



Story books

by Kirsten Deane
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Like most other children with Down syndrome, Sophie is a visual learner. And like most other children, she is very engaged with photographs and stories that involve her and the things she loves.

I decided I had to use that to my advantage very early on. I first started making books for Sophie when she was a baby. My first very crude attempt was a book about her family – everybody in her immediate and extended family had a page along with a simple story and their sign (everybody in our family had the first letter of their first name as their sign). I made this book by sticking photos in a sketch book and handwriting in different coloured textas.

Since then things have become a little more sophisticated. I read the excellent *Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers* by Patricia Logan Oelwein (available in the Down Syndrome Victoria library) and it gave me a million ideas of things to do. While the book has very good ready-made activities in the back, I used it to come up with things specifically tailored to Sophie.

My first books were about Sophie, her family, her friends and her daily activities. They were longer stories intended to be read to her. Every page had one or two photos and a small amount of text. I managed to get a copy of Boardmaker and on every page I included a couple of pictures so she would learn key concepts.

Then I started a series that were very simple and very repetitive so she could read them herself - "My School", "My Friends", "My Family". I kept the Boardmaker symbols on the page for reinforcement.

I have a Macintosh and I used Keynote to produce the pages of the book (Keynote is Apple's version of PowerPoint). Using Keynote allowed me to easily import digital photos, to move them around and add text.

I bought a very cheap laminator from the post office, laminated every page and had them bound at Officeworks. While laminating added an extra step, it meant the books actually lasted beyond the first day. Things have to be tough to survive in our house!

I now use the same system for a whole range of other things. Every weekend I try and take pictures of the

things we have done and do a page with a photo and some text for Monday's journal writing. In the beginning the pages were intended just to help with her recall, but now I try and write simple sentences which she can read and reproduce in her own handwriting in the journal.

I do the same thing during school holidays. I rarely laminate these ones – I just slip the pages into one of those spiral display books with the clear plastic inserts. This is because the teacher and the aide quite often do something with the pages and they need access to them.

I have also used the books to deal with "issues" that have arisen along the way. Sophie was driving us crazy at mealtimes by constantly hopping off her seat. Mealtimes were a constant battle to bring her back to the table. I did a very simple book with pictures of her sitting down at each mealtime – "I sit down to eat my breakfast", "I sit down to eat my lunch". The page "running away is a bad choice" always got a laugh from everyone! I have to say she still hops off her chair to give an enthusiastic demonstration of the day's events – it is NEVER enough just to tell, she has to show – but it is better than it used to be.

The system has also come in handy for school projects. Busy posters with lots of information and pictures don't really help Sophie present information to the rest of the class. One or two photos with a simple sentence enables her to present one idea at a time. This term for the first time she will present her work in PowerPoint. This is another reason for doing the books in presentation software – she can practice at home with the book before doing the presentation in class.

It sounds like a lot of work. And in the beginning I was slow. I have learnt through trial and error. I know you are wondering where you will ever find the time. But I have found that the things that work best for our family are the things we can work into our daily routine. Finding time, energy and headspace for all the extras is just so hard. So I have learnt to carry the digital camera around and knock off a page at a time in a couple of minutes where I can.



Tim's story

by Kate Calwell

In many ways, fifteen-year-old Tim Calwell-Browne is just like his classmates at Tarremah Steiner School, near Hobart, Tasmania. Like them, he participates in the challenging camps, completes woodwork, craft and English projects, takes part in the class play, and enjoys showing off his skills on the basketball court at lunchtime. And like them, being in Class 8 last year meant undertaking an unusually large-scale project, known in Steiner schools as the "Independent Project". (You can read more about Tim's Greeting cards project – raising funds for lost dogs - by visiting his website at www.timscards.org).

Tim's journey through life to this point has by no means been straightforward, so it fills us (his parents) with tremendous joy every day to see how wonderfully he engages with the people and activities around him because it wasn't always this way. Although Tim was diagnosed at birth with Trisomy 21, also known as Down syndrome, it wasn't until he was nearly six that we were able to name, and thereby "come to terms with" a second condition that was seriously affecting his development and behaviour at that time – autism.

A label like autism may be a blessing or a curse, depending on your perspective at any given time. For us initially, it was a great relief – we no longer felt helpless and alone with our differently developing child. Through the internet we were able to connect with many other parents who, like ourselves, were searching for anything that might help their child to learn and thrive again. We also sought advice from many experts, and experimented with various therapies, diets and supplements. Some helped, and were retained; others were eventually discarded. It was an emotionally fraught, hit-and-miss process, which I used to liken to "putting together a huge, unknown puzzle in the dark", yet we felt we had no choice but to continue.

Over time we found that a special diet and certain supplements helped to stabilise Tim's health, which had not been great for some years. We realised then how fundamental good health was to his learning and

development – and he slowly began to move forward. Even then, because of the nature of autism, each new skill had to be broken down into tiny steps, and taught in a particular way. The key was to find something – a favourite food or toy - that Tim wanted so much that he would be prepared to engage with us and play our "games" for a minute or two just to have the desired object back again.

Finding the object that had the power to motivate Tim was actually easy. From the time he was two years old when his brother Asher was born, Tim had been entertaining himself by repeatedly throwing anything he could get his hands on (particularly balls) into the bushes in the backyard. For a while - before we recognised this behaviour as a sign of autism - we thought it was cute the way he would thoughtfully watch the ball trickle down through the leaves, smiling to himself, and flapping his hands a little, then repeat the whole process, over and over...and over. It became clear that all we had to do, to build the bridge that would connect Tim to the world of people and learning again, was join him in his obsession with balls!

We consequently spent more time than you can imagine clowning around with balls, throwing, catching, kicking, or batting them – it didn't matter. Whatever entertained Tim became the medium through which we were able to teach him everything, from simple instructions like "clap hands" or "touch your nose", to reading sight words and practising speech. This made life at home very intense for many years, especially since our family by then included a third child, our daughter Miranda, who is now eight.

With the special intensive program and lots of assistance from his aides and teachers at school, from his brother Asher, and other helpers at home, Tim has made slow but steady progress in all areas. From the child who avoided challenges and was difficult to engage with, Tim has blossomed – and continues to blossom - into a truly delightful student and person, much loved by everyone who knows him, especially for his warmth and cheeky sense of humour!