

Transcript: STAY Tuned ep.15- “Nothing About Us Without Us” With  
AmandaGrace Krier from Youth MOVE National

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**Emily:** Welcome back to Stay Tuned, Supporting Transition Age Youth. This podcast is brought to you by the Transitions to Adulthood Center for Research at UMass Chan Medical School, Department of Psychiatry, and in partnership with our research sponsor, the National Institute for Disability, Independent Living, and Rehabilitation Research.

I'm your co host, Emily and today we are joined by Amanda Grace. Would you like to introduce yourself?

**AG:** Sure. I'm, I apologize if you can hear the snowplow outside. It just started to come by all of a sudden. But, my name is Amanda Grace Krier. I am a certified peer specialist in Pennsylvania, working predominantly with youth and young adults.

But I am, an employee at Youth MOVE National, and I am a youth program specialist and trainer.

**Emily:** Hey, welcome. It's nice to have you. And do you go by AG mostly or do you go by Amanda Grace?

**AG:** I go by [00:01:00] both. It's whatever, you know, anybody else is comfortable with. I understand that Amanda Grace sometimes is a mouthful for people.

Especially if you're not from the South where like double names is very common. So, you know, whatever floats your boat, I go by both.

**Emily:** All right, good. Well, I think we can just jump right into it. so I know that you do a lot of self advocacy. so I was wondering, first, can you define self advocacy?

And then can you also give us some examples of how you started advocating for yourself? So maybe like in work or in school or just in general?

**AG:** Yeah, so. The textbook definition of self advocacy is learning how

to advocate for, for your needs and your wants, but I think that self advocacy goes beyond so much more than that, because in approaching self advocacy, you have to know what your needs are.

You have to be able to sit down with yourself and be really open and honest about [00:02:00] what are my needs, what are my wants, and also trying to identify avenues in order to attain those needs. and. I, I learned how to advocate for myself, at a very young age through my mom. I think that as I continued to grow, especially as, you know, I continue to grow as a young adult, I had to learn how to advocate for my needs and wants without my mom there.

and that was a little bit of a challenge. you know, just like growing up is a challenge, but in. My work in my school. and I think that my first really big thing that I did, in advocating for myself as a disabled person is that I was being treated unfairly in the workplace. Myself and multiple people who identified as disabled were being treated unfairly, our hours were being cut, and we decided to stage a walkout.

and I was 17 years old, walking out of my work because I was being [00:03:00] treated unfairly because of my disability. And that was just kind of like the, the start of, of how I began to self advocate for myself. As a young adult.

**Emily:** Wow. That's really impressive that you were able to do that. I feel like not many people, are, well, I guess not even just brave enough to do walkout, but I feel like that, that is something that takes a lot of courage and You kind of have to be like at your wits end, I'm sure, so it's terrible that you got to that point, but I hope that it was actually helpful.

And I also think that it's great that your mom was a role model for you in that. Was she always like that? Like when you're growing up, was she always serving as a role model for advocacy or was it kind of as you got older?

**AG:** I would say yes, growing up. So I was diagnosed with Attention Deficit Disorder when I was around five years old.

And when my mom was doing a lot of the research [00:04:00] about what my life would look like. She was, she read a publication in the early 2000s that said not to expect much for my future because children with learning disabilities typically don't move on to higher education and that kind of set the tone that my mom was like, I'm going to have to fight for my child because nobody else is going to fight for my child.

And so it was it, it was an uphill battle through public school it really was that I had a 504 plan. So if you don't know what that is that is a accommodations document, and my accommodations were not anything that were crazy and they were not, trying to give me advantages that other kids didn't have.

It was more so, it's a document to, to provide equity in, in the classroom. And I had things on there, like, I get extra test time, or if I forgot a [00:05:00] pencil in my locker. That, The teacher could give me a pencil and something as simple as that was something that the teachers, a lot of them were not willing to accommodate for even though they, they were required to it was a fight that they didn't understand why I just couldn't remember to bring a pencil.

And I remember my mom going into my meeting in eighth grade with a handful of pencils that year. To give out to all the teachers because seventh grade was a nightmare and they said. We'll just, we'll just give her a pencil. It's not a big deal. So it, it really, it, it wasn't until I think ninth grade that I really started to, to believe in myself because I think that there is also a stigma when it comes to, Children with learning disabilities, and I thought I was stupid.[00:06:00]

I thought that there was something wrong with me. And it wasn't until ninth grade where I got a teacher who also had a daughter with ADHD. And he provided me to take tests audibly because I knew the answers. I just couldn't formulate them onto the page. And I went from a D student to a B student immediately.

and I think that was the start in a long journey of learning self advocacy because I also had to build up that, build up that courage in myself that I was worthy of, of so much more than, than what I was being provided within public schools and the treatment that was being provided in public schools.

**Emily:** Wow. Yeah, I think it's amazing really that you were able to well that first that your mom was able to do that for you. And then as you got older, you were also able to take on that role and stand up for yourself. [00:07:00] But yeah, I mean, I, I'm sorry that your teachers weren't as accommodating when you were younger.

I think that's, I'm sure that was very frustrating and definitely not okay. but I'm glad that you found some avenues to help make that work for you. And, you know, especially with like your 504 plan. I think that's something that a lot of people don't know about or like they just don't realize that they might qualify for it.

I know for me personally, like, I also have ADHD, and I, but I wasn't actually diagnosed until, like, this year, so I wasn't diagnosed until I was an adult, but when I do, when I look back on when I was in school, I do kind of think, like, yeah, it probably would have been helpful to have some sort of accommodation, and even if it is just little things, like what you're saying, like, You know, if I did forget a pencil and someone was able to give me one and it's just not a big deal and doesn't make you feel like stupid or forgetful or anything, you know, it's just everybody.

We're all wired [00:08:00] differently. And some people just need different things, you know, so I'm glad that you were able to finally figure out what did work for you, but it sounds like it was frustrating for a while well, that kind of goes into my second question. Actually, already answered a little bit, but, well, I guess I was wondering, like, were you always good at self advocacy or was that something that.

You had to kind of practice along the way. Was there something that happened that made you realize like enough is enough and pushed you to eventually stand up for yourself?

**AG:** I don't know if I was necessarily always good at self advocacy because I also had to learn how to do it in a manner that the people who I was speaking to were going to be receptive of what I was saying to them.

That, I think as women A lot of times. When we are assertive, we are told that we are [00:09:00] abrasive. now granted I might've been abrasive. I'm also from the Philadelphia area and we are a people who are known to be quite abrasive. but I did have to learn over time that, that I, I needed to sometimes change my tone.

And that Just because one person says no, that doesn't mean the answer is always no when it comes to self advocacy because that person just might not be in the space to understand the situation. And sometimes you have to revisit that multiple times.

**Emily:** Well, I like what you just said about, like sometimes you do have to go to different people, like not everyone is going to say yes, or not everyone is going to be accommodating the first time you ask.

**AG:** I don't know if that there was a point where I thought enough was enough. I think that a lot of my journey growing up. I always thought enough was enough that I [00:10:00] never really understood why I was treated differently.

and then I guess when it comes to advocacy in my personal journey, I guess I do have enough is enough moment when, when I became an adult.

when it came to, to seeing how youth serving systems are not always. As youth serving as youth friendly as they claim to be. So I guess that as an advocate, not so much as a self advocate, but when it comes to being a youth advocate or an advocate for youth, that that was my enough is enough moment that I was able to take my lived experience and say that this is not okay, that this system is not serving us.

And that there does not have to be a repeat of my story for younger generations, that we can evolve, that we can change the system, and that, like, our [00:11:00] voices can be heard, and they deserve to be heard.

**Emily:** Yeah, so yeah, you had, you know, your own struggles throughout your life, and then you also realized that other people were struggling with this, and the help wasn't adequate, or it wasn't doing as much as they claim to be doing.

So you started then advocating for other young adults as well, it sounds like.

**AG:** Yeah, I, I have a fun pastime where I like to bully legislators, that I spent a lot of time at the Pennsylvania State Capitol where I talked to legislators, about legislation that is going to impact youth about mental health funding.

And they don't always like to talk to me, but I'm a constituent I live here in Pennsylvania that this is something that affects my life that affects my brother's life that affects the youth that I work with, as a peer specialist, and so I, I definitely don't think [00:12:00] that bullying legislators is probably the best thing but sometimes.

As a constituent, you have to, to stalk a legislator, for lack of better words, in order to, to see results, to, to have your voice heard, especially, especially as a constituent.

**Emily:** Yeah. You have to be persistent.

**AG:** Yes. Persistent. Stalker's not a good word. Persistent, that's a good word.

**Emily:** We'll rephrase it a little, you know.

Um, I think that's really important, too, that you're able to, you know, take it to a higher level and, like, within your state, you know, you're able to stand up

for people. It's not just, like, you know, not just you, not just people around you, which that's amazing, too, but I think it's, it's really important that people realize, That's that's also an option that you can go even a step higher.

**AG:** Yeah, we have some really awesome youth who are here in Pennsylvania, who are refusing to take no for an answer when it [00:13:00] comes to their mental health within schools that we have a current bill here in Pennsylvania that we're awaiting approval. But it's already. Gone, um, in committee. So it's out of committee now, and it's going to be on the, either the house or the Senate floor, but it's going to allow students to have mental health days

[Mic bleed]

And that was a bill that was coauthored by youth for youth. and that's just, you know, one of the amazing things that youth advocates are doing here in Pennsylvania, that they're really having their voice heard, and it's just really awesome to see that there are certain people in legislation that will sit down and they will.

Hear us out and they will take action like they're not just going to say things to appease the public that they're actually going to put legislation to what what their words are going to take action.

**Emily:** Well, yeah, that is amazing. I think it's really important that we have things like mental health days and And also just [00:14:00] having young adults themselves be part of these conversations, because especially if it's affecting us, you know, and like, if the outcome is going to directly impact us, I think it's really important that we also have a say in what's being written and what's being decided on, but if, you know, if people aren't Really ready to take it to that level.

if like our listeners right now are, are wondering how they can start advocating for themselves. Do you have any like tips for how someone could start if they're completely new to this? like what types of things can they even advocate for or what would that look like?

**AG:** I think that something that is very, I don't want to use the word simple, but something that anybody can do, is that.

You can advocate for for legislation. and that is just as simple as sending an email. But I think when it comes to [00:15:00] self advocacy, you can start with with your doctor's office. I think that we don't always especially as youth, we don't always get our voices heard within the doctor's office because, you know,

sometimes your parents in the room, or, you know, your doctor might, might blow you off.

I don't know what, what the statute is in other states, but I know in here in Pennsylvania, not a lot of people know that at age 14, you were allowed to make medical decisions for yourself. That you're allowed to ask for your parent to step out of the room, you're allowed to have discussions about what medication, what treatments, you're allowed to have a say legally here in Pennsylvania.

And I think that needs to expand into more states as well. But it starts with, with having a conversation, but even more so I think it might even start with having a conversation with yourself in the mirror. You have to start [00:16:00] somewhere. And I think that building up your own self confidence and, who you are as a person is a great way to start that you are worthy of change. You are worthy of a beautiful and happy life, no matter what that looks like for you. so yeah, I guess like starting, starting out very small with just cultivating who you are, and then, and then building from there. And they're also amazing, organizations like the National Alliance on Mental Illness.

they have a chapter network. There's, you can go on their website and find a NAMI in your area. And they also have support groups and, educational classes that can teach you and how to strengthen your voice and how to advocate for yourself, whether that is in the doctor's office or whether that is to the Oval Office.

**Emily:** Wow, yeah, that's really, that's good to know. I'll have to look into that and, and link those for us in the description. but yeah, I, I mean, I really liked what you just said about, you know, even just starting with having a [00:17:00] conversation with yourself. That's really important because You don't know what you need to ask for unless you know what you need to ask for.

Like you don't, if you don't know what you need, then how are you going to even begin? So I do think that's really important. and I think also talking to your doctor is a, is good advice as well, because honestly, like that wasn't something that I. would have thought of, but that is a good place. Like, you know, especially if you are 14 or older and you're in a state where that's allowed, I think even if you have stigma at home or with your parents or whatever your situation is, it is good to know that you have that option.

And you can at least just like talk to them about it and, and see what your doctor says, because I feel like a lot of people wouldn't really necessarily think of that,

especially for Mental health, you know, you think of your doctor is more physical health, but that's that's good to know. It's good advice.

I know that you work with Youth MOVE National and on your [00:18:00] website there's a phrase, nothing about us without us. I was wondering if you could talk to us about what that means and what that means for you as well.

**AG:** Nothing About Us Without Us, is a term that started within, I believe, the disability community, but I think it applies to, to all serving systems that we deserve to have a say in In whether that is our treatment, whether that is legislation that affects us, we deserve to have a say in systems that directly impact us.

and what that means specifically for, for youth and young adults, in, in advocacy is. is that for a long time, youth have been removed from the conversation that, and even more so that more recently they've been given a tokenized seat at the table that, oh, we have a youth. [00:19:00] On our board, but nothing about us without us means that we really need to have equitable say in in things that impact us whether that is having a board and actually our voices being heard on that board that we just deserve a say that we are, we should be equal partners in in systems of change and there should still be nothing about us without us.

**Emily:** Yeah, I do think that's really important. And, yeah, we just, we had a guest recently, Josh from our Young Adult Youth Advisory Board. And we were kind of talking about this too, where there are a lot of places that have things like the, the YAB and, but it is more tokenizing. And, I mean, I think, like, what, from what I've heard, I think at UMass, luckily, like, we do actually, we do a pretty good job of, you know, not making people feel tokenized, but I think it [00:20:00] can be really easy for organizations to kind of just fall into that as a default, you know, because if they're not really listening to the young adults or if they're just not really taking what they're saying into account, then You know, it's kind of useless in a way.

It's kind of just wasting everyone's time. And so I do think, you know, I'm, I'm glad that like, where I work, we actually do a good job of it, but I'm sure that there are plenty of places that could use some improvements. do you have any advice for any organizations that Aren't necessarily doing a good job of that.

Like anything that you wish that people would do better?



**AG:** I think that my advice for organizations is to, to learn or even to remember that lived experience is something that cannot be replicated, that. I think that education and certifications [00:21:00] and degrees, I think they have their own space.

but there's something about lived experience that cannot be replicated in the classroom. It holds its own weight, and I think that if we have more inclusive spaces where people who have lived experience are able to come in and and be heard, it's going to create more well rounded, um, just well rounded facilities, well rounded curriculum, it's just going to,

to it's going to Expand more on whatever it is that the goal of of the board or the organization is trying to

**Emily:** [Mic bleed]

Yeah, yeah, I completely agree. And I liked what you said to about, you know, you can have these degrees. You can have this work experience, this life experience, really. But, you know, young adults, like we bring something unique to the table and like. Our [00:22:00] perspectives are really important, and especially if, like, you're an organization that's working for, for us, for young adults, then you, you can't really know what's going on with us unless you talk to us, you know, and, like, talk to, like, a variety of young adults, and not just, like, one, one person from one group or, like, So, I think that's really important.

You know, you, you kind of need that well rounded approach and you need to like actually be authentic about your goals and make sure that the young adults that you're talking to are actually. Like their, their voices are being heard

**AG:** and it needs to be an ongoing effort because as times change.

So, sort of the demographics that somebody who is 35, I'm even 25, and I don't have the same lived experience as somebody who is 15 years old, especially after the after post pandemic that we need to be continuously trying to attain [00:23:00] more and more lived experience as as the times change in order to really get a clear picture as to what the current lived experience is for for the younger generations and youth voice.

**Emily:** Yeah, 100%. And it's always gonna change and it's always gonna, you know, be different from generation to generation and, but that's, that's a good thing, you know, it's like, that's just how, well, that's just how life works. And

also, like, it's good to have those different perspectives and keep learning and growing.

Like, because we can learn and grow from people who are older than us, but it's, it goes both ways, you know, they can also pay attention to what's going on with us and make us feel heard and help us out if they have the power to do so.

**AG:** Exactly.

**Emily:** Okay. So anything we didn't cover that you wanted to make sure we talked about today?

**AG:** There is no right or wrong way to do self advocacy. [00:24:00] That self advocacy is all about. Getting your needs met and your needs might not be the same as my needs, but it doesn't mean that you're yours are any less valid.

So self advocacy looks different for everybody. And no matter what that looks like for you, it's valid.

**Emily:** I like that. I think it's also good to note that it's not selfish to advocate for yourself, especially if like, say you have ADHD or, you know, whatever it is like. We're not all the same and we're not all set up on the same playing field or whatever it may be, like with work, with school, just with daily life, everybody needs something different and I think it's, it's fine if you know what that is and you go after it and I think it's, it's actually really important that you do so.

Well, thank you so much for talking to us today.

**AG:** Thank you.

**Emily:** If you would like to contact us, you [00:25:00] can email us at StayTuned@umassmed.edu. And check out the Transitions ACR website at <https://www.umassmed.edu/TransitionsACR/> thanks for being here and be sure to stay tuned for next time.