DISCREET SILENCE:
DISABILITY IN POSTGRADUATE EDUCATION

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Theme 2 – Postgraduate Education

Abstract
Are there disabled postgraduates? An observation of access and opportunity is that disparities are always greatest in higher education because they reflect the attrition that has taken place in compulsory education. The author suggests this continues to be the case although aggregated figures may obscure this for reasons including: that "disability" is not a reliable measure; that numbers increase from the act of collecting data; that the majority of "students with disability" are not school-leavers; that most acquired an impairment after leaving school (or tertiary education). In an exploratory qualitative study of university students self-identifying as a "student with disability" the author found "disability" was often subsumed within other identities. The student concerns and preoccupations of participants were similar to that of "mature" students. Young disabled postgraduate students appear few and exceptional. The author outlines the issues drawing upon the study, a review of literature, and critical reflection of his own experience as a disability support worker since 1987.

Introduction

Disabled students are an equity target in tertiary education institutions (TEI). The prevalence of Students With Disability (SWD) has become a measure of affirmative action. Basic and fundamental questions are: What is disability? How is it measured? That is an ongoing debate in the area of statistics and public policy (Sampson, 1997) but it has barely begun for the population of SWD in postsecondary education (HEFCE, 1998; HEFCE, 1999; Horn & Berktold, 1999). The consequence of invalid measures is poor research, flawed policy development, confused management, and unsatisfactory outcomes for the staff implementing interventions.

The "disabled postgraduate" is an example of the paradox of "disability". Can there be a "disabled postgraduate" when this is an educational level so few achieve? Self-reporting at enrolment is still a choice. Some self-identify, some do not, and there are meaningful reasons for those decisions. This paper is an attempt to understand and describe these actions.

Concepts of Disability

The two dominant concepts of disability are the "social" and "medical" models. There is the ""physicality" of the body and the notion of the body as "deficit" and "invalid", and

best understood by the disciplines of medicine and psychology. This "medical model" has numerous critics who provide an alternative structural analysis of disability (Paterson & Hughes, 2000). A seminal work is the sociological approach of Michael Oliver (1990; 1996) who differentiates an individual's impairment from "disability" that is the disabling consequence when society is constructed in such a way that it excludes people with impairments. Definition and usage of "disability" and "impairment" and "disabled" remain much debated (Barnes, Mercer & Shakespeare, 1999; Beatson, 2000; Corker & French, 1999). "Disabled" is a term that is ascendant among politically active disabled people and is the language of the New Zealand Disability Strategy (2001).

Individual Identity

In New Zealand, Martin Sullivan (1999) has demonstrated the contradiction between the statement of acceptance of the social model of disability by TEI, and confused terminology within the same institutions and their documents. It illustrates that confusion abounds, which I have also found among students with impairments, too. To aid understanding I created a Typology of Identification and Identity.

Identification and Identity Typology

I have divided those who identified themselves as a SWD into four groups, for whom there are differing degrees of self-identification as a disabled person. Those identified as a "declaration" (positive identity), those who "disclosed" (negative identity), those who "notified" (low identity), those for whom it was a ""resource or support solution" (who had experienced disability and wanted it ameliorated, but had no or little identity as disabled). The value of creating a typology is to provide a key to the social construction of disabled students.

Disability Declared

Those who "declared" were likely to have initiated contact for resources. They could be said to have a secure identity around a "self-managed" impairment, which was more likely to be "socially acceptable" and/or they had acquired assertive skills to handle negative perceptions. Their impairment was also likely to influence their daily activities across many different situations including university. Their impairment was likely to be experienced as stable, part of their daily life, and they felt in control. Use of "special arrangements", are viewed as a matter-of-fact necessity to be negotiated.

Disability Disclosed

Those who "disclosed" were characterised by caution. They had previously experienced negative responses from people, sometimes because of stigma but also from "disbelief" because of a lack of understanding of impairment, particularly around medical conditions characterised by periods of recession and cyclic occurrence, whose "control" through medication might have their own detrimental effect. These may be "health" conditions that include fatigue and loss of concentration, psychiatric illness, and occupation overuse syndrome (OOS). Their impairment was likely to be experienced as unstable,

periodic, and they did not feel in control. Contact with "disability services" is likely to be a secondary solution suggested by others inside or outside of the institution.

Disability Notified

Those who "notified" as students with disability regarded their impairment as a normal part of human variation, and hence had low identification with "disability issues". They were characterised by daily self-management of their impairment, which was not usually visible. There were situations when impairment may lead to disability; this was expected, so "notification" was a preparation for those occasions. Examples of medical conditions were diabetes and epilepsy. Most of those reporting hearing and vision-impairment impairment will be "notifications".

Disability Supported

There are those who regard "disability" as a label attached as a condition of accessing a resource or support. They may regard their impairment as "difference" rather than "disability". There is no relationship to the extent of use of "disability services". A "one contact" example may be a student with a heart condition seeking a parking permit on campus. A "low contact" relationship may be a student requiring extra time at exams because of difficulty writing for a sustained period. Even a student with high levels of provided resources may conceive "disability" as difference, such as Deaf students who claim a cultural identity.

The Typology of Identification and Identity is a way of understanding the patterns presented by statistical accounts. When figures are presented, basic questions should be asked. What were the actual questions? What were the circumstances? When did this happen? What if the questions were asked again?

From Individual to Institutional Identity

The enrolment form is the key document in tracking the change from "individual identity" to "institutional identity". It is completed by an individual, but contributes to an institutional record. The enrolment form is foremost an "admissions form" to determine eligibility to the institution and entry to particular courses. "Disability" statistics are primarily derived from self-reporting on the enrolment form, which is different across different institutions, and has changed over time.

The enrolment "disability" questions are substantially the same wording as used by the State Service Commission Equal Employment Opportunity surveys and used with staff in the education sector. The results of a confidential 1990 survey of teachers has a pattern of steadily rising impairment, starting from around 6% of the cohort under age 25 years, peaking at around 22% of 55-59 year-olds. Every birth cohort reports around four percent as having an impairment prior to employment as a teacher (Dunn, Pole & Rouse, 1992). This suggests there is a "base" of about 4% of SWD and that "disability" should increase in prevalence with older students, as it does with any older population.

The Case of Postgraduates

The "Identity and Identification" typology was developed from exploratory research with undergraduates but seemed appropriate when I examined the qualitative study, "Issues Affecting Postgraduate Students With Disabilities At The University Of Otago" (2000). This study was the only New Zealand research I found specifically addressing postgraduate students and disability. There were no examples in the study of people who were "disability service" clients while not self-identifying as SWD, but this can be attributed to the methodology. They do exist, for example the elderly have always been represented in the "specials" for exam accommodations, "accommodated" on the basis of "disability", but "disability" subsumed by another identity (eg. University of Auckland News, 1999).

The Otago postgraduates reported a range of impairments including blindness and visual-impairment; hearing-impairment; physical conditions resulting in limited mobility and wheelchair use cerebral palsy, multiple sclerosis, head injury, breast cancer, leukaemia, chronic fatigue, arthritis, epilepsy, diabetes, chemical intolerance, occupational overuse syndrome, and psychological and psychiatric conditions. Some reported multiple impairment.

The Disabled Postgraduate: Pathways

"Postgraduate study [is] a natural <u>progression from undergraduate study</u> [and] is a commonly chosen option for individuals who have come back to university due to a <u>change of circumstance</u> which may be due to a change in ability, health or an existing condition. Postgraduate study is a natural means by which to <u>retrain and develop new skills</u>"
(underlining added) –Holt and McKay, 2000:52)

This observation suggested another typology, three groups to which can be added a fourth, students who <u>acquire impairment during the course</u> of their study. This also conforms to a model developed from "adult" pathways into higher education (Postle, 1995). Continuity and discontinuity in both "student role" and "impairment status" are factors.

A Typology of Pathways to Postgraduate Status and Disability

- <u>Progression from undergraduate study</u>
  This has the most continuity in both student status and in impairment status

- Returning to study after a <u>change in circumstance</u>
  This has the least continuity in both student status and impairment status

- Returning to study to <u>retrain and develop new skills</u>
  This has discontinuity of student status and continuity of impairment status

- Continuing to study after <u>acquiring impairment during the course</u>
    This has continuity of student status and discontinuity of impairment status

This is a typology of transition, with different dynamics and challenges depending on individual, institution, and the wider society. Many issues are common to all students, with or without an impairment, and across all levels of qualification.

The <u>progression from undergraduate study</u> is still a "transition" because the "delivery" of the curriculum is different with each level of qualification. The "coping strategies" developed in previous study may not be as effective, particularly if they have involved supportive peer relationships. A common experience for all postgraduates is isolation.

Students who return to study after a <u>change in circumstance</u> may be still very involved in that circumstance; as well as university study. The change in circumstance may or may not be connected to impairment. It may involve "life changes" such as children all at school, or reaching adulthood, a planned return to the paid workforce, or leaving the workforce. Too much change is a cause of stress, and for many in this study stress was a recurring outcome. For some, the option of studying part-time was important for balancing the time needed around impairment, including the physical consequences of sustained activity, and the time needed for study

For students returning to study to <u>retrain and develop new skills</u>, managing study and paid employment is likely to be the challenge. It is not clear how many continued to work while studying, but of the 32 (of 53 participants) who answered questions on full and part-time student status, 15 were full-time students and 16 were part-time. In the area of health, professional nurses with substantial experience but lacking undergraduate degrees are accepted into postgraduate study. Of the 42 participants who listed their course, 17 were in health.

There is another group who <u>acquire impairment during the course</u> after becoming injured, ill and/or impaired during their course of study. Examples were students who acquired head injury, multiple sclerosis and leukaemia.

There are issues for all students around returning to study after an absence of years (Donaldson & Graham, 1999; NCES, 2000). They have advantages of more life experience, particularly if they are bringing that experience to the topic they study. On the other hand, their previous academic may have been many years ago and under very different circumstances. Notably there are fewer and smaller classes and little student-student contact, so the supervisor relationship increases in importance. Also at postgraduate level there may be few or no one else studying the same topic, so accessing new information is necessarily a personal exercise. This places importance on the library and information collection, which is a problem for particular classes of impairment, including: -
- Blind and visually-impaired people who must have material first put into "alternative formats", either by themselves, or by others.

- People who have difficulty with the physical act of writing or typing.
- People who cannot concentrate for long, for reasons of general fatigue or disordered thinking as a consequence of impairment and illness.

Which Population?

The Otago study has statistics collected from the 1998 and 1999 enrolment forms of SWD at postgraduate and degree level. There has been a "disability officer" since 1991 but 1998 was the first year of additional external funding for support through the MOE Special Supplementary Grant. In 1998 there were 929 students who reported "disability", rising to 1474 in 1999. This was an increase of 5.4% to 8.8% of the total student population. There is also a separate count of students who "identify that their disability affected study".

TABLE 1: Identified Students With Disability as a Percentage of Total Students, All Formal Public Sector TEI by Otago University Students

Year	All iSWD	All Otago iSWD	Otago "Affects Study" iSWD
1998	2.7%	5.4%	1.8%
1999	3.2%	8.8%	2.6%

If the measure of "disability" is a valid measure, and the situation at Otago is similar to other New Zealand universities, then "disability" is more prevalent at higher levels of study, than lower. Is that really the case, or are other factors influencing reporting?

In New Zealand there is a substantial discussion of the conceptual and definitional issues in a report after analysis of the results from the first inclusion of "disability" in the 1996 census, and a follow-up sample in 1997 (Ministry of Health, 1998). The result was two populations of disabled people, those who do not require assistance, and those who were Disability Requiring Assistance (DRA). The same question "Which population?" is posed with the population identifying as Maori (EPMHRC, 2000). Aggregate measures are not sufficient to inform policy.

Equity practitioners in higher education realise this (Ramsey, 1998). There are differences in educational outcomes within the equity target populations of universities, and equity practice. When one examines the equity statistics (DEET, 1996) and literature (NCES, 2000), disabled people fit into a much larger category of people whose common characteristic is of difference. The institutional response in New Zealand is similar to the Australian experience and policy toward "adult" students (Postle, 1995). In the table below I have labelled those "special populations" as "non-traditional".

TABLE 2: Characteristics of Traditional and Non-traditional Student Populations

Traditional	Non-traditional
18-22	Over 25 years
Full-time	Part-time
Male	Female
Dominant ethnicity	Minority ethnicity
Upper SES	Lower SES
Residential	Commuter
Internal (on-campus)	External (off-campus)
Literate in English	NESB and ESL
Nondisabled	Disabled
First Years	

"In so many ways, the impediments to access which face disabled students stand proxy for the impediments faced by all under-represented group"
         NICHE Report 6, Section 4.7

The National Committee of Inquiry into Higher Education (NICHE) was a major United Kingdom examination of the area of lifelong learning, including students with disabilities. It makes familiar points, including the unreliability of statistical data; and the lack of research and understanding of disability. The report had noted a wide range of impairment among SWD and proposed a "deconstruction of the category "disability" … to facilitate the management of appropriate institutional responses to particular disabilities in a focused manner" (NICHE, 1997,r6.s5.8).

In the United States there are no statistical reports on postgraduate SWD, but the undergraduate patterns show considerable variation by categories of impairment, and differences in participation by age cohort. These patterns support the position that most students with impairments are not school-leavers but have entered postsecondary education later (Horn & Berktold, 1999; Lewis & Farris, 1999).

The American data is fuller, but their experience is cautionary. Questions around "disability" cannot be asked in "admissions" applications, instead responsibility is for the SWD to identify themselves, and provide verification of impairment. It is near compulsion, for if they do not, they are not "protected" nor required to be supported. The result is greater scrutiny, and contested definitions (Heyward, 1993; Miliani, 1996; Simon, 2001). The largest category, "Learning Disability", amounts to almost half of all SWD yet is a population that would find it hard to be recognised as "disabled" anywhere outside of the education sector (Vaughan & Bos, 1994). It is not about self-identity; in the end it is those failing in the knowledge economy that the institution recognises as students with disability.

Conclusion

I have concluded that the measures of disability in use are flawed. I consider it inevitable that "disability" will be re-defined and that measures around "impairment" will be used. My concern is that the new measures and new conceptions of "disability" do not become an attack on self-identity. Self-identity, issues of naming and labelling, and the internal and external consequences, are important issues. People with impairments already face scrutiny and disbelief, and may experience rejection, when they try to access services. There have always been far more who report "disability" at enrolment than contact "disability services". The "Typology of Identity and Identification" suggests this is the result of different understandings and motivations. The "Typology of Postgraduate Pathways" suggests that "impairment" may be secondary or layered over other concerns common to "adult learners". The interests of the institution in researching, monitoring, and managing "disability" should be balanced with sensitivity. It is however a debate that needs to take place as the generalising effect of aggregated data conceals patterns of failure and achievement. A discreet silence can become complicity in perpetuating inequity.

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