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MANDY JAY:
Good afternoon. This webinar is brought to you by the NTRC at Utah State University. We will be starting in about six minutes. Good afternoon. I am Mandy Jay and I am with the National Technical Resource Center. We have about four more minutes until this webinar begins. It is brought to you by the National Center for hearing detection and intervention or the NTRC. This webinar is being recorded and will be posted in the next few days. So, if anything disrupts your full attention you can go back and access the webinar on our website. And also, keep that in mind for sharing with other people who might benefit from the content of this webinar.

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We are just doing a quick audio check to adjuster speakers as needed. Michelle, would you like to give us a test?

MICHELLE JOHN:
Hi. This is Michelle speaking.

MANDY JAY:
You sound great! We have people rapidly joining and we will kick this off in about two minutes.

Good afternoon and welcome everyone. My name is Mandy Jay, and on behalf of the early hearing detection and national technical resource Center, or the NECN TRC, I would like to welcome you to this webinar. Assuming Competence: What to do when you don't know what to do. Presented by Michelle John.

Before we get started I have a few logistical items to run through for you. You should know that this webinar is being recorded and will be posted on infant hearing.org in the next couple of days. If anything disrupts your full participation today, please know you can access our website and you can also share this webinar with others who will benefit from the content.

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Thank you to our captioner and interpreters today and we appreciate your time and skills to bring accessibility to everyone participating in the webinar today. So, thank you to them.

OK. A couple of other things. After our presenter has completed her presentation, we will open up a Q and A box where you can type your questions for her to respond to. We will not be monitoring questions during the presentations and we ask that you hold off until we open that box. Jot down any questions that you have so you do not forget them by the end.

At the end of the webinar we will be posting a link in the chat box that will take you to a short evaluation of the webinar and will also produce a certificate of attendance if that is helpful for you. Be sure to do that before you sign off today.

So, with that said, I want to introduce Michelle John, are presented for today. I will read a bit of her bio but I don't want to interrupt her presentation time or take too much presentation time away from her because I have heard her present before and we want to maximize her time.

Michelle holds a dual bachelor of arts degree in psychology and sociology and a Masters of science degree in community Council in specialization from Springfield College. She also enters certification as an end-of-life tule through the University of Vermont. Currently, she is in the final portfolio stage of becoming a certified deaf blind intervener and is also newborn screening ambassador and works closely with the National Center on deaf blindness and is the governor appointed member of the Vermont developmental disability Council.

While spending many of her adult years pursuing higher education and proud of these accomplishments, she is just as quick to share that her life curves in a divergent direction. She educates her three children by being a stay-at-home parent. She is all things medical, educational, and physical care to her nine-year-old Deaf Blind child who has significant medical complexities and is a willing teacher to those with questions. Most often, her two other children.

With that, I will turn this over to Michelle and I will be back on with questions at the end for -- of her presentation. Shall, thank you.

MICHELLE JOHN:
Thank you so much. I'm embarrassed about but thank you! (Laughs) Good afternoon from snowy Vermont. We had our first snowstorm today so that is exciting and I thank you for joining me.

This presentation, I like to give a warning that the session might cause tears or changes in your Outlook and how you interact with your child or child you work with and possibly even your organization as a whole. This is a representation about a child that I love and adore, but some of this child's history will be given which can be emotional or blunt. Due to time constraints I feel that honest facts are the best policy for you to get the most out of this session. Do not fear, it will not be doom and gloom but to have facts it is critically important for you to understand how practitioners, service providers, and even family members can be influenced by what is often considered the standard.

This considered -- this can limit a child's progress. Some of what I share might range from joy to sadness and this program is unrated – though approved and I certainly hope that this will be a great session.

Let us see if I can move to the next slide. There we are!

So, assuming competence. We will watch the next slide and there will be a few video clips. I want to acknowledge that sometimes it is easy to assume a child does not have a particular set of skills and act accordingly. Noticing and naming these feelings that come up within us can help us take action to improve our connection, skills and level of professionalism.

So please notice what notions -- emotions you may have while you watch these videos.

(Video plays)

SPEAKER:
It's mama! Yes. Mama. Good job, mama! I think she wants to borrow your toy. Nice job sharing bud. What, honey? You did? Nice job talking! Yeah!

(Video plays)

SPEAKER:
Hi Tyson! Is mama taking videos of Tyson? Yeah, you see something over there. Who did you see? Is it your sister? Or your brother? Oh, you hear your brother, Lane? Yes! He's over there! That is right. Yeah, you want to see! What are they doing? Do you want to go and look? Yes. I want to look! Good job, bud. We will go see your brother now, OK?

MICHELLE JOHN:
So, think about the emotions you had while you watched the videos. Perhaps you feel happy, connected, confused or overwhelmed. You may have had other feelings and feel free to investigate those as well.

So, who is that child from the clip? It is Tyson. A DeafBlind plus child. He was expected to die immediately, the EEG showed minimal to no brain activity but for seizures, the ventilator showed no voluntary breath.

Surprise! He lived but he was a 'vegetable' with no awareness. He was brought home at six weeks old to die. Some diagnoses, but cerebral palsy, hypoxics encephalopathy which is a brain injury. Spastic quadriplegia, epilepsy, cortical visual impairment, bilateral sensorineural -- sensorineural hearing loss and failure to thrive.

Some of the technology needed to keep casing – Mike Tyson going includes BiPAP ventilation, suction, feeding to and pump, a hospital bed and oximeter. He has had multiple hospitalizations and a short life expectancy.

To share a brief history of how this happened, I will only be giving some of the many diagnoses and technology even to keep them going. There is so much more to discuss and we don't want to spend our time talking medical jive.

After being told Tyson had no brain damage with all four quadrants including the brainstem, he was told he had no awareness of who he, we, or anyone was or where anyone was or – anything. He was in a vegetative state and his brain function was being used solely to breathe, sometimes even forgetting to do that. And his heart function. Only basic life-sustaining measures, which were involuntary. No other function was available. Due to the significant brain damage he would soon 'forget' to breathe and keep his heart going and any second now, he would die. Wait for, any second now… Any second. Any minute now. This could be it.

First, it was to be over a day of life, then not live more than one month, two months, three, then six. He will not live a year, he will not see age 2. After turning three they stop telling us what age he would survive to. I would wish and hope for more. Those secretly terrified what will Marty would look like.

Tyson is my firstborn child and I know that that is now PTSD and birth trauma, equated a mother whose anxiety was on overdrive 24 seven for years. Unable to sleep and some days barely able to think. I was certainly no medical professional. How could I possibly know how to take care of this failure to thrive baby who could not see, hear, feel or no? His eyes would be open at times but he was looking through things, never at. No sign of recognition, just like they said.

What do you do with the comatose kid? Caretaker was all I could so I did with vigor and gusto. I would be the best caretaker there had ever been. I would be a personal pediatric intensive care unit. I would be the team of professionals it took while inpatient, all wrapped up into one person.

Now, this is all relevant and important information and is certainly, the medical history is important to have. But is there more? Perhaps things equally as important?

Welcome of the information on the previous slide is critically important to understand the history of how a child became who they are, let us reflect on the possibility that there is more to said child. Let us look at these next two slides together.

Who was that child from the clip? Tyson, a DeafBlind plus child. He has a significant medical history with limited life expectancy, multiple diagnoses and medical equipment requirements to sustain life. He is adorable and sweet. He enjoys listening to music, itsy-bitsy spider is thought to be a favorite. He likes feeling toys, going for walks, stores and shopping. His parents think they are projecting. He loves to be held and snuggled, and needs warmth and comfort. His favorite nonhuman cuddling companion is Gina, a huge, old, all-white long-haired cat whose preference is to lay on his legs. The part of his body that is always cold due to poor circulation.

Ponder for a moment what is here. Is it a lot or a little? Do you know baby Tyson well? Can you convince yourself that you actually know Tyson? Does the family? And what if this was your child?

So now let us look at information regarding older Tyson. You will medially notice there's a lot there. This slide is visually busy but you will also notice a keyword shift.

Who was that child from the clip? Tyson. My DeafBlind + child. He has a significant medical history, limited life expected to, multiple diagnoses and medical equipment required to stay in life. An amazing sense of humor, love to laugh and smile. He loves listening to music, classic rock, Bob Marley, the Bee Gees, the Beach boys, Katy Perry, Whitney Houston and unknowingly – John Mayer our favorites. He enjoys feeling toys, doing for walks, stores and shopping, watching the iPad, seeing his classmates, his siblings, looking at and listening to stories, Pictello books, all things water, his hair being washed, brushed her stroke, snuggles with family, siblings, and pets. Lava lamps, disco balls, camp! Maternal grand parents, going on boat rights, movement, silly voices, soft and cozy blanket, being warm, stuffed animals, getting haircuts, complement, and picking out clothes that are cool looking.

What does Tyson hate? Poopy diapers, old-school country music, randomly – Jack Johnson's music. Being cold, being alone, boredom, pain and discomfort, jackets, doing school work he does not enjoy, and seeing providers that do not get him. Prolonged loud noise or chaos, and blood draws.

That was a lot that I read. When you compare baby Tyson told her Tyson, is there a difference in detail? Do you feel you know Tyson better now? Is he now a more well-rounded person for you? Perhaps an extended – expanded version of baby Tyson? And did you notice that one keyword shift? He is not a child that my child!

Does that change the meeting for you? And how did we get from the first slide of doom and gloom medical history to kind of learning about Tyson, to really knowing Tyson.

Interactions with families, words and behaviours matter. For families of children with significant for multiple diagnoses and disabilities they may be overwhelmed, confused or scared. Your words in regards to their abilities and skills, the child's capabilities and your views about them have a much stronger influence than you may realize.

Am now going to give you a few rapid examples.

I will start with the simple one, calling me not by my name but calling me Tyson's mom. Not all families like this. I do not mind it per se but no one has actually asked me. I do not actually go by mom and mom is not a favourite either. I chose Momma and it is my preference.

I do not love being regulated just to Tyson's mom although I am extremely proud of that burned a title. However, I am more than just a mom. I suggest always asking. Do not assume people's comfortability with names or labels.

Now we will go a little bit deeper.

During the first two weeks of Tyson's six-week inpatient stay after birth, his neonatologist allowed Tyson to have donated breastmilk as I was pumping like a fiend from birth by producing nothing.

Breastmilk was literally the only thing I felt I had control over the time and I cannot even manage to do that correctly.

Breastmilk is best, was the mantra I had always heard. My body had already killed my kid and now I cannot feed him. What could I do correctly? I was utterly defeated standing by to watch my child die.

During rounds on another neonatologist shift I overheard this unknown Doctor, shared to a large medical team including a slew of residents, he cannot understand why the other doctor was allowing a dying child to waste the donor breast milk.

I was not able to touch or hold Tyson until day of life five for a variety of medical reasons. On day of life eight Tyson was to be excavated, removing his life-support to let him go. I had only had three days to touch him and only a few holdings. A few minutes prior to excavation I was holding him skin to skin, chest to chest as I had for every moment I was allowed.

It was a lot of hard work to get him skin to skin but keep the tubes in. I knew the hour was upon us, I had read all the books I thought he should hear, picked the grass and leaves for him to experience the outside world one time. We had taken the pictures, one of which you saw in the opening slide.

I was saying my lengthy goodbye. Squeeze. Now that cannot be, he was not really squeezing my chest. Squeeze. It is just the reflexive action they said. During my ridiculously drawn up goodbye, I told Tyson we loved him no matter what and we would never ever, not for one single moment be upset or disappointed if he felt he cannot continue.

He was in charge. He would choose -- and we would follow his lead. I understood if it was too much for his body or brain to gone he was enough for who he was and what the situation was and we were so proud of him for trying.

He leaps on and we will follow you anywhere -- you lead on

We had no idea that that moment was assuming confidence. As the entire medical team, my parents and Tyson's father circled around I clumsily clung to my child, squeezing so tight while the tubes were removed. Not one breath, they reminded us.

We waited. Then it came. And again and again. Involuntary reflex, it will stop soon.

But no, Tyson just kept breathing.

This makes no sense they said. He never took a voluntary breath. While on the ventilator it did all the work. I said at the time what felt like the dumbest thing but now realize was completely accurate, shrugging I said he was just resting. No need to work when you do not have to.

Another example, as Tyson continued to live he was switch to a gastronomy tool which required us to date of surgery. Although he was a little over two weeks old at this time, because he was not there they gave him no pain medicine whatsoever. He kept making this teeny tiny noise. I had never heard him make a noise.

It seemed voluntary and it was not him breathing funny. It was barely audible if there was too much background noise. But it was noise. I just knew he was in pain. I paged assistance and residents came by. He asked how I could possibly know if my child felt pain? When they did the pain response test, pinching him there was no response.

Have you had a literal whole or into your stomach and had no pain meds? That is what my baby was enduring. I said I do not know for sure if he is in pain, but he has always been this one way and now it is different. This resident thought I was out of my mind and projecting. He told me I was not willing to accept the reality and did not know the surgery was occurred.

Lower after will hold to appease me the postpartum dramatic mother, they gave Tyson a pain medication and the noise stopped.

During an outpatient visit a neurology head nurse told me I had to decide what type of mother I wanted to be after stating I thought Tyson seizures could be better controlled. Did I really want to be a mother who lived in an alternate... After stating the seizures could be better controlled she asked if I wanted to be a mother who lived an alternate reality were my child could or should receive treatment?

She questioned why it was so insistent he should live and suffer, let nature take its course instead. She said I was being selfish and really reevaluate what type of mother I wanted to be. Seriously she quietly chided, you have issues.

Within that same office on a different visit I stated I knew there was something wrong with Tyson to the neurologist. Tyson cannot move his body voluntarily but he was acting like a malfunctioning robot for lack of a better term. She scoffed and told me that was impossible and I was wishing Tyson could do something. I denied this theory and reminded her I had been the one to set up the appointment because I was seriously concerned about the malfunctioning robot who is my child.

She stated, I know you think you know. I wish you didn't know but my specialty is the brain and I promise you he is not doing anything I got a second opinion a few days later because I was terrified by the continued malfunctioning robot displays that were increasing in severity. And consistency.

When I called to inquire and explain I had no other way to describe my child and was desperate for a second opinion the doctor called out an hour later and said I must bring Tyson in the next morning. First thing, even before the office opened so he could see him.

He knew that Tyson specific brain injury was usually associated with and susceptible to a dangerous type of seizure disorder known as infantile spasms. Yes Tyson showed the telltale signs. He is having uncontrolled infantile seizures clinically by EEG and observationally.

More months of intramuscular injunctions… And in case you are curious, we do continue to see this neurologist who gave us some actual help. He is an amazing practitioner.

Remember these stories I'm sharing with you are happening in rapid succession. We are not talking about years, but rather weeks. Unless we forget Tyson is going to die any second now. By now I have resuscitated my child twice my back masking him and our emergency room knows us on a first name basis. We have made multiple paramedics cried dear due to our situation and I have our primary care is physician private number. She is officially unofficially on-call throws 24 seven.

We have Tyson's room in the pediatric care unit at this time. We know the staff and have our preferred people. I can still tell you the specials that rotate every week at their cafeteria.

While enduring all of that and untold number of medical and service providers asked how I knew he was in there. I did not per se but the thought of him being in there was nice. At times the feedback from these individuals affected my parenting, how often I held him, what I did with him. It made me question if I was literally losing my mind. Was I living in an alternate universe? Did I think more of my child and what he was? Could he really truly be in there?

Can my love for my first child overshadowed? I was giving my brain-dead son way too much credit, he was not able or capable of doing anything ever. Expect nothing but death, love him to death you crazy mother. There is nothing more than that for you or for him.

It is easy to forget one's early intervention is triggered, the family is likely still dealing with coming to terms with the diagnosis or diagnoses. They are having a variety of emotions in relation and are now being told their child needs early intervention. Most families do not really know what this is or what it could or should be.

They likely do not know if the services they are getting our best practices, necessary or relevant to their child. The most diagnoses or disabilities, the less a family is to make sense of it all -- the more

There are rotating cast and crew of case managers, service providers and many others who are suddenly in your home. Can you imagine? They are judging the state of your home because for some, it is literally part of their job. They judge how you look. Do I have clean clothes on?

The doorbell rings too often and the dog barks furiously every time. You cannot nap rest. What is this person's name? No clue. Why are they here yet again and what is their specialty?

Upon our first meeting with the case manager, Tyson was asleep and angled bassinet. She eased in an plunked herself out on my couch. She said she was Bethany my case manager and she asked the first question. Are you always like this? Pointing at him.

What?

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

Nice to meet you too I guess.

I remind you dear audience he was asleep like so many babies often do. Try to remember you are in their home and you are taking up space in their minds, not just in their homes. This is their child and this is nerve-racking. Believe they are trying their best to navigate this new landscape, are capable of making informed decisions with the best interest of their child or family in mind. Be relaxed, nonjudgmental, warm and open to the family and child.

Assume they are competent, capable and available to interactions, feedback and suggestions.

You might surmise I just gave that advice for a reason and you would be right. You know I have a story to tell.

During the early intervention physical therapy initial visit, the physical therapist flew through the door, not knowing what she was walking into. It appeared she was expecting a mostly functioning child. Tyson was sitting in a comfortable, reclined baby chair. Oxygen on his face and he looked like a newborn although he was months old, due to failure to thrive.

He is not moving because he literally cannot. He is just chilling as we called it. Please keep in mind all of this woman does this pediatric PT and early intervention and she has little decades of experience.

She walked over after I introduced myself and Tyson, laid one glance upon him, pivoted her upper body and said and I quote "I do not know what you want me to do with this."

Yes, that hand motion is a real thing. Let me say it again so you can really take it in. "I do not know what you want me to do with this."

This thing that she does not know what to do with is my terminally ill baby. My firstborn who I adore and am terrified of loving, I also do not know what the hell I am supposed to be doing with him.

Like most, I expected a healthy, perfect baby but instead I got this. This professional does not know what to do either? He is not even a person to her. What am I thinking treating him as a person? Is that right or wrong? Questioning my parent choices and feeling alone with a very sick baby, a baby who does not see or hear me and does not know where he is or who I am.

Or does he?

A provider who specializes in deaf blindness, who is doing a webinar next week and is a true treasure, came from her plan second visit. I must have mentioned something about my questioning of Tyson's abilities and availability. Her advice, assume confidence. You do not realize it but you already are. Keep going with it. Take it further, always assume competence. That he understands and is paying attention even if he cannot show it.

I was floored. I probably looked like that about you with the top of his head blowing off. No one had ever suggested this. In fact always the complete opposite. It is what has made me question my own abilities as a parent and sometimes my sanity. She believed in Tyson and in me. She assumed we were both competent, something that we needed a boost of skills, empathy and safety to learn and grow.

But, how would I know that Tyson was actually competent? One day, while sitting in a recliner, baby Tyson was resting in my arms. I was watching TV. I felt someone looking at me. Many of you probably know the feeling I am talking about. I kept watching TV but continually felt that sense of being watched, yet I am home alone. Or am I?

I gaze down to my left and there with Tyson. Are you? Are you looking at me? Do you see me? Not through me, not nothingness, but do you see me? It was eye contact. He had found his mama and I saw him too. He was in there. I was not crazy. I was not wrong and I was not a bad mother for wanting him to be in there, because he was!

We built upon that immediately. Always awarding times of eye contact. It was our first communication. We connected. I was fearful, I cannot deny that. In the beginning I questioned if I made it up. Assume competence I kept reminding myself.

Tyson used to smile only one having a seizure, it was both beautiful and absolutely heartbreaking. But don't worry, I did not bring those videos today.

To think this would be the only way I could see my boy smile upset me on multiple occasions. Tyson's fourth birthday rolled around, which we were not supposed to see and like I assumed it would be filmed -- filled with wonder, pain, and difficult emotions. The trauma often suffocated what could be a special day. On this birthday in the late afternoon, I did something I do not recall what – Tyson smiled. But, he did not cease. He just smiled. And I swore loudly, "holy…"

Questioning my sanity once again, I tried to replicate the smile. For a while, nothing but a few minutes later I came into his view again and he smiled. It was real. He was capable of emotions. Glad to see me. The dog came over not long after in he licked his hand and Tyson smiled 1/2 Elvis grin. I smiled. Happy birthday to us both. It was such a gift.

The last example is probably one of my favorites. For a child who is only supposed to live eight days, his birthday in the following seven days were always difficult, consistently filled with deep emotions and anxiety. I wanted to make it to one year, then two, then three – then I wanted five – half a decade. As time progressed I saw a big goal in sight. Eight years. Could it be possible? Yes. Yes it could. It did.

This child who was supposed to live eight days lived his entire eighth year and just turn 10! Talk about joy, happiness, tears. This kids that you see on the screen is truly something magical. It is incomprehensible in so many ways. And now we are dreaming big for 13 to make it to teenage.

So, what does it mean? It is OK to assume best intentions. Feel positive about that choice. It is never wrong to assume the competence of the person before you. Treat them like a person.

Allow the child to lead the way when possible, you are not hurting anyone by teaching them autonomy and self-worth.

And so it is cliché, there are true life lessons to be learned when we treat others the way we wish to be treated. Assuming competence feels good to all parties involved in the interaction, whether they are currently able to express it or not.

By assuming competence, I believed Tyson found reasons to stay. I know it will not be forever – I am acutely aware I am on Baller time. -- Borrowed time, but these moments up and life-changing. Treat as though his body is betraying him but his personality, his true being is alive and well. Capable in his own ways. It will simply take time and a whole lot of effort between himself and a communication partner to coordinate letting it out.

I was not wrong in following his lead, no matter how slow the journey is sometimes. These moments changed everything. You can have this for your child or family, or assist in creating these core memories for the families you work with as well.

So, lessons and takeaways. When best practices according to the professionals conflict, you need to have a strong ability in your competence. Silos. Stay in your lane to have awareness of the cars around you. Is there an exit coming up? Prepare the family.

Nonverbal does not mean noncommunicative. Positivity and belief in the child and family is critical.

And if you assume competence, the family will follow suit. It is OK if they need to have encouragement or gain self-esteem in this area. Assume competence in both the child in the family numbers and do not forget to assume competence in yourself. Lead by example.

It is easy to focus on your own specialty. Of course, this is important. However, sometimes it is important to learn about who else is involved with the family, what proverbial cars are around you? You might be giving suggestions or homework to the family, but is there a traffic jam? How many are also giving suggestions of things to work on daily to fit in with household duties, appointments, work and do not forget to connect your child!

Families often hear conflicting messages. Do all of the things in the best interest of the child but do not do all the things to avoid burnout. Connecting with her child is number one, but it's also super important that you do X, Y, Z daily or terrible things might happen like no progress.

For some of us, being told what to do means that we will at the expense of other things. The awareness and teamwork needed amongst all providers is critical to help find a balance that treats the child and family holistically. We are just trying to keep our highway clean. You can assist by ensuring there is regular communication amongst everyone who works with the child and family. This also takes the stress off the parent, who no longer has to play intermediary or go-between.

When important changes are coming, the more notice the better. That includes changes in providers, case managers, or moving into the school system. When possible, these things should not be a surprise. Families need time to prepare for the exit approaching. By giving extra support if needed, families can go into these changes feeling prepared, confident in the team and competent in their ability to adjust the said changes. This increases feelings of independence and self-worth.

And if I may, please, please me stress – nonverbal does not ever mean noncommunicative. Too often, professionals are putting the two as the same in teaching families the lesson. They are. Not. The same. While not necessarily using the language of the majority culture, it does not mean they do not have the ability to committee K. It might be language, sounds, sign language, body linkage, behavior, eye gaze, manipulative systems, touch cues and many many other ways.

Tyson communicate via vocalizations. Meaning, full blinks, eye gazes, tongue movements and or attempts at making noise, the only air comes out. Depending on his alertness, health status and other variables, Tyson will use one or more modes of communication to get his point across. Because each and every one of these were responded to as a bid for communication, he made the connection that I understood. Noises changed over time to clear, repeated sounds for yes or no, like or dislike, annoyance or happiness. And they are not the same to sounds used as positive and negative. He has a small repertoire. If the communication partners not noticing these as anything other than a special needs kid making noise, they are losing an incredible opportunity to get to know Tyson.

Finally, you must lead by example. If you assume you are competent, the child is competent, and families are also competent, with dedication, best practices, and yes – hard work – the sky is the limit. And no, children like Tyson will not get up and sing and dance, no matter how hard anyone works, but they may learn to enjoy watching, touching, movement, music, or any other number of things that vastly expand their quality of life. These are huge milestones for children with multiple disabilities. Never underestimate the power of reaching a goal. Ensure you know basic skills such as weight time and there is so much waiting, but the wait is worth it. And respond to any change as if it is a bid for communication.

The child, when assumed competent, do not miss the little ones because you are looking for the big ones. If you see it in others, your work grows and expands. You become competent and a well-rounded provider.

So, what can I do? Action steps. Assume your competence by adjusting your mindset on the child and family. Believe that they are available, able, and capable, matter the communication mode. The child is capable of communicating, the burden is on you to recognize it. Believe in the best in yourself, are you seeking best practices for your profession or family life, check in and are you having positive interactions and truly enjoying time with the child or family?

Believe that the child's diagnoses and/or disabilities do not prevent them from connection, learning, absorbing, changing, growing, loving, or having wants and needs, and preferences. Understand any child is whole being with thoughts and feelings, whether they are currently able to express them or not.

And if this is an area you feel that needs work, trust that you can start the change now. Start big, start small, just start. Believe that you are capable of change. It may not be easy, but it is feasible. Do not discount reach out to mentors, leadership, coworkers, agencies, organizations that are related. You can also suggest or seek associates who will help you in creating a workgroup or support group as a way to learn from each other. You can invite guest speakers and family numbers.

So, what are the systems that require changing to make assuming competence and natural part of EHDI, EI, educational systems and families?

It starts with individual thought processes then moves to agency organizational leadership, then policies and procedures through the department or agency of education, and legislation.

And then you have educational institutions and medical systems. I know. That list seems short, but it is also very overwhelming. I am sure some of you are nodding along with that.

So, what are the benefits of assuming competence? Increase self esteem for the child, family members and professionals. Increased self-worth and self-confidence for the child. Increased communication and connection for, and with the child! More appropriate policies, procedures, rules and regulations. Legislation that supports individuals with disabilities, and medical complexities. Increased funding for programs and other supports that benefit individuals with disabilities and medical complexities. Changes in medical providers, their staff, service providers and educational teams approaches, terminology, suggestions, and decision-making processes. And, changes or shifts in societal views. More positive views, and acknowledgment every person is not only capable of being, but actually is a productive member of society.

So, did you notice a theme? Increase. Positive results. Assuming competence is a natural policy position has untold benefits for all. From micro to macro changes. Top down, bottom up simultaneously is likely the most productive way to create change efficiently. We should not wait for a trickle-down effect. Instead, utilize the theory that a large collective can create more significant change. Ensuring policies, procedures, best practices, and personal values include assuming competence will automatically create sizing changes across all parts of society.

Something seemingly small as one child or family can begin this ripple effect. Enough ripples become waves. Something not so easy to ignore. The same goes for the learning process for a child. One notice of their bid for communication or show of understanding increases the chances of it happening again. It is positive reinforcement.

But I don't know what to do! Take a breath. It is OK not to know. Give yourself permission to acknowledge that you are not positive or know the answer at all. Do not shame yourself or the person asking. Beware of toxic positivity's and otherism. You can ask coworkers, your due diligence, and check oddball options including Reddit or Facebook. But most important, do not push away. Pull the individual or family towards you. Trusting relationships create safety for learning, trying new things, and feelings of being accepted and understood.

So many times when I discussed assuming competence I hear a lot of feedback. How do I know if I'm doing it right? I don't always have the answers. Even after this talk I still do not know what to do.

That is OK! You are not expected always know. You will never have all the answers. It might be something you of little to no knowledge of. You may not know what to do with this but you find out or respond accordingly. Take a deep, cleansing breath and give yourself permission to be honest in a kind way. If you give clear information on next steps you will take, when you get back to them and follow through, families will take you seriously and not question your abilities.

That competence you are assuming in them will be reciprocated back to you. If you panic, fear, avoid or discredit the requester question you automatically move -- lose any level of professionalism. There is no shame in not knowing. We are all learning everyday but there can be intense shame or responding appropriately and that will influence who you are and how your back personally and professionally. You say some thing out of turn, collect yourself and respond. If you feel like a failure, it is OK to seek help from a mentor, therapist or coworker that you trust. No one is perfect.

I encourage you to avoid falling into toxic positivity. Not everything is great all the time. Everything in life will not be OK and unfortunately, that has to be OK. Constantly turning a moment of vulnerability into saying everything will work itself out or happen for a reason – or any number of statements will sever a relationship you build.

I promise you that the family will not feel safe or trusting. They will feel unheard, unseen and it may lead to feeling of rejection or isolation. In a moment of vulnerable you can validate how difficult things are. You cannot fix it and throwing around toxic positivity will not help. Be real and if you can help, make the seduction. If not, uncomfortable though it may be, you may have to sit with her pain. This work is not easy and deftly is not for the faint of heart.

Lastly I want to acknowledge the newer… This can come out in languages used to describe families or views to describe families. And influences 121 work all the way up to policies and procedures. Use discuss families is a collective using they regularly? Is and why don't they just do XYZ? I do not understand why they do not do what t we say--

Why do they need more than one communication they are annoying and time-consuming. These are the nicer examples that have been stated to me in recent weeks and all I can say is, that does not sound so great to me. It would not feel great if I said why don't they, all the providers, get a clue there is more to family life and you?

That sounds trite and terribly offensive to me. Avoiding other isms is being cautious of an office versus them mentality and I know it is hard -- us versus them

Sometimes you will not agree with the actions of family takes and sometimes families will not agree with yours either, but by avoiding other isms and viewing the situations from a team standpoint you will feel a sense of camaraderie. You are assuming confidence. You are all on the same team because you have earned your spot.

Lastly, try to look for the best in a situation even if you are uncomfortable or unsure. Ask yourself what you should do? What feels innately right? Believe you are capable of making an informed choice. Trust me children and family members know when you are faking it and when you're pushing us away. Me know when you actually see us, believe in our abilities and genuinely support us and we certainly know the difference between what feels funny and what feels real.

Ask yourself, how can assuming confidence help you personally or professionally? Can you think of ways to incorporate assuming confidence into your life? How can talking about your emotions around shame, mistakes made and not assuming confidence assist you?

Have you ever had an experience where someone in the position of power thought you were not capable or knowledgeable? Felt as though you are not seen or believed? How did you fill in that moment?

An additional question to reflect upon, are you willing to allow others to take the lead in trust they know what is best for themselves or their family? Recognize that when you are assuming confidence you are partaking in both leading and following. Can you learn from your missteps and you better? Give yourself permission to say you are not shared and be willing to be vulnerable enough to be Tyson tough.

Now you might be asking me, what is she talking about when she says Tyson tough? When Tyson was born we attempted to come up with a family slogan to rally our own emotions and rain in catastrophic thinking. Tyson taught this so he landed on.

They thought we were bonkers for having a family slogan but it helped study the ship more than once. When I thought I was spiraling I took deep breaths and repeated it. Do you need to feel good? Do you need to feel… Do you need to feel good? Slogan that happens to include assuming confidence, when the centres even tougher times? Assume your confidence to find one that fits and use it as much as you need.

Do not let it be embarrassing or shameful. If it works, it is great. I do not think you are bonkers for using any method that a state that helps you. --- Safe

I want to thank you so much for sticking with me today. I recognize this was an emotionally and mentally involves session. I am incredibly grateful for your time and attention and choosing to be vulnerable with you all has been an another lesson in me assuming confidence and an audience being able to sit with this, me and with Tyson. Here you all are.

After the question and answer session, at he will go to assume confidence with others and be Tyson tough. Thank you.

MANDY JAY:
Thank you for a wonderful presentation.. A lot to learn.

I want to give you a chance to take a drink of water and for some questions to comment. We have some comments right now saying, wonderful thank you this is so valuable and important and all medical care providers should be required to watch.

Thank you so much for this opportunity I'm loving Tyson's mom.

We also asked if this presentation is in Spanish and we do not have it available in Spanish. Sorry about that.

The presentation will be recorded and online in the next few days at infant hearing.rg, please share it with providers and families, everyone and happy to have that - infant hearing.org

I will have a question while others may come in.

How do you share with parents who are starting out on this journey to assume confidence in themselves? A lot of this is talking about providers and how they should assume confidence in the family but if you are in the thick of it as mama or dad how do you, start?

MICHELLE JOHN:
I think that is a great question. I think unfortunately it starts inward, trying to believe that you have the ability and capability of being an appropriate parent, of having that innate sense of knowing what is right and wrong. Hopefully, some of these families have counsellors. There is that part of me talking.

I think being able to build up self-confidence and self-esteem is so critical. I do think, while it is very important to have that come from inside I will say because so many families see so many medical and educational service providers, that having those outside mirrors reflecting back what you are trying to feel inside is really empowering.

I do feel like it is a team effort, which most people do not love that answer (Laughs) But it is.

MANDY JAY:
Thinks Michelle. We have a lot of thank you for this presentation, thanks for sharing your journey and Tyson's life with us. Powerful, we need the families to hear your story as well. Not just providers.

MANDY JAY:
I am assuming that is what that implies... Assuming we all want to increase our competence and supporting families.

I hope that all parents will see themselves as an expert on their child, providers might be an expert in subject area and parent subject area are their child so they are experts in that subject field. Reminding parents they are the expert on their own child.

MICHELLE JOHN:
Absolutely.

MANDY JAY:
Thank you so much for your vulnerable presentation of the realness of raising her son so important on those days when Tyson tough is waning what do you rely on to get back on track?

MICHELLE JOHN:
I have had many months and years where that has not been the most skill set of mine. A lot of it is trying to remind myself that I need to get through this minute, this our, this session and start small.

It is much like people say when they have a hoarded room, start with one box.

I think sometimes people can get overwhelmed looking at the whole picture. How will I get through this week? This whole day? Sometimes you just have to say can you take a minute and splash water on your face? Can you regroup? If you cannot you have had to learn, I have learned to reach out to friends and maybe you have family, a counsellor or provider. Whatever your support system may be, neighbours or other families.

It is so difficult to be vulnerable but it is really important because that isolation can lead to a significant amount of depression and anxiety. I say from my own experience, on those harder days I have to find the willpower to keep going. Excuse my language, but sometimes it really sucks. It really does and I will never deny that.

It is so critical that we put ourselves and our children and families first in order to keep going.

MANDY JAY:
We have a few more questions coming in. I think this is a great one. How do you know when you are using toxic positivity versus just positivity?

MICHELLE JOHN:
That is a wonderful question. I know when I added this and I thought this might be tough for people to hear.

I think it is important to be positive, it really is. So I do not want to take that away. But toxic positivity is no matter what is going to be fine. Someone saying I do not know how I will pay the electric bill and then saying it will be fine. It works itself out. It won't.

Looking positive can be very different. We can work together to try to figure out how to pay your electric bill or let's see if there are grants or programs available. Certainly around children and their well-being and education, I think there is being positive that we are going to try and see if we can get little Joey to fill in the blank.

It is not a matter what everything happens for a reason. Nobody wants to hear that. Nobody wants to hear their child has autism for reason for God only gives you what you can handle. Nobody likes that statement either. It is those clichés that are toxic, I think being positive is more being supportive. If that is helpful. If it is not throw in the chat and say no try again (Laughs)

MANDY JAY:
-- Thanks Michelle. Are there support groups that you found meaningful to you

MICHELLE JOHN:
It took me a long time to be willing to delve into that but yes. Disability specific has been very helpful, hope for HIE is one for children with brain injuries like Tyson. At first I joined Facebook group and just watched and tried to feel comfortable and take it in.

Yes I will say, I was both isolated because of where I live but also I isolated myself for a long time. Depending on where you live, there are in person support groups and certainly online. Zoom has become a life changer for some families. Your state probably has apparent information Centre and you can also reach out to them for resources.

MANDY JAY:
We have a question about love languages. Do you know what Tyson's love languages? What is his favourite way of showing he is being loved? The person is reading for love languages in school book club.

MICHELLE JOHN:
It used to be gifts because he likes looking at things and now it is time. He just loves people and spending time and having undivided attention and people making of him. It is his favourite.

He wants the attention no matter where he is and if he does not get it every once in a while he will yell. And I have to say, everyone knows Tyson has arrived moving on. Time is a big one for him.

MANDY JAY:
We have time for one more question before we wrap up.

Are there is some suggested training opportunities related to toxic positivity?

MICHELLE JOHN:
That's a good one. I do not know but I would be so thrilled to (indiscernible) (Laughs) So you can email me and I can work on that. I do not know honestly offhand but it is becoming a huge thing in psychology and certainly picking up steam in education and service providers and even in the medical field.

I am sure there are, I just do not know any off the top of my head.

MANDY JAY:

You are being encouraged through chat to do it.

(LAUGHTER)

MANDY JAY:
Again, thank you for your presentation, coming through the chat. Which she was available in other languages.

Thank you again for your time, do not forget to fill out the evaluation and certificate at the end of this session. I will just bring that up. You so much Michelle, you are so appreciated and this presentation has been wonderful.

Thanks to everyone who participated, especially Michelle and our captioners and interpreters and all of the people behind the scene making this work. If you have any questions, Michelle's email is on the screen and be sure to fill out the certificate of attendance/evaluation form.

Thanks everybody and have a great day.

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