DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting November 2024 - DRAFT

Topic: Open Discussion

Points from discussion - Inclusion and activities

One parent raised that her daughter had been attending a group for young people with additional needs and that they had asked her to stop going because of her behaviour. Mum felt that the group should have been able to include her daughter, and she wanted to know about other parent's experiences.

Discussion covered the following.

A parent spoke about a theatre group asking his son to leave. The DSA wrote a letter asking them to reconsider their inclusion policy. However, they were unwilling to shift their position.

A parent talked about her son's attendance at a choir for people who have additional needs. Despite this being provided through short breaks funding, they asked that the parent attend also.

Another parent talked about how she a tried to enrol her son in as many clubs as possible (both mainstream and for those with additional needs). Some of these have worked but others haven't in terms of inclusion.

A parent of a teenager with dual diagnosis said she now pretty much steers clear of mainstream activities. Talked about picking battles. She enrolled son for an activity at a private special school but because her son was boisterous they told her that they could not meet her son's needs. He is quiet happy doing his own thing – attends football group for people who have Down's syndrome – runs up and down the sidelines but he does not join in with the game.

A parent talked about her son expressing his preference for activities (or not) as he got older. He has two young PAs, who take him to activities and the pub. More important for him to be part of a community than to actually go to clubs and socialise with peers. Talked about connection being important, this looks different for all of us.

The point was made that organisations that advertise themselves as inclusive are not always so.

Education and inclusion

One parent talked about battles in mainstream education, and questioned whether it was inclusive for her daughter. She felt that the message re adaptive learning is not getting through, and she is wondering if should now move her daughter to special school.

Another parent talked about children in mainstream school not necessarily being included and it is down to the headteacher. One of the parents talked about her son being in a special unit within a mainstream nursery and primary school and it worked. This was not available at mainstream secondary schools and they

decided to look at special schools. Recently they identified a residential college, but had to go to Tribunal to get a place from September 2025; in the meantime, he has a day placement at a college which is a three hour round trip a day.

There was a discussion about how specialised advice services such as IPSEA are difficult to access because they have a high demand for their services.

Parent moved her son to a special school, she struggled to make this decision but glad that she did.

A parent stated that it is about the needs of the child and what is the best school in the area, special school is not necessarily 'second best'.

iPads/Tablets

Discussion about usage and how much is too much?

One parent said that his son likes to have the tablet on during meals. Another parent said that her daughter was the same and they wouldn't have a meal/go to a restaurant without it. One parent said her son has the tablet on from 6.30am until breakfast and as soon as he comes home.

One parent said they managed to curtail her sons usage by introducing a weekly schedule including computer times. Initially this involved some negotiation with son but now he sticks to the schedule rigidly.

Another parent mentioned that the Ipad had helped her son's language development and he learnt phrases (strings of words and intonation) from watching things on TV and iPad (Gestalt).

COMING SOON

Tuesday 12th December 10.30am – midday



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/