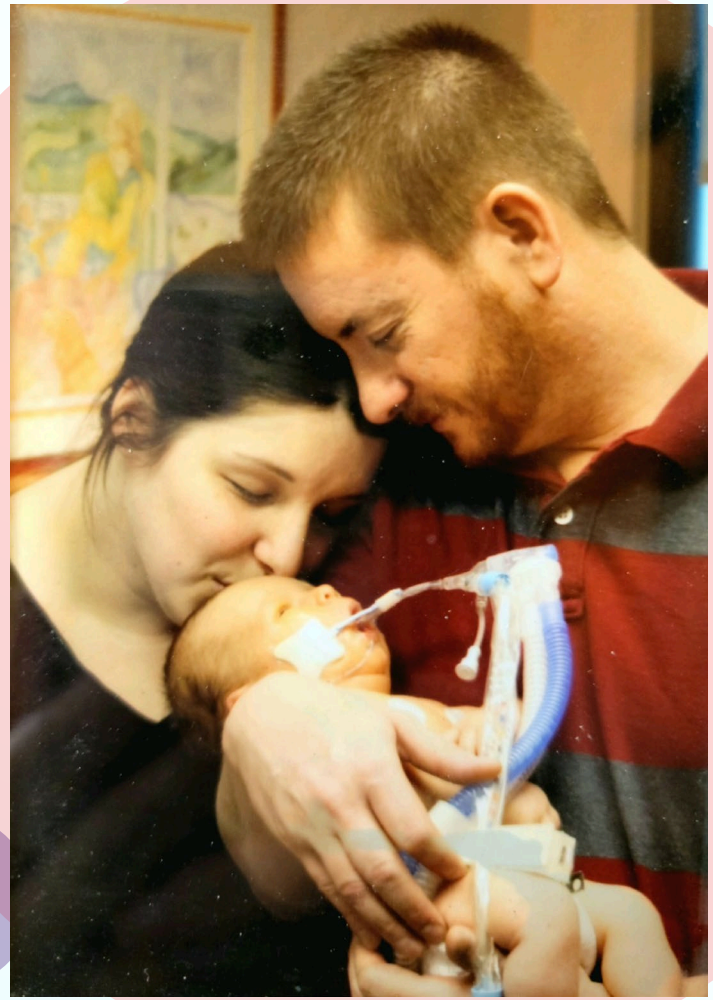

Don’t panic--This was a very special moment in time ☺

Assuming Competence: What to do when you don’t know what to do!

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Assuming Competence: Let's learn more by watching the video clips

Sometimes it's easy to assume a child does not have communication skills, and act accordingly. Noticing and naming these feelings that come up within can help us take action to improve our connection, skills and level of professionalism.

What emotions do you notice when you watch these videos?

List the emotions you felt while watching the video

1. Happiness
2. Connected
3. Confused
4. Overwhelmed

Other feelings? Please investigate those, too!

Who is that child from the clip?

Tyson, my 9 year old DeafBlind+ (Plus) child

-Born deceased via emergency c-section, revived after ~17 minutes of no oxygen, put on life support and cooling mat, extubated on Day of Life 8, expected to die immediately. EEG showed “minimal to no brain activity” but for seizures, ventilator showed no voluntary breaths.
-Surprise! He lived, but he was “a vegetable”, “no awareness”
-Brought home at 6 weeks old to die at any given time.
-SOME of the many diagnoses: CP, HIE (Severe), Spastic quadriplegia, epilepsy, CVI, bilateral sensorineural hearing loss,
-SOME of the Technology needs: oxygen, bipap ventilation, suction, feeding tube/pump, wheelchair, hospital bed, vest, nebulizer, oximeter
-Multiple hospitalizations
-Constantly given life expectancies

Who is that child from the clip?

Tyson, a 9 year old DeafBlind+ (Plus) child

Baby Tyson

-Significant medical history, with limited life expectancy, multiple diagnoses and medical equipment requirements to sustain

-Adorable, sweet

-Enjoys listening to music (itsy bitsy spider is thought to be a fave), feeling toys, going for walks, stores/shopping

-Loves to be held and snuggled, needs warmth and comfort

-Favorite non-human 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 body circulation

Who is that child from the clip?

Older Tyson

Tyson, a 9 year old DeafBlind+ (Plus) child

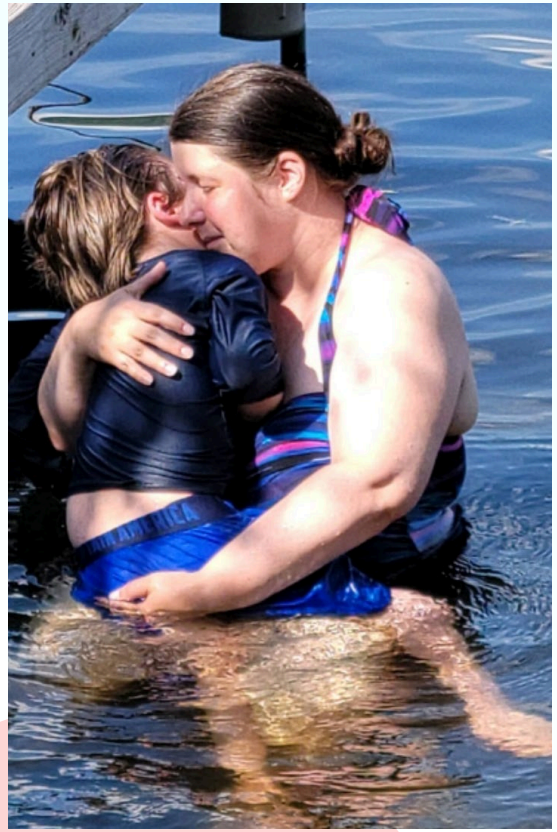
-Significant medical history, with limited life expectancy, multiple diagnoses and medical equipment requirements to sustain
-Amazing sense of humor, loves to laugh and smile
-Loves listening to music: Bob Marley, Bee Gees, Beach Boys, Katy Perry, Whitney Houston, and annoyingly, John Mayer are favorites. Enjoys feeling toys, going for walks, stores/shopping, watching Ipad, seeing classmates, playing with siblings, looking at and listening to stories, Pictello books, working with favorite providers, WATER!, hair being washed, brushed or stroked, snuggles with family, siblings and pets, lava lamps, disco balls, CAMP!!!, maternal grandparents, going on boat rides, bumpy rides, movement, silly voices, soft cozy blankets, being warm, stuffies, getting haircuts, compliments, picking out clothes that are “cool”
-Hates poopy diapers, old school country music, Jack Johnson’s music, being cold, being alone, boredom, pain/discomfort, jackets, doing school work he doesn’t enjoy, seeing providers that don’t “get him”, long term-loud noise/chaos, blood draws

Interactions with Families: Words and behaviors matter!

For families of children with significant or multiple diagnoses/disabilities, they may be overwhelmed, confused, scared.

Your words in regards to their abilities/skills, the child's capabilities, and your views about them have a much stronger influence than you may realize

Rapid-fire (-ish) Examples:
-"Tyson's Mom" (I prefer Mama, thank you!)
-Donated breast milk drama
-Extubation squeeze and you choose, I will follow your lead.
-Inpatient, after g-tube surgery- "How do you know he's in pain?"
-Neurology nurse- have to decide what type of mother you want to be
-Neurologist- you don't know, I have the medical background (infantile spasms)
-How do you know he's in there? You're giving him too much credit…



Early Intervention Interactions with Families: Words and behaviors STILL matter!

For families of children with significant or multiple diagnoses/disabilities, they may STILL be overwhelmed, confused, scared, constantly taking new information. Now, they are in this thing called “Early Intervention”.

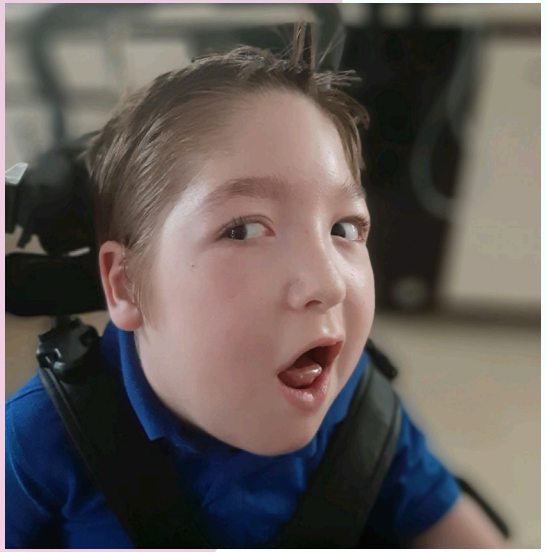
-Rotating cast and crew, revolving door, who does what and why? What’s your name again?

-You are in their home! Be relaxed, non-judgmental. Be warm and open to the family and child. Assume the family and child are competent, capable and available to feedback, suggestions and interactions.

Rapid Fire examples:
-Tyson, Mama and the EI case manager’s meet and greet
-Tyson and his first EI Physical Therapy appointment, in our home

…Or Does He?
Learning how to assume competence and feel good about it!

Rapid fire examples:
-Emma saves the day!
-Are you lookin' at me?
-Biggest birthday gift
-8 days becomes 8 years



It's OK to assume best intentions. Feel positive about that choice! It's 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 aren't hurting anyone by teaching them autonomy and self worth.

There are true life lessons to be learned when we treat others the way we wish to be treated. Though it's cliché, assuming competence feels good to all parties involved in the interaction, whether they are currently able to express it or not.

Lessons and Takeaways

-When “best practices” according to the professionals conflict.

-Silos—stay in your lane, but have awareness of the cars around you…

-Is there an exit coming up? Prepare the family!

-Non-verbal does NOT mean non-communicative

-Positivity and belief in the child/family is critical

-If you assume competence, the family will follow suit. It’s OK if they need to have encouragement or gain self-esteem in this area. Assume competence in BOTH the child and family members!

-Assume competence in yourself! Lead by example

What Can I do? Action steps!

-Assume competence—adjust your mindset on:

The child and family-are available, able, capable; no matter the communication mode

The child is capable of communicating—the burden is on you to recognize it

The best in yourself-are you seeking best practices for your profession or family life; check in-are you having positive interactions and truly enjoying time with the child/family

Believe the child's diagnoses and/or disabilities do not prevent them from connection, learning, absorbing, changing, growing, loving, having wants/needs/preferences

Understand any child is a whole being with thoughts and feelings, whether they are *currently* able to express them or not!

-If you feel this is an area that needs work, trust you can start the changes NOW!

Start big, start small, just start!

Thinking about the need or want for change, and mulling over this presentation may help

Believe you are capable of change. Might not be easy, but it is feasible

Don't discount reaching out to mentors, co-workers, leadership, related organizations or agencies, etc.

Suggest or seek associates who will assist you in creating a workgroup or support group as applicable. Learn from each other and as a group. You can invite guest speakers, family members.

What are the “systems” that require changing to make “assuming competence” a natural part of EHDI, EI, and families?

1. Individual thought processes
2. Agency/organizational leadership
3. Policies/procedures through DOE/AOE, legislation,
4. Educational institutions
5. Medical systems

Benefits of Assuming Competence

Increased 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/medical complexities

Increased funding for programs and other supports that benefit individuals with disabilities/medical complexities

Changes in medical providers/staff, service providers, and educational team approaches, terminology, suggestions, decisions making processes

Changes and/or shifts in societal views-positive views, acknowledgment every person [is not only being capable of but actually] is a productive member of society

But, I don’t know what to do!

Take a breath! It’s OK to not know.
Give yourself permission to acknowledge that you are not positive of or know the answer at all.
Do not shame yourself or the person asking.

THEN…

Do your due diligence

Ask co-workers, working groups, support groups, leadership, mentors, other families you know who have first-hand knowledge

Search the internet, libraries, journal articles. Ensure you are using reputable sources—or admit you are not sure if the source is reputable or not.

Check even seemingly oddball options such as Reddit, Facebook

Most importantly, don’t push away, pull the individual/family towards you. It’s about the connection! Trusting relationships create safety for learning, trying new things, and feelings of being accepted and understood.

ASK YOURSELF...

How can assuming competence help you, personally or professionally?

Have you ever had an experience where you thought someone in a position of power thought you weren't capable, knowledgeable? Felt as though you weren't seen or believed? How did you feel in that moment?

Can you think of ways to incorporate assuming competence into your life?

How can talking about your emotions around shame, mistakes made, and not assuming competence assist you?

How to use this Session

Assuming competence is the ability to notice, trust, inspire and interpret another individual's or your own actions, no matter how small they may seem. Just like other skills, assuming competence can be developed with education and practice.

This Session is meant for families, professionals, service providers, self-advocates, and the entire human race. Aliens and animals too!
Use in combination with other best practices, or as a stand-alone teachable moment. **Reflect** on what can done to change policies, personal views, and professional standards.

Use this session to help you:

- Notice and name your emotions around this subject
- Learn to interpret your emotions in action steps. Take the power and create change!
- Think about first steps towards change you want to engage in
- Be Tyson Tough!!!

Need more **help**?

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