

“Ears turned up to 11: sound perception in autistic people” – Carmen Rosas Pérez

Text notes of presentation

Hi everyone! I’m Carmen Rosas Pérez and this is my presentation on sound perception in autistic people. The title is “Ears turned up to 11”, which makes reference to the movie Spinal Tap, where a heavy metal band uses an amplifier that “goes to eleven” instead of stopping at 10. This is the way many autistic people describe their sensorial perception, like if their senses were more amplified.

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I will first tell you a little bit about myself. I’m from Spain, I have a masters in acoustic engineering, I like to do field recordings when I can, and I’m autistic all the time, I guess.

I studied and worked in telecommunication engineering, sound recording, a little bit of architecture and web design.

I’m interested in sound perception, impact of sound on people, aural and neurodiversity, and low frequencies.. among others.

And currently I’m doing a PhD on the impact of the sound environment on autistic people.

There is a picture of me, a white woman with dark hair, in an anechoic chamber with an omnidirectional loudspeaker and mini microphones in my ears (that I used to measure my Head-Related Transfer Function)

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This presentation has 3 major parts that will cover a bit of the perception process in people and some comments on how the perceptual evaluation of sound is normally studied in acoustics, including the consideration of vulnerable groups in noise guidelines. Then I will try to summarise some of the main research on sensorial differences in autistic people, and the risks for health and well-being associated to higher noise sensitivity.

These are the background topics for my PhD project, and I will explain also a bit about the study that we are currently doing, which includes interviews to autistic people on their experiences on different environments.

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In psychoacoustic we have parameters to measure (or at least to try it) the different range of sensations that sounds produce in people.

In their early study, Fletcher and Munson give high importance to psychosocial factors and the differences in individual perception (although it is true that for the creation of the equal-loudness contours they used the data of only eleven participants with what they considered “normal hearing”).

Sensations are individual, and they cannot be reduced to just “opinions” that we then put in the box of “subjective stuff we would rather not to think about because they complicate things a lot”.

They are a response, a reaction that is very objective for that person in that particular moment and context, and it has its reasons. If we measure skin conductivity, or any kind of brain signal, we get numerical values. But would we say that these values are more objective than the self reported annoyance just because we have the technology to measure it?

Even if this was the case, these values are also individual, so averages won't tell us the whole story.

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The perception process has been analysed from multiple perspectives, and in engineering we like to do these nice diagrams that are helpful to understand factors that could be involved.

But we have to be careful with the simplifications and assumptions, because people are not exactly systems that provide the same output given a certain input.

For example, not always a strong stimulus provokes a strong reaction, and a weak stimulus a weak reaction, so the reaction cannot be predicted from the physical properties of the stimulus. As Maschke puts it: "This simple approach doesn't do justice to the human being."

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Methods used in research on the perceptual evaluation of sound are often oriented to collect quantitative data, and experiences that deviate from the average are usually categorised as outliers. This can facilitate the implementation of more cost-efficient research and policies, at least in the short-term, but they can result in problematic conclusions on a theoretical and a practical level.

Common and important environments like homes, schools, healthcare facilities or offices, are usually designed using the values in acoustics standards as targets, when instead they are minimum quality standards. Also, these values and recommendations do not entirely prevent negative effects in the population.

Aural diversity is usually not considered in the design of regulations and standards in environmental and building acoustics. Thus, the psychological and physiological response of vulnerable people with higher sensitivity to sound, for example, is not taken into account, which can result in high levels of long-term distress and other negative effects.

The mismatch between the fulfilment of numerical requirements and the level of satisfaction of the population has been a constant since early investigations on the effects noise, and questionnaires have been introduced to complement the data from measurements in order to understand the problematics involved.

Anything that we evaluate in people is going to have a wide grade of variability, and acoustics research and practice needs to consider this diversity.

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Individual experience is more considered in audio (in part also because there are direct economic benefits in this)

For example, personalisation of Head Related Transfer Functions, which is how our torso, head and ears filter the sounds that we hear, is being implemented to increase the realism in spatial sound. There are generic ones made by averaging these dimensions from databases, but many people find them, in fact, too artificial. They somehow represent the ears of everyone and nobody at the same time.

It is important to embrace perception as a valid experience. As they say it in studios design: "If it measures good but sounds bad, we are not measuring the right thing."

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A preliminary analysis of 38 some of the most relevant studies on perception of soundscapes reveals a relatively high homogeneity in auditory characteristics of participants, who in many cases are young students.

Most of the remarks on limitations refer to the number of participants, the variety of soundscape samples and its implication for the statistical significance, but not to the lack of diversity that can imply differences in perception

In all the studies the participants have “normal hearing”, and only one study includes participants with any type of hearing impairment.

None of the studies report the inclusion of neurodivergent participants.

One systematic review on assessment of soundscapes includes only “studies assessing the factors that influence the perception of indoor acoustic environments by normal-hearing building users”.

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Sounds from any source and with any loudness can increase the levels of discomfort and stress on a daily basis, especially in vulnerable populations. Research has evaluated the effects of sound in, for example, children, the elderly, and healthcare patients.

These are some extracts about vulnerable groups from important guidelines.

However, the lack of representation of these groups is still observable in acoustics research.

The needs of vulnerable groups are mostly only addressed in the case of specialised settings (like special schools or facilities for disabled people).

But it is fundamental that human diversity is included in general studies on perception and building guidelines, in the same manner that we acknowledge the importance of diversity in acoustical characteristics of sounds and spaces.

In addition, this responsibility is reinforced by the legal obligation of fulfilling duties under the Equality Act.

Some important projects have addressed several aspects of autistic people’s sensory needs, for example, to compile recommendations for care settings, homes and other environments. These projects are valuable examples of research observing the priorities and participation of the communities that they are serving, in this case neurodivergent people.

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Neurodiversity refers to the natural diversity in cognitive functioning

Neurodivergent people have a different neurotype in comparison to what is considered as “typical”. These differences include autism, ADHD, dyslexia, or dyspraxia.

It is estimated that 1 in 7 people in the UK are neurodivergent.

This cognitive divergencies often involves significant sensorial and perceptual differences, with some theories suggesting that autism is a difference in how the information from the world is perceived, filtered, and processed, as well as differences in preferences for interactions and social style.

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What is not normal is normalcy.

As the authors of a recent study put it: “There is no universal, unconditionally optimal pattern of brain structure or function. [...] In isolation, any given behavioral, psychological, or neurobiological trait is typically neither good nor bad. Rather, the context a person is in, their age, social network, and environment, can have a huge influence on the costs and benefits of particular traits.”

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Research and personal accounts suggest that autistic people show consistent sensorial differences.

These differences are more related to responses to sounds rather than to the auditory system itself: there are no differences in hearing thresholds, but there is higher self-reported sensitivity, and more intense physiological responses, like higher heart rates.

This can lead to higher levels of annoyance and less tolerance to loud sounds and high/low frequencies sounds.

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But also, among others, to a superior pitch perception, “enhanced, stable and highly accurate representation of auditory events in the pitch and time dimensions”, identification and memorisation of musical notes and detailed analytical listening of the surrounding soundscape. Most of the participants in these studies, however, present “normal hearing” in standard tests.

Many autistic people make use of individual coping strategies like noise cancelling headphones, ear defenders or tinted eyeglasses to reduce the level of perceived stimuli, but some can have negative effects in hearing, and not everyone can afford them or make use of them.

It is also important to remember that everyone is different, and so there could be conflict of needs, also among autistic people.

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For some people it is easier to filter sounds out automatically. But for many autistic people this doesn't happen, so they tend to pay conscious attention to more stimuli around them, and habituation does not occur in the same level, or at all. This can be a biological advantage. For example, being able to hear a lion from afar while having a meal with your family shouldn't be considered a “deficit”. Or if you are birdwatching, it's quite useful to be able to see every little movement around or hearing quiet sounds and differentiate them.

Lack of habituation can also be positive if covering your ears or leaving a place with very loud music prevents hearing damage or constant high stress without noticing it. It is not that good not realizing how much a noise like the kitchen fan was affecting you until you switch it off. These are natural mechanisms meant to protect us.

And from a biological perspective, being indoors most of the time, as we do nowadays, is not the “normal” for human beings, like being surrounded by loud or unexpected noises for a long time. Sensory stimuli are triggers to grab our attention, so environments with many sounds can be quite draining for people with higher sensorial sensitivity.

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Sensory overload can have an impairing impact in autistic people's lives. "Lighting, temperature, sounds and smells are potential sources of sensory overload and distraction with a negative impact on employment outcomes", as well as on the ability to cope at university:

"The noise was impossible to filter out, and I couldn't cope with the shared kitchen"

"So much going on, but there was a few bars at the union, and one of those was quiet, there was no blaring machines, no loud music or anything, and that's where we tended to congregate."

Sensory sensitivities have practical implications in education, employment, financial security, social integration and participation, health and well-being.

There are, of course, many other barriers that can prevent people from having the right support and understanding of their needs, like stigma and lack of knowledge in society.

When an autistic person is experiencing a sensory overload and is in distress, this is often called "challenging behaviour".

And it is common to find references to impairments instead of differences, even when the results show superior abilities with respect to the non-autistic groups, like in many sensorial aspects.

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Noise levels can also affect the access of autistic people to basic services. In a recent study identifying the main barriers to healthcare for autistic adults, 90% of autistic participants marked one or more sensory challenges, compared to 29% of non-autistic respondents.

The most common challenge for autistic individuals was noise in waiting rooms, followed by crowded waiting areas, which can be related to the noise levels.

These were reasons to avoid or delay going to the GP, which obviously has short- and long-term adverse outcomes for health.

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Noise sensitivity has been identified as an influencing factor in numerous studies.

Cortisol level, blood pressure levels and annoyance are found to be more correlated with noise sensitivity than to noise levels, and it is associated with a higher risk of suffering negative effects of noise exposure, like hypertension, cardiovascular diseases, and premature death.

These studies include noise from neighbours, road, aircraft and railway noise. although there have not been major changes in guidelines and policies taking these results into account.

Far from constituting a minor nuisance, noise sensitivity can lead to individuals feeling overwhelmed, struggling to cope with changes and having control over their lives.

Being in a state of alert for long time or even a short time activates physiological and cognitive defensive reactions and the release of stress hormones.

Rates of stress-related illnesses like heart diseases, gastrointestinal problems, insomnia or diabetes are significantly higher in autistic people, particularly in autistic women.

It has been estimated that life expectancy is from 16 to 30 years shorter than the general population, being heart attacks and suicide the leading causes of death for autistic people without intellectual disability.

Now I will briefly comment some details about my PhD research, which is related to some of these topics.

We are doing now interviews to autistic people to identify:

- Common challenges that may not be addressed by current research on acoustics and perception.
- Elements that represent an “aural barrier” and need more attention.
- Common coping strategies.
- Elements with a beneficial effect in different contexts.
- And potential actions that could improve autistic people’s daily life.

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The results will be the base for next phases of the project, with a focus on providing practical and first-hand perspective to be considered by planners, developers, and policy makers, creating supportive environments, preventing negative effects, and facilitating beneficial ones if possible. Hopefully, all this will have a positive impact on autistic and non autistic people too.

It is important to note that it is not the intention of this research to form generic conclusions about the experience of all autistic people with sound. Perception and effects can be very different from one person to another, as well as in different moments in life or even in the same day for the same person.

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To finalise, I would like to discuss the consideration of acoustics as a social justice issue, since the negative effects of noise are more suffered by vulnerable and underprivileged population, and sometimes policies are not very focused on them. I think this also applies to any plan to improve soundscapes if we don’t fully consider the social implications of selling it as a way to increase the economic value of an area, which can create further inequality, segregation, and expel those who cannot afford it anymore.

It is also important to engage in a real participatory process with the communities, knowing that this is going to require an effort, that equity and inclusivity often do involve more work. But not everything should be a matter of cost-efficiency.

These are just a few quotes that illustrate this issue, but there is not much time to read them, I’m afraid.

So as main conclusions I would say that:

- Differences are not deficits. Diversity is not outlier data. Acoustics research and practice need methods considering them.
- Sensory differences can constitute a major issue for some groups of people. And this has an impact on health, social integration, financial security and overall well-being.

We have an ethical and legal duty to create environments that are less excluding from a sensorial perspective.

I wanted to finish with this quote as a reminder that there are many positive aspects of these differences too:

“I love being Autistic. I don’t just get sensory overload when things are bad, I get sensory euphoria when things are good.”

Thank you!

You can contact me also through my email or my website diffusefield.com