

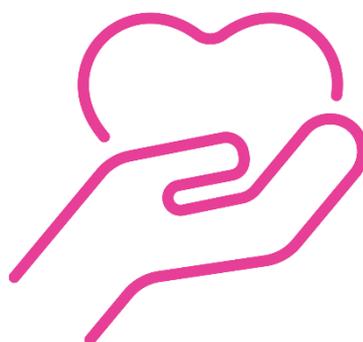
The bigger picture: what people think about adult social care

July 2023



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“Think about the bigger picture, including financial planning, practical considerations, and lifestyle factors, as well as how the person with a disability will be able to fulfil their hopes and dreams”.



- (Older man receiving adult social care (ASC) services)”



“What really makes me happy about my care is the fact I’m seen as a whole person with goals, skills and interests. Some of the things I need may extend beyond healthcare alone”.



- (Man in supported living)



“I understand my choices and work with practitioners and those close to me to make my decisions about my health and then I feel listened to and respected, and I receive information about my health and support in a way that’s clear to me”.



- (Woman receiving ASC services)

Executive summary

This project has collated feedback from a diverse group of 103 people in Bristol who draw on care and support, and unpaid carers. This included older adults, people with Learning Disabilities, people with mental health issues, people with Autism, people with physical and sensory impairment and their carers.

Healthwatch Bristol was commissioned to do this work for Bristol City Council Adult Social Care (BCC ASC) with the aim of better understanding people's experiences of ASC in Bristol and to inform their service commissioning. Healthwatch Bristol worked in partnership with BCC ASC to engage support and advocacy organisations and people with lived experience.

People's experiences of services have been documented so their voices can be heard, and their input incorporated into how services are designed, and work to meet their needs.

Participants told us what the most important aspects are about receiving ASC services:

- that the quality of care is paramount;
- that people who draw on care and support are offered a choice of care services;
- that staff providing care need to be consistent;
- how important respite care is for people who draw on care and support, and carers;
- that the wait for care reviews and reassessments is too long;
- care staff need to communicate with people who draw on care and support at all times particularly in response to changing needs;
- that care should be organised round the needs of people who draw on care and support, rather than around the needs of the institution;
- that care should look at the whole person, not solely at personal care needs;
- that carer and support staff communicate with the family of people who draw on care and support particularly when changes are taking place and their care needs change;
- for those in supported living, regular communication by care staff with the families of people who draw on care and support is very important;
- support to participate in social and cultural activities in the community to reduce social isolation of people who draw on care and support, and carers;
- the availability of mental health and emotional support services is very important.

Considerations to take forward

The feedback from people who draw on care and support and their carers evidences the need for:

- support workers to signpost people who draw on care and support to information on ASC services particularly Extra Care Housing for older people
- signposting to information on advocacy for people with Learning Disabilities, people with mental health issues and people with physical and sensory impairment
- readily available respite care opportunities for unpaid carers
- reduced waiting times for care assessments for people who draw on care and support
- reduced waiting times for carer assessments for unpaid carers
- accessible information and advice on eligibility for Direct Payments, Extra Care Housing and Advocacy (for example, in Easy Read)
- availability of mental health and emotional support for people who draw on care and support, and unpaid carers
- support for people and their carers to participate in social and cultural activities in the community to reduce social isolation
- increased availability of advocacy services for people with physical and sensory impairment
- advocacy for Black and minoritized ethnic groups to enhance the take up of Direct Payments.

Equalities statement

Healthwatch Bristol is committed to promoting equality and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects.

We include people's lived experiences in our work and identify and mitigate against barriers to enable people to become involved in our research. We address the participation needs of those who share one or more protected characteristic, or those that experience hidden discrimination, or are part of an 'invisible minority'. We provide access to communication support to adjust for people's needs and proactively assist people in attending events and meetings we hold.

Healthwatch Bristol will connect with existing patient bodies, organisations that support people who draw on care and support, and voluntary sector organisations to reach into, and develop relationships with, diverse communities, and inclusion groups.

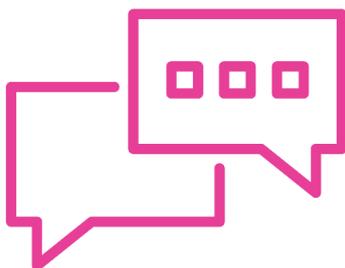
Background

BCC ASC provides support for people with a range of needs. This includes older adults, people with mental health needs, people with Learning Disabilities, people with physical and sensory impairment, people with overlapping or intersectional need and carers. This project was commissioned by BCC ASC to help inform commissioning of services.

This project has also been informed by the Care Quality Commission (CQC) who currently include collecting evidence of people with lived experience of care as a key principle of their quality assessment process:

"People using services, their families, friends and advocates are the best sources of evidence about lived experiences of care and their perspective of how good it is.

People's experiences are a required evidence category for all quality statements when assessing local authorities. We value people's experiences and weight them equally with other required evidence categories". (CQC, 2023)



Purpose

The aim of this project was to understand people's experience of using ASC services in Bristol to consider what might need to change and improve. The CQC single assessment framework has been a driver for this. This project will contribute towards the development of future commissioning models that will be commissioned using the single framework.

Engagement methodology

This project ran from April – July 2023. Focus groups were held online via Zoom and written feedback was collected between May – June 2023. BCC ASC contacted 25 care, support and advocacy organisations to inform them of the project. To recruit participants Healthwatch Bristol also contacted organisations in their networks and via their social media (see Appendix). This was followed up by telephone calls to staff within organisations to further recruit participants to the eight focus groups.

Co-production

Participants joining the focus groups were invited to a co-production meeting at the start of the project. This was held online via Zoom with 4 people who draw on care and support (older adults, people with physical and sensory impairment, and carers). The co-production meeting informed the themes and first series of focus group questions around people who draw on care and support' experience of social care. (See Appendix for focus group questions). All participants were remunerated for their involvement the co-production meeting.

Co-production meeting participants suggested the need for focus group discussions on people's experience of ASC to include:

- People's access to a social worker
- Accessing a face-to-face appointment with a social worker to review a care package
- Experience of people's contact with Care Direct
- Review of existing care packages (current waiting list)
- Dealing with and making enquiries about Direct Payments
- Flexibility of social care provision
- Support for carers' deteriorating health and physical capacity – where to go for this?

The literature we used in planning the two focus groups with people with Learning Disabilities was co-produced by Thinklusive in the form of Easy Read documents. These were created with participation of an advisory group of people with Learning Disabilities (see Appendix). This provided inclusive participant information sheets, consent forms, focus group questions and discussion information for people with a Learning Disability. We also had peer support from Healthwatch Essex who produced the Healthwatch England guide to engaging people with Learning Disabilities.

(<https://network.healthwatch.co.uk/guidance/2022-10-23/involving-more-people-learning-disabilities-your-work>)

Method

Eight focus groups were recruited and facilitated between April and June 2023. These consisted of:

1. Older adults – two focus groups: a. Experience of ASC b. A discussion of respite care and extra care housing
2. Adults with mental health issues – two focus groups: a. Experience of ASC b. A discussion of models of supported living
3. Adults with Learning Disabilities – two focus groups: a. Experience of ASC b. A discussion of models of supported living
4. Carers of adults who use ASC services – a discussion on support received, support required and respite care.
5. Adults with Physical and sensory impairments – a discussion of what a good service looks like, choice of care, self-advocacy and Direct Payment experience. (See Appendix Table 1. for details of further details of focus group topics discussed).

Each focus group included between 4 – 17 participants and was held online via Zoom which was the preferred method for most participants. All focus groups were facilitated by the Healthwatch Engagement and Co-Production Officer. Four focus groups were co-facilitated with the help of Healthwatch volunteers, experienced in hospital nursing, and Learning Disabilities. All participants in the focus groups were sent questions to be discussed ahead of the group. Participants were also prompted following question responses and discussion was encouraged in the group and in the Zoom Chat facility for those who preferred written response or who had access issues.

Feedback on experience of ASC services by carers was additionally collected via email after a very large response from carers. (14 participated in a focus group and 38 sent feedback via email). Written feedback from people with lived experience from the Chinese community was collected and translated by local interpreters. The interviews were conducted by a staff member from a Chinese community wellbeing organisation (see Appendix, Table 2). for details of focus group participants).

All participants were sent the participant information sheet and had to complete a consent form prior to participating in a focus group. They were remunerated with a high street shopping voucher for each focus group they participated in. All the online focus groups were recorded on Zoom for purposes of transcription.

Reflections on method

Using Zoom to facilitate focus groups with people who draw on care and support worked well in that Healthwatch Bristol was able to engage with a diverse group of people who draw on care and support and their carers and hear voices of seldom heard groups. People with physical and sensory impairments, people with Learning Disabilities, those with mental health issues, and people with

Autism, older adults, carers, and people on end-of-life care came forward to participate. During the focus groups participants were given the choice to have their cameras switched on or off, many chose to have cameras switched off to protect privacy. Participants also used the Zoom Chat facility to give their feedback; the facilitator fed the content of the Chat back to the group, which worked well. This enabled all participants to share their experience of social care services and what were often difficult experiences of living with a disability or long-term condition. The disadvantages of using Zoom to facilitate a focus group can be that the flow of discussion is not as fluid as during a face-to-face group and it can be more challenging to probe the discussion further.

Gaps in engagement

Seven out of eight of the focus groups had 8 + participants. The focus groups of people with mental health issues had four participants, this was a more challenging group to recruit. Healthwatch Bristol contacted several mental health support and advocacy organisations known to BCC ASC (see Appendix) however, few people who draw on care and support came forward to participate. It should be emphasised that several of the other focus groups revealed that people had experience of mental health issues, (the group with people with Learning Difficulties, and with older adults).



Findings

What's important to people who draw on care and support?

Participants felt that the most important things about the ASC services they received were:

- That the quality of care is paramount
- That people who draw on care and support are offered a choice of care
- That care needs to be consistent particularly staffing of respite care
- Direct communication of care/support staff with people at all times particularly in response to changing needs
- That the care looks at the whole person, not solely at personal care needs
- Carer and support staff need to communicate with the family of the person that is receiving care, particularly when changes are taking place and care needs change
- That the care is organised round the person rather than around the needs of the institution
- For those in supported living, ongoing communication with people's families by care staff is very important.

Older adults told us what is important to them:

"One is being listened to and heard, so that people aren't assuming what I need. The second thing I think is recognising that it increases my independence, not decreases it. I don't think you should be penalised for managing to do things by yourself, I think that should be celebrated." (Older man A)

"Adequate care, cleanliness and adequate staff". (Older man B)

"Think about the big(ger) picture, including financial planning, practical considerations, and lifestyle factors, as well as how the person with a disability will be able to fulfil their hopes and dreams." (Older man C)

People with mental health issues told us what is important to them:

"...consistency, care, respect from the services for you, it goes both ways obviously...." (Man A in supporting living)

"Consistency I think is the best because when the service is consistent you have all you need. You know where you stopped the last time and you know where to continue from, so that is the most important thing about adult care." (Man B in supported living B)

"A great carer, faster assessment time and inclusiveness in the society like (volunteering) and socialising that has been provided already...I have been

involved in volunteering and loved it; it makes me understand that I am still part of society". (Man B with mental health issues in supported living).

People with Learning Disabilities told us what is important to them:

"I like receiving my personal assistants in my home, the care and friendship, the help I receive from them, their knowledge, the helpfulness, they are interested in my well-being". (Man on Direct Payments)

"When I started to interact with them (staff) they asked me what sort of things I would like to do, whether I wanted to do activities like artwork but none of that was what I really wanted. I wanted something a little bit more challenging.... so they looked around and put me into some IT group and health and social care groups. I had limited knowledge about IT and...my main goal is that when I'm ready to go back in to (the) community, everything is (helped) by doing IT". (Man in supported living with mental health issues)

"I have PIP (Personal Independence Payment). I choose, I have care, we go out on trips, shopping, eating.... Flexible support. She (support worker) is good at IT". (Woman in supported living)

People with physical and sensory impairment told us what is important to them:

"What really makes me happy about my care is the fact I'm seen as a whole person with goals, skills and interests. Some of the things I need may extend beyond healthcare alone". (Man, P&SI group)

"I understand my choices and work with practitioners and those close to me to make my decisions about my health and then I feel listened to and respected, and I receive information about my health and support in a way that's clear to me". (Woman A, P&SI group)

"(That it's) equitable, providing care that does not vary in quality on account of gender, ethnicity, geographic location and socioeconomic status". (Woman B, P&SI group)

"Self-directed support to help me achieve changes in my life (which) gives an opportunity for me to have more choice and control, enabling me to enjoy greater independence". (Woman C, P&SI group)

Carers told us what is important to them:

"Caregiving for an ill, elderly or disabled family member can be a demanding job and nobody should face it alone. Using respite care services can be very beneficial for those giving care and receiving care". (Man carer A)

"One major thing I like about the support I get, which is the carer payment support and also the emergency card, I feel for me to get paid for the services I am providing, I have to put in my best and make sure I deliver appropriately. It gives me this encouragement to keep going and to actually be active and open doing in what I ought to do." (Man carer B)

"Day services and mental health support". (Man carer C)

Experience of social care

The first focus group with older adults, people with mental health issues, and people with Learning Disabilities respectively explored people's overall experience with ASC services. This included experience of referral to ASC, people who draw on care and support contact with social workers, choice of care services, care reviews and reassessment, experience of Care Direct, and what makes a good service.

Referral to ASC and contact with social workers

Feedback from older adults and people with Learning Disabilities indicated that they were concerned about the lack of continuity of care with social workers and having access to social workers.

"When I was first diagnosed (over 45 years ago), I had a brilliant social worker, she stayed with me for quite a few years but now you don't have an allocated social worker or occupational therapist. I personally feel it's a retrograde move because each time if you need another adaptation you have to go through everything again whereas if your OT or social worker was a caseworker, you wouldn't have to do that....when my social worker walks through the front door....she has got no idea about my illness and what I can and cannot do, it's not good that I have to keep going over things". (Older Woman)

"...you're then discharged from that social worker, so trying to get continuity of care can be hard". (Older man).

"I find it very difficult to communicate without my personal assistant being around me. The social worker when they came round, on my last review they wanted me to have half an hour on my own, to make me more independent however, I'm independent with my PAs". (Older man on Direct payments).

"...you know, not having a named social worker means that it's a bit like with the doctor's situation. You're chasing people but you don't know who you're chasing and you don't have anyone to link up with and so it's very easy to just forget. People who are probably, you know, less persistent than perhaps I would be, their voices get lost and people are just getting lost out of the system". (Parent carer of adult in supported living)

"...the person (social worker) that was originally with X once they were in the house (supported living) was like 'that's it, our job is done', you're signed off now, next time you need a social worker go through Care Direct, so that's what we tried to do. There was nothing after that, I mean that's the problem....not having a named social worker". (Parent carer of adult in Supported Living)

Choice of care

People in supported living felt largely that they had been given a choice of care in being given options around supported housing, and ongoing choice in for example, being involved in interviewing their support staff. Older people and those with mental health issues (who were not in supported living) also felt that they had been offered a choice of care.

“My daughter knew about all of my problems and chose a type of care that suits me and yes, I can say my choices were taken into account”. (Older man on end-of-life care)

“I was given an opportunity to choose a suitable alternative provider because I was going to wait longer than the maximum waiting time specified in my legal rights. Information to help me make decisions was available and I knew where to find it in a format that was accessible to me”. (Older man receiving home care)

“I felt I was listened to and my thoughts and opinions were taken in to consideration, and it was a good match”. (Man in group with people with mental health issues)

“D the person that was helping us, she did talk about all the different choices that were available to S, like employing people directly versus support with living, and she did really listen and try and work hard to listen to what S wanted, she really did understand what S’s needs were and what S hoped for the future”. (Parent carer of an adult in supported living)

“I live on my own in a flat just around the corner from my parents and I interviewed my own helpersMy helpers are nice here”. (Woman in supported living)

Care assessment and care reviews

Feedback on people’s experience of care assessments and care reviews was mixed. This included people with Learning Disabilities, older people and people with physical and sensory impairments. People in supported living were generally happy about the regularity of their care reviews. Others highlighted the importance of timely care assessments and reviews to give people care choices. Overall participants felt that:

- they wanted information provided for care reviews in an accessible format (people with communication issues)
- they wanted clear information on eligibility criteria for care in order to describe their needs effectively
- the length of time people had to wait for a care assessment was too long
- the length of time it took people to have contact with a social worker was too long
- cancellation of care reassessment appointments was frustrating for people who draw on care and support

- some had quality of care issues relating to the personal assistants or carers of people who draw on care and support.

"I get every month or I don't know how often, I get a big document like a questionnaire from I think it's (support organisation) who say how my support is going and would I like to change and what would I like? Some questions like that so that's good and I get (it in) Easy Read so pictures as well as short words so I can understand it, which is very helpful. I like that". (Woman in supported living)

"If I'm assessed based on my personal needs and personal budget, it will enable me to have more choices". (Woman in P&SI group)

"We handily get care reviews four times a year (by supported housing staff). I feel its sufficient for checking on and knowing how far you've gone and everything". (Man A in supported living)

"We have reviews here, six monthly and yearly reviews". (Man B in supported living)

"Social care services have been slow to review me and do a reassessment. They don't listen to me or take time to hear from me about my needs". (Man on Direct Payments)

"I need a care review because I'm trying to change the day centre I'm at because I need to get out of the (wheel)chair – I'm sat in the wheelchair for 12 hours. I asked for a review of my care needs – I should be able to go to a different day centre so I can get out of my wheelchair rather than being in the wheelchair (all day). I've been on a waiting list for a care review for 3 years now". (Man in supported living)

"(the) waiting list for assessments on new people who draw on care and support are up to three years. We have members of (advocacy group), they've been waiting two years plus for adaptations, let alone care.....I think when you're in the system....the response you get is a little bit quicker...it's the new people (people who draw on care and support) coming in who get the extremely long waiting lists". (Older Woman on Direct Payments)

"It took so long for me to be assessed and that wasn't such a nice experience. The time of assessment should be improved upon and more time for recreational activities should be included into the support I currently receive". (Man in P& SI group)

"The last social worker assessment made four appointments, three were cancelled, the fourth she did get through the door but her boss rang and told her to cut the assessment short to leave to go somewhere else. That was prior to Covid, so now it's been 18 months (waiting)". (Older Woman on Direct Payments)

“Continuation and re-evaluation should be done as fast as possible. The delay in getting processed is actually something that I never liked. It took a while for me to be evaluated to be able to get the end-of-life care that I'm on now. And I'd have to actually go back again to apply again if I should continue on it so if they can make it possible to do it for a longer period of time”. (Older man B)

“The system of assessment is based upon the eligibility criteria, which they won't tell me what they are. They won't tell me how they make their decisions. I am essentially asked to go into an assessment not knowing how to describe my needs according to the criteria and if I can't understand what I'm meant to be describing, it's not an accessible assessment”. (Man on Direct Payments)

Care Direct experience

Participants felt that Care Direct staff were helpful however they wanted to be offered a greater choice of services.

“It would be great if Care Direct could offer more varied service providers to the people who draw on care and support. At that time, the service providers that Care Direct offered to us were very limited and we had to make contact with the private care service companies ourselves, which is complicated and time-consuming”. (Woman carer)

“Responding to individual needs through flexible tailored support, including support to address immediate or urgent needs”. (Man carer)

“My thoughts would be the Council can provide a tailor-made 'one stop shop' to the people who draw on care and support, and they don't need to contact various teams/departments to ask for help and support”. (Woman carer)

What makes a good service?

Focus group participants overall in discussing their experience of ASC identified the following as contributing to a good service.

- The quality of the relationship people who draw on care and support have with their support workers
- Consistency of support workers
- Having services available at the time when they are needed
- Easily accessible accommodation (people in supported living)
- Feeling safe and secure (people in supported living)
- Being offered as much choice and control as possible as part of a service
- Being involved in the development of a care service through co-production
- Being supported to access activities in the community (people in supported living, and carers).

Participants felt that 'a good service' was one that is timely and offers flexibility for people, and a service that people who draw on care and support have been involved in developing.

"...a good service to me is a timely service where I actually have my needs presented to me on time and not slightly delayed to the point I feel like if maybe if I was able to do this or that, would just go up and do it". (Man on end-of-life care)

"A good service would be a tailor-made service to suit the service user's needs and a simple process so the service user can avoid any unnecessary delays". (Woman carer)

"A good service would be people listening to me and being patient with me if I don't understand, not speaking jargon (hard words and sentences), giving me the information". (Woman in group with people with Learning Disabilities).

"A service that gives the people who draw on care and support the sense of feeling empowered and feels like everybody's got input into how the services are run. What I think I'm trying to say is it's run very much on a co-production type model". (Man in P&SI group)

"I think consistency of staff is essential so that you know that you don't suddenly get agency staff in to fill a space". (Carer of adult living in supported living)

"...I would like the council to help train new caregivers to give them proper training". (Woman receiving day services)

Others commented on the importance of the wider context of service provision within in which ASC services are located and the need for accessibility:

"For me, developing the community infrastructure is essential – community changing facilities, better transport, accessible public spaces." (Man in supported living)

Future needs

In terms of future needs, participants highlighted that consistency of care staff, consistency of services and regular care reviews were important.

"Well, looking to the future, what I hope for is continued consistency with the services I get...possibly if I can get regular check-ups more, maybe more than I get". (Man A with mental health issues in supported living)02

"Change and consistency and keeping the same support worker". (Man B with mental health issues in supported living)



Carers' experience of ASC services

The project elicited significant interest from carers of people who use ASC services who were keen to have their voices heard. Carers provided feedback via an online focus group (14 carers), and through written feedback (38 carers). We actively sought and achieved the participation of carers from ethnically diverse communities via support organisations (Bristol Black Carers, Chinese Community Wellbeing Society, and the Carers Support Centre). These included unpaid carers (people who are not employed by the person they care for and often care for a family or extended family member), for example, carers of older adults, and parent carers of adults with disabilities.

Carers provide practical tasks, personal care and emotional support. The 2021 Census states that almost 34,000 people provide unpaid care in Bristol. This accounts for 7.6% of all people aged 5 years and over, a slightly lower proportion than the England and Wales average which was 8.9%. These figures are lower than expected. Census 2021 was undertaken during the coronavirus (COVID-19) pandemic. This may have influenced how people perceived and managed their provision of unpaid care and therefore may have affected how people chose to respond. (2021 Census, Office for National Statistics in <https://www.bristol.gov.uk/council-and-mayor/statistics-census-information/census-2021>).

ASC services used by carers (and the people they cared for) participating in this project included Direct Payments, adult housing support, carer payment, respite care, and information and support services and a carer support phone line, provided by BCC commissioned services (Carers Support Centre, Bristol Black Carers, and the Chinese Community Wellbeing Society).

Carers reflected a wide range of needs including the need for:

- increased availability of respite care opportunities
- respite care opportunities to be offered to and accessed by a more diverse group of carers
- a reduction in assessment time for respite care to relieve unpaid carers
- psychological and mental health support, and counselling
- social activities/outings and befriending as part of support for carers to address the isolation and stress often felt by those in caring roles
- information on financial support
- information on eligibility for Direct Payments
- information on what ASC support is available for carers overall

The importance of carer support and advocacy organisations was highlighted by focus group participants and by carers' written feedback for example, CCWS, Carers Support Centre, Bristol Black Carers, in referring people to ASC for a carers' assessment and in applying for Direct Payments on behalf of carers. The importance of staff acting as advocates for carers was also highlighted

particularly if language interpreting is needed or support for those with physical and sensory impairments.

What carers said they would like

Carers said that they would like:

- waiting times for care assessments to be reduced for the person they care for, feedback elicited revealed waiting times of between 1 year to 18 months
- waiting times for carer assessments to be reduced
- continuity of staff available to provide respite care
- improved training of staff who provide respite care to ensure quality of service
- increased payment for carers
- more information and advice on eligibility for Direct Payments for carers
- financial support for long-term carers for example caring for people (often family members) with for example, Dementia, which can impact on carers' employment prospects

What could be better about the support you receive?

Feedback elicited revealed that carers felt that support could be improved as follows:

- Providing training opportunities for carers
- Increased availability of respite care
- Consistency of paid carers to provider easily accessible respite care for unpaid carers
- More information on who can receive Direct Payments
- Increased choice of services available for carers

These were some of the comments related to the above:

"I think as a carer there should be improved access to training opportunities. I mean, if we (were) offered these opportunities where we can go out there and learn more skills and how to be a better carer, that'll be really useful for us as a carer and also having an expansion of support services. There should be a large choice (of services), so you just get to pick from the list what you want as a carer". (Woman carer)

"Respite care can be improved by increasing the amount of people who are deemed qualified for it and increasing the assessment time". (Man carer C)

"...a lot of people can benefit from respite care, but most do not get it in time and hence are discouraged to keep applying for it". (Man carer D)

".....so, what too can be improved for me I'd say is that a single carer should be assigned to me so it becomes hard for the person I care for to adjust (if there are many carers coming in). (Woman carer)

"There should be effective respite guidelines call for well-qualified, well-trained, and geographically accessible providers who can competently meet diverse and highly individualized family and care recipient needs". (Woman carer)

"More breaks, and you know, (to support the) emotional wellbeing of the carer." (Woman carer)

"Caregiving for an ill, elderly or disabled family member can be a demanding job and nobody actually should face it alone. Using respite care services can be very beneficial for those giving care and receiving care". (Man carer, E)

"I wanted to add that I received the sitting respite where I have someone come to take care of the person I care for, and I have received it a couple of time so, what I was thinking could be improved is now that I should have one specific person that comes all the time when I need respite care and not different people". (Man carer, F)

Carer assessments

Carers felt that carer assessments should provide carers with advice and information and remind carers when their reassessment is due:

"Carer assessment services should provide more than just an assessment. They should also provide advice, information and support to carers to help them access the services and support that they need". (Man carer)

"It would be great if there is a reminder for application of (carer) reassessment. I have missed it (for) the second year and not sure for the time to renew". (Woman carer)

Respite care

Carers emphasised the importance of respite care in:

- supporting the mental and physical health of carers
- helping maintain and in developing social connections in the community, reducing isolation which often increases as the burden of caring increases

Carers commented on the importance of respite care.

"It helps carers maintain their own health and wellbeing and adding to their quality of life – through respite and through increased opportunities for social connection, and social and/or physical activities that support health and mental wellbeing. For example, carers can receive respite to take a break from their care role, along with social, health and other supports, including personal or financial counselling, a group activity or a massage". (Man carer)

The group with older adults did not comment on experience of respite care.

What other support would you like as a carer?

Participants said that they would like the following to support them as carers: carer assessment, to increase the availability of respite carers, and mental health and emotional support.

“I would like the carer assessment. It gives an opportunity to record the impact caring has on your life and what support or services you need. The assessment will look at your physical, mental and emotional needs, and whether you are able or willing to carry on caring”. (Man carer A)

“I would love to receive a carers’ credit, added to my allowance to enable me meet up with my financial needs as a carer who does so many hours caring for my patients (people)”. (Man carer B)

“Respite care can be improved by increasing the amount of people who are deemed qualified for it and increasing the assessment time”. (Man carer C)

“We need day services and mental health support”. (Woman carer)

“Mental and psychological support”. (Man carer)

Feedback on ASC Services: Supported Living, Day Services, Extra Care Housing, Respite Care and Advocacy

Supported living

In giving feedback on their experience of supported living, people who draw on care and support people with Learning Difficulties, and those with mental health issues revealed:

- the importance of long-term supported housing as opposed to short-term, consistency of staff and management, and housing that is designed in a non-institutional style
- the importance of trained staff
- the importance of communication between staff and residents in order to maintain independence of residents
- the need to involve people who draw on care and support’ families in decisions about supported living, ongoing support and changes in care provision
- the importance of staff taking into account people who draw on care and support’ protected characteristics to ensure safety and equity of care provision
- the need for people who draw on care and support to access more activities in the community and increasing access to these activities and the need for support staff to explore the personal interests of residents.

"...the care home knows about your background – likes, hope and needs. This includes any needs you have because of your age, disability, sex, gender, gender identity, race, religion or belief or sexuality. Whether you are lesbian, gay, bisexual or heterosexual, also staff deal with incidents and accidents quickly and openly and they learn from mistakes. You feel safe and protected by staff, but you also have much freedom as possible to do the things you want to do regardless of your disabilities or other needs." (Older man C)

"The three things I find important about support living are that you will be getting the right help, having someone to talk to and spend some quality time with, meeting new people". (Woman receiving day services).

"... staff have the right knowledge, qualifications and skills to carry out their role so that you have a good quality of life. They know about your health needs and personal preferences and give you as much choice and control as possible.....Where appropriate your family and friends are also involved in decisions about your care". (Older man C)

Day services

Feedback on day services from people with Learning Disabilities and Carers revealed that people who draw on care and support valued the opportunity to connect with others in the community, to be supported to pursue their individual interests and to reduce isolation. There was concern that day services and day opportunities had decreased.

"...an opportunity for me to connect with others who are in similar situations. These groups offer emotional support, advice, and a sense of community". (Woman carer)

"Social amenities in the community should be changed regularly to ensure healthy living, having a variety of services". (Woman A in supported living)

"A lot of it is about access, creating equal opportunities so that people with multiple complex needs can access ordinary opportunities and community life". (Woman B in supported living)

Others commented on the need to make day opportunities more widely available and accessible for carers to take the people they care for:

"...increasing inclusiveness (of day services) is a welcome development".

(Man carer, E)

"I think the idea of having not just one location but having (day opportunities) in different locations, that makes it closer to carers and even those receiving the care is going to be very, very effective and it's going to work out well". (Woman carer, D)

Extra care housing

Feedback from older adults on Extra Care Housing included those who were living in this type of housing and those commenting on their knowledge of it. Focus group participants revealed the need for:

- signposting to information on Extra Care Housing particularly for diverse communities
- more information of what extra care housing consists of
- information on eligibility for extra care housing.

“I have extra care housing and it's been amazing but I feel the services they provide can be improved on, and provide more automated equipment for older people like myself to actually help me ensure I'm not so dependent on the extra care.... (Older man B)

“What I think about extra care housing is it's been great so far but I feel there should be a lot of awareness being done about it so that all the people that need to get services can know about them and be able to apply and be able to be assessed for the care. I feel not a lot of people know about their services”. (Older man A)

Several participants felt that there was a need for signposting to information on Extra Care Housing:

“Despite the fact that there's a lot of information on the council website, it kind of shoots people to a place to actually enlighten and educate people who would need the care, to actually encourage them to go and visit the website and get even more information”. (Older man, C)

“I know there's a lot of information on the Bristol website but I do not feel a lot of people in our community go on there to get information in their daily life so, I feel outside the website, it can be talked about in focus groups like this, on social media because a lot of people use social media now, talk about it in town hall meetings so that all the people that need to get services can know about them and be able to apply and be assessed for the care. I feel not a lot of people know about it”. (Older man, B)

Direct payments

Amongst people with physical and sensory impairments, and with carers, there were varying degrees of people's understanding and experience of Direct Payments. People emphasized the need for all those wishing to go on to Direct Payments to be assessed and thus be given choice and control over their care.

“Direct payments are available from health and social care trusts for someone who is assessed as needing help from social services”. (Woman in P&SI group)

“My opinion is people are different and their opinions should be respected. Anyone applying for direct payment should be able to afford their care themselves and should be assessed and given that opportunity”. (Man in P&SI group)



“Experience of taking and managing a direct payment is falling short of the intentions they’re trying in the policy. The principle is that people should be able to maximise the choice and control they have over the care and support they’re entitled to”. (Woman in P&SI group)

In the carers’ focus group, people felt that there could be more information available in an accessible format (as well as on the BCC website) on Direct payments and on eligibility for payments. This is illustrated by the following comments:

“... you said if we felt there were any barriers to it so, I think personally carers who might really want to take advantage of these payments, they do not have the proper information so they just give it out and then there's a whole lot of confusion and mismanagement and all of that so, I think if there's a proper information...” (Woman carer, D)

“...initial information for those using direct payments, how a personal budget is set, including a fair contribution, determining the direct payment and the level of flexibility around how a direct payment can be used”. (Woman carer, E)

“Need for availability of more staff to assess people for Direct Payments, I agree with X and I think adding more qualified people is good”. (Man carer F)

Advocacy

Understanding and experience of advocacy and self-advocacy varied amongst focus group participants in the physical and sensory impairment group and with those with mental health issues. One participant was involved in a self-advocacy group and shared their experience of this with the group. Several participants wanted more information on self-advocacy and organisations providing support in this area, and to know what the eligibility criteria is for an advocacy service. The following quotes reveal participants’ understanding of self-advocacy in ASC:

“Self-advocacy is fighting for your right as a patient which basically means working together with your health providers to come up with a plan to keep you in the best of health.” (Woman , P&SI group)

“Self-advocacy is letting people know that you need to intend to resolve issues, be a central part of decision making. I would like to learn more about it.” (Man, P&SI group)

“Self-advocacy for me is an individual's right to effectively communicate, share interests, convey and negotiate his or her own rights, needs, desires, and so on”. (Woman, P&SI group)

“Being a self-advocate means learning how to direct what you think you may need in terms of your health, also it means listening and learning from your healthcare providers”. (Woman, P&SI group)

“And then self-advocacy for me is an individual's way of effectively communicating, sharing interests, conveying and negotiating”. (Man, P&SI group)

“Self-advocacy, in my opinion, allows me to have a say in major decisions and options that suit me.” (Woman, P&SI group)

“For me, self-advocacy is the ability for an individual to effectively negotiate or assert his or her own interest, desires, needs and rights.” (Woman, P&SI group)

Participants highlighted the importance of the role of self-advocacy in supporting people with a diverse range of needs and acknowledging protected characteristics:

“For patients who are part of a minority, whether that's due to race, ethnicity, religion, culture or sexual orientation, (they) should self-advocate to confront potential bias because they may need some special health needs.” (Man, P&SI group)

“Before you can self-advocate, you need to learn all about your disability needs, strengths and weaknesses to be able to describe them”. (Woman, P&SI group)

Several participants had experience of participating in a self-advocacy group and spoke positively about this.

“I encourage people to take up if you're offered the chance of joining one then do because it's a brilliant way of getting to help make the decisions about how stuff that impacts you will help you moving forward.” (Man, P&SI group)

Participants were keen to have further information about local advocacy services and their eligibility criteria:

“I would appreciate it if you could talk more about it and explain if I can apply for it (an advocacy service)...and how it is going to help me as an adult with a disability.” (Man A, in focus group with people with mental health issues).

“It is a welcome development that the City Council is trying to develop such services. I applaud it and would use such a service.” (Man B, focus group with people with mental health issues).

Quality of life: what makes a meaningful day?

People in the focus group with Learning Disabilities were asked ‘What makes a meaningful day?’ This is what they said:

- the quality of relationship they had with a support worker
- being treated as an individual
- going out in the community, social activities and pursuing interests

This is shown by the following comments:

“..so having my support workers take care of me and provide my basic needs kind of what keeps me going because I don't know what I would do if I didn't have them around and also what they do for me that is meaningful is they don't just end in providing the basic support like cleaning, helping me,.....they actually have some discussion and make me feel at ease and at home”. (Man, end-of-life care)

“My staff encouraged me to move on to a better version of myself concerning my fears and trying new things”. (Woman B in supported living)

“I really feel the wonderful support workers my son gets are those that treat him as an equal, that treat him like a friend, almost not as someone who needs care so, I love that and that’s really important.....I am aware that my son’s choices are supported to do the activities that make his life meaningful”. (Woman carer of adult son in supported living)

“My staff encourage me to go for walks, coffees, and see new things. My staff treat me like a friend”. (Woman A in supported living)

“A meaningful day to me will be doing fun activities such as horse riding, seeing friends going to cafes”. (Woman C in supported living)

What do you like about the ASC support you get?

Participants liked the fact that their paid carer support was responsive to their needs, and that carers understood them, including people who draw on care and support with communication issues.

“Ever since I got on the end-of-life care, the care workers they have been attending to me – they have been so, so great. They listen to me, I have one that I have a connection with. I have difficulties communicating verbally but she understands me and understands my limitations. She helps me get through my daily activities and I’m most grateful for her service”. (Older man, B)

“Okay I would say one very thing I like about the support I get is the accessibility and quick responsiveness and for the fact that it could actually meet what I want”. (Older man, C)

How can Adult Social Care services be improved?

Feedback on ASC services overall revealed that people wanted:

- the waiting time for care assessments to be reduced
- care staff to be provided with more training to improve the quality of care
- access to more day opportunities in the community particularly as previous services had closed down.

"Things that can be improved (in terms of) the time (it takes) processing adult care – faster assessment time and a great carer just like the one I have now."
(Woman receiving day services)

"I would like the council to help train new caregivers, to give them the proper training. I think we don't have enough carers who are down to earth about their job". (Woman receiving day care services).

"I mean BCC over the last few years have shut down a lot of places where groups could go to which makes it really hard to try and be involved with people in the same position. I found with my support workers, they do a lot of things for me, but I've also been with (supported housing provider). They've also tried to get me to join groups so, I mean but a lot of places are closed down now so it makes it harder. I went to (day centre)and the toilets had been closed and that. So, it makes it harder for a person who's in a wheelchair to find a toilet".
(Man in supported living).

"....put investment in to improve housing and take advantage of technology to help those receiving care and the caregivers."(Woman receiving day services)

Considerations to take forward

The feedback from people who draw on care and support of ASC and their carers suggests the following.

1. The need for support workers to signpost people to information on ASC services particularly Extra Care Housing for older adults.
2. The need for signposting to information on advocacy services for people with Learning Disabilities and people with mental health issues.
3. The need for readily available respite care opportunities for unpaid carers.
4. Reduced waiting times for care assessments for ASC people who draw on care and support. Feedback revealed people who draw on care and support were waiting between 1-2 years for care assessments. (It was stated that waiting lists for care assessments for new people who draw on care and support are up to three years).
5. Reduced waiting times for carer assessments for unpaid carers.
6. Accessible information and advice on eligibility for Direct Payments, Extra Care Housing and Advocacy.
7. The need for mental health and emotional support services for unpaid carers.
8. The need for support (and day services) for people and their carers to participate in social and cultural activities in the community to reduce social isolation.
9. Increase the availability of advocacy services for people with physical and sensory impairment.
10. Increase the availability of advocacy services for Black and minoritized ethnic groups to enhance the take up of Direct Payments.

Recommendations for future engagement

Healthwatch Bristol recommends that BCC ASC set up an ongoing Co-Production Steering Group with a mixed cohort of people who draw on care and support to steer and feed into the process of further engaging people who draw on care and support. This could help inform the engagement process and feed into BCC's service planning and service commissioning cycle. People who draw on care and support involved in this project were asked whether they would be interested in participating in an ongoing engagement group and further feedback activities. 32 people said that they would be interested across the 5 cohorts (see Table 3. below).

Once a Co-Production Steering Group is set up, terms of reference and volunteer agreements would need to be developed and frequency of meetings agreed. All papers required for Steering Group participants would need to be produced in an accessible format for those who require this. Materials should be available in Easy Read and sent out to participants one week before meetings.

Table 3

Group	Number interested in further engagement
Older Adults	8
Carers	7
People with mental health issues	3
People with Learning Disabilities	2
People with physical and sensory impairment	12
Total	32

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Quality assurance

This project was co-designed using Healthwatch Bristol methods, delivered by Engagement and Co-production Officer Anna King (report author), peer supported by Dan Potts (Healthwatch Essex), and carer feedback supported by Susanna Giullari, Policy Engagement Lead, Carers Support Network. Graphics and pictures: Healthwatch England, The Centre for Ageing Better, Canva.

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Glossary

Description of Adult Social Care services

Community Support Services

Community Support Services (CSS) in Bristol are specific ASC support services for adults (18 years+) with eligible social care needs delivered within community settings or at home. Adults can receive services after having been statutorily assessed need under the Care Act (2014). In 2021/22, over 4,000 adults received Community Support Services in Bristol: over 1,750 older people and over 2,250 adults aged 18–64 years. (JNSA 2022–23 – Bristol Health and Wellbeing Profile)

This does not include specific home care provision but does include:

- Supported Living
- Support to Access the Community
- Day Services
- Time for You (support for carers to have a break)

Extra care housing (ECH)

Extra care housing, sometimes known as assisted living, is for older people with care and support needs who want to be active and independent. It is an alternative to residential care allowing older people to live in either one- or two-bedroom ECH flats, houses or bungalows which are part of complexes with public spaces that may include a restaurant, activity room, lunch club, hairdressers, shop. During 2021/22, there were over 440 ECH packages received by people aged 55 and over.

Direct payments

A direct payment is money provided to pay for care and support needs for people who have been assessed and choose to use the money to meet those assessed needs. This enables choice and control and can be used to employ a personal assistant, pay an agency for support or employ a family member as long as they do not live in the same home. In 2021/22, over 970 clients received direct payments in Bristol. Almost a third of the clients were aged 65 and over. (JNSA 2022–23 – Bristol Health and Wellbeing Profile).

Appendices

Appendix 1

Organisations involved in engagement and recruitment of participants

Bristol AgeUK

Brandon Trust

Bristol Age UK

Bristol Black Carers

Bristol Centre for Deaf People

Bristol Older People's Forum

Bristol People's Voice

Bristol Reclaiming Independent Living (BRIL)

Bristol Sight Loss Council

Carers' Support Centre

Chinese Community Wellbeing Centre

Independent Mental Health Network

Milestones Trust

The Care Forum

Thinklusive

WECIL

Appendix 2

Table 1. Topics discussed during focus groups

Focus group	Topics discussed
All groups (apart from Carers)	<ul style="list-style-type: none"> ASC service referral process Choice of care Care reviews and reassessment Service response to changing care needs Current support needs Future support needs
Older adults	<ul style="list-style-type: none"> Current support needs Future support needs Respite care Extra care housing
People with mental health issues	<ul style="list-style-type: none"> Supported living Support to access the community Advocacy
People with Learning Disabilities	<ul style="list-style-type: none"> Supported living Day opportunities Support to access the community
People with physical and sensory impairment	<ul style="list-style-type: none"> Direct payment support Advocacy and self-advocacy
Carers	<ul style="list-style-type: none"> Current support received Support needs Respite care Direct payment support Day opportunities

Table 2. Focus group participants

Focus group	Cohort	Women	Men	Total
1A	Older adults	3	7	10
1B	Older adults	0	8	8
Older adults in total (aged 65 + years)				14
2A	People with mental health issues	0	2	2
2B	People with mental health issues	0	4	4
People with mental health issues in total				4
3A	People with Learning Disabilities	5	5	10
3B	People with Learning Disabilities	5	5	10
People with Learning Disabilities in total				16
4A	Carers	6	8	14
Carer - written feedback via email	Carers	15	23	38
Carers in total				52
5A	People with physical and sensory impairments	10	7	17
People with physical and sensory impairment in total				17
Chinese Community Wellbeing Centre (CCWS) Written feedback	Chinese older adults (5 carers 1 older adult included in the above figures)	5	1	6
Total				103

Appendix 3

- Example of participation information sheet
- Example of participation consent sheet
- Focus group questions – experience of adult social care
- Focus group questions – feedback on adult social care services
- Adult social care feedback – interview questions

Appendix 4

Adult Social Care Project Consent Form (easy-read)

Appendix 5

Adult Social Care Project Information Leaflet (easy-read)

Appendix 6

Adult Social Care Project Focus Group Questions (easy-read)

Appendix 7

Adult Social Care Project Day Opportunities (easy-read)

Appendix 8

Adult Social Care Project Focus Group Questions 23 May 2023 (easy-read)

Appendix 9

Adult Social Care Project Support to Access the Community (easy-read)

Appendix 10

Adult Social Care Project Supported Living (easy-read)

To view or download appendices 3 – 6 for this report, please visit <https://www.healthwatchbristol.co.uk/bigger-picture-what-people-think-about-adult-social-care-july-2023>.

If you require this information in an alternative format, please email helen@healthwatchbnssg.co.uk.



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