The SOUNDSRITE Program



Auditory Differences

Stella Waterhouse is an author and speaker specializing in autism and sensory differences.

Personal experience has also made her passionate about helping people who live with the debilitating effects of auditory differences.

Such problems often affect people on the autism spectrum as well as those with Attention Deficit/Hyperactivity Disorder and other learning differences.

INTRODUCTION

Even as a child I was aware that certain situations made me very uptight though I simply didn't understand why. All I knew was that in a classroom full of noises - with chairs creaking, books rustling and pens scratching I just could not concentrate properly. That I hated the school dining room because sitting opposite someone when they were eating was extremely unpleasant. That some music was so painful that I either avoided it or had to stick my fingers in my ears to block it out.

Those problems remained throughout my teens and well into my adult life but like most people I simply adapted to the constrictions they placed on me. Being a natural introvert, it wasn't too much of a hardship to try and avoid the things that other people seemingly found pleasurable - like concerts, parties or eating out - although had I been more of an extrovert I would probably have found it very hard indeed.

Over the years I sometimes wondered fleetingly why most people liked nothing more than spending an evening out with friends in a nice restaurant. Didn't they hear the noise as the people with them chomped and gnashed? Why they enjoyed going to concerts or the opera - and didn't even block their ears at the painful bits? But like many others I pushed those thoughts aside as I got on with enjoying my life and work.

In fact, it was only when approaching 50 that I decided to write a short booklet on the links between autism and anxiety (something that has now grown into several full-length books as well as some shorter books for time-poor parents and teachers.)

However, once I began my research I suddenly discovered a frightening "new" world ruled by the sensory differences and great anxiety. It's a place where what the child hears is not necessarily what you hear. Where what the child sees is not what necessarily what you see. Where how the child experiences a hug is far removed from your loving feelings as the "hugger".

So, it was that one evening, sitting in my living room, with research books all around me, that I had my epiphany. Everything I was reading about was describing much of my sensory differences. And yet I don't have autism. Nor Asperger's syndrome. So how on earth could that be?

Intrigued, I went back to my books. More research. More reading. The results amazed me. Firstly, those sensory differences were - and are - far more widespread than I expected for they affect people from all walks of life. Secondly, they come in varying degrees and could affect either just one sense or several.

In one group we find people whose "mild" sensory differences give rise to physical symptoms like migraine or travel sickness. That's where I found myself – although while the sensory differences are mild that hardly does justice to the debilitating effects that frequent migraines etc can have on the person's life.

In another are people whose sensory problems may cause a variety of speech and language problems some of whom will also have learning difficulties like Attention Deficit Hyperactivity disorder or even dyslexia.

Finally we come to those who have the severest sensory differences – generally in all their senses: as found in people on the autism spectrum.

So, what did that tell me about myself? The main thing was that I had had hyperacusis (hypersensitivity to sound) for as long as I could remember although I never knew it. That explained just why I disliked some sounds, "hated" the sound of sopranos singing, avoided certain situations whenever I could and simply had to "get away" if a dog began panting when I was anywhere near it.

While the precise cause of my sensory differences is unclear there are certainly some family links for, whilst migraines run throughout several generations, I have clearly inherited hyperacusis from my mother. She has had it all her life - and, even now that she is rather deaf, she can still hear some sounds very well indeed.

So finally, I had managed to identify one aspect of my problem. Fascinating - but not really any help in dealing with its effects. But fortunately, my ongoing research into autism provided an answer.

I had always believed that the best (and only) way to understand just what it felt like to be autistic would be to read the accounts of people who lived with it on a daily basis. But at that time - in the late 1980s - the biggest snag was that few autobiographies existed: something you may find difficult to believe in this day and age when accounts abound.

My only other option was to talk to many of the 'autism" parents that I knew and read as many parental accounts as I could find. And it was there that I hit gold for among them was a biography written by Annabel Stehli, whose daughter Georgie had autism.

She describes the various sensory problems that Georgie had: most notably her hypersensitivity to sound which was later identified as a major factor in her "autistic" withdrawal and behaviors. As Georgie told her mom "The sound was the only thing that drove me crazy because I was so scared...and sound was going on all the time. It was hard to get away from it.

Fortunately, at the age of twelve Georgie underwent a treatment which corrected those so that after treatment she was able to tell her mom that: "... she was much more comfortable, that she no longer heard street noises three blocks away, or people flushing their toilets at the other end of the building, or the blood rushing through her veins".

Written several years after Georgie had been treated the book also included details of the who and the how; detailing the work of the late Dr Guy Bérard, a French Ear Nose and Throat specialist who spent much of his life working with a wide range of people whose common link was that they all heard and processed sounds in a somewhat unusual way.

During his career Dr Bérard developed a treatment called Auditory Integration Training or AIT which he then used successfully for many years with a vast number of patients, some of whom simply suffered from hyperacusis; others having associated problems that ranged from speech and language disorders to the learning difficulties I've already mentioned.

And that was one of those "light bulb moments". The moment I suddenly found that help was available. Help that I'd like to share with you. However before I do that perhaps I should tell you a little more about the often overlooked and misunderstood problem of hyperacusis for unless you have experienced it for yourself you may not fully appreciate how devastating it can be.

HYPERACUSIS

In a world where every day is permeated with a richness of voice, music, and "around" sound, hearing is one of our most important senses: one that enables us to communicate with others easily.

Even so our lives are often filled will less pleasant sounds: from traffic noise to the all-pervasive music that fills so many stores or those irritating and tinny sounds that blare out of the telephone while you wait to be connected. Hardly surprising that complaints about noise pollution are relatively common. And yet even those who complain or get stressed in noisy situations generally learn to block out those sounds as they concentrate on more important matters.

But what if you are not able to block out such sounds? Life would be intolerable, wouldn't it? That is why noise has long been misused as a form of torture: a misuse clearly portrayed in the movie The Ipcress File in which Michael Caine (who plays the hero, Harry Palmer) is sent to investigate why some leading Western scientists had been kidnapped only to reappear a few days later; brain washed.

If you have seen it you may remember how Palmer himself is kidnapped, coming round to find himself locked in a cell where he is subjected to a gruelling "brainwashing" session in which his kidnappers try to drive him mad with intense noise: sound that permeates his very being. The only way he can remain sane is to focus so intensely on something else that his brain blocks the sound out: so, he presses something sharp into the palm of his hand until it bleeds.

Imagine what it would be like to live in a world where such "torture" was a common daily occurrence. The first video in this mini-series mentioned a relatively little known, and often overlooked, condition. Hyperacusis - a hypersensitivity to specific sounds - can be extremely painful, debilitating and extremely stressful frequently interfering with the ability to concentrate.

Unless you have actually experienced hyperacusis yourself or found the pounding of music from a neighbor's house or at a concert or disco to be overpowering and painful, you simply cannot appreciate how devastating its effects can be.

So what does hyperacusis feel like? Strangely each person has individual sounds that they find intolerable. For some it is the louder sounds like that of a vacuum cleaner or a noisy washing machine and yet for others it is much quieter and seemingly innocuous sounds that cause problems; like a newspaper being folded, a dog barking in the distance, the hum of a fan or even the noise that other people make when they eat. Indeed, there are even some people who find some speech sounds hard to cope with, making conversation – even over a telephone – very unpleasant.

So how anyone could be tortured by such sounds? There seem to be two aspects to it. One, that people with hyperacusis hear even the quietest of sounds as if they are REALLY **LOUD**. This is the child who wouldn't go out in the garden because the beating of butterflies' wings and the noise of other insects was too painful. Or the child who, on visiting his aunt, refused to leave his Mom's car which was parked on the drive – simply because he could hear someone using a vacuum cleaner inside the house.

To make things even worse, the person simply cannot escape that sound for they cannot automatically

"block it out" as most people would. So, anyone who has hyperacusis is literally "tormented" by various everyday sounds that most people ignore or at least tolerate. Nor are those the only symptoms for some people also find that their ears actually hurt or just generally feel uncomfortable.

However, because it is not well-known condition, some people are actually unaware they have it. Even when they may have evidence something is wrong such as when their nearest and dearest may find they become irritable and short tempered in certain situations, perhaps when in the kitchen while someone is washing up.

Sometimes though even people who lack a diagnosis recognize that some specific sounds are too unpleasant to bear. Some go out of their way, often literally, to avoid particular situations: like the man who, whatever the weather, went out for a walk every time his wife did the vacuuming. Others may even cause family friction like the woman who kept turning the sound on the television down so low that the rest of her family couldn't hear it.

But take away the ability to control your environment and life can become extremely difficult as with the unfortunately named Mrs Fussy who took her neighbors to court because the noise from the birds in their aviary in their garden kept her trapped indoors.

Easy to laugh perhaps but if you have ever experienced anything like it you would know that hyperacusis can indeed make life a misery - as it does for many people who are hyper to some of the unavoidable sounds they hear at school or work.

Let's see if some well-known sufferers can tell us how it feels? Annie Proulx, the highly acclaimed author of "Brokeback Mountain", finds excessive noise hard to cope with and, as a child found that, 'the most dreadful sound in the world' was that of her mom vacuuming. Author V S Naipaul gave a clear indication of the distress such hypersensitivity can cause when he said how "immensely happy" he was when his hearing "began to degenerate".

Nor are they alone. One of the saddest things I have ever heard was someone saying that he was going to ask his doctor to operate to make him deaf. Difficult to imagine being that desperate isn't it?

Most of the research into this subject has generally been in relation to older people (mainly because hyperacusis is thought to be associated with or contribute to tinnitus) but despite that hyperacusis actually affects people of all ages and, despite reports that suggest the incidence is very low, seemingly affects quite a large proportion of the population.

Some acquire the problem after injury or illness and suddenly find that sounds that they previously enjoyed have suddenly become uncomfortable and extremely irritating. Hard to cope with when the music you like is suddenly so unbearably loud that you simply can't concentrate. Just imagine life in a busy family when you are continuously asking your spouse or children to talk quietly or getting irritable and tense with them because they have their music or the TV up too loud.

Then there are those who, like myself, have had the problem since childhood. Perhaps unsurprisingly it is also especially prevalent in children on the Autism Spectrum where, not surprisingly, it's effects can be both severe and even dramatic like the child who suddenly runs away and there's no obvious cause. Hyperacusis is the reason some children cover their ears in certain situations or refuse to go into places. Or become very agitated and upset at mealtimes or in noisy situations. Sadly though such behaviors are often misinterpreted as bizarre "autism related mannerisms" rather than being correctly identified as perfectly natural reactions to hyperacusis.

You have already heard about Dr Bérard's work and how it not only gave a name to a problem I had had from childhood but also offered hope to those with childhood hyperacusis. That hope spurred me on to train as an Auditory Integration Training practitioner in the late 1990s, after which I set up a therapy center (in the UK) where I used it with children and adults, the majority of whom had autism. During that time I also successfully treated my own hyperacusis: something that certainly reduced my stress levels and enabled me to enjoy things that I used to avoid.

Unfortunately, I had to close the centre when we moved to live in a small coastal town in Devon (in the UK) but even so I continued to research and write about both the sensory differences and Autism Spectrum – as I still do today.

Over the past five years I have been researching and writing my forthcoming series Autism Decoded – to be published next year. Despite that I have also made time to develop a home-based audio program broadly based on Dr Guy Bérard's ideas but with the additional benefit of my personal experience of hyperacusis and my research into and knowledge of the Autistic Spectrum.

Three tips for coping with the effects of hyperacusis:

- If you know which sounds hurt share that information with the other members of your family so that they can avoid them or warn you in advance (if they are going to use the vacuum cleaner for instance).
- Create a quiet "sanctuary" at home (or even the bottom of the garden) and preferably go there before the thing you dislike (vacuuming, washing up and so on) begins.
- Where possible avoid the situations you find uncomfortable in but if that is not possible use earplugs or listen to some soothing music through headphones.

The inability to tolerate the loud noises that other people take in their stride can be a problem too. Anyone which such a problem can find themselves literally overwhelmed by sound – and that can even have physical effects too. In her book *A Real Person*, Gunilla Gerland (who has Asperger's syndrome) describes how the noise of a moped revving disorientated her so much that the ground seemed to disappear beneath her and she expected to fall over or explode from the inside at any moment. Just imagine how awful that must be.

Hardly surprising that many children with learning disabilities like autism have a "meltdown" or freeze on the spot when a fire alarm goes off suddenly – as you may remember if you have ever seen the film *Rainman* where the main character Raymond simply covers his ears and screams; while staying in the room.

Then there is "super-sensitivity" when a person hears things that most other people are unaware of. My husband calls me "bat ears" because I always hear both sides of the conversation when he talks on the

phone, but other people are far more sensitive than me, hearing the hum of a whiteboard fan or even a mosquito in another room.

Once again children with autism are among some of the most sensitive (as is often reflected by the fact that they speak very quietly). That can lead to apparently strange reactions as with the one boy who ran off after hearing a "silent" dog whistle.

There are also some people with autism who are actually tormented by internal sounds; like the boy who said that his ears were noisy inside, making a constant 'shushing" sound, or the girl who said she could hear the blood flowing in her veins and the sound of her heart beating. Can you imagine it? Perhaps it is hardly surprising that many of them find it hard to concentrate and learn.

OTHER AUDITORY DIFFERENCES

Other common auditory differences can result in the person mishearing what has been said and that can cause misunderstandings and increased anxiety so understanding why it happens can help.

It is quite common to mishear words in songs, like the child who thought the Bee Gees' were singing "Ah! Ah! Ah! Ah! Ah! Stabilise! Stabilise!" when they gave their rendition of "Staying Alive". Even so there are many people who mishear more commonplace words, replacing them in their minds for another word, even if it is seemingly absurd or out of context. It can often be a gift for a comedian as it gives rise to terms like "holiday sauce" instead of "hollandaise sauce" or leaves someone "internally grateful" instead of "eternally grateful".

You may even have had a similar problem yourself when listening to a sales call over a telephone or to someone who has an unusual accent or simply mumbles. Easy to go from mishearing one or two words to substituting your own and, in the worst-case scenario, going on to misinterpret the whole conversation.

In the past Freudians thought that such slips were the expression of deeply repressed feelings or conflicts and yet, if your hearing is awry in some way - as with someone who is gradually going deaf, such slips are perfectly natural.

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Several factors can be involved in mishearing. These could include:

All it needs is for a child to have a slight deafness that goes unnoticed, and yet even that mildest of differences is enough to delay the development of speech and language. Such problems affect many children with autism although, once autism has been diagnosed some professionals stop looking simply attributing such problems to the autism itself.

Even so the signs are obvious once you know what to look for. One is that such children often have noticeable differences in the way they speak because they are unable to clearly hear the rise and fall of voices or the emotions they convey: something that is then reflected in a voice that is monotone, emotionless or overly loud.

This is the child who taps or bangs the wall as he walks (just as a deaf child might). A child who is fascinated by noisy things like the washing machine, lawn mower, noise of the sea or thunder. One who enjoys playing noisy games, banging, shouting, flushing the toilet, slamming doors, ripping paper – and more.

Similar problems can also arise when people hear better (or more quickly) with one ear than the other or if they mishear specific sound frequencies. That is because such things make it hard for them to discriminate between different sounds - so that they often 'mishear' words and even misunderstand whole sentences.

It makes it very hard for them to identify where sounds are coming from. A fairly minor thing you might think and yet it's impact can be tremendous. Imagine the potential danger of not being able to tell where the traffic is when you are on the pavement/sidewalk or hearing a siren when you are driving but being unable to tell where it is coming from.

Another aspect of this is that some people seem to hear the beginning and end of a sentence clearly but the middle is just a jumbled string of sound while others hear part of a sentence before it tails off into a mumble.

Any and all of the above can lead to a whole range of misunderstandings; some amusing, some confusing while those that relate to medicine or safety can be potentially dangerous. On occasions mishearing can even lead to arguments or disputes as when one person "hears" something that they misinterpret as rude or disparaging.

They can also cause great anxiety, as when a friend of mine had a sales call which started by saying: "This is an important call". Although she didn't hear the rest clearly just those few words made her think the worst. Was it the police or a hospital calling about a member of her family? It was only two or three hours later when she had contacted them all – and found that one of them has also had such a call and had heard it to the end - that she was able to relax.

As you will know if you have any of the difficulties mentioned, life (and your relationships) can be extremely hard at times. While you may be able to cope with a conversation between just you and one other person, especially if they recognize and makes allowances for your difficulties, it can be extremely hard to carry on a conversation in a group of people or in any noisy situation from a schoolroom to a bar.

Sadly, your problems may even be compounded when you see how easily others converse: and that may undermine or destroy your confidence and self-esteem.

To help people who have such problems:

- Make sure you speak clearly and slowly.
- Break information/requests/instructions into short sentences'
- Emphasize the most important things you want them to understand.
- Do not raise your voice it will not help and may make the person you are speaking to feel as if you are annoyed at them.

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• Make sure you do not mumble - or turn away - when you are talking.

If such things affect you or your child the 10 day home-based Soundsrite Program may be just what is needed.

THE SOUNDSRITE PROGRAM

Auditory Integration Training (commonly known as AIT) was developed by the late Dr Bérard. He used it to treat his own impending deafness as well as using it successfully with a vast number of patients. Their common link was that they heard and processed sounds in an unusual way so, while some had hyperacusis, others had a variety of auditory differences and associated problems like speech and language disorders or learning difficulties.

AIT is often referred to as an educational program. This non-invasive 10 day "listening" program simply consists of a wide variety of music, all of which has been specially modulated. That modulation is the key to "retraining" the ear, normalizing the way in which they hear and also helping the brain to process auditory information correctly.

In the past access to AIT has been limited, partly because of the expense and partly because it often used to entail traveling to a "treatment center" - often miles from home. Since experiencing the benefits for myself I began to wonder how I could make it more accessible to more people on the autism spectrum, as well as those with attention problems or sensory processing differences.

While there are now several home-based programs many people still go live with such auditory problems, some simply because they don't have easy access to such vital treatment. Some people may question my use of the word "vital" and yet that is exactly what it is for many children. That is because unless you hear clearly you will be at a very real disadvantage at home, in the classroom and throughout life.

"Vital" is also especially true in relation to children with hyperacusis for when some sounds are physically painful the child quickly learns to block them out, and can even become afraid to listen. And when that hyperacusis is extreme – as in autism – it results in the child blocking out both those painful sounds as well as those they need to hear if they are to socialize and learn.

Such factors spurred me on to develop an accessible, home based program. Aimed at helping people with a variety of auditory differences, including developmental hyperacusis and the problems associated with autism, it is very easy to use. All you need is a set of headphones and a reasonably quiet place where you can spend 2 half-hour sessions a day listening to music.

Unlike some other similar programs this is broadly based on Dr Bérard's ideas but has the added benefit of my personal experience of hyperacusis and of the program itself.

POTENTIAL BENEFITS

Unfortunately, results cannot be guaranteed but most listeners have reported a number of beneficial effects, although those are obviously dependent on the person's original difficulties. The potential benefits can include:

- reduced hypersensitivity to sound
- greater tolerance of loud noises and sounds that previously hurt
- reduced stress feeling calmer and less irritable
- better eye tracking
- increased confidence and self esteem

It also helps reduce some of the other effects like those involved in speech and language delays or some of the other associated difficulties found in children with learning differences, developmental delay or autism.

That means that the child may:

- be less hyperactive less impulsive and distractible
- behave better
- have clearer speech/improved articulation
- show less obsessive/compulsive behaviors
- sleep better
- be able to listen, concentrate and learn better than before
- have better understanding and be more able to remember things
- have less need to withdraw from situations
- be more communicative
- be more sociable even wanting to take part in social experiences

While the results above tend to be seen once the program is completed, some changes may be noticeable as soon as midway through the program. One example was the child who had always grabbed his mother's hand for reassurance when large trucks went past. A child who, by the 7th day into the program, was now peacefully unaware that one had just roared passed him. Another was the man in his 20s who had autism. After being afraid of cats all his life on day 6 of the program he went up to one and tried to stroke it.

Some of more obvious benefits will be seen after the program ends but progress often continue over the next few months; as the person becomes accustomed to hearing in a "new" way or gradually loses the "avoidance" techniques they have come to rely on.

Even so for some people, completion of the program provides a new beginning; especially if they have missed out on the usual developmental milestones and/or opportunities for learning in their early years. That's why the associated Handbook includes advice on Aftercare to enhance and consolidate the child's progress.

To determine whether this program would be helpful to your child

please fill in whichever is the most appropriate Checklist - as shown oveleaf.

CHECKLIST 1

MILD - MODERATE AUDITORY DIFFERENCES

These are often most noticeable when the child is young

- History of hearing loss/ear infections/developmental delay
- Has difficulty following conversations or verbal directions
- Mishears some letters/words and sometimes misunderstands what is said
- Relies on lip-reading, gesture, context or just plain guessing to understand what is being said
- Often asks people to repeat things
- Has dyslexia or tinnitus
- Has APD/CAPD see separate list below
- Has hyperacusis finds some specific sounds painful. May leave the room or even the house when something noisy like the vacuum cleaner is on
- Often irritable or loses temper for no apparent reason
- Light sleeper wakes easily
- Dislikes or avoids:
 - noisy situations/background noise
 - social contact or interaction
 - ➤ concerts
- Enjoys or seeks quiet spaces/places
- Has difficulty taking notes during speech or lecture
- Enjoys constant activity
- Often startled by sudden sound or movement
- Frequently notices sounds before others do
- Sings out of tune or have difficulty singing with others may always be a bar behind

CHECKLIST 2

SEVERE AUDITORY DIFFERENCES

Often found in people with ASD these severe differences are most noticeable in young children or when they first begin to occur.

- May initially be considered deaf
- Seems to ignore sounds/speech but may hear and recognize the rustle of sweet- papers etc.
- Speech difficulties -
 - > speech does not develop (but is not deaf) or development is slow
 - has echolalia
 - > speaks clearly but only occasionally; consistently mispronounces some words
 - > speaks in a monotone; too loudly; too softly
 - > develops speech only for it to deteriorate/disappear either gradually or suddenly
- If given two instructions is only able to carry out one task or does neither
- Dislikes some noises and demonstrates this by:
 - putting hands over/in ears
 - moving (or running) away
 - getting upset or distressed
 - ➢ going into 'a world of his/her own'
- A very light sleeper wakes easily
- Frightened of some animals like dogs or cats
- Seems to hear noises which other people might not be aware of e.g. the hum of fluorescent lights, people breathing etc.
- Can often correctly identify distant noises (before others hear them) or can overhear distant conversations e.g. both sides of a telephone conversation
- Dislike bathing, haircut's, shaving, teeth cleaning etc. Because of the noise of the
- water, scissors, razor etc.
- Dislikes the sound of a toilet flushing
- May finds mealtimes difficult as dislikes the sound of people eating
- Dislikes/gets upset in shops, crowded situations, shopping, rainstorms, wind, seaside etc.
- Learns/concentrates better in quiet surroundings
- Enjoys loud rhythmic noises i.e. Washing machines, vacuum cleaners
- Enjoys being in control of noisy objects e.g. likes playing with running water, flushing the toilet etc.
- Talks constantly/loudly
- Likes/does things that make a noise; squeaking toys, tearing paper, banging doors etc. as being in control of the noise makes it predictable and it also helps them block out other more unpredictable noises
- Likes listening to music for the same reasons as above

FREQUENTLY ASKED QUESTIONS

Q. Do I need a hearing test prior to taking the course?

A. You are welcome to arrange one if you would like to but, an ordinary hearing test will not pick up hyperacusis or some of the other differences, so it isn't really necessary.

Notes:

- An ordinary test may simply show that the child/adult has good or even exceptional hearing.
- Even so please use the checklist to ensure that your child is a good candidate for the Soundsrite Program.
- **Q.** Do I need to do anything?
- A. No all you need to do is sit somewhere quiet, put the headphones on and then relax and listen.
- **Q.** Does it hurt?
- **A.** The first few sessions are played very quietly in order to minimize any problems so generally most people find the music quite pleasant.

Initially a few sounds may seem a bit uncomfortable but the discomfort will fade as the program progresses.

- **Q.** Are there any side effects?
- **A.** Some people have no side effects at all.

Others may experience one or more of the following:

- excessive tiredness and/or irritability especially at the beginning of the course
- a mild headache, mild dizziness or increased car sickness particularly around the second day or for a brief time at the end.

Side effects are generally short lived and tend to indicate that the program is having a beneficial effect.

- **Q.** Can I take a break during the course?
- A. Yes. It's perfectly okay to take a couple of days off midway through the course (after session 10).
- **Q.** Does the program have to be repeated more than once?

A. In my experience the majority of people only need to use the course once – although some people may occasionally benefit from more than one course.

NOTE: While some practitioners suggest that it can benefit anyone who wants to improve their listening skills, The SOUNDSRITE program is **ONLY RECOMMENDED** for people whose hearing differences are interfering with their daily lives.

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