DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting September 2024

Topic: Summer break

- Was it different?
- What went well?
- What was a challenge?
- What did you learn?

Points from discussion

Several parents reflected on the difference between what they want and what their child wants and the best thing to do. Some parents were questioning continuing to put their child in different social situations during the holiday when they obviously preferred to be alone. There was concern that the summer break can mean no contact with peers unless parents arrange activities.

A couple of families had been abroad in the summer and one parent shared how the whole holiday revolved around their child having meals at set times and wanting to eat at same thing each day. Another parent also talked about planning the structure of their trip around mealtimes for her daughter, both mentioned their children wanting to be in their bedroom most of the time when away. Other parents mentioned their children wanting to go home.

Discussion around some parents noticing that their children do not interact with other children who have Down's syndrome. One parent said that her child relates more to children with complex needs without Down's syndrome and another that their child relates to people who have autism more.

One parent noticed her son played well with children younger than him and seemed happier to be with people who were perhaps developmentally similar.

"It is difficult not to impose my view of life on my child"

"I have stopped trying to create social situations"

Other ways of holidaying

One Dad talked about his son being supported to go away to the same hotel every year not far away from home with the option to come back if needed. This works well and everyone has a break.

Another parent mentioned using a large tent with 2 bedrooms so that her son can have a bedroom to stay in when they go to visit family on a camp site.

Others were considering whether it would work better for their child to go away with p.a.'s and this would also enable the rest of the family to have a holiday of their choice.

Holiday clubs

People had generally found that their child had enjoyed going but this would be for one week or two weeks of the holiday only. This left weeks where it was harder to balance activities/work

Some parents had spent the summer break sorting out logistical issues around education and had had a focus on the mental well-being of their child and used the space for building skills. One family had been supporting their child who had high anxiety following a health emergency.

Useful Links and resources

Mental_Wellness_full_book_final_2023.02.24.pdf (advocatehealth.com)

COMING SOON

Tuesday 5 November 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/

Any questions, please email:

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