

# **Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities**

**Meindert Haveman, Tamar Heller, Lynette Lee, Marian  
Maaskant, Shahin Shoostari, Andre Strydom**



**IASSID Special Interest Research Group  
on Ageing in Intellectual Disabilities**

Suggested Citation

Haveman, M.J., Heller, T., Lee, L.A, Maaskant, M.A, Shooshtari, S., Strydom, A. (2009). Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities/Faculty Rehabilitation Sciences, University of Dortmund.

Contact for additional copies

Department Rehabilitation and Education  
for Persons with Intellectual Disabilities  
Faculty Rehabilitation Sciences  
University of Dortmund  
Emil-Figge-Str.50  
44221 Dortmund, Germany  
0049-231-7557175 (Tel.)  
0049-231-7557176 (Fax)  
[jennifer.wodara@tu-dortmund.de](mailto:jennifer.wodara@tu-dortmund.de)

## CONTENTS

INTRODUCTION.....	4
METHODOLOGICAL ISSUES .....	4
DEFINITIONS AND CONCEPTS .....	6
What do we mean by the term ‘health’? .....	6
What do we mean by the term ‘ageing’?.....	9
Ageing and health from the perspective of the person with intellectual disability .....	11
LIFESTYLE AND MODIFIABLE RISK FACTORS.....	12
Smoking .....	12
Dentition and Oral Health risks.....	12
Poor nutrition.....	13
Overweight and obesity.....	14
Hypercholesterolemia and dyslipidemia .....	16
Low levels of physical activity.....	16
Combinations of health risk factors .....	17
SIGNS AND SYMPTOMS COMMONLY ASSOCIATED WITH AGEING .....	19
Deterioration in Mobility .....	19
Chronic non musculoskeletal pain .....	21
Disturbance of Vision.....	21
Decline in Hearing .....	23
Constipation .....	25
Bowel and Bladder Incontinence .....	25
DETERIORATION AND DISEASES MORE PREVALENT WITH AGEING.....	26
Brain and neurological function.....	26
Dementia .....	26
Heart disease .....	26
Diabetes .....	28
Hypertension .....	28
Gastrointestinal diseases .....	28
Skeletal disorders .....	30
Immune system pathology in people with Down Syndrome as they age.....	31
Cancer.....	31
Multimorbidity in older age .....	31
LIFE EXPECTANCY AND MORTALITY .....	32
HEALTH DISPARITIES AND MORBIDITY.....	33
HEALTH PROMOTION AND HEALTH PROTECTION STRATEGIES FOR OLDER ADULTS WITH ID .....	35
Primary prevention and Health Promotion Programmes .....	36
Systematic health screening of common conditions associated with ageing .....	36
General health screening for older adults with ID .....	37
DISCUSSION .....	38
CONCLUSION .....	40
REFERENCES.....	42
ABOUT THE AUTHORS .....	70

## INTRODUCTION

This paper summarises a review of the scientific literature over the past fifteen years on the topic of health risks associated with ageing in people with an Intellectual Disability. It is a review of descriptive observational research ranging from discussion at the social 'wellness' end of the spectrum through to analysis of the impact of ageing on the incidence of chronic physical illness. We have commented on the relevance of these findings for policy development and made recommendations for further research.

At a roundtable meeting in Geneva 1999 the Special Interest Research Groups on Ageing and on Health of the IASSID joined forces and presented an overview of knowledge up to 1999 with recommendations regarding physical health and healthy ageing (Evenhuis et al., 2000). In preparation for the IASSID World Congress in Cape Town, we reviewed the literature 1995-2008 in order to describe and discuss the state of science on the topic of ageing, health risks and Intellectual Disability. Other IASSID SSCA groups considered the literature on 'mental health', 'dementia' and 'aetiological groups'.

In using the search programmes Medline and PsycLit, the World Wide Web, tracing articles from the major journals on ID, and exchanging information about publications on this subject in our group, more than 300 articles and books were found on the subject of health/disease/impairment of (older) adults with ID. Because of lack of recent information, and also because of overlap in disease and risk categories, we did not strictly follow and discuss all ICF body functions and structures. Some headings are not mentioned at all whereas other body functions and structures are included in other categories. Because problems at young age can influence, are coexistent, remain unresolved or are complicating the health status of older adults with ID, our overview does include some papers on young people, if they enhanced our understanding of ageing and older people.

The information and evidence in this report is biased to the situation in North American, European and industrialized Asian countries (Australia, New Zealand, Japan, Hong Kong). In the selected literature there was almost a total lack of information about the ageing process and its consequences for persons with ID in low- and middle- income countries. Information about health conditions, risk factors, prevention and treatment for adults aged 30 years and older were scarce, apart from general WHO publications. There was one article found about older adults (35 years and older) in low-income countries (Nepal) published by Shrestha & Weber (2002).

## METHODOLOGICAL ISSUES

While there are many cross sectional and prevalence studies, there are few incidence studies about the health issues of elderly persons with ID. When the descriptive epidemiological studies of the last ten years are counted and compared, the ratio is less than 1:20 of incidence versus prevalence studies.

There are probably three reasons for this:

- (1) In order to attract the attention of service planners, researchers have been obliged to concentrate on younger people and/or on specific aetiological groups with critical mass;
- (2) Prevalence studies are restricted to a certain point of time, and can be completed within the limited financial resources usually available for research; and
- (3) Methodologically, prospective and retrospective cohort studies are more challenging than cross-sectional studies; because they need large samples of healthy individuals, close monitoring of exposure factors, and regular diagnostics sensitive to

change. Retention of interest over time and the risks associated with participants dropping out are also factors influencing poor uptake. And many may be daunted by the more complicated statistical techniques required.

Findings of research listed in this report are notably at variance with regard to the prevalence rates of health conditions associated with ageing in older adults with ID. For some conditions (such as constipation) the rates were quite similar. For other health conditions broad differences between studies were found. Prevalence rates, for example, with regard to vision problems in persons with ID differed between 18% and 99%. Such large inconsistencies in results between studies could be attributable to a number of factors such as differences in the characteristics of the study population (eg age, type of disability, level of disability, gender distribution), the operational definition of ID itself, and methods of detection or defining health conditions.

It is difficult to decide where normal variation ends and physiological aberration begins and the overriding confounder for definitive statements in all the literature we reviewed for this paper was the definition of a "case" – of good health, of risk factors, and of illness. As reviewers we were struck by the variation in the methodology at many levels:

- (1) type of information (population-based, case-register or information system, or data gathered on persons staying in residential facilities);
- (2) sample inclusion (by convenience, selection, random sampling, pre-stratification, nonresponse and refusal);
- (3) method of data gathering (medical charts review, interviews with participants, interviews with informed others, direct assessments of health status by physician, and laboratory testing);
- (4) small numbers and small samples (stability and representativeness of the results depending on sample size and sampling method);
- (5) investment in diagnostic resources (amount of person hours, trained staff, instruments, tests etc for valid diagnostic assessment of illness and disease);
- (6) quality and type of services (structure and quality of existing health, social and residential services can have an impact on the results of prevalence studies);
- (7) motivation to participate in research (outcomes of prevalence studies are affected both by response/non-response of the client, and the willingness of physicians and staff to participate in the study);
- (8) cohort effects. Experiences, harms, and problems in the past can differ between counties and countries, and can result in differences of reported health conditions in older adults with ID today. (Even the age structure of persons with ID can differ dramatically between Western countries eg in Germany and Austria compared to other Western European countries, caused by the systematic killing of persons with ID by the Nazi regime); and
- (9) culture and social structure of the environment. In comparing results of studies globally there is a risk of underestimating differences in climate, population density, wealth and income, cultural norms and values, and also of neglecting the pervasive impact of war, starvation, and epidemics (such as HIV, Cholera and Malaria) in low- and medium-income countries.

In most cases, proxy reports (by caregivers or parents), notations from medical records, physical examination or a combination of these methods have been used to determine the existence of a health condition or disease in the reviewed studies. It is evident that sensitive

physical assessment, medical examinations and tests would help to identify more health issues and at an earlier stage. Prevalence estimates of health conditions among the ID population based on proxy reports and medical records may be an underestimation of true disease prevalence (Haveman, 2004).

## DEFINITIONS AND CONCEPTS

### What do we mean by the term ‘health’?

The term ‘health’ is broad and implies a number of concepts and dimensions. The person in the street thinks being ‘healthy’ means ‘feeling well’, ie eating properly, sleeping well, exercising daily, not smoking, enjoying friends and not being in severe pain. The epidemiologist describes the ‘health’ of nations in terms of child mortality, longevity and (more sophisticatedly) quality of life years (QALYS). When clinicians speak of ‘health’ they usually mean ‘lack of illness’, and sometimes ‘lack of pain’.

Policy makers describe ‘health’ in terms of funding implications and they develop models that link service provision to health status of populations eg

- People who are well - need health promoting and health protection programs and services;
- People who are ‘at risk’ – need health worker attention regularly; and
- People who have illnesses – need hospitals and specialist health care.

**Preventive health** for people with ID has received increased attention in the last 10 years, as evidenced by several international publications such as Healthy People 2010 (US Department of Health and Human Services, 2000); Closing The Gap (US Public Health Service, 2002); Summative Report on Healthy Ageing for Adults with ID (WHO, 2000) and the European Pomona Projects I and II (Walsh et al., 2003 ). According to Frey, Temple & Stanish (2006) the new emphasis on preventive health is based on two paradigm shifts:

- “(1) from a medical model that disability is a biological abnormality requiring treatment to the concept of psychological, social, and environmental constraints that may interfere with functioning (Bickenbach et al., 1999), and
- (2) from the notion that health defined as the absence of disability or disease to viewing health as a global state of social, emotional, and mental well being (Rimmer, 1999)” (Frey et al., 2006, 1).

In an editorial of the Journal of Policy and Practice in Intellectual Disabilities, Emerson, McConkey, Walsh & Felce (2008) also point at the shift from a medically based individual model of disability towards disability as a social construct. They cite in this respect the position of Vehmas (2004), that “disability is essentially a social phenomenon and concept. It is constructed in particular social contexts and they determine the meaning it carries.” The authors, however, warn the reader to be not too dogmatic in this perspective. The importance of impairment as a significant factor should not be denied (Thomas, 2007) and a multidimensional model including various layers for describing and explaining disability should be preferred.

The World Health Organisation has led this concept of ‘health’ as a spectrum with its Assembly’s adoption of the **International Classification of Functioning, Disability and Health** (ICF) in 2001 (WHO). The ICF attempts to find a middle path between the medical model and the social model, suggesting that both are partially valid (VanLeit, 2008). With the ICF, a comprehensive view of health status is provided from a biological, personal and social

perspective. The function and disability domains of the ICF are described from the perspective of body systems, the individual, and society.

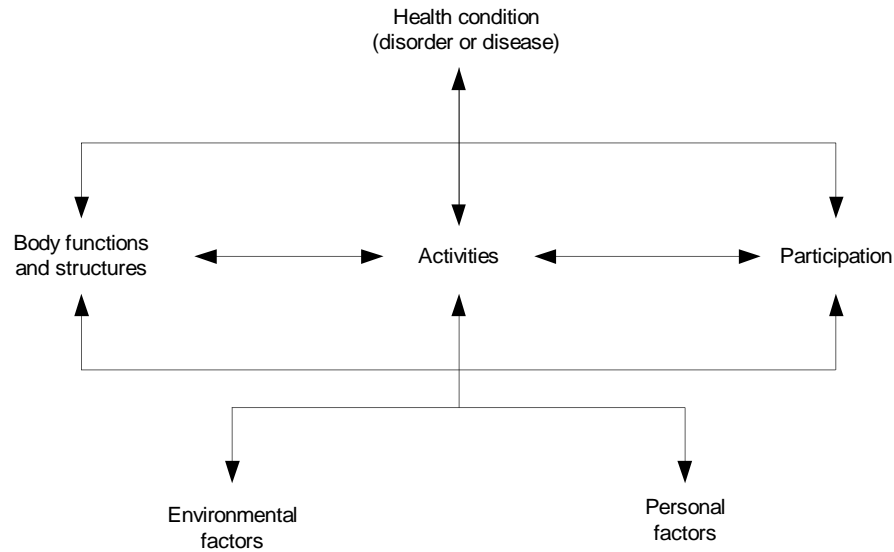


Figure 1 Interactions between components of the ICF. WHO 2001

**Body Functions and Structures** are defined as physiological functions or anatomical elements such as organs, limbs, and their components. **Activity** is defined as the execution of specific tasks or actions by an individual, while **Participation** is described as encompassing involvement in life situations (Jette, Norweg & Haley, 2008, 964). ICF's coding system with 1424 categories organized across 34 chapter headings is quite complicated. Consequently a shorter version of the ICF checklist (WHO 2003) was developed with less than 125 categories.

The body functions can be physiological or psychological in nature, associated with body structures, and categorized as mental; sensory and pain; voice and speech; cardiovascular, immune and respiratory; digestive, metabolic and endocrine; neuromuscular and movement-related; and skin and related structures. Problems in body function or structure are referred to as impairments (VanLeit, 2008, 992). This dimension represents the clinical aspects of diagnosis and case definition in epidemiological research.

The social dimension of the ICF consists of four broad categories. Activity refers to the execution of a task; difficulties are referred to as activity limitations. More globally (above the detailed activity level), Participation refers to involvement in life situations, and difficulties are called participation restrictions. **Contextual Factors** emphasize the role of non-impairment factors in the development of disability and include: environmental factors (categorized as products and technology; natural and built environment; support and relationships; attitudes; and services, systems and policies) and **Personal Factors** (individual characteristics such as age, gender, social background, education, and profession (VanLeit, 2008, 992). In this report we have tried to follow the ICF classification as much as possible in our discussion of health issues.

With regard to prevention and intervention in disease it is helpful to adopt a multi-axial approach with two dimensions of physical and mental health. The second dimension of the

health model includes the six types of variables which could affect health outcomes, such as antecedent predisposing factors, direct causes, pathogenetic processes caused by the etiological agent, manifestations of disease, treatment, and factors affecting prognosis.

A preventive perspective on health objectives helps to ensure a systematic approach to the major issues involved. The accepted definitions of primary, secondary and tertiary prevention remain a helpful concept in which the dimension of observation/explanation by the person, staff and physician can be connected with the dimension of intervention.

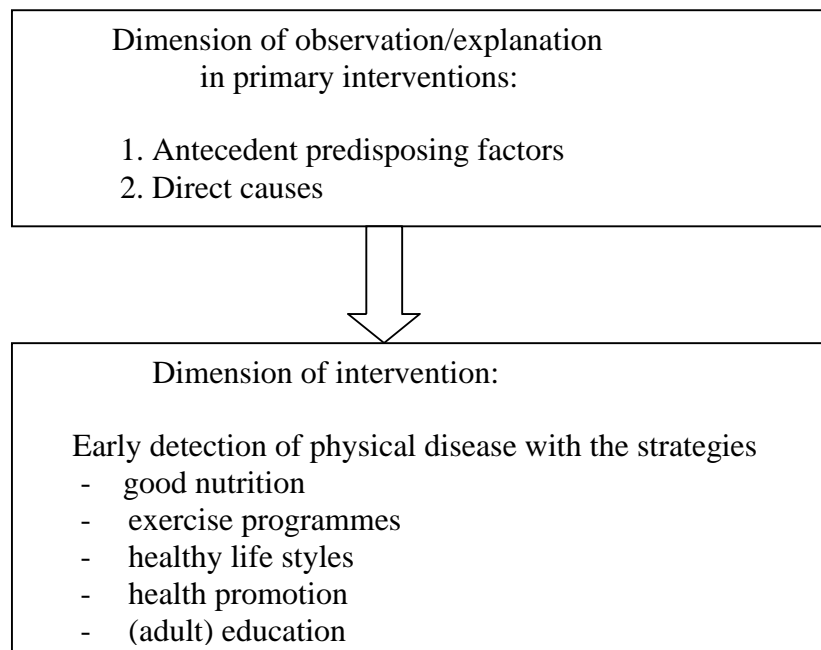


Figure 2: Approach to primary prevention

Primary prevention is directed at reducing the incidence of new cases of defined health disorder by altering the risk factors, and implies strategies such as good nutrition, exercise programmes, healthy lifestyles, health promotion and education.

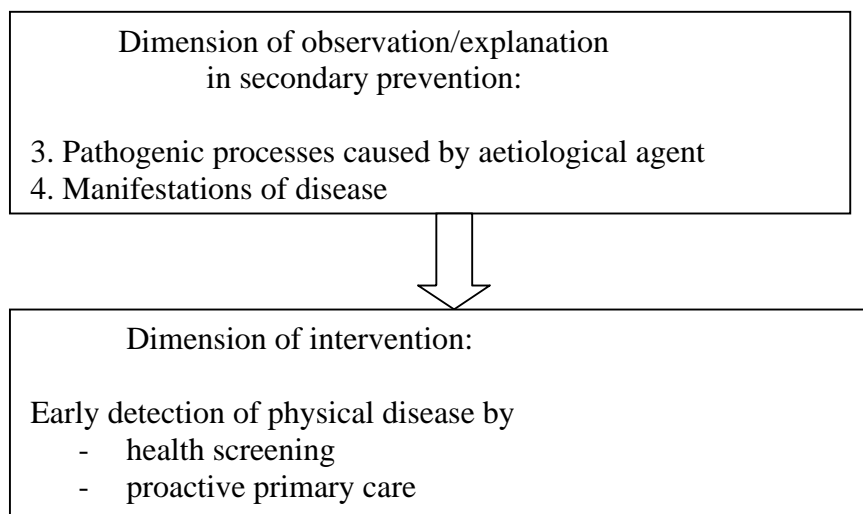


Figure 3: Approach to secondary prevention

Secondary prevention involves efforts to reduce the prevalence of a defined health disorder by reducing its duration, by early detection and prompt treatment. Health screening and proactive primary care are adequate measures in this respect, however, often with passive and non-informed roles for persons with ID.

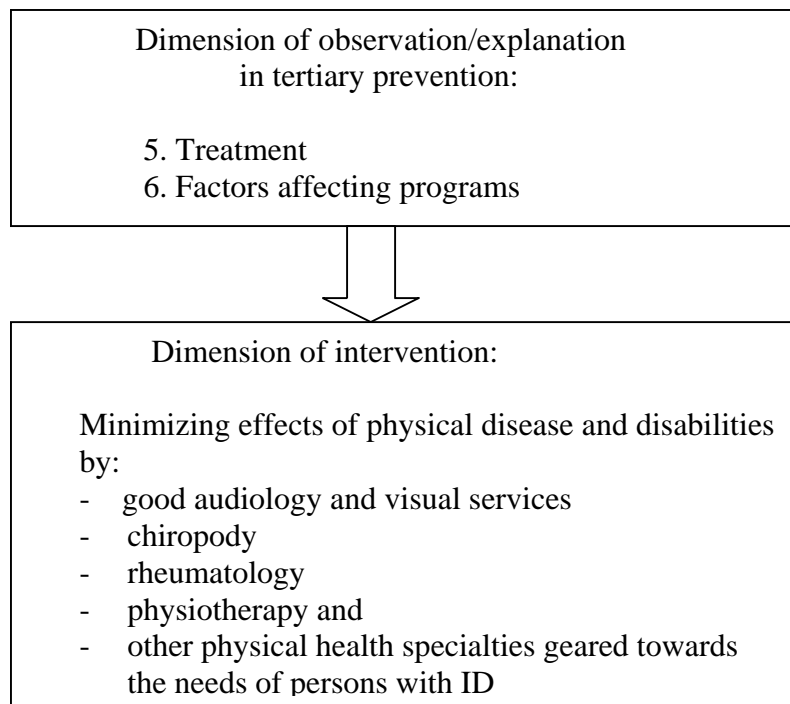


Figure 4: Approach to tertiary prevention

Tertiary prevention is designed to reduce the severity and disability associated with a particular disorder. The accessibility of adults with ID for health services, adequate training of health professionals and others, their attitudes, and the quality and effectiveness of specialized services become very important for health outcomes. In the prevention model (figures 2-4), factors of the social dimension of the ICF are the independent measures determining health status whereas health and its gradual manifestations of ill-health or impairment are defined in the clinical dimension.

#### **What do we mean by the term ‘ageing’?**

The term ‘ageing’ also is broad and implies various concepts and dimensions. **Biological ageing** refers to the physical state of the body in relation to the biological processes of growth, maturation, death and decay of organ and body functioning. Abnormal functioning of the body, and disease, can occur at any time but may be a result of the ‘normal’ ageing process.

There are two main theories in biological ageing research:

- That genetic preprogramming influences ‘turning on the ageing process’ or ‘turning off the maturation process’; and
- That ‘wear and tear’ of existing body reserve leads to opportunities for environmental influences (nutrition, smoking, pollution etc) to take effect.

Clearly there are implications of these theories for research in ageing in people with Intellectual Disability. The “wear and tear”- explanation is strongly connected with environmental, but also with psychological and social factors. **Social ageing** may be strongly influenced by legal, ethical, religious, or historical experiences. As members of the greater society, older adults are more underprivileged when they are long-term disabled. They are often unemployed or underemployed, disadvantaged in income and social status, segregated in a special system of work or activity, housing or leisure, and often dependent on the help of others. Scientific data about the impact on social ageing of those indicators of low social economic status, segregation and dependency on health and on the use of health services are very scarce.

Psychological, social and epidemiological cohort studies require the researcher also to consider the dimension of **historical ageing**. To explain today’s behaviour, adaptations, complaints, functioning, and health problems, the researcher needs to take into account the different opportunities and social structures that were available to people with disabilities who are old now, when they were young. For example, as a group, young adults with disabilities of today will know more about their bodies and the effects of smoking, unsafe sex and drugs, in general, when they are 60 years old, than those adults who have already reached this age. People in cared accommodation many years ago were offered cigarettes as a behavioural management ‘reward’. In the health field more operations and treatments are now available to young people with disabilities than were available in the past eg heart defect surgery and neurosurgical procedures.

In countries like Germany and Austria there is also the tragic side to historical ageing of individuals with Intellectual Disability. In those countries there are only a few individuals with ID who survived the systematic killing of persons with disabilities during the Nazi regime. Persons from the birth cohorts before the year 1945 are almost non-existent today in the disability statistics of those countries (Haveman & Stöppler, 2004).

Since 1980, Baltes and colleagues (1980a,1980b,1984,1990) have conducted studies on the psychological processes of development and ageing from a lifespan perspective. Their work resulted in a psychological model, called ‘selective optimization with compensation’. The central focus of this lifespan model is the management of the dynamics between gains and losses (i.e., a general process of adaptation), consisting of three interacting elements: selection, optimization, and compensation. It is expected that the lifelong process of selective optimization with compensation allows people to age successfully (ie to engage in life tasks that are important to them despite a reduction in energy). As is pointed out by Janicki (1998), this model does not fit well for persons with lifelong disabilities, because the three major components for healthy ageing: low probability of disease or disease-related decline; high cognitive and physical function capacity; and active engagement with life, are only valid for a well-functioning minority.

People with lifelong disabilities may have healthy and successful ageing, if they are educated appropriately, if they have productive coping and compensatory mechanisms during adulthood, and if they have been able to maintain control over their life activities. Throughout the world studies are revealing a growing ‘healthy’ cohort of people, mostly with mild Intellectual Disability, surviving to (biological) old age i.e over 70yrs (Bittles et al, 2002).

### **Ageing and health from the perspective of the person with intellectual disability**

For people with Intellectual Disabilities, **chronological ageing** may be merely a succession of days labelled ‘birthdays’ by their friends, upon which they enjoy a special meal, or receive special gifts. Milestones such as reaching age ‘50’, ‘60’ or ‘70’ are probably meaningless for persons who are able to count only to twenty. Cornerstone age events like reaching age 50 or 65, which could frighten members of the general population as steps to ‘old age’ and possibly ‘end of life’, may not have the same relevance.

**Functional ageing** (Haveman & Stöppler, 2004; Haveman, 2004) is much more important for persons with Intellectual Disabilities (ID). If adults with ID at advanced chronological biological age are noticing difficulty with walking, seeing, hearing, eating and talking, they may start to feel old. Urlings et al. (1993) documented in a qualitative study of older people with ID, that only for individuals aged over 70 is ageing a major topic of interest. They were able to relate the decline of self-help skills, and the anxiety of becoming physically ill and bedridden to the perceived concept of ageing. Growing old and dying were major issues for these older adults with ID. Fender et al. (2007) enquired into what people with ID thought about ‘health’. They identified three main themes: being able to do things and participate in activities; nutrition; and hygiene and self-care. But the physical experience of biological ageing (e.g. exercise intolerance) could not be explained by people with Intellectual Disability. Their understanding of the mechanism of physical illness was limited.

At a session on “Later Life Planning for Older Adults with ID” (Heller et al., 1996) in Germany one of the trainers asked the participants about the shape of the heart. After a period of silence one of the participants showed her by gesture the icon of the heart. Most of the older adults in the German and Dutch groups were not knowledgeable about the form, size and functions of basic organs in their body system (van Laake, 2006). Surprisingly some of them knew that people landed on the moon, but didn’t know that their heart is a pump for the blood stream. Most of these older adults never attended school, because school became compulsory at a time when they were already adults. As a consequence, they have limited biological and medical knowledge.

When disparities and inequalities in health and health care delivery are discussed in the literature, a basic but often neglected factor is this cultural lag in knowledge and language. Older adults with ID do not understand their body and they are not able to communicate bodily changes and sensations in the same way that others do. This is evident in day-to-day conversations: ‘Why should I walk, when I have easy accessible bus transportation? Why should I drink water, when I can drink Coke?’

As consumers we are trained to communicate with our physician using medical terminology, to have biological and physiological explanations and to expect various treatments. This is problematic for people with ID - the language and concepts are abstract and quite complex,. Lack of these language and communication skills may easily lead to dependency. This inability of older adults with ID to understand their bodies and to communicate symptoms in the same way as the educated general population must be taken into account in the provision of self advocacy training, in the education of health practitioners and in the policy development for specialist services.

Although involvement of patients in decision making in health care is important in improving quality of care through achieving more responsive services and better outcomes of intervention (Crawford et al., 2002), it is a fact that in most countries, adults with ID remain

largely excluded from frontline health care decision making (Fovarque et al. 2000). There are few published accounts of the views of people with ID on clinical intervention (Young, 2006). It is important that attempts are made to include people with ID in discussions about their health as a sign of respect, but also to ascertain insights that are not necessarily accessible from them, from third-party accounts (Rudick & Oliver, 2005).

## **LIFESTYLE AND MODIFIABLE RISK FACTORS**

### **Smoking**

Smoking is a risk factor for both cardiovascular disease and lung cancer. Little data exist on smoking rates among older adults with ID. Lower smoking rates (compared with the general population) have been noted among adults with severe ID, and equivalent or higher rates among community-dwellers, and adults with mild ID (McGillycuddy, 2006; Draheim et al., 2002b). In general, health problems related to smoking, alcohol, and use of illegal drugs are quite uncommon.

### **Dentition and Oral Health risks**

Xerostomia, dental caries, gingivitis, and periodontal disease are among the top 10 secondary conditions for individuals with ID that cause limitations in their daily activities (Traci et al., 2002).

**Dry mouth** (xerostomia) is a common and often overlooked health problem (Forsai & Calabrese, 2001). Once considered an inevitable consequence of ageing, it is now known that saliva production remains essentially unchanged in healthy elderly people, yet the secretion of the saliva may be indirectly dependent on the systemic health of a person as well as the number and type of medications they are taking. Medications used to treat high blood pressure, heart disease, diabetes, allergies, depression and many other conditions have been found to cause this condition. Diminished saliva flow is associated with increased burning/soreness of the oral tissues, difficulty chewing, speaking, swallowing, oral infections and overall mouth feel, all of which can adversely effect food selection and dietary compliance.

Although international studies have not provided definitive evidence of the prevalence of **dental caries** among those with ID relative to the general population (Owens et al., 2006; Shapira et al., 1998; Waldman et al., 1998), in one English study (Cumella et al., 2000) higher levels of untreated caries were found, and in an Australian community and institutional study (Beange et al, 1995) the most frequently underdiagnosed disorder was dental disease. Other studies report prevalence estimates of caries consistent with the general population (Shapira et al., 1998; Rao et al., 2001; Bradley & McAllister, 2004).

While most authors (Corbin et al., 2005; Glassman & Miller, 2003; Reid et al., 2003, White et al., 1998) mention a lack of effective oral hygiene in their sample, Gabre et al., (2001) reported better than average oral hygiene amongst Swedish people with ID. In fact, most studies that focus on dental caries discuss the overall percentage or overall mean number of decayed, missing, and filled teeth, and do not report the prevalence of individuals with ID who have dental caries (Owens et al., 2006, 32). A few studies have shown higher prevalence estimates of decayed, missing and filled teeth among persons with ID compared to the general population (Skyama et al., 2001). Other researchers have found lower prevalence estimates of such teeth among individuals with ID (Vazquez et al., 2002).

Some researchers found evidence that individuals with ID were more likely to receive poor treatment for caries, such as tooth extractions rather than restorations for dental problems,

compared with the general population (Shapira et al., 1998; Pregliasco et al., 2001; Vazquez et al., 2002). Balogh and colleagues (2004) studied regional variations in dental procedures among people with an intellectual disability in the province of Ontario, Canada. They found that overall dental procedures made up 40% of day surgery visits between 1995 and 2000. Moreover, they found that tooth extraction was the most common procedure used (15%).

Another common oral health problem among adults with ID is **gingivitis**. There is an increased incidence of gum disease, with gingivitis being 1.2 - 1.9 times higher than in the general population (Horwitz et al., 2000). Other studies report prevalence estimates of gingivitis in the range of 6 - 97% among persons with ID compared with estimates of 8 - 59% in the general population (Cumella et al., 2000; Hennequin et al., 2000; USDHHS, 2000; Lopez-Perez et al., 2002; Stoyanova, 2003; Lader et al., 2005). Those who are older tend to have higher prevalence estimates of gingivitis (Owens et al., 2006). Corbin et al. (2005) found the prevalence of gingivitis to vary with age (42% among 8 - 17 years, 58% among 18 - 34 years, 62% among 35 - 50 years, and 48% among 51 - 70 years) for participants at the 2003 World Summer Games in Ireland. Higher levels of gum inflammation were also reported for older participants of the UK Special Olympics by Turnet et al. (2008).

Within countries with regard to social-economic status and level of health insurance, as well as between countries, differences are found in oral and dental health status. An Australian study (Scott et al., 1998) noted that various types of dental disease, particularly periodontal disease, oral mucosal pathology, and moderate to severe **malocclusion**, were up to 7 times as frequent as in the general population.

Periodontal disease in persons with Down syndrome develops earlier and is more rapid and extensive than in age-matched persons from the general population (Zigmond et al., 2006). In spite of similar oral hygiene and gingival measures, persons with Down syndrome in the study of Zigmond et al. (2006), as opposed to the persons from the control group, had a severe periodontal disease. The prevalence, extent and severity of periodontitis in persons with Down syndrome were statistically significant greater than in the control group.

We have to conclude that with regard to oral health in older adults with ID essential information is still missing. The need for improved dental services and provider education has been highlighted in several reports (Reichard et al., 2001; Waldman & Perlman, 2002), but the oral health status of adults with ID and its remedies are not yet well-documented enough to plan services adequately. Special Olympics participants, for example, cannot be held representative of adults with ID in any society. In research there is a bias towards younger ages and less severe disability, such individuals are likely to be healthier and better supported (Reid et al., 2003).

There are many studies which reported that persons with ID have poorer oral and dental health compared to the general population (e.g., Scott et al., 1998; Denloye, 1998; Schultz et al., 2001; Horwitz et al., 2000). Given the reported disparities in oral/dental health, a number of studies highlighted the **need for improved dental services for persons with ID**.

### **Poor nutrition**

Behaviours such as the consumption of high-fat foods and inadequate intake of fruit and vegetables are likely to play a role in the development of obesity and elevated cardiovascular disease risk factors such as hypertension and diabetes, as well as cancer risks in adults with ID living in community settings, as they age (Draheim et al., 2007; Braunschweig et al., 2004).

Low-income status reported in the majority of the population with ID (Fujiura & Yamaki, 1997; Yamaki & Fujiura, 2002) may limit access to healthy food choices. Draheim et al. (2007a) describe and discuss in their article the results of three US studies (Braunschweig et al., 2004; Lindemann, 1991; Mercer & Ekvall, 1992) on dietary intake of adults with ID who reside in the community. The combined results suggest that adults with ID who reside in group homes consume a diet that is high in energy, high in fat, and low in fruit and vegetable intake. Their study found that 0-6% of the residents consumed the recommended 5 or more fruits and vegetables per day, and 15 -30% consumed the recommended <30% of calories from fat.

### **Overweight and obesity**

The WHO (1998) has endorsed four Body Mass Index (BMI) categories where a ratio of less than 18.5 is considered underweight, 18.5 to 25 is considered a healthy or normal weight, 25.5 to 30 is rated as overweight, and a BMI greater than 30 is considered as obese. These classifications are typically used in the literature that assesses obesity.

Numerous studies in the past twenty years have highlighted the high rates of overweight and obesity in people with Intellectual Disability compared to the general population. These studies need to be carefully reviewed – there are differences amongst those who are living with family, those who are in small cared-accommodation settings, those who are still in large aggregate settings and those who are linked with large numbers of profoundly underweight people. There are also differences in the definitions of measures of BMI and differences in the stages of de-institutionalisation of the cohorts. There may also be differences in the ratios of individuals with genetic predisposition to increased weight and differences in the medications prescribed.

Use of some antipsychotic medications, lack of physical activity and a lack of health education and promotion materials and programs on healthy eating, specifically aimed at ID population, are known to contribute to the issue of high rate of obesity in this group (van Schroyensteen Lantman-de Valk, 2005).

The rates of overweight and obesity are high in community dwelling adults with ID, both in the United States and in other developed countries such as Great Britain, Northern Ireland, Netherlands and Israel (Rubin et al., 1998; Lewis et al., 2002; Rimmer & Wang, 2005; Rimmer & Yamaki, 2006; Harris et al., 2003; Draheim, 2006; Moran et al., 2005; Yamaki, 2005). Generally the rates of obesity are lower in other countries (Bhaumik et al., 2008; Emerson, 2005; Kerr et al., 2003; Marshall et al., 2003; Bertoli et al., 2005; Hove, 2004; Merrick et al., 2004; van Schroyensteen Lantman-de Valk et al., 2000). Harris et al. (2003) reviewed the results of BMI measurement for the 443 adults with ID who participated in the Special Olympics World Games. Of those, 26% were obese (BMI >29) and an additional 6% were extremely obese (BMI>39). The researchers reported that the rate was significantly higher for the US participants than for participants from other countries. However, this commentary should be handled with care, because of the strong selective process for participation in Special Olympics.

With respect to subgroups, women, older individuals, those with less severe disabilities and those with certain syndromes (eg Down syndrome, Prader-Willi syndrome) were more likely to be obese compared to their counterparts. A wide range of estimates, namely from 2 to 50%, has been reported for obesity in the whole ID population (Gravestock, 2000; Emerson, 2005; Horwitz et al., 2000; Stanish & Draheim, 2005; Yamaki, 2005; Melville et al., 2008).

Stanish and Draheim (2005) reported that almost 80% of adults with mild to moderate ID who mostly resided in community settings were overweight or obese (including 45% obese and 8% severely obese). Yamaki (2005) used data from the National Health Interview Survey (1985 to 2000) and examined body weight status among adults with ID. He found a higher proportion of the ID group to be obese compared with the non-ID population. For example the rate of obesity among people with ID in the older age group (60-65) was 36.0% while only 24.1% of the older population without ID was found to be obese. In a population-based prevalence study of adults with ID aged 20 and over (N=1119) in England (Bhaumik et al., 2008) a prevalence estimate for obesity was found of 20.7%, 28.0% for overweight, 32.7% for normal weight and 18.6% for underweight. Obesity was associated with living independently/with family, having ability to feed/drink unaided, being female, having hypertension, having Down syndrome and the absence of cerebral palsy.

Contrary to other studies (Gravestock, 2000; Hove, 2004; Moran et al., 2005) in the study of Bhaumik et al. (2008) the largest differences in BMI between the ID and general populations were not found with regard to obesity, but in the underweight category.

In 2004, Moore, McGillivray, Illingworth, & Brookhouse investigated the weight distribution of an Australian sample of people with an intellectual disability using the BMI and the Percentage of Body Fat (PBF) formula. Forty-one females and 52 males with a mild to severe intellectual disability were assessed. BMI classifications revealed a higher percentage of females as overweight (41.4%) and obese (36.6%) compared to overweight males (30.8%) and obese males (30.8%).

Van Knijff et al, found similar percentages of overweight persons in the general Dutch population and the ID population. A wide range of estimates, namely from 2 to 45%, has been reported for obesity in the whole ID population (Gravestock, 2000; Emerson, 2005; Yamaki, 2005; Van Knijff, 2005). Adults with Down syndrome are more at risk for being overweight (Melville et al., 2005; Rubin et al., 1998; Van Knijff et al., 2005, 2006; Maaskant et al, submitted). Studies suggest that 25 to 48% of adults with Down syndrome are obese (Rubin et al., 1998; Gravestock, 2000; Melville et al., 2005). In general, people with mild ID and those who lived in the community are most likely to be overweight or obese (Bhaumik et al., 2008; Hove, 2004, Van Knijff et al., 2005, 2006; Maaskant et al., submitted). Van Knijff et al. studied the weight status in a Dutch residential study group (n=744). Adjusted risks groups for overweight (vs.normal weight) showed to be women (vs.men), persons with mild and moderate intellectual disabilities (vs. severe/profound ID, people with Down syndrome (vs.other etiologies) and elderly (50+ vs <50: adjusted OR=1.7 (90% CI: 1.3-2.3)). Changes in weight status (2002-2007) however, were not related to age or to living situation (campus site or community care) (Maaskant et al., submitted).

There are major concerns about the impact of obesity on health (Haslam & James, 2005). Obesity increases the risk of developing a broad spectrum of not only cardiovascular, but also of pulmonary, metabolic and neoplastic diseases, osteoarthritis, impaired fertility and complications of pregnancy, anaesthetics and surgery (National Audit Office, 2001; Haslam & James, 2005; Haslam et al., 2006).

Williams & McCubbin (2002) found in their study that individuals with ID who are overweight or have abdominal obesity are 3 to 10 times more likely to have elevated cardiovascular disease risk factors, such as hypertension, hypertriglyceridemia,

hyperinsulinemia, and low high-density lipoprotein (good) cholesterol levels than those who are not overweight or who do not have abdominal obesity.

Obesity can lead to serious medical problems, such as non-insulin-dependent diabetes mellitus, hypertension and cerebrovascular disease. In some syndromes, such as Prader-Willi syndrome, excessive eating resulting in obesity is one of the cardinal features (O'Brien, 2008).

### **Hypercholesterolemia and dyslipidemia**

Rates of hypercholesterolemia and dyslipidemia in adults with ID have not been reported as widely, but the existing data suggest that they are comparable to the general population (Rimmer, Braddock & Fujiura, 1994).

### **Low levels of physical activity**

A lack of regular physical activity and unhealthy eating habits, common factors associated with obesity in the general population, are also prevalent issues for persons with ID (Emerson, 2005; Braunschweig et al., 2004; Draheim et al., 2002; Fernhall & Pitetti, 2001; Graham & Reid, 2000). Age appears to be negatively associated with activity in adults with ID (Robertson et al., 2000; Emerson, 2005). A lack of physical activity can exacerbate already low Bone Mineral Density scores with potential consequences for early onset of osteoporosis and brittle bones (Kronhead et al., 1998). Physical activity and exercise may remain very limited in non-ambulatory people (i.e. with cerebral palsy) who are permanently reliant on using wheelchairs for mobility (van Schrojenstein Lantman-de Valk, 2005). Including more persons with severe and profound ID in physical activity research will probably further reduce overall rates of physical activity among persons with ID in population studies (Robertson et al., 2000; Emerson, 2005).

Considering that 60% of global populations not meet the minimum physical activity guidelines (WHO, 2003), it is difficult to conclude whether adults with ID are any less motivated to be active than those without ID. When adults with ID expressed a preference for inactivity (i.e. watching television) it was unclear whether this leisure activity was chosen more frequently than the general population and if this choice was based on a true preference or because of limited alternatives for other activities (Frey et al., 2005).

Robertson et al. (2002) stated that increasing physical activity is the most effective single intervention to improve the health status of a population of adults with ID. The effects are documented for physical health as well as for mental health (Mitra et al., 2005). Some studies suggest a link between lack of physical exercise and depression (Lane & Lovejoy, 2001; Pollock, 2001). In their study Strawbridge et al. (2002) reported a protective effect of physical activity on depression for older adults, including older adults with disabilities.

Evidence exists that physical activity reduces mortality and morbidity not only in coronary heart disease and hypertension (Sutherland et al., 2002), but has also preventive effects on obesity, type 2 diabetes, constipation, and osteoporosis for people with and without ID.

Lack of staff motivation to promote physical activity (Temple & Walkley, 2003a) and a lack of physical activity counselling (Frey et al., 2006) have been reported as constraints to active physical participation of adults with ID.

The standard recommendation is that accruing 30 minutes of moderate intensity physical activity (or 10,000 steps throughout a day) on most, preferably all, days of the week (WHO, 2003) serves as a preventative health measure. In a publication of Stanish, Temple and Frey (2006) eight studies in adults with ID are mentioned and discussed, in which physical activity, not exercise or fitness, are examined (Temple et al., 2000; Draheim et al., 2002a, 2002b, 2003; Temple & Walkley, 2003b; Frey, 2004; Stanish & Draheim, 2005a, 2005b). Very few people are meeting the activity guidelines. In the USA, less than one-third of the population with ID is engaged in sufficient physical activity to accrue health benefits (Centers for Disease Control and Prevention, 2005). Similar findings have been reported in some studies from England using the criteria of at least 12 bouts of 20 minutes of moderate to vigorous activity occurring over 4 weeks (Messent et al., 1998b; Robertson et al., 2000; Emerson, 2005). The proportion of participants meeting this criterion ranged from 4 to 20% (in: Stanish, Temple & Frey, 2006, 12).

Attempts at improving exercise tolerance have had varying results. Rimmer et al. (2004) and Tsimaras et al. (2003) did demonstrate significant increases in cardiovascular function following a 12 week period of sustained exercise, whereas Verela et al. (2000) demonstrated no change in cardiovascular function following a 16 week period of exercise. Gordon (2008) explains this disparity in outcomes by examining the exercise modality. Both Rimmer and Tsimaras used weight bearing exercise such as jogging, walking and stepping, while Verela used rowing on an indoor rowing ergo meter. According to Gordon (2008) these are clearly different physiological responses to these forms of exercise, with rowing being associated with more rest per action than either jogging or walking.

In another study Wang (2003) demonstrated that repeated jumping exercises enhanced bi-motor abilities in both Down syndrome and non-Down syndrome individuals, when performed over a 6 week period. The results indicated increased ability in skilled movements such as beam walk and floor heel-to-toe walk. Although the increased muscle tone and postural control may be beneficial in terms of overall lifestyle this effect did not necessarily minimise the risk for cardiovascular disease.

### **Combinations of health risk factors**

Merrick et al. (2004) point to important differences within the total group of persons with ID. They found in their study that persons with severe and profound cognitive impairments had lower rates of hyperlipidemia, less were overweight, less had type 2 diabetes and there were lower rates of hypertension compared with persons with mild and moderate ID. We also expect that smoking is less common in persons with severe and profound ID.

Little is confirmed about the total cardiovascular disease risk factor profile for older adults with ID. A recent Australian study gives some first impressions (Wallace & Schluter, 2008). The charts of 155 adults with ID aged 40 years and over who visited a specialized ageing clinic during a 41 month-period were reviewed. In that group 5% had a diagnosis of cardiovascular disease. Risk factor assessment found that 18% had hypertension, 8% elevated glucose levels, 27% elevated total cholesterol, 70% were overweight or obese, 11% were current or ex-smokers, and 96% had inadequate daily exercise. The prevalence of hypertension and smoking increased significantly with age.

The authors conclude that apart from lack of exercise and the status of overweight/obesity, the overall CVD risk factor profile for this group of older adults with ID appears generally more favourable compared to the age-matched general population, although the occurrence of all

risk factors is still common. They suggest that healthy lifestyle programmes for this population should focus on implementation of exercise and nutrition strategies.

Some studies have adults with Down syndrome as their study group. Pastore et al. (2000) demonstrated that in a group of 42 individuals with Down syndrome, 43% were diagnosed as obese and 20% had reduced Forced Vital Capacity scores. Sixty one percent of the group showed low exercise tolerance, which appeared to be associated with 91% of the group displaying mild tachycardia.

### **Syndrome-specific auto-immune riskfactors**

Autoimmune disorders arise when the body produces an inappropriate immune response (initially the innate immune response and later the acquired system) to its own tissue – it recognizes normal tissue as ‘foreign’ and develops antibodies, the production of which induces long term inflammation. The most well known are the systemic disorders of Rheumatoid Arthritis (Rheumatoid Factor) and Systemic Lupus Erythematosus (SLE) and the localized disorders of Multiple Sclerosis (anti-myelin basic protein), Hashimoto’s thyroiditis (anti-thyroid-peroxidase antibodies), diabetes mellitus (anti-insulin antibodies) and coeliac disease (anti-gliadin/gluten antibodies).

Coeliac disease occurs frequently in some people with some of the syndromes associated with Intellectual Disability, eg Noonan’s Syndrome (Amoroso, 2003), William’s Syndrome and Turner’s Syndrome (Giannotti, 2001) and in particular in Down Syndrome (Bakkaloglu, 2008; Gillespie, 2006). Alopecia (which targets hair follicles) also occurs commonly in people with Intellectual Disability and a novel locus on Chromosome 3 has been described as the Alopecia with Mental Retardation site (Wali, 2006).

Autism is a developmental communication disorder which generally manifests with Intellectual Disability. Maternal neuronal antibodies have been demonstrated to be the likely causative agent in some cases of autism (Dalton, Deacon et al., 2003; Van Gent, 1997; Flannery, 1994; Warren, Cole et al., 1990). Peripheral immune abnormalities in its presentation have been considered for some time (Menage, 1992; Burger, 1998). In the last five years the finding of neuroglial presence and innate neuroimmune abnormalities in the brain tissue and CSF of people with Autism have given weight to a proposal for immune system dysfunction in its neurobiology (Pardo, 2007; Hu, 2006; Singer, 2006; Pardo, 2005; Vargas, 2005; Vincent, 2003; Croonenberghs, 2002; Jyonouchi, 2001). The peripheral abnormalities include sensitization to common dietary proteins leading to gastrointestinal inflammation (Schneider, 2006; Jyonouchi, 2005; 2002), altered levels of immunoglobulins, abnormal T-cell mediated immunity, and deficient complement activity (Krause, 2002). There is also some evidence for an allergic/immune system dysfunction in the pathogenesis of the symptoms of Attention Deficit Hyperactivity Disorder (Niederhofer, 2006; Roth, 1991; Marshall, 1989).

A small number of people with Intellectual Disability are at risk of recurrent infections, because immune dysfunction is a feature of the syndrome with which their cognitive impairment is associated. The most easily identifiable (although rare) primary immunodeficiency disorders associated with Intellectual Disability are the velo-cardio-facial syndrome of DiGeorge, and Ataxia Telangiectasia – both of which are related to cell mediated immune deficiencies as well as humoral – in particular, IgA deficiency (Aguilar, 2008; Chun, 2004). In addition there are case reports of families with syndromes such as the 18-q deletion

syndrome of facial dysmorphism, mental retardation and recurrent infections (Dostal, 2007); and the MECP2 duplication in Xq28 families (Friez, 2006), in which IgA is a feature.

With improvements in detection and treatment of infections these individuals are surviving to older age, and schizophrenia and other psychoses are being diagnosed with greater frequency in this older group. Some researchers have suggested that there may be a relationship between the immune system disorders of people who also have Intellectual Disability, and the onset of the psychiatric disturbance (De Smedt, 2007; Oskarsdottir, 2004; Yamagishi, 2002; McDonald-McGinn, 1999; Murphy et al, 1999).

## **SIGNS AND SYMPTOMS COMMONLY ASSOCIATED WITH AGEING**

### **Deterioration in Mobility**

In her study of 70 people over the age of 60 years, over a ten year period, Evenhuis (1997) found that mobility problems were common, and unrelated to level of ID. As with ageing in the general population, this group's mobility was impaired due to musculoskeletal decline - arthrosis (27%) and hip fractures (13%), producing weakness and pain; neurological decline - stroke (3%), visual deterioration (7%), parkinsonism (11%), dementia (4%); and respiratory restriction (1%).

In a survey of 1371 adults with ID over the age of 40 years living in group residences in two areas of New York State, Janicki et al (2002) found an increased frequency of musculoskeletal conditions with increasing age, mostly related to osteoarthritis and osteoporosis. Using the same instrument (Greater Rochester Area Health Status Survey) a study in Israel (Merrick et al, 2004) and a study in Taiwan (Wang et al, 2007) demonstrated similar results with respect to musculoskeletal conditions whether the people lived in institutional or community settings.

Deterioration in muscular function occurs insidiously with ageing in adults with Muscular Dystrophies. A five year follow-up of 46 subjects in Sweden demonstrated measurable decline in functional muscle tests and in lung vital capacity (Dahlbom, 1999) and a qualitative survey of change over ten years reported increasing restrictions on mobility and increased fatigue and feebleness (Bostrom, 2004).

Strauss et al. (2004) studied the pattern of functional abilities and decline of skills in 904 adults with cerebral palsy over the age of 60 years in registered with the California Developmental Disabilities database. In those who were ambulant in adulthood there is a marked decline over 60 years. Survival of people who had lost mobility in later life was poorer than in the general community.

### **Increase in musculoskeletal pain**

It is surprising that Pain is a topic which is not discussed much in publications about the health of adults with ID, and it is almost non-existent as a topic in literature on older adults with ID.

The incidence of chronic pain associated with advancing age in the general population varies from 25 to 70% in people over 65 years and 8 to 37% in people between 25 to 34 years (Ageing Research Online, 2008). Recurrent acute musculoskeletal pain is a frequently reported symptom in older people, as is pain in other organ systems. It is believed that this is

related to ageing of those organs. In addition it has been postulated that the ageing brain may experience more pain. A recent project in Australia (Blyth et al, 2008) studied 1500 older men and concluded that central mechanism deterioration (associated with ageing) may be a factor in the persistence of pain in men with cognitive decline. Everyday pain and discomfort tends to be elevated among persons with ID (Symons et al., 2008), and increasingly prevalent in older adults with advancing age. However, empirical evidence about age-associated pain prevalence is still missing.

One study has shown higher rates of arthritis and back pain for the general population than for adults with ID. A postal survey of a random sample of 4000 persons with ID (with a 56% useable response rate) showed that people with ID in Wales had lower levels of arthritis and back pain compared to the general population (HMSO, Welsh Office, 1996). There are various explanations for this unexpected finding, which reflect the difficulties associated with all health-and illness-related reporting in people with ID.

First, a postal survey is not a very sensitive research tool to detect “pain” in persons with ID. Second, persons with ID have methods other than verbal reporting for expressing ‘pain’. Self-reports of pain are less common in persons with ID and less valid with regard to time, location and intensity of pain (Foley & McCutcheon, 2004). There are indications that reporting of pain by persons with ID decreases as cognitive impairment increases (Gabre & Sjoquist, 2002).

If a person with ID is unable to communicate with words, pain may be communicated in the following ways:

- vocal responses
- adaptive behaviour (e.g. rubbing of the affected area, avoiding certain movements, keeping area still)
- self-distracting behaviour (e.g. rocking, pacing, biting hand, gesturing)
- facial expressions (e.g. grimacing)
- withdrawal, low mood
- sleep disturbance
- self injurious behaviour
- hyperactive behaviour
- autonomic changes (increased/decreased pulse, blood pressure, sweating (Tuffrey-Wijne, 2008; Reynard et al., 2002; Astor, 2001; McGrath et al., 1998).

Third, pain assessment is quite difficult even for nurses and physicians. Even today, many assessment tools for pain for persons with ID are still in the stage of development (Regnard et al., 2007; Phan et al., 2005; Bromley et al., 1998), and most are tested only on specific subgroups of persons with ID (Breau et al., 2002; 2003; Defrin et al., 2004). Mere interpretation of nonverbal facial expressions has substantial limitations for the assessment of pain in this population (La Chapelle, Hadjistavropoulos & Craig, 1999; Bromley et al., 1998). In a study of Zwakhlen et al. (2004) a questionnaire consisting of 158 indicators of pain was used for 109 nurses from nine Dutch residences for persons with ID. All 158 indicators were mentioned as being important to indicate pain. Seven pain indicators (moaning during manipulation, crying during manipulation, painful facial expression during manipulation, swelling, screaming during manipulation, not using affected body part, and moving the body in a specific way of behaving) were reported as “very important” by more than 50% of nurses.

Fourth it is possible that persons with ID who are predetermined by comorbidity for back pain or arthritis were significantly underrepresented in the study sample or were overrepresented in the non-response group. An important group in this respect is persons with cerebral palsy. Sixty six per cent to 94% of adults with cerebral palsy experience pain, but are less likely than people with other disabilities to report that pain interferes with activities. Pain can be difficult to assess in this group since so many persons with cerebral palsy have communication or cognitive deficits (NCPAD, 2007). Reasons for musculoskeletal pain for patients with cerebral palsy are: spasticity leading to bony deformations, contractures, and joint stress; scoliosis; congenital dislocations and/or hip subluxation; and wheelchair use.

### **Chronic non musculoskeletal pain**

Back pain is only one example of chronic pain. Many older people, including persons with ID, are experiencing pain as they age with increasing frequency of occurrence of single or multiple medical conditions including osteoarthritis, osteoporosis, cancer, diabetes, constipation, hip fractures, dental problems, infections, headaches, pressure sores, gastro-oesophageal reflux etc. Pain that is not recognized or poorly managed can affect quality of life. As has been outlined above, as many persons with ID have difficulty communicating their pain or may not understand pain signals, they are at increased risk of not having pain adequately identified or treated.

There is some recent literature on site specific non musculoskeletal pain. Period pain and premenstrual syndrome in women with ID was systematically studied by Kyrkou (2005) with regard to women with Down syndrome. Compared to women with either autism or Asperger syndrome, women with Down syndrome were more often able to state that they had pain or point to the location of the pain. Women with Down syndrome appeared to have a higher rate of period pain than women in the general population, but the presence of pain had to be deduced more often by observers from behavioural changes.

While staff and physicians need to be able to recognize signs of pain and distress in persons with severe ID and limited verbal capabilities (La Chapelle, Hadjistavropoulos & Craig, 1999; Evenhuis et al., 2000), individuals with mild ID, who have potential communication skills need to be educated in the effective communication of pain or distress (Bromley et al., 1998).

### **Disturbance of Vision**

Many recent articles about vision in individuals with ID are cited and discussed in an overview article by Owens et al. (2006). We have used this overview for core information and added to it. Although causes of visual loss were thought to be present in rates similar to those in the general population for presbycusis, cataract, presbyopia, macular degeneration, glaucoma and diabetic retinopathy by the IASSID working group in 1999 (Evenhuis et al., 2000), more recent publications suggest otherwise.

There are differences in rates of vision impairment compared with the general population regarding overall, as well as age-specific and cause-specific prevalence rates. Data available now indicate that vision problems (e.g.; refractive errors, strabismus, cataracts, and kerataconus) are more common among individuals with ID than those without ID (Kapell et al., 1998; Carvill, 2001; Warburg, 2001a). As in the general population, there is a significant increase in vision problems in persons with advancing age (Janicki et al., 2002; Merrick et al., 2004). In a USA-study, Kapell et al. (1998) found that 9-16% of 45 to 64 years old, and 17 to 50% of 65 to 74 years old New York residents with ID had vision problems. The comparable rates for the general US population were respectively 5% of those between ages of 45 and 64

years, and 7% of those over 65 years. Other studies (Janicki & Dalton, 1998; Evenhuis et al., 2001b; Warburg, 2001b; Janicki et al., 2002; Kerr et al., 2003; van Splunder et al., 2003a, 2004) have reported that 18 to 99% of persons older than age 50 have vision problems.

The most common cause of decreased vision in individuals with and without ID is refractive errors, including hyperopia (farsightedness), myopia (nearsightedness), and astigmatism. While 4 to 25% of the USA general population has a refractive error, 27 to 52% of individuals with ID in the US and Canada has been reported to require corrections of refractive anomalies (USDHHS, 2000; Friedman et al., 2002; Congdon et al., 2003; The Eye Diseases, 2004a; USPSTF, 2004b). Van Splunder et al. (2003) studied a sample of 900 persons with ID in Dutch residential settings. 153 of 374 persons (41%) had inadequate prescriptions for refractive errors and 41 of 221 persons (19%) without any prescriptions benefited from new interventions.

While the overall population prevalence of strabismus ranges from 0.3 to 10%, researchers found the prevalence of strabismus among individuals with ID to range from 4 to 45% (Buch et al., 2001; van Splunder et al., 2003a, 2003b, 2004; Woodhouse et al., 2003). The prevalence of strabismus has been reported to range from 9 to 69% among individuals with Down syndrome, compared with less 1 to 10% in the general population, and 4 to 45% in individuals with ID from any cause (Woodhouse et al., 2003; van Allen et al., 1999; Buch et al., 2001; Merrick & Koslowe, 2001; Cregg et al., 2003; van Splunder et al., 2003b; 2004; Gormezano & Kaminsky, 2005; Murphy et al., 2005).

The prevalence of cataract (opacity of the lens of the eye, the capsule, or both) and keratoconus (swelling and scarring of the cornea) among individuals with ID also has been reported to be much higher than that in the general population (Warburg, 2001b; Friedman et al., 2002; Congdon et al., 2003; Foran et al., 2003; Kerr et al., 2003; Kleinstein et al., 2003; van Splunder et al., 2003b, 2004; The Eye Diseases, 2004b). British administrative data suggest prevalence estimates of cataracts as high as 28% among individuals with ID (Kerr et al., 2003), while a study of individuals with ID of age 60 years and older in Dutch residential homes found that 69% had cataracts (Evenhuis, 1995). Prevalence rates for keratoconus are higher among individuals with ID compared to the general population (1 to 19% versus less than 1%, respectively), with the condition reported to be more common among males than females with ID (Warburg, 2001b; van Splunder et al., 2004). These high prevalence estimates among individuals with ID may be due in part, to the association between cataract, keratoconus, and Down syndrome. Among older adults with Down syndrome vision problems tend to occur at an earlier age than in the general population.

In older adults with ID, in general, vision problems are not only more frequent, but the impairments are also more severe in many cases because of pre-existing childhood onset visual pathology (Evenhuis et al., 2000; IASSID, 2002), and other co-existing sensory and physical impairments. The IASSID publication on health guidelines for adults with ID (IASSID, 2002), refers explicitly to the health, educational and environmental implications of older adults with vision problems, because of the superposition of age-related losses upon childhood impairments.

Older persons with ID with lifelong vision impairment are in many cases not well prepared by educational measures, attitudes from others, rehabilitative efforts or changes in the physical environment to cope well with their vision problem. French (2007) interviewed six visually impaired persons with ID and their proxies about the education and training these persons

received from 1900 to 1970. It reveals that if visually impaired children with ID were given education at all, their needs were not usually met and they were frequently subjected to an oppressive and abusive institutional regimen. When new problems occur they are not well-prepared to deal effectively with them.

Persons who are daily in contact with adults with ID, family members or staff persons, are often not sensitive, experienced or informed enough to deal effectively with significant regression of vision function in their clients. In the UK, nursing caregivers assessed vision as “perfectly normal” for 49% of their clients although less than 1% were assessed as having normal vision on ophthalmological testing (Kerr et al., 2003).

Apart from persons with Down syndrome and older adults with ID there is another group of persons with high prevalence rates of visual impairment. In their study on 76 persons with severe and profound multiple disabilities, Van den Broek et al. (2006) found an unexpected 92% of clients to have visual impairment. Only 30% were known to have visual problems. None of the persons observed had normal visual acuity. The severity of the visual impairment was related to the severity of ID. In addition to the low acuity, impairments in the visual field, impaired contrast sensibility and impaired binocular functioning were found, as well as impaired visual attention, fixation and following. In 22% of the persons, refractive errors were found and glasses were advised. Responding to the high rates of formerly undetected cases of visual impairment in their study, Van Splunder et al. (2006) advise that all persons with severe and profound ID, and all older adults with Down’s syndrome should be considered as visually impaired until proven otherwise.

Detection, intervention and referral of vision and hearing problems is one of the main goals for proactive and comprehensive health assessments for adults with ID by General Practitioners, specially trained nurses or health teams (Fender et al., 2007; Hahn & Aronow, 2005; Lennox et al., 2007; Ruddick & Oliver, 2005). By using the Comprehensive Health Assessment Program (CHAP) in an Australian randomized controlled field trial, a 6.6-fold increase in detection of vision impairment was found by GPs in the intervention group compared with their colleagues in the control group (Lennox et al., 2007).

For adults with ID, routine screening for age-related visual loss at 45 years and every 5 years thereafter has been recommended (Evenhuis & Nagtzaam, 1998). If possible, this should be done by an ophthalmologist. An extra vision check at age 30 has been recommended for adults with Down syndrome (IASSID, 2002).

### **Decline in Hearing**

The prevalence of hearing impairment in the population of persons with ID is considerably higher than in the general population (Evenhuis et al., 2001; Beange et al., 2000; van Schrojenstein Lantman-De Valk et al., 2000). There is a high prevalence for conductive hearing loss caused by chronic middle ear infections and ear wax blocking the canal, and a moderate prevalence for sensorineural and mixed hearing loss. In particular, persons with Down syndrome are at a greater risk for loss (Meeuwese-Jongejeugd et al., 2006; Shott et al., 2001; Roizen, 1996).

As noted with vision there is also a strong increase in the prevalence of hearing impairments with age (Merrick et al., 2004; Janicki et al., 2002). The proportion of undetected hearing impairment is large, even among people with mild and moderate ID. Also in “healthy” self selected samples, like participants at the Special Olympics, high prevalence rates of

undetected hearing impairment were found. At the German Special Olympics Summer Games 2004, a hearing screen was conducted on 755 athletes with ID (Neumann et al., 2006). 38 % of the athletes failed the screening. 53% needed ear wax removal. 56% of the fails indicated sensorineural hearing loss and 13.6% indicated mixed hearing loss. 12.5% of the fails were caused by unremovable ear wax, 1.4% by ear canal affections, and 16.4% by middle ear problems. The authors estimate that because of the high failure rate, a high percentage of previously undetected profound hearing loss, and the frequent need for ear wax removal, nearly half of persons with ID need regular otological or audiological consultations.

Two years later during the German Special Olympics Summer Games 2006, 552 other athletes with ID had their hearing screened according to the international protocol of Healthy Hearing Special Olympics (Hild et al., 2007). This screening protocol includes otoscopy, measurement of distortion product otoacoustic emissions, and if necessary- tympanometry and pure tone audiometry (PTA) screening at 2 and 4 kHz. 195 athletes from this group underwent a full diagnostic PTA. The results of the screening and diagnostic PTA were compared. Of the 524 athletes who completed the screening protocol, 76% passed and 24% failed. Ear wax was removed in 48% of all athletes. 42% of the athletes were recommended to consult an otolaryngologist or an acoustician. Of the 99 athletes whose screening-based suspicion of a hearing loss was confirmed with a diagnostic PTA, 74 had an undetected hearing loss. The correlation (Cramer's V) between screening and diagnostic PTA was .98. The sensitivity of the screening was 100% and the specificity 98%.

These screening outcomes are excellent. However, detection of impairment will be significantly lower in situations with less financial means for screening, less expert knowledge and with an unselected group of adults, including old people, people with severe and profound cognitive impairments, and persons with challenging behaviour. The mean age of the athletes of this Special Olympic Summer Games was 27 years (age range 10-69 years). Hild et al. (2007) mention that the hearing loss of older adults with ID will be particularly more frequent and more serious, because ageing-related hearing loss is additive to earlier causes of hearing loss.

Again, and similar to vision problems, the age-related hearing loss of persons with Down Syndrome considerably exceeds the age-related hearing loss in other persons with ID, and reaches almost 100% after the age of 60 years (Meeuwese-Jongejeugd et al., 2006).

Reversible changes in hearing function are often neglected by staff members who are in direct contact with clients with ID. In a British study, nursing staff reported that 74% of the persons with ID had perfect hearing. Formal assessment indicated only 11% to have normal hearing, with 61% having mild hearing loss, 15% having moderate to severe loss, and 13% having profound loss. For many, but certainly not for all, removal of ear wax, was a solution to the problem (Kerr et al., 2003).

In the study of Aerts et al. (2003), 185 clients of 3 vocational centres for persons with ID, were screened for hearing impairment. It showed that more than half had hearing impairments. Risk groups for hearing impairment were persons with Down Syndrome and the elderly (60+yrs). All of whom had hearing impairments. This study also highlighted that in many cases hearing impairments had not been diagnosed previously and most were treatable to some extent.

Evenhuis et al. (2001) found a prevalence of hearing impairment of 21% in a Dutch residential sample of 672 persons with ID. The authors highlighted the need for adjusting the environment to the sensory limitations of clients, and the need for staff training to deal with limitations. Some years before, in the same country, Mul et al. (1997) found that 83 of 206 persons with ID (49%) who were registered with General Practitioners, had hearing impairments. In 80% of the cases, this diagnosis was unknown both to the General Practitioner and to family or staff.

Using the CHAP, Lennox et al. (2007) found in Australia a 30-fold increase in hearing testing, with high rates of potential hearing impairment and referrals to specialists.

Routine screening for age-related hearing loss for all adults with ID at age 45 and every 5 years thereafter has been recommended (Evenhuis & Nagtzaam, 1998). If possible, this should be done by an audiologist. Screening of the hearing function of adults with Down syndrome is recommended every three years throughout life (IASSID, 2002).

### **Constipation**

The most used definition of constipation in research (Böhmer et al., 2001) is bowel movement less than 3 times a week or the necessity to use laxatives more than 3 times a week. The prevalence rates for constipation in adults with ID are higher than in the general population (Lembo & Camillari, 2003; Talley et al., 2003).

Van Winckel et al. (1999) studied a random sample of 420 persons (mean age 29 years, range 2 to 72) in 21 residential care centres in Belgium for the use of laxatives. They found regular use of laxatives in 26.4%, and occasional use in 2%. Böhmer et al. (2001) analyzed a random sample of 215 persons with ID in 4 Dutch residential care centres. Nursing staff recorded constipation over a 6-months period. They found that 69.3% (mean age 31.8 years, range 6 to 77 years) had constipation during the observation period. Compared to the controls constipation was found more often with the following risk factors: non-ambulatory, cerebral palsy, anti-convulsive medicine, benzodiazepines, proton pump inhibitors and IQ less than 31 (Böhmer et al., 2001).

The lowest rate (8%) for constipation is reported by Morad et al. (2007) for adults age 40 and older in residential care in Israel. They confirm the findings of Van Winckel et al. (1999) and Böhmer et al. (2001) that age was not correlated with higher rates of constipation. Morad et al. (2007) conclude that the normal ageing process is in itself not a risk factor for constipation, but age-related conditions such as immobility, cerebral palsy, neurological disease, specific drugs and physical inactivity do contribute.

### **Bowel and Bladder Incontinence**

Poor control of bowel and bladder continence arises in the general population as it ages by reason of both central and peripheral neurological decline as well as mechanical issues related to childbirth and obesity. As with many bodily functions, continence has biological, behavioural and social dimensions. It is known that many young people with ID have biological problems with bowel and bladder incontinence, particularly those with cerebral palsy and spina bifida associated with their cognitive impairments. As those without existing physical impairments age, they may develop incontinence, like their peers in the general population as they become obese; or as their minds dement. Although the prevalence of incontinence rises with increasing age in people with ID, we found no significant studies citing continence difficulties as a major concern.

## **DETERIORATION AND DISEASES MORE PREVALENT WITH AGEING**

### **Brain and neurological function**

A number of studies have found a higher prevalence of epilepsy among persons with ID compared with the general population, in general practice, outpatient and in institutional settings. The estimated prevalence rates vary in range from 14% to 44% (McDermott, Moran, Platt, & Dasari, 2006; Lin, Wu, & Lee, 2003; Christopher et al., 2003; Espie et al., 2003; van Schrojenstein Lantman-de Valk et al., 2000).

Consequences of epilepsy include sudden unexpected death, trauma caused by falls leading to fracture and soft tissue injury, hospital admission, the impact on learning and development (IASSID, 2002), and the complex social impact of seizures (McGrother et al, 2006; Baxter, 1999). Loss of consciousness in fits can lead to burns and drowning. It is also apparent that epilepsy adds to carer strain and burden (Wilson, 1998). As is pointed out by Van Schrojenstein Lantman-de Valk (2005) inadequate dosage of anticonvulsants may diminish alertness. Long-term use of anticonvulsants may cause osteoporosis – an additional risk for fractures (Wagemans et al., 1998; Jancar & Jancar, 1998).

As in the general population (Amatniek et al, 2006; Hesdorffer et al, 1996), seizures may develop in people with Down Syndrome as they age as a precursor to the manifestation of dementia (Collacott, 1993).

### **Dementia**

Dementia is the syndrome of progressive memory loss, other cognitive loss (from a stable baseline), epilepsy and behavioural change that occurs with pathological deterioration of the brain. However, in advanced stages primary body functions are also affected, such as loss of vision and speech, incontinence and mobility (Haveman, 2005). Generally it is considered an older person's disorder. Amongst the population with Intellectual Disability we are aware of some genetic syndromes associated with extremely early dementia – eg Rett Syndrome, Angelman Syndrome. It is well established that people with Down Syndrome develop Alzheimer's Disease (the most commonly diagnosed cause for dementia) at a younger age than the general population (Tyrrell et al, 2001; Holland et al, 2000, 1998; Zigman et al, 1996; Prasher, 1997). There is also good evidence for increased prevalence of dementia in community populations of people with Intellectual Disability over the age of 65 years without Down Syndrome, compared with the general population (possibly because of the earlier age of onset) (Cooper, 1997; Strydom et al., 2007). The epidemiology, clinical presentation and management of dementia in older adults with ID has been reviewed by another IASSID SSCA group .

### **Heart disease**

Cardiovascular disease is the primary cause of death in people with ID in most western countries. The published relative and absolute cause-specific mortality rates in various countries for persons with ID have varied considerably as a result of factors related to patient selection, sample size, and quality and reliability of datasets. In many studies the subjects were drawn from institutional care or service registers (Maaskant, 2002; Janicki, 2002). With

only one exception, there have been no studies reporting cause-specific mortality trends in population-based samples.

The Finnish study (Patja et al., 2001) is based on a 35 year follow-up of a nation-wide population of 2319 persons with ID aged between 2 and 97 years. Of these persons 1095 died within this 35-year period. Vascular diseases constituted the largest group of primary causes of death at 36%. This percentage was lower than in the sex- and age-matched general population. The relative risk for vascular mortality was lower for men with ID in all groups and for most women except those with mild or moderate ID aged between 20 and 39 years. In the younger age group, congestive heart failure, aortic aneurysm and cardiomyopathy were the most common causes of cardiac death, and these were in people with Down and other syndromes with known associations with valvular and structural abnormalities.

Among the vascular diseases, acute cardiac infarction was the cause of death in 38% of cases, cerebral infarction or bleeding in 33%, congenital heart disease in 18% and pulmonary infarction in 6% of the cases. Mean age at death as a result of cardiovascular diseases was 63.2 years. Of those who died at an older age, vascular disease was cited less frequently than the general Finnish population.

Although not population based, other studies have noted increased reporting of congenital heart defects as a cause of death, in individuals with Fragile-X, Down and Rubenstein-Taybi syndromes (Barnard et al., 2002), and hypertension as a comorbidity in people with Williams and Turner Syndromes (O'Brien, 2008), but this appears to have had an impact on young and middle age mortality rather than old age mortality.

The findings from the Finnish study (Patja et al., 2001) with regard to causes of death are similar to those found in the USA (Strauss et al., 1998; Janicki et al., 1999; Esbensen et al., 2007). The most common causes of death in those studies were cardiovascular diseases, respiratory diseases and cancer. Some other reports indicate that cardiovascular disease-related death rates were greater for persons with ID than for the general population (Hill et al., 2003; Day et al., 2005). As those figures are not age-specific comparisons, the reported overall increase in cardiovascular disease prevalence with ageing and the elevated mortality risk for adults with ID may be due to the fact that adults with ID have a longer life-expectancy than decades ago.

With regard to prevalence, the frequency of cardiovascular impairments in persons with ID has increased in the USA (Cooper, 1998; Janicki et al., 2002), in Israel (Merrick et al., 2004) and in Taiwan (Wang et al., 2007). However, compared to the general population cardiovascular disease (CVD) prevalence, as well as its risk factors of hypertension, hyperlipidemia and adult-onset diabetes was lower in the USA study (Janicki et al., 2002) and the Israel study (Merrick et al., 2004) compared to the general population. Both research teams explain these differences with regard to the general population by underdiagnosis or by cohort effects. 'No ischemic heart disease' was found more frequently in older adults (age 45 and older) with ID in the US compared to the general population ( Kapell et al., 1998).

Van den Akker et al. (2006) studied cardiac diseases in a Dutch residential facility (n=436). It showed that the prevalence of cardiac diseases is higher in the older age groups. Taking the age-group of 30-49 years old persons as reference group, those aged 50-59 years, 60-69 years and 70+ had statistically significant higher risk (OR=1.78, 2.73 and 4.83) for cardiac disease. The elderly suffered more than younger from hypertensive and cerebrovascular diseases.

When adjusting for level of ID, sex and etiology (Down syndrome vs. other etiologies), elderly people (50+) had higher risk (OR: 2.44) for cardiac disease, compared to those aged under 50.

The behavioural risk factors for cardiovascular disease for adults with ID (Wilkinson, Culpepper & Cerreto, 2007) are similar to those for the general population and they include smoking (McGillycuddy, 2006), nutritional intake (Draheim et al., 2002b, 2007; Braunschweig et al., 2004) and exercise or physical activity level (Draheim et al., 2002b,c, 2003; Temple & Walkley, 2003; Frey, 2004; Stanish & Draheim, 2005, 2006a).

### **Diabetes**

Studies which report on diabetes in the USA show higher rates compared to the general population (Draheim et al., 2002a; Janicki et al., 2002), with a decreasing prevalence with increasing age. There is a significant chance that type 2 diabetes as well as other cardiovascular risk factors, are systematically underestimated for the group of older adults with ID (Janicki et al., 2002; Merrick et al., 2004); or there may be a 'survivor' confounder. It is notable that the percentage of adults with known cardiovascular disease risk factors, such as type 2 diabetes, hyperlipidemia, BMI more than 27, lack of weekly exercise, and hypertension, decreases as ID became more severe (Merrick et al., 2004). It is postulated that underdiagnosis may be occurring, or that nutritional intake and lack of smoking being influenced by carers, rather than person choice may be operating.

### **Hypertension**

The existing data on rates of hypertension in adults with ID is somewhat conflicting. Adults with ID may have more risk factors for the development of hypertension, such as obesity and inactivity (Bhaumik et al., 2008). One large study showed an inverse correlation of intelligence with blood pressure later in life, although not all subjects were people with ID (Starr et al., 2004). Other studies noted lower rates of hypertension but similar death rates from cardiovascular disease in adults with ID compared with the general population (Draheim, McCubbin & Williams, 2002; McDormett & Platt, 1997; Janicki et al., 2002), still others commented on higher rates of hypertension as adults with ID age (Cooper, 1998). These papers vary in their methodology and in their rates of inclusion of people with Down Syndrome. There are indications (Kapell et al., 1998) that adults with Down syndrome have, compared with other adults with ID, significantly lower rates of hypertension.

Janicki et al. (2002) collected health status information and patterns of morbidity on a large cohort of adults with ID aged 40 years or more living in small group, community based residences in the state of New York. Most subjects were characterized as being in good health with some conditions increasing with age (e.g., cardiovascular) and others declining with age (e.g., psychiatric). Although most conditions increased with age, their frequency varied by sex and level of disability. It was found that adults with ID had a lower overall reported frequency of signs of cardiovascular illness, including hypertension, hyperlipidaemia, and adult-onset diabetes. That being said, inconsistencies were found with mortality data among older adults with ID. A new study (Henderson et al, 2008) conducted in a similar area of the USA, demonstrated lower rates of overweight and higher rates of obesity in community dwelling adults (<5% over 65yrs) and similar rates of hypertension to the general population.

### **Gastrointestinal diseases**

Many older adults with ID were, or are, residents of large institutions and therefore at higher risk for hepatitis B, tuberculosis and *Helicobacter pylori* infections.

Numerous studies have verified high prevalence rates for **Helicobacter Pylori**(HP) infection in participants with ID who had been formerly institutionalised (Clarke et al, 2008; Kennedy, 2002; Morad et al, 2002) compared with those who had never lived in aggregate care and higher rates for those who had lived longer in institutional care (Wallace et al, 2002) and for those with lower IQ (Böhmer et al, 1997).

A study conducted in Canada (Kennedy, 2002) examined prevalence rates for Helicobacter Pylori and discovered that 80% of participants who had been formerly institutionalized suffered from the infection. This was 3 to 4 times higher than adults who never lived in an institution. A lower percentage (59%) was found in a recent study for persons with ID (and psychiatric patients) living in inpatient units (Clarke et al., 2008). Statistical analysis with regard to length of inpatient stay showed that 22% of the persons who stayed shorter than 4 years had a positive antibody test compared to 84% of those who stayed longer than 4 years. Treatment led to eradication of HP infection in 11 of the 12 people who were able to cooperate with testing.

Similar high prevalence rates of HP were found for persons with ID in other studies. Wallace et al. (2002) reported rates of HP infection of 87% for people with ID living in institutions, 78% for those previously living in institutions and 44% for those with no history of institutional care. Böhmer et al. (1997) reported a HP infection rate of 87% among 338 persons with ID living in institutions in the Netherlands, and noted an association with male gender, longer history of institutionalization and lower IQ. Morad et al. (2002) reported a prevalence estimate of 77% for persons with ID who were resident in institutions in Israel.

The high occurrence rate of HP is troubling. Many persons with ID are infected, and some of them can develop serious consequent conditions such as peptic ulcers and gastric cancer (Beange & Lennox, 1998). Duff et al. (2001) reviewed deaths from cancer in the Stoke Park Group of hospitals in England, and found that stomach cancer accounted for 48% of all deaths from cancer, with a further 25 residents dying from perforated stomach ulcers. They hypothesised that helicobacter pylori infections might be a factor. HP is recognized as the most important cause of chronic active gastritis, and HP colonization of the stomach is almost inevitably followed by histological signs of chronic inflammation. Chronic gastritis is now believed to predispose to metaplasia (cell abnormalities) and stomach cancer.

Although effective treatment of HP infections is available, recurrence rates are quite high. Wallace et al. (2004) re-tested 28 adults with ID 36 months after successful eradication therapy and found a recurrence rate for HP infection of 21% (7% per year).

The above mentioned HP prevalence rates for persons with ID are higher compared with the general population. But HP infection is also common in the general population. Up to 50% of the general population has HP infection (Goodwin et al., 1997). One study in the USA found an incidence rate of infection during childhood of 1.4% per year, with a prevalence of 24.5% at age 21-23 years (Malaty et al., 2002).

**Gastro-oesophageal reflux disease** (GERD), a disorder affecting 5-7% of the general population (IFFGD, 2003) is a major clinical problem in people with ID. It may be overlooked and underestimated (Evenhuis et al., 2000; Böhmer et al., 1999, 2000) in both institutionalised and community dwelling people with ID (Tracy and Wallace, 2001). GERD

is a disorder characterized by frequent backflow of gastric content into the oesophagus. Common GERD symptoms in the general population are (Forester et al., 2002):

- Heartburn 70-85%
- Regurgitation 60%
- Dysphagia 15-20%
- Angina-like pain 33%
- Bronchospasm 15-20%

The prevalence of GERD and reflux oesophagitis in people living in institutions is very high, especially in those persons with specific and well-defined risk factors. In a population of Dutch residential facilities, approximately one third of individuals with ID were diagnosed as having reflux oesophagitis (Böhmer et al., 1999), though other studies have found even higher prevalence rates (40 to 50%) (Böhmer et al., 2000; Tracy & Wallace, 2001). Possible predisposing factors include non-ambulancy, scoliosis, cerebral palsy, use of anticonvulsant drugs, benzodiazepines, and IQ less than 35. Symptoms in this population indicative of reflux are: vomiting, haematemesis, regurgitation, food refusal, recurrent pneumonia, rumination, and behaviour problems such as self-injurious behaviour, aggression, fear, screaming episodes, restlessness and depressive symptoms.

We did not find articles which dealt more specifically with GERD in older adults with ID.

### **Skeletal disorders**

In the general population it has been established (Gordon, 2008) that there is a relationship between aerobic fitness and Bone Mineral Density (BMD) (Kronhead et al., 1998), with the association suggesting that in those individuals who undertake regular exercise there are higher BMD scores; and a decrease in the value is associated with decreased levels of loading on the musculoskeletal system (Heinonen et al., 1999). Several studies reported that **osteoporosis** and associated **fractures** are more prevalent among the population with ID compared to the population without ID (Lesley et al., 2008; van Schroyensteen Lantman-de Valk et al., 2000; Beange and Lennox, 1998; Center et al., 1998; Lohiya et al., 1999;). Factors associated with osteoporosis were small body size, hypogonadism, and Down syndrome (Guijarro, Valero et al., 2008; Angelopolou et al., 2000), and combinations of these factors (Center et al., 2004; Nevill et al., 2002; Melton et al., 2000;). A lower peak BMD and lower muscle tone have been suggested among the predisposing factors (Center et al., 1998; Tyler et al., 2000; Mugica et al., 2002; Schragger, 2004; 2006).

Subgroups of people with ID are at an increased risk of fracture, and an increased risk of falling has been documented (IASSID, 2002). Lohiya et al. (1999) found that fragility fractures occurred 1.7 to 3.5 times more frequently among a population with ID. Similarly, van Schroyensteen Lantman-de Valk et al. (2000) found that fractures were 3 times more prevalent among people with ID compared with the population without ID. Glick and associates (2005) commented that fracture detection is often delayed in people with ID due to profound cognitive and skeletal disabilities, and lack of communication skills, in spite of the presence of pain.

Vonken et al. (2006) studied **musculoskeletal diseases** in 403 residential clients of a Dutch service provider. The study showed a prevalence rate of congenital musculoskeletal diseases (CMD) of 6%, with a higher prevalence in persons with severe/profound ID. The prevalence of acquired musculoskeletal diseases (AMD) was 20%, with a lower prevalence among persons with Down syndrome. The risk of having CMD, and AMD in general was not related

to age. However, elderly (50+) were more at risk of having arthrosis (adjusted OR: 2.87 (90% CI: 1.14-7.18)) than younger adults (30-49 yrs).

### **Immune system pathology in people with Down Syndrome as they age**

It has been established that both the innate and the acquired immune systems in people with Down Syndrome undergoes precocious ageing (Nespoli, 1993) with subsequent similar immune deficiency manifestations to the general population (Burkle, 2007; Effros, 2005); that **thyroiditis, coeliac disease, and diabetes mellitus** occur more frequently in people with Down Syndrome than in the general population (Cohen, 2006; Kinik, 2006; Hansson, 2005) and that there are altered T-cell activity and tumour marker levels in people with Down Syndrome (Prada, 2005; Oda, 1993; Ugazio, 1990).

Interestingly people with Down Syndrome can have high levels of triglycerides and high levels of CRP but no increase in the frequency of cardiovascular disease (Corsi, 2005). It is likely that this finding is linked to the high incidence of early development of Alzheimers Disease in people with Down Syndrome – a disorder now thought to be related to micro haemorrhage and inflammatory response (Hirayama, 2003). Standardised incidence rates of **leukaemia** in people with Down Syndrome are significantly higher than for the general population (Sullivan, 2007; Boker, 2002). Health issues associated with aging in adults with DS has been reviewed by another SSCA group .

### **Cancer**

Another consequence of the increasing life expectancy of persons with ID is that cancer are becoming more common (Hogg & Tuffrey-Wijne, 2008; Hollins et al., 1998; Janicki et al., 1999, 2002a; Maaskant et al., 2002; Patja et al., 2000; Strauss et al., 1998; Sullivan et al., 2004; Yang et al., 2002). In the studies of Janicki et al. (2002) and Merrick et al. (2004) a significant increase of cancer with age was reported, but with about the same frequency and rate as in the general population. Studies have shown that around one in ten persons with ID now die of cancer (Cooke, 1997; Hollins et al., 1998). This implies that like the rest of the population, many people with ID will require special pain and symptom control in palliative care at the end of their lives.

### **Multimorbidity in older age**

Multimorbidity can be defined as two or more conditions which occur together in individuals (Van den Akker et al., 1996; Kadam et al., 2007). Multimorbidity is quite common in older adults without ID (Fortin et al., 2005; Van den Akker et al., 1998). In a Canadian study (Fortin et al., 2005) the prevalence of having 2 or more chronic medical conditions in the 45 to 64 year, and 65 year and older age-groups was, respectively, 95% and 99% among women and 89% and 97% for men. The authors concluded that the prevalence of multimorbidity is quite high and increased significantly with age in both men and women. Patients with multimorbidity seen in family practice represent the rule rather than the exception (Fortin et al., 2005; Van den Akker et al., 1998).

Britt et al. (2008) used a large Australian primary care database and defined multimorbidity as the presence of morbidity in two or more domains. 83.2% of patients aged 75 years or older had multimorbidity, 58.2% had morbidity in three or more domains, and 33.4% in four or more. The most common morbidity combinations were arthritis/chronic back pain & vascular disease (15.0% of sample), a psychological problem & vascular disease (10.6%) and arthritis/chronic back pain & a psychological problem (10.6%).

Marengoni et al. (2008a,2008b)) explored the role of age, gender, and socioeconomic status in the occurrence of chronic diseases and multimorbidity in Sweden. Cardiovascular and mental diseases were the most common chronic disorders. Advanced age, female gender, and lower education were independently associated with a more than 50% increased risk of multimorbidity. A cluster analysis showed five clusters, three of which grouped circulatory, cardiopulmonary, and mental diseases. The last two clusters included only one disease (diabetes and malignancy) together with their consequences.

Older adults with ID need a comprehensive and developmental approach on multimorbidity, as well, because many of them have lifelong physical impairments and diseases which complicate the assessment, treatment and prognosis of other medical problems acquired during adulthood and old age. Surprisingly we did not find any publication about co- or multimorbidity in older adults with ID in our review of more recent publications. For the planning of adequate assessments and treatment of health problems of older adults with ID it would be of practical interest to know how different co-morbid conditions are clustered together. It is our expectation that the proportion of multimorbidity in older age-groups of adults with ID will be at least as high as those in general practice.

## **LIFE EXPECTANCY AND MORTALITY**

The life expectancy for persons with ID, along with the general population, has increased during the 20<sup>th</sup> century. Much of this increase can be attributed to improvements in nutrition, mastering the control of infectious diseases and early intervention in illness management.

The most significant increase in life expectancy is reported for individuals with Down syndrome. In 1900 the life expectancy for persons with Down syndrome was only 9-11 years. In 1946, this was increased to 12 years and more recently to 56 (Carmeli et al., 2003). Yang and associates (2002) reported that the mean age at death for individuals with Down syndrome was 26 years in 1983, which had increased to 49 years in 1997. The average age at death for persons with ID was reported as 66.1 years in another study (Janicki et al., 1999).

The published relative and absolute cause-specific mortality rates in various countries for persons with ID have varied considerably partly as a result of factors related to patient selection, sample size, quality and reliability of datasets. In many studies the subjects were drawn from institutional care or service registers (Maaskant, 2002; Janicki, 2002). With only one exception, there have been no studies reporting cause-specific mortality trends in population-based samples. This Finish study (Patja et al., 2001) was based on a 35 year follow-up of a nation-wide population of 2319 persons with ID aged between 2 and 97 years.

Although the cause-specific mortality figures from this study will differ with those from other countries because of differences in lifestyle, climate etc, from a methodological perspective it is the best study to date. Vascular diseases were with 36% the most important primary causes of death, but this was less than in the sex- and age-matched general population. The relative risk for vascular mortality was lower for men with ID in all age groups and for most women except those with mild or moderate ID aged between 20 and 39 years. In the younger age group, congestive heart failure, aortic aneurism and cardiomyopathy were the most common causes of cardiac death, and were often associated with malformations associated with Down syndrome and other syndromes. Among the vascular diseases, acute cardiac infarct was the cause of death in 38% of cases, cerebral infarct or bleeding in 33%, congenital heart disease

in 18% and pulmonary infarct in 6% of the cases. Mean age at death as a result of cardiovascular diseases was 63.2 years.

Although life expectancy for persons with ID has significantly increased over the last few decades, it has remained lower than the estimated life expectancy for the general population. This lower life expectancy is attributed to level of baseline ID in one Australian study (Bittles et al., 2002), which predicted a life expectancy of 58.6 years for people with severe-profound ID; 67.6 years for people with moderate ID; and 74 years for people with mild ID, based on projections from a study of 8,000 people on a state-based register.

Increased life expectancy could also be partially explained by the higher mortality rates in younger age groups (up to age 40) with ID, compared with the general population (Brown et al., 2001; Morgan et al., 2001; Merrick, 2000; Janicki et al., 1999; Hollins et al., 1998). The findings from the Finnish study (Patja et al., 2001) with regard to causes of death are similar to those found in the US (Strauss et al., 1998; Janicki et al., 1999; Esbensen et al., 2007). The most common causes of death in those studies were cardiovascular diseases, respiratory diseases and cancer. Janicki, Dalton, Henderson, & Davidson (1999) explored the mortality and morbidity characteristics of 2752 American adults (one state) with intellectual disability, age 40 and older, who died over a 10 year period. They found that although older adults with ID generally die at an earlier age than do adults in the general population, many of them live as long as their age peers in the general population.

Compared with the Finnish and US data it is astonishing that age and sex adjusted mortality rates for people with ID in England were 18 times higher than that of the general population (Hollins et al., 1998). In another study, a population-derived cohort of 693 people with intellectual disability in Australia was followed for a decade (1989 to 1999) to determine mortality rates, the demographics of the deceased, and causes of death (Durvasula & Beange, 2002). The general population of the same region was used for comparison. The authors found that age- and sex-adjusted mortality rates were almost five times higher than those in non intellectual disability group (standardized mortality rate of 4.9) in the younger age groups. The main cause of death was respiratory disease, followed by external causes and cancer. Of those who had died, the greatest proportion was functioning in the severe to profound range of intellectual disability, and half were living in institutional care.

Fisher & Kettl (2005) discuss how the average life expectancy for persons with mental retardation has improved over the years. A number of factors are found to be important in relation to increased life expectancy for persons with ID including better quality health and social services, residential placements in the community as well as advances in technology and programming. Higher mortality among people with ID was shown to be related to higher morbidity (e.g., Janicki et al. 1999; Hollins et al. 1998; Patja et al. 2000), race (Yang et al., 2002) and aboriginal descent (Bittles et al., 2002).

## **HEALTH DISPARITIES AND MORBIDITY**

Persons with ID, as a group, were found to have a higher rate of morbidity and diagnosed health problems. Studies that focused on health of adults with ID could be classified into three groups:

- (1) studies which described only health screening patterns or the presence or absence of diseases or chronic conditions among populations with ID (Vanlint & Nugent, 2006; van den Akker et al., 2006; Piachaud et al., 1998);
- (2) those which not only described the health status of ID population, but compared health status to that of the general population; and
- (3) those which not only described the health status of ID population, but compared that to the health status of population without any ID.

There were a limited number of studies which focused on health disparities for older adults with ID. The majority of published studies focused on the adult population with ID in general. Given the existing evidence on premature aging of some groups of persons with ID, we selected all the published studies which included persons with ID aged 30 years and above.

As is documented in earlier sections of this report, findings of published research is inconsistent with regard to the prevalence and incidence rates of chronic health conditions for older adults with ID compared with the general population or older adults without ID. Some researchers reported that the rates of a number of frequent chronic health conditions are similar between the older populations with and without ID. Some others found significant differences in rates of health conditions between older population with and without ID. Inconsistencies in the reported results could be attributable to a number of factors including differences in the characteristics of the study population (e.g., age, type of disability, level of disability, gender distribution), operational definition of ID itself, and methods of detection or defining health conditions.

In most cases, proxy reports (by caregivers or parents), or medical records, physical examination or a combination of these methods is used to determine the existence of a health condition or disease. It is evident that physical assessment, medical examinations and tests would help to identify more health issues, which are not associated with visible signs or symptoms.

From the studies reviewed we found evidence on health disparities for persons with ID, particularly in terms of prevalence of a number of preventable health conditions, which usually remain untreated among the ID population. For example, research shows that older adults with ID are more likely to have higher levels of osteoporosis and fractures as a result of decreased mobility (Beange et al., 1998; Center et al., 1998; Glick et al., 2005; Lohiya et al., 1999), dementia (Hogg et al., 2000), other mental illnesses such as depression (Thorpe et al., 2000), increased risk of abuse including sexual abuse (McCarthy, 1999), overweight and obesity (Rubin et al., 1998), and falls (Hsieh et al., 2001) compared to the general population or population without ID.

In 2004, Haverkamp and associates from North Carolina, USA compared data on health status, health risk behaviors, chronic health conditions, and utilization of medical care across three groups of adults: No Disability, Disability, and Developmental Disability. Data sources were the 2001 North Carolina Behavioral Risk Factor Surveillance System and the North Carolina National Core Indicators survey. The authors found significant disparities in health and medical care utilization for adults with developmental disabilities compared to non-disabled adults. Adults with developmental disabilities were more likely to be in fair or poor health, to lead sedentary lifestyles and seven times as likely to report inadequate emotional support, compared with adults without disabilities. Adults with developmental disabilities had a similar or greater risk of having four of five chronic health conditions compared with non-

disabled adults. Significant medical care utilization disparities were also found for breast and cervical cancer screening as well as for oral health care.

One study from the Netherlands showed that adults with ID were 2.5 times more likely to have diagnosed health problems compared with the population without ID (van Schroyen Lantman-de Valk et al., 2000). These researchers found that only 12% of the study population with ID did not have any health problems. This proportion was 21% for those without ID. Similarly, van Schroyen Lantman-de Valk and associates (2004) from the Netherlands found that people with intellectual disabilities had 1.5 times more contact with their general practitioner, more psychological and other health problems, and, higher morbidity than the general population. Using primary health care records (1990-2003), McDermott et al from USA (2006) analyzed common health problems among 3533 adult patients with and without disabilities from urban and rural settings. They found that the prevalence of dementia and epilepsy was significantly higher for adults with disabilities.

Van Allen and associates (1999) from the University of British Columbia also drew attention to the need to provide routine health care screening based on a study of 38 adults living with Down's syndrome at the provincial residential center in British Columbia. The authors summarized common health problems for 18 middle-aged and 20 elderly adults over a 12-year period from 1981 to 1992. The major health concerns were osteoporosis and resultant fractures, dementia/Alzheimer-disease, vision loss due to early onset of cataracts, hearing loss, cardiac diseases and pulmonary hypertension. In 2006, Lin and colleagues identified health characteristics of 1071 people with intellectual disabilities (ID) in Taiwan and assessed their emergency care utilization. They found that although the overall health of people with ID was reported as good/excellent, they carried a heavier burden of diseases than the national norm. The major illnesses were neurological, psychiatric, digestive, dermatological and cardiovascular in origin. Nearly half of the subjects reported an illness and close to one-fifth had used emergency care in the past 7 months.

Research shows that many of the health conditions among populations with ID remain under-diagnosed, diagnosed late or are inadequately managed (Webb et al., 1999; Baxter et al., 2006). For example, Webb and colleagues conducted a health screening of 1311 people with ID in New Zealand and found that 73% of the study population required health related actions such as review of the long standing medication regimens and surgery for previously undetected cancer cases. Baxter and colleagues from UK (2006) conducted comprehensive health checks for 190 adults with ID and reported on previously unidentified morbidity in this population. They found that 51% had new needs recognized and 9% had serious new morbidity discovered.

Findings such as these confirmed the concern usually expressed by the caregivers/parents of persons with ID that current health care systems, which rely on the patients to initiate the contact, will put persons with ID at increased risk of diseases/illnesses that remained undetected and unrecognized.

## **HEALTH PROMOTION AND HEALTH PROTECTION STRATEGIES FOR OLDER ADULTS WITH ID**

Given the evidence that considerable health disparities still exist for older adults with ID, there is plenty of scope for primary, secondary and tertiary prevention to improve the health

and reduce the disability of this population. As showed in figures 2 to 4 in an earlier section of this report, primary prevention implies strategies of health promotion, whereas secondary and tertiary prevention is directed on systematic and general health screening.

### **Primary prevention and Health Promotion Programmes**

Based on the numerous descriptive studies that have documented low levels of physical activity and high levels of obesity in the ID population, a significant need exists for community-based interventions that could improve these and lead to better health outcomes. Only recently have researchers begun to develop health promotion interventions for ageing people with an ID, primarily through the development and evaluation of Health Promotion Programmes (HPP) for groups of people (Lunsky et al., 2003; Marshall et al., 2003; Rimmer et al., 2004).

Podgorski et al. (2004) reported a pilot study of physical activity intervention for older adults with ID. The findings indicated that 92% of the participants experienced improvement in at least one domain of physical function. Physical activity sessions remained a popular choice within the day habilitation setting, and many participants sustained functional gains for a period of one year. Other promising programs included health educational material geared specifically to adults with intellectual disabilities (Heller et al., 2001; Heller et al., 2004; Mann, Zhou, McDermott, Poston, 2006). One such program was tested in a randomised trial (29 females, 24 males, mean age = 39.7 years) and consisted of a 12-week centre-based program using health behaviour education curricula along with an exercise and nutrition intervention. It demonstrated gains in health knowledge, physical fitness, coping strategies, healthy behaviours, and psycho-social well-being (Heller et al, 2004; Rimmer, Heller et al, 2004). Another program used a train-the-trainer model and has been shown to have benefits for both the individuals with disabilities and direct care staff (Marks, Heller, Rimmer, Sisirak, 2007).

### **Systematic health screening of common conditions associated with ageing**

Systematic health screening is employed in the general population for the early identification and treatment of common health problems. Since many of the targeted health problems have strong age associations, particularly malignancies such as cervical cancer or breast cancer, the screening programmes may have considerable benefits in older populations. Studies that compared participation and uptake of health promotion and disease prevention activities for adults with ID with that of the non-ID population (e.g., Strauss et al., 1999; Stein and Allen, 1999; Lennox et al., 2001; Iacono & Sutherland, 2006) have consistently shown that people with intellectual disability receive less preventive health care such as blood pressure checks or cervical smear tests.

Several of these studies focused on screening programs for cervical or breast cancer in women. Stein and Allen (1999) reported that only 13% of eligible women with ID in Great Britain had a record of cervical smear tests during the preceding five years compared with 88% of eligible women without ID. The poor uptake of cervical screening programs in adults with ID has also been demonstrated in other studies in the UK (Broughton and Thompson, 2000; Band et al, 1998) and USA (Lewis et al, 2002). There are now an increasing number of women with ID who fall within the highest risk age group for breast cancer (50-69 years). Although some studies found that the overall incidence of breast cancer in women with ID does not differ significantly from that of the general population (e.g. Patja et al., 2001; Sullivan et al., 2003), the rate of mortality due to breast cancer was found to be higher among ID population compared with the general population. For example, Strauss et al. (1999) found

that the risk of dying from breast cancer for women with cerebral palsy was three times higher than the general population.

In many countries, mammography screening programs are in place to reduce mortality due to breast cancer. However research shows that women with ID are among the least frequent users of these programs (Sullivan et al., 2003; Davies & Duff, 2001; Cowie & Fletcher, 1998; Piachaud & Rohde, 1998; van Schroyensteen Lantman-de Valk, 2002). Sullivan et al. (2003) found that out of 380 Australian women with ID, 34.7% had used mammography screening programs compared with 54.6% for the general population.

There have been only a few studies that have explored the factors which influence the uptake of screening programs such as breast cancer screening (e.g., Sullivan et al., 2004). Iacono & Sutherland (2006) described health screening activities involving a large group of adults living in Australia and explored how factors such as living arrangement, type and severity of disability, and age influenced rates of participation. Participation in screening services ranged from 3% to 58% with rates for certain services appearing quite low; especially when compared to equivalent screenings in the general population. Participation rates varied according to living situation, type of disability, and age, but not severity of disability. In addition, in the Australian setting part of the low uptake of screening may be related to the fact that recruitment for BreastScreen occurs via postal encouragement using the electoral roll, and the addresses of women with Intellectual Disability may not appear on that roll.

### **General health screening for older adults with ID**

Several approaches have been developed to encourage regular health checks that are targeted to the health needs of adults with ID.

The first approach is to use a systematized general health assessment or health check which is undertaken by a health professional such as a nurse or primary care physician. An example of a health check specifically developed for adults with ID is the Cardiff checklist (Baxter et al, 2006). There are indications (Felce et al., 2008) that the incidence of new health problems in follow-up yearly health checks in adults with ID are as high as in the initial screening. The authors conclude that annual health checking could be a justifiable intervention for adults with ID.

For older adults in the general population the Comprehensive Gerontological Assessment (CGA) has been developed, and found to be effective in clinic settings or as part of home visiting programs (Stuck et al, 1993). Elkan et al. (2001) conducted a meta-analysis of studies of home visiting programs to elderly people and showed that visits to older people can reduce mortality and admission to long term institutional care. Multi-dimensional assessments combined with follow-up visits also reduced nursing home admissions and improved survival and some benefits were related to the number of home visits (Stuck et al., 2002).

Starting in the US in 1994 CGA has been adapted for older persons with ID (Carlsen et al., 1994; Henderson & Davidson, 2000; Lennox et al., 2001; Acquilano, 2002). CGA, as described by these reports, were usually conducted by multi-disciplinary teams based in outpatient settings. The studies demonstrated that comprehensive assessments are useful in diagnosing previously unrecognized problems and instituting appropriate treatment and health maintenance activities. Hahn & Aronow (2005) investigated the role of an Advanced Practice Nurse who did follow up work, in addition to CGA, in a US setting.

In the UK, individualized health action plans (HAPs) which set out the person's health problems and health needs, linked with regular health checks, are currently being promoted by the government. Although the person with ID is involved with developing and keeping the action plan, the responsibility for maintaining it and facilitating the actions required lie primarily with the person's helper (health advocate, carer or health facilitator) (<http://www.bristollearningdifficulties.nhs.uk/HAP.htm>). The evidence-base for health action planning is limited.

Lennox et al. (2004) has developed a variation on a health check, which combines the benefits of a comprehensive assessment with a user-held health record in a so-called Comprehensive Health Assessment Program (CHAP). In essence, this is a user-held file containing personal health information as well as a checklist for the GP and additional information which cues the GP into considering specific issues e.g. the association between Alzheimer's disease and aging with Down Syndrome. The CHAP was tested in a randomized controlled trial in adults with ID and was shown to significantly increase health promotion, disease prevention and case-finding activity (Lennox et al, 2007). However, it has not been specifically adjusted for or tested in elderly people with ID.

Recently there have been several initiatives to develop health assessment measures which are user-led and which enhance self-report. Ruddick & Oliver (2005) described the development of a self-report health status measure for use with people with ID living in staffed community-based accommodation. The assessment schedule consists of six subscales: general health, physical functioning, bodily pain, vitality, mental health, and sensory functioning. This instrument was tested on 21 adults with ID and a mean age of 46.7 years, and had acceptable reliability and internal consistency.

Following a literature review and focus groups with users Fender, Marsden & Starr (2007) produced a health assessment that was administered to 57 adults with a wide range of ID aged 40 years and over (age range 40 to 79 years) living in the community. The items were based on the Comprehensive Health Assessment Programme (Lennox et al., 2004a) but included more aspects of functional age and self-defined health (Fender, Marsden & Starr, 2007; Starr & Marsden, 2008). With regard to physical activity, regular physical exercise and physical fitness (respiratory, grip strength, sit-stands, and timed-up-and-go) are measured, and feet and footwear are inspected. If participants are unable to provide information, carers might be asked instead. The assessment took 10 to 50 minutes to complete (Fender, Marsden & Starr, 2007; Starr & Marsden, 2008). This assessment needs to be evaluated further.

## **DISCUSSION**

Although there are limitations in some of the methodologies, our review of recent literature has led us to make some conclusions about the health status and health care experienced by people with Intellectual Disability as they age.

In high-income countries overall mortality rates for older adults (50+) are comparable to those in the age-matched general population. The medical conditions which are responsible for death are, in order and proportion, almost the same. We can conclude that with the exception of some diagnostic subgroups (e.g. Down Syndrome, people with epilepsy and people with cerebral palsy) older persons with mild to moderate ID have a similar life expectancy to their peers in the general population. Mortality rates for younger adults and children with ID, and for those with severe-profound ID however, are still higher compared to the general

population. Consequently older persons with ID might be considered as strong and healthy survivors of their birth cohorts. An active policy of health checks and inoculations, facilitated access to medical treatment and nursing care, a perspective of safe environments and nutritious diets, and discouragement of smoking, alcohol and illegal drugs both now and in the past could have contributed to this increase in life expectancy.

Cardiovascular disease is the most common cause of death, but there are no indications of excess mortality or morbidity due to cardiovascular diseases in older adults with ID. With regard to risk factors, relatively low rates of hypertension, hyperlipidemia and adult-onset diabetes are reported. This could be a real picture of the situation (e.g. low rates of hypertension in adults with Down syndrome) or it could be a false one due to underdiagnosis.

The most commonly reported risk factor (for many diseases) is overweight and obesity. Older people with Intellectual Disability have a high prevalence of obesity, but this is not necessarily higher than the general population. In several countries it is documented that in group homes, adults of all ages including the elderly, consume a diet that is high in energy, high in fat and low in fruit and vegetable intake. Lack of information and staff support but also lack of money to buy healthier but more expensive food could be possible explanations.

Physical activity and exercise levels amongst older adults with ID are generally considered low, but not necessarily lower compared to non-disabled peers in the general population. Low levels of physical activity combined with high energy diets likely play a major role in the development of obesity and elevated cardiovascular disease risk factors in older adults with ID, and these are also risk factors for type 2 diabetes, constipation, osteoporosis, incontinence and arthritis. Age appears in some studies to be negatively associated with activity in adults with ID.

As a preventive measure 30 minutes or more of moderate intensity physical activity on most, preferably all, days of the week is recommended (WHO, 2003) for all adults. However, not all older adults with ID are fit enough to be engaged in moderate intensity physical activities (e.g. cerebral palsy) and some may be seriously hindered by other medical conditions.

Pain in older adults with ID is a neglected area in published research. This is quite surprising as it is the major reason for patients in the general population to contact a physician, dentist or physiotherapist. A possible explanation for the lack of publications could be that pain is a complex phenomenon. Pain is subjective and personal, something difficult to measure, caused by various determinants and not always verbally well-expressed by older adults with ID. As many persons with ID have difficulty communicating their pain or may not understand pain signals, they are at an increased risk of not having pain adequately identified and tested. Glick et al. (2006) for example, discussed fracture detection as often delayed in people with ID due to profound cognitive and skeletal disabilities and lack of communication skills, preventing these individuals reporting the incidence of fracture itself or the associated pain. In terms of the current status of pain assessment and treatment among programmes for persons with ID, pain does not appear to be routinely considered a part of care (Symons et al., 2008).

The digestive system is a vulnerable body part for older adults with ID and is host for many painful experiences. The studies examining the number of decayed, missing and filled teeth among persons with ID are inconclusive, especially with regard to older adults with ID. The perspectives of the consumers on this issue are still missing. Constipation is quite common in (older) adults with ID. This could be due to the normal ageing process itself, but age-related

conditions such as immobility, specific drugs and physical inactivity could also be contributing (Morad, 2007). The high prevalence rates of helicobacter pylori and gastro-esophageal reflux and their secondary consequences need further attention in research and reporting.

Cancer is not an over represented pathology in older people with ID. This may be related to lifestyle practices in earlier years which may be protective eg non-smoking and lack of overindulgence in alcohol.

In this report, we noted the growing body of literature on health disparities for (older) adults with ID compared with the general population in terms of neurological function. There are systematic and significant differences in vision and hearing impairment with the general population regarding overall, age-specific and cause-specific prevalence rates. These rates are much higher and increase with advancing age. Evidence from several studies show that the persons who are in daily contact with older adults with ID (family members and staff persons) are in general not sensitive enough, are inexperienced and may be untrained to manage effectively the serious regression of vision and function of their clients. Especially affected, with high prevalence rates, are older adults with severe and profound multiple disabilities. We think that the statement of Van Splunder et al. (2006), that „all persons with severe and profound ID and all older adults (40+) with Down syndrome should be considered as visually impaired until proven otherwise“ is also valid with regard to hearing impairment.

Other areas of neurological function which deteriorate in older adults with ID at an earlier age include spasticity, continence and epilepsy. Dementia occurs at a younger age than in the general population. The frequency of mental illness increases as does the use of psychotropic drugs. There is little research at this time targetting the effects of the long term use of common medications in the now elderly person with ID.

Our review also confirms a poorer access to and uptake of preventive health care services such as pap smear or breast cancer screening programs among the adult population with ID compared to the general population or those without ID. Many studies highlighted the lack of health promotion programs and activities targeted at population with ID in order to reduce disparities. Systematic and regular health assessments are highly recommended to detect any ill-health condition at a very early stage for treatment among ID populations.

Several factors are now known to contribute to the health disparities experienced by people with ID as they age. These include individuals' lack of communication skills and supports, malnutrition, medication usage and lack of physical activity and exercise. There are also several factors related to health care systems. Several studies found that physicians and other providers often lack training and experience in treating individuals with intellectual disability and are reluctant to assume clinical responsibility for them.

## **CONCLUSION**

Current literature on research in people with Intellectual Disability in developed countries as they age is clear: that as persons with ID survive and live into older age, the combination of life-long disorders and their associated medications use, and the “normal” ageing processes, puts them at a greater risk for ill-health and an earlier burden of disease in terms of neurological decline, but cardiovascular deterioration and some cancers may be less common. Lack of physical activity combined with dental ill-health and inappropriate nutrition resulting

in overweight and obesity are the major preventable, and modifiable, risk factors; and these areas need to be addressed in younger age to enable people to develop healthy lifestyle habits that will ensure they continue to mature and age with a sense of wellbeing.

The current literature supports the concepts that an overall framework of provision of services that

- Create a healthy environment;
- Identify health risk early, including ageing itself;
- Manage illness appropriately; and
- Prepare for appropriate palliative care and end-of-life decision making,

needs to be stratified according to the level of assistance required by the individual. People with mild ID need education and encouragement, people with less ability for self determination need high quality input that satisfies their carers and their 'persons responsible'.

A key feature of the literature, also, was the call for effective training of health care practitioners:

- in taking time with people with communication difficulties,
- in building on the person's understanding of their own bodies and what 'health' should mean for them,
- in recognition of special features of illness in people with lifelong disability; and
- in appreciation of the earlier onset of symptomatology of increasing disability in people as they age.

It is important for cross sectional prevalence research to continue on health risks in older people with Intellectual Disability because we are still in transition in developed countries. It is even more important that incidence, prospective and post interventional studies are conducted to enable us to evaluate the factors contributing to success in making a difference to health and wellbeing as people with Intellectual Disability age.

## REFERENCES

- Acquilano, J. (2002). A comprehensive geriatric assessment clinic for adults with intellectual disabilities. Paper presented at the 12th International Roundtable on Ageing, Quality of Life, and Intellectual Disabilities. International Association for the Scientific Study of Intellectual Disabilities, Koriyama City, Fukushima, Japan.
- Aerts-Neggers, T.M.A, Schoonbrood-Lenssen, A.M.J., Maaskant, M.A. (2003). Gehoorverlies bij mensen met een verstandelijke handicap, resultaten van een screeningsonderzoek in drie activiteitencentra. *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten*, 29, 4, 238-250.
- Aguilar,L., Lisker,R., Hernancez-Peniche,J., Martinez-Villar,C. (2008): A new syndrome characterized by mental retardation, epilepsy, palpebral conjunctival telangiectasias and IgA deficiency. *Clinical Genetics*, 13,2, 154-158.
- Amatniek, J.C., Hauser, W.A., delCastillo-Casteneda, C., Jacob, D.M., Marder, K., Bell, K., Albert, M., Brandt, J., Stern, Y. (2006): Incidence and predictors of seizures in patients with Alzheimer's Disease. *Epilepsia*, 47,5, 867-872.
- American Heart Association. (2002). *Heart Disease and Stroke Statistics: 2003 Update*. Dallas, TX: American Heart Association.
- Amoroso,A., Garzia,P., Vadacca,M., Galluzzo,S., Del Porto,F., Mitterho,A., et al. (2003). The unusual association of three autoimmune diseases in a patient with Noonan Syndrome. *Journal of Adolescent Health* ,32,1, 94-97.
- Angelopoulou, N., Matziari, C., Tsimaras, V., Sakadamis, A., Souftas, V., Mandroukas, K. (2000). Bone mineral density and muscle strength in young men with mental retardation (with and without Down syndrome). *Calcified Tissue International*, 66, 3, 176-180.
- Aronow, H. U., Hahn, J. E. (2005). Stay Well and Healthy! Pilot study findings from an in-home preventive healthcare programme for persons ageing with intellectual and/or developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 18, 163-173.
- Astor, R. (2001). Detecting pain in people with profound learning disabilities. *Nursing Times*, 97, 40, 38-39.
- Bakkaloglu,A., Ozen,S., Besbas,N., Saatci,U. Balci,S., (2008): Down Syndrome associated with systemic lupus erythematosus: a mere coincidence or a significant association? *Clinical Genetics*, 46,4 322-323.
- Balogh, R. S., Ouellette-Kuntz, H., Hunter, D. J. (2004). Regional variation in dental procedures among people with an intellectual disability, Ontario, 1995-2001. *Journal of the Canadian Dentist Association*, 70, 681f.
- Baltes, P. (1980). Life-span developmental psychology. *Annual Review of Psychology*, 31,65-110.
- Baltes, P.(1984). *Life-span development and behavior*. Vol.6. New York: Academic Press.

Baltes, P., Brim, O. (1980; eds.). *Life-span development and behavior*. New York: Academic Press.

Baltes, P., Baltes, M. (1990). *Successful aging: perspectives from the behavioral sciences*. Cambridge: University Press.

Barnard, L., Pearson, J., Rippon, L. & O'Brien, G. (2002). Behavioural phenotypes of genetic syndromes: summaries including notes on management and therapy. In: O'Brien G. (Eds): *Behavioural Phenotypes in Clinical Practice*. London: Mac Keith Press.

Baxter, H., Lowe, K., Houston, H., Jones, G., Felce, D., Kerr, M. (2006). Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practitioners*, 56, 93-98.

Beange, H., McElduff, A., Baker, W. (1995): Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation*, 99, 595-604.

Beange, H., Lennox, N., Parmenter, T. (2000). Health targets for people with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 24, 4, 283-297.

Bertoli, S. et al. (2006). Nutritional status and dietary patterns in disabled people. *Nutr Metab Cardiovasc Dis*, 16, 100-112.

Bhaumik, S., Watson, J., Thorp, C., Tyrer, F., McGrother, C. (2008). Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. *Journal of Intellectual Disability Research*, 52, 4, 287-298.

Bickenbach, J., Chatterji, S., Badley, M., et al. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science and Medicine*, 48, 1173-1187.

Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., Montgomery, P. D. (2002). The influence of intellectual disability on life expectancy. *J Gerontol A Biol Sci Med Sci*, 57, M470-M472.

Blyth, F., Rochat, S., Cumming, R. et al. (2008): Pain, frailty and comorbidity in older men: The CHAMP Study. *Pain*, 140, 224-230.

Böhmer, C., Niezen-de Boer, M., Klinkenberg-Knol, E., Deville, W., Nadorp, J., Meuwissen, S. (1999). The prevalence of gastro-oesophageal reflux disease in institutionalised intellectually disabled individuals. *American Journal of Gastroenterology*, 94 (3), 804-810.

Böhmer, C. J., Klinkenberg-Knol, E. C., Niezen-de Boer, R. C., Meuwissen, S. G. (1997). The age-related incidences of oesophageal carcinoma in intellectually disabled individuals in institutes in The Netherlands. *European Journal of Gastroenterology and Hepatology*, 9, 589-592.

Böhmer, C. J., Klinkenberg-Knol, E. C., Kuipers E. J., Niezen-de Boer, M. C., Schreuder, H., Schuckink-Kool, F., Meuwissen, S. G. (1997). The prevalence of *Helicobacter pylori* infection among inhabitants and healthy employees of institutes for the intellectually disabled. *American Journal of Gastroenterology*, 92, 1000-1004.

Böhmer, C., Niezen-de Boer, M., Klinkenberg-Knol, E., Meuwissen, S. (2000). Review article. Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable? *American Journal of Gastroenterology*, 95 ,8, 1868-1872.

Böhmer, C. J., Taminiau, J. A., Klinkenberg-Knol, E. C., Meuwissen, S. G. (2001). The prevalence of constipation in institutionalized people with intellectual disability. *Journal of Intellectual Disability Research*, 45, 212-218.

Boker, L.K., Merrick, J. (2002): Cancer incidence in persons with Down Syndrome in Israel. *Down Syndrome. Research and Practice*, 8,1, 31-36.

Bostrom, K., Ahlstrom, G. (2004): Living with a chronic deteriorating disease: the trajectory with muscular dystrophy over ten years. *Disability and Rehabilitation* 26, 23, 1388-1398.

Bradley, C., McAllister, T. (2004). The oral health of children with Down syndrome in Ireland. *Special Care Dentistry*, 24, 55-60.

Braunschweig, C., Gomez, S., Sheean, P., Tomey, K., Rimmer, J. Heller, T. (2004). Nutritional status and risk factors for chronic disease in urban-dwelling adults with Down syndrome. *American Journal on Mental Retardation*, 109, 186-193.

Breau, L.M. et al. (2002). Validation of the Non-communicating Children's Pain Checklist Postoperative Version. *Anesthesiology*, 96, 3, 528-535.

Breau L.M. et al. (2003). The incidence of pain in children with severe cognitive impairments. *Arch Pediatr Adolesc Med*, 157, 12, 1219-1226.

Breau, L., Camfield, C., McGrath, P., Finley, G. (2007). Pain's impact on adaptive functioning. *Journal of Intellectual Disability Research*, 51, 2, 125-134.

Britt, H.C., Harrison, C.M., Miller, G.C., Knox, S.A. (2008). Prevalence and pattern of multimorbidity in Australia. *Medical Journal of Australia*, 189,2, 72-77.

Bromley, J. et al. (1998). The development of a self-report measure to assess the location and intensity of pain in people with intellectual disabilities. *Journal of Intellectual Disability Research*, 42 (Pt1), 72-80.

Broughton, S.; Thomson, K. (2000) Women with learning disabilities: Risk Behaviours and experiences of the cervical smear test. *Journal of Advanced Nursing*, 32,4, 905-912.

Buch, H., Vinding, T., Nielsen, N. (2001). Prevalence and causes of visual impairment according to WHO and United States criteria in an aged, urban Scandinavian population: The Copenhagen City Eye Study. *Ophthalmology*, 108, 2347-2357.

Burger, R.A., Warren, R.P. (1998): Possible immunogenetic basis for autism. *Mental Retardation and Developmental Disabilities Research Reviews*, 4,2, 137-141.

Burkle, A., Caselli, G., Franceschi, C., Mariani, E., Sansoni, P., Santoni, A., Witkowski, W., Caruso, I. (2007) : Pathophysiology of ageing, longevity and age related diseases. *Immunity and Ageing* ,4, 4-11.

- Carlsen, W., Galliuzzi, K., Forman, L., Cavalieri, T. (1994). Comprehensive Geriatric assessment: application for community residing, elderly people with mental retardation/developmental disabilities. *Mental Retardation*, 32, 334-340.
- Carmeli, E., Kessel, S., Bar-Chad, S., Merrick, J. (2004). A comparison between older persons with Down syndrome and a control group: clinical characteristics, functional status and sensorimotor function. *Downs Syndrome Research and Practice*, 9, 17-24.
- Carmeli, E., Merrick, J., Kessel, S., Masharawi, Y., Carmeli, V. (2003). Elderly persons with intellectual disability: a study of clinical characteristics, functional status, and sensory capacity. *Scientific World Journal*, 3, 298-307.
- Carmeli, E., Bar-Chad, S. et al. (2003). Five clinical tests to assess balance following ball exercises and treadmill training in adult persons with intellectual disability. *Journal of Gerontology (Med)*, 58A, 767-772.
- Carvill, S. (2001). Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research*, 45, 467-483.
- Center, J., Beange, H., McEjduff, A. (1998). People with mental retardation have an increased prevalence of osteoporosis: a population study. *American Journal of Mental Retardation*, 103, 19-28.
- Center, J., Nguyen, T., Pocock, N., Eisman, J. (2004). Volumetric bone density at the femoral neck as a common measure of hip fracture risk for men and women. *Journal of Clinical Endocrinology and Metabolism*, 89, 2776-2782.
- Centers for Disease Control and Prevention (2005). *Physical Activity for Everyone: Recommendations*. Atlanta, GA: Centers for Disease Control and Prevention.
- Chun,H., Gatti,R. (2004): Ataxia-telangiectasia, an evolving phenotype. *DNA Repair* 3,8-9, 1187-1196
- Clarke, D., Vermuri, M.,Gunatilake, D.,Tewari, S. (2008). Brief Report. *Helicobacter pylori* infection in five inpatient units for people with intellectual disability and psychiatric disorder. *Journal of Applied Research in Intellectual Disabilities*, 21, 95-98.
- Cohen,W.I. (2006): Current dilemmas in Down Syndrome clinical care: celiac disease, thyroid disorders and atlanto-axial instability. *American Journal on Medical Genetics*, 142,3, 141-148.
- Collacott, R.(1993): Epilepsy, dementia and adaptive behaviour in Down's Syndrome. *Journal of Intellectual Disability Research*, 37,2, 153-160.
- Congdon, N.G., Friedman, D.S., Lietman T. (2003).Important causes of visual impairment in the world today. *JAMA*, 290, 2057-2060.
- Cook, A. & Lennox, N. (2000). General practice registrars' care of people with intellectual disabilities. *Journal of Intellectual and Developmental Disabilities*, 25, 69-77.
- Cooke, L.B. (1997). Cancer and learning disability. *Journal of Intellectual Disability Research*, 41, 4, 312-316.

- Cooper S. A. (1997): High prevalence of dementia amongst people with learning disabilities not attributed to Down's syndrome. *Psychological Medicine*, 27, 609 - 616.
- Cooper, S. A. (1998). Clinical study of the effects of age on the physical health of adults with mental retardation. *American Journal of Mental Retardation*, 102, 582-589.
- Cooper, S.A., Melville, C., Morrison, J. (2004). People with intellectual disabilities. Their health needs differ and need to be recognized and met. *British Medical Journal*, 329, 414-415.
- Cooper, S.A., Morrison, J., Melville, C., et al. (2006). Improving the health of people with intellectual disabilities: outcomes of a health screening programme after 1 year. *Journal of Intellectual Disability Research*, 50, 667-677.
- Corbin, S., Malina, K., Shepherd, S. (2005). *Special Olympics World Summer Games 2003: Healthy Athletes Screening Data*. Washington, DC: Special Olympics, Inc.
- Corsi, M.M., Malavazos, A.E., Passoni, D., Llicastro, F. (2005): LDL receptor expression on T lymphocytes in old patients with Down Syndrome. *Immunity and Ageing*, 2, 3-7.
- Cowie, M., Fletcher, J. (1998). Breast awareness project for women with a learning disability, *British Journal of Nursing*, 7, 774-778.
- Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care, *British Medical Journal*, 325, 1263-1267.
- Cregg, M., Woodhouse, J., Stewart, R., et al. (2003). Development of refractive error and strabismus in children with Down syndrome. *Invest Ophthalmol Visual Sci*, 44, 1023-1030.
- Croonenberghs, J., Bosmans, E., Deboutte, D., Kenis, G., Maes, M. (2002): Activation of the inflammatory response system in autism. *Neuropsychology*, 45, 1, 1-6.
- Cumella, S., Ransford, N., Lyons, J., Burnham, H. (2000). Needs for oral care among people with intellectual disability not in contact with community dental services. *Journal of Intellectual Disability Research*, 44, 45-52.
- Dahlbom, K., Ahlstrom, G., Barany, M. et al. (1999): Muscular dystrophy in adults: a five year follow-up. *Scandinavian Journal of Rehabilitation Medicine*, 31, 3, 178-184.
- Dalton, P., Deacon, R., Blamire, A., Pike, M., McKinlay, J., Stein, J., Styles, P., Vincent, A. (2003): Maternal neuronal antibodies associated with autism and a language disorder. *Ann Neurol*, 53, 4, 533-537.
- Davies, N., Duff, M. (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research*, 45, 253-257.
- Day, S.M., Strauss, D.J., Shavelle, R.M., Reynolds, R.J. (2005). Mortality and causes of death in persons with Down syndrome in California. *Dev Med Child Neurol*, 47, 171-176.
- Defrin, R., Pick, C., Peretz, C., Carmeli, E. (2004). A quantitative somatosensory testing of pain threshold in individuals with mental retardation. *Pain*, 108, 1-2, 58-66.

Denloye, O.O. (1998): Oral hygiene status of mentally handicapped school children in Ibadan, Nigeria. *Odonto-Stomatologie Tropicale*, 21,84, 19-21.

De Smedt,B., Devriendt,K., Fryns,J.-P., Vogels, A., Gewillig,M., Swillen,A. (2007). Intellectual abilities in a large sample of children with Velo-Cardio-Facial Syndrome : an update. *Journal of Intellectual Disability Research*, 51,9, 666-670.

Dostal,A., Linnankivi,T., Somer,M., Kahkonen,M., Litzman,J., Tienari,P. (2007): Mapping susceptibility gene locus for IgA deficiency at del(18)(q22.3-q23): report of familial cryptic ,chromosome t(18q; 10p) translocations. *International Journal of Immunogenetics*, 34,3, 143-147.

Draheim, C. C., Williams, D. P., McCubbin, J. A. (2002). Physical activity, dietary intake, and the insulin resistance syndrome in nondiabetic adults with mental retardation. *American Journal on Mental Retardation*, 107, 361-375.

Draheim, C. C., Williams, D. P., McCubbin, J. A. (2002). Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation. *Mental Retardation*, 40, 436-444.

Draheim, C. C., McCubbin, J. A., Williams, D. P. (2002). Differences in cardiovascular disease risk between nondiabetic adults with mental retardation with and without Down syndrome. *American Journal on Mental Retardation*, 107, 201-211.

Draheim, C.C. et al. (2003). Cardiovascular disease risk factor differences between Special Olympians and non-Special Olympians. *Adapt Phys Act Quart*, 20, 118-134.

Draheim, C. C. (2006). Cardiovascular disease prevalence and risk factors of persons with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 1, 3-12.

Draheim, C.C., Stanish, H. I., Williams, D.P., McCubbin, J.A. (2007). Dietary intake of adults with mental retardation who reside in community settings. *American Journal on Mental Retardation*, 112, 5, 392-400.

Duff, M., Scheepers, M., Cooper, M., Hoghton, M., Baddeley, P. (2001). *Helicobacter pylori*: Has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 219-225.

Durvasula, S., Beange, H., Baker, W. (2002). Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual and Developmental Disability*, 27, 255-264.

Effros,R. (2005): Roy Walford and the immunologic theory of aging. *Immunity and Ageing*, 2, 7-10.

Elkan, R., Kendrick, D., Dewey, M., Hewitt, M., Robinson, J., Blair, M., Williams, D., Brummell, K. (2001): Effectiveness of home based support for older people: systematic review and meta-analysis. *British Medical Journal*, 323, 7315, 719-25. Comment in *BMJ* (2001), 323,7315, 708.

- Emerson, E. (2005a). Health inequalities and people with intellectual disabilities: An introduction to the Special Issue. *Journal of Applied Research in Intellectual Disabilities*, 18, 95-96.
- Emerson, E. (2005b). Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research*, 49, 134-143.
- Emerson, E., McConkey, R., Walsh, P., Felce, D. (2008). Editorial - Intellectual disability in a global context. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 2, 79-80.
- Elkan, R., Kendrick, D., Dewey, M. et al. (2001). Effectiveness of home based support for older people: systematic review and meta-analysis. Commentary: When, where, and why do preventative home visits work? *British Medical Journal*, 323, 719-725.
- Esbensen, A., Seltzer, M., Greenberg, J. (2007). Factors predicting mortality in midlife adults with and without Down syndrome living with family. *Journal of Intellectual Disability Research*, 51, 12, 1039-1050.
- Espie, C. A., Watkins, J., Curtice, L., Espie, A., Duncan, R., Ryan, J. A. et al. (2003). Psychopathology in people with epilepsy and intellectual disability; an investigation of potential explanatory variables. *J Neurol Neurosurg Psychiatry*, 74, 1485-1492.
- Evenhuis, H. M. (1997a). Medical aspects of ageing in a population with intellectual disability: III. mobility, internal conditions and cancer. *Journal of Intellectual Disability Research*, 41, 8-18.
- Evenhuis, H.M. et al. (1997b). Diagnosis of sensory impairment in people with intellectual disability in general practice. *Journal of Intellectual Disability Research*, 41, 422-429.
- Evenhuis, H.M., Nagtzaam, L.M.D. (1998, eds.). Early identification of hearing and visual impairment in children and adults with an intellectual disability. IASSID International Consensus Statement. SIRG Health Issues.
- Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N. Chicoine, B. (2000). Healthy ageing - adults with intellectual disabilities : physical health issues. Geneva, Switzerland : World Health Organization.
- Evenhuis, H., Henderson, M., Beange, H., Lennox, N. & Chicoine, B. (2001a). Healthy aging - adults with intellectual disabilities: physical health issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 175-194.
- Evenhuis, H., Theunissen, M., Denkers, I., Verschuure, H., Kemme, H. (2001b). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45, 457-464.
- Evenhuis, H. M. (1995a). Medical aspects of ageing in a population with intellectual disability: I. Visual impairment. *Journal of Intellectual Disability Research*, 39 ( Pt 1), 19-25.
- Evenhuis, H. M. (1995b). Medical aspects of ageing in a population with intellectual disability: II. Hearing impairment. *Journal of Intellectual Disability Research*, 39 ( Pt 1), 27-33.

Farsai, P.S., Calabrese, J.M. (2002). Aging with mental retardation: oral health for older individuals with disabilities. The ARC of the United States. January/ February; 1-8.

Felce, D., Baxter, H., Lowe, K., Dunstan, F., Houston, H., Jones, G., Felce, J., Kerr, M. (2008). The impact of repeated health checks for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 585-596.

Fender, A., Marsden, L. & Starr, J.M. (2007a). What Do Older Adults with Down's Syndrome Want from Their Doctor? A Preliminary Report. *British Journal of Learning Disabilities*, 35, 19-22.

Fender, A., Marsden, L., Starr, J.M. (2007b). Assessing the health of older adults with intellectual disabilities: A user-led approach. *Journal of Intellectual Disabilities*, 11, 223-239.

Fernhall, B., Pitetti, K.H. (2001). Limitations to physical work capacity in individuals with mental retardation. *Clin Exerc Physiol*, 3, 176-185.

Fernhall, B., McCubbin, J., Pitetti, K., Rintala, P., Rimmer, J., Millar, A., De Silva, A. (2001). Prediction of maximal heart rate in individuals with mental retardation. *Medicine and Science in Sports and Exercise*, 33, 1655-1660.

Fisher, K., Kettl, P. (2005). Aging with mental retardation: increasing population of older adults with MR require health interventions and prevention strategies. *Geriatrics*, 60, 26-29.

Flannery, K.A., Liederman, J. (1994): A test of the immunoreactivity theory for the origin of neurodevelopmental disorders in the offspring of women with immune disorder. *Cortex*, 30,4, 635-646.

Foley, D.C., McCutcheon, H. (2004). Detecting pain in people with an intellectual disability. *Accident and Emergency Nursing*, 12, 4, 196-200.

Foran, S., Wang, J., Mitchell, P. (2003). Causes of visual impairment in two older population cross-sections: The Blue Mountains Eye Study. *Ophthalmic Epidemiology*, 10, 215-225.

Forister, G. et al. (2002). Diagnosing and managing Gastroesophageal Disease. *Physician Assistant*, 26, 12J, 17-23.

Fortin, M., Bravo, G., Hudon, C., Vanasse, A., Lapointe, L. (2005). Prevalence of multimorbidity among adults seen in family practice. *Annals of Family Medicine*, 3, 223-228.

Fovarque, S., Keywood, K., Flynn, H. (2000). Participation in health care decision making by adult with learning disabilities. *Mental Health Care*, 3, 341-344.

French, S. (2007). Visually impaired people with learning difficulties: their education from 1900 to 1970 – policy, practice and experience. *British Journal of Learning Disabilities*, 36, 48-53.

Frey, G. (2004). Comparison of physical activity levels between adults with and without mental retardation. *J Phys Act Health*, 1, 235-245.

Frey, G. et al. (2005). „I'd rather watch TV“: An examination of physical activity in adults with mental retardation. *Mental Retardation*, 43, 241-254.

Frey, G., Temple, V., Stanish, H. (2006). Introduction: Preventive health and individuals with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 1-2.

Friedman, D., Congdon, N., Kempen, J. et al. (2002). Vision problems in the U.S.: prevalence of adult vision impairment and age-related eye disease in America. Washington, DC: Prevent Blindness America.

Friez, M., Jones, J., Clarkson, K., Lubs, H., Abuelo, D., Blaymore Bier, J. et al. (2006): Recurrent infections, hypotonia and mental retardation caused by duplication of MECP2 and adjacent region in Xq28. *Pediatrics*, 118,6, e1687-e1695.

Fujiura, G.T., Yamaki, K. (1997). Analysis of ethnic variations in developmental disability prevalence and household economic status. *Mental Retardation*, 35, 268-294.

Gabre, P., Martinsson, T., & Gahnberg, L. (2001). Longitudinal study of dental caries, tooth mortality and interproximal bone loss in adults with intellectual disability. *European Journal of Oral Science*, 109, 20-26.

Gabre, P., Sjoquist, K. (2002). Experience and assessment of pain in individuals with cognitive impairments. *Special Care Dentistry*, 22, 5, 174-180.

Gambarara, M., Dallapiccola, B. (2001): Coeliac disease in Williams Syndrome. *Journal of Medical Genetics*, 38, 767-768.

Gianotti, A., Tiberio, G., Castro, M., Virgillii, F., Colistro, F., Ferretti, F., Digilio, M.C., Gambarara, M., Dellapiccola, B. (2001): Coeliac disease in Williams Syndrome. *Journal of Medical Genetics*, 38,11, 767-768.

Gillespie, K., Dix, R., Williams, A., Newton, R., Robinson, Z., Bingley, P., Gale, E., Shield, J. (2006): Islet immunity in children with Down's Syndrome. *Diabetes*, 55, 3185-3188.

Glassman, P., Miller, C. (2003). Dental disease prevention and people with special needs. *Journal of the California Dental Association*, 31, 149-160.

Goodwin, C., Mendall, M., Northfield, T. (1997). Helicobacter pylori infection. *Lancet*, 349, 265-269.

Gordon, D. (2008). The benefits of exercise to a Down's syndrome population. Available at : [http://www.intellectualdisability.info/mental\\_phys\\_health/exercise\\_dg.html](http://www.intellectualdisability.info/mental_phys_health/exercise_dg.html) (Accessed on 15 July 2008).

Gomezano, S.R., Kaminski J.E. (2005). The eye care profile and outcomes of multi-handicapped adults residing in Wayne County, Michigan group homes. *Optometry*, 26, 19-29.

Graham, A. & Reid, G. (2000). Physical fitness of adults with an intellectual disability : A 13-years follow-up study. *Res Quart Exerc Sport*, 71, 152-161.

Gravestock, S. (2000). Eating disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 44, 625-637.

- Guijarro, M., Valero, C., Paule, B. Gonzales-Macias, J., Riancho, J. (2008). Bone mass in young adults with Down syndrome. *Journal of Intellectual Disability Research*, 52, 3, 182-189.
- Hahn, J. E., Aronow H. U. (2005). A pilot of a gerontological advanced practice nurse preventive intervention. *Journal of Applied Research in Intellectual Disabilities*, 18, 131-142.
- Hansson, T., Dahlbom, I., Rogberg, S., Nyberg, B., Dahlstrom, J., Anneren, G., Klareskog, L., Dannaeus, A. (2005): Antitissue transglutaminase and antithyroid autoantibodies in children with Down Syndrome and Celiac Disease. *Journal of Pediatric Gastroenterology and Nutrition*, 40, 170-174.
- Haslam, D.W. & James, W.P. (2005). Obesity. *Lancet*, 366, 1197-1209.
- Haslam, D., Sattar, N., Lean, M. (2006). ABC of obesity. Obesity – time to wake up. *British Medical Journal*, 333, 640-642.
- Harris, J. (2003). Time to make up your mind: why choosing is difficult. *British Journal of Learning Disability*, 31, 3-8.
- Haveman, M.J. (2004). Disease Epidemiology and Aging People with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1, 16-23.
- Haveman, M.J. & Stöppler, R. (2004). *Altern mit geistiger Behinderung*. Kohlhammer Verlag.
- Haveman, M.J. (2005). Diagnostik von Demenzprozessen. In: Stahl, B., Irblich, D. (Eds.). *Diagnostik bei Menschen mit geistiger Behinderung. Ein interdisziplinäres Handbuch*, 367-383. Göttingen: Hogrefe Verlag.
- Haveman, M.J. (2007). Health indicators for adults with intellectual disabilities in Europe; the Pomona Project. Paper at the State of Science Conference in Aging with Developmental Disabilities., Atlanta, GA.
- Havercamp, S. M., Scandlin, D., Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Reports*, 119, 418-426.
- Heinonen, A., Kannus, P., Sievnan, A., Pasanen, M., Oja, P., Vuori, I. (1999). Good maintenance of high-impact activity-induced bone gain by voluntary, unsupervised exercises: An 8-month follow-up of a randomized controlled trial. *Journal of Bone Mineral Research*, 14, 25-28.
- Heller, T., Factor, A., Sterns, H., Sutton, E. (1996) Impact of person centered later life planning training program for older adults with mental retardation. *Journal of Rehabilitation*, 62, 1, 77-83.
- Heller, T., Marks, B., Ailey, S. (2001). *Exercise and nutrition health education curriculum for adults with developmental disabilities*. Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, Chicago, IL.

- Heller, T. et al. (2004). Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities. 2nd edition. Chicago, IL: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois.
- Heller, T., Marks, B. (2002). Health promotion and women. In: Walsh P.N., Heller, T. (Eds). Health promotion and women with intellectual disabilities. London: Blackwell Science Publishing, 170-189.
- Heller, T., Miller, A., Hsieh, K., Sterns, H. (2000). Later life planning: Promoting knowledge of options and choice-making. *Mental Retardation*, 38, 395-406.
- Heller, T., K. Hsieh, Rimmer, J. (2004). Attitudinal and psychosocial outcomes of a fitness and health education program on adults with Down Syndrome. *American Journal on Mental Retardation*, 109, 2, 175-185.
- Henderson C. M., Davidson P. W. (2000). Comprehensive adult and geriatric assessment. In: Community Supports for Aging Adults with Lifelong Disabilities. Janicki M.P. , Ansello E.F. (Eds), 373-386. Paul H. Brookes, Baltimore, MD.
- Henderson, C.M., Robinson, L.M. Davidson, P., Haveman, M., Janicki, M.P., Albertini, G. (2008): Overweight status, obesity and risk factors for coronary heart disease in adults with Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 5,3, 174-177.
- Hennequin, M., Allison, P. J., & Veyune, J. L. (2000). Prevalence of oral health problems in a group of individuals with Down syndrome in France. *Dev Med Child Neurol*, 42, 691-698.
- Hesdorffer, D.C., Hauser, W.A., Annegers, J.F., Kokmen, E., Rocca, W.A. (1996): Dementia and adult-onset unprovoked seizures. *Neurology*, 46,3, 727-730.
- Hild,U., Hey, C., Baumann, U., Montgomery, J., Euler, H.A., Neumann, K. (2008). High prevalence of hearing disorders at the Special Olympics indicate need to screen persons with intellectual disability. *Journal of Intellectual Disability Research*, 52, 6, 520-528.
- Hill, D.A. et al. (2003).Mortality and cancer incidence among individuals with Down syndrome. *Archives of Internal Medicine*, 163, 705-711.
- Hirayama,A., Horikoshi,Y., Maeda,M., Ito,M., Takashima,S. (2003): Characteristic developmental expression of amyloid beta 40, 42 and 43 in patients with Down Syndrome. *Brain and Development*, 25,3, 180-185.
- HMSO, Welsh Office (1996), Welsh Health Survey 1995, London.
- Hogg, J. et al. (2000). Healthy Ageing: adults with intellectual disabilities: ageing and social policy. Geneva: World Health Organization.
- Hogg, J., Tuffrey-Wijne (2008). Cancer and intellectual disability: a review of some key contextual issues. *Journal of Applied Research in Intellectual Disabilities*, 21, 509-518.
- Holland, A.J., Hon, J., Huppert, F.A., Stevens, F., Watson, P. (1998). Population based study of the prevalence and presentation of dementia in adults with Down's Syndrome. *British Journal of Psychiatry*, 172, 493-498.

Holland, A.J., Hon, J., Huppert, F.A., Stevens, F. (2000): Incidence and course of dementia in people with Down's Syndrome: findings from a population-based study. *Journal of Intellectual Disability Research*, 44, 138-146.

Hollins. S., Attard, M., von Fraunhofer, N., McGuigan, S., Sedgwick, P. (1998). Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, 40, 50-56.

Horwitz, S.M., Kerker, B.D., Owens, P.L., Zigler, E. (2000). The health status and needs of individuals with mental retardation. Washington, DC: Special Olympics Inc.

Hove, O. (2004). Weight survey on adults persons with mental retardation living in the community. *Research in Developmental Disabilities*, 25, 9-17.

Hsieh, K., Heller, T., Miller, A. B. (2001). Risk factors for injuries and falls among adults with developmental disabilities. *Journal of Intellectual Disability Research*, 45, 76-82.

Hu, Y.Y., Zhong, N. (2006): Neuroimmunology of autism. *World Journal on Pediatrics*, 4, 260-263.

Iacono, T., Sutherland, G. (2006). Health screening and developmental disability. *Journal of Policy and Practice in Intellectual Disability*, 3, 3, 155-163.

International Association for the Scientific Study of Intellectual Disability (IASSID). (2002). Health guidelines for adults with an intellectual disability.

[http://www.intellectualdisability.info/mental\\_phys\\_health/P\\_health\\_guide\\_adlt.htm](http://www.intellectualdisability.info/mental_phys_health/P_health_guide_adlt.htm)

(Accessed on 15 July 2008)

International Foundation for Functional Gastrointestinal Disorders, Inc. (IFFGD). (2003). GI disorders in adults : Gastroesophageal reflux disease. Available at :

<http://www.iffgd.org/GIDisorders/GIAdults.htm>. (Accessed on 27 October 2003).

International Foundation for Functional Gastrointestinal Disorders, Inc. (IFFGD). About GERD. Available at : <http://www.aboutgerd.org> (Accessed on 27 October 2003).

Jancar, J., Jancar, M. P. (1998). Age-related fractures in people with intellectual disability and epilepsy. *Journal of Intellectual Disability Research*, 42 ( Pt 5), 429-433.

Janicki, M.P., Davidson, P.W., Henderson, C.M., McCallion, P., Taets, J. D., Force, L. T., Sulkes, S. B., Frangenberg, E., Ladrikan, P. M. (2002). Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research*, 46, 287-298.

Janicki, M. (2002). An ageing world: New issues, more questions. *Journal of Intellectual and Developmental Disability*, 27, 229-230.

Janicki, M.P., Dalton, A.J., Henderson, C., Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation*, 21 (5/6), 284-294.

Janicki, M. P., Dalton, A.J. (1998). Sensory impairments among older adults with intellectual disability. *Journal of Intellectual and Developmental Disability*, 23, 3-11.

- Jette, A., Norweg, A., Haley, S. (2008). Achieving meaningful measurements of ICF concepts. *Disability and Rehabilitation*, 30, 12-13, 963-969.
- Jokinen, N. S. (2003). Older adults with intellectual disability living in a community residential service. *International Journal of Disability, Community & Rehabilitation*, 2, 1,
- Jyonouchi, H., Sun, S., Le, H. (2001). Proinflammatory and regulatory cytokine production associated with innate and adaptive immune responses in children with autism spectrum disorders and developmental regression. *Journal of Neuroimmunology*, 120, 1-2, 170-179.
- Jyonouchi, H., Sun, S., Itolazu, N. (2002). Innate immunity associated with inflammatory responses and cytokine production against common dietary proteins in patients with autism spectrum disorder. *Neuropsychobiology*, 46, 2, 76-84.
- Jyonouchi, H., Geng, L., Ruby, A., Zimmerman-Bier, B. (2005). Dysregulated innate immune responses in young children with autism spectrum disorders: their relationship to gastrointestinal symptoms and dietary intervention. *Neuropsychology*, 51, 2, 77-85.
- Kadam, U.T., Croft, P.R., North Staffordshire GP Consortium Group (2007). Clinical multimorbidity and physical function in older adults: a record and health status linkage study in general practice, *Family Practice*.
- Kapell, D., Nightingale, B., Rodriguez, A., Lee, J., Zigman, W., Schupf, N. (1998). Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation*, 36, 269-279.
- Kennedy, C. (2002). Screening for *Helicobacter pylori* in adults with developmental disabilities – prevalence of infection and testing considerations for urea breath test, serology and whole-blood methods. MSc Thesis, Department of Community Health & Epidemiology, Queen's University, Kingston, Ontario.
- Kerr, A. M., McCulloch, D., Oliver, K., McLean, B., Coleman, E., Law, T. et al. (2003). Medical needs of people with intellectual disability require regular assessment, and the provision of client- and carer-held reports. *Journal of Intellectual Disability Research*, 47, 134-145.
- Kerr, M. P. (1997). Primary health care for people with an intellectual disability. *Journal of Intellectual Disability Research*, 41 ( Pt 5), 363-364.
- Kiernan, C. (1995). The use of anti-psychotic drugs with adults with learning disabilities and challenging behaviour. *Journal of Intellectual Disability Research*, 39, 263-274.
- Kinik, S.T., Ozcay, F., Varan, B. (2006): Type 1 diabetes mellitus, Hashimotos' thyroiditis and celiac disease in an adolescent with Down Syndrome. *Pediatrics International*, 48, 433-435.
- Kleinsteinst, R., Jones, L., Hullett, S. et al. (2003). Refractive error and ethnicity in children. *Archives of Ophthalmology*, 121, 1141-1147.
- Krahn, G.L., Hammond, L., Turner, A. (2006). A cascade of disparities: health and health care access for People with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 70-82.

- Krause, I., He, X.-S., Gershwin, M.E., Shoenfeld, Y. (2002): Brief report: immune factors in autism: a critical review. *Journal of Autism and Developmental Disorders* 32,4, 337-345.
- Kronhead, A., Moller, M. (1998). Effects of physical exercise on bone mass, balance skill and aerobic capacity in women and men with low bone mineral density, after one year of training- a prospective study. *Scandinavian Journal of Medicine and Science in Sports*, 8, 290-298.
- Kyrkou, M. (2005). Health issues and quality of life in women with intellectual disability. *Journal of Intellectual Disability Research*, 49, 770-772.
- LaChapelle, D., Hadjistavropoulos, T., Craig, K. (1999). Pain measurement in persons with intellectual disabilities. *Clinical Journal of Pain*, 15, 1, 13-23.
- Lader, D., Chadwick, B., Chestnutt, I. (2005). Children's dental health in the United Kingdom, 2003. London: Office of National Statistics. Available at: [http://www.statistics.gov.uk/CHILDREN/dentalhealth/down-loads/cdh\\_Summary.pdf](http://www.statistics.gov.uk/CHILDREN/dentalhealth/down-loads/cdh_Summary.pdf)
- Lane, A. M., Lovejoy, D. J. (2001). The effects of exercise on mood changes: The moderating effect of depressed mood. *Journal of Sports Medicine and Physical Fitness*, 41, 539-545.
- Lembo, A., Cammilleri, M. (2003). Chronic constipation. *New England Journal of Medicine*, 349, 14, 1360-1368.
- Lennox, N., Green, M., Diggins, J., Ugoni, A. (2001). Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research*, 45, 226-232.
- Lennox, N., Eastgate, G. (2004). Adults with intellectual disability and the GP. *Australian Family Physician*, 33, 601-606.
- Lennox, N., Bain, Rey-Conde, T., Purdie, D., Bush, R., Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology*, 36, 139-146.
- Lewis, M.A., Lewis, C.E., Leake, B., King, B., Lindemann, R. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports*, 117, 174-184.
- Lin, J.-D., Wu, J. L., Lee, P.N. (2003). Healthcare needs of people with intellectual disability in institutions in Taiwan: outpatient care utilization and implications. *Journal of Intellectual Disability Research*, 47, 169-180.
- Lin, J.-D., Yen, C.F., Loh, C.H., Hsu, S.W., Huang, H.C., Tang, C.C., Li, C.W., Wu, J.L. (2006): A cross sectional study of the characteristics and determinants of emergency care utilisation among people with Intellectual Disabilities in Taiwan. *Research in Developmental Disabilities*, 27,6, 657-667.
- Lindeman, A.K. (1991). Resident manager's nutritional concerns for staff and residents of group homes for mentally retarded adults. *Journal of the American Dietetic Association*, 91, 602-604.

- Lohiya, G.S., Crinella, F.M., Tan-Figueroa, L.; Caires, S.; Lohiya, S. (1999). Fracture epidemiology and control in a developmental center. *Western Journal of Medicine*, 170,203–209.
- Lopez-Perez, R., Borges-Yanes, S., Jimenez-Garcia, G. et al. (2002). Oral hygiene, gingivitis, and periodontitis in persons with Down syndrome. *Special Care Dentistry*, 22, 214-220.
- Lunsky, Y., Straiko, A., Armstrong, S. (2005). Women be healthy : evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 247-253.
- Maaskant, M., Gevers, J., Wierda, H. (2002). Mortality and life expectancy in Dutch residential centres for individuals with intellectual disability, 1991-1995. *Journal of Applied Research in Intellectual Disability*, 15, 200-212.
- Maaskant, M.A., Van Knijff-Raeven, A.G.M., Van Schrojenstein Lantman-de Valk, H.M.J., Veenstra, M.Y.. Weight status of persons with intellectual disabilities. Submitted for publication.
- Malaty, H., El-Kasabany Graham, D., Miller, C., Reddy, S., Srinivasan, S., Yamaoka, Y., Berenson, G. (2002). Age at acquisition of *Helicobacter pylori* infection : a follow-up study from infancy to adulthood. *Lancet*, 359, 931-935.
- Mann, J., H. Zhou, McDermott, S., Poston, M.B. et al. (2006). Healthy behavior change of adults with mental retardation: attendance in a health promotion program. *American Journal on Mental Retardation*, 111,1, 62-73.
- Marengoni, A. (2008). Prevalence and impact of chronic diseases and multimorbidity in the aging population: a clinical and epidemiological approach. Doctorate dissertation, Karolinska Institute, Solna, Sweden.
- Marengoni, A., Winblad, B., Karp, A., Fratiglioni, L. (2008). Prevalence of chronic diseases and multimorbidity among the elderly population in Sweden. *American Journal of Public Health*, 98,7, 1198-1200.
- Marks B., Heller, T., Rimmer, J., Sisrak, J. (2007). Health promotion for adults with intellectual and developmental disabilities (I/DD): train-the-trainer program (R1) Chicago, IL: University of Illinois at Chicago.
- Marks, B., Heller, T., Sisrak, J. (2006). Exercise and nutrition health education curriculum for adults with developmental disabilities. 3rd edition. Chicago, Illinois: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.
- Marshall, D., McConkey, R., Moore, G. (2003). Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health promotion activities. *Journal of Advanced Nursing*, 41, 147-153.
- Marshall,P. (1989): Attention deficit disorder and allergy: a neurochemical model of the relation between the illnesses. *Psychological Bulletin*, 106,3, 434-446.

- McCulloch, D.L., Sludden, P.A., McKeown, K., Kerr, A. (1996). Vision care requirements among intellectually disabled adults: a residence-based pilot study. *Journal of Intellectual Disability Research*, 40 (2), 140-150.
- McDermott, S. (2006). Variation in health conditions among groups of adults with disabilities in primary care. *Journal of Community Health*, 31, 147-159.
- McDermott, S., Platt, T., Krishnaswami, S. (1997). Are individuals with mental retardation at high risk for chronic disease? *Family Medicine*, 29, 429-434.
- McDonald-McGinn, D.M., Kirschner, R., Goldmuntz, E., Sullivan, K., Eicher, P., Gerdes, M., et al. (1999). The Philadelphia Story: the 22q11.2 deletion: report on 250 patients. *Genetic Counseling*, 10,1, 11-24.
- McGillycuddy, N.B. (2006). A review of substance use research among those with mental retardation. *Mental Retardation and Developmental Disability Research Reviews*, 12, 41-47.
- McGrath, P., Rosmus, C., Canfield, C., Campbell, M., Henniger, A. (1998). Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals. *Developmental Medicine and Child Neurology*, 40, 340-343.
- Medina, W.C. (2005). Nonverbal individuals with intellectual/ developmental disabilities experiencing GERD: from infants to older adults. *International Journal of Nursing*, 2,1, 2-10.
- Melton, L., Khosla, S., Achenbach, S., O'Connor, M., O'Fallon, W. Riggs, B. (2000). Effects of body size and skeletal site on the estimated prevalence of osteoporosis in women and men. *Osteoporosis International*, 11, 977-983.
- Melville, C., Cooper, S., McGrother, C., Thorp, C., Collacott, R. (2005). Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 49, 190-198.
- Melville, C.A. et al. (2005). Obesity in adults with Down syndrome : A case-control study. *Journal of Intellectual Disability Research*, 49, 2, 125-133.
- Melville, C. A., Cooper, S. A., Morrison, J., Finlayson, J., Allan, L., Robinson, N., Burns, E., Martin, G. (2006). The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services. *Journal of Intellectual Disability Research*, 50, 1, 11-17.
- Melville, C.A., Cooper, S.A., Morrison, J., Allan, L., Smiley, Williamson, A. (2008). The prevalence and determinants of obesity in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 425-437.
- Menage, P., Thibault, G., Matineau, J., Hérault, J. et al. (1992). An IgE mechanism in autistic hypersensitivity ? *Biological Psychiatry*, 31,2, 210-212.
- Mercer, K., Ekvall, S. (1992). Comparing the diets of adults with mental retardation who live in intermediate care facilities and in group homes. *Journal of the American Dietetic Association*, 92, 356-358.

- Merrick, J., Koslowe, K. (2001). Refractive errors and visual anomalies in Down syndrome. *Down Syndrome Research and Practice*, 6, 131-133.
- Merrick, J., Davidson, P. W., Morad, M., Janicki, M. P., Wexler, O., Henderson, C. M. (2004). Older adults with intellectual disability in residential care centers in Israel: health status and service utilization. *American Journal on Mental Retardation*, 109, 413-420.
- Messent, P.R. et al. (1998b). Physical activity, exercise and health of adults with mild and moderate learning disabilities. *British Journal of Learning Disabilities*, 26, 17-22.
- Meuwese-Jongheugd, A., Vink, M., van, Z. B., Verschuure, H., Eichhorn, E., Koopman, D. et al. (2006). Prevalence of hearing loss in 1598 adults with an intellectual disability: cross-sectional population based study. *International Journal of Audiology*, 45, 660-669.
- Mitra, M., Allen, D., Wilber, N., Walker, D. (2005). Prevalence and correlates of depression as a secondary condition among adults with disabilities. *American Journal of Orthopsychiatry*, 75, 1, 76-85.
- Moore, K., McGillivray, J., Illingworth, K., Brookhouse, P. (2004). An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample. *Journal of Intellectual and Developmental Disability*, 29, 4, 306-318.
- Morad, M., Merrick, J., Nasri, Y. (2002). Prevalence of *Helicobacter pylori* infection in people with intellectual disabilities in a residential care center in Israel. *Journal of Intellectual Disability Research*, 46, 141-143.
- Morad, M., Nelson, N., Merrick, J., Davidson, P. W., Carmeli, E. (2007). Prevalence and risk factors of constipation in adults with intellectual disability in residential care centers in Israel. *Research in Developmental Disabilities*, 28, 580-586.
- Moran, R., Drane, W., McDermott, S., Dasari, S., Scurry, J., Platt, T. (2005). Obesity among people with and without mental retardation across adulthood. *Obesity Research*, 13, 342-349.
- Mugica, I., Ansa, J., Sistiaga, F., Zabalza, R., Zubillaga, P., Merino, A., Maiedana, B., Visal, C. (2002). Digital computerized absorptiometry in the diagnosis of osteoporosis in a group of the severely mentally retarded. *Nutricion Hospitalaria*, 17, 213-218.
- Mul, M. et al. (1997). Slechthorendheid bij mensen met een verstandelijke handicap in de huisartspraktijk. *Huisarts en Wetenschap*, 40, 301-304.
- Murphy, J., Hoey, H., Philip, M. et al. (2005). Guidelines for the medical management of Irish children and adolescents with Down syndrome. *Irish Medical Journal*, 98, 48-52.
- Murphy, K., Jones, L., Owen, M. (1999): High rates of schizophrenia in adults with Velo-Cardio-Facial Syndrome. *Archives of General Psychiatry*, 56,10, 940-945.
- National Audit Office (2001). Tackling obesity in England. Report by the Comptroller and Auditor General. Her Majesty's Stationary Office, London.
- Nespoli, L., Burgio, G., Maccario, R. (1993): Immunological features of Down's Syndrome: a review. *Journal of Intellectual Disability Research*, 37,6, 543-551.

Neumann, K., Dettmer, G., Euler, H., Giebel, A., Gross, M., Herer, G., Hoth, S., Lattermann, C., Montgomery, J. (2006). Auditory status of persons with intellectual disability at the German Special Olympic Games. *International Journal of Audiology*, 45, 2, 83-90.

Niederhofer, H., Pittschieier, K. (2006): A preliminary investigation of ADHD symptoms in persons with celiac disease. *Journal of Attention Disorders*, 10, 2, 200-204.

Nevill A., Holder, R., Maffulli, N., Cheng, J., Leung, S., Lee, W., Lau, J. (2002). Adjusting bone mass for differences in projected bone area and other confounding variables: an allometric perspective. *Journal of Bone and Mineral Research*, 17, 703-708.

O'Brien, G. (2008). Behavioural phenotypes in adulthood. Available from: [http://www.intellectualdisability.info/mental\\_phys\\_health/P\\_phenotypes\\_go.html](http://www.intellectualdisability.info/mental_phys_health/P_phenotypes_go.html) Accessed on 23 October 2008.

Oda, M., Haklamada, R., Ono, K., Higurashi, M. (1993): A seroimmunological analysis of Down Syndrome. *Gerontology*, 39, (Suppl 1), 16-23.

Office of the Surgeon General. Health Disparities and Mental Retardation. Closing the gap: a national blueprint to improve the health of persons with mental retardation (updated 2004 April 27; cited 2007 February 27). Available from: [www.surgeongeneral.gov/topics/mentalretardation/](http://www.surgeongeneral.gov/topics/mentalretardation/).

Oskarsdottir, S., Vujic, M., Fasth, A. (2004): Incidence and prevalence of the 22q11 deletion syndrome: population based study in Western Sweden. *Arch Dis Child* 89, 2, 148-151.

Owens, P. L., Kerker, B. D., Zigler, E., Horwitz, S. M. (2006). Vision and oral health needs of individuals with intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 28-40.

Pardo, C.A., Vargas, D., Zimmerman, A. (2005): Immunity, neuroglia and neuroinflammation in autism. *International Review on Psychiatry*, 17, 6, 485-495.

Pardo, C.A., Eberhart, C. (2007): The Neurobiology of Autism. *Brain Pathology*, 17, 4, 434-447.

Pastore, E., Marino, B., Calzolari, A., Digilio, M., Gianotti, A., Turchetta, A. (2000). Clinical and cardiorespiratory assessment in children with Down syndrome without congenital heart disease. *Archives of Pediatric and Adolescent Medicine*, 4, 408-410.

Patja, K., Pukkala, E., Sund, R., Iivanainen, M., Kaski, M. (2006). Cancer incidence of persons with Down syndrome in Finland: a population-based study. *International Journal of Cancer*, 118, 1769-1772.

Patja, K., Molsa, P., Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of Intellectual Disability Research*, 45, 1, 30-40.

Patja, K., Eero, P., Iivanainen, M. (2001). Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research*, 45, 4, 300-307.

- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., Ruoppila, I. (2000). Life expectancy of people with intellectual disabilities: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44 ( Pt 5), 591-599.
- Phan, A. et al. (2005). The assessment of pain and discomfort in individuals with mental retardation. *Research in Developmental Disabilities*, 26, 5, 433-439.
- Piachaud, J., Rohde, J., Pasupathy, A. (1998). Health screening for people with Down syndrome. *Journal of Intellectual Disability Research*, 42,5, 341-345.
- Piachaud, J., Rohde, J. (1998). Screening for breast cancer is necessary in patients with learning disability. *British Medical Journal*, 316, 1979-1980.
- Podgorsky, C., Kessler, K., Cacia, B., Peterson, D., Henderson, M. (2004). Physical activity intervention for older adults with intellectual disability: report on a pilot project. *Mental Retardation*, 42, 4, 272-283.
- Pollock, K. M. (2001). Exercise in treating depression: Broadening the psychotherapists role. *Journal of Clinical Psychology*, 57, 1289-1300.
- Prada,N., Nasi,M., Troiani,L., Roat,E., Pinti,M., Nemes,E. et al (2005). Direct analysis of thymic function in children with Down's Syndrome, *Immunity and Ageing*, 2,4-10.
- Prasher, V. P. (1997) Psychotic features and effect on severity of learning disability on dementia in adults with Down Syndrome. Review of literature. *British Journal of Developmental Disorders*, 43, 85-92.
- Pregliasco, F., Ottolina, P, Mensi, C. et al. (2001). Oral health profile in an institutionalized population of Italian adults with mental retardation. *Special Care Dentistry*, 21, 227-231.
- Rao, D., Hegde, A., Mangalore, M. et al. (2001). Caries prevalence amongst handicapped children of South Canara district, Karnataka. *J Indian Soc Pedo Prev Dent*, 19, 67-73.
- Regnard, C. et al. (2007). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *Journal of Intellectual Disability Research*, 51, 4, 277-292.
- Reichard, A. et al. (2001). Perspectives of dentists, families and case managers on dental care for individuals with developmental disabilities in Kansas. *Mental Retardation*, 39, 268-285.
- Reid, B.,Chenette, R., Macek, M. et al. (2003). Prevalence and predictors of untreated caries and oral pain among Special Olympics athletes. *Special Care Dentistry*, 23, 129-142.
- Rimmer, J.H., Braddock, D., Fujiura G. (1994). Cardiovascular risk factors in adults with mental retardation. *American Journal of Mental Retardation*, 98, 510-518.
- Rimmer, J. H., Heller, T., Wang, E.,Valerio, I. (2004). Improvements in physical fitness in adults with Down syndrome, *American Journal on Mental Retardation*, 109,2, 165-174.
- Rimmer, J.H., Wang, E. (2005). Obesity prevalence among a group of Chicago residents with disabilities. *Archives of Physical Medicine and Rehabilitation*, 86, 1461- 1464.

Rimmer, J.H., Yamaki, K. (2006). Obesity and intellectual disability. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 22-27.

Rimmer, J. H. (2006). Obesity and Intellectual Disability. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 22-27.

Robertson, J., Emerson, E., Gregory, N., Hatto, C., Turner, S., Kessissoglou, S., Hallam, A. (2000). Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, 21, 469-486.

Robertson, J. et al. (2002). Lifestyle related factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, 21, 469-486.

Roizen, N.J. (1996). Down syndrome and associated medical disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 2, 85-89.

Roth, N., Beyreiss, J., Schlenzka, K., Beyer, H. (1991): Coincidence of attention deficit disorder and atopic disorders in children: empirical findings and hypothetical background. *Journal of Abnormal Child Psychology*, 19, 1, 1-13.

Rubin, S., Rimmer, J., Chicoine, B., Braddock, D., McGuire, D. (1998). Overweight prevalence in persons with Down syndrome. *Mental Retardation*, 36, 175-181.

Ruddick, L., Oliver, C. (2005). The development of a health status measure for self-report by people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 18, 143-150.

Scott, A., March, I., Stoken, M. (1998). A survey of oral health in a population of adults with developmental disabilities : Comparison with a national oral health survey of the general population. *Australian Dental Journal*, 43, 4, 257-261.

Schneider, C., Melmed, R., Enriquez, F.J., Basrstow, L., Ranger-Moore, J., Ostrem, J. (2006). Oral human immunoglobulin for children with autism and gastrointestinal dysfunction: a prospective open-label study. *Journal of Autism and Developmental Disorders*, 36, 8, 1053-1064.

Schrager, S. (2006). Epidemiology of osteoporosis in women with cognitive impairment. *Mental Retardation*, 44, 203-211.

Schrager, S. (2004). Osteoporosis in women with disabilities. *Journal of Women's Health*, 13, 431-437.

Shapira, J., Efrat, J., Berkey, D. et al. (1998). Dental health profile of a population with mental retardation in Israel. *Special Care Dentistry*, 18, 149-155.

Shrestha, S., Weber, G. (2002). The situation of older people with intellectual disability in Nepal: A pilot study. *Journal of Intellectual and Developmental Disability*, 27, 242-254.

Shyama, M., Al-Mutawa, S., Morris, R. et al. (2001). Dental caries experience of disabled children and young adults in Kuwait. *Community Dental Health*, 18, 181-186.

Singer, H., Morris, C., Williams, P., Yoon, D., Hong, J., Zimmerman, A. (2006): .....???)  
*Neuroimmunology*, 178, 1-2, 149-155.

Stanish, H., Draheim, C. (2005a). Assessment of walking activity using a pedometer and survey in adults with mental retardation. *Adapt Phys Act Q*, 22, 136-145.

Stanish, H., Draheim, C. (2005b). Walking habits of adults with mental retardation. *Mental Retardation*, 43, 421-427.

Stanish, H., Draheim, C. (2005c). Physical activity assessment using pedometer and questionnaire in adults with mental retardation. *Adapt Phys Act Q*, 22, 136-145.

Stanish, H., Draheim, C. (2006a). Walking activity, body composition, and blood pressure in adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20, 3, 183-190.

Stanish, H. & Draheim, C. (2006b). Relationship between walking activity, body composition, and blood pressure in adults with mental retardation. *Journal of Applied Research in Intellectual Disabilities*. In press.

Stanish, H., Temple, V., Frey, G. (2006). Health-promoting physical activity of adults with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 13-21.

Starr, J.M., Marsden, L. (2008). Characterisation of user-defined health status in older adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 52, 6, 483-489.

Stawski, M., Merrick, J. (2006). Mental health services for people with intellectual disability in Israel--a review of options. *Isr.J.Psychiatry Relat Sci.*, 43, 237-240.

Stein, K., Allen, N. (1999). Cross sectional survey of cervical cancer screening in women with learning disability. *British Medical Journal*, 318, 614.

Stoyanova, A.P. (2003). Measuring inequalities in dental health and dental care utilisation : evidence from Spain. 2003. Barcelona, Spain : Universitat de Barcelona. Available at : <http://riscd2.eco.ub.es/~creb/papers/DentIneq.pdf>

Strauss, D. (1998). External causes of death among persons with developmental disability: the effect of residential placement. *American Journal of Epidemiology*, 147, 855-862.

Strauss, D., Kastner, T., Shavelle, R. (1998). Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994. *Mental Retardation*. 36, 360-371.

Strauss, D., Cable, W., Shavelle, R. (1999). Causes of excess mortality in cerebral palsy. *Developmental Medicine and Child Neurology*, 41, 580-585.

Strawbridge, W., Deleger, S., Roberts, R., Kaplan, G. (2002). Physical activity reduces the risk of subsequent depression for older adults. *American Journal of Epidemiology*, 156, 328-334.

- Strydom A, Livingston G, King M, Hassiotis A. (2007): Prevalence of dementia in intellectual disability using different diagnostic criteria. *British Journal of Psychiatry*, 191, 150-157.
- Stuck, A.K., Siu, A.L., Wieland, G.D., Adams, J., Rubenstein, L.Z. (1993): Comprehensive geriatric assessment: a meta-analysis of controlled trials. *Lancet*, 342, 1032-1036.
- Stuck, A., Egger, M., Hammer, A., Minder, C., Beck, J. (2002). Home visits to prevent nursing home admission and functional decline in elderly people – systematic review and meta-regression analysis. *JAMA*, 287, 1022-1028.
- Sullivan, S.G., Glasson, E.J., Hussain, R. et al (2003). Breast cancer and the uptake of mammography screening services by women with intellectual disabilities. *Preventive Medicine*, 37, 507-512.
- Sullivan, S. G., Hussain, R., Threlfall, T., Bittles, A. H. (2004). The incidence of cancer in people with intellectual disabilities. *Cancer Causes and Control*, 15, 1021-1025.
- Sullivan, S. G., Slack-Smith, L. M., Hussain, R. (2004). Understanding the use of breast cancer screening services by women with intellectual disabilities. *Sozial- und Präventivmedizin*, 49, 398-405.
- Sullivan, S.G., Hussain, R., Glasson, E.J., Bittles, A.H. (2007): The profile and incidence of cancer in Down Syndrome. *Journal of Intellectual Disability Research*, 51, 3, 228-231.
- Sutherland, G., Couch, M.A., Iacono, T. (2002). Health issues for adults with developmental disability. *Research in Developmental Disabilities*, 23, 422-445.
- Symons, F., Shinde, S., Gilles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research*, 52, 4, 275-286.
- Talley, N., Jones, M., Nuyts, G., Dubois, G. (2003). Risk factors for chronic constipation based on a general practice sample. *American Journal of Gastroenterology*, 98, 1107-1111.
- Temple, V., (2000). Physical activity levels of individuals living in a group home. *Journal of Intellectual and Developmental Disabilities*, 25, 327-341.
- Temple, V.A., Walkley, J.W. (2003a). Physical activity of adults with intellectual disability. *Journal of Intellectual and Developmental Disabilities*, 28, 323-334.
- Temple, V.A., Walkley, J.W. (2003b). Living arrangements and training influences on participation in physical activity among intellectually disabled adults. *Med Sci Sports Exerc*, 35, 66.
- The Eye Diseases Prevalence Research Group. (2004a). The prevalence of refractive errors among adults in the United States, Western Europe, and Australia. *Archives Ophthalmology*, 122, 495-505.
- The Eye Diseases Prevalence Research Group. (2004b). Prevalence of cataract and pseudophakia/aphakia among adults in the United States. *Archives Ophthalmology*, 122, 487-494.

- Thomas, C. (2007). *Sociologies of disability and illness. Contested ideas in disability studies and medical sociology*. Basingstoke, UK : Palgrave Macmillan.
- Thorpe, L., Davidson, P., Janicki, M. (2001). Healthy ageing- adults with intellectual disabilities: biobehavioral issues. *Journal of Applied Research in Intellectual Disabilities*, 14, 218-228.
- Traci, M., Seekins, T., Szalda-Petree, A. et al. (2002). Assessing secondary conditions among adults with developmental disabilities : A preliminary study. *Mental Retardation*, 40, 119-131.
- Tracy, J., Wallace, R. (2001). Presentations of physical ; illness in people with developmental disability : the example of gastroesophageal reflux. *Medical Journal of Australia*, 175, 109-111.
- Tsimaras, V., Giagazoglou, P., Fotiadou, E., Christoulas, K., Angelopoulou, N. (2003). Jog-walk training in cardiorespiratory fitness of adults with Down syndrome. *Perception and Motor Skills*, 96, 1239-1251.
- Tuffrey-Wijne, I. (2008). Cancer, palliative care and intellectual disabilities. Available at : [http://www.intellectualdisability.info/mental\\_phys\\_health/cancer\\_id.htm](http://www.intellectualdisability.info/mental_phys_health/cancer_id.htm) (Accessed on 6 August 2008).
- Tuffrey-Wijne, I., Hogg, J., Curfs, L. (2007). End-of-Life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness : a review of the literature and available resources. *Journal of Applied Research in Intellectual Disabilities*, 20, 331-344.
- Tyler C., Snyder, C., Zyzansky, S. (2000). Screening for osteoporosis in community-dwelling adults with mental retardation. *Mental Retardation*, 38, 316-321.
- Ugazio, A.G., Maccario, R., Notarangelo, L.D. et al. (1990). Immunology of Down syndrome: a review. *American Journal of Medical Genetics Supplement*, 7, 204-212.
- Urlings, H.F.J., Haveman, M.J., Maaskant, M.A., van Schrojenstein Lantman, H.M.J., Claessens, M.J.J.T., Kessels, A.G.H. (1993). Qualitative research on ageing : How do mentally retarded persons themselves experience the ageing process. In : Schuurman, M.I.M., Flikweert, D.A. *Research on mental retardation in the Netherlands. Contributions to the 9th World Congress IASSMD. August 1992, Australia. 200-205*. Bishop Bekkers Institute, Dutch Society for the Study of Mental Deficiency 1993, Utrecht, the Netherlands.
- US Department of Health and Human Services. (2000). *Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols.* Washington, DC: U.S. Government Printing Office. Additional information available at: <http://www.healthypeople.gov/>
- US Department of Health and Human Services. (2002). *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. US Department of Health and Human Services, Washington DC.

US Department of Health and Human Services. (2005). The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. Rockville: US Department of Health and Human Services.

US Preventive Services Task Force (USPSTF). (2004b). Screening for visual impairment in children younger than five years: Recommendation statement. *Annual Family Medicine*, 2, 263-266.

US Surgeon General. (2002). Closing the gap: a national blueprint to improve the health of persons with mental retardation: report of the Surgeon Generals conference on health disparities and mental retardation. Washington: US Department of Health and Human Services.

van Allen, M., Fung, J., Jurenka, S. (1999). Health care concerns and guidelines for adults with Down syndrome. *American Journal of Medical Genetics*, 89, 100-110.

van den Akker, Maaskant, M. A., van der Meijden, R. J. (2006). Cardiac diseases in people with intellectual disability. *Journal of Intellectual Disability Research*, 50, 515-522.

van den Broek, E., Janssen, C., van Ramshorst, T., Deen, L. (2006). Visual impairments in people with severe and profound multiple disabilities: an inventory of visual functioning. *Journal of Intellectual Disability Research*, 50,6, 470-475.

van Gent, T., Heijnem, C., Treffers, P. (1997). Autism and the immune system. *Journal of Child Psychology and Psychiatry*, 38,3, 337-349.

van Knijff-Raeven, A.G.M., Hartong, S.P., Maaskant, M.A., van den Akker, M. (2006). Veranderingen in de gewichtsstatus van mensen met verstandelijke beperkingen. *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten*, 32, 4, 230-239.

van Knijff-Raeven, A.G.M., Jansen-Jacobs, C.C.M., Freens, P.J.W., Hoekman, J., Maaskant, M.A. (2005). Body Mass Index (BMI) bij mensen met verstandelijke beperkingen. *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten*, 31, 1, 3-17.

van Laake, M. (2006). Preparing adults with intellectual disabilities for later life: optimizing choice-making. Doctorate dissertation. Faculty Rehabilitation Sciences, University of Dortmund.

vanLeit, B. (2008). Using the ICF to address needs of people with disabilities in international development: Cambodian case study. *Disability and Rehabilitation*, 30, 12-13, 991-998.

van Schroyen Lantman- de Valk, H., Metsemakers, J., Haveman, M., Crebolder, H. (2000): Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice*, 17, 405-407.

van Schroyen Lantman-de Valk, H.M.J., Schupf, N., Patja, K. (2002). Reproductive and physical health in women with intellectual disability. In: (Walsh, P.N.; Heller, T., eds.). *Health of women with intellectual disability*, 22-40. Blackwell, Oxford.

van Schroyen Lantman-de Valk, H.M. (2005). Health in people with intellectual disabilities: current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities*, 18, 325-333.

- van Schroyen Lantman-de Valk, H.M. (2004). Morbidity and health-care use in people with intellectual disabilities in general practice: first results of a survey in the Netherlands. *Journal of Policy and Practice in Intellectual Disabilities*, 1, 107-109.
- van Schroyen Lantman-de Valk, H.M., Metsemakers, J. F., Haveman, M. J., Crebolder, H. F. (2000). Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice*, 17, 405-407.
- vanlint, S., Nugent, M. (2006). Vitamin D and fractures in people with intellectual disability. *Journal of Intellectual Disability Research*, 50, 761-767.
- van Splunder, J., Stilma, J., Bernsen, R., Arentz, T., Evenhuis, H. (2003a). Refractive errors and visual impairment in 900 adults with intellectual disabilities in the Netherlands. *Acta Ophthalmologica Scandinavica*, 81, 123-129.
- van Splunder, J., Stilma, J., Evenhuis, H. et al. (2003b). Visual performance in specific syndromes associated with intellectual disability. *European Journal of Ophthalmology*, 13, 565-574.
- van Splunder, J., Stilma, J., Bernsen, R., Evenhuis, H. (2004). Prevalence of ocular diagnoses found on screening 1539 adults with intellectual disability. *Ophthalmology*, 111, 1457-1463.
- van Splunder, J., Stilma, J., Bernsen, R., Evenhuis, H. (2006). Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. *Eye*, 20, 9, 1004-1010.
- van Winckel, M., van de Keere, N., Deblare, S., van Put, V., Robberecht, E. (1999). Use of laxatives in institutions for the mentally retarded. *European Journal of Clinical Pharmacology*, 54, 965-969.
- Vargas, D.L., Nascimbene, C., Krishnan, C., Zimmerman, A., Pardo, C. (2005). Neuroglial activation and neuroinflammation in the brain of patients with autism. *Ann Neurol*, 57, 1, 67-81.
- Vazquez, C., Garcillan, R., Rioboo, R. et al. (2002). Prevalence of dental caries in an adult population with mental disabilities in Spain. *Special Care Dentistry*, 22, 65-69.
- Vehmas, S. (2004). Ethical analysis of the concept of disability. *Mental Retardation*, 42, 209-222.
- Varela, A., Sardinha, L., Pitetti, K. (2001). Effects of an aerobic rowing training regimen in young adults with Down syndrome. *American Journal of Mental Retardation*, 106, 135-144.
- Vincent, A., Dalton, P., Clover, L., Palace, J., Lang, B. (2003). Antibodies to neuronal targets in neurological and psychiatric diseases. *Ann New York Academy of Sciences*, 992, 48-55.
- Vonken, M.T.H., Maaskant, M.A., van den Akker, M. (2006). Aandoeningen van het bewegingsapparaat bij mensen met een verstandelijke handicap. *Nederlands Tijdschrift voor de Zorg aan verstandelijk gehandicapten*, 32, 2, 98-111.

Wagemans, A. M., Fiolet, J. F., van der Linde, E. S., Menheere, P. P. (1998). Osteoporosis and intellectual disability: is there any relation? *Journal of Intellectual Disability Research*, 42, 5, 370-374.

Waldman, H., S., Swerdloff, M. (1998). Dental care for children with mental retardation : Thoughts about the Americans with Disabilities Act. *ADSC J Dent Child*, 65, 487-491.

Waldman, H.B.; Perlman, S.P. (2002). Providing dental services for people with disabilities: why is it so difficult? *Mental Retardation*, 40, 4, 330-333.

Wali, A., John, P., Gul, A., Lee, K., Chishti, M., Ali, G., Hassan, M. Leal, S., Ahmad, W. (2006). A novel locus for alopecia with mental retardation syndrome (APMR2) maps to chromosome 3q26.2-q26.31. *Clinical Genetics*, 70, 3, 233-239.

Wallace, R., Schluter, P., Webb, P. (2002). Environmental, medical behavioural and disability factors associated with *Helicobacter pylori* infection in adults with intellectual disability. *Journal of Intellectual Disability Research*, 46, 51-60.

Wallace, R., Schluter, P., Webb, P. (2004). Recurrence of *Helicobacter pylori* infection in adults with intellectual disability. *Internal Medicine Journal*, 34, 132-133.

Wallace, R., Schluter, P. (2008). Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *Journal of Intellectual and Developmental Disability*, 33, 1, 48-58.

Walmsley, J. (2004). Inclusive learning disability research : the (nondisabled) researcher's role. *British Journal of Learning Disabilities*, 32, 65-71.

Walsh, P.N., Kerr, M., van Schrojenstein Lantman-DeValk H.M.J. (2003). Health indicators for people with intellectual disability: A European perspective. *European Journal of Public Health*, 13, 47-50.

Wang, W.Y. (2003). Promoting balance and jumping skills in children with Down syndrome. *Perception and Motor Skills*, 94, 443-448.

Wang, K.Y., Hsieh, K., Davidson, P.W., Janicki, M.P. (2007). Carer reports of health status among adults with intellectual/developmental disabilities in Taiwan living at home and in institutions. *Journal of Intellectual Disability Research*, 51, 3, 173-183.

Warburg, M. (2001a). Visual impairment in adult people with intellectual disability: Literature review. *Journal of Intellectual Disability Research*, 45, 424-438.

Warburg, M. (2001b). Visual impairment in adult people with moderate, severe, and profound intellectual disability. *Acta Ophthalmology Scandinavica*, 79, 450-454.

Warren, R. P., Cole, P. et al. (1990): Detection of maternal antibodies in infantile autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 29, 6, 873-7.

Webb, O.J., Rogers, L. (1999). Health screening for people with intellectual disability: The New Zealand experience. *Journal of Intellectual Disability Research*, 43, 497-503.

Webb, O.J. & Rogers, L. (2002). The health care of people with intellectual disabilities. *nzfp*, 29 ,3, 188-193.

Welsh Office. *Welsh Health Survey 1995*. London: HMSO, 1996.

White, J., Beltran, E., Malvitz, et al. (1998). Oral health status of special athletes in the San Francisco Bay area. *Canadian Dental Association Journal*, 26, 347-353.

World –Health Organization (2000). *Ageing and intellectual disability: improving longevity and promoting healthy ageing: summative report*. WHO, Geneva

World Health Organization (2001). *International classification of functioning, disability and health*. Geneva: WHO

World Health Organisation (2002). *National cancer control programmes: policies and managerial guidelines*. World Health Organisation, Geneva.

World Health Organization (2003). *Global strategy on diet, physical activity and health*. Geneva: World Health Organisatio

Wilkinson, J.E., Culpepper, L., Cerreto, M. (2007). Screening Tests for Adults with Intellectual Disabilities. *JABFM*, 20, 4, 399-407.

Wilson, R. (1998). *Carer burden in learning disability with coexistent epilepsy*. Unpublished MSc thesis. University of Wales College of Medicine, Cardiff.

Woodhouse, J.M., Adler, P., Duignan A. (2004). Vision in athletes with intellectual disabilities: the need for improved eyecare. *Journal of Intellectual Disability Research*, 48 (8), 736-745.

Woodhouse, J., Adler, P., Dulgnan, A. (2003). Ocular and visual defects amongst people with intellectual disabilities participating in Special Olympics. *Ophthalmol Physiol Opt* 23: 221-232.

Yamagishi, H. (2002): The 22q11.2 deletion syndrome. *Keio J Med*, 51,2, 77-88.

Yamaki, K., Fujiura G.T. (2002): Employment and oncome status of adults with developmental disabilities living in the community. *Mental Retardation*, 40, 132-141.

Yamaki, K. (2005). Body weight status among adults with intellectual disability in the community. *Mental Retardation* ,43, 1-10.

Yang, Q., Rasmussen, S., Friedman, J. (2002). Mortality associated with Down's syndrome in the USA from 1983 to 1997: a population-based study. *The Lancet* ,359, 1019-1025.

Young, A.F., Chesson, R.A. (2006): Obtaining views on health care from people with learning disabilities and severe mental health problems. *British Journal of Learning Disabilities*, 34,11-19.

Zigman, W.B., Schupf, N., Sersen, E., Silverman, W. (1996): Prevalence of dementia in adults with and without Down Syndrome. *American Journal of Mental Retardation*, 100, 403-412.

Zigmond, M., Stabholz, A., Shapira, J., Bachrach, G., Chaushu, G., Becker, A., Yefenof, E., Merrick, J., Chaushu, S. (2006). The outcome of a preventive dental care programme on the prevalence of localized aggressive periodontitis in Down's syndrome individuals. *Journal of Intellectual Disability Research* 50,7, 492-500.

Zwakhaleh, S., van Dongen, K., Hamers, J., Abu-Saad, H. (2004). Pain assessment in intellectually disabled people: non-verbal indicators. *Journal of Advanced Nursing*, 45,3, 236-245.

## **ABOUT THE AUTHORS**

### **Meindert Haveman**

Meindert Haveman, Ph.D. is Professor and Head of the Department Rehabilitation and Education for Persons with Intellectual Disabilities in the Faculty Rehabilitation Sciences of the University of Dortmund, Germany. His research is focussed on Ageing and Health in Intellectual Disabilities.

### **Tamar Heller**

Tamar Heller, Ph.D. is Professor and Head of the Department of Disability and Human Development, and the Rehabilitation Research and Training Center on Aging and Developmental Disabilities at the University of Illinois at Chicago. In addition she is Director of the Institute on Disability and Human Development, the University Center of Excellence in Developmental Disabilities in Illinois. Her research interests are in lifespan health and family support.

### **Lynette Lee**

Dr Lynette Lee is a Senior Staff Specialist in Rehabilitation Medicine at Concord Hospital and Associate Professor in the Centre for Education and Research on Ageing, Sydney University, Australia. She has a special interest in Health Policy for people with Intellectual Disabilities.

### **Marian Maaskant**

Dr Marian Maaskant (epidemiologist) is research co-ordinator at Stichting Pergamijn (formerly Stichting Pepijn en Paulus) and senior researcher at the Governor Kremers Centre of Maastricht University (Department of Health Care and Nursing Science) in the Netherlands.

### **Shahin Shooshtari**

Dr Shahin Shooshtari is an Assistant Professor in Family Social Sciences and Community Health Sciences at the University of Manitoba in Canada. She is also a researcher with St. Amant Research Centre in Winnipeg, Manitoba. Her program of research focuses on Health, Aging and Intellectual Disabilities.

### **Andre Strydom**

Dr Andre Strydom is Clinical Academic Senior Lecturer at the Department of Mental Health Sciences, UCL School of Life and Medical Sciences, Charles Bell House in London. In addition he is Consultant Psychiatrist in Intellectual Disability, Camden and Islington Foundation NHS Trust, Great Britain.