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Does Disability Studies have Anything to Say to Music Therapy? And Would Music Therapy Listen if it Did?

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Abstract

In this article I enquire whether a worthwhile dialogue might be entered into between the disciplines of disability studies and music therapy. Considering disability studies alongside feminist theory, I ask whether insights from disability studies can be incorporated within music therapy education and practice. A comparative exploration of the roots and visions of both disciplines, along with a discussion of music therapy's struggle to establish an identity as a clinical profession, leads me to suggest that there are fundamental rifts which would make a constructive dialogue difficult. I draw on perspectives developed by disability studies theorists who have critiqued the development of disabling professions and discuss some examples of disability arts practice to highlight the philosophical differences dividing these two projects. I conclude by suggesting that music therapy realigns itself as a profession allied to the community rather than as a profession allied to medicine.

Keywords: disability studies, music therapy, medical model, social model, disabling professions, disability arts

Feminism and Music Therapy

In determining whether there is potential for a dialogue between disability studies and music therapy, the parallels between disability studies and feminist approaches need to be emphasised. Hahna and Schwantes (2011, p. 292), in their discussion of feminist music therapy pedagogy, identify the main goals of feminist pedagogy as including "socio-political change, empowerment, self-actualisation, consciousness-raising, egalitarianism, reflexivity, and a rejection of patriarchal and oppressive practices." They cite Hadley (2006, p. 397), who has listed important concepts for a feminist pedagogical approach to music therapy education as including, for example: the teacher as learner; power analysis; shifting from the banking system of education; incorporating subjective experiences and feelings; reflexivity; and advocacy (p. 293). Implied here is a requirement for music therapy educators and practitioners to develop a critical consciousness of their role as situated within emerging social contexts rather than in a clinical vacuum. These contexts are ones in which structures and relationships reflecting traditional notions of power, class, race, gender, socioeconomic status, and sexual orientation are either reproduced or challenged in everyday encounters – including within the relational triad involving client, therapist and music. The vision expressed here is for music therapy to have a role in the transformation of social relations. Within music therapy, however, it seems that there is not unanimous agreement about the requirement for a feminist underpinning. Curtis (2013) has drawn attention to a number of objections to the claims of feminist music therapists: 1) there is no need for feminism since music therapy is a female-dominated profession; 2) music therapists' work with their clients is personal not political; and 3) music therapists' work is neutral.

Both disability studies and feminist perspectives offer a critical perspective from which to gaze at socially constructed reality. Both understand the personal as being thoroughly political, because individual lives are only ever experienced and given meaning within cultural and structural contexts. While feminist perspectives are rooted in the life politics and perspectives of women, disability studies has emerged out of the experiences of disabled people. The subject of disability studies is not bodies or physical conditions, but society. The field of disability studies does not deal with how to "care" for disabled people. Rather, it offers a critical perspective on the mechanisms society has used to exclude disabled people and on how these can be challenged and changed. Just as feminism does not involve the study of women's biology to critique the social construction and experience of gender and gender inequality, neither does disability studies regard impairment as being a relevant starting point for the analysis of disabling social relations (Cameron & Moore, 2014, p. 37). The question is about whether, given music therapy's ambivalence about feminist theory, the discipline feels it necessary or otherwise to listen to what disability studies has to say.

The most straightforward, and possibly irreconcilable, difference between the perspectives of disability studies and music therapy scholars is both ontological and epistemological. It concerns not only the nature of what disability is but, following from this, the nature of what kind of knowledge about disability it is useful to produce. To put it simply, whereas music therapy typically identifies disability as an individual condition or physical limitation, within disability studies the term signifies an oppressive social relationship[1]. To be clear about this, a distinction must be made between what are known as the medical and social models of disability.

The Medical Model

The medical model is expressed most clearly in the World Health Organisation's 1980 International Classification of Impairments, Disabilities and Handicaps:

> Impairment: any loss or abnormality of psychological, physiological or anatomical structure or function

> Disability: any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (WHO, 1980 in Cameron, 2014a, p. 99).

Disability is here identified as an individual characteristic, as a problem caused by physical, sensory, cognitive or emotional disorder. While WHO has since updated its terminology, so that disability is now regarded as "an umbrella term, covering impairments, activity limitations, and participation restrictions" (WHO, 2012, in Mallett & Slater, 2014, p. 92), the key point is that disability is still regarded as an individual matter; as a problem to do with the way some individuals' bodies are made. The terms loss, abnormality, restriction or lack of ability are heavily-laden with cultural meaning and indicate a perception of impairment and disability as characteristics of individual deficit or personal tragedy.

When it is understood in this way, appropriate social responses to disability are regarded in terms of treatment and care by medical/technological means; prevention through biological/genetic intervention or screening; treatment through rehabilitation services; and prevention through early diagnosis and treatment (Rioux, 1997). Resources are targeted at individuals in order to fix them for participation in the world around them, while the environment in which they live is regarded as unproblematic. The responsibility is upon the impaired individual, with what is considered appropriate professional support, to make the effort to adjust and fit in. To be disabled is to have "something wrong with you" (Oliver, 1996, p. 30) which must be put right.

The medical model is regarded as problematic from a disability studies perspective in that it is materialised in everyday practice through the myriad of behaviours, decisions, and interactions taking place in the contexts in which disabled people experience their lives. It is put into practice through the ways that services are delivered, plans made, in gestures and assumptions, thoughts spoken and unspoken, hopes and expectations held. Because it is a dominant model of disability, reflecting the view of the world of the non-disabled, its character as a model, as a way of looking at things, is almost always overlooked. Medical model thinking does not appear as just "one way of looking" but as established fact. It is considered common sense to regard impairment as misfortune. This impacts upon disabled people's lives not just in terms of professional judgements and assumptions about what are appropriate services, but also in terms of the restriction of life opportunities, experiences and roles.

That music therapy is underpinned by a medical model outlook can be identified in descriptions of people with disabilities, and of people having intellectual disabilities, developmental disabilities, severe disabilities, cognitive disabilities, learning disabilities, profound disabilities and multiple disabilities (e.g. Meadows, 1997; Hooper, Wigram, Carson & Lindsay, 2008a; Lee & McFerran, 2013); or in Perry's (2011) statement that:

> when a music therapy intervention is focused on physical goals such as gait, or trunk and head control, an accurate description of physical disability is needed... I believe it is important to have a clear idea of the level of functional motor ability when selecting interventions and describing individuals' involvement in music therapy and motor classification scales can assist in this.

Bruscia's widely used definition also makes this clear:

Music therapy is a systematic process of intervention wherein the therapist helps the client to promote health, using music experiences and the relationships that develop through them as dynamic forces of change (Bruscia, 1998, p. 20)[2].

Rooted within what Frank (1997, p. 77) terms "the restitution narrative", which treats health uncritically as "the normal condition that people ought to have restored", the triadic relationship of music therapy involves identification of the disabled person as someone who needs professional help towards acquiring or developing competencies to enable them to achieve goals set by the therapist, e.g. "independence" (Hooper et al, 2008a). Change is to be achieved therapeutically, individually, and voluntarily. It involves the practitioner, recognised as a competent, credentialed professional, co-opting the client into her view of the situation, defined as reality, as an essential condition of carrying out her work (Abberley, 1995). Regardless of the kind of dialogue entered into between a client and music therapist, underpinning the relationship is an unquestioned premise that responsibility for change lies ultimately with the disabled person, and that the disabled person will benefit from this change.

The Social Model

The social model, which was developed initially by the Union of the Physically Impaired Against Segregation and later by Disabled People's International, redefines the terms impairment and disability:

Impairment: the loss or limitation of physical, mental or sensory function on a long-term or permanent basis

Disability: the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (DPI, 1981, in Barnes, 1992)

Described in these terms by disabled people themselves, impairment is recognised as a physical condition or as an individual attribute, while disability is identified as a matter of how society responds to, or fails to respond to, the needs of people with impairments. It is considered that not only has society omitted to include people with impairments, but that through its provision of segregated environments and institutions, such as residential homes, day centres and "special" schools, it has consciously organised itself to exclude people with impairments from ordinary life. From a social model view, disability ceases to be something that people "have" and is understood instead as an oppressive relationship, as something "done to" people with impairments. People have impairments but are not "people with disabilities." They are disabled by poor or non-existent access to the public places where ordinary life happens and by the condescending and unwelcoming responses of those who occupy these spaces. Rather than being an individual problem requiring cure, rehabilitation, normalisation or therapeutic intervention, disability is regarded as a structural problem requiring the removal of physical and social barriers (Cameron, 2014b).

This is not to overlook the fact that impairments exist or that impairment can at times be limiting, inconvenient and painful. Thomas (1999, p. 42) has coined the term "impairment effects" to describe:

restrictions of activity(which) may be directly related to, or caused by, having a physical, sensory or intellectual impairment (not being able to do certain things because of the absence of a limb or the presence of chronic pain or fatigue, for example).

Thomas is very clear, however, that these restrictions are not disabilities. "The fact that I cannot hold a spoon or a saucepan in my left hand is an effect of my impairment and does not constitute disability," she writes (Thomas, 1999, p. 43). This may, though, become the marker for other restrictions of activity which do constitute disability if other people decide that, because she cannot perform such actions, she is unfit to be a paid care worker or a parent and should be denied employment or the privilege of becoming a mother. Thomas argues that disability:

resides in the denial of rights, or the refusal to assist me in overcoming functional limitations, by allowing me to do things in an unconventional way, or by helping me to access instruments and technologies which would compensate for not being able to hold things "normally" (Thomas, 1999, p. 43).

The professional imposition of expectations that independence and normality (conceived in terms of physical self-reliance) are things disabled people should aspire to above all else (expressed in music therapy literature e.g. in Meadows (1997)), is identified as oppressive (Morris, 1991). There is a sharp conflict between this and the view developed within disability studies that independence is about disabled people having the right support to make meaningful choices and take control over their own lives.

Thomas argues, moreover, that impairment and impairment effects should not be regarded as "natural" or as pre-social, "biological" phenomena (Thomas, 1999). She makes the point that the way in which impairment and impairment effects are perceived by others and, as a consequence, experienced by disabled people, is shaped by the interaction of biological and social factors. The meaning attributed to impairment profoundly determines the sense that can be made of the experience of living with impairment. In this sense, at the level of everyday experience, disability and impairment effects interact, which is why it is important to be clear about the distinction between the two. This is a view endorsed by Hughes and Paterson, who have suggested that "disability is experienced in, on and through the body, just as impairment is experienced in terms of the cultural narratives that help to constitute its meaning" (Hughes & Paterson, 2006, p. 101).

The Disability Business

Disability studies writers (e.g. Albrecht, 1992) have described the emergence during the twentieth century of a vast army of workers employed in rehabilitation industries to manage the lives of disabled people. Within this analysis, disability is a relatively recent historical phenomenon, arising with the industrialisation of society, the move from a subsistence economy to a wage economy, the imposition of strict new rules about time and speed of production, new requirements for increased conformity and normality, and the economic and social marginalisation and institutionalisation of people with impairments (Goble, 2014). Prior to industrialisation, impairment had been considered an unexceptional part of life, and people with impairments had been included in ordinary life, working cooperatively within the family and community (Oliver, 1990; Barnes, 1997; Davis, 2013). As Oliver and Barnes (2012) have noted, although ignorance and prejudice were common, and differences in performance noted and sanctions often applied, physical difference was not made a basis for systematic exclusion from everyday life. With the coming of the factories there arose a need for a standard-shaped, standard-sized "able-bodied" worker, capable of seeing, hearing, comprehending and moving quickly enough to operate standard-sized machines in order to generate capital for manufacturers. People with impairments, who had not previously been thought of as representing a distinct section of society, became regarded as problematic, as unable to meet the requirements of the new system. Finding themselves excluded from employment on the grounds of being unable to keep pace with these requirements, many found themselves removed from the mainstream of economic and community life and placed in a range of institutional settings. It is within these institutions that people with impairments fell under the gaze of the medical profession and that disability first became regarded as a medical issue (Cameron, 2014c).

During the twentieth century the process of medicalising disabled people became ever more sophisticated, requiring access to expert knowledge, usually residing in the increasingly powerful medical and paramedical professions (Oliver & Barnes, 2012). In Oliver's (1996, p. 37) terms:

> ...the medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image... each one geared to the same aim – the restoration of normality. And each one of these pseudo-professions develops its own knowledge base and set of skills to facilitate this. They organise their interventions and intrusions into disabled people's lives on the basis of discreet and limited knowledge and skills.

Borsay (1997), reflecting on this, has noted the tendency of professionals to diagnose a problem in relation to what they themselves can offer. Abberley (1995, p. 224) refers to McKnight's (1977) argument that:

> despite a possible recognition that individual problems have their genesis and meaning in the social economic and political environment, services inevitably tend to abstract the recipient from that environment because of the individualised nature of the tools available to the practitioner, such that the recipient is defined as the problem and the professional the solution.

It is in the context of this argument that I would like to consider music therapy. Hooper et al. (2008a, p. 73) have noted that the earliest philosophical articles by music therapy pioneers Alvin, Lathom, Cleland and Swartz either considered how the practice "might benefit diagnostic sub-groups within intellectual disability or focused on the part it could play in conjunction with other interventions… or in the promotion of particular skills." This is echoed in Oliver's (1990, p. 48) critical observation that:

> many of the newer professions… either work in organisations hierarchically dominated by doctors or have their professional practice structured by a discourse based on the medical model.

In describing the way that "throughout their careers, music therapists have struggled to identify themselves as professionals who are worthy of merit", Clair (2007, p. 76) recalls the repeatedly disappointed attempts by music therapist Castor to have music therapy acknowledged as a viable approach to treatment by the American Psychiatric Association. Clair describes the determination of music therapists in their efforts to establish the profession:

> They persistently labored to authenticate the results of their interventions through carefully designed protocols, clinical outcome research studies, and subsequent presentations and publications.

From a disability studies perspective, the keenness of music therapists for acceptance, recognition and respect from the medical profession and its spin offs is intensely problematic. Taking on the trappings of pseudo-medical academic practice in terms of, for example, the development of positivist research, involves the entrenchment and stabilisation of already formidable disabling barriers. It imposes a medical model view, and further objectifies disabled people at the expense of buttressing the profession's status. Hooper et al, (2008b, p. 88) state that:

> Although the nature of active music therapy, which is grounded in one-to-one relationships, and often explores the emotional states of individuals, makes it a difficult task to gain scientific proof of its success, more studies are needed that provide valid clinical evidence from which to draw substantive conclusions about the efficacy of music therapy.

A critical disability studies view would regard this as self-justification of the perpetuation of the medical myth about disability.

The point is that research does not provide objective knowledge about the world from a neutral standpoint outside it, but always produces results implicit in its underlying assumptions. Research is always a creative and productive process which helps to produce the world (Oliver and Barnes, 2012). Medical model research which treats as "natural" and uncontroversial the understanding that disability is something "wrong" with individual bodies is underpinned by the ideology of normality (Oliver, 1996) and plays a part in maintaining disabling social relations.

Disability Studies academics have criticised the myth of objectivity that has characterised much traditional disability research and have proposed an emancipatory paradigm for its development. Priestley (1997, p. 91) has identified six core principles of emancipatory disability research:

1. the adoption of a social model of disability as the ontological and epistemological basis for research production
2. the surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
3. the willingness only to undertake research where it will be of some practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers
4. the devolution of control over research production to ensure full accountability to disabled people and their organisations
5. the ability to give voice to the personal while endeavouring to collectivise the commonality of disabling experiences and barriers
6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

A disability studies view would be wary about an outlook which continued to profess faith in medical model research as likely to yield useful knowledge about the experience of living with impairment in a disabling society.

Disability Arts

I will now briefly discuss three examples from the field of disability arts in order to illustrate the difference between arts (and music in particular) conceived as a tool for therapy and as a tool for advocacy. There is a clear relationship between disability studies and disability arts because, as different expressions or parts of the disabled people's movement, they give meaning to each other. As Campbell has expressed it, "the disability movement is a jigsaw – each piece is vital for the true picture to emerge" (Campbell & Oliver, 1996, p. 199). Masefield (2006, p. 22) defines disability arts as "art by disabled people for disabled people that speaks the truth about the disability experience" and to an extent I agree with this definition. Disability arts is art by disabled people that reflects upon and explores the reality of life with impairment in a disabling society and, while its role in establishing a collective affirmative identity is crucial, it needs to express itself outwards as well.

> Hello, good evening, thanks for coming to the show. And before you get too concerned, don't be. I've not forgotten my medication... this is actually how I speak! If anyone is struggling to follow me... well... tough shit... not much I can do about it! (Clark, 2014)

With these words disabled stand-up comedian Laurence Clark opens his show Moments of Instant Regret at a mainstream comedy club in Newcastle upon Tyne in the north east of England. Whereas music therapists might seek to classify "the idiosyncratic behaviors of adults with profound and multiple disabilities" (Lee & McFerran, 2013), Clark, a wheelchair user who has cerebral palsy and a distinct speech impairment, spends the next hour describing the idiosyncratic behaviours of non-disabled people with whom he has come into contact. He takes pleasure in drawing attention to the absurdity underlying the assumptions made about him by perfect strangers and to the inanity of the remarks they come out with: the flight attendant who refused to serve him a beer, saying "Don't you think you've had enough, sir?"; the waiter who ignored him and asked his companion "What does he want to eat?"; the householders who insist on giving him sweets when he takes his son out trick or treating. I am not sure which description, serious or profound, would be used to categorise Clark's cerebral palsy, but these are good terms for classifying the audience's laughter as he reflects on these and similar encounters with the non-disabled.

Clark's humour is about the experience of living with impairment in a disabling society. It is assertive, affirming and challenging. It asserts and affirms the rights of people with impairments to live in their own bodies without being required to try and be something they are not, i.e. normal. It challenges by asserting and affirming the right to be different. At the same time, it uses comedy in order to draw attention to the experience of disabling encounters as sites for acquiescence with or resistance to the ideology of normality (Oliver, 1996).

Hooper et al (2008b, p. 88-89) inform us that:

> Music Activity Therapy is an active music therapy intervention that employs a variety of activities, and, in particular, research has focused on how songs and singing meet the needs of individuals who have an intellectual disability... White and Allen (1966) demonstrated that participants with mild intellectual disability who sang out their psychological history... or took part in group singing developed "more positive and healthy concepts of self" than those who did not.

Singing can, however, take the form of self- and collective advocacy rather than therapy. The Fugertivs was a trash/punk band involving people labelled as having mild learning difficulties that developed from a disability arts project run in Sunderland in north east England by Tyneside Disability Arts in the late 1990s (Cameron, 2009). "The No Hope ATC" (Sheader, 1999) was a song emerging from the project that mused on the bleak prospects involved in perennial attendance at an Adult Training Centre:

> I woke up one morning with a bad pain in my head
> In came a care assistant who dragged me out of bed
> They tell me it's for my own good that I must go for training
> I've been training 27 years besides it's fucking raining
> The bus is outside waiting, they're hanging round for me
> To take me on a journey to the No Hope ATC...

Hooper et al (2008b, p. 89) refer to Brownell (2002) and Pasiali (2004) who set "a social story to music (a short story that shares relevant information about a person, skill, event or social situation and describes appropriate responses (Gray, 1998), and demonstrated that using songs in this way had the potential to decrease a targeted challenging behaviour." Presumably the challenging behaviour referred to had been identified by the therapist. Using music as a tool for advocacy rather than therapy, The Fugertivs set their own social stories to music, demanding a different interpretation of whose behaviour was challenging, shifting the focus onto the practices of workers in the social care systems in which they found themselves. This involved what Freire has described in terms of agents singling out elements from their "background awareness", and making them objects of consideration and objects of action and cognition (Freire, 1974, p. 56). It resulted in an altered subjectivity and a naming of disability as oppression, leading to "more positive and healthy concepts of self":

> By modifying the frame from one of innate deviance to one of oppression, individuals may come to feel angry not only because the system is unjust but because they have been made to feel ashamed... The activated feeling of anger propels stigmatized individuals into public space to behave collectively, and feelings of pride emerge (Britt & Heise, 2000, p. 257).

Disabled folk and blues singer Johnny Crescendo ends his performance poem "Disabled people aren't allowed to say 'fuck'" (Holdsworth, 1989) with the following verse:

> Disabled people are allowed to say
> Victim, brave, helpless, special,
> Little, severely, chronically,
> Profoundly, vegetable.
> But they're not allowed to say "Fuck."
> But they do.

Crescendo wrote this poem after he had been booked to perform at a residential home for disabled people, but told that he must watch his language. He used the poem to express anger at the way in which the medicalization of disability and the use of medical labels is used to limit life opportunities and experience. He challenges what is considered as challenging, and problematizes what is treated as acceptable.

The central issue is that whereas therapy implies a requirement for compliance with the view of the powerful (Arnstein, 1969), advocacy involves asserting the right to think, do and be otherwise. It is hard to avoid the conclusion that the perspectives of disabled people, as expressed in disability arts and disability studies, are set in opposition to those of music therapy.

Conclusion

In reading through numerous music therapy journals in preparation for writing this article, I have been struck by the number of times I have come across expressions of a sense that the profession feels under-recognised and undervalued. Register (2013, p. 159), for example, states that:

> Across its more than 60-year history of professional training and practice, music therapists have grappled with professional recognition and an appropriate self- and public identity.

Speaking openly, I would suggest that the issue with music therapy from a disability studies perspective relates precisely to its concern for recognition as a credible clinical practice. In other words, the things that music therapy aspires to in order to be recognised as a serious clinical profession are the very things that make it (from a disability studies perspective) a questionable enterprise. It is not that I believe music therapists are not good or well-intentioned people but that, in supporting a medicalising, individualising, normalising ideology, I believe they are complicit in the oppression of the very people they intend to help. As Young puts it:

> The conscious actions of many individuals daily contribute to maintaining and reproducing oppression, but these people are usually simply doing their jobs or living their lives and do not understand themselves as agents of oppression (Young, 1990, p. 42).

So does disability studies have anything to say to music therapy? And would music therapy listen if it did? I think the best analysis I can make of the situation would be to draw a parallel between the situation of music therapy and occupational therapy as described by Abberley (1995, p. 227) almost twenty years ago:

> If occupational therapy, through its stance of significant self-improvement, systematically obscures the social causes of disablement, then in the long run it can be of little use to those of its clients that cannot be "cured." Yet if it employs an analysis which incorporates the structural holism of the Disability movement, it undermines its own conceptual basis.

In other words, it's a tricky one. As a disabled person coming from a disability studies perspective, rooted in perspectives developed by disabled people in the disabled people's movement, I find myself unable to sound otherwise than critical of the music therapy business. Yet I recognise that if music therapists were to give any serious consideration to what I have had to say in this article, it would involve a fairly hefty reappraisal of their beliefs and approaches.

To conclude, however, I want to draw attention to a suggestion made by one of the founders of disability studies, the late Vic Finkelstein, who argued for a need for professions allied to medicine (PAMs) to realign themselves as professions allied to the community (PACs). His point was that:

> With this fundamental shift, both in focus and alliance, PACs could freely develop in harmony with disabled people's aspirations. There would then be no need for "care" services to plug gaps believed to be caused by disabled people's personal deficits (Finkelstein, 1999).

Perhaps realignment as professionals allied to the community would enable music therapists to regard disabled people as partners rather than as patients; and to give up aspirations to be recognised and valued as clinical practitioners, preferring instead to claim a reputation as emancipatory practitioners.

Notes

[1] See Jennifer Adrienne 2006 for an exploration of how music therapy, as a helping profession, perpetuates social injustices.

[2] Bruscia (2014, p. 53) has recently revised his definition to: Music therapy is a reflexive process wherein the therapist helps the client to optimise the client's health, using various facets of music experience and the relationships formed through them as the impetus for change. This still, however, implies a medical model.

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