

# Helping

## Our daughter

By Pam Mew

### The Role of Psychological, Visual and Communication Approaches in Helping Our Daughter



Susannah is a beautiful 16 year old, who has many interests and skills. Her hobbies include listening to music, dance, athletics, tennis, horse riding, climbing, caving and bowling.

She has not, to date, developed much spoken language, other than a handful of words. She has both communication and social difficulties, and therefore struggles to express herself and make sense of the world around her. When she was 10 years old she received a diagnosis of autistic spectrum disorder in addition to Down's syndrome. As she approached adolescence, her frustration started to manifest in her behaviour. We sometimes felt at a loss to understand her needs and how best to help her.

We heard that a clinical psychology service was being set up in our area for children and young people with severe learning difficulties and/or autistic spectrum disorder so we asked to be referred. It was a new service and there wasn't a waiting list so Susannah was assessed quite quickly.

She was clearly communicating something with each behavioural incident. The psychology assessment showed that there were two very clear themes running through her behaviour. One was her drive for independence. The other was the intense frustration

that she was feeling as a result of her communication difficulties.

With the support of the psychologist, we tried out various strategies and below is a summary of those that we have found to be particularly effective:

- Use "stay/go" symbols to give Susannah a means of letting us know whether she wants us to stay near her or leave her alone. She quickly understood what the symbols were for, so it had clearly been an issue for her. After all, what teenager wants their Mum or Dad breathing down their neck the whole time!?
- Susannah is very keen to do things for herself, so we give her as much independence and choice as possible. Whenever possible, she chooses her own clothes and activities and what she wants to eat at meal times. When she finds it difficult to make choices, a chart of symbols or pictures can help.
- Susannah wants to feel in control of her own space. She hates us interfering if she has not asked for our help, so we don't move or change anything in her immediate environment without asking her first.
- Susannah likes to be organised. It is very important for her to know what is going to be happening each day, so we keep a visual timetable at home which she helps to assemble each morning.
- Using symbols can really help Susannah to interpret the world,

understand what is expected of her and can gain her co-operation in a way that no amount of nagging can do. For example, she likes to leave the bath tap running, so we made an "off" symbol for her to use. Give her the symbol and she happily turns the bath tap off and puts the symbol on the tap to indicate that it should stay off. It works like magic!

- It's relatively easy to keep things calm and predictable at home, but outside home it can be more challenging. We therefore use symbols to help prepare Susannah for future events. For example if we are going to the doctors, we take the relevant symbols so that Susannah will understand what will be happening, particularly if she is likely to need an examination.
- Because she knows what will be happening she is able to organise herself and select appropriate clothes or equipment for each day's activities.
- Also when she gets "stuck" and refuses to budge, it's usually because she doesn't understand what's going to happen next. A selection of symbols on a Velcro strip can help her to move on.
- Symbols and pictures can also help Susannah do things independently. For example, we have produced charts to guide her when washing and drying herself.
- We use large sand timers to give her a visual representation of the passage of time. This removes the uncertainty of not knowing how long



she may have to wait for something to happen.

- We introduce new things and new ideas slowly and usually supported with symbols.
- We try not to respond directly when Susannah is displaying frustration. If we do, things can quickly escalate and become out of control. So we find it's better to ignore the behaviour, but then target our attention and praise on the times when she is calm and happy. We give her regular monetary rewards (10p) and she uses the money to buy things she likes such as jewellery and bath bombs.
- Learning new skills can cause frustration, so we encourage and congratulate her for any attempt she makes at any new skill and generally praise and compliment her frequently to boost her confidence and self esteem.
- We try to find ways to modify and calm the environment to reduce triggers that might cause distress for Susannah and thereby reduce the likelihood of an incident occurring. We also use distraction techniques when she is feeling upset.
- One of Susannah's current "things" is to let out a sudden ear piercing shriek. If we are out in public when the shrieking starts we show her a "shh" symbol. This is far less confrontational (and far more effective) than telling her to be quiet!

The visual support makes all the difference. Like many people with Down's syndrome, Susannah is a visual learner and the symbol remains visible long after the spoken word has disappeared from her conscious memory. All the symbols are produced on the computer using the Widget "Writing with Symbols" software

(which has now been superseded by Communicate in Print).

In addition to symbols, Susannah uses Makaton signs to communicate, but her signing has never been very accurate due to her fine motor difficulties. When she was 12, we bought her her first "talker" (a voice output communication aid, which uses symbol-based communication software). She now has a more sophisticated device, a Vantage Lite using Picture Word Power software, which was funded by our Local Authority. If we were introducing a communication aid now, we would probably try the iPad and Proloquo2Go software.

Susannah's "talker" has made a massive difference to her. She can now tell us what she wants to eat and what she wants to do. She can talk about people and activities that are important to her. To some degree, she can express her emotions as well. For example one morning she burst into tears and I didn't know why. Was she feeling unwell? I asked her what was wrong. She said only one word, "Val", and I understood immediately why she was upset. Val is her shared carer and Susannah was under the impression she was going to be staying at Val's house the next night. However, we had forgotten to put it up on her visual timetable, which left her feeling disappointed and anxious. We were able to rectify the problem immediately and soon Susannah was smiling again. Without the talker we would have struggled to understand why she was upset.

The talker has also played a huge role in Susannah's education. She learns new vocabulary very quickly. She

mostly talks in 1 or 2 word phrases but people can get the gist of what she is saying. She also uses her talker to read books out loud. Before she had her talker we didn't know the extent of her reading ability or her intellectual understanding. We weren't even sure that she was hearing well. However, now we know there's no problem with her hearing because she listens and joins in conversations!

Being understood gives her the confidence to sometimes try and use her voice to repeat the word she has just spoken on her talker, so maybe over time it will help her develop more speech as well. That would be amazing! Improving her communication has opened up her world and she is so much happier and more engaged as a result. She is now able to enjoy the company of others and is very proud of her own developing independence.

The combination of psychological, visual & communication approaches have played an important role in helping Susannah to understand the world and what is expected of her. She is more able to express her wishes and her needs and who she is as a person. As a result, the challenging incidents have reduced very dramatically, both in terms of their frequency and intensity. We, as parents, have gained confidence in our ability to deal with challenging situations and we continue to implement the strategies on a daily basis. When there is an incident, it's nearly always a communication and an indication that something needs to be done differently. Susannah cannot verbalise her feelings as other teenagers can, but she does make her feelings known in her own way. So we learn as we go and it's a great joy to see her blossoming into a happy and confident young lady.