

2. Health Inequality and Health Disparity among People with Intellectual Disability

2.1. Health Inequality and Health Disparity

Persons with intellectual disabilities experience a different level of health than their non-disabled peers. This health differential may be considered in two ways: health inequalities, a term generally used in Europe and with the WHO, and health disparities, which is almost exclusively used in the US. Health inequity refers to differences caused or facilitated by social or access issues and health disparity refers to differences due to underlying health pathologies. Both issues are increasingly important in public health policy (Graham, 2002) and have often been employed to explore regional and ethnic variation within and between countries. They also serve as outcome measures in accessing the effectiveness of health interventions.

In a seminal discussion document Whitehead (1990), asserted the importance of health disparities and inequalities, noting that disadvantage in health was closely linked to poor outcome across a range of health measures-not least mortality. Furthermore, Whitehead recognised that the concept had both medical and moral/ethical aspects. The same author identified seven main determinants of health differential, as listed below.

Whitehead's Determinants of Health Differences

1. Natural biological variation
2. Health-damaging behaviour if freely chosen, such as participation in certain sports and behaviours.
3. Transient advantage to one group when they are first to adopt a health promoting behaviour (as long as other groups can catch up fairly soon)
4. Health damaging behaviour where the degree of choice of lifestyles is greatly restricted
5. Exposure to unhealthy, stressful living and working conditions
6. Inadequate access to essential health and other public services
7. Natural selection or health-related social mobility involving the tendency for sick people

Whitehead's list highlights the complexity and inter-relatedness of health determinants which encompass both health inequity and health disparity concepts. Indeed, since identifying the cause of health differences is not necessarily an easy task, or even one that is addressed in the literature, the terms are used interchangeably in this report.

2. 2. Evidence of Health Inequalities and Health Disparities among people with Intellectual Disability

There is mounting evidence of the health disparity between persons with intellectual disabilities and their non-disabled peers. There have been several key sources for this evidence, including Special Olympics, the Office of the Surgeon General in the US, and a recently completed synthesis of peer-reviewed research literature.

2.2.1. Evidence from Special Olympics

Special Olympics, a non-for-profit organisation that promotes the acceptance of people with intellectual disability through sport, has been an important source of information on health inequities and disparities among people with intellectual disabilities. In 2000, Special Olympics commissioned a full review of literature examining the current health status of people with intellectual disability. The result, a publication entitled “The Health Status and Needs of Individuals with Mental Retardation” (Horwitz *et al.*, 2000; www.specialolympics.com) presents an evidence-base of health inequality and disparity across a range of health areas including physical health, mental health, sensory impairment, oral health and health care service utilisation. Examples from this literature are listed below:

- Obesity, for example, is reported as being more common among people with intellectual disability than in the general population with estimates ranging 29.5% to 50.5% (Rubin *et al.*, 1998; Rimmer *et al.*, 1993; Bell and Bhate, 1992; Simila & Niskanen, 1991).
- Cardiovascular fitness levels are cited as being lower among those with intellectual disability than the general population suggesting a more sedentary lifestyle (Fernall, 1993; Pitetti & Campbell, 1991).
- Vaccination levels of 77% for those with intellectual disability are lower than those reported for the general population at 91% (Schor *et al.*, 1981).
- Mental health disorders among those with intellectual disability are reported to occur at a rate 3-6 times higher than in the general population (Eaton & Menolascino, 1982; Walters *et al.*, 1995; Maino, 1996).
- The proportion of missing teeth to filled teeth is cited as being higher among individuals with intellectual disability when compared with the general population suggesting that extraction, rather than restoration, is the preferred choice of treatment (Svatun & Heloe, 1975; Nowak, 1984)
- Despite the increased prevalence of certain health conditions among people with intellectual disability, evidence suggests that individuals with intellectual disability do not receive preventative screenings (Ineichen & Russell, 1987; Beange & Bauman, 1990; Wilson & Haire, 1990; Kerr *et al.*, 1996; Jones & Kerr, 1997, Evenhuis *et al.*, 1997)

In addition to this review of literature, Special Olympics has commissioned other draft discussion papers highlighting disparities in health status and health services utilisation among those with intellectual disability. Regrettably, Johnson & Woll (2003) note that “this information has not been published in refereed journals, and the results have not been widely disseminated”.

2.2.2. Evidence from the US

Additional evidence of health inequity and disparity among people with intellectual disability comes from the United States. Following grave concerns relating to health status of people with an intellectual disability

the Surgeon General of the United States commissioned a ‘National Blueprint to Improve the Health of Persons with Mental Retardation’. The blueprint culminated in a national conference on Health Disparities and Mental Retardation and is published as *Closing the Gap: The Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation (2002)*. This document highlights the variation in health status and access to health care experienced by people with an intellectual disability in the USA. The report states:

Like other Americans, persons with mental retardation (MR) grow up, grow old, and need good health and health care services in their communities. But people with MR, their families, and their advocates report exceptional challenges in staying healthy and getting appropriate health services when they are sick. They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialised needs. (US Senate Appropriations Committee, Hearing Report No. 107-92

(U.S. Surgeon General’s Office, 2002: Closing the Gap: Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation; p. xi)

A vitally important aspect of this work was the development of action steps to address the issue. These include a call for the integration of health promotional strategies into the environments of people with intellectual disability, the inclusion of disability awareness training for health professionals, and an improvement in the overall quality of health care services provided for people with intellectual disability. In addition to these recommendations is a more fundamental call for greater understanding of the relationship between intellectual disability and health.

“The lack of population-based data on prevalence of MR (mental retardation) and the health status and service needs of this population impedes planning and allocating resources for their care. Failure to monitor the quality of their care hampers detection of prejudicial or inadequate treatment.....At the same time, individuals, family members, and health care providers need easily accessible, scientifically accurate, culturally relevant, and understandable information for prevention and health promotion, as well as for diagnostic and treatment decisions”

(U.S. Surgeon General’s Office, 2002: Closing the Gap; Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation p.5)

2.2.3. Recent review of research literature

Finally, a recent systematic review of the health inequalities and health care service provision experienced by people with intellectual disability has provided a valuable synthesis of the literature (Fisher, 2004). Peer-reviewed literature from 1992-2002 that specifically addressed issues of health disparity or gaps in service provision for people with intellectual disability was examined. Fifty-four articles were reviewed and classified into three categories: special health care needs, health promotion needs and unmet needs. The key findings in each of these categories are summarized below:

2.2.3.1. Special Health Care Needs

A total of 25 peer-reviewed articles were identified that examined issues relating to special health care needs. One of the most dominant themes emerging from these papers was that of mental health disorders. In fact, Fisher (2004) reports that over 50% of the publications in this category made reference to mental health issues. Specifically, “diagnostic overshadowing”, the fact that in the presence of an intellectual

disability, an accompanying mental health problem becomes less salient and significant, (Mason & Scior, 2004), was cited in numerous publications (Crews *et al.*, 1994; Gabriel, 1994; Glick & Zigler, 1995; Prosser *et al.*, 1998).

Visual and dental care needs were also present among the literature and were noted for being undetected and untreated (McCulloch *et al.*, 1996; Turner & Moss, 1996; Schultz *et al.*, 2001). Fisher (2004) notes that people with intellectual disability are doubly disadvantaged as dental or medical treatments may be withdrawn due to behavioural issues (Došen, 1993; Schultz *et al.*, 2001). The peer-reviewed articles reviewed by Fisher (2004) that relate to special health care needs are presented below.

Table 2.1: Special Health Care Needs for People with Intellectual Disability

Article	Country	Research base	Identified Health Care (HC) Need
Cooke, 1997	UK	↓=293	Cancer deaths: higher incidence of GI cancer
Crews <i>et al.</i> , 1994	USA	↓=1,273	Dual diagnosis with mental health; diagnostic overshadowing
Davidson <i>et al.</i> , 1994	USA	↓=199	Mental Health; aggressive behaviour, inadequate treatment
Durkin, 1996	USA		Residential needs & community supports
Evenhuis <i>et al.</i> , 1997	NL	↓=70	Special screening needs: hearing and visual
Frid <i>et al.</i> , 2001	Sweden	↓=211	Congenital heart disease in Down Syndrome
Gabriel, 1994	USA	↓=2	Dual diagnosis, need for education and treatment
Gill & Brown, 2000	USA		Need for routine gynaecological care
Glick & Zigler, 1995	USA	↓=112	Dual diagnosis, atypical symptom presentation
Howells, 1996	UK		Identified special needs, vulnerability to exploitation and abuse
Jacobson, 1998	USA	↓=44,810	Inadequate psychological services utilisation
Kennedy <i>et al.</i> , 1997	UK	↓=417	Nutrition needs/dysphagia issues
King, 1993	USA		Self-injury, mental health needs
McCarthy & Boyd, 2001	UK	↓=193	Mental health needs in Down Syndrome
McCulloch <i>et al.</i> , 1996	UK	↓=63	Undetected visual impairments
Meins, 1995	DK	↓=32	Atypical symptoms of depression, increased behaviour problems
Moss <i>et al.</i> , 1997	UK		Complex mental health needs, inadequate services
Nespoli <i>et al.</i> , 1993	Italy		Immunological aspects of Down's Syndrome
Prevatt, 1998	USA		Gynaecological needs, lack of education
Prosser <i>et al.</i> , 1998	UK	↓=68	Mental health issues, diagnostic overshadowing

Reiss 1993	USA		Mental illness among people with intellectual disability
Shultz <i>et al.</i> , 2001	USA		Dental issues, need for provider education
Temple <i>et al.</i> , 2001	Canada	↓=35	Alzheimer's in Down's Syndrome
Thompson 2001	USA		Need for future planning
Turner & Moss, 1996	UK		Identified risk factors: special screening needs

From Fisher (2004)

2.2.3.2. Health Promotion Needs for People with Intellectual Disability

Health promotion was the second category Fisher (2004) identified in the literature review. Common themes among these papers included the educational needs of health care workers (Grossman *et al.*, 2000; Evenhuis *et al.*, 1997), the need for comprehensive health care screening (Cooper, 1998; Lennox & Kerr, 1997; Došen, 1993), and the need for health promotion campaigns targeting general fitness among people with intellectual disability (Tracy & Hosken, 1997; Bell & Bhate, 1992). Papers identified through Fisher's review that examine these issues are presented below.

Table 2.2: Health Promotion Needs for People with Intellectual Disability

Article	Country	Research base	Identified Health Care (HC) Need
Barr <i>et al.</i> , 1999	Ireland	↓=373	Changing patterns of morbidity & mortality
Beange <i>et al.</i> , 1995	Australia	↓=202	Chronic health conditions undiagnosed or poorly managed: need for education
Bell & Bhate, 1992	UK	↓=183	Obesity prevalence and prevention strategies
Cooper 1998	UK	↓=134	Needs of older people & health care screening issues
Došen, 1993	NL		Need for mental health screening
Evenhuis <i>et al.</i> , 1997	NL	↓=70	Education need for active diagnosis & intervention of chronic health problems
Fernhall <i>et al.</i> , 1998	USA	↓=34	Need for cardiac fitness
Grossman <i>et al.</i> , 2000	USA		Provider education needs
Lancioni & O'Reilly, 1998	NL		Strategies to improve physical fitness & behavioural disorders
Lennox & Kerr, 1997	Australia		Needs for education & health screening
Martin <i>et al.</i> , 1997	UK	↓=60	Screening needs for chronic & mental health issues
Prasher, 1995	UK	↓=201	Prevention of obesity key for community dwelling residents, esp. those with Down's Syndrome

			those with Down's Syndrome
Rimmer, Braddock & Fujiura, 1994	USA	N=329	Health promotion & nutrition education needs for cardiovascular health
Tracy & Hosken, 1997	Australia	N=36	Smoking prevalence, need for education & prevention strategies
Webb & Rogers, 1999	New Zealand		Considerable health care needs; requiring screening programme development

From Fisher (2004)

2.2.3.3. Unmet Needs for People with Intellectual Disability

Fisher's (2004) third category of recent health related publications in the field of intellectual disability focus on unmet needs. Despite the increased physical and mental health problems experienced by people with intellectual disability, the literature suggests that they are less likely than the general public to receive adequate health care. Bond *et al.*, (1997) argue that primary health care professionals retain a perception that people with intellectual disability resident in the community require specialist health care services. This can result in individuals with intellectual disability falling between two health care systems and receiving neither. Some health care professionals inexperienced in providing treatment to people with intellectual disability report a level of discomfort in providing this care (Grossman *et al.*, 2000; Howells, 1996; Lennox & Kerr, 1997). Discrimination, stigmatisation and stereotypical beliefs regarding people with intellectual disability (Houghton, 2001; Parkes, 1996) have all been identified as factors contributing to unmet health care needs.

Table 2.3: Unmet Needs or Gaps in Care

Article	Country	Research base	Identified Health Care Need
Anderson <i>et al.</i> , 1998	USA		Effects of de-institutionalisation
Betz 2002	USA		MR policy paper, barriers to care
Bond <i>et al.</i> , 1997	UK	N=125	Provider attitude; unmet HC screening
Cooper 1997	UK	N=134	High rates of untreated illness
Driessen <i>et al.</i> , 1997	NL	N=475	Issues with access to MH services
Hoare <i>et al.</i> , 1998	UK	N=143	Caregivers' unmet psychological needs
Houghton 2001	UK		Unmet HC because of discrimination, stigmatisation & stereotypical beliefs
Jones & Kerr, 1997	UK	N=111	Unmet HC screening needs, e.g. thyroid
Nøttestad & Linaker, 1999	Norway	N=128	Access to qualified help reduced following de-institutionalisation
Parkes, 1996	UK		Rationing & stigma; unmet HC needs

Plachaud <i>et al.</i> , 1998	UK	n=54	Gaps in screening, e.g. thyroid in DS
Slone <i>et al.</i> , 1998	Israel	n=538	Different referral pattern due to income
Stores <i>et al.</i> , 1998	UK	n=110	Behaviour issues: unmet MH needs
USPHS 2001	USA		Barriers to care for MR identified

From Fisher (2004)

2.3. Conclusions

Health inequalities and health disparities are evident between those with intellectual disability and the general population. “The Health Status and Needs of Individuals with Mental Retardation” commissioned by Special Olympics in the United States cites an array of empirical research highlighting these disparities. On the basis of such disparity, the Report of the United States’ Surgeon General, “Closing the Gap” provides a national blueprint to improve the health of this population. A recent review of this area by Fisher (2004) however indicates that disparities remain specifically in the areas of special health care needs, health promotion needs and unmet need. Considerable effort is now required within the European Union not only to resource interventions to reduce these health inequalities, but additionally to support a structure that systematically monitors the impact of these interventions over time.

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