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What it means to be online for people with disabilities.

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Abstract

People with disabilities have traditionally occupied stigmatised identities due to less conventional ways of operating in daily life. The online medium with its absence of visible identity markers, which have typically determined how a person is read offline, combined with the constructive potential embedded within a largely textual medium, potentially, bring together greater control and flexibility in identity construction. The online medium, therefore, may offer social benefits to people with disabilities that are not available in other contexts. This research discursively explores what kinds of experiences are available for people with disabilities online. It argues that the online medium offers alternative subjectivities for positioning people with disabilities in the social world. Discursive findings, however, also show that operating online within a disabled identity creates marginalised experiences.

Discourse analysis, underpinned by a social constructionist philosophy, which emphasises the constructive nature of language in creating experience, is utilised as a methodology for gathering and analysing data. I have adopted Gilbert and Mulkay's (1984) concept of an 'interpretative repertoire' to manage the construction of discursive patterns identified in the data. Semi-structured interviews with 21 people with physical and sensory disabilities, who used the online medium daily, or several times per week, were carried out. Participants were recruited from various disability organisations in New Zealand and were invited to take part in an online interview via email, or another online communication program of their choice. Participants were met in person prior to the interviews to confirm the researcher's credibility and to build rapport.

Seven key repertoires were identified in the data, with each one organised around several discursive resources. A *choice to disclose* repertoire allows disability to become a flexible feature of identity to be revealed and/or concealed in a contextualised and occasioned fashion. The *accessing a socially valued subjectivity* repertoire enables people with disabilities to position themselves as valued members of the social world, free of the physical and psychological barriers constructed by others that surround disabled identities. A *transcendence* repertoire functions in the talk of people with disabilities by surpassing the physical, social, and psychological limitations arising from having to operate within a disabled body,

allowing far greater capacity for participation. A *participating in the world* repertoire affords people with disabilities the opportunity to be part of a wider community of relationships, people, interests, activities, and information, creating a sense of global belonging and connection. The *keeping safe* and *qualified deception* repertoires, together, enable people with disabilities to successfully manage the dilemma of participating in a medium where there is potential for substantial self-gain as well as harm. In contrast to the repertoires available for experiencing alternative subjectivities, which operate outside the oppression of disabled identities, a *disabling differentials* repertoire demonstrates the social disadvantages surrounding disabled identities online. Discursive findings are discussed in relation to disembodiment, as the online medium enables abilities to extend beyond the body, lifting the ceiling on standard ways of operating. This opens up psychological benefits as people with disabilities are afforded opportunities to access and participate within many dimensions of social life. At a collective level, political implications associated with the absence online of disabled identities are raised. Issues of technopower are also mentioned, along with future research directions. Overall, participants' constructions demonstrate how the online medium makes available a social space where people with disabilities can temporarily step outside the physical, social, and psychological constraints of operating within disabled subjectivities. This was cherished and celebrated.

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My chief supervisor, Keith Tuffin, also played a central role in the thesis by introducing me to discursive psychology and social constructionist ideas. Initially, I was resistant towards this ideology and its criticism of mainstream psychology thinking. However, I am grateful to this alternative approach for offering me a radically divergent and mind-bending philosophy for interpreting the world. This has enriched my life. Thank you Keith.

I would like to thank my parents, Don and Ronwen, for their ceaseless emotional and spiritual support throughout this journey. It would not have been the same without you. Discussions with my mother in 1996 regarding links between the Internet and people with disabilities helped plant a seed for this PhD. So, mother, thank you for thinking beyond the square and having the foresight to realise the potential of information and communications technology.

Mandy Morgan, my secondary supervisor, deserves special mention for being available to read this mammoth document at a crucial time. Your feedback has been valuable. I also appreciated your comments at the beginning when I was cultivating this project. Your questions were beneficial for defining the specific context for conducting the research. Thank you Mandy.

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Finally, I would like to pay special tribute to one of my participants with a terminal illness, who died a month after being interviewed. Thank you for sharing your experience despite the difficult and exhausting circumstances. I acknowledge the Simpson family for their support and interest.

Preface

Traditionally, the field of psychology has studied people with disabilities from a particular context. Firstly, this context has focused largely on psychiatric disabilities. Secondly, disability has been constructed as something to be cured, resolved, or minimised. In the field of psychology less emphasis has been given to studying people with physical and sensory disabilities. Similarly, there has been less interest in conceptualising disability as other than a physical and psychological deficit. This thesis privileges people with physical and sensory disabilities. Further, in deploying a social constructionist approach to research, this thesis privileges a discursive orientation to disability. This positions disability as a social practice constructed and constrained by the social context.

In addition to privileging people with physical and sensory disabilities within a discursive framework, this thesis aims to contribute to broadening knowledge about the online medium and the kinds of social experiences offered to people with disabilities. Considering the paucity of research about the social experiences of people with disabilities and the lack of discursive research carried out online, this thesis brings together these scholarly areas. This is achieved by understanding how people with disabilities are constructing their online experiences. Conducting research online about people's online experiences also highlights the legitimacy of deploying the online medium as a research context and topic, in its own right.

While this thesis is located within discursive psychology, it also intersects with cyberpsychology, disability studies, and the field of research encompassing computer-mediated communication (closely aligned with cyberpsychology). The interdisciplinary nature of this thesis is evident in *Chapter One*, which purveys the kinds of possibilities available for people with disabilities by drawing upon literature across these intersecting disciplines.

Chapter Two discusses my ontological and epistemological frameworks for researching how people with disabilities construct their online experiences. A social constructionist philosophy is delineated with emphasis on the importance of language in constructing social experience. *Chapter Three* discusses the benefits

of situating discursive research within an online context and specific advantages for participants with disabilities. The data collection process is described including my position and stake in the research, participants and recruitment, materials and procedures, rapport building, security issues, and ethics. My reflections on the data gathering process are considered. The pitfalls of deploying an online context for gathering interview data are also outlined.

Chapters Four to Nine provide a space in which to analyse participants' interview data. Each chapter is organised around a central discursive pattern generated from the data. *Chapter Four* begins by explaining how the discursive analysis was carried out and then moves to demonstrate the first of the discursive patterns, or interpretative repertoires identified: namely, the choice of people with disabilities to disclose their disability online and the subjective opportunities this brings. *Chapter Five* highlights the ability of people with disabilities to operate within socially valued subjectivities. Being able to transcend standard practices of operating in daily life and the highly positive experience this brings to the lives of people with disabilities is demonstrated in *Chapter Six*. *Chapter Seven* is organised around the idea that the online medium affords people with disabilities the opportunity to be part of a wider community of relationships, people, interests, activities, and information, which creates a sense of belonging and connection with the world. *Chapter Eight* moves on to look at how people with disabilities manage issues of safety and identity online, while *Chapter Nine* demonstrates how operating within disabled identities online constructs negative outcomes and positions people with disabilities as powerless and dependent.

Chapter Ten offers a space to bring together the research findings, firstly, through summarising these findings, which addresses one of the research aims, and, secondly, by highlighting how a majority of the discursive repertoires offer alternative subjectivities for positioning participants in the social world, thereby, addressing the second research aim. The psychological benefits of operating outside the social and physical constraints of a disabled identity are discussed, which opens up issues of disembodiment where abilities extend beyond the body, enabling access and participation within many dimensions of social life. This leads to an opportunity for incorporating philosophy underlying the social model of disability. At a collective level, the political implications of not disclosing a disabled

identity online are discussed. Technopower and issues for future directions are also considered in the final chapter.

Reflexivity is a theme that surfaces at intervals throughout the thesis. It first appears in Chapter Two with respect to analysing how I construct people with disabilities. In Chapter Three it is practised as I reflexively delineate my position and stake in the research, in addition to my reflections on the data gathering process. From another angle, reflexivity surfaces within several of the analysis chapters as I consider how my political, social, and cultural interests affect the repertoires constructed. This extends into the very way in which I have gone about analysing participants' interview data, inclusive of the partiality of my analysis, which is overviewed at the beginning of Chapter Four. Finally, in Chapter Ten, reflexivity is raised again as I revisit the partiality of my work from a variety of perspectives.

In the thesis each chapter is introduced with an abstract that provides a summary of the central issues to follow. Each of the analysis chapters also close with a summary of the central features generated from the interview data. In addition to the summary, a discussion of the analysis in relation to the available literature is incorporated in Chapter Eight. For other analysis chapters a general discussion of findings is carried out in the final thesis chapter.

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