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National Care Forum Response to House of Lords ASC Committee Consultation on the Invisibility of Care

This is the National Care Forum's (NCF) response to the House of Lords Adult Social Care Committee inquiry on 'Lifting the veil: Removing the invisibility of adult social care'. Our response draws upon a number of case studies from our members as well as intelligence from our regular calls and forums with members. We appreciate this opportunity to share our views, and are more than happy to produce any further information or oral evidence that might be required by the committee.

What is the National Care Forum?

NCF brings together over 160 of the UK's leading social care organisations, representing large numbers of care providers, offering thousands of services across the country, which are not-for-profit and always at the heart of community provision. Collectively, these organisations deliver more than £2.3 billion of social care support to more than 222,000 people in over 8,200 settings. The NCF membership body collectively employs more than 117,000 colleagues.

One of the fundamental challenges facing adult social care is that it is 'invisible'. Do you agree? What do you think explains this?

We agree with the premise that social care is invisible and we observe that it is invisible in a number of different ways, largely caused by how confusing and complicated the system is for everyone involved. There are a series of 'disconnects' in the adult social care system in England between different stakeholders, such as between central and local government, between DHSC and DLUHC, between commissioners and providers, and between those accessing care and support and their families on one hand, and the commissioners and coordinators of care on the other. Each of those 'disconnects' create points of tension for different stakeholders to navigate and indeed different stakeholders feel invisible at different points.

For the general public, social care is 'fuzzy' and not as well defined as the NHS which has a very clear identity, and principle of being free at the point of use. Adult social care feels hidden in comparison until you or a loved one needs it and then has to grapple with navigating local systems of assessments, eligibility criteria, care options and how to pay for them. **For parliamentarians and policy makers**, the complexity of the system has led to an overly simplistic narrative about what social care is and how to 'fix it', which adds to the invisibility many feel because they are absent from the narrative. This has too often seen social care synonymous with care homes for older adults who are frail, and individuals facing catastrophic care costs who are forced to sell their homes to pay the costs of care. This is certainly the experience of many, but social care is so much more diverse than this; it is not, as is often implied, a service to manage someone's mental and physical decline or a burden on the state's finances, rather it should be seen as a public service that enables people to live their lives to the full, in the communities that matter to them, in the way they want, despite their health and care needs. It is also much more than simply an appendage of a Local Authority or the handmaiden to the NHS.

Social care does not feel an equal partner to the NHS when it comes to policy making and funding, as well as the general public consciousness. One of the clearest examples to this is the approach to workforce planning. Adult social care is currently experiencing its worst workforce crisis, and yet, the focus is on NHS waiting lists which are in part caused by this crisis.

The workforce crisis in social care has been growing for a number of years and this has been systematically illustrated by the annual workforce reports from Skills for Care. In October 2021, Skills for Care's annual state of the adult social care sector and workforce report stated that there were 105,000 vacancies in social care while the number of job posts available had decreased over the previous 12 months. This means that while demand is going up for social care, capacity in the system is shrinking. As of April 2022, the vacancy rate in social care stood at 10.3% (it was 6% in March 2021), rising to 18.3% for nurses in social care.

The result of all this is growing unmet need and a greater burden placed on both social care workers and unpaid carers – these groups seem to be invisible to policymakers. According to a survey by ADASS, more than 500,000 people are now waiting for assessments, reviews, and/or care support to begin. Making the focus of resources and policymaking on the NHS elective recovery plans, without addressing care and support at home and in the wider community, means people's care needs increase, increasing burden being placed on unpaid and paid carers, and inevitably, more needing higher levels of hospital care.

An added issue is the gendered nature of social care; too often it is assumed that female family members will pick up care needs when the state fails to do so. This also impacts perceptions of care work itself. There are quite clearly a number of gendered assumptions about the value and prestige of care work. The demography of the social care workforce (82% female) illustrates this narrative.

For people using care and support services, invisibility also comes from how difficult it is to meet eligibility criteria and access care and support. Of particular note is the difficulty for some care recipients to get their care funded due to disagreements between NHS and LA commissioners as to who is responsible. A number of our members have also flagged the invisibility of people in in-patient settings. The Transforming Care agenda was partly aimed at getting people out of long-term settings and back into communities. People in these in-patient settings feel forgotten about despite our membership having the services to help.

Finally, the lack of data and academic research in social care will only serve to keep social care, and those seeking to access it, less visible to policymakers.

What are the key changes that need to be made to reduce the invisibility of adult social care? How can other public services (such as the NHS) play their part in tackling the invisibility of adult social care?

It is clear that we all need to change the current narrative and educate our citizens and our communities about what social care is and how it benefits society. We need a shift away from the negative narrative that currently exists to one that shows the potential for social care as enabling people and their communities. This will involve ensuring that a voice is given to those who access care and support, their carers and the workforce. Social care matters to us all and some point, the majority of us will need it.

From the perspective of our members, a focus on the workforce is a key element in resolving the invisibility of social care by reducing unmet need, enabling unpaid carers to have respite leave and enabling a more person-centred approach. There are a number of ways this can be achieved.

The Social Care Taskforce Workforce Advisory Group recommended back in the summer of 2020 that as a top priority, immediate action should be taken to improve the pay and recognition of the workforce:

- **Immediate Loyalty bonus**: Measures should be in place to retain experienced members of the existing workforce, for example a loyalty bonus for those who remain in post for a specified period of time (eg. throughout the winter). (**Note:** All other countries in the UK have paid their care staff a bonus in recognition of all that they have done over the last 18 months. The Workforce Recruitment and Retention Fund did not guarantee staff a bonus in England.)
- **Within three months**: Government should instigate a review involving employers, commissioners, and employee representatives with a view to implementing a new career-based pay and reward structure, in-year, for social care which will be:

    (a) comparable with the NHS and equivalent sectors;
    (b) fully-funded by Central Government;
    (c) mandatory on employers and commissioners of services

Neither of those recommendations have been met by the government – the second one in particular is essential if we are to make sure that care workers have the pay, terms and conditions that their skills and value merit. Great care needs great people and better pay, terms and conditions are critical to the future sustainability of care and support.

In addition to the above, we think the following are also needed:

- A fully funded registration scheme for social care workers in England like the other parts of the UK
- An equivalent to the NHS Workforce Survey for social care staff
- A social care workforce plan that considers the future demand and demographics of wider society
- Joined-up workforce planning, learning and development with the NHS

Another key aspect of the narrative that needs to change is the perception of adult social care as an adjunct to the NHS. Social care must be publicly recognised as an equal partner to the NHS, as two sides of the same coin seeking to deliver the best care and support for people, with people. Some of the recommendations above would help. From our perspective, there is much that that the NHS leadership and system as a whole can learn from adult social care providers about delivering great person-centred care. The new Integrated Care System structures offer a fantastic opportunity to bring the social cre provider voice to heart of strategic, joined up health and care decision making and planning. Without this voice, there is a risk that nothing will change.

Finally, despite receiving a lot of focus in the wider narrative, older adults are not often engaged in co-production or listened to when it comes to their care and support. A number of our members are calling for an Older People's Commissioner for England to help amplify their voice – to champion, celebrate and protect our ageing population – on a whole range of issues, not-least in terms of access to suitable housing and care services.

How would you define the purpose of adult social care? How does the invisibility of adult social care get in the way of achieving this purpose? To what extent does the definition of the purpose of adult social care differ for younger and for older adults?

Adult social care should enable and empower people to live their lives to the full despite their circumstances. It should support them to do what they want to do, when they want to do it and live surrounded by their community as far as this is possible. It should promote independence, holistic wellbeing and give individuals, their family and carers, a real involvement in their care and support.

We do not believe this purpose should change depending on age. How it is practically enacted might look different but the spirit should remain the same. For instance, for working age people in receipt of care, social care can empower them to enter or re-enter the workplace in a way someone in their 80s might not be looking to do or be able to do. It is about care tailored to that person.

Social Care Future puts it like this:

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

Invisibility in this context means that people aren't properly listened to when it comes to understanding what *they* want and need from care and support services or when they are unable to access services due to the pressures we've listed above: workforce shortages, growing unmet need putting pressure on wider system, health and LA commissioners unable to co-produce services and huge issues with funding and resources to support commissioning and choice. Co-production must be at the centre of good care and support. Systems need to have processes to enable this. Sadly, the Health and Care Act 2022 missed the opportunity to create mechanisms in the Integrated Care Systems for people who access social care services to have their voice heard. There is a mechanism for 'patients' of the NHS through Healthwatch but not everyone who accesses social care services needs NHS support or would class themselves as a 'patient' – this is a very unfortunate oversight. Case studies from two of our members, Active Prospects and Look Ahead, illustrate what good care and support can look like, and what it needs to look like on a wider scale in the future:

Active Prospects – Chris' Story

Chris (not his real name) is in his mid-20s and has autism, epilepsy and a severe learning disability. He moved out of the family home and into his new home in June 2020, at the height of the Covid pandemic.

This was a major adjustment for both Chris and his mum, as they had shared a home for all of his life. In advance of his moving in day, the team at Active Prospects made every effort to learn as much as possible about Chris and his transition needs. They listened to Chris, his mum, his social worker and health professionals to develop his 'This is Me' personalised support plan. This included making changes to Chris' living environment to ease his transition, such as recreating his old bedroom into his new home so that it was familiar, and working with his mum to create a bespoke sensory space in the garden.

Chris's mum was able to set goals for her son: "[The team] listened to me when I emphasised the importance of doing things a certain way, and worked on actively supporting him in important areas like improving his diet. After he moved in, his team sent me texts, photos and videos almost every day, they asked me questions to learn more about him, they kept him safe and they got to know him."

Before moving into his new home, Chris had resisted eating fruit and vegetables since early childhood. Chris's mum set his support team a goal of improving his diet. After much encouragement, "my vegetable averse son is now drinking a green smoothie every day! I couldn't wish for better people to be supporting him. I can see that my son likes his support workers, and that they enjoy supporting him. As for me, well, they provide such amazing support that finally, after what seems like a lifetime, I can sleep soundly at night."

Look Ahead – Joanna's journey from hospital to home

Joanna spent more than 22 years in a secure hospital setting until she came to Look Ahead. She is diagnosed with severe autism, epilepsy and severe behaviours of concern. Before coming to Look Ahead, Joanna was experiencing difficulties in her personal life compounded by the severity of her conditions. Throughout the time she was in hospital it was clear to both her family and commissioners that her quality of life was poor and the care she received didn't match her needs.

Transition to Look Ahead

Following an assessment, Look Ahead began working in partnership with a multi-disciplinary team made up of psychologists, nurses, occupational therapists, advocates and family members brought together with the sole mission of finding a suitable home for Joanna within the community.

Look Ahead firstly needed to find a property that would work given Joanna's physical and behavioural needs. With the support of Grand Union Housing Association and the supervision of their Business Development Team, together with input from an occupational therapist, a suitable property was identified and adapted to minimise any risk.

A 12-month transition plan was developed which slowly introduced staff to Joanna, supporting her and allowing her to set the pace. Transition had to stop following COVID-19 restrictions on visitors, but partnership work continued with regular meetings for updates and bespoke trainings arranged by the Multi Disciplinary Team (MDT) for staff. When transition restarted, staff were provided with all necessary skills to work with Joanna to minimise the disruptions of lockdown.

Person-centred care and support at Look Ahead

Look Ahead's team collaborated with the lead psychologist in Joanna's case to devise bespoke training for staff, specifically centred on Joanna's behaviour. Using the Positive Behaviour Support approach, training focused on helping the team address the motivations behind her behaviours and how to handle any possible incidents.

A plan was submitted to the Court of Protection that was designed to minimise hospital readmissions. It included a 'crash pad' environment, together with strategies to increase staffing levels and specialist input within 24 hours from a crisis, including on call and out-of-hours arrangements.

The plan is constantly evaluated to ensure the environment and staff skills, continue to meet Joanna's needs. This thrives on partnership with the wider multi-disciplinary team, including the family and Joanna herself.

Joanna's progress

Joanna's has been with Look Ahead for nearly two years. The placement hasn't been without challenges but Joanna continues to make great progress. Joanna's support team continually tailor their intervention strategies and are learning how to anticipate her behaviour. With a drastic reduction in incidents, staff have been able to introduce more activities based on Joanna's communication needs using specific tools. They will soon have use of a Motability car for Joanna to access the wider community and travel to the seaside and amusement parks as these are her aspirations.

What are the key challenges that people who draw on care and support and carers will face in the future, which are not factored into current assumptions related to the social care system, for example the fact that some families will age without children to care for them? How are these challenges different for younger and for older adults who draw on care? What should be done now to address them?

One of the key challenges facing people who draw on care and support and their carers is the pressure that changing demographics are placing on the health and care system at the same time as resourcing and funding not keeping up with demand.

Skills for Care estimates that by 2035, we will need a 29% increase in the number of adult social care jobs. At the same time, the government's own evidence review says that the number of over 65s is projected to increase by 43% (from 10.2 million to 14.5 million) and the number of adults aged 85 and over is projected to increase by 77% (from 1.4 million to 2.4 million) between 2018 and 2040. By comparison, the 20 to 64 population is only projected to grow by 3%. Currently the workforce is shrinking, as illustrated earlier in this submission. The age profile of the workforce is also skewed towards older age bands with relatively few under 25s. The result will be that the burden will fall on unpaid carers and this of course overlooks the fact that increasingly people are ageing without children to support them. Workforce planning is urgently needed.

Any workforce planning must also take into account an increasingly diverse population and reflect that. It must also be prepared for medical advances which allow people with complex needs to live longer.

There are also a number of other assumptions in the policy world which are not being addressed. How will people pay for their care needs if the state is unable to meet them or makes eligibility criteria stricter? An ongoing assumption in the policy world – even after reforms – is that individuals have housing wealth to fall back on to fund their care. This is increasingly not the case and is certainly not the case for many working age people. Home ownership is falling in younger age groups. If access to social care continues to be based upon being able to fall back upon housing wealth, we are in trouble.

Unpaid carers

Other respondents will be better placed to answer the questions posed relating to unpaid carers, but from a not-for-profit providers' perspective, families and unpaid carers contribute a massive amount of support to people. This continues even after someone receives formal care – informal carers will always remain essential and need to be valued more by our society. We note with disappointment that the Queen's Speech was silent on introducing legislation that would have granted unpaid carers the rights for a form of respite leave. We would add that you need a social care system that enables unpaid carer leave – that will require a workforce plan, greater recruitment and retention and a real commitment to listen to and work alongside unpaid carers and those they support.

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