

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

Päivi Adolfsson^{a*}, Christina Fjellström^a, Barbro Lewin^b and Ylva Mattsson Sydner^a

^a*Department of Food, Nutrition and Dietetics, Uppsala University, Uppsala, Sweden;*

^b*Department of Government, Uppsala University, Uppsala, Sweden*

(Received 20 June 2009; accepted 1 July 2010)

The food provision for people with intellectual disability (ID) in Sweden is organized within their own households. The aim of this study was to describe how foodwork – planning for meals, shopping for food and cooking – is performed in different social contexts in community settings involving people with ID, staff or both. Dietary intake in the main meals in relation to foodwork practice was also studied. Four different foodwork practices could be distinguished. For some participants only one kind of foodwork practice was found, but for most of them two or more different practices. There was a tendency that food items and dishes chosen and used differed depending on what foodwork practice was performed, which, in turn, affected the nutrient intake. More attention needs to be directed to these everyday matters as a means to increase the quality of support in food for people with ID.

Keywords: community housing; foodwork; intellectual disability; dietary intake

Introduction

Providing people in need of help and care with food and meals in their everyday life involves a complex web of activities performed by the social organizations designated for this work (Mattsson Sydner and Fjellström 2007). In the public sector, provision of food or food service has been characterized as eating out by necessity (Edwards 2000). This kind of food service, marked by large-scale cooking performed by professional catering in central kitchens that deliver meals to different units at set times, is a common phenomenon at institutions. Institutional life has been criticized over the years, particularly concerning people with intellectual disabilities (ID). For people with ID, this criticism has resulted in a transition from institutional living to community living in many countries in the Western world, a transition that began in the 1960s (Mansell 2006). This process was guided by the proposal of normalization (Nirje 1969), which is based on the idea that people with ID should be supported so that they can live like other people in society. Kebbon (1997) described the transition that has occurred as a shift from planning for a group to planning for the individual. Thus, planning has become a matter of flexibility and individuality rather than uniform models. The shift has also included a focus on cooperation rather than expert control as well as on small-scale rather than large-scale planning. This process meant that people with ID were regarded as consumers who were part of their own

*Corresponding author. Email: paivi.adolfsson@ikv.uu.se

everyday food provision. As a result, large-scale cooking was phased out and daily cooking became a task for every individual with ID and his/her caregivers (Bryan, Allan, and Russell 2000; Mallander 1999). This also resulted in a shift from meals at set times with limited choice of what to eat (Young 2003) to more individual mealtime arrangements.

In the future development of community services the quality of life (QoL) among people with ID is likely to depend on the facilitative role of staff, enabling support of individuals and especially those with complex disabilities (Mansell 2006). Adult people with ID who receive help and care in the community commonly live in different kinds of residential homes inspired by a model of service provision. According to Young (2003), the focus is on service based on education and training, a service that is flexible and tailored to each individual's needs and goals. In Sweden, adult people with ID have the possibility to apply for residential services and personal support in accordance with the law (Act 1993:387), the purpose of which is to strengthen the citizenship of disabled people (Lewin 2005). The law specifically states that persons with ID have the right to their own apartment, including a high standard and kitchen facilities. In sharp contrast to institutional practice, the elements of influence and participation in society and common welfare are described as important in this new practice.

The responsible and practical arrangements to provide people with ID with support and services, including residential services of good quality, are thus in the hands of the municipalities (National Board of Health and Welfare 2009). The main residential forms that have been developed in Sweden are group homes and service apartments – the latter will henceforth be called supported living (Mansell 2006). People living in group homes usually have more extensive needs, and the group home residences typically have common facilities, with a maximum of five to six residents and staff around the clock. Supported living, which also has access to common kitchen facilities, is aimed for those who need less support. Residents in such apartments usually receive support on demand, i.e. they take contact with the available staff when they need support with something. Those living in supported living, group homes or both could physically be located in the same building (= a residence) (National Board of Health and Welfare 2009).

Empirical studies on the everyday life of people with ID have generally analyzed and described their living situation concerning the social ambition of normalization, exemplifying different ways of organizing everyday life activities. People with ID as well as other people want to have control over the small, tangible and mundane issues in everyday life (Tøssebro 1992; Mallander 1999), such as eating a meal. The focus has been on the life situation of these individuals and on how normalization has influenced their lives, but there is little knowledge about how food and meals are managed on a daily basis. According to Mallander (1999), the arrangement of everyday life activities among this population group has been changed in line with the idea of normalization, yet people with ID still need support in terms of special living conditions and from professionals, which means that staff members are still responsible for many of their everyday activities. However, the intention is to manage everyday life in cooperation with and respect for residents. The goal is that all people with ID should have the same possibilities to make choices as people without ID. Because people with ID are a highly heterogeneous group, Burton Smith, Morgan and Davidson (2005) state that individuals with mild to moderate ID have almost the

same possibilities to make choices as people without ID, whereas individuals with moderate to severe ID have more limited possibilities to make choices.

According to the American Dietetic Association, people with ID form a vulnerable group with disparate problems in relation to nutrition (ADA 2004), which is why they recommend that people with ID should be provided with interdisciplinary nutritional services during their entire life span in their individual living environment (Position of the American Dietetic Association, 2010). Thus far, most research has focused on problems related to being overweight or underweight. Jolly and Jamieson (1999) concluded that people with ID living in the community in the UK have a wide range of nutritional problems and that these problems need to be identified. They also stressed the carer's role in relation to food, giving an example of how some staff personnel taking care of underweight persons expressed that an increase in residents' weight could make lifting of residents more difficult. At the same time, other staff personnel, taking care of people who needed weight reduction, expressed how this would affect the social pleasure of eating. In Melville and others' (2007) review of obesity in adults with ID one area of interest is the individual's living arrangements. They concluded that people living in restrictive environments (such as group homes or institutions) commonly have a lower body mass index (BMI) than people living independently or in family homes.

It is therefore important to understand how foodwork practice among a heterogeneous group of people with ID is managed today in a community setting. We use the term foodwork in the sense described by Bove, Sobal and Raushenbach (2003): planning menus, shopping for food and preparation of meals. The goal of normalization, which is guided by the notions of influence and participation, has to be put into practice by staff personnel everyday in their work with and for people with ID (as well as in relation to foodwork). These everyday activities have to be carried out with consideration to nutritional and health aspects, such as choosing, preparing and serving optimal foods when dealing with obesity, underweight and other nutritional problems. Yet, we know little about how this is done in the everyday life of people with ID.

The aim of the present study is therefore to describe how foodwork is performed in different social contexts in community settings involving staff, people with ID or both. Dietary intake in main meals (i.e. lunch and dinner) in relation to foodwork practice will also be studied.

Methods

The present study is based on participant observations and assisted food records of 32 individuals with ID living in community settings in a municipality in Sweden. These methods are time-consuming, but were chosen to obtain first-hand information on relevant data. People with ID are often represented by significant others (Biklen and Mosley 1988; Tøssebro 1998) because most of them are illiterate and some are non-verbal and thus unable to speak for themselves and participate in studies using questionnaires or interviews (Tøssebro 1998) that are commonly used in this kind of research otherwise.

The method of participant observation allows the researcher to establish personal contact with the participants, which allows understanding of the interaction between the actors in the field, as well as to work inductively (Patton 2002). The results from the participant observations that were directed to the social aspects on meals are

reported elsewhere (Adolfsson, Mattsson Sydner, and Fjellström, forthcoming). Main results from the assisted food records describing individual dietary habits, focusing on food and meal patterns as well as on energy and nutrients have been reported earlier (Adolfsson et al. 2008).

The Regional Ethics Review Board in Uppsala approved the study.

Participants

The 32 participants were recruited using a mix of convenience sampling and snowball sampling (Patton 2002; Bryman 2008). We aimed at recruiting people with ID living in both group homes and supported living but could not influence how many individuals would come from each of these settings; nor could we influence the number of individuals regarding age, gender and level of disability because of practical and ethical reasons. The community residences for people with ID 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 not going to be interrupted by the presence of the researcher. The recruiting process was made 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. 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 ID. Following their approval of the study, the leaders of the residential services were contacted. The leaders received information about the project and could themselves or together with the staff group make their judgements to recommend individuals who would be suitable to participate in the study. Finally, after receiving the information, each recommended individual decided whether to participate: two participants were able to make the decision themselves, 16 made it jointly with their trustees and for 14 their trustees made the decision because the participants were not able to make it themselves. In all, 18 men and 14 women aged 26 to 66 years were included.

Data collection

The participant observations as well as the three-day assisted food records for all participants were made by the first author between December 2003 and July 2005. In total, every participant was observed on three separate days, typically between 12 to 17 hours a day, to cover all the meals from breakfast in the morning to the latest meal of the day. Of the 32 participants, 16 belonged to the same residence as one or several of the other participants. Thus, for those who had the same schedule on a given day and stayed at the same time in the common kitchen facilities, it was possible to study two participants during the same observation day. This occurred nine times. The observations mainly took place in the kitchen of the apartment and in the common kitchen area, as well as at the grocery store when the participants and staff were shopping. Observations were focused on both the participants and the staff who supported them. Handwritten field notes were first made in a shorter form; later, these notes were developed on a portable computer. Field notes contained

descriptions of what happened and of some short verbal communications occurring between participants and staff (Patton 2002).

The assisted food records were made in line with Gibson's description (2005), i.e. all food, dietary supplements and leftovers were weighed on an ordinary kitchen scale during the three observation days for all participants. In a few situations estimation was needed, when participants or staff forgot that food needed to be weighed.

Data analysis of field notes

The analysis of the field notes was done with a qualitative hermeneutic method (Patton 2002). The field notes were read repeatedly, focusing on situations concerning planning, shopping and cooking (e.g. who participated in the activities, where these activities took place and how). In the next step of the analysis a code-tree was developed to sort out the field notes; sorting was accomplished using the MAXqda2 software, a computerized analysis programme for qualitative data (2004). The text segments of the field notes were interpreted in relation to the participants' possibilities to influence and participate. All four authors read the field notes and took part in the analysis and interpretation in relation to the different foodwork practices that were found.

Data analysis of food records

Lunch and dinner are commonly the most extensive meals of a day and need most preparation compared with the other daily meals. Therefore, food record data were used to compare the nutritional impact of the different kinds of foodwork practices by reporting the ingredients used at these particular meals and their mean values of energy, ascorbic acid, saturated fat and added sugar. Lunch was defined as an eating occasion in the middle of the day (after 10:30 and before 14:30) if the eating occasion consisted of prepared warm food or a substantial quantity of cold food. Dinner was considered a similar eating occasion, but occurred later in the day, i.e. after 15:45. Food records were analyzed using the dietary calculation software MATs (Nordin 1997) based on the official Swedish food composition database that at the time of the analysis included about 2000 food items (National Food Administration 2007).

Results

Of the 32 participants, nine lived in supported living and 23 lived in group homes. All participants with supported living had kitchen facilities in their own apartments and the foodwork arrangement was characterized as an individual household. Most of the participants living in a group home had their own apartments and kitchen facilities but the foodwork arrangements in their households varied (Table 1). The majority of them, however, shared the household with other residents, had their meals prepared in a common kitchen and used the individual kitchen facilities to a lesser extent or not at all. Three of the participants only had a room in a group home and thus were obliged to use the common kitchen facilities.

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

Table 1. Living organization and foodwork arrangements with access to kitchen facilities in supported living and group homes.

Living organization	Supported living	Group homes (individual apartment)	Group homes (individual apartment)	Group homes (individual room)
Foodwork arrangement	Individual household	Individual household	Shared household	Shared household
Kitchen facilities in use	9	6	10	–
Kitchen facilities not in use	–	–	4	–
No kitchen facilities	–	–	–	3

(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 though which practice was used depended on the circumstances. Thus, the participants' possibilities to influence and participate varied depending on the foodwork practice and the 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.

Foodwork by oneself for oneself

Foodwork for oneself by oneself is characterized by the fact that the participants do the work by themselves with little or no involvement of staff. Of the 32 participants, 18 used this foodwork practice at least occasionally, but four of them did so regularly. They all had an individual household and managed most of their foodwork in their own kitchens. Support from staff was generally limited to a daily check-up when the staff either phoned or visited them and had only occasional support from the staff in planning meals, doing the shopping and cooking. If a staff member accompanied them to the grocery store, he/she only interfered in the participant's shopping at the request of the participant. Thus, these participants were observed to have the main influence over everyday issues concerning what, how, when and with whom to eat:

When a staff member comes to help the participant cook his dinner, the participant has already done it. The staff member looks at what the participant is going to eat – soft tortillas with salami, prawns and tomatoes and comments, 'Is this the food you are going to eat?' 'Yes', the participant answers. The staff member replies, 'Then I'm not needed anymore'. (Fieldnotes: male, 41 years, individual household)

Some participants who also did a good deal of the foodwork themselves and had individual households did not act entirely independently although the support was more theoretical than practical. In these cases the staff showed their awareness with this theoretical support by giving advice and reminding participants about things related to the foodwork process:

The participant altered the menu since he forgot to take the minced meat out of the freezer. The staff member commented that the participant changes his mind often and does not adhere to the menu. However, when the staff member found out that the participant forgot to take the food from the freezer, the staff member said it was all right to change the food on the menu. (Fieldnotes: male, 28 years, individual household)

Even participants who shared the household with other residents commonly had their own kitchen facilities, which gave them the possibility to prepare a light meal by themselves and therefore make decisions about a small, everyday matter. For example, one participant prepared simple snacks everyday in her kitchen without using the stove.

Foodwork in cooperation with staff

Foodwork in cooperation between participants and staff was portrayed as a two-way communication that gave the participants the opportunity to both participate in and influence the foodwork. This kind of foodwork was observed among 20 of the participants. Those with individual households that needed support with foodwork received individual support from the staff members. These situations often included discussions between staff and participants that allowed the possibility for the participants to impact their everyday life:

The participant and a fellow resident went to buy food and before shopping they ate lunch at a restaurant, each together with their own staff member. . . . The participant asked the staff members if one of them could help him cook mincemeat sauce one day and they promised to help him with that. (Fieldnotes: male, 27 years, individual household)

Sometimes, foodwork situations had developed into learning situations in which the staff supervised and guided the participants to help them learn to manage different kinds of tasks in daily life. Such situations could also provide an opportunity to teach a resident to make decisions to become less dependent. The staff were especially concerned about health issues, often trying to influence the individual's food choice, to regulate food intake (e.g. by reminding the participant, when they planned meals together, to vary the food eaten at meals or to take suitable portions). Foodwork in cooperation also included situations in which the staff gave participants practical hints:

The staff member visits the participant now and then and when a staff member comes to her apartment and notices that warm water is running from the tap, the staff member asks the reason for letting the water run. She says that she needs to thaw the sausage. The staff member tells her that she could try putting the sausage in warm water rather than to let the water keep running. She follows the staff member's instructions. (Fieldnotes: female, 38 years, individual household)

For participants who shared the household with other residents, the opportunities to participate in and influence foodwork were more limited. These participants generally needed a higher degree of support in their everyday life and the foodwork was mostly done for the collective. Consequently, situations that could have encouraged influence and participation were less noticeable. Still, for a number of residences with shared households, participants did not share breakfast or snacks with others, but instead received individual support, which extended the participants' opportunities to make their own decisions. When such situations did occur, the degree of influence and participation still depended on how the work between the individual participants and staff was performed:

One staff member makes the participant a sandwich with cheese. The participant places himself in front of the kitchen cupboard. When the staff member asks him if he needs help, he nods 'yes'. The staff member gives him a plate and he puts his sandwich on it and puts the plate in the microwave oven without starting it, sitting down instead. The staff member starts the oven; when the sandwich has been warmed up for him, he walks with the plate and seems pleased. He dips his finger in the cheese, feeling the consistency. He seems delighted and then sits down. (Fieldnotes: male, 33 years, shared household)

The participants' ways of expressing their needs and wishes varied across individuals, as did their ability to communicate. The staff members' ability to understand the participants was also found to vary. When the staff could interpret specific requests, they provided support that allowed even participants with more extensive needs of support to influence the situation. This kind of support facilitated the foodwork and gave the participant more time for other activities:

The staff explained that earlier it was important for the participant to buy the ingredients and prepare the breakfast by himself. Breakfast, however, was seldom ready in time and therefore he often ate very little in the mornings. Consequently, the staff decided it would be better if he did not buy and prepare his own breakfast. Instead, the staff now served him a breakfast that he has chosen. In this way, he eats more food in the morning. (Fieldnotes: male, 35 years, shared household)

Foodwork disciplined by the staff

When the staff directed foodwork, the participants were expected to do as they were told. Thirteen of the participants had this type of arrangement sometime during the observation days. In such a situation the staff controlled the whole foodwork process, including making decisions and directing activities related to planning, shopping, preparing or cooking food. Participants at all levels of function, both with individual households and those who shared the household with other residents, found themselves directed by the staff. The participants seemed to have different attitudes toward this situation. For some participants, it appeared as positive support (the only way to participate) but for others it seemed to be a barrier because they did not want to participate in the foodwork situation:

The participant is supposed to lend a hand in the kitchen today, with the task of laying the table for him and the other residents. The staff members inform him what to do all the time; otherwise, he leaves the kitchen immediately. (Fieldnotes: male, 33 year, shared household)

For other participants, these situations were more troublesome and they tried to express what they wanted through different behaviours. When a participant's opinion about food choice was in conflict with the staff's opinion, the participant could have difficulties to influence the situation. This type of conflicting situation was particularly true for participants with weight problems in that the staff tried to control the participants' food choice:

When the participant who has profound vision impairment is shopping, the staff member helps her with most of the things . . . When the staff member does not notice, she takes a package from the shelf without knowing what it is and puts it in the trolley. After asking what it is, she learns that it is a package of popcorn and she says, 'popcorn isn't so bad; you can eat it sometimes'. When the staff member notices what she has

done, the staff member tells her that she cannot buy any popcorn because there is the risk of eating too much. Further, in the common area she is sometimes offered popcorn. The staff member subsequently removes the package of popcorn from the trolley. (Fieldnotes: female, 45 years, individual household)

However, weight problems or other specific reasons for restricted influence in the everyday foodwork were not always the cause for controlling a person; sometimes the participants were controlled without an apparent reason:

The participant got up at 7:30 in the morning and asked what he wants to have for breakfast. He answered that he wanted porridge. A staff member then cooked his porridge and gave him his medication with a glass of light juice. When he started to eat the porridge, he asked if he could have a sandwich, too. The staff person told him to eat his porridge. He did not get any sandwich during breakfast and the staff member did not explain why. (Fieldnotes: male, 40 year, shared household)

Sharing a household with others implies complex situations concerning foodwork. It involves negotiations, cooperation and communication between staff, the collective and the individual. For the participants in the present study, staff could direct the foodwork so that when a situation arose that enabled a resident to influence the situation, this person could be encouraged to get involved. For example, when residents were not all present in the residence, the staff had more time to motivate those who were present to participate in foodwork. The staff could also organize the foodwork such that the residents could be part of the meal and menu planning or assist the staff in cooking meals. If participants ate their breakfast alone, though sharing all other meals with other residents, the staff could support participation in foodwork (e.g. by asking the resident to lay the table).

Still, the participants who shared a household with others were less often in situations where they could influence a food-related activity than those who had an individual household. Yet, when the participants with individual households occasionally shared a meal with others in the common area, the staff usually disciplined the foodwork for those meals as well. Thus, the situation was the same for all participants, i.e. when activities were planned for several people, individual solutions were not possible and the staff tended to control these activities. Residences usually had common rules and timetables that everyone living in the residence was expected to follow. The participants' potential to influence could be limited by the staff's time constraints and participants had to accept certain details without being asked whether they approved of them:

The staff pointed out that the reason why they minced the participant's food together with another person's food is only rational. He does not really need meat so finely minced as the other person does, but he gets his food automatically that way. (Fieldnotes: male, 32 years, shared household)

Even for those participants with an individual household, the need for support affected their foodwork because of the restricted time of the staff members who were needed at several residents' apartments at the same time. When staff members provided support in the residents' apartments, circumstances could arise that could delay the staff schedule. When this delay occurred, it had consequences for the everyday life of those particular residents without their having a possibility to influence the situation:

Because the staff member who is supposed to help did not come on time, the participant is impatient because it is past the time when she usually gets support with cooking. The participant is eager to start cooking to get the dinner ready at the usual time; otherwise, she is afraid she is going to miss a big part of the TV programme she always watches when she eats her dinner. However, she does not take any initiative to start the cooking herself. (Fieldnotes: female, 29 years, individual household)

According to the staff, the financial situation in the municipality had resulted in cutbacks in support of activities during recent years. Resources had been reduced and new solutions had been introduced that put limits on residents' influence and participation. This reduction in resources had affected the lives of the participants at all levels of functioning and in all kinds of households. For instance, individual training in cooking that had been customary in some group homes where the residents share the household was no longer possible.

Foodwork by staff

Foodwork practice when only the staff took part in decisions and performed the practical work was observed primarily among participants with extensive need of support and help in their daily lives. The participants who were in great need of support were those who shared households. It was the only kind of foodwork outcome for seven of the 32 participants, but during the observation days, this kind of foodwork practice occurred for 14 other participants. In several group homes with a shared household the staff planned the meals for the whole residence once a week. The weekly shopping was typically done during the daytime when residents were away on their daily activities. The cooking was done collectively in the common kitchen, which often is an open area that allows the residents to come and go as they please. Several participants were in the kitchen when the staff members were cooking. Participants who have mobility problems or physically disabled were placed in the kitchen because the staff believed the residents could be stimulated by being together with other people:

The participant is often sitting in the kitchen and watching when staff members are cooking. The staff members do not ask her to participate, nor does she ask to participate. (Fieldnotes: female, 30 years, shared household)

Others wanted to stay in their own apartments when the staff did the cooking and turned up only after the meal was prepared. Not all participants were interested in participating in foodwork. Participation in foodwork was difficult for those participants with physical disabilities (e.g. vision impairment or spasticity). Of the 32 participants in the study, seven had such disabilities.

Outcomes of foodwork practices – dietary intake

The meals for a participant could be the result of different kinds of foodwork practices. To determine whether the different practices led to differences in dietary intake, the food that was eaten for lunch and dinner by all participants during the three observation days was analyzed in relation to the four practices of foodwork. This analysis included: (a) meals prepared from fresh ingredients, from semi-convenience products or as ready-prepared meals; (b) if fruits and vegetables were

included 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 type of ingredients used in the preparation of the main meals was found to differ across the different foodwork practices (Table 2). There was a tendency indicating that the amounts of fresh ingredients were more usual in meals that the staff members were involved in than in meals produced by the foodwork ‘by oneself for oneself’ and were most usual when the meals were produced by the foodwork ‘disciplined by staff’. The foodwork done ‘by oneself for oneself’ meant more frequent use of ready prepared meals than meals prepared with the other three foodwork practices and the foodwork ‘disciplined by staff’ meant most seldom use of ready-prepared meals.

As seen in Table 2, the intake of fresh fruits and vegetables was lowest from the meals that the staff members were not involved in, i.e. the foodwork ‘by oneself for oneself’. However, the intake of fruits and vegetables was also rather low from meals produced by the foodwork ‘disciplined by staff’ compared with the meals prepared with the two practices of foodwork that staff members were involved in.

The mean intake of energy, ascorbic acid, saturated fat and added sugar in every main meal was compared to the Nordic Nutrition Recommendations (NNR) (Nordic Council of Ministers 2004) (Table 3). The average intake of these nutritional components did not differ much between the different foodwork practices. Only the intake of saturated fat from the meals with the foodwork practice ‘disciplined by staff’ and the intake of energy from the meals made with the foodwork practice ‘foodwork by staff’ did not follow the general recommendations. Intake of added sugar was in general not high, but highest in meals from the foodwork practice ‘by oneself for oneself’. This practice also had the lowest intake of ascorbic acid, though that intake also followed the recommendations.

Discussion

Being dependent on support with foodwork is a reality for many people with ID, where the need for support is strongly related to the level of functioning of a person. In line with the legal right to support, based on the idea of normalization (National Board of Health and Welfare 2009), new kinds of households have been established

Table 2. The usage of different types of ingredient in main meal preparation in percent of all meals in relation to foodwork practice, and the occurrence of fruits and vegetables in these meals.^a

Foodwork practice (numbers of outcomes)	Fresh ingredients	Semi-convenience products	Ready prepared meals	Fruits and vegetables
Foodwork by oneself for oneself (29)	7%	41%	59%	34%
Foodwork in cooperation with staff (30)	53%	57%	20%	73%
Foodwork disciplined by staff (15)	60%	47%	7%	40%
Foodwork by staff (112)	53%	30%	25%	68%

Note: ^aAt main meals, such as lunch and dinner.

Table 3. Intake level of energy, ascorbic acid, saturated fat and added sugar in relation to foodwork practice according to Nordic nutrition recommendations (2004).^a

Foodwork practice (numbers of outcomes)	Kcal RI ^b = 660–885 ^c	Ascorbic acid (mg) RI ^b = 22,5 ^d	Saturated fat (g) RI ^b = 7,3–9,8 ^e	Added sugar (g) RI ^b = 16,5–22 ^f
	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>	<i>Mean</i>
Foodwork by oneself for oneself (29)	689	24.2	8.8	14.7
Foodwork in cooperation with staff (30)	687	33.0	9.3	7.6
Foodwork disciplined by staff (15)	712	25.8	11.7	4.3
Foodwork by staff (112)	510	31.8	8.3	4.5

Notes: ^aAt main meals, such as lunch and dinner.

^bAll RI values (recommended daily intake) are based on NNR concerning that energy intake at meals as lunch and dinner should consist of one third of the daily energy intake (25–35% is recommended, here 30% is used).

^cRI is based on 30% of NNR reference values for energy intake needs for women 31–60 years (660 kcal) and men 18–30 years (885 kcal) with sedentary work and limited psychical activity.

^dRI is based on 30% of NNR reference values for ascorbic acid (75 mg for both women and men).

^eRI is based on 30% of NNR reference values for saturated fat, i.e. max 10% of daily energy intake.

^fRI is based on 30% of NNR reference values for added sugar, i.e. max 10% of daily energy intake.

for people with ID. To increase our knowledge of foodwork practice in these households we examined how the foodwork in different social contexts was performed in different situations for the participants of the present study and related that to their influence and participation in foodwork. We also looked for tendencies on their dietary habits that could be related to the different foodwork practices.

First, our findings suggest that having an ID is not an obstacle to practicing one's right as a citizen and consumer. Many of the persons with ID participating in the present observational study were in many ways part of planning, preparing and cooking meals. They could both participate in foodwork and influence the outcome of the foodwork in their everyday life, which meant that they could choose the food they wanted to eat on a specific day and at a specific meal, as well as in a given situation and at a specific time of day. Consequently, the shift from collective and large-scale planning to individual and small-scale planning in the organization of everyday life among people with ID, as described by Kebbon (1997), has also been implemented in relation to foodwork for them. The most obvious examples of this shift were seen when the individuals themselves performed the foodwork. In such cases they were more likely to achieve an ideal standard of living comparable to that of other citizens in society.

However, such small-scale planning and respect for an individual's wishes and needs were not something that could be taken for granted, especially not for the participants with extensive needs of support. Thus, the four kinds of foodwork practice we found could be associated with the same person, depending on the situation, interaction and communication that had developed between that person and different staff members. On one day and in one situation, a person could

participate in and influence the foodwork, whereas on another day or in another situation the staff could direct that type of activity in everyday life.

Thus, influence and participation in relation to foodwork could fluctuate for the participants from day to day and situation to situation. Still, it was more common for those who had individual households to make their own decisions about food and meals than it was for those who shared the household with other residents. In the latter case foodwork practice was characterized by rational decision-making for the collective, which limited the possibilities for the participants to influence and participate in the foodwork. When only the staff performed the foodwork, especially in the shared households, participants were more likely to be passive non-participants. This kind of institutional foodwork practice was mainly observed among the participants with an extensive need for care and support. They received stereotyped solutions because the meal plan of the staff members was to serve food that accommodated everyone. Thus, discussions on having control over small tangible issues (Tøssebro 1992; Mallander 1999) could not be fully generalized to foodwork in the everyday life of the participants because it was not a consistently reoccurring phenomenon.

How foodwork was practiced largely depended on the staff and the social organization, but also the functional level of the participant, which underlines the problematic issues of institutional life that can still be observed despite the normalization process. Ortner (1994) discussed how practice could shape a system from a theoretical anthropological perspective. She suggested that practice could either reproduce the system or change it. She also referred to Bourdieu's thoughts on the importance of routines related to this process and to how actors are shaped by underlying organizational principles in the world of public observation and discourse. Goffman (1961) presented similar ideas by stressing that the system of institutional life continues by practising restrictive collective solutions, which creates total institutions. In the current study we observed both a change in the system and the system reproducing itself. When the system changed, it had successfully applied the normalization process, which enabled people with ID to influence the foodwork practice. When the staff performed the foodwork, the system reproduced itself. In such cases (such as in total institutions) the routines associated with institutional life were predominant, which could be explained by the underlying organizational principles.

However, the intended changes in the system had important nutritional implications. Individuals who lived rather independently were more likely to consume ready-prepared meals and less likely to consume fruits and vegetables during mealtimes than were individuals who received more support. They also consumed more added sugar. Thus, the nutritional problems observed among people with ID in a study by Adolfsson and others (2008) could be partly explained by the foodwork practice 'by oneself for oneself'. Such situations would seem to present more decisions to be made independently than individuals are able to manage. They are presented with freedom of choice, but lack the ability to reflect on the health implications. Using Ortner's (1994) words, this could be described as an unintended consequence of action. The action of the normalization produced a foodwork practice that promoted influence and participation, but the action also produced an unintended consequence, namely a nutritional risk situation for people that took responsibility for their own food consumption. Here we can observe a conflict between independency and nutritional health. This observation is in line with other

studies showing that the grade of independency for people with ID has to do with problems related to being overweight (Draheim et al. 2007; Hove 2004). However, as the present results show, other kinds of nutritional risks also exist. The meals prepared with the foodwork practice ‘foodwork by staff’ resulted in an average energy intake that was below the recommended level, indicating that this foodwork practice could partly explain the nutritional problems observed in the study of Adolfsson and others (2008). Further, the meals prepared with foodwork practice ‘disciplined by staff’ resulted in an average intake of saturated fat that was beyond the recommended level, which has been identified as a health risk (WHO 2003).

Based on the present results, dietary intake seems to be more balanced when foodwork practice was characterized by two-way communication, i.e. when staff involvement was coupled with people with ID having influence over their own food and meals in everyday life as in ‘foodwork in cooperation’. Such an arrangement typically meant that most meals were prepared using fresh ingredients, including fruit and vegetables and consequently less ready prepared meals were eaten. Foodwork practice that includes both staff and individuals with ID therefore allows both of these groups to be actors and to produce routines related to their joint interest in daily meals. Thus, the facilitative role of staff in community services, particularly that which enables support of individuals that Mansell (2006) saw as important for good QoL, has been confirmed in this study.

This study with a small sample has had its focus on the foodwork and dietary intake of a group of individuals with ID that lived in one specific municipality. The sample is purposefully small to allow the use of a study design with participant observations and assisted food records. Such a study design allowed the researcher to get close to the participants in the field and obtain firsthand information (Patton 2002; Bryman 2008). On the other hand, several limitations in sampling were inevitable and the participants were not randomly selected but took part on a voluntary basis. We have shown how foodwork for them was organized and what tendencies the different foodwork practices seem to have on the dietary intake of these individuals with ID. Because the number of meals prepared with the different practices was unequal, only tendencies of what the different practices could have for dietary intake and differences between them could be established. It should be noted that the transferability of the present results to another social context might be limited (Graneheim and Lundman 2004). A strength of the present study is the combination of data that included both participant observation and assisted food records, which gives the possibility to connect the circumstances of support and living situations to the diet of the participants. Moreover, the trustworthiness of data collected close to the participants minimized second-hand information and misunderstandings. The analysis process included all authors in order to achieve intercoder agreement (Bryman 2008). However, the small sample and large variation within this heterogeneous group imply for future research regarding for example the relation between disability and need of support on the one hand and participation and influence on the other. These relations can influence dietary intake.

It is important to pay attention to the different foodwork practices among people with ID in community settings because such practices can affect, perhaps unintentionally, the individual’s opportunity to influence and participate in food and meals, as well as affect the person’s dietary intake so that normalization will be for good and not for worse. Accordingly, more attention needs to be directed toward these everyday matters. Such knowledge is not only necessary as a means to increase

the quality of support in food for people with ID but it is also important for healthcare professionals who provide counselling for them in the health services.

Acknowledgements

This study has been financially supported by Stiftelsen Sävstaholm in Sweden. The study was performed at the Department of Food, Nutrition and Dietetics, Uppsala University

References

- Act 1993:387: Concerning support and service for persons with certain functional impairments. http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/9553/2006-114-29_200611429.pdf.
- Adolfsson, P., Y. Mattsson Sydner, C. Fjellström, B. Lewin, and A. Andersson. 2008. Observed dietary intake in Adults with intellectual disability living in the community. *Food & Nutrition Research* 52. <http://journals.sfu.ca/coaction/index.php/fnr/article/view/1857/2051>.
- Adolfsson, P., Y. Mattsson Sydner, and C. Fjellström. Forthcoming. Social aspects of eating events among people with intellectual disability in community living. *Journal of Intellectual & Developmental Disability* 35, no. 4.
- American Dietetic Association. 2004. Position of the American Dietetic Association: providing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. *Journal of American Dietetic Association* 104: 97–107.
- Biklen, S.K., and C.R. Mosley. 1988. 'Are you retarded?' 'No I'm Catholic': Qualitative methods in the study of people with severe handicaps. *The Journal of the Association for People with Severe Handicaps* 13: 155–62.
- Bove, C.F., J. Sobal, and B.S. Raushenbach. 2003. Food choices among newly married couples: Convergence, conflict, individualism, and projects. *Appetite* 40: 25–40.
- Bryan, F., T. Allan, and L. Russell. 2000. The move from a long-stay learning disabilities hospital to community homes: a comparison of clients' nutritional status. *Journal of Human Nutrition and Dietetics* 13: 265–70.
- Bryman, A. 2008. *Social research methods*. 3rd ed. Oxford: Oxford University Press.
- Burton Smith, R., M. Morgan, and J. Davidson. 2005. Does the daily choice making of adults with intellectual disability meet the normalisation principle? *Journal of Intellectual & Developmental Disability* 30: 226–35.
- Draheim, C.C., H.I. Stanish, D.P. Williams, and J.A. McCubbin. 2007. Dietary intake of adults with mental retardation who reside in community settings. *American Journal of Mental Retardation* 112: 392–400.
- Edwards, J.S.A. 2000. Food service/catering restaurant and institutional perspectives of the meals. In *Dimensions of the meal: The science, culture, business and art of eating*, ed. H. Meiselman, 119–33. Gaithersburg, MD: ASPEN Press.
- Gibson, R.S. 2005. *The principals of nutritional assessments*. 2nd ed. New York: Oxford University Press.
- Goffman, E. 1961. *Asylums*. New York: Anchor Books.
- Graneheim, U.H., and B. Lundman. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 24: 105–12.
- Hove, O. 2004. Weight survey on adult persons with mental retardation living in the community. *Research in Developmental Disabilities* 25: 9–17.
- Jolly, C., and J.M. Jamieson. 1999. The nutritional problems of adults with severe learning disabilities living in the community. *Journal of Human Nutrition and Dietetics* 12: 29–34.
- Kebbon, L. 1997. Nordic contribution to disability policies. *Journal of Intellectual Disability Research* 41: 120–5.
- Lewin, B. 2005. Disability law: Sweden. In *Encyclopedia of disability, volume 1, A–D*, ed. G.L. Albrecht, 451–2. Thousand Oaks, CA: Sage.
- Mallander, O. 1999. *De hjälper oss till rätta. Meddelanden från Socialhögskolan 1999:2* [A thesis about support for people with ID living in group and group homes and their own

- participation and influence in the daily life]. Lund, Sweden: Lunds universitet. (Not available in English.)
- Mansell, J. 2006. Deinstitutionalization and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability* 31: 65–76.
- Mattsson Sydner, Y., and C. Fjellström. 2007. Illuminating the (non-) meaning of food: Organization, power and responsibilities in public elderly care – a Swedish perspective. *Journal of Foodservice* 18: 119–29.
- MAXqda2. 2004. *Software for qualitative data analysis*. Berlin: Verbi Software.
- Melville, C.A., S. Hamilton, C.R. Hankey, S. Miller, and S. Boyle. 2007. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews* 8: 223–30.
- National Board of Health and Welfare. 2009. *Swedish disability policy – service and care for people with functional impairment*. http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf.
- National Food Administration. *NFA database 2.00*. <http://www7.slv.se/Naringssok/SokLivsmedel.aspx>.
- Nirje, B. 1969. The normalization principle and its human management implications. In *Changing patterns in residential services for mentally retarded*, ed. R. Kugel and W. Wolfensberger. Washington, DC: President's Committee on Mental Retardation.
- Nordic Council of Ministers. 2004. *Nordic nutrition recommendations*. 2004:13. Copenhagen: Nord.
- Nordin, M. 1997. *MATs: A nutrient calculation system designed for research and education*. v. 4.0. Västerås, Sweden: Rudans Lättdata. (In Swedish.)
- Ortner, S.B. 1994. Theory in anthropology since the sixties. In *Culture/power/history, A reader in contemporary social theory*, ed. N.B. Dirks, G. Eley and S.B. Ortner, 372–411. Princeton, NJ: Princeton University Press.
- Patton, M.Q. 2002. *Qualitative research & evaluation methods*. 3rd ed. London: Sage.
- Position of the American Dietetic Association. 2010. Providing nutrition services for people with developmental disabilities and special health care needs. *Journal of the American Dietetic Association* 110: 296–307.
- Tøssebro, J. 1992. *Institusjonsliv I velferdstaten* [Institutional life in the state of welfare]. Gyldendal: Ad Notam. (Not available in English.)
- Tøssebro, J. 1998. Researching the living conditions of people with intellectual disabilities. In *Methods for studying the living conditions of persons with disabilities*, ed. E. Hjelmquist and L. Kebbon, 24–35. Stockholm: Socialvetenskapliga forskningsrådet.
- WHO. 2003. *Diet, nutrition and the prevention of chronic diseases*. Report of a Joint WHO/FAO Expert Consultation. Geneva: World Health Organization Technical Report Series 916.
- Young, L. 2003. Residential and lifestyle changes for adults with an intellectual disability in Queensland 1960–2001. *International Journal of Disability, Development and Education* 50: 93–106.