

# Speech and Language Therapy with Galina

**Gerda Stevenson**

Parent, Scotland

## The creative approaches of a parent to speech and language development for her daughter

This article explains how Gerda Stevenson, a professional actress from Peeblesshire in Scotland, gathered ideas from a variety of sources about activities to promote speech and language development. She describes how she was inspired to help her own daughter, Galina, and to work with other parents in lobbying local officials to improve the provision of services for children with communication difficulties, including Down syndrome.

### **I introduced Galina to books when she was three months old – just as I did with her older brother**

In November 2001, a meeting was held with staff from Borders NHS Trust Speech and Language Therapy department and a local parent group, of which I am a member. Our (local parent) group had requested the meeting, as we felt that the speech and language therapy services in Scottish Borders were not reaching our children as effectively as desired, and indeed required.

Parents felt that there was a need for more information in relation to speech and language therapy. At this meeting, I was asked to compile a list of the information I'd gathered, and the resources I've employed, since

such a document could be useful to parents.

Rather than simply compile a list, I decided to describe how I'd used the information and resources. The following pages, written two years ago, chart my approach (from 1999-2001) to speech and language therapy with my daughter Galina. This has been a journey of discovery. Some people, including professionals, have expressed surprise and reservations about the level of input involved. One of them commented memorably, "Oh, it's such a lot of work, Gerda. I know Galina's benefiting, but don't you think she's maybe more a case of nature rather than nurture?" "Keep your eye on the ball, Gerda!" was my unspoken response.

I am a working mother and can't devote all my time to teaching my children. But with careful planning in advance (which is essential, since it's frustrating for Galina if I break the flow of our work by preparing in the middle of it), our structured work usually involves about 45 minutes per day, not necessarily in one block of time, sometimes a good deal less. To work in detail with my child has been the most bonding and rewarding experience. She responds so well to all kinds of therapy – there can be no advantage in not pursuing any worthwhile avenue. Much of what I described here relates to a child who has Down syndrome but, within the different approaches I have laid out, some elements will be applicable across the spectrum of disabilities. So, here is what Galina and I have done together, with help from some skilled and inspiring people.

### **Background to my situation: a personal viewpoint**

In April 1998, I gave birth to a baby daughter, who happens to have Down syndrome. At this point, I knew very little detail about Trisomy 21, the chromosome disorder that Galina has.

A friend wrote to me at the time of Galina's birth, saying that early intervention and stimulation are very important. Another friend told me about a little boy she knew, who had Down syndrome. "He's lovely, so sweet, but he doesn't speak. He had four words when he was a toddler: 'Mummy,' 'Daddy' and 'Postman Pat.' Then he stopped speaking. He'd said it all!" That story haunted me.

The more I read about the subject, the more I realised that speech is a significant difficulty for children with Down syndrome. I'd read that in terms of cognitive development, babies and children with Down syndrome can be on a par with their typically developing peers. It is obvious that a child who can think but can't communicate is likely to feel misunderstood and alienated. Such feelings could lead to deep frustration.

A local authority professional gave me a small book, *The development of language and reading skills in children with Down syndrome*,<sup>[1]</sup> by Sue Buckley and colleagues – this book was crucial for me as Galina's mother, like the sowing of a seed. This little book made it absolutely clear to me that early intervention

**Galina with her brother, Rob**



photographs by Gerda Stevenson

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in the form of signing and reading would be vital in relation to Galina's speech and language acquisition.

At this point, there was no support for such an approach from speech and language therapy or educational psychology departments in our area. Galina's first two speech and language therapists did not use signing. The professional who had loaned the book to me stated that she knew of no parent in our area who used signing; and that if signing was adopted, it was likely that only the mother would use the signs, so the child would be limited to signing with that one person alone. Having read the above-mentioned book, I thought, "Well, if Galina can at least communicate with me, and I'm with her most of the time, then that's better than her not being able to communicate with anybody."

### Organisations and materials I have used

I was given *Signalong – Phase 1*<sup>[2]</sup> by the local NHS speech and language therapist, when Galina was about 18 months old. The manual had no index and was impossibly slow to use because, by the time I'd ploughed through the book to find the sign for the word, I'd lost the context. I phoned Signalong in frustration, (fortunately their phone number was in the indexless book!) and explained my difficulty. It turned out that the manual I'd been given was ten years out of date, and that every Signalong manual is now published with an index. I immediately ordered my own copies, directly from Signalong, of *Phase 1* and *Phase 2* and their publication *Foundations – Learning Through Exploring And Creating*.<sup>[2]</sup> This was expensive, but invaluable. I mention this because such an experience of struggling with a manual, which is not user-friendly, can be disastrously off-putting.

At this point, I wanted to join a class in Signalong, but no such facility was offered in my area. However, Signalong will provide you with a contact list for courses in, or near your area.<sup>[2]</sup> We started using the signs at home and I have found this system very user-friendly, provided one has the up-to-date manuals! Galina also occasionally uses unadapted *British Sign Language (BSL)*, e.g. "hedgehog," which is a beautiful

sign in BSL. The mixture of modes arises from a very lucky opportunity that opened up for me in April 2000. I was invited, through a friend, to take part in a course aimed at teaching parents of deaf children to sign story-books for toddlers. The course was organised by my friend who was the administrator of a professional story-telling company for the deaf called *Stories in the Air*.<sup>[3]</sup> This course, of 15 weekly classes, was conducted in BSL, and was held at Donaldson's School for the Deaf, in Edinburgh. BSL syntax is, of course, completely different from Signalong. The latter is sign-supported English, whereas BSL is a completely separate language and culture, I discovered! You might imagine that this could be confusing, but actually it was not at all. I simply used what I wanted of BSL, and adapted it to Galina's needs. In fact, BSL, Signalong and Makaton<sup>[4]</sup> signs are all very similar.

Signing story-books was a wonderful way of learning to sign: children adore repetition, and of course, repetition helped me and Galina to learn the signs. The books were carefully selected by the course facilitators according to the following criteria:

- 1) great stories
- 2) brilliant illustrations
- 3) useful vocabulary which could be employed in everyday situations

Learning with other parents was hugely enjoyable, and therefore very motivating. There was always time for a chat to compare notes at coffee break. We weren't allowed to speak during the class – it was total immersion, signing in silence. As a professional actress, I found this experience particularly fascinating, since by day I was rehearsing the title role in *Phaedra*, at Edinburgh's Royal Lyceum, spouting pages and pages of text, being torrentially verbal. But, on Tuesday evenings for two hours, I had to communicate in silence.

With Galina, however, I'd always speak and sign simultaneously. It is important to understand that signing with a child who has Down syndrome is not an alternative to spoken language; signing is used as a visual support to the spoken word, acting to show children with Down syndrome what you mean. As a visual form of communication, signing is appropriate for children with Down



photograph: Barbara McDermitt

**Gerda and Galina signing for 'shoe'**

syndrome, who have strengths as visual learners, but do not learn well from listening alone. Research shows that early signing and early reading significantly enhance speech and language acquisition. Signing is not nearly as daunting as it sounds – the signs tend to be logical and easy to remember. On the whole, you only sign key words, so it's not a question of becoming a fully-fledged student of British Sign Language! Galina's signs are not always accurate, but I understand them, just as parents recognise their children's inaccurate early speech, from the context. Usually a child who has speech delay but is signing, will start, after a while, to speak as well as sign just as the parent/carer/teacher is doing. After some time, the child spontaneously drops the sign and speaks the word with confidence. I read about this process with fascination, I have adopted it, and it works.

A couple of weeks after I had started the night class course at Donaldson's, I placed a photograph of Rob, Galina's brother, near to her cot as she slept. When Galina awoke the next morning, she looked at the photo, and spontaneously signed her first three-word sentence. "Rob bagpipes door" and indeed, that is exactly what Rob was doing in the picture, playing the bagpipes at the

**Research shows that early signing and early reading significantly enhance speech and language acquisition**

front door. Galina was using her own sign that she had invented some weeks ago, for "Rob" and this was an absolutely thrilling moment for me!

I would urge parents not to wait until their child speaks: start signing as early as you can, when the baby is a matter of a few months old. Then begin a reading programme from age two.

Books are a constant and much-loved activity. Galina will spend ages leafing through her books, and attempts to sign and say the stories herself. I introduced Galina to books when she was three months old – just as I did with her older brother. When she was very small, I always faced Galina, propping the book up in such a way that she could see the pages and watch my hands and mouth speaking and signing. We also cuddled together on the sofa, or she would sit on my knee, and I'd sign, side-ways on, which she seemed to follow perfectly well.

I'm particularly interested in the approach of early reading as a tool in the process of spoken language acquisition. *The Down Syndrome Educational Trust (DownsEd)* at The Sarah Duffen Centre in Portsmouth has shown the most impressive results with children who have taken part in the early reading programme. I bought a most useful video from DownsEd, which demonstrates the effectiveness of their early reading programme, and have been circulating this video among parents and professionals.

I became a member of The Down Syndrome Educational Trust and have bought a lot of the teaching materials that they advertise in their catalogue. Central to their approach is the realisation that society's ignorance and low expectations of people with Down syndrome can have a negative effect on the lives of people with this extra chromosome.

## A conference that opened doors

In September 2000, I travelled to Portsmouth to attend an international conference held by The Down Syndrome Educational Trust. The local Rotary Club paid for my conference attendance fee of £200 and, fortunately, an old family friend gave me a bed for the night. The subject of the conference was *Speech, Language and Cognitive Development in Down Syndrome*.

It was completely fascinating, and I was lucky enough to meet a speech and language therapist there from a specialist speech therapy organisation called *Symbol UK*.<sup>[5]</sup> I wondered whether she might assess Galina. We arranged for her to visit us at home in February 2001, when Galina was two years and ten months. Galina's NHS speech therapist very generously agreed to join the meeting in her own time. Within fifteen minutes, the Symbol UK speech and language therapist demonstrated that Galina was capable of reading at least four words, through 'single-word matching' (see <sup>[6, p.77]</sup> for a description of this technique). The Symbol UK therapist drew up a target plan, giving us a structured programme to work on with Galina. So many possibilities opened up during this assessment, filling me with a new sense of motivation and indeed, inspiration.

The following July, I went down to London, to observe the same speech therapist working for a full day with a series of groups of children who have Down syndrome. These group therapy sessions run on a regular weekly basis. I have found the Symbol UK techniques tremendously imaginative and useful. I have been fortunate to have this work supported by Galina's current NHS speech and language therapist, our third in two years. NHS provision appears to be erratic in our area,

and lacking in continuity. There also appears to be a surprisingly varied level of knowledge among speech and language therapists.

Galina's current speech and language therapist and playgroup leader have taken on board my daughter's needs with enormous commitment. But many parents and, indeed, professionals, are understandably lacking in confidence in this area. Of course, there is no reason why anyone who has not explored this avenue should understand exactly how it works. A number of parents I have met have had little, if any, indication from professionals of the benefits of signing. It is vital, in my view, that professionals should actively promote this strand, within the many approaches to speech and language therapy.

## Music and movement

My approach to Galina's language acquisition has been a broad one. For example, I sang action songs and rhymes with her from a very early age. When she could sit up, she wanted to use her arms, and enthusiastically attempted to join in with the actions. But her balance wasn't good, and she easily keeled over. The local physiotherapist provided us with an excellent pillow, with extended 'arms', which gave support to Galina's sides and extended beneath her elbows. It soon became apparent that she needed a little chair with arms. I could not find one of the right height with arms, and so asked the occupational therapist if that department might have such a chair. Nothing could be found, but the occupational therapist ordered a small chair to be made for Galina, and this was the most liberating object imaginable. She could now sit, perfectly balanced and supported, and sign away to her heart's content, joining in with all our action songs, which she still loves. This chair was an essential part of Galina's speech and language development.

I remember noticing that before Galina could speak, she always joined in with a short, simple chorus of "La-la-la-la, La-la-la!" when she was listening to one of our action song tapes. She could pronounce the "la" sound perfectly in the sung context, though not, at that stage, in the spoken context, and I felt that the *singing* of the sound liberated

Galina dancing to 'Jungle Book'



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her articulation of it. I sense that singing can be a very useful and, of course, enjoyable route into elements of vocal production.

At the DownsEd conference in Portsmouth, I also met a speech therapist from the Netherlands, who works for the *Developmental Dysphasia Foundation*,<sup>[7]</sup> based in Amsterdam. She indicated that their organisation considers music to be an important element of speech therapy. Some weeks later, I received a most interesting letter from the team leader of this organisation, who is a child psychiatrist. He wrote about their work at the foundation, and it sounds fascinating. He considers music to be very important, because it is a right hemisphere brain function. Most intriguingly, he explained that the Developmental Dysphasia Foundation is particularly interested in the methods of those who coach top performers: actors, musicians, and athletes. Music is important for their work because it has a strong pre-verbal connotation. They also teach children with Down syndrome to read from the age of three. I'd love to have pursued the work of this particular organisation, but time and money have not permitted.

One of the best videos for action songs and signed nursery rhymes is produced by the *Makaton Vocabulary Development Project*.<sup>[4]</sup> Dave Benson Phillips is the irresistible presenter, and the extensive use of signing in this video is tremendously useful. Most importantly, the video is great fun, beautifully produced, with high production values, and is hugely popular with young children. It doesn't matter if your child is using Signalong because it's very similar to Makaton and you can pick the signs up easily from the video or adapt them as you wish.

When Galina was only a few months old, a friend sent me a very interesting and practical book: *Yoga for the Special Child – A Therapeutic Approach For Infants And Children With Down Syndrome, Cerebral Palsy, and Learning Disabilities*.<sup>[8]</sup> I found a yoga teacher to work with Galina and we have been doing yoga regularly for over two years now. Galina knows and practises many yoga positions. This has helped her to have an awareness of her body. She (Galina) often suggests that

we practise our yoga and will fetch her mat and book saying "Come on, Mummy - oga!" We have a glorious array of sparkly stickers and Galina chooses one at the end of each session.

## Speech Sound and Language Cards

The *DownsEd Sound Cards* <sup>[see 6, 76]</sup> were invaluable at an early stage. Galina greatly enjoys using the cards and I continue to use them with her, as a refresher every now and then. The cards show signs and pictures for each sound. The picture and the letter(s) for the sound are on the front, the sign on the back.

I also purchased the *DownsEd Language Cards*, a pack of 54 first words – the most commonly used nouns, verbs and other words that occur in a young child's daily life. The word appears printed on one side, and the picture on the other. An accompanying sheet is provided, giving the various uses and games that can be played with the cards.

Through the DownsEd catalogue I also ordered the *Winslow Press Verb Cards*.<sup>[9]</sup> These are large coloured photographs of people doing various everyday things. I sign whole short sentences for Galina such as "The girl is jumping", "Grandad is pouring juice", "The baby is crying." The latter was instantly a big hit: Galina is utterly grabbed by the photo of the baby crying and we always have to take time to talk about *why* the baby was crying. She is clearly thrilled by the implicit drama within this photo. I sometimes save this card as the reward and if Galina is not in the mood, I'll tell her "The crying baby's coming soon!" These have been very successful in sentence building. She now sometimes spontaneously produces her own fully constructed signed sentences, based on the Winslow Verb Cards: the other day she was watching Grandad at the table and said, as she signed: "Gadad is eating celery", without a sign for celery, since we'd never signed that word before. At present, we are working on a selected target group of twelve verb cards.

We're also using the *Winslow Press Verb Tenses* book,<sup>[9]</sup> which is made up of sequences, regular and irregular verbs. There are three pictures of each verb: past, present



Galina with her yoga teacher, Anne  
Suckling

and future tenses, e.g. "The man is going to brush the dog. The man is brushing the dog. The man brushed the dog." Grammatical construction is frequently a difficulty for people with Down syndrome. However, the student can undoubtedly benefit from regular rehearsal. Galina is definitely becoming aware of these elements. The other day, I asked her to put the chopped carrots into a pan, simply to keep her occupied while I was cooking. She dropped each piece into the pan from a height saying: "Carrot jumping!" As the carrot hit the pan, she said "carrot jumped!" She was developing her own game from the verb tense exercises we have been practising.

Through *Learning Development Aid (LDA)*, I have ordered some very interesting and useful cards, which I use to practice the skill of critical thinking. They are called *Why? Because*,<sup>[10]</sup> and at age three, Galina enjoyed them immensely, despite the information on the box saying they are aimed at children 4 years and above. The set contains paired cards colourfully illustrated and depicting various situations. I sign the whole sentence each time, which works wonderfully as a prompt for Galina, e.g. First card: "Why is the ambulance coming?" Next card: "Because the lady fell off her bike." Then lots of discussion follows about the lady's sore leg and her shopping lying on

the ground. First card: "Why are the children putting on their coats, and their hats, and their scarves?" "Because they're going to make a snowman."

Since we've been using these cards, Galina is attempting to use the future tense, signing simultaneously. Only yesterday, when my son left the house to go to bagpipe practice, Galina said, "Robbie is going to bagpipes." She was very consciously using the signed/spoken sentence structure we've been working on with the *Why? Because* cards, and the *Winslow Press Verb Tenses* book mentioned above.

There is no doubt that the rehearsal of these structures is essential for Galina – she finds it very difficult to just pick up and use language 'on the hoof', as most children do automatically. She seems to require a conscious, structured repetition in order to construct sentences with all their components. And, indeed, this is what all the research demonstrates.

## Reading

I have made lots and lots of flash cards, printing them out on the computer in bold, large letters, then laminating them, so that they are not spoiled by spillages and if they are bent, they just bounce back! I make two of each, since Galina learns to read by matching, picture to picture, then word to picture (or object), picture to word, then word to the word, and finally she can read the word on its own. Matching is the basis for her reading, and indeed for so much learning.

In common with many young children, Galina enjoys posting things, so we have incorporated posting the flashcards as part of our reading. We made a post-box from a cardboard shoe box, painting it bright red, and then sponge-printed golden butterflies all over it (Galina's idea). Once Galina knows the words well, a puppet (manipulated by me) holds up the flash cards, one at a time. Galina calls out each word, takes it from the puppet, and then posts it.

It is very important not to confuse teaching with testing – a process of errorless learning must be developed, so that the child is enjoying the process, and cannot fail. The child must not feel he or she has to perform. We know from research

that children and adults with Down syndrome are very susceptible to a sense of failure. They tend to develop an increasing use of avoidance strategies to get round doing something they don't want to do. Situations where low expectations and constant testing of aptitude prevail will hardly be conducive to maximising anyone's potential.

In 1866 Langdon Down, after whom the syndrome is named, wrote of people with Down syndrome: "They can only be guided by consummate tact. No amount of coercion will induce them to make up their minds to do that which they have made up their minds not to do." (Mind you, this sounds like my 13 year-old son, who doesn't have Down syndrome!)

Having learned to read the individual words, Galina and I read the sentence we've signed. Galina can now read the individual words in isolation and, also, combined in sentence form, pointing to each word from left to right, for example "The baby is crying." "Don't cry, baby." "The baby is walking." "The baby is sleeping." "The rabbit is eating." It is fascinating to note that articulation improves dramatically when Galina reads, rather than simply spontaneously speaking the words: e.g. for some time Galina had been saying "dow" for 'window', pronouncing only the last syllable (which is typical of a child with Down syndrome – short-term memory is often a problem, resulting in the child retaining only the last syllable). However, when she saw the word written down for the first time and I said: "window", she immediately said: "dindow", and only days later, having learned to recognise the written word, she said: "window." This process has occurred repeatedly. For ages, Galina was saying "moo" for "moon", but as soon as she learned to recognise the written word, she articulated the final consonant. Reading is a hugely helpful tool in achieving clarity of articulation as well as in building grammar.

I notice that Galina is also applying singulars and plurals correctly. Sometimes we'll practise plurals during our reading sessions. For example, I will hold up a flash card saying 'arm', placing it on my arm, then I say "arm" again. Next I hold up another example of the same

card and say "another arm", then I hold up a third flash card which says 'arms', and say "two armS", stressing the letter 'S'. Then I cover up the 'S', and say: "Look! It's the same now! Arm – oh-oh, the 'S' is hiding! Where's it gone?!" Then I make the 'S' reappear: "Boo! There's 'S'! Now it's NOT the same! It's 'armS' now! 'armS'!" Galina got the hang of this very quickly with all the double body parts: ears, eyes, legs etc.

She is sight-reading many words and short sentences consistently and is beginning to learn the alphabet. She demonstrates great interest in the letters within the words we are reading. For example, she will comment, pointing to a letter 'l' appearing in the middle of a word: "Long tree!" drawing her finger along the length of the letter 'l'; or she will say: "circles, round circles" pointing to the double letter 'o' in the middle of 'doors', or 'book.' So, she is beginning to develop an awareness of the combination of letters which make up words.

Again, through DownsEd, I ordered a wonderful book: *Teaching Reading To Children With Down Syndrome*.<sup>[11]</sup> This is written in a superbly accessible style for parents, and is a simple step-by-step approach, thoughtful, caring, child-centred and it works!

## Listening

There is much that I have read about Down syndrome which encourages parents and professionals to employ visual materials as much as possible in the development of our children. There is no doubt that this is very important but, by implication, this can suggest that children with Down syndrome are not auditory learners – indeed, I've read that this area is not one of their strengths. Certainly, it is true that among children with Down syndrome there is a greater likelihood of hearing problems. But, in Galina's case, she is very responsive to audio tapes. I think it's important not to assume that, just because the child has Down syndrome, he/she will respond in certain ways. Making assumptions can close doors.

I worked, at one point, in the BBC Radio Scotland Education Department, producing programmes for children of various ages. I still have copies of the Hopscotch pro-

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grammes that I produced for nursery and primary school children, aimed at four to six year olds. Each programme is in three five-minute sections: *the Song Box*, *the Story Box*, and *the Sounds Box*. A character presents the programme – sometimes a straightforward presenter, and sometimes a character like the Puddock (a frog), or the Moudie (a mole). Galina adores these tapes and listens to them again and again. She can repeat huge chunks of them along with the tape. I'm told that before the average child can speak a word, he or she has to have heard it spoken at least two thousand times. Repetition is crucial. I feel that the added strength of the audio tapes is that the listener is creating his or her own imaginary pictures, thereby exercising cognitive skills.

### Other resources

Through the Learning Development Aid catalogue I also ordered a large puppet, whose advertised name is Molly.<sup>[10]</sup> She has a wonderfully expressive face with a mouth and tongue that can be manipulated, and gloved hands, which can be used to sign. Galina enjoys her very much, and Molly adds variety and fun to our learning. Molly is a great bonus, because she becomes a participant, which means we can practise turn-taking – such an important social skill. Also, Molly can get things wrong, and then Galina has to help her. If Galina gets fed up, Molly can take over – there are endless possibilities here!

DownsEd has also produced a large folder entitled *Down Syndrome Issues and Information*, covering all aspects of development of children with Down syndrome, divided into different age-groups. I ordered the 0-5 years folder. This is a really valuable source of information, well presented and accessible.

During a period in the Sick Children's Hospital in Edinburgh, when Galina had pneumonia, I made contact with a paediatrician, who is involved with Down's Syndrome Scotland.<sup>[12]</sup> She suggested that my husband and I might be interested in the *Hanen Program*, a course for parents whose children have speech delay and learning difficulties.<sup>[13]</sup> We enrolled for this course, (which was free) and were part of a group of a dozen or so parents who

met on Tuesday evenings over a period of three months at the Sick Children's Hospital. Some sessions were replaced by home visits when, while playing with Galina, my husband and I were video recorded by the Hanen speech therapist who was assigned to us. Edited sections of the video would be shown at the next group meeting. The emphasis was always on the positive, so the course was highly motivating. It was valuable to share experiences with other parents and to come away with new ideas to work on with Galina before the next meeting. This is a Canadian programme, and is a subtle, detailed analysis of adult-child communication. The accompanying book, which is full of very thought-provoking, child-centred and practical ideas, often in the form of games, is entitled *It Takes Two To Talk*.<sup>[13]</sup> The Hanen organisation also runs a programme for parents whose children have Autistic Spectrum Disorder and training in Speech and Language Therapy.

At this point, Galina was 3 years and 8 months. She was speaking in two and three-word phrases, and occasionally in four and five word sentences. She was also beginning to use different tenses. "Gana (her name for herself) jumped off Daddy's arm," was a new utterance we heard, when her Dad lifted her from her high chair to the floor. She has been using this little sentence, adapting it in a variety of ways since then. She uses words of several syllables e.g: butterfly, caterpillar. We find the technique of clapping out syllables effective, e.g. "bu-tter-fly," (three claps) "win-dow," (two claps).

Galina's father, a native Gaelic speaker from Skye, speaks in Gaelic to Galina and her brother Rob at all times. Galina understands Gaelic very well, and is what is termed "passively bilingual;" i.e. because her environment is predominantly English-speaking and her father speaks virtually the only Gaelic she hears, she tends to reply in English. She never confuses Gaelic and English, when she does occasionally reply to her Dad in Gaelic. Today Galina said to herself as she was building Duplo bricks: "Gana building tower high up – suas ard," i.e. she repeated the last two English words of her mini-sentence in Gaelic: "high up – suas ard." so she appears to be aware of the

concept of translation. Her brother Rob went through Gaelic medium education at primary school, when we lived in Edinburgh, and is now fluently bilingual in Gaelic and English.

Since Galina has started to speak, she has begun to play and interact with the other children at nursery and playgroup. She is well integrated and accepted wholeheartedly by her peers.

Obviously Galina develops much more slowly than many children, and she will always have learning difficulties, but she is undoubtedly developing steadily. And, of course, the work continues! Any ideas are most welcome – the sharing of experiences is one of the most helpful and stimulating aspects of this journey we're on.

### Two years on ...

I wrote the above article two years ago. The good news is that within the last 18 months our local authority has run classes in signing for teachers, auxiliaries and parents, and Symbol UK has been employed in our area.

Galina is now 5 years and 9 months. She has an extensive vocabulary. There's no doubt that it often takes her longer than her peers to process information, and therefore conversation with Galina is not fast. It is essential to give her time – as we learned on the Hanen Program: Observe, Wait, Listen. On the whole, she speaks in full, well constructed sentences. "My Daddy's gone to the Country Store to buy

Galina with her friend David



Wallace and Grommet cheese, called Wensleydale," she said yesterday – although getting the Wensleydale out caused a few splutters! Occasionally, she will relapse into utterances such as "Mummy – ice cream!" but she can tell me about anything that has happened, and can express her needs eloquently. She can also express abstract thought. A couple of months ago, she was settling down to watch her Pinocchio video. The titles were going up, accompanied by that strangely memorable high-pitched male voice singing "When You Wish Upon A Star." Galina asked me, "Mummy, who's singing?" "I don't know," I replied. "I think it's Pinnocchio's father," she said and indeed, it is Geppetto who, in the story, wishes upon a star.

At present, Galina's favourite game is to play with me and her *Jungle Book* cuddly animals. "Come on, Mummy. We can make them talk. I'm Mowgli." Drama is such a liberating, creative way of learning to communicate.

Galina's current and excellent NHS speech and language therapist, the fourth, has willingly worked with our Symbol UK target plan, updated by the Symbol UK therapist on a second visit. She is delighted with Galina's development – both speech and social skills, and sees huge progress since the summer holidays, when Galina attended a daily group speech and language therapy programme for one week.

Galina attends the local school, where she is in Primary 1, alongside her peers. She has taken to school like the proverbial 'duck to water'. During the Christmas holidays, she couldn't wait to go back: her waking utterance on the first day of the new term was: "It's Monday – school's opened!" She takes the school minibus every morning with the other children from our village, and enjoys the daily round of "hellos", and "good mornings," commenting on the weather: "It's a foggy day, Paul," (to our lovely driver) "just like in my Postman Pat video!"

Galina is always invited to her classmates' parties. I make a point of inviting her friends to play at our house, and occasionally the compliment is reciprocated. It's true that the social side of her life requires some conscious engineering on my part – other parents are perhaps a

little unsure of what to expect initially. I was, however, greatly encouraged to hear from her class teacher, at the recent parents' evening, that a number of parents had commented on how much their children enjoy having Galina in their class.

There was a suggestion last year that she should repeat a year at the school nursery. I'm glad to say that the senior educational psychologist wisely advised us to send her into Primary 1 along with her peers. Her wonderful class teacher put in a huge amount of work, outside school hours, to prepare for Galina's entrance into Primary 1. Among other material, I have supplied her with Stephanie Lorenz's invaluable publications on inclusion,<sup>[15 for example]</sup> and the inspiring book *Working with Hannah*.<sup>[14]</sup> We are very aware of the potential pitfalls: communication difficulties can lead to anti-social behaviour, and Galina's frustration has sometimes resulted in shoving and occasionally spitting. It seems that there is little training in inclusion, and its success or failure often depends on the commitment and openness of individual teachers. Anti-social behaviour can be exacerbated by uninformed, untrained staff having low expectations of children with learning difficulties. Galina has two excellent auxiliaries who work with the class teacher as a team, maximising her opportunities to participate and learn within her peer group. She is not relegated to the corner, sitting on the auxiliary's knee. The class teacher has communicated to me how interesting she's finding the process of including Galina, and that much of the material I have given her to read is actually very useful to all of the children in the class.

As part of the local school reading programme, Galina and her classmates are working their way through a sound system similar to the *DownsEd Sound Cards*, although the signs that accompany the letter sounds are quite different. I wondered whether this would confuse Galina, but decided to take a 'wait and see approach.' In fact, she has no difficulty in learning another parallel set of signs for the same sounds. She is very aware that there are different ways of communicating – English, Gaelic and various modes of signing. "Mummy says 'badger,'

and Daddy says 'broc.' Daddy speaks Gaelic. Daddy reads me Gaelic books. You can't read Gaelic books, Mummy. Only Daddy," she told me recently. Actually, I can read a good bit of Gaelic, thank you, Galina!

Galina is continuing to read with enormous enthusiasm. She enjoys painting, is very good at colouring in, and is attempting to write. I use drama as much as possible as a motivating tool. Galina loves to dress up as Postman Pat. She writes the names of her favourite characters on envelopes, tracing over the dots I have already marked, which form the shape of each word. She finds it very difficult, as yet, to form most of the letters of the alphabet spontaneously herself, but is beginning to trace words very competently. The envelopes go into her postbag, and then, as Postman Pat, she goes around our house, knocking on doors, which I open (in character – just to keep my hand in as an actor between jobs!). Postman Pat reads the name and delivers the post to Miss Hubbard, Ted Glen, Peter Pan, Geppetto, Baloo – there seems to be no difficulty delivering post to different worlds – Greendale and Neverland in the same day!

The latest development at school is that Primary 1 has adopted *Numicon* which is proving to be a very effective numeracy system for many of Galina's class-mates. It's encouraging to know that inclusion can be a two-way process.

We continue with yoga, and a friend of mine does cranio-sacral treatment and massage with Galina, which, being very tactile, she adores. I have been working on 'left' and 'right' with her, using feathers, stroking her left ear, then right ear, left cheek, right cheek, left leg, right leg. I ask her to raise the arm or leg I'm touching with the feather, or feathers – sometimes I hold one in each hand, touching opposite sides simultaneously. She can now raise the left arm and right leg, or indeed any combination of limbs, as soon as she feels the feathers' touch. This game developed from Galina herself, when she found a feather in the woods, and asked me to stand still, while she stroked my face with it – a magical moment.

Many things have been said about people who have Down syndrome but my son made an observation, which

## Speech and Language Therapy with Galina

stays with me more than any. During a conversation when my husband and I were discussing Galina's development, and I was dwelling on the deficits rather than the strengths, Rob, age 12 at the time, chipped in "I never think about what she isn't."

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9. WINSLOW, Goyt Side Road, Chesterfield, Derbyshire, S40 2PH. Tel: 0845 921 1777, fax: 01246 551195, e-mail: sales@winslow-cat.com
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## Gardening with Galina

Every word we've planted,  
you and I, has been  
so slow to grow,  
each seed bedded deep  
in your mind's loam.  
In the silence, we've waited,  
as the seasons change, and meantime  
learned that hands can speak;  
until, at last,  
shoots of green sound reach  
from roots through your throat's reed,  
leaves unfurl, spilling sunflowers from your lips,  
dark seeds wreathed in gold for us to sow,  
more and more golden words for us to grow.

Gerda Stevenson  
November 2003

see next page for Editor's comments on this feature

## The following items are available from The Down Syndrome Educational Trust's Resources brochure:

*Down Syndrome Issues and Information Early Years Development Pack (0-5 years)*. Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-41-0

*DownsEd consonant sound cards*

*Winslow Press ColorCards – Verbs and Winslow Press ColorCards – Verb tenses*

**Video:** *Understanding Down syndrome (2) - learning to read* (1995). By Sue Buckley and Gillian Bird (1995). Portsmouth, UK: The University of Portsmouth.



**Editor's comment**

We are very grateful to Gerda for writing this excellent review of Galina's speech and language development. We would like to note a few points with regard to some of the issues that Gerda raises.

- a. Gerda comments that she has read that "in terms of cognitive development, babies and children with Down syndrome can be on a par with their typically developing peers". We felt that it is important that parents and teachers are clear about the exact nature of the difference between typically developing children and children with Down syndrome. The individual differences between babies and children with Down syndrome is great and it is certainly true that when children go to play group and school it is quite possible that there are other children in the group, with similar levels of non-verbal mental ability and/or speech and language delay. As far as babies are concerned, the social and cognitive differences between babies with Down syndrome and typically developing infants are much smaller than with older children. However, as children reach school age, the 'average' child with Down syndrome will have a non-verbal mental age of roughly half that of children of a similar age without a learning disability and their speech and language skills and verbal short term memory skills will be lower than this. This said, as Gerda comments below, it is crucial for everyone involved with caring for and educating children with Down syndrome to have high expectations.

*Gerda's response: I have always held the view that Galina is an intelligent individual, partly because she seems to be, but also because I think it's advisable to have high expectations. Professionals have expressed surprise, and have been excited by Galina's academic abilities. However, I think such reactions are possibly more to do with these individuals' initial expectations of a child with Down syndrome (hopefully now subverted!) than with Galina herself.*

- b. Gerda explains that she taught Galina to read single words by "matching, picture to picture, then word to picture (or object), picture to word, then word to the word, and finally she can read the word on its own". We would advocate matching picture-to-picture, word-to-word and then picture to word. There is no research to support whether one method is more effective than the other, however, we feel that the child needs to learn to discriminate the words through word-to-word matching activities before picture-to-word matching is introduced. Word-to-picture matching tests whether the child understands what the word means and should be done after the child has learnt to recognise the word. However, pictures will be helpful in the teaching of single words. For example, if you want a child to learn to read the word 'cat' you would show them the printed word and say it to them (when they are looking at the word), get them to match it to

another copy of the word and then afterwards show them a picture to put with it. This is not testing the child; it is simply using the picture to support the spoken word. However, in the teaching phase it is important that the picture appears, after the child has paid attention to the printed word and matched it to another printed word, otherwise they will not attend completely to the word. Experience suggests that the picture is more inherently motivating to them and they will look at the picture without paying attention to the word.

This said, it is crucial to add, that in the same way as scientific research informs parents' practice, real life experiences are the starting point for research. The most important thing about intervention with children with Down syndrome is that one reflects on the intervention activities that they have undertaken, adapting and developing them in line with how successful they have been for the individual child and parent/teacher.

*Gerda's response: I'm aware of the issue of the picture being more motivating than the word, when it comes to matching - I recall having a really interesting chat with Leela Baksi about this at that Downs Ed conference I attended. I don't know how I arrived at doing it with Galina the way I did, but anyway, it seemed to work. In fact, I think I started by sticking the flash cards to bits of furniture: 'door' on door, 'chair' on chair etc.*

- c. Finally, we would like to note that practices such as yoga, cranio-sacral treatment and massage do not have a body of scientific evidence to support their effectiveness as techniques to advance the well-being and development of children with Down syndrome. However, there are many indirect effects relating to these types of therapies, e.g. the additional social support of the therapist can have a therapeutic effect as can the contact with like-minded others and being included in community activities alongside children and adults with and without disabilities.

*Gerda's response: It is true that there is no research to back up the practice of yoga (and cranio-sacral treatment) in relation to people with Down syndrome, or indeed anybody, probably. However, it seems to me that yoga gives Galina a tremendous sense of body awareness. I sense that being able to hold inside your head an image which you can make with your own body, must help to enhance one's cognition. Galina has been able to draw a body with head, torso, legs, arms, eyes, nose, mouth etc. for about two years now, and I sense that this is partly to do with the fact that she has an awareness of her own body, through being asked to think about and physically create the shapes her body can make. Each position in yoga has a vividly descriptive name, e.g. 'The Dog', 'The Cat', 'The Bridge', 'The Tree'. I have no scientific basis for such a conclusion! But I think it's really interesting.*