DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting July 2025

Topic: Planning for holiday (staycation or away)

One parent shared that her daughter, who has autism, prefers to stay home rather than go on trips, finding them stressful and tiring. Another parent described similar challenges with her son, who also prefers to stay home but has found a solution through an agency organizing day trips during August when their usual PA is unavailable. Another parent discussed the challenges of managing two children with different needs, noting that while they both enjoy staying home with tablets, coordinating their needs during holidays can be difficult.

A mum discussed that they are not going away but that her son has plenty of activities, including horse riding camps and day trips like Chessington, and mentioned they are still deciding on a school for September. Another parent shared her family's previous holiday experiences, including a challenging all-inclusive trip to Lanzarote where they had to pay extra for connecting rooms, and a successful boys' trip to Disneyland involving her husband and son.

General discussion

The group then explored social care assessments and direct payments for children with disabilities, with specific advice provided to one person about pursuing support for her daughter. The final portion focused on educational challenges, particularly regarding one school situation and the difficulties in accessing appropriate support and legal assistance, with the group offering various resources and suggestions for advocacy and next steps.

Education issues

One parent discussed the challenges of finding a suitable secondary school for her son, who has apraxia explaining that despite his reading abilities and desire to learn, he has been kept at a lower level due to low expectations and lack of appropriate support from local schools. She has decided to pursue a virtual school called Kings InterHigh while maintaining his social connections through 21 Together. She mentioned that they are considering finding a solicitor but lack the funds to pursue legal action.

DSA Webinars and Resources

We let parents know about the forthcoming Dual Diagnosis webinars. We also reminded everyone to check the complex needs webpage for meeting notes and resources.

Next steps

We will look at relaunching for the September meeting to encourage regular attendees to return.

Next Meeting – Tuesday 23rd September 10.30am



Useful Links and resources

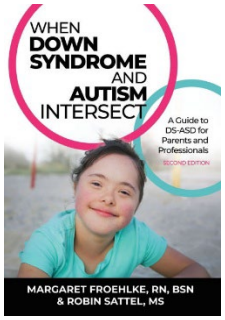
To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

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)