



Dual Diagnosis Forum

By Vanda Ridley, Communications Manager, Down's Syndrome Association

The DSA holds a meeting twice a year for parents of children who have dual diagnosis of Autism Spectrum Condition/Down's syndrome (ASC/DS) or who feel they would like to know more about this area.

Each meeting has an expert guest speaker providing information in the management and understanding of the condition. The meetings are an opportunity for people to get together, share their experiences and make new contacts.

Many of the parents who attend also belong to an on-line forum which helps provide the direction of future meetings. The forum is a place where parents and carers of children with ASC/DS can talk about any issues that concern them and get advice from each other. Details of how to join can be found on the Dual Diagnosis page of the DSA website.

In October 2013 Gill Bird, the DSA's developmental psychologist, gave a presentation which explored current thinking in regard to behaviour management and offered some practical solutions. Some of the issues raised were; how to support positive behaviour, developing communication skills, offering choices, play and leisure skills, setting expectations and rules, social stories and teaching and learning activities at school. Gill's presentation can be found on the 'Dual Diagnosis' page of our website.

In April this year we were lucky enough to welcome Professor Jeremy Turk to the DSA National Office to talk to parents about the use of medication in supporting behaviour. Professor Turk is a Consultant Child and Adolescent Psychiatrist at the London and South Maudsley NHS Trust and a Professor of Developmental Psychiatry at the Institute of Psychiatry. He is passionate about the mental health needs and welfare of children and young people with learning disabilities, and also those of their families.

Professor Turk spoke about when medication might be useful and emphasised that it should never be the first step in tackling a behaviour issue. Medication should only be considered once positive behaviour intervention strategies have been tried. He went on to say that once a decision has been taken to use medication this must not be in isolation. Everyone involved must continue to work together in supporting the young person's behaviour (family, school, social care, carers, health).

Professor Turk also sought to dispel some of the concerns held around medication by highlighting the targeted and refined nature of current medications now available, compared to the 'blunt instruments' such as Valium which were widely used in the past.

One of the major benefits of the ASC/DS meetings is for parents to meet together and share their experiences. There were many lively discussions throughout lunch and the chance to share information at our refectory table in our wonderful, newly refurbished, basement area (thanks to the support of Morgan Lovell).

It was obvious from some of the conversations taking place that a dose of humour coupled with inventiveness played a big part in helping parents to deal with some challenging situations.

After lunch DSA staff asked parents to share their experiences of supporting positive behaviour in their children. Some parents had brought along communication resources which had helped their children to make choices and to express their wishes.

People attending raised a number of subjects they would like to see at future meetings including preparing for adulthood, communication, meeting sensory needs and diet. Gill Bird will be addressing communication at our next meeting on 4 October 2014. In addition, Dr Parr, Clinical Senior Lecturer/Hon Consultant at the University of Newcastle and Dr Newall will be talking about their research looking at the range of ability and numbers of children with Down's syndrome who also have atypical behaviour and whether screening between the ages of three and five can indicate ASC in children with Down's syndrome.

Dr Parr also leads the Autism Spectrum Database-UK, which is a database of families of children with ASC, who have shown interest in participating in research.

If you would like to find out more about the Dual Diagnosis Forum, future meetings or the condition itself please look at our website or contact info@downs-syndrome.org.uk and one of our information officers will get back to you.

Speaker confirmed for 2015:

Saturday 18 April 2015 – Paul Isaacs (Autism Oxford) talking about living with autism.

Please email stuart.mills@downs-syndrome.org.uk if you would like to attend.

