

Off we go!

**Some animals are frightening
And some are sweet and kind
So let's go to the jungle now
And see who we can find...
(Andreae & Wojtowycz, 1996)**

Stephen Webster loves the rhyming verses of *Rumble in the Jungle* – in fact, like all his family, he just loves books. But little did his mother Avril suspect when he was born that he would inspire her to author books aimed at helping children with intellectual disabilities cope with the jungle of everyday life. The common themes, simple text and uncluttered, friendly pictures of the *Off We Go!* series – even the short guide for parents and teachers at the back – give merely a hint of the story behind the stories.

Avril's career in the computer industry was very important to her and, until Stephen was born nine years ago, she had a busy job that involved a lot of travel. Stephen spent most of his first year in hospital and the family was dealing with lots of unknowns – would he ever walk or talk? During this time the hospital physiotherapist asked how Avril would feel about becoming a stay-at-home mum. With this decision taken and Michael (6) and Rachel (4) now completing the family, life is very full, and Avril is channelling her creativity in new, wholly unexpected but ultimately rewarding ways.

Stephen (9) attends a special school in Limerick, Ireland. He has no specific diagnosis other than that of a moderate to severe intellectual disability but has been functioning at the developmental stage of 18 months to 2 years for "quite a time" and has significant sensory integration issues. Avril says his neurologist recently floated the possibility that Stephen may become an adult who is around this developmental level. While Avril feels "passionate about supporting Stephen to partake in family activities", everyday experiences in the community have been a real struggle. Supermarkets have proved overwhelming and Stephen found the experience of going to the dentist very upsetting. Avril's priority is to build Stephen's coping mechanisms and independence.

Intimate connection

An early indication of one of Stephen's strengths came during that long first year. As Avril says, "It is extra hard to try and bond with a new baby who is sick, when you are in hospital and when there are no smiles to encourage you. I wanted ways to communicate and connect with him. We are book mad in our house and from early on Stephen and I loved the intimate connection that books gave us. Books are our special time." Since then books and visuals have proved to be really useful tools to support communication and reduce frustration. One example is Stephen's scheduling board, a visual timetable with word + picture segments showing what he is going to do today.

The highlight of Stephen's day is showing his mum his personal newsbook from school. In this book the teacher draws a picture or two of things he has done in school. At home Stephen uses this book to share his school day with his family and this prompts him to initiate conversations, labelling the pictures and occasionally putting two words together. This is a two-way process as Stephen also returns to 'circle time' at school the next day (as do the rest of the class) with a visual record of what he has done with his family in the afternoon. This might involve a picture of an ice-cream, or the playground, or a cutting from a bag of marshmallows. The newsbook includes personal photos and information (my name is Stephen; my mum and dad; my brother and sister) and photos from key family occasions. Avril says the family has dozens of these journals now "and it's lovely to go back over them. It's like a hardback record making a story of his life and working as a communication tool."

Aware that life would be less stressful if Stephen could cope with visiting the dentist – waiting happily, saying hello and cooperating in the chair – or the hairdresser, or the supermarket, Avril wondered if books might help him prepare for transitions and overwhelming sensory situations. Such books do exist but the Usborne First Experiences series proved too cluttered visually while Scholastic's Barney books, which include going to the zoo and to a restaurant, scared Stephen as he does not identify with imaginary toys or puppets. When Stephen was aged two, his parents attended a Hanen course run by speech and language therapists; in addition to the impact of the programme in terms of putting words and speech in context, Avril had particularly linked in with the modules on books and craft. So, undaunted, she decided to create her own books, and sought advice from Stephen's current speech and language therapist, Jeanne Dippenaar. Jeanne suggested each book should be kept simple with no more than 10-12 simple pictures or "we will lose his interest and concentration". The language was to be just as Avril would say it in the real situation. Another of Stephen's strengths is his ability to pick up on rhythm and rhyme. Using short, easy-to-repeat sentences meant that he would be able to tell the stories himself after hearing the stories a couple of times. Stephen's favoured Spot books (Eric Hill for Frederick Warne) provided further inspiration for a clear, uncluttered feel.

Role play

The Webster's kitchen table became the creative hub. Avril used a digital camera and took pictures at local facilities to show the sequence of events. The internet yielded extra pictures where needed, as did the Writing with Symbols software already used for Stephen's scheduling board. Avril's husband Robert was vital in the creation of the books, not only with his support for Avril, but also his excellent computer skills. Every single day in the week running up to a visit Avril prepares Stephen with a

Going to the hairdresser, the supermarket, a restaurant, the doctor, the dentist and the swimming pool can be overwhelming experiences for children with intellectual disabilities. Inspired by her son Stephen's love of books, Avril Webster created a series to enable him to deal with everyday situations. Here she tells editor Avril Nicoll how, with the support of parents, speech and language therapists, an artist and teachers, the books are now available to help other families cope.



Michael, Stephen, Avril and Rachel Webster by Paul Dorrell, www.pauldorrellphotography.com

book, and takes it as a support tool to remind him, if necessary, while he is in the situation. She also uses the books to introduce role play, for example borrowing a cape from the local hairdresser, turning on the hairdryer and brushing his hair. This gives Avril hope that Stephen will move along the developmental level of imaginative play and she tentatively voices the question, "I wonder, I just wonder, if one day he will manage to go to the hairdresser on his own..."

Jeanne, the speech and language therapist providing a service to Stephen's school, said the books would in fact be helpful for *all* the children there. Avril discussed it with a fellow mother whose daughter Christia also attends the school. By chance, a close family friend who is an artist was very interested in the project. David Ryley tackled the swimming book first. It was well received at the school and the feedback from teachers was very helpful in knowing where things could be made clearer. Another vital source of advice was the mothers' support group where personal stories helped Avril decide what elements to include. David's illustrations of the main characters are based around Stephen and Christia. There is a multi-ethnic feel in line with Irish society, and there is also a young person in a wheelchair. A clock is used in pictures where the concept of 'waiting' or 'finishing' is involved and attention is given to the child's perspective of an event as a small person looking at big lights, objects or people (figure 1). Symbols are only used when a child can tell from the outside of a building what it is, but readers can add in other symbols themselves if they wish.

The idea was taken to The London Book Fair where Speechmark Publishing's Managing Director, Sarah Miles, saw the therapeutic potential of the series – and, as Avril says, "the rest is history!" While the books are suitable for any child, and may be useful linguistically and culturally for children learning English as a second language, Avril has found it a rewarding project because, "My special passion is for children with intellectual disability and autism, to help them cooperate. I want to share this with the other mums and dads." The series title *Off We Go!* underlines the idea of getting out to places in the community and the first group of the dentist, the supermarket, the doctor, swimming, the restaurant and the hairdresser will be followed up by going on an aeroplane, the optician, the cinema, buying new clothes, getting new shoes and going to a birthday party.

Avril's respect for and partnership with speech and language therapy teaches us much about encouraging and empowering parents. She recognises that speech and language therapy has a very wide input and "communication is not just about words". Although she feels there is not enough speech and language therapy available due to the size of caseloads, she admires Jeanne for her group work and as a "great facilitator", particularly through bringing mothers together for training sessions followed by a cup of coffee. As Avril says, such sessions work on many levels, and it's during coffee that mums hear ideas from their peers about how to get good, fun, visual programmes into the home. She also believes that, to have an impact, the speech and language therapist can't be detached but has to be involved, moving from being a therapist to becoming a friend of the family.

Jeanne agrees that speech and language therapy isn't only about enhancing communication for our clients; sometimes it is also about being a sounding board for a parent with a new idea, or a willing ear, or even a shoulder to cry on – always remembering that improved communication is still the ultimate goal. Reflecting on Avril's

Figure 1 Sample pages



story, and with 20 years' work experience, Jeanne found herself thinking about how universities can teach speech and language therapy students theory, how to do assessments and how to implement specific programmes. When on placement, students experience these elements in practice, dealing with two or three clients at a time. By the time we have completed our training we have learnt the difference between sympathy and empathy, and are aware of rules and procedures that should be followed. While this is all very necessary to starting a new life as a speech and language therapist, Jeanne recognises that this is only the beginning. She says, "What can't be taught is how to cope with a huge caseload, how to get staff involved in successfully running programmes and how to encourage parents of disabled children to focus on the *ability* rather than on the *'dis'* of disability. Experience teaches this part."

Jeanne is delighted that a casual remark of encouragement to a parent wanting help with writing social stories to assist her intellectually disabled child with transition and new experiences has led to an amazing series of books. She adds, "The books will benefit all children and their parents, whether it be at evening story time, improving their reading skills or - as they were initially intended - helping them cope with new and sometimes rather traumatic experiences." And, although Avril's motivation in creating the books was to help her own family and other children, since her first meeting with artist David Ryley in March 2006 she admits that the books have taken on a life of their own. Over the past year she has often said, "I'm too busy, I do not need these books!" adding that a project like this is always bigger

Off We Go! Reader offer

Speechmark Publishing is offering *Speech & Language Therapy in Practice* readers the chance to win one of THREE full sets of Off We Go! books. Each set comprises:

- Going to the Doctor
- Going to the Dentist
- Going to the Supermarket
- Going to the Restaurant
- Going to the Hairdresser
- Going Swimming

To enter this FREE prize draw, e-mail your name and address by 25th October to info@speechmark.net with 'SLTIP Off We Go! offer' in the subject line. The lucky winners will be notified by 1st November 2007. The Off We Go! books cost £6.99 each and can be ordered from Speechmark Publishing on 01280 845571. Alternatively, readers can purchase the whole series at the discounted price of £37.75 (10% off), order code 002-5403.



than you expect, and a bit like having another baby. But it has ultimately been worth it because "you are reaching out – and nothing beats the old-fashioned tool of a book, that special, intangible thing that happens when you are reading together on a couch or at bedtime."

Avril Webster would like to hear any feedback on the series and can be contacted via Speechmark Publishing, 8 Oxford Court, St James Road, Brackley, NN13 7XY, e-mail info@speechmark.net.

Reference

- Andrae, G. & Wojtowycz, D. (1996) *Rumble in the Jungle*. London: Orchard Books.
Webster, A. (2007) Off We Go! series. Brackley: Speechmark Publishing Ltd.

Resources

- Hanen courses, www.hanen.org
- Off We Go! books, www.speechmark.net
- Writing with Symbols 2000, www.widgit.com