

Upholding rights & valuing voices: Advocacy principles for coronavirus and beyond

Introduction

These operating principles seek to make sure that people who use social care and health services during and beyond the Covid-19 (coronavirus) pandemic are heard and listened to. It will be of most use to advocates and advocacy organisations but will be also relevant to people who use advocacy services and their family members, to Disabled People's Organisations, to social care and health professionals, and to those who commission advocacy services.

These principles are designed to shape our collective responses and make sure that no-one who needs our support is left out, that people's rights are respected, and nobody goes unheard.

These principles supplement the advocacy charter¹ but do not seek to duplicate or replace it. They sit between the high-level principles of the charter and more detailed guidance and practice requirements (including the Advocacy Code of Practice).

This is a consensus statement of principles that reflects our current understanding. We will build on and adapt these principles as our understanding changes.

Context

The coronavirus pandemic has shone a light on and exacerbated inequalities. There has been avoidable loss of life and many people have experienced dreadful conditions.² Overwhelmingly, those of us who already found it harder to have our voices heard have suffered greatest in the pandemic. Effective advocacy is ever more important as a tool to make sure that people's voices are heard, inequality is addressed, and rights are respected.

People working in health and social care have made tremendous efforts to support people, often in the face of adversity and a falling away of the safeguards and measures designed to protect people's rights and well-being. Further, in the face of these challenges, advocacy organisations have worked closely together to share insights, resources, and forge common approaches. These principles emerge as a result of this cooperation and are, in part, our response to findings from a survey of advocates carried out in June 2020 which exposed the challenges that we as advocacy organisations must address.³

The coronavirus pandemic has magnified the challenges that affect the lives of people who use advocacy services and that many advocates had been already seeking to address, such as issues around access and referrals, commissioning processes and independence, challenging decisions, and consistency of advocacy services.

1. <https://qualityadvocacy.org.uk/resources/advocacy-charter>

2. For example <https://www.cqc.org.uk/sites/default/files/INS2-8884435571.pdf>

3. The stark impact on people who use social care and health services was highlighted again by responses provided by 435 advocates across England and Wales to a survey conducted by the NDTi on behalf of advocacy organisations between 11 June 2020 and 26 June 2020. Work is underway to fully evaluate and disseminate learning from this.

Operating principles

Recognising the essential role of advocacy in supporting people during and beyond the pandemic we will:

1. **Make sure that people are heard, and their rights are respected**
2. **Communicate effectively and safely meet with people in person**
3. **Make sure that people can access advocacy**
4. **Take positive anti-discrimination action**
5. **Work together to promote systemic change**

1. We will make sure that people are heard, and their rights are respected

Due to the pandemic, fulfilment of people's statutory entitlements and respect for their human rights are at risk. The public health response has seen the stripping back of vital health and care services and severe and ongoing restrictions on people's liberty, private, and family life which for many people represent a very real threat to their human rights. Additionally, safeguarding is even more important due to enhanced risks, but more difficult due to the restrictions in place. We have a shared commitment to continue supporting people who are using the advocacy services to which they are entitled and to challenge decisions wherever needed.

This means we will:

Increase awareness of people's statutory rights and the applicable guidance

We will make sure that people have access to advocacy and promote the integral value of advocacy in upholding people's rights and wishes. We will refer to legislation and guidance in order to protect people's access to advocacy and hold ourselves to account for making sure people get the advocacy they need and deserve.

Challenge

While we recognise the difficulties that social care and health professionals and institutions face, we will fulfil our duty to support people to challenge wherever they wish to and to challenge on people's behalf when needed. We will use the full range of options available to us, including using professional supervision to ensure best practice.

Keep people's rights front-and-centre

We will take a rights-based and person-centred approach to make sure that people fully understand their rights, and others in turn understand their duties and responsibilities for fulfilling those rights. We will continue to support people to self-advocate and have control over the advocacy process as well as the services they use and the decisions that affect them. We will make sure that timely decisions are taken and that they are reviewed frequently.

2. We will communicate effectively and safely meet with people in person

Communication has always been at the heart of advocacy. Advocacy has continued, despite restrictions, thanks to creativity on the part of advocates and the people who use advocacy services, and through the practical assistance of staff and unpaid carers who support them. Meetings between people and their advocates have taken place within government guidance on social distancing, using digital communication tools as an alternative to in-person meetings, and using face coverings and personal protective equipment (PPE) when meeting in person.

Whilst in some circumstances, advocates can support some people effectively by videoconference, telephone, or email, this is often not the case. Restrictions on in-person meetings disproportionately affect people who most need and benefit from advocacy, including people with the most complex needs and who experience the greatest communication barriers. It is more difficult for an advocate to establish clearly what is happening to a person and to ensure privacy through remote tools. People with a wide range of needs cannot be adequately served by 'remote' working alone.

We will encourage and continue video and telephone contact where these genuinely provide effective communication. However, we recognise that there are limits to how we can communicate with some people and understand their views, world, and well-being without being physically present. Whenever this is the case, we will make sure that we meet with people in person, unless justifiably prohibited.

This means we will:

Increase awareness of people's rights to advocacy and the unchanged legal duties

We will meet with a person in private whenever this is reasonably requested⁴ or practical and appropriate,⁵ and raise awareness of the legal duty to meet privately. We will push service providers to facilitate this as much as possible and make reasonable adjustments in line with the Equality Act. With growing understanding of how to meet while minimising infection risk and with better access to personal protective equipment (PPE), the proportion of face-to-face meetings which are practical, appropriate, and reasonable will increase.

Use the full range of communication methods

We will recognise the different communication needs of people with whom we work. We will continue to make, and encourage others to make, reasonable adjustments to support people who do not use formal means of communication or face additional barriers in communicating, for example due to cognitive or sensory issues. We will seek to improve people's access to communication tools and will refer to legal guidance. Where access to communication technology is usually restricted, these restrictions should be reviewed. Every effort should be made to support people to communicate with their advocate.

Challenge decisions

If a visit is stopped, or as advocates we are prevented from meeting with someone, we will find out why and challenge decisions, where necessary. We will seek to make sure that blanket decisions around visits, contact, and support are not in place and challenge them wherever they are. We will reassure health and care providers that we have robust risk-management and decision-making systems in place to minimise infection risk and that we are acting responsibly, in line with best practice and latest guidance.

4. Mental Health Act; Mental Health (Wales) Measure

5. Mental Capacity Act; Care Act; Social Services and Wellbeing (Wales) Act

Recognise and manage risks

We will make sure that our risk assessments are practical and holistic. We will recognise that, in many cases, the risks to the person from not having support from effective advocacy to assert their wishes and rights will exceed the risks they face from coronavirus, particularly when infection risks can be minimised.

Meet safely in person whenever possible

We will always make sure that the person's needs and preferences are at the centre of decisions about meeting in person. We will continue to meet with people in person to provide necessary support to them in line with the law and guidance. This is likely to require a continuous increase in the frequency of face to face meetings. We will take all reasonable steps to mitigate risks and dismantle barriers to meet in person, while recognising that for some people and in some situations telephone or video communications can give people timely, quality, and effective advocacy support, where and when they need it.

Ensure access to PPE

We will make sure that advocates have PPE where needed, in line with the appropriate guidance, and know how to use it. We will work in liaison with care providers where needed, so that equipment used in a particular setting or circumstance is appropriate.

3. We will make sure that people can access advocacy

The pandemic has resulted in rapid changes to the lives of people who rely on social care and health services and new issues, risks, and concerns. There can be no doubt that it has increased the need for people to receive the independent skilled support that advocacy provides.

Yet, referrals significantly decreased in the first months of the pandemic⁶ which restricts people's access to advocacy, stops their voices being heard, and impacts on people's human rights and the lawfulness of actions taken by public authorities.

There are a range of reasons for the drop in referrals. These appear to include increased demands on health and care professionals, reduced face-to-face contact between social workers and people using services through assessments, care plans, and reviews, fewer advocates present in mental health wards and care homes, and some potential referrers not fully understanding that the legal duties to refer to advocates still apply.

Advocacy organisations and referral bodies must take concerted and positive action to facilitate access to advocacy to address these issues. Referral and access criteria and statutory requirements must be clearly understood, and referral mechanisms must be fully functional and easy to use.

This means we will:

Be adaptable

Given the enhanced pressures on health and social care professionals at this time, we will recognise how advocacy organisations can support the referral process by providing additional information and that we may need to make modifications to internal processes to facilitate referrals.

6. From data gathered across 44 Local Authorities, there was a 30% drop in advocacy referrals between March and May 2020, when comparing the same period in 2019.

Publicise the duty to refer

We will re-double efforts to ensure that people who may benefit from advocacy, as well as their families and community groups, are aware of advocacy services and can access them easily. We will take action to address any confusion health and social care professionals have around the duty to refer so that they fully understand their legal obligations.

Build good relationships

We will maintain and strengthen relationships with people who can refer to advocacy, and with people and groups who can raise awareness of their services.

4. We will take positive anti-discrimination action

Coronavirus has shone a light on and exacerbated pre-existing inequalities. Older people and people who use social care, disabled people, Black people and people from minoritised ethnic backgrounds, people with long-term health conditions, people with low incomes, people who identify as LGBTQ+, and those who experience multiple and intersecting forms of discrimination have been worse affected.

It is essential that advocacy organisations take positive action to make sure that people who are most likely to face structural inequalities and discrimination receive high-quality, well-designed support. As we move on from the initial and acute phases of response to the pandemic, we must review and refresh our approaches to reaching the people who most need our services, including people affected by structural inequality, bias, and discrimination.

This means we will:

Monitor service uptake, referral patterns, and outcomes

We will identify gaps in our services or where our services are not reaching the people who need them, by monitoring and tracking advocacy uptake so that we have data about who accesses our services and in which settings. We will use our monitoring data to better understand and take action to dismantle the barriers that some people face which mean they do not have access to advocacy services to which they are entitled. We will hold ourselves to account for improving our services and our ability to reach people and commit to making relevant data publicly available where possible and appropriate.

Review our service models to meet the needs of people who face discrimination

We will develop models of culturally competent advocacy that recognise the experiences of people who face discrimination and bias in their daily lives and the barriers that prevent them accessing advocacy support when they might want or need it. We will develop processes that encourage the recruitment of people from diverse backgrounds as leaders, advocates, and volunteers, including by tackling bias or structural discrimination in the recruitment process. We will recognise where training can provide a means to address discriminatory practices and behaviours. We will better embed our advocacy services within communities that face discrimination.

Engage with national work to address structural inequality

We will seek to embed learning and recommendations from experts and expert groups into our organisations, practices, and work-place cultures.

Partner and learn from experts and specialist organisations

We will recognise where we need to improve our insight and understanding of anti-discrimination work. We will take the lead from those who have expertise in tackling structural biases and discrimination and learn from people's lived experience of discrimination. We will engage in open and inclusive conversations to explore how we can do better and take meaningful steps to dismantle discrimination. However, we also recognise the need to invest our own time, energy, and resources into building knowledge and taking action. Relying solely on those who experience discrimination to take their time, energy, and resources to inform others, risks perpetuating inequalities and places the burden wrongly at the door of those who experience discrimination. We recognise that unless we are proactively challenging and tackling discrimination in all its forms, we are part of the problem.

5. We will work together to promote systemic change

Advocacy at an individual level is independent and firmly at the side of the person who uses the service. Our effectiveness can be enhanced by collaboration across the advocacy sector, including through sharing learning, insights, tools and developing joint publications, guidance, and resources.

Advocates are well-placed to identify systemic practices, behaviours, and attitudes which disproportionately impact people or threaten their human rights. By harnessing this insight, advocacy providers can inform commissioners and providers where things are not working for people or where poor practice threatens people's safety and well-being. By influencing policy, advocacy organisations can make a difference that delivers long-term change to large groups of people.

This means we will:

Work together

As advocacy organisations, we will share insights, resources, and approaches as we work together to deliver support to people through these challenging times and into the future.

Work not only with advocacy organisations

We will work effectively with people who use our advocacy services, informal carers and family members, community groups, health and social care professionals, commissioners, and providers.

Collaborate in meaningful ways

We will share insights, encourage systemic change to address concerns, promote access to advocacy and an environment that enables referrers to meet their legal duties, agree safe ways of meeting with clients in individual cases and particular settings.

Act on trends and inform national systems

We will ensure improvements are made to how services are delivered and encourage systemic change by identifying themes raised by people who use advocacy services and by advocates and we will share these insights with local and national government, NHS, and other health and care bodies. We will develop, and support the development of, guidance and initiatives which promote the voices and rights of people who use health and social care services.

Endorsement

These operating principles have been developed jointly and are endorsed by the following organisations:

advocacy
focus



Connected
Voice Advocacy



Warrington
Speak Up



Rethink
Advocacy



ASNEW
Advocacy Services North East Wales



The
Advonet
Group
Providing Independent Advocacy



the
advocacy
people

the care forum



VoiceAbility

If you want to add your endorsement to these principles, please email advocacy@ndti.org.uk