

Round-up of complex needs meeting (April 2023)

Topic: Arranging an event - what do people put in place or do you avoid

Who attended: We had 13 parents

Points from discussion

Several people talked about recognising whether the event/party is what the person who has Down's syndrome wants rather than it being an external expectation or what the parent wants. Asking/understanding what the person wants was the most important thing.

Birthday parties

Pre-planning– thinking about how many people and who the person wants to be there, "small and contained" or lots of people and loud music!

Several people talked about having an exit plan in place for attending events, that could include leaving their own party or someone else's.

It could be having a break by leaving completely for a short while or opting to sit in another room but still be part of the gathering.

A few people mentioned that they only put food out when it is time to eat e.g. cake.

Some people only arrange events in their home, some only away from the house.

Weddings/Funerals/Christening/Confirmation

Sitting where it is easy to leave.

Having distractions – toys, snacks, electronic devices

Having a role can be helpful to feel part of occasion.

General

If going to a new place can prepare by showing photos/videos or using social stories

Using incentives can be helpful.

Pre-empting/checking if there may be activities at the event that the person may not be able to manage.

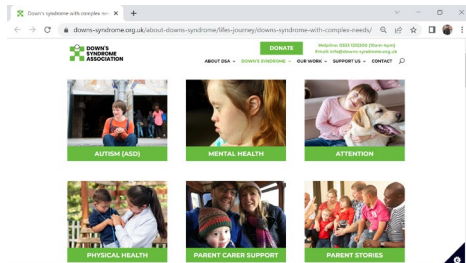
The person might want to do things with other people rather than parents and may behave differently.

There was a general discussion about how people can feel judged by others if the person they care for is struggling. Others said how they no longer worry



about what other people think and everyone should be accepted for who they are.

DSA



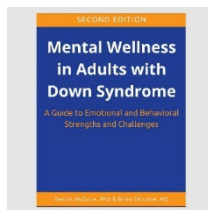
New complex needs webpage

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

Link to training page with all events

<https://www.downs-syndrome.org.uk/our-work/services-projects/training/>

Other



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