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DISABILITY AND MUSICKING: RESISTANCE, DEFIANCE, AND INNOVATION

Leon de Bruin, Anthea Skinner and Jane Southcott

Foreword by Evelyn Glennie

Disability and Musicking: Resistance, Defiance, and Innovation

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1. Musicking and Disability: Surveying the landscape

Introduction

In our previous book *Guerrilla Music: Musicking as resistance, defiance, and subversion* (de Bruin & Southcott, 2024) we set about an active reworking of social resources within social movements, and the creative and innovative experimentation and reflection upon musical actions that can make music and music makers agents for change. In so doing we expanded upon the notion of music making and Small's (1998) idea of musicking, involving all human actionable initiations and responses to music as a process and product that are intrinsically part of the ecology of the musical world. We sustain this broad definition of musical engagement and agency that engulfs "the extensive range of possibilities that humans have for engaging with music" (Karlsen, 2011, p. 111). We recognize that musicking can take place anywhere and can be done by anyone. As Small (1998) argues,

The fundamental nature and meaning of music lies not in objects, not in musical works at all, but in action, in what people do. It is only by understanding what people do as they take part in a musical act that we can hope to understand its nature and the function it fulfills in human life (p. 8)

This book, *Disability and Musicking: Resistance, Defiance and Innovation* similarly challenges traditional scholarly approaches wherein music is detached from the social relationships in which it is produced, transmitted, used, and judged (Williams, 2021). Embracing Small's concept, we acknowledge the enactment of music as a social reality, which "establishes in the place where it is happening as a set of relationships" (Small, 1998, p. 13). As we assert in *Guerrilla Music*, "it is through those relationships that musicking finds meaning through creation and activity" (de Bruin & Southcott, 2024, p. 1). Here we use musicking as an underlying principle to consider the practices of music within disability discourse as actions, communities, philosophies that are resistant, defiant, and subversive actions and practices. Recognising the significance that musical experience holds for people with disability and those around them establishes a departure from certain standard approaches to understanding our experiences of music. Higgins suggests that a Western aesthetic tendency "to treat music as an autonomous structural object and to

minimize concern with the holistic character of musical experience ... has obscured the experiential bases for recognizing music's ... roles with respect to ethical living" (Higgins, 2011, p. 114). More holistic approaches to musical experience mean broadening the scope of understanding and analysis in considering multivarious sites and forms of engagement with music.

The cultural and sociological aspects of disability, inclusion and access to musicking have largely been overlooked in larger political or social histories. In addressing these important issues, our concern has been to approach disability music making as cultural production both in itself and situated within larger political agendas. Expansively, we also explore the many ways in which people can and do engage with music, using the inclusive term musicking (Small, 1998) to capture this multifarious music making as integral to culture, history, place, time, and people. Whether reactionary, iconoclastic, or progressive in aim, procurement, and outcome, we seek to capture the active reworking of social resources within social movements, the creative experimentation of music and music makers as agents for change.

Inclusion of musicians with disability remains a critical challenge for any music practitioner and educator who aims for an open, expansive, negotiated, and democratic space for all participants. For us, inclusion in musicking allows and legitimates confrontations and resistances to inequities, powerlessness, and discrimination. We pose the question: How do we as music practitioners and educators address authoritarianism, hegemony, hierarchical strictures, and behaviours? We embrace a broad spectrum of musicking experiences – spanning continua between institutions and community, formal and informal practices, and different ways of being and doing. Within these, there are many socially constructed understandings of music and the ways in which we, as humans, make music with others.

In this volume, we focus on shared musicking practices, seeking perspectives from diverse stakeholders around the world. Insights gained from applying inclusionary practices and visions at individual, institutional, or community levels, represent an evolving often fluid practice, involving actions, performativities, methodologies, and philosophical underpinnings. Research of this kind can contribute to ongoing discussions about disability, inclusion/exclusion, accessibility/gatekeeping and all the ways in which people can feel that they belong (or not). We critique past and present musicking practices to offer glimpses of more democratic, equitable, inclusive, accessible, emancipatory, and innovative practices in musicking globally.

Both in concept and embodiment, disability challenges and exposes ingrained societal prejudices that favor uniformity and able-bodiedness over bodily diversity. In the world of disability, technologies can both enable and disable. As Garland Thomson writes:

> The cripple before the stairs, the blind person before the printed page, the deaf person before the radio, the amputee before the typewriter, and the dwarf before the counter are all proof that the myriad structures and practices of material, daily life enforce the cultural standard of a universal subject with a narrow range of corporeal variation. (Garland-Thomson, 1997, p. 24)

Examples such as these serve as enduring symbols for the ways in which society establishes criteria for a purported normalcy by including, and thus enabling, some bodies while excluding or disabling others. Such positioning is pervasive, thoughtless (in the literal sense), and ongoing. The recent outrage over the Saturday Night Live skit, "The Anomalous Man," underscores the use of tropes of disability as indicators of wrongness. Copious examples like this highlight the cultural positioning that emerges from the social negotiation of diverse bodies with societal codes of conformity. For all of us, negotiating our lived experiences is in essence a performative one: "To think of disability not as a physical condition but as a way of interacting with a world that is frequently inhospitable is to think of disability in performative terms—as something one *does* rather than something one *is*" (Sandahl & Auslander, 2005, p. 219).

Music performance can be seen as historically operating under codes that have the potential to exclude and stigmatize bodily divergence. So too the conventions of music performance frame certain behaviors, actions, and appearances as disabling. The concert performance is a venue with particularly high expectations for exemplary able-bodiedness, highlighting and showcasing the performer's prodigious skills and control of the elements of music (melody, harmony, dynamics, tone colour and tempo) through 'mastery' of technique (expression, agility, range, precision) and musical sensitivity (nuance, finesse, emotionality). Concert performance traditions also demand a sameness in ensemble performers that under normative pretenses are interrupted by visible difference, establishing a hyper-normative visual practice that must not interrupt audience engagement.

However, disabled performance can problematize this framework, juxtaposing what a performer's skills with their perceived deficits. Added complexities within this trope reside in visible and invisible disabilities, that can inform a listener of pre-ordained expectations based on their preconceived ideas of what should occur. Multiple

performativities lay at the centre of music and disability. The disabled performer, as Joseph Straus (2011) argues, has “a dual task: to perform music and to perform disability” (p. 126). Culturally positioned intertwinings shape each other so that it becomes impossible to disentangle them. Disability informs music performance, while music performance in turn informs the disability.

The terms (“visible disability,” “invisible disability”) invoke the sense of sight as a metaphor for awareness, but disabilities may be heard as well as seen—that is, their performance may be partly or even exclusively aural, visual, kinaesthetic, or acoustic. Disability studies has encouraged us to appreciate the many senses involved in perception and, in acknowledgment of the diversity of ways people experience the world, teach us not to elevate one sensory domain over another. Some speech impediments, for instance, are visually concealed but audibly apparent; other disabilities, such as blindness, may be visually apparent but audibly concealed.

These principles of disabled music performance are ubiquitous, constituting part of the expressive tension between codes of musical conformity and realities of bodily diversity that all performers ultimately encounter –but we all age, lose facilities and confidences. Some disabilities are visible, but many, indeed most, are invisible (Churcher 2022). Aging brings with it various ailments, sickness, and for a significant section of society a form of disability that requires ongoing medical, therapeutic or collective assistance. The point we make here, is that at some point in our lives we all become disabled, either temporarily or permanently. As individuals and as a society this realization raises the need to adopt an empathic stance that acknowledges our passage through life as individual, situated, and experientially attuned through conceptions of able/disablement.

Crip theory

The term ‘disability’ is, in many ways an artificial one. It is not defined as a set of observable, predictable traits but is understood as “*any* departure from an unstated physical and functional norm, disability highlights individual differences. In other words, the concept of disability unites a highly marked, heterogeneous group whose only commonality is being considered abnormal” (Garland-Thompson, 1997, p. 24). As such, there exists a range of somatic sensing among people with different kinds of disabilities because their needs and situations are so diverse. The argument could be made that a blind person, a paraplegic, a deaf person, and an amputee, have different physical and experiential histories. Garland-Thomson (1997) suggests disabled people are sometimes fundamentally isolated from each other, existing often as aliens within their social communities. In the late 1990s and early 2000s the academic concept of Crip Theory emerged from the writing of Robert McRuer (2006) and others.

Johnson and McRuer (2024) apply their *cripistemologies* to review their theoretical basis of lived, embodied experiences of disability and the knowledges (or *cripistemologies*) that emerge from such experiences. They make clear the critical ways in which certain identities materialize and become representative, often to the exclusion of others that may not fit neatly within the dominant vocabularies of disability. As McRuer and Cassabaum, 2021, np) assert:

> Many works in crip theory focus on the supposed *margins* of disability identification as well as on the *intersections* where gender, race, sexuality, and disability come together. Crip theory, additionally, offers an *analytic* that can be used for thinking about contexts or historical periods that do not seem on the surface to be about disability at all. *Cripping* offers a critical process, considering how certain bodily or mental experiences, in whatever location or period, have been marginalized or invisibilized, made pathological or deviant.

The evolving concept of crip theory forefronts disability as an organizing idea that brings together a variety of body cognitive and sensory states. Ironically, these movements often first formed as a result of the forced segregation of people with disabilities into institutions like special schools, residential hospitals and asylums (Garland-Thomson, 1997).

Disrupting the Normalcy of the Performance Body

Just as sidewalks and stairways permit the movements of some bodies while disabling others, so too do enduring conventions of music performance have the power to include and exclude. These conventions constitute a constructed normalcy of music performance that exclude, alienate, and critique disabled performers whose bodies do not conform. These norms of compliance exist in our perceptions of supposed technical mastery of musical instruments and the cultural expectation that they should be performed in a particular way—that work together to imply the bodily shape and preconceived aesthetic of their intended performer. The normal performance body usually possesses all limbs, with appropriate finger shape, dexterity, an ability to produce a conducive embouchure, breath support, and a recital length concentration span and stamina among other qualities. Conventional organization of musicians within ensembles implies a sightedness of both musician and conductor. Violin designs imply a co-ordinated, two-handed, two-armed, and multi-fingered performer, whilst woodwind and brass instruments

similarly imply a one- or two-handed performer, whose mouth is capable of forming a strong, airtight embouchure. For wind and brass instrumentalists and vocalists there is a need for lung capacity. Performing musicians are also expected to sit quietly between songs, to not fidget or make extraneous movements or noises on stage, and to remain quiet and listen intently and unquestioningly to conductors' instructions in rehearsals.

All of these features constitute the normal performance body, which, like all forms of constructed normalcy, establishes a template that real human bodies must strive to match. Performers who do not conform to this normal performance body (for instance, those with fewer hands, fewer fingers, weaker muscles, smaller lungs, less vision or different ways of experiencing the world or processing information, are deemed *impaired or less than*, enduring relegation and diminished opportunity and enterprise. More specifically small hands or fingers—usually unremarkable bodily features—may severely limit and even exclude participation in music making. Standardized piano keys, compositions with technical extremes, plus cultural performance practices that require adherence to a score's demands, imply the span of a large hand; many hands, inevitably, will be too small. Notably, the normal performance body is much more regulated than other social forms of constructed normalcy: even the tiniest deviations—a sore knuckle, a swollen lip, mild sinus congestion, a shortened pinky finger—can audibly impair a body during music performance. One need only remember the scene in the futuristic dystopian movie *Gattaca*, where the 12 fingered piano soloist is met with rapturous applause, rendering redundant all 10 fingered varieties (Niccol, 1997).

Cautionary tales aside, even just scanning the surface of these norms of musical aspiration in music performance highlights the power of the prevailing social narrative. We deem highly music performances that display extraordinary, superhuman, abled bodies with prodigious capabilities beyond most, and that challenge conventional feats of dexterity, coordination, musicality, and finesse. A performer who emerges triumphant has perfected their body's abilities to meet the challenge.

What has prevailed in conceptions of disability performance is the notion of accommodations in the form of devices, instrument manipulation or training. These can be perceived as artificially reducing an accomplishment by seeming to decrease the difficulty of the challenge (a smaller keyboard, holding devices, technology assisted sound creation). Conversely it may artificially inflate the accomplishment by seeming to increase the difficulty of the challenge (an adapted saxophone or clarinet that can be played one handed). From an audience perspective

an accommodated performance can be perceived less by about the achievements of the human body and more about the prosthetic and mobility enhancement.

Straus (2006) discusses this cultural malleability of disability within a musical context and cultural models of disability society, impairments can be stigmatizing and enabling in different cultural contexts. This highlights the hybridity of stigmatization, not just to the 'imperfect' person or to the 'abnormal' person, but also upon the exclusionary societies that may fail to accommodate bodily differences. Siebers (2008) progresses the concept through an "ideology of ability," defined broadly as a set of societal practices and beliefs that "describe disability as what we see in the past and hope to defeat in the future" (pp. 8-9).

There exist blurry distinctions between inability and disability. There are accepted musical accommodations (blind soloists, personalized score markings, anxiety medications) and forbidden musical accommodations (bowing left-handed, performing on a midi instrument within a conventional string or symphonic ensemble, 'stimming' during performance, layout changes to allow physical access to the orchestral desk) that lay along a continuum in which separation and distinction is arbitrary and culturally determined. These sociological considerations work to erode and rejuvenate traditions of Western classical music that are severely and enduringly conformational.

These tension points of performance accommodations reside within many in the disability music community. Many adaptive instrument designs seek to accommodate a particular performance application by suppressing any or most traces of disability. And here too, the underlying ideology may be across a spectrum between inclusion and conformation, and where adaptive instruments might appear strange and abnormal in their visual aesthetic or performance techniques that radically diverge from tradition (Skinner & Corn, Forthcoming). However, their sound still strives to match that of the nonadaptive model. Some may argue that to participate in an ensemble, to participate in a conformational musical tradition, the excluded performer must restrain their disability. Others argue their disabled students seek success on violin, or saxophone, or trumpet, and so the work of teachers in this space is to adapt instruments that make engagement possible (Baker, 2018; Fitzgerald & Ehsan, 2023; McCord & Fitzgerald, 2006). Sacks (1984) draws focus to the phenomenology of experience – of the teacher, the students and the social

capital conferred by accessing music spaces, performing tasks, and establishing musical relations that enable one to exercise the rights of normal citizenship.

Sociocultural constructions of what and how disability operates can be aligned with societal notions of fixity to disability positioned in relation to the unquestioned status of ableism as an ideological requirement of the disability/ability system. Fixity marks the experiential content of disability in one form or another— restriction, limitation, immobility, damage or deformity, leading to to unquestioned notions of ableism or exceptionalism. This is threaded with medicalised approaches to disability that include long-held social tenets that tend to locate disability as an atypical condition in relation to norms of physical and psychological abilities.

Such accounts construe disability as the product of the malformed, the misguided or the anti-social, which inevitably leads to suffering, and the search for a 'cure'. Seen through this lens, disability can be seen as either a curse or test from God, with the miracle 'sure' seens as a salvation for the disabled and nondisabled alike (Braidotti [1996] 1999). Governmental approaches tend to stress equality under the law which, perhaps ironically, can lead to exclusionary practices, without critiquing the conditions that preserve the disability/ability and inclusion/exclusionary dichotomy within such systems. This can be prevalent in education systems across Governments, schools, administrators and music teachers that sustain an ecology of exclusion and gatekeeping to music education (de Bruin, Skinner & Thompson, 2023). Rosemarie Garland-Thomson has challenged the disability/ability system, and her notion of fitting and misfitting within social norms works at "shifting disability from an attributed problem in the body to a problem of social justice" (Garland-Thompson, 2011, p. 592). Our fundamental premise here, in regard to disability politics in music, is that equal access and social justice is actioned "by changing the shape of the world, not changing the shape of our bodies" (Garland-Thompson, 2011, p. 597).

Cripping musical time and space

Central to our discussion of musicking is how music shapes the lives of people with disability and how it may contribute to their flourishing and the eudemonic possibility of a good life. We consider the ways that music may facilitate a sense of selfhood that can enable expression and the capacity for musical joy. While music is often connected to the idea of self-transcendence in allowing us to move beyond ourselves, the relationship between music and self-awareness of disabled musickers is an underexplored area. Higgins identifies three aspects of selfhood that emerge through music: it reveals our existence as temporal, embodied, and vital beings (Higgins 2011).

There are a number of ways in which the experience of disability can act on one's temporal existence. Living with a disability may enact the experience of one's life course, and the trajectory on which one maps out a future. Disability can radically transform the experience of time – travel, treatments, cognitive processing styles and life expectancies that may be impacted in specific ways. Discourses informed by medical models can further emphasise the dissonance between normal/nondisabled and abnormal/disabled bodies, as well as discerning between cognitive ability and musical ability. Kafer (2013), in *Feminist, Queer, Crip*, questions "What would it mean to explore disability in time or to articulate 'crip time'?" If people with disabilities experience their lives in temporally distinct ways, how might this reflect experiential and situated musicking encounters as a performer, or an audience? From a phenomenological, or lived experience perspective, there are important ways in which music can also transform the experience of time. Ford (2010) suggests that music is the only art that forms time through sound, and that as a result listeners' intentional time becomes that of music.

Hegel concerned himself with the concept of music time and space, asserting that music "penetrates the self, grips it in its simplest being" (1975, p. 908). This "gripping," encapsulates the inner, individual, and somatic sensation and interplay of internal complex relations brought into being by our individual musicking experience. We are not only moved by the music but also moved with it in a shared temporal landscape, achieving a synchrony in our embodied responses that bring us together in ways that verbal communication cannot. This can occur through organized or ad-hoc performance, in a classroom, a town square, or a musical experience unfolding organically, but it is also valuable and valued for its own sake.

Making and marking our senses of musical time together happens in musical performance. In playing in an ensemble, the individual's experience of experiencing time becomes a part of the communal rhythm and sensating of the performance, enveloping each participant into a personal and collective temporal whole. In some cases, it may be more or less rigid, allowing individual players to sense their own rhythmic placement and move within and across shared musical boundaries. This experiential encounter with music and musicking is not limited to the confines of the able-bodied. As we all, beginner or accomplished make malleable the elements of music (melody, harmony, rhythm, tempo,

tone colour) so too do our modes of expression and the capacity to experience transformation.

A case in point is the work of Bakan (2015) who through the ARTISM musical performance project enabled performers with autism to move beyond normative expectations. In expressing his and the students' transformative musical experiences, he believes that:

> people with autism are not necessarily any less spontaneous, intuitive, flexible, or improvisatory than other people are; rather, they appear to be that way because they are almost invariably forced to contend with life situations and settings in which their particular attributes and preferences for expressing spontaneity, intuition, flexibility, and improvisational ability are demeaned, or are patronized, or go unacknowledged or unrecognized altogether by their interlocutors. (Bakan, 2015, p. 299)

Thus, in the act of performing music together, people inhabit a *shared* temporal landscape. This forms connections, expressions and ways of communicating for individuals who, according to other normative measures, would not usually share time in this way.

Music as a way of thinking and resisting

Engaging with and in music activates our cognitive, social, emotional, and psychological abilities to receive, understand, make meaning from, and communicate musically and collaboratively. Engaging with music "fosters a productive flow that evolves through language, text, lyric, melody, beat, rhythm, and the organisation of time in space" (de Bruin & Southcott, 2024, p. 1). This engagement with music also affords everyone new modes of expression though performance and creation. Music affords the possibility of recognizing oneself and others as temporal, embodied, creative, and expressive beings. Engaging in musical experience confirms our own vitality as human beings: "Music, simultaneously engaging our physical, emotional, and intellectual receptivities, makes us feel fully alive. The dynamism of music, moreover, reminds us of our own dynamism" (Higgins 2011, p. 121). The animating power of music is achieved through a broad range of musical experiences that people with and without disabilities feel. This dynamism challenges certain medicalized attitudes, education systems that are out of touch, and socially prevalent assumptions and stereotypes about disability that are resisted, defied, and subverted by critical disability scholarship. Cultural theorist Papastergiadis (2002) refers to a "semiotics of

hybridity" or the language of hybridity that "becomes a means of critique and resistance to the monological language of authority" (p. 170).

Disability music as resistance, whether individual or collective is constructed through discourses and relations of power that undo "the priorities and disrupts the singular order by which the dominant code categorizes the other" (Papastergiadis, 2002, p.170). The work of Latorre and Sandoval (2008) articulates an artivism as "a hybrid neologism that signifies work created by individuals who see an organic relationship between art and activism" (p. 82).

Historically, social construct of disability has been perpetuated in multiple ways (including a broad range of scientific, psychological, and educational conceptualisations) that have approached inclusion and engagement (that is exclusion and non-engagement) with a range of administrative, organizational and pedagogically exclusionary practices. In some quarters the persistent view that people with disabilities are in a state of arrested development, of extreme passivity, incapacity and inherent tragedy, has contributed to their dehumanization that has justified and perpetuated many of the cruel and violent forms of treatment to which people with a disability have been subjected (Carlson, 2010; Trent 1994).

Through musical experience, people with a broad range of disabilities have the opportunity to perform, actively engage and simultaneously activate dynamic modes of being. Attending to the significance of music for people with disabilities can reveal a number of important dimensions of their lives: music can orientate our ways of communication and community; music can "call forth the self" (Sacks, 2007, p. 346) in ways that might otherwise be obscure, unexplored, or unnoticed, and can foster the cultivation of particular capacities and forms of joy that may contribute to the individual's flourishing (Carlson, 2013). There are many kinds of relationships between individuals with and without disabilities, and music can function in distinct ways in each of these.

Music has a means of transgressing normal barriers that prevent individuals with disabilities from connecting with others. These barriers might include the communication (for example in persons with limited verbal speech), and the social and structural barriers that prevent such relationships from being forged. Music "affords a ground for empathy with particular others" because it "creates intimacy" (Higgins 2011, p. 130). Musical

relationships can be transformative in that they overcome such obstacles and provide the possibility of finding grounds of commonality. Higgins states,

> One listens to music, not as lover, lawyer, or mother, but as a human being, and one relates to other listeners as human beings like oneself. This kinship is not grounded on the relatively contingent fact of occupying roles that are similar to or linked with those of other individuals. Instead, it is built on sharing the freedom of imagination that enables one to feel empathy with the movement of tones, the simultaneous bodily response to stimuli that one receives without inhibition. (Higgins, 2011, p. 132)

The notion that certain identities and self-perceived roles fall away in musical experience is an intriguing one, particularly in cases where music provides the basis for participation in a shared activity between individuals who might lack other means of establishing a connection. Musical experiences and relationships can provide the cultivation of certain virtues and qualities. As de Bruin and Southcott state, "music can activate emotional states that present to the conscious mind, through which we mediate our reasoning and relationality with our fellow humans" (de Bruin & Southcott, 2024, p. 3). It is through musical events, be they routine, planned, or spontaneous, that personal music boundary riding and boundary transgressing occurs (Higgins, 2012).

The process of valuing and gaining joy from musical experience, the possibility of a deeper appreciation for self and *others* can be developed. Musicking experiences engage a contagious and expansive emotional attunement with self and others that has ethical value because of what it can generate. Music fosters value in ourselves and others by being sensitive to aesthetic experience. In the act of vulnerability, we realise that we are joined in musical connection by shared vulnerabilities. Such vulnerability is precious for its contribution to ones' own life, but also as a precondition for openness toward others. The idea of an individual vulnerable to being moved by musical experiences radically shifts the conception of vulnerability that is so often associated with people with disabilities.

Communities of practice

Engaging in collaborative musicmaking is one way to partake in community, to establish and engage in a particular form of *being-with*, and to enrich our human lives. For those with a disability this is particularly prescient as they have been historically excluded or marginalized within ableist societies. Making music within groups provides connection and collaboration, a musical attunement to the *other* that can come in a variety of forms, in the act of listening together,

through joint participation in a musical performance, and in the relationship between audience and performer. What is significant about these moments is that they disrupt preconceived ideas of the relationship between the “nondisabled”, the “disabled”, and the audience. There is a shared experience that is centered on a third plane in which the traditional binaries and imbalances are dismantled.

There is also value in moving beyond the designations of disabled/nondisabled altogether when considering music and disability. First and foremost, it is important to explore the nature of experience *as musicians* rather than remaining ensconced in the abled/disabled binary. In theorizing about relationships between individuals, in reacting on the power of *being-with* in a musical context, new roles and identities may emerge as rich models for Disability Studies scholarship.

Identity is confirmed and evolved in the act of musicking. For some this may be defined as an intrinsic aspect of being a part of a community. For others it may represent a more temporal and transient experience, as we touch on Wenger’s (1998) influential notion of communities of practice as powerful modes of musical gathering and music making, where “collective conscience forms an emotional bond within a group who share learning and engagement” (de Bruin & Southcott, 2024, p. 3).

Musical communities can be temporary or permanent, large or small, improvised or well defined, professional or amateur, with dynamic or fixed boundaries. The vast range of musical encounters and relationships that can be established within musicking practices may serve as a basis for rethinking the very nature of community and the actions by which we consider access and inclusion. The Scottish musician Evelyn Glennie, who is deaf, remarks of the musical group INTERplay, that a band for people with disabilities is about inclusion not exclusion:

> Society cannot continue to disable themselves through their need to categorize people or make assumptions as to another individual’s abilities. ... The human body and mind are tremendous forces that are continually amazing scientists and society. Therefore, we have no choice but to keep an open mind as to what the human being can achieve. (Weeks, p. 51, 2010)

Overview of our approach

This book interrogates many of the issues, questions and tensions that reside within disability scholarship generally, and in music and disability specifically. Our conception of lived experience extends beyond medical binaries of ablist/disablist approaches to cognition and access, understanding musical cognition and perception as enacted, embodied, embedded and enacted (Newen et al, 2018). We forefront "the body as a lived, experiential structure and the body as the context or milieu of cognitive mechanisms" (Varela et al., 1991, p. xvi). Such an approach resists limiting models of disability and approaches to music and disability that simply perpetuate and reify essentialist modes of intelligence and definitions of disability. We challenge existing assumptions about disability, replacing older problematic approaches to engagement, enactment, and community with more capacious and varied approaches that open up new and innovative paths of action and inquiry. This involves recognizing the nature and value of shared musical experience and dismantling preconceived limitations of disabled forms of musical expression. Exploring the creativities, places, spaces, and emerging professionalisms, we seek to understand and explain better the development of musical lives, to learn from and celebrate these forms of musical experience, and to critically analyze the affordances and constraints to illuminate recognition, celebration, formalization, and innovations in the field.

The scholarship in this book reports on various practices, approaches, methodologies and acts. As we articulate and iterate the intentions of our first book in exploring musicking, resistance, defiance and subversion, we here build on this by highlighting the continuum of musician movements that reflect these qualities. Within this, we investigate "practices and meaning systems used by musickers that often are built on underlying contrasts and dissonances of things that are unequal, unfair and unacknowledged" (de Bruin & Southcott, 2024, p.3).

The authors provide wide ranging lenses on investigation. Several assert an ethical and equitable distribution of musicking in a wide, positive, and enabling sense. This reflects musicking that remonstrates access to traditions, genres, behaviours, that includes our imagined ideals, and attitudes all underpinned by a praxial ethics of care that is the responsibility and right of all involved. Many of our contributors cut into broad understandings of culture as musicking practices embedded in social and temporal contexts. A significant standpoint is the questioning of institutional cultures that may limit and dominate musicking and musickers. Understanding culture existing at both the micro and macro level, our authors provide for very different understandings of musical wisdom, teaching, and learning. Another dominant essence imbued across this scholarship is the emancipatory approaches to musicking that liberates and challenges oppressions. We

understand that emancipatory practices are agentic, providing the ideal for all in full participation in decisions, programs, and behaviours that impact all involved. Many of our authors delve beneath these questions and emancipatory principles and practices, highlighting for whom, when, where, and in the many cultural and musicking contexts emancipatory practices facilitate agency, wellbeing and transformation for able and disabled people.

This book brings together a unique collection of research work that extend philosophical underpinnings and theoretical frameworks in relation to disability /critical disability and inclusion. We divide this book across four sections that discretely explore disability musicking practices that mark:

- evolving practices and movements,
- disabled performativities,
- new epistemologies in disability teaching and learning.

Across the three engagements we explore individual and collective practices, self-propelled, community and shared practices that in some cases represent social and cultural and even political movements. Disabled people themselves have historically often been excluded from the very discourses in which they are talked and theorized about. In contrast, the vast majority of authors in this volume identify as disabled, deaf, or neurodivergent. Further we give voice and expression to disabled performers who each provide insightful, defiant, and in some cases astounding musicianship. We explore new epistemologies- ways of looking at and understanding truth from disabled perspectives. Here we evince innovative musicking practices; curriculum and pedagogical frames that span formal, institutional and informal/community activities; and activisms for societal, philosophical and social change and evolving educational practices. We underpin these investigations through the lens of musicking, acknowledging the varied ways and places in which music is performed, composed, and experienced, reminding us that the lived experience of music is distinct from theorizing and philosophizing about it.

We hope our aim meets the outcome of representing with fullness and complexity the lived musical experiences of people with disability in the process of trying to give voice to them in theoretical works. Our concern is salient, given that people with disability are often spoken about rather than given the opportunity to speak for themselves. Our attempts

to explain, analyze, and describe both music *and* disability can, through bringing these elements together, establish new dimensions of understanding that can be further advanced by critical disability scholars, philosophers, and educators and the inclusive musical spaces they create.

Many people with disability experience stigmatization and isolation. The possibility of sharing their musical lives with others may prove to be fertile ground in which friendships, social connections, and musical skills can grow. In this way, this attention to disability music will reform exclusionary practices within and beyond the world of Disability Studies, and generate new modes of engagement, community, and flourishing.

Overview of chapters

This book then seeks to re-establish new terrain in disability studies and music by forefronting disabled voices and experiences and understandings. In so doing we highlight through the lens of disability lived experiences music's productive affects, performativities, relational dimensions and new perceptions of understanding that shape approaches to teaching and learning. Scholarly and musical exploring of this kind reveals how music's multidimensionality arises in the tensions of its aesthetic, experiential, social, and political values.

Our first section begins with Skinner and de Bruin who in Chapter 2 explore the *Adaptive Music Bridging Program,* an ensemble initiative in Melbourne Australia where students aged 8-14 can learning an instrument - conventional or adapted - and participate in an ensemble. Highlighting the dialogic, democratic and solidary mode of musicking asserts pedagogies of participation and implications for often restrictive mainstream music educational practices. In Chapter 3 Kolin provides a self-reflective account of workshops, arguing that educational and teacher practice can offer more holistic understandings of what music experiences promote, offering insights into evolving praxis in music disability studies.

In Chapter 4 Reimann explores the collective that is *Tralala Blip*, an ensemble of disabled musicians. The group discuss both their inner and outer sense of a community of practice and the wider abled/disabled/musicking ecology and the growth and sustenance of self-sustaining performativity and connection. Chapter 5 sees MacGlone investigating *Limelight Music*, discussing the co-facilitative practices that promote interdependent yet emancipatory musicking. This chapter argues the valuing of diverse abilities and the creating of shared leadership structures that provide understandings of ways which disabled musicians' contributions are key to extending practices in community music. Chapter 6 by Cameron and Williams places values of community and inclusion by reflecting on disabled perspectives. They

assert a rubatic framework of temporality, drawing on the embodied experience of *rubato* to better understand crip time. They offer insights into the ways in which embodied musical knowledge informs understandings and enactments of crip time.

Section two investigates the exciting diverse and innovative capacity of disabled performativities. Chapter 7 explores the musical world of Guilhem "Pone" Gallart. A French hip-hop artist of huge popularity, this reflective/reflexive account surveys the terrain and font of his work, emerging from the Marseille hip-hop scene. Acquiring myotrophic lateral sclerosis, Pone now composes using adaptive technology and continues to create, produce and collaborate. We provide this text for both English and French readers. In Chapter 8 we explore the performative world of Melinda Smith and collaborator Alon Ilsar. This bi-reflective prose unveils a musical ecology based on shared creativities, ideations and collaborative elan spanning the production of *Conduit Bodies.* In Chapter 9, Lubet firstly explores social confluences of music pertinent to disabled musicians in jazz. His self-reflective experiential discussion of what it means to perform disability ties in with emergent scholarship in this important area. In Chapter 10, Bakan and Msumba explore guitar performance and self-discovery in finding self-devised technologies, amidst a constancy of normative societal pressures and struggles.

Our third section, 'New Epistemologies in Disability Teaching and Learning' starts with a provoking critical reflection. Squires and Thompson in Chapter 11 offer a rarely explored student and teacher perspective to a co-designed research project centred around autism-friendly music-making workshops. Vignette driven events and reflections provide deep insights into the challenges in providing safe spaces, and what they may look like. Rarely are we privy to the construction of an inclusive tertiary program, and in Chapter 12, bell takes us through the syllabus design and embedded facilitative engagements incorporated in a disability centered music education course. Just how well are instrumental music teachers trained for and feel adept with disabled learners? Chapter 13, by Raine and Thompson offer a scoping study on teaching approaches employed with students with disability by instrumental music teachers. They articulate values, benefits and shortcomings described in the literature, offering implications for the training of music teachers. Chapter 14 explores the continued existence of black disabled performers since North America's colonial past. Here Leroy Moore surveys this history- from slave ships, minstrelsy, blues, jazz through to his activities with *Krip-Hop Nation.* From this assertion, Moore questions black disability and inclusion, and its ongoing presence in America's

history. In Chapter 15, Laes connects many of the threads spun here, bringing together both the questioning of anti-ableist dogma, whilst offering a philosophical and praxial way forward for music education.

Through the lens of music and musicking, this book approaches inclusion, access and opportunity with the scholarly virtues of generosity, openness, respect, and tolerance. As musickers, we also appreciate how these qualities underlie the relationship between audience and performer; and the distinct forms of knowledge necessary for musical creation and collaboration among musicians. The disabled body and mind have much to say and add to the discourse surrounding critical disability studies in music. Innovative musical, verbal, gestural and nonverbal expression and communication make disabled musicking and practices an exciting place for co-creators and audiences.

Further, we suggest the disabled body and mind play significant roles in the evolution of modern aesthetics, as we and other noted critical disability scholars theorize and performatise disability as a unique perspective and resource. As Siebers argues: "Disability aesthetics refuses to recognize the representation of the healthy body-and its definition of harmony, integrity, and beauty—as the sole determination of the aesthetic" (Siebers 2010, pp. 2-3). This book asserts a disability aesthetic that embraces beauty that may seem by traditional standards to be broken, but yet are not less beautiful or valid, but more so, as a result. We examine how music and musickers can create a counterhegemonic space and movement within which disabilities that were once stigmatized can and should now be celebrated and valorized. We are all of benefit by embracing this perspective to music, disability, and a shared voice for all.

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PART 1: EVOLVING PRACTICES AND MOVEMENTS

2. Inclusive music practices for students with a disability: Feedback for agency and resilience in the Adaptive Music Bridging Program ensemble

Anthea Skinner and Leon de Bruin

Introduction

Musical experience can reveal dimensions of the self, establishing relationships, and promoting new kinds of flourishing that can challenge dominant assumptions about the lives of people with disabilities. Ensemble learning and collective music making provides a powerful social interaction that invites teachers and students to share and extend their thinking beyond their own individual capabilities (Chi & Wylie, 2014; Scardamalia & Bereiter, 2014). Central to this is the role feedback plays in the learning interactions for students. Music ensembles and ensemble-based learning provide an environment that is both situated and dynamic in the processes and performance of musical, potentially laden with relational and interpersonal outcomes (de Bruin, 2018).

Dialogue with students exists as a complex and dynamic process, requiring mediated interactions, a relational space in which both teachers and learners understand differences between learning now and learning next. Feedback allows students with and without disabilities, to see themselves in new ways as future learners. What is clear is that significant evidence points to similar instructional and management approaches across all educational settings, both those termed 'mainstream' and those termed 'special' (K.de Bruin, 2019; Graham, 2023). Many effective general teaching behaviors identified in impactful process/product development are appropriate for engagements with disabled students in inclusive classes, music studios, and ensembles.

In this chapter we use the Adaptive Music Bridging Program (AMBP) as a case study to explore agency and self-determination among students with disability in an instrumental music setting. We investigate the perceptions of student participants and their parents, and also interrogate our own assumptions as educators and musicians about pedagogy and the role of feedback in musical engagement and learning. We explore pedagogies we have adapted in this program, in particular dialogic forms of feedback that promote capacities and capabilities of students. We investigate how such interactions may equip students with the tools they need to explore their musical and social creativity with others, to choose and learn to play an instrument, participate in an ensemble and to set and meet their own musical goals.

The Adaptive Music Bridging Program

The AMBP, a collaboration between the University of Melbourne and Melbourne Youth Orchestras, was established in 2023 and at the time of writing had welcomed its second cohort intake. This program invites students with a disability to engage in instrumental lessons cultivating musical skills, literacies and knowledge in an ensemble-based program. As its name suggests, the AMBP is designed to act as a bridging program, with students being supported to move into mainstream ensembles as their skills develop (Melbourne Youth Orchestras, 2024). The success of this program and its students implicates important critical questions for the field of disability studies and mainstream music education, regarding the marginalization and exclusion of people with disabilities, the value of pedagogic, relational and theoretical discourse and applications that allow music teachers to approach their profession with access and equity at the heart of what they do, who they teach, and what they aspire for their students.

Feedback dynamics

Formative feedback is defined as "information communicated to the learner that is intended to modify [their] thinking or behavior for the purpose of improving learning" (Shute 2008, p. 154). It provides an actionable set of understandings for all learners by drawing on cognitive, relational, and communicative modes (Black & Wiliam, 2009) and has been identified as a "key characteristic of quality teaching" (Carless, 2006, p. 219). Understanding feedback as a social process can underpin the development of human relationships and the relational interactions between teacher and learner. Dialogue within the instrumental and vocal ensemble can thread modelling, scaffolding and coaching of learners through activities involving explicit instruction. The instrumental music ensemble can also involve igniting curiosity in self and others (de Bruin, 2021).

Instrumental music teaching involves the modelling of an exemplary performance, but also the behaviours, attitudes, curiosities and enjoyment gained from making and learning. Scaffolding directs learning by supporting the physical and mental actions used, clarifying goals and deconstructing the task to "do- able" chunks. Coaching dialogically engages a student in the learning process. Coaching can involve a highly personalised intra-active engagement that involves knowledge about the student, their response to tone, gesture, calmness, intensity and humour. An ensemble context can at times intensify and unite collective feelings of togetherness, entrainment, and the activating of a genuinely motivating climate of engagement.

Such teaching practices aim to spark sustained learning and promote students' knowledge building, self-esteem, meta-cognitive skills and identity as music learner (Burwell, 2012; L. de Bruin, 2018a) These teaching skills rely on a dialogic interactivity that involves a teacher's receptiveness, insightfulness, and responsiveness of interpersonal connection (L. de Bruin, 2022) that foster feelings of safety, belonging, and self-esteem.

Whilst feedback can provide essential skills and knowledge, it also establishes affiliative and empathic communion between teacher and learner that can enhance sustained learning and engagement (Eisenberg & Liew, 2009). Feedback can support learners in mediating their own individual and joint efforts as they socially, cognitively, emotionally, and motivationally become involved in musical process and product (Laible &Thompson, 2007; de Bruin, 2019). Feedback can also align common perceptions of a collaborative learning process with teachers and peers, the role of self in collaboration, and the shared and iterative fine-tuning of cognitive, behavioral, motivational, and emotional conditions evident in musical ensembles (Hadwin et al., 2017).

Central to the role of feedback is a dialogic pedagogy whereby teachers expand students' thinking beyond learners' internalization of knowledge. As L. de Bruin (2023) asserts, dialogue "relationally orients engagement and facilitates the active 'doing' of teacher modelling, coaching, scaffolding, and reflective episodes that guide the student towards developing skills, growing independence and confidence in the learning process" (p. 2). This highlights both the communicative power of feedback and the interrelationship at the core of successful engagement and learning for these cohorts.

Feedback operates as a moment-to-moment guiding of students' immediate actions. It can indicate current ability, progress shown and steps to improve (Hattie & Timperley, 2007). This in turn impacts student learning management and their inclusion in the exploration of learning and self- management processes (Korpershoek et al., 2016). Impactful, thoughtful feedback thus can feed into capacities of autonomy, self-control, self-direction, self-discipline, and goal orientation for learners with or without disability.

As effective as feedback may be, students need to be in the classroom, engaged, included in quality educational activities that provide learning, belonging and wellbeing. This has historically not been available to students with a disability. Various countries and educational jurisdictions have applied recent human rights mandates that have created various approaches and terminology towards disability, and various understandings and applications of what disability is, how such populations are included or excluded, deemed 'special', and are provided with 'special', inclusive,

and mainstream educational experiences. Understanding these provides insights into the context of research in the field.

Disability, USA/Canada/UK/Singapore/Australian nomenclature and contexts

The United Nations' International Convention on the Rights of Persons with Disabilities (United Nations, Article 24) ascribes access to inclusive education for people with disability on an equal basis. Though a contested educational space in terms of definition in Governmental Policy, and educational application across numerous countries, the term special education as a generic term is used to describe accommodated education for disabled students such as those with learning disabilities, learning difficulties, communicational, emotional and behavioral challenges, and physical disabilities. The USA authorizes special education for children with disabilities through assistance and supports in mainstream education and schooling (Dragoo, 2018). Canada applies special education that provides specially designed instruction, assistance and supports, without defining location of such programming (BC Ministry of Education, 2015). The UK provides special education for those with a disability in mainstream schooling (Gov.UK), also initiating 202 special needs schools segregating students by their specific need. In Australia, mandates provide access for those with a disability to mainstream schooling (Victorian Government). Australia also maintains 502 segregated setting special education facilities, determined to be phased out by 2052 (Australian Government, 2023). Special education is not part of the education policy in Singapore (Strogilos et al., 2021). There is a global movement toward the term inclusive education, that places the thrust of educational provision to including those that choose mainstream schooling.

Critique of exclusionary and segregated practices are many and varied, but centre on access, equity and equality to a full education opportunity (Friend & Bursuck, 2009; Norwich & Kelly, 2004; Warnock, 2010). Inclusive education is viewed through two modes: justification: the ethical right to be included in all educational activities afforded learners including music and the arts; and implementation: the effectiveness of a systems approach to inclusive practice (Artiles & Kosleski, 2016).

The level and scope of curriculum on offer, teacher training and the way teachers and support staff are deployed in inclusive and segregated settings provide additional differences striated across countries and states (see Sokal & Katz, 2020). These settings operate within their own political sphere of influence and reform toward inclusive education approaches

(Cologon, 2019; de Bruin, 2019). Whilst access to quality instrumental music education is of salience here, these varying mechanisms provide insights into how we may interpret research amongst these populations.

Engaging disabled students

Studies in inclusive classroom settings on special needs (SEN) in Canada (Buzza & Dol, 2015) and Korea (Kang, 2018), have identified isolated feedback strategies specifically focused on goal setting and student self-control (Nelson & Manset-Williamson, 2006). Teather and Hillman's (2017) Australian study found underestimated numbers of students with disabilities in Australian schools experiencing exclusive "gatekeeping", non-participation in numeracy/literacy testing and access to school choice, resulting in poor educational outcomes. A New Zealand study by Spence (2009) found disabled students having difficulties relating to and having meaningful relationships with other students, including rejection and harassment from peers. A UK context (Symes & Humphrey, 2010) found disabled (SEN) students experienced lower levels of peer support, higher levels of rejection and bullying, arguing that the principles of inclusive education may not be effectively played out in practice. Educators within special/inclusive education models have tended to focus on teaching low-level, deficit skills instead of enhancing a full spectrum of capacities and goals through modelling and feedback (Lindsay et al., 2013).

Feedback directed towards disabled cohorts has been criticized for the superficial, affirmative and praise laden verbiage that offers limiting educational improvement (Towndrow et al., 2010). Students with disabilities and struggling learners benefit from systematic instruction involving the direct teaching of differentiated, targeted incremental learning goals with calibrated prompting that is faded as learners gain confidence and respond to feedback (Albarran & Sandbank, 2019).

Solberg et al.'s US study (2012) found quality high school learning experiences improved efficacy and self-determination for youth with a disability. Janney and Snell (2006) found teacher approaches that instilled learning and engagement for all in inclusive classrooms settings occurred where teachers differentiated through content, process, outcome and the learning environment according to each student. US scholar Tomlinson takes a universal approach (2017, p. 4) arguing that "in a differentiated classroom, the goal is to have students work consistently with a wide variety of peers and with tasks thoughtfully designed not only to draw on the strengths of all members of a group but also to shore up those students' areas of need". Mitchell's (2008) Australian

study found inclusive, differentiated practice, and frequent group work that encouraged social skills contributed to overall educational achievement. De'lEtoile (2005) found disabled music learners responded to consistent room arrangement, routines and clear expectations for behavior with strategic transitioning between activities. Fitzgerald (2006) found positive benefit in incorporating parents as a support group within a US band program. McCord's (2006) extensive scholarship with young disabled musicians outlines planning through color-coding or simplifying parts, strategic positioning within an ensemble, and adapting instruments for bespoke use.

Teacher activity is thus oriented to more than imparting skills, but to developing a students' sense of belonging, resilience and ability to successfully engage and adapt, pointing to how inclusion alone is not enough (Pettigrew & Tropp, 2006). The relationships between modification, student participation and strength, and an inclusive ethos renders the music ensemble an appropriate site for such adaptations. It points to the benefits of instrumental music as a mainstream undertaking, rather than as a therapy or isolated experience, and how inclusion can potentially impact all music learners.

However, there is an underlying subtext to which students with a disability are not deemed compatible to individual, small group learning, or being part of an ensemble, despite evidence of strategic pedagogies that can provide this. Studies involving school, higher education and community disabled music ensembles have suggested prejudices existing through longstanding and unfounded preconceptions of music teachers' deeming disabled students too time consuming, incapable of what is considered 'acceptable' performance standards, and too difficult to provide for in regard to access, placements, and participation in ensemble environments (Abrama, 2012; Hammel & Hourigan, 2017; Thompson et al., 2024; Watts & Ridley, 2012).

Adaptive Music Bridging Program: Ensemble recruitment, participation and activity

The Adaptive Bridging Music Program was created to service disabled students who had been excluded, dissuaded or gatekept out of school instrumental music departments in our city, providing musical engagement otherwise refused. The study was established to identify and analyze pedagogies and strategies that allowed disabled students to engage in a sustained developmentally structured instrumental music education band program. Ethics was granted to obtain audio-visual and informal interview data with students, parents and

tutors involved in initial recruitment, instrument selections, and weekly engagement in ensemble activities, gaining longitudinal data of student musical development, belonging and wellbeing.

The study investigators include Skinner, a disabled musician, instrument maker, researcher and band administrator, and de Bruin, an experienced instrumental music teacher, ensemble director and researcher. Part time paid staff of five across the Junior Band and Foundation Ensemble (two music therapists, one music teacher, one teaching assistant and one engineer), the majority of whom also identified as disabled and/or neurodivergent, assisted. Our choices in staffing were also influenced by our methodology. Key to the educational philosophy behind the AMBP is the idea that students with disability benefit from having disabled role models (Shah et al., 2004). Most students were accompanied by at least one parent, guardian or support worker during rehearsals, who either sat at the back of the room, or sat next to the student providing attendant care depending on the needs of each student.

Initial recruitment for this study was done through targeted media coverage in music, education and disability publications and online fora (Link Disability Magazine 2022), which directed parents to online platforms (Melbourne Youth Orchestra, 2024). Students and parents were then invited to attend a "Come and Try Day" to meet with program leaders and choose an instrument to play. Students could choose from concert band instruments (woodwind, brass, and percussion), as well as a range of specialist adaptive instruments.

Rehearsals

In rehearsals, students were divided into two groups, "Foundation Ensemble" and "Junior Band." These groups were not based on musical skill, but on ability to access musical instruments. Students with very high support needs required extra time to develop bespoke pedagogies, instruments and literacy techniques in Foundation Ensemble. This ensemble focused on creating soundscapes, chord progressions, rhythm, dynamics and melody, as well as ensemble skills like playing together and taking turns. At the end of the first year two of the three Foundation members graduated into Junior Band and continue to play with that ensemble, with a third member discontinuing the program prior to the end of the year. The following discussion is based around the first two years of Junior Band rehearsals.

Activities in Junior Band were tailored for the group based on preferences expressed through the participatory process of the classes. The ensemble commenced with a band method book (Pearson, 1993), establishing a common musicality of fundamental competencies concerning

rhythm, pitch, dynamics, timbre and tempo. The ensemble engaged in improvisational techniques such as imitation, call and response, and individual soloing using established rhythms and pitches. This was supplemented with beginner band repertoire. Adaptive instruments such as a manipulated violin, a foot keyboard and the frog-o-phone (soft toy frog with eight pads electronically 'hacked' to create a midi instrument capable of playing a transposable octave) integrated well.[1] Though not a facet of this study we feel it worth mentioning that our presumption at the outset of this study was that the biggest factor hindering access to music education would be technological and that the majority of our students would require specialist adaptive equipment. This was confounded by almost all students selecting and successfully engaging on conventional instruments.

(insert image 1 here)

Our participants played percussion (tuned and untuned), piano, trumpet, violin, and cello. As an inclusive participatory group, students often selected the length of time spent on songs, the development of the improvisations, chose and developed musical games that the group enjoyed, particularly taking turns conducting the group. Student interests often led to unplanned activities, for example one autistic student with a love of engineering asked to look inside the piano, leading to a discussion of piano design.

Approach

The programs of music workshops are delivered as weekly, 1.5-hour classes on Saturdays during school terms. They operate within Melbourne Youth Orchestras' (MYO) existing ensemble program and are co-located with their other junior ensembles. Students share administrative and break facilities with mainstream ensembles. As the AMBP is a bridging program, students are encouraged to graduate into mainstream ensembles as their skills increase. Students have participated in MYO's Summer and Winter School programs. At the end of our first year, as our Foundation Students graduated into the Junior Band, the first of our Junior Band members also graduated into MYO's Melbourne Youth Junior Strings (Topfield, 2024).

[1] The foot keyboard and frog-o-phone were designed by Monica Lim with the help of Ango Zhu, both students at the Melbourne Conservatorium of Music, University of Melbourne.

Pedagogy-in-participation is a pedagogy built upon a participatory, democratic and inclusive approaches (Oliveira-Formosinho & Formosinho, 2016). This means embracing the respectful challenge of creating conditions for children, families and practitioners to use the agency at their disposal to enjoy collaboration (Formosinho & Passos, 2019), and to develop solidary action. We enacted this, asserting that a rights-based approach transformed pedagogic praxis involving teachers, students and parents involved in thinking, feeling and doing in this ensemble.

This chapter reports on research sustained during the first year of operation with the aims of providing detailed qualitative evidence of musical, health and wellbeing impacts. We address the following questions:

(1) How do the effects of the AMBP classes impact participants' sense of agency and resilience?
(2) What are the benefits beyond music making for students within the AMBP?
(3) What potential do such community-oriented music programs have to benefit a broad range of young people with disabilities?

Methodology

This study gathered data from 16 student participants and their parents or guardians (in a few cases, paid support workers also contributed) in the AMBP. As the researchers were embedded in the learning and teaching activities, they occupied a close learning relationship with students that evolved across the year. This is no different to what may occur in a music ensemble music experience in schools. Ethical approval allowed for data to be gathered through a range of approaches, with informed consent for research participation gathered from parents, and child assent forms being completed by students. To inform potential interviewees, accessible printed or recorded information sheets were prepared detailing the voluntary, confidential, and anonymous nature of participation and how data would be gathered and used.

A key consideration in our methodological design was to avoid medicalization of the children in our cohort. It was vital to our team, both as educators and researchers, that the children's experience of the participating in the AMBP focused on playing music and being part of an ensemble. They were informed of the research aspects of the project, their day-to-day experience of the program was not one of being experimented on, or in any way reminiscent of occupational therapy or other allied health appointments.

Discussions with parents and students 10 minutes before the commencement as well as during and after the rehearsal were recorded via video camera. This provided lucid interactions between staff, students and parents across the learning event. Although participants were aware of the cameras, and occasionally waved or made faces at them in the first few rehearsals, they soon came to regard them as a regular part of the class environment.

Weekly discussions were prompted by questions such as: "What did you like about the rehearsal?", "What shall we do next week?", "What made that bit tricky?" allowing for students to both reflect on activities and co-design the future steps of the research. Students were also encouraged to think about the questions over the week and provided feedback via a parental email or in the next lesson, if those methods suited their cognitive styles more than in-class discussion.

Analysis

The data was gathered as part of a qualitative action research approach, with researcher de Bruin in the role of ensemble director, and trumpet player. Visual media paired with participatory action research provides community-based research that meaningfully engages participants and can support processes for knowledge co-creation, group development and cooperation (Jewitt, 2011). Participatory approaches have been regarded as potentially transformative experiences for disabled communities (Danieli & Woodhams, 2005). Interpretative phenomenological analysis (IPA) was used to focus on individuals' sense making as they redefined their understanding of musical self and perhaps evolve through an externally imposed concept of self (MacLeod, 2019). IPA offers a hermeneutics of empathy and questioning whereby the researcher attempts to understand the insider perspective and illuminate it from an external position (Smith Flowers & Larkin, 2009)

Weekly audio-visual material with student and parent comments were reviewed by both researchers and organized into tentative pools of thought relating to student engagement, feelings, challenges, successes from participation in the ensemble along with researchers' reflective notes of each weeks developments. The coding process occurred across 15 weeks and consisted of two main steps: categorization and reduction (Charmaz, 2003). During the categorization, quotes were recognized, and specific codes were assigned to them. The reduction step sorted the codes into categories. Researcher Skinner, as observer provided a multiple perspective and triangulation of the data throughout the analysis process

(Bogdan & Biklen, 1998). The categories represent the engagements and reflections of the students, parents, and the researchers derived from the year-long engagement. The major categories are reported below: musical agency, community and connectivity, wellbeing in and beyond music.

Findings

Musical agency

Collaborative and inductive feedback in teaching emphasizes the creation of active learning environments that permit critical thinking and discovery. Inductive learning through ensemble work engages students to be active learners involved in the co-creation of music, generating an inquisitiveness to seek facts, procedures, and guiding principles. Students responses reflected a range of pro-active agency:

Student, aged 10: I chose the drums. I play with one hand, but when I get excited, my other hand adds random notes.
Student, 14 (via AAC[2]): My (midi) instrument can be made to sound like anything, but I like using it to play drums the most. I can also lead the band, conducting with my feet.
Student, 12: I like making suggestions- faster or slower, loud bits and softer bits. We can make our own music.
Student13: I play at home and mix my bit with the band. I like how we are all getting better.
Student 11: I hear everyone trying their best, listening to instructions. We sound better each week.
Student, 12 (via AAC): We chose my favourite song to play in the concert.

Parents offered their thoughts to musical agency:
Parent of 9-year-old: The dynamic of the band provides a sense of possibility – of kids being able to contribute to direction and decision making, being heard, being respected, working on things at home, having a team to be a part of, being responsible for their actions in the band.
Parent of 14-year-old: Involvement is encouraged with whatever they can contribute, it allows for everyone's ability to play, feel included, cared for and getting the instruction they need.

[2] AAC or Augmentative and Alternative Communication refers to using modes of communication other than speech. These might include a combination communication boards and devices, sign language, gesture and facial expression (Speech Pathology Australia, 2023). Quotes from students using AAC have been 'translated' into standard English.

Parent of 10-year-old: There is praise and positivity, but also attainable challenges placed before them to achieve in their own way. That's very empowering.
Support worker of 12-year-old: I know nothing about music, and (my client) needs lots of time and support to learn her parts. The teachers give me the information I need to help her practice.

Researcher reflection: One student has had a noticeable change to his relationship with his mobility aids and his concept of himself as a disabled person as a result of these interactions. Michael, a ten-year-old boy with cerebral palsy was highly reluctant to use either his walking sticks or his wheelchair when he started rehearsals. A percussionist, he insisted on sitting on a drum stool to play, rather than in his wheelchair which provided specialized seating support that allowed him to play in a more balanced manner and during break time he would often fall over attempting to walk with the other students without his sticks. Prior to joining AMBP, Michael was the only one of his friends to use walking aids and he just wanted to look like his peers. As refusing to use his wheelchair seating was adversely impacting his playing, his teachers and parents began trying to help him see his aides in a wider context. One staff member who uses similar walking aides, challenged him to races (and did not let him win), we told stories of famous musicians who had similar disabilities or who played seated, and when he complained that he did not want to sit in a wheelchair because he wanted to play drums like the other kids it was pointed out to him that the child playing drums next to him was also in a wheelchair. Slowly Michael started agreeing to use his mobility aides, both in class and more broadly. He also made a close friend in the band who has ADHD and can now regularly be seen being pushed around the playground at high-speed in his wheelchair (with adult supervision) during rehearsal breaks

Participants had agency at all stages of the process; they choose to engage in selecting their instrument, how to join in (or not), and once a member, their voices shaped rehearsal organization, structure, and their ideas became part of songs which formed the group's repertoire. Parents and support staff acknowledged motivation to practice, and the commitment to self and to others providing a basis for agency.

Community and Connectivity

Music activities assisted in the building of personal, cultural, and social connectivity. Through engagement in activities and the emergent interactions unfolding in rehearsals, individuals came to internalize social and cultural influences and developed as individuals

and as a team. Rehearsals involved the suggestion and flow of ideas between students. Break times quickly became an important time for student interaction, with children playing card games. Returning from semester break found some students arriving with souvenirs from their holidays to present as gifts to their friends.

Student and parent reflections:

Student, 9: Everyone hears me at band. We have to concentrate together.

Student, 12: Being part of the trumpet section is great. I think we talk more together than the other sections.

Student, 12: I like how we play in band and then relax together playing games. Do we have to stop rehearsals during the holidays?

Student, 10: I made a friend at band. She can't speak but we play together.

Student, 10: We're all different. We work out our own way of conducting and composing together.

Student, 8: I used to cry when my little sister played her instrument because I couldn't join in. Now she comes to rehearsal with me.

Parent of 9-year-old: The ensemble's inclusive ethos means everyone is part of the ensemble and is entitled to an equal sharing of suggestions and ideas. This is a major value the band provides students, allowing them to grow as individuals, musicians and as a community.

Parent of 12-year-old: My daughter finds it so hard to make friends, but she has a friend in band. They sit next to each other, and he always says hello and asks her how she is even though he knows she can't answer. Last week they were seated apart, but he still came up to speak to her at break time.

Teacher reflection: We as experienced educator- researchers understand that participating in an educational experience is not a one-way process of teacher/conductor centric, didactic teaching. It involves a holistic and integrated, interpersonal and interactive process where educators share power with children and families and honor their voices and agency. We feel children and their families have the right to be, to belong, and to participate, including the right to participate in the decision-making processes regarding matters that concern them, and to learn in companionship, harmony, and dialogue with each other. Such a prevailing attitude fostered student engagement and connectivity.

Students found the ensemble conducive to forming friendships through the shared experience of music making. For some the ensemble represented a musical outlet through which

bonds and camaraderie was formed. For others this sense of belonging and participating eroded the societal limitations they thought existed to exclude and 'other' them.

Wellbeing in and beyond music

Wellbeing connects to aspects of place and space. Identity and belonging are pronounced social and emotional benefits that extend to social-emotional learning and the maintaining of positive goals. The ensemble activities promote a protective and social learning environment that buffers against adversity by including supportive peers, positive teacher influences and opportunities for success in a climate of camaraderie. Students asserted that:

Student, 9: I can be myself in band, we all can.

Student, 10: I like being part of the band, having friends that can make music together- it's the best.

Student,12: Music helps me concentrate. At school, classes are boring but band time goes so fast.

Student, 12: I'm part of a team!

Parent of 12-year-old: Students seem to respond strongly; I see growing confidence and perseverance to be the best they can be in their musical endeavors.

Parent of 9-year-old: There is an overriding sense of care and consideration There are musical values to achieve. There are challenges, meltdowns, but everyone is there supporting each other through personal episodes. It's an environment that allows them to grow.

Parent of 12-year-old: They feel safe and confident, and they take this to other aspects of schooling and life. They are enriched because of this experience.

Teacher reflection: Rehearsals had a plan but often deviated with an inner elasticity and adaptivity. Like all students, band members learned the rules of engagement within an ensemble, which for most was a new experience. Students learned music literacies and etiquette within ensembles. At times this seemed challenging. Some did have meltdowns or withdraw in their own way, and we took the time to allow students to return from the brink without being withdrawn from the ensemble. All of us- teachers, students and parents learned from witnessing these incidents. We assisted and comforted affected students in breaks. Organizing attention to unified musical direction requires focus and concentration and silence which were not always forthcoming from all ensemble members. Experiencing these mediations together was and continues to be a powerful learning and community building experience for everyone.

This pedagogy-in-participation approach has promoted a deep connectivity between students and teachers through the clear enacting of educational intentionality. This involves music engagement that encompasses senses of being and feeling, orienting students' development of the image of self, joined with the image of others. Our pedagogic approach encouraged exploration and communication both musically and dialogically, supporting the development of a learner's agency and belonging through learning, feeling, and expressing with peers. By engaging all students and allowing them a voice we facilitated their input, narration, and creation of meaning making about the learning experience and their place in it. These facets of engagement induced a reciprocity of engagement between educator and student, crafting thinking, development, and evaluation of the learning-teaching process. This required a pedagogic refining requiring ongoing listening to children, parents and carers. It involved empathic interactions with them, building and evaluating learning contexts, appropriate engagement with all children and families to build sustained and equitable relationships (Sousa et al., 2019).

Discussion

Context-based participatory research in music ensembles provides an experientially situated and democratic perspective to agency, community and wellbeing. Learning events for both teachers and learners in the ABMP reveal the evolution of a collaborative praxeological development enabling purposeful action and benefit for both students and teachers. Making instrumental/ ensemble music education work and making it work better in the everyday practice of teaching engages our capacity to shape feedback moments to be helpful, positive, and empowering for all students. It means music educators, in their relationality, empathy, and responsiveness to student needs are willing to improvise, adapting a pedagogy and philosophy extruded from engagement and experience with diverse learners.

Feedback can be about a task, product, a process, or performance towards completing a task. It too is improvisatory, providing dialogic feedforward moments that promote musical development but also student self-efficacy, and self-beliefs about themselves, their roles and their capacities as learners. It can sustain enthusiasm and motivation to persevere with a task. Iterating de Bruin's (2018) assertion, feedback entails a complex tapestry of modelling, scaffolding, dialogue, and time sensitive contextual thinking that evolves for all learners, whether or not they are disabled. We don't just model or scaffold how to hold or play an instrument, we model and scaffold attitudes, behaviors, curiosity, community, and inclusion. The findings do point to significant detail concerning the development of

both the ‘how’ and ‘what’ of feedback quality, and how this enhances students’ agency and autonomy in our, and perhaps any music ensemble.

Students and parents felt that teacher-student interactions encouraged agency to share experiences. This nurtured bonds important for the construction of interpersonal activity and sensation of being part of a community (Eisenberg & Liew, 2009). In addition, feelings of student belonging to the ensemble were fostered as students and parents found challenge, success, positive experiences and companionship. Pedagogy opened up action, observation, listening, and voice within the ensemble. It made visible the physical and social context of learning and the interactivity between both children and teachers.

The findings provide valuable insights to engagement and direction of effort in such ensembles. Valuing every student in our ensembles and our diverse ensemble populations mean we need to ensure feedback and dialogue that connects and is meaningfully expressed in a way that is felt and understood by all. This should include on-going differentiation strategies that can guide students in engaging in self-correction of thoughts and actions. This has implications in how music education and ensemble work actively engages and sustains teachers and students relationally and empathically.

Resonating with general classroom differentiation and inclusion practices surveyed, these results indicate that a range of disabled children in music ensembles can be accommodated by teaching practices that are beneficial to the class as a whole, making it eminently possible to serve disabled and non-disabled children together in regular music classrooms and ensembles. This can occur without warranting a total re-vamping of ongoing instructional programs, since pedagogic strategies that meet the needs of many disabled students in primary and secondary schools are also likely to be effective practices for the majority of students.

Complexity within a teacher’s pedagogic palette would include providing calibrated positive feedback, engaging in dialogic discourse aimed at enculturating learners into ways of engaging and acting within an ensemble, and allowing this discourse to thread positive opportunity and reflection on critical events and learning actions. The supportive behaviors and personalized adjustment strategies directed at specific students created a positive learning climate that promoted belonging, community and agency (Pettigrew & Tropp, 2006)

(insert image 2 here)

Conclusion

The teacher's role in the music ensemble implicates musical, affective and motivational components that are felt by disabled and non-disabled students. Inclusion, teachers perceptions of engagement, student self-efficacy and community are to be critically considered and applied to include all learners. These findings have important implications for the role of dialogue and feedback in teaching band or ensemble activities and its pedagogic applications as a vessel for musical, social, communicative and relational impact and benefit. Dialogue before, during and after the rehearsal is all absorbed by students. It can encourage student purpose to learning through effective strategizing and reflecting whilst also facilitating acute engagement to content and practice and can provide stimulus for development and connection to teacher and peers.

We acknowledge difference between usual school practices and the situated involvement of parents and families in this ensemble. The participatory, democratic, and equitable learning and teaching arrangement within the AMBP ensemble offers a deep connectivity between children, families and teachers. It provides a glimpse into how music ensembles in schools and music departments can be powerful social and community assets. This provides directions for future research regarding implications of inclusive music education and teacher practices and their attitudes to a more caring and empathic society.

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3. *Teaching, learning, unlearning: working with students and performers with disabilities in the music community*

Diane Kolin

A few years ago, I was co-teaching an Early Childhood Music class. My students, aged 4 and 5 years old, were sitting in the classroom, waiting to sing their favourite songs. A new student joined – let's call him John. He was curious, eyes wide open like the other students. He was having fun like the other students. Sometimes he joined the others for an activity group, sometimes he just ran to the drum set and imagined his own rhythmic patterns. He wanted to try all the instruments in the room, touch them, feel the texture. This day, we had a guest, a violinist. The young students watched, admiring and discovering the new sonorities. John wanted to try the violin too. He jumped on the guest, arms raised toward the instrument, ready to grab it. My colleague held him and talked to him peacefully while I gave him a percussion instrument, but our technique did not work. The focus of the young boy was entirely on the violin, not understanding why he could not touch this new amazing music box. John is a young non-verbal autistic, hyperactive child. That particular day, unable to calm him, we had to call his mother to help us. The children of my classroom were incredibly understanding and loving.

Surrounding him, they told John that it was ok. It made me realize how lucky I was to work with this incredible class. Of course, they are too young to understand how important it is to create an inclusive environment. Yet, as a teacher with multiple disabilities, this episode shook me. It was the first time I felt unable to find a way to let all the children of my class fully enjoy music, since I failed with John this day. But I was wrong. I did not fail, I had to unlearn my notion of failure and just accept the way John appreciates, experiments, learns and lives music. He was here on the next class, and the following ones, until the end of the year. His mother told me how much he enjoyed the class. This episode made me reflect on my own learning years. Some of us were lucky to have a music teacher bringing music to class at the same age as my students, and it probably helped those who continued their music journey later in life. Some of us may remember the time when we were growing up, sitting quietly, listening to the teacher, singing solfège, experiencing ear training, progressing with the "official" book.

Do you remember any child with disability in your classroom? Since my jump into the disability world, I don't. This jump, due to a progressive neurological disease, made me use several mobility devices such as crutches and a wheelchair. Growing up in music, thinking of myself as a student, I did not see any other student with disability around me. Later, becoming a teacher, I had no student with disabilities, at least none that "came out" as disabled, until recently. Today, as a wheelchair user, I am one of the rare teachers in my music school with what appears to others as a visible sign of disability (my wheelchair), although I am sure there are others. It depends on the way disability is defined and understood. My own understanding beyond my personal experience shaped thanks to the conversations with colleagues who adapted their classrooms to several situations: students who have epilepsy, vision problems, allergies, also need to be accommodated. This episode with John awakened something in me.

It became important to me to propose a musical program that was open to all. The next time the class gathered together, we did not change anything noticeable, at least not by the students, and not by anybody who would sit and observe the class. What changed, however, was my realization that the music education system needed to do better. John finished the year like all the other students, he ran, he played musical chairs, he never wanted to do activities that required holding hands, but he was either in the middle of the circle or playing instruments on the side with me or one of the volunteers.

As a result of this experience, I proposed something new to my music school: a set of workshops to teach students of all ages to experience music differently. At this time, I was in my second year of doctoral studies in music at York University in Toronto, Canada. The music school, Community Music Schools of Toronto, had a community music partnership with York University, so the project was financially supported by the university. The project was called "A Discovery of Adaptive Instruments" (Kolin, 2023) and consisted of a series of four workshops that allowed different age groups of students to discover aspects of music they never experienced before, such as the use of new technologies as musical instruments, the opportunity to play instruments without touching them, to read a Braille music score, and to sing a song in American Sign Language, with guests who could guide us in some of the workshops.

At the end of the year, the students who chose to perform proudly showcased what they learned: the Sign Language Music group performed the song they learned, which was "The Greatest" by Sia, and another group demonstrated how they could play music differently than taught in traditional programs, without scores, but with colours, verbal cues, a rhythm box, an

iPad. Depending on the complexity of the instruments you want to explore, these workshops can be very costly if you use digital tools (for instance if you purchase a tablet or a set of connected gloves interfaced with a specific program) or very cheap if you take the instruments you already have and use it in a totally different way (such as a guitar played with feet or used as a percussion, or a piano played by two students each performing with one hand), or even silent instruments or air-instruments for students who have sensory issues. The possibilities are unlimited. I learned a lot in the process of imagining and leading these workshops.

The students asked questions, were committed, tried new things. It is important to engage with all the participants, including the teachers, the staff members, and the parents. Keep an open discussion: what you think would work does not necessarily work with this particular group of students, or even one student in the group. Find more about the student's interests and work around it. And if observation is preferred, make it an observation workshop, watch videos, awaken their curiosity. Sometimes the time to adapt and to prepare is as important as the time of action. Since then, I opened my company, ArtsAbly. We are still delivering the workshops and offer assistance to those who want to create their own "playground." We also provide accessibility assessments services, free resources about disability art, and a weekly podcast featuring artists with disabilities.

Perception of disabilities

Interestingly, conversations with parents can sometimes bring back to the way the society perceives disability (Babik & Gardner, 2021; Junaidi & Dewantoro, 2020). Popular in the UK, the US, and Canada, the field of Critical Disability Studies (CDS) brings together a variety of theoretical perspectives and multidisciplinary approaches, and their evolutions from the 1990s to today, such as disability and gender (Hillyer, 1993), disability and queerness (Kafer, 2013; McRuer, 2006), disability and activism (Berne, 2015; Clare, 1999), disability and race (Bell, 2012), disability and ableism (Campbell, 2009), disability and medicine (Murray, 2023), disability and arts (Linton, 1998). CDS explores the different definitions and notions of disability, either as a physical, neurological or biomechanical problem to be rectified by medical treatment and interventions. This approach is referred to as the "medical model," describing the way institutions or societies 'dis-able' people systemically and socially, based on long-rooted

assumptions that people with disabilities are less capable than able bodied individuals. I will give a simple illustration by going back to my own classroom. I remember a conversation with a mother of a child who was not one of my students, and who asked me: “What are you doing in the music school?” I responded, “I teach voice.” “Oh! Are you working with hospitals?” I was a bit surprised by the question, and I tried to understand what brought her to this idea. I replied that I was not. She then asked: “Are you doing music therapy?” “No, I am only giving voice lessons.” I wanted to go further with her, and perhaps I should have done so, but it was a festive event (an end-of-term recital), and I did not want to turn the conversation into a CDS course.

Breaking assumptions

What happened here is an example of “logical” connections driven by assumptions: I am a wheelchair user, thus the relation with something medical made sense to this person, either working in a hospital or teaching something medically related such as music therapy, instead of simply considering that I was a regular voice teacher. Today, fortunately, there are more and more conversations about the place of individuals with disabilities in the society, not as disabled but as a human person being part of the society. These conversations are driven by another CDS model called the “social model of disability” (as opposed to the medical model), which views the origins of disability as the mental attitudes and physical structures of society, rather than a medical condition faced by an individual.

Essentially, the social model says that individual limitations are not the cause of disability; rather, it is society’s failure to provide appropriate services and adequately ensure that the needs of disabled people are taken into account in societal organization (Buder & Perry, 2021). Western society is frequently hiding behind systemic sets of rules supposedly accommodating the needs of people with disabilities. People with disabilities had to fight for their rights to change the rules that were working against an inclusive model, starting with access to accommodations, transportation, and the labor market (Newnham & LeBrecht, 2020; Heumann & Joiner, 2020). Societies and rules have improved in recent years: constructing sidewalks and entrances that are wheelchair accessible, for example, can turn a disability into an ability (Buder & Perry, 2021), improving access to anyone, not only wheelchair users but also mothers with strollers and travellers with rolling suitcases. Yet, it is sometimes easier to talk with children who are less exposed to adults’ assumptions about disability, who are consequently less shy to ask questions and are more open to dialogue. However, nowadays, social media has

become part of the society's learning process and assumption developing, which impact both children and adults. Social media adds a digital aspect to human communication, with its own rules (thoughts have to be shared in the form of images or videos), and its own rhythm (the videos have to last 90 seconds maximum, faster than a regular conversation).

Musical education and access

In both instrumental and classroom *music education, despite discussions of inclusion and openness that are indeed more frequent nowadays, many schools still have difficulty accommodating students and teachers with disabilities. For example, many conservatories still struggle to offer appropriate accesses to musical education to their students, such as adaptive instruments or adapted schedules, or accessible classrooms for their teachers (Téllez Vargas, 2018). Instead, the same outdated teaching and learning methods that are taught for many years prevail in these institutions. Fortunately, teachers who are willing to change and research out of the box options for their students force these more rigid institutions to evolve, in addition to updated disability laws for public spaces, and I further develop this later in the chapter.*

This evolution of teaching and learning practices also comes with more information of what students with disabilities can and cannot do. For instance, music can be performed by students with limited mobility or missing limbs. An adaptive instrument is an instrument made to fit the needs of the person playing it, for example a flute made for a one-handed flutist. An adapted instrument is a traditionally made instrument which is transformed or on which an additional accessory is used to facilitate playing, for example a trombone with an extra stand to hold the instrument, so that it can be played with one hand. Music can be read by students who are blind or have sight issues. A score can be noted on a music staff or in Braille music. Braille music uses the same dotted notation system as alphabetical Braille but as a musical language, defining the value, name and position of each note on a staff. In digital forms, both could be used on a computer, a tablet or a smartphone, with specialized or traditional music programs, so that it could be heard instead of read. Music can also be experiences by students who are deaf or hard of hearing, either by working with vibrations (Glennie, 2015), which consists of an increase of the basses and material such as big speakers carrying

vibrations across a room or a stage, or devices able to convert sound into vibrations such as tactile vests or belts.

Learners can also sing using Sign Language Music (Maler, 2024). This is slightly different from signing simple words as it uses vernacular sign language so that the music, the words and the rhythm match the signs. Although more and more Sign Language Music videos are available online, finding good teachers within the Deaf community is essential for a better understanding of the process. This list is certainly not exhaustive. Each student might come with their own adaptive or adapted equipment, or new technology inventions (Ciufo et al., 2024). Conversations about access needs become necessary to adjust classrooms to the needs of the students, instead of asking teachers to adapt to traditional teaching and learning methods that might not work for them. By providing a variety of options, the teacher will meet the needs of more students, sometimes without realizing it. If the students don't have to ask, they will feel more included.

Roles models and teachers thinking outside the box

Cases of discrimination and critique of ableism on artistic practices in the music world did not start when the first books and articles about music were published in the field of CDS (Straus, 2011). An early example is the Scottish percussionist Evelyn Glennie who published her autobiography in 1990 at the age of 25 (Glennie, 1990). Glennie recounted her experience of gradually losing her hearing from age 8 to 12, and still being able to receive music education thanks to a teacher who worked with her to find teaching methods which she demonstrated in a TED Talk entitled "How to truly listen" (Glennie, 2007). However, when she applied for the Royal Academy of Music, she was first denied access since it made no sense to the jury to admit a deaf student. She appealed and one of the members of the jury gave her a second chance. Only then could she show her talent, that entirely fitted the excellence standard the Academy was looking for. Not only did she get admitted, but she also broke the preconceived ideas that her only possibility for a career would be to integrate into an orchestra, or in other words, to be "hidden behind" an orchestra. She wanted to be a soloist, which once again was seen as impossible by her teachers. History proved them wrong. Through her performances and her workshops, she now educates people to "hear beyond the ear" (Glennie, 2015).

More recently, with increased conversations about diversity and inclusion, voices started to rise in the music industry to narrate more stories of discrimination and lack of role models

(Kolin, 2021; Recording Academy, 2021). Lachi is an American singer-songwriter, touring performer, producer, actress, author, disability advocate and cultural activist based in New York City. She was born legally blind, meaning that her visual acuity was less than 20/200 in both eyes after correction (definition by the Canadian National Institute for the Blind [CNIB]).

In an interview with the author in October 2020, Lachi talked about her struggle with the lack of role models. She found none that perfectly worked for her, to the point where she could say "I want to be like her when I grow up." Looking at mainstream media such as TV or radio, there were male visually impaired singers and there were black women singers, but none with a disability. As a result, she became that role model for the next generation of performers with disabilities. In college, she opened up, ready to show her abilities to the world. She played the piano and sang for her friends, in cafes, in her college; she never stopped. But once she reached the professional level, discrimination was back again since nobody in the industry knew how to accompany and help musicians with visual impairments, behind or on the stage. She had to figure out how to do it by herself.

Another musician who is a disability rights activist and who talks a lot about her experience and what she learned as a touring musician with disability, is the American violinist Gaelynn Lea. I interviewed her in 2021. Her musical journey started when she heard an orchestral concert in fourth grade that made her want to join her school orchestra when she was in fifth grade. She reached a perfect score at her listening test, which intrigued the teacher enough to give her a chance:

The teacher was very motivated, I think, to try to help me find a way. She said: "You have a really good ear." And she was upfront. She said: "I don't know if this will work. I've never tried to modify an instrument for anyone before, but I think you should play, so why don't we try to experiment?" (…) She said: "Maybe you can hold the violin like a cello and then see if that works for you." (…) So that's what I did. I've been doing that for 27 years now, with some minor modifications.

Lea was the winner of 2016 edition of NPR's Tiny Desk Contest. She learned a lot from her first tour. She came back with the decision that she would not perform in non-accessible venues anymore. She also became a public speaker, educating the audience on

the importance of language used to mention people with disabilities in our current society. For instance, in one of her public interviews, she stated:

Talking about disability in the media is a really important piece of the discussion because there's a few really negative things that come out of representing disability without being authentic about it. The first is the idea of “her life is really difficult and somehow she still managed to make this art.” There was one newspaper article that I did an interview for. It went great, I thought, and when the article came out, the first line was: “It didn't look like she'd be able to do much with her life until she found music.” That just doesn't represent anything that I said during the entire interview. (…) I want to see that change because if people realize that we don't talk about other forms of diversity as "overcoming" - you don't "overcome" your race, you don't "overcome" your gender. I see disability as another extension of diversity in that way. (Lea, 2021)

Nothing About Us Without Us

If today people with disabilities know how to fight for their rights, it is thanks to the pioneers in disability activism who spent countless hours negotiating and discussing with politician and lawyers, protesting in streets, tired of being considered as invisible. Just like the civil rights movements progressed and people battled for their own guarantees of equal social opportunities and equal protection under the law – right to vote, to receive an education, to have a recognized identity, regardless of race, religion, or other personal characteristics – the disability rights movement has fought for equal opportunities and equal rights for all people with disabilities. This section gives three examples of evolutions of civil rights laws in favour of people (including musicians) with disabilities.

One of the most striking examples is the American Disability Act, signed and adopted in 1990 in the United States. The movie *Crip Camp* (2020) shows images of the fight for an equitable and fair disability law, through different protest movements across the country, until the current ADA was signed. It features many personalities in the Disability Rights movement, including Judy Heumann. In 1973, a new bill called the Rehabilitation Act was proposed to the Congress. It was supposed to set a non-discriminatory law covering race, ethnic origin and sexual orientation.

At the very end of the list, Section 504, was also supposed to make transportation, employment, education, health care and public buildings accessible to people with disabilities.

President Richard Nixon first vetoed the Rehabilitation Act, arguing that it would be too expensive to apply, and then signed it because of political pressure, but never implemented Section 504. As a result, inspired by Civil Rights movements, groups of disability activists gathered in streets, and sit-ins were held across the country to force the application of Section 504. The longest sit-in, and probably the most impactful, was in San Francisco. It started on April 5, 1977, and lasted 25 days. More than 150 protesters occupied the building. They were well organized, were helped by other groups such as the Black Panthers, union members, civil rights organizations, local communities. Activists and protesters continued to work with the government over the next 13 years, until a completely independent bill, the American Disability Act, was passed on July 26, 1990 (Newnham & LeBrecht, 2020).

In the UK, the Disability Discrimination Act 1995 (c. 50) was voted by the Parliament of the United Kingdom to fight against discrimination and harassment previously lived by people with disabilities in the UK. Prior to DDA, the first law supposedly protecting the rights of people with disabilities in the UK was the so-called “Disabled Persons (Employment) Act 1944” (Gov.Uk, n.d.) which was not only outdated but was neither followed nor respected. The most common prejudice was the exclusion of people with disabilities from places due to fire hazards. Like in the USA, assumptions of what people with disabilities could or could not do led to unemployment and lack of accommodation.

On 13 December 2006, the United Nation (UN) adopted the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) which was opened for signature on March 20, 2007. This act provided the complements needed by the UK to make the DDA a stronger law: it was intended as a clear reaffirmation of the rights of persons with disabilities (Fraser Butlin, 2011). The DDA was repealed on 1 October 2010 and replaced by the Equality Act 2010, which is still in place today.

In the province of Ontario in Canada, the Accessibility for Ontarians with Disabilities Act, 2005 (AODA) was the first omnibus legislation in Canada to set mandatory accessibility standards that identify, remove, and prevent barriers for people with disabilities in key areas of daily living. Based on the 2001 Ontarians with Disabilities Act, the Ontario government decided to further elaborate on this Act. In 2005, the Accessibility for Ontarians with Disabilities Act (AODA) came into effect, identifying

five barriers to accessibility for persons with disabilities: attitudinal, architectural and physical, organizational or systemic, information or communications, technology. This new Act's purpose is to create accessibility standards that organizations from public, private, and non-profit sectors must follow and to make an accessible province for all Ontarians (AODA.ca). However, according to the legislation, these regulations must be implemented before 1 January 2025. This chapter being written only a few months before the AODA deadline, it is unlikely to happen.

The common thread between these laws is that the intention is there, the legislation is there, but the society is still not ready to become entirely accessible. The assumption is that it will cost too much money. Legally, it would potentially be more expensive for these companies in case of non-compliance; important penalties are announced, but it seems that the fines are seldom imposed. These laws supposedly positively impact disability inclusion in the music industry, including music education, and visibility of performers with disabilities in the musical scene. There are now governmental supports such as grants, although companies struggle to find them.

New constructions are supposed to follow accessibility guidelines in construction codes, but it is still too rarely the case. Cultural centres and concert halls provide access for the audience, although limited to a few seats that are not always well placed and are sometimes expensive. Stages are almost never accessible to performers with disabilities. In recent years, driven by the motto "Nothing About Us Without Us," which has been used by Disabled Peoples Organizations as part of the global movement to achieve the full participation and equalization of opportunities for, by and with persons with disabilities (United Nations, 2004), artists with disabilities have formed coalitions, with the idea that one voice is not enough to change things, but many voices together might make a difference, following the path of the Disability Right Activists from the 504 Sit-In. The examples that follow illustrate the federation of musicians with disabilities and the projects they were able to create, that still exist and grow today.

Attitude is Everything is an organization based in the UK that "connect(s) disabled people with music and live event industries to improve access together." It was launched by Suzanne Bull and her team in 2000. Financially supported by the Arts Council England, Attitude is Everything has worked for more than 20 years to improve accessibility for deaf and disabled audiences, artists, volunteers and professionals in the live music and events industries. More than 200 venues and festivals across the UK have joined Attitude is Everything's Charter of Best Practice. In 1999, Arts Council England offered Suzanne Bull a grant to run a pilot programme to

improve disabled people's access to live music. The pilot program was successful, and in 2000, the Attitude is Everything Charter of Best Practice and pilot programme was launched at Camden Dingwalls, London. They also signed their first 10 Venues to the Charter, recruited 10 disabled 'Mystery Shoppers' – volunteers to collect feedback about gigs at those venues – and they produced their first ever project report on what access was like for disabled music fans at the time.

In 2005, their Disabled Stewards Festivals Programme launched at Glastonbury. In 2008 they became their own independent charitable organisation and limited company and receive their revenue grant from Arts Council England. In 2019, they hosted their first awards ceremony, the 'Outstanding Attitude' Awards at Islington Assembly Hall. 2020 marked their 20th anniversary. They started their Accessible Employment Guide at the Moth Club, East London. In 2021 they founded the Audience Access Alliance, a coalition of 13 disability and access organisations and networks.

Their revolutionary approach was a game changer for artists with disabilities but also for venues who started integrating best practices and signing the chart. It is also worth mentioning the role of Arts Council England who financially supports many artists and groups working with artists with disabilities in the UK. The country was one of the first in the world to dedicate a big amount of their budget to encourage initiatives involving the disability arts sector.

Another example of organization that is supported by Arts Council England is the Paraorchestra, an ensemble of disabled and non-disabled professional musicians that aims to blend artforms, genres, and technology to create large-scale music projects that challenge ideas of what an orchestra can and should be. It was co-founded by conductor Charles Hazlewood and television director Claire Whalley in November 2011. The Paraorchestra made their debut at the Closing Ceremony of the London 2012 Paralympics. Charles Hazlewood has conducted some of the greatest classical repertoire with some of the best orchestras in the world. He won first prize in the European Broadcasting Union Conducting Competition during his early twenties and is now a significant presence on British television and radio (Hazlewood, 2024). Paraorchestra exists to recognise and showcase disabled musicians with extraordinary abilities, and to demonstrate their full integration into orchestral music. Their aim is to shift perceptions of disability in creating a visible platform for disabled musicians who are able to perform

at a high level appropriate for the ensemble dynamic, integrating talented players with disabilities into mainstream performances. The ensemble plays an unconventional mix of acoustic, analogue, digital, and assistive technology instruments, drawing on the unique talents of their musicians and collaborating with high profile artists from across genres to create new and accessible orchestral music experiences.

This project continues to evolve. Its dynamism is generated by the talented musicians involved, as well as the interaction between the performers and the audience. Today, they are the only orchestra in the world pro-actively increasing their representation of professional disabled players, whilst creating meaningful opportunities for world-class music making and career development. The organisation applies a person-centric method of working that prioritises consultation and collaboration with each individual, in turn removing the barriers that prevent disabled players from performing at their very best (Paraorchestra, 2024).

In a series of interviews I have made for my doctoral research, I discussed with several disabled artists the topic of the solitude of musicians with disabilities because of the lack of accessible and welcoming structures, but also the arguable meaning of creating an ensemble "only with/for musicians with disabilities" because of the lack of collaborative opportunities in the mainstream music industry. Artists with disabilities want to be included, not assembled in their own group, but are frequently forced to do so. The Paraorchestra succeeded in creating an environment open to both disabled and non-disabled musicians. They are an addition to the diversity of options that exist today for musicians who want to integrate an innovative organization, becoming an important part of the music scene in the UK. We need professional ensembles that welcome musicians with various forms of technical knowledge, from amateurs to semi-professional musicians. The Paraorchestra are an Arts Council England National Portfolio Organisation since 2017.

In the USA, the New York Chapter branch of the Recording Academy (the organization organizing the Grammy Awards) asked Lachi to lead an online conversation with selected artists with disabilities, including Gaelynn Lea, both of whom were mentioned earlier in this chapter. This public talk reiterated the serious lack of visibility, access, and representation for music professionals with disabilities. After the event, the Recording Academy told Lachi that they would like to renew the experience and they would "reach out to them." But there was no "them." Lachi invited individual musicians who she knew, but there was no organization in the

USA that could serve as an aggregator. Shortly after this experience, Lachi and Lea decided to imagine such an organization.

Founded in May 2021 and established in January 2022, RAMPD (Recording Artists and Music Professionals with Disabilities) is a professional platform equipping the music and live entertainment industry with disability inclusive tools, programming and strategy. RAMPD also connects the industry to a global directory of peer-vetted music/sound creators and industry professionals with disabilities, neurodivergence and other chronic or mental health conditions, to find source and hire—bringing competitive opportunities, visibility and community to their professional members while offering disability inclusion to Industry/Venue partners. RAMPD's Mission is to amplify Disability Culture, promote equitable inclusion, and advocate for inclusive and accessible spaces in the music and live entertainment industries.

Since its creation, RAMPD has partnered with the Grammy Awards to make music's biggest night more disability-inclusive, helping push for a visible ramp to the stage, American Sign Language, audio description and more at the ceremony, finding visibility in NYTimes and Billboard. In 2022, RAMPD was named a Zero Project Honoree at the United Nations for its innovative solutions, and in 2023 was named a Music Business Association Agent of Change. RAMPD's member development initiatives are fiscally sponsored by the Stacey Park Milbern Disability Justice Fund (RAMPD, 2024). These three examples of projects highlight the work of musicians with disabilities and show that an idea launched by one single individual about creating a better world for artists with disabilities can grow with time and team effort. As a result, it benefits everybody, aligned with the principles of the social model of disability endorsed in CDS.

As for music education, I would suggest that teachers need examples of role models, and supporting organizations to show students with disabilities what they could possibly do, in terms of adaptations, performing possibilities, and even career paths for students who want to go further. Moreover, teachers and students without disabilities need to see musicians with disabilities in the mainstream media to add to the diversity of teaching and learning methods and performing practices that exist today.

Conclusion

Traditional ways of learning and teaching music in the Western world often creates barriers for students with disabilities in the music classroom, in which teachers do not always make the effort to accept the students' diverse access needs. Moreover, there is a notion of excellence which reinforces the idea of opposition between abled and disabled bodies, either able or unable to follow the norms. If teachers start to think outside the box, they have to be creative and work as a team with the student to find the proper accommodations, thus unlearning traditional ways of teaching to be able to progress with the student. This chapter highlighted examples in which students, teachers and musicians had to fight for their rights to grow, sometimes unsuccessfully, and sometimes after insistence and stubbornness.

My personal observations and reflections provide a concomitant reflexive lens through which my teaching work and teaching philosophy intertwine. It also highlights connection between understanding and action. The creation of a series of workshops triggered a resultant dialogue about disability and accessibility in the classroom with students, parents and colleagues.

Following the paths of disability rights activists who found inspiration and support in civil rights movements, this chapter also highlights how musicians with disabilities have formed coalitions to work together with venues, artists, volunteers, governments, with initiatives that will grow and hopefully lead to more similar projects across the world. The adage "Nothing About Us Without Us" (United Nations. 2004) continues to guide the disability community toward a more accessible future, without the assumption that a person with disability cannot make it. If we continue the work of the previous generation of artists with disabilities, the future generations of music students will have a multitude of role models, and teachers who won't have to struggle to find the right accommodations. As a proud teacher, a proud woman, a proud disabled artist, I believe that it can be achieved. But, as we know, it takes a village.

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4. Tralala Blip: Found sound manipulations, beauty from devastations, a not so linear story.

Randolf Reimann

Tralala Blip are an Australian electronic ensemble of differently-abled musicians hailing from the Northern Rivers of New South Wales. Over the past decade they have carved out a unique position in the Australian electronic music community. Tralala Blip have created a range of approaches to instruments, performance and composition that allows them to create, record and maintain a touring schedule together. Revered internationally for their relentless pursuit of a level playing field in music creation, their goal is to reconsider the nature of creativity, especially music making, and to push these processes beyond any sense of the normative or commonplace. For them, the future is expansive and multi-abled, and Tralala Blip invite you to get amongst it.

A day in the life

> Randy: We really need to get cracking on the new songs, (I say to Lydian as I'm handed a coffee).
>
> Lydian: Why's that?"
>
> Randy: I just received an email about Tralala Blip performing at ART|JOG festival in Yogyakarta next year and it'd be good to have a new album out by then.
>
> Lydian: "Oh cool" Liddi (Lydian) responds
>
> Randy: Actually, we need to do two new albums as they also want your solo project to perform too.
>
> Lydian: "Yessss! we're gonna be busy" Liddi exhales and types Lydian Dunbar, Zachary Luckie, Randolf Reimann, Mathew Daymond & Phoebe Rose into his phone.
>
> Randy: My phone vibrates…
>
> Lydian's text is in front of me, "that's our names for the festival so they can book our flights."
>
> "Thanks, Liddi, lets head back to your studio and get cracking".

We leave the café, pass the Bangalow Hotel, cross the train tracks and duck a swooping magpie. Bangalow is Liddi's hometown and the music video for the Tralala Blip song Pub Talk from the album *Eat My Codes If Your Light Falls* was filmed at the Bangalow Hotel. Lydian and I wrote the lyrics, lamenting the dying act of truly listening. One morning Lydian arrived at my studio

obviously upset about something. I asked him "What's the matter?" and he told me about the night before at the pub. He got frustrated and sad because someone had walked away from him when he was midway through telling a story.

"They didn't want to listen anymore. There were lots of talking and music and my voice is too soft. They didn't want to listen because I have Down Syndrome."

Liddi described a scene of scattered energy, disjointed and fractured conversations. Some of us struggle to be heard and we take longer to communicate our meaning in a conversation. It's a frustrating incongruity with the live band / performative workplaces we sometimes find ourselves in. I suggested we write a song about it and Liddi agreed with a smile. Only days before we had borrowed a friend's vintage Roland 808 drum machine and had spent a day sampling it into our Elektron Digitakt sampler. Liddi and I thought about that particular night before, and the scattered energy of the pub, so we proceeded to experiment with the Digitakt's sequencer, specifically, it's probability algorithms and it's polymeter (multiple sequences playing at the same time but of different lengths) capabilities. A nonlinear, scattering pattern of the 808's kick drum and hi-hats started to sound a lot like Lydian's experience of the night before. Here's the lyrics that Liddi wrote with my help:

Pub Talk
Are you listening to me?
Can you read my body?
I am same but different
My heart is full of sound and light
Are you scared of my love.

Back at Lydian's studio we look over some of Zac's recent song ideas for direction on where our drum machines and sequencers should traverse. One song has a working title of Blood Atlas in which Zac traces his heritage back to the Vikings of Norway and the Gallowglass of Scotland. Another song that is underway is titled Lightning Hands in which Zac and the members of the band, Tralala Blip, can shoot lightning from our hands. We take aim at the political/corporate/media towers of

corruption, but also at the lowly thugs on the mean streets of Lismore, in regional NSW, Australia (Northern Rivers Creative, nd).

Zac has encountered his fair share of bullying while riding his bike on the streets of his hometown. Writing, singing, dancing, and making noise in response is an act of summoning the energies of his ancestors to give him the power to stand up to the oppressors.

While creating in the studio, Tralala Blip will spend hours, sometimes days sculpting a sound to ensure it can carry our voices. Sometimes the sound has to be a battleship, sometimes a butterfly or flying saucer, and other times it's a half-broken radio tower on the outskirts of our regional hometown-and the signal is weak and glitchy.

Zac once told me that he was done with having Down Syndrome. I had just picked him up from his home and we were on our way to band practice. As usual, I asked him how his week had been. "I'm pissed off Randy, I'm done with having Down Syndrome." I quietly listened as Zac told me that this week, he had been run off his bike by a car where the occupants called him a retard, (his bike was a right-off). He'd also been bullied by school kids on his way past the sports fields and harassed while ordering scallops at the local fish n chip shop. Not a good week.

Zac looks beyond identifying as someone with Down Syndrome, even though others at times insist on reminding him. He identifies as a strong man with Viking and Gallowglass bloods.

Blurred distinctions, vivid outcomes.

While Zac and Phoebe work together on drum machine and step sequencer, Mat works on accompanying visuals with his modular video synthesiser. Mat's modular system receives a clock pulse from Lydian's drum machine to ensure his kaleidoscopic imagery stays synchronized to the beat. Mat will usually connect his phone to his video synth's input and stream video content live into the psychedelic mix. It is no exaggeration to say that Mat creates from the time he wakes to the moment he falls asleep. Yes, he does make time to eat meals, and he does breathe oxygen like the rest of us, but that saying "they live and breathe their art" - that's our Mat Daymond.

A drop sheet is now part of our tour luggage requirements so Mat can lay it over the motel bed linen in the morning and keep creating in the wee hours while the rest of the band are still asleep. We've all heard stories of rockstars destroying motel rooms, smashing mirrors, throwing TV sets out the window etc, Mat has destroyed his fair share of motel bed linen, getting

entirely immersed in his creativity, pulling all night benders with paint, pens, glue-guns and paper. Never drugs or alcohol. A maximalist by the very nature of his incessant, volcanic creative energy, Mat will keep adding layers of sonic or visual material until it has reached a density that resonates with his experience of the world around him. Some speculate that Mat's obsessive creative nature is linked to his autism, but Mat has stated to us that it comes from a place of suffering. "World suffering, watching the media and personal suffering too." Like Liddi's experience at the pub, Mat's deep perception of the world tells him things are often nonlinear, seemingly random, and non-sensical.

In Liddi's small bedroom studio, Mat's modular video synthesiser immerses us all in a kaleidoscopic womb of random images coming from Mat's phone's photo library and youtube videos. The visuals feeding back inspiration into what Phoebe and Zac are creating with their machines. Was that a UFO or a hat or a mushroom cloud? Is that a daisy chain of Christopher Walken's dancing, or is it a starfish spinning?

Blip time Vs Crip time

"I love space/time I hate space/time a glitch in our minds as we wander time." Liddi sings these lyrics from a new Tralala Blip song called The Snake and Saucer that will appear on our next album.

At any given Blip session, one could be immersed in a flurry of disparate ideas or thoughts. Phrases morph and mingle and mutate, released from multiple sets of lips reverberating in the wilds of the studio with its tangle of cables, array of boxes, vibrating speaker cones and kaleidoscopic visuals. Often times, Phoebe or Lydian will be the scribe with pen and paper, but recently Phoebe has been occupied with her baby Ada and so Delia 2 has stepped in as scribe. Delia 2 is one of our beloved cassette recorders, named after Delia Derbyshire, an unsung heroine of British electronic music. Our Delia 1 can't record sound but can play back the cassette tape at different pitches, like a synthesiser changing the pitch of an oscillator. Of course, at this point in time with the development of digital technology we could easily record these lyric writing sessions with our phones, but using cassettes is more fun and also another opportunity for later sonic manipulation within our explorative song writing techniques. These lyric tapes are sometimes fed into our granular samplers / effects modules and chopped up into small audio chunks or audio dust. We can randomise the playback order of these chunks with

sequencers that employ probability and randomisation algorithms. I think William S. Burroughs and Brion Gysin would have appreciated this technique.

Hardware music sequencers are such an important element to Tralala Blip's workflow and in recent years, there have been a lot of creative developments when it comes to these instruments. It is also worth noting that although there are many software versions of step sequencers available, we have found personally that the tactile nature of hardware is much more engaging and inspiring. We go deeper into the journey of creating our music when we are touching our electronic music instruments. It's not just about the end result, the journey of making sounds is just as important, and this journey will take as as long as we like, it's a Blip time rhythm.

Early analogue sequencers mostly operated in a linear fashion playing 4 or 8 notes sequentially in a never-ending cycle. These rudimentary step sequencers can be very hypnotic and indeed, Tralala Blip still have a lot of fun with them employing short three or four or five note cycles. But adding random elements to our music that can sometimes seem to make no musical sense, actually makes sense and feels right to us. Our lives often feel nonlinear so why should our music always be locked into a predictable, sequential pattern? Like the rhythm to Pub Talk employing a lot of probability and random triggers in its creation, our song Voltage Flowers, also from the album *Eat My Codes If Your Light Falls* (album title by Mat) is an example of a lyric collaboration using nonlinear cut-up technique.

Fallen codes of the night
Computers they will not fight
Raindrops fall on the circuit board
There are no keys to the door

Voltage Flowers
Growing Towers
Falling Hours
Burning Showers

See my eyes in the city bright
Buildings too high filled with life

Need more time under mirror balls
Back in time we wanted more.

These lyrics were written by Mat, Zac, and me. Phoebe worked on the instrumental track in the background, Lyd inserted an old cassette into Delia 2 and pressed record. Everyone sat around listening and speaking out any thoughts that arose. Zac mentioned raindrops and Mat quickly responded with "Raindrops fall on the circuit board" and codes that fell in the night. The music conjured softness, flowers and nature for Zac and for Mat it was codes and circuits and a city at night. A modular synth sat on the table in the studio, and to me, the tangle of colourful cables and flashing lights was like a garden of voltages. We sent the lyric cassette through a data bending module and tried to interpret the sliced-up words that came out the other end. New strange phrases and fragments and meanings resulted that were no longer linear but seemed to tell a new story, a result of collaboration between us humans and between us humans and our beloved machines. The machines did not produce the rhyming verses to the song, Mat and I took on that process.

We write with the Tralala Blip collective in our being, in our hearts, our minds and our spirits. After being together for many years, we now embody a collective spirit as well as our individual ones. Sometimes, one of us will be physically absent from a weekly jam or writing session but the rest of us will feel their presence and sometimes their voice will speak to the members who are physically present at that particular juncture of space and time. We write songs about our experiences, trips, people, floods, strange new worlds of our imaginings, our dreams, love, the more than human world and welcoming and not so welcoming communities operating in a normative universe, and then, of course, we subvert those normative postulations.

The None-Human Collaborators.

Over the many years that Tralala Blip have been together (we started in 2007), unique relationships with our instruments, environments, community and each other have evolved. These are relationships that can't be forged during a one day or one week workshop about creating electronic music. Although these workshops can be fun, enlightening and educational, when a group of individuals get together every week,

month after month, year after year, immersing themselves in vibrational fields of sound and energy, where ideas are shared, breath is shared, dreams and emotions, where intimate connections entangle humans with the machines they create with, a myriad of divergent cognitions are bound to flourish. Lydian will often take a clean dry paint brush to his instruments and gently remove any dust that has accumulated. One morning while doing his dusting ritual I heard him say "hello my love" to his favourite synth. I knew exactly how he felt. I often sit in my own studio and admire my instruments, sometimes gently touching and stroking them and sometimes just saying hello. I don't even have to turn them on, I sometimes just like to be with them. "Hello, my love" he said this with a gentle, light stroke like someone petting their cat upon awakening in the morning. Everything vibrates and even when the power's off and the voltages have stopped flowing through the circuits of our machines, an emotional connection remains, the tender buttons of our drum machines remain sensuous even when they sleep. "Hello, my love" an utterance that could easily be forgotten as quickly as his words evaporated as they left his lips. But these delicate, fleeting interactions feel an important part of the world of Tralala Blip.

It is a real collaboration between humans and machines, although, the humans of Tralala Blip often have the final say in what becomes part of a Blip song and what is discarded. A drum machine may play the rhythm to a Tralala Blip song, but it is a human member of Tralala Blip that programs the beat on the machine, and it is a human that chooses which beat stored in the drum machines memory is the one for that particular song.

In our musical world, sound design is just as important as song writing, so experimenting with timbre and effects gets a whole lot of Blip time. Everyone in Tralala Blip has a number of their own instruments and effects units that we have all accumulated over the years, sometimes Zac may plug his Korg analogue synth into one or two or three of my effects units, Lydian or Mat may then punch in a sequence on the Synthstrom Deluge sequencer. Someone will hit play (and also record. Always Press Record!) and then we will all reach over and around each other tweaking knobs, pushing buttons or just stand around dancing or listening. Usually after about thirty to forty-five minutes of jamming, someone will press stop and then we will all sit back and listen to what just happened. These improvised sonic explorative sessions often inspire our lyric ideas, and then get condensed into a 4-minute pop song.

As well as writing songs of resilience to conjure strength to face a sometimes hostile world, over recent months spanning 2023-2024 our little blip community of buttoned gadgets and humans have been collaborating on more cosmic inspired songs. On a recent Lydian Dunbar

tour of Poland, Liddi dropped into the factory of one of our favourite instrument builders, Soma Laboratory in Warsaw. He was given a tour of the factory and shown some new instrument prototypes that they were working on. But a highlight for Liddi was seeing the manufacturing of his favourite effects device, the Cosmos.

Soma call this device a drifting memory station and indeed, whenever us Blippers plug it in, our collective minds set adrift starward. Unlike most looping effects pedals, the Cosmos has a large array of sound memory in which recorded sounds undergo constant non-linear recombination, spontaneously generating an ever-changing soundscape. The results can be very hypnotic without becoming boring through endless repetition. Liddi will sometimes play a very simple 2 or 4 note melody from his Arturia Microfreak synthesiser into the Cosmos. Those notes will slowly drift around the stereo field, deviating from Lydian's original rhythm, sometimes overlapping creating harmonies, overtones and clouds of gentle sonic material that inspires us to explore songs about moon gardens and alien bases on its dark side, of pubs on distant space stations and Venusian love vibrations.

We create original music in collaboration with our machines and that make us feel a connection with these electronic sound generators and sonic manipulators. All these energies converging and entangling, a trust we have forged together through years of open exploration and feeling safe to express ourselves spontaneously in hope of discovering or unearthing a new or dormant part of ourselves. These discoveries and creations of ours have been embraced by the larger electronic music communities, as well as the more explorative and open experimental art communities worldwide.

The embracing creative communities Vs the ableist mainstream.

Tralala Blip have been invited to festivals and events as Dark Mofo Tasmania, Open Frame Brisbane, Volume AGNSW Sydney, Soft Centre Sydney, Illuminate South Australia, Liquid Architecture Melbourne, Unsound Poland and ZKM Germany to name but a few (Tralalablip, nd). At all these festivals we have been treated as equals and as professionals. But every now and then, we are invited to perform at an event where it soon becomes clear that we were a last-minute thought and a box to tick for funding purposes. These are now rare, but when they do happen, it is really quite saddening.

One such performance happened in The Valley in Brisbane a couple years back where an annual mainstream music industry event invited us to play. We were told via email when soundcheck was and that someone from the festival would be there to meet us and orientate us. Mat, Zac, Liddi, and I arrived on time for soundcheck, Phoebe would come separately as she had work that day. In the venue, the four of us found a table close to the stage, I looked around the crowded room and saw three people with staff laminates, they noted our entrance. One was standing at the bar and was wearing a Xanadu t-shirt, so I thought I'd introduce myself. 'Nice shirt' I said- he literally looked me up and down and turned away. Meh, I looked around for someone else with a laminate but could no longer see them. I went over to the sound guy and introduced myself and even though I had sent them our tech rider weeks ago, this person had no idea of our requirements.

As such, time ran out and we went without a soundcheck. The band playing before us was a Reggae covers band. They were good, but this was a really bad match for an original band like Tralala Blip and as there was next to no promotion for our performance, we played to mainly random punters wandering in off the mall. Oh and no one from the festival came up to meet us, welcome us, orientate us or say goodbye as we packed up and left after our performance. I was kind of astonished by this but was soon brightened by the thought of the small independent promoters around Brisbane such as Roused At!, Open frame and Lawrence English of Room40 who have treated us so well and embraced us wholeheartedly into the live music scene. They have become our community.

It seems that it is still the case that mainstream promoters and events are way behind the curve. Inclusion for mainstream events today seems more like something they feel they should do to look good for their own sake and has very little to do with truly supporting, promoting and nurturing artists with different abilities. Different and less common art has never seemed of any real interest to the mainstream in my humble opinion. The mainstream relies on merging tributaries of new creative practices to introduce vital ecological components that insures its own survival. It's astonishing to me that the mainstream generally has no interest in the goings on beyond the shallows of its banks. Especially when history shows that everything that ever happens in the mainstream is a watered down and diluted version of what is rooted in smaller tributaries, the underground, and the fertile and sometimes murky undergrowth.

Only days after starting Tralala Blip in 2007, I knew there was an audience for us beyond playing at disability services for family members to go 'Aaww…'. My musical roots are in the

DIY hardcore punk scene of Sydney in the 80's and early 90's. I was vocalist for a band called *Massappeal*. We took that name as we knew we would never have mass appeal playing our kind of music and that things with mass appeal are generally quite safe and boring. We followed our own instincts, even when it strayed far from punk's own restrictive formulas. I found beauty in dissonance and noise and feedback. I immersed myself into other, less common music genres of the time like industrial, techno, no wave, post punk, free jazz, ambient and dub. My passion grew and grew and grew and now, all these years later I am even more curious and passionate than I ever was. I have lost a fair chunk of my hearing through reckless abandonment via immersion in sound, but hey... I've gained some beautiful band mates who pick up the slack with my shortcomings.

So, after the first jam of Tralala Blip, I knew that a small experimental sound art collective called *Sound Crucible* run by Rex Hardjadibrata in Lismore would appreciate what we were doing. I was right. They embraced us with loving arms, and we quickly found a home. It is good to have an idea of who may appreciate your work, and then contact them.

The Flood, the mud and the Isopropyl.

The Lismore flood of 2022 affected most artists living there, including Tralala Blip (Lismore City Council, 2022). Two members of Tralala Blip spent the night wet and cold on their roofs with their pets and loved ones waiting to be rescued with some of our beloved musical instruments submerged beneath us covered in mud and water. The weeks that followed would connect our regional community deeper than it already was. People lost everything in that flood and lots of musicians were not spared this experience of loss.

The week leading up to the flood, Tralala Blip were doing a residency on the Gold Coast in collaboration with Back to Back Theatre from Victoria. The collaboration was part of their Radial series and Tralala Blip would compose the sounds as well as perform (dance) for the film. After the last day of shooting Tralala Blip travelled back south to Lismore only to find the town readying itself for a possible flood event. My van had about $7000 worth of instruments in it that we used on the Radial collaboration. We decided to park it on the highest area of Lismore and walk home to prepare for a bit of flooding.

The flood was much worse than anyone expected or predicted but thankfully we survived and my van and the equipment inside it survived too. Phoebe's instruments floated safely on the flood waters in a watertight case as she huddled on her roof with her dog Esther. I too spent the night on a roof with a friend and her cat, Kiki.

The next days revealed the impact and devastation the flood imparted on our friends and community. Inches of mud infiltrated many homes and art and music spaces. Word spread through our social media groups to use Isopropyl to clean electronic instruments. Soon all supplies of Isopropyl in our region were gone, and so Tralala Blip got back in the van and travelled back up to the Gold Coast visiting numerous hardware stores to get as much as we could. We had to act quickly as all our friends' beloved instruments were in desperate need of washing and cleaning fast. Some of our interstate fans also sent boxes of Isopropyl.

Upon our return from the Gold Coast we drove around the mud covered and devastated streets of Lismore handing out Isopropyl bottles to our friends. Tralala Blip set up a cleaning station at Liddi's place and commenced going through boxes of muddied instruments from our community, especially from our close friends at the SeeSpace warehouse in South Lismore and Elevator Artist Run Initiative Gallery in the town centre. We washed them first with water and then Isopropyl. It really seemed counterintuitive to submerge electronic instruments in water. But for us, in our small, isolated community, it was their best hope, their only hope. We lost our Macbook Pro to the flood, along with our projector, some synths and sound processors. With isopropyl and water and care we saved our mixing desk, some microphones, an analogue modular system and everything in my van. A next to silent, but deafeningly beautiful, compassionate call to action enriched our community with strength and solidarity. Tralala Blip were humbly part of this action.

Band, environment, human symbiosis

As we have naturally evolved deeper into our craft over these years together, our interactions with the world have sometimes caused us to pause and question our relationships. Liddi will often say how he loves nature and that is why he likes to record the sounds from the environment and put them into Tralala Blip or his solo compositions. More recently while sitting by a creek or the ocean we have mused over what the creek or ocean might want to say. And with this question we have started to think of our sonic interactions with the environment around us, with the water, the wind, the earth, more as collaborations.

We don't have to intellectually understand our collaborative chemistry but the rockpool as a metaphor seems to viscerally reflect our connection with both our work and with this immediate environment and world around us. Romantic? Perhaps. But what fun we have had recently recording our synthesisers onto old cassette tapes then unspooling them over a waterfall in The Channon NSW, leaving them for days and nights in the stream letting the water and ochre have their way/say with the tape, then letting the sun dry the tape before spooling them back inside their cases with an old Bic pen.

Playing these cassettes back in our beloved old tape players is a bit dodgy so we record the output directly into Ableton on our laptop and have that isopropyl ready to clean the heads of the tape player immediately after. It's a way of talking to our environment, the earth, and listening as it speaks back to us. We did a similar experiment with a cassette we found on a street after the flood.

The results of these collaborations are wonderful sounds that we could not create by ourselves. This reminds me of the time Tralala Blip were invited by ZKM to do a residency in Karlsruhe, Germany. Microphones were set up at different locations around the city with all their outputs fed live into the Cube at ZKM. The Cube is an amazing performance space with an array of dozens of speakers on each wall and the ceiling. Tralala Blip manipulated these feeds live from the city with our instruments in a live performance. We responded to the sounds of the city, voices in a café, a tram pulling into a station, traffic at an intersection, the ambient sound of a park. Our filters, resonators, granular samplers and FX boxes reshaped and transformed these voices of the city. We alchemized the seemingly random sounds of Karlsruhe into pulsating and undulating atmospheres synchronised to our drum machines and sequencers.

About 14,500 km from Germany in Kandos, a small town in the Central Tablelands of New South Wales, members of Tralala Blip further explore the possibilities of field recordings with The Useless Assembly. The Useless Assembly is a loose collective of artists with different abilities that primarily work out of an art space/warehouse in South Lismore called SeeSpace. The name Useless Assembly came from the fact that most of the sound making devices the ensemble use are only partly operational and purchased second hand from the Lismore tip shop or on online from second hand forums.

For Kandos' 2024 Cementa Festival, I was given the role as musical director for the Useless Assembly (Cementa, 2024). During two residencies in Kandos leading up to the festival all members of the Useless Assembly collected sounds in and around Kandos and the nearby Ganguddy National Park using old portable cassette recorders, digital recording devices and phones. On numerous occasions, I snuck under the fences into the old cement factory to collect field recordings. The factory structures became reverberant, cavernous spaces of corrugated iron and concrete. In the silos, in the huge metal drums full of clinker crusher balls, in underground tunnels and railway lines strange, disembodied voices were captured on tape and memory card.

By the end of the second residency for Cementa Festival 2024, Liddi, Mat, myself and the other seven members of the ensemble had accumulated quite a lot of field recordings and now it was time to look at how we wanted to process these recordings and work together to compose a 45-minute Disco Concrète live performance.

Searching for found sounds amongst the detritus of past industrial sites and the wilderness of Ganguddy National Park was a significant part of our creative process. We used old looping cassettes originally created for old answering machines and we would edit the digital recordings in Ableton Live software or our hardware samplers. Liddi received a diploma from SAE in sound engineering (the first person with Down Syndrome to receive this) so he did quite a bit of the editing and helping other band members. Like Delia, we would all spend hours and hours experimenting with the raw recordings, processing the signal through granulating and resonating effects in our modular rig, passing it through old guitar FX pedals and partly functioning echo units. The resonators can turn the raw sound of traffic whooshing by into a string ensemble and the granulators alchemising wind into percussive shards of glitchy melodies.

One can imagine that an ensemble of ten sound artists playing field recordings all at once for 45 minutes could sound terrible. So, I suggested that our assembly split into three mini ensembles working independently but paying attention to the collective themes of our work that was titled, Disco Concrète. One member of our ensemble was also given the task of costume design, and Disco Concrète not only sounded fantastic, but looked amazing too.

To me, what made this project successful was the time, attention and limitations we collectively afforded to this project. Everyone in the collective spent more time listening to the other members sound compositions than their own work within the performance. At the same time, everyone's creative work had space and time within the performance to shine and be heard. Within our smaller micro ensembles, one person may focus more on the lower frequencies of

their field recordings while another on the higher frequencies and another on rhythmic found sounds or mid-range drones. These considerations enabled individuals to recognise their important place within the collective's sonic creation. Given this project's experimental nature, another important part of the work as my role as director, was expressing my genuine excitement and enthusiasm for everyone's input. It is infectious and before long, everyone is listening and encouraging each other. This gives people confidence to own and exploring their creative impulses in areas that may have been a little intimidating or unfamiliar to their usual field of creative exploration.

Epilogue/no conclusions

Back at Lydian's studio, Phoebe is getting ready to lay down some vocal tracks for a song on our new album. Liddi is setting up a microphone while Phoebe straps baby Ada to her chest. Ada has big fluffy earmuffs on and sleeps through the entire session. Phoebe joined Tralala Blip in 2014 when we were doing a theatre project in collaboration with NORPA and Urban Theatre Projects Sydney called My Radio Heart. The theatre project required a female for a specific role and the director asked us if we knew of anyone local who may fit? Lydian remembered Phoebe from The Wasp Factory, a venue she ran in Lismore with her then partner. Phoebe loved the idea and soon after, became a fulltime member of Tralala Blip.

Being deeply involved in the arts community of our regional home, working for the regional art gallery and running an independent arts and performance space, Phoebe was immediately struck by the raw creative energy and originality of Tralala Blip. She loved our openness to exploring new ideas while maintaining a strong identity as an electronic pop group. She loves Mat's art too. So much so that during our residency at ZKM in Karlsruhe she got a tattoo of one of Mat's illustrations on her arm. Mat sat by her side watching his art take up new residency on his bandmate's body.

Phoebe's main instrument at this early stage of being in the band was a homemade single oscillator, monophonic synth. It had such a nasty sound and Phoebe would smile devilishly whenever it would rudely insert itself into the mix. It mostly acted as segue between songs to avoid any awkward silences as we all set our instruments for the next song. Her other instrument for live performances is a Critter & Guitari Kaleidoloop. This little blue metal box with wooded buttons and a microphone is great

for capturing parts of our performance and then reintroducing those elements whenever Phoebe feels it appropriate, or inappropriate. Her love of noise and playful sonic disruptions has encouraged us all to explore more unconventional sounds within our loose electronic pop creations.

Our weekly Blip sessions often have a plan, but we also bring into each session an equal amount of openness to the energy and direction the collective wants to go in on that day. Sometimes preconceived ideas seem impossible to manifest, and we submit to working granularly, forsaking the bigger picture for a bit, just to have movement. But oh, the fun of sometimes getting lost in the minutia of a sound, a drone. This Blip time can sometimes seem piecemeal and nonlinear, and a narrative can start to form somewhere seemingly disparate from one's original thoughts, but through collaboration we realize ideas, elements, musical moments that connect us to each other.

Writing this chapter involved the sharing and reflecting on experiences. The chapter I hope captures a collective synthesis of creative energy and adaptivity rather than a singular focus on any individual, that captures the Tralala Blip spirit. Over the years together we have all come to trust in our collective talent and our vaporous, homogeneous visions to take us into new or unexplored territories. We never focus on our abilities or lack of, Tralala Blip are way beyond that now. Some might see us as having great patience with each other, but in fact, we collectively enter the parallel world of Blip time/space, submitting totally to the moment and to each other. I feel sorry for the person at the pub who didn't have the patience or presence to listen to Lydian's story. They truly missed out.

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5. Into the Limelight: investigating an emancipatory practice of co-facilitation in inclusive music workshop

Una MacGlone

Introduction

In this chapter I investigate the empowering potential of co-facilitation within inclusive music workshops, focusing on its role in fostering professional growth for three musicians. In this exploration, co-facilitation refers to the collaborative delivery of music workshops by at least 2 team members. I critically situate co-facilitation within the framework of Critical Disability Studies (CDS), drawing upon *interdependence* as a key concept to challenge traditional hierarchies and normative assumptions around music facilitation and disability.

I begin by outlining my positionality, then give details about the musicians and organisation involved in the research projects that informed this study. CDS and interdependence will be introduced as the theoretical framework underpinning this work. A brief overview highlights the sparse literature concerning disabled musicians working in educational and facilitative roles in music. Drawing on three separate studies with musicians working for the same inclusive music organisation, Limelight Music, I examine how co-facilitation has influenced the professional development of each musician. The chapter concludes with a discussion proposing that co-facilitation can provide a flexible and emancipatory space where the unique contribution of musicians with diverse backgrounds can be recognized and developed.

Positionality

I view my positionality as a researcher as evolving. There are fixed elements: I identify as a non-disabled, white, cis-woman who has benefitted from living in a wealthy Northern European country (not least having a low-cost music education and over the

years, support from our national funding body for creative work). The Positionality Wheel from Noel (Noel & Paiva, 2021) has been a useful tool to help my conceptualisation of how one's positionality can develop and change through the lifespan. For example, a researcher's motivations and views of the world can change through education such as postgraduate study and life experiences such as parenthood (Noel & Paiva, 2021).

I have worked with *Limelight Music,* the music charity who employs the musicians I focus on in this chapter, in two large research projects, one over 2018-2019 and the other over 2021-2024. Over these projects, I have observed over 300 hours of workshops and spent around 200 hours on focused video analysis. I have interviewed many of their staff, sometimes multiple times and worked with the organisation as a 'supporting musician'. This close relationship is important to articulate, however, as my chapter is firmly qualitative, it is not positioned as a weakness. There are always asymmetrical power dynamics to be aware of and negotiate in this type of research, however. For example, in an ethnographic trailing study with a jazz education organisation, Johansen (2021) describes the "importance of shared reflection and mutual respect of the worldviews of the participants" (p. 22). The dimension of shared reflection has been a crucial thread in my work with Limelight. Each publication about the organisation has gone through at least two rounds of member checking via email and then followed up by a meeting to talk about any aspect of the writing. This procedure has been informed by CDS, for example, in the exhortation for researchers in disability research to consider "why are *you* here ?" (Goodley et al., 2019, p. 981, emphasis added). Such reflexivity around positionality is necessary, as, historically, disabled people have been marginalised and even oppressed by research, while those researching them may benefit through publications which advance careers (Inckle et al., 2024). There is, therefore a political dimension which needs attending to, with contemporary CDS frequently positioning itself as aiming to *benefit* disabled people (Goodley et al., 2019; Inckle et

al., 2024). One contribution this chapter aims to make is to raise awareness of the professional skills of musicians in the study and offer understandings of ways which disabled musicians' contributions are key to extending practices of community music.

Introducing Joseph, Mark, Brooke and Limelight

The musicians from each of the three studies examined in this chapter, describe their identities in different ways. Joseph who plays guitar identifies as autistic; Mark, who plays drumkit and guitar, wears hearing aids and does not identify as disabled; Brooke is an actor and singer who identifies as visually impaired – but also that she is still negotiating this identity. All are happy to be named in academic publications and this is rechecked before any new writing. They all work for Limelight Music who describe themselves as a "Scottish equalities professional music training and production company, specialising in high quality training and developmental opportunities for people with impairments" (Limelight, n.d).

As articulated in previous work (MacGlone et al., 2020), Limelight have a policy to facilitate workshops in teams, always with at least one woman and one disabled musician. The size of the team can vary between 2-6, depending on the budget, the nature of the project or if there are trainees. When discussing this policy with Limelight staff, they proposed that participants generally respond more promptly to instructions and learn songs more quickly from female workshop leaders. They suggested an important factor is that the higher pitch and brighter timbre of women's voices make them easier to perceive than male voices. They also proposed that the mix of male and female staff with and without disabilities provided a range of experiences which enriched workshops and fostered inclusion by demonstrating this at the level of workshop staff. Limelight view this as a key value of their organisation (Limelight, n.d.).

Critical Disability Studies and Interdependence

CDS critically examines the structures of oppression and exclusion that shape the experiences of disabled individuals in everyday life, as well as in professional spaces (Davis, 2016). This complexity demands interdisciplinary approaches (Davis, 2016), and can therefore draw on diverse literatures and different models of disability (Kafer, 2013). In CDS, scholars such as Dan Goodley propose that disablism and ableism together, function as dual and intertwined forces of exclusion (Goodley, 2014). Disablism refers to the systemic exclusion of people with sensory, physical, or mental impairments, manifesting through various social, economic, and cultural barriers. This exclusion can take multiple forms, from outright discrimination to more subtle, relational practices that reinforce marginalisation. Within the context of music education and facilitation, disablism is visible in historical practices that have excluded disabled musicians from leadership roles, often reinforcing traditional hierarchies that view disabled individuals as recipients rather than providers of musical education and facilitation (Laes & Schmitt, 2016; Laes & Westerlund, 2018).

Ableism upholds a view of an ideal person as a set of values associated with autonomous individuals who conform to normative physical and cognitive standards (Goodley, 2014). For example, Goodley (2014) describes ableism as a cultural logic that privileges able-bodiedness and idealistic forms of health and personhood. Productivity within "hyper-capitalist frameworks" (Goodley, 2014, p. 21) is valued. This notion aligns with research concerning work in the music industry and the pressure of expectations for musicians to present professional identities as very productive, expert individuals who are resilient and strong (Gross & Musgrave, 2020). Such attitudes can also be appreciated in reports about the music industry which indicate that higher levels of discrimination are experienced when disabled musicians disclose information relating to their disability (Musicians Union, 2024).

I situate co-facilitation as a practice that actively resists these forces. By examining co-facilitation in inclusive music workshops, this approach rejects the ableist focus on independence and the exclusion of disabled individuals from professional roles. Instead, co-facilitation emphasizes the important notion of interdependence, valuing diverse abilities and creating shared leadership structures that may allow disabled and non-disabled musicians to collaborate and learn from one another. This aligns with the construct of an ethics of integration wherein new concepts and educational practice are born from encounters where all are "transformed by mutual experience" (Semetsky, 2013, p. 54).

Interdependence in CDS emphasizes the collaborative and relational aspects of accessibility, where access is achieved through interactions among people, technologies, and environments (Kafer, 2013). It acknowledges that people with disabilities, like all individuals, engage in mutual support systems (Goodley, 2014) and disability can be understood as being produced in interactions (Kafer, 2013). Conceptualized as an extension of ideas first developed in social models of disability (see Oliver, 1990), Kafer's (2013) political/interactional construct of disability asserts that disability may be contingent on the environment, people, objects and norms (Bennett et al., 2018). Interdependency recognizes the contributions of people with disabilities in shaping their access solutions and seeks to dismantle hierarchies that view dis/abilities in isolation. It also recognizes that everyone, disabled or not, relies on help and encouragement from other people in day-to-day life (Kafer, 2013).

In a recent study examining interdependence as a conceptual framework for critically examining the functions of assistive technology, Bennett et al., (2018) proposed four tenets which summarize this framework and have relevance for music research: 1. **Relations**: there is a focus on how people, devices, and environments connect and work together in making accessible experiences. When interactions are highlighted, actions and encounters can allow appreciation of

collaboration in access processes and what can be influential. 2. **Simultaneous assistance**: This aspect recognizes that people often provide and receive assistance in dynamic, overlapping ways, rather than in one-way transactions. The role of personal relationships as a resource for multiple forms of support is also key. 3.**Visible contributions of disabled people**: Interdependence highlights often-overlooked efforts made by people with disabilities in creating accessibility and advocates recognition of these contributions. And 4. **Challenging hierarchies of ability**: This perspective contests hierarchical views that value certain abilities over others, promoting a view of all contributions as essential as everybody is mutually reliant and that people's needs for support are changeable.

Music contexts and co-facilitation

Despite research in inclusion in music education and community music proposing that a next important step for the field is to employ disabled teachers and facilitators (Darrow, 2015; Laes & Schmitt, 2015; Laes & Westerlund, 2018), literature is relatively scarce (MacGlone et al., 2022). One reason for this may be that expertise in music and music teaching may be very often associated with narrow and fixed ideas about what constitutes excellence (MacDonald & Saarikallio, 2024). Consequently, these "ableist … reductionist views" of musicality impact selection into and success in music study and careers (Laes & Westerlund, 2018, p. 35). How music is transmitted to others (i.e., taught, facilitated, shared) is also culturally-bound; for example, in the pervasive master-apprentice model, where the 'master' upholds an ideal position of possessing expert knowledge which is passed to the apprentice in a process of conscious imitation (Westerlund, 2006). Despite this there are disability arts scenes in many countries across the world wherein diverse forms of knowledge and experience are valued and

experimentation is encouraged (see bell, 2017; Docherty, 2019; Numata, 2016; Laes & Westerlund, 2018; Skinner & de Bruin, 2025, in this publication). Within musical careers that disabled musicians access, performance and creative pathways (e.g., performer, composer) are more common than those involving facilitation or education (e.g., community music worker; teacher) (Musicians Union, 2024). Inaccessibility of spaces in schools and employers' assumptions of unreliability were offered as reasons for this in a recent UK census of disabled musicians (Musicians Union, 2024).

What is co-faciliatation?

In music, facilitation can be understood as distinct from teaching in that activities, goals and pedagogies all have concurrent flexibility that can accommodate variability in participants' ability, mood and/or preferences (Bhachu, 2019). For example, a facilitator may work on some activities with a specific aim for participants to gain in confidence before they move to others which have the purpose of improving music skills (MacGlone et al., 2022). Despite these distinctions, practically, examples of music education may overlap with music facilitation, for example in prioritising flexibility and responsiveness in improvisation pedagogy (Johansen et al., 2019). Co-facilitation and co-teaching can involve teams with complementary expertise, brought together to work on specific projects, often with therapeutic aims. For example, the Aardvark Program, a music therapy and community songwriting initiative in Melbourne was designed for young people facing adversity, focusing on personal, social, and musical growth (McFerran & Hunt, 2018). Co-facilitation by a music therapist and a professional songwriter was seen as central to the program's effectiveness, because the combination of therapeutic techniques and musical expertise enabled facilitators to address the varied needs of participants (McFerran & Hunt, 2018). Importantly, this professional collaboration required extra time for planning and an open attitude from both professionals, who maintained defined roles and responsibilities in the

project pertaining to the practitioners 'strengths and responsibilities' (McFerran & Hunt, 2018, p. 48).

A contrasting example of interdisciplinary co-teaching in higher education is found in music-drama and music-physics partnerships in Sweden and Ireland respectively. Informed by a Vygotskian theoretical framework, this article utilized the zone of proximal development (ZPD) to contextualize the teachers' descriptions of how their professional skills developed through the projects (Nilsson & Kerrin, 2022). Four main findings were: 1. Subject synergies: Teachers gained a deeper understanding of their own and their partners' disciplines. 2. Problem solving as a catalyst for creativity: Co-teaching facilitated spontaneous problem-solving and creative moments. 3. Insights into collaboration: Successful collaboration depended on mutual respect, trust, and a willingness to learn from each other. 4. Expanded professional identity: Participants reported a significant expansion of their professional identities through the collaboration. (Nilsson & Kerrin, 2022, pp. 83-87).

These two examples indicate contrasting positions. In the first example, disciplinary boundaries between the songwriter and music therapist were maintained, this may be due to ensuring the therapeutic aims were met in a way which satisfies specific wellbeing aims and outcomes. The second example articulates some transfer between disciplines, arguably that "problem solving" indicates a willingness to understand the other's approach to teaching or subject matter. The potential for co-facilitation for inclusive practice can be appreciated through the lens of interdependence. The shared focus on analysing interaction and collaboration of people with different kinds of knowledge and expertise thus offers potential for understanding how the practice of co-facilitation may be inclusive.

A broad research questions guided the meta -analysis of three existing studies:

What can the experiences of three diverse musicians tell us about dimensions of co-facilitation in an inclusive music charity?

The following section summarizes each study and then compares common themes.

Background to studies

The three studies are nested within two large research projects, the first, Music as Social Innovation (MaSI) investigated social impacts of community music workshops with disabled adults in two phases (MacGlone et al., 2020; Wilson & MacDonald, 2019). Improvements in individuals' self-expression, confidence, mood, and social skills were apprehended in both phases. The second was my postdoctoral study, *Music Creativity & Wellbeing* funded by the British Academy. Its focus was to investigate wellbeing impacts of community music with children and young people with additional support needs in mainstream and special schools. As well as social and wellbeing impacts, Limelight practitioners' approaches to workshop delivery formed a further area of interest and investigation in both projects.

The methods of investigation for this aspect of the research in both projects were semi-structured interviews, analysed with reflexive thematic analysis (Braun & Clarke, 2022). I now give a brief overview of Limelight's approach followed by a summary of each study the musicians were part of, before I highlight common themes across the three cases.

What happens in a Limelight workshop?

The structure of a Limelight workshop typically involves an opening and closing song, with activities in central section being tailored for the group and the project aims. Songwriting, creating music to go with a story, making and realising graphic scores and music and movement

are all examples of previous projects' focus. A key aspect in facilitating these activities is in the tailoring for the groups' interests and abilities (Wilson & MacDonald, 2019; MacGlone et al., 2022). This happens in the moment (e.g., adapting song lyrics) and also in when planning workshops (e.g., bringing a bass guitar in for a young person). Limelight works with different groups – for example, in mainstream and special schools (with children and young people aged 3-18) and in day centres for adults with disabilities. Practitioners bring musical skills on different instruments (guitar, hand drums such as djembe, keyboard, bass guitar) and are all confident singers. They have "varying backgrounds with different sets of practical knowledge (e.g. music, drama and musical theatre) and roles (e.g. musician, actor, director and writer)" (MacGlone et al., 2022, p. 396). The approach of Limelight is for all practitioners to benefit from sharing knowledge and approaches informed by different artistic disciplines (MacGlone et al., 2022). Roles, although defined as workshop leader and workshop assistant are flexible, assistants regularly lead activities within workshops and contribute ideas for new workshop programmes. Workshop leaders often use humour to "play with and subvert roles … casting themselves as less leaderlike ... allowing themselves to appear vulnerable" (MacGlone et al., p. 397). This strategy is intended to make participants "feel at their most comfortable" (MacGlone et al., p. 392) and to not seem like a teacher (i.e., with authority over the content and order of activities). The importance of responding participants and prioritising their confidence has a restorative aim and also demonstrates the flexibility of goals in Limelight workshops (MacGlone et al., 2022).

Study 1 - Joseph

In MacGlone et al. (2022), Limelight's approaches to workshop facilitation were explored in an interview study with 5 musicians – 2 experienced facilitators with 30 years of experience each and three trainee workshop leaders. At the time of the study, Joseph had around

eight years of experience as a workshop assistant. The main themes, common to all interviewees were:

1. That all created a personalized pedagogical identity; and

2. the importance of key interpersonal processes such as individualized communication and building relationships.

Joseph's description of his role in music facilitation also revealed his distinctive approach shaped by his experiences being educated in special schools. Unlike other facilitators, Joseph emphasized the importance of including participants' carers in interactions. He particularly valued giving participants space to develop confidence— a purpose that he articulated was influenced by his own experience attending a special school. Joseph identified a personal goal for his practice in reflecting on the ways in which his and the other practitioners' actions could create a relaxed atmosphere for the groups they worked with. He also identified the importance of developing activities, such as role-playing games with nursery children, to capture their imagination. He also noted that his own role in Limelight afforded him flexibility to design workshops that resonated with his experiences and the values he had as a practitioner. This was crucial to him, he described people with disabilities often being "treated like robots, you can't move this way or that way" (MacGlone et al., 2022, p. 395). He described learning from one Limelight mentor in particular, but, that people in the organisation helped each other.

Study 2- Mark

Mark's views were captured in a study which researched the experiences of those delivering and participating in creative workshops involving music, drama and graphic scores. At the time of the study, he had around four years of experience with Limelight. His co-facilitator Cat was also interviewed, and a child-led focus group was held with the seven children (aged 10-

12) who participated in the workshops. A key focus for Mark and Cat was to foster an inclusive environment. To achieve this, multiple ways for the children's participation were created, to encourage self-expression and creativity in whichever artistic form the children felt most comfortable. Mark emphasized the value of allowing children to experiment freely, facilitating a space where they could express their ideas and "honouring" their creative impulses. Mark's distinct contribution to the workshops was to reinforce Cat's spoken instructions with musical cues on his guitar, creating what he described as a "soundtrack" that accompanied her speech. This was enacted by, for example, playing a quick ascending phrase just after Cat asked a question. This approach provided an engaging channel for children to understand and interact in the workshops. Mark worked closely with Cat, articulating that their "special communication" was a key feature of his comfort in facilitating workshops. He described using different forms of communication depending on the acoustic properties of the rooms they were in for workshops. In smaller rooms with low ceilings, he described having to take his hearing aids out and relying on lip reading, due to distortion. One significant aspect of Mark's work with Cat their aim to facilitate what they called "golden nuggets"—moments where the group's energy, ideas, and creativity aligned and a sense of flow was experienced (see Csikszentmihalyi, 1991). Mark viewed these moments as integral to fostering a sense of agency and belonging for the children, making them feel as though they were part of a collaborative, inclusive and creative process.

Study 3 -Brooke

Prior to working with Limelight, Brooke had challenging and complex experiences in training and professional contexts which were shaped by inadequate approaches and solutions towards accommodating her visual impairment. Despite these difficulties, she pursued an acting degree and was awarded this in 2022. At the time of the study, she had around six months experience with Limelight. During her studies and in subsequent professional acting jobs,

Brooke frequently encountered accessibility challenges. For example, some directors were unresponsive to or dismissive of her access requirements, such as making adequate lighting adjustments to accommodate her visual needs. She repeatedly encountered this “art over access” attitude, where her access needs were dismissed as they would have “changed the artistic vision” of the production. As a consequence, she often hesitated to ask for adjustments out of concern for being perceived as “pushy.”

In contrast, at Limelight, Brooke was supported in a variety of ways. For example, her co-facilitators give her a spoken description of people’s non-verbal actions in the workshops. She described this as becoming a comedic dialogue between herself and co-facilitators that the workshop participants joined in with and over time became part of the musical activities themselves. When Brooke started working with Limelight, she was given space and time to figure out for herself how best she could contribute to the facilitation team. This type of work where moment-to-moment responses to the facilitation team and the participants was unfamiliar to her, her previous experience as an actress required memorisation of choreographed movement and directed interactions.

Brooke described listening and tuning into the other facilitators’ singing first, comparing her intonation to theirs. She then listened to the guitars, and her voice in relation to them, analysing if she was in time with them. Once she was comfortable doing this, she was then able to focus on the ways in which the participants were joining in. Brooke felt a sense of fulfilment in working – “all I wanted to do was share my love of the arts and creativity with people, however that is possible.” She sought out different mentors in the organisation and was able to ask different individuals about key aspects for progression of her skills. For example, she talked to another visually impaired practitioner about specific logistical aspects, such as her apprehension about working with young children (as they are more likely to move around in a

workshop space). She sought musical and creative advice about delivering workshops and how she may incorporate story telling from another practitioner.

Cross case analysis

Across the three studies, while each musician had bespoke support from Limelight, common themes can be identified. The relationships each musician had with other Limelight staff allowed them to make their own, individualized pathways for professional development. This may sound contradictory, however, the flexible distribution of leadership and responsibility in Limelight created an environment for collective constructions of knowledge and expertise. In Joseph's case, his wish to enable confidence and think about how he and the team could best achieve this was possible through analysing interactions in the facilitation team and reflection on how participants responded to these. Mark's close relationship with Cat was important as they, at times, needed to customize their communication in the workshops in response to the demands of the environment. This illustrates the emergent nature of access needs and the significant changes needed at times to enable Mark's work as a facilitator. The solution to an environmental issue was in changing pedagogical approach which required Cat and Mark to be flexible in their collaboration. Brooke's choice of different mentors for distinct aspects of her role is noteworthy. Mentoring can incorporate different styles and models, however, "sensitivity, responsiveness, situational awareness, flexibility, and subject and pedagogic expertise" have been described as key attributes contained within *one* mentor (Barrett & Zhukov, 2024, p. 1). The multidimensional processes described by Brooke in how she gained skills and experience in facilitation were supported by people that she chose as most suitable. This agency for Brooke in curating her own relationships in the organisation is therefore an important feature of her experience.

Innovation was another common theme, each of the three musicians created novel ways of delivering workshops. This was through devising new activities (Joseph), creating musical cues to enhance the narrative of the workshops (Mark) and designing a method for listening and analysing musical contributions in workshops (Brooke). Although Limelight has a commonly used structure and indeed uses particular songs to start and end the workshops, there was space for innovation in other activities. Each of the three musicians also developed their own pedagogical approach within the teams informed by personal values and aims for the people they worked with. Joseph was keen to foster confidence as a restorative action which recognized that children attending special schools may be restricted in opportunities. Mark wished for the children in the study to experience "golden nuggets", experiences of flow and fulfilment through playing music and being creative together. Brooke was motivated for others to experience her love and sense of accomplishment she had when being creative and engaging with the arts.

Returning to Interdependence

Limelight workshops were structured to be flexible and tailored to the needs and abilities of participants but there is also a corresponding accommodation in the delivery teams depending on the needs of practitioners as well as their expertise, interests and values. This aligns with Kafer's (2013) proposal that disability and access can be appreciated through interactions among people, technologies, and environments. For example, Joseph's emphasis on including participant's carers in conversations and Mark's coordination with Cat demonstrate how relational support structures are woven into the workshop's facilitation to enhance participation and communication. Brooke's partnership with sighted facilitators at Limelight, who provided her with visual cues, demonstrates how interconnected relationships support accessibility and also, that they can be creatively folded into the workshop activities.

Assistance flowed multi-directionally and simultaneously among these musicians and their colleagues (Bennett et al., 2018; Kafer, 2013). Mark, for instance, both gave and received support through coordination of his musical skills with Cat's verbal instruction to enhance communication in the workshops. Joseph, too, adapted his facilitation style to benefit participants' needs in ways he viewed as important based on his lived experience. His experience opened up access to valuable knowledge for the rest of the team thus potentially benefitting everyone's professional development. The fluidity of roles and responsibilities was necessarily emergent and evolved based on the priorities of the workshops. This represents a radical departure from constructions of one expert holding all of the knowledge about music and facilitation and consequently knowing what the best thing is for people (see MacDonald & Saarikallio, 2024; Westerlund, 2006).

Each musician contributed uniquely to accessibility, underscoring the value of visible contributions by disabled individuals (Bennett et al., 2018). Mark's use of musical cues to create soundtracks to supplement spoken instructions showcased his musical innovation in co-creating a multimodal experience for the children with Cat. As mentioned, Joseph's lived experience in special education shaped his empathetic and inclusive values. Brooke's proactive role in creating an accessible environment for herself, and the systematic care she demonstrated to analyse the musical contributions of others emphasized the importance of choice and personalisation in her professional context.

The agency and creativity that each person demonstrated in their working lives contributes to the collective knowledge and practice of Limelight, with the potential to benefit more workshop participants as well as practitioners with and without disabilities. Each musician's approach was informed by their own experiences and background, which shapes their

facilitation style and the workshop atmosphere. This contrasts with Brooke's professional experience as an actor where directors valued "art over access" and thus represents a view of inclusion that appears "tick-box", in that a disabled person was present. The neglect of her personal comfort, however, represents a harmful form of disablism (see Goodley, 2014).

Limelight's flexible and distributed approach to leadership and mentoring supports the idea of breaking down traditional hierarchies of sole-authorship in music (see Gross & Musgrave, 2020; MacDonald & Saarikallio, 2024) in favour of collaborative and creative sharing of knowledge. The opportunity for Brooke to seek different mentors for various aspects of her role, and the collective problem-solving between facilitators like Mark and Cat, show how Limelight valued diverse forms of expertise and co-creation. This challenges conventional norms in educational settings and aligns with Kafer's (2013) vision of dismantling 'ability hierarchies' in favour of more inclusive and relational practices.

Each facilitator in Limelight was encouraged to innovate based on personal motivations and the needs of the participants. For example, Joseph developed activities to foster confidence, and Brooke refined her auditory skills and focus of attention to understand how her contributions fit with other musicians and participants. This emergent and responsive pedagogy reflects interdependence and co-facilitation by showing that facilitators and participants continuously shape each other's experiences in mutually beneficial ways.

Conclusions – what were key aspects of co-facilitation in Limelight Music

Through this examination of three musicians' experience working for Limelight Music, key aspects of co-facilitation in this context can be extrapolated. It was emergent as decisions were made on what were determined as the priorities of the moment. These situational, creative decisions coalesced into patterns of flexible practice and shared knowledge. In this way co-

facilitation was co-created. This may seem obvious, but this was absolutely necessary for Limelight's diverse teams and shouldn't be decided by one person. Co-facilitation was responsive to environments, people and music aligning with Kafer's (2013) theoretical positioning of disability or access as being created through and in interactions with such elements. For the three musicians, co-facilitation was relational to their values, aims and experiences; this was demonstrated in their creative musical and pedagogical choices.

Returning to Brooke's experiencing of "art over access", hierarchies in performing, the privileging of often white male constructions of creativity and expertise in the arts are not the topic of this chapter – however - performance in music and the arts, inform how it is facilitated, taught, talked about and vice versa. Joseph, Mark and Brooke's experiences within Limelight and co-construction of inclusive practice through giving opportunities to innovate and develop through co-facilitation, firmly challenge traditional ideals of creativity and expertise.

In response to a question posed by the editors of this volume – how do we as music practitioners and educators address authoritarianism, hegemony, and hierarchical strictures, and behaviours? I propose that it is essential that the role of music practitioners, music educators and music researchers is to listen to, create with, learn from, be flexible with, and to be supported themselves when working with diverse musicians. Agency was absolutely key to all three musicians; organisations (e.g., music, charities, universities) have to create an environment that affords this in musical activities, music projects and research. In the way that each musician was an expert in responding to the priorities of the moment in unique ways, they need have a role in defining what future priorities for practice and research are in co-facilitation and community music.

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6. Dreaming in Rubatic Time: An Embodied Resistance to Chrononormativity in Academia.

Skylar Cameron and Annika Williams

Navigating the intertwined worlds of voice performance and academia as disabled musicians highlights the friction between rigid temporal norms and the embodied realities of disabled and chronically ill bodyminds. Through initial reflective vignettes we offer glimpses into our experiences that serve as acts of embodied resistance, highlighting the necessity of challenging chrononormativity. Through the lens of "rubatic time," we start with ourselves rather than others, drawing on our embodied knowledge of musical flexibility and collaboration to reimagine accessible, non-linear approaches to time that honour the lived realities of disabled individuals—and hence, we begin as we mean to go on:

> Skylar: My eyes open sluggishly, and I hurt more than usual, making it hard to fathom moving. It feels like I haven't really slept for the past nine hours. I turn my sleep apnea machine off, turn on a soft, dim light, and start answering emails on my phone. A notification reminds me to "take meds… WITH FOOD," so I fumble for my pill box and grab a granola bar. After gulping down a handful of pills, I continue replying to emails, reminding myself to sit up to protect my vocal folds from stomach acid—especially important since I have to practice for an upcoming performance. No matter how hard I try to maintain a "part-time" workload, academia treats part-time as full-time, with all the same expectations. Navigating this world as a disabled singer brings unique challenges. I'm constantly caught between the demands of the opera industry and academia, both rooted in non-disabled norms, even as the world still contends with an ongoing pandemic. Time in both spaces feels rigidly linear, yet strangely flexible, full of unwritten rules that are hard to decode. It's always about doing as much as possible within a set timeframe, a measure of productivity and success according to non-disabled norms. My training revolves around manipulating my body to optimize performance—especially crucial when my body is my instrument—but the expectations of singing often clash with the realities of my bodymind.

I vividly recall a doctoral recital where I struggled to stand upright, my heart rate surging above 160-170 bpm, as blood flow to my brain was reduced. In moments like that, breathing and remembering cues feels like a monumental task. Yet, it's standard to stand and sing from memory for 60-70 minutes. How can I meet expectations of "perfect" performance, based on non-disabled standards, when my brain isn't getting enough oxygen? Cognition is essential for singing, but I must also stay grounded in my body– even though I need more focus just to think clearly when blood flow to my brain is reduced. When I'm afforded moments to slow down and follow my own timeline, I can finally think, breathe, and manage the juggling act that singing requires. I've learned to embrace my sense of rubatic time, knowing I feel best when I listen to my sense of bodymind- my being, feeling, expressing self that unfolds in its own pace.

Annika: As an undergraduate voice student, I was fortunate to work with the same fabulous collaborative pianist for all four years of my degree. Through this years-long collaboration, I came to know rubato as elastic and grounded in myself and my bodymind enough to trust myself as a performer and collaborator. If, in the moment, a musical phrase takes longer, we find that time together. If I needed an extra breath where I don't usually take one, or if her page didn't turn properly, we found each other and could trust those moments of elongated time to reorient ourselves. As I reflect on this collaboration, it illuminates both the apparent musician's struggle with musical timing and the less-apparent struggle of a neurodivergent, chronically ill student with time and how these two struggles entangle with one another.

In the four years of negotiating this collaboration in a variety of performance and non-performance contexts, my collaborative pianist and I discovered that a passage can sound the same from one day to the next and yet feel different. Sometimes, even if I am singing a passage the same as before, my sense of timing can feel detached and out of sync as my mind leaps to anticipate potential issues in the next bar. My brain goes into overdrive to either numb or hyperfocus on parts of my body that trouble it. My instrument is caught between the frantic energy of navigating our collaboration and the

engrained memory of how singing this passage should feel but does not. I know most of my mistakes are with rhythm and timing; I will never be able to feel at ease without careful collaboration and building of trust because this is something I have been made to feel is fundamentally and inexplicably "wrong" with me, my processing, and perception, that is a burden I am responsible for placing on musicians I collaborate with. In this instance, the tempo never settles into my body, even if it sounds consistent, because it is underscored by an anxiety that the time is not "right" and that I cannot align myself with the "right" timing. It is outside me, and I am trying to reach for it as everything moves too fast for me to process.

Disability, academia, resistance, and defiance

As Western classical musicians embedded in academia, we inhabit a unique position where we continually navigate temporal nuances as artists yet face institutional demands to adhere to academic time, which is linear and normative. Particularly as queer, disabled musicians-scholars with intersecting identities, we often face pressure to adhere to these demands, sometimes at the expense of our bodyminds–where physical and mental aspects are deeply interconnected and function as a unified whole (Price, 2011). This pressure creates a palpable tension within us. In response to our experiences of this tension, we explore within ourselves: how can we use our knowledge of time as musicians to connect to and center disabled embodied knowledge, resist ableist understandings of time, and embrace diverse models of progress and achievement? What might the music conservatory look, feel and sound like if we could grasp and feel the ebb and flow of temporal rhythms and acknowledge the interconnectedness of our own personal experiences, mainly through disability justice-informed practices? We inquire into how our embodied musical knowledge informs our understanding and enactment of crip time. Crip time, stemming from critical disability studies, is a more flexible temporality experienced by disabled and chronically ill bodyminds (Chen et al., 2023; Kafer, 2013; Kim, 2020; McRuer, 2018; Samuels, 2017). We propose the new term "rubatic time" as a framework for understanding crip time through our understandings of musical time, and in doing so, offer a possible imaginary of a more flexible academia that prioritizes collective access, mutual support, and embodied engagement by embracing the push and pull of nonlinear paths, crip time, and alternative temporalities. We are not the only ones to question the impositions of

traditions, institutions, and regimes. As Samuels and Freeman (2021) ask, “What if temporal rhythms and their attached notions of normalcy, productivity, and community were forever cripped, detached from chrononormative capitalist structures and predicated instead on the myriad realities of bodyminds along a spectrum of abilities?” (p. 252)

At present, society and academia are governed by a normative clock, a concept Freeman (2010) terms chrononormativity—temporal norms regarding the timing and sequencing of life events, which shape and regulate individual bodyminds. Our lives are “structured by time as a vector of power” (Freeman & Samuels, 2021, p. 245). In North American contexts, chrononormative temporal measurements structured by white, cis-hetero, and non-disabled people dictate societal and political norms (Freeman, 2010). These norms are socially organized according to dominant temporal experiences that appear and feel natural to those they privilege (Ahmed, 2006). Therefore, time functions as a social construct that masks the often hidden rhythms of privilege (Cosenza, 2014; Zerubavel, 1981), obscuring inherent complexities and reinforcing societal expectations prioritizing productivity. This pervasive cultural influence not only reinforces but also perpetuates various forms of oppression, including colonialism (Harjo, 2019), white supremacy, misogyny, cis-heteronormativity, classism, and ableism (Puar, 2017). These temporal standards further marginalize and exclude under-recognized groups, emphasizing the societal expectation that one’s value is contingent on conformity to normative productivity and temporal standards. The intersection of these temporal norms with capitalist values reveals the deeper connections between time regulation and socio-economic structures.

This system becomes even more oppressive as the pace of life accelerates. As Susan Wendell (2013) observes,

> When societal expectations for speed increase, more people become disabled—not only due to the physical toll of trying to keep up but also because fewer individuals can meet the new standards of ‘normal’ performance. Limitations that were once inconspicuous in a slower-paced society become disabling, further marginalizing those who cannot conform to these intensified demands. (p. 59)

Moya Bailey underscores the harmful impact of chrononormative pressures, particularly on disabled individuals. She asserts that “this pressure exacerbates disability, creates impairments,

and even leads to premature death" (Bailey, 2022, p. 285), highlighting the severe consequences of society's rigid temporal expectations. Bailey further critiques the exploitation inherent in these norms, arguing that "disability is not the problem; rather, the problem is society's, particularly employers', refusal to acknowledge the exploitation of our labor and bodyminds" (p. 286). Her observations reinforce the idea that chrononormativity not only marginalizes but also actively harms those who cannot conform to its standards, particularly within the context of neoliberal capitalism.

In this context, ableism further perpetuates these harms by creating societal barriers that exclude those who do not meet normative standards, with chrononormative academic time being one such barrier for disabled scholars. Ableism, intertwined with white supremacy, settler colonialism, and capitalism, promotes beliefs and practices that value conformity to normative temporalities. Talila "TL" Lewis (2020) defines ableism as a system that places values on people's bodies and minds based on socially constructed ideas of normalcy, intelligence, excellence, and productivity. These ideas are deeply connected to anti-Blackness, eugenics, colonialism, and capitalism. As a result, people's worth is often based on their appearance and ability to perform and conform to societal expectations successfully. Importantly, Lewis notes that you do not have to be disabled to experience the effects of ableism. For bodyminds to live in opposition to the chrononormative timeline is to exist with an embodied tension that challenges a sense of belonging. For our purposes, the concept of chrononormativity offers the opportunity to explore the intersections of temporal norms, crip time, embodiment, and musical timing.

Musical timing has its own rules and practices, much like chrononormative time. We specifically consider the musical term *rubato* as a form of expressive timing. Ironically, most music students learn what *rubato* means in a rush, as we frantically memorize a list of music terms and definitions for an exam or are critiqued by teachers or competition adjudicators. We might rattle off that *rubato* is derived from the Italian word "rubare" (to rob) and is sometimes referred to as "stolen time" because the time that is taken to be expressive within a given tempo must then be given back later by shortening something else. While this 'stolen time' definition is a common starting place for students, a more nuanced definition describes *rubato* as ignoring the notated instructions for tempo and rhythms in favour of artistic expression (Rosenblum, 1994). The term *rubato* encompasses various changing and flexible ways of altering tempo. However, through practice, the word eventually links itself to the feeling of altering time in our bodyminds

and music. Feeling the altering of time opens up possibilities for changing our temporal frameworks and finding alternative temporalities.

Disabled activists and scholars have long considered alternative experiences of time from a disabled bodymind perspective (Freeman, 2010; Gill et al., 2002; Price, 2011; Samuels, 2013; Schalk, 2022; Zola, 1988). Queer feminist and disability theorist Alison Kafer describes crip time as bending the clock to meet disabled bodies and minds rather than bending disabled bodies and minds to meet the clock (2013). In this way, disabled and chronically ill people have a unique relationship to time that requires them to listen more closely to the rhythm of their bodyminds (Raghavan, 2020). It understands that what constitutes disability is based on a normative understanding of time (McRuer, 2006).

Crip time asks for vulnerability and collaboration and moves away from "crip failure" and toward more accessible and equitable practices (Walsh, 2023). Crip time, therefore, reflects a reclamation of time by disabled individuals, asserting the value of their own temporal experiences and needs. In academia, crip time can be used to confront chrononormative notions of progress to re-conceptualize time and recognize that we can teach and learn through different notions and engagements with temporality (Soklaridis et al., 2021). Crip time can be explained and understood as a concept. Still, within the context of the conservatory, where our bodies and minds are both scrutinized at every performance, rehearsal, and lesson, it can be much harder to feel and to know crip time in one's bodymind. *Rubato*, on the other hand, is felt keenly in the musician's bodymind - albeit differently for each individual—making *rubato* a functional template through which to understand and embody crip time.

We call this practice of using *rubato* to connect to crip time, rubatic time. Linguistically, rubatic comes from *rubato* and the suffix *-ic*, meaning of, pertaining to, resembling, characterized by, or relating to, so rubatic time is a way of experiencing time that is like *rubato* in that it is grounded in our bodies and minds, it is co-created, and it offers a flexible resistance to chrononormative expectations. Thus, rubatic time may illuminate how disability or crip time is already embedded in parts of music education or performance to provoke a new lens for understanding disability as art (Marcus, 1993) and how Western music (art) education can use a more disabled artistic approach to pedagogy. What would music education and academia look like in rubatic time?

Creating *Rubato*

The collaborative music-making process highlights the relational nature of both *rubato* and rubatic time. While we may sometimes slip into *rubato* without reflective thought, our decisions as to exactly how *rubato* is expressed are made concerning the time period of the composer, the context of the music, text setting in vocal works, where and when we are performing, other musicians, the audience's expectations, and abilities of our bodies, minds, and instruments at that moment. The execution of *rubato* depends on these surrounding circumstances, much like how rubatic time and flexibility in academic settings vary with context.

First, consider the *rubato* of a solo performer. As an unaccompanied soloist, you entrain to the original tempo, and in slowing down, feel the pull between your slowing and the original tempo. There may also be an interplay between your *rubato* use and how other well-known performers employ it in the same piece, how teachers and coaches prefer it, or the temporal pressure of a timed recital or jury with strict penalties for deviating from the time limit. Even as a soloist, *rubato* is informed by relationships between the self and others and the relationships between parts of the self. In an academic scenario, this might involve using rubatic time to resist chrononormative expectations when you can, knowing that such decisions could have consequences.

Secondly, we look at the large ensemble. In this musical scenario, the conductor is in charge and dictates when and how much to alter the tempo. Designating one leader organizes the ensemble yet also leaves the ensemble vulnerable to the temporal interpretation of one person. An academic parallel might be a large institution dictating the timeframe everyone must work within. The institution can change its policies (likely due to the dedicated advocacy of exhausted students, faculty, and administrators). However, in this structure, everyone must still follow the unified direction of the institution. Even with significant policy change, the temporal flexibility implemented will primarily reflect the wishes of those writing the policy, who are often the most privileged within the academy.

The third possible context is chamber ensemble *rubato*. In a small ensemble, the group agrees upon *rubato*, and the individual leading the change in tempo varies. If one musician has a challenging and attention-catching line while the others have simpler parts, the person with the difficult line can lead the use of *rubato*. If another musician has a long phrase and limited breath, the ensemble will accommodate them and not slow down too much. This adjustment can be

made whether the breath is planned in advance or spontaneously needed during the performance. Here, *rubato* mediates not only the relationship between musicians but also the relationship between the planned and the spontaneous. In rubatic time, the spontaneous and the planned are not antagonistic; instead, they both play a role in how we navigate time. In an academic context, this resembles a class or a group of colleagues working together to accommodate each other, taking turns leading and following, caretaking, and being cared for.

Rubatic Time In Practice

As discussed, *rubato* and rubatic time can be created in several inter- and intra-personal contexts. But what is the result of using rubatic time? Ashley Taylor discusses the reclamation of slowness as advantageous for academia, possibly allowing for a more equitable and democratic approach to education that questions norms surrounding pace and productivity (2019). An ethics of pace that prioritizes moving at the "speed of trust" (Brown, 2017, p. 41) and promotes a more democratized relationship with time can challenge and disrupt harmful patterns in academia (Bailey, 2021, p. 288). A more sustainable approach to learning can lead to better knowledge engagement, nuance, profound meaning-making, and critical and careful questioning, all leading to a better comprehensive understanding of information. While appreciating the benefits of slowness, it is important not to equate crip time to slowness.

Reducing crip time to only needing more time suggests that disabled people can and should be made maximally productive by simply giving us more time rather than changing the system that demands everyone be productive all the time (Kafer, 2021). *Rubato* does not only mean slowing down. *Rubato* may sometimes involve a slight speeding up, for example, speeding up to express excitement or anticipation. Alternatively, *rubato* can include slowing down and pausing momentarily; for example, a performer may decide to slow down as they approach a caesura. This pause offers the chance to regroup and then continue, either at the same a new tempo and the caesura informs how the following phrase is approached.

Similarly, rubatic time in academia does not only mean slowing down. Academic time can inflict harm by not providing enough time and taking too much time to give assistance or accommodations. Margaret Price (2024) describes an accommodations timeloop wherein the institution delays the process of getting time-sensitive accommodations as the person seeking

accommodations suffers the cost and then is forced to use their resources to accommodate themselves. Within this loop, the institution takes on the role of timekeeper and arbitrates the flow of time until the individual exerts unsustainable amounts of energy to work against this flow. The timeloop could be interrupted by implementing rubatic time: the process of arranging accommodations could be accelerated, thus allowing an academic to move at a sustainable pace or academic deadlines and milestones could be paused to allow time to arrange accommodations before an academic continues their work.

Rubatic time changes how we relate to one another. In music, *rubato* is a way to express emotional nuance (Rosemblum, 1994). These moments of musical expression cannot be created if the musician adheres rigidly to the metronome, so an emotional connection with the listener is made by taking time. Price, drawing on Moten and Harney (2013) and works by Maurice Stevens, argues that abundance—of time, space, and resources— is required to create actual gatherings of people where ideas can be exchanged and support can be shared (2024, pp. 174–175). In a larger social context, rubatic time gives time for gathering and learning with others but also allows for the flexibility to take more time to reflect on ideas and needs or move faster to act on them. The inflexibility of academic time may preclude connection and community building; *rubato* and, therefore, rubatic time, even outside a musical context, necessitates it.

Rubatic time also disrupts normative notions of goals and progress. Linear progress is central to our capitalist society and institutions. In this context, productivity is a measure of efficiency that often equates to economic success. In *Ableism in Academia,* Nicole Brown and Jennifer Leigh (2020) add that continuously reinforcing ableist temporalities creates an endemic bias for ableism in academia. Chrononormativity in academia creates a standard of non-disabled ideals of excellence. The concept of academic time is based on non-disabled ideals and expectations. Academia seeks to homogenize and normalize what it means to be a successful scholar or student by prioritizing performativity, efficiency, and productivity. These priorities become the standard we all strive for.

The value of students and faculty becomes directly correlated to the pace of their work output, with the ongoing expectation of publication to secure funding. A quicker and higher productivity rate is perceived as being a successful and more worthy academic. This creates an expectation for linear progress and a continual increase in the quantity of a student's productivity throughout a degree. Being "too slow" raises questions about whether someone is the right fit for academia. Attending to our bodyminds when we are not moving with maximum normative

productivity brings forth the inherent biases of chrononormative time. We are conditioned to feel shame when we take time to rest or slow our pace, highlighting how slowness challenges our sense of belonging and normative productivity-driven ideals. This shame underscores the systemic discipline of normative time, which is ingrained in our culture and is socially organized to privilege specific temporal experiences (Freeman, 2010; Halberstam, 2005). How can we gauge our value if we aren't being productive in linear ways? An absence of linear goals and progress marks *rubato*. The goal of *rubato* is not to finish a piece of music more efficiently or move on to the next piece of music as fast as possible. There is no overarching, measurable metric of achievement in *rubato* or rubatic time, and its value comes from using time flexibly.

Not only does academic time enforce rigid notions of productivity for scholars, but it also influences our teaching and the way we approach our students' academic trajectories. Academic curricula and pedagogy tend toward a one-size-fits-all approach with less focus on the pursuit of knowledge and more focus on a market-like model, known as the theory of academic capitalism (Soklaridis et al., 2021). It creates an outcome-oriented "efficiency paradigm" that is noted by Sokilardis et al. as the "primary driving force behind chrononormativity and ableism in academia." Focusing on the rate of productivity rather than students' knowledge acquisition impacts their learning, well-being, and sense of belonging. Time is often treated as a quantifiable measure in education, leading to rigid scheduling and pacing that requires students to learn and "perform spontaneously in restricted time frames" (Price, 2011, p. 63). This obsession with quantity affects creativity, reflection, and human relationships in academia (Fischer et al., 2012). Within a rubatic temporal framework, there are not the same rigid notions of progress. In a musical context, the individual performer's choices can influence the overall perception of an entire piece of music. Alan Dodson (2002) considers this further with Lerdahl and Jackendoff's discussion of hypermeter in *A Generative Theory of Tonal Music* and a hypermetrically ambiguous passage in Mozart's Symphony No. 40 in G Minor. In this passage, how a performer interprets the music and uses expressive timing changes how the listener understands the hypermetric structure, and performers can interpret the music in multiple ways without one correct interpretation or one correct hypermetric structure. Applying this concept from music to a social context suggests that

an individual scholar's unique needs and choices can shape an academic career. Each career can be structured differently from others and still be successful.

The productivity norms in our institutions can be challenged by embracing interdependence, collaboration, and alternate ways of knowing and creating. Recognizing the need for a cultural shift, collective accountability is imperative to transition from individualism (prioritizing the individual over the collective) to a more relational and sustainable approach (Price, 2024, p. 169). Collective access, which moves from individualism towards a non-hierarchical, community-focused, more access-centered approach, can transform organizational policies and practices into more inclusive and sustainable. This concept is grounded in the principles of Disability Justice, which recognize the inherent value of each bodymind with their diverse strengths and needs. Disability Justice, coined by disabled, queer, and trans people of colour within the Disability Justice Collective, advocates for a more intersectional approach to the disability movement—a movement that has historically centered experiences of white cis-het disabled individuals (Piepzna-Samarasinha, 2021).

At its core, Disability Justice envisions a world where people are not merely tolerated but deeply valued (Piepzna-Samarasinha, 2018). In the academic context, Disability Justice challenges the standardized, ableist structures of time—such as rigid deadlines, accommodation delays, inflexible schedules, and expectations of constant productivity—that are not just inconvenient but actively harmful to disabled individuals (Bailey, 2021; Price, 2024).These structures impose a one-size-fits-all model that often fails to accommodate the diverse needs and rhythms of disabled people.

To reshape these academic forces, we need an intersectional approach to temporality (Soklaridis et al., 2021). Rubatic time is inherently intersectional because it draws from multiple perspectives, including those from Disability Justice, to challenge normative structures in academia. Just as *rubato* in music is not merely about slowing down but creating expressive timing that can involve speeding up and slowing down, rubatic time in academia is not simply about giving more time to tasks. It is about restructuring the flow of time to support individual needs better and promote a more democratic and inclusive environment. This flexible approach can help disrupt the linear, goal-oriented progress that often dominates academic settings, similar to how rubato can disrupt the rigid structure of a musical piece to create a more meaningful and nuanced performance.

Conclusion

We imagine a rubatic academic time that rejects academia's chrononormative timelines by considering the experiences and needs of the individuals involved. With rubatic time, we can reframe academic expectations and move away from an ableist idea of what productivity should look like. In a rubatic course, progress might unfold in waves rather than following rigid deadlines, embracing nonlinear advancement and recognizing that setbacks are a natural part of learning rather than failures. Rubatic time is, by definition, a collaboratively created temporality that can account for multiple intersecting access needs. A course designed with rubatic principles may still include challenging content, but it will not be temporally inaccessible solely because the individual bodymind is at odds with the course's rhythmic flow and pacing. There is no universal approach to implementing rubatic time, so rather than provide institutional guidelines with clear end results, we offer examples of experiences where time and temporal expectations were co-constructed. We share these experiences not to suggest they are the only way, but rather with the hope that they serve as a reminder of the knowledge we all hold and a call to learn from each other. A rubatic classroom is possible, because it is happening. It's just that the teachers, lecturers, administrators and rule makers within academic institutions need to be aware of how, when and why rubatic time – and accommodations can exist in harmony (Thompson et al., 2024).

> Annika: It's February 2021, in the midst of our first year of pandemic school. I sign on to Microsoft Teams for my Feminist Philosophy class. My peers and I join the call, a mix of cameras on and cameras off. The professor begins the class, turns on captions, and starts recording the call to post on our course page. I'm taking notes for the class notes library today so that anyone who misses the class has notes, and I'm also gaining participation points by taking these notes. The class begins with some housekeeping announcements about our next assignment, which we can choose one of several possible formats for. Our professor also reminds us that we have seven automatic extension days we can put towards any assignment without any extra communication required. I'm feeling overwhelmed and exhausted, so I keep my camera off and take the community notes quietly while my roommate has a Zoom meeting in the room next to mine. I have a few questions and I can't quite pay attention well enough to string together a coherent

sentence today, but I know I can ask my questions during office hours or during the next lecture. The next lecture is asynchronous and shorter, but the professor hosts a coworking Teams call during the time synchronous class would take place. During this time, we are free to drop in and watch the asynchronous lecture or work on anything while body doubling and connecting with everyone else in the call. The chance to ask questions and work alongside my professor and my peers while the rest of the world feels so unfamiliar means that these calls quickly become a highlight of my weeks. No matter what happens with the rest of the semester, I know in this class I will be okay.

Skylar: In September 2024, I was nervous about taking an in-person class. Walking into a small, stuffy classroom, I felt my anxiety spike—until I saw the professor wearing a KN95 mask and a keffiyeh. I thought to myself, “Okay, they get it.” They asked how we felt about the space, giving us the option to share our thoughts and concerns. We decided to move to their research lab, a larger and more comfortable environment with air purifiers, flexible seating options like a couch, floor cushions, ergonomic chairs, and movable tables, and space to move freely.

From day one, they spoke about intersecting acts of community care and asked the class to reflect on our values and the possibility of masking. After that discussion, everyone masked consistently for every class, creating a shared sense of safety and solidarity. We collectively discussed an ethics of pace, emphasizing a “speed of trust” (brown, 2017) and a sense of rubatic flow that centered autonomy within a collaborative community. Assignment extensions were built into the course, so deadlines didn’t loom as threats, and there was no penalty for being late to class—we were encouraged to arrive when we could, knowing we’d still be welcomed. Together, we crafted a manifesto defining how we wanted to share the space, outlining our stakes, shared agreements, and commitments to care. It acknowledged power dynamics and created room for ongoing discussions about access needs and personal boundaries. For the first time in academia, I knew my bodymind needs would be met with care—no matter what—and I never missed a class. It wasn’t just a space to learn but a space where I could truly be.

"We move together with no body left behind" (Sins Invalid, 2015)

"Wherever you are is where I want to be" (Mingus, 2010)

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PART 2: DISABLED PERFORMATIVITIES

7. My eyes, my voice, my spirit, my music

Guilhem “Pone” Gallart

This chapter appears in both English and French languages

Prologue

Guilhem “Pone” Gallart is a musician living in France. He was born in Toulouse and moved to Marseille at 19 years of age. He is a musician, hip-hop artist, producer, and writer. In 2015 Pone discovered that he had amotropic lateral sclerosis (ALS) which caused him to rapidly develop tetraplegic paralysis. With the wider public lacking information about this disease, in 2015 he published a website titled ‘ALS for Dummies’(ALS Quebec). Pone continues to write, compose and produce music using adaptive technology.

Pone’s early work emerged from the rise of French hip hop in the 1990s that provided an ethnic musical vitality in Marseille. This chapter firstly surveys the socio-cultural movement that contributed to the development of this form of music, and the cultural mileu of its most revered exponents. In 2024 Anthea Skinner and Leon de Bruin met with Pone on a research trip exploring France’s disability music culture. Their dialogue with Pone has continued, threading this series of face to face and online discussions into a reflective and powerful view of his musical life. Pone’s work is featured in various online media platforms, but the complex context of this time is often minimised. We assist Pone in providing a substantive backdrop to Marseille’s social and cultural setting, and in devising this chapter with him. Many in France and Europe will know of his work, and we provide a French translation for that benefit.

Hip-hop, rap, resistance and defiance

Musical movements do not occur in a vacuum and they are often a reaction to what came before. Social movements, political machinations and the social semiotics of medium and message all play a part in how humans signify musicking practices across specific social and cultural circumstances. In fact, music movements may emerge from positions of resistance, defiance, and even subversion. In *Guerrilla Music*, de Bruin and Southcott assert that:

> Music holds a central place in social encounters and engagements as a form of resistance and revolution. Music is so powerful that it may require banishment by ruling authorities. Either as a rallying call, or by another extreme, a cunning munition of critique and subterfuge, music has been and continues to be a powerful weapon of both ruling institutions and 'the people'. Time and time again music and music makers continue to demonstrate the ability to unite people from different socioeconomic, religious and ethnic backgrounds to come together for change. Music across the ages has planted the seeds of doubt and flamed passions to inspire changes politically and socially, both big and small. (de Bruin & Southcott, 2024, p. 1)

Hip-hop and rap music historically reflects a critique and resistance to the language of authority. Hip-hop represents an *artivism,* in which musicking practices collectivise communities through discourses and relations of power that "disrupts the singlar order by which the dominant code categorises the other" (Papastergiadis, 2002, p. 170). Hip-hop provides a guerrilla tactic "revealed not by its initial impact of actions, but through its enduring impact, its unpredictable nature, its capacity to infect, incubate and infiltrate communities, populations and societies so as to instigate zeitgeist change and attention both locally and worldwide" (de Bruin & Southcott, 2024, p. 8).

This chapter first provides a contextual backdrop to the emergent hip-hop scene in Marseille that Pone experienced. Those initial and evolving musical, communal, and artistic experiences are then explored through the voice of Pone through which he shares with us his compelling and powerful journey through music, disability, and his infatigable spirit of creativity.

Hip-hop and rap Français in Marseille

The social and urban transformation of Marseille can only be fully understood by considering the role of migration in France. Marseille's post industrial movement from ship building, tile manufacture, and agricultural produce refinement dates back to the sixteenth century (Temime & Attard-Maraninchi, 1990). Marseille has always been a city of immigrants, where from the eighteenth century through to post second world-war, Italian, and German migration which started in the 18th-century giving way to post-World War II refugee populations from Armenia, Greece, and Spain (Temime, 1985).

French colonialism and its complex legacies also saw Algerian, West and North African migrants moving to the relatively poorer districts in the northern part of the city. The very materiality of Marseille is reflected in this presence, particularly in the stalls of the *comptoir maghrébin* (North African market), that represent Algerian, Moroccan, and Tunisian infusions throughout the city's northern neighborhoods (Missaoui & Tarrius, 2000). Marseille's civic culture has evolved alongside waves of immigration, and is reflected in this enriching of local culture.

The 1990s in particular ushered in the urbanization of the city's northern, eastern, and southern outskirts as well as in the old neighborhoods along the port that also shaped the identity of the city center (Bechini, 2022). In 1995 local government in Marseille initiated the *Euroméditerrannée*, an urban renewal project that occupies an area of 480 hectares. This redevelopment sought to service office and high- technology amenities and promote Marseille as a business enterprise city. Development served as a flashpoint to its bordering some of the most deprived districts of the city, the invading gentrification of these areas displacing decades old migrant communities (Andres, 2011).

Marseille has and remains to be an enigma amongst the French. It is the second most populous city in France and perceived as the last great working class French city (Dell'Umbria, 2012). Sociologist Andre Donzel described Marseille as:

> not so much the poorest city in France, as the most unequal: a place where gated communities proliferate while poverty remains well above the national average. (La Marseillaise, 2013)

The city encompasses a southern district of predominantly white, affluent suburbia, with the north marked by intense deprivation, omnipresent violent gang turf and narcotic wars, and complex social issues between marginalised communities (Leroux, 2017). This blend of cultures, ethnic communities and circumstance saw Marseille develop a reputation as a global node for 'world musics' (Denning, 2005). Groups such as IAM and Massilia Sound System both came to prominence with music that sought on the one hand to valorise a multicultural, tolerant image of the city, and on the other to rail against corruption, inequality and racism (Mackay, 2017).
By the mid 1990's Marseille curated a creative economy model based on urban renewal and business oriented activity that socially alienated and displaced immigrants, workers and those most vulnerable to political manoevering (Zukin, 1995), in an attempt to outwardly valourise socially Marseille's diversity and supposed tolerance, whilst supressing its deep-seated postcolonial fears and patent inequalities. This was done in the face of the extreme right-wing

Front National, to whom Marsellaise hip-hop artists and rappers adopted a combative principle declaring to be a *cauchemar des xenophobes* (nightmare of xenophobics) (IAM, 1991), a position of resistance through their music.

The 1990s marked the beginning of home grown hip-hop and rap in France (Durand, 2002). The emergence of rap and hip-hop is often linked to the contexuality of housing projects in New York's South Bronx that reify powerful origin stories and "sounds of the city" (Forman 2002, p. 69) but also through the creation of links that nourish a sense of belonging and historical logic. For many young people Marseille provided a fertile backdrop through which immigrant families and communities formed social bonds and new forms of solidarity (Savage et al., 2003).

This was created amidst challenging and incendiary circumstances; a persistent politically evasive positioning by the French political establishment, a rising and often marginalised ethnic youth, a prevailing rejection of local cultural production, where local musicians, producers and promotors sought a position within the established music economy (Gasquet-Cyrus, 1999; Gastaut, 2005). Piscopo-Reguieg (2013) notes that whilst being ignored by established production houses, "Marseille rap … is a vibrant culture which has indelibly shaped the image of *la cité phocéenne* [city of the people of Marseille)]". This musical idiom was not only practiced, produced, and appreciated locally, but as Mackay (2017) argues, bore "a richer, more powerful symbolic connection to contemporary Marseille than any other form of cultural expression" (p. 51). Artistic expression that then emerged was local rather than Parisien, self revealing in its references to African and Asian roots, empowering in its immigrant perspectives and storytelling, and defiant of enduring mainstream attitudes.

La Fonky Family

Growing up in Marseille, a group of youth, Rat Luciano, Sat l'Artificier, Don Choa, Menzo, Fel, DJ Djel and Guilhem "Pone" Gallart championed what they described as Marseille's unique diversity, an idea embodied through the multi-ethnic composition of their group reflecting the consitutencies in their community. This crew was an illustration of Marseille's diversity and melting pot: Algerian, Corsican, Spanish, Comorean, and Carribean descendants that formed the core of Fonky Family. They established themselves at the pinnacle of this genre, with their seminal recording 'Bad Boys de Marseille' (La Fonky Family/Akhenaton, 1995). These

musicians reconceptualised hip-hop in France beyond North American cultural hegemonies. Initial dispersal of rap and hip-hop worldwide empowered ethnic populations and “mobilised new forms of identity” that “reterritorialised multi-ethnic spaces” (Gross, 1994, p. 150). Local hip-hop and rap and musicking became a tool for youth affiliation, that provided a space of its own within which local meanings could be inflected against a global backdrop (Nooshin, 2011).

Pone recalls of this time:

> We started from nothing, no contact with anyone, no parent musicians or mentors as such. From our modest backgrounds , it was a great love that took us to unimagined places.We as La Fonky Family worked on a film soundtrack, and released some albums, and toured to much acclaim. We went our ways as our individual interests expanded, as did our visions of what we could do. Little did I know that my eyes would be so profound in my continuing creativity and musicmaking.
>
> A hip-hop artists‘s voice is their fingerprint- it signifies our stance, our mood. My voice was a thick southern French Marseille accent, with what my wife calls a, slight ‘hair on the tongue‘.

Fate and cataclysm

In 2014 Pone began to find walking becoming difficult. Soon he required assistance to not only walk, but also to turn the pages of the books he read to his children. In 2015, he was diagnosed with amyotrophic lateral sclerosis, or A.L.S., an incurable neurological disease. He said that,

> For me, well, this was a cataclysm. This condition slowly paralyzed my muscles from head to toe. It shocked me to my core, and also my wife, Wahiba, and my two children.

Nothing could prepare them for the fast onset of this condition that would lead to him becoming tetraplegic. For Pone, the worst part was losing control of his voice, becoming mute. For a while, he could only communicate through a spelling card. Wahiba would patiently run her fingers over the letters, stopping when Pone would blink. Together, they would slowly form sentences. “It was horrible,” (The Guardian, 2020). Pone elaborates:

I think back to this time. I cried. It took me to very dark places in my mind. In moments like this we do consider our own presence on earth. But from this, good did come.

> Firstly acceptance- my environment, where I need to be, and what I need around me. I thought what I needed to do to continue to make music and express myself. Personally, at the start of the illness, I did not want to be fitted for adaptive devices. Degeneration is very difficult to live with. Today I've been living thanks to machines for 6 years and I'm very happy about it. My voice was gone – but not lost. I had recordings but not enough. I found someone, Marc-Antoine Le Bret, a 37-year-old comic. He did celebrity impressions, and I asked for his help in creating a new voice to match my old one.

Mr. Le Bret immersed himself in old audio and video recordings of Pone, like clips from a family vacation to Morocco, and of course watched footage of Fonky Family. For Le Bret, this became "the most beautiful challenge of my lifetime" (NY Times, online). Pone's recordings carried the heavy southern accent. It was this accent, his fingerprint, that Le Bret aimed to copy as best he could, absorbing his character, spark, and elan. He produced about 250 stock phrases that allowed a digital voice processing software to learn Pone's distinctive vocal nuances. And so, Pone transitioned to a digitally generated voice activated via his computer using eyegaze technology. As Pone remarks, "Now I could use my 'actual' voice once again" (Konbini, 2021).

A reflection on disability

Pone was intrigued to contribute to the current volume exploring disabled music, artists, ways of being and creating in music. Our discussions touched on his experiential encounters with disability. He was clear to delineate that despite societal generalisations of terms that coalsce with attitudes towards disabled people, in reality circumstances are individual, idiosyncratic, and personally understood and lived with. He says:

> First of all, I would like to distinguish two things: disability from birth and disability suffered following an accident or illness. I belong to the second category. I am not able to talk about birth disability, but when we lose faculties that seemed "normal" to us, we inevitably miss them.

> When I fell ill and gradually lost my physical abilities, I had been composing for over 25 years. At the start of the illness, I didn't think it was still possible to make music. When I realized that I could still produce, it was a revolution.

My eyes are a mouse

When Pone speaks, an infra-red sensor tracks his eyes as they move across his computer keyboard screen. This enables him to write text that is then read out by the computer. The process takes concentration and is time consuming. We discuss his life, family, and music, minutes pass, we expectantly await as Pone writes amidst the whoosing of the repirator that keeps him alive.

For Pone, family is the bedrock of what keeps him going. His parents visit his home in Gaillac, north of Toulouse. About his room, family photos and gold records adorn the walls. He recalls the moment the family gathered on his bed to hear his new voice for the first time. A profound and bittersweet moment. He realises he probably faces a shortened life, but family provides an inspiration to keep going. He does this through his music. Pones explains: "I have a computer equipped with eye tracking. It's an infrared strip that captures the movement of my pupils and software transforms them into data. My eyes are a mouse." (personal communication)

Pone cannot spend hours at one time improvising or adapting samples, but he focuses for hours across the day with intense concentration, and then relaxes and recuperates as the next musical ideas flow.

> I use the eye gaze software and (midi program) Ableton. I compose and create here from the bed. I make it through my eyes, they allow me to put my soul into my music. (personal communication)

Pone has created a number of albums both solo and in collaboration with other artists. His 2019 album inspired by Kate Bush, *Kate and Me* incorporates the sound of his breathing device, his environment still a creatively fertile playground of ideas (Pone, 2019).

> I don't remain locked in the formulas that have made my previous work famous. I believe in experimentation, in always looking forward, and exploring the qualities of acoustic atmospheres with my equiptment and my musical imagination. (personal communication)

Pone urges that :

> This album Kate and Me, it is the first album to be composed, produced and mixed solely with the eyes. The fruit of a long process, and one I am proud of. (personal communication)

Inspiration from music and within

Pone brings a philosophy etched from his personal upbringing, musical experiences, and cameraderies. This reveals a continual re-devising of self, of finding place and space to allow ones' inspirations to take flight. This is a challenge exacerbated by Pone's condition, and overcoming adversity has been propelled by an insatiable curiosity and creativity. We conclude with Pone's thoughts on this:

> When you have a major disability, you have to have plans, it's vital. Music is a wonderful project. It brings people together, we never stop learning, and with a little patience, we obtain results that are good for morale. Thanks to technology, particularly eye tracking, we can have access to computing. This expands my knowledge and adaptive development into areas that include music composition, software,sampling, among others, which is very useful in cases of severe physical disability. We can flourish, find a place in society, and feel useful again.
>
> Music, like life continues to be an adventure for me. I see this illness as one of life's journeys. Even though I would not wish this on anyone, it's about living through one's circumstances. I still have the most important things I need: My head and my heart, my family, and now a black belt in patience.

Acknowledgements

We gratefully thank Pone and Wahiba for welcoming us into their home and allowing us to discuss his life with us. The text represents both what Pone discussed with us in person, speaking to us directly through his computer, as well as email conversations we engaged in over the ensuing months. We also thank our interpreter in France Sandrine Eifermann and Emmanuelle Missios in Melbourne for assisting with translation and the French text.

Prologue

Guilhem “Pone” Gallart est un artiste aux multiples facettes vivant en France. Né à Toulouse, il a déménagé à Marseille à l’âge de 19 ans. Il est musicien, artiste hip-hop, producteur et écrivain. En 2015, Pone a appris qu’il était atteint de la sclérose latérale amyotrophique (SLA), ce qui a rapidement entraîné une paralysie tétraplégique. Du fait du manque d’informations accessibles au grand public sur cette maladie, en 2015, il a publié un site internet intitulé « SLA pour les nuls » (ALS Québec). Pone continue à écrire, composer et produire de la musique en utilisant des technologies d’assistance.

Pone a fait ses débuts avec la montée du hip-hop français dans les années 1990, mouvement qui a apporté une vitalité musicale ethnique à Marseille. Ce chapitre examine avant tout le mouvement socio-culturel qui a contribué au développement de cette forme de musique, ainsi que le milieu culturel de ses plus grands représentants. En 2024, Anthea Skinner et Leon de Bruin ont rencontré Pone lors d’un voyage dans le cadre de leur recherche sur la culture musicale des personnes handicapées en France. Ce dialogue s’est poursuivi, menant cette suite de discussions en face à face et en ligne à une réflexion approfondie sur sa vie musicale. Le travail de Pone est présenté sur diverses plateformes médiatiques en ligne, mais le contexte complexe de cette époque est souvent minimisé. Notre collaboration avec Pone vise, d’une part, à fournir un cadre substantiel au contexte social et culturel de la scène marseillaise, et d’autre part, à élaborer ce chapitre avec lui. Beaucoup en France et en Europe connaissent son travail, et nous proposons une traduction française à cet effet.

Hip-hop, rap, résistance et défiance

Les mouvements musicaux ne se créent pas ex nihilo et sont souvent une réaction à ce qui les a précédés. Les mouvements sociaux, les manœuvres politiques et la sémiotique sociale du médium et du message jouent tous un rôle dans la manière dont les pratiques musicales sont signifiées par les humains à travers des circonstances sociales et culturelles spécifiques. De fait, les mouvements musicaux peuvent émerger de positions de résistance, de défiance et même de subversion. Dans "Guerrilla Music", de Bruin et Southcott affirment que :

La musique occupe une place centrale dans les rencontres et les engagements sociaux en tant que forme de résistance et de révolution. La musique est si puissante qu'elle peut nécessiter une interdiction par les autorités au pouvoir. Soit comme un appel au rassemblement, soit, à l'autre extrême, comme une critique habile et détournée, la musique a été et continue d'être une arme puissante, à la fois pour les institutions dirigeantes, et, pour « le peuple ». La musique et les musiciens continuent, comme ils l’ont fait à maintes reprises, à démontrer leur capacité à rassembler et à unir des personnes de différents milieux socioéconomiques, religieux et ethnique en faveur du changement. La musique à travers les âges a semé le doute et attisé les passions pour inspirer des changements politiques et sociaux, grands et petits. (de Bruin & Southcott, 2024, p. 1)

La musique hip-hop et rap reflète historiquement une critique et une résistance au langage de l'autorité. Le rap and hip-hop représente un activisme, dans lequel les pratiques musicales collectivisent les communautés à travers des discours et des relations de pouvoir qui « perturbent l'ordre singulier par lequel le code dominant catégorise l'autre » (Papastergiadis, 2002, p. 170). Le rap fournit une tactique de guérilla « révélée non par l’impact initial de ses actions, mais par son impact durable, sa nature imprévisible, sa capacité à infecter, incuber et infiltrer les communautés, les populations et les sociétés pour initier des changements d'esprit et capter l'attention, tant au niveau local que mondial » (de Bruin & Southcott, 2024, p. 8).

Ce chapitre présente d'abord un contexte à la scène hip-hop et rap émergente de Marseille que Pone a connue. Ces expériences musicales, communautaires et artistiques initiales et évolutives sont ensuite explorées à travers la voix de Pone, qui partage avec nous son parcours captivant et saisissant, par le biais de la musique, du handicap et de son infatigable créativité.

Le Hip-Hop et le Rap Français à Marseille

La transformation sociale et urbaine de Marseille ne peut être pleinement comprise sans prendre en compte le rôle de la migration en France. Le mouvement post-industriel de Marseille, allant de la construction navale à la transformation des produits agricoles, en passant par la fabrication de tuiles, remonte au XVIe siècle (Temime &

Attard-Maraninchi, 1990). Marseille a toujours été une ville d'immigrants. La migration italienne et allemande s'est déroulée du XVIII jusqu'à l'après-Seconde Guerre mondiale, puis, a laissé place à des populations réfugiées post-Seconde Guerre mondiale en provenance d'Arménie, de Grèce et d'Espagne (Temime, 1985). Le colonialisme français et ses héritages complexes ont également conduit des migrants algériens, ouest-africains et nord-africains à s'installer dans les quartiers relativement plus pauvres du nord de la ville. La matérialité même de Marseille est reflétée dans cette présence, en particulier dans les étals du « comptoir maghrébin », qui représentent les influences algériennes, marocaines et tunisiennes à travers les quartiers nord de la ville (Missaoui & Tarrius, 2000). La culture civique de Marseille a évolué en parallèle avec les vagues d'immigration, reflétant ainsi l'enrichissement de la culture locale.

Cependant, les années 1990 en particulier, ont inauguré l'urbanisation des périphéries nord, est et sud de la ville ainsi que celle des vieux quartiers le long du port, ce qui a également modifié l'identité du centre-ville (Bechini, 2022). En 1995, les collectivités locales ont initié le projet de renouvellement urbain *Euroméditerranée*, couvrant une superficie de 480 hectares. Ce réaménagement visait à pourvoir des bureaux et des équipements de haute technologie, et à promouvoir Marseille comme ville d'entreprise commerciale. Ce développement fut un point de rupture avec les quartiers les plus défavorisés de la ville, l'envahissement de ces zones par la gentrification déplaçant des communautés de migrants établies depuis des décennies (Andres, 2011).

Marseille a toujours été et reste une énigme pour les Français. C'est la deuxième ville la plus peuplée de France et elle est perçue comme la dernière grande ville ouvrière française (Dell'Umbria, 2012). Le sociologue André Donzel décrit Marseille comme : « pas tant la ville la plus pauvre de France, que la plus inégale : un lieu où prolifèrent les communautés fermées tandis que la pauvreté reste bien au-dessus de la moyenne nationale » (La Marseillaise, 2013).

La ville comprend des banlieues sud principalement blanches et aisées, et des banlieues nord marquées par une grande pauvreté, des guerres de territoire et de stupéfiants omniprésentes, et des problèmes sociaux complexes entre les communautés marginalisées (Leroux, 2017). Ce mélange de cultures, de communautés ethniques et de circonstances a fait de Marseille un carrefour mondial pour les « musiques du monde » (Denning, 2005). Des groupes tels que IAM et Massilia Sound System se sont hissés au premier plan avec une musique qui cherchait d'une part, à valoriser une image multiculturelle et tolérante de la ville, et

d'autre part, à dénoncer la corruption, l'inégalité et le racisme (Mackay, 2017). Au milieu des années 1990, Marseille a développé un modèle d'économie créative basé sur le renouvellement urbain et orienté vers l'activité commerciale, ce qui a déplacé, et socialement aliéné, les immigrants, les travailleurs et les personnes les plus vulnérables aux manœuvres politiques (Zukin, 1995), le tout, dans une tentative de valoriser ostensiblement la diversité sociale et la prétendue tolérance de Marseille, tout en réprimant ses peurs postcoloniales profondément enracinées, et ses inégalités flagrantes. Cela s'est fait face au Front National, parti d'extrême droite, contre lequel les artistes hip-hop et les rappeurs marseillais ont adopté un principe combatif déclarant être le *cauchemar des xénophobes* (IAM, 1991).

Les années 1990 ont marqué le début du hip-hop et du rap autochtone en France (Durand, 2002). L'émergence du rap et du hip-hop est souvent liée au contexte des projets de logement dans le South Bronx à New York qui réifient des mythes fondateurs symboliques et des « sons de la ville » (Forman 2002, p. 69), mais aussi à la création de liens qui nourrissent un sentiment d'appartenance et une logique historique. Pour beaucoup de jeunes, Marseille a fourni un cadre fertile au sein duquel les familles et les communautés immigrées ont formé des liens sociaux et de nouvelles formes de solidarité (Savage et al., 2003).

Cependant, cela s'est fait dans des circonstances difficiles et incendiaires ; un positionnement politique ambigu et persistant de la classe politique française, une jeunesse ethnique en hausse et souvent marginalisée et, un rejet prévalant de la production culturelle locale, alors que les musiciens, les producteurs et les promoteurs locaux cherchaient à se faire une place au sein de l'économie musicale établie. (Gasquet-Cyrus, 1999 ; Gastaut, 2005). Piscopo-Reguieg (2013) note que bien qu'étant ignoré par les maisons de production établies, « le rap marseillais (…) est une culture vibrante qui a indélébilement façonné l'image de la cité phocéenne » (ville des habitants de Marseille). Cet idiome musical n'était pas seulement pratiqué, produit et apprécié localement, mais comme le soutient Mackay (2017), nourrissait « un lien symbolique plus riche et plus puissant avec la Marseille contemporaine que toute autre forme d'expression culturelle » (p. 51). L'expression artistique qui a alors émergé était locale plutôt que parisienne, se révélant dans ses références aux racines africaines et

asiatiques, s'affirmant à travers ses perspectives et ses récits d'immigrés, et défiant de tenaces attitudes conventionnelles.

La Fonky Family

En grandissant à Marseille, un groupe de jeunes, Rat Luciano, Sat l'Artificier, Don Choa, Menzo, Fel, DJ Djelfa et Guilhem « Pone » Gallart, ont défendu ce qu'ils décrivaient comme la diversité unique de Marseille, une idée incarnée par la composition multiethnique de leur groupe, ainsi que d'autres groupes, au sein de leur communauté. Cette équipe était une illustration de la diversité et du melting-pot marseillais : des descendants d'Algériens, de Corses, d'Espagnols, de Comoriens et de Caribéens formaient le cœur de La Fonky Family. Ils se sont imposés au sommet de ce genre musical, avec leur enregistrement séminal « Bad Boys de Marseille » (La Fonky Family/Akhenaton, 1995). Ces musiciens ont reconceptualisé le hip-hop et le rap en France au-delà des hégémonies culturelles nord-américaines. La diffusion initiale du rap et du hip-hop dans le monde a permis aux populations ethniques de s'affirmer et « a mobilisé de nouvelles formes d'identité » qui ont « reterritorialisé les espaces multiethniques » (Gross, 1994, p. 150). Le hip-hop et le rap local et les pratiques musicales sont devenus un outil d'affiliation des jeunes, offrant un espace distinct dans lequel les significations locales pouvaient être infléchies par rapport au contexte global (Nooshin, 2011).

Pone se souvient de cette époque :

> « Nous sommes partis de rien, sans contact avec qui que ce soit, sans parents musiciens ni mentors. De nos origines modestes, c'est un grand amour qui nous a emmenés dans des endroits inimaginables. Nous, en tant que La Fonky Family, avons travaillé sur une bande-son de film, sorti des albums et fait des tournées avec beaucoup de succès. Nous avons pris des chemins différents au fur et à mesure que nos intérêts individuels évoluaient, tout comme nos visions respectives de ce que nous pourrions faire. Je ne pouvais pas imaginer à quel point mes yeux deviendraient si essentiels à ma créativité et à ma création musicale. »

> « La voix d'un artiste hip-hop est son empreinte digitale - elle exprime notre point de vue, notre humeur. Ma voix avait un épais accent marseillais du sud de la France, avec ce que ma femme appelle un léger « cheveu sur la langue ».

Destin et cataclysme

En 2014, Pone a commencé à trouver difficile de marcher. Bientôt, il a eu besoin d'aide, non seulement pour marcher, mais aussi pour tourner les pages des livres qu'il lisait à ses enfants. En 2015, il a été diagnostiqué avec une sclérose latérale amyotrophique, ou S.L.A., une maladie neurologique incurable.

« Pour moi, eh bien, ce fut un cataclysme. Cette condition a lentement paralysé mes muscles de la tête aux pieds. J'ai été ébranlé au plus profond de moi-même, ainsi que ma femme, Wahiba, et mes deux enfants. »

Rien n'aurait pu les préparer à l'apparition soudaine et à la progression rapide de cette condition qui le conduirait à devenir tétraplégique. Pour Pone, le pire était de perdre le contrôle de sa voix, de devenir muet. Pendant un certain temps, il n'a pu communiquer qu'à l'aide d'étiquettes de lettres. Wahiba passait patiemment ses doigts sur les lettres, s'arrêtant lorsque Pone clignait des yeux. Ensemble, ils construisaient lentement des phrases. « C'était horrible », se souvient Pone. (The Guardian, 2020)

> « Je repense à cette époque. J'ai pleuré. Ça m'a emmené dans des endroits très sombres de mon esprit. Dans des moments comme ça, on réfléchit à sa propre présence sur terre. Mais quelque chose de bon en est sorti. Avant tout, l'acceptation - mon environnement, où je dois être et ce dont j'ai besoin autour de moi. J'ai réfléchi à ce que je devais faire pour continuer à faire de la musique et pour m'exprimer. Personnellement, au début de la maladie, je ne voulais pas être équipé de dispositifs d'assistance. La dégénérescence est très difficile à vivre. Ça fait 6 ans que je vis grâce à des machines et j'en suis très heureux. Ma voix était partie - mais pas perdue. J'avais des enregistrements mais pas assez. J'ai trouvé quelqu'un, Marc-Antoine Le Bret, un humoriste de 37 ans. Il faisait des imitations de célébrités, et je lui ai demandé de m'aider à créer une nouvelle voix qui correspondrait à celle que j'avais. »

M. Le Bret s'est immergé dans d'anciens enregistrements audio et vidéo de Pone, comme des clips de vacances en famille au Maroc, et bien sûr, il a regardé des séquences de La Fonky Family. Pour Le Bret, c'est devenu « le plus beau défi de ma vie » (NY Times, en ligne). Les enregistrements de hip-hop de Pone relayaient un lourd accent du sud. C'est cet accent, son individualité, que Le Bret a cherché à imiter du mieux qu'il pouvait, s'imprégnant de sa personnalité, de son dynamisme et de son élan. Il a produit environ 250 phrases types qui ont permis à un logiciel de traitement vocal numérique d'apprendre les nuances vocales

caractéristiques de Pone. Ainsi, Pone est passé à une voix générée numériquement, activée via son ordinateur en utilisant la technologie de suivi oculaire. Comme le remarque Pone, « Maintenant, je pouvais utiliser ma 'véritable' voix à nouveau » (Konbini, 2021).

Une réflexion sur le handicap

Pone était intrigué à l'idée de contribuer au présent volume, qui se propose d'explorer la musique d'artistes handicapés et les façons d'être et de créer en musique. Nos discussions ont abordé ses rencontres expérientielles avec le handicap. Pone a clairement expliqué que, malgré les généralisations sociétales et les comportements stéréotypés envers les personnes handicapées, chaque situation est en réalité unique, idiosyncratique et vécue de manière personnelle. Il dit :

> « Tout d'abord, je voudrais distinguer deux choses : le handicap de naissance et, le handicap subi suite à un accident ou à une maladie. J'appartiens à la seconde catégorie. Je ne suis pas en mesure de parler du handicap de naissance, mais quand on perd des facultés qui nous semblaient "normales", inévitablement, on les regrette.
>
> Quand je suis tombé malade et que j'ai progressivement perdu mes capacités physiques, je composais depuis plus de 25 ans. Au début de la maladie, je ne pensais pas qu'il était encore possible de faire de la musique. Quand j'ai réalisé que je pouvais encore produire, ce fut une révolution.

Mes yeux sont une souris

Quand Pone parle, un capteur infrarouge suit ses yeux qui se déplacent sur l'écran de son clavier d'ordinateur. Cela lui permet d'écrire un texte qui est ensuite lu par l'ordinateur. Ce processus demande de la concentration et prend du temps. Nous discutons de sa vie, de sa famille et de sa musique, les minutes passent, nous attendons avec impatience pendant que Pone écrit au milieu du bruit du respirateur qui le maintient en vie.

Pour Pone, la famille est le socle qui le maintient en vie. Ses parents viennent lui rendre visite chez lui, à Gaillac, au nord de Toulouse. Dans sa chambre, des photos de famille et des disques d'or ornent les murs. Il se souvient du moment où sa famille s'est réunie autour de son lit pour entendre sa nouvelle voix pour la première fois. Un moment intense et doux-amer. Il sait que sa vie est probablement raccourcie, mais sa famille lui donne l'envie de continuer ; ce qu'il fait à travers sa musique. Pone explique : « J'ai un ordinateur équipé de suivi oculaire.

C'est une bande infrarouge qui capture le mouvement de mes pupilles et le logiciel les transforme en données. Mes yeux sont une souris. »

Pone ne peut pas enchaîner les heures de travail sur toute une journée, à improviser ou à adapter des échantillons. Il doit travailler par intermittence, se concentrant intensément quelques heures, puis se détendant et récupérant, laissant affluer les idées musicales, avant de reprendre.

> « J'utilise le logiciel de suivi oculaire et le programme (midi) Ableton. Je compose et crée ici, depuis mon lit. Je le fais avec mes yeux, ils me permettent de mettre mon âme dans ma musique. »

Pone a créé plusieurs albums, solo et en collaboration avec d'autres artistes. Son album de 2019 inspiré par Kate Bush, *Kate and Me*, incorpore le son de son appareil respiratoire, son environnement étant un terrain fertile de créativité et d'idées (Pone, 2019).

> « Je ne reste pas enfermé dans les formules qui ont rendu mon travail précédent célèbre. Je crois qu'il faut expérimenter, toujours regarder vers l'avenir, et, d'un point de vue plus personnel, explorer les qualités des atmosphères acoustiques avec mon équipement et mon imagination musicale. »

Pone souligne que :

> « Cet album *Kate and Me*, est le premier album à avoir été composé, produit et mixé uniquement avec les yeux. Le fruit d'un long processus, dont je suis fier. »

> « Quand on a un handicap majeur, il faut avoir des projets, c'est vital. La musique est un projet merveilleux. Elle rassemble les gens, on n'arrête jamais d'apprendre, et avec un peu de patience, on obtient des résultats qui sont bons pour le moral. »

Aux sources de l'inspiration : la musique et l'être intérieur

La philosophie de Pone est façonnée par son éducation, ses expériences musicales et ses amitiés. Cela révèle une refonte continuelle de soi, une reinvention perpetuelle de la recherche d'une place et d'un espace, pour permettre à ses inspirations de prendre leur envol. Il s'agit d'un défi, exacerbé par la condition de Pone, et c'est grâce à une curiosité et une créativité insatiables qu'il lui a été possible de surmonter l'adversité. Nous concluons avec les réflexions de Pone à ce sujet :

« Grâce à la technologie, en particulier le suivi oculaire, nous pouvons avoir accès à l'informatique. Cela accroît mes connaissances et renforce mon fonctionnement adaptatif dans des domaines tels que la composition musicale, l'utilisation des logiciels, l'échantillonnage, entre autres, ce qui est très utile dans les cas de handicap physique sévère. Nous pouvons nous épanouir, trouver une place dans la société et nous sentir à nouveau utiles.

La musique, comme la vie, continue d'être une aventure pour moi. Je vois cette maladie comme l'un des voyages de la vie. Même si je ne souhaiterais cela à personne, il s'agit de vivre « ses circonstances ». J'ai encore les choses les plus importantes dont j'ai besoin : ma tête et mon cœur, ma famille, et maintenant une ceinture noire en patience. »

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8.Conduit Bodies: Embodiments and Dialogues in performative disability

Melinda Smith, Alon Ilsar, Anthea Skinner, Leon de Bruin

Introduction

Disability is a permanent and pervasive aspect of humanity. Attitudes towards disability and those with disability vary widely, and respond to prevailing medical, social, and cultural attitudes that limit/delimit concepts of both who is considered disabled and what people with disability are capable of. Similarly, the lived experience of disability evolves in time and space, both for the individual and for society as a whole. By considering this critical perspective, the exploration of the lived experience of people with disability provides the possibility to transform everyone's thinking and understanding. This involves an empathic openness to positionality, that considers the various intersectionalities at play and approaches one can take to elucidate meaning and experience.

For many able people, the concept of what it means to live with disability is something they only understand superficially, with attitudes often coloured by "deeply ingrained stereotypes about vulnerability, incapacity and/or weakness" (Bollier et al, 2021, p. 4). This becomes further problematized when we consider that many disabilities remain unseen, causing people with such disabilities to constantly navigate a pathway between disclosure and 'passing' as non-disabled (Sapir & Banai, 2023). Matera et al. (2021) suggest there is limited perspective taking when considering disabled lived experience, though this may be enhanced when engaged in the presence and knowledge sharing of a disabled person.

The exploration of the performative and the personal for those with a disability is not new, with Garland-Thomson asserting such work can challenge the "social relationships in which one group is legitimated by possessing valued physical characteristics, maintain(ing) its ascendancy and its self- identity" (1997, p. 7). Much work in the field of critical disability studies attend to how discrepancies between actual bodies and expected bodies are characterized and defined within particular contexts. The four authors of this chapter come together passionately exploring significant constructs of normative preconceptions within the field of music. We provide a lens of inquiry that provides new perspectives to disabled performativity as a perpetually creative act; a cognitive flow in this case between performer and inventor.

Musicians, dancers and artists use their bodies as sources of cultural identity, as transmissive, physical and intelligent presences that play, move, and perform through and with social meanings (Albright, 2000). Musicians utilize skill, knowledge, and intellect learned and trained through being and becoming (Southcott & de Bruin, 2023). Performance allows us to

show our human bodies as we reach out to the world, expressing our strength, exuberance, vulnerabilities, and emotion. Artistic expression can be moving, exhilarating, but also dangerous and challenging (Yoo, 2021), and through reflection and performance can become a form of self-making in response to historical and personal circumstances (Bruner, 1996).

For artists with disability exploring this socio-cultural relationship with the body in a public sphere often involves taking aspects of ourselves that we have been taught were weak or ugly and embracing their inherent strength and beauty, turning audience's low expectations of us on their heads. Indeed, many performers, including Bob Flanagan, Ian Dury, John Lydon (Johnny Rotten), Ian Curtis and Macy Gray, have built their stage personas around the transgressive image of their disabled bodies or brains (Skinner & Kapuscinski-Evans, 2021). It can even be argued that the entire punk aesthetic, is based on celebrating the non-normative body (McKay, 2009).

Whether artists are disabled or not, collaborative artistic projects involve processes of negotiation, as each member finds ways to express and meld their ideas with those of their co-creators. We are capable of framing our active minds, of expressing the human condition and its myriad complexities, and in doing so expressing our individual and collaborative identities. When collaborators come from diverse disciplines or have widely differing life experiences, this process of collaboration can present epiphanies of creation and exploration. Risks may be greater, but so too are the potential rewards. This chapter takes a post-qualitative approach to discussing the creative collaboration involving a disabled performer and a non-disabled inventor. It involves the creation of a gestural controller, the AirSticks 2.0, by Alon, and his performative collaboration with a performer, Melinda. Recollections of the collaborative and creative process are investigated through the growing connection and complexity developed between the pair.

Evolving practices are identified through the situatedness or each practitioners' lens of operation and communicative dimensions cultivated in place and space, in which the concept of crip time is explored. Interactive and relational dynamics forefront time theory within cripped spaces, places and experiences that includes team entrainment (Kelly & Barsade, 2001), positive performance feedback (Ilies & Judge, 2005) and the relational and empathic qualities agents enact in influencing a state of engagement (Podsakoff et al., 2006). These qualities can extend to shared music and arts performance in the sensating of flow states, empathic understanding, and our capacity to disconnect with both our self-conscious selves and time (Csikszentmihalyi,

2015). This also takes into consideration musical inventions as cultural probes that stimulate reflections on the relationship between humans and technology (Gaver et al., 1999).

Musicians can bring about unique and idiosyncratic characteristics of an instrument (De Souza, 2017; de Bruin, 2018a), how instruments can alter our mode of being, and our evolving relationship with our instrument as a probe into musical possibilities (Tahıroğlu et al., 2020). We draw recollections of creative incidents in this collaborative project as a means of exploring the emergence of critical posthumanities as "a supra-disciplinary, rhizomatic field of contemporary knowledge production" (Braidotti, 2019, p. 52). We do so by sharing achievements, tensions, fears and joys in the maelstrom of the creative process between inventor and musical creator, and the synergistic alignments prevalent in such a dynamic. We share our significant experiences, immersions, and life stories that affect us personally and professionally. From a post-qualitative perspective, the ways of knowing and representing are called into question in order to open up spaces for reflection, challenging the very concepts through which we perceive reality and that constitute us as researchers. (Lather & St Pierre, 2013).

Voices and experiences

Post qualitative inquiry, like autoethnography, can allow scholars to utilize their own experiences to interrogate power structures and provide a platform for "voices and experiences that are frequently erased" (Caivano & Naumes, 2002, pp. 11-12). It "combines autobiography and ethnography to systematically describe and analyse personal experiences and observations" (McMillan & Morreale, 2023). Autoethnography is regularly used in disability music research to allow the voices of disabled participants to be heard alongside those of their non-disabled collaborators.

A post qualitative approach can provide insights to practice-led research, uncovering the ways in which "personal lives and cultural experiences intertwine in the creation and interpretation of musical works" (Bartleet & Ellis 2009, p. 7). This involves sensitively exploring the interconnectedness between creative lives and the relationships crafted between them. We intertwine the experiences and recollections of two performers interrogating their own performance practices, while also exploring their practice-based interconnectedness. This brings forth the creative voices; co-authors Melinda Smith, a dancer and a disabled person who speaks through an assisted audio controller device (AAC), and Alon Ilsar, an inventor absorbed in his inventive domain and muse. Co-authors Leon de Bruin and Anthea Skinner are collaborators

facilitating these voices as we gather an “assemblage of ruminations on the nature of the self” within this dyadic relationship (de Freitas & Patton, 2009, p. 486)

We as co-researchers embrace the entanglements of self (the auto of autoethnography) as subject, as subjective viewer and reviewer and as post-qualitative collaborators negotiate these entangled relations as they become reconfigured (Barad, 2007). This stance brings forth parallels and difference, it “nurses bubbling curiosities and yearnings which it aspires to explore and negotiate” (Singh et al., 2021, p. 2).

Through vignettes, certain beliefs, assumptions, and personal experiences of musician and inventor are explored. Maintaining a performative essence, personal reflection and reaction is engaged within a discursive practice. Through self-reflection this investigation focuses upon an “analytic attention to an array of material-discursive forces through which bodies realise their capacities to act, connect, move” (Fullagar & Taylor, 2021, p. 38). We hope to find within these thick and layered experiences, understandings of the developing creative practice, collaborative communion and evolving artistic practices that make redundant prevailing tropes concerning disability.

A post-qualitative research position is always multifaceted and woven from theoretical diversity. We problematize certain hegemonic foundations of research; the unknown, and openness as a condition and form of knowledge. Gathering our understanding through experiential encounters and reflection realises our questioning as “rhisomally moving in ever-changing directions, interpreted and narrated as an entanglement” of dynamics, relationships and movements that also relocate and displace researchers. (Deleuze & Guattari, 2004, p. 16). We aim to open spaces that are creative and divergent, incorporate the liminal, the bodily and the sensory features that arts-based research can afford. We recognize new sensory ways to connect with the world and accept the role of the body as open to other forms of knowledge and perception (Leys, 2011).

We introduce the two artists Melinda and Alon, and their evolving reflections on thoughts and practices recounted on their working relationship. Through creative decisions made in crafting the 50-minute duet, *Conduit Bodies*, we further examine artistic agency, and communicative intra-action. In doing so we write of the body as a cultural text, as personally political statements evidencing an epistemic/aesthetic praxis based in performative writing. These stories involve the tenseness of negotiation, the push and pull between the aesthetic and the epistemic that creates the evidence of performative post qualitative ethnography.

Performative identities

Melinda Smith: I am a dancer with disability, I don't walk, and talk quite slowly, my movements and speech are affected by cerebral palsy, and I'm also hard-of-hearing. I usually rely on Augmentative and Alternative Communication (AAC), which combines electronic communication devices with speech, sound effects, sign language and gesture. I began my professional dance career in my 40s, as there was no accessibility to dance education for me in my childhood. Expressing myself is important to me, it's something I feel comfortable doing. I enjoy dance, visual art, and as someone fascinated by gravity and motion and I have for a long time wanted to create music. I tried drumming but became frustrated by the inability to match the sounds I heard in my head.

Alon Ilsar: I had a drum kit at home, I met a guitarist at school, and we jammed and got some gigs. I watched some great improvising drummers and wanted to study so I did an Arts degree and played in bands- I played in Circus Monoxide- playing, touring, bouncing off jugglers and acrobats, creating together in a dynamic theatrical environment. I was also drawn to electronica but was frustrated by not being able to make the sounds I was hearing from formative bands. I found solutions by adapting a virtual reality gaming controller as an apparatus that could be manipulated to create electronic music. Anthea introduced me to Melinda during COVID via zoom, as she was interested in experimenting with a musical instrument she could utilize through movement.

The first performance

After initially meeting online, the team organized workshop sessions that allowed the calibration of the AirSticks to Melinda's unique needs and movements.

Melinda:

Music has always been a part of my world. It never felt like I became a musician- my body has constantly engulfed rhythms and beats, even without physical instruments. I dreamed about holding guitars or running my fingers across a keyboard- there were those moments of envy but I took it as part of my life. The AirSticks made things possible and exciting for me to be part of the physical music world. They have given me the potential to push my imagination and creativity. I remember the first experience with the AirSticks- mindblowing! The possibilities were oozing out

of me. Making music and collaborating alongside another receptive musician has been one of the coolest and amazing things I have done. It's awakened a part of me I thought I couldn't have.

Alon recalls Melinda's first performance using the AirSticks:
It was at Dance House. She started in the audience, in her wheelchair. The piece involved moving out of the audience, out of the wheelchair, and onto her walker, moving and dancing with the walker, back to the wheelchair and then returning to the audience. A simple but profound performance. It incorporated recorded found sounds, poetry and her musical creative layering of sounds within that. I was mesmerized by the performance and the experience. Mel's performance had a duality - it proposed the question to the audience as well as opening up lines of flight of what is possible by Mel physically, but also musically, artistically and experientially. It provoked questions to what was possible with the AirSticks. The audience were confronted by Mel's movements, but also the rationalisation of where and how the sound was emerging from movement. For everyone in the room there was this sense of creativity, movement, and possibility.

Artistic collaboration and refinement

Reflecting on this first play on the AirSticks, Melinda established three performative decisions that were built upon in future sessions. She explained that:

- for the first her in her life, her spasms, which she would usually attempt to 'control' and 'hide', became intrinsic facets of the musical tone, shape and phrasings that she would converse with.
- she would prefer to not have to grip an object like a thin drumstick as this takes up a lot of her focus but would instead prefer to wear the device.
- performing music with other people was a huge motivator in developing the project.

In the next session together, Melinda explored a virtual cello, using a 'bowing' style action to create sustained sounds. She did not feel at ease, this mode detracting from the more natural dance movements. Aside from being a dancer, Melinda is also a poet and had written a poem about her relationship with her spasms that she had typed into her electronic communication device, recording its electronic voice. Alon and Melinda's collaboration with the AirSticks allowed her to trigger lines from the recording around her like plucking strings on a harp. As she played with this, Melinda would react to her text, adjusting, pausing and refining phrases that were synched to a rhythm that threaded pulse, texture and groove with the text.

Melinda: A few days after that first performance we met together and experimented with the device. Alon gave me a drumstick with an AirStick strapped to it and I began improvising. Any movement that had enough 'energy' to it would trigger a note, with the threshold being adjustable in the AirStick's software. The more energy the louder the note. Different pitched notes were positioned all 'around' me, with high notes above and low notes below. I twisted my wrist, and I could bend the pitch slightly. A simple pentatonic scale was chosen over eight octaves, and a tempo was set. A second AirStick was given to me, this one triggering a more percussive sound. Controlling both AirSticks simultaneously in each hand was a little overwhelming. Alon used the second AirStick and we created a duo, mirroring, reacting to each other's gestures and sounds. I came to the quick realization that my arm spasms could be incorporated as a performative and sonic element. I recall being overjoyed, creatively in the moment, from this adaptive epiphany.

Alon: My main instrument is the drum kit, and like many instrumentalists I have an emotional affection towards it. I've always loved the four-limb approach one can take with the instrument; I feel like I 'dance' to play it properly. This transparent connection between movement and sound requires me to explore timbre through hitting, caressing, rubbing, kicking and stroking different surfaces with different held objects. My interest in sounds is from finding a 'voice' and a personal narrative, telling a story. I found a fascinating synergy and connection in seeing Melinda deeply improvise with the instrument and her body in the moment, responding to the musical gestures created. This was a revelation of sympatico of experience between Mel and I.

Melinda and Alon continued to collaborate, learning to communicate successfully, both by embracing the realities and complexities of communicating with AAC, and in finding a shared artistic vocabulary. Phalen's reflections on the importance of acknowledging the discomfort when collaborators first meet (2015, p. 789) was particularly relevant in this collaboration, as both performers had to repeatedly ask each other to repeat or explain themselves in order to be fully understood. Numerous false starts, misunderstandings, and miscommunications occurred initially. Frustrations were felt. Both performers opened themselves up to each other, taking performative risks and learning from initial assumptions, resolving seemingly perplexing issues and clarifying questions to move forward together.

Over time the duo developed shared communication skills, empathic understanding and an inclusive rehearsal and performance pedagogy, centred around their strong improvisation backgrounds in their respective fields. Improvisation between the two developed as a schema of skills and knowledge production used to construct musical responses and conversations (de Bruin, 2018b) and as such was an integral part of the performative communication. Understanding moved from dialogic to sonic exploration, building a psychological and emotional connection. A mutual background in improvisation meant that they not only had well-developed communication skills as performers, but also understood that collaboration involved the idea of working to create a shared performance language. For Alon this was an intrinsic part of his musical being, for Mel, a sensation borrowed from everyday life and brought into the musical sphere:

Alon: As a drummer I have a reflex to listen, to interact and develop ideas. This is the basis of communication and the basis of a shared language.

Melinda: I collaborate every day, often in mundane ways with carers or co-workers. But to relationally, emotionally and musically collaborate was something borrowed- skills well developed but that found new flight through music making.

Communication, empathy and intra-action are human traits developed over time that can be adaptive to musical engagement (Wegerif, 2013). Phalen suggests 'such a sensation may not necessarily give rise to identical experiences, but rather joint experiences that have become associated with a particular feeling' (2015, p. 792).

Melinda reflects on *her* experience:

Melinda: Alon encouraged me to listen to various sounds that could be activated by my movement and this motivated me to explore deeper layers. I was able to concentrate on my creativity rather than the instrument itself. My body becomes the instrument, and the instrument an extension of myself. I verbalized ideas; I used the AAC less often. I slowed down the pace of my talking, chose my words. We listened to each other more deeply and intently on taking each other's ideas on board. This led to deeper conversations and understandings of each other's creative desires, which in turn led to a more natural creative flow and flair between us.

Sharing and reflecting

Investigating dis/abled creative processes allows a critique of the epistemological (modes of thought) and the ontological (practices enabled by modes of thought). It promotes the identifying and questioning of the taken-for-granted assumptions in which, "one can no longer think things

as one formerly thought them, [and] transformation becomes both very urgent, very difficult and quite possible" (Foucault, 1988, p. 155).

As dialogic interlocutor between Melinda (disabled performer) and Alon (non-disabled inventor), we- Leon (non-disabled researcher) and Anthea (disabled researcher) maintain truth, authenticity and emergence of feelings as we apply an interpretivist and analytical aspect to the dialogic connectivity between these memories and self-analysis by the artists. We do this with care, passion and empathy, but also to disrupt the disciplinary, exclusionary canons by including the knowledge of the disabled and creatively dispossessed, making public the knowledge of creative practices and possibilities imbued upon creative action and receptivity in this setting.

Crip time

Musicians regularly consider playing in time, playing with time, strict time, becoming faster, slower, to be in free time. We are attuned to allying a curious and creative sense to what time can mean to us. The concept of time has emerged as a significant facet of critical disability studies. Garland-Thomson (1997) refers to what she refers to as the difference between her time and normate time. This sense of personal time-space is not set, but personal and idiosyncratic. Price (2009, np) suggests this involves a "flexible approach to normative time frames", whilst Kafer asserts that "rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (Kafer, 2013, p. 27).

Barad (2007) refers to an agental realism in which the experiential is personalized, enacted and embedded within ones' own time-space continuum. To understand this, Barad draws on Bohr's (1987) suggestion of a person using a stick to navigate a dark room. How one uses the stick as the apparatus of engagement harbors an agental cut, a moment where exteriorities within emerge into the world:

> The stick cannot usefully serve as an instrument of observation if one is intent on observing it. The line between subject and object is not fixed, but once a cut is made (i.e., a particular practice is being enacted), the identification is not arbitrary but in fact materially specified and determined. (Barad, 2007, pp. 154-155)

Exploring each other's human experiences, actions, and cuts across chosen exteriorities allows Mel and Alon to craft their own collaborative invention, improvisation and adaptation. Crip time reflects this personal-cultural action amidst a multiplicity of cultural, historical, and social materialities that we each inhabit as disabled and non-disabled collaborators.

Melinda: My everyday life is so controlled by time. The AirSticks are freeing in a way I never expected. It pushes my imagination to new places. When making music, I go into a zone and time just disappears. The AirSticks give me the opportunity to work at my own pace, my mind and body are in another place. The frustrating part is not being able to set them up myself- there is a grounding in the mundanity of the everyday, but music especially opens a freedom that takes hold and takes me to places I never imagined. My time can take hours what may seem like minutes. I can use time exploration in many ways, for me it's another musical asset. Music making can be open-ended in its creation and I can share my flights of imagination with Alon.

Alon: Mel is an incredibly generous and exploratory musician. She might throw ideas about sounds, but once she has a 'mental mapping' she simply plays and plays and plays with it until there's a natural control of creating. I watch and gain a deep satisfaction watching Mel converse with the sound created and the time-sense explored.

Crip time is a form of time travel, it is a creative act of body and mind that for Melinda allows the exploration and engagement in new rhythms, structures, patterns of thinking, feeling and moving. Crip time is adjusting speech, technologies, breaking language and structures to new shapes of uttering and listening. Crip time is devising communication systems, gestures, motifs, shared creative esperanto that can nuance the temporal shifting in collaboration and intra-action.

Communicative intra-action.

Melinda and Alon cultivated a shared performance practice built upon shared understandings, creative freedom, experimentation and respect. The AirSticks were in one sense 'mapped' to respond to Smith's ways of moving. Smith also mapped herself to the apparatus as a physically generated sound creation device. In their study of musical instrument design for people with disability, McMillan and Morreale (2023) found that designers' views on the success or otherwise of their own instruments are often a function of their own pre-determined goals and their assumptions of the needs of a prototypical user. Melinda and Alon adapted the sensitivities and refinements together to best align Melinda's movements, sounds and musical decisions, with Alon shunning initial generic ideas and embracing a bespoke utilization for Melinda as a dancer/musician.

Melinda and Alon worked to create an embodied dialogue both between themselves as performers and between themselves and the instrument. Verbal and gestural communication enhanced this as they worked to develop a dialogue between their bodies and the AirSticks. Melinda suggests that artistic collaboration has always been a process of embodied dialogue, noting that:

…now our conversations are not just language, they are a mix of body language, sound, voice, poetic writing, drawings. When you think about it, we probably use less words than anything else in our conversations.

This involved an intimacy of the musician-instrument relationship in which communication occurs through the instrument as an extension of the body (McMillan & Morreale 2023). For Smith however, creating an embodied dialogue with the technologies responding to her body goes well beyond her performance practice and is an inherent part of everyday life. Negotiating, and even collaborating with technology has, of necessity, always been a part of Smith's life practice via wheelchairs, speaking devices and hearing aids, as well as performance practice. In that sense, the AirSticks are merely the next in a long line of assistive devices (Boswell et al 2023, p. 517).

Conduit Bodies

Melinda next wanted to create a duo work where both she and Alon performed on stage. This autobiographical performance which came to be known as Conduit Bodies involved episodes including a 'duo' with one of her wheelchairs (which she affectionately calls Xena) acting as the other dancer. It improvised movement and music creating, involving choreography with many of Melinda's everyday technologies, – a wheelchairs, typewriters, laptops, AACs, guitars, drums and the AirSticks. Conduit Bodies explored possibility and impossibility.

Melinda describes this suite:

As a composer I referred to my experiences and life events to create musical scenes and textures. 'The Schoolyard' references my dealing with bullying and discrimination. It incorporates white noise, the more I moved, the less intense the sound and visuals. A direct metaphorical analogy of how I felt and reacted, stillness yielding silence. 'The Typewriter' is an artifact of inspiration, my way of communicating dialogue and poetry. This composition required me to delve into past experiences, remembrances, to use time as an exploratory strategy that allowed memories to bubble forth and negotiate the sounds I wanted.

That process gave me accessibility to thoughts and creative actions, and I created these sounds extending from my mouth, face, body and the space around me. My relationship with musical instruments is bitter-sweet; I love music and have a dedication to music making but also a frustration of not being able to bring forth the sounds that I hear in my mind. 'The Guitar Lesson' captures my confrontation with playing guitar- but the AirSticks allow a virtuosic 'air guitar' moment. 'The Nullarbor' captures an event in my life, where I was able to unlock my legs after years of them being stiff straight. 'The Sound of My Voice' recalls my own voice reciting poetry recorded on a tape cassette for the first time when I was 9. Hearing my own voice during rehearsals and performances brought me much joy but also revelation. I could never comprehend why people found it so hard to understand what I was saying. But when I heard the recording, I realised I could not understand myself. I was shocked! - it was a strange realization, but one that helped me develop speech patterns that were more understandable. 'The Invitation' is a duo between Alon and myself. It's an exchange of musical ideas, a beckoning for me to rise from my wheelchair using the AirSticks, but reciprocally an invitation to Alon to stand up from the drum kit and share the performance space. We give a freedom of expression to each other- that's what is so brilliant about this project.

Alon suggests that:
I'm very much in my element throughout these scenes. Hidden in the background, sitting behind a drum kit, complimenting with movement with electronic sounds guitar and embodied drumming. As a co-performer I'm interacting and improvising with Mel- she wants to collaborate and has a desire to get away from prevailing conceptions of the disabled artist working only as a soloist. Our performances provide new insights into each other's capacities and capabilities. Mel not only wants to use the AirSticks but she wants to know how they work, as an artist gaining a deep sense of the malleability of the medium. We took the time- we both sensed what we needed, what we found to question, and discuss in our own way. We have changed, found a common ground of deliberation, actions and reflection. As collaborators we appreciate each other's ideas and how we push each other into new creative spaces.

This musical exploration between Melinda and Alon reconfigured possibilities of communication and musical performance. Reimagining is experienced not just by the performers, but also by the way it grasps the audiences' belief systems and expectations and

blurs what is actually possible with their preconceptions of disabled musicmaking. Melinda's immersion with the AirSticks was deeply creative and carefully crafted. Her practice demonstrates dynamic interactions between brain and body, the physical, emotional and the social environment.

The collaboration between Melinda and Alon highlights intriguing ways in which creativities emerge, and that whilst normative approaches may consider creative possibility limited within a disabled body, the opposite is true. This approach helps us better understand creativity not only in terms of products and outcomes, nor the phenomenon that is confined to the inner mental domain of an agent, but rather as an essential aspect of how individuals and groups bring forth worlds of meaning through embodied and shared processes of dynamic interactivity. This enforces significant possibilities of creative interaction between disabled and non-disabled performance and the meaning making and exploring that such intra-active participation can show. The collaboration allows for a deep immersion into the performance relationship as well as the exploration of the apparatus. For Melinda this is deeply meditative; immersive, collaborative, explorative of artistic possibility. Alon's AirSticks 2.0 and Mel's exploration, experimentation and refinement of expression and compositional ideas allowed both performers to shine.

In many artistic collaborations, the use of advanced technology is seen as potentially dehumanizing, as turning people into machines. This project, as in many performances featuring artists with disability, turns this idea on its head. By supporting speech, movement, listening and music-making, the technologies that Melinda utilises both in performance and in day-to-day life facilitate inter-human interactions, making us all more human, not less. Musical explorations of this kind challenge the historicity of preconception and highlight the unnatural nature of what exists.

Rorty (1986) suggests that "if we once took seriously the notion that we only know the world and ourselves under a description" (p. 48), we might choose to rewrite that description and re-describe the world and how we see ourselves in it. Arts collaborations of this kind give us all agency to do-see-be-live differently. Critique does not begin with the assumption that what exists is wrong or in error; rather, critique interrogates our assumptions that structure the discursive and nondiscursive, the linguistic and the material, the embodied and enacted, words and things, the epistemological and ontological. Challenging our presuppositions, to "refuse what we are"

(Foucault, 1982, p. 216) and what we have been led to believe provides an essence of freedom, and a vibrant fusion of horizons of what might be (Gadamer, 1975).

Conclusionary thoughts

Music can take us to events, spaces and places that mark significant moments in time. In the phenomenology of our lived experiences, we can lose our sense of time both as listener and as a performer (Schultz, 1976). Music ebbs within us, engages and involves our minds in ways we cannot stop or control. It can take over our bodies, control our movements, inform our actions and mark our situatedness of being amongst music. Rather than music being sound organized in time, time organized through sound extenuates the temporalities of what can be confining or determined understandings. In examining musical exploration, co-collaboration through the experience of this project, of non-disabled inventor and disabled performance artist brings to question the normative conceptions of time. Deleuze's (2004) conception of becoming, plateaus and lines of flight render an intimation of time and prescient conceptions of nonlinearity.

We argue not another 'othered' approach to the clock, or for accommodations for crippled-being, but instead for how people - disabled people and those that work in their sphere - experience time differently. Time comes imaginatively, creatively, exploratively, it can be a space of deep intimacy and meditation. Time is presence and an attitude to it. For some it may be a quiet revolution extending normative ideas of crip time. For others like Sheppard (2020) it may be "a failure to move from past to present to future in a straight line or at the required pace; a failure to progress from dependences to normatively defined independence" (p. 40). Concerning theoretical conceptions of time, such variations of temporal immensity highlight the sense-making notions of temporality and time as is related to our experiential understandings of reality. For those entering this realm, disabled or not, there exists a re-sensing that embraces the multiplicious, the contradictory and lived-in experiential fluidity of the now.

There is a phenomenological sensibility to crip time in that lived experience dictates the meaning making of immersion. This challenges us to move beyond popular theoretical practices in crip theory of 'slowing down' to grapple with what we deem as critical performative spaces in which time no longer organizes being, experience or haecceity. Understandings of these kinds and the interrogation of cripped art extends knowingness of cripped being and cripped possibilities. It extends how disability makes art in the world, rather than the world making disability, reframing ways of being in the world (Straus, 2011). We hope further examinations of

musical/artistic practice in, with, and between disabled artists and inventors can further question conventional temporal and normative assumptions by imagining new critical and lived mindbody possibilities of meaning outside of current disability reality and existence constructs.

Note

The work *Conduit Bodies* was performed in its first iteration at te Victorian College of the Arts Dance Theatre in February 2023. A second performance season of *Conduit Bodies* occurred October 2024 at the Arts House, North Melbourne Town Hall as part of Alter State.

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9.Composing and Performing Disability

Alex Lubet

A Personal Note

In Summer 2020, at the height of the COVID pandemic, I had right rotator cuff surgery. I had serious pain and limited mobility for months. Access to medical care was slowed. While my physical limitations might not have reached a level widely be regarded as disability, as a professional multi-instrumentalist and composer, any impaired facility had significant implications for my art. My surgeon anticipated a less than full recovery of the use of my arm, while expressing confidence that I would be able to play my instruments.

Any limitations would be cause for concern in my field. My rehabilitation took a year. In its initial stage, I had little use of my right arm and could not perform on my plucked string instruments in a conventional manner. This was an existential concern. This experience, the injury, and the musical composition that resulted from a serious (though ultimately temporary) impairment is the impetus for this essay.

I am principally a composer-performer who performs his own music. Were I principally/exclusively a composer – common in "Western classical music" – the inability to use my arm would present little/no problem. This has been especially so since the advent of music technologies that include playback of (conventionally) notated scores. These largely supplant older means of hearing one's compositions-in-progress, playing them on an instrument or simply imagining. In addition to hearing simulations of one's works for voices and instruments, music

technologies have long been used to generate/transform myriad sounds and create music in a wide variety of idioms across cultures.

I postpone discussing this episode in my career until the end of this essay, as it belongs in the category of the most radical and experimental forms of disability musicking. We will proceed toward that conclusion, with an agenda as follows:

- **Technology and Disability Accommodation**
- **Disability Musicking/People with Disabilities Making Music**
- **Disability Performance: Jazz, Blues, and Rock**
    - Django Reinhardt
    - Horace Parlan
    - Oscar Peterson
    - Cedell Davis
    - Others/Rock: Rick Allen, Bill Clements
- **Disability in Western Classical Composition**
- **New styles**
- **New idioms**
    - Alex Lubet: *On the Seventh Hour*
    - Pauline Oliveros et al: AUMI (Adaptive Use Musical Instrument)
- **Conclusion**

Technology and Disability Accommodation

Electronic/digital media as tools for musical creativity specifically for artists whose physical disabilities render instrumental/vocal real time performance impossible has been

employed for decades. An early example is the studio of the Vancouver Adapted Music Society, whose equipment includes “a range of innovative breath-operated musical equipment that allows people with high-level disabilities to sample the magic” (Vancouver Adapted Music Society, 2024). Another example is the Smirnoff Mindtunes project enabled a quartet of quadriplegic musicians to create a work of Electronic Dance Music using technology that enabled them to translate brain waves into sound. While the potential of this technology is great (within and beyond music), this project was, unfortunately a one-off (DJ Fresh & Mindtunes, 2014).

The most widely disseminated technology for disabled musicking is likely the Adaptive Use Musical Instrument or AUMI (The AUMI Editorial Collective, 2024). The brainchild of composer-performer Pauline Oliveros and occupational therapist/drummer Leaf Miller (The AUMI Editorial Collective, 2024), AUMI is an ongoing project involving numerous collaborators (including, in a tiny role, this author). AUMI can be played with any kind of movement, even the eyes, and is thus apt for musicians with any level of physical impairment. By virtue of its radical adaptability, AUMI has made a singular contribution to disability musicking that will be revisited in depth at the conclusion of this essay.

Disability Musicking/People with Disabilities Making Music

I have held that making music is a human right, regardless of impairment (or any element of identity) since my/the first publication in the field of disability studies and music (Lubet, 2002). My interest here, though, is more specific. While countless disabled people make/have made music across the full range of impairments, whether the nature of the music made has been a result of the nature of their impairments is a matter yet to be thoroughly interrogated. It is of great interest because it may reveal that (people with) disabilities are responsible for innovative, even unique contributions to music.

While this subject became a matter of interest to me because of my own impairment, its examination revealed other, more significant examples. It is thus important also to consider when music made by an artist with an impairment does not differ from music made by more typically abled artists. This is not intended to be judgmental. Transcending the limitations that might be imposed owing to an impairment – or exposing the lack of limitations owing to said impairment – are both of value. Of notable importance is the contribution of violinist Itzhak Perlman. One of the greatest living performers on his instrument, his polio has clearly had no impact on his playing. However, disability access and accommodation have always been concerns for Perlman and he has long been an important advocate for disability rights (Brain & Body, 2023).

Social confluence

The foundational theme of my *Music, Disability, and Society* (2011) is the theory of "social confluence;" the idea that, in contemporary, technologically advanced societies (and perhaps others), the fundamental unit of identity is not the nation-state, moiety, (extended) family or other group, or even the individual, but the "social confluence;" the character of existence in the moment, place, and situation, which may frequently change as situations shift. I draw from the work of anthropologist Arjun Appudurai (1996), who views "cultures" not as groups, but as performances, things done in time and place. Such performances – a term of special significance for music – are constantly reinventing. I see performance – social confluence -- as the basic unit of identity, at once both cultural and embodied. In earlier research (Lubet, 2011), I examined the social confluence of disability in music. In particular, I argued that disability status within music can differ greatly from disability status in other contexts.

The example of blindness offers valuable perspectives. Few would doubt that blindness imposes challenges to performance of what the (Burgstahler, 2009) with Disabilities Act, "activities of daily living" (U.S. Department of Justice Civil Rights Division, n.d.). These

difficulties are often social constructs, such as the lack of Braille signage in elevators or audio signals at traffic stops. But I would argue, there are, in blindness, limitations to performance that Universal Design and disability accommodations cannot (yet?) address. Even at the conferences of the Society for Disability Studies, there have been presentations by visual artists where sighted individuals not trained in Audio Description were expected to "translate" paintings and sculptures into something their blind friends could comprehend and appreciate. (Even professional Audio Description may be unable to accomplish this.)

Within the social confluences of musics, the disability status of blindness varies greatly across musical praxes, from severely limiting to (almost?) entirely non-disabling. Much of the practice of Western Classical Music utilizes visual notation. In addition, ensemble performance, especially large groups, often demands that performers follow a conductor. Braille music notation cannot be read while simultaneously performing. The exception that proves the rule is the Chamber Orchestra of Al Nour Wal Amal. Based in Cairo and comprised entirely of women, it is the world's only blind orchestra (Al Nour Wal Amal Association. n.d.; Lubet, 2011). While negotiating the logistics of the music profession challenges blind (and otherwise disabled) musicians, it is important to consider what takes place in the moment of performance. At that time, blindness may not be disabling. In musics less dependent/not dependent upon visual notation, blind musicians have excelled, even at times to the point of 'owning' their genre. Elsewhere I have argued that African American performance practices are more accommodating to disability in general and blindness in particular than Western Classical Music, owing to lesser dependence on notation and greater latitudes of performer choice (Lubet, 2011). In jazz, there have been blind artists among the giants (not all Black themselves), including pianists Art Tatum (1954) and (white) George Shearing (1992), and multi-instrumentalist Rahsaan Roland Kirk (1969). In popular music, Ray Charles (1997) and Stevie Wonder (2024) are legends.

The blues is unique in the West in its relationship to blindness (Lubet, forthcoming). Many artists, even some who were sighted, adopted the sobriquet "Blind," which the late neurologist/author Oliver Sacks characterized as "almost an honorific" (also in Irish music) (2008, p. 173). These include Blind Lemon Jefferson (1927), Blind Boy Fuller (1940), and Blind (or Reverend) Gary Davis (1967). Any prestige associated with the title "Blind," did not necessarily (if ever) confer improved working conditions or enhanced quality of life. Elsewhere, in Ukraine (Kononenko, 2015), and Japan (Matisoff 2006; Miles 2000), there were once classes of mendicant blind minstrels, who were protected employment classes by virtue of their disability, unimaginable in the "free market" USA.

Notably, none of the above-mentioned artists (or the many other "Blind" or simply blind blues musicians) in these African American musical idioms performed *musically* in a manner noticeably different from their sighted colleagues. (Stage presence could be another manner, in, for example, the live appearances of Ray Charles and Stevie Wonder.) In addition, blindness has almost never been a topic of blues lyrics, despite the hardships it has surely imposed (Taylor and Barker, 2007). Thus, blindness is not disabling in the social confluence of blues performance. Disability is not responsible for music made differently from that of sighted artists. Surely, this is the case as well in other musical practices in which sight is not a critical factor in performance. However, artists with other impairments, especially those whose limited mobility mandates alternative technical approaches to instruments and voices, have created musically distinctive, even innovative practices. It is the work of and on behalf of such artists – this author included – whom I refer to as "composing and performing disability."

Disability performance

I distinguish between work made by disabled musicians that is apparently no different from that of more typically abled artists and that which results from disability and differs

significantly in its aesthetic. While it may be that future scholars might conceivably discover, for example, stylistic differences between the works of blind and sighted blues and jazz musicians, there is currently no such evidence. It is difficult to imagine, particularly given the extraordinary technique of jazz pianists such as Tatum and Shearing. It could certainly be argued that the blind multi-instrumentalist Rahsaan Roland Kirk had a unique technical and aesthetic approach – playing multiple horns at once, some of them rare variants on the saxophone – but this skill bore no relation to his blindness. I focus on several important jazz musicians with disabilities who excelled.

Django Reinhardt

There have been jazz musicians whose physical impairments have impacted their technical and aesthetic approaches. Most notable is guitarist Django Reinhardt who, owing to an injury in a fire, lost much use of two left-hand fingers. Reinhardt's technique was thus idiosyncratic and inspired distinctive harmonic and melodic ideas, though these are arguably subtle. Benjamin (2003) at once masterfully demonstrates the innovations driven by Reinhardt's disability – relatively minor in the activities of daily living, but potentially devastating for an instrumentalist – and argues that the guitarist transcended those limitations.

Reinhardt surely achieved transcendence in his field. He has influenced many guitarists both within and beyond it; including not only jazz guitarist Wes Montgomery and blues legend BB King, but country singer-songwriter Willie Nelson (Randall, 2018). Within Reinhardt's own genre, Jazz Manouche (or "gypsy jazz" or "Hot Club"), Givan has observed that some guitarists even emulate Reinhardt's disabled technique by playing their melodic solos (both improvised and copies of Reinhardt) with only two fingers (Givan, 2014). There is only one film clip of Reinhardt playing (1945), revealing his left

hand impairment which might assist such others. Further, Givan proposes that the contemporary emulation of Reinhardt's French jazz idiom (strikingly different from the American jazz of its time) is driven by an orthodoxy that is antithetical to a fundamental principle of jazz. Thus, one of the most influential of jazz artists and the first important European exponent of the art form (Givan, 2003), whose disability significantly if subtly informed his style, has been not simply influential on a grand scale but is emulated, even copied to the point of idolatry that could be understood as anti-jazz. Two jazz pianists, Horace Parlan and Oscar Peterson, are notable for their innovative, if quite different, approaches to the instrument. The differences are attributable to their different impairments. Their disability histories are also quite dissimilar.

Horace Parlan

Pianist Horace Parlan was a youthful polio survivor. The disease left him significantly hemiplegic on his right side. His right hand was largely immobile, which limited his playing essentially to two fingers that functioned much like the mallets percussionists use on marimba, vibraphone, or xylophone. Thus, other than slow, lyrical lines, mostly in parallel octaves, Parlan's melodies were mostly played by his virtuosic (fully able) left hand, which also bore most of the responsibility for bass lines and harmony. The relative simplicity and pacing of his right-hand melodies were distinctive, as was its role in accompaniment, above the faster left hand melodies in the middle of the texture (Lubet, 2011, pp. 51-56).

The distinctiveness of Parlan's approach was subtle. He was the subject of my keynote address at the 2010 Guelph Jazz Festival Colloquium (Lubet, 2010). Several members of the audience, largely jazz scholars, told me they had listened to Parlan for many years and had heretofore been unaware of his impairment. That Parlan's limitations went unnoticed by jazz experts owed largely to his musical vocabulary. Apart from the unusual textures mandated by his disability, it fit into the wide stylistic mainstream of his times. His slower-than-typical right hand

yielded a lyricism distinctly his own. This was obviously possible for fully able players as well, but might not have occurred to them in the context of their technical facility.

What was arguably most remarkable about Parlan, though, was less the subtle differences in his playing than the company he kept; his acceptance into the ensembles of major figures in jazz, among them Charles Mingus and Archie Shepp, who chose him over his competition with fully abled hands, because of his creativity. While jazz is characterized by improvisation and other wide latitudes of interpretation, it is at times composed (and fully notated). Parts could have been written that would have been impossible for Parlan, for whom almost the entire classical repertoire was (pun intended) out of reach. Particularly notable are recordings of duets Parlan with tenor saxophonist Shepp (Shepp and Parlan, 1977) and Parlan's solo albums (1994), where the lack of a bass player renders the textures especially spare). The documentary *Horace Parlan By Horace Parlan* (2002) includes valuable performance video.

Oscar Peterson

Unlike Horace Parlan who acquired a disability in childhood, Oscar Peterson began his career as an able-handed pianist, noted for his prodigious technique. A stroke in 1993 severely limited the use of his left hand, rendering him a nearly entirely one-handed pianist until his death in 2007. In this context, it is notable that the great majority of one-handed classical pieces, including two famous concertos (by Ravel and Prokofiev) were for the left hand (Beek, 2018). Likewise, the three most famous one-handed classical pianists – Paul Wittgenstein, Leon Fleisher, and Gary Graffman – all played with their left hand.

Assessments of the quality of Peterson's disabled artistry vary greatly. They range from questioning his continuing to perform to applauding the innovations driven by his

impairment (Lubet, 2013). My own analysis emphasized a greater reliance on his bandmates, in particular guitarists, to supply chordal texture his right hand could not, what I call "piano prostheses." (Lubet, 2013, p. 151). Like Parlan, the textures of Peterson's post-stroke ensembles are not typical, sparser, and certainly different from those of his earlier performing career, although he was always fond of guitarists who provided chording as well as solos. Otherwise, his style remained, as he himself described it, "traditionalist" (Block, 2001). Although he relies more upon his guitarist for chording than before his stroke (or than non-disabled pianists do), his approach to melody, harmony, rhythm, and form, as well as his choice of repertoire, remain unchanged.

Regarding career trajectory, comparison between Parlan and Peterson is complex. Parlan, well known and respected but not iconic, had an entire career as a pianist whose disability defined his technique. Parlan, his colleagues, and even jazz as an idiom and an idea, as well as African American culture as a whole, deserve credit for his success.

It is impossible to know whether or how successful a career Peterson might have enjoyed had he began as a disabled pianist. As aforementioned, the one-handed classical repertoire is dominated by works for left hand alone. It might be surmised that there are aspects of left hand positioning, including easier access to the bass register, that make it less disadvantageous than right hand only playing. Parlan's numerous duet and solo recordings, in which he bore responsibility for a full texture, support that supposition.

Drozdov et al (2008), however, attribute this instead to the prevalence of right handedness leading to a greater frequency of disabling accidents for that hand and thus a greater demand for left hand only repertoire. Regardless, there is little doubt that Peterson's reputation as one of the great jazz pianists of his time (Canadian Jazz Hall of Fame, n.d.) had a role in

enabling him to continue performing after becoming disabled. Peterson can be seen/heard post-stroke in a performance of his signature "Sweet Brown" (2004).

Cedell Davis

Blues vocalist and guitarist Cedell Davis contracted polio at age ten, having only begun to learn his instrument. The disease impaired the movement of both his arms and legs. Naturally right-handed, he was forced to switch to left-handed play. Further, no longer able to fret the strings with his left hand, he played using a knife. Jon Pareles (2017) quotes New York Times critic Robert Palmer's observation that Davis's impairment inspired "a guitar style that is utterly unique, in or out of the blues."

After decades of working mostly in juke joints, Davis began recording in 1976. Championed by Palmer, he began touring nationally and internationally, was admired by Yoko Ono and Mick Jagger, and recorded backed by members of REM and Pearl Jam (Pareles, 2017). Davis is distinguished from the jazz artists discussed above in that the difference between his style and that of his blues colleagues is far from subtle. To see it is to recognize that his creativity flows from a disability significant within and beyond music (Davis, 2009).

Others/Rock

The artists discussed, though they all have large reputations, are but a sampling. In a previous publication (Lubet, 2018) I examine disability accommodations utilized – and often invented by – hand/arm impaired instrumentalists. These range from adapted playing technique to prosthetics to modified instruments. For reasons including the artists' class and cultural roots, most are non-classical musicians who play guitar or electric bass. However, accommodations also exist for virtually every important Western instrument (Woldendorp & van Gils, 2012).

My previous publication (Lubet, 2018) does not analyze these musicians' styles. Perhaps distinctive stylistic features would surface under closer examination. This is particularly likely of Rick Allen, the famous acquired amputee (from an auto accident) drummer of the band Def Leppard, who uses a technologically enhanced drum set (Jewel & Morelli, 2019), and one(left)-handed electric bassist Bill Clements (whose adaptive technology is simple and inexpensive) (/, 2007).

Disability In Western Classical Composition

There are hundreds of works for piano, one hand, the great majority for the left hand. The remainder are mostly for the right hand, but some may be played by either hand. The impetus for most of these works has been to provide repertoire for disabled musicians. Most of these pianists have been amputees and many works were intended for the many amateur pianist veterans wounded in war, while some were commissioned by professional soloists (Drozdov et al, 2008).

The most famous of these war-wounded veterans was Paul Wittgenstein, a right arm amputee. Composers who wrote for Wittgenstein include Maurice Ravel, Serge Prokofiev, Erich Korngold, and Paul Hindemith, each having written a concerto. A musical conservative, Wittgenstein refused to play the Prokofiev and Hindemith works (Howe, 2010). The Ravel is the most famous (Beek, 2018).

Two of the most famous one-handed pianists, Leon Fleisher (Ho, 2018) and Gary Graffman (Tonebase, n.d.), are/were not amputees. A performer, conductor, and teacher, Critic Elijah Ho (2019) called Fleisher "One of the most refined and transcendent musicians the United States has ever produced." Rather, they were impaired by focal dystonia, a neurological condition. Focal dystonia is task-specific, often triggered by overuse, and thus impaired their piano playing while leaving other functions unaffected. It is most likely to affect classical

musicians (Altenmüller & Jabusch, 2010). Botox treatments eventually enabled Fleisher to return to two-handed play, within limitations (Green, & Scolnik, 2024).

Both these left hand pianists commissioned new works. William Bolcom's 1996 *Gaea, for Two Pianos Left Hand and Orchestra*, written for Graffman and Fleisher, is unique in that it can not only be performed as the title describes, it can be split into two compositions, published as *Piano Concerto Nos. 1 and 2* [each] *for Piano Left Hand and Chamber Orchestra*. The respective chamber orchestras are complimentary in their instrumentation. The premiere performance of *Gaea* (Bolcom, 1996) can be heard/viewed online.

In piano performance, the hands operate in the same manner and independently, each able to produce the typical sounds of the instrument by themselves. Thus, composition for one hand presents no technical challenges. While the same applies to other keyboard instruments, such as harpsichord and organ, there appear to be no such works one-handed works in their repertoires (D. Billmeyer, personal communication, September 27, 2024). The same distribution of duties to the hands applies to percussion, yet there is not one-handed classical repertoire for those instruments either (F. Meza, personal communication, September 27, 2024).

There are also no pieces for injured yet functioning hands, akin to the pianism of Parlan and Peterson (or guitarists Reinhardt and Davis). Likely the main reason is that Western classical music compositions are written with generic levels of technique in mind; for "piano" rather than the idiosyncrasies of a particular pianist. Even when one composes a work for one's own use or is commissioned by a particular artist, the implicit intention is almost without exception that the work will be available for others to perform, based on standardized technique for the instrument(s) and/or voice(s).

Impairments like Parlan's or Peterson's are always different, and a work composed to suit an idiosyncratic impairment – as if there were any other kind -- would not be "marketable." Thus, classical composers leave out the impaired hand entirely.

Like the playing styles of the jazz artists discussed earlier, one handed piano compositions sound different from those for both hands. The differences may be subtle, especially in works that are highly virtuosic and utilize the whole range of the instrument, like the Ravel Concerto (1931). Interestingly, Bolcom's *Gaea*, the most unique contribution to the repertoire in its modularity, may sound more typical than any other, when played in its full realization, with two hands playing, albeit two left hands (Bolcom, 1996).

The many one-handed works have been a boon to disabled pianists. Of course, they sound different from works for both hands, though in varying degrees, depending on their level of virtuosity. Casual listening may not reveal the difference at all. They do not innovate in the tonal or rhythmic language, only in their textural limitations. This is likely intended. The integration of these works into the standard repertoire – they are often performed by typically abled pianists -- may thus be read as disability inclusion.

There are no such adaptive classical works for instruments other than piano, in particular winds and strings, where the hands are not independent. This would require technical innovations and research. There are, however, adaptive instruments and assistive devices that make it possible to play standard repertoire with one hand (Woldendorp & van Gils, 2012).

New styles

What has preceded is a review of important music in which hand/arm impairments have generated performances and compositions that depart from norms of their genres and thus innovate, typically in manners that are subtle and limited to musical texture, the density and

interactivity of musical lines. Impaired hands cannot readily play as many notes as typically abled hands. Of the artists discussed above, the one with arguably the most unique sound, not only texture, but also pitch relations and timbre (tone color) is blues guitarist Cedell Davis. This owed mostly to his inability to fret the strings with his left-hand fingers, requiring him to play with a knife instead.

The artist best known as disabled is jazz guitarist Django Reinhardt. His sound is easily identifiable, partly owing to his hand impairment, which, for example, made note bending and fast chromatic (all twelve notes) scales particularly idiomatic. In addition, he was limited in the chords he could play but used this to his advantage to create a unique harmonic style. Reinhardt was one of the first prominent solo jazz guitarists, arguably the first important European jazz artists, and a hugely influential artist within and beyond jazz. Reinhardt may also be credited with having developed a distinctive jazz idiom, known today as *jazz manouche*, a reference to the Roma group to which Reinhardt belonged, many who played this style (Givan, 2014). The most distinctive feature of this style is its instrumentation; the archetypal combination comprised of lead and rhythm guitars, violin, and double bass. This stands in marked contrast to contemporaneous American combos, which would typically feature horns, piano, and drum set (as well as bass and sometimes guitar).

Reinhardt should be seen as an innovator *within* jazz, though not only or even mostly owing to his impairment. Bluesman Cedell Davis may also be viewed as an innovator *firmly rooted in the blues*, whose inventions are (almost) entirely due to his impairment, albeit without the mass of disciples that Reinhardt continues to influence. Both artists should be seen as radically original *within their respective traditions*.

New idioms

I propose here that disability can be and has at times been the impetus for radically new idioms that challenge or even break with traditions. What follows are two examples. One is the work of a sole creator, arguably unique but not (yet?) influential. The other is at once a new technology, a new genre, and a new movement.

Alex Lubet, *On the Seventh Hour*

When first approached to contribute to this volume, I intended to write an essay devoted to one of my own compositions. The much larger topic of *Composing and Performing Disability* has obviously taken on a life of its own, though one that remains loyal to the question I asked myself, owing to my disabling injury; could a new music result from the challenges of a disability? While the legacy of performers like Django Reinhardt and Oscar Peterson, as well as compositions like the piano concertos of Ravel and Bolcom stands, my focus was upon whether entirely new idioms might arise from disabled musicking.

I injured my right arm in 2020. During post-surgical rehabilitation, I was unable to use that arm to play music at all and was otherwise severely limited. I was told that my recovery would be incomplete. But being unable to perform was for me not an option. Having surveyed the stringed instruments I play, I concluded that the only one on which I could make music one-handed was the metal-bodied resonator guitar, often known as dobro or National Steel Guitar (both brand names). The instrument is meant to be fretted by the left hand with a glass or metal slide, the same technique for which Cedell Davis instead used a knife that he could grip with his impaired hand. Without use of my right hand, I could not hold the instrument and had to purchase a special table for that purpose. I could use the slide, but only by striking the strings hard enough to simultaneously fret and sound them. I did employ this technique and the

distinctive sound it made, but it could not be the basis for much of, let alone an entire composition.

Most of the 17–minute work, *On the Seventh Hour*, utilizes two other left hand only techniques. One is simultaneously fretting and plucking the strings with my left hand, by which I could produce harmonics (most readily understood by non-musicians as "flute tones"), usually in combination with the open (unfretted) string. I could thus produce "multiphonics," two and sometimes three pitches on a single string. I had used the latter unusual technique for many years, but never with only one hand.

The other left-hand technique employed was to strike the body (and sometimes the strings) of the guitar in different places with a wide variety of drumsticks and mallets (and a few other "beaters") used by percussionists (including my wife). This produced a plethora of interesting pitches and tone colors. The extent to which the resonator guitar is played as a metallophone percussion instrument, rather than using a slide, is the composition's most distinctive feature. Because almost every sound in *On the Seventh Hour* is succeeded by one that switches to a different stick, beater, or finger technique, the work cannot be played live. It was almost entirely recorded one sound (out of hundreds) per take, the individual sounds later assembled in the editing studio. Disabled composers' reliance on recording techniques rather than live performance is also a feature of music produced by the aforementioned Vancouver Adapted Music Society (Vancouver Adapted Music Society, 2024) and Smirnoff Project. (DJ Fresh & Mindtunes, 2014) *On the Seventh Hour* (Lubet 2023) can be heard here https://www.youtube.com/watch?v=JLzFEp2zBuk. The reviews (Neuma, 2023) are excellent, in particular Bergstein (2023), who writes:

hampered by a temporary disability that denied him the use of one hand, it is not only impressive, it is nothing short of miraculous.

I humbly compare my work to that of Cedell Davis only in that it is an individual's contribution, rather than an influencer or movement leader. To the best of my knowledge, Davis has no disciples or imitators (nor do I), only admirers, likely owing in no small part to a guitar style so deeply a result of his impairment. We play(ed) essentially the same instrument (electric v. resonator guitar), albeit in very different, different sounding ways. The respective styles are deeply motivated by the different abilities of our hands, which would seem to make imitation by or even influence on others unlikely. While Davis is a bluesman through and through, I (humbly) believe my own work to be genre crossing. I am a classically trained composer influenced by many musical traditions, of which blues is among the most important. I mostly compose for string instruments of American folk music that I play myself. Although all the sounds in *On the Seventh Hour* are produced on my resonator guitar, the composition's very existence is so dependent on recording studio technology that it is arguably a work of electronic music.

Pauline Oliveros et al: AUMI

Of far greater importance than my small contribution to disability composition and performance is AUMI, the Adaptive Use Musical Instrument. Initially conceived by composer/performer/humanitarian/activist/author/philosopher Pauline Oliveros (1932-2016) and occupational therapist/drummer Leaf Miller, AUMI is an evolving music software instrument that continues to have contributors and users, all of whom Oliveros regarded as "researchers" (Tucker and Pence, 2024). Among AUMI's great virtues are:

1) That it can be played by any kind of movement, even eye movement, and is thus operable by users with even the most significant mobility impairments. It is also not sight- or hearing-dependent and can be used by blind and hearing-impaired users as well.

2) That is a free download, available on several platforms (AUMI, 2024)

Sherrie Tucker and Ray Mizumura-Pence, members of The AUMI Editorial Collective responsible for *Improvising Across Abilities* (Tucker & Mizumura-Pence, 2024), a volume dedicated to all aspects of AUMI praxis (I am a contributor), observe in their Introduction:

> AUMI is easy to use but difficult to describe (p. 4).; AUMI is not precise. It is not like you wiggle a finger and AUMI immediately plays the note you wanted…it behaves like another player (p. 6), and, AUMI is not so great for those wishing to develop reliable levels of control over its output or perform existing repertoires. … Control often implies hierarchies of power that disadvantage people with disabilities and other marginalized people (p. 7).

As the volume's title states, AUMI is intended for "improvising across abilities." It is an extension especially of the principal goal of Oliveros' *Sonic Meditations* (2022), written for "people who were not necessarily trained musician vs" (p. 2), noting that "I have always valued working with those who are not trained and are not experts. Music should not be imprisoned by expertise!" (p. 2). AUMI extends that value to the (nearly?) all-inclusive, creating music community that liberates all bodies regardless of (dis)ability. Any thorough discussion of AUMI requires a sampling of soundings (see, for example, 2017; Abedin, 2019; Mills College Adaptive Instrument Ensemble, 2019a & 2019b). While the solo improvisation in Abedin 2019 and the performance by the Mills College Adaptive Instrument Ensemble ((2019a) feature simple scales, the Ensemble's festival performance (2019b) includes more conventional and controllable

instruments as well, enabling more complex tonalities. In all three examples, there is little pulse or meter, the free rhythm uniquely "AUMI."

One element of AUMI's distinctiveness is that it has spawned a community that attempts to eschew hierarchy of government or, more important, ability. This is likewise the reason that the editorship of *Improvising Across Abilities* is credited to the AUMI Editorial Collective. That AUMI *responds/reacts* to its player rather than *obeying* and that it insists upon improvisation (I am deliberately anthropomorphizing here) is a radical departure from the dominant praxis of Western Classical Music and its ethic of control.

Although the Mills College group's videos are of public performances, it bears recalling that Olivero's co-conceiver Leaf Miller, is an occupational therapist, in search of an instrument for her young clients to *play*. Audiences or even ensembles are entirely optional. In this respect, AUMI differs from the goals of the above mentioned high-tech Vancouver Adaptive Music Society (2024) and the Smirnoff Mindtunes Project DJ Fresh & Mindtunes (2014), whose goals are/were to enable disabled artists to create works in conventional idioms for audience reception (Lubet, 2024).

As foremost an enabling, empowering, even liberating activity, rather than a generator of music for passive listening, AUMI has birthed a paradigm shift, at least within cultures of commoditization.

conclusion

Disabled playwright and actor Neil Marcus (1954-2021) famously said "Disability is not a brave struggle or courage in the face of adversity. Disability is an art. It's an ingenious way to live" (Williams 2021). This is equally true in music as in theatre. Disability composition and

performance are inherently innovative, in ways that range from subtle to revolutionary. All should be appreciated.

At this writing, I am dealing with another injury, this time to my left hand. I am unsure if/how it will impact my playing or for how long. I am excited to meet the challenge.

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10. “With My Tribe”: Autism, Neurodiversity, and the Recuperative Musical Life of Jennifer Msumba

Michael B. Bakan and Jennifer Msumba

“My whole life had been a game of strategy, always trying to figure out how I was going to navigate my way around a confusing and overwhelming world.”

Jennifer Msumba (2021, p. 130).

The above statement by Jennifer Msumba, from her book, *Shouting at Leaves* (Msumba, 2021), is likely relatable to most readers. Life, after all, is a game of strategy for all of us, its rules of engagement frequently confounding. Yet, as *Shouting at Leaves* reveals in no uncertain terms, the stakes of that game have at times been unusually high for Jennifer, in some cases literally a matter of life and death.

This chapter explores the life and musical artistry of Ms. Msumba based on three convergent streams: biography, online interview-based ethnography, and song analysis and interpretation. The narrative flows in both linear and interlocking fashion along these pathways to reveal knowledge and understanding. The opening biographical sketch, which is based almost exclusively on Jennifer’s account of her life story in *Shouting*, leads directly to a moment of encounter between Jennifer and Michael that was chronicled in an online, texting-based interview conducted in February 2024. That interview, in turn, offers key points of departure for exploring a recording of the song “Light in the Dark,” which was composed collaboratively by Jennifer and members of her band in 2023. Ultimately, the song becomes a gateway to reflection upon the preceding biographical sketch and interview, drawing consideration to broader issues relating to the musical and lived experiences of autistic and otherwise neurodivergent individuals vis-à-vis the people, communities, institutions, and organizations with whom they engage (see

also Bakan, 2021; Bascom, 2012; Cook & Perkis, 2022; Fein, 2021; Fein & Rios, 2021; Kapp, 2020; Sequenzia & Grace, 2015; Silberman, 2016; Walker, 2021).

Before continuing, it is important to provide a brief note about the chapter's authorship. It was written, by Michael Bakan, which accounts for his frequent use of a first-person narrative mode of presentation. However, the content on which the chapter is based—from the *Shouting at Leaves* memoir to the interview transcript, to the song "Light in the Dark" itself—come from Jennifer Msumba, who was integral to the process of dialogic editing that shaped the chapter into its final form. The reader's awareness of this co-authorship process is important here at the outset.

Early Life

Now entering her fifties and living a fulfilling, productive life as a singer-songwriter, multi-instrumentalist, book author, filmmaker, and YouTuber, Jennifer Msumba is an autistic woman with obsessive compulsive disorder (OCD) and post-traumatic stress disorder (PTSD). She suffered myriad forms of physical, psychological, and emotional torture in the names of "treatment" and "therapy" for decades prior to gaining her self-described freedom from the horrors of institutionalization. These experiences shape her current life situation and, importantly, her music and other modes of artistic expression.

Jennifer grew up in Andover, Massachusetts, a middle-class suburb north of Boston, USA. Her mother, a teacher and cartographer, was Italian-American. Her father came from Malawi, in southeastern Africa. Jennifer and her three older siblings—a sister and two brothers—were tended to mainly by their mom while growing up, though their dad was deeply involved with and committed to the children as well, despite his arduous schedule as a perpetually busy cardiologist. "My dad was loving, compassionate, and generous," Jennifer

writes, and the "bond between me and my mom could not be closer" (Msumba, 2021, pp. 12-13). She was also very close to her three siblings, though the boys were prone to teasing her a good bit, as big brothers are inclined to do. Jennifer describes herself as having being "a super creative kid," albeit one who other people regarded as peculiar, and different (Msumba, 2021, p. 16). She was autistic, but that diagnosis would not come until the age of 33, by which time experiences had impacted greatly on her freedoms and self-expression.

Music was a constant presence in the Msumba household, and it was one of Jennifer's great passions. She spent countless hours as a young child listening to her parents' classical records and her brothers' Michael Jackson and Pat Benatar albums. When her dad surprised the family one Saturday evening with a brand-new piano, three-year-old Jennifer quickly found her way to the keyboard, figuring out how to play melodies she had heard at home and at church. It was not long before her mother signed her up for piano lessons. "I learned quickly," Jennifer recalls. "Music was logical. It had a set of rules and I liked that. When I followed those rules, the notes created beautiful shapes and sound waves. It made so much sense to me. The differences in the notes were distances I could see. The corresponding spaces made notes in my mind. My mind made a map for me to follow" (Msumba, 2021, p. 17).

As for music, so too for mathematics, which also was logical and had strict rules. "Math made me feel light," Jennifer recalls, "and I didn't have to use words or feelings to communicate my answers. Numbers and symbols were exact in their meaning. They presented no surprises. Because math is black and white, I didn't feel the weight of the gray realm—the realm of words, feelings, and emotions" (Msumba, 2021, p. 35).

Jennifer took up the violin when she was in the third grade (around age eight). She showed prodigious talent on the instrument and her school music teacher soon determined that she had absolute pitch. A disproportionately high incidence of absolute pitch among autistic

musicians is well established in the research literature (Brown et al., 2003; Dohn et al., 2012; Mottron et al., 1999). The violin was Jennifer's "saving grace in elementary school" (Msumba, 2021, p. 18). As a biracial, undiagnosed-autistic girl who was beginning to develop the tics, obsessions, irrational fears, and behavioral rituals that would ultimately lead—again, many years later—to an OCD diagnosis, school social life became challenging. She was often teased or mocked by other students, excluded from social activities, and singled out as "odd" or "weird." Such experiences of othering took their toll on her self-esteem and self-regard. The violin practice room became her refuge. As happens with many school-age children, a musical space became her haven. "I found a place where I felt safe at school," she reports. "I belonged. No bullies. No teachers putting me down. Just beautiful, intricate music" (Msumba, 2021, p. 18).

Narratives of musical experience as a form of refuge appear with some frequency in the oral histories of autistic musicians. Donald Rindale (pseudonym), an autistic attorney with degrees in law, music performance, and musicology who co-authored his eponymous chapter of the book *Music and Autism: Speaking for Ourselves* (Bakan, 2021), accounts for his youthful experiences playing the trombone as follows: "I found ensemble performance to be a welcome refuge from the interpersonal entanglements I had to endure in the outside world. The music did not laugh, or judge, or make nasty comments, or quizzical facial expressions and gestures at the sight of some unexpected behavioral tendencies. For these reasons, I will always love it" (Rindale, in Bakan, 2021, p. 45).

High School and Institutionalization

As it turned out, Jennifer was good, really good, on the violin: by the sixth grade, she had been promoted to the high school music program and was playing in the All Town Orchestra (Msumba, 2021, p. 18). As the years went by and high school and puberty became Jennifer's new realities, however, her life entered a downward spiral. The converging impacts of her

undiagnosed OCD and autism, combined with bullying, social exclusion, and escalating bouts of anxiety and depression, led to meltdowns, and sometimes to full-on collapses. There were joyful moments of success and acceptance—playing in the orchestra, starring on the field hockey team, performing her first original song at a talent contest and receiving a standing ovation—but for Jennifer the negatives far outweighed the positives.

Jennifer became wrought emotionally and was committed to a psychiatric hospital by her parents at age 15, ushering in a traumatic period that would encompass the next 18 years. She would endure myriad forms of mistreatment during this time and be deprived of the rich musical life that had sustained her up to that point. The first hospitalization lasted about 10 days, during which time Jennifer was finally diagnosed with OCD. Realizing she had a condition that "was real and had a name," and that "it wasn't my fault," proved cathartic, at least momentarily, and when her doctor prescribed medications he said would help her, Jennifer was convinced that she would soon be cured (Msumba, 2021, p. 54).

The prescriptions, however, were for highly potent, anti-psychotic drugs that were completely inappropriate for OCD treatment. Jennifer's symptoms worsened. "Soon my whole world would become a blur for many years to come," she reports (Msumba, 2021, p. 54). She was discharged prematurely when the insurance coverage ran out but was back in hospital not long afterward following another incident. The second hospitalization was deeply traumatizing. Jennifer was subjected to abusive treatment. "I was often restrained using a four-point restraint—where my wrists and ankles were locked into cuffs at each corner of a stripped-down bed," she recounts. "The cuffs were always so tight that my hands would throb and go numb." On one such occasion, "I was crying loudly when suddenly, a male nurse came into the room. He grabbed a pillow that was under my head and put it over my face. He pushed down and was smothering me, screaming, 'Shut up b----!'…. I couldn't breathe. He [was] killing me. I tried desperately to take

a breath but my oxygen supply was cut off as the pillow filled my mouth and nose" (Msumba, 2021, pp. 58-59).

Luckily, another staff member flung open the door. "Are you crazy? Stop!" he screamed at the assailant. Jennifer chronicles what happened next: "The offending nurse yanked the pillow off me and walked out of the room. I gasped and took a deep breath. I received no apologies, [and] the staff kept me in those restraints well into the night" (Msumba, 2021, p. 58).

For years, Jennifer was in and out of psychiatric hospitals, residential schools, and, finally, group homes. She was eventually committed to the state mental hospital for an indefinite period, where she was forced to sit on the floor of a cold, empty "seclusion room" for hours at a time. "If I verbally refused to comply," she reports, "I would be put into four-point restraints … The only thing I was allowed to have for entertainment was a deck of cards …" (Msumba, 2021, p. 73).

The situation was unbearable, so when the opportunity to move to a new residential program at the Judge Rotenberg Center (JRC) south of Boston arose, Jennifer took it without hesitation. The JRC was a beautiful facility. It was decorated with joyful Disney character statues, colorful rugs, fancy furniture, and abundant wall art. Right from the start, however, Jennifer sensed that "something wasn't right" (Msumba, 2021, p. 75), and when her mother was required to sign away her rights to serve as her daughter's legal guardian, she, too, took pause. But both Jennifer and her mother acquiesced; they had to get her out of that hospital, and this was their chance.

Jennifer was immediately immersed in a program of Applied Behavioral Analysis (ABA) at JRC. Her "treatment program" as she recounts, was completely ill-suited to her still-undiagnosed autism. Things went from bad to worse, spurring a series of "behavioral incidents" that climaxed in her smashing her head through a wall, then a glass window. She was ultimately

enrolled in JRC's notorious CESS (contingent electric skin shock) "treatment" program, wherein any "unwanted" or "inappropriate" behavior was answered by a painful electric shock coursing through her body.

It was a desperate and seemingly hopeless situation until one day in 2009, when Jennifer received an unexpected invitation to attend and speak at a guardianship hearing before a judge concerning her case. She seized the opportunity, writing a compelling statement about her desperate wish to be discharged from JRC, which she read directly to the judge at the hearing. It worked. She was released from JRC and into the care of her mother, whose guardianship status was also now restored.

Making Music – A Small Step Out of the Dark

Jennifer's next move was to a group home facility in faraway South Florida. Now 33 years old, she was finally diagnosed with an autism spectrum condition, yielding the implementation of a long overdue program of appropriate and compassionate care, treatment, and accommodations. Many of the "problematic behaviors" that had been "treated" at JRC were dramatically reduced—or vanished altogether—in this new, supportive environment.

Music was a key piece of the puzzle in Jennifer's journey back to wholeness. Her former musical life had been quashed during the many years of institutionalization. Her old keyboard was now shipped from Massachusetts to Florida and she acquired a guitar, a bass guitar, a ukulele, and a violin. She also set up a makeshift home recording studio to produce and post her songs and videos onto YouTube.

"It pained me for years to know I had something inside to share, but that I wasn't allowed to," Jennifer recalls. "I was locked away both physically and mentally. Now, I was making a

small step out of the dark. Music was cathartic for me and for my listeners. It brought me back to my childhood, comforted my body, and made me feel calm" (Msumba, 2021, pp. 119-120).

The first song Jennifer wrote and posted to YouTube during this creative renaissance period was "When You Were Born." It is "about bullies and trials in life," she explains, "but in the end you are only getting older so you need to let those hard memories go in favor of laughter, love, and life" (Msumba, 2021, p. 126). Jennifer's revived musical life merged with a renewed religious life. She joined a local church and quickly secured a spot as the keyboard player on the church's worship team. Feeling that she had found a real place of belonging in the church community—socially, musically, and spiritually—did wonders for her happiness and self-confidence. The other worship team members "weren't just my friends because they felt bad for me or I had something they wanted, they were *true*. They took the time to get to know and understand me and my autism. We grew give-and-take relationships and reciprocal appreciation for each other … I started to feel very safe, … like a real honest adult in the world. What a gift. My days were happy and full" (Msumba, 2021, p. 128).

This same period of growth also saw Jennifer branching out into human rights advocacy work. "I started to make friends who supported me in my effort to stop the cruelty from happening to others. I was invited to speak a few times at conventions and panels about institutional abuse. I was honored to have those opportunities, and even more glad that the truth was spreading. Maybe freedom could come for more victims" (Msumba, 2021, p. 122).

Then came the COVID-19 pandemic. Jennifer's newly opened world was slammed shut. She was cut off from her friends and fellow musicians. The old hauntings began to resurface, but she had grown stronger, more resilient. Music was now her ally, and she used it to powerful effect.

“With My Tribe”

In 2021, when the world started opening up again in the wake of the worst of the pandemic, Jennifer’s fervent productivity through the COVID times had yielded a voluminous catalog of original songs, many YouTube-posted recordings and videos, a podcast, and the published memoir *Shouting at Leaves* (Msumba, 2021). Thus, when an opportunity to apply for a fellowship to support her continued artistic and professional pursuits emerged, she took it, and the application was successful. Jennifer became a Flutie Fellow.

The fellowship-granting organization was the Doug Flutie Jr. Foundation for Autism, or DFJFA. DFJFA was established in 1998 by Laurie Flutie and her former football star husband, a. Their son, Doug Jr.—aka Dougie Jr.—was diagnosed in early childhood with a rare autism spectrum condition called Childhood Disintegrative Disorder (CDD), and when the Laurie and Doug discovered that services available to autistic people and their families were extremely limited, they decided “to form a foundation to help those who were less fortunate” than themselves (*Doug Flutie,nd*).

The overarching mission of DFJFA is to “help people and families affected by autism live life to the fullest” (About the Doug Flutie Jr. Foundation, 2024a). This translates into a well-structured, well-funded program through which the Foundation “works with the Fellow and their family/network to make connections and build relationships in chosen industries/communities in an effort to increase opportunities by utilizing our brand and platform” (*Flutie Fellows*).

As Jennifer explained to me during a February 2024 interview, DFJFA sponsorship has been essential to her creative and professional development as a musician. Their support initially funded her growth as a solo artist, but more recently it has also enabled her to move in an exciting new direction: co-founding, performing with, and writing and producing for an excellent band comprised exclusively of autistic, DFJFA-affiliated musical artists. The band was formed in

2023 and has had several high-profile performances, including at the Foundation's 25th anniversary STARS of the Spectrum Music Festival at Boston's Fenway Park baseball stadium. The band members are always paid for their performances, and their expenses are covered as well. Everything is conducted in a highly professional manner.

"I think now that I have gotten to know the Flutie Foundation better," Jennifer explains. "I feel it really is run with the intention of helping autistic artists and athletes to achieve *real* goals—not to be tokenized and like, 'Awww, how cute.' They are actually setting us up to be independent and successful in real world careers or interests. That's completely different from what I've experienced with some other organizations run by non-autistics, where they parade us around but I could tell we were just being used. I also avoid organizations like Autism Speaks that have nothing to show for all the money they are taking in except research on how to cure or, frighteningly, 'prevent' autism by identifying it before birth. That kind of research scares the shit out of me."

"I don't mind it being run by non-autistic folks," Jennifer continues, cycling back to the Flutie Foundation. "Being in a *band* with other autistic musicians-Music + Autism-that's one thing, and it's great; but that's a totally different experience than Autism +Politics/Organizations. I've had many toxic interactions in the latter realm-with organizations run by autistic people and non-autistic people alike, to be honest, and I avoid it. These organizations can be bad or they can be good, regardless of who is running them. Nobody is perfect, and everything is gray, even though I wish it could be black and white. But I can at least say that the Flutie Foundation has treated me right."

"Light in the Dark"

During our interview, Jennifer was eager to share information with me about her band and their most recent production: the recording and video of “Light in the Dark.” (Doug Flutie Jr Foundation, 2024b) The song debuted at the Flutie Foundation’s Holiday Spectacular event on December 19, 2023, and dropped on YouTube the next day. “Our lead singer is named Cierra June,” Jennifer tells me. “She is 23 and has goals to become a pop singer. I help her write songs, and she performs and records them so she can include them on her upcoming, debut album. If the music takes off, I will still benefit because I have writer’s credits on the songs, so that is cool and another way to be part of a genre I normally wouldn't be interested in.”

“My other close working relationship is with a young man named Jake, who’s only 16,” Jennifer continues. “He is Christian, like me, and we are working on writing contemporary Christian music to record and to also perform live! Jake is incredibly talented. He plays eight instruments at a professional level. Both Cierra June and Jake are autistic, too, but we are all so different. Cierra June is very extroverted and actually enjoys noise and stimulation. Jake is more calm and introverted, but when he gets on the stage, he shines! His younger sister, Sky, is also autistic and a musician. We have all played together, in different combinations. If it’s just me and Cierra June, I usually play guitar, since she has a big, amazing voice and I admit I could not keep up with her singing-wise, LOL. If it’s me, Jake, and Sky, we all sing together and do harmonies, and we play our own instruments.”

Cierra June, Jake, Sky, and Jennifer all exude radiant joy on “Light in the Dark.” Jennifer kicks things off with a catchy keyboard riff over a funk/gospel drum groove before singing the first verse over a descending I-vi-V-IV progression (in B-flat major): “I wanna shine like a star in the sky / Things are hard but I never let my spirit die / I’ve been smiling since the day I was born / Yeah, I was made for more.” Vocal harmonies enhance the second verse, with Jennifer

still leading the way: “Building my life on things that I believe / Can’t convince me that I won’t achieve / Looking up and it’s love that I see / Yeah.”

After watching the video, I compliment Jennifer on the work before asking her to take me back through the process of its creation. The initial idea for the song, I learn, came from her. “I was inspired by a cool chord progression I heard on social media,” she recounts,

> and I learned it by ear and then changed it around to make it my own. I got really excited about it, and so I texted my then-*new* friends and asked if they wanted to write a song to it. Cierra June was very excited and said yes. We hopped on a Zoom and then I started a shared document for our lyrics, and we worked them out in real time. She recorded tracks in her room and sent them to me. Meanwhile, I recorded my parts at my house. I put the tracks together and we had a rough demo.

“It was a good start,” Jennifer continues, “but I felt like it needed something more, something cool like a guitar solo. And I thought of Jake! I had not really interacted with him much, so I was kind of nervous to approach him, but I sent him the demo and he loved it and wanted to be a part of it. He made suggestions about adding pads and synth lines. I sent him the Logic Pro project [with the demo tracks Cierra June and I had recorded] and gave him free rein to add what he wanted. The result was amazing! He wrote and recorded the bass lines and the guitar solo.” Inspired by his contribution, Jennifer invited Jake to become a full creative collaborator on the project. She added Sky onto the invitation as well. They both enthusiastically signed on.

With the band now fully assembled, it was time to move forward in earnest. “We all recorded individually at our own little setups at home,” Jennifer explains, “then Jake and I created a final demo that we sent to Cooper Hyde, who is the mixing and mastering professional

that works with the Flutie Foundation [and is not autistic]. He did a beautiful job of pulling everything together into a finished product.

(Neuro) Divergent Experiences of Musical Collaboration

Jennifer's joyful account of her collaboration with Cierra June, Jake, and Sky on "Light in the Dark" piqued my curiosity about how that experience compared to her previous musical collaborations, including with non-autistic musicians like me. In April 2022, Jennifer and I performed a couple of shows together in Tallahassee, one at the university where I teach (Florida State University), the other at a small live music venue called Blue Tavern. The programs consisted exclusively of original songs by Jennifer, with her singing and accompanying herself on either guitar or piano and me playing drum set on some numbers, hand percussion on others. Tallahassee bassist Jack Straub completed the trio, which we billed under the name Jennifer, Jack & Bakan (JJB). This video, (Msumba,2022) produced by the Tallahassee-based filmmaker Ian Weir, chronicles JJB's Blue Tavern show.

Taking her experiences with JJB and her "Light in the Dark" as a point of departure, I asked Jennifer to talk about similarities and differences between working with autistic and non-autistic musicians. Her response was enlightening:

> So, what was different in the collaboration with Cierra June, Jake, and Sky was that everyone had a skill set and knew their strengths. They didn't try to fight for the spotlight. Like, we all know that Cierra June is the best and most powerful singer, and it was just natural to give her [the lead in] the chorus. But she was humble and never *asked* to be the lead. Also, everyone was super focused and worked diligently on their parts. Communication when writing the lyrics was great because as autistics, we tend to be very honest and blunt. If someone suggested a line that was not very good, we would just say

> 'nah,' and no feelings were hurt. I loved that because no one took it to hurt their pride. Also, it was *fun*. We all have our quirks and are wired similarly but are also different. Remember how I said Cierra June loves stimulating environments? But Jake and I don't; and Sky, Jake's little sister, has *tons* of energy and loves excitement as well, like Cierra June. It was just a great learning experience, and I felt *FREE*!

"It is definitely possible to have great musical collaborations with non-autistic musicians," Jennifer continued, now addressing my autistic versus non-autistic musician collaborations question more directly, "but I feel where the difference lies is that I literally felt like I was with my 'tribe' when collaborating with my autistic friends. I felt a sense of belonging and comfort. I was less worried about my stims or bluntness [than usual]. I think, more than there actually being a difference so much in those attributes listed above, it was an innate sense of *belonging* that I felt. Almost like being a foreigner somewhere and then returning to my home country. Comfort! And then, in that comfort, I was able to perform better, to write better, to let my thoughts and feelings out."

"I have done writing sessions [and performed] with non-autistic musicians who I knew quite well, and I always felt 'squirrely' about it, like, uncomfortable," Jennifer confessed. "Even with you and Jack [Straub]. That was a good experience, and you guys played great. Still, though, I felt nervous with Jack when we were *off* stage, even though he was really nice. I felt a bit of a block between him and me when we were *not* performing, like when I was talking to him. As for you, you're kind of autisticky, so I feel more comfortable with you, I think. LOL." "Hahaha re: me being 'autisticky,'" I reply. "I take that as a compliment (and realize it's pretty much true as well). I love the way you articulated that difference." "Anyways," Jennifer concluded, "I don't feel that nervousness, that discomfort, when collaborating with my autistic friends. I feel excited and happy, and I *want* to be there."

Conclusion

After almost two decades living through hell in one institution after another, culminating with the horrors of the Judge Rotenberg Center, Jennifer now finds herself in a pretty good place. She lives in relative peace and safety; finds comfort and fellowship in her church community; enjoys a seemingly healthy, productive, and mutually beneficial relationship with the Flutie Foundation; and gets to make music with a group of good friends—her tribe, her band—who share much in common with her and accept one another largely on their own terms. She is also continually finding new media and vehicles beyond music to express herself artistically and advocate on behalf of others: writing books, making films, hosting her thriving YouTube channel. She is a member of Mensa International. She has an adorable emotional support dog. She is getting her art and her message out into the world, and people are listening, watching, and paying attention. Many things are going right for Jennifer Msumba, and she has earned every good thing that comes her way.

Yet the traumas, fears, and abuses of the past resonate into the present. Jennifer lives with constant awareness that she is susceptible to new situations, to new conditions and circumstances that could again make her vulnerable to abuse and mistreatment. Living autistic is fraught with such challenges. It is hard; it is disenabling. There is always that proneness to disruptive oscillations between positivity and confidence, on the one hand, and the traumatic memories that indelibly resurface, eroding confidence and driving anxiety, on the other. Making music has proved immensely beneficial to Jennifer in her efforts to stay to the positive side of that vexing dialectic—to be open to the light—but the threat of precarity is never far away.

In the spring of 2022, Jennifer was one of the featured performers at a major music and literature festival. The festival's location was a long way from her South Florida home, requiring

an overnight stay and the full-time supervision and assistance of a professional caregiver assigned to ensure Jennifer's safety and well-being. All of this would have been fine had the caregiver herself not turned on Jennifer, subjecting her to abusive treatment. Jennifer, under duress, managed to contact a family member, who was then able to orchestrate a quick action plan to get her out of harm's way. But when the "caregiver" was later confronted by Jennifer's care team, she fabricated a story that Jennifer had assaulted *her* during an autistic meltdown. The lie was ultimately exposed, and the woman fired.

As I reflect upon the journey of this chapter—Jennifer's journey, her trials and tribulations, her music, her words—I am reminded of a poem composed by another of my autistic co-authors and longtime musical collaborators, Mara Chasar. It goes like this:

> Living with Autism shouldn't be hard
>
> And we don't want to make it hard
>
> So even if you can't
>
> Just try to understand
>
> That all we need from the world is acceptance, inspiration, and love.
>
> (Chasar, in Bakan et al., 2021, 236)

It does not seem like too much of an ask, yet this desire—this need—is seldom met in the day-to-day lives of autistic and other neurodivergent people, certainly not consistently. And so, people like Jennifer, like Mara, must become resilient to survive. They must become like dandelions.

"Dandelion" is the name of one of Jennifer Msumba's best-loved songs. Its catchy chorus sums up the gist of this chapter well and seems a fitting place to close. "La la la la, I'm a dandelion weed…" Jennifer sings. "I paint an orange-

yellow scene… they don't want me on the green. But, ya, I come back every spring. Can't get rid of me."

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PART 3: NEW EPISTOMOLOGIES IN DISABILITY TEACHING

11.Growing Pains and Ethical Dilemmas in Music and Autistic Co-Design Research

Vik J. Squires and Grace Thompson

This chapter presents a critical reflection on a co-design research project centred around autism-friendly music-making workshops that intended to foster wellbeing (Thompson et al., 2022). The critical reflection will take the form of a dialogue between two people, Vik and Grace, who embody multiple roles and ways of relating to each other within the context of the research. This dialogue explores issues related to what we call the 'growing pains' of research in autistic and music projects, and therefore it is written mostly in first person to highlight the subjective and interpersonal nature of this reflection.

We have both struggled with, in different ways, clumsy collaborations and tokenistic participant advisory groups. We both have desires to work in partnership and wish to embrace the messiness that comes with this but also hold serious concerns about inherent power issues in research teams and the possibility of doing harm to participants and researchers alike. We will present a series of vignettes from this project that exemplify these concerns and will discuss the difficulties we experience in trying to determine the beneficence of research into music groups that have an intention to foster participant wellbeing at their core.

We met in 2021, through the co-design research project mentioned above. Grace (she/her) was the lead researcher and is also a music therapist who has worked within the autistic community for many years. She is not autistic, but as a physically disabled woman, she believed she could sensitively oversee a collaborative and empowering project that aimed to give research participants a say in the design of the music workshops. Vik (they/them) began as a participant in the project, while also working towards a PhD in musicology. Despite exhibiting autistic traits from a young age, Vik was not diagnosed as autistic until the age of 23, when they were able to

save up enough money for the assessment. When Vik first heard about the project, they saw it as an opportunity to find connections and understanding from the autism community through their special interest, music. Our first vignette explains Vik and Grace's personal experiences related to starting the project.

Vignette 1: Getting Started

Vik

A friend messaged me asking if I had a minute and if she remembered correctly that I was autistic. It was one of the first times someone had brought up my diagnosis with me since I had publicly "come out" only a month or so before, and I was excited to have someone reach out to me about it. None of my friends were particularly surprised when I announced my new neurotype, maybe because I had spent the past 23 years failing the normal test. She said that one of her lecturers was running a project I might be interested in and then sent me a Facebook post asking for input on autism friendly music workshops. This excited me further, because doing anything music related, especially in an environment made for autistics sounded amazing. Additionally, this was midway through the Melbourne COVID-19 lockdowns, so I was lonely, bored and there was the potential of getting a grocery voucher out of it which I needed because my job was now non-existent. Filling out the survey was easy, and I was quick to accept the team's request for a follow-up interview, but doubts started to creep in. I was a PhD candidate. I was a researcher too. Why was I still seeing myself as a subject?

Grace

I had been planning this project for several years, starting with a survey study where my research team asked young autistic adults to share their views about participating in music-making workshops and their suggestions for how we could make the workshops more accessible

and "autism-friendly." I was excited by this first step into co-design research and deeply engaged with the survey responses. Since this new project was informed by the survey data, I believed that it was built on a good understanding of the elements that could make the music workshops more accessible for autistic young adults. I felt like I was finally living my values, and that this approach was going to be "right" for the autistic research participants.

Introducing the Research Project

This project was a pilot study, which means that the research team planned to work with a small group of participants to see what was feasible before making further plans for a larger study. Grace's team recruited thirteen autistic people and allocated them to one of two workshop groups based on their musical interests or instrumental skills. Each group would be offered five workshops weekly on Saturdays. Things were looking good to the researchers at this point. However, four people did not come back after the first workshop. The researchers were unsure of their reasons for only coming to one workshop; receiving limited feedback is a common thing when undertaking research with young people. Vik took part in three of the five workshops and remained in contact with Grace via email and face-to-face conversations, during and after the project; however, throughout the project Vik became increasingly uncomfortable with their participation.

Co-design research is gaining traction, particularly when vulnerable or underrepresented people are the focus. Trisha Greenhalgh and colleagues (2019) recognise this increased engagement with co-design modes of research; however, they also acknowledge that co-design methodologies widely differ from project to project, with such methodologies being used for a single project and not being repeated. The lack of regularity in co-design methodologies enables collaboration between researcher and research participants. In the field of autism research, co-

design has the advantage of creating greater access to the autistic community for researchers; however, there are many ethical considerations which need to be addressed for co-design research to become positive and an overall benefit for the autistic community. This chapter functions to define the growing pains present in autistic research and how co-design seeks to be a part of this development. Furthermore, we highlight the ethical issues which can arise with co-design research and propose ways to navigate these while fostering participant wellbeing.

Defining the Growing Pains

The Merriam-Webster dictionary (n.d.) defines growing pains as: "the stresses and strains attending a new project or development." This definition reflects the current transition occurring with autistic research. Additionally, it reflects the negotiations made throughout the lifespan of the project and the collaborative relationship Vik and Grace formed.

Within both academia and wider society, discourse surrounding autism has been shifting away from the lens of a disorder and instead to considering autism as a difference or way of being (Davies, 2022). Once pathologized and considered a childhood disorder, understandings of autism have expanded due to autistic advocates reconceptualising autism as an identity, which is communicated through terms such as neurodiversity and neurodivergent (Botha & Chapman, 2024; Beck 2024). Due to this shift away from a medicalised approach, research practices have adapted to not seek a cure, but rather aim for social change (Singer, 2017). The adoption of co-design research methods is one such change, which seeks to maintain the utility of autistic research while minimising harm (den Houting, 2021). Nevertheless, this transition from what autistic research was and what it will be is not without its growing pains.

As described in Vignette 1, the research team was feeling confident they had made a good start with co-design by first completing a survey study to gather perspectives from the autistic

community that would inform the next phase of the project (see Thompson et al., 2020 for full details of the initial survey study). The research team included three people with diverse experiences and knowledge. One researcher is autistic, one has a physical disability, some have neurodivergent family members, and all work with autistic people through their professional roles as either a music therapist, psychologist, or humanities academic. The diversity in the research team could be seen as a strength and already fulfilling some of the principles of co-design by including academics with various forms of lived experience. But there are deeper considerations underpinning this assumption of diversity that we will return to later.

The project was approved by a Human Ethics Review Committee and advertised as "Autism-friendly music-making workshops for social connection." In the plain language statement, the research team explained to potential participants that "we are planning to deliver music workshops as a way for young people to get together and have fun. We hope that the workshops will also help people feel good and provide a chance to meet new people." When describing the data collection processes, the plain language statement explained "we will ask you questions about what you liked the best about the music workshops, your rating of personal wellbeing, what helped your wellbeing, and whether you enjoyed the social connections in the group."

> Looking back, we consider there was a problematic conflation of the study's intentions: music workshops (which can imply developing music skills), social connection (which can imply meeting new people) and wellbeing (which can imply feeling better). Despite the inclusion of researchers with various forms of lived experience of autism and disability, the team did not fully consider how the project might be understood by the participants. With backgrounds in music therapy and psychology, the research team were seeking to respond to a report by the Australian Autism Research Council (2019) which

identified that research into the health and wellbeing of autistic people is an important priority for the autistic community. The links between music participation and wellbeing are becoming widely acknowledged (Krause et al., 2019), with music therapists and psychologists tending to assume that a therapeutic application of music engagement is useful for autistic people. This assumption has been challenged and problematised by autistic music therapist Jessica Leza (2020), who calls on music therapists (and other therapy professionals) to unambiguously explain how they work in partnership with autistic people. So, while the project was informed by the initial survey study, the advertising for the new study did not make it clear enough what participants should expect, what they might be expected to do, and what a focus on wellbeing would mean. Our second vignette highlights one issue we experienced that may have been related to a lack of planning for different participant expectations for these music workshops.

Vignette 2: The First Meeting

Vik

I received my diagnosis three months before Melbourne's first lockdown in 2020. I had self-diagnosed myself in 2018 at the age of 20, after a birthday party for my autistic partner, which resulted in me spending the entire night noticing similarities between me and his other autistic friends. I had sought out a formal diagnosis so that I could access disability supports when commencing my PhD at the start of 2020, but I was too self-conscious to begin inquiries into support. The workshops felt like an opportunity to practice advocating for my needs and become comfortable with being visibly autistic. The isolation imposed by lockdown enabled me to see that I had been masking, acting out socially expected behaviours and suppressing visible autistic traits. By the time of the first workshop, I had unmasked to the point where entering an

unfamiliar environment was physically painful. So, I overpacked and maybe overdressed. Yellow pants, pink top, bulky ear defenders and sunglasses tinted so dark that I could only make out the outlines of objects, but they functioned well at keeping the light out. Going to those workshops was my first time gathering with other autistics in a space which had been curated for us and it underwhelmed.

I arrived at the workshops and was instantly put off by the number of people who were there. I knew that some participants would want to have support people with them, but I assumed that would have been factored into the number of attendees to ensure a small number; nevertheless, the foyer felt suffocatingly packed. When Grace introduced herself to me, I immediately asked for the breakout room so I could stim in private. The breakout room was my first red flag, because it was not a room. It was a small open area outside the workshop room, which anyone could walk past. There were comfy couches, ideal for lounging, but it offered no privacy. If someone needed the bathroom and left the workshop while I was mid-stim, I didn't know how I would respond. I didn't want to feel embarrassed about stimming, but I didn't know the other participants yet. I couldn't rely on our shared diagnosis to save me from judgement. And what about the researchers? Would they take notes on my stimming? Would they find it amusing? There were too many uncertainties for me to feel safe.

Grace

After planning this project for so long, being further delayed by the lockdowns in Melbourne during 2020 was excruciating. When the lockdown restrictions were lifted in 2021, my team leapt into action. On the first day, I was in hyper-friendly mode. I wanted everyone to feel welcome. I wanted everyone to feel comfortable to be themselves. What I didn't anticipate was how many young adults would turn up with their whole family to meet the research team.

Suddenly the meeting area was full of people, and it felt chaotic. I noticed Vik, brightly dressed, and sitting on their own. After pleasantries and checking details, Vik asked me to show them the breakout room which had been requested in the initial interview. I had booked a room for the workshops at the University knowing there were student lounging areas in an expansive corridor area near the main workshop room. The lounge area was an open space, but it was in a nook that to me looked cosy and friendly. It was separate to the workshop room, but close by, and on a Saturday I thought it would be fairly quiet. I eagerly showed it to Vik, feeling very proud of myself for reliably attending to the requests of various participants. However, when Vik saw the space, they felt it was unsuitable. My heart sank. Feelings of imposter syndrome swelled. The raw reality of needing to live up to the promise of offering "autism-friendly' music workshops was exposed. I scrambled to book a small studio room with more privacy for the following week.

Harm and The Growing Pains of Ethics

The next section includes a vignette that reveals our vulnerabilities within the project, both as researchers and participants. At this point, we will focus on aspects of co-design related to ethics and will return to discuss the growing pains with co-design itself in the next section.

Music therapy and psychology research can be described from a medical or objectivist stance as being "intervention" focused, where the benefits of the "treatment" are tested and evaluated through research (Cohen, 2016). These projects must receive ethical approval before they can commence, and the long-standing convention is to pre-define what will be offered to participants and articulate the expected risks and benefits to the ethics review committee. This convention has its genesis in the design principles of randomised controlled trials, where the objective is, as the name suggests, to control the variables and limit bias. The challenges

associated with gaining approval for flexible and responsive intervention studies, as unfolds in co-design, have been noted:

> The need (on the one hand) to co-create and adapt interventions for the purposes of maximising fit and (on the other hand) to pre-specify them for the purposes of ethical approval creates a tension for which there is no simple or formulaic solution. (Goodyear-Smith et al., 2015, p. 3)

The growing pains of the intersection between human research ethics principles and the aims of co-design research are substantive. Ethics review boards start from the premise that research participants are a vulnerable population, and the risks of their participation must be acknowledged and minimised (Locock & Boaz, 2019). Co-design research, particularly with autistic people, often emphasises participatory and inclusive principles. Autistic-led research guidelines have highlighted that researchers should work to "empower autistic people, and to facilitate equitable and trusting collaborative relationships between academics and community members" (den Houting, 2021, p. 3). The juxtaposition of these two different approaches, viewing autistic research participants as either "vulnerable" or advocating for "equitable relationships" with academics (some of whom will also be from the same community), creates quite a head-spin for researchers in this space. Further, the intersection of different identities for autistic people is also rarely considered (Leza, 2020), and this lack of awareness turned out to be a significant growing pain in this project, as described in our following vignette.

Vignette 3: Acknowledging Harms

Grace

Vik emailed me after the second workshop to tell me about an incident that happened to them involving a family member of another participant. To summarise, as each young person and

team member arrived, we invited them to make their own name tag that included their pronouns. The family member noticed that we were adding pronouns and said something along the lines that their adult child wouldn't understand what these were about and were unnecessary. I observed that Vik gently explained to the family member that including pronouns is helpful and respectful, but the family member brushed off Vik's answer. As I guided the family to the exit, I explained (out of earshot to the group) that this project is inclusive, and pronouns are an important way for people to feel welcomed. Vik was understandably shaken by the interaction. They left the room, and another team member was outside to offer support. As soon as the group was settled and working with the workshop facilitator, I went out to join Vik and we had a short guitar lesson where I showed them two chord shapes, and we improvised some singing over the top of the guitar accompaniment. Had I repaired the harm? I wasn't sure.

In their email, Vik explained that this encounter had made them feel unwelcome in what was supposed to be a safe space. Vik's email was powerful and gave me so much to think about. I met with the team to plan for the following weeks and was so relieved when Vik showed up for the next workshop. But after the third workshop, Vik decided that the program was not for them. I thought about Vik a lot over the remaining weeks, and I felt that they might have a lot of feedback to offer. We sent out the invitations to all participants to have a final interview, and I was delighted that Vik signed up for an interview time.

Vik

When arriving at the second workshop, I was in a better headspace. Grace had arranged another breakout room, which provided me with privacy. When I entered the workshop, I felt that it would be an improvement on the previous week. The week before I felt so unsafe that I lost my ability to speak and had remained mute for most of the session. I was going to participate

and be chatty and maybe drop one or two train references to see if anyone other than me fit that particular autistic stereotype; however, I never got the opportunity to, because when I did use my voice I was shut down by a parent who did not see the importance of pronouns. I left the room and stayed with the research team for most of that workshop. Grace showed me how to play some chords on the guitar, while the parent's words replayed in my head.

I had a panic attack on the evening before the third workshop but still forced myself onto the train the next day. I wanted to learn to restring my guitar, which the workshop facilitator had told me she would teach me. So, I went back with my guitar and during that workshop it was damaged. It was only a small scratch, but it is a scratch I see whenever I play it. I spoke to my partner ahead of the fourth workshop, who asked if it was worth going if it was causing so much anxiety each week. A friend, who I had told about the pronoun incident, sent me a pair of earrings she had hand-painted which said, "Don't assume my pronouns," and encouraged me to put myself first. I messaged the team and did not return.

The Growing Pains of Co-Design

Vignette 3 highlights the challenges with trying to address power inequities between researchers and participants, and working towards building trusting and meaningful relationships in co-design projects. Perhaps writing this chapter together is a sign that somewhere along the way a relationship did develop between us. In this critical reflection, we have attempted to unpack some key moments in our relationship growth, and so we offer Vignette 4 to highlight the value of relationally "hanging in there" and taking a leap of faith during co-design research.

Vignette 4: Building Bridges … Slowly

Vik

I still cringe about the final interview. It was clear that the team had not considered the overlap between autistic and gender-diverse identities, so me being a trans autistic in the midst of my transition would have been a bit to juggle. When I was deadnamed in the interview, I decided to not hold back. I had been sending emails after almost every workshop with ideas on how to improve it. This was my hyper-literal interpretation of "any feedback would be greatly appreciated." I attempted to mould the workshops to how I thought they should be. I wanted a sensory room. I wanted pronouns on name tags. I wanted clear signage that the workshops were safe spaces for both autistic and queer people. I wrote up documents after each workshop, because I wanted them to be better, but also because there was a niggling feeling that something was not right. Through no intention of the researchers, harm was done to me. The more I contributed, the more I felt used. I did not want to be a participant anymore. I was a researcher, so why was I not working as one?

After that interview I felt that I had burned all bridges connecting me to the project. So, when I received an email from Grace, I was expecting one of two things: a generic update on the project; or a thinly veiled, yet professional sounding, "fuck off." I was not expecting a job offer. I met up with Grace and she was genuine in wanting to have me as a co-researcher. She was willing to give me a lot of control and I was going to get paid more than a voucher for participating. Most importantly, Grace's acceptance of me helped resolve some of the doubts I had about using my experience as a basis for research. She recognised both my skills as an academic and the value of my lived experience.

Grace

This small and messy project continued to challenge my thinking about research within/with the autistic community. Vik was/is fierce and generous, and meeting them has

profoundly changed the way I think about ethics in research. I am so grateful for their willingness to keep the dialogue between us going. This project promised "autism-friendly" music workshops, yet we were only at the start of understanding what this concept might involve. I can now see the watermark of ableism hiding in this concept, which raised important questions for me: can an event really be "autism-friendly" for every autistic person? Doesn't this kind of assume that one set of accessibility considerations will work for all autistic people? Deeper reflection on these topics is needed when planning my next project.

The offer of free "music-workshops" in this research project seemed to be appealing, but perhaps the focus on wellbeing and collecting data was at odds with that agenda. The questions I'm left with, and that the research did not attempt to answer, are whether participants signed up due to their desire to engage with music, or to meet wellbeing needs, or both… and how would they define "wellbeing" outcomes.

Where To Next?

It was during our subsequent work together, once Vik had joined the project as a researcher, that we identified a particular aspect of the growing pains related to co-design: addressing the decreasing access to autistic communities. There is an increasing selectiveness on the part of autistic organisations and the types of research they are willing to advertise and be affiliated with, thus making recruitment for new autistic research difficult. Jennifer Smith-Merry (2019) cites this as one of the benefits to co-design practices within disability research as it enables easier access to disabled communities through the reputation of a disabled 'co-researcher.' Smith-Merry states that loaning the creditability from disabled 'co-researchers' is desirable "because of a history of poor practices by researchers who have not respectfully engaged with people with a disability when conducting research" (2019, p. 1942). This

assessment does not fully unpack the reasons why disabled organisations or communities, including autistic groups, may feel a responsibility to safeguard themselves from researchers. Reflecting on our experiences, we consider there is a predatory undertone of this employment of disabled individuals to reinstate researchers' access points to spaces they have been barred from because of previous harm. While not all researchers may have directly caused this initial harm, they are nevertheless connected to it through their institutions and status as researchers. This concern is echoed in calls for disabled research to only be conducted by disabled researchers (Smith-Merry 2019); however, we argue that this would not necessarily end all issues of harm and representation in disabled research.

The status of disabled researchers (and in the case of our project, autistic researchers) is in a dubious position. Despite a growing awareness of the disability rights movement's mantra "nothing about us without us" (Charlton, 1998), not all co-design practices seek to onboard disabled researchers or validate the contributions of disabled participants with researcher or author status. The co-design practices employed by this project team engaged with both methods, by including autistic researchers and seeking input from autistic young adults through the means of a survey. Nevertheless, problematic academic hierarchies remained unchallenged. The moniker of "lived experience researcher" inadvertently demotes the disabled researcher as second to non-disabled researchers. Additionally, the hiring of disabled/autistic researchers to fill a void created by the lack of lived experience, could risk minimising the capabilities of disabled/autistic researchers as it only places value on their lived experience and not their other research skills. This approach may limit or prevent such researchers from gaining leadership roles in later projects ensuring they are always in lesser positions within a hierarchical system.

It is important to address the issues within academic power structures, because as Sandra C. Jones (2023) highlights, academic careers have the potential to be compatible with autistic

individuals. Jones singles out special interest as one aspect of this compatibility, arguing that "academia offers something that is uncommon in many other careers but is well-suited to autistic people: the opportunity to make a career from their special interests" (2023, p. 2190). Co-design practices offer a pathway into academia for autistic researchers; nevertheless, we question whether co-design practices that emphasise the disabled/autistic researchers' identity rather than their academic skills are actually empowering or controlling. Furthermore, Jones highlights the paradoxical and problematic nature of disclosure, with her arguing "if you do not disclose, it is hard to advocate for your needs, but if you do disclose, you risk experiencing negative reaction due to ignorance and stigma" (2023, p. 2190). In co-design practices the burden of disclosure is present, but it is a burden only placed on the disabled/autistic researcher. The contributions of disabled and autistic researchers are invaluable, but there is a risk of harm when stigma still prevails. The uneven impacts of stigma are explored in our final vignette.

Vignette 5: Obfuscating Roles

Vik

At the beginning of 2021, Grace emailed the journal article which was informed by the initial survey responses and interviews. I was eager to read, especially because I wanted to know what other autistics had to contribute. I started reading and quickly my anxieties took hold, as I felt that people who knew me would be able to work out that I was one of the participants. I began to consider how the details of my autistic traits in combination with stigma surrounding autism could be used against me and impact my academic career. Even before my formal diagnosis, I have faced the challenge of having others impose what they view as my incapabilities onto me and have used these to limit me as they see fit. I was never allowed to go on school camp, because I might have an episode. I was never called on in class to read out loud, because I might stammer and then be bullied by other students. I was never invited out by

friends, because they decided it just wasn't my thing. What if people read the publication, identified me and then have it confirm all their assumptions? I wanted control over how people perceived me, but in this project, I felt I had lost the ability to do that.

I have been a research participant since I was a toddler, in and out of the Royal Children's Hospital for treatment for a variety of health conditions. I don't know how many publications there are out there in the world with my data. I am used to being studied, but it was through my experiences with this project that I realised the agency I lost, and how I had to carry the burden that comes with sharing so much of my experiences with researchers.

Being elevated to the position of researcher for this project alleviated some of these concerns. Going through the ethics approval process for my own PhD also gave me the language I needed to identify the reasons for my feelings of unease about the project. Nevertheless, once being hired as a researcher for the project, in meetings with the research team I was overly cautious with how I presented myself, believing that they would see me as an imposter. I was grateful for the opportunity and the career development it could offer, but I feared that it would pigeonhole me into positions which only required my lived experience and limit my ability to further grow my career due to harmful stigma.

Grace

Vik's concerns related to disclosure and stigma revealed to me how easy it is to take power for granted. From my position as an "experienced" researcher, I overlooked the risk of stigma for the participants, and in Vik's case, an early career researcher. As a physically disabled person, I also failed to recognise the different ways that stigma might play out in academia for autistic people. When someone notices my physical difference, or when I disclose my disability to others, I notice the mixed responses I receive. Some people seem to hesitate to ask further questions and unsure about how to respond. However, the majority of people seem to be inspired

by the adversity I have faced. Both responses are quite one-dimensional, and I am aware that some people will always "see" my disability once it is disclosed, and my disabled identity seems to be front and centre whether I want it to be or not.

> These concepts of stigma and disclosure are complex, and as more researchers with marginalised identities engage in projects related to their identities, the implications for co-design need deeper consideration. There seems to be a rather simplistic assumption that researchers with marginalised identities will just "know what to do," yet my experience of this project have made me question everything I thought I knew about ethics and power.

Considerations for Stereotypes and Representation

In addition to stigma's role in disclosure and the status of disabled/autistic researchers, there is the issue of representation. Another lesson learnt from the workshops was the difficulties faced in achieving and maintaining its status as "autistic-friendly." The stigma surrounding autism is due in part to prevalent stereotypes of what autism "looks like." These stereotypes have impacted peoples' access to diagnostic tools and supports, because they do not match the traditional understanding of autism (Huang et al., 2020). This issue has impacted women, gender-diverse individuals, and people of colour. Disability and autistic advocates therefore emphasise the importance of representation and the acknowledgement of the variations with autism and intersecting identities. Reflecting on the workshop participants within this research project, while there may have been some similarities, the participants varied in their presentations of autism and the supports they required, and in some instances, this resulted in conflicts in how to run the workshops and maintain the space as safe for all. In constructing a co-design project, diversity within a community must also be considered, as a single disabled/autistic researcher (or even several) will not ensure all members of a community will be

represented. Therefore, we put forward that the adequacy of representation must always be acknowledged as a limitation of the research to ensure previous stereotypes are not being replaced with new ones.

The growing pains in autistic research have no simple solution, as even the inclusion of autistic researchers as part of co-design practices comes with consequences. There are significantly more pressures and uncertainties for the disabled/autistic researcher, which further highlights the privilege of researchers who are neither disabled nor autistic. This is not an argument for the end of co-design nor the inclusion of those with lived experiences; however, it is to say that more consideration is needed in the creation of such projects, which includes greater supports, especially regarding career development, for disabled/autistic researchers providing their lived experiences.

Concluding Reflections: Ethics in the Future

Following a period of growing pains, there usually comes some form of development or transformation. The workshops were intended as a pilot project to utilise music-making to enhance the wellbeing of young autistic adults; however, it exposed unaddressed ethical dilemmas at the heart of co-design practices. The benefits of co-design are often primarily from the researchers' perspective: greater access is achieved and feedback from participants in some form is guaranteed. Nevertheless, in exchange for these benefits there can still be a potential for harm through the different burdens placed upon participants and autistic researchers. Researchers need to deeply reflect on the potential for harm in co-design projects, since the harms may be harder to predict and plan for in this relatively new approach to disability research. We believe there remains an underlying power imbalance present in co-design research, which is highlighted through the risks disproportionately impacting individuals who supply their lived experiences.

This imbalance must be decreased to ensure an ethical use of co-design and achieve a positive impact on people's lives through contributions to research.

By having this dialogue, conflicts within the initial project's aims and construction are clear. Finding a balance between music-making, promoting wellbeing and attempting to maintain a safe-space for all participants proved to be a multifaceted challenge, which placed strain on participants. The feedback which was informed by lived experience brought these issues to the forefront of this discussion. It is because of this that we still see co-design as a viable approach to autistic research; however, more must be done to minimise harm and promote the skills of autistic researchers which do not merely relate to their lived experience.

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12. Nothing About Us Without Us in the Syllabus: Designing and Facilitating a Disability-Centered Music Education Course

adam patrick bell

Not for Music Education? First Impressions of Disability Studies

Although a decades-old interdisciplinary discipline that can be found in diverse faculties across universities worldwide, disability studies is a relative newcomer to the field of music education. My first encounter with disability studies as a field was in a meeting with an acclaimed disability studies scholar at a university in Toronto. At the time I was living in Toronto working as a music teacher in the public school system and was interested in pursuing doctoral studies because I perceived the field of music education to be lacking in the way it typically discussed and approached teaching disabled students/students with disabilities. As a teacher, the only training I received related to disability was in special education, but none of it was specific to music. Of the few resources to which I had access, most focused on how to make disabled students/students with disabilities fit into a choir or band class. I read "how to" articles that framed disabled students/students with disabilities as problems to be solved—a problematic premise from my perspective. Prior to becoming a teacher, I had supported several disabled people/people with disabilities as a social worker for a community-based disability organization and I was well aware of how they were marginalized from music making. Perhaps, I thought, I could do some research in this vein to help make music education a better, more inclusive practice and profession. Disability studies seemed like a good place to start. The disability studies professor with whom I met was courteous and professional, but it didn't take long in our discussion until they explained that disability studies did not have space for my research

interests—supporting disabled people/people with disabilities in music education contexts. I remember leaving that meeting baffled as to why anyone would participate in a field that only focused on theorizing about disability.

As you might have guessed, I did not end up studying at that university in Toronto, and furthermore, I steered clear of disability studies altogether while pursuing my doctoral degree in New York City. It took some time, but I eventually came back around to disability studies after engaging with the work of Alex Lubet (2010, 2011). His writings were the first I encountered that grappled with the complexities and nuances of disability in music contexts, and to discuss and critique how systems of music education are oftentimes ableist. It's been over a decade since these early encounters with disability studies and it has profoundly altered how I perceive and think about disability and thereby radically altered how I approach music education in my research and teaching. I begin with these personal experiences of my early encounters with disability studies because they serve as critical reminders of how challenging it can be to engage with this interdisciplinary field. I'm mindful that most, if not all students in my disability studies course have not encountered the field previously. The last thing I want for my students is for them to feel alienated the way that I did when I was first introduced to disability studies. Disability is complex and so it follows that disability studies is a field full of challenging questions and ideas that need to be navigated carefully and thoughtfully. This begs the question: How do we introduce music educators to disability studies?

Designing a Disability Studies Course for Music Education

In this chapter I present my perspective on and experiences of designing and facilitating a "Disability Studies and Music Education" course at the postsecondary level for graduate students. In particular, I focus on how I foreground the disability rights slogan "nothing about us

without us" (Charlton, 1998), to guide the design of my course, including considerations related to modality, content, and assessment. Influenced by "Care Work as Course Design" by currie and Hubrig (2022), I seek to craft the course such that access is built into all aspects of its design. I do not want to have conversations about access; rather, by aspiring to strive toward "access intimacy" (Mingus, 2011) and practice "collective access" (Sins Invalid, 2019), I want the class-as-community to *do* access by ensuring that it is built into all aspects of our course. The syllabus—a core document in postsecondary education that sets the agenda for a course—is designed such that it is not merely *about* disability and music education, but instead grounded in the knowledges and experiences of disabled people. I implement this with a "course as conference" model, in which disabled artists and academics, many of whom also identify as disabled people, provide keynote presentations and/or performances thereby infusing the course with diverse perspectives on disability and music education. Complementing our weekly guest presentations, our course readings cover a range of topics, which I discuss in the section, "Disability Perspectives: Readings." Additionally, students are positioned as central agents in the course by presenting and participating in roundtable and paper presentations to promote peer-led learning, peer discussions, and peer reviews. In sharing my perspective and experiences facilitating a "Disability Studies and Music Education" course, it is my hope that other postsecondary instructors might learn *with* me as we navigate a relatively new direction in music teaching scholarship.

Syllabus as an Agenda for Access

Syllabi components and requirements differ from place to place but at their core, these documents tend to detail the agenda of the instructor. I've worked at three different institutions—one in the United States and two in Canada—and found their policies and processes to be similar. An ethical syllabus is designed in such a way to make meaningful space for students'

perspectives, needs, and wants. I come to the first class with an agenda of my own and discuss what previous classes have done, but I strive to be genuinely open to and accepting of the suggestions of the students. For example, in past courses I have modified or changed assignments, and curated the readings and guest speakers based on students' suggestions. Nevertheless, a course title (e.g., Music Education and Disability Studies) is required prior to meeting students as is a "course description," which is essentially an advertisement. Course descriptions can be deceptively difficult to craft because in just a paragraph or two they must capture the ethos of the course. Here, I provide the description from my most recent offering of Music Education and Disability Studies:

> In this course we will examine the complex construct of disability as both an identity and experience in the context of music education. Engaging with readings and other media such as videos and podcasts that draw on key concepts and ideas from the interdisciplinary field of disability studies, we will survey and discuss how disability is framed and experienced in diverse music teaching and learning contexts, both past and present. Furthermore, this course will provide opportunities to examine how disability intersects with other marginalized lived experiences (e.g., race, gender, sexuality), and both the promise and problems that music poses for "inclusion."
>
> Modeled on the concept of a "continuing conference," this course will seek to make connections between topics discussed from week to week. Given that "music education and disability studies" is intentionally broad in scope, students are encouraged to "roam" and engage with topics related to disability and music education that are of particular interest to them. Therefore, this course will provide opportunities for students to engage in inquiries focusing on topics of their choice under the vast umbrella of music education and disability studies. Students will be expected to present on their chosen

topics and facilitate discussions. In addition, this course will include guest speakers who will present on specialized topics related to the course.

Another component of a syllabus that is required prior to the course commencing is a statement of learning outcomes, which I find difficult to determine in advance of having met the students I will teach; however, if conceptualized similarly to the description as an advertisement of sorts, it's an opportunity for the instructor to make transparent their intentions. In my syllabus, I provide the following statement:

During this course, students will:

• examine, evaluate, and discuss relevant literature and other media related to music education and disability studies

• discuss their understandings of theory related to music education and disability studies

• conduct a literature review on a topic of interest related to music education and disability studies

• present on a topic of interest related to music education and disability studies

• integrate accessibility considerations into all assignments

There are some other required components of the syllabus, specifically a schedule and a description of assignments, but at least in my working context, these components do not need to be fully defined, which allows for student agency because they can influence the design of assignments and how they are assessed.

Accessibility

Last but not least, most syllabi have some required language, which some instructors might disagree with and/or wish to improve upon. This is relevant because most syllabi require language related to disability "accommodations." For example, the following is the required statement from my institution as of 2024:

> Students work with Accessible Education which provides recommendations for accommodation based on medical documentation or psychological and cognitive testing. The accommodation policy can be found here: https://www.uwo.ca/univsec/pdf/academic_policies/appeals/Academic%20Accommodation_disabilities.pdf

For the sake of brevity, I'll bypass discussing my institution's policy and instead provide the statement I am permitted to insert into the document as a preface. In doing so, it is my intention to "get out in front" of the problems I perceive as inherent in my institution's individualized (and often medicalized) conception of disability and attempt to signal to my students—regardless of their disability identities and experiences—that accessibility isn't something the institution can give us; rather, accessibility is something we need to strive to provide to each other:

> The following statements are required components of a syllabus as determined by the Senate. These policies may not adequately address a learner's accessibility needs. In an attempt to address our collective access needs as a class community, we will discuss and navigate accessibility continually through regular check-ins. All members of the class are encouraged to dialogue with the instructor about their individual access needs if they do not feel comfortable doing so amongst the class. Because access is relational and access needs can conflict, there can be no guarantees that all access needs will be met; however,

as a class, we will strive to make our learning environment as accessible as possible to everyone involved, inclusive of students, the instructor, and guests.

With this statement, I attempt to "set the tone" of the course to be anchored to access. How can we have a course that centres disability if accessibility is not foundational to all that we do together? For this reason, the course is offered in a hybrid format, meaning that students can attend and participate in person or online. Understandably, everyone has their preferences and opinions regarding in person and online learning, but these should not be conflated with accessibility. I stress to students that one learning modality is not better than the other; rather, they are different, and each has its own advantages and disadvantages relative to each person. A concern that has been expressed by students regarding this hybrid teaching context is how the experiences of attending online versus in person compare. I suggest that our collective aim should be to ensure that we support each other, and to strive to realize a learning context in which everyone involved can thrive.

For a first reading, I defer to the wisdom in "Access Intimacy: The Missing Link" by Mia Mingus (2011), which for most students provides a perspective that they seldom encounter. Typically, the students in my course are accustomed to accessibility being a set of standards required by law in public buildings such as the provision of ramps or elevators, or prescribed as "best practices," such as considering multiple modes of learning. These are all good things, but what Mingus describes is personal and relational and holds humankind to a higher standard. In short, we must know each other to "get" each other's access needs. As Mingus describes, access intimacy is intangible, one knows it when they experience it. Not having to ask for accommodations because they are already provided is an indicator that access intimacy has been realized. Yet, as Piepzna-Samarasinha (2022) realistically points out in *The Future Is Disabled*, making things accessible for each other might not materialize instantly or equitably. Instead,

access is something that requires work and dedication amongst all involved, and it can get messy and emotional because access needs can compete and even conflict. By beginning the course with this conversation, both the students and instructor are caused to consider access as a set of actions that they must continually commit to and adjust to as needs change—this is no easy feat, but it is reflective of reality and is a disability-centred model tethered to principles of justice that can be applied to any context in which two or more people interact. Access intimacy, therefore, is an aim, value, and skill that is applicable everywhere and to everyone. By introducing the concept and practice of access intimacy in the first class, the course is immediately imbued with disability knowledge, a hallmark of disability studies.

Disability Perspectives: Readings

Core to any course are readings and this is an area that students can influence based on their expressed interests. My typical practice in the early goings of the course (weeks 1–4) is to try and establish a shared understanding of some important concepts in the field of disability studies. In the latter part of the course (weeks 5–12), I tend to have students steer us collectively towards topics that are of most relevance and/or interest to them. To support this approach, I have a library of topics that they can peruse, but also, I invite them to introduce new topics, and in some cases, our guest speakers also suggest readings. The key principle is that as the instructor I do not solely steer whose knowledge we engage with; instead, as a class, we decide democratically which readings to include.

Following the first week in which we concentrate on accessibility, I pair the work of Davis (2006) on normalcy with newer scholarship by Indigenous author Ineese-Nash (2020). My reason for doing so is to: (a) steer us away from what Bell (2006) aptly called "white disability studies"—a reference to the fact that most disability studies research in the field, at least initially,

was by white (disabled) people and about white (disabled) people; and (b) steer us toward Indigenous perspectives so that we do not begin solely with Western European epistemologies. We commence with Davis (2006) because his framing of normalcy is reflective of what most students in my classroom will have grown up with—that is, the idea that disability is something that can be measured and sorted, which ultimately creates a sociocultural climate for disability to be framed as an individual abnormality that falls outside of the so-called normal bounds of the bell curve. These ideas from the science of statistics that originate from the early-to-mid 1800s might seem like an arbitrary place to begin, but the primary point I stress is that these centuries-old ideas remain pervasive in our contemporary society.

In contrast, the writing of Ineese-Nash (2020) presents a different worldview. Ineese-Nash, who is Anishinaabe (Oji-Cree), draws on the knowledge of predominantly Anishinaabek communities to explain how "disability" as a label is a colonial idea and may be incompatible with the perspectives of Indigenous peoples. Sharing the Anishinaabe story, the Gift of the Stars (Annangoog Meegiwaewinan), Ineese-Nash summarizes: "When a child comes into being on earth, it is a gift for the entire community. If a child presents as disabled, there is an understanding that there is something to be learned from that experience to strengthen the community as a whole" (p. 40). With this "polar pairing" of Davis (2006) and Ineese-Nash (2020), it is my aim early in the course to make clear the muddiness of disability studies. One must make peace with the reality that countering conceptions of "disability" co-exist, and that the ramifications of these understandings have important implications for the profession of music education, both in research and practice. I find that these readings make for productive prompts for considering our own understandings and conceptions of disability. One exercise we engage in is to look up definitions of disability according to various agencies (e.g., the Canadian federal

government and the World Health Organization), which inevitably produces more questions than answers regarding what disability is.

Inevitably, an introductory course on disability studies must at some point make space and time to discuss disability models. As another polar pairing, I opt for Oliver (2009), who is often credited as a pioneer of the social model. In this chapter, Oliver defends the social model against critiques such as those leveled by Shakespeare (2013), whose model I refer to as being "interactional." What I appreciate about Oliver (2009) is that he outlines the social model's origins as being directly tied to the disability rights movement—it is political—and that importantly, the social model is something to be done—it is activist. I stress to students that what Oliver and other social model thinkers propose is radical for the profession of music education because responsibility of the so-called problems of disability is shifted to societal systems. Importantly, with the introduction of the social model also came an awareness of its apparent opposite, the individual model or as it is often called, the medical model. Oliver is convicting and convincing with his assertion that "impairment" is distinct from the experience of "disablement," but Shakespeare's (2013) incisive critiques of the social model serve to provide students with an excellent example of how to think about, with, and through different disability models. Shakespeare's arguments and explications of how the social model does not adequately account for all experiences of disability returns us to the messiness that Oliver's social model seemed to have cleaned up. It is worthwhile to note at this juncture that none of these readings discuss music or music education. My rationale for not including music-based readings that discuss disability models is based on my experiences having taught this course multiple times and learning from students that they find the readings by the authors of the original concepts (i.e., Oliver, 2009; Shakespeare, 2013) clearer and more helpful. As a principle, I do not assign articles I have authored as readings in my own classes because I think it may be difficult for

students to be openly critical of them, but for those who are interested, I have published pieces that attempt to illustrate disability models with music-based examples in collaboration with wheelchair basketball player and singer-songwriter Patrick Anderson (Bell, 2017) and drummer Cornel Hrisca-Munn (Bell & Hrscia-Munn, 2020).

Although there are many disability models, I do not delve into any others because as I explain to my students, the point is not to memorize them all, but rather, to be able to understand them as they are encountered. For example, the cultural model is helpful for understanding how different cultures influence our thinking about disability, whereas the religious model is helpful for understanding how different faith systems and religious practices influence our thinking about disability. All models have value, but no model is perfect as they all have their own respective strengths and weaknesses. The broader point I hope that students grasp is that there are a multitude of ways that one might try to understand disability and answer the questions of who, what, where, when, why, and how (i.e., Who is disabled? What makes someone disabled? Where is disability? When is someone is disabled? Why is someone disabled? How is someone disabled?). Such questions provide entry points into the continual pursuit of understanding disability. One additional point related to these readings is worth making: They present an opportunity to think about and discuss Oliver's (2009) and Shakespeare's (2013) use of identity-first language (i.e., disabled people), which contrasts with the more commonly used convention in educational settings in Canada of people-first language (i.e., people with disabilities).

My last prescribed reading steers the class toward disability philosophy, and specifically the work of Beaudry (2020). What I admire about his thinking is how he gives us a framework to categorize the variety of readings we will encounter in the class. For example, his categorization of medical and social models as "first order" accounts of disability that are "close-ended" because they are (a) determinate and (b) reductionist, lays bare the thinking that underpins them,

and tidily explains the logic of Oliver (2009). Scaffolding on this foundation, Beaudry (2020) explains how the interactional model forwarded by Shakespeare (2013) is similar in that it is (a) determinate, however, it diverges by rejecting a reductionist account and instead opting for a (b) mixed approach by making conceptual space for the co-existence of medical and social model thinking. Helpfully, Beaudry extends his explication to include more recent accounts of disability, which he terms "second order" because they are "open ended," and points out that they have (a) referents (i.e., ways for determining disability that are subjective) and/or (b) values (i.e., ways for understanding disability as negative, neutral, or positive). Finally, his suggestion for a fifth account, one that is "radically" open ended because it does not require referents or values, instead just a self-selected identity, is compelling yet controversial. Taken together, Beaudry's framework provides theoretical tools to navigate the seemingly unending number of disability models and theories that the field serves up.

Beyond Beaudry, I direct students to other topics including but not limited to feminism (Garland-Thomson, 1994); queer studies (Kafer, 2013); the intersectionality of race with disability (Annamma et al., 2013; Bailey & Mobley, 2018); the intersectionality of race, gender, and sexuality with disability (Schalk & Kim, 2020); Black disability politics (Schalk, 2022); Mad studies (Bruce, 2021); and, disability justice (Kafai, 2021; Sins Invalid, 2019). As I've discussed elsewhere (Rathgeber & bell, 2024), I am cautious and careful in my presentation and discussion of works by marginalized and multiply marginalized authors because I recognize that while I may not be the intended audience, my students might be. Therefore, I have an ethical responsibility to ensure that they are aware of and have access to these sources.

Disability Perspectives: Guests

The course is structured as a continuing conference based on the idea that students will learn how to develop research skills throughout the semester and acclimate to academic activities such as discussions and presentations. One way for students to learn these skills is for them to experience them modeled by experts. Aside from the first few classes, I schedule guest speakers to join us each week and share their knowledge with us. The guests I invite include academics who do disability-related research as well as artists who create and/or perform music. I find that our guests' approaches to their talks range in wonderful ways—some guests opt for a more formal and presentational approach whereas others take a more casual and conversational approach. While the approaches to sharing knowledge may be diverse, the common thread amongst the guests is the richness of knowledge they share with us as a community of learners. In any given offering of the course, I typically have 6–8 guest speakers, and I find that this number gifts us a broad collection of perspectives on disability and music education. Below is a list of some of the guest speakers we have had the privilege of hosting in our class:

- Warren Churchill
- Jason Dasent
- Teri Dobbs
- Juliet Hess
- Robert Hutson
- Miss Jacqui
- Molly Joyce
- Diane Kolin
- Dyllan Lambert Monroe
- Xi Li
- Ado Nkemka

- Jesse Rathgeber
- Rena Roussin
- Stefan Sunandan Honisch
- Gift Tshuma

Assignments

For many students, the syllabus is synonymous with assignments, and this is understandable given that their success in the course hinges on their performances on tasks that are assessed by the instructor. I endeavor to craft assignments that are reflective of authentic practices in research, which is why I use a continuing conference course design. The assignments are designed to build upon each other and follow an arch with respect to workload, with the third assignment being the peak of demand upon students. By placing the third assignment approximately three-quarters through the semester, my hope is to avoid the busy times associated with mid-term and final exams in other classes. Table 1 presents an overview and timetable for the assignments. Notably, most assignments are flexible regarding due dates to accommodate students' schedules.

Table 1

Assignments Overview

Assignment	Detail	Weighting	Due Date
Assignment 1	Presentation Pitch	10%	Week 3
Assignment 2	Discussion	20%	Weeks 4&5
Assignment 3	Presentation	50%	Weeks 6-10

Assignment 4	Facilitation	20%	Weeks 11&12

Following, I provide the brief descriptions of each assignment from the syllabus along with some contextual commentary. As I discuss with my students, the assignment descriptions are accompanied by approximate durations in minutes—these time estimates are intended to be guidelines for presenters to prepare accordingly, not hard rules. Kafer's (2013) explanation of "crip time" is helpful in explaining why we need to be flexible with how we think about time:

> it is this notion of *flexibility* (not just 'extra' time) that matters. Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognizing how expectations of "how long things take" are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need "more" time but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds. (p. 27)

Embracing a flexible approach toward time and planning accordingly allows for students to take the time they need to present and discuss assignments.

Assignment 1: Presentation Pitch (approximately 10 minutes) – 10%

The presentation pitch is intended to be a relatively informal presentation of approximately 5 minutes, followed by an instructor-facilitated discussion of approximately 5 minutes. It is an opportunity for students to share their ideas on potential topics for Assignment 3

(presentation). Students are required to have identified at least 1 related reading/media source to their topic(s) of interest and share the main point(s) of the source(s). In addition, students should discuss (1) what or who is the focus of their proposed presentation, (2) why this topic is of interest to them, (3) how they anticipate preparing the presentation going forward. Following the presentation, we will have an open discussion in class about the topic, which can include asking questions and offering suggestions.

Contextual Commentary: I have two aims for this assignment. The first aim is to create a culture in the classroom in which students are encouraged to share their ideas. The second aim is to create a culture in the classroom in which we perceive each other as professional peers who are expected to provide feedback and help each other as we develop research projects. Furthermore, I model the role of a moderator in a discussion, a role all students are required to assume in Assignment 2.

Assignment 2: Discussion (approximately 10 minutes) – 20%

Building on Assignment 1, students are tasked with leading a discussion. As a source for discussion, students are asked to engage with non-academic media produced by disabled persons. One example is Alice Wong's podcast, Disability Visibility: https://disabilityvisibilityproject.com/podcast-2/ Specifically, students are asked to consider how the media they chose to engage with informs their thinking about music education and disability.

The student leading the discussion is required to provide (1) a brief (no more than 5-minute) introduction and overview of the topic, and (2) questions to generate a 5-minute discussion. Based on previous experiences with this exercise, 3 question prompts should be prepared in advance to generate discussion. The student leading the discussion is also required to facilitate the discussion, which entails inviting peers to share their perspectives on the topic(s).

Contextual commentary: Students are organized into groups of about four people for this assignment and facilitate the discussions themselves. As a result, this assignment functions similarly to a roundtable at a conference. Aside from the primary aim of requiring my students to engage with the knowledge of disabled people, the skill I hope my students develop is how to generate and facilitate a discussion, as well as how to participate in one.

Assignment 3: Presentation (approximately 20 minutes) – 50%

Assignments 1 and 2 lead toward Assignment 3, building a foundation for it. Students are required to give a 15-minute presentation followed by a 5-minute discussion on their chosen topic. The presentations should serve as evidence that students have engaged with 12 or more sources related to their chosen topics.

Contextual commentary: My primary aim for this assignment is for students to engage deeply with a topic in which they are interested and invested. In doing this assignment, they demonstrate the development of many skills, including reviewing and synthesizing literature, and preparing and sharing a research presentation.

Assignment 4: Facilitation (approximately 5–10 minutes) – 20%

Building on what we have learned together throughout the semester, this final assignment tasks students with designing a participatory music-making activity that applies their knowledge of accessibility to music teaching practice. Students are tasked with (1) creating a plan that explains (i) *what* they will do (ii) a rationale that justifies *why* they chose this approach, and (iii) detail *whose* knowledge they drew on to create the activity; and (2) implementing the plan in class.

Contextual commentary: The aim of this assignment is to end the semester by demonstrating that the learnings about disability studies can and should be implemented in action in spaces of music education. This assignment is an opportunity for students to practice this skill and experience the types of professional development activities that are typically offered at practitioner conferences.

Assessments: Peer Review and Thinking Outside the Rubric

To instill in students the value of peer review, all assignments revolve around this professional practice. In the first two assignments, peer review occurs informally, and students are given full credit for completing these tasks. Given the higher stakes of the third assignment, together with the students, we discuss the assessed components of this assignment so that they are clear and create a document called "criteria." We also create an accompanying document that specifies how the criteria will be assessed. This document resembles a rubric, but it is more malleable because it encourages students to think outside the rubric and be credited for aspects of their presentations that are not included in the criteria. This design was arrived at collaboratively with students based on their desire for clear guidelines that are also flexible. A required component is embedding accessibility practices into assignments, such as considering the legibility of slides, using captions and image descriptions, and providing a script that is compatible with a screen reader. Assignment 3 has four assessment components: the presentation, the presentation slides, the presentation script, and participation in peer reviews of presentations. The aforementioned criteria and flexible rubric are applicable to the presentation, slides, and script, whereas the peer reviews require all students to complete a feedforward form for each other's presentations. The feedforward form is based on the principles of "CAOS," which means to give constructive, actionable, objective, and specific comments. By placing a

premium on peer review as integral to assignments, students are provided with authentic experiences of how to engage in this practice.

Concluding the Conference

Each iteration of this course I have taught, much like every conference I have attended, could be improved. Regardless of my enthusiasm for this course and my efforts to make it engaging, not all students are sold on disability studies and/or excited about a course design based on the model of an academic conference. To these students, I am like that university professor in Toronto who introduced me to disability studies in my mid-20s. I can only hope that like me, these students will give disability studies another chance later in life. In contrast, some students find disability studies almost immediately impactful and since having taken the course have presented at peer-review conferences and/or are undertaking projects in which disability studies is central or related to their theses/dissertations. For these students for whom the course is what I hoped it would be—transformative—I am bolstered by knowing how they apply disability studies in their lives as music educators. What I hope I have provided in this chapter are some insights on how I go about teaching disability studies in music education at the graduate level. I perceive my approach as one of many possible permutations from which an instructor might adopt and/or adapt aspects that suit their teaching context. If more people in the profession of music education can engage with disability studies wholeheartedly, our teaching and research practices will steer—sharply, I hope—to disability-centric ways of knowing and doing music education.

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13. Approaches To Studio Music Teaching for Students with Disabilities: A Scoping Review of the Literature

Melissa Raine and Grace Thompson

Introduction

In Australia, like many countries, equal opportunity acts exist that protect the rights of students with disabilities to participate in education on the same basis as other students (Victorian State Government, 2010). For students attending government funded schools, each state provides frameworks to ensure that reasonable adjustments will be made to support the participation of students with disabilities in education in accordance with the *Disability Standards of Education Act* (2005). The frameworks protecting against discrimination for music lessons taking place outside of the school system are less clearly defined. Therefore, access to instrumental music lessons for students with disabilities can be highly varied.

This chapter explores the barriers to and enablers of access to instrumental music lessons for students with disabilities. To address this aim, we conducted a scoping review of the literature related to pedagogical approaches to studio instrumental music lessons for students with disabilities, and in particular for autistic students. The term "studio music lessons" refers to education contexts where teachers offer individual or small group lessons in a particular instrument. This form of tuition is commonly offered in Australia and is sometimes also known as "private music lessons." Studio music lessons can also be offered within the school system where children are taken out of the classroom for individual or small group tuition. In contrast to classroom teaching in school contexts, there are no standard requirements for studio music teachers to have a qualification in teaching (Victorian Institute of Teaching, 2021). Studio music

teaching has been described as a component of a musicans' "portfolio" approach to their careers, where they engage in a range of work in which teaching may just be one aspect (Bennett, 2008). Teaching environments, teacher qualifications, and teachers' selection of pedagogical practices as well as curricula, are accordingly diverse. These pedagogical practices can include different philosophies, approaches, methods, strategies, and training. In this varied landscape, there is no consistent, shared source of knowledge available to studio music teachers of pedagogical practices relevant to students with disabilities. As a largely unregulated professional community, studio teachers must seek out their own professional development activities, such as through music teacher associations (VMTA, 2023).

There is growing awareness that students of all abilities can be successful in learning to play a musical instrument, and that there are a range of benefits from engaging in music education for all students. Little is known about the pedagogical approaches music teachers currently use when teaching students with disabilities, which impedes the formulation of recommendations for teaching practices, and consideration of an evidence-informed approach to meeting the needs of diverse learners. The pathways for acquiring knowledge and skills to support students with disability, and in particular autism, are not clear; nor is it well understood whether studio music teachers are working towards the same learning goals with students with disabilities as those applied to non-disabled students.

Our rationale for this scoping review was to identify teaching approaches employed with students with disabilities by instrumental music teachers, the modes in which the teachers' knowledge was acquired and their practices developed, as well as perceived barriers and gaps in provision. The analysis of the literature aimed to build a better understanding of factors impacting access to music education for young autistic people, and how the situation can be improved. The research questions guiding the review were as follows:

1. What barriers to and enablers of access to studio music lessons for disabled or autistic students are described in the literature?
    a. Are particular values and philosophies associated with barriers to and enablers of access to music education for disabled or autistic students?
2. What types of benefits of music education for disabled people are described in the literature?

Method

With our intention being to broadly explore a distinct aspect of music education, namely the salient considerations relating to studio music lessons for students with disabilities, we conducted a scoping review of the literature. Scoping reviews are a suitable approach where researchers seek to identify knowledge gaps, and/or to clarify concepts related to a particular topic (Munn et al., 2018). Unlike systematic reviews which seek to evaluate the strength of evidence, scoping reviews focus on providing an overview of a topic and therefore a formal assessment of the methodological quality of the included literature is not undertaken (Arksey & O'Malley, 2005).

Literature Search Procedure

A keyword search was conducted of EBSCO databases, producing results in RILM Abstracts of Music Literature and OAIster/Worldcat; ProQuest; PsycInfo, and Google Scholar. Search terms were related to descriptions of disabilities or conditions including: autism; autism spectrum disorder; neurodiversity; disability; special educational needs; and special student. In addition, we searched terms related to their exposure to teaching contexts including: private music instruction; studio music teaching; music studio; studio music lessons; private music instruction; music teaching; and music teacher training. We did not specify outcome search terms

as we wanted to search broadly for studies on studio lessons and disability, with a focus on autism. The selected terms were combined using the Boolean operators “AND” or “OR.”

Inclusion and Exclusion Criteria

As an informal indicator of quality assessment, the search was limited to peer reviewed articles and conference papers, as well as book chapters and theses. We therefore excluded grey literature and non-peer reviewed articles. Included sources needed to be focused on studio music lessons (individuals or small groups), with those based within classroom contexts excluded. Sources also needed to be either reporting research outcomes (quantitative or qualitative), or be clearly describing a teaching protocol, strategy, practice, or method. We limited our search to articles published from 2006 onwards, as this was the time when the United Nations published the Convention on the Rights of Persons with Disabilities (2006) (See Table 1 for inclusion and exclusion criteria).

Table 1

Inclusion and Exclusion Criteria

[see separate document for Table 1]

Screening of Sources

A total of 107 retrieved sources were identified from our search of databases and imported for screening into Covidence, a literature review platform. In addition, 12 items were

added following a hand search. After removing 44 duplicates, the titles and abstracts of 63 items were screened by both researchers to determine eligibility. All 63 were considered eligible to proceed to the full-text review stage. Where conflicts occurred between the two reviewers, consensus was achieved via discussion. Forty-nine studies were excluded according to the criteria in Table 1 (see figure 1 - PRISMA flowchart). A summary of the characteristics of the included studies is shown in Table 2.

Figure 1

PRISMA Flowchart

[see separate document for Figure 1]

Data Extraction and Synthesis

We created a data extraction template within Covidence to identify text related to our research questions and the key characteristics of each source. Items related to the key characteristics included: date of publication, genre, country of data collection for research articles, description of students' disabilities, pedagogical approach or method, and musical instruments taught. Items related to addressing the research questions included: values and philosophy of the teacher or teaching approach, barriers to access, enablers of access, benefits of music education described, and attitudes of music teachers. The annotated data was cross-checked by each author, with discrepancies resolved collaboratively.

Following the extraction of the data, we first created a table of the key characteristics of each source (see Table 2). To address our research questions, we worked collaboratively to inductively code the extracted data. We were informed by principles of content analysis, since the data related to a priori research questions (Cho & Lee, 2014; Elo et al., 2014). Following Braun and colleagues (2019) process of codebook thematic analysis, we grouped codes from the data extraction process into themes related to the a priori research questions. Next, we looked for patterns across these codes and identified sub-themes emerging from the analysis.

Findings

Study Characteristics

We found 14 sources that focused on studio-based music teaching practices used to support the learning of students with disabilities, and in particular autistic students. Five (sources 2, 4, 6, 11, 13) were expert opinion directed at teachers; three (sources 1, 3, 7) were studies based on surveys and interviews of teachers; one (source 5) was a qualitative study of methods used by teachers; one (source 8) was an evaluation of a training workshop for teachers; two (sources 9, 10) were case reports of students; and two (sources 12, 14) were qualitative studies of student responses to lessons prepared by the researcher.

The expert opinion sources generally focused on providing advice and strategies that would promote access to the benefits of instrumental learning. The four studies investigating teacher experiences explored relationships between teacher attitudes and knowledge about autism and other disabilities, finding that teachers who were better informed generally had better attitudes about teaching these students; the use of appropriate strategies and willingness to adapt pedagogical practice were also recommended. The four studies of student experiences broadly

found that teachers' knowledge of student conditions, thoughtful adaptation or reconceptualization of the student relationship with the instrument, and careful attention to student responses, assisted autistic and disabled students' participation in music education.

Table 2

Included Sources Summary of Characteristics

[see separate document for Table 2]

Themes emerging from the analysis

Our findings are reported below and organized according to our research questions. Table 3 provides a map of the main themes relating to our research questions, the emergent sub-themes based on our coding of the data, and the sources of the data.

Table 3

Mapping of Themes and Subthemes

[see separate document for Table 3]

Enablers of Access to Studio Music Lessons for Disabled or Autistic Students.

We identified a recurrent expectation in all 14 sources that teachers who customize pedagogical practices to the student's unique learning profile enable access to music education for students with disabilities. Adaptations were often aligned with philosophies relating to inclusion. In these frameworks, a strengths-based approach to disability was commonly cited, and teachers were often regarded as providers of opportunity for their students. Within these sources, flexibility, patience and willingness to adapt lessons seemed to be important teacher characteristics for supporting these values. In practical terms, teaching practices were described as breaking down tasks, adjusting the pace of lessons, incorporating multi-sensory modes of learning, and departing from standard techniques whenever such strategies were considered beneficial to learning. There was also emphasis on teachers creating meaningful connections with students. A teacher who engaged with the student as an individual was considered to be well positioned to adapt the lesson materials to be meaningful for that student. Knowledge of the student's condition was also recommended to improve access. Some attention was paid to institutional support, training, and access to professional development, as well as collaborating with other supporters of the student, and some sources briefly noted environmental considerations, but most of the studies focused on what teachers did in the lesson. No single music instructional method was found across all of the studies to be especially suited to supporting the learning needs of autistic students.

Barriers to Access to Studio Music Lessons for Disabled or Autistic Students.

We found that across all of the sources, less consideration was given to barriers to access to studio music lessons for students with disabilities. Our analysis of the data revealed that barriers to access fell broadly into two categories; teachers holding perspectives of autistic and disabled students that derived from a focus on deficits, and teachers seeming to lack the capacity or willingness to adapt their pedagogical practices. Our analysis revealed that teachers' seeming

inflexibility could also be associated with inadequate training and resources. Some sources suggested that teachers sometimes misunderstood their students during lessons due to a lack of understanding of students' conditions. Teachers might not have strong awareness of issues relating to disability due to a lack of appropriate training opportunities. Teachers having reduced access to information related to disability was associated in some sources with the positioning of music teachers as experts in nurturing music excellence, who, as such, are not expected to acquire expertise in child development or disability.

Values and Philosophies Associated with Barriers and Enablers. Some sources described teachers' philosophy of including parents in music lessons as a value that could impact access. However, we found that parental involvement was considered to be both an enabler and barrier in different contexts; parent-teacher communication could improve learning, but parents were also perceived as interfering with or unsupportive of learning. Teachers' attitudes were generally considered to be enablers of student learning. An attitude of responsibility from a teacher was considered in some sources to have a significant effect on the quality of lessons. We found that teachers' beliefs about their personal responsibility to make appropriate adaptations were considered to enhance a student-centered learning environment, and that these values were in keeping with the student-centered and strengths-based philosophies that were associated in our sources with enabling access to education.

Benefits of Music Education for Students with Disabilities. Codes related to the reported benefits associated with studio music lessons for students with disabilities included both musical and non-musical aspects. Musical benefits included instrumental and performance skills, general knowledge, and creativity. Alongside the musical benefits, non-musical benefits such as developmental outcomes across multiple domains, and positive experiences associated with wellbeing, were also perceived to be important lesson outcomes. The musical benefits identified

did not appear to be specific to students with disabilities. Some of the categories of non-musical benefits described appeared to be particularly relevant for autistic students, such as considerations related to the sensorimotor, social, communication and emotional regulation domains. Other categories, such as inclusion, developmental advances and providing opportunities for wellbeing-enhancing activities, appeared to relate more broadly to students with disabilities. All of these benefits can also be relevant for students without disabilities, but we found it noteworthy that non-musical benefits were prominent in the sources.

Discussion

This scoping review sought to identify perceived barriers to and enablers of access to studio-based instrumental lessons for autistic or disabled learners. Our analysis found that for enabling access, the literature placed high value on teachers adopting student-centered, strengths-based approaches. Adherence to traditional teaching practices, standard curricula and assessment regimes were associated with a lack of student-centeredness. Along with inadequate teacher knowledge about the student's condition, we found that adherence to traditional approaches was considered to be a barrier to learning for autistic students. We also observed that studio lessons were thought to offer to autistic and disabled people both musical benefits and non-musical benefits associated with developmental achievement and wellbeing. Philosophies of inclusion were generally held by teachers using student-centered approaches. These teachers regarded patience and flexibility as important attitudinal factors that were closely related to their inclusive outlook and the value placed on student-centered, label-free approaches. These findings conform with research into inclusion in classroom education, which is more extensive than literature on inclusion in studio lessons. Flexibility, made possible by teachers' skilful use of feedback to progress students' learning towards success, and the belief that success can be achieved by all students when they are respected as learners and people, are more broadly associated with

excellence in teaching (Hattie, 2012). We found that there are significant gaps in knowledge about criteria employed by teachers to customize lessons, about the dissemination of knowledge amongst teachers, and about what constitutes a successful lesson outcome. We also consider that there are potential contradictions between teacher values and their pedagogical practices. There seemed to be a lack of contextualization of studio lessons within the learner's life or in relation to social and cultural considerations. These gaps and inconsistencies raise questions about what is being achieved in the lessons.

Increased Access … But to What?

In the sources analysed for this review, committed teachers who embrace child-centered, strengths-based approaches valued getting to know their students and tailoring their practices to the individual's needs. A philosophy of inclusion usually grounded these teacher beliefs and practices. Our review found that the methods and standards used to determine what constitutes a successful lesson outcome are unclear. This lack of clarity may be related to the varied definitions of inclusion in educational contexts (Nilholm, 2020). The strong attraction to customized lessons may promote inclusion in the sense that more students receive access to instrumental lessons if lessons are tailored to their needs, but it might also reinforce a distinction between practices considered to be suitable for differently abled learners, which are more closely aligned with quality-of-life considerations, and approaches practiced within mainstream learning, which are more closely associated with specifically musical outcomes. Waitoller (2020) argues that such distinctions are implicit in contemporary educational practices informed by a neoliberalist philosophy; "Even when trying to move away from special education and deficit models, current educational practices generate new and more sophisticated sorting mechanisms based on deficit and medical models" (p. 98). In this formulation, the best intentions to address the child's unique learning needs are doomed by socioeconomic forces that maintain segregation;

in this case, in the form of ableist criteria for fulfilling an economically productive social role (Waitoller, 2020). The relevance of this argument to studio music lessons for students with disabilities requires further investigation.

Pickard's case report (2019) addressed the dichotomization of music provision for learners with disabilities that occurs when "strategies for 'inclusive' provision […] don't interrogate or problematize the underlying discourse around normalcy and diversity," leading to "'differentiation' for 'special' learners" that reinforces an abled/disabled dichotomy (p. 12). Pickard advocates for teacher knowledge of the learning profile associated with specific conditions rather than inclusion based on one ableist paradigm. This recommendation implicitly addresses the repeated observations in the literature about inadequate training, professional development, and the characterization of studio teachers as music experts that positions knowledge about the learner as subsidiary.

Customization Without Standardization?

Our analysis found strong endorsement for the view that a customized approach to instrumental lessons was well suited to studio music lessons for students with disabilities, in which standardized evaluation of music achievement did not play a significant role. Without a shared framework of lesson evaluation that is relevant to both disabled and non-disabled students, the criteria for formulating learning goals and appraising lessons appeared vague and inconsistent in the reviewed sources. This distinction potentially reinforces the dichotomous modes of teaching and access outlined above. There were some exceptions; Soo (2019) employed the Sounds of Intent framework – an objective measure that could be used to evaluate progress – to situate musical engagement in a developmental framework. Weishaar's (2014) evaluation of results using the US National Standards of Music Education showed student

responses to be more complex than previously represented in research. These divergent examples suggest that the role of standardized evaluation for learners with autism and disabilities requires further exploration.

Teacher Attitudes and Training: A Cause and Effect Dilemma

We observed in the data a possible tension between music teachers striving to be student-centered yet lacking knowledge of pedagogical practices that could promote musical achievement in students with disabilities, and in particular autistic students. Gaps in training, professional development and resources were identified in some sources as problems needing to be addressed (Parkes, 2015; Polischuk, 2019, Dumlavwalla, 2020; Weishaar, 2014). Au and Lau (2021) and Parkes (2015) found that teacher knowledge about autism provided through specialized training improved attitudes towards autistic students. Increasing access to such training may therefore result in teachers who are better prepared to teach autistic students, in turn improving their access to studio lessons, but there were some indications in the literature that this situation is more complex. Dumlavwalla (2020) found that teachers did not always access appropriate training when it was available. We found that reviewed sources did not identify why teachers might not avail themselves of appropriate professional resources, but two studies (Au & Lau 2021; Norris, 2020) raised teacher fear of disability as factors in their decision-making about the students they worked with. Jiminez (2012) also referred to teachers ending lessons when students did not respond to traditional practices. Adhering to standardized approaches could function as a form of gatekeeping, providing some teachers with a means of maintaining a sense of control over their own experiences of teaching by limiting students to those who respond positively to traditional instructional practices. Norris (2020), one of the two studies that interrogated the concept of inclusion (the other being Pickard, 2019), speculated that such reservations can be understood as adherence to hegemonic cultural beliefs rather than malicious

acts of exclusion. Greater availability of appropriate and relevant training for studio music teachers is one potential response to the perception of inadequate knowledge-gaining opportunities. Improving such access might not yield improvements. Tarantino and colleagues (2022) have argued that increased "infusion" of pre-service teachers with disability-specific content does not on its own improve teaching; rather, it needs to occur in conjunction with opportunities to synthesize theories and guiding principles with personal practices and beliefs, which collectively shape how teachers organize learning environments.

Prior attitudinal factors may affect whether or not teachers incorporate student-specific adaptations in their lessons. This factor may be more significant in a studio rather than a classroom setting, as teachers in a studio lesson environment generally have more discretion over the selection of students. The complexities of the relationship between access to appropriate training and/or knowledge acquisition, teacher attitudes, teacher values and provision of studio lessons to students with disabilities were not clear from the sources reviewed. We observed that this issue was framed in terms of a dichotomy between mainstream education, associated with traditional approaches and standardized curricula, as suited towards "neurotypical" or "able" learners, and special needs education, characterized by individualized approaches, as suitable for "other" learners. Tarantino and colleagues (2022) found that the experience of working with students with special educational needs and disabilities built confidence and promoted positive attitudes in physical education teachers in school environments. In a studio environment, music teachers may be able to be more selective and less exposed to such experiences, and therefore less likely to learn through experience.

Inconsistent Notions of Child-Centeredness

Another potential difficulty raised in our analysis is that widespread adherence by teachers to a child-centered philosophy varies in application. Norris (2020) described a discrepancy

between teachers' embrace of the principle of flexibility and the "firm limits to their flexibility" in lessons, including restricting choice of music and alternatives to learning standard notation (p. 106). Dorita Berger (2017) offered a strengths-based, inclusive philosophy in the introductory sections of her book *Kids, Music n'Autism*;

> we need to think beyond the 'spectrum' and instead investigate the abilities of a child, rather than focusing on disabling limitations […] there are no such things as "dis abilities"—but rather 'in abilities' in some ways of functioning within 'typically expected' manners, therefore necessitating access to alternative abilities and possibilities. (p. 25)

In the chapter included in this study which elaborated on characteristics of lessons suitable for autistic learners, Berger maintained a distinction between "treatment" and "training," arguing that therapy "can correct some of the deficits adequately to prepare the child for learning to play an instrument" (p. 74). This distinction is perhaps an "in ability" in Berger's terms, but also appears to be ableist, assessing the child's suitability for music learning based on a perception of deficits.

In another apparent disjunction between principles of child-centeredness and practice, one study found that the presence of multiple instruments in the teaching space encouraged spontaneity (Weishaar, 2014), whereas other studies prioritized reducing distractions to promote focus on the pre-determined instrument (Dumlavwalla, 2020; Parkes, 2015; Soo, 2019; Steele & Fisher, 2011). These potentially contradictory views raised the question of perspective – distracting for whom, and from what? There is not necessarily evidence to indicate that a child who may have pronounced attentional difficulties benefits from such an arrangement – it may be more of an aspiration of the teacher than a verified child-centered practice, based on a teacher's

assumptions rather than the collaborative or cooperative engagement associated with child-centered values. Seeking out student perspectives could offer further clarification, but these were not commonly included in the reviewed sources.

Parent feedback, and indeed parents more generally, were found to occupy contradictory roles in relation to their children's instrumental learning. In some studies, parental involvement was considered valuable (Jiminez, 2012; Pickard 2019), while in others, teachers were uncomfortable with parental involvement (Norris, 2020). The significance of parental feedback was correspondingly unstable, with some teachers using it to modify teaching and others preferring to inform parents of practice requirements; Steele and Fisher (2011) valued communication by teachers to parents but did not articulate a role for parental feedback to teachers. In Walker's ecological model of disability (2023), derived from the work of Urie Bronfenbrenner, families of children with disabilities play a significant role in the mesosystem as providers of opportunities for their children to participate in educational and community activities. Inconsistencies in parental roles in the sources reviewed may be symptomatic of confusion about the concept of inclusion more generally (Simplican, 2015). This confusion may also indicate inadequate consideration of how demographic features of students or their families may be impacting the availability and characteristics of studio lessons. Waitoller (2020) points out that parents, especially those from minority backgrounds, are frequently disempowered in contemporary educational environments, further diminishing opportunities for meaningful inclusion of students. Of note, our sources predominantly represented North American contexts, and did not explore these issues. Given the vague and sometimes inconsistent statements of benefits, outcomes and strategies for autistic and disabled students, it is unsurprising that parents and teachers were often misaligned in these circumstances. The variation in attitudes towards

parental involvement indicates a need for further research into the context within which studio lessons are offered.

What of Instrumental Pedagogical Approaches?

Our analysis of these fourteen sources revealed that a variety of music instructional methods were described. This diverse range of well-established methods included Suzuki, Dalcroze, Eurhythmics, Kodály, Orff, and Yamaha (Berger, 2017; Dumlavwalla, 2020; Froehlich, 2013; Parkes, 2015; Steele & Fisher, 2011). Other methods referred to included adaptions to music notation formats, such as Figurenotes (Kaikkonen, 2015) and color coding systems (Norris, 2020; Pickard, 2019; Platz, 2021; Steele & Fisher, 2011). Some sources referred to learning theories that were associated with special education such as errorless learning (Pickard, 2019), Sounds of Intent (Pickard, 2019; Soo, 2019), and applied behavioral analysis (Polischuk, 2019). No single teaching method was found to be best suited to music lessons for students with disabilities, but factors such as teacher beliefs, values, attitudes, and knowledge of disability, seem to have a larger impact on accessibility. The emphasis on teacher attributes within the included sources may indicate awareness that relational adaptivity contributes to learning, but the sources do not refer to a framework for understanding these processes (see further research by de Bruin, 2018; 2022). The cognitive apprenticeship model, for instance, includes modelling, scaffolding, coaching, exploration and fading as subcategories of teacher-initiated interaction that promote that transfer of knowledge (de Bruin, 2019). It is possible that such strategies are occurring without being explicitly recognized when teachers refer to the tailoring of their methods for students with disability. Promoting the dynamic interpersonal techniques employed by a teacher from the status of "intuitive" to structural elements of the learning process may shed light on the profusion of methods alongside the emphasis on the personal qualities of the teacher found in our sources.

Future Directions

The analysis of the fourteen studies included in our review revealed that factors enabling access to music education for students with disabilities are often related to teachers' knowledge of disability, and their values, beliefs and attitudes towards students with disabilities. For example, sources that generally favored child-centered, flexible and, broadly speaking, holistic approaches to studio lessons for autistic and disabled students, strongly advocated for improving access to quality music education for a diverse range of students. These attitudinal factors are also highlighted by the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) as critical for the inclusion of students with disabilities in all forms of education. In contrast, standard curricula and strategies were sometimes associated with inflexibility and a deficit focus, in that it takes "extra" work to accommodate students with disabilities, which is onerous on teachers (Tarantino et al., 2022). Inclusion and standardized approaches seemed generally to be broadly opposed in our findings, and the former was considered the more favorable approach for the needs of students with disabilities or autism. However, a strong focus on lesson customization unsupported by a standardized methodological framework may run the risk of inconsistent and subjective implementation. This dilemma raises the question of whether the strong focus on student-led learning succeeds in broadening access to instrumental learning, or whether these lessons are in some sense distinct from goals and strategies that commonly guide lessons for non-disabled students.

Limitations

Within the parameters of a scoping review, we included a range of sources and did not evaluate the quality of the research studies included. More than a third of the sources included

were in the form of an expert opinion or commentary article or book chapter, and three were case reports with vignette examples of student outcomes and experiences. Five research studies documented student responses to lessons, leaving four others that inquired into teacher experiences. We did not distinguish between home-based and school-based studio teaching. Further research into whether school-based studio teachers have more access to professional development would be beneficial. Although there was generally strong endorsement of student-centered approaches, reports of student feedback were limited. Identifying appropriate ways of including the perspectives of children with disabilities, whose voices may not conform with individualist notions of self-expression, would improve the evidence for claims of child-centered practice (Tisdall, 2012). Consideration of parent feedback within the research studies was also inconsistent, suggesting that the relationship of studio lessons to the child's ecology, in which parents play a crucial role, would benefit from clearer formulation.

Conclusion

From the perspective of inclusion, the emphasis on the well-intended practices identified in our review may inadvertently bolster a double standard rather than providing improvement in access, reinforcing the unspoken assumption that music education for students with disabilities is related more closely to quality of life — that is, it is therapeutic — and less to musical achievement. Attending to individual student learning profiles, and applying standardized teaching practices, are not inherently opposed. Our interpretation of the findings suggests that a balanced evaluation of the student's skills and capacities, synthesised with relational elements of teaching such as attunement, flexibility, and getting to know the student, could be beneficial for the provision of music education in a studio environment for students with various abilities and challenges. Committed teachers may enhance their pedagogical practices with reference to a framework that expands our view of the bell curve and renders visible the continuity of

individual students' learning experiences, rather than reinforcing the compartmentalization of ability. Training opportunities for less experienced teachers may also improve through the development of systematic approaches and resources that complement a strengths-based focus, and are seen as valid for all learners. It may be desirable for future research to investigate the relationship between the philosophies that inform studio music lessons for children with disabilities and the pedagogical approaches to music education that are, or are not, being employed. Resisting the drift of lesson customization and standardization of approaches away from each other, and promoting instead their convergence may contribute to the process of supporting studio music teachers to develop practices for fostering achievement in all learners.

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14. Not Inclusion Because Black Disabled Entertainers Have Always Been Here

Leroy Moore

We, as Black disabled people, must not fall for the recent movement in our society locally, and globally that says we must fight for inclusion. Inclusion into what? And so this chapter will push back to say that we, people with disabilities especially Black disabled people – from Moses with his speech impairment to the original creation of the Dozens of Black disabled ancestors who were forced to entertain the White slave ship crew members (Smith, 2014). Their telling of short snappy stories later became the foundation of battle rap, the impetus behind many blind and physically disabled Blues artists, minstrel show artists who were also Black and disabled. Since the first ship to the colonial states, we have always been here, fighting for liberation and inclusion, access and opportunity.

This chapter shows that in many cases these early Black disabled entertainers were resisting at the same time creating music and movements, whether they be movements of freedom from oppression, or freedoms of expression and creativity such as The Jazz Movement by Rahsaan Ronald Kirk, to today's Krip-Hop Nation. This highlights Black disabled musicians working together as music makers and at the same time activists. As a Black disabled radical activist/artist I must put the title of this book, *Disability and Musicking: Resistance, Defiance, and Innovation*, into the work of a Black radical activist and educator, the late Walter Rodney (1942-1980), a Guyanese historian, political activist and academic. This current book actually follows a previous collection of resistant, subversive and defiant musicking called Guerrilla Music (de Bruin & Southcott, 2024) that looked at community musicking. This word resonated with me. Walter Rodney coined the term, *guerrilla intellectual* (1990), his purpose: to use his knowledge in service of the working poor. He described himself as a guerrilla intellectual, committed to studying the concrete realities of the working class. He believed in the centrality of education in revolutionary struggle and, alongside his work as a professor.

Tunde Adeleke's (2000) essay: Guerrilla Intellectualism: Walter A. Rodney and the Weapon of Knowledge in the Struggle for Black Liberation, explained that the black intellectual must become a guerilla intellectual (GI) to address "the initial imbalance in power in the context

of academic learning" p.41) between blacks and whites. The underpinnings of education being books, reference materials, and theoretical assumptions have and continue to be controlled and manipulated by whites. Given this disparity, the black intellectual had no choice but to adopt guerilla tactics. Rodney urged black intellectuals to embrace a first and major struggle, that is, over ideas, by using their positions within the academy to challenge Eurocentric ideas. Furthermore, as a product of bourgeois environment, the GI must first free himself from the entrapment of bourgeois culture, indeed from the Babylonian captivity of bourgeois society. Rodney prioritized three ways of accomplishing this freedom.

He suggested firstly that the GI should vigorously attack those distorted ideas within his discipline that are used to legitimize European domination and hegemony. Secondly, the GI should transcend disciplinary focus and challenge the dominant social myths in society, particularly those that are used to mask the ugly realities of society. Thirdly, the GI should fully commit to the masses by getting closer to, and grounding with them, gaining insights into the true character of society and culture. Cabral alludes that only then will change happen, “a reconversion of minds-of mental set-is thus indispensable to the true integration of people into the liberation movement” (2009, p.6)

Accomplishing these three functions became, for Rodney, the litmus test for ascertaining the depth of the intellectual's commitment to the interests and redemption of the people. This involves creating a linkage between the theoretical underpinnings and the practical realities of experiences. Rodney firmly believed that unless, and until, a black intellectual is willing and able to effect this kind of transcendence, he remains in the class of enemies of the people. As he declared, "all of us are enemies to the people until we prove otherwise." (Adeleke, 2000, pp. 41-42). In my Masters’ thesis, I argue (Moore, 2023), that it’s time for Black disabled scholars/activists/artists/authors to Krip the writings and theories of Cedric J. Robinson (2013) relating to Black Radical Tradition. I continue this kripping here with the work of Rodney.

A historical reevaluation

I use the term Krip, and Krip-Hop to reclaim Black disability history and to flip it into self-pride and international solidarity. regarding the abbreviation from cripple to crip, the latter was reclaimed by the critical disabled community as an insider language. herein lay a tension

point impacting towards people with disabilities by non-disabled people, especially those in power. From the disabled community, the term crip segued academia mostly by White disabled academic scholars like Alison Kafer (2013), and Robert McRuer (2006).

This recent critical disability activism and disability scholarship has reclaimed the word crip from the word cripple shows both terms remain vital. A historical survey of mainly but not exclusively Black disabled entertainers such as Boogie Woogie piano and dancer, Clarence Clemens (1887-1957), born with a limp and thus calling himself Cripple Clarence Lofton, dancer Henry Mack Heard (1924 –1991) experiencing amputation of one leg and one arm after a car accident, from which Crip Heard was born. He loved to dance and continued dancing after the car accident mostly in black vaudeville theaters and nightclubs during the late 1940s and 50s. A 2004 New York Times article (2004) claimed that "with one arm and one leg, he upended assumptions that disabled people could not lead fulfilling lives, and his artistry had audiences clamoring for more". As early as the 1940s Black disabled performers challenged attitudes, boldly turning the (then) derogatory term crip, into a stage name, declaring pride in his body's unique power of expression. My recent work (Leroy, 2023) has raised the profile of Black artists who used disability terms as their stage names, including Arthur Jackson (1911-1977) aka Peg Leg Sam, Joshua Barnes Howell (1888-1966) aka Peg Leg Howell. Numerous others have received scholarly attention, as I explain:

> *We also had soul singers like Peg Leg Moffett with his 1967 song, The Shocker so it's not shocking that this tradition of having a disability title in your name. The most famous in Hip-Hop to carry on this tradition probably by reality that his health disability forced him to realize his eating habits was Phife Dawg with his stage name that clearly told his disability, The Funky Diabetic. Of course, there are many White Hip-Hop artists who also carry out this tradition of having a disability title in your name that are underground like Wheelchair Sports Camp and Blind Fury*. (Moore, 2023)

The term crip from a Black perspective emerged outside the entertainment industry. Los Angeles street gangs of the 1970s found an authentic realism in nicknames. I share this dialogue between gangster Stanley Tookie Williams, who co-founded the Crips gang in LA. Firstly my poem:

Tookie Gave Me Permission, It didn't fall from the sky

Wasn't in an academic archive, I didn't make it up

It didn't start in Hip-Hop, A Black newspaper in San Francisco

Liked my pen, don't you know, They published my news

Of Black disability issues, Was writing to disabled prisoners

Word got around about Michael Manning, Helped to get his freedom

Questions came from Freedom Archives, "Leroy, you still want to ask Tookie Williams questions?", My chance of a lifetime

Had to narrow it down to two, Question number one....

"Is it true that the word Crip came from a disabled gang member?"

Question number two, will stay between I and the late Tookie

Tookie wrote back thanking me for my letter and told me the following:

"I read the Bayview newspaper, and I like your writing and organizing. If your organization was around in my day, a lot of Black young men who became physically disabled would have had a chance to not only be an activist but to be proud of disability with your help turning hopefulness and pity into Black disability empowerment! By the way, yes, the Crips had a physically disabled member so we called him Crip for short so among the other stories of how we got our name, Crips, this is one of them."

Sincerely

Your Brother, Tookie Williams (personal communication)

In the early 2000's I created Krip-Hop Nation using the term Hip-Hop and societal negativity to this term, turning it into an empowering and political term. Earlier African history that has ties to disability and Hip-Hop resides in Black folk tales of the creation of the Dozens on slave ships and battle rap. Smith's discussion of this argues:

> *Several other terms have been utilized to describe The Dozens, such as hiking, snapping, cracking, woofing, sounding, and signifying, but the term "dozens" appears to predate them all having first entered into the lexicon in the late 1800s. Scholars, however, do not agree on the etymology of the term. The most prevalent theory appears to be that African slaves who appeared to be "defective" were sold at a discount in lots of one dozen. Therefore, to be in The Dozens means you must have some type of physical or mental defect to be ridiculed.* (Smith, 2014, p. 2)

The roots of Hip-Hop have longstanding historical ties to disability. Bible stories refer to Moses, one of Jesus's disciples who had a speech disability. Jesus didn't heal him and so gave him his brother, Aaron, to speak for him what we would call today an accommodation. People with disabilities have always been here, especially Black disabled people. Having dispelled the myth of inclusion, we return to Black disabled performers, mainly musicians.

Krip-Hop and historied Black disabled performers

The separation of disabled Africans from their families continued after slavery was in theory abolished. Downs (2008, np) surveys that:

> *disabled slaves were virtually left enslaved under the control of plantation owners proves the extent to which the notion of freedom was consistently tied to questions of labor. If a discourse of equality truly emanated throughout the South, then all slaves would have been free, not just those who could work or those who were connected to wage-earning freed people. But this was clearly not the case; disabled slaves were left in the plantation South.*

The 13th Amendment of the US Constitution did little for how Black disabled people were treated in this country even after ratification of slavery abolition. Once Black generations had left

the plantation home, they fared little better. Thomson (1997) refers to how many Black disabled people were hired in freak shows between 1835-1940. Thompson (1997, p. 59) writes:

> *Several physically and mentally disabled black men were displayed under the title "What Is It?" a name that expressed the freak's ambiguous humanity and challenged spectators to resolve the disparity between this body and their expectations. Barnum's advertising poster challenged onlookers to make the distinction: "Is it a lower order of MAN? Or is it a higher order of MONKEY? None can tell! Perhaps it is a combination of both." Billed as "missing links," the "What Is It?" figures complemented after the midcentury a growing interest in Darwinian distinctions between humans and gorillas. For instance, in 1860 a black microcephalic man, as Barnum, introduced William Henry Johnson with the exclamation, "What Is It?" depicts him as "a most singular animal" who was neither human nor beast, but "a mixture of both-the connecting link between humanity and brute creation.*

Another Black performer was Joice Heth,

a black woman already on exhibit in Philadelphia in 1835 as George Washington's 161-year-old nursemaid and dubbed The Greatest Natural and National Curiosity in the World (Reiss, 1999). *Thompson continues: Barnum bought the right to show her for one thousand dollars, turning his new possession into the first act of a long and profitable career. Dismissed by the public as a hoax and later renounced with a mixture of chagrin and pride by Barnum himself, Joice Heth is nevertheless the quintessential American freak: a black, old, toothless, blind, crippled slave woman, she fuses a combination of characteristics the ideal American self-rejects. Joice Heth thus represents America's composite physical other, the domesticated and trivialized reversal of America's self-image. (Thomson, 1997, p. 59)*

I suggest that people with disabilities, especially Black disabled people, were a cornerstone of the entertainment industry before television and the beginning of the music industry. Baraka complements this stance, urging that “music and melody is not the only way the gap between American culture and African American culture was bridged (Baraka, 1963, p. 14).

Today we find a powerful disability rights movement, disability studies and disability Justice and Krip-Hop movements that have all increased more than disability pride. More importantly, scholars assert the expansion of disability history, politics, radical voices and cultural expression. There needs to be more research and writings about art history concerning people with disabilities, especially people of color with disabilities within their own ethnic culture.

With this in mind, I again return to the prequel to this publication, *Guerrilla Music: Musicking as Resistance, Defiance, and Subversion* (de Bruin & Southcott, 2024). Here, they write that:

> Guerrilla Music investigates the myriad ways and idiosyncratic situations and contexts in which defiances, resistances, and subversions exist … the act and essence of music resistance can be harboured in various ways and guises, represented in a continuum spanning reluctant subordination and acquiescence, to destructive, violent dismantling (de Bruin & Southcott, 2024, pp. 4-5)

This stance vindicates how Black music since the beginning of the United States represents a resistant, defiant and subversive role in American and African American history. Despite the removal of our language, drums, and culture, Black music continues to be a powerful form of resistance used to uplift othered Black and Black disabled people out of oppression (Baraka, 1963).

An early song, *Follow the Drinking Gourd* offers insights into disability, resistance and subterfuge. History recalls a one-legged sailor, known as Peg Leg Joe, who visited numerous plantations as he made his way around the South. At each job, he would become friendly with the slaves and teach them the words to the song, *Follow the Drinking Gourd*. Each spring following Peg Leg Joe's visit to these plantations, many young men would be missing from those plantations. Peg Leg Joe's plantation visits focused on the area north of Mobile, Alabama, around 1859. A clandestine escape route had been established that travelled north to the headwaters of the Tombigbee River, through the divide, and then down the Tennessee River to the Ohio River. To guide the slaves along the way, the trail was marked with the outline of a human left foot and a round circle in place of the right foot (Owen Sounds Black History, 2004). I argue that the making of the secret lyrics, and the passing on to the community is a fine example of Guerrilla Music/musicking.

Early Black disabled entertainers resisted identity tropes yet at the same time created music and social movements. My work with some of my Black disabled musician elders, the Blind Boys of Alabama, the late Little Jimmy Scott, the late Rob DA Noize Temple and late Celeste White retold stories of raw discrimination in the Jim Crow south. Theirs was a longstanding defiance of protest. Rowden's (2009) work discusses blind Blues and jazz musicians. Wald (2013) explores how one of the first American Black Folk singers was a guide to most famous Blind Blues artists during their travels through the South. I had an opportunity to interview Josh White Jr. years ago and he told me one amazing fact as follows:

There were 66 different blind black street singers my old man led. From the age of 7 to16 and a half, none would teach him how to play. So he would pick up the guitar of whomever he was leading at the time when they would go off and do whatever they were going to do without their guitar and dad would play it in whatever tuning it was in and with his own raw talent he found his way. In the early 1900s there were many blind blues street singers all across the south and they were not begging, they would stand on the different streets and EARN a living. (personal communication) that the recording industry had their pick of blind blues singers to record (Moore, 2016)

Here I offer the lyrics to my remake of *The Blind Man Stood on the Road & Cried:*

The blind man stood on the road and cried, Yes, a blind man stood on the road and cried
Hollowing gentrifiers give me back my home, Crying gentrifiers give me back my home
Moaning oh my lord please save old me, Crying Jesus help my community

Crying Jesus help my community

Yes a blind man stood on the road and cried, Tell me where are your shoes

Tell me where are your shoes, Crying Jesus save my poor community
Yes a blind man stood on the road and cried
Now this is the gentrification Blues I sing, Now this is the gentrification Blues I sing
Crying O'Lord save my poor community, Yes a blind man stood on the road and cried
Well the blind man stood on the road and cried, Yes a blind man stood on the road and cried

Crying O'Lord save my poor community, Well the blind man still on the road and crying

Similarly, the work of Dorthaan Kirk and Rahsaan Roland Kirk, a blind black jazz musician that started the Jazz & Peoples' Movement in the 1970's resonates with a highly political musicking (Tress, 2008). Black and used the stage to deliver his pro Black politics and loose ties to the Black Panther Party. The Jazz singer Al Hibbler's political actions, picketing and marching with Martin Luther King in the 1960's forced his music label to drop him (Zelenak, nd).

Accounts at the scene describe Al Hibbler leading pickets in Birmingham, with police refusing to send him to jail, despite his efforts and wishes. "You can't work and anyone who goes to jail has to earn his food…you can't do anything, [not] even entertain." In response, Hibbler lamented, "The police are trying to segregate me from my own people." (New York Times, 1963a, b; Iton, 2011). An under explored activist, I explain Al Hibbler and his activism through my poetry, entitled, Jazz Man Turned Civil Rights Activist

Al Hibbler with Martin Luther King

On the protest lines, he sang

Police reacted in pity

Refuse to arrest him, that was cops' story

Ain't I a man

Equal opportunity

Human dignity

Hibbler standing tall in the Alabama sky

It was 1963

King hoped Hibbler's arrest would generate more publicity

To protest, Al Hibbler, one of the first celebrities

“It's going to be two blind cats and a wildcat-Ray Charles, Al Hibbler and Sammy Davis Jr.,"

Al reacted after hearing about the shooting of Malcolm X

That’s when he called MLK

Record label didn’t like that

Frank Sinatra brought Al’s back

Under his own label

Al always wanted to be at the table

When police refuse to arrest him

Al said, that’s discrimination at the highest level!”

Jazz Man Turned Civil Rights Activist

Al Hibbler was the ish

I bet his name was in MLK’s “Letter from Birmingham Jail",

Like Ivory coined, Jail No Bail

I lastly highlight that when Black disabled musicians come together to make music they can do so as a resistive, defiant action. This book, *Disability and Musicking: Resistance, Defiance and Innovation* (de Bruin, Skinner & Southcott, 2025) offers an emancipatory lens as the editors refer to musicking that liberates and challenges oppressions. They also understand that emancipatory practices are agentic, providing the ideal for all in full participation in decisions, programs, and behaviours that impact all involved. Important work, there is still a lack of written scholarly articles on the collaboration between disabled musicians, especially Black disabled musicians, and what that may mean for connection, community and social action.

A point of context is the meeting between the late soul singer Teddy Pendergrass aka TP 1950 –2010) and Johnnie James Wilder Jr. (1949 –2006). Both became disabled in the middle of their music careers. Pendergrass (1998) discussed this coming together as a gathering of

musicians who live proudly as wheelchair users. The documentary *The Story of Heatwave* (2010) features

Roselyn Benson, Johnnie Wilder's wife. She discloses Johnnie's anxieties about being accepted as a disabled performer. The documentary also tells of inaccessibility encountered across his life on the road being a constant pressure and demoralizing facet of life. Both TP and Johnnie discuss the realization that people would only look at them with sympathy, pity and questioning. In these cases, this is a symptom of the systemic and societal mistreatment that these disabled musicians have endured over their lives.

Hip-hop- Krip-hop

Hip-Hop's emergence, first in New York and then across the world brings authentic and contemporary resistances and defiance to societal and systemic prejudices and neglect. The first cyphers of this form of urban music located in the Bronx, where Black youth took electricity from the street poles, advertised and tagged their presence via graffiti, and crafted a performative space in the alleyway and bypasses upon which cardboard laden ground was the conduit to the breakdancers movements.

Rodney's term, guerrilla intellectualism takes on a youth oriented empowerment as Hip-Hop in the 1990's moved from music making to music reporting and journalism (Vibe Magazine, The Source and The Village Voice to name a few). Pioneers in Hip-Hop journalism including Greg Tate, Kevin Powell and Harry Allen captured evolving culture as candid images and visceral reportage reflected the growing urban Black hip-hop movement and its appropriations across the world. Although today Hip-Hop is considered mainstream and a multi-billion dollar industry, artists emergent in the beginnings of such underground movements used guerrilla tactics to get their art out there. It's interesting that all three Hip-Hop journalists, Greg Tate, Kevin Powell and Harry Allen express both interest and support of the history of disabled hip-hop artists and the concept of Krip-Hop Nation.

Whilst social media platforms like MySpace, YouTube, SoundCloud and now Spotify allowed artists to control their art, it also provided a place to bring music products and consumers together. Texts such as Davey's (2013) Guerrilla Marketing for Artists, and Snobhob's online series discussing Hip-hop, Marketing, and Black Culture are part of wider sub-cultural

and social semiotics that “underscore the increasing ontological and epistemological gap between modernist and post-modernist conceptions of resistance (de Bruin & Southcott, 2024, p. 5).

In qualifying the alignments between this and disability/race /gender social issues, guerrilla is a trope long applied to socio-political machinations, human conflict and confrontation. It is the music practices, stories, communities and musickers that resist, defy and subvert by silence and non-compliance, reluctant subordination, and subversive depowering. (de Bruin and Southcott 2024). In plain language guerrilla musicking is any activity involving or related to music performance, such as performing, listening, rehearsing, or composing. Taking DYI as an acronym for "Do It Yourself" refers to independence, self- design and bespoke intentionality.

Hip-hop takes the improvisatory reflexes imbued in jazz and adds an embodied movement and performativity. I see guerrilla musicking and DYI going hand in hand no better than the early days of Hip-Hop that displays these two concepts. Many Hip-Hop authors like Jeff Chang in his groundbreaking 2005 book, Can't Stop Won't Stop: A History of the Hip-Hop Generation writes about how the beginnings of Hip-Hop.

In the early Bay Area (San Francisco) music scene of the 1980’s up to the late 1990’s, a Black blind music engineer and musician, Joe Capers turned his basement in East Oakland into one the first fully accessible music studio. Joe’s work in home studio development once again invokes a guerrilla musicking -guerrilla recording. The recording of music in an independent and irregular manner using limited resources found quality, effectiveness and audiences for music that could not be performed, not recorded by the large white recording corporations.

Until the late 1970s, music could be recorded either on low-quality tape recorders or on large, expensive reel-to-reel tape machines. Due to their high price and specialized nature, reel-to-reel machines were only practical for professional studios and wealthy artists. In 1979, Tascam invented the Porta-studio, a small four-track machine aimed at the consumer market. With this new product, small multitrack tape recorders became widely available, and grew in popularity throughout the 1980s made it possible for the late Joe Capers to build his home music studio.

It took a San Francisco Bay Area disabled music collective named Krip-Hop Nation to bring the work of Joe Capers in the spotlight. In 2017, what can be called guerrilla advocacy was the implementation of an aggressive marketing technique to educate and motivate people to orchestrate for policy change. From the work of Leroy Moore and Naru Kwin, together with Krip-Hop Nation help convince Mayor Jean Quan and the City of Oakland to designate the month of August every year to be "Joe Capers Month" in Oakland, California. (Joe Capers Project, nd).

Today Hip-Hop has become a multi-billion dollar industry, though it continues to struggle with ableist attitudes and beliefs. Krip-Hop Nation as a collective since 2002 continues to use guerrilla music making, guerrilla marketing, guerrilla recording and guerrilla advocating to promote and elevate talent and politics into the music arena and conscience of the general public. Guerrilla techniques, and Rodney's term guerrilla intellectualism fits well in Krip-Hop Nation's mission by:

> *educating about the music, media industries and general public about the talents, history, rights and marketability of Hip-Hop artists and other musicians with disabilities. Krip-Hop's main objective is to get the musical talents of hip-hop artists with disabilities into the hands of media outlets, educators, and hip-hop, disabled and race scholars, youth, journalists and hip-hop conference coordinators. Krip-Hop Nation's public education has many avenues i.e. Internet magazine's columns, workshops, Internet radio show, publications and our famous mixtape series to name a few reporting on the latest news about musicians with disabilities.* (Krip-Hop Nation, 2024)

(INSERT IMAGE HERE)

Image: Leroy's scooter with a Black fist breaking through the seat with pink headphones and carrier on, cane leaning against the scooter and an open leather man bag. Artist: Hash24

Today in 2024 there are more and more organizations by musicians with disabilities who have made mainstream advances. The Coalition for Disabled Musicians, Recording Artists and Music

Professionals with Disabilities-RAMPD, Can Do Musos, and Drake Music in the United Kingdom are but a few. The music industry, compared to other industries, hasn't made a comparable move to be open to disabled people who are musicians, especially women with physical disabilities.

The 2009 Diversifying Hip-Hop: Krip-Hop Homo-Hop conference at University of California at Berkeley organized by Krip-Hop Nation brought together queer and disabled Hip-Hop artists to talk about ableism and homophobia in Hip-Hop. A 2019 live performance event including music, poetry, skits, dancing, speaking to our ancestors involved Disabled Women, Femmes and Warriors with headliner AJ420, called GenderKrip Planet.

In 2023 Hip-Hop celebrated fifty years. However, throughout that year Hip-Hop artists with physical disabilities were not featured or mentioned. In twenty-five years Krip-Hop Nation has not been invited to any Hip-Hop conferences. It is for these reasons, and many more that I pursue further study. I do so following Walter Rodney's philosophy of guerilla intellectualism, and grounding it with my Black and disabled communities to continue to assert a physical space for political education and increased cultural expression locally and globally

Krip-Hop Nation has a presence both musically, politically and socially. Through it, we envision a society where the opportunity for cultural expression, whether mainstream or underground, is embraced. It is critical that present and future disabled artists, especially Black/Brown disabled cultural workers, thinkers, and writers are studied from an anthropological non-ethnocentric perspective. We need to honor those that came before us, activating through our communities both locally and internationally.

Further expansion of the Krip-Hop Institute's work is to operate as a cultural, activist, and inclusive platform and meeting space for the community. KHI specializes in the accurate representation of those who are marginalized, especially disabled, Black, and the intersection between the Black disabled community therein.

People with disabilities make up the largest minority group in the world with a number as big as 1.3 billion people experiencing some sort of disability. This represents 16% of the world's population. In the US there is only one museum on Disability History, the National Disability History Museum in Buffalo, New York. However, people with disabilities have been a part of all aspects of life including entertainment from the beginning of enslavement, entertainment, Blues

to Hip-Hop. This chapter offers a complex appraisal of our music, Black music made by disabled people. It problematizes the many superficial orientations to inclusion beyond access, opportunity and equality. It asserts we have always been here, on the one hand advocating and on the other making, creating, and being. We do so armed with well-honed guerrilla tactics, asserting our space and place, the myriad ways, situations and contexts in which defiance, resistance, and subversion reinforce this fact.

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15. Toward an anti-ableist music education: Reconsidering the complex politics of inclusion

Tuulikki Laes

Introduction

In recent music education research, critical conceptualizations of diversity in terms of ethnicity, gender, sexual orientation, religion, and socioeconomic class have revealed power relations that determine who is included/excluded in music educational communities (Kallio et al., 2021; Talbot, 2018). However, within these conceptualizations, the social divisions arising from disability continue to be underrepresented in the analyses of social inequalities (Bradley, 2016). In music education, disability is often considered a separate category of teaching (Draper, 2024); one that is "often forgotten, dismissed or overlooked as an important part of what we consider to be diversity" (Darrow, 2015, p. 204), rather than one dynamic of intersectional identities among others, and a culturally composed and shared narrative of the body. That is, "a narrative that is similar to the ways we have come to understand the identities (and fictions) of race and gender" (Brueggeman, 2013, p. 283). Consequently, a simplified, binary social distinction between abled and disabled bodies/body-minds perpetuates inclusion and diversity discourses.

Within the broader educational sphere, processes of binary social distinction are particularly robust in music education, where the proclivities for educational factions that label students as (non)-gifted, -talented, or -exceptional thrive. Such labeling practices include various demands for qualities related to aesthetic components as well as physical and sensory individual capacities required for the technical craft. When disabled persons are welcomed onstage in music education, they are often selected with a focus on their exceptional grit and determination, reinforcing a cultural script of "overcoming disability" (Churchill & Laes, 2021) or as a "feel-good factor" for the audience (Fautley & Daubney, 2018), reassuring them that inclusion has thus been achieved.

Hence, while disability in music education is generally framed within the discourses of inclusion, through e.g., normalization, differentiated instruction, and assistive technologies (Rathberger, 2019), these practices often derive from hegemonic, nondisabled perspectives and

"reaffirms ableism in an unconscious and unproblematized manner" (p. 10), which continues to free the "center" of music education from the struggles of questioning its ableist practices (Bell, 2017; Churchill & Laes, 2021; Draper, 2022; Draper, 2024; Rathberger, 2019).

In the past several decades, thanks to the perseverant work of critical disability researchers and activists such as Mike Oliver, the conceptualizations of disability have moved away from the individual deficit model toward a more helpful understanding of disability as a social construct (Oliver, 2013). Furthermore, to challenge the able-disable binary, Dan Goodley (2018) has introduced the term dis/ability to emphasize the interrelation of disability and ability by linking ableism (the idea that able body-minds are superior) with disablism (the idea that disabled body-minds are inferior). At the same time, however, neoliberalism has become the reigning ideology of our era followed by a new rise of individualism where individuals are held accountable for their success or failure and the understanding of physical and mental weaknesses are often pointed as human deficiencies. This tendency of framing social issues as individual problems rather than systemic ones is designated by Goodley and Lawthom (2019) as "neoliberal-ableism" that accounts for the stifling practices associated with a contemporary society that increasingly seeks to promote the species typical individual citizen" (p. 235).

Music education scholars have identified reversal effects of neoliberalism. These include increasing pressures of accountability towards market-oriented consumerism (Woodford, 2019) that push music education programs to prioritize measurable outcomes and career-oriented skills and align them with consumer demand for marketable careers, thus reducing artistic freedom as well as the support for a lifespan engagement of "fundamental human intrigue with music" (Myers, 2008). Furthermore, the notion of performativity through competition (Powell, 2023) is manifest in the overemphasis of measurable achievements—like awards, rankings, and technical prowess—over holistic music experiences that foster creativity, collaboration, and personal expression.

The "centrality of ability (and its counter ability)" (Goodley & Lawthom, 2019, p. 237) in terms of "erasing disability from the center of music education" (Churchill & Laes, 2021) is closely linked to these adverse developments toward hyper-individualism and competition as the defining characteristics of the neoliberal era. Hence, this chapter attempts to continue challenging the perpetuating definitions of ableist concepts and discussions toward a more

complex and political discussion about including dis/ability theories, discourses, and dis/abled individuals in music education.

Despite devoted calls to create more socially and musically inclusive environments for individuals with disabilities, the ableist hegemonies and stigmatizing views of disability have remained largely unchallenged in music education due to the uncritical adoption of the special education agenda that—no matter how well-intended—is based on dividing students into the categories of "normal" and "special". As identities within the times of liquid modernity (Bauman, 2000) are "always situated as complex, intersectional, and socially constructed—not as fixed or rigid" (Davis, 2013, p. 5), assigning individuals to dualist normal/special categories seems outdated yet persistent in the educational sphere. Indeed, despite thirty years since UNESCO's Salamanca Statement (1994) that introduced the fundamental idea of full inclusion of all students in schools and classrooms, studies show that inclusion is still "exception not a norm" (Graham et al., 2020).

Studies concerning inclusion in music classrooms highlight the lack of preparedness of music teachers to create and implement inclusive strategies and adopt inclusive educational ethos beyond the normal-special binary, which may limit dis/abled students' peer interactions and access to the regular curriculum (Draper et al., 2019; Pino, 2022; Wong & Chik, 2016). Hence, similarly as in other educational fields, music education has maintained a narrow understanding of inclusion as an educational policy that only concerns physically integrating students with special educational needs or disabilities into regular classrooms. This narrow understanding portrays inclusion as a "majority versus minority issue," making it "a political problem" (Bauman, 2012, p. 76).

Due to the special/mainstream professional silos in the field, those in "the center" of music education lack interest in challenging the ableist hegemonies and political complexity of inclusion (Churchill & Laes, 2021). This perpetuates the field by maintaining an ostensible political neutrality (Laes et al., 2024) by adhering to "a sanitized vision" of music education (Woodford, 2019, p. 22). Hence, the question of inclusion is not only about how the "marginalized" are treated in music education but also about how to radically engage with democratizing music education that goes beyond student-centered practices, new music repertoires, and praxialist values (Laes et al., 2024).

In seeking more democratic alternatives, I will first discuss the problem of special education and the new, more radical, and political forms of inclusive education that counteract the dualist notion of "normal" and "special". Then, I will examine dis/ability from a performative aspect in music and music education, extending to how music teacher education and music professionalism can strive for new and more complex (and inclusive) understandings of expertise and ownership in music through performing disability. Finally, through these theorizations of inclusion and intersectional perspectives on disability, based on my keynote address at the *ISME Commission of Special Music Education and Music Therapy Online Pre-Conference Seminar* (Laes, 2020), I will put forward a complex political view that may help us envision how and why ableism could be dismantled in music education.

Special education and the unspoken question of power

Historically, there are implicit assumptions about disability in society that have led to a generally shared view that "special education is the only place to successfully teach students with learning disabilities" (Kirby, 2017, p.176). This implicit assumption forms the ground for special education as a normative discipline (Kirby, 2017) that is based on categorizing language and systems (Demetriou, 2020). Against this hegemony it is not surprising that inclusion lacks clear definition, standards, and objectives as an alternative to special education practices (Francisco et al., 2020; Saloviita, 2020). Consequently, education professionals are navigating between diagnosis awareness and thinking "beyond the label" (Draper, 2018, p. 31) while "trying to design instructions and strategies that would bridge the gap caused by the disabilities" (Francisco et al., 2020, p. 11). As disabled students are often considered dependent on professional intervention in terms of treatment, special educational support, and professional care, any enactment toward full inclusion is usually articulated as an ambiguous "process" (Saloviita, 2020) or "problem" that demand more resources and causing additional workload for the teachers (Francisco et al., 2020, p. 8).

In music education, the medical model of disability based on the functional limitations discourse is often supplemented by the assumed benefits of music for such labeled students, incorporating therapeutic effects that often remain immune to critique and may seem mystical to those outside the music therapy profession. Critique of the music therapy clients' imposed "sick role" emphasized by the medical model (Oliver, 2013) has been addressed within the music

therapy field, with articulations of a more positive task "to increase possibilities for action" rather than underline the functional limitations (Ruud, 1998, pp. 51-52).

In the same vein, special music education has moved away from stigmatizing segregation toward integration and normalization with benign aims to respond to individual students' needs (Francisco et al., 2020). However, such helping professionalism may sometimes risk creating dependency rather than emancipatory and transformative processes (Young & Mintz, 2008). Helping professional roles can maintain hidden barriers in setting limited goals for students and generating feelings of pity as a form of "psycho-emotional disableism" (Hughes, 2012). The high expectations of how music can help students with special needs and disabilities risks overrunning the questioning of power relations. They manifest in professionals' practices that reveal a "lack of awareness of the complexities of the individual experience of disability" (Atkins 2016, p. 3), for instance by ignoring that the students do not necessarily wish to be helped but included as equal participants. Consequently, individuals assigned to the disability category are expected to act according to the predetermined, bounded agency rather than exceeding the norms in unexpected and, in some cases, undesirable ways when the outcome does not meet the aesthetic and quality criteria required for successful overcoming narratives (Churchill & Laes, 2021).

Music therapy and special music education are thus intertwined at the fringes of music education, causing confusion about which professional group is responsible for dismantling the norms and structures in music related practices that perpetuate functional deficit models, This perpetuates the unclear relationship between special and inclusive education, addressed by numerous critical scholars in various contexts (Allan, 2010; Demetriou, 2020; Enslin & Hedge, 2010; Florian, 2019; Graham & Slee, 2008; Liasidou, 2012; Schwab, 2020; Slee, 2019), also in music education (Churchill & Bernard, 2020; Churchill & Laes, 2021; Darrow, 2015; Laes, 2017a; Rathberger, 2019). In other words, as long as the field of music education settles for leaving the responsibility for showcasing "inclusive practices" to special music education or therapy professionals, inclusion can be used as a means for maintaining the status quo "within which several disguised forms of marginalization, discrimination, and exclusion are operating" (Liasidou, 2012, p. 9; see also Graham & Slee, 2008).

The entrenched professional mental models that create social distinction between normal and special students, also beyond special education, not only affect how music teaching is organized in school classrooms but also have a long-term effect on the opportunities to engage in

democratic musicianship in professional contexts, media, popular culture, and society. Consequently, the practice of paving expanding and flexible professional pathways for differently abled persons has thus far remained absent in higher music educational contexts (Laes & Westerlund, 2017; Laes, 2017b; Lunn, 2021; Thompson et al., 2024). In other words, music education generally tolerates difference as long as the professional ideal of the expert musician is not challenged (Odendaal et al., 2020; Ruddock, 2016). As Albi Odendaal and others (2020) remind us, leaving ableist discourses unchallenged can also have negative consequences for the professional education of music and music education through maintaining "the narrow interest on highly skilled expert musicians, and by reducing musicality into a biological and genetic phenomenon" (p. 362). Taking the yet unspoken questions of power hierarchies and elitist notions of musicianship caused by ableist structures and practices beyond special education arenas can expand the professional music field to embrace "different strengths, perspectives, and types of expertise as opportunities for cooperation" (Laes & Westerlund, 2018, p. 10) that not only promote inclusion but also contribute to expanding transformative music professionalism.

In a previous critique of the ableist center of music education that so rarely engages with matters of dis/ability (Churchill & Laes, 2021), we have considered the ideology of ability, following Siebers (2011), as a framework for critically exploring the ways through which music educators can break away from the dichotomous struggles of special/normal or other categorizations in music education. As suggested by Churchill and Bernard (2020), the ideology of ability is the dominant response to disability in the music education field. We further elaborate (Churchill & Laes, 2021) that such an ideology is not only a form of erasing disabled bodies and identities from the picture of music education but also a form of educator performativity, which has to do with maintaining the ableist center of music education. In this way, the responsibility for challenging the contradicting aims and ideologies between special education and the inclusion principles not only concern special music education professionals but also teacher education and the professional field more broadly.

Performing dis/ability in music education

The persistence of the modernist notion of the disabled body as an individual deficiency over more recent social-cultural, relativist disability models in music education (Dobbs, 2012; Oliver, 2013) points to the domination of the performativity-oriented ethos in music education (Kanellopoulos, 2015) which manifests itself through the use of student selection and music

criteria that define who is entitled to learn and perform music and what "real" musical agency or musicianship looks and sounds like (Burnard & White, 2008; Ruddock, 2016). As Odendaal and colleagues write, these selective methods paint "a dystopian picture in which individuals will be rightfully included or excluded from musical education based on their genetic code, and where it is legitimate that only those with the right genetic framework receive access to music education" (Odendaal et al., 2020, p. 366). While the notions of talent and musical aptitude have been given more critical scrutiny, the performativity orientation continues to legitimize processes of social distinction in music education that might otherwise seem politically questionable and unequal.

Performativity agendas in education typically attempt to translate "complex social processes and events into simple figures or categories of judgments" (Ball, 2003, p. 217, see also Kanellopoulos, 2015). The educational institution carries the burden of categorizing students based on school performativity and individual characteristics, which in itself contradicts the ethos of inclusion (Enslin & Hedge, 2010). Furthermore, the performativity aspect in higher music education and its institutional models is more burdensome than in other subjects due to its ableist and elitist views on musicianship (Odendaal et al., 2020). Music education scholars have identified how the performativity agenda is bolstered by neoliberal educational policies "highjacking" music performance and even creativity and student-centered practices to prop up and produce competence-oriented educational practices (Kanellopoulos, 2015; Powell, 2023).

At the same time, as musicologists Lerner and Straus (2006) noted, "a disability may remain invisible until it is performed" (p. 9). They consider performing disability as "attention to disability and impairment" that "brings greater attention to music as a manifestation of our embodiment, whether that be as listeners, composers, or performers" (p. 1). The same need for embodied attention goes with performing disability in music classrooms. Although it has been stated quite unsurprisingly that pre-service teachers are more likely to construct positive attitudes towards inclusive education if they have had the chance to engage in real encounters with disabled people during their studies (Cook, 2001: Draper, 2024; VanWeelden & Whipple, 2013), enacting critical discursive learning in music teacher education contexts for example through teaching with and by disabled people themselves, rather than teaching "about" disability, is still unusual (Bremmer, 2023), and is still in many ways considered inconceivable because of the dominance of performative musico-pedagogical models (Kanellopoulos, 2015; Laes & Westerlund, 2018). However, as experimented by music education scholars, challenging the

performative aspect of dis/ability through inclusive partnerships and collaboration between non-disabled and disabled individuals is not a simple task, as mere participation does not equate with inclusion (Laes, 2017b; Majerus et al., 2020; Nichols, 2016).

Music performance as an embodied practice can also highlight the pathology of individual bodies. Kuppers (2001) has drawn our attention to the apparent hypervisible-invisible paradox in performing disability in arts contexts, where a disabled performer is simultaneously invisible due to their categorized "outsider status" in the public sphere and hypervisible as "instantly defined in their physicality" (p. 26). Due to this paradox, disability is often regarded as what is performed over the musical content; hence, the "performance" emerges from the individual who exhibits some form of identified difference (Churchill & Laes, 2021). Hence, performing dis/ability in music and the arts can provide narratives of possibility or exclusion within broader social-political contexts, which also affect the performance. However, while critical histories of dis/abled bodies are rarely included as a category in the art education curricula due to their complexity (Derby, 2011), securing political sensitivity should not come at the expense of maintaining an ableist environment in higher arts education.

Music educators can promote anti-ableist framework by challenging traditional performativity-oriented models, encouraging inclusive performance contexts, pedagogies and curricula that support diverse body-minds and artistic pathways, questioning social and societal norms that limit access to musicking and professional musicianship, and addressing intersectional experiences of minoritized groups in music education. Engaging with performing dis/ability can take place through participation in intentional discussions and various ways of musicking with differently abled individuals, also in higher music educational settings.

A complex view on inclusion: staying with the trouble

The imperative of inclusion is a global educational policy that promotes equality of opportunity and respect for diversity, terms that are, paradoxically, used in the neoliberal notions of performativity and accountability (Atkins, 2016). As articulated by Lennart Davis (2013), "diversity" has become an ideal of "the new normality" that is well suited to the core ideology of neoliberalism through its celebration of superficial differences between (self-interested) humans, serving the image of a consumerist free-market world (Davis, 2013, pp. 2-3). Disabled bodies, nevertheless, rarely fit in this "big tent of diverse nationhood" (p. 3) unless they are represented in a photogenic manner that serves the appearance of the desired diversity.

As Sean Powell (2023) contemplates, “the neoliberal version of inclusion creates an object of desire and then seeks to give everyone equal opportunity and access to that object—a version of ‘diversity’ and ‘inclusion’ that nonetheless operates through exclusion” (p. 110). This sleight of hand often goes unnoticed by educators who might have implicit biases where they normalize certain behaviours, structures, or policies without questioning their possible discriminatory impact, for example by uncritically regarding their role as helping professionals who engage with “freeing the marginalized” (Koivisto, 2022, p. 30). Consequently, “education professionals have become so comfortable with the concept of inclusion (and, in some organizations, comfortable with the belief that inclusion is ‘successful’)” (Atkins, 2016, p. 3) that the inclusion discourse is now uncritically adopted without practical implications.

While these idealized notions of “successful inclusion” are consistently used to envision education free from exclusion and discrimination, a more complex approach indicates that inclusion is not necessarily a task for educators to perform successfully by ensuring that once all people are included, it becomes a normal condition of society (Biesta, 2009). Rather than seeing inclusion one-directionally bringing those in the margins to the center, educational theorist Gert Biesta regards inclusion as a “sporadic” process of democratization that “disrupts the existing order” (p. 110). In this process, those who include and are included cannot be separated. Instead, it is a constant “democratic experiment” of confronting the complexity of educational choices between opportunities, limitations, values, and power (Biesta & Osberg, 2010). This complex view on inclusion urges music educators to view inclusion as an ongoing political responsibility embedded within education itself, requiring imagination beyond normalized structures to create meaningful and equitable musicking experiences for all as “a place for experimentation with the possibility of the impossible” (Osberg, 2010, p. 164).

Democratic inclusion can thus be considered “a political project” that aims not to prove or disprove that all human beings are equal, rather, the project is about ongoing reflection of what can be done differently under the current circumstances (Biesta, 2009; Laes, 2017a). A political project is simultaneously “a space of freedom and public deliberation”, and “a space of power, conflict and antagonism” (Mouffe, 2005, p. 9) where questions are posed concerning “the very way in which society is instituted” (Mouffe, 2005, p. 9) and our commitment to “existing together” (Biesta, 2013, p. 113).

Freeing educators from the fear of making "right" and "wrong" choices while critically acknowledging that education always involves the exertion of power points to the significance of inclusion directions rather than its outcomes. Inclusion as an ongoing political project cannot be realized only through teaching future teachers how to make education more inclusive through instructional strategies but also to enable spaces for risk-taking through experiments and reflections that do not have a clear, predetermined outcome but require education professionals to "stay with the trouble" (Biesta, 2013; Haraway, 2016) rather than attempting to solve the problems.

Staying with the trouble conforms, as Biesta (2009) states, that inclusion is not only the main purpose of democracy but also one of its main problems—which makes it a political question. Hence, I suggest three starting points for further considerations of inclusion as a political project. First, inclusion as a political project acknowledges that everyone has something to teach and learn from each other. The inclusion question is more than just a question about who (in the minority) should be included (by the majority); it is about how we enable everyone's participation effectively in the political where matters important to everyone are deliberated and dialogically negotiated (Biesta, 2009). In music education, these matters can cover the negotiation of the aesthetic and social qualities of music/-king, including the question of who is entitled to be a musician or what level and characteristics of expertise are needed to teach something important and meaningful to others about music/-king.

Second, the inclusion project is not only about the professional (re-)organizing and breaking of physical, social, and pedagogical barriers; it also requires a more comprehensive transformation of the institutional structures and mental models penetrating the field. As Powell (2023) provocatively writes, inclusion is not about providing "more resources to 'losers' so they may compete with the 'winners'" (p. 112) while maintaining the field as it is. Resistance to the kind of change that requires a total dismantling of mental models has been identified in the studies of institutional music education systems. These mental models manifest not only on the level of individuals' attitudes but in ideologies that are materialized in the structure "as institutional spaces, established practices, and tacit knowledge", and which in music education have been identified as residing within elitist spaces and structures (Väkevä et al., 2022, p. 423). Therefore, more resources directed to special educational professionals, equipment, or ideas—to include "losers" in the environment where "winners" thrive—is simply not enough to make democratic inclusion real in music education communities. Instead, music education

professionals must engage with profound and ultimately uncomfortable questions about their accustomed habits on maintaining "musical quality" (Väkevä et al., 2022, p. 425) and holding on to the professional mental models at the expense of perpetuating ableism and inequalities in music education.

Third, due to the perpetuating professional boundaries between mainstream and special music education, many music educators may operate within homogeneous environments that do not expose them to diverse viewpoints. This can lead to a narrow understanding of what constitutes inclusion and what it looks like in music education. It is also worth acknowledging that change can be difficult, and some music educators may feel threatened by altering long-standing practices. They may cling to traditional methods that they perceive as effective, despite evidence of inequity. Hence, constructing an anti-ableist framework for music education requires collectively staying with trouble and persevering with questions that have no settled solutions.

Reconsidering the im/possible as a democratic experiment

Expanding the customary understandings of inclusion in music education may provide a lens through which we can reflect upon the goals of inclusive music education in broader terms than the mere "tolerance of difference" (Laes & Westerlund, 2018; Matthews, 2015). While—at its best—inclusive music education might result in "better music education for everyone, having an impact beyond the 'target groups' through social integration, cultural participation, and reciprocal transformation" (Laes, 2017a, p. 69), a complex politics of inclusion operates beyond the level of teaching practices and effective policies. Complexity requires disagreement, collision, and radical transformation of the status quo on individual, social, and political levels. As long as inclusion is considered mainly a concern of the special education profession making a social distinction between normal/special, it implies a question: who is fit enough for democracy? Who has the right to construct their musicianship on their own terms, participate in musicking, and work professionally in the field of music education in accordance with the same goals as other learners and actors, not having music merely as a tool for therapeutic, rehabilitative, or other (externally defined) benevolent goals?

As much of the discussion of inclusion takes place within the special interest groups of disability scholars, music therapists, and special music educators, an important question is where should we undertake discussions about what democratic inclusion looks like in music education, and with, or by whom? Hence, the critique here is not necessarily aimed at any specific professional group but more broadly, toward contemporary music education professionalism that (sometimes unconsciously) bolsters categorization processes in determining who is defined as "normal/special". However, inclusion as a democratic experiment is not about rethinking terminology but rather what action is needed to change the patterns of different socially determined realities, educational processes and professionally organized structures. Inclusion may be seen as "an illusory concept" per se (Atkins, 2016) unless we are ready to transform the scripted realities and problematize the "taken for granteds" in the currently dominating practices and discourses of music education.

Indeed, inclusion can simultaneously appear as an arena of endless possibilities yet an ideal that is impossible to achieve. However, inclusion as a democratic experiment reaches beyond simply including those who are decentered in the "existing order" of the center of music education. Instead, democratic experimenting is about reformulating the order in such a way that new identities, new ways of doing and being become possible and can be "counted" (Biesta, 2009) and "new options and representations of (co-)performing disability" can be forged (Churchill & Laes, 2021, p. 141). Hence, democratic experiments may be found at the intersection of the im/possible where the boundaries of those who include and are included are blurred.

Conclusionary remarks

The neoliberal ecosystem, fueled by individual choice, competence, and competition, not only sustains but benefits from ableism. As I have suggested in this chapter, constructing a democratic, anti-ableist music education framework within the neoliberal-ableist socio-economic landscape (Goodley & Lawthom, 2019), does not mean abandoning difference but rather taking into account the broad dynamics of the intersectionality of different social categories of human diversity as inseparable (Bradley, 2016; Darrow, 2015). This approach means a shift away from one-dimensionality in terms of normality, ability, expertise, quality, or success, to a pluralist stance, where differences can be embraced and where different

individuals and communities of expertise can thrive and teach as well as learn from each other. It is a shift toward a much broader and complex understanding of diversity and inclusion, with contextual interrogation of both the possibilities of and the restrictions on gaining political agency and ownership within (and beyond) music education for everyone in ethical, structural, and political dimensions. There is no need to establish consensus with regards to what "real" inclusive music education looks like. Instead, the constant troubling of power relations, false dichotomies, deficit categorizations, and traditional policies, as well as assuming inclusion as a political project, are imperative for reaching beyond the narrow and adverse understandings that thus far have perpetuated ableism within all levels of music education. What music education needs most to take new steps towards an anti-ableist framework is complexity treatment.

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CONCLUSION

16. Provocations and Horizons

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This scholarship has brought together what we consider a dazzling array of voices, attitudes, events, actions, and movements. This book includes cultural, sociological, educational and political aspects of disability, inclusion and access to musicking that have largely been overlooked in political or social musical histories. In addressing these important issues, our concern has been to approach music making by musickers with disabilities/differences as a cultural production both in itself and situated within larger personal and political agendas. In doing so we have offered disabled musicians of all ages, educators, facilitators, political activists and artivists a space and place to share their experiences and disseminate their research. In doing so we enact a public pedagogy that fosters inclusion in musicking, legitimating and encouraging confrontations and resistances to inequities, powerlessness, and discrimination.

The preceding chapters have focused on individual and shared musicking practices, seeking perspectives from diverse stakeholders with very diverse understandings of personal and shared experiences. Our collaborating contributors offer insights gained from applying inclusionary practices and visions at individual, institutional, or community levels, representing an evolving and often fluid practice, involving actions, performativities, methodologies, and philosophical underpinnings.

By investigating "practices and meaning systems used by musickers that often are built on underlying contrasts and dissonances of things that are unequal, unfair and unacknowledged" (de Bruin & Southcott, 2024, p. 3) this collection of scholarship further challenges ableist and conventional belief systems. Despite changing perceptions, too often we encounter disability understood in normative and medical models which no longer accord with person first principles.

As we have said, many traditional forms of musicking operate under codes that have the potential to exclude and stigmatize bodily divergence, where the conventions of music performance frame outdated behaviors, actions, and views toward disability. Through the application and adoption of crip theory and associated cripistemologies the writers of these chapters affirm the lived, embodied experiences of disability and the knowledges that emerge from musicking experiences whilst maintaining a criticality of

diverse representations concerning the inclusion of some that may not fit neatly within dominant vocabularies or awarenesses of disability.

Our authors provide wide ranging lenses of investigation that span the equitable, but also the ethical distribution of musicking in a wide, positive, and enabling sense. This reflects musicking that asserts an access to traditions, genres, behaviours, ideals, and attitudes. We argue that this book and recent scholarship by others, point to what we see as the *disabled turn* in musicking and arts practices. Beyond disruption, this critical disability movement defies and disrupts ableist sensibilities and narratives that yearn towards a norm, or worse a cure.

Moving normative (and separatist) attitudes aside, we suggest that the mind and body that might be seen as disabled or different, in reality provides an embeddedness, embodiedness and livingness, that benefits all arts practices, and music specifically. The inclusion of all is a benefit to all. Disability studies and performativities play significant roles in the evolution of a modern aesthetic to all genres of performance that embrace musicking, living, and being. We agree with the well founded assertions of Straus, who suggests that “disability is a source if enduring fascination, a means of shattering conventions and establishing new structural paradigms and new kinds of beauty”(2018, p.38).

Modern aesthetics, as an evolving sense of creativity and possibility arches beauty towards disability and disability towards multivarious engagements and lives as modes and means of creativity. This means the significant broadening and, in some cases, the radical subversion and disruption of traditional notions of beauty. Siebers (2010, p. 134) concurs arguing “artworks that exemplify an aesthetics of disability may thus turn traditional conceptions of aesthetic beauty away from ideas of the natural and healthy body”.

Our experiential, phenomenological and sceptical perceptions and accountings have underscored for us embodied understandings of musical phenomena as a universal trait of human cognition. It is through musicking that we extend our capacity as embodied musical agents. Musicking and disability offer novel and innovative ways of perceiving body, music, time, space, place, and community. The musical body maintains its own precious, embodied intellectual and physical complexity. This book contributes to the ongoing unfolding of critical disability studies in music, bringing to our attention the creative impetus of individuality and difference.

This book asserts a disability aesthetic that embraces beauty and creation for all, whilst also arguing how music and musickers eagerly create counterhegemonic spaces and movements. A significant standpoint here is the dismantling of institutional cultures that may limit and overpower

musickers and their musicking. Understanding that culture existing at both the micro and macro level, our authors provide for very different understandings of musical wisdom, teaching, and learning.

We also acknowleged the affordances of emancipatory approaches to musicking that liberates and challenges oppressions, forging new ways of being and doing in musicking. We understand that emancipatory practices are agentic, providing the ideal that all should be involved in full participation in decisions, programs, and behaviours that impact all involved. Our first book exploring Musicking: Guerrilla Music (de Bruin & Southcott, 2024) found diverse voices of resistance, defiance and subversion in musicking practices around the world. Many of our authors in this, our second book reveal forms of resistance, solidarity, emancipatory principles and practices underpinned by a praxial ethics of care that is the responsibility and right of all involved. More broadly we suggest that efficacious and apt ethical musicking must exist in a frame of respect, justice, and relational collaborations.

The organisation of this book, across evolving practices and movements, disabled performativities, and new epistemologies in disability teaching and learning brings together a unique collection of research work that extends philosophical and theoretical frameworks concerning disability, inclusion, access, and opportunity. Our collaborating authors provide wide ranging lenses on investigation, each with a particular and potent mix of practices, approaches, and methodologies that illuminate provoking experiences of musicking, resistance, defiance and innovation.

This book establishes new terrain in disability studies and music by forefronting disabled voices, experiences and understandings. In so doing we highlight through the lens of disability lived experiences the productive affects of musicking, via performative actions, relational dimensions, and new perceptions of understanding. Adopting these principles and practices also shapes music teaching and learning, both individual and collective. Scholarly and musical exploring of this kind reveals how the multidimensionality of music arises in the tensions and resolutions of its aesthetic, experiential, social, and political values. It is because of this that disability studies continue to uncover what we feel is a most profound, diverse, and exhilarating innovation in music performativities.

Many of our contributors have scythed into broad understandings of culture as musicking practices that are embedded in particular social and temporal contexts. We provide a questioning of institutional cultures that limit and dominate musicking and musickers. Understanding culture as surrounding musickers at both the micro and macro level, we provide very different understandings of musical wisdom, teaching, learning, and education. This scholarship reinforces emancipatory approaches to musicking that liberates and challenges oppressions. We understand that emancipatory practices are agentic, providing the ideal for all in full participation in decisions, programs, and behaviours that impact all involved. We offer examples of how, for whom, when, and where, the many cultural contexts musicking practices facilitate agency, wellbeing and transformation for abled and disabled people.

Musicking is a universal aspect of human cognition: we each understand the world through our intimate idiosyncratic and personal knowledge of our own bodies – both proprioception and interoception. Accordingly, we understand music making as a human artistic expression that is an essential facet of embodied human agents, each with particular capabilities, inclinations, and motions in time and space. Whether disabled or not, this book marks an underlining social and cultural acceptance of musicking, despite its resistive defiant intimations, is borne from the unequivocable right for all bodies and people to engage in harmonious, integrated musicking.

This book marks philosophical ideas that both support and critique a politics of identity and bodily experience, enacting processes, actions and movements that disturb, destabilise and dissolve normative attitudes, identities and difference.This *disabled turn* represents a new variability and turn toward music and the arts that thrives on the diversity of human biological, creative and cultural life. Once we adopt the turn, it is impossible to be otherwise.

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