head is turned towards that direction.	
Looks at page	Eyes are focused on page and the head is turned towards that direction.	
Looks at storyteller	Eyes are focused on (the face of the) childcare worker and the head is turned towards that direction.	
Wave or clap hands	Move one's hand back and forth in greeting or brings two hands together and puts them on each other in one movement. Sound is not necessary.	
Positive response or nod/shake no	A positive response to the object/storyteller, for example imitation of the same behaviour performed by the childcare worker or answering a question. Nod: lower and raise one's head slightly and briefly (especially in greeting, assent, or understanding) Shake no: move head from left to right side or vice versa.	
Gesturing and Pointing	Gesture: Uses signs or gestures with hands that fit or describe a word or sentence. Pointing: When a child uses the outstretched arm and index finger to focus attention on a particular referent. For children who cannot use their index finger or other finger, this part is not necessary.	
Reaching for the object/page	Extend one's hand or arm in an attempt to touch or grasp the object/page.	
Short touching	Stroking the object/page, hitting the object, touching the object for less than two seconds, without grasping the object/page.	
Manipulation	Holding the object/page, or non-functional manipulation (e.g., shake, rattle) the object for at least two seconds.	
Functional manipulation	Press the button, or relating to the way in which the object works or operates (i.e., using it in a functional manner). The manipulation of objects to construct or to create something.	

(Attempt to) Sing, repeat	Every attempt a child makes to say, sing or repeat words. Words do not
or say words	have to be pronounced correctly. Note: this item is different than 'Happy
•	vocalisations'.

Note: The specific more detailed instructions for using the RS is found in Appendix 1.

MISC.

To draw conclusions about the effectiveness of MSST, it was important that the childcare workers carried out MSST with good quality. When the childcare workers did not follow the method and procedures of MSST, no conclusions could be drawn about the effectiveness of the active components of MSST in the daily practice (Ten Brug, van der Putten, Penne, Maes, Vlaskamp, 2011). Also, the participants might have just benefitted from extra attention they got from the childcare workers. To measure the quality of MSST provided by the childcare workers, the Multisensory Storytelling Integrity Scale (MISC) was developed. The quality was judged on 5 required therapy actions (e.g. giving the child time to respond and encouragement) and 6 requirements concerning the quality of social behaviour of the trainer (e.g. positive reinforcement and dynamic reading). The 11 items and their definitions are shown in Table 2, the scale and more details about the items can be found in Appendix 2 and 3. The item 'procedural mistakes' was scored by counting the mistakes made by the childcare worker during the therapy. The amount of procedural mistakes was separately analysed to check whether the procedures of MSST were followed. The item will not be included in further analyses. Scores were between 0 and 6 per training session, with the mean between .96 and 1.15 mistake per session. This means the childcare workers usually don't make a lot of mistakes in the training sessions. The other items were scored on a 5-point Likert-Scale. The item 'time for exploring' was scored by a Likert-Scale measuring the percentage of time the childcare worker shows the object or the page within the range of the senses of the participant (<60% = score 0, 60-70% = score 1, 70-80% = score 2, 80-90% = score 3, >90% = score 4).The other 9 items were scored on a 5-point Likert scale for quality (0=poor, 1=moderate, 2= Average, 3= above average, 4= good). The total MISC-score is the sum of all the items. Firstly the internal consistency of the subscales and total scale were analysed. Cronbach's Alpha of the subscale 'Therapy actions' was between .48 and .58, which is considered poor. Cronbach's Alpha of the subscale 'Social behaviour of the trainer' was between .48 and .54, which is considered poor. Cronbach's Alpha of the total MISC-score was between .70 and .75, which is considered good. Therefore, only total scores were used. Secondly, the relation between the Overall Quality-item and the total MISC-score was checked. Pearson's r was

between .70 and .89, which is considered a high correlation. Lastly, to determine the interobserver reliability of the MISC, ten randomly selected videos were scored by the current researcher and an intern who was also working at the residence. Analyses showed that the reliability was good (rs=.836, n=10, p<.001).

Table 2. The Subscales and 11 items of the MISC

11 items per subscale	Definition
Therapy actions	
Procedural mistakes	Number of deviations from the fixed elements of the MSST procedure (e.g. preparation of the therapy session, sequences of the pages/objects, showing all pages/objects/ red box)
Time for exploring	The total time the childcare worker shows the object or the page within the range of the senses of the participant. The participant needs to get enough (visual and physical) time (i.e. minimal 3 seconds) to take initiative or to explore the stimuli offered.
Verbal encouragement	The quality of verbal encouragement provided by the childcare worker to explore the object by using words as touch, feel, smell, see.
Encouragement through action	The quality of encouragement provided by the childcare worker by showing and offering the participant the objects in a way that is adapted to the participants needs and fits within the story
Positioning of the participant	The quality of the position of the participant provided by the childcare worker. The participant needs to be in a position where he can interact with the childcare worker, explore the objects and is comfortable.
Social behaviour of the trainer Positive facial expression	The quality of positive facial expression from the childcare worker. Smiling: form one's features into a pleased, kind, or amused expression, typically with the corners of the mouth turned up and the front teeth exposed
Eye contact	The quality of eye contact from the childcare worker with the participant. It is not necessary that the participant looks back.
(Positive) Physical contact	The quality of positive physical contact between the childcare worker and participant.
Direct positive reinforcement	The quality of positive and direct reinforcement provided by the childcare worker (e.g. looking, reaching, manipulation) after a response from the participants occurs
Exciting/ dynamic reading	The quality of the reading, in terms of excitement and dynamics, provided by the childcare worker (e.g. childcare worker uses her emotions in the reading and brings the story with enthusiasm)

Sensitivity to the participant	The quality of sensitivity to the participant provided by the childcare worker (i.e. remove the object when the participant turns his head or pushes the object away.
Overall quality of the session	

Motor Functioning. To study the effect of motor functioning of the participants on MSST, data on the Fine Motor Functioning (FMS) and Gross Motor Functioning (GMS) was available from another study conducted at the residence (Spek, 2014). The Fine and Gross Motor Scale for children with severe multiple disabilities (FGMS) was used in this study. The fine motor subscale consists of seven sequential ways of reaching and grasping. The participants had to grasp three objects in different sizes and received a score between 0 and 6, see Table 3. The total FMS score was the mean from the three object-scores. The objects and more specific description of the ways of reaching and grasping can be found in Appendix 4.

Table 3. Possible scores for the FMS

- 0 No reaching
- 1 Reaching, but no contact
- 2 Contact only (no grasping)
- 3 Primitive squeeze: palm and fingers enclose the object
- 4 Hand grasp: claw-like move from above, with fingers and thumb in a parallel position
- 5 Inferior pincer grasp: grasping with a stretched thumb and several fingers
- 6 Superior pincer grasp: grasping with a bended thumb and forefinger

The gross motor subscale is based on various studies on motor development (Allen & Alexander, 1997; Frankenburg & Dodds, 1967; Husaini, et al., n.d.; Shirly, in Netelenbos, 1998; Ornitz, Guthrie & Farley, 1977). The gross motor subscale consists of 13 gross motor milestones, see Table 4. The total score is the number of mastered milestones. Cronbach's Alpha of the total FGMS was .91 for FMS and .91 for GMS, which is considered excellent. The inter-observer reliability was measured between two observers. Analyses showed that the reliability was good, FMS (rs=.933) and GMS (rs=1.00)

Table 4. The 13 gross motor milestones

- 1. Foetal position
- 2. Lifting head
- 3. Sit with support
- 4. Sit with support; head steady
- 5.Roll over from prone to supine position
- 6. Roll over from supine to prone position
- 7. Sit without support; body is not upright
- 8. Sit without support; body is upright
- 9. Creep
- 10. Crawl
- 11. Standing with support
- 12. Walking with support
- 13. Walking without support

Preliminary Results

The pre-test responsivity scores at wave 1 for the two groups were compared to test whether the participants were properly matched. The group receiving MSST in the first period (M=8.21, SD= 6.18) was not significantly different from the one receiving MSST in the second period (M=8,43, SD=6,18).

Normality checks showed that the distribution of the RS scores were rightly skewed. A square root transformation was not enough to normalize the distribution. Therefore, a log transformation was applied to normalize the distribution. Tables will contain means before the log transformation. Because of the small sample size, also trends with a p between .05 and .01 were reported. There were no deviations from assumptions for the MISC.

Mean MISC scores (without procedural mistakes) at the three measurements were calculated to determine the quality of the training the childcare workers provide. Attainable scores on the MISC are between 0 and 44. The descriptive statistics are presented in Table 5. The mean MISC-scores are around 29, which means that the quality is at an acceptable but not perfect level.

Table 5.

Mean MISC-scores and Standard Deviations at the three Measurement moments

	Mean (M)	Standard Deviation (SD)
MISC_T1	28.46	5.28
MISC_T2	29.63	5.43
MISC_T3	30.28	4.74

Results

Effectiveness of the Multisensory Storytelling Intervention

The effectiveness of the MSST-intervention on responsiveness will be presented separately for the trained story and the untrained story.

Trained story.

Development of responsiveness during training. To examine the development of responsiveness (RS) during MSST trainings, a one-way repeated measures ANOVA was conducted, using the therapy periods of both groups (regardless of whether MSST took place in the first or the second period). The development in RS was analyzed using three measurements: at the first (m1), fifth (m2) and tenth (m3) session of MSST. The means for responsivity are shown in Table 6. The analyses yielded a significant overall within effect in the mean levels of responsiveness, F(2,86)=19.61, p<.001, with a significant linear increase, F(1,43)=27.91, p<.001, as well as a significant quadratic effect, F(1,43)=4.37, p<.05. Posthoc analysis, using a Sidak correction, indicated that the mean level of responsiveness at m3 was significantly higher (p<.001) than the mean level of responsiveness at the other measurements. The mean level of responsiveness at m1 and m2 did not differ significantly from each other. In conclusion, these findings show that the participants improved their responsiveness during training with MSST, but only after 5 sessions.

Table 6.

Mean RS-scores at the three Measurement moments for the Trained Story, the Groups taken together

	Mean (M)	Standard Deviation (SD)
m1	8.22	5.59
m2	8.52	5.72
m3	9.89	5.96

Untrained story.

Therapy versus control group. To compare the outcomes of the therapy-group, with the outcomes of the control-group in the first period, again a repeated ANOVA was used with pre- and posttest RS scores on the untrained story as dependent variables and group (MSST versus control) as between factor. The means for RS are shown in Table 7. A significant effect of group in the mean levels of responsiveness was found, F(1, 42)=9.12, p=.004. Posthoc analysis, using a Sidak correction, indicated a positive trend in the level of responsiveness in the therapy group, F(1,21)=3.02, p=.097. A significant decrease of responsiveness was found in the control group, F(1,21)=19.97, p<.001.

Table 7.

Mean RS-scores at the Pretest and Posttest, separated by Group (Therapy- vs. Control)

	Means (SD) pretest	Means (SD) posttest
Therapy-group	8.21 (6.18)	9.45 (7.02)
Control-group	8.43 (6.18)	7.33 (5.62)

Residence vs. day-cares. To examine differences in responsiveness after receiving MSST training between the participants of the residence and the day-cares, this variable (location) was included in the analyses for the trained as well as the untrained story. As there are no level 2 participants at the day-cares, the level 2 participants from the residence were excluded from the analyses. No interactions with the within factor were found for home versus Day-care; the participants of the residence and the day-cares do not differ from each other for both the development during the training and the untrained story.

Comparing control and therapy period within group 2. A within group comparison for the untrained story was conducted to compare the mean RS-scores at all three waves, for the group that was a control-group in the first period (T1 tot T2) and received MSST in the second period (T2 to T3). The means for responsivity are shown in Table 8. An overall significant within effect was found, F(2,42)=9.82, p=.001, with a significant quadratic effect, F(1,21)=7.41, p<.05. Post-hoc analysis, using a Sidak correction, indicated that the previously discussed significant decrease between T1 and T2, p<.001, and the increase between T2 and T3 was not significant. Yet, no significant difference was found between T1 and T3 either, which indicates that the participants did seem to return to their starting level of responsiveness.

Table 8.

Mean RS-scores at the three Measurement moments for Group 2 for the Untrained Story

	Mean (M)	Standard Deviation (SD)
T1	8.43	6.18
T2	7.33	5.62
T3	8.26	6.59

Maintenance effect.

Short term maintenance effect. The differences in responsiveness as measured by the RS-scores of the untrained story were analyzed at three measurement moments in group 1. As group 1 only received MSST training during the first period (T1-T2), the second period (T2-T3) was used to measure the short term maintenance effect. The means for responsivity are shown in Table 9. A significant quadratic effect was found, F(1,21)=6,15, p<.05. Post-hoc analysis, using the Sidak correction, shows, as discussed before, a positive trend in the level of responsiveness was found between T1 and T2, F(1,21)=3.02, p=.097. This was followed by a decrease between T2 and T3, which just missed significance (p=.058). There was no significant difference in RS between T1 and T3.

Table 9.

Mean RS-scores at the three Measurement moments for Group 1 for the Untrained Story

	Mean (M)	Standard Deviation (SD)
T1	8.21	6.18
T2	9.45	7.02
T3	8.02	6.15

Long term maintenance effect. The long term maintenance effect of MSST of the untrained story after a year of low frequency training was examined by comparing the RS-scores of the pre- and posttest in 2014 (Willems, 2014) with the RS scores of the pretest of the new untrained story of this year. The means for responsivity are presented in Table 10. A significant quadratic effect was found, F(1,26)=13.25, p=.001. Post-hoc analysis, using the Sidak correction. A significant increase in the level of responsiveness was found between the pretest and posttest of last year's research (p<.01), followed by a significant decrease between the posttest of last year's research and the pretest of present study (p<.05). Results show no significant differences between the pretest of last year's study and the pretest of this year's study.

Table 10.

Mean RS-scores at the three Measurement moments for Group 1 for the Untrained Story

Measurement moment (research year)	Mean (M)	Standard Deviation (SD)
T1 (2014)	6.99	5.73
T3 (2014)	10.30	7.19
T1 (2015)	7.77	5.43

Moderating effect of Motor functioning.

A regression analyses was conducted, to determine whether the initial level of motor functioning of the participants predicted the progress in responsiveness during MSST, with the posttest RS-scores of both groups (for group 1: T2, for group 2: T3) as dependent variable and the pretest RS-scores of both groups (for group 1: T1, for group 2: T2) and the FMS and GMS scores and interaction between pretest and motor variables as predictors. No significant moderating effects were found for initial motor functioning, see Table 11.

Table 11.

Beta's for the Hierarchic Regression analyses of Motor functioning

Predictors		β	Standard Error (SE)
Model 1	Constant	.539	.162
	Pretest	.731**	.090
Model 2	Constant	.540	.172
	Pretest	.673**	.109
	FMS	.015	.016
	GMS	.000	.019
Model 3	Constant	.896	.268
	Pretest	.409*	.185
	FMS	035	.043
	GMS	026	.054
	Pretest* FMS	.031	.024
	Pretest* GMS	.014	.027

Note: * p<.05, ** p=.000

Discussion

The purpose of present study was to determine the effectiveness of Multi-Sensory Storytelling intervention on the responsiveness of youth with profound multiple disabilities in a Children's Home and associated day-care centres in South-Africa. As expected, development during training was found. More specifically, the increase in responsiveness was mainly found in the second half of the training, after the fifth session of MSST. This confirms the importance of repetition for individuals with (profound) mental disabilities (Piaget, 1951, 1952; Brodin, 2005; Vaughn et. al., 2003). However, it is still unknown if the responsiveness could further improve with more than ten sessions of MSST. Further research could point this out. Also, it could be that the responsiveness will further increase if the quality of the MSST-training is further improved. The quality of the training was evaluated at an acceptable but not perfect level. Therefore, a recommendation for future research is to further educate the childcare workers in performing MSST training.

Secondly, as a test for the capacity of 'learning by analogy', it was studied if responsivity also increased to another MSST story that was not trained. For the therapy-group

that received training in the first period a small increase in responsiveness was found in responsivity, although it just missed significance. The difference with the control group was significant, but this was mainly due to the fact that in this group responsivity unexpectedly *decreased* after 6 weeks without MSST. The effect of training on the new untrained story was further examined by a within group comparison in this control group that received MSST in the second period. It was expected that after the decrease in responsiveness during the first period, this group would improve their responsiveness during the second period, where they received MSST. However, although the levels of responsiveness did return to their original level, this effect was not significant. In conclusion, there is not much evidence for the capacity to 'learn by analogy' in the present findings.

Similar negative findings seem to be present for the maintenance of earlier small 'generalization' effects to the untrained story. The small increase in responsivity to the untrained story in the first period, was followed by a decrease in responsiveness, which just missed significance, when the therapy was stopped for six weeks after a period of high frequency MSST. The responsiveness of the participants dropped back to their original level at the start of the training. Also, no long term maintenance effect was found from gains to the untrained story from previous year's MSST period. The responsiveness scores decreased when MSST was trained less frequently for a period of 8 months.

A lack of the 'generalization' effect is quite common in research with individuals with intellectual disabilities (Ferretti & Buterfield, 1992; Lifshitz, Weiss, Tzuriel & Tzemach, 2011). For the participants in present study, it seems that transferring the learned responsiveness to a new story with different sensory stimuli is too difficult. It is recommended that future research uses the same sensory stimuli in a new story, or the same story with different but similar stimuli, to examine whether the participants recognize and respond to the stimuli or the story. An explanation for the small positive effect on the untrained story in one of the groups could be that responsiveness increased due to a building up a more trusting relationship between the childcare worker and the participant during training of the other story (Pamis, 2002; Petry, 2004; Brodin, 2005; Ten Brug et al., 2012; Penne et al., 2012). This relationship might promote the participants social responses to the story (i.e. looking at and smiling to the childcare worker), which could explain the small increase in responsiveness found for this untrained story. The fact that responsiveness decreased when MSST was stopped, regardless of whether MSST was received in the first or the second period, seems to

support this suggestion. Future research could point this out by analyzing differences between social responses and responses to the objects and story separately.

Research confirms that individuals with PMD often have difficulty maintaining new developed skills (Ferretti & Buterfield, 1992, Frey & Kaiser, 2011; Case-Smith, 2013). However, in the present study the maintenance effects have only been measured for responsivity to the untrained story. Moreover, to measure the long term maintenance effect, a different story than last year was used. So it is questionable if we really measured a maintenance effect of the MSST intervention. It is very well possible that the maintenance effect is stronger when measured with the story used in the MSST training sessions. Therefore, for further research on the maintenance of MSST, it is recommended that progress at all three waves (pre-tests and posttests) are measured with both the story used during training and the new untrained story. And for measuring the long term maintenance, last year's story should be used.

The final question concerned possible moderators for effectiveness. Against expectations, no differences between the participants of the residence and the day-care centres were found, in both groups RS increased during training. An explanation for this finding could be the use of new stories. Maybe the new stories triggered a high motivation to learn, resulting in more responsiveness during the training, regardless of age, background and earlier experience with MSST.

Also, no effect of level of motor functioning of the participants on the progress in responsiveness was found. These findings seem to implicate that MSST training has the same effect on responsiveness, regardless of their motor abilities. An explanation for these findings could be that the procedure of the MSST training is adjusted to the individual abilities of the participant, so that every participant is challenged at his own level of functioning (Vygotsky, 1978). As such, MSST seems to be an applicable intervention for this very diverse group of individuals with PMD.

Present study has several strengths. Forty-four participants took part in the research, which is considered a big sample size when investigating Profound Multiple Disabled individuals. Another strength is the design of this research. The study used a control group, where most previous research investigating the effectiveness of MSST lacked a control group (Pamis, 2002; Jonckheere, 2008; Young et al., 2011). Furthermore, the effectiveness was not only examined by comparing the effect between the therapy group and the control group, but also by comparing the control group with its own baseline. Thereby, effects due to possible

differences between the groups were eliminated. Lastly, in this research on the effectiveness of MSST, the effects of learning by analogy and maintenance were examined.

Of course, the present study also has some limitations. Firstly, maintenance effects have been measured for the increase in responsiveness to untrained stories, which the participants were unfamiliar with. So the lack of findings do not necessarily imply a true lack of maintenance. Secondly, in this study a correction for the age and differences in background between the residence group and the day-care group was not possible, because of the different age composition in the two sub-populations. These limitations should be taken into mind in future research. Also, the differences between social responses and responses to the objects and story should be analyzed to investigate whether the increase in responsiveness reflects merely an increase in social relatedness with the trainer, or also a larger focus on objects and their affordances. A last recommendation for future research is replication of the findings in similar populations and situations.

In conclusion, the findings of this research provided support for the hypothesized effectiveness of the MSST intervention in terms of development in responsiveness during training. Repetition seems to be a key aspect in the training of individuals with PMD. Further research is recommended regarding the maintenance of the trained effects, as well as the ability to transfer learned experiences to similar but slightly different situations.

References

- Allen, M.C., & Alexander, G.R. (1997). Using motor milestones as a multistep process to screen preterm infants for cerebral palsy. *Developmental medicine & child neurology*, 39, 12-16.
- American Association of Intellectual and Develepmental Disabilities (2015). *Definition*. Verkregen op 28 juni 2015 van http://aaidd.org/intellectual-disability/definition
- Ben-Itzchak, E. & Zachor, D.A (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism.

 *Research in Developmental Disabilities, 28, 287-303.
- Bottcher, L., Flachs, E.M., & Uldall, P. (2010). Attentional and executive impairments in children with spastic cerebral palsy. *Developmental Medicine & Child Neurology*, 52:2, 42-47.

- Brodin, J. (2005). Diversity of aspects on play in children with profound multiple disabilities. *Early Child Development and Care*, 175(7-8), 635-646.
- Brug, A., ten, Putten, A., van der, Penne, A. & Vlaskamp, C. (2011). Multi-sensory storytelling for persons with profound intellectual and multiple disabilities: An analysis of the development, content and application in practice. *Journal of Applied Research in Intellectual disabilities*, 25, 350-359.
- Case-Smith, J. (2013). Systematic review of interventions to promote social—emotional development in young children with or at risk for disability. *American Journal of Occupational Therapy*, 67(4), 395-404.
- Chan, S., Fung, M. Y., Tong, C. W., & Thompson, D. (2005). The clinical effectiveness of a multisensory therapy on clients with developmental disability. *Research in Developmental Disabilities*, 26, 131-142.
- Chemero, A. (2003). An outline of a Theory of Affordances. *Ecological Psychology*, 15, 181-195.
- Chen, Z., Sanchez, R. P., & Campbell, T. (1997). From beyond to within their grasp: The rudimentals of analogical problem solving in 10- and 13-month-olds.

 *Developmental Psychology, 33, 790 801.
- Farrell, M. (2012). Educating Special Children: An introduction to provision for pupils with disabilities and disorders. New York: Routledge.
- Ferretti, R. P., & Butterfield, E. C. (1992). Intelligence-Related Differences in the Learning, Maintenance, and Transfer of Problem-Solving Strategies. *Intelligence*, *16*, 207-223.
- Frankenburg, W.K., & Dodds, J.B. (1967). The Denver Developmental Screening Test. *The journal of pediatrics*, 71(2), 181-191.
- Frey, J. R., & Kaiser, A. P. (2011). The use of play expansions to increase the diversity and complexity of object play in young children with disabilities. *Topics in Early Childhood Special Education*, 31(2), 99-111.
- Gibson, E. J. (1988). Exploratory behaviour in the development of perceiving, acting and the acquiring of knowledge. *Annual Reviews of Psychology*, *39*, 1-41
- Glazer, S. M. & Burke, E. M. (1994). An integrated approach to early literacy. Boston: Allyn & Bacon.
- Gogate, L. J., Bahrick, L. E., & Watson, J. D. (2000). A study of multimodal motherese: The role of temporal synchrony between verbal labels and gestures. *Child development*, 71(4), 878-894.

- Grove, N., & Peacey, N. (1999) Teaching subjects to pupils with profound and multiple learning difficulties. *British journal of Special Education*, *26*, 83-86.
- Hogg, J., Cavet, J., Lambe, L., & Smeddle, M. (2001). The use of 'Snoezelen' as multisensory stimulation with people with intellectual disabilities: a review of the research.

 *Research in Developmental Disabilities, 22(5), 353-372.
- Hotz, G. A., Castelblanco, A., Lara, I. M., Weiss, A. D., Duncan, R., & Kuluz, J. W. (2006).
 Snoezelen: A controlled multi-sensory stimulation therapy for children recovering from severe brain injury. *Brain Injury*, 20(8), 879-888.
- Husaini, M.A., Jahari, A.B., Husaini, J.K., Widodo, Y., Harahap, H., & Soewondo, S. (n.d.). Motor Milestone Development Card: a simple technology for use in primary health care. Retrieved August, 22, 2015 from www.gtid.net/acmr_17/pdf/9-KMS-Card.pdf.
- Keane, M. K. (1988). Analogical problem solving. Chichester, UK: Ellis Horwood.
- Lacey P. (2006) Inclusive literacy. PMLD-Link 18, 11–13.
- Liefshitz, H., Weiss, I., Tzuriel, D., & Tzemach, M. (2011). New Model of Mapping Difficulties in solving Analogical Problems among Adolescents and Adults with Intellectual Disability. *Research in Developmental Disabilities*, *32*, 326-344.
- Longhorn, F. 1988. A sensory curriculum for very special people. London: Souvenir Press.
- Majnemer, A., Shikako-Thomas, K., Lach, L., Shevell, M., Law, M., & Schmitz, N. (2013). Mastery motivation in adolescents with cerebral palsy. *Research in Developmental Disabilities*, *34*,3384-3392.
- Miller, S., & Pennycuff, L. (2008). The Power of Story: using Storytelling to Improve
 Literacy Learning. *Journal of Cross-Disciplinary Perspectives in Education.*, 1(1),
 36-43
- Monaghan, P., & Rownson, C. (2008) The effect of repetition and similarity on sequence learning. *Memory and Cognition*, *36*, 1509-1514.
- Multiplus (2008). *Handleiding: Multi-sensory storytelling. Verhalen voor mensen met ernstige meervoudige beperkingen.* Expertisecentrum, Leuven.
- Netelenbos, J.B. (1998). *Motorische ontwikkeling van kinderen. Handboek 1: introductie.*Amsterdam: Uitgeverij Boom.
- Ornitz, E.M., Guthrie, D., Farley, A.H. (1977). The early development of autistic children. *Journal of Autism and Childhood Schizophrenia*, 7(3), 207-229.

- Pamis (2002). Developing literacy skills through Multi-sensory Story-telling in children and young people with profound and multiple learning disabilities. Final Report. Dundee, University of Dundee.
- Pamis (2004). Sensitive Stories Project, Using multi-sensory stories to help people with profound and complex disabilities understand difficult topics. Dundee, University of Dundee.
- Papoušek, H., & Papoušek, M. (1995). Intuitive Parenting. In M.H. Bornstein, M. H. (Red.), Handbook of Parenting: Volume 2 Biology and Ecology of Parenting (pp. 183-203). New Jersey: Lawrence Erlbaum Associates Publishers.
- Penne, A., Brug, A., ten, Putten, A. van der, Vlaskamp, C., & Maes, B. (2012) Staff interactive style during multisensory storytelling with persons with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 56, 167-178.
- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in intellectual Disabilities*, 18, 35-46.
- Piaget, J. (1951). Play, dreams and imitation. Melbourne, Australia: Heineman
- Piaget, J. (1952). The child's conception of number. London: Routledge Kegan Paul.
- Shams, L., & Seitz, A. R. (2008). Benefits of multisensory learning. *Trends in cognitive sciences*, *12*(11), 411-417.
- Smith, L. B., & Thelen, E. (2003). Development as a dynamic system. *Trends in Cognitive Sciences*, 7, 343-348.
- Vaughn, S., Kim, A. H., Sloan, C. V. M., Hughes, M. T., Elbaum, B., & Sridhar, D. (2003).Social Skills Interventions for Young Children with Disabilities A Synthesis of GroupDesign Studies. *Remedial and Special Education*, 24(1), 2-15.
- Vygotsky, L. (1978). Mind in Society. Cambridge, MA: Harvard University Press.

Non-published studies:

Eck, T., van (2013). Evaluation of Multi-Sensory Storytelling in children with profound multiple disabilities at Sizanani children's home. Utrecht: Utrecht University.

- Halfens, J. (2011). Multisensory Storytelling: the effect on positive Social Responsiveness in Children with Profound Multiple Disabilities. Utrecht: Utrecht University.
- Spek, A. (2014). An Evaluation of Conductive Education for Children with

 Neurodevelopmental Disorders in a Residential Home in South Africa. Utrecht:

 Utrecht University.
- Willems, N. (2014). Sense the story: The effectiveness of an adapted version of Multi-Sensory Storytelling on the responsiveness of children, adolescents and young adults with Multiple Disabilities at a Children's Home in South Africa. Utrecht: Utrecht University.

Appendix 1. Observation Schema Responsiveness Scale															
Unit:					9	Story:									
Date:					ı	Period:									
Name + number	· childca	re worke	er:		ı	Measurement:									
Name + number	child:				-	Total t	nera	py time	:						
	Red	Page	Page	Page	Pag		ge	Page	Page	Page	End	Total			
	box	1	2	3	4	5		6	7	8	song	time			
Total time															
Emotional		0		1			2			3		4			
responses															
Positive facial	N	Never Rarely				Occ	asio	nally	Half of	the tim	е Мо	re than half-			
expression		(0%)		(1-10%)			(10-40%)			-60%)		Always			
												(>60%)			
Emotional	Red	Page	Page	Page	Pag	e Pa	ge	Page	Page	Page	End	Freq/time			
responses	box	1	2	3	4	5		6	7	8	song				
Positive facial															
expression															
Нарру															
vocalisations															
Attention	Red	Page	Page	Page	Pag		ge	Page	Page	Page	Eng	Freq/time			
	box	1	2	3	4	5		6	7	8	song				
Looks at object															
Looks at page															
Looks at															
storyteller															
<u> </u>	L	1		1	1			l		<u> </u>	<u> </u>	I			

High symbolic cognitive responses	Red box	Page 1	Page 2	Page 3	Page 4	Page 5	Page 6	Page 7	Page 8	End song	Freq/time
Wave and clap hands											
Positive nod/shake no											
Gesturing and pointing											

Manipulations	Red	Page	End	Freq/time							
of objects and	box	1	2	3	4	5	6	7	8	song	
page											
Reaching for object/page											
Short touching											
Manipulation											
Functional manipulation											

Verbal	Red	Page	End	Freq/time							
responses	box	1	2	3	4	5	6	7	8	song	
(Attempt to) sing, repeat or say words											

Total SRS score					

Appendix 2. Observation Scheme Multisensory Storytelling Integrity Scale (MSIC)

Unit: Date: Period: Measurem I. Therapy							-	e + nu	ımber ch		_					
Procedu	Prepa of the	aration the erapy ssion	Seque of pag		Seque of obj		Forgi pag		Forgot show object	а	dui	ject still here ring the xt page	Using t same pa twice	age	Forgot to show the red box/sing the end song	Tot
Mistakes															308	
Time fo			0			1			2			3			4	
		N	ever		R	arely		0	ccasional	ly		Half of th	ne time	Mor	e than hal	f-Alwa
	(0-60%)			(60-70%)				(70-80%)			(80-9	0%)		(>90%)		
Time for ex	ploring	!														
	<u>, , , , , , , , , , , , , , , , , , , </u>		Re		Page 1	Pag 2	ge F	Page	Page 4	Pag 5	ge	Page 6	Page 7	Page 8	End song	Tot
Total time s			he													
runge of the	e serise.	<u> </u>														1
Evoking a r	ocnonc	•	0-	Neve	or.	1- 0	ccasio	nally	2= Regu	ılarlı		3= Ofte	20	1- /	Always	
Verbal enco			0-	INCV	<u> </u>	1-0	ccasio	ilaliy	Z- Nego	ilaliy		3-010		4-7	iways	
			0=1	Poor		1=N	loderat	te	2=Avera	age		3=Abo		4=G	ood	
Encourager action (show the object in	wing ar	nd offerin	g													
			0=1	Poor		1=N	loderat	te	2=Avera	age		3=Abo		4=G	ood	
Positioning	of the	participar	nt													

II. Social behaviour of the trainer:

Communicative skills	0=Poor	1=Moderate	2=Average	3=Above	4=Good
childcare worker				average	
Positive facial expression					
Eye contact					
(Positive) Physical contact					
Direct positive reinforcement					
Exciting/ dynamic reading					
Sensitivity to the participant					_

	0=Poor	1=Moderate	2=Average	3=Above	4=Good
				average	
Overall quality of the session					

Appendix 3. Description of Multisensory Storytelling Integrity Scale (MSIC)

I. Therapy actions:

Procedural mistakes, means that the therapy sessions have a certain structure with fixed elements which should be the same for all sessions (i.e. sequences of the pages/objects, showing all pages/objects, showing the red box and singing the end song to the participant). If the childcare worker switches the sequence of the pages, score it as one mistake (i.e. 'fault sequence of page'). If the childcare worker forgets the page afterwards, score another mistake (i.e. 'forgot to show a page'). In the end, all mistakes should be added together, which forms the total score.

<u>Preparation of the therapy session</u>: All disturbing sounds should be scored as one mistake except for disturbing sounds that are 'extern' (i.e. someone else entering the therapy room). It also means that you should score a mistake when the childcare worker has to prepare the story after the red box is already showed or when the childcare worker has to look for the correct object-page (i.e: if the childcare worker does this more often during the session, only score one mistake on 'preparation'). Also score one mistake if the battery of an object is low or when there is no juice in the cup.

<u>Sequence of pages:</u> If the childcare worker switches the sequence of the pages, score it as one mistake.

<u>Object still there during the next page</u>: <u>Sometimes the participants hold the objects longer than is prescribed</u>

<u>Using the same page twice:</u> If the childcare worker uses a page twice, only score the first time the childcare workers uses a page. Also score this as one mistake (i.e: most of the time when this occurs, the childcare worker used the wrong sequence of pages as well).

<u>Forgot to show the red box/sing the end song:</u> Score one mistake if the childcare worker asks if he/she has to do something in the end and then sings the end song after a hint.

Time for exploring: the participant has enough time (i.e. minimal 3 seconds) to take initiative or to explore the stimuli offered.

Exploring a object consists of 2 behaviours; time to look at an object when held by the childcare worker

(visual exploring time) and exploring the object when the participant holds the object himself (physical exploring time). Physical time can be both active (the participant explores the object their self) or passive (the participant is unable to explore the object their self, so the childcare worker makes sure that the participant can explore the object with their help, for example by moving the butterfly in front of the participant).

Both should be scored by measuring the time in seconds.

<u>Visual time:</u> Visual exploring time can be both for the exploration of the page and the object when showing them to the participant. Only time visual time for the page when the childcare workers intentionally turns the page to the participant. The same for objects, only time this when the childcare workers shows the object intentionally to the participant.

<u>Physical time</u> This can only be scored with objects. You start the time when a participant touches the object. Only score time when the object belongs to that page and the participant is really exploring the object. For photos only score exploring time when the participant holds the photo. <u>Total exploring time</u>: Add the score on visual and physical time.

Dit item wordt gescoord door middel van een stopwatch die de tijd bijhoudt.

Evoking a response: The childcare worker tries to evoke a response from the participant by using verbal encouragement and encouragement through action.

<u>Verbal encouragement:</u> The childcare worker encourages the participant to explore the object by using words as touch, feel, smell, see.

<u>Encouragement through action:</u> The childcare worker encourages the participant by showing and offering the participant the objects. This needs to be adapted to the participants needs (for example when the participant can't reach to the objects by himself). It is important that the participant childcare worker offers the object long enough and grabs the attention of the participant (for example by calling the participants name). The way the objects are offered have to fit within the story, so that the participant will understand why the object is offered.

Positioning of the participant: The participant needs to be in a position where he can interact with the childcare worker (for example make eye contact) and can explore the objects. This can be on a chair, in a wheelchair, lying down on the bed or on the lap of the childcare worker.

II. Social behaviour of the trainer:

Positive facial expression:

When a childcare worker has a positive facial expression the whole time during a page, you score only one time. If the childcare worker still has the same positive facial expression the second page, you score one time again as it is a new page.

Eye contact:

For scoring eye contact it is not necessary for the participant to look back at the childcare worker as this scale only measures the childcare worker. It's about the attempt of the childcare worker to make eye contact. When the childcare worker looks away from the participant for more than one second, score eye contact again.

(Positive) Physical contact:

All physical contact should be scored except for negative contact, like hitting. Helping a participant to touch the voicepad for example should be scored. Also hugging should be scored.

Direct positive reinforcement:

There is positive and direct reinforcement when a desired response is strengthened by the presentation of a positive or rewarding stimulus of the participant childcare worker after the response occurs (Skinner, 1963).

A desired response of the participant can be any response scored by the SRS scale: smiling, happy vocalisations, looking at a object/page/storyteller, reaching for a page/object, manipulation of a object/page, pointing, etc. The reinforcement can be verbal or non-verbal (i.e. smiling, nodding, touching, cuddling etc.) but has to be immediately after the desired response.

Exciting/ dynamic reading:

The story will be exciting and dynamic when the childcare worker uses her emotions in the reading and brings the story with enthusiasm.

Sensitivity to the participant:

The childcare worker will accommodate to the participant when necessary (i.e. not touching the participant anymore after the participant shows negative reacting while being touched, stop showing an object when a participant is screaming).

Every time that the childcare workers tries again after a obvious negative reaction of the participant should be scored (i.e. if the childcare worker tries three times to put on some sunglasses after the participant tries to avoid it, you should score this three times).

Overall quality of the session: *Give an overall score off the quality of the session.*

Appendix 4. Description of the fine motor scale (FMS)

The used objects







Picture 2. Crayon (middle object) Picture 3. Block (big object)



7 milestones in reaching and grasping behaviour



Reaching, but no contact (1)



Contact only, no grasping (2)



Primitive squeeze (3)



Hand grasp (4)



Inferior pincer grasp (5)



Superior grasp (6)