Hidden Voices Episode 4 - High School Transition & IPSE

Shannon M. Turner 0:09

Welcome to Hidden Voices where we are uncovering the stories of Georgia’'s residents with developmental disabilities. I'm your host Shannon M. Turner.

Shannon M. Turner 0:32

Today we're talking about the high school transition. Hey, Les, can you play your graduation song for us?

Les Lebron McBride 0:39

May 24s gonna be my day. My day to graduate. I never gonna stop. I never gonna stop. I never gonna stop. I gotta keep working. I gotta get this money.. I can't give up on life. Life is too short to give up. Never gonna stop and get this money. Take care of my family.

Shannon M. Turner 1:09

When you think about all the tropes that come with high school graduation, senior prom, the cap and gown, crossing the stage to receive a diploma, throwing your cap up in the air with the rest of the graduating class, going to parties with friends, talking about what's next. It tends to be filled with so much hope, accomplishment, and promise. But graduating from high school is not always an excitement filled turning toward the next chapter in every case. For one population in particular, it can be the most anxiety producing, even potentially dangerous period of time in their lives. I'm talking about people with developmental disabilities.

Shannon M. Turner 1:56

I can't stress this enough to you folks. This is literally one of the most precarious times in the life of a person with developmental disabilities, because reaching the end of high school means the end of regularly provided supports from the education system. The pressure turns up for families who have to figure out the complex system of waivers and waitlists and to piece together supports within the larger governmental system, mostly without the needed outreach and education from that system itself. Families are catapulted into this new world of disjointed and changing processes and obscene amounts of paperwork to be placed on nebulous lists for an undetermined amount of years.

Shannon M. Turner 2:41

In other episodes, we've talked about how factors like race, socio-economic class, and where you live in the state can impact your outcomes within the education system. But after graduating high school our current societal values say that a person with a developmental disability is evaluated by factors such as how significant their disability is, how they communicate, and how educated, persistent, and resourced those around the person are to push the right levers within the system to secure a waiver. These are factors that make the difference at this stage of whether a person is integrated into post-secondary education, a job, or society at all. And this stage can potentially set the path for all that comes after in a person's life.

Shannon M. Turner 3:40

So many variables have come to play until this point as to whether you were set up for success. There's the importance of early childhood intervention programs. There's the question of whether your family had good supports along the way. And then comes the real doozy because it lasts 13 to 17 years of a person's life: how good was the education system which you grew up in? All school systems are not created equal. What seems to be fairly standard is this: there's often the choice between being in a self-contained classroom for most of the day with a few elective courses out and about with neuro-typical kids, or students could possibly be mainstreamed into general classrooms all day long. And, as we'll talk about later, some people graduate at 18 but most school systems have the option for students in special education programs to stay on until 22 receiving additional life skills, community integration and job readiness training. Some parents choose to keep their students in for the extra years because they feel their student really needs additional time and training to move into adulthood. To be honest, though, often that four years just buys them extra time to figure out how they're going to support their loved one. This is when a lot of people start applying for the Medicaid waiver for the first time and sometimes they wish they'd started a lot earlier.

Shannon M. Turner 5:03

When people with DD graduate from high school at whatever age, they reach the end of their publicly mandated supports, they come to this fork in the road. And most likely the options consist of going to a day program, getting a job, or continuing on in a post-secondary education program. Other more ominous situations might be a person being on what is known as the school to couch pipeline if no resources or programs are available. And worse yet, would be if a family doesn't even have the resources to support them at all at home, and they are sent to live in a nursing home. We'll look at that last possibility as a stark reality in our next episode about housing and transportation. Today, though, we're going to look at three very different scenarios of people who are all roughly the same age. They're all not far out of high school, so we'll be able to see just a few of the different possibilities of where you might go when you come to that fork in the road.

Shannon M. Turner 6:11

Mateo Hasani is 21 years old and lives in Lawrenceville, Georgia. When we met Mateo, he literally just graduated from high school like three weeks before, and his family was struggling with figuring out what comes next in his life. High School was a good time in Mateo's life, and it's been a big change to leave school and move into the unknown. Ada reads a letter that Mateo’s teacher read at his graduation.

Ada Hasani 6:37

If there were a dictionary definition.com for Mateo, it might say something like a charismatic young man who is prepared for life and ready to be done with school. Mateo, we are also excited for you as you finish up the last few days of your educational career, a career that has lasted almost 20 years. You are so fortunate to have you, your devoted and hard working parents advocating and pushing for what you need, right along with you. I hope you always keep your charisma, your fun-loving attitude, and your awesome smile that is contagious. This world, this school and myself are all better for having known you. Mateo, you will always remain in our hearts.

Shannon M. Turner 7:30

Mateo has cerebral palsy, epilepsy, and significant intellectual disability. He lives with his mom, dad, and brother and his family loves him deeply. Here's his mom, Ada, describing Mateo.

Ada Hasani 7:44

He is a very quiet, very happy boy. He's a happy boy, he always smiles and you know, always happy. He never cries. Very gentle, very soft.

Shannon M. Turner 7:59

Mateo's family emigrated from Albania 17 years ago, working hard to bring their whole family to America in hopes of a better life for Mateo.

Ada Hasani 8:08

If we would have been in Albania and we would have lived there, Mateo would never have gone to school. They don't have that special classes or special program for kids with disabilities. They don't have it. I would have never worked, I would have stayed home, taken care of Mateo. So yeah, looking back on 17 years, we are better here.

Shannon M. Turner 8:28

Mateo's mom and dad work opposite shifts for Publix so they can switch off on his care, but pretty soon Mateo will start attending a day program which is one option on the menu of choices for people with DD as they graduate. Day programs are one place where people with a developmental disability spend a lot of time in adulthood. Like anything else, these programs vary widely in terms of their mission and quality. It's important to point out though that day programs are segregated group care. This means that as a society, we are segregating a group of people and defining their level of integration with wider society based on arbitrary characteristics. The possibility exists to fully include people with developmental disabilities into society, instead of transporting people with disabilities to separate programs during the day away from everyone else. Parents shouldn't have to consider choices between a day program that sits their loved one in front of a TV all day and a day program that has field trips. The person with a disability should have the support they need to make decisions about their own life, and the direction they want to take.

Shannon M. Turner 9:38

Better questions we can focus on during this transitional time might be: how can we best support communication and set up the processes and equipment to make communication a reality with others? Would they like to work with metal fabrication? Or would they like to start a B2B software business? And what are the steps to make these dreams happen? For our current reality, however, Mateo's family is navigating the existing system of day programs. Ada is researching carefully the only available option for Mateo of being at a day program. Since at this time Mateo hasn't had the support he needs to be able to communicate with others, the priority is for quality caregivers who will keep Mateo's best interests at heart.

Ada Hasani 10:22

When I was there at the graduation that day, I had tears in my eyes you know, I said to myself, you know I'm here. There were days in our life when we thought we were going to lose him, you know, so being able to get through what we have gone through and have him with us. It's a lot, so I said, “At least we're here, you know, he made it, and here we are.” But then again, it's another chapter which is like, Okay what is going to happen now, this is the most scariest one.

Ada Hasani 10:57

We're trying to get him in a day program and I just went to the place to sign papers and it's just one problem after another sometimes it just never gets any easier. But only because he cannot do anything for himself doesn't mean that he is supposed to be stuck at home and never go anywhere. You know, I work right now, but if this program is not going to work for Mateo, I can't work either. How am I going to support my family? It's hard. I mean any place he can be comfortable, you know, and being around people we can trust, because we have to trust these people first right? We just want him to be comfortable.

Shannon M. Turner 11:41

One thing that's been holding up the process is that Mateo does not yet have a Medicaid waiver, which would allow his family to have so much more in-home support and access to the day program. With this funding, his parents might no longer be like two ships passing in the night all the time, as they switch off shifts of work and caring for Mateo.

Ada Hasani 12:03

As I said, you know, finding a place for him like NOW/COMP waiver has a lot to do with it. You know like they're the one who has to approve. It's just hard to get all the information or find a way, we did find a place which was $5,000 a month, of course we can't afford that. If he gets NOW/COMP waiver maybe things will change. See all these years, you know like year after year we learn something. Some parents don’t even know the NOW/COMP waiver exists, Mateo has been on the list for all these years. If you have another family you know, then they don't know, you can tell them. That's how I feel, you know like more information you have is just you pass it on to somebody else. And I learned to, now see even NOW/COMP waiver, we're waiting and you know, we want to get it. I don't even know how that works.

Shannon M. Turner 12:57

Wishing them luck on their Medicaid waiver application, and also with hopes that the day program is the right place for Mateo. We move now to one of the most exciting options for a lot of people as they graduate high school, and that is college.

Shannon M. Turner 13:21

Remember last episode how we talked about this unique network of parent mentors and school districts across the state? Well, here we are again, with the opportunity to tell you that Georgia is leading the nation. This time, it's by providing inclusive post-secondary education programs, IPSE for short, in about 10 schools across the state. These programs tend to have some focal points depending on the school where they're housed. For instance, the program at Kennesaw State has some emphasis on culinary arts, whereas Destination Dogs at UGA has a bit of communications focus. At the top of our episode, we heard an original song from Les McBride, who is a student in Georgia State's IDEAL Program. GSU, in case you don't know, is located squarely in the middle of downtown Atlanta. Its buildings are woven between Atlanta's sprawling governmental and business district. The IDEAL program, IDEAL stands for inclusive digital expression and literacy is a part of the Center for Leadership and Disability. Most IDEAL students are interested in some kind of new media. On the day, we went to visit the IDEAL program, we got to sit in on a meditation course the cohort was taking together

Fam Squad Member 14:37

Everything in life comes at you, and it's gonna keep coming at you. You know other waves that the way that the ocean has waves and life has waves too, and De'onte talked about that a little bit. And those waves are gonna quit coming at you, but you can learn how to get on top of ways and learn how to be calm with those waves come at you and that’s what mindfulness is supposed to help you do.

Shannon M. Turner 15:09

This is a great example of the kind of ongoing non-academic training students have the opportunity to experience while attending IPSE programs. They share a core curriculum that involves topics and cultural competence like, workplace expectations, and dating, and friendships. From there students have other classes that help them with their academic area of focus. When we met with the IDEAL students, ostensibly, the interview is with Les who is studying music production, Mandel Montilius, a future game designer, and De'onte Brown, aspiring horror filmmaker. However, since all the students in IDEAL are studying different media productions, we turned a lot of the podcast production duties over to them that day, sharing responsibilities for interviewing, recording, taking pictures, etc. We even had an artist who provided some graphic transcription on the side. All in all, we had nine students producing different parts of the interview. Also, there's a robot in their building so it was pretty much the most fun day ever. Les, Mandel, and De'onte are all around 22-23 years old, have mild intellectual disability, are from different parts of Metro Atlanta, and they're all nearing graduation from their program. Les and De'onte talk about first coming into the IDEAL program.

Les Lebron McBride 16:35

It was amazing. I never had that through middle school high school, but it was a good supportive program.

De'onte Brown 16:45

It felt great and I was excited to start college because I didn't know that they had a program like this for us.

Shannon M. Turner 17:10

In IDEAL, they've each pursued a different field of study, and they talked to us about what they've been up to.

De'onte Brown 17:16

Well, I came here to study film, because of two students that was here in the program, and they were peer mentors. And their names are Phil and Jade and they are film students, and they are the reason why I'm doing film and why I love it so much.

Les Lebron McBride 17:47

I grew up listening to rap. I really like music. And so, I do music on my own, and just do like, go around the world one day. Help artists do shows behind the stage. And just have a good decent, you know living life.

Shannon M. Turner 18:07

Across the state, along with the core curriculum and some of the standards that all IPSE programs share. They also have another common component, peer mentors. These are paid positions about 10 hours per week for neuro-typical students who might be in a similar academic department or just have a personal interest in full inclusion. They work alongside IPSE students providing tutoring, classroom support, and socialization. De'onte and Mandel tell us about their peer mentors.

De'onte Brown 18:37

Well the peer mentors, they are here to help us with what we need with school work, or to get a job, or to go to a game that we want to go to. Ben, I had a screenwriting class and so he would go in the classroom with me, and he would sit next to me and he would help me with my classwork. He would help me with my homework.

Mandel Montilius 19:28

Karen helped me with an art class. I just, to get like a good grade and everything in class. Just try to be concentrated and focused.

Shannon M. Turner 19:43

IPSE programs last for two years and graduation gives you a certificate, often qualifying you to work in your trade. This is really crucial to understand because most IPSE grads don't need a Medicaid waiver. They are able to work on their own and lead fully integrated lives without supports. The reason why I'm spelling that out for you though, is IPSE itself is a program that needs funding. In fact, most IPSE students have to pay full tuition and only emerge with that certificate - not a diploma at graduation. There are a few scholarships available for them. The need for IPSE is also a need for public systems priorities. There are a couple of other options that might look similar to IPSE such as Goodwill or Warm Springs, but these programs again segregate people with developmental disabilities away from the general population. So, this is another place to get involved in advocacy. Tell your legislators to move funding priorities toward IPSE programs, or advocate to the Department of Education to make dual enrollment for students with developmental disabilities possible. These changes will pay off in dividends for countless graduates in the future, but don't take our word for it.

De'onte Brown 21:00

It’s a good program to support. It helped me and it can help anybody else. I think they need more programs like these in every college.

Shannon M. Turner 21:19

From downtown Atlanta we head due west to Peachtree City. Actually, we're going just outside of Peachtree City to the suburb of a suburb called Sharpsburg. Katy Ann Killingsworth is a 19-year-old woman with down syndrome. She's the youngest person in our group because she graduated at 18. Katy Ann and her sister really enjoyed being homeschooled. Her family had been planning for a long time for what came after graduation. Katy Ann was on track to go to an IPSE program just like the Fam Squad called Project Wolves. A brand-new program at the University of West Georgia just an hour away from her home. When I say, they've been planning for this moment for a long time, I mean like they'd been driving out, meeting with the program’s administrators, helping them get this brand-new program set up. As a part of this inaugural class, Katy Ann's picture was on the recruitment brochure to bring in other students for the future.

Katy Ann Killingsworth 22:17

Oh, I love the college, I love the classes, I love my friends. I have great memories if I go to something with my mentors.

Shannon M. Turner 22:26

So, there she was experiencing her first year just like she and her family had planned for. She was enjoying being in college classes with her peers after all those years of homeschooling. The days were full, her mom Juanita would drive her out a few days a week, sit and wait while Katy Ann took classes and then drive her home. All this work, she and her family were putting in for her education and then Katy Ann's program didn't work out for her. The backstory about what happened is kind of complicated, but at the end of the day, after that planning, after just one semester, there was this new fork in the road. Some people will tell you that planning will save you from every possible disaster, but sometimes there are things that you just can't plan for. However, this does give us the opportunity to talk about yet another option for many people after they graduate, which is to enter the workforce. Katy Ann already had a job at Chick-Fil-A, she loved it. In fact, when she had her mom would go through the drive thru every week on the way to speech therapy appointments, she told the manager through the window that she wanted to come work for him one day, and she did.

Juanita Killingsworth 23:43

And what did you tell Mr. Allen, like when you're like 13 or so?

Katy Ann Killingsworth 23:47

I went and asked him to get a job.

Juanita Killingsworth 23:49

Yeah, even when you were 13 you asked him for a job. So then when you turned 18...

Katy Ann Killingsworth 23:55

I told him, I have school, I asked him, tell him I want a job.

Shannon M. Turner 24:02

But Katy Ann doesn't want to just work for Chick-Fil-A. She has other dreams too. The academic reason for attending project wolves was that she wanted to become qualified to work in early childhood education. Guess what? She's already gotten the job of her dreams at her church's daycare center, Juanita explains:

Juanita Killingsworth 24:23

Her goal was to work at our preschool at church when she finished and she's doing that. We're already where she wanted to be, and she would have maybe been more prepared. The spring semester she would have actually interned at the daycare on campus. The plan was that every semester she would have done a little bit more either more time each day, more days, you know, so she would have been more prepared and more ready, you know, but they're teaching her that there.

Shannon M. Turner 24:57

One of the big challenges for Katy Ann with work is transportation, mom, Juanita, is her only mode of transportation, and this is in part due to Katy Ann still being on the waitlist for Medicaid waiver.

Juanita Killingsworth 25:10

Here, we don't have that opportunity to do that. In fact, some of our parents, we've been kind of chatting back and forth about creating something, I mean, we do have a county transportation that focuses mainly on our seniors, but you can't, it's difficult to try and be at a place at a specific time, or she may be on that van for a couple hours to get Chick-Fil-A, you know, just down the road. So, we just don't have the opportunities here to make that happen. So many things are like this well-kept secret and unless another parent tells you about it, a lot of times you don't know, if you don't have support from other parents, your child is not going to be nearly as successful, I don't think.

Juanita Killingsworth 26:01

Katy Ann lives a full rich life. She's maybe not as independent as she liked to be one day but she's working on it. So, thank goodness when the path she planned for ended. It didn't mean she fell off a cliff.

Shannon M. Turner 26:25

You know that song they play at high school graduation? It's called pomp and circumstance. It wasn't originally intended to be about school or graduation at all, but rather about war. The title comes from Shakespeare's Othello, a line that talks about the pride, pomp, and circumstance of glorious war. Hopefully, when you graduate high school, it doesn't feel like you're gearing up to do battle just to find the right place for yourself in the world. It does seem though that circumstance has a whole lot to do with where you might end up.

Shannon M. Turner 27:07

You've been listening to Hidden Voices. Tune in next time as we explore housing and transportation. Another key factor that can make or break the life of a person with a developmental disability. We'll explore transportation access, and a variety of housing scenarios for living your best life. Or maybe not.

Shannon M. Turner 27:32

Hidden Voices is sponsored by the Georgia Council on Developmental Disabilities. This podcast is part of a series of stories called the Storytelling Project, a collaboration between L'Arche Atlanta and GCDD. You can find out more about GCDD’s advocacy at gcdd.org. And about L'Arche Atlanta's community of people with and without disabilities at larcheatlanta.org that's L-A-R-C-H-E atlanta.org. Other strategic partners are Resurgence Impact Consulting and Story Muse, made in partnership with FRQNCY Media. I'm your host Shannon M. Turner. Irene Turner is our Executive Producer, Enna Garkusha is our Producer, DonTae Hodge and Cooper Skinner are our Sound Engineers. We are recording at Listen Up Audio in Atlanta, Georgia.