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**Brighton and Hove City Council**

**Learning Disability Strategy**

**Priorities for people with Learning Disabilities**



**A consultation with people with learning disabilities**

**Brighton and Hove Speak Out**

**July– October 2019**

**Speak Out**

Speak Out is an independent advocacy organisation working with adults with learning disabilities living in the Brighton and Hove area. We work with people in several ways including 1:1 issue advocacy, Self-advocacy groups and drop in services around the city. Our self-advocacy groups represent key demographics, such as young people, older people and an LGBTQ group. We also have a regular presence in day services, sheltered housing, residential homes and supported living throughout Brighton and Hove. We continue to explore new ways of engaging hard to reach and marginalised individuals whose views often go unexpressed.

**Local Context**

The current Brighton and Hove Council Learning Disability Strategy covers the period from 2015 to 2019. The council are formulating a new strategy and have asked for the views of people with learning disabilities to inform the focus of this work.

**This report:**

The report will reflect the issues that people with learning disabilities have identified as of utmost importance in their lives. These are the priorities they say have most impact on their wellbeing, self-care, independence and engagement with support services.

It will explore whether people with learning disabilities feel that the current strategy has adequately addressed these areas. It will also outline what further improvements they think the council could make.

**Methodology:**

During the consultation period April 2019 until July 2019 Speak Out consulted 33 people with learning disabilities around the city.

* Individual private interviews
* 1 older persons focus group
* 1 younger persons focus group
* Drop in attendees
* 3 ‘pop up’ drop ins: Team Domenica, Patching Lodge, St John’s
* Day service users at Grace Eyre

All interviews were face to face in locations chosen by interviewees. Discussion consisted of set questions to prompt exploration of personal experiences and views.

In addition, we were able to draw on a body of work based on the views of people with learning disabilities around issues such as Employment and volunteering, wellbeing, Health Improvement services, and access to activities and information.

**Demographic:**

All participants were residents of Brighton and Hove and between the ages of 16 and 85.

**OVERVIEW**

**What matters most to people with learning disabilities**

People with learning disabilities expressed a very clear view of their priorities. These are the issues in their life that they feel contribute to their levels of wellbeing, self-care and engagement with services. They are also areas that people feel have been ignored adding to a feeling of marginalisation and social isolation.

**Mental health:** People with mild learning disabilities are telling us that they are facing a mental health crisis.

Many report that isolation and anxiety are increasing and they do not know where to turn.

* Mental health problems are often ignored by others
* Referrals for support are rare.
* Waiting lists are long.
* Support is short term.
* People feel desperate.
* Mental health is not addressed in their health action plan or annual health check.
* Those with communication needs find it more difficult to access help.
* People tell us they have harmed themselves as a result of the condition of their mental health.

**Relationships:**

Nearly everyone mentioned relationships as an area that needs more support and understanding

* Support to maintain friendships for people who no longer attend a day service
* Support to get out and meet new people
* Conversations about safe friendships, mate crime and financial abuse
* Information about abusive relationships and coercive control.
* Conversations and information about sexuality and gender identity
* Access to sexual health information and services
* Sex education
* Support to have a relationship
* Support to find out about dating
* LGBTQ peer groups and support for people with learning disabilities

**Overview**

**What matters most to people with learning disabilities**

**Support:**

People said that the quality and amount of support they receive has an enormous impact on their life and wellbeing.

Good support enables people to

* Keep active
* Learn new things and have new experiences
* Keep safe
* Make healthier choices
* Manage their money
* Be more independent
* Engage with relevant professionals
* Be a part of their community

However quality, reliability and amount of support varies widely sometimes having a negative impact.

People told us about their negative experiences

* People are unable to keep appointments or go about their day because staff do not turn up or are late.
* Poor interpersonal relations cause client to feel distressed and unable to trust staff.
* Staff taking personal calls or not being fully engaged with client lead to frustration over wasted time.
* Staff leaving early to get to another client.
* Only enough time to cover essentials.
* Having to ‘choose’: e.g. between getting groceries, making an appointment or sorting finances.
* Last minute changes to routine and staff members that cause anxiety.
* No support allotted to trying new activities
* Not being deemed eligible for support and having to rely on family members.
* Inadequate support to maintain friendships and socialise.

**Overview**

**What Speak Out Has observed**

Speak Out has gathered observations through

* Conversations at drop ins
* Short term pieces of drop in advocacy
* Self-advocacy groups
* One to one advocacy casework
* Outreach work

**Access to Healthcare**

Health inequalities remain a dominant theme in the conversations we have with people with learning disabilities about their lives

* People still say they are fobbed off and sent away.
* Systems for making appointments and reception staff are daunting and cause anxiety.
* The accessible information standard is not implemented.
* People are given information and letters they can’t understand
* People do not receive referrals into health improvement services
* A lack of information sharing

**Making Plans for old age**

* People with learning disabilities are living longer. They are also at far greater risk of dementia, frailty and multiple long-term health conditions than the rest of the population.
* There is a lack of forward planning which leads to crises and people having less choice of where they will live.
* There is a shortage of residential placements for adults with learning disabilities and dementia.
* Staff are not sure who to approach with questions about dementia. They are not sure what the pathway is. Medical or social care?
* Some people are living in accommodation that is inaccessible. E.g. first floor rooms for people who struggle to use stairs, or in accommodation with faulty lifts.

**What People Said about the last strategy**

The current strategy comprises of four main areas each with five key aims.

* Being my own person
* I have a place I can call home
* I can work and learn
* I can get Out and about and travel
* I can try new things and go new places
* I get good information and advice
* Feeling a part of things
* I can see my friends and family when I want
* I can choose to have a relationship
* I feel part of my community
* I can use all the services in my city
* I am involved in decisions that affect me
* My choices My decisions
* I am able to make decisions
* I feel listened to and treated with respect
* I am in control of my money
* I can plan for my future
* I can choose how supported I am
* Healthy and Happy.
* I know how to make healthy choices
* I can be fit and active
* I can have fun
* I get good healthcare
* I can get good mental health care if I need it

**Being my own person**

1. I have a place I can call home

Secure, supported and appropriate housing is the foundation of people’s lives.

*‘A safe haven. Otherwise it’s unsettled, a horrible feeling’*

Some people said their housing situation had improved in the last five years. This view was most common to those who live in supported or sheltered accommodation: the most positive being those living in sheltered/supported accommodation with onsite staff and a communal area.

*‘I’ve got my own space. My own flat. Where I lived before was rubbish. We weren’t allowed to sit in the lounge. We had to sit in our rooms. I get support to go out when I want.’*

Young people who are still at home with their family say that the opportunity to move on to living that is more independent is their main aim. Planning, new skills and assessment need to be in place before they can embark on the next steps in their journey to independence. This raises the importance of the role of the new Transitions pod.

Young people over 25 in a family home that meets their care needs do not often have the opportunity to choose more independent living. This may cause problems in later life when the option of being at home may no longer be possible. It also sets them aside from their peers who have moved on into a more adult world.

Many older people are living in housing that will not address their needs in the very near future. This is often compounded by the onset of dementia, which is very common in people with learning disabilities. Planning for old age needs to start sooner in much the same way as transition for younger people.

Older people benefit most from sheltered and supported living. Many are able to enjoy independence and social connections through Care Link buttons, onsite staff and communal areas. Those who are not able to go into the community without high levels of support are able to enjoy social interaction and activities through the communal area

1. I can work and learn

Work, education and volunteering boost confidence and wellbeing. It is not only an opportunity to gain new skills but also become a part of a community.

*‘I feel more proud.’*

*‘You meet new people. It’s rewarding.’*

Most people who volunteer say support workers and social workers have introduced them to their voluntary roles. Successful placements are often due good ongoing relationships between staff and clients. This enables them to assess what role and level of responsibility would be appropriate.

The Supported Employment Team is a vital resource. It provides the opportunity for meaningful work and volunteering roles for people with learning disabilities.

Some people who have not been referred to the SET report losing confidence and suffering setbacks due to insufficient support from employers and lack of understanding about what their needs are.

‘*I was volunteering, they didn’t support me properly. I wasn’t sure what I should be doing. They were not very nice. They said I was lazy.’*

Similarly, a lack of ongoing support can have a detrimental effect on educational opportunities. People told us that SEND schools and colleges were able to meet their support needs educationally. However, those accessing courses in mainstream colleges reported signing up to courses only to drop out because they did not receive the level of support required. Others described not being able to attend courses because of physical access problems.

‘*With courses there is not enough support to carry on. I got onto a course but they didn’t find out what I needed.’*

‘*They didn’t give a chance for me to learn properly. It’s disappointing.’*

*‘It feels like we are not wanted.’*

*‘Not having qualifications stops me getting a job.’*

1. I can get Out and about and travel
2. I can try new things and go new places

Many people need support to go out, make new journeys, go to new places and attend appointments. This support comes from a support worker or family member.

A major area of difficulty was highlighted by people who live in residential care who are not able to go out independently.

They spoke of not being able to go out as planned when there is a staff shortage. Other restrictions arise when people have to ‘share’ staff with others. This practice leads to compromising on daily activities and hobbies, leaving activities early, arriving late or sometimes missing out altogether on interests.

This is particularly difficult for people who have previously been very independent with a broad sphere of interests. Physical frailty may make it unsafe for them to continue to go out alone.

‘*I have to wait for staff to take me everywhere. It hasn’t been easy for me at all. Because of my age, it is really hard. They say sorry you can’t go out because we are short of staff.’*

In recent years, some residential services have sold the communal vehicles that were at the disposal of residents for weekend outings and attending activities and day services. Many people now have to pay for individual taxis, the cost of which can sometimes be prohibitive.

1. I get good information and advice

Easily accessed and freely available information is commonly in formats that are hard to understand for people with learning disabilities. They rely on easy read resources and supporters who will go through information clarifying details and explaining things as they go. This means that people with learning disabilities are reliant on those around them when they want to find something out or deal with a problem.

* Support staff:

Dependent on the amount of time allotted to client, willingness of staff to search for easily understood information and respect for client’s interests and autonomy.

* Family member:

Dependent on skills in finding information, respect for choices and views that might differ from theirs and time to research.

*‘Support workers withhold information if they think you worry too much’*

*‘Not having information makes you anxious.’*

*‘There’s nothing I can do’*

*‘I have to wait for a staff member to look into it.’*

Easy read resources have increased and improved hugely in the last few years. These are now regularly being cascaded through the provider forum so that they reach managers, support workers and carers.

A range of advice and advocacy services are available locally. Ongoing sharing and signposting will give people with learning disabilities better access to more informed choices and the right support.

**Feeling a part of things**

1. I can see my friends and family when I want

Those who say they get ample opportunity to spend time with friends/family told us that this is facilitated through the following:

* Attending a day service, such as Grace Eyre
* Drop ins or peer support groups. E.g. Speak Out and Grace Eyre Friendship Group.
* Paid activities and outings by organisations like Spiral
* Socialising in communal areas of housing schemes

However, some people say that they have not been able to maintain their friendships. This has had a negative impact on their wellbeing.

B lives in their own flat in a supported scheme; she receives support to go out in the community. Her current accommodation gives her a feeling of independence and freedom

She used to live in a group home and attend a day service. Although her living situation is much improved, she misses her friends many of whom access a day service through Grace Eyre. She spends most of her time with support workers and feels she has no friends where she lives or in the community.

*‘I’ve got my own space now. But I miss Belgrave; I miss my friends. I went on Monday Tuesday and Wednesday. We used to go out in the minibus.’*

*‘I’ve got my own space but I miss my friends. I’ve told carers I miss my friends’*

1. I can choose to have a relationship

People who need support to travel and go out said that the issue that has the biggest effect on their quality of life is lack of support to have a relationship.

*‘I would like to meet someone. I would like to go on dates. I’d like to find out more about heart venture, I’ve told my carer.’*

*‘I want to go out for a meal with my girlfriend. We see each other at Grace Eyre. Someone would have to come with us. We want to go on a date.’*

*‘I live at home. I would like to see my boyfriend more. He works during the week. I don’t see him much. We don’t live near each other.’*

See **What matters most to people with learning disabilities**

1. I feel part of my community

Everyone would like to feel part of their community, however people say that they do not feel it is possible. Many feel nervous of the reception they receive when they are out. They say there is still a lack of understanding about learning disabilities. This means that they are often met with impatience, rudeness, staring and sometimes even name-calling.

Three people who said they were a part of their community all live in stable family environments where the household is well established in the community.

Physical access also plays a part in people’s feeling of inclusion in their community. One wheelchair user said that he had tried to volunteer in his community but struggled because many places are not accessible.

1. I can use all the services in my city

The majority of respondents said that they would need support to access all services in the city. The barriers are still numerous

* Finding out about a service
* Contacting the service
* Getting referred
* Attending
* Getting there
* Service making reasonable adjustments
* Accessibility

1. I am involved in decisions that affect me

See My choices, my decisions below

**My choices, my decisions**

1. I am able to make decisions

People say they need support to make decisions. They need information, time to process and the opportunity to talk through the possible repercussions of any decision. Although the opportunity for choice is present, the means to understand and weigh the choice are not always there.

Many respondents said that they felt they often did not have enough information to make informed decisions.

‘*I need information to make decisions. It feels like support workers withhold information if they think you worry too much.’*

Others said that they felt like a nuisance for asking questions or that the queries they had were ‘stupid’.

1. I feel listened to and treated with respect

Some people said that they felt their views and choices are shown more respect now than they have been in the past. They are asked their opinion and invited to make choices about the things that matter in their lives. They know they have rights and that there are opportunities to claim them.

However, some still say they feel ignored and side-lined.

*‘I have been told off before. By the manager at home. I feel like I’m not allowed to say certain things, that I’m making trouble.’*

*‘They said it’s stupid to worry about that. Just forget it. But I can’t. I just want them to listen, but they get annoyed.’*

Most commonly, people complained of being ignored by support staff, medical staff and other professionals.

1. I am in control of my money

Most people say that they have the support of someone else to manage their money.

* Support worker
* Family member
* Shared lives carer
* Money Advice
* Residential manager

Issues arise for people with mild learning disabilities when those they are dealing with do not understand that they have a learning disability. This often results in penalty payments, debts, unwanted subscriptions and direct debits.

Speak Out often deals with these cases in our drop-ins.

1. I can plan for my future

The recent work on the transition pathway for young people with learning disabilities has proved vital. This has been a difficult area historically. In the past, there has been concern that planning was insufficient and decisions were often lost in the system. This made people feel that everything ‘dropped off’ at 26. The new three-pod system aims to address this.

The continuing of a more robust transition pathway should form a significant part of any new strategy.

‘*It’s really difficult to work out what I want to do in the future.’*

People with learning disabilities are living longer than ever before. They have a higher risk of dementia and frailty than the rest of the population. This leaves them needing very specialist care in later life. Planning is often reactive leaving people at risk of crisis. Any new strategy needs to address the need for more forward planning to address people’s changing care and support needs as they get older.

1. I can choose how supported I am

The nature of support that people receive can be at odds with what they perceive their needs to be.

*‘Ask us what support we want not what you think we need. Ask us and then listen!’*

*‘I didn’t want someone to come shopping. I wanted someone to show me how to cook for myself.’*

*‘I would like support for some things, they say I am too able. But they don’t know. I have to rely on my family for everything. I feel guilty and sometimes I don’t want to ask. There’s lots of things I need help with.’*

*‘It’s better now. When I first lived by myself I was nervous. There wasn’t enough support. It was frightening. Now I get help to pay my rent and bills. I get that now but I didn’t before.’*

One factor is the individual relationship between support worker and service user.

‘*If they know you and you get on well they can say ‘are you sure you want to buy that, it’s got a lot of sugar. But with some people they are just rude and bossy and you get upset. It spoils the trust.’*

**Healthy and happy**

1. I know how to make healthy choices

People with learning disabilities have a greater risk of obesity and type 2 diabetes than the general population. This is a contributing factor to the lower life expectancy they experience.

We hear from people with learning disabilities that their GP is not always willing to refer them for the extra support they need to make lifestyle changes.

Referrals to the health trainers in the healthy lifestyles team are designed to support individuals in the choices they make. However, these referrals are not often made leaving many at risk of chronic conditions.

1. I can be fit and active
2. I can have fun

The Council Healthy Lifestyles Team has developed a more accessible route to activities and information. They have a presence at most LD events, a 1 front door phone number, activities for people with learning disability and inclusive sessions. They also produce easy read publicity.

Although access to information and sessions has improved it must be stated that there remain a great many people who still require support to attend sessions.

1. I get good healthcare

People with learning disabilities are still facing numerous barriers to accessing the health care they need. The views and experiences of local people are recorded in a Speak Out report (available from [emmalopez@bhspeakout.org.uk](mailto:emmalopez@bhspeakout.org.uk) )

The continued work of the Health Facilitator to highlight the importance of statutory requirements placed on GP surgeries is of vital importance. These requirements have been formulated to address the inequalities people with learning disabilities face.

1. I can get good mental health care if I need it

People with learning disabilities are more likely to experience mental health problems than the rest of the population. The lack of adequate mental health support was the foremost issue affecting those we spoke to. They were clear that this needs to be addressed in the Learning Disability Strategy.

See **What matters most to people with learning disabilities**

**Recommendations for Learning Disability Strategy**

* Emphasis on ensuring that support is of a consistent standard no matter who the provider or staff member.

This should include a protocol for people to follow should they wish to report any issues. The pathway must be clear, well publicised and accessible to people with learning disabilities.

This channel should come through the council and not individual providers.

* Guidelines and code of conduct that apply to all support workers from all providers.
* Specific work needs to be done on the mental health needs of people with learning disabilities. A citywide multi agency approach should be developed with the aim of partnerships with communities, third sector, public health, the health and well-being board and CCG.

This includes the work of the Health Facilitator, social prescribing (Together Co), Healthy lifestyles team, Health trainers and providers.

* Older people need to support to make decisions about their future in much the same way as young people who are part of the Transitions process.

Conversations, planning and commissioning need to start much earlier in order that decisions and changes are proactive rather than reactive.

Older people will soon make up a large part of the third pod and this should be reflected in targeted support.

* Support for the work of the Health Facilitator and the Thumbs Up to Good Health team in their programme of training and awareness raising for GP surgeries. Highlighting the importance of the Learning Disability Register locally aims to improve primary care for people with learning disabilities
* There is a wide body of easy read resources covering many issues to do with sexual health. Raise awareness of these materials and any appropriate training that can facilitate conversations about sexuality, gender identity and sexual health and healthy relationships.
* Earlier intervention, education and awareness of Sexual Health and Contraception Service ( SHAC ) is vital in preventing crisis. ( For example partnerships between SHAC and schools and colleges)