DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting November 2025

Topic: Support

Meeting summary

One parent shared her frustration about her sons experience at a new residential college, highlighting issues with lack of consistency around routine, lack of independence training, and unhealthy eating habits. She feels that the promises made prior to him attending have not materialised.

Another parent then shared her experience around the challenges with her son's residential school placement, which she feels is completely unsuitable. She has identified a more suitable place but the local authority are not currently supporting this option. She is also receiving a care package for him at home and is concerned that if there is a reassessment she may lose this.

Another person shared her experience as a foster carer, describing the difficulties faced caring for her 14-year-old foster son who has Down's syndrome. He is non-verbal, and is hitting people when out in public, which has led to police involvement. She has requested occupational therapy and evaluations for autism or ADHD.

A few parents mentioned applying for health and welfare deputyship, with one person sharing her experience of the form, emphasizing the importance of documenting specific examples of when the best interest process failed. There was a general consensus of how important documenting all relevant information is for evidence.

Another parent mentioned her daughter's high anxiety which influences her behaviour and how people seem to think that this means she can't do things, she will shout when she's overwhelmed. Her daughter is also very selective about food and the dietician has just discharged her as she is now putting on weight. She has a referral to endocrinology.

Another parent mentioned her son's behaviour being misinterpreted when on his way to activities and people thinking that dropping to the floor is a

sign he didn't want to go rather than looking at what support is needed to help him.

One Dad sharing how scaling down social activities has been beneficial for his daughter. The conversation ended with information about upcoming webinars, helpline availability, and future meeting dates.

Next Meeting – Tuesday 9th December 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

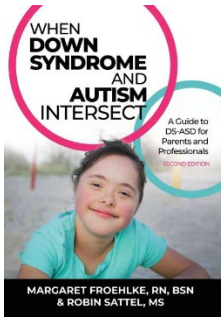
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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)