

>> Good morning. Thank you all for coming at this very early hour. I always say, at conferences, that it's only us educators who do very early morning late into the afternoon and weekends. That's why you know you're an educator. Only education do we do Saturday, Sunday and any other day they need us. My name is Jane Thierfeld Brown. I want to welcome you this morning. Come on in, lots of seats up front, and I won't call on you. I promise. I'm Jane Thierfeld Brown. I'm an assistant clinical professor at Yale Child Study in the Yale medical school. I work with college students with autism from all over the country there and, sometimes, all over the world. I also am the director of the group called College Autism Spectrum. Believe it or not, we've been around for about 20 years. We're three disability services people in colleges who recognize that we had a lot of students with autism about 20 years ago and started providing services to families and to school districts and to students, and for the past ... I'm just beginning my 3rd year. I've worked for PDE and PaTTAN, and this is the only place I can present where you know what that means because anywhere else, they do not. I work for PDE and PaTTAN and work on the AACHIEVE Project, which I'm happy to say some of you may have heard of now, which even 6 months ago, I would've been shocked if you knew what that was. But the AACHIEVE project is a collaboration of high schools and colleges, and I'll talk a little bit more about that during the session today. We've got lots to do in an hour and a half, but I will absolutely answer any question you have. So if you have questions, please make sure and ask them while you're thinking of it. If you're thinking of it, somebody else is too, and I'd rather address it then because if you're like me and wait until the end, you won't remember. I certainly wouldn't. They are videotaping this session, so we need any questions to be sent through the mic, or I will repeat them, and Sheri, who is our ... Sheri is going to be playing Vanna White, this morning, and Vanna-Sheri will get the mic to you whenever we need. So I want to get a little bit of an idea of who the audience is. Bless you. How many of you are teachers, guidance counselors, education professionals? Okay. How many of those are guidance counselors? Okay. How many are parents of kids on the spectrum? Okay. And how about the rest of you, professionals and agencies?

>> OVR.

>> OVR? Yay! Thanks for coming. So glad you're here. Anybody else, students on the spectrum who are here? Yay. Thanks for coming. Anyone else? What am I missing? Okay. So the part I didn't address in my introduction: I'm also a parent of three kids, and my youngest is a 25-year-old who's severely autistic, not going to college, but I live what you folks that are parents of kids on the spectrum are living, and a lot of that, you're going to hear during today's conversation. So let's get started, and, please, if you have questions, I'm going to be checking in a lot, especially with the parents. Some of this is going to be hard to hear. I speak very truthfully. I speak from having 38 years experience as a disability service provider at colleges. I just left last year after 23 years, I think, at University of Connecticut School of Law where I was the Director of Student Services and Disability Services, but I've been in disability services since 1979, and I really feel strongly that parents aren't getting a lot of the information that they need about the chance in services from high school to college, and a lot of it is because we put so much requirement on educators, teachers, professional staff and schools that for them to keep up on what's going on in the colleges is impossible. So I'm glad we have a good mix, today, of educators and parents. So with that, let's get started. A lot of you have seen these statistics from the CDC, the Center for Disease Control and Prevention. Right now, from a study done in 2013, the numbers that we know we have of folks on the

spectrum are one in 68. The group that you're dealing with in high school is the one in 68. The upper edge of that study are your students who are rising seniors. So we, in college, are still dealing with the one in 100 from the 2006 study. But finally ... Because myself and my colleagues have been banging that drum at colleges for about 20 years, saying, "You have to be ready. They're coming. They're coming." And they've been saying, "What are you talking about?" Now, they're not saying that, anymore. We have lots of colleges across the country, including in Pennsylvania, that have 100 and 150 students on the spectrum. The college with the top number, right now, in the country is University of Texas at Dallas. They have 450 students on the spectrum diagnosed and disclosed to their disability services offices. And what we know about folks on the spectrum at college is for every student who is diagnosed and disclosed to disability services, there's one or two out on campus who have not told anyone, and that's a lot of what we're going to talk about, today. We know this is the fastest growing developmental disability, and if you skip down to the bottom, what hits me most strongly is that right now, we have a \$90 billion annual cost, and most of that is not where all of you are in K-12. It's in adult services. People are adults for a whole lot longer than their kids. They're only in that kid phase up to age 18 or 21. Autism does not affect life span, so you can have people in adult services from 21 until 60, 70, 80, 90. So we know that in 10 years, that annual cost will be 200 billion to 400 billion. We have to find a better way to deliver these services. This was done just last month on July 10. [INAUDIBLE] did a really interesting study showing that the prevalence has risen from one in 150, in 2000, to as high as one in 45. I have the slides. I gave the slides to the conference coordinator, so you'll have this citation. But there's a really interesting visual that I really think shows the impact of these diagnoses. If you notice, way up in New England is where it's really red. That's the one in 45. I live smack in the middle of that, and I have to tell you. That's exactly what we're seeing. It's very, very high. You'll notice in the northwest corner, just that tip, it's also one in 45 there. Now, [INAUDIBLE] posits that this is because that's where the intense prevalence of diagnosticians are, so that it's not ... I don't know that I totally agree with him, but that's why you're seeing more of it. It doesn't mean it doesn't exist in the other places. The folks might just not be diagnosed. So you see, in Pennsylvania, you're in that yellow in your northeast corner, and that's around one in 50 to one in 55. The green is one in 68. So it's not that huge a difference, except ... Do I have any snowbirds in the audience? No? Down in Florida, we're back to one in 100, and there's lots of speculation since this article came out. There's been lots going on, on blogs because Florida has a more senior population. Are they putting more into their senior services and less into their schools? Because people, as we all know, move for services. So were all the people moving out that need the services and going to some of these other states? We don't know, but it's a very interesting article and very new. So where have families been? And, families, I'm not doing this to make you relive it. That's not my intent, but I think sometimes, educators need to hear, when you get to that table, what you bring with you. And often, we don't share that because we always feel it's inappropriate when we're going to those IEPs. But getting a diagnosis, or as we call it, somebody dropping the autism bomb on your family, changes everything. And so you have to think about how that's affecting yourself as a parent, how it's affecting your family, how it's affecting the siblings of that child on the spectrum and how it's affecting your extended family. Is anybody going to understand, or as in most families, including my own, aren't there just going to be people that say, "You know, if you just gave him more structure and rules, he'd really be fine. You just aren't parenting well." And we all hear that sometimes. Sometimes, parents, we even hear it in the grocery store. Don't we? Yeah. It's difficult, and yet when people get to you at the education tables of the IEPs, they're really expecting or hoping either that you're really going to help, or they're expecting a fight because that's what everybody has told them, that you have to fight for

services. So people are bringing a lot to this table where we know they have to first come to grips with the diagnosis. I see some families that, the minute they get that diagnosis, they click into mode. I call it warrior mode because sometimes, that's where we have to be in order to get services for our kids. And the way I always explain it to schools, and I did over all those years with my son, "I'm going to be your biggest advocate. You need somebody to write a letter to the legislature, I'm your person. You need somebody to fight for something in this school or raise money, I'm your person. You mess with my kids' services, I become commando mom." It's really innate. It's like the mother bear protecting her cubs. You can't help it when your kids cannot advocate for themselves at that level. So they're bringing a lot of that to the table, and I also often am sitting on both sides of the table, so I hear from the educators about parents coming in again. But sometimes, we don't know what that parent has already been through. Sometimes, securing services is easy. Sometimes, your kid just gets whatever they need right away. Sometimes, you have to fight for it. But what we know is that from kindergarten through 12th grade, parents are advocate and CEO of that child's education, and they have to be. For the more severe kids on the spectrum, it's because they do not have the voice or the ability to advocate for themselves. For the students who are less severe, those students need to develop to some point before they can start that self-advocacy. And we know that elementary and secondary school is a lot more about the services and the initial learning, but then once students are ready to graduate, there's that big decision. Is the student going to be college-ready, or are we looking at something else? Are we looking at a gap here? Are we looking at 18 to 21? So let's talk about how to get those students ready because at graduation, everything changes. We know the students are really adults, but in the world of special education, everything changes with the high school graduation. The laws change. Who's in charge changes. The expectations of the students change, and we know the temptations and consequences change greatly. And the accommodations really do change, and we have to talk about that more because what we're seeing in the colleges is a lot of parents coming in and saying, "But you don't understand. You have to do this. It's in his IEP." There is no IEP at college. It's a whole different world that we're going to talk about. So ACT is the biggest high-stakes exam. Do most of your students take ACT or SAT?

>> SAT.

>> SAT? Okay. It depends where you are in the country, and, believe it or not, it depends where you are in Pennsylvania. But most of the students take the SAT. We find overwhelmingly that students on the autism spectrum do better on the ACT. It's a different kind of knowledge. So, educators and parents, if your students are about to take these high-stakes tests, think about the ACT. Okay? But according to the ACT, and this is from "CBS News: MoneyWatch," according to the ACT, 89 percent of high school teachers believe their students are well or very well-prepared for freshman-level work. By contrast, 26 percent of faculty feel these kids are ready. That's a huge difference, and I got to tell you, it's true. Anybody else here work at colleges? You do. I see Michelle. Which college are you at?

>> University of Scranton.

>> Scranton?

>> I'm at Penn State.

>> Penn State.

>> Arcadia.

>> Arcadia.

>> Millersville.

>> I'm sorry?

>> Millersville.

>> Millersville! Sorry, couldn't hear. Oh, hi. And Michelle is from LCCC. I'm hearing the same on all the campuses I work at. Are all of you hearing the same thing? I'm getting lots of head nods. Faculty are feeling very strongly that students are not prepared. Yes? Go ahead. I'll repeat.

>> My question is that, is that just general-ed students or students overall?

>> Is that general-ed students? Are those students with disabilities, as we refer? Or are those general students? In general. This is not just students with any kind of IEP or mandated special ed. There are seats up here. I really don't mind. I won't call on you. I promise. It's general students, but I think we're seeing so many students that ... Here is the reason. College readiness is fundamentally different than high school success. It's very different, and yet we're not addressing that because as one of the special-ed directors in our AACHIEVE project, which I'll talk more about later, as one of them put it very well, through AACHIEVE, they learned that they're making students very good at high school. And that was so powerful to me because you can be very good at high school, but what happens when high school ends? Are you ready for everything else? And what we're finding is not necessarily. The measures of college readiness don't capture the multifaceted dimensions of adult readiness and college readiness. This is

from EPIC, Educational Policy and Improvement Center. So who's the driver? In high school, it's the parents and the guardians. It's the teachers. It's all of you guidance counselors, all of us who really care about and love these students. But in college, it's the student. The student is the driver. Are we giving them any time for driver's ed? Are we teaching them how to become advocate and CEO of their education? Are we giving them time to ... The other graphic we used to use is in ninth grade, they're sitting in the backseat with somebody else driving. In 10th grade, we want them in the front seat, learning how to advocate from themselves, and by junior, senior year, we want them in that driver's seat. We want them knowing how to advocate for their own needs. And we're so busy making sure that they're really, really good at high school that we're forgetting all of this. So what changes for parents? Parents, I'm going to call on you now. We're not videotaping the group, so we won't rat you out to anybody. How many parents are still waking their kids up in the morning? A couple. Okay. Your kids with autism? A couple. That has to ...

>> And my kids without autism.

>> The comment was, "And my kids without autism." Are you waking your husband up too? I got to ask.

>> [INAUDIBLE]

Does anyone else here?

>> Oh, that's good.

I think the important thing is, it starts with the waking up. I talk to way too many families. I talk to lots and lots of families of folks on the spectrum, every week. And there's way too many families that aren't even thinking about this very basic independent living skill, and they're saying the line that I hear way too often, "But, Dr. Brown, you don't understand how bright she is." "But, Dr. Brown, he's got 800 SATs, math and verbal. You know, let him sleep." You know? Over and over and over, we see, and I'll show you some research later, but by eighth grade, students have to be waking themselves up, otherwise, honestly, we got to think about whether college and work are even possible. We've yet to find the job, folks, that you don't have to wake up for. We can't find that. It's not going to work. Okay? And the students who say to me, heard about one last night again. Got through the whole summer ... Most colleges have summer final exams this week. Got through the whole summer class, didn't even go to a quarter of the classes, never woke up for them and said, "Why would I? I know all that stuff." Took the final exam, didn't know it as well as he thought he did. Didn't work out so well. But that's really number one, is the student waking themselves up, and do they have those independent living skills that we often ignore in our more academically capable students in our schools. We think, "Oh, but, you know, he's in all honors classes," or, "He's in all standard college prep classes and a couple of honors or AP. Why

would we worry about the independent living skills that we worry about for the much more severe or systematic students?" Because we have to. That's what shows adult success. And what our mantra is, we're not just looking for a college degree. We're looking for students who become independent, successful adults. A bachelor's or a master's or doctorate does not magically make you an independent, successful adult. Okay? Parents, you okay? I know this is hard to hear, but you need to hear it. It's really crucially important. What about FERPA? FERPA stands for the Family Educational Right to Privacy Act, otherwise known as the Buckley Amendment. It's what we in higher ed live under. We have to be as careful or more careful than all of you about confidentiality. We can neither confirm or deny if a student is registered at our campuses without permission from that student. We don't know if you have a restraining order against the person who is calling the registration office to say, "I need to know if my son or daughter is registered for classes." We're in a different world than you are. We can't talk to parents. There's this myth out there that if you sign a FERPA waiver at most colleges, then the college can talk to you all they want. Not true at 99.9 percent of colleges across the United States. A FERPA waiver means if the student has an emergency, such as they're transported to a hospital, they can call you. That's it. That's all it means. And most general counsel at colleges will tell you that. There are several colleges, especially private or religious-based institutions that operate a little differently. But the overwhelming majority do not because operating differently has gotten them into trouble. So you get very little information where we're used to getting a really free-flowing information from our high schools. So that's a really important thing to remember.

>> Can I ask you a question?

>> Sure.

>> I'm sorry to interrupt, but ...

>> No. That's okay.

>> Why is that? Why ...

>> Why?

>> Why is the likelihood of having a, you know, restraining order against you as a parent, why cannot the student sign something, and so the parent can talk to the professor or talk to the teachers or talk to them, you know, as far as progress goes and that type of thing?

>> Several reasons. So the question is, "Why? If the students sign something, why can't a parent talk to the teachers, talk to the professors, talk to the administrators?"

>> Why? [INAUDIBLE].

>> So a lot of it is about numbers. A lot of it is about numbers. We work very differently than high schools. From my work for the past couple of years in Pennsylvania, I've found that most special-education resource teachers or autism-support teachers have a case load somewhere between 15 and 40? Is that correct? And I think 40 would be high. Right? So that's about what these very specialized teachers in the high school have. The average disability service provider in this country has a case load between 150 and 600. In Pennsylvania, the average is around 300. Michelle, what's your case load? How many students do you have at LCCC that use disability services?

>> Three hundred and twenty-seven.

>> Three hundred and twenty-seven. And how many professionals, like yourself, are in ... Michelle is the director. There's you and ...

>> One point five.

>> One point five for 327. That's average. Both Kutztown and Edinboro have about 600 students and have two professionals each, one point five at one, two at another. So we work at a whole different level. And if we have to look through every time somebody calls for us, out of those students, to say, "Oh, wait. I have to talk to this parent, this parent, this parent and this parent, we'd never get to work with the students. We can't."

>> I don't mean the disability offices or the disability office. I mean, as a general human, if you don't have a disability. You know what I mean? If you have ... If you give your parents ... I don't know. I think they have to learn some independence skills as well.

>> Absolutely.

>> But my son would not be in college right now if I did not move things along for him.

>> But I think that's what has to change ...

>> Yeah.

>> ... because we're seeing it in the employment setting too. Parents at that level, if you're ready to go to college, we've got to back the parents out. The students have to learn to handle these things, and, in my opinion, a lot of what the problem is ... I'm holding up my cell phone. At college, we call this the umbilical cord because, you know, for those of us ... Now, I'm older than most of you in this room, but if we had a problem when we were in college, we couldn't call Mom and Dad. That was saved for Sundays, maybe for 5 minutes because you were in a line at the pay phone. I mean, I'm dating myself here, but I'm 60. I'm not 100, you know, but that's what we did, and that was our contact with our family. We had to solve those things ourselves, and I don't think that was a bad thing. Now, you call your parents a few times a day. "Gee, I have to drop this class. What do you think I should take?" "I don't know. You decide. You're the person that's at college. I'm not." We have to back off because it's happening in employment too. I'm seeing so many students lose jobs within the first week because they're taking a professional job, but nobody has allowed them to be independent enough to take a professional job.

>> And I think there is a small ... Because my son, he's working full-time, 40 hours a week. He's going, you know, he's in the steel mill. You know, he's doing ... So there ... What do I want to say?

>> I understand.

>> A happy medium between it, you know, like, but if I had ... I don't think he'd be in college. What would he be doing if I wasn't motivating him?

>> He may not.

>> Yeah.

>> But if you went to college, did somebody do all that for you?

>> No.

>> Okay. We have to think about this. I mean, if the student isn't motivated to get through college, should they be there? It's a good question. Yes? Go ahead.

>> Well, wasn't FERPA created, well, if my memory serves, because there was this lady who entered college to escape from her abusive household.

>> Yes.

>> And then her father came and asked, "Where is my daughter?" And then they were like, "She's in room so-and-so," and then he murdered her.

>> Exactly.

>> Oh, my god!

>> That was many years ago, and that was one of the reasons that a lot of things came up because then, also, the student said, "I've been disconnected from my family for so many years," but nobody at the college knew that. So once you're in college, there's a different level of independence expected so that if every office or every ... For those of you in the room who ... I'm assuming most of you went to college, since most of you are educators. Can you ever imagine one of your parents calling one of your faculty members? It happens daily, now. Right! I mean, that usually is the response, like, "Oh, my gosh." But that happens daily. It's not appropriate. That's when the students are supposed to be able to handle their independence and their education. But are we giving them the time? Or are we tightening that net so close in high school that there has to be someone else to pull the strings and make things happen when the student goes to college? So, again, and I'll skip through in the interest of time, but that's what we really do look at, is taking the diploma the right thing? I would talk just briefly about foreign language. If you're taking students on the autism spectrum and saying, "Gee. You know, they're really struggling with foreign language, so let's eliminate that as a requirement."

>> Jane, here's a question back here.

>> Yes? Go ahead.

>> So it's more of a comment.

>> If you could talk in the mic, that would be great.

>> It's more of a comment than a question.

>> Got to turn it on. Sorry, Sheri. Thank you. Go ahead. Go ahead, Jen. I can try.

>> So it's kind of more of a comment than a question because I think one of the failures of higher ed is that we forget, not only are students transitioning, but parents are transitioning, and I think you make a really good point, and I think colleges and not just programs like mine, but the whole university ...

>> Yes.

>> ... all students, needs to begin to come up with how to be ... develop a capacity to support parents. Again, just ... I'm a parent too. You can't just cut a parent off at the knees, and all of a sudden, just because my son or daughter went to college, I'm no longer a significant person. And so what we try to do in our program is, not only do we have capacity to support the student, but we also develop capacity to support that transition for the parent, and it's been really successful for us because other than the student, they're one of the strongest informants for me until I get to know the student well ...

>> I agree.

>> ... until the university does. So ...

>> I agree with what you're saying for some people in the population. I don't think it's appropriate for everyone. And I think, again, we have to look at what we're doing. You know, we didn't do that years ago, and now, ... Years ago, they didn't even talk about parent orientation. Now, everybody has a parent orientation. But if you notice, there's always some videos online of how some schools have to physically move the parents out and close the gate, and then they take the parents somewhere off campus because that's the only way they can get them to disconnect from the child.

>> But I think that way helps do that. That's our purpose, is to help them kind of redirect those attentions to other work, you know?

>> And I think it's true, but I think, maybe, even that, we have to do better in high schools to start that process because parents are too hesitant to start stepping back and not be so intimately involved in their kids' education. So thank you, great comments. So just because I'm behind in time, I'm going to go through these a little quickly. You have all of these but high school versus college. In high school, our students are structured for about 14 hours a day. They're waking up very early. They're going off to high school very early. Hopefully, they're getting 2 or 3 hours of homework a day. If your kids ... I'm going to go through my ... Please, take these off the accommodations-list list as we talk, today. If one of the things, in the accommodations, you have for your sons and daughters or for your students is, all homework gets done at school, please, take that away as soon as possible. I know, for some students, they really need it, but what it does is it never teaches that student how to structure their time to get work done, and then they go off to college, and they have no idea how to do that, so we're hoping that students have 2 or 3 hours of homework a day, that they have frequent quizzes, noncumulative tests in high school, and most content is from a textbook or from any lecture or discussion in class. In Pennsylvania, you have about 20 or 25 students per class and usually in one building. Once they get that diploma, they move onto college, where they've gone from 12 to 14 hours a day that are structured to, now, 12 to 15 hours a week, lots and lots and lots of unstructured time. We expect students to spend 2 hours outside of class for every hour they're in class. So if you're taking 15 hours, we expect 30 hours that you're spending studying. But you have to initiate that studying yourself, and you have to be motivated to study. You're going to have two or three cumulative exams per semester, but now, you've got to integrate and synthesize from a textbook, from research, from the lectures, from the PowerPoints, from, maybe, recommended readings and pull everything together. You could have 10 to 300 students in a class. Most colleges go by whatever their biggest room is. That's their biggest class. Penn State, I would think it's got to be 600, at least, and I'm sure you have a few 600-person auditoriums, and you've got an entire campus to negotiate. This is drastically different, and sometimes, I talk to families that their student on the spectrum has had a very rigid schedule in a very rigid place, and they're applying to, maybe, a place like Penn State, and I want to say, "Let's talk about whether this is a good match." But we have to think about that difference in structure, and we know that students with autism do much better with structure, and college is very unstructured, and you have to be self-motivated in order to get through. So what we know is this is a lot about resilience, and, again, in the interest of time, resilience is the capacity to recover quickly from difficulty and being able to be tough. So about 4 years ago, I did some research because I was hearing too much from parents, "Oh. You don't understand how bright this student is." So I really wanted to look at, is that what gets a student through college? Is that what makes you successful at college? And what we found is that, no, academic ability is number five. It's important. It's in the top five, but it's number five out of the top five. Number one is resilience. Number two is that social communication interaction. This is not just on students on the spectrum or students with disabilities. That social communication interaction, "Gee. I missed class today. I wasn't feeling well. Do you have notes I can copy?" That's social interaction. That gets you through. Executive function, "I've got a paper due, but I've also got an exam this week. Maybe I have to do the paper beforehand." And Mom and Dad and teacher are not telling you to do that. You need to know to do that, big difference. Self-regulation, if something really bad happens, "A significant other broke up with me. A friend was mean to me. My friends didn't include me in going to dinner or going to a movie. Can I get over that and still study and do what I need to?" And then, "The fact that I got an 800 on the SAT is important." I'm sure all of you see this. We have all seen people that we didn't think were really

academically at the top of your list be really successful in college. And we've all seen students who were academically at the top of your list not be successful in college. There's other factors that we have to consider for students on the spectrum, and we have to start walking on them earlier in order to make people more successful at that next level. So what we know is to build resilience, we need to work on two through five. So very quickly, again, and this is from that stellar academic site, psychcentral.com, but it makes sense, and it really is talking to us just as laypeople, not just as educators. It looks like it was written to all of us who work on students, IEPs. Don't accommodate every need. And what do we always do? We want to make sure that student doesn't fail. Avoid eliminating all risk. And what do we do as parents? I want to take out every bit of risk because I don't want my kid in trouble. Teach problem-solving, we do this all the time, and it's done from a good place, a good heart. But teachers are so busy that you see each other in the morning for coffee and say, "Ooh, you know what? Kevin has an exam today, and he needs extra time." And the other teacher says, "But I know there's an assembly, and he really ought to go to the assembly." So somebody says, "You know what? Let's let him go to the assembly. He can use that last period of the day for his extra time for the test. You tell Kevin. I'll tell the teacher. Great. Have a good day." And they leave. They've just solved the problem, and I'm sure the parents would say, "Great. See? They take such good care of my kid." But what they've done is take away that problem-solving learning from Kevin so that Kevin, now, when he has that problem at college, and he comes to me and says, "I can't take extra time for my exam, I have a lab right after." And I say, "Well, what are you going to do?" He's going to look at me and say, "I don't know." And my first response is going to be, "Well, when this happened in high school, what did you do?" And the comment I get most ... and pardon the gender reference. I apologize in advance. Almost every student exclusively says to me, "I don't know. There was a lady." Right? They don't know if you're a speech pathologist, a social worker, a teacher, a resource teacher, a guidance counselor. They just know there was a lady who took care of all of this. But what we've done is rob Kevin of that opportunity to learn how to deal with these issues, and at college, if you think about it for a minute, in Pennsylvania, I'm going to lower it and say, "Average, about 300 students on a case load, each taking four or five classes. That's 1,500 classes. That's 1,500 exams times two or three. Now, we're up to 3,000 or 4,500 exams going through one person in the disability services office. Do you follow me on this? This is why we can't do it. This is why the student has to be responsible, and they should be. But what's where the big difference is. We have to teach the students how to handle these kinds of things. So don't provide all the answers. Avoid the catastrophic terms that we all do as parents. "You keep that up, you'll never go to college!" I can't tell you how many times we've said that in our household, and my two neurotypical kids went to college. My son is on the lower end of the spectrum. He's very low-functioning, so not going. But we said it all the time, "Let the kids make mistakes and help them manage their emotions. Don't manage the emotions for them." Big difference. This is why the Psych Central makes sense in this. It really is good. So very important stuff, laws you need to know because I don't think this is getting out nearly enough. This is from my colleagues, Lisa King, Lori Wolfe and I. We all took lots of time revising this over the years. I think this was 7 years in the making until we finally got it to a place that we like that makes sense. So if you use it, and if it's helpful, please, use it. Just keep college autism spectrum on the bottom, please. It's in a couple of our books. So IDEA, which is what most of you in this room work within, the Individuals with Disabilities Education Act, which you all know better than I do. This is federal law of education entitlement. FAPE is very big, Free and Appropriate Public Education. The responsibility is the parent and the school. It is based on success. When my son was in third grade, and my very wonderful school district, which really does a great job in special education and students with autism, they came to me

when he was in third grade and said, "We're so sorry. We don't have a program for your son." And I said, "Oh, my gosh. What are you going to do?" And they kind of looked at me, and I said, "Well, but you know better than I do that the federal law says the program has to meet the child's needs through IDEA." So they found an out-of-district placement, but I didn't want him to go out of district, but we had to. But it's based on success. You cannot fail out of special education. All of you in this room have to make other arrangements for students who are struggling. It's based on services that are evaluation, remediation and special accommodations under one of the 13 federal diagnostic labels. So all of this goes through K-12, but once you get that diploma, you have the party, you wear the nice cap and gown, you're now in the adult world of the ADA, which we now know of as the ADAAA, the Americans with Disabilities Act Amendments Act. This is not federal law of entitlement. This is civil rights legislation that does not come with funding. K-12, you get money for special ed from the federal government. Colleges do not. There is no money behind this. The responsibility is now the student, not the parents'. It's based on equal access. It would be very nice if all of us who ever paid a college tuition for a class were guaranteed success. "You give me that tuition. You're going to get an A or a B." It doesn't work like that. It doesn't. To all of us who ever got something that wasn't an A or a B, yup. We base this on reasonable accommodations and our charge, our federal mandate is to level the playing field. We have to take away physical barriers, and we have to make academic accommodation. That's all we can do, but we can't place unfair advantage. It's based on the level of functional impairment in a major life activity. These are totally different laws. Higher ed has no special education. It doesn't exist in higher ed. We make accommodations to level the playing field, and I don't feel like we're explaining that well enough to parents or to educators, and we need to because, as opposed to, and I understand your comments about, "We have to let the parents in more," and in some cases, we do, but we have to start teaching our students earlier. We aren't just saying, "Oh. We have to make them so good at high school," but we're not getting them ready for anything else, and that's where the issue is so that some of our very bright students with autism, we're seeing not getting any of those other services because they're doing well in school, and maybe they're not a behavior issue, and so they take away everything else that might really help all of this. The other very important thing that ends with IDEA, and this is really important, is manifestation determination. Is that a familiar term to everyone, manifestation ... For anyone who it's not because I'm seeing a couple heads shake in the "no" way. Manifestation determination is a part of IDEA that says if a student breaks a code of conduct for school, there has to be a determination meeting to see if the behavior was a manifestation of that student's disability. If it was, the determination committee has the ability to either make that sanction severely reduced or to go away, or they can keep the sanction. What we're hearing way too much at college ... Because this does not exist in the adult world or in college. Way too much at college, when a student has a problem, parents are calling and saying, "Well, you can't hold her responsible for that. She has autism." Not only can we, we have to, or we're breaking the law. So all that changes. If a student doesn't understand social interaction, and they're accused of stalking because that social interaction piece is not making sense to them, we can't say, "Oh, you know that person that's been following you around campus? Don't worry about it. She has autism." That doesn't exist in college. And most of you would not have accepted that as an answer. The response is usually from a parent, "You mean I'm paying you \$40,000 so my kid can't feel safe walking to her residence hall at night?" This is a different world, and we're not paying attention to it enough beforehand so that manifestation determination leaves with IDEA, but the drastic differences between IDEA and ADA, I feel like, are not being addressed enough to the high school setting and to the parents

because we really ... Any questions on this? Because this is a really important point. Yes! Just yell because I don't think we have a working mic.

>> It's not a question. It's just kind of ...

>> Oh. Wait. One second, we do have ... Yes?

>> It's not a question. It's just from an OVR standpoint.

>> Right.

>> I think we see this because someone will say, "Well, I don't have to do that work," or, "I don't have to do that task because I have a disability." And I'm like, "No." And I have to explain to them, "That's not the case. Just because you have a disability doesn't mean you don't have to do something."

>> So I really appreciate that perspective. Thank you. That OVR perspective and that employment perspective because, again, are we looking for a college degree?

>> Right.

>> Or are we looking for independent, successful adults? And it's so important, and the more we say, "Listen. You have a disability. So we're going to take all that away," the more we're robbing that student of what they might be able to do in the future. Yes?

>> I was wondering about ...

>> Oh, wait. I'm sorry. The mic is right behind you.

>> Oh, I'm sorry. Hi. I was wondering about ... You keep saying K-12, and I'm thinking, K-21.

>> Yes. Sorry.

>> And I think it's ... And I'm a college person, so I think K-12, once you showed up. But I wonder if ... And you may be speaking to this later, but my experience with school districts is, they're like, "Oh. He's bright. She's smart, definitely graduate. Good luck," you know, "High five," as opposed to putting the responsibility on school districts to think about that time between 12 and 21.

>> Absolutely.

>> And I just wanted to know your perspective or how ... Who is going to take responsibility for changing the conversations?

>> Yes.

>> Because often, school districts come ... students come to us, and I think, "Why did you take a diploma? What were you thinking?"

>> Exactly. Yes.

>> "How did they talk you into this?" And it feels criminal.

>> I couldn't agree more. I think that often, some of these students that we're working with are underprepared, and because students had academic ability and didn't have behavioral issues, they fall through the cracks. Pennsylvania ... And this is a few slides ahead, but I'd rather address it now. Pennsylvania is dealing with this, and they are the only state in the country. We are incredibly progressive. We are working with high schools, and we're working from ninth graders on to change all of this. That's the AACHIEVE project, and that's what we're hoping, within a year or 2, is going to flood out to all the other high schools because we need to start working earlier, but for my colleagues and higher ed in the room, we've known that for the 40 years I've been in higher ed, that we needed to work earlier. Pennsylvania is one of the only places that's actually doing it. We need to do that, and we need to address it. So, yes, when I raised my hand, I'm hoping to address that more, and the more of us, the better. Yes, right behind.

>> I'm an OVR counselor as well.

>> Good.

>> And, like, for the parents, it's, like, when we get them, it's like they only have one summer between being babied ... I'm sorry, not to ... being babied and being a complete adult ...

>> I know.

>> ... like independent, and, you know, when we get them, and we're trying to work with them, it really is, like, what she was saying when it comes to, "They're so used to people doing everything for them." They literally come to us, and they're like, "So are you going to pick my classes?"

>> Exactly.

>> And I'm like, "No. Like, I'm going to help you until ... I'm going to give you your guidance and counseling," but they literally do not know how to ... They don't know how to even get on the bus and come to an appointment by themselves because they're like, "Well, my mom is out of town. I can't do that."

>> Right.

>> And they're 18 years old. So a lot of it is, like, they're expecting us to kind of do every single thing.

>> Right.

>> And it's, like, I've seen that it's gotten worse and worse every year.

>> Absolutely. And it has to be a partnership and because ... The difficulty is ... because I run into this as a parent all the time. The spectrum is so wide. You've got people ... And, again, when I refer to my son, my son is 25, but he functions somewhere between a 3 and 5-year-old level. He's a very severely impacted person with autism, and we love him to pieces, anyway. He's a wonderful kid, but he's severely impacted. Then we have people who are college-bound and going to be completely independent and competitively employed and some of our most brilliant people in the world and everything in between. So it's really hard to talk about autism because we're talking about so many

different kinds of people, but if you have someone who is college-capable, if you have someone who is going to be competitively employed, we got to start this much earlier, and it has to be the school and the parents and OVR. That's why we're all learning so much about the pre-employment transition services and the WIOA, and we're now getting everybody involved much sooner. One more question, then I want to get through some slides.

>> So it's not a question. It's a comment.

>> Yes.

>> I'm sure I'm going to rub some State people the wrong way.

>> That's okay.

>> I totally apologize. So maybe we need to start, you know, because K-12, and I'm a transition coordinator, and my soapbox is, as we go through high school, taking away those accommodations that you are not going to get, weeding them out. But when it comes down to it, when you are going through the compliance monitoring, if your T is not crossed, if that word is not in there, if you did not take every single step, and the parent did not agree because if you want to take something out, that will only benefit the student in the future, if the parent or someone else doesn't agree, you can't do it.

>> Right. No. You're absolutely right.

>> So our hands on the K-12 side are so, so tied because, I mean, I have these presentations. I work with some of the community colleges and do the stuff with the parents, but we're so tied, and they're so into, like, the paperwork piece. "Is the signature on the right line with the right date?" And let's rubber-stamp that.

>> I understand.

>> But we're looking at the wrong things.

>> I understand what ...

>> And I think until we change that, so ...

>> I'm sorry to interrupt. I understand.

>> Sorry.

>> I understand what you're saying. And I agree. I think the bureaucracy in all of our states has become cumbersome, not just Pennsylvania. However, it's also ... We're not working in partnership enough. I think if we can get to the point where the parents feel like, "I'm to an IEP, and we're going to make plans for my ... Or a PPT. And I'm going to be making plans for my son or daughter for the next year, and the teachers are all on my kid's side, and the school district's on my kid's side." When we can get to that point, then we can be productive. So in case we don't get to it with time, the top three things we want to look at trying to take out of those SDIs, those high school accommodations: the homework at school. That's really counterproductive to teaching somebody how to be able to structure their time outside of school, especially at college or at work. Study guides, please, please, start taking away the study guides. All of use in disability services hear way too much. "So are you going to be making my study guides?" "No. You're going to be making your study guides." "I don't know how to do that." Let's teach the students how to put their study guides together so that they can function outside of high school, rather than being handed what they need. That's where that difference in readiness ... If you're handed what you need to study. You memorize it. You go in. You take a test on that. How are you ever going to learn to try and integrate any information, if you can integrate, and, yes, you might need those study guides in ninth, maybe even 10th grade, but after that, how are you going to ... You've now got this great team around you who can help teach you that. There aren't those people to teach you that in college. That's not the piece of what we do, and they're finding way too much in colleges that they have to go back and teach things that people needed to learn in high school. And that's where we're have so much trouble. So those need to be taken away. What did I say? Study guides, homework, what else did I ... I'm missing something else. I'm sorry?

>> Accommodations.

>> Accommodations. Yes. So I'm missing one other. Well, I'll just mention it, but this isn't one of them. It will come back to me. If your student uses a one-to-one aide, you need to start weaning that off. That doesn't happen in college, and it also isn't paid for in college. The only way aides are paid for in college is through independent living centers, and that's not for focus. That's for health-related reasons or physical-disability-related reasons. You don't get someone to pay for an aide. That's personal service in college. We don't pay for technology. We don't pay for aides. Different laws, we're under completely different laws. The 504 Plan, I hear a lot from parents. "Here's the 504 Plan. This is what you have to

follow." 504 that we follow is completely another law than 504 Plan in high school. So your 504 Plan does not continue. In college, you need to bring us your documentation. We look at the documentation to determine accommodations. And then we determine those in negotiation with the student. That's part of the law, not with the parent, with the student. So it's really important to be able to have that negotiation, and that's what we work on. So this is what I was talking about. And what happens then is the disability services puts together letters that the student takes to their professors that says ... It doesn't identify the disability. It says student gets time and a half on exams, or student needs a notetaker. Yes, in the back?

>> I stepped out for a second. So I hope you didn't go over this.

>> That's okay.

>> But I'm also a VR counselor.

>> Lots of VR people. I'm so glad you're here.

>> I love your presentation so far.

>> Thank you.

>> Explaining more to parents about there's a difference between academic accommodations and modified curriculum ...

>> Oh, my gosh.

>> ... because a lot of the times in the IEP, I sit in meetings and explain to families, "There is no modified curriculum. There is no reduced choices. There is no word banks. There is no spelling approximations."

>> Yeah. That's not special education.

>> There's a difference, and you can request accommodations at the college level, but all of those modified curriculum changes cannot be made. And that's very hard for a parent during a kid's senior year, and I'm hoping because we're doing a lot morning earlier now with students, we can explain and educate families way before they're getting ready to graduate, but that's hard for parents as well.

>> I couldn't agree more, and it's hard for colleges because ... Especially if your kids are applying two places outside of your school districts, which most of our students are, thank goodness. I hear way too often language that ... And I think everyone I work with at PaTTAN and PDE can tell you that I've had to be trained in K-12 language because we don't speak K-12 in higher ed. And you guys don't speak higher ed. So we use a totally different language. So when those transcripts come in, we don't know if someone has had modified grades, modified curriculum. And so our admissions departments are looking, and then sometimes, I'll hear from a transition coordinator or a special-ed director, "Well, come on. You know, it's a 199." When I say, "Well, what's a 199?" "You don't know what a 199 is?" "No." And a 199 in your district might be a 620 in your district. It might be a 530 in your ... I don't know what that means, nor do the college admissions directors. So we sometimes get these transcripts, and somebody's got a 3.5 GPA, and we don't know that that's modified grades, modified curriculum. It gets really difficult, and then, again, you know, no special education in higher ed. So know all those accommodations with ... Let's take away two of the multiple choice choices. My other least favorite. "If everybody else is doing four homework assignments, you only have to do two. If everybody has to do two pages of math problems, you do the evens, or you do the odds." Modifying homework is not going to happen at that next level. So that and ... Oh. I just remembered my third least favorite accommodation, well, that causes problems. You get extended deadlines for everything. Most colleges have taken that away. We cannot do that because we learned long ago that that is a sure way for people to fail. If you have an extenuating circumstance, of course. We're humans in colleges, but if you're doing assignment one, and you get extra time, the class has moved onto assignment two. You don't really know what's going on because you haven't finished assignment one. You get assignment one, but now, you don't know what's going on in assignment two because the class is already on assignment three. What we found is so many people saying their students are flunking classes because of this accommodation and losing lots of money. So very rarely, now, will colleges do that as a blanket accommodation. If you need it for an extenuating circumstance, though. Quick question?

>> I just had a comment.

>> Yes.

>> There's a lot of concern about grades in high school. I teach high school, and a lot of kids have modifications and accommodations that make those grades elevated.

>> Yes.

>> And we're trying to fade them away so that the grades are actually where they're supposed to be, and we're not [INAUDIBLE]. The parents have to think, like, not worry so much about their grades and fading away the modifications [INAUDIBLE] to see truly what that student can do on their own.

>> Exactly.

>> And it's a really hard conversation to have.

>> It is. It's very hard. Believe me. It's a really hard conversation.

>> Yes? Very quickly only because ... Yes?

>> My son had AP classes. So they got 10 extra points. So he knew in his mind, "Well, if I get an 85, it's really going to be a 95."

>> Yeah.

>> I mean, he manipulated it. And I'm like, "Let's not do that with AP." I mean, it's great they offered AP, and he was bright enough to go in them, but do we have to give him 10 extra points? I don't know, some other accommodations.

>> Well, and I always have to ask now because so many places, when I say, "What's your GPA?" people will tell me, "Oh, a 4.5 out of 6."

>> Yeah.

>> What does that mean? And everybody uses different numbers now all across the country. So we know there's no one right way to go to college. We've got technical schools, and we've got vo-tech schools and trade schools. We've got private institutions, and we have colleges with additional support programs. So you really want to think with your students about how far people are going to be from home, whether they're going to stay on campus. Are they ready for that independent living on campus? And our mantra in our autism programs, please, remember, another AP class does not compensate for

poor hygiene. Okay? If somebody doesn't know to shower every day, it doesn't matter if they've got a 4.5 out of 4 because people aren't going to want to work with them in a group or sit next to them in class or be their roommate. Those independent-living skills are crucial. So is the size of the classes and the campus appropriate, the curriculum, and is there a specialized program? And we are going to talk about those. We have to think about how students really respond to sensory stimulation. This room is not terribly bad because the colors are kind of plain. The rug is nice and plain. The room I was in last week at the autism conference had one of these blazing rugs with big patterns that I know most people college students on the spectrum could not function in. But we have to think about that as barriers to our students' learning. The social issues become much more intense in college because students really need to interact in order to negotiate the campus. But we know to transition students with autism, we really need a good plan. The family and the school needs to know the student, needs to know that not everybody is ready at the same time. Sometimes, we have to think about those 18 to 21-year-old programs, if there's an appropriate program. A lot of times, the 18 to 21-year-old programs are made for people like my son, and if you're about to go to college, that's not going to be a helpful program. So you have to have the appropriate kind of program. There's lots of different ways you can do dual-enrollment, going to a community college during your senior year to help you get ready for those kinds of college accommodations. That helps tremendously, and we do that a lot within Pennsylvania. So I wanted to get to this slide because this is some of the transition goals, and we're finding, especially through our AACHIEVE project, which I'm getting to now, that the transition goals are often a problem and that we need to really work on what those students need to work on, and we can't just do it senior year. We have to look earlier. We know that students need a current assessment in order to move onto college. That's what's going to determine their accommodations. It has to address all the skills and weaknesses. I'm going to be saying to the student ... The first meeting at disability services, we usually will have a parent come with the student, but after that first meeting, I'm meeting with the student, not the parent. So the student needs to know how they function academically, where they might struggle and where they're really good, really important. Including medical information, review accommodation needs and pare down to those necessary accommodations because that's what the student is going to get in college, not the smorgasbord of what they may get in high school. The student needs to understand that assessment. Way too many parents are saying, "I don't want it to affect him. I really don't want him or her to read it." Well, guess what they do in our offices? At disability services in college, first thing they do is come in and say, "They never let me see that. Can I read that?" And that's their information. We have to give it to them. So if you're keeping it from the student, it doesn't make a lot of sense. And people really need to practice disclosing to teachers. Often, we do that for the student in high school. Have I harped on the waking themselves up, you know? Okay. My OVR colleagues will love this, but way too many folks with any disability are not getting work experience before they go to college. And I hear ... I work with lots of employers, and what I hear from employers daily is, "I'll take someone with any kind of work experience over somebody with a 3.9 or 4.0 any day of the week. I want to know that someone knows how to work, how to respond to a supervisor, how to work with other people and how to be an employee, how to dress for work, how to show up on time. I'll take that over somebody who was smart in class any day. And I think that's true, and we have to remember that because it's not just those good grades that are going to get someone to get and keep a job. The keep is really important. Getting a job is one thing. Keeping a job is a very different thing. So here's the plan. Only took me ... Somebody remind me. I have until 10, Sheri?

>> Mm-hmm.

>> Thank you. Okay. Yes?

>> Is there any program in place that helps people on the spectrum help get a job?

>> Absolutely. Great question.

>> Yeah. I volunteer over at the Pittsburgh Zoo.

>> Oh, great.

>> Yeah. And I applied for several paying jobs.

>> Wonderful. That's what the Office of Vocational Rehabilitation is for, and as soon as you're ... Well, let's talk right after. I can try and connect you with one of these OVR counselors who's here, who can help you with that. Okay?

>> Okay.

>> Great. Thank you. Good question. So here's the plan. AACHIEVE stands for ... I might need help. Is Kathryn here? Kathryn, you may need to help me. This I get stuck on. It's an Autism College High School Integration for Educational and Vocational Excellence. Did I get it? Lynne, did I get it? I got it. Thank you. Donna Alvino and I made it up, but I can't remember it for anything. Sorry. I know what it means, but it's just I always say, well, for AACHIEVE. So what are we doing? Yes?

>> [INAUDIBLE]

>> Are you a plant? I've been asked to repeat and I will. An Autism College High School Integration for Educational and Vocational Excellence. Actually Donna came up with that. I said, "Let's use the word achieve." And she went, "How about?" Just amazing to me that people can do that. So here's where we started. We wanted places for our students to land and we found that in Pennsylvania two years ago, we only had three private schools with specialized programs for students with autism. When I started this work 20 years ago, there was one program in the country. The next year there were two. Right now, there's about 55. By fall there may be 60 specialized programs in the country. The great news is for

everyone in this room, the Commonwealth of Pennsylvania has more programs than any state in the country and as of this fall, you have 10, which is amazing. I mean, a lot of states are begging for one. So we started at Edinboro an IUP. They started two years ago with programs and a semester later Kutztown and Westchester began. So as of last year, we had four specialized programs. Each had five to 10 students. As of this year, those schools all have ... Let's see. Kutztown has 10. Edinboro, IUP and Westchester all have between 15 and 20. That's telling us the numbers are quickly multiplying. Not everybody with autism who's in disability services is doing these specialized programs. This year, we're adding Slippery Rock, [INAUDIBLE] and Michelle is here in the back, and Bucks County Community College. We wanted at least two community colleges, and this is about all we can manage for this year. But seven is more than any other state has and there's three private schools, Drexel, Mercy, Hearst, and St. Joseph University. So here's where they are. I'm hoping you can see this. We're missing a couple of high schools. But what we did once we started the colleges, we then looked at feeder high schools and started working with students from 9th grade on. This past year, we worked with Norwin, Blairsville, Tamaqua, and Westchester. In the spring, we added Great Valley, Saucon Valley, and East Penn. And now this fall ... Those aren't up. We're adding Upper St. Clair, Riverview, Gerard, Chadsford, Unionville, Chadsford, Great Valley, and I'm missing one. Yes, and I think I'm missing one more in the west. But we're at 11 high schools. We work monthly with those high school. Oh, sorry. Here they are. I just had to go to the next one.

>> Saucon Valley.

>> Saucon Valley. Thank you. So we're adding Unionville, Chadsford, Garnet ... No. That one is ... Gerard, Upper St. Clair, Riverview. So we've got 11 high schools. We've got seven colleges we're working with. And what we do is ... Oh, sorry. Nope. What we do is go with 9th grade students. Sometimes they've added 10th or 11th grade students at some of the high school, and we meet every month. We meet with the team, the teaching team, and the professionals. We meet with the students, and we meet with the family. And we're getting ... Everybody has a kick-off similar to this where they're hearing about the differences between high school and college. Then we're working with the students who are learning to be very self-directed, take responsibility, know how to choose their classes, know how to prepare to be a college student. And it's, so far in the one year, going really well. We've had three students graduate, all three of whom are going off to college. And not only ... One is going into a program for students with autism. The other two are going to ... One is coming here to Penn State. I think the difference is that we're getting to the family earlier and we're getting the family and the school to realize that it doesn't have to be contentious. And many of those families have fought and in some cases sued to get accommodations. But when someone like me from the outside can say, "I see that your son or your daughter has an accommodation list that is longer than what my very low functioning son had." So if we're going to talk about college, if this student is capable, we really need to talk about it. And it turned out the student was like valedictorian of their class. But the SDIs were like this. And we Sometimes need to look at it. I understand parents are afraid to take those away because they fought so hard to get them number one, and number two, what if the student needs it. But instead saying, you know what, if we take it away, if you need it back, we can talk about it. This isn't something like it goes into the abyss and you can never get it again. Yes, with a lot of parents it's going to be harder and with some parents, it's going to be easier than you think if everybody is on the same page. We've got the colleges and some of the students mentoring those high school students. Then through programs like Peg Monahan's at SAP, we've got some employed folks mentoring the college students. So we've got people coming down. So

when a college student says to a high school student and their parent, "If I only knew that I should have changed these accommodations before I went to college, that really would have helped." Hearing that from a student rather than from the person who's holding those accommodation strings changes things drastically. And we constantly ask those college students what would you really have wanted to learn in high school? What would have had you better prepared for this? That's helping a lot and it's helping the students. So a couple more and then I want to take questions if we can. What we really need and what we're working on in AACHIEVE is to get students to be prepared for all of these, to talk about the impact of the diagnosis, to really think about those housing issues. Do I need a single? Am I spending 300% of my energy to get through classes every day so that when I go back to a residence hall room, I might look more autistic than I want a roommate seeing me? And I might need some privacy there. I might need to rock. I might need to stim. And if I do, is that more important than trying to have a roommate? And for a lot of people it is. But folks need to know that. Can they take care of their own hygiene and self-care? A brilliant mom whose name I never got, it was in a big session, came up with something for her son that I've used ever since. So thank you, anonymous mom, wherever you are. But she came up with for her son and now we laminate it and put it in everybody's rooms, take care of yourself. And she spelled S-E-L-F. S was for sleep. E for exercise. L for liquid because her son got dehydrated very quickly and always forgot to drink water. And F was for food because he would eat junk if he didn't have time to really eat. And that S-E-L-F made him be independent. He had to remember something very easily and it was easy enough that I still remember it and I don't remember much. And that's really important, that kind of thing, to teach the students. So we laminate that and have students put it in their residence hall rooms because it helps them remember those basic things. Are students refilling their own meds? Do they know how? And if that prescription runs out, do they know how to get another prescription? I can't tell you how many students have problems in college because they run out of a medication, they don't know how to refill it, they don't know how to get a prescription and they just don't do it.

>> What was the L?

>> The L stood for liquid. Sleep, exercise, liquid, and school. Brilliant, brilliant, brilliant. On dietary issues, we have a lot of folks on the spectrum that only eat white foods or only eat square foods, or have real food preferences. I just read a great article that a mom scribed for her eight- or nine-year-old daughter, and she described why it's scary to eat. And it made so much sense and it made so much sense for college students that I sent it to all of our college programs. And this little girl said, "I'm busy doing something and then you want me to move rooms, go to a room that smells different, the chair feels different, and then you want me to have food in my mouth and it might feel different, make my body feel different. Then I'm so worried about what's going on in the other room. Are people touching my stuff? Will my game still be going on? Will it smell different when I go back? Will somebody else have touched the keyboard?" That anxiety was overtaking. It made so much sense. I sent it to every college I work with and said, "Here's the anxiety we're dealing with." And now we're saying to people, "Oh, don't worry about it. I'll find a room for you to take your exam." What if that room smells different? What if the chair feels different? All those things that we don't think about that are barriers to that student's education. And that's what we really need to think about. So sometimes the things that are written for younger folks impact higher ed just as much. Stress tolerance in general, we find that anxiety is the number one issue that is a barrier for folks on the spectrum. So we need to address the anxiety and what's causing the anxiety in order for folks to learn appropriately. Transportation is always an issue. And, oh, my gosh, if I could solve something in Pennsylvania, that would be it, folks. Let me tell you. We

have programs that are running beautifully, but we can't get people to them. That's a really big issue. So we have to work on that. And behavior and conduct issues. Disability never excuses behavior once you're out of high school. Really important thing to remember. So we really have to remember that folks on the spectrum remember that. So self-advocacy is crucial and we're working on ways to help high students develop more self-advocacy skills sooner because that, we know, is crucial not only to high ed but for work. And that special interests really can become careers. We had one student years ago who we could not get motivated to do anything except make costumes for Comic-Con. She made great costumes for Comic-Con. I didn't know any of the characters she was making. I do now. But I've known the young woman for a very long time. We found a retired special education teacher that I had known that I asked to really teach her how to sew, not just glue gun costumes together. But could you really teach her how to put in a zipper, how to set a sleeve, how to really do things? And it was a match made in heaven. This woman had just retired after I don't know how many years, how many decades. But phenomenal special education teacher and she was also a phenomenal seamstress. And they got together like two, three times a week because they just really enjoyed each other's company. Her sewing skills went way up because the woman was sensitive to her needs as a young woman with autism. We got her an internship. I say "we" because it makes me feel better. I got her an internship at a costume shop at a big theater in Connecticut, and she just took off. She ended up getting a degree in costume design and theater, and that interest that was sort of like what is this huge fuzzy pink blob I'm looking at? You know, I had no idea. It was an anime character at Comic-Con, and before we knew it, her friends at Comic-Con were paying her to make costumes for Comic-Con. It became a job. I think it's those things that we sometimes have to look at and find an innovative way to get to, and she struggled some in college. So we had to find the right program for her to get through that degree. So it's not like any of this will be easy. The motivation has to come from within. With that student, we said, "You can make all the Comic-Con costumes you want so long as you also do this. You know, you have to make one Victorian costume for this play that they've asked you to, and then you can make all those." So that motivation she learned. Find the hook and use those small rewards. This is our book for parents, our book for college professionals and our five-point scale with Carrie Dunbar. I made it with [INAUDIBLE]. So now questions. What do you want ... Oh, good. Okay. Can we start with Kathryn? Can you yell and I'll repeat it?

>> Yeah, I just wanted to see if you wanted [INAUDIBLE].

>> Oh, thank you.

>> [INAUDIBLE]

>> Thank goodness. Thank goodness you're here. I wouldn't have remembered. At 12:45, we're doing a session just on AACHIEVE about all the different pieces, how it works and what it's about. Figuring nobody would know what AACHIEVE was, I called it something different: PDE PASSHE Collaboration. It's in 204. Do we know what number it is?

>> Section G11, room 204. So right [INAUDIBLE]

>> Thank you, Kathryn. G11, room 204. That's from 12:45 to 2:15, and we're going to talk about all the pieces of AACHIEVE and have some people, including Michelle and a couple of the high school people who are in AACHIEVE. They're here, and everybody is going to talk about how it worked and what it was. I'll get right to you. I've got two questions here. Yes?

>> The girl you were talking about, I have the exact opposite problem as her. I can be motivated. I'm easily motivated to do schoolwork, but I have trouble being motivated to do anything else.

>> So you're motivated to do schoolwork, but you don't like doing the other things?

>> Yeah.

>> I have some ideas for you. Can we talk right afterwards? I would really like to give you a couple ideas. Is that okay?

>> Of course.

>> Oh, great. Thank you.

>> So this might be answered in the afternoon session. However, I'm going to be a moderator so I couldn't attend.

>> That's okay.

>> So, what is the criteria for the students that you're looking for. Like, for example, we ran a summary program for students going from transition to college, and some of the applications we got, I'm going to be honest, their IQ was like 70. And I'm like, "They're not going to survive in college." Like, let's be realistic. And even some of the accommodations that we had this year, I like was like "these are not going to be appropriate." I mean, we all adapted as the program went. But I was curious to see what you guys utilize as your criteria for looking for your high school students.

>> I think Jessica Mazaika, who is the Autism Support Teacher at Tamaqua, puts it best. She uses the term college-curious. And so for students who are college-curious, they're using that as one of the benchmarks. Because I think there are enough programs. We have a number of programs in Pennsylvania for students who are with ID so that if there are students who are interested in college but that a typical degree-seeking program would not be appropriate, there are programs that are available. The AACHIEVE programs are for people who are degree-seeking and they have to first be admitted to the college. Then they can apply to the AACHIEVE program. So in other words, if you want to go to Kutztown, you have to apply to Kutztown first. Their program is called My Place. And then to get into My Place and then you ... you get into Kutztown, then you apply to My Place.

>> Oh, I apologize. I thought it was for the high school kids. That's where I was [INAUDIBLE]

>> It is. Oh, okay.

>> Wait. So is it more freshman [INAUDIBLE].

>> Yes, freshman in high school.

>> How do we even know if they're going to get into college.

>> Okay. Sorry. I'm answering this on the college level [INAUDIBLE] programs. So for the high school students, we don't know. But I think for somebody ... If you have somebody with autism who has a 70 IQ, that would probably ... What we're doing with AACHIEVE may be a little different, but we still can do a lot of those skills and still help the student direct to an appropriate program for a college. But most of

these students that we're working with are people who are going to four year degree-seeking programs. So are you running a bridge program in the summer? Is that what ... Okay.

>> Yes. Yes. It's different but I was just curious just in regards to how ... because again, the parents, what they think and the student thinks is not what really happens.

>> Right.

>> So I was just curious how you navigated that system. Like, what was your ...

>> I meet with the parents usually. I do a lot of parent meetings, and I sit down with the parents and say well let's see what really is appropriate. Because the important thing and one of the first things I say to parents is ... And the woman in the back had mentioned something about modified curriculum and modified grades. There's a very specific law in higher ed that says we may not fundamentally alter the curriculum. You know, we can make basic accommodations or reasonable accommodations, but we may not fundamentally alter the curriculum. So what I say to parents is you're looking at what it takes to get into college, and that's the wrong thing. You really need to be looking at what it takes to get out of college. Because why would you go to a college that you could graduate from. So, let's see what's required. And when I sit down with families and say, okay, so you're going to have to take two math courses and two history courses and one philosophy and you're going to need three writing requirements. And when parents say, "Oh, well, he or she can't do that." Oh, okay. Then let's look at some other options. And that's what people really think they're going to be able to go into a college and modify the whole curriculum. That's not how it works. There was another question here, or can I go over here? Okay. You had a question.

>> Yes.

>> Yes.

>> I was going to ask where do we get those books, resources on the website? Or how do we get those?

>> Oh, the books? Our books are on ... I'm sorry. I'm always ... I'm really bad at the shameless self-promotion. My publisher makes me put it wherever I present, but I really ... you can get them on Amazon. If you just put my name in, the books come up. And all our books are ... Jane Thierfeld Brown. But if you go to AAPC, Autism Asperger's Publishing Company, they're all on there.

>> Oh, okay.

>> Okay.

>> Thank you.

>> You're welcome. Yes?

>> I want to make a comment for those that are in the room. I'm part of the Tamaqua High School group that work [INAUDIBLE]

>> Oh, good. I didn't recognize you from Skype. I'm sorry.

>> So I think it's important for you guys to know that when Jane is telling you she's meeting with parents and families, a lot of this is done through the computer. We meet with her monthly and she's on the

computer screen in Connecticut and we're in Tamaqua High School [INAUDIBLE] all join together [INAUDIBLE]. So she is there actively meeting with us. When she saying monthly [INAUDIBLE] part of helping us make plans for what each student [INAUDIBLE] we had like one senior, one junior, two sophomores, and we're just going to keep working with them all the way through the process right now. We're meeting with [INAUDIBLE] and Kutztown University collaborating. And I think it's important to know that [INAUDIBLE] how is she meeting with you [INAUDIBLE] Connecticut. But she's there on the computer screen and we're having interactive conversations with her about troubleshooting [INAUDIBLE]

>> And thank you so much. Thank you for bringing that up. And when I meet with the parents, I often very politely say to the team, "thanks very much. I'm just going to meet with the parent and student now."

>> Yeah.

>> And so we have that privacy for them to say, "But, Jane, you don't understand. If we take this away, this will ..." And I can hear that and say "Let me address that with them. Let me find out if that's going to come back if the student needs it. Let me find out if this is going to be problem." We can do that in a private kind of way. And as a parent and somebody from college, I can talk to people a little bit differently. And it's worked well so far because I think after a couple meetings, the parents really understand, I'm trying to make their kid successful. I'm not just trying to just get them out of high school because we follow the students all the way through and we really want them to be successful right through to employment. So thank you. Yes?

>> Do you have any advice for [INAUDIBLE] talking with parents, having these smaller conversations with them? Because we get a lot of pushback from the parents and they often then will go above our heads to our supervisors requesting different agency or a different counsellor [INAUDIBLE] their kid because they don't like what we're telling them.

>> Yeah.

>> Do you have any advice?

>> I think the most important thing is for the agency to understand the parents and for the parents to understand the agency. The reason I started all this by saying you have to understand that the parents getting this diagnosis and what it's like. You have to understand the family that says, "My kid is never going to live independently. What is that going to do to us as a family? What is that going to do to ..." you have to understand where that family is coming from. You have to understand are there siblings involved that resent the parents and the sibling with autism. And what that stress has brought the family that they're now bringing to you. I think until we can get to that point where everybody really understands each other, and the parents understand what limitations OVR has and the school has, that the school can only do so much. I think until we get to that point, and the other thing that I've been working hard on in Pennsylvania and because you're such ... I'm from a state that's like the size of a thumbnail compared to you guys. It's hard to even do it in Connecticut. But we really need more parent support in a broad way in Pennsylvania so that families of older folks on the spectrum can talk to the younger folks. I think that makes sense because there isn't a lot of support for families who can't even get out to support meetings because there's no care for their kids. And I think it's got to be more

communication and understanding between the families and then the reality of what is out there and what their son or daughter may have to deal with as an adult, and have the ability to deal with as an adult. I wish I had good answers. I think it's more people that are parents of folks on the spectrum talking to those folks on the spectrum, parents. Yes? One more.

>> Just a statement, but it really rang to me when she said she looked at these papers that I color-coded again and again. And she looked at them and she goes I know you handed these to me for years. I wasn't yet ready.

>> Exactly.

>> I'm ready to read these and I'm really to make a phone call. I really wasn't ready before.

>> And I think that's so important.

>> And I was like holy cow.

>> Yep.

>> Here you are. You're trying to do all these jobs and hats. I totally get why you weren't ready. Unfortunately the counter kept going.

>> Exactly.

>> But you weren't ready.

>> Right.

>> I respected that tremendously, and it really rang true. So I fight very hard to understand that perspective because that's [INAUDIBLE] I get it as a teacher [INAUDIBLE] time all you've done [INAUDIBLE] sometimes you're not ready to do something.

>> Exactly.

>> But you just have to handle it even though you've explained it three or five, 10 times. Each time is [INAUDIBLE].

>> Exactly. And even if you get a little bit ... I just want to make sure that the video gets that. The comment was parents can get things over and over, but if they're not ready to get the information, it's not going to sink in. And I think that's an excellent point and I think that's where it's all about the timing. And I think that's true for OVR too. It's an impossible thing to hear that your kid may never be able to work competitively. It's an impossible thing to hear that your kid is not going to be able to graduate from college for whatever reason. Or sometimes it's impossible to hear your kid needs to get ready to go to college, and they're going to have to live independently. Let's help get them ready for that. I think both things can be incredibly difficult unless you're ready to deal with it. What we need to do as a state and as educational institutions is to help folks where they are, meet them where they are, and help bring them where we as a group know they need to go. And as they're ready, not necessarily when we think they're ready. And the same with the students. Not all the students are ready at the same time. I see hundreds and hundreds of really successful students who start college at 24 or 25, and they're incredibly successful. But the angst that family has gone through from 18 to 24 or 25 is monumental. But

knowing that maybe with that development, it can help. I know we're out of time. I want to thank you for all you do for people with autism. Thank you for coming.