

Narrative-based Conversations with Children who are Congenitally Deafblind

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Abstract

Children who are congenitally deafblind all too often miss out on narratives, which are commonly used in daily life to socialise and educate, simply because they do not encounter narratives like others who have sight and hearing. This paper describes a narrative-based approach to everyday conversations. In two case-studies communication partners developed strategies and competencies to make narratives accessible to learners who do not have full use of a formal language. Events containing crucial characteristics of narrative and strong focus on use of gestures drama and mime facilitated subsequent conversations between the partner and child. Comparison between baseline and post-intervention videos showed an increase in the quality of these conversations with enhanced participation, a more balanced reciprocal flow, and a wider variation of expressive forms of communication. This paper offers practical implications for incorporating a narrative approach into the education of children who are deafblind.

Keywords

Deafblind, narratives, conversations, education, communication partners

Introduction

In the education of children with congenital deafblindness there tends to be a focus on providing structures, creating predictable routines, working with scripts and using calendar systems (Hart, 2006). All these elements are of crucial importance as a secure basis of stability. The predictable nature of routines can elicit opportunities for communication however the kind of communication that everybody enjoys is that between human beings who share feelings and interests (Rødbroe & Souriau, 1999). Stories often offer a way to share feelings and interests and besides them being perceived as enjoyable they potentially also enable the child to become communicatively more productive. It is commonly agreed that stories play an important part in life (Bruner, 1990; Nelson, 1996; Heijnen & van Rooij, 2008). Unfortunately this doesn't apply to everyone. People with neither sight nor hearing or with limited use of distal senses will not be exposed to stories in the same way as those who can see and hear.

This paper outlines a narrative approach that offers a way to overcome the lack of or limited exposure to narratives. It enables children with deafblindness to encounter and share narratives as well as to participate in creating them. Furthermore, it allows them to enjoy those moments all over again when the narratives are recalled during a narrative-based conversation. This approach is designed to enhance existing teaching strategies, to complement and enrich the learning environment by creating opportunities that are worth talking about (Nafstad & Rødbroe, 1999; Heijnen & van Rooij, 2008).

The paper is organised into three major sections. The first section outlines narratives from a theoretical perspective, by defining narratives, exploring the relation between narratives and language as well as the link to memory. The second deals with the more practical competencies a communication partner should develop in order to successfully share narratives and narrative-based conversations with children who are deafblind. The third section describes two case studies that demonstrate the positive effects of this narrative approach. The paper ends with a discussion including implications for practice.

Understanding Narratives

Characteristics of narratives. Nelson (1996) defines narrative as having six separate components. The first very basic one is that narrative is structured around an unfolding series of events through time. An introduction or orientation is followed by several actions that happen in a certain order. Scripts, like narratives, contain a sequence of events over time leading to a goal. But such a sequence of events on its own lacks the second crucial feature of narrative: departure from the predictable 'canonical' occurrence. This is what makes a story a story: something unusual or unexpected happens and needs to be explained. In other words, there is a complication that needs to be resolved. Within the format of a narrative it is

possible to make sense of the non-canonical (Bruner, 1990). Narratives are not objective but are told from a certain point of view, a particular perspective of time, person and situation the third characteristic. The fourth component is that narratives recapitulate themes of cultural significance, they convey messages which can be either clear and explicit, or implicit and under the surface. The fifth component relates to structure (microstructure and macrostructure). The macrostructure is the overall structure of a narrative or an episode. A simple narrative involves an orientation of the current situation, an exposition, complication(s), a crisis which leads to a climax followed by a final resolution. This gradual build-up of tension triggers curiosity and induces excitement. More complex narratives will have several of these sequences with a number of climaxes. The sixth and last component, narrative devices of discourse grammar, relates to how a narrative is actually told. In oral language people can use different voices for the various characters. In sign language the storyteller can use the signing space to lay out the scenario. Characters are designated different points in the space and the storyteller changes position to indicate who is speaking (Hendriks, 2004). The following section will explore which narrative devices of discourse grammar can be used with children who can neither hear different voices nor see visualizations.

Narratives and language. Studies by Bruner (1990) and Trevarthen (1999) confirm that it is possible to communicate stories in a non-conventional manner. Narratives can be shared without the use of actual words. Facial expressions, movements of hands, arms and whole bodies, as well as vocal sounds can be used to act out and convey messages. Nelson (1996) verifies that narratives can be displayed in many non-verbal forms like dramatic play, dance, mime, pictures and silent film. Donald (1991, p. 168) uses the term 'mimesis', defined as "the ability to produce conscious, self-initiated, representational acts that are intentional but not linguistic". Therefore, it is feasible to share and create narratives with people who do not have access to more formal means of language.

The video 'Ingerid and the crab' from the Traces DVD (Vege, Bjartvik & Nafstad, 2007) confirms that the specific narrative devices of gestures, drama and mime can be successfully used with individuals with deafblindness. In the video, a young woman called Ingerid encounters a crab for the first time in her life. Ingerid's partner, Gunnar, proves to be an expert in sharing stories without much conventional language. In a bodily-tactile manner he expresses his excitement which makes Ingerid curious to find out what he is 'talking' about. Gunnar uses gestures and mime to convey to Ingerid what is about to happen and to comment on what is being experienced. The day after, in a completely different environment, they are able to recall what had happened by using the same gestures to dramatise the event, the same lay-out of space as in the actual event, and by mimicking certain movements. This example clearly shows that narrative devices of drama, gesture and mime are the main vehicles for sharing narratives with children who are congenitally deafblind. It also shows it

is crucial to have a communication partner who is able to convey messages, make comments, initiate and sustain conversations.

Narratives and memory. Bruner (1990) uses the phrase 'the power of narrative' to emphasise how important narratives are for learning processes. Narratives play a significant role in the development of memory. Nelson (1996) uses the term 'memory talk' to describe conversations between parents and children about past events. Engel (1986) found that even very young children were able to 'co-construct' a narrative about events previous experienced when invited by their mothers to participate and make contributions. Reese, Haden and Fivush (1993) also conducted a study on conversations between mothers and their offspring. They indicate that the narrative format supports the organisation of memory as a coherent whole by giving children a framework that helps them to learn how to remember. Through her study on the social construction of memory, Tessler provides additional evidence for the memorial function of narratives. She examined the effects of adult framing during the actual experience and found that children of mothers who used a narrative style as a framework remembered much more of the event itself (Tessler & Nelson 1994). Enhanced memory of an actual event could potentially enable the child to become communicatively more productive during a conversation about it afterwards. From the above it is evident that the communication partner plays an essential role in the introduction and implementation of a narrative approach. Therefore strategies and competencies required by a partner for such an approach need to be explored.

Partner Competencies

Partners need to have highly developed skills, sensitivities and insights to participate in the world of children with deafblindness, where touch and proximity are crucial (Janssen, Riksen-Walraven and van Dijk, 2003). The partner fulfils an essential role in conveying and interpreting messages. Therefore, what exactly is the role of a partner and what are the specific competencies needed not only to share narratives but also to engage in conversations that have equal participation? The following six competencies have been identified which will help and enable the partner to become a good communication partner.

Attention. During a shared experience a key responsibility of the partner is to detect and then follow the child's attention. This will be the prerequisite for grasping and interpreting the utterances that will develop from this focus of attention. Utterances that can give the partner an idea of what the child is thinking about can include vocalisations, movements, signed or vocal words and deictic gestures (Rødbroe and Souriau, 1999). When the partner has an impression of what the child is interested in, or what the particular highlights are, he or she should align with it in a manner that the child will recognise. The purpose is to establish a 'shared here-and-now' (Rommetveit, 1974) between the child and the partner in which their contexts overlap.

Narrative style. In order to build up suspense or excitement, a narrative style should be developed. The partner's emotional involvement is essential as it will often have a contagious effect. This requires the ability to trigger the child's curiosity by communicating in a bodily-tactile manner that there is something very interesting or exciting. Miles (1998) stresses the importance of the hands, which have to compensate for the lack of vision and hearing. Often not only the hands but also the whole body can take over these functions, by which tension and excitement can be expressed and perceived. It is essential for the partner to elaborate on the utterances of the child, for instance by imitating their expressions in a bodily-tactile manner. Sensitivity and responsiveness to their utterances and expressions will form a basis for possible social interactions or 'conversations with bodies' and over time this could then develop to real communicative contributions of the child (Hanning-Zwanenburg, 2008; Janssen & Rødbroe, 2007). The partner should also comment on what has already been experienced during the event through the use of drama, gesture and mime, both with and without the objects first used. This can be done by mimicking certain actions or movements.

Scaffolding. The term 'scaffolding' has been developed to describe the type of assistance offered to support learning with skills beyond the child's capability (Bruner, 1983). After mastering the task or skill, the partner begins the process of fading, gradually removing the scaffolding to allow the child to work independently. To scaffold a conversation, the partner should first try to re-construct the setting of the event as much as possible. This can be done not only in a linguistic manner but also through the use of drama, mime, space and body-positions and through the use of objects that are similar to the objects of the actual event. The partner ought then try to recall the highlights from the event by using the same expressions. If the child's expressions were already commented upon during the actual event it will be easier to revive them during the subsequent memory talk.

Balanced participation. Often the partner has certain ideas and expectations of how the child should respond during an experience or in a conversation. When the child is more passive or slower than the partner expects, there is a risk that this partner will try to compensate by becoming more active. If this continues the child is likely to participate less (Daelman, Nafstad and Rødbroe, 1993). Partners need to establish a balance between the child and themselves. There are several ways to stimulate reciprocity. The partner should build in slots for the child to respond by pausing to give time to reflect and contribute (Miles and Riggio, 1999). By changing hand positions a turn can either be given or taken (Mesch, 2001). The partner could deliberately change hand positions at a salient moment to give a turn so that the child has the opportunity to make a contribution. Each contribution should be confirmed and incorporated in the conversation. This will enable the child to 'co-author' the story.

Planned and improvised. A narrative approach can be used in a planned fashion. A partner could design an event and use novelty or unexpected incidents (a departure from the canonical) to create tension like suspense or excitement. For instance, well-known routines could take place in completely different environments or the partner could make deliberate mistakes. Improvisation within the narrative approach can be very successful. On any day so-called 'golden' learning opportunities often occur but a partner needs to be alert to seize the moment by involving the child in things like problem-solving. An illustration of the kind was captured on a DBI Communication Network video (Daelman, Nafstad, Rødbroe, Souriau and Visser, 2001), where the partner drops his keys by accident. Instead of just picking them up, he involves the young woman in the whole process of missing, searching and finding the keys. Therefore, it became a meaningful experience that was memorable and fun to talk about. Nelson (1996) notes that both the telling and understanding of stories require practice.

Topic of the experience/story. When the topic is interesting it will motivate and stimulate the child and most likely there will be more (or more intense) highlights during the event. When there are more highlights it will be easier for the partner to scaffold a conversation about the experience which will lead to more contributions from the child (Ahonen, Bolwerk, Heijnen and Souriau, 2008).

Case studies

The following research questions were formulated for the case studies: a) Is it possible for partners to design an event that is worth conversing about? b) Does the narrative approach increase the quality of conversation? Increased quality defined as: enhanced participation of the child, a balanced reciprocal flow and a wider variation of expressive forms of communication.

Participants and Setting

The study was undertaken at the Holy Land Institute for the Deaf in Jordan, which also has a deafblind department. This is a small and young programme providing education as well as residential support. The children Mahmoud and Nadia were selected for the case studies as they both are congenitally deafblind. Mahmoud, aged fifteen at the time of the study, was born premature. He has a severe hearing loss (71-90 dB) and has a little light perception in one of his eyes. Mahmoud is extremely curious and expressive and loves to be with people. He has a wide vocabulary of Jordanian sign language which he receives in a tactile manner. He is also able to express himself by signing, gestures and body language. Nadia, nearly eight years old, was also born premature. She has a profound hearing loss (>91 dB) and is completely blind. Nadia is quiet and often content to be by herself. Her level of expressive and receptive language is very basic, she uses a few key signs and mainly

expresses herself through gestures and body language.

Khitam was Mahmoud's communication partner in the case study. At that time she had worked in the department for only nine months. Her background is in social work. Aya' was Nadia's partner. She had worked with deafblind children for nearly three years and is a certified special education teacher. Neither partner had received deafblind-specific education before joining the department as it was not currently available in Jordan.

The study followed the tenets of the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects, and was approved by the Institutional Review Board of the Holy Land Institute for the Deaf in Jordan. Informed consent was obtained from the parents of Mahmoud and Nadia and from the communication partners.

Intervention

Purpose. An intervention was designed to build a narrative approach. First of all partners were trained in creating events that would be worth conversing about. Then, most importantly, they had to develop specific strategies and competencies necessary to improve the quality of a conversation. Such a conversation would include enhanced participation of the child, a balanced reciprocal flow and a wider variation of expressive forms of communication (with a strong focus on gesture, drama and mime).

Procedure. The intervention took place in the form of a Partner Development Programme. The theoretical knowledge and the specific practical competencies outlined above formed the foundation from which the programme was planned and developed. It consisted of a series of eight lessons along with personal coaching to equip partners to cultivate a narrative approach.

Implementation. The eight lessons were given on a weekly basis over a period of two and a half months. There were four different focal points in the lessons. Firstly, three components of the definition of narrative were selected for in depth study in order to bring about the envisaged change: a) departure from canonical happenings - in other words, incorporating novelty, b) macrostructure: deliberately building up suspense/tension, and c) narrative devices of discourse grammar. Secondly, regarding narratives and language, the use of gesture, drama and pantomime were thoroughly explored, being an excellent medium for sharing stories with deafblind individuals because they can be conveyed in a bodily-tactile manner. Thirdly, the intervention specifically focused on using narratives to frame memory for subsequent conversations (memory talk). Finally, the partner competencies particularly examined were: a) identifying and aligning with highlights, b) using a narrative style, c) scaffolding conversations appropriately and d) ensuring balanced participation between both partners. Besides the weekly lessons, there was at least one session of individual coaching per week to try and put in practice what had been discussed that week. For instance, after the

first lesson the partners were tasked to design and implement an event that contained novelty or an unexpected happening. They were given specific advice and guidance throughout the process.

Design of the Study

The effects of the intervention were assessed in two individual case studies. Single baseline recordings of both partner-child pairs were taken at the beginning of the study. The observations consisted of two components: a) an event set up as a narrative and b) a conversation about the event (memory talk). After the intervention single post-intervention recordings were made. These post-intervention observations had the same structure of event and conversation. The conversation components of the observations were compared specifically to evaluate the quality of the conversations before and after the intervention. Qualitative and quantitative data were gathered in the form of transcriptions and field notes. These field notes describe the characteristics of narratives and essential partner competencies used during the events and conversations.

Transcription

The conversation components of the baseline and post-intervention recordings were transcribed in order to analyse any change in quality of the conversation. All contributions of both partner and child were written down and marked with different styles. This ensures a clear overview of the form and frequency of each partner's contributions, which enables detailed comparison between baseline and post-intervention conversations. The different forms of expressive communication were: a) Jordanian sign language (formalised and standardised), b) Jordanian sign language with voice (verbal support in the form of Arabic words), c) voice only (spoken Arabic), d) gestures, drama and pantomime (non-formal body language and movements), and e) emotional expressions (facial and bodily expressions signifying emotions). Figure 1 illustrates part of the transcription of the conversation between Khitam and Mahmoud about their game of hide and seek with Imad.

Figure 1: Fragment of transcript conversation 'Hide-and-Seek': Mahmoud and Khitam.

KEY: Sign language Sign language with voice

VOICE ONLY Emotional expressions

Drama/gestures/pantomime

Khitam: Play together later where?

Mahmoud: Play

Khitam: Office, remember? Office, smiles

Khitam: You search search where Imad.

Mahmoud: Imad fast bending down and grabbing movement, smiles

Khitam: laughs out loud Imad "here" bending down together with Mahmoud.

Mahmoud: **Bends down even further** *laughs* empty

Khitam: <u>Later search search again, Imad where?</u>

Change of hand-positions

Mahmoud: reaches up and reaches down

Khitam: "there, there" Imad nothing empty, remember you search search Imad bending down

together with Mahmoud.

Mahmoud: reaches down even further. Makes standing up movement with his hands.

Khitam: <u>Right, Imad</u> "here" remember office, play office finished.

Mahmoud: nods

Khitam: <u>Later where, remember?</u>
Mahmoud: At the end, playroom
Khitam: <u>Right, playroom, right!</u>

Mahmoud: Smiles and nods

Khitam: You who together search search search search search. who?

Mahmoud: Balls, empty.

Khitam: Laughs out loud Bravo, right Mahmoud, later you Imad together search search

where Khitam, where Khitam.

Mahmoud: Khitam

Khitam: You search, Khitam "there" bending forward movement.

Observation and Reliability

The baseline and the post-intervention conversations of both case studies were transcribed by the main observer. To ensure reliable results, the four recordings were also transcribed by a pair of second observers working together. These were chosen against the criteria of knowledge of Jordanian sign language and Arabic as well as basic familiarity with the students involved. An introduction and training session for the observers included a detailed explanation of the transcription methodology and sufficient practice on video-sequences not used directly for this study. They were trained till 80% inter-observer agreement was reached between them and the main observer. The inter-observer agreement was calculated by dividing the number of agreements by the total number of agreements plus the disagreements and multiplying by 100. The inter-observer agreement across all categories was found to have a mean of 92.1% (range 90.5% - 94.5%).

Results

Table 1 gives an overview of the baseline and post-intervention conversations between Khitam and Mahmoud. The different contributions are counted and categorised. In the baseline conversation (a story about a music-toy without batteries and a search for the right size batteries) Khitam limits herself to two different forms of communication. Mahmoud only responds with emotional expressions. In the post-intervention conversation (after they played 'hide and seek' with Mahmoud's friend Imad) Khitam uses a wider variation of forms of communication and Mahmoud is able to contribute to the conversation with more than just emotional expressions.

 Table 1

 Overview conversation contributions between Khitam and Mahmoud.

	Baseline: "Music-toy and batteries"		Post-Intervention:	"Hide and seek"
	Khitam	Mahmoud	Khitam	Mahmoud
				28 words/
Sign language	-	-	-	sentence
Sign language with voice	10 sentences 8 words or	-	44 sentences	-
Voice only	clusters	-	2 words	-
Gestures/Drama/Pantomime				18
Emotional expressions	-	-	14 expressions	expressions 14
	-	7 expressions	3 expression	expressions

Data from the field notes give more insight in how Khitam implements the narrative approach: She expresses excitement to start the game in a bodily-tactile manner by using muscle tension to show her eagerness to get up to search after allowing some time for Imad to find a hiding place. She builds up suspense towards climaxes by actively searching together and by making comments in between through gestures and signs like: 'maybe there', 'no, empty' and 'hurray'. She then dramatises the event during the conversation by using the same lay-out of space, the same searching gestures, and by mimicking the different actions of the game.

Table 2 gives an overview of the different contributions to both baseline and post-intervention conversations between Aya' and Nadia. During the baseline conversation (about inflating and deflating a balloon) Aya' is the only one who communicates and there is not a single contribution from Nadia. In the post-intervention conversation (a story about beads and a necklace) Aya' uses a wide variation of communication forms.

 Table 2

 Overview conversation contributions between Aya' and Nadia.

	Baseline: "Balloon"		Post-Intervention: "Beads"	
	Aya'	Nadia	Aya'	Nadia
Sign language	-	-	1 sentence	-
Sign language with voice	4 sentences	-	11 sentences	-
Voice only	1 word	-	-	-
Gestures/Drama/Pantomime	2 expressions	-	19 expressions	5 expressions
Emotional expressions	-	-	1 expression	-

She focuses on incorporating gesture, drama and mime and Nadia is able to contribute to the conversation in the same way. From the field notes it is clear that also Aya' uses a narrative approach. Her own curiosity for the new toy is expressed in a bodily-tactile way though muscle tension and gestures which triggers Nadia's interest. They enjoy stringing a necklace together, taking turns. A specific highlight of the event is when Nadia wears the newly-made necklace and it suddenly falls down on her lap. Aya' builds on this unexpected happening by commenting on it right away by mimicking the same actions with her hands.

Discussion

The Partner Development Programme was designed to improve the quality of conversations between partners and children. The two case studies clearly show the programme to be effective. Both partners succeeded in designing exciting events that were memorable and worth conversing about. Compared to the baseline events the post-intervention events contained more components of narrative. There were clear departures from the canonical by playing in a different area and using a new toy, both partners expressed curiosity and excitement in a bodily-tactile manner which had contagious effect on the children. This was shown in Mahmoud's eager participation as he could hardly wait to start searching. There were gradual build-ups of suspense leading to several climaxes, and the particular narrative devices of gesture, drama and mime were incorporated in the form of comments during the actual event which facilitated framing of memory. As in Nadia's case, Aya' comments on the falling of the necklace made it a memorable moment.

When comparing the baseline and post-intervention conversations there is a clear increase in the quality of conversations. During the baseline conversation with Mahmoud, Khitam focuses on the 'why' question. She repeatedly asks Mahmoud, "Why was there no music?" It is obvious from Mahmoud's emotional expressions that he is thinking about the question but is not able to express his thoughts. The post-intervention conversation is of much better quality. Besides sign language Mahmoud and Khitam use gesture, drama and mime to recall the event. Khitam clearly shows her newly-gained ability to build upon

highlights and scaffold the conversation. She deliberately gives Mahmoud turns by changing hand-positions and she incorporates his contributions in the conversation which results in balanced participation with a reciprocal flow between the two of them.

In Nadia's case, Aya' uses the same gestures, drama and mime from the actual event during the conversation to try and recall the highlights of the event. Together they remember the necklace falling down. Aya' scaffolds the conversation and tries to establish balanced participation by regularly pausing to give Nadia time to reflect and respond and by changing hand-positions to give her turns. Although this does not result in an equally balanced conversation, Nadia's participation is enhanced. A start has been made and it is envisaged that over time, with practice and appropriate guidance, she will be able to participate further.

When comparing the two case-studies, Mahmoud made more progress. This was probably due to differences in personal characteristics, although they have not been analysed in depth. The expressive and outgoing Mahmoud was able to play an equal role and participate fully in the conversation. Nevertheless, even a very introverted childlike Nadia was able to make some meaningful contributions to the post-intervention conversation which were not present at all beforehand.

As narratives are all around and play an important role in everyday life, they need to be made accessible to children with congenital deafblindness. The narrative approach outlined in this paper enables partners to design an event that will be memorable and worth talking about by incorporating significant components of narrative. Specific partner competencies provide practical guidance on how to develop a narrative style to facilitate framing of memory that in turn enables the child to participate in a subsequent conversation about the past event. From the case studies it can be concluded that a Partner Development Programme is a useful and structured way for partners to develop and implement a narrative approach.

When experiences are never talked about, partners do not know what thoughts and emotions may still be present in the mind of a child. Furthermore, half the fun and excitement lies not in the experience itself, but in recalling and sharing it with someone else afterwards. Therefore, narratives and narrative-based conversations can and should also play an important role in the education of children who are congenitally deafblind. In this way, a world of stories and excitement can open up to children who otherwise may never have the opportunity to experience them.

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