

Systematic Literature Search on Health Promotion Strategies for Adults with Intellectual Disabilities

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### **1. BACKGROUND**

#### 1.1 Defining Intellectual Disability (ID)

Intellectual disability (ID) is not a disease itself, rather it is a condition that is characterized by significant limitations in both intellectual functioning and adaptation in conceptual and practical skills (van Schrojenstein Lantman-de Valk & Walsh, 2008); though engaging in community living and social skills can also be affected (Fisher, 2004). Examples of adaptation skills include communication, self-care, and self-direction. Diagnosing the presence of ID is usually conducted by a psychologist using established criteria including having an intelligence quotient (IQ) score of 70 or below, with an onset of the condition before the age of 18 (APA, 1994).

There are a number of terms that have been used by healthcare professionals to define intellectual disability. The term "mental retardation", though still used within the International Classification of Diseases (ICD-10), is currently considered unacceptable by most (World Health Organization, 2001). The term intellectual disability (ID) is generally preferred, and will be used in this paper.

### **1.2 Population Demographics**

Though there is no official rate of ID in Canada, it has been estimated that approximately 1% of Canadians has an ID, and reported prevalence rates tend to vary between 0.7% and 3% (Crawford, 2008). Though this represents a relatively low proportion of the overall population, ID nonetheless affects a non-trivial number of individuals and families (Fisher, 2004). It has been estimated that within developing countries there are over 60 million persons with some

level of intellectual disability and continues to rise due to improvements in health care and quality of life indicators (World Health Organization, 2001).

Currently, 12% of persons with ID are 65 years of age or older, and this proportion is expected to reach 25% by 2040 (Davidson, Prasher & Janicki, 2003). Consequently, the need for healthcare services is expected to increase.

#### 1.3 The Health of Persons with ID

Historically, the definition of health was one of a biological perspective, where health was looked upon as being without disease or disability. Through this narrow perspective on health and wellness, people who had disabilities of any form were seen as being unhealthy and were largely ignored in regards to research in prevention, health care or health promotion strategies. Instead research has been focused on the consequences that occur with disabilities such as increased prevalence of disease or common disorders (Sutherland, Couch & Iacono, 2002). Within the last decade the health needs and priorities of people with ID have been receiving increasing amounts of attention (van Schrojenstein Lantman-de Valk & Walsh, 2008). The main health care priorities for people with ID across the world include having access to basic healthcare, having adequate nutrition and housing, being educated as well as having political, social and economic stability (Evenhuis, Henderson, Beange, Lennox & Chicoine, 2001). Health care discrepancies have been noted, especially for persons with ID living in developing countries, as not only having the majority of the population but also the majority of persons with ID (World Health Organization, 2001).

While most research to date has been focused on the health needs for those living in more developed countries, the same priorities and barriers to health occur across the world (World

Health Organization, 2001). Research looking at these barriers to health and wellness show that persons with ID have a higher prevalence of health problems compared to the general population, and that disparities in care often arise when health needs are unrecognized and unmet (van Schrojenstein Lantman-de Valk & Walsh, 2008). Persons with ID experience significant health inequalities as compared to the general population (Melville et al., 2008). These inconsistencies are not to be overlooked; though persons with ID represent a relatively low percentage of the overall population, this condition affects a substantial number of individuals and families (Fisher, 2004).

# 1.3.1 Life Expectancy

The average life expectancy for those with ID is 66.1 years, which has been steadily increasing (Fisher, 2004). Because of this longer life expectancy, those with ID are now more likely to confront the same age-related illnesses as the general population such as chronic illnesses including cardiovascular disease, diabetes and cancer. Due to the increases in chronic illnesses, health care provided to those with ID needs to shift from being treatment focused to include health prevention and screening strategies as used in the general population (Fisher, 2004).

While the life expectancy for those with ID is increasing, it is still well below the average for persons without disability (Evenhuis et al., 2001). As evidence by the relatively lower life expectancy, premature death is a concern in this population (Cooper et al., 2006). The most common causes of mortality among persons with ID include respiratory, cardiovascular, and gastrointestinal diseases, neoplasms, and external causes (e.g., accidents and poisonings) (Balogh, Ouellette-Kuntz, Bourne, Lunsky & Colantonio, 2009); many of which are preventable.

#### 1.3.2 Health Problems

The presence of an ID predisposes individuals to increased risk for a number of significant health concerns (Cooper et al., 2006). Persons with ID have specific conditions and diseases that occur more common than in the general population, including: epilepsy, mobility problems, hearing and visual disorders, mental illness and Alzheimer's disease (Sutherland et al., 2002). Secondary health conditions such as obesity, fractures, poor oral health, constipation and gastro-oesophageal reflux disease (Hamilton, Hanskey, Miller, Boyle & Melville, 2007; van Schrojenstein Lantman-de Valk & Walsh 2008) are also prevalent. A recent study determined that approximately 41% of people with ID experience ill-health as secondary medical disorders in some capacity (Cooper et al., 2006).

Over the past decade, health behaviors including physical activity, diet, smoking and alcohol consumption have been found to be major determinants of preventable morbidity and mortality amongst the general population. These lifestyle choices can also influence the health of adults with ID; in fact, poor lifestyle choices have been shown to have even graver consequences to the quality of life and longevity of persons with ID (Sutherland et al., 2002).

#### 1.3.3 Health Care

Due to their disability, persons with ID often have difficulty interacting with their environment, live below the poverty line, and feel separated from society (Fisher, 2004). Due to these compounding factors, persons with ID are more likely to experience disparities in health promotion and health care service delivery through unrecognized and poorly managed medical conditions (Fisher 2004; Lennox et al., 2007). The response to the needs of those with IDs has not been decisive, and the best way forward have been debated since the advent of deinstitutionalization in developed countries (Balogh et al., 2009). While deinstitutionalization has improved the lives of those with ID, this improvement also has had a cost as it has shifted the primary responsibility of care from specialized health care services to the community care facilities, which often function without sufficient preparation, training, or financial support (Balogh et al., 2009). Persons with ID are now depending on family members or community organizations for support, and these individuals may not be equipped to detect and identify health problems (Fisher, 2004).

Since deinstitutionalization, the medical care of persons with ID has shifted to primary health care (i.e., family doctors, general practitioners), who may not have expertise or experience in ID (Cooper et al., 2006; Fisher, 2004; van Schrojenstien Lantman-de Valk, 2005). Further, there has also been a lack of active co-ordination and co-operation between healthcare providers in providing health care to persons with ID (Jansen, Krol, Groothoff & Post, 2006).

There are many potential access barriers for persons with ID, including communication, mobility and accessibility (Cooper et al., 2006). When persons with ID are able to receive services, there may still be barriers to care associated with this disability including the stigma of having a disability and not having adequately trained health care professionals or resources available for the unique needs of this population (Fisher, 2004). The reality of the difficulties in seeking health care services that should be considered of equal value to those for the general population needs to be addressed.

A medical approach to health care service has largely focused on service providers as the key players in understanding the health of adults with ID. However, with the emergence of health promotion and recognition of its importance, it has been recognized that health outcomes are influenced by factors beyond what health services provide. In this field, research has shifted from a focus on what is causing ill health to trying to understand why adults with ID have much higher rates of preventable illness; representing a shift from curing to caring about the health needs of persons with ID (Sutherland et al., 2002).

#### 1.3.4 Health Promotion

In addition to questionable health care, very little health promotion is used amongst this vulnerable population; this is problematic given the high risk for a number of health conditions in this population (Marks & Heller, 2003).

Health promotion strategies and disease prevention need to be further researched to overcome the health care inadequacies and needs for persons with ID. As those with ID continue to age, more chronic illnesses and secondary health concerns will emerge. This can add huge costs to the health care system when ill health goes unnoticed (Fisher, 2004).

While health inequalities have been made known for persons with intellectual disabilities, developing sound research studies regarding this population is difficult. Various ethical concerns including informed consent, risks involved with clinical experiments and the accuracy of care giver information all contribute to diverse difficulties when conducting research with this vulnerable population (World Health Organization, 2001). Due to various communication and mobility difficulties, researchers will need to overcome these barriers when working with persons with ID (Fisher, 2004). Health care professionals, support workers and carers for those with ID need to be made aware of effective health promotion strategies that are currently available to improve the overall health and wellbeing of this population (Evenhuis et al., 2001).

# **2. OBJECTIVES**

The objective of this paper is to provide a systematic review of effective health promotion strategies that could improve the health and wellbeing of persons with ID. Areas of focus included health assessment and screening measures, health behaviours, and health education including health care provision.

#### **3. METHODS**

#### 3.1 Criteria for Considering Studies

In this section, the types of studies, participants, interventions, and outcome measures considered in this review are described.

## 3.1.1 Types of Studies

Studies that were considered in this review included randomized controlled trials, controlled clinical trials, controlled before and after studies, and cross-sectional studies that incorporated controlled comparisons. Studies with adequate sample sizes were also sought to ensure accurate results.

## 3.1.2 Types of Participants

Participants included persons with ID who were 16 years of age or older, their families, health professionals, or other supports. Participants with ID were living in community settings with varying degrees of support, from independent to supportive living arrangements (e.g., group home); studies conducted in institutional settings were excluded. Severity of disability was not a criteria component on its own, rather studies needed to include participants with communication capabilities, unless data was gathered from carers of support persons when communication was not possible. Degree of disability ranging from mild/moderate to severe/profound was noted when it was reported in the study.

### 3.1.3 Types of Interventions

Since health promotion strategies aim to improve the overall health of a population, improvement in overall health and wellness are guiding principles. To be included in this review, the health promotion strategies employed in the studies needed to adhere to health promotion guidelines, as stated in the Ottawa Charter for Health promotion (World Health Organization, 1986). As such, the health promotion strategies employed must: (1) advocate for good health through political, economic, social, cultural, environmental, behavioral and biological methods; (2) enable good health through achieving equality in health through equal opportunities and resources; and (3) mediate (i.e., health promotion efforts need to involve all public sectors including government and non-government groups, voluntary organizations, media and individuals). In addition, the health promotion strategies employed must be capable of leading to: (1) building healthy public policy; (2) developing supportive communities and environments; (3) strengthening community actions and developments; (4) developing personal life skills through health education; (5) reorienting health services to be accessible to all; and (6) looking for improvements for the future (World Health Organization, 1986).

The health promotion strategies that were included in this review adhered to the above criteria, and included the following types of intervention studies: health assessment; health screening; health behaviour; and health education including health care provision. As financial interventions were not within the scope of this review, cost-effectiveness and cost of care studies were not included.

#### 3.1.4 Types of Outcome Measures

While the specific types of outcome measures resulting from the health promotion strategies/ interventions employed were not used as inclusion or exclusion criteria, this review focuses solely on physical health. Therefore, studies specifically related to mental health were excluded.

#### 3.2 Search Methods for Identifying Studies

Electronic data bases including PubMed, OVID and Cochrane were searched for primary studies between January 2004 and October 2009; these dates were used as an initial search guideline to find the most recent studies available on health promotion strategies for persons with ID. After this initial search yielded an unsatisfactory number of appropriate studies, the date range was expanded to include a breadth of ten years, from January 1999 to November 2009; inclusion of earlier ranges yielded a satisfactory sampling of applicable studies.

The PubMed search strategy included articles within the criteria of health promotion combined with the search terms of intellectual disability, mental retardation, learning disability or developmental disability. Search field was entered as: health promotion AND (intellectual disabilit\* OR mental retardation OR learning disabilit\* OR developmental disabilit\*). Limits placed on the search included English as language of publication and articles focusing on human subjects.

The OVID database was searched using the Journals@OVID selection, including EMBASE and Ovid MEDLINE and used the keyword health promotion combined with the terms of intellectual disability, mental retardation, learning disability and developmental disability. The limits described above (English language, human subjects) were also applied here.

Finally, the Cochrane database was searched using the keywords health promotion and intellectual disabilit\* or mental retardation or learning disabilit\* or developmental disabilit\*. Again, the same limitations were applied to the search including English language and human subjects.

#### **4. DATA COLLECTION**

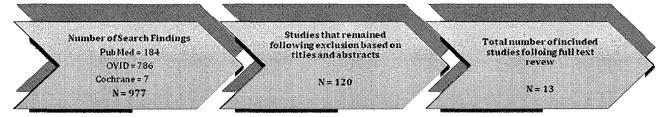
#### 4.1 Study Selection

All studies identified using the search strategies listed above were reviewed for possible inclusion by first reading the title and abstract; studies were excluded when they were clearly not related to the topic objectives of the review. Then, remaining studies were reviewed based on their full text to deem if they met the inclusion criteria.

#### 4.2 Search Results

Following the literature search through PubMed, Ovid and Cochrane databases, a total of 970 potential studies were identified. Upon initial review (i.e., review of title and abstract), 120 (12%) met the preliminary inclusion criteria. Each of the 120 articles was subsequently read in its entirety. From this, only 13 studies met the full criteria for inclusion (see Figure 1).

Figure 1: Search results from all databases from publication years 1999 to 2009



# 4.3 Included Studies

The 13 studies that were included are described in the next section (i.e., section 5.1). Among the included studies there was one randomized controlled trial (Lennox et al., 2006), one controlled clinical trial (Cooper et al., 2006), five controlled pre/post studies (Carmeli, Orbach, Zinger-Vakin, Morad & Merrick, 2008; Chapman, Craven & Chadwick, 2008; Ewing, McDermott, Thomas-Koger, Whitner & Pierce, 2004; Melville et al., 2006; Rimmer, Heller, Wang & Valerio, 2004), and three were cross-sectional with control comparisons (Cooper et al., 2006; McGuire, Daly & Smyth, 2007; Melville et al., 2008).

Not all studies included information on all aspects of the population sampled. Using the population demographics presented, over half of the study's samples sizes were small and had 100 or fewer participants (Allan, 1999; Carmeli et al. 2008; Chapman et al., 2008; Cooper et al., 2006; Hensel, Rose, Stenfert Kroese & Banks-Smith, 2002; Melville et al., 2006; Rimmer et al., 2004; Tsimaras, Giagzoglou, Fotiadou, Christoulas & Angelopoulou, 2003). Studies by McGuire et al. (2007) and Ewing et al. (2004) had between 100 and 200 participants, and Lennox et al. (2007), Melville et al. (2007) and Lewis, Lewis, Leake, King & Lindeman (2002) had comparatively larger samples (453, 945 and 353 participants, respectively). Studies used population samples from developing countries around the world; five of the thirteen were conducted in Scotland or Ireland (Allan 1999; Cooper et al., 2006; McGuire et al., 2007; Melville et al., 2006, 2008). The level of intellectual impairment varied across the studies, from mild to profound impairment.

#### 4.4 Excluded studies

Of the 120 studies that were reviewed in full, 107 were excluded; reasons for exclusion are described in section 5.2. The most common reason was due to a lack of control comparison group, as well as study designs that did not meet inclusion criteria (e.g., descriptive studies).

### **5. RESULTS**

# 5.1 Description of Included Studies

In this section, characteristics and findings of included studies are presented. Studies have

been categorized according to the type of health promotion strategy employed, including: (1)

health assessment; (2) health screening; (3) health behaviour; (4) health education; and (5) health

care services.

# 5.1.1 Characteristics of Studies Related to Health Assessment Strategies

In this section, results related to health assessment as a health promotion strategy for

persons with ID are provided in Table 1; key findings are also discussed.

Lennox et al.,	2007
Methods	Study Design: Randomized Control Trial
	Types of Intervention: Health Assessment Program
Participants	Persons with ID living in community settings within supportive accommodation, Carers and General
	practitioners
	Setting: Queensland, Australia
	Sample size: n=453 in 34 clusters, with an average of 14 participants in each cluster. Clusters were
	matched on size, age and proportion with Down's syndrome into pairs with each pair randomized to
	either receive the intervention or control
Intervention	Intervention: Received the Comprehensive health assessment program. Carer completed a medical
	history that the general practitioner will review, followed by an examination and then will assist
	with the development of a health action plan.
	Control: Received routine and usual care only
Outcomes	Outcomes were reviewed one year post intervention through the GPs records.
化物理学识别	Outcomes included:
	<ul> <li>Health promotion through the sensory impairment or obesity identification</li> </ul>
	• Disease prevention through immunization, blood pressure checks, and women's health
	needs including Papanicolau smear, breast examinations or mammography tests
	Identifying new diseases
and the second	Management of sensory impairment or obesity
Results	Outcome measures (Risk Ratio, Confidence Interval)
	• Vision (3.8, 1.1-7.6)
	• Hearing test (30.0, 4.0-230)
	o Immunization – tetanus (9.1, 4.2-19)
	$\circ$ Woman's health screening (7.9, 1.8 – 35)
	• New diseases diagnosed (1.6, 0.9 – 2.8)
Conclusion	Statistically significant improvements were seen in health promotion and disease prevention
n dan se	outcomes as compared to control group
Summary	Results showed that through the use of the Comprehensive Health Assessment Program (CHAP)
	there was an increase in the health practitioners awareness of the health needs of those with ID

**Table 1: Studies Related to Health Assessment Strategies** 

The study by Lennox et al. (2007) showed that health care reviews conducted in primary care settings substantially lessened the gaps in health care provision faced by adults with ID. An annual health assessment can encourage the identification of health problems early on, as well as the use of appropriate health interventions (e.g., health promotion, disease prevention). Lennox et al. (2007) also found that through the health assessment, health promotion and disease prevention outcomes for the patients significantly increased compared to those of the control group; in particular, significant increases were noted in detection of hearing and vision impairments, attention to immunization records, identification and management of obesity, and screening for women's health needs. Moderate increases were also shown through increased detection of new diseases and ailments, which may have previously gone undetected. This study holds solid findings for implications for public health methods for persons with ID, as the randomization procedure eliminated selection bias that may have affected the findings. The improvements to the health of those with ID are only noted as initial steps to treatment, through preventative and detection measures. For this reason, the study is unable to test to the overall improvements of health assessment to overall health. As findings showed health improvements with improved healthcare practices, implementation of routine health assessments among persons with ID has the potential to significantly improve the health status of persons with ID at the same time as reducing the likelihood of unmet health needs.

#### 5.1.2 Characteristics of Studies Related to Health Screening Strategies

In this section, results related to health screening as a health promotion strategy for persons with ID are provided in Table 2; key findings are also discussed.

#### **Table 2: Studies Related to Health Screening Strategies**

medical files using a semi-structured form. Nurses further met with each person together with carer to complete a health assessment and examination. Findings were discussed with a general practitioner and a summary of findings including recommendation were sent to person's own GP Outcome measures were reviewed through persons medical records and assessment with person and career one year following health screen. Control: Received standard treatment onlyOutcomesNew health needs including health monitoring and promotion needs that were identified one year completion of the health screen.Results1-year health Outcome Data (I: Intervention, C: Control) o Incidence of New disease: I: Mean 4.8, C: Mean 2.26, p=<0.001 o Met new health needs: I: Mean 3.56, C: Mean 2.26, p=<0.001 o Met health promotion Needs: I: Mean 3.56, C: Mean 1.38, p=<0.001 o Met health monitoring needs: I: Mean 1.70, C: Mean 1.26, p= 0.039ConclusionIncidences of health needs that were detected and levels of needs that were met were significantly greater in control group. Health promotion and monitoring needs that were met were found to be significantly greater for intervention group as well (p = 0.001 - 0.039). Findings support that	Cooper et al., 2	006
Participants       Persons with ID, carers, nurses and general practitioners         Setting: Glasgow, Scotland       Sample size: 50 intervention participants each individually matched for gender, age and level of ID with 50 control participants         Intervention       Intervention: Nurses experienced with working with persons with IDs reviewed each participant' medical files using a semi-structured form. Nurses further met with each person together with carer to complete a health assessment and examination. Findings were discussed with a general practitioner and a summary of findings including recommendation were sent to person's own GP Outcome measures were reviewed through persons medical records and assessment with person and career one year following health screen.         Control: Received standard treatment only         Outcomes         New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         Control: Received standard treatment only         Outcomes         New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         I-year health Outcome Data (I: Intervention, C: Control)         Incidence of New disease: I: Mean 4.8, C: Mean 2.26, p=<0.001         Met new health needs: I: Mean 3.56, C: Mean 1.38, p=<0.001         Met health promotion Needs: I: Mean 1.70, C: Mean 1.38, p=<0.001         Met health monitoring needs: I: Mean 1.70, C: Mean 1.26, p= 0.039         Incidences of health needs that were detected and levels of needs that were	Methods	Study Design: Controlled Clinical Trial
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Sample size: 50 intervention participants each individually matched for gender, age and level of ID with 50 control participants         Intervention       Intervention: Nurses experienced with working with persons with IDs reviewed each participant's medical files using a semi-structured form. Nurses further met with each person together with carer to complete a health assessment and examination. Findings were discussed with a general practitioner and a summary of findings including recommendation were sent to person's own GP Outcome measures were reviewed through persons medical records and assessment with person and career one year following health screen.         Control: Received standard treatment only         Outcomes       New health needs including health screen.         Control: Received standard treatment only       0         Outcome of the health screen.       0         Control: Received standard treatment only       0         Outcomes       New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         Results       1-year health Outcome Data (I: Intervention, C: Control)         O Met new health needs: I: Mean 4.8, C: Mean 2.26, p=<0.001	Participants	Persons with ID, carers, nurses and general practitioners
ID with 50 control participants         Intervention       Intervention: Nurses experienced with working with persons with IDs reviewed each participant' medical files using a semi-structured form. Nurses further met with each person together with carer to complete a health assessment and examination. Findings were discussed with a general practitioner and a summary of findings including recommendation were sent to person's own GP Outcome measures were reviewed through persons medical records and assessment with person and career one year following health screen.         Control: Received standard treatment only         Outcomes         New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         Control: Received standard treatment only         Outcomes         New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         Control: Received form. Nurses: I: Mean 4.8, C: Mean 2.26, p=<0.001	NR A RUC	Setting: Glasgow, Scotland
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Outcome measures were reviewed through persons medical records and assessment with person and career one year following health screen.         Control: Received standard treatment only         Outcomes         New health needs including health monitoring and promotion needs that were identified one year completion of the health screen.         Results       1-year health Outcome Data (I: Intervention, C: Control)         • Incidence of New disease: I: Mean 4.8, C: Mean 2.26, p=<0.001         • Met new health needs: I: Mean 3.56, C: Mean 2.26, p = 0.001         • Met health promotion Needs: I: Mean 3.56, C: Mean 1.38, p=<0.001         • Met health monitoring needs: I: Mean 1.70, C: Mean 1.26, p = 0.039         Conclusion       Incidences of health needs that were detected and levels of needs that were met were significantly greater in control group. Health promotion and monitoring needs that were met were found to be significantly greater for intervention group as well (p = 0.001 – 0.039). Findings support that	Intervention	carer to complete a health assessment and examination. Findings were discussed with a general
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		greater in control group. Health promotion and monitoring needs that were met were found to be
sustained health benefits can occur through interventions for persons with ID through a clinical		sustained health benefits can occur through interventions for persons with ID through a clinical
health screen intervention.		

A 2006 study by Cooper et al. was the first to be conducted that showed the sustainable benefits of health screening to health outcomes for adults with ID when compared with receipt of standard medical care. The study was conducted over a one year period, where the outcome was evaluated one year after the initial health screen was completed. The health screen focused on the person's physical and mental health as well as development and behavior problems. Physical health outcomes included identification of new health needs, health monitoring, and receipt of health promotion services. Over the course of the study period, the incidence of health need detection occurred more than twice as often as those in the controlled groups; the number of new health needs that were being met was also significantly greater among the experimental group. Significant levels were also seen in the level of met health promotion needs (i.e., dental checkup, eye test, diet and exercise, and immunization for influenza and hepatitis) and health monitoring (i.e., chronic disease management, annual drug review, and annual review of thyroid function). Overall, when compared with those only receiving standard medical care, persons with ID who receive an annual health screen showed sustained health improvements over the study period and beyond. This study showed that through minimal staff time, training, and cost, a screening intervention can be effective in improving health outcomes for persons with ID.

#### 5.1.3 Characteristics of Studies Related to Health Behaviours

In this section, results related to health behaviours as a health promotion strategy for persons with ID are provided in Table 3. Key findings are discussed for each of the identified studies; an overall summary is also provided.

The study by Carmeli et al. (2008) was conducted to examine the effect of a physical training program on the well-being and self-image of older adults with ID; specifically, whether improved fitness was related to positive changes in perception of health and well-being. Both the experimental and control group were evaluated before and after the study period; the intervention group received an exercise program, and the control group were taught a new vocational activity. The results showed no change in the experimental group's BMI, though changes were seen in their perception of well-being. In particular, overall feelings of social isolation were reduced and energy and physical mobility levels improved. Findings also highlighted that a strong support system and positive reinforcement were essential to the success of the individual.

# **Table 3: Studies Related to Health Behaviours**

Table 5: St	udies Related to Health Benaviours
Carmeli et al.	, 2008
Methods	Study Design: Controlled Before and After study; Type of Intervention: physical training effects on
	overall well-being and self-image
Participants	Older adults with ID; Setting: Israel; Sample size: 62 volunteers from within two residential care
	centers having had resided there for at least 5 years. Participants were selected if only requiring
	minimal assistance for most activities of daily living and having only mild intellectually disability.
Intervention	Intervention: Exercise Group received a physical training program three times a week for 10 months
	straight; Control: Participants were matched with intervention group according to age and sex and
	did not receive any physical intervention, but were instead shown an unrelated vocational activity.
Outcomes	Perceived well-being and self image
Results	Dimensions of Well Being (Mean results as a percentage), (I: Intervention, C: Control)
	• Energy: I: 51.46, C: 22.73, $p = 0.001$
	• Pain: I: 3.78, C: 3.21, $p = 0.797$
	• Emotional reactions: I: 31.6, C: 32.4, $p = 0.445$
	• Sleep: I: $38.11$ , C: $39.30$ , p = $6.58$
	• Social Isolation: I: 29.89, C: 12.55, p = 0.001
	• Physical mobility: I: 34.76, C: 1192, p = 0.001
Conclusion	A positive relationship was found between perceived wellbeing and physical training from those
	receiving the physical training intervention. Findings support that there is a relationship associated
	with a physical training program and how one feels about their own well-being, specifically for
	energy, social isolation and physical mobility
Melville et al.	
Methods	Study Design: Cross-Sectional Study with control comparison
	Type of Intervention: Measure and compare the prevalence and factors associate with obesity
<b>D</b> 41 4	between those with ID and the general population
Participants	Persons with ID 16 years of older; Setting: Glasgow, Scotland; Sample size: 945 living in community settings
Intervention	Intervention: participants were assessed by their BMH, height and weight to compare with
	demographic data, level of ID, mobility, and living arrangements
	Control: Comparisons to the general population were made using the 2003 Scottish health survey
Outcomes	Obesity
Results	Incidence of Obesity
	• Females with ID: 39%, Females in General Population: $25.1\%$ , $p = <0.01$
	• Males with ID: 27.8%, Males in general population: 22.7%, p = <0.05
Conclusion	There is an increased prevalence of obesity found in persons with ID
McGuire et al	
Methods	Study Design: Cross-sectional questionnaire survey with control comparison
	Type of Intervention: Assessing the health and lifestyle behaviors for persons with ID
Participants	Persons with ID, carers; Setting: Western Ireland; Sample size: 157 carers of adults with ID living in
	residential group homes or with family were randomly chosen from a total population of 400.
Intervention	Intervention: Survey was conducted by the primary carers that looked at the lifestyle and health
	behaviors for people with ID. The survey was developed using the elements from the National
	Health and Lifestyles Survey (SLAN). That is used to evaluate the health status and behaviors of the
	general population in Ireland; Control: Results from study participants were compared to the results
Outcomen	of the SLAN from the general population on their overall health status.
Outcomes	Weight and physical activity, Nutrition, Smoking and Alcohol Consumption, Level of choice, Use of medical services, Gender differences
Results	Health behaviour measures (%), (I: Intervention, C: Control)
Acouits	<ul> <li>Exercise: I: 25.9, C: 59</li> </ul>
	<ul> <li>Smoking: I: 2.6, C: 24</li> </ul>
Conclusion	<ul> <li>Alcohol: I: 8.4, C: 74.3</li> <li>Adverse health behaviors for persons with ID included lack of both exercise and health eating</li> </ul>
Conciasion	choices leading to increased risk of being overweight or obese. Smoking and regular alcohol
	consumption rates were significantly lower than those found in the general population.
	consumption rates were significantly lower than most found in the general population.

Table 3: Studies Related to Health Behaviours (Continued)

Rimmer et al.	a 2004
Methods	Study Design: Controlled Before and After study; Types of Intervention: Exercise Training Program
Participants	Persons with Down syndrome living in group homes, with family members or other supported
	housing who have been sedentary for over a year; Setting: Large Metropolitan area/surrounding
	suburbs; n=52, aged 30-70, randomly assigned to exercise group (n=30) or control (n=22)
Intervention	Participants had pre-intervention measures taken: blood sample, resting ECG, heart rate, and blood
	pressure as well as basal temperature, strength testing and Peak Vo <sub>2</sub> testing; Intervention: Training
或使用出口。	group received 12 week exercise sessions including 30-45 minutes of cardiovascular exercise and
	15-20 minutes of muscular strength and endurance; Control: Did not receive exercise program
Outcomes	Cardiovascular fitness, strength and body composition
Results	Cardiovascular fitness Outcomes
	• Peak VO2: $F(1,37) = 17.84$ , $p = < 0.01$
	• Heartrate: $F(1, 37) = 8.79, p = <.01$
	• Time to exhaustion: $F(1,39) = 7.06$ , $p = .05$
	• Maximum workload: $F(1,39) = 15.21$ , $p = <0.1$
	Strength Outcomes
	• Bench Press: $F(1.44) = 21.73$ , $p = <.0001$
	• Leg Press: $F(1,44) = 27.33$ , $p = <0.001$
	Body Composition Outcomes
	• Body Weight: $F(1,44) = 7.96$ , $p = <.01$
Conclusion	Cardiovascular exercise training lead to significant improvements in fitness, strength, endurance and
<b>T</b> .	body weight. Changes in BMI were not significant
Tsimaras et a Methods	Study Design: Controlled pre-post test design; Type of Intervention: Effects of a 12-week aerobic
Methous	training program was evaluated for persons with Down's Syndrome
Participants	Male Adults with Down's Syndrome with mild to moderate intellectual disabilities, practice nurses;
Тагссраць	Setting: Greece; Sample size=25; 15 assigned to the experimental group and 10 to control group
Intervention	Intervention: Pre and post-training analysis was performed on the peak heart rate, minute
Anter vention	ventilation, oxygen consumption and exhaustion time. The intervention trained three times a week
	for 12 weeks. Each session involved warm-up activities, 30 minutes of jogging and walking and
	cool down exercises. Control: Received no structured exercise training during 12-week study period
Outcomes	Peak physiological measurements and capabilities
Results	Fitness Variables for Intervention group (M, SD)
	$\circ$ VO2 peak, 1/min: Pre: (2.08, .5), Post: (2.46, 0.7), p = <0.05
	$\circ$ VO2 peak, ml/kg/min: Pre: (29.6, 8.8), Post: (35.7, 10.7), p = <0.01
	• Time to exhaustion: Pre: (7.9, 1.3), Post: (9.7, 1.9), $p = \langle 0.01 \rangle$
Conclusion	The experimental group showed significant improvements in peak oxygen consumption, ventilation
	and time it took to reach exhaustion. No significant improvements in any physiological parameters
	were seen in the control group.

In their study, Melville et al. (2008) examined the prevalence rates of obesity of persons with ID as compared to the general population. Measures analyzed included demographic and socio-economic characteristics, weight, body mass index (BMI), mobility, weight, visual and hearing impairments, and problem behaviours. The characteristics of persons with ID who took part in the study were compared to those from the general population. Compared to the general population, both men and women with ID were more likely to be obese. In addition to having an increased prevalence of obesity, there was also found to be a difference between age and weight status as compared to the general population, with an increased likelihood of obesity occurring in early adulthood among persons with ID. These findings suggest that persons with ID are at an increased risk for early onset of obesity-related diseases, including cardiovascular disease, diabetes and cancer. Therefore, health promotion and physical activity will need to be encouraged during the childhood and adolescent years in this population. Further analysis also found that there is a greater difference in the prevalence of obesity for women and men, where women with ID were more likely to be obese. Therefore health promotion programs that target young women with ID are especially needed.

The study by McGuire et al. (2007) looked at the health behaviors that adults with ID engage in to determine the effects of specific health promotion interventions. A survey was conducted by those providing support to persons with ID, looking at lifestyle factors, demographic characteristics, decision-making opportunities, and areas where lifestyle changes might be beneficial. As there was not a lifestyle and health behavior questionnaire available for people with ID, one was developed using the National Health and Lifestyles Survey that is currently used for the general population. Control comparisons used this survey to get results from those with ID to compare with those without disabilities within the same region. The survey found that 68% of the ID sample was overweight or obese; only 25.9% of the sample participated in regular exercising compared with 59% of the control sample. While persons with ID sample did have a lower intake of sugar and fatty foods, they did not consume enough fruits and vegetables, carbohydrates, dairy and protein. Smoking was found to be significantly lower than the general population with only 2.6% of people with ID listed as smokers (compared with 24% from the general population). Similar results were found with alcohol consumption; the majority of persons with ID never drank alcohol, while the majority of the general population consumed drinks on a regular basis. While some health behaviors were found to be significantly lower in persons with ID compared to the general population, areas of health concern still involve the increased incidence of obesity which should be addressed through health promotion strategies including increasing physical activity levels and following a healthier diet.

Work by Rimmer et al. (2004) tested the effectiveness of an exercise program for persons with Down's syndrome. Concern over lack of physical activity for this population arose with adult's high rates of sedentary behavior including very low levels of physical activity in this subset of the population. Study participants lived in the community setting and had been sedentary prior to the experiment for at least the past year. Pre-test measurements were taken for comparison. Following the 12-week exercise program, the exercise training group improved in all outcomes measures for cardiovascular fitness, strength and body composition. The control group that did not receive the training showed only slight improvements or no change, and some even declined in various areas of measurement. Given the short time-line of the study, these findings need to be valued as a longer invention may lead to even more gains is physical endurance and composition. These gains in physical fitness can lead to increase overall health improvements, as the type of training and exercise used in this study can lower the risk of chronic disease (e.g., cardiovascular disease, diabetes and stroke). When compared to the general population, persons with Down's syndrome have a more significant decline in overall physical fitness, suggesting that as the life span for persons with Down's syndrome increases, they may be more susceptible to earlier decline in physical functioning and increased likelihood of health complications associated with la ack of physical activity. For this population, Rimmer, et al.

(2004) found that improving physical fitness levels can lead to improved functioning levels as well as to greater independence.

The study by Tsimaras et al. (2003) evaluated a 12-week aerobic training program for adults with Down's syndrome. Low cardiovascular fitness has been attributed to the general sedentary lifestyle that is more often seen in persons with ID. Having low cardiovascular fitness has led to persons with Down's syndrome unable to do routine activities of daily living as well as leading to a decrease in employment opportunities. Before and after measurements on peak physiological measures were used to determine effectiveness of the program. The experimental group received a training program involving a combination of walking and jogging for three times a week for a period of twelve weeks. Following the program, the experimental group showed significant improvements in peak oxygen consumption, ventilation and time it took to reach exhaustion. To test overall physiological effects of the training program, a treadmill test was used to show cardio-respiratory efficiency of the program. While the average heart rates before and after training did not differ significantly, how the participants were able to respond and carry out the exercise did significantly improve post-training, showing that there was overall improvement in the persons capability to perform continuous and sustained physical work. While the participants showed poor cardio-respiratory fitness, this may be in part due to the lower peak heart rate levels that were seen within this population not only in this study but in previous research as well. Overall lower peak oxygen consumption (VO<sub>2</sub>) values may be due to increased body fat also seen in this population. Overall, improvements were seen in the experimental group's fitness levels, showing that with proper training people with Down's syndrome can improve their overall fitness capabilities.

### 5.1.4 Characteristics of Studies Related to Health Education

In this section, results of search strategies related to health education as a health promotion strategy for persons with ID are provided in Table 4, and key findings are discussed.

The study by Melville et al. (2006) examined whether a training intervention targeted at primary health care professionals could increase their knowledge of ID issues and overall sense of self-efficacy. Primary health care services play a crucial role in providing appropriate and efficient care for persons with ID, and are in part responsible for current unmet health needs for this population. The intervention was tested by three groups: training material package plus a 3hour training event, printed materials only, and the control group. Overall, professionals who received the training intervention showed significant increases in terms of their knowledge of ID issues and self-efficacy compared to both professionals who received only printed materials and the control group. The results highlight that this type of training intervention has an impact, and may even lead to a reduction in the health inequalities experienced by persons with ID due to a lack of health care provider knowledge or expertise.

Work by Ewing et al. (2004) focused on testing the impact that an 8-week cardiovascular disease risk reduction program had on persons with ID when compared with a control group from the general population. This program was comparable to one normally used for health promotion strategies within the general population. The program focused on knowledge about healthy behaviours, including exercise, healthy nutrition choices, stress reduction, communication, and motivation to change behaviors, in addition to relapse prevention strategies. Knowledge of these health behaviors was evaluated before and after the study. Significant differences were observed between persons with ID and the general population group's health knowledge and BMI, where persons in the general population showed significant improvements in both areas. The lack of significant changes among persons with ID may be due to the fact that they often receive support for completion of daily activities, including meal preparation. Therefore, their food is prepared for them and they do not have a great deal of control over what is being serviced. For this reason, similar intervention programs should also be developed that target support staff.

The study by Chapman et al. (2008) looked at findings from an analysis of the long-term impact of the Body Mass Index (BMI) for persons with ID who received health practitioner assistance in reducing obesity. As adults with ID have been considered to be at a higher risk of being obese, they are also at increased risk for associated health problems and reduced life expectancy. The intervention group for this study received direct support from a healthy living coordinator who gave advice for physical activity and die and provided health promotion materials. Among persons in the control group, 35% were classified as obese initially and this rose to 45% after the six years of study. Conversely, the rates of obesity dropped by 6% in the experimental group over the same period, though this finding did not reach statistical significance. This insignificance is most likely due to the relatively small sample size available for analysis over the course of the longitudinal study. Chapman further noted that non-significant findings may also be explained by the fact that the intervention that was received in an area that had other local health initiatives being implemented.

# **Table 4: Studies Related to Health Education**

	udies Related to Health Education
Melville et al.	
Methods	Study Design: Controlled Before and After study
	Type of Intervention: Training intervention for primary care nurses working with persons with ID to
	increase knowledge and self-efficacy within their role
Participants	Persons with ID (n=201), practical nurses (n=63); Setting: Glasgow, Scotland
Intervention	Intervention: received training intervention involving a written training package and a 3-hour face-
	to-face training event to build upon the written materials. One group received the training materials
	and the event; another intervention group received the training materials only.
	Control: Nurses who did not participate in either training intervention
Outcomes	Health professionals knowledge and self-efficacy regarding the health needs of people with ID
Results	$\circ$ Knowledge for caring for persons with ID increased (F = 5.6, p = 0.005), compared to control
	$\circ$ Self-efficacy improved with intervention (F = 2.079, p = 0.04), compared to control
Conclusion	Both interventions resulted in a statistically significant increase in nurses knowledge of caring and
	working with persons with ID compared to the control group. Receiving both forms of training
	including printed materials and a three-hour training session was associated with significantly
	greater knowledge and self-efficacy than those receiving the printed materials only.
Ewing et al., 2	004
Methods	Study Design: Controlled Before and After study
	Types of Intervention: Cardiovascular disease risk reduction teaching program
Participants	Persons with ID with an IQ of less than 70, mild to moderate ID levels
	Sample size: Intervention group with persons with ID, n=92, Control group normal learners, n=97
Intervention	Intervention: Persons with ID who received a group 8-week health intervention program to improve
	cardiovascular risk factors, emphasizing exercise, healthy nutrition choices and stress reduction
	Control: Normal learners who received a health program with similar teaching content
Outcomes	Body Mass Index, knowledge of healthy eating choices, fruit and vegetable intake, and exercise
Results	Outcomes Percentages (M), (I:Intervention, C: Control)
	• BMI decreased: I: 18.5, C: 44.3, $p = <0.01$
	• Fruit and Vegetable intake: I: 55.4, C: 65.9, $p = 0.14$
	• Knowledge: I 43.5, 58.8, $p = 0.04$
	• Exercise status: I: 69.6, C: 73.2, p = 0.58
Conclusion	Significant differences were found between the intervention and control groups in regards to BMI
	and knowledge of healthy eating choices, where the normal learners showed a greater increase in
	positive knowledge and BMI changes compared to those with ID.
Chapman et a	
Methods	Study Design: pre/post quasi experimental design with control comparison; Type of intervention:
计规划分析法	Health practitioner input for reducing obesity among adults with ID
Participants	Persons with ID, Health practitioners
	Sample Size: Intervention: n=33, Control: n=40
	Setting: United Kingdom
Intervention	BMI was measured for both groups following six years after intervention group first received health
	practitioner input on reducing obesity
	Intervention: Health practitioner intervention including individualized support through initial and
	follow-up home visits with persons with ID and careers including advice for improving physical
	activity and diet. Health promotion materials, activity programs and liaisons with health
	professionals were also provided.
	Control: No intervention
Outcomes	Changes in Body Mass Index (BMI)
Results	Changes in BMI, (I: Intervention, C: Control), (SD: Standard Deviation, M: Mean)
	<ul> <li>Baseline BMI: I: M- 34.09, SD 5.62; C: M- 28.35, SD 6.29</li> </ul>
	• BMI at 6 months: I: M- 33.76, SD 5.36; C: M- 28.72, SD 6.22
	o BMI at 1 year: I: M- 33.47, SD 5.43; C: M- 28.67, SD 6.20
	0 BMI at 6 years: I: M- 33.07, SD 5.98; C: M- 28.51, SD 6.67
Conclusion	While intervention group showed improvements with more weight lost, differences were not
	significant.
and the second second second	

# 5.1.5 Characteristics of Studies Related to Health Care Provision

In this section, results of search strategies related to health care as a health promotion

strategy for persons with ID are provided in Table 5, and key findings are discussed.

Lewis et al., 2	Idles Related to Health Care Provision 002
Methods	Study Design: Cross-Sectional comparison study; Type of Intervention: Data collection looking at health status and quality of available care for persons with ID using historical data collection, physical and dental examinations, blood analysis, and review of medical records.
Participants	Persons with ID, including those who also have cerebral palsy, autism, epilepsy and other genetic disorders; Setting: Los Angeles, California, USA; Sample size=353.
Intervention	Intervention: Nurse practitioners examined health histories from medical records as well as gathered information from study participants or their caregivers and then performed complete physical examinations on each subject. Control: Health status indicators were compared amongst the sample to those living at home, living with family or friends and with those living in community care facilities to determine differences
Outcome	Health indicators
Results	Characteristics (%): Comparing those: (Living at home, living with family/friends, living in community facilities) Health Habits Want to lose weight (40, 25, 19.3), p = <0.01 Exercise (36.4, 43.8, 40) Smoke (20, 3.1, 5.2), p = <0.001 Drink alcohol (20, 9.4, 1.5), p = <0.001 Preventative health practices TB test (69.1, 78, 96.3), p = <0.001 Tetanus (47.3, 65, 51.9), p = <0.001 Tetanus (47.3, 65, 51.9), p = <0.001 Hepatitis B (21.8, 21.4, 46.7), p = <0.001 HIV tested (23.6, 3.1, 3.7), p = <0.001
Conclusion	Preventative health services were lacking, especially for those living at home. Results support the existence of health discrepancies amongst persons with ID based on living arrangements.
Hensel et al.,	
Methods	Study Design: Matched cross-sectional comparison study Type of Intervention: Questionnaire was used to determine whether the relationship between quality of life indicators and overall life satisfaction differs between persons with ID and those without.
Participants	Persons with ID, Matched non-disabled people; Setting: United Kingdom; Sample size: $N = 31$ adults with ID living in community settings and 31 matched persons without disabilities
Intervention	Intervention: Adults with ID who were living in the community were interviewed and assessed using the Comprehensive Quality of Life Scale. These subjects were matched with people who did not have disabilities to complete a parallel questionnaire. The questionnaire used a pre-test control to ensure that participants understood the questions being asked. Control: Control participants were matched by age, gender, residence and ethnic origin and were sent the quality of life questionnaire when agreed to participate
Results	Quality of Life Scale Domains (Means), (I: Intervention, C: Control)         • Material: I: 72.04, C: 62.1, p = 0.114         • Health: I: 66.12, C: 81.72, p = 0.002         • Productivity: I: 39.78, C: 76.08, p = <0.001         • Intimacy: I: 72.04, C: 69.89, p = 0.666         • Safety: I: 70.16, C: 78.76, p = 0.070         • Community: I: 30.51, C: 52.69, p = <0.001         • Emotion I: 50.27, 67.74, p = 0.003
Conclusion	Participants with ID showed a significant higher overall importance for the quality of life indicators
	then compared to the control group, excluding health and community involvement.

## **Table 5: Studies Related to Health Care Provision**

#### Table 5: Studies Related to Health Care Provision (Continued)

Allan 1999	
Methods	Study Design: Cross-sectional comparison study Type of Intervention: A project was designed to test whether persons with ID would use and value available health care services through revising the methods that services were being offered to include a drop-in health service clinic that is accommodating to persons with ID. This intervention was then used to see if the type of available services would encourage use from persons with ID and thus become more aware and value their health needs.
Participants	Persons with ID, support persons, health care providers Setting: Scotland Sample size: Two centers were compared with 30 consultations from center A, and 44 at center B.
Intervention	Intervention: Drop in healthcare services was established for persons with ID. Services was provided by a specialist health care provider specifically designed for those with ID who are trained to be able to listen to the patients and provide health information that was understand and appropriate to meet each patient's needs. The clinic had an atmosphere that was informal and non- threatening to reduce the apprehension and stress of the patients. Data was collected through interviews and included type of consultation that occurred and overall outcome Control: Comparisons were made be developing two separate centers with equal services offered to compare health outcomes
Outcomes	Reduce gaps and inequalities in provision of health care persons with ID
Results	Qualitative interviews recording: Age, Gender, Health Challenges, Type of Consultation, Outcomes comparing two drop-in centers
Conclusion	Providing drop-in services did assist in bridging the gap in providing health care to this population. It was found the at persons with ID do think about and value their own health

The study by Lewis et al. (2002) was conducted to assess the quality of health care that was being provided for adults with ID. Comparisons were made between persons with ID living at home, those living with family or friends, and those living in community-based care facilities. Findings showed that persons living independently or with family/friends were at higher risk for obesity than those living in care facilities; this is most likely to due to having a greater access to food in combination with less regular exercise incorporated into daily activities. As community-based care for persons with ID becomes the main form of service delivery, certain methods of health care provision will need to be revised. Currently, there is reluctance amongst physicians to care for this population, due in part from attitudes related to having to provide health promotions services, lack of training for caring for this population, as well as lack

of financial incentives (i.e., more time needs to be scheduled for patients with ID). These barriers

show that health care system changes need to occur to be able to provide adequate care for persons with ID.

The study by Hensel et al. (2002) compared persons with ID's self perception of quality of life and health to those of the general population. To test overall life satisfaction, the Comprehensive Quality of Life Scale was used to look at health, productivity, intimacy, safety, place in community, and overall emotional and material well-being. Findings showed that people with ID place a greater importance in their lives on the quality of life scores as compared to the general population. Only overall health and community involvement scored as equally important for the experimental group of persons with ID and the controlled group from the general population. This study shows that for this population, great importance is placed on all aspects of their lives, with aspirations for improvement and change. In particular, the experimental group showed that they would like to have more responsibilities either at work or home, have an increased social life or develop their interests further. While persons with ID place great importance on their overall health, they were found to be less satisfied with their current health status than participants without ID in the control group, even though it was found that they received more health checks and interactions with health care providers. Hensel et al., (2002) also noted that while persons with ID did receive more health checks, the fact that these checks were performed with specialists (or within a special services framework) lead the participants to feel as though they are different (i.e., require different services), which consequently led to overall dissatisfaction with their health status. The awareness of and discomfort with 'special' health care service provision should be taken into account in service delivery for persons with ID.

The study by Allan (1999) looked at improving health equality among persons with ID by focusing on improving health services that were available to this population. The following needs were identified as being most important for persons with ID: having a health practitioner that is accessible, being given the time to discuss health concerns, and having health information explained so that it is understood. These recommendations and needs lead to developing a dropin health clinic with a health care worker who specialized in working with persons with ID. Results showed that by identifying the specific needs of those with ID, current gaps in quality care could be easily identified and then targeted. Through this specialized service, the patients were given time and space to talk about their health, leading to more appropriate health advice given and health promotion strategies taught through methods that could be understood. Through establishing this drop-in clinic, more self-referrals were being made by persons with ID, therefore showing that (1) they are aware of their own health needs, and (2) feeling comfortable with a service provider is important in this population. A health care service provided in the community that is needs-focused was found to reduce the gaps and inequality to health care practice for those with ID.

#### 5.2 Description of Excluded Studies

Upon initial evaluation, a number of studies were thought to be relevant for further analysis for possible inclusion in the findings of this review, however after full text articles were examined in regards to the methods used within the study in question, studies were eventually excluded for a variety of reasons. One of the main reasons for exclusion included studies not having control measures to compare with their experimental sample. Barr, Gilgunn, Kane & Moore (1999); Dovey & Webb (2000); Harrison & Berry (2005); Lunsky, Straiko & Armstrong, (2003); Mann, Zhou, McDermott & Poston (2006); Merriman, Haw, Kirk & Stubbs (2005); Peterson et al. (2008) and Stanish & Daraheim (2007) all were cross-sectional studies, however did not include control measures. Before-and-after studies that did not include a control group included Aronow & Hahn (2005); Felce et al. (2008); Harrison & Berry (2005); and Jones et al. (1999). Other study designs were also excluded including descriptive studies (Messent, Cooke & Long, 2001; Temple, 2007; Wang, Hsieh, Heller, Davidson & Janicki, 2007) and review studies (Jansen, Krol, Groothoff & Post, 2006; van Schrojesnstien Lantman-de Valk, 2005). The studies by Romeo, et al. (2009) and Webb & Rogers, 1999 were excluded as they were not research studies per se; rather evaluated health promotion project implementation. The study by Sullivan, Hussain, Threlfall & Bittles (2004) was excluded as it used secondary data to compare persons with ID to the general population.

Along with being inadequate study designs methods, unmet participant criteria also warranted exclusion of certain studies from being used in this review. Having an inadequate sample size was a concern for the reliability and generalizability of the findings to the ID population as a whole and therefore, Gibbs, Brown & Muir (2008); Lynnes, Nichols & Temple, (2009); Temple, Frey & Stanish (2006) and Temple, 2009) were excluded due to using an especially small sample size. As previously mentioned, this review also focused on looking at health promotion strategies for adults with ID, and therefore studies involving children, adolescents or youth were excluded (Emerson & Turnbull, 2005; Marshall, McConkey & Moore, 2003; Nachshen, et al., 2009; Stanish, 2009).

#### 6. DISCUSSION

Results of this review found that both health assessment and screening tools were beneficial to improved health care and health promotion strategies for persons with ID. For this review, health assessments were regarded as being routine evaluations of a patient's health status that are usually conducted on a set schedule at various intervals in a person's life. These could include quarterly or annual assessments, or at various milestones. Health screening interventions were conducted to look specifically for possible disease or illness. These types of screening tools would be used if changes in one's health and wellness have occurred or as the patient enters different life stages including older age. As both health promotion tools looked at detecting ill health, for the purpose of reporting this review's findings and recommendations they will be reviewed together.

Both Lennox et al. (2007) and Cooper et al. (2006) showed that sustainable health benefits can be achieved for persons with ID through health assessment and screening measures. Lennox et al. (2007) showed health gains in areas of detection of new diseases and disease prevention as well as vision and hearing impairment, and women's health assessment, while Cooper et al. (2006) found health improvements in the areas of health monitoring and health need detection. Both studies found that health promotion gains were also noted following assessment and screening, including a higher number of interventions related to dental and eye examinations, diet and exercise and increases in immunizations. Most notably, both studies showed the health assessment and screening led to increased detection of health problems and diseases, and therefore treatment of these conditions, which undoubtedly has long-term beneficial effects on the health and wellbeing of persons with ID.

Lifestyles and health behavior choices can have a direct affect on persons with ID, in particular those with milder impairments as they often experience more choice in their health decisions (World Health Organization, 2001). These choices can involve passive lifestyle roles including a sedentary lifestyle. This is often seen from those with ID who are not encouraged by their caretakers or health care professionals to live more active lifestyles nor are relayed the benefits that this would lead to for their health (World Health organization, 2001). Regarding health behaviours, while Chapman et al. (2008) noted that health practitioner inputs can lead to improvements in BMI for persons with ID, additional studies in this review also showed that such improvements could be achieved through health behavior change (McGuire et al., 2007). Specifically for individuals with Down's syndrome, both Rimmer et al. (2004) and Tsimaras et al. (2003) found that exercise or aerobic training programs lead to cardiovascular improvements, as well as improved physical strength, body composition, oxygen consumption, ventilation and overall fitness. While these outcomes are beneficial to immediate health benefits, long term benefits are also associated with improved cardiovascular fitness. Overall physical fitness was shown to have a strong connection with lowering the risk of chronic health conditions and improving functional independency for those with Down's syndrome (Rimmer et al., 2004). Along with physical improvements to health, emotional improvements were also seen with physical activity and training in leading to positive improvements in perceived well-being and overall self-image (Carmeli et al., 2008). Having improved self-satisfaction can lead to long-term gains and commitments to physical activity across the lifespan.

For the purpose of this review, health education was viewed from two perspectives. First, as education provided to persons with ID and second, as education targeting support providers (including health care professionals). Providing education for persons with ID must first take into account the person's level of ID and ensure that messaging is appropriate so that it is understood by the individual. In addition, health education should also take into account the unique learning styles of persons with ID – for example, use of hands-on, individualized approach rather than classroom-style education (Ewing et al., 2004). Specific programming may have to be developed as was needed in the study by Ewing et al. (2004). The Health Education Learning Program (HELP) was developed to provide classes on nutrition, exercise, communication, stress reduction and ways to motivate change while preventing possible relapse. HELP was originally designed for normal learners and was adapted to this population. While improvements were seen within the experimental group of persons with ID, greater improvements in BMI and knowledge of healthy eating choices were seen amongst the normal learners group. This data shows that persons with ID are able to comprehend and learn through health promotion education.

The health education provided to those supporting persons with ID have also been found to benefit not only those with ID, but also to increase the knowledge and confidence of the supporters. A lack of knowledge and expertise in ID issues among health care providers is a significant barrier that needs to be overcome; not having the appropriate knowledge or skills to provide appropriate care for this population can lead to increased health inequalities (World Health Organization, 2001). Melville et al. (2006) showed that a training intervention program for primary nurses that provided information on the specific health needs of people with ID (e.g., health promotion, screening and communication barriers) led to an improved sense of selfefficacy and increased knowledge in how to best provide care to this population. Health care providers who do not have knowledge of ID or of the special needs of persons with ID may not be equipped to provide appropriate or adequate care, leading to greater inequalities in health care delivery. Training programs in the form of both printed materials and lecture series can assist to eliminate these barriers (Melville et al., 2008).

This review found that health practitioner encouragement and advice promoted healthier lifestyles among persons with ID, which also lead to decreases in health care discrepancies (Allan, 1999; Chapman et al., 2008). Allan (1999) and Chapman et al. (2008) both showed improvements in health following inputs by health care professionals, though neither reached levels of statistical significance, possibly due their relative small sample sizes. That said, health practitioner inputs did assist in the identification of health needs, and also helped to bridge the gap in health care services.

When the types of one-on-one health promotion activities used in these studies was added to the current health plans for those with ID, it was found to lead to more opportunities for discussion of personal health concerns or health goals to incorporate a healthier lifestyle. When advice is given on a one-on-one basis, there is an increase in the understanding of persons with ID about what is being discussed and more opportunity for questions and dialogue. A more individualized approach to health care delivery for persons with ID is needed. Accountability was found to be a significant motivator for the general population for improving healthy eating habits and with assistance in weight loss. Therefore it is not surprising that when individual health motivation is incorporated into the health care services for people with ID, that positive outcomes occur (Chapman et al., 2008).

#### 7. RECOMMENDATIONS

In this section, recommendations are made related to health assessment and screening, health education, and health behavior for improved health outcomes.

#### 7.1 Recommendations for Health Assessment and Screening

Primary health care provision plays a critical role in improving the overall health and wellbeing of persons with ID (Felce et al., 2008). Improved health status can be attained through routine care with general physicians and other health professionals that involve an overview health assessment at each visit. While persons with ID may consult their primary care providers at an equal rate to those in the general population, those with ID still receive significantly less preventative care than the general population leading to an increased risk of further health complications (Hensel et al., 2002). Throughout the lifespan, adults with ID should have access to the same preventative and protective health care strategies offered to the general population. Therefore, regular health screening should be encouraged among persons with ID, as mental and physical health conditions that often present atypically frequently go undetected, and because limited communication skills may further impede the individual's ability to indicate that something is wrong (Evenhuis et al., 2001; World Health Organization, 2001).

Health care provision for persons of ID will need to involve tailor-made health care plans that describes their health status, particular risks, and possible courses of actions; the plan must be updated at regular intervals and at specific transition points to ensure its appropriateness and relevance to current needs (van Schrojenstein Lantman-de Valk et al., 2005).

The majority of persons with ID show specific syndromes that have clinical implications beyond the ID itself. These syndromes can be caused by toxins, injuries, infections and genetic disorders that affect the nervous system or other organs during development. Effects of these should be watched carefully throughout the lifespan (Evenhuis et al., 2001). For example, Down syndrome is a more common chromosomal disorder that leads to a higher risk of infectious, oral health, cardiac, musculoskeletal and other organ system disorders. In addition, older adults with Down syndrome are at an increased risk of early dementia and age-related hearing and vision loss, and so monitoring of signs of these conditions should be a part of routine health care (Rimmer et al., 2004).

While some persons with ID do not show specific syndromes, there can be related developmental disabilities that can lead to disease, or result in secondary illnesses or impairments (Sutherland et al., 2002). Therefore when syndrome-specific disorders are known, health screening should start early on in life and, ideally, be conducted on a regular basis throughout the person's life.

Persons with ID still have the same needs for disease prevention, diagnosis, and treatment as the general population. Therefore, standard preventative health measures that are currently recommended for the general population should also be applied to persons with ID. It has been suggested that age-appropriate health screening should be mandatory in this population as well, including standard immunization schedules (Evenhuis et al., 2001). Persons with ID should receive these same preventative health practices and screening measures throughout the lifespan including dental checks, sensory impairments and cancer screens. These health screens are even more important among persons with ID, given the increased risk for comorbid medical conditions, and among older adults with ID as age-related morbidity comes into play (World Health Organization, 2001). In spite of greater need for such services, very few general practitioners currently use health screening measures for persons with ID. Perhaps, in order for more health providers to adopt routine health checks among persons with ID, there needs to be more good quality evidence that they are effective in this population. Incentives are also needed to promote the use of health assessments as they are often much more time consuming to the practitioner – for example, given atypical presentation and limited communication skills (Hogg, 2001).

When easily identifiable health conditions go unnoticed, the likelihood of medical complications, functional impairment, and decreased life expectancy increases. For this reason, health screening and health evaluation are all the more important and necessary among persons with ID (Felce et al., 2008).

## 7.2 Recommendations for Health Education

A high level of health needs combined with a low level of disease prevention and lack of appropriate treatment/care unnecessarily complicates the life of persons with ID. Limited communication, mobility and accessibility; lack of resources; and lack of knowledgeable health care providers are but some of the barriers to service faced by persons with ID (Cooper et al., 2006; Fisher, 2004; van Schrojenstein Lantman-de Valk , 2005). Along with being unfamiliar with ID itself, health care professionals are also unfamiliar with the spectrum and the specific health needs of persons with ID. In general, persons with ID have more difficulty in finding and getting the health care they require (Balogh et al., 2009); the inequity in health care services needs to be addressed.

Accessing health care for persons with ID can be hindered due to a lack of competency from health professionals in part from not receiving the required medical training (Betz, 2002). The topic of health care for persons with ID currently receives very little attention in medical

schools, leading to uneducated professionals needing to provide care to this high needs population (Hogg, 2001). Curriculum reviews will need to investigate how to incorporate health education regarding caring for persons with ID into current training and continued education.

Funding under the current fee-per-services policy can also lead to increased barriers to competent care as providing care for persons with ID can be time intensive and burdensome, leaving some professionals unable to cope with being insufficiently reimbursed for the additional time needed to adequately care for this population (Betz, 2002). Therefore, providing care to persons with ID may need to be reevaluated to allow more time and therefore higher fees for payment associated with routine visits.

Access to health care services can be restricted due to having an inadequate medical history of the person with ID, health of training for caring for this population, difficulties when communicating required treatment and having a lack of understanding in consent issues (Hogg, 2001). To overcome these discrepancies, training could be provided to the person with ID and their caregivers as well as the health professionals providing the care. For example, individuals with ID and their caregivers could be provided with take home materials stating the health problem and guidelines to overcome this concern. In order to promote general well-being, adults with ID and their caregivers need to receive ongoing education regarding healthy living practices specifically for the appropriate age and mental capabilities of the person with ID including nutrition and exercise, oral health care and on the consequences of high risk health behaviours (World Health Organization, 2001).

For health professionals, there should be continuing education opportunities and courses for persons providing health services to persons with ID to become more trained and educated in caring for persons with ID (Hogg et al., 2001). Continuing education needs to include evaluation methods within the curriculum so that information being taught with standards of care in mind and will show a level of understanding for the needs of this population (Betz, 2002).

Understanding this high needs population may be required to look beyond merely offering information and instead look towards the goal of developing a postgraduate accreditation for general practitioners regarding providing care for all persons with disabilities, including ID (Hogg, 2001).

Health practitioners can assist in overcoming these barriers to care by incorporating a health management plan that can be followed and understood by both the individual with ID and his/her support person/family. Health management plans should incorporate screening to identify new needs, as well as follow up to monitor existing concerns. Health promotion and disease prevention activities should also be incorporated (van Schrojenstein Lantman-de Valk et al., 2008). Specific requirements for adequate healthcare should accompany the health management plan. As the population of those with ID live longer, health care providers must adopt a life-span perspective that looks at identifying the onset and progression of an illness as one ages (Evenhuis et al., 2001). Increased life expectancy will lead to an increased risk of acquiring age-related diseases and conditions that have not previously been seen before in this population (Fisher, 2004). Specifically regarding people with ID, research has shown a higher prevalence of cardiac conditions, hearing impairment, epilepsy, endocrine programs, skin disorders as well as mental and oral health concerns (Sutherland et al., 2002). Therefore, health education needs to be improved through nutrition, exercise, oral hygiene, and safety concerns as well as why and how to avoid risky health behaviors (Evenhuis et al., 2001).

Knowledge transfer regarding best practices for primary care needs to be made available to physicians. This can be done through a variety of means including formal consultations,

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clinical guidelines, and training seminars. On-line support networks should also be established for primary care providers to discuss available supports, resources and health promotion and screening methods with other specialists (e.g., mental health practitioners, social workers and community nurses) who may interact with the individual on a routine basis. Support for primary care physicians treating people with ID needs to involve continued education and communication of best practices for this population (Evenhuis et al., 2001).

Health care provision itself is often linked to poor health outcomes in this population. For many people with ID, receiving adequate health care involves a multitude of people, which can lead to confusion for the person. Individuals may see a variety of medical specialists, dentists, mental health providers, and other professionals (e.g., behaviour therapist) on a routine basis. Effective health care should incorporate case managers for the most optimal utilization of these health services for those with complex health needs (Evenhuis et al., 2001). Co-operation between General Practitioners (GPs) and other healthcare professionals is a key component of improving care. Increasing the co-operation and communication between healthcare professionals and the specific GPs is an important area to improve the primary health care of those with ID (Jansen et al., 2006).

#### 7.3 Recommendations for Health Behavior

Studies have shown that promotion of healthy behaviours among persons with ID has positive results (Stanish & Frey, 2008). While persons with ID may not be able to seek out physical activity programs on their own, they are often willing to participate when given the opportunity and encouragement to do so. Reinforcement strategies and assistance with participation are crucial to the continuation of the activity; therefore it is important to plan for supports to ensure successful participation (Hsu, 2009; Stanish & Frey, 2008).

In this population, it will also be important to explain not only the activity itself, but also the positive effects of the activity to health (Hamilton et al., 2007). Although information regarding the benefits of activity alone may not motivate behavior change or maintain healthy behaviour, it remains nonetheless important. Therefore, health education plans should be directly tied to physical activity programs to ensure that activities have meaning beyond simply enjoyment (Proulx, 2008; Stanish, Temple & Frey, 2006).

Physical activity plans also need to be communicated and developed with the unique needs of the individual in mind. For example, social connection, motivation and practical support will need to be considered in order to facilitate participation in physical activity (Temple, 2009). Plans that were developed and used in the general population may not be motivating or appropriate for persons with ID, as they may not have the skills or understanding of the safety precautions required to participate in specific activities. Fitness professionals may need to be reminded that modification of the activity is needed to accommodate all ability levels and how abilities will likely vary depending on the severity of the ID (Stanish & Frey, 2008). Physical activity plans need to take into account the surrounding supports that are available to the individual that can assist to motivate and improve outcomes of the program including caregiver involvement as well as accessibility issues (Hamilton et al., 2007).

Transportation, costs, and available assistance are also issues that need to be addressed. Activities do not need to be complicated; instead, subtle lifestyle changes can be altered to increase the level of activity. Paid instructors may not be needed as long as support workers are taught the skills needed to encourage routine physical activity (Stanish & Daraheim, 2007). Overcoming barriers to a healthy lifestyle can be also assisted by: teaching the caregiver and trainers on appropriate motivational strategies and positive reinforcement that is appropriate and effective for persons with ID; including low physical activities that are not as burdensome in the activity program; ensuring the activity is fun and one that involves social involvement with others their own age and with similar abilities; allowing the participants to have the opportunity to choose their own activity; and being flexible to modify the activities as nobilities of the person with ID deem necessary (Stanish & Daraheim, 2007).

Alongside training, there needs to be development of new health promotion strategies – including and beyond promotion of physical activity, that are relevant to persons with ID; currently, there is an absence of health promotion programs designed with the unique needs of this population in mind (van Schrojenstein Lantman-de Valk, 2005). Within North American, Australia, and many European countries, governments have eliminated the majority of large, publicly operated institutions; this has led to more persons with ID living in the community in a variety of small group or home based settings. This has lead to an increase in lifestyle choices and community interaction, especially for those with milder ID. Health promotion initiatives that target these lifestyle concerns are needed. People with ID and their supports need to receive appropriate and continued education regarding healthy living practices that are applicable to their current life stage. Further, informing persons with ID on what is healthy and what it means to be healthy, as well as the consequences of ill health is an essential component of health behaviour education (Sutherland et al., 2002).

#### 8. IMPLICATIONS FOR PUBLIC HEALTH PRACTICE

Implications of implementing health promotion strategies in the areas of health screening and assessment, health behaviours, health education and health input given from practitioners will lead to empowerment for those involved, further education being developed and improvements in evidence based decision making (van Schrojenstein Lantman-de Valk , 2005). Developing a health promotion strategy for persons with ID will focus on eliminating treatable or avoidable health problems. Empowerment of people with ID can be achieved through several forms including improvement of decision making abilities and communication through non-text methods, allowing those that cannot read to have access to health promotion education (Marks & Heller, 2003). Providing this education through more efficient health promotion materials can lead to an increase in healthy lifestyle and allowing persons with ID to be more aware of their own health and means that they have to control it (e.g., lifestyle and behaviour choices). Educating health professionals on screening, disease prevalence and common disorders and illnesses affiliated with ID can not only increase the health of this population but also reduce costs to the health care system (van Schrojenstein Lantman-de Valk , 2005).

Improving overall public health initiatives to better the health of persons with ID will also lead to improved health care outcomes in regards to acquiring the necessary available services. Having access to health services that include both health promotion and available supports will lead to the greatest possible quality of care (Hogg et al., 2001). Better understanding of the unique needs of this population will lead to health care providers and policy makers being able to effectively modify standard healthcare practices and service needs to better suit persons with ID. Tailoring health care initiatives will include better health care for all involved, as the person with ID will have more control and choice over health treatments, will have their own personal needs and wishes included in their health plan and will lead to support plans that will be individually tailored to suit specific needs (World Health Organization, 2001).

# 9. IMPLICATIONS FOR FUTURE RESEARCH

There is currently a lack of understanding on how persons with ID view their overall health in general, which makes it difficult to develop health promotion programs for this population. Strategies need to first look at how this population understands health in general.

Current findings of this review show that while various health assessment, behaviors and education methods have been analyzed for persons with ID, there still is a need for further evidence to find effective and efficient health promotion strategies to care for this population. As there has been a shift in responsibility of care for persons with ID as more are living in community and supportive housing arrangements, more research needs to be done on health promotion strategies that would be useful for this population with the involvement of both friends and family with a community focus and available resources in mind.

To provide evidence-based practices for health promotion programs targeting person with ID, studies involving large samples will assist to understand how persons with ID resemble that of the general population in terms of health promotion needs. Large sample sized studies will also be able to effectively show any inequities in health status and health care delivery methods. Studies involving longitudinal follow-up measurements will better show the outcomes of the health promotion programs and strategies (Walsh, 2002).

As previously mentioned in this review, there is a need to provide evidence-based practice standards to front-line support workers and health practitioners who work with persons with ID. As communication and cooperation is a barrier for many health promotion initiatives, there needs to be more research that specifically looks at developing effective programs for persons with varying levels of ID severity. Guidelines and measures need to be designed that will act as bench marks for health screening purposes in areas such as mental health, existing pain, clinical diagnosis, and quality of life measures (Evenhuis et al., 2001). Early research has shown that through implementing health assessments into routine primary health care has lead to increased health promotion activity. The extent of these findings still needs to be determined, including methods and areas of health promotion strategies (Felce et al., 2008).

While most research to date has been done looking at persons with ID living in developed countries, a world-wide perspective on the health of those with ID is required. There needs to be connections between researchers both in industrialized and developing countries to promote trans-cultural as well as cost-effective health care practices and research. This will lead to allowing information exchange concerning research to further develop best-practices and care that can be used in culturally applicable methods that are relevant to all persons with ID regardless of their geographical location (Evenhuis et al., 2001).

Past research has often looked at the incidence of disease when looking at positive health outcomes. Research needs to focus on lifestyle indicators to promote health and wellness. Also ones perceptions on their own health is an important component to quality of life (Sutherland et al., 2002). Currently there is a lack of understanding on how a person with ID looks upon their own health, as they are often not educated on what it means to live healthy. Therefore future research will need to look at what strategies may be beneficial for persons with ID to live active and healthy lives and to also then understand both the benefits and consequences that their health choices can have on their lives (Sutherland et al., 2002).

An area of health promotion research that is currently not being analyzed would involve looking at the impacts of being allowed choice and decision making capabilities would have on individual's lives. Persons with ID who are living in supported housing arrangements are often given little opportunity to make decisions regarding their health and lifestyle, however being allowed choice on their own health-related behaviours and choosing their involvement in activities most likely increase adherence (Marks & Heller, 2003). Future research should look at whether allowing the opportunity to exercise their own decision making capacity will assist in overcoming health promotion barriers (Sutherland et al., 2002).

Further issues involving practicing the most appropriate care also needs to be assessed, including issues on providing informed consent for health care treatment. Adults with ID should always be made aware of all medical procedures or treatment that is being recommended for them and their consent should be given when the individual is at a capacity to do so. Instead of looking to the caregiver for all treatment decisions, communication strategies should first focus on the obtaining approval from the person with ID and then to the caregiver as a last resort. Further research should look into effective strategies for communicating in this capacity as well as providing information for caregivers to assume this role only if deemed absolutely necessary (World Health Organization, 2001).

# **10. CONCLUSION**

It is apparent that the health status of adults with ID is not at equal levels to those of the general population (Sutherland et al., 2002). Developing specific health promotion strategies for persons with ID will bring about necessary policy change that can assist to decrease the inequalities that are seen within the health care system involving utilization and standards of care for this population. Health promotion strategies will allow persons with ID to better achieve their own health goals through equal opportunities for health services and resources in areas of supportive environments, access to information and having the personal choice to make informed health decisions (Marks & Heller, 2003).

As the life expectancy of persons with ID increases, families and caregivers will now have new pressures and problems associated with caring for this population for much longer periods of time (Lennox et al., 2007). Persons with ID will also be faced with the same chronic and older-age diseases as those without disabilities. Unfortunately, to date, health promotion programs have been overlooked as reliable and available methods of improving health outcomes for persons with ID, leading to greater inequalities in health status (Marks & Heller, 2003).

Recommendations for improvements in health care outcomes for persons with ID would include improving current use and understanding of available health screening and monitoring means, offering advanced education and training for medical practitioners for caring for person with ID, as well as providing health education and information to this population and their caregivers (Hogg, 2001). To make the most efficient health promotion efforts, programs need to involve coordinated efforts from all individuals involved including persons with ID, families and caregivers, health professionals and support from community resources. Community-based health promotion programs will allow the recipients to feel empowered and in control of their own health and wellness, leading to increased satisfaction and participation of health behaviors (Marks & Heller, 2003). Improved quality of life measures are easily attainable for persons with disability through health promotion efforts that are developed through a community focused, life span perspective (Krahn, Hammond, &Turner, 2006).

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