

## **Round-up of complex needs meeting (March 2024)**

We started with introductions, there were some people who were attending for the first time. We then summarised the previous meeting and introduced the session topic.

**Topic:** Sensory Differences

### **Points from discussion**

This was a lively and much needed conversation with most parents recognising sensory differences in the person they care for. Some parents had been referred to various services including CAMHS. For a number of attendees there was a recognition during the session that many of their child's behaviours were likely to be due to sensory differences.

**We asked parents about their child's sensory differences.**

### **Personal Care**

Quite a number of parents talked about their children's challenges around personal care (e.g. hair, teeth, dressing, continence). Some challenges appeared to be due to oversensitivity to touch whilst others, such as continence, were probably associated with the individual not being able to recognise sensations associated with needing the toilet.

For some, they had seen improvements as their child got older.

### **Eating**

Many attendees talked about their children failing to recognise when their mouth was full leading to their stuffing food in their mouths and choking. For others, sensory differences impacted on diet and, in some cases, led to eating refusal. A few instances were mentioned whereby people had put non-food items in their mouths and, in some cases, swallowed them.

## **Temperature and clothing**

A number of children and young people refused to wear certain clothing and discarded heavy warm clothing. One parent talked about her son's preference for creating a cold environment in his bedroom by opening windows, even in winter, at the risk of becoming unwell. For some there was a clear preference for cold showers only.

## **Noise**

A parent talked about how their child enjoyed loud music when they were in control of it but that they found unexpected loud noise difficult. This led on to a discussion about whether individuals could experience under and over stimulation at different times in relation to their senses.

## **Healthcare**

Accessing healthcare appointments was difficult for a number of people and blood tests were generally a challenge.

Some children refused to wear hearing aids and glasses.

## **We asked parents about their child's behaviours.**

These included self-soothing and regulating behaviours such as chewing fingers and other items, rocking, and bouncing and dangling items in front of the face.

## **We asked parents about accommodations and strategies they have tried.**

One parent put together a rescue kit which contains items that can be used to meet his sensory needs; this travels around with him.

Another talked about how introducing an electric toothbrush has made brushing teeth so much easier as his daughter enjoys the sensation.

Modelling self-care tasks and using strategies to let the person know how long a self-care task will last had been helpful for some (e.g. countdown with a mobile phone timer).

Providing minced/mashed food and thickening drinks had helped some children.

Chewy tubes proved useful for some but not others.

Some parents talked about how using a hierarchy of exposure, whereby the person was exposed in a controlled way over time to something that they might find difficult, had helped.

Top tip from one parent was shopping for and finding toys in the pet shop that met sensory needs - their child loved the process and the toys. Another parent said that they did the same.

### **We asked parents whether they had accessed a sensory assessment.**

Difficulty obtaining a sensory assessment was acknowledged.

One parent had pushed for this, they mentioned the need for a sensory assessment being part of an appeal to Tribunal. Their child subsequently received a block of OT sessions.

Another parent sought a private sensory assessment.

### **Autism**

There was a discussion about seeking a diagnosis of autism and why that might be helpful. One parent said she had asked for a diagnosis, but professionals felt her child was too young; it was suggested that they adopt a wait and see approach. Another parent said that their daughter does not have a diagnosis but that as a family they work on the assumption that she has autism and put appropriate strategies in place.

### **Useful Links and resources**

Sensory Processing Strategies (Katie Frank) – Free webinar from the European Down Syndrome Association (EDSA)

[Sensory Processing Strategies to Support Community Participation in People with DS throughout the Lifespan – European Down Syndrome Association \(EDSA\)](#)

Sensory Processing Differences (Chapter 12) – '*Mental Wellness*' book – now a free PDF

[Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges \(2nd Edition\) | Adult Down Syndrome Center \(advocatehealth.com\)](#)

2<sup>nd</sup> Edition of the book '*When Down Syndrome and Autism Intersect*' (Froehlike & Sattel) – Available from online book sellers.

## COMING SOON

### Dual Diagnosis of Down's syndrome and Autism webinar



**11<sup>th</sup> April 2024 - 10 to 1130am**

### Dual Diagnosis of Down's syndrome and Autism webinar



**2<sup>nd</sup> May 2024 – 10 to 1130am**

To book go to our Training Page - [Training - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk/training)



## **Complex Needs Webpage**

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

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