

# Dual Diagnosis, Autism Spectrum Condition, Down's Syndrome and complex needs

By Stuart Mills, DSA Information Officer

## DSA Complex Needs and Autism Forum

We are delighted to have launched our DSA Forum for families where a family member with Down's syndrome has complex needs and/or a diagnosis of autism. This is a closed forum; a safe place for family carers to help each other, share information and ask questions. This inclusive forum is for everyone who cares for a person with Down's syndrome who has complex needs. Please note this forum is not open to professionals. Please apply to join at <http://dsadiscuss.downs-syndrome.org.uk>

## Events

The DSA held two events in the North West of England in October 2016; one was a meeting for families and the other a training day for parents and professionals. Thank you to the Bury Down's Syndrome Group for their support with the events.

## Understanding Dual Diagnosis of Autism Spectrum Condition (ASC) and Down's syndrome

### A training day for practitioners and parents in the North West

We were really pleased that we had a room packed with parents and practitioners from various health and education settings.

Geraldine White (Chartered Psychologist) gave a presentation on current thinking about dual diagnosis Autism Spectrum Condition (ASC) and Down's syndrome (DS), approaches to diagnosis, and what happens after diagnosis. This was followed by a discussion about support strategies for children with dual diagnosis ASC/DS, including how to support communication, sensory differences and behaviour.

It was heartening to hear from practitioners about the good support

they provide for children and families in their localities. There was a great deal of shared experience and the participants were very open to learning more about dual diagnosis and how to support individuals and their families/carers.

## Meeting for families in North West of England

### Dual Diagnosis Autism Spectrum Condition and Down's Syndrome

It was great to meet the parents and siblings who came along. It was a really positive day with lots of discussion, sharing of experiences and humour. We heard about parent's proud moments and the good things their children are doing.

*'Our adult daughter met the mayor and showed him around her workplace; she held her head up and she was confident'*

*'I am proud of holding a successful 8th birthday party for my daughter. It was tailored to her needs so we invited fewer children, we served her favourite food which is beans on toast, and we kept the celebration short.'*

Geraldine White talked about wellbeing in children and adults with dual diagnosis ASC/DS and complex needs. This was followed by a presentation from Jane Mitchell (Registered Learning Disability Nurse and Mindfulness Teacher) about parents recognising the pressure they are sometimes under and looking after themselves. Both sessions were very well received.

We asked for ideas as to how we can build on the work we have been doing around dual diagnosis and complex needs. The parents were keen to stress their need for contact with fellow parents. They urged the DSA to continue raising awareness of

dual diagnosis among professionals particularly those working in education and autism services.

## Meetings for families

We organise meetings for families who have an interest in ASC/DS. We try to invite a guest speaker with insight and practical experience of ASC/DS to each meeting. Families find the meetings a good opportunity to form support networks and for the sharing of ideas and experiences. Here is what parents have said about past meetings:

*'I am not alone!'*

*'Just grateful to have been a part of an interesting day with great people, listening to other's stories. Listening to groundbreaking new research was encouraging'*

*'Meeting and chatting with other parents in the same boat is so important and valuable'*

*'I was nervous about coming but the day/the group/the speakers were all very relaxed and informal. Thank you.'*

You can find out more at [www.downs-syndrome.org.uk/for-families-and-carers/dual-diagnosis/](http://www.downs-syndrome.org.uk/for-families-and-carers/dual-diagnosis/)

## Case studies and Journal articles

We are always looking for case studies about people's lives to use in our work. Parents at the Bury meetings told us they wanted to hear more positive life stories about teenagers and adults with dual diagnosis ASC/DS and/or complex needs. If you would like to contribute case studies or write an article for the Journal, please get in touch with us: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)