

Barnardo's Bristol Care Leavers Service

A Health Offer for Care Experienced Young People

2021

Introduction

Care Leavers Unite Bristol (CLUB) was set up and funded by Barnardo's in 2015 as a campaign group led by care experienced people. We are currently engaged with 40 people; 20 of whom are young parents. CLUB funding has enabled us to run various activities and events, including Jam nights, cycle groups, a women's group, parent and child activities and days out and community learning sessions.

The Personal Health Budget service gave us the opportunity to fund activities and experiences that enhance wellbeing, purchasing items like; bikes, pamper products, gym memberships, gardening tools and musical instruments.

Previous CLUB campaigns have explored issues including loneliness and isolation, public transport and stigma. CLUB's campaign focus since July 2020 has been mental health. This report summarises the information gathered from our work since July 2020 including focus groups, surveys and digital media work.

In February 2021 we made a podcast of our experiences of mental health support, you can listen to it <u>here</u>. Through 2020 and 2021 we made a film called *Good Day Bad Day*, you can watch the film <u>here</u>

In May 2021 CLUB was invited to contribute to an NHS pilot to develop a health offer for care experienced people. In June and July 2021 we held three focus groups looking at mental health, primary health and health services for parents. We created a consultation on mental health for our peers and 36 people responded. We have included the report in the Appendix.

This report includes 8 specific asks from CLUB to be included in the health offer for care experienced people.

1. Stigma

Our Concern

The concern raised most often was stigma and stereotypes. We find it difficult to talk to GP's about how we really feel. Doctors make judgements based on our family history. Those that are parents feel that their parenting is questioned based on their background and that being care experienced labels them as problematic.

GP's focus on drug and alcohol use as the primary problem. We feel individuals misuse substances because of how they feel and to escape from past experiences and trauma. This creates a barrier when accessing services and prevents honest discussion.

Our Voice

"99% of the time they ask you if you have had drugs – why would they ask that?"

"They know about your family background and their mental health. It's kind of like your mum had this so I think you may have it – they definitely put a label on you."

"One dentist I wanted to register with found out that I had registered with them eight years ago when I was living in a hostel and they wouldn't let me reregister because I had missed three appointments with them. I was in a totally different position that I was then but they didn't care about what I had been going through and I tried to explain but then I was like 'why am I trying to explain?'."

"I don't think many doctors are aware of what a care leaver is and the additional support they might need."

"If you are a care leaver and you ask for a midwife is flags up your family history and they ask you all about it and you automatically get allocated a social worker (pre-birth assessment)".

Our Ask

We want more training and awareness for health professionals on the specific needs of care experienced people within services. This includes a basic understanding of the effects of trauma in order to understand behaviour. We want Care Leaver Champions within health services who would link up with services and advise on our health needs.

2. Information and Accessibility

Our Concern

Health centres can be hard to get to on public transport and it is difficult to get GP appointments. We have to call early in the morning and then use phone credit waiting on hold. This leads to some of us using A&E for advice and treatment.

We feel that if you are not in a good place with your mental health then it is difficult to have the motivation and clarity to look for what services can help. Some of us use the internet to self diagnose and this creates unnecessary anxiety. We also feel retraumatised by having to repeat our story when accessing new services.

Our Voice

"If I needed a doctor tomorrow, I would go to A&E, or I would ring 111, they will sort it out."

"You ring in the afternoon because I stay up late and I can't get to the phone at 8.30am in the morning, especially if I have had a bad night."

"Sometimes it is hard to even express why you are there – I start shaking and get anxiety even when I am just talking to the receptionist – I would rather go with my support worker when I go to the doctors and let them talk instead of me."

"If I look on Google I just think I have got everything and all the symptoms."

"I was 21 and I hadn't spoken to my PA for a while and in closing session I informed them that I was pregnant and the PA approached my next of kin to find out and the pre-birth assessment was done retrospectively but I had no support from midwife and health visitor."

Our Ask

To improve how we find out about services and access information. We want workers from services to speak at our groups. We want outreach work in our communities where health centres are geographically inaccessible. We want Care Champions to support and advocate for us. We want to be signposted by other care experienced people who have a had a good experience of a service and we need tips for good internet searches.

3. Healthy Lifestyles

Our Concern

We have all had experiences of leading unhealthy lifestyles. This includes not getting out of the house and feeling isolated, eating poorly, mismanaging money, living in poor conditions, drinking too much, substance abuse, not exercising, overuse of social media, bad sleeping habits and associating with the wrong people.

Our Voice

"Sometimes I don't want to go out if I am having a bad day and don't go down the path I went down with drink – it helped sometimes but also made me have bad depression."

"When I keep myself busy I feel less lonely, less isolated and less depressed and when you are less busy you start to look at other people and compare yourself with them and do the wrong things like drink up, smoke up."

"How do you get in the right frame of mind to actually go for a run if you having a down day and you have no motivation and it's raining."

"I spend a lot of money on takeaways."

Our Ask

We need support to lead more healthy lifestyles. We need advice on diet, sleep, exercise, relationships, stopping smoking, drinking less and learning to be happy in our own company. We would like to receive support from those who have lived unhealthily and have chosen to change bad habits and behaviours. We also feel that focussing on activities that promote a healthy lifestyle are beneficial like pamper groups, cooking and bike rides.

4.Peer Support

Our Concern

Peer support is important to many CLUB members and many of us are keen to help others. This might include accompanying someone to an appointment or supporting each other to engage in activities. We advise and comfort when others are low or anxious. Friends and family are our first contact when our mental health is poor so we need to give the right information and advice. However, sometimes we are too engrossed in our own lives and not resilient enough to support someone else. We need to know when not to help.

Our Voice

"When it's extreme mental health the only person that can give me help is my mum, she's the only who can deal with it."

"Some people want their lives to be worse than yours and I tell them I've got depression and they say 'so do I' and I'm like 'but you don't!'."

"I can already sense and feel something from a person – they don't need to say anything to me and I end up feeling some emotion from them."

"They need to look at body language and how anxious they are, the way they move, some people pace, some tap their foot, some twiddle thumbs – you need to look out for any signs of distress. They want someone to talk to and they want someone to listen and they want someone to be there when they let it all out."

Our Ask

We want to receive mental health first aid training to help our friends and family if they are needing support. We need the knowledge to support others and the confidence to be clear when we are not in a position to help and should refer elsewhere.

5. Choice, Control and Understanding Therapy

Our Concern

We are not always ready for therapeutic interventions and don't have enough information about the process to decide to participate. Activities are effective because they can be immediate, help you learn new things, meet new people and avoids the formality of therapy. Activities help make us feel engaged to prepare for therapy. The views and ideas of care experienced people should inform the activities offered.

Our Voice

"While I am doing stuff and keeping my hands busy, drawing, painting or whatever for me it's easier to talk about stuff because I am not looking at her (counsellor)."

"I've got a counsellor at the moment, and she understands, and we do things together like art, going out for drinks and she doesn't push me to talk about my problems and sometimes I just don't feel like it."

"I had a chance to do some counselling and therapy, but it wasn't really my thing because I've done something like that before and it wasn't a thing I was comfortable with."

Our Ask

We need more information about therapy, what it involves and what to do if we are not ready for the commitment. We would like there to be more choice and control on the type of therapy and the therapist. We would like to have more structured and planned activities for care experienced young people to support mental health as part of the therapy, or as additional support. We would like to be part of a planning group to select activities including being aware of resources available in order to gauge scope and regularity of the activities.

6. Personal Relationships

Our Concern

We want support to recognise the signs of toxic relationships and to avoid being subjected to exploitative situations and coercive control. We want to raise awareness of the importance of positive relationships with peers and partners and the difficulty of living with a lack of respect and freedom. It can be hard to call for help from the police or professionals out of fear of being called a 'grass' and so continue in destructive relationships.

Our Voice

"I had to leave my old flat as they used to come and smoke weed and I didn't like it."

"Try to find people that you like to be around and someone who makes you feel happy and isn't going to put you down and turn around and make your day worse."

"They tell their problems to the wrong people and they need to tell their problems to people who understand them and have sympathy for them."

"I would try and keep away from people that I know are bad for me and try to hang around people that are good for you."

"It's better to be in a bad relationship than no relationship at all."

Our Ask

We would like to participate in workshops that help us learn about healthy relationships. To gain skills and knowledge on how to love and respect ourselves before learning how to care for anyone else. We want to recognise when we are in toxic and unhealthy relationships and how to get out of them. Where appropriate we would like to deliver part of this training.

7. Relationships with Workers

Our Concern

The relationship with our workers is key and transformative to our development. We need honest relationships, where both parties know a little about each other without fear of contravening policies around disclosure. We find it therapeutic and rewarding when workers reveal something about their own struggles and the ways in which they have overcome problems. The group is concerned that workers often receive conflicting messages about their own 'self-disclosure' and how beneficial it can be just to spend time with young people and getting to know one another in an honest and human way.

Our Voice

"A lot of us young people think that workers are pure robots, they go home to their nice big house that they own, they sit at their dinner tables with knives and forks and they have no worries or financial concerns."

"A lot of professionals are too worried what they can say and what they can't say – so they give off this persona of blankness."

"We feel like they are above us, they don't come across as human and genuine when they are completely closed off."

"I know a lot of social workers feel bound by the legislation around this issue, they don't know what they are free to say and they're not and that can give them a bit of an internal stutter."

Our Ask

We would like training in developing relationships with workers, especially in sharing information about each other without having concerns around boundaries. Care experienced young people could be involved in delivering this training with and to PA's, Social Workers and Senior Managers.

8. Knowing Our Rights

Our Concern

We feel disempowered and anxious receiving heath care, especially from GP's. The experience can be distressing and brings up feelings of annoyance, shame, anger and stress. Some of us have received poor advice in regard to being transgender and non-binary. Those of us that are parents feel judged and that our concerns are not taken seriously. We all feel we don't fully know our rights. We don't always fully understand our diagnosis, medication use and how information is shared about us.

Our Voice

"I went to the GP and he said; 'don't worry you're fine, go home and have a cup of tea and a rest' and I told him the same thing 3 times but when I took a Social Worker he was then all serious and saying 'I'm sorry and we will provide you with medication'."

"I do feel that concerns that young parents have over their children's behaviour are not taken seriously and sometimes blamed on behavioural disorders. Parents are fobbed off and lot of the child's behaviour is blamed on parenting skills."

"A diagnosis is just a label and something else to talk about and judged about and be blamed for it – it is your fault and you the bad person. Why do people need a diagnosis to get support why can't they just get the support anyway?"

"I had lots of pain in one of my births and I felt like I had to kick up a fuss to get the attention of a higher level of consultant. I do believe that care leavers are not taken seriously and should receive priority appointments like the old and young do."

Our Ask

We want to know our rights in regard to our health care and get the right support and information appropriate to our needs, including LGTBQ+ individuals and care experienced parents. We want to understand the pros and cons of having a diagnosis, using medication, being assessed and transparency about how our information is shared. We want to feel confident and reassured when we receive support with our health care.

Appendix. 1

Care Leaver Mental Health Survey How we did it (methodology)

Off the Record and Barnardo's wanted to know more about what stops people using mental/emotional health support services so that we can work together with care leavers and services to make them more helpful.

- The draft survey was co-designed by OTR, Barnardo's and 3 care experienced young people. The final survey was co designed with input from a further 3 care experienced young people.
- · Everyone involved in co-production had experience of mental/emotional health issues.
- A £5 reward was offered as an incentive for completing the survey. The survey was promoted by P.A.'s, and the BCC and Barnardo's Facebook pages, as well as direct contact with potential participants, particularly targeting those who had received a personal health budget.
- 38 responses were received and 14 of those said they would be interested in further campaigning on this issue.
- (See Appendix 1 for Survey and Appendix 2 for information informing care leavers about the survey)

Our main barriers to accessing services are:

- don't know enough about services
- stigma
- long waiting lists
- don't know how to refer ourselves
- past experiences of services

What's important to us is:

- Flexibility
- Location
- Worker choice
- Online access
- Environment

Results from access to care leaver mental health survey

For mental health support we choose to speak to our GP and friends first of all.

Nearly two thirds of us would speak to our PA. We would attend A&E before speaking to the mental health crisis team.

- 62% of us have talked about mental health with workers
- 76% of us feel involved in decisions around mental health
- 92% of us have experienced loneliness and isolation
- 53% say our social life is talked about in our pathway plan

We can't put our mental health crisis on hold while we wait for an appt We should be at the top of the lists for Crisis, Housing and Mental Health

No more waiting lists

What young people said

A little more support around group work

We need more time to express our feelings and our thoughts Make it easier to access the mental health team and make the waiting list shorter so people don't have to wait a month to receive help

We need more knowledge of available services Someone to help in the first instance that records stuff for you so that you don't get overwhelmed and not [get] help

Feedback from the Focus Group

- Young people don't know enough about available services including wider community services e.g. Sanctuary, Mindline, activity-based clubs
- "We go to A&E because we know at least we'll be seen by someone"
- A number of young people said "being told by the Crisis Team to make a cup of tea or have a bath isn't always helpful"
- Helplines should be answered by a person, ideally with a video function
- Specialist workers or champions, who understand what it's like for care leavers, to be in each mental health service
- "We needs to be able to self-refer"
- "We really need waiting lists to be shorter"
- PA's to have really good training in mental health to support young people, with a specialist mental health worker based in Social Care.
- Good relationships with workers is really important
- Immediate mental health appointments available in emergency

What next?

- Explore better ways of young people being able to access information, social contact and knowledge of services
- Promoting a culture of choice and control for young people needing mental health support
- Empower care leavers to help others and offer peer support through broadening access to information and advice, as well as helping to facilitate this
- Share recommendations and ideas with Corporate Parenting Panel via Digital Conversation and work with them to promote change