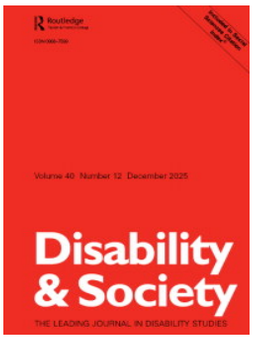

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"It's about equality!" Disability advocacy in the UK

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ABSTRACT

Advocacy means taking action to support people to secure their rights, pursue their interests, and obtain services they need. This study aimed to find out people's knowledge and experiences of advocacy, as well as their recommendations for the improvement of advocacy services. Forty-six people from various regions of the UK were interviewed online, and 193 people completed a survey. Participants had different impairments, and some were family members of disabled people, most of whom experienced impairment and disability themselves. People said that they would like more access to advocacy services to support them with many areas of their lives, such as to reduce isolation, accessing employment and healthcare, support with benefits and help with documentation, financial support and advice, and to challenge inaccessibility and discrimination. There is a need for improved general statutory advocacy that involves disabled people as advocates, along with greater awareness of what is offered.

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Disability advocacy; statutory services; advice; benefits

Points of interest

- Disability advocacy is an important requirement that helps people exercise their rights and choices
- Disability advocacy services usually offer help based on impairment type
- There is a need for general advocacy services paid for by the state, to provide support with common issues and barriers
- There is a clear need to put disabled people, and their families, at the centre of advocacy designs in the future

Link to accessible research summary: https://drrebeccafish.wordpress.com/2023/11/27/407/

Introduction

Advocacy interventions provide advice and support for a person to access and use a specific service or resource, such as legal, housing and financial support, help to access services and benefits, informal counselling, and

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support to improve physical or psychological health. Advocates may be trained lay mentors, community, healthcare or legal service employees, or volunteers (Daly, Barrett, and Williams 2017). An advocate provides support, information, and representation, with the aim of empowering the person and enabling them to express their needs and choices. Independent advocacy is therefore crucial to achieving more choice and control for disabled people (Townsley, Marriott, and Ward 2009). We refer to the need to pay attention to commissioned general advocacy here, which we define as advice and help for disabled people that is not tied to particular services or impairment type (Newbigging, Ridley, and Sadd 2021).

Since 2016 there has been no formally commissioned general advocacy services for disabled people in the UK. This has meant that disabled people have only had access to statutory advocacy that delivers advocacy on a limited number of issues. Disabled people were disproportionately affected during the COVID-19 pandemic (ONS 2021), experiencing what Shakespeare, Ndagire, and Seketi (2021) referred to as 'Triple Jeopardy'. This was related to inequities in access to public health messaging, as well as measures such as self-isolation and physical distancing disrupting the services disabled people rely on, and the consequent worsening of existing health conditions (Armitage and Nellums 2020; Kuper et al. 2020; Macdonald and Wilde 2025). These issues increased the need for disability advocacy in various forms (Nerlich et al. 2021).

Although self-advocacy services exist in the UK, there are many barriers that hinder participation (Bruce 2020; Petri, Beadle-Brown, and Bradshaw 2021). Furthermore, critics of self-advocacy argue that it places the duty of action onto the disabled person and has been claimed to 'perpetuate neoliberal-ableist ideals of independence, compliance, and self-containment' (Bruce and Aylward 2021:22). The provision of general advocacy services alongside self-advocacy for disabled people is therefore a necessity. Related to this, the *Advocacy Quality Performance Mark Code of Practice* (Qualityadvocacy.org.uk 2014) states:

> People are entitled to be in control of their own lives but sometimes […] they may find themselves in a position where their ability to exercise choice or represent their own interests is limited. In these circumstances, independent advocates can help ensure that an individual's rights are upheld and that views, wishes and needs are heard, respected and acted upon.

When it comes to activities of general advocacy services, the updated Advocacy Charter by the National Development Team for Inclusion (NDTi) advises that advocacy can promote social inclusion, equality, and social justice by:

> …. taking action to support people to say what they want, secure their rights, pursue their interests and obtain services they need. Advocacy providers and advocates

> work in partnership with the people they support and take their side, promoting social inclusion, equality and social justice. (NDTi 2018)

It is important that advocacy has a proactive role in prevention, promoting wellbeing, and safeguarding, rather than just a reactive role in managing crises and complaints (NSW Ageing & Disability Commission 2019). The process involves the advocate working in partnership to help the person set and achieve their own goals. It is therefore an individualised, person-centred approach rather than a prescriptive or hierarchical intervention.

Recognition of the need for advocacy grew out of the social model of disability. UPIAS (1976, Principle 15) reflects this by stating that disabled people are interested in 'changing our conditions of life, and thus overcoming the disabilities which are imposed on top our physical impairments by the way this society is organised to exclude us.' Consequently, Principle 16 states that disabled people as a minority group need help to live a 'fully human' life. The benefits of advocacy for disabled people are distinct in three areas. First, disability advocacy enables disabled people to participate in the decision-making processes that protect and advance their human rights. Second, individual advocacy supports disabled people to exercise their rights through either one-to-one support, or by helping people to advocate for themselves individually, through a third party, or on a group basis. And finally, systemic advocacy seeks to influence longer-term structural and policy changes to ensure the rights of disabled people are upheld (NSW Ageing & Disability Commission 2019).

The first statutory right to advocacy in the UK came under the provisions of the Mental Capacity Act 2005 with the introduction of the Independent Mental Capacity Advocate or IMCA (Rapaport et al. 2006). The role allowed people who were deemed to lack capacity to understand their situation and have their voice heard, making sure they were appropriately supported to make decisions about their treatment. This was followed by the introduction of Independent Mental Health Advocates (Newbigging et al. 2015) and then Care Act Advocates, under the provisions of the Mental Health Act 2007, and the Care Act 2014 respectively.

These statutory roles place emphasis on promoting people's rights and wellbeing, however they have been criticised for focusing on very specific circumstances, excluding those who may need advocacy for other reasons (Hardwick 2018). At the time, it was feared that the creation of statutory advocacy would lead to community-level, independent advocacy becoming overlooked, as the right to general advocacy was not made a legal imperative (Hardwick 2014). This makes the case for general disability advocacy all the more important.

In light of the pandemic, which followed years of austerity cuts in services for disabled people in the UK, this research explored how advocacy is

experienced in practice, and whether and how advocacy provision needs to change.

Challenges to the provision of advocacy in the UK

Advocacy services provide a cost-effective solution by encouraging both preventative strategies, and innovation. When advocates become involved in a person's life at an early stage, they can reduce the likelihood of adverse situations escalating to crisis point, helping the person to have more power and control, and therefore resilience (Atkin and Kroese 2022). Advocacy is cost-effective because it tailors services to individuals, avoiding one-size-fits-all solutions. However, there are challenges to advocacy provision. Raising awareness of advocacy services remains difficult due to the rise in digital communication, which highlights a divide between those who have the resources to take part in such communications, and those who do not (Gelfgren, Ineland, and Cocq 2022).

There are other challenges to providing effective advocacy services, such as

- making sure the service reaches the groups that need it most,
- a lack of defined outcomes that make systematic evaluation difficult,
- the issue of the ongoing short-term funding model that hinders the capacity to make longer term plans,
- the power of funders to threaten the independence of advocacy services,
- the risk that smaller organisations may disappear due to focus on the government statutory roles.

The literature shows there is a need for research into advocacy requirements, and national policies with co-produced standards that cover general advocacy (Drage 2012; Rapaport et al. 2006; World Health Organization 2019).

The objectives of this research were to examine disabled people's knowledge of and needs for advocacy in the context of everyday experience, and to produce recommendations for how disabled people can be supported better in the emerging post-pandemic social situations.

Method

As researchers, we were chosen to do this project due to our knowledge and experience of Disability Studies research, as well as our lived experience of disability and long-term health conditions. We recruited participants using social media and purposive sampling through various organisations in the North of England, to be involved in either a survey or online interview.

Interviews

Potential participants expressed their interest *via* a local disability website, meaning that participants were self-selected. Prior to the interview, each participant was provided with information using an online form, specifying that they would be involved in an online interview, and that all identifying information would be kept confidential and anonymous. Participants were informed that they could withdraw their interview data partially or fully for two weeks after the interview, and that their data would be kept confidential and anonymous. Patton's (2002) checklist for ethical research was followed to ensure ethical adherence. As independent researchers, we were unable to apply for institutional ethical approval, however, we are experienced in qualitative research on sensitive subjects. Therefore, we were mindful of the importance of ethical principles, including the need for emotional support and understanding for interviewees sharing their experiences. Forty-six people agreed to be interviewed and they were given a £30 shopping voucher as a thank you for their time, as recommended by the UK organisation *Involve*. Around three quarters of interview respondents were women ($n = 35$ or 76%) and there was a wide spread of impairment type, age, race and gender self-identification. Most interviews were recorded but six people did not want to be recorded so notes were written by the researcher. Interviews were anonymised on transcription.

Interviewees were asked the following general questions, but participants were allowed to shape the direction of the interview and the themes discussed:

1. Please tell me what your understanding of advocacy is.
2. What were your advocacy needs during the pandemic?
3. Were there any changes in the support and advice you received?
4. How do you think advocacy is best done?
5. What are your support and advocacy priorities for the future?

Online survey

The online survey was designed using themes that were arising from the interviews, and were similar to the interview questions above. The survey link was publicised through the researchers' networks. In total, 193 responses were received; although a third were only partially completed and therefore discounted.

The first part of the survey specified that all responses would be kept confidential and that the researchers would include anonymised quotations from the survey in reports and publications. There was a £50 prize draw for one randomly drawn winner.

We approached a disability consultancy organisation to construct an easy read version of the survey, and this was completed by people who required this format.

The research team met a number of times to discuss the themes arising from the data. We analysed the large amount of qualitative data into themes of enquiry using the software NVIVO. Throughout this process, we used Braun and Clarke's (2019) stages of reflexive thematic analysis to allow us to interpret patterns of understanding within the dataset, picking out relevant quotes that the research team as a group felt represented each theme. These are presented in the following section:

Results

The interview and qualitative survey data were arranged into the following major themes: Understanding advocacy, perspectives on advocacy services, future advocacy needs, and what advocacy should be. We give an overview of each theme below:

Major theme: understanding advocacy

Few people had understandings of policies around advocacy, or of the processes of advocacy itself, and there were a wide range of interpretations of what advocacy really means. Key themes raised included raising people's voices, assisting access to benefits, and ensuring more choice and independence.

Several people were involved in self-advocacy groups, especially people with learning disabilities. One survey respondent described self-advocacy as:

> Speaking up for yourself, standing up for your rights. Making sure you're getting the right help at the right time when the person needs it!

Another person explained that they saw advocacy and activism as inseparable in their own life and involvement in disabled people's groups, e.g. peer advocacy, and political groups.

Another interviewee showed how having an advocate can result in more confidence and independence in seeking support and understanding entitlements, whilst also leading services to take unmet needs much more seriously:

> To have an advocate, or someone who represents you, certainly helps to deal with the stress. And I think it lets authorities know that you're not on your own. You know, so you're less vulnerable. When people think you're on your own, you can be taken advantage of. If you've got somebody there that is representing you, supporting you, and is alongside you, then you're stronger. It helps keep the person safe… it's about equality!

Some interviewees had experiences as an advocate for others, and/or had been involved in peer advocacy; understandably these people had better knowledge of advocacy. Every participant wanted more advocacy, demonstrating many unmet needs. One statement seems to sum up the attitudes of participants:

> An advocate does not advise anybody, it is not advice. It is help, support and choices. When a person cannot speak for themselves, then that is when an advocate is brought in. The outcome is empowerment. And the main outcome, the biggest outcome, is for somebody to be able to self-advocate for themselves.

Participants in contact with medical and social care professionals often said that they had received information on their entitlements and where to go for further support and guidance. Whilst this suggests that information sharing on advocacy is key to cascading knowledge, it is also dependent on the relationships that people have with professionals in their lives, where good relationships are more likely to lead to excellent outcomes, and less trustworthy relationships can lead to a reluctance to seek further support (see also Wilde 2014).

One example of the distrust of advocacy and support came from disabled parents, where there were significant concerns that contact with professionals may result in children being taken from them; this is common - as Crow (2003) and Olsen and Clarke (2003) have pointed out. One woman had only used services when absolutely necessary, despite having many needs for support. This is particularly imperative in situations where there are perceptions of parental incompetency, or in situations of domestic abuse (Balderston et al. 2019). It is common for disabled people to have understandable fears of such intervention (Ryan 2018).

That is, professionals can be seen as a threat to independence, security and even life; as one interviewee said, *'A lot of [disabled] people do have a fear of authority.'*

Many had heard the word 'advocacy' but didn't relate this to themselves. This tendency was most common in interviews with people who were older or from working-class/non-professional backgrounds. Some older people and many of those with learning disabilities were significantly reliant on the guidance of family members, so access and understanding of advocacy and support was dependent on those who advised them.

Many family members who support disabled people saw their responsibilities for their relatives increase sharply during the pandemic, due to withdrawal of services, and the difficulties of balancing new needs/obligations with employment commitments (Wilde 2022). Additionally, there were others who had to struggle for their own support needs to be met while having primary responsibility for elderly parents. In the absence of reachable advocacy, one woman's son helped her with an application for benefits:

> People like me don't know what's out there, at all. You know, and don't think even they help us out. If it weren't, weren't for my son, I would not have had much help. I'm not saying it's not out there. But I wouldn't have known.

A wide range of advocacy services had been used by the participants we interviewed. Those mentioned included solicitors, alcohol related services, housing association groups, visual support services, welfare rights, Citizen's Advice, local charities, holistic therapy, psychological therapies, domestic abuse services, mental health consultancy, family support, respite services, and social prescribing.

Several people said that they had been trying to get disability advocacy for a long time (years), but had not succeeded. In some cases, this meant that they had little knowledge of entitlements, with one person saying that she had not yet been able to apply for benefits due to her inability to make or receive phone calls. One woman described herself as '*housebound*' and said that she had approached several organisations and statutory agencies with none offering support:

> It's just constant. My whole life is consumed by trying to get support and medical help for my illness. I don't have time for anything else in my life.

Survey responses also showed that people had used certain services for help and advice, but these were often impairment specific, and many did not offer general advocacy:

> The community mental health team haven't given me the support I need during, before or after the pandemic.

> Yes, many times I was not supported for my own needs. It was not on my terms at all.

> There doesn't seem to be much out there in terms of support unless you have a specific disability or condition.

Major theme: perspectives on advocacy services

The interviewees reported many helpful aspects of advocacy. Valuable aspects included: having a forum to speak in, follow-up communications, and check-ups on wellbeing. The latter two of these were particularly important to people with mental health-related difficulties, but continuity and consistency of support was important for all disabled people. For some, support was essential for access to medical care, such as one man who needed a support worker to communicate unmet needs to medical staff when he was hospitalized.

Those who were able to use self-advocacy services expressed the high value of social activities provided through agencies. One person said, *'This organisation has been a godsend for us….an absolute godsend.'*

There were a range of problems people experienced in seeking or securing support and advocacy services. It was common to hear that people were not considered 'disabled enough' to be granted support, and/or did not live in the right area:

> There is a postcode lottery, local services aren't available because they are in the City.

There was agreement that the pandemic, and cuts to welfare, health, and social care had led to the diminishment of community resources. One man spoke of his belief that people had become '*more introverted*' due to services merely signposting:

> I think especially with what's happened in recent years with all the austerity cuts, a lot of those little pockets of charities were retrained in certain ways to signposting people. Without those drop ins, those coffee mornings, walks, whatever, without them existing in the first place how do people flag up the right services?

Some interviewees commented on peer support systems and had provided helpful peer-support to others, e.g. in communicating COVID-19 information. This was especially true in communities of people with learning disabilities. One person said they believed that peer-support was one of the more promising areas of practice but was concerned that projects to train disabled people as advocates would only last as long as their funding.

Where there are several members who are disabled in the same family, it is rare for the needs of the family to be taken holistically. Often, when there is a disabled child, the parents receive little help for their needs, and if both parents are disabled, there is usually a failure to consider the impacts this has jointly, individually, and as a family. Clearly, this can result in a fear of accessing services, especially when reductive decisions are made about competency. One woman said that she felt *'very judged'* by some of the professionals she had been supported by.

Survey responses demonstrate the difficulties here:

> I know people who don't come within the area, and they need services which they can't get from Citizens Advice.

> I had problems getting support before lockdown, and it was even harder during and after.

Major theme: future advocacy needs

Many people spoke of the lack of universal guidance on how to gain support. This might suggest the need for a trustworthy brokerage service. For example, one interviewee said:

> I think you have to be pointed in the direction. If you're unaware, I think you need somebody to say to you, 'You can go here for help. Or I can help you get services you need.' But if you're not in hospital, or you're not attached to a social worker, it's difficult if you just don't know and are struggling at home.

There was a need for much better advertising about what was available:

> I don't think there's enough adverts to direct people to those services.

> It should be well-advertised in public buildings, libraries, doctors. Anywhere like that, clinics…. chemists, because everybody uses a chemist!

> There needs to be much more out there. Like, through the TV, through the radio, to communicate to disabled people that this is the person who is going to be much more hands on at helping people.

> Because there's more to life than constantly scrolling through a screen. If it was actually put in a printed leaflet, put through your door that would attract attention…. are you aware of this meeting service? Just a little bit more local support? …if you ask for help, you're not going to be judged by it - everybody needs help at some point in their life.

Like many, one participant pointed out that disabled people have been *'left in the lurch for far too long'*, pointing out that they're not getting the right information, and explaining that:

> Not only is there not enough help available, but there is not enough said about it, it's not up front enough to get the message out there to disabled people. It needs to be absolutely put at the top of the list.

Some said that advocacy could be made more accessible, taking into consideration a wide range of impairments, including mental distress. One person suggested that widespread sharing of information might be better if it was coordinated centrally:

> [We need] some sort of Tsar of help with disabled people's problems, where they can delegate work for this specific reason, to help the disabled people who are out there in their absolute thousands.

Survey responses made similar recommendations, for example:

> Be available in all local health hubs. To be fully staffed, to have answers to help us feel heard supported and an equal partner. I don't want to be pushed from pillar to post for months on end, repeating my story, taking time and effort to find I have achieved nothing.

While many acknowledged that escalating costs of living including energy and heating were a problem for many, there was much concern about how this was particularly affecting disabled people, and the potential impact in future. As a group who experience many additional living costs, including higher energy use due to necessities such as wheelchairs,

ventilators, and so on, and are disproportionately in poverty (JRF. 2021), it is unsurprising that levels of anxiety about the future were high. One person expressed his fears about what he described as a *'massive'* future demand for advocacy on finances:

> A lot of things are going up and up in price vastly. And in my particular case, it's unlikely that benefits will go up along with inflation.

Some interviewees recommended that there was a great need for service providers to understand more about '*hidden impairments*', as well as reaching younger disabled people, who may not see themselves as potential users of advocacy services. One woman, in her mid-20s with many needs for support, said:

> This is gonna sound really daft. I feel like because of my age, I really shouldn't have that many medical problems […]. I could have the best social worker in the planet, and it would still make me feel like crap.

A lot of interviewees were concerned about loneliness and isolation. This is clearly an urgent issue for many disabled people, particularly those who live alone, indicating a need for outreach services.

A parent with a health condition who was also the parent of a disabled person with severe learning disability in residential care expressed how difficult it was to get advocacy for their adult child, and that misapplied ideas of independence can sometimes obstruct advocacy for adult children or parents. She put forward an eloquent case:

> I can show rafts of evidence, that showed that my son is very much not at the centre of his care. And people feel absolutely fine about making decisions on his behalf, pretending they are in his best interests without ever doing any investigation whatsoever about what might be in his best interest? I often say to them, how do you know what's in his best interest? You met him for 15 minutes? I'm pretty confident you can't communicate with him so how have you made that decision? If it's in his best interest, then as a family member, I want to be involved in that decision […] unless it's a clinical decision when we've got to get a doctor to make a more informed, knowledgeable decision than me.

Survey respondents also specified areas that they would need help with in future, such as:

> Advice on mobility aids/home adaptations, financial help, housing options, rights to care.

> Issues like supported housing, access to work, clubs, groups and activities in the area, which would enable me to meet similar, and new people. Maybe just general advice too. Some people do not even realise they are on the spectrum or may have a hidden disability, so it would be helpful for people like this to be able to seek advice and possibly a diagnosis.

As stated previously continuity and consistency are seen as key to support, for example:

> I'd like to be able to just pick up the phone to talk to somebody when I need somebody to talk to, they will just be there at the other end of a phone or ….I could meet them, like once a week or whatever, just to go for a coffee or whatever. Yeah, that would be really good.

Many supported such ideas of making contact, with a considerable number saying that they did not like using technology or social media, and some not using it at all.

Alongside recommendations for more face-to-face services, one woman also suggested a more involved role for those who were the users of such services, saying:

> It would have to feel like I was part of it and I had support when I needed it

As she suggested, one of the more fundamental conditions in the delivery of advocacy and support which leads to advocacy, is the quality of person-centredness:

> Even if you got five people with the same condition, it isn't going to look the same for them, it's not going to have the same impact - this idea of one size fits all is really flawed. It needs to be personalized sometimes, it feels like the solution that is offered is to slap a plaster on it, and pretend it's not there, which I kind of find borderline disrespectful of me as a person.

> Services should be automatically tailored to people's access needs whatever they are, without making assumptions about people's level of need based on their level of impairment. Like someone who has no friends or family is therefore in greater need than people who may seem to have a more severe impairment.

Major theme: what advocacy *should* be

Despite to somewhat low levels of knowledge of what advocacy is, has been, and could be, many interviewees had strong and valuable views on what it should be, for example:

> [Advocacy] should be showing people the way in, you know.

Many interviewees spoke both implicitly and explicitly of the need for greater flexibility. But many thought this should be person-centred:

> I think that the first point of call should be asking that person, what they need, and how they need to be supported.

Some interviewees suggested that many organisations should be less hierarchical and also less concerned with metrics and outputs. One person stated that services need to be *'genuine, and respectful'* saying *'arrogance doesn't work.'*

> Being treated equally. That's very important to me, equally and fairly, and you shouldn't have to fight for it. But …organisations are very busy. And then you've got the funding bodies who want to cut funding, that's their role. They don't seem to be interested in the person anymore. I don't know whether they ever have been… it's really about cutting funds.

Many stated that it is important that advocacy should not be run by services, and should remain independent from funders:

> And you know the different information and different options, they wouldn't have an axe to grind if they are independent. So they would hopefully provide some more objective advice and information.

Despite a common call for local, face-to face-services and advertising, there were also recommendations for online support groups, and home support visits for those who could not leave their own homes. Some reported that they thought advances in the use of technology to support people during the pandemic improved things a lot for them, and that this might mean a greater recognition of the need for such services afterwards. They expressed disappointment that this had not occurred and that things had gone back to an undesired 'normal' creating new risks, e.g. for some of whom were unable to have the COVID-19 vaccination.

Other people talked about the importance of managing expectations. One woman argued that advocacy should be non-judgmental, and that if services are time limited, the service providers should be clear about this. She also stressed the need for accessible information about services offered, and meaningful assistance for people who experience barriers in accessing information. She also suggested a form of '*semi-formal advocacy service*' to help parents navigate school systems.

Some ideas for advocacy improvements were impairment-specific, such as one person who said that services for Deaf people '*cannot be geographically bound as there are so few Deaf people*'. Similarly, some people with impairments such as M.E., who find it difficult to leave their homes, spoke of the need to retain strong online support. In terms of the vexed area of advocacy for people who have limited verbal communication and 'severe' learning disabilities, someone suggested that:

> For nonverbal communicators, I would like them all to have an advocate who is appointed to them. And as far as possible, that the advocate is consistently used for that person.

Some people thought that the need to recognize the diversity of disabled people was a key goal for advocacy organisations. One person said they had experienced oppressive '*phobic*' attitudes using services for LGBTQI + groups and has also found that there is LGBTQI+ phobia in certain disability groups.

Interviewees suggested a number of areas which might help in widening advocacy for more people. These included access to a *'benefit health check to make sure that you're getting all the money you're entitled to'*, a source which would available through local authorities, '*whether that's as a carer or via pots of money that might be available to you joining local DPOs and disabled led groups.*' Drawing on their own considerable experience of advocacy work, one person stated that health, housing and Access to Work should be priorities for advocacy work.

Some interviewees mentioned the need for funding for smaller organisations that employ peer advocacy workers, who understand what it is like to be from a marginalised group:

> Because [peer workers] have the lived experience and they may be able to ask different questions. And you know, perhaps sometimes create better rapport with participants.

> I believe it's kind of basic as part of their role, I mean being very aware of intersectionality and different, you know, sensitivities around these issues. I imagine that people who go for advocacy, they don't have just one identity. It is important to know that.

Survey respondents also recommended accessible tailored consultations, such as:

> Tailored support and accessible formats. Not just digital by default, some people prefer digital or remote but others face additional barriers and it is better for them face-to-face.

Discussion and conclusion

Overall, disabled participants in this research, as well as those who were family members of disabled people, had much to say about advocacy services. This was both in terms of their perception and knowledge of them, as well as the need for more awareness and better access to advocacy.

It is clear from the results that there is a need for personalisation and tailored services. In particular, families were asking to be treated holistically, because dealing with professionals and practitioners often felt hierarchical and reductive (see also Fish and Morgan 2021). As Wilde and Millett (2011) points out, prohibitive attitudes towards disabled people as parents are apparent in many services, where disabled families are expected to adapt to the assumed norms of non-disabled families in order to fit administrative categories. Wilde (2022) argues that this is because professionals continue to define disability individualistically, as a personal attribute, rather than seeing the causes of disability as organisational, economic and attitudinal.

The results also show that there is need for much wider scope of advocacy than is offered by statutory services, as participants had used advocacy

services for many types of issue, and felt that they would need more advocacy help in other areas in future. People stressed the importance of independent advocacy services, that involve people with lived experience as a way to build trust and relationships. This supports the literature that argues for the need for personalisation in every aspect of services for disabled people.

Leadbeater's (2004) framework for understanding various forms of personalisation is relevant here, in showing what the choices in the service delivery of advocacy are. He described a continuum of approaches towards personalisation, ranging from those which pay lip service to people's needs (shallow personalisation) to those that involved clients in shaping and controlling service delivery (deep personalisation). Shallow personalisation treats clients impersonally as consumers, where people are 'put on hold, kept at arm's length, tricked by the fine print, not told the whole story, redirected to a website, treated like a number' (2004:80). Indeed, we heard many such ideas from the interviewees and survey respondents, alongside calls for disabled people to be much more involved in setting advocacy agendas and contributing to the design of advocacy schemes. At the other end of the continuum there is deep personalisation through participation, perhaps the ideal strategy for the delivery of tailored support and advocacy, as many of our participants expressed.

Advocacy related to work and benefits was particularly important in this study, especially as it is not uncommon to believe that having a job makes you ineligible for benefits. Work problems have been exacerbated for some by COVID-19. This included being pushed towards early retirement or losing jobs because of the risk of infection, and was especially true of people had asthma and other respiratory conditions. Other changes included moves to hybrid working or reduced/changed working roles. This had a variety of effects on people, with some speaking of longer-term damage to income and associated anxieties, and a loss of feelings of independence due to an increased reliance on partners or family members.

One significant worry for people in this study, and in other research (Macdonald and Wilde 2025; Wilde 2022) was the social impact of advancing use of technology. Some of the participants expressed their anxieties around the inaccessibility of technology, deterring people from social events, online and otherwise. Drawing on wider literature about these impacts, it is clear that COVID-19 contributed to a severe reduction in, or withdrawal of health and social care services including respite (Flynn et al. 2021). These losses were reflected in many agencies serving disabled people across Europe (Rosken, Angelova, and Wilde 2021).

It is important that advocacy continues to be commissioned on a long-term basis, allowing capacity to build infrastructure so services can be provided in a deeply engaged way rather than merely referring and signposting people to other agencies (Cantrell, Booth, and Chambers 2024; Fish, Hibbin, and Simmill-Binning 2022; Fish, Riley, and Wheeler 2024). Roberts et al. (2012)

comment on the potential problems of reducing funding for advocacy, arguing that there will be a move towards crisis intervention rather than early intervention, and this will result in increased costs for health and social care services. According to Action for Advocacy, potential impacts of reduced advocacy services include disempowerment (which will undermine health and social care reforms aiming for increased choice and control to tackle inequalities), debt and homelessness, mental health issues, fewer opportunities for gaining skills, and fewer opportunities for employment in advocacy services (Action for Advocacy 2011). The reliance on statutory funding has been an enduring concern throughout the years, as demonstrated by this quote from 2003:

> [F]unding conditions and short term grants create organizational uncertainty, diversion of purpose, staff turnover, and increasing bureaucratization, all of which affect advocacy negatively (McColl and Boyce 2003:390)

Limitations of study

We recognise the limitations of this study, including our recruitment of self-selected interview participants mainly from the Northern area of the UK, alongside a more general survey that would have benefited from wider distribution. Responding to the articulated need for a review of all forms of advocacy (Newbigging, Ridley, and Sadd 2021), we acknowledge that this study is part of the continued conversation about post-pandemic recovery for disabled people and social care services.

Conclusion

To conclude, the present research demonstrates the multiple marginalisation experienced by disabled people in their contacts with services, and firmly supports the need for general advocacy services, as a way to improve quality of life. We recommend further research into advocacy good practice, as well as models of advocacy, in order to develop outcome measures that demonstrate the complexity and significance of work that advocacy services accomplish day-after-day.

Recommendations for development and progression of services are as follows. Disabled people and their families need:

- Advocacy in many areas, for example: addressing isolation and loneliness, employment and discrimination, access to healthcare including help with mental health, access to benefits and help with documentation, financial support and advice, help with communication and inaccessibility, help finding information and advice.

- Increasing knowledge and awareness of advocacy services and what they can help with.
- Better access to information about: rights, where to get help, impairment specific information, help for families and local services, to address digital and health inequalities for disabled people.
- Services that employ disabled people, with the right knowledge and skills to give them advice and support.
- Services that are independent and confidential, making use of multi-agency working and information sharing where beneficial.
- There is a clear need to put disabled people, and their families, at the centre of advocacy designs in the future.

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