

Jane's education

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Jane has Down syndrome, oral dyspraxia and a small hole in her heart. She had, when last tested before entering primary school, an average IQ and her understanding of language has always been at least age appropriate. The development of her speech has been delayed and has caused problems throughout her education.

Jane is my granddaughter. Before Jane's first birthday I had been to The Sarah Duffen Centre in Southsea, the home of The Down Syndrome Educational Trust (DownsEd). I had worked as a SENCo in a main stream primary school where we had pupils with Down syndrome but until Jane was born I had never heard of The Sarah Duffen Centre. Following the advice given by DownsEd Jane was taught to sign from an early age using Makaton.

Jane's pre-school education started shortly after her birth with Portage. Jane was 'taught' by her mother as she followed the guidance given by Jane's Portage worker, Speech and Language Therapist and Occupational Therapist. At the age of three she started nursery school, both state and private.

The state nursery school had enhanced staffing, with a member of staff who was fully trained in signing and who was responsible for a group of up to four children with SEN. Jane was the only child in the group for some time. All the staff could sign so Jane quickly became a

fully integrated member of the class. The only problem was that the nursery was not in the same area as the primary school which Jane would attend. To ensure that she remained in contact with the children she had grown up with at play-school, she also went to the local private nursery for two sessions a week. Again she had her own support worker and again all the staff could sign.

Starting Primary school

The transition to primary school was preceded by formal assessment and a statement was issued. This enabled the school to put in place the necessary staff for full time support by a trained Makaton signer and, at a later date, lunchtime support. The SENCo from the primary school attended a review meeting at the nursery and observed Jane for a few minutes. The reception class teacher did not visit the nursery, and the LSA was not released for such a visit, but visited in her own time. During the summer term Jane had weekly, half-day visits to the school to ensure that she was familiar with the surroundings and staff. Her mother supported her on these visits and although Jane met her class teacher her LSA was never released to spend time with her.

On her entry to primary school Jane had almost no spoken language but communicated very well through using Makaton. Receptive language was

age appropriate. She brought in her wake a Speech and Language Therapist (SALT) and an Educational Psychologist (EP) each offering advice. The Occupational Therapist (OT) began visiting Jane in school towards the end of the reception year. There was limited knowledge within the school about Down syndrome and none of the staff felt it necessary to learn to sign.

Within a few weeks of entry I was asked if I could give any advice. There had been a change in staff in the Psychology Department, which left the school without an EP. The previous EP had stated that Jane had covered all her pre-reading skills and there was no reason why she should not start reading. We were aware that her lack of speech may cause a problem and had carefully selected reading books that would be of use, books that could be signed. These books, together with other useful materials, were given to the school to use with Jane. As Makaton is a support to language you always speak as you sign. Jane also 'spoke' as she signed, but it was the signing which revealed her understanding. As the LSA was the only person who could sign she appeared to become increasingly responsible for Jane's education. Too much responsibility seemed to be placed on her and she was never given any appropriate training.

Throughout the reception year I visited the school to talk to the SENCo, the class teacher and the



LSA. There were many instances when Jane would not display the same level of ability in school that she did at home. On such occasions I would work with Jane in school while members of staff observed. Fortunately Jane always worked well with me and we were able to give the staff some proof of what she could do. However, this had limited success since Jane often refused to work for the LSA and would be taken to various members of staff, such as the SENCo or the Headteacher, for being 'naughty'. Such punishment had little effect on her; she was getting away from her classroom and her work. She could have seen these punishments as a reward.

She was quickly gaining the label of a child with problem behaviour. Perhaps if the class teacher could have used Makaton such

problems would not have arisen. It was suggested that Jane worked for rewards. Initially this suggestion was rejected but later tried. It had limited success since the rewards were not negotiated with Jane and were not viewed as rewards by her. It was more rewarding for her to watch the staff get annoyed!

To try to maintain Jane's learning her parents found a teacher who specialised in teaching dyspraxic children and also had experience of children with Down syndrome. This was a success, as the teacher soon realised how manipulative Jane could be and was able to work with her on the appropriate level of work. Her tutor became a great support for Jane's learning and also for her parents. Jane continued to learn at home and the discrepancy between her achievements at home and school continued to widen, even though her tutor had offered to work with the school. Her mother began to feel that she had been labelled as a 'pushy parent' and that her knowledge and experience were not valued as she was not a teacher. This was both frustrating and upsetting but Jane was making progress, was happy at school and her social development was fine.

Missed opportunities

Towards the end of the year the EP had become involved and it was suggested that a teacher from the special school meet Jane and her LSA. As a result of the initial meeting it was suggested that both Jane and her LSA would spend one half day, each week for five weeks in the special school, with Jane working with an appropriate group of children. Only one of these visits took place. One of the reasons which was given was that the school could not afford the

transport; in reply Jane's parents offered to pay for taxis or to use their own car. This offer was refused.

Communication on a daily basis was done through a home/school book. This was maintained as Jane was unable to tell her parents what she had been doing at school. Its use should have been to keep the parents informed and enable them to discuss, with their child, what had been happening. It was filled in by the LSA. The LSA was also delegated to receive the child at the beginning of the day and to hand her back when school finished. No parent wants to be confronted with a list of their child's wrong doings. Negativity is not going to help the parent, the child or the relationship between the home and school.

A further issue arose when the LSA was ill. There was no one with whom Jane could communicate effectively. There was another LSA in the school who could sign but she was never used to cover for absence. On one occasion, whilst the LSA was not in school, there was an instance of 'bullying'. Jane would come in distressed after play and no one was able to get to the bottom of the problem. Once the LSA returned to school, the problem was solved, Jane told her what had been happening and it was dealt with. With that wonderful thing referred to as 'hind sight' it would have solved many problems if two LSAs had shared the post.

Noticeable improvements

At the beginning of Year 2 there was a sudden improvement in Jane's behaviour. The class teacher saw signing as an essential to enable her to work with Jane. A weekly, ten-minute meeting was also arranged to enable

Jane's education

the class teacher and parents to pass over information. The help that had been offered by the private tutor was welcomed. There began to be a closer working partnership between home and school and the frustration and anxiety that the parents had suffered for two years began to subside.

By this time the responsibility for Speech and Language Therapy had passed from the health authority to education. The programmes were set as usual but suddenly access to information was denied to the parents. SALT now only worked with the child and the school, whereas previously the information and programme of work had been given to both the parents and the school. The programme of therapy that was to be delivered daily was not shared with the parents. The result was that during school holidays, at weekends and when the LSA was ill Jane received no speech therapy. As Jane's speech had always been a major issue this became a cause for concern. The problem was never resolved.

At the beginning of the summer term Jane began to receive two hours a week, school based additional tuition (SBAT) delivered by a specialist teacher. The specialist teacher gathered information from both parents and the private tutor. Jane was no longer able to avoid working in school. The SBAT teacher soon discovered that Jane could be very manipulative when she decided that she didn't want to work. She knew exactly how to convince people that she could not do things, that the work was too hard and that she didn't understand it. She had been perfecting these skills for the past two years.

It has taken almost 3 years of constant stress for the parents to establish some true meaning to the words 'parent partnership'. There can be no doubt

that the decision to send Jane to a mainstream school remains the correct one, but many of the problems which have arisen could have been avoided with more effective communication. I have come to understand why many parents of children with Down syndrome choose to send their children to special school for their secondary education. The choice between mainstream and special school can appear to be a choice between socialisation and acceptance within the community and appropriate education. The knowledge and expertise which does exist is not easily accessible to the mainstream school.

It was not until Jane was born that I began to fully understand the enormous strain that having a child with SEN puts on a family. It is so easy for small misunderstandings to grow out of all proportion, to cause sleepless nights and tears of frustration and helplessness. It is so difficult to maintain some semblance of normal family life, for the sake of the other children within the family, without the added strain and exhaustion of having to constantly fight for your child's right to an appropriate education.

Jane is happy, mischievous, determined, devious and surrounded by friends and people who care about her. She is learning to read, write and work with number. Her academic achievements are now behind those of her peers, but that was always expected. With the differentiation of her work Jane will be able to continue to learn, and hopefully continue to stay with her friends. Her social development and her ability to communicate are more important than academic achievement. Even when she could not talk she usually managed to make herself understood. She has always initiated conversations, originally by using Makaton, but in recent

months her speech has improved so much that she can often be understood by those who know her, but Makaton will still remain essential to her further development.

In many ways Jane is just like any child of her age. She enjoys swimming, Brownies, dancing class, gym club and going to school. Her achievements are those of the many people who have helped her since her birth and have supported her and her family throughout her life.

My sincere thanks go to all such people.

Despite this 'tale of woe', Jane is making progress in academic subjects and she is well integrated into the school community. Her academic achievements are a result of the efforts made by her parents and her tutor, but this is not the reason why I have chosen to write this article. Jane is fortunate that she has both a mother and a grandmother in education, as they have been able to make up for the limited knowledge within the school and maintain the constant battle to attempt to ensure that she has the academic education to which she is entitled. At a recent conference, run by Sue Buckley and her team from DownsEd, it became apparent to me that many parents are, quite naturally, concerned about the education which their children are receiving but may I suggest that one of the main factors



which should be constantly considered is that such children have a slower rate of development. There is time, lots of it, for these children to achieve their potential and the concern about their education should not overshadow the great pleasure and satisfaction that there can be in watching and taking pleasure in this slower pattern of development. Every small step in the right direction is celebrated with joy and relief. Please do not waste this precious time by becoming over concerned about the rate of progress that your child is making. It is a fine balancing act, but there is the knowledge and support available for parents, it sometimes just takes time and effort to access it. I feel that I am possibly 'preaching to the converted' but do try to stand back and enjoy their childhood, and share your experiences with other parents who may benefit from your knowledge and support.

My thanks go to all the people who work so hard to make the knowledge which we require available to us and to ensure, through their work and support, that our children can have the care and support which they deserve.

To finish on a positive note, the hole in Jane's heart has finally healed and with a new headteacher in place, and intervention and support from the LEA there are now strategies being put in place to address some of the issues which have caused so much concern for Jane's family. Her speech, as predicted by the speech and language therapist several years ago, has improved with amazing clarity and speed over the past twelve months. We were advised that she would not have any 'useful' language until she was 10, she celebrated her tenth birthday last weekend.

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National Examinations 2006: Entry Level Passes in GCSE Year!



Congratulations to sixteen year old Charlotte Horner, who sat National Examinations in her GCSE year at Entry Level and passed Entry Level 1 for Mathematics and Science, Entry Level 2 for English and Food Technology and a GCSE pass for Art.

Charlotte's work experience and Prom night were featured in the last issue of *Down Syndrome News and Update*.

Charlotte is now at Yeovil College in Somerset and has settled into her daily routines. She continues to study basic skills in more practical ways and is also learning about skills for life. She has also enrolled on the Drama Course and is playing a 'detective' in her first play.