

Hero Stories: A Coping Strategy for a Child who has Autism

Linda Jones

Parent

Rosina Merry

University of Waikato

Donna Mitchell

NZCare Group

ABSTRACT

This paper explores Hero Stories, a different narrative approach developed to support a child with autism to gain self-control and allow him to navigate his world as a competent and capable learner. It examines the development and use of 'Hero Stories books' as a strategy for assisting a child with autism to cope with stressful situations within the home and school, and explores how these stories can contribute to enhancing a child's sense of themselves as thinkers and powerful learners, in charge of their lives.

Practice paper

Keywords: *Autism, coping strategies, stories*

INTRODUCTION

The impact of autism on a child, his/her family, the community, and educators can be significant. Children with autism have varied learning styles, differences in communication, and social skills, making it very hard to effectively work through difficulties and to move into a situation where learning opportunities can occur, or to create a more positive situation generally (Hanley-Hochdorfer, Bray, Kehle & Elinoff, 2010; Schopler, 1995). Stories have been used in education for a number of years with a range of formats and purposes, including enhancing children's learning opportunities and as a tool to cope in stressful situations.

Learning stories are a narrative, formative assessment framework that are based on the notion of narratives that capture multiple voices, foreground the value of learning dispositions, acknowledge children's strengths and interests, and make transparent the teacher's actions in teaching contexts (Carr, Hatherly, Lee & Ramsey, 2003). Social Stories were developed by Carol Gray and have been used as an intervention tool successfully for a number of years. The framework for Social Stories has specific criteria to follow to support individuals who have autism to cope in certain situations (Gray, 2010). Hero Stories are founded on a credit-based view similar to Learning Stories, with a focus on coping, not unlike Social Stories. However, the difference with these stories

is that they aim to support the child to develop and learn coping strategies, and promote the child's own voice. Building on the concept of positive self-talk, they provide a framework that prompts the child to imagine situations that maybe stressful and to practice coping through being the 'Hero' of the story. By repetition of the stories, the child is supported to learn what to do outside of the immediate difficult situation. The coping skills can then be drawn on when needed and later generalised to a range of situations. These stories respond to individuals' needs, are flexible and represent a positive option for supporting children with Autism Spectrum Disorder (ASD) to learn self-regulating strategies.

STORIED APPROACHES

Stories can include commentary on the role of social partners, practices and tools. They can provide a motivating tool for children to return to at times of uncertainty, developing default responses in the presence of uncertain learning opportunities and circumstances. "Stories are powerful research tools. They provide us with a picture of real people in real situations, struggling with real problems" (Witherell & Noddings, 1991, p.280). Bruner (1996) points out that stories can describe not only what does happen, but also what ought to happen. They can set out what is of value, what is expected. Carr, Smith, Duncan, Jones, Lee, and Marshall (2010) argue that stories can document 'what we do here' and 'what we ought to do here' in a variety of settings, including early childhood settings, schools and homes. When they contain examples of success and competence they can enhance children's sense of themselves as thinkers and powerful learners, providing a navigational device that assists them to be more in charge of their lives. Stories are more powerful when they contain links to the child's own life experiences and to future possibilities, rather than being documentation of a specific experience (Margrain, 2010).

SOCIAL STORIES

Carol Gray's Social Stories were developed in the United States of America during 1991 (Gray, 1994; 2010). They have been used in a

variety of forms of intervention for children with autism. She describes Social Stories as a strategy that provides individuals who have autism with accurate information regarding situations they encounter, and argues that these stories have had a positive impact socially and academically for some individuals with autism. Social Stories are written in response to individual children's needs, which are identified in a number of ways, including social skill assessments. The story may, depending on the need, emphasise social skills, teach routines, teach academic material and address a wide range of challenging behaviours. Social Stories have a particular sentence structure: descriptive, perspective, directive, and control sentences. More importance is placed on the descriptive and perspective sentences, with a ratio of at least three to five descriptive/perspective sentences for every directive and/or control sentence. This ratio must be maintained regardless of the length of the social story. Gray (1994; 2010) states this is based on the theory that the fewer directive and control sentences, the more opportunities for the individual to determine his/her own response to the situation, although some children will require more directive statements than others. Gray believes that Social Stories may not need to be illustrated to be effective and that at times, illustrations can be too distracting and defining for some children. However, there is a view that these stories can be more effective for some children with autism, providing visual images focused on what people are thinking and doing (Chan & O'Reilly, 2008; Spencer, Simpson & Lynch, 2008; Thiemann & Goldstein, 2001; Margrain, 2010).

BACKGROUND TO THE CASE STUDY

Sam had undergone many interventions by professionals during his lifetime, some from a medical perspective, others with an educational focus. He also had difficulty interacting with others, and during times of frustration or anxiety he would hurt others around him. When he was five years old his mother was told by a medical professional that he had definite behavioural problems, delayed thought/verbal expression, and a lack of emotional perception of self and others. He also had delayed gross and fine motor skills and was unable to socialise with his peers. The professional diagnosis was autism. At the time of this case study Sam was presenting with some very challenging behaviours, and another medical professional suggested to his mother that she should put him on medication for his abnormal behaviours. She did not see this as a good option for him. Sam had difficulty with expressive communication processes, and found communication difficult, having particular difficulty expressing his feelings, such as when he

was unwell, if he was worried about something, or explaining when he was frustrated or angry. Coping with daily situations and transitions had become very stressful for Sam and challenging for those people in his life trying to cope with his behaviour and to understand him. Sam's mother was aware from his behaviour that at times he was unhappy and distressed, and this was impacting on his relationships at home, at school, and within the community. She sought a referral through The New Zealand Society for Intellectually Handicapped (IHC), seeking help from their Behaviour Support Service.

METHODOLOGY

This was a case study about the development and use by one family of 'Hero Stories' as a coping strategy with a young child who has autism. It explored how 'Hero Stories' were developed in this one case, and how they are being used by the family. It was written primarily from the viewpoint of the parent, and is essentially the mother's story, but it also includes other perspectives. The purpose of the study was to explore the use of Hero Stories as an alternative communication strategy with a young child who has autism.

THE DEVELOPMENT OF HERO STORIES

Hero Stories were an idea jointly developed by Sam's mother alongside the IHC's Behaviour Support Service team after they had received a referral for Sam, completed a comprehensive assessment, and developed a multi-element plan. The main issue identified at the time was Sam's inability to cope during some situations, and, as a result, he would try to hurt himself and others around him. One of the team members met with Sam's mother and the school staff on a monthly basis, and also met with her at her home, as a number of the issues causing concern at home were different from those at school. It was at one of these meetings at home that the concept of Hero Stories was discussed as a form of narrative documentation with dispositional potential and 'navigational' elements for children with learning difficulties.

The basis of these books came from the concept of Gray's Social Stories, however, the Hero Stories books have a more flexible approach. They are still written in response to individual situations, and in this instance were developed as part of a response to a referral for behaviour support intervention. The IHC assessment plan identified the need for Sam to learn coping strategies. Hero Stories came about as a way to support Sam in practicing what to do in a given situation, before he was faced with it. The notion of priming is inherent within the

Hero Story books with a focus on understanding others' perspectives, feelings and strategies for use in the future embedded in each of them (Scattone, Tingstrom & Wilczynski, 2006).

The IHC team member, along with Sam's mother, identified a number of antecedents and they discussed how they could prime Sam to have a strategy which he could draw on when these occurred, so that he could have control over his behaviour. The concept of positive self-talk was discussed as a tool that could be included in the Hero Stories (Boutot, 2009). They believed that if they could teach Sam to use this strategy during difficult situations by recalling the messages in the Hero Story books then he might be able to cope better in response to them. Sam appeared to be a visual learner; he found written text uninteresting, but he enjoyed pictures, and was able to focus using visual clues (Schneider & Goldstein, 2009). The concept of using positive self-talk was introduced in the books by using speech bubbles, making Sam the hero of the stories, and portraying him solving problems in a positive manner. Sam's mother would read the books with him most days, at no particular set time and they became a natural way for Sam to practice what to do in response to a difficult situation in advance.

THE HERO STORY BOOKS

The Hero Stories books were initially written by Sam's mother and a member of the IHC team, and later, by Sam himself. Over time, these books continued to develop and evolve to suit Sam's requirements. The original research focused on the use of these books both within the school and home settings, and the early books formed the data for this paper. The first book developed was about breakfast time at Sam's home. Breakfast time was identified as an antecedent; a situation that was regularly stressful for Sam. During breakfast time Sam didn't want anyone to look at him and he would build a structure with the cereal boxes, so that his brother and mother could not see him. This created a lot of difficulty for Sam, his younger brother, and his mother, as no one else could share the cereal at breakfast time without causing Sam great anxiety. It was decided to develop a book about this situation. "We knew what we wanted and (IHC team member) figured the outline and I took the photos and brought them back and she helped me set them up" (Parent).

Figure 1 sets out the script of this book. The first photo is an image of Sam eating with his brother. The other photos reflect the feelings in the text, such as Sam feeling upset, Sam staying calm, his brother feeling safe, his mother and brother feeling proud of Sam, and lastly, of Sam feeling proud of himself for staying calm. This is a description of the story and the images.

Figure 1. The Breakfast Time Script.

Breakfast Time	
This book was the first to be developed and aimed to support Sam in learning the skills to share and control his frustration while the family had breakfast.	
 <p>Sam is eating.</p>	 <p>Sam is upset. Stop!</p>
<p>Page 1</p> <p>This page outlines the antecedent. It uses short statements and the visual cue of Sam and his brother together.</p>	<p>Page 2</p> <p>This page outlines a clear statement of feelings. "Sam is upset." This is important to help Sam learn about emotions. The first self-regulator statement of "Stop!" is introduced.</p>



Page 3
 This page introduces the start of problem solving. Photos prompt Sam to remember occasions of past enjoyment with his brother. It aims to link those positive experiences with the outlined stressful one. Thought bubbles are used here to teach Sam the difference between thinking to yourself, and the speech bubbles are used to represent talking out loud.



Page 4
 A clear statement of what to do when stressed is outlined here, i.e. "Stay Calm". Short statements are used so as not to confuse Sam with too much information. The text says "Stop, take a deep breath, think of something nice, stay calm".



Page 5
 The first statement of the outcome 'remaining calm' is highlighted here. The concept of impact on others is introduced with a photo of Sam and his brother together. This reflects his brother feeling safe.



Page 6
 Photos of Sam's mother and brother with a clear statement of them being proud of him is used here as reinforcement to Sam's positive dealing with breakfast time.

Book including photos reproduced with Sam's, his brother's and his mother's permission.

A particularly important aspect of this book is a statement of Sam being proud and taking control over his emotions, making him the hero of the situation. The text on each page is supported by real images of Sam, his brother, and his mother. When Sam becomes stressed he tends to hyperventilate, so some of the earlier books have a cue for Sam to try to control this. Each story had the following sequence embedded into it 'Stop, take a deep breath, think of something nice, stay calm'. His mother says that this has helped Sam to think about happy times with his brother, and that there is a positive outcome when Sam can stop

and calm down. She believes that the photos in the book have had a big impact on Sam, as at times he does not have good memory retention and the books help him to remember so that the next time he is in a similar situation, he knows what to do.

Following the success of the first book, a book to encourage Sam to play with his brother was developed. Sam had some difficulty with sharing his play space and toys. The development of this particular hero book raised some ethical issues for his mother and the IHC team member, as Sam was not aware that the photos his mother was taking of

him were for the hero book. His brother knew they were 'for a project' but did not fully understand what it was. Sam's mother felt it was hard to put them in this situation, but she believed the photos needed to be taken in a meaningful context. However, she had to take into account the risk of placing Sam's brother in an unsafe situation for a very short time whilst they were taken. The images in this book are of Sam and his brother playing side by side, and at times sharing some Lego with each other. It follows the same sequence as the other books, and the text is centred on Sam and his brother playing together, with Sam feeling proud because he was able to take control of his feelings in this situation; he is keeping both himself, and his brother safe.

Sam's mother said that she could see that Sam could not understand certain aspects of play. For example, if someone came into the hut to join in his play and he wasn't finished what he was doing, he thought it was all ruined. However, she said you could explain to Sam that the play could still carry on, that they could both be safe, that Sam could still have his toys and his play would still remain his. The Hero Story books helped Sam to understand this. Sam's mother found herself looking for other situations where the Hero Story books could be used, but she was always mindful of the importance of not exploiting personal privacy issues when creating them.

DEVELOPING THE HERO STORIES BOOKS FURTHER

As further books were developed, Sam began to express his own feelings and ideas in them. Sam's mother has described the process of creating a book with Sam to try and help him to understand that other children had special things that were just like his. At the time, Sam was having difficulty when he saw children at school with toys the same as his ones at home, and would often end up in conflict with another child, believing the toy was his. At times he would go into other children's school bags and take their toys out and bring them home.

"He didn't have the understanding that other people had special things. He knew he had special things, but not that other people had special things too, and they were going to be hurt or upset when they lost them or when he took them home." (Parent)

This book was called 'My Special Things'.

"I basically chose and set up the kids at school with their special things and he took the photos, because he loves taking photos and it's something he can participate in." (Parent)

Sam's mother wrote the captions 'I'm Harry' and 'Hello my name is Fred' for the story, and she was going to use thought bubbles expressing feelings in them. When she and Sam read the book that night using just the photos and the introductions, it created a lot of discussion between them.

"And he would come up with his own ideas; 'oh did you know that's Fred's special toy and he probably feels sad. I'd feel sad if I lost mine'. So he could actually put his thoughts and feelings into it." (Parent)

She says the impact of this book was huge:

"He doesn't take other peoples things any more and he has an understanding of other people's belongings, and that was only after one reading but we still looked at the pictures sometimes. He loved the pictures and was probably just as happy looking at the pictures; he could see how proud these people were of their toys and how happy they were that they have their own toys." (Parent)

THE HERO STORIES PROCESS

Sam's Hero Stories books were not used when he was stressed or in a crisis situation. They were kept in the book box in the lounge, along with the family's other reading books and read at different times during the evenings or weekends. The stories were not read in any strict order or sequence and the aim was that they would become a part of the daily household routines.

"They weren't a routine, like at 5 o'clock we are going to read the, or before dinner, they were just going to be around and were picked up if there was spare time, we would just slot them in." (Parent)

Some times Sam's mother read the stories just to Sam, and at times she read them when Sam and his brother were together.

The notion of progress has emerged as the books have become more complex and as Sam has had more input into their development. His mother says that progress can be measured by the positive changes in Sam's behaviour and his ability to transfer a concept from a book into another situation. She feels Sam has grown in confidence and has increased his literacy and problem-solving skills since the books were first implemented. Sam was able to use the scanner and computer at school, and has become very skilled at developing his own stories. He has taken control of his own learning. Sam has been able to develop self-regulation skills, and apply them in different situations with the help of his Hero Stories books. The progress over time with Hero Stories has included Sam becoming much more involved

in the development of the books, implementing them into the school, involving the rest of Sam's class, and the teaching staff using them as a form of assessment and linking them to curriculum work at school. Some of the outcomes for Sam from the use of the Hero Stories books include a decrease in his challenging behaviour over a range of areas and developing the ability to be able to come up with his own solutions for some stressful situations. Sam is able to think about and discuss stories in context, outside the reading of the story and apply this to real situations.

"They help him to visually find ways of coping with situations in a calm time so that when a stressful situation arises he can visually reinforce how to cope with the problem." (Parent)

Sam's mother maintains that Sam's input into the development of the Hero Stories books has been critical to their success as he has a sense of ownership of the content. She believes that it is very important the books must be for fun, as well as formal learning.

CONCLUSION

Sam's Hero Stories books began through a partnership between Sam's mum and the IHC Behavioural Support team to help Sam learn some coping strategies. As the books evolved, Sam had an increasingly active role in shaping them, taking ownership of their construction. Sam's books were gradually implemented into his school and his teachers were able to integrate them into his class work. It is evident that Hero Stories have been successful well beyond the original concept. These stories have supported Sam's inclusion in the school and his local community. They have enhanced Sam's learning opportunities, and enabled him to take an active role in coping with difficult situations. Hero Stories are focused on the child in the story being in control and learning alternative coping strategies. They are based on the notion that the child becomes the hero by being able to develop self-control in challenging situations, gaining both a sense of achievement and the ability to take control of their behaviour, enabling them to navigate their way through the complexities of the world as a competent and capable learner.

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AUTHORS' PROFILES

Linda Jones



Linda Jones is Sam and Tyler's mother. She continues to be involved in supporting Sam to use stories to help him navigate his way through the complexities of his world. Linda is an early childhood teacher and has a strong belief in the power of stories for all children. Linda uses narrative in her teaching practice and believes that strategies such as Hero Stories can work for children in a range of transitions in mainstream settings as well as for supporting children who have special needs.

EMAIL
lgj@slingshot.co.nz

Rosina Merry



Rosina Merry is a senior lecturer and coordinator of the Graduate Diploma ECE in the Department of Professional Studies in Education, University of Waikato. She worked in the early childhood sector for a number of years, firstly as a teacher and then as a director of a large community childcare trust before coming to the University of Waikato. Rosina held the position of the National President of Te Tari Puna Ora 0 Aotearoa New Zealand Childcare Association for nine years, and has been involved in the development of a range of early childhood legislation and Ministry of Education Research contracts over a number of years. Rosina is currently working on her PhD through which she is exploring graduate teachers identities as technologists. Her other research interests include: different ways of teaching and learning in an online environment; ICT and disability; and transition within early childhood settings.

EMAIL
rosinam@waikato.ac.nz

Donna Mitchell



Donna Mitchell is currently working as Group General Manager for NZCare Group Ltd where she has responsibility for:

- Disability services for people with both physical and intellectual disability
- Mental Health and Addictions Services
- Explore Specialist Trans-disciplinary team

Donna has a strong commitment and passion to community presence and participation for all people and strongly endorses the objectives of the New Zealand Disability Strategy. She has been employed in the disability sector for many years in a variety of leadership/managerial roles. At the time of this research she was employed by IHC. During this time she has demonstrated a commitment to inclusive practices and believes that all individuals have the right to have active roles within their local communities. It is this vision and her passion for it that drives her leadership and decision-making.

EMAIL
donna.mitchell@nzcaregroup.co.nz