Speaking Up - Being Heard
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Multi-Sensory Storytelling: For People with Profound and Multiple Learning Disabilities

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Sharing stories exists in every culture as a way of entertaining, educating and simply experiencing the connections with others that stories often create. Traditionally storytelling has involved imparting information verbally, that is then passed through generations. Stories make up a significant part of our day as we dedicate a lot of our time to reading books and listening to the stories of others. As an integral part of our lives, we use storytelling to interact with others and make sense of the world around us. Taking many forms, stories can be expressed in ways that allow information to be accessible to a diverse range of people of different ages and abilities in various contexts. People with profound and multiple learning disabilities (PMLD) are one such group of people who can also experience the richness of storytelling.

Importance of Storytelling

Storytelling has been used as a powerful method of educating children and young people (Ofsted, 1998; Fuller, 1999; Grove, 2009), the importance of this has been placed on the development of skills in understanding and communication. The positive effects of storytelling on educational attainment have been well recognised (Fox, 1993). In addition, storytelling encourages both social and emotional development (Fox-Eades, 2006; Thomas & Killick, 2007) as it creates a place in which close interactions can be experienced. Early intimate relationships for example are so often highlighted as crucial to the well-being of children (e.g. Trevarthen, 1977). Storytelling more recently is thought to play an important role in the development of these early relationships (Hughes, 2004) and has led to a campaign by the National Literacy Trust in the UK for parents to read to their children in order to promote their social, emotional and cognitive development (National Literacy Trust, 2007).

Developments in Multi-sensory Storytelling

Through education and leisure, those with difficulties in communication such as people with PMLD experience a transformation in their engagement with others using sensory storytelling. Using the multi-sensory approach which is not based solely on language, aims to enhance social interactions and facilitate the learning experience for people with PMLD. Multi-sensory storytelling techniques (MSST) in general have been shown to have therapeutic benefits for individuals with PMLD by providing novel and stimulating experiences. Multi-sensory techniques have also been identified as therapeutic for individuals with PMLD as they provide novel and stimulating experiences. Multisensory environments (Pagliano, 1999), sensory curriculums (Longhorn, 1988) and basal stimulation (Frölich, 1998) are among these multi-sensory approaches that provide this therapeutic experience. The principles behind the multi-sensory storytelling technique particularly highlight the significance of interaction with another by meeting the individual through narrative and sensory stimuli via their intact sensory capacities. Here the aim of multi-sensory storytelling has been to provide an experience of narrative using sensory stimuli in which interactions between listener and storyteller may arise. This has been important for enriching the lives of people with PMLD.

PAMIS’ Real Lives: Real Stories project developed personalised stories that were based on Chris Fuller’s Bag Books and her multi-sensory storytelling techniques. The project allowed young individuals with PMLD to engage with the Scottish Elaborated 5-14 Curriculum, particularly in the area of communication. Learning targets were built into the stories linking directly into the child’s...
Individual Education Programme (IEP). From this an Advisory Committee of parents and professionals was established and PAMIS’ Sensitive Stories project was developed. The Real Lives – Real Stories project aimed to encourage interaction in which the individual learned to accept and share feelings, be receptive and expressive. Additionally, the project aimed to enhance collaborative work between families and schools and provide a resource for families, teachers and professionals to facilitate learning. During that project it emerged that several parents and teachers were concerned about issues affecting their children and requested a method of exploring these issues using the same storytelling method. Based on the young person’s real life situations and experiences 10 multi-sensory personalised stories were developed. The topics explored medical procedures, sexual health care, growing up and transition. The overall aim of this project was to help the young persons’ understanding and acceptance of these sensitive, difficult, topics. Additional learning was also encouraged through specific targets including developing their fine motor skills, while others were to increase the tolerance of touch and turn-taking. Both children and adults with PMLD were involved in the two research projects described above, although the majority of participants in the Real Lives: Real Stories were school age children and young people.

The Outcomes of Using Multi-sensory Stories

Ten individuals contributed to our research on the behavioural changes that occurred during sessions of storytelling (Young, Lambe, Fenwick & Hogg, 2011). Our research involved behaviourally analysing videos of storytelling sessions and using qualitative analyses to understand the views of parents and teachers. Our behavioural study showed that the stories were effective in socially and educationally engaging listeners; by the last session of storytelling the majority of listeners were demonstrating an interest in the stories by looking at and touching the pages more. Some listeners were engaging more with the storyteller through looking behaviours and vocalisations. Feedback from parents and teachers strongly supported these behavioural observations. The majority of parents and teachers thought that their child had shown achievements in their learning targets. Most of these achievements can also be shown through our behavioural study. Some parents and teachers observed a reduction in stereotypic behaviour such as head nodding and ‘challenging behaviour’ such as extreme physical aggression. Additionally, teachers particularly found the multidisciplinary approach invaluable as an aid to learning. They described the process as engaging; both parent and teacher could spend time understanding more about the individual with PMLD. The Project therefore had positive and far-reaching outcomes for both listener and storyteller.

Bereavement & Loss Project

Recent research around the issue of bereavement revealed the need for a project that would allow for the topic of loss to be intellectually accessible to people with PMLD (Young, Lambe & Hogg, 2011). Carers of individuals with PMLD are becoming increasingly concerned with issues surrounding bereavement and loss. With the continued advancement of medical science, people with PMLD are living longer and as such a considerable number are surviving their carers (Institute of Public Care, 2009). Coupled with social inclusion, this has meant that questions of how these people are to live well are raised a lot more widely. Individuals with PMLD have often been represented as a marginalised population of society (Scottish Executive, 2000) and therefore often face difficulties in accessing the community. There is little, if any, adequate research and support however for individuals with PMLD regarding their experiences of bereavement, despite the evidence to suggest that a considerable number are adversely affected by loss.

It is understood from the responses of carers that individuals with PMLD require a way in which to explore loss that is intellectually accessible. Recommendations included a development in the understanding of loss and PMLD, research into the use of sensory approaches with bereaved individuals with PMLD with the help of existing professionals in the area of PMLD. Our pilot research study points to the value of follow-up work, particularly in the area of developing intellectually accessible materials as the possibility that these individuals may be better supported has significant outcomes for many people with PMLD and their carers.

Conclusion

Reasons for the positive outcomes of the PAMIS Sensitive Stories Project may be found in the format of the stories; they encourage shared attention of a topic, a chance for social interaction and exploring sensitive issues. The stories cloak the sensitive issue that allows for accessibility and sensitivity. If stories are told well they allow the listener to enter a different kind of ‘space’ where a strong engagement with the story and others may arise. In their article entitled ‘The Teller, The Tale and The Told’, Killick and Frude (2009) suggest that the experience of ‘live’ storytelling is a richer experience than the reading of a bed-time story as it brings the storyteller and story listener into a different ‘space’ that is interpersonal and interactive that in effect increases emotional experience. This ability to engage may otherwise be quite challenging because the topics are indeed sensitive ones and because the communicative impairments of the listeners make interaction difficult. The Sensitive Story Project, however, allowed these individuals to overcome these barriers by providing the communicative means and a safe context within which to
explore the issues. The stories provide an extraordinary sensory experience that rapidly fosters the engagement of the listeners. In doing so the Project has played a transformative role in the lives of both the listener and storyteller. Together with carers’ reflections on the positive outcomes of using multisensory storytelling, the confirmations from the behavioural research suggests that the Sensitive Stories positively engage and highlight how educationally valuable they are to people with PMLD and their carers.

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References


