People with learning disabilities call for urgent changes to resuscitation decisions about their own lives, as Ombudsman releases new report

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Today the British Institute of Human Rights (BIHR) releases a new report produced with people with learning disabilities, their loved ones and supporters, detailing the need for big changes to the way do not attempt cardiopulmonary resuscitation (DNACPR) decisions are made in healthcare. The report, published alongside England's Health Ombudsman's review, spotlights how these decisions are being made without people's involvement, sometimes fuelled by discriminatory attitudes about disabled people rather than medical factors. People with learning disabilities call for significant and urgent changes to DNACPR decision making, so that they and their loved ones can make informed decisions, where medical professionals meet their duties to uphold people's human rights.

A Do Not Attempt Cardiopulmonary Resuscitation notice (commonly abbreviated to DNACPR) is a notice placed on a patient's file saying that if their heart or breathing stops, doctors will not try to restart it. As Rebecca, shares in BIHR's report:

"This is a sensitive and emotional subject that needs to be discussed openly. These honest conversations are important to us, we should always be involved in any conversation about our lives and should have our voices heard. We all have a right to make decisions about ourselves.'

The report was commissioned by England's Health Ombudsman and sits alongside its review of end-of-life care, which was also released today and calls for improved DNACPR conversations for everyone. The Ombudsman's report notes that whilst DNACPR discussions are positive when done correctly, this is not always happening, and in some cases, doctors breached people's human rights by not even informing them or their family that a DNCAPR notice was made.

Shaunie a member of user-led advocacy organisation My Life My Choice, who contributed to BIHR's report, shares his experiences supporting peers, saying that **"this always gets brought up as being wrong on so many different levels because doctors don't consult with parents. Parents are then on the back foot and have to fight. The process is so bad, it really is."**

Similar experiences are echoed by family members and support workers, such as Certitude Care Manager Anthony. Anthony discusses the challenges of making complaints as a service provider and highlights that DNACPR decisions can be left off the NHS's most widely used database system.

BIHR's research report, published today, sets out clear recommendations from people with learning disabilities and those who support them, including that there is an urgent need for healthcare professionals, services and systems to provide accessible information on the decision-making process and to make it clear that people can challenge DNACPRs. Alongside the written report, BIHR has produced a series of videos explaining the research and featuring commentary from participants, together with Easy Read translations, all available on BIHR's website and YouTube channel.

BIHR's CEO, Sanchita Hosali, says,

"Poor decision-making around the use of DNACPR risks breaching people's legally protected human rights.

"Whilst the Covid pandemic threw a spotlight onto the discriminatory and disproportionate use of DNACRP decisions for many groups, this is a long-standing human rights risk faced by many people with learning disabilities.

"Today's report is directly driven by the experiences of people with learning disabilities, their loved ones and supporters. People have shared powerful stories of their experiences, and their fears should they ever need resuscitation. We should all stop, listen and take action on the recommendations, to ensure people with learning disabilities have equal respect for their human rights in healthcare, particularly when critical decisions like DNACRP are being made. As Lara, who took part in our research says "I just don't want this to be something that gets shoved on a

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Notes to editors:

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- The British Institute of Human Rights (BIHR) is a registered charity working across the UK to achieve social change through human rights by working directly with people, communities and public bodies to change practice and amplify this evidence of human rights in action to influence policy.

- In 2020, the British Institute of Human Rights (BIHR) carried out independent research into the use of DNACPRs during the Covid-19 pandemic and found potential discrimination in the way they were being applied – with nearly 10% of people with care and support needs saying they had experienced DNACPRs without being involved in the decision or had been pressured to agree to one.

- The Parliamentary and Health Service Ombudsman (PHSO) commissioned the British Institute of Human Rights (BIHR) to carry out new research into how DNACPRs are viewed by people with learning disabilities and produce a set of recommendation. BIHR's findings have been used to inform the PHSO's new report, also released today, "End of life care: improving 'do not attempt CPR' conversations for everyone". The report also draws on research into the experiences of older people undertaken by the organisation Compassion in Dying. The PHSO report calls for urgent improvements to the process and communication surrounding DNACPR decisions. To contact the PHSO press team: press@ombudsman.org.uk, 0300 061 4996. To contact the Compassion in Dying Press team: Molly Pike, Media and Campaigns Officer, Molly.Pike@compassionindying.org.uk, 07929 731181.

- Details of the individuals, groups, and organisations involved in BIHR's research is available in our report; please contact BIHR for any requests ahead of publication.

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