

5.3.1. Literature Review of Health Indicators for People with Intellectual Disability

5.3.1.1: Indicator 1.1 Prevalence

Definition:

Prevalence in health statistics is the measure of the number of cases of a given disease existing at a certain time expressed as the proportion of a population with the disease at any time in a year. For prevalence statistics from different studies to be comparable, the length of period under consideration asked must be the same. The main sources of disease-specific data for incidence and prevalence data across a range of EU countries are: health interview surveys, cross-sectional population surveys, panel/cohort surveys, medical records/administrative statistics, hospital records, disease-specific registers, general practice (GP) records and administrative notifications (Eurostat, Concepts and Definitions Database – accessed October 2004: <http://forum.europa.eu.int/irc/dsis/coded/info/data/coded/en.htm>)

Prevalence studies:

Intellectual disability is common, affecting between 1-2.5% of the general population in the Western world (Gillberg & Soderstrom, 2003). It usually leads to major functional impairment and lifelong need for support and interventions.

Numerous studies have been carried out internationally examining the prevalence of intellectual disability, yet most of these studies report widely varying prevalence rates. Several reasons may account for the disparity in findings. Richardson (1989) asserts that the lack of a clear definition of “mental retardation [intellectual disability]” in many studies and the lack of a description of the methods used in selecting participants are some of the problems faced in determining the prevalence of intellectual disability. Indeed prevalence studies based on service user registers and institutionalised populations have been found to yield lower estimates than studies undertaken using a population screen (Fujiura, 2003; Emerson et al., 2001; Larson et al., 2001), suggesting an under-utilisation of services.

Despite such challenges an array of prevalence studies have been conducted. Overall prevalence rates typically vary from approximately 3.31/1000 (Beange & Taplin, 1996) to as high as 16.6/1000 (Boyle et al., 1994). Beange and Taplin (1996), for example, in Australian study of 20-50 year olds living in the Northern suburbs of Sydney found an overall prevalence of 3.31/1000. Several studies have found similar prevalence rates to this study (e.g. IMSERSO, 1999). McGrother et al., (2002), for example, investigated prevalence rates of South Asian and Caucasian adults in Leicestershire in the United Kingdom and reported a rate of 3.2/1000 for South Asians and 3.62/1000 for Caucasians. Other studies report higher prevalence rates (e.g. Wellesley et al., 1992). Larson et al., (2001) report a higher prevalence estimate in the United States at 7.8/1000, although the authors note that this figure excludes institutionalised people. A similar prevalence estimate is reported in Irish study using the 2001 Irish National Intellectual Disability Database of service users where a prevalence rate of 7.3/1000 is reported (Mulvany, 2003). Norway has cited similar prevalence estimates; Stromme et al., (1992), in defining intellectual disability as an individual with an IQ of less than 70, cite a prevalence range between 6.7-11.9/1000.

A recent publication by the Intellectual Disability in Europe Working Papers is helpful in demonstrating the differing prevalence rates found throughout Europe. The nature of data collection for these studies is highly influential in determining the cited prevalence rates. Typically prevalence estimates are based on a percentage figure extrapolated to the entire population. Schadler et al., (2003), for example, using a 0.56 per thousand figure estimate that there are currently 420,000 people with intellectual disability in the Federal Republic of Germany, of whom 185,000 are under 18 years and 235,000 who are over 18 years.

Beltman (2002) estimates that there are approximately 49,400 people with mild to moderate intellectual disability in the Netherlands, while Haveman (1998) records 102,000 individuals at all levels of disability.

Other prevalence estimates in the Netherlands are based on the identification of people with intellectual disability attending primary care health services. Van Schrojenstein Lantman de Valk et al., (1997) for example, identified 318 people with intellectual disability attending such services, 0.65% of the study population.

Similarly, Beadle-Brown et al., (2003) cite Emerson et al., (2001) who summarised prevalence rates across a range of studies in the United Kingdom and determined that estimates of severe intellectual disability are typically 3-4 per 1000 and rise to 10 in 1000 for those who have mild level of intellectual disability. This figure can be contrasted to the Government document 'Valuing People' which estimates 210,000 people in England have severe and profound intellectual disability and 1.2 million have mild to moderate intellectual disability based on a 25 in 1000 estimate (Department of Health, 2001)

In Spain, the National Federation of Mental Retardation Association (FEAPS) maintains a database of 686 service agencies that provide services to people with intellectual disability. This database identifies 232,236 individuals yielding an estimate of 0.58% (Salvador-Carulla et al., 2003). This figure is however challenged by a Spanish prevalence study that employed the National Household Survey. This study recorded a prevalence estimate of .33%. In contrast to both these findings, the Institut d'Estadística de Catalunya (2002) cite a national prevalence estimate of 0.54% based on a survey of regional databases maintained by the 17 Autonomous Communities in Spain.

Finally, Ericsson (2003), in a study conducted in Sweden reported that 4 in 1000 people had requested support from the municipalities in June 2000, but acknowledges that some people may have attended other agencies and are thus not accounted for in the findings. Together these European studies reveal a wide variety of methods and findings among studies aiming to estimate the prevalence of intellectual disability and support Richardson's (1989) criticism that many studies' lack of detail regarding sample selection and method make it difficult to determine to whom the results apply.

Estimates and Level of Intellectual Disability: Mild Intellectual Disability

Prevalence figures for mild intellectual disability are more varied than that for severe intellectual disability (Emerson et al., 2001). Based on recent epidemiological research, Emerson et al., (2001) assert that that less than 10 per 1000 people have mild intellectual disability, although when entire populations have been screened, much higher incidence rates of 25-30 per 1000 have been found. This finding is thought to reflect the fact that some individuals with mild levels of intellectual disability are not in contact with service providers and therefore are excluded from prevalence studies based on service user registers.

Several studies involving adults with mild levels of intellectual disability have reported considerably lower rates of between 1.12/1000 and 2.91/1000 (Department of Health, 2000; Beange et al., 1996; Mulvany, 2003). An Australian study carried out in Sydney reported a prevalence rate of 1.12/1000, defining mild intellectual disability as an individual with an IQ of 56-70. While an Irish study of 26,668 people who are on Irish National Intellectual Disability Database, reported a prevalence of 2.91/1000 (Mulvany, 2003). In a comparison of prevalence and incidence rates of intellectual disability for 1966 and 1985-1986 in Finland, Heikura et al., (2003) noted a shift from severe and moderate intellectual disability to mild.

Studies involving children typically report higher rates of mild intellectual disability (Richardson, 1989), with estimates varying between 3/1000 and 29.1/1000 (Wellesley et al., 1992; Stromme & Valvatne, 1998; Murphy et al., 1995; Bashir et al., 2002; Leonard et al., 2003).

Prevalence studies among children in developing countries also tend to report high prevalence rates. Islam et al., (1993), for example, carried out a population-based study of 2-9 year old children in Bangladesh and found a prevalence rate for mild intellectual disability of 14.4/1000. Similarly, a recent study of children living in rural South Africa similarly found a high rate of 29.1/1000 for mild intellectual disability (Christianson et al., 2002).

Estimates and Level of Intellectual Disability: Severe and Profound Intellectual Disability

Estimates of the prevalence of severe and or profound levels of intellectual disability are typically lower than those reported for mild levels of disability. Arvio et al., (2003), for example, in a recent study of 341,227 individuals reported that the prevalence of mild intellectual disability was 0.43%, a figure lower

than the 0.13% reported for those with severe to profound levels of intellectual disability (IQ<35). The authors note that almost all of those with severe and profound intellectual disability (92%) reported between one and six additional handicaps. Higher figures have been reported from studies conducted in Asia. Suzuki (1990) and Suzuki et al., (1991), for example, examined the prevalence of children with severe levels of intellectual disability in Japan and reported figures ranging from 0.49/1000 to 0.68/1000.

Specific Syndromes

Down's Syndrome is the most common specific cause of intellectual disability, and has received most attention in terms of prevalence estimates. Prevalence studies on Down's Syndrome have been carried out in Japan, the UK, Australia, Singapore and Hawaii. Estimates of prevalence vary between .58 per 1000 to 2.2 per 1000 live births, with most studies reporting the rate at close to 1 in 1000 (Orton et al., 2001; Beange & Taplin, 1996; Bower et al., 2000; Irie, 1999; Lai et al., 2002; Lopez et al., 1995; Stoll et al., 1994; Hoshi et al., 1999; Forrester & Merz, 2002). Irie (1999) for example found in a population based study of 500,000 people in Japan, that the prevalence of Down syndrome in live births from 1988-1992 was 1 in 1000. Lai et al., (2002) found that the prevalence of Down's syndrome fell from 1.17/1000 to .89/1000 livebirths between 1993 and 1998. The authors suggest this finding reflects antenatal diagnosis and selective termination. In Glasgow, Scotland, Lopez et al., (1995) identified 1.2 births per 1000. The authors report that while the birth prevalence did not vary significantly over time, there was a significant increase in pregnancy prevalence, suggesting a significant increase in pregnancy terminations. In contrast to this finding Iiyasu et al., (2002) have recently reported that the prevalence pregnancy of Down's Syndrome in Glasgow between 1980-1996 did in fact rise over time. The prevalence rate for Down's Syndrome has been found to be highest in Far East Asia (2.2/1000), followed by metropolitan Honolulu where it is 1.9/1000 (Forrester & Merz, 2002). Hoshi et al., (1999) found an increased risk of Down's Syndrome with advancing maternal age.

Correlates:

The prevalence of intellectual disability has been found to be greater in males. Several studies report a male female ratio of approximately 3:2 (Leonard et al., 2003; Christianson et al., 2002; Wellesley et al., 1992). Fragile X syndrome is also higher among males (Elbaz et al., 1998; Laxova, 1994). Laxova (1994), for example, reports prevalence estimates for Fragile X of 1 in 1000 for males and 1 in 2000 for females, while Elbaz et al., (1998) found a prevalence of 6.7% in males and 0% in females in a sample of 248 children in Guadeloupe.

The prevalence of intellectual disability is also associated with socio-economic status. Islam et al., (1993) note that findings from their prevalence study conducted in Bangladesh revealed that while mild intellectual disability is associated with socio-economic status, severe intellectual disability is not. Similarly Stromme & Valvatne (1998) suggest that the low prevalence of mild intellectual disability reported in Norway may be a function of high socio-economic status.

Very little is known about the prevalence of developmental disabilities in developing countries, despite the potential high risk (Durkin, 2002). Based on the data available, it appears that severe intellectual disability is higher in developing countries compared to prevalence estimates from industrialised countries (Durkin, 2002).

Conclusions:

Prevalence studies of intellectual disability have been conducted throughout the Western and developing worlds. Findings however vary markedly. Reasons for this variation are largely based on differences in definition of what constitutes intellectual disability and different methodological designs. The lack of consensus on these issues suggests that comparisons across studies should be made with caution. Trends in the data have however emerged suggesting that between 3 and 10 per 1000 individuals have intellectual disability. Figures in excess of 30 per 1000 have however also been reported.

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5.3.1.2. Indicator 1.2. **Living Arrangements**

Definition:

Living arrangement may be defined as the place in which a person resides. It includes living at home with both parents, at home with one parent, at home with sibling (s), at home with relative (s), living with non-relative(s) (e.g. neighbour, family friend), adoption, foster care (includes 'boarding out arrangements'), living independently, living semi-independently (maximum 2 hours supervision daily), vagrant or homeless, living in an institution, living in a residential group home, living in a community home, living independently, living in a nursing home, living in a psychiatric hospital, other intensive placement with special requirements due to challenging behaviour or other intensive placement with special requirements due to profound or multiple handicap.

Influence of Living Arrangement:

Better outcomes have been shown for those living in community settings (Felce & Emerson, 2001; Felce et al., 1998; Heller et al., 1998; Howard & Spencer, 1997). People with intellectual disability, for example, have been shown to display increased adaptive behaviour in community settings compared with living in institutions (Felce & Emerson, 2001), those with challenging behaviour have better outcomes than for those living in traditional settings (Felce et al., 1998), better health has been reported compared to those living in nursing homes (Heller et al., 1998), and quality of life has been found to increase when people move from large group homes with institutional features to community settings (Howard & Spencer, 1997). Additionally an Israeli study comparing community residential provision to living at home found that those living at home had more dental problems, however those in community settings had more medical problems (Lifshitz & Merrick, 2003).

Prevalence:

The prevalence rates for where people with intellectual disability live vary across countries. Studies from the Netherlands, for example, suggest that about 45% of people there live in group homes or institutions, while 55% live with family or on their own (Landelijke tabellen clientenregistraties Vereniging Gehandicaptenzorg Nederland, 2000; Mensen met een verstandelijke Beperking in Nederland, Universiteit Maastricht, 2002). National Irish data reveals that the majority of people with intellectual disability in Ireland live in a home setting (61.2%), with 2.6% living independently, 11.6% living in community group homes, 12.9% living in residential centres and 6.7% residing in another service (Mulvany, 2003). The same may be said of the Federal Republic of Germany, where research suggests that 85% of those under 18 years live with their families, 15% in homes, and 60% of adults live with their families (Berlin Memorandum, 2001). In the United States, research suggests that the number of people living in institutions is declining, with an increase in the number living in community residential settings (Polister et al., 2002). A large-scale study of 2.97 million Americans with intellectual disability also showed that a large cohort lived at home with ageing family members (Fujiura, 1998).

Measures:

The following measures have been used to assess peoples' living arrangements:

The Home Quality Rating Scale

The Family Environment Scale

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5.3.1.3: Indicator 1.3. **Daily Occupation**

Note: the focus of this literature review is largely on employment as a form of daily occupation for people with intellectual disability. This emphasis reflects the evidence base regarding daily occupation options for this population.

Definition:

Employment is an activity or service performed for another especially for compensation or as an occupation (Merriam-Webster Dictionary of Law, 1996).

Introduction:

There has been increasing emphasis in recent years, especially in the United States, on the participation of people with disabilities in the labour force. Until the 1960's and 1970's it was believed that people with intellectual disability were incapable of working in the open labour market, but this assumption is largely no longer tenable (Bray, 2003). However, despite this, unemployment remains high amongst this population. The vast majority of research on disability and work has been undertaken in the United States, with some research having been carried out in the United Kingdom, Canada and Australia (Bray, 2003). There is a dearth of research originating in Europe.

Prevalence:

People with disabilities participate in the labour force at consistently lower rates than individuals without disabilities (Butterworth & Gilmore, 2000; Jenkins, 2002) with more than 80% being unemployed (Harris et al., 2000). Yet, more than 1 in 3 people with intellectual disability aspire to having a job (McConkey & Mezza, 2001).

Several studies have yielded high rates of unemployment for this group (Yamaki, & Fujiura, 2002; Ashman, Suttie & Bramley, 1995; Mank, 1994; Wehman & Kregel, 1990) with actual rates of employment for people with intellectual disability varying from as low as 16.9% (Moran et al., 2001) to 40% (Bruinink & Thurlow, 1988). For example, Gilmore and Butterworth (1997) found the rate to be 29% compared with 62% for the entire population, while a recent study of 10,169 people with intellectual disability in South Carolina in the States found the rate to be 22.7% (Pierce et al., 2003). Common employment options are outlined below:

Competitive Employment:

Studies indicate that few people with intellectual disability are in competitive employment (Bruininks & Thurlow, 1988; Putnam, Pueschel & Gorder-Holman, 1988; Ashman et al., 1995; Olney & Kennedy, 2001; Wehman et al., 1985). In the United States, the number of people with intellectual disability, and in particular those with moderate and severe disability, entering into competitive employment is increasing, with 52% in 1985 in competitive employment compared to 78% in 1998 (Butterworth & Gilmore, 2000)

Sheltered employment/ Day Programs:

Most people with intellectual disability work in either sheltered employment or day services (Bray, 2003; Schalock, McGaughey & Kiernan, 1989; Haring and Lovett, 1990; Bruinink and Thurlow, 1988). Haring and Lovett (1990) in a study of 58 people with mild to profound intellectual disability found that 57% of people attend sheltered workshops or day-activity centres for minimally paid work-related activities, while Bruinink and Thurlow (1988) report a rate of 75%. The rate may be even higher for people with Down Syndrome, with one study finding that 70 out of 71 adults with Down syndrome were in sheltered workshops (Putnam, Pueschel, & Gorder-Holman, 1988).

Supported Employment:

Supported employment, where an individual with intellectual disability is supported by a Job Coach in the working environment, embraces six core principles, which are placement first, ongoing support, financial remuneration, universal eligibility, integrated setting, and career development and choices (Bennie, 1996). Research has shown that supported employment is both cost effective (Cimera, 1998), and has numerous benefits including more employment in the competitive labour market (Goldberg et al., 1990), higher job levels and higher wages (Mawhood & Howlin, 1999; Mc Donnell et al., 1989). People with intellectual disability have been found to be the primary service group of supported employment (West et al., 1992). Although it was originally developed to enable people with the most severe disabilities to work in 'real jobs', this group have been shown to be minimally represented in this form of employment (Kregel et al., 1989).

Integrated Employment:

The rate of integrated employment in the United States varies from as little as 4% to as high as 60% depending on the state (Butterworth & Gilmore, 2000). Figures from the US indicate a growth in the number of people with intellectual disability in integrated employment with 26% of all people receiving day and employment services in integrated employment in 1996 compared to 14% almost 10 years prior, in 1988 (Butterworth & Gilmore, 2000).

Correlates:

Gender and the severity of disability have both been found to be salient factors in determining employment. Women have been shown to have lower levels of employment, lower paying jobs (Levy et al., 1994; Julius et al., 2003) to work fewer hours and to have jobs traditionally stereotyped by gender (Olney et al., 2000). Figures on labour force participation from the States for example, show that 35.5% of men with disabilities compared with 31.9% of women with disabilities were employed in 1997 (Burkhauser et al., 1999).

People with mild disability have greater work opportunities than those with profound disability (Solberg & Raschman, 1980). An Irish study of 382 people with mild intellectual disability group yielded an employment rate of 75% (O' Callaghan & Toomey, 1983). While studies including people with profound disability show them to be minimally represented in supported (Kregel & Wehman, 1989) and open employment (Richardson et al., 1988). Solberg and Raschmann (1980), for example, found that 26% of people with severe intellectual disability were employed in contrast to 50% for those with mild to moderate disability. People with Down Syndrome have also been found to have negligible placement in employment (Thomson et al., 1995).

Employer/Industry:

People with disabilities disproportionately participate in service industry jobs (Butterworth & Gilmore, 2000; Botuck et al., 1992), such as the food service, manufacturing, retail (Fesko, Temelini & Graham, 1997), and janitor, laundry and cleaning (Moran et al., 2001). An American study of job tenure in 10,169 individuals with intellectual disability, for example, reported that 28% of individuals worked in the food service, 18% in manufacturing, 15% in disability services, 10% in groceries and 5% in retail (Pierce, McDermott & Butkus, 2003).

Barriers to Employment:

There are a multitude of interrelated reasons for the persistently high rate of unemployment among people with intellectual disability (Mank, 1994; Wehman & Kregel, 1995; Gosling & Cotterill, 2000; West et al., 1999). These include a lack of funding of ongoing support services, and poorly defined procedures for inclusion of people with severe disability (Kregel et al., 1989). For example, people with severe intellectual disability in integrated work settings have been shown to receive less information and training than non-disabled workers (Rusch et al., 1995). In addition, many initiatives to reduce work disincentives have been in effect for only a brief period of time (Sowers, McLean & Owens, 2002), disincentives continue to exist (West et al., 1999; Sowers, McLean & Owens, 2002) and in the States Medicaid (ie. the US program that

pays for medical assistance for certain individuals and families with low incomes and resources) regulations continue to allow providers to offer facility-based services (Mank, 1994 in Sowers, McLean & Owens, 2002).

Policy issues aside, there are a number of other (individual and social) reasons impeding the employment of people with intellectual disability. A study of key workers in day centres for people with disability viewed poor concentration, communication skills, and motivation as common obstacles to obtaining employment in people with intellectual disability (McConkey & Mezza, 2001). Another study of trainer logs in supported employment found that 25% of supported employees had reported sexually-related incidents of conflict with employees or customers (Reitman et al., 1999). And, lastly, many professionals and families do not believe that a job in the community is a feasible or important goal for people with intellectual disability (Sowers, Dean & Holsapple, 1999). The largest number of complaints of discrimination, which is mostly in employment, come from disabled people in New Zealand (Human Rights Commission, 2001) and Canada (Crawford, 1992).

Benefits of Working:

Evidence suggests that people with intellectual disability aspire to work for the same reasons as people without disability; they enjoy working in “real” paid jobs in the community (Bray, 2003). Individuals with jobs in the community have been shown to have significantly higher levels of quality of life (Kraemer, McIntyre & Blacher, 2003; Winer, 2000). People with intellectual disability have also been shown to indicate higher levels of employment satisfaction than those with other disabilities (Fesko, Temelini, & Graham, 1997), thus suggesting the possible importance of work for this population. In a study of employment aspirations of people with intellectual disability attending day centres, key workers believed that the main benefits of paid work for this population are increased self-esteem, independence and confidence (McConkey & Mezza, 2001).

Competitive employment has been found to illicit greater psychological well-being (Jiranek & Kirby, 1990) and higher life satisfaction (Salhever, 2000) compared to unemployment and it has also been found to foster higher rates of job satisfaction compared with sheltered employment (Jiranek & Kirby, 1990). In addition, people in competitive employment have reported greater feelings of control (and competence, Winer, 2000) compared with those in sheltered employment (Wehmeyer, 1994). Those in supported employment also report greater life satisfaction than those in sheltered employment or unemployment (Winer, 2000).

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5.3.1.4: Indicator 1.4. **Income**

Definition:

Money received, especially on a regular basis, for work or through investments (Oxford Reference Online www.oxfordreference.com accessed October 2004)

Introduction:

There is a dearth of research examining the income levels of people with intellectual disability. Most studies that have been conducted originate in the United States making it difficult to generalise findings to European Member States. One thing that is clear, however, is that the income levels for people with intellectual disability are significantly less than that of the general population.

Correlates:

People with mild intellectual disability may have greater income prospects compared with those who have more severe forms of disability (Solberg & Rashmann, 1980). An Irish study of 382 past-pupils of special schools for mildly intellectually disabled children in Ireland, found that of approximately 56% of participants in open employment, 66% earned wages sufficient for financial independence (O'Callaghan & Toomey, 1983).

Men may also be more advantaged compared to women. Some studies have found that women earn less than men, which may be due to lower levels of occupation or fewer working hours (Olson et al., 2000).

Income levels & Poverty:

Numerous studies have shown low- income levels for adults with intellectual disability (Kennedy, 2000; Yamaki & Fujiura, 2002), even when earnings from employment and government income support programs are included (Yamaki & Fujiura, 2002).

Studies from the United States, such as Bruininks and Thurlow (1988), for example, found that the average annual income for young adults with moderate to severe intellectual disability was \$1,500. More recently, a large study of 11,743 people with intellectual disability yielded a weekly income of at least \$50, which amounts to approximately \$2,400 annually (McDermott et al., 1999), while another study reported an hourly income of \$4.87 (Fesko et al., 1997). According to Dickinson and Verbeek (2002), much of the observed lower wages between those with intellectual disability and those without, is due to differences in productivity.

It is therefore not surprising that people with disabilities experience high rates of underemployment, which can lead to high rates of poverty. Based on family income, Butterworth and Gilmore (2000) reported that 25% of men with disabilities and 32% of women with disability were living in families with an income below the poverty line. Again these figures relate to an entire population of people with disabilities in the United States; unfortunately figures specific to intellectual disability are very limited. An in-depth survey of 107,400 people with developmental disabilities in the States however found that people with intellectual disability had the highest percentage of any group with a household income below the poverty threshold (Gilmore & Butterworth, 1997). Given these statistics it seems that poverty is an area of particular concern for people with intellectual disabilities.

Intervention:

A few studies have examined the effects of employment services for people with intellectual disability (Decker & Thornton, 1995; Solberg & Raschmann, 1980; Hill et al., 1987) and reported an increase in earnings as a result. A cost benefit analysis of these services also showed that the annual earned income exceeded the cost of the program (Solberg & Raschmann, 1980; Hill et al., 1987), thereby making it a viable option.

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5.3.1.5: Indicator 1.5. **Life Expectancy**

Definition:

The World Health Organisation defines Life Expectancy as “the number of years of life that can be expected on average in a given population”. www.euro.who.int/observatory/Glossary

Introduction:

Marked changes in the life expectancy of people with intellectual disability have occurred since the latter half of the past decade. Carter & Jancar (1983) examined mortality rates from 1930-1980 and found that while mortality rates were considerably higher for all age groups of people with intellectual disability, compared with the general population, the difference between the two has become relatively small in more recent times. Similarly, Puri et al., (1995) in a more recent study of hospitalised people with intellectual disability between 1981 and 1990 reported a continuing trend for increased longevity in both males and females, with mean death ages approaching those in the general population.

Correlates & Risk Factors:

A strong association has been found between mortality and severity of intellectual disability (Miller et al., 1991; Chaney & Eyman, 2000; Eyman et al., 1993; Eyman et al., 1990; Strauss & Eyman, 1996, Patja et al., 2000) and, in general, people with profound disability have a reduced life expectancy. Chaney and Eyman (2000) in a study of 2,444 people over 60 years found that 61.7% of deaths occurred among those with profound intellectual disability. Miller et al., (1991) found that people with profound intellectual disability had higher rates of mortality than people with mild or severe disability, and furthermore, were more likely to die as a result of respiratory diseases. Heart disease, on the other hand, was the most prevalent cause of death found in those with mild to severe disability. Several studies support the latter findings (Blisard et al., 1988; Hollins et al., 1998; Patja et al., 2001). Hollins et al., (1998), for example, found in a study of 2,000 people with intellectual disability followed over 8 years, that respiratory disease was the leading cause of death in 52% of the study population, compared with only 15% of males and 17% of females in the general population. Patja et al., (2001,) in a 35 year follow up study, found that cardiovascular diseases, respiratory diseases and neoplasms were the most common causes of mortality, with disease mortality high up to 40 years but not thereafter.

Mortality rates in people with intellectual disability are influenced by a wide range of interacting factors (Hayden, 1998). Many of the risk factors associated with mortality have been identified in the literature. Eyman et al., (1990) in a large British study found that immobile participants, particularly those necessitating tube feeding had a substantially reduced life expectancy. Other studies have found similar results (eg. Chaney & Eyman, 2000; Eyman et al., 1993; Eyman et al., 1988; Eyman & Call, 1991; Eyman et al., 1989; Kastner et al., 1994). People over 50 years who have not been toilet trained have been found to be at greater risk of death (Eyman et al., 1988) as have older people whose mobility, eating and toileting skills have regressed (Eyman et al., 1989). Kaveggia (1985) found the highest rate of death in people with inborn errors of metabolism. Several studies have found that common risk factors included younger age, lower IQ, non-ambulation, presence of epilepsy, the origin of the disability, poor nutrition, and little ability to communicate (Eyman et al., 1986; Chaney & Eyman, 2000).

Sudden deaths have been found to most prevalent in older people, with an increase in the number of deaths due to arterial degenerative disease (Carter & Jancar, 1984) and in those with slightly higher IQ's, those with epilepsy, and in those with developmental cranial anomaly diagnosis (Chaney & Eyman, 2000). No difference in risk factors for suicide between people with intellectual disability and the general population have been found (Patja et al., 2001). People with intellectual disability as a result of increasing longevity, are now more at risk of developing cancers, particularly gastrointestinal forms (Jancar et al., 1984).

Prevalence:

In the past mortality rates for people with intellectual disability, have been considerably higher than that of the general population, and although studies continue to report higher rates (eg. McGuigan et al., 1995; Hollins et al., 1998; Maaskant et al., 2002), in recent times the difference is diminishing as noted in a 50-

year survey by Carter and Jancar (2001) of mortality. The life expectancy of people with intellectual disability has become substantially higher in recent decades (eg. Elwood & Darragh, 1981; Masaki et al., 1981; Baird & Salovnic, 1987; Baird & Sadovnick, 1988; Bell et al., 1989; Eyman et al., 1990; Mc Grother & Marshall, 1990; Eyman et al., 1991; Eyman et al., 1993; Kastner et al., 1993; Mc Guigan et al., 1995; Puri et al., 1995; Hayden, 1998; Hollins et al., 1998; Jagger et al., 1998; Janicki et al., 1999; Patja et al., 2000). Bittles et al., (2002) found that the median life expectancy of people with mild intellectual disability was 74 years, for moderate disability was 67.6 years and for profound was 58.6 years. Thus, people with mild disability do not have a poorer life expectancy than the general population (Patja et al., 2000), unlike people with profound disability, where the proportion of expected life lost may be >20% for all ages, compared with the general population (Patja et al., 2000). In the Netherlands, at age 5, the life expectancy of people with intellectual disability in Dutch residential centres is 41 years, while at 30 years the life expectancy is 36 years (Maaskant et al., 2000).

Several subgroups of people with intellectual disability have shorter life expectancies. People with Down's syndrome have been shown to have a shorter life expectancy (Masaki et al., 1981; Baird & Sadovnic, 1987; Malone, 1988; Bell et al., 1989; McGrother & Marshall, 1990; Eyman et al., 1991; Maaskant et al., 2002) with a study of 1,332 people with Down's syndrome reporting a life expectancy of 58.6 years, and 25% of the sample living to 62.9 years (Glasson et al., 2002). Strauss and Eyman (1996) found no difference up to 35 years of age between this population and people with other forms of intellectual disability, but after 35 years, rates doubled every 6.4 years compared to every 9.6 years for people without Down's syndrome. A lack of basic adaptive skills in those over 40 years is a major predictor of mortality (Strauss & Zigman, 1996). Additionally, men with Down's syndrome have been found to have a significantly greater life expectancy than females with the same condition (Glasson et al., 2003). People with cerebral palsy also have a poorer life expectancy (Blair et al., 2001; Wieseler et al., 1995). Blair et al., (2001) found that half of those with an IQ/DQ <20 survived to adulthood, 76% with an IQ/DQ of 20-34, and 92% for people with higher IQ/DQ scores.

While the life expectancy of those with intellectual disability is increasing it should be recalled that the risk of dying before the age of 50 was reported in one study to be 58 times higher for people with intellectual disabilities compared to the general population (Hollins et al., 1998).

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5.3.1.6: Indicator 2.1.

Epilepsy

Definition:

Epilepsy is the most common brain disorder in the general population. It is characterized by recurrence of seizures, caused by outbursts of excessive electrical activity in part or the whole of the brain. The majority of individuals with epilepsy do not have any obvious or demonstrable abnormality in the brain, besides the electrical changes. However, a proportion of individuals with this disorder may have accompanying brain damage, which may cause other physical dysfunctions such as spasticity or mental retardation. (World Health Organisation, 2001b)

Introduction:

Overall, a heightened prevalence of epilepsy has been observed within the population of persons with intellectual disabilities. Within this group, higher prevalence is associated with greater severity of disability (Shepherd & Hosking, 1989). Further, evidence indicates higher mortality – not always directly linked to seizures (Forsgren *et al.*, 1996) – and consequent influence on the quality of life – for this population. While a hypothesis suggesting that there may be a nutritional connection to help account for the finding that individuals with Down's Syndrome are much more likely to develop seizure disorders than others, evidence is by no means conclusive (Thiel & Fowkes, 2004).

Prevalence – children

The prevalence of epilepsy among children with intellectual disabilities has been investigated in several countries: the rates reported of this very frequent additional handicap range widely. Commenting on efforts to increase the availability of dental services for children in this group, Waldman, Swerdloff *et al.*, (2000) cite reported rates of epilepsy ranging between 5 and 50 per cent.

All children aged 5-16 years with mild, moderate and severe levels of intellectual disability in Sheffield, UK were surveyed (Shepherd & Hosking, 1989), yielding an overall prevalence rate of epilepsy of 18%. Rates varied with severity of intellectual disability, from 7% to 67% among children with severe intellectual disabilities and a physical disability.

Similar prevalence rates have been documented elsewhere. A prospective cohort study in Scotland UK reported that 15% of n=221 children with intellectual disabilities had epilepsy by the age of 22 years: there was a lower risk in the absence of associated disability or injury, and the authors note that remission in later life is not atypical for individuals in this population (Goulden, Shinnar *et al.*, 1991). A crude prevalence rate of 1.2 per 1000 (12%) for active epilepsy was reported in a sample comprising all individuals with intellectual disabilities in a northern Swedish county (Forsgren, Edvinsson *et al.*, 1990) on a given prevalence day. The age-specific prevalence for 0-9 years was higher for females. Individuals with epilepsy had more severe levels of intellectual disability.

In Wales, UK, a prevalence of epilepsy of 16% was found within a population of n=1595 individuals with intellectual disabilities aged 5 years and over who were identified by using a range of available datasets (Morgan *et al.*, 2003).. Those who had epilepsy were more likely to use secondary care health services than those with intellectual disability only.

In a Swedish population-based study of 48,873 children aged 6-13 years, Steffenburg, Hagberg *et al.*, (1995) identified n=98 children with active epilepsy, yielding a prevalence rate of 2.0 per 1000: the rate was higher among those children with more severe disabilities. Steffenburg, Hedstrom *et al.*, (1998) identified n=44 children with mental retardation (intellectual disabilities) who had intractable epilepsy: a high frequency of more severe intellectual disability and additional major neuroimpairments was ascertained in this group.

Prevalence studies of intellectual disabilities within populations of children with epilepsy have also been completed. Among n=580 Nigerian children with epilepsy, 18% had intellectual disabilities (Iloje & Paed, 1989). Children with *status epilepticus*, early onset of seizures and a long delay before treatment were factors associated with an increased likelihood that children with epilepsy would also have intellectual disabilities. In Finland, Sillanpaa (1992) collected information on disabilities and handicaps among an unselected

population sample of children 4-15 years old, finding a prevalence of epilepsy of 0.68% in the study population. But among those children with epilepsy, 31.4% were found to have intellectual disabilities.

Also reporting from Finland, Airaksinen, Matilainen *et al.*, (2000) presented longitudinal data relating to a total of =151 children with intellectual disabilities identified at 8 or 9 years: by the age of 10 years, 19% of the children had epilepsy. Information about epilepsy was gathered until the children were 22 years old. These authors concluded that the cumulative risk of epilepsy varied according to the severity and cause of intellectual disability as well as the presence of additional disabilities. The cumulative probability of epilepsy remission tended to increase with age (Airaksinen, Matilainen *et al.*, (2000).

Prevalence – adults

In their prevalence study of all children and adults in a northern Sweden county, (Forsgren, Edvinsson *et al.*, 1990) found active epilepsy in 20.2% of individuals with intellectual disabilities. These authors reported that the prevalence of epilepsy was slightly higher for males, or showed no differences between the sexes, in all age groups after age 9 years. Johannsen, Christensen *et al.*, (1996) conducted a prevalence study in Aarhus, Denmark, among n=72 individuals with Down syndrome aged between 14-60 years. They identified twelve participants (17%) with epilepsy.

McVicker, Shanks *et al.*, (1994) found that 9.4% of n=191 persons with Down syndrome aged 19 years or over in Northern Ireland had epilepsy: the prevalence increased with age, reaching 46% of those aged over 50 years. These authors concluded that late-onset epilepsy in this population is associated with clinical evidence of dementia.

Within an epidemiological cohort of n=392 Australian young people (that is, aged from 8-22 years) with intellectual disability, n=115 (29%) were identified as having epilepsy (Lewis, Tonge *et al.*, 2000). No differences on measures of psychopathology distinguished the groups with and without epilepsy. The authors suggest that epilepsy has little or no influence on problem behaviours for young people with intellectual disability. It is noted that this study included individuals whose age range spanned groups of both children and adults in studies carried out elsewhere.

Related mortality and morbidity

That epilepsy is associated with a significantly increased mortality in persons with MR (intellectual disability) was the conclusion of Forsgren, Edvinsson *et al.*, (1996), in their cohort, longitudinal study in Sweden. This increase related to seizure type and frequency, although death was seldom directly due to seizures themselves.

Patients on a large register (n=1595) created in Wales, UK who had both intellectual disability and co-existing epilepsy used secondary care services more often than those who did not have epilepsy. The authors suggest that individuals with epilepsy may be admitted to hospital for fractures and soft tissue injuries as well as for seizures (Morgan, Baxter *et al.*, 2003). When patterns of residence and psychiatric diagnosis among individuals in this register were examined, it was found that the distribution of the sample was correlated significantly with deprivation, and that former institution residents generated more admissions per 1000 patients than community patients (Morgan, Ahmed *et al.*, 2000). These authors suggested that the relatively higher use of medical as opposed to surgical services may be accounted for in part by the greater prevalence of epilepsy in this group.

Lund (1985) found that 18.2% of a Swedish sample of n=302 adults with intellectual disability had epilepsy, of whom about half had a present state psychiatric diagnosis (compared with just 26% of those without seizures). This author suggested that the association between epilepsy and psychiatric is likely to be complex although not fully understood.

In their study of the incidence of sudden unexpected death of 180 individuals with and 125 without epilepsy in a residential facility for persons with intellectual disability in the USA, McKee & Bodfish (2000) reported a rate of 3.6 per 1000 patient years among those with epilepsy, compared with a rate of 1.3 in the non-epilepsy group.

Summary

The evidence surveyed here from studies in several countries and across different age groups indicates that people with intellectual disabilities have higher prevalence rates of epilepsy than the general population.

Rates increase with severity of disability and there may be some remission as individuals reach adulthood. However, the onset of epilepsy among older adults with Down syndrome, for instance, suggests a different etiology and process is at work. Demographic, residential history and individual characteristics have been found to be related to the prevalence of epilepsy. These findings, together with greater presence of people with intellectual disability in the community in the wake of institutional closures, are likely to have substantial impact on the structure and delivery of health services for this population.

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5.3.1.7: Indicator 2.2. **Oral Health**

Definition:

Oral Health refers to the degree to which a person's teeth and related structures are free from pain, and are functional in the tasks of mastication and swallowing. Oral health also contributes to functional articulation and socially relevant esthetics (Waldman, et al., 2000). Oral disease and dysfunction include periodontal disease (disease of the teeth's supporting tissues with associated degeneration of bony support), caries or cavities, risk to systemic health due to a dental infection, bruxism or tooth wear due to grinding or clenching, and dental trauma (Hennequin & Veyrune, 1999).

Introduction:

The community integration of persons with intellectual disabilities has brought many positive changes to these individuals, their families and professionals who are interested in and provide care for this population. This decentralization, however, has also been associated with access and continuity challenges in delivering many health care services, including oral health services. Two service delivery features inhibit the provision of quality oral health care for this population in the community: 1) service providers lack training, experience, accessible facilities and interest in providing services to this population and 2) 'gatekeeper' practitioners (pediatricians and/or general practitioners) may not routinely recognize oral health care as a priority (Waldman, et al., 2001). Cost considerations may also discourage practitioner participation in some settings (Gotowka, et al., 1982; Hobdell et al., 1975). Finally, persons with intellectual disabilities often present with characteristics that put oral health at risk. These include unique head and neck anatomy, jaw ligament laxity, muscle weakness, abnormal gag reflex, use of dental-deleterious medications, and varying abilities to participate in oral health care (Hennequin & Veyrune, 1999).

Measuring Oral Health

The World Health Organization's 'Oral Health Surveys – Basic Methods' (WHO, 4th Edition, 1997) is the definitive guide for the object assessment of Oral Health. The DMFT measure is generally considered the primary indicator. The DMFT is the number of permanent teeth that are decayed, and missing or filled due to decay. Other oral health indicators are the CPITN index (Community Periodontal Index of Treatment Need), Dental Trauma, and Tooth Wear. Each indicator has detailed assessment criteria. Direct observation and self-report have also been used to assess oral health (White et al., 2003).

Prevalence:

The literature on oral health in persons with intellectual disabilities demonstrates an emerging understanding of the prevalence of oral disease and dysfunction. The comprehensive assessment of oral health, involving numerous features (as noted in the measurement section above), has allowed researchers to focus on differing aspects of this phenomenon. The resultant inconsistency across studies makes comparisons difficult.

A few trends, however, have become apparent. Numerous studies have found that persons with intellectual disabilities demonstrate more periodontal disease, greater numbers of untreated caries, oral pain and more missing permanent teeth than would be expected in their non-disabled peers (White, et al., 2003; Pregliasco et al., 2001; Cumella et al., 2000; Vignehsa et al., 1991; Forsberg et al., 1985; Palin, et al., 1982; Tesini, 1980). Inferior dental care in numerous countries, characterized by extensive periodontal disease, untreated caries, tooth loss, and limited dental treatment, was also seen in this population (Reid et al., 2003; White, et al., 2003; Martinex, et al., 2002; Mitsea et al., 2001; Arvio et al., 1998; Evans et al., 1991; Maiwald & Engelkensmeier, 1990; Thornton et al., 1989; Svatun & Heloe, 1975). The incidence of caries, however, was low in several studies (Gabre et al., 2002; Gabre et al., 2001; Strohaug, 1991).

Correlates:

Although the literature is inconclusive, several covariates appear to be related to oral health status in persons with intellectual disabilities. Level and etiology of intellectual disability, living situation, and comorbidities have been explored. As these factors are inter-related, it is likely that interaction effects and confounding variables will eventually clarify the relationships.

Level and etiology of intellectual disability - Persons with mild intellectual disabilities have been shown to have more caries when compared to those with moderate or severe intellectual impairment (Gabre & Bahnberg, 1997; Gabre, 2000; Gabre et al., 2001; Kendall, 1992), even though other measures of oral health were better (Kendall, 1992). Persons with Down's Syndrome appear to have generally poorer oral health than persons with non-Down's Syndrome intellectual disability (Shyama et al., 2001; Corneja et al., 1996; Randall et al., 1992; Ulseth et al., 1991; Stabholz et al., 1991).

Living situation - Persons with intellectual disabilities living in group homes have been found to have poorer oral health than persons living in other types of structured environments (Thornton, et al., 1989), and poorer than those living in their own apartments (Gabre & Gahnberg, 1994). When Tesini (1980), however, looked at age, degree of intellectual impairment, institutionalization and socio-economic status as determinants of oral health, institutionalization was the major determinant of poor oral health.

Co-morbidities - Increased mobility has been associated with poorer oral health (Karjalainen et al., 2002) although this variable has not been extensively studied.

Intervention:

Two of the studies cited previously that report low caries data for persons with intellectual disabilities (Gabre et al., 2002; Gabre et al., 2001) followed and frequently monitored the oral health of persons with intellectual disabilities, suggesting close contact with dental health professionals is effective in improving oral health. Findings from Cumella et al., in 2000 reinforce the importance of this ongoing contact; subjects in this study were found to be generally unaware of their oral health, relying on appearance and the lack of pain to judge their own dental needs.

Research is beginning to define features of oral health programs that are effective with persons with intellectual disabilities. Barriers to access and treatment (Rawlinson, 2001; Connick & Barsley, 1999; Connick, et al., 1999; van Grunsven & Koelen, 1990) are being identified. The effectiveness of treatment techniques is also being investigated and includes aids to facilitate oral examinations (Geary et al., 2000), the use of electric toothbrushes (Bratel & Berggren (1991), the frequency of toothbrushing (Palin-Palokas et al., 1984), and frequency of health education interventions (Shaw & Shaw, 1991).

Conclusion: The emerging literature on the oral health status of persons with intellectual disabilities documents significant oral health morbidity and a reduced status relative to persons without intellectual disability. Several important covariates may be associated with this reduced status, but the literature is incomplete. Attention needs to be directed at identifying these covariates, and designing and evaluating treatment approaches that meet the needs of this group.

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5.3.1.8: Indicator 2.3. **Body Mass Index**

Definition:

BMI as defined by Eurostat's Concepts & Definitions: The Body Mass Index of Quetelet's index is a measure of a person's weight relative to his or her height that correlates fairly well with body fat content in adults. The BMI is accepted by experts as the most useful measure of obesity in adults when only weight and height data are available. BMI is calculated ... as the result of dividing body weight (in kg) by body height (in m) squared. If the result is between 18 and 20 the person is underweight, and is severely underweight when below 18. A person with a BMI between 27 and 30 is overweight and severely overweight with a BMI of 30 or more. There is no international consensus about the classification of moderate obesity and a range of 25-30 is sometimes used.

(<http://forum.europa.eu.int/irc/dsis/coded/info/data.conded/en/g1009324.htm>)

Introduction:

Since the 1990s, the prevalence of obesity and overweight in persons with intellectual disorders has been a rising concern. There is general agreement that persons with intellectual disabilities are at greater risk for obesity than the general population. The associated serious co-morbidities (e.g. cardiovascular disease and diabetes) give urgency to understanding this phenomena and identifying ways to combat it. BMI has been the primary tool used to document obesity/overweight in the multiple prevalence studies in the literature, the majority of which have looked at individuals with Down's Syndrome.

Prevalence:

The literature reports wide agreement on the increased prevalence of obesity and overweight among persons with Down's Syndrome and other forms of intellectual disability. The studies have relied primarily on BMI and the WHO classification system to define these conditions. Generally consistent findings are seen in studies with both large and small samples although the reported prevalence rates vary widely. It seems likely that these varying rates are related to, among other factors, country of data origin and year of data collection as obesity rates vary across countries (Harris, et al., 2003, Frey & Rimmer, 1995) and are changing over time. Data from eight studies are summarized below:

Reference	Subjects (n)	% overweight	% obese	% underweight
Bell and Bhate (1992)	Intellectual disability (n=183)	Males: 71% Females: 96%		
Greco (2003)	Intellectual disability (n=22)	5%	30%	
Prasher (1995)	Down's Syndrome (n=201)	Males: 31% Females: 22%	Males: 48% Females: 47%	
Rubin et al., (1998)	Down's Syndrome (n=283)	Males: 45% Females: 56%		
Simila & Niskanen (1991)	Mental retardation (n=112)	16.9%		29.5%
Van Schrojenstein Lantman-de Valk (1998)	Intellectual disabilities	8.8%	4.1%	
Robertson et al., (2000)	Intellectual Disabilities (n=500)	Males: 27% Females: 24%	Males: 13% Females: 24%	Males: 4% Females: 7%
Marshall et al., (2003)	Intellectual Disabilities (n=407)	27%	31.5%	16.7%

Comparing persons with and without intellectual disabilities:

Studies that have directly compared persons with and without intellectual disabilities on obesity/overweight measures have not consistently supported a higher prevalence of obesity/overweight in persons with intellectual disabilities. Murphy, et al., (1992) found no differences between BMI, age controlled BMI and other measures of obesity between a group of persons with intellectual disabilities and controls. Similarly, when Sharav & Bowman (1992) looked at thirty sibling pairs (one with Down's Syndrome and one without) no significant BMI difference was found.

In addition to BMI, researchers have used other measures to consider obesity/overweight in persons with intellectual disability. Using body composition as determined by deuterium dilution, bioelectrical impedance analysis and skinfold measurements, Luke et al., (1996) found no difference between subjects with Down's Syndrome and control subjects. Allison et al., (1995), however, found that persons with Down's Syndrome had lower resting metabolic rates than persons without Down's Syndrome, which could facilitate obesity/overweight.

Correlates:

Several correlational relationships have been noted between obesity/overweight and covariates. Differential rates have been noted across gender, as seen above. Several social factors have also been investigated. Living circumstances have been associated with differing rates of obesity/overweight. Rubin et al., (1997) found that individuals with Down's Syndrome were more likely to be overweight if they were living in a family as opposed to a group home setting. Simila & Niskanen (1991) and Prasher (1995) likewise found that serious obesity was associated with living with parents. Finally, in a study of 364 adults with mental retardation, Rimmer et al., (1993) found the lowest rates of obesity among those living in institutions. Fujiura et al., (1997) investigated BMI relationship with lifestyle variables of friendship, social opportunity and physical competency and found them to be "potent predictors" after the effects of diet, exercise and physical status were controlled.

The degree of intellectual impairment also may be related to weight. In a sample of 282 persons with intellectual impairment, Hove (2004) found that those with severe impairment were more likely to be underweight and those with mild impairment were more likely to be obese. Rimmer, et al., (1993) and Simila & Niskanen (1991) present similar data showing higher relative obesity rates among those with less severe intellectual impairment.

Other obesity/overweight measures:

As mentioned above, researchers have used a variety of tools, in addition to BMI, to consider obesity/overweight in persons with intellectual disabilities. These include skinfold measurements (Murphy, et al., 1992; Luke, et al., 1996), the Shukla's Nutrition Index (Sanchez-Lastres, et al., 2003), percent body fat (Frey & Rimmer, 1995), and resting metabolic rate (Allison, et al., 2003; Chad et al., 1990).

Intervention:

The literature is remarkably limited in reporting the effectiveness of intervention strategies to decrease the high prevalence of obesity/overweight in persons with intellectual disabilities. It does not appear that health screenings alone are effective in reducing the prevalence, although health promotion classes hold promise (Marshall, et al., 2003).

Conclusion:

Obesity and overweight are significant conditions associated with intellectual disability. Methodological issues make it difficult to accurately pinpoint their prevalence and comparisons to the general population are inconsistent. The literature, however, strongly documents the wide spread occurrence of these deleterious health conditions in this population. Although receiving less attention in the literature, the high percentage of persons with intellectual disabilities who are underweight is also a public health concern. Certainly, continual monitoring of BMI in this population is indicated, along with further efforts to identify difference between those with the condition and those with normal weight. Finally, intervention strategies that address the issue in the context of the unique needs of this population need to be designed, implemented, and assessed.

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5.3.1.9: Indicator 2.4. **Mental Health**

Definition:

According to the Report of the Surgeon General (U.S. Department of Health and Human Services 1999) 'mental health and mental illness are not polar opposites but may be thought of as points on a continuum. Mental health is a state of successful performance of mental function.....mental illness is the term that refers collectively to all diagnosable mental disorders' (p.4)

In the past, symptoms of mental health disorders were often 'shadowed' by a previous diagnosis of mental retardation (intellectual disabilities). But more recently, it has become apparent that individuals with intellectual disabilities may also incur mental health disorders and indeed there is evidence that they are at increased risk of some. The authors of a recent review of literature related to the prevalence of mental health disorders among people with MR (intellectual disabilities) found that different conditions – such as schizophrenia, dementia, mood disorders and substance abuse – were often grouped together and termed 'mental health disorders' (Kerker, Owens *et al.*, 2004).

Introduction

Lack of mental well-being has become a major public health concern in Europe (STAKES, 1999), reflected in the establishment of a dedicated EU Mental Health Working Party at Luxembourg in November 2003. People with intellectual disabilities have an increased risk of developing emotional disorders (Borthwick-Duffy, 1994). They are more likely to suffer from mental ill health – including behavioural, personality, autistic-spectrum and attention-deficit hyperactivity disorders (Deb, Matthews *et al.*, 2001). Yet generic mental health services do not always meet their needs (Vanstraelen, Holt *et al.*, 2003). Estimates of the prevalence of psychiatric/mental health disorders in the population of persons with intellectual disabilities vary, due to difficulties in diagnosis as well as to limitations in research methodologies (Kerker, Owens *et al.*, 2004). The reasons for reports that prevalence varies according to the severity of intellectual disability are likely to be complex. Implications for health service professionals and systems charged with meeting the mental health needs of people with intellectual disabilities, particularly in the wake of a move from institutional to community living, are widespread.

Prevalence

Gustafsson & Sonnander (2004) found prevalence rates ranging from 34% - 64% for mental health problems in Swedish samples of adults with intellectual disabilities, concluding that these were similar to overall occurrence figures in comparable studies in the USA, UK and Denmark. These authors noted that the number of adults registered for mental health care was relatively low: it was apparent that only some adults with mental health problems were being treated.

Taylor *et al.*, (2004) used the PAS-ADD checklist to survey a sample of n=1155 adults with intellectual disabilities living in community, residential care and hospital settings in the UK, yielding an overall prevalence rate of mental health problems of 20.1%. These authors concluded that the checklist was accessible and sensitive, but that further investigation is needed about its specificity.

Challenging behaviour was associated with increased prevalence of psychiatric symptoms - especially anxiety and psychosis - in a Danish sample of n=165 persons with intellectual disabilities aged 18-30 years (Holden & Gitlesen, 2003). But these authors caution that some issues are not fully understood, such as causation on an individual level, and the nature of disorders among those with severe or profound levels of intellectual disability.

Two UK studies investigated prevalence of mental health disorder among older people with intellectual disabilities. Higher prevalence rates for psychiatric morbidity were found among n=165 adults with intellectual disabilities aged 65 years or over when compared with adults aged 20-65 years (68.7 v 47.9%) (Cooper, 1997). Elsewhere in the UK, Patel, Goldberg *et al.*, (1993) carried out a prevalence study in n=105 people aged over 50 years and found a combined case prevalence of 21.0%: the prevalence of dementia was 11.4%.

The authors of a cross-sectional study of a very large sample (n=60,752) of adults with intellectual and developmental disabilities aged from 21 to more than 74 years in the USA found that about 25% had psychiatric diagnoses and the frequency did not decrease with age grouping (Davidson, Janicki *et al.*, 2003). Morbidity was associated with behavioural symptoms in all but the oldest grouping.

Children and adolescents

In community studies of adolescents and children with intellectual disabilities from the USA, and population-based studies in the Netherlands and the UK, behavioural symptoms were commonly identified among children and adolescents with mental health disorders.

Sevin, Bowers-Stephens *et al.*, (2003) gathered longitudinal data about the prevalence of psychiatric disorders among n=150 adolescents aged from 11.6 to 19 years with developmental disabilities who had been hospitalised in the USA. Disruptive behaviour disorders were commonly diagnosed, and nearly one-third of the sample were diagnosed with a mood disorder. These authors found evidence for disagreement between current and previous (available records) diagnoses. In a population (n=497) of adults and adolescents with Down syndrome in the USA, an overall prevalence rate of psychiatric disorders of 22.1% was found: those aged under 20 years often displayed disruptive and repetitive behaviours and anxiety disorders.

Dekker & Koot (2003) selected randomly a total of n=474 children attending special schools for people with intellectual disabilities in the Netherlands. A total of 21.9% of those who took part in the study had anxiety disorder, 4.4%, mood disorder and 25.1%, disruptive disorder. Impairment and co-morbidity were high. These authors drew attention to the finding that less than one-third of the children with a psychiatric disorder received mental health care.

Emerson (2003) carried out a secondary analysis of data from the Mental Health of Children and Adolescents in Great Britain, a survey that collected information on 10,438 individuals aged from 5-15 years. He found that the prevalence of conduct, anxiety and pervasive developmental disorders and hyperkinesia was significantly greater among those with intellectual disabilities than among their peers. Factors associated with psychopathology among children and adolescents with intellectual disabilities were age, gender, social deprivation, family composition, number of potentially stressful life events, the mental health of the child's primary carer, family functioning and child management practices.

Methodological issues

Clinical methods of identifying psychiatric symptoms and interpreting these correctly for the population of people with intellectual disabilities are as yet imperfect. For various reasons, a correct diagnosis - among adolescents, for example - is a test for professionals (Sevin, Bowers-Stephens *et al.*, 2003). In addition, community settings, where people in this population increasingly live and work, pose certain challenges to accurate diagnoses. Among a sample of n=205 people in community day programmes in the USA, just 11.7% had a recorded psychiatric diagnosis and yet an overall rate of disorder of 39% was found (Reiss, 1990). Salvador-Carulla, Rodriguez-Blazquez *et al.*, (2000) determined the point-prevalence of psychiatric problems among n=130 adults in a vocational setting in Spain: psychiatric diagnoses were made for 32.3%. It was also found that morbidity was *hidden* - that is, not previously diagnosed - in half of the psychiatric cases. The authors recommended development of standardized instruments appropriate for non-clinical settings as well as specific training for health professionals.

Appropriate methods to identify mental health disorders among people with severe or profound levels of ability (Holden & Gitlesen, 2003) are required. Finally, several authors in the studies reviewed here urge training of health professionals in making diagnoses, particularly clinicians who may not have been trained initially to work with people with intellectual disabilities. Patel, Goldberg *et al.*, (1993) pointed out that direct care staff who support people with intellectual disabilities may be aware of symptoms of psychiatric disorder, but unaware of their clinical significance.

Research methods may also hinder clear understanding of the mental health needs of people with intellectual disabilities. Studies in the literature may be based on either administrative or population studies (Kerker Owens *et al.*, 2004).

Health services

The findings of prevalence studies indicate that health service professionals must review practices and policies related to providing mental health care to people with intellectual disabilities.

Cooper (1997) found higher psychiatric morbidity among elderly (compared with younger) adults with intellectual disabilities in a region of the UK, and suggested that this finding warrants further investigation by service planners and clinicians.

Concluding their extensive review of literature on mental health disorders among individuals with MR (intellectual disabilities), Kerker, Owens *et al.*, (2004) recommended (1) a refreshed focus on training of health professionals; (2) use of representative national data in prevalence studies; and (3) for researchers to draw representative samples in future studies of this kind .

Writing in the United Kingdom, Vanstraelen, Holt *et al.*, (2003) commented that the arrival of effective treatments makes it a matter of great importance to diagnose accurately psychiatric disorders among people with intellectual disabilities, and to ensure that primary care health professionals have appropriate advice and training in this specialist area. Emerson (2003) cited evidence that social deprivation and family functioning were among the variables that predicted an increased risk of psychopathology among children and adolescents with intellectual disabilities in a UK study. He concluded that support services must respond to the needs of the family as well as the child.

Summary

Available evidence indicates that there is a higher prevalence of some mental health disorders among people with intellectual disabilities: they are more often identified as having anxiety and psychotic disorders, but are less likely to be substance abusers (Kerker, Owens *et al.*, 2004). A variation in occurrence rates is apparent, probably due to challenges in diagnosing conditions among individuals in this population, and also to methodological limitations of previous research reporting prevalence rates. Reasons for an association between prevalence of mental health disorders and severity of intellectual disability are not clear. Reliance on community-based, rather than population-based data may under-estimate true prevalence. The implications of higher prevalence rates for practice and policy so as to identify and meet the mental health needs of individuals with intellectual disabilities are wide-ranging.

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5.3.1.10: Indicator 2.5. **Sensory Impairment**

Definition:

ICD 10 defines moderate visual impairment as visual acuity <0.3 in the best eye with the best correction, severe visual impairment as visual acuity <0.1 and blindness as visual acuity <0.05. Hearing impairment is defined as hearing in best ear-without hearing adjustment is less than 40 dB; this value is the average of hearing capacities at 0.5, 2 and 4kHz. Deafness is defined as hearing in best ear without adjustment as less than 80dB.

Introduction:

Research indicates that sensory impairments such as visual and auditory impairments are more common in people with intellectual disability (Carvill, 2001). Numerous studies have been conducted investigating visual impairment in people with intellectual disabilities. Studies have been carried out in Canada, the US, Sweden, Norway, the UK, Denmark and Australia. Ocular disorders have been found to be common in people with intellectual disabilities (eg. Van Allen, 1999; Woodhouse et al., 2000). Findings indicate a high prevalence of visual impairment in people with intellectual disability yet insufficient treatment of ophthalmic and optometric conditions is common across all countries from which this data is derived (Walburg, 2001). Similarly, a greater prevalence of hearing impairments have been reported for people with intellectual disability, but adequate health screening for hearing impairment is seldom in place.

Correlates:

VISION:

Several factors have been found to be associated with visual impairment (VI). These include severity of disability, limited ambulation, physical disability, age, gender and Down's syndrome. Visual impairment is higher in people with severe intellectual disability compared to those with mild intellectual disability (Evenhuis et al., 2001; Van Schrojenstein et al., 1994; Jacobson, 1988; Mc Cullough et al., 1996; Janicki & Dalton, 1998; Woodhouse et al., 2000). VI has been reported in 51% of people with severe disability, with a combined sensory impairment (visual and auditory) prevalence rate of 20% (Evenhuis et al., 2001), while blindness has been found in 25% of people with profound intellectual disability (Van Schrojenstein et al., 1994). Prevalence rates of VI have been found to be higher in people with Down's syndrome (Evenhuis et al., 2001), and those with limited ambulation, fundamental skills deficiency and severe physical and neurological disabilities have been shown to have a lower mean visual acuity (O'Dell et al., 1993).

The prevalence of visual impairment has been shown to increase dramatically with age (Warburg, 2001; Evenhuis et al., 2001; Van Schrojenstein et al., 1994; Van Buggenhout et al., 1999; Day, 1989). Poor vision has been reported in 36% of adults between 60 and 79 years and 50% of adults 80 years and over (Janicki & Dalton, 1998). Elderly people in community and institutional care have also been found not to receive glasses for near vision (Warburg, 2001; Woodhouse et al., 2000). Lastly, the incidence of refractive errors has been shown to be higher in men (60%) than women (40%; Levy, 1984).

HEARING:

Like visual impairment, older age and Down syndrome are associated with higher rates of hearing impairment (Evenhuis et al., 2001). People with severe and profound intellectual disability also experience higher rates of hearing impairment, although these groups have been found to be rarely use hearing aids (Van Schrojenstein Lantman de Valk et al., 1994). People with hearing impairments have been found to be at greater risk of death across all levels of intellectual disability (Patja et al., 2000). Deafness is more common in males than females (Admiraal & Huygen, 1999).

Aetiology of Impairments:

VISION:

Warburg (2001) reported that the most frequent causes of visual impairment were myopia, cortical visual impairment, optic atrophy, cataract and keratoconus. While Evenhuis (1995) found cataracts and hyperopia to be the most common conditions causing visual impairment.

HEARING:

Admiraal and Huygen (1999) in a Dutch study of 122 deaf pupils found that 48% of hearing impairments were acquired, 17% inherited, 4% were chromosomal and 30% were of unknown origin. The most important acquired causes were congenital infections, such as rubella and CMV, severe prematurity, kernicterus and meningitis. Similarly, infection was the most frequent cause of hearing impairment in a study by Van Schrojenstein Lantman de Valk et al., (1994). Most of the aetiological studies on hearing impairment have reported a high proportion of unknown causes (Admiraal and Huygen, 1999).

The incidence of people affected by both visual impairment and hearing impairment is far greater than by chance, due to the fact that a number of conditions lead to extensive neurological damage, causing a range of disabilities including intellectual disability (Carvill, 2001).

Intervention:

Screening for visual and hearing impairment is vital in this population as a proper diagnosis of impairment is seldom made (Nagtzaam & Evenhuis, 1999) and many health problems are missed (Wilson & Haire, 1990; Carvill, 2001; Kerr et al., 2003). Regular professional assessment of eye disorders, visual acuity and refraction are warranted in residents in both hospital and community care (Warburg, 2001; Prokesova et al., 1990; Beange et al., 1995; Mc Cullough et al., 1996; Janicki & Dalton, 1998). The importance of active screening for hearing impairments from an early age has been stressed in the literature (eg. Evenhuis, 1995).

Special attention should be given to people over 50 years, people with Down's syndrome, and those with severe and profound intellectual disability because these groups have the highest frequency of visual and hearing impairment (Van Schrojenstein Lantman-de Valk et al., 1994, 1997).

Because hearing tests for people with intellectual disability are problematic (Wilson & Haire, 1990; Yeates, 2000), Yeates and Moorey (1996) suggest establishment of specialised services for people with intellectual disability comprising of people skilled in both audiology and intellectual disability.

Prevalence:

VISION:

Visual Impairment: The prevalence of visual impairment (VI) in adults with intellectual disability has been reported less often than in children (Warburg, 2001). However, prevalence in adults is very high (eg. Van Schrojenstein Lantman de Valk et al., 1997). Rates of visual impairment vary from approximately 15-30% (Warburg, 2001; Janicki & Dalton, 1998; Van Schrojenstein Lantman-de Valk, 1998; Van Buggenhout et al., 1999; Bogsten et al., 1999; Day, 1987; Haugen et al., 1995; Howells, 1986; Thomas et al., 1988) with higher rates for people with Down's syndrome (Schrojenstein Lantman-de Valk, 1998; Schrojenstein Lantman-de Valk et al., 1994). However, some studies have reported higher rates of up to 68% (e.g. Beange et al., 1986, 1990; Wilson et al., 1990). The difference in rates reported is due to both differences in how visual impairment is measured i.e. whether by testing or questionnaire, and the variation in definitions used (Carvill, 2001). According to Carvill (2001) looking at the extremes of prevalence found, rates are between 8.5 and 200 times that of the general population.

The majority of people with intellectual disability have a moderate visual impairment with a visual acuity of ≤ 3 (Orel-Bixler et al., 1989; O'Dell et al., 1993); rates typically vary between 20% and 28% (eg. Arnestad, 1995; Bogsten et al., 1999; Sacks et al., 1991; Haire et al., 1991; Evenhuis et al., 2001; Haugen et al., 1995). Jacobson (1988) in a Swedish study of 228 adults with intellectual disability found that 23% had severe visual impairment, with a visual acuity of < 1 , while more recently Evenhuis et al., (2001) in a study of 672 institutionalised Dutch people found that 13% had a visual acuity of < 1 . A study of people with Down's

syndrome found that 34.7% of people with Down's syndrome had poor vision in contrast to 19% of people without Down's syndrome (Van Schrojenstein Lantman-de Valk et al., 1994).

People with mild intellectual disability report better rates of visual acuity than those with severe disability. For example, Mc Cullough et al., (1996) found that 12% of people with mild intellectual disability had a visual impairment of ≤ 25 , compared with 40% for people with severe disability, and 100% for those with profound disability. The prevalence of moderate to severe visual impairment has also been found to be higher in ageing people (60-92 years) with intellectual disability (27.9%) compared to those without intellectual disability (.66% 60-69 years, 13% >80 years; Evenhuis, 1995). Optic atrophy, cataracts and keratoconus¹ have been reported as common (Warburg, 2001).

Refractive errors: A high prevalence of refractive errors in people with intellectual disability is evident in the literature. Prevalence rates vary between 30% and 73% (eg. Aitchison et al., 1990; Mc Cullough et al., 1996; Orel-Bixler et al., 1989; Prokesova et al., 1990; Van Allen et al., 1999; Levy, 1984; Gnad & Wesson, 1992). Levy (1984) also found a higher prevalence in males, 60% versus 40% in females.

Astigmatism: The prevalence of astigmatism is higher in people with intellectual disability compared to the general population (Woodruff et al., 1980; Jacobson, 1988; Haugen et al., 1995; Bogsten et al., 1999; Woodhouse, 2000; Haugen et al., 1995). Rates for astigmatism of greater than 1 dioptre have been reported between 34% and 59% (eg. Woodhouse et al., 2000; Bogsten et al., 1999; Woodruff et al., 1980).

Glasses: A high percentage of people with intellectual disability have been shown to require glasses due to ametropia² (Arnestad, 1995; Jacobson, 1988; Haire et al., 1991; Prokesova et al., 1990; Haugen et al., 1995; Bogsten et al., 1999; Woodhouse et al., 2000). Yet numerous studies indicate that many people with such problems have never had glasses (eg. Arnestad, 1995; Jacobson, 1988; Warburg, 2001; Levy, 1984; Jacobson, 1988; O'Dell et al., 1993). Jacobson (1988), for example, in a Swedish study of 228 in an institution for people with intellectual disability found that 83 people required glasses, but only 13 had glasses before the study. Additionally, a number of people have been found to be wearing inappropriate prescription glasses (Orel-Bixler et al., 1989; Aichison et al., 1990). The prevalence of prescriptions given to people with intellectual disability ranges between 20% and 46% (Bogsten et al., 1999; Arnestad, 1995; Haire et al., 1991; Van Splunder et al., 2003; Arnestad, 1995).

Blindness: The prevalence of blindness reported by care staff has been found to vary between 3.6% and 4.4%. (Warburg, 2001). Beange et al., (1995) found blindness in 4.4% of people with intellectual disability compared to a normal prevalence of .2% in Australia. Blindness has been found to be particularly high (23-37%) in people with severe and profound intellectual disability (Warburg, 2001).

HEARING:

There have been many studies examining the prevalence of recognised and unrecognised hearing impairment in people with intellectual disability (Carvill, 2001). Prevalence rates of hearing impairment in people with intellectual disability are much higher than that of the general population (eg. Crandell & Roeser, 1993; Van Schrojenstein Lantman de Valk et al., 2000). However, similar to visual impairments, rates reported vary according to how hearing impairment is measured. The incidence and prevalence of deafness is about 1 per 1000 in the general population (Kitson & Fry, 1990). Rates vary from as little as 11% and as high as 50.9% in people with intellectual disability (eg. Van Schrojenstein Lantman de Valk, 1998; Thomas et al., 1988; Beange et al., 1986, 1990, 1995; Howells, 1986; Evenhuis et al., 2001; Van Schrojenstein Lantman de Valk et al., 1994, 2000; Wilson & Haire, 1990; Evenhuis, 1995; Yeates, 1989, 1992, 1995; Janicki & Dalton, 1998).

Evenhuis et al., (2001) found that the prevalence of hearing impairment in people under 50 years with mild intellectual disability was 21%, compared to 0.2%-1.9% in the general population. They also found that combined sensory impairment was high (20%) amongst those with severe to profound intellectual disability. Van Schrojenstein Lantman de Valk et al., (2000) reported a prevalence rate for ear problems of 16% in people with intellectual disability, compared with 9.5% in the general population in the Netherlands. Lavis et al., (1997) found widely differing rates according to the method of testing used. They

¹ Keratoconus is an abnormal cone-shaped protrusion of the cornea of the eye

² Ametropia is an eye abnormality such as nearsightedness, farsightedness or astigmatism resulting from faulty refractive ability of the eye

found a rate of 38.9% where a hearing test was used, and 9.4% where a questionnaire assessment was used. Yeates' (1989, 1992, 1995) found in a British study that only 20% of people with intellectual disability had normal hearing.

The prevalence rate for people with Down's syndrome has been found to be higher (Yeates, 1989, 1992, 1995; Van Schrojenstein Lantman de Valk et al., 1997) with Van Schrojenstein Lantman de Valk (1998) reporting a hearing impairment rate of 23.1% in people with Down's syndrome compared to 11% in those with other intellectual disabilities. Similarly, an earlier study by Van Schrojenstein Lantman de Valk et al., (1994) found a 28% prevalence rate of hearing impairment in people with Down syndrome in contrast to 8% in people with other forms of intellectual disability. People with Down's syndrome are particularly prone to developing a hearing loss in early middle life (Yeates, 1989, 1992, 1995).

Age has also been shown to be a factor contributing to hearing problems (eg. Cooper, 1998; Van Schrojenstein Lantman-de Valk et al., 1997; Janicki & Dalton, 1998). Evenhuis (1995) found that 16.7% of 60-70 year olds and 33.3% of over 70's with intellectual disability had moderate to severe hearing losses in contrast to 7% and 18% respectively in an ageing population without intellectual disability.

Deafness: A higher prevalence of deafness has been found in males. For example, Admiraal & Huygen (1999) found in a study of deaf pupils that 63% were males and 37% females, Cremer et al., (1994) found 54% were males and 46% were females, while Newton (1985) observed a male predominance of 54%.

Measures:

Measures that have been typically used to assess vision and hearing include:

Vision:

Bust D test

Cardiff vanishing optotypes

IASSID: International Consensus Statement Early Identification of Hearing and Visual Impairment in Children and Adults with an Intellectual Disability

Keeler

Kay pictures

Landolt's C ring

LH charts

Osterberg charts

Snellen's E chart

STYCAR vision tests

Teller preferential looking procedure

Hearing:

Oto-Acoustic Emissions

Comprehensive Adult and Geriatric Assessment (CAGA)

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5.3.1.11: Indicator 2.6.

Mobility

Definition:

Mobility is defined as the quality or state of being mobile (Webster's Revised Unabridged Dictionary, © 1996, 1998).

Correlates:

Lack of mobility has been found to be associated with a number of negative factors. For example, Kobe et al., (1994) found in a sample of 203 non-ambulatory individuals with profound intellectual disability a high prevalence of physical and medical problems, as well as high rates of maladaptive behaviours such as self-injurious, stereotypic and aggressive behaviour.

Mobility disorders place people with intellectual disability at risk from developing metabolic bone disease (Wagemans et al., 1998; Mugica et al., 2002). Mugica et al., (2002) recently found that bone mineral density was significantly lower in individuals with severe intellectual disability compared to the general population, with 25% presenting with osteopenia (a condition of bone in which decreased calcification, decreased density, or reduced mass occurs) and 22% with osteoporosis. The authors partly attribute these findings to low levels of mobility.

Mobility has also been found to be linked with life satisfaction. Adults with lower mobility assistance needs in both group homes, and semi-independent and independent apartments in the community have been shown to report markedly higher lifestyle satisfaction (Schwartz, 2003).

Residential Provision:

Unsurprisingly, a higher number of people with mobility problems have been found to live in hospitals (Hand et al., 1996). Hand et al., (1996) found that 77% of people with mobility problems in a sample of 51 people were living in hospitals, rather than with their families, in rest homes or in community-based facilities. Borthwick-Duffy, Eyman and White (1987) who examined de-institutionalisation and community residential placement in 66,367 people with intellectual disability in the state of California, assert that ambulation is an important factor in the consideration of residential placement for people with intellectual disability. Thus people with mobility problems are probably more likely to be institutionalised than those without such problems.

Mortality:

The life expectancy of people with intellectual disability is shorter than that of the general population (Eyman, et al., 1990). Non-mobility has been found in several studies to be a significant predictor of mortality in the former population (Eyman et al., 1993; Eyman et al., 1988; Eyman & Call, 1991; Chaney & Eyman, 2000). For example, Eyman et al., (1993) report that individuals who are unable to move their extremities or bodies voluntarily or who require tube feeding have very shortened life expectancies. The study reported that survival estimates in a sample of 128, 248 people with developmental disabilities, including intellectual disability, were short when individuals were immobile and could not roll over regardless of arm-hand use or feeding status. Similarly, the same authors in an earlier study (Eyman et al., 1990) compared three groups; those who were immobile and required tube feeding (subgroup 1), those who were immobile but could eat with assistance (subgroup 2) and those who were mobile and could eat with assistance (subgroup 3) and reported similar findings adding that group one had the shortest life expectancy (4-5 additional years), followed by group 2 (8 additional years) and lastly group 3 (23 additional years).

Prevalence:

Studies examining mobility in people with intellectual disability typically address mobility impairments, however prevalence studies are limited. Hand and Reid (1996) found in a sample of 1,063 people with lifelong intellectual disability in New Zealand that 21% had musculoskeletal impairment. Mobility

impairments have been found to increase with age in people with intellectual disabilities (McCarthy & Mullan, 1996; Evenhuis & Heleen, 1997; Janicki & Jacobson, 1986), which is similar to that of ageing people in the general population. Evenhuis and Heleen (1997) report the rate of mobility impairment at 30% in people between the ages of 60 and 75 years, increasing to 58% in those over 75 years of age.

Functional skill losses were found to be most prominent in mobility as well as in fundamental activities of daily-living skill areas in a study of 10,532 elderly individuals with intellectual disability (Janicki & Jacobson, 1986).

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5.3.1.12: Indicator 3.1. **Physical Activity**

Definition:

Physical activity is typically defined in terms of engagement in exercise over a specified timeframe. Eurobarometer surveys commonly define such activity as exercise twice weekly (European Commission, 2002)

Correlates:

Studies examining physical activity in people with intellectual disability have shown that exercise has positive physical and psychological implications.

Chanias, Reid, & Hoover (1998), conducted a meta-analysis of 21 individual studies to determine the effects of exercise on health-related physical fitness of individuals with intellectual disability and found large effects for muscular and cardiovascular endurance, and moderate effects for muscle strength and small effects for flexibility. Similarly, Tsimaras et al., (2003) found improved aerobic capacity for a group of 25 male adults with Down Syndrome, compared to a control group, following a systematic and well-designed aerobic training programme. Physical activity has also been associated with better health including reduced abdominal obesity and decreased likelihood of hyperinsulinemia (Draheim, Williams & McCubbin, 2002).

Several studies have investigated the relationship between physical activity and psychosocial factors and have yielded positive outcomes, such as increased self-esteem (Castagno, 2001), more positive self-perceptions (Dykens & Cohen, 1996), higher social competence (Dykens & Cohen, 1996), increased friendship activity (Castagno, 2001), improved life satisfaction and lower rates of depression (Heller et al., 2004). Weiss et al., (2003), for example, examined the relationship between involvement in the Special Olympics and self-concept and participant competency and found that participation in the games positively influenced participants' psychological well-being, with greater involvement indicative of more positive general self-worth.

Additionally, a review of the literature on the effects of physical activity on intellectual functioning, behaviour and self-concept has demonstrated a consistent positive relationship between exercise and behavioural management including effects on stereotypic behaviour, maladaptive behaviour and work performance (Gabler-Halle et al., 1993). However, detailed research is lacking, thus more controlled empirical research is needed in order to generalise these findings (Weiss et al., 2003).

Why People Participate & Barriers to Physical Activity:

In a recent study of participation motives of Special Olympics athletes, Shapiro (2003) found that athletes main reasons for participation in the games were for task oriented and social integrative reasons, such as winning ribbons and medals, playing with others, getting exercise, doing something they are good at and having fun, rather than for ego oriented reasons.

However, significant inequalities exist in opportunities and choices to be physically active between the general population and people with intellectual disabilities (Messent, Cooke, & Long, 1999). Several factors mitigate against people with intellectual disabilities' involvement in physical activities. Messent, Cooke and Long (1999) identify some of the salient barriers, which include unclear policy guidelines in residential and day service provision, together with resourcing, transport and staffing constraints, participant income and expenditure, and limited options for physically active community leisure.

Prevalence:

People with intellectual disability have very low levels of engagement in physical activity. Research indicates that they are typically the most inactive and sedentary members of the population (Messent, Cooke & Long, J, 1999).

Rates of physical inactivity are high across settings, with Draheim et al., (2002) reporting little or no leisure time activity in 47-51% of adults in a community-based setting, and Karjalainen et al., (2002) reporting severely reduced or absent physical activity in 45% of institutionalised adults in a Finnish study.

Other studies vary widely in the rates reported for physical inactivity. In a UK based study of 24 adults with mild to moderate intellectual disability, Messent, Cooke and Long (1998), reported that 22% of individuals were below recommended minimum levels of physical activity, while in another study by the same authors that year, they reported rates at 93%. More recently, Temple and Walkley (2003) found that 68% of adults living in supported group homes were below the Australian national guidelines for physical activity participation.

It is therefore unsurprising that a review of the literature reveals that people with intellectual disability have very low levels of physical fitness (Fernhall, 1993). Messent et al., (1998) found in a sample of 24 adults with mild and moderate intellectual disability that mean cardiovascular fitness levels were 20-28% lower for males and 42% lower for females compared to average values for the general population.

These findings suggest that there is not enough moderate or vigorous physical activity choices available in day and residential care settings to meet Government health recommendations (Messent, Cooke & Long, 1998).

Measures:

Measures that have been used to assess physical activity include:

The Rockport Fitness Walking Test

The Maximal Treadmill Test

The Maximal Shuttle Run Test

The Submax Cycle Ergometer Cycle

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5.3.1.13: Indicator 3.2. Challenging Behaviour

Definition:

Challenging behaviour refers to behaviour which places the individual or others in physical danger, results in destruction of their immediate environment, causes at least an hour's disruption, or behaviour which limits or delays access to ordinary community facilities (Scottish Office, 1998). It can encompass aggression, self-injury, destructiveness, hyperactivity, inappropriate sexual or social conduct and bizarre mannerisms, which adversely affects the health and safety of both the sufferer and the carer.

Correlates:

Challenging behaviour is an issue of current and pressing concern (Van Berckeraer-Onnes et al., 2002). Several factors have been shown to be associated with the presence of challenging behaviour. Studies have found that those with more severe intellectual disability display higher rates of challenging behaviour (Deb et al., 2001; McClintock et al., 2003; Sigafoos et al., 1994) and more severe forms of challenging behaviour (Emerson & Bromley, 1995). Carvill and Marston (2002) found that sensory impairment can lead to higher rates of behavioural problems. Those who are more likely to need assistance in eating, dressing, and washing, be incontinent and have more restricted expressive and receptive communication display more demanding challenging behaviour (Emerson et al., 2001; Borthwick-Duffy, 1994; Johnson & Day, 1992; Kiernan & Kiernan, 1994; Oliver et al., 1987; Rojahn, 1994). Clegg and Sheard (2002) looked at the relationship between challenging behaviour and insecure attachment, and found that those with an insecure attachment, i.e. 'over-investing in one or few relationships which becomes a source of jealousy' were significantly more likely to display challenging behaviour.

Links have been found between gender and challenging behaviour, although the exact nature of this association remains unclear. Emerson et al., (2001) found that two-thirds of people identified with challenging behaviour were male, and other studies reported similar results (eg. Borthwick-Duffy, 1994; Johnson & Day, 1992; Kiernan & Kiernan, 1994; Oliver et al., 1987; Rojahn, 1994; Sigafoos et al., 1994; Harris, 1993). A meta-analysis of prevalence and cohort studies conducted over the past 30 years supported the finding that males display significantly more aggression than females (McClintock et al., 2003). However, other studies have reported contrary findings (eg. Deb et al., 2001; Maurice & Trudel, 1982). Deb et al., (2001) for example, found that severe behavioural problems were associated with females, as well as severity of intellectual disability, a history of epilepsy and attendance at day activities.

Challenging behaviour has also been found to be associated with an increased prevalence of psychiatric symptoms in some studies (eg. Holden & Gitlesen, 2003; Jenkins, Rose, & Jones, 1998; Paclawskyj, Matson, Bambury & Baglio, 1997; Moss et al., 2000), although in some cases the correlation has been low (Rojahn, Borthwick-Duffy & Jacobson, 1993). Psychiatric symptoms and challenging behaviour may co-exist particularly in adults with severe and profound intellectual disability (Thompson & Reid, 2002).

Some evidence has been found connecting living arrangement and challenging behaviour. The link is again a tentative one. According to several authors challenging behaviour is more likely to feature in hospital settings (Quereshi & Alborz, 1992; Harris, 1993; Qureshi, 1994; Sigafoos et al., 1994). Lowe et al., (1998), for example, found that 5 people out of 42 identified with challenging behaviour lived at home, 17 in community services and 17 in hospitals. Harris (1993) found a prevalence rate of aggressive behaviour of 38.2% in hospitals compared with 9.7% in day facilities. While Deb et al., (2001) found better outcomes for people living in the community, followed by family home and last traditional services. Similarly, Felce et al., (1998) reported significant gains of the community home model in contrast to traditional services. Ohters however have reported different findings (eg. Emerson et al., 2001; Joyce et al., 2001; Stancliffe et al., 2002).

Function:

According to Emerson and Bromley (1995) the most common functions of challenging behaviour are self-stimulation, for self-injury, destructiveness and 'other' challenging behaviours, and securing the attention of carers for aggressive behaviours.

Intervention:

It has been suggested that well-trained staff and effective behavioural intervention can aid in the reduction of challenging behaviour exhibited by people with intellectual disability (Department of Health, 1993). A study by Hastings et al., (1995) highlights the importance of experience and possibly adequate training in the area of challenging behaviour. The authors found in a study of 246 staff, that experienced staff held beliefs about challenging behaviour that were more consistent with contemporary theories than inexperienced staff. This can have important implications for the way in which staff deal with challenging behaviour. Anti-psychotic medication has also been used to treat people with challenging behaviour (eg. Sigafos et al., 1994), although the benefit of these drugs is questionable. Brylewski and Duggan (1999) in a systematic review of their efficacy found no evidence either for or against the use of such drugs for the treatment of challenging behaviour. There has been a particular awareness in recent times of the importance of basing intervention on an accurate understanding of the processes maintaining challenging behaviour (Emerson et al., 1995; Carr, 1994; Carr, Robinson & Palumbo, 1990; Horner, 1994; Iwata, 1994; Mace, 1994; Mace, Lalli & Lalli, 1991; Mace & Roberts, 1993).

Prevalence:

A high rate of behavioural disorders has been reported in people with intellectual disability. Challenging behaviour is a particular problem in this population. Estimates of the prevalence of challenging behaviour vary widely. This is in part due to varying definitions used, and the difficulty in defining such problems particularly because they depend on the perception of people witnessing such behaviours (Deb et al., 2001). It may also be the result of different measurement instruments being used. Prevalence rates vary from 5.7% to as high as 64% (Kiernan & Qureshi, 1993; Kiernan, Reeves & Albortz, 1995; Qureshi, 1991/2, 1993, 1994; Emerson et al., 1995; Qureshi & Alborg, 1992; Mansell, 1993; Smith et al., 1994; Jacobson & Janicki, 1985; Koller et al., 1983; Deb & Hunter, 1991a; Harris, 1993; Sigafos et al., 1994; Emerson et al., 1997; Jacobson, 1982; Borthwick-Duffy, 1994; Emerson & Bromley, 1995).

For example, Emerson et al., (1995) reported a rate of 6.1% for people defined as having an intellectual disability in North West England and Qureshi & Alborg (1992) reported a rate of approximately 7%. Sigafos et al., (1994) in a study of 2412 people with intellectual disability, found that 11% showed aggressive behaviour although a much higher number displayed self-injurious behaviour (34%). More recently, Emerson et al., (2001) found that 10-15% of people in contact with educational, health or social care services for people with intellectual disability in two areas of England displayed challenging behaviour, with 5-10% displaying more demanding challenging behaviours.

Several studies report very high rates of challenging behaviour. Smith et al., (1996) in a UK study reported behaviour disorder in 64% of their study population. Jacobson and Janicki (1985) found it to be 57-60%. Koller et al., (1983) found 59% of a population-based sample of people with intellectual disability had behavioural disorder, while Deb & Hunter (1991a) found in a study of 300 adults with intellectual disability, half of whom had epilepsy, that 55% had behavioural problems. Deb et al., (2001) in a recent study of 101 adults between 16 and 64 years in Wales found that 60.4% had at least one behaviour disorder. Twenty-three percent displayed aggression, 24% self-injurious behaviour, 36% temper tantrums, 26% overactivity, 29% screaming, 38% attention-seeking behaviour, 20% objectionable habits, 18% night-time disturbance and 12% showed destructiveness.

People exhibiting challenging behaviour often display more than one form of this behaviour. Emerson et al., (2001) found that the majority of people showed two or more forms, which included self-injury, aggression, destructive behaviour and 'other' behaviour. Similarly, in an earlier study Emerson (1995) found that 44% displayed more than one form of challenging behaviour, with this elevating to 79% for people with more severe challenging behaviours. Other studies support these findings (eg. Harris, 1993; Joyce et al., 2001; Murphy et al., 1993; Sigafos et al., 1994).

Measures:

Measures that have been used to assess challenging behaviour include:

- Checklist of Challenging Behaviour
- Developmental Behaviour Checklist
- Reiss Screen for Maladaptive Behaviour
- Checklist for Challenging Behaviours (CCB)

Psychopathology Instrument for Mentally Retarded Adults (PIMRA)
Behavior Problems Inventory (BPI-01)
Scales of Independent Behaviour (SIB-R)
Vineland Maladaptive Behaviour Scale
Disability Assessment Schedule
Clinical Behaviour Checklist for Persons with Intellectual Disabilities (CBCPID)
Yudofsky's Overt Aggression Scale
Behaviour Problem Inventory

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Indicator:

Self-Injury as a component of Challenging Behaviour

Definition:

Self-injurious behaviour is a prevalent and disabling disorder among adults with intellectual disability (Collacott et al., 1998). It is a highly problematic and damaging behaviour with profound implications for an individual's quality of life (Symons, Koppekin, & Wehby, 1999) and health (Mikkelsen, 1986; Wieseler, Hanson & Nord, 1995). It can lead to increased risk of institutionalisation (Lakin et al., 1983) and to exclusion from community-based educational services and vocational training (Shlalock et al., 1985). Although definitions of self-injury vary, they generally include the requirement that the actions exhibited by the individual cause damage to the self (Hillery, 1999).

Correlates:

Few epidemiological studies have been carried out examining the disabling and poorly understood disorder in adults with intellectual disability (Collacott et al., 1998). Existing studies however, have revealed several correlates.

Self-injurious behaviour has been found to be more common in individuals with severe or profound intellectual disability (Deb et al., 2001; Kahng et al., 2002; Read, 1998; Matson et al., 1997; Sigafos, 1995; Kebbon & Winddahl, 1986). Kebbon and Winddahl (1986) for example, found in a sample of 1,198 individuals displaying self-injurious behaviour in Sweden, that 87.2% were classified as having severe or profound intellectual disability.

Studies show that self-injury is more commonly found in individuals with a lower chronological age, lower developmental quotient, a higher frequency of autistic symptoms (Collacott et al., 1998), and in those with social skills deficits (Duncan et al., 1999) and poor communication skills (Deb et al., 2001; Emerson et al., 2001). Emerson et al., (2001) report that individuals with more demanding challenging behaviour, which includes self-injury, are more likely to need greater levels of assistance in eating, dressing, and washing and are more likely to be incontinent.

Self-injury has been associated with a wide range of maladaptive behaviours including challenging behaviour (Emerson et al., 2001; Kiernan & Alborz, 1996) and compulsive behaviour (Bodfish et al., 1995;

Oliver & Petty, 2002). Additionally, concurrent sleep problems have been shown to be significantly more prevalent in individuals displaying self-injury (Brylewski & Wiggs, 1999; Matson et al., 1997; Symons, Davis & Thompson, 2001), although the nature of such links remains unclear (Brylewski & Wiggs, 1999).

Studies examining gender differences in self-injury have reported mixed findings. In a 35-year review of the literature, Kahng et al., (2002) found greater prevalence amongst males. Additionally, Emerson et al., (2001), in a total population study of the prevalence of challenging behaviour also found that two-thirds of participants displaying disruptive or socially unacceptable behaviour, which included self-injury, were males. Other studies however have shown significant associations with female gender (Deb et al., 2001) or have yielded no gender differences (Collacott et al., 1998).

Interventions:

Psychological interventions to combat self-injury have developed over the past 30 years (Halliday & Mackerell, 1998) with a slight increase in the use of reinforcement-based interventions in contrast to punishment-based interventions (Kahng, Iwata & Lewin, 2002). Although several behavioural interventions have been found to be effective, most service users are unlikely to receive such help, but rather are more likely to be medicated or restrained (Emerson, 1992). Oliver et al., (1987) found in a population of 616 adults and children with self-injurious behaviour that only 2% were enrolled in formal psychological treatment programmes, while nearly half were receiving psychotropic medication. Furthermore, although evidence supports the efficacy of both psychopharmacology and applied behaviour analytic approaches, these are seldom combined in intervention studies (Oliver & Petty, 2002).

Emerson (1992) believes that intervention should be provided in the least restrictive manner, and that attention should be focussed on helping the service user to develop alternative competing behaviours to self-injury. Halliday & Mackerell (1998) advocate a multi-disciplinary approach, which recognises the multi-factorial nature of self-injury and addresses comprehensively the variety of factors contributing to the development and maintenance of self-injury.

Prevalence:

Individuals with intellectual disability are more likely to present with self-injurious behaviour than individuals without intellectual disability (Hurley, Folstein & Lam, 2003). Prevalence figures vary widely across studies (Emerson et al., 2001; Collacott et al., 1998; Deb et al., 2001; Oliver et al., 1987; Rojahn, 1986; Bodfish et al., 1995) ranging from as low as 1.7% to 46.7%. (Rojahn, 1986; Bodfish et al., 1995). This disparity is largely as a result of the methodology of the studies, the definition used and the populations studied (Hillery, 1999).

For example, several studies suggest that self-injurious behaviour is higher in institutional settings (Kebbon & Winddahl, 1986; Oliver et al., 1987). Oliver et al., (1987) found that 50% of individuals displaying self-injurious behaviour lived in hospitals, compared with 28% in non-hospital residential care and 21% living at home. Similarly, Kebbon and Winddahl (1986) reported that 71.3% of people with self-injurious behaviour were living in institutions. While Rojahn (1986) in a sample of 25,872 non-institutionalised people with intellectual disability in Germany, found the prevalence of self-injury to be as low as 1.7%. Hillery and Mulcahy (1997) however found that the occurrence self-injurious behaviour was not related to environment but that severity was greater in those living in residential centres. This reinforces Emerson's (1992) belief that little direct evidence exists to support the view that institutional environments are a major cause of self-injurious behaviour.

Other studies report prevalence rates of 4% (Sigafos et al., 1994; Emerson et al., 2001), between 4 and 10% (Oliver & Petty, 2002), 17.4% (Collacott et al., 1998) and 24% (Deb et al., 2001). Bodfish et al., (1995) reports the rate at 46.6% in a sample of people with severe or profound intellectual disability. According to Hillery (1999), in order for future epidemiological studies to be useful for furthering international approaches to self-injurious behaviour, consensus must occur on the parameters for choosing populations for study.

Measures:

Measures that have been used to assess self-injury include:

The Disability Assessment Schedule

Questions about Behaviour Function Scale

Diagnostic assessment for severely handicapped II
Self-injury behavioural understanding questionnaire
Self-injury/self-restraint checklist

Self-injurious behaviour has negative ramifications for both the physical health and psychological well-being of individuals with intellectual disability. Early intervention along with a proactive approach to prevention (Oliver, 1993) is paramount. Further information regarding self-injurious behaviour and particularly its treatment, can be found on the Database Problem Behaviour, which includes 885 empirical studies (Duker et al., 1996).

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5.3.1.14: Indicator 3.3. **Psychotropic Medication Use**

Definition:

Psychotropic medication use may be defined as the percentage of the population who have used anti-psychotic medication prescribed by a physician during the past (surveys specify either A: two weeks or B: one month period). It may also be the proportion of respondents taking more than one medication and proportion of respondents receiving a review of their medication on a three- month cycle as recommended by IASSID (Lennox et al., 2002).

Correlates:

Stolker et al., (2002) found in a study of ,2052 people with intellectual disability living in a group home residence that young age as well as psychotic, anxiety and aggressive symptoms were significantly associated with the use of anti-psychotics and anti-depressants. In addition, those with problematic behaviour used multiple drugs (17.3%) more often than a control group (7.3%).

Kiernan et al., (1995) found that the use of anti-psychotics was especially prevalent in institutions and other care facilities. Similarly, Robertson et al., (2000) found differences between forms of residential provision in rates of medication receipt. They suggest that while the receipt of anti-depressants is predicted by symptoms of mental health problems, the receipt of anti-psychotics and hypnotics/anxiolytics is predicted by variables related to challenging behaviour.

Concerns:

The high use of medication, particularly neuroleptics amongst people with intellectual disabilities is an issue of international concern (Webb & Rogers, 2002). Prevalence rates for mental health problems have been found to range from approximately 20-30% and yet the use of neuroleptics is often higher. According to Webb and Rogers (2002) the use of neuroleptics is much higher in New Zealand than the prevalence of mental illness.

The reasons for this may be largely due to the persistent problem of overuse of neuroleptic medications for behaviour management where people with intellectual disabilities are prescribed anti-psychotic medication for behavioural purposes rather than for mental health related problems (Reiss & Aman, 1998; Wressell et al., 1990; Molyneaux et al., 2000; Robertson et al., 2000). However, the effectiveness of these drugs in reducing maladaptive behaviour is questionable, since a systematic review of the literature provided no evidence for the benefit of these drugs for people with intellectual disability and challenging behaviour (Brylewski & Duggan, 1998). Their use for such purposes is therefore a controversial one (Santosh & Baird, 1999; Deb & Weston, 2000; Aman et al., 2000). As a result, a reduction has occurred in the number of prescriptions for these medications in the United States (Briggs, 1989; Poindexter, 1989), although Emerson et al., (1997) reported an increase in a longitudinal study carried out in England (cited in Ahmed, 2000). Both Ahmed et al., (2000) and Bradford (1996) believe that a large proportion of these people can have their medication reduced or withdrawn.

A further concern is the lack of training received by direct service staff in the area of drug treatment. According to Christian et al., (1999), this lack of training represents a barrier to appropriate monitoring and management of pharmacotherapy for people with intellectual disabilities, and they therefore advocate for the establishment of a systematic training programme educating direct service staff about psychotropic medication.

Prevalence:

Studies have shown that people with intellectual disability are more likely to be taking prescribed medication than the general population (Wilson & Haire, 1990). Studies have been published on the use of many drugs for behaviour disorder, which includes anti-psychotics, anti-depressants, antiepileptics, mood stabilisers, psychostimulants, beta-blockers, psycho-stimulants, beta-blockers, opioid antagonists and anti-anxiety drugs (Deb, 2003). In particular, a high prevalence in the use of psychotropic medication is evident

among people with intellectual disability (King, 2002), with anti-psychotic drugs appearing to be the most commonly prescribed type of medication (Spreat et al., 1997).

The prevalence rate for use of psychotropic medication varies between 20% (Anderson & Polister, 1993) to as high as 66.3% (Hogg, 1992). Several studies have found the rate to lie close to 40% (Burd et al., 1997; Spreat et al., 1997). For example, Spreat et al., (1997) found in a statewide survey in Oklahoma in the US, that 22% of adults with intellectual disability were prescribed anti-psychotics, 9.3% anxiolytics and 5.9% were taking anti-depressants.

Clarke et al., (1990) found that 36% of adults with intellectual disability who did not have a diagnosis of a mental health problem were receiving psychotropic medication. Deb and Fraser (1994) argue that 14-30% of prescribed psychotropic medications are administered to control behaviour disorders. Hogg (1992) reported a rate of 66.3% for the use of psychotropic or anti-convulsant drugs, however since this study applied only to children and adults with profound intellectual disability and multiple physical and sensory impairments, the prevalence is unlikely to be this high across the population of intellectually disabled.

Webb (1996) found in a New Zealand study of IHC residents that 54% of people were taking neuroleptic medication. Sixty percent of this group were taking two or more medications, 27% were taking three or more, and 10% were taking four or more concurrent neuroleptic medications. Rogers and Webb (2001) found medication use high in people with high health needs, with an average of 3.3 medications per person. These medications included mainly laxatives, inhalers, shampoos/creams, anticonvulsants, mutivites and benzodiazepines. Similarly, Anderson and Polister (1993) found a high rate of polypharmacy in a study of psychotropic medication use in older adults. Twenty percent were taking 3 or more medications with primary central nervous system effects. The authors found that the potential for additive drug effects or other drug interactions was clearly present, while the diagnosis of functionally impairing adverse drug effect was made only in adults in whom alterations of medication regimen were possible, which resulted in functional improvement (Henderson & Davidson, 2000).

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5.3.1.15: Indicator 4.1.

Hospitalisation & Contact with Health Care Professionals

Definition:

Hospitalisation may be defined as the act or process of being hospitalised (Journal of the American Medical Association)

Correlates:

The paucity of studies examining hospitalisation in people with intellectual disability makes it difficult to establish any given correlates. No gender differences have been shown (Sherrard, Tonge & Ozanne-Smith, 2001). Lin, Wu and Lee (2003) in a recent study of outpatient utilization in Taiwan found that the need for outpatient care was determined by a variety of factors including age, type of intellectual disability, the place of medical treatment, having a family physician, accessibility of medical care, the time-consuming nature of medical visits, having an illness, intellectual disability accompanied by other disabilities and lastly, the need for rehabilitative care.

Prevalence:

Despite the high prevalence of health related problems in people with intellectual disability, very little is known about the rates of hospitalisation amongst this population. The limited number of existing studies, however suggest, that rates may be higher in people with intellectual disability compared to the general population. Beange, McElduff & Baker (1995), for example, found significantly increased rates of hospitalisation in 202 people with intellectual disability in Northern Sydney compared to the local population. Likewise, in a study of injury in young people with intellectual disability in Australia, Sherrard, Tonge and Ozanne-Smith (2001), found that the rate of injury hospitalisation was twice that of the general population, with falls being more common than transport or intentional injury. Wang, McDermott & Sease (2002) similarly found that admission to hospital for injury was more likely to be from a fall than a motor vehicle crash. However the authors also report that people with intellectual disability had a lower proportion of accident and emergency visits related to injury and were less likely to have multiple A&E visits for injuries in comparison to the general population.

Lin, Wu & Lee (2003) in their study of outpatient care utilization in Taiwan used a cross-sectional survey of 1,390 people with intellectual disability and found that people with intellectual disability were likely to make more outpatient visits per year than members of the general population. The average monthly number of outpatient visits per person was 2.18 (approximately 26 visits per year), with paediatric clinics being the most frequently utilised.

Psychiatric Admission: Previous studies have indicated a higher prevalence of mental health problems among people with intellectual disability (Lund, 1985; Holland & Koot, 1998), however again it is not known how many actually receive psychiatric inpatient care and treatment. Gustafsson (1997) carried out a study in Sweden to investigate the prevalence of people with intellectual disability admitted to general hospital psychiatric units and reported a low frequency of psychiatric care utilisation among people with intellectual disability in contrast to corresponding figures in the general population. He discussed the findings in relation to how the level of intellectual disability might influence referral or diagnoses, the length of admissions, and the support provided within special services to people with intellectual disability and mental health problems. This finding of low utilisation may represent an under utilisation of care, due to environmental and individual factors that serve as barriers to such care. Services for those with a dual diagnosis have been found to be lacking in access, availability, and adequacy in the US (Jacobson, 1998) and the need for improved access to special psychiatric services for those with intellectual disability has been documented (Menolascino et al., 1986).

The findings on hospitalisation, although limited, indicate a heightened need for healthcare provision for adults with intellectual disability, with particular attention to injury prevention programs, which may reduce the care and cost resulting from injury.

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5.3.1.16: Indicator 4.2. **Health Check**

Definition:

Medical check-up refers to visits to a medical doctor, such as a General Practitioner or a Specialist during the last 12 months for health checks.

Introduction:

There has been a considerable increase in the life expectancy of people with intellectual disability over the past 30 years, and such changing patterns of morbidity and mortality have led to an increasing recognition of the health needs of this population (Barr et al., 1999). As a result, there is has become a greater need for health screening amongst this population.

The Role of GP's in Medical Provision:

Significant change has occurred in the provision of specialist health services to people with intellectual disability, with the move away from institutions to an emphasis on care in the community (Bailey & Cooper, 1997; Eastgate & Lennox, 2003). Consequently, the provision of primary medical care for these people is becoming primarily the responsibility of community services.

Several studies have addressed GP's attitudes to, and perception of their role in, the care of people with intellectual disability (Bond et al., 1997; Dovey & Webb, 2000; Gill, Kroese & Rose, 2002). Findings suggest that GP's largely accept their role as primary health care providers for people with intellectual disability (Kerr, Dunstan & Thapar, 1996; Dovey & Webb, 2000), however several negative attitudes prevail. For example, GP's feel that the move from hospital to community residencies will greatly increase their workload (Bond et al., 1997), and are generally not in favour of playing a role in health promotion and health screening initiatives for people with intellectual disability (Bond et al., 1997; Kerr, Dunstan & Thapar, 1996), such as annual health checks and assessing hearing and eyesight, and they are reluctant to adapt their behaviour to accommodate this group (Gill, Kroese & Rose, 2002).

Thus these negative attitudes, along with a limited awareness of the health care needs of people with intellectual disability (Thornton, 1996) may in part contribute to the current inadequacy of primary health care. Possible additional contributing factors include negative attitudes towards the concept of normalisation, inadequate education (Dovey & Webb, 2000; Turner & Moss, 1996), a shortfall in financial and human resources, and poor collaboration with the specialist team (Thornton, 1996).

However, the fact that people with intellectual disability have significantly more health problems compared to the general population (Lin, Wu & Lee, 2003; Lantman-De Valk et al., 2000), necessitates a more proactive attitude by GP's towards this group (Lantman-De Valk et al., 2000).

Correlates:

Very few studies highlight any correlates to medical check ups. A study of breast cancer screening in women with intellectual disabilities showed failure to use screening services was highest in unmarried women and was positively associated with severity of disability, the presence of physical disabilities and urban residence.

The issue of residency has surfaced in several studies, with Stanfield et al., (2003) in a recent study of oral healthcare in clients following relocation from hospital to the community, finding that attendance patterns with a dentist were less regular for residents in the community. Operative dental treatment and oral health education were also lower for this group. Similarly, Halstead et al., (2000) found primary care consultations lower in community residents compared to NHS Trust residents, with 42% of community clients not having been seen in a year. They also found that those with a severe disability and those with a behavioural disturbance more frequently saw the doctor for a variety of physical problems.

Lastly, Stein & Ball (1999) in a cross-sectional case note survey found that consultation rates with GP's were highest in those living in staffed group homes. Additionally, the authors found that consultation rates were independent of sex and age.

Intervention:

Evidence of health gains have been revealed as a result of systematic health checks, and early identification and treatment of health problems are believed to enhance quality of life for both people with intellectual disabilities and their carers (Eastgate & Lennox, 2003; Van Allen, Fung, & Jurenka, 1999). Bollard (1999) highlighted the clinical effectiveness of performing checks within the primary health teams (PHCTs). Martin et al., (1997) in a study of health gains through health checks found that significant gains were noted with regard to physical disorders, while Webb & Rogers (1999) in a study of health screening in New Zealand found that the introduction of annual health screens for people with intellectual disability in residential facilities resulted in 73% of screened people requiring follow-up interventions, thus reinforcing the importance of health checks.

Kapell et al., (1998) emphasize the importance of increased access to health care for the screening and treatment of age-related disorders, to prevent the development or delay the impact of certain conditions, such as thyroid disorders, sensory impairment and nonischemic heart disorders and to promote healthy ageing.

Prevalence:

The growing body of literature on the medical needs of people with intellectual disability indicates a wide range of unmet needs. In a recent review of the literature, from 1992 to 2002, on health disparities and intellectual disability, Fisher (2004) found deficiencies in health screening in people with intellectual disability. In fact people with intellectual disability have been shown to consult their GP's less than others with special needs including those under 5 years of age and those over 75 years (Jones & Kerr, 1997).

Debate exists however as to whether people with ID see their doctor more or less than the general population, due to conflicting estimates of consultation rates in the literature. Some studies have found no difference in consultation rates between people with intellectual disability and the general population (Whitfield, Langan & Russell, 1996; Wilson & Haire, 1990), although people with intellectual disability have been found to receive less preventative care and to consult for different types of problems (Whitfield, Langan & Russell, 1996).

Other studies indicate that the consultation rates are higher in people with intellectual disability (Stein & Ball, 1999; Lin, Wu, & Lee, 2003; Hensel et al., 2002). For example, Stein & Ball (1999) found in a sample of 112 adults with intellectual disability, that 80% had contact with their GP's, 18% had consulted on average more than once every 2 months, and the average contact rate for the sample was 4.6 per person per year. According to Howell (1986) four or more consultations per year with a GP constitutes an 'adequate' consultation rate.

Numerous studies however support the view that people with intellectual disability have less contact with GP's compared to the general population. Studies suggest that between 50 and 80% of people with intellectual disability have had contact with their primary care provider in the previous 12 months (Singer et al., 1986; Howells, 1986; Wilson & Haire, 1990; Lennox & Kerr, 1997; Piachaud et al., 1998). Wilson & Haire (1990) found that people with intellectual disability living in the community had an average of 2.7 medical visits per year, compared with a national average of 3 for men and 5 for women. They also report that 24% had not seen their GP in a year. Halstead et al., (2000) similarly, report contact rates of 2.4 for a community- based sample, with 42% of people in their sample not having been seen or examined in a year.

Several small community-based studies have found that only 30-47% of people with intellectual disability receive care from specialists (Singer et al., 1986; Allison et al., 2000; Piachaud et al., 1998), despite the finding in one study that 92% of people had medical needs that required specialist medical care (Minihan, 1986).

The need for further action in relation to cardiovascular status, sensory deficits, mobility, mental health and aspects of sexual health is evident in the literature (Barr et al., 1999; Kerr et al., 2003; Langan, Whitfield & Russell, 1994;). Numerous studies have highlighted the need for greater attention to be paid to hearing and sight tests (Langan, Whitfield & Russell, 1994; Kerr et al., 2003; Evenhuis et al., 2001; Woodhouse, Adler & Duignan, 2003; Mc Cullough et al., 1996; Warburg, 2001). For example, Block, Beckerman, & Berman (1997) in a study of vision profiles of the athletes in the 1995 Special Olympics found that 65% of 905

participants involved in the study had not received eye care for more than 3 years, despite the presence of ocular health problems such as refractive errors, poor distance monocular acuity and strabismus. Similarly, at the Special Olympics in 1999, the Special Olympics Opening Eyes Vision Health Program found that 32% of athletes had never had an eye exam and almost 20% had not had their last eye exam within the 2 previous years (SOI, 1999a in Horwitz et al., 2001). Early diagnosis, and frequent assessments and intervention can however prevent long- term effects of increased prevalence of uncorrected visual anomalies (Woodruff et al., 1980; Bartlett, 1987, in Horwitz et al., 2002).

Studies of breast cancer screening have also shown that only about a third of women with intellectual disability have used mammographic screening (Sullivan et al., 2003; Davies & Webb, 2000), compared to 54.6% in the general population (Sullivan et al., 2003) with general practitioners and practice nurses playing very minor roles in breast screening these women (Davies & Webb, 2000).

Similarly, deficits in mental health care are evident in the literature (Mc Carthy & Boyd, 2002; Cooper, 1997). Cooper (1997) found in an English study that 75% of those with mental health problems had received no treatment. While Jacobson (1998) found in a sample of 45,810 adults with intellectual disability that 37% of participants had no contact with a psychologist during the past year, and only 26% had at least weekly contact.

Measures:

Measures that have been used to assess health in medical check-ups include:

The Cardiff Health Check
The St. Georges Health Check
Structured Health Check

The literature relating to primary health care services suggests that professional training and access to services, needs to be improved for people with intellectual disability (Turner & Moss, 1996).

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5.3.1.17: Indicator 4.3. **Health Promotion**

Definition:

Health promotion, as defined by the Ottawa Charter for Health Promotion (1986) refers to the “process of enabling people to increase control over, and improve, their health”

(see http://www.euro.who.int/AboutWHO/Policy/20010827_2) accessed 22.10.04)

Correlates:

Only one study was found which referred to correlates of health promotion. A study of breast cancer screening in 2,370 women with intellectual disabilities in Australia showed that failure to use screening services was highest in unmarried women and was positively associated with severity of disability, the presence of physical disabilities and urban residence (Sullivan et al., 2003).

Prevalence:

Health promotion is a critically important area for people with intellectual disabilities given the increase in life expectancy for this population in recent decades. However, despite this, a major lack of research exists examining either the prevalence of health promotion for this group or the necessity of having health promotion strategies in place to address the numerous medical needs of these people. The few existing studies indicate that health screening and health promotion for this population is less than adequate (Whitfield, Langan & Russell, 1996; Kerr et al., 1996a).

In the United Kingdom, the Department of Health are recognising the importance of health promotion as a means of improving the health of people with intellectual disability. They emphasize the need to involve carers, parents, health professionals, teachers, social services staff and people with intellectual disabilities themselves in health promotion, however the lack of specific guidance or legislation has been criticised on the grounds that it has led to patchy health promotion services at local level (Turner & Hatton, 1998). A survey of 149 UK provider organisations found that only 25% had developed a health promotion policy specifically for people with intellectual disabilities (Turner, 1996). Several other researchers advocate a holistic approach to health promotion (Marks and Hellar, 2003; Marshall et al., 2003). Marks and Hellar (2003) also assert that at the core of health promotion is the need to address issues of poverty, poor health, and unemployment while accounting for social, cultural and economic differences.

Barriers against achieving a holistic approach to health promotion however include the reluctance of GP's to play a role in health promotion and health screening initiatives for people with intellectual disabilities (Bond et al., 1997; Kerr, Dunstan & Thapar, 1996). A case-control study of GP's care of adults with intellectual disability found that GP's took significantly fewer recordings of blood pressure and cervical cytology tests than that of the general population (Whitfield et al., 1996).

Health promotion for cancer is one of a number of areas that is neglected and under-resourced in Britain, because it is seen as less relevant to people with intellectual disabilities despite evidence that independent living may increase such risks (Turner & Hatton, 1998). Furthermore, sexuality is an area often ignored for people with intellectual disability, yet there is a need to promote healthy sexuality in these people (Ailey et al., 2003). McRae (1997) in a study of health care needs in women with intellectual disability found that preventive and well-woman needs were not being met. Studies of breast cancer screening in women have shown that only about a third of women with intellectual disability have used mammographic screening (Sullivan et al., 2003; Davies & Webb, 2000), compared to 54.6% in the general population (Sullivan et al., 2003) with general practitioners and practice nurses playing very minor roles in breast screening of these women (Davies & Webb, 2000).

Despite it being well known that people with intellectual disability are at high risk of contracting the hepatitis B virus, universal vaccine strategies have not been implemented even though epidemiological data indicate the effectiveness and efficacy of vaccinations (Vellinga et al., 1999). Arulrajan et al., (1992) found that initial screening for hepatitis B amongst a hospital population of people with intellectual disabilities in Southampton, UK, provided valuable information, was cost effective and was better than a blanket immunization policy for all residents. Furthermore, Tyler and Bourguet (1997) assert that physicians need to look for Hepatitis B among newly deinstitutionalized people with intellectual disability.

A study of health characteristics and behaviours of adults with mental retardation residing in three living arrangements found that in terms of cholesterol, people living in group homes and family homes had higher cholesterol levels. The authors therefore argue for health promotion and disease prevention initiatives for people living in these higher risk environments (Rimmer et al., 1995).

There is an urgent need for further studies investigating health promotion in people with intellectual disabilities, given that this group experiences a far higher rate of ill-health in comparison to the general population.

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5.3.1.18: Indicator 4.4. **Special Training for Physicians**

Definition:

This indicator seeks to examine the presence of specific training for primary care physicians in treating patients with intellectual disability. The literature review does extend beyond this group of health care professionals where deemed relevant.

Attitudes to Training:

Goodenough & Hole-Goodenough (1997) in a study of US family practice residencies found little enthusiasm among residency directors about the need for training in the care of people with intellectual disability, with low value being placed on training for helping families access services, behaviour management and comprehensive long-term planning, which are areas family physicians are most often faced with.

Attitudes towards people with intellectual disability and attitudes towards training in the field may go hand in hand, with one influencing the other. Wolraich & Siperstein (1983) suggest that training issues may explain differential attitudes of health professionals towards people with intellectual disability. They found, for example, that paediatricians were significantly more pessimistic about the ultimate abilities of adults with intellectual disability compared with psychologists and educators, and they asserted that such differences may be the result of training differences. Similarly, a British study of stigmatisation of people with intellectual disability in general hospitals, asserted that nurses were likely to retain negative attitudes towards people with intellectual disability in the absence of education and training (Shanley & Guest, 1995).

A recent US study of general psychiatry residents' perceptions of specialised training that they received on an inpatient unit for individuals with intellectual disability and mental health problems, found that 98% of participants believed that such training was useful, 56% rated training as sufficient preparation, and 84% reported that training should be required during psychiatric residencies (Reinblatt et al., 2004). Direct supervision and didactic sessions with a psychiatrist experienced in the field of intellectual disability were cited as the most useful elements of training.

Thus these findings reinforce the view that health professionals who have received specialised training tend to regard it as worthwhile and necessary. Additionally, a study of GPs' attitudes towards healthcare for people with intellectual disability found that simply increasing GPs' awareness of their practice behaviour has a variety of important implications for training and ongoing education (Lennox & Diggins, 2000).

Impact of Training:

Several studies have examined the impact of various staff training programs and found positive results. Felce et al., (2000) and Jones et al., (2001) both assessed the effectiveness of active support training in staffed community residences. A package of procedures was implemented which included activity planning, support planning, and training on providing effective assistance, and it was found that active support resulted in significant increases in assistance received by residents and in their engagement in activities.

Harper & Wadsworth (1992) investigated the benefit of an educational program focussing on health care professionals use of basic communication skills when providing health care information to adults with intellectual disability. The program included a self-study instructional text and a 20-minute companion video providing methods of communicating with a person with intellectual disability in medical and dental care settings. They found that resident physicians, medical students, nurses and nursing assistants all improved their communication skills, knew more about intellectual disability, and were more proactive in health care interviews following training.

Lastly, a state-wide public and professional education program on Fragile X Syndrome in New Jersey found that the program resulted in increased efforts at diagnostic screening, provision of client and family support services and prevention (Keenan et al., 1992).

Some studies however have found no effect for educational and training level of staff. Duker et al., (1999) in a Dutch study found that educational and training level did not differentially affect resident-oriented care, such as stimulative custodial care, recreation and training. Similarly, a higher proportion of qualified staff in community housing schemes was not shown to be a positive attribute by Felce, Lowe & Jones (2002) in a recent study, but rather greater prior experience was associated with staff spending more time directly with residents and residents receiving more assistance.

Prevalence:

There is a general lack of familiarity with intellectual disability and little exposure to interdisciplinary training on the part of primary care physicians (Birenbaum, 1995; Harper & Wadsworth, 1992). Little effort is directed at training health care professionals in behaviours and attitudes effective in communicating with people with intellectual disability (Harper & Wadsworth, 1992). Training professionals and direct care staff remains a challenge to purchasers and providers of services for intellectual disability and mental health in both the UK and the US (Bouras & Szymanski, 1997; Fenton et al., 2003; Turner & Moss, 1996).

Research on specialised training in the field of intellectual disability is largely descriptive in nature. Actual figures on the prevalence of training are limited. A study of ten medical schools in Australia found that half of the schools displayed significant gaps in their teaching when compared to the ideal curriculum on intellectual disability, with only a few comprehensively covering all areas of training (Lennox & Diggins, 1999).

General Practitioners: Studies of GP's indicate significant gaps in specialised training (Cook & Lennox, 2000; Lennox & Diggins, 2000; Phillips, Morris & Davis, 2004; Iacono et al., 2003; Einfield, 1996; Singh, 1997). GP's are generally untrained at either undergraduate or postgraduate level, although several studies have shown they express the desire to receive improved specialist support (Minihan et al., 1997; Lennox & Chaplin, 1996; Lennox et al., 1997, in Lennox et al., 2001; Singh, 1997). Philips, Morris & Davis (2004) recently sought to identify the educational needs of 252 practicing GPs in nine health areas in Australia and found that the health areas on which many GPs reported to be inadequately trained mirrored the areas which were perceived as being of poor standard. These areas were behavioural and psychiatric conditions, human relations and sexuality issues, complex medical problems, and preventative and primary health care. Over 60% of GPs rated their prior training as inadequate and ninety-four percent of participants were interested in receiving further education, particularly in behavioural and psychiatric conditions, human relations and sexuality issues. Similarly, Lennox et al., (1997) found that over 75% of a representative sample of Australian GPs consider themselves inadequately trained, with only 10% having received postgraduate training. Ninety-three percent believed that further training would lead improved healthcare for this population. A study of GP's in England, Wales, and Northern Ireland, found as little as 5% of GPs had received any formal training in intellectual disability (Singh, 1997).

Cook & Lennox (2000) suggested a number of possible solutions to the current inadequacies of GPs provision of health care to this group such as improved GP registrar training, as well as a handbook on intellectual disabilities. According to the Royal Australian College of GPs (RACGP, 1998) and several researchers in adult education (Craig, 1990; Imel, 1994), identification of educational priorities through needs analysis is the first step in the development of an educational programme, thus creating a learner centred approach (Phillips et al., 2004).

Several studies have investigated training in intellectual disability within US family practice residencies (Goodenough & Hole-Goodenough, 1997; Tyler, Snyder & Zyzanski, 1999; Collins & Graham, 1980). Goodenough & Hole-Goodenough (1997) found that only 32% of family practice residency programmes taught related didactic sessions, 24% plan clinic patient care for this population, and 42% affiliate with a residential care facility. Psychiatrists also had more training than family practice residents. Another US study reported that 84% of programmes provided residents with one or more experiences and 60% instructed residents in this area (Tyler, Synder & Zyzanski, 1999). It has also been found that a larger proportion of paediatric than family practice programs teach diagnosis of intellectual disability, educational placement of people with intellectual disability, placement in special education, interdisciplinary teaming, and organisation of the school system (Collins & Graham, 1980).

Nurses & Therapists: There is a paucity of studies involving nurses and therapists, however the few existing studies indicate a lack of specialised training on intellectual disability for these health professionals (McConkey & Truesdale, 2000; Hahn, 2003; Slevin & Sines, 1996; Stanley, 1999). In a Northern Irish study of reactions of nurses and therapists in mainstream health services to contact with people with

intellectual disability, it was found that measures of confidence at meeting were significantly lower for people with intellectual disability than for those with physical disability, and both nurses and therapists felt unprepared and were more likely to seek advice on people with intellectual disability (McConkey & Truesdale, 2000). Thus, this suggests the need for greater education and training as advocated by the authors. Similarly, Hahn (2003) highlighted a number of pilot developmental disabilities nursing projects in North America and called for the need for greater integration of curriculum about nursing care of people with intellectual and developmental disabilities into basic nursing education at all levels. The need for greater training is further reinforced by the finding that from some studies of negative attitudes held by many health care professionals including nurses towards people with disability. Previous research indicates that nurses would welcome this intervention (Barr, 1990).

Psychiatric Training: Despite the high prevalence of people with intellectual disability who require care for mental health problems, general psychiatric residents are rarely formally trained to treat this population (Reinblatt et al., 2004). This issue has been addressed in several Canadian and Australian studies (Lennox & Chaplin, 1995; Lunsy & Bradley, 2001; Burge et al., 2002), although US and European data is lacking. Lunsy and Bradley (2001) for example, reported that less than 50% of Canadian psychiatric training programmes provide mandatory clinical experience in the field of intellectual disability, while another Canadian study found that 59% of senior psychiatry registrars believed that more training on developmental disability was needed in residency programmes (Burge et al., 2002).

Support Staff: Lastly, a recent study carried out on 119 people with intellectual disabilities' experience of accident and emergency departments and hospital wards, showed a great reliance on support staff during hospitalisations and follow up interviews with 11 participants, illustrated that hospital staff displayed a lack of skills and knowledge in intellectual disability (Iacono & Davis, 2003). Thus, it appears there is a clear need for more specialised training across all health professionals, including GPs, physicians, nurses, therapists, psychiatrist, care staff and hospital support staff.

Dentistry: A few US studies have assessed specialised dental training in the area of intellectual disability (Mouradian & Corbin, 2003; Romer, Dougherty & Amores-Lafleur, 1999; Wolff et al., 2004). Findings typically illustrate minimal training in intellectual disabilities in US dental schools. A study of pre-doctoral education in special dentistry across Canadian and US dental schools, for example, found that 53% of schools provided less than 5 hours didactic training in special care dentistry, and in 73% of schools, clinical training comprised of only 0-5% of pre-doctoral students' time (Romer, Dougherty & Amores-Lafleur, 1999). Similarly, a more recent study reported that 68% of participants received 5 hours or less of didactic training, 60% reported they had little or no confidence in providing care and 74.6% reported little or no preparation in providing care (Wolff, 2004).

An obvious lack of postgraduate/specialised training is evident across health professions from the literature. It is therefore important that educational programmes are developed based on the learning needs identified by health professionals.

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