Autistics Present Symposium: Foundations for Divergent Minds

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# Autistic Parenting Panel

Court (Alison) Falk, Morénike Giwa Onaiwu, Emma van der Klift, Lei Wiley-Mydske

>> RECORDING IN PROGRESS.

>> WE ARE RECORDING AND READY TO ROLL.

LEI, WOULD YOU LIKE TO INTRODUCE THE PANEL?

OR SOMEONE, ANYONE. OH, WE CAN'T HEAR YOU, LEI.

>> LEI: CAN YOU HEAR ME NOW?

OKAY. I'M NOT REALLY THE BEST AT INTRODUCTIONS.

>> I CAN'T HEAR LEI. MAYBE IT'S JUST ME.

THEY CAN HEAR YOU, IT'S JUST ME. GO FOR IT.

>> LEI: I THOUGHT WE COULD ALL INTRODUCE OURSELVES.

I'M LEI WILEY-MYDSKE, I'M A COMMUNITY OUTREACH COORDINATOR FOR AUTISTIC WOMEN NETWORK AND I RUN THE LEI WILEY LIBRARY.

I'M SITTING IN FRONT OF A BOOKSHELF AND I HAVE LONG BLACK HAIR AND DARK GLASSES.

>> MORENIKE: I WILL GO NEXT.

HI, EVERYONE, I'M MORENIKE.

MY PRONOUNS ARE SHE AND HER AND THEY AND THEIR.

I'M SITTING IN A ROOM THAT HAS AN OFF-WHITE WALL.

ON ONE SIDE OF ME IS A PICTURE WITH COLORFUL LANDSCAPES.

ON THE OTHER SIDE THERE'S A QUILT, COLORFUL QUILT.

I'M IN A LEATHER OR FAUX LEATHER CHAIR.

BLACK EXTENSIONS, DARK SKIN, BLACK.

I JUST PUT ON LIP GLOSS.

I FORGOT WHAT COLOR IT IS, BUT IT'S CUTE.

HAPPY TO BE HERE WITH YOU ALL.

MULTIPLY DISABLED AUTISTIC ADULTS, A PARENT, DO SOME WRITING AND AUTISTIC PRESENTER IS MY HOME CONFERENCE.

IT'S WHERE I LOST MY KEYNOTE VIRGINITY, SO I LOVE YOU ALL.

HAPPY TO BE HERE WITH MY AMAZING PANELISTS I HAVEN'T SEEN IN SO LONG, SO IT'S SO NICE TO SEE YOU ALL.

>> EMMA: COURT, DO YOU WANT TO GO DO YOU WANT ME TO GO?

>> COURT: YOU CAN GO FIRST.

>> EMMA: I'M EMMA VAN DER KLIFT AND I'M A WHITE FEMALE PRESENTING PERSON WITH SLIGHTLY FRIZZY GRAY HAIR AND I'M WEARING MY FAVORITE BLACK AND GRAY SWEATSHIRT BECAUSE I ONLY EVERYWHERE BLACK, BUT IT DOES HAVE A WHITE CAT ON IT JUST TO LET YOU KNOW.

LET'S SEE, WHAT ELSE CAN I SAY?

I'M SITTING IN A SMALL OFFICE ROOM AT MY HOUSE AND LANCE BILL.

DID NOT GET TO SAY WHAT UNSEEDED LAND I'M SITTING ON.

HERE IN BRITISH COLUMBIA, I AM IN CANADA.

WHAT ELSE CAN I SAY?

I'M A LONGTIME ACTIVIST AND DISABILITY RIGHTS CIRCLE ACTIVIST LONG BEFORE I UNDERSTOOD MYSELF AS AUTISTIC.

30 YEARS WORTH AND I'M REALLY HAPPY TO BE HERE WITH THESE WONDERFUL WOMEN OR NONBINARY PEOPLE.

>> COURT: CAN YOU HEAR ME?

OKAY.

MY NAME IS COURTNEY BUT EVERYBODY CALLS ME COURT.

I RUN A NEURODIVERSITY LIBRARY AND I'M A DIGITAL MEDIA CONTENT MANAGER FOR AWN AND A PARENT OF 3 AUTISTIC KIDS.

I'M AUTISTIC AND I HAVE A BUNCH OF CHRONIC HEALTH ISSUES.

I HAVE RED HAIR AND DARK GRAY T-SHIRT.

BEHIND ME IS JUST A BED WITH A BUNCH OF CLUTTER ON IT.

HOPEFULLY NONE OF THAT IS VISIBLE.

>> WE CAN'T SEE THE CLUTTER, SO THAT'S GOOD.

>> COURT: I THREW A BLANKET OVER IT, SO THAT'S GOOD.

THANKS.

>

> SARA: AWESOME.

I'M SARA SANDERS GARDNER AND YOU CAN'T SEE ME, BUT THAT'S NOT IMPORTANT.I'M JUST GOING TO READ QUESTIONS SO THEY CAN ANSWER FOR US.ARE YOU READY?

ALL RIGHT, SO THE FIRST QUESTION IS, TO ANYONE, DO YOU THINK THAT GENTLE/RESPECTFUL PARENTING OF AUTISTIC KIDS IS OR CAN BE COMPATIBLE WITH ABA APPLIED ANALYSIS?

>> LET'S NOT ALL TALK AT THE SAME TIME.

THEY HATE IT WHEN WE DO THAT.

>> I COULD NOT LIE GROWING UP BECAUSE MY FACE SAYS EVERYTHING.

THE SHORT ANSWER IS NO.

IT IS NOT COMPATIBLE WHATSOEVER.

WHATEVER IT IS, IT'S NOT COMPATIBLE.

I'M GOING TO PREFACE THIS BY SAYING -- I KNOW THIS IS AUTISTIC PRESENT IN MY PEOPLE AND ALL THAT, BUT I KNOW WE MIGHT HAVE VISITORS AND WHOEVER.

I'M JUST GOING TO SAY THIS.

I'M NOT GOING TO INDICT THE UNKNOWING PARENT WHO HAS THEIR CHILD IN ABA BECAUSE A LOT OF PEOPLE DO NOT KNOW ANYTHING ELSE.

THAT IS WHAT THEY SHOVED DOWN YOUR THROAT WHEN YOU ARE SITTING IN THE OFFICE GETTING THE DIAGNOSIS.

THEY'VE GOT THE 100 DAY KIT AND ALL THESE DIFFERENT BCB A FLYERS AND THEY TELL YOU YOU GOT TO HIT HARD, HIT EARLY, YOUR LIFE IS GOING TO BE DESTROYED, YOUR CHILD IS GOING TO WONDER OUT AND DROWN AND DIE.

YOU HAVE TERMINAL CANCER AND YOUR CHILD DOES, TOO.

SOME PEOPLE DON'T KNOW WHAT ELSE IS OUT THERE, AND SOME PEOPLE ARE IN GEOGRAPHIC AREAS WHERE THERE IS NOTHING ELSE.

THERE IS VERY LITTLE THAT PEOPLE CAN BUILD FOR, UNFORTUNATELY, BEYOND ABA.

EVERYTHING BECOMES A ABA PROGRAM WHETHER IT IS OR IT ISN'T.

SUPPOSEDLY EVIDENCE-BASED.

I SAID THIS BEFORE THAT MY DAUGHTER WAS ORIGINALLY IN AN ABA PROGRAM.

I DIDN'T KNOW ANYTHING ELSE.

THEY TELL YOU DON'T DO THIS, DON'T DO THIS, THIS IS EVIDENCE-BASED AND EVERYTHING ELSE IS CRAP.

YOU DON'T FIND OUT THE TRUTH UNTIL LATER.

IT TOOK A WHILE BEFORE I WAS EDUCATED.

FORTUNATELY I ALREADY HAD COLUMNS MYSELF, AND THIS IS BEFORE I EVEN KNEW MY DIAGNOSIS.

I KNEW BETTER FOR MY SON.

I DID NOT PUT HIM IN THERE.

MY DAUGHTER STILL BEARS THE ANXIETY.

I WANT EVERYBODY ELSE TO HAVE A CHANCE TO ANSWER, BUT I FEEL VERY STRONGLY ABOUT THIS BECAUSE I FEEL LIKE THERE'S THIS MOVEMENT TODAY WHERE PEOPLE ARE LIKE YEAH, ABA USED TO BE LIKE THAT, BUT IT'S NOT ANYMORE.

EVERYBODY IS GETTING ALL THESE OLD -- YES, EVERYTHING HAS A PAST.

EVERYTHING HAS SKELETONS.

I'M TALKING ABOUT THE SORTED NOW AND I DON'T WANT TO TALK ABOUT YOUR BAD APPLES.

I WANT TO TALK ABOUT AS A PHILOSOPHY.

AS A DISCIPLINE OVERALL IT IS COMPLIANCE-BASED INTERVENTION THAT DOES NOT TAKE INTO ACCOUNT INTERNAL AND INTRINSIC ASPECTS OF A PERSON, AND THERE'S ONLY SO MUCH YOU CAN OBSERVE AND YOUR OBSERVATION WHAT IT MEANS IS OFTEN INCORRECT WHEN IT COMES TO AUTISTIC PEOPLE.

I JUST DON'T SEE, UNLESS A PERSON IS REALLY IN DANGER OF DISLOCATING THEIR EYESOCKETS OR HARMING THEMSELVES, I DON'T SEE HOW THERE CANNOT BE SOME TYPE OF COMPARABLE WAY TO OFFER SOME TYPE OF SKILLS OR SERVICES TO SOMEONE IN A WAY THAT DOES NOT TRAIN THEM THAT THEY HAVE NO AUTONOMY AND MAKE THEM BASICALLY A SITTING DUCK TO BE GROOMED.

>> WELL, I WILL GO NEXT IF YOU LIKE.

I ALSO SAY ABSOLUTELY NO UNEQUIVOCALLY.

THIS, AGAIN, AS HE MENTIONED BASED ON BEHAVIORALISM.

IT'S BASED ON A COMPLIANCE MODEL, AND THE COMPLIANCE IS ALSO BASED IN A LOT OF UNDERLYING SOCIAL PERCEPTIONS AND BIASES THAT TELL US THAT BEING AUTISTIC OR DISABLED IN ANY WAY IS WRONG AND THAT NEEDS TO BE REMEDIATED OUT OF US.

IT'S AN EXPRESSION OF AN UNDERLYING ABELIST IDEA.

I HAVE HEARD ABA LIGHT.

I'M SORRY, IT'S STILL BEHAVIORISM.

I THINK IT ACTUALLY IS INCOMPATIBLE OF THE GOALS OF GOOD PARENTING BECAUSE WHAT WE WANT FOR OUR KIDS IS RESILIENCE, SELF-ACCEPTANCE, HAPPINESS, CONFIDENCE, AND A GOOD SENSE OF PERSONAL SPACE.

AND ABA VIOLATES ALL OF THE ABOVE.

SO THAT'S MY PEACE.

>> I ALSO WAS A NO, I DON'T THINK IT'S COMPATIBLE AT ALL.

I THINK THAT SOME OF WHAT I'VE SEEN RECENTLY OF GOOD ABA IS JUST MANIPULATION, AND I DON'T THINK YOU CAN BUILD A RELATIONSHIP WITH YOUR CHILD THAT'S BASED ON MANIPULATING THEM TO ACT HOW YOU WANT THEM TO ACT.

>> WITHOUT THEM KNOWING YOU ARE DOING IT TO THEM.

>> LEI: AND IT'S NOT A WAY TO BUILD A TRUSTING RELATIONSHIP EITHER. I FEEL LIKE IF YOU WANT TO PARENT OR CHILD RESPECTFULLY NEEDS TO BE BASED ON RESPECT AND NOT MANY RELATION.

I DO NOT THINK ABA IS COMPATIBLE.

>> I AGREE, TOO.

I WROTE SOME NOTES DOWN, SO IF I'M NOT LOOKING UP IT'S BECAUSE I'M LOOKING AT THEM.

WE NEVER DID ABA, BUT I UNDERSTAND SOME PEOPLE DO IT BECAUSE THERE'S NOT ANY OPTIONS.

AND EVERYTHING THAT BOTHERS ME IS ABA GETS SO MUCH CREDIT FOR EVERYTHING.

IF YOU COMPARE THE 15-YEAR-OLD CHILD TO HOW THEY WERE AT 3 OR 4, THERE'S GOING TO BE A TON OF CHANGES.

IF WE DIDN'T DO ABA THEY WOULD STILL BE RUNNING IN THE ROAD OR WOULD NOT HAVE DONE THIS.

ALL I SEE WITH MY OWN CHILDREN, WHO ARE 10, 12, AND 12, THEY CHANGE FROM US JUST TEACHING THEM THINGS AND RESPECTING THEIR BODY AUTONOMY.

TALKING ABOUT THINGS LIKE CONSENT.

IT MAKES PEOPLE THINK THAT THE ONLY WAY THAT AUTISTIC PEOPLE CAN LEARN IS THROUGH ABA AND IF YOU DON'T PUT YOUR KIDS IN ABA, IT WILL BE A 3-YEAR-OLD FOREVER.

THEY WILL NEVER GAIN ANY SKILLS AND LEARN ANYTHING.

I CAN SEE IN MY OWN HOUSE THAT'S NOT TRUE AT ALL.

NO, I DON'T THINK IT IS BECAUSE THE FOUNDATION OF RESPECTFUL PARENTING IS FOCUSING ON YOUR RELATIONSHIP, LIKE TRUST AND CONNECTION.

I DON'T KNOW HOW I COULD DO THAT AUTHENTICALLY WITH MY KIDS.

AND THEN ALSO, HAVING PEOPLE IN MY HOME OR TAKING THEM PLACES WHERE THAT PERSON IS MANIPULATING ALL THE THINGS THEY DO AND TRY TO CHANGE THEM.

I DON'T THINK IT'S COMPATIBLE.

>> MORENIKE: IF IT'S OKAY, TRISH, SOMEONE MENTIONED SOMETHING IN THE CHAT.

IF IT'S OKAY TO CHIME IN ON THAT IF YOU ALL ARE ALL RIGHT WITH THAT.

WHEN I WAS GOING TO SAY IS I WANT TO SAY THAT, YOU KNOW, I KNOW ALL THINGS ARE NOT CREATED EQUAL.

YOUR CHILD MIGHT LIKE THE ABA THERAPIST.

THEY MIGHT SEEM REALLY NICE.

IN MY CASE MY DAUGHTER IS LIKE YAY, PEOPLE WHO LOOK LIKE ME.

AND SO THERE'S -- OR THEY MIGHT SMILE AND HIGH-FIVE OR WHATEVER.

I'M NOT SAYING THAT THE PERSON IS DRAGGING YOUR CHILD BY THE EARLOBE AND SMACKING THEM AGAINST THE WALL AND SAYING SHUT UP OR ANYTHING LIKE THAT.

I'M JUST SAYING OVERALL IT'S AN ABUSIVE PRACTICE.

THE REASON WHY WE TALK ABOUT THINGS LIKE LAND ACKNOWLEDGMENT, WHICH I FORGOT MINE, SO THANK YOU, EMMA. IS BECAUSE OF THE FACT THAT YAY, I'VE GOT THIS BEAUTIFUL HOME IN HOUSTON, TEXAS THAT WAS STOLEN.

THAT'S JUST THE TRUTH.

SO, THE REALITY OF WHAT SOMETHING IS AND HOW IT CAME TO BE CAN'T BE IGNORED.

I THINK WHAT HAPPENS IS THAT PEOPLE, SOMETHING CAN WORK AND THAT DOESN'T MEAN THAT IT'S WORTH THE COST I GREW UP IN THE SOUTH.

EVERYBODY SPANKED THE HECK OUT OF THEIR KIDS FOR EVERYTHING, RIGHT?

THOSE KIDS KNEW HOW TO BEHAVE IN A STORE AND BUILDING AND CHURCH.

THEY SIT QUIETLY.

THEY WERE TERRIFIED THOUGH.

YEAH, YOUR CHILD IS NOT THROUGH A MELTDOWN AND HAVE A TANTRUM IN THE STORE, BUT THEY ARE FULL OF ANXIETY ON THE INSIDE.

SLAVERY WAS EFFECTIVE ECONOMICALLY.

IT'S A GREAT SYSTEM FOR SOME.

JUST BECAUSE SOMETHING IS EFFECTIVE DOESN'T MEAN THAT IT'S WORTH THE COST.

AND I AM NOT SAYING THAT THERE AREN'T SKILLS.

AND ONE THING THAT OSWIN SAYS A LOT IS THAT A LOT OF PEOPLE JUST MAKE THERE'S A LOT OF THINGS THAT HAVE BEEN ATTRIBUTED TO ABA THAT ARE NOT NECESSARILY ABA.

THERE'S A LOT OF CROSSOVER WITH THE SOCIAL SCIENCES.

THE DATA KEEPING, DOCUMENTATION, WHICH IS REALLY GOOD.

IT'S SOMETHING THAT CAN BE UTILIZED IN OTHER FIELDS.

IT TYPICALLY ISN'T, AND YES, THERE ARE WAYS THAT ARE UNIQUE TO ABA, BUT THERE ARE THINGS THAT ARE NOT.

KEEP DOCUMENT TATIAN IN EDUCATIONAL SYSTEM OR CLINICAL PRACTICE.

THERE'S A LOT OF THINGS THAT ABA HAS BORROWED AND MADE THEIR OWN.

JUST BECAUSE KIM KARDASHIAN BOUGHT A BUTT DOESN'T MEAN THAT SHE ORIGINATED THAT.

TAKE BITS AND PIECES OF THE THINGS THAT WORK FOR YOUR CHILD, IF THERE ARE BEHAVIORAL ISSUES I'M NOT SAYING LET THEM RUN WILD AND HAVE NO TYPE OF INTERVENTION.

I JUST DON'T THINK IT'S AN INTERVENTION THAT'S WORTH IT.

IF MY CHILD IS ACTING OUT, DO I WANT TO SWAP HIM ON THE HEAD WITH A 2 TON CLOVER TO STOP HIM?

IT'S EXCESSIVE.

>> ARE WE READY FOR THE NEXT QUESTION?

I THINK PEOPLE WILL WANT TO HEAR IT.

WE ARE READY TO HEAR QUESTION NUMBER 2, WHICH I WILL ALSO PUT IN THE CHAT.

THANK YOU, BB, FOR THAT REMINDER.

QUESTION NUMBER 2 IS, WHAT ARE THE ALTERNATIVES TO ABA THAT YOU THINK ARE HELPFUL?

>> EMMA: CAN I START THAT ONE?

IN ORDER TO ANSWER THAT QUESTION, I FEEL LIKE I HAVE TO BACK UP A BIT.

MY PARTNER, NORM, AND I ARE BUSY WRITING A BOOK LOOKING AT THE PARALLELS BETWEEN PHYSICAL THERAPY AND COMPLIANCE BASED THERAPIES.

OUR CONTENTION IS THERE'S MORE GOING ON IN THE THERAPY ROOM THEN THERAPY.

THIS IS SOMETHING WE HAVE TO LOOK AT.

WE BELIEVE IT IS NOT AND HAS NEVER BEEN A NEUTRAL ACTIVITY.

IT'S POLITICAL AND IT'S SOCIAL AND IT REINFORCES MANY OF THE THINLY VEILED IDEAS THAT ARE OUT THERE IN SOCIETY.

SO, IN THIS CONTEXT WE ARE REALLY WARY OF REPLACEMENT MODELS.

MODELS AT ALL.

ARE WE JUST PLANTING ONE THING WITH SOMETHING ELSE?

RATHER THAN PROPOSING ALTERNATIVE THERAPIES, WE BECAME MORE INTERESTED IN CHALLENGING AND DECONSTRUCTING THE PRACTICES THAT ACTUALLY SUBJUGATE PEOPLE TO A DOMINANT IDEOLOGY THAT ACTUALLY OPPRESSES THEM.

WITHIN MAYBE IT'S MORE IMPORTANT TO STAY AWAY FROM THE QUESTION, SHOULD WE DO THERAPY?

BECAUSE THAT'S A YES OR NO ANSWER.

SAY INSTEAD, WHAT IS EXACTLY IS THERAPY?

WHAT ARE THE MESSAGES INHERENT IN THERAPY?

WHAT DOESN'T ACTUALLY ACCOMPLISH?

DOES IT ACCOMPLISH WHAT WE THINK IT A COMPASS IS, AND DOES IT ACCOMPLISH OTHER THINGS WE DON'T INTEND?

THERE'S NO ATTENTION PAID TO THOSE QUESTIONS.

AND THEN PEOPLE SAY, ARE YOU IN PLAYING WE SHOULDN'T DO ANYTHING AT ALL?

LET PEOPLE LIE AROUND AND DO NOTHING?

NO, I DON'T THINK SO.

NORM AND I ARE LOOKING AT THE DIFFERENCE BETWEEN ACCEPTANCE AND RESIGNATION.

CATEGORICALLY REALLY DIFFERENT, AND ALSO CHALLENGE AND DOMINATION.

ALSO REALLY DIFFERENT THINGS.

HOW CAN WE MOVE INTO A PLACE OF ACCEPTANCE AND CHALLENGE OURSELVES?

IT'S NOT BECOMING COUCH POTATOES, BUT RECOGNIZE THAT RESIGNATION AND DOMINATION ARE THE ARTIFACTS OF OPPRESSION AND WE NEED TO TALK BACK TO THEM.

WE ARE MORE INTERESTED IN QUESTIONS LIKE IS YOUR CHILD HAPPY?

WHAT ARE YOU NOTICING?

ANYWAY, THAT'S MY 2 BITS WORTH.

>> LEI: I THINK THAT AUTISTIC KIDS ARE EXPECTED TO DEAL WITH A LOT OF THERAPIES THAT THEY DON'T NECESSARILY NEED.

A GOOD REPLACEMENT WOULD BE PARENTS EDUCATING THEMSELVES ABOUT WHAT ACTUALLY HELPS AUTISTIC PEOPLE, AND RIGHT BEHIND ME I HAVE THIS BOOK

[LAUGHING]

>> EMMA: 10 BUCKS

>> THIS IS AN AMAZING BOOK.

I WANT TO BUY IT FOR EVERY SCHOOL AND EVERY PARENT.

IT'S AMAZING.

I THINK A GOOD WAY IS FOR A PARENT TO NOT THINK YOUR KID NEEDS TO BE ENGAGED IN ALL THESE THERAPIES AND YOU NEED TO EDUCATE YOURSELF.

I THINK THAT THERE ARE SOME THERAPIES THAT CAN BE HELPFUL IF THEY ARE NOT BASED IN COMPLIANCE AND MANIPULATION.

THINGS LIKE SPEECH THERAPY THAT IS FOCUSED ON COMMUNICATION AND NOT VERBAL SPEECH ONLY.

OCCUPATIONAL THERAPY WAS REALLY HELPFUL, TOO.

AND IT KIND OF HELPED LEARN HOW YOUR BODY MOVES AND WHAT TO LISTEN FOR AND WHAT SENSITIVITIES YOU MIGHT HAVE OR WHAT THINGS YOU SEEK OUT I ALSO THINK THINGS CAN BE THERAPEUTIC AND THEY ARE NOT THERAPY.

THERE'S A BIG PUSH NOW FOR HORSE THERAPY FOR AUTISTIC PEOPLE.

WHEN I WAS A CHILD I DID HORSEBACK RIDING AND IT WAS REALLY FUN.

THERE WAS NO THERAPY BUT IT WAS EXTREMELY THERAPEUTIC TO ME BECAUSE I LIKE ANIMALS AND IT WAS NICE AND IT HELPED ME TO STAY CALM. IT WASN'T STOPPING ME FROM BEING AUTISTIC.

IT WAS JUST A THERAPEUTIC THING FOR MY MENTAL HEALTH.

I DON'T THINK WE NEED 40 HOURS OF SOMETHING ELSE TO REPLACE ABA.

I JUST THINK KIND OF LET KIDS BE KIDS AND PARENTS BE MORE EDUCATED.

>> I HAVE BEEN ASKED THIS QUESTION A LOT, LIKE MANY TIMES OVER THE LAST 10 YEARS.

A LOT OF PEOPLE THINK THERE'S ONE SPECIFIC ALTERNATIVE, SO WE WILL SWITCH FROM ABA TO THAT.

I DON'T THINK IT NEEDS TO BE REPLACED, BUT ALSO BECAUSE KIDS DESERVE TO HAVE A CHILDHOOD AND FOR SOME REASON IT SEEMS TO BE UP FOR DEBATE WHEN IT'S AN AUTISTIC CHILD.

2 OR 3-YEAR-OLDS SHOULD SPEND 40 HOURS A WEEK IN ABA.

FOR US I HAVE 3 AUTISTIC CHILDREN AND MY OLDER DID OT WHEN THEY WERE YOUNGER AND MY 10-YEAR-OLD, WHO IS NONSPEAKING, DID SOME SPELLING LESSONS WHERE HE'S LEARNING TO COMMUNICATE.

THE PLACE HE GOES IS VERY RESPECTFUL.

IT'S VERY CENTERED AROUND NOTHING TO DO WITH FIXING.

BUT I ALSO THINK LYNN'S CHANGE NOTICING AUTISM AS A PROBLEM OR ILLNESS OR SOMETHING THAT'S STOLEN YOUR CHILD.

IT'S NOT JUST PARENTS.

IT'S LIKE WHAT SOCIETY TELLS A LOT OF PEOPLE, TOO.

IF YOU SEE YOUR CHILD IS A PILE OF BEHAVIORS, IT'S HARD TO THING ABOUT NOT PUTTING THEM SOMEPLACE AND WHO WOULD BE WORKING WITH THEM.

WE DID NOTICE AS OCCUPATIONAL THERAPISTS STARTED IMPLEMENT THINK SOME ABA TACTICS THAT WE ENDED UP STOPPING GOING BECAUSE WE HAD A GREAT OT, BUT SHE GOT REALLY EXCITED ABOUT ABA AND THOUGHT SHE COULD IMPLEMENT IT IN A RESPECTFUL WAY AND IT DIDN'T WORK OUT THAT WAY.

FOR US, FOR MY FAMILY, THE BEST THING WE DID PEOPLE TALK ABOUT MELTDOWNS AND STUFF WAS REDUCING EXPECTATIONS.

WE KEEP OUR SCHEDULE NOT SUPER BUSY IF WE CAN HELP IT.

WE TRY TO NOT HAVE A BUNCH OF APPOINTMENTS IN A ROW.

WE ALSO DON'T FORCE THINGS THAT AREN'T REALLY NECESSARY.

THERE'S A LOT OF THINGS TO DO WITH HOLIDAYS OR TAKING YOUR KIDS TO BUSY THINGS THAT THEY FEEL MANDATORY MAYBE AT SOME POINT, AND I UNDERSTAND THIS ISN'T ALWAYS POSSIBLE.

THERE ARE DOCTORS APPOINTMENT THAT HAVE TO BE DONE, BUT I THINK UNDERSTANDING THAT ALL KIDS DESERVE TO HAVE A CHILDHOOD TO PLAY AND NOT HANG OUT WITH PEOPLE WHO ARE PAID TO SPEND TIME WITH YOU.

EVEN IF THEY LIKE THEIR ABA THERAPIST, WHAT ELSE DO THEY KNOW?

THEY ARE SPENDING THEIR WHOLE WEEK THERE.

MAYBE THAT PERSON IS NICE AND FUN.

I THINK THE FACT THAT IT'S REALLY NORMALIZED, AND I'VE HAD A LOT OF PEOPLE SAY OH, SO YOU JUST DO NOTHING?

THOSE AREN'T THE ONLY 2 ANSWERS, LIKE ABA OR NOTHING.

I FEEL LIKE THERE'S A LOT OF WAYS YOU CAN TEACH HER CHILDREN AND EXPOSE THEM.

YOU CAN GET TO KNOW PEOPLE WHO MAY BE ABLE TO HELP, AND AS THEY GET OLDER CYSTIC CULTURE GETTING TO KNOW OTHER AUTISTIC PEOPLE.

I JUST THINK NOT SEEN THEM IN NEED OF FIXING IS THE BIGGEST STEP TO REALIZING THEY DON'T HAVE TO BE IN THERAPY.

IT CERTAINLY DOESN'T MEAN EVERYTHING IS PERFECT.

SOMETIMES WE TRY SOMETHING AND IT REALLY DOESN'T WORK.

SOMETIMES I PUSH WHEN I SHOULD HAVE BACKED OFF.

IT'S A TRIAL AND ERROR THING.

>> MORENIKE: WE CAN MOVE ON IF WE NEED TO. I DON'T HAVE TO ADDRESS THIS QUESTION.

I TYPED SOME STUFF INTO THE CHAT, SO I'M FINDING ANOTHER ONE.

>> I THINK WE HAVE TIME TO HEAR WHAT YOU HAVE TO SAY.

>> MORENIKE: OKAY, SO EVERYTHING EVERYBODY HAS BEEN SAYING MAKES A LOT OF SENSE.

IT'S VERY INTERESTING.

WHEN I WAS DOING MY MASTERS DEGREE WE TOOK ALL THIS COURSEWORK ON DEVELOPMENT, AND IT WAS JUST SO INTERESTING THAT WHEN DISABILITY IS NOT INVOLVED THERE'S ALL THIS TALK ABOUT THE NEED FOR BIG BODY PLAY AND FREE MOVEMENT AND EXPLORATION IN THIS, THAT, OR THE OTHER.

AS SOON AS DISABILITY COMES INTO PLAY YOUR CHILD CEASES TO BE A CHILD.

IT'S PRETTY RIDICULOUS.

I THINK ABOUT THE FACT THAT, A LOT OF WHAT HAS BEEN SAID MAKES A LOT OF SENSE.

FIRST OF ALL, ASSESS YOUR LIFE AND HOME OVERALL.

WHAT CAN YOU DO?

DO YOU HAVE A BEEPING FIRE ALARM THAT YOU CAN FIX?

DO YOU HAVE THINGS SET UP A CERTAIN WAY OR NOISE?

WHAT CAN YOU DO TO MAKE THE HOME ENVIRONMENT MORE COMFORTABLE?

THINK ABOUT YOURSELF WHEN YOU WALK INTO A BUILDING OR ROOM, WHAT'S OVERWHELMING FOR YOU?

ADDITIONALLY, YOU CAN SEE WHAT ELSE MIGHT BE HAPPENING.

I OFTEN SAY THAT AUTISM DOESN'T TRAVEL ALONE, AND TRAVELS IN PAIRS.

MY KIDS, A LOT OF STUFF GOING ALONG WITH AUTISM.

WE HAD SKIN STUFF, ONE HAS CARDIAC DISEASE.

THAT'S ANOTHER STORY.

WE HAD THINGS THAT NEEDED TO BE -- WE HAD FOOD VERSIONS, THINGS THAT NEED TO BE ADDRESSED.

EVERYONE LOVES TO THROW EVERYTHING INTO THE AUTISM BUCKET AS IF EVERY SINGLE THING IS AUTISM.

SOME THINGS ARE RELATED TO AUTISM AND SOME ARE NOT.

WE WERE ABLE TO ADDRESS THE OTHER ISSUES MY KIDS HAD, AND THAT HELPED A LOT.

WE WERE ABLE TO HELP THEM GUIDE US.

IF THERE INTO SOMETHING AND THEY LIKE IT, GET INTO THAT, TOO.

FOSTERS CONNECTION AND RELATIONSHIP AND SO FORTH.

AVOID THINGS THAT ARE LOUD OR BUSY PLACES.

DON'T DO THE WALMART ON A SATURDAY MORNING THING PROBABLY NOT WITH ANY KID, BUT DEFINITELY NOT WITH AN AUTISTIC CHILD.

IF THERE'S OTHER THERAPIES THAT CAN WORK, WE DID OCCUPATIONAL THERAPY.

WE DID SPEECH THERAPY.

WE DID PLAY THERAPY.

WE HAD SOME PHYSICAL THERAPY.

FEEDING THERAPY.

WE HAD A DIETITIAN THAT WE SAW.

HOPEFULLY YOUR CHILDREN DON'T HAVE ALL THE STUFF GOING ON MINE HAD GOING ON WITH THEMSELVES.

WHAT I'M SAYING IS SOMETIMES, AND JUST BREATHE.

NO ONE IS ON ALL THE TIME.

IF YOU THINK ABOUT MY COUSIN DOES THE EUTERPE STAGE MAKEUP IS VERY, VERY HEAVY FOR A REASON.

NO ONE WALKS AROUND WITH THAT STUFF ON ALL DAY.

YOU COME HOME AND YOU TAKE IT OFF.

IF ABA IS SOMETHING PEOPLE ARE SUPPOSED TO ENGAGE IN 24/7, NOT JUST WHEN THE THERAPIST IS THERE.

YOU ARE SUPPOSED TO AT HOME WHEN THEY DON'T USE WORDS TO ASK SOMETHING, IGNORE THEM.

IT'S NOT AN AUTHENTIC WAY TO BE NEXT NOT PARENTING.

AND I JUST FEEL LIKE I'M NOT SAYING IT DOESN'T PRODUCE RESULTS.

I CAN TELL YOU THAT MY DAUGHTER CAN PASS IF SHE WANTS TO AT TIMES.

MY SON WILL NEVER PASS EVER.

BUT AT WHAT COST?

THE ANXIETY THAT SHE HAS AND THE MIGRAINES SHE HAS FROM THAT TIME.

AND THAT WAS WITH GOOD ABA THAT I WAS WATCHING PHYSICALLY THERE.

AND NO ONE IS ON THEIR A GAME.

TEACHER, PROVIDER, ANYONE.

THERE'S OTHER WAYS.

EVERY CHILD IS DIFFERENT.

EVERY SITUATION IS DIFFERENT.

>>

EVERY SITUATION IS DIFFERENT.

I DON'T THINK THERE'S A COOKIE CUTTER ROUTE, YOUR CHILD HAS THIS, THEY NEED THESE THERAPIES.

NO, THEY DON'T NECESSARILY NEED TO.

>> RIGHT.

>> THANK YOU.

WE'RE GOING TO MOVE ONTO QUESTION 3 AND LET ME PUT IT IN THE CHAT AS WELL.

IT IS WHEN YOUR AUTISTIC CHILD IS NEWLY DIAGNOSED, YOU ARE OFTEN PRESENTED WITH INFORMATION FROM PROFESSIONALS AND THERAPIES AND TOLD TO FOLLOW UP ON MORE INFO FROM ORGANIZATIONS LIKE AUTISM SPEAKS.

CAN WE TALK ABOUT WHY THAT IS HARMFUL AND WHAT PROFESSIONALS CAN DO INSTEAD TO HELP FAMILIES AND EMPOWER AUTISTIC KIDS?

>> I'M GOING TO LET Y'ALL ANSWER THIS BECAUSE I DON'T KNOW IF I CAN ANSWER THIS ONE WITHOUT PROFANITY.

>> [LAUGHTER]; OKAY, I'LL GO.

IF IT'S OKAY, I MIGHT TOO.

WHAT IT DOES, WHAT'S HARMFUL IS PLAYS INTO ARM MA GET TEN MINDSET THAT IS PUT FORWARD.

WHAT WILL HAPPEN TO MY CHILD.

ALL BASED ON SOCIETAL IDEAS, IT'S MEDICAL, PITY BASED, ALL THOSE THINGS.

UNFORTUNATELY, A LOT OF THOSE PROFESSIONALS HOLD THOSE BIASES AND DON'T RECOGNIZE THEY DO. THEY COMMUNICATE THEM TO THE PARENTS AND PARENTS HAVE TO SLOG THROUGH THAT.

AND IS UNCONSCIONABLE.

GETS MORE INTENSE.

WE'VE TALKED TO LAWYERS WHO REFUSE TO SUGGEST ANYTHING OTHER THAN THE CONVENTIONAL APPROACHES LIKE ABA BECAUSE THEY MIGHT GET SUED AND WE KNOW PEOPLE LIKE ONE WOMAN FROM NEBRASKA HAD TO MOVE WHILE SHE WAS DOING HER DOCTORAL DISSERTATION ON DISABILITY BECAUSE SHE REFUSED TO PUT HER KIDS THROUGH ABA AND THIS IS NOT AN UNUSUAL THING.

I DON'T KNOW, I THINK WHAT WE COULD DO, ONE MORE THING, IF YOU LOOK AT CLINICIANS AND OTHERS WHO ARE WORKING IN THE FIELD OF DOMESTIC VIOLENCE, WHO ARE WORKING IN THE FIELD OF LGBTQ ISSUES AND WORKING ON MANY OF THOSE ISSUES, THEY ARE COMING AT IT FROM A, THE STANDPOINT OF SOCIAL RESPONSIBILITY AND POLITICAL UNDERSTANDING AND THE POWER DYNAMICS AND THEY'RE KIND OF TAKING THAT APART WITH THE PEOPLE THAT ARE COMING TO SEE THEM.

WHEN IS THIS GOING TO MOVE INTO DISABILITY CIRCLES SO DON'T JUST GET THE PITY AND ALL OF THE REST OF IT. WHEN ARE WE GOING ENCOURAGE PARENTS TO TALK BACK TO THE SOCIAL VOICES THAT ARE TELLING THEM THERE'S SOMETHING WRONG WITH THEIR KID.

AND OLD TROPES LIKE CHRONIC SOIL AND OVERCOMING ONE DISABILITY.

LIKE YOU SAID MORÉNIKE, YOUR CHILD IS GOING TO GET HIT, AND BLAH BLAH.

THAT'S WHERE WE SEE WE NEED PROFESSIONALS THAT ARE GOING TO TALK ABOUT PRIDE, ROLE MODEL, INTRODUCE KIDS TO ROLE MODELS WHO HELP THEM BECAUSE THEY UNDERSTAND WHAT IT'S LIKE TO LIVE IN OUR SKIN.

IF WE CAN GET PROFESSIONALS TO DO THOSE THINGS, HEY, WE'RE PART WAY THERE.

CAN I JUST SAY ONE MORE THING, I ALWAYS REALLY LIKE TO QUOTE FOUCAULT HERE, I LOVE THIS QUOTE, I LOVE IT. FOUCAULT SAID PEOPLE KNOW WHAT THEY DO, THEY FREQUENTLY KNOW WHY THEY DO WHAT THEY DO BUT WHAT THEY DON'T KNOW IS WHAT THEY DO DOES.

>> REMINDER TO PANEL, THE QUESTION IS WHEN YOUR CHILD IS NEWLY DIAGNOSED, YOU ARE GIVEN A WHOLE BUNCH OF INFORMATION FROM PROFESSIONALS AND THERAPIES AND TOLD TO FOLLOW UP WITH ORGANIZATIONS LIKE AS, CAN WE TELL WHY THAT'S HARMFUL AND FAMILIES CAN DO INSTEAD.

>> DID I GO OFF THE SCRIPT?

>> NO, I WAS NOT REPRIMANDING YOU.

>> I WOULD DO IT IN PRIVATE IF I WANTED TO.

>> [LAUGHTER].

>> A LOT OF PEOPLE, WELL, I MEAN, THE FACT THAT AUTISTIC PEOPLE DON'T LIKE ‑‑ IS A BIG SECRET.

BUT I KIND OF WANTED TO ADDRESS THE LAST PART ABOUT WHAT PROFESSIONALS IN THESE ORGANIZATIONS COULD DO, THAT'S NOT JUST LISTENING TO US BUT YOU KNOW PAY US, EMPLOY US.

WHEN YOU HAVE A BOARD OF DIRECTORS ‑‑ THAT'S NOT GOOD ENOUGH.

NEEDS TO BE MAJORITY OF AUTISTIC PEOPLE IF NOT ALL AUTISTIC PEOPLE IN ORDER ACCURATELY KNOW WHAT'S BEST FOR US, YEAH.

IT'S REALLY HARD LIKE MORÉNIKE SAID TO TALK ABOUT THOSE THINGS WITHOUT PROFANITY SO.

YEAH.

MOST ORGANIZATIONS EVEN LOCAL TO ME ARE PARENT LED AND THAT'S WHAT GETS THE FUNDING, AND THEY'RE RECOMMENDING THINGS LIKE 40 HOURS A WEEK OF ABA AND ARE GOING TO GIVE YOU RESOURCES THAT ARE NOT NEURODIVERSITY INFORMED AT ALL.

YEAH.

LISTEN TO AUTISTIC PEOPLE IS A SIMPLE ANSWER AND THAT'S ALL THEY HAVE TO DO.

AND WE'VE BEEN TRYING TO GET THEM TO DO IT FOR A LONG TIME, HOPEFULLY IT WILL HAPPEN SOON.

>> THERE'S A QUESTION IN THE CHAT.

SORRY LEE, THERE'S A QUESTION IN THE CHAT THAT GOES TO YOUR POINT YOU ARE SAYING THAT SOMETIMES PEOPLE ARE COURT MANDATED OR SOCIAL SERVICES STRONGLY ENCOURAGED TO USE THINGS LIKE ABA OR OTHER THERAPIES THAT HE BELIEVE ARE NOT BENEFICIAL FOR THEIR CHILDREN.

BUT IN THIS CASE, PARENTS NEED TO BE AWARE OF ALTERNATIVES TO ADVOCATE FOR.

ONE THING I'M THINKING FOR THIS CONFERENCE, WE'LL GATHER A LIST OF THOSE THINGS AND POST THEM.

IS THERE A PLACE WHERE IT EXIST ALREADY WHERE PEOPLE CAN FIND THAT?

>> I DON'T KNOW.

>> I DON'T THINK I UNDERSTOOD WHERE YOU WERE SAYING.

ALTERNATIVE IDEAS OR RESOURCES OR INFORMATION?

>> IS THERE ALREADY A

>> LIKE A REPOSITORY ‑‑

>> YES.

>> I DON'T THINK THERE'S A COMPREHENSIVE ONE, NO.

I THINK THERE ARE DIFFERENT ORGANIZATION THAT'S HAVE DIFFERENT THINGS IN DIFFERENT PLACES.

CORRECT ME IF I'M WRONG OF COURSE.

BUT I FEEL LIKE I DON'T FEEL LIKE THERE'S A ‑‑ INSTEAD OF THIS DO THIS TYPE OF THING.

MORE OF A SUGGESTION.

SOME PROGRAMS MIGHT BE ONLY IN A PARTICULAR REGIONAL AREA OR WHATEVER, YOU KNOW, OR OTHER SUGGESTIONS.

I DON'T KNOW ONES THAT IN ONE CENTRAL PLACE THAT.

BUT I THINK THERAPIST IN NEURODIVERSITY COLLECTIVE ARE WORKING.

I THINK THAT WILL BE WONDERFUL TO HAVE SOMETHING LIKE THAT.

I DO WANT TO SAY FEW COMMENTS IN AUTISM SPEAKS.

IT'S INTERESTING, THE OLD AUTISM SPEAKS ONE-HUNDRED-DAY KIT IS SO AWFUL.

I WISH I STILL HAD IT. BECAUSE SOMETIMES PEOPLE, YOU KNOW, PEOPLE WILL BE LIKE, I DON'T UNDERSTAND WHY YOU ARE SO UPSET.

SOMETIMES I GO TO AUTISM SPEAKS, THAT'S ON AUTISM SPEAKS WEBSITE, WOW.

I KNOW BECAUSE THERE'S AUTISTIC PEOPLE TRYING TO REFORM WITHIN.

THERE ARE CHANGES THEY'RE TRYING TO MAKE.

BUT PEOPLE DON'T REALIZE, YOU KNOW, WHAT PEOPLE HAVE BEEN TOLD.

THE STORIES, THE EXAMPLES, IT'S JUST REALLY TRAUMATIZING.

WE PROBABLY WON'T HAVE TIME, IF WE DO, I'M WORKING ON A BOOK WITH SOME OTHER PARENTS AND WE'RE TALKING ABOUT THE EXPERIENCE OF BEING BLACK AND THE FIRST CHAPTER IS ABOUT THE DIAGNOSIS.

THE WAY YOU'RE TOLD. AND I HAVE THE STORY THERE ABOUT MINE AND BASICALLY HOW I TRIED TO ABANDON MY CHILDREN, SAFE HAVEN, AT THE EMERGENCY ROOM BECAUSE HOW INCOMPETENT I WAS MADE TO FEEL ABOUT BEING ABLE TO RAISE THEM.

I THINK YOU KNOW THE WAY YOU TELL SOMEONE SOMETHING, YOU KNOW, YOU CAN ‑‑ THERE COULD BE A STUDENT AND THEY ARE TAUGHT ABOUT BEDSIDE MANNER AND HOW TO ADDRESS THINGS.

WE HAVEN'T SEEMED TO FIGURE OUT HOW TO STILL KEEP THE HUMANITY IN PERSON HOOD OF AN AUTISTIC PERSON.

AND WHEN YOU ARE DELIVERING INFORMATION.

THEY'RE NOT DIAGNOSE.

AND SHOULDN'T BE TALKED ABOUT OR COMPARED TO A TERRORIST ATTACK ON THE TWIN TOWERS.

>> IS IT OKAY IF I ANSWER THIS ONE? I THINK EVERYTHING THAT ALL OF YOU HAVE SAID IS GOOD.

I WAS GOING TO ADD.

THE ENTIRE PROCESSES IS PATHOLOGIZING.

THEY GIVE YOU QUESTIONNAIRES AND EVERYTHING ON THERE MAKES IT SEEM LIKE THE ONLY RIGHT WAY TO DO THINGS IS THE OPPOSITE WAY OF WHAT YOUR CHILD IS DOING.

IF THEY SPIN THE WHEELS ON A TOY CAR INSTEAD OF PUSHING IT ON THE GROUND, THAT'S BAD.

BUT ALSO THE WAY THEY DELIVER THE NEWS, YEAH.

IT'S LIKE PITY HE AND ALSO, THEY TRY TO SAY THINGS LIKE ALLOW YOURSELF TIME TO GRIEVE.

WE'RE ‑‑ I DON'T THINK WE'RE IDEALLY THINKING OF OUR CHILDREN OR OURSELVES AND NEUROTYPICAL, CAN YOU SIGN OFF ON THIS AND SAY WE'RE AUTISTIC.

SOMETIMES YOU NEED A DIAGNOSIS FOR SOMETHING LIKE KIDS FOR A WAIVER, MY TEN‑YEAR‑OLD SON WHO IS NON‑SPEAKING, WE'VE BEEN WORKING ON AAC APPS AND SPELLING.

IT'S BEEN A SLOW PROCESSES AND THE STATE I LIVE IN, ABA IS MANDATORY FOR ALL KIDS IN SCHOOL.

SO HE'S NOT IN SCHOOL, ON TOP OF THAT, EVEN THOUGH MY HEALTH IS GOOD AND I LIKE TO PUT HIM IN SCHOOL.

THERE'S NO RESPECTFUL OPTION.

ONLY CLASS IS INTENSIVE ABA CLASS.

THEY'RE TRYING TO SAYING NOT PUTTING HIM IN ABA IS EDUCATIONAL NEGLECT.

WE HAVE A GOOD SOCIAL WORKER RIGHT NOW, BASICALLY TO SAY IT'S CHILD ABUSE TO NOT PUT YOUR KID IN ABA, I'M NOT SAYING IT'S CHILD ABUSE TO PUT THEM IN.

BUT THE FACT THAT DISABLED PARENTS ARE HAVING TO FIGHT TO SAY THEY DON'T NEED THIS. CONSTANTLY HAVING TO EXPLAIN.

BECAUSE PEOPLE WHO SEE AUTISM THROUGH LIKE THE TRAGEDY LENS OR PITY, THEY SEE MY SON AS SOMEBODY WHO YOU KNOW, THEY DON'T THINK HE'S CAPABLE OF VERY MUCH.

PEOPLE TALK AROUND HIM AND NOT TO HIM.

PEOPLE TELL ME HOW SORRY THEY FEEL FOR ME.

SO EVERYTHING ABOUT THE DIAGNOSIS PROCESSES IS JUST HARD.

LIKE I WAS SICK TO MY STOMACH THROUGH THE WHOLE THING.

I HATED IT. I FEEL LIKE IT NEEDS TO BE SCRAPPED AND REDONE DIFFERENTLY.

I DON'T THINK IT CAN BE FIXED.

I DON'T KNOW.

NOT TO BE NEGATIVE, THAT'S JUST MY EXPERIENCE.

I DON'T THINK THE CURRENT MODEL CAN BE FIXED.

HAS TO BE LIKE BROKEN DOWN AND REBUILT COMPLETELY DIFFERENTLY.

>> AGREED.

>> COUPLE OF QUESTIONS FOR YOU FROM THE Q & A IF YOU DON'T MIND TAKING THOSE.

I AM AN SLP AND I'M TRYING TO DO NEURODIVERSITY AFFIRMING PRACTICE, WHAT INFORMATION CAN I GIVE TO PARENTS WHO ARE NOT YET AWARE OF THIS WAY OF THINKING AND TRY TO INSIST THEIR CHILD NEEDS SOCIAL SKILLS GOALS, SPEECH‑LANGUAGE PATHOLOGIST.

>> SEND THEM TO ALL THE BLOGS THAT ARE OUT THERE THAT HAVE LINKS TO ALL THE OTHER BLOGS THAT ARE OUT THERE LIKELY BLOGS, ALEAH KELLY'S BLOG.

MANY MANY OTHERS AND GET THEM TALKING TO OTHER PARENTS ABOUT WHAT'S GOING ON.

THAT WOULD BE MY ADVICE, FIND THE ROLE MODELS, FIND THE PEOPLE WHO ARE DOING THINGS DIFFERENTLY AND THEY ARE THERE.

>> I WOULD SAY THOUGH, THIS IS WHAT ‑‑ SO EVERYBODY'S AT A DIFFERENT PLACE IN THEIR LIFE, RIGHT.

SOME OF THESE PEOPLE, YOU KNOW, WE HAD A FRIEND, WE ALL HAD A FRIEND WE LOST SANDY WHO USED TO TALK ABOUT GIVING PEOPLE GRACE IN SPACE.

SOME PEOPLE ARE NOT READY FOR SOME OF THE STUFF OUR PEOPLE HAVE TO SAY.

THAT'S WHY I'M GLAD EMMA MENTIONED THINGS LIKE, THERE'S SOME PEOPLE WHO HAVE TAKEN THE EFFORT TO TRY TO YOU KNOW BE THAT BRIDGE BUILDER AND KIND OF ANSWER THOSE QUESTIONS WHERE SOME PEOPLE, YOU CAN'T DO THAT.

IT'S LIKE I'M NOT IN A PLACE WHERE I CAN HANDLE THAT, NO.

SOME PEOPLE CAN.

IF YOU CAN GET PEOPLE AND RESOURCES WHERE IT'S GOING TO MEET THEM WHERE THEY ARE, WORK WITH THEM, KIND OF YOU KNOW, TRAINING WHEELS, RIGHT.

SOME PEOPLE ARE NOT READY, YOU COME IN HERE, THEY'RE SCALED.

YOU START TELLING THEM THEY ABUSED THEIR CHILD BECAUSE OF ABA AND YOU ARE GOING TO THROW THEM TO NCSA, YOU ARE.

A LOT OF AUTISTIC PEOPLE WELL INTENTIONED, WELL MEANING, WE GET PASSIONATE IN OUR STYLE, THESE PARENTS ARE NOT READY TO HEAR THAT.

NO ONE, AND IT'S NOT THAT YOU SHOULD TELL LIES, NOT THAT YOU SHOULD HAVE CODDLE PEOPLE, THERE'S DIFFERENT ROLES.

I DON'T GO TO PEDESTRIAN DIE TRUST WHEN I'M HAVING ISSUES WITH MY SKIN, I GO TO DERMATOLOGIST.

EVERYONE SHOULD NOT HAVE BEEN TO ALL THINGS TO ALL PEOPLE.

DON'T FEEL LIKE IF THERE'S A PARENT CRISIS AND THAT'S GOING TO TRIGGER YOU THAT YOU'RE THE ONE THAT HAS TO ADDRESS IT, IT WOULD BE BETTER TO BUMBLE AROUND, AN APPROACH THAT WORKS FOR THEM SO THEY UNDERSTAND AND BE RECEPTIVE.

IT'S MORE CALM DOWN, STOP, AND BREATHE.

THERE ARE RESOURCES SO THERE'S RESOURCES THAT ARE OUT THERE FOR PARENTS OF NEWLY DIAGNOSED CHILDREN, SOME ARE LOW‑COST, SOME ARE FREE THAT PEOPLE CAN REVIEW.

THERE ARE SOME BOOKS, I PUT NEURODIVERSITY BOOK LIST.

SARA MENTIONED THE RABBI, HAS GOOD INFORMATION ON THIS.

YES.

I'D SAY MAYBE THEY CAN READ SOME OF THE OLDER THINGS LIKE DIARY OF A MOM AND YOU KNOW THINKING ‑‑ AUTISM.

SOME THINGS ARE PRAGMATIC, BUT WE'VE GOT TO BE CAREFUL.

THEY'RE JUST NOT THERE.

THEIR NEUROLOGY IS DIFFERENT.

A LOT OF THESE PARENTS ARE NOT AUTISTIC BUT NEURODIVERGENT THEMSELVES SO THEY'RE ALREADY DEER IN HEADLIGHTS.

IMAGINE BEING TOLD YOU DON'T KNOW ANYTHING, I'M AUTISTIC, AND YOU DO, YOU DON'T KNOW ANYTHING ABOUT MY KID.

AND THE PROFESSIONALS ARE TELLING YOU I GOT XYZ THOUSAND DEGREES.

YOU DON'T KNOW ANYTHING.

PROFESSIONALS TELLING YOU DON'T KNOW ANYTHING AND I'M THE ONE THAT GAVE BIRTH TO THIS KID.

YOU GOT, IT'S A DELICATE DANCE.

I THINK SOMETIMES WE UNINTENTIONALLY PUSH THEM OVER THAT EDGE.

AND I'M NOT SAYING WE PUT THEM ON THE EDGE.

SOCIETY PUT THEM ON THE EDGE BY MAKING IT SEEM LIKE AUTISM IS THE WORST THING IN THE WORLD.

WE GOT TO; OUR APPROACH DOESN'T ALWAYS WORK I'M GOING SAY IT. IT DOESN'T, AND WE NEED TO UNDERSTAND, I THINK IT'S HARD TO HAVE EMPATHY FOR SOMEONE NOT IN THE SITUATION.

I DON'T THINK PEOPLE UNDERSTAND HOW MUCH FEAR THAT THEY PUT IN YOU.

THEY TELL YOU, IT'S NOT A GUESS.

IT'S A FACT, IT'S A GUARANTEE YOU ARE GOING TO GET DIVORCE, IT'S A GUARANTEE YOUR CHILD IS GOING TO BE SEXUALLY ASSAULTED, ALL THESE THINGS ARE BEING TOLD TO YOU BY AUTHORITY FIGURES WITH FACES AND NAMES AND FIGURES ATTACHED TO THEM WHEN YOU ARE AT YOUR WITS AND I DON'T KNOW IF PEOPLE CAN UNDERSTAND THE POSITION WHERE THESE PARENTS ARE PUT IN AND THEREFORE PUT THEIR CHILDREN IN THESE HORRIBLE SITUATIONS AS A RESULT.

>> IT'S THAT ARM MA GET DEN MINDSET AND IT'S ENCOURAGED.

>> WOULD YOU LIKE YOUR FOURTH PANEL QUESTION NOW?

>> SURE.

>> THANK YOU MORÉNIKE.

QUESTION NUMBER 4, DO YOU THINK THAT BEING AUTISTIC GIVES YOU AN ADVANTAGE AS A PARENT, ARE THEIR WAYS TO MAKE PARENTING HARDER?

>> I THINK FOR ME THERE ARE SOME ADVANTAGES AND I THINK THAT PART OF IT IS BECAUSE MY AUTISTIC CHILD AND I HAVE SIMILAR ‑‑ AND WE'RE VERY SIMILAR.

WE BOTH ENJOY QUIET AND KIND OF KEEPING TO OURSELVES A LOT.

IF I HAD LIKE SOMEONE WHO WAS MORE OF A SENSORY SEEKER THAN I AM IN CERTAIN WAYS, THAT WOULD BE MORE DIFFICULT.

I ALSO THINK BEING AUTISTIC HAS MADE ME QUESTION A LOT OF THE THINGS THAT WERE TOLD PARENTS SHOULD DO AND HOW CHILDREN SHOULD BEHAVE.

AND I'VE NEVER REALLY ‑‑ LIKE, I DON'T ‑‑ I NEVER WANTED A TYPICAL KID, I GUESS.

TO ME ANY KIND OF BEHAVIORS THAT OTHERS THOUGHT WERE STRANGE, I DIDN'T EVEN SEE ANYTHING AT ALL.

THAT'S JUST HOW MY KID IS.

SO I THINK IT'S HELPED ME TO BE MORE EMPATHETIC.

AND I THINK THE THING THAT PROBABLY MAKES IT HARDER IS JUST ABLEISM IN GENERAL.

I LIVE IN A STATE WHERE DISABILITY ALONE CAN HAVE YOUR PARENTAL RIGHTS TAKEN AWAY.

AND I KNOW THROUGH AWN MEET UPS I HAVE, HELD, MET SOME PEOPLE THAT HAVE HAD THAT HAPPEN TO THEM, THE WHOLE REASON THEIR CHILDREN WERE TAKEN BECAUSE THEY HAD A DISABILITY AND DIDN'T GET THE SUPPORT THEY NEEDED.

IT'S BEEN IN THE BACK OF MY MIND AND I'M WAITING TILL MY CHILD TURNS 18.

NOT LIKE I THINK I'M A BAD PARENT, I DON'T DO TRADITIONAL THINGS.

WE HOMESCHOOLED AND OPTED OUT OF THERAPIES AND THERE'S JUDGMENT THERE FROM OTHER PEOPLE.

THEY DON'T CARE ABOUT TIMELINES AND WHERE MY KID IS AT A CERTAIN TIME.

IT'S NEVER BEEN A BIG DEAL TO ME AND IT IS TO OTHERS.

I THINK THAT WILL BE THE BIGGEST DOWNSIDE KNOWING AS SOMEONE WHO IS AUTISTIC, I HAVE THE PRIVILEGE OF SOMEONE WHO IS NON‑DISABLED TO MAKE THESE LIKE HARD LINES.

I'M NOT GOING TO DO THIS BECAUSE I COULD HAVE IT CHALLENGED.

SO, THAT WILL BE THE THING.

OTHERWISE, I THINK I REALLY, I DON'T KNOW, I LOVE BEING A MOM.

I LOVE MY KID.

AND WE HAVE SO MUCH FUN TOGETHER AND I THINK IT'S BECAUSE WE'RE SO SIMILAR.

EVEN LIKE I HAVE FUN WITH MY NIECES AND NEPHEWS WHO ARE NOT LIKE ME AT ALL WHO ARE OUTGOING.

I THINK I JUST LIKE KIDS.

>> I LOVE THAT THING YOU WROTE LEI ABOUT I ALWAYS WANTED YOU.

I THINK THAT'S SO LOVELY.

I'M AUTISTIC AND MY KIDS ARE NOT HOWEVER MY SON IS HARD OF HEARING THAT POST CERTAIN THINGS THAT PARALLEL IN SOME WAYS.

BUT I THINK WHAT WAS REALLY WONDERFUL ABOUT ‑‑ MY KIDS ARE GROWN UP NOW.

THEY'RE BOTH ADULTS AND ON WITH THEIR OWN LIVES AND I'M PROUD OF THEM AND ADORE THEM.

I THINK THAT WHAT WAS REALLY GREAT IN OUR FAMILY WAS THAT WE REALLY SUBSCRIBED TO THE IDEA OF PARALLEL PLAY.

WE ALWAYS DID THAT.

AND WE ALSO SUBSCRIBE TO THE WHOLE IDEA OF ACCEPTANCE AND NOBODY WAS INTERMEDIATING ANYBODY ELSE.

AND TO THIS DAY, MY KIDS DON'T TRY TO REMEDIATE ME.

THEY GREW UP WITH A FAIRLY STRANGE MOTHER ACCORDING TO THEIR FRIENDS WITH HUGE ART INSTALLATIONS THAT APPEARED IN THE MIDDLE OF THE LIVING ROOM.

WHY DOES YOUR MOM DO THAT FUNNY THING WITH HER HANDS AND ALL OF THAT STUFF.

YOU KNOW THEY JUST ROLLED WITH IT AND THEY STILL DO.

AND I THINK THAT WAS THE BEAUTIFUL PART.

WHEN THEY WERE REALLY YOUNG, I NEED LOTS OF HELP BECAUSE SOME OF THE SENSORY ISSUES WERE HARDER AND THE FACT THAT KIDS ARE LIKE RIGHT THERE ALL THE TIME AND MY CAPACITY TO DEAL WITH INTERPERSONAL STUFF, I NEEDED DOWNTIME.

THAT WAS HARD.

HONESTLY, AGAIN, I'M AN AUTISTIC PARENT THAT DIDN'T HAVE AUTISTIC CHILDREN HOWEVER WE WORKED IT OUT.

WE'RE STILL CLOSE TODAY AND THERE YOU GO.

THEY MAY HAVE HAD TO DO MORE STUFF WITH ME THAN I EVER HAD TO DO WITH THEM.

>> I CAN GO IF THAT'S OKAY.

A LOT OF WHAT LEE SAID IS TRUE FOR ME TOO.

IN TERMS OF THE CHOICES WE'VE MADE BY NOT DOING THERAPY AND MY TEN‑YEAR‑OLD HAS ALWAYS BEEN HOMESCHOOLED.

MY 12‑YEAR‑OLDS WERE HOMESCHOOLED THROUGH FOURTH GRADE AND BECAUSE OF MY HEALTH I DID HAVE TO PUT THEM IN PUBLIC SCHOOL LAST YEAR WHICH WAS MOSTLY REMOTE.

I THINK ABLEISM IS LIKE, IT MAKES IT, DOES MAKE IT HARD.

AND I ALSO WORRY ABOUT NOT FROM A OH, YOU KNOW WHEN I'M GONE, I'M THE ONLY PERSON IN THE WORLD THAT MY KIDS YOU KNOW CAN BE TRUSTED.

IT'S MORE SO JUST TRY NOT TO HAVE A PESSIMISTIC WORRY ABOUT YOU KNOW WHAT'S GOING TO HAPPEN TO MY KIDS WHEN THEY'RE OLDER BECAUSE OF ABLEISM NOT BECAUSE THEY'RE AUTISTIC.

BECAUSE OUR SOCIETY DETERMINES PEOPLE'S WORTH BY THEIR ABILITY TO PRODUCE AND EARN.

I THINK BEING AUTISTIC HELPS ME AS A PARENT IN TERMS OF HAVING A LOT OF EMPATHY AND ALSO FROM ‑‑ I WAS ABUSED, BEATEN, HAD A TERRIBLE CHILDHOOD AND I NANNIED.

I WAS A LIVE IN, LIVE OUT NANNY AND I ALWAYS LOVED KIDS.

I THOUGHT BEING A PAST WOULD BE EASIER FOR ME BUT THAT WAS DEFINITELY NOT THE CASE.

I THOUGHT IT WOULD BE EASIER.

I THINK IT'S BETTER, I FEEL LIKE BEING AUTISTIC HAS HELPED ME AS A PARENT BUT ALSO DO FIND WITH ME AND MY 3 AUTISTIC CHILDREN THAT OUR SENSORY NEEDS CAN COLLIDE.

I'M EXTREMELY QUIET.

I COULD NOT TALK FOR WEEKS OR MONTHS PROBABLY.

I LIKE QUIET, I'M LIKE A HOME BODY.

MY DAUGHTER IS VERY SOCIAL.

SHE TALKS ALL THE TIME.

AND SHE'S LIKE SENSORY SEEKING SO IF MY KIDS ARE CLIMBING ON ME, SOMETIMES I FEEL A LITTLE BIT, I'VE WORKED ON KIND OF KNOWING MY TRIGGERS AND THEN TRYING TO PUT ON NOISE CANCELING HEADPHONES.

AS THEY GOTTEN OLDER, I COULD TALK MORE ABOUT WHAT I DO AND DON'T LIKE.

IT'S GOTTEN BETTER.

SO IT'S ALSO GOOD LESSON IN BODY AUTONOMY I COULD SAY.

I DON'T LIKE WHEN YOU CLIMB ON ME LIKE THAT.

I RESPECT THEIR BODY AUTONOMY AND THEY RESPECT MINE.

IT'S NOT ALWAYS PERFECT.

I THINK IN TERMS OF HAVING A CHILD WHO TALKS A LOT OF THE TIME, ESPECIALLY DURING COVID, SOME DAYS I FELT LIKE RAW ANXIETY.

I COULDN'T WAIT TO BE ALONE.

I LOVE MY KIDS AND LOVE BEING AROUND THEM, THEY ARE ALL SUCH GOOD PEOPLE.

BUT I THINK IT'S HARD TO JUST HAVE TO BE A PERSON WHO IS SENSITIVE AND HAS EMPATHY AND TO SORT OF SEEING THE WORLD AND BEING WORRIED ABOUT WHAT'S GOING TO HAPPEN, KIND OF ANXIOUS BY NATURE SO.

THINK THAT WAS IT.

>> OKAY.

YEAH, SORRY.

>> I KNOW WE'RE ALMOST OUT OF TIME, I WROTE STUFF IN THE CHAT.

I WON'T REPEAT THOSE THINGS BUT SHARING THE CHALLENGES.

IN TERMS OF THE STRENGTHS, I FEEL LIKE BEING AUTISTIC, THERE'S THINGS ABOUT BEING A PARENT THAT SOCIETY SAYS SHOULD BE A PARENT THAT KIND OF SUCK AND ARE HARD AND STRESSFUL.

CARPOOL AND SMALL TALK.

BUT MY HUSBAND IS SO MUCH BETTER AT THAT STUFF.

WHY IS THIS STUFF, BIRTH HAVE TO DO THAT, I SUCK AT IT. BECAUSE I'M AUTISTIC, I'M REAL.

MY KIDS KNOW THEY'RE GOING TO GET THE TRUTH WHEN THEY COME TO ME.

THEY CAN ASK ME ANYTHING.

I MAY NOT TELL THEM, THEY KNOW I'M GOING TO EXPLAIN TO THE BEST OF MY ABILITY WHY, THE REASON BEHIND THINGS.

I'M NOT EXPECTING YOU TO DO SOMETHING JUST BECAUSE.

THEY WILL KNOW I WILL SAY I DON'T KNOW.

THEY KNOW I WILL SAY I WAS WRONG, I'M SORRY.

I DON'T HAVE THIS HIERARCHY OR DICHOTOMY BETWEEN THE ADULT IS A PERSON AND THE CHILD IS SOME KIND OF PION, YOU KNOW, NO, WE'RE DIFFERENT AGES AND DIFFERENT PLACES IN OUR LIVES BUT YOU HAVE SOMETHING TO CONTRIBUTE, SOMETHING TO SAY, YOU HAVE CHOICES, OPINIONS AND YOU MATTER.

YOU KNOW, AND SO IN SOME WAYS I FEEL LIKE MY CHILDREN, THERE'S STUFF THEY COME TO TALK TO ME ABOUT THAT I KNOW KIDS DON'T TELL THEIR PARENTS AND THERE'S STUFF SOME OF THEIR FRIENDS TELL ME, I'M LIKE OH, MY GOSH.

SO I'M GRATEFUL FOR ‑‑ WITH, TO HAVE A RAINBOW, YOU HAVE TO HAVE RAIN.

THERE ARE DEFINITELY CHALLENGES, DAYS WHERE I'M CRYING AND FEELING LIKE I CAN'T DO THIS.

AND THERE'S DAYS WHERE I'M JUST THANKFUL FOR THE OPPORTUNITY FOR THESE WONDERFUL PEOPLE THAT I GOAT HAVE IN ANY LIFE AND GET TO TRY TO STEER IN THE RIGHT DIRECTIONS.

>> I'M GOING JUMP IN AND SAY WE NEED TO GIVE PEOPLE JUST A COUPLE MINUTES BREAK BEFORE KASSIANE AND MORÉNIKE COMES BACK.

PANEL, IF YOU HAVE A LAST WORD YOU WANT TO SAY, PEOPLE ARE WANTING TO BE ABLE TO CONTACT YOU AFTER THIS, YES, GO AHEAD AND PUT YOUR CONTACT INFORMATION IF YOU WANT TO IN THE CHAT.

AND THEN WE'RE GOING TAKE A 5‑MINUTE BREAK.

I'M GOING TO KEEP THE RECORDING GOING.

IF I STOP IT, IT'S GOING TO BE A PAIN IN THE NECK.

ACTUALLY, I'M GOING TO STOP IT RIGHT NOW UNLESS YOU HAVE SOMETHING YOU WANT TO SAY.

GO AHEAD, TALK.

OR JUST LAUGH AT ME, THAT WOULD WORK TOO.

ALL RIGHT.

SO WE'RE GOING END THE PARENT PANEL AND WE WILL HAVE THE CLOSING KEYNOTE WITH ‑‑ WHICH WILL BE IF I CAN SCROLL DOWN TO IT. WE'RE TAKING THE WHEEL, AUTISTIC DRIVER OF AUTISM RESEARCH.

WE'RE GOING TO GIVE YOU 4 MINUTES BREAK.

BE BACK IN 4 MINUTES.

I'M NOT GOING TO PUT UP THAT THING BECAUSE IT DOESN'T WORK VERY WELL.

JUST FOUR MINUTES.

ALL RIGHT.

SEE YOU IN FOUR.

[4‑MINUTE BREAK]