

ACT's Focus on Research Conference 2023

Sensory Features and Anxiety in Autism: Implications for Families and Practitioners

A two-day in-person and virtual conference hosted by ACT

Thursday, April 27, 2023 Friday, April 28, 2023

Using Artificial Intelligence to Improve Quality of Life of Autistic Children with Decreased Sound Tolerance

Presented by Elina Birmingham, PhD & Siamak Arzanpour, PhD

Territorial Acknowledgement

As visitors on this land, ACT - Autism Community Training is grateful for the opportunity to work and learn on the ancestral and unceded territory of the Skwxwú7mesh (Squamish), x^wməθk^wəýəm (Musqueam) and səlilidəta?+ (Tsleil-Waututh) people who have lived in this area since before recorded time. These nations are həndəminəm and Skwxwú7mesh speaking peoples. The həndəminəm (Halkomelem) and Skwxwú7mesh (Squamish) languages are part of the Salish Language family, which dates back many millennia. We pay our respects to elders past, and to those present and emerging. As settlers to this land, we are committed to working towards reconciliation.

Simon Fraser University respectfully acknowledges the x^wməθk^wəỷəm (Musqueam), S<u>kwx</u>wú7mesh Úxwumixw (Squamish), səlilwəta?+ (Tsleil-Waututh), qicəỳ (Katzie), k^wik^wəλəm (Kwikwetlem), Qayqayt, Kwantlen, Semiahmoo and Tsawwassen peoples on whose unceded traditional territories their three campuses reside.

Event Schedule

All times are Pacific Daylight Time (PDT)

8:15 am	_	9:00 am	Registration / Log on with Zoom Link
9:00 am	-	9:15 am	Introduction by Michelle Schmidt
9:15 am	-	10:15 am	Keynote Presentation by Connor Kerns, PhD
10:15 am	-	10:45 am	Break
10:45 am	-	12:00 pm	Panel: Experiences with Anxiety
12:00 pm	_	1:00 pm	Lunch

Day 1 – Thursday, April 27, 2023

1:00 pm	-	3:10 pm	Research Presentations
Day 2 – Fri	day,	April 28, 2023	
8:15 am	-	9:00 am	Registration / Log on with Zoom Link
9:00 am	-	10:00 am	Keynote Presentation: Tiffany Woynarski, PhD
10:00 am	-	10:30 am	Break
10:30 am	-	11:45 am	Panel: Early Development & Sensory
11:45 am	-	12:45 pm	Lunch
12:45 pm	-	1:45 pm	Future in Research

Accessibility

ACT is committed to preventing, as well as identifying and removing barriers facing people interacting with our organization. Moving forward, ACT will make every effort to provide real time captioning as well as American Sign Language (ASL) interpreters for all our events.

Acknowledgements

We are grateful to Elina and Siamak, who will be presenting on their work on decreased sound tolerance (DST) in autism and the use of artificial intelligence to improve quality of life for autistic children – including the listening device they have developed that both detects and filters out specific sounds to deliver a "clear" signal to the user's ears. ACT is grateful to Elina and Siamak for sharing their research on the use of artificial intelligence to enable autistic children to meaningfully participate in educational, community, and family activities.

Over the years, those who have attended ACT events know that as we are a small not-for-profit organization, we depend on community collaboration and support to sustain our work. We deeply appreciate the many autistic individuals, parents and caregivers, professionals, and organizations across British Columbia who volunteer their time, donate funds, provide sponsorship, and help spread the word – especially during these challenging times.

Thank you also, to Still Interpreting Inc. for providing ASL Interpretation and Accurate Realtime Inc. for providing communication access realtime translation (CART) services.

Free Resources from ACT

<u>Autism Videos @ ACT (AVA)</u> – Over 80 quality online videos on diverse topics, including Toilet Training, Sleep, Mental Health, IEP's, Research, and much more – all available free, thanks to our sponsors!

<u>ACT's Autism & Intellectual Disability (AID) Search</u> – Keyword search over 2,000 records containing evidence-based, practical information resources in 36 languages sourced internationally, including B.C.-based community resources useful to families and community professionals.

<u>ACT in Chinese</u> and <u>ACT in Punjabi</u> – ACT has been able to both create and identify valuable resources for the Chinese-speaking and Punjabi-speaking communities in British Columbia.

<u>ACT's Autism Manual for B.C.</u> – A manual for parents and community professionals with 13 chapters, including New Diagnosis Process, Contracting with Professionals, B.C. Education System, Building a Community Group, and more!

<u>ACT's Event & Training Alerts</u> – Sign-up to keep in touch with our upcoming events and training opportunities.

<u>ACT's Facebook</u> – ACT carefully sources interesting, insightful stories to inform our community of over 9,000 followers.

Using artificial intelligence to improve quality of life of sound-sensitive children on the autism spectrum

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1

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Partner ACT-Autism Community Training

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2

Autism and sound sensitivity

Sound sensitivity, or decreased sound tolerance (DST)

- Broad term that describes people who show abnormal responses to sound
 without any corresponding differences in hearing thresholds
- Common in Autism: estimated prevalence 50-70 % (Williams et al., 2021)
- Significantly interferes with autistic children's participation in everyday activities
- (Scheerer et al., 2021)

 Associated with poorer mental health and quality of life in adults (Scheerer et al.,
- Associated with poorer mental health and quality of life in adults (Sch in prep)

Problems for understanding DST in autism

• When trying to manage DST, we are met with 2 problems

- 1. There are patterns, but there is no pattern...
- 2. Current solutions for helping those with DST are limited
- 4

Problem 1: There are patterns but there is no pattern

Example: Types of DST (Fackrell et al., 2017; Williams et al., 2021)

- Hyperacusis (the perception of everyday sounds as excessively loud or painful. These sounds would not bother most people.)
- Misophonia (excessive and inappropriate emotional responses to specific trigger sounds often human-produced sounds, such as chewing, lip-smacking, sniffing, swallowing, and tapping)
 Phonophobia (a specific phobia of sound)
- Filonophobia (a specific probla of source
- However, these conditions are not mutually exclusive (Scheerer et al. in preparation), and the lines
 between them are difficult to draw
- Unrelated to hearing thresholds (Williams et al., 2021)

Problem 1: There are patterns but there is no pattern

Example: Reactions to sound vary in type and intensity

- Stressed (82%), irritable (64%), scared (52%), nervous (48%)
- Reactions can be context-dependent
 Even aversive sounds are not always aversive (e.g., if person has control over the

Scheerer et al., JADD 2021

sound)



Problem 1: There are patterns but there is no pattern



7

Caregiver examples

- "He says that dogs barking, buzzers and crowded areas that are loud make his ears hurt and is scary for him. He says it's scary because it surprises him."
- "He says the sound of sweeping with an outdoor broom hurts his ears and is painful. He says the sounds at a hockey game or in a crowded mall are annoying and make him feel irritated and overloaded."
- "He has said that when a sound bothers him he can't concentrate on anything else and it's distracting"

8

Caregiver examples

"My son has had sound sensitivity since he was an infant. It affects everything we do, simple outings to a mall – we have to plan carefully around the washrooms, the flush toilets are very loud; the hand dryers are very loud. We have to make sure we use the toilet at home first, and make sure that wherever we go whether it's a restaurant or a mall that we can access a handicapped bathroom; he still needs assistance with toileting so we make sure that one of us can be in there and that we do not run the dyers, I pack paper towels and Kleenexes in my purse to dry his hands or he can use my sweater to avoid using the hand dryers.

Caregiver examples

"In the school setting, the noise at lunch time in high school cafeteria prevents my daughter from making social connections. She isolates herself in a hallway...but as EA's do not monitor her at lunchtime, they miss an opportunity to encourage a few students to spend some time with my daughter in another location. Instead, every lunch is spent in solitude."

"Screeching, wanting to hit, run, knee himself in face"

"Completely 'freaked out'. He could hear an ambulance siren at least 3 minutes before anyone else heard it. Very frightened and tearful."

10

Examples from autistic adults

- "Unable to fully participate in society because so many noises trigger me and so few people are willing to understand and accommodate. Attempts to get accommodation usually results in being bullied and/or abused."
- "It makes it much more difficult and makes me much more stressed and irritable. I have four children and it has made activities with them more stressful as well."
- "I avoid going in public places that I know will be too noisy for me and have almost been hit by cars because my noise cancelling headphones drown out vehicular sounds which I also happen to be afraid of"

11

Problem 1: There are patterns but there is no pattern

- Mechanisms of DST are unclear and potentially numerous (Williams et al., 2021) • <u>Increased central auditory gain</u> (Auerbach 2019), possibly driven by auditory brainstem dysfunction or excitation/inhibition imbalance in cortical and/or subcortical areas (Williams, 2021)
- <u>E/I imbalance</u>: imbalance in the ratio of excitatory and inhibitory neurotransmission (E/I ratio) in key subcortical and cortical auditory structures (McCullagh et al., 2020),
- <u>Problem with sensory gating</u>: abnormal (thalamic) sensory gating/filtering system, leading to sensory overload (Miller et al. 2009; Matsuki et al., 2014)
- Sensory-Limbic connections: heightened activation of primary sensory cortices and amygdala, i.e., increased saliency and arousal (Green et al. 2015)
- We don't yet know which of these is most relevant but each has implications for treatment/management

Problem 2: Current solutions are limited

- Behavioural (e.g., Avoiding noisy settings: 82%); warning child of upcoming sound: 94%)
- Exclusion
- Relies on the presence of a knowledgeable human
- Wearables (e.g., Ear defenders, ear plugs, noise canceling headphones)
- Block too much
 - Safety concern Social Exclusion
- Do not block enough (e.g., fail to block the very sounds that are problematic) None can deal with the individual nature of the problem

13

Desired solutions (autistic adults)

- "Understanding in others no gaslighting (e.g. "you're too sensitive"), Ability to tune out triggering sounds"
- "Headphones or ear muffs that block background noise but allow a main focus sound to pass through (eg if a person is talking to me in a busy restaurant, block all the other sounds except the person's voice)"
- "Understanding employers that will accommodate for these things."
- "More accessible noise canceling earwear."
- "I wish it was appropriate to wear headphones everywhere and in every situation"
- "Ear plugs that cancelled noise but allow me to hear what I need to hear"

14

Overarching Goals and Expected Impacts

Develop and test new solutions that are better suited to the

- unique problem of DST in autism
- Smart device that intelligently detects and filters aversive sounds that are specific to the end-user

Increase participation in social, educational, and recreational

settings

- Improve quality of life
- Lead to better educational and social outcomes

Our device

Two parts:

- 1. Detect the sound (deep neural networks): Siren, dog barking, baby crying, car horn, jack hammer - with 98% accuracy
- 2. Manage sound:
- suppress the signal by stopping the transfer of the signal from the
- microphone to the headphone • attenuate the ambient sound by lowering the volume
- remove the aversive sound signal from the mix-signal (smart filtration) • or mask the ambient sound by playing pre-recorded sounds

Parts 1 and 2 occur within 1.375 sec of sound onset

16

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17

Additional features

- Device will learn over time (intelligence)
- Fully customizable
- · Gradual exposure function will be built in for those who wish to use it
- · Safety signals (e.g., tactile or visual alert when siren detected)







Step 2: filtration

- After an aversive sound is detected, the system can decide how to manage the sound
- A potential solution to DST is to selectively filter only the aversive sound as opposed to blocking all sounds
- The challenge is, as we said earlier, there not a general pattern so typical digital signal processing techniques that are used in noise canceling headphones are not effective.

22

Demo of filtration performance



23

Comfort rat	ings	(autist	ic adults)	
	Mean	SD	t-test vs. baseline (p value)	
Siren baseline	3.72	0.44		Higher ratings reflect
Siren with Music	2.78	0.79	0.03	more
Siren with White Noise	2.67	1.00	0.02	discomfort. 1=very
Siren with Filter without Speech	2.61	1.11	0.02	comfortable, 2=somewhat
Siren with Filter with Speech	3.28	0.91	0.21	3=somewhat
Dog baseline	3.56	0.46		uncomfortable;
Dog Barking with Music	3.22	0.71	0.26	4=very
Dog Barking with White Noise	2.58	1.25	0.06	Baseline = no sound
Dog Barking with Filter without Speech	1.94	0.73	0.00	management.
Dog Barking with Filter with Speech	3.17	0.79	0.09	



Participant feedback (autistic adults)

"Seemed to work very well... It's the same as noise cancelling headphones with sound, it was good. I prefer the filtering over music or white noise - still able to hear what is going on around me.

When I listen to music or white noise, I am cut off from all sound, which in some situations could be problematic...

Could not hear the dog barking at all, other than through the external laptop speaker."

25

Current and next steps

 Test the device in an immersive virtual reality (VR) setting (Spring & Summer 2023)

- Seeking participants to give us feedback on our approach!
- Youth and adults
- Compensation for participation
- 2. Field test the device in a real classroom setting (Nov 2023-March 2024)
- Youth and adults
- Community settings
- \$100 honorarium
 In partnership with
- In partnership with ACT-Autism Community Training



Thank you

We are deeply grateful to the autistic individuals and their families who have participated in our study so far

