

Written evidence from POhWER (COV0152)

Background & Context

- **POhWER is a national human rights advocacy Charity** who supported 55k people with direct services, 253k with information and advice and 442k with digital information support during 2019-2020. During lockdown, we supported c.7k service users a month.
- **13.9 millionⁱ or 22% of the population people live with disability** in the UK – of which 1.5ⁱⁱ million live with a learning disability and 850,000ⁱⁱⁱ diagnosed with dementia. Disability is more likely to affect older adults over State Pension age who account for 45%ⁱ of the disabled people in the UK.
- Advocacy services may in theory be accessed by anyone when they are vulnerable and need a helping hand to make their voice heard, not just those living with mental health and disability.
- **Many people in the UK do not have access to advocacy** and therefore further marginalised by barriers to access.
- **COVID-19 poses a significant human rights threat to vulnerable people**, health and care worker capacity and prudence within decision-making.
- **A disproportionate number of COVID-19 deaths have occurred in a Care Home setting.** Official government figures estimate Care Home deaths to account for approximately 1/3 of total^{iv}, whereas conflicting research suggests these estimates to be closer to 22,000^v of total.
- **POhWER has observed a significant rise of the applications of blanket Do Not Attempt to Resuscitate (DNARs)**, threatening the human rights of vulnerable people. We regularly report and escalate these cases to our multi agency safeguarding bodies through our work.
- **It is not clear how regulatory and oversight bodies are working together** to identify and report cases, address these concerns or investigate breaches which sit at the cross-section of social care and human rights.

Groups disproportionately affected by the COVID-19 pandemic

The UK's COVID-19 response has been largely focused on efforts to reduce the spread of the virus, however paid little attention to how the lives of people living with mental health, impairment and disability have been impacted.

People living with mental health, impairment or disability have been disproportionately disadvantaged due to COVID-19 because of barriers not fully considered or resolved in the UK's COVID-19 response:

- Barriers to public information due to poor public health information accessibility.
- Difficulty with social distancing because of support needs requiring them to be within close proximity of others, physical necessity or because they are institutionalised.

- Lack of access to peers with shared 'lived experience' who can support during times of distress.
- Poor future planning to address pent-up demand for mental health and care services post-lockdown.
- Lack of understanding by local and central government on how to address gaps in information and services to ensure mainstreaming of requirements.
- Serious disruptions to the services they rely on.
- Additional factors placing them in position of further inter-sectional discrimination including race, ethnicity, religion, sexual orientation, gender identity, digital exclusion, low income, education, literacy and other forms of socio-economic disadvantage.

We have observed laws and standards on safeguarding and human rights protections slipping. One example of this is how DNARs have been set up:

- The use of blanket DNARS is illegal and a breach of human rights - no crisis or pandemic should threaten these protections.
- A Do Not Attempt to Resuscitate (DNAR) decision is made in anticipation of cardiac arrest to ensure someone expected to experience this does not suffer trauma or indignity. A DNAR is not an instruction to stop all treatment or access to care. A DNAR should never be set-up on the basis of someone's protected characteristic.

There have also been some courageous actions by local authority workers, healthcare practitioners and care workers who have reported these cases to POhWER, police, ambulance, local authority, local NHS CCGs and Health Boards, Care Quality Commission under threat of bringing their organisations into reputational disrepute. We need greater protections for these workers to be able to escalate and whistleblow accordingly.

The Mental Capacity Act and Care Acts have insufficient provisions for crisis situations such as the Coronavirus pandemic. Easements on areas related to individual's rights have further marginalised vulnerable and socially excluded people.

The advocacy cases we at POhWER have observed and managed over the last few months are in breach of Equality Act protections not least the right to life (Article 2 ECHR), the right to liberty (Article 5 ECHR).

COVID-19 impacts & recent POhWER advocacy cases

We have observed some significant breaches of human rights as part of our work which appear to be correlated to COVID-19 as organisations are undermining law or safeguarding measures impacting people with protected characteristics.

We noted a disproportionate skewing of COVID-related transmission and deaths in the ONS data which impacted BAME communities and those living with autism and learning disability. The socio-economic impacts of job losses and furlough schemes will have been felt by lower income households and the elderly.

Some recent cases POhWER advocates have been managing have highlighted a few areas where we believe human rights violations have occurred in social care:

- **Policy-based blanket DNARs/DNACPRs being mandated** by individual social care institutions for people living with autism, dementia or learning disability. No consultation with that individual, their families or including an advocate.
- **Healthcare treatment for people with mental health or other disabilities being de-prioritised** by social care institutions or NHS bodies as lower priority than those patients without protected characteristics during COVID-19.
- **Bypassing of advance care plans and/or ReSPECT process** entirely.
- **Stopping of treatment for people living with dementia or learning disability** without consultation or safeguarding.
- Cases where GP practices and paramedics informally contacted care homes asking for blanket DNARs to be put in place with protected characteristics.
- **A lack of provisions or reasonable adjustments for vulnerable people** being admitted unaccompanied with learning disabilities or dementia explaining COVID-19 treatment and admissions process to hospitals.
- **A lack of consultation with families, clinicians or IMCAs** in preparing advance care plans or supporting individuals with DNARs.
- **Vulnerable people are not receiving the support they need to assess their care and support needs** due to Care Act Easements under Coronavirus Act 2020. Care Act duties are not being fulfilled by local authorities across the UK and legal challenges being raised.

POhWER has observed a slackening and deterioration of social care and human rights safeguards across the wider system.

POhWER has been impacted during lockdown by restrictions on what units and locations we can provide our services in, such as closures of hospital wards, secure units and care homes. We have been able to move swiftly to a remote model delivering support to the most vulnerable.

For many of the people we support, an advocate is someone they trust, someone who they know will stand up for their rights and fight their corner. Not being able to see their advocate is a challenge for some people, but we have worked really hard to make sure we can stay in touch with people, making sure they can continue to speak with and have contact with their advocate.

It is the impact on the people who don't have a voice that really concerns us. Advocacy services are playing their part in raising awareness of these issues and doing their utmost to ensure people's rights are protected during challenging times.

Immediate Priorities, we are asking for:

In 4-8 weeks' time:

- As advocates return to places of work at institutions, **ensure personal protective equipment is fully funded and provided** by the government to ensure Charities are not out of pocket with unexpected expense.
- **Emergency funding for Charities working in the role of social advocacy** to address the immediate societal crisis, help ease pent-up demand and ensure safeguards are monitored and human rights upheld.
- **Stricter penalties and fines** for individuals and organisations found to be breaching human rights in social care.
- **Education funding** to enable wider scale training to enable GPs, Primary Care Practitioners, Hospitals and Care Homes to receive information on best practice.
- **Review and re-assess risk profile and impact of the Care Act and Mental Capacity Easements** under Coronavirus Act 2020.

In 3-6 months' time

- **Formation of a Task Force** which brings together Health & Social Care, Private Sector and Civil Society organisations to review COVID-19 human rights impacts and to identify reform measures for the future.
- **Introduction of a human rights in social care whistleblowing process** to multi-agency government agencies and oversight bodies.
- **Independent enquiry into safeguarding and human rights breaches** during COVID-19 pandemic to understand why failures occurred and to identify measures to strengthen policies, procedures and controls.

08/07/2020

Helen Moulinos, Chief Executive POhWER

About POhWER

POhWER was established in 1996 by our founders all of whom had disabilities and were fighting social injustice and challenges in their lives. POhWER supports marginalised, vulnerable and social excluded people through its' charitable work across the UK.

<https://www.pohwer.net/>

ⁱ Source: Scope, "Family and Resources Survey 2016/2017".

ⁱⁱ Source: Mencap Research, May 2020.

ⁱⁱⁱ Alzheimer's Society, Key facts and statistics on dementia and other dementia related topics. May 2020.

^{iv} Office for National Statistics (ONS), April 2020.

^v London School of Economics, Care & Policy Evaluation Centre Research Unit, May 2020.