

# Significant others' perspectives on experiences of meal-oriented support and diet counselling for adults with intellectual disabilities who live in supported housing

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The quality of meal-oriented support for people with intellectual disabilities is important for their health. The aim of the present study was to explore the experiences of meal-oriented support and diet counselling for adults with intellectual disabilities living in supported housing, from the perspective of housing staff and mothers. Five focus group interviews, including nine supporting staff members and nine mothers, were conducted. The interviews were analyzed using systematic text condensation. Five themes appeared; Extensive needs of the individual, Staff skills determine the food intake, Informal caregivers make up for shortage of support, Effective collaboration with a registered dietitian is needed and Responsibility of the organization state that professionalization of staff is needed. Lacking resources, such as time and nutritional knowledge, insufficient considerations of individual needs, and high staff turnover influence the meal-orientated services negatively. This study brings to the fore, staff working practices and the complexity of providing meal-oriented support for people with intellectual disabilities. Staff need skills to perform individually tailored support. This is best accomplished through effective collaboration between housing staff and relatives underpinned by knowledge from a registered dietitian. The working practices must be structured at the organizational level of the services.

**Keywords:** person centred care; parent; staff; registered dietitian; focus group; community living; food related support

## Background

People with intellectual disabilities are a vulnerable heterogeneous group. A recent review revealed discrepancies between the health of people with intellectual disabilities and that of people in general in high-income countries (O'Leary *et al.* 2018). O'Leary *et al.* (2018) called for more health promotion, including more health checks and increased information on the health risks associated with an unhealthy lifestyle for people with intellectual disabilities.

Most adults with intellectual disabilities in Sweden live in community based residences (Statistics Sweden 2022). They are eligible to apply for social services and support that are public financed and a responsibility of the municipalities, the services are optional (SFS 1993:387 1993). Support in housing may be provided in ordinary housing and in supported housing (*i.e.* a group home with own apartments for each resident or an intermediate form 'servicebostad'). The level of need in meal-orientated support such as planning, cooking and support at meals varies among the individuals (Adolfsson *et al.* 2012).

Kuijken *et al.* (2019) and Umb Carlsson (2021) concluded that staffs' working practices greatly affected the residents' possibilities to achieve a healthy lifestyle. Studies have found that staff in housing feel that they do not have relevant knowledge to provide high quality support in that context (Olsson and Gustafsson 2020,

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Hewitt and Larson 2007). While the real requirements are complex, the work is typically viewed as requiring little skills, and the staff turnover is traditionally high (Hewitt and Larson 2007). The staff ask for professionalization of their working role (McEwen *et al.* 2021).

The limited awareness of staff competence affects the nutritional status of people with intellectual disabilities, since it seems to be a particular lack of knowledge and skills in nutrition (Franssen *et al.* 2011, Ruud *et al.* 2016, Hamzaid *et al.* 2018, Davies and Matuska 2018, Doherty *et al.* 2020, Overwijk *et al.* 2021). Studies also show that many different factors may influence food intake of people with intellectual disabilities negatively (Ball *et al.* 2012, Hamzaid *et al.* 2018, Redley 2021). These can be directly related to problems with eating and drinking, as well as getting food into the mouth or swallowing. Moreover, the speed of eating and comorbidities can also affect food intake (Ball *et al.* 2012). This population commonly faces poor food choices, deficient nutrient intake, and difficulties with weight including obesity, being overweight or underweight (Adolfsson *et al.* 2008, Franssen *et al.* 2011, Koritsas and Iacono 2016, Hamzaid *et al.* 2020). One consequence of staff's insufficient knowledge is that nutritional problems of individuals with intellectual disabilities are not diagnosed in time, and thus treatment can be delayed or not carried out at all (Franssen *et al.* 2011, Adolfsson *et al.* 2019).

Little is currently known about how the nutritional support directed to people with intellectual disabilities, works. Registered dietitians (RDs) are the professionals trained to consult on nutritional problems. However, RDs are seldom specifically trained to work with individuals with intellectual disabilities (Baker *et al.* 2018, Butler *et al.* 2018, Adolfsson *et al.* 2019). Adolfsson *et al.* (2019) studied RDs work in Swedish context and showed that the RDs own knowledge about the specific living conditions of people with intellectual disabilities living in supported housing is poor (Adolfsson *et al.* 2019).

Person-centered care (PCC) (Waters and Buchanan 2017) involves the individual's private sphere, *e.g.* formal and informal caregivers. Parents of adults with intellectual disabilities, as informal caregivers, want to be part of the care system and contribute to the well-being of their adult children (Cuskelly 2006, Koelewijn *et al.* 2021). To be involved as informal caregivers increases their sense of well-being (Hakobyan *et al.* 2020). Person-centeredness should be part of the organizational culture (Waters and Buchanan 2017), where staff are also valued and given the necessary resources. Thalen *et al.* (2021) found that PCC increase the stability in individuals' lives when they were isolated during the recent pandemic. According to Sladdin *et al.* (2017), PCC improves dietetic practices and helps RDs establish trusting relationships with their clients.

They point out that a positive RD-client relationship is needed to create a successful interaction. The RD should show empathy, trust and respect using 2-way communication. Sladdin *et al.* (2017) emphasize that dietary counselling needs to be individualized. The individual's unique needs and wishes should be respected and joint decision-making should be applied (Sladdin *et al.* 2017). Moreover, RDs consider that working in a person-centered manner also requires effective health care collaboration (Jones *et al.* 2021).

To assure the nutritional health of people with intellectual disabilities, adequate meal-oriented support, is necessary. However studies show that improvement is needed and several categories of persons need to be involved. The aim of the present study was to explore the experiences of meal-oriented support and diet counselling for adults with intellectual disabilities living in supported housing from the perspective of housing staff and mothers.

## Method

The study had a qualitative approach. Focus group interviews (Patton 2015) were performed with housing staff and mothers of adults with intellectual disabilities. The Regional Ethical Review Board of Uppsala (Reg. no. 2017/224) approved the study design.

## Informants

Purposeful sampling was carried out to find key informants who had great knowledge about the issues under study (Patton 2015). The participants were recruited by a notice in a local member magazine for people with intellectual disabilities in central Sweden. The invitation was directed to staff working in housing for adults with intellectual disabilities and to family members of adults with intellectual disabilities. In total, 18 persons agreed to participate in the focus groups; nine of them were staff members, two men and seven women, in ages between 23 and 63 (M 38, Md 40) with several years' experiences of work with adults with intellectual disabilities. The rest of informants, nine were mothers of adults with intellectual disabilities.

## Data collection

Five focus groups were formed of which two with staff members (group A and B), two with mothers (group C and D) and one with both staff and mothers (group E). Every session had a moderator, the first author, and a facilitator, the third author. Before each session, information about the study was provided to the informants verbally and in writing, including an explanation of free will, anonymity and confidentiality. The informants were also told that the sessions would be audio recorded for later transcription. Each focus group session began with the moderator describing the results of the study on RDs' experiences of working with adults

**Table 1. The correlation between final themes and initially identified themes.**

Final themes <sup>1</sup>	Preliminary themes <sup>2</sup>
Extensive needs of the individual	<ul style="list-style-type: none"> <li>• Needs</li> <li>• Personal issues related to disability</li> </ul>
Staff skills determine the food intake	<ul style="list-style-type: none"> <li>• Explanations</li> </ul>
Informal caregivers make up for shortage of support	<ul style="list-style-type: none"> <li>• Needs</li> <li>• Personal issues related to disability</li> </ul>
Effective collaboration with registered dietitian is needed	<ul style="list-style-type: none"> <li>• Needs</li> <li>• Experiences of consultation</li> <li>• Personal issues related to disability</li> </ul>
Responsibility of the organization	<ul style="list-style-type: none"> <li>• Explanations</li> </ul>

<sup>1</sup>Step four = Final themes.

<sup>2</sup>Step one = Preliminary themes.

with intellectual disabilities (Adolfsson *et al.* 2019). The informants discussed the main findings of said study *i.e.* late contact with an RD; nutritional knowledge among individuals with intellectual disabilities and supporting staff; the information from an RD associated with consultation and RDs knowledge about the living conditions of individuals with intellectual disabilities. Thereafter, matters concerning the informants' experiences of meal-oriented support in housing for adults with intellectual disabilities were discussed. The sessions lasted between one and one and a half hours.

### Data analysis

The audio recordings were transcribed verbatim, and the transcripts were analyzed using systematic text condensation (STC) (Malterud 2012). First, all transcripts were read by all three authors to get an overview of the material. Thereafter, the authors discussed the content of the material. Four preliminary themes emerged from the material describing the experiences of meal-oriented support and diet counselling (Table 1). In the second step, using Nvivo software, the first author identified meaning units in a preliminary sorting of the data into code groups, based on the preliminary themes. These code groups were discussed by all authors and some re-sorting of the meaning units was done to achieve mutual agreement. In the third step of the analysis, each code group served as an analytic unit, and the meaning units were sorted into subgroups. Thereafter, every subgroup served as an analytic unit. Condensation of the content of the meaning units in each subgroup was carried out and the meaning units were labelled with headings illustrating their content. At this stage, some adjustments between the subgroups were made. The fourth step of the analysis involved describing the phenomena in each theme using the most relevant content and meanings, and the themes were renamed to more distinctly describe the content and in the end, there were five different themes, *e.g.* subtitles (Table 1). Authentic quotations from the five focus groups were chosen to illustrate and confirm the results.

### Results

Nine staff members working in supported housing and nine mothers of adults living in own housing accepted

to be interviewed collectively in a total of five focus groups. Generally, there was no difference between the issues discussed in the different groups despite the fact that staff and mothers had different relations to the individual with intellectual disabilities. The same themes emerged in all groups, although the relationship to individuals with intellectual disabilities were obviously different between the staff and the mothers.

The results are presented in five themes; *Extensive needs of the individual*, *Staff skills determine the food intake*, *Informal caregivers make up for shortage in support*, *Effective collaboration with registered dietitian is needed* and *Responsibility of the organization*.

#### Extensive needs of the individual

The first theme shows that the informants were especially concerned with how the meal-oriented support is performed for individuals with severe disabilities. These individuals often have extensive complex problems and need individualized routine procedures for medication, eating and drinking.

The informants pointed out that it takes time to learn how to take care of individuals with extensive complex problems, including dysphagia. To eliminate the risk of nutritional deficiency, staff need special skills, *e.g.* ensuring the right consistency of food and appropriate feeding methods for each individual they serve. In addition, to meet the extensive needs of an individual, more time is needed at meals. For an inexperienced staff member, the time for feeding should be even longer, allowing the individual to ingest the nutrition she/he needs.

Mother 1: my daughter is a very complicated person, there is so much you have to transfer, how to lift from bed, and how to change diaper and how to feed, the consistency of the food and how much it should be and how much on the spoon and eh, all routines around and that it should be calm and not to chatty and that you have to feed in a special way, and that some spoons of food and then five spoons of liquid, because she doesn't drink, therefore all liquid should be portioned by spoon. It is, very, very much you have to teach.  
– Focus group D

An individual may also have difficulty expressing his/her opinions about food and food preferences. The informants indicated that, in such situations, staff need to be responsive. Otherwise, and especially if the staff

member does not know the individual well, there may be a risk that the individual refrains from the food served, although still being hungry.

Mother 2: for P it is so, that the staff would say that we buy a grilled chicken so we can divide it, then he would immediately say yes and that we should have those 'pierogies', he likes, he doesn't like those boxes very much. – Focus group E

According to the informants, for staff to maintain knowledge of each individual, a representative is needed – someone who is well acquainted with the individual's various signals and behaviours. This could be a staff member with long experience or a relative who understands the individual's wishes and needs and can explain them when new staff is introduced.

Staff 1: When you work with a person who is very tired or does not have big appetite or is very demanding, then it may be difficult to notice the changes if you don't know the person very well. – Focus group B

### **Staff skills determine the food intake**

The second theme revealed that the quality of the meals is dependent on the knowledge of each supporting staff member. Although daily support usually includes meal-oriented support from staff, the informants reported that staff skills are not always adequate. They pointed out that, without appropriate knowledge and skills, it is difficult for staff to recognize the effects of poor diet on the individuals and their special nutritional needs. In addition, the informants felt that the lack of suitable knowledge and skills results in ill-considered menus containing semi-finished or ready-made food with little variation, which rarely meets the specific needs of each individual.

Staff 4: Sometimes there is a problem that the food is too unbalanced – that it is the same kind of food all the time and a lot of candy. Nothing worked. And then it is difficult to do something if you are not in a staff group with the same preferences.

Staff 2: You should have consensus in the staff group, so you don't make the same food or something that a staff member prefer him/herself.

Staff 4: We did not agree at all, some thought it was a violation not to be allowed to buy and eat whatever you wanted. – Focus group A

Moreover, according to the informants, in housing where meals are collectively cooked for several individuals, the food is sometimes not served and portioned based on individual needs. This means that portion sizes for a sedentary individual may be as large as those for a highly physically active individual.

Mother 3: There is another resident that needs to eat a lot, because he is so thin, and yes, needs extra, and actually, M only needs to watch in order to increase in weight. But they do not drink soda or such. – Focus group C

The informants also reported that, given the right competence, staff can more easily reach agreement on

nutritional matters. In their view, individuals can become confused when there is no consensus within the staff group. Support varies from staff members and decisions and rules for meals are dependent on the staff member who is in charge.

Further, the informants mentioned the staff schedule, which often includes periods of leave of several days. Getting caught up on all information about each resident after a period of leave can take time. This information can include reports from the latest consultation with health care contacts, such as an RD. If the staff member does not follow up on all the information, he/she may endanger the quality of support and the health of the individuals. The informants also claimed that such information is sometimes difficult to understand because the wording is vague and there is insufficient time to read the information or for verbal handover.

Staff 2: You read everything that you haven't read before, from the last shift and onwards.

Staff 1: There is also a shortage there

Staff 2: Yes, the shortage exists because there is not always time to write down exactly when it happened and you don't always have time to read. If you have been away for several days, what happens when you are scheduled or if you been away for vacation, then you have much to read and that time doesn't exist.

Staff 1: It can also be that the staff member that accompanied to the RD doesn't remember everything. – Focus group B

Mother 4: You have to assume that the staff wants the best, then it probably is a lack of time or something else that make them miss and not manage if there are many (persons to take care of) – Focus group C

### **Informal caregivers make up for shortage of support**

The third theme explains the mothers' perception of meal-oriented support in their adult child's housing. They explained that many parents in similar situations need to help their adult child with food-related tasks even though the individual receive support from the housing staff. Family members make efforts, e.g. to ensure that the food contains enough vegetables, to help the individuals maintain ingrained cultural eating habits, or to throw away old food.

Mother 2: Because, just like we feel with P we, me and my husband, look at the plates, and we cook almost all of Ps food, otherwise it will be a box with pie, pizza or what you take out from the freezer.

Mother 1: Exactly

Mother 2: Huhu, this is how I feel about it, – yes and I know that there is another in the stairwell where the parents or the mother do exactly this, it is a young man who is adult, he is a person that, then, yes has other eating habits. – Focus group E

According to them, giving hints or making comments on the food served in their children's residences without upsetting the staff is a delicate matter. One way

to avoid the comments being perceived as criticism is to try to make them humorous.

Mother 1: That you as a relative sits in the knee of the staff, you can't, you can't be critical, so I just said 'oh, then it was a lot of sausages this week', I said something like that in a humorous way. – Focus group E

The mothers expressed their worries about the future. Their children have someone to turn to as long as the parents are nearby. However, they fear what will happen the day they can no longer provide this care. They wonder who will ensure that their children's needs are met then.

### ***Effective collaboration with registered dietitian is needed***

The fourth theme shows the informants' experiences of the nutritional consultation by an RD. The informants reported that nutritional consultation works well when it involves effective collaboration between RDs, the individuals themselves and significant others. They pointed out that knowledge exchange and effective collaboration is needed because many RDs are not familiar with the living conditions of adults with intellectual disabilities. RDs may not realize the challenges associated with living in supported housing.

The informants found consultation with an RD to be valuable when the RD has a personal dialogue with the individual and considers his/her perspectives. They felt that an RD's efforts to persuade an individual to make changes in his/her eating habits are not comparable to what significant others, such as staff or relatives, can achieve through their efforts. In their view, while the individual perceives the advice offered by an RD as objective, comments and advices from significant others are perceived as nagging.

Mother 1: I can tell like this that we go on like you say and then I think like this, it will be different when S sits and talks to the RD, then it will be more, she (RD) asks, how are you S and is your stomach OK and so on. Yes, you know that it is healthy for you to exercise too – Focus group E

The informants argued that, due to the heterogeneous and often complex needs of individuals with intellectual disabilities, to succeed with consultations, an RD must be a generalist in nutrition, but also have special skills in working with these individuals. These complex problems must be considered before any advice is given. A combination of physical conditions including but not limited to constipation, epilepsy, and obesity can counteract the treatment of other conditions.

Mother 2: Yes so, she has to have her medicine for her seizures and that is not administered outright but in that case we give her those cheese balls so we put it in there so everything goes down and they (RDs) don't think she should have them but instead those flavourless things that you give to babies, I don't know their name, but they taste absolutely nothing and she doesn't want them. What is most important then, that she gets her medicine or that we follow the advice from the RD? – Focus group C

However, when significant others are involved in an RD's consultation, the possibility of successful results is enhanced. The informants also claimed that, when an RD includes tangible aids, such as portion size measurement aids, the advice is easier for an individual to understand, follow and accept. Consequently, measurement aids and advice on frequency of intake of different foods also make it easier for significant others to convince the individual to follow the advice and change his/her diet.

Mother 2: More than eleven kilos, I don't know but he told me, but then he went to an RD and then he was told that his mother had told that you can't eat pizza so often and then it turned out that once a month he can eat, he can eat pizza according to the RD. It solved, it solved it in a way – Focus group E

The informants argued further that an RD's consultation must be based on the individual's entire life situation and needs and be individually tailored based on professional assessment. They pointed out that an RD with insufficient knowledge of cognitive limitations and without extensive knowledge of the individual's everyday life can hardly achieve the intended results through consultation.

Mother 1: H has measures, she got it from her RD, divided, but it doesn't help if you fill up, but it doesn't help if you top up with a lot of other things. Or? – Focus group C

It is important that advice be given so that a recipient without special nutritional competence can understand it. The informants claimed that extensive explanation may be needed for an individual or the staff supporting him/her to understand the need for changes in food habits. The RDs also need to realize that individuals with intellectual disabilities do not always ask questions, even when they do not understand.

Staff 2: If you meet an RD and get the advice to eat more grain products you ask what grain product is, like that. Then it is better that you write so it would be best if it was written down.

Staff 1: Maybe, instead of writing grain product, use a picture, on wheat or whatever

Staff 2: a person with intellectual disability, most of those who have an intellectual disability will not ask a counter question even if they don't understand. – Focus group B

The informants explained that, for people with an intellectual disability, almost all of whom need daily support, the information should not be presented verbally alone. Instead, the information needs to be spread to everyone involved in a residence, in easy-to-read format, using common words (not professional language) and pictures. Moreover, they explained that contacting an RD can be rather difficult.

Staff 3: Yes, he sees an RD, he sure do, but not regularly. But it is so hard to reach her and to get an appointment with her. You can't just phone, and if you have the time, you need to try repeatedly to get hold of her.

Interviewer: So you can't even book an appointment?



Staff 3: No, it needs a considerable effort, is very tricky, you have to phone several times. – Focus group A

The informants reported that, for individuals with intellectual disabilities, the first impression is important. Future contacts are negatively affected if an RD does not interact well with an individual, but is instead experienced as acting insensitively.

Mother 3: I thought I got a relatively harsh impression of the RD, as we got reprimands at our first visit and that was BMI facts and it was to lower and eh as a goal be slimmer and that was what we had to follow. It can be very difficult for a person and, yes – Focus group D

According to the informants, RDs may sometimes feel it is unnecessary to meet with the individual him/herself, instead suggesting a meeting with the supporting staff. This is not an acceptable service; the RD should interact with the individual and direct the advice to him/her.

Staff 1: She didn't even need to meet O, that was interesting, no, he shouldn't accompany. We went there, she said that O didn't need to be there, that was grotesque, O should of course be there, it is important, it was about him having gained weight, then it would be important to see the person, we thought – Focus group A

### Responsibility of the organization

In the fifth theme the informants argued that the authorities do not prioritize the quality of support provided for people with intellectual disabilities. According to them, responsibility for meal-orientated support in housing needs to be at the organizational level of the services. They emphasized that ensuring good quality meal-oriented support requires sufficient resources. They pointed out that the organization needs to guarantee a professional approach based on knowledge of nutritional issues among staff and that the support should be individually tailored, which it can be when an individual has his/her own household.

Staff 1: Yet we have a good grip on what O eats because we write down exactly everything he eats and everything he drinks and if he eats fruit how many times, and vegetables so we have a quite, – so we see, we write down on a type of calendar so we see how often he eats it we often cook large meals so we have in the freezer, we don't do it every day but there is a lot to choose from, and we can see what we can take that he has not eaten so it shouldn't be the same thing – Focus group E

The informants explained that, within the organization, it is not always obvious that providing meal-related support is time-consuming. In their view, lack of time may be a reason why meals need to be prepared quickly and why semi-finished or readymade meals are chosen.

Moreover, the informants pointed out that it is easy for young people without experience and people without proper training to get employment in community housing. This leads to short periods of employment,

causing unstable conditions for people with intellectual disabilities. They stressed the need for introductory courses for newly hired staff to train them in proper support provision. They specifically highlighted the need for lectures in cooking and nutrition that give staff general knowledge in nutrition, which many of them do not have.

Staff 2: There's quite a mixed knowledge, or rather a very low knowledge amongst the staff.

Staff 1: And that you as staff don't feel how it is to eat meat balls and macaroni every day. You go there and make something simple, since it takes less time from you.

Staff 2: you make what the individual prefers. There is so much more you need to know about this. Many in this group have problems with consistency. So you really need to know a lot about food. Many (staff members) have their own ideas. I think this is extremely important. A lot of education is need about this. – Focus group B

Mother 1: It is really tricky I think, especially regarding the staff, now it hasn't been a big turnover the last year, but they are young, there are a lot of boys. You wonder, but wonder, it doesn't need to be a preconception, but from experience of having spoken to them it says that they don't 'have much to contribute – Focus group C

According to the informants, general knowledge in nutrition is needed if staff are to understand and deal with the advice RDs give to the individuals they support. They also suggested that, in community housing, as long as competence in food-related tasks is insufficient, regular contact with an RD is necessary.

### Discussion

The present study explored the experiences of meal-oriented support and diet counselling for adults with intellectual disabilities living in supported housing, as revealed through the perspectives of supporting staff and mothers. Five themes were identified as particularly important to take in to account: (1) Extensive needs of the individual, (2) Staff skills determine the food intake, (3) Informal caregivers make up for shortage of support, (4) Collaboration with registered dietitian is needed and (5) Responsibility of the organization.

It may be noted that staff and mothers had similar reflections, although they have different relationships with people with intellectual disabilities. A clear difference was that mothers, although not formal caregivers, emphasized that they cannot relinquish responsibility for ensuring that the needs of their adult child are met. Irrespective rights under the laws (SFS 1993:387 1993) and responsibility of authorities, they are worried about how the meal-oriented support of the individual is taken care of. That food intake is a big problem for many individuals is also presented in earlier research (Ball et al. 2012, Redley 2021). According to the mothers, parents act as guardians for the values and standards affecting their child, and to ensure that the child is treated as an individual. They stressed that parents

know and understand their child well. If staff turnover is high, parents stand for continuity. Earlier studies confirm this standpoint from parents of individuals with intellectual disabilities (Cuskelly 2006, Koelewijn *et al.* 2021).

Both staff and mothers were concerned over the high staff turnover. Several reasons for high staff turnover has been identified *e.g.* low salaries, inadequate practices and low job satisfaction caused by poor workplace organization (Hewitt and Larson 2007). Furthermore, informants had observed that many new staff members lack knowledge and skills in nutrition and in meal-oriented support. That staff lack competence in food and nutrition has been shown in several studies (Franssen *et al.* 2011, Ruud *et al.* 2016, Hamzaid *et al.* 2018, Overwijk *et al.* 2021). Such shortcomings can lead to poor meal-oriented support and negative health effects, a special dilemma can arise when the staff's duty is to guide the individual to healthy choices that do not correspond to the individual's wishes (Ruud *et al.* 2016, Redley 2021). Even adults with intellectual disabilities consider that staff need relevant skills and knowledge in meal-oriented support to provide high quality support (Davies and Matuska 2018, Doherty *et al.* 2020). According to Redley (2021), better training of staff and simple models need to be developed to decrease the risks for negative health effects. As a partial solution, Franssen *et al.* (2011) and Adolfsson *et al.* (2019) suggested development and introduction of an instrument for early detection of nutritional problems among people with intellectual disabilities.

The results of the present study showed that the participating mothers were concerned about a future, when they no longer would be able to support their child. Such concern was also seen among many parents in similar situations (Cuskelly 2006, Koelewijn *et al.* 2021). A challenge for practice is to find possibilities to include family members in the support without restraining the independence of the individual. Although both staff and mothers stressed the importance of collaboration, the results visualized the inequality in their relations. Mothers felt responsible to ensure a positive relationship with staff even if they had different opinions on the support provided. The individual with intellectual disabilities is considered to benefit if conflicts are avoided. Cuskelly (2006) and Koelewijn *et al.* (2021) have also shown that when parents experience resistance from the staff, they become frustrated, which can lead to conflicts.

The informants in the present study demanded effective collaboration with RDs to ensure sufficient nutritional health of people with intellectual disabilities. They were satisfied with RDs' professional skills and knowledge in general. According to them, RDs do not always realise the individual's total situation and understand that RDs cannot be specialists in every

individual's needs. Therefore, knowledge of all individuals, staff and informal caregivers is required for diet counselling. RDs earlier acknowledge that their knowledge is not sufficient concerning consequences of intellectual disabilities for meal-oriented support *e.g.* how to respond to individuals' own wishes (Adolfsson *et al.* 2019). As experts, RDs consider that meeting nutritional needs is more important than satisfying personal wishes (Sladdin *et al.* 2017, Jones *et al.* 2021). In meeting with persons with intellectual disabilities, there can also be considerable misunderstanding if the information is not adapted to the communication skills of the individual (cf. Tøssebro 1998). To ascertain a 2-way communication, an RD needs good communication skills. RDs have earlier expressed that their communication skills need to be improved for them to be able to reach consensus with individuals with intellectual disabilities (Adolfsson *et al.* 2019).

The PCC approach could be beneficial in care contacts for people with intellectual disabilities who are dependent on and receive different types of support. This approach covers the individual's entire situation and to be successful, it needs established contacts between various health care professionals, staff and informal caregivers. The use of PCC (Hakobyan *et al.* 2020) shows that the interaction between the formal (in this study the staff) and informal (in this study the mother) caregiver might benefit not only the well-being of the individual with intellectual disability (Thalen *et al.* 2021), but also that of the informal caregiver. The families worries about needs not being met, may diminish if they are included in PCC, but it is also necessary to involve the individual him-/herself in order to take his/her personal preferences and wishes into account. Adults with intellectual disabilities ask for knowledge, to be more able to take an active part in their meal-oriented support (Umb Carlsson, 2021).

As seen in the present study, the informants perceived a lack of resources such as education and time to perform the service properly. The informants were concerned about many newly hired staff members being young and without experience and knowledge of supporting people with intellectual disabilities. Informants emphasized that the responsibility for well-functioning services is on the organizational level and therefore is a responsibility of the service providers. This was strengthened by results in research of Umb Carlsson (2021).

A limitation of the study was that information from significant others was obtained only from staff and mothers, no fathers or siblings participated the study. To get a holistic picture, it is necessary to supplement the information in the present study with first-hand information provided by persons with intellectual disabilities themselves. Another limitation of the study was that it was performed in a Swedish context, which

means that the results may not easily be transferable to other countries with different living conditions for adults with intellectual disabilities. However, regardless of living conditions, meal-oriented support and diet counselling are relevant for health and well-being.

The results were strengthened by the fact that although this was a qualitative study performed with five focus groups – two with staff, two with mothers and one mixed to gain diverse perspectives – the content of the discussions did not differ between the groups (Patton 2015). A study-specific interview guide was developed in advance to obtain information related to the study aim. The results have been presented to people representing the informant groups to assure the credibility of the study (Patton 2015). All three authors participated in the analysis process, read all the transcripts from the five focus groups, and discussed the preliminary and later the final themes until consensus was reached (Patton 2015, Malterud 2012).

## Conclusions

The need to improve the nutritional health of adults with intellectual disabilities is well known. This study brings to the fore, staff working practices and the complexity of providing meal-oriented support for people with intellectual disabilities. Staff need special skills to perform individually tailored support. The results highlight the need for effective collaboration that is underpinned by knowledge from dietitians, housing staff and relatives. However, fundamental changes in working practices must be structured at the organizational level of the services.

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