OMELAS, OHIO

Good morning! My name is Justin Martin. Chairperson Carruthers, Ranking Member Liston, and members of the House Finance Subcommittee on Health and Human services, thank you for the opportunity to provide testimony on HB33.

I'm an English teacher, so we're going to start with a few remarks *about* my remarks. The first thing you're going to realize about me is the wheelchair. The second's probably the ponytail. But the third thing you'll realize is that I'm not nervous. My voice isn't shaking. That's unusual for a private citizen, unaffiliated with any organization, not protected by any umbrella. But the reason I'm about to silence this whole room and make more than a couple people cry is simple: I'm practiced at this. This is my fourth time appearing before this body since 2015, having to justify my own humanity and defend my own future in front of a revolving door of strangers who have not yet had to face the kinds of things I've had to face. Four times now, I've had to drop everything in my life in hopes of hanging onto anything in my life. That is not a fact that anyone should be proud of me for: they should spend that energy on being deeply ashamed of our state even as they hope it changes for the better.

Not even two weeks ago, a new student of mine approached me shyly during lunch with the same question every able-bodied person always has: *is being in a wheelchair hard?* I told him that it was, but not for the reasons everyone assumes. I was born disabled: I've never wanted to play soccer or rock-climb. I told him that there's a device for getting me around and he was looking at it: getting around is the easy part. The hard part about being disabled in this country is dealing with the undeserved power hanging over us, power given to people who could go their whole lives without understanding ours. There is no machine that creates justice, no machine that can give empathy to the unwilling. I told him that the hard parts of being disabled in this country have legislative aides, office phones, and very little time for me.I told him that one day, if he worked hard in this democracy, he could replace the hard parts himself. He could be the easy part. Heck, you all could leave this room as the easy parts.

Out of respect for your time, I've decided to use only 250 words for every sleepless night I've had this year wondering what happens when my parents die. I hope that this rule enforces some kind of a time limit, even if it takes a while to get you to fully understand my isolation

For twenty-three years, I've been a resident of Ohio, and for twenty-six years I've had cerebral palsy, used a wheelchair, and needed the help of others to get in and out of bed, dress and undress myself, take a shower, prepare meals, use the bathroom, wipe afterwards, and get to and from the places I want to go. In medical jargon, the things I just listed are called 'activities of daily living'.

But more importantly, for seven years I've been an educator, and for…three months I've been a high school English teacher, which means I know how bored a roomful of people become when faced with an unknown voice and an abstract term. Statistics can help us understand the world, but human beings need stories to truly *feel* it. ‘Activities of daily living’ will mean nothing to you until I tell you a story – and maybe, if I treat this like English class, I won’t have to take a personal day. I’m stealing today’s story from a science-fiction writer, the late Ursula K. LeGuin.

LeGuin was always curious about two things: how people lived right now, and how people *could* live later, if we had the courage to try. These things are difficult to write about – both because we spend so much time averting our eyes from our fellow citizens in the present, and because imaging the future is a tricky business. The question of how to live feels huge.

And so she tended to start by asking us to imagine somewhere small, somewhere specific. In 1973, she asked us to imagine a city called Omelas. It’s a beautiful city; in their Festival of Summer, “the ringing of the boats in harbor sparkled with flags. In the streets between houses with red roofs and painted walls, between old moss-grown gardens and under avenues of trees, past great parks and public buildings, processions moved.” In other words, the people of Omelas are free; they are as free as most of you in this room have the ability to be, even freer. During the festival, “a marvelous smell of cooking goes forth from the red and blue tents of the provisioners. The faces of small children are amiably sticky; in the benign gray beard of a man a couple of crumbs of rich pastry are entangled. [...] An old woman, small, fat, and laughing, is passing out flowers from a basket, and tall young men wear her flowers in their shining hair. A child of nine or ten sits at the edge of the crowd alone, playing on a wooden flute”.

But then LeGuin asks all of us to imagine just one more thing about Omelas. She asks us to imagine that this utopia has a price, and that the price is a person.

“In a basement”, she says, “under one of the beautiful public buildings of Omelas, or perhaps in the cellar of one of its spacious private homes, there is a room. It has one locked door, and no window. A little light seeps in dustily between cracks in the boards, secondhand from a cobwebbed window somewhere across the cellar. In one corner of the little room a couple of mops, with stiff, clotted, foul-smelling heads stand near a rusty bucket. The floor is dirt, a little damp to the touch, as cellar dirt usually is.

The room is about three paces long and two wide: a mere broom closet or disused tool room. In the room a child is sitting. It could be a boy or a girl. It looks about six, but actually is nearly ten. [...] and the door [to its room] is locked; and [it knows that] nobody will come. The door is always locked; and nobody ever comes, except that sometimes--the child has no understanding of time or interval--sometimes the door rattles terribly and opens, and a person, or several people, are there. One of them may come in and kick the child to make it stand up. The others never come close, but peer in at it with frightened, disgusted eyes. The food bowl and the water jug are hastily filled, the door is locked, the eyes disappear. The people at the door never say anything, but the child, who has not always lived in the tool room, and can remember sunlight and its mother's voice, sometimes speaks. "I will be good," it says. "Please let me out. I will be good!" They never answer. The child used to scream for help at night, and cry a good deal, but now it only makes a kind of whining.”

I don't have the luxury of treating this child as fictional. That child reminds me too much of what this state has allowed to happen to me. I too "have not always lived in the tool room" and I too can "remember the good times" – three years ago, when I lived on-campus at Kenyon College, we were able to recruit a well-paid team of direct support professionals that lived in the third floor of my apartment–my roommates and I took up the first and second floor. With my DSPs only a text message away, I could get up and go to bed whenever I needed to. I could make plans with friends on the spur of the moment rather than four weeks in advance or never – I could go out to eat, go to the movie theater, attend meetings and classes and internships regardless of when or where they were My world, which used to be colorless and narrow, was now impossibly wide and impossibly bright. It's only when you can leave a house every day that it becomes a home, a place you miss. Any place you don't know how you can leave becomes a prison. I was given privacy, too – enough privacy to form friendships, to fight, to grieve and to think. I could call my parents and treat them like parents – they could be happy with me and for me, waiting for the latest accomplishment instead of wondering if today would be the day their bodies would make it impossible to care for my daily needs. They were allowed to rest and to age.

Then, COVID hit, which was no one's fault. Becoming a DSP felt riskier, which was no one's fault. At the same time, services we all use and value – fast food, retail – began paying their workers an attractive living wage; unquestionably a good thing. Individual DSPs looked at their options and saw that, as the state began to fumble and delay, the grass was greener on the other side and yellowing on this one. Glitches in billing software meant that DSPs weren't being paid for weeks and months at a time. Of course they left the job that made my life possible. I would have left, too.

I got my teaching license in June of 2022 after graduating from Vanderbilt University. Every day since then, for hours a day, my mother and I have been searching for DSPs – to enable me to move out, to enable me to live on my own again, to enable me to get to and from work, to enable me to see the new *Cocaine Bear* movie, or go on a date, or go to an art museum, or get a little drunk sometimes, or visit a friend in need. When wages were fair, my mother, who I love dearly, found me *six providers* in a middle-of-nowhere town with two restaurants and a post office. She had to cold-call hundreds of people, but we found them. This same woman – and her more than capable child, and his incredible caseworker – have not found a single provider since the pandemic began. All the while, while a handful of senators at the federal level decide not to spend a *cent* of our country's immense wealth on fixing this problem, you sit here in Ohio forming working groups and debating whether we should pay these people thirteen dollars an hour, or sixteen, or maybe we can manage twenty.

If you've finally begun to wonder what I've been doing in the meantime, unable to leave my house unless my mother takes me out, I'll tell you: I've been thinking about one particular wasp's nest, the most memorable one I've ever heard other disabled people tell me about. The wasps had constructed it hanging off a broken ceiling rafter. They were wasps, and so they didn't know their nest was hanging inches above a disabled man's bed, at the kind of warehouse you're forced to live in when you're disabled and your parents can no longer care for you and no one is paid enough by the state to be your DSP so that you can live in your own home. I do not know how many days or weeks the disabled man had to complain about the wasp's nest above his bed before the state removed it. I invite you to think about how much time may have passed. I invite you to wonder how you would have slept, if it had been your bed. I invite you to wonder *if* you could have slept, and I invite you lastly to wonder how much you would want someone to be paid to take care of you in a home you chose, if the alternative was sleeping with your nose so close to an active wasps' nest that I'm sure you could smell it.

I have lost so much, and yet I have lost so much less than others who cannot speak to you today. My mind flips wildly, like a coin down a wishing well, between the reality where I once again get to live a full life and the reality where I am the person sleeping under the nest, not only grieving my parents someday but grieving any chance at freedom. There is a person I want to be someday, and that person does not live in a place like that – no happy person does. I try to maintain my sanity and happiness by immersing myself in my job (for as long as mom can drive me there) and talking to old friends on the phone: it rarely works for long. Your head does weird things with time when you can barely leave your home: without a favorite coffee shop, fresh air in a park, the days run together and you forget where you live. A bedroom and living room, repeated day after day, do not add up to a life. I have felt for too long now that I don't live anywhere.

But then, when I was sitting wide awake at 3A.M. two weeks ago, trying to think of how I could possibly show you what I've been forced to live through, I realized: I do live somewhere. I live in Omelas, Ohio, behind a door that no one has bothered to open and everyone knows is there. When I last testified about the need for DSPs, I was able to bring a busful of college friends behind me: today, because of your choices, I bring only my loneliness and anger. I haven't seen most of them in years.

Le Guin tells us that the children and adults of Omelas invent ways to justify or minimize the suffering they see the child going through. They pretend that it can't think, and when it can't talk, they pretend they don't know what the child would say. They think that they are good people; they tell themselves that the child is wretched, or else superhuman, capable of withstanding things that normal people could not. They convince themselves, in a thousand little ways, that there is no other way, that this is how it's always been and will always be. Maybe they establish an Omelas Child Working Group, a blue-ribbon commission, to identify the problem. Maybe the suffering child gets to go to a day program twice a week. Very smart and very free people decide on another person's behalf how much freedom is enough. They do everything but fling open the door that they themselves built, free the child they themselves trapped. And it is all so easy and life goes on for everyone but the folks behind the door. Each time I testify, once the governor's office starts sweating, there's a frantic search for whoever's 'putting me up to this': is it my mother? Is it the ARC of Ohio, or Disability Rights Ohio, or George Soros? There are people in this room right now trying to find out my motivation, because they can't accept one simple fact: if *you* had this much grief, and rage, and sadness – and you will, once you become disabled in the society you chose to make – it would power you for decades, all the while killing you.

With an ounce of care at any level of government, this could have been prevented. Let's be clear: because of your inaction to this point, and the inaction of Congress, it was not prevented. If you stem the unnecessary suffering of disabled people by making this a freedom budget of at least $20/hour, we will still have suffered too long. But for many of us, the hurting will stop growing any bigger, and something will grow in whatever space is still inside us.

LeGuin ends her story by promising that, one by one, quietly, there are people who choose to walk away from Omelas, towards somewhere just. Every day at work, I dictate the day's learning target to my friend and colleague Kevin, and he writes it on the board for me before his class becomes mine. We ask ourselves what we want our students to be able to do by the end of the period: describe the techniques of good interviewing, identify the parts of a resume.

But there's a secret learning target, always: when we teach, we are trying to sell them on the world. They have already told us they won't bother to vote, that in this world it's consequences for the many and community for the few. We are trying to convince them that while they may have lives studded with too many locked doors of despair, each and every door has a hinge: We are trying to convince them that there is a use in pounding, and listening to the pounding down the street. We are trying to convince them that if enough people pound loudly enough, and their neighbors do too, doors open briefly and then come off entirely. So choose, so tell them: is there a point to the pounding? What is the end of this story? What is the name of the city you chose for me, and is it a place I can ever love?