

Episode 12- Selective Mutism and Occupational Therapy

Hello and welcome to the Selective Mutism HELP, Home Educational Learning Program, Podcast, my name is Kelly, and I will be your host. This podcast aims to give you the help you need to support the person in your life affected by Selective Mutism. In this episode I will be talking about how Occupational Therapy could help someone with Selective Mutism. I'll be talking about what Occupational Therapy is and how it helped our daughter begin to overcome her Selective Mutism. Let's get started.

Welcome to episode 12 of the Selective Mutism HELP Home Educational Learning Program podcast. My name is Kelly, and I am a parent of a child with Selective Mutism. Being that I am a parent and not a medical professional, this podcast is for informational purposes only. To be honest, I had no idea what Occupational Therapy, or OT, was for the longest time. I would read and re-read the definition of Occupational Therapy over and over again – a form of therapy for those recuperating from physical or mental illness that encourages rehabilitation through the performance of activities required in daily life. I never understood how it would help our daughter with SM. She didn't have a physical or mental illness where she needed rehabilitation. She performed very well in her daily life – she could get dressed herself, feed herself, played well, and was academic, she just couldn't speak in certain situations. A very good friend of mine worked as an OT, so I invited her out to dinner so she could tell me more about it. She gave me information such as it helps people find ways to work around or through an obstacle in their life so they can live their best life. Ok, it kind of started making more sense. I still wasn't sure how it could help someone with Selective Mutism, so I met up with a mom whose SM child went through Occupational Therapy. She told me they would do various exercises to help reduce the level of her son's anxiety. They would use weighted vests and blankets and do arm compressions to help relieve some of the anxiety he was feeling. They had great success with it. Alright, this was starting to sound a little better. The reason I was looking into OT was because I felt like something was preventing our daughter from progressing to the next level with her ability to communicate. We had done CBT with an SM specialist and we had her on a therapeutic dose of medication, but she still seemed stuck and I felt like something more could be done to support her brain on a different level than CBT and medication.

So, in October of her kindergarten year, a year and a half after her being diagnosed with SM, I scheduled her an OT evaluation, still not knowing how any of this was going to help. I had my reserves going into the evaluation, but about 5 minutes in I realized this was the best decision for our daughter. I felt like it was the first time I was actually being heard when it came to the concerns we had with our daughter. If any of you are familiar with Anna Biavati-Smith, she says over and over again that SM is more than the fear of talking. For our daughter it was sensitivities to sound, inability to control her emotions causing tantrums and meltdowns, issues with balance causing her to trip a lot, not being able to do simple things like jumping jacks, bedwetting, her inability to sit still and the need to be constantly doing something, oh and of course, not being able to talk in school or to extended family. As I went through all of these things the therapists were truly listening, showing compassion, and not passing judgement on me as a parent. It was so freeing as a parent to get all that out and to actually feel heard. As I was talking to them about all my concerns, they were doing different evaluations with our daughter. They did various puzzle like exercises, had her throw objects at a target, tiptoeing, among many other things. The most amazing part of the evaluation was how engaged our daughter was during it. She did everything they asked her to do and they never put her on the spot to answer a question vocally or told her she needed to speak. She was so relaxed and had so much fun.

It took a couple weeks, but we finally got her evaluation back. It was found that she had significant auditory processing deficits which made it difficult for her to stay on task in busy environments – made sense why she was having meltdowns when she got home. Schools are busy all day long and to have issues with trying to focus on a task at hand when all you are focused on is the sounds around you, that has got to be exhausting! She was unable to manage unpredictable environmental stimulation which resulted in emotional dysregulation – another reason she was having meltdowns at home. She would seek out movement to regulate her state of arousal which meant she was constantly fidgeting and moving, which could potentially cause a safety risk. They also noted that even though she was attending well to the therapist doing the evaluation, she would frequently check in with me by looking in my direction or physically touching me – she has pretty severe separation anxiety with me. I'll actually be going more in depth about this in a future episode. During the gross motor part of the evaluation they were able to find that she had decreased timing and sequencing throughout bilateral coordination tasks and had limited crossing of the midline. Her movement patterns were deliberate and laborious instead of smooth and mature. The biggest surprise that occurred happened when they started testing her vestibular system. The vestibular system has to do with the small structures within the inner ear and it gives us a sense of balance. It allows the body to know where it is in space in relation to gravity. It helps us know when we are right side up, upside down, or if our head is tilted to one side or the other. To get a sense of how developed or underdeveloped the vestibular system was for our daughter, they had her lay on her side on a spin board. It does exactly as the name implies, it's a board that spins. My understanding is that a well-developed vestibular system will allow a child to be spun 10 times with minimal nystagmus or shaking of the eyes, or at least a quick recovery from the eyes quivering. After our daughter was spun in a slow circle one time, her eye quivered back and forth for 13 seconds. Thirteen seconds! I was shocked and astonished! I also became very emotional. I could not believe just how bad things must have felt for our daughter. Her body really had no idea where it was in space. If her feet were dangling, she wouldn't know how far they were away from the ground which is why she was always wrapping her legs around chairs. She needed to feel a sense of grounding. If she set something down and turned around, she wouldn't be able to know where she put the item because to her it fell into a black hole. No wonder why she could never find anything when I asked her to! Since her body didn't know where it was in space, it created a lot of anxiety. That anxiety manifested into Selective Mutism. If I was felt like I was falling into an abyss constantly, I wouldn't want to talk to anyone either! How scary! Everything was starting to make sense to me. We were hopeful that once we strengthened her vestibular system that her anxiety would begin to lower and she would begin speaking.

Some of the exercises they would do to strengthen her vestibular system were to lay on a four wheeled square scooter on her tummy and push herself across the floor with her arms. They would have her roll a ball by putting her head down and rolling the ball between her legs. Or stand back to back with the therapist and hand a ball over their heads then pass it between their legs. They would create obstacle courses where she would have to climb over or under various objects. At home we would jump on the trampoline or have her roll in the living room or down a hill if it was nice out. She would lay on her stomach on an exercise ball and rock forward and back. We got hoppy balls so she could have races with her little brother. It was any activity that would allow her head to change planes – up and down or side to side.

In addition to working on her vestibular system, they were working on her understanding of emotional regulation by using the Zones of Regulation. The Zones of Regulation is a program created by an OT named Leah Kuypers. I highly recommend researching her information by going to www.zonesofregulation.com to learn more about what the colors of the various zones

mean and how our kids can get tools to work through the different zones. This gave us a way to talk to our daughter about her emotions and how they changed in different situations. It was also a way for the teachers to use the same language we were using to have consistency when talking about emotions with her. It can be very hard for a child with SM to have an understanding of different emotions and I guess that can make sense because if they are in a heightened state of anxiety or fight/flight/freeze, how are they supposed to be able to feel any other emotion? Just a random thought I had as I continue to work through and try to understand all of this.

Some of you may be thinking, that's great that the OT works on all this, but what if they don't have an understanding of SM? I can tell you that our Occupational therapist had never worked with a child with SM. I can also tell you that she was more than willing to learn! The best part about OT was that all of the movement activities to help with the vestibular system didn't require any talking. Our daughter was able to move her body which she loved to do. Since she was doing things she loved to do, her anxiety was lowered. After a few sessions of rapport building and body movement we started working on our daughter communicating with the therapist. We talked with our daughter about how hard it would be to communicate in different ways with her therapist. Again, communicating is more than just talking, our daughter indicated it would be medium hard to nod her head yes or no. So we started out with head nods to yes/no questions. Our daughter is very big into animals, so I told the therapist to have a bunch of pictures of animals on a slideshow and ask "Is this a dog?" "Is this a cat?" "Is this a monkey?" whatever yes/no question she wanted to ask to give our daughter an opportunity to answer with a head nod. She did it with no problem! The next time we asked our daughter how hard would it be to answer a yes/no question with mmhmm or uh-uh? and she again indicated medium hard. Same thing, our therapist would show various animal pictures as yes/no questions about it and our daughter was able to answer mmhmm/uh-uh. The next session she was working on whispering yes/no into the therapists ear. This was actually our therapists idea because it was a way for our daughter to answer without having to make eye contact. She was able to answer with a yes/no vocally into the therapist's ear. From there everything just snowballed. Our daughter began answering forced choice questions, open ended questions, and even spontaneously speaking about random things she was thinking about. All of this happened within a month of weekly, 1-hour occupational therapy sessions. We were so happy.

After 4 months, we were able to reduce her medication dose in half. She was speaking to her teachers, her classmates, her extended family members, and ordering in restaurants. We were so happy! Plus, she was starting to understand her emotions more and was able to understand why her heart would be so fast and her tummy would hurt in certain situations. Our results to OT may not be the same for everyone. I honestly don't think she would have made the progress she did in such a short amount of time without the help of an OT. It gave us a different understanding of where her anxiety was coming from. Once we could start supporting her vestibular system and give her fun exercises to do to strengthen it, her mind wasn't in such a constant state of anxiety.

During Day 3 of the Spring 2021 Selective Mutism H.E.L.P. Online Summit, I was privileged to interview two amazing occupational therapists, Marlee and Alexi, who started their own company called Sense-ational Spaces. It was in that interview I finally had my ah-ha moment of what the definition of Occupational Therapy really meant. Plus, I was able to learn even more about the various sensory system our body has and ways to decrease anxiety by addressing the different systems that may be underdeveloped. Also, during Day 3 of the Spring 2021 Summit, I interviewed Charlotte Davies who talked about sound processing and how that can contribute to anxiety issues. With the auditory processing deficits that was discovered during our

daughter's OT evaluation, the information Charlotte provided was so helpful. I'll leave a link in the episode notes to access this interview as well as a coupon code to save on lifetime access.

I should also mention, that it was through OT that we were able to find out about retained primitive reflexes which gave us an even greater understanding of where our daughter's anxiety was coming from. If you haven't already, I recommend taking time to listen to episode 4 titled Rhythmic Movement Training and How it Relates to Selective Mutism. I talk about primitive reflexes and what we've done to help integrate our daughter's primitive reflexes.

Don't forget, I am now offering Parent Coaching for parents of children with SM that may need extra support in helping their child overcome Selective Mutism. I offer a free consultation which will give us an opportunity to talk about the areas your child may be struggling in and how to accomplish specific goals that are important to you. For more information and to schedule your free consultation, go to www.smhelp.org and click the Parent Coaching tab. And, as always, if you ever have questions about Selective Mutism, feel free to email me at smhelp2020@gmail.com or send me a message on Facebook or Instagram. Take care everyone.

Links from this episode:

<https://www.zonesofregulation.com>

<https://www.senseationalspaces.com>

https://www.smhelp.org/store/p12/Spring_2021_Online_Summit_-_Individual_Days.html

- Use coupon code **podcast12** to save 15% off any individual day of the Spring 2021 Selective Mutism H.E.L.P. Online Summit.

<https://www.smhelp.org/parent-coaching.html>

- Fill out the Parent Coaching form to schedule your free consultation