>> Good morning, everybody. I'm going to start because I'm going to have to talk really fast, even for me. Welcome to assuming competence, what to do when you don't know what to do, I'm Michelle John, president of Vermont Hands & Voices, and a lot of other things. I want to give a trigger warning, this session may cause tears, changes in our out look on how you interact with a child or your organization as a whole.

I will likely give the most truthful presentation around a child I love and adore, some of the child's history will be given and will be blunt. Honest facts will be my best policy for you to get the most out of the time. I will not be offended if you don't feel this is for you. Having facts is important to understand how practitioners, service providers and family members can be influenced by what is often concerned the normal standard and how this can limit the child's connection progress and interaction. Some items may evoke strong emotions, from joy to sadness. This program is unrated, viewer discretion is advised.

I hope you choose to say -- I swear it will be a great session. If you find I'm talking to quickly, just let me know. This was easily an hour-long session, so if at the end you feel it should be, put that down on the evaluation. [Chuckles]

And I'm so sorry I have to have my notes, so I'm going to have to flip back-and-forth. So just excuse me. Lovely IT gentleman and presenter-ready room helped me. There used to be videos on this, it's on the next slide. What we are going to do is take a peak at some videos. Sometimes it's easy to assume a child does not have communication skills and act accordingly with them. Naming them can help us take action to improve connections, skills and level of professionalism. Ask yourself while you watch these, what emotions do you notice? Maybe... how do I make it play? I don't know.

Do you know how to make it play?

[Pause].

>> PRESENTER: Oh, Lord. How did I end up over there?

Okay, can you hear it?

[Video].

>> Video: What honey?

Good.

Nice job talking.

>> PRESENTER: Now let's see if I can get the next one to play. I can.

>> Video: Is mama taking videos of Tyson? You see something over there. Oh, who did you see?

Is it your sister?

Or your brother? Oh, you hear your brother, Lane? Yeah, he's over there. That's right. Yeah, you want to see. What are they doing? Ugh, do you want to go and look?

Yes, I want to look.

Good job, Bud. We'll go and see your brother now, okay?

>> PRESENTER: So real quick, think about the emotions you felt while watching the video. Perhaps you felt happiness, connected, confused, overwhelmed, maybe other feelings. When you have time feel free to investigate those as well. So [clears throat], excuse me, and we all seem to be clearing our throats today.

Who is that child from the clip? That's Tyson, my 9-year-old DeafBlind child.

Revived after 17 minutes of no oxygen, and he was extubated, life support was removed on day of life 8, expected to die immediate me. The ventilator showed no voluntary breaths. Surprise, he lived but he was a vegetable, with no awareness. He was brought home at 6 weeks old to die at any given time. Some of the many diagnoses he has include SP, Insephalopathy, visual impairment, bilateral sensory hearing loss.

Technology needs, oxygen, feeding tube, pump, gnash liar. He has had multiple hospitalizations and constantly given life expectancies. I wanted to share history and know, I only listed some of the many diagnoses and medical technology or equipment that keeps Tyson going because there's so much more to discuss. After being told Tyson had no brain activity, we were informed he had no awareness of who he, we, anyone or where he was. Or any -- anything.

He was in a vegetable tae state. And certainly to keep his heart function going, basic life sustaining measures which were unvoluntary. No other function would be available. Due to the significant brain damage he would soon forget to breathe or keep his heart going and die. Any second now, wait for it... any moment... this could be it...

First it was to be over at day of life 8, then not more than one month, two months, 3, he won't live a year, after turning 3 they stopped telling us what age he would survive to. Thank you.

I would wish and hope for more of those -- what one day would look like. Tyson is my first born and that terror mixed with what I know how as birth trauma, as well as -- 24/7 for years. Unable to sleep and some days barely able to think and certainly was no medical professional so I couldn't know how to care for this failure to thrive baby who could not see, hear, feel or know. His eyes would be open but he was looking through things, never at. No sign of recognition of anything, just like they said. What do you do with a comatose kid? Care take was all I could do so I did it with vigor. This is important information but is there more? Perhaps things equally as important so who is that child? Baby Tyson. He has a significant medical history with limited life expectancy, he is adorable and sweet, enjoying listening to music, itty-bitty spider is thought to be a favorite. He likes feeling toys, going for walks, loves to be held and snuggled, he needs warmth and comfort, his favor nonhuman cuddling companion is Gina a while long cat whose preference is to lay on his legs, the part of his body that is always cold due to poor body circulation.

So let's reflect on the possibility that there's more to said child. So, let's look at this one. Baby Tyson. What is here? A lot offer a little? Do we know baby Tyson well? Can you convince yourself you know Tyson? Does the family? What if this was your child? Do you know your child?

[Pause].

>> PRESENTER: Sorry, pages are stuck together. So now let's look at information regarding older Tyson. Still has a limited life expectancy, medical requirements to sustain. He is an amazing sense of humor, loves to laugh and smile, loves listening to music, Whitney Houston and annoyingly John Mayor, favorite. Enjoys feeling toy, going for walks, stores and shopping, watching an iPad, playing with his sibling, looking at and listening to stories, working with favorite providers, water is a huge one. Hair being washed, brushed or stroked. Snuggles with families, camp balls -- sorry. Disco balls and camp. His maternal grandparents, adored them. Going on rides, silly voices, soft blankets, stuffies, getting haircuts, completes, picking out clothe that he considers cool. He hates poop diapers, being cold, being alone, board, pain discomfort, jacket, doing school work he doesn't enjoy, seeing providers that don't get him and long-term long noise and chaos.

When you compare baby Tyson to older Tyson is there a difference in detail? Is there an expanded version? How do we get from the far slide of doom and gloom medical history so kind of learning about Tyson to really knowing Tyson?

So for families of children with significant or multiple diagnosings of disabilities, their families may be overwhelmed confused scared. Your words and regards to their abilities to skills, child's camables have a much stronger influence than you realize. I'm going to give you a few rapid firerish examples.

So Tyson's mom, calling me my home. I don't mind it but no one has asked me. However I don't go by "Mom". I dislike mom and Mommy annoyed me. I those Mama and it's my preference. I don't love being regulated to Tyson mom, although I'm proud of that title. But I'm more than just a mom, you would have to inquire to know. So donated breast milk. During 6 week inpatient state after work, allowed him to have donated breast milk as I was pumping but producing nothing. Breast milk was the only thing I felt I had control over and I couldn't even manage to do that correctly. Breast milk is best, was the mantra, my body had killed my kid and now I couldn't feed him. What could I do correctly? I was utterly defeated standing by to watch my child die. During rounds on another shift, I overheard him share to a large medical team including a slew of residents who are learning doctors, he couldn't understand why the other doctor was allowing a dying child to waste the donor breast milk.

So [off mic] and you choose, I'll follow your lead. I hadn't been able to hold or touch him until day of life five it was a lot of work to get him skin-to-skin and keep the tubes on him. To experience the outside world one time, we had taken the pictures. I was saying my goodbye. Squeeze, no. That can't be, he wasn't really squeezing my chest. Squeeze.

It's just a reflection -- reflective action, they said. During the drawn out goodbye I told Tyson we loved him no matter what and we would not be upset or disappointed if he felt he couldn't continue. He was in charge. He would choose and we would follow his lead. We understand if it was too much to go on, he was enough for who he was and what this situation was and we were so proud of him for trying. You lead, son, and we will follow you anywhere. We had no idea at that time that moment was assuming competence. As the entire medical team, my parents, and Tyson father circled around, I clung to my child while the tubes were removed. Not one breath. We waited and then it came.

And again, and again. Involuntary reflex, they said. It will stop soon. But no... Tyson just kept on breathing.

This makes no sense, they said. He never took a voluntary breath while the life support did all the work and I said what at the time felt like the dumbest thing but it was accurate. Slug shrugging I said, he was just resting. No need to work when you don't have to.

So example 3, after he continued to live he switched from an NG tube to a gastronomy tube which required a sedated surgery and he was two weeks old, they gave him no pain meds what so over.

He kept making a noise, it seemed unvoluntary, but it wasn't him just breathing funny. It was barely audible but it was a noise. I just knew he was in pain. I paged assistance and a resident came by and he asked how would I know if my child felt pain, when they did the pain response test, pinching him, there was no response. Well, I don't know about you guys but have you had a hole in your stomach and no pain meds? He's always been this one way and now he's different. But this resident thought I was out of my median and he did not know a surgery had occurred.

Really ten minutes, guys I haven't even started. This is terrible.

Low and behold, the postpartum dramatic mother, they gave Tyson medicine. The noise stop. I'm going to now shorten these to extremely short. Sorry.

So during on outcome visit, I had to decide what type of mother I wanted to be. Did I want to be a mother that lives in an alter Anna reality where my child could or should receive treatment.

Thank you.

[Pause].

>> PRESENTER: Seriously, she said, you have issues. Within that same office on a different visit I knew there was something wrong with Tyson. I'm trying to skim through to give you the good parts. He looked like a malfunctioning robot. Told me that was impossible. I was just wishing he could do something and said, I think you know you know.

I know you wish it was different, but I have the medical degree, and my medical background specialty is the brain. I promise you, he's not doing anything. I got a second opinion a few days later, he had what is called infantile spasm, a significant form of epilepsy that needs immediate intervention. So yes, Tyson was a malfunctioning robot who was displaying something he needed. Remember these stories I'm sharing are happening in rapid succession. We are not talking about years, it's weeks.

Everyone knows us in the ER by our first names and while doing all of this, an untold number of medical and service providers asked how I knew he was in there and I didn't.

I have a lot more to say but we have to move on. So early intervention, it's easy to forget once early intervention is triggered the family is likely dealing with coming to term with the diagnoses, having strong memo educations, and they need early intervention, but what the heck is that? They don't know how all this comes together, there's a rotating cast and crew of people service provider, suddenly in your home.

Can you imagine they are judging how you're dressed, what everything looking like, and you can't have a rest, and what is that person's name again? No clue.

What is their specialty? Why are they here, yet again?

So again, very rapid fire, because seriously guys, this is a long presentation. So our case manager came in, Tyson was asleep in a bassinet. She said I'm Bethany your EI case manager. So he is always like this?

Um... what?

Do you ever hold him?

How often would you say you hold him? Every couple of days or less than that?

During the EI physical therapy initial visit and this is my favorite story so I'm going to give it to you, Tyson was sitting on the floor and he was in a comfy infant chair, he look like a newborn though he was months old. He was not moving because he can't. She walked over and pivoted his up body and said, and I quote "I don't know what you want me to do with this".

And the hand motion was real. Let me say it again.

I don't know what you want me to do with this. This, this thing. She doesn't know what to do with my terminally ill baby. Like most I expected a healthy baby but instead I got this. This professional doesn't know what to do either? He's not even a person to us.

I started questioning myself, my parenting and feeling alone with a very sick baby, a baby who doesn't see or hear me and don't know who he is or who I am.

Or does he?

So rapid fire examples. Wonderful woman named Emma Nelson, if you don't know her you should seek her out, she's amazing, she came for a visit and she said, I said something to her about questions Tyson's abilities and his availability. Her advise, assume competence. You don't realize it but you already are. Keep going with it, take it further, competence. I was floored. She believed in me and in Tyson. She assumed we were both competent, we needed the booth of skills safety and empathy.

5 minutes? You put that sign down.

One day while sitting in a recliner -- this needs to be an hour-long, this is ridiculous.

I was sitting in a recliner and I was home alone and felt someone looking at me. You know what I'm talking about when you feel someone looking at you, but I'm home alone. So, I look down and on my left side is Tyson, and there he was. Looking at me. And I thought: You see me? Not through me, not nothingness. But me?

I swear to you it was eye contact, he found his mama and I saw him too. He was in there.

[Pause].

>> PRESENTER: Tyson used to smile while only having seizures. I didn't bother to bring those videos, don't worry. To think this was the only way to see my boy -- and I assumed like every other birthday would be difficult. I did something, I don't recall what, but Tyson smiled. I questioned my sanity, and tried to replicate it and he didn't do it. And he smiled. It was real. He was happy. Last example, probably one of my favorites, for a child that was only supposed to live 8 days. His birthday the following 7 days were difficult. Guess what? He just turned 9.

So lessons and takeaways, I'm probably down to one minute. So please, please let me stress something, this is a huge takeaway that I need you to understand. Nonverbal does not ever ever ever mean noncommunicative. Too often professionals are putting the two as the same. They are not. Communication bids while not necessarily using the language of the majority culture, thank you for that, does not mean they divinity have the ability to communicate. It might be oral language, body language, writing, behavior, behavior outbursts are a communication. Sorry, I get a little testy about that.

So Tyson communicates by vocalization, tongue movements or attempts to make noise, but only air comes out. You must lead by example. If you assume you are competent, the child is competent and family members are competent, with dedication, the sky is the limit and they are never going to get up to sing and dance but our beliefs in their capabilities means they will learn things such as enjoying watching, touching, movement, music or any other number of things. These are huge milestones for children with multiple disability. Wait time, I won't talk about it because I only have two minutes. Wait time, super important. Give wait time for people to think about things. What can you do? He's are action steps. I'm supposed to red them to you but guess what we don't have time. I'm so sorry, my PowerPoint is available on the website in the app. Feel free to read. So here are some systems that require changing. From your own thought process all the way the through educational institutions. Higher education needs to catch up. That's my spiel. And medical systems too, they are very, very behind the rest of us. So there are a lot of benefits of assuming competence. And I'll just say this, notice a theme? The word increased.

There's a lot of positive results of assuming competence. It's a natural policy and position that has untold benefits from micro to macro.

Sorry, guys I'm stressed out, this is terrible. It's important to -- if any showing of understanding or anything because it increases the possibility of it happening again. It's positive reinforcement, the child needs to know that you acknowledge it because they will not replicate that behavior if you don't acknowledge it. But I don't know what to do. So many times I hear when I discuss assuming competence -- you know what I'm saying... people will say I don't know what to do, how will I know if I'm doing it right? I don't always have the answers, that's okay. You're not expected to always know. You'll never always have the answers. People may ask you something, family, co-worker, child and you either have little to no knowledge or something you've never heard of. You may not know what to do with this, but you will find out and respond accordingly. You certainly don't speak using inappropriate or ableist language. You take a deep breath, give yourself permission to be honest. And when you get back to them and follow through, families are going to take you seriously and not question your abilities. That competence yourself assuming will be replicated back to you. So if you discredit you lose any authority level of professionalism and/or confidence the individual had in you. There's no shame in not knowing. We are all learning every day. There can be intense shame for responding inappropriately and that will influence who you are and how you act, personally and professionally, if you say something out of turn, take a few deep breaths, collect and correct yourself. If you are embarrassed or feel a failure, it's okay to seek help. No one is perfect no matter how hard you try. Your best bet is to look for the best in the situation, even if you're uncomfortable, unsure if you're doing it right. It's no what do you want me to do with this. It's, what can we do with this? This awesome person or family, ask yourself what should I do? What feels right? Children and family members know when you're faking it and when you're pushing us away. We know when you see us, believe in our abilities and support us.

So anyway, I'm stopping now. Thank you all so much. I really appreciate this.

[Applause]