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Building a better understanding of adult social care

Jon Glasby and colleagues suggest short and long term measures to tackle the invisibility of adult social care

In December 2022, the UK House of Lords Adult Social Care Committee argued that adult social care (box 1) is largely “invisible”: something that happens behind closed doors, that is about “them” rather than “us,” and that is poorly understood by the public, the media, and policy makers.¹ Among many examples of this from their report was the view of Jeremy Hunt, former secretary of state for health and social care, that the invisibility of adult social care is “deeply entrenched” in our society. Another example was a November 2021 survey including 1561 unpaid family carers in the UK that suggested over 90% feel ignored by government.² A written submission from the Health Foundation to the committee reported that members of the public had a limited understanding of social care, had not thought about their own future care needs, and wrongly thought that future care will be funded through taxation.^{1,3}

In the view of the committee, this results in services that are underfunded, a workforce that is undervalued and underpaid, and a system that is only really seen in terms of the impact it has on the health service, hardly ever in its own right. Although social care has come to national attention in recent years, the focus has been on the cost of care homes and paying for

care for those who need it and not on the intrinsic value of enabling good lives.¹

We argue that these longstanding issues were particularly exposed during the pandemic, with tragic consequences. While some of our proposed solutions to tackling the invisibility of social care are more immediate, practical actions, others entail long term social, cultural, and political change. In making this case, we focus on insights from England, the Netherlands, and Sweden, selecting these to include a range of systems, including high tax or publicly funded Scandinavian services, more insurance based approaches, and a more mixed economy of care.

Focusing on health to the detriment of social care

During the pandemic, the immediate focus in many countries was on acute hospital care, with a tendency to overlook adult social care.⁴ This had tragic consequences for many people’s lives and the wellbeing of care workers.^{5,6} Whereas systems were rapidly put in place to supply hospitals with extra funding and as much personal protective equipment (PPE) as was available, social care staff were initially almost entirely neglected.^{7,8} Restrictions on visitors to care homes also meant that many residents, some with dementia and near the end of their lives, were unable to see loved ones.⁹

In England, the government was subsequently severely criticised over an early decision to discharge people from hospital to care homes without initially testing for covid-19, inadvertently spreading the virus to particularly clinically vulnerable populations.^{5,10} In Sweden, in contrast to many other countries, the government’s initial emphasis was largely on advice and guidance, leading to greater degrees of personal freedom and a preference for voluntary social distancing rather than compulsory “lockdowns.” However, they were criticised for doing “too little, too late” in terms of enacting measures to sufficiently protect frail older people and other at-risk groups.¹¹ In the Netherlands, the first priorities were the

availability of hospital and intensive care unit beds, making PPE available in clinical settings, and overall mortality rates, and not the quality of life of frail or disabled people in the community or the wellbeing of often unprotected care workers.¹²

Longer term neglect

This prioritisation of health over social care was partly the result of an understandable desire to protect hospital services and intensive care in an unprecedented crisis. However, deep down, it was also to do with a broader failure by policy makers and by society as a whole to understand and value social care in its own right.¹

In England, the House of Commons Public Accounts Committee argued that years of inattention, funding cuts, and delayed social care reforms were compounded by the government’s slow, inconsistent, and, at times, negligent approach to giving the sector the support it needed during the pandemic.⁵ Examples of this neglect included the 25 000 people discharged from hospital to care homes without first being tested for covid-19 and delays in producing an action plan for social care (which came some four weeks after guidance had been produced for the NHS).⁵

In Sweden, covid-19 shone a spotlight on existing problems, such as chronic underfunding, fragmentation, understaffing, insufficient education

KEY MESSAGES

- Adult social care is often largely “invisible”—low profile, poorly understood, and therefore often neglected by the public, the media, and policy makers
- This was particularly apparent during the pandemic, with tragic consequences
- We need to raise awareness of the importance of social care (with policy makers and the broader public), better understand the breadth of the contribution it makes, and develop a more positive vision for adult social care more generally

Box 1: What is adult social care?

Adult social care means the practical care and support that disabled and older people draw on to live their lives. It can include assistance with activities of daily living such as getting up/washing/getting dressed/eating/going to the toilet, as well as support for unpaid carers. While these are often associated with particular service models (home care, residential care, and so on), many countries enable people to choose how funding is spent on their behalf, playing an active part in co-designing their own support.

and training, inadequate managerial and medical support, and poor terms of employment.^{11 13 14} For example, one quarter of the care workforce are employed by the hour, with staff sickness or self-isolation leading to even greater use of casual workers (often with less or no formal training).¹⁴ There was a scarcity of PPE, especially in the first months, and care home residents, home care recipients, and care staff were not initially prioritised for testing. More than one third of care homes reported lacking preconditions to provide individual assessment and treatment for residents with covid-19.¹⁴

In the Netherlands, the national expert committee advising the government was initially dominated by epidemiological and economic perspectives, with less social science input.^{12 15} This meant that the focus was often on clinical issues, rather than broader impacts, such as the negative effects of multiple lockdowns on older or disabled people living alone or on youth mental health. As a result, there were considerable shortages of PPE for home care and nursing home staff—even greater than those in hospital services. Also, the national expert committee did not seem to discuss issues such as the best way to balance prevention of infection with the

Box 2: Moving beyond professional boundaries for a better understanding of each other's roles

Although only an anecdotal example, a powerful illustration of looking beyond our own professional boundaries is provided by a senior geriatrician who thought he knew little about the community services to which he discharged people from hospital. He therefore took a week's leave and shadowed local home care workers. He was amazed by the complexity of needs which these workers manage on a daily basis, operating almost entirely on their own with minimal support and on very low wages. He now has much more confidence in the services which his patients receive after hospital and much more respect for partner agencies, using this to build a series of more effective interprofessional relationships which help him to navigate traditional service boundaries (personal communication). Clearly, individuals should not have to use their holiday to fix systemic problems, but there may be scope to build on these insights through more formal mechanisms such as joint training or shadowing schemes.

importance of (family) contact for people in care homes (particularly at the end of life). The overall situation was made worse by staff shortages, poor working conditions, and a lack of emphasis on infection prevention in such settings in the years before the pandemic.^{12 15 16}

As the pandemic progressed, there was greater recognition by policy makers, the media, and the public of the challenges facing adult social care.⁵ However, most policies and media accounts tended not to consider social care in its broadest sense and on its own terms, focusing on parts that affect the health service, such as care homes and services for older people, and overlooking the experiences of disabled people of working age or on community services that support people to live independently in their own homes.^{6 7} This led to care packages being reduced or cancelled, buildings such as day centres or respite units being closed, and people employing their own personal assistants unable to source PPE⁷—much of which initially went unreported and so was probably not apparent to the general public.

Even when policy makers became increasingly aware of these issues, action was limited by a lack of understanding of the nature of the sector. For example, English care services are provided by around 17 900 private, voluntary, and public organisations across 39 000 sites,¹⁷ many of which are encouraged to compete with each other for public service contracts. This is different from the health service, where providing PPE (as one example) to large, publicly owned hospitals—while still challenging—is relatively straightforward in comparison.

Valuing social care in its own right

Adult social care funding is not “dead money” that governments have to spend to meet the basic needs of disabled and older people, but a form of social and economic investment we make in ourselves as a society.^{18 19} Raising its profile defies simple answers, but possible solutions might entail a mix of short term, practical actions, alongside longer term social, cultural, and political changes.

Many adults have cross cutting health and social needs that span traditional professional and organisational boundaries. Raising the profile of adult social care within health services would therefore be an important first step. All health professionals can commit to increasing their personal understanding of

social care and to building broader relations beyond the walls of their workplace. In practical terms, this might include a greater focus on interprofessional education in pre-qualifying and post-qualifying training programmes,²⁰ and medical revalidation processes. However, it might also entail individual professionals taking responsibility for their own development, above and beyond the formal mechanisms in place (box 2).

During the pandemic, radical changes were possible in timescales that would never usually be achievable. Many localities moved quickly to create a series of flexible, practical, joined-up services to meet people's needs in an emergency,^{7 12} often making considerable use of digital technology²¹ and working closely with the voluntary and community sector. An important and life changing contribution was also made by families, volunteers, and local communities.²²⁻²⁴ Indeed, a survey of at least eight European countries highlighted that the average number of weekly hours of care provided by family carers increased by nearly 20% during the pandemic, and over 10% of respondents started to provide care as a result of the pandemic.²⁵

While this was often born out of necessity and could be a source of considerable stress, it is an important reminder that the bulk of care has always been delivered by family and communities. Moreover, many social care services have historically been “deficit focused” (focusing on what is “wrong” with the person). In contrast, responses to covid-19 had to build on the community based supports we all draw on to live our lives, supplementing these networks and relationships with some formal support where needed. This might be described as being more community oriented and strengths based—and such approaches have much to offer more generally in terms of future social care reform.²⁶

Longer term government action is needed to build a stronger care and support infrastructure capable of overcoming the considerable workforce, funding, and service pressures being experienced in response to tightening fiscal budgets and population ageing and multimorbidity.^{12 17} While this might look different in different countries, the House of Lords Adult Social Care Committee,¹ as one example, sets out a series of recommendations to achieve this, including a realistic, long term funding settlement; a properly resourced workforce strategy; and establishing a powerful

national commissioner for care and support to strengthen the voice and identity of the sector. These calls are recent (December 2022) but the fact that they came from the heart of the UK establishment may give an indication of the real and current nature of these issues.

Above all, social care is perhaps its own worst enemy by tending to describe what it does in terms of a series of “services” that help people with particular “activities of daily living” (box 1). Instead, it might be better to focus on the care and support on which we all draw to live our lives. For example, #SocialCareFuture is a UK coalition aiming to bring about long term change through a social movement rather than a specific health or social care policy.¹⁹ Made up of people who draw on care and support, as well as families, professionals, managers, and politicians, the movement promotes a system of social care that helps people to lead their chosen lives. It argues: “We all want to live in the place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us . . . When organised well, social care helps to weave the web of relationships and support in our local communities that we can draw on to live our lives in the way that we want to, with meaning, purpose and connection, whatever our age or stage of life.”¹⁹

It is hard to see how anyone could disagree with the #SocialCareFuture vision. The difficulty, of course, is taking a set of services which were not designed with these aspirations in mind and making such a vision a reality. As Peter Beresford, a social work academic, has commented²⁷: “Social care is not rocket science. It is much more complex and subtle than that.” While the longstanding invisibility of adult social care was so tragically exposed during the covid-19 pandemic, this has also created a moment when there may be scope to better understand and value the contribution it makes, raise its profile, and build on lessons to better design and deliver adult social care and support in future.

Contributors and sources: JG is a non-executive director of an NHS trust and of a local authority children’s service. He was a special adviser to the House of Lords Adult Social Care Committee. CF is a member of the Coalition for Personalised Care, the Social Care Sector COVID-19 Stakeholder Group, and the NHS Assembly and a trustee of the Race Equality Foundation, and the Social Care Institute for Excellence. LH is a board member and past president of Eurocarers, an expert adviser to the National Board of Health and Welfare in Sweden regarding informal (family) carers, care, and carers support. MM is a professor of innovation and the governance of integrated care at Tilburg University/TIAS and a board member of the International Foundation of Integrated

Care. This article is based on insights from leading academics, people who draw on care and support, organisations that support unpaid family carers, and organisations that seek to implement evidence in adult social care, from England, the Netherlands, and Sweden, countries with a range of health and social care systems. All authors provided informal advice to the social care system and to national policy makers during the covid-19 pandemic.

Public and patient involvement: CF has personal experience of drawing on care and support, and chairs the board of Think Local Act Personal (a national partnership of more than 50 English organisations committed to transforming health and social care through personalisation and community based support). LH has been an unpaid carer to relatives in the UK and Sweden.

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