DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting April 2026

Topic: Accessing Healthcare

Meeting summary

We began with a parent sharing her positive experience of healthcare for her daughter with the same paediatrician and GP from birth. Another parent mentioned challenges accessing healthcare for her daughter who hasn't left the house for over a year, this has made attending appointments difficult although some health professionals have facilitated home visits. A father shared his experience with his son's communication difficulties, speech processing, severe sleep issues and the challenges they have faced with assessment, diagnosis and accessing services.

One parent talked about who is responsible for managing her son's healthcare whilst he is at residential college, he has a heart condition and if he has a temperature, he needs to be given antibiotics quickly. As advised, he is now registered with a GP near the college however he spends 13 weeks of the year back at home and mum raised issues around this situation. We discussed the importance of health needs being written into care plans so that college staff are aware and they can respond appropriately.

Another mum talked about how difficult it is having a child who is non-verbal and not able to communicate pain and illness and how she is constantly having to interpret his needs through behaviour and other signs. One parent told us about her frustration in trying to obtain appropriately sized incontinence pads through the nursing service along with difficulties in accessing physiotherapy for her son's hypermobility, gait and motor skills.

The parent of a 9-year-old told us about his sleep apnoea and not being able to tolerate the CPAP mask. They also raised the issue of ADHD, and we talked about how the presence of untreated sleep apnoea would complicate any attempt to investigate this.

General Discussion

A parent talked about the long waiting list for her son's autism assessment and her concerns about how his sociable behaviour might affect the outcome. Other parents told us about their positive experiences of assessment and they highlighted the skill and knowledge of the assessors. Another referenced the book '*When Down syndrome and*

Autism Intersect' in which it mentions that autism symptoms can be masked in people who have Down's syndrome. Jane and Stuart flagged up DSA's webinars about autism.

Next Online Meeting



Tuesday 2nd June 10.30 - Midday

In person meeting Monday 8th June 10 –3pm London

For more information and booking: Down's syndrome with complex needs - parent/family carer regional support meeting - London - Downs Syndrome Association

Useful Links and resources

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

Complex Needs Webpage

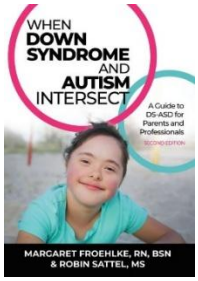
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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)

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