



# Crippling the Muse

## Contributors

### Inclusive Research Skills Training Day Workshops

**Researching with people whose illness or disability means they lack the capacity to 'consent': What do you need to know about the Mental Capacity Act 2005?**

*Gillian Loomes, University of Leeds*

Involvement in research is key to the representation of disabled people in society - and their lack of involvement, and consequent lack of 'voice' have been challenged extensively (e.g. Barnes, 1996; Nind and Searle, 2009; Nind, 2011). Such challenge is situated in a wider context of commitment to collaboration and co-production, particularly by academic Research Councils. E.g. the Economic and Social Research Council (ESRC) states that "We are committed to knowledge exchange and encouraging collaboration between researchers and business, the public and civil society" (ESRC, 2016) and projects such as the N8 Research Partnership on co-production have informed the ESRC Impact Toolkit.

An area where such issues are acutely located is the involvement in research of people with disabilities/illnesses who lack the capacity to give informed consent. The legal, ethical and methodological dilemmas raised by this research, affecting academics across disciplines, as well as health and social care practitioners who engage in practice-based research, have been highlighted in a Special Issue of the York Policy Review, edited by Gillian Loomes, (Loomes, 2016 – see here) which is related to her own ongoing PhD research.

In this workshop, we will cover the legislative framework for research participation of adults who lack the capacity to provide informed consent (the Mental Capacity Act 2005) – along with relevant policy and practice guidelines. We will then think collaboratively about what this means for us as researchers, and how we can work within this framework to encourage meaningful involvement, participation, and 'voice' in research for disabled adults who lack capacity to consent.



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### **Carrying out Research with Disabled Children & Young People: Reflections of a Non-Disabled Researcher**

*Sarah Mawby, University of Leeds*

In this workshop Sarah will share her experiences of devising adapted research interviews for disabled children and young people. First, an overview of the methodological research literature in this area will be given, with a critical reflection on the ethical considerations discussed in this literature. Then, Sarah will reflect on her own experiences of devising adapted interview techniques for disabled children and young people. This will be a reflexive account, taking into consideration Sarah's 'outsider' status as a non-disabled researcher and the ways in which the literature affected her approach to devising adapted interviews for the disabled students taking part in her research. Alternative, creative, co-productive approaches to research will then be considered and we will work together to devise retrospective research methods for these students.

### **How Does it Feel to be Included?**

*Carley Stubbs, University of Leeds*

This workshop will begin with an overview of an Inclusive Research project that used Applied Theatre practices to facilitate a sense of inclusion and belonging for the research participants. This overview will explore the co-production process, detailing how we collaboratively shaped and negotiated the research space by using games and playfulness as a driving energy. The second part of the workshop will be participatory in nature. You will be invited to explore how it feels to be included by joining in with games and other playful activities. We will then have some time for reflection on the activities and some questions.

### **Inclusive Research with People with Learning Difficulties**

*Dr Rebecca Fish, University of Lancaster*

Rebecca Fish has been doing research with people with learning difficulties since 1997. This workshop will introduce the principles of inclusive research with people with learning difficulties. Rebecca will talk about some of her research projects and show how she made her documents and information easier to read. There will be some activities so people can have a go at making easier to read documents.



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### Keynote Speaker: Dr Paul Whittaker, OBE



Paul was born in Huddersfield in 1964 and has been deaf from birth. After gaining a music degree from Wadham College, Oxford, and a Post-graduate Diploma from the RNCM he founded "Music and the Deaf," which he ran for 27 years before leaving in 2015 to pursue a freelance career. In 1992 he began signing major musicals in the West End and on tour, including *Les Miserables*, *Phantom of the Opera* and *West Side Story*, and has also worked with *The Sixteen*, *Rambert*, *Opera North*, *National Youth Choir of GB*, and at the *BBC Proms*, *Edinburgh International Festival* and *Aldeburgh Festival*. He currently runs signing choirs in the North of England and recently created an online signed song teaching resource [www.sibsl.co.uk](http://www.sibsl.co.uk). Paul was awarded an OBE in 2007 for Services to Music and holds Honorary degrees from the University of Huddersfield and the Open University.

Music and disability have been a huge part of Paul Whittaker's life from a young age and his keynote speech will cover some of his experiences and observations. His specific field is music and deafness and over several decades he's seen attitudes to music and disability change tremendously – usually for the better but not always. This will be a very personal view of the subject and hopefully stimulate some thought and debate.



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## Spoken Presentations: Music, Health and Wellbeing

### **Blowing the post-human trumpet: Changing the humanist subject in music therapy practice through a disabled lens**

*Carolyn Shaw*

This pre-recorded presentation will discuss my shift away from humanistic thinking in music therapy practice towards post-humanism. I became aware of the problematic dominance of humanistic thinking in music therapy practice during the analysis stage of my PhD research, which is an autoethnographic study exploring how the close examination of my experience of disability and illness impacts on my understanding and implementation of practice. In particular, I found that humanism's ableist tendencies of the body and psyche that mark those who count or do not count as human, needed to be addressed. Humanistic ideals of autonomy, control, self-determination, independence and rationality also inscribe these characteristics as pertaining to the "good citizen" and exclude disabled ways of being that demand interdependence, or a sharing of autonomy and control. In short, disabled people still struggle to be considered fully human within this discourse. Alternatively, Braidotti's (2013) post-human subject is a relational entity (interconnected and interdependent) that is embodied and embedded (Braidotti, 2013). Post-humanism forms an "enlarged sense of interconnection between self and others, including non-human or 'earth' others, by removing the obstacle of self-centred individualism" (Braidotti, 2013, p. 190). I contend that post-humanism offers more possibility to form a positive disabled identity as it holds the central demand not to be pressured by society to adopt a "normal" body. Like post-humanism, disability has troubled the traditional conception of what it means to be human. To demonstrate the differences in humanistic and post-humanistic thinking in music therapy practice a video of a segment of a session will be played and discussed. I do so to uncover how humanism and its effects have become naturalised and normalised within music therapy practice. This presentation seeks to address the ableism inherent within this discourse and to find alternatives that do not restrict disabled people and their music.

### **A misunderstood guest, a misunderstood host: Music therapy within disability studies**

*Giorgos Tsiris*

Despite sharing certain interests, questions and critiques with regards to disability and music, the dialogue between music therapy and disability studies remains relatively underdeveloped. Recent initiatives have attempted to address this gap (Hadley, 2014), but music therapy's absence from key subsequent publications regarding music and disability studies (e.g. Howe et al., 2016) is indicative of the weak engagement between these two fields.

In 2013, and in response to Straus's (2011) reflections on music therapy from a disability studies perspective, I argued that music therapy is a 'misunderstood guest' (Tsiris, 2013). This misunderstanding is partly based on an incorrect assumption that music therapy is a homogeneous field within which a medicalized, deficit approach to disability is commonly accepted. Whilst challenging this



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assumption, I laid out certain sociocultural music therapy perspectives which could offer a platform for further exchange and mutual learning between music therapy and disability studies. Indeed, this platform has been used for dialogue and critique since then (Honisch, 2014), and in this presentation I take some of these emerging dialogues a step further. Carrying on with the metaphor of the 'guest', I reconsider some earlier arguments around music therapy's contribution in the study of music and disability. I also question to what extent the field of disability studies has similarly been a misunderstood 'host' by music therapy scholars and practitioners. By promoting interdisciplinarity (Tsiris et al., 2016), this questioning opens up a constructive dialectic space where learning and re-learning of practices and concepts is intertwined with professional vocabularies, frameworks and agendas within and around music therapy.

### **"Lost & Found" - Therapeutic song-writing with stroke survivors**

*Sonia Allori*

I had my first stroke several years ago and while recovering, my hungry brain decided to do a part-time PhD in composition and to train part-time as a music therapist. After 6 years I had achieved both qualifications and re-started my career as a musician, composer, researcher and music therapist. What can music do for the stroke-affected brain? I had insider knowledge and decided to devise a project working with other stroke survivors transitioning from the hospital stroke ward back home. Stroke affects people in different ways and this was obvious from the first group music session where everyone had their own experiences and their own stories to tell of their recovery.

The effects of music upon the brain are well-known and have been shown to gain positive results in self-esteem, cognitive processing, motor skills and communication skills in stroke patients and those recovering from traumatic brain injury (Purdie, 1997). When you combine principles of music therapy groupwork with a simple model of CBT and therapeutic song-writing where does the music creation process factor into recovery and of positive outcomes? Baker (2013) in her study of therapeutic song-writing process states, "Modified grounded theory methods led to the construction of three themes ... 1) music conveys messages and emotions, 2) music has clinical purpose, and 3) music enhances self-expression". When I applied a CBT frame-work to the writing of expressive song lyrics and melodies with stroke survivors I think I learned and benefitted as much from the discoveries as did the group members. We had all transitioned from our former selves, had lost parts of ourselves and were constructing new parts to create new identities within our now differently working brains and bodies.

In the "Lost and Found" project we all felt a shift in perspective: for me a sense of reaching an important point of epiphany in my creative practice. Key outcomes for group members included: steps towards acceptance and increased level of confidence; finding their literal voice and increased movement in arms and fingers; expressing moments of darkness and joy in the recovery period; finding others who understand the changes and the fatigue and brain fog and frustration and do not judge. In this paper I trace the journey of those striving to create new thoughts and experiences and a new life from the things now lost and guided by someone just a little bit further down the road of recovery.



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### Spoken Presentations: Music Performance Disability

#### **The social model of disability from a music technology (and ADHD) perspective**

*Charles Matthews*

The social model of disability is presented as the foundation for much current inclusive and Disabled people-led arts practice in the UK. It is a rights-based approach, which redefines disability by focusing upon the barriers and denial of rights created by society, rather than an obligation for Disabled people to adjust as a result of an impairment or perceived deficiency.

In discussing the social model, it's important to acknowledge more general removal of barriers, such as adjustments to buildings that can be of benefit to everyone. But what does this mean in context; for example, how is the social model applied more concretely to the field of music technology? Is electronic music culture somehow more inherently inclusive or accessible? What kind of action can be taken to establish equality of access, with this in mind? Where are the problems with this approach?

In this paper I examine how the social model of disability offers an alternative to culturally embedded approaches to access to music, which I suggest are often subtly biased towards impairment-oriented (e.g. charity or medical) models. I examine this through three overlapping areas:

- Acknowledging access: inclusion and normalisation of electronic means of sound production, including adapted instruments.
- Questioning classicism and virtuosity as social norms: the full integration in musical culture of diverse voices, playing styles, and ways of experiencing works.
- Moving towards development "by" and "with", rather than "for" Disabled people: ensuring access at the point of creation and composition, and opportunities to adapt or create derivative works through an open-source ethos.

This is an attempt to describe an attitude developed through several years of play, facilitation, and making, for the most part taking place in overtly "accessible" musical settings. In particular I draw upon recent work as a Drake Music associate musician, development of the Kellycaster in collaboration with John Kelly and DMLab, and subsequent endeavours to develop inclusive practice in other settings.

Examples are provided from recent conversations with Disabled musicians in the UK and Canada, as well as my own lived experience as I explore my identity as an openly ADHD artist through the social model.

#### **'Pop Prosthetics': Exploring negotiations and tensions surrounding the use of prosthetics in popular music**

*Robbie McDermott*

This paper draws on research from my PhD on popular musicians with limbs and/or digits which are absent (LDA). For them, the choice of using and not using prosthetics to play instrumentation is complex. When using prosthetics, disabled musicians may use those which can be tailored specifically for the techniques necessary for playing their instrument of choice. These prosthetics may be similar in form and



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function as the limb and/or digit it is trying to supplant. An example of this is the prosthetic fingers used by rock musician Tony Iommi of Black Sabbath (guitarist with partially absent digits) to allow him to fret the guitar using his residual digits. Conversely, other disabled musicians use prosthetics which are far removed aesthetically and/or functionally from typical limbs and/or digits. An example of this is the guitarist Lefty Williams who was born without a right hand. He uses a homemade device to enable him to strap a guitar pick to his residual limb.

In contrast to these examples, some disabled musicians have bypassed prosthetics and any form of assistive musical aids altogether. Instead, they have adjusted to traditional instrumentation. Sometimes, these adjustments are relatively slight: bassist Bill Clements (absent right hand) plays one-handed using his left hand on the frets in a percussive manner, for instance. Others are more dramatic, such as guitarist Mark Goffeney (born without arms) who uses his feet to fret and strum the guitar simultaneously: a technique aided by the unorthodox tuning he employs.

Other disabled musicians have used technology to adapt traditional instrumentation; reconfiguring it to their specification. We can think here of the rock drummer Rick Allen (left-arm amputee; Def Leppard), who has used a number of electronic pedals placed by his left foot, programmed to play each particular drum he would have previously played with his left arm. I also include reference to the example of jazz pianist Oscar Peterson (a stroke affected one side of his body), following Alex Lubet's work on him, who used his fellow musicians to compensate for his post-stroke impairment because he essentially became a one-handed pianist (Lubet, 2013).

The paper is intended to illustrate that versions of prosthesis are important in creative music-making, and lo-fi as well as technological innovations can have considerable prosthetic impact.

### **Access all Arias: an exploration of the challenges of inclusive practice within the operatic music performance industry**

*Dr Kerry Firth, and David Cane*

A collaboration between a visually impaired opera singer and a musicologist in the field of disability studies, this paper will explore issues of disability (in)equality and (lack of) diversity within the classical music industry. Emphasis is placed on the early stages of a developing operatic career during which discrimination on the basis of disability is particularly prevalent. The presentation will identify some of the forms that this discrimination can take and, with specific reference to a new, Manchester-based inclusive operatic initiative, *Access all Arias*, will suggest ways in which these prejudices can be challenged. Questions to be addressed include: how can some of the more subtle forms of discrimination that appear during the audition process be best articulated? In what ways can *Access all Arias* be an open-forum for discussions surrounding accessibility and representation? What role can an inclusive practice have in changing attitudes and breaking down barriers within the industry more widely, and, as company, how can *Access all Arias* flourish as an inclusive practice whilst avoiding enfreakment and/or becoming 'inspiration porn'?



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This paper combines theoretical discussion with practical experience and seeks to embody Mike Oliver's conception of emancipatory research. For Oliver, true emancipatory research must be borne from the lived-experiences and perspectives of disabled people rather than merely playing lip-service to them. The overall intentions of this paper, then, are not only to provide a sounding board for issues related to discrimination, but are also involved with the proposal of a model for putting processes of inclusion into practice.

## Spoken Presentations: Reflections on Practice

### **The depiction of dwarfism in Alexander Zemlinsky's *Der Zwerg* (1911) from source to stage**

*Charlotte Armstrong*

When the Austrian composer Alexander Zemlinsky requested a libretto for a new opera in 1911, his brief was simple: 'Write about the tragedy of the ugly man'. Zemlinsky's vision was realised a decade later with the completion of *Der Zwerg* (*The Dwarf*). The combined perspectives of disability theory and opera studies highlight the problematic use of disability in opera narratives, where it functions variously as a stock feature of characterisation, a metaphorical device, or a form of comic relief. The additional insights offered by theatre and performance studies highlight the *ways in which the interpretation and representation of opera's disabled characters in contemporary productions* reinforce stock character tropes and shore up damaging disability stereotypes. This paper draws upon these combined perspectives to critically examine the representation of dwarfism (and disability more widely) in Zemlinsky's original libretto, and in two contemporary productions of the opera (Graz Opera and Lisbon National Theatre, 2017).

In the libretto, the exoticisation and dehumanisation of the nameless protagonist draws upon a rich socio-historical context in which dwarves were commodified as a source of entertainment. This paper explores the dramatic 'Othering' of the Dwarf, who serves as an embodiment of abnormality, and is juxtaposed with an idealised, healthy, and crucially, 'normal' counterpart (the Infanta). Despite the prevalence of such problematic ableist tropes, the opera pertains largely to a social model perspective of disability. With this in mind, the paper will highlight the way in which the opera can be understood as a critique of the cultivation and celebration of conventional aesthetic norms during the turbulent socio-political climate in which the work was composed. Nevertheless, the perpetuation, even aggravation, of such negative disability representation in contemporary productions of Zemlinsky's work poses questions about the 'performance' of disability on opera stages today.

*Recent years have seen the pejoratively termed process of 'cripping up' being used to describe portrayals of disability by non-disabled performers in film, television, and theatre. The appropriation and mimicry of the disabled body in contemporary opera production, however, has rarely been considered. By examining the costuming and staging of the central protagonist in the performances*



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at Lisbon and Graz, this paper will illustrate how opera companies continue to utilise certain techniques by which performers undergo a process of 'cripping up'. The examples used are representative of the wider trend of problematic depictions of disability in contemporary opera production. As such, they serve as a useful lens through which to highlight broader issues surrounding disability representation in opera production, with regards to both casting and the questions of authenticity.

Zemlinsky's opera serves as a pertinent case-study of the representation of disability in opera in both the past and present. This paper therefore poses a preliminary framework that might be developed further so that opera companies can begin to address and avoid the problematic 'performance' of disability in future productions.

### **'A Way not *The* Way': A presentation and micro-workshop exploring practical approaches to music and disability**

*Sarah Fisher*

Through this presentation and micro-workshop I will share my experience of developing as a musician with a disability, who also teaches and how the impact of the 'A way, not *The* way' approach has had on participants I have worked with on the Community Music Spark project at Sage Gateshead as well as my ongoing development.

Through autoethnography, I have developed a pedagogical approach which I believe provides a useful insight into how to facilitate the musical development of people with special educational needs and disabilities. In sharing this pedagogical approach, I hope to encourage more musicians to feel confident about working with participants who have disabilities. Using Participatory Action Research methods, I led a collaborative enquiry into the experiences of learners and myself as fellow musicians involved in practical music making.

The most important elements which constitute this pedagogical approach include: the relationship between teacher and student; motivation; constructive criticism of musicality, not of disability; and the development of *a* way, not *the* way to teach new musical skills.

Disability is a big part in all of these elements; finding the right balance between the music and the abilities of the student / teacher is imperative in the development of learning and teaching music.

Before any musical ability truly develops, it's important to form a relationship of trust and understanding between teacher and student, as this relationship facilitates student motivation.

Having a positive, motivational attitude can benefit a person with a disability, as it allows them to develop their musical skills as well as their confidence. Once the motivation to progress is developed, musicality skills begin to blossom. By working together and understanding their collective ability, both the teacher and student can build on their knowledge of what is achievable and the student can reach their full potential. Criticism is important in musical development but it's important that only the music is criticised, not the disability; this is only achievable with a strong relationship between the teacher and the student. Due to the physical limitations of my disability I have adapted the ways I play certain musical elements. I describe this as finding 'a' way to play things, not necessarily 'the' way most people are taught.

Drawing on all this I discuss a number of findings, including, the value of reflection as a tool for learning, and the relevance for other learners of the four 'pillars' of my philosophy within my work at Sage Gateshead.



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Through my experiences as a musician with a disability who also teaches, I have been able to put into practice some of these elements and developed my own teaching approach. Music is an easier medium for me to communicate in than spoken language, and by leading some body percussion activity as part of this presentation I hope to be able to demonstrate 'a' way to lead where we can still achieve a high level of musicianship regardless of ability.

### Composing without a cure

*Ben Lunn*

2018 is a curious year, Autistic self-advocacy is getting stronger and stronger by the year, however efforts to 'cure' Autism are getting more and more intense. Be it the Minnesota state suggesting building an 'Autistic Registry', Colorado State proposing that Autism is an epidemic, or Emma Dalmayne having to remind everyone pouring bleach into Autistic children is wrong. A portion of the world is fighting to improve Autistic lives and another portion is trying to extinguish them. Then there are composers simply trying to find a voice in the midst of this.

This talk will look at multiple Autistic composers and how they feel within the world around them. Discussing personal circumstances, their fears, their hopes, and celebrating their work, this will be a rare opportunity to hear composers who would otherwise fall into the scenery surrounding them.

## Panel Presentation: Bournemouth Symphony Orchestra

### **BSO Resound - Forming and directing the world's first disabled-led ensemble as part of a professional orchestra**

*Lisa Tregale & Alexander Campkin*

The Bournemouth Symphony Orchestra (BSO) is the first professional orchestra in the world to have a professional disabled-led chamber ensemble at the heart of their activities. As a grantee of the first tranche of Arts Council England Change (ACE) Makers funding, they are currently hosting a training placement for James Rose, a conductor with disabilities, to accelerate his development, experience and confidence as an artist. Of the 20 successful applicants to the ACE Change Makers funding stream, the BSO is not only the only orchestra to receive funding, but is also the only disabled-led music project in the country to receive funding through the scheme.

This panel discussion – led by Lisa Tregale, Head of BSO Participate and Alexander Campkin, Composer in Residence at BSO Resound – will discuss the Bournemouth Symphony Orchestra's process of nurturing and supporting disabled musicians and leaders. Things that will be covered will include:

- Identifying and recruiting musicians and composers – barriers to engagement
- How do you work as an ensemble with different and multiple requirements?
- An exploration of ensemble directing styles



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- Positive and negative aspects of working with formal and informal learning styles and bringing traditional and non-traditional instruments (AMT) into the same ensemble
- People's perceptions of disability. What does the audience think?
- Challenging the traditions
- Repertoire
- Initial impact and reception

Alexander Campkin asks:

"How many people are being judged on their disability rather than their ability as a musician? My own prejudices were shattered sitting on the audition panel for BSO Resound, which taught me that there is an amazing and untapped wealth of talent. I have discovered that in order for musicians with disabilities to compete on a level playing field, changes need to be urgently made. 1 in 5 people in the UK have a disability, but this is not represented in classical music. My own musical journey was changed forever after medical symptoms and the diagnosis of multiple sclerosis aged 17, months before I was due to make a concerto premiere with the Arad Philharmonic in Romania as a viola player. However, I feel very fortunate to be able to express myself through composing music. I passionately want to be part of building a world in which everyone can express themselves creatively through music, and in which disabled and non-disabled musicians work alongside each other as equals."

## Video Poster Presentations

### **Ticketing Without Barriers**

*Jacob Adams (Attitude is Everything)*

Slideshow presenting the key findings of Attitude is Everything's 2018 State of Access Report, which focuses on the barriers Deaf and disabled music fans face when seeking to book access to live music and how to remove them. Launched on 9<sup>th</sup> April 2018, this major report contains quotes and stats from a public survey, and a vision for achieving Ticketing Without Barriers via an unprecedented industry coalition announced with the launch. Attitude is Everything is an Arts Council England Sector Support Organisation that has worked for the past 18 years with audiences, artists and the music industry to make live music as accessible as possible. For more info visit [www.attitudeiseverything.org.uk](http://www.attitudeiseverything.org.uk)



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### Uncovering narratives of hearing loss in Beethoven's late quartets

*Hannah Anderson*

Ludwig Van Beethoven is regarded as one of the greatest composers of the Classical canon and continues to be known as one of the most famous musicians of all time. So widely is his background and persona known that even casual discussions about Beethoven invariably turn to his experience of profound, fluctuating hearing loss. Beethoven's deafness is one of the most romanticized stories in the Classical music world, which is unsurprising given his historical context. During Beethoven's lifetime, the mysterious nature of losing one's hearing was widely believed to be tied to the process of losing one's mind and deafness was virtually synonymous with 'madness.' The image of Beethoven as a deaf, desperate, and forlorn romantic genius lingers to this day.

Modern scholarly narratives about Beethoven and his works play upon this image, and nowhere is it more propagated than in analyses of the Late Quartets. Written during the later years of his life when he had completely lost his functional sense of hearing, Beethoven's String Quartets No. 12-16 and the *Große Fuge* are radically divergent from any of his earlier works and the works of his contemporaries. The traditional explanation for their character is that Beethoven became obsessed with his deafness and impending mortality, driving him to pen otherworldly, disturbing, and nonsensical music. It is difficult to reconcile Beethoven's musical maturity and obvious compositional skill with such a premise, however, and it is similarly unsatisfactory to describe the varied and complex emotional content of the Late Quartets as music completely consumed by grief. In-depth musical analysis of the Late Quartets reveals almost unparalleled levels of formal and stylistic complexity, and while Beethoven's letters and writings do imply he wrestled greatly with his deafness and coming death, the creative genius of the Late Quartets and the medical, textual knowledge of our modern day compel many to conclude that it is insufficient to continue to view them as the products of morbid obsession.

This paper will provide a novel view of the Late Quartets by connecting original musical analyses to medical findings in audiology and personal experiences of hearing loss from the author and other d/Deaf musicians. In the process, it will uncover how Beethoven's profound hearing loss is woven tightly throughout the fabric of the quartets and provide an alternate source of their form, style, and character. It will further explore the ways in which musical experience can be altered and enhanced by hearing impairment and examine the implications of this discussion on Western definitions and philosophies of music, sound, and sensory disabilities.

### The Kellycaster: examining collaboration and equality in instrument development

*John Kelly and Charles Matthews*

What does it mean to form a collaboration between Disabled People and non-disabled people in a music technology context? Why is a shared understanding of values and beliefs underpinned by Disability Equality and the Social Model so critical to creative collaborations in access-driven instrument building? The Kellycaster is a new type of guitar. It redefines how a physical guitar can be played with physical



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strings and a digital fretboard system. It is an instrument made to further Guthrie's notion of a weapon for protest. It is ground-breaking in an emerging movement towards Disabled artist led instrument development projects.

In this video presentation we will share our journey through the development of the Kellycaster (with the support of Drake Music's DMLab) to illustrate the importance of collaboration and interdependence between Disabled & non-disabled people who are musicians, coders, and makers. Based on our lived experience as Disabled and non-disabled practitioners within different contexts, we will examine how our respective practices within and beyond music technology have changed as a result of this project, made our work together stronger, and brought something new to our understanding of collaboration.

### **#CripTheMusic: Disabled people's access to live music**

*Rebecca Porter*

The purpose of this paper is to examine the accessibility and inclusion of disabled people at live music events. Where musicology and disability studies have intersected, it has largely focused on disabled people as performers. Disabled music audiences have had no academic sociological analysis. Moreover, legislation such as the Equality act (2010) and article 30 UNCRPD (right to participate in cultural life) and article 9 (accessibility) should remove barriers to experiencing live music. However, as shown by the charity Attitude is Everything (2016, 2018) this is not the case. I conducted a survey of UK concert goers with impairments to understand ticketing, accessibility information, and the physical environment of live music events. The Initial results from this survey show that being able to get a ticket to an accessible seat/area, some venues not offering PA tickets, issues with how participants were left with negative perceptions feeling segregated from the rest of the audience. Some participants with invisible impairments reported feeling judged for needing accessible facilities. Despite drawbacks, most participants thoroughly enjoy seeing their favourite bands, and enjoying live music, however, it is clear there is so much more venues could be doing to improve their accessibility.

### **Equal Access to Music?**

*Jane Williams & members of The Turning Tides Project*

There are many well-rehearsed debates about the barriers that prevent disabled peoples' 'access' to and 'inclusion' in the musical life of their communities. The narrative often focuses on either the unequal experience of disabled people as 'audience' or the 'inspirational' performance of people with physical impairments.

Following the London Olympics and Para-Olympics there has been an increased interest in tackling the lack of access to musical opportunity that is available to Disabled People. 'Inclusion' in music has thus become a box that it is desirable to tick: It is much easier to claim 'inclusion' than it is to achieve it.



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In the current climate there is undoubtedly the opportunity to remove some of the barriers that prevent equal access to music. A practical approach that supports community musicians and music educators to access the knowledge base of Disability Studies and apply it to the creation of musical opportunity is essential if music organisations are to achieve more than a paper 'Inclusion Strategy'

The Turning Tides Project (TTTP) aims to make equal access to music, the arts and life a reality for people with 'learning disability' or 'autism' labels. Everything we do seeks to demonstrate the application of a Social Model Approach. We believe that in an inclusive environment everyone can do anything that they really want to. TTTP has a Big Band that creates original music, tours and performs regularly. We'd like to share what we've achieved, so far, through taking a Social Model Approach. An extract of a filmed performance and recorded interviews with band members will be used to:

- Introduce The Turning Tides Project and TTTP Big Band
- Share some experiences and stories about:
  - Challenging the assumption that we are 'audience' not 'performers'
  - Dispelling the myth that music for people with 'learning disability' labels is a 'day care opportunity'!
  - Ownership of original material (when work is created collectively in a facilitated environment, who does it belong to? And what performance rights apply?)

### **The Gloves Are On**

*Kris Halpin*

In this video I will discuss my journey touring a solo live show on an international scale. I'll briefly tell the story of my tour, The Gloves Are On, and its challenges and successes. I'll talk about my access challenges such as the logistics of all that travelling with a wheelchair, and also the access challenges to performing (the weak link in all this being that venues accommodate disabled audience members; artists, less so...

The film presents an optimistic look at the realities of being an in demand, full time disabled musician working at an international level in a wide range of venues, from clubs to festivals to world famous concerts halls.



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### Poster Presentations

#### **The perceived effect of musical training on the experience of mainstream education for children with high-functioning Autistic Spectrum Conditions**

*Rachael Salter*

Children with high-functioning Autistic Spectrum Conditions (ASC) often have average or above-average intelligence, yet struggle to succeed in mainstream education (Baron-Cohen et. al., 2009). Current practice favours intervention when supporting young people with ASC (Hourigan & Hourigan, 2009), however these methods often take young people out of the classroom which creates a barrier to inclusive education. As a young person with Asperger's Syndrome, I feel that being regularly involved in musical performance had a significant positive impact on my experience of, and success in mainstream education and reduced the need for interventional methods. Existing studies explore a variety of aspects of the relationship between music and ASC (Baron-Cohen et. al., 2009; Hourigan & Hourigan, 2009), however, there is little research into the effects of musical training on the experience of education for children with ASC. This poster presentation will present the preliminary findings of a pilot study investigating the impact of musical training and regular ensemble performance on the experience of mainstream education for children and young people with high-functioning ASC.

#### **Differentiation as Celebrating an Able Identity or Perpetuating an Ableist Perspective? Critical Perspectives on an Evidence Based Approach for Instrumental Tuition for Musicians Who Have Down's Syndrome**

*Beth Pickard*

This paper will present a framework for differentiating instrumental tuition for individuals who have Down's syndrome, which draws from the evidence-base which asserts that there is a recognisable learning profile amongst learners with Down's syndrome (Dykens *et al.*, 2006; Eugene and McGuire, 2006). This literature will be examined critically and cautiously, and its reductionist, deficit-based potential identified. The value of applying this evidence-based approach to music education will be considered through three brief case studies which explore music making with learners who have Down's syndrome. The case studies will demonstrate potential differentiation of provision according to the evidence-based learning profile, while recognising and celebrating a wide range of musicians' personalities, communication styles, preferences, instruments and intentions. The context of other published examples of working inclusively with musicians with Down's syndrome and learning disabilities will also be considered (Cross, 2005, 2007; Heaton *et al.*, 2008; Hammel and Hourigan, 2011; Ott, 2011; Bell, 2014; Jaquis and Paterson, 2017). Having presented this evidence-based approach to differentiating music education to enable learners with Down's syndrome to play an instrument, read music, and develop enriching musical relationships; a



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further critical stance will consider whether such methods of differentiation are synonymous with inclusive education (Alton, 1998; Hodgkinson, 2015), or whether the construct of differentiation in itself further perpetuates the dominant ableist discourse (Moore and Slee, 2012; Penketh, 2016). While there is potential for an approach based on learning profiles according to such a broad shared experience as 'Down's Syndrome' to be reductionist and overgeneralised, this paper suggests that this can be a strength-based foundation for music educators, who report as often lacking in confidence or experience to engage with learners with additional needs (Jones, 2015). From the perspective of the musician who has Down's syndrome, it is their human right and disability right to make music (Lubet, 2011) as well as a "fundamental human occupation" (Williams, 2013, p. 39). Enabling this creative expression through a meaningful and relevant approach is the ethical responsibility of an inclusive music practitioner (Atkinson, 2011; Bell, 2014), and it is hoped that research into approaches which increase confidence in practitioners as well as success for musicians can be nurtured. Introducing a wider range of informed methods for music educators could be beneficial to a great number of learners, regardless of whether they identify as having a specific or additional learning need. Rather than utilise the learning profile as recognition of areas of deficit to develop (Fidler, Hepburn and Rogers, 2006; Iacob and Musuroi, 2013), this study will see the learning profile as a recipe for access and success: providing a "maximally supporting learning environment" (Wishart, 2002, p. 18; cited in Germain, 2002, p. 53) to nurture successful outcomes (Lemons *et al.*, 2018). Widening understanding and acceptance of a multitude of approaches to music education, reflecting the diversity of experiences of musicians, aligns with a neurodiversity perspective, which celebrates the value and validity of diverse experiences rather than recognising such diversity as a deficit or a disability (Silberman, 2015; Woods, 2017).

### ***Vaguely Artistic*: Disabled Musicians as Experts in an Inclusive Community Music Project in Higher Education, From a Social Confluence Perspective**

*Beth Pickard and Tanya Dower*

This poster presents a project developed as part of a music module on a Creative and Therapeutic Arts degree in a higher education context. While the module had historically been taught on campus through a range of simulations and theoretical projects, this initiative sought to recognise the expertise of disabled musicians in preparing community musicians for professional practice (Lerner and Straus, 2006; Lubet, 2011; Lubet, 2014a), and enabled their insight and expertise to be communicated through an experiential learning project design (Elflein, 2009; Mortimer, 2017). The project was developed through professional networks and 'locally curated' learning (Penketh and Waite, 2017), enabling a thorough and honest exploration of the multifaceted potential of the project. The existing members of inclusive punk rock band, *Vaguely Artistic*, were consulted by the artistic director to consider whether they were interested in engaging in a pedagogical collaboration. With the band's investment in the project, an organic framework emerged for a music student to become immersed in the work of the band and to become an honorary member for a semester. This pedagogical design draws from Lubet's (2014a) theory of social confluence, where the disabled musicians are recognised as authorities rather than service users through their specialism and insight in this particular domain, and this transforms their social role. The university brief was broad, enabling the



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disabled musicians to remain as experts in the context of the project, and encouraged the student to develop her understanding of inclusive music practice through her lived experience of being a member of *Vaguely Artistic*. She was encouraged to explore a composition based activity and an arrangement based activity with the group, in a collaborative and participatory context, as well as writing a critical reflection on this experience. The student's engagement in the rehearsal and creative process as well as her final performance was assessed. To accompany and contextualise the practical project experience, a series of theoretical seminars were taught where rich discussion was facilitated around contemporary theories of disability and popular music and the student was encouraged to critically consider how her lived experience related to these existing theoretical frameworks (Lerner and Straus, 2006; Waltz and James, 2009; Straus, 2011; Lubet, 2011; McKay, 2013; Howe *et al.*, 2016). The outcomes of the project were multi-faceted. There was significant learning from a pedagogical perspective about developing innovative assessment designs which enable authentic learning in context, but also the challenges of aligning this with university policies and expectations (Jung, 2011; Piacitelli *et al.*, 2013). The student remained as a permanent member of *Vaguely Artistic* and has since been performing locally and internationally with the group at a range of mainstream, inclusive arts and disability arts events. The student's critical reflection shared a wealth of valuable insights regarding her lived experience of working with *Vaguely Artistic*, namely of multiple dualities and dichotomies in her experiences. Dower (2016) insightfully discusses the duality of being disabled/non-disabled, outsider/insider, academic/social group member, and the negotiation of process/product and articulates with passion and insight the impact of learning from experts in their field.

### **Towards performance-focused accessible instruments**

*Jacob Harrison*

Music Technology and Digital Musical Instruments (DMIs) have dramatically increased the range of options available for creating and participating in music over the last several decades. For musicians with access needs for whom performing music with a traditional instrument is not possible, new DMIs offer routes into music making which would not otherwise be available. Innovation in Accessible Instrument design tends to come from three separate streams: academic research, commercial products, and bespoke DIY projects. The goals and intended outcomes from these three areas of Accessible Instrument design are diverse: academic research tends to place an emphasis on the therapeutic uses of Accessible Instruments, such as muscular and cognitive rehabilitation for stroke survivors, or sensory devices for use by music therapists and Special Educational Needs (SEN) practitioners. A common theme amongst commercially available Accessible Instruments is universal accessibility, often at the expense of musical diversity (i.e. a simplified control scheme which limits the user to a particular set of notes or modulation strategies). Bespoke or DIY accessible instruments tend to focus on the specific access needs of an individual, thereby removing the constraints of universal accessibility, and affording a wider range of musical output.

In this paper I attempt to address some of the issues surrounding Accessible Instrument design in academic research, and look at ways in which researchers can learn from the state of the art in other areas. In particular, I propose a distinction between



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‘Therapeutic Devices’ (i.e. instruments designed to serve a therapeutic or medical benefit) and ‘Performance-Focused Instruments’ (instruments designed purely for enabling greater access to music making for disabled musicians), using an overview of existing Accessible Instruments which are emblematic of these two approaches.

I propose that one approach to designing performance-focused instruments is to consider the musical culture that the instrument might exist in, and its role within a performance. When designing accessible instruments to fulfil the role of an existing instrument, we can assume that faithfully recreating the sound of that instrument is of primary importance. But to what extent do other factors such as the aesthetic form of the instrument and the method of interaction influence the success with which an instrument embodies that musical role? To answer this question, I present two user studies which make use of prototype guitar-based accessible instruments which were designed to explore the influence of interaction modality and global form on the degree to which an instrument fulfils a musical role. The first user study focuses on an adapted bass guitar designed to be played without the fretting hand. The second study features four variations on a guitar based instrument. Each variation represents varying degrees of ‘guitar-likeness’, featuring a combination of a guitar inspired global form, or physical guitar strings as an input method.

These findings suggest that the ‘cultural capital’ of an existing instrument can be captured and maintained in new accessible instruments, through careful consideration of the global form and interaction modality.

## **Help Me Sing: Promoting vocalisations in music sessions with learners with Profound and Multiple Learning Difficulties**

*Rosie Rushton*

Fundamentally as practitioners we must address why we are singing with our learners and what we are hoping to develop, continually reflecting upon and refining our practice. The National Plan for Music Education, Department for Education (2011) stated that ‘*children from all backgrounds should have the opportunity to learn to sing*’ but as practitioners how best can we enhance and promote vocalisations from learners with PMLD? This research looks at the opportunities for, and responses to, proactive contributions and creative output during pre-composed lyric based songs and non-lyric-based supported singing within a music session. It investigates whether singing *to* learners with PMLD provides an opportunity to sing *with* them, and whether either method of practice offers more opportunity for musical independence, prompts increased responses, musical conversation or creativity from the learners. It aims to consider the reasoning behind singing simple familiar songs with learners with PMLD and the impact of the involvement from support staff in enhancing musical experiences. Audio recorded data was collected over three whole class music sessions. Context of the vocalisations in relation to Ockelford’s Sounds of Intent Framework was also considered. The results highlight the pace, and dominance of adult initiated singing, in which learners fall into the role of listener rather than creator, and discuss how best to address this to facilitate the space and flexibility for learners with PMLD to find their voices.



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### Preparing Teachers for Inclusive Music: Considering a Universal Approach in Music Education Teacher Training

*Amanda McClintock*

Variations in ability are inherent in music classrooms and ensembles. Students with previous musical experience are often side by side with students who may be brand new to music education. Additionally, music is one of the first inclusion placements for students with disabilities (Adamek & Darrow, 2010) and teachers are commonly expected to teach one or more self-contained classes of students with more severe disabilities (Salvador & Pasiali, 2016). Given this need for a wide range of differentiation in music instruction, considering a universal approach in music education may increase access for students of all abilities. While music education researchers have advocated for the implementation of universal approaches in practice (Adamek & Darrow, 2010; Blair & McCord, 2015; Jellison, 2015; McCord & Watts, 2006), this presentation seeks to extend that call by considering the integration of the principles of universal design for learning (UDL) throughout methods courses for preservice teachers.

Universal design for learning involves flexibility in planning and implementation of curriculum to meet the individual needs of learners of all abilities (CAST, 2013). UDL is one example of a framework teachers may use to anticipate barriers to learning and adapt instruction, curriculum, and materials in advance to meet all learners at their individual level. The UDL framework includes three principles that support teachers' efforts to promote the achievement of high standards by students of all abilities. This is done by providing multiple means of (I.) Representation, (II.) Engagement, and (III.) Action and Expression (Meyer, Rose, & Gordon, 2014).

Universal design's inclusion in the Higher Education Act led researchers in special education to evaluate best practice for including the framework in teacher professional development, lesson planning, and preservice training (Courey, Tappe, Siker, & LePage, 2013; Smith, Robb, West, & Tyler, 2010; Spooner, Baker, Harris, Ahlgrim-Delzell, & Browder, 2007). Spooner et al. (2007) found that direct instruction in UDL practices increased teacher integration of these principles considerably. By weaving these principles throughout music education methods courses, including opportunities to experience UDL as a student, undergraduates will gain repeated experience with the model. Integrating explicit instruction in the UDL framework throughout methods courses will provide undergraduates recurring opportunities to practice differentiating instruction to meet the needs of all learners.

This presentation will provide an overview of universal approaches to education and the application and inclusion of the framework of universal design for learning in preservice methods courses. Although applicable to all areas of music teacher preparation, the implementation, challenges, and potential benefits of UDL in preservice music teacher training will be explored through the lens of general music. Our pursuit to make music accessible for everyone begins by providing preservice music educators experience and instruction in UDL throughout their methods courses to establish a foundation for considering the needs of all learners and predispose teachers to differentiate for students of all abilities.



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