AUTUMN 2023

WHOLE LIFE ADVOCACY

Understanding what people use advocacy for and what type of advocacy they use, alongside any barriers to accessing advocacy

We are the User Engagement Team at Wiltshire Centre for Independent Living. We have facilitated and produced this report for Wiltshire Council under our contract to provide a Wiltshire Service User Engagement Service.

We work alongside people with lived experience of using health and social care services to support, encourage and facilitate them to have their say. We aim to ensure their voices are heard and that they are able to contribute to and influence how services are shaped and developed.

We use creative and interactive ways of engaging with people, co-producing each piece of work uniquely, to value the authentic voice of all service users.

This report has been created from the voices of disabled, autistic and older people in Wiltshire. Thank you to everyone who attended our workshops and took the time to share their thoughts, ideas and experiences.

A particular thank you to:
The Medley Day Centre
Young Pioneers
Wiltshire CIL Pioneers

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Key Messages

1 Advocacy is an important service, which could be of great benefit to people now and in the future. However, many people are not fully aware of what advocacy services are available and how to access them. A well promoted advocacy service would help more people to access advocacy support. This is particularly important for people who could benefit from non-statutory advocacy.

2 Communication is key. Advocacy services need to understand individual needs and adapt how they communicate to meet these. The services provided should be adaptable and flexible to accommodate people's needs and preferences.

3 All aspects of an advocacy service needs to be accessible. This includes everything from website accessibility and physical accessibility through to providing information in different formats to meet different communication needs.

Methodology

We hosted four interactive workshops for people interested in advocacy. Workshops took place in a variety of settings including a day centre, community meeting room and our own training room. In total, 14 people attended workshops, allowing for focused and in-depth discussions.

The workshops explored a range of relatable case studies, which described people who were experiencing challenges in their lives. People discussed how advocacy could be used in each scenario and what format this might take. We also considered any barriers or challenges people may have in using an advocacy service.

In addition to the workshops, we also conducted an online survey to gauge people's understanding of advocacy.

The majority of people had heard of, and were familiar with the term advocacy. However, people went on to say that despite being aware of the term, they did not necessarily fully understand what advocacy is.

Have you heard of advocacy?

Yes 76% No 24%
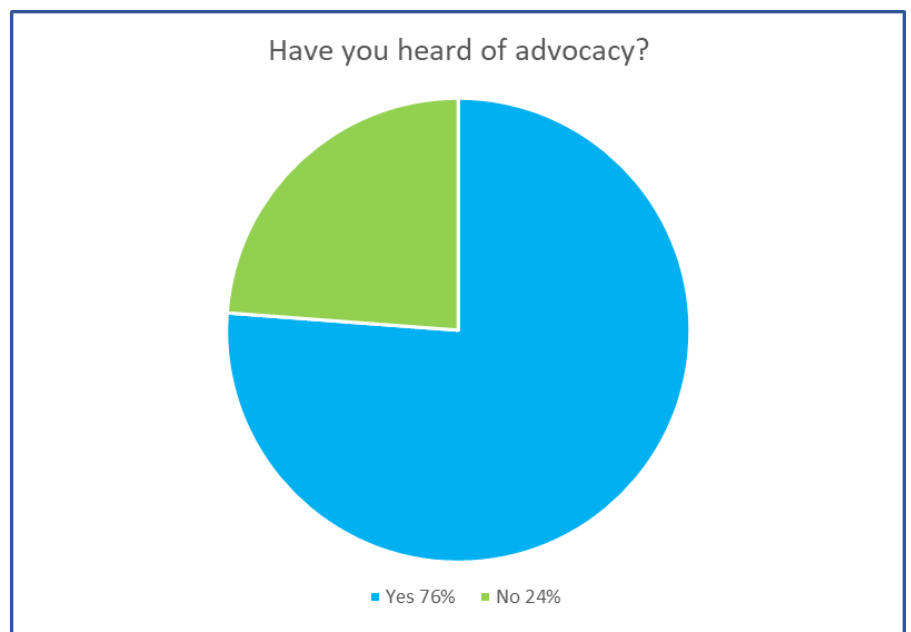
"The term needs to be explained as it doesn't describe what it does"
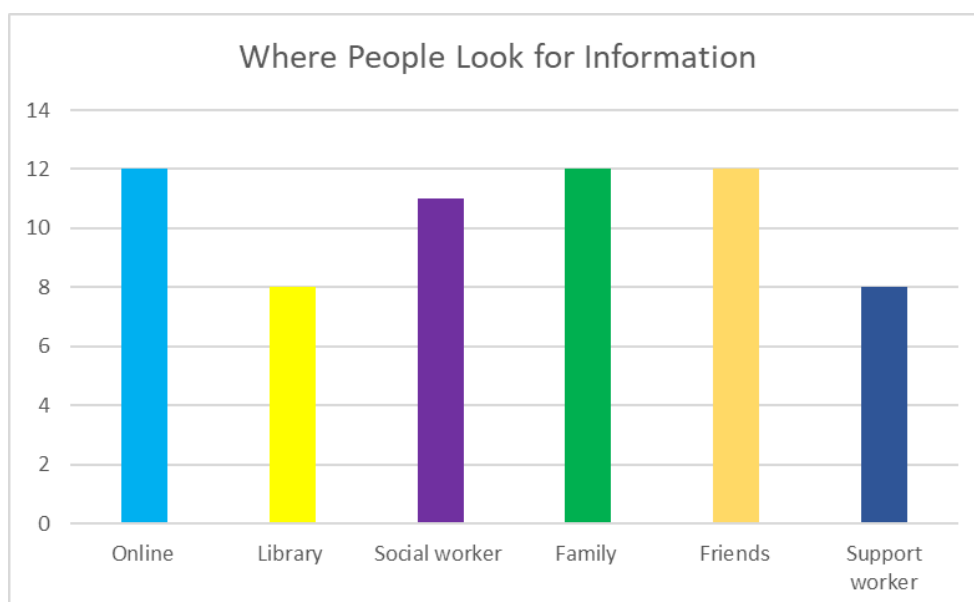
"Need a more explanatory word – 'advocacy' itself is too vague"

Finding Advocacy Services

2/14

During the workshops we asked if people were aware of advocacy services in Wiltshire. Only two people were aware that there is an advocacy service in Wiltshire, one because a relative works within the service. However, this person also expressed that they were not sure what the service offered.

We then talked about where people might look for information about advocacy.

Where People Look for Information

Category	Value
Online	12
Library	8
Social worker	11
Family	12
Friends	12
Support worker	8

The main places people would look for information about advocacy are online or in a library. People would also ask other key people in their lives; Social Workers, family, friends and support workers. However, it was noted that not everyone can go online, and even if people can they may need information in different formats to meet their individual needs.

"Not everyone can read, and what is accessible for one person might not be for the next individual"

It was important for people that information about advocacy services is widely available, and in a variety of place in the community. Citizens Advice, G.P. surgeries, posters in the community and Wiltshire Council website were all suggested as important places to have information.

Communicating With Advocacy Services

People expressed that how an advocacy service communicated with individuals was of key importance. In particular, advocacy services should be able to adapt to individual needs and preferences to support effective communication. For some people, face to face contact is vital for communication:

"My mum is very bright but profoundly deaf - she needs someone that can speak clearly as she lipreads, and understands how to work with deaf people"

"Speaking on the phone for me is really hard. I find I get cues quite wrong and make myself look silly. So face to face is always best for me"

Other people prefer to communicate online, either by computer or text as this can help them express themselves better. One participant in the workshops was non verbal and chooses to communicate via a smartphone App.

"I find it easier to type than speak, because my brain is whirring at 100 miles an hour and I can't get across what I mean and get misunderstood"

Security of information was an issue for some people, who would prefer to communicate with an advocate by WhatsApp as data is encrypted.

The range of answers given highlight the importance of taking the time to ask people how they would like to communicate. It also illustrates that people should have access to a variety of communication methods at each stage of the advocacy process, from making initial contact, engaging in support and making decisions.

How information about advocacy is presented was also raised as important for individuals. Information should be written in clear, understandable language and be presented in a variety of different, accessible formats. This applies to both paper-based resources and online web-based resources.

"Important to have everything in easy read"

"advocacy services need to give notes of the meeting people attend"

Knowing how long the service might work with/support someone on an issue was an important.

"Anticipated time frames can be useful, so you know what is happening"

People recognised that there may be issues the advocacy service might not be able to support with, and that there might be a need to refer to other services. This was seen as a positive action, provided there was good communication.

" I approached the Advocacy People for help with PIP but they couldn't do this. They gave me contacts for other places I could go, so I'm now getting support. It's important if they can't help that they let you know who else might be able to"

Another area people felt they might struggle to access an advocacy service is around the **physical accessibility** of offices where appointments might take place. These need to be fully accessible for disabled people with parking onsite or very close by and be fitted with hearing loops as a minimum standard. One participant expressed concern that if this were not the case they might be expected to meet in a community setting, which would not be suitable for confidential conversations. Other individuals would need advocacy to go to them in their own homes.

"Some people would need the advocacy service to come to them, as they may not be able to access the community readily"

People had a number of ideas about how the advocacy service could be more accessible across Wiltshire;

"The service could do pop ups in different parts of Wiltshire, so even if their main base is in a different area people can still find out about it"

"It needs to be county wide - it feels as though everything is put into Trowbridge or Chippenham and it can feel quite cut off in Salisbury"

Case Studies

None of the people who participated in this piece of work had used advocacy services before. However, we used case studies to frame discussions about things that an advocacy service could work with and support people with now and in the future.

Jill

Jill is 38. She has a teenage daughter who is at university. Jill has good friends and enjoys her work at a local hair salon.

Jill has medication for anxiety, and for a diagnosed mental health need.

Jill needs to go to the doctor to talk about her medication as she thinks it is making her unwell.

Jill has not seen the doctor in a long while and had emailed to get an appointment, but she could only get a standard appointment. (About 10 minutes).

Jill is worried about her appointment and feels the Doctor doesn't really know her and won't listen to her.

How could an Advocate support Jill?

People suggested a number of ways that an advocate could support Jill;

- **The advocate could request a longer appointment for Jill.**
- **They could help her write down what she wants to discuss with the doctor.**
- **They could support with recording the appointment, or getting a summary of the discussion so Jill can look back at what they talked about.**

Case Studies

Neil

Neil is a 22-year-old that lives at home with his mum. Neil went to a special school and had help with his education.

Neil does not work and claims benefits. His mum used to help him with this, but can't any more.

Neil wants to live in his own home. He has applied to the council online to access housing. They have said that he needs an appointment to discuss his application.

Neil communicates by using a special voice app on his phone. It can sometimes take a while for him to respond to questions using this app. Neil does not write but can read very well.

How can Advocacy support Neil?

There was a discussion around whether Neil's mum or family should support him in attending the appointment. Some people said family should support. However, others said it would be better to have someone independent and outside of the family to support Neil achieve his wishes.

Overall, people agreed that it should be Neil's decision who should support him. People thought the service would need to adapt to Neil's way of communicating and might need to give Neil longer appointments to facilitate this.

"The advocate could ask questions for Neil to be sent before interview so Neil can prepare himself"

Case Studies

Bill

Bill is 65. He lives in supported living. He has learning disabilities and epilepsy. His movement has started to become more difficult, but he enjoys sailing and is interested in Lifeboats.

Bill lives in Wiltshire and likes to visit his sister at the seaside, where he can enjoy the lifeboats.

Bill wants to move closer to his sister. Bill has told the staff where he lives lots of times, and no-one has come to talk to him. He got upset last week and the manager at his home, said he must talk to the Social Worker.

Bill struggles with explaining what he wants to say and when stressed, it affects his epilepsy.

How can Advocacy support Bill?

People felt it was important that an advocate would spend time getting to understand Bill's wishes before any meetings;

- **The advocate should ask "what do you want to do?" and stand up for Bill.**
- **The advocate should talk to Bill before important meetings, establish what he wants to say and then take over using his own words if necessary.**
- **It is important to get an idea of what he wants to say before he goes to the social worker, otherwise he may get worked up and anxious.**

The Importance of Advocacy

Although people said the term advocacy is a bit unclear in explaining what advocacy is, it was recognised as being a very important and valuable service for a variety of reasons.

Advocacy for people who are not able to communicate their own wishes was seen to be particularly important. **"It is the non verbal people with the most complex needs who would probably need advocacy the most"**

People related this to their own life experiences and those of their families, looking ahead to how advocacy might play a role in the present and future.

"Even if you have power of attorney if you are close to a situation you may not see the bigger picture and make the best decisions, so an advocate could be good to ensure the persons voice is heard."

"My biggest fear as a parent is D's life later on, maybe if we are not around or able to care for him any more. Because he is non verbal how will his voice be heard when things go wrong? When I think about some of the care homes (it is a small amount) but it has happened with non verbal autistic people. When we are not here to be his voice he will need someone else."

"For some people who need advocacy it takes a long time to get to know them and understand their wishes (i.e.non verbal autistic people with SEND) so the service needs to be present for as long as this takes"

Conclusion

Throughout this consultation, we have heard the experiences and ideas of disabled people on advocacy services. Whilst many people were familiar with the term 'advocacy', people were not fully aware what advocacy entails or how it could support them. During our workshops, we found that as people became more aware of what advocacy is, they were able to identify the potential benefits of advocacy services. This was both in relation to the case studies and also their own or relatives lives, both at present and in the future.

The different ideas shared during the consultation can be culminated in a summary of the expectations people have for advocacy services in Wiltshire.

Disabled people in Wiltshire believe advocacy services should...

- Actively promote advocacy in a range of settings, including in the community and online.
- Educate and explain what advocacy means and how it could support people.
- Present information about the service in a variety of accessible formats.
- Engage with people in ways that suit their individual needs and preferences including face to face, on the phone and online.
- Be flexible and adaptable.
- Offer a physically accessible space for people to meet confidentially.
- Be a countywide service.
- Be present for as long as the service is needed.
- Signpost people to helpful alternative places, if the service is unable to offer the support that is needed.

Produced by Wiltshire Centre for Independent Living, User Engagement Team
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