

## Responses spelled out by Markus Oulette and Peyton Thorpe (both have nonspeaking autism) via text-based communication on a letterboard

Video of Peyton (and his communication partner, Taler Warner) Demonstrating the Disconnect Between Intent and Physical Volition: <https://youtu.be/bAaUY72HSbE>

Questions to Self-Advocates Peyton Thorpe (age 20) and Markus Oulette (age 20)

**Antigone: Can you describe what physical challenges you face with your body?**

PT- MY BODY OFTEN FEELS LIKE IT HAS A MIND OF ITS OWN. IT'S A CONSTANT BATTLE TO GET MY LIMBS TO COOPERATE. I HAVE TO FIND WHERE I AM IN SPACE, FIGHT MOTOR LOOPS AND REPETITIVE STIMS AND TRY TO MAKE MY MOTIONS SMOOTH. IT'S LIKE IM RUNNING A RACE BUT MY BRAIN IS WATCHING FROM THE STANDS, AND MY BODY IS SPINNING IN CIRCLES AND RUNNING BACKWARDS. MY BRAIN UNDERSTANDS BUT IT'S LIKE MY BODY IS DAYDREAMING.

MO - MY DAY DREAMING BODY IS THE PERFECT ANALOGY. MY BODY IS LIKE A PUPPY THAT JUST WATCHED A RABBIT RUN BY, IT KNOWS WHAT IT SHOULD DO BUT THE PULL OF OTHER THINGS MAKES IT ALMOST IMPOSSIBLE. IMAGINE WANTING TO PICK UP A GLASS OF WATER BUT WHEN YOU GO TO REACH FOR IT, YOUR HAND ISN'T THERE. SO YOU FIND YOUR HAND, FLAPPING BY YOUR HEAD AND YOU CAN'T GET IT TO MOVE. JUST AS YOUR FRUSTRATION KICKS IN YOUR HAND STARTS TO MOVE AND YOU KNOCK THE CUP OVER.

PT: STRUGGLE, FRUSTRATION, JERKY MOVEMENTS, REPEATED. THE DESPISED MANTRA OF MY EXISTENCE.

**Antigone: Can you describe the issues you face with visual control and visual processing?**

MO: WHEN I'M OVER STIMULATED MY VISION ONLY FOCUSES ON ONE THING. I HAVE A REALLY HARD TIME CONTROLLING MY EYES, SOMETIMES PROMPTING HELPS BUT IT CAN BE FRUSTRATING. IT TAKES A LONG TIME TO LOOK AT WHAT I WANT, AND SOMETIMES IT HURTS AND I GET A HEADACHE.

PT: YOU KNOW WHEN YOU'RE WATCHING A HOME VIDEO AND THE CAMERA IS MOVING AROUND A LOT, THAT'S KIND OF WHAT MY VISION IS LIKE. IT CAN BE IMPOSSIBLE FOR ME TO LOOK AT WHAT I WANT WITHOUT PROMPTING. MY VISION IS REALLY SHAKEY AND SOMETIMES COLOURS ARE REALLY BRIGHT. PROMPTING AND PRACTICE HELP BUT IT CAN BE PAINFUL, I THINK MOST OF MY HEADACHES ARE FROM MY VISION STRUGGLES. STRUGGLE IS DIFFERENT DAY TO DAY

**Antigone: What do you want your teachers, doctors, therapists to know when they are working with you?**

PT- I AM NOT DUMB!! I AM A GROWN ASS MAN AND I DESERVE TO BE TREATED AS SUCH. DIRECT YOUR QUESTIONS TO ME, DON'T INFANTILIZE ME. I WANT TO ADVOCATE FOR

MYSELF, I JUST NEED SOME PATIENCE. ADDRESS MY MOTOR SEPARATELY SO I CAN TELL YOU WHAT MY STRUGGLES ACTUALLY ARE. AND PLEASE GOD, NO STICKERS. I CAN DO ANYTHING WITH A LITTLE SUPPORT.

MO: WE AREN'T DUMB! TAKE YOUR STICKERS TO THE ACTUAL KIDS. SPEAK TO ME. PRETEND MY SUPPORTS ARE LIKE A SERVICE DOG, DON'T DISTRACT THEM FROM DOING THEIR JOB. CALLING MY BODY LIKE ITS A SEPARATE ENTITY HELPS TOO. IT FEELS FOREIGN TO ME SOMETIMES AND THAT HELPS. TREAT ME LIKE ANY OTHER PERSON MY AGE.

PT: YES, MY BODY FEELS FOREIGN SOMETIMES. BODY COACHING HELPS, LIKE BREAKING TASKS DOWN.

**Antigone: What helps you most when learning a new motor skill?**

PT- BREAK IT DOWN INTO STEPS AND THEN BREAK THOSE STEPS DOWN INTO STEPS. MOVEMENTS LIKE SITTING DOWN IN A CHAIR ARE MADE UP OF A BUNCH OF DIFFERENT STEPS. MY BODY MIGHT NEED HELP TURNING SO IM FACING AWAY FROM THE CHAIR, OR BENDING MY KNEES. DON'T MAN HANDLE ME, WALK ME THROUGH THE STEPS. YOU MIGHT NEED TO TOUCH A LIMB TO HELP ME FIND IT. GO SLOW AND LET ME KEEP TRYING.

MO: DON'T MAN HANDLE ME! THATS A SENSORY NIGHTMARE. LOW, CLEAR INSTRUCTIONS FOR EACH STEP. COACH MY BODY PARTS INDIVIDUALLY. REMEMBER, I'M PROBABLY FRUSTRATED IF MY BODY ISN'T COOPERATING. GIVE ME BREAKS AS NEEDED, MY SENSORY SYSTEM NEEDS IT.

PT: LOTS OF BREAKS ARE REALLY NEEDED. IF MY SENSORY SYSTEM BECOMES OVERWHELMED IT COULD BE A DAY RUINER.

**Antigone: What is least helpful to you when learning a new motor skill?**

MO- GETTING ALL THE STEPS AT THE SAME TIME. WHEN PRACTITIONERS GIVE UP TOO EASILY. SWITCH UP THE PROMTS, DON'T GIVE UP ON ME.

PT: WHEN PRACTITIONERS GIVE UP ON TASKS I FEEL USELESS AND RETARDED. WHEN THERE IS TOO MANY PEOPLE IN THE ROOM. FEELING LIKE A SHOW HORSE GIVES ME ANXIETY. GO SLOW, MOTOR SKILLS DON'T NEED TO BE A SPEED RACE.

MO: BE MINDFUL OF ANXIETY OVERALL. LEARNING NEW SKILLS IS HARD.

**Contact Info for Peyton or Markus or their communication partner / practitioner Taler Warner:**

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