DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting June 2025

Topic: Experiences of including people with complex needs in local groups

We asked parents for suggestions around what groups might put in place to promote better inclusion for children and their families and issues that groups should be made aware of. Here is what they said:

- Offer a variety of activities
- Create a relaxed atmosphere
- Be aware that that children who have complex needs may not always wish to interact but just being there will be enough.
- Offer one-to-one support if possible
- Have the option of different seating for families of those with complex needs when putting on an event
- Make a break-out space available
- Provide access to outside space.
- Hold specialist events for families of children who have complex needs
- Cater for dietary requirements
- Don't expect people to stay to the end of a session for treats/food
- Stagger arrival times to avoid people having to wait in a busy reception area.
- Provide staff with awareness raising training about the needs of people with complex needs.
- Offer genuine inclusivity rather than just a warm welcome.

This information will be used to inform an article for DSA's Journal about local groups and inclusion of people who have complex needs. A parent who runs a local group agreed to send additional suggestions via email.

General discussion about community activities.

One parent talked about the lack of activities in their area and a few other parents offered helpful suggestions. We flagged up DSActive and DSEngage. Another parent mentioned her son's successful inclusion in a local cricket group. Short break funding had been used by a parent for a personal trainer for her daughter, they talked about the value of one-to-one activities that are tailored to individual need.

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Chicken Shed Theatre, London was highlighted by a parent as an example of an inclusive environment that her son (who has seizures) enjoys attending, she felt this was due to an open attitude and good staff training. They felt confident in leaving their son in the care of Chicken Shed.

Health Issues and Eating

We had a discussion around health issues (including sleep apnoea, thyroid, hearing, sight and seizures). DSMIG was mentioned as a source of information and Maggie Woodhouse was highlighted as a great source of support and knowledge around vision issues. A parent who was attending for the first time mentioned the difficulty of accessing a paediatrician for his daughter. We will contact this parent to offer further support.

One parent was concerned about her daughter's change in eating habits, and it was suggested that they look at medical reasons for this. It was mentioned that there was a family history of Coeliac disease. They decided to ask for a general health check for their daughter.

Another parent talked about her son's feeding difficulties; he has muscle laxity and seizures. It was suggested that she contacts DSA's SALT specialist, Gwen Toner.

Regression

There was a brief discussion about the nature of regression with one parent talking about her experience with her son. We flagged up the regression webinar and our webpage.

DSA Webinars and Resources

We let parents know about the forthcoming supporting well-being of adolescents and adult's webinar. We also reminded everyone to check the complex needs webpage for meeting notes and resources.

Next Meeting – Thursday 17th July 10.30am



Useful Links and resources

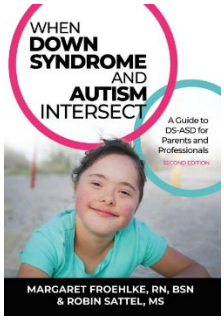
To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

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)