

Learning Disabilities Focus Groups Summary

Executive Summary

Crime

All the participants that lived independently had experienced crime in one form or another. Living on a higher floor, double door entry systems and video intercoms were all thought to help with feelings of safety in the home.

On the streets many participants had been verbally or physically abused and people were confused about the correct number to call for the emergency services.

Transport costs were seen as a problem, the participants were often faced with the choice to not go out or to risk walking home alone in the dark as taxi's were too expensive.

The effects of crime were long lasting with participants citing serious long lasting issues coping with the fear and distress when they had been victims of crime.

Social Lives

Having friends and social groups to spend time with was valued but not everyone had the social life they wanted. In particular, organised network groups, charity groups and churches were valuable social outlets.

Barriers to having an active social life included time off work, lack of money, transport constraints, staffing costs, residential living area and frequent changes in circumstances.

Health

People were generally positive about the health services they used, GP's were considered friendly and explained instructions thoroughly. It was sometimes difficult to see your own GP (but this wasn't normally considered a problem). However, appointments were sometimes hard to book and frequently delayed. If it was difficult to get an appointment then people would use the walk in centre or A&E. People were also happy with the service from pharmacies.

Housing

Some participants felt their current housing situation was appropriate, stable and in a good area but everyone had some periods of unstable accommodation and most had spent at least some time in a hostel and/or moved in with family. Other reasons for being dissatisfied included house and/or local area being inappropriate for their needs, bullying or harassment in their neighbourhood, lack of/poor choice of housing/area.

In addition, all participants voiced fears about the forthcoming changes to benefits and none were entirely clear how it would affect them.

Most housing was housing association one person used a private landlord.

Some of the participants were very positive about their current living arrangements, saying that they felt safe had the freedom to do what they wanted and people were generally happy with the maintenance service provided by housing association Curo and with the service provided by private landlords.

Employment

All participants had worked at some point in their lives although secure, paid employment was difficult for people with learning disabilities to find. Barriers to finding employment include anxiety, poor health, discrimination, and application forms.

Some people lacked confidence about working due to previous bad experiences which included feeling out of their depth, communication issues, prejudice and bullying.

Participants felt that the employment issues were twofold and that both getting and keeping a job was difficult.

Rationale and Methods

A key element of the Joint Strategic Needs Assessment (JSNA) is public consultation. A gap was identified in the views of people with learning disabilities and so a series of focus groups was commissioned on five key topics to explore the views, opinions and experiences of people with learning disabilities living in B&NES.

The advocacy group “Your Say” worked with the PCT and council to develop and conduct the 5 groups.

Eight participants with learning disabilities took part in five focus groups, conducted in September/October 2012. Table 1 shows the age and gender mix of the participants.

First Initial	Gender	Age Group
P	M	25-30
B	M	60+
N	M	40-45
A	M	45-50
D	F	35-40
S	F	35 - 40
H	F	25-30
J	F	60+

Table 1: Age and Gender of Participants in focus groups.

There were 5 groups on 5 different topics and not all participants took part in all groups. The topics were health, social life, crime, employment and housing

Results

Crime

Taking part – B, P, N, J

This group consisted of three males who all lived independently and an elderly woman who lived in supported accommodation that was always staffed. As a result, the three males had all had experiences of crime whereas the female didn't – probably as she was with staff at all times. It would have been interesting to have the experiences of a woman who lived independently as well.

Crime at Home

Participants lived in quite different areas of B&NES. Generally Bath city centre, Midsomer Norton, Paulton and Timsbury were felt to be relatively safe areas to live in but a number of participants had felt very unsafe living in Fox Hill.

“I wouldn't recommend living in Fox Hill to anyone”

“If anyone offered me money to move back to Fox Hill for whatever amount of money, I would tell them no thank you.”

A number of participants had experienced break in's, vandalism and theft in their homes and one had experienced illegal forced entry from bailiffs. This left them feeling unsafe long after the experience was over.

“The bailiffs, what they did to the property and that has left a very lasting effect on the property and their presence is always there.”

“Every time after someone had been in our house it felt that they were still there like a ghost shadow.”

Participants generally thought that living on the ground floor made them feel less safe and that having more than one entry door to gain access increased feelings of safety. The trade button was cited a number of times as a problem as it meant that people could gain access to communal areas without a key or fob and therefore knock directly on people's front doors. It was thought that a video intercom would help participants to see who was there before they answered the door.

Crime on the street

On the street, most participants had experienced verbal abuse and bullying. Some had also experienced physical violence and others had been tricked and blackmailed.

“this man came up to me and he grabbed hold of me and started beating me up, I didn’t know him....he hit me and I ended up having a broken rib”

“A youth blew a whistle in my face and I grabbed his arm....then 6 weeks later he came up to me and said do you remember me, you grabbed me by the arm, well I’m going to tell the police about it as I’m only 19 years old...Then he borrowed money off me, he took money. He said you can lend me money...and I fell for that....I gave him money because I thought he really was going to the police”

One participant had also been the recipient of an intended attack at work.

“There was the incident at the previous cleaning job where the vacuum cleaner was rigged with a carrier bag that exploded, and I’ve never been able to return back to work again.”

Similarly to the crime at home this had lasting effects and had led to depression, anxiety and even in one case suicidal thoughts.

(referring to a previous physical attack) “I don’t think it matters how long ago it was, it always stays with you, you go on and do many things like meetings but those memories always come back”

“....I know about this time last year I had this operation and that the time I just wished I died on the theatre table. I have felt like cutting my wrists....”

Barriers to safety

During the discussions about crime in the home and on the street a number of issues arose that were barriers to feeling or being safe.

As mentioned previously, living on the ground floor made people feel unsafe and it was seen as preferential to live in a flat on an upper floor with more than one entry door.

Money was also seen as a barrier as lack of money often meant that if buses were not running then people had to walk places at night as taxi’s were too expensive, leaving people faced with the isolation of not going out or with the risk of walking home alone in the dark.

“Most of it is because of the buses, if I miss the 11’oclock one at night I can’t get home and I’m not paying nearly £35 for a taxi.”

Groups of teenagers were consistently seen as a problem and in particular around vandalism and attacks in the home but one participant was keen to point out that adults had also been a problem.

One participant had been tricked by someone he know who then bought friends to his house and stole from him

Sources of help

During the discussions participants often referred to people or situations that had helped them feel safer. If someone felt that a crime had been or was about to be committed they had turned to the police with mixed results, one participant was insulted by the police after a burglary.

“The police officer who came to see us told us that - well you both were thick”

People were also either unaware or unhappy with victim support services.

“That’s who I was on about as to me I don’t think they were good enough, they came for about two weeks and then they just left us.”

In particular the participants found the addition of another telephone number for the emergency services quite confusing.

“The reason I didn’t call the police because with the person who was harassing, I discovered that I called the wrong police emergency number, I called 911 instead of calling 999....I find that it may be a little confusing to which number to call”

“Yes”

“Its 101 now, then they ask you if you want 1: Avon and Somerset police or 2: Avon and Wiltshire police”

“I would call 999....but I might call 911”

Family, the advocacy group, and the church had provided support for people after an incident.

“Can you think of things that help you feel safe?”

“...going to church and meeting the people, it helps that you feel knowledge that meeting lots of different people that are good.”

Knowing people and feeling that people in the local area knew them also made people feel safer

“...I find that alright because everybody knows me.”

“I know there is a café by the bus station and they are ever so friendly”

People tried to find safe well lit routes home when they walked and to seek out populated areas when they felt unsafe

“I’m ok when I go out in Bath as there are plenty of people around and there are shops that I go into”

Conclusions

All the participants that lived independently had experienced crime in one form or another. Those who were living or had lived in Fox Hill had all experienced vandalism, break-in’s or theft whilst living there, whilst those living in other areas of B&NES felt safer in their homes. Living on a higher floor, double door entry systems and video intercoms were all thought to help with feelings of safety in the home.

Out on the streets many participants had experienced verbal abuse and physical violence, again, particularly in the fox hill area although also in Bath City Centre. The police had sometimes been a help in these situations but people were confused about the correct number to call.

Money, in particular relating to transport was seen as a problem as participants felt that when buses weren’t available, the choice was to not go out or to risk walking home alone in the dark as the cost of getting a taxi was too high.

Participants primarily turned to family, advocacy services (including Citizens advice Bureau), their local community and the church for help and support with crime issues.

The effects of crime were long lasting with participants citing serious long lasting issues coping with the fear and distress when they had been victims of crime.

Employment

Taking part: P, N, P, A

There were no females taking part in this discussion so it would have been useful to see if their experiences were similar to the males.

Generally the picture of employment was unstable, with jobs lasting a short time, often with low or no pay, punctuated by long periods of unemployment.

“It was only part time. It was like a temporary job and it finished, that job was in 1986-1987. I’ve not had a job for 20 years now”

Wanting a job

Most people wanted to work but had some reservations due to their ability to physically do jobs and meeting new people

“Well after that last job it knocked my confidence and I still wouldn’t know how I feel around people I don’t know.”

“Well I will be 60 next April so I’m not sure really. I really like time and I think in one way I should really be taking it easy. I would have liked to work”

“Well, I’m just a bit frail and if they get me to do anything heavy I may get a stroke”

In particular everyone was worried about the changes to their benefits caused by working

“I worked 5 days a week but my benefits got affected badly and that was a worry”

“Is that a worry for you all?”

“yes”

“always”

Barriers to work

Getting paid, secure work was seen as a challenge, with people citing ill health, tough economic climate, application forms and prejudice as barriers.

“...I find that there aren’t many jobs out there but there are lots of people applying for these...”

“You go down to a job and they ask you what you can do so I’ve told them I’m a trained gardener and had experience and all that then they turn round and say to me – you’re not good enough.”

“so you don’t think you got a fair chance?”

“no I don’t”

“...I think half the reason I can’t get a job is because I can’t answer the questions on the forms. I can do my name, date of birth and then after then I am completely buggered.”

“I would find that [filling in forms] difficult, my mum helps me”

Perceived barriers to work were varied and cumulative.

“If you had a choice would you want to work?”

“Depends on how time consuming it would be and I would worry about the benefits and being in the wrong job, being with people I don’t know and I hope this doesn’t affect my asthma”

Reasons for Loosing/Leaving jobs

Poor physical and/or mental health had contributed to many peoples leaving or loosing jobs.

“I had 8 months off work and I was badly ill and when I returned they gave me my P45, showed me the door and told me to get out. They just gave my job to someone else”

“...then they gave me the push, they said I had too much time off because I cut my hand”

Bullying had also sometimes been the reason for leaving a job.

“Something to do with a man saying something to me, he was being a bully so I went back home.”

“The supervisor expected me to do extra work for free, which I refused. I was forced to be terminated because I refused.”

And one participant admitted being fired for stealing some money

“I nicked money once, only a little but they said I had to go.”

However, some participants had spells in satisfying paid work and many participants had taken part in college courses and back to work schemes.

“I’ve done many courses at Bath College since then”

“I did my computer course down the college”

Participants felt that the employment issue was twofold and that both getting and keeping a job was difficult

“I feel that the Council any job that they find us that they have to do something like light work that they make sure that they keep you there and so you won’t get told off”

Conclusions

All participants had worked at some point in their lives although secure, paid employment is difficult for people with learning disabilities to find. Barriers to finding employment include anxiety, poor health, discrimination, and application forms.

Some people lack confidence about working due to previous bad experiences which can include feeling out of their depth, communication issues, prejudice and bullying.

Participants felt that the employment issue was twofold and that both getting and keeping a job was difficult

Social Lives

Taking part: N, P, S,

Two males and one female between the ages of 25 and 45 took part in this group giving a good representation of the genders although it would have been ideal to also have an older persons views on social lives.

All the participants clearly valued having a social life but the three participants had mixed experiences socially, with some having a wide circle of friends and family to socialise with and others feeling more socially isolated. There was also a wide variety of social activities that people undertook, including Bingo, sports, evenings out, church, volunteering, cinema. Many of these events were organised as part of social network events organised by voluntary groups and charities such as Mencap. They found these highly enjoyable.

“It’s that feeling, it doesn’t matter how much you spend all together. You feel good after having a good night out, I feel on a high after I have been out.”

“It’s cool, we have loads of fun”

Barriers to Social Lives

Time off work, lack of money, transport constraints, staffing costs, residential living area and frequent changes in circumstances were all cited as barriers to having an active social life

“time off working, how much I was working, money was very very tight. When you are on your own with limited funds its very very hard. I spend a lot of time on my own and it would be nice to get my life back on track”

“Pensford is nothing and you have no social life, all there is basically walking or pub life”

One participant pointed out that you needed friends to have a social life but that having a social life gave you more friends, so if someone didn’t have anyone to attend social events with it would be difficult to get started.

Conclusions

Having friends and social groups to spend time with was seen as valuable but not everyone had the social life they wanted. In particular organised network groups, charity groups and churches were valuable social outlets for the participants.

Barriers to having an active social life included time off work, lack of money, transport constraints, staffing costs, residential living area and frequent changes in circumstances.

Housing

Taking part: D, P, N, H

Two males and two females of ages 25-45 took part in the housing session, one of whom was in a wheelchair.

Some of the participants were happy with their housing situation, being housed in appropriate, stable housing in a good area but some were unhappy. Most of the housing was housing association although one participant topped up their benefits and used a private landlord.

Unstable Housing

Although some people were happy with their current living situation, everyone had some periods of unstable accommodation and most had spent at least some time in a hostel and/or had to move in with family.

"I moved between 2000 and 2004 I moved 6 times."

"I moved into a hostel and that was horrible, it was a total dive that was waiting for a refurbishment and there was over 20 girls living together and they used to beat the hell out of each other."

"When I came back [from college] I had to go and live with my mum and dad for a while. It felt weird living with my mum and dad because there was nowhere else for me to live then after I finished my course"

Inappropriate Housing

A number of people cited how inappropriate their house and/or local area was for their needs. In addition, a number of people mentioned having experienced violence, bullying and harassment in their neighbourhood, forcing them to seek to relocate.

"Its way too big for me and it's not easy to manage for a single person living in a two bed flat."

"...the next thing I will get them [Curo] to do is the kitchen so I can actually use my chair in the kitchen....., so if I can't stand for long enough I have to go for convenience food which isn't good."

"My problem is that I feel very isolated at times, I don't get out for days....I certainly feel cut off and I can't go anywhere because I live on a hill...The biggest problem where I live is the shop - CO-OP I can't get around and to get at the end of the aisles it's difficult in a chair."

Lack of choice

A theme that repeatedly emerged from the discussion was lack of/poor choice of housing. In addition, one participant wanted to move into the B&NES area

but wouldn't have been able to if he hadn't been able to move in with a relative.

"I didn't actually choose to have the property I was only allocated by the council."

"There were other properties we had to look at but they were not good for the areas especially being Snow Hill, very inappropriate"

"...there wasn't much of a future there so I was thinking of maybe coming into Bath, but because I was living in Wiltshire it was difficult because I was living in a different county...so I had to go and live with my mother who lives in Keynsham so had to be in the same country to apply for housing in Bath"

Fear for the Future

All the participants voiced fears about the forthcoming changes to benefits and none were entirely clear how it would affect them.

"That's properly one of the scariest things that I worry about when all the changes happen because I have a two bedroom property and at the moment I don't know if I am going to get enough benefits. At the moment I'm on disability benefits but no one can give me a straight answer and it's changing in April which is 5 months away and nobody can tell me what is happening."

Positives

Some of the participants were very positive about their current living arrangements, saying that they felt safe had the freedom to do what they wanted.

People were relatively happy with the service provided by the housing association Curo and with the service provided by private landlords.

One participant also pointed out how much things had improved in his housing situation.

"Back in 1986 I had to share with another male resident; I had to share the same bedroom, that is how much has changed."

"I live in Keynsham, I have to go through big security gates to get into my flat, a safe place, a nice place."

"Is there anything you would change about your flat/house, the area, neighbours or street?"

"I wouldn't change anything...nothing gets in my way"

Conclusions

Some of the participants were happy with their housing situation, being housed in appropriate, stable housing in a good area but everyone had some periods of unstable accommodation and most had spent at least some time in a hostel and/or had to move in with family. Most of the housing was housing association although one participant topped up their benefits and used a private landlord.

Other reasons for being dissatisfied included house and/or local area being inappropriate for their needs, bullying or harassment in their neighbourhood, lack of/poor choice of housing/area.

In addition, all the participants voiced fears about the forthcoming changes to benefits and none were entirely clear how it would affect them.

Nevertheless, some of the participants were very positive about their current living arrangements, saying that they felt safe had the freedom to do what they wanted and people were generally happy with the maintenance service provided by housing association Curo and with the service provided by private landlords.

Health

People were generally positive about the health services that they used.

Primary Care

GP's were generally thought to be good and to explain instruction thoroughly, although it was sometimes difficult to see your own GP (but this wasn't necessarily considered a problem).

“When you go to see your doctor, do they talk to you and make sure you have understood what they are telling you?”

“I have felt that way”

“Yeah”

“I had some pictures taken and talk about any side effects that I might have had and any other little problems. How many times I put it on and take it off and any nasty side effects I may have had.”

Appointments were sometimes hard to book and frequently delayed.

“I told them that it was an emergency and the reason why I wanted to see them and what it was about, I just got told to get lost – well they didn't actually say this but it felt like that in that manner.”

“So when you go down for your appointment are you likely to be seen at the time you were given?”

“No”

“No, you've got to wait, have to wait a long time usually”

“No, can be as long as ten minutes sometimes”

“Longer even, sometimes they are not even there and you have to go and see one of the nurses”

If it was difficult to get an appointment at the GP then people would use the walk in centre or A&E. Long term conditions such as asthma were often managed by the practice nurse and people were also happy with the service from pharmacies as they were prompt and explained things well.

Secondary Care

Participants didn't have recent experiences of hospital care.

Preventative Health Care

Not all participants had received a flu vaccination (although not all would need to).

Participants reported that they would take doctors' advice about lifestyle issues.

“Listen to them and what they are saying, because it is usually for you own good.”

Conclusions

People were generally positive about the health services that they used. GP's were generally thought to be good and to explain instruction thoroughly, although it was sometimes difficult to see your own GP (but this wasn't necessarily considered a problem). However, appointments were sometimes hard to book and frequently delayed.

If it was difficult to get an appointment at the GP then people would use the walk in centre or A&E. Long term conditions such as asthma were often managed by the practice nurse and people were also happy with the service from pharmacies as they were prompt and explained things well.