



Round-up of complex needs meeting (Mar 2023)

Topic: Open discussion – focussed on Down's syndrome and ASD

Who attended: We had 11 parents attending caring for people between the ages of 10-38 years old

Points from discussion

- Knowing when to accept that child doesn't want to do something and when to push – about finding a balance that works, sometimes you nudge, sometimes step back.
- Not imposing my expectations on to my child, pulling back not interfering
- Reflecting on when it's something I want rather than what they want.
- Square pegs in round holes with Down's syndrome services and Autism services
- Supporting child to be as independent as can be in their own way.
- Doing things they love but sometimes revisiting and checking things again
- Allowing ourselves to leave when it isn't right for them, going with the flow – we release ourselves.
- Trusting instincts as a parent and can only do what you think is right at the time.
- Anxiety a big issue
- Being confident in knowing child and asking others to make adjustments rather than feeling judged.

Below is a list of resources that were mentioned during the meeting.

DSA



New complex needs webpage

https://www.downssyndrome.org.uk/about-downssyndrome/lifes-journey/downs-syndromewith-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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