Commissioned by the Parliamentary Health Service Ombudsman

DNACPR NOTICES AND PROCESS

Research with people with learning disabilities and their supporters

The British Institute of Human Rights

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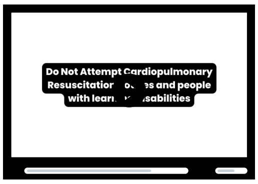
Separate documentation: notes from interviews and groups discussions provided separately to PHSO along with a supplementary, but standalone accessible version of this report in Easy Read.

EXECUTIVE SUMMARY

"I think it's lovely that we're being asked to have a bit of a value within the process which I wouldn't have thought was going to happen for a while yet and it's nice that it's started."

- Sarah, Warrington Speak Up



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SCAN ME

The Parliamentary and Health Service Ombudsman (PHSO), given the number of complaints received and its subsequent research, has recognises that it is important to look further at the experience of people with learning disabilities on the processes and use of do not attempt cardiopulmonary resuscitation (DNACPR). This report presents the research PHSO commissioned the British Institute of Human Rights (BIHR) to carry out into elements of the current system that are problematic for people with learning disabilities and put together a set of recommendations to improve it.

This research project was commissioned specifically to ensure that people with learning disabilities have a key space in the PHSO's forthcoming reporting to clearly explain their lived experience of DNACPRs and set out the recommendations they want to see to improve the process and practice of issuing such notices. Given the PHSO's jurisdiction, this project was focused specifically on England, and people's interactions with healthcare in relation to NHS England (NHSE).

It was key for the PHSO that this research prioritised quality over quantity, with more focused work with a smaller number of people, rather than volume or general research.

This research has been conducted with people with learning disabilities directly, with additional input from people who provide support as family members, carers, or other supporters.

All research was person centred, and BIHR have prioritised working with organisations that are led by and for people with learning disabilities. People who have participated in this research, have both the expectation, and assurance, that we will accurately record and present their voices and views in this report.

After extensive facilitation of online discussion workshops, individual interviews and collaboratively produced follow up materials, we concluded that:

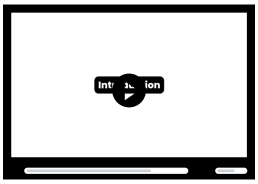
- There is a deeply held and shared belief among people with learning disabilities and their supporters that the current processes around DNACPRs are discriminatory and difficult to understand.
- People with learning disabilities that we worked with to felt that sometimes their lives were worth less than people without learning disabilities, and this is seen in the reasons used for DNACPR notices. They were clear that 'learning disability' should never be put as a reason for a DNACPR notice.
- There is a significant need for far more accessible information on DNACRPS which should be available as standard, without relying on people with learning disabilities and their supporters having to specially request it (particularly at a point where significant life decisions are being made).

- The wishes, thoughts, and feelings each person with learning disabilities who is part of a DNACPR decision must be central to that decision-making. This includes people who have been assessed as lacking mental capacity to make that decision. In such situations, there is a need for greater family/supporter involvement to ensure people's wishes, thoughts and feelings are given due consideration.

Information note

DNACPR stands for 'Do not attempt cardiopulmonary resuscitation (CPR)'. It means that if a person has a cardiac arrest or dies suddenly, then a decision has been made directing healthcare professionals on treatment, including not performing CPR on the person. There are many reasons why a person might have a recorded DNACPR decision. Some people choose to have one because they do not want to be resuscitated in an emergency. Other times healthcare staff may decide that a DNACPR decision needs to be made, for example, because someone is so unwell from an underlying illness, that CPR will not prevent their death. DNACPR only specifies whether a person will receive CPR or not, it is not a removal of any and all healthcare. People who have a DNACPR in place should still receive other appropriate healthcare treatment, as needed.

INTRODUCTION



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SCAN ME

The Parliamentary and Health Service Ombudsman (PHSO) commissioned the British Institute of Human Rights (BIHR) to research how the DNACPR process is viewed by people with learning disabilities and produce a set of recommendations setting out what changes they would like to see.

This research has focused on the direct involvement of people with learning disabilities, who have lived experience of DNACPRs, including such notices/orders applied to them and self-advocacy experience on the use of DNACPRs. During the course of the research period, the brief was expanded to include involvement of people with direct experience of the DNACPR process through supporting a person with learning disabilities who has a DNACPR notice (“supporters”). This was important to capture the experiences of people with complex learning disabilities, who were not able to participate in this research intervention.

The questions PHSO seek to answer are as follows:

What works at the moment in the DNACPR process for people who use NHS-funded services, their families and carers using the NHS?

What does not work at the moment in the DNACPR process for people who use NHS-funded services, their families and carers using the NHS?

How would people who use NHS-funded services, their families, and carers like the process to work if they were designing it from the beginning?

Do people believe they've been unfairly treated (on account of their age or disability) in their experience of the process?

If you have experienced an issue with the use of DNACPR, have you formally complained and if not, why not? What are the barriers to making complaints about this issue?

As agreed with PHSO, BIHR sought to answer these questions through a series of sub questions which have been worked through with focus groups of people with learning disabilities, and 121 sessions with supporters. Please find the questions we have used at Appendix I and a full list of participants at Appendix II.

What we have learnt through this process and our subsequent recommendations are presented here in a standard format written report, alongside a series of videos created by people with learning disabilities and in an Easy Read resource to ensure that our findings are accessible. The three sets of materials are designed to complement each other and be taken as a single output, remaining as accessible as possible.

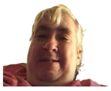
RECOMMENDATIONS FOR CHANGING THE DNACPR SYSTEM

In this section we set out the recommendations from across the research project. We have provided these as:

A. Shared recommendations from all participants
B. Specific recommendations from people with learning disabilities
C. Specific recommendations from supporters

These sit alongside the specific research outputs developed by and with people with learning disabilities involved in this research:

- Recommendation videos produced with BIHR support,



Click here to hear from Mary

Click here to hear from Andy & Sal

- Independently produced video commentary

Click here to hear from Becky & Sarah

- Independently produced blog commentary (provided separately to PHSO, pending publication)
- Easy Read Recommendations reflecting the shared recommendations from people with learning disabilities (provided separately to PHSO, pending publication)

A. Shared recommendations from all participants

Reviewing the research findings access all the participants, the following recommendations have been identified:

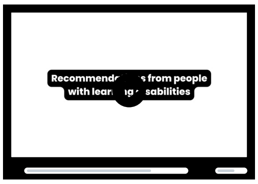
1. There is an urgent need for healthcare professionals, services, and systems, to provide people with learning disabilities, and their supporters, with accessible information (in variety of formats) on the decision-making process, and to do this automatically, rather than requiring people to request it.

2. Whilst the law requires this, the everyday practice must be that people with learning disabilities are at the centre of decision-making on DNACPRs. If they have been assessed as lacking mental capacity to make this decision for themselves, their wishes and feelings must still be central, and their loved ones or supporters should also be involved in decision-making.

3. A person's learning disabilities should never be the reason for a DNACPR being issued, this is discriminatory.

4. Healthcare professionals, services, and systems where DNACPR decisions are made must make it clear that people with learning disabilities and their supporters, can question, challenge, and complain about DNACPRs. The processes to enable this must be supportive and accessible, and external accountability bodies hold decision-makers accountable for unlawful DNACPR practices.

B. Specific recommendations from people with learning disabilities



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SCAN ME

These recommendations are available in Easy Read in the accompanying accessible resource. Although the Easy Read text may differ to the text here (this is to ensure that the recommendations are available in an accessible format) the conclusions are the same.

The recommendations are underpinned by a clear and deeply held experience and belief that parts of the current DNACPR system is unfair to people with learning disabilities.

1. ENHANCED ACCESSABILITY OF INFORMATION: Make all information about DNACPR notices and decisions fully accessible to people with learning disabilities or other access needs. Provide information in plain language, easy-read formats, audio versions, and with visual supports. Alternative forms of information should be offered as standard; people with learning disabilities should not have to ask for information they can understand.

2. FURTHER FAMILY INVOLVEMENT: Always involve individuals' families and loved ones in DNACPR decisions to aid understanding and provide emotional support to the individual. But also respect when a person with learning disabilities does not want other people involved; it should be their choice.

3. LEARNING DISABILITIES SHOULD NEVER BE GIVEN AS A REASON FOR A DNACPR NOTICE: Although participants recognised that people with learning disabilities may have other health conditions that may need to be considered when making decisions about DNACPR, a learning disability on its own should never be a reason not to resuscitate someone.

4. MORE RESPECT FOR INDIVIDUAL CHOICES: Prioritise the individual's choice in the DNACPR decision-making process. When making a DNACPR notice, healthcare staff should always start from the assumption that the person has capacity to make the decision for themselves. When a person with learning disabilities has been assessed as lacking capacity to make decisions about DNACPRs their wishes should still be considered, and the involvement of their loved ones is even more important and supported by the law.

5. FURTHER PROMOTION OF ADVOCACY AND PERSON-CENTRED SUPPORT: Establish accessible and supportive processes for individuals who want to express concerns or escalate issues related to DNACPR decisions and care. As with recommendation 1, any alternative format of information should again be offered as standard, and people with learning disabilities should not have to ask for them.

6. IMPLEMENT AN OPT-IN SYSTEM: There was support for having a cross-systems approach to DNACPR notices which made them part of an opt-in system. This would put people with learning disabilities at the heart of decision making, ensuring they could opt-in if they choose to, and reduce the imposition of notices which people felt were unfair. Where a mental capacity assessment has found that a person with learning disabilities does not have capacity to make a decision about the use of a DNACPR notice, then this system would add more weigh to the best interests' assessment and the prioritisation of what that person would want if they could make the decision for themselves.

C. Specific recommendations from supporters

Click the image on the left or scan the QR code on the right to watch this section as a video.

SCAN ME

Recommendations from families, carers and supporters mirror the issues raised by our contributors with learning disabilities and provides additional important support and context for future action on DNACPR processes.

As with the views of people with learning disabilities, the recommendations are underpinned by a clear and deeply held belief, and experience that the system is unfair to people with learning disabilities. A key thread was the urgent need to make sure the DNACPR process is accessible at every point, so people can understand what is happening, the decision that are being made either with or about them, and their rights. This will also help address the strongly held feeling that decisions are being made arbitrarily.

1. ACCESSIBLE INFORMATION AT THE RIGHT TIME: Accessible information must be available about DNACPR notices, and actively communicated to those involved in the process before a DNACPR notice is issued.

2. COMPASSION, CONSULTATION AND CAPACITY: If a DNACPR notice is to be issued, there should be thorough and compassionate consultation with the individual and their support network throughout the process. There should be mental capacity assessments and best interest assessments completed during this process as standard if there are concerns raised about the appropriateness of the DNACPR.

3. COMPLAINTS NEED TO OPEN AND EFFECTIVE: The complaints process should be more accessible, open to families and those who work closely with people with profound and multiple learning difficulties. At present key workers and support staff feel they cannot take part in the process to make the voice of people with learning disabilities they support heard in complaints processes. This is particularly important for individuals who do not have a family network around them.

4. COMMUNICATION: Once a DNACPR notice is issued, it must be swiftly clearly communicated across all NHS systems and social care provisions supporting the person, likewise (and even more so) if it is removed. There must also be very clear communication to those who work with an individual about what a DNACPR notice means, should they fall ill suddenly whilst under the care of staff at their place of residence.

WHAT WE DID: PEOPLE AND PROCESS

The project has been led by Phoebe Craig, one of BIHR's Human Rights Officers, who has a professional background in Special Education Needs and Disability and is certified in Easy Read production.

A. The people we worked with

> "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.
>
> - **Rebecca, Warrington Speak Up**

The PHSO's brief was to focus on the voice of people with learning disabilities who have experienced DNACPRs and widened to include both people with learning disabilities with lived experience of speaking up on the use of DNACPRs and to close supporters of people with complex learning disabilities where they have had to challenge the use of such notices. BIHR therefore prioritised working with self-led and/or self-advocacy groups, in addition to member-led groups, and organisations supporting people with learning disabilities who have specific experience on the use of DNACPRs.

Below we set out the people and organisations we worked with to produce this research report; more information is available in Appendix II. Additionally, we discussed this work with a number of other people and organisations (also set out in Appendix II).

There was strong support for this research from all the people, groups, and organisations we contacted, demonstrating how important it is for policy work to include lived experience as part of this approach.

PEOPLE WITH LEARNING DISABILITIES WHO PARTICIPATED IN THIS RESEARCH:

- **Shaunie** from My Life My Choice, Shaunie is an avid campaigner for the rights of people with learning disabilities and the community, he has particular focus on DNACPR notices.
- **Sarah and Rebecca** from Warrington Speak Up, who have taken part in campaigns to raise awareness of the rights of people with learning disabilities.
- **Suzie, Lindsey, Anthony, Linda, Fiona, Syed, Neil, Gavin, Phil, Karen, Victoria, Stephen, Shirley, and Dawn** from the Stop People Dying Young Group, coordinated by Inclusion North.
- **Lara, Kate, Sal, Andy, and Mary** from The British Institute of Learning Disabilities.
- Learning Disability People's Network – a group of people with learning disabilities being supported by Turning Point, including **Lou** (who is quoted in this report).

SUPPORTERS OF PEOPLE WITH LEARNING DISABILITIES WHO PARTICIPATED IN THIS RESEARCH:

- **Marie Anne**, family member, challenged a DNACPR placed on her brother, who has learning disabilities.
- **Darren**, a Care Manager at Turning Point, who has challenged the use of DNACPRs on people with learning disabilities supported by his service.
- **Anthony**, a Care Manager at Certitude, who has challenged the use of DNACPRs on people with learning disabilities supported by his service.

B. Process we used to carry out the research

ACCESSIBILITY AND FLEXIBILITY

From the start BIHR's process has been driven by accessibility. All information, including initial and introductory contacts was first made in Easy Read. The key outputs, which sit alongside this report (video series and Easy Read Research Resources) are also in specific formats chosen by the research participants.

Flexibility has been key to this process; recognising that it is important to ensure support and good lead in time when working with people with learning disabilities (Appendix III sets out our Reflections for Future Work).

BIHR worked with people, groups, and networks that we have strong links with through previous work with people with learning disabilities in general, and in particular on the issue of DNACRPs. (Examples can be found here).

WORKSHOPS AND INTERVIEWS

BIHR sought to answer the questions the PHSO wanted us to investigate through a series of sub questions (see Appendix I). We used both Easy Read workshops and 121 interviews to capture people's experiences, their recommendations, and to determine the outputs they want from this process. The workshops and 121 interviews have been structured around the following themes:

- **Experiences and views of DNACPR in general**
- **Exploring potential discrimination in the use of DNACPRs**
- **Effectiveness of current means to complain about DNACPRs**
- **The changes people want to see happen**
- **How people want their views shared**

The workshops with people with learning disabilities provided a space to come together, share experience and identify shared themes and actions. BIHR analysed the findings and developed recommendations directly alongside the people participating to ensure accuracy.

Additionally, a key self-advocacy group which has undertaken significant work on the use of DNACPRs – Stop People Dying Young Group – held a special meeting of members to review the research questions and share their views as part of this research.

People with learning disabilities identified key actions they wanted to take to feed into the research outputs, including filming video testimonials and writing a blog. Following the final workshop three videos have been made by participants that directly state recommendations for PHSO that they have formulated in response to workshop discussions. These recommendations have been summarised and incorporated into the full recommendations, available in Easy Read text alongside the videos and this report.

Interviews were also held with 3 supporters (1 family member and 2 care managers), to provide additional information on the experiences of people with learning disabilities who have been unable to advocate for themselves in situations where DNACPR notices have been used.

WHAT PEOPLE TOLD US

This section provides further information on the findings from our research, which underpin the recommendations. It is structured:

A. Findings from people with learning disabilities

i) Overall findings across the research
  - Common themes
  - Specific issues
  - Conclusion

ii) Detailed Findings: Workshops

iii) Detailed Findings: Stop People Dying Too Young Group

B. Findings from supporters of people with learning disabilities

i) Overall findings across the research
  - Common themes
  - Specific issues
  - Conclusion

A. Findings from people with learning disabilities

This section covers the findings from work directly with people with learning disabilities, both through workshops conducted by BIHR, their self-created videos, and the special meeting of the Stop People Dying Young Group.

i) OVERALL FINDINGS

The perception of the DNACPR system across all research is one of concern for the rights, dignity, and autonomy of individuals, with a strong emphasis on the need for accessibility, consultation, and a more respectful and inclusive approach to healthcare decisions.

There is a shared sentiment that systemic changes are needed to ensure that DNACPR decisions are made in a rights-respecting way, supporting people’s individuals' wishes and choices.

Common themes

1. LACK OF CONSULTATION: A recurring theme is the lack of proper consultation when DNACPR decisions are made. Individuals and their supporters are often not included in the decision-making process, regardless of their capacity to understand the implications. This lack of consultation is seen as a major issue which impacts individuals' rights.

2. ACCESSIBILITY: The need for improved accessibility of information about DNACPR notices is emphasized repeatedly. This includes the importance of having information available in easy-to-read formats, audio versions for those who have difficulty reading, and other forms. Especially important was the point that accessible versions are proactively offered by healthcare staff, rather than requiring individuals to request them. Accessible digital formats and clear, empathetic communication were also highlighted.

3. RESPECT FOR INDIVIDUAL AUTONOMY: Respecting individual autonomy and choice in DNACPR decisions is a consistent theme. Many participants stress that decisions should be based on the individual's wishes rather than assumptions made based on disabilities or health conditions. A repeated concern was that individuals who have been assessed as lacking mental capacity to make a decision about DNACPR should still have their wishes considered, even if they have been assessed as not having capacity to make the decision for themselves. In this situation the involvement of family/supporters is even more important.

4. INVOLVEMENT OF FAMILY/SUPPORTERS: The involvement of family members, loved ones or supporters in DNACPR discussions is considered essential to aid understanding and ensure that the individual feels supported in making a decision. This is seen as a critical aspect of fair decision-making. This should happen where the person with learning disabilities chooses it. Where they choose not to include other people, that should be respected by staff in the DNACPR decision making process. When a person with learning disabilities has been assessed as lacking capacity to make a decision, the involvement of their family becomes even more important, and is supported by the law.

5. ADVOCACY AND SUPPORT: Several participants highlight the challenges individuals can face when advocating for themselves in the DNACPR process. This includes difficulties in making complaints or expressing concerns about health-related decisions and care. Advocacy support, alongside a supportive complaint processes and accessible information are seen as important to address these challenges.

6. SOCIETAL ATTITUDES: Several participants spoke about the need to change societal attitudes, particularly the misconception that disabled lives are of lesser value. This is about reshaping the perceptions of disabled people and challenging such stereotypes.

Specific issues

1. NOT RESPECTING AUTONMY AND LACK OF TRANSPARENT DECISION-MAKING: Participants highlight instances where DNACPR orders have been put in place without the knowledge of the patient or their family/supporters. This is seen as a significant issue, as it involves critical medical decisions being made without the involvement of the individuals affected. There are concerns that this is not lawful.

2. ACCESSIBILITY OF INFORMATION: The need for information about DNACPR to be provided in accessible formats is a specific issue. Some individuals may struggle to access and understand complex medical terms, necessitating the provision of information in plain language, Easy Read formats, audio versions, and visual supports. There is also an emphasis on avoiding medical jargon to aid understanding.

3. TIME FOR INFORMED DECISIONS: People with learning disabilities need sufficient time to process information and make informed decisions about DNACPR. Rushing the decision-making process is viewed as problematic and may prevent individuals from being able to make an informed decision about crucially important healthcare.

4. ONE-SIZE-FITS-ALL APPROACH: The participants express concerns about the inadequacy of a one-size-fits-all approach in DNACPR decisions. Processes must recognise and account for individuals have varying needs and preferences; the process should be tailored to accommodate these differences.

> "I think it should be about listening to everybody and especially listening to the actual person rather than making that assumption."
>
> \- Kate, BILD

Conclusion

In summary, the participants collectively highlighted significant concerns about the DNACPR process, including the lack of consultation, accessibility, and respect for individual autonomy. **Addressing these issues requires a clearer and more inclusive approach that always respects individuals' rights, and in particular their right to autonomy.**

ii) DETAILED FINDINGS

We ran 2 workshops with 6 people with learning disabilities, 1 with Shaun from My Life My Choice and Sarah and Rebecca from Warrington Speak Up. And 1 with Andy, Kate, Lara, and Sal from the British Institute of Learning Disabilities. You can find out more about the people who took part in Section 3 of this report. Details about the organisations they work with and are supported by, are included Appendix II. (The more detailed summaries of these workshops provide a better insight and have been provided to PHSO in a separate document).

> "I think it's unfair based on learning disabilities alone. Going through the work I do regularly and the campaigning group as well, 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."
>
> **- Shaunie, My Life My Choice**

Key takeaways

- Ensuring fully accessible DNACPR information for people with learning disabilities or particular access needs.
- Valuing individual patient's wishes over assumptions based on disabilities or health conditions.
- Involving families and loved ones and supporters in DNACPR decisions, where the person wants this.
- Preference for an opt-in system for DNACPR notices, which means people are part of a proactive system based on choice.

On accessibility

- Offering DNACPR information in easy-to-read formats.
- Providing audio versions for people with reading difficulties.
- Proactively offering accessible materials without requiring requests.
- Consistent, accessible information in doctor's surgeries.

On choice

- Emphasizing individual choice, wishes and feelings in DNACPR decisions.
- Not imposing DNACPR notices when a person with learning disabilities with mental capacity to make this decision has rejected a DNACPR.
- Being open and transparent about the use of DNACPR notices with people with learning disabilities and, where they want it, their loved ones, and supporters.
- Still considering the wishes of people with learning disabilities when they have been assessed as lacking mental capacity to make DNACPR decisions for themselves and recognising the important role of supporters in ascertaining people's wishes.
- Rejecting the sole use of disability as a DNACPR determinant.

On accountability

- Highlighting challenges in providing feedback or raising issues, emphasizing the need for accessible and supportive complaint processes.
- The consistent experience of unaddressed complaints and unmet accessibility needs, which needs to change.

> “I just don’t want this to be something that gets shoved on a shelf and forgotten about.”
>
> **- Lara, BILD**

A key overall message was stressing the paramount importance of respecting and listening to all individual’s wishes and choices in DNACPR decisions, irrespective of disabilities or health conditions. This needs to be done through equitable participation for people with disabilities in DNACPR decision-making. All people with learning disabilities we worked with were clear there is an urgent need for real and meaningful change.

iii) DETAILED FINDINGS: STOP PEOPLE DYING TOO YOUNG GROUP

Members of the Stop People Dying Too Young group at Inclusion North held a special discussion based on three of the accessible questions BIHR put together for this DNACPR research (see Appendix I).

The questions they focused on were:

- **What would you keep the same about the DNACPR system?**
- **What would you change about the DNACPR system?**
- **What is the most important thing to change about the DNACPR system?**

After analysing the discussion held by the group, BIHR has produced the following summary. We have used this summary to inform the collated recommendations from people with learning disabilities at Section 2 and at Section 2 (b) of this report. It has also informed the collated Easy Read recommendations found in the accompanying accessible resource.

Aspects of the DNACPR process that the group think should be kept the same, but built upon or improved:

1. The foundational understanding that disability should never be the sole reason for withholding resuscitation efforts, although more consistent adherence to this principle is necessary.

2. It should remain a priority that healthcare professionals possess a comprehensive awareness of patients' rights under all legislation, but particularly the Human Rights Act as several legal cases on DNACPR decisions have hinged on human rights. (See below, Section 5, BIHR’s Human Rights Analysis)

3. The practice of thoroughly documenting DNACPR discussions and decisions in a patient's medical records to uphold transparency is of vital importance.

4. Continue affording individuals the opportunity to actively engage in decisions around their healthcare. As the Mental Capacity Act provides, the families of those without capacity must continue to be involved in all cases.

5. Individuals should be more consistently informed about their option to establish an Emergency Health Care plan.

Aspects of the DNACPR process that the group think need revision:

1. Wider accessibility: Address the challenge posed by the non-legally binding nature of DNACPR decisions, by this the group meant the incorrect assumption that a DNACPR notice is final and cannot be challenged. This is hard to understand and needs to be explained in a way all those involved can understand.

Simplifying the language and acronym employed in DNACPR discussions will increase accessibility and comprehension for a wider audience - this is very important to people with learning disabilities.

2. Better and clearer recording: build on the electronic system's capacity to flag DNACPR preferences, diminishing the reliance on physical documents such as the yellow envelope, which can be difficult to locate, particularly during times of heightened stress. Physical documents shouldn't be stopped, just making sure that there is both electronic and physical information available that will be accepted by medical professionals.

3. The consideration of incorporating DNACPR discussions within annual health check-ups for those to whom it is relevant.

4. The establishment of standardised procedures and guidance to ensure uniform decision-making and accountability: concerning the equitable valuation of every life and mitigating the potential influence of the decision maker's personal values.

5. The development of an effort to reshape societal attitudes (perceived or otherwise), with a particular emphasis on debunking the misconception that disabled lives possess lesser value than others.

B. Findings from supporters of people with learning disabilities

Through Turning Point, Darren and Marie Anne took part in the research. Darren is a care manager providing residential accommodation and has direct experience supporting a person he supports to challenge consecutive DNACPR notices. Marie Anne successfully challenged a DNACPR notice that was put on her brother, who has learning disabilities, with no prior notice or involvement. It is important to note, that although they are not currently working together, Marie Anne and Darren do know each other and have worked together to support Marie Anne's brother in the past.

Through Certitude, Anthony took part in the research. Anthony is the registered manager of a care provider in London who has experience working directly with people with learning disabilities he supports in the service who have DNACPR notices.

To find out more about Turning Point and Certitude, please see Appendix II.

The shared perception of the current DNACPR process is generally negative. All supporters reflected on individual and personal experiences, and Anthony and Darren were also able to draw on broader experiences as they are professionals in the health and social care field.

Common themes

1. LACK OF CONSULTATION:

- In all three conversations, a prominent issue was the lack of proper consultation when DNACPR notices are placed on individuals.
- Family members and individuals themselves are often not included in the decision-making process, regardless of their capacity to understand the implications.

2. COMMUNICATION ISSUES:

- Communication problems were highlighted as a big issue for everyone we spoke to. This includes instances where sensitive DNACPR discussions are held over the phone, which is seen as inadequate for such an important and sensitive subject, or no discussion is held at all.
- Lack of clear, accessible, and empathetic communication is highlighted as a significant concern.

3. UNFAIRNESS:

- The general unfairness of DNACPR decisions is seen as the most obvious issue throughout. When asked if they thought the process was fair or unfair, there was no hesitation in strongly stating that it was felt to be unfair.
- The unfairness is always attributed to the fact that people are discriminated against because they have learning disabilities. This commonly manifests itself through the assumptions and arbitrary processes of those making decisions about DNACPR which exclude people from decisions about their own care and treatment, and the lack of proactive action on reasonable adjustments such as accessible information to support people involved in decisions about their lives.

4. COMPLAINTS AND ADVOCACY:

- Efforts have been made to address DNACPR-related issues through complaints and advocacy in all three cases. Some with more success than others.
- The complexity and challenges associated with the complaints process are highlighted. However, advocacy efforts (both in making complaints and external to the complaints process) have been successful in some cases.

5. NEED FOR TRANSPARENCY AND INFORMATION:

- There is a consistent call for more transparent and accessible information about DNACPRs.
- Stakeholders, including individuals, families, and care providers, express the need for clear guidelines and information regarding DNACPR decisions and processes.

6. INVOLVEMENT OF A WIDER CIRCLE:

- Involving a wider circle of people around individuals is emphasised in all three cases.
- This includes family members, key workers, care providers, and advocates. The importance of mental capacity assessments and best interest meetings is stressed as missing from the process entirely, or not being done before a DNACPR decision is made.

Specific issues

Each person introduced a specific issue:

Marie Anne emphasised the involvement of a key worker (Viv), an MP, and the commissioning body in overturning DNACPR decisions.

Anthony discussed the challenges in making complaints as a service provider and the role of GPs in decision-making. He also noted that it is unacceptable that such important legal decisions can be left off of System One (the most widely used database system in the NHS).

Darren highlighted issues of contradictory information, secondary DNACPRs being put in place without consultation, and the involvement of a family member, Marie Anne, who raised concerns through media channels.

Conclusion

Overall, these common themes and specific details across all three interviews reflect the complex and multifaceted challenges associated with DNACPR decisions in healthcare and care settings. They underscore the need for improved communication, fairness (perceived or otherwise), transparency, and inclusivity in the process to ensure the wishes and best interests of individuals are upheld.

> "Often what gets put on the certificate, the cause of death, is learning disability. Well, for heaven's sake, you don't die from a learning disability, you die of something else."
>
> \- Lou, Turning Point

BIHR’S HUMAN RIGHTS ANALYSIS

A DNACPR decision, whilst a medical decision, must also be made within the law. This includes the Human Rights Act (HRA) which sets out both the legally protected human rights of individuals and the legal duties on public bodies to uphold these rights across all their decision-making. Public bodies include the NHS, and in addition those performing public functions, such as private or charitable providers of healthcare, are also covered as “functional” or “hybrid” public bodies. This means the actions (and inactions) staff, including decision-making making about whether to make a DNACPR notice in respect of an individual person, through to the policies and procedures used, are all subject to the duty to uphold people’s human rights. Additionally, regulators and other public bodies with accountability functions, such as ombudsman, are also covered by the legal duty to uphold people’s human rights across their functions.

Human rights legal duties on public bodies, including healthcare staff

It is clear, therefore, that healthcare staff, who are involved in DNACPR decision-making, as well as the local and national governmental bodies, have a legal duty to uphold people’s human rights across their actions. The legal duty to uphold people’s human rights includes:

the duty to respect, i.e., not breach people’s human rights;

the duty to protect, i.e., to take positive, proactive, reasonable action to prevent breaches of people's human rights both at a systems level, and in individual situations where a person's rights are at risk of serious harm;

the duty to fulfil, i.e., to investigate when things have gone wrong and risked people's human rights and prevent future breaches.

DNACPR decision-making may engage a range of people's legally protected human rights in the HRA, in particular (though not limited to): [1]

RIGHT TO LIFE (ARTICLE 2, HRA)

Everyone has the right to life; disabled people have an equal right to life. This right is absolute, it can never be restricted; this means public officials cannot deliberately take away a person's life. Medical staff can decide to withdraw or withhold treatment where someone is at the end of their life and treatment would cause more harm and/or where a person is not fully conscious and will not recover. Treatment which medical staff may refuse to provide could include not providing resuscitation, which may be in an emergency or critical situation. It may also be following the making of a DNACPR decision. Any DNACPR decision must be medical; decisions made for other reasons, such as discriminatory views on disabled people, will not be lawful as it will breach Article 14 of HRA (see below).

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[1] For example, other human rights in the HRA that may be engaged could include the right to be free from inhuman and degrading treatment (Article 3, an absolute right); the right to freedom of thought, conscience, and religion (Article 9, holding of beliefs is absolute, manifestation of belief can be restricted).

RIGHT TO INVOLVEMENT IN DECISIONS ABOUT CARE AND TREATMENT, PART OF THE RIGHT TO RESPECT FOR PRIVATE LIFE (ARTICLE 8, HRA)

The right to respect for private life includes a range of elements which are clearly engaged by DNACPR decision-making and processes, including:

- protection of people's physical and mental wellbeing;
- the right to make decisions about your own life, including care and treatment, including unwise decisions, ensuring communication needs are met will be key to the ability to make decisions and potential discrimination (see below); [2]
- the right to be involved in decisions about one's life, including where there has been an assessment that one lack's mental capacity to make that decision, ensuring communication needs are met will be key to involvement and potential discrimination (see below);
- the protection of your relationships with those important to people, including family and wider relationships;
- upholding confidentiality, including of private information.

Whilst this right can be restricted by public officials (including DNACPR decision making, systems and processes), they must follow a specific legal test of:

Lawful, i.e., is there a law which allows the restriction; we find there are often assumptions that because something is standard practice that there is a legal justification for it, this should never be assumed, the law underpinning decisions that restrict human rights should be clear.

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[2] If there are queries about whether a person is able to make a decision about a DNACPR, then a Mental Capacity Act (MCA) assessment should be conducted. The use of the MCA still needs to be human rights compliant; section 3 of the Human Rights Act means all other law and policy should be interpreted and applied in a way that makes it compatible with human rights (unless there is no way this is possible). This means even if people lack capacity to make a decision about DNARs, their wishes and feelings must still be an important part of the decision-making process for medics.

Legitimate aim, i.e., this is set out in the text of Article 8, and in DNACPR tends to rest on the protection of the person or the wider community.

Proportionate, i.e., all the potential options have been considered, and the option least restrictive of the person's rights, whilst still achieving the aim, has been chosen by the public official. This is often where we see most change at BIHR. Too often the most restrictive option is taken without exploring alternatives, whereas the HRA directs the least restrictive approach should be taken. This provides an important legal tool for challenge, reassessment and change in decision-making to make them more rights-respecting.

The use of DNACPRs in general, and in relation to people with learning disabilities, raises issues around who has legal authority to make decisions about a person's care and treatment. Both the Mental Capacity Act and the Human Rights Act start from the assumption that people can make decisions about their own care and treatment, and if there are doubts about this then a mental capacity assessment should be undertaken. The Human Rights Act additionally protects against discrimination on the grounds of disability (see below). The courts have said that a "DNACPR decision is one which will potentially deprive the patient of life-saving treatment, there should be a presumption in favour of patient involvement. There need to be convincing reasons not to involve the patient." (see Tracey case, below).

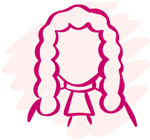
If a person is assessed as lacking capacity to make a DNACPR decision, there is still the legal right to be involved in decision-making, and for any subsequent best interest's decision made by healthcare staff to take that person's wishes and feelings into consideration (Article 8 Human Rights Act, section 4 Mental Capacity Act). In these situations, families and supporters can have an important role to play is supporting people's wishes to be known. Not involving family members in these situations in DNACPR decision-making can have significant legal consequences. For example, failure to actively consult family members can be a failure to comply with section 4(7) of the Mental Capacity Act and mean that staff do not have the defence of reasonable belief the person lacked capacity, in any claim that the person's human rights have been breached under the Human Rights Act (see Winspear case, below).

THE COURTS: the potential difficulty of discussions around DNACPR is not a reason to not involve people in these decisions.

David Tracey challenged the placing of a DNACPR notice on Janet Tracey's medical file; Janet was David's wife. She was diagnosed with terminal lung cancer and later the same month was involved in a serious car accident which required significant hospital treatment. Janey Tracey was considered to have legal capacity to make decisions about her care and treatment. However, medical staff placed a DNACPR notice on her file without her knowledge or that of her family. The Court of Appeal made it clear that decisions involving treatment, including where a patient has a terminal illness, and in DNACPR decisions, the right to respect for private life in Article 8 HRA is engaged. The court said:

> “[A] DNACPR decision is one which will potentially deprive the patient of life-saving treatment, there should be a presumption in favour of patient involvement. There need to be convincing reasons not to involve the patient … doctors should be wary of being too ready to exclude patients from the process on the grounds that their involvement is likely to distress them … The duty to consult … involves a discussion, where practicable, about the patient’s wishes and feelings that is better undertaken at the earliest stages of the clinical relationship so that decisions can be reviewed as circumstances change. That involves an acknowledgement that the duty to consult is integral to the respect for the dignity of the patient.”

Court of Appeal in R (on the application of Tracey) v Cambridge University Hospitals NHS Foundation Trust and Secretary of State for Health (2014)



THE COURTS: the fact someone has been found to lack mental capacity to make a DNACPR decision does not mean they and their family should be excluded from the process – such a failure to involve breaches human rights.

Elaine Winspear challenged the decision of medical staff to impose a DNACPR on her son Carl (28 years old with cerebral palsy) without the knowledge of his family. The court found this was a violation of his Article 8 rights, under the Human Rights Act. The court was clear that section 4(7) of the Mental Capacity Act imposes a duty to consult those identified in the section (e.g., family) unless it is not practicable and appropriate to do so (i.e., active steps must be taken to consult, rather than simply passively taking into account views that the decision-maker may be aware of).

A failure to comply with this MCA duty means that the decision-maker cannot then rely on the defence in section 5 MCA (protects staff from legal liability if they have a reasonable belief the person lacked capacity) in any claim that the person's human rights have been breached under the HRA.

As can be seen throughout this research report, people with learning disabilities, their families, carers, and supporters, repeatedly share concerns about these issues not being addressed. Reviewing the experiences of people involved in the research, it is difficult to see how the 3-stage test for restricting this right to choice, and involvement is being met. Rather, the experiences speak to approaches which do not involve people with learning disabilities, nor their families, carers, or supporters, and which are very difficult to challenge.

RIGHT TO NON-DISCRIMINATION IN THE PROTECTION OF THESE RIGHTS (ARTICLE 14, HRA)

This means none of the above rights should be restricted in a way that is discriminatory. Differential treatment must be objectively and reasonably justified, if not it will be discrimination. This means that differential treatment which supports people to enjoy their rights equally with others, for example through making adjustments in communications for disabled people, is not discriminatory. Rather, this may be an important part of upholding human rights, ensuring that any restrictions are not disproportionate. Differential treatment which treats people worse than others, is likely to be discriminatory. Differential treatment on the basis of disability is a "suspect" ground, that means legally it is more likely to be discrimination.

Elaine Winspear v City Hospitals Sunderland NHS Foundation Trust (2015)

The HRA lists a number of grounds but also ends with “or other status”.[3] This means discrimination includes a range of statuses, such as being homelessness or in receipt of benefits. It also covers discrimination based on a combination of reasons, e.g., being discriminated against because someone is a young woman with a learning disability (sex and disability), or the combination of physical health issues and having a learning disability (health status and disability).

As can be seen throughout this research report, people with learning disabilities, their families, carers, and supporters, repeatedly share concerns about differential treatment, which is worse, on the basis of learning disability, throughout DNACPR decision-making, systems, and processes.

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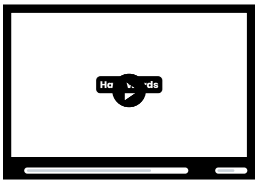
[3] This works differently to the Equality Act, which has 9 protected characteristics: age; disability; gender reassignment; marriage or civil partnership; maternity; race; religion or belief; sex; or sexual orientation.

GLOSSARY



Click the image on the left or scan the QR code on the right to watch this section as a video.

SCAN ME

Best Interests Meeting: If someone does not have the capacity to make a decision, professionals must decide what would be in that particular person’s ‘best interests’. They must consider what that person would have wanted, what their current wishes are and include their family where possible.

BIHR: The British Institute of Human Rights

BILD: The British Institute of Learning Disabilities

Cardiopulmonary Resuscitation: Restarting the heart or someone’s breathing.

DNACPR: Do not attempt cardiopulmonary resuscitation.

Emergency Health Care Plan: A pre-designed plan of action for a health emergency for a person with an additional care need. It has information about that person, what they need, and they would want to happen to them.

Mental Capacity: Often referred to as ‘capacity’, this is whether or not someone is able to understand a decision and what it means for them. Legally, it is always specific to each decision made, rather than a blanket term.

Mental Capacity Assessment: An assessment to deem if someone has the mental capacity to make a specific decision.

PHSO: The Parliamentary and Health Service Ombudsman

Supporter: We use the term supporters to include family members, loved ones, and other people important to person with learning disabilities, including care support workers.

APPENDIX I: BIHR'S FULL RESEARCH QUESTIONS

Below is the list of accessible questions BIHR have written to reflect the original questions PHSO sought to answer. PHSO's questions were:

1. What works at the moment in the DNACPR process for people who use NHS-funded services, their families and carers using the NHS?
2. What does not work at the moment in the DNACPR process for people who use NHS-funded services, their families and carers using the NHS?
3. How would people who use NHS-funded services, their families, and carers like the process to work if they were designing it from the beginning?
4. Do people believe they've been unfairly treated (on account of their age or disability) in their experience of the process?
5. If you have experienced an issue with the use of DNACPR, have you formally complained and if not, why not? What are the barriers to making complaints about this issue?

BIHR's Accessible Questions:

These are available in easy read format in the accompanying accessible resource.

Experiences and views of DNACPR in general

- Is there anything you like about communication of DNACPRs?
- Is there anything you don't like about communication about DNACPRs?

Exploring potential discrimination in the use of DNACPRs

- Is the DNACPR process fair or unfair?
- Why is it fair or unfair?
- Do you think any unfairness is because of having learning disabilities?
- Do you think there was unfairness for other reasons, for example your age, other disabilities, or other reasons?

Effectiveness of current means to complain about DNACPRs

- Have you ever made a complaint about DNACPR?
- Who did you make the complaint to?
- If you complained in more than one way, which was the best?
- If you have not complained about DNACPR, why not?
- Is it difficult to make a complaint?
- Why is it difficult to make a complaint?

The changes people want to see happen

- What would you keep the same about the DNACPR system?
- What would you change about the DNACPR system?
- What is the most important thing to change about the DNACPR system?
- What would you keep the same about the DNACPR system?

How people want their views shared

- We need to make your answers into a report, how would you like to do this?
- We can make videos, text, drawings, or other ideas.

APPENDIX II: FULL DETAILS OF PARTICIPANTS

Individuals involved in this research

People with learning disabilities

- Shaunie from My Life My Choice, Shaunie is an avid campaigner for the rights of people with learning disabilities and the community, he has particular focus on DNACPR notices (see below for more information about the group).

- Sarah and Rebecca from Warrington Speak Up. Both Sarah and Rebecca both take part in campaigns around raising awareness of the rights of people with learning disabilities (see below for more information about the group).

- Suzie, Lindsey, Anthony, Linda, Fiona, Syed, Neil, Gavin, Phil, Karen, Victoria, Stephen, Shirley, and Dawn from the Stop People Dying Young Group, coordinated by Inclusion North (see below for more information about both groups).

- Lara, Kate, Sal, Andy, and Mary from The British Institute of Learning Disabilities (see below for more information about the group).

- Group of people with learning disabilities being supported by Turning Point, including Lou (who is quoted in this report).

Supporters of people with learning disabilities

- Marie Anne, family member, challenged a DNACPR placed on her brother, who has learning disabilities.
- Darren, a Care Manager at Turning Point (see below), who has challenged the use of DNACPRs on people with learning disabilities supported by his service.
- Anthony, a Care Manager at Certitude (see below), who has challenged the use of DNACPRs on people with learning disabilities supported by his service.

Organisations involved in, and supporting, this research

Self-led and learning disability organisations and groups (in alphabetical order):

Inclusion North: A Community Interest Company based in the North of England. Inclusion North exists to make inclusion a reality for all people with a learning disability, autistic people, and their families. Inclusion means everyone living good lives as valued members of society. We work to change society so that everybody can have a good life. We raise awareness of the barriers to inclusion for people with a learning disability, autistic people and their families, and work to remove them. We include people with a learning disability, autistic people, families, carers, organisations that support them, and their communities in our work.

Learning Disability England: LDE is a membership organisation, made up of self-advocates, people with learning disabilities and their self-advocacy organisations; family and friends of people with learning disabilities, and their organisations; and paid supporters, including support provider organisations. Members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others. LDE brings people and organisations together to create a movement for change where people with learning disabilities, families, friends, and paid supporters come together on an equal basis.

My Life My Choice: A self-advocacy organisation. Our vision is a world where people with learning disabilities have choice and control over their own lives and are treated without prejudice. It is important to us that we are independent and user-led – all 15 of our trustees have learning disabilities. Our vision is to make sure that the views of people with learning disabilities are taken seriously by both professionals in the services they use and the wider public. We "Power Up" their lives so they can make a positive contribution to society. We make sure that there is independent support for people with learning disabilities in Oxfordshire to have their say, claim their rights and take control of their own lives.

Stop People Dying Too Young: A group of people with a learning disability, autistic people, and family carers, who work together each month on the Leder Programme They are connected to the regional Leder Governance Board, and to the national work happening on the programme. They look at what we are learning from the Leder programme and speak up about what needs to change to end health inequalities. They develop training resources for professionals and accessible information for people to raise awareness of key issues. They campaign for the lives of disabled people to be valued as much as everyone else's.

They have been working together for the last 5 years and are part of Inclusion North, who have self-described above. The people involved in the discussion were Suzie, Lindsey, Anthony, Linda, Fiona, Syed, Neil, Gavin, Phil, Karen, Victoria, Stephen, Shirley, and Dawn.

The British Institute of Learning Disabilities: BILD champions the human rights of people with disabilities. We work to develop the skills and culture necessary to understand people's needs and improve their quality of life. Our approach applies a rigorous evidence base, broad expertise, and long-standing experience to find and enable both short and long-term solutions that bring about lasting change. BILD includes BILD for the Future , a groups of over 30 people from eight self-advocacy organisations. They work with BILD to make sure it's work is rooted in the real life experiences of people with learning disabilities and autistic people. BILD staff supported BILD for the Future members to participate in this research.

Warrington Speak Up: At Warrington Speak Up we believe in, and actively promote a society that is inclusive, celebrating who people are and valuing the contributions they make. We believe that everyone, regardless of their situation, needs or disability, has a right to be heard and respected, to have choice, control, and freedom over their lives and to be safe from discrimination, harm, or abuse. We treat all people as an individual, working hard to protect your rights and what matters most to you, taking time to understand and see things from your perspective and offer support that is right for you. If an important decision is being made about your life, we will stand by you, give a voice, and make sure your views and wishes are heard. Our aim is to help you make sense of your options, think about the consequences, make an informed decision, and have the confidence to express your views. At Warrington Speak Up we believe that advocacy matters and makes a difference in people's lives.

Organisations directly supporting people with learning disabilities:

Certitude: We provide support across London to people with learning disabilities, autistic people, and people with mental health support needs. We support people to develop new skills, meet new people and live the life they want – so they can bring their own unique brilliance to the world.

Choice Support: We believe good support can only work when it is designed to give people what they really want. This means understanding people's hopes and dreams, as well as their needs. We don't make assumptions about people, and we won't try to fit you into something that isn't right for you. Instead, we try to create support that fits you.

Turning Point: Turning Point is one of the UK's leading health and social care providers. From detox treatment to supported living, its services help people tackle substance use and mental health issues, and those with learning disabilities lead independent lives. For over 50 years, Turning Point has opened up opportunities for people with a learning disability to safely enjoy their healthiest and happiest life. Our highly specialist, independent service improves quality of life for over a thousand people, living as independently as they wish. Building skills, growing confidence, and enabling greater social inclusion through high quality and forward-thinking support.

APPENDIX III: REFLECTIONS FOR FUTURE WORK

BIHR has reflected on the development and delivery of this project, which we believe provides useful reference points to inform any future work of this nature.

1. The importance of qualitative engagement work directly with people affected by the issue

Every single person and organisation BIHR discussed this project with shared how important they consider this work, including those who were not able to contribute. In particular, the approach of PHSO to develop a process for its policy work to include direct work with the people impacted by the issue in hand, which sits alongside the PHSO's work. It was important to be able to share that this research will both inform PHSO's work and will be published as a standalone outputs as well. This approach to experience-informed policy work, by a public body, was unanimously welcomed, and we hope that PHSO will continue to develop its approach both in relation to DNACPR work, and more widely.

2. The importance of this research being based on paid participation

Ensuring that people are paid for their participation in the research is an important corollary to point 1 and undertaking experience-informed research. The PHSO clearly flagged this in the original tender, setting the expectation that paid participation is important. One of the challenges for BIHR, is that the budget for the development and delivery of the research project and the participation budget were a single pot of funding.

This can make it difficult to appropriately cost the work, and certainly BIHR has sacrificed full cost-recovery for this project in favour of ensuring a robust participation budget for the people with learning disabilities who have taken part in the research. We would suggest that future experience-informed research work has a ring-fenced budget specifically for participation costs, with a continency to allow for maximum support for people with learning disabilities.

3. Ensuring a good lead in time for working with people with learning disabilities, to ensure the right support is in place, both generally, and particularly in the current challenging climate

It quickly became clear that the initial 6 week timetable would be challenging to meet, for a number of reasons. BIHR had factored in time constraints, for example, working in accessible Easy Read formats from the start (including the first initial communications), rather than starting with standard versions and translations. However, 6-weeks can be challenging for people who have set routines and finding a space to add in participation in research. This can be an additional challenge for people with learning disabilities who may have fairly tight timetable around the support and services they are accessing and being able to make participation in an additional project work around their schedules. Additionally, whilst this research was unanimously welcomed by all the groups we spoke with, including by and for groups, it was clear that voluntary groups, charities, and associations are really stretched. Partly there is an element of timing, having initially started the research period in the summer holidays, where staffing capacity is often lower. But more than this, it was clear that the impact of the cost-of-living crisis is being felt by disabled people groups and organisations and stretching to participation in research – even when paid research, which was welcomed – was still challenging. This is a wider economic issue, outside of the PHSO's remit, but it does further support the points made about budgetary provision, above.

4. The importance of the central voice being that of people with learning disabilities who are directly affected, but not excluding those with self-advocacy and campaigning experience and supporters

Rightly, the original brief for this research focused directly on people with learning disabilities, with direct experience of having challenged a DNACPR. All groups BIHR discussed this research with, including those directly led by and for people with learning disabilities agreed with this approach. However, it became clear that it would be important to widen the scope of the research to also include people with learning disabilities who have been directly involved in advocacy around the use of DNACPRs (even if they had not personally experienced one). Additionally, as we worked with more people with learning disabilities and self-led groups, the importance of engaging with family members, carers and supporters was really underlined. This was especially important for people with complex and/or multiple learning disabilities and/or additional support needs, who can be the most vulnerable positions to decisions about care and treatment being made without their involvement. In these situations, the light can be shed by family members, carers, and supporters about the systems issues with DNACPRs were important information for this research.

5. Flexibility of approach

Throughout the research project, ensuring maximum flexibility has been key. There have been challenges (outlined above), particularly around the capacity of people to participate within the initial timeframes, and understanding from people with learning disabilities why a wider pool of participant experience was important. Added to this there have been significant capacity issues for self-led, by and for, organisations and groups. For BIHR in the development and delivery of this work, this context has required significant flexibility of approach, the provision of contingency plans, and creative approaches to the research.

This has included short notice changes to schedules workshops, being available for individual and group interviews, and ensuring that capture of the outputs responded to people’s needs and wishes, including video, audio, and written formats. Additionally, on PHSO’s side, the context required parallel flexibility, responsiveness to the challenges as they emerged in both the development and delivery process, and review of contingencies. This flexibility, and in particular the extended time frame, was key to the successful delivery of the research project.

The key overall reflection is that the approach to experience-informed, paid, research by the PHSO is a positive development which we hope will continue and grow.

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