DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting March 2025

Topic: WDSD Theme – Improve our support systems

What does the theme mean to you and your family - what would improve support for the person you care for?

How has the DSA supported you?

Webinars

People mentioned how the DSA helpline has been a source of support – a couple of people mentioned Stuart by name.

- Speaking to a person really important
- Personalised support

Common themes

Transition – points raised.

This is a difficult time and support available for managing this can be insufficient.

There is less support or none as the person gets older.

Support generally

Secondary schools tend to not involve parents as much which can lead to child being excluded from activities/excursions.

Only receive support in a crisis

Everything is a battle.

Most parents talked about how they have had to fight or battle to get services for their child, often support is only agreed on appeal.

What support someone has is dependent on parents who are willing and able to fight

The support available can be dependent on the finances of the local authority.

Inconsistent eligibility criteria between places

Support is not needs led

Diagnosis of autism opens up additional support

Enquiries jane.mitchell@downs-syndrome.org.uk stuart.mills@downs-syndrome.org.uk

Positive examples of support working

One parent described support her son had from a P.A. that worked really well and her son flourished. It also fostered independence.

You feel stronger having someone support you, being on your side when in meetings with services (for example SENDIAS)

A school that invited children to come in in the holidays to do fun activities as part of transition to get to know the building.

Good support is often about individuals and their personalities

Next Meeting – Thursday 8 May 10.30am



Useful Links and resources

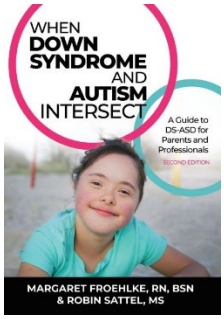
To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

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)

Enquiries jane.mitchell@downs-syndrome.org.uk stuart.mills@downs-syndrome.org.uk