DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting January 2025

Topic: Communication

We had a discussion centred around how people's children communicate and what has been helpful in aiding this. A few people mentioned how they have to work out what their child is wanting/telling them/needing and we heard how people use a variety of tools to support their child's communication.

Common themes

A few people mentioned how it is harder for people who don't know their child to understand what they are communicating.

Non-verbal communication

Several people talked about how their child had not developed speech yet or was very late to develop verbal skills and one person said their child is now choosing not to use spoken language having previously used it.

Behaviour was mentioned as a way of communicating.

Verbal communication

Some of the points that people raised were:

- Child getting stuck in using repetitive phrases.
- Impact of stress and anxiety on speech.
- Reduction in using verbal skills/talking quietly as getting older.
- Talking in telegraphic language – no conjunctions.
- Infection as a result of glue ear stopped son using words.
- Child only wants to talk about what they want to.

Communication supports.

Several people mentioned AAC electronic devices (one person mentioned the TD Snap app). One person said son will only use AAC on his terms

Other supports mentioned were.

- Grid
- Makaton
- PECS
- Widget symbols

One person felt her son understood signs but did not want to use them himself.

It was acknowledged that communication aids support development of verbal skills although some people had avoided them initially.

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Language development

One parent mentioned Gestault and another parent expanded on this as a way her son had developed language.

Communicating pain

There was a discussion about how several children find it hard to locate pain and communicate it to parent. One child had recently used past experience to communicate current pain.

We mentioned the new pain resource that has just been launched.

https://www.downs-syndrome.org.uk/wp-content/uploads/2024/12/Pain-resource_FINAL_19.12.24.pdf

Some helpful tools were mentioned

- Body Maps
- Cards with body parts
- Faces

One parent talked about a resource she had purchased (picture below)



Cartoons

Several people mentioned that their child likes to watch cartoons in different languages and one parent felt it was because of the intonation.

Relaxation techniques

In terms of stress impacting verbal communication one parent mentioned using calming techniques such as Mindfulness.

We mentioned a recording that is part of our emotional well-being resources.

https://on.soundcloud.com/pBpGCMjok3qFV52x6

Other

One parent talked about how repeated ear infections had impacted their child's communication development. The same parent talked about their child having issues with food consistency following physical difficulties in the past.

Next Meeting – Thursday 6th March 10.30am



Useful Links and resources

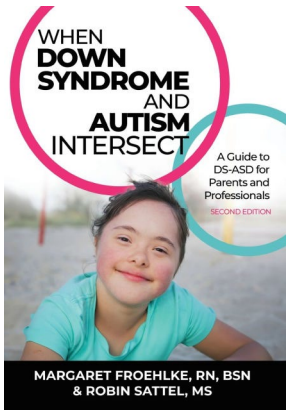
To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

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)