Ryan's Story

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Personal experience
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Our son Ryan was diagnosed with autistic spectrum disorder (ASD) when he was aged two years and seven months. At this time he was unresponsive to his name, had virtually no words and definitely no comprehension of verbal language. Ryan did not follow simple instructions or understand the consequences of his actions. I knew that other children of the same age were talking and understanding, and I kept thinking Ryan would understand, but that it might just take another six months. Ryan did not interact with other children, or make eye contact with others. He was not pointing. He did not use toys for the purpose they were intended – instead everything was lined up. Much to our delight, Ryan was a very cuddly boy.

Another boy with ASD attended the same kindergarten as Ryan, and he was using photographic visuals (palm-sized photographs) as a means of learning and communication. We were able to talk to his mother about ASD and share the same Educational Support Worker (ESW), who was competent with the use of visuals. At this time we were referred to the Ministry of Education, Special Education (GSE) and to Acorn House, a support group for parents using photographic visuals with their child. The psychologist at GSE introduced us to the Photographic Learning and Communication Strategies System, which involves using visuals for clear unambiguous communication. After learning the strategies and seeing how the other children had progressed, I was keen to try this with Ryan.

From that point on, I took my camera everywhere. I used three rolls of film in the first week – the camera shop loved me. I took photos of everything around us, plus ones I thought we might need in future (I have always believed in being well prepared). We went to friends' and relatives' homes and took photos of them individually and in groups. We took photos of their houses, toilets, eating areas, cars and much more. My parents have both our children a lot and have always been very supportive of our use of visuals with Ryan. We had several sets of visuals: one for my parents, one for the car, one to take visiting, one for the kindergarten and one for home. Producing all these visuals has a financial cost, but what price could we put on minimising our child's and our own stress level by helping Ryan to communicate, to understand, and to contribute to the world we all live in?

When Ryan was first diagnosed, his only forms of communication were finger pulling, squealing and tantrums. He constantly had a frown on his face. Although we were desperate for Ryan to talk, our main goal was to teach him to communicate with us in a way that removed confusion. Using photographs (rather than drawings) along with verbal prompts meant others could quickly understand what Ryan wanted. Initially verbal prompts were kept simple because we didn't want to confuse Ryan by adding in small, high frequency words that had no meaning for him. We hoped these would come later, and they have.

We decided that our first step would be to start with food, drink and toy choice visuals. There were no words on the visuals because these would only cause confusion or distraction. We put visuals of the food Ryan was allowed at any time on a choice board on the fridge, and locked the food cupboards. We also gave Ryan choices of what he wanted to drink. We would ask him, "Ryan, what do you want?" We would take his hand, shape it into a point and by holding his hand, point to the items repeating, "Ryan, what do you want? Do you want water or juice?" At first Ryan wouldn't respond so we would make the choice for him. As we took the visual off the board we would say, "Ryan chose juice. Well done, Ryan." We would then give him the juice and reinforce this by saying, "Good boy, Ryan. You chose juice. Here is juice." We would then show him the visual of the juice and the cup of juice. Sometimes we would choose the less preferred choice of water. It didn't take Ryan long to get used to this and very soon he was making his own decisions. This process enabled Ryan to communicate with us when he wanted something to eat or drink, and reduced the stress felt by others when he could not communicate what he wanted.

We also gave Ryan toy choices. We locked all of his and most of his sister's toys away in a room. People often asked, "Why use a choice board when he could take you to a cupboard and indicate in some way or another what it is he wants?" Or, "Why lock the food and toys away?" The answer to both these questions is that we needed to teach him to enter our world to communicate. We could have left the toys out so he could play with them, but he didn't know how to play with them in an appropriate way. All Ryan's choices were reinforced with much enthusiasm, including lots of clapping, and high fives.

After choices, we moved on to sequences. Whenever we went out in the car, we would put the visuals of our destinations on a board in front of Ryan's car seat. We would go through these before we left, both visually and verbally. We would reinforce where we were at each destination by pointing to the visual and saying, for example, "School". Next we would point and say, "School now kindy". This was a very simple way of introducing him to sequences.

The next step was routines. We started routines involving only three steps, for example, get undressed → bath → pyjamas. We introduced bed time routines, morning routines and, finally, kindergarten routines. If we said, "Ryan, toilet", and then took him to the toilet, he would get most distressed. We soon realised that it was important to show him the visuals, not just to verbalise, and to finish with something desirable, such as using a visual sequence that shows playdough → toilet → wash hands → playdough. It really helped. It was essential that we finished our sentences like this when giving Ryan an instruction, as children with ASD do not always understand that there is an end to something if it is not clearly stated. Before we did this Ryan thought that he had to stay in the toilet and could not go back to his activity.

The next step was to introduce a daily schedule which covered the main events that would happen in our day. At Ryan's first kindergarten they would refer to the date each day so we included the date at the top of the daily schedule board. Every morning and throughout the day we would say, "Ryan, check your schedule."

We feel it is essential for all the people working with a child with ASD to have regular meetings to plan for the child's learning, address any problems and to generally make sure that everyone is working towards the same goals. Our early intervention team included me, the GSE psychologist, Ryan's ESW and often my mother. When my husband was able to, he would attend as well. We had support team meetings every fortnight and I really appreciated these; indeed our future would not have been as rosy without our support team. The first agenda item for team meetings was to discuss particular behaviours – not necessarily bad behaviour but some behaviours needed to be addressed before further learning could progress.

The psychologist devised a programme for Ryan using the concept of themes. One that was a lot of fun was 'the beach'. I made many aids to teach Ryan different aspects of the theme. I made a Velcro board indicating a sandy shore and rock pool. I would say to Ryan, "Where does the boat go? Where shall we put the starfish? How many fish are there? Where will the girl sit?" Ryan loved this activity. He would jump on to the blue area and say, "Jump into the water … splash … swimming." We would ask him questions such as, "What does fish start with?" We found the beach words in early reader books. We would also have counting cards with objects found at the beach and work sheets and cards where Ryan had to match the word to the picture. We would give him scrabble-type letters and he made the words with them. Themes gave us a focus, and he learned a lot while he was having fun. Music was another trigger for Ryan's learning, and he loves singing, dancing and musical instruments.

Ryan's first kindergarten focused on a letter of the week. We also started focusing on these at home. I produced visuals with the letter we were working on. We would say the letter, name the object and make the sound the letter made. One of the best ideas I have had was to draw with chalk on the trampoline. I wrote the letters 'A a' and drew pictures of an ant, apple and Anthony from the Wiggles. I would hold Ryan in front of me with my hands on his waist, and I would say, "Jump on the letter A – A makes the sound a a a a ant, a a a apple, a a a Anthony". We would jump on each picture as we said it. We ended up going very fast to make it lots of fun. Ryan loved this activity and learnt extremely quickly this way. Soon he was sounding out and recognising letters and numbers. We covered capitals and lower case letters in the same way.

Identifying and labelling colours was something we thought Ryan would never understand. I remember before we started any formal type of learning, we worked on making Ryan more aware of the environment around us. We walked to the park a lot. On the way to the park we would feel the green grass and look up at the blue sky. We then moved on to walking slowly then walking fast, jumping, hopping, big steps, little steps and so on. We must have looked a sight to the people passing.

It was important when teaching him colours to only focus on the colour and remove other variables. We cut up paper of different colours into the same sizes and shapes. That helped him see a difference between the colours and not be distracted by the objects or shape. If we were showing him a blue car, it was the car he was focusing on and not the colour. Once we established a colour, we would look through books and identify the different objects in that colour. After that we started generalising with different objects out in the community. There is a red fire engine. The traffic light is red. When we put away toys such as blocks, I would say, "Pack away the blue blocks, now the green ones."

We needed to work in small, deliberate steps, and constantly checked everything for ambiguities. Children with ASD have a unique learning style and we needed to make sure each step was cemented before we moved on to the next one. It took Ryan six months to understand the concepts of up and down. The learning steps could be so slow, but we needed to remain determined, and to keep it simple.

Ryan became adept at doing insert puzzles, and we needed to move him on to interlocking puzzles. That was an eye-opener for me. Ryan was only looking at the shapes and trying to match the female to the male piece. He was oblivious to the picture. Now he has the gist of it and can complete the puzzles well.

Ryan had three different ESWs during his kindy years. Each one did a fantastic job and joined in many activities with Ryan. These included swinging on the swings and completing the obstacle course. We would provide a visual sequence to show Ryan what would be happening, for example, trampoline → gym ball → crawl to the classroom. This emphasis on Ryan's sensory issues allowed optimum learning to take place during the one-to-one work time. This work time , although more formal, was still fun and consisted of

activities like drawing Lazy 8's for fine motor skills, completing mazes, joining the dots, drawing a line to an object, using brainy blocks, putting together sequences, and reading and writing. Since Ryan has learned to learn, he has been like a sponge.

Mat time for Ryan was very difficult. Children with ASD can experience sensory issues such as disliking the close proximity of so many people, bright lights and other distractions. Ryan has never liked sitting and waiting quietly, and we needed to help him cope with sitting quietly on the mat. To help Ryan, we shortened mat times and gave him a squeegee ball or a feather to hold to help calm him and satisfy his stimulatory or sensory issues. We also gave him rewards and acknowledgement to reinforce his sitting quietly. All of these tactics were backed up by the use of photographic visuals. Mostly, Ryan would be at one-to-one work time while the other children were at mat time. This arrangement reduced opportunities for distractions from the other children and Ryan was able to concentrate on his tasks. He did participate in the last mat time of the session because this was important to ready him for school. Ryan's kindergarten was very receptive to our suggestions.

When we first started working with Ryan at kindergarten we added a sequence to his daily schedule to show Ryan what we would be doing each session. This let him know what was expected and what activities he could look forward to. For example, baking was scheduled for most mornings and it was something that Ryan really enjoyed. Mostly they baked scones, so I made new recipe cards with photographs for the kindergarten, and also made a book on baking at kindergarten for Ryan. This included washing his hands before and after baking, putting the scones into the oven, and then leaving them to cool down before they could be eaten. Baking at home was also a great way to teach Ryan shapes, colours, and actions. A lot of learning took place during baking – and we were able to eat our produce. Ryan still loves baking.

Ryan's and his ESW's day at kindergarten could easily be thrown into bedlam by unexpected events. One of these was a fire alarm. In order to alleviate Ryan's distress and help him cope with this I made him a fire alarm at Kindy book. I also pointed out to him that not all fire drills mean a fire and the teachers and children needed to have practices. To help Ryan to make sense of the purpose of a fire drill, I added pages showing the damage a fire can do and how it can hurt people and property. Wet days at kindergarten were another difficulty – Ryan was unable to understand why he could not go outside. We made another short book explaining why, and provided alternative activities to do inside.

By the time he was three years old, Ryan knew a lot of nouns. He could name people and places, and many other objects. Ryan could name the toilet, but he had no idea what it was for. One of the first behavioural issues we started working on was toileting, which has been the longest and the most difficult, but also one of the most rewarding.

With reading and writing, it was also very important throughout all of Ryan's learning that we ensured he understood the words that he was reading or writing. Children with ASD are great rote learners, but just because they can say or write something does not mean they understand it. From the age of three, Ryan could write 'warning' and we had told him what it said, but he didn't know what it actually meant. I did not know where he had seen the word to be able to write it in the first place and I later found out that it is at the beginning of every video. When Ryan was four years and 11 months, we started him on writing sentences and made photographic visuals with step-by-step instructions to help him construct the sentences.

Ryan likes close contact with familiar people, and would constantly sit on his ESW's knee. This was a habit we needed to discourage before he started school. To deal with this, we made a mat out of a laminated piece of blue paper with the words 'Ryan sit here' on it and one for his ESW marked 'Fiona sit here'. We gradually moved the mats apart so that Ryan could get used to sitting by himself. In May 2003, Ryan started school. He had a gradual transition into a class with nine other children with ASD. We made him five books just to get him to morning tea time. These books were essential for Ryan to understand and cope with the routines in an environment totally new to him. At school, Ryan is reading and writing well but we need to constantly work with him to ensure he reaches his potential, and understands what he is writing. His reading level is well above his level of comprehension.

When we bought a video of the times tables and a wall chart for our daughter, Ryan commandeered them and taught himself multiplication to the 12 times tables and beyond. Ryan has also memorised the calendar for 2005 and 2006. He can tell you the day for whatever date you tell him, and can remember the date certain things happened – he is like my little diary. We always tap into Ryan's interests and use these to further his learning, and we need to keep him interested and motivated. For his participation in our family shopping, we made a visual shopping list with numbers, photos and words for the vegetable shop. Ryan would read it, go and find the required items, and count them into a bag. Like all other children with ASD, Ryan has difficulty in understanding the world around him and it is up to us to help him in the best way that we can.

Now Ryan is able to read and understand many of his visuals are text. I will add photographs in times of stress or in new situations to help dispel his anxiety. Getting to where we are today has been a steady progression over several years. It may be tempting for parents and teachers to rush through the stages of visual intervention but it is important to remember that we could not achieve realistic or sustained results by using words and then sentences too quickly. Ryan could not read all the words in his books, but by having them there, it allowed whoever was going through the book to provide consistent information.

Tantrums were an everyday occurrence and were extremely difficult to manage. They evoked a great deal of unwanted attention from onlookers. Ryan has an older sibling so we needed to go out a lot and were unable to hide at home until his behaviour had improved. I started to plan ahead by making visuals or books. When Ryan has any change in routine or a special event coming up, I make him a book to help him understand and cope with it. Ryan loves these

books and they really work for him. We produced a book for waiting quietly at the doctors so Ryan would have choices other than going into the doctors' rooms trying to play with their computers, which he had been doing. He needs to be provided with alternatives because he is unable to think of these on his own. Visuals often need to be made after behaviour has occurred in order to prevent it from reoccurring. After a number of accidents with eggs, we made a visual of broken eggs all over the floor. The 'broken egg' scenario has not happened since then.

Taking turns has been another difficult issue for Ryan. We helped Ryan understand the fact that others were allowed a turn, by making visuals of Ryan and his sister on the trampoline. We would put it in a sequence board, showing Ryan's turn until the timer goes, then his sister's turn, then Ryan's turn, and we added in words – 'Mummy's turn, then Ryan's turn.' Although he did not always like this, he did understand.

Occasions such as Christmas, with all the different and spontaneous events, could cause immense stress for Ryan and all of us. Christmas now goes off without a hitch because the books we produce are extremely detailed. Ryan asks me to make these books and he likes to help. In the early stages, and sometimes even now, Ryan objected to visuals telling him what to do when it wasn't what he had planned. He does understand the purpose of the visuals and, backed by the consistent reinforcement of the members of our team, he understands that he must comply.

When I think back to where Ryan and I started, I remember thinking, I am not a teacher – where on earth do I start – Ryan is depending on me – I know nothing about teaching. Even some of the terms used by the teachers were foreign to me, but if Ryan was to progress, I needed to take on the role of teacher as well as parent. At times the responsibility was overwhelming. I have learned a lot and I have two bits of advice for working with children who have ASD: be consistent and use photographic visuals.

The stresses and strains of dealing with ASD meant I did tend to give in too much. Often I would blame the autism for Ryan's behaviour, which obviously had a lot to do with it, and because of this I was not strict or consistent enough. The turning point of Ryan's compliance was the day Ryan's psychologist said to me, "You need to take control and follow through. Don't go with him when he pulls you – take him to the visual board and get him to show you what he wants." From this point on we took control and became a lot firmer with Ryan. Despite the obvious reactions from him we stuck to our guns and both Ryan's and our family's life has improved considerably.

We don't know what Ryan's future will bring, but it is up to us to help him as much as we can. He still processes information differently and needs help understanding what is happening around him. We will keep using photographic visuals to help him with all of these issues. I believe he will do well in his life. We continue putting in the time and effort, and also ensure that he continues to be taught in the right environment and in the right way.

A lot of people ask me how Ryan's sister copes with Ryan and his ASD. We are very fortunate, and Danielle is the best sister Ryan could ever wish for. She is extremely patient and she loves Ryan unconditionally. We have been open and honest with her from the time of Ryan's diagnosis. I think having a brother with ASD has opened Danielle's world. She attends special needs classes for swimming, trampoline and gym with Ryan. She accepts all the children there for who they are. I asked her if she would like to write a piece on 'having a brother with autism'.

She wrote:
When your brother or sister has ASD it's hard because you talk differently to them. They go to a different school and it's hard because he gets a little more attention. It's hard to explain why he is different. Sometimes when I'd explain about him, people would say, "Yeah I get it, he's dumb", though he knows his times tables already. He's seven. My friend's brother doesn't know it, so Ryan's not dumb! He could spell words when he was three that I couldn't spell when I was six. He could open 30 windows in one computer session. So he's not dumb after all … sometimes I'll be talking on the phone, when there is a call on the other line, and it's for my mum and she's talking about my brother.

We deliberately think in small, literal steps. We examine everything for ambiguities. Every day there are more things that I can verbalise which he will understand and follow, or comment on. This has been bought about largely by the use of visuals. They are a major part of our lives now, and always will be. However, visuals aren't where it begins and ends. They can't provide a cure for ASD, nor are they the magical answer. They do not work in isolation. Photographic visuals are, however, a very powerful tool for learning and communication. To be truly effective their use has to be taught and used correctly along with an understanding on how the mind of a child with ASD works. It also requires a one hundred percent effort and commitment from everyone involved with the child – and not just his mother. But isn't that true of anything that's worthwhile?

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