

Down's syndrome and autistic spectrum

Diagnosis of Autism Spectrum Disorder (ASD) is far from straightforward, even in cases when there is no other condition present. When the child also has Down's syndrome, parents have often struggled to obtain a diagnosis, faced with professionals insisting that their child's behaviour was an inevitable consequence of the syndrome. Fortunately these problems are lessening, as dual diagnosis is now reasonably well documented.

However, having obtained the diagnosis, what then? There is currently a shortfall in information about the very particular needs of this group. Much of the information available to us has so far focussed on diagnosis. It is often said that once autism is identified, it becomes the 'primary diagnosis', at least as far as education is concerned. The National Autistic Society has a wealth of excellent information about education matters.

Nevertheless, we hear from parents that they feel stranded, fitting in neither with the local Down's syndrome group, nor with local autism groups, and that our 'standard' Down's syndrome information does not apply to their child.

We do recognise that we are still not doing enough to meet the needs of this group of our members. As a step in the right direction, the DSA with the help of DownsEd International have set up an email group for parents and those with a professional interest in dual diagnosis DS/ASD. The group currently has just over 70 members.

To subscribe to the new email group send an email to: LISTSERV@listserv.down-syndrome.net with **SUBSCRIBE DS-AUTISM-UK** in body of message or go to: <http://listserv.down-syndrome.net/SCRIPTS/WA-DOWNS.EXE?A0=DS-AUTISM-UK> and follow instructions.

We would like to hear from you via the DS/ASD email list if you are a family carer of a person with Down's syndrome and ASD. What are your experiences? What advice or support have you found helpful, and where are the gaps? What advice would you give to other people in the same situation?

If you do not have access to the Internet, we would love to receive your input via the post (c/o Stuart Mills, Information

Office, DSA). We are holding an informal meeting for parents whose children have DS/ASD at the DSA on Sunday 27th September. Please contact Stuart at stuart.mills@downs-syndrome.org.uk if you wish to attend.

Kayte Brimacombe's son Gabriel has dual diagnosis. He featured in our Shifting Perspectives exhibition in 2005 and 2006. Here is an extract from her article taken from this years' Shifting Perspectives booklet.



'Gabriel was born at home after a rapid labour on 6th December 1995. We were so overwhelmed and excited by his arrival that we dismissed as routine the midwife's suggestion that he may have Down's syndrome. After our first magical night with him

we followed advice and took him to hospital. He was officially diagnosed. We were devastated but there was more news to come, we were told Gabriel also had a heart defect. The brutal fact that his life was at risk helped us to put his learning disability into perspective. Down's syndrome no longer seemed such a big deal. Gabriel had open heart surgery at 3 months and although it was a traumatic experience for us all, he soon recovered. In the following months Gabriel seemed to be developing well for a baby with Down's syndrome. He passed all his early milestones – sitting up, crawling and then walking within 18 months. I remember feeling full of pride when a paediatrician remarked that he was the brightest infant with Down's syndrome he had ever seen. I took Gabriel to our local baby groups and he seemed to enjoy the other children. He laughed readily and took to Makaton



disorder/dual diagnosis

signing (often used as a stop-gap when speech is delayed) with ease. He breast-fed ferociously and would ask for more. Words were starting to come; I have him on video saying Mama and Dada asking for his favourite toys. Gabriel loved music and he would request his favourite songs imitating all the actions. He would wave goodbye and blow me a kiss. Life with Gabriel was fun and his future looked bright.



Sometime after his 2nd birthday things started to change. We noticed his eye contact dropped off and he developed obsessive rituals. Gabriel's development started to plateau then regressed. We were desperate to find out what was going on for

Gabriel and eventually came across some information about dual diagnosis on the internet. As I read Joan Medlen's article 'More than Down Syndrome' in the September 1999 issue of 'Disability Solutions' I realised Gabriel could also have autism. He was finally diagnosed with autism at 4 years 9 months. By now he had a little sister, Grace. Gabriel was attending a special school for children with moderate learning disabilities and it was clear that the staff did not know what to do with him. It became apparent that autism was his primary disability and we needed to gear his education around that. Good educational provision for children with autism is scarce and we were preparing to home school Gabriel when he was offered a place at Treehouse, the first special school for children with autism in the UK where the principles of ABA (Applied Behavioural Analysis) are applied.

Update May 2009

Gabriel is now 13 and still attends Treehouse. Initially he seemed to respond well but even maintaining what he learned has proved a struggle and at times elusive. Despite skilled and dedicated teachers he has made little progress. His communication skills are far less developed than when he was 2 years old. He remains non-verbal although he can use a sign for 'yes, more, help' and a card for 'No' which he carries on his waistband.

He now has another little sister, Lily, who is 4. His teenage years are proving to be the most turbulent for the whole family. Gabriel has a further diagnosis of ADHD for which he is on medication. He has no sense of danger and has to be watched constantly. He still needs less sleep than us. His self-help skills are severely delayed and we are still working on toilet training, eating and dressing. When Gabriel turned 12 his long-standing tendency to hit his head changed into quite extreme self-injurious behaviour. His moods can change dramatically from one minute to the next. At school he is frequently restrained for his own safety and at home we often have to use a soft-helmet to prevent tissue damage. Reducing his challenging behaviour has become our main priority. We are in a long-standing battle with our local authority for appropriate overnight respite to support the whole family. We are told he could go to residential school (at vast expense to the LEA) but that is not what we want, we just need more support to enable us to carry on caring for him at home. There was a time when Gabriel's autism seemed like the enemy, now it seems as though social services are.



I no longer think about wanting my little boy with 'just' Down's syndrome back. I am now focusing on how I can make sure that each day brings him some joy, that he has the best possible quality of life. He still loves water: be it splashing in

the shower or going swimming. He enjoys horse riding and swinging on his swing with his sisters. He loves to cuddle up and read his favourite books with us and dance to music. Above all I want him to stay with his family where he belongs. My journey with Gabriel has brought me to a place of acceptance I could never have imagined. For all Gabriel's complex challenges I only have to see his enormous smile each morning to be reminded to live in the moment as he does. When Gabriel does learn something new, such as pulling on his socks, as he did this year, I am moved to tears. Gabriel has given me the opportunity to discover what it really means to love unconditionally. I will continue to do all I can to be the best advocate for my son'.

