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ABBREVIATIONS

- ASC: Adult Social Care
- EBE: Expert by experience (including those using, caring for and volunteering in adult social care)
- LAs: Local Authorities
- NIHR: National Institute for Health and Care Research
- The partnerships: The six NIHR-funded social care partnerships described in the introduction.

EXECUTIVE SUMMARY

- Adult social care is not so much invisible as ignored. The sector is chronically underfunded and undervalued, leading to a fragmented, dysfunctional system in which service users' needs are unmet and workforce's issues unrecognised.
- Resolving the invisibility of adult social care requires major changes, including transforming the public perception of adult social care, substantial investment in the workforce, and addressing the funding deficit.
- The invisibility of adult social care exacerbates the stigma experienced by people drawing on care services and their carers. Individuals belonging to marginalised groups are impacted by this to a greater extent.
- The current purpose of adult social care as defined by the Care Act is too narrow, reinforcing the notion of invisibility.

- The key challenges for the future are: ageing without children, availability of informal care, housing, the economics of care and the sustainability of the adult social care workforce.
- True integration of health and social care (from access to delivery) could reverse the fragmentation of the care sector and enable people to access the support they need when they need it.

INTRODUCTION

1. As part of its commitment to capacity building in adult social care (ASC) research, the National Institute for Health and Care Research (NIHR) has funded six social care partnerships in England. The partnerships aim to improve the quality and quantity of social care research, using a range of co-productive, research-in-practice methods. By working with local authorities (LAs), practitioners, providers, and experts by experience (EBE), the partnerships are ideally placed to rapidly consult with different stakeholders and respond to calls for evidence in ASC.
2. We have chosen to address Qs 1-7 of topic one because this topic aligns with the core aims of the partnerships: to raise the profile of ASC and build essential research capacity to inform evidence-based practice, support innovation and improve outcomes for those using its services and their carers. We have omitted Question 8 on the impact of COVID19 because so much has been published on this already (1–5). This response reflects the views of 30 people from the six partnerships: 7 EBEs, 8 practitioners, 15 researchers working in the field. The quotes used throughout this document are their voices; collected through group discussions, individual interviews and written responses.

Q1 One of the fundamental challenges facing adult social care is that it is 'invisible'. Do you agree? What do you think explains this?

3. When considering the notion of invisibility, we must first ask the question: <u>invisible to whom</u>?
4. "*For someone using services, they're there*" (EBE). However, visibility for those unfamiliar to ASC can be a barrier to access.
5. Social care has existed alongside the NHS since 1948 but it lacks a clear identity. There is no National Social Care Service. When people need support, accessing social care can feel like navigating a labyrinth. There is no single point of entry to ASC, no equivalent to the local General Practitioner (GP) to assess your needs and refer you on to specialist services. Rather, you have to take the mental leap of "*picking up the phone to call the council, who also run the libraries and empty [your] bin.*" (practitioner).
6. Unlike the NHS, "we *only become aware of [social care] when we or someone we know needs it.*" (EBE). This necessarily means that receipt of social care is associated with dependency, of needing help, "*whereas health care is seen as being people's 'right' to receive, and not something you can be blamed for accessing."* (Practitioner).
7. ASC is delivered by approximately 17,700 organisations, employing 1.54m people (6) and they feel ignored and unvalued. Staff wellbeing is low, turnover high and retention challenging (4). *"If you ask my colleagues, the workforce, they will say they are second [class] citizens, compared with the NHS.."* (Practitioner).
8. The fact that *"adult social care always sits behind and separate from health"* (EBE) has contributed to an 'othering' mentality. This was demonstrated on a devastating scale at the start of the pandemic when the needs of the NHS were prioritised above those of ASC: *"We saw the high court decision last week … certain decisions were made to discharge people from hospital into care homes without testing. The whole policy world continues to tack social care on to other things."* (Provider representative).
9. In 2020-21, long-term support was provided to 841,245 adults in England at a cost of £15.6bn, not including those who fund their own care. LAs receive the equivalent of 5,250 requests for support a day (7). Less than half will receive some kind of service (8), meaning they will either continue to live with unmet needs (which will have a negative impact on their health and wellbeing) or fund their own care. A lack of integration between health and social care data (9) means that many become invisible to the system as a whole - until there is a crisis or hospital admission (10).
10. **ASC is not so much invisible as ignored and undervalued. Chronic underfunding by subsequent governments and a fragmented system for assessing needs and delivering care have led to those needing and working within ASC to feel invisible, their needs unrecognised**.

Q2 What are the key changes that need to be made to reduce the invisibility of adult social care?

11. "*Major key changes are required. Not just 'tinkering' with the service. A full root and branch change*." (EBE)
12. In our consultations three key themes emerged:

13. **Improving the public perception of ASC:**
14. ASC is still a low-status sector, with its contribution to the health and wellbeing of the nation under- recognised and under-valued: "*The low status of the sector is also a gendered issue, linked to the under- valuation of so-called 'women's work'.*" (Provider representative).
15. Government policy needs to promote ASC as equal to health and reduce the stigma about needing care. "*Promote social care …. in a way that promotes strengths, prevention of need and enablement of skills etc rather than just carer provision, safeguarding etc*." (Practitioner).
16. Normalise the use of ASC to enhance public recognition that care is needed throughout life and for many reasons and circumstances: *"More information about (social care) services should be available in public libraries, pharmacies, GP surgeries, Day Centres etc."* (EBE)

17. **Investing in the workforce:**
18. "…*there's still a perception that people working in social care are "only" a social care worker, which I just find immeasurably patronising"* (Provider representative).To attract and retain people with the right values and qualities, there needs to be significant step-change in the working conditions, pay and professionalisation of the workforce (4). Ideally, a common career structure between health and social

care. “*Social care workers should be regarded in the same way as health workers - as professionals, not just as ‘anyone can do this’”* (EBE).

19. The ASC workforce has a disproportionate number of women and people from minority ethnic communities, including a large migrant workforce (11). These characteristics, alongside the invisibility of ASC as sector, place the ASC workforce at greater risk of discrimination, abuse and inequalities (3).

20. Addressing the funding deficit:

21. “*Care workers have to be paid more, commensurate to the value they offer and their importance to our economy. This will go some way to creating parity of esteem with the NHS.”* (Practitioner).
22. **Sector-wide improvement requires significant financial investment and system-level change. Our partners suggested creating one national health and social care service, with a shared budget, branding, and career pathway for staff.**

Q3 How does this invisibility reflect the experience of social care for people who draw on care and support and their carers, and does this experience vary by age range and particular circumstances?

23. “*Invisibility of ASC means people aren't aware they should be demanding help and therefore end up not getting it.”* (EBE).
24. In a culture which emphasises independence and personal responsibility, there is unsurprisingly a stigma around needing help. *“Government needs to create a culture where inter-dependency is recognised as a truer representation of how people live their lives.”* (Practitioner).
25. Older people and people with learning disabilities make up the majority of the population who draw upon ASC. They are often reluctant to ask for help and struggle to understand and navigate the system.
26. People with invisible illnesses or disabilities were identified as another group who may find it more difficult to access ASC, precisely because it can be difficult to demonstrate their needs. *“People generally accept that very elderly people and people with visible disabilities may need social care but find it harder to accept that people who may seem completely well on the outside may also not be able to look after themselves for various reasons.” (EBE).*

27. **The invisibility of adult social care exacerbates the stigma experienced by people drawing on care services and their carers. Individuals belonging to marginalised groups are impacted by this to a greater extent.**

Q4 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?

28. In our consultation, people said that the Care Act definition was too narrow and contributed to the invisibility of ASC. Whilst there is potential for ASC to help people's well-being and independence, it is rarely resourced or delivered. A recent survey found that "61% of [social services] are having to prioritise their assessment capacity to only people with life and limb safeguarding or at the point of hospital or reablement discharge" (10). This was corroborated by our own partners: *"We just act when it's a crisis. And then we move on."* (Practitioner).

29. ASC should be about the well-being of the population but there is no time for value-based care or relationship-building: *"If you're operating in a society that doesn't share (those values), doesn't give you the resources, doesn't give you the time or the funding, then you [can't practice your values]."* (Researcher).

30. The purpose of ASC is*: "To provide the help needed to enable a person to live as full and independent life as possible and to allow their carers to continue with their own lives without having to worry."* (EBE)

Q5 To what extent does the definition of the purpose of adult social care differ for younger and for older adults? How can future reform best address these differences?

31. The purpose of ASC is the same for all age groups. ASC is in place to support those who may be vulnerable, unable to support themselves or are just in need of extra support, regardless of age or 'client group'. *"I don't think age is relevant as care should be independently assessed for everyone. Reform needs to improve the accessibility and individual tailoring for all." (EBE).*

32. **Needs vary by age but the goal is always to support people to live the best life possible. Categorising people by age does not help. Future reforms should consider people's identities: *"…it needs to be a broader conversation around [differences that impact needs]: sexuality, gender, ethnicity, race, all of those kinds of things."* (Researcher).**

Q6 The key challenges people who draw on care and support and carers will face in the future and what should be done to address them.

33. "*I have no children and my husband passed away 18 months ago so I am now on my own. If I visited care groups now to put in place some support for when I needed it, where would I go? There is no-where, we are being encouraged to arrange our funeral but there is nothing to set up support for our old age, apart from a formalised legal statement or 'living will', and this only covers things like CPR and ongoing care in a hospital."* (EBE).

34. There are a number of key challenges, including: ageing without children and availability of informal care, suitability of housing, the economics of care and the sustainability of the ASC workforce. This needs to be recognised and addressed 'head-on': *"This all revolves around funding and who should pay. We need to be honest. There is not an everlasting pot of gold - people are going to have to plan for their and their family's support."* (EBE).

35. **Many of the future challenges relate to issues we have described in previous sections: chronic underfunding, workforce issues and lack of systems-level integration between health, social care and housing. Having a safe place to live (housing), being free from pain and ill health (health) and having your personal care needs met (social care) are all basic human needs, inextricably linked. Only once these are in place can we focus on quality and living the life we want. Currently, the system is failing to meet these basic needs for hundreds of thousands of people (10).**

Q7 How can other public services (such as the NHS) play their part in tackling the invisibility of adult social care?

36. "*Why do we have a different route into ASC to health? With*

Multi-Disciplinary Teams these could address the route to ASC, rather than a faceless web page from the local authority." (EBE).

37. Our consultations emphasised the importance of bringing together public services, from access through to delivery. "*Work together in action not just words. Be willing to share budgets. Talk about Health and Social Care not Health* ***or*** *Social Care, so that the one is implicit in the other."* (EBE).

38. Although the new Integrated Care (ICS) System sites aim to do this to a certain extent, there is still a very long way to go: "*[Health] teams hadn't really started thinking about social care involvement at the highest level of the ICS systems until we and others pointed out that they hadn't got structures in place*." (Provider representative).

39. Local areas can work "*together to support people and communities, [by] working closely with community wardens to identify people [with unmet needs]."* (Practitioner). In North Somerset, grassroots community groups have raised awareness of services at the community level delaying and preventing needs and signposting people into services who might otherwise have been missed.

40. We do not have a single 'long-term care' system in the UK. As such, the pressures and resources of health and social care are traded against one another, and it is not clear who has ultimate responsibility for the individuals seeking help.

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