DOWN'S SYNDROME ASSOCIATION



Round-up of complex needs meeting (July 2024)

Topic: Communication

- How does the person you care for communicate?
- What supports do you put in place to facilitate communication?
- Do you feel the person you care for is able to communicate their needs effectively?

Points from discussion

Forms of communication

Some parents had children who are verbal, but this looked different from person to person. The consensus was that verbal communication does not always mean better understanding and expression.

'Although my son can talk this does not necessarily mean he can describe what is bothering him.'

For one parent their child's verbal communication has been less understood in school since not having a regular TA.

People talked about their children using a range of ways to communicate including sounds, objects of reference, symbols, photos and pictures, messaging and iPads.

One parent stressed that all behaviour is communication and that it was important not to press people to use spoken language when they were struggling.

It was acknowledged that previously acquired spoken language may diminish due to a number of factors (e.g. autism, regression, mental health).

The groups identified a number of common traits and tips

- Better receptive understanding compared with ability to express selves verbally.
- Giving the person the right amount of processing time (different for everyone) was vital.
- Consideration needed to be given to the communication environment (reducing distractions and stressors).
- Children sometimes needed time to self-regulate before communicating.
- Short simple sentences may help.

- Visual timelines and literal communication may help.

Some people regularly used and repeated set phrases they had learnt from the films and TV for example. Others mentioned that their children sometimes got stuck in a loop repeating a word, phrase or question. One parent said that her daughter repeated her own words back to her (known as 'echolalia').

It was recognised that some people may be keen to seek approval and tell others what they think they want to hear. It may be useful to check and to try and be as sure as possible that what they are communicating is what they want.

One parent gave an example of her son communicating about a health issue as if he were experiencing it when in fact it was another family member.

Another person mentioned that the person they care for may communicate about something that happened some time ago as if it has just taken place.

A number of parents said that their child found messaging on phones easier as it meant less emotion and visual distractions.

A parent said that she used any tools that might be useful in supporting her son's communication and did not believe this deterred him from using spoken language.

Stress/emotion and communication

It was generally recognised that anxiety reduces the ability to communicate.

Some people, including those with spoken language, were able to communicate basic needs but found communicating emotions challenging.

Useful Links and resources shared by parents

(*We do not endorse any non-DSA information/resources/tips shared between parents during these sessions.)*

Proloquo2go - **https://www.assistiveware.com/products/proloquo2go**

The Hospital Communication Book by the learning disability partnership board in Surrey - Hospital Communication Book

Widgit - Online tool that lets you create, print, share and translate symbol materials for visual, communication and learning support - Widgit Online -

Widgit Health - Visual support for healthcare (widgit-health.com)

Gestault Language Processing - a style of language acquisition where children learn phrases first and then break them down into words - Instagram accounts: @speechdude, @bohospeechie, @thespeechden

TD Snap communication app - [TD Snap® on the App Store (apple.com)]

COMING SOON

Thursday 12th September 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/]

In person meeting Manchester – Monday 23rd September

[Down's syndrome with complex needs - parent/family carer regional support meeting - Manchester - Downs Syndrome Association (downs-syndrome.org.uk)]





Any questions, please email:

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