Raisa Habersham 0:01

It sounds like you have to basically beg people just to help you.

Nick Papadapoulos 0:08

Yeah.

Raisa Habersham 0:09

I mean, how does that make you feel?

Nick Papadapoulos 0:11

Makes me feel terrible, like ruins my day. Like I have to pull out my hair just to get the lunch menu in this place.

Raisa Habersham 0:25

Welcome to Hidden Voices, I'm your host Raisa Habersham. Join me on my journey to learn more about the experiences of Georgia residents with developmental disabilities guided along the way by my co-host and mentor, Derona King.

I remember the first time I went inside a nursing home. I was 11 and my grandmother had just moved into one after being diagnosed with cancer. It definitely didn’t feel inviting. I hated everything about the place: The fluorescent lights gave the “home” a pale look. The building exterior wasn’t inviting; the food didn’t look appetizing and I wondered if my grandmother -- a woman who cooked every day of the week -- even liked it. The entire place did not feel friendly to me. There wasn’t a trace of hope in that facility. It seemed like a place where people were sent to slowly die. It felt like a last resort for people who couldn’t afford 24/7 home care for a loved one, like my family. The entire place made me depressed and I became deeply worried about the conditions my grandmother was living in. She would eventually die there. I think a lot about what dignity, if any, she had in her final moments. There is an expectation around nursing homes, one so familiar that it’s often written into television and movies: nursing homes are the places where old people are dropped off and forgotten. So, when Derona told me younger people were also in nursing homes, I was surprised. I couldn’t think of a reason why a person my age or younger would need to be in a nursing home.

Derona King 2:25

In the state of Georgia are several organizations back I believe in 2005, or six, that developed something called the children's freedom initiative. In 2005, we still had mental health institutions. And at that time, in Georgia, there were still, I think, nearly 50 children being warehoused in these institutions, and the children's freedom initiative in the children living in these large facilities. So what happened with the institutions closing is that sort of went somewhere, right? There were some incident to nursing facilities. And then the next movement was to make sure there weren't children. in nursing facilities. However, children means anyone who has not reached the age of 22. So if you're 22, or 23, or 27, or even 35, and you have a disability, you can wind up living in a nursing facility. And so it begins a lifelong journey of isolation for people, number of people with disabilities. That's a problem.

Raisa Habersham 3:34

So what's the difference between a nursing home and a nursing facility? Is it requirements?

Derona King 3:42

You hear me saying facility because I have a pretty clear picture of what I think a home is. And people who advocate particularly for inclusion for people with disabilities, like to make it really clear what a home is. So when you think of home, would you have a key to your own home?

Raisa Habersham 4:00

Yes, I would.

Derona King 4:02

Would you expect someone who doesn't live in your home to be able to walk into your space?

Raisa Habersham 4:09

No, I would not. I will probably be very angry at that person.

Derona King 4:14

Do you would you expect to have a choice about what foods you eat?

Raisa Habersham 4:21

Yes, definitely.

Derona King 4:24

Would you have an expectation of people living with you that you hadn't invited to live with you?

Raisa Habersham 4:30

Oh, god, no. Not at all.

Derona King 4:33

Would you desire autonomy?

Raisa Habersham 4:37

Yes.

Derona King 4:39

So home is a place. Home is a place where I had personal choice, where I have freedom, where I decide who comes who goes, when I leave, when I come back, what I eat, what I don't eat. In a facility, people typically don't have those choices. As an options, they're typically living with people that they don't know. There are people walking around them coming in and out of their room, in some medical uniform, deciding when they get up, deciding when they eat, deciding what they eat. If I'm married, and my spouse also lives in the facility, it's a pretty good chance of rapport that we live in separate rooms. So even intimacy with your spouse would be denied. So when I say facility, I'm describing and making a point of experience. So what most people who live in congregate nursing facilities experience, there is no autonomy, there is very little choice. So I make a clear distinction about home and facility. Not that there's a regulation that separates the two. But the reality of what happens behind the welcoming family room that you enter into. Once you get beyond that is a very different process.

Raisa Habersham 6:07

Oh my god. So it mean, two things, I just now realize my grandmother was in a nursing facility. If I recall correctly, that's basically how it was structured. But also it doesn't seem like there's like a such thing as a nursing home. Like that term is just misused.

Derona King 6:31

That is the point that I've so laboriously made. Home is a place where we make choices. Home is a place where we get to take off our shoes and kick up our heels. And if I want to walk on my sofa, right now, I can do that without punishment. It's also a place where I can choose to be alone. Or I can choose to have people here. And so one of the struggles for people that we know is the growth isolation that occurs for people who live in congregated facility flight nursing facilities or group facilities, though loneliness is often what is helping people to die, the isolation, but physical isolation, the separateness of a distance, distance creation, from the wider community. Remember when we're talking about faith, right? What we all need is the love and acceptance and isolation. The physical isolation separates many people from that love and acceptance. We've got an our nation now, of the licensed facilities, there's about 15,000, maybe six or 700, licensed nursing facilities, and nursing facilities are big business. They're huge business. And so looking at people as individuals, and ensuring that people are not feeling isolated and separated is not a part of the business model for nursing facilities.

Raisa Habersham 8:13

Knowing that young people were living in a nursing home – correction nursing facility – was very eye-opening for me. Derona suggested I speak with Nick Papadapoulos, a 43-year-old man with cerebral palsy living in a nursing facility. Nick is originally from New York but moved to Athens, Georgia in 2007. Before he was placed in a nursing facility he was very active in his community, working as a peer advocate at the Center for Independent Living and raising awareness about disability issues. Everything changed when he got sick while visiting a friend. Nick developed a pressure sore which led to him being hospitalized. After two weeks he was sent to the Brown Health & Rehabilitation Center. He has lived at the nursing facility since that day. That was four years ago. When I spoke to Nick, he had been stuck in his bed all day...literally. He practically has to beg people to help him into his wheelchair. And often that can take hours.

Nick Papadapoulos 9:17

Well, let's see, my day so far has been I woke up at like 10 o'clock, and I told him I wanted to get up, you know, get me into the chair. And they told me I had to be patient. And I was like, Okay, so then, after waiting for a while, I fell asleep kinda. And they woke me up for like medicine around 11. And I was like, can they get me out but then they're like, well, they're at lunch now. After lunch came and went. And it's like, you know, two something now. So after three I kind of generally like, say forget about it, and I just stay in bed for the whole day. Cuz it's like after three, like, I have to make a major stink, like, call repeatedly and just badger them. Badger. Badger. Badger Badger. They're just so sick of me that they, you know, get me up. So most of the time, especially if it's like short staffed, and so I end up being in bed for sometimes the whole weekend. Or sometimes like several days during the week. It's like I go into Vegas, like rolling for my luck to see if I can get up in my chair.

Raisa Habersham 10:34

This is big. As a wheelchair user, Nick relies on his chair for mobility, the way that I rely on my legs. It's how he gets around, and the nursing facility denying him access and assistance getting in his chair infringes a type of confinement, that is not okay to force on anyone. Why and how Nick got into the nursing home is a complex situation. And it has to do with the different elements of paperwork, the Medicaid waiver, housing, transition authorities and transition funding coming together in order for him to get out and have a place to live with the care he needs. He was told he could fast track to get the services he needs. If he stayed in the nursing facility for 90 days, it has now been over 1500 days.

Can you walk me through I guess, how did it get to this? You know, I know that it wasn't your intent to stay in a nursing home for four years.

Nick Papadapoulos 11:34

I was visiting with a friend and I got sick. And I had a pressure sore. And we had decided to go to the local hospital here. You know, after the two weeks, like I was in the midst of trying to search for an apartment. And they were like, well, we can't, we can't hold you. So that's how Brown Health and Rehab came. And I fought it tooth and nail I was like I'm not staying here. Like typically, it takes 90 days to get somebody out into the community. So 90 days doesn't sound bad to get my independent care waiver and all my services back. And then when we found the apartment, then transitional services team, they were like, well, we can't let him out into the community because, you know, in the nursing home, he needs two health care workers to help him. They seem to be putting obstacles in my way to impede me from leaving this facility.

Raisa Habersham 12:32

Wow. So I want to talk a little bit about why you had to go to a nursing home, because you said you left the hospital. And you were there for two weeks. Was there an option for you to stay with a friend? Or was it just outright a requirement that you had to go to a nursing home?

Nick Papadapoulos 12:50

Well, I tried to stay with a friend but like, you know, my friends were, I guess they didn't have the space or they weren't comfortable sharing their space with me. So I ended up having to go into the nursing home, which I thought was like, only temporary because I thought like housing would be found. And then I could get my home health aide with my waiver and everything would be good. No. Disability housing in Georgia is insanely rare.

Raisa Habersham 13:21

Can you talk to me about what your life was like before you got into this nursing home?

Nick Papadapoulos 13:26

You know, I used to get into a car or a van and just go like I had friends in the community and Athens and was my caregiver. We would just go on day trips, you know, say Simon islands for fishing. I mentioned like photography and going to concerts and doing video you know, like hobbies? Just having a full life having relationships, the stuff that's vital for life.

Raisa Habersham 13:56

Can you do any of those hobbies now in a nursing home?

Nick Papadapoulos 14:01

No.

Raisa Habersham 14:03

What restrictions do they have?

Nick Papadapoulos 14:05

Well, to start, we have the age difference. I'm about 43 and the average resident in here is 70, 80 plus, you know, so. We have the generational gap and relationships are kind of discouraged between staff. So you know, the only people that are my age are my peers, our staff, and I can't have relationships with them for obvious reasons, because it's, you know, a professional setting for them.

Raisa Habersham 14:41

Can you have visitors?

Nick Papadapoulos 14:44

Not since COVID No, I haven't had visitors in about almost a year.

Raisa Habersham 14:51

Many days, Nick isn't assisted into his chair and spends almost all of his time in bed. And like many other facilities, COVID-19 restrictions have greatly limited all potential social interactions. At the time of this interview, Nick wasn't allowed to have any visitors or leave the premises of the facility due to COVID-19 restrictions.

Nick Papadapoulos 15:12

Yeah, this is a geriatric prison. I mean, we have our commissary, we had a store, you know, the same things that you value in prison: socks and bodywash is what you value in here.

Raisa Habersham 15:28

We've talked a little bit about, you know, COVID-19 and the restrictions in place, particularly for nursing homes and how it's affected you, you know, what are ways has the nursing facility been affected by COVID-19?

Nick Papadapoulos 15:44

Well, several ways. I mean, they have to wear PPE gear, a lot of the staff staff have gotten sick, residents have gotten sick, despite all our precautions. COVID swept through this nursing home once, and decimated, you know, impacted the population quite a bit. For the most part, most of us are requested to stay in our rooms.

Raisa Habersham 16:09

What does that do to you mentally?

Nick Papadapoulos 16:12

Well, honestly, it's torn me up mentally like, like, you know, not being able to touch anybody, not being able to hold a loved one, not being able to meet a friend, hug a friend. To laugh with a friend, I haven't laughed in a long time. I can't meet my family. I haven't seen my family in four years.

Raisa Habersham 16:39

During our interview, Nick asked a nurse to help him into his wheelchair. I waited 20 minutes for Nick, hoping he was finally being transferred out of bed. When he rejoined the call, I could feel Nick's frustration and disappointment.

Nick Papadapoulos 16:54

Now I'm still in bed, they couldn't get me out. Nobody charged the battery.

Raisa Habersham 17:00

Wow. What does a typical day look like for you?

Nick Papadapoulos 17:04

You basically witnessed the first half, like basically, you know, it's, it's one of two things, it's, you know, I get out. And I get in the chair, which offers me a little more mobility, and a little more agency, because I can basically get stuff done on my own on basically, mobile, and I can communicate with whoever I need to communicate, I try to keep it light hearted, you know, even though I'm in here, doesn't mean I have to be like miserable, like all the time, I try to bring the party wherever I am. And then before COVID, we used to have some activities during the day, but those kind of stopped after COVID. So there's no more activities. But I'm usually like, mobile in the chair. But I'll watch some YouTube and maybe a couple movies, I'll FaceTime people, because that's how my social activity is. I usually FaceTime or zoom chat or like I'll call people on the phone. And that's basically it. And that's like in the chair like, but when I'm in the bed, a lot more difficult. And I'm basically more at their whims when I'm in the bed, because I'm immobile.

Raisa Habersham 18:24

So it sounds like you have a more structured day, when you're in your chair. And you're pretty much at the mercy of the staff, when you arrange your nursing day.

Nick Papadapoulos 18:35

Yeah, you know, when you're in the band, you have a tendency to want to sleep more. You know, being up is a psychological thing. Like, if I want to get some sunshine, like, I might sit out in the courtyard in my chair, in my bed, I don't have much of anything I can't move.

Raisa Habersham 18:52

And how often do you get to be in your chair?

Nick Papadapoulos 18:56

It really depends on the day like if, depends on who the CNA, which CNA I have. It depends on if management is on the floor and available. Like if I could speak to a manager, a unit manager, then I have a better chance of getting stuff accomplished. If I got to speak to the administrator, that's the best way to get stuff accomplished.

Raisa Habersham 19:19

So you have to escalate things up the chain in order to basically sit in your chair.

Nick Papadapoulos 19:25

Yeah. A lot of times.

Raisa Habersham 19:28

That has to be so draining and frustrating.

Nick Papadapoulos 19:31

Like I said, when it takes a whole mission to get a lunch menu, you can imagine when everything else is like in here, it's like nothing is easy.

Raisa Habersham 19:41

Despite all of the strict safety practices in place, Nick contracted COVID-19. He described the treatment he received in the hospital as slightly better than what he received in the nursing facility.

Nick Papadapoulos 19:54

COVID I felt like I got hit by a, like a, I felt like a truck ran over me, my body felt like really weak, there was points where like, I would try to breathe. And because my body wouldn't oxygenate I was, I felt like I was gasping for air. Like here, they wanted to treat me here. And I was like, I am not gonna stay in this nursing home, they put up a fight. So I wouldn't go to the hospital. And I had to demand my rights and demand the fact that I wanted to go to a hospital. And if they didn't, I would cause problems.

Raisa Habersham 20:33

Why do you think they wanted to treat you in the nursing home?

Nick Papadapoulos 20:37

Because when you leave a nursing home to go to a hospital, it's the Medicaid double billing rule, like they won't, they can't double bill. But if I go to a hospital, now they're paying the hospital to take care of me. So when I'm in the hospital, this place doesn't get paid.

Raisa Habersham 20:54

How was your treatment in the hospital, compared to that in the nursing facility?

Nick Papadapoulos 21:02

The hospital was way better. They have staff, they, they came in, check my vitals every few minutes, they checked in to see if I was okay. They have more money, more access to better equipment, better supplies, they gave me vitamins, to help me get past the COVID. They gave me better tools for survival.

Raisa Habersham 21:28

How were you treated once you returned to the nursing facility after your COVID treatment?

Nick Papadapoulos 21:36

So they walked me to my room, transfer me to the bed and forgot about me. For hours. They didn't give me my call, like, they forgot that I was even in the building.

Raisa Habersham 21:48

Oh my god.

Nick Papadapoulos 21:49

See, if you're not visible, you get forgotten quickly. That's one other reason why I like to be in the chair. Because I'm right there, you can't forget about me, I'm in your face. You know, I'll tell it to you like this. Like, if I can go through this and get out and give somebody else hope that they can get out, then you know, then it's worth it. And you know, there might be somebody who, who feels like they can't go on. But if they see my story, they hear about me, and they can go on and fight this and be the next advocate, then I've done my purpose I've done, I've done something I made some kind of change.

Raisa Habersham 22:37

When, not if, Nick gets out of the nursing facility, he hopes to continue his advocacy work, and help others find their voice and advocate for themselves. One question I did want to ask you is when you are out of the nursing home, what are some of the first things that you want to do?

Nick Papadapoulos 22:58

Well, one of the first things I want to do is go travel, see some outside, see, see some trees, feel some sunshine, talk to some friends, you know, just class and just get that sense of community back. And then I want to get back into the workforce. I want to get back into that my advocacy role. You know, because once I'm out, it's not just about me, I have to try to free other people that are in here.

Raisa Habersham 23:30

Talk to me a bit more about your advocacy work, and you know how you got involved with it?

Nick Papadapoulos 23:35

Well, it started when, in 2009, when I worked for multiple choices as a peer supporter, I guess it got really hardcore when I ended up in here because, like, that's when I found out about Georgia advocacy. And when I started advocating for myself, is when I got into the whole like, advocacy hardcore, like that became my life. Literally, that's what my life is about now, just getting out there. Getting the word out, getting funding for a lot of these waivers, because waivers are freedom for people with disabilities, it allows them to be fully realized as human beings out in the community. And who wouldn't want that? They want to have purpose. And when you're in this place, you don't have a purpose. The only time you get a purpose is when you're outside the community.

Raisa Habersham 24:33

One final question I did want to ask you, I'm told that you only wear a hospital gown. Is that correct?

Nick Papadapoulos 24:41

Yeah, that's like my, my freedom fighters symbol. I won't, I won't give into the lie. When I first got here, they're like, Oh, this is your home. This is not my home. You know, you don't have privacy. You don't have self agency or you have a limited form of self agency. I'm one of the lucky ones, I can talk, I can vocalize, I can make a fuss, you know, I can call the right authorities if I need to. What about people who can't, who don't have that voice, who can't speak up for themselves?

Raisa Habersham 25:17

Nick's story left me feeling defeated. He'd been stuck in this back and forth battle for four years, his life decisions were essentially being controlled by an entity that appeared to not care about his basic human needs. I couldn't stop thinking about my grandmother. What kind of conditions did my grandmother suffered through in that nursing facility where she took her last breath? I call Derona with a heavy heart.

Derona King 25:45

Woof, I guess we'll take a deep breath here. And how are you feeling?

Raisa Habersham 25:52

You know, I would say, you know, his situation left me very stressed and very disappointed. I know, last we spoke, I said that nursing homes feels like a place where you go to die. And he proved that just in his story. And I can't imagine being in my 40s, I can't even imagine being the age I am now and being stuck in a place that I don't want to be in. And not having the choice to leave.

Derona King 26:35

Yeah, I think Nick, and he used the words, he's living in a geriatric prison. Yeah, that was pretty powerful. For me. We talked previously just in talking about nursing homes, and you asked me what the difference was between a nursing home and a nursing facility, because I often use the word nursing facility. Does next description sound more clear on why I tend to refer to them as nursing facilities, rather than homes?

Raisa Habersham 27:11

Yes, it does. I mean, that's a very stark reality. Putting it that way. Nick talked a lot about the outside. And, you know, I've never had to think about what the outside is. And you really think about your freedom as an able bodied person.

Derona King 27:35

And he said that it is the difference between feeling stuck, and being stuck, right? There's a wide berth there. And next situation, and the situation of many people with developmental disabilities is not the feeling of stuck, it is the being of stuff. And all of our systems seem to support the ladder that being stuck.

Raisa Habersham 28:04

There was for me an expectation that, you know, you have your basic needs met, I would not have expected someone to wait, what five hours to be put into a wheelchair, five hours. That don't know, I don't know who would tolerate that.

Derona King 28:24

People who don't have power, have to tolerate that. And that is the majority of people who live in these facilities, and particularly those who have no one, to speak up for them or to be present with them. And Nick touched on that, you know, he is able to, as he said, to pester or annoy, if he gets out into the hall, he can make his voice heard. And there are far too many people who aren't able to, to move from point A to B without some assistance or support, or literally don't have a voice. And a place like the place where Nick lives is even more dangerous for someone who doesn't have the ability to speak up for themselves and make themselves heard.

Raisa Habersham 29:13

It makes me feel uncomfortable, but I think it makes me angry. I feel like there's so many rights being violated and taken away. Speaker when that guy felt very hopeless. I felt like there was this emptiness and I'm just like, what, where do you go on from here? You know, you're stuck in limbo. And what do you do? So what happens in a situation like Nick's? Are there any options for him? Join us for the next episode of Hidden Voices, where we'll talk about self advocacy and how one citizen advocate grew in his role as friend and advocate.

This podcast is a collaboration between the Georgia Council on Developmental Disabilities, Resurgens Impact Consulting, Citizen Advocacy of Atlanta and Dekalb and L’arche Atlanta made in partnership with FRQNCY Media. I’m your host, Raisa Habersham and Derona King is my co-host. Our Executive Producers are Irene Turner from The Storytelling Project and Michelle Khouri from FRQNCY Media. Enna Garkusha is our Producer. Matthew Filler is our Editor. Hidden Voices is sponsored by the Georgia Council on Developmental Disabilities. This vision is a state in which all persons are included in all facets of community life, have choices while exercising control over their lives and are encouraged to achieve their full potential. GCDD advances social and policy changes that further and integrated community life for persons with developmental disabilities, their families, friends, neighbors and all who support them. This podcast grew out of their larger GCDD Storytelling Project. You can find out more about them and their great advocacy work for and about people with developmental disabilities at GCDD.org.

Transcribed by https://otter.ai