## SPEECH THERAPY WITH GALINA



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### Introduction

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 group requested the meeting: we felt that S.A.L.T. 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. I was asked at this meeting to compile a list of information I'd gathered, and resources I have 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 I'd gathered. The following pages, written two years ago, chart my approach (from 1999-2001) to S.A.L.T. 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 you're 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's Syndrome. But within the different approaches I've 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 OWN SITUATION: A PERSONAL VIEWPOINT

In April 1998 I gave birth to a baby daughter, who happens to have Down's Syndrome. At this point, I knew very little about the actual details of this particular chromosome disorder — Trisomy 21 — which Galina has.

#### Syndrome

3am, and a globe of the world illuminates your sleep.
Pentland rain beats on the slates above the perfect sphere of your head.

I saw you first on a screen — sound brought you to light, the curve of your brow a bright and distant moon; I knew there was a chance of that one chromosome.

I spin the globe
on its plastic axis:
oceans and continents
flicker over your face;
from the delicate slant of your eyelids
I'd guess Siberia or Tibet
if I didn't know.
Like that butterfly in China
your breath taps the air,
and shells strung for your delight
shift slightly on their threads.

You fill a space too small to pin-point on the map, but your territories are vast, unfolding before me a unique identity.

Gerda Stevenson, 1998



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's 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 likely to be a significant difficulty for children with Down's Syndrome. I'd read that in terms of cognitive development, babies and children with

Down's Syndrome are frequently on a par with their typically developing peers. It's 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.

I was given a small book by a local authority professional — this book was crucial for me as Galina's mother, like the sowing of a seed. Its title is: THE DEVELOPMENT OF LANGUAGE AND READING SKILLS IN CHILDREN WITH DOWN SYNDROME, by Sue Buckley, Maggie Emslie, Gilly Haslegrove and Pat Le Provost, published by the University of Portsmouth and the Down Syndrome Educational Trust, Portsmouth. (Note: the use of the term Down without the apostrophe 's' in all the Down Syndrome Educational Trust material. The same applies to American literature on the subject.)

This little book made it absolutely clear to me that early intervention 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 therapy or educational psychology departments in our area. Galina's first two speech therapist 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 anyway, 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 I HAVE CONTACTED, AND MATERIALS I HAVE USED TO WORK ON GALINA'S SPEECH THERAPY

I was given a SIGNLONG manual — Phase I — by the local NHS speech therapist, when Galina was about I8 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 I0 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 I and Phase 2, and their Foundations — Learning Through Exploring And Creating. 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.

We started to use SIGNALONG. I've found this signing system very user-friendly, provided one has the upto-date manuals! Galina also occasionally uses unadapted BSL (British Sign Language), e.g. "hedgehog," which is a beautiful sign in BSL. The mixture of modes arises from a very lucky opportunity which 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. 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 wasn't at all. I simply used what I wanted of BSL, and adapted it to Galina's needs. BSL, SIGNALONG and MAKETON signs are in fact 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. Also, the books were carefully selected by the course facilitators. The criteria were:

- I)great stories;
- 2) brilliant illustrations,
- 3)useful vocabulary which could be employed in everyday situations.

To be 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 would always speak and sign simultaneously. It is important to understand that signing with a child who has Down's Syndrome is not an alternative to spoken language — it is used as a visual support — a bridge to spoken language. 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 sign only key words, so it's not a question of becoming a fully-fledged learner 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 its 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. And, after some time, the child quite 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'd 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's exactly what Rob was doing in the picture — playing the bagpipes at the front door. (Galina was using her own sign that she'd invented some weeks ago, for "Rob.") This was an absolutely thrilling moment for me!

I would urge parents not to wait until their child speaks, because the child may not without intervention. 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 2.

Books are a constant and much-loved activity. Galina will spend ages leafing through her books, and attempts to sign and speak out 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, sort of side-ways, 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 (Down's Ed) 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 Down's Ed, 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 their teaching materials, which they advertise in their catalogue. Central to their approach is the realisation that society's ignorance and low expectations of people with Down's Syndrome can have a negative effect on the lives of people with this extra chromosome.

#### A CONFERENCE WHICH OPENED DOORS



In September 2000, I travelled to Portsmouth to attend an international conference held by the Down's Syndrome Educational Trust. (The local Rotary Club paid for my conference attendance fee of £200. Fortunately an old family friend gave me a bed.) 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 there a speech therapist from a specialist speech therapy organisation called SYMBOL UK. 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 (it was a Saturday afternoon). Within fifteen minutes the SYMBOL UK speech therapist demonstrated that Galina was capable of reading at least four words through matching. 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 inspira-

tion. 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's Syndrome. This group therapy runs on a regular weekly basis. I have found the SYMBOL UK techniques tremendously imaginative and useful. I've been fortunate to have this work supported by Galina's current NHS speech 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 therapists.

Galina's current speech 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. Many do not fully understand the crucial point that signing is employed as a technique in order to elicit spoken language, and, emphatically NOT in order to enhance understanding. The latter may be a bonus, but most of the children who can benefit from signing have excellent cognitive skills. Of course, there's no reason why anyone who has not explored this avenue should understand exactly how it works. A number of parents I've met have had little, if any, indication from professionals of the benefits of signing. It is vital, in my view, that this strand, within the many approaches to Speech and Language therapy, should be actively promoted by professionals.

#### MUSIC AND MOVEMENT

My approach to Galina's language acquisition has been a broad one.

I have sung 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 was not 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. But it soon became apparent that she needed a little chair with arms. I couldn't 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 O.T. 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 when she was listening to one of our action song tapes — this went:

"La-la-la, La-la-la!" 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 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 Down's Ed conference in Portsmouth, I also met a speech therapist from the Netherlands, who works for the Developmental Dysphasia Foundation, 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 their foundation is particularly interested in the methods of those who coach top performers: actors, musicians, and athletes. Music is important for the foundation's work, because it has a strong pre-verbal connotation. They also teach children with Down's Syndrome to read from the age of 3. I would 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 MAKETON DEVEL-OPMENT FUND. 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.

When Galina was only 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. This book is by Sonia Sumar, published by Special Yoga Publications. I found a yoga teacher to work with Galina, and we have been doing yoga regularly for over two years now. Galina knows and can practise many yoga positions. This has helped her to have an awareness of her body. She will often suggest that we do yoga, and will get her mat and book out herself. "Come on, Mummy — oga!" We have a glorious array of sparkly stickers, and Galina chooses one at the end of the session.

#### LANGUAGE CARDS

The Down's Ed Sound Cards were invaluable at an early stage, and I continue to use these with Galina, as a refresher every now and then. This is a way of rehearsing consonants, and their combinations (e.g. b, c, d, f, sh, ch, etc) using supporting signs and pictures — the picture and the letter(s) for the sound are on the front, the sign on the back of the card. Galina enjoys these cards greatly.

I also purchased the Down's Ed Language Cards, which offer a pack of 54 first words — the most commonly used naming, action 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 same catalogue I also ordered the Winslow Press Verb Cards. With these cards (large coloured photographs of people doing various everyday things) I sign the whole short sentence for Galina. "The girl is jumping." "Grandad is pouring juice." "The baby is crying." The latter was an instant big hit: Galina was utterly grabbed by the photo of the baby crying, and we always had to take time to talk about why the baby was crying. She was clearly thrilled by the implicit drama within this photo. I sometimes save this card as the reward, if Galina isn't in the mood, telling 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.

We are at present only working on a selected target group of twelve verb cards.

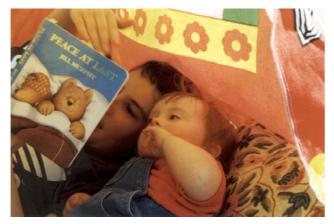
We're also using the Winslow Press Verb Tenses book, which is made up of sequences, regular and irregular verbs. There are three pictures of each verb: past, present and future tenses: "The man is going to brush the dog. The man is brushing the dog. The man brushed the dog." Grammatical construction is frequently a difficulty for people with Down's Syndrome. However, the student can undoubtedly benefit from regular rehearsal. Galina is definitely becoming aware of these elements — she demonstrated an example of this the other day, quite spontaneously: 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!" And 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 are used to practice the skill of critical thinking. They are called WHY? BECAUSE, and 3 year-old Galina enjoys them greatly, even although — according to the information on the box — they are aimed at 4 years and up,. These are a set of paired cards colourfully illustrated, depicting various situations, and I sign the whole sentence each time, which works wonderfully as a prompt for Galina: (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, her shopping lying on the ground etc. "Why are the children putting on their coats, and their hats, and their scarves?" "Because they're going to make a snowman," etc.

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, etc. 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.

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's 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's 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's 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: "The baby is crying." "Don't cry, baby." "The baby is walking." "The baby is sleeping." "The rabbit is eating," etc. It is fascinating to note that articulation improves dramatically when the Galina reads, rather than simply spontaneously speaking the words. E.g. for some time Galina had been saying "dow" for 'window' — i.e. pronouncing only the last syllable (which is typical of a child with Down's 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, said: "window." This process has occurred repeatedly — e.g. 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.

This, for example, is the kind of thing we do with flash cards, during our reading sessions:

"arm" — I hold up one flash card which says 'arm', placing it on my arm, and I say "arm."

Then hold up another card of the same, 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-read-

ing 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 e.g. 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 the Down's Ed, I ordered a wonderful book: Teaching Reading To Children With Down Syndrome by Patricia Logan Olwein, published by Woodbine House. 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's Syndrome which encourages parents and professionals to employ visual materials as much as possible in the development of our children. And there is no doubt that this is very important. But by implication, this can suggest that children with Down's 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's 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's Syndrome, h/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 programmes, which I produced for nursery and primary school children aimed at 4-6 year-olds. Each programme is in three 5-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. She has a wonderfully expressive face with a mouth and tongue which 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 practice 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!

Down's Ed has recently produced a large folder entitled ISSUES AND INFORMATION, covering all aspects of development of children with Down's 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 paediatrician, who is involved with Down's Syndrome Scotland. 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. 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, we 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. (The Hanen organisation also runs, for example, a programme for parents whose children have Autism Spectrum Disorder, and training in Speech and Language Therapy.)

Galina is now 3 years and 8 months. She is speaking in two and three-word phrases, and occasionally in four and five word sentences. She is also beginning to use different tenses. "Gana (her name for herself) jumped off Daddy's arm," was a new utterance a few days ago, 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 — "bu-tter-fly," "win-dow," etc.

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 — 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.

(Gerda Stevenson, January 2002.)

#### **WORD LIST**

The following is a list (with a short introduction) which I made 8 months ago, when Galina was signing a lot, as a bridge to speech.

Galina's current words (185) signed and/or vocalised — April 2001. Age 3 years.

Galina signs as in SIGNALONG, (which is sign supported English). As explained earlier, she occasionally uses BSL (British Sign Language).

Galina is now beginning to put more words together, and is beginning to drop signs, although she still uses many. Her word combinations are attempts at sentences such as: "Mum book knee Eeneh", meaning "Mum read a book to Galina, who will sit on your knee."

GALINA'S 185 words, vocalised and /or signed. [v = vocalised, s = signed]

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Galina — v & s (says eeneh, points to self)
                                                        broccoli — v (says colli )
Mum — v (says Mum, & mummy)
                                                        bubbles — v & s (says ba-ba, and signalong)
Dad — v & s (says Dad, & Da -y; signs letter F —
                                                        buggy — v (says bug)
father)
                                                        buttons — v & s (says buh, and signalong)
Rob — v (says ob )
                                                        bye-bye — v & s (says bye and waves)
Lucky — v & s (says cky, signs 'dog')
                                                        cake — v (says cake )
apple — v & s (says apa, and signalong)
                                                        car — v & s (says car, )
baby — v (says baby )
                                                        cards — v (sayscards)
back — v & s (says back, and points to back)
                                                        cat — v & s (says maow and signalong)
badger — v & s (says baah, and signs stripes on eyes)
                                                        chair — v & s (says chair and signalong)
                                                        chin — v & s (says chi and points to chin)
bag — v (says ba)
bagpipes — v & s (says ba-pa, signs playing chanter)
                                                        clock — v & s (says cochk, and signs her own tick-
bake — v & s (says bake, signs mixing cake in bowl)
                                                        tock sign)
ball — v & s (says baw, and signalong)
                                                        clouds — v (says couds )
bark — v (says bark)
                                                        coat — v & s (says coh and signalong)
bath — v & s (says bath, signs splashing)
                                                        counting — v & s (says two, fee, four, fav, though not
bear — v (says bear )
                                                        always in that order (!) and points to similar objects or
bed — v & s (says be, signalong, same as sleep)
                                                        holds up fingers)
bee — v & s (says bee, and signs 'flowers' — her
                                                        cow — v & s (says cow )
                                                        crocodile - v & s (says kile, and signs jaws smacking
associative logic)
bib — v (says biff )
                                                        with both hands)
big — v & s (says big, and signs arms out wide)
                                                        cry — v (says cwy )
bike — v (says bike )
                                                        crying — v (says cywi )
                                                        dark — v & s (says kark, and signalong)
bird — v & s (says too-too, and signalong)
biscuit — v & s (says bist, and signalong)
                                                        David — v & s (says vay, and signs a letter 'd')
blue — v (says boo )
                                                        day — v & s (says day, and sigs arms semi-circle
boat — v & s (says boa, signalong)
                                                        dog — v & s (says goch — like loch, and signalong)
boo (as in peek-a-boo ) — v & s (says boo, and signs
hands over eyes)
                                                        door — v & s (says door, and signalong)
book — v & s (says book, and signalong)
                                                        down — v (says dow)
boots — v (says boos )
                                                        dress — v (says dess )
bottle — v & s (says bo, and signalong)
                                                        drink — v (says dichk)
bounce — v (says bow )
                                                        drum — v & s (says duh-duh and signs playing drum,
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beating with two drum-sticks)
                                                       kiss — v (says kiss )
                                                       knees — v & s (says knee, and points to knees)
duck — v (says quack)
ears — s (points to ears)
                                                       kneeling — v (says kneeli )
eat — s (signalong)
                                                       Leo — v (says Eeo )
Eeyore — v (says Eeyaw )
                                                       light — v & s (says aas, and signalong)
Eilidh (Gaelic name pronounced Aylie ) — v & s (says
                                                       me — v (says me )
                                                       Miles — v (says Miwes )
Aylie, and signs)
Emily — v (says Elily )
                                                       milk — v (says michk)
eyes — v & s (says eyes, and points to her eyes)
                                                       monkey — v & s (says mmm, and signs monkey wav-
elephant — s (signs elephant's trunk)
                                                       ing arms)
                                                       mouse — s (says mouse, and bsl sign — index finger
fire — v & s (says fiye, and signalong)
fish — v (says fis, )
                                                       to side of nose)
flower — s (signalong)
                                                       moon — v & s (says mmm, and signalong)
fork — v (says fochk )
                                                       my — v (says my )
fox — v & s (says foss and signalong)
                                                       neck — v (says eck )
frog — v (says fochg )
                                                       no — v (says no )
giraffe — v (says faff )
                                                       nose — v & s (says nose, and points to nose)
go — v (says go )
                                                       off — v (says off )
gone — v (says goch )
                                                       oh dear — v (says oh dear )
granny — s (signs double 'g')
                                                       olive — (says ov or vol)
grandad — v & s (says ga-ga, and signs 'g' then 'd')
                                                       orange — s (signalong)
green — v (says gee)
                                                       owl — v (says ow )
                                                       pants — v (says pass )
ground — s (bends down and touches the ground)
grass — s (signalong)
                                                       pasta — v (says pa st)
guitar — v (says tar, and sometimes guitar )
                                                       paw — v (says paw )
hair — v (says air )
                                                       peas — v (says peas )
ham — v (says am )
                                                       phone — v & s (says pho, and signalong)
hands — v (says ads, and points to hands)
                                                       pee — v (says pee — toilet)
hat — v & s (says at, and signalong)
                                                       piano - v & s (says dao, and signs playing up and
hedgehog — s (bsl sign — like a fan of spikes)
                                                       down keyboard)
hello — v (says ello )
                                                       pig — v & s (says pig, and signalong)
hen — s (signs hens wings, like chicken dance)
                                                       Piglet — v — (says Pigluh )
hide — s (signs peeking from behind hands)
                                                       piggy-back — v & s (says back, and points to back)
honey — v (says uhney )
                                                       pillow — s (signs both hands above shoulders, fin-
horse — v & s (says hoss, and signalong)
                                                       gers and thumb feeling softness, bsl)
hot — v & s (says oss, and signalong)
                                                       pink — v (says pichk )
house — v (says ouse)
                                                       play — v (says play )
hungry — s (signs same as sign for eat: fingers to
                                                       please — v (says pease )
mouth)
                                                       plum — v (says pluh )
hurt — s (points to 'sore' bit — usually pretending,
                                                       Pooh — v (says Pooh, as in Winnie The)
and puts on a petted lip! I think it's a new game.)
                                                       poo (as in toilet) — v (says poo, and also cache
is — v (says is )
                                                       — Gaelic for poo )
Isabel — v (says bella )
                                                       pup — v (says pup )
juice — v (says joo )
                                                       purple — v (says puhpuh )
Keiko — v (says Keiko, Japanese doll's name)
                                                       push — v (says puss )
key — v & s (says key, and signs turning key)
                                                       rabbit — s (signalong)
                                                       rain — v & s (says way, and signalong)
kick — v (says kich)
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rice — v (says wye )
                                                       swing — v & s (says wheee! and signs swinging back
red — s (signs index finger to bottom lip)
                                                       and forward)
run — v & s (says wuh-wuh, and signs arm move-
                                                       soup — v & s (says poos, and signs spooning energet-
ment as when running)
                                                       ically into mouth)
                                                       tail — s (signs tail wagging with right hand)
same — v (says muss )
scarf — v (says carf )
                                                       tea — v & s (says tea, and signs drinking with pinkie
sea — v (says sea, )
                                                       finger in air — elegant!)
sheep — v & s (says baa-baa, and signalong)
                                                       teeth — v & s (says teeth, and points to teeth)
shoes — v (says oos, )
                                                       thank-you — v (says kaa-oo )
Simon — s (signs letter s )
                                                       thumb — s (waggles thumb)
                                                       toes — v & s (says toes, and points to toes)
sleep — v & s (says peep, and signalong, same as
bed)
                                                       toast — v (says toas)
snake -v & s (says sss, and signs forked tong snaking
                                                       tomato — v (says taao )
along)
                                                       tree — v & s (says kee, and signalong)
sock — v (says osk, sometimes koss )
                                                       trousers — v & s (says too-doo, pointing to each leg
Sophie — v (says Phee )
                                                       in rhythm with sound)
specs — v (says pess )
                                                       umbrella — v (says bella )
                                                       up — v (says up )
splash — v & s (saysplass, and signs splashing — great
                                                       van — v (says va )
enjoyment!)
stairs — v & s (says tais, and signs hands flat, one on
                                                       vest — v (says vess)
top of another, getting higher)
                                                       water — s (signalong)
star — v (says taa )
                                                       white — v (says whice )
stick — v (says kik )
                                                       yellow — v (says lello )
stone — v & s (says tone, and signalong)
                                                       yes — v (says ess )
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#### UPDATE



I wrote the above article 2 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. I am aware that I couldn't possibly compile a list of Galina's current vocabulary, since it is now so extensive. 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 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. And she can

also express abstract thought: a couple of months ago, she was settling down to watch her Pinnocchio 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 therapist — the fourth — has willingly worked with our SYMBOL UK target plan (updated by the SYMBOL UK speech 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 therapy programme for a week.

Galina attends the local school, where she is in Primary I, 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. But I was 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 educational psychologist wisely advised us to send her into Primary I along with her peers. Her wonderful class teacher put in a huge amount of work — outwith school hours — to prepare for Galina's entrance into Primary I. Among other material, I have supplied her with Stephanie Lorenz's invaluable publications on inclusion, and the inspiring book WORKING WITH HANNAH, available through the Down's Ed Trust. We are very aware of the potential pitfalls — communication difficulties can lead to antisocial 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 the opportunities for Galina 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.

Galina is continuing to read with enormous enthusiasm. She enjoys painting, is very good at colouring in, and is attempting to write.

The latest development is that Primary I 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.

Gerda Stevenson, January, 2004.

#### LIST OF CONTACTS

Down Syndrome Educational Trust, The Sarah Duffen Centre, Belmont Street, Portsmouth, Hampshire, PO5 INA.

Tel: 023 9285 5330 Fax: 023 9285 5320

E-mail: enquiries@downsed.org

Web Site: http://www.downsed.org/

The following items numbered 1-7 can be ordered through the Down Syndrome Educational Trust. They have an excellent catalogue, which is worth ordering first.

- I) THE DEVELOPMENT OF LANGUAGE AND READING SKILLS IN CHILDREN WITH DOWN SYNDROME, by Sue Buckley, Maggie Emslie, Gilly Haslegrove and Pat Le Provost, published by the University of Portsmouth and the Down Syndrome Educational Trust, Portsmouth.
- 2) ISSUES AND INFORMATION, a large ring-binder folder with inserts covering all aspects of development of children with Down's Syndrome, divided into different age-groups. I ordered the 0-5 years folder. This is a really very valuable source of information, well presented and accessible.
- 3) The Down Syndrome Educational Trust Sound Cards
- 4) Teaching Reading To Children With Down Syndrome by Patricia Logan Olwein, published by Woodbine House.
- 5) Video: Understanding Down Syndrome (2) Learning to Read, (PAL VHS), a video tape in which Professor Sue Buckley explains the research on reading development in children with Down Syndrome, much of it carried out by herself and colleagues since 1980. Teaching methods are illustrated by children with Down Syndrome.
- 6) Winslow Press Verb Cards.
- 7) Winslow Press Verb Tenses.

Note: The Winslow material can also be purchased through Winslow Press itself: address, phone and e-mail listed below in Hanen Program section.

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The SIGNALONG Group, (enquiries to Michael Kennard, Secretary),

Communication and Language Centre,

Historic Dockyard,

Chatham Maritime,

Dock Road,

Chatham,

Kent,

ME4 4TZ.

Tel: 01634 819915.

I ordered Phase I and Phase 2, and their Foundations — Learning Through Exploring And Creating, directly from Signalong.

Signalong will also provide a list of contacts who are running Signalong courses in, or near your area.

SYMBOL UK — Specialist Speech Therapy for children with speech disorders across the spectrum of disabilities. SYMBOL UK offers training, therapy & consulting. Services include:

- \* Weekly group/individual therapy; arranged with groups of families
- \* Training workshops for parent/school/staff/others involved
- \* Intensive Therapy holidays in the summertime in Devon
- \* Assessment/reports to contribute to the statementing process (in Scotland this is termed the Record of Needs process), at the request of parents or LEA's and reports for annual review
- \* School visits; one off, for advice or training, or regular, to support staff in drawing up and monitoring speech and language therapy targets in Individual Education Plans

(Symbol UK address on next page)

SYMBOL UK.

Woodlands Farm,

Paddlesworth Road,

Snodland.

Nr. Maidstone,

Kent.

ME6 5DL.

Tel: 01634 244000 Fax: 01634 244074

E-mail: duffysymbol@cs.com

Stories In The Air (story-telling group for the deaf community). This group has run courses in signing books

for toddlers, and is currently making a video to support this work. Contact:

Thelma Petty at Donaldson's School for the Deaf:

Tel: 0131-337 -9911

Learning Development Aid, Product Development, LDA,

Abbeygate House,

East Road,

Cambridge,

CBI IDB.

Tel: 01223 357744 Fax: 01223 460557

Orderline telephone: 01945 463441

I ordered the following items from LDA: (They have an excellent catalogue.)

- 1) WHY? BECAUSE cards, to practice the skill of critical thinking.
- 2) Molly. A characterful puppet, who has a wonderfully expressive face with a mouth and tongue which can be manipulated, and gloved hands, which can be used to sign.

The Hanen Program, 1075 Bay Street, Suite 403,

Toronto,

Ontario, Canada, M5S 2B1.

Tel: (461) 921 1073 Fax: (416) 921 1225 E-mail: info@hanen.org Website: www.hanen.org

You can purchase the book "IT TAKES TWO TO TALK" (which accompanies the Hanen course) through:

WINSLOW, Goyt Side Road, Chesterfield, Derbyshire, S40 2PH.

Tel: 0845 921 1777 Fax: 01246 551195

E-mail: sales@winslow-cat.com

MAKATON DEVELOPMENT PROJECT,

Tel: 01276-61390

Video: Makaton Nursery Rhymes: action songs and signed nursery rhymes, presented by Dave Benson Phillips — extensive use of signing in this video. It doesn't matter that the video is presented in Maketon if you're doing SIGNALONG — they are very similar, and easy to adapt from one to the other.

YOGA for the SPECIAL CHILD, by Sonia Sumar (a user-friendly book).

A Therapeutic Approach for Infants and Children with

\* Down Syndrome

\*Cerebral Palsy

\*Learning Disabilities

Publisher's address:

Special Yoga Publications,

Route I,

Box 1559,

Buckingham,

Virginia,

VA 23921,

USA.

Tel: (804) 969-2668 Fax: (804) 969-1962

E-mail: Info@specialyoga.com Web: www.specialyoga.com Developmental Dysphasia Foundation,

Stichting Dysphatische Ontwikkeling,

Apollolaan 68, NL-1077 BD Amsterdam.

Tel: +31+(0)206791758

The Developmental Dysphasia Foundation is a non-profit organisation.

Their assessment and treatment team include:

- \* a child psychiatrist
- \* a child neurologist
- \* speech therapists
- \* occupational therapists
- \* a psychologist

The following is an extract from the Developmental Dysphasia Foundation leaflet:

Indications for referral:

#### I. Abnormal speech development:

Whenever parents describe their child as having 'delayed' speech, developmental dysphasia should be seriously considered in the differential diagnosis. When parents remark that the child seems to understand their language, yet does not speak, (or hardly), this may point to developmental dysphasia. A child who at the age of two does not speak a single word, has an abnormal speech development.

#### 2. Developmental Dysphasia:

Developmental Dysphasia is a syndrome in which development of speech in the child is disturbed, while deafness or gross cerebral damage can be excluded, and functioning of the speech musculature in general is unimpaired. Frequently the clinical picture is complicated by secondary impairment of intellectual and effective development. Complex motor problems (dyspraxia) are also frequent associated factors.

Down's Syndrome Scotland, 158/160 Balgreen Road, Edinburgh, EHII 3AU.

Tel: 0131-313-4225 Fax: 0131-313-4285.

The Institute For Neuro-Physiological Psychology (Scotland), 2 Stoneycroft Road, South Queensferry, West Lothian, EH30 9HX.

Tel: 0131-331-4744 e-mail: INPP@ic24.net