Students with Disability: Data Collection for Reporting in New Zealand Universities

A thesis presented in partial fulfillment of the requirements for the degree of Master
of Philosophy in Rehabilitation

at Massey University, Palmerston North, New Zealand

Rosemary J Harris

2003

Abstract

The Ministry of Education in New Zealand has dedicated funding to increase the participation of people with disability in tertiary education. However there has been no standardised system in place for defining disability, categorising impairment, or collecting, maintaining and reporting data about tertiary students with disability, in order to determine the eventual impact of this initiative. The present study utilised a cross-sectional survey in a single stage sampling procedure, to gather information from the eight New Zealand universities regarding definitions of disability and categories of impairment used to collect data, as well as the source of data collection and numerical characteristics of the population. Data collected showed a steady increase in the population of university students with disability from 3,039 in 1998 to 4,358 in 2000. However the findings were consistent with the evidence in the literature review that it is currently not possible to know the real number of these students because of the differences in data collection and reporting across institutions. These findings indicated that data was not sourced in the same way across institutions. Furthermore, information was kept in segregated databases in some institutions, which did not all have a means of exchanging data with their general student record system. The Ministry of Education's reporting template introduced in 2001 was found to provide only a partially standardised framework for reporting on data. There must also be a systematic method of collecting and maintaining data across tertiary institutions, including clarification of the sets of students to be counted, so that all institutions are counting students in the same way. The present study identified confusion in language and definitions, with the terms impairment, disability, illness and injury being used interchangeably. The International Classification of Functioning, Disability and Health was suggested as providing a practical functional model for data collection, which could be used as a platform for establishing definitions and clarifying the language around disability and impairment, as well as providing an international standard for establishing consistency.

Acknowledgements

I would like to thank my Primary Supervisor, Professor Steve LaGrow, who has been involved in teaching me over seven years. He kept me going through the dark times and always believed I could do it. Thanks also to my Secondary Supervisor, Gretchen Good, for her unfailing encouragement and support.

A big thank-you to the busy Disability Coordinators around New Zealand who gave of their time to fill out the questionnaire.

Many thanks to my son Sam who checked my maths, and to my friend, Graphic Designer Susanne Dwyer, for typesetting the questionnaire.

I am eternally grateful to Massey University's extramural study programme, which gave me such a golden opportunity when I really needed it.

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 01/85.

Table of contents

List of tables and figures

Tables

Figures

Introduction

In New Zealand and around the world, it is recognised that tertiary education is the key to securing better career paths, better quality of life and standards of living, and ensuring a more equitable, culturally dynamic and informed society (Ministry of Education, 1998). Participation in the tertiary sector in New Zealand has increased substantially over recent years and is above the Organisation for Economic Cooperation and Development (OECD) average. In 1998, 68% of New Zealand school leavers entered a tertiary programme leading to the equivalent of a bachelor's degree or higher. This was the highest rate of all the OECD countries, 28% over the mean rate of 40% (Centre for Educational Research and Innovation [CERI], 2000).

There are 4 kinds of public tertiary institutions (TEIs) in New Zealand: a) universities (n=8), b) polytechnics (n=20), c) colleges of education (n=4), and d) wananga (n=3), which among them enrol over 300,000 students each year. Universities are generally the largest institutions, with an average of over 15,000 students formally enrolled at each (Ministry of Education, 1998).

In 1999 there were seven universities in New Zealand: Lincoln University, Massey University, The University of Auckland, The University of Waikato, University of Canterbury, University of Otago and Victoria University of Wellington. On the first of January 2000, the Auckland Institute of Technology became the Auckland University of Technology, New Zealand's eighth university (Ministry of Education, 1998).

As the tertiary population has continued to grow, so has the diversity of the population of students enrolled. Prior to the late 1970s, little emphasis had been placed on access to tertiary education for people with disability in New Zealand. Initially the focus was on transition to work courses or 'special', non-integrated education, rather than on the participation of students in mainstream tertiary institutions (Lang, 1993). In 1981, the International Year of the Disabled raised awareness of the needs of people with disability and prompted the formation of groups such as the Assembly of People with Disabilities; this increased awareness of disability issues spread to university campuses as well (Dell & Sandbrook, 1996).

Alexander and Bridgman (1982) undertook a survey of New Zealand tertiary institutions, which enquired about the numbers of students identifying with disability and whether universities had a systematic method of identifying these students. Only the University of Auckland and Canterbury University had a systematic means of identifying students with disability, the others had to provide estimates (Alexander & Bridgman, 1982). At the time of this study (1982), the collection of data about students with disability was not a requirement for reporting in tertiary institutions.

The University of Auckland reported 56 students enrolled with disability, the University of Canterbury 8; Lincoln University estimated it had 3 students with disability, the University of Waikato estimated 2, Victoria University estimated 25; neither Massey University nor the University of Otago offered an estimate of the number of students with disability enrolled. The numbers reported were incomplete, both the authors and the institutions believed there were more.

These figures, if only estimated and incomplete, still indicated a low participation rate among students with disability at universities. This was partly due to an absence of formal structures to ensure student support. Other reasons included: lack of access and information; misconceptions or negative expectations of parents, teachers or students; low levels of confidence or encouragement of potential students and financial need (Andrews, 1992; Lang, 1993).

The participation rate of tertiary students with disability (TSDs) has increased from 1982, but records are not available to indicate exactly by how much. For example, data collection began at Massey University in 1992 when there were 261 students; this number increased to 348 in 1996 (Dell & Sandbrook, 1996). Data collection related to students with disability over this period was not required by either the Ministry of Education or Massey University, rather, data was collected to make a case to the University for providing services and support to this group of students.

Mandatory reporting did not begin until 1997, when the Ministry of Education introduced a Special Supplementary Grant for Tertiary Students with Disabilities to come into effect in 1998. The purpose of the grant was to increase the participation of people with disability in tertiary education by improving access to educational opportunities at tertiary institutions and increasing the level of enrolment and academic achievements of these students (Ministry of Education, 1997a). The grant was based on a sum of $29.95 (including GST) per equivalent full-time student (EFT). The grant was based on the total number of EFTs enrolled in a given tertiary institution, not just students with disability, so was a significant sum of money for larger institutions. For example the University of Auckland reported 22,113 EFTs in 1999 (The University of Auckland, 2000), which equates to a supplementary grant of $662,284.35.

The Special Supplementary Grant had certain conditions attached, which were mandatory for institutions receiving the funding. The first condition was that universities had to identify TSDs as a target Equal Educational Opportunities group in their Charters by 31 December 1999. The second condition was that universities were required to complete separate annual reporting on the provision of support services for TSDs, including identification of the variety of services provided and their costs. The third condition was the gathering of baseline data on the enrolment numbers, course participation, course completion rates and graduation or certification rates of TSDs (Ministry of Education, 1997b).

TSDs were defined by the Ministry of Education for the purposes of the Special Supplementary Grant as: 'those who self-declare as such on the enrolment form, together with those who do not but who approach, or are referred to, the Disability Coordinator during the year' (Ministry of Education, 1997a). The 'Notice of Purpose for the Special Supplementary Grant' and the 'Conditions of the Grant', were sent to tertiary institutions by the Ministry of Education. Individual universities then set their own objectives for the funding and the Vice-Chancellors and the Senior Manager at the Ministry of Education signed them off.

From this point, each university was required to specifically include statements about the provision of support to students with disability in public documents, including the Charter and the institution's annual objectives. All public tertiary education institutions in New Zealand rely heavily on funds raised through taxes by government with over 80% of all gross revenue coming from this source (Dixon, Coy & Tower, 1994). It is now widely accepted that information about the objectives of an organisation using public money is important and should be disclosed in an annual report. Objectives are largely discretionary, even though they have to be put to the Ministry of Education in some detail as part of the funding process. Annual reports are generally regarded as a primary vehicle by which universities communicate information about their activities and achievements to their many stakeholders, and so are fundamental to discharging accountability to these stakeholders (Dixon, Coy & Tower, 1994).

Reporting requirements became more stringent with the introduction of the Special Supplementary Grant. In the 1990s tertiary institutions provided individual student record data to the Ministry of Education electronically, and in earlier years summary data was provided on paper returns for each institution (Ministry of Education, 1998). As a result of the Special Supplementary Grant, universities were required to report data on students with disability in three different ways: a) in the Single Data Return (SDR) sent to the Ministry of Education electronically three times a year, b) in the annual report on the Special Supplementary Grant for the Ministry of Education and c) in a university's annual report.

In order to provide services to students with disability and meet the Ministry of Education requirements, each university asks students to voluntarily self-identify by a positive response on student enrolment forms or by contacting the disability services at their institution during the year. This information is kept confidential and is used to facilitate service provision, as well as to collect data for reporting to the institution and the Ministry of Education.

As instructed by the Ministry of Education, the Single Data Return provides data taken from the enrolment form on the number of students who voluntarily identify as having a disability at the time of enrolment (Ministry of Education, 2002). The annual report on the Special Supplementary Grant provides data on the number of students who self-declare as such on the enrolment form, together with those who do not, but who approach or are referred to the Disability Coordinator during the year (Ministry of Education, 1997a). It is not clear where universities source the disability data for their annual reports. This means there are two different instructions from the Ministry of Education for collecting data for two of the reports and no clear instructions for the annual report. This would suggest a possible disparity between the sets of data collected.

Policymaking has been hindered by the lack of reliable information about the number of students involved in higher education. The Ministry of Education has no real idea of the numbers of students with disability studying in tertiary education because of the lack of consistent data (McKay, Rowlands, Ballard & Smith, 1998). Charlton (1997), recommended that as an outcome of her research into the key factors that attract and retain students with disability at tertiary institutions, support be given to the collection of accurate data on TSDs by creating standardised questions on the enrolment forms of all institutions and standardising data collection.

Prior to 2001 there was no standardised framework for collecting data about students with disability. In 2001, the Ministry of Education decided to address this by developing a standardised reporting template for tertiary institutions to use when reporting on the Special Supplementary Grant, the implication being that tertiary institutions would begin to collect the same data about students with disability and report on it in the same way. Mandatory reporting using the template will be from 2003.

As part of the 1999 Budget, the Government also announced the development of a Data Warehouse for the tertiary education sector by January 2002. This project involves the provision of computer hardware and software to enable the Ministry of Education to collect, store and analyse information on the tertiary education sector, reflecting the Ministry's need for consistent and uniform data across tertiary institutions. The establishment of the data warehouse is fundamental to the implementation of the new demand-driven tertiary funding system, provision of high quality advice to Government about tertiary education, and the ability of Government to plan, forecast, monitor and report on developments in tertiary education in New Zealand (Ministry of Education, 1998).

In order for the data collected for the Data Warehouse to be meaningful, it must be valid and reliable. Validity refers to the ability of data to measure what it purports to measure. Without adequate validity, it is not clear what something is measuring. Reliability is the consistency of measurement from time to time when results are similar on different occasions. The essence of reliability is that the results can be relied upon to be an accurate representation of that which is being measured (Creswell, 1994). If data is not reliable, then no clear statement can be made about what has been measured.

The importance of consistency in the collection and reporting of disability data is paramount if it is to be useful. Variation in information about people with disability in national data sources creates variation in estimates of prevalence, incidence, performance and contributions (Andrews, 1992). Estimates from data produced using different categories for classifying subgroups of individuals with disability create confusion for users of this information, including policy analysts and decision makers. A low level of student identification at tertiary institutions impedes planning and support service development for people with disability (Andrews, 1992).

Timely access to reliable disability data and therefore the profile of students with disability is required to facilitate more effective reporting, planning, and design and delivery of support services, at both a national and regional level. This thesis will investigate how data has been collected for reporting purposes in the eight universities in New Zealand. The definitions and categories that are used will be compared as well as how and where data is collected, to see where there is variability or similarity between universities. This will provide an opportunity for universities to inform process, before reporting to the Ministry of Education using the template becomes mandatory in 2003.

Literature review

Tertiary institutions in New Zealand are required by law under the Human Rights Act of 1993 to provide reasonable accommodations for students with disability. The Special Supplementary Grant for Tertiary Students with Disabilities (Ministry of Education, 1997a) provides a proactive mechanism to increase the participation rate of people with disability in tertiary education in New Zealand. Meaningful data to measure the participation rate depends upon reliable systems for the collection and reporting of data, to compare across institutions and years nationally and to compare to other countries internationally.

It is difficult to estimate the number of tertiary students with disability (TSDs) that may need support, or to make international comparisons, as there has been no uniform system for collecting data in New Zealand and it is difficult to estimate from other countries overseas for the same reason. Internationally, data shows that very different categories of students across countries are reported as being in need of additional support. The Organisation for Economic Cooperation and Development (OECD) recognises this and is working towards developing a more uniform approach to international data collection. This effort has begun with primary and lower secondary school students. Tertiary students will be the focus of future studies (CERI, 2000).

To provide a basis for comparisons, various OECD countries have now developed their own national categories used to identify primary and lower secondary school students with disability, learning difficulties and disadvantages within a tri-partite international taxonomy (CERI, 2000). Category A, in this taxonomy, corresponds broadly to needs arising from impairing conditions, Category B includes those experiencing learning or behaviour difficulties for no clear reason, and Category C covers students from disadvantaged backgrounds. Different countries identify very different proportions of students in categories A, B and C as being in need of additional support; some of this variation may be due to some differences in the way the categories are defined or interpreted across countries (CERI, 2000).

Using this approach, data collection is based on the additional use of resources made available to support students to access the curriculum, whatever the cause of the difficulty may be. Student numbers are identified for the purposes of comparison in terms of the additional public and/or private resources allocated to ensuring access. In other words, data is collected for the purpose of measuring resources allocated rather than participation rates, and student numbers are only obtained as a means of determining the relative costs across categories. It is interesting to note that in almost all countries substantially more males than females are reported to be receiving additional resources (CERI, 2000).

At the tertiary level, however, the purpose of data collection is mainly to determine participation levels of TSDs as opposed to comparing resource allocation. However, there has been no standardised practical system for collecting this data across countries. This makes international comparisons tenuous, resulting in difficulty obtaining a meaningful picture that could be used for policy and evaluation.

There are two international categories of definitions that apply to students with disability. They are educational definitions and definitions of disability.

Educational Definitions

The International Standard Classification of Education (ISCED) was designed by the United Nations Educational, Scientific and Cultural Organization (UNESCO), in the early 1970s to serve as an instrument suitable for assembling, compiling and presenting statistics of education both within individual countries and internationally. Member states were invited to apply these new standards in the reporting of education statistics so as to increase their international comparability (ISCED, 1997).

ISCED presents standard concepts, definitions and classifications which cover all organised and sustained learning opportunities for children, youth and adults including those with disability, irrespective of the institution or entity providing them or the form in which they are delivered. Whilst ISCED may be easier to use for collecting enrolment data, it is a classification of educational programmes and does not deal with the flow of students through the education system (ISCED, 1997).

In 1995, CERI published the first set of data making comparisons in the field of special needs education. This work strengthened the view that a different comparative framework would need to be developed if reliable and valid comparisons were to be made. This was because the definitions used were so different among countries that comparisons were almost impossible to make (CERI, 2000). In 1996 the first discussions began with countries on developing a resource-based definition. This would help to overcome different national interpretations of concepts such as special educational needs, which cover very different populations of students who are experiencing difficulties in accessing the curriculum (CERI, 2000).

At the same time, the UNESCO standards for classifying education systems (ISCED) was in the process of being revised and the definition of special needs education was updated and reformulated to reflect policy developments. UNESCO countries agreed on the tri-partite system in which students were divided into three cross-national categories (Category A included needs arising from impairing conditions, Category B included those experiencing learning or behaviour difficulties for no clear reason, and Category C covered students from disadvantaged backgrounds).

The OECD decided not to pursue a classification system for the tertiary sector because of the deficiencies in their post-compulsory database and the need to concentrate in the first instance on a central core of concerns at the primary and lower secondary school level (CERI, 2000). Also the collection of data at the tertiary level has a different emphasis, it is not just about resourcing systems, but also about participation in the system. The lack of a uniform classification system has resulted in a lack of standardisation of data collection at an international level regarding the participation of students with disability attending tertiary institutions.

Definitions of Disability

Educational definitions are resourced based and relate to input needs of the institution. Definitions of disability relate more to the categorisation of students who have these needs. Multiple competing sets of terminology have led to confusion when collecting and reporting disability data. In order to encourage researchers to use a more precise, objective and internationally recognised terminology, the World Health Organization (WHO) developed the International Classification of Impairment, Disability and Handicap (ICIDH) in 1980. It has appeared in fifteen languages and its three-part structure was accepted worldwide as providing both a scientific model of disability and the basis for a common language for clinical use, data collection and research.

Impairment is defined as "any loss or abnormality of a psychological, physiological, or anatomical structure or function" (WHO, 1980, p.47). Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980, p. 143). Handicap is defined as "any disadvantage for a given individual, resulting from impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" (WHO, 1980, p.183). Thus, people with a disability are those who have a functional limitation resulting from an impairment, which may or may not result in a handicap.

Disability may arise as a direct consequence of impairment, or as a response by the individual to impairment and reflects disturbances at the level of the person (WHO, 1980, p.144). Disability is categorised in the ICIDH across nine categories: behaviour disabilities (awareness disabilities, disabilities in relations), communication disabilities (speaking, listening, seeing, other communication disabilities), personal care disabilities (excretion, personal hygiene, dressing, feeding and personal care disabilities), locomotion disabilities (ambulating, confining, other locomotion disabilities), body disposition disabilities (domestic, body movement, other body disposition disabilities), dexterity disabilities (daily activity, manual activity, other dexterity disabilities), situational disabilities (dependence and endurance, environmental, other situational disabilities), particular skill disabilities, other activity restrictions (WHO, 1980, pp. 144-147).

Impairment and/or disability may lead to a handicap on the societal level. Handicap arises from the environment in which a person lives and the circumstances that place individuals at a disadvantage relative to their peers when viewed from the norms of society (WHO, 1980, p.184). The ICIDH includes the seven dimensions of handicap as: orientation handicaps, physical independence handicaps, mobility handicap, occupation handicap, social integration handicap, economic self-sufficiency handicap and other (WHO, 1980, p. 184). Each category is defined separately and includes a scale category with it for identifying the degree of handicap.

In response to international calls for its revision and the need to develop a more inclusive classification system that could incorporate a broader view of disability, WHO began a consensus-based approach in 1995 that culminated with the issuance of ICIDH-2 in 2001. Two of the three classification categories, disability and handicap were replaced by the concepts of activity and participation. 'Activity' was proposed as a term to replace 'disability' to allow the classification to capture a broad range of human performance (Gray, Welch & Hollingsworth, 2000). Participation in major life activities was suggested as a new classification category to replace handicap. Personal and environmental factors were proposed for inclusion in ICIDH-2 as contextual factors (Gray et al., 2000).

'Disability' as a term to cover all aspects of the classification system was deemed to be inadequate and was replaced by the phrase 'the disablement process'. These changes were reflected in renaming the classification system as the International Classification of Functioning, Disability and Health (ICF). The ICF is a theoretical model for describing the consequences of disablement. The ICF has conceptual distinctions between three levels of disablement outcomes: impairments at the organ level, disabilities at the person level and handicaps at the societal level. Three broad arenas are differentiated: organ system performance, performance of activities of daily living at the person level and role performance as a member of society (Whiteneck, Fougeyrollas & Gerhart, 1997).

For tertiary students, the broad activities involved are: auditory (e.g. hearing a lecturer), cognitive, (e.g. learning or processing data), communicative (e.g. asking questions) manual (e.g. taking notes), motile (e.g. getting from lecture to lecture), personal care (e.g. toileting or eating), social (e.g. interacting with staff and other students) and visual, such as reading or seeing overheads (Bruce & Washington, 2000). If a student is unable to perform any of these activities due to an impairment, s/he may be considered to have a disability.

The ICF recognises disability as a dynamic state of restricted function affected by a) the interaction of the person and their health condition (including impairment) with b) the activities they desire to do (and any difficulties they may have in carrying these out and c) the environmental and personal factors (restrictions on participating in the community, such as physical access or discriminatory attitudes) in which they find themselves. An individual's functioning in everyday life is the result of a complex relationship between these three components and thus a person's participation in activities, such as tertiary education, is either facilitated or restricted by environmental or contextual factors (Parmenter & Riches, 2002).

Research by Gray et al. (2000) indicated that people with and without disability as well as professionals and non-professionals were nearly unanimous in their support for the proposal that the ICF should cover diseases, disorders, injury and trauma. Using a classification system that has general acceptance among the major stakeholders can provide a basis for discussing solutions to shared concerns. Throughout the literature at present, there is confusion between disability and impairment. The terms are often used interchangeably and it is therefore difficult to make sense of data collected. The purpose of the ICF is to provide a common framework for establishing definitions and a shared language for consistent and reliable data collection (Meltzer, 1999). Data can then be compared within and across countries.

However without the current use of a consistent classification framework, definitions of disability still differ considerably from one country to another. Because of this, apparent differences between countries in the prevalence of disability are inevitably greater than those that really exist. Even within an individual country, definitions can be inconsistent. While countries such as Australia, Spain and the United Kingdom use WHO's 1980 international classification of impairment disability and handicap, they do not necessarily use it consistently. In Australia, for example, there are regional variations in usage and it is not always clear to the Australian Bureau of Statistics which definition is being used in any given case (CERI, 1997).

Other countries use very different criteria. In Norway, a distinction is made between educational disability and disability in relation to work, and in Italy, the statistics for those with disability in tertiary education are based on the certification process by which children with disability are deemed to have a right to educational support. Among those identified as having a disability, the differences in proportions considered to have different types of impairment causing the disability also vary considerably from one country to another, this is probably largely attributable to differences in criteria for classification, rather than to real differences (CERI, 1997).

The OECD recommended that a simpler model for collecting data was required which could provide more comparable data across countries (CERI, 2000). Data about TSDs must monitor participation levels to account for the use of public monies and for the development of policy and planning. Currently countries are counting TSDs but the picture is confusing as the terminology is inconsistent. The aim of the ICF is to provide a common language to improve communication between service providers, other public sectors, and people with disability, in order to facilitate the proper comparison of data within and across countries. As such, it is designed to be used as a statistical and a research tool for monitoring the participation of people with disability in the tertiary education sector.

Classification by Impairment

Although populations may be defined by disability, historically, people with disability have been defined and classified according to their diagnosis or type of impairment. Impairment is the most basic consequence of a disease, injury or congenital abnormality and may be temporary or permanent. Impairment may be measured by type or degree of impairment and people categorised according to those and compared accordingly.

The ICIDH lists 14 classes of impairment with numerous sub-categories: intellectual impairments (impairments of intelligence, memory, thinking, and other), other psychological impairments (impairments of consciousness, wakefulness, perception, attention, emotive and volitional functions, behaviour pattern impairments), language impairments (impairments of language functions and speech), aural impairments (impairments of auditory sensitivity, other auditory and aural impairments), ocular impairments (impairments of visual acuity, other visual and ocular impairments), visceral impairments (impairments of internal organs and other special functions), skeletal impairments (impairments of head and trunk regions, mechanical and motor impairment of limbs, deficiencies of limbs), disfiguring impairments (of head and trunk regions, limbs, other disfiguring impairments), and generalised, sensory and other impairments - generalised impairments including multiple impairments, sensory impairments and other impairment (WHO, 1980, pp 47-53).

Eligibility for service provision has often been determined by such classification systems, but significant gaps and overlaps in service provision commonly occur (Parmenter & Riches, 2002). The use of categories of impairment to describe people with disability has come under criticism, particularly by people with disability, for the use of negative terminology based on a medical model of disability and the premise that disabling factors are located within the person (Gray et al., 2000).

A further problem with categorising people by impairment has been the lack of consistency in the language used. The OECD found that there were no consistent definitions of categories of impairment across countries, not only of emotional and learning impairments but also of apparently clear-cut categories such as hearing, vision and physical impairment. Comparisons were further confounded by the fact that different countries had different kinds of categories. The Italian report was the only one to use the composite category 'psychophysical', into which 78% of TSDs were placed, and the Australian statistics differed from other countries by using the category of impairment in manual dexterity, within which some 9% of TSDs were placed (CERI, 1997).

There is also debate about the lack of educational utility of descriptive categories that are derived from medical classifications. Categories of impairment can be viewed as having only partial implications for educational provision or for the development of teaching programmes, which inevitably have to take the whole student into account. However, if meaningful international comparisons about the participation of people with disability in the tertiary education sector are to be made, the allotment of students into straightforward and operationally defined categories would substantially simplify the situation and improve the possibility of making policy-relevant decisions based on internationally valid comparisons (CERI, 2000).

Rates of Participation

Although the participation rate for all citizens in tertiary education in New Zealand is high and the number of school leavers entering a tertiary programme leading to the equivalent of a bachelor's degree or higher is among the highest in the OECD (CERI, 2000), it is not clear exactly how the participation rates of TSDs in New Zealand compare to other OECD countries. At first glance it does appear to be low with the percentage of TSDs per total student population reported as being 2.1% in 1998 and 2.4% in 1999 by headcount across all eight New Zealand universities (see Table 1). While this figure compares favourably with those reported for Australia, where the rate was reported to be 2.4% in 1997 (Higher Education Division, 1999), it is lower than the 3.0% reported for the USA (Lewis & Farris, 1999) and the 3.3% reported for the UK (Nye, 1997). However it is hard to know how these figures actually do compare as they are all collected in very different ways and represent quite different things.

By examining the individual university annual reports in New Zealand, data can be gathered on the numbers of TSDs studying across the eight universities in 1998 and 1999. As can be seen in Table 1, the participation rate of 2.4% per total number of students at university in 1999 represents a headcount of 3,634 students as opposed to equivalent full time students (EFTs). It is not clear if other countries are using headcounts or EFTs. It is also not clear if the definitions used are the same across all universities in New Zealand as well as across the various countries.

Table 1

Tertiary Students with Disability in New Zealand Universities in 1998 and 1999 by Headcount and Percentage of the Total Student Population

UNIVERSITY	1998 total number of students	1999 total number of students	1998 TSD headcount	1999 TSD headcount	% TSDs in 1998	% TSDs in 1999
AUCKLAND	26,110	26,985	576	612	2.21%	2.27%
A.U.T.	24,878	26,319	517	548	2.08%	2.08%
CANTERBURY	12,528	12,191	300	501	2.39%	4.11%
LINCOLN	3,918	3,792	75	80	1.91%	2.11%
MASSEY	32,393	37,666	593	518	1.83%	1.38%
OTAGO	16,945	17,133	317	445	1.87%	2.60%
VICTORIA	13,946	14,391	470	455	3.37%	3.16%
WAIKATO	12,542	12,483	210	475	1.67%	3.81%
TOTAL	143,260	150,960	3,058	3,634	2.13%	2.41%

Note. The figures in this table were taken from each university's annual report in 1998 and 1999. These reports are referenced under the universities' names in the references section; the figure for the number of TSDs studying at Waikato University in 1999 was supplied by the Ministry of Education in its report on the Special Supplementary Grants for 1999 (Ministry of Education, 2000).

The percentage of TSDs per total student population ranged from 1.38% at Massey University in 1999, to 3.81% at Waikato University in 1999. Smaller institutions such as Lincoln University did not appear to have more students with disability enrolled, unlike the UK where smaller institutions reported larger numbers (Nye, 1997). It is not clear how the data in each university's annual report was compiled, whether it only represents students who self-declare on the enrolment form, or whether it includes students who utilise disability services during the year and whether this is consistent across the universities.

In the USA, the Office of Special Education and Rehabilitative Services, U.S. Department of Education (OSERS) requested a study containing the first nationally representative data collected about TSDs. A report discussing the outcomes of the survey was written in 1999. The report found that 3.0% of students disclosed a disability. However, the student counts differed across institutions with 28% of institutions in the survey indicating that their counts only included those students to whom services or accommodations were provided. 38% reported that their counts were based on students who provided verification of their impairment regardless of whether services or accommodations were provided; 22% included students who identified themselves to disability support services regardless of verification or provision of services and 12% said that their counts were based on all students that had been reported to the disability service, regardless of whether the office had any contact with them (Lewis & Farris, 1999).

These results show that different subsets of students were counted. Counting only students who are provided with services or accommodations in an institution is more likely to capture students with disability who require support to participate in the tertiary environment and more likely to provide an accurate picture of how resources are expended. These counts are likely to be lower than counting all students who disclose as having a disability but who are able to function without assistance. In order to make data comparable across institutions, it is important to be clear about which students are being counted and to count the same subsets.

Information contained in the OSERS report was restricted to those students who had identified themselves in some way to the institution as having a disability or impairment, since these were the only students about whom the institutions could report. Students who identify themselves to an institution are a subset of all students with disability, since some students may choose not to identify themselves to their institutions (Lewis & Farris, 1999). Students are not required to disclose unless they wish to and institutions are therefore not aware of all students with disability.

Figures in the UK are drawn from the Higher Education Statistic's Agency (HESA) student record form, which contains a field to record disability data. This data is based upon the student's own self-assessment of disability, is not dependent upon verification and is provided voluntarily (Nye, 1997). Disability status was known for 81% of the population of all students in 1995/96, with the rate increasing annually. Of the students whose disability status was known, 3.3% were reported as having a disability, 52% of all students reported were female (Nye, 1997). Since it is optional for individual students to report a disability, as in the USA, there is accordingly information not known about the whole of this population.

HESA student data was collected from more than 180 institutions, defined as publicly funded higher education institutions. Among these institutions there was a diversity of size and provision and there were some interesting disparities of the proportion of students with disability at each institution. Higher proportions of TSDs were reported at smaller institutions (Nye, 1997). The percentage of students reported as having a disability (3.3) was small compared with 14% of the population as a whole (Adams & Brown, 2000), but higher than that in the USA (3.0), Australia (2.4) and New Zealand (2.4).

What remains unclear is exactly what factors go in to make up these statistics. As with the Lewis and Farris (1999) study, the language used in the coding framework for collecting data was confusing, with impairment (e.g. hearing impairment) mixed with medical conditions (e.g. asthma) and disability (e.g. personal care support). What is clear, however, is that the data is not based upon contact with or receipt of services, as with most of the data collected in the USA. Thus, the two are not directly comparable.

National data was collected in 1997 for each university in Australia against each of the equity performance indicators for each of the equity groups, to track changes in participation rates over the period 1991-1997. The main points to emerge from the data were that there were large variations in access rates for TSDs across universities, ranging from 0.2% of commencing students to 9%. There was also an increase in the participation of TSDs between 1996 and 1997 (the only two years for which data was collected), from 1.9% to 2.4% of the student body (Higher Education Division, 1999). This is lower than the findings of the studies from the USA (3.0) and the UK (3.3) and the same as that collected for New Zealand in 1999.

The Western Australia State Disability Office undertook a demographic study of TSDs in 1999. The purpose of the survey was to review the number of students with disability in secondary education and tertiary education and training, to identify trends and specific issues across sectors in Western Australia. The ratio of TSDs at various universities in this part of Australia ranged from 0.7% to 3%. The 0.7% was suspected to be a data collection issue rather than an actual reflection of the population. It did not reflect the expected figure of over 2% and there was no explanation for it being significantly different to other universities (Johnson, 2000). As in the UK, data was not based upon contact with or receipt of services and there were different ways of sourcing data and different categories used for data collection.

National Definitions

It is difficult to draw conclusions about the participation rates of TSDs from the data collected because of the lack of consistent definitions of disability both within and across countries. At universities, students with disability from New Zealand, the USA, the UK and Australia were defined through self-identification by a positive response on student enrolment forms. In New Zealand and the USA, students who contacted disability services during the course of their study (but may not have disclosed on the enrolment form) were also included in some of the counts, unlike the UK and Australia who only collected the enrolment data. Also the way that disability was defined and the way in which the question was asked of students was not always made clear. The language often confused impairment and disability and it is not always clear in which of these categories data is being collected. All countries have a number of different definitions that are used to capture national data and each country has regional variations in the way that they ask for disability data.

In New Zealand, for example, the Human Rights Commission, the Ministry of Health and Statistics New Zealand each define disability differently. The common theme through these definitions is that disability results from impairment at the organ level, lasts over time (at least six months) and has a limiting effect on people's lives, with individuals requiring some kind of ongoing support. This is in line with the disablement process of the ICF in which disablement is viewed as a process that starts with a disease, injury or abnormality, becomes recognised as an impairment at the organ level, manifests as disability in the performance of activities of daily living and may ultimately lead to the inability to participate or fulfil social roles (Whiteneck et al., 1997).

The definition of disability under the Human Rights Act (1993) is very wide and covers most forms of impairment. Disability in the Act means:

> 'Physical disability or impairment; physical illness; psychiatric illness; intellectual or psychological disability or impairment; any other loss or abnormality of psychological, physiological, or anatomical structure or function; reliance on a guide dog, wheelchair, or other remedial means; the presence in the body of organisms capable of causing illness' (Human Rights Commission, 2000, p. 3).

This definition is very impairment focused and covers loss or abnormality of body structure or physiological or psychological function. It touches only lightly on activity as being the reliance on remedial means and leaves out participation altogether. It is therefore likely to apply to a wider group of people, people with impairment who may not have a disability. It is also not actually clear what is meant by disability and is somewhat tautological (e.g. disability means physical disability).

The Ministry of Health has a definition of disability that is used to identify who is eligible for Government funded disability support services. This definition is as follows:

> 'A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory or age-related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required' (Ministry of Health, 1995, p. 4).

For the purpose of the 1996 Household Disability Survey and the 1997 Disability Survey of Residential Facilities, Statistics New Zealand used the 1980 ICIDH definition of disability as a basis to define disability as any perceived limitation in activity resulting from a long-term condition or health problem; lasting or expected to last six months or more and not completely eliminated by an assistive device. The focus was not on identifying the nature of the disorder or disabling condition, but rather the limitation in activity resulting from it (Disability Counts, 1998).

The census form asked individuals if a health problem, or a condition, (lasting 6 months or more) caused difficulty with, or stopped people from doing: everyday activities that people the same age can usually do; or communicating, mixing with others or socialising; or any other activity that people the same age can usually do; or no difficulty with any of these. It also asked if people had any disability or handicap that was long-term, lasting 6 months or more (Statistics New Zealand, 2001). This question very clearly related disability to activities at the person level and participation as the extent of a person's involvement in life situations. As with the ICF, there was an attempt in the census not to classify people, but to describe the situation of each person.

The 1996 Household Disability Survey and the 1997 Disability Survey of Residential Facilities were the first major surveys of disability to be carried out in New Zealand. The surveys provided an extensive database on the characteristics of adults and children with disability, the nature of their disability and their requirements for equipment and support services. Information gathered from the surveys and reported in Disability Counts (1998), was intended to provide a basis for informed discussion, decision-making and planning. However, on the basis of these definitions there appeared to be a very high rate of people reporting disability in the census.

20% of New Zealand adults and children in the survey reported some level of disability (one in five). The one in five figure was the same as that reported from the USA census results (Bureau of the Census, 1997) and higher than that in the UK, where it was 14% of the population (Adams & Brown, 2000). In Australia the level of disability reported was 14.6% for the population under 65 (Australia's Welfare, 2002).

Of the people in the New Zealand census who identified as having a disability, 10,600 persons across all age groups in the Household Survey indicated that they were currently enrolled in university in 1997, this figure increased to 12,400 in the second Disability Survey in 2001 (Disability Counts, 2002). This was well above the figure of 3,603 collected by New Zealand universities. This is possibly because a number of people with impairment rather than disability responded positively to the question, which was broadly phrased. It may also be because some students do not wish to disclose a disability to their institution or are not in need of support from disability services. This may be particularly so for students who undertake distance or extramural study.

In the USA, to be considered as having a disability under the Americans with Disabilities Act (ADA), a person must have 'a physical or mental impairment that substantially limits a major life activity, have a record of such impairment or be regarded as having such impairment' (Department of Justice, 1992, pp. 8-9). This definition covers impairment, activity and participation by implication, so is similar to the ICF. The ADA was signed into law in 1990 and extended the mandate for non-discrimination on the basis of disability to both state and local governments. The ADA covers education and covers all persons with disability in the USA, whether or not they are citizens and without regard to racial or ethnic origin, including international students (Lynch & Gussel, 1996).

The way in which disability is defined and categorised, or the way questions are asked in surveys, may be different to the way it is defined by the ADA. In California for example, 6% of all college undergraduates enrolled in tertiary education identified themselves as having a disability in response to the question: 'Do you have any disabilities, such as hearing, speech, mobility impairment, or vision problems that can't be corrected with glasses?' (Horn & Berktold, 1999). This figure was double the 3% reported by Lewis and Farris in 1999. It is confusing for people who fill out surveys when the words disability and impairment are used interchangeably as above. The numbers are more likely to reflect the numbers of people with impairment rather than disability, particularly when the question is not related to activity and participation.

In the UK, the Disability Discrimination Act (DDA) was passed in 1995 and came into force in 1996. The Act makes it unlawful to discriminate against people with disability in connection with employment, the provision of goods, facilities and services or the disposal or management of premises, but it does not cover access to education (Adams & Brown, 2000). The definition of disability is 'a physical or mental impairment, which has a substantial and long-term adverse effect on an individual's ability to carry out normal day-to-day activities' (Disability Discrimination Act, 1995, p.2). Following on from the DDA, each university in the UK is required to produce a Disability Statement setting out its policy and provision for students with disability.

The DDA also gives guidance on determining exclusions from the definition – certain conditions that are not to be regarded as impairments for the purposes of the Act. These are: 'addiction to or dependency on alcohol, nicotine, or any other substance (other than in consequence of the substance being medically prescribed); the condition known as seasonal allergic rhinitis (e.g. hayfever), except where it aggravates the effect of another condition; tendency to set fires; tendency to steal; tendency to physical or sexual abuse of other persons; exhibitionism and voyeurism. Also, disfigurements which consist of a tattoo (which has not been removed), non-medical body piercing, or something attached through such piercing, are to be treated as not having a substantial adverse effect on the person's ability to carry out normal day-to-day activities' (Disability Rights Commission, 2001, p. 4).

The DDA is similar in its definition to the ADA. It also takes a similar stance to the ICF in relating disability to actions and by implication, functioning. The exclusions from the definition are also consistent with the ICF, because disability results from an impairment at the organ level and it is this interrelated effect that disablement has on an individual.

In Australia the definition of disability used by the Australian Bureau of Statistics is based on that of the World Health Organization. It is not, however, the only definition used in compiling Australian statistics concerning disability, and it is not always clear as to which definitions are being used in different regions. It is in essence the following:

> 'Disability is the presence of one or more limitations, restrictions or impairments which has lasted, or is likely to last, for six months or more. A handicapped person is a disabled person aged five years or over who is further identified as being limited to some degree in the ability to perform certain tasks in relation to one of five areas: self-care; mobility; verbal communication; schooling; employment' (CERI, 1997, pp. 38-39).

This definition is not as close to the ICF as the USA and UK definitions. Although it covers impairments, it is primarily activity or task related. It also treats handicap as an activity limitation thereby confusing disability and handicap and it includes impairment as a class of disability instead of a cause.

Confusion in Categories

Universities collect data on the participation rate of TSDs in their institution and data is also collected on the categories into which TSDs fall. This is in order to predict and report on resource allocation and to assist in providing appropriate services to students. The lack of consistency in the categories used makes it impossible to make valid comparisons on the profile of TSDs within and across countries. Any data reported on percentages of students within categories does more to illustrate the language problem than it does to add anything meaningful to the profile of students across countries.

In New Zealand, the USA, the UK and Australia, categories varied between universities. In all four countries, reports use the words 'disability', 'impairment' and 'illness' as if they were the same, which is confusing for classification as well as inclusion criteria. Impairment and illness exist at the organ level, whereas disability manifests at an activity level. Impairment does not necessarily result in disability (Meltzer, 1999). It is not clear whether reports have collected data on students with impairment, or students with disability, or both.

In New Zealand, a survey undertaken by Kirkland in 1990, found that 2.8% of students at the University of Otago self-reported as having a disability. Categories in which data was collected are in the table below.

Table 2

Categories of Impairment at Otago University in 1990

Type of disability	%	Type of disability	%
Arthritis	3%	Multiple Sclerosis	1%
Asthma	4%	Other	1%
Back/Neck/Lower Limbs	9%	Paraplegia/Quadriplegia	2%
Chronic Fatigue Syndrome	5%	Physiological Conditions	4%
Diabetes	2%	Pregnancy Difficulties	3%
Epilepsy	3%	Psychological/Psychiatric	7%
Hearing Loss/Deafness	11%	Specific Learning Disability	4%
Heart Problems	2%	Upper Limbs/Hands	5%
Injury/Operation	13%	Vision Loss/Blindness	19%

(Kirkland, 1990, p.15).

As can be seen in Table 2, most of the types of disability were in fact impairments, some were also illnesses or medical conditions as opposed to impairments, while at least one (Specific Learning Disability) was a type of disability. It is interesting to also note the inclusion of pregnancy difficulties in Table 2. Kirkland (1990) was quite open about including temporary and recurring impairments under categories of disability. The dilemma about whether to include students with temporary impairments in the counts of TSDs when they may receive support funded from disability services continues in New Zealand universities currently. If one institution includes students with temporary impairments and another does not, reporting and comparing outcomes for TSDs across institutions becomes meaningless (McGrew & Algozzine, 1995).

Kirkland (1990) also reported on the types of anomalies underlying the broader categories, which gave a fuller picture of the definitions of categories. For example, in the category of 'physiological conditions' were: kidney problems/renal transplant, cerebral palsy, stroke, ankylosing spondylitis, blackouts, gastro-intestinal disease, hydrocephalus, muscular dystrophy and ulcerative colitis. Under the category of 'other' were: 'extremes of height and stuttering' (Kirkland, 1990, p.26). Because of the number and range of categories, there were only a small number of students in the 'other' category (1%). However, collecting information on the types of impairment or illness or medical condition students have, does not give a picture of how many students subsequently have a disabling condition or activity limitation that requires accommodations or support from their institution. It is only relevant if the students have first been identified as having a disability.

Categories in which data has been collected vary across the universities in New Zealand. For example, there has been variability in the categories used when requesting information from students at enrolment in the enrolment handbooks or registration forms. In 2001, Massey University requested students with disability to indicate one (or more) of the following categories of disability: mobility, medical, hearing, vision, learning, speech, dexterity, mental health, OOS/RSI (Massey University supplementary forms: Resources and support for students with disabilities, 2001). The University of Otago requested students to tick one (or more) of the following categories: hearing, visual, physical, learning, psychological/psychiatric or other (University of Otago 2001 Registration Form, 2001).

The University of Waikato (The University of Waikato 2001 enrolment handbook, 2001) and Victoria University (Victoria University of Wellington 2001 guide to enrolment, 2001), requested students to self-define the category that described their disability. The categories differ across universities and it is not clear if they are to be categories of impairment, categories of impairment causing disability, or categories of disability. In either case the concepts are mixed. These differences present challenges for meaningful national comparisons.

In the UK there were variations of practice between England, Wales and Scotland, with no central information source for Northern Ireland. Institutions don't apply a common definition of disability, or which impairments result in a disabling condition. Epilepsy is used as a category of impairment in one institution but not in another, which means statistics are not easily comparable across the UK (Report 6: Widening participation for students with disabilities, n.d.).

HESA's information is collected from universities in the following coding framework:

Table 3

HESA Categories of Disability

00	No known disability	06	Mental health difficulties
01	Dyslexia	07	An unseen disability e.g. Diabetes, epilepsy, asthma
02	Blind/partially sighted	08	Multiple disabilities
03	Deaf/hearing impairment	09	A disability not listed above
04	Wheelchair user/mobility difficulties	98	Information not sought
05	Personal care support	99	Not known

(Nye, 1997, p.11).

There is clearly confusion in the language in Table 3. 'No known disability' is neither a definition nor a category of disability and does not provide useful information regarding type of disability. The table mixes impairments such as hearing impairment, with medical conditions such as asthma, and disability such as personal care support which is activity based. The true extent of data collected in the categories in the UK is also obscured by the large numbers of 'not knowns' and a significant proportion of 'not listed' (Report 6, n.d.). In Nye's study (1997), the unknown total was 18.9% of students. The largest numbers of students (43%) are in the category 'an unseen disability, e.g. diabetes, epilepsy, asthma' (Nye, 1997).

These are medical conditions and quite probably the majority of students in this category would be able to function without any activity limitations in the tertiary environment and would therefore not be considered to have a disability per se.

It is not possible to compare the data from New Zealand in Table 2 with the data from the UK in Table 3 in any meaningful way, because of the differences in terminology. Likewise, data collected in the USA (Lewis & Farris, 1999) and Australia (Johnson, 2000) used different categories for data collection again and as with New Zealand and the UK, there were regional variations in the categories used.

In the USA, the State of Florida lists its categories of impairment as: visual disability; physical disability; hearing disability; specific learning disabilities; speech disability and other disabilities. Other impairments included: mental, psychoneurotic or personality disorders; cardiovascular and circulatory conditions; blood serum disorders; respiratory disorders; diabetes and epilepsy (University of Florida Faculty Guide, 2001). In California, disability status was coded into the following categories: learning disability, orthopaedic impairment, other health-related impairments, non-correctable vision impairment, hearing impaired or deaf and speech impairment (Horn & Berktold, 1999). One of the difficulties when examining these categories is that impairment and disability are considered interchangeable, as well as differing from one state to another.

Of the approximately 3% of students disclosing with disability in the USA, learning disability was the most frequent disability reported, with almost half the TSDs (45.7%) in this category (Lewis & Farris, 1999). The term 'learning disability' or 'learning disabilities' is commonly used to describe 'a range of diverse impairments which cause significant difficulties in perceiving and/or processing information' (Massey University, 1996, p.53). The term is not clear, as it is difficult to know whether students are reporting an impairment or a disability and whether students with low literacy levels or English as a second language may also be counted in this category. However, learning disability is in fact a disability and not an impairment.

Lewis and Farris (1999) found that impairments frequently mentioned by tertiary institutions in the USA for which categories were created included: brain injury (traumatic or acquired brain injury, head injury), developmental disability (e.g. intellectual impairment, autism), neurological impairment (e.g. seizures, epilepsy, Tourette's Syndrome, cerebral palsy) and substance abuse. Some institutions counted students with multiple impairments in the 'other' category and a few institutions counted students with temporary impairments here, particularly if those impairments required support services or accommodations. In addition some of the institutions did not know the specific impairments of all or some of the students they included in their counts. There was no consistency or clarity in the terminology used.

Universities in Australia have to report to the Department of Education and Youth Affairs (DETYA) annually on equity groups, which DETYA partly funds in universities. DETYA determines the categories that universities have to report on as: medical condition, unspecified, learning, vision, physical/mobility, hearing and other. Unfortunately these categories don't pick up certain groups such as students with a mental health disorder or those with a learning impairment or higher spectrum disorder, so it is difficult to obtain a meaningful TSD profile (J. Johnson, personal communication, April 4, 2001).

Data in Australia is collected on a wider number of categories for institutional purposes but as in New Zealand, the USA and the UK, there are variations in the definitions and categories across states (Johnson, 2000). What is interesting is the large category of data comprising 18 % 'unspecified' and 8% 'other'. This means for 26%, or just over a quarter of students, there was no information on the type of impairing conditions that required support at university (Johnson, 2000). This is probably because there were only limited categories for reporting. The categories were also not necessarily sensitive to emerging trends or to some groups of students; for example, students with mental illness were in the student body but were not reflected in the data collection.

Across New Zealand, the UK, the USA and Australia, data differed considerably because of the variety of categories for collection and reporting. Any results and conclusions drawn from reports therefore have to be viewed in context. One of the recommendations from the Australian report was that data collection and recording be reviewed to better identify the target population for the tertiary sector and identify emerging trends (Johnson, 2000).

Maintaining and Verifying Data

The way in which data is maintained and verified is also important as it relates to the accuracy of the data source. The Lewis and Farris report (1999) was the only report to enquire about the record-keeping capabilities of institutions. There were five different systems for collecting and maintaining data in this study. Half of the institutions reported that their records about TSDs were maintained only in paper files by the office or person responsible for providing support services and 20% indicated that records were maintained in a separate computerised database by disability services. Records were maintained in a computerised database as part of the general student record system and were accessible to various institutional offices at 13% of institutions. They were part of the general student record system but accessible only to the disability office at 8% of the institutions, while 9% of the institutions reported that they maintained no formal records about students with disability. Large institutions were more likely than medium-size institutions, which were more likely than small institutions, to indicate that records were maintained in a separate computerised database by the disability office or Coordinator (Lewis & Farris, 1999).

The report by Lewis and Farris (1999) was also the only one to enquire whether institutions required documentation from students regarding their disability status. 84% of institutions in the USA that enrolled TSDs in 1996-97 and 1997-98 required verification of a student's disability. Most institutions requiring verification accepted a medical evaluation/statement or a psychological evaluation/statement as verification; about three quarters accepted a vocational rehabilitation agency evaluation. About a quarter of the institutions indicated that testing or formal evaluation of disability by the institution's Disability Coordinator was accepted and about a quarter indicated that they accepted an informal evaluation or determination by the institution's Disability Coordinator as verification (Lewis & Farris, 1999).

Disclosure

The issue of disclosure is not a key theme of this thesis, but is worth mentioning as it does affect data collection. Data collection is restricted to those students who identify themselves in some way to the institution. Those who do are a subset of all students with disability, as some students may choose not to identify themselves in this manner (Lewis & Farris, 1999). No matter which procedure is used to request students to identify themselves, it is generally reported that the response rate from students is at times very low, reflecting concerns that that they have a desire not to seek support in their studies (Andrews, 1992). There is little argument with the contention that students should not be required to reveal a disability unless they wish to and that institutions cannot, therefore, be expected to be aware of all students with disability (Alexander & Bridgman, 1982). This will affect using this type of information for determining participation rates.

Disclosure may also depend upon the type of impairment that leads to disability in the tertiary education setting. Disability may be thought of as activity, or task specific. A person with a hearing impairment may need no assistance if the environment is accessible because all the lecture theatres have a loop system for amplification. However, a Deaf student who requires an interpreter will need to disclose to an institution in order to access this service, as interpreters are not automatically provided in every lecture theatre.

Conclusion

It is evident from the presentations of data concerning the prevalence of disability in tertiary institutions that the criteria used to define disability and the categories used to collect disability information differ considerably from one country to another, as well as within countries. This is also true of New Zealand. If national and international progress in this field is to be assessed effectively, it is essential that countries arrive at common definitions of disability and categories of impairment in order to collect meaningful and comparable data (CERI, 1997).

The percentage of TSDs participating in tertiary education is relatively small at around 3 percent of the total student population. Because of their small sample size, differences between surveys resulting from the way in which disability is defined and impairment categorised, or the way questions are asked, can appear very large. Nonsampling errors can be attributed to a number of sources including: an inability to obtain complete information about all students in the institutions in the sample; ambiguous definitions; differences in interpreting questions; an inability and unwillingness to give correct information; mistakes in recording or coding data; errors of collecting, processing, sampling and inputting missing data (Henderson, 1995).

The goal of ring-fencing funding for students with disability is to increase the participation of people with disability in tertiary education. Data that has been collected shows a steady increase in numbers. Improved information about the tertiary education system for providers, the government and students has been identified as a factor in New Zealand which will assist the sector to continue to respond positively to the challenges it faces. To be successful, providers of tertiary education will need good information on which to base their planning (Ministry of Education, 1998). In order to obtain reliable data, there must be a consistent method of collecting and maintaining data on TSDs across tertiary institutions. The record keeping and reporting capabilities of institutions should be equivalent and transparent.

Each New Zealand university has a general student database that collects and stores information about students. Information specific to students with disability is also collected as a requirement for receiving the Special Supplementary Grant, for reporting purposes, and to enable the management and planning of disability services across campuses. Universities report data on students with disability in three different ways: a) it is reported electronically in the Single Data Return (SDR) sent to the Ministry of Education three times a year, b) in a university's annual report, and c) in a separate annual report to the Ministry of Education on the Special Supplementary Grant for Tertiary Students with Disabilities. Each of these reports is an official record, which can be audited.

The present study will investigate how data has been collected and maintained on TSDs for reporting purposes in all eight New Zealand universities, one sector of the New Zealand tertiary education system. The definitions of disability and categories for data collection that are used will be compared, as well as how and where data is collected, to see where there is variability or similarity between universities. The definitions and categories will be compared against the framework provided by the WHO's international definitions and categories. The Ministry of Education's 2001 standardised reporting template will also be examined, to see if it has facilitated the process of consistent data collection.

One of the recommendations from the report on the disability survey in New Zealand was that there is a need for more complete information on which to base policy, service planning and funding. This needs to be nationally consistent data (Disability in New Zealand, 1998). Ideally the New Zealand data collected should also be comparable to that collected by other countries, thereby adding to the knowledge base internationally.

Method

Research Problem

There is little reliable data available in the public domain about the population of TSDs studying at universities in New Zealand. To date there has been no standardised system in place for defining disability, categorising impairment, or collecting, maintaining and reporting data, nor has there been any standardisation in reporting. There has been variability in the categories used across universities when requesting information from students at enrolment in the enrolment handbooks or registration forms. It has not been clear how universities define disability or collect disability data for reporting purposes. Yet all universities do report data on TSDs and the Ministry of Education has provided the universities in New Zealand with funding to increase the participation of these students in this sector. Although there has been an increase in the reported number of TSDs in New Zealand, it is hard to know with certainty how many are studying and how New Zealand compares to other countries in this.

Research Aim

The aim of the present study was to find out where there was variability or similarity between universities in the collection, verification and reporting of disability data, as well as the definitions of disability and the categories of impairment used for data collection, to determine if data collected was consistent and reliable. Data collected was also compared against the framework provided by the WHO's international definitions and categories.

Research Questions

The following questions were addressed:

- Does the disability data collected for reporting purposes come from the same source for different reports?
- Does the disability data reported differ across reports?
- How do universities keep their records on students with disability?
- Which subsets of students with disability make up the headcounts that are represented in the data provided?
- Do the definitions of disability used for data collection vary across universities and if so, to what degree?
- Is disability status verified and if so, how?
- Do the categories of impairment used for data collection vary across universities and if so, to what degree?
- Do the definitions of disability and categories of impairment vary from those proposed by the WHO in the ICIDH and ICF?
- How does current practice relate to the Ministry of Education's 2001 reporting template?

Participants

The participants were the eight universities in New Zealand, each represented by a Disability Coordinator. Five universities are located in the North Island and three in the South Island. Auckland, in the north of the North Island, has the largest population and has three universities: the Auckland University of Technology, The University of Auckland and the Albany Campus of Massey University. The University of Waikato is situated in the central North Island. Massey University's Palmerston North Campus is further south, then Victoria University of Wellington and Massey University's Wellington Campus. In the South Island are the University of Canterbury, Lincoln University and the University of Otago.

The universities range in size from Massey University, reporting a headcount of 36,391 students in 2000, to Lincoln University, reporting 3,688 students. Each university has established disability services and has at least one Disability

Coordinator or equivalent. The Disability Coordinators were the people most likely to have access to the information that would answer the research questions. The Disability Coordinators were therefore recruited as participants in this study, through their Student Service Managers, and as representatives of their university.

Procedure

This study used a cross-sectional survey in a single stage sampling procedure with the entire population being canvassed. A questionnaire was developed based on questions asked by the National Centre for Education Statistics in the US (Lewis & Farris, 1999) and the OECD questionnaire (CERI, 2000). This was done in order to be able to make comparisons with national and international data where possible. Permission was sought and granted from both organisations regarding copyright.

The questionnaire comprised nineteen questions designed to obtain data pertinent to the research questions. The questionnaire was piloted by sending it to two Disability Coordinators not taking part in the present study; one from an Institute of Technology, and the other a campus Disability Coordinator, one of several from a larger university. Although there are eight universities, several universities comprise more than one campus and have more than one Disability Coordinator.

The research proposal was submitted to the Massey University Human Ethics Committee (MUHEC) as part of an application for approval of proposed research procedures involving human subjects (see Appendix A). The application comprised a description of the research topic; any ethical, legal or cultural concerns; the questionnaire (see Appendix B), a letter to the Student Service Managers in each university (see Appendix C) and an information sheet for the participants (see Appendix D). Feedback from this process was incorporated into the questionnaire. Approval to proceed with the research was granted by MUHEC in July 2001.

Once MUHEC permission was granted, the letter was sent to the Student Services Manager in each university requesting permission to send the questionnaire to their Disability Coordinator as a representative of the university. Once permission was obtained, the questionnaire was mailed to the Disability Coordinators with the Information Sheet outlining the objectives of the research, how the information would be used, their rights as participants and what would happen to the data on completion of the project. In universities where there was more than one Disability Coordinator, one questionnaire was mailed for one response.

Analysis

Due to the size of the population involved in this study, the level of analysis was descriptive. Responses were compared across participants to see where there was similarity or differences among universities. Questions investigated the definitions of disability used when collecting data and the reasons for these definitions. Categories of impairment used to collect data were compared, as well as any additional categories of students receiving assistance from disability services. Categories of impairment being used in universities in 2000 were also compared against categories in the Ministry of Education reporting template developed in 2001 and the ICIDH and ICF definitions of disability and impairment. Responses to open questions were categorised and reported by frequency of response.

How data was collected and where it was stored for reporting purposes was examined across universities. Statistics on the number of TSDs studying in New Zealand universities and the gender ratio were collected and compared to international data. The different types of reports were also compared for consistency of data.

An analysis was made of the subsets of students used to make up the counts of students with disability, whether the counts used in various reports were unduplicated and the percentage of students that declared to their institution that they had a disability on the enrolment form. Verification and types of verification of disability status required by universities were compared and opinions collected on the advantages/disadvantages of collecting data on students with disability by headcount, as opposed to equivalent full-time status (EFT).

Originally it was planned to use a Delphi technique to arrive at agreed recommendations on the categories for data collection, however because of the confusion in terminology and the implementation of the Ministry of Education's template, this part of the study was dropped as being redundant and unnecessary, in favour of promoting the ICF as a framework for data collection.

Consent and Confidentiality

The Student Service Managers and then the Disability Coordinators who were invited to complete the questionnaire, were deemed to have given their consent by the act of returning it. This was stated on the Information Sheet (see Appendix D), including the right to decline to take part or to refuse to answer any particular questions. Those who did not return it by the due date were advised they would receive one follow up with the questionnaire attached electronically. In order to get a high response rate, follow-up was important and a delicate matter without offending or pressuring the participants. Participants were also advised in the Information Sheet that follow up contact might be necessary for clarification purposes.

Individual students could not be identified by the numerical archival data, which focused on total numbers of students and numbers within categories of impairment. All responses from individual Disability Coordinators, particularly in the open-ended questions in the questionnaire, were regarded as confidential and an assurance was given that information would be reported in such a way that the source would not be able to be identified. Because the population size was finite and New Zealand is a small country, it was not possible for the researcher to guarantee individual universities anonymity. The researcher undertook to comply with the Code of Ethics and the relevant legislation and to report any issues that could potentially damage the reputation of Massey University to the Supervisors and MUHEC if advised by the Supervisors.

There was a potential conflict of roles in the present research as the researcher was also a Disability Coordinator. The researcher had professional contact with other Disability Coordinators and this could have made them feel pressured to respond to the questionnaire. Participants were assured in the Information Sheet that their response or lack of response would not in any way affect the researcher's professional involvement with them (see Appendix D).

Summary

The present study used a quantitative method involving a cross-sectional survey in a single stage sampling procedure. A questionnaire sought to gather information from the eight New Zealand universities regarding definitions of disability and categories of impairment used to collect data, as well as the source of data collection and numerical characteristics of the population. This data was collected to determine the current situation and possible implications. Ethical considerations were covered and data analysis methods outlined. The entire population of universities was compared from a 100 percent response rate.

Results

The present study comprised a population survey by way of a questionnaire mailed to the Disability Coordinator of each university in 2001, effectively sampling the entire population of universities (N=8) in New Zealand. The questionnaire sought to gather information regarding the participation rates of TSDs, the source of data collection, as well as the definitions of disability and categories of impairment used when collecting data, in order to determine the current situation and possible implications. Eight out of eight questionnaires sent were returned, although not all of the respondents answered every question.

Participation Rates

Participants were asked to provide the total headcount of students with disability in their institution for the years 1998, 1999 and 2000.

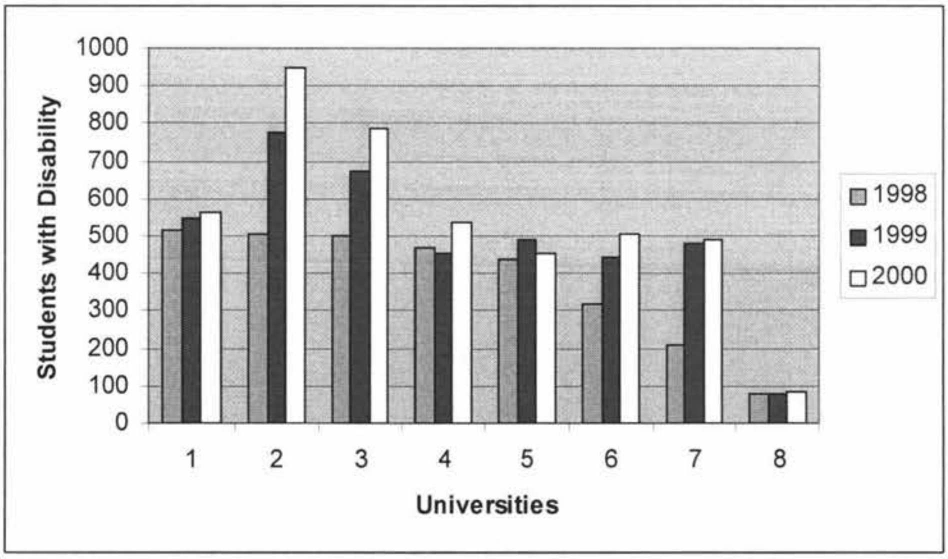

Figure 1. Headcount of University Students with Disability in 1998, 1999 and 2000 Received from the Respondents

The total headcount of TSDs reported by the participants in Figure 1 for 1998 was 3,039. Four of the participants had a different total from that reported in their institution's annual report for that year; across all the universities the figure was 19 lower than the 1998 annual report total (3058). This did not affect the percentage of TSDs per total student population, which stayed at 2.1%. For 1999, the total headcount reported by the participants was 3,938, which was 304 higher than the 1999 annual report figures (3,634). Five participants reported a different total from their institution's annual report, the overall percentage of TSDs per total student population being 0.2% higher.

For 2000, the participants reported that the headcount of TSDs per total student population was 4,358. The figures ranged from 2.16% to 3.84% of the total student numbers across institutions, with the overall percentage calculated at 2.97%. As can be seen in Figure 1, all the universities increased their numbers of TSDs from 1998 to 2000 but not all the increases were consistent, with two institutions (i.e. 4 and 8) having a year where their separated numbers decreased.

The Disability Coordinators reported the data provided for Figure 1 was sourced in three different ways: a) from the general student record system ($\underline{n}$=3), b) from the Disability Office/Disability Coordinator ($\underline{n}$=1) and c) from a combination of the general student record system and the Disability Office/Disability Coordinator ($\underline{n}$=4). Seven participants responded to the question asking which statements best described the headcounts in Figure 1. There were five different combinations of statements, as can be seen in Table 4.

Table 4

Description of the Headcounts Provided by the Participants in Figure 1

Combinations of Statements	Subsets of Students	Number of Participants
1	Students who identified themselves to the disability service regardless of whether disabilities were verified or services were provided	2
2	Students who were reported to the disability service as having a disability, regardless of whether the service had any contact with them	2
3	Students for whom services were provided and who fell within the definition of disability provided for the SDR	1
4	Students who identified themselves to the disability service regardless of whether disabilities were verified or services were provided and students who were reported to the disability service as having a disability, regardless of whether the service had any contact with them	1
5	Students who identified themselves to the disability service regardless of whether services were provided and students who were reported to the disability service as having a disability, regardless of whether the service had any contact with them	1

The headcounts provided by the participants were likely to be higher than those for the SDR, because the SDR only captures those who self-declare at enrolment, whereas all seven participants in Table 4 collected data on a wider range of students. It was not possible to verify this, as the SDR figures are not in the public domain.

All the participants (N=8) indicated that the headcounts were unduplicated and each student with a disability was counted only once. Only one participant was able to provide data on the gender of TSDs in 1998, when males comprised 43% of the headcounts in that institution and females 57%. Three participants were able to provide this information for 1999 and 2000. Males averaged 40.6% and females 59.4% across the three universities and two years for which this data was available.

Currently all data is reported on students with disability by headcount, which counts each individual student regardless of whether they are studying full-time or part-time. Seven of the eight participants responded to the question asking for comments about the advantages/disadvantages of collecting data by headcount versus EFT (students with equivalent full-time status). One participant felt that students should be counted by EFT; three felt they should be counted by headcount and two felt that both headcount and EFT were relevant.

Sources of Data Collection

Universities report data on TSDs in three different ways: a) it is reported electronically in the Single Data Return (SDR) sent to the Ministry of Education three times a year, b) in a university's annual report, and c) in a separate annual report to the Ministry of Education on the Special Supplementary Grant for Tertiary Students with Disabilities (SSG). These are all official reporting mechanisms. However, it is difficult to compare the data across these reports as the people responsible for producing them differ across universities and because much of the information is not in the public domain.

Institutions send the SDR electronically to the Ministry of Education, which is usually a function of information technology services to obtain from an institution's general student database. The SDR figures are not in the public domain. A university's annual report is prepared by designated staff who may not necessarily ask for input from the Disability Coordinator. Although the annual reports are in the public domain, they don't always include disability data. The figures for the SSG report are prepared by the Disability Coordinator in some institutions but not in others, and these reports are not in the public domain.

When asked where disability data was sourced for the SDR, four of the eight participants reported it came from the general student record system. The other four stated it came from a combination of the general student record system and the Disability Office/Disability Coordinator's records. When asked where disability data was sourced for the university's annual report, one participant reported that it came from the general student record system; two reported it came from the Disability Office/Disability Coordinator, and five from a combination of both.

Maintaining Data

The way in which data is kept is important as it relates to the consistency of data across institutions. Six participants stated that records about students with disability were maintained as part of the general student record system used to collect and store information about all students. Four participants stated that data was also kept on a separate database in the office responsible for providing support services to students with disability, so disability data was stored in two places at these institutions.

Two participants maintained disability data only in a separate database in the office responsible for providing support services to students with disability. Two participants indicated they also used paper files for recording data. Participants stated that data was accessible only to the office responsible for providing support services to students with disability in seven institutions, whilst in one institution the data was also accessible to various institutional offices, such as enrolment staff.

Definitions of Disability

The Single Data Return.

Participants were asked to give the definition of disability used by their institution to collect statistics for the SDR and the reasons for using the particular definition. In retrospect, this question was not very relevant, as the researcher subsequently discovered that the Ministry of Education defines this for universities (Ministry of Education, 2001). There is a compulsory field in the SDR entitled 'Disability Indicator' and the field is sourced by a positive response on the enrolment form to the question: ' Do you live with the effects of significant injury, long term illness, or disability?' (Ministry of Education, 2001).

As would be expected, five of the participants provided definitions that were very similar to the question above asked in the Disability Field. However, one participant thought that the Ministry of Health (1995) definition was used as a basis for collecting SDR data and another provided the definition from the Ministry of Education's Notice of Purpose for which Special Supplementary Grants may be used (1997a). Because this data is entered and extracted independently from disability services, and SDR returns are confidential, not all the participants may have been aware of the details in the data field.

However, the SDR is taken from each university's general student record system and is not affected by the Disability Coordinators in any way. The Ministry of

Education's disability question is part of the enrolment or registration form used by each university. A code is entered in the SDR for the student's response to this question as: a) no disability identified, b) disability identified, or c) disability not stated (question asked of student, but no answer was provided). This information is extracted electronically three times annually from the general student record system along with the rest of the data required by the Ministry of Education (Ministry of Education, 2001).

Disclosure on the enrolment form.

Participants were asked if they could identify the percentage of TSDs using disability services, who indicated they had a disability on the enrolment form. From the four participants who responded there was wide variability in their perceptions, ranging from 17% and 18% for two, to 52% and 68% for the other two. In any case, it appears that the SDR may not account for all students with disability who participate in the university sector.

Eligibility for disability services.

A further question asked whether the definition of disability used to determine eligibility to disability services in an institution was the same as the definition used to collect data for the SDR sent to the Ministry of Education. Four participants answered yes, three answered no and one did not answer the question. Those who answered 'no' included a wider range of students in their data collection, such as students with temporary impairment and international students. This means their institutional counts of TSDs would be higher than the numbers in their institution's SDR and higher than institutions that did not include these students.

However, five of six participants indicated they provided disability support to students who fell outside the definition of disability used to collect statistics for the Ministry of Education, another two participants stated that their institutions were providing support to a wider range of students than were being counted for reporting purposes. Two participants emphasised that disability was self-defined by the student and not defined by the institution, though as a general rule documentation was required from students outside the definition who were seeking assistance from disability services. There were differences in responses between the participants, not only in the definitions of disability underpinning service delivery, but also in opinions for the need for one.

Verification of disability status.

All eight universities required verification of disability status. Participants were asked about the types of documentation or verification their institution required in order for a service to be provided. All eight institutions accepted medical evaluations/statements and all the institutions also accepted psychological evaluations by a counsellor or psychologist. Five institutions accepted informal evaluation or determination by the Disability Coordinator and four also required students with learning disability to produce verification. Two institutions stated that they also accepted documentation from a former school or relevant specialist. Only one institution required testing or formal evaluation by the Disability Coordinator (as opposed to informal evaluation).

Categories of Impairment

Participants were asked whether they also collected data under categories of impairment. Of the eight participants, seven reported they were doing so and one was not.

Table 5

Categories of Data Collection in Seven Universities

Category of Data Impairment	**Number of Institutions Using the Category**
Learning	7
Mobility	7
Hearing	6
Vision	6
Mental Illness	4
Other	4
Speech	4
Medical	3
OOS	3
Blind	2
Deaf	2
Chronic Pain	1
Dexterity	1
Epilepsy	1
Head Injury	1
Long Term Illness	1
Long Term Injury	1
Sensory	1
Short Term Illness	1
Short Term Injury	1

As can be seen in Table 5, the categories mixed disability and impairment and included injury and illness as well. Learning and mobility are disability categories. Hearing and vision are impairment categories, sensory may be hearing or vision or both. It is not at all clear what the category 'medical' means. The Ministry of Education in New Zealand has recognised the importance of standardising data collection across New Zealand tertiary institutions. They have developed a reporting template, which will be mandatory for reporting from 2003. The template lists fourteen categories for data collection: deaf, hearing impairment, blind, vision impairment, specific learning disability, medical (includes asthma, chronic fatigue syndrome, diabetes, epilepsy, multiple sclerosis, neurological and all other medical impairments), head injury, mental health, physical/mobility, speech, temporary impairments, unspecified impairments and other. The template also asks for information about students with multiple impairments (Ministry of Education, 2001). The categories are similar to those already being collected by the participants in Table 5; the main differences are the clarification of 'medical', and the inclusion of temporary impairments, which attempts to separate impairment from disability.

Five of the eight participants answered the question regarding the number of students under each category.

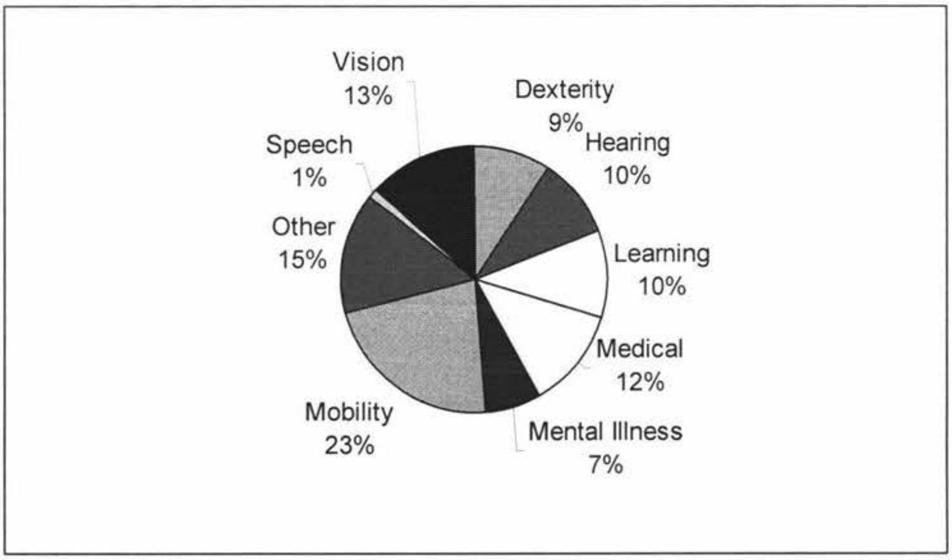

Figure 2. Percentage of Students by Category of Data Collection in Five New Zealand Universities

As can be seen in Figure 2, the largest category of impairment recorded was mobility, which is a disability (23%); the second largest was 'other' (15%).

Seven participants answered the question that asked how students were put into categories. Whilst all seven participants stated that their universities accepted self-definition by the student, four participants stated they also required documentation by a relevant professional, three accepted the judgement of the Disability Coordinator and five a combination of the above. Four of the seven participants obtained data on categories of impairment and disability from the general student record system, three from the Disability Office/Coordinator and one from a combination of the two.

Summary

The results indicated variability across New Zealand universities in the way that data was collected, maintained and reported. The annual count of TSDs per total student population increased annually across universities from 2.13% in 1998 to 2.97% in 2000. Students were counted by headcount in all the universities and the counts were unduplicated. However, it was difficult to estimate the reliability of the data collected. For each of the reporting requirements, different subsets of students were included in the counts. Data was sourced differently and prepared in different parts of the institution. There were differences across the universities in the way that disability was defined and the categories in which data was collected. Data was maintained in different ways, with some institutions keeping data in two separate databases. Methods of verification of disability status differed and there appeared to be a low percentage of students disclosing to institutions on the enrolment form. One of the major hindrances for evidence-based research on data collection of TSDs is that much of the information is not in the public domain for comparisons.

There will be a discussion of the results in more detail in the next chapter. This will include the problems with reliability of the current data and some suggestions for improving data collection. The definitions of disability and categories of impairment will be compared to those in the WHO's ICIDH and ICF and the Ministry of Education's template. The final chapters will include the conclusions, a discussion about the limitations of the present study and some suggestions for further research.

Discussion

Alexander and Bridgman (1982) found that New Zealand universities had no systematic method of identifying TSDs in their institutions. Sixteen years later, McKay et al. (1998) concluded that the Ministry of Education in New Zealand still had no real idea of the number of TSDs because of the lack of consistent data. The aim of the present study was to find out whether there was consistency across New Zealand universities in the collection, verification and reporting of disability data, as well as the definitions of disability and the categories used for data collection, from 1998 to 2000.

Consistency is a requirement for reliability and reliability is a minimum condition for validity. This means that data cannot be considered valid if it is not at least demonstrated to be reliable. The results of the present research indicated that whilst data collection methods had improved since 1982, TSDs were still not being counted across universities with any consistency, therefore the data gathered continued to be neither reliable nor valid.

Participation Rates

Data collected for the present study found that the percentage of TSDs per total university population from 1998 (2.4) to 2000 (2.97) appeared to be similar to the data available for Australia (2.4), the USA (3.0) and the UK (3.3). It was also similar to the findings of Kirkland in 1990, which found that 2.8% of students at the University of Otago self-disclosed with disability. The percentages of TSDs reported across all the universities increased from 2.13 in 1998 to 2.97 in 2000. However, not all the increases were consistent, with two institutions having a year when their numbers decreased. Participation rates varied according to how the data was collected which makes the figures unreliable and it is difficult to know how they actually compare.

Smaller institutions in general did not appear to have more TSDs enrolled, which differed from the UK findings (Nye, 1997). There did not appear to be a correlation between the size of an institution and the number of TSDs. Data from the three participants that responded indicated there were more female than male TSDs, however the number of participants who responded was too small to generalise that there were more female than male TSDs across all the universities. This limited response was contrary to the findings of the OECD (CERI, 2000), where in almost all countries more males than females were receiving additional resources, although Nye (1997) found that 52% of TSDs on the HESA database were female.

The population of TSDs that the Ministry of Education is attempting to measure is not consistently defined. In its widest sense, the counts included all the students who disclosed with disability on the enrolment form, plus all the students who contacted disability services, plus some students with whom the disability services had no contact, plus some students who didn't even have a disability. In its narrowest sense, the population included only those students who disclosed on the enrolment form. In fact, out of seven participants, five were collecting data on different subsets of students. Where institutions were collecting data on the wider group of students, their counts were higher. Adding to this confusion were three different reporting requirements for the Ministry of Education, with two different sets of instructions, not all necessarily prepared by the same people in an institution, and it is no wonder it is difficult to make sense of the whole picture.

In order to untangle the picture a little, it is important to remember why the data is being collected. The disability data collected is mandatory for reporting purposes and provides accountability to the Ministry of Education for the targeted funding for TSDs. The goal of this funding is to increase the participation rate of people with disability in tertiary education. The point of collecting data is to see if the participation rates are increasing and to compare the participation rates across tertiary institutions nationally as well as with other countries internationally. Data is also collected to find out the categories of students utilising resources, for planning and accountability purposes.

So the Ministry of Education is interested in two different things, the participation rate of TSDs and how its resources are being expended (on what categories of students). One of the reports, the SDR, is intended to provide information on the participation rates of TSDs in universities. The report on the SSG is intended to provide information on how resources are expended as well as the participation rate. There seem to be no instructions for a university's annual report. In fact for 2000, only five universities included data on the participation rates of TSDs in their annual reports. The Ministry of Education describes the students that should be counted, but doesn't define who should be counted. The lack of clarity has lead to data being sourced on different groups of students in different ways across the universities.

Data Collection

For the SDR, data is taken from the enrolment form on the number of students who give a positive response to the question: ' Do you live with the effects of significant injury, long term illness, or disability?' (Ministry of Education, 2001). This data is sent electronically to the Ministry of Education three times a year. The participation rate collected here depends upon how many TSDs disclose at enrolment. The results supported Andrew's 1992 findings, that no matter which procedure is used to request students to identify themselves, it is generally reported that the response rate from students is at times very low.

Information was collected from four participants who could identify the percentage of students receiving disability services who also disclosed on the enrolment form. There was wide variability, from 17 and 18% to 52 and 68% of the total number of TSDs. The percentage of students who disclosed was unrelated to the total headcounts of an institution. This clearly indicates that basing the counts of students only on those who disclose on the enrolment form is not a reliable or even useful measure of the population. In fact, some institutions may be disadvantaged by the SDR counts which could seriously under report the participation rate.

This information is interesting if it is compared to the New Zealand census results. 10,600 persons who claimed to have a disability in the 1996-1997 New Zealand Household census survey and 12,400 in the 2001 New Zealand census survey indicated that they were currently enrolled in university (Disability Counts 1998, 2000). This is more than three times the number of students reported by the participants. This discrepancy may be reflective of a low disclosure rate at universities compared to the generally high figures collected by the census.

The participants' response to the question about where the SDR was sourced was also interesting. Not all the participants knew about the compulsory field in the SDR, even though it had been in place since 1998. This illustrates the problem that occurs when data is sourced in different parts of an institution. There may not be good communication between departments, and instructions that are sent to institutions from the Ministry of Education may not filter down to the people providing services at the grass roots level.

Four of the eight participants thought that the SDR was sourced from a combination of the general student record system and the Disability Office records. However, universities send the SDR directly to the Ministry of Education three times a year. This is a function of Information Technology Services rather than the Disability Office. Clarification was sought by a follow-up e-mail to the participants who had indicated the SDR data came from a combination of sources. Only one of the four respondents indicated that the Disability Office staff could enter disability data into their general student record system. The other respondents did not enter data into their general student record system, but kept it on a separate database, so this segregated data would not in fact have been incorporated into the general student record system for the SDR.

These three respondents clarified that there were two separate databases, which were capturing two different sets of data. The general student record system collects information on students who disclose as having a disability at enrolment. They may not identify to the Disability Office, as they may not need a service. The Disability Office captures data on students who identify to the service. This set of students may not all disclose at enrolment. In theory then, the university where the Disability Office staff were able to enter disability data into their general student record system should have had a higher number of students in their SDR than the other universities. Because the SDR totals are not in the public domain, this cannot be verified.

Instructions from the Ministry of Education describe the data to be collected for the SSG report as: 'those who self-declare as such on the enrolment form, together with those who do not but who approach, or are referred to, the Disability Coordinator during the year' (Ministry of Education, 1997a). There is immediately a problem with this because of the way in which the two sets of data are maintained across universities. Consistency in maintaining data is important as it relates to the accuracy of the data source. Whilst there were different ways of maintaining data across universities and different levels of access to that information, the variation was not as great as found by Lewis & Farris (1999), possibly due to the smaller number of participants in the present survey. Overall, data collection methods in New Zealand universities were more progressive, with all universities using a computerised system for record keeping and none keeping records in paper files only.

Six participants used a separate computerised database from the general student record database for recording data. This is possibly because their general student record database was not capable of capturing all the data required to provide disability services in an institution. This would include details of support provided to individual students such as the provision of a note taker, or equipment loaned.

The Ministry of Education's reporting template also asks for details including costs of support hours per student and number of support hours per student and most, if not all, university student databases would not be set up to capture such detail. The development of segregated databases has been a response to the request for an increased level of detailed data for service provision and for reporting, combined with the importance of ensuring students' privacy.

When data is stored in two different places there must be a process to aggregate this data to get a true total for reporting purposes. This would involve combining the information in the general student database and the Disability Office database to arrive at the total number of TSDs as requested by the Ministry of Education for the SSG report. This is not simply a matter of adding together the total from the general student database and the total from the Disability Office database, as there is no way of knowing how many students will be in both, although all the respondents (N=8) indicated that their headcounts were unduplicated and each student with a disability was counted only once,

If information between the two databases could be exchanged and adjusted for duplications, the Ministry of Education would then get the true number of students disclosing at enrolment plus the additional students who did not but who were recorded as contacting disability services during the year. Only one participant at the time of the survey indicated they had a mechanism for doing this, which reinforces the current problem of separate unreliable counts.

To add to this problem, there was another level of students counted by the participants for the SSG report across institutions. These included counting students who were reported to the Disability Office as having a disability, regardless of whether the service had any contact with them, through to only counting students who received support and who fell within the institution's definition of disability. The subsets were so varied that the data collected cannot be accurately compared across universities. There needs to be further clarification from the Ministry of Education at this level to enable consistent practice.

For the university's annual reports there are no instructions, some universities don't include disability data at all. Participants reported that universities sourced data for their institution's annual report in three different ways: a) from the general student record system (n=1), b) from the Disability Office/Disability Coordinator (n=2) and, c) from a combination of the general student record system and the Disability Office (n=5). This combination of data sources is different from the collection of data for the SDR and the participant's totals. Three of the five participants using a combination of the general student record system and the Disability Office data, clarified that they were able to access the general student record system and compare it with the numbers of students on their database in the Disability Office in order to arrive at a total for the annual report. In this way the number of students declaring at enrolment, plus those who accessed disability services during the year could be collected for the Ministry of Education.

There were differences between some of the data reported in individual university annual reports and the participant's figures for the three years in which data was collected. For 1998, the total headcount of TSDs reported by the participants was 3,039. Four of the participants reported a different total from their institution's annual report for that year; across all the universities the figure was 19 lower than the 1998 annual report total (3058). For 1999, the total headcount reported by the participants was 3,938, which was 304 higher than the 1999 annual report figures (3,634). Five participants reported a different total from their institution's annual report.

For 2000, the participants reported that the headcount of TSDs per total student population was 4,358. Not all the universities published disability statistics in their annual report for 2000 (AUT annual report 2000, 2001; Lincoln University 2000 annual report, 2001; Massey University annual report 2000, 2001; The University of Auckland annual report 2000, 2001; The University of Waikato annual report 2000, 2001; University of Canterbury annual report 2000, 2001; University of Otago annual report 2000, 2001; Victoria University of Wellington 2000 annual report, 2001). For those five that did, only one total matched that of the annual report. Differences in the participants' figures ranged from two to 326 higher than in the annual report, the latter being a huge variation. Variation occurred when data was collected from different sources. In some institutions the annual plan data reflected only data collected on TSDs at enrolment, in others, the Disability Office figures were added in.

Headcount Versus Equivalent Full-Time Students (EFTs)

It is difficult to know whether the data from Lewis & Farris (1999), Nye (1997) and the Higher Education Division in Australia (1999) counts students by headcount or by full-time status, as this is not specified. If each country were to clarify the counts, it would increase the validity of international comparisons. Currently data for all students in New Zealand universities is reported in their annual reports by headcount and EFT. Data on the participation rate of TSDs is reported by headcount, which counts each individual student regardless of whether they are studying full-time or part-time.

The participants had different opinions as to which way of counting TSDs was preferable. Three of the six participants who responded felt that counting TSDs by headcount was preferable, as individual TSDs could be time and resource intensive regardless of whether they were studying full time or part-time. Two participants felt that both headcount and EFT were relevant because a student's part or full-time status was also important. One participant felt that students should be counted by EFT as this ensured students could study in their institution of choice.

The Special Supplementary Grant is allocated according to the total EFTs in an institution (all students). It would be difficult to fund by the EFTs of TSDs, as some of these students are unable to study full-time and choose part-time study. It is also not possible to predict in advance how many students with high support needs will be enrolling in any given year. As two of the participants mentioned, a TSD studying part-time can be very resource intensive. Headcounts give a clearer idea of the number of TSDs studying at a particular tertiary institution and more accurately reflect the participation rate.

Definitions of Disability

The ability to obtain valid and reliable data about the participation of people with disability in tertiary education relies upon a common understanding, both nationally and internationally, as to what constitutes disability. Determining the parameters of this definition requires a precise, objective and internationally recognised terminology (Meltzer, 1999). Disability and impairment are different. Put simply, disability is the *consequence* of impairment. Within and across countries, definitions of disability differ and impairment and disability are confused, this confusion is also reflected in the data collected by universities in New Zealand.

The Ministry of Education in New Zealand doesn't define disability; rather it describes TSDs for the purpose of collecting data on participation rates (as opposed to eligibility for support services). This method of data collection relies upon individual students self-identifying and having an understanding of disability and how it differs from impairment. As well as the description used to capture the participation rates of TSDs; there are definitions of disability used across the eight New Zealand universities to determine eligibility for service provision.

Four of the seven participants stated that the definitions used as criteria for service provision were similar to the question asked for the SDR. Three participants used a wider definition that included providing services to any students who approached the Disability Office, including students with temporary illness, injury or impairment. In other words they included students who did not have a disability in their definition of disability. These three participants added that as a general rule, documentation was required from this group of students before they received assistance from disability services. Two participants emphasised that disability was self-defined by the student.

There was some confusion between the definitions used to determine TSDs and students who were actually provided with services by the Disability Office. Five of six participants indicated they provided disability support to students who fell outside the description of TSDs used to collect statistics for the Ministry of Education. Four included students with temporary/ short-term impairments, and two provided support to international students. Without a common definition, data is being collected on a diverse range of students and there are no common criteria across institutions. This makes the data collected unreliable for comparisons across institutions.

There were differences between the participants, not only in the definitions of disability underpinning service delivery, but also in opinions for the need for one. There was a division between those participants who were using an institutional definition ($\underline{n}$=2) and those who felt students should be able to self-define ($\underline{n}$=5). Participants reported that definitions in some universities varied from the more formal one underpinning service delivery ($\underline{n}$=4) to a more flexible one to include a wider group of students to whom services were actually delivered ($\underline{n}$=3). The participants had different reasons for using the definitions they did and their views differed as to the usefulness of a definition of disability.

It was apparent from the verbatim comments from five participants that Disability Coordinators were often put in a difficult position, as they were approached by students who may not have had a disability, but who were requesting their support and the participants were concerned that they be able to maintain some flexibility about who was provided with a service. This is fine, but what is not clear is whether these students are also being counted in the TSD count. If one institution includes students with temporary impairments and another does not, reporting and comparing outcomes for students with disability across institutions becomes meaningless (McGrew & Algozzine, 1995).

The percentage of students with disability enrolled in tertiary education is relatively small. Because of their small sample size, differences between surveys resulting from the way in which disability is defined, or the way questions are asked, can appear very large. If national and international progress in this field is to be assessed effectively, it is essential that countries arrive at common definitions of disability in order to collect meaningful and comparable data (CERI, 1997). The ICF lends itself to providing such a tool because it is already used for collecting data across disciplines and permits the comparison of data across countries.

Verification of disability status.

Verification of disability status relates to the provision of services within institutions rather than the participation of TSDs. This formal type of verification for support to be provided is different from the participation counts that rely on self-disclosure. Students eligible for services are included in the counts, but they are only one of the subsets counted. Participants from six New Zealand universities reported they also provided support to students whose disability status was not verified. The requirements in New Zealand were similar to those found by Lewis and Farris (1999), in which a high number of institutions in the USA at times requested formal or informal verification of disability status as a requirement for disability services to be provided. Across New Zealand universities, all participants accepted a range of formal documentation and five also accepted informal evaluation by the Disability Coordinator.

All eight participants stated their institution accepted medical evaluations as well as psychological evaluations by a counsellor or psychologist. Five participants accepted informal evaluation by the Disability Coordinator and four also required students with learning disability to produce verification. Two participants stated they accepted documentation from a former school or relevant specialist. Only one participant stated their institution required testing or formal evaluation by the Disability Coordinator (as opposed to informal evaluation). Another participant also clarified that formal evaluations were for tests and examination accommodations only, not for disability services to be provided. Eligibility for disability services at this university was by informal evaluation by the Disability Coordinator.

Categories for Data Collection

Classification systems are important because they serve a number of functions: as statistical tools for the collection and recording of data; as research tools for the measurement of outcomes, quality of life or environmental factors; as clinical tools used in needs assessment, treatment and outcome evaluation; as social policy planning tools, and as educational tools for curriculum design and social application (Parmenter & Riches, 2002). They provide a common language and framework for the coding of information. In the tertiary education sector, this information could be used to track resource allocation and to identify trends or gaps in service provision.

As in the findings from the USA, the UK, Australia, and historically in New Zealand, the classification systems in which data was collected varied across New Zealand universities from 1998 to 2000. Of the eight participants, seven were collecting data in categories and one was not. The categories used were: mobility and learning ($\underline{n}$=7); hearing and vision ($\underline{n}$=6); mental illness, speech and 'other' ($\underline{n}$=4); medical and occupational overuse syndrome ($\underline{n}$=3); blind and deaf ($\underline{n}$=2); chronic pain, dexterity, epilepsy, head injury, long-term illness, short-term illness, long-term injury, short-term injury, sensory, short-term illness and short-term injury ($\underline{n}$=1). It is difficult to make any sense of this data when the language mixes health conditions and temporary impairments, with impairments that may or may not lead to disability in a tertiary setting and when not all institutions are collecting information under the same categories.

Seven participants responded to the question asking how students were put into categories. This occurred in different ways across the universities. Whilst all seven participants claimed to accept self-definition by the student, four participants stated they also required documentation by a relevant professional, three accepted the judgement of the Disability Coordinator and five a combination of the above. The participants sourced the categorical data on TSDs from the general student record system in three institutions, the Disability Office database in three institutions and from both databases in one institution.

Five of the eight participants answered the question regarding the numbers of students under each category. From largest to smallest, they were: mobility (23%), other (15%), vision (13%), medical (12%), hearing and learning (10%), dexterity (9%), mental illness (7%) and speech (1%). The largest category was mobility, which is in line with the 1997 and 2000 census findings, yet is probably more reflective of disability than impairment.

These findings differed from those reported by Kirkland (1990), when the numbers of students in the categories of vision, hearing and learning totalled approximately a third of all the TSDs at Otago University. The largest category of mobility also contrasted with the findings of Lewis and Farris (1999) and Horn and Berktold (1999), who found that the largest number of students were placed in the category of learning, with mobility second and this also contrasted with Johnson's (2000) findings where 39% of TSDs were placed in the category 'medical'.

The category of 'other' into which 15% of New Zealand university students with disability fell does not really provide any useful information regarding these students, rather, it leaves a black hole in the data collection. This problem occurred in the data collected in Western Australia where just over a quarter of TSDs were categorised under 'unspecified' and 'other' (Johnson, 2000), and was also true of the data collected in the UK, where the unknown total was nearly 20% (Nye, 1997).

The Ministry of Education's template.

The Ministry of Education in New Zealand has recognised the importance of standardising data collection across New Zealand tertiary institutions. To address this, a reporting template was developed and from 2003 it will be mandatory to report data for the Ministry of Education using the template, but only for the Special Supplementary Grant report, not for the other two reports. The template lists fourteen categories for data collection: deaf, hearing impairment, blind, vision impairment, specific learning disability, medical (includes asthma, chronic fatigue syndrome, diabetes, epilepsy, multiple sclerosis, neurological and all other medical impairments), head injury, mental health, physical/mobility, speech, temporary impairments, unspecified impairments and other. The template also asks for information about students with multiple impairments (Ministry of Education, 2001).

The language used in the template does little to sort out the existing confusion between impairment and disability. Under the ICIDH (WHO, 1980), deaf and hearing are both aural impairments that may or may not lead to a communication disability. Likewise, blind and vision impairment are ocular impairments that may or may not lead to a communication disability or a dexterity disability. Speech is a language impairment that may result in a communication disability. Learning is not listed as an impairment in the ICIDH, it is a very generalised term which includes a whole range of possible impairments to do with the way information is perceived or processed (Massy University, 1996). The term 'medical' relates to the cause of an impairment, as does head injury, which may result in an intellectual or psychological impairment, which may then lead to a behaviour disability for example. Mental health is not an impairment, rather it is a state of well-being, and mobility is a locomotion disability (WHO, 1980).

That the Ministry of Education is trying to relate support costs to categories in the template is obvious. The categories of deaf and blind are separated out of hearing impairment and vision impairment because of the assumed higher costs associated with supporting these students. However, a deaf student who is studying extramurally may only require the support of an interpreter for a three-day campus course, as opposed to an internal student who might require interpreter support every day of the week. A university may have a large group of students with Occupational Overuse Syndrome who are time and resource intensive. Placing this group under the 'Other' category may not give a true indication of how resources are being utilised. It will still be difficult to 'fit' students into the set categories using the template.

One way to simplify the data collection system would be to use the broad functions involved under disability or activity in the ICF to replace the categories in which data is currently collected. The eight activities necessary for participation in the tertiary environment are: auditory (e.g. hearing a lecturer), cognitive, (e.g. learning or processing data), communicative (e.g. asking questions) manual (e.g. taking notes), motile (e.g. getting from lecture to lecture), personal care (e.g. toileting or eating), social (e.g. interacting with staff and other students) and visual, such as reading or seeing overheads (Bruce & Washington, 2000).

The advantage of using these categories is that they are practical task-focused categories under which information related to disability rather than impairment can be collected and under which data directly related to the tertiary environment can be collected. It would solve the problem of language confusion and because it covers all the tasks involved in participating in tertiary education, would do away with the problem of 'unknowns' and 'others', thereby collecting data on all TSDs.

This would give the Ministry of Education a clearer idea of where resources were being allocated and would simplify data collection for institutions. These categories would also make it easier for students to self-define and it would not really matter how students were placed into categories, data collection would still be more consistent and relevant.

Categories of impairment have only partial implications for disability services, which inevitably have to take the whole student into account. However, if meaningful national and international comparisons are to be made, the allotment of students into straightforward and operationally defined categories would simplify the situation and improve the possibility of making policy-relevant decisions based on valid comparisons (CERI, 2000). Collecting data under the ICF activities model with functions being specifically related to activities in the tertiary environment, instead of categories of impairment, would simplify and clarify the data collection process as well as facilitating international comparisons.

Summary

The findings above were consistent with the evidence in the literature review that it is currently not possible to know the real participation rate of students studying with disability at universities because of the differences in practices across institutions. The problems with the current processes in New Zealand for capturing accurate data include: reports being prepared in different areas by different people within an institution at different times of the year, data collected on different subsets of students, as well as different sets of data being maintained in separate databases.

Individual universities currently have a systematic way of identifying students with disability. The Ministry of Education's template provides a partially standardised framework for reporting on data. However, in order to obtain consistent and meaningful data, there must be a systematic method of collecting and maintaining data across tertiary institutions. The record keeping and reporting capabilities of institutions should be equivalent and transparent.

Full information about the reporting requirements of the Ministry of Education need to filter down from the top level of the university to the 'grass roots level' and across departments so that university staff are fully informed; from the Vice Chancellor, to the people responsible for producing annual reports, to Information Technology Services producing the SDR, to disability services staff collecting the data, to the people responsible for inputting data into the general student record systems. Only then will there be an informed and collaborative response to data collection and reporting within universities as well as across universities.

The Ministry of Education currently does not have an accurate count of the number of TSDs studying at universities in New Zealand. How is it possible therefore to describe the population they are funding? Statistics are being collected, but they are not being made public and they need to be put in the public arena to inform policy and practice. The consequence of invalid measures is poor research and flawed policy development.

The collection of accurate data is further complicated by the confusion in the language around disability and impairment. 191 countries have accepted the ICF as the international standard to describe and measure disability (WHO, 2001). Using the ICF to provide a standardised language and framework for the collection of data would greatly improve the current situation in New Zealand. Then the data collected by the Ministry of Education's Data Warehouse would be valid and meaningful.

Limitations

The population size was small (N=8), however it represented all New Zealand universities, thus the entire population.

The questionnaire asked for the definition of disability used by universities when collecting statistics for the Single Data Return (SDR). This question was confusing as the universities send the SDR electronically to the Ministry of Education. The question the Ministry of Education asks universities to report on for the SDR is the number of students who live with the effects of significant injury, long-term illness, or disability (Ministry of Education, 2002).

Recommendations by the researcher may be totally academic, as the researcher does not have the power to affect change in processes across universities, but can only gather the data and suggest that such a change would be of use.

Conclusion

The Ministry of Education in New Zealand has dedicated funding to increasing the participation of people with disability in tertiary education. Data that has been collected shows a steady increase in numbers. However, the way students are identified and the way data is collected, maintained and reported is not consistent across universities. It is difficult to make sense of data collected because of the variations in practice. This thesis has identified the need for valid and reliable data to be collected about the participation of TSDs studying in New Zealand universities, in order to inform policy and practice and for making relevant national and international comparisons.

Confusing the issue is the fact that there are three different reports for which data is not sourced in the same way across universities. In some institutions these reports are prepared in different sections of the university and at different times of the year. Information is kept in segregated databases, which don't all have a means of exchanging data. Relying upon information disclosed at enrolment is not a reliable measure of the participation rate of TSDs.

The Ministry of Education's reporting template provides a partially standardised framework for reporting on data. However, in order to obtain consistent and meaningful data, there must also be a systematic method of collecting and maintaining it across tertiary institutions. There need to be some clear directives on this from the Ministry of Education. There needs to be clarification of the definition of disability and of the sets of students to be counted, so that all institutions are counting the same students. A student who indicates on an enrolment form that they have an impairment may not necessarily have a disability in the tertiary environment. The wording on the form needs to be clear to those who fill it out, to those who do the data entry and to those who collate the data for reports.

Definition is the key to reliability and reliability is essential for validity. What is badly needed is a practical functional model for collecting data, which uses clear language. Currently there is great confusion in the language, with impairment, disability, illness and injury used interchangeably. In order to make national and international comparisons based on categories of disability, a number of simplifying assumptions must be made which bring similar students together with a common descriptive categorical name. The International Classification of Functioning, Disability and Health provides a practical functional model, which could be the platform for establishing definitions and clarifying the language around disability and impairment as well as providing an international standard for consistency.

Suggestions for Further Research

A future survey could be sent to the rest of the tertiary institutions in New Zealand to see whether the results in the present study were consistent across the different types of tertiary institutions.

A future study could look at the enrolment patterns of TSDs and compare them to students without disability to see whether the numbers are increasing at the same rate or at a higher rate, as a result of funding from the Special Supplementary Grant. Studies could look at the demographics of students studying with disability, including gender ratios. It should also be possible to know whether the funding is attracting more school leavers or mature students and whether the achievement rates of TSDs are increasing.

The Ministry of Education has a valuable repository of information in the Data Warehouse. Commissioning research that provides access to this information could be a starting point for both refining the current system and improving data quality. When this is achieved, the groundwork will have been laid for extending analyses into a comparison of outcomes and opening the possibility of linking inputs to outputs. These are among the challenges for the coming years (CERI, 2000).

References

Adams, M. & Brown, P. (2000). *The times they are a changing: Developing disability provision in U.K. higher education.* Paper presented at the 2000 Pathways Conference, Canberra, Australia.

Alexander, M. & Bridgman, C. (1982). *Further education for disabled people: A New Zealand survey.* Wellington: Further Education for the Disabled Group.

Andrews, R.J. (1992). Tertiary students with disabilities: Participation and support. *Australian Disability Review, 2*, 15-30.

Auckland Institute of Technology annual report 1998. (1999). Auckland: Auckland Institute of Technology.

Auckland Institute of Technology annual report 1999. (2000). Retrieved Feb 23, 2001 from: http://www.aut.ac.nz/corp/news/reports/aut-annual-rpt/2000/

Australia's Welfare 2001. (2002). Retrieved Jan 19, 2003 from: http://www.aihw.gov.au/publications/aus/aw01/index.html

AUT annual report 2000. (2001). Auckland: Auckland University of Technology.

Bruce, G. & Washington, A. (2000). *The role of disability support workers in tertiary education and training: Guidelines for teachers, instructors and administrators.* (unpublished). Retrieved Oct 11, 2002 from: http://www.deakin.edu.au/tedca/ncet/education_and_training/functions_involved.html

Bureau of the Census. (1997). *Census Brief 97-5: Disabilities affect one-fifth of all Americans.* U.S: Department of Commerce, Economics and Statistics Administration.

Centre for Educational Research and Innovation. (1997). *Post-compulsory education for disabled people*. France: Organisation for Economic Co-operation and Development.

Centre for Educational Research and Innovation. (2000). *Special needs education: Statistics and indicators*. France: Organisation for Economic Co-operation and Development.

Charlton, J. (1997). *Key factors in attracting and retaining students with disabilities at tertiary institutions*. Christchurch: Canterbury University.

Creswell, J.W. (1994). *Research design: Qualitative and quantitative approaches*. California: Sage Publications.

Dell, D. & Sandbrook, P. (Eds.). (1996). *A celebration of difference*. Palmerston North: Massey University.

Department of Justice. (1992). *Nondiscrimination on the basis of disability in state and local government*. Retrieved Sept 29, 2001 from: www.usdoj.gov:80/ crt/ada/reg2.html

Disability counts. (1998). Wellington: Statistics New Zealand.

Disability counts. (2002). Wellington: Statistics New Zealand.

Disability Discrimination Act 1995. Retrieved Sept 19, 2001 from: http://www.legislation.hmso.gov.uk/acts/acts1995/95050--a.htm

Disability in New Zealand: Overview of the 1996/7 surveys. (1998). Wellington: Health Funding Authority and the Ministry of Health.

Disability Rights Commission. (2001). *Information and legislation*. Retrieved Sept 26, 2001 from: www.drc-gb.org/drc/InformationAndLegislation/Page311.asp

Dixon, K., Coy, D. & Tower, G. (1994). *Tertiary education institutions' annual reports*. Wellington: New Zealand Ministry of Education Study.

Gray, D.B., Welch, P.M., & Hollingsworth, H. (2000). Comparing perspectives of people with disabilities and professionals on the ICIDH-2 Beta 1. *Journal of Disability Policy Studies, 11* (3), 171-178.

Henderson, C. (1995). Postsecondary students with disabilities: Where are they enrolled? *American Council on Education Research Brief Series 6*, 6. Washington D.C: American Council on Education.

Higher Education Division. (1999 March). *Equity in Higher Education*. 99-A. Occasional paper series. Canberra: Department of Education, Training and Youth Affairs.

Horn, L. & Berktold, J. (1999). *Students with disabilities in postsecondary education: A profile of preparation, participation, and outcomes: Statistical analysis report.* (Report No. NCES-1999-187). Washington DC: National Center for Education Statistics. ERIC Document Reproduction Service No. EC307247.

Human Rights Commission. (2000). *Special education and human rights: Factsheet#9*. Auckland: Human Rights Commission.

International Standard Classification of Education: ISCED 1997. (1997 November). France: United Nations Educational, Scientific and Cultural Organisation.

Johnson, J. (2000). *A demographic study of students with disabilities in post secondary education*. Western Australia: State Disability Liaison Office.

Kirkland, C. (1990). *University education for students with disabilities: A report to the University of Otago, Dunedin New Zealand.* Dunedin: University of Otago.

Lang, K. (1993). *We can do it: University education for students with disabilities: A report for CAN-DO (Campus Abilities and Disabilities Organisation)*. Wellington: Victoria University of Wellington.

Lewis, L. & Farris, E. (1999). *An institutional perspective on students with disabilities in postsecondary education: Statistical analysis report*. (Report No. NCES-1999-046). Rockville, MD: U.S. Department of Education. ERIC Document Reproduction Service No. EC307368.

Lincoln University 1998 annual report. (1999). Christchurch: Lincoln University.

Lincoln University 1999 annual report. (2000). Christchurch: Lincoln University.

Lincoln University 2000 annual report. (2001). Christchurch: Lincoln University.

Lynch, R.T. & Gussel, L. (1996). Disclosure and self-advocacy regarding disability-related needs: Strategies to maximize integration in postsecondary education. *Journal of Counseling and Development, 74* (4), 352-358.

Massey University (Ed.). (1996). *Tertiary students with disabilities: A resource guide for staff*. Palmerston North: Massey University.

Massey University annual report 1998. (1999). Palmerston North: Massey University.

Massey University annual report 1999. (2000). Palmerston North: Massey University.

Massey University annual report 2000. (2001). Palmerston North: Massey University.

Massey University supplementary forms: Resources and support for students with disabilities. (2001). Palmerston North: Massey University.

McGrew, K.S. & Algozzine, B. (1995). The identification of individuals with disabilities in national databases: Creating a failure to communicate. *Journal of Special Education*, *28* (4), 472-487.

McKay, D., Rowlands, M., Ballard, K. & Smith, K. (1998). Disability and tertiary education: A study in three settings. *New Zealand Journal of Disability Studies*, *5*, 51-65.

Meltzer, H. (1999). The ICIDH-2 – using the classification for statistics and research. *Statistical Journal of the United Nations ECE 16*, 31-36.

Ministry of Education. (1997a). *Notice of purpose for which special supplementary grants may be used: Massey University 1998*. Wellington: Ministry of Education.

Ministry of Education. (1997b). *Special supplementary grant: Tertiary students with disabilities: Conditions: Massey University 1998*. Wellington: Ministry of Education.

Ministry of Education. (1998). *New Zealand's tertiary education sector: Profiles and trends*. Wellington: Ministry of Education.

Ministry of Education. (2000). *Report on special supplementary grants for 1999.* Appendix B: University of Waikato. Wellington: Ministry of Education.

Ministry of Education. (2001). *Tertiary students with disabilities (TSD) special supplementary grant: Standard reporting template*. Wellington: Ministry of Education.

Ministry of Education. (2002). *Single data return (SDR)*. Retrieved Oct 20, 2002 from: www2.minedu.govt.nz/Step/News_Information.asp

Ministry of Health. (1995). *Disability support services funding formula 1996/97: Technical guide*. Wellington: Ministry of Health.

Nye, M. (1997, December). The Higher Education Statistics Agency's data on students with disabilities in higher education. *Skill Journal*, *59*, pp10-13.

Parmenter, T.R. & Riches, V.C. (2002). *Assessment and classification of support needs*. Paper presented at the December 2002 Pathways Conference. Sydney: Sydney University.

Report 6: Widening participation for students with disabilities. (n.d.). Retrieved Oct 24, 2001 from: www.leeds.ac.uk/educol/ncihe/r6_069.htm

Statistics New Zealand. (2001, 6 March). *New Zealand Census: Individual form*.

The University of Auckland annual report 1998. (1999). Auckland: The University of Auckland.

The University of Auckland annual report 1999. (2000). Retrieved Feb 02, 2001 from: http://www.auckland.ac.nz/ipa/anrep00.pdf

The University of Auckland annual report 2000. (2001). Auckland: The University of Auckland.

The University of Waikato annual report 1998. (1999). Hamilton: The University of Waikato.

The University of Waikato annual report 2000. (2001). Hamilton: The University of Waikato.

The University of Waikato 2001 enrolment handbook. (2001). Hamilton: The University of Waikato.

University of Canterbury 1998 annual report. (1999). Christchurch: University of Canterbury.

University of Canterbury 1999 annual report. (2000). Christchurch: University of Canterbury.

University of Canterbury 2000 annual report. (2001). Christchurch: University of Canterbury.

University of Florida faculty guide. (2001). Retrieved Nov 19, 2002 from: http://www.ada.ufl.edu/publication/faculty_guide/categories.htm

University of Otago annual report 1998. (1999). Dunedin: University of Otago.

University of Otago annual report 1999. (2000). Dunedin: University of Otago.

University of Otago annual report 2000. (2001). Dunedin: University of Otago.

University of Otago 2001 Registration Form. (2001). Dunedin: University of Otago.

Victoria University of Wellington 1998 annual report. (1999). Wellington: Victoria University of Wellington.

Victoria University of Wellington 1999 annual report. (2000). Wellington: Victoria University of Wellington.

Victoria University of Wellington 2000 annual report. (2001). Wellington: Victoria University of Wellington.

Victoria University of Wellington 2001 guide to enrolment. (2001). Wellington: Victoria University of Wellington.

Whiteneck, G., Fougeyrollas, P., & Gerhart, K.A. (1997). Elaborating the model of disablement. In: M. Fuhrer (Ed.). *Assessing medical rehabilitation practices: The promise of outcomes research*. Baltimore: Paul H. Brookes.

World Health Organization. (1980). *International classification of impairment, disability and handicaps: A manual of classification relating to the consequences of disease*. Geneva, Switzerland: Author.

World Health Organization. (2001). *The international classification of functioning, disability and health (ICF)*. Geneva, Switzerland: Author.

APPENDIX A

APPLICATION FOR APPROVAL OF PROPOSED RESEARCH PROCEDURES INVOLVING HUMAN SUBJECTS

APPLICANT:

Rosemary Harris
Disability Coordinator
Student Services
Massey University
Private Bag 11-222
Palmerston North

Telephone: (06) 350 4320
E-mail: R.J.Harris@massey.ac.nz

PROJECT:

Title: University students with disability: How uniformly is data collected and reported in New Zealand? (N.B. this is a working title)

Status: Masterate

Funding source: $250.00 from the School of Health Sciences

Clinical trial status: No

ATTACHMENTS:

Questionnaire
Letter
Information Sheet

SUPERVISORS:

Primary Supervisor:
Professor Steve LaGrow
Rehabilitation Studies, School of Health Sciences
Ext: 2248
E-mail: S.J.LaGrow@massey.ac.nz

Secondary Supervisor:
Gretchen Good
Rehabilitation Studies, School of Health Sciences

Ext: 2245
E-mail: G.A.Good@massey.ac.nz

SIGNATURES:

Applicant:

Supervisors:

DATE: 12 June 2001

OFFICE USE ONLY

Received: **Decision:**

APPLICATION FOR THE ETHICS COMMITTEE

1. DESCRIPTION

1.1 Justification

In 1997, the Ministry of Education introduced a Special Supplementary Grant for Tertiary Students with Disabilities. The purpose of the Grant was to improve the access of students with disability to educational opportunities at tertiary institutions and increase the level of enrolment and academic achievements of these students.

The Special Supplementary Grant had certain conditions attached, including the collection and reporting of baseline data on enrolment numbers. Universities report data on students with disability in three different ways. It is reported in the Single Data Return (SDR) sent to the Ministry of Education three times a year, in the University's annual report and in the annual report on the Special Supplementary Grant for the Ministry of Education.

There is a lack of reliable information about the numbers of tertiary students with disability involved in education and no information has been available about the record keeping and reporting capabilities of tertiary institutions regarding these students. The Ministry of Education has collected some information, but there is no way of knowing if it has been collected and reported in any uniform manner.

Variation in information about people with disability in national data sources creates variation in estimates of prevalence, incidence, performance and contributions. Estimates from data produced using different categories for classifying subgroups of individuals with disability create confusion for users of this information, including policy analysts and decision makers.

This thesis will investigate how data has been collected for reporting purposes in the eight Universities in New Zealand. The definitions and categories that are used will be compared as well as how and where data is collected, to see where there is variability or similarity between Universities. This thesis aims to serve as a starting point for consensual decisions on data collection and therefore contribute to good practice in the field.

1.2 Objectives

The main objective of this research is to investigate the uniformity of data collected for reporting about students with disability studying in New Zealand Universities.

In order to achieve this objective, the following questions will be addressed:

- What definitions of disability are used by each University for collecting data

- Where is the data collected

- Which students are represented in the data provided

- How are records maintained

- What categories of impairment are used for data collection

- How is data verified

- How represented are students with disability across New Zealand Universities

- How does data on student numbers compare to the Ministry of Education data

These questions will form the basis of a questionnaire, which will be sent to each of the eight Universities (see Appendix B).

1.3 Procedures for Recruiting Participants and Obtaining Informed Consent

There is a Disability Coordinator at each of the eight Universities and these people will be the people most likely to have the information required to answer the questionnaire. Permission will be sought from the Student Services Manager or equivalent at each University to contact the Coordinators and send them the questionnaire (see Appendix C). Coordinators will be sent an Information Sheet (see Appendix D), outlining the objectives of the research, how the information will be used, their rights as participants and what will happen to the data on completion of the project.

1.4 Procedures in which Research Participants will be involved

The initial procedure will involve the eight participants answering a questionnaire comprising 20 questions. This will take approximately an hour to complete, depending upon how readily available the information is to the participants. The questionnaire will be posted out. Follow up contact with the participants may be necessary for clarification purposes; this will be made clear in the information sheet. If questionnaires are not returned by the date requested, one e-mail request with an electronic copy of the questionnaire attached will be sent as a reminder. Feedback will be provided to the participants on the findings and consensus will be sought on definitions and categories using a Delphi technique, in order to arrive at agreed recommendations for data collection.

1.5 Procedures for handling information and material produced in the course of the research including raw data and final research report

The information from the questionnaires will be kept as confidential information in a locked filing cabinet when they are not being used. They will only be available to the researcher and supervisors. Each of the participating Universities will receive a copy of the results. The final research report will be available from the Massey University library.

1.6 Procedures for sharing information with Research Participants

At the end of the research, each of the participating Universities will receive a copy of the results.

1.7 Arrangements for storage and security, return, disposal or destruction of data

At the end of the research, the questionnaires will be destroyed.

2. ETHICAL CONCERNS

2.1 Access to Participants

Access will be obtained by seeking the permission of the University via the Student Services Manager or equivalent, to send the questionnaire to the Disability Coordinator (see Appendix 2).

2.2 Informed Consent

The people who are invited to complete the questionnaire will be deemed to have given their consent by the act of returning it. This will be stated on the Information Sheet (see Appendix 3). Those who do not return it by the due date will receive one e-mail follow up with the questionnaire attached electronically.

2.3 Anonymity and Confidentiality

Individual students will not be able to be identified by the numerical archival data. All responses from individual Disability Coordinators, particularly to the open-ended questions in the questionnaire, will be regarded as confidential and will be reported in such a way that the source will not be able to be identified. Because the sample size is small and New Zealand is a small country, it will be possible to identify individual Universities and it is not possible for the researcher to guarantee them anonymity.

2.4 Potential Harm to the Participants

There will be no harm to individual students with disability. Care will be taken to ensure that comments from individual Disability Coordinators are kept anonymous. It is not the researcher's intent to compare the results in a way that criticizes individual universities, rather the research is an investigation to find out about current practices.

2.5 Potential Harm to the Researcher(s)

It is not envisioned that there would be any potential harm to the researcher.

2.6 Potential harm to the University

The researcher will comply with the Code of Ethics and the relevant legislation and will report any issues which may potentially damage the reputation of the University to the Supervisors and the Ethics Committee if advised by the Supervisors.

2.7 Participants Right to Decline to Take Part

All participants will be advised in the information sheet of their rights, including the right to decline to take part or to refuse to answer any particular questions.

2.8 Uses of the Information

The information that is obtained will be used in the presentation of a Masters thesis and any publications or presentations which may ensue. A copy of the results will be given to each of the participating Universities.

2.9 Conflict of Interest/Conflict of Roles

There is a potential conflict of roles in this research as the researcher is a Disability Coordinator at one of the institutions being surveyed. The researcher has professional contact with other Disability Coordinators and this may make them feel pressured to respond to the questionnaire. Participants will be assured that their response or lack of response will not in any way affect the researcher's professional involvement with them. If the researcher is contacted by any of the Coordinators regarding this research during working hours, the time will be made up.

2.10 Other Ethical Concerns

No other ethical concerns are evident at the present time.

3. LEGAL CONCERNS

3.1 Legislation

The following legislation may impact on this study:

- **3.1.1** Intellectual Property Legislation e.g. Copyright Act 1994
- **3.1.2** Human Rights Act 1993
- **3.1.3** Privacy Act 1993
- **3.1.4** Health and Safety in Employment Act 1992
- **3.1.5** Accident Rehabilitation Compensation Insurance Act 1992
- **3.1.6** Employment Contracts Act 1991

3.2 Other Legal Issues

Each institution will have their own policies for dealing with information regarding students. The researcher will comply with these.

4. CULTURAL CONCERNS

The researcher will be sensitive to the cultural background and values of the participants in the research.

5. OTHER ETHICAL BODIES RELEVANT TO THIS RESEARCH

5.1 Ethics Committees

No other ethics committees involved.

5.2 Professional Codes

Code of Rights, Health and Disability Commission.

6. OTHER RELEVANT ISSUES

None known.

APPENDIX B

➢ *Disability Questionnaire*

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 01/85. Completion and return of the questionnaire implies consent.

Who is responsible for ensuring the completion of this Questionnaire?

Please give details in the box below:

Name: ____________________

Job title: ____________________

Institution: ____________________

Address: ____________________

____

Telephone number: ____________________

E-mail address: ____________________

➢ *Disability Questionnaire*

Please answer the following questions by ticking a box or by writing in the space provided.

➢*Q1.* What definition of disability is used by your institution when collecting statistics for the Single Data Return sent to the Ministry of Education?

Please provide this definition in the box below:

➢*Q2.* Why do you use this particular definition?

➢*Q3.* Where in your institution does the data concerning students with disability provided in the Single Data Return come from?

- The general student record system ☐
- The Disability Office/Disability Coordinator ☐
- Other (please describe): ☐

➢*Q4.* Is the definition of disability used to determine eligibility to disability services in your institution the same as the definition used in Q1? *Please circle answer.*

Yes – *go to Q6*
No

Please provide the definition used to determine eligibility to disability services in your institution in the box below:

➢*Q5.* Why do you use this particular definition?

➢*Q6.* Where does the data reported in your University's annual report come from?

- The general student record system ☐
- The Disability Office/Disability Coordinator ☐
- Other (please describe): ☐

➢*Q7.* What was the total headcount of students with disability in your institution in 1998, 1999 and 2000?

Year	Male	Female	Total
1998			
1999			
2000			

➢*Q8.* From where was the data in Q7 above obtained?

- The general student record system ☐
- The Disability Office/Disability Coordinator ☐
- Other (please describe): ☐

➢*Q9.* Which one of the following statements describes which students are represented in the counts that you provided in Q7?

- Only students to whom services/accommodations were provided and who fell within the definition of disability provided in Q1 (if the definitions in Q1 and Q4 were the same, please tick this box) ☐
- Only students to whom services/accommodations were provided and who fell within the definition of disability provided in Q4 ☐
- Only students to whom services/accommodations were provided regardless of whether they met the definition of disability provided in Q1 and Q4 ☐
- Students who provided verification of their disability regardless of whether services/ accommodations were provided ☐
- Students who identified themselves to the disability service, regardless of whether disabilities were verified or services/accommodations were provided ☐
- Students who were reported to the disability service as having a disability, regardless of whether the service had any contact with them. This includes information provided to the office about students with disability by other offices (e.g. the enrolment or examinations office), even if the disability service had no contact with them ☐

➢ *Q10*. Which one of the following statements describes the counts of numbers of students that you provided in Q7?

These counts are unduplicated. Each student with a disability is counted only once ☐

These counts are duplicated. Each student is counted by each disability he or she has or each disability for which services are provided ☐

Other (please describe): ☐

____

____

____

____

➢ *Q11*. Which of the following statements describes how your institution maintains the records about students with disability used to prepare the counts in Q7?

- Records are maintained in a computerised database as part of the general student record system and are accessible to various institutional offices such as enrolment staff ☐
- Records are maintained in a computerised database as part of the general student record system but are accessible only to the office or person responsible for providing support services to students with disability ☐
- Records are maintained in a separate computerised database by the office or person responsible for providing support services to students with disability ☐
- Records are maintained in paper files by the office or person responsible for providing support services to students with disability ☐

➢ *Q12*. Do you know the percentage of students using disability services who indicate they have a disability on the enrolment form? *Please circle answer*

No – *go to Q13*
Yes

Please indicate in the box provided the percentage of students who make use of Disability Services who have indicated they have a disability on the enrolment form:

☐

➢ *Q13*. Do you use categories of impairment when collecting data about your institution/ disability service? *Please circle answer*

No – *go to Q18*
Yes

Please list the names of the categories over page.

There is provision for up to ten categories. If more than ten categories are used for data collection in your institution please add them in Appendix 1.

1	
2	
3	
4	
5	
6	
7	
8	
9	
10	

➢*Q14.* Are there students who are receiving disability support services in your institution that do not fall within the definition of disability provided for Q1? *Please circle answer*

No- *go to Q15*
Yes

Please describe the types of students receiving disability services, but not considered to fall within the definition of disability provided for question 1.

There is provision for up to five categories below. If there are more than five, please add them in Appendix 2.

1	
2	
3	
4	
5	

➢*Q15.* How many students did you have in each of the categories for Q13 and Q14 in 2000?

There is provision for up to ten categories below. If there are more than ten categories, please add them in Appendix 3.

	CATEGORY	Female	Male	Total
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

➢*Q16.* From where was the data in Q15 above obtained?

- The general student record system ☐
- The Disability Office/Disability Coordinator ☐
- Other (please describe): ☐

➢*Q17.* Are students put into categories of impairment by

- The Disability Coordinator ☐
- Self-definition by the student ☐
- Documentation by a relevant professional ☐
- Other (please describe): ☐

➢*Q18.* What types of documentation or verification of disability does your institution require in order for a service to be provided?

- Medical evaluation/statement ☐
- Psychological evaluation/statement ☐
- Testing or formal evaluation by your institution's Disability Coordinator ☐
- Informal evaluation or determination by your institution's Coordinator ☐
- Other (please specify): ☐

➢*Q19.* Do you have any comments about the advantages/disadvantages of collecting data on students with disability by headcounts versus EFTS?

Thank you for taking the time to complete this questionnaire. If there are any further comments you wish to make, please do so below.

APPENDIX 1

Relates to Q13. Do you use categories of impairment when collecting data about your institution/disability service?

Additional categories of impairment used for data collection.

11	
12	
13	
14	
15	
16	
17	
18	
19	
20	

APPENDIX 2

Relates to Q14. Are there students who are receiving disability support services in your institution that do not fall within the definition of disability provided for Q1?

Please describe the types of students receiving disability services, but not considered to fall within the definition of disability provided for Q1.

6	
7	
8	
9	
10	
11	
12	
13	
14	
15	

APPENDIX 3

Relates to Q15. How many students did you have in each of the categories for Q7 and Q8 in 2000?

	CATEGORY	Female	Male	Total
11				
12				
13				
14				
15				
16				
17				
18				
19				
20				

APPENDIX C

Sample letter to Universities

Address

Date

Dear [Student Services Manager or equivalent]

My name is Rosemary Harris, Disability Coordinator at Massey University, Palmerston North. I have chosen to carry out a research project to find out how data has been collected and reported about students who study with disability in the eight Universities in New Zealand. This project contributes to fulfilling the requirements for my Masters degree in Philosophy (Arts). It also aims to fill a gap in current knowledge and serve as a basis for consensual decisions on data collection, thereby contributing to good practice in the field. This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 01/85.

I am writing to ask your permission to send a questionnaire to your University's Disability Coordinator. This will take approximately an hour to complete, depending upon how readily the information is available. The questionnaire will be posted out. Follow up contact with the Coordinator may be necessary for clarification purposes. If questionnaires are not returned by the date requested, one e-mail request with an electronic copy of the questionnaire attached will be sent as a reminder. Feedback will be provided to the Coordinators on the findings and consensus will be sought on definitions and categories using a Delphi technique, in order to arrive at agreed recommendations for data collection.

Individual students will not be able to be identified by the numerical archival data. All responses from individual Disability Coordinators, particularly to the open-ended questions in the questionnaire, will be regarded as confidential and will be reported in such a way that the source will not be able to be identified. Because the sample size is small and New Zealand is a small country, it will be possible to identify individual Universities and it is not possible for the researcher to guarantee anonymity. However, it is not the researcher's intent to compare the results in a way that criticizes individual universities, rather the research is an investigation to find out about current practices.

If there are any questions about this research I can be contacted via Massey University by telephoning (06) 350 4320 or e-mailing: R.J.Harris@massey.ac.nz. Any questions or concerns may also be directed to my Primary Supervisor, Professor Steve LaGrow, (06) 350 5799, ext: 2248, e-mail: S.J.LaGrow@massey.ac.nz

Yours sincerely

APPENDIX D

University students with disability: how is data collected and reported in New Zealand?

INFORMATION SHEET

1. I am Rosemary Harris, Disability Coordinator at Massey University, Palmerston North. I have chosen to carry out a research project to find out how data has been collected and reported about students who study with disability in the eight Universities in New Zealand. This project contributes to fulfilling the requirements for my Masters degree in Philosophy (Arts). It also aims fill a gap in current knowledge and serve as a basis for consensual decisions on data collection, thereby contributing to good practice in the field.

2. This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 01/85. If you have any questions about the project I can be contacted at Massey University by telephoning (06) 350 4320, or e-mailing: R.J.Harris@massey.ac.nz. You may also direct any questions or concerns to my primary Supervisor, Steve LaGrow, (06) 350 5799, ext: 2248, e-mail: S.J.LaGrow@massey.ac.nz

3. The Student Services Manager at your University has given me permission to send the questionnaire to you as the Disability Coordinator for your institution.

4. The initial procedure will involve answering a questionnaire comprising 19 questions. This will take approximately an hour to complete, depending upon how readily the information is available. The questionnaire will be posted out. Follow up contact may be necessary for clarification purposes. If questionnaires are not returned by the date requested, one e-mail request with an electronic copy of the questionnaire attached will be sent as a reminder. Feedback will be provided to you on the findings and consensus will be sought on definitions and categories using a Delphi technique, in order to arrive at agreed recommendations for data collection.

5. The information that is obtained will be used in the presentation of a Masters thesis and any publications or presentations, which may ensue.

6. The information will be written up and a copy of the results will be given to each participating University.

7. Individual students will not be able to be identified by the numerical archival data. All responses from individual Disability Coordinators,

particularly to the open-ended questions in the questionnaire, will be regarded as confidential and will be reported in such a way that the source will not be able to be identified. Because the sample size is small and New Zealand is a small country, it will be possible to identify individual Universities and it is not possible for the researcher to guarantee them anonymity. However, it is not the researcher's intent to compare the results in a way that criticizes individual universities, rather the research is an investigation to find out about current practices.

8. The information from the questionnaires will be kept as confidential information in a locked filing cabinet when they are not being used. All raw data will be shredded at the end of the project.

9. It is assumed that filling in and returning the questionnaire implies consent. Your rights as a participant include the following:
    to decline to participate;
    to refuse to answer any particular questions;
    to withdraw from the study any time;
    to ask any questions about the study at any time during participation;
    to provide information on the understanding that your name will not be used unless you give permission to the researcher;
    to be given access to a summary of the findings of the study when it is concluded.

    Participants will be assured that their response or lack of response will not in any way affect the researcher's professional involvement with them.

Thank you for taking the time to read this information and if you do wish to take part in this research, please complete the questionnaire and return it before Friday October 19, 2001.

Yours sincerely
Rosemary Harris