DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting May 2025

Topic: Open Discussion/

Diagnosis of Autism

Diagnostic overshadowing – services putting autism traits down to the child having Down's syndrome, parents meeting blocks to assessment from education or autism assessment team.

Discussion around whether diagnosis is needed, point made that even if needs are currently being met diagnosis is about future proofing. A diagnosis will inform future package of care and important when parents are not around anymore. People will know what to expect when they know the person has the additional needs.

Different experiences shared by parents about processes. Inconsistency around provision depending on which local authority people are under.

Discussion around autism diagnostic process and the experience of those assessments and whether there need to be guidelines.

A discussion around how all people with Down's syndrome are different as are those with autism and representation is important, often the more able people will be the ones who are more seen and it is important to find ways to ensure there is awareness of all people who have Down's syndrome.

Parent support groups need to cater for those who have complex needs, one parent talked about introducing quiet areas and soft play.

Education

Pressures on schools and for children have increased, discussion around mainstream and special school. One parent talked about her son attending a separate unit within mainstream and this worked well as good transition and tailored curriculum.

Health transition

One parent praised the hospital transition they had had.

Another parent mentioned the option of "pending discharge" in her area

Speech

One parent mentioned reduction and change in verbal communication in her son - wanted to know if usual in teenage years, SALT had said related to autism. She will contact Gwen.

A discussion about children's tv programmes that are loved such as The Wiggles!

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

Next Meeting – Thursday 12th June 10.30am



Useful Links and resources

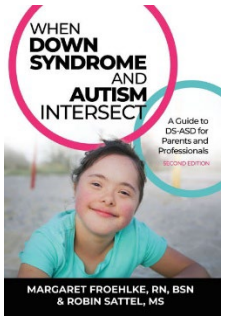
To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

Complex Needs Webpage

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

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