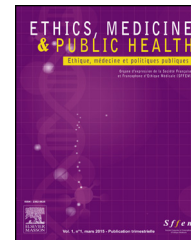




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METHODOLOGY

beyond normative ethics: Ethics of arts-based disability research



Au-delà de l'éthique normative : déontologies de la recherche provenant du disability arts

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Summary In Western culture, the pervading medical model of disability has characterized disability as a problem in need of a solution: an unwanted condition that demands a cure. Even the word ‘disability’ is unavoidably negative: structurally it signifies a loss or a lack, a state that exists only because it falls short of something better. Contrary to mainstream thinking, disability is not a natural state of inferiority or a stroke of misfortune; rather, disability is a culturally fabricated narrative of embodiment. As Scully (2008) observes, representations of disability, created in the main by non-disabled people, tell normative bodies what they want to know – or think they want to know about non-disabled people. Arts-based mediums have the potential to effect positive change and alter prevailing perceptions of embodiment. Disability arts provide individuals living with disabilities with opportunities to communicate their perspectives in sustainable ways and speak back to culturally dominant images and stories. One such initiative, Project Re•Vision, uses the power of arts-informed research to tell stories from the position and leadership of those who embody difference. In doing so, the project

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seeks to challenge conventional understandings of disability as an ailment to be cured. Although much academic discussion has focused on arts-informed research ethics, there has been little consideration of the ethics of conducting “disability” arts-informed research. Our paper will therefore explore what is distinct about disability arts-informed research, as well as the unique ethical issues that arise when working with non-normative bodies.

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MOTS CLÉS

Recherche éthique sur le handicap ; Contes numériques ; Différence intrinsèque

Résumé Le modèle médical du handicap, qui envahit la culture occidentale, caractérise le handicap comme un problème en besoin d’une solution : une condition indésirable qui exige un remède. Le mot handicap lui-même est construit de façon inévitablement négatif : structurellement, il signifie une perte ou un manque, un état qui existe seulement en ne pas être à la hauteur de quelque chose de mieux. Mais le handicap, contrairement à la pensée dominante, n’est pas un état naturel d’infériorité ou d’un coup de malheur ; plutôt, le handicap est un récit culturellement fabriqué et incarné corporellement (corporéité). Comme Scully (2008) remarque, les représentations du handicap, créées en général par des personnes non handicapées, disent aux organismes normatifs ce qu’ils veulent savoir – ou pensent qu’ils veulent savoir sur les personnes handicapées. Les médiums artistiques ont le potentiel d’effectuer des changements positifs et modifier les perceptions dominantes de corporéité. Disability Arts permettent à des personnes vivant avec un handicap la possibilité de communiquer leurs points de vue de manière durable et de parler de nouveau à des images et des histoires culturellement dominantes. Une telle initiative, le Projet Re•Vision, utilise la puissance de la recherche guidée par les arts pour raconter les histoires générées par les gens qui incarnent la différence. En ce faisant, le projet vise à contester l’interprétation conventionnelle du handicap comme une maladie à guérir. Bien que beaucoup de discussions académiques mettent l’accent sur la manière dont une déontologie artistique peut guider la recherche, il y a peu de considération de comment une déontologie « disability arts » peut être mobilisé dans la recherche. Notre article vise à clarifier comment le « disability arts » peut guider l’entreprise de la recherche, ainsi que les questions déontologiques qui se posent lorsque l’on travaille avec et dans des corps non-normatifs.

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Introduction

The representational history of people with disabilities and body/mind differences can largely be characterized as one of being put on display or hidden away ([1] p 514). Medicalized conceptions of disability and mind/body difference have retained a powerful influence on the public’s perceptions, shaping negative attitudes towards disabled people. The stigmatized connotations of inadequacy, deficit, and dependency continue to form the background to the stereotypical ways that society understands disabled people’s lives ([2] p 25).

In insidious and pervasive ways, including interactional and representational ways, our culture is taught that people with disabilities live unlivable lives ([1] p 524). Individuals who live in and with different embodiments are taught to normalize themselves, apologize for their differences, or live uninhabitable embodiments ([1] p 524). Bioethicist Scully [3] thus advocates for the creation of “reconstructive narratives” that seek to revalue the particularities we think of as impairment and deviance. Such narratives, she suggests, have the potential to disrupt

conventional understandings of normalcy and generate new ways of thinking about variant bodies/minds ([3] p 115).

Arts-based initiatives have increasingly been regarded as a promising way to create and center, without normalizing, representations of individuals who have previously been relegated to the margins.¹ Project Re•Vision, a CIHR (Canadian Institutes for Health Research) funded initiative, uses the arts-based research methods of digital storytelling and drama to tell stories from the position and leadership of those who embody difference. In doing so, we strive to challenge conventional understandings of disability as an ailment to be cured, eliminated or overcome.

Like any research method, though, ethical issues must be considered when using arts-based research methods as a tool for public engagement and perceptual change. To date, literature in the field has been primarily concerned with the content and form of arts-based research ([4] pp 1–2).

¹ In this paper, we use the pronoun “we” primarily to refer to ourselves as authors and as Project Re•Vision facilitators and participants.

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