

Good afternoon Chairwoman Muth, Chairman Bizzarro, Senator Williams, and Representative Benham. Thank you for the opportunity to provide testimony on neurodiversity-affirming education today.

My name is Sharon Janosik. I am an autistic adult with 7 years of experience working as an advocate for people with disabilities, their families, and within the autistic community. I volunteer as a School Director for the Bethel Park School District, and as a person with a disability and parent of children with disabilities on Pennsylvania's Special Education Advisory Panel, which advises the Pennsylvania Department of Education, Bureau of Special Education on the needs of children with disabilities in schools. I also work at the PEAL Center, Pennsylvania's IDEA mandated Parent Training and Information Center. I am here today as someone who cares deeply about disability, neurodiversity, education and all of those intersections. I am a neurodivergent person who parents neurodivergent children; I've heard from neurodivergent people and their families from all across our state, country, and globe; and I work every day to ensure that we are all heard, and treated in ways that benefit us, and respect our dignity and value.

Imagine that you've had a bad day. You are overwhelmed and frustrated and I order you to complete a math worksheet that you don't understand. You decline and I insist, over and over, until I turn my back on you. Imagine that I refuse to acknowledge your cries and pleas for help, for reassurance, for safety, for soothing and completely ignore you—and your need to feel connected, grounded, regulated, protected, and cared for—until you not only manage all of your own emotions, but also complete that worksheet that overwhelmed you in the first place. What kind of friend, spouse, employer, neighbor, or even stranger passing by would I be to deny you human compassion and concern in that moment? Neurodivergent students are very likely to be treated this way by uninformed and ill prepared staff in schools. We must and we can do better.

The most recent Pennsylvania data from school year 2020–21 details how many students with IEPs are educated in the least restrictive environment for 80% or more of their school day. That means they spend at least 80% of their time in their neighborhood school, in a General Education classroom, with non-disabled peers—it means that they are included. The data is concerning when we look at each disability category. Only 50% of

students with an Emotional Disability, 40% of students who have Autism, 9% of students with an Intellectual Disability, and less than 4% of students with Multiple Disabilities are included in school for most of the day. We also know that being a student who is also Black, brown, Indigenous, foreign born, English language learner, living in poverty, or LGBTQIA+, only compounds the problems and reduces the opportunities.

We can see that neurodivergent students in Pennsylvania are not being included enough. There are over 37,000 students with IEPs who have autism; that number doesn't include those who don't receive Special Education services. As of 2020, 1 in every 36 children are diagnosed with Autism in the United States. This is a growing population and our schools are not prepared to include autistic students in ways that are beneficial.

Additionally, this data does not look at families who have had to make the heart-breaking decision to remove their children from district brick and mortar schools, and place them either in cyber schools or homeschool settings, because they could not rely on their local public schools to provide physical and or emotional safety for their children . I speak with so many families and people with disabilities who tell me of the trauma from school systems that don't recognize or support the unique ways their brains work. They are secluded and restrained; they are bullied by both adults and by peers; they're required to perform like their non-disabled peers without the supports or accommodations that their disabilities necessitate; they are expected to conform to societal and behavioral norms that do not match their internal processing or how their disability presents itself. When they don't meet these expectations, they are punished, shamed, and humiliated, instead of compassionately supported, accommodated, and taught. So many families have to remove their children from public school in order to protect them from the widespread ignorance about neurodivergent people and what they need.

Some of the educational practices that benefit neurodivergent students and our entire school communities are:

- Learning directly from neurodivergent adults in order to understand what might be problematic and what students are experiencing
- Compassionate methods of dealing with behavior concerns, like Dr. Ross Greene's Collaborative & Proactive Solutions, that are not focused on compliance, control, restraint, or shaming

- Universal Design for Learning
- Professional Development for staff on how brains work under stress and the result of chemicals flooding the brain
- Deeper understanding of both how trauma influences behavior and how staff can avoid creating additional trauma
- Multi-Tiered Systems of Support
- Co-regulation
- Meaningful Inclusive Education

The neurodiversity paradigm and the social model of disability explain that when people have differences in their brain wiring, it is merely a difference. It is not a deficit and it does not need to be fixed, cured, or hidden. We need to embrace the diversity of the human experience, which includes disability, and understand that we are all wondrously made to be exactly who we are. It is part of the diversity of humankind that makes all of us stronger.

The social model of disability recognizes that there is nothing wrong with the person; rather, it is society that refuses to adapt expectations and provide accommodations for all people to equally access the world in physical, emotional, social, behavioral, and economic ways.

Ableism is the idea that non-disabled people are preferable, and the assumptions that people with disabilities have a worse life, need help, and want to be not disabled. Sometimes ableism is aggressive, destructive, discriminatory, bigotry, meanness and bullying. However, ableism can also be benevolent, which is when people with good intentions and a genuine desire to help, still advance the harmful ideas that disabled people have less value, don't want to be disabled, that being non-disabled is better, and that disabled people need or want to be fixed or cured. Unfortunately, helping professions are full of people with benevolent ableism, including many educators. We need to start reflecting on the purpose of Special Education, because it is NOT about trying to fix children with disabilities, so that they are no longer disabled, or they no longer appear to be disabled, or they minimize their impact on the non-disabled world.

Special Education is actually about helping children with disabilities understand their strengths, their weaknesses, and what kinds of accommodations and supports they will need to live full, rich, active lives in

the community. It's about developing the skills of self-advocacy, including saying NO and expecting that to be respected. It's about helping children learn what their rights and responsibilities are, what their needs are, and how they can meet their needs as adults. Special Education is not about fixing children so that no one will know they are disabled—it is about empowering them and helping them to be proud of who they are.

In order to make this lens shift--this heart and mind shift--we must learn from actually disabled, neurodivergent people. There are thousands and thousands of neurodivergent adults who have first-hand experience of being disabled, being students in school, and having their own children in school. They explain their lives, their experiences, what they really needed, how they were negatively impacted by our education systems, and what they want for themselves. There are entire communities of people providing this education, professional development, and research. We must center the lived expertise of people with disabilities and stop telling them that non-disabled people know better than they do about their experiences, about how those experiences made them feel, and about what they actually needed. We have to stop thinking about our system of education as something that is fixed and limited and into which disabled people must fit.

Instead, we need to reimagine public education, so that it is built for all. We cannot simply add disabled children to our agenda, and force them into a system that is set up to discourage and punish difference, to require everyone to fit into the same box, to expect everyone to achieve the same results in the same ways—the ways which only work for people without a disability. Neurodivergent students in schools cannot be an afterthought, a side-car, a segregated group—schools must be re-conceptualized to include them in authentic, respectful, relationship building ways.

So much progress has been made in just the last decade on brain science, trauma, and how those two interact. Most educators know Maslow's Hierarchy of Needs: that before any child is available to learn, they must feel physically, emotionally, and relationally safe, supported, respected, and confident because our brains cannot support the higher-order thinking and learning processes until our basic assurances of safety are met. Why is it that so many school systems have completely disregarded those needs for neurodivergent children? Why do so many educators say things like, "It doesn't matter why the student is upset, I have to make them not act this way by whatever means necessary, including punitive and damaging

ways.” I argue that we must apply Maslow’s Hierarchy to every single student so we will recognize where we have gone wrong. Somehow, schools have learned to exempt neurodivergent students from the category of human being—and they are no longer afforded the same interaction, relationship, trust, respect, or sense of safety that we still freely give to children without disabilities.

While the recent emphasis on trauma informed education is a vast improvement, I find that most people fail to recognize both how differently trauma is impacted by disability, and how disability impacts trauma. We must remember that the experience of trauma is from the viewpoint of the person experiencing it. If you are a neurodivergent person, what you experience is vastly different from what non-disabled people experience. Trauma for a neurodivergent person could be a result of intense sensory overstimulation or intense emotional dysregulation. I also believe that almost every child with a disability has had some level of relational trauma: they have sought reassurance and comfort from the adults who are responsible for their safety and those adults did not understand their experience, and were unable to provide comfort and reassurance. Instead, they were punished, shamed, excluded, humiliated, yelled at, and made to feel wrong or bad for having a disability that makes meeting non-disabled expectations without support and accommodation impossible.

Brain science can now explain the various brain regions that are involved in tasks, emotions, reactions, and behaviors. We can now explain what happens when someone senses a dangerous situation: the cascade of hormones that floods their brain and literally shuts off the higher-order thinking part of their brain--they can only fight or run. But we don’t often consider, in a school setting, whether or not we are causing trauma and this trauma response by our actions, by the environment, by the expectations and demands, by the corrective discipline, and by our attempts to control behaviors that don’t make sense to non-disabled people. The very first thing school systems must do is to learn from neurodivergent people, believe them when they tell us what they experience, believe them when they tell us what they need, and acknowledge their lived expertise in being neurodivergent.

So many things in our society and schools just do not work for most neurodivergent people. Schools reflect that very narrow range of acceptable experience and behavior in the rules that far too many

educators were taught to manage their classrooms, to hold as expectations for behavior, and that are applied to everyone without exception or instruction. Things like whole body listening: eye contact, quiet hands and feet, bottom on the chair, or crisscross applesauce on the floor. That may well be how students without neurological and physical differences learn best, but neurodivergent students cannot learn this way. Educators and parents MUST learn from neurodivergent people what they need in order to focus, listen, and learn. Students might need to fidget, doodle, pace, or look away in order to concentrate. They may not have the core muscle strength or joint stability to sit in ways that work for others. Why are we unwilling to accept that what works for most does not work for all?

There is such a reliance in schools on harmful methods to control neurodivergent children and make them comply with the ways non-disabled people find acceptable. Compliance-based discipline, regardless of how we label it in “positive” terms, is the idea that students make choices--some of which are “bad” and some of which are “good.” The assumption is that all children at all times have the capacity to understand and be able to make choices that match the choices of non-disabled people. Forced compliance and control tells children with disabilities that their needs are less important than other people’s comfort, that they are inherently wrong and must be corrected, and that it is unacceptable to exist authentically as a neurodivergent person. Schools should not withhold sensory tools, movement breaks, comforting objects, attention, and love until the child complies with demands that do not work for the student--that cause pain, discomfort, distress, and confusion—or that the student does not understand, or needs modification, support, and adaptation to complete. Having the ability to do what you need to do, so that you can stay attentive and regulated in order to focus and learn is the basic floor of human respect and dignity. Yet, all of these things are very often denied to students with disabilities until a non-disabled adult, with no understanding of the experience of disability, is satisfied with their performance of “appearing not to be disabled.”

Children in school are often shamed and humiliated--publicly told how much the adults disapprove of their behavior and their inability to meet expectations. But when the reason for those inabilities is their disability, what does that communicate to them and to their classmates? It tells them that they are broken, that they are wrong, and that they have no right to have their needs meet. Using rewards and withholding of rewards to

attempt to change behaviors with no understanding of what underlying problem is being communicated, is almost universally encouraged with the assumption that the child is “making a choice,” and, “needs to be more motivated in order to make the choice we prefer.” This is intensely damaging. We cannot just expect children with a disability in the area we’re concerned about to simply not have the disability, or to hide the fact that they have one, or to know and understand better ways to communicate their distress. We also have to acknowledge how very often schools ignore all of their very clear self-advocacy and communication that there are problems and then refuse to do anything about whatever is causing the distress in the first place. Neurodivergent students are simply expected to suffer in pain and they learn that no one is going to help them, because their experience is “wrong.”

Dr. Ross Greene, who created Collaborative & Proactive Solutions, writes that, “Kids do well when they *can*, *not* when they “want” to.” This is the underlying principle behind this method of dealing with challenging behaviors: it is NOT a problem with motivation. We must collaborate with the student and uncover what problems are occurring for them, from their perspective, and whether or not they have the skills to meet our expectations. Dr. Greene also writes, “The child is not *giving* you a hard time; the child is *having* a hard time.” There is always a reason and there is always a way to work through the problem so that both the child’s needs and the adult’s expectations are met or adjusted to fit the situation. Yes, it takes time—but we can put in the time to reduce problems up front or we can put in that same time dealing with the problems and the trauma, later.

Often, adults will say that we need to ignore the behavior we don’t like so as not to encourage it. But behaviors are expressions of emotions and needs. We can comfort those emotions and we can meet the needs that the behavior is expressing; that does not mean we are rewarding the behaviors. It means that we are actually teaching a child that we care for them, that they are valuable, that we value their concerns and their experiences, and that we want them to feel safe and welcome within our relationship and schools.

When we use behavioral models of control that do not center or account for an individual’s personal and private experiences, perceptions, and emotions, we treat children as inanimate objects or animals who don’t have the capacity for those thoughts and feelings. This mindset leads us too

often to restraining or secluding students in schools. Many people don't know that Pennsylvania doesn't collect data on students who are secluded in schools, because the School Code prohibits seclusion. What this means is that the number of students who are kept involuntarily in a space—whether or not it has a door and or a lock—is unknown. Those rooms absolutely exist in schools across PA, but we don't collect data on them. I know from my experience that seclusion happens far, far too often and that schools simply know of no other alternatives.

We do collect data on restraints at the state level; however, we only collect it on students who have an IEP. Students who have a documented disability but don't qualify for special education and are served under a 504 Plan aren't counted; and, neither are students who might have a disability that's not documented or identified. With the yearly data we do have, we see that most Local Education Agencies have at least one incident of restraint. While the Department of Education encourages de-escalation strategies, we aren't yet teaching about co-regulation and other ways of working with students, like the CPS method, that drastically and immediately drop the rate of restraints and seclusion.

Schools have got to start realizing that neurodivergent students who are upset, are upset for a reason. Until we deal with the reason and solve that problem, they will continue to be increasingly upset, and we will continue to restrain and seclude. Restraint is dangerous. It's dangerous for students and it's dangerous for staff. We must start to recognize that every time we create a physical situation of trauma for a student, we are compounding it by the relational trauma we are also creating. Schools are unintentionally guaranteeing more and more trauma reactions, which are then viewed as a bad behavior choice, which is then met with more restraint and seclusion. Co-regulation and Collaborative & Proactive Solutions are effective, and better choices schools can make.

Many neurodivergent students are also non-speaking. There is an assumption that people who do not use mouth words to communicate do not have any access to language. Again, brain science shows that language processing, generating, and oral speech are all processed in different parts of the brain. Students who are non-speaking are presumed to be non-knowing, not able to understand written or spoken language, not able to communicate, to be intellectually disabled, to not be able to think or experience emotion. It is all too common in schools for these children to



never be provided with in an effective method of communication that works for them with appropriate instruction and sufficient, comprehensive modeling. There are non-disabled specialists that act as gatekeepers to communication systems and who falsely believe that students must first demonstrate a host of skills, including acceptable behavior, before getting a robust method of communication. Since not being able to communicate effectively is very often at the root of concerning behaviors, adults are effectively denying access to the very thing that will reduce the behaviors: a communication method. When communication systems are provided, adults often limit the vocabulary, keep the system at school, restrict access to a keyboard, remove words they find inconvenient, don't get Professional Development on how to use or teach it, and trial it for incredibly short periods of time. All human beings, regardless of disability, have a right to a system of communication. This is such a primary and fundamental right, that it should shock the conscience that students graduate high school without a way to communicate and that students entering Kindergarten are not immediately provided with a system of communication.

In order to truly provide appropriate education for neurodivergent students in the Commonwealth of Pennsylvania, we must get to a place of providing good, appropriate, inclusive education for all students. Inclusion is not simply about being in the same space; inclusion means that you are part of the community, you have been planned for, you are welcomed, the environment has been adapted for your needs, and the instruction and activities are designed to ensure that you can be successful. By appropriately using UDL (Universal Design for Learning,) MTSS (Multi-Tiered Systems of Support,) and appropriate, respectful accommodations, modifications, and instructional strategies, ALL children with all levels of disability and educational need *absolutely can* be included at least 80% of the time.

We must stop thinking of public schools as factories that produce identical graduates; the machinery of public education is set up to only except raw materials of a certain type—non-disabled. Neurodivergent students don't even get through the sorting mechanism into the shoot of our machinery. They are routinely moved aside to separate settings, because currently, the public school factory doesn't have the capacity to seamlessly include all kinds of students. That is our job: we can no longer accept that segregated settings are equal. We know they aren't equal. They aren't equal when we

segregate students by gender, by color, by race, and they're not equal when we separate students by disability. We must change our systems, our hearts and minds, our professional development, the way we deploy our resources, the way we teach pre-service teachers--both General Education and Special Education. We must build into our schedules time for Special Education teachers to consult with General Education teachers. Special Education teachers are not taught how to be consultative with General Education teachers, teaching them how to modify their lesson plans, and General Education teachers are not taught how to teach students with disabilities. There are so many amazing resources available to help school district administrators, teachers, and principals how to shift their systems to a truly inclusive system where we no longer reject a student's presence because they have a disability. The TIES Center and the IRIS Center both provide wonderful comprehensive systems to help school systems make this shift. PaTTAN (Pennsylvania's Training & Technical Assistance center,) is the training arm of the Department of Education and has Inclusive Practices resources, as well as an Inclusive Practices team who will help any teacher, principal, or district leader, create truly inclusive schools that will be affirming and safe for neurodivergent students.

In Pennsylvania, the most obvious roadblock to this necessary shift is the local control that all 676 Local Education Agencies in Pennsylvania are afforded by our Constitution. Each school district gets to decide what they are going to do, as long as it is within the law. Because inclusive practices are not a right afforded to every child in the Commonwealth, many schools simply do not want to change how they will educate students. Without legislative action, the Department of Education can only promote and encourage inclusive practices and better ways to think about students with disabilities.

We must find ways to help Pennsylvania schools make this absolutely necessary shift towards policies and practices that are safe and affirming for neurodivergent students, to hold them accountable for doing so, to provide the financial support they will need for Professional Development and substitutes, and to assess how well they are implementing these changes.

Just as the quality of a child's education should not depend on their ZIP Code and their local community's tax base, the quality of special education

services should not depend on whether or not your local leaders and school employees understand disability and inclusive education. But it does. Some schools have embraced inclusive education, while other schools have never heard of any of these concepts and will not avail themselves of the resources to help them begin to see their students in a more honest light. They've never had the training and they're not going to ask for it. They may not "believe" in disabilities that they cannot see, or they may not believe that ableism exists. So many neurodivergent students are trapped in systems that don't understand them, don't respect them, don't treat them with the same worth and dignity, and that cause them tremendous amounts of physical and psychological pain each day.

We can, and we must, do better for neurodivergent and all disabled Pennsylvanians. We must learn how to presume competence and hold high expectations for all learners. We must learn how to accommodate and modify our instruction, activities, social opportunities, expectations, and rules in every area. We must learn how to learn from neurodivergent children and adults and believe their lived expertise.