

Brighton and Hove

SPEAK OUT



Advocacy Project

Health

Information from The Big Meeting and Advocacy Groups June 2011

41 people with learning disabilities gave their views in this report including

- 4 Speak Out groups
- Belgrave Day Service,
- Avondale Day Service,
- Scope (2 homes),
- Care Co-ops
- 1 independent person

People taking part ranged from those who receive no service at all to those who receive 24 hour care.

Health Workshop

We all got into different groups to talk about different areas of health. These were:

- Staying happy (mental health)
- Health Action Plans and other accessible health tools
- Accessing health professionals
- Staying healthy

Brighton and Hove Speak Out, Manor Offices, c/o Emmaus, Drove Road, Portslade, BN41 2PA

T: 01273 421921

E: info:bhspeakout.org.uk w: www.bhspeakout.org.uk

Registered Charity No 1076995

Registered Company No: 3807112

Staying happy/mental health

The things that made people happy were:

- Doing art to help forget stress and express myself (3 people do this)
- Go for a walk to make me feel better
- Seeing my dog. Talking him out for walks always makes me feel happy
- Being sociable and being round people
- Go to films...happy ones
- Eat chocolate!
- I do lots of colouring and drawing
- I help people a lot...disabled people
- Help people
- It's important to have something that makes you feel important
- N lives in a small house which makes her happy. It's her birthday soon so she'll go for a meal to Devils Dyke and drink wine!
- Like seeing family (3 people)
- Like seeing my sister's kids
- Going to my day centre (3 people)
- Having people around me
- Helping at D's home (person with learning disabilities has a job supporting Residents group Meeting at a registered care home)
- Helping other people
- Having my own TV in my room
- Going to Speak Out and seeing friends and having a laugh
- Having residents meetings so you can say what you like, .they take notes
- Having a girlfriend and being in love
- Doing the relationships course at the day centre...to learn about relationships
- Water gardens
- Do the Moulsecoomb allotments
- Someone told us that the owner of their home had tried to put them off from having a gay relationship which the 2 people with learning disability had started.. This made them feel awkward
- Staff argue with each other in front of residents in my homes. Residents don't like it. It makes us feel unhappy.

Things that would make me happy

- Seeing my friends outside the day centre...staff don't offer to help.
- Getting help with a dietician. I'm on pills that make me eat more and I want help
- I would like to go out for a meal with my boyfriend. (X lives in the same residential home with boyfriend but has never been out with him. They stay in and watch tv together)

When I'm not happy

- I go quiet and pace up and down
- Do art to help me cope
- Get very anxious so I don't want to be with people
- I tear my clothes
- An advocate recently reported that his partner (person with learning disability) who has an existing health complaint and lived alone was in the habit of calling the ambulance 5 times a week due to the stress of experiencing pain alone. He has since moved to a flat in a larger complex and has people around him. Since moving, he has called the ambulance once in 5 months.

Summary of important issues regarding mental health

- **People want relationships and friendships.** People need the support to see friends and partners outside regular planned activities such as day services. Whilst many people would like this, some houses do not offer this support to people at all. Residents often accept this as they do not feel they can challenge their homes or have the right to ask to see their friends. It is something they would like to do but accept that they can't
- **People want to feel useful and important.** 4 people talked explicitly about needing a role in society and needing to feel useful and help others.
- **2 people at the meeting had suffered bereavements in the**

past week. Neither of them took any time off their normal activities. It brings up the question whether people are supported well with bereavements.

- **People need good support around issues to do with sexuality.** Staff should not impose their own moral views of relationships on people with learning disabilities.
- **Staff need to make sure they do not argue in front of people with learning disabilities**

Health Action Plans and other accessible health tools

- People looked at Hospital Passports, Health Action Plans and health pictures and said what they thought about them
- T, M and K had not seen Health Action Plans
- No one in one group (8 people) had HAP, Health Assessment or Hospital passport or knew that they had them
- K went to hospital for a broken hand. She has broken it 3 times. The second time she broke it the hospital did not plaster it or explain clearly to her why they were not plastering it. She felt they were messing her around. It did not heal properly and she still gets pains from it. They did not give clear information and they did not listen to her.
- Accessible pictures are useful for Doctors to tell you information
- 'good information pictures...would like to show them to the Doctor
- Some people thought pictures would be useful to help health staff to work with people with learning disabilities
- Someone at the meeting with complex needs pointed to the happy, sad faces and seemed to find these meaningful.
- M thinks he has a hospital Passport but does not know where it is kept or if it was used when he went into hospital.
- Other people say they would like a hospital passport. It is colourful and accessible. People like it.
- M is not sure why these tools are not more accessible. He thinks the council should run a small accessible workshop at the King Alfred Centre for people with learning disabilities to understand these tools
- Doctors have hospital passports
- Moved to different surgery....have to ask for HAP. It took ages for old Doctor to send his info to the new doctor. I don't know if he sent the old HAP.
- My notes weren't written up from the Annual Health check
- Trying to stay healthy need support.
- What food is slow releasing?
- Hospital passport good for doctors. It's giving the doctors and

- hospitals , more information
- My Health Action Plan: need to go through it to find out more information
 - S doesn't have Health Action Plan or Annual Health Check as had no support worker
 - People liked the accessible e.g Health Action plan with one sentence and a picture on each page.

Summary of key findings about accessible health tools

- **People owning their own plans**

22 of the 23 people at the Big Meeting do not think they have a Health Action Plan. This does not mean that they do not have one or their health needs are not catered for. However, as the Health Action Plan is meant to be an accessible tool for people to use in order that they understand their own health needs better, it is not a good sign that they have no knowledge of them, let alone have their own copy to keep (as they should do). There is a need to promote Health Action Plans to people with learning disabilities so they can start to take more responsibility for their own health.

- **People like hospital passports**

They are colourful and accessible. One person at the meeting has one. No one else thinks they do. If they do have one it is not familiar to them and they don't know where it is kept.

- **People who do not get support from social services do not get a Health Action Plan from doctors even though they say they would find it useful**

- **People liked accessible pictures ' If can't read there are pictures, it's good.'**

People liked the picture tool which is on the Brightpart website for health professionals, but had never seen them being used by Doctors, Nurses etc. These tools are available and they should find a way into being used by mainstream health services to support the understanding of people with learning disabilities

Going places, seeing people.....

Seeing Doctors and other health professionals

Positive/neutral

- go to the dentists every 6 weeks and see the same dentist'
- 'I go to the hospital for blood tests'
- 'the optician...see him at home'
- I get supported to see the Doctor when I feel I need to
- GP at Whitehawk sorts you out
- GP tells me what to do to help myself
- S likes the hospital because they are friendly and nice when they give her regular tests
- Would like to see a dietician. I would like to see what food is healthy. I am not sure how to access dietician. Nurses tell me to go to the gym.
- 'see the dentist at home'
- Staff make regular appointment for me. A lady from Conway Court came and helped me to learn to clean my teeth. I had pink teeth and had to clean them'
- 'I can understand them' (Doctors etc)
- My keyworker helps me to understand letters
- 'I cannot understand (letters) so staff read it to me'
- 'Quite happy with Doctors hospitals'
- 'yes, happy'
- 'I like hospital'
- 'doctor is round the corner...isn't far. Receptionist is nice. Doctor is ok'
- One person felt the nurses looked after her and exercises helped me.
- Good chemist at Seven Dials. They bring it to the house.
- 'went up to see the doctor at the hospital, had support, good.'
- One person had hearing tests at hospitals, they asked her to put shapes in a box. She could not understand what they said. Somebody came and signed it which was better.

Negative

- K didn't see a doctor and wanted to
- K did not like cold food in hospital
- 'Doctors aren't doing their job right. They are not giving us an idea what they are doing...not helping. Give us more information. Don't tell us that they cannot do anything to help. We asked him (the Dr) to send a prescription to the chemist but he just doesn't do it. Then the chemist start to moan at him. I don't have a HAP. Doctors doesn't want to listen. Go to support team to get help.
- 'I hate hospital'
- 'I don't like hospitals'
- 'Haywards Heath hospital is better than Brighton one, nice and new.'
- Hospital ' Stayed for four days, I was bored.'
- My house does not take me to the doctors when I say I need to
- 'I don't go to a dentist...haven't got one and I would like to go to a dentist' (Tony)
- 'I get annoyed at my dentist. She had to re do my filling'
- Dentist tell me off for not brushing well. I have phobia of needles'
- 'places are not easy to get into in a wheelchair'
- 'sometimes we have trouble understanding Doctors and nurses'
- 'They need to slow down'
- 'I don't always like going to the Doctors. They might find something wrong with me. I could talk to staff to make it better. Doctors should be more helpful. Sometimes they say things I don't understand'.
- 'don't like the dentist'
- 'Doctor is cold as ice'
- 'Receptionist is horrible'
- One person who had stopped having physiotherapy wanted support to move her limb.

Support for people to access healthcare

- One person who lives in a supported housing block but gets most support from outside agency felt had no help at home when she was seriously ill, ' I told them I wasn't well. I wanted

somebody to help me get up. They came in the room and told me to get a tablet and go back to bed. I'm not on their list because I am independent. Was dragging myself to friend's flat. He called staff, they got ambulance'

- At recent Speak Out training event, Sheltered Housing manager raised issue that someone with learning disabilities who lives there just hasn't been to the dentist because her support package does not include this. She was not convinced a care review would address this.
- Worry from a few people that if they are ill they will give it to staff.

Summary of what people think about seeing Health Professionals

- **Some people are happy.** They get the support they need, like the health staff and understand what's going on
- **Some people do not like accessing health services.** It is unclear why this is. Some people obviously fear what might happen. There is room to do extra work on what people's fears are and what can be done to alleviate them
- **People with milder learning disabilities don't get the support they need to access healthcare**

About staying healthy

Food and drink

'I eat well. Fruit.' (3 people)

'I eat lots of fruit and loads of oranges...give me vitamins'

'I would like to know what food make fullness as can't eat pasta'

'I don't always buy fruit like you meant to'

I like fruit' (3 people)

'I eat salads and fruit. Staff help but I get them when we go shopping. I choose'.

'We can't eat salads

B talked about not getting to eat salad at the moment because there has been an ecoli bug on salad vegetables in Germany. She's missing eating salad.

Healthy lifestyle choices

'I would like to ride a bike'

'I drink 1 glass of wine a week'.

'Very picky with food'

'need more information'

'I do not smoking'

'I go out for lots of walks and bus rides. Gets me out in fresh air. I would like to go out to a gym but I need more money to go to a gym'.

'get exercise and eat right amount of food'.

Eating the right food...fruit, salads (2 people)

'doctor gives advice on losing weight...do exercise, running'

'tried to do more than 30 minutes...do it fast walking'

'I like walking'

'I like jogging'

Want to know what food will calm you down...slow release

1 person was not aware at all about healthy eating...relied on carers to provide healthy meals

What stops you being healthy?

'some kinds of food...burgers and chips'

'smoking. Too much caffeine, chocolate, rice pudding'

'tablets'

'I have tablets'
'can't do gym...feel less confident'
'want to do diet'
'can't swim...got problems with my ears'

'I would like to do more...to feel confident. I can't swim...i would love to.

Having health tests

'I have blood tests. It doesn't hurt'
'we have lots of tests on our eyes'
Dentist check ups'
'I have my feet checked'
'have blood, hospital, hearing test'
'they are alright..not always though'
'have my feet done'
'the man comes to my house to do my feet. My nails get long'
'the nurse was nice....blood test'
'I have blood test...they are good'
'I have CT screening'
'they are ok'
'blood tests...check my medicine. Good'
'see the chiropodist near my home...a lady'
'MRI scan, it wasn't too bad.'

Communication from Health services

- One person got a letter which alarmed her ' got a letter a few weeks ago and said I've got cancer and I've got diabetes. Had to tear it up. I cried.' *

Summary of issues about staying healthy

People need more information

People talked about understanding some issues relating to healthy diet and exercise. However they need more help to understand more subtle messages. Examples include

- someone being told she cannot eat salad because of the ecoli bug prevalent in beansprouts in Germany at the time.
- Alternative healthy foods ir pasta
- Understanding slow release food (GI)
- Health services need to know who on their patient list has a learning disability. Letters that they send out should be accessible so people understand them. (see *)

People need more support/information to carry out healthy lifestyle choices (eating and exercise)

People talk about wanting to try out different exercise options (gym, swimming, cycling) but either lack the confidence, money or understanding about how to access these.

It is unclear whether people understanding healthy lifestyle choices equates to people making healthy lifestyle choices.

People's experience of health checks seems to be limited mainly to blood tests, chiropody and eyes/dentist.

It's not clear how many people access other forms of health screening

Recommendations

Re mental health:

- Services should place a greater importance on supporting people to friends and partners outside the times of college courses , day services and other day activities and help to support them to have a meaningful role in society
- Services should include people more when people close to them pass away and support them better in their grieving
- Service staff should support people to make choices about sexual issues without imposing their own sense of morality

Re health tools:

- Services need to concentrate attention on involving people in their person centred health plans (HAP, Hospital Passports) so people themselves can be more proactive in making better health choices
- People with mild learning disabilities who do not access LD services would benefit from having Health Action Plans available in order that they learn more about maintaining a healthy lifestyle.
- People with learning disabilities would like more health services to use pictures in order to aid communication.

Re seeing health professionals:

- People with learning disabilities need more support to manage and understand the fears associated with seeing health professionals so they can get the healthcare and support they need.
- People with milder learning disabilities should get additional support to access health provision which is often not included in their support packages.

Re staying healthy:

- People need more information and support to make healthy lifestyle choices, not just be told what they should do

Re: communication

- Ensure letters are accessible and do not alarm people

Report compiled by Sarah Pickard and Ingrid Ashberry June 2011