

*Contents*

Opening.....	1
Health is fragile 03:13 .....	2
High school to college with disabilities 04:36 .....	2
Psychiatric support. A challenge. 13:46 .....	4
Parents included 15:54 .....	4
Next hurdle – successful employment 20:14 .....	5
A sedentary life 22:51 .....	6
Look for needed supports until found 24:55 .....	6
Breakthroughs 27:17 .....	7
Creating opportunities 29:15 .....	7
Closing 31:50 .....	8

*Opening*

There were times when you see such a breakthrough for them, such an incredible breakthrough. It's simple things, but they matter because what happens to these kids growing up is they grow up realizing how different they are from other kids, they don't realize that there's much more about them that's like other people than but they only see their differences. They grow up feeling very... They have no self-esteem, no self-confidence whatsoever. And so any little thing you can do like just getting them out of their parents' house and a few successes under their belt is huge for them because they think they're going to spend their lives in their bedrooms and their parents' house. And then that's where they're going to live. That's not what their parents want for them, of course. Opportunities for them to go to college. For them to get out of their parents' house. To work a job even if it isn't the job the ideal job for them. Any success at all in the least little thing tells them 'I did that I can do it. I can do it.'

Today, we talk with Mary Lawler, a teacher and a trailblazer in support of young adults on the autism spectrum transitioning into college. As a Special Education teacher, Mary found that entry to a path to college and success in college wasn't open for young adults on the autism spectrum. She opened that door, first in high school and then in college, developing a program that created an opportunity for personal breakthroughs. In the patient/caregiver activist world, we often talk about 'patients included.' Mary is an expert in 'parents included.' Mary's leadership and compassion inspire me.

**Health Hats:** Mary, thanks for joining me.

**Mary:** You're welcome. Thanks for having me.

**Health Hats:** I'm sitting here with Mary Lawler. How long have we known each other, Mary? You were one of my wife's first friends and one of her oldest friends. And I've known Ann for 46 years. You probably knew her ten years before that.

**Mary:** We met when we were 14.

Health is fragile 03:13

**Health Hats:** So, a while. Do you remember where you were when you first realized that health was fragile?

**Mary:** Yes. I was 14 years old. My father was 42. My mother was in the hospital, having a skin graft on her ankle, and my father had a heart attack. I spent that summer taking care of my five younger siblings. So, I worried about my dad for the rest of my life. I worried about him dying suddenly. So, yeah, health is fragile. I learned it early.

High school to college with disabilities 04:36

**Health Hats:** I'm doing a series on young adults with complex medical conditions who are transitioning from pediatric to adult medicine. In this series, I've interviewed people who are young-young adults, and mid-young adults, and adults, and some of their parents. Then sometimes together. And a clinician who works with young adults. I was interested in talking to you because of the work you've done with young people on the autism spectrum who are going to college. I remember you telling me about your work with this group of people. Can you tell me about the work you've done?

**Mary:** I started in school districts overseeing programming for children with disabilities - special education programming. About ten years into that career, New York State changed its requirements for graduation and began to require that all students, even those with disabilities, take and pass five Regents exams to graduate from high school, except for the most seriously disabled children. Everybody thought that most children with disabilities could not meet that standard. Now they did have a safety net for them so they could, for the first five years of this requirement, they could take a less demanding exam. If they got at least an 85 on it, they could earn a Regents diploma. That helped. But over the next five years, we worked and succeeded in getting most kids through a Regents level curriculum and Regents level exams to graduate.

**Health Hats:** What kind of disabilities are we talking about here?

**Mary:** Well, these are children with reading disabilities, dyslexia, and other reading disabilities, DeGraff dysgraphia. They can't write. They have thoughts in their heads, but they can't get them on paper well. More general learning disabilities where they don't do well academically even though they're intelligent. Attention deficit disorders, emotional disturbance problems, Asperger's Syndrome. All of those invisible disabilities that people like to think are hokey, but they're not. They're very real to the people who have

them and the people trying to teach them. We increased the number of students earning Regents diplomas being forced by New York State to do that. Then, as my career responsibilities changed and I became the director of special education, and I had to complete the data collection process for the State of New York, I realized that even though these children were getting Regents diplomas, they were not going to college. The guidance counselors, the school counselors, were not encouraging them to go to college. People didn't believe that they could go to college and be successful. So then we figured out that they could be successful in college if they had the kinds of supports they had in high school. But college is generally don't provide that level of support. They'll give some test accommodations extended time, separate location. But not one-on-one tutoring, interceding for the students with professors, which is a huge piece of support. So what happened was this man approached the school district I was working for and talked about wanting to start a college program for these students as they attended college. And we identified a small private college in Buffalo, New York, who was very interested and avid to work with us to provide support. We were going to provide all the support for them. They would provide the primary instruction. And so that was the first program that I worked in.

**Health Hats:** This was after you left the school district.

**Mary:** I left the school district to do it. Because I and all of the special ed teachers at the high school level knew that these kids could do more. They were smart kids ending up working in grocery stores. They weren't pursuing post-secondary education. So we started a support program for them, and it can be very effective. Some of their needs are very complex, and they're a little more difficult. But many of them were able to take pass college-level courses with the kind of support we were providing. Several of them out of the first group of 18 kids ended up earning a college degree - a bachelor's degree in everything from business to English literature to accounting. So the support we provided was 1) individual tutoring if they needed it. 2) And this was so big what came to be called executive functioning support, organizational skills support, time management support. Soft things like perseverance despite the anxiety, despite a failure. To be able to bounce back to be able to say, 'okay I'm not going to quit just because I had one failure. I'm going to keep going.' The ability to sit in a classroom and listen and know you're not catching it all and not panicking and running out or quitting. So these are soft skills that they need for all of life. But so many people learn it in college, high school and college. These are the skills you learn that people don't realize you're learning. Nobody teaches it to you, but you learn. So we taught it very explicitly to these students. There was a guy, Danny. I don't remember his name, but I could get it for you once I get home. He did amazing work in this area, identifying these skills. And then we were able to teach them these skills. And they're crucial. And so we did that executive functioning support, social skill development, social thinking. Teaching them how to think socially in ways that they don't come naturally to them. Basic life skills. They are learning to go to bed on time. Get up in the morning. Get to class on time. Set alarms, so you don't get distracted in the library and forget to go to your afternoon class. Just time management is so big for them.

Psychiatric support. A challenge. 13:46

**Health Hats:** What was their interaction with the medical system?

**Mary:** Well, the biggest interaction with the medical system, by far, was that many of them were on psychotropic drugs? [Psychotropics: Any drug capable of affecting the mind, emotions, and behavior]. These are all controlled substances, so we had to transfer them from their treating physician that was now out of town and get them Buffalo-based physicians, psychiatrists, etc. to monitor and prescribe these drugs.

**Health Hats:** How'd that go?

**Mary:** It was hard to find good psychiatric treatment. Buffalo is not a small city but not a huge city. The number of psychiatrists is limited and what I mean by a good psychiatrist is not one who knows his or her stuff, but one who understands these students and that's a subcategory of Psychiatry.

**Health Hats:** So did you end up identifying well, here's one, two, three that did get it and then work with them? Send your students to them?

**Mary:** Yeah, And the thing is that psychotropic drugs have some fairly serious side effects. Often it makes students sleepy. So you deal with not wanting to get up in the morning a lot. It's a big problem for them. It can flatten their affect, and they already struggle with social things. And so they don't come across to people as particularly personable or social.

**Health Hats:** So finding the right balance, right?

Parents included 15:54

How about your interaction with the parents? Can you tell me a little bit about that?

**Mary:** Yeah, the program that I ran was very expensive. Plus there was college tuition and room and board and all of that added on to it. The parents of these students, for the most part, not always but for the most part, were very very committed to their children and maximizing their well-being and getting them a good education. They were willing and able to invest in it. And so the parents were very supportive by and large. Always some problem parents. Many parents have worked hard throughout their child's life, trying to get them to fit into the education system. And often the healthcare systems that they dealt with. In our program, we stayed in very close touch with parents. We talked to them two or three times a week. We made sure, first of all, unlike so many things in college; they don't contact parents. They don't think parents should be involved anymore. They tell parents, 'leave them alone. Let them do what they're going to do.' But that doesn't work for our students. And so I found parents who I knew had fought hard with school districts. They were often the biggest headaches of school districts. I knew who those parents were, but they know their child better than anybody and they were a great source of strategies and ways of helping their kid be successful. So we would definitely access that as a

resource. And then we would keep them informed about little successes because a student can do something today, like pass the test and that's a victory. Passing a test is a victory for one of these students. So we would let parents know. Hey, he got a B on this test, or he got to class on time every day this week. The parents had this constant sense of 'it's working'. It gave them a lot of hope and optimism for their son or daughter. Some parents, because they've had to do so much throughout their child's life, they have trouble letting go. We started saying the things the colleges were saying, 'don't talk to your student independently and tell them what to do.' Or if they call you five times a day tell them, 'no, don't call me five times a day. Call me three times a week.' Otherwise, go to Mary or go to Vicki or go to Kristen so that they were accessing us as their support rather than their mom or dad. And that helped them become more independent because these kids, young adults, struggle so much with anxiety. Anxiety is by far their worst enemy. And they can be on medications for anxiety and still struggle with severe anxiety, especially when they feel overwhelmed or they don't know what to do in a situation or somebody approaches them, wants something from them, and they don't know how to respond. It just sets them into a tailspin.

Next hurdle – successful employment 20:14

**Health Hats:** So you did this for ten years?

**Mary:** I did it for eight years.

**Health Hats:** How long ago was it?

**Mary:** I stopped about four years ago.

**Health Hats:** In the last year have you heard from or heard of former students? And so tell me a little bit about that. So what's happened in that period since you saw them last in their lives?

**Mary:** The next hurdle is successful employment in their field of Interest. For instance, Jacob got a degree in accounting. He had close to a 4.0. If not 4.0, I would say a 3.8-grade point average, graduated with honors from a good college, but cannot find a job in the field. And that's because his other issues make it difficult for an employer to find enough value in him. He knows the counting inside and out. But he's distractible. He panics. He blurts things out that people know you shouldn't say at work.

**Health Hats:** So are the challenges pretty much behavioral or are they also a precarious medical condition or other?

**Mary:** It depends on the person? Some have comorbid serious health problems. Well, I guess anxiety is a medical condition. So that's a big one. One of our students had diabetes. One of our students had serious allergies. We always had to watch him.

**Health Hats:** Sounds like there was a lot of coordination in this.

**Mary:** Huge amounts of coordination.

A sedentary life 22:51

**Health Hats:** On the one hand you were providing, I'm not saying primary care, but you were the primary supporters. But then there were also things that were beyond your skill that were part of success?

**Mary:** Yes. The other thing about these young people that affects their health status is they are extremely sedentary. They spend hours and hours and hours behind computers. So that is where they are the most comfortable. That is where they can be themselves. They have friends all over the world that they play video games with and the relationships that they can't have in person, but they're good at the game. And so these people other people like to play with them. So that's a problem. They don't eat healthy food. We tried. We had a wellness piece to our support program where we took them out hiking, and you know, took them places where they exercised, and we taught them how to eat well, but it wasn't their food of choice. So they eat very poorly. A lot of them are overweight, considerably overweight. So although when they're young, those habits haven't profoundly affected their health yet if they don't change...

**Health Hats:** And psychotropics don't help either. Yeah, that makes it all so much more challenging.

See the show notes or my website [www.health-hats.com](http://www.health-hats.com) for more information, to subscribe or contribute. If you like it, share it. Thanks.

Look for needed supports until found 24:55

**Health Hats:** If you were going to advise parents or either high school or college programs now, what's at the top of mind in terms of pearls of wisdom that you've gotten from all these years that you would say after all this time?

**Mary:** Well, you have to have the supports that that individual needs. They don't all need all of it. But they need what they need and to look for it until you find it. The good news is...

**Health Hats:** Look for which support?

**Mary:** Yes. Look for a situation, a college, or an independent program that supports these students in college that is going to work for your son or daughter. Some of them need way more support than others. Some need medium support, and some need more support. More and more colleges across the country are starting their own program. They probably don't provide the kind of support that we provided. We were like for the most, the students who needed the very most support. Our program was designed for them. And then there's in between things.

**Health Hats:** So customization?

**Mary:** Believe that they can do it. There's no way they're going through college in four quick years. It's going to take six years. Very few of them can handle a full-time course load. Start with two courses, three if they do that, well. Make sure they're connected with a good counselor that will work closely with them. Connected to someone who can monitor their medication: a medical person, a psychiatrist, or a nurse practitioner or someone who can get to know them well and that they'll confide in about how they're feeling about things.

[Breakthroughs 27:17](#)

There were times when you see such a breakthrough for them, such an incredible breakthrough. It's simple things, but they matter because what happens to these kids growing up is they grow up realizing how different they are from other kids, they don't realize that there's much more about them that's like other people than but they only see their differences. They grow up feeling very... They have no self-esteem, no self-confidence whatsoever. And so any little thing you can do like just getting them out of their parents' house and a few successes under their belt is huge for them because they think they're going to spend their lives in their bedrooms and their parents' house. And then that's where they're going to live. That's not what their parents want for them, of course. Opportunities for them to go to college. For them to get out of their parents' house. To work a job even if it isn't the job the ideal job for them. Any success at all in the least little thing tells them 'I did that I can do it. I can do it.'

**Health Hats:** So. not only are you saying that they have a success, but they know they have a success. So it's the two together.

**Mary:** Something as big as earning a college degree. I mean in and of itself it is such a tremendous accomplishment for them if they work in a grocery store afterward, not the ideal, but what an accomplishment for someone like this.

[Creating opportunities 29:15](#)

And of course more and more I'm hearing, and I see people starting companies for these people which is a great idea. I know a guy, a Dad who started a program of like computer graphic design or something in a lot of these kids do computers really well. And he started this whole graphic design company just for people on the autism spectrum. Wow, and so there are more and more of that kind of thing happening, which is encouraging. When I was still working in the program, a woman who had a big big job on Wall Street worked for like a big financial institution. I don't remember the name of which one doesn't matter. She was very successful. She had a son with Asperger's syndrome and when he approached college age and all of that she quit her job and she started a not-for-profit to help these kids get internships on Wall Street. I got one of our students in the program. I was an offer from a company on Wall Street, but he said they called him instead of us and he said 'well, no, I'm not all that interested'. It blew his opportunity. But more and more, I see little things happening along those lines, and that is

huge. More and more colleges are starting programs. I know the college we worked with, they've started their own. They learned from us how to do it and started their own program, and they can do it less expensively. It's not quite what we did. We had the staff who would go to student apartments and wake kids up in the morning. Colleges aren't going to do that.

**Health Hats:** You're a trailblazer.

**Mary:** In a way, yeah. I didn't do it myself. I mean you had to take a team. Sure takes a really big good team to do.

**Health Hats:** Well, thank you. This is great. Thank you so much. I appreciate you taking the time.

**Mary:** No problem. I enjoyed it.

Closing 31:50

Best health, living at maximum capacity given your genetics, social circumstances, and physical environment, requires a team. We think of health teams often as people (patients), caregivers and parents, and medical professionals. We can forget about the people on our team in the community: leaders like Mary Lawler, creating opportunities for best health. Thank you, Mary.