

Choice and Control over Food and Cooking

**For people with learning disabilities in
Brighton and Hove.**

Report By Brighton and Hove Speak Out.

**October 2010
(updated feb 11)**

**Consultation with Big Meeting and Advocacy Groups Network
In partnership with Brighton and Hove Food Partnership.**

Choice and Control over Food and Cooking for People with Learning Disabilities.

Background to consultation

The advocacy groups' network consists of three advocacy groups and the Big Meeting, which is a bi-monthly meeting for all advocacy groups, and user forums around the city. Supported by Speak Out, individuals at the Big Meeting give feedback on their lives. The Link group takes issues raised to the Learning Disability Partnership Board. This report reflects the feedback from the advocacy groups' network.

Over the last two years individuals within Speak Out advocacy groups have raised issues around lack of choice and control over food and cooking at registered residential care homes. Others living more independently have raised the need for developing cookery skills.

In response to two advocacy groups interest in menu planning and cooking, the Brighton and Hove Food Partnership worked with Speak Out on cookery demonstrations and skill development. These were enjoyed by the groups but highlighted the lack of experience people with learning disabilities have had in food preparation and cooking. It was clear that many people had not had the experience of handling ingredients, chopping and preparing food and using a cooker. The need for accessible participatory cookery sessions, and 1:1 support for some individuals was highlighted. Also raised was the issue of accessible recipes. Subsequently the Tuesday Speaking Up group has given some feedback on accessible recipes developed for those with English as second language. One person with mild learning disabilities took part in the Food Partnership's Cookability Course designed to teach cooking skills, techniques, and nutrition aimed at those wishing to pass on cookery skills to groups. Although this person gained skills from the course that she is now using, she felt that in order to participate fully she needed 1:1 support.

Asking one of the groups if they would take the recipe home and get support to cook it, only one person felt confident to do this and that was to her parent's house not at her residential care home. The food sessions illustrated the enthusiasm and curiosity around food and the desire to be involved in cooking food.

Brighton and Hove Food Partnership who offer cookery development skills to community groups wish to engage with people with learning disabilities and offer them appropriate support. In partnership with Speak Out they have been talking to the two advocacy groups interested in food. Speak Out has also asked for feedback on this issue from a wider group at the Big Meeting. Consultation with people with learning disabilities included feedback from 16 people at the Big Meeting July 2010, 7 people from the Tuesday Speaking Up Group and 10 people from the Loud and Clear group in September 2010. Those consulted included people living in registered residential care, shared

lives placements, living with parents and living independently with floating support.

Quotes in the report represent common experience rather than just individual.

The Issues

Food Preparation and Cooking.

Access to the kitchen and Food

In February 2009 at the Big Meeting an individual raised an issue within her registered residential care home they were being refused drinks and only given them at regulated times. A lack of choice and control and a fear of complaining by residents was raised in several registered care homes. To address this several pieces of work were undertaken to increase choice and control and to support people with learning disabilities to understand their rights around raising issues. The impact of this work can be seen from the feedback from one person living in one of the care homes where work took place.

September 2009

Said she doesn't get choices about what she eats and she is not involved in cooking. She loves cooking and when she stays with her mum she cooks

November 2009

She told us she was very happy about big changes at their house. The inspectors came and told the staff they need to stop doing things for people and help them to do things for themselves. *'Everybody in our house is doing their own thing, making breakfast, making their own packed lunch'*

March 2010

She told us in her house now some people get chance to cook. They make their own biscuits, pizza. They have 1:1 support

Subsequently in February 2011, this person has feedback that no-one is cooking again, although residents express they want to. She is not sure why.

Although there was a temporary improvement in one home, it was evident from the consultation that this was not happening in other residential care homes. The majority of people consulted who live in residential care and some shared lives are still not involved in food preparation and cooking.

Two people fed back during the consultation that they make their own sandwiches or cake but on further questioning this seemed to be a one off occasion. Where people were being given the chance to make their own sandwiches it was clearly a unique experience for them.

Two people said in their residential home staff go to the fridge, choose food, get it out and make tea and packed lunch.

Two other people said they were actually not allowed in the kitchen. *'They think you might get scalded. It's dangerous. Don't do any cooking. They think it's dangerous.'*

The other said *'I am not allowed in the kitchen. Only one person is allowed who is steady on their feet. The staff are worried about people with epilepsy being in the kitchen.'*

One person felt she can't cook because of difficulty seeing things and her hands not being dextrous enough. She said she had made her packed lunch once, *'I like doing it.'* During a cookery session at Speak Out this person was chopping food for a recipe.

Several people who make drinks independently outside of the home are not allowed to touch the kettle at home and make their own drinks.

'Do cooking at Walsingham Road. Don't do it at home.'

Where people are doing some cooking in residential homes it can be very infrequent and not actually integrated into making meals. One person said he made cakes at home occasionally but he doesn't cook meals.' *They do it for you.'* He felt using knives was difficult for me.

In some houses it appears there is a cook who makes the meals with little room for involvement for residents. *'We've got a cook in the house. He does the dinner; I get my cooked dinner from him.'*

All this points to a lack of flexibility, over-caution in risk assessment and lack of support or skill available to facilitate involvement in activity in the kitchen.

Two people lived independently in their own flat within a supported housing complex with floating support said they only eat tinned vegetables because they are worried about cutting themselves on the knives. They said they liked fresh stuff and healthy food but eat tinned food. This means that they are not getting the benefits of nutrient rich fresh fruit and vegetable. When making a salad was suggested the idea was taken up with enthusiasm. Several people in this living situation are supported to use microwaves rather than the oven. This may mean they are eating pre-prepared food rather than cooking with fresh ingredients. Three of the people consulted wanted to learn how to use their ovens. One person with a fully equipped kitchen was going out to cafes

for every meal. He said he hasn't had any help '*The homemaker, they are busy they say.*' He is now being supported to learn cooking skills.

Developing Cookery skills

Both Speak Out advocacy groups wanted support to develop their cookery skills. Several people wanted specifically to know how to use a cooker.

Only one positive example of all round staff support emerged in the feedback from one young person in a residential home focussing on life skills. She is supported to plan menus, shop and cook her own food and think about healthy eating.

Choice of Food and Drink

Only 3 people from residential carehomes told us they got a choice of what to eat each night.

In one home there is a meeting to decide what to eat and another home people could choose from a choice of dinners.

One person said, '*When so and so is on you have to eat what's given to you.*'

Two people who help themselves to drinks and snacks said there were two days in the week where there's hardly anything in the fridge. There is no more until the weekly shop. If they want for e.g. yoghurt they have to buy it themselves.

Another person in a shared lives situation said she doesn't get a choice of what's for dinner. She helps with shopping but is not allowed to cook only make sandwiches.

In one extreme example of lack of choice, someone told us that, '*Don't get to choose or make own dinner or lunch. Staff choose it. Give me food don't like and I just leave it. I don't like pasta. I have it four times a week.*'

Healthy Diet

The Tuesday Speaking Up Group invited a health promotion worker into the group in 2008 to talk to them about healthy eating, salt and blood pressure and food and diabetes. Generally people are not very informed about healthy eating unless they have diabetes or a particular health condition. A few people

are concerned about weight but are confused about the messages they have had around food and weight.

One person who has recently been diagnosed with a heart problem has been given more in depth dietary advice and is feeling empowered by being able to positively influence health through changes to diet.

One person with diabetes wanted information on possible puddings rather than piece of fruit she was given every day.

Nutrition is definitely an area where people have limited knowledge. Increasing knowledge would help people make their own choices around shopping, menu planning and cooking.

Growing Food

Several people had positive memories of being involved in growing food in the past either with a parent/carer at an allotment or in a residential care situation. They were keen to be involved in growing food at home again.

A few people work on allotment projects and one person would like to at weekends but doesn't have transport. One person when asked if they take food home from the allotment to be cooked said, *'I don't eat them. They get taken to another centre. Took potatoes home once to carer. Would like to. Eventually I'll ask.'*

Another person who studies at Plumpton brought home a tomato plant to look after at home which was put in an inaccessible place that she couldn't get to.

These two examples show a lack of value placed on the skills people are developing and a lack of confidence in people demonstrating what they have learnt at home.

Summary of Consultation.

- **Everyone with learning disabilities wanted to prepare and cook their own food, and choose what they want to eat.**
- **Skills people are developing outside of home situation are not being valued, used and built on at home in the kitchen and garden**
- **Very few people are choosing food, shopping and cooking in registered residential care homes.**
- **More consultation needs to be done with people with learning disabilities around understanding of healthy eating and the information they would like.**
- **Both people in registered residential care and living more independently need support to develop cookery skills and confidence with equipment and kitchen tools.**

- **Several homes and staff do not want residents in the kitchen and fear for dangers of kitchen equipment. The way risk assessments are done needs to be looked at.**
- **Residents' access to their own kitchen and food must be addressed.**
- **Barriers are put in the way of people participating in cooking and these reinforce people's lack of belief in their skills.**
- **Creative approaches to involving residents in choosing and cooking food need to be explored and implemented**
- **Training of staff in facilitating cooking and healthy eating advice needs to happen.**
- **Some people would like their residential homes to grow food in their garden and be involved in this.**

Increasing Choice and Control

Following on from this consultation Speak Out and the Food Partnership are working on a project proposal to increase choice, control and skills of people with learning disabilities alongside training support staff. The Food Partnership are finding out from support workers and residential homes what the barriers are to involving residents with cooking and what training needs the support workers have.

A pilot project, is proposed run jointly with the Food Partnership Cookery Development Workers and Speak Out Advocacy Worker/Nutritionist. They will work with both people with learning disabilities and support staff. Participants with learning disabilities will develop cookery skills, explore ways of being supported in cooking and develop knowledge and skills around healthy diet. They will cook for the support workers demonstrating their skills. Accessible resources will be developed. Issues highlighted by participants will be feedback to support workers. The support workers will be trained in cooking, facilitation, and healthy eating. Funding is needed to develop and run this project.

In addition to the proposal for a cookery project, the Food Partnership can offer advice and support to residential homes to start growing food in their garden.