Communication tips for parents and carers of children with Down’s syndrome and ASD

Caroline Dawson (mum to Lottie and Millie)

Millie and Lottie are identical twins, with Down’s syndrome. However Lottie also has a dual diagnosis of ASD (Autism Spectrum Disorder), which means there are notable differences in how the twins communicate.

The girls were premature, but only Lottie had to undergo surgery at seven months old to close an AVSD (atrioventricular septal defect). We did not have any concerns or see any real differences in their development for the first 3 years.

We decided to dual educate the girls with two days at a mainstream school and three days at a special school. The differences in communication and development became apparent during reception, but were initially overlooked due to other factors including thyroid function, hearing and a dominant twin!

We started to hear warning bells in year one when Lottie’s language stopped developing and she started to display sensory issues. Everyone was very understanding and talked about Lottie’s additional complex needs and we were advised to remove her from dual placement and put her full time in the special school. This was a difficult period, not because she was attending a special school full time but because it underlined the huge difference between the girls’ development.

In year 2 I asked Lottie’s school what ‘complex needs’ meant for her and we agreed to have Lottie assessed for ASD. The process was quick and everyone was very supportive. I initially discussed the assessment with Lottie’s class speech therapist and was asked if I wanted to sit in the autism assessment observation. This involved two therapists. One was working with Lottie whilst the other therapist observed her, made notes and videoed her. It was clear to me that Lottie was showing signs of being on the autistic spectrum. It was lovely to hear the therapist say Lottie had so many positive qualities but I knew we would have the diagnosis. I believe that the process was straight-forward for us because Lottie has a twin sister and everyone could see the difference between the girls. We had done everything from the start in exactly the same way and had not treated the girls any differently.

The dual diagnosis has helped everyone who works and plays with Lottie to understand her communication and social needs and to introduce strategies which are right for her.

Lottie is verbal and can use full sentences, but they tend to be descriptive or after a prompt. While she has a good range of words, she doesn’t normally use them to communicate. She will not make spontaneous requests or engage with others verbally, but she can make choices if given relevant options. Lottie was given the opportunity to sign from a young age and used signs up until she was two and a half years. While she no longer uses sign language to communicate, she does understand signs and will respond if signed to. I use sign language to help her understand verbal communication.

In contrast to Lottie her twin sister Millie has excellent communication skills. She is very social, reads beautifully and loves to socialise. This means that at home Millie can dominate and answer for Lottie. From my own experience of having two children with Down’s syndrome, it has highlighted the differences in communication methods for those with complex needs.

As with other children with Down’s syndrome, it is important to try a variety of different communication methods and see what your child likes and understands. For Lottie, we have found that visual prompts are very effective. At school they use PECS (Picture Exchange Communication System) to help Lottie’s spontaneous use of language.

Lottie sometimes has difficulty taking the PECS to an adult. She requires physical prompts to guide her hand to touch an adult for attention. She may pick up the picture but will not take it to the relevant person. To help her understand this better, we have created two PECS boards at home. One is linked to her routine board, which is downstairs near the kitchen and refers to ‘snack time’ and ‘choose’. The other is linked to ‘play time’ which will link to highly motivating activities i.e. hide and seek; singing; ring o’ roses; cooking. I am hoping that this will lead to spontaneous language rather than simply responding to a ‘choice’ question. We are also hoping that this will involve Lottie ‘travelling’ i.e. coming downstairs to make a request.
We also use PODD boards (Pragmatic Organization Dynamic Display) to assist in her communication and involvement in activities. For example, we have a PODD board for her current story of ‘going on a bear hunt’. This board provides visual prompts for all of the key words used in the book i.e. ‘bear’; ‘hunt’; ‘over it’; ‘under it’; ‘scared’. The PODD boards are also used to request help and prompt Lottie in activities such as use of the toilet - pants up/down; tap on etc. These have helped Lottie to follow a routine at home and she is now become more independent in these activities.

One of our aims in using these strategies is to help Lottie communicate choices with people outside her direct family. Lottie will often use gestures or take my hand when she wants something – she will lead me to the product or place she wants to be taken. Whilst I know what she wants, not everyone will have this level of understanding so it is important for Lottie to be able to communicate her needs with a range of people.

We have seen a development in her communication thanks to these techniques. She has used the PECs strip to make choices and is vocalising these choices as well as giving me the ‘I want’ strip. She has used PECs with family members and friends and is really happy to be given the opportunity to make these choices. We have also seen some challenges associated with her developing communication. She has difficulty managing transitions and communicating her emotions. She has the loudest yell imaginable and is very good at telling us if she is unhappy. Although this can be difficult at times, I love the fact that she knows her own mind and is now prepared to communicate her views. Prior to this she was sometimes lost and people did not always see her or hear her.

Lottie does not express her emotions through words or pictures – she does so through sound. She will shout when unhappy or frustrated.

She also uses ‘happy noises’ when excited or happy and tends to flap hands or stiffen her limbs. We have started to introduce pictures of emotions and while these are not working at the moment, I believe they will help Lottie in the future.

My other helpful aids to communication

Routine board
Lottie enjoys reading off the list. She will also take over any pictures from the list and hand them to us and will state what the picture is describing i.e. park.

‘Real’ picture books
We take pictures of activities over the weekend. These are sent into school for Lottie to ‘talk about’. These are really effective in getting Lottie to use her language. Real photos are highly motivating for Lottie and are helping her at school to answer ‘where’ and ‘who’ questions. We also use real pictures to help Lottie to make choices. Lottie is making progress with her reading and this in turn is helping language. We try to use ‘family pictures’ or act out the stories from school to help motivate and prompt language.

Quiet happy voice
This is important in dealing with anxiety. For this, I come down to Lottie’s level, place my hands on her shoulders and use a very quiet, happy voice to explain. We find using a happy voice (like Mr Tumble) really helps to calm a situation.

Sensory activities
Lottie has better communication after we have done some ‘engaging’ activities such as ‘Row the Boat’. These were identified by our OT as good strategies to help Lottie to engage.

Motivation
Communication is assisted by using highly motivating activities. For example:

• a visit to family

• she enjoys cooking and will sing cooking songs, or shout ‘stir it!’

• hide and seek – which we have found is really good at developing her communication. We hide ‘dog’ then ask “who is hiding?“; “where is dog hiding?”; she enjoys answering.

Lottie tends to avoid social contact, participating in social activities, or using her communication skills unless she is highly motivated. She does not use spontaneous language unless highly motivated.

A happy Lottie tends to lead to better communication.

These are some of the things that have helped us to support Lottie:

• Do not give up and remember what works one day may not work the next. If it doesn’t work one day, it could come back in a couple of months’ time!

• Look at how your child communicates with you – you will be surprised at how much they do communicate, how they feel and what they enjoy.

• Seek advice! Your child’s Speech and Language therapist can provide you with advice. You can contact the DSA for information and support on communication concerns. Speak to other parents through forums or support groups; they might have ideas that you have not tried yet.

• Incorporate any strategies into everyday play or daily activities and enjoy those activities. Sometimes feeling like a parent rather than a ‘therapist’ is the most important part of building communication, particularly through play activities.

One difficulty we have faced has been coping with the comparison between Millie and Lottie. I can sometimes dwell on what it would be like if both girls were making similar progress and I get upset at how people can gravitate towards Millie. When we were told we had twin girls with Down’s syndrome, we focused on the positive of their shared
characteristics; the fact that they would play together, share similar interests and we hoped to use the same strategies to help them make progress. On reflection, I suspect life would be easier if Lottie was not on the autistic spectrum, but we are learning not to focus on the negatives. She loves to listen to music, sing, swim, cook, play games and she has a lovely sense of humour. Lottie struggles with her fine and gross motor skills, balance and engaging with other children. If you look carefully, however, you will see her engaging with others. You will see that she wants to join in games, but needs help to do so. You will see her enjoy praise when she gets something right, how she touches people to say ‘hello’ or shouts out their name in delight, how she gets sad when her sister is upset and gives her a hug.

Lottie’s dual diagnosis has helped me see these things more clearly and has made me realise how important it is to get to know Lottie and not just the label.

Facebook The DSA Complex Needs and Autism Group

The Information and Training Team have set up a new, closed group on Facebook specifically aimed at parents and carers of children, young people or adults who have additional needs associated with an autism spectrum condition, or who are described as having particularly ‘complex needs’. This may include people with a wide range of other health, development or support needs who need creative, sensitive support to be able to participate in family, school and/or community activities. To apply to join, type ‘the DSA complex needs and autism group’ into your Facebook search bar and click ‘join’.

Natalie

Sue and Steve Wilson

We really cannot believe that it will be 30 years this June since our little Natalie was born. As some other readers will understand, it was a shock and a huge worry to be given the diagnosis of Down’s syndrome. Steve and I and our family have had to travel an exciting but nonetheless steep learning curve over these years.

Natalie was born on a sunny morning in June 1987. It was my second pregnancy, the first having ended in a stillbirth. As you can imagine it was quite a shock to be told the news that Natalie had Down’s syndrome. For a few weeks after her birth we had Natalie fostered. This gave us a chance to grab the challenge with both hands, gather information, meet other parents and generally come to terms with the diagnosis. We read as much as we could lay our hands on about how to nurture our little bundle. We brought her home at five weeks, a tiny soul who wouldn’t feed properly but who loved to sleep all the time.

We were very lucky to be assisted in the first few months and years by our lovely Portage visitor, Bonny, who has remained a friend to this day. Bonny gave us all lots of encouragement and broke down what seemed like never-ending tasks into manageable steps. With Bonny’s support Natalie walked, talked and responded extremely well to every bit of stimulation given to her. She attended mainstream playgroup, nursery and, with a Statement of Special Educational Needs, our local primary school. I gave birth to her little sister, Caroline, when she was 3½ and our little family was complete and spent many happy years together as a unit. Natalie went to high school at 11 and took exams alongside her peer group at 16. She had regular health check ups and apart from having tonsils and adenoids removed at 5 and grommets fitted for glue ear, she was very lucky health wise. College courses came and went over the next 5 years, with funding issues and frantic researching to find relevant placements for Natalie to attend.

She did us proud and left full time education with 3 GCSEs and numerous certificates in core subjects, basic and life skills.

However, as lots of parents know once our sons and daughters leave education there is very little on offer. It fell to me again to research...