

Food choice by people with intellectual disabilities at day centres: A qualitative study.

Luke Cartwright University of Hull

Marie Reid University of Hull

Richard Hammersley University of Hull

Chrissie Blackburn University of Hull

Lesley Glover University of Hull

Acknowledgments

We would like to thank and acknowledge Bob Walley NHS Lothian, for providing valuable support to the research endeavor.

Funding

This work was supported by the Chief Scientist Office of the Scottish Government.

Abstract

People with intellectual disabilities experience a range of health inequalities. It is important to investigate possible contributory factors that may lead to these inequalities. This qualitative study identified some difficulties for healthy eating in day centres. (1) Service users and their family carers were aware of healthy food choices, but framed these as diets for weight loss, rather than as everyday eating. (2) Paid carers and managers regarded the principle of service user autonomy and choice as paramount, which meant that they felt limited in their capacity to influence food choices, which they attributed to the home environment. (3) Carers used food as a treat, a reward and for social bonding with service users. (4) Service users' food choices modeled other service users' and carers' choices at the time. It is suggested that healthy eating should be made more of a priority in day care, with a view to promoting exemplarily behaviour that might influence food choice at home.

Key words; autonomy; diet; food choice; intellectual disability; obesity

People with intellectual disabilities are thought to experience a number of health inequalities, and one important health risk is obesity, the rate of which may be as much as 59% higher than in the general population (Doody and Doody, 2012: 460). Obesity increases the risk of a number of chronic and serious conditions such as diabetes, depression, stroke, and heart disease. Furthermore, these conditions develop in people with intellectual disabilities at a younger age than in the general population, which may be due to the higher incidence of obesity within this group (Doody and Doody, 2012). This may account in part for the lower life expectancy of people with intellectual disabilities when compared to the general population (Scottish Executive, 2004).

Approximately three to five per 1,000 of the general population have intellectual disabilities (Spanos et al, 2013: 90), although the precise number is unknown (Emerson and Hatton, 2008). In Scotland, it has been estimated that approximately 120,000 people have intellectual disabilities (Scottish Executive, 2004), and that most of them live with family carers. This paper focuses on the users of day centres for people with intellectual disabilities and shall refer to them as 'service users' to avoid issues of terminology and diagnosis. Most people who used these services had received a diagnosis of an intellectual disability at some point.

This paper examines some of the factors that may influence weight status amongst services users. Qualitative data were gathered from four key stakeholder groups: paid carers; family carers; day centre project leaders; and

service users. The support offered to service users with intellectual disabilities from family and paid carers has been identified as a key component in meeting the needs of this service user group (Spanos et al, 2013).

Indeed, the risk of obesity is higher in service users who live with families, or in small group homes, than it is in those living in residential care. It has been suggested that the promotion of individual food and other health behaviour choices is a key cause of this difference (Doody and Doody, 2012; Rimmer and Yamaki, 2006). Service users living institutionally may have less choice and autonomy than do those living domestically. The overall aim of this paper is to develop an understand of how service users and carers perceived issues of diet and healthy living. The tensions between freedom of choice plus autonomy and healthy living is the overarching theme discussed here. The focus of this paper is on the choices that were available to service users with intellectual disabilities, the social context of those choices, and the impact that these may have had on the way decisions were made by the service users.

Method

The data were collected in East Lothian, Scotland. The research was approved by the Ethics committee of Queen Margaret University. Grounded theory methods were used, with data being collected from the participants during one to one semi-structured interviews (Glaser and Strauss, 1967). Four participant groups were recruited by contact and advertising at local day care centres for people with intellectual disabilities.

To supplement the one to one interviews, two focus groups were conducted with service users. This enabled the collection of rich contextual data from the service users themselves in two different environments thereby increasing the quality and depth of the data that was taken from this key participant group (Charmaz, 2006). Additionally, carers completed food diaries for a service user in their care, but this led to substantial under-reporting, with a mean reported energy intake of 987 kcal per day (SD 177), so these data were not utilised.

As one of the participant groups involved in this study was particularly vulnerable (the service users with intellectual disabilities) it was essential to have robust procedures to ensure fully informed consent was obtained from all participants. The recommendations made by Cameron and Murphy (2006) were used. All written materials for participants with intellectual disabilities were edited to have a Fleisch-Kincaid reading Grade of 4.7. All potential participants were given information explaining the nature and scope of the research sufficiently in advance of the interviews to allow them to reflect on and consider participation. There was an initial session where the researcher verbally explained the research and potential participants could ask questions. For the service users with intellectual disabilities the background information about the study was also provided in what Cameron and Murphy (2006: 114) describe as an 'illustrated summary letter.' After reflection and discussion, by signing the illustrated summary letter the participants with intellectual disabilities provided their consent to taking part in this research. Prior to interview (or focus group) continued consent was checked verbally. Throughout the interviews, the researcher observed nonverbal cues and monitored the communication

between participants with intellectual disabilities and any carer present. The purposes of this monitoring were to ascertain whether the participant with intellectual disabilities continued to consent (which was re-checked verbally periodically), to identify any leading or suggestion that may have been taking place, and to reduce the participant with intellectual disabilities providing responses to questions that may have been given to please the carer rather than representing their reality.

Service users' semi-structured interviews focused on concrete experiences of eating and activity, including what they had eaten in recent meals and recent exercise and activity. Table 1 below outlines the topics that were discussed with each participant group. Carers went through a typical day in terms of the food and activity of a participant that they cared for. Carers also completed a one-day food diary for that person. Project leaders were asked for examples of the meals and activities normally provided in their service. For all, there was additional exploration of: healthy and unhealthy eating; healthy and unhealthy activity; participants' roles in choosing and preparing food for the person with an intellectual disability; how activities were chosen. Communication about food and activity and any potential barriers to healthy eating or exercise were also explored in both individual interviews and focus groups.

Table 1. Topic schedule

Topics for service users

- Q. What is your favourite food?
- Q. What did you have for breakfast this morning?
- Q. Do you think this was a healthy or an unhealthy breakfast?
- Q. What foods do you think are healthy?

Topics for both carer groups (family carers and paid carers)

- Q. How important do you think it is to eat a healthy diet?
- Q. What is your role in choosing foods that [name] eats?
- Q. Is there regular communication about food and nutrition?
- Q. How much does [name] have a choice in what is eaten?
- Q. What are your own eating behaviours like around [name]?
- Q. What do you think would help in ensuring [name] makes healthier food choices?

Topics for Project Leaders

- Q. What foods does your service provide for clients?
 - Q. What do you believe makes a healthy diet?
 - Q. How close or far is this to what clients actually eat?
 - Q. How much do clients have a choice in what they eat?
 - Q. How far do you think clients' food choice can be influenced by carers?
 - Q. What do you think can be done to ensure clients make healthier food choices?
-

Interviews and focus group meetings were audio-taped and then transcribed by a professional transcribing service. Data were analysed with Grounded Theory following the constructivist methods described by Charmaz (2006). This first stage in the analysis process was the coding of the data. The coding process is the main analytical device in grounded theory; Glaser and Strauss (1967) argued that data should be coded into as many segments as possible, often down to the level of a sentence, or clause. Following the initial coding, 'groups of codes were formed and collapsed into categories' (Birks and Mills, 2011: 94).

At this stage in the analysis, themes started to emerge from the data and memos were then utilised to make the analysis more abstract (Charmaz, 2006).

The following discussion is drawn from the main themes that were developed from the data and the analysis process described here.

Results

A total of 42 participants were recruited into the study with this total being made up of 10 paid carers, 10 family carers, 10 service users and 12 project leaders (of day care services for the over-18s).

Informed choice and autonomy

One of the main themes to emerge from the data was about choice and personal preference. The project leaders considered the notion of service user choice and autonomy as being central to the conceptual framework that guided the principles of how the services that they were responsible for were run:

[W]e try and focus mainly on the social model promoting independence. Making sure people have clear rights in their life, to take responsibilities, to make choices, to take risks if you like. So it is the social care model that we base all our work on (Project leader 8).

It's really difficult because it's not impossible [to] force somebody to eat a salad, people with disabilities you know are not equal in terms of their status or their perception of themselves. So you could force and just say, "You're not having chips," or "You're not having this". We don't do that, we can't do that. All we can do is encourage them to take fewer chips and encourage them to think about the consequences of having heavy, fatty daily meals here (Project leader 6).

The project leaders attached importance to making sure that the service user had autonomy and choice. The model that was said by the project leaders to be the dominant perspective that guided the work of the day centres that they managed was described by one of the project leaders as 'the social model'. It

appeared to be based on a social democratic framework first developed during the 1980s, which 'started as a process of increasing the capacity of people with mental illness and learning disabilities to manage their own lives' (Payne, 2005: 299). The social democratic model is grouped together with other theoretical frameworks that Payne (2005) describes as empowerment and advocacy perspectives. However, Payne (2005: 314) cautions that when utilizing these theoretical frameworks it is important 'not to use the idea of empowerment to avoid responsibility for assessing and providing for appropriate care and support.'

One specific example that was discussed was food choice and there were issues about getting the balance right between autonomy in food choice, and facilitating healthy food choices. Service users had a midday meal at day centres and were free to decide what foods they would eat from the canteen. The project leaders were explicit that service users should be encouraged to make informed decisions about the types of food they selected from the whole menu on offer in the canteens at the day centres the service users attended. The food provided in the day centres was usually designed to meet the needs of a range of service users, not just those with intellectual disabilities. Consequently, menus usually included some healthy options, but also unhealthy foods:

It is full fat milk the blue top milk that is all we use (Paid carer 7).

Portions seem quite large I would say...like it's not totally junk food all the time you know...he's ordering like chips all the time (Paid carer 3).

The food here all comes from the kitchen we don't have any say we've tried to say we don't want pies we don't want chips...but it's never

materialized they just keep saying it's cooked in healthy oil (Paid carer 9).

Despite these problems, the paid carers used the autonomy and choice model and encouraged the service users to make informed decisions about food, rather than choosing for them:

We give [him] a choice and give him an informed choice...he wants stew and tatties then it's his choice he's an adult (Paid carer 1).

The final decision would be left to [her]...We wouldn't be allowed to [the] policy is it's freedom of choice and it's their choice (Paid carer 5).

Her mum will phone up and say well [she] said that she has only had this for her lunch is this true? Obviously some other staff have been there and they have not actually said no...They have just said oh well [she] said that so ok (Paid carer 8).

I don't think we can impose it [healthy eating] but I think we can encourage it (Paid carer 11).

So, in practice the model led to the paid carers regarding the service users as capable of making informed decisions, including about diet. Indeed, many of the service users, when asked about healthy food could identify foods such as baked potatoes and salads as healthy choices:

Researcher: What sort of food do you think are healthy?

Service user 4: Erm salads and erm baked tatties.

Cos potatoes cos potatoes are good for you good good for good for you (Service user 2).

Researcher: So when you tried to lose weight before what did you eat?

Service user 3: Salads.

The social setting of food choice

The ability to translate concepts and ideas such as “baked potatoes are healthy” into choices that are made in social situations is not straightforward. Decisions such as what to select from the canteen menu were influenced by other people using the service at the same time. As one of the paid carers stated “[i]t is a very social time for the service users so they choose who they sit with” (Paid carer 8). Paid carers further identified examples of when service users had been influenced by others around food choices:

Yeah, yeah, she has changed her eating habits...[One of the other service users] used to eat a lot and I mean a lot of bars of chocolate and [she] would eat with him (Paid carer 5).

I think when everybody else has got them [deserts] it is really difficult to say you’re not having that (Paid carer 6).

Yes and all the different dynamics that are going on around the lunch time as well...Certain dynamics when different people sit together and what that causes when they might eat, they might not eat their dinner or they might, you know, it is just keeping an eye on everything (Paid carer 8).

These quotations suggest that even when healthy choices were available, and the service users knew there were healthy options on the menu, they did not necessarily make those choices for social reasons. The service users were influenced by others and the choices they were making.

Staff attitudes to healthy eating

The difficulties that service users with intellectual disabilities had in making healthy choices were increased by the inconsistent messages that paid carers collectively provided about healthy eating, with these inconsistencies being accepted by the project leaders rather than being challenged and dealt with:

[Y]ou’ve got some people on the team who will consistently follow the programme and then along comes somebody else who can’t be

bothered with the fact that person might get upset, so they just give them a chocolate biscuit, or they think it's nice, "I'll be your pal, you can have two packets of crisps today because I want to be your favourite carer," when in actual fact it's that kind of you're teaching somebody a process and trying to change their response to things, but people don't appreciate why something has to be done in a certain way. So it can be a very frustrating world to be in (Project leader 7).

I think also the staff team are quite fixed in how they're prepared to see food and the difficulty of removing themselves from their own thoughts about food for themselves and their families and so on. I think that's a huge problem because it comes back to that fundamental – people have so much invested in their own family experience, and so by mentioning anything like this I think people become very defensive. Staff are and you've got to get past all that. I think that's the biggest challenge. You can have all the information available but people have got to be, I don't know [if its] about buying into it but it's something like that (Project leader 9).

There was an acceptance amongst the project leaders that staff would offer inappropriate food to service users with intellectual disabilities. Although the project leaders described having a 'duty of care' (especially in terms of offering choice) this duty did not appear to extend to ensuring paid carers and other staff within the Day Centre behaved as role models during the time they were working for services funded by the state to look after this vulnerable service user group. Consequently, the service users were enabled to consume food with high sugar/fat content in a number of ways:

I know he will eat chocolate drops. He will eat three or four packets of those if you let him because we occasionally take those out as a snack to have when we go out walking or that (Paid carer 11).

We have had a lot of temporary chefs in on last week they made biscuits and cake which were lovely and I said to them well we say just say a little bit of what you fancy is ok (Paid carer 8).

We also have staff bring in a big box of biscuits from home (Paid carer 7).

So, the expectation that staff would promote and support healthy food choices by service users was in conflict with other social issues surrounding food. These included that staff attitudes to healthy eating varied, on the one hand encouraging healthy choices at meal times (while taking care not to be too directive and remove autonomy) while at other times using food as a treat, for example, by bringing in sweets and biscuits from home. Moreover, the food choices that other service users and paid carers made in the moment, influenced the foods chosen by the service users, as the quotations above illustrate.

Diet at home

Family carers tended to consider weight loss to involve 'going on a diet' rather than a lifestyle of healthy eating. Diet for the family carers frequently related to short term changes in eating habits and following popular commercial diet programs:

When I first did a diet with him we gave him what do you call those things? Weetabix (family carer 1).

They know she is on a diet and they try to watch what they give her (family carer 8).

I go to Weightwatchers and I had [service user] on that same sort of thing (family carer 4).

Well if [service user] is on a diet it's more salads and soup and may be Weightwatchers jelly with fruit (family carer 10).

In support of the short term approach outlined by these family carers, one of the service users described how he had lost weight in the past, with the description offered reflecting the approach that is evident in the quotations from

the family carers above. The method he had taken to weight loss had been successful in the short term but had ultimately not been sustainable:

Researcher: Have you ever been, have you ever tried to lose weight before?

Service user 4: I've gone, I weighted 9 stone last time and I put it all back on cos I done that too quickly last time.

Researcher: And what made you decide to lose weight last time?

Service user 4: Cos I never ate.

Researcher: You just stopped eating?

Service user 4: Aye, I never ate. Well, but I have to eat.

Researcher: OK so how quickly then did you put the weight back on? When you started eating again?

Service user 4: Mm.

Furthermore, being on a diet was frequently described as limiting certain food types such as cheese and processed meat, rather than promoting the consumption of a diet high in complex carbohydrates, fruit and vegetables. "She's allowed one packet of crisps a day" (Family carer 4). Again the interviews with the service users reflected this short term approach and the limiting of certain food types:

Researcher: You're on a diet? Why are you on a diet?

Service user 7: Lost weight

Researcher: Why do you want to lose weight?

Service user 7: My mum says

Researcher: Your mum says – ok. So what does your mum say to you about your weight?

Service user 7: Your not allowed chocolates. Not allowed chocolates.

Furthermore, there was a tacit belief that diet fizzy drinks were a good choice:

[T]hat's what she always asks for diet coke (Family carer 2).

And cans of diet coke [service user] likes his cans of diet coke (Family carer 1).

[S]he doesn't have wine she has diet coke (Family carer 3).

Cereal bars were also singled out as being a positive choice:

[S]o the Weightwatchers things are healthy sort of cereal bars and things like that" (Family carer 4).

As were some types of crisp:

He's got to have some things he likes...Low fat crisps or quavers"
(Family carer 1).

There was a focus on short term diets replacing the least healthy components of the diet with healthier alternatives, such as lower fat crisps, or diet soft drinks, rather than in making sustained lifestyle changes. Implicit in the concept of 'the diet' is that whilst not dieting people can eat what they like, within reason, and it was commonly assumed that service users liked unhealthy choices including chocolate and crisps (see above), which the paid carers felt they often consumed at home (see below).

The assumption that the service users enjoyed unhealthy choices appeared to be underpinned by a belief that they had only a limited opportunity for pleasure:

Food is one of the few oral pleasures that a lot of people with learning disabilities ever get within a mile of (Project leader 6).

I think one of the few erm pleasures a lot of these people have got is food you know (project leader 1).

Another project leader concern was that they could not police what the service users were eating in the home environment with this being a source of tension between the day centre staff and the family carers:

I don't want to incriminate anybody but I'd say that the service users that live at home with parents tend to be more overweight than the service users who are supported in their own tenancies by agencies. Erm, and it's, you can just about look at each one and see who's supported in a house and who's supported by their families. Erm, and the demographics show that the, most of our service users come from sort of poorer backgrounds if you like, erm to the point that, where most of their income is the incapacity benefit that the person, offspring bring in because of their disability. So very difficult to get them to change, erm, and really, is it our place to do that? You know? And

you're really taking with one hand and giving with the other, we're trying to do one side of things then they go home and weekends and evenings they're stuffing their face with whatever keeps them quiet and happy I suspect (Project leader 1).

The paid carers also felt that unhealthy eating habits were developed and maintained in the home setting:

She has quite a sweet tooth and I think...I don't know how long she's actually had it...so it may be that she's going down the same road as her mum (Paid carer 2).

Some parents will specify to take their kids to soft play and then McDonalds for their tea (Paid carer 6).

I would say going by the photos that we saw last week on her phone it is not as healthy as it could be at home (Paid carer 8).

Of course, the problems of unhealthy eating in families are not unique to families including someone with an intellectual disability. However, some family carers described additional challenges. Food could provide structure and routine and they used it to manage challenging behaviour. Service users could be resistant to changes in diet and become difficult: moodiness, conflict and lack of cooperation were mentioned, sometimes involving serious and entrenched difficulties.

For example, one father (Family carer 5) had twin adult sons with severe autism, prone to violent and challenging behaviour. The meals the father served had to contain specific ingredients for example, a particular brand of cheese and shape of pasta in macaroni cheese (which had to be served on Tuesday and Wednesday) in order to taste, smell, and feel 'just right'. Otherwise there was a serious risk of his sons hurting themselves or others. He spent significant amounts of time trying to buy the right ingredients within a very limited budget.

Even in less extreme situations, attempts to change food habits were generally perceived by parents as having negative effects on family/home life. Food practices had developed over years, and were often contextualised by continuing struggles and hardship in day-to-day life. Most of the participating families also lived in deprived areas with limited means. For example, as the quotation from project leader 1 above indicates, many of the families relied upon the state benefit income they received that was paid to them due to their offspring's disabilities. In this context weight management was often not top priority, and meals were made up of foods reflecting traditional and affordable ingredients, which were not particularly healthy.

Another issue was that, as they aged, parents felt that they were less able to care for their child. For example, after a back injury one father was barely able to cook for his daughter, so most evenings she would have a packet of biscuits and a flask of coffee, which she would eat in her bedroom (Family carer 6).

Discussion

The day centres where the paid carers and project leaders were employed fit the description of a 'community of practice' that is offered by Bradshaw and Goldbart (2013: 3). Within this type of setting, social learning theories that promote the importance of interpersonal relationships to transfer knowledge by 'learning by doing' are the most frequently utilized form of training for staff groups (Bradshaw and Goldbart, 2013: 3). Socially learned behaviour is defined as action that is guided by the observation of other people's behaviour. Social

learning has been classified in the literature in a number of ways for example stimulus enhancement, contextual imitation, response facilitation and observational conditioning (Rendell et al, 2011). What is of significance here is that the service users formed personal relationships with the paid carers and were immersed in an environment that valued knowledge transfer between staff members, which relied upon learning by doing. The lack of consistency about the foods available and chosen may have led to additional uncertainty for the service users, leading to an increased propensity to make impulsive food choices (Willner et al, 2010), based in part on what other people were choosing at the time.

People do not always make healthy food choices, and this applied to service users in this study. There were four salient issues at day centres: Day centre staff facilitating unhealthy choices, including using high fat sweet food for various social purposes; service users being momentarily influenced by the eating behaviours of staff and other service users; a model of weight loss by diet rather than by healthy eating; staff views that eating habits were created at home but that they did not have the right, or competence, to try and modify them.

At day centres, there were concerns amongst some staff regarding unhealthy food choices, but at the same time some staff behaviours promoted unhealthy choices. Questionable behaviours included the inclusion of unhealthy choices on the canteen menu, such as fried foods and high fat cakes and treats, the provision of unhealthy foods for treats, special occasions and sociability, and

the use of treat foods for social bonding between staff and service users. These behaviours were taken for granted and largely unchallenged. This contrasts for example with the more directive healthy eating policies widely adopted in schools and hospitals. The dominant model of the day care centres appeared to be the social model that considers people with intellectual disabilities to be adults fundamentally entitled to autonomy and choice. This should not change in the interests of health promotion, but autonomy and choice does not necessarily extend to tolerating staff promotion of unhealthy choices, either by inappropriate menu planning, or by activities involving treats or the preparation of unhealthy food. Marshall et al (2002) propose that paid carers need to receive training to ensure they are able to offer an appropriate level of care to service users with intellectual disabilities. Furthermore, they suggest healthy eating goals should feature in 'job descriptions' and 'staff supervision' (Marshall et al, 2002: 152). It would also seem appropriate that day care services developed specific healthy eating policies and practices, which for instance regulate the availability and use of high fat high sugar foods.

Health choices cannot be divorced from the social and economic circumstances in which people live. Neither is the relationship between food and health confined to its nutritional importance: food has a social and emotional significance (Rogers, 2009: 13).

Another issue was that despite knowledge of healthy choices, food choices depended also on the social setting of eating at the day centres. Rogers, (2009) identifies shared mealtimes as being social events that offer emotional importance to individuals. The meals selected in the canteens at the day centres were consumed in communal eating spaces. Service users would eat their food with other service users with the paid carers reporting that service

users would choose to sit in friendship groups. Of particular significance to this study is the assertion made by Chadwick and Crawford (2005: 40) that the influence of environment on eating behaviour 'is largely outside the conscious awareness and may influence food choices even when individuals are consciously aware of such influence and wanting to behave differently.'

Following on, Willner et al (2010: 387) found that service users with intellectual disabilities frequently make decisions 'impulsively' by 'choosing the immediate reward' and have difficulty making consistent choices. Willner et al (2010: 388) further assert that individuals with 'a diagnosis of "learning disability" could be assessed as lacking capacity...' The Mental Capacity Act (2005) specifically emphasises that capacity be assumed as a starting point, followed by assessment if a person's actions suggest that it is compromised. Therefore, it may be appropriate to take their eating behaviours as evidence that their capacity is limited, especially when both they and their families express the desire to lose or manage weight. It would then be appropriate to structure services so that choices are less easily made primarily on the basis of there being unhealthy food available and other people consuming it, or offering it to them. This would be the least restrictive option that services could take and is in keeping with policies that have been adopted in other settings such as schools and hospitals.

Service users knew the types of food that they should be selecting for health, but nonetheless they often chose unhealthy options, because these were

available in the canteen, or as items provided by care staff, and because the social setting facilitated these choices.

Another issue was the common family carer understanding of 'the diet' as the means of losing weight, where this consisted primarily of replacing unhealthy foods with low fat/ low sugar alternatives. Marshall et al (2002) suggest that carers of individuals with intellectual disabilities have a more significant impact in addressing poor diets than health professionals such as doctors and nurses. It is therefore necessary for carers (both family carers and paid carers) to promote long-term healthy diets rather than promoting short-term changes that may not lead to sustained improvement in the health of individuals with intellectual disabilities.

The final issue was that the staff view that eating habits were learned and maintained in the home contributed to inconsistent practices regarding healthy eating. Day centres used the philosophy that service users had the right to make informed decisions and that they were 'adults' (Paid carer 1). According to this autonomy and choice model, paid carers should let service users choose the food that they wanted, and support them in those decisions. According to the model, it was unfortunate that decisions were often unhealthy, but unavoidable because food choices were learned at home.

Therefore, paid carers and project managers struggled to reconcile the part of their role that involved more active health promotion (for instance encouraging

healthy food choices more robustly and hoping the effects diffused back home) with the autonomy and choice model.

In response to the duty of care that the paid carers and project leaders articulated that they had, there was evidence that the paid carers were keen to limit the extent to which they could be responsible for the poor eating habits and food choices that the service users made. This manifested as tension between the family carers and the paid carers. However, there was a greater level of dissatisfaction about what happened in the home environment than that articulated by the family carers about what happened in the day centre. This may have been driven by the pressure felt by the paid carers about the health and wellbeing of the service users with the paid carers having a level of professional responsibility. By including the need to promote healthy diets at all times in job descriptions as Marshall et al (2002) suggest this avoidance of responsibility may be minimised and paid carers may work more consistently to deliver in this key area.

Moreover, paid carers' suspicions that unhealthy eating habits were learned and maintained at home should be reason for more action, not less. Staff were probably correct to express concerns about service users' diets at home, but this was a complicated and sensitive issue. There is a clear need to implement a Care Programme Approach (<http://www.nhs.uk/CarersDirect/guide/mental-health/Pages/care-programme-approach.aspx>, accessed 20th March 2014), so that service users, their families and their paid carers agree about diet and appropriate food choices whilst in the day centre or otherwise under

professional care. An individual's care plan should include agreed solutions to personal and situational barriers to healthy eating. For example, the plan should consider any limited or rigid food preferences, and offer strategies to enhance the diet by getting people to try healthy foods as well, rather than prohibit the preferred foods. The plan should also consider the reality of the food available in day centres and what other people tend to eat there, as this may not be readily changed in all centres. Finally, the plan should not be puritanical, but recognise that food is a valuable source of pleasure, as well as nourishment. A potential difficulty is that not all service users had formal NHS contact, or an NHS key worker, which identified them as a person who should have a care plan. There may also be a need for day centres and families to discuss healthy living less formally.

As well as the Care Programme Approach for individuals, there is a general need to have policies and practices encouraging healthy eating at day centres, as has happened at many hospitals, schools and colleges. If service users learned to model and enjoy healthy eating behaviours, then they might bring some of those home.

Ideally project leaders should address issues of choice and capacity, and how decisions could be influenced in a way that gave the service users the freedom to make decisions but with the range of choices being offered consisting of food that is consistent with a healthy balanced diet. As Marshall et al (2002: 152) assert 'managers and staff have a responsibility to ensure that their clients are making informed decisions, and to balance the client's right to choose with their

own duty to care.’ Furthermore, paid carers need to be more aware of the influence they can exert by the action they take. From the perspective of the service users’ the paid carers occupied a position of power. By promoting activities in the day centre such as cake making and by bringing biscuits and chocolate into the centre to share with the service users mixed messages were being sent. There is a need for consistent policies and practices and enhanced staff training about health promotion.

To contextualise these results and conclusions, it is important to emphasise that the issues and solutions offered are much the same as those for obesity and unhealthy eating in the general population. Everyone has the capacity to make free and informed choices about their diet, yet the obesity epidemic itself indicates that peoples’ capacity to consistently make healthy choices is limited and requires effort, changes in social norms and attitudes, and the availability of healthy food choices that are actually going to be chosen in the moment.

In summary, the evidence presented here appears to suggest that more effective ‘working in partnership’ between the various actors tasked with the caring responsibility, would lead to better long term outcomes for the service users and perhaps for others in the households in which they lived. Food choices and healthy living should be part of people’s care plans.

References

Birks, M. and J. Mills (2011) *Grounded Theory: A Practical Guide*, London: Sage Publications.

Bradshaw, J. and J/ Goldbart (2013) ‘Staff Views on the Importance of Relationships with Knowledge Development’ in *Journal of Applied Research in Intellectual Disabilities*, doi: 10.1111/jar.12020

Cameron, L. and J. Murphy (2006) 'Obtaining consent to participate in research: the issues involved in including people with a range of learning and communication disabilities' in *British Journal of Learning Disabilities*, **35**, **113 – 120**.

Chadwick, P. and C. Crawford (2005) 'Human food choice and nutritional intervention' in *Nutrition Bulletin*, **38**, **(1)**, **36 – 42**.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*, London: Sage Publications.

Doody, C. M., and O. Doody (2012). 'Health promotion for people with intellectual disability and obesity' in *British Journal of Nursing*, **21**,**(8)**, **460 - 465**.

Emerson, E. and C. Hatton (2008) *People with Learning Disabilities in England*, Lancaster: Centre for Disability Research, Lancaster University.

Glaser, B. and A. Strauss (1967) *The Discovery of Grounded Theory: strategies for qualitative research*, London: Aldine Transaction.

Marshall, D., McConkey, R. and G. Moore (2002) 'Obesity in people with intellectual disabilities: the impact of nurse-led health screenings and health screenings and health promotion activities' *Journal of Advanced Nursing* **41**, **(2)**, **147 – 153**.

Payne, M. (2005) *Modern Social Work Theory*, Basingstoke: Palgrave macMillan.

Rendell, L., Fogarty, L., Hoppitt, W., Morgan, T., Webster, M. and K. Laland (2011) 'Cognitive culture: theoretical and empirical insights into social learning strategies' in *Trends in Cognitive Sciences*, **15**, **(2)**, **68 – 76**.

Rimmer, J. and Yamaki, K. (2006) 'Obesity and intellectual disability' in *Mental Retardation and Developmental Disabilities Research Reviews*, **12**, **(1)**, **22 – 27**.

Rogers, J. (2009) 'Whatever's on her plate: Food in the Lives of People with Learning Disabilities' in *British Journal of Learning Disabilities*, **26**, **(1)**, **13- 16**.

Scottish Executive (2004) *Improving the Health and Wellbeing of People with Learning Disability and/or Autistic Spectrum Disorder*
at <http://www.chp.scot.nhs.uk/wp-content/uploads/Improving-the-Health-of-People-with-Learning-Disability-and-or-Autistic-Spectrum-Disorder.pdf>
(accessed 9th May 2013).

Spanos, D., Hankey, C., Boyle, S., Koshy, P., MacMillan, S., Matthews, L., Miller, S., Penpraze, V., Pert, C., Robinson, N. and C. Melville (2013) 'Carers'

perspectives of a weight loss intervention for adults with intellectual disabilities and obesity” a qualitative study’ in *Journal of Intellectual Disability Research*, **57, (1), 90 – 102.**

Willner, P., Baily, R., Parry, R. and S. Dymond (2010) ‘Evaluation of the ability of people with intellectual disabilities to ‘weigh up’ information in two tests of financial reasoning’ in *Journal of intellectual Disability Research*, **54, (4), 380 – 391.**