DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting July 2026

Topic: Holiday

Going away

One parent discussed planning a family trip, and the importance of choosing the right accommodation which has activities tailored to her son and is catered ensuring she has a break. She shared how showing him pictures of destinations and asking him to make choices has helped to successfully book several trips. There are however challenges with PA availability as her son wants to go on some trips without family.

Another mum discussed challenges with planning holidays for her son, who struggles with anxiety and change, and shared how she manages his stress through weekly planning boards and gradually introducing him to new activities. We discussed how showing photos of destinations in advance may help alleviate anxiety, which mum plans to try.

Another parent also shared her experience of managing holidays with her son using strategies such as creating visual schedules and breaking activities into manageable steps. They also avoid crowded urban areas when away.

Another discussed the challenges of planning holidays with her daughter noting that her low motivation and short attention span make holidays difficult. They now schedule activities for her during school holidays which gives them a break, or she is content doing her own thing at home. She shared that while holidays present struggles, medical appointments and dental visits work well as she enjoys the focused attention from healthcare providers. They are exploring respite care options to enable family holidays with their other child.

Direct payments and transition

One parent discussed the challenges with the transition to adult services and their preference for wanting respite care over personal assistants. There was a general discussion about Needs Assessments including carers assessments and the importance of evidencing needs. Also discussed who can be employed as p.a.'s with Direct Payments.

Other

One parent shared her positive experience of attending a new group with her son run by Learn and Thrive, through the Manchester Down Syndrome group.

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Another parent raised issues with her daughter's swallow and was looking for advice. It was suggested that she only take professional advice around this Finally a parent provided feedback about a recent eye test for her son noting that while the optometrist was knowledgeable, the testing approach was not well-suited to his needs

Next Online Meeting



Tuesday 15th September 10.30 - Midday

In person meeting Thursday 24th September 10 –3pm Sheffield

For more information and booking: Down's syndrome with Complex Needs Parent Family Carer Meeting Sheffield - 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

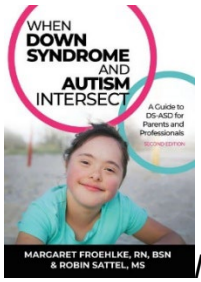
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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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