#SocialCareFuture

It's My Life

National Care Standards for the people, by the people

NOVEMBER 2026



IMPACT
Improving Adult Care Together

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UKRI Economic and Social Research Council

The Health Foundation



About this project

In its manifesto for the 2024 election, the Labour Government promised to create a National Care Service for England, backed by National Standards. After taking office, it appointed Baroness Louise Casey to lead an Independent Commission with a remit to develop a plan that would deliver these commitments. Ministers have made clear that they expect National Standards to be developed in the coming years, and initial work has begun around digital standards. This has prompted a range of organisations working in the social care field to start work around developing national standards.

Recognising the vital importance of getting national standards right, Social Care Future convenors Anna Severwright and Tricia Nicoll brought together members of their movement in Birmingham in December 2024, with support from the Social Care Institute for Excellence (SCIE) and Birmingham University colleagues, to start a conversation about what people who draw on care and support would want to see included in any future national care standards. The aim was to be proactive in ensuring people who draw on care and support had a voice in the creation of new standards.

The resulting discussion in Birmingham identified a range of areas of interest, as well as significant concern that, if people who draw on care and support were not included in discussions, national standards may lead to worse outcomes for people. In particular, the discussions surfaced concerns that national standards may lead to a homogenisation of care which would reduce people's ability to have choice and control over their lives.

To build on this work, and as part of IMPACT Networks exploring Citizen Leadership across the UK, Social Care Future and Think Local Act Personal came together to support conversations about the potential shape and content of national standards. This report was developed as part of that programme of work, and was led by a group of 12 individuals who came to form a Network, supported by the IMPACT centre at the University of Birmingham (a list of their names is included in Appendix 1).

The Network aimed to draw on the evidence around how care standards had been developed previously in England and in other jurisdictions and to consider whether and how these processes might inform future work on national standards for adult social care in England[1]. A question we returned to throughout the process was: *"How and why would standards be different if people who drew on care and support were in the lead?"* We drew on our own experiences of drawing on care and support and of working with care providers and commissioners to improve care, to think about what good care and support looks like. And we considered how we could turn these ideas into national standards that might drive improvements in care and support.

Across the four meetings, we discussed:

- Overarching domains and principles for national standards
- Specific ideas for standards in two key domains
- The infrastructure and processes that should be in place to develop, implement and enforce standards

The discussions were complemented by further discussions, convened by TLAP and involving a wider group of people who draw on care and support and other colleagues. These considered how we could define standards around two key areas of interest – self-directed support and commissioning. We did not attempt to develop a comprehensive suite of standards through this process, rather we sought to:

- uncover the key principles we want to inform standards.
- demonstrate the value and necessity of involving people who draw on care and support in the development of national standards.

[1] We were fortunate to be able to draw on the expertise of Catherine Needham and Laura Griffith, from the University of Birmingham, who shared the findings of their review of approaches to developing national standards.

Standards with purpose

Standards help us to define, understand and check whether something is a good (or adequate) version of the thing it is meant to be. You can't define standards without understanding the core purpose and nature of the thing you are setting standards for.

To set standards for social care we need to be clear about what social care is and what it is for.

Social care is not well-defined – the public lacks a clear understanding of it, partly because the term "social care" encompasses a range of responses, ways of working, services and supports provided by a wide range of organisations, to hundreds of thousands of people with different lives, needs and aspirations. The Care Act 2014 attempts to codify the purpose of social care in terms of support for people's wellbeing.

We think this understanding of social care is helpful, but would prefer a clearer vision or purpose statement to be set out for social care, ahead of starting to set standards. This vision must be developed and agreed with people who draw on care and support. National standards should then be built around the vision for social care.

Our vision should help us understand the "destination" for all social care activities and services. The standards we set can then act as a route map to this destination.

Social Care Future describes a vision for social care that starts from the recognition that

> ***"We all want to live in a place we call home with the people and things we love, in communities where we look out for one another, doing the things that matter to us".***

Social care can then be understood as the set of services and supports that enables people who need some help to achieve those things. This vision was developed with people who draw on care and support after extensive discussion and crafting and would be a good option to use as part of a set of standards.

Standards that drive change

We want national standards to be a tool for positive change in social care. They should support progress and improvement on an ongoing basis.

Getting the balance right is important: We want to be aspirational for the care system, and we want there to be **positive pressure on systems to do better,** so we don't want standards that just describe the minimum. At the same time, we don't want to set standards that can't be met and which float adrift of people's real experiences of the system. We've seen this happen before – for example the system "talks the talk" on delivering "person-centred" care but all the while people are experiencing less autonomy and control over their care. We need to have the infrastructure in place to deliver care that meets the standards we set.

We want standards that are effective. Standards need to **drive change in cultures and behaviours**, and to support the development of the right **skills and competencies** among the "workforce" defined and developed broadly. However, too many of the standards we reviewed from other places and which we've experienced, seem more likely to drive the production of policies and documentation, without really changing what people do.

We also want standards that **empower people who draw on care and support** to get the care and support they want and need and enable them to demand better from the system.

We think that describing standards in terms of people's experience and then providing guidance and (where appropriate) training to people offering support around how we can achieve these experiences, will be important.

It is also important to find ways to create feedback loops around care standards, so that people can understand quickly whether standards are being met and can take action to improve. We want to create a culture of learning and improvement around the assessment of standards, rather than one of box ticking and reporting.

Handing over power

Standards are a means of control over a system – they create guardrails and a map for that system's activity and set boundaries for how it can and should behave. The standards we set for care and support should ensure that everyone is able to access care that is effective in achieving its core aims and meeting the vision set for it.

However, currently regulations and standards are more often used to limit people's agency and choices than to give us power within the system. For example, we discussed how obligations placed on care providers around safeguarding and safety were too often used as an excuse to restrict the freedom and autonomy of people who draw on care and support.

We want any new standards to support a transfer of power away from systems and organisations, towards people who draw on care and support. To make this happen, people who draw on care and support must lead the process of developing new care standards, and our involvement must not end there.

People who draw on care and support live every day with the consequences of decisions made by the system. We know what it feels like when support works well, and when it doesn't. That experience is essential if standards are to reflect what really matters in people's lives. This is why we must be integral to the development of standards and why our role cannot stop at the design stage.

The processes and mechanisms for reviewing and refreshing standards, for supporting their implementation and for policing and enforcing them should be held by people who draw on care and support. As one Network participant put it, ***"We don't want a new sheriff in town, we want to be handed the badge and gun ourselves."***

For people who draw on care and support to trust in the assessment of standards, this work must also be carried out by people who have understanding and experience of the system.

We believe these roles could appropriately be taken on by disabled people's organisations within communities (although to make this possible we will need to rebuild infrastructure that has been lost in some places, and to ensure they are appropriately resourced). We may be able to learn from bodies like Greater Manchester's Disabled People's Panel, as we develop new structures for this work.

Standards must be accessible to, and enforceable by people who draw on care and support. We think it is important that people are able to access the full range of support they may need to secure the care and support they need in the places they live – this includes access to information and advice, to advocacy and to legal services. We believe local disabled people's organisations could also play a role in supporting people to provide feedback on their care and to seek redress when things are not up to standard.

Making sure people know and can enforce their rights and hold organisations accountable for meeting standards will require proactive action to ensure that people have the knowledge, skills *and* confidence to do this. At present, too many disabled people, and particularly those from minoritised and racialised communities, feel unable to enforce their rights due to a lack of confidence, and fear of repercussions, often rooted in past experiences, so action to address these barriers is vital.

Local organisations – including Disabled People's Organisations and Local Authorities – should also play a role in aggregating local data to draw out key lessons and identify areas for action.

With local organisations playing a more significant role, national oversight could then be focussed on monitoring issues across populations, to identify changes in patterns of need and in the support people are choosing and its outcomes. Crucially, national oversight would also be required to identify and act on inequity.

What standards?

We spent time considering the overall content of standards – including the high-level concepts around which standards should be organised.

Key principles and domains

In our discussions we identified some key principles that should inform the development of standards. These are:

- **Standards should be framed around things that matter to people, and which can be understood by everyone who draws on care and support.**
- **The quality of care and support should be measured by people's experiences and how they are enabled to do things that matter to them.**
- **Standards should set out what good care and support looks and feels like for people who draw on it.**

People who draw on care and support have already spent time articulating what good care and support is like for them – for example in creating the **Making it Real** framework of 'I' and 'we' statements, which set out what good care and support looks like for people who draw on it, and how people who work in care and support should behave. We don't need to start from scratch in this work.

- **Standards should be broad enough to encompass the full diversity of care and support. We should not set standards that are applicable only to certain models of care.**

Social care is complicated and it changes, both for individuals and at a societal level over time and in response to wider shifts in society. We need standards that are broad enough to be relevant to the hugely diverse range of people who draw on care and support and the range of support they choose to meet their needs.

- **Standards should be universal**
- **Standards should not duplicate regulation**
- **Standards should be expressed in terms of rights – drawing explicitly on the UN Convention on the Rights of Persons with Disabilities and the Human Rights Act. They should set out clearly who should hold power in the system**

When we looked at other sets of standards that had been developed in other countries, and previously in England, we recognised a range of issues that we would also want to see reflected in our standards – these included important concepts such as wellbeing, dignity and choice and control. However, in addition we felt standards should be explicit in requiring care and support that enabled people to have a life of meaning and purpose and aspiration We also recognised co-production and equity as vital cross-cutting themes.

In addition, we want to set standards that can drive key system behaviours that are often neglected by other frameworks including:

- **Ensuring people have access to information, advice and advocacy and have the knowledge, skills and confidence to use them**
- **Encouraging the provision of early and proactive support**
- **Including family members and loved ones**

Language

We recognised that the terms we use in setting standards are very important. We want to be crystal clear about what we mean by the words we use so that no one can wriggle out of meeting them. In that regard, we recognised that terms like "person-centred" and "co-production" are often misinterpreted.

We thought it would be helpful to set standards out in terms of outcomes, but also in terms of people's direct experience of care. For example:

Standard: People get the support they need to enjoy a good life, feel safe, and make their own choices.
Outcome: People can live the life they want, do the things they enjoy with support when needed, and feel confident and in control of their daily life.
How it will feel: You will feel safe, valued, and respected. You will have confidence in your decisions, a sense of freedom in your daily life, and the comfort of knowing support is there when you need it.

We thought it would also be helpful to relate each standard to the underlying rights frameworks upon which it is built.

Exploring two important areas for standards

We spent time discussing two potential areas of standards in more detail. We thought about how we could set standards for "person-centred" care and for "safe" care. These were areas where we'd identified that very often "the system" – by which we mean service providers, commissioners and policy makers - understands terms differently to us.

Person-centred care

We recognised that the term "person-centred" is designed to signify a shift in how the system works – orientating support around a person, rather than forcing a person to move towards sources of support. But we felt that the term "person-centred" failed the test of being easy for everyone to understand.

We thought that words like "choice" and "control" are more meaningful to people. We also thought the idea of being "in charge" was useful.

A key question for us is whether people feel that they have choices in their lives and about their care and support and whether they feel they are ultimately in charge of their own lives.

We thought when people experience this care that is up to standard, they will feel listened to and respected.

We recognised that respect for people's identity and culture are also important values to build into standards in this area.

When care is up to standard, we will be able to see a link between what matters to the individual and the kinds of things they are supported with.

We also think that it is vital that care is flexible – so that it can change and respond, when people's needs change.

We would want to be clear about the different kinds of things around which people should have choices and of which they should be in charge. These include:

- Where you live and who you live with
- Who you spend time with
- Who provides your care
- The things you do day to day – like what you wear and what you eat

We think it might be helpful to explain what *shouldn't* happen – we don't want people to be faced with a narrow list of options, or to have to fit their needs and wishes into checklists. Care that is up to standard would not feel rough or rushed.

We also recognised some challenges for standards around choice and control, including that:

- Supporting people to have choices and be in charge of their own lives is difficult where they may lack capacity. However, we noted that there are existing laws governing how decisions should be made for people who lack capacity. We want to avoid qualifying basic standards for care services with phrases like "as far as possible", as these very often become a hiding place for constraining people's agency and autonomy.
- Many people often don't have as many choices as they would like, for example, due to their financial circumstances, or the availability of services in their area. However, for us the key principle is that people's wider choices should not be constrained because they happen to need care and support.

Safety

Too often safety standards are used to protect systems, organisations and professionals, instead, and sometimes at the expense, of people who draw on care and support. When we discussed the aspects of safety that we wanted to see captured within our framework of standards we identified a need for standards around:

- ***Personal* safety**
- **Safety *within our identities***
- **Safety *within* the system**
- **Safety *from* the system**

In relation to ***personal* safety** we want standards that recognise the interplay between risk and safety and which empower people to make our own decisions about the appropriate balance that we want to establish in our own lives.

People's sense of safety will differ from one individual to the next, so we need to be able to define our own balance of risk and safety. The elimination of all risk is not a desirable aim. Standards must address people's sense of safety in all aspects of their lives – not just in care settings or when accessing care. People need to feel safe doing the things that matter to them. A key indicator should be whether people *feel* safe - and it might be sensible to ask separately about safety at home and in our communities. However, we should balance this, by also asking people about whether they feel able to take risks and try new things, when they want to.

We want to avoid care standards which duplicate other legislation and regulation that already exists to protect people from direct harm – including rules around food safety etc. This is something we saw in other standards sets and which we don't want to replicate in England. We want standards that are focused on the things that matter to people, not just on meeting legal minimums.

Considering **safety *within* the system**, a core principle must be that engagement with the social care system does not expose an individual to additional risk – either by dint of poor practice, inappropriate staffing, a lack of contingency planning, the need to battle the system, or by the imposition of restrictions on a person's freedoms of choice and aspiration. We need safety from a life that is less than it would have been outside the system.

We discussed that this would be evidenced by receiving care from people we trust; having a clear back stop and back-up plan if things go wrong; feeling safe when interacting with care systems and services.

Considering **safety *of identity***, we want people's diversity to be respected and for them to feel free expressing their culture and identity.

There is a link between safety of identity and safety within the system, in so far as some groups face significantly greater risk of harm within the system. We therefore need standards to emphasise equity of outcome, to proactively drive shifts around those disadvantaged by their identity – for example we need to address the unacceptable inequity of outcomes for people with learning disabilities when accessing health and care services.

Finally, to secure **safety *from* the system,** we need to limit the extent to which systems can restrict individuals' choices – including around risk taking. We recognised that principles such as "least restrictive option" already exist in law, and we thought these might provide a useful model.

Safety *from* the system is also about being able to safely challenge when things go wrong, or you disagree with what is happening to you. This means securing access to mechanisms for redress. As noted earlier, we want to see these structures controlled by people who draw on care and support.

Measuring what matters

We want the standards we set and the ways we assess those standards to be meaningful to a wide range of people in a wide range of circumstances receiving a very wide range of supports.

We think the ultimate measures of effective care systems are the outcomes and experiences of people who draw on care and support. We believe these matter far more than the tangible things that are delivered by care services. So, **we want less assessment of policies, processes and practices and more use of data around experiences and outcomes.**

For this to happen we will need to massively increase the extent to which data is gathered about people's experiences of care and support and the outcomes in their lives and the involvement of people who draw on support and their organisations in making judgements linked to this data.

We believe there is potential to use technology to make it far easier for people to provide live feedback on their experiences, and to feed this into systems to support immediate improvement, as well as to enable longer term data capture and analysis. We want standards that require action on all feedback - both positive and negative – using it to inform services, commissioning and strategy in co-production with people who draw on support.

We also think it is useful to look at data around who has been involved in developing care and support plans, services and strategies.

At the individual level, everyone who draws on care and support should be meaningfully involved in their care and support planning; at local level we should be able to see clear evidence around how people who draw on care and support and their organisations have been involved in developing services and support, as well as how feedback from people who draw on care is informing activity; and at system and national level we should have clear mechanisms for people who draw on care and support to be involved in developing and implementing strategic approaches.

We also want to use data to root out inequity. As part of our suite of standards we should require improvements to be made in reducing inequity year on year.

What's next?

We don't yet know who will be tasked with developing national standards to support a National Care Service, and when this work will commence, but we believe it is vital that people who draw on care and support are in the driving seat of this work.

We want standards that drive cultures and behaviours towards a renewed and aspirational vision of our social care future.

Thinking about the next steps, we believe:

1. National Standards should not be developed until we have a clear and agreed vision statement for the National Care Service.
2. People who draw on care and support must be involved in developing this vision.
3. The Standards we set should provide a road map towards the vision – driving the cultures and behaviours that will help us get the kind of care and support that achieves our vision.
4. Standards should help everyone involved in social care to understand what good care is like.
5. People's experiences and outcomes must be the main measure of whether good care is being delivered.
6. To understand whether we are meeting new care standards we will need to hugely increase our capacity to hear directly from people who draw on care and support about their experiences.
7. Standards should be independently assessed and monitored by organisations led by people who draw on care and support, providing support and challenge to individuals and organisations in local communities, as well as at national level.

We stand ready to play our part in this work and look forward to having the opportunity to do so.

Appendix 1: Network members

1. Rich Amos
2. Rick Burgess
3. Clenton Farquharson
4. Rachel Mason
5. Joanna Mawdsley
6. Andy McCabe
7. Ian McCreath
8. Tricia Nicoll
9. Martin Routledge
10. Isaac Samuels
11. Kate Sibthorp
12. Scott Watkin

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