Demographics and characteristics of people with an intellectual disability

Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability

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PLAIN LANGUAGE SUMMARY

Counting and describing people with an intellectual disability

There are lots of different ways to say what intellectual disability is. These different ways are called **definitions.**

These different definitions make it hard to count how many people there are who have an intellectual disability. Another difficulty is that some people do not agree that they have an intellectual disability because they do not like the name or label of "intellectual disability".

Different ways to count people with an intellectual disability

There are four ways to work out total numbers:

- to set up a central list in a country with everyone's name put on it
- to study a group of babies or children over a number of years and count how many are born with or develop an intellectual disability
- to ask all service providers (like IHC) to say how many people use their services
- to do a survey of everyone in the country (a census) and find out how many of them have an intellectual disability.

Studies in New Zealand

There have been a few studies in different parts of New Zealand and two big studies.

The two big studies were done in 1976 and after the last census in 1996. The older study found that **in a group of 1000 people, about three to four people had an intellectual disability**. The latest study found a rate of about **ten people per thousand**.

Both studies found more children had an intellectual disability than adults, and more males than females.

Two other studies have been done. One of these tried to count how many older people had an intellectual disability. This study found **about one to two people in a group of 1000 older people**, had an intellectual disability.

The other study tried to find out how many adults with an intellectual disability had children of their own. They found that **about two to three families in every 1000 families** had a parent who had an intellectual disability.

Studies in other countries

The most recent study in USA found **about eight to nine people in every 1000** people had an intellectual disability, and there are more people who have mild disabilities than

there are people with more severe disabilities. They also found more males than females, and more children than adults.

Lots of other studies have been done and they all get different numbers. This is mostly because of all the different definitions and different ways of counting.

From all the different studies, we can conclude that:

- people will be missed if we only count the ones using disability services
- probably the most accurate numbers come from big surveys of everyone
- children are more likely to be described as having an intellectual disability than adults are
- more males have an intellectual disability than females
- some people with an intellectual disability do not need to use support services, or only use them some of the time
- there are probably **about 7 to 13 people** with an intellectual disability **in every group of 1000 people**
- there are probably about 3 to 4 people in that group who have more severe disabilities and need ongoing support
- the numbers of people with milder disabilities are probably between 3 and 9 people in every 1000 people
- trying to count how many people with an intellectual disability is very difficult and takes lots of money and time.

What other problems do people with an intellectual disability often have?

People with an intellectual disability are all very different individuals. Some of them have extra health problems or disabilities that can make their lives harder.

The most common extra disabilities are:

- epilepsy
- physical disabilities, for example affecting their walking
- sight problems
- hearing problems
- speech difficulties
- behaviour problems.

What causes an intellectual disability?

Lots of different things can cause an intellectual disability. These can happen:

- before birth
- during or soon after birth
- during childhood.

It is also important to look at how the development of people with an intellectual disability can be affected by their upbringing and education.

For lots of people with an intellectual disability, we do not really know what caused their disability. When we learn more about this, we may be able to prevent these things happening.

What does this report say we need to do?

1. We need to realise that people who use services at present are only **some** of all the people who have an intellectual disability. There are other people who might need support too.

2. The easiest group to count is those people who need services every day. These people may also have other disabilities too.

3. Staff need to be properly trained to support people who have health problems or extra disabilities.

4. We need more studies to find out how to help people who only need support some of the time.

DEMOGRAPHICS AND CHARACTERISTICS OF PEOPLE WITH AN INTELLECTUAL DISABILITY

Introduction

A prior review of definitional issues in intellectual disability revealed the complexity of defining what is essentially a social construct. Definitions differ over time, place, and discipline. Even when a definition has widespread support, such as the 1992 AAMR (American Association on Mental Retardation 1992) definition, its application in practice may differ from the criteria and assumptions set out in the Manual.

Trying to establish the incidence and prevalence of intellectual disability in a particular population, is just as fraught with difficulties as naming and defining intellectual disability. Incidence refers to the number of new "cases" of intellectual disability within a specified time, whereas prevalence refers to the actual number of people with an intellectual disability in a given population at a given point in time.

Estimating incidence is complex because of the multiple risk and causal factors associated with intellectual disability, and the variable times in the first 18 years when "diagnosis" may occur. Definitional issues are obviously a significant factor, particularly in terms of diagnosis in the very early years, as "intelligence" measures at this stage have poor predictive validity. Measures of the changing incidence of common conditions associated with intellectual disability are useful in the area of prevention, and the evaluation of prevention programmes (Coulter 1996).

This review will focus primarily on prevalence, given its more common usage and greater relevance for estimating current and future needs for services. Many complex factors affect prevalence estimates. As previously discussed, no single definition and diagnostic procedure is accepted by all involved. Furthermore, social and environmental influences affect the feasibility and validity of prevalence studies.

If intellectual disability was assumed to be accurately diagnosed by a score on a standardised intelligence test, then approximately 2.3 percent of any population might be expected to have an intellectual disability (ie, those people scoring at least two standard deviations below the mean). But many of these individuals would **not** have concurrent problems in adaptive behaviour, and would therefore **not** meet the contemporary requirements of the definition which has the widest professional acceptance. A contemporary conception of intellectual disability now recognises that intellectual and adaptive functioning can **change** over time in an individual. A child may meet the criteria for intellectual disability during their school years but not in adulthood. Intellectual disability is **not** necessarily a permanent, biological condition, but represents a social evaluation of an individual's current behaviour compared to others of the same age and culture.

> *Mental retardation (intellectual disability) does not denote a single disease or entity with a single cause, mechanism, natural course, or prognosis. It refers to a heterogenous behavioral syndrome, characterized by impairments in a person's current level of intellectual and adaptive skills.* ***MR is not necessarily lifelong.*** *Persons who carry this diagnosis present with a wide spectrum of abilities,*

disabilities, and clinical and behavioral pattern (American Academy of Child and Adolescent Psychiatry 1999, emphasis added).

A further confounding issue is the stigma attached to any label like "intellectual disability". This societal stigma has led to the wide variations of labels used throughout history and across countries. As the label acquires a stigma, less pejorative labels are used instead. The people who are labelled are now more likely to reject all labels and substitute more preferred terminology eg, "self-advocates", or refuse to acknowledge any disability.

There is also increased controversy over the fact that a label of intellectual disability is "more likely to be applied to individuals of lower socioeconomic status and ethnic, racial and cultural minority groups" (Larson, Lakin, Anderson, Kwak, Lee and Anderson 2001: p 234). All of these complex issues contribute to the variability in prevalence estimates. The various methods used in prevalence studies also affect the results obtained.

Methods for estimating prevalence

Larson et al (2001) provide an excellent overview of the main strategies used to estimate the prevalence of people with an intellectual disability in the population. The following outline is based on their description.

Registries

Registries of people with an intellectual disability can only be developed in countries in which some form of mandated reporting is in force. There are major ethical and practical difficulties in setting up and maintaining any form of register, and its accuracy at any point of time is questionable. A register is also likely to be problematic as a basis for service planning, due to changes over time in geographic location and disability status, particularly for the largest group – people with a mild intellectual disability.

Birth cohort

Prospective studies which follow a birth cohort may provide useful findings related to changes over time and other demographic characteristics. However, as with any longitudinal method, attrition (people involved "dropping out") will affect prevalence estimates. A further limitation is the fact that prevalence estimates can only be accurate within a particular historical and social context. For example, findings about adult characteristics and service needs will be different in a birth cohort who had little access to education, compared to adults who all had a right to attend school when they were young. Prospective studies are also very expensive to undertake and the findings are slow to emerge.

Administrative prevalence

The most common method of estimating prevalence relies on notification by government and service agencies of people "known" to have an intellectual disability, because of their receipt of special income and/or services. This method has limitations for service planning, as it fails

to identify service gaps or people needing services, and also does not identify those who use general rather than disability support services. It is also highly dependent on the array of services and eligibility requirements at a particular point in time. Extending case-finding to generic sources of support and care, eg, general practitioners, can increase coverage, but it cannot overcome the problem of obtaining information from people who reject a label of intellectual disability and/or manage to "hide" their learning difficulties.

Population based survey

In a population based survey an estimate is obtained through some sort of screening of a random or representative sample of the total population. The accuracy of such a survey is limited by refusals to participate, and failure to obtain information which is perceived as stigmatising by participants.

Prevalence studies in New Zealand

There are few published prevalence studies on intellectual disability in New Zealand. The following review covers some smaller, localised surveys, the most comprehensive survey undertaken (Morrison, Beasley and Williamson 1976), the most recent population survey undertaken in conjunction with the 1996 National Census, and some smaller prevalence studies of specific subgroups of people with an intellectual disability.

Localised surveys

A survey in Auckland and Northland resulted in a prevalence rate of **3.71 per 1000,** of children and adults with an IQ below 85 and accompanying 'clinical need' for support (Densem 1972). The survey relied on notification from government and community organisations who provided services. People with an intellectual disability in hospital services were included. This survey would have excluded some people with mild disabilities who were not receiving special services.

There has been at least one unpublished New Zealand report on the prevalence of people with an intellectual disability, as a basis for service planning. Mitchell and Whitehead (1993) reviewed the literature, calculated age-specific prevalence rates, and made recommendations regarding service planning to the Midland Regional Health Authority. These researchers applied the age prevalence estimates from UK research (Fryers 1993) to the Midland Regional Health Authority's district, based on 1991 Census data. They only provided estimates for those people with a "severe intellectual disability" which they defined as those with an IQ less than 50. Their prevalence estimates for adults of 20 years of age and older ranged from **below 1.0 per 1000** for those over 74 years **to 5.0 per 1000** for those aged 20-24 years. The **average rate** for adults as a whole was **2.9 per 1000.** Prevalence rates for each 5-year age band in the **total** population ranged from 1.0 to 5.0 per 1000. The total estimated number was 2078. These researchers note that their estimate, if applied nationally at that time, would have yielded a national estimate of 10,400 individuals with a "severe intellectual disability", corresponding to a similar estimate by IHC of 10,500.

Mitchell and Whitehead (1993) recommended that, for the purposes of service planning, priority should be given to those with "severe intellectual disabilities" as they defined them (p 18). They also pointed out that this group has declined in prevalence since the 1970s, but that it is not possible to fully explain this decrease due to multiple, possible contributing factors. These factors include: environmental hazards; maternal age, patterns of marriage and attitudes to contraception; programmes of amniocentesis and abortion; neonatal screening; complications of communicable disease; improvements in perinatal care; and early intervention programmes for infants and young children (p18-9).

Comprehensive population survey

The most detailed prevalence survey in New Zealand was undertaken in the period May 1971 to August 1972, following the 1971 Census (Morrison, Beasley and Williamson 1976). The terminology used at that time was "intellectual handicap" which was defined as follows:

> *The term 'intellectually handicapped refers to those people who are unable to lead independent lives in the community because of reduced intellectual functioning and impaired social adaptation (p 10).*

This functional definition was in line with the general use of the term "intellectual handicap" at that time, which, although originally intended to cover the full range of intellectual disability, had come to be used to refer to those with at least a moderate degree of disability. The term "intellectual handicap" had been introduced into New Zealand by the parents' organisation founded in 1949, which became IHC. It was a term which was not used outside of New Zealand.

Five categories of intellectual disability, or "mental retardation", taken from a WHO classification at that time, were adopted. These categories were based on IQ as follows:

Table 1: IQ categories in Morrison et al survey

Borderline	IQ	71-85
Mild	IQ	52-70
Moderate	IQ	36-51
Severe	IQ	20-35
Profound	IQ	below 20

Thus, the scope of this earlier definition and classification included a much larger proportion of the population than later definitions, with its inclusion of the "borderline" category of IQs. In fact the survey itself mostly only identified those with IQs below 52, as the inclusion criteria reinforced this more limited focus. To be included, people had to meet one or more of the following criteria:

- *Those excluded from ordinary schooling, or unable to obtain regular, independent employment because of intellectual limitations.*
- *Those living in psychopaedic, psychiatric or public hospitals with a primary diagnosis of mental retardation.*

- *Those receiving an invalid benefit on the grounds of mental retardation.*

- *Those considered to be moderately or more severely retarded according to WHO classification, either from formal psychometric testing or as judged by expert professional opinion and treated as mentally retarded (p 11).*

These criteria illustrate clearly the historical and social context of definitions of intellectual disability, as well as the confusion of varying terminology, often used concurrently.

The aims of the survey were much broader than a quantitative prevalence study. They were:

- *to ascertain the prevalence of intellectual handicap in New Zealand*
- *to record in broad terms the physical characteristics, degree of independence and self-care and the patterns of behaviour identified, as judged by the family*
- *to record the composition of the family and the features of the family environment, and the effect as perceived by the family of the presence of an intellectually handicapped person*
- *to record the need for services and facilities for the intellectually handicapped, as perceived by the family (p 7).*

The five regions to be surveyed were chosen to represent major population characteristics, based on the results of the 1971 Census. These regions represented 27.83 percent of the total population aged 0-64 years, and included Northland, Waikato and Coromandel, Wellington, Mid and South Canterbury, and Southland. The upper age limit of 64 years was used because of perceived difficulties in the diagnosis of intellectual handicap in elderly people, and identifying them in the community.

The survey methods chosen used a combination of strategies. All available sources of service provision provided an "administrative prevalence" estimate, including educational sources such as special education provisions. The then Department of Social Welfare also identified the names of adults on invalid benefits and contacted their parents or relatives on behalf of the researchers.

The survey authors acknowledge the limitations of these methods, in underestimating the community population, particularly those with milder levels of disability. It was also impossible to identify accurately which region some of the hospital population had originally come from and to find their next-of-kin. These problems were due to the common practice in the 1950s-1970s of moving hospital residents from one hospital to another, in order to maintain hospital capacity in various parts of the country. During this era many people with an intellectual disability lived in a succession of hospitals and poor records or loss of records resulted in long-term or permanent loss of contact with family. The survey authors report that 432 people living in hospitals had no known next-of-kin.

The survey schedule involved a complex set of questions on demographic data, information on individual characteristics and family experiences. Information was gathered through detailed interviews with relatives or others responsible for the care of the individual. The survey sample identified 2,396 individuals with an intellectual disability under the age of 65, in the five survey regions, which had a total population of 728,896 at the time of the 1971 Census. The overall prevalence rate found was therefore **3.29 per thousand.** Because of the unusually low prevalence rate in the Wellington region (2.65 per thousand), the authors

suggest that the unweighted mean of the prevalence rates of the five regions – **3.5 per thousand** – is probably a more accurate estimate.

As would be expected, there were marked variations in prevalence at different ages. There were statistically significant differences in prevalence rates among regions, and among different age groups. The lowest rate was in the oldest age group (50-64 years), and the peak was in the 15-19 year old age group The largest change in prevalence rates between consecutive age groups was the sudden increase at school age, when the demands of school tasks would have highlighted difficulties or delays which were not so apparent during the preschool years. These differences in prevalence rates at different ages are consistent with many other prevalence studies, but generalisations may not be valid for contemporary New Zealand. Major changes have since occurred in health care, early identification, compulsory education and changes in how education is delivered, and increased longevity. There are thus many factors that would affect the results of a similar prevalence study if it were undertaken today. Similarly, the extreme regional differences found in this survey are unlikely to be replicated today.

The higher prevalence rate in males is a consistent finding in most studies, and probably represents the higher male rate of some genetically-based conditions which result in intellectual disability, and the well-recognised greater biological vulnerability of boys to negative developmental outcomes. There may also be social factors involved in terms of different expectations for males and females, and more perceived "behaviour problems" in boys, leading to higher referral rates.

The survey also reported ethnicity rates, based on a reduced sample of 2,245 for which ethnicity data were available. Overall, the proportion of Maori in the sample was higher (11.3%) than would be expected on the basis of the population at the time (7.9%). The prevalence rates for Maori in the Northland and Waikato and Coromandel regions were also significantly higher than the prevalence rates for non-Maori. Some of these differences were related to the age distribution of Maori within the general population, with half of the Maori population at that time being under the age of 15 years.

When the degree of intellectual disability was examined, as would be expected because of the survey's methods, only a small proportion of the sample had mild disabilities. The results were as follows:

Table 2: Percentages of group in each category

Degree of intellectual disability	**%**
Mild	19.2
Moderate	37.5
Severe	29.6
Profound	8.7
Not known	5.0
	100

It could be argued that, for the purposes of planning services for people with an intellectual disability, this restricted focus is justifiable. However, it may also seriously underestimate the

number of people with mild disabilities who may need support at particular times in their lives when additional environment stressors make coping more difficult.

The survey authors use the prevalence findings to predict the numbers of people with an intellectual disability in future years. The projected figure for 1996 was 13,700. According to the most recent figures available (1996/97), the total numbers of "people with intellectual disabilities requiring assistance", is 27,399 (Table 3.4: p 54), twice as many as predicted from the 1971 survey (Health Funding Authority, Ministry of Health undated).

Population survey based on national census

The first national, population-based study of disability in New Zealand was carried out by Statistics New Zealand in 1996/97. The information was sought to provide a basis for policy development and planning for disability support services. In terms of information on intellectual disability, however, the data gathered can only be regarded as indicative for people with an intellectual disability, due to significant problems in definition and ascertainment.

The following questions in the disability survey were used to indicate possible intellectual disability:

Question No.

22. Do you have a condition or health problem, which has lasted or is expected to last for six months or more, that makes it hard in general for you to learn?

24. Do you need help from other people or organisations because of an intellectual disability or handicap?

25. Did you go to a special school or receive special education because of an intellectual disability or handicap?

With regard to children, the following survey questions were used to indicate possible intellectual disability:

10. Is this child limited in his/her activities as a result of:

- *intellectual disability/handicap or intellectual developmental delay?*
- *learning disability (eg, dyslexia, attention deficit disorder)?*

11. Does the child attend a special school or special unit or class (because of a long-term condition)?

12. Does the child have an Independent Education Plan (IEP), Education Development Plan (IDP) or an individualized programme?

The "definition" of intellectual disability used merely states:

> *Includes people who need support or help from organisations like IHC or People First, or who have been to a special school or receive special education because of an intellectual disability or handicap (Statistics New Zealand 1998: p 56).*

This circular definition also reflects an out-of-date understanding of the current service and educational contexts pertaining to people with an intellectual disability in New Zealand. People First is a self-advocacy organisation, not a service provider; IHC is now only one of a range of service providers; many children with an intellectual disability now enjoy an inclusive education within ordinary classes in ordinary schools. Furthermore, many adults with an intellectual disability, particularly those with less severe disabilities (ie, the largest numerical group) are very unlikely to self-identify as having an intellectual disability or handicap

The survey questions also confuse a number of conditions or difficulties which are **not** typically included in intellectual disability (eg, learning disability, attention deficit disorder), and many of the questions relate to a range of types of disability.

The prevalence rates reported were highest in the school aged group (5-14 years), confirming the findings of other prevalence studies. The findings were:

- under five years, 7 per 1000
- five to 14 years, 17 per 1000
- **fifteen to 64 years, 7 per 1000**
- over 65 years – unreported due to small numbers.

These rates are similar to a recent USA census-based survey (Larson et al 2001). They are likely to include some individuals who would **not** normally meet an accepted definition of intellectual disability. However, the results probably also reflect some under-ascertainment, in that some individuals would not self-identify as having an intellectual disability.

The survey also reports the useful finding that people with an intellectual disability (as identified) report the highest "disability requiring assistance" to disability ratio of any disability group. This fact is useful for service planning, in that the prevalence rates should provide a reasonable estimate of actual support services needed.

Prevalence studies of special groups in New Zealand

Two prevalence studies of particular subgroups of people with an intellectual disability in New Zealand have been undertaken.

Hand (1993) carried out a study of older people with an intellectual disability, ie, those born before 1940 (also reported in Hand 1994 and Reid and Hand 1995). With increasing survival to older ages of this population, research into this older group has increased markedly since the mid 1980s. Information on which to plan future services was sought.

Hand's study took place over the three years 1989-1991, and collected detailed information about the study population. The method used included administrative prevalence figures from

disability support services and hospitals. However, Hand also used intensive community case-finding, surveying generic health providers such as general practitioners and registered rest homes. This latter additional method identified 18 percent of the total group. The criteria for inclusion relied on very broad functional designations. The sample accepted as "older people with intellectual disabilities" those who had been "administratively defined as having mental retardation, officially defined as such by a health professional, and/or treated as such by the community they had lived in" (p 428). The study identified 1,063 older people with an intellectual disability, with equal proportions of men and women, and 4 percent who were Maori. Five percent of the group were or had been married. Forty percent were said to have a borderline or mild intellectual disability.

The **national prevalence rate** found in this study was **1.47 per 1000** (Hand 1993), reported as 1.43 per 1000 in Reid and Hand (1995). However, this rate masks the significant range of regional rates which ranged from 0.41 per 1000 (East Coast) to 7.13 (Westland). These variations reflect the presence of large institutions in some localities during this period, and the past practice of moving people around the country to keep institutional beds full. In this study, the proportion of people found in the North Island (46%) compared to the South Island (54%) bears no relationship to the total populations of the two islands.

Hand's prevalence rate of 1.47 is lower than the earlier prevalence study of Morrison et al (1976) who found a prevalence rate of 1.78 per thousand for people aged 50-64 years. They apparently found no people older than 64 years. Hand, however, identified at least 118 people of 70 years of age or older. Her age groups do not identify the size of the 65-70 year old group

Reid and Hand (1995) outline the complex challenges of prevalence research with this population group. There were uncertainties about the validity of individual "diagnoses", with many very old or missing records (p 10). Even though the methodology had been piloted first, there were still many unavoidable delays during data collection, with separate ethical approval having to be obtained from 14 separate area health boards and other agencies (p 10). Fortunately this difficulty experienced with multicentre studies is not as great in the current system, but is still a concern to researchers.

There were also issues of "lost cases", with an estimated 256 people appearing to be "lost" to the hospital system. The records of community service providers also contained numerous anomalies (p 110).

Long distances resulting in time and travel costs influenced the process of data collection (p 11). The researchers estimate that 50 percent of their time spent in case finding was spent on only 20 percent of the total group. Reid and Hand note the importance of identifying a "hidden" group in prevalence studies of people with an intellectual disability, a point also reinforced by an Australian study of older people with an intellectual disability (Bigby 1995). This latter point was also relevant to a later prevalence study of a special sub-group

Mirfin-Veitch, Bray, Williams, Clarkson and Belton (1999) sought to establish prevalence estimates of adults with an intellectual disability who were also parents. Increasing research attention has been paid to this group over the last 10 years, due to the perceived increase in the number of adults with an intellectual disability having children. As a subgroup this is probably one of the most "difficult to count", as the majority of these parents have a mild intellectual disability, do not usually use disability support services, and reject a label of

intellectual disability. This study sought to pilot a method of estimating the prevalence of relatively small groups who were very difficult to locate and identify, for various reasons. It has been used, for example, in studies of the "psychiatric, homeless" population (Fisher, Turner, Pugh and Taylor 1994) and of prostitutes who are HIV-positive (McKeganey, Barnard, Leyland, Coote and Follett 1992).

The "cases" identified for this prevalence estimate came from an extensive community case-finding exercise in Otago and Southland. Ethical approval was obtained from both the Otago and Southland RHA Ethics Committee. Notifications came from people other than the individuals themselves, but only the minimum identifiers necessary to match multiple notifications of the same individual were sought.

The group surveyed included the following Otago and Southland individuals and agencies: all disability support service providers, all government and community providers in the area of family and child wellbeing, all general practitioners, obstetricians, and midwives, all early childhood care and education services. As Reid and Hand (1995), found in their research, the process was long and complex. It involved an initial telephone contact and two stages of postal survey and many delays and challenges. As well as demographic information, the survey also obtained data on respondents' perceptions of the support needs of parents who have an intellectual disability.

Parents with an intellectual disability were defined as adults of over 18 years who had one or more children under 18 years, whether living with them or not and who, in the opinion of the professional concerned, had a general intellectual disability to a degree which affected their ability to cope with most adult tasks without some support, training, or supervision. Parents who experienced cognitive impairment due to mental illness, or acquired head injury in adulthood were excluded from the study. A checklist for identification of intellectual disability in parents was included, with the initial information sent to potential respondents, and then again with the questionnaires forwarded to those respondents who chose to take part in the study. The checklist helped respondents decide whether individual parents actually matched the definition used in this study. Broad, functional definitions of degree of intellectual disability (ie, mild, moderate, and severe) were also included with the questionnaire to assist respondents' estimates (Mirfin-Veitch et al 1999).

This study identified 46 individual parents with an intellectual disability in Otago and Southland. Appropriate statistical analyses in capture-recapture methodology, when applied to this figure yielded an estimated total of 105 parents, and an estimated prevalence rate of **2.51 families per thousand families** in which at least one parent had an intellectual disability. Of the 96 children of the 46 parents, 41 percent were no longer being cared for by their parents, who nevertheless received very low levels of formal support.

This study illustrates the difficulties of establishing prevalence rates to use as a basis for planning for special supports for particular subgroups of adults with an intellectual disability. However, it also illustrates the value of using estimation techniques to account for non-notified cases, a particular problem when considering people with "milder" disabilities who often do not use traditional disability support services and reject the application of a disability label to themselves. Therefore their support needs are often unmet.

Prevalence studies in other countries

Contemporary national survey

The most recent comprehensive national overseas survey provided prevalence estimates of "mental retardation and developmental disabilities" in USA (Larson et al 2001). The prevalence estimates are based on extensive information about disabilities in individuals, from the National Health Interview Survey in 1994 and 1995. This discussion will focus only on the reported prevalence rates for intellectual disability (mental retardation), as the term and category of "developmental disabilities" is not used in New Zealand for service eligibility or planning.

Larson et al report previous prevalence estimates since the 1970s ranging from 3.5 per 1000 to 12.0 per 1000 (for 10 year olds) (p 235-6). They note the influence on findings of: study location, demographic characteristics of the sample, and the methods and definitions of intellectual disability used (p 235).

The National Health Interview survey in USA randomly samples 46,000 households with 116,000 members. A special Disability Supplement was added to the Survey in 1994 and 1995, to gather information on the non-institutionalised population of people with disabilities. People with an intellectual disability were identified in one or more of the following ways:

- if a household member said that a person in the household had an intellectual disability
- when an intellectual disability was indicated as the cause of age-specific limitations in general activities
- if intellectual disability was identified as the primary cause of limitations in specific activities, or listed as the reason for a doctor's visit, or visit to another relevant health professional.

Also, if people identified a specific condition often associated with intellectual disability, follow-up questions were undertaken. Other inclusion and exclusion questions to estimate the severity of any reported learning problem were also included.

Overall, 1,611 people were identified as having an intellectual disability (mental retardation) in the 1994 and 1995 samples. The findings of this study yielded prevalence estimates as follows:

- combination of intellectual disability (mental retardation) or developmental disabilities (non-institutionalised) – 15.8 per 1000
- overall prevalence of an intellectual disability (mental retardation) (those who were non-institutionalised) – 7.8 per 1000
- combined prevalence for intellectual disability (mental retardation) including those in institutions – **8.73 per 1000.**

General findings from other prevalence studies were confirmed with children being much more likely to have been identified as having an intellectual disability, developmental disabilities, or both.

Larson et al stress the importance of a comprehensive approach with a number of "screens", to identify people with an intellectual disability. For example, only 38.4 percent of the sample members who met the criteria for intellectual disability actually responded affirmatively to a question about having "mental retardation". Also, a large number of people who did have an intellectual disability did not report activity limitations. Similarly, a large number of people who **did** report activity limitations did **not** meet the criteria for intellectual disability.

Reviews of other prevalence studies

McLaren and Bryson (1987) provided a useful review of epidemiological studies of intellectual disability. These authors used the term "severe" to refer to intellectual disability associated with IQs less than 50. In a summary table of prevalence rates found in 21 studies, the following ranges of prevalence rates are reported:

- **"mild" intellectual disability** (ie, IQ 50-70) – **a rate of 3.7 to 5.9 per 1000;** far below the rate of 2 to 3 percent predicted on the assumed distribution of IQ scores in the population
- **"severe" intellectual disability** (ie, IQ below 50) **– a rate of 3.0 to 4.0 per 1000,** but higher rates are found with total population screenings, rather than administrative prevalence estimates.

The review of these studies also confirmed the following conclusions:

- prevalence of intellectual disability increases with age until about 20 years, after which it decreases from 7 to 5 to approximately 4 per 1000 (p 244)
- in almost all studies, the highest ascertainment rate was between 10 and 20 years of age (p 244)
- intellectual disability is more prevalent in males, with most researchers reporting a male-to-female ratio of about 1.6:1, probably reflecting both biological risk factors and sex-role expectations (p 247).

Wen (1997) provides a critical review of prevalence studies in Australia, most of which were confined to local areas. There were large variations in estimates at State level, with a range from 3.4 per 1000 to 46 per 1000.

With regard to the Australian Bureau of Statistics Survey in 1989-90 (ABS disability survey) Wen reports three different estimates which illustrate three different derivation methods. He explains that the source of the variation lies in:

- the way responses to survey screening are categorised
- the inclusion of different "disease" codes (ICD codes)
- the inclusion of all "disability conditions" or just the main one (p 17).

Three different methods of derivation in the ABS disability survey yielded prevalence estimates of approximately 6 per 1000, 7 per 1000, and 19 per 1000.

These issues of derivation methodology are relevant to all population based surveys, such as the recent New Zealand survey (Health Funding Authority and Ministry of Health undated) and the American survey (Larson et al 2001).

Three ABS disability surveys had been carried out by the time of Wen's review. As with similar national surveys, data relied on self-reporting, with various "screening" questions about impairments and restrictions. Surveys such as this cannot, for obvious reasons, collect IQ scores, and therefore rely on inferences from reported functional limitations or conditions.

The three ABS surveys reported prevalence estimates of **4.8, 6.3, and 5.4 per 1000.** In a recalculation from the 1993 survey, when a different approach which was based on the reporting of **all** disabling conditions, was used, the prevalence estimate increased to **18.6 per 1000.** This approach picks up more information, particularly identifying people who have multiple disabilities.

The prevalence estimates from the 1993 ABS disability survey showed the typical marked variations by age group. Rates increased until about age 10-14 years with a peak of 20-22 per 1000, declining among adolescents to a **prevalence rate in adulthood of about 16 per 1000.** These estimates also showed a consistently higher prevalence rate among males than females, but after age 40, there was no consistent pattern of sex difference in prevalence.

The introduction of an "age of onset" criterion into the prevalence calculations in the 1993 survey resulted in an 11 percent reduction from the previous figure.

Wen (1997) also reports on a national Australian survey of disability support services in 1995, based on a national data set. This survey showed that intellectual disability was the most common disability type in service recipients (68.4%). These data do not include children at school.

Birth cohort studies

The use of birth cohorts to estimate incidence and prevalence is rare. Two studies of birth cohorts provide information on cumulative incidence and prevalence rates, as well as causal factors and characteristics.

Katusic, Colligan, Beard, O'Fallon, Bergstralh, Jacobsen and Kurland (1996) studied a birth cohort of children born from 1976 to 1980 in Rochester, Minnesota. They found the **cumulative incidence** of intellectual disability by eight years of age was **9.1 per 1000,** and was similar for boys and girls. Data were collected from a combination of school and medical records for a total of 3,287 children from the original birth cohort of 5,919 children. The 2,606 children not included had moved away or died. Thirty children were identified as having an intellectual disability. Unlike other studies, Katusic et al found more than twice the cumulative incidence for "severe" intellectual disability in girls as compared to boys, but the reverse pattern for "mild" disability.

Katusic et al note that their overall findings are similar to three other birth cohort studies in Finland and Sweden. They also accept the study's limitations due to the considerable loss of participants from the original birth cohort and the predominantly white, middle class community in which the study was undertaken. It is also important not to draw firm conclusions about adult prevalence from this study on children, due to the changes in prevalence rates at different ages.

A birth cohort study which followed a group of children with an intellectual disability into early adulthood was undertaken by Richardson and Koller (1996) in Aberdeen, Scotland. Five birth cohorts of 1950 to 1955, totalling 13,842 children provided the original population from which the birth cohort were selected. In total, 221 participants with an intellectual disability were the basis of prevalence analyses. A group of children without disabilities, matched on age, gender, area of residence and SES, were also selected for comparative analyses.

The children were identified through administrative prevalence methods and through the results of group intelligence tests given to every child in Aberdeen at ages seven, nine and eleven years. A variety of methods were used to trace the children as young adults. The eventual study population included any child born between 1951 and 1955 who had been administratively classified as intellectually disabled at any time up to 15 years of age.

The study found cumulative prevalence rates of **12.5 per 1000,** 3.3 for "severe" intellectual disability, and 9.2 for "mild" intellectual disability. Like most other studies, Richardson and Koller found a ratio of 1.19:1.00 (boys to girls) for "severe" intellectual disability, and a ratio of 2.2:1.00 for "mild" intellectual disability. This study also confirmed the differences in prevalence rates at different ages with the highest rates between eight and fourteen years.

These researchers conclude that research on the prevalence rates for people with a "severe" intellectual disability (IQ less than 50) has consistently shown a rate around 4 per 1000 for the last 50 years, with no indication of any long-term downward or upward trends (p 295). They suggest that factors affecting increases and decreases balance out over time for this group. Therefore, they conclude, because this is the group who inevitably need ongoing support services, this prevalence rate provides a baseline for essential services (p 296).

In contrast to this conclusion, the recent UK Department of Health report (2001) concluded that the numbers of people with a "severe" intellectual disability may increase by around 1 percent per annum for the next 15 years. This report also cites an apparent overall prevalence rate of about 29.4 per 1000 (calculated from the brief information provided).

With regard to "mild" disability, however, with its significant age fluctuations in prevalence, it is difficult to compare prevalence rates from different studies. As shown in the previous review of definitions, many changes have occurred in how mild intellectual disability has been defined and the location of the "cut-off' point. Also changes in attitudes and societal provisions, in areas such as education and employment, also affect prevalence rates which are typically calculated administratively (ie, based on use of disability support services). For example, Richardson and Koller found that 18 percent of the young adults who had been classified previously as "mildly mentally retarded" no longer used disability support services and were functioning adequately in adaptive skills. Therefore they could no longer be defined as "mentally retarded".

Richardson and Koller conclude:

> *One of the central points we have tried to emphasize in reporting this research has been the enormous diversity in the personal characteristics and histories into adulthood of the children who met the definition of mental retardation … We have devoted considerable attention to those about whom least is known: the approximately one-half of all the children classified as mentally retarded who after leaving the*

special school managed to live without receiving adult MR (mental retardation) services (p 306-7).

Summary of prevalence findings

Larson et al (2001) provide a succinct summary of the "state-of-the-field" in prevalence studies of intellectual disabilities:

> *In summary, there are many systematic approaches to studying the prevalence of mental retardation… Each method has notable limitations, and together they show the complexities of establishing a meaningful range of estimates for the prevalence of … mental retardation (p 237).*

The following conclusions appear to be most strongly supported by the available research:

- prevalence estimates using administrative prevalence methods (agency notifications) will underestimate prevalence
- population-based surveys yield the highest estimates but have problems in accurate identification
- there are higher prevalence rates among children, particularly those with "milder" disabilities
- there are higher prevalence rates in males
- the number of people needing support at any point in time is less than the overall prevalence at that time
- overall prevalence rates generally range between 7.0 to 12.6 per 1000, with the most recent studies yielding estimates at the upper end
- prevalence rates for people with a "severe" intellectual disability (usually defined as IQ less than 50) show a relatively stable rate of around 3.0 to 4.4 per 1000
- prevalence rates for people with a "mild" intellectual disability vary considerably, ranging from 3.7 to 9.2 per 1000, and are unstable over different age groupings
- prevalence studies in intellectual disability require considerable resources of time and money.

In conclusion, prevalence rates of intellectual disability are a gross and somewhat unreliable basis for planning support services. They tend to mask the enormous heterogeneity of the group subsumed under the label of "intellectual disability".

Characteristics of people with an intellectual disability

The application of the most commonly used definitions of intellectual disability to individuals, results in an extremely heterogeneous group of people. Large proportions of the group, particularly those with an IQ less than 50, will have additional physical disorders and impairments. A significant proportion, possibly more than 50 percent of those with a "mild" disability, will "disappear" from formal disability services on reaching adulthood. For example, Richardson and Koller (1996), in their longitudinal study, found that 72 percent of those with a mild intellectual disability "disappeared" at adulthood. Therefore adult prevalence rates for this group will be unstable.

The most common associated medical conditions experienced by people with an intellectual disability are: epilepsy, Down syndrome, cerebral palsy, and musculoskeletal conditions. There are also high rates of motor, sensory, and communication impairments in people with an intellectual disability. Morrison et al (1976) found the percentages set out in Table 3.

Table 3: Percentage of sample with additional conditions and impairments:

Condition	% age
Epilepsy	21
Down syndrome	20
Cerebral palsy	14
Musculoskeletal conditions	12
Fine motor impairment	32
Gross motor impairment	37
Visual impairment	26
Hearing impairment	8
Speech impairment	74
Behaviour problems	44
Psychotic symptoms	7

Multiple disabilities were common, with 25 percent of the group having four or more conditions or impairments, although additional conditions are higher in the group with a higher degree of intellectual disability (ie, those with IQs below 50).

Morrison et al found most of the rates of additional disabilities were highest in children, except for sensory impairments which did not differ by age.

For many of these categories, the same problems of variations (in terminology, definition, assessment and methodology) are found as those that affect prevalence estimates of intellectual disability. Particularly for additional problems relating to behaviour problems or disorders, definitions vary widely and the reliability of ratings may be very poor, and may be associated more with socio-economic factors or a hostile environment than a function of intellectual disability.

McLaren and Bryson (1987), in their review of epidemiological studies found the most common single disorders associated with intellectual disability to be as follows (with comparisons to Morrison et al):

Table 4: Findings from various studies on associated conditions

	McLaren and Bryson (1987) % age	Morrison et al (1976) % age
Epilepsy	15-30	21
Cerebral palsy and other motor impairments	20-30	26
Behavioural and/or psychiatric disorders	30-40	51
Sensory impairments	10-20	34
Speech and language	"common"	74

The findings reported by Morrison et al (1976) fall within these reported percentage ranges from a variety of studies, except for higher percentages for sensory impairments and behaviour/psychiatric disorders.

Wen (1997) reports the findings of an Australian ABS survey in 1993. Many people with an intellectual disability had multiple impairments or disabilities, as follows:

Table 5: Disability/impairments from Australian 1993 ABS survey

Disability or Impairment	% age of total people with an intellectual disability
Psychiatric	20.1
Acquired brain injury	12.6
Vision	1.1
Hearing	6.7
Speech	23.0
Physical	40.7
Neurological	3.7
Other	21.9

When data were combined for all people with an intellectual disability (whether it was identified as the main disabling condition or not), 40.5 percent also had psychiatric disabilities and 71.1 percent also had physical impairments or disabilities. These findings illustrate the problems in service planning for "people with intellectual disabilities" as an assumed homogeneous group. They also suggest that some people served under other "disability labels" will also have an intellectual disability.

In summary, people with an intellectual disability often have additional impairments to cope with as well as their learning difficulties. Given that most of these additional problems are also present during the developmental years, their effects on learning and opportunities for interactions with the social and physical environment will be complex.

For many of the group of people called "mildly" intellectually disabled, additional risk factors associated with socioeconomic factors such as poverty and unemployment, add additional negative stressors which affect overall functioning.

One of the other "risks" faced by people with an intellectual disability is what has been termed "diagnostic overshadowing". This refers to the tendency for the presence of intellectual disability to be used as an **explanation** for all developmental progress and behaviours. It is essential that thorough assessment of all possible causes – from health conditions or other impairments – is undertaken when developing interventions or making prognoses, particularly to identify sensory impairments or untreated health conditions. This is particularly critical when "behavioural or psychiatric disorders" are involved. Further work on this is beyond the scope of this review.

Finally, a basic understanding of the enormous range of etiological factors in intellectual disability reinforces some of the points made in this review of the characteristics of people with an intellectual disability.

Etiology of intellectual disability

Intellectual disability in an individual may have a specific etiology, such as Down syndrome, but it is not synonymous with that etiology. All people with Down syndrome are different and function within a wide range of strengths and difficulties. Some individuals with Down syndrome may **not** meet the criteria of a functional definition of intellectual disability (such as the 1992 AAMR definition).

The classification of intellectual disability into etiological groups is valuable for specific purposes. The 1992 AAMR Manual sets out four reasons for such classification:

- the particular etiology may include other health or physical conditions which imply the need for special health oversight or support services
- some conditions are treatable if they are diagnosed early (eg, PKU)
- there may be specific prevention programmes related to some conditions, and it is necessary to have accurate information on which to design and evaluate such programmes
- it may be helpful to have accurate information regarding etiologies for administration, research, or clinical practice (p 69).

Unfortunately it is still not possible to identify the specific etiology or cause(s) of intellectual disability in many individuals. McLaren and Bryson (1987) concluded that the cause is unknown for approximately 30 percent of individuals with a "more severe" intellectual disability (IQ less than 50), and for approximately 50 percent of individuals with a "mild" intellectual disability (IQ 50-70/75). With increasing scientific knowledge of early human development, it may be possible in the future to identify some of these causes.

Broad categories of causation

Traditionally, intellectual disability has been conceived as arising from two very broad sets of causes – causes of biological origin and environmental factors, labelled as "psychosocial disadvantage" (AAMR 1992: p 70). However, as pointed out by McLaren and Bryson (1987), this simplistic distinction does not fit the reality of developmental interactions. They report that more than 50 percent of people with an intellectual disability have more than one

possible causal factor. Also, development reflects the cumulative and interactive effects of various risk and "resilience" variables.

The notion of multiple risk factors which also interact at different stages of development is more congruent with contemporary knowledge about intellectual disability. AAMR (1992) describes the four categories of causal factors as:

- *biomedical: factors that relate to biological processes*
- *social: factors that relate to social and family interaction*
- *behavioural: factors that relate to potentially causal behaviours eg, maternal alcohol use*
- *educational: factors that relate to the promotion of intellectual and adaptive skills (AAMR 1992: p 71).*

These four factors intersect with **timing** of when the factors occur, ie, whether they affect the parents, or the person with an intellectual disability, or both. Thus there may be **intergenerational** influences resulting in an outcome of intellectual disability in individuals. Luckasson et al (AAMR 1992) stress that this conception is very different from past eugenic theories and practices.

> *Current ideas about intergenerational effects stress their origin in **preventable and reversible influences of adverse environments,** and understanding these effects will facilitate community inclusion and enhance functioning (p 71).*

Prevention of intellectual disability therefore needs to be conceived at three different levels – primary, secondary, and tertiary – and consider prospective parents, parents, unborn infants, young infants and children, **and** adults with an intellectual disability (Coulter 1996).

The various disorders and conditions in which intellectual disability **may** occur are too numerous to list, and some are extremely rare. However, they can be classified under the following headings and subheadings (AAMR 1992: p 81-91).

I. Prenatal Causes

A. Chromosomal Disorders, eg, Down syndrome; Fragile X syndrome
B. Syndrome Disorders, eg, Tuberous sclerosis; Sturge-Weber syndrome
C. Inborn errors of metabolism, eg, Phenylketonuria (PKU); Mucopolysaccharide Disorders
D. Developmental Disorders of Brain Formation eg, neural tube closure defects such as spina bifida
E. Environmental Influences eg, placental insufficiency; fetal hydantoin syndrome

II. Perinatal Causes

A. Intrauterine Disorders, eg, placenta previa; premature labour
B. Neonatal Disorders eg, intracranial haemorrhage; neonatal seizures

III. Postnatal Causes

A. Head Injuries
B. Infections eg, meningitis
C. Demyelinating Disorders eg, post immunization disorders
D. Degenerative Disorders eg, Rett syndrome
E. Seizure Disorders
F. Toxic-Metabolic Disorders eg, lead intoxication
G. Malnutrition
H. Environmental Deprivation
I. Hypoconnection Syndrome

McLaren and Bryson (1987) concluded from their review of epidemiological studies of intellectual disabilities that cross-study comparisons of studies on etiology are difficult because of differences in categorisation. Nevertheless, they concluded that chromosomal and genetic disorders probably account for 40 percent of the incidence of "severe" intellectual disability, with other prenatal factors accounting for 20-30 percent of cases. Perinatal factors are found to account for approximately 11 percent of those with "severe" intellectual disability. Studies into the role of postnatal factors have yielded less consistent findings, ranging from 0.8-12.8 percent, with most authors reporting 3 percent or 12 percent. No particular study variable appeared to explain these differences (p 249). As previously noted, for 25-40 percent of people with a "severe" intellectual disability, the causal origin is unknown.

With regard to "mild" disability, there is much less research available, with a large percentage of cases of unknown etiology (45-62%). A significant proportion of infants and children are reported to have experienced a history of postnatal trauma and/or neglect (p 251).

The picture of etiology also changes over time. For example, McLaren and Bryson note that fetal alcohol syndrome may be more common now than Down syndrome, as the single most common prenatal etiology. Socio-economic factors are correlated with perinatal factors, and postnatal causes are four times as likely in urban as in rural areas.

Advances in biochemistry, genetics, and neuroscience will no doubt lead to greater understanding of the multiple causes of intellectual disability, particularly more severe intellectual disability. These advances in knowledge may also lead to effective prevention strategies for many disorders. It has been estimated that 35-60 percent of the causes of a more severe intellectual disability are genetic (Moser 1992), and great advances are expected from research such as the Human Genome Project. These advances may be much further in the future than was envisaged ten years ago, however. Moser wrote in 1992:

> *It is likely that not far beyond the year 2000 it will become possible to develop DNA markers for all or most of the genetic disorders associated with mental retardation (p 144).*

Advances in knowledge, when they come, are also likely to raise complex ethical and policy issues. Is prevention of intellectual disability which relies on prenatal screening and abortion, – to prevent the **lives** of people with disabilities – a noncontroversial success? Population screening programmes also involve many complex ethical and cost-benefit issues which must

be addressed before their introduction. People with an intellectual disability themselves need to be informed and involved in these debates too (Ward 2001).

Service policy and planning implications that arise out of considerations of etiology go far beyond disability support services. In terms of prevention, for example, there are implications for maternal and infant health services, for family violence and child abuse prevention, for head injury prevention, for early educational intervention, and for appropriate education and health services for all people with an intellectual disability. This approach to intervention needs to be "ecological", based on an understanding of how "the interactions between individuals and their environments results in mental retardation" and how "risk factors from multiple dimensions interact across generations to result in mental retardation" (Coulter 1996: p 112).

Conclusions and implications

This review has illustrated the practical difficulties and variations in results of prevalence studies of intellectual disability. In terms of service planning, however, the majority of people with a level of disability requiring ongoing support can be more easily and accurately counted.

People whose disabilities may require less support or more intermittent supports are less easy to identify in prevalence studies. Nevertheless a proportion of this group are more likely to be negatively affected by environmental stressors such as poverty and unemployment. They are also more likely to become parents, to experience mental illness, and to have problems with alcohol or other drugs. They may also reject any support from services with a disability label.

This review has also shown the enormous heterogeneity of people with an intellectual disability, and the challenges many of them face with additional health conditions and impairments. Consideration of causative factors has showed the complexity and breadth needed in any prevention programmes.

The following implications deserve consideration in the planning of support services for people with an intellectual disability.

Service planning which relies only on administrative prevalence estimates will under-estimate the number of people with an intellectual disability who may need supports at some time in their lives. Such estimates only report on those individuals known to current services. They are also likely to be limited to disability support services. With the trends in New Zealand towards promotion of independent living, open employment, and the development of "cross-disability" support services, estimates which rely on notifications from services will become more unreliable. Support services are likely to increase their provision of intermittent and time-limited support, and decrease the number of services which provide 24-hour support for all aspects of daily living and accommodation.

The most reliable prevalence estimates are for those people with an intellectual disability who need intensive and/or pervasive supports. In terms of traditional classifications of intellectual disability, these estimates usually refer to people with more significant degrees of limitations in intellectual functioning and adaptive skills, or those with a "moderate" or greater degree of intellectual disability.

Services for people with an intellectual disability must be adequately resourced to meet the special needs which arise from their other health conditions and impairments. There is also considerable evidence that people with an intellectual disability often have a high number of unmet health needs and avoidable health problems (for a summary, see Bray 1996). Staff working in support services need to be adequately trained to meet the needs of people with health conditions and/or multiple disabilities.

Research in the New Zealand context is needed to identify the unmet needs of people with an intellectual disability who do not usually require 24-hour support, and to identify the barriers to meeting these needs. Current policy and funding structures are not well designed to provide intermittent or tailored support services to individuals with milder degrees of disability. Generic systems are also usually uninformed about intellectual disability and often fail to identify and meet the needs of people with an intellectual disability, particularly those whose difficulties are exacerbated by environmental stressors.

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