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Food Related Activities and Food Intake in Everyday Life among People with Intellectual Disabilities

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Abstract

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The aim of this thesis was to study food, eating and meals in the everyday life of 32 women and men with intellectual disabilities (IDs) who require varying levels of supervision. They lived in supported living (rather independently) or group homes in community-based home-like settings. Observations during 3 days, assisted food records and anthropometric measurements were used to collect data. Dietary intake on the group level showed a varied diet and sufficient intake of all micronutrients, but a low dietary fibre intake. On the individual level, inadequate intake of micronutrients was observed, with many participants being obese, overweight or underweight. Everyday support with food, eating and meals was seen in four praxis: *foodwork by oneself for oneself*, *foodwork in co-operation*, *foodwork disciplined by staff* and *foodwork by staff*. These four practices resulted in large variations in dietary intake. The first praxis entailed more convenience food and less vitamins, the second and third, more fresh ingredients and high energy intake, and the fourth, low energy intake but rather high intake of vitamins. Sharing of meals was least common in supported living and more common in group homes and daily activity centres. The participants' social eating spheres consisted mostly of other people with ID and staff members, and seldom other people. Whereas some preferred solitary eating, many participants considered eating together as important, but required staff support in establishing commensality. However, disturbing behaviour, as determined by the staff, could result in solitary eating. In conclusion, supporting the group rather than the individual sometimes created less favourable dietary, eating and meal outcomes. This problem needs to be addressed in order to establish food security at the individual level. In addition, actions should be taken to ensure that people with intellectual disabilities receive sufficient support to meet their individual needs and aspirations.

Keywords: Nutrition, Intellectual disability, food security, community living

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“One must be sensitive to know what a person wants, – in that everyone tells very clearly about what they want, if we only listen”

(A staff member talking about the persons that do not express themselves in words)

To my Family

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Adolfsson, P., Mattsson Sydner, Y., Fjellström, C., Lewin B., Andersson, A. (2008) Observed dietary intake in adults with intellectual disability living in the community. *Food & Nutrition Research* 52.
- II Adolfsson, P., Fjellström, C., Lewin B., Mattsson Sydner, Y. Foodwork among people with intellectual disabilities and dietary implications depending on staff involvement. *Scandinavian Journal of disability research*. In press.
- III Adolfsson, P., Mattsson Sydner, Y., Fjellström C. Social aspects of eating events among people with intellectual disability in community living. *Journal of Intellectual & Developmental Disability*. In press.
- IV Adolfsson, P., Mattsson Sydner, Y., Fjellström C. Food, eating and meals in the everyday life of individuals with intellectual disabilities - a case study. Submitted.

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Abbreviations

AR	Average requirement
BMI	Body mass index
BMR _{est}	Estimate basal metabolic rate
EI	Energy intake
E%	Per cent of total energy intake
FAO	Food and Agriculture Organisation
FIL	Food intake level
IQ	Intelligence quotient
ICD-10	International Classification of Diseases – 10 th revision
ICF	International Classification of Functioning, Disability and Health
LI	Lower level of intake
MJ	Mega joule
PAL _{obs}	Physical activity based on observations of the physical activities
SD	Standard deviation
WHO	World Health Organisation

Introduction

For people with intellectual disabilities, the past few decades have been a process in many countries of de-institutionalisation of services toward community-based settings. The philosophy of normalisation has led to several reforms in the welfare states of the Western world (Mansell, 2006). The leading countries in this area are Sweden and Norway, countries where the current law provides the right to community services for people with intellectual disabilities (Mansell, 2006). Grunewald (2003) showed that the services for intellectual disabled persons in Sweden have shifted over the past 30 years from mainly institutional to only community services.

In Sweden, as in other Scandinavian countries, normalisation is understood and interpreted in the spirit of Nirje (1969), which entails that all people should be integrated into society with other citizens and have similar living conditions as other people (Nirje, 1969; Tideman, 2004). Society is thus obligated to create possibilities and give the necessary resources for individuals whose disabilities limit them from having a life comparable to that of other people (Tideman, 2004). Normalisation should not strive to change people with intellectual disabilities to become “normal”, but to give them opportunities to be part of a normal everyday life on their own conditions. In this sense Tideman (2004) explains that normalisation is an endeavour whereby every individual can actively participate in society. Tideman (2004) further points out that full participation for a person with an intellectual disability can be seen as she or he having equal living conditions as a person without intellectual disability, yet being the same age and living in the same society. It was thoughts like these that 40 years ago inspired Nirje to recommend that meals for people with intellectual disabilities should be “during the span of the day, you may eat in large groups, but mostly eating is a family situation which implies rest, harmony, and satisfaction” (1969).

The development of de-institutionalisation has changed many everyday activities (e.g., food and meals). An understanding of the food provision system and meal organisation for people with intellectual disabilities in today’s community settings in Sweden has not been studied to any great extent. Studies evaluating these rather new living arrangements are required and essential in achieving good health and providing proper support and services (e.g., food, eating and meals) for people with intellectual disabilities. Thus, the problems that need to be discussed are the organisation of food and meals for people with intellectual disabilities, their health characte-

ristics and to recognise the importance of the social meaning of food and meals for an individual's overall health and food security (c.f. p. 19).

Intellectual disability – definitions and classifications

Sweden does not have any official statistics over the total number of people with intellectual disabilities. However, the National Board of Health and Welfare does have statistics over people that use their right for the services that are entitled for people with intellectual disabilities in accordance with the Act Concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387). According to the latest statistics, there are 50 174 individuals with intellectual disabilities who in 2009 used different services (42% are females and 58% are males), in this group 28% are children and adolescences under 20 years of age (National Board of Health and Welfare, 2010).

People with intellectual disabilities are a heterogeneous group of people (Mervis, 2001), often with more complicated health issues than those of the general population (Sutherland, Couch, & Iacono, 2002). Common for these people is a diagnosis indicating significant sub-average intelligence and a significant limitation of adaptive skills, both before adulthood and during the developmental period of life (Mervis, 2001). It has been established that information about people's intelligence, adaptive skills and additional diagnoses is necessary to determine their service needs and for a better understanding of their life situation (Harris, 2006), which is done in Sweden when a person is recommended supported living or a group home. Several classifications have been developed to better understand the effects of intellectual disabilities for a person. In several of these classifications the limit is set at an intelligence quotient (IQ) of 70, which means that a person with an IQ of approximately 70 or below is classified as having intellectual disabilities (Gustafsson, 2003). With a score of 70 as the IQ limit, about 1% of population is estimated to have intellectual disabilities (Harris, 2006).

The International Classification of Diseases (ICD-10) (WHO, 1992) is one of the several classification systems used today. It identifies four levels of intellectual disabilities: mild, moderate, severe and profound. According to ICD-10, an adult person with mild intellectual disability has some learning difficulties, but manages everyday living in society rather well and without support. A person with moderate intellectual disability often needs some support with everyday living though the person has skills in communication and self-care. People with severe and profound intellectual disabilities completely depend on continuous support with everyday life (1992). The adaptive skills are related to conceptual, social and practical skills relevant for persons in their actual living environment (home, work and community) in relation to their background, cultural group and age (Snell & Luckasson, 2001; Gustafsson, 2003).

The World Health Organisation (WHO) has developed yet another type of classification, namely the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This classification is a bio-psycho-social model based on integration of two opposing models of disability, a medical model that clarifies the disability as a medical problem within an individual and a social model that considers the disability as being mostly dependent on social factors in the individual's environment (WHO, 2001). However, the ICF does not classify a person, but classifies a person's health characteristics within the context of individual life situations and environmental impacts. According to the ICF, "It is an interaction of the health characteristics and the contextual factors that produces disability" (2001, p 242). These changes in attitudes toward disability can also be seen today in the intentions of Western societies when forming support and services for people with intellectual disabilities. In Sweden, the policy is to deliberately neutralise the negative effects that the environment can cause for persons because of their disabilities (National Board of Health and Welfare, 2009).

Although these classifications will not be used and discussed further in relation to the participants in this thesis, they do give some understanding of the overall life situation and everyday life among people with intellectual disabilities.

Organisation of living arrangements and need of support

People with intellectual disabilities have different needs of support and services: to manage daily living, many of them are dependent on support from others throughout their life. In Sweden, the responsibility for their health and social and financial security is governed by three political levels (state, county and municipality) (National Board of Welfare and Health, 2009). The central government is responsible for general planning of resources and for legislation; the County Councils have the main responsibility for the health care services; and the municipalities are responsible for social services. All services should be individually formed to suit the individual, with the ambition that all individuals, even those with extensive needs, can have their own private homes while still receive high-quality care (National Board of Health and Welfare, 2009). Thus, the law also guarantees several measures for a person (SFS 1993:387). An example of one measure is qualified counselling from professionals (e.g., dieticians, occupational therapists, psychologists or physiotherapists) who except their professional skills, are expected to have an understanding of the life of a person with major functional impairment. An example of another measure is housing with special services, which is an apartment either in a group home or in supported living settings (Table 1).

Table 1. Two alternatives housing arrangements in the community for people with intellectual disabilities according to present Swedish legislation. The Table is constructed by the author and based on data from the National Board of Health and Welfare (National Board of Health and Welfare, 2007)

	Group home	Supported living
Location of the apartments	All apartments in the building belong to the group home or the apartments are connected to each other in a apartment block	Apartments are in the same building or in the same housing area.
Standard of the apartments	Apartments should meet the Swedish building standards and include a kitchen area, bathroom and bedroom	Apartments should meet the Swedish building standards and include a kitchen area, bathroom and bedroom
Access and characteristics of a base	A base, a common area of a group home, is required and it has to be situated near the apartments. There has to be room for all the residents to be present at the same time and a kitchen should be included for common meals	A base, a common area, for people who share the same staff group, is required, but it does not have to be of the same size as in group homes and give same opportunities for the individual as the base of a group home does.
Size of the residence	Limited to five to six apartments. The residents need to feel that they belong to the group and feel they have a social interaction with the other residents if this does not exceed more than five apartments can be allowed.	No exact limits of how many apartments can be connected to the same service group. However the housing should be integrated with regular housing in the area without giving an institutional impression of the housing type. This limits the number of apartments.
Directed to	For people with extensive needs	Supported living is for people who cannot manage to live independently but do not need support 24 hours a day
Staff	Permanent staff group with 24-hour service	Permanent staff group

To understand how the apartments in the group home can be connected to the common facilities a diagram is shown in Figure 1.

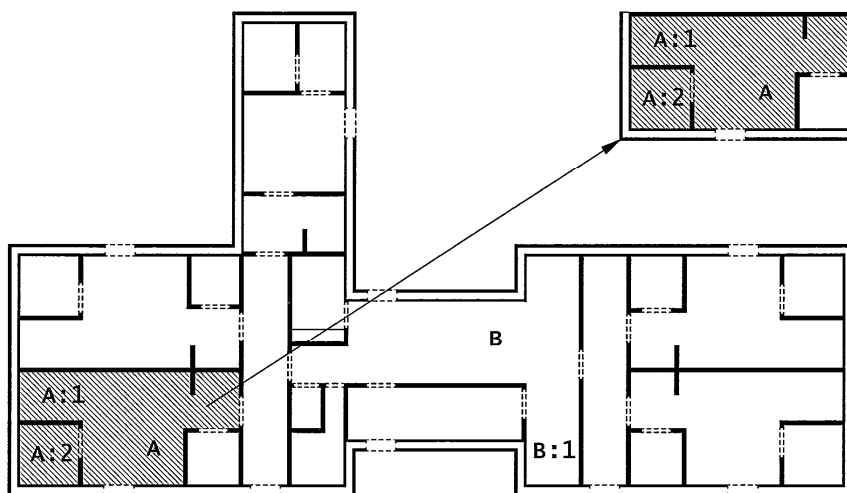


Figure 1. An example of a group home with five separate apartments and a base. A) a private apartment, A:1) the kitchen in the private apartment, A.2) the bedroom in a private apartment, B) the base, B:1) the kitchen in the base. (An evacuations map for a group home was used with a permission of a group home leader, to create this figure)

A third example of measures is the right to organised daily activity that offers meaningful occupation during weekdays. The activity should be suited to the skills and needs of the individual and thus can be expected to vary considerably between individuals (National Board of Health and Welfare, 2009). A fourth example of a measure is the right to a “personal contact” person. A personal contact person should serve as a companion and help an individual to lead an independent life by reducing social isolation.

As can be seen the current Swedish legislation indicates that everybody should have good living conditions with the various measures being individually adapted.

From institutional to individual solutions

Ever since people with intellectual disabilities have been offered care in Sweden, food seems to have been included in the services. In the early period of food service food was prepared within the residences and the wife of the superintendent could be expected to be the housekeeper with this person taking care of all food service (Svensson, 1995). According to the instructions for the matron for an institution in the 1920s, the residents were supposed to be served simple food but of good quality (Svensson, 1995). In the 1940s, when institutionalisation was seen as the correct solution to deal with the social problems in society, both old people and people with different disabilities were offered living arrangements in large institutions (Hansen et

al., 1996). However, this was also a time when criticism against the institutionalisation started (Ericsson, 2002). The regularly conducted inspections of the institutions included the review of food service, which indicates that food service was regarded as an important factor in the care of people with intellectual disabilities. An inspection report from 1955 includes a schedule for the daily menu in an institution (Svensson, 1995). At eight o'clock, the residents were served porridge or gruel and a sandwich for breakfast; at noon, they were served two cooked dishes for lunch; at four o'clock in the afternoon, the meal included sandwiches with milk or buns with coffee; and the last meal of the day, at six o'clock in the evening, was a lighter meal (e.g., a sausage or a sandwich with milk) (Svensson, 1995 p. 153). The report also shows that one fruit was served to everyone once a day.

New large institutions were still being established in the 1960s and 1970s (Svensson, 1995). In those institutions the meals were planned, prepared and cooked for a large number of people in central kitchens before delivery to the living quarters (Mallander, 1999). However, at that time, increased criticism could be discerned against institutionalisation, the inhuman treatment of citizens and the inefficient bureaucracy in the public sector (Hansen et al., 1996). People with intellectual disabilities were treated more as objects than as human beings. This attitude meant professionals at the central level did the overall planning and design of the services while individual wishes and needs were not considered (Sandvin & Söder, 1996).

The criticism resulted in a modernisation of the public sector in Sweden, where the services for people with intellectual disabilities were gradually decentralised and deregulated (Hansen et al., 1996). What is seen here is how the philosophy of normalisation started to influence the development of services. From 1967, people with mild intellectual disabilities were offered community-based housing and daily activities (SFS 1967:940; Ericsson, 2002).

In 1986, the services for people with intellectual disabilities were on a voluntary basis (SFS 1985:568). The people were offered five kinds of special services concerning personal counselling, daily activity and different solutions for both temporary and permanent housing. With support of this legislation, de-institutionalisation was actually started. At this time, food service was still organised in the central kitchen and all residents ate their meals at the same time in a dining room (Mallander, 1999). However, the National Board of Health and Welfare now required the food service to be moved to the living quarters nearer the residents (Svensson, 1995). To improve the services, the current legislation (SFS 1993:387) replaced the law from 1985. With changes in services in general the food service was also changed. This change resulted in a system where food was no longer delivered from central kitchens, but instead the staff at the residence or the residents themselves were given the responsibility for the provision of food (Mallander, 1999). These organisational changes have meant that people

with intellectual disabilities participate to a greater extent in different activities (e.g., grocery shopping and cooking) than they did before de-institutionalisation (Gabre, Martinsson, & Gahnberg, 2002).

The food organisation in community residences today

Except for the illustrations of changes in food service in the study of Mallander (1999), other recent studies have shown that food service for people with intellectual disabilities are still changing (Ringsby Jansson, 2002; Olin, 2003). However, the focus of these studies (Mallander, 1999; Ringsby Jansson, 2002; Olin, 2003) was not explicitly on food, but as food is a part of people's everyday life, it can be seen as an analytic way of looking generally at the everyday life of people with intellectual disabilities. The participants in Mallander's study that lived in a nursing home had their food delivered from a central kitchen to the living quarters, but after moving out to community residences, the everyday activities involving food, called foodwork by Bove, Sobal and Rauschenbach (2003) and including planning menus, shopping for food and preparation of meals, were activities within the residences. The foodwork often involved the residents. The studies of Ringsby Jansson (2002) and Olin (2003) were done later and showed that foodwork was preferably done on a more private basis within each resident's apartment with support from the staff.

These changes illustrate that changes in the living conditions also implied changes in food service, with staff not being specifically employed for food service (Mallander, 1999; Ringsby Jansson, 2002; Olin, 2003). The food service for people with intellectual disabilities thus seems to have been developed to be more individual and private, particularly for those that are able to take care of some food-related tasks, as was the case for the majority of the participants in these three Swedish studies.

However, the development of the services is an ongoing process in which all solutions have not been optimal. The participants of the Mallander's study (1999) that did not have joint meals with others could only get support with dinner preparation once a week because of limited staff resources. Some participants in both Ringsby Jansson (2002) and Olin's (2003) studies rather had joint meals in the residence because they considered their apartments to be of such private space that they did not want others, including staff, coming into their home. Thus, these individuals more or less abandoned support with foodwork rather than let the staff into their apartment. All three researchers (i.e. Mallander, 1999, Ringsby Jansson, 2002 and Olin, 2003) give examples of the food that participants had eaten when they did not get staff support or when they were offered staff support but rejected it. These dishes and food items were foremost characterised by ready to eat

with or without heating up, but not cooking from raw ingredients and can thus be considered as convenient food.

The de-institutionalisation process was taking place in Norway at the same time (Mansell, 2006), where changes in food provision in services for people with intellectual disabilities, as described above, could also be seen. A Norwegian study showed that the staff were not always sure what to promote-- the individual solutions or the collective (Sandvin, Söder, Lichtwarck, & Magnussen, 1998). On the one hand, having separate meals allowed the residents to make their own choices, but it also meant a more isolated life than the life of those who had joint meals. On the other hand, the joint meals could remind the individual of life in the institution, with few choices and regulated meals. In his study about everyday life in Norwegian group homes Folkestad (2003) observed that although the residents shared the household and their own kitchens in the apartments were not in use, their private kitchens had still a symbolic value for the residents' appreciation of the apartment being their home.

Health characteristics among people with intellectual disabilities

The presence of additional disabilities is rather common among people with intellectual disabilities (Gustavson, Umb-Carlsson, & Sonnander, 2005; Harries, Guscia, Nettelbeck, & Kirby, 2009), such as visual impairments, hearing deficits, cerebral palsy and epilepsy. Further, the prevalence of additional mental and behavioural disabilities is common (e.g., hyperactivity, anxiety and mood disorders) (Gillberg & Soderstrom, 2003; Gustavson et al., 2005; Harris, 2006). These additional disabilities may limit the individual's activities in everyday life. The type and number of additional disabilities vary from person to person, but they occur more often among people with severe and profound intellectual disabilities than for those with mild or moderate ones (Harries et al., 2009).

Studies that consider the physical well-being of people with intellectual disabilities have often looked at body weight. For instance, it has been established that overweight and obesity are more frequent within this population than in the general population (Rimmer & Yamaki, 2006; Marshall, McConkey, & Moore, 2003; Hove, 2004; Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; Melville, Cooper, Morrison, Allan, Smiley, & Williamson, 2008). Furthermore, underweight appears to be more frequent within this population than among the population in general (Hove, 2004; Bhaumik et al., 2008). The determinants for obesity in people with intellectual disabilities are complex but seem to be associated with gender as women are more often obese than men. Age and level of disability (mild intellectual

disability) and less restrictive living arrangements are also associated with obesity (Rimmer & Yamaki, 2006; Marshall et al., 2003; Hove, 2004; Bhaumik et al., 2008; Melville et al., 2008). Occurrence of underweight, however, seems to depend on age and severity of disability, where it is more common among younger and those who cannot feed themselves (Gravestock, 2000; Bhaumik et al., 2008). Underweight is also related to food refusal and self-induced vomiting (Hove, 2004; Bhaumik et al., 2008).

In Norway, Hove (2007) found different kinds of eating dysfunctions among people with intellectual disabilities living in different community settings. In this study eating too fast, bolting the food, food refusal and excessive eating were recognised in over 60% of the study population. The living conditions with poor food choice and lack of physical activity, as well as the fact that people with intellectual disabilities live longer today than earlier can be a reason for the increase in cardiovascular diseases (Robertson, Emerson, Gregory, Hatton, Turner, Kessissoglou, & Hallam, 2000; Draheim, 2006). The fact that diet-related diseases are increasing among women with intellectual disabilities at a higher rate than in men with intellectual disabilities make women a more vulnerable group and thus they need to receive more attention (Rimmer, Braddock, & Fujiura, 1994; Evenhuis, Henderson, Beange, Lennox, Chicoine, & Working Group, 2000).

Swedish studies on health aspects of people with intellectual disabilities living in community settings are rare (Gabre et al., 2002; Gustavsson et al., 2005). In one study, however, Gabre et al. (2002) found changes in total body weight among this group of people in the process of de-institutionalisation, i.e. when moving from institutions to community settings.

Food security

The Food and Agriculture Organisation (FAO) and WHO (1992) underpin the importance of food security, especially among socially vulnerable and disadvantaged groups, such as older people and people with disabilities. The concept of food security is multifaceted and, not surprisingly, has been defined in different ways. The FAO's definition is as follows: "...when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life" (FAO, 1996). Germov and Williams (2008) extend the definition: "the availability of affordable, nutritious and culturally acceptable food for each and every individual (p. 406)." Thus, it is required within a household to have sufficient knowledge and the ability to supply each household member with a balanced diet on a sustainable basis (FAO & WHO, 1992). According to Jaron and Galal (2009), a balanced diet is an assurance of access to adequate macronutrient and micronutrient intake and central to food security.

Food security can be established on different levels in society: at a community, household or individual level (Anderson, 1990). Pinstrup-Andersen (2009) stresses that even if food security is established at the community or household level, it does not automatically mean that the food is secured for each individual. To increase knowledge about food security at the individual level and to facilitate the construction of new policies and programmes for food security, Pinstrup-Andersen states that measurements on an individual level (e.g., anthropometric measurements) should be carried out. Anthropometric measurements are about physical dimensions of a body. According to Gibson (2005), one way to make such measurements is to establish an individual's body mass index (BMI). Jaron and Galal (2009) explain that although the balanced diet is important for food security, still, because of people's different life styles, and social and cultural backgrounds, the diet can vary between individuals.

At the community level, the countries in the Western world are generally thought of as food secured. Reasons for household food insecurity, the antonym of food security, vary. Gorton, Bullen and Mhurchu (2010) conducted a literature study to find explanations for the lack of food security within households in high-income countries. They emphasised that there are several factors that influence food security either positively or negatively: *economic factors* (e.g., income and overall living expenses), *physical factors* (e.g., different disabilities, ill health and low household standard with poor household facilities), *political factors* (e.g., governmental policies and welfare support systems) and *socio-cultural factors* (e.g., skills and knowledge in nutrition and cooking, household composition and social networks) (Gorton, et al., 2010).

It is well-established that food insecurity is not always a threat of not having access to enough food, but can be related to overweight and obesity (Townsend, Peerson, Love, Achterberg & Murphy, 2001; Ulijaszek, 2007). Ulijaszek (2007) points out that the relation between obesity and food insecurity is the negative effects of health that obesity causes. He means that increased obesity in the industrialised nations where food security is assured at the population level can be explained by several factors: convenience, with increased industrialisation of food production people access food easily; economics, while more energy-dense food costs less the prices of fruit and vegetables have increased in price, and despite this, physical activity among the population in industrialised nations has decreased (Ulijaszek, 2007). Ulijaszek suggests that the above mentioned factors can cause positive energy balance (i.e. the calories you take in is greater than the calories expended) with weight gain as a result. Still, Townsend, Peerson, Love, Achterberg and Murphy (2001) assert that overweight is connected with not always having control over access to food, i.e. people are sometimes forced into temporarily involuntary food restrictions because of external influences, and tend to eat more when they have access to food.

The diversity of food insecurity and its consequences are crucial when human health and well-being are of central interest. For people with intellectual disability, the level of disabilities determines the level of support (ADA report, 2004). Still the needs of people with intellectual disabilities are not always recognised or treated (Bryan, Allan & Russell, 2000; Cooper, Melville, & Morrison, 2004).

Food is also an agent for constructing meaning in everyday life, i.e. we choose food that is culturally acceptable to us (Menell, Murcott, & van Otterloo, 1992). The food people choose to eat is related to their culture (Fischler, 1988). The socialisation of food is an ongoing process throughout a person's entire lifespan (Beardsworth, & Keil, 1997). In society meals are considered both as food events and as social events, where eating and drinking together with other people are controlled by cultural and social codes (Sobal, 2000). Commensality, defined as sharing a food event with others (Sobal, 2000), appears usually among individuals belonging to the same social group (Grignon, 2001). The social meaning of food and the need of sharing a meal with others seem to be elementary for people, because the missing commensality during a meal is often substituted with something else (e.g., watching TV) (Sobal, 2000, Holm, 2001; Mestdag, 2005). Sobal (2000) maintains that for many researchers a meal is not considered as a meal, but only as an eating event if the food is eaten alone. To avoid loneliness over meals at home people living in a single household sometimes compensate the missing commensality by sharing the meals with friends or meeting other single people in organised meeting places such as cafés or clubs (Grignon, 2001; Sobal, & Nelson, 2003). Breakfast seems to be a food event that people in general accept to eat alone and do not miss the company of others (Kjærnes, Pipping Ekström, Gronow, Holm, & Mäkelä, 2001; Sobal, & Nelson, 2003; Mestdag, 2005)

Dietary recommendations

Many countries have dietary recommendations as part of their national health policies. The objective of these recommendations is to give adequate dietary advice to the population. In Sweden, the recommendations are valid for healthy groups of people and therefore general, but when necessary specified for different gender and age groups (Nordic council of Ministers, 2004). The Swedish recommendations include advice about the sufficient intake of essential nutrients and the meal pattern, the need of a varied and balanced diet, intake restrictions for certain food items and the importance of physical activity. For energy intake, reference values are given instead of recommendations of specific energy intake levels. This is done because an adequate energy intake for a person is related to that person's actual energy expenditure, i.e. there should be a balance between the intake level and the

expenditure level. Because these kinds of recommendations are directed to the population in general, it is necessary to stress that people with special conditions and needs might require adapted food composition. People with intellectual disabilities do not have any special dietary recommendations as a group, but many have additional conditions and impairments that can be a reason for special recommendations. An example of when special attention and adapted food composition are needed is when a person has continuous involuntary movements and increased muscle tone, which people with cerebral pares have and therefore are in greater need of energy (Johnson, Goran, Ferrara, & Poehlman, 1996). For an average person the easiest way to meet the recommendations is to have a varied and balanced diet (Bruce, 2000).

Research question

As discussed above, people with intellectual disabilities are a heterogeneous and vulnerable group. In many countries their living conditions have changed considerably. Previously, many of them lived a regulated life in institutions, but today they are mostly offered a life in a community setting, with the intention to let them live like other people in society, which includes an individual life with possibilities to participate and influence the everyday decisions in their lives. Parallel with these changes, changes in their health status have been noticed: for example, underweight, overweight and obesity are more usual among this group today than for the previous generation and for the population in general. Because all these changes have occurred in countries with established food security at the community level, we should recognise it as a problem that needs to be examined in more detail at both a community and individual level.

Aims

The overall purpose of this thesis is to examine and describe food, eating and meals in the everyday life among people with intellectual disabilities living in community residences.

The specific aims are:

- To describe the dietary habits of individuals with intellectual disabilities living in community residences, focusing on intake of food, energy and nutrients as well as meal patterns (Paper I).
- To describe how foodwork is performed in different social contexts in community settings involving staff, people with intellectual disabilities or both. Dietary intake in the main meals (i.e. lunch and dinner) in relation to foodwork practice will also be studied (Paper II).
- To gain an understanding of commensality among people with intellectual disabilities living in community-based settings in Sweden (i.e. in supported living and in group homes), to observe social eating patterns in these settings and to determine what implications such patterns may have for an individual's everyday life in relation to food and meals (Paper III).
- To examine the everyday life of two persons with intellectual disabilities (one who is obese and one who is underweight) and the everyday support they receive with respect to food, eating and meals (Paper IV).

Methods

This thesis has its starting point in a personal pre-understanding of the everyday life of people with intellectual disabilities and on academic education in food. The self experienced, by working within it, social organisation supporting people in need with food was seen as problematic in several ways, but without having documented it. The “empathy and insight” that Patton (2002) discusses will develop from contact with the people interviewed and observed during fieldwork had thus began before the actual scientific documentation on the topic. This exploratory study did not approach the problem from a theoretical standpoint other than that a particular phenomenon was to be studied and understood, i.e. “*verstehen*”. Patton writes,

The *Verstehen* tradition stresses understanding that focuses on the meaning of human behaviour, the context of social interaction, an empathic understanding based on personal experience, and the connections between mental states and behavior. The tradition of *Verstehen* places emphasis on the human capacity to know and understand others through emphatic introspection and reflection based on direct observation of and interaction with people (Patton, 2002, p. 52).

Still, during the research process several theoretical concepts were sought after in the scientific literature in order to better understand the phenomenon under study.

This approach to the research field largely depends on qualitative data, which is why an observational approach was chosen for the present research. However, since food and nutrition were part of the phenomenon to be understood, quantitative data needed to be collected. Thus, the methods used are observational in combination with assisted food records.

The study was carried out in one of the largest municipalities in Sweden. Totally, 421 adults with intellectual disabilities were living in 71 community residences at the time the study was conducted. Approximately 30 participants were deemed a sufficient number of people to be included in the study. In the end, 32 persons participated.

The observational approach (Patton, 2002) and assisted food records (Gibson, 2005) are both time-consuming methods, but were chosen because they allow the collection of first-hand information. People with intellectual disabilities are often represented by significant others (Biklen, & Mosley, 1988; Tøssebro, 1998) because most of them are *illiterate* and some are non-

verbal and thus cannot participate in studies that employ questionnaires or interviews (Tøssebro, 1998). Questionnaires and interviews are methods that otherwise are commonly used in research about food habits. When food records are used as a method, the records are usually taken care of by the study participants themselves (Gibson, 2005). Because people with intellectual disabilities most often need assistance with food records (Humphries, Traci, & Seekins, 2009) (the circumstances for the project offered this assistance), food records and participant observations were seen as suitable methods to give first-hand information about dietary food intake and social eating patterns in different contexts. All data were collected from December 2003 to July 2005.

Study participants and the recruitment process

The study participants were recruited using a mix of convenience and snow-ball sampling (Patton, 2002; Bryman, 2008). The recruitment process began in October 2003 and ended in May 2005. The intention was to recruit people with intellectual disabilities living in group homes or supported living. However, it was not possible to influence how many individuals would come from each of these settings; nor was it possible to influence the number of individuals on such variables as age, gender and level of disability because of practical and ethical reasons. The community residences for people with intellectual disabilities are non-public settings and to get access to these kinds of settings the researcher needs to obtain permission (Bryman, 2008). Further, it was important to find participants that could cope with a researcher following them during the day, recording their food intake and participating in their everyday life for three days, as well as to assure that the everyday life of the co-residents of the participants was going to be interrupted as little as possible by the presence of the researcher. The recruiting process was done in several steps. To obtain access to the community residences the study needed to be accepted on different levels in the administration of the municipality (Figure 2). Thus, the project was first introduced to the supervisor of the administration of care and education and to the manager of community residences for adults with intellectual disabilities. Following their approval of the study, the leaders of the residential services were contacted. These leaders received information about the project and could separately or together with the staff make their judgments to recommend individuals who would be suitable to participate in the study. Finally, after receiving the information, each recommended individual decided whether to participate: 2 participants were able to make the decision themselves, 18 made it jointly with their trustees and for 14 the trustees alone made the decision because the participants were not able to make it themselves. Totally 34 participants participated in the study (15 women and 19 men) and 32 completed the study

(14 women and 18 men). The distribution between the genders corresponds rather well to the overall distribution of gender in the latest Swedish statistics (National Board of Health and Welfare, 2010). A guarantee was given to all participants that they could terminate their participation from the study at any time. Therefore, two participants (both lived in a group home), who seemed to be troubled during the first day of the study, were dropped from the study after consulting with them and the staff in the group homes. The age of the participants ranged from 26-66 years (mean age 36 years). The participants were not chosen based on their diagnoses, which were not known to the research group.

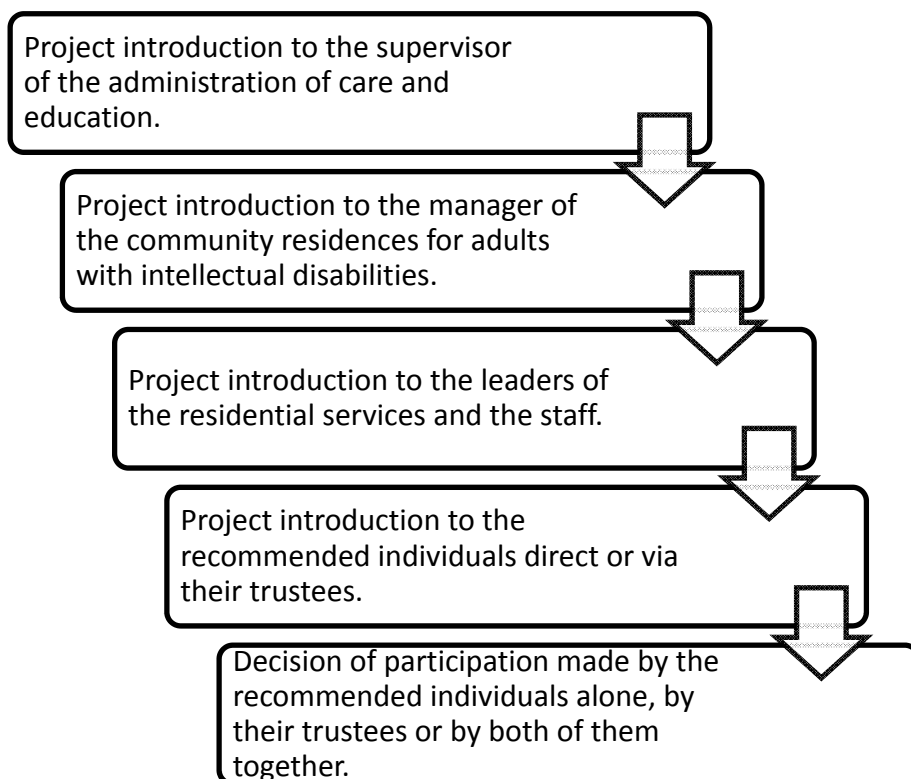


Figure 2. The recruitment process

The extreme or deviant case sampling method was used to choose participants for Paper IV (Patton, 2002): two participants (the most overweight and the most underweight) were purposefully selected from the main project's 32 individuals (14 women and 18 men). Both of these persons were women.

Living conditions and household arrangements of participants

The majority of the participants (n=23) lived in *group homes* while the rest (n=9) lived in *supported living* (for more information see Table 1). Of the participants who lived in group homes 16 had completely equipped apartments, 4 more had own apartments, but did not have kitchens in use (of whom two used the facilities for storing personal items and two did not have any kitchen facilities at all). Three participants living in group homes had only a room of their own without private kitchen facilities at their disposal. The participants living in supported living had fully equipped kitchens (Figure 3).

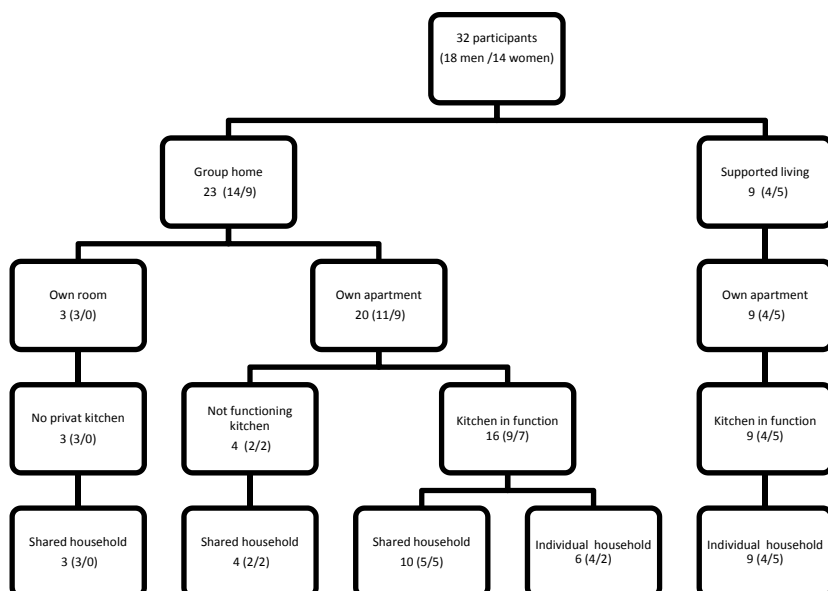


Figure 3. The participants' living conditions.

The participants could also be characterised from the dimension of household arrangements. One kind of household was an *individual household* (15 of the participants 6 living in group homes and 9 in supported living had this arrangement). The foodwork in the individual household was done usually only for the owner of the household and the food in the household was his or her private food. The other kind of household was a *shared household* (17 participants all living in group homes had this arrangement). In a residence where the residents lived in the shared household, the foodwork was usually directed to all members of the household at the same time; the food in the shared household was common for all household members and they shared the costs for the food.

All participants had daily contact/communication with the staff for support; five of the participants needed support with eating.

Data collection

Observations (II-IV)

The type of research strategy used in collecting the data cannot be defined as “participant observation”, according to the anthropological tradition, where the participant observer would be expected to spend a minimal of six months in the field (Patton, 2002). Recent research within the field of caring sciences and health observations where the researcher follows for several days in a specific context is often referred to as participant observation (e.g., Kayser-Jones, & Pengilly, 1999; Ringsby Jansson, 2002; Mattsson Sydner, & Fjellström, 2006; James, Andershed, Gustavsson, & Ternestedt, 2010). Further, in this study participant observation has been used not only as an overall description of the researcher following the study participants during a certain period, but also how the researcher participates in the everyday life of the participants for a limited time. Still, even though the observations for each individual were limited to three days, the organisation as such was observed for a longer period (in total three months, which is why participant observation could be justified as a definition of the research method used in this thesis).

Furthermore, the role of the observer was partial, i.e. the observer only participated in some activities surrounding food. It was an overt observation in the sense that everybody knew why the observations were done (and who made them). In addition, an explanation of the purpose of the investigation had been given to everyone (Patton, 2002). The observations were not broadly focused, but instead focussed specifically on food, eating and meals in everyday life.

Observations in which the researcher acts as a participant facilitate the study of ongoing phenomena (i.e. everyday activities in food eating and meals) from an inductive and discovery-oriented perspective (Patton, 2002). Further, the method allows the researcher to establish personal contact with the participants, which increases understanding of the interaction between the actors in the field (Patton, 2002). Using the method of participant observation, the observer could take part in the everyday life of each participant. Thus the observations were made openly and candidly. As state previously each participant were observed over three days. To cover all meals from early morning to the evening the observations were typically done between 12 and 17 hours per day. In order to include possible variations in the participants’ eating patterns the goal was to observe during two weekdays and on one day during a weekend or holiday. The days for observation were chosen so that they were convenient for each participant. The planned structure, however, was not desirable for three participants and therefore two were observed on three ordinary weekdays and one on three holidays. These kinds of adjustments were needed because the observer had to negotiate access to the research field. Because the observations were made openly, the character

of the observer varied, depending on circumstances, from passive to active. Because the observer assisted with the food records during the meals, the presence of the observer in the field could be classified as natural (Bryman, 2008). Before the observation period took place, contact was taken with the residences and all the main details of the procedure were decided with the participants or with the staff of the residence.

The observations mainly took place in the kitchens of the apartments, in the kitchen area in the bases, in the kitchen area or lunchrooms at daily activity centres and in restaurants, as well as at the grocery store when the participants went shopping. Observations focused on both the persons with intellectual disabilities and the supportive staff. Handwritten notes were made first in short-form and later these notes were developed in an electronic file on a portable computer. Field notes contained descriptions of what happened and of some of the short verbal communications that occurred between the study participants and other people (Patton, 2002). Notes were taken on how activities (such as planning, purchasing, cooking and tidying up after the meals) were accomplished. The eating occasions were also noted, as was the way in which the meals were arranged and who took part in the meals.

Of the participants, 16 lived in the same residence as one or several of the other participants. Thus, for those who had the same schedule on a given day and who had a shared household, it was possible to study two participants during the same observation day. This occurred nine times.

Assisted food records (I, II, IV)

When an individual's food intake is studied with assisted food records, a kind of weighed food records, it entails that everything the person eats during a pre-established time is weighed and recorded (Gibson, 2005). The participants themselves usually manage weighed records by providing them with instructions on how to use portable kitchen scale and document the food they eat. If for any reason, participants cannot manage this task, it is suitable that somebody else assists with the procedure (Bingham, Cassidy, Cole, Welch, Runswick, Black, Thurnham, Bates, Khaw, Key, & Day, 1995). Several participants in this study were not able to manage keeping food records. It was also regarded as uncertain if the staff supporting them had time to carry out the food records because they usually worked in groups and therefore supported several individuals at the same time. Thus, the participants were assisted to carry out the food records during the three-day observation period.

All food, dietary supplements and leftovers were weighed on an ordinary kitchen scale. The time for the eating occasion and the designation of the food were recorded. In a few situations these had to be estimated (e.g., if a participant or the staff acted quickly without considering weighing before eating/feeding or before disposing the leftovers or in the event food intake

happened unexpectedly). The participants and the staff were asked to report any unexpected food intake before and after observation hours.

Anthropometric methods and records of physical activities (I; IV)

Total body weight and height of the majority of the participants' were measured without shoes and with light clothes on during the observation days. The data for six persons who needed special equipment for measuring were taken from recent health control documentation made by healthcare professionals at the habilitation centre. The staff at the respective residences supplied this information.

During the three days of observation, the author registered the participants' physical activities in a diary every 15 minutes for about 14 hours per day. The participants or the staff were asked to estimate the physical activities for the rest of the day (Paper I).

Data analysis

Different eating occasions were defined according to the amount of food and the time of day. These definitions were used to analyse the distribution of the food items and energy over a single day in Papers I, II and IV and to describe the commensality among the study population in Papers III and IV. Breakfast was the first eating occasion of the day. Lunch was an eating occasion in the middle of the day (after 10.30 am and before 2.30 pm). To be classified as lunch the eating occasion had to consist of prepared hot food or a substantial quantity of cold food. Dinner was a similar eating occasion, but occurred later on in the day (after 3.45 pm). All other food consumption was defined as in-between meal consumption. Adjustments to these definitions were made if participants or staff used the terms differently. For example, if a participant's first eating occasion on a given day was during the coffee break at the daily activity centre at nine o'clock and he or she did not call it breakfast, it was defined as in-between-meal consumption.

Observations, field notes and the theoretical concepts

In Papers II, III and IV the field notes were analysed using a hermeneutic process, i.e. to understand and interpret the field notes (Patton, 2002). In the beginning of the analysis the field notes were read through before a coding plan was designed. Each of the three studies had a different focus. For studies II and III, different code trees were developed. In the next step of the analysis, sorting was accomplished using MAXqda2 software, a computerised programme used in qualitative research (Verbi software Berlin, 2004).

In Paper II, the focus was on *foodwork* in the sense described by Bove et al. (2003): planning menus, shopping for food and preparation of meals. The main interest of Paper II was directed to the participants' activities and where and how activities were done. The field notes were read repeatedly, focusing on situations concerning planning, shopping and cooking (e.g., who participated in the activities, where and how these activities took place). The text segments of the field notes were interpreted in relation to the participants' possibilities to influence and participate. All authors of Paper II read the field notes and agreed with and took part in the analysis.

Focus in Paper III was the eating occasions: who took part, where these eating occasions took place and the nature of the situation. The sorted field notes were then used in analysis and interpretation in order to identify the theoretical concepts of commensality developed by Grignon (2001) and Sobal (2000). The shared meals were categorised using Grignon's (2001) three paired types of commensality.

Domestic commensality	–	Institutional commensality
Segregative commensality	–	Transgressional commensality
Everyday commensality	–	Exceptional commensality

Here, domestic commensality was defined as shared meals in the participant's home, which could be either the individual living area or the common eating area. Institutional commensality was defined as sharing meals in the facilities for daily activities. Segregative commensality was defined as a meal situation in which the staff did not share food with the participants, but could sit by the table during the meal. Transgressional commensality was defined as meals at which the staff shared both food and table with the participants. Everyday commensality was defined as meals eaten both at home and at the daily activity centre. Exceptional commensality was defined as meals shared with friends, family members, birthday meals, or, for example, meals eaten outside the home in public restaurants. Sobal's (2000) concept of "units, circles and partners" was sought for in the data. All authors of Paper III read the field notes and agreed with and took part in the analysis.

A quantitative (categorical) data analysis was done in Paper III to establish the total number of meals eaten alone or as a communal activity. The analysis was made with manual calculations based on the data analysed using content analysis. The calculations were made of the number of meals for each person that were eaten alone or in the presence of other people during each of the three observation days. The number of meals eaten in the presence of others divided by the total number of meals was defined as commensality frequency. Moreover, the percentage of occurrences of the different kinds of commensality in the communal meals was calculated.

Paper IV had focus on the everyday practice of food, eating and meals of the two persons (i.e. the most overweight person and the most underweight person) specifically chosen for the study. The field notes were repeatedly read through and subsequently condensed to a narrative for each individual to obtain an in-depth description of the person in relation to the purpose of the study. All the authors then read the field notes and the narratives for both individuals to assure that all relevant data were included.

Assisted food records (I, II, IV)

The food records (Papers I, II and IV) were analysed using a dietary calculation software MATs (Nordin, 1997) based on the official Swedish food composition database that at time of the analysis included about 2000 food items (National Food Administration 2007). The items that were not included in the database as dietary supplements and some food products were coded as similar products or were added to the computer programme based on data collected from producers of the food items. The software was applied to calculate each participant's energy intake and intake of the selected nutrients. The presented levels of sucrose (Papers I and II) included only added sugar and excluded the sucrose from fruits and vegetables. The descriptive statistical analysis was performed with Windows Minitab Version 15. The data were presented as mean \pm standard deviation (\pm SD), as well as ranges for some of the variables.

In Paper I, the food items were categorised in food groups according to the Swedish food composition database and in agreement with the food item categorisation in a national study of dietary habits done in Sweden (National Food Administration; Becker & Pearson, 2002). Energy density was calculated for the whole diet, except water, coffee, tea and soft drinks (Ledikwe, Blanck, Kettel Kahn, Serdula, Seymour, Tohill, & Rolls, 2005). The Nordic Nutrition Recommendations (Nordic council of Ministers, 2004) were used as a comparison regarding the participants' observed meal patterns and their intake of micronutrients and dietary fibre, as well as proportions of macronutrients in their food intake. For micronutrients, the average requirement (AR) was used as a reference value. For vitamin D and calcium, which are not given an AR, the lower level of intake (LI) was used. These are the reference values that, instead of the dietary recommendation, should be used in dietary surveys according to The Nordic Nutrition Recommendations (Nordic council of Ministers, 2004). Because the guiding values may differ depending on gender and age, all participants have been compared with the AR and LI values as determined by their age and gender. For the participants' intake of dietary fibre, the lowest level of recommended daily intake for adults (i.e. 25 g per day) was used. To examine how participants' total intake of fruit and vegetable matched the national recommendations of the total intake, only those items included in the national recommendations were used. Thus, pota-

toes were not included and only 100g juices as maximum were included (National Food Administration, 2004).

In Paper II, information from food records about the ingredients used in meals was used to compare the nutritional impact of the different kinds of foodwork. Meals chosen for this comparison were lunch and dinner, commonly regarded as the most extensive meals of the day and that needed most preparation compared with the other daily meals. The study objects were the ingredients used in these particular meals and the mean values of energy, ascorbic acid, saturated fat and added sugar in the meals. The mean values of energy, ascorbic acid, saturated fat and added sugar in the lunch and dinner meals from the analysis with MATs in relation to the recommended intake were analysed.

In Paper IV, the food records were used to depict the meal pattern of the participants by showing the distribution of the energy intake over the day. The proportions of macronutrients in participants' observed dietary intake were calculated and discussed for some specific meal or type of meal, as well as to compare these proportions with the Nordic Nutrition Recommendations (Nordic Council of Ministers, 2004).

Anthropometric method and records of physical activities

Information of the participants' total body weight and body height was used to calculate their BMI and their estimate basal metabolic rate (BMR_{est}). BMR_{est} was calculated using the Schofield equation (Schofield 1985). Each participant's daily physical activity level (PAL_{obs}) was assessed based on the diary and a nine-level scale (METs) (Bouchard, Tremblay, Leblanc, Lortie, Savard, & Theriault, 1983). The food intake level (FIL), a ratio between energy intake (EI) and BMR_{est} , was calculated and compared with PAL_{obs} . Similar values were observed between FIL and PAL, indicating good agreement in energy intake and expenditure; FIL also yields information about how valid the observed intake is (Johansson, Åkesson, Berglund, Nermell, & Vahter, 1998). The calculations of BMI for the group are shown in Table 2.

Table 2. The distribution of the BMI for the study group according to the WHO classification (WHO, 2000).

	BMI according to the WHO classification	All (N=32) Average 26	Men (N=18) Average 25	Women (N=14) Average 29
Underweight	<18.5	4 (13 %)	2	2
Normal weight	18.5-25	12 (38 %)	8	4
Overweight	25-30	7 (22 %)	5	2
Obese	30>	9 (28 %)	3	6

Ethical considerations

Studies about the living conditions of people with intellectual disabilities should not be prevented by the difficulties in informing the participants about the study procedure and in finding methods to carry out the studies (Harris, 2006; Tøssebro, 1998). The trustees for all but one participant were informed. The decision about who should be giving the informed consent (the individual in question or his or her trustee) was the trustees'. Informed consents were obtained verbally. Participation in the study was voluntary and the participants could at any time and without giving any reason, terminate their participation.

The data were recorded in such a way that they could not be linked to the participants (anonymous data). Because random numbers were used in identifying the participants, their identities cannot be associated in any way with the data. In Paper IV, pseudonym names were used to protect the identity of the participants and information that could identify them was not included.

The study was approved by The Regional Ethical Review Board in Uppsala.

Findings

Observed dietary intake in adults with intellectual disability living in the community (I)

Paper I described the dietary habits of the participants. In particular, the study examined meal patterns and intake of food, energy and nutrients. The participants' energy intake varied between 4.9 and 14.0 MJ/day and the mean intake of macronutrients matched the suggested distribution in current recommendations (Nordic council of Ministers, 2004) (Table 4). As seen in Table 4, the daily eating occasion that contributed most energy for the majority of the participants was either lunch or dinner, but for nine of the participants in-between-meal consumption contributed more energy than any of the other meals. Participants' meal patterns were regular, with at least one daily hot meal. Most of the participants consumed breakfast on a daily basis. On average, the physical activity level was low for the entire study group (Table 3).

Table 3. Participants' physical activity level and total daily energy intake, the percentage of energy intake from different macronutrients and energy distribution from the daily meals.

	Mean	SD	Range	Median
Total energy intake MJ	8.9	2.2	4.9-14.0	8.6
Protein (E %) ¹	15	2.6	11-21	14
Fat (E %) ¹	31	6.3	13-40	33
Carbohydrate (E %) ¹	53	6.7	40-73	52
The distribution of daily energy from breakfast (%) ²	20	8.2	1-35	21
The distribution of daily energy from lunch (%) ²	27	7.3	11-41	28
The distribution of daily energy from dinner (%) ²	27	6.9	13-43	27
The distribution of daily energy from in-between-meals (%) ²	26	10.9	7-56	27
PALobs ³	1.4	0.12	1.2-1.6	1.4

¹ E % = per cent of total energy intake. A recommended level for E % according to the Nordic Nutrition Recommendations for Protein is 10-20 E% for fat 30E% and for carbohydrates 50-60 E% (NNR 2004).

² The recommended energy distribution from different meals is for breakfast, 20-25 %; for lunch, 25-35 %; for dinner 25-35%; and for in-between-meals, 5-30% (NNR 2004).

³ PALobs the physical activity based on observations of the physical activities for each participant

The food groups that contributed most energy were milk products, bread, meat products and buns and cakes. All participants consumed bread (mostly for breakfast or in between-meals) and all participants except one consumed vegetables and milk products during the three observation days. Seventeen of the 32 participants had a daily consumption of vegetables and fruit below 250 grams and only 7 had a consumption that was above 500 grams, which is the national recommendation in Sweden. Vegetables were often consumed at meals and a fruit in between-meals. Fruit consumption was generally lower than vegetable consumption. Consumption of sweets and crisps was low, the majority consumed buns and cakes. Water, lemonade and other juices as cold drinks at meals were more usual than milk and soft drinks.

For eight of the 32 participants, intake levels of all the studied micronutrients were above the level of AR and these participants intake level of dietary fibre was above the daily recommended intake requirement. The tendency was that those participants with a daily consumption of vegetables and fruit above 500 g had an adequate intake of micronutrients, as well as an adequate intake of dietary fibre. The micronutrients that were most common to have intake levels below the AR were retinol, thiamine, riboflavin, folic acid, iron and selenium. For those micronutrients, 19-34 % of the participants showed an intake level below AR. All the participants (n=17) that had a daily consumption of fruit and vegetable below 250 grams had an inadequate (below the recommended 25 grams) daily intake of dietary fibre. The results also showed that the participants who had an intake level of riboflavin and thiamine below AR of these micronutrients consumed soft drinks, lemonade or water as mealtime beverages rather than milk. Those participants (n=6) who had an inadequate intake of at least four micronutrients as well as an intake of dietary fibre below 25 grams per day had either normal weight (n=4) or underweight (n=2). Furthermore, the results showed that those six participants that had used dietary supplements, such as vitamin supplements, nutrition enrichment in food or supplemental nutrition instead of food, had at least one micronutrient or fibre intake below the AR, even when the contribution from supplements was included.

Foodwork among people with intellectual disabilities and dietary implications depending on staff involvement (II)

Paper II described how staff or people with intellectual disabilities, or both performed foodwork in different social contexts. Dietary intake at lunch and dinner in relation to foodwork practice was also studied. Foodwork arrangement in different social contexts resulted in different foodwork practices that could be distinguished as follows: (a) foodwork by oneself for oneself, (b) foodwork in cooperation with staff, (c) foodwork disciplined by staff and (d)

foodwork by staff. For some participants, only one kind of foodwork practice was found. However, for most of the participants, two or more foodwork practices were common depending on circumstances. Thus, the participants' possibilities to influence and participate varied depending on the foodwork practice and social context. The food items and dishes chosen and used for lunch and dinner differed depending on what foodwork practice was performed, which, in turn, affected nutrient intake.

The practice of *Foodwork by oneself for oneself* was characterised by the participants doing the work themselves with little or no staff involvement. Few participants used this foodwork practice regularly significant for them was that they had individual households, however other participants also used this practice, but to a minor extent. *Foodwork in cooperation with staff* was portrayed as two-way communication that gave the participants an opportunity to both participate in and influence the foodwork. This practice was more common for participants with an individual household than for those who shared a household with other residents. For participants who share a household, the easiest way to extend their possibilities to cooperate with staff was if they did not share food with others, which was rather common for breakfast or snacks. *Foodwork disciplined by staff* was practiced staff controlled the whole foodwork process and the participants were expected to do as they were told. For some participants, it appeared as positive support and the only way to take part in foodwork, but for others it seemed to be a barrier because they did not want to participate in the foodwork situation or the foodwork did not work out as they had expected it to do. *Foodwork by staff* entailed foodwork situations in which only staff made decisions and carried out the practical work. The participants with this type of foodwork arrangement were those requiring a great deal of support and care.

The meals for the participants resulted in different foodwork practices. To determine whether the different practices led to differences in dietary intake the food that was eaten for lunch and dinner for all participants during the three observation days was analysed in relation to the four practices of foodwork. This analysis included (a) meals prepared from fresh ingredients, from semi-convenience products or ready prepared meals, (b) fruits and vegetables in a meal and (c) the nutrient components in the meals, which included mean intake of energy, ascorbic acid, saturated fat and added sugar.

The types of ingredient used in the preparation of the main meals were found to differ across the different foodwork practices. Whereas the amounts of fresh ingredients tended to be more usual in meals that the staff members were involved in, the foodwork done "by oneself for oneself" meant more frequent use of ready prepared meals than meals prepared with the other three foodwork practices. Moreover, the intake of fresh fruits and vegetables was lowest from the meals that the staff members were not involved in (i.e. foodwork for oneself by oneself), but also rather low from meals produced by the foodwork "disciplined by staff" compared with the meals prepared

with the other two practices of foodwork (i.e. foodwork in cooperation with staff and foodwork by staff). The highest intake of fruit and vegetables were from meals produced with foodwork in cooperation with staff.

The mean intake of energy, ascorbic acid, saturated fat and added sugar in each main meal was compared with the Nordic Nutrition Recommendations (Nordic Council of Ministers, 2004). The average intake of these nutritional components was similar from the different foodwork practices. It was only the intake of saturated fat from the meals with the foodwork practice “disciplined by staff” and the intake of energy from the meals with the foodwork practice “foodwork by staff” that were not in accordance with recommendations. Intake of added sugar was generally low, but highest in meals from the foodwork practice “foodwork by oneself for oneself”. This foodwork practice also had the lowest intake of ascorbic acid even though it followed recommendations.

Social aspects of eating events among people with intellectual disability in community living (III)

Paper III examined social eating patterns in supported living and group homes for people with intellectual disabilities using the theoretical concept of commensality (sharing food and meals with other people). In the study 521 eating events (i.e. meals and snacks) were observed among the 32 participants. The calculation of the frequency of commensality showed that lunches and food eaten in between meals (snacks) were more often shared with others, whereas breakfasts and dinners were meals most often eaten alone. Meals were more often consumed alone at home for those with supported living. In the group homes individuals would sometimes eat alone, but they were less likely to eat several consecutive meals alone over the course of one or several days.

Overall, the participants shared a majority of their meals with other people, mostly with intellectual disabilities and staff. When looking at the distribution of the meals in the three paired types of commensality (c.f. p. 31), it was found that domestic commensality was most common at breakfast and dinner, whereas institutional commensality was most common during the lunch meal and the snacks during between meals in the morning and afternoon, and mostly eaten at the daily activity centre. Segregative commensality appeared mostly on meals eaten in the participant’s home, whereas transgressional commensality was most common at the meals in the daily activity centre. Most meals could be characterised with everyday commensality. Meals characterised with exceptional commensality were generally rare. In all, nine meals (five lunches, one dinner and three between meal snacks) were eaten in public restaurants.

To eat alone meant that the participants did not belong to a *commensal unit* – “those sharing a particular meal” – which could be exemplified by persons who share food and table at work every day. When the staff at the residence were present at meals, it mainly entailed a physical presence and only rarely involved the sharing of food or meals. However, when other people with intellectual disabilities were present, usually they shared food and meals and were thus part of the same commensal unit. The participants considered eating together as important, a view supported by the staff’s comment that the residents expressed a desire to share food and meals with one another. It was obvious that staff support was important in establishing commensality and commensal circles in the participants’ everyday life. The residents greatly appreciated cooking and baking together with the staff and then inviting friends, other residents, to a meal.

Yet, it was common for the residents to declare that they preferred to eat alone. Wanting to eat alone was prompted by problems associated with the meal situation and other fellow residents making a disturbance. In addition to *avoiding commensality as a personal choice*, it was observed that the staff refused some of the residents’ *commensality*. Staff did so of several reasons, e.g., if a resident was seen as too noisy or too inclined to disturb dining companions. If residents did not abide by the rules established by the staff, it could result in solitary eating. According to the personnel, rules surrounding meals were important to help organise the daily work. Staff in some residences declined to share meals with the residents or even using the same plates and utensils as the residents; however, the reason for this attitude was not clear. In addition rules set up by the municipality resulted in solitary eating among the people with intellectual disabilities that participated in this study.

Food and meals in the everyday life of individuals with intellectual disabilities – a case study (IV)

Paper IV examined everyday lives of two persons (one obese and one underweight), Amanda and Doris, and their support in everyday practices with regard to food, eating and meals.

Amanda was a 45-year-old woman with a BMI of 48. In addition to her obesity, she had profound vision impairment and an injured knee that limited her activities. Amanda had a first floor apartment with a kitchen and two rooms in supported living. Her daily energy intake on days 1, 2 and 3 was 7.4, 9.2 and 7.7 MJ, respectively. Basic directives that the staff had decided on were aimed at helping her lose weight, which she had accepted. The directives considerably influenced her meal outcomes, whereas her wishes and opinions played a subordinate role. According to these directives, her lunch included a staple food that was rich in carbohydrates, but this staple food

was not included in the dinner meal. To keep the content of fat and carbohydrates as low as possible in her diet, she was ordered to consume mostly fruits and carrots between the main meals. However, the consumption of fruits and carrots contributed her daily energy intake of carbohydrates to be rather high (66 E%). According to the current nutrition recommendations, carbohydrates should contribute with 50-60 E% of the daily energy intake (Nordic Council of Ministers, 2004). Not all of the staff personnel strictly followed the directives and Amanda also tried to undermine the directives whenever she could. The residential conditions offered some social contact during certain meals that, on occasion, gave her the possibility to share with her co-residents. However, the basic directives forced her to refrain from the food that others in her company ate sometimes. Thus, taking part in a meal or a party did not always mean that she connected socially with others; instead, she seemed to experience isolation and loneliness. Amanda expressed that she wanted to spend time in the base in order to be in the company of other people, which helped her to avoid thinking of food constantly

Doris was a 51-year-old woman with a BMI of 16. Because Doris had severe disabilities, dysphagia and spasticity and was nonverbal, she required support for all of her everyday activities. The staff had to understand and interpret her signs to communicate with her and in this way discover her basic needs and wishes. Her apartment was located in a group home for five residents. It was planned that when the particular group home was built the residents would share the household and that all cooking was going to be done in the kitchen of the base dining facility. In Doris apartment the area that was intended to be her private kitchen was used as a storing room for her wheelchair and for her special physical training equipment. Her daily energy intake was 5.8, 5.8 and 7.1 MJ during days 1, 2 and 3, respectively, of the observation period. The menu plans concerning Doris were primarily made to suit the skills of the staff. Her meals were not experienced as social activities, although she ate all her meals in the base dining facility in the presence of other people. The staff had different feeding approaches, and discussions about how to feed Doris were conducted among the staff members. Her meal pattern was irregular. For instance, sometimes she ate nearly every hour, whereas at other times she did not eat anything from 6 to 7 hours in the daytime to over 13 hours in the night hours. The needs of Doris were adapted to the needs of the other residents and to the circumstances (e.g., working schedule and skills of the staff). However, coincidental reasons, such as the staff forgetting to order specific food items from the grocery store or incorrect delivery from the crockery store could also affect her diet.

Discussion

The main purpose of this thesis was to examine and describe the food, eating and meals in the everyday life among people with intellectual disabilities in community residences in Sweden. The findings presented in four papers at the group and individual level have raised the question of whether people with intellectual disabilities in community living are food secured, using Germovs and Williams (2008) definition, “*food security is the availability of affordable, nutritious and culturally acceptable food for each and every individual*” (p. 406). In the context of this thesis the dimensions nutritious and culturally acceptable food will be discussed, as well as the problems and dilemmas that may be a hindrance in attaining these two dimensions of the food security concept.

Food security and nutritious food

The findings on dietary intake among the participants on the *group level* indicated food security in general, where the participants were found to have a regular meal pattern and a varied diet, which is also recommended (Nordic council of Ministers, 2004). On the group level, all food groups were represented and the group had a sufficient intake of all micronutrients, although the intake of dietary fibre was low (Paper I). A varied and balanced diet has been established as important for food security and therefore central for good health and well-being (Jaron, & Galal, 2009).

Although food security was determined on a group level, it does not automatically mean that all members of the group are food secured (Pinstrup-Andersen, 2009), as was clearly demonstrated in the present findings. The anthropometric measurements (in this study BMI) showed that many of the participants were obese, overweight or underweight indicating food insecurity on an *individual level* (Pinstrup-Andersen, 2009). Another indication on the individual level was the inadequate intake of micronutrients, an adequate intake of micronutrients is important for food security (Jaron & Galal, 2009). Interestingly, several of the participants with the lowest intake of micronutrients were people with normal weight. Their condition of food insecurity was not revealed through the measurement of BMI. Thus, using BMI as a general health measurement is inadequate, even though it is often used to determine the physical health of people with intellectual disabilities (Rimmer, & Yamaki,

2006; Marshall et al., 2003; Hove 2004; Bhaumik et al., 2008; Melville et al., 2008). However, based on the present study, BMI as a sole measurement of general health did not reveal the risks of other nutritional problems. When food security is also judged, those persons that do not have any problems with their weight should be included. Therefore, in addition to BMI, nutritional aspects should be included in the future in the special set of health indicators that has been established for people with intellectual disabilities within the European region (van Schrojenstein, Lantman-de Valk, Linehan, Kerr, & Noonan-Walsh, 2007). According to van Schrojenstein et al., the basis for the development of this set was the health indicators for the European community. This set of health indicators for the general population includes elements of nutrition (Kramers, 2003). Elements of nutrition should also be necessary for the special set of health indicators for people with intellectual disabilities, especially since several studies have shown that at times some have an unbalanced dietary intake and eat selectively (Gravestock, 2003; Robertson et al., 2000; Hove, 2007; Position of the American Dietetic Association, 2010).

It is well-known that people with intellectual disabilities are a vulnerable group in society. Because of their special needs, society must take basic responsibility for their health and well-being (National Board of Health and Welfare, 2009) by offering them support and care when needed. However, the support they are offered in Sweden, according to the current legislation, should be based on respect of an individual's right to self-determination (SFS 1993:387). Papers II, III and IV, showed that this is not always achieved in practice and that certain organisational interests may override an individual's right to self-determination. The majority of the study participants were to some extent dependent on support for food, eating and meals. Yet, many of the participants in supported living had only minor daily contacts with the staff, which resulted in problems related to food and meals. It was shown that foodwork (planning menus, shopping for food and preparing meals) in the participants everyday life could be achieved in different ways. However, possibilities for self-determination were seen in relation to the foodwork practices *foodwork by oneself for oneself* or *foodwork in co-operation with staff*; both of these practices were far more common among participants with individual households. These participants were therefore more involved in foodwork and received more individual solutions than the participants who shared a household. Although self-determination could be achieved and the individual could make choices either independently or with support from the staff, there were indications that the practice that entailed co-operation between the person with intellectual disabilities and staff resulted in a more favourable dietary intake. This more favourable dietary intake in the *foodwork in co-operation with staff* was manifested in the use of more fruit and vegetables in the menu and more frequent use of fresh ingredients than in the *foodwork by oneself for oneself*. This difference may be explained using Harris' (2003) argument that people with intellectual disabilities need social support from

professionals and staff to help them when choosing among several alternatives. The author specifies that before making a choice the consequences of different choices need to be considered. Moreover, Jenkinson (1993) points out that because people with intellectual disabilities are similar to people in the general population, they want (and need) to play an integral part in the everyday decisions of their life, including decisions related to eating. Both Jenkinson (1993) and Harris (2003) have noted that to have the opportunity to make choices in everyday life is important among for people with intellectual disabilities in determining their own course of action. This view indicates that two-way communication between an individual and staff is preferred rather than letting persons with intellectual disabilities making a decision entirely on their own. Advantages of two-way communication were observed in the present study regarding foodwork practices. Jenkinson (1993) and Harris (2003) also found that environmental factors (e.g., being part of a group) can be a hindrance when it comes to making individual choices. Such a hindrance was observed in the present study when *foodwork disciplined by staff* and *foodwork by staff* were practiced.

In Paper II there was a tendency indicating that foodwork practices with involvement of staff increased the use of fresh ingredients at meals and that the meals included more fruit and vegetables. However, the finding in Paper II showed that there was no guarantee of a favourable dietary intake even when the staff made all the decisions concerning food, eating and meals. This finding was discussed further in Paper IV, where it was suggested the staff members do not always understand the relationship between food choice and nutrition, or the consequences of certain decisions regarding eating and meal situations.

Traditionally, in institutions food and nutrition were not the direct responsibility of the staff in the residences; rather, this responsibility was in the hands of trained professionals that cooked the meals in central kitchens. Because of the changes in the living conditions of people with intellectual disabilities, today the staff members working in community residences are expected to have the necessary skills and knowledge in food and nutrition. However, there is no assurance that today's staff are trained and educated in these areas as were their skilled predecessors. Harrington and Honda (1986) wrote nearly 25 years ago, that the work that staff in community residences do has not been recognised and that relevant education for various tasks is sorely needed. Humphries, Traci and Seekins (2004) have pointed to shortcomings in knowledge and skills in food and nutrition among staff personnel who support people with intellectual disabilities. These authors found that the staff established nutritional goals and made decisions about the residents' food without having nutritional skills or consulting health professionals, which resulted in an unhealthy diet for the residents. However, the results of Humphries, Traci and Seekins (2004) indicate that the staff seemed to have a genuine interest and were positive in receiving counselling in food and nutrition.

In Sweden, staff members who support people with intellectual disabilities in their everyday life are expected to deal with food-related tasks. They are required to have general knowledge about food and beverages and, if necessary, obtain additional knowledge from other professionals. Staff should also have the competence to prepare meals, take into account the special needs of a specific individual and help with eating and drinking if required (National Board of Health and Welfare, 2006). According to a report by the National Board of Health and Welfare (2006), many staff personnel nowadays have temporary employment and lack formal training in the profession. It should be noted, however, that formal training does not include any special courses in food and nutrition (National Agency of Education, 2001 pp. 38-40). Moreover, to work as staff personnel in community residences formal training is not always considered necessary. Rather sufficient competence in the profession can be acquired by in-work learning or with a combination of formal training and in-work learning (National Board of Health and Welfare, 2006). Thus, a support system of nutritional counselling and education is necessary to provide staff personnel with adequate knowledge and skills to manage all problems related to food, eating and meals, as well as to increase the food security of people with intellectual disabilities. Some parallels can be drawn between people with intellectual disabilities and old people in the sense that both belong to the category of vulnerable people that require support and care. Mamhidir (2006) studied nutrition of old people in sheltered housing and concluded that efforts are needed to educate staff in nutritional issues because without adequate education staff do not have sufficient skills to notice or treat the nutritional problems of old people. She recommends greater co-operation between the staff and other professionals in multi-professional teams, a view similar to that of Humphries, Traci and Seekins (2004), who suggested there is a need to educate staff personnel working with people with intellectual disabilities in food and nutrition.

However, counselling in nutritional issues is a part of the support system for people with intellectual disabilities in Sweden, but counselling is directed to the needs of an individual with intellectual disabilities (SFS 1993:387), rather than giving general counselling to staff personnel. Because the most frequently asked issues concerning counselling are information about nutrition and advice about physical activities and weight check-ups made by a nurse or a dietician at the habilitation centre (Umb-Carlsson, 2008), special efforts are needed to make the nutrition counselling more effective, including training of staff. Moreover, as discussed in Sweden and elsewhere, professionals involved in health counselling require more knowledge about people with intellectual disabilities and their living conditions (Kozma & Mason, 2003; ADA-report, 2004; Gustavson et al., 2005; Position of the American Dietetic Association, 2010).

Food security and culturally accepted food

As Fischler (1988) and Menell et al. (1998) have proposed, human beings learn from an early age the meaning of food. People also learn what kinds of food and meals are acceptable in their culture. Consequently, culturally accepted foods involve shared ways of thinking about a deeply rooted phenomenon in a group or culture that has developed over generations and in different contexts. By doing this, certain values and norms will have developed related not only to what is acceptable food but also different practices, including how to eat and behave, how to prepare food and present meals. Thus, planning menus, shopping for food, preparing meals, eating and sharing food and meals are incorporated in a person's everyday life and connected to various aspects of life, such as norms, behaviours and taste. These aspects are what define what culturally acceptable food is to every individual. Food security can therefore be difficult to attain if an individual does not culturally accept the food. According to Pinstrup-Andersen (2009), this should be understood and referred to as an individual or a household's preferences of commonly used everyday food, and not exceptional or extravagant food. As seen in Papers II and IV, the decisions as to what to eat for the study participants were often made by staff (staff also assisted with the foodwork). They decided the content of the menus and the daily food preparations and thus had the final decision on what food would be served to an individual in the residences. Therefore, it is uncertain how much an individual's private preferences can influence his or her food-related activities when support is given to a group and not to the individual (Papers II and IV). In those cases in which the individual made his or her own decision, the culturally accepted food often did not include nutritious food, which was yet another problem in relation to self-determination and food security.

In the process of de-institutionalisation (Mansell, 2006) follows the ideology of individualisation. The food service in earlier institutions with specially employed staff in central kitchens (Svensson, 1995; Mallander, 1999) has been replaced by a general understanding that an individual with intellectual disabilities takes part in the activities related to food as much as possible while still having access to the support he or she wishes or needs (National Board of Health and Welfare, 2007). According to Beck (1992) and Warde (1997), people in general are expected to act individually, which has resulted in changes in traditional boundaries and regulations in society (Beck, 1992; Warde, 1997). Beck claims that today each person is taught to live individually, with "him or herself as the centre of the action" (Beck, 1992 p 135). Warde (1997) therefore believes that such changes have influenced the household organisation and the divergence of information that people receive from experts and media about what has become suitable to eat and that this process has had effects on individualisation in food practices. Mestdag and Glorieux (2009) agree with Warde in their study of the

changes in commensal patterns in Belgium over time. In their paper the authors argue that access to convenient food has facilitated the individualisation of food consumption in society. They believe food has become easy to manage also for people without special skills in this area (Mestdag & Glorieux, 2009). The increased selection of convenient food in the market has most likely influenced the food habits of people with intellectual disabilities too. In the present study some of the participants could manage their foodwork individually, often because of the possibilities that convenient food gave them (Paper II). However, as seen from earlier studies the choice of convenient food was made when the person did not have any other reasonable solutions at the moment, and not necessarily because the person preferred that food (Mallander, 1999; Ringsby Jansson, 2002; Olin, 2003). If the convenient food can be a way to increase independence and individualisation of a person, the food, however, needs to be in accordance with the food preferences of the individual. Furthermore, the food needs to be in accordance with the required nutrients in order to guarantee his or her food security in all aspects.

Yet, Warde (1997) also calls attention to the fact that today individualisation is not always something that is obvious for people. Limited individualisation can occur in a household in which the members of the household are dependent on the person responsible for the foodwork. In the present study it was not typically only one person who took care of the foodwork: the most common situation was that there was a staff group that managed this task according to their prearranged schedule. Consequently, the food served in a residence could be suited to the skills and preferences of a staff person taking care of the foodwork at the moment, rather than chosen with the residents' preferences in mind (Paper IV). When the food is chosen under such conditions, this can create another kind of problem in relation to food security, namely that while people with intellectual disabilities are entitled to support that gives them the right to influence their everyday activities, staff personnel do not have sufficient skills to meet these needs and expectations. Most studies in which problems related to food and cultural aspects within a social organisation have been associated with older people. Mattson Sydner and Fjellström (2006) discussed, for example, the importance of everyday rituals and rules associated with culinary rules, i.e. culturally accepted food and customs within elderly care and that staff members working with older people were largely unaware of this phenomenon. Sidenvall, Fjellström and Ek (1996) discussed what problems occur when old people move into geriatric care. One problem was that the old people experienced a different meal culture than the one they were familiar with previously. This change could have serious consequences for their social and nutritional well-being, which made Sidenvall et al. (1996) conclude that the staff should be more sensitive to the conditions and needs of old people. This thinking, of course, could be

extended to people with intellectual disabilities. This is especially true when establishing food security from the perspective of culturally acceptable food.

One dimension of food security and culturally acceptable food is the social dimension. Commensality could be experienced in different ways among the participants in this study; however, it was common for the participants to eat breakfast alone, but those with an individual household could eat all their meals at home without the company of other residents or staff (Paper III). Breakfast is the meal that is the most commonly accepted meal to be eaten alone in Western society, whereas dinner is more customary to be shared with other people (Kjærnes et al., 2001; Sobal & Nelson, 2003; Mestdag, 2005). However, dinner in the present study was, after breakfast, the meal most often eaten alone, and although several participants desired commensality, they ate their meals in the absence of others. It turned out that these participants represented those persons who lived more independently (Papers II and III). Yet, there were also those in a shared household that were left to eat independently, rather than preferred independent eating, which once again illustrates Warde's (1997) discussion of a person in authority limiting the individualisation of others in a household.

As seen in Paper III, shared daily meals were arranged in the base of the residence, and not in the residents' private apartment. According to the manual of residence practices for caregivers (National Board of Health and Welfare, 2007), the base of a residence should be used to arrange social activities for people living in a residence to increase their social interactions; the purpose of these activities should not be to rationalise the support. Moreover, even though to share a meal with others is highly appreciated by many, not all people feel this way. Accordingly, some caution needs to be taken at mealtimes when persons with special problems (e.g., dysphagia) are involved. These persons might require a calm environment to make it easier for them to focus on eating and to avoid choking (Sheppard, 1991; Kayser-Jones & Pengilly, 1999; Chadwick, Jolliffe, Goldbart & Burton, 2006). Such an environment would help in achieving food security for these individuals. Although these people require a relaxed and quiet environment when they eat, it does not mean that they do not enjoy the company of others during other activities (Chadwick et al., 2006; Balandin, Hemsley, Hanley, & Sheppard, 2009).

Commensality is culturally desired by many; however, for the residents in this study, the possibility for such arrangements was not always supported by the social organisation. Gorton, Bullen and Mhurchu (2010) found in their literature review that household composition could influence food security in different ways. They pointed out that risks could be found within large households, similar to what was found in paper IV, i.e. individual needs were overlooked in favour of the needs of the group. However, Gorton, Bullen and Mhurchu (2010) also found risks for food insecurity in single households, findings in agreement with that of McIntosh and Kubena (2003).

McIntosh and Kubena (2003) studied food insecurity in old people, finding that there is a connection between nutritional health and social support. It seems that people are more motivated to cook when they share meals with others (McIntosh & Kubena, 2003). Because individuals with intellectual disabilities do not form a homogeneous group, it is paramount that studies on people with intellectual disabilities are conducted on the individual level.

On a group level, food security has been shown not to be a major problem among people with intellectual disabilities. However, on an individual level this issue is far more problematic and can be explained by several factors connected to the social organisation studied in this thesis. First, persons with intellectual disabilities are a heterogeneous group that are in need of varying support ranging from very minimal support to full support. However every person should be offered individual support, which is especially important when an individual's needs and preferences are not possible to compromise. As it stands now, there is a dichotomy between the group and the individual, with the individual in the shadows of the group, making the individual at risk for food insecurity. These risks of food insecurity are not always considered in the everyday life of the individual. Contributing to this is the lack of knowledge among staff that may result in individuals being provided with an inadequate dietary intake or limited self-determination, or both. In the present study several of the participants with the lowest intake of micronutrients were those with normal weight. This observation shows that it is insufficient to use only BMI as an instrument to determine general health. BMI is not infallible; yet, it is used in the special set of health indicators that has been established for people with intellectual disabilities. Nutritional aspects are important components of health and hence need to be included in a set of health indicators in order to facilitate the early discovery of health defects and allow earlier actions for the improvement of health.

Methodological considerations

Using the method participant observation allowed the researcher to get close to the participants in the field. In addition using assisted food records as the reference method allowed to obtain first-hand information (Patton, 2002; Bryman, 2008). Although the study group was small, at the time of the study it included approximately 7% of adults with intellectual disabilities living in community residences in the municipality under investigation. However, caution should be exercised because the study group was chosen from only one municipality. Consequently, the problems that have occurred in this context could have been different if the study had been done in another municipality or if the participants were from several municipalities. Therefore, generalising the findings from one setting to another is questionable (Graneheim & Lundman, 2004; Patton, 2002). Observations *in which the research-*

er was a participant in the everyday life of the people that participated in the study made it possible to avoid second-hand information, which was especially good because many were illiterate and some were even non-verbal (Biklen & Mosley, 1988; Tøssebro, 1998). Participant observation allows the researcher to establish personal contact with the participants, which, in turn, facilitates the researcher's understanding of the interaction between the actors in the field and to work inductively (Patton, 2002). It is also easier to do the study inductively with first-hand information that gives an understanding of certain situations that might not have been revealed in a more structured setting. In contrast to interviews the researcher has a better opportunity to get more information because in interviews it is not certain that participants remember everything or they may not report things they feel are not meaningful to the purpose of the study. Moreover, certain matters can be sensitive and difficult to discuss in an interview (Patton, 2002). The method of participant observation also facilitates collecting similar information from participants who belong to a heterogeneous group, such as people with intellectual disabilities.

To choose the *assisted food records* as a complement to participant observation was rather natural in that there are several barriers for people with intellectual disabilities to collect such records on their own (Humphries, Traci & Seekins, 2009). By assisting with the records, the researcher played a natural part during the meals without actually taking part in them.

Recruitment of participants followed ethical procedures and was thus in the hands of people within the community organisation. Confidentiality policies made random selection impossible, a fate felt by other researchers who have allocated similar populations (Draheim, Stanish, Williams & McCubbin, 2007). The population of adults with intellectual disabilities is generally a heterogeneous group, with different types of disability and with participants of varying age and gender (Harris, 2006). Thus, the results of this thesis, which included participants with a wide range of BMI and energy intake from different kinds of households with varying solutions for foodwork that resulted in different choices of food items and diverse solutions for meal arrangements, may provide a relatively adequate picture of the general mix of adults with intellectual disabilities living in similar conditions. Still, because of the heterogeneity and the small size of the group, these results cannot be generalised. However, the collection of data using several methods provides a possibility to link the context of support and living situations of the participants to their diet and gives a fuller understanding of the participants' living situation.

When *analysing the data*, the presence of the researcher must be taken into consideration, i.e. awareness must be given to the potential effects the researcher could have on the behaviour of those being observed. Because of the large number of hours of observations conducted in this study the results could be seen as trustworthy in the context described.

The observation period was limited to 3 days. However, to observe adults with intellectual disabilities for additional days was not considered possible. This limited observation period has surely had consequences on the comprehensiveness of the data. In addition, it probably excluded information on special social events, such as birthdays, holidays and feasts and thereby affected the findings on the distribution of participants eating alone or together with staff and other people.

Although the descriptions of the dietary habits mainly focused on food items and meal patterns, nutrient intake was also described. A weight food record is considered as the most precise method available for estimation of food and nutrient intake (Bingham et al., 1995). Thus, more than 3 days would have certainly increased the precision of the nutrient intake estimates. However, as previously mentioned, to be with the participants more than 3 days was not considered feasible. However, all records were performed by the same person and not by the participants themselves. Thus, precision in the recording of food was probably very high in the present study. Moreover, the generally good agreement between FIL and PAL_{obs}, was most likely a result of the assisted food records and that collection was made by the same independent observer. In the dietary calculations presented in Paper II the number of meals prepared with the different practices was unequal; therefore the purpose of the illustration was only to show tendencies, consequently the interpretations should be made with caution. In the case study (Paper IV) other kinds of illustrations from food data records were made. These illustrations were also based on unequal data and show only tendencies of the dietary intake for the participants.

To achieve good inter-coder agreement all authors were included in the analysis process in the different papers. This method of analysis, which is a strength of the thesis, is described in detail elsewhere (Bryman, 2008).

The present study has not focused on such factors as level of intellectual disabilities, additional disabilities and gender, although these factors are known to be important variables when examining food and nutrition among people with intellectual disabilities (e.g., Rimmer & Yamaki, 2006; Hove, 2004). Gender is particularly important to study because in a previous study in Sweden it was shown that persons with intellectual disabilities in community settings are commonly treated as gender neutral (Umb-Carlsson & Sonnander, 2006). Thus future studies need to address these factors in order to gain a more complete understanding of food security in vulnerable groups.

Conclusions

The activities surrounding food and its consumption are central to the everyday life of most people, including individuals with intellectual disabilities. In this context the following findings are especially relevant:

There was considerable variation in energy intake among the study participants, but all participants showed a similar meal pattern.

The intake of vegetables and fruits was generally low.

The intake of several micronutrients was below the average requirement for almost one-third of the participants and the intake of dietary fibre was generally low in the whole study group.

Both underweight individuals and persons with normal bodyweight were among those who had low intake levels of several micronutrients. The results thus demonstrate that all members of this heterogeneous group should be regarded as individuals with unique nutritional needs.

The findings indicate that an individual's dietary intake may be influenced by how the foodwork is specifically organised for this person.

An individual's possibility to influence and participate in food and meals largely depends on the different foodwork practices. Individual solutions increase the possibility to influence food-related activities.

The findings reveal that sharing of meals (commensality) among people with intellectual disabilities is dependent on support from other people.

The participants were part of more than one commensal unit; yet, these units typically consisted of staff members and other people with intellectual disability. Only rarely did people from outside this social organisation, such as family and friends, constitute a commensal unit.

Individuals who lived a relatively independent life were more likely to eat alone, either voluntarily or involuntarily.

To guarantee food security for persons belonging to a heterogeneous group, actions need to be taken to ensure that the support they are offered meet their individual needs and maximise their potentials in the least restrictive way.

Some reflections for the future

For good living conditions, food security needs to be assured among people with intellectual disabilities. Therefore, more emphasis must be given to the everyday activities surrounding food.

Individualised support in food is required in order that, meals function to fulfil the individual's needs regarding not only basic nutrition but also social and cultural aspects.

People with intellectual disabilities who are independent should be provided continuous educational support and dialogue sessions about food and nutrition.

People with intellectual disabilities should be supported by a staff sufficiently knowledgeable in food and nutrition.

Professionals (such as dietitians) need to be a regular part of the supporting organisation in order to have a dialogue and co-operate with each individual. For this, they need knowledge about and insights into the social organisation for people with intellectual disabilities.

Nutritional aspects are important components of health and therefore must be included (in addition to BMI) in the European set of health indicators for people with intellectual disabilities.

More studies on the individual level are required. People with intellectual disabilities are generally treated as gender neutral, but important differences in health between the genders have been reported in the literature. Thus the gender perspective has to be recognised in future studies on food, eating and meals and the relationship between food security and poor health among people with intellectual disabilities.

Swedish summary – Sammanfattning på svenska

Personer med utvecklingsstörning är en mycket heterogen grupp, med olika grad av begränsad intellektuell förmåga och ofta även andra funktionsnedsättningar. Därmed finns också ett varierat behov av stöd och hjälp i vardagslivet. Målet idag är att personer med utvecklingsstörning ska leva som andra människor, varför institutionsboendet övergetts till förmån för boende i kommunal regi, dvs. en avinstitutionalisering. Deras liv ska utmärkas av individualisering och självbestämmande och det legala stödet finns i lagen om stöd för vissa funktionshinder (LSS). Enligt lagen har de rätt till en rad olika stödåtgärder från samhällets sida. Ett sådant stöd är rätten till egen bostad, LSS-bostad, där service och omvårdnad ges av en personalgrupp. Det finns huvudsakligen två olika alternativ, lägenhet i en gruppboende eller en servicelägenhet. Alla ska ha tillgång till gemensamma utrymmen, där de boende i en bostadsgrupp ska erbjudas samvaro och service. Även i andra länder i västvärlden skapas numera förutsättningar för personer med utvecklingsstörning att leva ute i samhället. Det har visat sig att förändringarna i vardagslivet har haft negativa effekter för hälsan i denna heterogena grupp, till exempel har antal fall med under- och överviktiga ökat bland dem och är mer frekventa än hos övriga befolkningen.

Syftet med min studie har varit att undersöka och beskriva matrelaterade aktiviteter för personer som bor i LSS-bostäder. I studien ingick 32 män och kvinnor. Deltagande observationer och assisterade vägda kostregistreringar användes som huvudsakliga metoder, men även deltagarnas längd och vikt dokumenterades för BMI-beräkning, även deras fysiska aktivitet registrerades.

I den första delstudien undersöktes matvanor, ätande och måltider gällande livsmedelsgrupper, energi och näringsintag, samt måltidsmönster. Deltagarnas näringsintag varierade från 4,9-14,0 MJ. Viktigaste energikällorna var i flertalet fall mjölk-, bröd- och köttprodukter men deltagarnas energiintag var också högt från bullar, kakor, saft och läsk. Ett fåtal hade det rekommenderade dagliga intaget på 500 g från frukt och grönsaker, intaget av kostfibrer var lågt för mer än hälften av deltagarna och för en tredjedel var intaget av flera mikronäringsämnen otillfredsställande. De personer som använde kosttillskott hade trots detta för lågt intag av minst ett vitamin eller mineral, eller kostfiber. De deltagare som hade för lågt intag av fyra eller flera mik-

ronäringsämnen och kostfibrer var antingen under- eller normalviktiga. Resultatet visade vikten av att även normalviktiga personer bör betraktas som personer med särskilda behov när det gäller kost och näring och att var och en bör behandlas utifrån sina individuella behov.

I den andra delstudien undersöktes hur det matrelaterade arbetet var organiserat för deltagarna. Fyra olika praxis kunde konstateras. Den första praxisen innebar att individen skötte arbetet själv och var vanligast för personer som var självständiga och hade ett individuellt hushåll. Vid måltiderna lagade enligt denna praxis förekom färre färska ingredienser och mer färdiglagade rätter och maten innehöll mindre C vitamin, men mera socker än måltiderna lagade enligt övriga praxis. Nästa praxis innebar att individen samarbetade med personalen. Denna praxis var vanligare för personer som hade individuellt hushåll, men förekom även för personer som delade hushållet med andra. När måltider lagades med denna praxis var användningen av halvfabrikat vanlig och grönsaker och frukt förekom oftare än vid de övriga fallen vilket förmodligen var anledningen till att innehållet av C-vitamin var högst från dessa måltider. I nästkommande praxis styrde personalen det matrelaterade arbetet och talade om vad som skulle göras och individerna gjorde som de blev tillsagda. Denna praxis var den minst vanliga. Måltiderna som var resultat av den innehöll mest färska ingredienser och minst färdiga rätter, och både energiinnehållet och innehållet av mättat fett var högst från dessa måltider. Den fjärde praxisen, som innebar att personalen skötte allt, var mest vanlig och förkom framför allt för individer som saknade fysiska möjligheter att delta själv i det matrelaterade arbetet eller saknade intresse. Utmärkande för den var att användningen av halvfabrikat var lägst, medan energiinnehållet från måltiderna var lågt, och innehållet av både C-vitamin och av frukt och grönt var relativt högt.

I den tredje delstudien undersöktes sociala aspekter på ätande, dvs. att dela mat och måltider. Generellt kunde konstateras att frukost och middagar oftast äts utan sällskap. Lunch och mellanmål var vanligt att äta tillsammans med andra, oftast med personer från det egna boendet eller från den dagliga verksamheten. De som hade individuellt hushåll intog oftast måltiderna i enskildhet. Deltagarna hade olika önskemål, några som vanligen åt ensamma saknade någon att dela måltiden med, medan andra som hade möjlighet till gemensamma måltider kunde känna sig störda av sällskapet och ville helst äta ensamma. Vissa ville dela måltiden med andra, men fick inte för personalen, eftersom de störde andra. Personalen vid de dagliga verksamheterna deltog vanligtvis i måltiderna där, men boendepersonal deltog däremot sällan i måltiderna även om dessa organiserades gemensamt. Att förverkliga önskingar om gemenskap vid måltider, eller att komma samman för att exempelvis laga mat eller baka, berodde i stor utsträckning på personalens stöd. De sociala nätverken kring måltiderna utgjordes främst av andra personer med utvecklingsstörning eller personal. Vänner och släktingar förekom mera sällan vid måltiderna.

I den fjärde delstudien var fokus riktat mot två enskilda individer från studiegruppens 32 deltagare, nämligen mot den som hade det högsta och den som hade det lägst BMI-värdet, vilka båda var kvinnor. Personen med ett högt BMI (48) hade ett individuellt hushåll. Personalen hade satt upp regler för att hjälpa henne att gå ner i vikt. Enligt reglerna skulle hennes mat innehålla lite kolhydrater och fett, men mycket frukt och grönsaker, få extravaganser var tillåtna och hon skulle motionera varje dag. Personalens arbetssätt varierade och de tillämpade reglerna olika. Den andra personen hade lågt BMI (16) var spastisk, hade sväljsvårigheter och behövde mycket stöd. Hon delade hushåll med andra i en gruppbostad. Hennes mat och måltider var anpassade till personalens färdigheter och till de andra boendes måltidsrutiner så att det blev så smidigt som möjligt för alla. Anpassningen till personal och de andra boende innebar att hennes måltidsmönster var mycket oregelbundet.

Resultaten av studien visar att för att kunna garantera att personer med utvecklingsstörning har en tryggad tillgång till mat, bör individens behov tillmötesgå. Det innebär att var och en ska ha tillgång till den mat som tillfredställer de primära näringsbehoven och måltider som motsvarar deras kulturella och sociala förväntningar. Därför bör de som är delaktiga i de matrelaterade sysslorna, om det är personen själv och/eller en personalgrupp ha tillfredställande kunskaper för att tillmötesgå detta. Vidare för att alla ska uppnå god hälsa, bör de möjligheter som att kunna erhålla rådgivningen t.ex. av en dietist, som personer med utvecklingsstörning har rätt till enligt LSS-lagen, användas även i ett mer preventivt syfte.

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