DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting September 2025

Topic: Sensory Issues

A parent shared how her son's sensory-seeking behaviours, such as finger chewing and flicking, help him cope. She emphasized the importance of not interfering with beneficial sensory behaviours. Another parent described challenges with her son's sensitivities, particularly around hygiene and comfort behaviours. One parent highlighted her son's issues, including preferences for cold temperatures and loud music, as well as difficulties with swallowing. Various people shared their experiences of sensory assessments with differing levels of usefulness. A parent talked about her son's recent diagnosis of CVI (cerebral visual impairment) who also has a hearing impairment and implications for sensory behaviours.

A parent shared her daughter's intense focus on colouring, flapping, and stimming, while another described her daughter's regression and increased stimming during puberty. One mum mentioned her son's recent autism diagnosis and ongoing sensory and medical challenges, including haircuts, showers, and food textures. The discussion highlighted the impact of puberty, hormones, and medical issues on sensory behaviours in children who have Down's syndrome and autism, as well as the importance of understanding and accommodating these needs.

A parent shared her daughter's struggles with sensory behaviours and regression during puberty, highlighting the challenges of managing these issues. Many parents in the group shared touching behaviours and following this there was a discussion around the importance of teaching public and private.

The group addressed a question about nail biting, suggestions including the use of a mobile manicurist, providing alternative sensory activities, and ensuring a calm environment to reduce anxiety. Parents discussed the importance of liaising with school to ensure everyone understands their child's sensory needs and what needs to be in place to enable them to feel calm and relaxed.

The discussion emphasized the importance of the issue of sensory differences and how much it impacts on the lives of people who have Down's syndrome and their families.

Enquiries jane.mitchell@downs-syndrome.org.uk stuart.mills@downs-syndrome.org.uk

Next Meeting – Tuesday 4th November 10.30am



Useful Links and resources

To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

Complex Needs Webpage

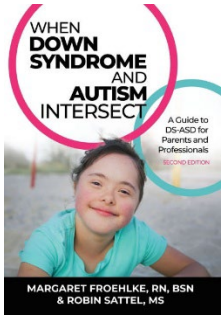
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

Complex Needs Facebook

The DSA Complex Needs and Autism Group | Facebook

Books

When Down Syndrome and Autism Intersect is available at usual booksellers



Mental Wellness in Adults with Down Syndrome – link to free PDF:

Mental_Wellness_full_book_final_2023.02.24.pdf (advocatehealth.com)

Enquiries jane.mitchell@downs-syndrome.org.uk stuart.mills@downs-syndrome.org.uk