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Health in the Musical Profession: A Human Rights Investigation at the Intersections of Identity, Reputation, and Resources

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Health in the Musical Profession: A Human Rights Investigation at the
Intersections of Identity, Reputation, and Resources

Senior Project submitted to
The Division of Social Studies
of Bard College

By

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Annandale-on-Hudson, New York
May 2020

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INTRODUCTION

When I was just beginning my research for this project, I interviewed a musician whom I'll call Leah whose career and life has changed dramatically due to her health¹. She told me about her experiences trying to adapt to her body's changes due to an injury while striving to meet the performance standard that she had established in her successful career — high standards of excellence which were expected by her employers. When recalling the practice schedule she upheld while working to meet her professional commitments as an injured musician, Leah said,

I would meticulously make these charts of recovery because I was trying to come back and play [concertmaster for a famous music festival concert]. And so I'm practicing five minutes a day, 10 minutes a day, 20 minutes, 20 minutes twice a day. And I would work it up to the first rehearsal. And then I'd be like hmm that's not really working. But I was so determined to come back and play because I really didn't believe that this was as bad as it was. And because I'm a very organized and chill practicer, I just believed that if I did this, I would be able to get through it...Eventually, I realized that my fourth finger was just not going to work. So I started to finger [the piece] using only three fingers, which is kind of crazy, but I thought I might be able to pull this off. I know a cellist once who did something like this, you know. So I thought, I'll see if I can do it...Then, of course, it turned out, since these tendons are connected, that really both of those fingers were down. So then I thought, wow, I wonder if I could just do it with two fingers. And so I wrote that in a couple pages. I was like 'I'm an idiot, you cannot play the violin with two fingers'. So I ended up calling the contractor and having to call [the conductor] and tell him I wasn't able to do it.

Leah's story drew me into the world of professional musicians who are faced with a unique set of challenges when they experience illness, injury, or disability. Her diligent work ethic when practicing her instrument captured my attention, especially when it was self described as "chill". The idea that this meticulous planning and adjusting in response to injury could be framed as "chill" certainly speaks to the intensity of the music field, and the intensity of the

¹ All interviewees quoted have been assigned pseudonyms.

musicians, like Leah, who thrive in it. She worked relentlessly to do everything within her control to adapt to her body's limitations at that time - starting with the four left hand fingers used for violin fingering, and going down to two. Leah took responsibility for her professional commitment, and tried everything she could think of before having to resign from the gig. It was this conversation that reinforced my drive to understand this population of musicians who face illness, injury, and disability, and now, to write this paper to share with you.

Musicians are known for their intense practicing schedules, for centering their lives around their craft, for working so incredibly hard, and for pursuing performance perfection. When musicians get sick or injured, those qualities do not disappear. Musicians continue to work to make their careers work. "Just try harder" is no way to respond to this determined and resourceful community when they are facing a health related obstacle. In most cases, this is the messaging they have already told themselves! Another interviewee, Elise, has multiple chronic illnesses. She told me about the immense pressure to push through discomfort and disability for the sake of continuing with professional performance commitments. She said, "if there is no one who can sub for us, it's dependent on you. If it's a small chamber group and if it's a duo, it's just two of you. There is no finding a sub. The only choice in this type of work is the show must go on, is to work when you're sick. There just isn't a way around it". This idea of having only one option, one that can lead to discomfort and even harm to the bodies musicians work so hard to build, is part of a greater landscape of feeling trapped — within one's own bodily capacities, and within the culture of the music field. This music field culture is the backdrop of these ill, injured, and disabled musician's individual experiences, and it is this backdrop that I hope to bring into

the foreground and make more visible in my examination of each individual musician's experience.

Considering this context in the midst of individual stories of suffering and perseverance, dedication and disappointment, I remember an interviewee I'm calling Jason, who, reflecting on his experience with a performance related injury said, "talking about something just makes it feel less terrifying. If you're able to express outwardly 'this is what I'm dealing with', the more people you tell, the more strength it gives you to deal with it". This is why I am writing this paper. I want to share the experiences of musicians whom I've learned from, who are part of a larger community of ill, injured, and disabled musicians who struggle with their health and its effect on their performance careers. I hope that in doing so, I can bring awareness to this issue. There is so much to learn from this resilient and reflective population.

I feel it is important to acknowledge the position from which I write this paper, as a student of human rights, and as a musician. While it is the former identity that set me on this path to conduct research as part of an exploration of injustice, the latter identity as a performing artist is what shaped the way I approached this topic of musician's health, and the way I discuss the nuanced interactions of illness, injury, and disability on musicians and their careers. I empathize with them as a member of their community. The testimony I give about the music field is not written to incriminate the profession that I care so much about. Rather, it is rooted in research and a broad collection of musicians' personal accounts combined with my love, as the writer, of creating, sharing, and listening to music. Alongside my interviewees, I know and feel, intellectually and viscerally, what the stakes are in the music field as it is today, which fails to provide adequate support for musicians who are living with illness, injury, and disability. This

paper comes out of a passion for music, and the hope that this art form, and the institutional structures that uphold it, can be more transparent, accommodating, and accessible to people who are ill, injured, and disabled.

On a micro scale, my research is about the experiences of my interviewees with their accounts of self advocacy for accommodation as musicians navigating illness, injury, and disability. They individually claim their human rights in a field that does not effectively protect them. On a macro scale, this is a paper that reflects and acknowledges the crucial need for the arts as a key element of creating and expressing culture. As David Krakauer, Grammy-nominated jazz, classical, and klezmer clarinetist shared with me: “the arts are the opposite of corporate greed, xenophobia, and hatred between people. The arts defends the border between civilization and barbarism in our society”². When arts are valued for their contribution to society, the support and protection for artists becomes crucial. Holding these two levels of reality with me throughout this research process, I conducted research into musicians’ complex experiences and suffering at the interface of career and illness, injury, and disability, that goes largely overlooked and unaddressed. I studied the experiences of artists who contribute enormously to our culture and society, while considering the right to culture, including music, as an essential element of civilization, and a tool combatting the divisive rights-violating forces in the world.

My interviews with musicians who had experienced illness, injury, and disability were my favorite part of this project. I was deeply honored by each interviewee’s decision to share their time and experiences with me. I feel so grateful to have learned from their experiences of

² David Krakauer (professional clarinetist), interviewed by Jillian Reed, April 2020.

navigating discrimination, questions of artist identity, and job and financial insecurity, as a result of their challenges with health. To the 15 interviewees reading this paper now: Thank you from the bottom of my heart. I know the responsibility that comes with holding and sharing your stories, and I will do everything I can to learn from your experiences and work, with this paper and beyond, to make the music field a more accommodating and empathetic place to have a human body.

CHAPTER 1: Musician's Dedication to Their Art

Leah's story of determination and dexterity in the face of an injury and professional commitment offers the reader a look into the world of musicians and their dedication to their art. The more this world is explored, the clearer it is that musicians face a unique set of expectations for excellence in their field. Reliability, flexibility and consistent precision of music performance are the qualities most valued by music colleagues and employers. Even more commonly associated with the musician qualities and identity are the artistry of expression and musical storytelling abilities that musicians have; what musicians say with their music. The former set of criteria for a good musician are fully wrapped up in the physical body and its ability to deliver a product again and again. The latter is the mind and soul of a performer, encompassing what one chooses to do with their acquired bodily skills.

Not everyone is inclined to be a musician, but those who are choose it despite the widespread narrative that it is never an easy path. They choose the music field because they love to create and share music. They have something to say with it, and people want to listen. So what happens when their "something to say" goes unshared due to an illness, injury, or disability? What happens when musicians need accommodations to continue to share their art? When musical voices are silenced due to the stigma against addressing musicians health and access to care?

This project was motivated by the observation that, while the music field demands stable perfection, our bodies are constantly changing with aging, illness and injury, adjustment and recovery. No one is fully able bodied for their whole life, musicians included, and discussions

about musician's health, wellbeing, and rights are crucial to prevent unnecessary performance related injuries, and accommodate illness, injury, and disability when cases arise. Unfortunately, these conversations about musician's health seem to happen only in the context of health crises, in scrambles to find musician substitutes, cancelled performances, and lessons of how *not* to practice one's instrument. A human rights approach can provide a useful framework for considering these issues.

Is there a way that ensembles, conservatories, and music organizations can discuss musician's health in a proactive, non judgemental way that acknowledges the human condition as susceptible to illness and injury and corporeal differences? This question hits at the uncomfortable crux of two cultures clashing: one that upholds absolute excellence with minimal consideration for the bodies that deliver it, and the other that promotes human rights with integrated acknowledgement of the foundational needs of bodies. In the face of illness, injury, and disability, many of my interviewees were grappling with these two conceptual frameworks that emphasize different things. The discourse of excellence proved insufficient in addressing my interviewees' needs as musicians with health challenges. In fact, the music culture was at odds with their health, encouraging them to push through their pain and perform despite their physical ailments. We saw this happen with Leah, whose story begins this paper. Her determination to adapt when confronting the loss of her finger dexterity due to injury reflects the exemplary work ethic of musicians. But even her carefully detailed charts and plans B and C were not enough to get her compromised body to meet the standard of excellence at that time for that concert. When unable to perform at the level expected of her, she had to drop out of the concert, which impacted her financially, professionally, and emotionally.

In the best of times, the culture of excellence is a dear friend to musicians. It is what drives us to spend hours upon hours fastidiously refining a five minute piece to share with the world. The results of this hard work can be beautiful, and eye opening and revelatory! However, the culture of excellence has proved inept at aiding musicians whose bodies are ill, injured, or disabled and in need of adjustment, accommodation, or care to be able to thrive (or even survive). Those words and ways of relating to physically and mentally compromised bodies do not translate well to the culture of excellence, thus leaving musicians in a field that has few formal protocols to help them in instances of illness, injury, and disability. Without a framework of protections for musicians built into the value system of the music field, musicians are left in an abyss of compromises and half measures that inconsistently combine professional ethos with often informal health, labor, and antidiscrimination human rights practices. This haphazard confluence of two narratives - one that upholds physical delivery of a consistent product, and the other that advocates for protections for all bodies regardless of their physical abilities - is important to address in order to frame the ways my interviewees talked about their health and career experiences as ill, injured, and disabled musicians. An interesting aspect of human rights discourse is that most people who reference and claim their rights do not do so with explicit "Human Rights" field language. However, I found it useful to make sense of my interviewee's personal accounts through this lens — one that acknowledges the inherent value of the human. A primary example in this paper of a musician claiming their rights was from an interviewee I'm calling Sonya who stated, in the face of chronic illness, "I had to learn very quickly to be my own advocate". Another interviewee, whom I'm calling Kara, described how her relationship to her health changed when she shifted from a framework of excellence, in which her sick body

was a barrier to her success, to that of human rights, in which her body, for its own sake, deserved care and accommodation. She said:

I wasn't trying to figure out what's going on to help my body, it was more to help my career, and I was mad. I was like, I hate my body. I don't want this to be happening to me. And now, this is not what I would choose if I had the option, but it's like, OK, well, this is just how my body works and it works a little bit differently from everyone else's. And that's OK. I just have to live a little bit differently from everyone else.

This tension that Kara described captures exactly what happens when the dominant culture of a field does not incorporate the reality of the human body's fragility into its business plan. When Kara got sick, she first blamed her body for threatening her career, and not the other way around.

As captured in accounts from my anonymous interviewees alongside public stories about famous musicians, we can see that the discourse of excellence is far more prominent and powerful in the music field than that of human rights. The trope of the "tortured artist" is a concept that this field hasn't fully outgrown — one that somehow still exists side by side with the rights-based society that we all live in. Awareness of this discord has increased some dialogue about musician's health, alongside more effort to incorporate the values of self care into the culture of the music field. However, talking about health as a right and talking about health as an occupational asset are two different languages, as we saw in Kara's story. So, when the pursuit of health interferes with musical performance, it is at odds with the very fabric of the music field and its culture of excellence.

With these two dominant cultures considered, we can continue to shift the narrative about musician's health away from individual blame, and explore the larger institutions that shape the culture of excellence in the music field, including conservatories, orchestras, and music organizations. This is an essential starting point to address the needs of ill, injured and disabled

musicians and enact change in the way musician's bodies are viewed and treated. Additionally, this reframing can affect, on an individual level, the way musicians relate to and care for their own health.

Many of the most famous musicians in history have had an illness or disability, from Beethoven's deafness to Schumann's mental illness and institutionalization, to today's Itzhak Perlman with a history of polio³. The health history of these individuals has been integrated into the narratives we tell about them, and even fetishized, their inspiring backstories making the music they produce even more poignant. They are depicted as heroes who have overcome tremendous odds to share their incredible music with the world. And they have. But why have their stories not led to more change in the way the music field relates to bodies facing illness, injury, or disability? This is an important context to consider when reading all of my interviewee's stories in the coming chapters. Their stories of physical, psychological and social suffering as a result of illness, injury, and disability are part of a vast landscape of experiences that include even the most model musicians that the classical music world has seen in the past 300 years.

³ For more information, reference below:

This book discusses one of Beethoven's musical sketches in which he wrote, "Let your deafness no longer be a secret – even in art". Solomon, Maynard (November 1998). *Beethoven* (2nd revised ed.). New York: Schirmer Trade Books. p 162.

Eric Frederick Jensen, "5 Things You Never Knew About Schumann", October 8, 2012, <https://www.npr.org/sections/deceptivecadence/2012/09/20/161482421/5-things-you-never-knew-about-schumann>.

Itzhak Perlman, "I woke up and I couldn't walk": This is the polio that should become just a memory", April 20, 2015, <https://www.jpost.com/Opinion/I-woke-up-and-I-couldnt-walk-This-is-the-polio-that-should-become-just-a-memory-398720>.

Key Terms

First, it is important to clarify the term “musician” and elaborate on the types of careers possible for musicians. This information is necessary to identify musicians and their experiences, and pinpoint the areas of the field that leave musicians most vulnerable in the face of illness, injury, and disability. For this paper, “musician” refers to a professional vocalist or instrumentalist who performs and/or teaches music as their primary source of income, as well as those pursuing degrees in conservatories and music schools. The musicians I am focusing on for this paper are primarily those who live in the United States and are trained in classical or jazz performance. While there are many vocalists and instrumentalists who perform their music “on the side” as a supplement to their income, or simply as a source of pleasure, I will focus on professional musicians who rely on their ability to perform and get compensation for their performances as their livelihood. I make this choice because I am interested in investigating the consequences of reduced ability to work as a musician due to changes in physical ability. Full time musicians are the most involved with the music field that relies on able-bodiedness, and therefore, experience the most severe vocational consequences of reduced physical ability in the face of illness and injury.

Other terms that are important to define here are illness, injury, and disability. These terms will be grouped throughout the paper and occasionally used somewhat interchangeably. Each has different causes, manifestations, and term connotations. However, illness and injury cause changes in physical ability, and disability refers to a physical or mental status that is a deviation from the able-bodied norm. The Americans with Disabilities Act (ADA) defines

disability as “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment”. In contrast, the nondisabled “norm” (whose existence defines disability) is assumed to be able-bodied and able-minded, or physically and mentally uncompromised. While acknowledging that the term disabled can encompass and express the physical and mental experiences and status of a diverse population, in this paper, I will use it when referring to musicians who have a corporeal condition that is outside of what is societally acknowledged as able bodied, those who identify as disabled, and those whose illness or injury has caused a change or ongoing changes in their physical ability as the primary or secondary symptom of their diagnosis. I will use “ill and injured” alongside “disabled” to include musicians who have chronic conditions or have experienced changes in physical ability that have affected their careers and quality of life. Thus, everyone I refer to within the population of ill, injured, and disabled musicians is or has been physically or mentally compromised in a way that deviates them from the idealized standard of the physical norm in a particular and identifiable way. Even though those ways they differ include diverse conditions that are chronic, permanent, and fleeting, deviance from the norm is what unites them as a population.

My discussion of illness, injury, and disability will include music performance-related injuries, including tendonitis, and illnesses that typically affect musicians, like task-specific focal dystonia. However, I am not centering my research on the “occupational hazard” injuries that commonly affect instrumentalists. Rather, I am interested in the ways in which illness and injury, including cancer, broken bones, and panic disorder, which could affect any body, specifically and uniquely affect musicians as a distinct population.

Methods

Before starting this project, I knew that there was suffering of ill, injured, and disabled musicians, and felt that there was room for improvement in the music field as it relates to health difficulties. However, aside from talking to musicians around me, I didn't know the scope of the problem. I started by scouring the Bard library for sources to learn more, looking for formal discourse on this topic that felt so important to me. As a Human Rights and Music Performance dual degree student, I was interested in explorations of health in the music field with a human rights lens. Remarkably, I was unable to find any documented written works or research that explored these issues inclusively - no investigations that look holistically at the experiences and challenges of musicians who face illness, injury, and disability during their careers. Intrigued by the topic and its surprising lack of exploration, I set out on two parallel tracks of research, conducting in-depth personal interviews and distributing an anonymous survey. I became the interviewer, the survey maker, and the ethnographer to learn about this issue from the musicians it directly affects.

Realizing that there was no way to gain an understanding of this diverse population through library research, I conducted interviews with musicians who had experienced illness, injury, or disability. These interviews, which are Bard Institutional Review Board (IRB) approved and protected by strict anonymity measures, allowed me to learn from 15 musicians' firsthand experiences with illness, injury, and disability. Here, I must add that this research likely would have been impossible if I were not a musician myself, with firsthand experience of the nature of the music field, and my own personal experiences with illness. This context and

baseline understanding of what musicians go through while interfacing with illness, injury, and disability not only helped shape the questions I posed at the start of this research, but also gave me credibility and fostered trust with the musicians who chose to share their stories with me. Additionally, I had the support and reach of a wide network of musician peers, colleagues, and mentors who spread the word about my research.

I have maintained the anonymity of my interviewees by removing any personally identifiable information from the pieces of their stories that I share here, and I have assigned each of them a pseudonym. The importance of preserving anonymity is entwined with the importance of researching this topic; it is vital to talk openly with musicians about health, and the career affecting, reputation altering effects of illness, injury, and disability. Because deviations from able bodiedness are often met with stigma, protecting my interviewees with anonymity was the best way I could ensure that my research did not cause any threat to their comfort or livelihood.

Once my head was full of anecdotes of personal experiences and my heart heavy with a new grasp at the complexity of the issues faced by this population, I wanted to understand how common and widespread it is that musicians' health disrupts their careers. The more interviewees I recruited on social media and conversations I had with musician friends and colleagues, the more it felt like musicians whose lives and careers had been changed by illness and injury were everywhere. I decided to conduct an anonymous Musician's Health Survey to get more quantitative data of musicians wellbeing, requests for and delivery of accommodations, and use of performance healthcare services. This anonymous Musician's Health Survey was created in accordance with the Bard Institutional Review Board (IRB) policies. Survey respondents were

recruited through emails and posts shared from my personal social media, including Facebook and Instagram. All survey responses were anonymous, detached from any personal identifiable information including emails and IP addresses. There were also no questions on the survey that required musicians to disclose their instrument, gender, specific work details, or where they live. The two main demographics questions were age range and musical occupation.

Along with the multi-step processes and precautions I took to get my research methods IRB approved, there is the responsibility to carefully contextualize the data gathered with my survey. 200 professional musicians and music students, ages 18+, took my survey. This is a small sample relative to the large population of musicians in the United States⁴. Additionally, due to social media distribution of my survey, it is impossible to know how many musicians viewed the Musician's Health Survey and chose not to take it. Therefore, I do not have a response rate. Due to this limited information, I must emphasize that this survey is not representative of the United States Classical Musician population as a whole. This is a biased sample skewed towards those active on social media and those inclined to take online surveys. Musicians who have close personal connections with illness, injury, or disability may have been more inclined to respond to this survey titled "Musician's Health Survey". Therefore, data collected from the 200 musicians surveyed cannot be used to make generalizations about health in the music field as a whole. However, there is much to be learned from the reported experiences of this selective population of 200 musicians who chose to share their career and health information with me.

⁴ "NEA Announces New Research Note on Artists in the Workforce", National Endowment for the Arts, October 28, 2011, <https://www.arts.gov/news/2011/nea-announces-new-research-note-artists-workforce>.

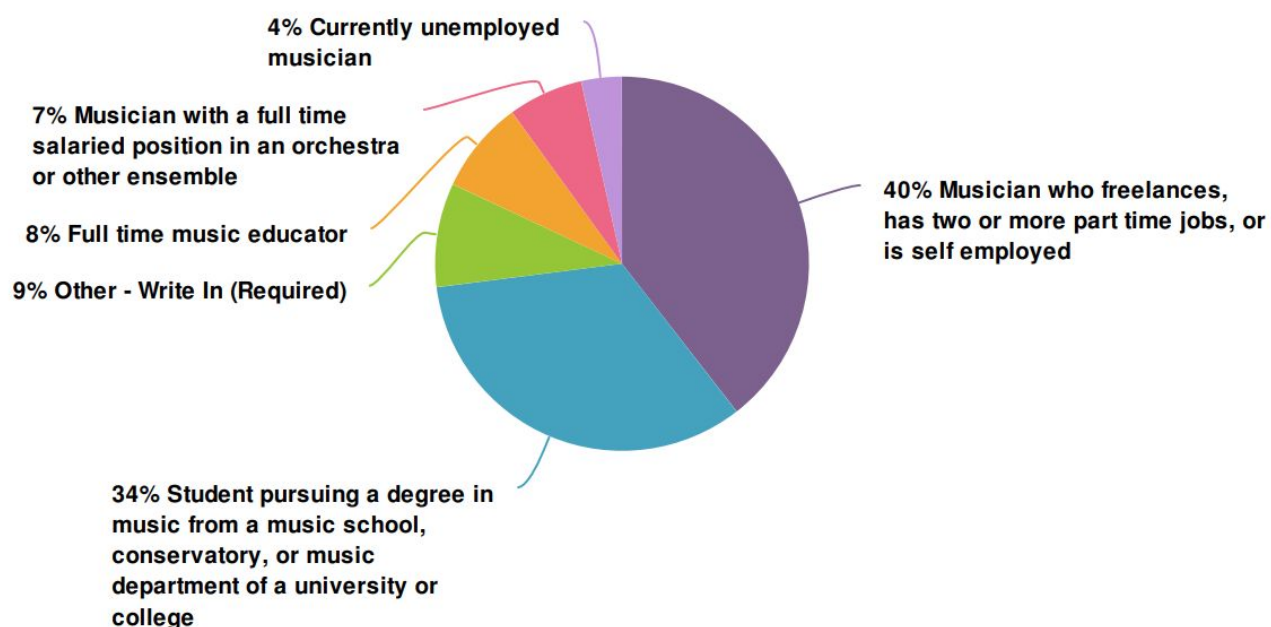
Occupations

Musicians are known for having diverse careers of performance, pedagogy, and entrepreneurship. This comes largely from the reality that it is difficult to make a living from just one contract with a concert series or orchestra. Because most musician's careers have so many components, it is complex to attempt to separate musicians into clearly distinct professional categories. However, surveying 200 musicians, in my Musician's Health Survey, I found that the most common professional category was that of freelancers, those with two or more jobs, and those who are self employed. This category, which going forward I will refer to as freelancers, made up 40% of the 200 musicians I surveyed. Unsurprisingly, given the age of many of musician peers who chose to take the survey, the second largest group represented, 34%, were musicians who are currently pursuing degrees in music performance.

The third most selected response was "other" when survey respondents reported their professional relationship to music. This presented an interesting reminder of what has already been said: most musicians pursue multifaceted career paths that allow them to share their music with various audiences, teach, and piece together a salary. In the write-in portion of the "other" category, some surveyed musicians elaborated on their freelancer status, which includes performance and pedagogy. One described themselves as a "freelance musician who plays in four regional orchestras and teaches/coaches during school hours as an independent contractor", and another is a "Teacher/Performer with 9 years in a professional orchestra, and 30 years touring in chamber music ensembles". Others reported that they were in the midst of changing careers, going part time, or retiring, one as a "Part-time music educator and performer, and a

full-time mom with a doctorate degree”, and another as a “retired full time opera chorus singer”. Finally, others underlined some musician’s reality of holding full time performance-adjacent jobs in conjunction with freelance work on the side. These survey takers, who included “Full time arts administrator and gigging musician”, and “full time music educator who freelances” show in another way the adaptability required in the music field in order to make a living.

1. What is your professional relationship to music?



For a more vivid picture of the busyness and diversity of a freelancing musician’s career, here is Leah’s description of her typical schedule:

I considered an average normal week 21 services a week. That means three things a day. That means if I have one day that I'm not doing that much, I was doing four things. There were weeks that I had twenty eight services. It could be an orchestra rehearsal for three hours, a chamber music rehearsal for two at a friend's house, a jingle recording for an hour and a half, and then a concert. That's what I would call a four service day.

Leah's four service day is not only incredibly busy, but also reflects how utter flexibility and commitment outside of the typical "9-5" is often necessary to maintain a liveable wage.

These profiles of professional musician careers provide the scope of job options for musicians. Having found how common it is for musicians to work as freelancers in some capacity, it is important to consider what makes that type of work unique. Freelance musicians generally work gig to gig, meaning that one performance is often the audition for the next one. Therefore, being at the top of one's field, and presenting oneself as competent, reliable and flexible are incredibly important at all times. Additionally, freelance workers are less likely to have health insurance provided by an employer, making access to medical care when sick, and the question of medical leave, more complicated.

The inability to work while in a profession that is contingent upon being able bodied and reputationally reliable can have deleterious effects for freelance musicians who become sick or injured during their careers. Additionally, unlike full time work and salaried positions, freelance work requires employees to be chosen not just at a one-time interview, but over and over. For inclusivity and brevity in this paper, musicians who freelance, have two or more part time jobs, or are self employed, will be referred to as freelance musicians. The freelancer burden of needing to be hired consistently to piece together work means that reputation is very important. Elise, another interviewee who has multiple chronic illnesses, talked about the unique pressure she feels as a freelancer dealing with illness, reflecting, "I feel like there's this extra struggle to be

resilient and reliable”. With a similar focus on reliability, Sonya said, “I have to work very hard at getting gigs and keeping them and remaining as reliable as I possibly can, and keep myself in good working order and take care of my body. And it can be very stressful trying to manage that all the time”. This begs the question, how could it not be “very stressful” living with the pressure to care for a sick body while asking so much of it for the sake of your livelihood? With the reality that illness and injury can make it difficult for musicians to have the always-guaranteed musicianship that seems to be expected of them, ill, injured and disabled musicians reported feeling immense pressure to prove themselves “worthy” of being hired.

Musician’s Health

Musician’s health, like that of people in every other profession, is a result of endless combinations of genetic predispositions, habits and activity level, food and housing access, and external factors including socioeconomic status, geography, and medical care access⁵. On top of that, occupation and resulting strain produces additional health risks. Musicians are not unique in the way that they get sick, although they often report facing unique struggles due to their occupation and its reliance on dependable bodily performance. Despite the association of “musician’s health” as music performance related injury, it is important to acknowledge that musicians are susceptible to all the same illnesses and injuries as everyone else, with extra physical demand and risk for injury added. Musician’s bodies are whole bodies, subject to more than injury from the precise movements they repeatedly perform for music occupations. This all

⁵ “What are social determinants of health?”, Centers for Disease Control and Prevention, <https://www.cdc.gov/nchhstp/socialdeterminants/faq.html>.

adds up to reinforce that musician's health struggles are not all directly caused by their occupation.

Musicians face the health challenges that people in every other field face — acute sickness, chronic illness, disability, injuries, with the significant burdensome addition of other performance-related chronic and acute injuries. A central theme in this paper will be simultaneously recognizing the diversity of the musician's bodily experience while noting the shared experiences and struggles that ill, injured, and disabled musicians face as those who deviate from the able bodied norm. Viewing the musician as a dynamic and whole person is an important starting place when the goal is to learn how to address the unique health and health-related occupational difficulties experienced by this population.

Why not focus on performance related injuries only, as those are the health concerns most specifically caused by and causing damage to musicians? I am choosing to explore musician's health in a more all-encompassing way, because, as a musician, I know that musicians do not live in a vacuum sealed practice room. We have dynamic lifestyles with varying demands, and we have diverse bodies — there is so much more that can hurt us than repeating a scale sloppily one too many times. This inclusion is not meant to sideline the very real and career-threatening effects of performance related injuries, such as tendonitis and carpal tunnel syndrome, but rather it is meant to acknowledge that addressing musician's health requires so much more than instructing individuals to do a better job at practicing their instruments.

Reputation

Continuing to shift the focus away from narratives that musicians' health struggles are always the responsibility of the individual leads us to a secondary level of complexity: a musician's reputation, which can be found at the intersection of musician's health and music career. A musician's reputation isn't simply one category among many that affects their career; it is the essential determiner of employability, image and success. Therefore, the topic of gaining, preserving, and threatening reputation is central to conversations about musicians' health. The way one is perceived — as successful, reliable, flaky, or inconsistent — has immense power, and can determine whether one is hired, rehired, or fired from work. This is particularly true in the gig economy, in which a musician's performance for one job is often the basis for deciding whether or not they are offered another job. The way they are perceived is as important as the way they perform.

As a result of this truth, some musicians, due to their health status, are left with a tarnished reputation despite their regained or unceasing ability to perform. Therefore, unlike most other fields, musician's health and vocation are not centered solely around cases where physical limitations deem employees incapacitated, unable to do a job, or in need of workplace modifications to make a job accessible. The question is not "can you do the job or not". The question is "why should I choose you, and trust you to do this job?". Sonya discusses reputation as this fundamental facet of music performance careers:

Especially in the professional performing role, there is a great deal of pressure to remain at your A-game 24/7. Always ready for an audition, always ready for a gig, always ready to perform at your absolute tip top. If you're unable to get a gig because you're healing an injury, then you may not get hired by them again. Because they can't rely on you. There's

a stigma that if for any reason you'd have to say no, that those that may hire you can't trust you to be reliable enough for them to want to hire you again.

As Sonya describes, one's ability to be at their "A-game 24/7" is an important aspect of being a musical performer. But ability to perform the job is not the only burden: a musician must also guard their reputation to increase their chances of being hired again. A musician must show employers that they can "rely on you" and trust in your performance ability so they will choose to "hire you again".

So how do health and reputation relate to one another? Health status, when disclosed, can damage musician's reputations and leave them subject to discrimination. This is because illness, injury, and disability *can* render some musicians, in some circumstances, unable to perform. And because of this association, any disclosure of physical ailment or difference, regardless of its affect on individuals' musicianship, can be seen as a liability, thus damaging musician's reputations for the long term. Additionally, anything that deviates from the able bodied established norm is often met with unease and inequity. With the discomfort and uncertainty that can come from interacting with someone who is ill or disabled, (perhaps from reminding others of their own mortality), people are more likely to judge and perceive them as incompetent or undependable. As Rosemarie Garland Thomson, disability studies writer asserts, "Constructed as the embodiment of corporeal insufficiency and deviance, the physically disabled body becomes a repository for social anxieties about such troubling concerns as vulnerability, control, and identity"⁶. This phenomenon of projecting "social anxieties" onto disabled bodies is noticeable in

⁶ Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York, New York, Columbia University Press, 1997), 6.

work environments, when physical difference is mistaken for unreliability. Elise, a flutist and pianist with invisible illnesses, talked about the way her employers and colleagues related to her and her body after she disclosed her health status:

If they aren't sure what to do to help you, they start asking you what you are doing to lessen your burden. Out of that, the conversation can go awry and then it can turn into judgement. Like, 'are you doing what's best for you and your body to be able to do this so that I can count on you? Are you doing all the right things? Oh, is it really the best thing to stay home or are you trying to avoid and shirk your responsibility?'

The quick descent into judgement and assumption of moral flaws or bad work ethic, as described by Elise, captures the skepticism faced by people with disabilities, particularly those whose health conditions are not visible. While harsh, the assumptions of a musician's shortcomings based on their health status is not solely the action of intentionally cruel individuals. Rather, they reflect our culture's ableism enabled by the lack of protection of disabled performing artists. On top of that, there is the simple reality that the music field is a crowded one. With so much competition, it is likely that any reasons to narrow down lists of candidates for job opportunities, while conscious or subconscious, are considered.

On the other side of the reputation conversation is our self-perception as musicians. In a field where expectations are high and competition is huge, there is pressure for musicians to aim for and project flawlessness and consistency. This is an admirable goal as well as a burden, when considering that our bodies are vulnerable to illness and injury. The internalization of these expectations of excellence against the realities of our bodies causes stigma around musicians' experiences of health issues. Stigma is the consequence of the discord between what is expected and what is experienced. It feeds a sense of shame and secrecy that often accompanies illness, injury, and disability in the music world. This clashing of performance pressure and perception,

and the experience of our bodies as musicians, is part of what creates high stress in the music field, particularly in the face of illness, injury, and disability.

Culture Of Silence - Stigma

In this field where reputation has to be maintained and upheld as the determinant of occupational success, anything that could negatively impact it is a threat. Musician's bodies that are anything outside of the expected able bodied "perfection" are seen as a liability, and in order to preserve reputation in the face of illness, injury, or disability, the threat is attempted to be managed by controlling or concealing the narratives around individual musician's health. The idea that musician's health and deviation from health is purely disruptive to reputation and career makes it a topic that is taboo. It creates a stigma of musician's health that is internalized, self-perpetuated by individual musicians, and enforced by the threat of a tarnished reputation and its potential to cause unemployment.

Elise also discussed this tension as someone living with chronic and invisible illnesses. She said, "If you broadcast that you have this illness or something, like, I'm trying to fight the stigma but at the same time in the event that I'm around people who have the ability to give me the job, they wouldn't want to hire me for that reason. I just feel that — it's an invisible illness. A lot of time I show up and I do the job and I go home and people never know that I'm in so much pain". Even in her description of this situation, the Elise was vacillating between fighting stigma by broadcasting her health status, and preserving her reputation and protecting herself from discrimination by concealing her illness. It seems that in the consideration of these two things,

she has often chosen the latter — the one that they have found allows her to continue her freelancing career with a reputation undamaged by others' knowledge of her physical pain.

Providing another perspective of health stigma in the music field, another interviewee, Harper, talked about her experience with the onset of a debilitating chronic illness while a senior in an undergraduate music program. She said that her main instrumental professor was

very supportive, but was very adamant that I not tell anybody that it was a health issue. I was heading into grad school auditions. [They] said, 'don't tell anybody'. My playing tanked, too. And [they] said 'tell people, you're making a technical adjustment'. I can't remember what [they] said to say, but [they were] very clear that I shouldn't [disclose] - and I don't think [they] said it out of meanness but rather protectiveness and an understanding of the industry.

It was this “understanding of the industry” that lead a successful professor, who had the best intentions for their student in mind, to encourage Harper to keep quiet about her health to protect her from facing reputation and future education-threatening discrimination.

There have been increased efforts in recent years to confront the stigma around talking about musician's health, particularly within the field of Performance Healthcare. These important resources will be discussed in Chapter 2. However, these means of tending to the health of musicians and creating more dialogue about musician's health does not single-handedly resolve the issue of reputation and discrimination based on health status. Stigma continues to be at the center of the issue of musician's health because musicians are harmed when their reputations are harmed. Sometimes, the effect on reputation is proportional to the way a musician's illness, injury, or disability has altered their performance abilities. However, in many cases, a musician's reputation is altered after the public learns about their illness, injury, or disability, despite the fact that their ability to perform has *not* been changed in a significant way. Reputation within this culture is shaped by the perceived ability more than the actual ability of

musicians; sometimes this reputation benefits the career success of musicians with health issues, and sometimes it harms it. Because reputation does not have to represent the truth of a musician's performance capacity and the way their disability affects or does not affect their musicianship, it can feel scary and difficult for musicians to manage when their illness, injury, and disability are disclosed in the music world. With the power of reputation comes the stigma of anything that could alter one's positive reputation. This, of course, includes illness, injury, and disability.

A musician friend of mine told me about a big book of musician related injuries and disorders and ways to address them that her professor kept in her studio. Whenever her students exhibited any issues that warranted help from the big book of problems, she would carefully instruct them to read a selected paragraph, and *only* that paragraph that pertained to their challenge. Students would cover the other pages with sheet music while reading, cognisant of the professor-perpetuated fear that reading about other disorders described in the book could cause them to contract them themselves. The same idea was transferred to Task Specific Focal Dystonia, a "movement disorder that interferes with the performance of particular tasks such as writing, playing a musical instrument, or participating in a sport", which is known for ending some professional musicians' careers⁷. When it was brought up over dinner with several of my musician friends, one said, "I mean it's not even something we should be saying out loud". If we are afraid to learn about, hear about, and talk about musician's health, how can we go about properly addressing it?

⁷ "Task Specific Focal Dystonia", NIH Genetics Home Reference, <https://ghr.nlm.nih.gov/condition/task-specific-focal-dystonia>. Accessed May 2020.

This chapter has established that there are certainly issues in the way that musician's health and healthcare is addressed. As we have seen in the accounts of interviewees, this confluence of music field culture, stigma, illness, and disability, leaves a population of musicians with immense physical, emotional, and occupational suffering. But clearly, there is much more information needed to understand the scope of this issue, especially before exploring the elements working to mitigate this issue by aiding and protecting this population.

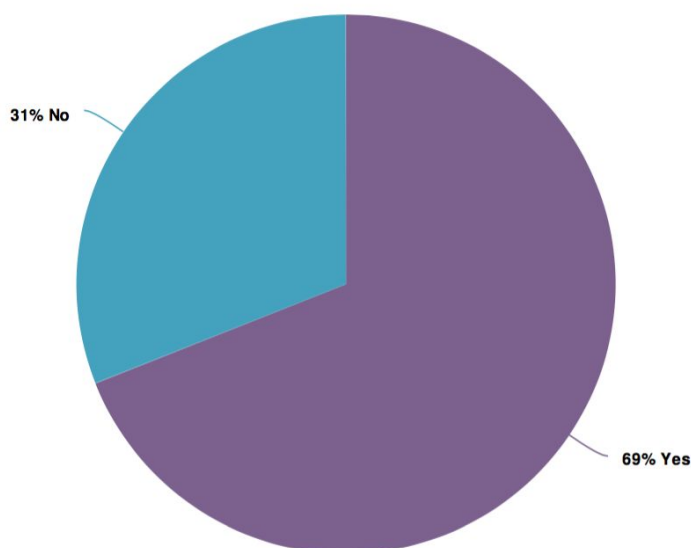
Musicians are living in a tension between the culture of excellence in the music field, and the rights based framework of claiming their inherent value and need for accommodation and access in the face of illness, injury, and disability. Bringing this disharmony of demands to life, clarinetist David Krakauer said "Art is about the struggle of the human condition in all of its amazing messiness"⁸. Musicians seek to create music reflecting the "struggle of the human condition", but while doing so, they are asked to be the opposite of messy. They are asked for performance 'perfection'.

⁸ David Krakauer (professional clarinetist), interviewed by Jillian Reed, April 2020.

CHAPTER 2: Ill and Injured Musicians' Identities

Currently, the external demands of music performance careers do not match the reality of most musician's bodies at some point in their lives, whether that is due to a chronic illness, an acute injury, or a disability. Of the 200 musicians I surveyed, 69% of them reported having or having had an illness, injury, or disability that "limited or interfered with [their] ability to play [their] instrument in a significant way". While that limitation may only last two weeks, or for the rest of their lives, it is important to acknowledge the magnitude here. "Ill, injured, and disabled musicians" refers to 138 out of these 200 musicians at some point in their careers.

3. Have you ever had an illness, injury or disability that limited or interfered with your ability to play your instrument in a significant way?



Value	Percent	Responses
Yes	69.0%	138
No	31.0%	62

Totals: 200

Harper, a former flutist, told me about a time when she did everything she could to meet the expectations in a professional commitment while tending to the primary needs of her disabled body. After taking eight months off from playing her instrument due to her health condition, she said, “I got a call from a group I had played with once before. They were a little bit of a step up to the groups that I had played with previously.” They hired her to perform in an eleven minute piece, and excited for the musical opportunity, she committed. She recalled:

I spent about eight months working my way up to being able to play that. I accepted the gig and I started with playing 30 seconds a day, and every week I would increase another 30 seconds. I was able to get to the point where I hired someone to fly with me to the gig. They took care of me for the week, I hid a wheelchair in a car and lay down during all of the rest just pretending I was like a kind of a musician lying on the floor rather than like, ‘Oh my God, I can barely sit up’ and made my way through it. I was mostly happy with how I was playing, except at the end of longer days of rehearsal. I just couldn't keep the pitch. I kept going really flat because I couldn't keep my airspeed up because again, like my body was just like, ‘yeah, you worked really hard on eleven minutes. This is your fourth hour of rehearsal’.

Harper’s story here is woven together by the interplay of different tensions - the tension between visibility as an artist and as a person who is ill, the tension between fatigue and pushing through, and the tension between a sick body and a musician’s mind. This last strain was reflected in Harper’s conversation with her body. Her comment to her body, “you worked really hard on eleven minutes. This is your fourth hour of rehearsal”, seems to be in response to the musician mentality of pushing through, calling for an acknowledgement of her bodily limitations and needs in the midst of musical performance demands. Her inner dialogue reflects a struggle of identity.

Harper’s story may sound similar to Leah’s, which opened this paper, because this kind of story is not uncommon. Within it, there is so much to learn not just about a musician's individual strength, but about the culture of the music field that leads to musicians going to these

lengths to make beautiful music and meet career commitments in the face of illness, injury, and disability. Harper's experiences as a musician with significant chronic illness brings up several questions about the way a musician's identity is affected by health, and the way that the culture of the music field shapes that identity.

Culture of Music Making

Identifying the scope of the issues faced by physically compromised musicians requires examining the institutions that shape the culture of the music field. Of those institutions, conservatories and music schools are an important place to start. Most classically trained musicians begin their instrumental studies anywhere from age 4-10, and take private lessons in addition to school music programs, with many also participating in regional orchestras, music festivals and pre college prep programs. By acknowledging this, we can see that the culture of the music field is something that many professional musicians were raised with. Thus, the intensive environment that is standard for conservatories and music schools is perceived by music students as part of a logical progression in the culture of excellence. They did, after all, thrive in this music culture long enough to get selected for a conservatory based on an adequate audition. It is at the undergraduate level where most musicians begin their ascent into the professional music world. They study their instruments intensively under the mentorship of their private lesson teacher, they perform in orchestras, chamber groups, and they give solo recitals. Most musicians, while in undergraduate through doctorate music programs, begin shaping their professional reputations on and off campus, gigging, and forming extensive professional networks with other musicians. It is here in these conservatories where musicians also learn what

qualities are most valued in their field; the culture of excellence, the work ethic, and the personal conduct.

When considering conservatories and how they shape these health care practices of musicians, it is important to mention that there *are* resources built into music school programs that facilitate conversations about musician's health with emphasis on performance healthcare and mental health. These programs, including Alexander Technique, and other performance wellness practices, while often only elective classes, begin to address the fundamental need for conservatories to include health and health care practices into the musician's identity and duty. Interestingly, many of my interviewees who went to school in the early 2000s or before recalled having only minimal access to these services in their music school curriculums. It seems that conversations about musician's health, and moving away from the "tortured artist" trope have been increasingly prioritized in recent years in these important institutions. This offering reflects is a cultural shift that is very encouraging to see! But there are fewer discussions about the apparent precariousness of the music field — conversations outside of individual healthcare — about the commonality of ill, injured, and disabled musicians. Alongside this, musicians with illnesses, injuries, and disabilities are rarely recognized for their challenges and enormous artistic contributions in the music field. As interviewee Sonya said so well, as a chronically ill flutist with her masters degree, who spent six years in the United States Army Band:

We need to have conversations that people are living with these issues and they are still able to perform and they are still worthwhile in the music sector and in the industry, and they still have a lot to contribute. I think one of the first places that that needs to start is in our conservatories and universities, because you're cultivating those lifelong views and those lifelong habits when you're teaching these students how to live as musicians, because that's essentially what they're doing, is teaching us how to live as musicians. And just pushing through pain to get through whatever semester it is might not necessarily be the right answer. If we can cultivate that way of taking care of ourselves and understand

that it's OK to slow down our training. And if it's part of our training, then that's going to carry with us throughout our entire careers.

Sonya underscores the power of conservatories to shape not only work habits or technique on musician's instruments, but in a broader sense, to teach us "how to live as musicians". This phrase "how to live as musicians" refers to the unique culture of musicians — the work ethic, importance of reputation and reliability, and the way that subscribing to those requirements, alongside music practice and performance, creates the musician's identity. Within that musician's identity, there is very little space held for illness, injury, or corporeal otherness that can threaten those qualities of reputation and reliability. As Sonya says, conservatories should be more aware of the power and responsibility that comes with shaping musicians' identities when they teach music students to be career musicians. This awareness and transparency must include acknowledging the prevalence of ill and injured musicians, while destigmatizing conversations about musician's health. As part of a more honest look at musician's range of health statuses, conservatories should name and champion the valuable contributions that ill, injured, and disabled musicians make to the music field. This includes not only the music icons Beethoven, Schumann and Perlman mentioned in Chapter 1, but also other successful musicians whose health status didn't change the fact that they "have a lot to contribute".

Many of my interviewees were recent music school graduates or students who talked about the way in which their education shaped their experience with illness, injury, or disability. Jason, a full time freelancing jazz musician told me about his experience with tendonitis when he was in an undergraduate music program. He gestured to the culture of music schools as places that encouraged excellence without advocating for people to take adequate care of their bodies.

He said, “there's the pressure of just being in this environment with great musicians and wanting to improve and wanting to push forward, which is very helpful and necessary. But it can cause people to overexert themselves. Which is what happened to me, I think”. His performance related injury required him to take several months away from his instrument, requiring him to modify all of his performance-based classes.

In addition to the experiences like Jason's, where the culture of conservatories drives students to overexert and injure themselves, there are more complicated cases in which music school culture does disservice to ill and disabled musicians. Kara, who is one solo recital away from getting her degree, reflected on music school as a disabled musician currently on medical leave. She said, “I think the hardest thing about music school is that you get so sucked into music, you don't really do anything else. I don't have any hobbies anymore. So now I'm just like, um, what do I do?” Having dedicated so much of her time and energy to honing her craft, with demands that afforded little time for anything else, her identity became centered around her musicianship. Now that she is living at home and working to meet the needs of her body while practicing her instrument independently, she has reflected on the ways she overexerted her body while at school. Undiagnosed and living with symptoms including bouts of paralysis, extreme fatigue, and pain, she maintained an incredibly full conservatory schedule. She said, “I was very much like ‘school's more important and I'm not really that sick anyway’. It wasn't really until I couldn't focus on school anymore that I realized “Oh, there's a problem. I'm doing more than a person should be doing and also doing it while very ill”. These comments caused me to reflect on this musician's relentlessness in pushing herself, and wonder how long Kara had been operating with those academics-before-body priorities before she “couldn't focus on school anymore”.

Were these self-sacrificing qualities ones that she was shaped to accept as normal in her music studies even before conservatory? Music schools place musical performance excellence at the top in the hierarchy of priorities, which means that health, and the pursuit of healthcare, are often secondary concerns. Kara's story shows how that secondary concern of health often only gets appropriate attention when the primary focus — musical performance — is no longer possible.

When in music school, like Kara, Harper had a relationship to her health that revolved around its effect on her musicianship; how her body controlled her performance as a musician. When reflecting on her illness, which now requires being on disability with caretakers, she recalled,

I would always get a really bad cold four or five days before an audition. I would often lose my voice, which are now symptoms that I have a way of framing and understanding. But at that point, I didn't pay attention to the fact that I always had colds. And I just thought that, you know, I was kind of a bad [musician] and a bad student. I mean, I think that it was really hard on my self-esteem as a musician.

Harper's language "framing and understanding" her symptoms as part of a larger medical issue came much later, after she graduated with her bachelors and spent one year in a conservatory masters program. Her current descriptions of her health experience as a person with a disability were delivered with immense respect for her body. While she was in school, her struggles with musicianship caused by her health conditions were interpreted as a personal failing. After all, her health condition had made it difficult to thrive as a performer, and without open dialogue in her music school about musician's health, and while learning within a greater music field culture that rarely accounts for corporeal differences, she had little other framework provided to her to make sense of what was going on.

Harper's self blame when her body didn't allow her to perform the way she prepared it to was one of the most widely expressed responses to illness, injury, and disability that my 15 interviewees shared with me. Even before the blame, many of the musicians I interviewed talked about the process of first denying that they were sick, reporting the immense pressure they were under, whether from themselves or their employers, teachers, or colleagues. Nadia, a pianist who had a performance-related hand injury said,

I remember a couple of rehearsals early on where I just couldn't really play, but I hadn't really acknowledged yet what was going on. And that was very hard. That was like ego challenging because, you know, it almost felt like, 'wait, you don't have the chops to play this'. What was missing from the conversation was that I can't practice because I'm injured. And then taking a year and a half or so trying to find solutions, that was really soul searching. It was really, really difficult. I'm not going to say that I kept this beacon of light, I knew where I was going, I had faith the whole time and it all worked out. It was a lot more dark night of the soul than that.

Here Nadia captures part of the difficulty of confronting illness and injury in the music world. In conservatories and beyond, musicians often precariously place their self esteem with their performance excellence. And therefore, illness, injury, and disability are not only perceived as a personal failing (as discussed with Harper's story), but also as an impairment of their sense of self worth. The denial that Nadia first experienced was a way of delaying that encounter with her self perception and her place in a culture that left her unprepared for the somewhat inevitable case of illness, injury, or disability.

This denial of illness or injury caused, for many of my interviewees, a delay in seeking medical care. Several interviewees' illnesses and injuries were very severe by the time they got medical help and/or a diagnosis. This presents a serious and pressing problem. With a diagnosis or for those undiagnosed, an external acknowledgment that something was wrong, my interviewees expressed feeling relief. Zoe, a bassist with a master's degree who had dealt with

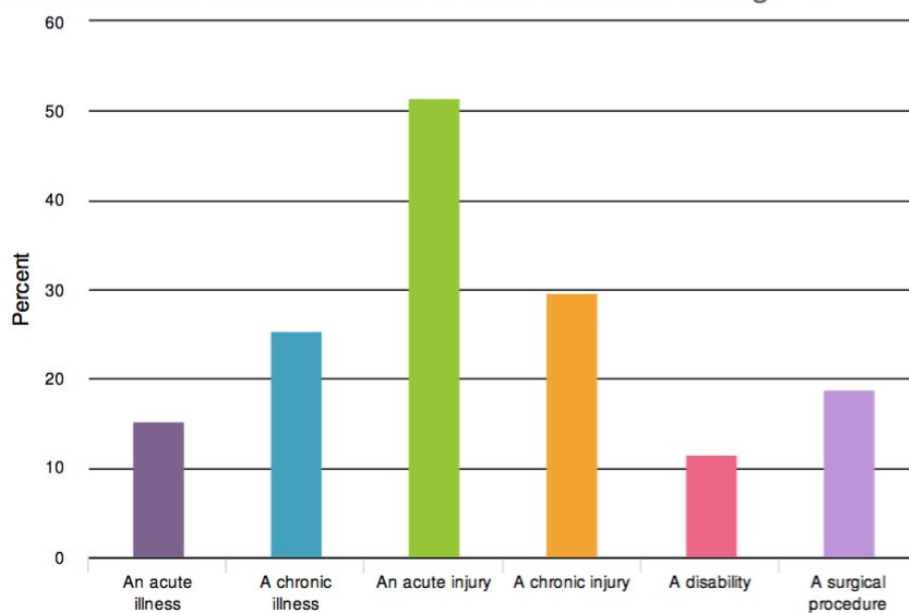
chronic pain associated with playing her instrument said “I went to a hand specialist who told me that I had torn the ligaments in both of my wrists. And then I started treatment for that...I felt kind of relieved to have a specific thing and also it made me feel less like it must be my fault.” Having a diagnosis validated Zoe’s experiences of pain when performing her instrument. This medical intervention further assisted in separating Zoe's self blame from the reality that her injury was not a personal failing or “fault”. All the issues explored in this section stem from the way musicians relate to their bodies, including the delay in seeking medical care and self blame for illness and injury. The musician-body relationship is the product of the culture of music making which shapes the musician identity and the way musicians are taught to occupy their bodies.

Spectrum of Musicians’ Health Conditions

The terms illness, injury, and disability encompass so many different types of bodily conditions, and often types of suffering. When I discuss my research, I use these categories together, unifying the experiences of my diverse group of 15 interviewees, as well as the 69% of the 200 musicians I surveyed who reported experiencing an illness, injury, or disability that significantly affected their career performance. I asked those 138 musicians who had experience with their health deviating from the norm to select which categories best described their illness, injury, and/or disability. Their selections, which could be multiple per survey participant, reflected a diversity of ailments experienced by this population. As shown in the chart below, the most common health concern experienced by my survey respondents was an acute injury, affecting 51%, or 71 out of 138. Beyond that clear outlier, chronic injury and illness were the

health conditions most affecting this population, reported by 29.7%, and 25.4% of the survey respondents respectively. Exploring the different qualities of chronic and acute illnesses and injuries is important to understanding the scope of challenges and experiences that these musicians face.

4. How would you describe your illness/injury/disability? Select all that apply *please note that mental illness is included in acute and chronic illness categories*



Value	Percent	Responses
An acute illness	15.2%	21
A chronic illness	25.4%	35
An acute injury	51.4%	71
A chronic injury	29.7%	41
A disability	11.6%	16
A surgical procedure	18.8%	26

Visibility Of Illness

The visibility or invisibility of one's illness, injury, and disability is a quality that shapes one's experience in the music field. While acknowledging the incredible diversity of all that it means to be ill, injured, or disabled, visibility of those ailments and experiences can open one up to the outside world's relationship to health and able bodiedness. This means, at times, being offered accommodations before asking, and also being discriminated against before having the opportunity to show one's capacity. People are not always sure how to appropriately interact with the embodied reminders of human health fragility. As disability scholar Stacy Simplican says in her book *The Capacity Contract*:

Although one in five people will experience disability in her life, the public presence of disabled people still manages to cause surprise...our anxiety about disability is both aesthetic and existential. Aesthetic anxiety refers to fears about physical bodily differences and the perceived failures of some bodies to attain norms of perfection. Existential anxiety stems from the fear that disability will erode human capacities that are essential to human flourishing and human relationships ⁹.

The anxiety that Simplican described here is the undercurrent of reality that people with disabilities are forced to face whenever their corporeal differences are visible to the rest of the world. This applies to musicians who, as performers, are always being watched and assessed by audience members and colleagues.

There are musicians whose illness or injuries are made visible with their use of a cast, muscle taping, hearing aid, or a mobility device like a wheelchair. And there are those whose medical symptoms are visible with baldness from chemotherapy, panic attacks, or tremors. This

⁹ Stacy Clifford Simplican, *The Capacity Contract: Intellectual Disability and the Question of Citizenship* (Minneapolis, Minnesota: University of Minnesota Press, 2015), 3.

population experiences their bodies “outing” them as ill, injured, or disabled to the world whenever their symptoms or medical or adaptive devices are visible.

This quality of visibility is interesting to consider when recalling Harper’s experience of playing for a gig with an 11 minute piece, and having to lay down on the floor between rests to make it through each rehearsal. I was struck by her decision to hide her wheelchair in the car and not disclose what was going on to her colleagues and employer. In her account of her experience, she did not even consider disclosing her health condition to them at the time. It seemed, instead, she spent all her energy working to maintain her professionalism and deliver her performance at the gig. What a strange music field culture that teaches musicians it’s more acceptable to be perceived as an eccentric, even melodramatic performer laying down during rehearsal, than a disabled musician who is working with her body to perform a piece with excellence. Why did she hide her wheelchair and conceal her disability alongside it? While this question is important to ponder, it is difficult to answer. However, the only reason Harper had this decision was because she could, at the time of the story, make her illness invisible to the outside. Kara has had a different experience with visibility. She said, “I am very visibly ill, not in terms of looking sick, but I mean, I’m in a wheelchair. It’s pretty obvious something’s going on. I don’t fear disclosure because you can see it - there’s no hiding it. So I almost have to be like, ‘yep, this is what I’ve got going on’”. Kara, at the time of her interview, did not see illness invisibility as an option for her, the way Harper did for her gig. The fact that “something’s going on”, visible by the use of a wheelchair, meant that Kara was constantly finding herself disclosing her health status without any choice in the matter.

Zoe shared her experience receiving treatment for the torn ligaments in both her wrists, and how it gave intermittent visibility to her injury. Her hand specialist instructed her to wear wrist braces when not performing her instrument, and also used muscle taping as part of her treatment. This made her deviance from corporeal perfection visible to the outside world, including her musical colleagues. Due to the importance of musician's reputation, and the stigma around open conversations of illness and injury in the music field, as discussed in Chapter 1, Zoe expressed being self-conscious about wearing her protective wrist braces around other musicians. She said, "for a little while earlier this year when I was wearing wrist braces when I wasn't playing, I would wear them to go to orchestra. I was very aware of the looks I was getting from people going into the building. I felt very insecure about wearing them around - it just seemed so visible, like 'there's something wrong with me'". This alertness around visibility is real and socially enforced by the threat of discrimination. However, the injury visibility that made Zoe hyper-aware of other's perceptions of her, and put her at risk for discrimination was the same thing that opened her up to a community of other musicians who have experienced similar injuries. Because, after all, illnesses and injuries among musicians are so common. Zoe said, "there was a handful of people in orchestra with me who have noticed that I've taped something and have started talking to me about it because they're also taping something or have taken time off". Having a physical indicator of an experience, in this case muscle taping, allowed others to understand Zoe and what she was experiencing as an injured musician who was still successful as an orchestral player. When musicians are able to come together over situations of illness, injury, and disability, the isolating individualism of each experience lessens, which can help alleviate individual feelings of fault. Even better, these connections can form communities of

musicians who are able to mutually support one another during times of illness, injury, and disability with understanding and compassion.

Blind Orchestral Auditions

Another place where (in)visibility is an important factor is in orchestral auditions. A necessary gateway to gain, or “win” a performing role in any orchestra, blind auditions are high stakes, demanding, and designed to eliminate bias based on personal connections and gender discrimination^{10 11}. Their design is centered around the use of a screen between the auditioner and the panel of judges, or employers, who are assessing whether or not the auditioner would be able to meet the demands and be a good fit for the orchestra. The screened audition practice did not originate from the first famous orchestras; its conception came much later in the 1970s and 1980s, when orchestras sought to integrate more female musicians into their predominantly white male profiled orchestras¹². In 1981, Jeanne Baxtresser, one of my former flute professors, won the position of principal flutist of the NY Philharmonic, becoming the very first female to hold the position. Toyin Spellman-Diaz, oboist of successful wind quintet the Imani Winds, was one of the first black women to perform in the NY Philharmonic wind section in 1998, and the Chicago Symphony in 1999, respectively.

¹⁰ “Winning a job” is the language many musicians use when receiving a job offer after a successful audition.

¹¹ Claudia Goldin and Cecelia Rouse, "Orchestrating Impartiality: The Impact of 'Blind' Auditions on Female Musicians." (*The American Economic Review* 90, no. 4, 2000), 715-741.

<https://gap.hks.harvard.edu/orchestrating-impartiality-impact-%E2%80%9Cblind%E2%80%9D-auditions-female-musicians>

¹² In the paper “Orchestrating Impartiality: The Impact of ‘Blind’ Auditions on Female Musicians”, researchers Goldin and Rouse stated that “Female musicians in the top five symphony orchestras in the United States were less than 5% of all players in 1970 but are 25% today [2000]”. The percentage of women in orchestras has grown since then, continuing to show the effectiveness of blind auditions in mitigating gender based discrimination in the orchestral musician hiring process.

In my personal studies as a flutist, I have seen first hand the benefits of having “blind auditions”. These policies are in place for orchestral placement auditions at Bard Conservatory, alongside other music schools, and professional orchestras. For these auditions at Bard, women are advised not to wear shoes, such as high heels, that could identify them as women to the adjudicators listening behind the screen, thus eliminating any chance of influence or discrimination based on gender.

In addition to being preventative measures against racial and gender based discrimination, blind auditions are a way to protect musicians with illnesses, injuries, and disabilities that are visible or made visible by medical or adaptive devices. Kara talks about this benefit as someone whose illness is visible with the use of a wheelchair: “Something that sort of puts us at an advantage over other fields is that our interview process is anonymous. They're gonna have no idea that my legs can be completely paralyzed and I could be playing the audition”. This anonymous “interview process” allows for performance skill, and not physical appearance (and the baggage that can come with it) to make the first impression. Unfortunately, there *is* the inevitable moment that happens before hiring when the screen comes down between the interviewee and interviewer. This moment, which occurs for a select number of chosen auditioners, takes place in the final “round” of auditions. Zoe has been taking several orchestral auditions, and with the torn ligaments in her wrists, she thought carefully about her injury’s visibility. She talked about the way she planned to protect herself against potential discrimination based on her health once the protective audition screen was removed:

I took some auditions where I knew that the screen would come down for the last round. So I was thinking ‘if I make it that far, I’m definitely not wearing tape on my wrists when anyone will see me’, because I was worried that that would make me look like a liability. Like they wouldn't want to hire someone who might need to take time off in the future”.

Zoe's planning to protect herself from potential discrimination based on her health reflects the limitations of blind auditions to thoroughly protect musicians with visible braces, wheelchairs, or corporeal differences from discrimination. Certainly, blind auditions are not the catch-all solution to address the potential threat of discrimination that visible disability can pose for musicians pursuing employment.

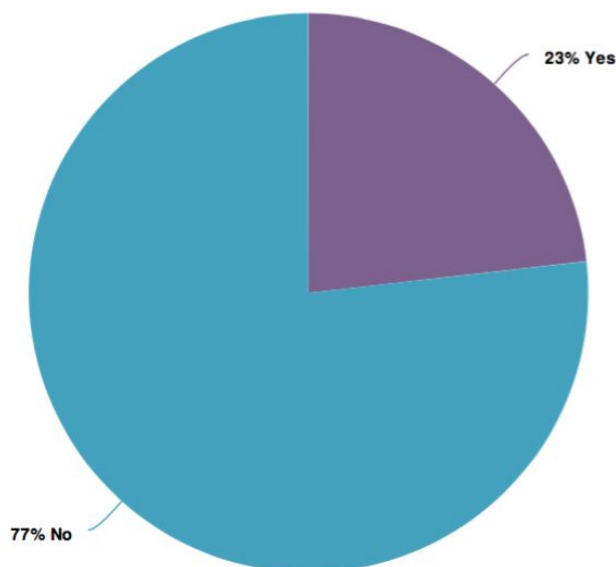
The array of challenges experienced by musicians with visible illnesses discussed in this section could lead one to assume that invisible illnesses must be easier to manage, given that they do not threaten to "out" musicians as physically compromised. However, invisible illnesses pose their own unique struggles and demands on the musicians they affect. Musicians with invisible illnesses hold a great burden of choosing to hide or claim their ailments according to what best serves them, their personal comfort, and their music careers.

Invisible Illness

The conversation of illness visibility inevitably leads to that of invisibility, and the way that having condition that is not apparent to the outside shapes the experiences of ill, injured, and disabled musicians. In my survey of 200 musicians, 138 of them reported experiencing an illness, injury or disability that affected them in a significant way. Of those 138, 106 (77%) live with a condition that is not externally visible. Many of my interviewees are also part of the population of ill, injured, and disabled musicians whose medical conditions are not outwardly visible. Their health conditions include a range of debilitating chronic illnesses and injuries, including chronic migraines, endometriosis, fibromyalgia, carpal tunnel syndrome, and spinal disc herniation. Because of their illness's inconspicuousness, they have the highest chance of

“passing” as healthy based on appearance. Therefore, this population has the most choice in whether or not they disclose their illness/injury.

5. Was/is your illness/injury/disability visible? *this includes visibility from the use of mobility devices, muscle taping, hearing aids, etc.*



Value	Percent	Responses
Yes	23.2%	32
No	76.8%	106
Totals: 138		

My interviewees expressed a range of struggles, benefits, and inner conflicts of having an unnoticeable illness. The invisibility of their deviation from able bodiedness could serve them if they wished to keep their illnesses private. Non disclosure could be a beneficial decision either for their own comfort or their efforts to protect themselves from stigma and threats to their reputation as dependable freelancers. However, for the very same reason it is easier for them to keep their illnesses private, it is more difficult for them to explain their illnesses and needs and

be believed and appropriately accommodated. Elise, who has several chronic invisible illnesses, said:

I think for me personally, this has been a journey of learning how to advocate for the conditions that I have. They're invisible illnesses, they're not something that people can see or equally understand or comprehend. And I have been misunderstood, I've been called a hypochondriac. So there's a constant educating of people of my perspective. And then there's also educating them about my needs not because I want special treatment, but because I want to ensure success with the group, success of the ensemble, success of the event.

Elise needs to advocate for herself, not for “special treatment” but to allow for the creation of the best music possible with a creative process that allows for her physical needs to be met. Her need to press for her own fair treatment, including simply getting her “perspective” heard by her colleagues and employers, is helpful to frame in the human rights discourse. In this lens, Elise is claiming her rights as a musician with a chronic illness. She must advocate for herself because there are no protections and protocols in place in the music field to claim and uphold her rights for her. This advocacy work becomes the burden of each individual because there are no legal policies to protect musicians in Elise’s circumstance. Elise’s need for rights claiming and defending reveals the major gaps in rights protection for ill, injured, and disabled musicians. On top of the task of advocating for herself, Elise needed to make her invisible illnesses believed by colleagues and employers to even justify asking for accommodations.

In addition to Elise, other non-male identified interviewees who had chronic pain illnesses, including Sonya, emphasized the difficulty they experienced when trying to get others to believe the magnitude of their illnesses, and resulting needs. Sonya talked about one of her chronic illnesses, endometriosis, which affects the female reproductive system¹³.

¹³ Endometriosis is a painful disorder in which tissue similar to the tissue that normally lines the inside of your uterus grows outside the uterus. “Endometriosis”. Mayo Clinic,

There is a stigma on its own with Endometriosis. It's very difficult to get a diagnosis. It usually takes five to 10 years and a lot of times women are dismissed because, 'oh, it's just a bad period. You're just tired. Oh, whatever, it's bad cramps. I have bad cramps, too'. And so a lot of women who have that diagnosis are dismissed. There is a stigma with female reproductive diseases that they're not legitimate. And it's very uncomfortable to talk about - a lot of people don't want to talk about those kinds of things. And so bringing those kinds of things up with employers is very difficult, especially with illness and injuries that are considered invisible disabilities. It's not something where you have a cast on or you're in a wheelchair or you have a cane or something like that. So that adds a layer to the difficulty in creating an understanding with others.

Here, Sonya addresses a layer of complexity on top of the conversation of “invisible disabilities”.

Some illnesses and disabilities have stigma that extends beyond the stigma of illness and injury as a whole in the culture of the music world. In her case, the stigmatization of endometriosis has affected multiple areas of her life and livelihood. Accompanying Elise and Sonya, other interviewees reported having their pain dismissed by orchestra managers and colleagues who did not understand or believe the severity of their suffering, and therefore need for accommodation at times. There is a researched and widespread issue of women’s pain (and more specifically, the pain of women of color) not being taken seriously by medical professionals or the general public¹⁴. Not being believed about the severity of one’s symptoms not only undermines the potential support a doctor could provide, but also means that one’s reputation could be controlled by a narrative of being dramatic, weak, or undetermined. Already one can see that there is another tier of complexity in discussing musician’s wellness. The grouping of musicians as a population, and

<https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656>. Accessed May 19th, 2020.

¹⁴ Jennifer Billock, “Pain bias: The health inequality rarely discussed” BBC Future, May 22 2018, <https://www.bbc.com/future/article/20180518-the-inequality-in-how-women-are-treated-for-pain>.

Meghani SH, Byun E, Gallagher RM, “Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the United States”, *Pain medicine* (Malden, Mass.) vol. 13, 2 (2012).

labeling their health struggles as unified would be insufficient without acknowledging the challenges and privileges of some groups of musicians over others depending on gender, race, ethnicity, wealth, and appearance - including illness visibility and invisibility. Musicians have many intersecting identities that can make it easier or more difficult to get proper medical care in the United States medical system. Moreover, these identities outside of musicianship and health can make it more difficult to be believed for having medical conditions, and still valued enough to be accommodated for music jobs¹⁵. This additional layer of strain can cause yet another: difficulty with mental health.

Mental Health

The mental health of musicians is an extremely important subsection of this study, not only because of the way mental illnesses can directly affect musician's lives and careers, but also the way that mental health is affected secondarily when musician's face other health challenges.

Alex, a nonbinary opera singer talked about their experiences with anxiety as a performer:

One of the hardest things is because I'm a singer, and my anxiety and panic attacks will manifest themselves so physically, just being able to even sing shortly before or shortly after experiencing a panic attack, is difficult, especially to perform at the level that's required, you know, at this stage just because to sing you have to be so relaxed and be in the moment and not feel like you need to be in control all the time. And, you know, an anxiety or panic attack is like, 'oh, my God, I'm losing control and I need to be in control' and your chest tightens, and all the muscles specifically around what you use to sing are tight and therefore it's hard to sing. So that's probably the hardest part.

Here, the very physical reality of panic attacks come to light, where the "chest tightens", constricting the very muscles needed to perform, as well as affecting the mental space necessary to be vulnerable and make music. They elaborate on this idea of vulnerability, saying, "When

¹⁵ Naomi Gingold, "People With 'Invisible Disabilities' Fight For Understanding", NPR, March 8, 2015, <https://www.npr.org/2015/03/08/391517412/people-with-invisible-disabilities-fight-for-understanding>.

you're singing or performing, you're being vulnerable, you're putting the musical part of yourself out for the world to see. That's scary in and of itself. But when you're in the midst of anxiety or panic its not always possible". Alex's message brings with it the important reminder that, in some cases mental health can limit musical performance as significantly as physical health, making it "not always possible". As a musician in an undergraduate program, Alex discussed their anxiety in the context of a place where it seemed very common.

I guess the sad reality is like, you know, hardly a week goes by in the [performing arts center] where you don't find someone just having a panic attack like in the hallway, which you know, is bad in the sense of like, you know, the creative community puts a lot of pressures on ourselves and we're probably more likely to have anxiety or depression or whatever. But I always see, you know, at least three or five people stopping to ask if they're okay or need anything, which is, I think, reassuring.

Considering back to the culture of conservatories previously discussed in this chapter, I am struck by how casually Alex framed something that seems like a significant issue that could truly warrant reshaping the way music is taught at the collegiate level. The stress and trauma experienced by this student and those around them is, in their telling, a normalized part of the physical landscape of their academic environment.

Two other interviewees talked about the way their mental health affected their lives as musicians. Dana, a flutist in her second year of a masters program told me about the way her anxiety and depression affected the way she viewed her future as a musician, as well as affecting her performance: "This past year, I thought, 'why am I even here? Why am I doing this?' And I think maybe it's because of all of the extra projects and the extra anxiety where it's hindering the performance and is hindering why I'm doing this". Here, Dana underscores what Alex illustrated in their description of panic attacks: that mental health can challenge, or "hinder" musical performance. Moreover, Dana's questions about her future are not something to dismiss as

baseless, to attribute solely to her mental health diagnosis, or use to make assumptions about her musician qualifications (which are abundant). Rather, her concerns about entering the music field full time are rooted in the understanding that the music field is rarely an easy one to enter and thrive in, even for those with a masters degree. On top of that, as this paper strives to illustrate, it is particularly unaccommodating to those with chronic illnesses, mental and otherwise. Another interviewee, Finley, had similar questions after he graduated from a conservatory masters program. He reflected, “After graduating, I took my longest streak of not opening my instrument case I could remember...just because of being so distraught and just needing so much of a break from it”. Many of my interviewees discussed needing to take time away from instrumental practice due to illness, injury, and disability. Finley’s expressed need to take a break from practicing is equally as necessary for health as a musician with tendonitis requires them to take time away from their instrument.

Leah, whose musical pursuits began in childhood like most classically trained musicians, talked about the way her identity as a musician impacted her mental health in her youth. “The truth of the matter is, I was way too tangled up in my identity as a musician. And to be honest, when I was like 15, I started slitting my wrists all the time, tried to kill myself, all related to playing the violin”. Leah shared this experience with me in a surprisingly nonchalant way, framed casually as part of her broader description of being a musician. The idea that self harm and suicidality could be naturalized in the culture of music as something musicians experience is shocking, concerning, and stresses the desperate need for increased dialogue and action to address the way the music field affects musician’s health.

Disclosure

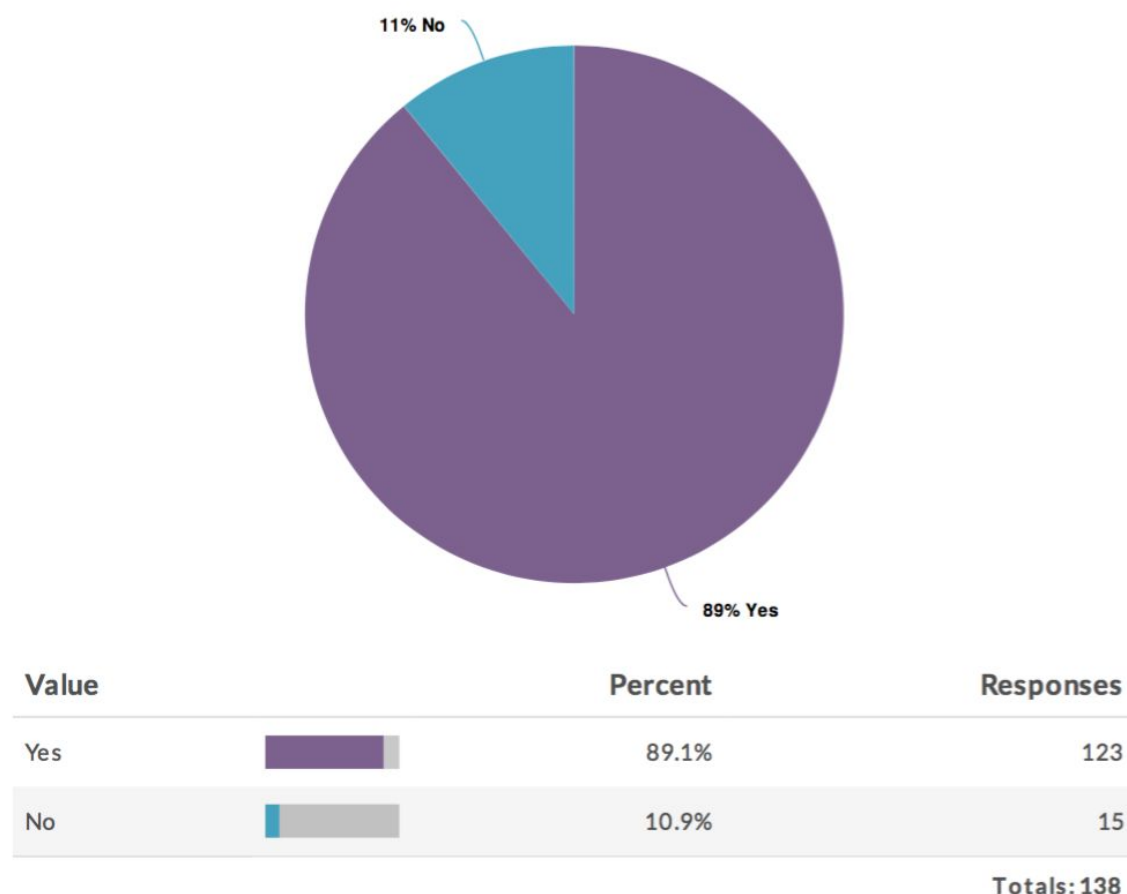
Having discussed the experiences of musicians with visible and invisible illnesses, injuries, and disabilities in somewhat of a binary, here I want to recognize the continuum between visible and invisible health conditions. Whether visibility fluctuates due to the use of arm braces, like Zoe and the torn ligaments in her wrists, or Harper, and her intermittent use of the wheelchair when she took the 11 minute gig and hid her wheelchair in the car, it is always something that affects the way musicians are perceived. Moreover Alex's panic attacks are identifiable from the outside, but not something that everyone who knows them witnesses. Many musicians who can vacillate between illness visibility and invisibility choose whichever appearance they think could threaten their career the least. As we have seen in interviewee's stories, this often means concealing illnesses, injuries, and disabilities.

Musicians with permanent or passing periods of illness invisibility including the experiences of 106 out of 134 musicians surveyed about their illness, injury, or disability visibility who claimed that their health condition was not visible, have the ability to "pass" as nondisabled and/or healthy. Therefore, they have the choice of whether or not to disclose their health status to their employers and colleagues. Nondisclosure avoids external stigma and the chance for discrimination, whether it is done as a personal privacy choice or as a deliberate career decision. Choosing not to disclose one's health status requires one to have a different explanation for any challenges, limitations, or absences they have in their work. As a reminder, there is no legal protective policy acting as an intermediary in the freelance music world; no one to receive a vague doctor's note, discuss and plan accommodations, and offer professional,

legally grounded support when asking for workplace accommodation without the need to disclose diagnosis. In considering these factors, nondisclosure of health status makes a musician ineligible to receive significant accommodations. This puts musicians in the position of needing to choose between their personal privacy and reputation, and their chance at receiving accommodations that could enable continuation of their career.

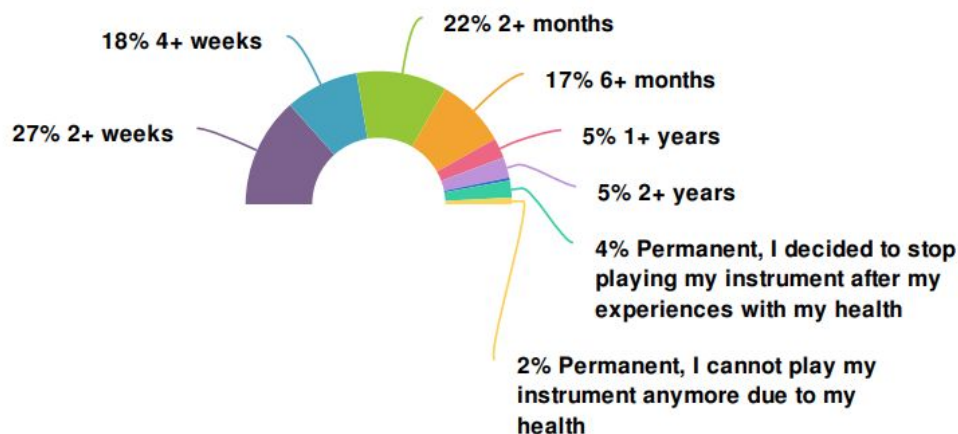
The severity and duration of an illness or injury is another important element to consider with the question of disclosure. For populations of ill or injured musicians who recover within several weeks to several months, disclosure was reported as the best option. This way, they were able to give employers, colleagues, and other relevant people in their field the explanation as to understand why they needed to say no to job opportunities or find substitutes. In turn, they were able to preserve their reputation as dependable and let employers know when they would be available for work in the future. Musicians who have chronic injuries/illnesses have a more complex relationship with disclosure (when it's a choice), communicating with employers, and dealing with periods when unable to work. For them, it is not disclosure of a temporary situation, but rather, the notification of an ongoing circumstance that likely affects many areas of their life. The range of experiences in ailment affect and duration amongst my 200 survey respondents is represented below. 123 out of 138, or 89% of musicians who had an illness, injury, or disability reported that it had prevented them from practicing their instrument for some period of time.

7. Has your illness/injury/disability ever caused you to stop practicing or performing your instrument?



Considering the responses of those 123 survey respondents whose illness, injury, or disability prevented them from practicing their instrument, we can see the wide range, from 2 weeks away from practice, to permanent inability to play, of outcomes for these surveyed musicians who had different ailments. This gives an important reminder that while ill, injured, and disabled musicians are being considered as a unified population, they all face different challenges and durations of illness that determine the effect on their careers.

8. For how long were you unable to perform/play your instrument due to illness/injury/disability?



To continue the conversation of illness visibility and its consequences, below I will discuss my interviewees relationships to the question of health disclosure. Jazz bassist Jason, who had tendonitis while in undergrad shared his positive relationship with disclosure, and how it helped him navigate his professional relationships while he was unable to perform:

I just wanted to be super open about it because there is a stigma about it. Obviously, there is a fear of losing work and stuff like that. But at the same time, I also find that the vast majority of musicians I come into contact with luckily are very compassionate and understanding people. So I was able to explain “this is what's happening”, I would love to play, but I just can't now. Please hit me up again in the future or I'll reach out to you when I'm back and able to do this.

Jason shared that his decision to disclose his temporary injury was easy to make. He chose to be transparent with his professional contacts who wanted to hire him during the time he was unable to play bass. While he did not regret his decision, he reflected,

I can say with almost complete certainty that it probably took me a little longer to get back into the scene once I was able to play. Because obviously if you tell someone I can't play right now, they'll remember that. Plus there's the whole like out of sight, out of mind saying. So the combination of people not seeing me out playing, and some people knowing explicitly that I could not play made it a little harder for me to get back in. But it ultimately worked out.

Even while endorsing the compassion and understanding of people hiring and working with musicians, Jason acknowledges the career setback that declining gigs, and disclosing a less than able bodied health status can cause.

Dana, whose experiences with anxiety are discussed the section on mental health, provides another case in which public disclosure and professional reputation were considered. She told me about her decision to talk about her mental health in a semi - public way on social media while in the spring semester of her masters program. She was “having a really, really rough week”, and decided to post on her professional music Instagram page saying:

‘It wasn't the best week. I really had some doubts about myself as a performer’. Pretty much the platform of the post was ‘you aren't alone. We all have good days and bad days. If you need someone to vent or talk to, I'm always here. Just shoot me a message because grad school is tough. Real life is tough. But we're all in this together’. And within five minutes, my main professor contacted me to take it down because she said it put her studio and the university in a bad light.

Dana's seemingly benign post acknowledging the difficulty of being a graduate music student and performer, and offering support to those who may be in similar positions as her was policed by her professor as harmful to her studio and university's reputation. Dana's story provides another example, this time externally enforced rather than self-perpetuated, in which a musician has to stay silent about their struggles with health out of protection and prioritization of their image over their well-being. Dana, while addressing her teacher in the interview, said, “You only care about you and your professional development. You don't care how I was actually doing, not

once did you ask how I was feeling or how you can help”. Dana’s frustration here comes with the realization that she is expected to maintain not just her own reputation, but also that of her professor and her university. In this way, she had to censor herself to create a more marketable professional identity that did not include mention of any stigmatized health conditions. This censorship is concerning for many reasons, not least of all its dissonance with the idea that artists are important vehicles for expressing vulnerable truths.

Harper discussed concealing her illness to appease her employers of any concern for performer dependability. “I think that there is a sense of right as a contractor, you want to hire people that are going to actually show up and play well, and freelance is pretty brutal for people who have illnesses, so you hide them”. Harper’s idea of an employer’s “right” to a quality artistic product is an interesting angle to explain the reasons musicians conceal their health statuses. Having considered Harper’s reasons for nondisclosure, here is Harper’s story about when and why she decided to disclose:

It was a huge step for me to show a picture of myself in a wheelchair. There was a point when I wanted to start online dating. I was like, 'I want to figure out how to date', but it's very hard when you can't sit up for long or leave the house very easily, so I have to do this online. But anybody can find your profile, so I don't want to put anything in an online profile that I'm not comfortable with a musician knowing. But I want to be really open with whoever I'm dating that these are my health problems.

Harper’s deliberation about posting a picture of herself in a wheelchair on a public forum shows the tension of needs between her in-music identity and outside of music identity. The openness of communication about lifestyle and needs, including health problems, that is essential to building close relationships is the same thing that can be a liability in the professional music world. This creates a situation in which Harper felt like she had to choose what she valued more - open communication that fostered connection, or reputation preservation, which can be

isolating. As her illness maintenance became more demanding, her previously dominant music identity fell out of focus. Reflecting on her chronically ill and disabled identity she said, “Now I’m completely open about it. It was really interesting for me because that was very tied in with my letting go of my identity as a musician. I really felt like as long as I potentially had a future freelancing, that I couldn’t disclose too much”. To be clear, this feeling that she “couldn’t disclose too much” was in no way sourced from individual shame of disability. Rather, it came from awareness of her dependence on a system that discriminates. As explored in Chapter 1, it was Harper’s undergraduate teacher who told her to not disclose her health status to the professors at the graduate schools to which she applied. Harper fully understood the possible repercussions of a musician outing one’s self as outside the able bodied norm, and for as long as she identified as a musician who could have a “future freelancing”, she chose to protect herself from discrimination. With the retirement of her musician identity, she felt free to express herself fully without fear of negative repercussions.

Like Harper, Nadia spoke about her transition into disclosure, sharing the reasons why for a period of her piano performance related injury, she chose to keep her health experiences private. Her reputation and identity as a musician played largely into her decision. As a pianist whose performance related injury was not permanent, she reflected:

I think I was pretty quiet about a long time because I just felt so uncertain. I really rejected the idea that it was going to become part of my identity. I didn't see myself that way. I didn't want to let that be my story. So it took me deeply diving in and retraining my technique and having success over a months and months and months of retraining. It took being on the other side of that before I could really start being open about it.

Nadia did not choose to disclose her experiences with injury until she was certain she was “on the other side” of it, able to assure anyone who learned of her injury that she was no longer a

“liability”. While Harper disclosed her illness when she let go of her musician identity, Nadia shared her health status when she could frame it as a success story, one that maintained, if not bolstered, her reputation of excellence in the music field. As Nadia remarked in her interview, “you're expected to be a machine”. With this expectation, musicians do not want to disclose any weakness that has not been repaired or resolved.

The question of a musician’s disclosure and nondisclosure of illness/injury is central to the conversation about their access to accommodating resources versus their protection from stigma in the field of music. Still, after examining five of my interviewee’s personal accounts of grappling with the decision of disclosure, it is clear that this decision is cloaked in layers of complexity, both from the unique experiences of each individual, and the large structural shortcomings of the music field that fail to protect them. Musicians want to know that when they are vulnerable in sharing their health status and asking for accommodation or support from their colleagues and employers, they will not be discriminated against, or denied opportunities in the future. Unfortunately, there are currently no policies that can protect them in these circumstances. To make matters worse, even if there were legal protections in place, instances of opportunity denial based on health status would be difficult to prove in court in the fiercely competitive gig economy.

Outcomes

Thus far I have explored the scope of the problems facing ill, injured, and disabled musicians regarding their options for (non)disclosure, reputation preservation, and identity in a field that shapes a musician’s identity alongside a performance career. I will now turn to the

outcomes of my interviewees' and survey respondents' experiences with health issues as musicians, with a focus on their identities and ways the systems in place allowed them to unfold.

Within the group of 15 musicians I interviewed, one small subpopulation had injuries, illnesses, and disabilities that, for a large amount of time, or permanently, prevented them from playing their instrument. The rest of the interviewees experienced being mentally or physically compromised in a way that affected their ability to play their instruments, but did not prevent them from doing so. These effects include limited endurance, compromised precision, and considerable pain and/or fatigue accompanying performance. Jason, when reflecting on the musicians in their life who had also experienced an injury, told two stories that exemplify two possible outcomes for musicians who are injured.

I have a friend who's a really great guitar player. Maybe three years ago he got in a really bad car accident. He was OK, except for one of his hands got really fucked up. He was really upset because obviously he couldn't play guitar for a few months. And one of the musicians in Miami who plays with him very often set up a Kickstarter for him and they raised almost \$15,000 for him. But also, you know, everybody just kept checking in on him and saying like, 'yo, man, how are you feeling? Let me know when you feel like you might want to start playing again, because I'll, of course, reach out to you'. And he was already working a ton anyways. He was one of the best guitarists in that area. But when he felt comfortable to get back into it, it was a really smooth and easy transition from what I recall him telling me, because he was a part of this community, you know?

This story illustrates the precariousness of a musician's ability to perform — anyone could get into a car accident like this guitarist. But it also shows the incredible community that is built and maintained in the music world. Musicians look out for each other, each keenly aware of their colleagues contributions to their field, and aware that their colleague's setbacks due to illness, and injury could happen to them. In this story, they supported their friend financially, emotionally, and helped give him a "smooth and easy transition" back into his career once his hand healed. In stark contrast to Jason's first story, he recalled the experience of a bass player

acquaintance who also had an accident that caused an instrumental performance-limiting injury.

Jason recalled:

I haven't thought about this in years, but I did know a bass player who got in a serious accident. I think he was skateboarding or something and he may have broken his wrist or some kind of an injury and he doesn't play anymore at all. So I think whatever happened was serious enough to really impede his ability to play the bass. But I haven't talked to him in so long that I honestly can't remember, and I guess that just goes to show like if someone gets to a point where they're not able to play anymore, then, as sad as this is, it's like that community maybe kind of dissipates.

When this bassist lost his ability to perform due to an injury, he also lost his identity as a career musician. On top of those losses, he lost his place in the community of other musicians who continue to perform. These stories illustrate two different outcomes that are possible within the current structure of the field and the lack of support one receives when illness and injury renders one unable to perform on their instrument.

Identity

The musician's identity and work ethic have been central themes throughout these first two chapters, as integral forces that shape the experiences they have when faced with illness, injury, and disability. I have discussed musician's relentless dedication to making art, the unique role of reputation on musician's careers, and the way stigma and illness (in)visibility affects disclosure and accommodation access. Here, I want to hold a space for exploring the scope of musician's identities, and the way that they have been shaped by illness, injury, and disability. Thus far, depictions of my interviewees could lead to the impression that this population of musicians, or perhaps all musicians, are eccentric, type A, and doggedly determined in a field where it is challenging to find widespread success. I want to acknowledge that the heart of these

identities is the determination to create art. Throughout history, a distinct population of musicians has felt this urgency to contribute to society through their meticulously honed craft. As David Krakauer shared with me, “What we do as artists is our weapon to fight this battle for culture and humanity. We have to perfect our craft to have the best weapon that we possibly can”¹⁶. The relentless pursuit of performance perfection is for a greater purpose than simply proving one’s individual artistic craftsmanship; honing instrumental facility is done to allow for the greatest possible artistic expression of culture.

Renown flutist, educator and Season Artist of the Chamber Music Society of Lincoln Center, Tara Helen O’Connor reflected with me about the powerful allure of pursuing a career in music, despite the numerous financial and personal challenges it presents.

Many dream of a life and career in music but the majority of children who experience the joy of music do not actually pursue it beyond high school. A career in music is a daunting prospect both financially and emotionally. For the select few who become musicians, there is no choice. There was never choice. From the moment they began as children, their desire and drive was so strong, their particular focus was so intense and their deep need to practice for hours on end to create and master the art form was all consuming. Who would choose a life full of financial insecurity, intense competition and the knowledge that it will be a life of failure and success while daily working to attain a goal that is ultimately unattainable? The very same children who pursue their life’s dream of becoming a musician. They are the ones who never question the rigors of the journey and who seem to be put on the path with no other option. It’s as if music had chosen them¹⁷.

Within O’Connor’s description here is the underlying message that a career in music is so much more than that, a career. With this occupation comes a musician identity that is inextricable from one’s body and mind, past work, and goals for the future.

Illness, injury, and disability can have a profound impact on a musician's sense of self and their identity, particularly when considering the reason musicians do what they do. Below I

¹⁶ David Krakauer (professional clarinetist), interviewed by Jillian Reed, April 2020.

¹⁷ Tara Helen O’Connor (professional flutist), interviewed by Jillian Reed, April 2020

will discuss the experiences of several interviewees whose illnesses and injuries caused them to not only change their careers, but also question their identities as musicians.

The Non-Performing Musician's Identity

My first interview was with a musician who I'm calling Avery who left his college's music program after receiving a serious cancer diagnosis at age of 20. He offered a unique reflection on his musician work ethic and identity, and the way that it shifted when he had to change career paths due to illness.

It's a lot different because when you're doing music, you can sort of have a very central idea of who you are and what your goals are. There's always a next logical thing to do, next piece, with very tangible goals and skills that you're building. A lot of life besides music is not like that. So it's a little bit untethering I guess in that way.

The "untethering" that Avery talks about here reflects so much more than simply adjusting to a new career path; it shows the way that the musician's identity can be all-encompassing. When music performance is no longer a viable occupation for him due to his health condition, Avery has to grapple with his identity as a musician, and reassess his goals.

My second interviewee, Leah, whose story starts this paper, is a musician with a long performance career that was altered by an injury. She, like Avery, reflected on the changes in identity that come when performers, due to health, stop performing:

There's a lot of sadness in not being able to do it. But what I've realized is that the music is still there and I'm still a musician. And I don't have to judge myself by how well I played yesterday. That's what I felt like as a concertmaster. I felt like I was only as good as the last note that I played last night on stage...I just feel like it's enabled me to be able to tap into sort of a more generous and less self-centered side of myself now because I do think that ultimately to be a great musician, you kind of have to be narcissistic in a way, because you have to practice all the time and you have to tell people you can't see them.

Leah continues to have a life that is centered around music as an educator, and she no longer allows her value as a musician to be determined by “how well [she] played yesterday”. Her new relationship to music, prompted by her injury, has allowed her to explore different sides of her self, including those that were unable to be in the foreground while she had to “practice all the time”. While her injury required her to change her career, she realized that all the elements of her musicianship, including her work ethic and musical vision, continue to be hers. She is “still a musician”.

Remember Harper’s story from the beginning of this chapter, when she hid her wheelchair in the car and devoted every ounce of her energy to performing an 11 minute piece for a professional gig? From then, to the time I interviewed her, her relationship to music changed significantly, as discussed within the topic of disclosure. When I asked if she has continued to play music after getting her diagnoses and while her conditions worsened, she replied, “No. I can't even listen to music. I have really bad sound sensitivity now. It just kind of gets translated into pain. And I'll hear a symphony that's super standard that I've known my whole life and I won't remember what it is”. Harper’s illness has changed her identity as a musician, and affected her enjoyment as a music consumer. Her 11 minute gig ended up being her last performance.

Since then I haven't been able to play at all. I've at various points tried playing long tones. But what I found is if I do that I have to give up everything else in my life and I still can't really play. And everything else in my life includes making sure that I have care so I can eat. I really need to prioritize those things.

As Harper shows in her story, some illnesses demand the full attention of the bodies they inhabit, making certain careers, in her case, music, an impossibility.

The Ill and Injured Performer's Identity

Fully recovered and 8 years past his experience with tendonitis, Jason reflected on how his inability to perform for a several months threatened his sense of security about his future as a musician.

It was really very, very challenging, at first, especially. I just felt really sad. I was just really upset and very worried that I was going to, you know, not be able to play again. I would have dreams super regularly where I was totally fine. Which was unusual because I usually don't have recurring dreams, but that was one that came up a lot while I was injured was 'Oh I'm totally fine and I can play and its cool' and then I'd wake up and be even more upset.

The reality that his body was getting in the way of him fulfilling his work as a musician was distressing, and it caused him to question if he would "not be able to play again". This peril of identity, the idea he could remain a musician unable to make music, was so powerful that it was regularly carried into his dreams. Having learned from his experience with injury, he said, "Having to take the time off and getting other perspectives made me realize, 'oh, wait, I really need this in my life, I really care about it. And so I need to care for myself and for my body to make sure that I can do this'". He understood on a deep level that the health of his body determined whether or not he could maintain the identity, and accompanying career, of a musician.

Unlike Jason, whose recollections of a threatened musician's identity are in his past, Sonya, who has chronic illnesses, is constantly managing her musician's identity alongside her disabled identity. She told me about her process of grappling with her identities, and how she came to understand how much they affected one another.

I had to go through a mourning process and a healing process of understanding that I was not going to be able to perform the way I wanted to anymore. I had to get okay with

understanding that even though I wasn't performing as much and I was teaching more instead, that that didn't mean that I was any less of a performer. And that didn't mean that I was any less of a musician.

Sonya realized that she could preserve her identity as a musician with so much to contribute to the field, while also acknowledging and caring for the needs of her body.

Kara's experiences with multiple chronic illnesses took her in and out of being able to play her instrument. Her story shows the nonlinear nature of illness, and the ways that it can affect one's performance career in different ways at different times. She recalled, at a flare in her undiagnosed illness, "I was having a lot of problems where my heart rate wasn't consistent. So I was getting dizzy a lot and I passed out at a gig I was playing and ended up having to give up my spot in the performance because I was physically too sick to play". Despite Kara's delays in her performance career, as a result of serious health instability, she reports now:

I've been really lucky to be able to still play after undergoing treatment for my first condition. Because my current undiagnosed condition mostly affects my legs, so they are pretty much constantly affected, but it doesn't affect my arms that often, and usually my arms will go back to normal pretty quickly. So I don't have to deal with my arms being nonfunctioning on a regular basis.

To clarify, when Kara says "affects", she is referring to bouts of paralysis and extreme fatigue that require her to rest and use a wheelchair for mobility. Kara's delivery of her stories was as notable as the experiences themselves; she was so casual and frank in describing passing out at a public gig, a situation that sounded scary and vulnerable for the health aspect alone, coupled with the disappointment of losing a performance opportunity. Moreover, her descriptions of her arm and leg functioning could be perceived as breezing over the significant daily attention they demand and discomfort they cause. I also see in Kara's conversation the importance of being able to depend on her body enough to practice her instrument, something she feels "lucky" to do.

Her nonchalance reminded me of Leah's account of her mental health in her youth, and Alex's description of their school's arts building halls routinely filled with students having panic attacks. I feel the need to pause for a moment to remark and reflect on the normalized suffering faced with resilience by this remarkable group of musicians.

Financial

It would be neglectful to share all these ill, injured, and disabled musicians' experiences in the physical, psychological, emotional and reputational spheres without acknowledging the financial component to this issue. Money is an important part of this population's struggle, because for anyone, career struggles and health struggles almost always pose a financial burden. Whether your health prevents you from performing, or your damaged reputation limits the number of gigs you can get, when you don't work, you don't get paid.

Jason, even as an undergraduate who was not completely financially independent, faced the harsh reality that his tendonitis kept him from playing his bass, and therefore, cut him off from his stream of income. "At that time I wasn't working full time or super regularly as a freelance bass player like I am now. But obviously that was difficult monetarily because I wasn't able to gig". Jason's halt in income while injured caused temporary financial insecurity that would have had a more severe outcome had it happened while he was the full time "freelance bass player" that he is today. Leah's performance-limiting injury came at the height of a full career, unlike Jason's mid undergraduate tendonitis, and this produced a greater financial strain.

I had to pay my mortgage and I had to support my kids. And I couldn't play the violin. I couldn't even fold laundry or wash dishes much less mow the lawn or anything. I was a homeowner by myself and you know, the first month was not a big deal. But then I started think, what if I can't pay my mortgage? I took out a home equity loan on my house and started to use that to pay for things.

Even as a top professional in her field, she did not have access to paid medical leave to support her and her family. In this system lacking supports, she had to navigate changes to her self identity as a musician along with the financial stress that came with being a homeowner and mother while unable to work.

Harper reflected that conversations about money within the music field community are infrequent. “Among the people that I knew, there wasn’t a lot of discussion about financial literacy. So there wasn’t a whole lot of discussion about like this is a precarious field. You should have an emergency fund in case you get sick”. In the music field there is a lack of conversations about money and the reality that illness, injury, and disability can render musicians temporarily and permanently unable to perform. While not always possible for musicians piecing together a salary, there should be more encouragement for musicians to save relief funds for themselves.

The threat of musicians losing income and their very identities due illness, injury, and disability is the undercurrent of this paper. Throughout this chapter, I have demonstrated the complex, high stakes nature of the situations musicians find themselves in when their bodies do not function the way they planned for due to illness, injury, and disability. A large portion of the musician population faces the threat of losing financial security *and* their sense of self at the same time due to two common and natural bodily phenomena: illness and injury. This presents a nuanced and significant problem that needs to be addressed.

There is a reckoning of the true meaning of a musician’s identity in the face of corporeal changes when they limit a musician’s ability to continue to be the artist they once were. Going forward, there must be a broader sense of what “living as a musician”, as Sonya called it, really

is. A person who creates music should be able to hold the identities of musician and disabled concurrently, without one threatening the other. In addition to this cultural shift, I will explore the supports currently in place to address the physical and financial strains on this population in Chapter 3.

CHAPTER 3: Resources and Responses

Organizations

When I asked my interviewees about resources that helped them get through their health and career struggles due to illness, injury, and disability, many responses were focused on individual and community support. They did not cite policies or organizations that helped formally guide them through their career setbacks, financial difficulties, health concerns, and questions of identity while dealing with career-affecting illness, injury, and disability. While my research showed institutional structures of support, interviewees spotlighted cases where individuals helped individuals. Jason, the freelance jazz bassist, discussed both the need for support, and the reason people choose to support musician's careers, particularly during challenging times with health:

I think people are compassionate and understand the importance of caring for the people around them and the world around them. When these things [illness, injury] happen, it's a mix of that compassion and knowing that there aren't certain concrete things we [musicians] can rely on when it gets difficult. That makes people willing and able to go out of their way to help someone in a tangible way, sometimes donating money to a campaign or just reaching out for emotional support.

The focus and reliance on the individual to help musicians in times of illness, injury, and disability is the product of the current patchwork of support that does not offer adequate formal protections for musicians.

This chapter is devoted to exploring the resources for musicians in the United States who wish to take preventative measures to protect their health, or need access to health treatments, legal aid, or funds due to an illness, injury or disability. Having investigated the missions and

capacities of musician-supporting organizations and funds, I have found that collectively, they form a disjointed patchwork of support, rather than an organized overarching system for musicians in need. Even when considered all together, (representing maximum resource access, which most musicians do not have), these services do not fully mitigate the unique struggles of musicians who face illness, injury, and disability. They instead make a patchwork with services that overlap, and holes that leave ill, injured, and disabled musicians in precarious situations and without support.

Investigating the resources available for ill, injured, and disabled musicians is an extremely important aspect of my research. As a whole, it shows that key issues in addressing the struggles of ill and injured musician's are from both a lack of resources, and a failure to access and coordination with existing resources. In the previous chapters, the wide range of experiences and challenges ill, injured, and disabled musicians face have emerged from issues of health and altered ability to perform, reputation, stigma, disclosure, and discrimination of ill/injured musicians. How do different organizations and societal structures come together to address these established issues?

The language of Human Rights studies is very helpful here in categorizing the organizations and systems that support musicians' careers and health. With the discussion of each resource subgroup — relief funds, unions, etc — I will note whether the organizations' missions fall within human rights or humanitarian work, with the exception of the health and wellness care category. More precisely, I will identify whether each organization either asserts or protects human rights legally/contractually, or is one that provides humanitarian charity. The human rights rooted organizations include cooperatives that advocate for labor rights, disability

rights, and access to healthcare. The humanitarian based organizations ground their work in ideas of charity, providing for populations in need with voluntary nonprofit fund and service gifting. These frameworks for addressing issues are conceptually different, and they shape the way that musician's needs and worthiness of support is perceived. Within this charity framework, musicians rely on individual generosity and willingness to accommodate, as mentioned at the beginning of this chapter. Whereas, within the human rights framework, aid is the fulfillment of what is just and deserved.

When musician's aid is framed as a right, it represents a value system where the arts and culture, and those that create and maintain it, are upheld and supported. As discussed throughout this paper, music provides a great service to society. The human right to access culture, including music making, requires protecting artists as essential architects of communication, intercommunity connection, and civilization as a whole. David Krakauer, an internationally renown klezmer, jazz, and classical clarinetist advocates for this model, saying "We need to defend the arts as something of great value that we as artists offer to the society. I believe that society needs to recognize that and come to the table"¹⁸.

In tension with the model of rights claiming and defending, is the humanitarian model, which frames aid as an act of charity and goodwill. In reference to the current 2020 crisis of COVID-19, an interviewee whom I'm calling Donovan reflected on the perpetuated narrative of musicians as being in need of charity, something that he believes fails to acknowledge the tremendous importance of the arts, not for each artist's sake, but for our culture at large:

The New York Times put out this thing where they were talking about arts funding and going, 'OK. Musicians can't play now. So now with the Coronavirus, just give to your favorite artists and think of it as an enormous busking basket, and the artist is playing on

¹⁸ David Krakauer (professional clarinetist), interviewed by Jillian Reed, April 2020.

the street and you throw them a few coins'¹⁹. And I was insulted to the core by that. Because we spend thousands of hours of work to deliver something amazing to the music consumer and the music consumers think of us as beggars. This is just not cool. I mean, we work so hard to deliver something of the highest, highest quality. And with the highest standards. And as I said, you know, we often can spend thousands and thousands of dollars doing it.

As mentioned above, the framework for charity shapes the general public's perception of artists and the importance of supporting music. Describing all musicians as buskers in need of donations reflects the charity narrative, and it affects more than non-musicians' impressions of musicians; it affects musicians' perception of themselves. The tension here is profound, between artists who "work so hard to deliver something of the highest, highest quality", and music consumers (and who isn't a music consumer?), who "think of us [musicians] as beggars". The feeling of being under-acknowledged goes beyond the semantics of conversations about musicians. As explored throughout this chapter, these ideas are found in the very structures of support available to musicians who face illness, injury, and disability.

The differing frameworks of charity and rights are useful to name, because the way an issue is addressed shapes the way people perceive the issue itself. But whether they pursue rights claiming, or request favors/aid, this population of ill, injured, and disabled musicians *is* in need of support to thrive in the music field as it is today, as was evident in Chapter 1 and Chapter 2's explorations. Elise, the flutist and pianist with ulnar neuropathy and chronic pain illnesses, talked about the need for accommodation, and its importance as an equalizing tool. She shared, "to ask

¹⁹ For reference, here is a quote from the article that Donovan was referencing: "So if you like what you hear, donate. Think of the industry as a giant Central Park busker, happy to play but leaving that guitar case open and ready for tips."

Joshua Barone, "The Coronavirus Hasn't Slowed Classical Music", The New York Times, March 31, 2020, <https://www.nytimes.com/2020/03/31/arts/music/classical-music-streaming-coronavirus.html>.

for an accommodation - I had to learn that it doesn't mean that I was less than, it just means that I need things. We're all individual and unique people. There are things that some of us will need in order to have just as positive a contribution as many able bodied people". Here, Elise's sentiment harkens back to the cultures of excellence and rights claiming discussed in Chapter 1.

Acknowledging the fact that we are all "individual and unique" holds space for the reality of corporeal differences, and the reality of different bodily needs. Accommodations and other resources are an important way to account for that reality in a compassionate way. This benefits not only ill, injured, and disabled individuals; it allows community access to the potential of all musicians who have "positive contributions" to the arts to make. In this sense, accommodation in response to rights claiming can, in fact, support the culture of excellence that is so prized in the classical music world.

With an understanding that the ways musicians are aided or not reflects how musicians are considered in society, and shapes the way musicians see themselves in their field, I will now explore the breadth and depth of service organizations for musicians. These organizations whose mission is to support professional musicians include labor unions, nonprofit organizations with financial relief funds, healthcare services that cater to musicians, and other less formal aid structures in place. To fully explore this patchwork of musician-supporting organizations in practice today, I will discuss individual organizations' missions, reach, benefits, and shortcomings while considering how they contribute to the medley of resources available today for this population. I will also consider whether each organization gives their support within the frameworks of rights advocacy, charity, individual informal accommodation, and healthcare.

Unions

When considering resources for musicians with a human rights lens, unions are the clear place to start. However, despite musician's unions' long standing support of musicians, including those facing illness, injury, and disability, Leah, the violist whose story started this paper, was the only one of my 15 interviewees who reported union membership. Her membership was long lasting, and she enthusiastically mentioned, "I actually joined the union when I was 14 years old". Jason, a younger jazz freelance musician, associates musician unions with an older generation, or even a different type, of musician. He was not aware of the resources that could come with union membership:

A lot of musicians that I know nowadays are not in the musician's union. I'm not in the musician's union. My dad is because he's a music educator. So I don't really know if there's anything in place within the union to help protect against the kind of thing if you're out of work because of an overuse injury or something like that. Maybe there are some things in place to help with that. However, when it comes to freelancing, if there is anything, the lines are very blurry. So it's hard for me to say, what would be helpful? Like what kind of system could be in place to help these people out?

To begin to answer some of Jason's questions, I will profile the two primary labor unions available to musicians today: The American Federation of Musicians (AFM) and American Guild of Musical Artists (AGMA). In these profiles, I highlight their missions, what the commitment of joining entails, and any gaps in service or access that needs to be addressed.

American Federation of Musicians

The American Federation of Musicians is the largest, most widely used musician's union in the world. The union has 80,000 reported instrumental musician members from the United

States and Canada. Their union mission statement plants them firmly as staunch human rights advocates:

We are the American Federation of Musicians of the United States and Canada, professional musicians united through our Locals so that:

- We can live and work in dignity;
- Our work will be fulfilling and compensated fairly;
- We will have a meaningful voice in decisions that affect us;
- We will have the opportunity to develop our talents and skills;
- Our collective voice and power will be realized in a democratic and progressive union;
- We can oppose the forces of exploitation through our union solidarity²⁰.

They resolve to “oppose the forces of exploitation” and “build political power to ensure that musicians’ voices are heard at every level of government to create economic opportunity and foster social justice”. AFM brings traditional union goals and practices to the highly specialized field of music.

AFM unites instrumentalists in many different fields, with members who perform with symphonies and theater companies, work as freelancers, and record for digital media, including film, TV and radio, commercials, streaming, and new media. The musician’s union has “collectively negotiated strong contracts with benefits including pensions, healthcare, job security and better wages—including vacation, sick leave, personal time off, and seniority pay” for orchestral and theater musicians²¹. Important labor standards including healthcare, sick leave, and personal time off are not established or protected for many musicians outside the union.

²⁰ “Mission and Bylaws”, American Federation of Musicians, <https://www.afm.org/mission-bylaws/>. Accessed January, 2020.

²¹ “Our Musicians: Symphonic”, American Federation of Musicians, <https://www.afm.org/our-musicians/symphonic/>. Accessed January, 2020.

For freelance musicians, one of the most vulnerable musician populations, AFM boasts the power of unity, saying, “Join together with AFM musicians to have a voice, build power and earn a decent living. Many of us standing together are more powerful than any of us standing alone”²². This call for unity, a trademark of any union, acknowledges the difficulty of making a “decent living” while working independently as a freelance musician. This difficulty is present in the gig economy when musicians are healthy and fully able-bodied, and the shortcomings and risks of freelance work are amplified when musicians are unable to work and perform due to illness or injury. It is also worth noting that the “unity” the union boasts is in contrast to the individualizing experiences of musicians facing illness, injury, and disability, who on their own have very little protection in the face of health status disclosure. Could musician union membership be the solution to the isolating experiences of career threat in the face of health difficulties that my interviewees reported?

Leah, as an AFM member, relied on union-provided health insurance when she became injured and in need of health care, including surgeries. The quality of her union health insurance was determined by the amount of work she had as a musician. As a freelancer, the calculation of her tier of health insurance was based on the amount of work she did in the previous six months.

If you make over the top minimum, you would be on a plan A. Between that amount and a lower threshold, you were on a more basic plan B, and under that you fall off the plan entirely [and lose your insurance coverage]. Because freelancers have so many employers, the calculation of income from performance has to be made on the work you already did, rather than your salary, hence the six month delay [in receiving insurance and losing it after ceasing to perform]. So I was okay for the beginning of the time I was disabled — I was reaping the benefits of having worked so much for the previous six months, so I was on health insurance. But because I was not contributing during that time, I fell off the plan half a year later.

²² “Our Musicians: Freelance”, American Federation of Musicians, <https://www.afm.org/our-musicians/freelance/>, Accessed January, 2020.

Leah's account of one service of the AFM reveals a system designed to exclude any musicians who have an illness, injury, or disability that limits their ability to perform for more than six months. This exclusion reflects the paradox of the employer-based healthcare system, and applies to union provided healthcare as well. When a health condition renders one unable to work and in need of medical care, work and health insurance are lost, and healthcare becomes unaffordable. This applies to Leah's circumstance, and surely many more musicians whose health conditions make it difficult or impossible to perform their musical instrument for their livelihood.

Even with its health insurance coverage shortcomings, the AFM provides a wide net of protection for its union members. Between the advantages of collective bargaining, the community networking opportunities provided by the Locals, and the services tailored to different musicians' needs based on their job and standing contracts, AFM membership is a beneficial opportunity for instrumental musicians. However, membership has a fee, and more significantly, even with the breadth of services and strength in "unity", it does not provide a full blanket of protections that a musician facing health challenges may need throughout their career. We saw the union's limitations with Leah's loss of healthcare when she was unable to perform. Having analyzed the extent of AFM's services, one can imagine the way that AFM could serve union musicians who face career-affecting illness or injury. Any unionized musician would have support with contract negotiation, so presumably there would be disability-related musician protections in those contracts, as with any fair employment contract. Additionally, AFM has a fund for disabled musicians called the Lester Petrillo Memorial Fund, which grants disabled musicians (as defined by the AFM trustees) with "modest amounts of [financial] assistance to

qualified applicants on an emergency basis”²³. This fund could help support an ill or injured musician in crisis, but it would not be able to compensate for not having health insurance, or for the lost income of musicians who lose their jobs or are unable to work due to an illness, injury, or disability.

American Guild of Musical Artists

The American Guild of Musical Artists (AGMA) is a labor union that represents professional vocalists, including opera and concert singers, as well as production personnel, dancers, and concert and dance companies in the United States.²⁴ Their mission, similar to AFM and other labor unions, is to negotiate

collective bargaining agreements for its members that provide them with these vital benefits: guaranteed salaries; rehearsal and overtime pay; regulated work hours; vacation and sick pay; access to low-cost health benefits; good-faith resolution of disputes; and protection of their legal and contractual rights.²⁵

AGMA goes on to say that they “protect the legal, civil and artistic rights of our members, through an aggressive, litigious constant vigilance.”²⁶ This use of the words aggressive, litigious and vigilance, terms often with negative connotations, show the serious stance that the organization takes in the face of any threat to the “legal, civil and artistic rights” of AGMA members. This statement, even more explicitly than AFM, uses rights language to clearly align the mission of musician unions to the work of the Human Rights field. This connection to human

²³ “Petrillo Memorial Fund, American Federation of Musicians, <https://www.afm.org/petrillo-memorial-fund/>. Accessed January 2020.

²⁴ “FAQ Page”, American Guild of Musical Artists, <https://www.musicalartists.org/faq-help/faq-page/>. Accessed January 2020.

²⁵ “FAQ Page”, American Guild of Musical Artists.

²⁶ “FAQ Page”, American Guild of Musical Artists.

rights advocacy is again emphasized on the AGMA website, where they state “Without forceful advocacy and defense of their rights, artists may be vulnerable to exploitation or illegal discrimination. They need protection”²⁷. This claim of human rights defense through AGMA union services both demonstrates the perceived stakes of musician exploitation without union protection, and supports the idea that supporting musicians is something that the collective should be entitled to, with collaboration and “forceful advocacy” of musician’s rights.

There are fees associated with AGMA membership that can be as high as \$3,100 for the first year in the union.²⁸ Inability or unwillingness to pay these fees results in the loss of “Member in Good Standing” renders members “ineligible to work for an AGMA company. If you are in arrears for more than 30 days you may be suspended and incur a reinstatement fee of \$250.00.”²⁹ For an ill or injured musician, this penalty for inability to pay union fees on time could be extremely detrimental. This monetary demand on top of medical bills, contributes to financial stress and hardship. These cases of illness, injury, and disability are when musicians need musician-supporting organizations. Instead of giving support, unions may penalize musicians who are unable to pay dues for any reason. AGMA’s penalty fee and blacklist of union members who are unable to pay are concerning. However, as the only prominent American vocalists union, there is little competition, leaving American vocalists who want to be in a union with the burden of agreeing to AGMA’s terms.

²⁷ “History”, American Guild of Musical Artists, <https://www.musicalartists.org/about-agma/history/>. Accessed January, 2020.

²⁸ “FAQ Page”, American Guild of Musical Artists.

²⁹ “FAQ Page”, American Guild of Musical Artists.

Having researched both AFM and AGMA, it becomes clear that both unions provide services that are valuable to working musicians and are in line with other union missions. They provide valuable resources to musicians with an emphasis on rights. Both unions require a financial investment, and engagement with the organization to get benefits. This is not inherently bad, as engagement and leadership is a fundamental aspect of unions and how they function. But it must be noted that union membership is a commitment that takes time, energy, and financial investment.

Both unions' mission statements use clear human rights language, emphasizing that the fight for their members' rights are the central focus. Musician's rights are addressed as artist and labor rights. As is typical with labor unions, AFM and AGMA's work is based in legal rights with the belief that their work helps provide the protections that everyone deserves and should be entitled to. The AMF Disabled Musician Fund, a service of AFM, however, is an example of humanitarian-rooted gifting. This fund is meant for musicians in emergency situations, and has the disclaimer that it is "not intended to replace health insurance or provide general loans, but does supply modest amounts of assistance to qualified applicants on an emergency basis"³⁰.

Many musicians are not educated about unions or their labor rights in college or conservatory music programs. This lack of formal education about unions brings us back to Jason's confusion about what a union could do for him as a jazz freelancer. Union membership and participation can provide useful services and contribute to musician's understanding of ways they are protected and areas where they may choose to fight for further protection. However, as a rights advocacy organization, they provide very little charity relief funding, besides a negligible

³⁰ "Petrillo Memorial Fund", American Federation of Musicians.

scholarship, for musicians who are facing financial and career setbacks due to medical issues. The AFM's disabled musicians fund could not possibly support all 80,000 AFM members who are bound to have a change in physical ability in response to illness, injury, or aging over the course of their career and union membership. While I assess that the unions are beneficial resources for professional instrumentalists and vocalists alike, it is apparent that these two organizations do not have the resources to address and mitigate the unique and challenging experiences of musicians who face career-affecting illness and injury.

Disabled Musician Funds

As discussed in reference to the AFM disabled musicians fund, charity based relief funds are only effective in extreme situations. Relief funds are not sustainable if everyone applies for them and qualifies to receive them. But as discussed in Chapter 2, most every musician *will* face an illness, injury, or disability at some point in their lives, and many of them will have periods of financial need due to career setbacks caused by their illness, injury, and disability. In extreme circumstances, including the current Covid 19 pandemic, when large populations find themselves unable to work due to illness, the inability of emergency funds to address all musician's emergency financial need becomes clear.

As part of the current patchwork of support for musicians, disabled musician funds do not acknowledge or address the scale of this reality. In her interview, Harper addresses the structural vulnerabilities of life as a musician, with its unsubstantial financial safety net:

If you're supporting yourself along as a musician, you don't have disability insurance the way that you would with a regular job. You don't have unemployment insurance in the same kind of way. And I think that puts you in a pretty precarious situation. Musicians are not getting paid bank. They may not have a year long or six month emergency fund saved up.

As a former professional musician and a chronically ill person who now relies on Social Security Disability benefits to meet her basic needs, Harper is acutely aware of the “precarious situation” most musicians find themselves in.

Among the resources to help musicians who are ill, injured, or disabled, the majority of formal aid is through charity funds that gift money to musicians facing health challenges. The musicians’ funds below is just one from a much larger list, which includes many local and specific grants and resources. All of the funds are non-profit services that are grounded in charity values of helping musicians who are experiencing financial difficulty in the face of illness, injury, or disability that interferes with their careers. There is an abundance of these funds, but they are disjointed and parts of separate organizations. In this way, some areas of need have ample coverage, while other musician’s needs go unaddressed, leaving some demographics within the larger population of ill, injured, and disabled musicians to fall through the cracks. Each fund has a slightly different mission and criteria for selecting who from the applicants to grant their financial support. As an example, the Sweet Relief Musicians Fund considers the applicant eligible if they can document a health diagnosis, a financial need, and “show that at least 50% of their annual income [came] from their work as a musician” before their illness³¹. Below are funds that provide money for musicians who apply and demonstrate financial need as a result of illness or injury, and are deemed worthy by the organization’s mission.

AGMA Relief Fund

Lester Petrillo Memorial Fund for Disabled Musicians

Musicares

Musicians Foundation

Music Maker Relief Foundation

Sweet Relief Musicians Fund

³¹ “Eligibility”, Sweet Relief Musicians Fund, <https://www.sweetrelief.org/request-assistance.html>.

The Actors Fund Disability Support
The California Jazz Foundation
The Dizzy Gillespie Memorial Fund

The existence of these funds acknowledges that musicians are periodically in need of financial assistance when facing precarious situations with their health, ability to work, and in some cases, ability to access healthcare. These one-time sum grants can provide extremely important short term relief by paying a hospital bill or rent, keeping a musician in crisis financially afloat for a brief time. Funds like these fall into the humanitarian framework of aid. As small scale monetary gifts, these funds make up an important, albeit narrow corner of the musician's patchwork of support. They do not address the larger systems that contribute to issues of lack of healthcare coverage, the uncertainty of working in a gig economy, and the unstable nature of being in a field that is so reliant on being able bodied.

While it is encouraging to see efforts to provide financial relief for ill and injured musicians, it is apparent that these funds do not begin to address the structural systemic shortcomings of the freelance music field that leave disabled musicians in need of outside temporary financial assistance. Because these funds are shaped by narratives of charity, they are not something that any musician is, or believes they are, entitled to. Unlike human rights, which are rooted in upholding “the fundamental human rights...the dignity and worth of the human person”, humanitarian charity is more like a gift³². As Fassin writes in *Humanitarian Reason: A Moral History of the Present*, “those at the receiving end of humanitarian attention know quite well that they are expected to show the humility of the beholden rather than express demands for

³² “Universal Declaration of Human Rights”, United Nations Human Rights Office of the High Commissioner, December 10 1948.

rights”³³. In this humanitarian model, ill, injured, and disabled musicians are not entitled to financial aid when their health conditions make it difficult or impossible to perform. They are fortunate to receive help in times of need, but have no right to receive it.

The current 2020 coronavirus pandemic is demonstrating that financial relief funds are essential to aiding musicians within the current structure of our gig economy. Due to the United State’s declaration of a state of emergency and the limitations placed on the size of gatherings permissible in public places, musical performances are being cancelled for the foreseeable future. These precautionary practices, in the midst of a global public health crisis are, when viewing the issue as a whole, a small price to pay. Musicians are moving to online streaming platforms and continue to create, teach, and share music. However, electronic mediums demonetize artistic products, making them much less profitable for the artists than live performances. Musicians are left with the reality that cancelled gigs mean no payment. No payment means that many musicians are struggling to pay for rent, food, and any medical expenses.

As an internationally touring musician, David Krakauer is keenly aware of the way this pandemic has affected the lives of musicians, his own included. He has increased his use and promotion of the membership service Patreon. On this platform, appreciators of his artistry, patrons, sign up to pay him a monthly sum, from \$1 to \$100, for exclusive music videos and recordings he shares with them. Looking beyond the career adaptations needed during this time, he reflects on the larger structural issues that have allowed for this crisis to affect so many individuals, and showcase the shortcomings of our government and culture: “We live in a broken

³³ Didier Fassin, *Humanitarian Reason: A Moral History of the Present*, Trans. Rachel Gomme (Berkeley, California: University of California Press, 2012), 3.

society in the United States in terms of protections for all of its citizens. And I think the Coronavirus has just shown a massive spotlight on that”³⁴. In the face of this brokenness, Krakauer queries whether these obvious structural shortcomings could help us “look at things in a different way and make some changes”.

Of course, a pandemic, while topical, is far from the only situation when emergency fund services are needed. In many cases, including the pandemic, one-time checks in the mail are not enough to support the needs of injured, ill, and disabled musicians. These funds serve some musicians in crisis, but are not a substitute for other ways to support musicians who are facing challenges with their occupations due to their health. Giving a one time stipend does not address the nuanced and interwoven physical, financial, and occupational needs of musicians. One would not expect emergency funds to solve long term problems, but these relief funds are nonetheless a large part of the musicians support network. Sometimes, musicians need this charity, but we also need more protections and long term plans.

Health Insurance and Healthcare Resources

Considering long term plans that can aid this population of ill, injured, and disabled musicians, health insurance is an important place to start. Whether access to health insurance is considered a privilege or a right, it is largely agreed upon as a key resource in maintaining the health of a population. Pertaining to musicians, Jason argued, “I think that healthcare should be universally accessible in general. I think that if you are a musician, that is your livelihood, it's how you make your money, and there should be support available for that”. Jason advocates for

³⁴ David Krakauer (professional clarinetist), interviewed by Jillian Reed, April 2020.

the human right model of healthcare, in which healthcare is “universally accessible” to everyone, including musicians who are making artistic contribution to society. Beyond his assertion that there “should be support available”, is the underlying support structure of health insurance, which organizationally acknowledges that all bodies are susceptible to get ill, injured, or disabled at some point in their lives. The United States of America’s privatized healthcare system where people collectively buy into access to preventative and curative medical treatment recognizes the need to maintain and care for our bodies. Health insurance exists because the alternative of paying all medical bills out of pocket would generally be impossible.

Healthcare is incredibly important for musicians (along with everyone else), and is sometimes difficult to access, no matter the musician’s health status. Early into this project, when I realized that many of my interviewees reported having difficulty accessing quality medical attention and resources, I thought that perhaps all the challenges identified here could be addressed by healthcare! Of course the situation is much more complicated than that; nonetheless, healthcare is essential for those who are ill, injured, and disabled, especially while working in a career that relies on physical performance. For that reason, health insurance, healthcare, and the complications with accessing it, are an important component of my project research.

It is important to learn the different ways that insured musicians obtain healthcare. Additionally, I must acknowledge the prevalence of uninsured musicians, exploring what leads to this issue and lack of a health safety net. The Future of Music Coalition published an article in

2012 called “Healthcare for Musicians: What’s Next?”. In this article, author Daniel Lieberman discusses the issue of uninsured musicians, asserting,

The reasons that so many musicians lack health coverage are largely structural. Musicians routinely work as independent contractors, and supplement their music income with part time employment, which generally leaves employer-provided health coverage out of the equation. Musicians may be able to purchase individual insurance plans privately, but many report that this option is out of their reach financially. While cost is a significant barrier, musicians’ lack of awareness about plans, options and strategies for obtaining coverage is also a factor.³⁵

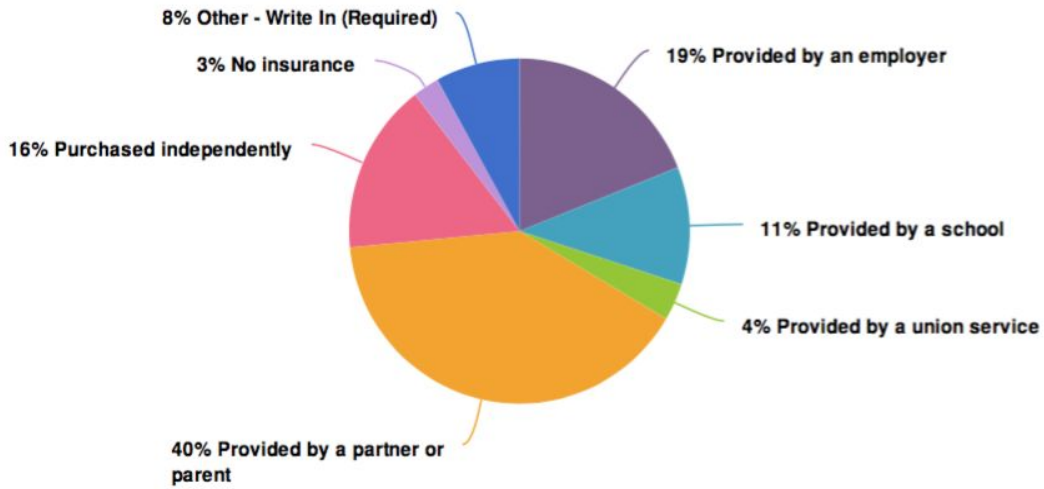
Within this area of research, I must emphasize that lack of health insurance, and insufficient specialized healthcare for musicians are not the sole causes of music career disruption in the face of illness and injury. Many musicians who face illness/injury have health insurance and healthcare providers, and their careers are still severely affected by their disability. That said, affordable, available, and effective health care are vital to the survival and success of musicians who face illness and injury, as with every other population.

Curious about the healthcare access of a population larger than my 15 interviewees, I centered most of my Musician’s Health survey around healthcare and access to health insurance. The 200 musicians surveyed reported access to health insurance through a number of different avenues. Of that population, shown in the chart below, only 5 respondents, or 2.5%, reported having no health insurance. One striking finding was that 80 out of 200 musicians, 40%, relied upon the healthcare of a parent or partner. While some this number could be attributed to the survey population having 65 responses between the ages of 18-24, with many young adults opting to stay on their parent’s health insurance for as long as possible. However, this could suggest that many musicians are relying on the support of other individuals, not larger

³⁵ Daniel Lieberman, “Health Care for Musicians: What's Next?”, Future of Music Coalition, Accessed September 13th, 2019. <https://futureofmusic.org/blog/2012/07/10/health-care-musicians-whats-next>.

organizations, to provide them with health insurance. 38 respondents (19%) reported having health insurance that was provided by an employer, while 32 respondents (16%) purchased their health insurance independently. Despite the 6 given survey responses, there were still two more prominent options that were revealed in the “Other” section: Medicare and Medicaid. These 8+ choices for obtaining health insurance, in which no choice seems categorically prominent in my survey of 200 musicians, reflects the scattered means by which musicians seek to have their fundamental needs met.

18. What is your access to healthcare?



Value	Percent	Responses
Provided by an employer	19.0%	38
Provided by a school	11.0%	22
Provided by a union service	3.5%	7
Provided by a partner or parent	40.0%	80
Purchased independently	16.0%	32
No insurance	2.5%	5
Other - Write In (Required)	8.0%	16

Totals: 200

When talking to my interviewees about their access to healthcare, it became clear that obtaining health insurance was far from the only hurdle they needed to get over to receive adequate medical attention. Leah underwent a significant surgery, and found that in recovery, her doctors were ill equipped to give medical advice about when she could return to her career. She said:

I mean, the funny thing is my second surgeon basically said when he saw me after two weeks, he said, you can start playing again. I thought, really? But in the end, that just shows that doctors - I mean, he's a great surgeon - but doctors don't know anything. I mean, it's really hard to play the violin. You can't just, like, start playing the violin. It does not work this way.

Doctors can be experts on how the human body works, but if they don't understand the complex demands of musical performance, they are unable to give reasonable recovery times for their patients. This could lead to musicians putting themselves at risk of injury, slow recovery, or give musicians unrealistic return to work dates required by their employers or colleagues.

Non-salaried musicians may budget differently, thinking they would be able to work sooner than they could.

Elise also experienced a doctor give music performance advice that was unhelpful and inaccurate:

When I got diagnosed with endometriosis, I had this doctor, who I guess was trying to prepare me for all my options. I'm like, 'I have things that I want to do. I've been trying as hard as I can... But now you're telling me that maybe I can't even play the flute anymore? And said "yeah maybe you might have to [change your career path] when you're gonna spend rest of your life dealing with pain management.

Now a successful musician with a masters degree, this advice was not helpful or true for Elise, nor was it grounded in medical knowledge of the demands of being a musician. Kara also had a discouraging experience with a doctor who was filling in for her primary physician, who

assumed her health issues would deem her ineligible to be a professional musician. Kara recalled “She was like, well, if I was your doctor, I would tell you to quit your instrument or quit playing. I had just told her I was a junior in school for music performance”. These dismissals of ill, injured, and disabled musicians in medical contexts is discouraging and misinformed. Musician’s corporeal differences and health challenges do not disqualify them from having tremendous capacity to contribute to the music world. Doctor’s lack of knowledge and perspective about the requirements of the music field make their music performance related claims tenuous. So what about doctors who specialize in musician’s health and the overuse injuries that commonly affect musicians? This question brings us to Nadia’s story. Nadia is a pianist who experienced a performance related overuse injury in her right hand that affected her career and graduate school education.

I was referred to a hand specialist who had a piano in his office. I was like, how amazing. He had me play for him, which when I look back at that, first of all, no, you don't want to recommend that somebody who's injured and in an inflamed state play their instrument. I felt uncomfortable in that environment. I felt the power dynamic was really messed up. The doctor you know, had the white coat, the structure, the authority in that. And then it was so confusing to me because he's like, ‘here, sit down to play at the piano’, which felt like a piano lesson. But like who are you to watch me play? It was such a strange combination of authority that was very disempowering. I didn't feel heard. I felt put on the spot. I felt like, how are you going to know? I didn't trust that process. I played part of a Beethoven sonata or something. And he goes ‘well, your fortes could have been a little louder’.

This hand specialist’s office that attempts to target the unique needs of musicians evidently missed the mark. He critiqued her musical performance, particularly criticizing that at times it was not loud enough, failing to recognize that putting any significant amount of pressure on the piano keys caused his patient, Nadia, pain. This focus on musical performance over health and wellbeing is absurd in the context of a doctor’s office, and it connects back to the uncomfortable

tension between the culture of excellence and the claiming of the rights and needs of the human body as discussed in Chapter 1. In addition to disregarding the potential harm he could cause by asking a pianist with an inflamed overuse injury to play, this doctor neglected to the emotional vulnerability of being an injured musician pursuing help (and hope) through healthcare. Nadia shared,

At that stated stage of things, I felt withdrawn. I felt like I didn't have a physical body. I felt so detached from myself and my music and so afraid. I was holding my breath like 24 hours a day and trying not to mess it up further. I don't remember a single benefit coming out of the appointment honestly, I just remember the experience being uncomfortable.

Nadia's experience of dissociation as an injured musician illustrates an important layer of suffering and trauma that musicians often face when they are ill or injured. There is immense emotional suffering that comes with the compromised ability to perform when musical performance and musicianship is part of one's identity as well as livelihood. From an understanding of that emotional space, as well as a learned skepticism for specialists who do not fully understand the field of music, Max, a trombonist who experienced Task Specific Focal Dystonia, decided to circumvent the medical model of care for his health issue

I never sought medical attention. I didn't go for a formal diagnosis, I thought it was just a problem that Brass pedagogy would take care of. And to be honest, I'm glad I went that route. My opinion is that a lot of neurologists misunderstand what task specific focal dystonia is as it applies to musicians”.

To expand on the ways that neurologists misunderstand the condition that Max lived with, he explained,

One of the things often prescribed to musicians with dystonia is Botox to deaden the nerves, but that is a Band-Aid and it's a toxic Band-Aid³⁶. It doesn't actually treat the

³⁶ Botulinum toxins are widely used in the treatment of focal dystonias. For more information, see:

P K Nigam and Anjana Nigam, “Botulinum Toxin”, Indian Journal of Dermatology, 2010, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2856357/>.

cause. Focal dystonia in musicians is a learned movement disorder, so deadening the muscles doesn't actually help the neurological signals from the brain to the muscles, so you're not really helping anything. But people listen to their doctors because they're doctors.

Max here addresses the power dynamic in the mainstream medical model that can affect musician's access to quality healthcare that is tailored to the needs of, and demands placed upon, their bodies. He said, "People listen to their doctors because they're doctors", but doctors who have devoted years to medical school and gaining a breadth of knowledge to help a wide array of people with health needs, they are at times unable to be maximally effective when relating to the unique healthcare needs of musicians.

Returning to Nadia's story, her experience with the hand specialist was not the end of her pursuit of healthcare for her performance related injury. She said,

I started out down the path using everything approved from the insurance standpoint, which you could think of as starting fairly mainstream and going into some of the more alternative routes over time when I didn't find success with any of the more mainstream solutions. In fact, something made it worse.

This transition from the mainstream covered-by-insurance appointments to alternative wellness modalities is one that many musicians make. Whether they deviate from mainstream medicine entirely, or they use both mainstream and alternative medicine concurrently, many musicians take advantage of the array of practices and resources called Performance Healthcare.

Performance Healthcare

Nadia's search for medical help for her performance related overuse injury lead her further away from the "white coat" environment of the hand specialist into a holistic practice of

acupuncture, massage, and Chinese herbs, along with a nuanced emotional understanding from her health provider:

I started seeing an acupuncturist in my neighborhood and that was the first treatment I received that helped the symptoms. It was a combination of acupuncture, massage and Chinese herbs combined with her therapeutic approach, just acknowledging what I was going through...There was an intake process where I would sit and share how I was feeling, so it was holistic in that sense. And I felt very safe. It was like this little quiet living room I could go where I felt like it was the only place someone was really seeing the whole picture.

Acknowledgement of this “whole picture”, not solely fixating on her injured hand, or highlighting the extent of its affect on her musical performance, reaffirmed Nadia as a whole person. The acupuncturist was able to identify the ways that Nadia had been susceptible to this injury, address the emotional and physical effects of the injury, and help her more effectively. This help, which brought Nadia out of the state of acute inflammation from her injury, combined with years of retraining with her piano teacher, allowed for Nadia to fully recover from her injury. Nearly 20 years later, she has a dynamic and successful teaching and performing career. Nadia’s story shows alternative medicine’s capacity to help musicians, particularly in cases where mainstream medicine has failed.

This “alternative medicine” described in Nadia’s story is part of a large and vaguely defined world of healing and wellness practices that are outside the realm of scientifically rooted, established, and regulated medical services routinely covered by health insurance. As became clear in the previous healthcare section, many musicians find themselves falling through the cracks of the mainstream medical model, which often does not have adequate specialization to understand and address the unique needs of musicians facing illness, injury, and disability. This shortcoming in one part of the musician support patchwork is what leads many musicians to seek

care through alternative medicine avenues. Many of these services are performing artist specialized, and fall under the subcategory of “Performance Healthcare”.

Performance Healthcare is a broad field of wellness practices that aim to support musicians in caring for the needs of their bodies which face considerable physical demand, preventing performance related injury, as well as offering ways of maximizing the capacity of each musician’s body through mental and physical conditioning. As a field, it has been the keystone in opening up a dialogue about the foundational claim of this paper: the fact that musicians are uniquely at risk of injury from their occupations, just like athletes (whose injuries and bench times are assumed and integrated parts of their careers). This field has put pressure on conservatories to discuss musicians’ need to care for their bodies. Academically based wellness services, Alexander Technique and Feldenkreis, are now incorporated in many music school curriculums. Moreover, the Performance Healthcare field has been integral in fighting the stigma of talking about physical pain that limits music performance, and “playing through pain”. It has opened up a much needed dialogue about the importance of talking about health in this field where physical performance and emotional composure are essential to success. However, this field can have a narrow perspective on all the illness and injuries that can affect a musician’s ability to thrive in the music field as it is today.

Many musicians do not get injured from practicing scales, or ill from orchestra rehearsal. We know musicians lives do not solely entail music practicing and performance. However, the times we talk about music performer’s wellness, we often consider the musician’s life in a vacuum. In this controlled setting in our imaginations, their health is a direct consequence of the way they hold their bow, hydrate and structure their rehearsal schedule. This leads to an

emphasis on individual responsibility, both for the cause of the health status and for its resolution. The focus on individual responsibility leads to musicians' feelings of self blame, and neglects a population of musicians whose chronic illness and disabilities can neither be prevented nor cured by Performance Healthcare or medical intervention. As a professional musician with several chronic illnesses, Sonya called for increased inclusivity in areas of the Performance Healthcare field:

I would really like to see factions of the Alexander technique and body mapping community use the platform that they have, and train their technicians to help their students and patients who have chronic illnesses or injuries. Instead of it all being about injury prevention, I would love to see there be dedicated training with actually working with musicians with these issues.

Sonya here calls for the expansion of two types of performance wellness in order to include the population of musicians whose health experiences are often overlooked in the music field. Kara, as another musician who has chronic illnesses, illustrates how performance healthcare needs a holistic approach that considers chronic health conditions *and* learned performance habits together. She articulated that “You can't separate your illness from issues caused by your playing because issues in your playing could be caused by your illness. So it's this huge web they really can't untangle”. The true interconnectedness of health conditions, movement habits, and occupational demands is at the forefront here. Wellness practitioners need to consider health in an integrated way.

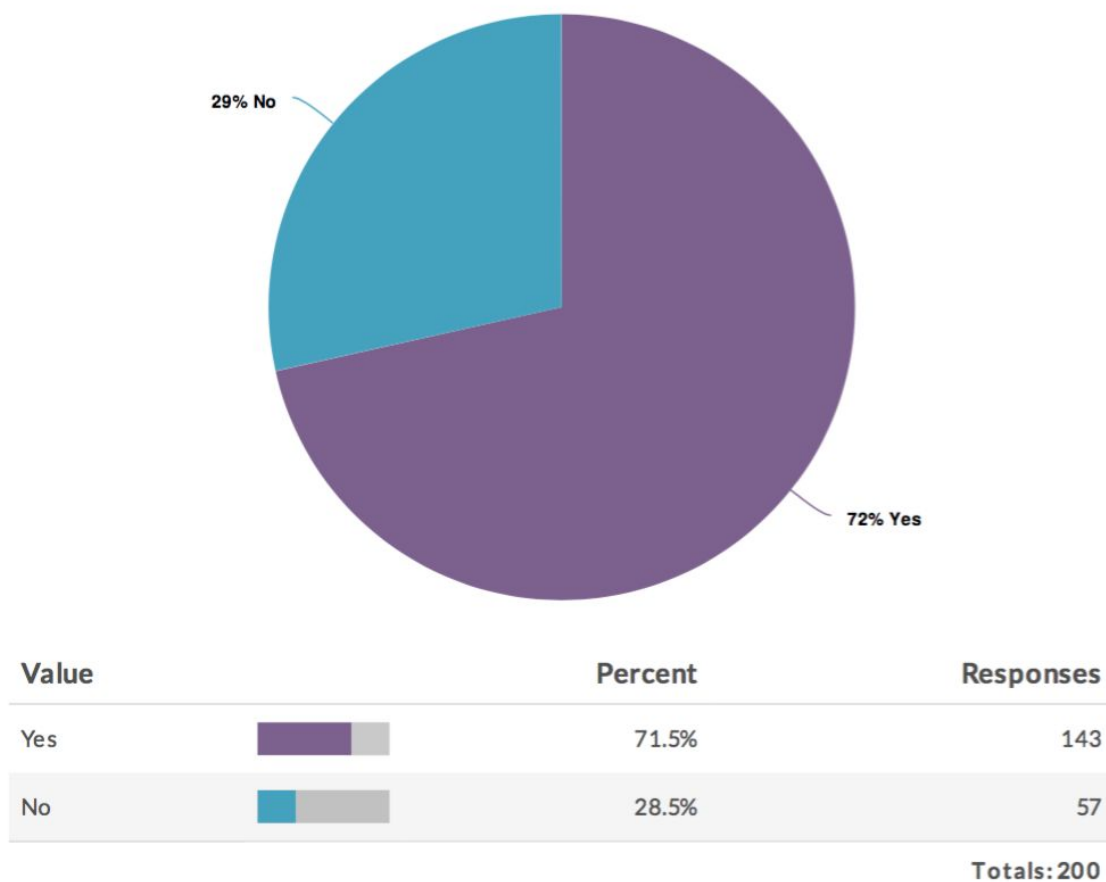
Examples of Performance Healthcare practices are numerous, and will be explored throughout this section. Leah, as a busy and successful freelance musician, utilized numerous performance healthcare services as maintenance for her body which had intensive athletic demands from her career.

I've spent an inordinate amount of money, especially in the last twenty years in my career, paying for either chiropractors or acupuncturist or massage therapists. And I basically would try to see people every two weeks. It's very expensive to go to a city and do that. But I tried to do that and I would also plan it around concerts so that I would get a treatment maybe five days before an important concert.

Leah's routine described here is not unlike that of professional athletes who utilize sports medicine services as part of their physical maintenance. As a musician who relied on her body to deliver consistent musical performance each day, trips to the chiropractor or massage therapist were occupationally worthwhile. However, as Leah mentions, these services, which are frequently not covered by insurance, can cause one to spend an "inordinate amount of money" while filling in the gaps in insurance-covered healthcare services.

Leah's widespread use of these wellness services was also common among the 200 musicians I surveyed. Out of all of them, 143, or about 72% reported utilizing at least one type of wellness service.

19. Have you utilized any music performance healthcare/wellness programs to benefit your health and in turn, career as a musician? For example, Alexander Technique, massage, acupuncture etc.



The clear majority of these 200 surveyed musicians, as well as the 15 musicians I interviewed chose to utilize these healthcare services during their career. Some of the surveyed musicians reported using performance healthcare services even when they had reported never experiencing a significant illness, injury, or disability that affected their ability to perform their instrument. This suggests that, while mainstream medical care, aside from annual physicals, is based on referrals and targeting issues, this world of alternative medicine and healthcare is oriented toward *prevention* as well as illness and injury treatment.

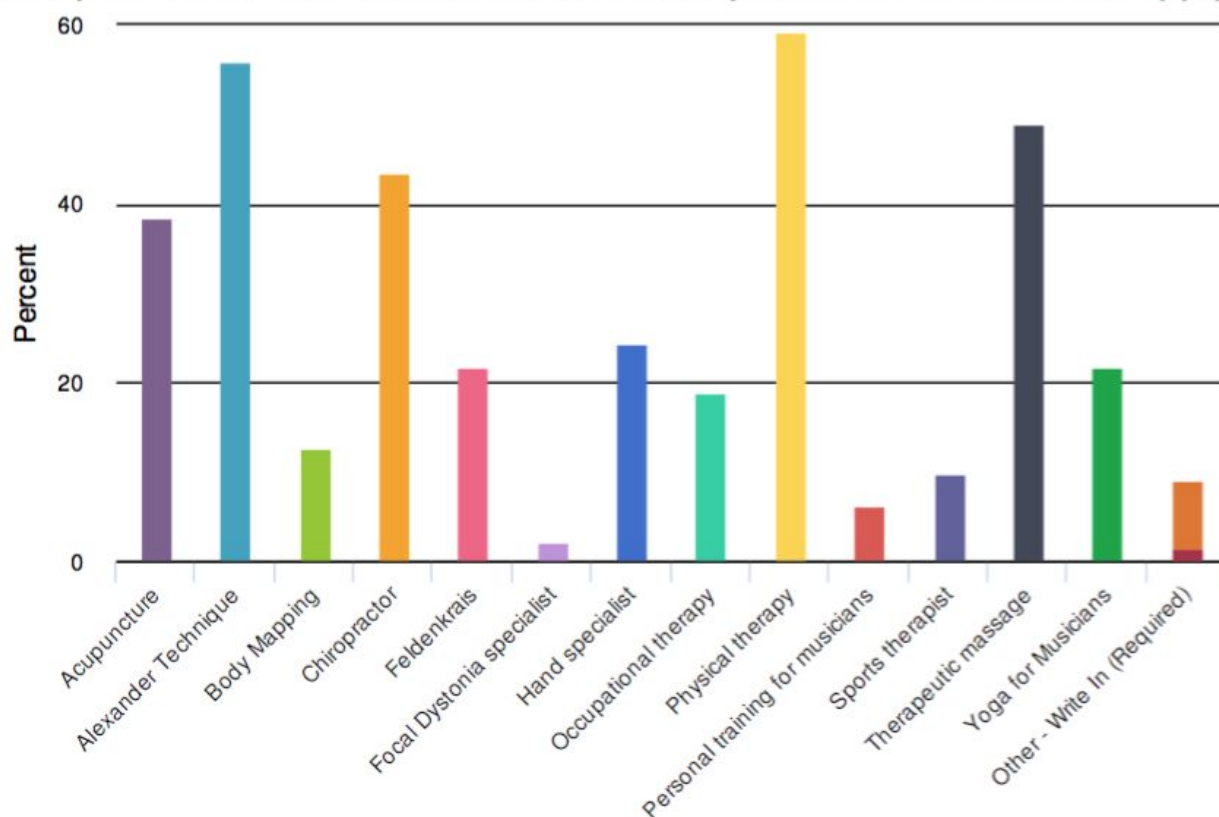
An example of musician health maintenance through performance healthcare comes from Finley, my interviewee who shared his experiences with anxiety and depression as a flutist who just completed graduate school. While in graduate school, he went to his school's Alexander Technique teacher. He described how much Alexander technique benefited him as someone whose health struggles have caused him to disconnect from his instrument: "It's really been helping to strengthen my relationship with my instrument because it becomes a part of my body". This holistic approach which addresses the musician's body as a whole, and then acknowledges the unique demands on that body due to the performance of a musical instrument was incredibly helpful for many of the musicians I interviewed. Elise, a flutist and pianist who experienced mechanical issues due to chronic migraines, among other chronic illnesses and injuries, told me about pursuing care from a chiropractor:
















I was with a chiropractor right at the end of my masters while I was having all the mechanical issues [due to severe chronic migraines] and this person's specialty was sports medicine. She saw the connection between sports medicine and medicine for musician's bodies because what we do is very physical...She would ask me questions like, 'how do you hold your instrument? I want to know what parts of your body get the most wear and tear from holding your instrument'. I feel that that affected some of her decision making in determining how to make adjustments on me.

Acknowledging the musician's body as one with athletic demands that can benefit from "sports medicine" is incredibly important when working to ease performance related pain and prevent overuse injury. In Elise's case, where her chronic illness was the source of instrumental performance limitations, the chiropractor was able to acknowledge the underlying health condition of her body while working to understand the occupational strains she was working under.

The 143 surveyed musicians who reported using performance healthcare, like Nadia, Leah, Finley, and Elise, took advantage of a wide array of services that are grounded in acknowledgment of the musician's whole body, and the unique stresses it undergoes as an instrumental performer.

21. Which performance healthcare services have you used? Select all that apply:



Value		Percent	Responses
Acupuncture		38.5%	55
Alexander Technique		55.9%	80
Body Mapping		12.6%	18
Chiropractor		43.4%	62
Feldenkrais		21.7%	31
Focal Dystonia specialist		2.1%	3
Hand specialist		24.5%	35
Occupational therapy		18.9%	27
Physical therapy		59.4%	85
Personal training for musicians		6.3%	9
Sports therapist		9.8%	14
Therapeutic massage		49.0%	70
Yoga for Musicians		21.7%	31
Other - Write In (Required)		9.1%	13
Other - Write In (Required)		1.4%	2

It is unsurprising that so many surveyed musicians, as well as my interviewees, chose to try and regularly benefit from performance healthcare services, considering the way they are framed and marketed to musicians. Performance healthcare, a broad category of support modalities, aims at aiding musicians' wellbeing, and is often promoted as a way to boost one's performance ability, be it through injury prevention, improved stage presence, or increased

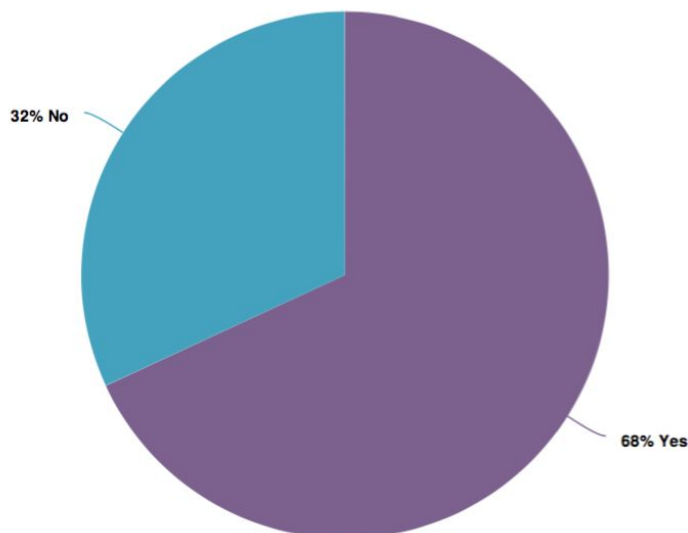
strength or lung capacity. As this messaging is about increasing performance ability, it aligns itself squarely with the culture of excellence, the language of musicians it most aims to serve (and recruit as clients). The pursuit of health motivated by career benefit rather than health for its own sake, is a cultural translation challenge between the culture of excellence in the music field, and the language of rights claiming and healthcare access in the human rights field, as discussed in Chapter 1. Adept at marketing to musicians, performance healthcare is a powerful resource to help musicians, as described by many of my interviewees.

Most performance healthcare wellness resources require training and licencing from accredited institutions, but not all of them have been clinically proven to be effective in helping musicians with illness and injury. This point, however, may reflect the lack of formal research into modalities to aid musicians more than the shortcomings of performance healthcare itself. Within the less formally regulated practices, there is often less legally constrained medical language. Those who claim expertise on the health needs of musicians are not required to have additional certifications, even though these claims can entice musicians to pay more out of pocket for their services. This presents an issue: performance healthcare practitioners hold a tremendous responsibility for the care of musicians. As the interviews and survey results would suggest, musicians are willing to invest their money and energy in performance healthcare services, particularly when there is an implication that those services will benefit their music careers. Some of these practitioners are not adequately trained to provide proper care, but receive clients regardless who are desperate for help with their physical conditions to ease the strain on their performance careers. Ill, injured, and disabled musicians, as a population whose support

network is patchy, unstreamlined, and full of holes, are vulnerable to pursue any services that claim to aid and acknowledge their bodily and career experiences.

Throughout this section, I have discussed the widespread use of alternative and supplemental medicine, and more specifically, Performance Healthcare, by musicians who have chronic illnesses and disabilities, as well as those with short and long term injuries. Additionally, through the survey data of performance healthcare users, it was clear that even musicians who did not have a performance affecting illness, injury, or disability, chose to utilize performance healthcare as preventative care, and to maintain and maximize their body's capacity as a performer. Considering the survey data of 138 out of 200 musicians who reported having an "illness, injury or disability that limited or interfered with [their] ability to play [their] instrument in a significant way", in the chart below, we can see the breakdown of how many of those musician's health conditions was determined by their performance career. Out of 138 respondents, 94, or 68% of them reported being physically compromised due to their instrumental practice and performance.

6. Was/is your illness/injury/disability music performance related (e.g. an overuse injury or task specific focal dystonia)?



Value	Percent	Responses
Yes	68.1%	94
No	31.9%	44
Totals: 138		

This research indicates that musicians with overuse injuries, and other conditions directly related to their musical performance, are a large part of the demographic of musicians who pursue performance healthcare for their conditions. Max, an interviewee who had task specific focal dystonia, solely sought the medical assistance of someone outside of mainstream medicine, whom I'll call Shannon. He told me about the methods she used, saying, "She's not a doctor medically speaking. Her approach is very holistic and it goes about retraining the brain as

opposed to prescribing medication or anything like that. She developed all sorts of exercises and different things to do on the instrument and off the instrument with other tools that rewire the brain". This "retraining the brain" was an intensive methodical process that required following a strict set of exercises and protocols. During this time, Max was in a master's program in a prestigious music school. Due to his condition, his ability to play trombone - what he was in school to study and make a career of - was significantly limited.

I spent most of my first year there just working on stuff on my own. I didn't play even with the trombone choir and I started off in a brass quintet and I eventually stepped down from it because I couldn't keep up. I spend my time in my apartment just working on my exercises from [Shannon] and working with her through it. I saw her a lot more than I saw [my private lesson teacher] that year.

This time spent dedicated to these retraining exercises was isolated from his peers and the music making that is typically the central focus of a musician's graduate school experience. Undeterred by this, he continued with the protocol with the same relentless energy that I have grown used to seeing in musicians who are working through their experiences with an illness or injury. "I trusted the process and I trusted what [Shannon] was doing with me. Even though I had to stay on the sidelines, I was confident I would be able to play again". This faith in the process was powerful, and it came without Shannon's methods having a grounding in formal medical studies, and without insurance coverage, which lead to the accrument of significant expenses. Beyond the financial burden, Max acknowledged the difficulty in accessing the Task Specific Focal Dystonia retraining that he got from Shannon. He said, "I don't believe that retraining isn't possible for people, but it takes a lot of time, unfortunately, because it's extremely specialized and there's really only a few people in the world that do it. It can be very expensive and it can involve travel and it takes a lot of time, energy, focus and money". While he believes that

everyone with this debilitating diagnosis can be “retrained” to be able to perform their instruments again, the list of barriers to accessing the “retraining” methods are numerous and likely make this type of treatment inaccessible to many musicians affected by this disorder.

While the obscurity of Max’s treatment outside of the traditional medical model may seem apt only in cases of specific diagnoses like Task Specific Focal Dystonia, several other interviewees reported similar success. Jason, a freelance jazz bassist who had tendonitis while in an undergraduate music program, pursued an unconventional treatment at the recommendation of his friend, who had experienced back problems that affected his drum career.

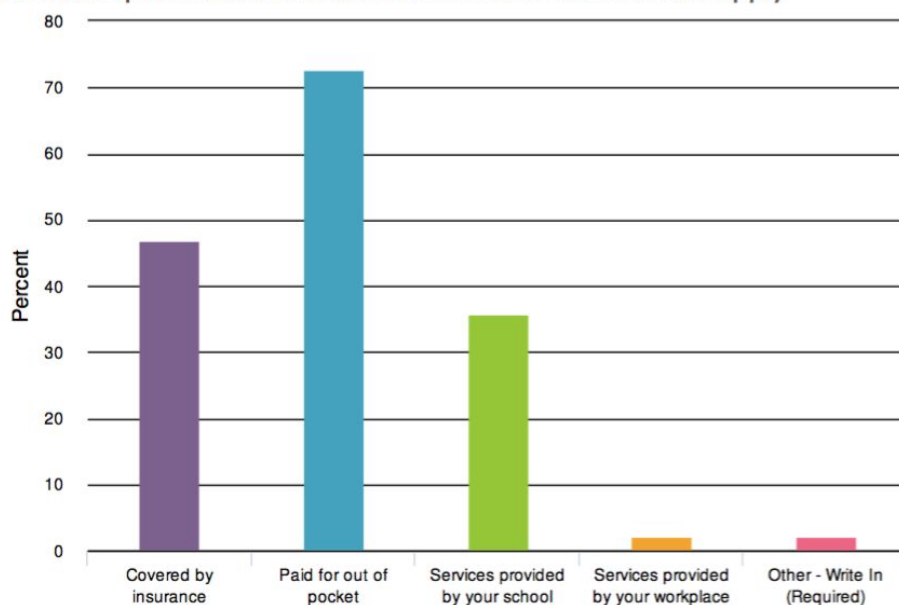
I can't even really describe what he did. He's this guy who was a sports therapist and trainer for a while. His background is in functional neurology as well. We did a lot of meditative and creative work. [My friend] knew I was having problems. He recommended me to this guy. And I was really reticent because, you know, I couldn't pay for his services through insurance. And it was like one fifty per session - obviously very expensive. But I ended up going and within two months, maybe even a little less than that, the difference was massive. I felt way, way better.

Curious about the extent of the financial burden of these appointments, particularly for a college student, I asked how many times he went to this care practitioner. His reply, “I would say between 15 and 20 is my guess. And then I eventually did stop because I was starting to feel better. Obviously, I wish that this guy that I was seeing was covered by insurance. I'm not entirely sure why it was not”. These out of pocket expenses add up, in Jason’s case, to somewhere between \$2,250 - \$3,000 to address the injuries that affect musicians ability to perform their instruments.

Jason was not an outlier in his experience of paying 100% out of pocket for his medical care. 143 survey respondents were asked to indicate *all* the ways they accessed and paid for performance wellness services 104 of them (about 73%) indicated that the expenses were “paid

for out of pocket”. The next most common method of payment for this population was through insurance, which was reported by 67 out of 143 musicians: about 50%. The obvious overlap amongst these two groups of 73% and 50% reflects the reality that many musicians try many different types of performance healthcare to meet their needs.

20. Were those performance healthcare services Check all that apply



Value	Percent	Responses
Covered by insurance	46.9%	67
Paid for out of pocket	72.7%	104
Services provided by your school	35.7%	51
Services provided by your workplace	2.1%	3
Other - Write In (Required)	2.1%	3

As we have seen in Max and Jason's experiences, access to performance wellness services are often contingent on access to significant financial resources. While cost is surely a barrier to many musicians seeking alternative and supportive medicine, it is not the only impediment. Geographic location also determines access to many performance healthcare modalities, because many - particularly those solely specialized for musicians - are only available in metropolitan areas. Sonya talked about her difficulty accessing healthcare from professionals trained to serve the unique needs of musicians:

Obviously having access to physical therapists and primary care physicians who have experience working with musicians and people in that career field, that would always be an ideal. They can drastically lessen the healing time of injuries and help with symptom management for illnesses. But most of us, especially freelancers, are never going to get that access to those kinds of specialists.

The wellness services encompassed in performance healthcare are expansive, but unfortunately, access to those services is not so inclusive. Fortunately, acknowledging the benefits of some performance healthcare services, many conservatories and music schools give their students access to Alexander Technique and other wellness courses. 51 of the 200, or 37% of surveyed musicians reported utilizing performance healthcare services that were provided by their school. This access to performance healthcare services in one's school is incredibly important and beneficial to music students. We have acknowledged the inherent physicality that comes with a music career, as 'athletes of the small muscles'. It is prudent for music schools to eliminate the cost barrier associated with supplemental wellness care such as Alexander Technique, and support their students in caring for their bodies. Moreover, as discussed in Chapter Two, the elements of musicianship that conservatories focus on in their pedagogy sends a message to their students about what they value most for music students and musicians. Alongside performance

excellence, the health of the students aiming to build a career in the physically demanding music field ought to be a high priority.

Jason, who was in an undergraduate program from 2010 - 2014, reflected on his school's access to musician's health services: "I think [performance Healthcare] has been implemented into the curriculum now. But no, I don't remember that being the case when I was in school at all. And I think the reason is because more and more people started to have issues". Could it be that student musicians are getting injured at higher rates today than ever before? Perhaps, aware of the intense competition and often poor compensation of the music field, musician's are practicing more recklessly and putting themselves at higher risk for overuse injury. More likely, though, musicians have always suffered from overuse injuries, among other health issues, and the only shift has been the beginning of acknowledging and addressing the structural and cultural frameworks that allow these health conditions to gravely affect musician's careers and lives.

Teacher Accommodations

In this competitive field, many musicians pursue at least an undergraduate degree in music performance. A core component of higher education in music is the private lesson, typically one hour per week, where each student has the invaluable opportunity to learn from their professor who has achieved excellence at their instrument. This setup of private lessons, difficult to find in any other field's educational system, is a unique and valuable opportunity for music students to learn to perform better with the close support of someone whose musicianship they admire. The one-on-one lesson time, talking about instrument technique, as well as larger career goals can foster a healthy and trusting relationship between mentor and mentee. Most

everyone I interviewed who had recently been in school talked about one or more teachers who were supportive of them during a hard time, including times of illness and injury. Those who struggled with an injury, mental health, or another illness during college reported feeling that the way their college professors recognized, understood, supported, and accommodated their health status largely determined whether or not they succeeded in the academic environment. This dynamic puts tremendous pressure and individual responsibility on music professors. Their roles are ill defined when solely considered “professors of music performance”. As will become clear in the following stories, music professors have much more dynamic and expansive roles. Nadia, as a pianist with a masters degree and a community music school of her own deeply understands the powerful relationships between music teachers and students.

We all end up having an intimate close relationship with our primary instructor. And that can be both very healing and helpful and supportive, but it can also be filled with misinformation. And as a structure, we have so much faith in our teachers that their responsibility is so huge. So when the information is misinformed, it can just be so devastating because you're so ready to just accept what you hear from that role model.

This faith in, and reliance on music mentors that makes their responsibility “so huge”, includes support in maintaining health and preventing performance related injury. Jason, who practiced his bass with posture with positioning that lead to him getting tendonitis, shared with some hesitation,

I will say one thing that was a little strange was that some of these technical oddities that I had, like the way I was holding my left hand specifically as an easy example, I was very surprised that my teachers didn't notice that and address it. And I wish that they had. And I think that, you know, I honestly do believe that that is part of their responsibility to see that and address it.

As Jason claims, in addition to a private teacher’s responsibility to educate their students on how to play well, they need to teach their students how to play in a way that will not cause them pain

and injury. This leaves music educators in the position of needing to be a teacher, ADA coordinator, and performance healthcare expert. It is no wonder that several interviewees described their teachers as their saving grace or someone they felt let them down. Finley gave an account of one of his peers who received jointly medical and parental support from a teacher during a mental health crisis: “She said, ‘there was a time where my professor looked at me during my lesson and she took me to the counseling center’ and it’s like you never forget stuff like that”. While that story shows a professor going above and beyond their designated role as a music educator, Finley thinks that professors helping their students with their health should be the standard, and one that they receive training for: “with the rise of your mental health awareness, I think that universities should train professors to be prepared to help students through. Help them find the resources, but also just be there for them. Just be a listening ear”. Perhaps, asking music professors to go through an additional training would seem excessive, but it would not be if these educators are already doing their best to fill the role of music mentor *and* health coach, *and* counselor. Training could make the job that they are already improvising or experts in, easier. In the academic environment where music students are encouraged to push themselves to their physical limits (and beyond), private music professors, as explored in Chapter 2, have a tremendous amount of power to teach their students how to relate to and care for their bodies.

Harper shared two differing experiences with equally dedicated music professors from her undergraduate and graduate music school programs. As discussed in Chapter 1, Harper’s undergraduate professor told her to keep her chronic illness concealed when she was preparing for grad school auditions, saying, “‘don’t tell anybody’”. Later, once in a graduate school

program, Harper reflected, “it was my grad school teacher who really gave me permission to be sick”. This shows the power of music professors, as role models and mentors, to help their students navigate experiences with illness, injury, and disability. When Harper’s graduate school professor granted her “permission to be sick”, she was allowing Harper to acknowledge and address her body’s needs outside of the culture of excellence that was described in Chapter 1, in which her health was not just a liability, but something worth caring for for its own sake. When music professors’ focus is on the culture of music performance excellence more than the framework of rights and accommodation claiming, it can be damaging for disabled musicians like Harper.

Elise shared a time when her teacher was so focused on pedagogy that she did not take into account the unique needs of her student: “I had a teacher who gave me a B in my lesson with her because everything else I did was great, but she was mad that I wouldn’t hold the flute the way she wanted me to hold the flute even when I explained to her that that would be that would be bad for my body because of my ulnar neuropathy”. This was the most blatant discrimination that my interviewees reported experiencing with their professors. Most of my interviewee’s professors were much more understanding, perhaps because, as musicians themselves, they each have likely experienced an illness or injury themselves over the course of their career.

Max’s relationship to his graduate school professor was filled with gratitude, and since his professor was his main source of accommodation and support during his experiences with Task Specific Focal Dystonia, he attributed most of his success to his him. He said, “honestly, I think if I went anywhere else that I auditioned, I probably wouldn’t be playing today”. This is an important example of the essential supports and accommodations that many music professors

provide. In Max's case, and many others, these interpersonal supportive relationships are incredibly meaningful for both the student and the professor, and often take the place of formal structures of support, including ADA offices.

While in a small graduate conservatory program, Elise's experienced the "worst phase" of her "neurological health and migraines". Having lived with chronic illnesses that were not visible on the outside for her entire adult life, she knew that she had to advocate for herself to get the accommodations she would need to maximize her educational experience while caring for her medical needs.

The first day I went in and spoke to the Dean, I said, 'this is what it is. I know it's a small school, so you don't have an office for students with disabilities. So I'm here to talk to you about what we need to do so I get what I need'. And he essentially said, 'Just be in contact with your professors. I don't think it's a big deal'. And it never was, even when I got really sick.

Elise acknowledged that there was no office for students with disabilities, and figured out another avenue of support that would allow her to get what she needed.

We have these institutions in place but yeah that's just common sense at a small school. I always got what I needed, even when my migraines got really bad. I communicated to my teachers. I graduated with an A average. And that was largely due to me feeling comfortable to come to them and say, this is how I'm suffering, this is what I'm doing to make sure I'm taking care of myself just so you know. And there were some people who were like, 'is she sick? I don't really know' but they weren't people in positions of power and authority over me. And I graduated with my merit scholarship. In fact, it was with the highest GPA.

This is a success story of a student with chronic illnesses getting adequate accommodations and understanding from her educators, and thriving in her musical pursuits. This is an example of self advocacy being met with responsiveness outside of a legally framed students with disabilities office, which in other academic contexts would be an intermediary to facilitate limited

accommodations in Elise's graduate program. Elise's success in this situation relied on her self initiative and good interpersonal communications in the absence of any designated support offices that would help her as a chronically ill music student seeking accommodations.

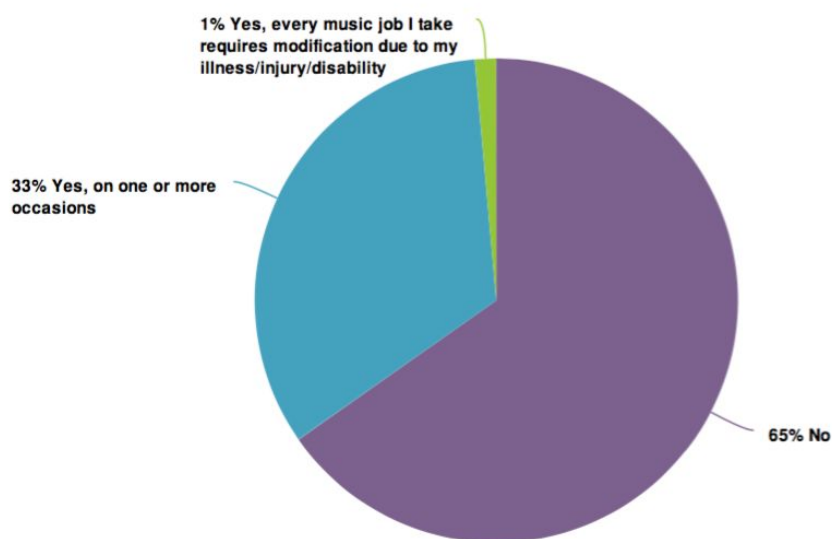
Peer Accommodations

Thus far, I have discussed many of the formally organized methods of addressing musician's experiences with illness, injury, and disability. These supports span from charity relief funds, to union's rights activism, to different forms of healthcare. I examined the extensive role of music teachers, who provide support for their students as well as accommodations in times of need. Here, I will address one of the most widespread solutions to the unique issues that ill, injured, and disabled musician experiences: musicians supporting other musicians. This goes beyond the special relationship of teacher and student, and applies to music colleagues, ensemble leaders, and collaborators. Through my interviews and survey, I heard many accounts of musicians helping each other. Some musicians talked about getting the support of a community of other musicians who had experienced illness or injury, and others described being accommodated with flexibility and compassion by their musician colleagues.

Throughout this paper, I have come back to the foundational reality at play here, that musicians are susceptible to experiencing illness, injury, and disability at some point in their lives, and many cases, this significantly affects their music performance careers. Many musicians with illness, injury, and disability rely on the relationships they have built with peer musicians to ask for, and hopefully be granted, accommodations. This instance of physically compromised musicians asking for accommodations is reflected in my survey, where out of the 138 musicians

who reported experiencing a significant illness, injury, or disability, 46, or 33.3% had asked for an accommodation or modification to an aspect of a professional commitment due to their health condition.

10. Have you ever asked for an accommodation or modification to an aspect of a music professional commitment due to an illness, injury or disability?



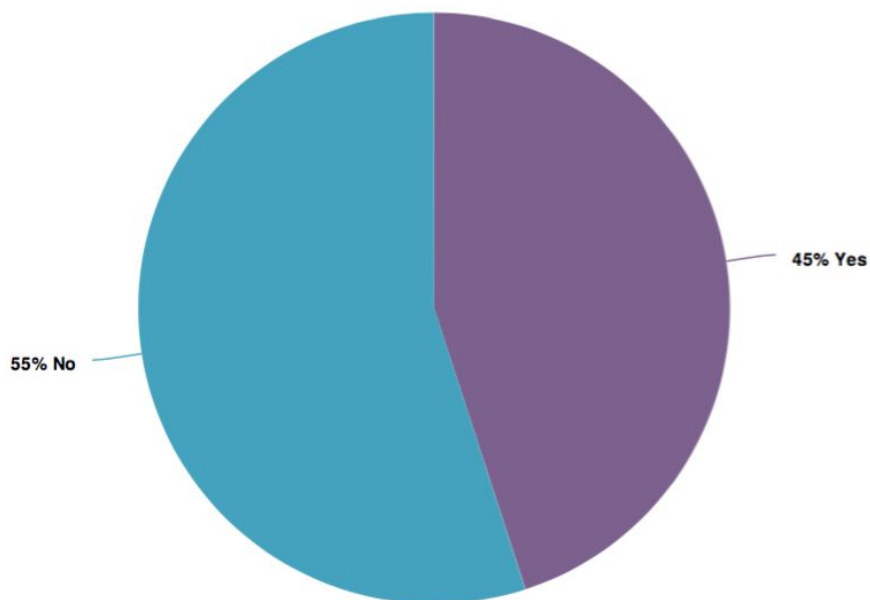
Value	Percent	Responses
No	65.2%	90
Yes, on one or more occasions	33.3%	46
Yes, every music job I take requires modification due to my illness/injury/disability	1.4%	2

Totals: 138

Of the 200 musicians surveyed, 45% of them reported working at some point in their career with a musician who requested an accommodation or modification to their performance job. This

indicates that nearly half of the musicians surveyed have had direct reminders that musicians' bodies are susceptible to changes in health that can affect their livelihood.

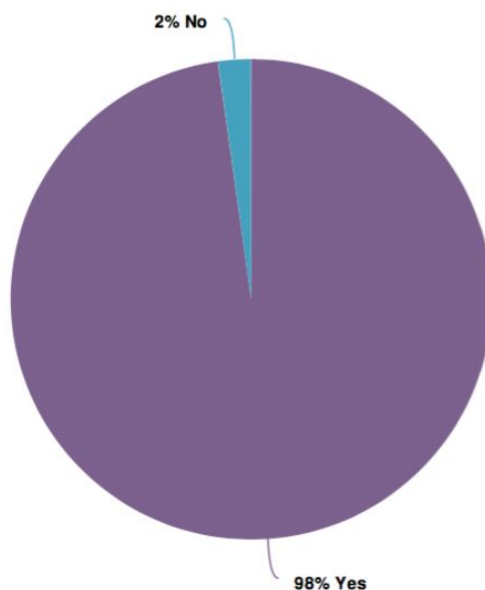
12. Have you ever collaborated, rehearsed, organized, or performed with a musician who asked for accommodation or modification due to their illness/injury/disability?



Value	Percent	Responses
Yes	45.0%	90
No	55.0%	110
Totals: 200		

With that reminder of one's own vulnerabilities, and the opportunity to help a fellow musician through a facility/setting, musical/programming, or scheduling adjustment, 88 out of 90 respondents reported being able to meet their ill, injured, or disabled colleague's accommodation request.

14. Were you able to meet their request?



Value	Percent	Responses
Yes	97.8%	88
No	2.2%	2
Totals: 90		

This rate of success in musicians receiving accommodations when they ask for them lead me to ponder: What about the musicians who are afraid to ask for support due to the stigma talking about musicians health, or the threat of compromising their reputations? This is a case that, while challenging to measure, is important to consider. Thinking back to her stories about nondisclosure, I am reminded of Harper, and her inaccess to accommodations until she chose to out herself as disabled and ask for help:

There was a stage where, like I remember going into my therapist's office once and there was somebody there wearing a music festival shirt. And so I asked, 'are you a musician?' And they said, 'yes'. And I said, 'Oh, I'm a musician, too. But I can't play right now because of health problems.' And that was a big moment for me being able to just

verbally say to another musician, I had more problems and she was like, ‘oh, yeah, that happens’. And I thought ‘wow there are people who really understand this’. And then there was a stage where everybody was telling me about musicians who had health problems. So all of a sudden, this invisible world came to me. When I got sick [my friend] started telling me about his colleagues in his orchestra, that one of them used an oxygen tank during performances and during rehearsals.

When Harper was open about her health status, she suddenly had access to “this invisible world” of ill, injured, and disabled musicians. She was able to learn their stories, which, like hers, were mostly concealed from the rest of the world in response to the realities of reputation and health stigma in the music field. In addition to their stories, Harper could see the interconnected web of support created and maintained by musicians with and without experiences of illness, injury, and disability. These musicians rely on the charity of one another.

Is this system of charitable aid, bolstered by optional performance healthcare and union support, sufficient in addressing the needs of ill, injured, and disabled musicians? Is the informal system of peer kindness and aid enough to fill the gaps in the patchwork of musicians’ support? Unfortunately, no, it is not. As we have learned from some interviewees, and can imagine with the limitations of individual generosity, there are musicians who fall through the cracks of this charity system as it exists today. Furthermore, even when musicians receive peer accommodations, they have no guarantee that they will get aid in the future, with another colleague or for another gig. This gives the impression that perhaps the worst part of the current system, for those who are not completely excluded, is the insecurity musicians feel within it. Musicians know that there is nothing to protect them if their friends/teachers won’t; if charity fails. The peer accommodation system that offers the most prevalent form of support to ill, injured, and disabled musicians is not strong enough to effectively support everyone on its own.

In the face of that reality, are there any other policy protections grounded in rights and law available to this population?

ADA

When considering the rights of ill, injured, and disabled musicians outside of the charity model discussed above, the primary legal framework to explore is the Americans with Disabilities Act (ADA). This act, passed in 1990, provides legal protections for disabled Americans against discrimination in educational and workplace settings. It also dictates that all public spaces conform to accessibility measures³⁷. The ADA has five titles outlining the broad scope of regulations and protections for people with disabilities in the United States. When considering the application of those protections for musicians with disabilities, the policies in several titles emerge as crucial to discuss.

Title I lays out the fundamental employment protections for people with disabilities, and requirements for employers. Employers with 15 or more employees are required to provide “reasonable accommodations” for all employees who have disabilities, and these disabled employees are required to be able to fulfill the “essential functions” of the job³⁸. The language used here is broad, with what is considered “reasonable” spanning from providing reserved parking, to allowing a flexible work schedule³⁹. The need for reserved parking does not apply to many ill, injured, and disabled musicians, and a flexible work schedule would not be considered “reasonable” by conductors or employers who expect attendance and full participation at every

³⁷ “What is the Americans with Disabilities Act (ADA)?” ADA National Network, <https://adata.org/learn-about-ada>. Accessed May 2020.

³⁸ “Reasonable Accommodations in the Workplace”, ADA National Network, <https://adata.org/factsheet/reasonable-accommodations-workplace>. Accessed May 2020.

³⁹ “Reasonable Accommodations in the Workplace”, ADA National Network.

rehearsal and concert. Moreover, the scope of ADA’s employee protections fails to include anyone who is self employed, or part of a small business. As was made apparent in Chapter 1, many musicians are freelancers, have two or more jobs, or are self employed. The very nature of many performance careers precludes musicians from receiving these protections.

As described in Title I, music schools and conservatories fall under the category of “secondary, undergraduate, or postgraduate private school, or other place of education”: places where students with disabilities benefit from ADA protections⁴⁰. These protections require that schools hire an ADA coordinator. For educational affairs, the ADA National Network states:

Accommodations and program modifications should be individually designed to meet the needs of the student with a disability. Accommodations and modifications of policies and practices are not required when it would fundamentally alter the nature of the service, program, or activity or give rise to an undue financial or administrative burden⁴¹.

Many ADA coordinators in universities are not specifically trained in working with disabled students and their teachers to make “accommodations and modifications” to courses in the performing arts. This means that the formal protection options for ill, injured, and disabled students are most often replaced by informal aid and accommodation granted by professors and music programs. Examples of these types of accommodations have been discussed throughout the paper. Additionally, music programs may argue that accommodations that require changes to rigid performance practices and tradition for the sake of a single disabled artist causes an “undue burden”. This leaves the ADA relatively toothless to protect musicians in the most basic ways.

⁴⁰ “Subchapter III - Public Accommodations And Services Operated By Private Entities”, Americans With Disabilities Act of 1990, as Amended, <https://www.ada.gov/pubs/adastatute08.htm>. Accessed May 2020.

⁴¹ “What are a public or private college-university's responsibilities to students with disabilities?” ADA National Network, <https://adata.org/faq/what-are-public-or-private-college-universitys-responsibilities-students-disabilities>. Accessed May 2020.

Between the lack of tailoring the current ADA protections to benefit ill, injured, and disabled music students, and the shortcomings of the law itself, music students with corporeal differences and health issues are significantly underserved and underprotected. Kara told me about her encounter with the ADA office at her university. The ADA coordinator was able to help her get accommodations in her non-music classes, formally mandating extra time on exams and flexible attendance. However, she was unsure of her jurisdiction in the school of music, and unable to effectively aid Kara in getting the educational support and accommodation she needed. Recalling what the ADA coordinator said to her, Kara said, “she was like, ‘I don't really think we're gonna be able to get much accommodations for orchestra’. And so she's basically like, ‘your only real choice is to just like not do it this semester’”. Could that be considered a “reasonable accommodation”, or a case in which ADA law did not require an accommodation because it would cause “undue financial or administrative burden”⁴²? Because participation in orchestra all 8 semesters is a graduation requirement for instrumentalists in her music school, Kara was left with the medical, educational, and financial decision of taking a leave of absence. For any non-performance field, the ADA would have offered a structured protocol of accommodations for a student in Kara’s position. Her situation exemplified the shortcomings that ADA has in protecting the equal educational opportunities of disabled students in the performing arts.

Title III addresses public accommodations for people with disabilities. It states:

No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of

⁴² “What are a public or private college-university's responsibilities to students with disabilities?” ADA National Network.

any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation⁴³.

This protection against discrimination “on the basis of disability” asserts the need for accessibility in “any place of public accommodation”⁴⁴. Considered public spaces, and therefore protected under this law are all places that function as “an auditorium, convention center, lecture hall, or other place of public gathering”⁴⁵. This includes concert halls, and other music performance spaces, meaning that these places where people share music are required to be wheelchair accessible and open to all people regardless of their disability status. There have been several lawsuits in response to music performance spaces that were noncompliant with ADA accessibility standards. The famed Lincoln Center in New York City faced a lawsuit in 2012, *United States of America, V. Lincoln Center for the Performing Arts, Inc.*, due to Avery Fisher Hall’s “architectural barriers” preventing wheelchair accessibility⁴⁶. Like many buildings designed in 1962, this performance hall did not have disability inclusion in mind. Since their lawsuit in 2012, they have made adequate changes to be in compliance with the ADA⁴⁷. A similar lawsuit was filed in 2019 regarding the New Haven Center For Performing Arts⁴⁸. These lawsuits enforcing accessibility to performing arts spaces via the ADA are important signs of progress for accessibility in the arts. However, while accessibility for entrance and audiences of performance spaces is widely enforced under Title III’s protections for “public space[s]”, there

⁴³ “Subchapter III - Public Accommodations And Services Operated By Private Entities”, Americans With Disabilities Act of 1990, as Amended.

⁴⁴ See note 43 above.

⁴⁵ See note 43 above.

⁴⁶ *United States of America, V. Lincoln Center for the Performing Arts, Inc*, 12 Civ. 5030 (NY 2012), <https://www.ada.gov/lincoln-center-cd.htm>.

⁴⁷ See note 43 above.

⁴⁸ *Settlement Agreement Between the United States Of America and New Haven Center for Performing Arts, Inc*, (Connecticut 2019) https://www.ada.gov/new_haven_performing_arts_sa.html.

are cases in which accessibility *onto* the stage of performance halls is overlooked. This failure to consider the needs (and even existence) of musicians with disabilities, particularly those with mobility impairments, was seen with my interviewee, Kara. She told me about performing in a wind ensemble concert in 2019 on a top 25 university stage that was wheelchair inaccessible. “The last concert I was in, — I had my wheelchair by then — my dad had to carry me backstage and my mom had to bring the wheelchair backstage so I could get in it. And then I had to wheel myself onstage, which was also difficult because, you know, all the chairs and stuff”. In this moment, Kara was failed by her university and their noncompliance with ADA law. The United States Access Board states that, to be compliant with ADA, “An accessible route shall connect wheelchair seating locations with performing areas, including stages, arena floors, dressing rooms, locker rooms, and other spaces used by performers”⁴⁹. This policy was clearly not followed by Kara’s university, reminding us that law does not immediately enact change; citizens, in this case musicians and those who see their value, need to fight against injustice with the support of the law to get their needs met.

As the only wheelchair user in the music school that year, Kara faced this inaccessibility, relied on the assistance of her parents, and had to “wheel [herself] onstage”, navigating the obstacles of chairs and other musicians filling the stage. Surely, the conductor, 50+ other musicians, and audience saw her navigate this difficult situation. Why have none of them, as bystanders, pushed for this wealthy university to make its stage accessible and comply with the ADA? The university’s inaction to directly improve a disabled music student’s education

⁴⁹ “ADA Accessibility Guidelines (ADAAG)” United States Access Board, <https://www.access-board.gov/guidelines-and-standards/buildings-and-sites/about-the-ada-standards/background/adaag#4.1.7>. Accessed May 2020.

opportunities is representative of the institutional oversight and lack of protections for musicians and other performing artists with disabilities.

While not a catch-all protective policy, the ADA is a profoundly important law that gives “civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age, and religion”⁵⁰. Passing the ADA reflected a bipartisan ideology of equality between people with and without disabilities in the United States. The ADA’s legal framework provided the policy underpinning needed to support a cultural shift to include people with disabilities in more realms of public life, including workplaces and schools.

This monumental law provides an important framework, but does not provide adequate protections for performing artists - a population that contributes so much to our society. As seen in the Teacher and Peer Accommodation sections, many musicians do not seek accommodations through the ADA, whether because they do not know about how it could help them, their particular needs are not protected by the ADA, or they prefer individualized informal accommodations.

⁵⁰ “What is the Americans with Disabilities Act (ADA)?” ADA National Network.

CONCLUSION

This investigative paper has made clear that the United States is fundamentally lacking a political commitment to protecting the musicians who contribute so much to its society. Musicians need political recognition and support through expanded legal protection. Subgroups of ill, injured, and disabled musicians in the United States fall through the cracks in the current patchwork of support that has weak legal underpinnings, leaving musicians to suffer excessively. Due to this often ineffective patchwork of support, some musicians, whose health statuses alone did not determine unfitness for a music career, were doomed to lose and leave their jobs in musical performance. This lack of sufficient infrastructure results in a country whose artistic output is determined by those who are lucky enough to navigate mixture of personal and professional relationships and a broken system of legal support. When art is made today in this manner, many ill, injured, and disabled artists who have so much to contribute are excluded.

Protecting and accommodating artists will *not* hold back the music field. The image of the “old union-protected musicians who can barely play anymore” is the basis for the counterargument, implying that protecting the careers of musicians would interfere with the culture of excellence. Maybe in that example, it is true that playing “quality” changes over a lifetime, but if culture does not allow for the full diversity of human expression and experience, human rights for those groups becomes all the more vulnerable. Musicians with illness, injury, and disabilities are able to contribute so much to the music field, and many of them do, as their circumstances within the current patchwork of support allow them to. Their ailments and corporeal differences cannot be translated to ‘invalid’ or ‘unable’ and dismissed. The inclusion

of people with disabilities in the arts is not just essential for the protection of musicians' human rights, but for the continued inclusion of the larger population of people with disabilities as stakeholders in society.

When considering my small scale research, it looks like most musicians do a fairly good job at taking care of one another, circumnavigating the glaring gaps in the legal supports available. This speaks to the work ethics of musicians to adapt, advocate for, and invent new ways of creating music that allow many ill, injured, and disabled musicians to contribute their artistic visions and performances to our society. It also reflects the musician's determination to care for one another in a field that is often, from the outside, characterized as catty and cutthroat. This system of colleagues helping one another is not limited to the music field — we see interpersonal charity support amongst professionals in many different careers. However, the fact that musicians rely heavily on these interpersonal informal modes of support *is* unique, and worth addressing. Ill, injured, and disabled musician's reliance on informal interpersonal accommodations to preserve and maintain their livelihood reveals a fundamentally flawed system that does not adequately protect musicians. Artists who are essential to creating and maintaining culture still find themselves at risk of discrimination.

As discussed in Chapter 3, when musicians' support is framed as an act of charity, ill, injured, and disabled musicians view the aid they receive as a product of their own interpersonal relationships and luck instead of something they, or any musician in their circumstance would be entitled to or deserving of. Aid to this vulnerable population comes from the optional generosity of individuals in a musician's life, and because this system is haphazardly functional, it reduces the pressure to implement stronger protective policies. Even the ADA, which provides some

legal protections for people with disabilities in the United States, does not provide adequate aid for musicians. This reflects the way that the government views artists: as nonessential, and not important enough for legal protection. Without the effective legal framework asserting and protecting the rights of these performing artists, musicians are left having to individually fight for their proper treatment to continue to make music.

Many musicians, with their formidable work ethics, have shared with me their success stories in navigating their complicated experiences with their disabilities and careers. There is no doubt that these artists are resilient and determined to make music. However, I need to acknowledge the darker side of this. It is exhausting to care for one's body, to hone and maintain one's craft, and to constantly have to self advocate for proper treatment with every individual colleague, mentor, and employer. Even when their needs are met for one conservatory class or job, there is no legal protection or guarantee that they will be met in another professional context. This causes a constant sense of unease and insecurity that accompanies and exacerbates the stress of sickness and injury. Aside from the ADA and its policies that are difficult to apply to the music field, there is no legal backup for musicians facing illness, injury, and disability who need accommodation.

Throughout my interview with jazz bassist Jason, he kept using the word "lucky" when describing his experience receiving basic accommodations from his professors and from employers. Reflecting on his experience with tendonitis while in an undergraduate program, he said, "I was very lucky in that the faculty were super understanding of my situation. That's not always the case. So I count myself very lucky for that". The interpretation of receiving appropriate accommodations as "lucky" was common amongst my interviewees. Many of my

interviewees claimed their own personal luck for having an accommodating teacher, or being allowed to take breaks during chamber music rehearsals. A musician's future success being determined by the kindness and flexibility of whomever they have access to in their educational or career setting, is also evidence of a music field susceptible to unregulated power dynamics. As explored in the teacher accommodations section, the absence of coordinated ADA protections in most conservatories means that individual music professors have tremendous responsibility to, and resulting power in offering support and guidance to their students. But why are musicians not protected beyond their own circle of connections who will informally help them? More pressingly, why is it that musicians feel like it is merely good luck for having employers, colleagues and educators who value their health and rehabilitation, and are willing to be flexible or make basic accommodations? Musicians must demand the same compassionate protections as those in other fields who have better legal labor and disability protections.

Demands

The Americans with Disabilities Act could provide adequate musician's protections with an amendment, something which has been done before. There was an amendment passed in 2008, 18 years after the original ADA was signed into law. This proposed amendment could expand the Title I workplace protections to include disabled workers in businesses with less than 15 employees, and could use more precise language to describe the ways to accommodate disabled students in the performing arts, acknowledging the unique demands of the field, and nature of their conservatory academics. ADA requests in this realm should not be so easy to

dismiss, and “undue financial and administrative burden” is overly broad⁵¹. The changes needed may require financial investment and structural adjustment.

Acknowledging that passing an amendment in federal law is an enormous undertaking, and one that would not address the immediate needs of the ill, injured, and disabled population, I will address some ways to maximize the music field’s benefit of the current ADA law.

Conservatories, as creators and custodians of music culture, and as educators of how to live as career musicians, can improve the way they support their students by interacting more with the ADA legal support structure. Here are some ways conservatories can improve:

1. Mandate educational sessions for all administrators and professors addressing the wide range of barriers that music students with disabilities face. Institutions should be given clear guidance on how to discuss and interface with sick, injured, and disabled musicians. Help them understand the wide scope of what it means to be ill, injured, and disabled. Many music professors will already know this, but will benefit from a designated time to face the scope of the issue and plan for ways they can make different accommodations.
 - a. Some musicians can play their instrument well, and need a ramp to access the stage
 - b. Some musicians can play their instrument well, and need flexible attendance due to a chronic condition
 - c. Some musicians can play their instrument well, and need frequent practice breaks to allow their body to recover from the physical strain of instrumental performance

2. Educate every school’s ADA coordinator about the unique educational/career demands of performing artists. This will help them understand the culture and needs of students in these fields of study when they seek ADA accommodations. Giving ADA coordinators a greater chance to understand the expectations of music programs will help them advocate effectively for the needs of music students with disabilities. It will also allow ADA coordinators to fulfill the role that some interviewees expressed their professors informally do today. Students need to be educated about the stigma, the shortcomings of

⁵¹ <https://adata.org/faq/what-are-public-or-private-college-universitys-responsibilities-students-disabilities>

the current ADA, and what accessibility challenges they may face in their conservatories and careers as ill, injured, and disabled musicians.

3. Educate students that they are not required to disclose the details of their health status to their professor, colleagues, or employers. As discussed in Chapters 1 and 2, there is a significant stigma around health in the music world that is rooted in realities about reputation and discrimination. While at times ineffective in the current model (where many ADA coordinators do not understand the full expectations of conservatories, or the possible ways to accommodate disability), working with an intermediary can help students receive accommodations and avoid unwanted public disclosure or discrimination.
4. All conservatories must teach their students about their rights as performers within the current ADA system. Part of a comprehensive performing arts education is preparing students to enter the music field prepared with tools to deal with illness, injury, and disability — health challenges that they will likely face during their lifetimes. These information sessions will also contribute to destigmatizing conversations about illness, injury, and disability.

While an important part of mitigating the issues ill, injured, and disabled musicians face, an amendment to the ADA would not address everything. The music field, and those who are members and supporters of it, need a cultural shift in the way they consider and relate to physical differences and ailments in the performing arts. The stigma about musician's health, as discussed in Chapter 1, is shaped and perpetuated by conservatories, and other educational institutions in the music field. The fear of talking openly and addressing musicians' wellbeing has larger repercussions in orchestras and professional gigs in which musicians' careers and reputations are on the line. Many student musicians look up to the successful musicians in professional orchestras and chamber music festivals. They need role models who remove the taboo from acknowledging that all bodies, including their own, are vulnerable to illness, injury, and disability.

Destigmatize Conversations about Health

There must be a cultural shift in the way the music field regards musicians' bodies, acknowledging the reality that illness and injury are ailments to *plan* for and work to prevent when possible. For this paper, I focused on the experiences of 215 musicians I interviewed and surveyed, yet by engaging in this research, I learned so many more musician's stories. Illness, injury, and disabilities affecting musicians and their careers is a widespread reality, not the story of a few exceptional circumstances. This understanding needs to be built into the framework of the music field, from conservatories, to professional orchestras, to reach the employers for bands on cruises and corporate retreats, and even the general public who hire chamber groups for their dinner parties and weddings.

Destigmatizing conversations of musicians wellbeing means more conversation about musician's bodies. Musicians are not exempt from the illness and injuries of everyday life, genetic predispositions or unprecedented accidents. In addition to those ailments, musicians are subject to many occupational hazards of overuse injuries, illnesses. The physicality of music performance — the fact that we need our bodies to complete very specific and precise actions as musicians — needs to be acknowledged more openly. Beyond the theoretical, more professional musicians should openly talk about their health experiences to open a space for honest conversation.

Finley, whose experiences with anxiety and depression were discussed in Chapter 2, told me about his experience reading the book *Flute Stories: 101 Inspirational Stories from the World's Best Flute Players*, which discusses the lives of famous flutists.

It talks about how Emmanuel Pahud had struggled, he had some major depression struggles. Tom Nyfenger who taught at Yale, he unfortunately took his own life, as someone of that status who is one of the top flute teachers. Just knowing that those kinds of flutists struggled as well — Reading about I was like, oh, my gosh. Having those kinds of stories and seeing how they relearned, they persevered and then they got back into it.

Finley got strength from hearing that musicians he admired had also faced difficulties with their health. It normalized his own experience and gave him the encouragement to keep going, knowing that musical success can be achieved concurrently with health challenges.

Further cultural change can happen by intentionally building communities of ill, injured, and disabled musicians to come together, and share their experiences. I am sure a group like that could propose many more ideas to add to the ones listed here about ways to support the musicianship of ill, injured, and disabled musicians. Kara talked about this idea, contrasting it with her own isolating experience of being disabled as a musician: “I think some sort of official network that provides opportunities and stuff and offers assistantships and residencies and resources specifically for ill and disabled musicians would be helpful. Right now we're pretty invisible. Its really, really hard to find other disabled musicians to connect with”. As Kara expresses here, ill, injured, and disabled musicians need to fight through the multiple layers of stigma and fear of disclosure to reduce isolation and create community with each other.

The coronavirus pandemic is requiring musicians to change the way they make music, and has the potential to transform the entire performance industry. Perhaps this time of crisis presents the perfect opportunity to reflect on the ways musicians, and their supporters, can come together to shape a more resilient and inclusive field of music, in which bodies are acknowledged as susceptible to illness, injury, and disability, and performing artists are upheld for their valuable, irreplaceable contribution to society.

Future Research

I am grateful to have been able to conduct primary research in this topic of the experiences of ill, injured, and disabled musicians. My 15 anonymous interviews taught me so much about the breadth of career and identity struggles that musicians face alongside their health diagnoses. While I advocate for more open conversations about musicians' health in the future, I also acknowledge the stigma and risk to reputations that make discussing health openly a liability and personal sacrifice. With that in mind, I think there should be research moving forward that collects more anonymous personal accounts of illness and injury amongst musicians. These stories, detached from the names of those who experienced them, will still hold power in starting conversations, as I hope this paper does, about the prevalence of musicians with musicians whose careers are affected by, illness, injury, and disability.

In addition to qualitative research, there must be systematic quantitative data collection about this population. My survey reached 200 musicians, and, as discussed in the Chapter 1 methods section, it could not pass statistical significance testing. Further data collection on this population, done with a broader scope and outreach, could be helpful in gaining a greater understanding of musicians' health, and its correlations with access to healthcare, performance wellness services, and other support modalities. However, the research gathered for this paper is adequate to conclude that we need more than just conversations and awareness about musician's health and support structures: we need *action* to address the insufficient and incohesive patchwork of support that career musicians currently rely on in the face of illness, injury, and disability.

Final Reflections - Musicians Are Really Resilient!

I spent a year thinking about this population of ill, injured, and disabled musicians, while learning how to be an interviewer, survey maker, and ethnographer. I keep coming back to consider my interviewees' stories, reflecting on their perseverance, passion, good humor, and grace in navigating their health challenges as musicians. I am left with a greater picture of what a musician's identity is, and all the different elements and organizations, interpersonal pacts, and legal policies, that contribute to what makes the music field what it is today: incredibly valuable, and desperately in need of some change.

Appendix

Musician's Health Survey Report 2020

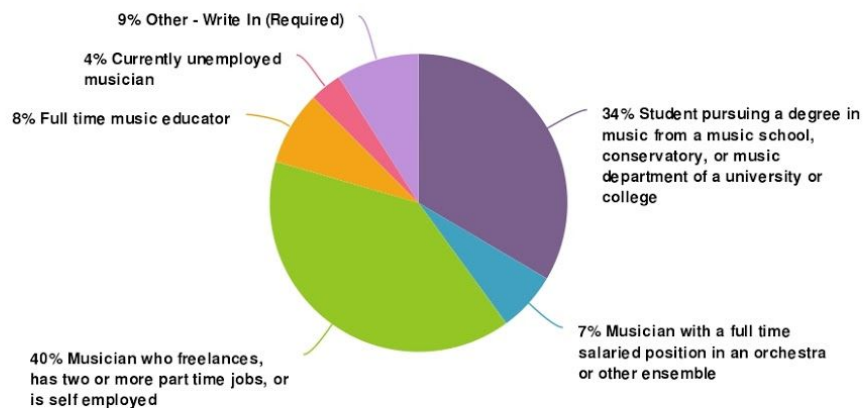
Jillian Reed

Response Counts

Completion Rate:	100%	
Complete		 200

Totals: 200

1. What is your professional relationship to music?

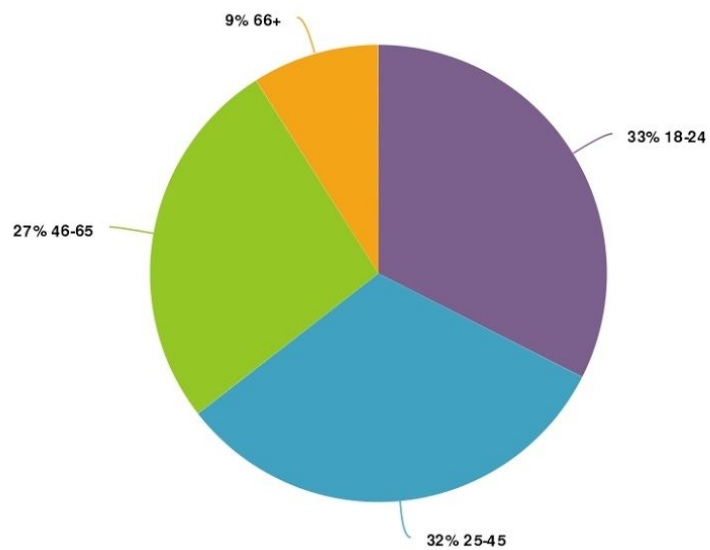






Value	Percent	Responses
Student pursuing a degree in music from a music school, conservatory, or music department of a university or college	33.5%	67
Musician with a full time salaried position in an orchestra or other ensemble	6.5%	13
Musician who freelances, has two or more part time jobs, or is self employed	39.5%	79
Full time music educator	8.0%	16
Currently unemployed musician	3.5%	7
Other - Write In (Required)	9.0%	18

Totals: 200

Other - Write In (Required)	Count
Former Musician- changed careers	1
Former full time musician changing careers (in grad school)	1
Former music educator, former music student, current part-time freelancer	1
Formerly full time freelancer- not currently playing professionally	1
Freelance musician who plays in four regional orchestras and teaches/coaches during school hours (as an independent contractor).	1
Full time arts admin and gigging musician.	1
Full time music educator and Musician who freelances	1
I am an educator and freelance musician but was a full-time musician for over 30 years	1
I spent 10 years in a professional string quartet and 29 years in the Metropolitan Opera Orchestra. For the past 20 years I have taught.	1
Orchestra Now- Training Orchestra	1
Part-time music educator and performer, and a full-time mom with a doctorate degree	1
Performer and Music Educator	1
Retired freelance musician	1
Teacher/Performer/9 years professional orchestra/30 years touring Chamber music ensembles	1
full time opera chorus singer, retired	1
full-time music professor, was full time freelance	1
organist, retired music teacher	1
teacher	1
Totals	18

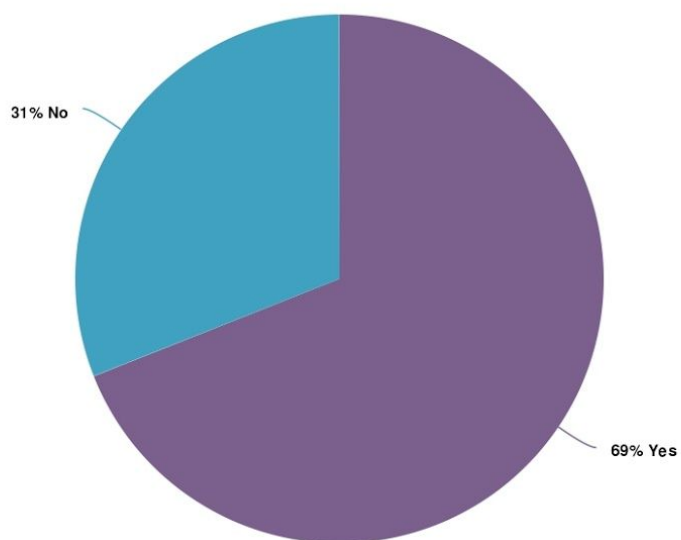
2. What is your age?





Value		Percent	Responses
18-24		32.5%	65
25-45		32.0%	64
46-65		26.5%	53
66+		9.0%	18

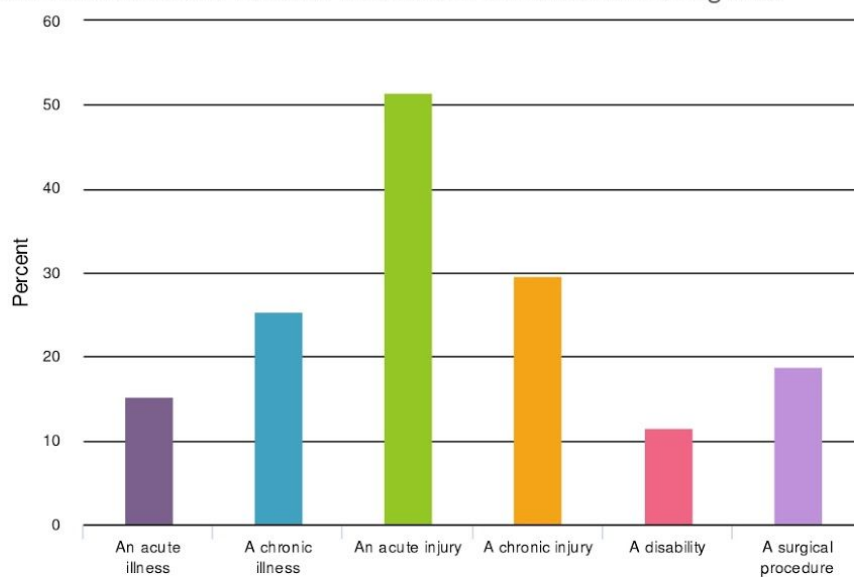
Totals: 200

3. Have you ever had an illness, injury or disability that limited or interfered with your ability to play your instrument in a significant way?



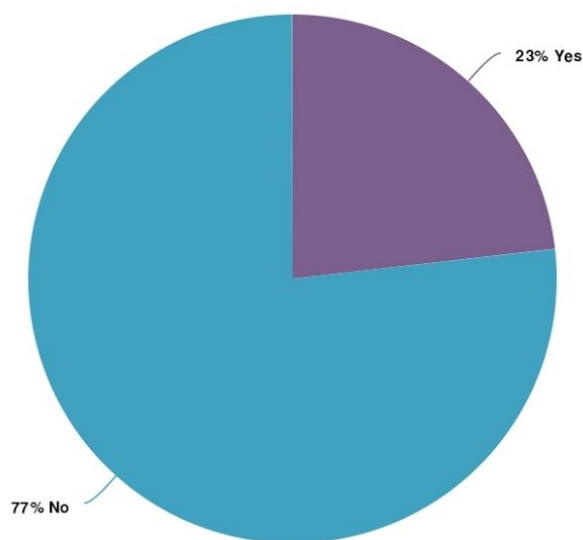
Value		Percent	Responses
Yes		69.0%	138
No		31.0%	62
			Totals: 200

4. How would you describe your illness/injury/disability? Select all that apply *please note that mental illness is included in acute and chronic illness categories*



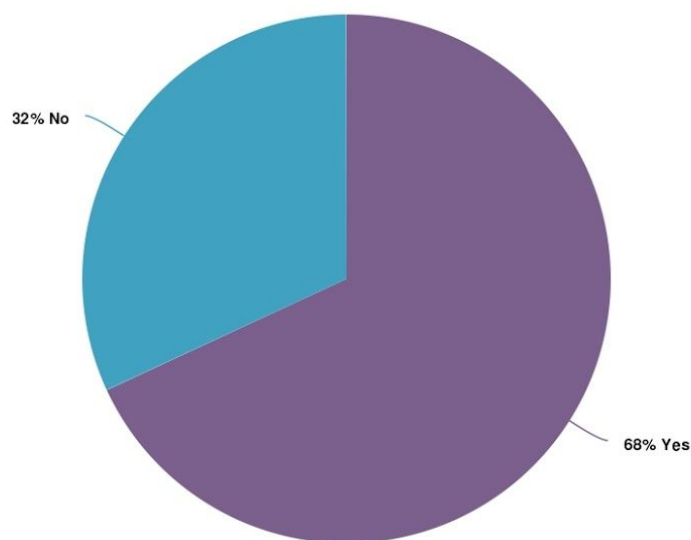
Value	Percent	Responses
An acute illness	15.2%	21
A chronic illness	25.4%	35
An acute injury	51.4%	71
A chronic injury	29.7%	41
A disability	11.6%	16
A surgical procedure	18.8%	26

5. Was/is your illness/injury/disability visible? *this includes visibility from the use of mobility devices, muscle taping, hearing aids, etc.*



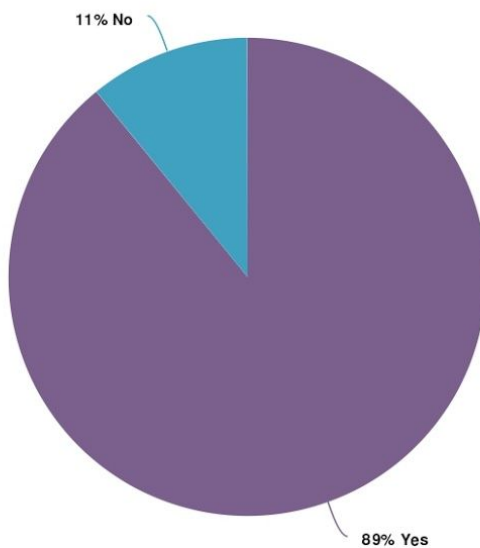
Value	Percent	Responses
Yes	23.2%	32
No	76.8%	106
Totals: 138		

6. Was/is your illness/injury/disability music performance related (e.g. an overuse injury or task specific focal dystonia)?



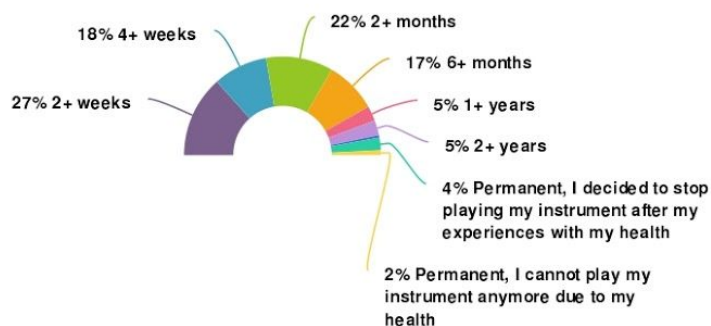
Value	Percent	Responses
Yes	68.1%	94
No	31.9%	44
Totals: 138		

7. Has your illness/injury/disability ever caused you to stop practicing or performing your instrument?



Value		Percent	Responses
Yes		89.1%	123
No		10.9%	15
			Totals: 138

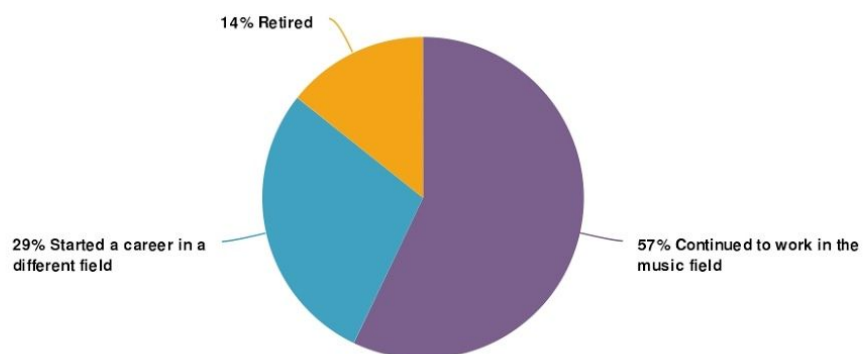
8. For how long were you unable to perform/play your instrument due to illness/injury/disability?






Value	Percent	Responses
2+ weeks	26.8%	33
4+ weeks	17.9%	22
2+ months	22.0%	27
6+ months	17.1%	21
1+ years	4.9%	6
2+ years	4.9%	6
5+ years	0.8%	1
Permanent, I decided to stop playing my instrument after my experiences with my health	4.1%	5
Permanent, I cannot play my instrument anymore due to my health	1.6%	2

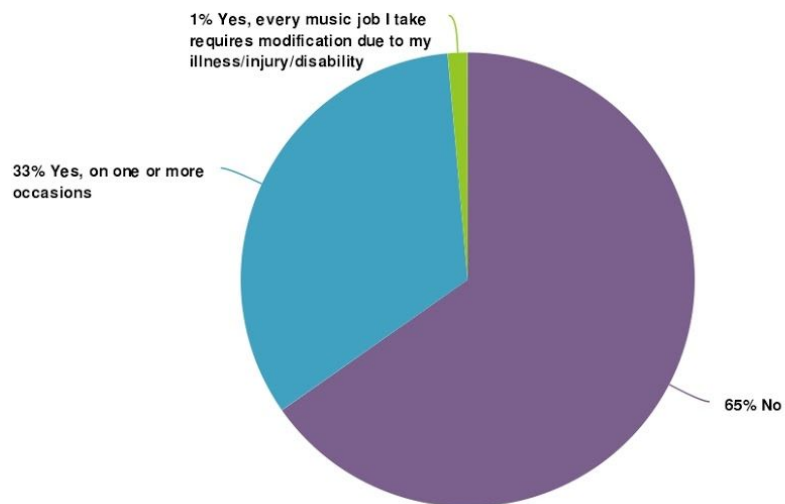
Totals: 123

9. Since you stopped playing your instrument, have you



Value		Percent	Responses
Continued to work in the music field		57.1%	4
Started a career in a different field		28.6%	2
Retired		14.3%	1
			Totals: 7

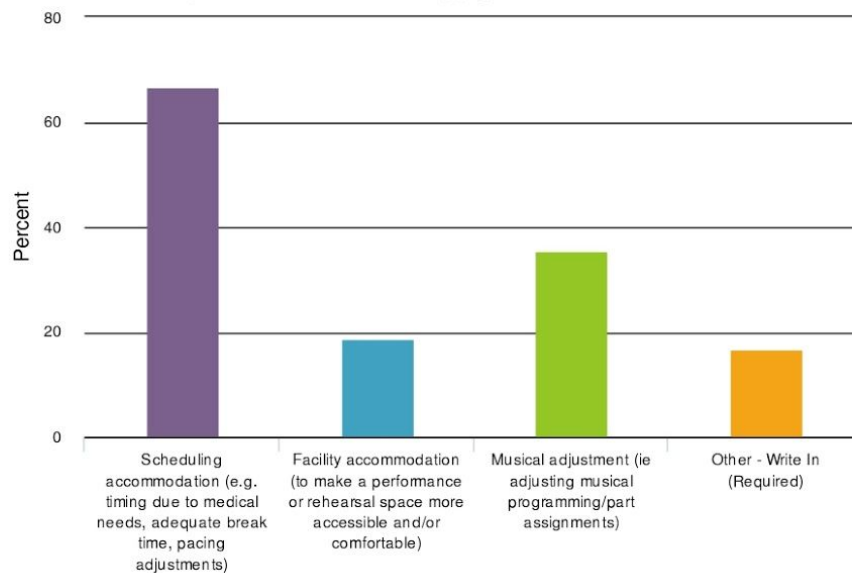
10. Have you ever asked for an accommodation or modification to an aspect of a music professional commitment due to an illness, injury or disability?



Value	Percent	Responses
No	65.2%	90
Yes, on one or more occasions	33.3%	46
Yes, every music job I take requires modification due to my illness/injury/disability	1.4%	2

Totals: 138

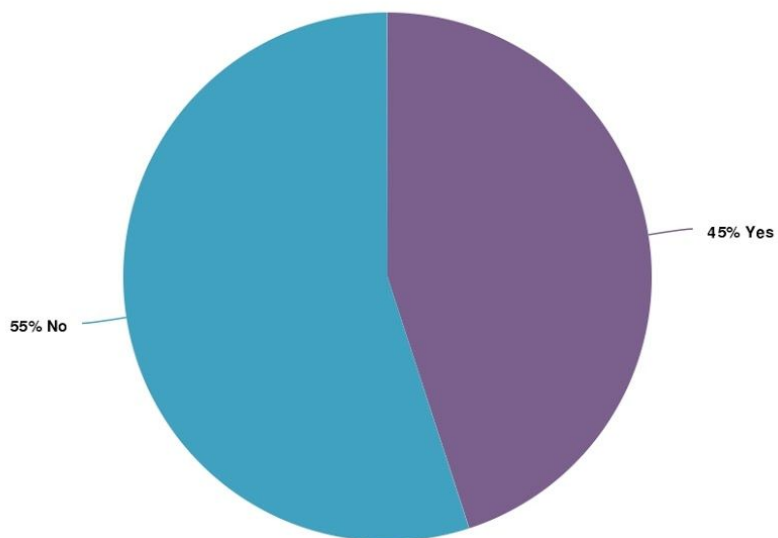
11. What was that request? Select all that apply



Value	Percent	Responses
Scheduling accommodation (e.g. timing due to medical needs, adequate break time, pacing adjustments)	66.7%	32
Facility accommodation (to make a performance or rehearsal space more accessible and/or comfortable)	18.8%	9
Musical adjustment (ie adjusting musical programming/part assignments)	35.4%	17
Other - Write In (Required)	16.7%	8

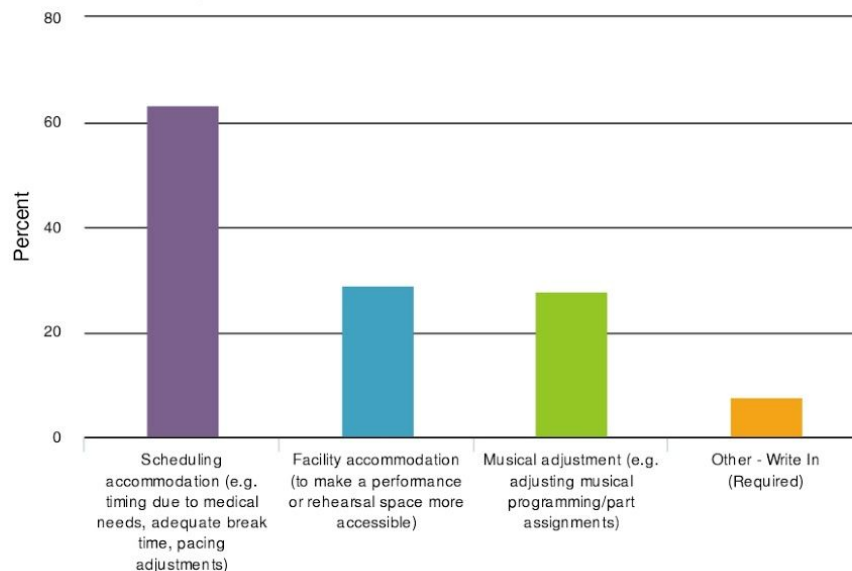
Other - Write In (Required)	Count
Cancelling performances	1
Change of performance date	1
I asked a colleague to make reeds for me.	1
I withdrew from some of my commitments	1
Need more warm up time	1
One cancellation. Several requests to change repertory. My injury is repertory specific.	1
enlarging music	1
keyboard transportaion	1
Totals	8

12. Have you ever collaborated, rehearsed, organized, or performed with a musician who asked for accommodation or modification due to their illness/injury/disability?



Value	Percent	Responses
Yes	45.0%	90
No	55.0%	110
Totals: 200		

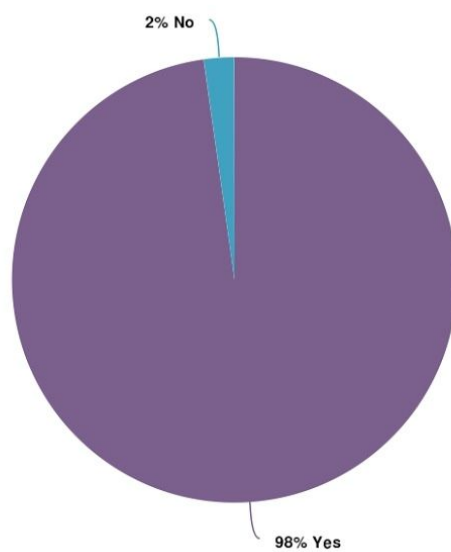
13. What was their request?


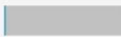


Value	Percent	Responses
Scheduling accommodation (e.g. timing due to medical needs, adequate break time, pacing adjustments)	63.3%	57
Facility accommodation (to make a performance or rehearsal space more accessible)	28.9%	26
Musical adjustment (e.g. adjusting musical programming/part assignments)	27.8%	25
Other - Write In (Required)	7.8%	7

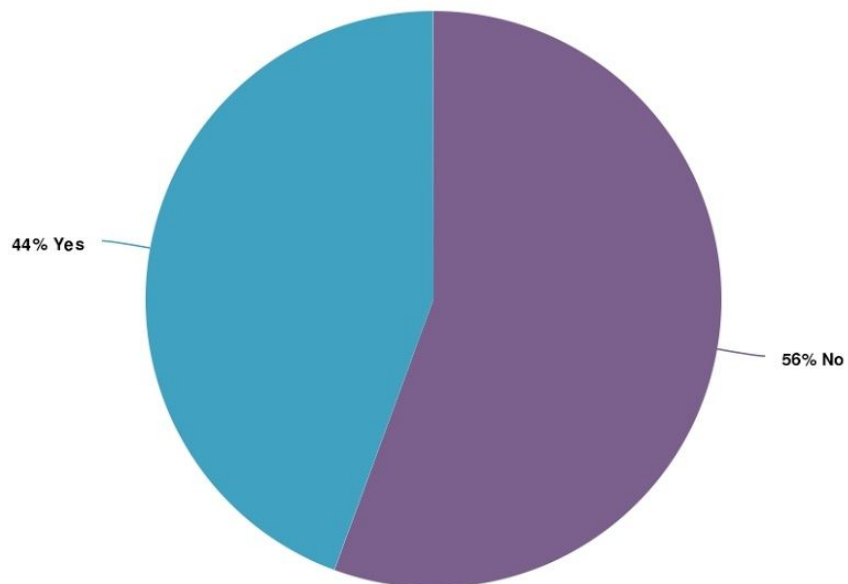
Other - Write In (Required)	Count
A Violinist asked to sit alone and not to share a music stand. I asked to sit on the inside to save my neck.	1
Disabled parking available	1
Had to cover certain parts for someone with a shoulder injury. They were able to play the other parts.	1
Physical accommodations with beginning instrumental students (e.g. a stand to support a trumpet to allow a girl with three fingers between her two hands to play)	1
Sick leave	1
lighting and separate stand for visually impaired	1
wheel chair access	1
Totals	7

14. Were you able to meet their request?



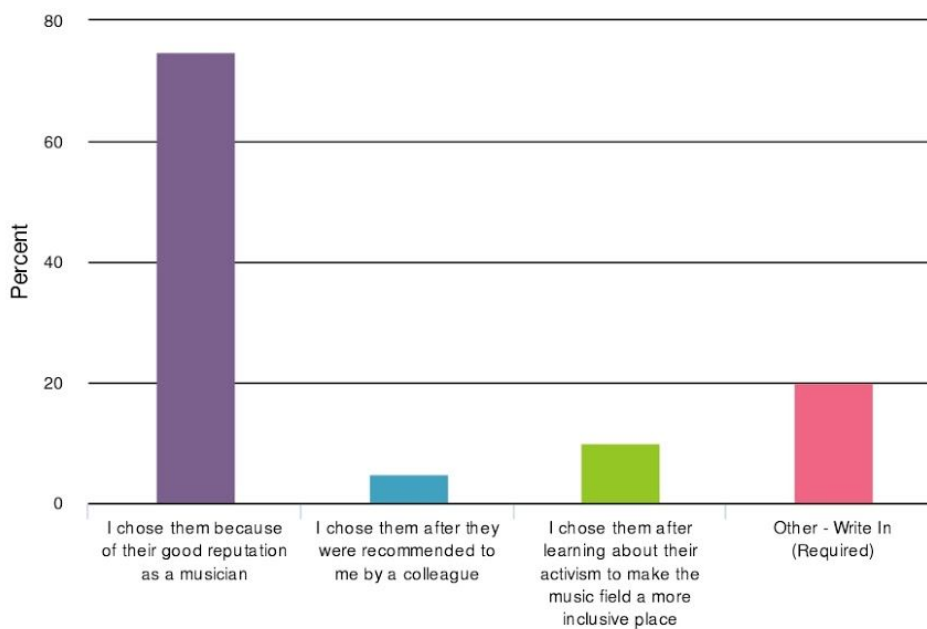
Value		Percent	Responses
Yes		97.8%	88
No		2.2%	2
			Totals: 90

15. Were you aware of your colleague's illness, injury or disability before deciding to work with them/collaborate?



Value	Percent	Responses
No	55.6%	50
Yes	44.4%	40
Totals: 90		

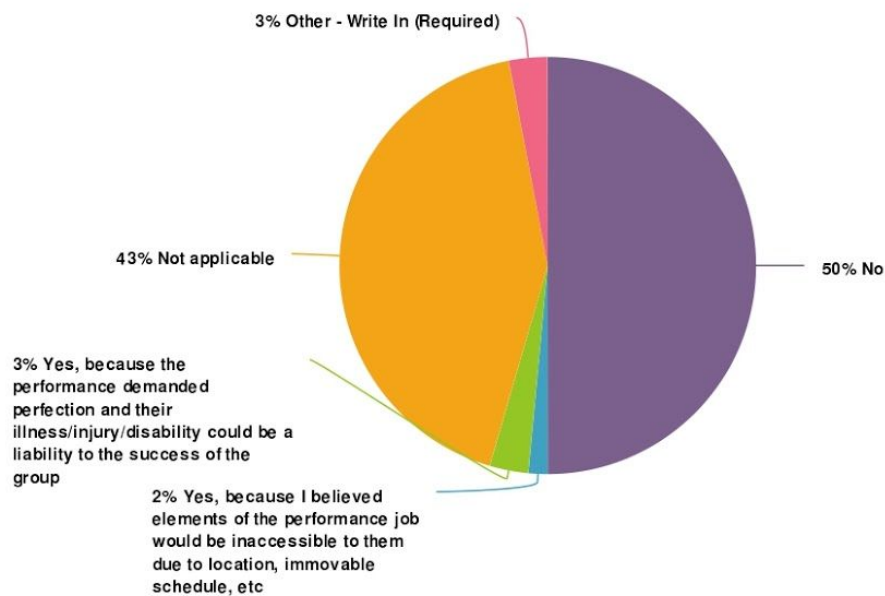
16. For those aware of a colleague's illness/injury or disability, why did you choose to work with them?



Value	Percent	Responses
I chose them because of their good reputation as a musician	75.0%	30
I chose them after they were recommended to me by a colleague	5.0%	2
I chose them after learning about their activism to make the music field a more inclusive place	10.0%	4
Other - Write In (Required)	20.0%	8

Other - Write In (Required)	Count
As a member of the violin section, I accepted it without any reservation.	1
Assigned collaborative partner, unaware of her injury. But we were both assigned to perform together in a time when we were struggling with our injuries. I doubt she vocalized her concerns to anyone other than her piano teacher.	1
I already had a working relationship with this musician	1
I chose them because they were a key collaborator and co-organizer	1
Player was a contracted musician.	1
Student in a public school	1
The musician was a student (not my own). Their disability had no impact on the decision to work with them.	1
tenured musician suffered medical trauma and ended up in a wheel chair but that didn't change their tenure status	1
Totals	8

17. Has an otherwise qualified musician's health status ever impacted your decision NOT to hire them?

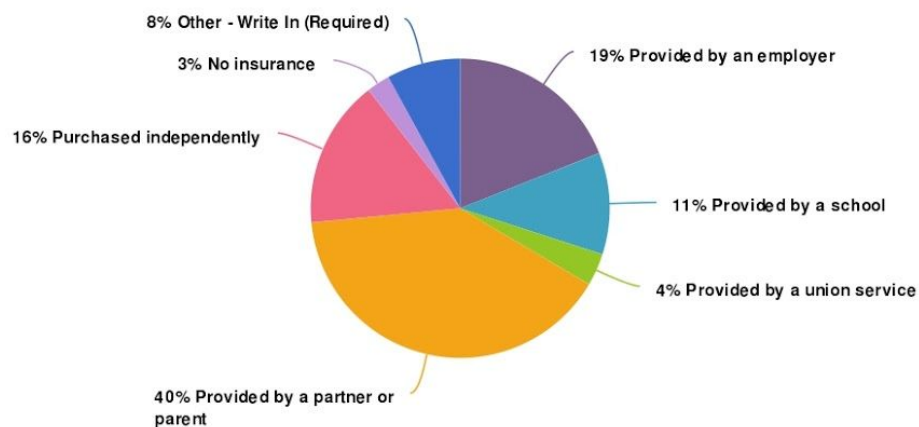


Value	Percent	Responses
No	50.0%	100
Yes, because I believed elements of the performance job would be inaccessible to them due to location, immovable schedule, etc	1.5%	3
Yes, because the performance demanded perfection and their illness/injury/disability could be a liability to the success of the group	3.0%	6
Not applicable	42.5%	85
Other - Write In (Required)	3.0%	6

Totals: 200

Other - Write In (Required)	Count
I would actually choose both Yes options. Also, I would argue with the phrase 'demanded perfection'. That standard is never attainable. The question is always whether someone can do the performance and collaborate in a successful manner. I would definitely not hire someone who was injured—both out of self-interest, and out of concern for their health.	1
Not an employer	1
One musician suffering a manic depression and became disruptive to the Ensemble.	1
Yes - it did not seem that the rigorous schedule would be well tolerated by the individual and I did not want to cause them additional stress/harm.	1
Yes, because the person had suffered a stroke and was no longer able to move or react quickly enough for what the job required.	1
n/a	1
Totals	6

18. What is your access to healthcare?

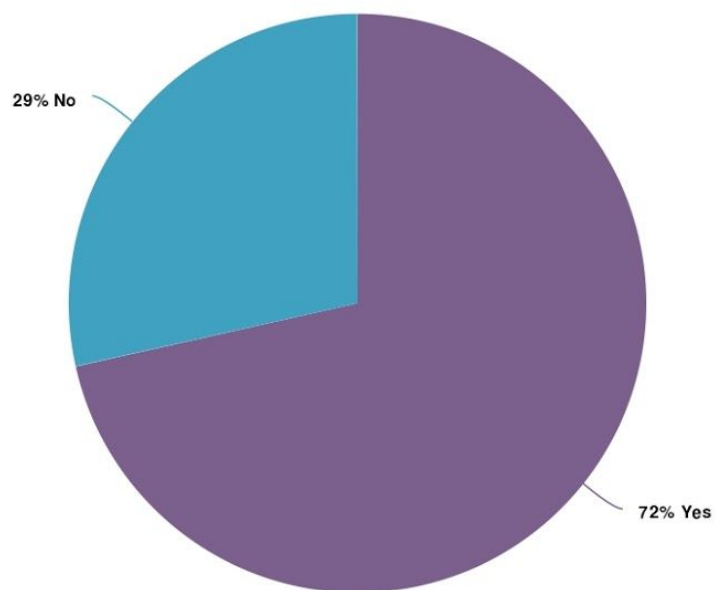


Value	Percent	Responses
Provided by an employer	19.0%	38
Provided by a school	11.0%	22
Provided by a union service	3.5%	7
Provided by a partner or parent	40.0%	80
Purchased independently	16.0%	32
No insurance	2.5%	5
Other - Write In (Required)	8.0%	16

Totals: 200

Other - Write In (Required)	Count
Medicare	4
Government (Medicaid)	1
Govt, I live in Canada. Also extended coverage provided by my employer	1
Guided Physiotherapy Online	1
Half year with insurance, half year without	1
I live in a country that provides health care	1
Medicaid	1
Medicaid/MassHealth	1
Medicare	1
Primary care - Medicare, Secondary insurance through my wife	1
State	1
State Medicaid	1
government medicare	1
Totals	16

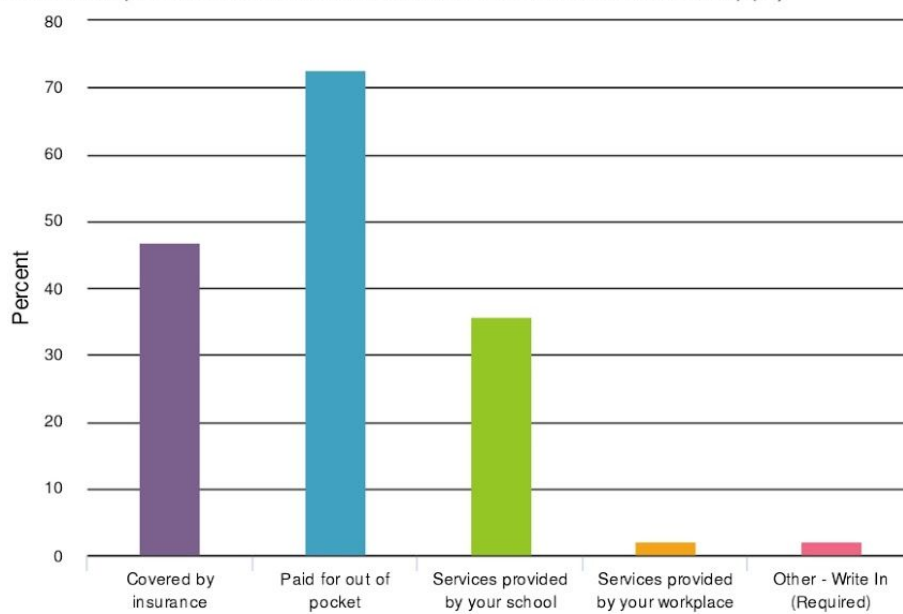
20. Have you utilized any music performance healthcare/wellness programs to benefit your health and in turn, career as a musician? For example, Alexander Technique, massage, acupuncture etc.








Value		Percent	Responses
Yes		71.5%	143
No		28.5%	57

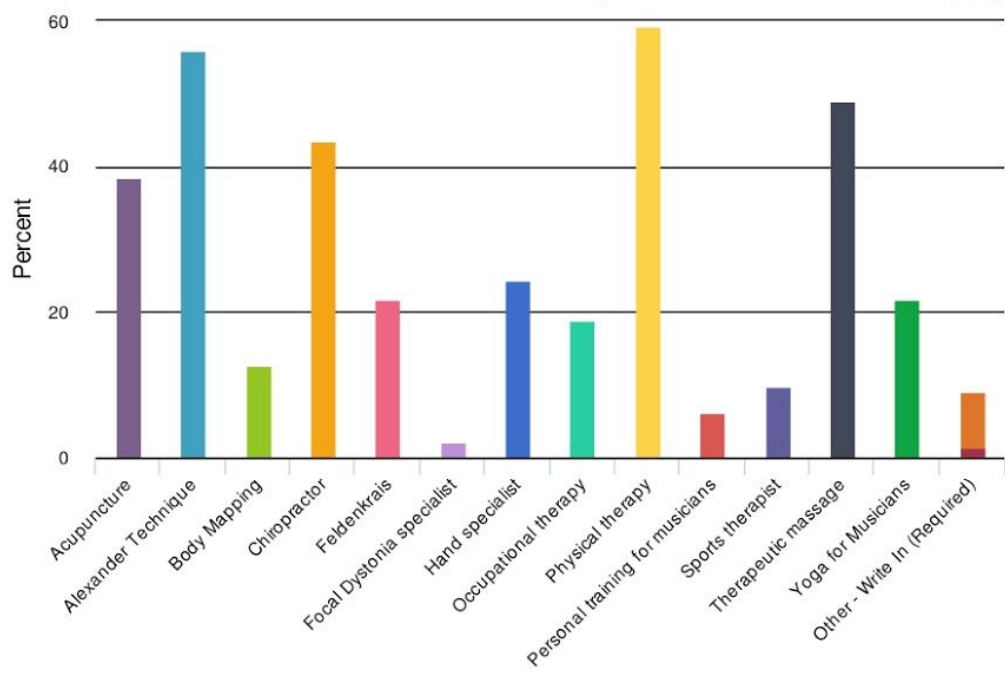
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







21. Were those performance healthcare services Check all that apply



Value		Percent	Responses
Covered by insurance		46.9%	67
Paid for out of pocket		72.7%	104
Services provided by your school		35.7%	51
Services provided by your workplace		2.1%	3
Other - Write In (Required)		2.1%	3

22. Which performance healthcare services have you used? Select all that apply:



Value		Percent	Responses
Acupuncture		38.5%	55
Alexander Technique		55.9%	80
Body Mapping		12.6%	18
Chiropractor		43.4%	62
Feldenkrais		21.7%	31
Focal Dystonia specialist		2.1%	3
Hand specialist		24.5%	35
Occupational therapy		18.9%	27
Physical therapy		59.4%	85
Personal training for musicians		6.3%	9
Sports therapist		9.8%	14
Therapeutic massage		49.0%	70
Yoga for Musicians		21.7%	31
Other - Write In (Required)		9.1%	13
Other - Write In (Required)		1.4%	2

Other - Write In (Required)	Count
Acupressure, Non-needle vaccinations, Athletic training, pilates, Functional medicine, nutritionist	1
ENT Doctor	1
I am a licensed Body Mapping educator and (almost) a certified Yoga teacher.	1
Massage	1
Sport doctors who specialize on arms injury and back injury	1
Swimming	1
TENS Unit	1
Taubman approach for pianists	1
Yoga (not musician specific), osteopathy	1
cranial sacral therapy	1
ear plugs	1
osteopath	1
psychiatric therapy	1
Totals	13

Other - Write In (Required)	Count
Chinese herbs	1
Personal training in gym	1
Totals	2

Bibliography