

Focus on Dual Diagnosis: Information, Research and Experience

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The DSA has recently begun a series of focus meetings for parents who have children with a dual diagnosis of Down's syndrome and Autism Spectrum Condition (DS/ASC).

These meetings are designed to be informative for parents, with experts in the field sharing research and information, and an opportunity for parents to share their own experiences and network with one another.

The first meeting was held on the 5 October and was successful, with positive feedback from attendees.

The session was attended by 18 parents and 3 DSA staff: Gillian Bird, Stuart Mills and Vanda Ridley. Gillian started the morning with a presentation that gave an overview of autism and interventions; what is currently known about DS/ASC; an overview of current thinking around children with Down's syndrome; interventions for supporting social development and positive behaviour; and communication skills and how best to support these in the child's environment.

The second part of the session gave parents an opportunity for discussion. Parents shared with each other their own experiences as well as coping strategies and other practical suggestions. During this discussion, parents were also able to offer ideas about what they would find useful from the future focus meetings.

Future meetings

The DSA came away with a list of actions which included compiling a collective list of behavioural issues and resolutions, to then be shared as a general resource for parents and schools. Parents would also like to see longer sessions with more opportunity for discussion; feedback indicated that this was perhaps the most useful part of the meeting.

There was also a desire that the DSA might share new and interesting research into DS/ASC, as well as a list of useful websites and resources, amongst the group.

Further suggestions for the content of future meetings included information and advice around supporting socialisation in children who are reluctant; encouraging and supporting interpersonal skills and friendships; transition at 18+ and adult care, education and housing options; mental health and depression; health issues; eating difficulties and cleft palates; understanding autism from the perspective of the person who has autism.

Communication

Perhaps the most prominent issue that was raised by parents was around communication difficulties.

Communication is one person conveying a message, verbally or non-verbally, to another, and interaction happens when one person responds to the other person's communication.

Children with ASC may have the ability to speak or sign, read and write but find it harder to use these skills effectively to interact with others in a sociable way.

The National Autistic Society (NAS) has a useful article which gives some advice about communicating and interacting with a child who has ASC.

They suggest that it is important to observe the ways in which the child communicates, in order to identify their communicative strengths and needs, and to be able to respond to and interact with them effectively. Also important is to understand why the child is communicating. By understanding the purpose of their communication, NAS suggests that you can help them to find more ways and reasons to communicate.

The full article, 'Communication and interaction' along with others on social isolation and social skills, can be found on the NAS website www.autism.org.uk.

The next focus meetings will be on:

Saturday 5 April 2014

Professor Jeremy Turk will be coming to speak about clinical management of DS/ASC.

Jeremy Turk is a Consultant Child and Adolescent Psychiatrist in the South London and Maudsley NHS Trust's Behavioural Phenotype Learning Disabilities Service, and a Professor of Developmental Psychiatry at the Institute of Psychiatry.

Saturday 4 October 2014

Dr Georgina Warner and Dr Jeremy Parr will be coming to speak about recent research.

Georgina Warner from the Institute of Psychiatry, Kings College, London will be reporting results of a recent piece of research which attempted to identify the range of ability and numbers of children with DS who also have atypical behaviour.

Jeremy Parr is a Clinical Senior Lecturer and Consultant in paediatric neurodisability at the Institute of Neuroscience, University of Newcastle and will be reporting the findings of his research, in collaboration with the Children with Down's Syndrome Study, into whether screening between the ages 3 and 5 indicates ASC in children with DS.

If you would like to find out more information about dual diagnosis, our focus meetings or would like to join our DS/ASC email group, please visit: <http://www.downs-syndrome.org.uk/information/familiescarers/dual-diagnosis.html>

If you are interested in attending either of the above meetings, please email Stuart at: stuart.mills@downs-syndrome.org.uk

All DS/ASC focus meetings are held at the DSA national office, Langdon Down Centre, 2a Langdon Park, Teddington, Middlesex TW11 9PS.