



MEDICAID MATTERS

Justin Martin Rallies His Community to Defend Waiver Services

MARCH 2017



**Disability
Rights** OHIO

We have the legal right of way.



Cover and page 2 photo credit: Dalton Powell

INTRODUCTION

My name is Justin Martin. I'm currently a sophomore English major at Kenyon College in Gambier, Ohio. I also have a disability, cerebral palsy, which means that I use a wheelchair because of excessive - and sometimes painful - muscle tension. I can't dress myself, shower independently, get into or out of bed on my own, or get onto and off of a toilet without help from Medicaid-funded independent care providers, who use a track-lift system to get me places. I couldn't physically get to college without the Medicaid-funded lift in my family's minivan.

You don't go to a college like Kenyon to stay stagnant: you go there, frankly, because you believe in your ability to help change the world in huge ways. Again, frankly, there's not a person who knows me that does not believe that I can do just that: as a politician, as a writer, as a high-school teacher. The only time that they begin to doubt the inevitability of my work is when my health and well-being intersects with bad public policy devised by people who will never even meet me.

In the past two years alone, this has almost occurred twice. In 2015, the state legislature tried to abolish independent providers - those people who shower, dress, and wipe me - which would have prevented me from attending college. After several days of testimony from seemingly every disabled person in Ohio, the proposal was shelved.

Then, in 2017, a similar rule was proposed by the Department of Developmental Disabilities. While not eliminating providers entirely, it would not allow them to work more than 40 hours per week individually. That policy would have put a 14-hour hole in my schedule in which I could not dress, use the bathroom, etc., making college impossible. Between my first testimony and my second, I'd gained a lot of friends in college - good public policy allows bonds to form - and my friends demanded that they also testify on my behalf. Together, for me and so many other disabled Ohioans, we got that second proposal struck down as well. My friends' testimonies are compiled in this booklet, so that you can see what even a small cut in disability services can do to a community.

But what you're contemplating now isn't just a disastrous small cut on an isolated service like independent providers. What you're contemplating now, just as my post-college life begins, is a catastrophically large cut to all of Medicaid - the van, the medicine, the lift, the wheelchair, emergency funds for the providers, the roll-in shower, the leg braces, the glasses, the surgeries. Everything. My shot at a future is a fragile thing, and now more than ever, I'm sleepless about it. A world without Medicaid is a world without me, and a country that doesn't protect and empower its most vulnerable is a failed joke. I will let my friends help you imagine the possibilities that come from the right decision, and the horrors that come from the wrong one.

Whichever decision you make, you'll be hearing from me and my people.

FULL TESTIMONY: JUSTIN MARTIN

Members of DODD,

Before I introduce myself, I'd like to begin by telling you my favorite joke. It's autobiographical, and goes like this: just days after I was born three months premature, a doctor told my mom, "Mrs. Martin, we find it best not to expect too much out of these kinds of children." This was the first example of an able-bodied person implying one insidious thought that has followed me in all its varied forms throughout my whole life. That thought, that little voice says: people like you are too much to handle. People like you are not worth it. If anyone loves you, it's because they don't understand who you are yet: once they understand, they will leave, and you will die alone as the devil intended. I understood that thought before I knew my own name. But now I know my name.

My name is Justin Martin. I'm currently a sophomore at Kenyon College in Gambier, Ohio, where I'm on my way to becoming an English teacher. For our purposes, it's helpful to note that I have cerebral palsy, meaning that in order to keep going to school, one brave man or woman, paid for with state funding, needs to be on-call in case I need to shower, get in or out of bed, get dressed, or have my ass wiped. Since, like all of you, I don't know from day-to-day exactly when these things will happen, it is critical that an independent provider - a well-paid and skilled person whom I have chosen to hire - is available 24/7. But if I am to be perfectly honest, going over these autobiographical details seems ridiculous at the moment. In the spring of 2015, I sat in a building right across the street and gave those exact details to the Health and Human Services subcommittee when they were debating whether to slash independent providers from the budget. After days and days of testimony from disabled people like me, the proposal was abandoned. But it was my testimony that made the front page of the Columbus Dispatch the next morning, under the headline "Disabled Plead Lawmakers for Just World."

After my testimony, several members of the Committee swore up and down that I'd opened their eyes. This testimony made such a splash that I was invited to a closed-door meeting with Greg Moody, Governor Kasich's Director of Health Transformation. The Kasich administration expressed that the disability community simply didn't understand this catastrophic regulation: once we understood it, cooler heads would prevail. Director Moody had prepared a Powerpoint, and on the third slide was a pie chart. One small slice of that chart was for people like me, people who only used independent providers. With his laser pointer, Director Moody circled the small slice and said "this is all we're cutting". I turned on my microphone, leaned in, and expressed the truth: that slice was my entire life. Director Moody had not devised some ingenious way for the state to be frugal: he had simply recycled the same implication of that doctor talking to my mother and tried to pass it off as new. Director Moody was saying to me "you're simply too much work". Everyone in that room knew it, and enough people in this state knew it that the proposed law died.



You will hear many of my friends express today that I am a strong advocate, but this is only partially true: I used to be a weak one, because at the end of the day, I didn't know what I was fighting for, just who I was fighting against. At the end of the day, after so many leaders in my life found coded ways to say that they honestly didn't care whether I lived or died, I wanted to die. That doctor told my mother she had given birth to a burden: a burden that was not just weighing her down, but weighing the world down. The law reinforced this idea. Eating lunch alone everyday in my high-school cafeteria reinforced this idea. When it was required, I could provide the illusion of fighting: but at the end of the day, no one outside of my home fought for me, and nothing outside of my home was worth fighting for.

The 22 people you see behind me are people I met at Kenyon College. The 22 people behind me took a journey that I'm not sure anyone in the Kasich administration has bothered to take: when they met me, each one was afraid of me, could barely talk to me. But in the following testimonies, after two years together, you'll see how each of these incredible people has learned to be afraid for me, or more precisely, afraid of what this proposed rule will do to me. The memories we've made together, the memories we will make, are what I fight for today. I want to live, and I want to live so badly, because I have the privilege of living with these incredible people.

Maybe, like the *Dispatch* said, my original testimony was a plea. But a person with something to fight for doesn't plead. They give an ultimatum.

Let me not talk down to you by mincing words. I understand the necessity of political calculation - I read the same political theory books you did in college. I understand that some good people must sometimes support bad policy. I understand that complying with federal overtime law is expensive. I understand that in years past, not knowing or caring about how central these issues are is something that has gone unpunished. That era should have ended long before I was born, but since it didn't, it ends today. Whatever political third-rail is most intimidating to you, it is time to treat cutting person-centered disability services in the same way. Which is to say the following:

I've heard from credible sources within DODD that this hearing is basically a formality; the spirit of the rule is set in stone, and the best we can hope for is cosmetic changes. That will not suffice. You were smart enough to get me into this situation, which means you're smart enough to get me out of it. You will abandon this policy and replace it with one which doesn't cause me to lie awake at night, and you will do so with unprecedented speed.

If that doesn't happen, or if it happens and then gets undone, I will have to enter a building like this again, and I will enter it with a whole hell of a lot more people. Only a week ago, I was hesitant to get a bus together on such short notice: I felt like a burden. I heard that doctor again, and I heard Greg Moody, and I heard the Kasich administration. But these people - my people - insisted I wasn't a burden. These people - my people - demanded I take them to this building, because these people - my people - hold only one thing sacred: the life we live together. If anything

stands between me and the life we live together, these people - my people, will mock it, will call against it, will picket against it. These people do not hold any mercy in their hearts for systems that hold no mercy for the vulnerable. If you stand against them, if anyone in the Kasich administration ever again cuts provider hours or provider pay - the jobs that you hold will be shaken, the institutions you populate - will be torn apart. And if, after their jobs are lost, no one who values disabled lives in word and deed can fill those jobs - then these people, my people will fill them.

If you pledge to me, in front of everyone in this room, that you will not touch Independent Provider funding without calling me first for as long as you live, I will fervently and publicly support you, as will my people. You will have committed what's unfortunately a rare act of basic decency towards your disabled constituents.

In the Oval Office right now sits a man who openly mocked bodies like mine. My hope, these days, is largely shattered. I am looking for champions to restore that hope - folks who can tolerate a few attack ads about how they increased the budget, but who could not sleep at night knowing that their actions caused one disabled person to drop out of college. I am confident that some those leaders are the people who will testify on my behalf today. But I honestly have no confidence whether or not any of those champions sit before me right now, in seats like yours - several members of the Kasich administrators who came up to me after my first testimony saying that I had opened their eyes are now silent on this new proposal.



Good public policy empowered me. Good public policy saved, and then changed, my life. [...] Good public policy can do this, has done this, and will do this for so many other marginalized people. Bad public policy will bury us, figuratively and literally.

I am not saying this to attack the character of the Department of Developmental Disabilities or the Kasich administration: I am saying this to give those institutions the opportunity to demonstrate that character for what I believe to be the first time. I want to have underestimated the number of people who stand for me when it is inconvenient: I certainly underestimated that number at this time last week.

Good public policy empowered me. Good public policy saved, and then changed, my life. Good public policy brought me to my people, and my people to me. Good public policy can do this, has done this, and will do this for so many other marginalized people. Bad public policy will bury us, figuratively and literally.

If I sound hyperbolic or unserious right now, I'd urge you to consider what exactly it is I'm fighting for: without a well-paid independent provider, I wouldn't have gone to college and met the first group of real of friends I've ever had. I wouldn't have seen my writing grow by leaps and bounds right alongside my capacity for empathy. I wouldn't have had my first crush, first beer, first all-nighter, or first Toni Morrison novel. And the reason that you don't hear a tremor in my voice right now is that there's a whole galaxy of other firsts I'm willing to fight for: the first class I teach, the first time no part of me feels unwanted, the first book I write or show I host, my first child.

James Baldwin once worried that racist attitudes and racist policies led white people to experience "the death of the heart". I am here today, in every sense of the word "here", because I worry more than ever about the death of your hearts, of our hearts. I worry that years of making the expedient decision, out of cheapness or fear, has clogged your arteries. I worry that you will choose to give up a fight I can never give up. I worry that you will forget my humanity a little more every day that you don't see me. I worry that you will not bother to tell your current and future colleagues about what you saw today. I worry that the slow death of the able-bodied heart could make my fight for basic liberty into an endless one. But for every fiber of me that feels like we're already there, two more fibers of me feel like resuscitation is still possible in America, if our leaders have principle.

So I'm left with the following question for the members of the Kasich administrations: do you have principles which value disabled lives without compromise, or do I need to introduce those principles into this government myself? Will I be reviving our heart with you, or will I be the one doing it instead of you? Will you rise to the example of my people, who grew and loved past fear, or will my people and I have to show this country how to do your jobs ourselves?

I am not a burden: policies like yours are. Disabilities are not burdens: organizations like yours are. My life is not a burden: apathy like yours is. My people and I will see those burdens transform themselves immediately, or we will throw those burdens, gladly and in public, to the ground.

That is what you ought to expect out of these kind of children.

Thank you.



TESTIMONIAL EXCERPTS

ADAM ALUZRI

In economic and policy terms, Justin's absence would be the equivalent of brain drain. In personal terms, Justin's absence would constitute a tragedy, not just for him but also for his friends, professors, and even distant acquaintances. Justin makes me a better student and a better person with every conversation we have, and that's because he has an uncanny ability to reach into my mind and show me a new form of art, a new show, a new philosophy, or a new injustice and make me care about it viscerally. Without him and people like him, my life will be boring at best and nihilistic at worst. As with every other point in this testimony, I encourage you to interpret this as applicable to the entire disabled community in Ohio, so, in aggregate, imagine the same awful effect but scaled up tens of thousands of times.

TOBIAS BAUMANN

Friendship with Justin has been so rewarding, but constantly fraught with the fear and uncertainty that I've come to learn is typical for people with developmental disabilities who rely on the bureaucracy to maintain their



Photo credit: Dalton Powell

regular life. It seems like every month there's a new thing that might force him to leave Kenyon and go back home. He's had issues with his wheelchair breaking and trying to get a good replacement, he's had to provide OOD with excessive documentation to stay in and now, he's facing the possibility that he won't be able to employ the people he needs to in order to stay at Kenyon. My friends and I will be so devastated if this policy passes because he will more than likely have to leave. I'm upset that seemingly all I can do to help is come here and testify, but I hope it will make a difference. If you approve the new rule, you will not only be ripping apart the small community that me, Justin, Jack, Conner, and everyone else has built here at Kenyon, you will be ripping apart the friendships and support networks of people with disabilities all across the state. Furthermore, this policy is going to deny the opportunity to even go to college, or get a job, or even leave the house to so many people who rely on independent providers.

BRANDONLEE CRUZ

To study the humanities is to study humanity, itself. When you study the humanities, it means studying what it means to be a human— what it means to be alive. Socrates states that, “an unexamined life is a life not worth living.” What he means is that a life without self-reflection, re-evaluation, is not a life worth living.

Without good literature – without good teachers of literature – we will continue to

live an unexamined life. Without a great teacher and poet like Justin Martin, I would have continued to have lived an unexamined life on disability. I would have probably overlooked the decision to cut funding for independent service providers. But, because of Justin's literature and his teachings of literature, to me, I have called out of work and school – and will continue to do so – to be here, testifying against such budget cuts. Because, I know that if these cuts go into fruition, he will be unable to attend Kenyon. He will be unable to continue to studying English at this institution. Perhaps, not become an English teacher. When critiquing books of poetry Justin has said that he judges a book by how well he knows the author after reading. He judges it by how well the writer can tell him about their humanity. By what his work does for me, I would expect no lesser standards from him.

WES DAVIES

As one of a mere handful of disabled students attending Kenyon, my friend Justin Martin has had to juggle finding qualified care providers in and around Gambier, Ohio, balancing his academic life and social life, and using that social life to essentially serve as an ambassador for a school mainly made up of students like me, who are accustomed to taking his daily experience for granted. I care deeply about Justin: before I knew him personally, reading his poetry moved me to tears, and since we became friends he has been there for me as a unwavering source of humor, compassion, and support. I look forward to the day when I can see him teaching in his own classroom, using his education at Kenyon to show new generations of students how to not take what they have and what he's fought for for granted. The strongest people I've met in my life have been the ones who have had to fight the hardest; I look forward to the day when Justin does not have to be strong just to survive, and can get the full provider care he needs because the necessity of that care and the necessity for his bodily and personal autonomy are not taken for granted. I hope that in your consideration of adopting this rule, you recognize the importance of Justin receiving the care and education he deserves, and understand that there are many more people at Kenyon and in the world who would not be the people they are today if he they had not met him.

LYDIA FELTY

There are few people who deserve to be at Kenyon every day, few who have fought to be here and worked their asses off to be here the way Justin has. Too many students glide through life without being aware of much outside their own circle, their own needs, and their friends' needs. Justin, in every possible way, reminds us to look beyond what we see and where we're from, and to really think about what we're doing, what we're saying, why we're doing everything we do. To do anything that would further hinder Justin's ability to stay at Kenyon would be the greatest of all disservices to this campus. This state should be incredibly proud to have Justin Martin in its ranks, to be able to call such an incredible human being one of our own, and we should act like it.

DEREK FORET

Now I could mention how Justin and I met and share positive memories of us. I could spend much time on the goodness of his values and character. I could even say how much of an inspiration he has been to me. But doing any of these things creates a false equivalency while ignoring the issue at hand. We are currently discussing an issue of justice, not of what is nice or good. It is not our goal today to convince you that Justin is deserving of some favor or that you should help him because of the adversity he has faced. The false equivalency is found in believing that Justin's life is like our own. The issue at hand is that his life is and will never be remotely close to ours. To us, assistance means making our life easier. To him, it means ensuring his life is livable.

Does that make you uncomfortable? Good. This shouldn't be comfortable to hear. Because of Justin I know that true listening requires discomfort. It is not pleasant to think how Justin lives a life that we would not want due to nothing more than an absence of luck in the genetic draw. The implications of this fact cause unease. For example, Justin and I recently figured out that we were both three-month preemies. He due to his cerebral palsy and me due to a dying twin the doctors were unable to save. Did that make you uncomfortable? How about this: I'm not the one who is forced to depend on the state to let me go to school. Which reason for being born early would you rather have?

The point of bringing up this discomfort is neither to guilt nor to persuade. It is how we truly listen to the disabled. Not by using their stories as motivation - calling Justin brave only shows our true cowardice - but by recognizing the reality and implications of our difference.

GEORGE GOLDMAN

The image of Justin and Kenyon together did not fit with my idea of what the students who come to Kenyon look like. Justin's mere presence as a disabled person on a college campus made me feel uncomfortable. Unsettled. And yes, afraid.

Before I knew Justin by name – in other words I thought of him merely as “one of two disabled people at Kenyon whose ability to be here I still don't fully understand-person” – I would pass him on the way to class or at the dining hall feeling a mixture of distant pity and aversion to contact.



The only way for able-bodied students to end the visceral fear and discomfort that comes with disabled students on campus is to continue enabling more disabled students to come and change the idea of what it means to be a college student.

No one during my four years at high school had cerebral palsy. No one in the dozens of Kenyon brochures I had received in the mail had cerebral palsy. No one in any of the hundreds of college brochures I looked through had cerebral palsy, either. To me, Justin was alien. Out of place. And I know that I was not, and continue to not, be alone in these feelings.

When Justin enters a room or moves down a path on campus, Kenyon students stare, recoil, mutter words under their breath and overall pretend to not notice his very existence. But that does not mean that more disabled students should be deterred from coming to Kenyon or any other college or university. In fact, it means the opposite. The only way for able-bodied students to end the visceral fear and discomfort that comes with disabled students on campus is to continue enabling more disabled students to come and change the idea of what it means to be a college student.

DR. ANDREW GRACE

I write to urge you to NOT ADOPT rule 5123:2-9-03 limiting the number of hours that domestic service workers are able to work per week. In my position as Professor of English at Kenyon College, as well as co-Director of the Kenyon Review's Young Writers program, I have had the privilege of being Justin Martin's teacher, and have known him for four years. I would be there with him in person this morning if my teaching schedule allowed it. I can say with full confidence that, in my 13 years of teaching at schools like Stanford University, Washington University in St. Louis and Kenyon, Justin is one of the most brilliant students I have ever worked with. His academic work is staggering, and he is already an accomplished poet. He is also one of the most active and valued members of the Kenyon community. We do not have many disabled students on our campus, and Justin has been a wonderful advocate and spokesman for those with disabilities, which I imagine is a role that the members of your organization would appreciate. Put simply, Kenyon would not be the same without Justin. He is essential.

LIAM HORSMAN

As anyone here on Justin's behalf will tell you, he is one of the most generous people on Kenyon's campus: generous with his intellect, generous with his compassion, and, above all, generous with his time. College students are busy, but Justin creates time for everyone. In serving as a discrimination advisor, he creates time to advocate for anyone in need on our campus. As an associate for The Kenyon Review, he creates time to attend literary seminars and readings, and he always asks the best questions. Whenever Justin raises his hand to make a comment, I have to prepare myself, because I know his point will be one of the most engaging, thought-provoking ideas I hear that day.

Justin creates time for less-pressing issues as well – namely, me. I first met Justin last spring when I was preparing to write my senior thesis. I emailed to ask if he wanted to meet at some point in the next month, and he replied within the hour, asking if I was free in the next day or two. We met, and he came up

with more interesting ideas in the first five minutes of our conversation than I had considered in a month of working on the project. Since then, Justin has always been there—in cases where I actually needed the help of a friend, or in cases where I simply needed smart feedback on a piece of writing. There have been instances where I've messaged Justin at 1 a.m., not expecting him to respond until morning, only to have him write back a couple minutes later.

Justin does not have to make time for me or all the other people at Kenyon he supports. Like everyone else, he has his own life to worry about. But what separates Justin from everyone else is his willingness to still go out of his way and create time for anyone who needs it.

Rule 5123:2-9-03 is about time: about how many hours may be spent providing for a disabled individual, and the circumstances in which that individual may receive additional care. It is a rule that decides who is worth our time, and how much time they deserve. As my presence and the presence of everyone else from Kenyon here today indicates, Justin deserves our time. College students are busy – I work 15 hours a week at two campus jobs to help pay for school. But I missed work this morning to tell you that my time at Kenyon has been made all the better by his contribution to this school. For me, knowing Justin has been one of the great honors of attending Kenyon. For Justin, attending Kenyon should be his right—not something he has to fight for every two years.

LAUREN MICHAEL

Justin is my friend in thinking at Kenyon. If he didn't have the opportunity to attend Kenyon, I would certainly be at a loss. I would have worked with another student who was blasé and only wanted to discuss questions for our class at minimum. I would not have had the quality of conversations ranging from religious experiences to the nature of empathy. Justin has this propensity for asking valuable questions that others take for granted. Not having someone with this skill at Kenyon is a serious loss for our community. In fact, Justin deserves to be at Kenyon more than most of us. His writing and depth of thought surpass many of our fellow students.

Without Justin, I would not have had the opportunity to learn about stories other than my own. Hearing the stories of people who have experiences improve our capacities for empathy.

ETHAN J. MURRAY

I could tell you a story about how Justin opened my eyes to the plight of disabled people and taught me how to become a better person. You will hear some of those stories, and I hope they help you recognize how much of a teacher Justin is to us already.

But this story is a little different. This story is different because I am autistic, and I was no stranger to disability before Justin came to Kenyon College.

Here's the difference between my experience and Justin's: my disability is invisible,



Growing up with an invisible disability taught me how to pretend. It taught me, silently, that my difference was something to cover up with scripts and quiet hands and utter denial. And then Justin came to Kenyon College and he was visible and articulate and proud of who he was, and maybe disability wasn't new to me, but that was.

classes this semester, of finally not being the only disabled person in the room. Justin didn't just bring education to Kenyon College. He brought community and relief to those of us who were already fighting.

while his is pretty obvious. People are scared of him when they see his wheelchair, and people are scared of me when I say the words "mentally disabled." They avert their eyes when I struggle to read a number my brain insists is a painting. They shrink away when I say "if I go into that room crowded full of people, I will cry, and I will throw up, and then you'll be dealing with a mess, so let's not do that, OK?"

Growing up with an invisible disability taught me how to pretend. It taught me how to hide. It taught me, silently, that my difference was something to cover up with scripts and quiet hands and utter denial. And then Justin came to Kenyon College and he was visible and articulate and proud of who he was, and maybe disability wasn't new to me, but that was. The power I felt for my community in his words – that was new. The safety of hearing his voice, of knowing he would be in my

RENA NEWMAN

All we able-bodied people have that vague understanding of the life of difficulty that accompanies disability - but it was only Justin who made it clear to me that it doesn't have to be that way, that the difficulty is created by structures that do not support him and others like him. That each of us have the opportunity to decrease suffering. That you, right now in this moment, have the opportunity to decrease suffering. He will be making a testimony, bearing himself up to you with great vulnerability for his rights. Know this: you have the opportunity to decrease suffering in the world. Therefore, you must. [...]

But this testimony is not just about how much Justin gives. This is about how many others like him who are capable of just as much if not more will be cut off from the world, whose gifts will not be disseminated and known. If this proposed rule goes through, the devastation you will cause is immense. If you cannot understand this on its own, simply by loving him, you have an example of why you need to care.

DEVON MUSGRAVE-JOHNSON

My name is Devon Musgrave-Johnson, and I help Justin run The Ballpit Whalers, one of the top two improv groups on Kenyon's campus.

Justin started this group on campus when he realised that there was a group of students who wanted to do improv but were unable to join the other improv group on campus because of accessibility or space available in the other group.

Justin never complained that he didn't get into this other group. He never whined that their performances were in an inaccessible location. Instead, he did something about it.

Justin is a person who does something in the face of injustice. He creates his own group, he gets a job as a discrimination advisor, he lobbies to people like you to make sure that his rights and the rights of others are not taken away.

Justin is an inspiration not because he is a kid in a wheelchair who gets out of bed in the morning, but because he helps other people get out of bed in the morning. He created a welcoming space on campus for people looking to try something new with The Ballpit Whalers, he is a person to talk to as a discrimination advisor, and he has been a constant source of compassion for everyone who comes in his path.

RACHEL NELLI

My name is Rachel Nelli, and I am a public school teacher of 18 years, all of it in the great state of Ohio. One of my most memorable students was a young man named Justin Martin, who has CP. Recently, he brought to my attention that the federal government has mandated that aides for the disabled must be paid overtime. Ohio's Department of Developmental Disabilities, in response, is creating a new rule to mandate that overtime for aides be illegal, so that we won't have to foot the bill.

Tell me then, please, how much would it cost for you to give up some of your freedoms that you take for granted every day? How much to be able to get dressed in the morning? Make your breakfast? Tie your shoes? Use the bathroom by yourself? How much is your



How much is your independence worth to you?

How much is it worth to you to travel for more than eight hours so you can do your job, visit your family or take a vacation? How much is it worth to you to be able to get out of bed at night to use the bathroom on your own? A dollar? Ten? A hundred?

independence worth to you? How much is it worth to you to travel for more than eight hours so you can do your job, visit your family or take a vacation? How much is it worth to you to be able to get out of bed at night to use the bathroom on your own? A dollar? Ten? A hundred?

What would you do if you could never again choose to live somewhere where providers weren't easy to come by? Or if you wished to travel or work or have any kind of independence at all where you wanted to have it, just like everybody else?

How much do you deserve your independence?

I shouldn't have to ask you that question. You should be appalled that I would even question your right to live your life the way you wish to live it.

I also shouldn't have to ask you why you think that another law-abiding, hard-working (and he works harder than anybody I know) American should not have the same rights and independence you take for granted.

If you would not give up any of those freedoms I mentioned above, then you have no right whatsoever to deny them to a disabled person. We are either a society where all men are created equal, or we are a society content to have second-class citizens. The latter is unacceptable.

DANIEL OLIVIERI

My name is Daniel Olivieri and I am Justin's roommate. We share a bathroom and I often borrow his shaving cream without permission. We work on movie scripts together and stay up late worrying about our love lives. Now I'm not sure if you've been lucky enough to talk to Justin one on one, but if you ever do you might end up discussing the 99 names of God or arguing about the quality of the seventh Harry Potter book.

Now, today we from Kenyon are ostensibly here because Justin Martin, as a person with disability, depends on our support to live a happy, full life. But as his roommate I can tell you that we're actually here because we need Justin's support for us to live happy, full lives. Let me explain.

Living with Justin means that I can observe him anthropologically. And I've noticed two things about Justin from being his roommate: he stays up very late and he is almost always on Facebook. Justin stays up late and is almost always on Facebook because there are people who need him to be on Facebook. I know I'm one. We need Justin to be on Facebook because we need Justin to listen to our problems at 3 in the morning. We need someone with Justin's level of compassion to hear our problems. As his roommate, I've seen Justin support people through very tough things. I've seen Justin talk people through depression, through break ups, even through feelings of suicide. And so when it seems that we're all here because Justin needs our support, we're really here because we need his support. If he'd never been able to come to Kenyon College, we never would have gotten it. The physical proof of Justin's compassion is that his compassion fills buses. The proof of his compassion is in the audience today.

BRENNAN STEELE

My name is Brennan Steele and I am a sophomore at Kenyon College. My Freshman year of college, I was randomly assigned as a roommate to Justin Martin, with whom I have since become very close. As his roommate, I have experienced what it is like to live with someone with a significant physical disability. In the mornings, while I could get up and be out the door within 5 minutes to make it to a class, Justin had to schedule a 30 minute routine into his morning, and his evening, for that matter. Some of his aides could speed this process along to around 20 minutes, but for the most part it was a time-consuming process. As his aides were in and out of the room often, I also got to know many of them well, even receiving Christmas and birthday presents from some of them. This year, I am not rooming with Justin but am sharing an on-campus apartment with him and several of our friends. We are living in an apartment typically reserved for upperclassmen because of Kenyon's willingness to accommodate Justin's needs and keep him on this campus.

GRAEME TAYLOR

I imagine that to many in the legislature, this rule looks attractive as it seemingly serves to control larger overhead costs for the providers program. My own representative, Mr. Carfagna, is very well known for negotiating low contracts for the taxpayers (an attractive quality). I understand why this may seem like a "win-only" scenario. I'm not someone to think that we need to give people "more" than what they need. I do agree with the sentiment that "no one owes you anything" – I think it applies to all. But everyone deserves to have an equal opportunity, and I am fine with, no, I am insistent on my society providing that. It's why I support taxes for public schools, firefighters, and policemen. We don't question the fact that we set minimum standards for everyone's education and safety, but similarly we don't question what we are doing when we impact the health care of the disabled.



As his roommate, I have experienced what it is like to live with someone with a significant physical disability. In the mornings, while I could get up and be out the door within 5 minutes to make it to a class, Justin had to schedule a 30 minute routine into his morning, and his evening, for that matter.

LANE YATES

I met Justin on Facebook during the summer of my freshman year at Kenyon, and we immediately hit it off due to our mutual interests. [...] We became slightly estranged over my sophomore year due to social tensions I was dealing with, and a worsening condition in my mental health. As the summer started up again, we began to rekindle and in my Junior year we started meeting once a week to talk for two hour stretches of time about our aspirations of comic book writing and curating a mini-book club just for the two of us. [...] Because of those meetings, I became progressively more comfortable with myself, and my writing. I felt compelled not to just follow the path of my life as foretold by my parents or my teachers, but to really take a chance on living a life I could be proud of. Justin taught me how to be proud of myself. He's the first person, my mother notwithstanding, who told me any of my writing was worth something. He was the first person I felt comfortable being genuine with at Kenyon, and because of that push he gave me, it has allowed me to live more authentically in my own skin.

HAYLEY YUSSMAN

As you can see, a multitude of Kenyon students are willingly foregoing their normal Thursday activities in order to defend Justin's rights and his ability to continue his education. Some of us know him very well, and others of us are acquaintances who are regularly inspired to action by his powerful presence. But we all have one goal: to illustrate to you why it is absolutely crucial for you to undo your most recent ruling preventing caretakers from working more than 40 hours per week. This ruling effectively prevents disabled persons in rural areas from pursuing higher education, and this prevention is in direct violation of all moral, constitutional, and legal sensibilities. In a place like Gambier, Ohio, where Kenyon College is located, it can take years to locate and secure one or two adequate caretakers. For someone who requires 24 hour care, a limitation on the amount of working hours for caretakers resigns them to a life at home, hopefully with care from family members, and without the promises of societal and educational integration.

RONAN WEBER

I met Justin Martin once here, once there, through eloquent posts on Facebook and friends eager to introduce us. I don't remember when we crossed the line from acquaintances to friends, except maybe as a smile when I cracked a joke about a professor, an offer for coffee, a glance over glasses, passed lemonade, opened cans of juice, scattered snacks, hellos and how are yous and good thank yous exchanged while passing on our separate ways around town. Throughout the first semester I have ever spent away from home, Justin became a figure I aspired to follow, to love, to try to keep up with, both figuratively and literally, because that wheelchair can move when he wants it to. He is also, already, a very good teacher.

LEAH ZINKER

I am a junior at Kenyon College. I met Justin last year in a poetry workshop. His seat was next to mine, and one day he asked me to help him pack his bag at the end of class. This was the moment of fear to which Justin alluded in his own testimony. I didn't know how to respectfully pack up his bag, whether to look at him while I did, whether I should talk to him. So I chatted a little and mostly hummed to myself until I was finished. This fear dissipated after a few classes because the moment was no longer about power, about awkwardness, or about ability and disability. Now, I enjoy packing up for Justin because it provides a moment of togetherness – we can chat, but we don't have to. His request for help was a moment of vulnerability, as was mine of helping. This mutual trust allowed me to overcome the fear, to gain friendship and a commitment to accept the work-in-progress nature of people.

I urge you to prevent the institution of this new rule because it instills a new fear in me. It instills the fear that I will no longer have Justin in my life, that no one else at Kenyon will either, that Justin will not only be deprived of his world but also of the whole world, of his independence. Kenyon would be at a loss without Justin's eloquence, his inquisitiveness, his compassion, and his leadership. Just as he pushes me to write more challenging and more honest poetry, he challenges our whole campus to become a more truthful, a more active, and a kinder campus.

Nonetheless, it wouldn't matter if Justin never wrote poetry, if he contributed little to class, or if he was not a student leader. Justin is a person. Justin, like any other young American, has the right to education, to independence. The American story is often one of individuals reaching beyond their circumstances to pursue life, liberty, and happiness – to aim higher and achieve more greatly than they were able to at the beginning of life. I believe strongly – for better or for worse – in this complicated American hopefulness, and I believe that the government must work to protect the individual, his ability to pursue the possible. This rule deprives my friend Justin and countless others of the possible.

A few weeks ago, I was packing up with Justin after class. I had recently returned from a semester in Europe, and he said, "I missed that humming." Please don't take away the person who notices my humming. Don't take away the person who lets me know my humming is ok. Justin, I'd miss your humming too.



I believe that the government must work to protect the individual, his ability to pursue the possible. This rule deprives my friend Justin and countless others of the possible.



**Disability
Rights** OHIO

We have the legal right of way.

Disability Rights Ohio

50 W. Broad St., Suite 1400
Columbus, Ohio 43215-5923

614-466-7264 or 800-282-9181

FAX 614-644-1888

TTY 614-728-2553 or 800-858-3542

disabilityrightsohio.org