DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting March 2026

Topic: WDSD

Meeting summary

The meeting focused on Down Syndrome Awareness Week, exploring themes of community, friendship, and inclusion. Some parents talked about how their children prefer solitary activities only occasionally engaging with others. One parent said their child has a need for quiet time at home which sometimes limits his activities. Other parents said that their children enjoyed joining in online and in-person activities including dancing and signing groups. A parent said that her daughter preferred adult company to that of her age group. Another parent talked about her son's strong relationship with caregivers.

One parent felt her son had really progressed in communication and social activities although he still struggles with loneliness. Other parents talked about their children's challenges with communication and social interaction. Another parent raised how hearing loss and mobility issues have affected her son's ability to interact and communicate although he still has a desire to participate in group activities. A couple of parents talked about how their children's behaviour impacted on their inclusion. One parent talked about how her son's sensory differences and continence issues limit his friendships. Parents expressed the difficulty of finding suitable social settings for their children as well as the isolation it brings to them as parents.

General Discussion

Parents talked about ongoing challenges accessing college provision because of their child's complex needs and the impact on family life. Towards the end of the meeting, parents talked of their children's progress and the joy they bring. The conversation concluded with a message of acceptance and choosing battles wisely, as well as the need to enjoy moments of peace amidst the ongoing advocacy.

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Next Online Meeting



Thursday 23rd April 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

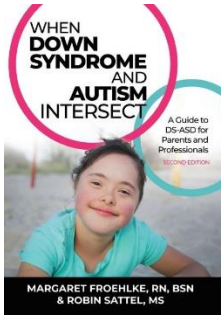
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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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