



healthwatch
Bedford Borough



Supported Living Feedback report

March 2024

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Introduction

Healthwatch Bedford Borough is the local, independent voice for the public in health and social care services. One of the ways that we fulfil our role is to carry out focused projects each year and develop our annual work plan based upon public priorities.

What we did

In June 2023, Healthwatch Bedford Borough began working in partnership with Bedford Borough Council's Strategic Commissioning and Procurement Team, and [Voiceability](#), Bedford Borough's chosen advocacy and involvement service. The focus of the activity was to capture the Service User and Carers voice with the local Supported Living provision and co-produce the new Supported Living Framework specification with people accessing these services.

As a team, we designed two bespoke surveys, one [standard version](#) and one [Easy Read](#) version. These were loaded onto Healthwatch Bedford Borough's SNAP survey portal and sent out via email to each Supported Living service provider, as well as a hard copy Word version for those service users who wished to take part on paper, with the support of a Carer, Support Worker, Parent or Guardian.

We undertook **3** focus groups during the Autumn. These focus groups took place in the following settings:

- **Centre for Independent Living, Gadsby Street**- Learning Disabilities/Autism service users & support staff (September 2023)
- **Affinity Trust & Creative Support** Learning Disabilities/Autism service users and support staff, Centenary Hall, Kempston (October 2023)
- **Anvil House**- Mental Health service users and support staff (October 2023)

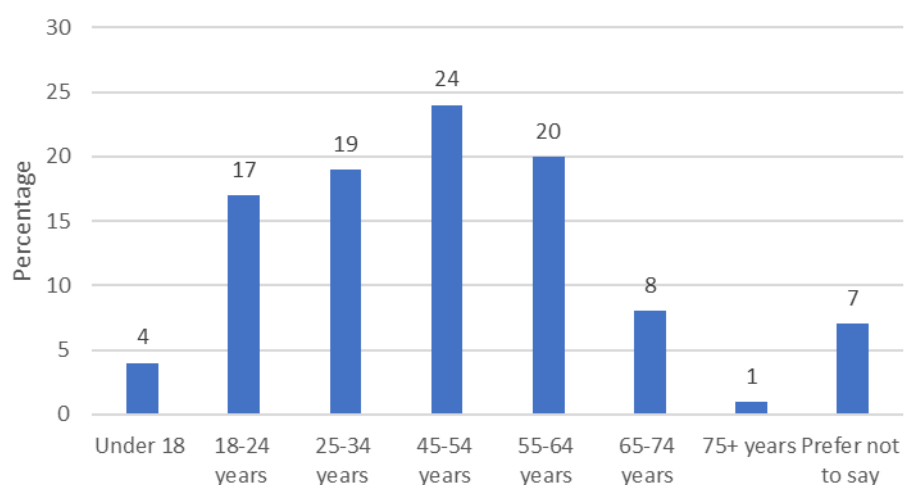
Who took part?

There were **107** completed surveys. **76%** of the people who completed the surveys said that they had received help to complete it. Of these, **63%** said that they had received help from a support worker, **7%** were helped by a family member, **1%** by a friend and **5%** by someone else.

When asked if they had any communication needs **53%** said that they had no communication needs. **12%** said that they had other communication needs than the ones listed. **19%** said that they could not read or write. **5%** said that English was not their first language, a further **5%** reported to use Makaton as their primary language, **3%** used British Sign Language (BSL) and **3%** advised that their primary communication method was lip reading.

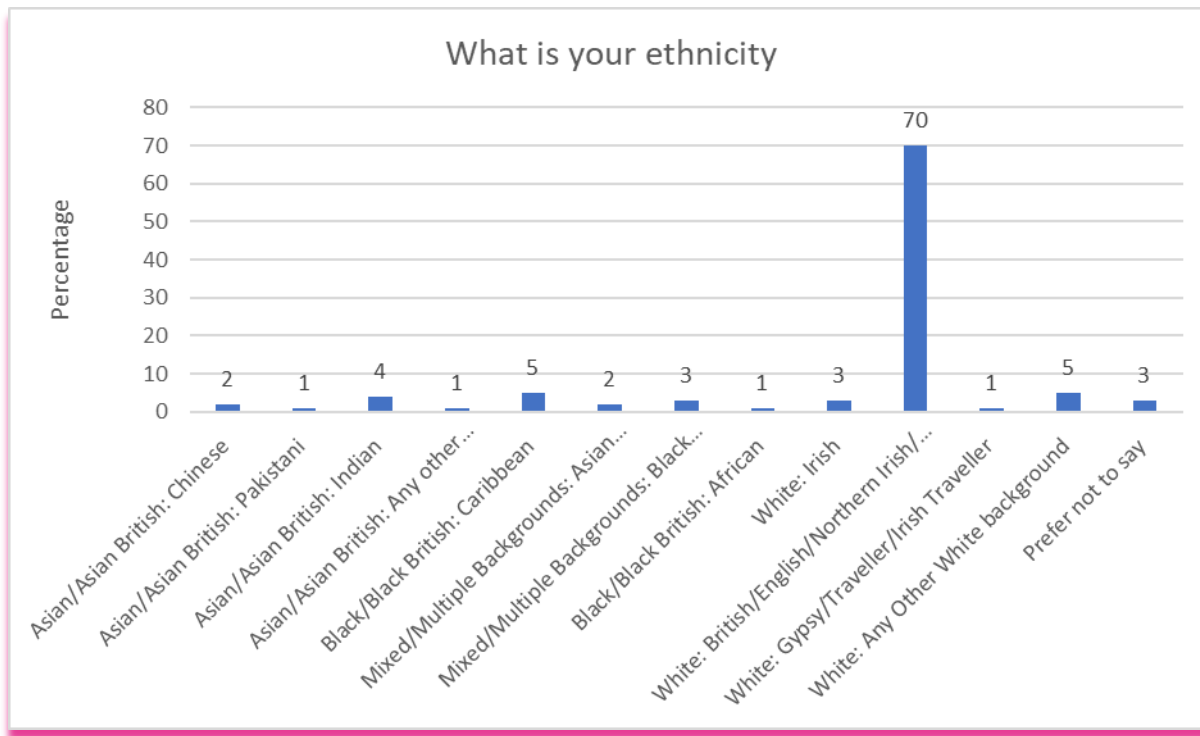
When asked about their gender or sex, only **24** people gave any answer to the question. **7** said that they were women and **10** that they were men. **7** said that they preferred not to say.

What is your age group



People responded advising they were from a range of ages, with the largest group at **24%** saying that they were aged 45-54 years old. **20%** reported that they were aged 55-64 years old, **19%** that they were 25-34 years old, **17%** said that they were aged 18-24 years old. **8%** of

respondents were aged 65-74 years old, **1%** were aged over 75 years, and **4%** said that they were aged under 18 years.



The largest ethnic origin identified by the surveys was White British. This cohort made up **70%** of the

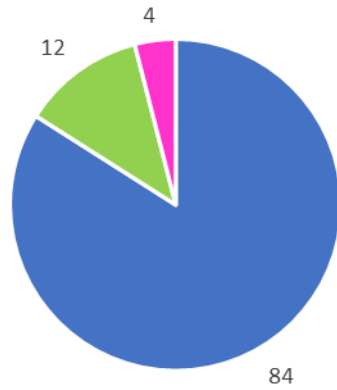
respondents. This next largest groups were those from other White backgrounds **5%**, Black/Black British: Caribbean was **5%**, and Asian/Asian British: Indian was **4%**.

Less individual demographic information was collated from the participants in the focus groups, but there was a total of **19** service users who participated across the three focus groups.

Data Analysis

There were **107** completed surveys in total, but not all people completing the survey answered every question. Therefore, percentages have been worked out on the number of responses to individual questions, including those where they have opted for 'Not Applicable' as their answer.

I live the life I want

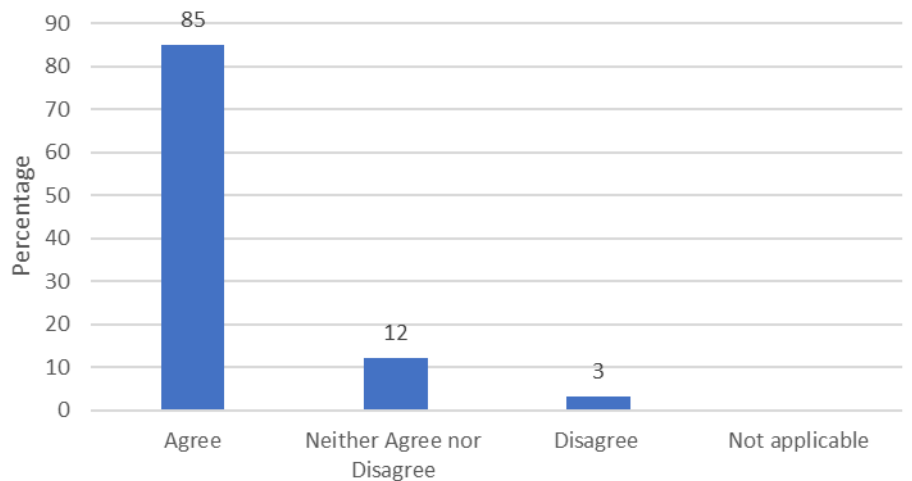


■ Agree ■ Neither Agree nor Disagree ■ Disagree

84% of people who answered the question said that they lived the life that they want. **4%** said that they did not lead the life that they want. **12%** neither agreed nor disagreed.

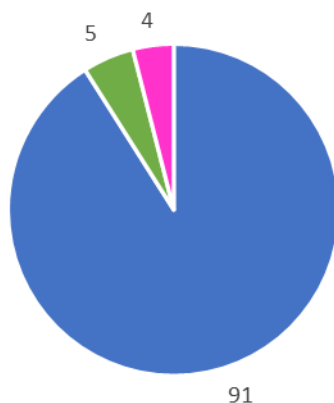
85% of people who answered the question said that they can do the things that are important to them. **3%** of people said that they cannot do the things that are important to them. **12%** neither agreed nor disagreed.

I can do the things that are important to me



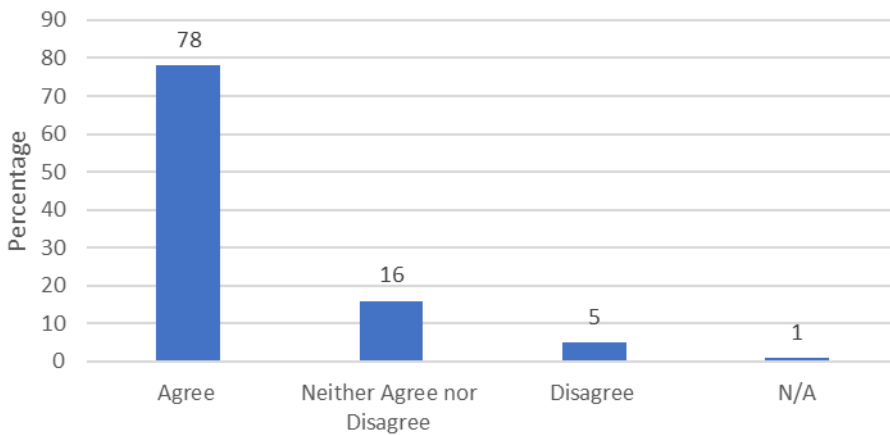
91% of the people who answered the question said that they felt safe in their home. **4%** said that they did not feel safe in their home. **5%** neither agreed nor disagreed.

I feel safe in my home



■ Agree ■ Neither Agree nor Disagree ■ Disagree

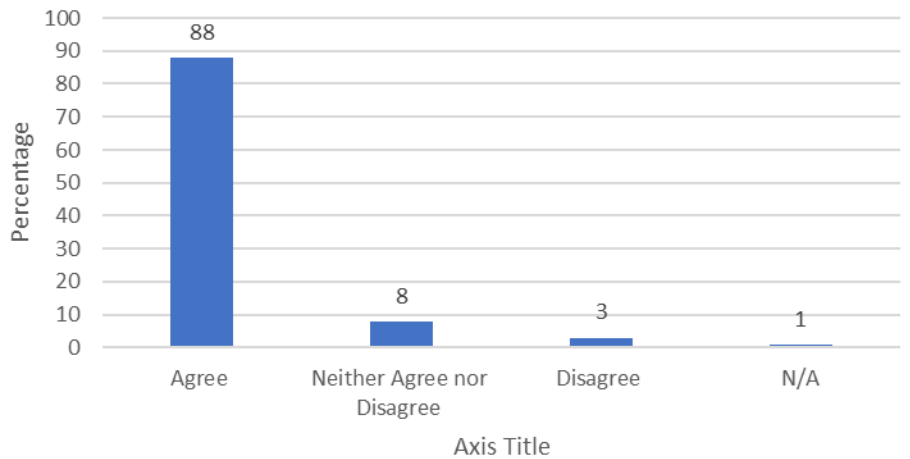
I know how to raise concerns or complaints and feel listened to if I do



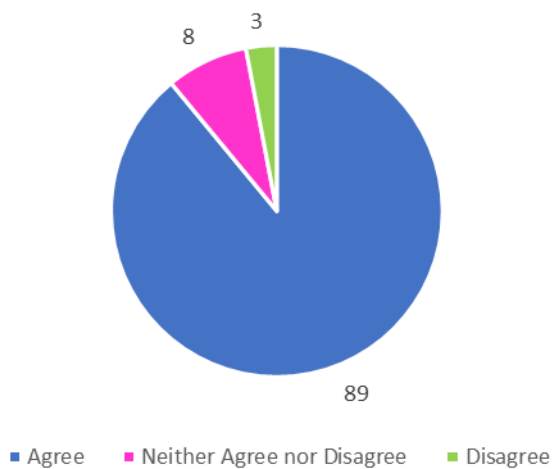
78% of people said that they knew how to raise a complaint or concern, and that they felt listened to if they did so. **5%** of people said that they did, and **16%** neither agreed nor disagreed.

88% of people who answered the question agreed that they were able to choose what their home looks like, **3%** disagreed, and **8%** neither agreed nor disagreed.

I choose what my home looks like

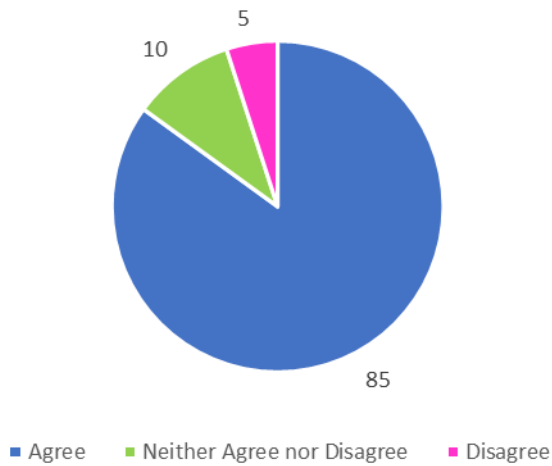


My home is in the local area where I want to live



89% of people agreed that their home is in the local area where they want to live, **3%** disagreed, and **8%** neither agreed nor disagreed.

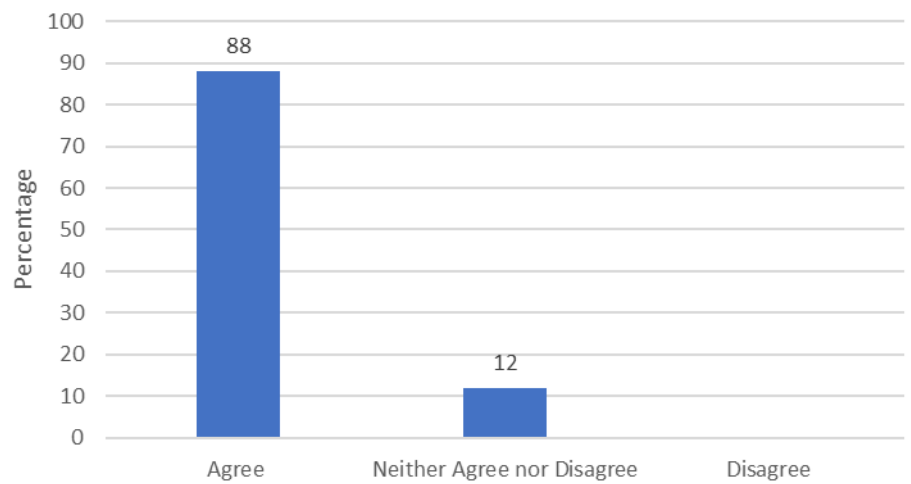
I am involved in planning my support



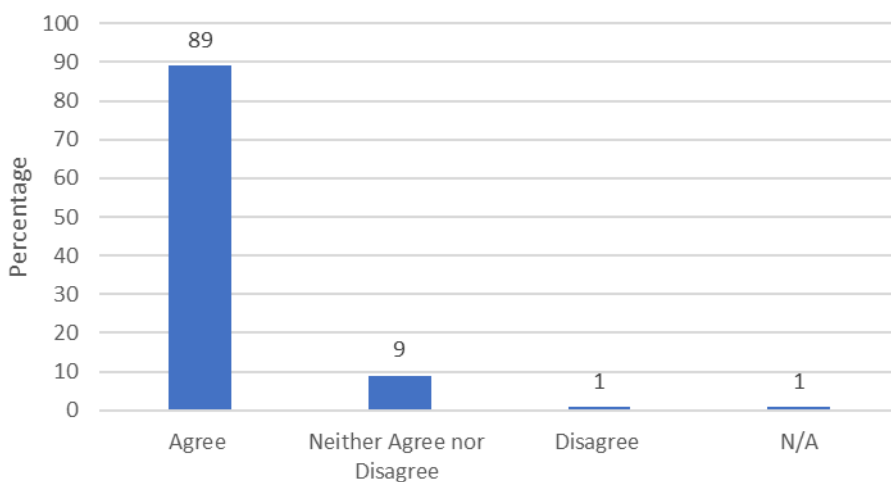
85% of people who answered the question said that they agreed that they were involved in planning their support, **5%** disagreed that they were involved and **10%** gave a neutral answer.

88% of people agreed that they felt respected and that their opinions mattered, nobody disagreed, and **12%** gave a neutral answer.

I feel respected and that my opinions matter

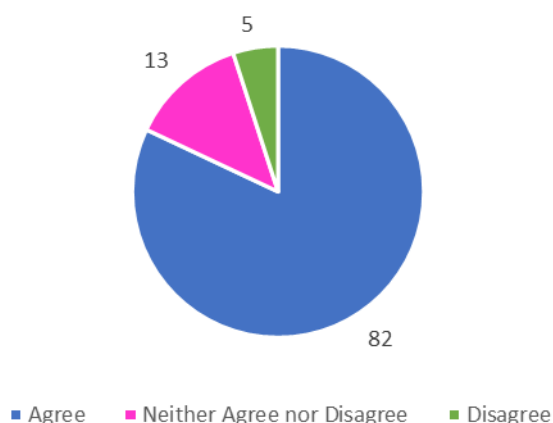


If I am unhappy or worried my staff help me



89% of people agreed that if they were unhappy or worried, their staff would help them, **1%** disagreed, and **9%** gave a neutral answer.

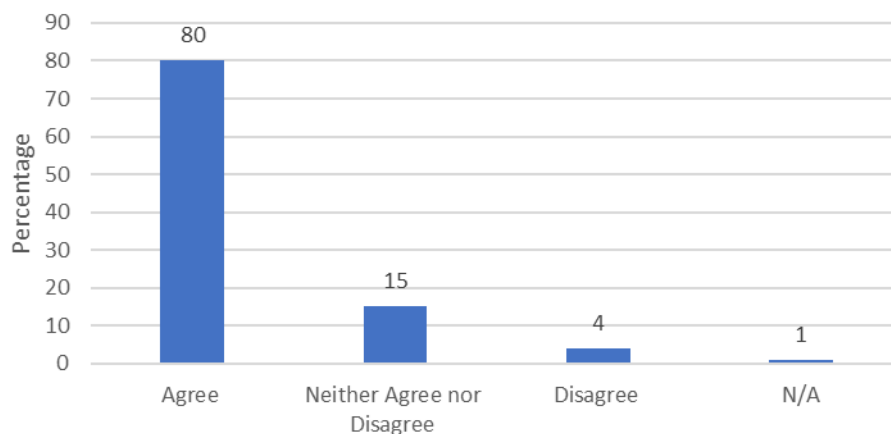
I see/speak with my family and friends as much as I want to



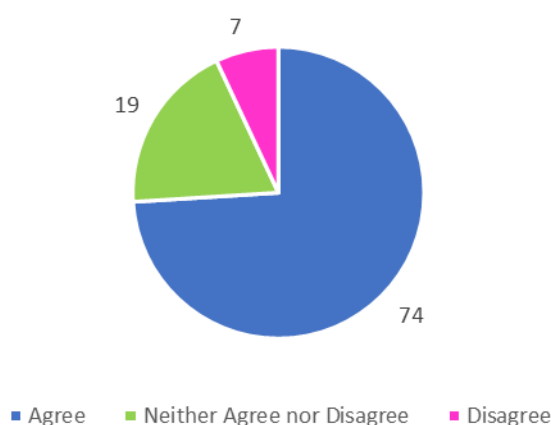
82% of people who answered the question said that they saw or spoke to their family and friends as much as they want to, **5%** disagreed, and **13%** gave a neutral answer.

80% of people said that they spent time with people who share their interests, and that they can meet new people, **4%** disagreed, and **15%** gave a neutral answer.

I spend time with people who share my interests and can meet new people

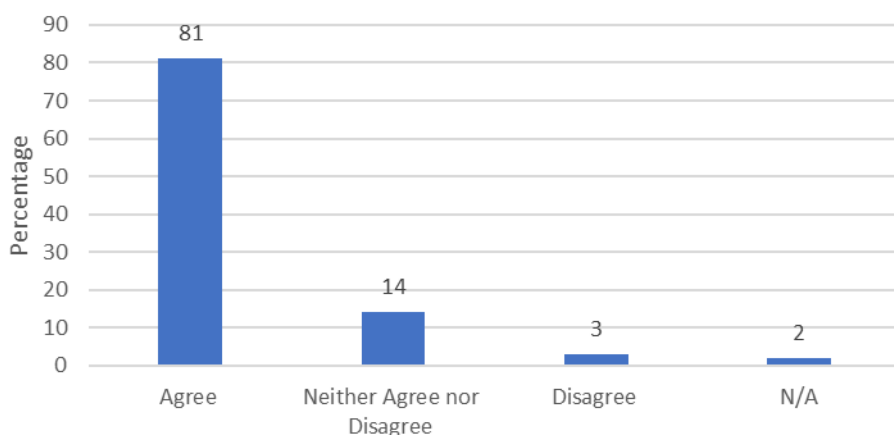


I know about activities and social groups in my local area



74% of people agreed that they know about activities and social groups in their local area, **7%** disagreed, and **19%** gave a neutral answer.

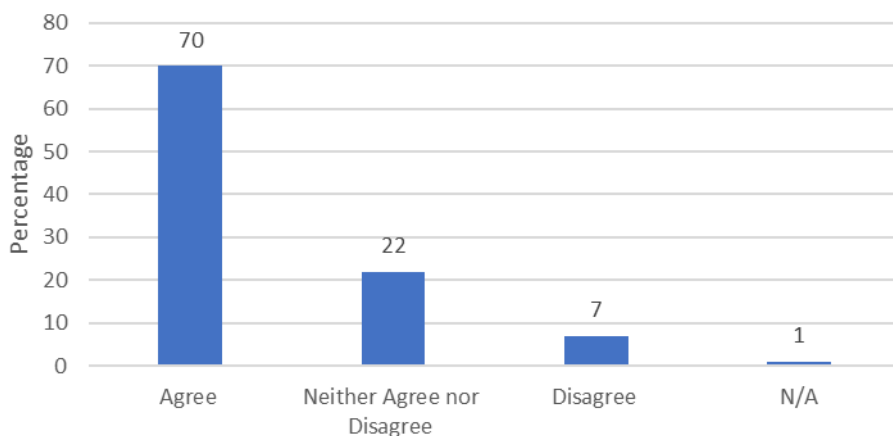
I can get information and advice to make decisions for myself



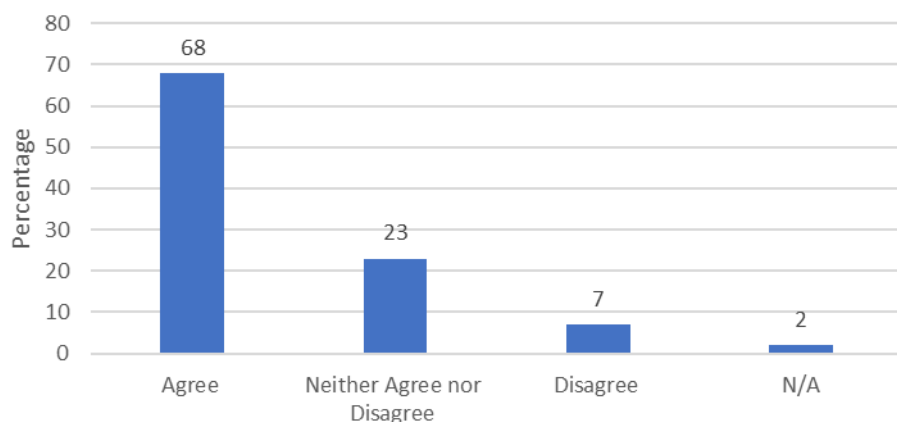
81% of people agreed that they can access information and advice to make decisions for themselves, **3%** disagreed, and **14%** gave a neutral answer.

70% of people said that they knew what is in their records, and that they can access those records if they wanted to, **7%** disagreed, and **22%** gave a neutral answer.

I know what information is in my records and can access the records if I want

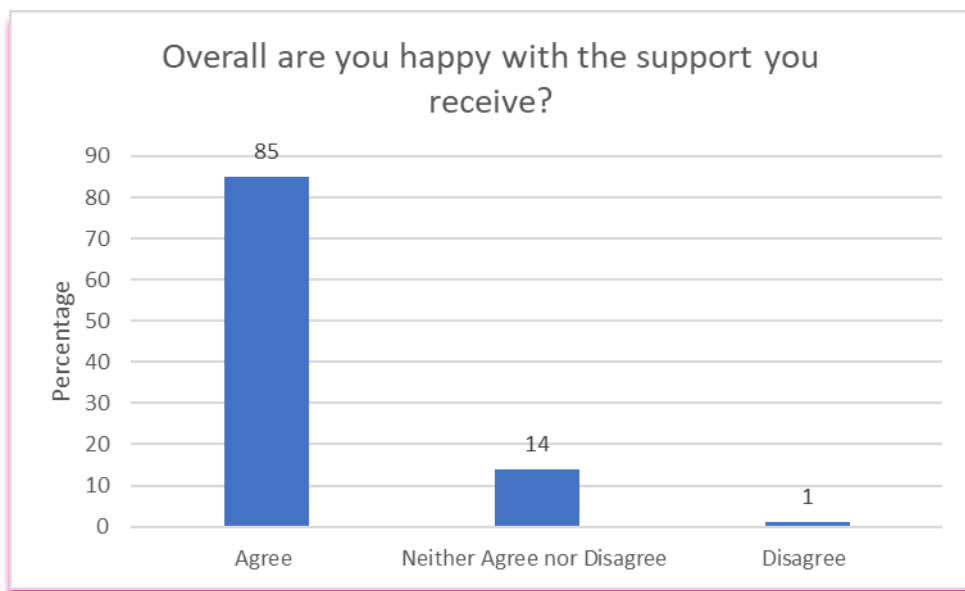
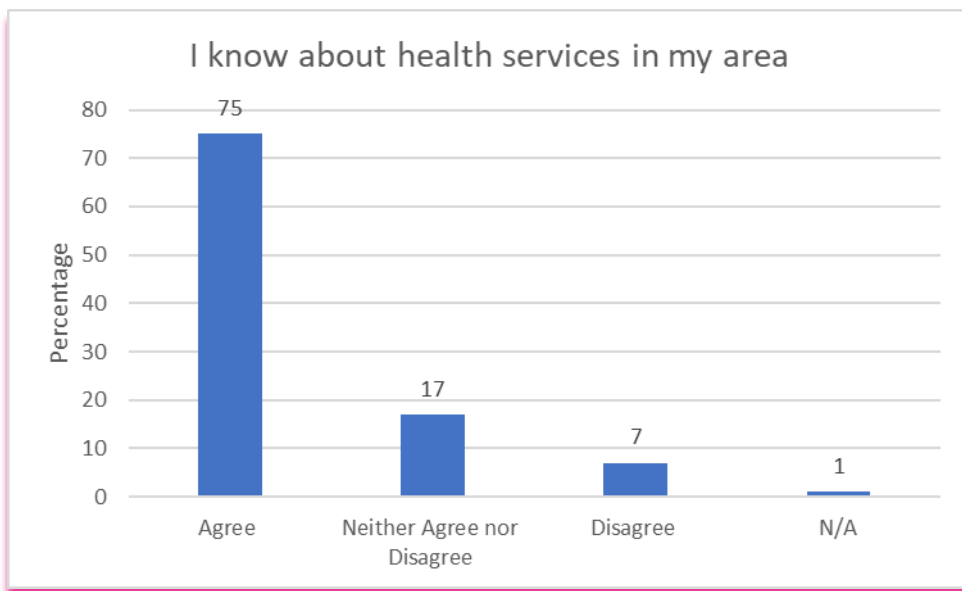


I can learn, volunteer or work if I want to



68% of people who answered the question said that they could learn, volunteer or work if they wanted to, **7%** disagreed that they could do so, and **23%** gave a neutral answer.

75% of people said that they knew about health services in their area, **7%** disagreed that they knew about health services, and **17%** gave a neutral answer.



85% of people agreed that overall, they were happy with the support that they received, **1%** disagreed, and **14%** said have a neutral answer.

Feedback

When asked what the best things were about their accommodation, a number of the comments were about the staff that supported the participants. Examples of comments include *'staff are lovely and always helping me'* and *'I think the support worker is amazing.'*

Others commented on their accommodation such as having an *'ensuite bathroom'* or *'my newly painted bedroom'*. For others it was having their *'own private space'* and having space where they can *'watch TV... so no-one can tell me to turn over.'*



Being safe and supported was mentioned by some people with one person saying they were in a *'safe environment with staff I trust.'* Another said that they *'feel safe and secure in my home.'*

For others being able to be independent was important to them with one person commenting that they were able to *'live the life I want to live'* and another that the support enabled them to be *'as independent as possible.'*

Being part of a shared household was commented on positively, with one person saying that they *'enjoy the company'* and another that *'I like the people I live with.'* Others liked living alone with support saying that *'I love living in my own flat'* and *'I like being by myself.'*

When asked what could make their accommodation better, there were relatively few comments with a lot of people saying that there were no improvements needed as they were *'happy with everything'*; or that *'our home has improved a lot.'*

However, where there were comments about improvements that were needed, which related to the following themes:

- **Cleaning**- There were some comments about the need for more cleaning in the homes, whether in terms of *'more support with cleaning'*, or other people living in

the home ensuring that they keep things clean and tidy by *'putting the right things in the bin'*; or *'making sure we keep on top of tidiness- I don't like it scruffy.'*

- **Welfare**- Others suggested there was a need for more support. One person commented that *'sometimes my welfare checks do not happen. I understand that I am not the only person who lives here but would still like staff to come and make sure I am okay.'* Another said that they *'would like the staff to check on me more, and staff not playing with their phones.'*
- **Access to records**- One person commented that they would like access to their records. They said that they *'have not been asked about my support plan since they have been moved to the digital system. Some of the support staff complete the notes from my support after they have left my property... I would like to see what they have written about me.'*
- **Continuity of care**- There were some comments about wanting continuity of staff with people saying they would like *'more staff that stay'* and another that it could be improved by *'not changing staff so frequently, I would like to get to know the staff better.'*



- **Activities**- There were also suggestions that there could be more activities with suggestions of *'more outings and holidays'*; having *'more puzzles and toys to play with'*; and *'more sensory trips.'*

When asked if they had anything else they wished to tell us about, there were a mixture of positive and negative comments. Positive comments were generally about the support received, the staff or the accommodation, with similar comments to those previously given.

One negative comment related to issues with neighbours or other housemates, with the person saying, *'I don't like how staff tell me what to do with my apartment. I have told them only clients/ other residents knock on my windows and they told me to close my blinds even though I need natural light in my flat.'* Another said that *'one of my neighbours upstairs can keep me awake at night because of loud music, and also I can hear them moving about.'*

There were comments about the way that accommodation could be improved with suggestions of a *'pond'* in the garden, or a *'common area for get-togethers.'*

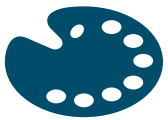
Focus Groups

There were **three** focus groups undertaken as part of this project, with **2** of the sessions being facilitated by Healthwatch Bedford Borough, in partnership with Bedford Borough Council and Voiceability. A total of **19** service users took part in the groups, alongside the support staff.

The feedback from each group was generally positive with participants saying that they were happy with their living arrangements.

People said that the staff were *'kind and helpful'* or *'amazing'*.

One group spoke about whether they felt safe in their current accommodation with all members of the group agreeing that they felt safe in their respective homes. One person said that *'I feel safe with my carer'* whilst another said *'I keep myself safe.'*



Taking part in activities and pursuing their interests

Two groups said that they were able to request activities that they wanted to do, and the staff would make the arrangements for that to happen. They generally agreed that if they wanted to go somewhere they were supported to do so, with one person stating that their support worker *'gets the tickets and we go to see the matches'*. Another person said *'I go horse riding every Tuesday with my carer, and I won a trophy for [horse] jumping in a competition.'* However, the other group said that whilst they had coffee mornings, they would like more social activities that they could take part in.

Participants were asked about how they found out about local activities that they could get involved in. Participants said that there was a lack of information on what was available. It was commented that *'we used to get something sent us by the Council'* but they were *'not sure there is anything now.'* It was also commented by staff supporting participants that there had been monthly newsletters sent out in previous

years, but these were no longer received. It was commented that *'we struggle to find any decent listings now. We have to ask around to see if anyone has seen a 'What's On page' advertised.'*



Ability to make choices

People said that they were able to make decisions about things like the décor of their rooms and what they would like to eat. When discussing décor, one participant said, *'I choose the paint I want and then the staff help me get it'*; another advised how *'I didn't like my carpet, so my Dad and I went and chose one that would Hoover up better.'*

One group spoke about how they met as a household to decide on meals for the week, and then took it in turns to do the shopping with the support workers. Others had different living arrangements, and one person said that they *'get to choose which shops I shop at.'* Another reported that they liked a specific type of meal and that *'my support worker helps me to buy these when we have checked in the freezer.'*

People said that they had learned life skills such as money management at the day centres they attend, but that this was also supported by the staff at their accommodation too. One person said that *'staff help me take out money and budget.'*

One group, when asked about their ability to get information and advice in order to make decisions for themselves, said that information and advice was not easily available in a format that was accessible, and that support for decision-making lay mainly with their support staff. One person said, *'I've got no idea how to get information'*; whereas another reported *'staff make decisions with me.'*

Employment and volunteering

One group said that they all had either paid work or voluntary positions. However, the majority of people in another group said that they did not have access to employment or volunteering opportunities. This was very much in line with the overall feedback from the surveys. Service users, staff and Managers in this focus group reported that they had no prior knowledge of the Supported Employment Team at Bedford Borough Council when asked.



Healthcare

Two groups spoke about healthcare. Both groups said that they were taken to regular appointments. They were able to ask staff to make arrangements for appointments for other health issues as they arose.

However, one group were less sure about access to healthcare services. They were very unsure about what health and care services were available to them in the local area, aside from their GP and their annual Learning Disability health checks. It was commented that *'I don't have a clue'* and one person asked, *'How would we know about them?'*

There was very little understanding of preventative health education, healthy living initiatives, or the role of local pharmacies. Some people knew about dentists and had been over the years, although not all had accessed oral health checks and/or treatment. Some participants said that they needed support from the dentist, with one person saying, *'Sometimes I am unsure of the dental treatment, so staff help to explain it to me.'*



Care planning and access to records

Those that spoke about their involvement in their care and support planning, said that they felt involved and that their needs were met.

However, there were differences in access to records between different groups. The smaller focus group reported that they were able to access their care records, but another group were all unsure about what records they had, or how to access them. One person said that they had *'never heard of it'*, with another answering, *'what are they then?'*



Making a complaint

The groups discussed whether they knew how to make a complaint if the need arose. Everyone in the groups agreed that they would be able to raise a complaint freely with staff. One person said, *'if I did want to make a complaint, I'd go to the Managers and tell them what had happened.'*

When asked what they would do if they were unhappy with something. Most of the group said that they would be able to go to staff and would *'talk to staff in private,'* with one saying that *'the staff have helped me get through difficult things when I've been upset.'* One group said that they would go to their key worker first but if they could not help or were not available, they were happy to speak to other staff members. Another participant said that their *'Mum would talk to me about it.'*



Contact with friends and family

One group spoke about whether they could see or speak to their family members when they wanted to and they agreed that they could do so.

One person said, *'I call my dad every day on my mobile phone'* and another that *'I ring my sister or go and visit her whenever I want.'* Those who had deceased family members said that they were able to visit the cemetery, and one said that the *'staff help me to buy flowers.'*

When asked if they were able to spend time with people who had the same interests the group gave mixed feedback, with some saying that they had *'met a couple of people,'* and another saying they had *'met new people ...and can meet them outside...if I want to.'* However, they said that they did not want to do so, and this was echoed by others in the group with one person saying, *'I feel different about meeting new people. No, no, no!'*

Two people said that they had limited contact with other people with one saying, *'we don't really see people unless we live with them'* and another saying *'Apart from people in my house or my brother, no.'*

Communication provision

Whilst undertaking the focus group for Affinity Trust & Creative Support, it was noted that there was a service user who was not engaging in the session or offering feedback.

This was a considerable way into the session. When staff were questioned as to whether they knew why this could be, they advised that the service user was non-verbal, and his primary communication method was Makaton.

The facilitator asked the service provider Manager why they had not ensured that a Communicator had attended with the group, or these additional communication needs flagged with Bedford Borough Council. The Manager, when questioned further, advised that they didn't realise this would be necessary.

The facilitator from Healthwatch Bedford Borough used British Sign Language (BSL) to gauge if this would be an effective, alternative communication method for the remainder of the session, and was able to ascertain that the service user had a basic understanding of BSL. When asked whether the service user had understood the session, the response was that he had not.

REACH Standards

The groups gave feedback on the [REACH Standards](#), with a general agreement that they seemed like a good fit. It was commented that *'they are fair, and we agree this is right and it's a good standard of service.'*

Accessible formats

When discussing the definition of Supported Living, the issue of literacy and additional communication needs was discussed. It was recognised that there is a need to ensure all literature and communication aids are in accessible format, noting how popular the video option was with the groups.



Recommendations

Recommendations made from findings

1

Access to records

Just under a third of survey respondents reported they did not know what information was in their records and that they could view their records should they so wish to. Focus group participants shared similar feelings on the subject.

Good care planning should include transparency in relation to record keeping, to support a person-centred care approach. This can make a huge difference to people's lives. It enables individuals with long term conditions and disabilities to plan their care, have strategies in place to cope with exacerbations of their condition and/or sensory overload, and enables them to have all the relevant information they need to make informed choices and decisions. Supporting people to self-care means they have more confidence and control over their condition or disability and supports them to understand how it affects their lives.

Healthwatch Bedford Borough would recommend that in line with contract monitoring requirements, Supported Living providers are required to provide information to the Local Authority on how they will achieve transparency relating to service users having access to their individual records and care plans, and closely monitor this vital component.

2

Employment and volunteering opportunities

Just under a third of survey participants reported not having been in paid employment or accessing volunteering opportunities across Bedford Borough. This sentiment was reiterated during focus group activity, although with a far higher percentage in one session.

Only **5.1%** of adults with a *learning disability* known to their *local authority* in England are in **paid work** (*NHS Digital, 2021*). The proportion of adults with a learning disability in paid *employment* varies by region. Limited access to employment, difficulty using public transport, emotional health problems and social stigma may increase the risk of loneliness among people with a learning disability (*Macdonald et al., 2018; Wormald et al., 2019*).

People with profound and multiple learning disabilities (PMLD) have smaller social networks, which consist mainly of family members (*Kamstra et al., 2015*).

Despite the common understanding that friendships are often made during paid employment or whilst undertaking volunteering opportunities, the friendship needs of people with profound and multiple disabilities (PMLD) are often ignored, perhaps due to their communication difficulties and the lack of understanding by potential employers pertaining to the safe management of risk and training on reasonable adjustments.

Some application processes may involve assessment tests or interviews. These processes should not unreasonably disadvantage disabled people. Section 60 of the Equality Act is particularly important as regards what you can and can't ask about the disability of an applicant when recruiting.

In light of this feedback being mirrored by support staff and Managers, Healthwatch Bedford Borough would recommend the need for a deep dive to look at available employment and volunteering opportunities for service users locally, employers being further scoped and ensuring regular face-to-face liaison and Easy Read e-bulletins promoting available positions are sent out monthly by the Supported Employment Service.

3

Access to Health and Care services

Almost a quarter of survey respondents alluded to having very limited knowledge of local Health and care provision. In comparison, a far larger proportion of focus group participants reported they had almost no knowledge of local community health service provision or other services e.g. Pharmacy First, Talking Therapies etc., other than GPs. This largely centred around their Annual Learning Disability Health Checks.

Over 1.2 million people in England have a learning disability and face significant health inequalities compared with the rest of the population. Health promotion as a term was first coined by the medical historian Henry E Siegrist in 1945. He stated that good living conditions, physical activity, education, rest, and recreation were key to promoting good health for all.

Healthwatch Bedford Borough would recommend the need for increased tailored preventative health education, clearer teachings on healthy living including appropriate education and learning support pertaining to the individual roles within primary, acute and secondary care, and the need for Supported Living providers to encourage service users to attend outreach health education sessions with support staff.



4

Continuity of care and staffing

Whilst this wasn't an issue for all survey respondents or focus group participants, some comments have been submitted around the poor retention of staff and the lack of continuity that having a transient workforce offers, whilst often not seeing longevity of service.

The complex needs of these service user groups mean they require stability, continuity and the ability to form bonds with their support staff. This in turn means they feel safe, and confident to raise the alarm and ensures a level of trust.

Healthwatch Bedford Borough would recommend that the procurement team look at the service provider recruitment offer to ensure that it attracts high-quality staff and considers a robust mechanism for adequate training and development, career progression, promotes retention of staff, as well offers an attractive pay scale.

5

Activities and social interaction

A very common theme that ran through the data from survey respondents and focus group participants was the lack of access to local 'What's On' listings. This sentiment was echoed by support staff and Managers at the focus groups.

Service users, their families, their support staff, and providers should have ready access to up-to-date listings for local activities, clubs and groups. In a *survey* conducted by Sense, **over half** of disabled people reported feeling lonely, rising to over three-quarters (**77%**) for those aged 18-34 (Sense 2017). Loneliness is associated with physical and mental health problems and poorer quality of life (Leigh-Hunt et al., 2017 Macdonald et al., 2018).

Healthwatch Bedford Borough would recommend the reinstatement of 'What's On' listings. The communication format needs to be fully accessible for those with disabilities and low levels of literacy e.g. should include soundbites and video recordings, as well as Makaton and BSL options.

In line with other Local Authorities across BLMK, we would suggest the need to invest the time and resources in building a website such as '[Step Forward Luton](#)' hosted by Luton Borough Council and supported by the VCSE sector across Luton.

6

Health Education

Across survey respondents and more so in focus group participants, there appeared to be very little understanding of preventative health education, healthy living initiatives, oral health or the role of local pharmacies.

Using oral health as an example, whilst some service users had visited a dentist in the past few years, several claimed to have not. There may be cognitive, physical and behavioural challenges that impact on someone's ability to undertake daily oral care and cope with dental visits. These include:

- not understanding the importance of tooth brushing or forgetting to do this
- limited mobility making it difficult to brush teeth physically
- sensory problems that mean someone doesn't like being touched
- behaviour that makes it hard for someone to support oral care
- limited communication – problems in communication between the patient and dentist are a major barrier to successful dental treatment

Healthwatch Bedford Borough would recommend considering looking at 'best practice' health education modelling from other areas, such as the peer-led dental-ambassador training programme from national charity **Well Connected** which showed high levels of engagement from participants and improved knowledge, empowerment and self-care.

7

Accessible Information and communications

When analysing the survey data, of the **107** responses received, **83%** of survey respondents opting to access the standard version survey filled it out with full support, compared with **57%** that responded to the Easy Read survey with support. When looking at data to see the impact of using Easy Read materials with clear picture images and plain English, **43%** of respondents stated that they had completed the survey **without** the need for additional support. This data by its own merit shows the need for clear, concise and accessible information and basic Easy Read communications.

There are different ways of making information easier to understand for people with a learning disability and/or Autism. Everyone is

different and has different ways they like to get their information.

Things that should be considered include:

- Simple text
- Easy Read
- Short film clips/visual recordings incl. Makaton and BSL
- Audio recordings incl. the use of voice notes, audio CDs and MP3 soundbites
- Having conversations face-to-face
- Using specialist software
- Targeted campaigns through tailored social media platforms
- Using picture systems

When assessing a service users primary communication and information need, one should remember that a standard '*one size fits all*' approach neither works nor complies with legislation in relation to the **NHS Accessible Information Standard**. Providers must ask each service user how they prefer to communicate and receive information. This was of particular concern regarding the service user that was non-verbal who was brought to one of the focus groups without a Makaton Communicator.

During the focus groups, particularly when discussing medical appointment letters, the need to book appointments, and when trying to gauge feedback on the **REACH Standards**, many participants advised that they were unable to read or write to any degree, therefore consideration must be always made to accessibility.

Healthwatch Bedford Borough recommends a deep dive of existing Equality and Inclusion mechanisms with those holding Supported Living contracts at present, and suggests a detailed, robust explanation of service provider requirements regarding this section by woven into the service specification of the contract moving forward.

Summary

With the renewed commitment to transforming the way in which care and support is delivered to people with a Learning Disability and/or Autism in line with the Care Act

2014, the focus of this project has been on outcomes, personalisation, wellbeing, and choice.

By speaking to service users, carers, and support staff to research whether these key areas are being met, and after careful evaluation of a considerable amount of data, we conclude that there is a need to strengthen the Supported Living provision to support service users in Bedford Borough to avoid crises further down the line. This approach will support people to become active members of their communities, with all the benefits that consideration of the wider determinants of health and wellbeing brings forth, e.g. a flourishing employment and volunteering offer, bespoke health and wellbeing education, ensuring information is in accessible formats to comply with the [Accessible Information Standard](#), and that there is ongoing access to local activities and social groups to avoid social isolation.

This report brings together the current good practice taking place across Bedford Borough but equally recognises that improvements will only be achieved by visionary leadership, a focus on human rights-based approaches, person-centred care and support, workforce development, service user and carer voice and co-production, and a willingness to reflect and learn.

It aims to support commissioners across health and social care to work together to commission the range of services and support required to meet the complex needs of this diverse group.

Thank you!

Healthwatch Bedford Borough, Bedford Borough Council and Voiceability would like to thank Supported Living service users, their families, support staff, Day Centre services, and service providers for taking part in this project.

We hope that the learning outcomes from this report will go some way to ensuring that Supported Living service users feel valued, supported by the wider community, and empowered to live healthy lives, not just now, but for decades and generations to come.


healthwatch

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