

Zoom Meeting 28th November – Summary 6.30-8.00pm

Neurodivergence and often overlooked Presentations: Prosopagnosia (face blindness), Aphantasia (the inability to visualise images in the mind's eye) & Synesthesia (blended or cross-wired senses).

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Host – Cassandra Clemens

Transformational neurodivergence coach and founder of Heal Your Confidence Community Interest Company

kassandra.clemens@outlook.com

[linkedin.com/in/Kassandra-clemens-coach](https://www.linkedin.com/in/Kassandra-clemens-coach)

Heal Your Confidence Community Interest Company

Website: www.healyourconfidence.com

Email: hello@healyourconfidence.com

Facebook page <https://www.facebook.com/healyourconfidence>

LinkedIn business page

<https://www.linkedin.com/company/heal-your-confidence>

Panellists

Rachel Bennetts

Rachel.Bennetts@brunel.ac.uk

Will Roseby

W.Roseby@sussex.ac.uk

Noam Sagiv

noamsagivphd@gmail.com

Plus 31 attendees. Several spoke up while others contributed via a lively chat (only available to attendees).

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Definitions:

Prosopagnosia: affects the ability to process faces.

Synaesthesia: stimulation in one sensory modality is accompanied by experiences in additional, unstimulated senses.

Aphantasia: reduced or complete absence of visual imagination.

Summary

- Face blindness (prosopagnosia) and synaesthesia manifest in diverse ways, impacting individuals' perceptions and daily functioning
- There's significant overlap between neurodivergent conditions (e.g. autism, ADHD) and atypical sensory experiences
- Personal experiences are crucial for advancing research and understanding of these conditions
- Sleep, nutrition, and stress management play important roles in managing symptoms

Research Insights

- Genetic links between synaesthesia and autism
- Challenges in diagnosis due to compensatory strategies
- Importance of subjective experiences in understanding conditions
- Potential for training to improve face recognition
- Prosopagnosia & navigation skills
- Connections to EDS (Ehlers-Danlos Syndrome) and POTS (Postural Orthostatic Tachycardia Syndrome)

Panellists

Rachel Bennetts

Rachel is a lecturer in Psychology at Brunel University of London. Her research specialises in face processing with a particular interest in why some people are good at it while others struggle. People might struggle only slightly or to the extent that they cannot recognise close friends and family in a photo or their own child when they pick them up from school. Understanding how they are processing the faces might tell us why they are not very good at it. Rachel is also interested in developing some training to help people with face recognition; so far, progress has been slow.

More recently, Rachel has become interested in face recognition in neurodivergent individuals, particularly around dyslexia. A growing body of research link face recognition with dyslexia. Her team has also looked into the link between autism and face recognition.

Will Roseby

Will is a postdoctoral researcher at the University of Sussex with a core interest in understanding the relationship between brain structure and dynamics and conscious perception. His particular focus lies in describing global properties of the brain that could affect information flow in 'atypical' individuals, such as those with synaesthesia and autism. His work concerns how differences in the brain lead to differences in perception. He has become quite interested in using a statistical and mathematical

methods to analyse how the brain's structure and function is different in synesthetes as well as people with autism and how this might relate to perceptual differences. Will recently completed a PhD in the molecular contributions to behaviour. Will has lived experience of synaesthesia.

Noam Sagiv

Noam is a senior lecturer in Psychology at Brunel University of London. His current research interests concern the cognitive and neural bases of human perception and consciousness. Specific research interests include cross-modal interactions and synaesthesia. He started his research with neurological patients who perceived the world differently, usually perceiving less than most people.

When Noam learned about synaesthesia, he became fascinated that there are people who perceive more than most others. Noam has some lived experience of synaesthesia.

Discussion

Due to the sometimes intimate, personal experiences speakers are sharing, only the panellists are named below.

Face Blindness (Prosopagnosia)

Difficulty recognizing faces out of context, even close friends/family

“I felt embarrassed at times because it seems that I might not recognise someone and not be saying hello, but actually I have no recognition of their face. But if I've spoken to someone and got to know them a bit, and there's been some sort of connection, then I will remember who they are.”

“My husband will say ‘he's been to our house five times before’ and I just would not recognise them [or] when I'm out people will say hello to me and I have not got a clue who they are... I thought it was probably something to do with my

memory... it's only when I'm in my 60s that ...I realise this is what I've been experiencing throughout my life, but I've got an explanation for it now [autistic].”

Rachel (summarised): The term *face blindness* can be misleading, as it suggests a complete inability to process faces, overlooking the nuanced difficulties many experience. For those affected, recognising and learning faces often requires significant effort, leading to social challenges. Researchers are striving to raise awareness of prosopagnosia as a genuine condition, emphasising that it is not about inattentiveness or rudeness but a real cognitive difference impacting social interactions.

Noam: “[if you] fail to recognize close friends and relatives out of context... then it's probably the real thing.”

Compensatory strategies & abilities: focusing on hair, clothes, voice, or gait

“...context is all because if you see somebody in the environment that you're used to seeing them in then it's easier to remember who they are.”

“I have to focus on the face and everything around the faces like glasses or earrings and shoes and I also have an ADHD...”

“I've been diagnosed with ADHD and autism...I exceptionally remember the sound of their voice... they might call me after 30 years, and I know after a couple of seconds who they are...I struggle to find their name, but I know exactly who they are, and everything that happened between us.”

“I'm really focusing on the shoes [of people I meet] besides the head area [to recognise people].”

Rachel: “...people develop different compensatory strategies...for a lot of people with perseverance, it's not a complete absence of recognition...”

Noam: “...people with developmental characteristics [neurodivergence] have had a lifetime of experience compensating for [their inability to properly recognise faces].”

Gender differences: some find one gender easier to recognize than the other

“I cannot recognise male faces; I don’t know who [male actors] are.”

Rachel: “when I talk to people who have lots of recognition problems, it's common for them to really struggle with one gender over the other.”

Potential crossovers in processing, hereditary & role of trauma

Rachel: “we do see a lot of issues with navigation in our participants who also report face recognition problems”

Will: “[for] the majority of people who have these kinds of experiences, it's mostly genetically determined. And there's a large kind of genetic overlap between synaesthesia and autism.”

Can it be diagnosed?

Rachel: “is there a formal medical diagnosis?, not yet.’. You can [do] the tests from labs like the labs that I collaborate with to get a confirmation... It's not going to be something that convinces the NHS [as] different universities will use different tools.”

Noam: “personal experience can be sometimes more valid than a test”

Positive coping strategy

“[The test] confirmed that I was really bad at recognising faces. And then I started to just tell people, you know, I'm really bad at this. [If] I'm not saying hello to you... just say hello to me and I will slowly [remember you] and it will be okay.”

Synaesthesia

Noam: “When people start telling me about their synaesthesia, they start by saying they're not sure if this is synaesthesia... most of the time the answer is probably yes; there are many variations... individual differences in perception.”

Audiovisual: seeing shapes/textures internally when hearing music

“I see shapes and colours when I listen to music; I see it within myself... [manifestations] can be very different from person to person, so some people might see it out in front of them.”

Mirror-touch: feeling sensations when seeing others touched

“when I see someone touching another person ... I can [sometimes] feel it on my own body.”

“...I can feel like almost my muscles are flexing when I'm drawing someone running or climbing...”.

Noam: “Mirror-touch is quite predictable. if you see someone being touched on their hand you feel touch on your hand in the same place So it feels A lot less arbitrary that other types of synaesthesia.”

Time-space: visualizing time as shapes/colours in space

“I see [time] in terms of the year like a wheel with all the months being different colours and I kind of move around the wheel as I go around the year...”

“I've always been told I'm good at remembering day to day things ...I just seen them on this wheel with like flags and things...I see [days of the week] as different colours and ...I see [years] like a continuous line going backwards and to the right [taking] a 45 degree turn at the millennium and it comes towards the left...”

“I felt it was quite normal to give colours and spatial visual place to dates or numbers or letters.”

Noam: “colour sequences, like days of the week, months of the year, numbers, letters, that's fairly common (> 4%), and some have colour for numbers (approx. 1.5%).”

Number/letter-colour associations

“I see numbers and colours when I listen to music and sometimes when if I hear a particularly musical voice... I visualise colours and numbers. I've always done that since I was little...”

Noam: “colours [and letters tend to] appear to be random.”

Experiences between waking and sleeping

“I could start to see the sound on a sort of pentagram, just flowing through this pentagram, and going through my ears.”

“I don't have synaesthesia during most of my waking hours, but I have experienced a few occasions in synaesthesia colour for sound.”

Noam: “I'm...working on a paper ... entitled nocturnal synaesthesia.”

Taste-word associations – not discussed

“[when] words have particular tastes”

Noam: “Essentially, all sensory combinations are possible, although the distribution is not uniform ... some are more common than others... We don't understand this completely, but we suspect that it has something to do with the proximity of the appropriate or relevant sensory areas in the brain. The closer the two areas are the more likely it is that they'll be cross-wired in such a way that they will produce synaesthesia.”

Neurodiversity and co-occurring ‘atypical’ sensory experiences

Noam (summarised): Recognising certain conditions can be difficult due to the influence of environmental factors. While a condition may have been lifelong, it often becomes apparent only when usual coping mechanisms fail in challenging situations. People tend to assume others perceive the world as they do, complicating both personal awareness and research efforts. Many conditions remain unidentified

simply because the right questions haven't been asked, emphasising the value of individuals sharing their experiences to enhance understanding.

It can be challenging to distinguish certain conditions because environmental factors often complicate matters. A condition may have been present throughout a person's life, but it becomes more noticeable when coping mechanisms fail in difficult circumstances. This can lead to a delayed realisation of the condition's impact. It's common to assume others perceive the world as we do, making it harder for individuals and researchers to identify and understand differences. Many issues go unrecognised simply because the right questions haven't been asked, highlighting the importance of individuals sharing their experiences to advance understanding.

The lived experience element in diagnosis

Noam: “[as a researcher] your personal experience sometimes tells me more than a test that's not particularly fit for purpose...[and] also helped me figure out what sort of research questions I should be asking, because without that input, I wouldn't know where to start with synaesthesia...I have to rely on your own testimonies to even begin to know what questions to ask. The test we devise are all based on performance. But there's one more question that we almost never ask, and this is what you actually see [how do you experience this]?”

Aphantasia

The speaker only realised he had aphantasia as an adult when someone else described their own experience vividly.

“...when I was younger...I was very isolated from any kind of reality as a child...I was just constantly [mentally] processing...trying to figure out people and understanding people... I was unable to speak very often, and that opened up people's judgment of me, and so I was given labels very often.

“[Now], just having that sense of clarity...it's really enabled me to connect with people in a much more authentic way, feel more secure in myself, which then drops all the need for processing and masks...”

Professionals need to ask the right questions to help individuals with aphantasia, as visualisation will not work.

Next Steps

- Explore creating a forum for sharing diverse perceptions and experiences of the world
- Next Open Zoom Discussion event: Thursday **30th of January**, 6.30pm British time

Additional links and recommendation

Rachel Bennetts recommends -

<https://prosopagnosiaresearch.org/face-blindness/research-participation>

This is the site for our research group - you can register your details here and complete some screening tests and take part in other research

Dr Noam Sagiv recommends -

Article on synaesthesia and hypnagogic imagery

https://www.researchgate.net/profile/Carol-Steen-2/publication/315960501_Synesthetic_Photisms_and_Hypnagogic_Visions_A_Comparison/links/64ea37d90acf2e2b52187f20/Synesthetic-Photisms-and-Hypnagogic-Visions-A-Comparison.pdf

On Sleep: <https://www.youtube.com/watch?v=aXflBZXAugQ>

Pauline -

A few years back I worked with a PhD student who was also a lecturer/artist in woven textiles. Her research/thesis was on "A Grapheme Synaesthete's A–Z of Colour

A textile practitioner's response" - to explain more here is an extract from her Abstract: "This work explores the re-construction of the alphabet colours of five grapheme synaesthetes, and observes the interrelationship between these colours once they have been categorised and re-located into a series of woven 'colour charts', using the 'paint chart' format as 'a platter to serve colour' as Joseph Albers once remarked." The full dissertation containing photos of her final exhibition showing the amazing range of woven colours are available at

<https://repository.mdx.ac.uk/download/7d766fad8eeff71425dc4e0373e871f74b0bf67cc29105c843c2e8d72beecc74/13247072/GJFereday%20thesis.pdf>