



#SpeakUp: Luv2MeetU - Accessing health and wellbeing services for people with a learning disability

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of between £500-£1000 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.

By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.



Luv2MeetU

Luv2MeetU is a friendship and dating organisation for adults with learning disabilities and/or autism. We support our members by helping them to make friends, share interests and to develop relationships. We provide a range of activities and events from bowling, meals out and barge trips where members can meet new people as well as experience new activities. We strive to provide a range of opportunities that the members themselves have requested. These events run throughout the year.

There is also a 1-1 dating service available for any-one who is interested in developing a romantic relationship. Members are matched, for example, according to age, interests and compatibility. They are supported through the beginning of a relationship and chaperoned by a member of staff particularly on a first date.



Healthwatch Sheffield

Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.



Background

During Covid-19, it has become particularly important to support our members through lockdown, as many of them have felt isolated and suffered from anxiety and depression. We have provided on-line events and 1-1 phone calls if needed.

The need for this service and the extra support was evident whilst carrying out the survey for Healthwatch.

What did we want to find out?

This report is based on a questionnaire of forty-eight questions, which we completed with our Luv2MeetU members. We wanted to understand several aspects of how our members felt about health and well-being services in Sheffield before as well as during covid and the impact it has had on them:

- How they feel about accessing the right health service for their needs?
- What effect covid has had on them
- How they feel about the level of support that they have
- How they felt services could be improved
- Did they feel that anything was missing in service provision?

Who did we speak to?

We spoke to 14 Luv2MeetU members.

They come from across Sheffield and each have unique requirements regarding their physical and mental health, which means they have to access different services and organisations within the Council, NHS as well as independent organisations.

The people who took part in the survey also have different levels of ability, meaning that the questions were answered in a variety of ways ranging from understanding that something was an issue, to putting forward really creative ideas. This is where we benefitted from a group setting, as people could help each other with explanations and ideas.

There were members who live in supported living, as well as those who live at home with their parents. Some of the members have jobs or volunteer and some need full time support. We first asked the group a range of questions about themselves:

What is your ethnicity?



13 people were White British, 1 person was Black British

What is your gender?



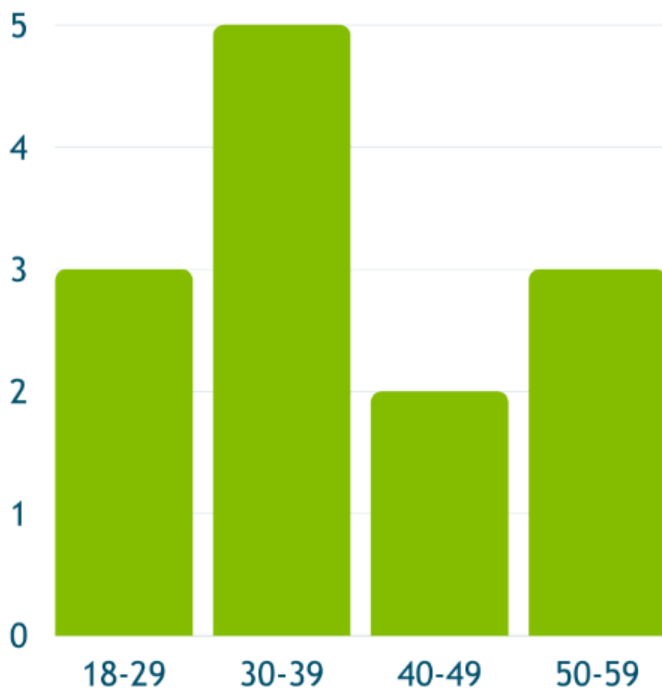
8 people were male, while 6 were female

What is your sexuality?



13 people were heterosexual, 1 person was bisexual

What is your age?



We spoke to people from a wide range of ages. The youngest member was 18, while the oldest was 59

What disabilities or health conditions do you have?

Disability/health condition	Number of people
Learning disability/difficulty	12
Physical or mobility impairment	3
Autism	3
Mental health	2
Hearing impairment	1

Most people had a learning disability. Some people had more than one disability or health condition

Findings

Introduction

The information for this survey was gathered in a group setting, with just a couple of people completing it on a 1-1 basis. The group settings were beneficial as they helped to spark conversation and ideas between the participants. It led to some really useful and interesting thoughts.

The questionnaires were completed on a digital tablet with a mixture of different ways used to ask a question, for example expression emojis, multiple choice, or space for a longer answer where appropriate. This worked really well as it made the whole process more interesting and interactive for the participants.

Most people answered all the questions. Some weren't sure of certain questions, especially the ones that started "What do you think about..." but very often, talking around the subject and generating ideas would help those who were finding the concept slightly harder. This was another great benefit of the group sessions.

Section 1: Accessing support for mental health and wellbeing

First, we asked people about mental health and wellbeing support - how they were currently feeling, whether they felt they had enough support, where they would seek out further support, and what else they'd like to be able to access.

How are you feeling about life, especially since Covid-19?



Whilst this shows a mixed response in how people are feeling, it is encouraging that the majority feel that they are coping well as we come out of covid. While answering this question there was positivity about the future as well as worry about taking this step, and the anxiety people were feeling about moving forward.

Do you feel supported when something is wrong or you feel you are struggling?

10 people said they had ‘some support’, and 3 said they were ‘very supported’. Nobody told us they had ‘little’ or ‘no support’, though 1 person did choose not to answer. The answers to this question are reassuring as it showed that most people felt that they had a good amount of support.

Who supports you? Who would you go to if there was a problem?

There was a box to fill in for this question. Most people said they relied on staff in their supporting living situation or support workers. This might be because they are in more direct contact with staff on a day to day basis and so it makes it easier to access that support.

10 people said they were supported by professionals (8 by supported living staff, 2 by support workers, and 1 by a key worker). 7 people said they were supported by their family (including parents, siblings, and partners). These do overlap - 4 people felt they had the support of a professional as well as people in their personal lives, so some people felt that they had more than one avenue of support that they were able to access.

How would it help to have more support? Explain what extra support you would like?

Some people struggled with this question, finding it hard to imagine what extra support would look like. 9 people said they feel okay with their current level of support:

“I feel I have enough support”

“I’m very independent and don’t feel I need extra support”

5 people did say they would like more support. Some people specified what this could look like for them, while others were not sure:

“I would have more individual support so I could do more things”

“Extra time with people”

“I would like a bit more support so I could go out and do things and cooking”

“Yeah, more personal support”

“I would feel better, it would be great to have another person to go to, but I’m not sure who”

Some people were more able to go out by themselves and not rely on a high level of support. The people who do need support to go out were requesting more of this - they want to allow themselves that time out of the house to build their confidence and independence. They really feel the consequences of not having enough support.

Can you give me an example of support you've had recently for mental health and wellbeing? How could it have been improved?

Some people hadn't needed to seek support recently:

"I've not had any recently, I've been at work most of the time"

One person hadn't sought support for other reasons:

"I struggle asking for help"

Where people had sought support, this came from a lot of different places, but most people said that professionals had been able to help them:

"My social worker helped me keep calm when I felt angry."

"I've been supported by staff for my mental health."

"Dentist has helped me and staff when I've felt low."

"I've had support from house staff when my friends bullied me."

"Mum and house staff for when I was feeling down"

"Teachers were very helpful when I struggled at college. It would be great to have a specific person though to go to"

Most people struggled with the second half of this question, however the answers to the first part shows a theme relating to mental health and low mood due to lockdown and the worry of Covid-19. However, it also shows that some people are coping well.

What support has worked well for you?

This question gave people a chance to think a bit more about how their support works and who supports them, throwing up some new information and depth. Having staff or a support worker present or easily reached was helpful for most people - 8 people shared comments about available staff:

"Having staff around and knowing they can get me to a doctor"

"Having staff who can take me out"

6 people also said that having family members they can rely on was helpful:

“My boyfriend and family have supported me and it was good”

“Having my grandad. I speak to him every day”

What would you like to change about your mental health and wellbeing?

5 people said they didn’t feel the need to change anything:

“Nothing really, I feel fine and happy”

“I feel ok at the moment”

For other people this question built on the theme of being anxious. People recognised that they needed to build up confidence as restrictions are lifted in order to be able to go out again successfully. Also, people were thinking about how health and wellbeing can be improved with nutrition in particular:

“I need to build up my confidence and getting out more”

“To be able to eat better”

“Being able to eat healthier and being more confident”

“I would like to be fitter and feel less sad when people leave”

“Feeling more confident about going out and remembering how to be with people”

Other people shared ambitious wishes:

“Not to have to go to work so I could feel happier”

“I would love to be lord mayor”

What is it like leaving the house after lockdown and seeing people again?

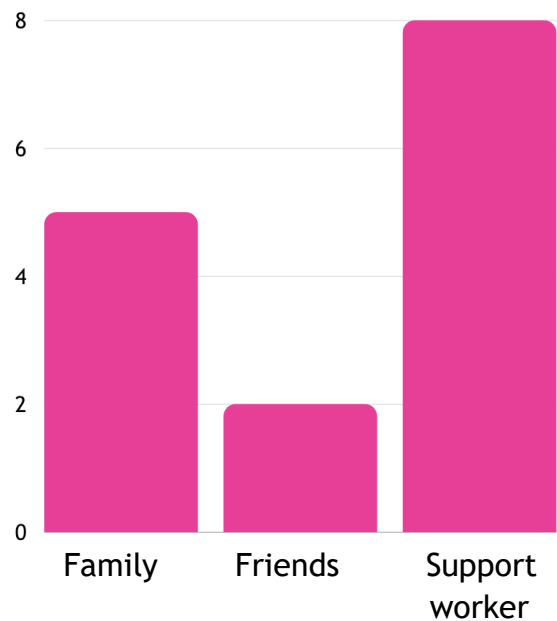


This was a very positive reaction and although people are suffering from anxiety and low mood there is a real need and want to get back to some normality.

Who do you ask for help if you feel anxious or nervous?

This was a multiple-choice question with three options, family, friends and/or support workers. People could choose more than one answer.

It was interesting with this question to see if the answers varied with the previous questions relating to support when the question was specifically to do with anxiety. The majority of people still rely on their staff for support.



Is there anything else that's on your mind or worrying you in relation to your mental health and well-being?



This was a yes or no question. Eight people answered no and six answered yes so, a fairly even split between those who feel that they are doing ok and those who are struggling a bit. Below are the worries that were on people's minds that came out of the group discussion:

“Worried about health and exercise”

“Getting more support with food and more time with support”

“Not being able to meet new people”

“Worried about weight and exercise and my mum is”

“Takes medication to stop thoughts”

Section 2: Accessing statutory health and social care services

We also asked people about their experiences contacting health and social care services when they needed treatment or check ups, as well as exploring what people’s current level of understanding was about the kind of care they could get.

Do you feel confident contacting any healthcare service you may need such as doctors, dentist, sexual health clinic, counselling or others? Why is that?

The group was split on this question - 7 people said ‘yes’ and 7 people said ‘no’. Some people gave further additional comments to explain their answers, with many saying they would ask support staff to help them contact services:

“I wouldn’t know who to ask.”

“I would ask staff as I wouldn’t feel confident.”

“I wouldn’t feel sure, I’d ask staff.”

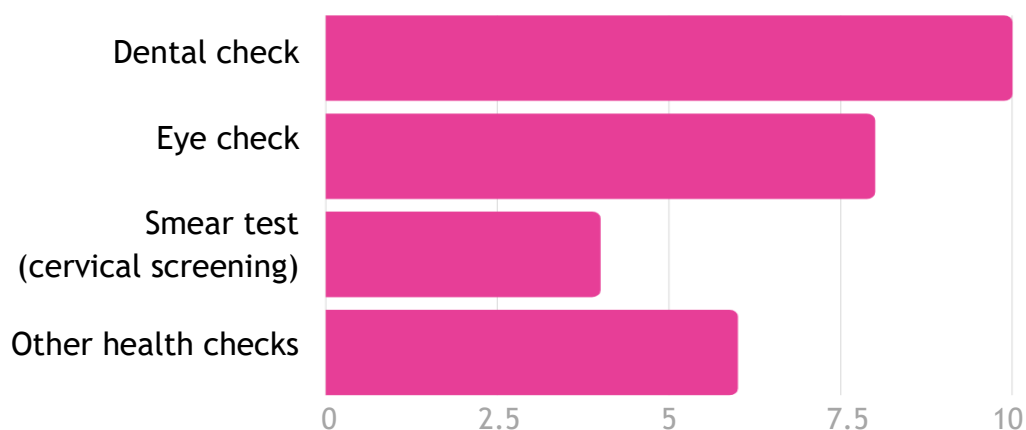
“Unsure of numbers and who to ring.”

“I’m still young so feel a bit anxious.”

Do you know that you can contact your doctor’s surgery and chat to them online or over the phone?

11 people said ‘yes’ and just 3 people said ‘no’. This helped to gauge people’s understanding and knowledge about how the system works. The large majority saying ‘yes’ suggests that it is confidence and knowledge of knowing the right numbers to call, rather than knowing how the system works, that make people unsure of doing so.

Which of these health checks do you regularly book? (select all that apply)



Are they easy to contact and get to? Why is that?

6 people said they found it easy to contact their normal health care services. 8 people said it wasn't easy.

Several people gave additional information to explain their answer. Due to the group situation it is hard to pin point whether it was only people who initially said it wasn't easy who gave the following answers. As discussions and conversations came out of the questions, people would add additional points after listening to other's opinions. The responses were as follows:

"Because of being in a queue on the phone"

"I need to have help with contacting and getting there"

"Waiting and dentist was closed in lockdown"

"Waiting, getting an appointment"

"Having to wait"

"Can't always get an appointment and can be tricky to get there"

"I have multiple conditions in different cities so makes it hard"

Are your visits to the doctor's surgery or dental clinic a good experience?

This was a yes or no question. 5 people said no, visits were not a good experience. 9 people said that they were a good experience.

What went well?

Not everyone answered this question, but some interesting points came out of it. People felt positive about their experience when they felt they were looked after, and when explanations were easy to understand, making it less intimidating:

"Just being looked after."

"I feel relieved when the problem is sorted."

"They explained a lot of things."

"It just all went well."

"Appointment was quick"

"Not intimidating, I'm quite used to it."

What went wrong?

Everyone apart from one person had examples of when something had gone wrong. The key themes were not understanding the treatment properly, and anxiety, along with waiting times:

“Because I panic too much, because they’re explaining things and I don’t understand.”

“Having to wait.”

“Just difficult to get an appointment.”

“Always a queue.”

“No seats as so many waiting.”

“Having to wait.”

“Delays so I’ve had to wait, if someone has more serious problem.”

“When I had a canular put in the nurse wasn’t very gentle. I have a lot of procedures so if people aren’t gentle it’s hard.”

Do you know which service to call depending on what you need help with?

A yes or no question with eight people saying yes, they would know who to call and five people saying they wouldn’t or would be unsure. One person didn’t answer.

Have you had any appointments with any of these healthcare services recently?

This was a multiple-choice question.

Three people didn’t give answers. It’s hard to be sure how accurate this question is - some people may not be confident in saying they had been to a sexual health clinic, for example, especially in a group setting.

Health service/professional	Number of people
Dentist	7
Doctor	8
Optician	5
Sexual health clinic	0
Nurse	0
Counselling	0
Other	3

Has it been easy to access healthcare services during Covid? Why is that?

Only 1 person said that it has been easy to access healthcare services during covid. 13 people said that it wasn't easy. Most people gave additional comments to explain their answer. 9 people said that it was difficult to make an appointment during the pandemic:

“Difficult to get appointments and can't see people easily”

Other people talked about the rules changing, which is something that people have struggled with - people were unsure what to do:

“Because all the rules changed”

There was a feeling that people were more isolated and nervous due to 'normal' services being closed or harder to access:

“Dentist was closed and really hard to get through to the doctor”

Others talked about different issues that made it hard to access care:

“Waiting for call-backs all day and I've got things to do”

“I've felt low so appointments etc feel harder”

Have you had difficulty with the following?

- A) Booking a dental or doctors appointment**
- B) Finding help with mental health issues**

We learnt that 13 of the 14 people we spoke to had difficulty booking a dental or doctors appointment.

Everyone who had struggled to find help with mental health issues had also struggled to access dental or doctors appointment, leaving them without multiple avenues of support.

Only one person had had no difficulty at all.

Have you had difficulty with any of the following?	Number of people
Booking a dental or doctors appointment	4
Finding help with mental health issues	0
Both of the above	9
Neither of the above	1

Do you have any comments about the health care and support that's available to you from the NHS? What are they?

People found this question quite hard to think about, but did offer some thoughts, both positive and negative:

"I'm happy with the NHS"

"More support if I do have to self isolate"

"Could be faster"

Are there any gaps in the health care or support you receive? Is there something missing that would make you feel more supported?

A yes or no question with just two people saying that there were gaps and twelve saying no. The two comments we heard about gaps in provision both amounted to the same idea:

"A person I could ring about low mood."

"Easy person to reach to ask simple questions or if something was worrying me."

Although there are only two answers recorded, it did lead to a general conversation about how useful it would be to have someone that could be just an easy phone call away.

Overall, what do you think about the level of health care and support that's currently available in Sheffield?



Average support

Good support

Very good support

Despite having suggestions for how support could improve, nearly all participants still thought that the general level of health care and support in Sheffield was good. Nobody selected 'very poor support'.

Section 3: Access to information and involvement

We asked people how they would find information about health and support services, and how they would prefer to receive this information - including some insightful ideas about booklets and workshops.



Have you used the NHS App and do you know how to use it?

The group was split on this question - 7 people had used the app and 7 people had not.

Do you know that you can book appointments, order repeat prescriptions and get general health advice such as advice on covid using the NHS app?

The group was also split on this question - 7 people did know what you could use the app for, and 7 people didn't.

Relatedly, one person made a comment in a later question about the NHS Covid-19 app, saying they were hesitant to use this:

“Scared about the NHS app as don't want to have to self-isolate”

Do you know where to get leaflets and information about all the different kinds of health services?

9 people said yes, they did know where to get information. Most people said they would Google anything they wanted to know. 5 people said that they were unsure or didn't know where they would look for information.

Would you like a booklet with contact numbers and information on all the different health care services?

Only 3 people said that they wouldn't want a booklet with this information in it. The other 11 were keen on the booklet idea and thought it would be really useful.

Do you have any suggestions for how this booklet should look?

Nearly everyone (13 people) shared ideas about how this booklet should look. It sparked quite a conversation! There were some really good suggestions and people seemed to be really engaged with the idea of a booklet that was especially designed for them, with information regarding health care and well-being in one place. Key ideas were around it being easy to understand, in an Easy Read or accessible format, and using pictures and colours to help illustrate the information:

“Bigger text and pictures”

“Small bits of information”

“Like a newspaper”

“A magazine style leaflet”

“Easy Read”

“A small book”

“Pictures and letters to be bold”

“Easy to understand and pictures”

“Big writing and pictures”

“Bullet points, each line to be different, colour coordinated”

Are leaflets about health and well-being easy to understand?

Most people (10) said current leaflets were easy to understand. 4 said they weren't.

Are there any health issues where you think having a leaflet with information would help?

There were some really good ideas about what information people would find helpful. It gave a good insight into what subjects were important to people.

4 people said they'd like a leaflet about exercise, and 2 people wanted one about healthy eating. 3 people thought a leaflet about general health would be helpful - health checks, and everyday health.

Other suggestions included:

“A happy leaflet...how to be happy”

“How to keep safe when out and about”

“Something more specific to rarer conditions”

Would you be interested in joining a workshop on health and well-being?

Only 3 people said no - 11 said that they would like to take part in a workshop.

Would you like to do a first aid course?

There wasn't huge enthusiasm for first aid courses as a specific workshop topic - 9 people said they wouldn't be interested, with 5 saying they would.

Have you been on any health and well-being workshops?

Despite people's interest in being part of a workshop, only 1 person had been on one before. They had been to an Art Therapy and Music workshop.

Do you have any requests for a particular workshop you would like to attend?

People came up with some really good ideas for workshops and things they would like to know more about. There was an excitement around learning new skills or developing something like cooking. People are also wanting to gain confidence and be independent and able to successfully complete basic skills for themselves:

“To be able to talk to people about my mental health”

“Healthy cooking”

“How to cook and managing myself better”

“Food ones and music for wellbeing”

“General advice in a health centre”

“Confidence, people skills and anxiety”

“Support with mental health and gaining confidence”

Would you like to be an ambassador for health and well-being and support other members by helping them find information and support?

This was a very 'marmite' question! People were very keen or very definite that they wouldn't want this role. 4 people said 'yes' and 10 people said 'no'.

Conclusions and recommendations

Conclusion

Completing the survey, mostly in groups, generated thought-provoking conversations and ideas. Sharing the experience seemed to bring out a more engaging and fun atmosphere for participants and produced some interesting answers, though of course the group setting may have meant some people didn't want to share more personal experiences. Most people felt positive about the care and support they had accessed, but did identify areas for improvement.

Many of the individuals we spoke to as part of this project had high levels of access to support workers, especially those who lived in support living environments. As such, their access to further support and information may be different to those of individuals who live in other settings and do not have this access.

Some common themes arose from the questionnaires around how people were feeling, their experiences of accessing services, and their ideas for further support.

People shared common feelings and concerns about support during and after Covid-19 restrictions:

- Many people felt that although they had enough support within their homes, there wasn't enough when it came to going out.
- There was a real drive to be independent, wanting to be out and about and learning new skills such as cooking and eating healthily.
- Linked to both of these, people wanted support to grow their confidence following lockdown.
- Many people had struggled, especially during Covid-19, with low mood. However, most felt they had been supported to manage this by staff or family members.

Some people had struggled to access health services during the pandemic:

- Most people said they had struggled to access a service or appointment - sometimes this was due to not understanding how the service worked, but also focused on lack of confidence or knowledge of who to call, or what to do when Covid-19 rules changed.

- People raised issues relating to waiting times for doctors, dentists, and hospital appointments. The discussions that came out of the questionnaire referred to anxiety or unease about waiting for appointments and feeling uncomfortable in waiting rooms. They would like to see a system that would make people with learning disabilities more at ease in waiting rooms.

People offered suggestions for how care and support could be more accessible and suitable for people with a learning disability:

- When Covid-19 meant access to services changed, people did not know who to call and began to lose confidence trying to access services. People would like clearer information about restrictions and alternative avenues of support which are easy to understand.
- People wanted to access one-off workshops to help them learn new skills around health and wellbeing - for example cooking and nutrition, physical exercise, and mental health.
- People were keen on the idea of a booklet which could provide information about the kinds of health and social care support that might be available to them, explaining how these services worked and how to access them.
- There was also interest in a one-stop service for people with a learning disability to call when they experience issues related to low mood and anxiety. People felt that knowing a service was geared towards them with clear instructions on how to access help would be beneficial.
- People also wanted clearer information about any future Covid-19 restrictions - presented in a way that was easy to understand for people with a learning disability, for instance posters with large text, pictures, and clear instructions that could be displayed in healthcare settings, supported living environments etc.

Recommendations

The recommendations below are based on the findings in this report, as well as ideas shared by participants. These recommendations are aimed at commissioners and providers of health and social care services working with adults with a learning disability and their families.

- Support packages -should be reviewed in light of the additional support people need to regain confidence going out after the pandemic. Enough 1:1 hours to allow people to go out should be a central part of support packages to support people's mental wellbeing.
- Health providers should review waiting areas and create a 'quiet' area if space allows, designed to feel welcoming for people who may be anxious about the main waiting area.
- Commissioners should produce clear, accessible information for people with a learning disability to understand what health and social care services are available, how they work, and how to access them. This could take the form of an Easy Read booklet, with large text, images, and clear instructions. Commissioners should consider co-producing this with adults with a learning disability and voluntary sector groups to ensure it meets their needs.
- In the light of any future Covid-19 restrictions or rule changes, commissioners/providers and public health officials should ensure that information is provided to people with a learning disability in a way that they can understand, and can easily access.
- Health related workshops should be commissioned/delivered to help people with a learning disability to explore health and wellbeing topics such as cooking, healthy eating, physical exercise, and mental health, in order to support their independence and wellbeing.
- Mental health commissioners should explore the possibility of a service (or team within a service) who specialise in supporting people with a learning disability with their mental health. This could take the form of specialist workers within SPA who can provide initial support and signposting in a tailored way.