

From THE DEPARTMENT OF NEUROBIOLOGY, CARE  
SCIENCES AND SOCIETY  
Karolinska Institutet, Stockholm, Sweden

# **HEALTH PROMOTION FOR ADULTS WITH INTELLECTUAL DISABILITIES: EVALUATION OF A MULTI-COMPONENT INTERVENTION IN COMMUNITY RESIDENCES**

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**Karolinska  
Institutet**

Stockholm 2014

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Printed by Åtta.45

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ISBN 978-91-7549-605-4

# Health promotion for adults with intellectual disabilities: Evaluation of a multi-component intervention in community residences

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

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## ABSTRACT

People with intellectual disabilities (ID) have an increased risk for ill-health, partly due to low physical activity and an unbalanced diet. Caregivers who support adults living in community residences face a dilemma when trying to support healthy behaviours without encroaching on autonomy. The overall aim of this thesis was to evaluate the effects of a novel health intervention directed at both staff and residents in community residences for people with ID and to describe and analyse barriers and facilitators in the implementation process.

An intervention was developed to promote physical activity and healthy diet among adults with ID in community residences. According to Social Cognitive Theory, behaviour, personal factors and environmental factors all interact. Therefore, the intervention entailed both strengthening the individual and influencing the social and physical context. The intervention comprised three components: 1) the appointment of a health ambassador; 2) a study circle for caregivers; and 3) a health course for residents.

The intervention study was designed as a cluster randomised controlled trial including 30 residences and 130 individuals. The primary outcome was physical activity, measured through pedometry. Secondary outcomes were dietary quality measured through digital photography, BMI, waist circumference, satisfaction with life assessed on a scale and residence health promotion work routines assessed with a questionnaire. Outcomes were related to intervention fidelity. A separate study was conducted to develop and evaluate the scale used to assess satisfaction with life. To study barriers and facilitators in health education for adults with ID, data were collected through evaluation notes, observations and a group discussion with course leaders. To study the implementation process, interviews were conducted with managers and health ambassadors.

A positive intervention effect was found on physical activity, with an average increase of 1 608 steps/day among participants in the intervention group ( $P = 0.045$ ). A positive intervention effect was also found on work routines, with an average increase of 7.1 percentage points on a self-assessment scale among residences in the intervention group ( $P = 0.016$ ). No significant effects were found on dietary quality, BMI, waist circumference or satisfaction with life. The qualitative studies suggested that it is important to support motivation for change during the process and to support the residents not only within the health course, but also within the social and physical context.

Even greater effects might be achieved by improving the implementation strategies and the dietary aspect of the intervention. In order to maintain the positive effects in the long term, sustaining procedures must be established and issues regarding health promotion and empowerment should be continuously discussed among caregivers as well as at a management level.

## LIST OF SCIENTIFIC PAPERS

- I. Bergström H, Hagströmer M, Hagberg J and Elinder LS. A multi-component universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomised controlled trial. *Research in Developmental Disabilities*, 2013;34:3847-3857.
- II. Bergström H, Elinder LS and Wihlman U. Barriers and facilitators in health education for adults with intellectual disabilities – a qualitative study. *Health Education Research*, 2014;29:259-271.
- III. Sundblom E, Bergström H and Elinder LS. Understanding the implementation process of a multi-component health promotion intervention for adults with intellectual disabilities in Sweden. *Journal of Applied Research in Intellectual Disabilities* (accepted for publication).
- IV. Bergström H, Hochwälder J, Kottorp A and Elinder LS. Psychometric evaluation of a scale to assess satisfaction with life among people with intellectual disabilities living in community residences. *Journal of Intellectual Disability Research*, 2013;57:250-256.

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## LIST OF ABBREVIATIONS

DSM	The Diagnostic and Statistical Manual for Mental Disorders
FUB	Riksförbundet för barn, unga och vuxna med utvecklingsstörning (The Swedish National Association for Persons with Intellectual Disability)
ICC	Intra-Class Correlation
ICD	The International Classification of Diseases
ID	Intellectual Disability
IQ	Intelligence Quotient
LSS	Lag om stöd och service till vissa funktionshindrade (Act concerning Support and Service for Persons with Certain Functional Impairments)
RCT	Randomised Controlled Trial
SCT	Social Cognitive Theory
SES	Socioeconomic status
WHO	World Health Organization



## **FOREWORD**

For nearly ten years, I have worked with health promotion targeting adults with intellectual disabilities. When I first started, it was within the scope of a Stockholm County Council project. The aim of this project was to map the situation regarding physical activity, diet and weight-related health among adults living in community residences in Stockholm County, and to develop some kind of support to meet the needs identified. The results showed that there were significant health needs among the residents, as well as support needs among caregivers. Information materials for both residents and caregivers and education days for caregivers were developed, but it became clear that information and isolated education sessions were not enough to meet the needs.

At this point my colleagues and I at the former Unit of Applied Nutrition, Stockholm Centre for Public Health started to discuss how to develop an intervention that would more comprehensively meet the needs we had discovered. Thanks to the Public Health Fund in Stockholm County and the Sävstaholm Foundation, it became possible to develop a multi-component intervention, and to evaluate it scientifically. The project has resulted in several materials which I hope will be used in practice, such as an intervention manual and a study circle material. This thesis, along with other scientific articles, represents the outcome of my research in this field so far.



# 1 BACKGROUND

## 1.1 HEALTH INEQUALITIES

### 1.1.1 Distribution of health

Health is not equally distributed among different groups in the population, neither globally nor in Sweden. Epidemiological research shows that factors like education, income and cultural background are crucial for morbidity and mortality (1). For this reason, the World Health Organization (WHO) has appointed The Commission on Social Determinants of Health the task of analysing the situation and coming up with suggestions for how to lower social inequalities in health. The Commission has concluded that health and illness in all countries, regardless of income levels, follow social gradients: the lower the socioeconomic position, the worse the health (2). In cases when systematic differences in health are avoidable they are judged to be unfair, and labelled 'health inequities' (2). The Commission calls on the WHO and all governments to lead global action on the social determinants of health with the aim of achieving health equity. Society and global organisations should come together to take action, and the actions should include the empowerment of people, communities, and countries that currently do not have their fair share (2).

The overarching objective of public health policy in Sweden is to create societal conditions for good health on equal terms for the entire population, but The Public Health Agency of Sweden has concluded that the overall objective has not been achieved (3). Despite Sweden being a welfare state, with free education, social benefits and tax-financed health care, there are substantial social inequalities in health (4). All major causes of death at a population level, such as cardiovascular diseases, cancer, accidents, suicide and alcohol-related diagnoses, are more prevalent among people with low education. People with low education also have lower self-rated health and more mental ill-health (4).

The inverse relationships between high socioeconomic status (SES) and unhealthy behaviours encompass diverse underlying causal mechanisms. Pampel et al (5), who have based their conclusions on a broad review of literature in sociology, economics and health, suggest nine different explanations for higher smoking, lower exercise, poorer diet and excess weight gain among people with low SES. The explanations consist of: 1) deprivation, inequality and stress, 2) fewer benefits of health behaviours for longevity, 3) latent traits, 4) class distinctions, 5) lack of knowledge and access to information about health risks, 6) less efficacy and agency due to less schooling, 7) poorer access to aids for healthy behaviour, 8) fewer community opportunities, and, 9) social support, social cohesion and peer influence that is not as supportive of healthy behaviours.

Mackenbach (6) has proposed three hypotheses that might explain why inequalities in health remain also in welfare states like Sweden. First, inequalities in access to resources have not been completely eliminated by the welfare state. Second, due to greater intergenerational mobility, the composition of lower socioeconomic groups has become more homogeneous

with regard to personal characteristics associated with ill-health. Third, due to a change in epidemiological regime from communicable to non-communicable diseases, through which consumption behaviours have become the most important determinants of ill-health, there has been an increase in the marginal benefits of the intangible resources to which a higher social position gives access.

### **1.1.2 Health inequalities and intellectual disability**

People with disabilities are as a group disadvantaged in several respects and carry a large proportion of Sweden's disease burden (7). Low self-rated health is more than ten times as common as in the general population, and impaired mental health and poor dental health are more than twice as common (7). Parts of the higher disease burden among the group with disabilities can be explained by the disabilities per se. However, the odds ratio of poor health decreases by around a third when adjusting for age, level of education, lacking cash margins, sedentary leisure time, obesity, discrimination and social participation (7). This means that health in this group could, theoretically, be improved by increasing social participation, decreasing obesity, increasing physical activity, improving the financial situation and decreasing discrimination.

People with intellectual disabilities (ID) seem to be more vulnerable to poor health and behavioural risk factors for poor health than groups with other disabilities (8). People with ID have limited ability to correctly understand and answer questions about their health, which is why they are often not even included in national health surveys (8). According to Emerson (9), there are five key determinants of health inequalities that affect people with ID. First, people with ID have a greater risk of exposure to social determinants of poor health, such as poverty, poor housing, unemployment and social disconnectedness. Second, they suffer from an increased risk of health problems associated with specific genetic and biological causes of the disability. Third, the disability implies communication difficulties and reduced health literacy. Fourth, behaviours like poor diet and lack of physical activity increase health risks, and fifth, there might be deficiencies related to access to health care (9).

The concept of health literacy refers to knowledge, motivation and competencies of accessing, understanding, appraising and applying health-related information within health care, disease prevention and health promotion (10). Having an ID implies significant limitations in intellectual functioning, making understanding and use of health information difficult. Therefore people with ID do not, to the same extent as others, participate in health education, health promotion interventions or health screening interventions (11). In Sweden, people with ID access health care through the same channels as other citizens, requiring knowledge of the health care system and the ability to search for health-related information.

People with ID in Sweden are entitled to support in everyday life, but resources are limited. Managers and caregivers in community residences for adults with ID experience economic restraints and shortage of staff at the same time as they have many requirements to fulfil (12). There are no specific educational requirements on caregivers working to support people with

ID in Sweden, and the provision of continued training depends on management priorities (13). The work includes a wide variety of tasks, including assistance with personal hygiene, time planning, communication, grocery shopping, cooking and contacts with relatives (13). Without adequate education and training, it is difficult to provide the support needed within all these areas.

## **1.2 INTELLECTUAL DISABILITY**

### **1.2.1 Terminology and classification**

Intellectual disability refers to a condition implying significant limitations in intellectual functioning, significant limitations in adaptive behaviour, and a manifestation of these symptoms before adulthood (14). ‘Intellectual disability’ (ID) has emerged as the preferred term, although other terms are used as well (15). For example ‘mental retardation’ is sometimes used in the USA, ‘learning disabilities’ in the UK and ‘developmental disabilities’ in Australia. The terms do not encompass exactly the same conditions, and the definitions might also differ between English-speaking countries. For example ‘developmental disabilities’ is a synonym for ID used in Canada, but when used in other countries it includes other developmental disabilities as well, such as autism and cerebral palsy (16). This should be kept in mind when interpreting research results, because studies do not necessarily include comparable individuals.

There are several classification systems for ID used globally. The International Classification of Diseases (ICD) is the diagnostic instrument most often used, followed by the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (14). In this thesis, the term ‘intellectual disability’ (ID) is used, referring to individuals with an Intelligence Quotient (IQ) below 70, adaptive problems, and a manifestation of these problems before adulthood. The disability can be categorized as mild (IQ of 50-70), moderate (IQ of 35-49) or severe/profound (IQ < 35). People with mild ID have the ability to communicate effectively and live a relatively independent life, with only minimal support in their daily lives. People with moderate ID can, with lifelong support, have relationships, communicate, handle money, travel on public transportation, make choices and understand daily schedules. People with severe or profound ID are almost totally dependent on others and require extensive support with every part of life, from personal care to participation in activities (11). The wide variety of support needed implies that people with ID make up a heterogeneous group.

### **1.2.2 Prevalence and causes of intellectual disability**

According to a meta-analysis of population-based studies, the prevalence of ID globally is 10.4/1 000, which corresponds to a little more than 1 % (17). Studies on adults show a lower prevalence of 4.9/1 000, corresponding to 0.5 %. The prevalence is higher among men than among women, and also higher in low-income countries (17). In 2012, approximately 64 000 Swedish residents received support through regulations in a law called LSS, the Act concerning Support and Services for Persons with Certain Functional Impairments (SFS, 1993:387), which regulates rights for individuals with ID and some other disabilities in

Sweden (18). This number corresponds to 0.7 % of the Swedish population, but includes both people with ID and people with e.g. autism or acquired brain injuries.

The causes of ID differ, and are unknown in more than half of the cases (19). The most common known causes are chromosomal syndromes, among which Down's syndrome is the most prevalent (19). Different syndromes imply various physical impairments and medical needs, emphasizing the heterogeneity within the group of adults with ID. For example, a high prevalence of obesity is found among people with Down's syndrome (20, 21) and food seeking behaviour, often resulting in morbid obesity, is common among individuals with Prader-Willi Syndrome (22). This thesis focuses on the vulnerability of living with an intellectual impairment in a society where daily choices have to be made regarding consumption behaviours, impacting health and quality of life. It does not focus on the medical aspects of ID.

### **1.3 HEALTH AND LIVING CONDITIONS OF ADULTS WITH ID**

#### **1.3.1 Physical and mental health**

Among people with ID, there is a higher prevalence of both physical and mental ill-health than among the general population, with a higher prevalence of several conditions, such as epilepsy, skin diseases, sensory loss and fractures (23). According to a Swedish study, the mortality rate is also much higher than among the non-disabled population (24), although people with ID now live longer than previously expected, and the ageing of people with mild ID appears to be equal to that of the general population (25). Some health problems are related to the cause of the disability, for example in the cases of perinatal problems, motor handicaps, epilepsy and sensory impairments (23). Other problems, such as obesity and fractures, might instead be related to behavioural factors, such as lack of exercise, poor eating habits or medication use (23).

Research indicates that a significantly higher percentage of people with ID is overweight or obese compared with the general population. The obesity prevalence is especially alarming, with a reported prevalence of 19-38 % among people with ID in Nordic and European countries (20, 26, 27), compared with 9-19 % in the general population in this region (28, 29). The high prevalence of obesity is a major concern, because it might lead to several negative health impacts, such as cardiac and circulatory problems, respiratory problems, cancer, musculoskeletal problems, gastric problems and endocrine disorders (11). The prevalence of heart diseases in the target group is high, and expected to rise because of an ageing population (30). In Sweden, a high prevalence of cardio-metabolic risk factors have been found already among adolescents with ID (31). People with ID are also more likely to develop type 2 diabetes than the non-disabled population (32, 33). Underweight is not as common as overweight and obesity, but more prevalent than in the general population (26).

The prevalence of obesity and ill-health also varies within the heterogenic group of people with ID. Women are more likely to be obese than men (21, 26, 34) and the prevalence of

obesity is higher among individuals with Down's syndrome than among others with ID (20, 21, 34). People with mild ID are more likely to be obese, while people with severe ID are more likely to be underweight (20, 21, 26, 34). Related to this, several studies show that people living in less restrictive settings and are able to eat and prepare meals independently are more likely to be obese than those living in more supervised settings (34, 35). Additionally, younger people have shown a greater risk of being underweight, while older people have shown a greater risk of being overweight (26, 34). Within the group of people with ID, women, the elderly and those with mild or moderate ID are not only more likely to be obese, but also have an elevated risk for heart diseases (30).

The prevalence of mental health problems varies depending on the diagnostic criteria and research methodology, but seems to be significantly higher among people with ID than in the general population. In a British population-based study of people with ID, half of the population suffered from mental illness (36). According to a review, approximately one-third to half of each sample was medicated for psychiatric concerns, although the medical diagnoses did not support this level of medication use (37). The most prevalent type of mental illness in the British study was problem behaviours, e.g. verbal or physical aggression, destructive behaviour, demanding behaviour etc. (36). Women were more likely than men to suffer from mental ill-health, and people with severe ID were more likely than people with mild ID to suffer from mental ill-health. Also, eating disorders have been found to be more prevalent among adults with ID than among others, with binge eating disorder as the most common diagnosis (38).

Satisfaction with life has shown to be comparable to, or only marginally lower than, what is typically reported in the general population (39, 40). Variation in subjective well-being has shown to be related to indicators of socioeconomic position, social relationships (39), social support and interpersonal skills (41). Cummins concluded that the determinants for a satisfying life for people with an intellectual disability involve the same core issues as for nondisabled people (40). People with ID have increased longevity, and therefore there is a range of health problems of heightened concern, including cognitive decline, dementia, mental health problems, cardiovascular diseases and ill-health related to poor nutrition and lacking physical activity (42).

### **1.3.2 Health-related behaviours**

According to research, many adults with ID have an unbalanced diet, with insufficient intake of fruit and vegetables (43-47), too high intake of dietary fat (44) and a more frequent consumption of white bread than the population in general (47). According to a Swedish study, a high proportion of energy came from between-meal consumption (45). A study on overweight individuals with ID reported low intake of fruit, whole grains, dark green and orange vegetables and non-hydrogenated vegetable oils (48). Managers and caregivers in residential settings have in interviews described problems with disordered eating, high energy intake, low food diversity and little time spent on cooking (12). A high intake of convenience

food, fast food, TV dinners, soft drinks and chips has been described by managers, caregivers and individuals with ID themselves (49).

A great proportion of people with ID do not meet the recommendations for physical activity (47, 50-55). Compared with the general population, people with ID are less physically active, and a majority of those who exercise engage in mild exercise requiring minimal effort, e.g. yoga, easy walking or light gardening (46). The most common physical activities reported in an American study were walking and indoor chores, e.g. mopping, vacuuming or sweeping (54). The most common regular physical activities reported in a British study were walking, water-based activities and exercises (56). According to community-based studies, the physical activity is especially low in the evenings and on weekends (52, 53). Qualitative studies describe a sedentary lifestyle (12), with watching TV as a daily routine (57). According to some studies women with ID are even less physically active than men with ID (54, 55).

Levels of alcohol consumption, smoking and illicit drug use have been reported to be lower than among the general population (43, 46, 58, 59), except in a British study on adults with self-reported intellectual impairments, which reported higher rates than among the non-disabled peers (47). Although the prevalence of alcohol and illicit drug use is low, the risk of having a substance-related problem among ID substance users is comparatively high (60). Managers and caregivers in Swedish community residences have described substance abuse as a considerable problem for some individuals (12). Although the problem is relatively small today in numbers of people, it is possible that an increase will occur in the future. Young people with ID growing up today have not experienced institutional care and restrictions, but a society where tobacco, alcohol and illicit drugs are easy to access.

Other factors that might impact health include a lack of daily routines, hygiene problems, loneliness and problems in relations, and illegal or unacceptable behaviours (12). Aversion to care, due to fear or for other reasons, might also affect health outcomes. For example, managers and caregivers have experienced that some individuals are reluctant to accept daily support, health care, medication or social services, when actually needed (12).

### **1.3.3 Living conditions and housing**

In Sweden, as in many other countries, there has been a transition in housing conditions for people with ID (61, 62). All institutions are now closed in Sweden and adults with ID live in society, with or without assistance. Individuals diagnosed with ID are entitled to support according to the LSS law, The Act concerning Support and Services for Persons with Certain Functional Impairments (63). This act regulates ten different rights; 1) advice and other personal support, 2) help from a personal assistant, 3) patient escort service, 4) help from a personal contact, 5) relief service in the home, 6) short stay away from the home, 7) short period of supervision for school children, 8) arrangements for living in a family home or in residential arrangements with special service for children, 9) residential arrangements with special service for adults, and 10) daily activities for people of working age.



There are two main types of community residences in Sweden: group homes and homes with supported living. A group home is an alternative for people with comprehensive care needs where support is provided around-the-clock. Homes with supported living offer a living alternative with higher levels of independence, where the residents have access to support when needed (64). In both types of residences, each resident has an own apartment with a kitchen and a bathroom. Meals are sometimes served in a common dining room, but the residents can always choose to cook by themselves and have their meal in their own apartment. The municipalities are responsible for the residences, which can be managed by the municipalities themselves or procured and run by private companies. The residents are entitled to an individual plan, which should be drawn up in consultation with the individual (63). The municipality is responsible for coordinating the plan, providing qualified counselling from professionals and organising daily activities (65).

The caregivers working in community residences in Sweden have differing backgrounds and education. As there are no specific educational requirements, there are employees with no basic training at all as well as employees with academic degrees (13). It is common that caregivers have some kind of secondary education within the fields of health care or recreation, not necessarily with a focus on disabilities. Caregivers with long experience might have worked in large institutions, carrying knowledge and experience from a culture where attitudes to disability were different from today. Young employees might on the other hand not know about the conditions in the institutions, where some of the older people with disabilities have grown up (13).

The transition from institutional life to community living, in Sweden as well as in other developed countries, has led to a shift from a group perspective to an individual perspective (66). The individual's right to self-determination is emphasized, and this development has had a positive effect on quality of life (67). Although the development towards an increased participation in society is positive, it also gives rise to new challenges, such as making daily choices. Living in a society where one is supposed to make choices every day requires individual skills, skills that people with ID may not always possess due to limited health literacy. For example, the individual has to choose what, when and how much to eat, whether to exercise or not and how to transport him or herself. Facing those new challenges has not only led to increased quality of life but also to increased physical ill-health. According to a Swedish study on food arrangements and oral health, people moving from institutions to group homes did not increase their incidence of dental caries, but did increase their energy intake and body weight (68). Similar results were seen in a British study where the proportion of individuals with a weight outside the normal range increased, after these individuals moved from institutions (69).

According to a British study, self-reported intellectual impairments are significantly related to socio-economic disadvantage (47). In Sweden, people with ID have limited access to the labour market and have a lower average income than people without disabilities (70). Many individuals with ID are offered daily activities, and their main income is a disability benefit

from the social insurance system. People with ID typically also live a more limited social life compared with others in society. For many individuals, social contacts are with parents, siblings, caregivers and maybe a few friends (70). People with ID and non-disabled people do engage in the same types of leisure activities, although people with ID are more often onlookers at arranged activities and less often choose activities that require active involvement.

Gender differences in living conditions are considerably smaller in this population than in the Swedish society as a whole, implying that having ID is a more important determinant than gender (71). In a Swedish study, no differences were noted between women and men with ID regarding finances, family and social relations, housing, transport, community participation or personal safety. The only differences were in regards to type of employment, with women working in traditionally female-dominated jobs and men in traditionally male-dominated jobs, and type of leisure activities, with women more frequently visiting the library and reading books (71).

People with ID rely heavily on the staff that supports them in everyday life, and their possibilities to maintain good health and access health care when needed therefore vary depending on care and living arrangements (37). Although people with ID in theory have the same access to primary health care as anyone else, this might not always be the case in practice. According to a Swedish study, people with ID usually have access to a family doctor in primary health care, but despite this people with ID who have mental health problems do not always receive mental health care (24). People with ID meet health care personnel within the regular health care system, but the health care staff might not always have knowledge about special needs of people with ID. In a British study, primary health care nurses showed a positive attitude towards working with people with ID, but a need for training was identified (72).

#### **1.3.4 Assessing health and health behaviours**

People with ID are often not included in health surveys, because they might not answer complicated questionnaires or understand the purpose of a study, if not explained adequately. They are often not included in health promotion interventions either (11), although strategies have been described for both recruitment and consent procedures (73). There are several challenges in assessing health among people with ID, but this should not be a reason to exclude this population or to fail to measure health outcomes, but rather a reason to develop new data collection methods.

It is possible to use interviews as well as questionnaires among people with ID, although this poses several challenges. People with ID might for example experience difficulties when making quantitative judgments and direct comparisons (74). It might also be difficult for them to understand abstract concepts and there is a tendency for acquiescence regardless of the content. For this and other reasons, it is argued that more attention must be paid to establishing the validity of questionnaires for the target group (74). Proxy reports might be

useful in some cases, but responses from people with ID and proxies cannot be assumed to tally. Several studies show discrepancies (75-77), although some studies show good agreement (78, 79). Furthermore, proxy reports from caregivers and relatives are suggested not to be used interchangeably, as these two groups have proven to provide different information related to diverse viewpoints (80).

Assessing physical activity and diet at a population level is challenging in general due to the complex nature of these behaviours, and it is not always easy to decide which instruments to use. Common methods when assessing physical activity include self-reporting through questionnaires and motion detectors, such as pedometers and accelerometers. Self-report questionnaires are easy to administer and cost-effective, but have limited accuracy (81). When assessing physical activity among individuals with ID it is also necessary to take the cognitive limitations of the target group into consideration. According to one study, there is low agreement between physical activity assessed through a proxy-respondent questionnaire and through pedometry, showing that questionnaires have limited reliability to assess physical activity among adults with ID (82). Pedometry is an objective method for assessing total physical activity, and has proven to be a feasible method among adults with ID (83), but only measures the number of steps taken over a certain period of time. An accelerometer measures body movement in terms of acceleration, but is on the other hand both more complex and more expensive.

Dietary assessment methods are known to be associated with a high risk of misreporting (84). Among individuals with ID, it becomes even more challenging to assess dietary habits, because several of the assessment methods require skills on the part of the studied individual, such as the abilities to remember, count, estimate amounts or write. Dietary assessment methods previously used in this target group include assisted food records (45), questionnaires (44) and digital photography (85). Assisted food records are considered to be relatively precise, but are also time-consuming. Questionnaires entail difficulties previously mentioned, and therefore it might be necessary to choose short and simple questionnaires, and to provide adequate support, if this method is to be used (44). Personal digital photography is a relatively new methods, which appears to be a feasible, reliable and valid method for assessing dietary quality in people with mild to moderate ID, who have daily staff support (85).

Assessing quality of life is not easy, as it is a complex and multidimensional construct influenced by both personal and environmental factors, which has both subjective and objective components (86). The subjective aspect, e.g. satisfaction with life, is challenging to assess among individuals with ID due to cognitive limitations and difficulties to adequately construct questionnaires (74). Several scales have been developed for assessing satisfaction with life among the target group, but they are usually time consuming and challenging to use parallel with other assessments as they comprises many items (87-89) or incorporates a pretesting protocol (90).

## **1.4 HEALTH PROMOTION**

### **1.4.1 Foundations for health promotion**

The first International Conference on Health Promotion was held in Ottawa on 21 November 1986. In The Ottawa Charter for Health Promotion, health promotion is defined as the process of enabling people to increase control over and improve their own health (91). In health promotion, participation is essential to sustain effects. People have to be at the centre of health promotion actions and decision-making processes, making it important to increase empowerment and health literacy. Empowerment is the process through which people gain greater control over decisions and actions affecting their health (92). According to Cattaneo and Chapman (93), empowerment can be defined as an iterative process in which the individual has to develop self-efficacy, knowledge and competence to be able to set personally meaningful goals. Health literacy is critical to empowerment by improving people's access to health information, and their capacity to use it effectively (92).

Health promotion represents a social and political process, which is not only directed at strengthening the skills and capabilities of the individuals, but also at changing social, environmental and economic conditions for health. Determinants for health include a range of factors, such as individual health behaviours, social status, education, working conditions, access to health care and physical environment (92). Social Cognitive Theory (SCT) builds on the assumption that personal factors (cognition), environmental influences and behaviour all interact, expressed as the construct Reciprocal Determinism (94). Observational Learning is another important construct within SCT, and includes the idea that it is possible to learn new behaviours by observing others. According to this theory, both individual factors and environmental factors should be targeted within health promotion.

Defining the problem is the first step in building the causal logic of a health promotion intervention (95). A problem theory includes a detailed description of the social or health problem in the target population, as well as risks and protective factors, including barriers and facilitators for health-related behaviours. The problem theory is used to identify mediators and outcomes, but is not extensive enough to plan an intervention. Another kind of conceptualization, called 'programme theory' is needed to specify how the intervention will change the mediators. To develop a programme theory, the malleable mediators should be identified, to be used as intermediate outcomes (95).

According to Fraser et al (95), the steps in intervention research following the step mentioned above include to; 2) create and revise programme materials, 3) refine and confirm programme components, 4) assess effectiveness in a variety of settings and circumstances, and 5) disseminate findings and programme materials. During the second and third steps, revisions and refining are done through expert reviews, pilot testing and efficacy trials. The purpose of an efficacy trial is to estimate programme effects under optimal conditions with high control, meaning that the programme developer supervises the delivery of each step of the intervention. To develop a full understanding of the impact of an intervention, a sequence of

studies is required. During the fourth step, an effectiveness study is conducted to test whether the intervention produces a desired outcome when implemented under practice conditions (95).

The implementation of an intervention can be based on Proctor's conceptual model of implementation research (96). This model distinguishes between intervention components and strategies for implementation. According to this model, the implementation strategies are used to implement the intervention components, including strategies on various levels; organisational levels as well as group and individual levels. They might include education on a group level as well as supervision and support for providers (96). For an intervention to be called evidence-based, it should have been tested in at least two rigorous trials using sound measures and data collection procedures, showed consistent positive effects and reported significant long-term follow-up (97).

#### **1.4.2 Barriers and facilitators of health-related behaviours**

Barriers and facilitators of health-related behaviours among adults in community residences can, according to an interview study with managers and caregivers, be found at the level of the individual, staff, relatives, organisation and society (12). At an individual level, barriers may be intellectual, behavioural or due to physical limitations, habits or attitudes (12). Safety concerns in relation to use of kitchen utensils (e.g. stoves and sharp knives) have been identified as barriers to a healthy lifestyle (49, 98), as well as lack of motivation, stress, ageing (98), lack of self-efficacy, difficulties in transferring skills from one environment to another (49) and lack of awareness of options (99). Older age, having immobility, epilepsy and faecal incontinence have been identified as predictors of low physical activity (100).

Presence of illness has, in one study, been identified as a facilitator for healthy behaviour, because people with chronic diseases were particularly interested in promoting health (98). In another study, adolescents with ID were more likely to eat healthy food if they perceived their health status as excellent (101). Opportunities for self-determination, development of individual capabilities and meaningfulness and social connectedness have been identified as important resources for the residents (102). For physical activity, routines and familiarity as well as activities that are perceived as enjoyable have been identified as facilitators (103).

Barriers on a staff level include routines set to suit staff rather than residents, differing opinions among staff, personal habits of staff members as well as over-protection and control (12). Inadequate or negative support from caregivers has been identified as a barrier (98, 99), but support from caregivers can also constitute a facilitator, when the caregivers for example assist with activities (98). Caregivers working in community residences in general have a low level of education and even if they have basic care education, it is not likely that knowledge on nutrition and physical activity was included. Caregivers included in a British cross-sectional study had a low level of knowledge regarding public health recommendations on diet and physical activity (104). In that study, caregivers rated intrapersonal barriers to change within the individual with ID as more important than interpersonal or external

barriers. If caregivers feel this way, it might affect their belief in themselves as role models and message carriers, by not acknowledging their own importance. This could be seen as alarming, given that caregivers have the possibility to provide important support (105). If they do not see themselves as important, they may not put enough effort into supporting the residents. On the level of relatives, there might be difficulties in the communication between staff and relatives, over-protection and offering of unhealthy alternatives (12). Relatives and other people close to the individual with ID may also play an important supportive role, as support from others has been identified as a facilitator for physical activity (103).

At an organisational level, barriers include economic constraints, shortage of staff, low educational level among staff, varying requirements to fulfil and lack of health promotion work routines and guidelines (12). Barriers for physical activity on this level include transportation issues, financial limitations and lack of routines and guidelines (100). Structure and flexibility within the organisation, goal-setting, cooperation with other actors and staff knowledge have been identified as important resources within the organisation (102). At a societal level, barriers include new needs and demands among the target group, because young people with ID have grown up among others in society instead of in institutions. Other barriers include integration problems, an individualistic society climate, lack of knowledge in society and not the least an obesogenic environment (12). According to an American study, adults with ID had few environmental resources and opportunities in relation to physical activity (106).

### **1.4.3 Ethical dilemmas**

Self-determination relates to an individual's possibilities to determine his or her own fate or course of action without compulsion (107). Nirje was one of the first to use the term within the disability literature, arguing that choices, wishes and desires of people with disabilities have to be taken into consideration as much as possible (108). Self-determination is considered even more important for people with ID than for others in society, because of the frequent threats to personal control for this group (109). When asked, people with ID who have lived in institutions and then moved to an apartment, with a resultant higher degree of personal freedom, do not want to go back (110). People want to be autonomous and to decide for themselves in their own lives. Wullink et al concluded that people with ID have the basic human right to autonomy and should be empowered to actively participate in society (111).

Despite the intense discussion on self-determination, it seems to be difficult to realize in practice, and several studies report a low level of self-determination regarding both major and minor life decisions among people with ID (111). The level of self-determination is influenced by both environmental and intrapersonal factors, of which some are possible to affect (112). Several authors have emphasized the importance of supporting autonomy, for example by teaching self-determination competencies (109, 111).

An inadvertent consequence of supporting people to make their own choices is that this support often leads to unhealthy food choices (113). There are many factors affecting the

decision-making of people with ID, such as cognitive ability, socio-economic status, past experience of choices, lack of knowledge and physical ability. Beliefs, attitudes and opportunities of the caregivers might also affect choices, as well as the carer's ability to teach and management support (113). An individual with ID might not always understand the full consequences of a choice. Smyth et al conclude that it is important to teach decision-making, but that it is perhaps equally important to teach decision-making without encouraging unhealthy eating and thereby increasing the health risks in the population (113).

While caregivers want to support the residents to healthy behaviours, this is not an easy task. If the residents make choices that negatively influence their health, attempts to support healthy behaviours might constitute a threat to autonomy (12). When caregivers and managers in Swedish community residences were interviewed about how they viewed their own role in relation to health promotion, five qualitatively different categories emerged; 1) The Parent, 2) The Manipulator, 3) The Coach, 4) The Educator, and 5) The Libertarian (12). These categories ranged from the most protective and controlling category, 'The Parent', to the least protective and controlling category, 'The Libertarian'. This variation in views highlights the ethical dilemma of supporting healthy diet and physical activity among adults with ID living in community residences.

According to Nilstun (114), there are three ethical principles to follow in health work. The principle of autonomy states the moral obligation to respect another's right to self-determination, the principle of beneficence states the moral obligation to benefit others, especially not to harm them, and the principle of justice states the moral obligation to act fairly in the distribution of burdens and benefits. Especially the first two of these principles may come into conflict when promoting the health of adults with ID. The principles do not provide guidance in balancing them one against the other when making moral decisions (114), which might explain why the caregivers sometimes are faced with difficult ethical dilemmas.

#### **1.4.4 Health interventions**

There is an urgent need for interventions aiming to improve diet and physical activity among adults with ID. The question that arises is – what works? According to a review on health promotion interventions targeting people with ID, there is some evidence for fitness and psychosocial benefits of physical activity interventions (115). Positive outcomes include improved fitness, weight reduction, better attitudes towards exercise and improved satisfaction with life. Nutrition interventions show some weight reduction for those who are overweight, but there is stronger evidence for an effect of interventions including both a physical activity and a diet component (115).

Health screening in itself has a limited impact on obesity levels among adults with ID (116). Health education interventions for overweight and obese individuals, including sessions on diet and physical activity, have in some studies resulted in decreases in BMI, although the decrease have not always been substantial or significant for the entire group of participants

(116-119). Exercise interventions, including opportunities and support for training, have shown effect on fitness and BMI (120-123). Health education in combination with exercise has shown an effect on attitudes towards training and satisfaction with life (124) as well as on BMI, healthy behaviours and self-efficacy (125). Individual coaching has shown positive effects on health risks, though not more than a health risk appraisal combined with written feedback (126), and BMI, although the effects were not significant at follow-up (127, 128). In a review on weight loss interventions, it was concluded that most interventions include education, while only a few include behavioural components, such as teaching self-control techniques or self-monitoring of food intake (129).

Another review on weight loss interventions concludes that it is important to take the context into account and to involve caregivers (105). It has also been pointed out that nurses have a key role in supporting and motivating both caregivers and participants to achieve and maintain healthy behaviours (129). A majority of evaluated interventions target the individuals with ID themselves, through health education sessions, exercise opportunities or coaching. Caregivers, employers, relatives and other people supporting individuals with ID are identified as important, having a role in identifying activities and assisting with participation (51). Although it is important that these people have the knowledge, skills and resources to give adequate support (51), there are not many interventions targeting these groups.

In a review on carer-led health interventions to promote the health of adults with ID, studies on other target groups than adults with ID were included as well, because of the paucity of research in this field (130). The authors concluded that caregivers had successfully delivered health promotion in a range of health settings and invited researchers to include both caregivers and care recipients in the development of interventions. In a few intervention studies caregivers have been involved, such as in an American nutrition intervention consisting of menu and meal planning (131, 132). This intervention included materials and training for staff to be able to improve menu adequacy in group homes, and had positive impacts on food systems changes and acceptability to users, planned and served foods, and cost changes associated with implementation. Family or paid caregivers were also involved to support participants in a British weight loss intervention, which comprised nine sessions and resulted in a significant decrease in body weight and sedentary behaviour (119).

Due to a lack of controlled trials, and a lack of qualitative studies, it is difficult to draw clear conclusions regarding what is effective in improving health outcomes (129, 130). According to a review on weight management interventions the majority of the studies have methodological limitations such as no sample size justification, small heterogeneous samples, and no information on randomisation methodologies (133). Based on current evidence, it appears that a health intervention targeting adults with ID should cover both nutrition and physical activity, and might include health education, opportunities and support for physical activities, coaching and/or behavioural components (115-119, 123-129). It is preferable to include not only the individuals themselves, but also people supporting them in their



everyday life, such as caregivers and/or relatives (51, 105, 129). Based on this, there is justification for a multi-component intervention, targeting individuals as well as caregivers.

Furthermore, it is important to make sure that effects are sustained over time. Although interventions might lead to short-term improvements, there is a lack of knowledge regarding how to develop, implement and sustain interventions (129). Therefore, it is important to use the best available knowledge regarding intervention components and implementation theories, as well as to develop implementation strategies, adapted for the specific target group and setting.

#### 1.4.5 The development of a novel health intervention

The health needs regarding physical activity- and diet-related health of adults with ID and the shortage of evaluated health promotion interventions for the target group highlighted a need for developing and evaluating a novel health promotion intervention. The health problem among adults with ID in this thesis was defined as ‘physical activity- and diet-related ill-health’, and a problem theory was developed to identify possible causes of the problem (Figure 1).

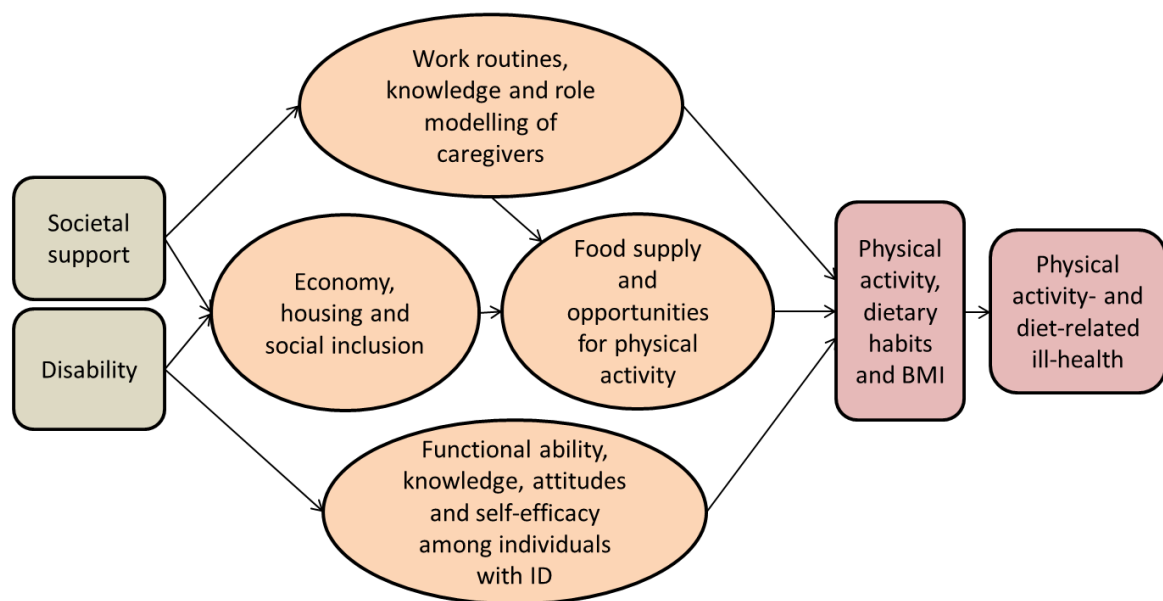


Figure. 1. Problem theory on which the intervention is based.

Physical activity and dietary habits, as well as BMI status, were identified as direct causes of the health problem. Functional ability, knowledge, attitudes and self-efficacy among individuals with ID were identified as individual factors influencing health behaviour, and these factors are believed to be influenced by the disability itself. Physical activity, dietary habits and BMI are also believed to be influenced by environmental factors, such as food supply and opportunities for physical activity, as well as work routines, knowledge and role

modelling of caregivers. The caregivers are believed to influence physical activity and dietary habits both directly, by role modelling, and indirectly, by supplying healthy foods and opportunities for physical activity. Food supply and opportunities for physical activity are also influenced by economy, housing and social inclusion. Societal support, such as laws and regulations regarding people with disabilities, are believed to influence economy, housing and social inclusion as well as knowledge among caregivers, in terms of possibilities for education and training.

Based on the problem theory, work routines, knowledge and role modelling of caregivers, food supply, opportunities for physical activity and knowledge, attitudes and self-efficacy among the individuals could be identified as malleable mediators. A programme theory was developed to specify how the intervention would change the mediators. As mediators were identified among both individuals with ID and caregivers, the intervention was developed to target both these groups. This strategy also followed the basic concepts of SCT, according to which personal factors, environment and behaviour all interact (94).

This health intervention was developed because of the urgent need for health promotion targeting adults with ID. Before deciding if an intervention should be implemented in society, it has to be evaluated regarding effectiveness. It is also important to gather knowledge about the process, to know what actually happened during the intervention period, and in which way the activities might have influenced the outcomes.

## **2 AIM**

The overall aim was to evaluate the effects of a novel health intervention directed at both staff and residents in community residences for people with intellectual disabilities and to describe and analyse barriers and facilitators in the process.

### **2.1 SPECIFIC AIMS**

- To investigate if a novel three-component intervention targeting both the residents and the caregivers could improve physical activity and dietary habits among people with intellectual disabilities living in community residences. (Paper I)
- To explore barriers and facilitators in the implementation of a health course for adults with mild or moderate intellectual disabilities. (Paper II)
- To explore aspects important to the implementation process of the intervention, as perceived by health ambassadors and managers. (Paper III)
- To develop and evaluate an easily administered scale for assessing satisfaction with home environment and leisure time among people with mild or moderate intellectual disabilities, living in community residences. (Paper IV)

### 3 METHODS

#### 3.1 STUDY DESIGN AND PARTICIPANTS

##### 3.1.1 Study design

The design of the intervention study is a cluster randomised controlled trial, the study protocol of which has been published (134). Because the intervention targeted the individuals and the caregivers collectively in each residence, the unit of randomisation was the residence. Reporting was carried out according to CONSORT guidelines for cluster randomised trials (135).

The trial was conducted under real-world conditions, and therefore can be considered an effectiveness study (95). It is preferable to conduct an efficacy trial prior to an effectiveness trial, to study the effects of the intervention when delivered under optimal conditions (95). In this case, an effectiveness trial was conducted without a previous efficacy trial, because it was not considered useful to create an unrealistic and possibly uncomfortable situation for residents with presence of the research team members in the community residences. The thesis consists of four studies, and the relation between the studies and the intervention is shown in Figure 2.

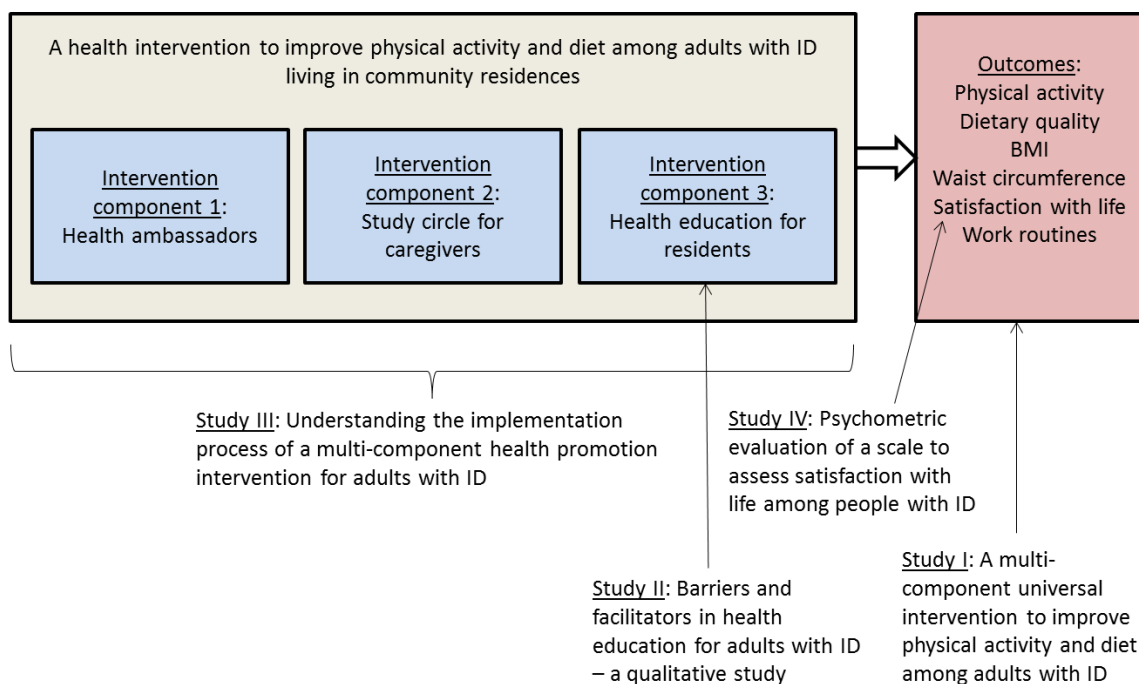


Figure 2. The four studies included in the thesis, and their relation to the intervention.

The effect of the intervention was assessed on both individual and residence levels, and was related to fidelity (Study I). Experiences and perceptions among people involved in the intervention were studied through interviews, group discussions, observations and evaluation notes, and analysed using qualitative methods (Studies II and III). Psychometrics was used to assess the reliability of the Life Satisfaction scale (Study IV).

#### *3.1.1.1 Qualitative methods*

Qualitative methods are appropriate when there is a need for studying a selected phenomenon in depth (136). Within qualitative research, it is possible to study the life-world of people, including feelings, motivation and other subjective aspects among individuals and groups (137). An inductive qualitative method is used if there are no previous studies on the phenomenon and a deductive method is useful if the purpose is to test an already existing theory in a new context (138). In intervention research, it is often useful to combine quantitative and qualitative methods, where qualitative methods are used to get a better understanding of the quantitative results (139). One or more data collection methods might be used for this purpose, such as interviews, focus group discussions, observations, surveys with open-ended questions or different types of documents.

Trustworthiness of qualitative work can be achieved by credibility strategies, transferability strategies, dependability strategies and confirmability strategies (140). Credibility requires adequate submersion in the research setting and can, for instance, be enhanced by prolonged field experience, reflexivity and triangulation. Reflexivity refers to assessment of the influence of the researcher's own background and triangulation is based on the idea that multiple perspectives ensure that all aspects of a phenomenon have been investigated (140). Credibility of research findings also deals with how well categories and themes cover data and how to judge the similarities within and differences between categories, for which representative quotations from the transcribed text can be used (141).

Transferability is about the extent to which the results can be transferred to similar contexts. It is up to the reader to decide if the results are transferrable, but to facilitate this decision it is important to describe the context as well as possible. Dependability relates to the consistency of findings. To achieve dependability it is essential to describe the exact methods of data collection, analysis and interpretation. Finally, confirmability can be achieved by an external auditor following the process, to understand how and why decisions were made, but also through triangulation and reflexivity (140).

#### *3.1.1.2 Psychometrics*

Psychometrics is used for the development and evaluation of scales. The dimensionality of a scale can be analysed using factor analysis, a statistical method used to describe variability among items within a scale by identifying a factor structure. One main guideline in the construction of scales is the concept of simple structure, which means that an item should have a high factor loading on only one factor and low factor loadings on the remaining

factors (142, 143). Reliability of the scale can then be estimated using Cronbach's alpha coefficients (144, 145).

### **3.1.2 Ethical aspects**

Ethical permission for this study was obtained from the Regional Ethical Review Board in Stockholm County, No. 2009/1332-31/5. The individuals with ID were individually asked to participate in the study, and gave informed consent. All participants received information in easy-to-read Swedish, and caregivers were encouraged to explain further. They were also informed that they had the right to terminate participation at any time. The trustees were provided written information as well, but did not have to agree to participation. As the intervention and the assessments did not include any health risks or physical discomfort, the individuals were allowed to make the decision of participation on their own.

Because of the intellectual disabilities of the participants, it was not always possible to know if they had understood all aspects of the assessments. Therefore, they were asked again about participation each time there was a new assessment. For each separate assessment the individuals had the right to decline to participate, still having the possibility to stay in the study and take part in other assessments, if desired. During the observation study, extra precautions were taken because of the sensitive situations that could arise, and the participants were carefully informed about the observation, their participation in the study and their right to decline participation. Caregivers and others involved in the intervention, who participated in qualitative studies, gave informed consent to participation as well. All data were treated as strictly confidential and it is not possible for readers of reports or scientific articles to identify individuals or residences. Quantitative data are presented in aggregated form and qualitative data are abstracted into categories and themes. Citations and excerpts are anonymized.

### **3.1.3 Recruitment of participants**

#### *3.1.3.1 Recruitment for the RCT*

The power calculation was based on the assumption of an average 25 % increase in physical activity, assessed as steps per day through pedometry. Calculations were performed with the 'Sample size calculator for cluster randomized trials' (146). The calculation was 2-sided, and power was set to 80 %, the significance level to 5 %, and cluster size to five individuals. The calculation showed that 32 community residences were needed to detect a significant change in physical activity of 25 % between the intervention group and the control group.

Inclusion criteria for community residences were mild or moderate ID of the residents and at least three residents who chose to participate in each residence. Recruitment took place between May 2009 and February 2010. All community residences in Stockholm County were invited to participate, through a letter to each of the 26 municipalities and 14 city districts within the County. Out of an approximate number of 500 residences, 60 residences expressed an initial interest and were assessed for eligibility. Six did not meet the inclusion criteria, and

21 declined participation after receiving more information about the project, because of time restraints or for unknown reasons. A total of 33 residences were left for baseline assessments.

A simple randomised design was used, and a researcher with no knowledge about the participants conducted the randomisation. Thirty-three sealed envelopes, each containing an identification number for a residence, were mixed in a basket, and the first 17 envelopes were assigned to the intervention group. The remaining 16 envelopes were assigned to the control group. In total, 139 individuals were included. After baseline assessments, but before the intervention started, three residences with a total of nine participants, randomised to the intervention group, dropped out. According to managers and caregivers, the reasons for dropout were reorganisations or other reasons not directly connected to the intervention. The drop-out residences were not included in the analysis.

### *3.1.3.2 Recruitment for qualitative studies*

Recruitment for the study on barriers and facilitators in health education for adults with ID (study II) was done between August 2010 and March 2012. In total, 16 study groups with 83 participants and eight course leaders were included in this study. The majority of these courses were conducted in the intervention group, but a few were also conducted in the waiting list-control group, after the intervention was completed.

Recruitment for the study on the implementation process (study III) was based on all 14 community residences in the intervention group. A total of 13 health ambassadors and eight managers were involved in the intervention, and they were all invited to participate in this study. Three possible respondents declined participation or were not reachable and one interview had to be excluded due to insufficient quality of the recording. In total seventeen interviews were included in the analysis.

### *3.1.3.3 Recruitment for the psychometric evaluation of the Life Satisfaction scale*

The psychometric evaluation of the Life Satisfaction scale (Study IV) was conducted on the baseline data. Of the 139 participants who completed the baseline assessments, 132 were scored on the Life Satisfaction scale, and were included in the psychometric evaluation study. The seven individuals who did not participate were either absent, chose not to participate or did not have the cognitive ability to answer the questions.

## 3.2 THE INTERVENTION

### 3.2.1 Description of the intervention

The intervention comprised three components: 1) The appointment of a health ambassador in each community residence, who attended network meetings with the other health ambassadors; 2) a study circle for caregivers based on the principles of peer education; and 3) a health course for the residents. All three components were supposed to be implemented over a period of 12-16 months. The intervention components were designed to target the identified malleable mediators (Figure 3).

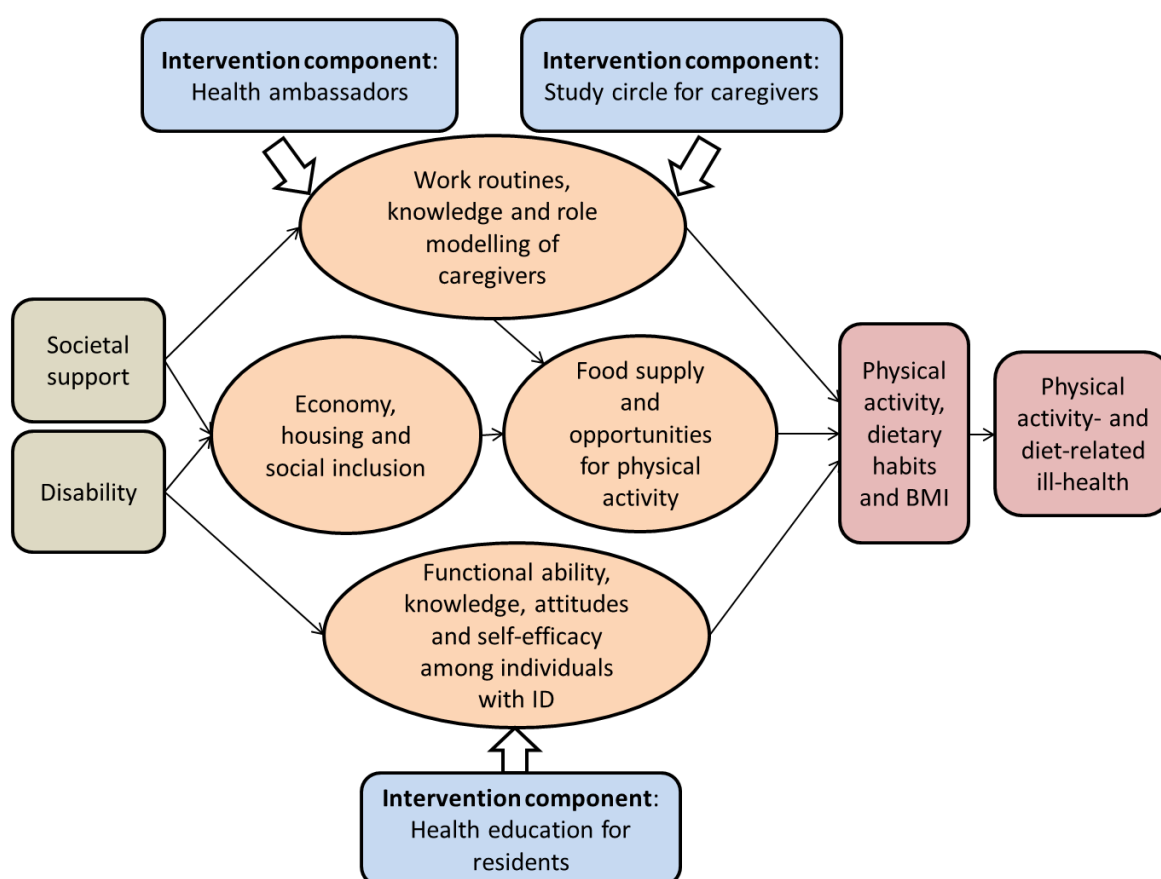


Figure 3. Programme theory, specifying how the intervention will change the mediators.

In order to achieve additional information about the views of managers and caregivers regarding the delicate task of promoting health without encroaching on autonomy, a qualitative interview study was conducted (12). To achieve acceptability and appropriateness of the intervention, the details of the intervention components were developed in consultation with a reference group. The reference group consisted of managers in community residences



as well as representatives from The Swedish National Association for Persons with Intellectual Disability (FUB) in Stockholm County. The feasibility of the components was then tested in a small number of community residences.

### 3.2.1.1 *Health ambassadors*

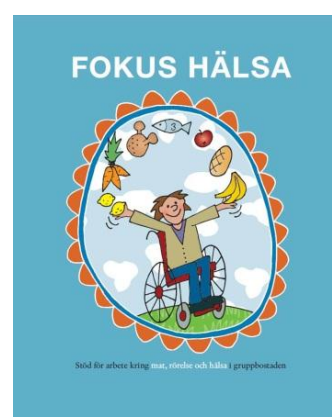
The ‘Health ambassador’ component was based on the common practice to appoint ambassadors for various issues in community residences. The aim of this component was to increase knowledge about health-related behaviours and health promotion among ambassadors, and to share ideas on strategies for work routines and role modelling between ambassadors. A health ambassador was appointed among the caregivers in each community residence, collectively by the staff and/or the manager. The task of the health ambassador was to provide health information to colleagues and to organise health-promoting activities for the residents.

All the ambassadors were invited to six network meetings of three hours each, to improve knowledge and discuss work routines with one another. Each network meeting included lectures or workshop activities and discussions based on the needs and interests expressed by the group. The themes of the network meetings, which were determined together with the health ambassadors, were: 1) Introduction to the intervention; 2) Diet; 3) Motivation; 4) Cognitive aid; 5) Physical activity and 6) Inspiration and coaching. The ambassadors also received coaching in terms of follow-up phone calls and information materials sent out by e-mail or mail.

### 3.2.1.2 *Study circle for caregivers*

The ‘Study circle for caregivers’ component was developed through continuous discussions with the reference group. The aim of the study circle was to increase knowledge about health-related behaviours and health promotion among caregivers, and to discuss and decide on role modelling and work routines to support healthy behaviours. Food supply and opportunities for physical activity were also supposed to be influenced. The study circle was named ‘Focus Health’ and was intended for the staff in each residence. It included ten sessions of approximately 90 minutes each, at which health promotion work was to be discussed and planned. A discussion leader was appointed from within the staff in each residence to lead the sessions. The study circle was based on a written material developed for this intervention. A dummy of the written material was tested in three community residences and then refined.

The written material included ten chapters, each including a theme, discussion questions, a matrix to define strengths and weaknesses and a task to formulate goals to improve existing work routines regarding physical activity and diet. The themes were: 1) Health and quality of life; 2) Autonomy and ethics; 3)



Diet and health in media and society; 4) Healthy dietary habits; 5) Physical activity; 6) Availability and accessibility; 7) Habits and attitudes; 8) Motivation and support for behavioural change; 9) Cooperation; and 10) How to sustain good work.

### 3.2.1.3 Health education for residents

The ‘Health education for residents’ component was developed by ‘Studieförbundet Vuxenskolan’, a national educational association for adults. The aim of the course was to improve health literacy and healthy behaviours in a pleasant way. Knowledge, attitudes and self-efficacy of the individuals were targeted through health information, possibilities to try new foods and activities and possibilities to develop new skills. The health course was named ‘The Driver’s license for health’ and was offered to the residents in each participating community residence. The course was offered in common rooms in each residence, also using the kitchen and the outdoor areas within the neighbourhood. It encompassed ten sessions of approximately 90 minutes each, and covered five areas: 1) physical activity, 2) diet, 3) mental health, 4) relaxation and 5) culture/aesthetics, such as painting and other creative activities. The course was conducted based on a manual and was led by course leaders from the national educational association for adults. The course leaders had various backgrounds, but all received one day of training focusing on the content of the manual.

The manual included ten suggested themes, one for each of the ten sessions, such as ‘a tasty and healthy breakfast’ and ‘foreign countries’. A list of 25 alternative themes was provided in case any particular theme did not fit. According to the manual, each session should begin with a small group discussion and end with regrouping and presentation of the assignment of the week, which could be to try healthy snacks or to perform a physical activity at home. All sessions included the preparation and tasting of a healthy meal/snack and some kind of physical activity or exercise.



### 3.2.2 Implementation strategies

Implementation strategies can be considered to consist of planned activities and efforts to get users to implement an intervention with high fidelity. The implementation of the intervention was based on Proctor’s conceptual model of implementation research (96) and adapted for the intervention (Figure 4). In this model, strategies for implementation are separated from components of the intervention, and the outcomes are specified at each level. In this intervention, we included an introductory information meeting for managers and caregivers, a one-day training for the course leaders in the health course for the residents, newsletters to the residences and coaching on demand. The information meetings provided information about the intervention and the evaluation, and the participants were given the opportunity to ask questions. The one-day training for the course leaders in the health course for the residents

was organised by the educational organisation ‘Studieförbundet Vuxenskolan’ and focused on the content of the manual. Newsletters were sent out regularly and coaching included contact by telephone and e-mail.

Intervention components	Implementation strategies	Outcomes		
		<u>Implementation outcomes</u>	<u>Residence outcomes</u>	<u>Individual outcomes</u>
Health ambassadors	Introductory information meeting	Feasibility	Work routines	Physical activity
Study circle for staff	One-day training for course leaders	Fidelity	Knowledge	Dietary quality
Health education for residents	Newsletters	Acceptability	Role modelling	BMI and waist circumference
	Coaching on demand		Food supply	Satisfaction with life
			Opportunities for physical activity	Knowledge, attitudes and self-efficacy

Figure 4. Intervention components, implementation strategies and possible outcomes.

### 3.3 DATA COLLECTION

At baseline of the intervention, data were collected on sex, age, ethnicity, daily activities/work, family relations and physical ill-health or disabilities of the residents. A structured questionnaire was used in discussion with each individual, in some cases with support from caregivers. Data on outcome variables, at individual and residence level, were collected at baseline and after completed intervention, i.e. after 12-16 months. Data on fidelity were collected during the process. Qualitative data were collected as the basis for information about barriers and facilitators in the process during the health course and after the end of the intervention.

#### 3.3.1 Outcome variables

A number of outcome variables were measured at baseline prior to randomisation, after completion of the intervention and at follow-up one year after completion. The primary outcome was physical activity, assessed as steps/day, through the use of pedometers. Secondary outcomes were dietary quality, BMI, waist circumference, satisfaction with life and work routines. The only mediator assessed was work routines, which to some extent included aspects of knowledge among staff, role modelling, food supply and opportunities for

physical activity. Knowledge, attitudes and self-efficacy regarding physical activity and diet among the participants were not assessed as it is difficult to assess adequately, and as the resources did not allow for development of relevant scales.

### *3.3.1.1 Physical activity*

As the intervention focused on increasing overall physical activity levels, a measure of total physical activity was used. Objective measures were chosen to assess physical activity as self-reporting was considered to be associated with bias, because of intellectual and cognitive limitations among the participants. Pedometers were chosen because they were considered to be easy for the target group to understand and handle. The pedometer Keep Walking LS2000 was used, because it shows good compliance with accelerometers (147) and has been recommended for research purposes (148). The pedometer has shown some differences from the accelerometer, but these differences were not expected to pose any serious obstacle to the measurements in a moving adult population (149).

Researchers presented the pedometer to the participants, together with caregivers, and instructed them how to wear it correctly. The participants were told to use the pedometer during seven days and to write down the results, by filling in a form each evening, with support from caregivers if needed. All participants who used the pedometer for at least three days were included in the analysis, because a period of three days has been shown to be enough to predict the average number of steps/week among moving adults with ID (83). The outcome variable was calculated as average number of steps per day.

### *3.3.1.1 Dietary quality*

As the intervention focused on improving dietary habits, indicators were chosen to assess aspects of dietary habits which were considered important within the target group. It is known that people with ID in general have an unbalanced diet with a lack of fruit and vegetables (43-48), and therefore the focus was on dietary quality. Dietary quality was initially operationalised as 'food diversity', 'lunches complying with the plate model', 'dinner complying with the plate model', 'vegetable consumption', 'consumption of fruit and berries' and 'consumption of non-core foods'. Food diversity was included as a diet including a variety of food groups is associated with positive health outcomes and reduced mortality (150, 151). The plate model (152) was used as this is a tool to plan a balanced meal, facilitating a diet with the right proportions of different nutrients. The model includes three different food groups in given proportion: 1) carbohydrate-rich foods like potatoes, rice or pasta (37.5 % of plate surface), 2) vegetables, root vegetables, fruit and berries (37.5 % of plate surface) and 3) protein-rich foods like meat, fish, egg or pulses (25 % of plate surface).

Dietary quality was assessed through the use of cameras, Canon PowerShot A480. This method was developed and tested by the research team because the available methods were judged to be inappropriate, due to the cognitive and intellectual limitations among the participants (85). During the test, the participants photographed all foods and beverages

consumed during one day, while observed, and the inter-rater reliability was tested between two independent raters. The method proved to be feasible, reliable and valid when assessing dietary quality in people with mild or moderate ID who have daily support from caregivers (85). In this study, the research team presented the camera to the participants, together with caregivers, and instructed them how to use it. The participants were instructed to take pictures of everything they ate or drank during three days, of which two should be weekdays and one should be during the weekend.

Food diversity was assessed as a sum of points, where one point was assigned when a participant consumed any amount of food from the following food groups: 1) meat, meat products, soy products, 2) fish, 3) eggs, 4) fruit and berries including juice, 5) vegetables, root vegetables, pulses, 6) dairy products, 7) pasta, rice, potatoes, 8) bread and 9) cereals (85). To assess lunches and dinners according to the plate model each meal was visually compared with this model and coded as complying with the model or not. Consumption of vegetables, fruits and non-core foods was assessed as occasions per day these foods were consumed, irrespective of amount. Initial analysis of the photographs showed that food items eaten between meals were often overlooked, and because fruits and non-core foods are often consumed between meals, these indicators were not included separately in the final analysis.

In the final analysis, the photographs were coded and analysed based on four aspects of dietary quality, which were also outcome variables: food diversity, lunches complying with the plate model, dinners complying with the plate model and vegetable consumption. Food diversity referred to the average number of food groups eaten per day, vegetable consumption referred to the average number of occasions per day when vegetables were consumed, and lunches and dinners complying with the plate model referred to whether or not the first photographed weekday lunch and dinner for each participant complied with the plate model.

### *3.3.1.2 BMI and waist circumference*

Data on height and weight were collected by trained research assistants from the research team during visits in the community residences. Participants kept their clothes on, which was considered important in order to avoid violating integrity, but were asked to take off shoes and heavy clothing. Waist circumference was measured at the narrowest point between the lowest rib and the iliac crest. To measure height, a stadiometer (SECA 214) was used, to measure weight, a scale (SECA Robusta 813) was used, and to measure waist circumference, a tape measure (Omron) was used. The scale was calibrated before the first measurement, as well as between the first and the second measurement.

BMI was presented as a mean for the whole group, as well as for men and women separately. Participants were categorized within different BMI categories, defined as underweight BMI < 18.5 kg/m<sup>2</sup>, normal weight BMI 18.5-24.99 kg/m<sup>2</sup>, overweight BMI 25-29.99 kg/m<sup>2</sup>, and obese BMI ≥ 30 kg/m<sup>2</sup> (153). Waist circumference was presented as a mean for the whole group, as well as for men and women separately. Participants were also categorized according to different waist circumference categories, defined as healthy waist circumference

< 80 cm for women and < 94 cm for men, mild abdominal obesity 80-87.99 cm for women and 94-101.99 for men, and abdominal obesity  $\geq$  88 cm for women and  $\geq$  102 cm for men (154).

### 3.3.1.3 *Satisfaction with life*

Satisfaction with life was mainly studied to monitor possible adverse effects of the intervention. Although several scales have been developed for assessing satisfaction with various aspects of life among people with ID (87-90), none was short enough while still covering the needs of this specific intervention, with focus on satisfaction with home environment and leisure time. Therefore, a multifactorial scale was developed and tested for its psychometric properties. The scale was developed by combining relevant items from different questionnaires for assessing satisfaction with life, by use of pilot tests and reconstructions.

The scale that was developed, tested and used included four factors: 1) satisfaction with housing environment; 2) satisfaction with life; 3) satisfaction with meals; and 4) satisfaction with recreational activities. The scale included twelve questions, to which possible responses were 'good' (happy face = 2), 'in between' (neutral face = 1) or 'bad' (sad face = 0). Each question was read out loud to the participants by a researcher. The participants answered by saying the answer or by pointing at a picture of a happy, sad, or neutral face. The outcome variable was a total mean score, a sum between 0 and 2, where 2 corresponded to 'good'.

### 3.3.1.4 *Work routines*

Data on work routines for meals, physical activity and health were collected through a questionnaire developed for this purpose (134). The questionnaire included 26 items within three domains: 1) general health-promoting work; 2) food and meals; and 3) physical activity. The items covered important aspects related to the malleable mediators within the problem theory, not only work routines but also aspects related to knowledge among staff, role modelling, food supply and opportunities for physical activity. Examples of items were 'staff competence', 'support for leisure time activities', 'nutritional content of common meals', and 'indoor and outdoor physical environment'. Each item had four response alternatives, corresponding to "fully in place" (3 points), "partially in place" (2 points), "under development" (1 point), and "not in place" (0 points). Outcomes were reported as the mean percentage of the total score as well as of each domain.

Face validity of the questionnaire was confirmed by testing with caregivers and their superiors. Test-retest reliability was assessed in two separate assessments, three weeks apart, in 30 residences not included in the trial. Analysis was done using intra-class correlations (ICC) using a two-way mixed model with absolute agreement. ICC was 0.80 for the total score, 0.84 for general health-promoting work, 0.78 for food and meals and 0.83 for physical activity. Reliability was considered excellent as an ICC coefficient higher than 0.75 has been suggested to indicate excellent agreement (155).

### **3.3.2 Intervention fidelity**

Fidelity describes the extent to which an intervention is carried out as it was intended (95). Knowing if an intervention was carried out as planned, or which parts of a complex intervention were implemented, is essential to understanding which factors contributed to an effect. To be able to study fidelity, it is important to define the core components of an intervention (95). In this study, the core components were defined as the three main components: 1) health ambassadors and their attendance in network meetings, 2) the study circle for caregivers, and 3) the health course for the residents. Fidelity was assessed based on participation of residents and caregivers in these activities. Attendance at health ambassador network meetings was documented by the research team, the number of sessions held in the study circle for caregivers was self-monitored and the number of sessions held in the health course for the residents was documented by the course leaders.

A scale was created where each component could provide a maximum of 30 points. This number was chosen for practical reasons. As we did not know if any intervention component was more important than the others, we decided to give the same maximum points to each component. Health ambassadors' level of activity was assessed as attendance at network meetings: Five points were given for each meeting, which gave a maximum possible score of 30 points. Level of activity in the study circle for caregivers and in the health course for residents was assessed as the number of sessions held; three points for each session gave a maximum possible score of 30 points for each component. To study a possible dose-effect relationship, the intervention residences were divided into high fidelity or low fidelity, by splitting at the median value of the total fidelity score.

### **3.3.3 Qualitative data sources**

#### *3.3.3.1 Study II*

In the study on barriers and facilitators in health education for adults with ID, data were collected through three sources: 1) evaluation notes from course leaders, 2) observations during course sessions, and 3) a group discussion with course leaders. By using several sources for data collection, triangulation was achieved, which supports the trustworthiness of the study (136).

Evaluation notes from the course leaders were collected to monitor the implementation of the courses. Observation was chosen because it provides insight into interactions and captures context and process (156), which makes it a preferable method when exploring what is happening during a group activity. This method was also chosen because it was possible to include all participants, irrespective of verbal skills. The observer played the role of 'observer-as-participant', someone who spends most of the time observing, with only a small proportion of time spent participating in the normal group activity (157). The observations were unstructured, allowing the observer freedom to collect information that was unique to individual incidents, and overt, in the sense that participants were informed about the observation and the reason for it (158). To capture the attitudes and experiences among

course leaders, a group discussion was conducted, inspired by focus group discussion methodology (159). Questions concerning four predetermined topics were discussed: 1) the target group, 2) the pedagogical situation, 3) cooperation and support, and 4) practical issues.

### 3.3.3.2 *Study III*

In the study on the implementation process, interviews were chosen to gain deeper understanding of the perceptions of the managers and health ambassadors (137). Two different semi-structured interview guides were used during the interviews, one for the health ambassadors and another one for the managers. The questions in both guides covered five factors affecting implementation as described by Durlak and DuPre, with a focus on barriers and facilitators (160). The interview guide used for the managers had more focus on organisational issues than the one used for the health ambassadors, as the managers were expected to know more about administration and management.

## 3.4 ANALYSES

### 3.4.1 Statistical analyses

Statistical analyses were performed using the statistical programme package IBM SPSS Statistics (version 18 and version 20 for Windows, 2011, SPSS Inc., Chicago, IL). A p-value < 0.05 was considered significant.

#### 3.4.1.1 *Descriptive statistics*

Differences in baseline characteristics between the intervention and control group, between men and women and between the residences that dropped out and those that were included, were tested using the t-test for continuous data and the  $\chi^2$  test for categorical data. Intra-Class Correlation (ICC) was calculated for residences and the primary outcome variable steps/day at baseline, comparing the variance within residences with the variance between residences.

#### 3.4.1.2 *Linear regression*

To test possible intervention effects, linear regression was used for continuous outcomes and modified Poisson regression was used for dichotomous outcomes (161). In the initial analyses, the variables sex, age, movement disability, and type of residence were used as covariates. Only 'type of residence' was a significant covariate for several outcomes, and therefore included in the analyses. The final analyses on individual outcomes were conducted as multi-level regression analyses when possible, with regard to sample size, due to the hierarchical nature of the data. The data were adjusted for baseline values and type of residence. We also controlled for the possible interaction between the assignment group (intervention/control) and the variable 'type of residence'. Because there was an interaction, we performed a stratified analysis on this variable. Effects were analysed in relation to fidelity in the intervention group only, by including a dichotomous dose-variable in the regression equation (high/low fidelity). Effect size was calculated for the primary outcome variable physical activity based on Cohen's *d* (162).



### 3.4.1.3 Psychometrics

The dimensionality of the Life Satisfaction scale was evaluated through factor analysis, with Bartlett's test of sphericity used to determine whether the correlation between the items was adequate for conducting the factor analysis. Kaiser's criterion (eigenvalue  $> 1$ ) was used to determine the number of factors, the method of principle-component analysis was used to estimate the solution and varimax rotation was used to facilitate interpretation of the factor loadings (143, 163).

One main guideline in the construction of scales is the concept of simple structure, which means that an item should have a high factor loading on only one factor and low factor loadings on the remaining factors (143). In the present sample, consisting of 132 respondents, a factor loading of 0.50 was considered significant (164). Consequently, it was decided to retain only items that had loadings that were equal to or greater than 0.50 on a single factor and had loadings below 0.50 on the other factors. Reliability of the scale was estimated using Cronbach's alpha coefficients (144, 145). The obtained sub-scales and the total scale were described with regard to arithmetic means, standard deviations, skewness, kurtosis and correlation coefficients.

### 3.4.2 Qualitative analyses

All transcripts in both qualitative studies (studies II and III) were analysed by using qualitative content analysis, according to the procedure described by Graneheim and Lundman (141). The texts were divided into units of meaning, which were then condensed and labelled with codes. The codes were compared based on differences and similarities and sorted into subcategories and categories. The categories were illustrated with quotes from interviews or excerpts from observations. Ultimately, overarching themes at a latent level were identified from the contents of all categories. Analysis in study II was performed by the author of this thesis (H.B.) and discussed continuously with the last author (U.W.). The analysis in study III was performed by the first author of that article (E.S.) and discussed continuously with one of the co-authors (H.B.).

The themes, as well as categories and subcategories, were defined through inter-subjective agreement between the authors to enhance the trustworthiness of the study (141). In cases of disagreement, the transcripts were carefully reread until consensus on the categorization was reached. Quotations were used to illustrate the connection to the transcripts, and thereby enhance credibility. Transferability was enhanced by thick descriptions of the settings and contexts.

## 4 RESULTS

### BASELINE CHARACTERISTICS

#### 4.1.1 Characteristics of the residences

In total, 30 community residences entered the intervention study (study I), 14 in the intervention group and 16 in the control group. About two thirds of the residences were group homes, and a smaller proportion of the residences were homes with supported living (Table 1). A majority were managed by municipalities, while a few were managed by private companies or non-profit organisations. In a majority of the residences, common meals were served at least one day per week. There were no significant differences between the intervention and the control group, regarding types of residences, management, number of caregivers or number of residents.

Table 1. Characteristics of the residences participating in the intervention study.

Variable	Group homes n = 21	Homes with supported living n = 9	Total n = 30
Management			
Municipality, number (%)	16 (76.2)	9 (100.0)	25 (83.3)
Private company, number (%)	4 (19.0)	0 (0.0)	4 (13.3)
Non-profit organisation, number (%)	1 (4.8)	0 (0.0)	1 (3.3)
Number of caregivers, mean (SD)	8.0 (3.2)	5.7 (1.9)	7.3 (3.1)
Number of residents, mean (SD)	6.4 (3.1)	8.4 (2.7)	7.0 (3.1)
Serving common meals $\geq$ 1 day/week, number (%)	20 (95.2)	8 (88.8)	28 (93.3)

#### 4.1.2 Characteristics of the participants

In total, 130 participants entered and 129 completed the study (Table 2). Of those entering the study 74 (57 %) were women. The age of the participants ranged from 20 to 66 years, with a mean age (SD) of 37.8 (10.8) years. Among the participants with mobility impairment, only two individuals used a wheelchair. There were no significant differences between the intervention group and the control group in regards to any characteristics except for prevalence of diabetes, which was higher in the intervention group ( $P = 0.049$ ).

Table 2. Characteristics of the participants, presented as absolute numbers (%).

Variable	Men n = 56	Women n = 74	Total n = 130*
Ethnicity			
Born in Sweden	48 (85.7)	60 (82.2)	108 (83.7)
Born in Europe, outside Sweden	2 (3.6)	5 (6.8)	7 (5.4)
Born outside Europe	6 (10.7)	8 (11.0)	14 (10.9)
Daily activities/work			
3-5 days/week	51 (91.0)	68 (93.2)	119 (92.2)
Not at all	5 (8.9)	3 (4.1)	8 (6.2)
Family relations			
Having a partner	14 (25.0)	25 (34.7)	39 (30.5)
Having child/children	1 (1.8)	4 (5.6)	5 (3.9)
Having no family/relatives	1 (1.8)	1 (1.4)	2 (1.6)
Physical ill-health or disabilities			
Mobility impairment	8 (14.3)	11 (15.1)	19 (14.7)
Visual or hearing impairment	22 (39.3)	40 (54.8)	62 (48.1)
Asthma or allergy	11 (19.6)	16 (21.9)	27 (20.9)
Epilepsy	11 (19.6)	12 (16.4)	23 (17.8)
Diabetes	4 (7.1)	3 (4.1)	7 (5.4)

\*There is one missing value for all variables except for family relations, where there are two missing values. Percent is presented as percent of actual number of participants.

#### 4.1.3 Outcome variables at baseline

The outcome variables at baseline are shown in Table 3 and 4. In total, 35 % of the participants reached at least 7 500 steps per day. About half of the participants had lunch (51 %) and dinner (54 %) according to the plate model on weekdays. During weekends, 28 % had lunch and 59 % had dinner according to the plate model.

In total, 2.4 % of the participants were underweight, 27.8 % were normal weight, 27.0 % were overweight, and 42.9 % were obese. Among women, 62 % had a waist circumference over 88 cm, which indicates abdominal obesity. Among men, 38 % had a waist circumference above 102 cm, indicating abdominal obesity. There were no significant differences in outcome variables between the intervention and control group except for work routines, where the control group scored higher on the total score ( $P = 0.027$ ), as well as on the domain of general health-promoting work ( $P = 0.044$ ).

Table 3. Residence outcome variables at baseline, presented as mean (SD).

Variable	Group homes n = 21	Homes with supported living n = 9	Total n= 30
Work routines (% of full score)	64.1 (12.0)	67.1 (11.3)	65.0 (11.6)
General health promoting work	60.0 (18.5)	68.5 (16.8)	62.6 (18.2)
Food and meals	55.6 (10.3)	52.1 (9.4)	54.5 (10.0)
Physical activity	77.8 (14.2)	80.1 (10.8)	78.5 (13.1)

Table 4. Individual outcome variables at baseline, presented as mean (SD).

Variable	Men n = 56	Women n = 74	Total n= 130*
Steps/day	7971 (5757)	6478 (4183)	7036 (4872)
Meal quality			
Food diversity (food groups/day)	5.5 (1.2)	5.7 (1.0)	5.6 (1.1)
Vegetable consumption (occasions/day)	1.6 (0.6)	1.5 (0.7)	1.5 (0.7)
BMI (kg/m <sup>2</sup> )	26.8 (4.9)**	30.3 (7.2)**	29.2 (7.1)
Waist circumference (cm)	93.4 (12.1)	92.9 (14.7)	93.7 (15.1)
Satisfaction with life (points on 0-2 scale)	1.8 (0.2)	1.7 (0.3)	1.7 (0.3)
Housing environment	1.9 (0.2)	1.8 (0.4)	1.8 (0.4)
Meals	1.9 (0.4)	1.8 (0.3)	1.8 (0.4)
Recreational activities	1.9 (0.3)	1.8 (0.5)	1.8 (0.4)
Life	1.7 (0.3)	1.6 (0.5)	1.6 (0.4)

\*There are 32 missing values for steps/day, 39 missing values for meal quality, 4 missing values for BMI, 6 missing values for waist circumference and 11 missing values for satisfaction with life.

\*\*Significant difference

## 4.2 EFFECTS OF THE INTERVENTION

### 4.2.1 Effects at residence level

A significant intervention effect was found on total work routines ( $P = 0.016$ ) as well as for the domains of general health promotion work ( $P = 0.010$ ) and physical activity ( $P = 0.043$ ). No significant effect was found on the domain of food and meals, although a small improvement was observed.

### 4.2.2 Effects at individual level

A significant effect was found on physical activity, assessed as steps/day, controlling for baseline values, clustering, and type of residence. The participants in the intervention group increased their physical activity by 1 608 steps/day, which was significantly more than the control group ( $P = 0.045$ ). ‘Type of residence’ was found to moderate the effect of the intervention. Therefore, a stratified analysis was performed showing that the increase was statistically significant only in homes with supported living ( $P = 0.031$ ). The effect size for the primary outcome variable was  $d = 0.29$ . No significant effect of the intervention was

found on BMI, dietary quality, or satisfaction with life, although outcomes for waist circumference were in the desired direction.

### 4.2.3 Intervention fidelity

Each intervention residence received a fidelity score, with a maximum possible score of 30 points for each of the three components, and a maximum possible score of 90 points in total (Table 5). The component that was performed with highest fidelity was health education for the residents.

The median value of the total score was 65 points. The seven residences that had more than 65 points in total were included in the high fidelity group and the seven residences that had less than 65 points were included in the low fidelity group. The high fidelity group improved their results more than the low fidelity group as regards both work routines and physical activity, but this difference did not reach statistical significance.

Table 5. Intervention fidelity (n = 14 residences).

<b>Intervention components</b>	<b>Points, median (min-max)</b>
1: Health ambassadors (maximum 30 points)	15 (0-25)
2: Study circle for staff (maximum 30 points)	18 (0-30)
3: Health education for residents (maximum 30 points)	30 (0-30)

## 4.3 BARRIERS AND FACILITATORS IN HEALTH EDUCATION

In this qualitative study, we identified one overarching theme and four main categories describing barriers and facilitators in the implementation of a health course for adults with mild or moderate ID. The overarching theme, ‘creating an individualized supportive context’, describes the challenge of educating people with ID towards empowered and well informed decision-making regarding their own health. There is a need for support not only within a course, but also from the social and physical environment. It is important that the environment supports the use of the skills learned, to extend their use in everyday life.

Four categories were identified at a manifest level: 1) ‘individual characteristics’, implying various needs, 2) ‘pedagogical strategies’, used to meet those needs, 3) ‘interaction within the course’, dealing with active and less active participation and 4) ‘structures’, including learning climate and organizing. Most courses were carried out without the presence of caregivers which, according to the course leaders, provided an opportunity for the participants to increase autonomy. However, the course leaders also expressed that the caregivers were not involved enough to be able to contribute as much as needed. The individual health plan, which was included in the manual as an option for relatives or caregivers who wanted to support the participant, was not used by anyone.

#### **4.4 UNDERSTANDING THE IMPLEMENTATION PROCESS**

In this qualitative study, we identified one overarching theme and four main categories that captured aspects important to the implementation process of this multi-component health intervention, as perceived by health ambassadors and managers. The overarching theme, ‘supporting motivation for change’, was identified from the contents of the main categories. It describes the importance of supporting motivation for change among managers, caregivers and residents when implementing a health intervention in community residences. Both caregivers and residents have to find their individual motivation to make changes, and the support has to be tailored to each residence as well as to each individual, taking specific needs and preferences into account.

The experiences of the implementation process are described in four main categories: 1) intervention characteristics, 2) individual commitment, 3) organisational capacity and 4) societal factors. The compatibility and flexibility of the intervention was important, as well as external input and support. Information meetings for the entire workgroup, well ahead of the intervention, were desired. Competence and interest among the staff were important, as well as interest among residents and relatives. Important factors within the organisation included work routines, resources, work climate and leadership. Local policies, accessibility to healthy environments and media messages also influenced the implementation.

#### **4.5 PSYCHOMETRIC PROPERTIES OF A LIFE SATISFACTION SCALE**

The analysis of the Life Satisfaction scale supported a four-factor solution with twelve items. The four factors were: 1) Satisfaction with housing environment; 2) Satisfaction with life; 3) Satisfaction with meals; and 4) Satisfaction with recreational activity. The four factors explained almost 70 % of the variance in the data set. Cronbach’s alpha coefficients for all sub-scales were above 0.70, indicating that the reliabilities of the sub-scales were satisfactory. Correlations between the four sub-scales ranged from 0.06 to 0.52, indicating low to moderate inter-correlations between the four sub-scales.

## **5 DISCUSSION**

This thesis aimed to evaluate the effects of a novel health intervention directed at both staff and residents in community residences for people with intellectual disabilities and to describe and analyse barriers and facilitators in the process.

To the best of my knowledge, this is the first scientifically evaluated universal intervention to promote physical activity and healthy diet among adults with ID, targeting both staff and residents in community residences. The intervention was evaluated regarding both effect and process, contributing knowledge and experience valuable to future research and health promotion targeting people with ID. The intervention is unique and important, because it targets one of the most vulnerable groups in society, carrying higher avoidable disease burden than the general population.

### **5.1 BASELINE CHARACTERISTICS**

The outcome variables were assessed at baseline to enable evaluation of the effect, but also to contribute valuable information about health among adults with mild or moderate ID in Swedish community residences. The sample was not randomly selected and therefore the results might not be generalizable. On the other hand, there is no reason to believe that the community residences and the individuals in this study differ to a great extent from other residences or individuals with mild or moderate ID. The staff and the residents voluntarily joined the intervention, which might implicate an interest in or a need for health promotion. Apart from this aspect, they did not stand out in any way. The residences covered various geographic locations within the County and included municipality- as well as privately administered residences. The residents represented various ages and had a variety of additional physical disabilities.

#### **5.1.1 Physical activity**

At baseline, about one third of the participants (35 %) reached a minimum of 7 500 steps per day, which is an approximate recommendation for health reasons (165). Comparable figures are not available for the general adult Swedish population, but for the neighbouring Finnish population, it has been reported that about 50 % of the women and 37 % of the men meet this recommendation (166). The average number of steps/day in this sample was 7 036, which is slightly higher than the results of a Norwegian study on adults with Downs syndrome, Williams syndrome and Prader-Willi syndrome (6712 steps/day) (55), but lower than the results from both the Finnish study (7499 steps/day) (166) and from a Norwegian study in the general population (8 314 steps/day) (167). A report by the Stockholm County Council shows that there is a need to promote physical activity in the entire population, with special efforts towards certain groups (168). Based on these results adults with ID are one of the groups in need of special attention in this respect.

### **5.1.2 Dietary quality**

The participants on average consumed vegetables 1.5 times per day. The frequency does not say anything about amounts, but it is reasonable to assume that vegetables should be consumed at least twice a day to reach the recommended amount of 500 grams of fruit and vegetables a day (169). A low intake of fruit and vegetables is not a problem only in this group. According to a Swedish survey, only two out of ten Swedish residents reach the recommendation of 500 grams of fruit and vegetables per day (170). As this study assessed vegetable consumption in occasions per day, and the national survey estimated the percentage that met the recommendations, it is difficult to make comparisons. Still, it is possible to conclude that the dietary habits of people with ID as a group are not satisfactory from a health perspective. There are several studies pointing out dietary problems, including a low intake of fruits and vegetables, among adults with ID (43-47).

About half of the participants had lunch and dinner according to the plate model during weekdays, and even fewer during weekend lunches. There are not corresponding figures to compare with the general population, but as Swedes in general do not eat as much vegetables as recommended (170), it is possible to assume that they often do not eat according to the plate model either. Regardless of the possible need for improved meal quality in the population in general, there is clearly room for improvement in this group. The domain “food and meals” in the questionnaire about work routines was also the domain given the lowest scores. Taken together, this indicates a need to give more substantial support for healthy diets, including support for an increased intake of fruit and vegetables, in this target group.

### **5.1.3 BMI and weight circumference**

Both overweight and obesity were common among the participants at baseline, and the prevalence of obesity was particularly alarming. In total, 43 % of the participants were obese, which can be compared with 12 % among men and 11 % among women in the general population in Stockholm County (171), although the latter data are self-reported and therefore probably a few percentage points too low.

There was a statistically significant difference between men and women, where women were more often overweight or obese, as well as more often having a large waist circumference. In the general population in Stockholm, men are more likely to be overweight and obese than women (171). International research regarding people with ID also shows that women with ID are more likely to be overweight or obese than men with ID (20, 26, 34, 43, 172). From this it can be concluded that it is important to support people with ID to achieve and maintain a healthy weight, but also to have a gender-specific approach in health promotion targeting this group. The women did not only have higher BMI and waist circumference, but were also less physically active, although this difference was not significant. That men with ID are more physically active than women with ID is supported by research (54, 55). Gender differences in living conditions are smaller in this group than in the general population, but women with ID are working in traditional female-dominated jobs and read more than their



male counterparts (71). This might imply that women with ID lead more sedentary lives, which also results in more overweight and obesity.

#### **5.1.4 Satisfaction with life**

The participants in general scored relatively high on the Life Satisfaction scale. This could suggest that they were satisfied with those aspects of life that they were asked about: housing environment, recreational activities, meals and life in general. Mean overall happiness with life has in other studies been shown to be comparable to, or only marginally lower than, what is typically reported in the general population (39, 40).

From an outside perspective, it might be surprising that people with ID should be satisfied with their lives, as they more often than others experience poverty, poor health and social exclusion. Some research suggests that there is little association between objective and subjective well-being within this group (173). On the other hand, there is research suggesting a negative association between socioeconomic disadvantage and subjective well-being among adults with ID (39). The participants in this study might to some extent be satisfied with their life situation. It could also be hypothesized that it is difficult to compare one's life situation with other possible scenarios and to reflect on the differences, when having intellectual and cognitive limitations.

## **5.2 EFFECTS OF THE INTERVENTION**

The main finding is that this universal intervention to improve physical activity and diet, targeting both caregivers and residents in community residences for people with ID, was effective in improving physical activity and work routines. The results are encouraging and in line with earlier interventions aiming for health promotion or weight reduction, showing that interventions that include physical activity, diet and health education may have beneficial effects (115, 129).

### **5.2.1 Positive intervention effects**

The analysis showed that there was a statistically significant effect on physical activity as well as on work routines for general health promotion and physical activity. The possibilities of increasing physical activity or decreasing sedentary behaviour in the target group are demonstrated by other interventions including health education (119, 125), although there are interventions without effect on physical activity as well (174). Due to lack of research within the field it is difficult to compare and draw clear conclusions on what parts of the interventions contribute to make them effective or not. When comparing with other interventions one must remember that evaluated interventions differ in several aspects. Most of the evaluated interventions target the individuals themselves, without involving the caregivers to the same extent as was done in this intervention (116, 117, 174). Moreover, most intervention studies are not universal, but targeting those already overweight, with the aim of weight loss (116-119, 125).

The effect on physical activity was stronger in homes with supported living, where residents are generally more independent than in group homes, in which the residents rely more on support from the caregivers. This result is not entirely unexpected, as it seems probable that individuals with higher intellectual and cognitive capacity can more easily motivate themselves to make lifestyle changes as a result of the intervention. Community residences with high intervention fidelity improved their performance more than residences with low fidelity; both on physical activity and on work routines, although the difference was not statistically significant. This dose-effect is encouraging, as it suggests that higher fidelity in future studies could lead to even better results.

The positive intervention effect on the domain 'physical activity' within the work routine questionnaire, and the positive intervention effect on the individual outcome variable 'steps/day', strengthens the logic of the problem theory, according to which work routines of staff influence healthy behaviours of the individuals both directly and indirectly. According to a review on staff training in intellectual disability training which aims to increase knowledge while enhancing skills and attitudes is potentially the most successful approach to developing effective and committed staff (175). The intervention also aimed to influence mediators on an individual level, such as knowledge, attitudes and self-efficacy among the residents. As these mediators were not assessed, it is however not possible to know if they were influenced as well and whether or not they contributed to the impact on physical activity. This will have to be tested in future studies.

## **5.2.2 Lack of intervention effects**

No significant effects were seen on dietary quality, BMI, waist circumference or satisfaction with life, although the trend for waist circumference were in the desired direction and possibly clinically of importance. The lack of effect on dietary quality can be related to the lack of effect on work routines for 'food and meals', which according to the problem theory should mediate effects on dietary quality of residents. Based on this, it might be concluded that the focus of future studies should be to improve work routines of caregivers regarding food and meals. There are a few intervention studies that have reported an effect on dietary habits, indicating the possibilities of achieving an intervention effect, although these studies have not included control groups (118, 125). In this study however, it cannot be excluded that the assessment of dietary quality of residents was not sensitive enough to measure small changes which might have occurred.

We did not expect to see significant effects on BMI or waist circumference, as the study did not have the necessary power (134). International intervention studies show that it is possible to achieve effect on BMI (116, 118, 119, 122, 125, 127), but most of these interventions had a more intense focus on weight loss among already overweight individuals which our intervention did not have, as it was a universal intervention aiming at improving physical activity and diet regardless of weight status. However, changes were in the desired direction. In future studies with more participants and higher fidelity, the effects observed here could become statistically significant.

A majority of the responses on the scale to assess satisfaction with life were on the positive end at baseline, leaving limited room for improvement. On the other hand, the scale was used primarily to monitor potential adverse effects in this vulnerable group. No deterioration was detected, which was taken as an indication that changes in work routines were not perceived negatively by the participants.

Lack of effect on some variables could be due to inefficient intervention components, inadequate implementation or possibly insensitive measurement methods, as mentioned above. A combination of these three factors is probably the best explanation, and there is room for improvement in future studies. By documenting changes in work routines in a more detailed way, it would be possible to get more information about routines that work and which ones do not work.

### **5.3 IMPLEMENTATION**

The implementation of the three-component intervention was supported by the research team, but considerable responsibility was also put on the manager, the health ambassadors and the caregivers. They had the possibility to choose when, and to some extent how, to implement the components. Therefore, it was important to evaluate how they succeeded and how the intervention was perceived.

#### **5.3.1 Intervention fidelity**

Fidelity varied between the community residences within the intervention group, which might be explained by factors described in the qualitative study on the implementation process. Several important barriers and facilitators for implementation were found within the organisation and within society, such as policies, accessibility to healthy environment, work routines, resources and leadership. As the residences were located in different municipalities and different organisations, it is possible that the local support for implementation varied widely.

Fidelity was higher for the component that was directed toward the residents, (The driver's license for health) than for the two components targeting the caregivers (Health ambassadors and Focus Health). This might be explained by the fact that the course was led by an external person from the national educational association 'Studieförbundet Vuxenskolan', while the other components required greater efforts on the part of the managers and caregivers. According to the qualitative study on the implementation process, the managers and caregivers appreciated external input and support, at the same time as lack of financial and staffing resources could become an obstacle. The high fidelity for the resident component does not imply that all individuals participated at each session though, as only number of sessions was included in the fidelity score, not numbers of participants.

To facilitate intervention implementation and fidelity, it is important to make sure that the caregivers receive necessary support. Information meetings should, according to the study on the implementation process, target all staff and be organised well ahead of the intervention.

According to Durlak and Dupre (160) the goal of training is to prepare providers effectively for their new tasks, but also to attend to their expectations, motivation and sense of self-efficacy. Furthermore, it is important to make sure that the organisation has the capacity to support the caregivers during implementation, in terms of supportive work routines, financial and staffing resources, and a supportive leadership. It is also important to remember that the caregivers within this study not only took part in the intervention, but also in data collection. The caregivers had to fill in the work routine questionnaires and support participants with photography and pedometry, which could have been perceived as burdensome as it included a considerable amount of planning. Future intervention studies should therefore focus both on supporting caregivers to implement the intervention and to minimise the impact on caregivers in terms of data collection.

### **5.3.2 Barriers and facilitators in health education**

Supporting people with ID towards empowered and well-informed decisions regarding their own health constitutes a challenge. The study on health education for people with ID showed that it is important to create an individualized supportive context when planning a health course for this target group, to enable healthy behavioural changes within everyday life. This support should not only be present in the learning situation, but also in the physical and social environment outside course sessions.

The participant's caregivers, trustees and relatives are crucial elements in the social context, which is seen as an important contributor to empowerment since it constrains or facilitates the efforts of the individual (93). The importance of the caregivers' involvement has also been emphasized in several studies (51, 105, 130). Therefore, time needs to be spent not only on planning the contents of the course itself, but also on planning how to include caregivers, relatives and other significant people within the context surrounding the course. More effective collaboration could possibly be achieved by more frequent communication between the course leaders and the caregivers, enabling discussions on how to support the participants during and after the course period. The participant's trustees and relatives, as well as day centre staff, could also be involved in creating a more individualized supportive context.

The aim of the health course was to support the participants in improving their health literacy and health behaviour, but in most cases no individual goals had been set and thus no actions towards a goal could be taken. The individual health plan of the manual, which was intended for caregivers and relatives, was not used, maybe due to the limited collaboration with caregivers and relatives. To increase empowerment, individual goal setting should also be included and evaluated (93). The inclusion of self-monitoring techniques, such as goal setting, is also supported by a meta-regression of healthy eating and physical activity interventions targeting other populations within communities, primary care and work places (176).

### **5.3.3 The implementation process**

The interviews with managers and health ambassadors showed that it was important to support the motivation for change among managers, caregivers and residents. One of the strengths of the intervention was that it was adapted to existing values and practices in the residences, which was achieved by including managers and representatives of the target group in the development of the intervention (134). The flexible and participatory approach was also appreciated, allowing for local tailoring. A high degree of compatibility and adaptation is known to facilitate the implementation of an intervention (160) and increase sustainability (177).

The fact that the intervention involved both caregivers and residents was seen as a facilitating factor. The importance of including caregivers in health promotion interventions and involving them in the process is supported by previous studies (105, 178). Health ambassadors and managers expressed that additional support during the initial phase would have facilitated implementation. To educate and prepare caregivers well is important to increase their commitment to the work (129). Family members and trustees could be involved to a greater extent as well. This idea is supported by an American study on eating habits in group homes, where one of the conclusions was that it is appropriate to include training for family members supporting relatives with ID (44).

It is well known that the organisational capacity is important for implementation (160). This study showed that a supportive working environment with a flexible schedule and a dedicated manager contributed to successful implementation. Resources and availability of staff were mentioned, and as in previous studies it was reported that understaffing prevented opportunities for physical activity (100). Municipality-specific factors, such as policies and availability of training facilities, also affected the implementation. The results show that support from the municipality is very important in order to maintain commitment to the work. As pointed out in a review on the subject, agency structure, such as policies and staffing ratios, can influence involvement in health promotion activities (115).

## **5.4 METHODOLOGICAL CONSIDERATIONS**

There were several methodological challenges to consider when evaluating this health intervention.

### **5.4.1 Study design and sample**

Leading experts in intervention research have called for clear descriptions of complex interventions for behavioural change, as incomplete descriptions restrict replication of successful interventions (179). In this thesis, the intervention and the components are described in detail, as well as the problem and programme theory. A study protocol has been published before implementation (134). In addition, an assessment of fidelity is included, defined as the extent to which an intervention follows its programme theory (95). This is a strength, as it increases understanding of causation (180).

The rigorous design, including multi-level analysis, gives support to the study's internal validity. Another strength was that the intervention was evaluated in terms of both outcomes and processes. The results apply to both municipality and privately administered community residences in various parts of Stockholm County, and it can be assumed that the results can be generalized to municipalities throughout the country. A manual has been developed for this purpose (181). As the materials are in Swedish and at some extent adapted to Swedish conditions, they are not as easily used outside the country, but knowledge derived from this intervention can be of use in similar interventions in other countries as well. The results of the qualitative studies can be transferred to similar contexts and serve as a basis for improvement and development of this and other interventions.

The fidelity criteria were quantitative and not detailed enough to provide qualitative information on performed activities. Fidelity rating scales can be developed to include the number of sessions, as in the present intervention, but they can also include measures of the process, relating to the way in which services are delivered (95). Process measures focus on the quality of services, such as the use of prescribed programme principles or the level of participant involvement. According to Gearing et al (182) major ingredients of fidelity include the design of the intervention, training elements, monitoring of intervention delivery and monitoring of intervention receipt, i.e. elements that focus on whether participants received the treatment or activities. In this intervention, no criteria for measuring the quality of the process were used, and methods for assessing fidelity could be improved in regards to this aspect in the future.

It can be discussed whether an evaluator should be internal or external. The use of an internal evaluator can be criticized, because the internal evaluator might have difficulties in conducting an independent examination. On the other hand, an internal evaluator is well informed, which increases the possibilities of producing relevant results that can contribute to improvements of the intervention (183). In this case, the author of the thesis participated in both the development and the implementation of the intervention, and also conducted a large part of the evaluation. This might constitute a dilemma and to minimize the risk for this, the analysis was continuously discussed with co-authors not directly involved in the intervention. The author of the thesis conducted the quantitative data collection, which was considered rather objective, as well as the study of the health course for the residents, which was developed and conducted by the external organisation 'Studieförbundet Vuxenskolan'. It was not considered appropriate for the author to conduct the interviews with the managers and health ambassadors though, and therefore these were conducted by another member in the research group who was not involved in the intervention.

Conducting research on people with ID might create ethical dilemmas. Because of the participants' cognitive and intellectual limitations, it might in some cases be difficult to be sure that they have understood the information about the study correctly. Therefore, the participants were asked about participation not only at the beginning of the intervention, but also each time there was a new study phase or assessment. Even though research on people

with ID might create ethical dilemmas, not conducting research would constitute an even greater dilemma. According to Nilstun's ethical principles, it is important to respect every individual's right to self-determination, but it is also important "do good" (114). In order to develop adequate support for people with ID, with the aim of improving their health and well-being, research is essential.

A limitation of the study was the relatively small sample and missing values on different outcome variables, which threatened the statistical power of the study. There were several missing values on the primary outcome variable steps/day, which implies that the effect was only studied in part of the group. It is debatable whether the participants using pedometers differed from those who did not use the pedometer in any way, and how that would affect the generalizability of the results. We understood, however, that participants' use of pedometers was more closely related to the caregivers' abilities to provide support than to the characteristics of the individuals themselves.

#### **5.4.2 Data collection and assessment methods**

Collection of data among adults with ID creates several challenges with regard to the individual's interest and ability to participate in each specific measurement and the motivation and ability of caregivers to provide support. The collection of data was challenging because of the intellectual and cognitive impairments of the participants, which sometimes made it difficult for them to understand the purpose of the assessments. Several assessments required support from caregivers as well and in those cases their involvement might have been even more important than the abilities of the residents. Data on height, weight and satisfaction with life were collected by the research team, and the number of missing values on these variables are small. Data on physical activity and dietary quality were assessed by the residents themselves, with support from caregivers, and for these variables the numbers of missing values are much higher.

Total physical activity was assessed as steps per day using pedometry. The advantage of this method is that it is objective, easily administered and has been shown to be feasible among adults with ID (83). However, pedometers do not give any information about intensity, duration or frequency of activity. An alternative would have been to use accelerometers. An accelerometer is a device that measures body movement in terms of acceleration, and can be used to estimate the intensity of the physical activity (184). In this case, it was judged as more important to offer an easily administered device, which the participants could understand, than to assess all aspects of physical activity.

Although a rather simple device was used for assessment of physical activity, there was a large number of missing values. In future studies, more effort should be made to support and motivate both participants and caregivers to take part in the assessments. It could also be important not to burden the participants and caregivers with too many different assessments at the same time. Another "risk" with using a simple device that the participants were able to understand and handle, such as the pedometer, was that it might have inspired them to be

more physically active than normal. This is positive when used as an intervention component, but not as good when used in evaluation. As the participants might have been inspired to walk more than usual, it might be assumed that the result on the variable steps per day is a little higher than what it would normally be. On the other hand this would be true for the control group as well and therefore not influence the outcome of the study.

The method used to collect data on dietary quality was tested for validity and appeared to be a feasible, reliable and valid method for assessing dietary quality in people with mild to moderate ID who have daily staff support (85). In this study, no significant intervention effects were seen. There are two possible explanations, one is that there was no effect, and the other that there were positive effects but the assessment method was not sensitive enough. It is noteworthy that data on dietary quality were remarkably stable from baseline to the end of the intervention, pointing to the reliability of the assessment method of digital photography. Missing values constituted a problem, and the proportion of missing values was considerably higher than in the validation study (85). One reason for this might be the presence of an observer in the validation study, which might have worked as some kind of reminder. Another reason might be that digital photography in this intervention study was one measurement among several, while in the validation study it was the only assessment. Conducting too many assessments at the same time might have been perceived as burdening or confusing to participants and caregivers.

The Life Satisfaction scale was tested for reliability, but not on repeated occasions. Considering the intellectual impairment and the known difficulties connected to this, it could be assumed that questions might have been misunderstood (74). It has previously been reported that people with ID may have a tendency to answer “yes” to questions regardless of content, which to some extent could explain the consistent choice of the response alternative “good” (74). Many participants, however, varied their responses, which indicates that they did not answer “yes” or “good” regardless of the content of the question. As with the dietary quality, the results were relatively similar before and after the intervention, indicating good reproducibility.

Work routines were assessed through self-assessment by caregivers and managers, which can be seen as a weakness. However, it is difficult to measure detailed knowledge on daily routines in any other way, and the questionnaire used was tested for reliability.

Qualitative data were collected from several sources in both qualitative studies. This triangulation of data supports the trustworthiness of the studies (136). Managers, health ambassadors and study circle leaders were interviewed or were offered the chance to take part in a group discussion. Evaluation notes were collected from the study circle leaders as well. The participants with ID were not interviewed, which can be viewed as a weakness. It would have been relevant, and possible, to interview the participants in the study on health education. The reason for using observations instead of interviews or group discussions was that this method made it possible to give attention to all participants, including those who had



difficulties in expressing themselves verbally. Observation is also a preferred method when the aim is to study interactions and processes (156).

## **5.5 FUTURE DEVELOPMENTS**

To be able to label an intervention as efficacious, it should have been tested in at least two rigorous trials using sound measures and data collection procedures, showing consistent positive effects and significant long-term follow-up (97). A one-year follow-up has been conducted, as well as a second study. The follow-up, carried out in eight of the 14 intervention residences, showed that the improved work routines were retained, whereas physical activity among residents was not (185). However, due to high attrition it is not possible to make firm conclusions regarding sustainability of the intervention on this basis.

The second study was conducted as a quasi-experimental study in eight municipalities in Sweden, among which five, with 42 residences, were included in the intervention group and three, with 28 residences, were included in the comparison group. Due to limited resources only one of the three components, the study circle for the caregivers was included and evaluated, using the questionnaire on work routines. The results showed a statistically significant effect on total work routines ( $p = 0.006$ ) as well as for the domains of general health promotion ( $p = 0.045$ ) and physical activity ( $p = 0.004$ ). Again, no significant effect of the intervention was found on food and meal work routines (unpublished results). These results were strikingly consistent with the results of the first study, strengthening these findings.

Both studies showed an effect on work routines regarding physical activity, but not on food and meals, and therefore there is a need for further development of the diet component. The intervention included materials on diet and health for the caregivers, but not as much for the residents. Therefore, it might be useful for future studies to develop pedagogic materials on diet and health that can be used by the residents themselves with or without support from caregivers. A third study, which is a large-scale implementation study, is also planned. The purpose is to evaluate the intervention in real-world circumstances using the manual in regards to process and effect. The responsibility for the implementation will be on each participating municipality, which will appoint a project coordinator and implement the intervention based on a manual.

In addition, there is a need for developing and evaluating additional strategies like policies both at the municipality level as well as at residence level. It would also be of interest to study the effect of type of residence (group homes or homes with supported living) and with regard to gender of residents. Samples would have to be stratified and powered accordingly. Workplaces and daily activities is another setting where health promotion activities could be performed and evaluated. Other important target groups are adults with ID who live on their own, or together with other family members, as well as young individuals adults with ID about to move from their family home.

## 6 CONCLUSIONS

This three-component intervention to promote physical activity and diet among adults with ID living in community residences proved to be effective in improving physical activity among residents and work routines among caregivers. No effects were seen on dietary quality or on work routines to support healthy eating, and therefore the intervention has to be improved in regards to the dietary aspect. Even greater effects might be achieved by improving implementation strategies to increase fidelity. This can be supported through policies, an organisation with sufficient resources and a supportive leadership, and by training and preparing managers and caregivers well ahead of the intervention.

When implementing the intervention, it is important to support the motivation for change among managers, caregivers and residents in order to achieve maximum benefit. Individuals with ID can be supported through a health course, but need support from the social and physical environment surrounding the course as well. In order to maintain the positive effects in the long term, sustaining procedures must be established and issues about health promotion and empowerment should be continuously discussed among caregivers as well as at a management level.

## 7 ACKNOWLEDGEMENTS

The work at this thesis was done at the Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, and was financed by the Sävstaholm Foundation. The intervention was initiated in the former Centre for Public Health, Stockholm County Council, and was financed by The Public Health Fund (HSN 0802-0339).

I wish to express my sincere gratitude to all of those who, in various ways, have supported me during the work on this thesis. First and foremost, I wish to thank all participants in the studies: the residents in the community residences as well as caregivers, managers and study circle leaders from Studieförbundet Vuxenskolan.

My special thanks to:

*Liselotte Schäfer Elinder*, my main supervisor and co-author, for always being supportive and positive, whatever difficulties we have encountered. Thank you also for your continuous and detailed feedback on my work, from which I have learned a lot.

*Maria Hagströmer*, my co-supervisor and co-author, for supporting me with data analysis and for sharing your knowledge on physical activity and assessment methods. Thank you also for your ever rapid feedback and support with practical issues.

*Ulla Wihlman*, my co-supervisor and co-author, for sharing your knowledge on qualitative methods. Thank you for always seeing the bigger picture, and asking me the important questions.

*Jacek Hochwälder*, my co-supervisor and co-author, for sharing your experience in psychometrics.

*Jan Hagberg*, my statistician and co-author, for sharing your experience in statistics.

*Elinor Sundblom*, my co-author, for sharing your experience in nutrition and for all the good discussions on qualitative analysis. Thank you also for being such a good colleague and friend.

*Anders Kottorp*, my co-author, for sharing your experience in construction of scales.

*Gunnar Bergström*, my mentor, for listening and for sharing your experiences from the academic world.

*Ida Gråhed*, my project assistant, for assisting me with all the assessments in the community residences, when we have been carrying scales on buses and trains. Thank you also for keeping track of all those information letters, questionnaires and telephone calls.

*Marianne Leissner*, my project assistant, for assisting me with the initial assessments in the community residences.

Additional colleagues and friends in our research group ‘Community nutrition and physical activity’, for always being supportive, particularly: *Gisela Nyberg*, *Emma Patterson* and *Åsa Norman*.

I also thank my mother *Karna* and my late father *Jan*, and all my other family members, for always being supportive. In particular, I want to thank my husband *Peter* for listening, having all those good discussions and always believing in me.

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